

SUMMER/FALL 1996

# The CMTA Report

Vol. 11, No. 3 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.*

## Response Exceeds First-Year Goal of Armington Challenge

The CMTA raised over \$45,000 for its research fund, exceeding the first-year goal of the Armington Challenge by more than \$20,000. This tremendous response is a clear indication by our membership that research is our highest priority. It also bodes well as we enter year two of the three-year \$75,000 challenge grant.

Heralded at its inception as a means for elevating fundraising efforts and accelerating research activities, the Armington grant is fulfilling those objectives. The CMTA partnership with the Armington family could not have come at a better time for the organization or in the history of medical research. The Medical Advisory Board recently convened at the American Neurological Association meeting to discuss plans for the Third International Conference on CMT Disorders to be held in October 1998 in Montreal, Canada. The conference will be a landmark summit for disparate world experts to interact and exchange ideas.

Dr. Michael Shy, recipient of the first Armington research grant (to be detailed in the winter issue of the newsletter) and one of the conference organizers, expressed his optimism: "I believe the recent advances in the understanding of Charcot-Marie-Tooth disease make it the most exciting field of neurology today." Dr. Shy went on to say, "In no other disorder, or group of disorders, are the molecular abnormalities causing the disease, the pathogenic mechanisms of how these genetic mutations cause the disease, and the therapeutic approaches to treat the disease being worked on with such vigor."

*"I believe the recent advances in the understanding of Charcot-Marie-Tooth disease make it the most exciting field of neurology today. In no other disorder, or group of disorders, are the molecular abnormalities causing the disease, the pathogenic mechanisms of how these genetic mutations cause the disease, and the therapeutic approaches to treat the disease being worked on with such vigor."*

**—Dr. Michael Shy, recipient of the first Armington research grant**

With funding from the challenge grant, the CMTA will aggressively launch new research initiatives in preparation for the International Conference. The importance and timing of the Armington gift cannot be overstated. In recognition of the family's leadership, the CMTA invited Elizabeth Reardon, daughter of the Armingtons, to become an ex-officio member of the research committee of the board. In a message to the board, President Diane Freaney expressed her personal gratitude by saying, "The CMTA has always emphasized the need to support research, but the Armington Challenge has created a real sense of urgency for our efforts."

### CMTA BOARD

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## Our Year in Review

**1996** This year the CMTA made numerous advances in the areas of networking with members, improving communications, educating ourselves and the medical community, strengthening our board, supporting research, and most especially, fundraising.

I was very pleased to have met with so many of you this year. And with each encounter, I was struck by the strength and positive attitudes of our members. One person told me that people with CMT are overachievers. That certainly describes the people that I have met.

Many members come from large supportive families who keep in touch through newsletters and reunions. They focus on their abilities and maintain very active lives—golf, tennis, scuba diving, and hunting are just some of their numerous pursuits. Though not always the best, they are certainly the most determined. They are interested in exercise, diet, vitamins, and other programs to maintain and improve their health. Many members connect with one another through support groups, e-mail, and telephone referrals.

Our members worry about future generations and the progress toward finding a cure. At the same time, they want to know what the

*Kay Flynn, Support Group leader, Paul Flynn, CMTA Director, and others met before the Yale conference to discuss the many aspects of dealing successfully with CMT.*



health care profession is doing to make their lives easier now. They can live with the inconveniences (aching braces, falling, frequent pain), but do not believe them to be inevitable. They are concerned about insurance and health care in this country and the actual and potential level of the care they receive.

We added a record number of new members this year, many of whom contacted us through the Internet and e-mail. Additionally, our board has expanded to sixteen, including four new members; Joe Beernink, Computer Manager, Westminster, Colorado; David Grachek, Executive Search Consultant, Jacksonville, Florida; Krista Hall, Registered Nurse, New Market, Maryland; and Loren Miller, Accountant, Seattle, Washington. We are excited to begin working with our new board members and look forward to harnessing their energy and enthusiasm.

The CMTA organized two Patient/Family Conferences this fall, one in Delaware and one in Connecticut. We did not anticipate that both conferences would be sold out; future conferences will be held in larger facilities. Conference attendees enjoyed meeting other people with CMT and learning more about the genetics and treatment of the disease.

We are particularly grateful to those members who took the time to critique the program and make suggestions for improvements. At a member's suggestion, we hosted a hospitality suite, which 25 people attended, the night before the Yale conference. It was an important gathering not only for social reasons but for the tremendous value of hearing one another's experiences and coping mechanisms. We will hold similar meetings from now on.

The Third International Conference on Charcot-Marie-Tooth Disorders will be held in October 1998 in Montreal, Canada. The CMTA Medical Advisory Board met in October at the American Neurological Association meeting to begin planning the conference. Dr. Robert Lovelace, MAB Chairman, began the meeting by saying, "We've really made incredible progress in our understanding [of CMT] and there are few other areas [in neurology] that have come forward so rapidly."

Dr. Michael Shy, drafter of the preliminary conference agenda, will place special emphasis on integrating the different areas of research into



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# CMTA MEMBERSHIP/ORDER FORM

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

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

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

*If outside the US, please see Treasurer's Note on adjacent page.*

the same sessions. For instance, rather than having investigators at separate sessions, neurophysiology, pathology and genetics will be incorporated into common sessions.

After listening to the impressive agenda, Dr. Walter Bradley commented that "...[the conference] is two years away and some of [the agenda] will be old hat by then..." All agreed to maintain some flexibility within the agenda for leading issues at the time of the conference.

Fundraising has been taken to a new level, in large part because of the extraordinary generosity of the Armington family. The Evenor Armington Foundation initiated a three-year research challenge grant of \$75,000. Our members responded to the challenge and contributed over \$45,000 in the first year. This enabled the CMTA to award two major fellowships during the year and to budget for two more in 1997.

Dr. Peter Denton is currently using his grant at Duke University, Durham, North Carolina, to investigate the gene locations for CMT Type II. In January, Dr. Michael Shy's study at Wayne State University in Detroit, Michigan will be directed toward the development of an animal model for CMT Type IA (the P<sub>0</sub> knockout mouse), with the ultimate goal being possible gene therapy for the disorder.

Through the generosity of a board member, Steve Khosrova, and a matching gift from Salomon Brothers, we also will award three summer fellowships in 1997. The first grant will be named the Caroline Redell Memorial Fellowship after the convener of the first CMT support group. The other two will be named The Salomon Foundation Charcot-Marie-Tooth Summer Research Fellowships.

The year 1996 was a very successful one, but we still have many challenges ahead. Charcot-Marie-Tooth disease does not have name recognition and there is no cure. In 1997, we hope to make substantial progress toward these goals.

