WINTER 2000

The CMTA Report

Vol. 15, No. 1 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.

EMAIL CMTA AT:
CMTAssoc@aol.com

CMTA Office Relocates

By PAT DREIBELBIS

For all of you who read the last issue of the newsletter and learned of the devastation of the flooding that followed Hurricane Floyd, the fact that the office of the association has relocated comes as no surprise. For a while, we were optimistic that the building we had been housed in for the last nine years would rebuild and be better than ever. Unfortunately, the damage was so profound on the ground level of the building that finances dictated that the building be left for demolition. So, as of October 31, 1999, we were officially without a headquarters.

Luckily, we were able to find a new office on the ground floor of an assisted living building only three miles from our former offices. We were able to move in mid-November and have been functioning somewhat normally since then. The new location is much more spacious than the former office and the building we are in is less than a year old and is fully handicapped-accessible. With that added accessibility feature, we are optimistic that we will be able to enlist the aid of volunteers in the near future to better serve you and advance the cause of CMT.

Slowly but surely, the damaged items are being replaced or cleaned and returned. We apologize for the lack of reprints for the last few months, but our paper files have finally been cleaned and are back in our possession. They are not perfect, but at least we have samples of the many scientific papers that we have been accumulating for over 15 years. A flood is a good reminder, although an unpleasant one, of the need to have as much information as possible stored in data files on the computer.

The Residences at Chestnut Ridge is the new high-rise home of the Charcot-Marie-Tooth Association.

Several members of the organization deserve notice in this article for their significant gifts to assist us in recuperating from the flood. They are The Buuck Family, Joy Rushfeld, Steve Khosrova, Robert and Pamela Kleinman, Lavon Phillips, Lawrence Porterfield, Rick Alber, and Doris Lancaster. As is always the case, the members of this organization have been very supportive of our efforts and are the reason for our existence.

In addition, the staff of the CMTA would have, literally, gone crazy without the help of President Jack Walfish, who drove from New Jersey almost every day during the worst of times and continues to assist in the rebuilding effort despite his recent cataract surgery. We thank him for his long and, sometimes, thankless hours of work.

President's Annual Report

By JACK WALFISH

Many Thanks

to those of you who sent donations to help us rebuild our offices after Hurricane Floyd. More is still needed, and the CMTA continues to gratefully accept contributions designated towards this effort. Please send checks, made payable to "CMTA", to The CMTA, Attn: Flood Relief, 2700 Chestnut Pkwy., Chester, PA 19013.

Each year, one of the jobs of the President of the CMTA is to prepare an annual report which is published in conjunction with the auditor's report of our financial status. It is a time to reflect on our many accomplishments and to think about the work that needs to be done for the future.

Because of circumstances, we were unable to have our annual meeting at the end of our fiscal year. The audited report, published last year, shows that our expenses exceeded our revenue. We avoided being in a deficit situation because we had built up some reserves. I am positive that this can all be attributed to the above-average amount of expense generated by the Third International Conference on CMT, which we hosted in Montreal, and which served to enhance the professional reputation, dignity, and standing of CMTA among scientific researchers worldwide—well worth the additional expense and effort.

Once again this year, the audit shows that the organization had expenses in excess of revenue. To some extent, our emphasis on raising money for research has hampered our efforts to support our operational expenses. We have resolved to focus more on our operations accounts in this fiscal year.

The CMTA funded four (4) $4000 summer Fellowships and three (3) $3500 Post Doctoral Grants, the results of one of which will be published in a highly regarded medical journal this year.

As of this date, we have cut expenses and our revenues are exceeding them handily. We have more paid members than ever before, and those numbers seem to be increasing. In many ways, until the untimely and certainly unexpected flood, we were financially healthier than at any time in our 15-year history.

Our toll-free 800 number and our Home Page discussion link are both very popular; our Physician's Handbook continues to sell, and we have reprinted an amount that we believe will hold us until it can be completely revised. Several doctors on our Medical Advisory Board are currently at work on that project.

To further wave the CMTA flag and make our name more well known, we staff informational booths at several medical conventions, such as the neurology and genetics meetings.

Despite the increasing number of paid members, we continue to grant Scholarship Membership to a record number of people who cannot afford the fees of $35. This year alone, more than 500 people requested scholarship memberships.

September 16, 1999, was a sad and devastating day in our history. That is the day that Hurricane Floyd caused the creek behind our building to flood the parking lot and building to a level which reached above the desk tops in our office. In the nine years we had been housed there, nothing of this nature had ever occurred.

The damage was devastating, on both a material and a personal level. It pained me just to look at the ruins.

We worked, temporarily, on several bridge tables in a second-story room of the same building, but we had to vacate, eventually, because all services were cut off. We have found new space, as you read in the cover story, and it is very spacious and should offer us the potential to increase our services to you, our members.

We lost three computers. Luckily our server was situated atop a tall file cabinet, so with some hastily obtained new computers we were able to get back to work fairly promptly. All paper records are damaged, and we will try to replace them as we move forward. Boxes of newsletter, pamphlets and books were destroyed.

As of this writing I estimate that it will cost us between $20,000 and $30,000, to replace all the damaged furniture, computers, printers, etc. All this in addition to increasing our costs for the rent, light, and other utility bills.

This was certainly an unfortunate setback, just when we were looking forward to a wonderful year, but we remain optimistic. We are continuing with plans to publish a Genetics Handbook, and a book about how schools and teachers should treat children who have CMT to help them adjust and feel accepted by their peers.

Despite our losses, we are still "in business" and are working to serve our members and friends in the new millennium. We have ambitious plans and as always, we have hope for a new year of service to our members.

SPECIAL OFFER: Get All The Facts...

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

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

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

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

cut here

CMTA MEMBERSHIP/ORDER FORM

Name:____

Address:____

____

Phone Number: ____

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

	QTY	COST	TOTAL
Charcot-Marie-Tooth Disorders: **A Handbook for Primary Care Physicians**		*active members* $15 ***inactive members*** **$20**	
Membership Dues		$35	
CMT Facts I ☐ English ☐ Spanish		*active members* $3 ***inactive members*** **$5**	
CMT Facts II ☐ English ☐ Spanish		*active members* $5 ***inactive members*** **$7**	
CMT Facts III		*active members* $5 ***inactive members*** **$7**	
CMT Facts IV ***NEW PUBLICATION***		*active members* $8 ***inactive members*** **$10**	
VCR Double Tape: Wayne State Conference		*active members* $25 ***inactive members*** **$40**	
VCR Double Tape: duPont Conference		*active members* $25 ***inactive members*** **$40**	
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 Armington Challenge for CMT Research			
Shipping & Handling *Orders under $10 add $1.50, orders over $10 add $3.00*			
TOTAL			

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

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Card Number____________________________ Expiration Date ____________

Signature ____

Mail to the CMTA, 2700 Chestnut Parkway, Chester, PA 19013

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.

