AUTUMN 1995

The CMTA Report

Vol. 10, 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.

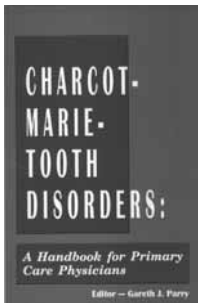
Our Year in Review

1995 has been another exciting year for the Charcot-Marie-Tooth Association; a year in which we reached two significant milestones in our growth. The first research grants were awarded from the CMT Research Fund and *Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians* was published by the CMTA.

In June, the Charcot-Marie-Tooth Association Student Fellowships were awarded to three CMT researchers and their students. The researchers have completed their work and will submit their reports by year end. We will report on the results in *THE CMTA REPORT* during 1996.

Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians is the first medical text devoted solely to the diagnosis and treatment of Charcot-Marie-Tooth. The handbook was written by the CMTA Medical Advisory Board. Ten members of the Medical Advisory Board each contributed a chapter based on their specialty. Dr. Gareth Parry edited the handbook, in addition to contributing a chapter.

The handbook was written for primary care physicians; however, it is also an excellent resource for people with CMT. Many of our members are ordering two books—one for themselves and one for their primary care physician. The handbook provides an opportunity for people with CMT to improve their health care by working in partnership with their primary care physician.



The Physician's Handbook is now available. See order form on page 3.

On December 1st, the CMTA will award the Anita Harding Post-Doctoral Fellowship for Research in Charcot-Marie-Tooth Disorders. The grant review committee rated four of the applications received as excellent and worthy of funding. Unfortunately, we have funding for only one project this year.

We are developing a "CMTA home page" on the Internet which we hope to complete by year end. Until then, the CMTA can be reached at TSLY45A@prodigy.com. We received our first e-mail yesterday from a CMTA member.

We want to thank the Board members who retired during the past year for their dedication and commitment to the CMTA. We also want to welcome four new Board members: Louise Smith, founder of CMTnet, an on-line information repository, and a Massachusetts resident; Ardith Fetterolf, Kansas City support group leader; Dr. William Quinn, a podiatrist from Milwaukee; and Paul Flynn, Associate Director of Development at Seton Hall University Law School.

We are proud of what we have done, but we still have a lot of work ahead. In January, we are planning a Board Retreat which will focus on our vision, our mission, and our future programs. The CMTA exists to serve our members. So, please write and let us know what you would like to see accomplished in the next year.

I look forward to guiding the CMTA to an even more successful year in 1996. Thank you to all our members for your support.

Diane M. Freaney,
President

YOU CAN REACH CMTnet ON THE INTERNET @URL<http://www.ultranet.com/~smith/CMTnet.html>

PERSONAL PROFILE:

Chuck Genrich

About this time last year, Chuck Genrich was told that he was going blind by one of the top opthalmologists in the Greater Washington, D.C. area. Chuck had been diagnosed with CMT just 24 months before, still the news about his vision came as a blow. "I had been taught since early childhood that diamonds are made under pressure, and no matter what, you must never give up."

Today, thanks to a unique procedure developed at the Wilmer Eye Institute at John Hopkins University Medical Center in Baltimore, Maryland, Chuck is able to see and his eye problem has been cured.

For over 15 years, Chuck's vision was deteriorating and his quest for a solution to this puzzling problem went unanswered. Between April and August last year, Chuck visited his doctor 14 times and was fitted with four progressively stronger pairs of glasses. By the end of 1994, his vision was 20/500 in the right eye. His doctor told him the only thing left to do was to patch the eye. During this exam, the doctor leaned over and suggested this treatment: "Chuck, just don't listen to your eye, pretend the pain is not there."

Recognizing the futility of this kind of advice, Chuck called a friend at Yale Medical School who advised him to visit the Wilmer Eye Institute at John Hopkins. He was diagnosed with a unique cataract condition that had been seen only 3 times before, and never in someone as young as himself. Not only was Chuck not going blind, but Johns Hopkins had developed a surgical procedure to *cure* his problem.

