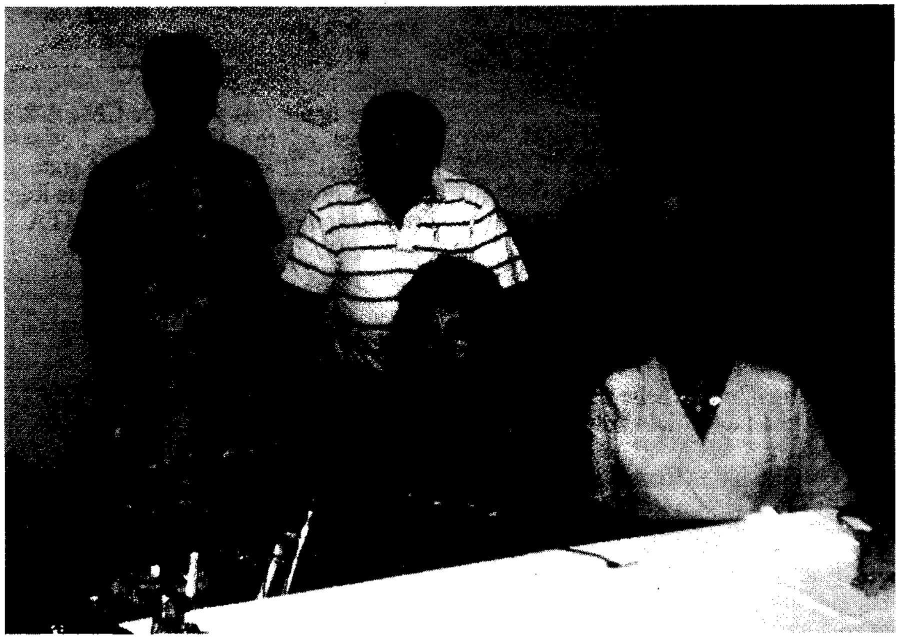
Charcot-Marie-Tooth Association

THE CMTA REPORT

Summer 1995 **ISSN # 1067-0181** **Vol.10/No.3**

Providing information on Charcot-Marie-Tooth disease (a.k.a. Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neuropathy. Contents © 1995, CMTA. All rights reserved.

New Officers Elected to CMTA Board of Directors



Seated: President Diane Freaney, Corresponding Secretary Sue Elmer, Vice-President Ann Beyer. Standing: Chairman of the Board Ed Butchko, Treasurer Jack Walfish, Recording Secretary Mike Molinari.

The Charcot-Marie-Tooth Association held election of officers for its National Board of Directors in August. Elected to serve the Association were Ed Butchko, Chairman of the Board; Diane Freaney, President; Ann Lee Beyer, Vice President; Jack Walfish, Treasurer; Susan Elmer, Corresponding Secretary and Michael Molinari, Recording Secretary.

Ed Butchko, of Hilton Head, South Carolina is a graduate of St.Peter's College in Jersey City, New Jersey,as well as Stanford University Graduate School of Business in California. Mr.Butchko held positions in customer service, finance and human resources development with the IBM Corporation before relocating to South Carolina. Just prior to leaving IBM, Ed worked as a consultant with IBM Business Partners in areas of customer service and total quality management.

Newly elected Board President, Diane Freaney, of Lafayette Hill, Pennsylvania, is a graduate of Syracuse University, Newport University, Harvard Business School and the University of Pennsylvania. Currently, Diane is chief financial officer and administrative officer of the Philadelphia Foundation.

Diane is a certified public accountant in New York and Pennsylvania and is a member of the National Society of Fund Raising Executives.

Ann Lee Beyer of Upper Saddle River, New Jersey, has been named the new CMTA Vice President. Ann is a graduate of Ramapo College of New Jersey and has an M.A. in anthropology and education from the Teachers' College. Mrs. Beyer is currently a Ph.D. candidate in the applied anthropology program at Columbia University in New York City.

Ann started one of the first CMT support groups in the United States and has been instrumental in establishing a network of support groups across the country to help others with CMT help themselves. Ann also conducts self-help workshops for people who have CMT.

A published author, Ann co-wrote the chapter, "Charcot-Marie-Tooth and the Family: Psychosocial Aspects," published in a book on neuromuscular disorders, Muscular Dystrophy and Other Neuromuscular Diseases: Psychosocial Issues.