CMTA Announces Three $35,000 Grant Recipients

The Charcot-Marie-Tooth Association made its first research grants in the summer of 1995 and has continued its support of research dedicated specifically to Charcot-Marie-Tooth disorders in each of the subsequent years. For the year 2000, the three awards go to Dr. Ken Inoue, at Baylor College of Medicine, Dr. Edguardo Arroyo from the University of Pennsylvania and Dr. Emilia Ianakova from Wayne State University.

Dr. Ken Inoue was granted a continuation of his fellowship from 1999 in which he sequenced the entire 1.5-Mb CMT duplication/HNPP deletion region. He is working with Dr. James Lupski on a project entitled "Characterization of a Myelin Transcription Factor, SOX1O, Responsible for Myelin Deficiencies in Both the PNS and the CNS." The study will attempt to understand the role of SOX1O in myelin development by creating a transgenic SOX1O mouse. The mice will then be studied to understand the PNS (peripheral nervous system) and the CNS (central nervous system) phenotypes and how the morphology of the myelin in these tissues is affected.

Dr. Edguardo Arroyo will be studying "The Reorganization of the Axon Membrane in Animal Models of CMT" at the University of Pennsylvania under the direction of Dr. Steven Scherer. Dr. Arroyo will use animal models such as the Trembler and TremblerJ mice, P0+/- mice, Cx32 mice, and myelin-associated glycoprotein mice to study whether the extent of axonal membrane reorganization is related to the degree of demyelination and remyelination. Axonal loss and not demyelination, per se, causes the clinical deficits seen in CMT type 1. Thus, understanding how demyelination leads to axonal loss is key to understanding the pathogenesis of CMT.

The final full-year grant has been awarded to Dr. Emilia Ianakova from Wayne State University, working with Dr. Michael Shy, a member of the CMTA's Medical Advisory Board. Dr. Ianakova's project is entitled, "Tissue-Specific Gene Therapy for CMT 1." In order to produce gene therapy for CMT 1, replication-defective adenoviruses can be used to introduce genes into Schwann cells and neurons in the peripheral nervous system. This year's study intends to extend those studies by generating and utilizing adenoviral vectors which express the neurotrophic factors GDNF and CT-1 to prevent secondary axonal degeneration and promote regeneration in the P0 knockout mouse model of CMT1.

These studies are made possible by the support of our generous members, who give as much as they can, both small and large amounts, to support the work of researchers dedicated to finding a cure for CMT.

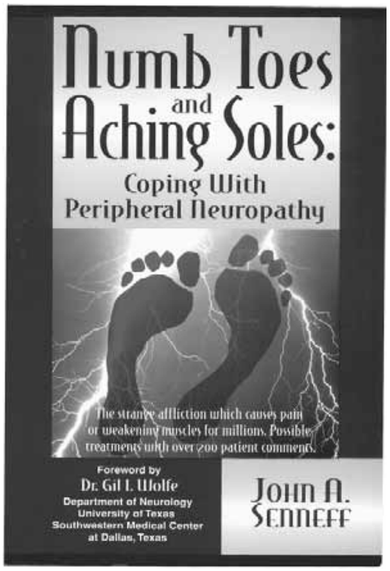
SPECIAL OFFER: "NUMB TOES AND ACHING SOLES"

Some of you may recall I reviewed the book, *Numb Toes and Aching Soles: Coping with Peripheral Neuropathy*, in the Summer 1999 issue of the *CMTA Report*. At the time I wrote that the book "is a very thorough resource for anyone coping with CMT and the attendant pain," even though, as I said, not every section would be relevant for us. I added that, personally, it "would be a desk reference for me from now on."

The publisher of the book, MedPress, is now kindly offering Association members a special 20% discount from their regular prices. Consequently the hardback version, normally $29.95, will be $23.95 to members, and the paperback, listed at $19.95, will be available at $14.95. Shipping and handling charges of $4 are in addition.

Members may either telephone their orders in to MedPress with credit card information using the toll-free number 1-888-633-9898, or mail checks to MedPress, P.O. Box 691546, San Antonio, TX 78269. It will be necessary for you to identify yourself as an Association member in either case.

The order form at the MedPress web site (www.medpress.com) may also be used. That web site, incidentally, offers a good deal of information on the book. Just add "CMTA" after your name and the 20% reduction will be made, even though the form as printed is programmed to show the full price.



Summer Fellowship Report

Pregnancy and Exacerbation of Peripheral Neuropathy in Charcot-Marie-Tooth Disease

By TINA K. KRALJEVIC, University of Virginia Medical School Class of 2002

(Editor's note: Pregnant women may wish to share this article with their doctors.)

OBJECTIVE:

To assess the frequency and severity of increased peripheral neuropathic symptoms in Charcot-Marie-Tooth disease (CMT) associated with pregnancy.

BACKGROUND:

We evaluated a young woman with pre-existing CMT who became persistently non-ambulatory owing to worsened peripheral neuropathy during pregnancy. Significant progression of peripheral neuropathy in CMT with pregnancy has been reported in individual cases and small series. Because of the smaller number of reported cases, the frequency, severity, and duration of such worsening are unknown. Although women with CMT may be relatively more susceptible to the neuropathic consequences of pregnancy-related conditions such as compressive neuropathies*, diabetes, and hypothyroidism, worsened CMT neuropathy during pregnancy may be independent of these known risks. A survey was performed as a preliminary investigation of increased peripheral neuropathic symptoms during and subsequent to pregnancy in women with CMT. Despite the limits and biases of such an uncontrolled investigation, if the perception of increased neuropathic symptoms is relatively common, it may provide the impetus for a formal, controlled study.

DESIGN/METHODS:

The Charcot-Marie-Tooth Association newsletter mailing list was used to generate a random list of 1000 women. These women were sent a questionnaire to identify onset, worsening, and persistence of peripheral neuropathic symptoms in distal extremities, walking difficulty, and falls during previous pregnancies. Responders included as subjects for data analysis met the following criteria: female sex, clinical CMT diagnosis supported by family history, electrodiagnostic studies, molecular genetics or nerve biopsy, and one or more pregnancies at or subsequent to the CMT diagnosis.

RESULTS:

Of the 1000 questionnaires mailed, 512 were returned. Responders were excluded for the following reasons: male sex (50), nulliparous (no pregnancies) female (33), incomplete questionnaire (63), and uncertain diagnosis or non-patient (41). 325 responders met subject inclusion criteria and were analyzed. In these women, the mean age was 48.7 years with an average age of 31.4 years at the time of CMT diagnosis. 28% (90) affected women experienced initial or worsened neuropathic symptoms. Of these affected women, an identified peripheral neuropathic comorbidity† such as diabetes, thyroid disease, or compressive neuropathy was reported in 14, while 76 had no apparent comorbidity over 138 pregnancies. In the latter group, walking difficulty increased in 70% (96) and falls increased in 43% (60) of pregnancies. Postpartum improvement was reported in only 33% (25) of affected women without apparent comorbidity, with a mean time to improvement of 5.1 months.