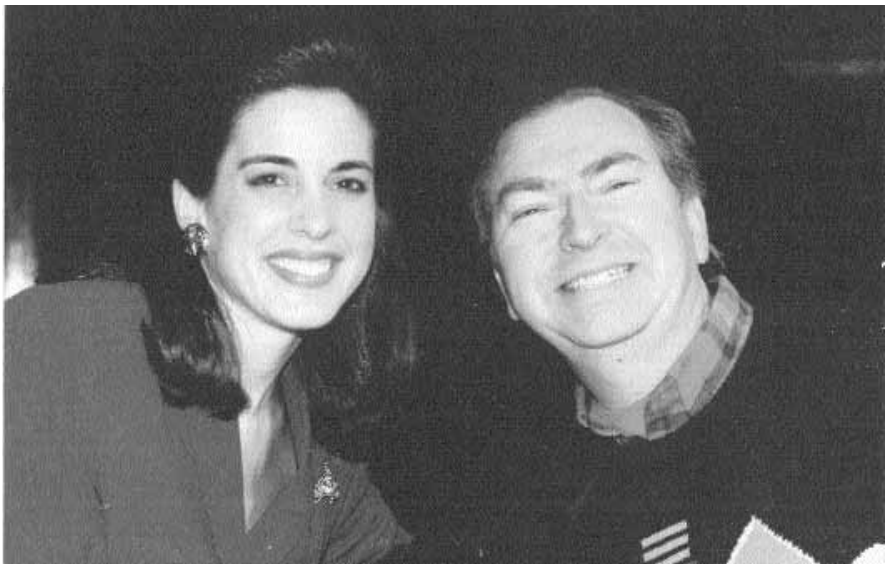
Chuck returned to two eye specialists who were both familiar with the impact of CMT, neuro-muscular diseases, and their connection with visual difficulties.

Two weeks later, Chuck prepared for surgery. A tiny ultrasonic device was inserted just outside Chuck's cornea. The device broke the cataract in his eye into fine pieces which were then suctioned out.

Then the doctor implanted a new artificial lens, about the size of an aspirin, into Chuck's eye. The following day the bandages were removed, and the doctor declared the operation a stunning success. "I was simply euphoric," Chuck said, "It was as if I had awakened from a very bad dream!"

Chuck has returned to a more complete work schedule with both teaching and consulting assignments. A graduate of Colgate, Harvard, and Oxford University, Chuck has received 4 community leadership citations.

Chuck's CMT, has necessitated accommodations in his lifestyle. With the help of a cane, AFO's, and careful management of fatigue, Chuck has been able to cope with the challenges that are commonplace with this disease.



Miss America 1995, Heather Whitestone, who has been deaf from birth, visited Chuck Genrich at the kickoff luncheon of a special program for hearing impaired children sponsored by Ms. Whitestone.

WISDOM IN THE EYE OF THE FROG

by Robert Vermeulen

Readers will not view the subject of genetics in the same way after completing Robert Vermeulen's profound and deeply affective book. *Wisdom in the Eye of the Frog* goes beyond simply discussing the nature of heredity and human difference. Vermeulen probes how small genetic differences among people lead to unequal ability and skills. Sections include ways individual choice can be used to rectify the inequality, an exploration into modern techniques of genetic screening, development of the brain and much more.

To order by phone, call 1-800-2RUT-LEDGE (1-800-278-8533). The cost is $22.95 plus $3.50 shipping and handling.

Long Distance Love

Long Distance Love is a non-profit 501(c)(3) organization that connects people who have the same illness so that they can communicate for mutual support. Long Distance Love seeks to alleviate the devastation illness can bring by providing a friend who is experienced with or who has overcome the same health problem and whose support can help guide the way. Participants are matched based upon a number of criteria including age, health problems, symptoms, personal background, attitude, hobbies and interests. People of all ages participate and their health problems range from the most common to very rare disorders. Family members, friends, and caretakers can be connected as well via LDL's Family Network.