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IN THIS ISSUE:

PHYSICIAN'S HANDBOOK

NOW AVAILABLE !!!

details on page 13

New Officers - cont'd from front page

Retired professor, Jack Walfish of Cranbury, New Jersey, will be serving the CMTA Board in the capacity of Treasurer. Mr. Walfish is a graduate of the U.S. Merchant Marine Academy in Kings Point and the Fashion Institute of Technology of New York. Jack was discharged from the military having attained the rank of lieutenant.

A former scoutmaster, Mr. Walfish is immediate past-president of the Clearbrook, New Jersey Chapter of the Deborah Hospital. Jack has a license as a professional engineer in manufacturing from the state of California and is a certified cost engineer of the American Association of Cost Engineers.

Michael Molinari of Staten Island, New York, has been re-elected as recording secretary. Molinari has a B.A. from St. Francis College, Brooklyn, New York. As a member of the entertainment industry, Molinari was a DJ in New York City clubs during the 60's. Currently, Mr. Molinari is Director of Scheduling in Staten Island Borough Hall.

Susan Elmer, of Rochelle Park, New Jersey, has been named corresponding secretary to the CMTA Board of Directors. Mrs. Elmer has a B.A. from Adelphi University , Garden City, New York.

Elmer is Director of DIAL Central, a non-profit Center for Independent Living in Clifton, New Jersey, which assists persons with disabilities in living independent lifestyles. Susan is also a member of the New York area Metropolitan Task Force on Public Awareness for the Muscular Dystrophy Association. A retired athlete, Sue competed in the 1988 Paralympics in Seoul, Korea, as a swimmer.

The new CMTA Board of Directors are committed to locating and assisting persons with CMT. Besides hosting conferences on Charcot-Marie-Tooth, the Board has targeted national CMT chapter development, a public awareness campaign, and research fundraising as some of their goals over the next few years. Anyone interested in becoming more involved with the Charcot-Marie-Tooth Association can call the national office at 1(800) 606-CMTA.

Items of Interest

1. The Social Security Administration recently established " Social Security Online." Through Internet, computer users can now access a wide range of Social Security information including publications describing disability insurance and supplemental security income (SSI) programs. Users may copy and print material from "Social Security Online" and redistribute it to others. The Internet address is www.ssa.gov.

2.Once again this year, the CMTA is a member of the Combined Federal Campaign. If you work for the state or federal government, look for this logo and remember to give to the CMTA.

A MEMBER ORGANIZATION OF
Health
CHARITIES OF AMERICA

3.Nearly 100,00 children in this country do not have permanent homes and wait to be adopted. For many of them, it is especially difficult to find families because they are disabled. The National Adoption Center is committed to finding a family for every child who needs one. They have found that people who are familiar with disabilities are often more comfortable about adopting a child who has special needs. The Center maintains a national registry, the National Adoption Exchange (NAE) that lists children from around the country who are waiting for families. For more information about adoption, or about registering on NAE,contact the National Adoption Center at 1-800-TO-ADOPT.

4. Demos offers a book called A Guide to Legal Rights for People with Disabilities by Marc Stolman for $19.95. The book covers the legal topics most often encountered by people with disabilities such as Social Security, wills, and durable power of attorney. Disabled people often encounter discrimination and need to know about the Americans with Disabilities Act, which protects jobs and requires public facilities to be made accessible to them. This book provides the most comprehensive explanation of the ADA available. Call Demos at 1-800-532-8663 to order.

5. For Families of Children with Special Needs: A Calendar of Resources (Birth to Age Ten) is packed with information for parents on topics such as being an advocate for your child, working with professionals, finding affirmation and support, and grieving and then coping with your life. The calendar is easy to read and use and is available from ASW Publishing, Seattle, WA for $7.95. You can call to order, 1-206-937-3698.

6. It is possible for CMT patients to get Life Insurance at standard rates, but you must act before January 1, 1996, because of expected industry changes. For example, a non-smoking male with CMT, age 32, can get a $100,000 policy with a 15 year level premium by paying $ 258 per year. For more information, call Tony or Hank at K & I Associates (610)499-7446 or (610)-499-7450.