Thank you all for your incredible generosity and continued support of the CMTA.

Diane Freaney  
President

	QTY	COST	TOTAL
<b>Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians</b>		members \$15 non-members \$20	
Membership Dues		\$25	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		\$3	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		\$5	
CMT Facts III		\$5	
VCR Tape: CMT Neurology		\$15	
VCR Tape: Physical Therapy & Occupational Therapy		\$15	
<b>NEW! VCR Double Tape: duPont Conference</b>		members \$25 non-members \$40	
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 CMT Research</b>			
<b>TOTAL</b>			

 Checks payable to the CMTA VISA  MasterCard

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.*

## Capacity Crowds at A.I. duPont and Yale Conferences

### UPCOMING CONFERENCE ALERT

*Two conferences for spring: On April 5, 1996, at the Shriner's Crippled Children's Hospital in St. Louis, Missouri. The date for Madison, Wisconsin is to be announced.*

**D**r. Harold Marks hosted the conference at the A.I. duPont Institute in Wilmington, Delaware, on September 21, 1996. More than 150 people filled the auditorium to hear presentations on CMT in the pediatric population, orthopaedic considerations, genetic research, and selecting shoes ("How to Find the Right Shoe," page 12) and orthotic devices. Survey responses were positive and offered suggestions for improvement. Attendees were anxious for the next conference and pleased with the very personable approach of the presenters.

Dr. Jonathan Goldstein hosted the conference at the Gaylord Rehabilitation Hospital, Wallingford, Connecticut, on October 19, 1996. Again, despite a tremendous rainstorm that swept the East coast, the auditorium was filled to capacity with over 150 attendees. For the first time, the CMTA, assisted by the Westchester County, New York, support group, hosted a hospitality suite on the Friday night preceding the

*Above: Some of the CMTA members who filled the Gaylord Auditorium to capacity on October 19, 1996.*

*Below: The audience at the A.I. duPont Institute listened to an afternoon presentation by Dr. William MacKenzie.*



conference. Approximately 25 people met and discussed various concerns including surgery, custom shoes, motorized scooters, support group formation, and the problems of CMT in the adolescent population.

Saturday's conference included a presentation on an electrical stimulation study conducted at Gaylord ("Electrical Stimulation Strength Increase..." abstracted on page 5) and others on physical therapy, orthotics, and physiatry. One of the attendees expressed interest in starting a support group at Gaylord; information about that group will be available in the spring.



### GET THE PATIENT/FAMILY CONFERENCE ON VIDEO

Tapes of the Patient/Family Conference on CMT at the A.I. duPont Institute on September 19, 1996 are now available. The tapes feature presentations on CMTA and children, physical therapy (including finding shoes to fit), genetics, orthotics and orthopaedic surgery. The tapes were professionally filmed and edited and offer a comprehensive overview of CMT and its treatments. The two tapes run approximately three hours and are \$25 for members of the CMTA, \$40 for non-members.

## PUBLICATION ABSTRACT

### *Electrical Stimulation Test Results in Charcot-Marie-Tooth Diseases*

**Francis X. Palermo, MD** (Gaylord Rehabilitation Center, New Haven, CT)

**C**harcot-Marie-Tooth creates a profound conduction slowing (Type I), distal extremity weakness, and more proximal weakness. The muscle fibers atrophy because of lack of motor axon input rather than intrinsic muscle pathology. Conversely, the lack of muscle fiber activation fails to provide the axon with needed growth factors. Electrical stimulation applied to the motor points of atrophic muscles should activate nerve and muscle and thus reverse some atrophy.

Isometric stimulation was not tolerated. Brief trains simulating walking or cycling patterns (200–400 msec) were well tolerated and were able to create repetitive muscle contractions. In this study, nine patients with CMT I and two patients with CMT II were evaluated with isokinetic torque systems (Lido and Biotex).

The muscle groups that were able to create minimal torque output were tested before and after three to four months of five days per week stimulation, intensity 105 to 125 mA. First-month stimulation time was 20 min and thereafter increased to 40 min five days a week. Trains of 400 msec of 50-Hz pulses with 50- $\mu$ sec duration were applied each second to the knee or ankle flexors and extensors in a reciprocal fashion.

Visual analogue scales (VAS) were used to evaluate subjects' sense of balance and fatigue before and after. Ten of the 11 subjects demonstrated large percentage torque and endurance (work) increases in either the ankle dorsi-flexor/plantar-flexor pairs or the knee extensor/flexor muscle groups. Torque improvements were most notable in the



*Dr. Francis Palermo answers questions from the audience as Dr. Jonathan Goldstein, host of the Yale Conference, looks on.*

ant.tib. (50% to 300% through 30 degrees) ( $n=4$ ) and knee extensors (30% to 125% through 60 degrees)( $n=6$ ). Work output increased over 200% in eight of 10 subjects.

Eight subjects noted an improvement on the VAS in fatigue. Seven noted an improvement in balance. One subject was unable to obtain a contraction and did not show strength gains. Patients with CMT can benefit from brief repetitive patterned stimulation in both quantitative strength (torque) and endurance (work) and can improve their sense of balance.

*Editor's note: Although this abstract is technical in nature, patients interested in pursuing electrical stimulation as a treatment should show this to their physiatrist. Dr. Palermo can be contacted at the Gaylord Rehabilitation Center (1-203-624-3140) for more information.*

## WE'RE NETWORKING...

*CMTA Board members and staff attended the American Neurological Association meeting, the American Podiatric Medical Association meeting and the annual meeting of the National Organization for Rare Disorders. All three conferences resulted in increased awareness of CMT and the work of the CMTA. Highlights from each will appear in subsequent newsletters.*

## RESEARCH NEWS

## 3,4-Diaminopyridine Treatment Ineffective

by Louise Smith

## ■ OF INTEREST

The Friends' Health Connection provides customized one-to-one support for individuals and their families with health-related problems. People are connected so they can communicate one to one for friendship and mutual understanding. Participants are matched on criteria such as age, illness, personal background, surgeries, interests, etc. Health problems range from the most common to very rare disorders.

If you are interested in completing the survey form, call 1-800-48 FRIEND and find out how a friend can make a difference!

**D**rs. James Russell, Anthony Windebank, and C. Michel Harper, Jr. conducted a study at the Mayo Clinic on the use of 3,4-diaminopyridine (3,4-DAP) for the treatment of chronic stable demyelinating disorders. Diana Eline published her experiences as a study participant in *The CMTA Report*, Summer, 1993 ("The Mayo Clinic Dynamine Study: A Personal Account").