Long Distance Love was founded nearly seven years ago by 24-year old Roxanne Black. At the age of 15, Roxanne was diagnosed with systemic lupus, a chronic inflammatroy disease. Wanting to communicate with someone her own age who understood what she was going through, she decided to establish Long Distance Love. Since that time, LDL has continued to grow and has touched nearly 4,000 people worldwide.

Through the years, Long Distance Love has been praised by very prominent individuals. Roxanne has received more than two dozen honors for her work, including a Point of Light award from former President George Bush. Her story has been featured in the media worldwide.

Because Long Distance Love is just a phone call away, it provides an advantage over traditional support groups, which can be inaccessible to people with chronic illnesses or who are located in remote areas of the country. The support network asks new members to donate $ 10, but no one is turned away if they can't contribute.

People in New Jersey can join Long Distance Love by calling (800) 48-FRIEND. Callers outside the state can call (908) 418-1811. Hot lines operate Monday through Friday from 9 a.m. to 5 p.m.

cut here

CMTA MEMBERSHIP/ORDER FORM

Name:_____

Address:_____

_____

Phone Number: _____

	QTY	COST	TOTAL
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		*members* $15 *non-members* $20	
Membership Dues		$25	
CMT Facts I ☐ English ☐ Spanish		$3	
CMT Facts II ☐ English ☐ Spanish		$5	
CMT Facts III		$5	
VCR Tape: CMTNeurology		$15	
VCR Tape: Physical Therapy & Occupational Therapy		$15	
VCR Tape: CMT Genetics		$15	
VCR Tape: Orthopedic Surgery & CMT		$15	
CMT Informational Brochure ☐ English ☐ Spanish		FREE	*Send Self-Addressed Stamped Envelope*
Physician Referral List: States: _____ _____ _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research			
TOTAL			

☐ Checks payable to the CMTA

☐ VISA ☐ MasterCard

Card Number_____ Expiration Date_____

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.

GIFTS WERE MADE TO CMTA IN MEMORY OF

Sophie Jacobson Adler
Ruth Edelheit

Kathryn Pauline Agee
Agee Family

Ralph Binford
Marilyn Dodge

Sophia Lambert Bradwick
Faye Bradwick

Miron Canaday
Bank of Boston
Raymond & Dorothy Torres
Doreen Spitzer

Paul Doherty
Joan & Clarry Vater

Martin Edelheit
Ruth Edelheit

Ruth Feen
Stuart Feen

Grace G. Hawkes
Joanne Field

Matthew Panagis
Westchester, NY
Support Group

Joseph Rabinowitch
Rebecca Brezel

Jack & Lillian Rose
Phyllis Goodman

Rebecca Sand
Judith Goldman
Elizabeth Levy
Rosemary O'Brien

Esther Swarbrick
Dorothy Gamble

GIFTS WERE MADE TO CMTA IN HONOR OF

Butch DeStefano
Marianne DeStefano-Hill

Karol Bradwick Hitt
Faye Bradwick

Charlotte Karr's 75th Birthday
Shirlee, Debbie, Shari and Al & Family

Shirley Loughan
Gloria Bowers

Ask the Doctor…

Dear Doctor,

Whenever anyone discusses CMT, they refer to it as a peripheral neuropathy. What exactly does it mean to have a peripheral neuropathy?

—D.S. New York

The Doctor replies:

If you think of the nervous system as the electrical circuitry in your house, then the wires that supply various lights and appliances would be the peripheral nerves, while the fuse box and the main cable would be the central nervous system (the brain and spinal cord). Peripheral nerves are the nerves that extend outside the brain and spinal cord.

There are three types of peripheral nerves: motor, sensory, and autonomic. Motor nerve fibers carry signals to muscles to allow motions like walking and fine finger movements. They're like the cords that supply power to appliances that do work, like a power saw or a washing machine.