7. The Equal Employment Opportunity Commission (EEOC) has clarified the Americans with Disablities Act (ADA) by ruling that it is illegal for an employer to discriminate against a worker on the basis of his or her genetic makeup. The problem of discrimination by employers had made many people hesitant to take genetic tests that might show they are vulnerable to an hereditary disorder. For some diseases, the tests can help people make medical and lifestyle changes that might prevent or delay an illness, or reduce severity. People with suspected genetic disorders have feared that their employer might learn the results of the tests and prevent promotions or fire them because of anticipated disability or because their medical expenses might increase health insurance costs.

The recent proliferation of genetic discoveries has made this EEOC ruling extremely important because just about every human being has at least a few mutant genes, many of which may have no medical consequence and some of which may not affect a person until a very old age (e.g.Alzheimer's Disease). Yet there has been no prohibition against use of this information to deny a person a job simply because the employer suspects the worker might not be healthy. The unknown is becoming increasingly predictable because of major scientific advancements, and civilization must catch up to science by creating rules to prevent misuse of this knowledge. (From The Orphan Disease Update published by NORD, The National Organization of Rare Disorders.

8. Have you ever been told about Social Security's best kept secret benefit called PASS? If not, you are not alone. Most Social Security representatives have not heard about it either. A PASS (Plan for Achieving Self-Support)is a way in which a person with a disability sets aside money to reach a work goal. For example, a person could use a PASS for an education, for job training, or to start a business.

Any person who receives SSI because of a disability may have a PASS. If you do not get SSI, but get SSDI or RSDI, you can start a PASS to become eligible for SSI. Money put into the PASS does not count as earned income for most government programs such as HUD or social services. Having a PASS may even make you eligible for Medicaid with the state paying your Medicare premium.

A PASS must contain the following elements. The PASS must be in writing, contain a specific work goal which the person can probably reach, state how long it will take to reach the goal, state what resources or income will be used to reach the goal and explain how the PASS money will be kept separate from your other money.

To set up a plan, contact your local Vocational Rehab Service, your local chapter for Independent Living, a professional PASS writer, or Social Security to help you write a PASS. If you are going to write a PASS yourself, then contact Social Security at 1-800-772-1213 and ask for POMS(Program Operational Manual System) Part 05 00870.000, Plans for Achieving Self-Support for Blind and Disabled Persons. Other material from Social Security containing PASS information includes: Publications number 17-004 and 05-11017.

9. The Dana Alliance for Brain Initiatives is sponsoring two free public forums illuminating the latest advances in brain research. The first, "Successful Aging and the Brain" will be held in association with AARP, on Wednesday, October 25, 1995 from 2-4 pm at the National Press Club in Washington, DC. The second, "A Lifetime of Brain Fitness" will be held on Sunday, November 12, 1995 from 3-5 pm at the Salk Institute Auditorium, Salk Institute, in La Jolla, CA. Both events will allow for questions from the floor. Please call 1-800-645-0346 to reserve a space at either event. Seating will be limited.

10. Karol B. Hitt, former President of the CMTA, has announced her resignation from the national board of the association. The Board of Directors of the CMTA wishes Karol a long and happy retirement.

11. A catalog of products designed to improve the quality of living is Accessibility by Invenco. The catalog offers health products and products for daily living at reasonable prices. To order a catalog, call customer service at 1-804-845-2529.

12. The American Orthopaedic Foot and Ankle Society recommends thinking of your shoes or sneakers as a corset. The laces let the corset in and out and allow for a good fit. Improper fit and poor lacing are a dangerous combination. They can cause a variety of foot ills such as blisters, hammer-toes, and chronic heel bruises. If you have a high arch, bump on the top of your foot, a bone that sticks out, nerve pain or tendon injury, try leaving a space in the lacing to alleviate pressure. Simply skip the eyelets near the point of pain.

Honoraria

In Honor Of:	By:
Drucilla Lake	Betty Smith
Dr. Rebecca Brezel	Bonnie & Melvin Hirshowitz
Rebecca Sand	Sybil Whitman
Gary Hanks	Karlyn Roller
Mrs. Bettie Appleyard	Foster Tolliver
Rebecca Sand	Flora Weiss
Charles & Tom Lynch	Christopher Lynch
Megan Knuth	Ellen Knuth
Bernie Bernstein	Barbara & Robert Bernstein
R. Gordon Bradwick's birthday	Faye Bradwick
Diane Kosik	Joseph Higgins
Sharon & Norman Pearl's Anniversary	Gayle Wolf

Progesterone May Play a Role in Preventing Nerve Diseases

Several articles in the science sections of leading newspapers this summer have reported on the work of French researchers into the previously unrecognized role that the sex hormone progesterone might play in the repairing and replacing of the protective covering around some nerves.