CONCLUSION:

This survey of a large cohort of parous women with CMT suggests that pregnancy is associated with worsening of peripheral neuropathic symptoms in a significant subset of these women. In most of these women, no peripheral neuropathic comorbidity was reported. A minority of these patients perceive postpartum recovery. The data do not distinguish between symptoms and objective neuropathic findings. Nonetheless, the perception exists in a subset of CMT patients that significant and persistent peripheral neuropathic worsening occurs during pregnancy. This finding merits a prospective, controlled study in parous and non-parous women with CMT and in a control group of pregnant patients.

OF INTEREST

The Kleberg Cytogenetics Laboratory is a part of the Medical Genetics Program at Baylor College of Medicine. They offer FISH (fluorescence in situ hybridization) testing for both Charcot-Marie-Tooth disease, type 1A and for hereditary neuropathy with liability to pressure palsies. The Kleberg Laboratory is a full-service laboratory offering 10-day turnaround time, shipping or courier services, expert consultation, and a color FISH photograph accompanying all written reports. Contact the lab at 1-800-411-GENE (opt. 1).

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*carpal tunnel syndrome is an example of a compressive neuropathy

†comorbidity is a second disorder

GIFTS WERE MADE TO THE CMTA IN HONOR OF:

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James Bintz
Paula Bintz

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Sam DiCara
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Henry Friedman's birthday
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Daniel Max
Mr. & Mrs. Adam Max

Joe Morena, with thanks
Martin Sterling

Mrs. John Ruddy's 80th birthday
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Mom & Dad

GIFTS WERE MADE TO THE CMTA IN MEMORY OF:

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CMTA Remembrances

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

Honorary Gift:
In honor of (person you wish to honor)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____
____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____
____

Amount Enclosed: ______________________________
☐ Check Enclosed ☐ VISA ☐ MasterCard
Card # ______________________________
Exp. Date ______________________________
Signature ______________________________

Gift Given By:
Name: ______________________________
Address: ______________________________
____

General Guidelines and Precautions for Exercise

(These hints appeared in the publication of PLS Newsletter, an information exchange for persons with Primary Lateral Sclerosis.)

1. Seek the expertise of an occupational or physical therapist who is experienced with neuromuscular disease. A referral from a physician, as a prescription, is required.

2. Exercise programs must be tailored to meet the needs of the individual, incorporating his or her unique strengths and weaknesses, as well as the person's interests. Each exercise program should be reviewed very 2 to 3 months, by the therapist, to see if the regimen is still appropriate. At the time of reassessment, the therapist may modify the program to account for changes in the person's condition or ability.

3. Avoid exercise that is weight-bearing as well as calisthenics.

4. When feeling more fatigue on certain days, avoid aerobic exercise and focus instead on simple range-of-motion exercises to promote energy conservation.

5. Never exercise without taking rest periods.

6. Stop immediately if you experience cramping.

7. Stop exercising if you experience joint pain when performing range-of-motion exercises. You should, ideally, stretch to the point of mild tension.

8. The number of repetitions of any exercise should depend upon the individual's level of endurance or the fatigue he or she experiences. Never exercise to the point of exhaustion or even fatigue.

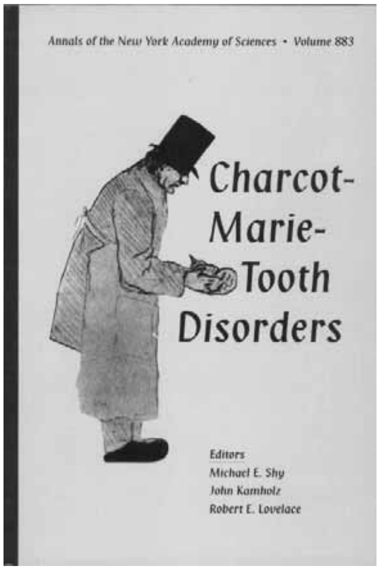
9. Stretching should not be stressful. Consciously exhale with each stretch. Stretching exercises are extremely important at all functional levels. Individuals experiencing weakness or spasticity tend to develop tight muscles.

THE LATEST CMT RESEARCH INFORMATION AVAILABLE

The New York Academy of Sciences has published the advances in CMT research as Volume 883 of its *Annals*, one of the oldest continuous scientific series published in the United States. This volume was edited by Robert E. Lovelace (Columbia University, New York City) and Michael E. Shy (Wayne State University, Detroit, Michigan) and includes contributions on genetic causes of most of the demyelinating forms of CMT; the molecular biology of peripheral nervous system structure and the function of many of the molecules involved in the pathogenesis of CMT; the development of viral vectors to introduce genes into the peripheral nervous system; and the identification of trophic factors to promote nerve regeneration and remyelination. This is the official proceeding of the meeting jointly sponsored by the CMTA and The New York Academy of Sciences in October, 1998.

The list price of the *Annals* Volume is $150.00 (plus $5.00 per book, shipping and handling), but **CMTA members are invited to purchase the book at a price of $80.00** (+$5.00 shipping and handling) until April 3, 2000.

Call the Academy at 1-800-843-6927, ext. 342 or email: publications@nyas.org, or fax 1-212-888-2894 and identify yourself as a CMTA member. You can view more information about Charcot-Marie-Tooth disorders on the Academy web site "catalog" page at www.nyas.org



Annals of the New York Academy of Sciences • Volume 883

Charcot-Marie-Tooth Disorders

Editors
Michael E. Shy
John Kamholz
Robert E. Lovelace

Dynamic Bracing for CMT

By JEAN-PAUL NIELSEN, CP

(Editor's note: Jean-Paul Nielsen has been treating patients with CMT for the last 15 years. He is a certified pedorthist and the president of the VirtualGait Network.)

There are three generally accepted reasons for bracing the lower limbs:

1. to prevent any deformity from progressing,
2. to correct an existing deformity, and
3. to increase or improve function, especially that of walking.

There is little question that preventing a deformity from progressing or getting worse is the most important. As a deformity progresses it causes permanent elongation or lengthening (from microfiber damage) of some of the ligaments of the joints involved. This damage is permanent and usually results in decreased walking function. However, preventing a deformity from progressing is relatively easy to accomplish if the proper force systems are incorporated into a brace when the deformity initially manifests itself.

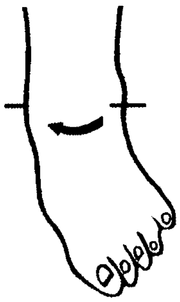


fig. a

fig. b

The mechanical patterns generally found in the lower limbs of some individuals with CMT are rotary in nature (figs. a & b). The ankle axis (transmalleolar axis) in figure a internally rotates in the same plane as the floor (transverse plane). This results in a depression of the arch and an outward rotation of the forefoot. The knee as well often rotates to the inside.