Sensory nerves carry information to the brain about shape, movement, texture, warmth, coolness or pain from special sensors in the skin and from deep in the body. They are like the cables that supply power to instruments that sense things, like your home's thermostat.

The autonomic nerve fibers are those that are not consciously controlled, like those that supply the bladder, intestinal tract,and sexual organs. Among other functions, they help to control the pace of heart beats, maintain blood pressure, and control sweating. In that way, they are like the cables in your house that supply things that are self-regulating, like the electrical cables supplying your furnace that automatically switch off and on as the house gets colder or hotter.

Dear Doctor,

Several people in my family have been diagnosed as having CMT, but they have each had different tests or no tests at all. How is CMT normally diagnosed?

—C.G. Arizona

The Doctor replies:

The first approach is knowing the patient's family history. The physician will also ask about muscle weakness, muscle cramps, persistant prickling numbness or pain. Observation of typical CMT clinical symptoms such as a high arch or the typical stork leg appearance will also help the physician make his/her evaluation.

The second approach to diagnosis is the neurological evaluation. The physician may access muscle strength and sensation (ability to recognize pinprick and vibrating sensation). These are simple and painless examinations.

The third approach is known as an electromyographic examination. This test has two components.The first is the nerve conduction test. A physician performs this test by applying a


Charcot-Marie-Tooth Association

THE CMTA REPORT

Service Dog— Joe Ehman's Best Friend

Special Education... Your Child's Rights

We've Changed Our Look!

By the time you've reached this page, you have surely noticed that the CMTA Report has a very different look. We've changed our layout style and, hopefully, have made the newsletter easier for you to read. We intend to keep the content as informative as it has always been, but we hope that the increased white space and the new design will make your reading more pleasurable.

When anything changes, it takes time to adjust. Please let us know what you think of the new design, but wait until you have seen several issues.

small electric shock to nerves, for example, in the region of the knee and ankle. The voltage is recorded with sensitive electronic amplifiers from a disk pasted to the skin overlying the muscle. In CMT, the speed of the impulse along the nerve is decreased, indicating an abnormality Type I. Most people do not find the shocks excessively uncomfortable.

In some severe cases, the physician may request a second part of the electromyography be performed. This test is called needle electromyography. A slender needle is inserted into several muscles and the electrical discharges are recorded. From such an examination, the electromyographer can learn whether nerve fiber degeneration or regeneration has occurred. Most patients report some discomfort from the procedure but tolerate the test because it can give a firm diagnosis.

A less frequently used test is the nerve biopsy which involves removing a sample of nerve tissue, which is examined for damage. This test is most often used in research settings.

Dear Doctor,

On CMTA's list of neurotoxic drugs is included "mega doses" of vitamins A, B6, and D. What is a mega dose of each of the three vitamins?

I ask because I have been advised to take multivitamin supplements, yet all those multivitamins I have seen in the drug store contain vitamins A, B6 and D. The multivitamins all contain at least 100% of USRDA for those three vitamins; some multivitamins contain 200% or more. Consequently, I don't take any multivitamins at all, as i have no idea if 100% of the USRDA for vitamins A, B6, and D is a mega dose. If you could define how many mg constitutes a mega dose for those vitamins and what is a safe dose, I would appreciate it.

—F.E. California

The Doctor replies:

This question is often asked by people with CMT. It is simply that a mega dose is 10 times the amount of the recommended daily allowance. It is simplier to understand as 10 times the recommended allowance for each vitamin than to try to tell someone each dosage amount. On any multivitamin package, you will find the amount of the daily allowance that is provided. It would be unusual for any single dose of a multivitamin to contain mega doses of one of the vitamins on the neurotoxic list.

Support the CMTA

by applying for our Action MasterCard on page 11. Everytime you use the Action card the CMTA will get a percentage of your purchase dollar amount!

CMT 1B Preimplantation Embryo Diagnosis

by Haruhiko Sago, Hak-Soon Kim, Roger Pederson and Roger Lebo

Editor's note: This study was financed in part by a summer internship provided by the CMTA.