Animal studies have shown that progesterone, known mainly as a female sex hormone, is produced locally in the peripheral nervous system, where it promotes the formation of the myelin sheath that surrounds nerve fiber.

The findings, published in the June issue of Science, suggest that a form of hormonal therapy might be developed for some diseases that result from the loss of myelin around nerves. (CMT Type IA) The French researchers said that their research with mice showed that the source of the progesterone that affected peripheral nerves was the Schwann cells near the nerves and not hormones, produced by the sex glands, that normally circulate in the body. The work indicates that the same compound made in different parts of the body can play totally different roles at different sites.

It has long been known that progesterone is synthesized in the central nervous system by glial cells and appears to play a role in neurotransmission, helping signals get from one nerve to another. The new research now shows that progesterone is synthesized by Schwann cells in the peripheral nervous system, the network that connects the nerves of the central system to the rest of the body, where it promotes myelin formation during nerve regeneration.(Myelin is a white,fatty substance that acts as an electrical insulator for nerve fibers that keeps their impulses from going astray. Myelin is made by Schwann cells in the periperal nerves.)

The French research involved exposing the sciatic nerves in the legs of male mice, freezing the fibers and recording how the damaged nerves regenerated. They chose male mice because their level of circulating progesterone is normally much lower than that of females.

The concentration of progesterone near the damaged nerves remained 5 to 10 times as high as levels in the blood, increasing as Schwann cells and new nerve fibers increased and as the Schwann cells were actively myelinating the regenerating nerves. When researchers added progesterone close to the damanged nerves, there was a significant increase in the thickness of new myelin sheaths. It was unclear whether progesterone initiated myelination or simply stimulated the continuing process of Schwann cells making myelin proteins.

This work of the French scientists offers hope that there may soon be a new approach using hormone therapy for demyelinating diseases.

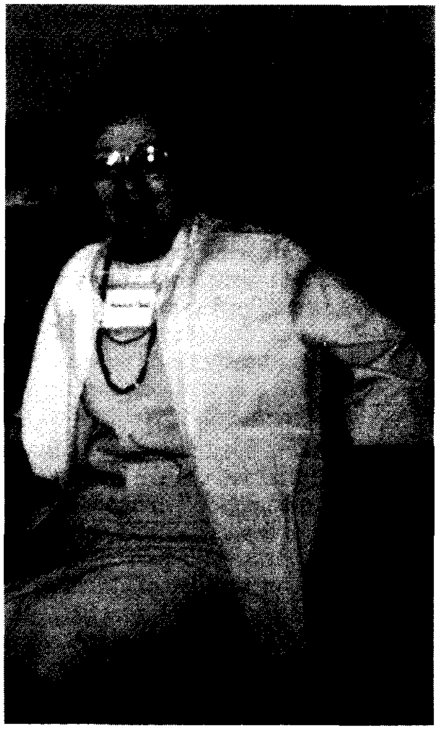
New Fundraising Schedule Announced

The CMTA Board of Directors has announced a plan to solicit its membership three times per year. The solicitation in February will be for the Research Fund. In the summer, solicitation will be for membership in the CMTA and in the late fall or early winter, a solicitation will benefit the general fund of the organization.

The first new solicitation for membership has just taken place. Prior to this change, members were asked to renew in the month in which they originally joined the organization. As we grew, that became overwhelming and the new plan was instituted. If you had just given prior to receiving the mailing, you were not expected to renew again. Membership is valid for one year and no one is ever removed from the mailing list unless a year goes by without any response from that person. Please be aware that a line is always included on membership forms for persons who cannot contribute but wish to remain active. It is important to return the form with that information so that your account is updated for the new year.

If you have any questions about your current status, you can call the office and inquire. The newsletter is normally mailed only to active members of the organization. Other benefits, such as a reduced fee for publications of the CMTA, make keeping an active status valuable.