Unfortunately, this drug treatment is not effective in treating CMT Type I.

Provided here is a summary of the study findings to help readers better understand what testing entails. CMT Type I causes demyelination of the nerve. The potassium (K+) channels located under the myelin at the nerve's nodal regions are involved in the generation of the nerve's resting potential, the prevention of nerve reexcitation, and the stabilization of nerve firing after the event. As the K+ channels become exposed, repolarization is impaired. The drug 4-aminopyridine (4-AP) has been shown in animal studies to block K+ channels and to improve nerve conduction in regions of nerve demyelination. In addition, aminopyridines enhance neuromuscular transmission at the junction between the nerve and the muscle. The use of aminopyridines also has been tested as a potential treatment for multiple sclerosis.

Of the 34 adults participating in the Mayo Clinic study, 27 had CMT Type I. Participants were given either 3,4-DAP or a placebo during the first four days. During the next five days, no treatment was given to allow the drug to wash

out of their systems. During the subsequent four days, those who had been given 3,4-DAP were given a placebo, and those who had been given a placebo during the first week were given 3,4-DAP. In this double-blind crossover study, it was unknown to both the participants and the investigators until after the tests were completed during which period the 3,4-DAP was administered.

The 3,4-DAP pill was administered four times a day. The pill dosage was gradually increased from 5 mg four times a day for the first day to 10 mg for the second day, to 20 mg for the third and fourth days. The tests were performed both before treatment and 1 to 2 hours after the final administration when the drug is most prevalent in the blood stream.

A series of tests was conducted to measure isometric muscle strength, sensory ability (pinprick, vibration, cold, etc.), and electrophysiology. The nerve conduction studies measured the distal, median, ulnar, and peroneal compound muscle action potential; the median and ulnar sensory nerve action potential; and the motor and nerve conduction velocities.

None of the series of tests showed a statistically significant change with the treatment of 3,4-DAP. A mild facial tingling sensation was experienced by 71% of the participants, and 35% experienced mild light-headedness.

**Reference:** Russell, JW, Windebank, AJ, Harper Jr., CM, "Treatment of Stable Chronic Demyelinating Polyneuropathy with 3,4-Diaminopyridine." *Mayo Clinic Proceedings* 1995; 70:532-539.

## Sunshine Foundation Seeks Referrals

The Sunshine Foundation is a nonprofit children's charity that grants dreams and wishes to chronically ill children. The majority of the dreams they answer are to visit Disney World and other attractions in central Florida. The Sunshine Foundation now has a Dream Village 15 minutes from Disney World on a 21-acre site in Loughman, Florida.

When Sunshine answers a child's dream to go to Disney World, they assume all the costs that are accrued by such a trip. They provide air travel, accommodations for a five-day/four-night stay at the Dream Village, transportation during their stay, expense money, and admission tickets to Universal studios, Disney World, and Sea World.

The CMTA can refer any child that would benefit from the program. Several criteria must be met:

1. The child must be between the ages of 3 and 21.
2. The child must be chronically ill, terminally ill, or physically impaired.
3. The child's family must be financially unable to do this on their own.
4. The child must not have received a prior wish from this or any other wish foundation.

To be considered, please send the child's name, age and a brief history of his or her diagnosis with the parents' names and address to the CMTA. The Sunshine Foundation will mail out the required paperwork and when the application is completed, the board of directors of the Sunshine Foundation will make the final decision.

# Call for Participants

*Editor's Note: Michael Shy, MD, at Wayne State University in Detroit, Michigan, explains the study he and his colleagues are undertaking and the need they have for subjects.*

We see CMT patients in the context of our multidisciplinary neuromuscular clinic at the Wayne State University School of Medicine. The goal of the clinic is to provide the highest care possible to patients with neuromuscular disease, in particular to those with CMT. We also provide genetic counseling and, when necessary, genetic testing for the various forms of the disease. Both myself and Dr. Richard Lewis have specific training in the care of patients with diseases of the peripheral nerve. The clinic employs two neurogeneticists, Dr. James Garbern and Dr. John Kamholz, a psychiatrist, Dr. Steven Hinderer, as well as specialists in pulmonary disease, nutrition, and psychiatric counseling.

We are interested in developing clinical trials in patients with CMT1A similar to the type of trials being conducted in patients with diabetic peripheral neuropathy or, for example, Lou Gehrig's disease. As you may know, the mechanisms of how these disorders cause neuropathy are not well understood. However, the recent discovery of various growth factors for nerve cells and the ability by molecular biological techniques to mass produce these growth factors have made the growth factors attractive candidates to promote regeneration of damaged nerves in various forms of peripheral nerve disease. Although CMT1A is, of course, caused by genetic abnormalities in Schwann cells, which ensheath peripheral nerves, there is emerging

evidence that much of the weakness in patients occurs following degeneration of the nerve after the Schwann cell damage.

Prior to trying their growth factors on patients with CMT, biotech companies need to know if they can measure beneficial effects of the compounds in a defined time period, for example, a year. This is potentially a problem with CMT1A patients, who may show little outward change in a year's time. Therefore, we have been asked by the 17-university medical center organization of which we are a member (The Peripheral Neuropathy Clinical Trials Group) to develop methodology for evaluating progressive weakness in CMT patients so that they can be followed in clinical trials. We plan to evaluate patients by clinical exam, quantitative motor testing, quantitative sensory testing and what is called *motor unit analysis*. None of this testing involves needle EMG. The exam and the quantitative motor and sensory testing are completely painless. The motor unit analysis involves some mild "shocks" such as occur in nerve condition velocity testing. Because we are not certain which ages are best to study, we are especially seeking patients who have three generations of family members to test. Because we need to know precisely the disease we are hoping to treat, we need patients who have genetically defined CMT1A. If patients do not as yet have genetic diagnosis, we can help perform these through our clinic. Our tentative plan is to evaluate patients a total of three times in one year.

We currently have no financial support for this project so that we cannot pay patients or pay for travel to our clinic. However, because we feel these evaluations are worthwhile, we will not charge patients more than their insurance will cover for any of the evaluations.

Please call Izabella at 313-577-1689 to schedule an appointment or for more information.