Also found is the opposite rotary mechanical pattern (fig. b). The ankle axis in figure b externally rotates in the transverse plane. This results in an elevation of the arch and an inward rotation of the forefoot. The knee also tends to rotate to the outside. Both patterns are difficult to correct once the deformities have progressed. The external pattern, however, is often more difficult to correct, as the foot tends to excessively become more rigid.

Both patterns are usually correctable. However, correcting an existing deformity is considerably more difficult than preventing a deformity from progressing. This is because, in addition to the elongation of ligaments on the stressed side of the involved joints, there is a tightening (contracture) of tendons, muscles, and soft tissues on the other side of the joints involved. Often these contractures appear to be rigid and resist attempts to straighten the joints. In most instances, these can be mechanically stretched with a brace that incorporates force systems that apply constant pressure. Manual stretching alone is insufficient, as studies have indicated that a minimum of six hours per day is necessary to slowly correct a deformity.

To walk normally is the wish of all human beings. Improving function with a brace, especially that of walking, depends primarily on two things:

1. preventing deformity and correcting existing ones, and
2. providing a mechanical substitute for muscle weakness.

Preventing deformity and correcting existing ones are necessary because deformities change the mechanical alignment or position of certain bones. In general, each segment or bone that is misaligned creates an abnormal force during walking. This weakens the main force necessary for normal walking.

A brace must also substitute for muscle weakness in the lower limbs. Since 1996, the member orthotists of the VirtualGait Network have been designing and fitting dynamic orthoses (braces) for individuals affected by hereditary motor and sensor neuropathies. These braces, including the Helix and the Double Helix, are designed to prevent and correct most lower-limb deformities. In addition, because of their custom graphite construction, these braces provide a high degree of dynamic function similar to the dynamic response prostheses used by amputees.

Just as the normal foot loads the Achilles tendon during walking for an energy return, the VirtualGait braces are engineered to provide dynamic push-off when loaded by the body's weight. This combination of custom correction and energy return has given many individuals with CMT a near-normal gait.

Because any product must do something, the VirtualGait clinicians have also developed outcome technology to quantifiably measure structural and functional improvements. Because orthotics (bracing) is a mechanical discipline, the outcome performance of any brace when combined with the user can and should be measured.

Helix ™

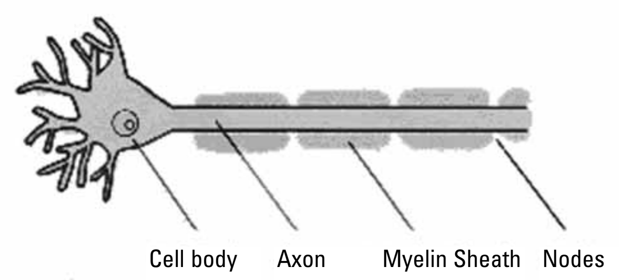
The VirtualGait Network is currently finishing the construction of its new Internet web site devoted entirely to the bracing needs of individuals with CMT. This site should be online by the end of the year at CMT-Bracing.net. For more information, visit VirtualGait's own web site: virtualgait.com, or e-mail at cmt@virtualgait.com. The Network is headquartered at 601 S. Rancho Drive, Ste. B-14, Las Vegas, NV 89106, (702) 388-9909. Currently the Network has clinical offices in Las Vegas, San Diego, and Vancouver, BC, Canada.

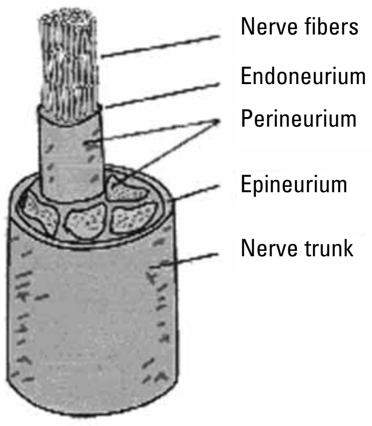
What does a peripheral nerve look like?

The basic unit of the peripheral nervous system is the "neuron" or nerve cell. Its job is to carry information by electrical impulse from one part of the body to another. Each nerve is made up of a cell body and a long projection or process called an "axon." The axon carries impulses between the cell body and nerve terminals called "receptors" in the muscles, skin, or internal organs.

Many axons are wrapped with a membrane, known as the "myelin sheath," which insulates the axon so that it can conduct electrical impulses faster and more efficiently. Myelin, which can renew itself, is produced by another cell type called the "Schwann cell" that lies right alongside it.

Axons travel together in bundles, called "nerve trunks," in a special compartment, the "endoneurium," which also contains blood vessels supplying nutrients to the nerves. These bundles span the body like wires in an intricate electrical network.

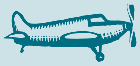




Courtesy of The Neuropathy Association.

OF INTEREST

If a patient must travel long distance for specialized medical evaluation, diagnosis or treatment, call the National Patient Travel Center at 1-800-296-1217. This service is a program of Mercy Medical Airlift in support of Angel Flight America.



CMTA Support Group News

California - North Coast Counties

At the group's last meeting, they listened to speaker, Dick Patten, a certified pedorthist, describe how he is building bracing directly into shoes. The next meetings are scheduled for February 5, 2000, and May 6, 2000.

California - Berkeley

The group will meet again on March 18, 2000, with neurologist Dr. Richard McCarthy from San Rafael, who specializes in neuromuscular diseases. Dr. McCarthy will be bringing an EMG machine to the meeting and explaining how it's used, what it tells, and the mysteries of CMT diagnosis. The group is skipping their May meeting because of renovations at the usual location and will meet again in July. Ruth Levitan, the current leader, is looking for someone to take over her responsibilities of finding speakers and chairing the meetings because of her husband's health problems. Please let her know if you are able to help out.

Colorado - Denver Area

Marilyn Mund Strand had her first meeting of the Denver area support group on January 28, 2000. She reports that only three people attended, but that it was terrific. It was a cold, snowy night and that probably contributed to the low turnout. The three attendees compared symptoms, ideas for dealing with CMT, and general items of concern. The group will meet again on March 27, 2000, at Glory of God Lutheran Church, Wheat Ridge, CO.

Roy Desjarlais, a staff clinician at The Upledger Institute, demonstrates "light touch" therapy or CranioSacral Therapy on a CMT support group member.

CMTA Members in the News

Milda Vizbar, a long-time friend of the CMTA, was featured in *Quest*, the publication of the Muscular Dystrophy Association, Volume 6, Number 6. Milda is an artist known for her colorful illustrations in children's books. Some of her works are displayed in the MDA Art Collection in Tucson, Arizona. The collection features more than 200 pieces of art created by more than 300 artists from 2 to 82 years old, all of whom are affected by neuromuscular diseases. Her painting "Sing Out!" is featured on one of the 1999 MDA Holiday Wishes cards and was chosen as the cover for the Volume 6 issue of *Quest*.