In Loving Memory:
Rebecca Sand



This summer the CMTA lost its single greatest supporter, Rebecca Sand. Rebecca was the consummate volunteer- a person who throughout the years mailed thousands of letters for the CMTA, who was an active participant in the Delaware Valley Support Group of the CMTA, who routinely sponsored "white elephant" sales in support of CMT research, who probably distributed more "gray brochures" about CMT than any other person in the world.

For Rebecca, the CMTA was a passion and she worked hard at making that passion known to everyone around her. No one could have been Rebecca's friend and not have been asked to support the CMTA in one way or another. So dedicated was Rebecca to her cause that she was the "model" patient at Jefferson Medical School for new students learning about CMT. She showed them what a patient with CMT might look like and made sure they would not forgot her or the disorder.

Many people made donations to the CMTA in memory of Rebecca and the comments of two of them tell the story of Rebecca's life. Her sister-in-law wrote, "I know the work of the Association was very near and dear to her heart, especially the area of research, because of the involvement of several members of our family." And, a friend wrote, " In loving memory of Rebecca Sand, who, despite her physical disabilities, thought of others, always."

The CMTA marks, with great sadness, the loss of Rebecca Sand.

Memorials

In Memory of:	By:
Doris Steckler	Ray and Betty Meyer
	Kay and Delbert Schettler
	Paul and Charlotte Rohde
	Cliff Wilhelm and Eileen Haralson
	John and Karen Rassler
	Wayne and Marge Broesemle
	Chris and Mary Miller
	Dr. and Mrs. Ed Biel
	Billy and P{atty Wilhelm
	Kelly, Cherie and Chance Wilhelm
	Nettie Wilhelm
	Joan Hennes
	Nyla Tognarelli
	Laudie and Jeanette Veverka
	Paul and Jane Glander
	Donna and Bob Kovaloff
	Ken and Sandy Haraseth
	Judy Fisher
	Leo and Connie Ladbury
	Ella Mae Lockrem
	Marie Hanselmann
	Pat Liska
	Mary and Dale Jurgenson
	Dennis and Janel Stradinger
	Maxine Whittle
	Renee Vietch
Jerry Klicko	Gayle Wolf
Sidney Wolf	Gayle Wolf
James Rudisaile	Florence Rudisaile
Sonny Goldsmith	Marilyn Prashker
James Rudisaile	Florence Rudisaile
Margo Luntz	Emily and Bob Louer
Eleanor Teleweck	Anita Bennett
Anna Dean	Nickola Overstreet and Sean Miller
Anna Dean	The Harden, Gaw and Lesher Families
Sebastian Aquino	Art, Alberta, and Nancy Kohl
Arnold Thall	Charlotte and Paul Brieff
Eleanor Teleweck	Regina and Joseph Gilmore
Ida Hoffman	Reeva Sterling
Suzanne Burns	Norman Pearl
Anna Dean	Joan Scheller
Matthew Panagis	Kay Flynn
Edward C. Hills	Shirley Hubbard
Helen Wainwright	Dubby & Berny Bernstein
Rebecca Sand	Mildred Commaker
	Frances Doner
	Rose Freed
	Ruth Hermann
	Marilyn & Phil Uchitel and Family
	Mr. and Mrs. Morris Woolman & Family
	Clara Braslow
	Evelyn and Paul Becker
	Joseph and Lyna Levin Zommick
	Nancy and Joel Weisberg
	Karol B. Hitt
	Gertrude Gubernick
	Pearl and Percy Sand
	Mr. and Mrs. Isadore Miller & Family
	Emily and Charles Weiner
	Pat Dreibelbis
	June Campbell
	Mary Martha Shema
	Eleanor Shore
	Minna Sand
	Mr. and Mrs. Mark Sand

Ask the Doctor

Dear Doctor:

My 14 year old daughter has CMT Type IA. She has extremely high arches and bears weight on the outside of her feet when she does not have her orthotics on. She has muscle weakness, but does not have dropped foot. Plantar fascia release and a Jones Procedure are being talked about for her. At what point in the progression of CMT is plantar fascia release indicated? What are the long term effects of this surgery? Does the fascia tighten up over time? Have any long term studies been done on people who have had this surgery?