Our laboratory has been working to develop a reliable test to distinguish normal embryos from embryos carrying a CMT mutation so that only embryos not affected with CMT can be implanted into the mother's womb. This procedure, called preimplantation diagnosis, will provide at-risk couples an alternative means to have only children without CMT while avoiding other options like prenatal diagnosis and possible termination of an affected fetus, gamete donation from an individual without CMT, adoption, or having no children.

In vitro fertilization has provided an alternative to couples otherwise unable to have children. A woman with no trouble having children produces about 10 eggs during each in vitro fertilization cycle. If the husband's sperm fertilize all of these eggs from a couple at risk for a child with a common CMT1 gene, half the embryos will carry the CMT gene and the other half will carry only normal genes. Our studies of the Trembler mouse indicate we will be able to segregate normal human embryos from CMT embryos with a reliability of 97%. Unaffected embryos would then be implanted into the mother's womb to develop normally.

Preimplantation diagnosis biopsy involved testing 2 cells from an 8-cell embryo for a CMT mutation. Then, only normal embryos with 6 cells are selected and returned to the mother's womb. A CMT Association grant funded us to test whether mouse embryos with a 50:50 chance of receiving Trembler mutation could be distinguished from normal embryos. When both cells gave the same result in 31 embyros, this result was confirmed in 30 embryos by testing the remaining cells. Thus, the diagnosis was correct 97% of the time. The Trembler mouse mutation causes the trembling in mice and would cause CMT Type 1A in humans. Since this test found a single DNA base change in the Tremble mouse embryo, any CMT mutation could be tested from any single cell. Our current test for a human CMT1B gene mutation gave similar results using patient blood cells. Now we are making DNA test changes to further improve upon the reliability prior to offering a test to all CMT1B patients. Together with a planned CMT1A test for gene duplication, these tests could serve over half of all CMT patients.

The CMT Association is the first organization founded to help patients with a specific disease that supported developing this technology. This decision to support the research was at least as important as the research funds provided because it reflected the agreement by some health professionals and patients that preimplantation diagnosis could be used to increase the liklihood that the children of CMT patients will not have CMT. We thank the CMT Association for supporting this project to provide an alternative to prenatal diagnosis, gamete donation, adoption, or having no children.

BLOOD TEST AVAILABLE

The blood test for diagnosing CMT Type IA found on chromosome 17 is available from Athena Diagnostics. They can be reached by calling 1-800-394-4493, ext. 106. Ask for Gina, customer service tepresentative. A physician must order the shipping kit. The cost of the test is $425.00

Profiles of Neuromuscular Diseases, Hereditary Motor and Sensory Neuropathy, Types I and II

An abstract of a study which appeared in a supplement to the American Journal of Physical Medicine and Rehabilitation*, Volume 74, Number 5. September/October 1995.*

Data were collected prospectively for an impairment and disability profile for 86 hereditary motor and sensory neuropathy, types I and II (HMSN) subjects over a 10-year period. Our data confirm that HMSN is a slowly progressive disorder that has a very heterogeneous phenotypical expression. The disorder was characterized primarily by diffuse muscle weakness with prominent distal atrophy. The mean manual muscle test (MMT) strength grade for all muscle groups combined was 3.9 +-0.7 MMT units. There was a slowly progressive decline in strength, only -0.15 MMT units per decade. Distal muscle groups were weaker than proximal muscles, and the decline in strength of

Medical Advisory Board Meets in Washington, DC

Four members of the CMTA's Board of Directors, Diane Freaney, Ann Beyer, Dr. Robert Lovelace and Jack Walfish staffed a booth where doctors could buy the new handbook and where sample copies of the CMTA's newsletter and medical brochures were available. Information about the summer internships provided by the CMTA was available, as well as information about the $35,000 post-doctoral grant that will be awarded in January 1996.