—Michael Shy, MD, Associate Professor of Neurology and Molecular Medicine, Wayne State University, Detroit, MI, French Gene Research

## GREAT NEWS!

*The first Evenor Armington Research Grant recipient has been chosen. Dr. Michael Shy, a researcher and clinician at Wayne State University in Detroit, Michigan and a member of the CMTA's Medical Advisory Board will receive the grant, effective January 1, 1997. Details of his study will be announced in the winter newsletter.*

*Also, the Third International Conference on Charcot-Marie-Tooth Disorders will be in October 1998 in Montreal, Canada.*

Genethon is a French non-profit laboratory conducting DNA research on many hereditary diseases. They are particularly interested in blood samples from patients with Charcot-Marie-Tooth Type 2. Patients wishing to participate in this research should ask their doctor to contact: Jon Andoni Urtizberea, MD, Medical Director, Association Française Contre Les Myopathies (AFM), 1 Rue de L'Internationale, BP 59-91002 EVRY CEDEX, FRANCE; phone: 011-33-1-6947-2828; Fax 011-33-1-6007-1216.

## OF INTEREST

E-Z Key is an invention that provides additional leverage to facilitate turning the key in an automobile or any keyed entry system such as car doors, home doors, etc. Rick Draeger, the inventor, designed the E-Z Key for his mother who became physically unable to start her car because of CMT. There are two versions, one for car ignitions and one for door entries. For further information on the device, call 1-800-492-3279. (Several members of the Kansas City Support Group have tried the key in their cars.)



## NOTES TO FINANCIAL STATEMENTS

### 1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### Nature of Operations

The Charcot-Marie-Tooth Association (the Association) was incorporated under the laws of the Commonwealth of Pennsylvania as a nonprofit corporation in October 1983 and is registered with the Commonwealth of Pennsylvania as a charitable organization. The Association was established to sponsor, encourage and undertake scientific investigations of the causes and cures of Charcot-Marie-Tooth Disease. The Association receives the majority of its support from private donations.

#### Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires the use of estimates based on management's knowledge and experience. Accordingly, actual results could differ from those estimates.

#### Contributions and Recognition of Donor Restrictions

The Association reports gifts of cash and other assets as restricted support if they are received with donor stipulations that limit the use of the donated assets. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions.

#### Fair Value of Financial Instruments

The carrying amount of cash, accounts receivable, accounts payable and accrued expenses approximates fair value as of June 30, 1996 because of the short term nature of these items.

#### Equipment and Depreciation

Equipment is recorded at cost. Depreciation is provided on a straight-line basis over the estimated useful lives of the assets.

# Charcot-Marie-Tooth Association

## INDEPENDENT AUDITOR'S REPORT

To the Board of Directors  
Charcot-Marie-Tooth Association  
Upland, Pennsylvania

We have audited the accompanying statement of financial position of Charcot-Marie-Tooth Association (a Pennsylvania nonprofit corporation) as of June 30, 1996, the related statements of activities, cash flows and functional expenses for the year then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free

of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Charcot-Marie-Tooth Association at June 30, 1996, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.



August 26, 1996

## STATEMENTS OF FINANCIAL POSITION

JUNE 30, 1996 WITH COMPARATIVE TOTALS FOR 1995

ASSETS	1996	1995
<b>CURRENT ASSETS</b>		
Cash	\$136,460	\$115,378
Accounts receivable—grant	25,000	
	<u>161,460</u>	<u>115,378</u>
EQUIPMENT—Net of accumulated depreciation of \$6,189 and \$4,357	5,104	2,065
OTHER ASSETS	265	165
<b>TOTAL ASSETS</b>	<u>\$166,829</u>	<u>\$117,608</u>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable	\$ 3,104	\$ 2,066
Accrued expenses	250	427
<b>TOTAL LIABILITIES</b>	<u>3,354</u>	<u>2,493</u>
<b>NET ASSETS</b>		
<b>UNRESTRICTED</b>		
Operations	92,410	80,937
Board designated for research grants and education	14,179	14,179
<b>TOTAL UNRESTRICTED</b>	<u>106,589</u>	<u>95,116</u>
<b>TEMPORARILY RESTRICTED—</b>		
For research grants and education	56,886	19,999
	<u>163,475</u>	<u>115,115</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<u>\$166,829</u>	<u>\$117,608</u>

## STATEMENTS OF CASH FLOWS

JUNE 30, 1996 WITH COMPARATIVE TOTALS FOR 1995

	1996	1995
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Change in net assets	\$ 48,360	\$ 12,468
Adjustments to reconcile change in net assets to net cash provided by operating activities		
Depreciation	1,832	1,285
Increase in		
Accounts receivable - grants	(25,000)	-
Other assets	(100)	-
Increase (decrease) in		
Accounts payable	1,038	(157)
Accrued expenses	(177)	177
<b>Net cash provided by operating activities</b>	<u>25,953</u>	<u>13,773</u>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchase of property and equipment	(4,871)	-
<b>NET INCREASE IN CASH</b>	<u>21,082</u>	<u>13,773</u>
<b>CASH - BEGINNING OF YEAR</b>	<u>115,378</u>	<u>101,605</u>
<b>CASH - END OF YEAR</b>	<u>\$136,460</u>	<u>\$115,378</u>

The accompanying notes are an integral part of these financial statements.

# Financial Report as of June 30, 1996

## STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 1996  
WITH COMPARATIVE TOTALS FOR 1995

	1996		TOTAL	1995 TOTAL
	UNRESTRICTED	TEMPORARILY RESTRICTED		
<b>SUPPORT AND REVENUES</b>				
Contributions	\$128,393	\$71,887	\$200,280	\$105,247
Conference fees, net	-	-	-	2,090
Interest income	5,261	-	5,261	3,495
Miscellaneous	16	-	16	104
	<u>133,670</u>	<u>71,887</u>	<u>205,557</u>	<u>110,936</u>
<b>NET ASSETS RELEASED FROM RESTRICTIONS</b>				
Satisfaction of program restrictions	<u>35,000</u>	<u>(35,000)</u>	<u>-</u>	<u>-</u>
<b>TOTAL SUPPORT AND REVENUES</b>	<u>168,670</u>	<u>36,887</u>	<u>205,557</u>	<u>110,936</u>
<b>EXPENSES</b>				
Program services	154,074	-	154,074	95,288
Management and general	3,123	-	3,123	3,180
	<u>157,197</u>	<u>-</u>	<u>157,197</u>	<u>98,468</u>
<b>CHANGE IN NET ASSETS</b>	11,473	36,887	48,360	12,468
<b>NET ASSETS - BEGINNING OF YEAR</b>	<u>95,116</u>	<u>19,999</u>	<u>115,115</u>	<u>102,647</u>
<b>NET ASSETS - END OF YEAR</b>	<u>\$106,589</u>	<u>\$56,886</u>	<u>\$163,475</u>	<u>\$115,115</u>

## STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 1996  
WITH COMPARATIVE TOTALS FOR 1995

	PROGRAM SERVICES	MANAGEMENT AND GENERAL	1996	1995
			TOTAL EXPENSES	TOTAL EXPENSES
Salaries and benefits	\$ 30,386	\$ -	\$ 30,386	\$23,909
Publications and supplies	54,365	-	54,365	38,751
Occupancy and office expense	11,751	350	12,101	12,223
Research fellowships	35,000	-	35,000	12,000
Conference expense	18,232	-	18,232	4,437
Professional fees	2,508	2,773	5,281	5,863
Depreciation	1,832	-	1,832	1,285
	<u>\$154,074</u>	<u>\$3,123</u>	<u>\$157,197</u>	<u>\$98,468</u>
<b>TOTAL FUNCTIONAL EXPENSES - 1996</b>	<u>\$154,074</u>	<u>\$3,123</u>	<u>\$157,197</u>	<u>\$98,468</u>
<b>TOTAL FUNCTIONAL EXPENSES - 1995</b>	<u>\$ 95,288</u>	<u>\$3,180</u>	<u>\$98,468</u>	<u>\$98,468</u>

## NOTES (cont'd.)

### Tax Status

The Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. The organization is registered as required with the Pennsylvania Bureau of Charitable Organizations.

### In Kind Contributions

Volunteers have donated their time to the organization's program and administrative services and its fund raising campaigns. The value of this contributed time is not reflected in these statements since it is not susceptible to objective measurement or valuation. The Association occasionally receives donations of property and equipment. The value of these assets is not considered material and is therefore not reflected in the Association's funds.

### 2. CONCENTRATION OF CREDIT RISK

The Association maintains a cash account balance at a bank located in Philadelphia, PA. The total of these balances are insured by the Federal Deposit Insurance Corporation up to \$100,000. During the year, the Association may have a cash balance in its financial institution in excess of the limit. At June 30, 1996, there was no uninsured amount. The Association also maintains uninsured money market cash balances at a financial institution located in Philadelphia, PA. At June 30, 1996, the uninsured balance at this financial institution was approximately \$130,000.

### 3. CONDITIONAL PROMISE TO GIVE

A private foundation has authorized a grant of \$75,000 with \$25,000 authorized at June 30, 1996. The remaining \$50,000 will be paid over the next two years. The annual contribution of \$25,000 is contingent upon the Association's ability to match this amount from the general public. The \$50,000 remaining balance of the contribution is not recorded in the current year, but will be recorded as the Association meets the matching requirement each year.

*The accompanying notes are an integral part of these financial statements.*

## OF INTEREST

Information about the U-Step Walking Stabilizer (featured in the Winter 1996 issue) can be received from the In-Step Mobility Products, Co. at 1-800-558-7837 or 847-676-1275 (in Illinois).



# My African Safari: A Portrait of an Adventure and an Adventurer

By Dr. William Quinn, a member of the CMTA Board of Directors

Anyone who has a hectic work schedule and an active life takes time out to think about what they would do if they could find more free time. My passions are hunting, fishing, and enjoying the great outdoors.

This past August, I was fortunate enough to experience the outdoor adventure of a lifetime: an African safari. Two friends and I spent two weeks hunting big game animals in the country of Namibia.

Before I continue with my adventure, let me digress and quickly tell you about my CMT. I was diagnosed when I was 13 years old. I have one brother with the disease. We have the X-linked variety with no other relatives showing any signs or symptoms. I was always athletically active despite my CMT. Before high school ended, it became necessary for me to wear braces. I wear rigid AFO's on both legs that can cause unique shoe and boot fitting problems. Hiking and hunting require different shoes and boots, and modifications to fit the braces are necessary. I have always felt the benefits of my

*Dr. William Quinn poses with the "big game" he successfully hunted in Namibia.*



outdoor activities outweighed temporary discomfort and distress.

Now back to Africa. The plane ride was extremely long, 15 and a half hours going; 18 hours coming back. We flew from New York to Johannesburg and then to Windhoek, Namibia. Requesting an aisle bulk-head seat near the rest rooms paid great dividends, as I was able to remove my braces during the flight and still get around. Once in Namibia, our safari outfitters picked us up at the airport. We had a four-hour jeep ride out into the African bush. The area we hunted in was the Western Kalahari Desert, which was extremely dry with very sparse, but rugged, vegetation. Our accommodations were quite civilized, with beds, showers, and drinkable water. The entire outfitter staff was extremely hospitable and very entertaining.

Large expanses of open area with several small rocky mountains and rocky high ground were typical. Our hunting was mainly done on foot, after enduring long, open-air jeep rides to get to specific areas. Surprisingly, my feet did very well. The only medical problem I encountered was a cracked rib that only hurt when I laughed.

The hunting was terrific and the photographic opportunities were superb. To properly hunt and photograph undisturbed animals in the wild requires long hours of walking and stalking. Often we needed to climb up on the high, rocky outcroppings to use binoculars to find the small herds of animals. Although I was usually last up the hill, I always made it and the rewards were worth the discomfort.

If any individual with CMT has the desire to participate in adventurous activities, they can fulfill their dreams with detailed planning. Choosing the right outfitter and circumstances with the right physical conditions, along with being honest about your abilities (to your outfitter and yourself), should allow you to enjoy all the adventures you choose to undertake.

The experience in Africa was truly wonderful. Without reservation, I am planning a second trip, hopefully in the not-too-distant future.



## Member Starts Golf Group

**A**ndora Peddrick, a CMTA member from Blue Bell, Pennsylvania, is interested in starting a golf group. Possible activities would include group outings, weekend golf trips, and exchanges of ideas and news about special equipment and beneficial instruction.

Andora started playing golf about a year ago in an effort to stay active and to share a love of her husband's. Diagnosed in her 30's, she has been a teacher and has managed a hotel in the Caribbean, a video store, and a restaurant. Andora has been a lap swimmer for years and started golfing after attending a clinic for the disabled at the Bryn Mawr Rehabilitation Hospital.

Her husband has designed and patented a golf glove which has improved her grip and overall game.

Regardless of ability, CMTA members, families, or friends are invited to call Andora at 215-641-1806 to join the new golf group.

Members outside of Pennsylvania might follow Andora's lead by initiating similar sport/recreation activities as well.