An Orthopeadic Surgeon replies:

At age 14, if the high arches bother the patient and produce calluses which need trimming because of weight bearing on the outside of the foot, it may be necessary to do some corrective surgery. Plantar fascia release will help but at this stage, it may be important to rebalance the foot musculature surgically because even after plantar fascia release, the child could still walk on the outside of the foot. Therefore, it may not be sufficient just to have that done. The Jones procedure is directed at the big toe and may help if that is deformed, otherwise, there needs to be a specific reason why it is to be included (which was not given in the question.)

If only the plantar fasciotomy is done, I would expect the high arch to persist and the fascia would tighten up over time. We have done muscle balancing operations on children at age 14, and sometimes younger, for many years, and have found that generally, this has helped the deformity and has improved the high arches over a long time.

Dear Doctor:

My ten year old daughter has muscle cramping in her calves. Last month the cramping was so severe she could not bear any weight on her foot for 3 days. Is this type of cramping unusual in people with CMT?

An Orthopaedic Surgeon replies:

We have seen cramping. This may be due to the nerve irritation and I would recommend that the mother take her 10 year old daughter to see a neurologist who may have had some experience in the use of medication to see if there could be some improvement or not. If there is not significant improvement to help relax musculature, I would recommend that she have a pair of polypropylene, light weight ankle foot orthoses (AFO) prescribed with the ankle at neutral so that it may support the musculature and help improve the cramping.

Dear Doctor:

I am a sixty five year old male. After having experienced numbness in my feet and lower legs for many years. I had a neurological evaluation and was diagnosed as having CMT eight years ago. There is no family history of leg problems. Several different tests including electromyograms and nerve biopsies have been made but the doctors haven't been able to determine which type of CMT I have.

Now to my questions: I have a major problem with very severe recurrent muscle cramps. I know that some leg cramps are associated with CMT, but the doctors I have talked with have never experienced anyone that has muscle cramps as severe as I do. These cramps can occur at any site on the body and result in actual knotting up of the muscle which can be visually observed. I would be interested in any comments you might have concerning this situation.

My second question concerns a broken leg that I have that I can't get to heal. I lost my balance and fell causing a clean break in my fibula bone just above the ankle. This was six and a half months ago and it still has not healed. Is this a problem common to CMT patients? I take 250 mg of Dilantin daily to help control my cramps. Could the Dilantin be a cause of the bone not healing?

The Doctor answers:

Cramping does occur because of nerve irritation and also because weak muscles may have been stretched. I would recommend that this older gentleman have a re-examination by his neurologist to see if any pharmocological agents could be used, and, if not, by an orthopaedic surgeon to see whether the foot and ankle could be supported.

In answer to his second question, fractures are not known to heal slower in Charcot-Marie-Tooth patients. Use of some medications can interfere with bone healing, and a review of his medications and his need for them and their possible side effects and complications should be done by his prescriber.

Dear Doctor:

My 14 year old daughter was on penicillin for strep throat. On the final day of taking this medication, her hands became very weak and she had difficulty even lifting up a glass. This passed after one day. I read on the list of drugs to be avoided if you have CMT, that Penicillin in large IV doses should be avoided. Could this reaction my daughter had have been caused by the penicillin?

The Doctor replies:

It is unlikely that the symptoms your daughter exhibited are related to the use of penicillin by mouth. It is known that some medications can be neurotoxic, i.e., irritating to the central or peripheral nervous systems. Neurotoxic reactions have been described with the use of penicillin, but only in very high doses that have been administered intravenously (into a vein) or intramuscularly (into the muscle). Neurological reactions which have been described include, but are not limited to, hallucinations, lethargy, confusion, twitching, dizziness, and seizures. Transient weakness, such as your daughter experienced is not among the adverse reactions thus far identified. I would recommend you inform your daughter's pediatrician of this possible side effect.

Dear Doctor:

I have CMT and am investigating alternative therapies to assist in maintaining my health. What information do you have regarding Chelation treatment? Would this be helpful or be detrimental to a person with CMT?