The Medical Advisory Board of the Charcot-Marie-Tooth Association met on October ??, 1995, in conjunction with the meetings of the American Neurological Association in Washington, DC. The primary topic for the MAB members was the recent publication of the CMTA's handbook for primary care physicians. The doctors present discussed Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians and were unanimous in their praise of the book. Complementary copies of the book were provided to each member of the MAB.

the ankle muscles was greater than for the proximal muscles. There was no side dominance. Anthropometric data revealed that distal atrophy may be masked by subcutaneous fat in female subjects. On average, HMSN subjects produced 20-40% less force than normal controls, using quantitative isometric and isokinetic strength measures, even when MMT scores were normal. Pulmonary and cardiac abnormalities were uncommon, as were spinal deformity and joint contractures. Only 1 individual had severe restrictive lung disease, and 12 (14%) had a history of significant respiratory complications with no age or disease duration effect. As with the other neuromuscular diseases, maximum expiratory pressure was more affected than forced vital capacity. Fourteen individuals (30%) had abnormal electrocardiograms, and six (7%) had a history of significant cardiovascular complications with no age or disease duration effect. Kyphosis was the major spine deformity. Cardiopulmonary responses to exercise testing were markedly abnormal, showing reduced aerobic capacity. Functional evaluations and timed motor performance tests showed only mild disability in most individuals. With timed motor performance testing muscle weakness translated to impaired motor performance skills. Overall, mean scores on intellectual function and neuropsychological profiles were normal.

Charcot-Marie-Tooth Association

NOTES TO FINANCIAL STATEMENTS

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Organization
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.

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.

Donated Services and Property and Equipment
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 are not considered material and are therefore not reflected in the Association's funds.

Property and Equipment and Depreciation
Property and equipment are reported at cost. Depreciation is provided on a straight-line basis over the estimated useful lives of the assets.

INDEPENDENT AUDITOR'S REPORT

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

We have audited the accompanying statements of financial position of Charcot-Marie-Tooth Association (a Pennsylvania nonprofit corporation) as of June 30, 1995 and 1994, the related statements of cash flows for the years then ended, and the related statements of activities, and functional expenses for the year ended June 30, 1995. 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 audits 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 audits provide 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, 1995 and 1994, its cash flows for the years then ended, and the results of its activities for the year ended June 30, 1995, in conformity with generally accepted accounting principles.

Bala Cynwyd
August 15, 1995

STATEMENTS OF FINANCIAL POSITION

JUNE 30, 1995 AND 1994

	1995	1994
ASSETS		
Cash	$115,378	$101,605
Security deposit	165	165
Computer equipment, net of accumulated depreciation of $4,357 and $3,072	2,065	3,350
TOTAL ASSETS	$117,608	$105,120
LIABILITIES AND NET ASSETS		
Accounts payable	$2,066	$2,223
Accrued expenses	427	250
TOTAL LIABILITIES	2,493	2,473
NET ASSETS		
Unrestricted	95,116	81,154
Temporarily restricted	19,999	21,493
TOTAL NET ASSETS	115,115	102,647
TOTAL LIABILITIES AND NET ASSETS	$117,608	$105,120

STATEMENTS OF CASH FLOWS

YEARS ENDED JUNE 30, 1995 AND 1994

	1995	1994
CASH FLOWS FROM OPERATING ACTIVITIES		
Changes in net assets	$ 12,468	$ 28,476
Adjustments to reconcile changes in net assets to net cash provided by operating activities		
Depreciation	1,285	1,285
Increase (decrease) in		
Accounts payable	(157)	2,223
Accrued expenses	177	-
Net cash provided by operating activities	13,773	31,984
NET INCREASE IN CASH	13,773	31,984
CASH - BEGINNING OF YEAR	101,605	169,621
CASH - END OF YEAR	$115,378	$101,605

See notes to financial statements.