Congratulations to Dr. Kenneth Fischbeck, a member of the CMTA's Medical Advisory Board, who was recently elected to the Institute of Medicine, part of the National Academy of Sciences. Dr. Fischbeck has recently become affiliated with the National Institutes of Health in Bethesda, MD, after years at the University of Pennsylvania. The institute's 588 active members are chosen for their contributions in the field of medicine. Dr. Fishbeck was chosen because of his research in molecular and cellular biology.

Congratulations, also, to Medical Advisory Board member, Dr. Michael Shy and his colleagues, John Kamholz, Agnes Jani, Daniela Menichella, James Garbern, Richard Lewis, Karen Krajewski, Jack Lilien, and Steven Scherer for their recent publication, "Charcot-Marie-Tooth Disease Type 1: Molecular Pathogenesis to Gene Therapy" in *Brain, A Journal of Neurology*. The article was just published in the February 2000 issue of the journal. Those of you who have visited the CMT clinic at Wayne State University in Detroit, MI, or who attended our patient/family conference there will recognize many of the authors.

CMTA Support Groups

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

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

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

California—Los Angeles Area
Place: SHARE Unity Room, Marina Del Ray
Contact: Serena Shaffer, 818-841-7763
E-mail: SerenaM71@aol.com

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

Colorado—Denver Area
Place: Glory of God Lutheran Church Wheat Ridge
Meeting: Quarterly
Contact: Marilyn Munn Strand, 303-403-8318
E-mail: mmstrand@aol.com

Florida—Boca Raton to Melbourne
Place: Upledger Institute, Palm Beach Gardens
Meeting: Quarterly
Contact: Cynthia Gracey 561-243-0000

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

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

Massachusetts—Boston Area
Place: Lahey-Hitchcock Clinic, Burlington, MA
Meeting: Every other month, the first Tuesday
Contact: David Prince, 978-667-9008
E-mail: baseball@ma.ultranet.com

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

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

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

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

Missouri/Eastern Kansas
Place: Mid-America Rehab Hospital, Overland Park, KS
Meeting: First Saturday each month except January, July, and September
Contact: Ardith Fetterolf, 816-965-0017, fax: 816-965-9359
E-mail: ardi5@aol.com

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

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

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Hospital
Meeting: Monthly, Saturday
Contact: Kay Flynn, 914-793-4710
E-mail: alma622@worldnet.att.net

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

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

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

Oregon—Willamette Valley
Place: Brooks Assembly of God Church
Meeting: Monthly
Contact: Regina Porter, 503-591-9412 Maryann DiStefano-Hill 503-585-3341
E-mail: moonglow21@aol.com

Texas—Dallas/Ft. Worth
Place: Harris Methodist HEB Hospital
Contact: Greta Lindsey, 817-281-5190 or Shari Clark, 817-543-2068
E-mail: jdsbclark@webtv

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

South Florida Support Group has "invigorating" meetings at The Upledger Institute

Want to get in touch with your "inner physician" while exploring the mind/body connection?

Want to explore CranioSacral Therapy self-help techniques?

Want to get acquainted with others with CMT and learn how they manage?

The Upledger Institute in Palm Beach Gardens, Florida, has been the host of three support group meetings for the growing South Florida support group. At these very informative meetings, we've had mini-sessions in CranioSacral Therapy and lectures and demonstrations by the terrific staff at Upledger. Held at the Institute's facility, in a large room used for unique intensive-therapy programs, goodies such as fresh fruit, cookies, tea and coffee help make the evenings memorable. Of course, the most important result of these meetings is the face-to-face contact we gain with each other, which is so important for sharing of resources and questions.

"Having these sessions at Upledger, in their professional facility with the highly trained staff joining us for presentations, encourages the meetings to take a positive, pro-active course," says Cynthia Gracey, one of the co-organizers of the meetings and a CMTA Board member.

"The exposure we are getting to these highly trained staff who actually teach classes all around the world in their fields is unbeatable, and the people coming to the meetings leave on a positive note," adds Terri O'Hare, the other meeting co-organizer.

The meetings start with the group seated in a large circle of chairs, with each person telling a little about his or her history with CMT. Others will offer questions or suggestions, making this a very lively portion of the session. The Upledger speaker sits in the circle with the group and often addresses issues brought up by the group in the presentation that follows informally, and often performs actual demonstrations on group members. Near the end of the meeting, the staff breaks out with group members for mini-sessions in CranioSacral Therapy in the private massage rooms.

The meetings end with everyone feeling a little better, both physically and emotionally.

CranioSacral Therapy is a modality that Cynthia Gracey has utilized over the years as a way to invigorate her muscles and her spirit. CranioSacral Therapy uses a gentle touch method to release restrictions in the craniosacral system to improve and enhance the body's natural healing process. It has been effective for a wide range of medical problems associated with pain and dysfunction. CranioSacral Therapy is increasingly used as a preventive health measure for its ability to bolster resistance to disease and sustain overall good health.

With the combination of a great facility, informed, professional staff presenters, interesting topics, and enthusiastic attendees, the new year of meetings in Palm Beach Gardens is well on its way. For information, contact Cynthia Gracey at pathcg@aol.com, or Terri O'Hare at to'hare@kimley-horn.com. We'll see you there!

The CMT group meets in a wide circle to discuss personal stories and gain insight from Roy Desjarlais, LMT, CST-D, of The Upledger Institute.

Vitamins...the latest scoop

(The following information was compiled from articles on the Internet and in the February 1, 2000 issue of Women's Day. *Don't begin any new medication without first consulting your doctor.)*

Theoretically, a person who eats the recommended number of servings of each of the five food groups in the USDA's Food Guide Pyramid should be getting all the vitamins and minerals needed to prevent deficiency. However, a study in 1994 found that most adult women were deficient in iron, zinc, vitamin B6, calcium, magnesium and vitamin E, while men were short on zinc and magnesium. In addition, certain vitamins and minerals may be beneficial in higher doses than the daily requirement.

Antioxidants have been highly praised for years for their ability to attack oxygen-free radicals that are associated with cancer, heart disease and cataracts. Among them, **vitamin E** has been most praised for its ability to boost the immune system, prevent cataracts, slow the progression of Alzheimer's disease, and reduce LDL (the "bad" cholesterol). Vitamin E is particularly necessary as a supplement because it is found primarily in food that people try to avoid, such as vegetable oils, nuts, seeds, and wheat germ. The recommended dosage for healthy people is 100 to 400 IU, with a larger recommended dose of 400 to 800 IU for those who already have heart disease or diabetes.

Another antioxidant, **vitamin C**, does seem to lessen the symptoms of a cold and its duration if taken immediately at the onset of the cold in doses of 1,000 mg a day. Vitamin C may also prevent or delay cataracts. However, regularly taking more than 1,000 mg of vitamin C can cause abdominal cramps, diarrhea, urinary tract problems, and possibly kidney stones.