## GIFTS WERE MADE TO CMTA IN MEMORY OF

**Ralph H. Binford**  
Marilynn Dodge

**Anne Bernstein**  
William Bernstein

**Mr. & Mrs. A.A. Carlson**  
Jeanne Corbin

**Edward Coogan**  
Kay Flynn

**Ruth B. Davidson**  
Jean B. Waldron

**Martin Edelheit**  
Ruth Edelheit

**William Feather**  
Mrs. Samuel T. Hubbard

**Dr. Milton Greenberg**  
Marilyn Prashker

**Kevin Healy**  
Robert & Ann Healy

**Sophie Jacobson Adler**  
Ruth Edelheit

**Nellie Nan Kelley**  
Laurel Financial Group  
Karen Cooper Burkett  
Mark & Wynola Shultz  
Apryl Chidiac

Fraternal Order of Eagles  
Cooper Brothers  
Mr. & Mrs. Joe Moore  
Barbara & Jay Feuer  
Carrie Robbins  
Girl Scout Troop #1909

**Alfred T. Marks**  
Mr. & Mrs. Paul Magnani  
Unibase Direct, Inc.

**James Palmer**  
Irene Palmer  
Armond & Alberta Rist  
Bob G. Kester  
Dan & Beverly Rezendes  
Family

Geraldine M. Solari  
Katherine DeAbrary  
Elvira Pedevilla  
Denny & Arlene Bertelsman  
Helen L. George

**Rebecca Sand**  
Rose Freed  
Helen Stanton

**Victoria Smith**  
Terry Light, M.D.

**Sheldon Thomas**  
Mrs. H.C. Lewis

**W. J. Van Huss**  
Harris Methodist H.E.B

**Richard F. Walker**  
Greg Walker  
Chris Gilchrist  
David B. Wood  
Patricia A. Fitzsimmons  
John & Janet Buttgeriet  
and Girls  
George & Edith Rist  
Charles & Vinnie Turner  
Mr. & Mrs. Edward  
Gianolini  
Roberta Oswald  
Ruth Records  
Susan Neal

**Dorothy Williams**  
Joan Martucci  
The Grammes Family  
Patricia Weldon  
Mrs. Alois Gutekunst  
Ms. Suzanne Gutekunst  
Bell & Howell Co.  
Employees  
Alois Gutekunst's  
Co-Workers  
Mrs. Lois Kesack

## GIFTS WERE MADE TO CMTA IN HONOR OF

**Barbara Bernstein's  
70th Birthday**  
Bernie & Dubby Bernstein

**Gail Gadd's Birthday**  
Roy C. Gadd

**Paul Gomez**  
Kay Flynn

**Emily & Bob Louer's  
Anniversary**  
Mr. & Mrs. Arthur  
B. Mayers  
Susan Louer

**Donald LeFurge**  
His Family  
Donna Spears  
Russell Le Furge  
Dale Le Furge  
Rita Morgan

**Charles T. Lynch**  
Helen K. Lynch

**Ms. Janet Smith**  
International  
Library Systems

**Alex Segal's Birthday**  
Helen Segal

**Faustino & Maria  
Velazquez**  
Leonor Deetjen

**Mrs. Ruth Wendkos'  
Successful Surgery**  
Selma Rothstein  
Estelle C. Bandler

**Hart Wurzburg's  
75th Birthday**  
Jane Logan  
Fred & Ann Ullman  
Floraloise A. Goodkind

# How to Find the Right Shoe

From a presentation by Maureen Donohoe at the duPont Conference, Wilmington, Delaware

*Maureen Donohoe demonstrates why an inappropriate shoe will have too much flexibility for the CMT foot.*



**W**ith Charcot-Marie-Tooth, one tends to have a stiff, high-arched foot. One will weight-bear with more on the outside surface of the foot in a supinated position. It is not uncommon to have hammer toes.

The “upper” or top of the shoe should be made of a material that allows the shoe to “breathe,” such as leather, synthetic leather, or a mesh. It should be flexible and have a wide toe box.

The “insole” or the sock liner should be easily removable to allow for an orthosis. The “midsole” or the layer between the sole and the shoe is where the shoe’s shock absorption is stored. It should be made of a flexible material such as polyurethane or EVA.

The shape of the shoe should be curved (bean shaped) or semi-curved. Board-lasted shoes look like cardboard inside and are stiffer and good when using an orthosis. Slip-lasted shoes have stitching along the inside of the shoe. This makes the shoe more flexible and is a better choice when not wearing an

orthosis. Combination-lasted shoes have a board in the heel for stability and slip last in the front for flexibility. These are difficult to find but not a bad choice with or without an orthotic device.

The “heel counter” is the back of the shoe and should be stiff and snug. It should be deep enough to allow one to wear an orthosis without pistoning the foot out of the shoe. Laces help to hold the foot in the shoe. It is best if there are several lacing options to allow for comfort.

For dress shoes, men need a shoe with a wide toe box and a deep heel counter. Shock-absorbing soles such as crepe are good. If you choose not to use an orthotic device, the shoes can be taken to a shoe repair person to have Reverse Thomas heels put on. Women should avoid high heels. They should look for a shoe that buckles or ties rather than one that slips on. The heel counter should be firm, but the forefoot should be flexible.

*Editors note: For more about finding shoes that fit, see page 14, Letters to the Editor.*

## How to Give to the CMTA...

### MAKING A BEQUEST

There are a number of ways of continuing your interests in the Charcot-Marie-Tooth Association through your estate plans. One simple and meaningful way is to include a bequest in your will.

Your attorney can help prepare your will and choose the best wording for your particular circumstances. Following are sample provisions for review by your attorney:

#### For a Specified Amount

I give and bequeath to the Charcot-Marie-Tooth Association, Upland, Pennsylvania, the sum of \_\_\_\_\_dollars, to be used as determined by the Board of Directors; (or for research or operations).

#### For a Percentage of an Estate

I give and bequeath to the Charcot-Marie-Tooth Association, Upland, Pennsylvania, \_\_\_\_% of my estate, after payment of all debts, expenses, and taxes to be used as determined by the Board of Directors; (or for research or operations).

### GIFTS OF STOCK

A gift of appreciated stock can save you taxes when you make a donation to the CMTA. For example, if you make a gift of \$1,000 using stock that cost you \$100, you save \$252 in Federal income taxes, so the gift only “costs” you \$748.

#### To make a gift of stock:

For stock held in a brokerage account, send a letter directing your broker to transfer the shares:

\_\_\_\_ Shares of [name of security]

PaineWebber Inc. DTC # 221

2 Logan Square, 24th Floor, Philadelphia, PA 19103

Attention: Carol Thompson

For credit to the Charcot-Marie-Tooth Association

Account # JH45207-74

For actual stock certificates, send the certificates with a letter to Carol Thompson at Paine Webber Inc. using the above address and account information.