Financial Report as of June 30, 1995

STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 1995
WITH COMPARATIVE TOTALS FOR 1994

	UNRESTRICTED	1995 TEMPORARILY RESTRICTED	TOTAL	1994 TOTAL
SUPPORT AND REVENUES				
Contributions	$ 94,741	$10,506	$105,247	$105,385
Conference fees, net	2,090	-	2,090	2,592
Interest income	3,495	-	3,495	2,360
Miscellaneous	104	-	104	213
	100,430	10,506	110,936	110,550
Net assets released from restriction	12,000	(12,000)	-	-
TOTAL SUPPORT AND REVENUE	112,430	(1,494)	110,936	110,550
EXPENSES				
Program services	95,288	-	95,288	79,917
Management and general	3,180	-	3,180	2,157
TOTAL EXPENSES	98,468	-	98,468	82,074
CHANGE IN NET ASSETS	13,962	(1,494)	12,468	28,476
NET ASSETS - BEGINNING OF YEAR	81,154	21,493	102,647	74,171
NET ASSETS - END OF YEAR	$ 95,116	$19,999	$115,115	$102,647

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 1995
WITH COMPARATIVE TOTALS FOR 1994

	PROGRAM SERVICES	MANAGEMENT AND GENERAL	1995 TOTAL EXPENSES	1994 TOTAL EXPENSES
Salaries and benefits	$23,909	$ -	$23,909	$23,040
Publications and supplies	38,549	202	38,751	31,186
Occupancy and office expense	12,000	223	12,223	11,975
Research fellowships	12,000	-	12,000	-
Conference expense	4,437	-	4,437	10,878
Professional fees	3,108	2,755	5,863	3,710
Depreciation	1,285	-	1,285	1,285
TOTAL EXPENSES - 1995	$95,288	$3,180	$98,468	
TOTAL EXPENSES - 1994	$79,917	$2,157		$82,074

See notes to financial statements.

NOTES (cont'd.)

2. TAX STATUS
The Association is exempt from income tax under Section 501(c)(3) of the Internal Revenue Code and, accordingly, the financial statements do not reflect a provision for income taxes.

3. CONCENTRATION OF CREDIT RISK
The Association maintains cash account balances at one financial institution. The total of these balances are insured by the Federal Deposit Insurance Corporation up to $100,000. During the year, the Association may have cash balances in its financial institution in excess of the limit. At June 30, 1995, balances were in excess of insurable amounts by approximately $31,000.

4. FUND FOR RESEARCH GRANTS AND EDUCATION
Funds have been designated and restricted for research grants and education as follows:

Designated by board from contributions received prior to July 1, 1993,included with unrestricted net assets.	$14,179
Restricted by donors as a result of an annual appeal conducted in fiscal year 1994 and 1995.	31,999
Less net assets released in fiscal year 1995	(12,000)
	$34,178

WRITE TO US!

Pat Dreibelbis, Editor
The CMTA Report
CMTA
601 Upland Ave.
Upland, PA 19015

OUR APOLOGIES:

If you ordered the *Physician's Handbook* in the summer and have not yet received it, please call the office and one will be mailed to you that day.

1-800-606-CMTA

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

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

Letters to the Editor:

Dear CMTA,

Our daughter Grace is 6 years old and they (Doctors) are about 80-90 percent sure she has CMT. She began having problems at about 2 1/2 years after she twisted her ankle. Three and 1/2 years later, she has no movement from the knees down and is beginning to develop weakness in her hands. They are (fingers) contracting up and she has difficulty zipping, opening locks, buttoning, etc.

Treatment has consisted of wearing braces on feet/lower legs and recently hand splints around the house. She has also, for the first time, begun a physical therapy routine to strengthen the healthy muscles. Because it began at such an early age, she does not let it slow her down. She does a great job keeping up with the other children.

We have lived in three different states since they first diagnosed the problem...allowing consultations with at least 4 different neurologists. The mystery for us is that neither side of the family has ever had CMT or any symptoms (that we know). We would love any information about other young children who have CMT, especially ones where it progressed this rapidly. Information on what has been the most helpful. regarding treatment or physical therapy would be appreciated.

Our most recent move has brought us to Indiana where there is no contact person available. The CMTA newsletter has been very helpful. It has given us, unfortunately, more insight into the disease than the doctors have.