Beta carotene, a plant-based antioxidant, transforms in the body to **vitamin A** and is believed to protect against some cancers. The three **B vitamins—B6, B12 and folic acid—** are used to protect against heart defects and promote mental sharpness. All three B vitamins have been linked to a lower instance of heart disease and heart attacks because they lower the blood level of a substance called homocysteine, which can lead to heart disease and other vascular disorders. Folic acid can also be necessary to prevent birth defects and is recommended in doses of 400 mg daily for all women capable of becoming pregnant. Folic acid can be found in supplements, as well as in fortified foods such as enriched bread, flour, rice, pasta and breakfast cereal.

Vitamin B12, if deficient, can cause mental confusion. Severe deficiencies can cause fatigue, nerve damage and dementia, but depression and confusion can appear with even minor deficiencies. Older people are particularly susceptible for deficiency because they can't absorb B12 from regular food sources such as meat, fish and chicken. They need to take a supplement or eat specially fortified foods like breakfast cereals.

Vitamin B6 in doses over 100 mg per day can cause difficulties with balance, numbness, muscle weakness and nerve damage. (B6 is listed on the CMTA's toxic drug list in mega doses.)

Calcium, magnesium and vitamin D are all required to keep our bones healthy and strong. Calcium is particularly useful in reducing the risk of osteoporosis and is recommended in doses of 1,000 mg for adults to age 50 and 1,200 mg for ages 51 and older. Despite eating cheese and drinking milk, the average woman in America gets only about 600 mg of calcium per day.

Vitamin D is necessary to allow the body to absorb and use calcium and phosphorus. Vitamin D is available in only a few foods, mostly dairy, and is normally produced under the skin after exposure to the sun. The recommended daily value is 200 IU for people under 50. For older persons who have trouble absorbing the vitamin from food, the recommended amount is 400 IU.

Magnesium is a mineral necessary for healthy teeth and bones. It is found in whole grains, nuts, legumes, shellfish and dark leafy greens. The recommended amount for men is 350 mg and for women, 280 mg.

The USDA brochure *Nutrition and Your Health: Dietary Guidelines for Americans*, is currently available from Centrum at 1-800-597-2267.

OF INTEREST

Raising a Child with a Neuromuscular Disorder: A Guide for Parents, Grandparents, Friends and Professionals by Dr. Charlotte Thompson is available from Oxford University Press. The ISBN number is 0-19-512843-5. The book addresses questions and difficulties that parents of a diagnosed child have to face from the time of initial diagnosis to adulthood.

Charcot-Marie-Tooth Association

INDEPENDENT AUDITORS' 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, 1999, 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, 1999, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.

Cogen Sklar

July 30, 1999

STATEMENT OF FINANCIAL POSITION

JUNE 30, 1999 WITH COMPARATIVE TOTALS FOR JUNE 30, 1998

ASSETS	1999	1998
CURRENT ASSETS		
Cash	$132,154	$210,391
Unconditional promises to give	54,250	101,662
	186,404	312,053
EQUIPMENT - Net of accumulated depreciation of $19,063	17,193	17,925
OTHER ASSETS	1,888	1,627
TOTAL ASSETS	$205,485	$331,605
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	$ 6,235	$ 10,093
Accounts payable - research grant	-	35,000
Accrued expenses	71	250
TOTAL LIABILITIES	6,306	45,343
NET ASSETS		
UNRESTRICTED		
Operations	81,762	76,396
Board designated for research grants and education	-	14,179
	81,762	90,575
TEMPORARILY RESTRICTED	117,417	195,687
TOTAL NET ASSETS	199,179	286,262
TOTAL LIABILITIES AND NET ASSETS	$205,485	$331,605

STATEMENTS OF CASH FLOWS

JUNE 30, 1999 WITH COMPARATIVE TOTALS FOR JUNE 30, 1998

	1999	1998
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	$ (87,083)	$103,992
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities		
Depreciation	5,232	4,420
Donated equipment	(4,500)	-
(Increase) decrease in assets		
Unconditional promises to give	47,412	(101,662)
Other assets	(261)	(1,362)
Increase (decrease) in liabilities		
Accounts payable and accrued expenses	(4,037)	5,088
Accounts payable - research grant	(35,000)	35,000
Net cash provided by (used in) operating activities	(78,237)	45,476
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase of property and equipment	-	(4,301)
NET INCREASE (DECREASE) IN CASH	(78,237)	41,175
CASH - BEGINNING OF YEAR	210,391	169,216
CASH - END OF YEAR	$132,154	$210,391

The accompanying notes are an integral part of these financial statements. See page 16.

Financial Report as of June 30, 1999

STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 1999

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED JUNE 30, 1998)

	1999			1998
	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL	1998 TOTAL
SUPPORT AND REVENUES				
Contributions	$243,341	$197,344	$440,685	$505,996
Interest income	8,547	-	8,547	8,517
Donated equipment	4,500	-	4,500	4,300
	256,388	197,344	453,732	518,813
NET ASSETS RELEASED FROM RESTRICTIONS				
Satisfaction of program restrictions	275,614	(275,614)	-	-
TOTAL SUPPORT AND REVENUES	532,002	(78,270)	453,732	518,813
EXPENSES				
Program services	461,013	-	461,013	364,970
Management and general	28,404	-	28,404	26,105
Fundraising	51,398	-	51,398	23,746
TOTAL EXPENSES	540,815	-	540,815	414,821
CHANGE IN NET ASSETS	(8,813)	(78,270)	(87,083)	103,992
NET ASSETS - BEGINNING OF YEAR	90,575	195,687	286,262	182,270
NET ASSETS - END OF YEAR	$ 81,762	$117,417	$199,179	$286,262

The accompanying notes are an integral part of these financial statements. See page 16.

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 1999

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED JUNE 30, 1998)

	1999				1998
	PROGRAM SERVICES	MANAGEMENT AND GENERAL	FUNDRAISING	TOTAL EXPENSES	TOTAL EXPENSES
Salaries and benefits	$ 67,990	$17,167	$26,093	$111,250	$ 91,595
Publications and supplies	72,774	694	24,725	98,193	81,721
Occupancy and office expense	19,673	2,070	-	21,743	25,297
Research fellowships	157,044	-	-	157,044	121,000
Conference expense	138,080	-	-	138,080	72,441
Special event	-	-	580	580	3,672
Consulting	1,528	-	-	1,528	12,019
Professional fees	-	7,165	-	7,165	2,656
Depreciation	3,924	1,308	-	5,232	4,420
TOTAL FUNCTIONAL EXPENSES	$461,013	$28,404	$51,398	$540,815	$414,821

The accompanying notes are an integral part of these financial statements. See page 16.

CHARCOT-MARIE-TOOTH ASSOCIATION
NOTES TO FINANCIAL STATEMENTS—JUNE 30, 1999

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Operations

The Charcot-Marie-Tooth Association (the Association) was established to create awareness of Charcot-Marie-Tooth (CMT) disorders within the health care community and the general public, and be a leading source of information regarding CMT disorders. The Association encourages, promotes and supports research into the cause, treatment and cure of CMT. The Association also facilitates education and support for persons affected by CMT.