Please send copies of your letter to Pat Dreibelbis at the CMTA, 601 Upland Avenue, Upland, PA 19015 so that we may acknowledge your donation. If you have questions, please call Carol Thompson at 800-523-4144 or Pat at the CMTA office (800-606-2682).

# Letters to the Editor:

## *Type 2 Volunteers Needed for Study*

Dear CMTA Report,

For patients diagnosed with CMT Type 2, there is a lab at Duke University working on CMT2. I have this diagnosis. The problem with Type 2 is that the markers appear in different places for different families so there's no test yet. The researchers weren't able to use my family info at this time because of the nature of the research at this stage. If you can contribute family/genetic info to this project, you bring the test closer for others, as well.

The man to contact is Jeff Stajich at P.O.Box 2900, Duke University Medical Center. His e-mail is [stajich@morgan.mc.duke.edu](mailto:stajich@morgan.mc.duke.edu)

## *Suggestions from Readers*

Dear CMTA Report,

As a sufferer of CMT Type II, I take a lot of interest in media reports concerning alternative therapies and vitamin supplements. Just recently an article appeared about carnitine therapy. It was recommended for post-polio sufferers because carnitine deficiency causes fatigue, muscle pain, and muscle weakness. The nutrient is found mainly in red meat and avocado. Polio survivors have less muscle tissue in their affected limbs and a lower capacity to store sufficient carnitine.

I decided to try it and I take 4 grams a day. The results after about 8 weeks were better than I expected. I have a lot more energy; I feel great; and my muscles, especially in my calf are getting bigger. I do not get fatigued like I used to.

I hope you find this information useful.

—R.F. Western Australia

Dear CMTA Report,

I have CMT. I recently had an irregular heartbeat and as a result, started taking magnesium tablets ( my magnesium level was low and the tablets were to regulate heartbeat, i.e. muscle contractions.) I've noticed fewer legs cramps at night since taking the magnesium. I wonder if others have had a similar experience.

—D.B. Statesville, NC

## *A Question for Readers*

Dear CMTA Report,

I have a problem. I've had CMT for some 40 years and until recently have been getting along reasonably well with a cane. It's one my father bought many years ago when it was fashionable for a gentleman to carry a cane. It is both thin and very light. I now find that I have better support with a forearm crutch, but can't go more than 25-30 paces without my hand feeling like it's falling off, causing me to drop the crutch.

Questions: Does anyone else have this problem? Does anyone know of a lighter version of this crutch? If so, could you send me some information on it in care of the CMTA?

—T.R. Virginia Beach, VA

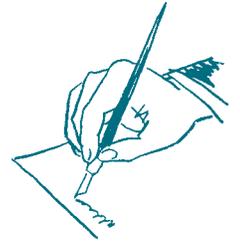
## *Penpals Wanted*

Dear CMTA Report,

I would like to correspond with others (in English, en français, oder auf deutsch). I'm a 29-year old woman with CMT who has overcome much of it through weight-lifting and a use-it-or-lose-it attitude. I was diagnosed at the age of 14 after years of wondering why I couldn't run like the other kids, and why I was such a klutz.

The best thing I ever did was pay attention to myself instead of the doctors ( although doctors now know so much more and are great as guideposts). Instead of being put in a wheelchair like they wanted, I ignored them and continued in the ballet classes I had just started to try to get some coordination. Of course, there are things I couldn't do, but I loved to dance so much I just couldn't imagine giving it up for a wheelchair. The disease did get the best of me a lot as a teenager. I was on crutches often.

I couldn't keep up dance while at college, so I started swimming, using weights, and doing light aerobics (because of fatigue, I couldn't do high impact). My desire to remain walking without braces, crutches, etc. was so strong that I pushed myself a lot. I have read that people with CMT are not supposed to exercise much because they will burn out their system. Well, I really don't believe that, especially since it's now



## 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.*

## ■ OF INTEREST

A CMTA member has success with a sock manufactured by the Thorlo company. They are three pair for \$30.00 and are padded to protect bony pressure points. The controlled stretch of the sock adjusts to the shape of your foot and reduces friction and bunching. Call "The Active Foot" at 1-800-543-7286 to order or to request a catalogue.



## More Letters to the Editor:

been a decade that I've been exercising and I've been off crutches, etc. for three years.

Recently, a doctor who specializes in CMT (in Montreal) biopsied a nerve from my ankle and compared it with my original biopsy taken when I was 14. Although my EMG and EEG are still weak, the nerve sheath itself looks a lot healthier than it did. He told me to keep up whatever I was doing.

In addition to exercise, I also take lecithin. There are plenty of studies out there on the Net about lecithin and improvement in nerve sheath in people with cerebral palsy. I started taking it when I was 16 after reading initial studies. Now they use it as an accepted treatment for Alzheimer's disease because they discovered it does slow down, and, in some cases, stop the progression of Alzheimer's disease. I would love to hear from other people with CMT and about their experiences. I am a translator, living just outside of Montreal.

e-mail address: nickelltrad@autoroute.net

### *Relief for the Feet*

Dear CMTA,

We in Kalamazoo appreciated the recent listing in the newsletter of Okun Bros. Shoe Store, which carries extra-depth shoes. We have had excellent results from another local store that also does custom shoe making. Their address is: Corey's Bootery, 1016 East Cork Street, Kalamazoo, MI 49001.

—C.L. Kalamazoo, MI

Dear CMTA,

In the past forty years, I have spent a great deal of time and money looking for a pair of shoes that fit me well and feel comfortable. I am a 64-year-old woman who has had surgery three times since 1984.

I have a very short, wide foot with an over-developed arch. One foot is 1 1/2 sizes smaller than the other and rolls to the outside. Add hammer toes and a woman's sense of vanity...it was quite an order to fill. I have purchased orthopedic shoes, had orthotic inserts made, etc. without success.

In 1987, my daughter found a shoemaker who provided a solution for me and for others. His name is Mr. Andre Feuerman of the Leach-Kale Co., 1261 Broadway, NY, NY 10001, tele-

phone number (212) 683-0571.

Enclosed are photographs of three different pairs of shoes that Andre has made for me. I have had the beige, lace-up shoes for over five years and I wear them for a part of almost every day, particularly when I'm doing a good bit of walking. I call the other two pairs my "dressy shoes." I have had physicians and orthopedic practitioners tell me these are the finest orthopedic shoes they have ever seen.

There are two caveats: you will need to travel to New York City for your first pair and the shoes are expensive. However, nothing has been of greater help to me. I will be happy to talk with anyone who would like more information. I can be reached through the CMTA.