—E.K. Indiana

Editor's note: Parents wishing to correspond with E.K. may address letters to the CMTA office and they will be forwarded to the family.

Dear CMTA,

I would like to inform other CMT patients of some remarkable doctors in Tucker, Georgia, who have had tremendous luck in surgically correcting foot deformities caused by CMT. Their names are Dr.Dalton McGlamory, Dr. Alan Banks and Dr. John Ruch and they are associated with Peachtree Podiatry. Their phone number is 770-938-5974.

Dr. McGlamory has developed some of the techniques that he uses and has traveled extensively lecturing to other physicians on the subject. Patients come to their office from all across the country and many CMT patients have had very positive results.

The doctors cannot cure the disease, but they can increase a patient's ability to walk which certainly helps people deal better with the disease.

A very pleased patient. *—N.M. Georgia*

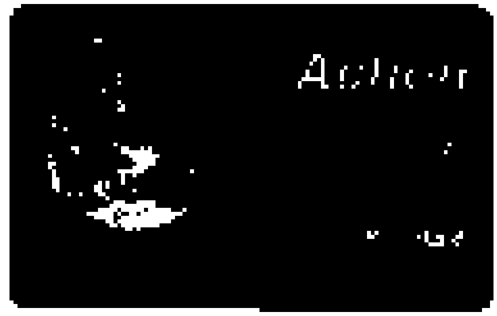
How to obtain a list of the CMT Support Groups...

In an effort to make room in the newsletter for articles of interest to our readership, the editorial staff made a decision to remove the Contact Person page from the newsletter. We will continue to add new names to the list of contact persons, and we will continue to announce support group formations when they occur. If you would like the current list of support group leaders and contact persons, please send your request to the office of the CMTA with a self-addressed, stamped business size envelope.

SUPPORT THE CMTA by applying for an Action MasterCard.

Action MasterCard offers a no fee credit card which returns a portion of the money charged on that card to the sponsoring organization. The CMTA is currently offering this MasterCard to its membership. If you wish, by applying, receiving, and using the Action MasterCard issued in the CMTA's group name, you can contribute to us every time you spend money. We hope that many of our members will choose to apply for this new credit card as a means of supporting our work.

Take *Action*™
to earn money for
Charcot-Marie-Tooth Association
...and save money for yourself!



- Travel Accident Insurance
- Travel discounts and dividends
- Convenience checks for writing
- Instant cash at thousands of ATM machines
- Card Holder Newsletter
- Eye Wear discounts

OR...

82

Check Account Choice: (Only One)
☐ Individual Account
☐ Joint Account

PRIMARY APPLICANT

For Position Only
Separate Mechanical Provided to the Printer

TRANSFER OF BALANCE REQUEST

CO-APPLICANT or SPOUSE

CREDIT DISCLOSURES

[illegible]	[illegible]	GRACE PERIOD FOR PURCHASES	METHOD OF COMPUTING THE BALANCE FOR PURCHASES	LATE PAYMENT FEE	OVER THE LIMIT FEE	CASH ADVANCE FEE
[illegible]	[illegible]	[illegible] Days	Average Daily Balance (excluding New Purchases)	[illegible]	[illegible]	[illegible] of Transaction

SIGNATURE(S)

X ______________________ Date
X ______________________ Date

FOR INTERNAL USE

MEDICAL ALERT:

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

Adriamycin
Alcohol
Amiodarone
Chtoramphenicol
Cis-platinum
Dapsone
Diphenylhydantoin (Dilantin)
Disulfirarn (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Mega Dose of Vitamin A
Mega Dose of Vitamin D
Mega Dose 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.

What is CMT?

…is the most colmnon inherited neuropatly, 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/foreaml.

…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 crampmg, loss of some normal reflexes, and scoliosis (curvature of the spine) is sometimes present.

…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 dommant 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

Crozer Mills Enterprise Center
601 Upland Avenue
Upland, PA 19015