Basis of Presentation

The Association follows Statement of Financial Accounting Standards (SFAS) No. 117, Financial Statements of Not-for-Profit Organizations to prepare its financial statements. Under SFAS No. 117, the Association is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Restricted and Unrestricted Support

The Association follows SFAS No. 116, Accounting for Contributions Received and Contributions Made in recording contributions received. Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence and/or nature of any donor restrictions.

Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a 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. There are no permanently restricted funds.

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.

Functional Allocation of Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefitted.

Equipment and Depreciation

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

Tax Status

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

In-kind Contributions

Volunteers have donated their time to the Association'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. During the year ended June 30, 1999, the value of donated assets is $4,500 and is reflected in the Association's funds.

Unconditional Promises to Give

Unconditional promises to give represent payments due in future periods for awards recorded as temporarily restricted support and revenue.

Prior year Comparative Data

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended June 30, 1998, from which the summarized information was derived.

NOTE 2 - CONCENTRATION OF CREDIT RISK

The Association maintains a cash account balance at a bank located in Philadelphia, PA. The balance is 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, 1999, there were no uninsured amounts at this bank. The Association also maintains uninsured money market cash balances at a financial institution located in Philadelphia, PA. At June 30, 1999, the uninsured balance at this financial institution was approximately $120,000.

NOTE 3 - CONDITIONAL PROMISES TO GIVE

In 1997, a private foundation authorized a grant of up to $100,000 to be paid over the years 1997 to 1999. An annual contribution of $25,000 to $50,000 is contingent upon the Association's ability to match from $75,000 to $150,000 in contributions from the general public. The Association will receive $1 from the foundation for every $3 the Association raises for the research budget, subject to the above minimum and maximum. The contribution is recorded as the Association meets the matching requirement each year. The contribution receivable was $50,000 at June 30, 1999 and is included in this category.

NOTE 4 - TEMPORARILY RESTRICTED FUND

At June 30, 1999, the temporarily restricted fund had a balance of $117,417 comprised of monies for research grants, and education.

NOTE 5 - LEASES

The Association leases its office premises on a month-to-month lease. Total rent expense was $5,478 for the year ended June 30, 1999.

Ask the Doctor

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

Dear Doctor,

I was diagnosed with CMT at the age of 34. I'm now 60 years old and work full time and am only mildly affected with the disease. I have borderline high blood pressure and my doctor just prescribed 25 mg daily of atenolol, a beta blocker. My question is "Do beta blockers have adverse side-effects on CMT patients?" I have already noticed that my extremities are much colder since I started on atenolol. Fatigue and muscle weakness are noted as possible side effects. What is your opinion on the use of beta blockers by people with CMT?

The doctor replies:

Provided there is no evidence of muscle damage (high CPK0 or vascular insufficiency (Doppler studies), there is no reason why beta blockers should not be used for hypertension in patients with CMT. The cardiologist should be aware of any EKG changes.

Dear Doctor,

Are there any connections between CMT and carpal tunnel syndrome? Since November, I've had symptoms that might indicate this problem. What is the possible treatment if it is carpal tunnel? Therapy, surgery, or ultrasound? My overall balance problem is also worsening.

The doctor replies:

CMT is one of a number of neuropathies (including the one related to diabetes) that makes the median nerve at the wrist more vulnerable to the carpal tunnel syndrome. This is also so for any entrapment neuropathy, but a detailed electrodiagnostic study is necessary for an exact evaluation. Treatment should be early and thorough; it is recommended that the neurologist advising you on your CMT work closely with the hand or plastic surgeon.

Dear Doctor,

I have a question about flu shots. I have read in several places that flu shots are recommended for people with CMT, but when I went to get a flu shot this year, they had a warning up that said that the shot was not recommended for people with neurological disorders such as MS. Given that CMT is a neurological disease, are these flu shots recommended or not?

The doctor replies:

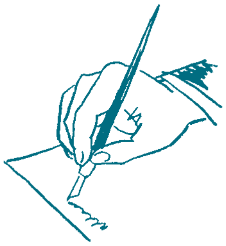
MS is thought to be an immunological disorder and, on this basis, flu shots are sometimes not recommended. This is not the case with CMT, but you should check with your personal doctor.

"ASK DR. DONAHUE" PUBLISHES CMT INFORMATION

A popular syndicated column by Dr. Paul Donahue once again appeared across the United States and Canada with a headline and lead question concerning Charcot-Marie-Tooth disorders. Twice in the past, Dr. Donahue has published questions and answers about CMT with the organization's 800 number. The first time the column appeared, the office was swamped with over 900 phone calls. The second appearance seemed to reach a much smaller audience and the response was much easier to handle. This third column on CMT once again caused the phone lines to be busy all day long for over three weeks. In addition, the answering machine was constantly "overfilled" with 65 messages.

In all, the records we kept indicated that we mailed out to callers over 569 packets of information. Several of the callers said that they had been diagnosed with CMT years earlier and this was the first time they had ever seen anything in print about the disorder. Of course, as is always the case, many callers confused CMT with Charcot joint or Charcot foot and were disappointed to learn that we did not offer information on those deformities. The mention in the answer about drop foot and imbalance problems also caused many older people to call wondering if CMT might be the explanation for their foot problems and their idiopathic (unexplained) neuropathy.

The CMTA appreciates Dr. Donahue's ongoing commitment to informing his reading public to the existence of our organization and the information that we offer.



WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Parkway

Chester, PA 19013

CMTAssoc@aol.com

The CMTA reserves the right to edit letters for space.

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

Letters to the Editor:

Dear CMTA,

Please accept this donation to the association in memory of my mother. She suffered from CMT most of her life, especially in later life. She passed away last January at the age of 73.

As a young woman, she had mild symptoms, allowing her to marry and raise a family, but they gradually became worse. Originally, the doctors thought she had a mild case of polio. She was correctly diagnosed in mid-life, after having six children and passing it to one of my sisters and two of my brothers. A couple of falls about twenty years ago resulted in badly broken bones from which she never fully recovered—she endured chronic pain and lost a lot of her mobility. She did manage to maintain much of her independence. In addition to physical suffering, I think she tended to feel guilty for passing the gene. Of course, she also suffered some of the social stigmatization that a physical disability brings.

I knew she wore leg braces, but I was too young to understand. As an adolescent, I sometimes used to be embarrassed to be with her in public when she had to use her crutch. I still didn't understand. As an adult, I finally got to know her as a person and a friend. I became proud of her and recognized the strength she showed in the face of such adversity. I finally understood.

Last Christmas we had the traditional family gathering. She was sick with a cough and we all noticed she was weak. She couldn't go to church. We talked. She seemed contemplative. I remember later that day sitting with her in the front room with warm sunlight filtering in through the sheer curtains and the sound of her favorite Boccelli arias. It was very peaceful and it felt good simply being together. Little did I know. Dad and I took her to the hospital the next morning. She had pneumonia. We were all with her, three weeks later, when she passed away.