—Gay Jacobs, Birmingham, AL



### Dear CMTA Report:

The following address and telephone number may bring help to someone with a drop foot caused by CMT. This company, Early Winters, offers a catalogue of ski clothing. The ankle brace for the right and left foot is a sturdy and very tightly knit fabric brace with two velcro straps. I wear these; as a result I have fewer stumbles. In fact, when I wear both I do not stumble. I can work in the garden, walk on gravel or stone. The price is \$20.00 per brace. My brother, who wears an AFO brace, wears these heavy fabric ones when he wants relief from the heaviness of the plastic.

Here are the company's address and phone number:

Early Winters, 1 Quality Circle  
Kearneysville, WV 25429

1-800-458-4438 (a call will bring a catalogue to anyone who requests it.)

—H.S. Ossian, IN

# CMTA Contacts

Following is a list of CMTA contact persons and support group leaders. There are many CMTA support groups, but more groups are needed. The CMTA will help you set up a group in your area. For information about forming a group or being a local contact person, please inform the CMTA by mail, fax 1-610-499-7487, or call the office at 1-610-499-7486. This page will appear in the newsletter whenever space permits.

## Alabama/Greater Tennessee Valley

\* Bill Porter 205/386-6579 work  
205/767-4181 home

## Arizona

Lavon Little 602/516-0539

## California

\* Janice Hagadorn 805/985-7332 after 5  
(Oxnard/Thousand Oaks)

\* Denise Miller 805/251-4537  
(Canyon County/Saugus)

\* Freda K. Brown 707/573-0181  
(Santa Rosa)

Gary Oleze 619/944-0550 after 6

Sandra Huntley 310/597-3728

Felice Gail Viggers 805/492-2840

Verna M. Sabo 818/892-6706

Mary Micalizzi 619/441-2432 after 6

Bob Hedge 310/645-2761 9-5

Lisa Parks 916/751-2019

916/673-5099

Richard Zall 714/492-9877

(Orange County)

## Colorado

\* Dr. Gregory Stilwell 719/594-9920  
(Denver area)

Roberta Cummings 719/846-5611

## Connecticut

Mary Rehm 203/744-2786

\* Kay Flynn 914/793-4710  
(Fairfield)

## District of Columbia

\* Lorraine Middleton 202/362-4617  
6-9 pm

## Florida

William Brady 904/443-6271

Mary Beeler 407/295-6215 9 am-8 pm

Harold Wilson 407/465-3656

Pat Ports 407/965-3691

M-W-F 4-9 pm

Joe Ellenbogen 305/921-4660

Edward Carhart 305/567-1066

9:30-5:30

Beatrice Bannister 407/737-3267

Robyn Cohen 407/622-5829

M-F 8-9:30 pm anytime weekends

Erika Stilwell 305/232-9066

\* Walter Sawyer 561/336-7855

## Georgia

Nancy Lee McCutchen 770/925-1020

## Kansas

\* Ardith Fetterhoff 816/763-2176  
voice mail 816/756-2020

## Louisiana

Bobbie Marberry 504/872-0895

## Maryland

Jean Iler 410/987-5432

Linda Ember Miller 410/882-4019

Robert Kight 410/668-3054

## Massachusetts

Wayne Cardillo 413/298-3156

\* Donald Hay 617/444-1627 9 am-7 pm  
(Boston)

Jim Lawrence 508/460-6928

Jennifer Brelsford 413/538-9579

## Michigan

Robert D. Allard 517/592-5351

Debbie Clements 616/956-1910

\* Suzanne Tarpinian 313/883-1123  
(Detroit)

Laurie Vasquez 517/893-4125

## Mississippi

\* Julia Prevost 601/885-6482

\* Henry/Brenda Herran 601/885-6503  
(Jackson)

Mae Blackledge 601/763-5151

## Minnesota

Rosemary Mills 320/567-2156

Grace Wangaard 612/496-0255

## Missouri

\* Ardith Fetterhoff 816/763-2176  
voice mail 816/756-2020

Allan Degenhardt 816/942-1817

Carol Haislip 314/644-1664

Lisa Minzer, RN 314/978-0557

## New Hampshire

Mary Knightly 603/598-5451

## New Jersey

Janet Saleh 908/281-6289

Linda Muhlig 609/327-4392

Gary Orson 609/584-9025

M-F 6-10 pm & weekends

Russell Weiss 908/536-6700

## New Mexico

Jesse Hostetler 505/536-2890

## New York

Joe Ehman 716/442-4123

Internet:KOLOB@Multicom.org

Diana Eline 201/861-0425 before 9 pm  
(New York City)

Abby Wakefield 212/879-9517

\* Bernice Roll 716/584-3585  
(Rochester)

\* Kay Flynn 914/793-4710  
(Westchester County)

Amy Gander 518/373-9907

Angela Piersimoni 607/562-8823 after 2

Sharon McAvey 718/380-3792

afternoon & evening

William Carrington 718/486-6953

4-11 pm

## North Carolina

Emily Louer 704/849-2367

Diane Rodden 910/584-3655

\* Susan Salzberg 919/967-3118 5-9 pm  
(Durham)

Raymond Woodie 910/838-3221

## Ohio

Roger Emmons 216/286-6485

Suzanne Lammi 513/339-4312

Norma Markowitz 215/247-8785

## Oklahoma

Leah Holden 405/255-4491

## Oregon

Marianne DeStafano-  
Hill 503/585-3341

## Pennsylvania

Dennis Devlin 215/269-2600 work  
610/566-1882 home

Patricia Zelenowski 717/457-7067

Camille Walsh 215/747-5321

Janet Fierst 412/487-0757

Mary MacMinn 215/322-1073

Carol Henderson 215/424-1176

Tony Petre 412/647-8324

## Rhode Island

Robert Matteucci 401/647-9154 in pm

## Texas

Karen Edelson, DPM 214/542-0048

214/542-0122

M-T-Th 8:30-5

## Virginia

\* Mary Jane King 804/591-0516  
(Tidewater)

## West Virginia

\* Joan Plant 304/636-7152 after 6 pm  
(Central)

Barbara Compton 304/636-5456 24 hrs.

\* Denotes support group leader

## 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.

## 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, Macrochantin)  
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 med-  
ication, please discuss it  
fully with your doctor for  
possible side effects.

# What is CMT?

- ...is the most common inherited neuropathy, affecting approximately 125,000 Americans.
- ...is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ...is slowly progressive, causing deterioration of peripheral nerves which 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.
- ...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 the focus of significant genetic research, bringing us closer to answering the CMT enigma.
- ...Type IA and CMTX can now be diagnosed by a blood test.

## *The CMTA Report*

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

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