She wrote me a generous check that Christmas (she hated not being able to get out shopping). Now, I'm passing it on to you.

—*T.L., Palo Alto, CA*

Dear CMTA,

I just wanted to let you know that I find the little tidbits of information on tools and adaptive devices that you publish very useful. In the last issue of the newsletter, you showed a new type of Fiskars scissors that have a spring lock mechanism and I purchased them for my father. He loves them and is now able to help my mother cut coupons and recipes from the newspaper—something he hadn't been able to do in years.

I've also gotten him some of the Good Grips kitchen gadgets that were featured a few years ago in the newsletter. They are marvelous and I even enjoy using them myself, as the padded handles make the vegetable peeler and the small paring knife very comfortable. The line is expanding and the manufacturer is Oxo. The tools are available in the houseware department of most large stores.

I wanted to thank you for those handy hints and to let other readers know the suggestions are worth pursuing.

—*T.J., FL*

Dear CMTA,

(This letter appeared in the newsletter of the CMT support group/California North Coast Counties.)

I was a very active child and adult, until the age of 64, but CMT showed up in everything I did. When I was in grammar school in the 1930's, I fell off the monkey bars before I was half way up. Walking on a narrow ledge on the way to school, I would fall off after three or four steps. Kids laughed at me because I couldn't do it, placing foot in front of foot. I couldn't ride a bike. My own children tried to teach me when they were in junior high, but I couldn't keep my balance.

I loved sports—any kind. I was always the last to be chosen, though, for any sport. I was too slow, always coming in last. By high school, they had taken me out of P.E. and I was put in a modern dance class. We danced in a production at the 1939 Worlds' Fair and in Christmas pageants at the Oakland Auditorium. My balance was getting worse. When activities were over at the end of the day, I would be exhausted. My mother thought I was lazy, not knowing what was really wrong.

I worked for 25 years selling patio furniture, up and down stairs, arranging furniture. At the end of the day, customers said I was limping, but I was not aware of it. At age 60, I went camping for the first time. For three weeks, every morning, we hiked three miles up and down nature trails. I was always behind, out of sight at times. At age 64, I knew there was a problem. I tripped on the sidewalks, stumbling and falling. My lack of balance was more noticeable. I was seen by a podiatrist and at a sports clinic, thinking the problem was my feet. They said it was not a foot problem, but a nerve problem.

I was sent to a neurologist, who said it was a possible hereditary nerve imbalance. He didn't mention CMT. I had only 25% nerve conduction to the peripheral nerves. He said braces would help, but I wasn't ready to accept braces, so I had inserts made to be put in my shoes. My arms and hands tested okay.

By age 70, my balance got worse and I had to use a cane. At 74, I got braces after realizing I had foot drop. At age 76, I was seen by another neurologist who said I had CMT. Now that I am 78, I use a walker or cane outside and a walker in the house. My arms and hands are now losing muscle and I drop things and cannot pick up small objects or do buttons. Tying shoes is very difficult.

My mother and aunt showed signs of CMT such as walking problems and fatigue. One daughter of mine has been tested and was negative. The other daughter has not been tested but is beginning to show signs of imbalance, fatigue and dropping things.

I'm a searcher for answers to the problem of CMT. I found out about Traeger Body Work (it stimulates the nerves) and have had Traeger treatments once a week for 1$^{1}/2$ years. I am now able to raise my toes more than 2 inches. Before, they would not move. My hands are now quite flexible. My balance has improved.

Do not give up! Research is the answer.

—M.F., Santa Rosa, CA

Dear CMTA,

I applied for SSI and they sent me to see a neurologist. I haven't seen a neurologist in years. The doctor said, "Oh, you have CMT." I assumed he knew all about it. I felt better knowing he had done some research. Then, he told me to walk on my heels. I said that I couldn't. He asked why. I told him I had heel cord surgery. In response, he told me to walk on my toes, saying that heel cord surgery shouldn't affect that. I told him I couldn't walk on my toes, either. He suggested that I hold onto the wall and I told him even that wouldn't help.

He examined my hands and told me they were wasted. Then, he took a small toothpick-like instrument and began poking my hands to see if I could feel the difference in the pricking sensation. It was painful in most spots—very painful in some.

Finally, he told me to close my eyes and stand with my arms out. I'm more stable with my arms out than just trying to stand with my eyes closed, but I was very uncomfortable. He pushed me, but did not let me fall. I didn't like this experience at all and certainly hope after all of the "tests" that I am approved for SSI.

—Jacee (from the Internet)

Dear CMTA,

Several individuals in our support group have mentioned problems with constipation. I use a concoction I read about in an article by Dr. Paul Donohue, a physician who writes a newspaper column. Mix 2 parts applesauce, 2 parts bran, and 1 part prune juice. Keep refrigerated and use 1 tablespoon as needed. It is all natural and a good solution to the problem.

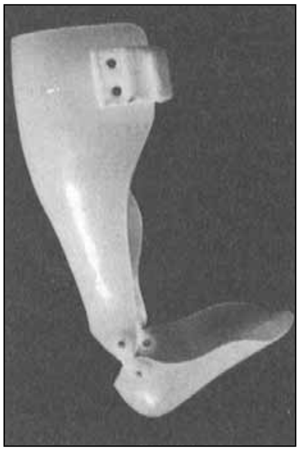
—D.W., MO

Dear CMTA,

A few months ago, I was sent for an evaluation of my ankle-foot orthosis (AFO) and discovered a hinge-type device marketed for braces that separates the foot from the leg segment of the brace. The hinge allows flexibility of my foot and increased motion. I was thrilled to find that walking up and down ramps or inclines was much easier and that once again, I could use the foot pedal on my sewing machine. This hinge also makes walking less stressful because I now have a more normal heel-toe strike pattern.

I hope others will find this information useful. These braces have opened up things to me that I found impossible in my old fixed-ankle AFOs.

—R.A., IL



Hinge-type ankle brace described above

(Editor's note: Most CMT patients cannot use articulated (hinged) braces because of their ankle and leg weakness. Ask your doctor or your orthotist if you believe you might be a candidate for this style of AFO.)

MEDICAL ALERT:

These drugs are toxic to the peripheral nervous system and can be harmful to the CMT patient.

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

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

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

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

What is CMT?

… is the most common inherited neuropathy, affecting approximately 150,000 Americans.

… may become worse if certain neurotoxic drugs are taken.

… can vary greatly in severity, even within the same family.

… can, in rare instances, cause severe disability.

… is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.

… is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.

… causes degeneration of peroneal muscles (located on the front of the leg below the knee).

… causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).

… does not affect life expectancy.

… has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.

… is sometimes surgically treated.

… is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.

… Types 1A, 1X, and HNPP can now be diagnosed by a blood test.

… is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

The CMTA Report

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

CMTA

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