Ask the Doctor - cont'd

A Neurologist replies:

The patient needs to remember that CMT is a heterogeneous group of genetic disorders that affect the peripheral nerves (the wires that conduct impulses from the brain and spinal cord to the muscles). For three of these disorders, the gene that is defective and its protein product have been found. The cause of CMT1A is a defect in a gene on chromosome 17 which codes for Peripheral Myelin Protein 22 (PMP22). The cause of CMT1B is a defect in a gene on chromosome 1 which codes for Myelin Protein Zero (MPZ). The cause of CMTX (the x-linked form) is a defect in a gene on the X chromosome which codes for Conexin 32. These genetic abnormalities disturb the content or function of the proteins, all of which are associated with myelin. Myelin is the proteolipid or insulation around the nerves. When the myelin around nerves is defective, conduction of nerve impulses is slowed, and this produces weakness of the muscles that receive signals from the nerves. At this time, the exact function of these proteins and their abnormalities in hereditary neuropathies is not known, hence we do not have a treatment to stop or slow the progression of these neuropathies. An understanding of the molecular mechanisms responsible for CMT is required for the development of any effective therapeutic intervention. Gene therapy is also on the horizon. Physical therapy, braces and surgery are important treatments because they improve the symptoms, but, unfortunately, they do not affect the progression of the disease.

The patient specifically asked whether chelation could be used to treat CMT. Chelation therapy is a method of removing the metal ions from the body. Some ions, such as lead, arsenic, mercury, thallium, gold and platinum can produce neuropathies. However, these neuropathies are clinically and electrophysiologically different from the hereditary neuropathies. When a neuropathy is caused by metal ions, high levels of the ions can be found in the blood. Chelating agents, which firmly bind to the metal ions, are used for the treatment of these neuropathies. However, chelating agents can produce several adverse effects, including some neurological problems. Since there are no metallic ion abnormalities in CMT, chelation therapy is not an appropriate treatment for CMT.

Referrals Available

The CMTA has compiled a list of neurologists, orthopedists, physiatrists (a physiatrist is a physician trained in physical medicine and rehabilitation) and podiatrists who have a special interest in CMT. We can also access respiratory specialists. Additionally, we have listings for pedorthists. A pedorthist is a practioner who provides care to the patient by fitting orthopedic shoes and devices, at the direction of and in consultation with physicians.

To receive any of these referrals send a stamped self-addressed business-sized envelope indicating the geographic areas needed to: CMTA, 601 Upland Avenue, Upland, PA 19015.

For hand surgeon referrals contact the American Society for Surgery of the Hand, 6060 Greenwood Plaza Blvd., Suite 100, Englewood, CO 80111-4801, Ph.303/771-9236. §

Please note:

If you were interested in being part of Dr. Jeffrey Vance's study of CMT Type II, the phone number listed in CMT Facts III is incorrect.
Please call 1-919-684-6274 to register for the study.

The South Florida support group will be meeting at the Medical Center of Port St. Lucie, Florida on November 11, 1995. The meeting will be held from noon to 3 pm. Call Walter Sawyer, group leader, at 407-336-8624 if you can attend so that he can prepare for the correct number. Each attendee will be asked to bring a covered dish to share.

Two other new groups are starting. One is in Nevada under the direction of Stuart Norris. The other is in Ohio under the leadership of Megan Acord. If you did not receive information in the mail about the group near you, please call the office.

"Go Go" Gomez Gets Going Across Iowa

This summer Paul Gomez and his father; Ken, rode across Iowa as participants in the Registers Annual Great Bicycle Ride Across Iowa, known simply as RAGBRAI. This might not ordinarily be significant, except that both Paul and his father have CMT. Readers might remember Paul from a patient profile article in the Summer 1994 issue of the newsletter.

Ken's cousin, Jeff Leahy, a physical therapist, sent the following comments on the ride and the people who made it. He writes: "Both Ken and Paul deal with their CMT remarkably well - always a positive attitude. They completed the entire ride: nearly 500 miles. Enclosed is a picture of the device/setup Ken and Paul fashioned in order to have Paul's usual wheelchair available during the trip. I think this is a fine example of how to cope with a disability...look at the possibilities and not the inabilities."

CMTA Disability Survey Results- Part I

by Diana Eline, M. A.

A great deal of thanks goes out to all of you who participated in the disability survey that I conducted in November, 1993. Of 1,027 surveys that were mailed out, I received 485 responses, a 47% response rate. This is an incredible response for a mailed survey. I am certain that this reflects the CMT population's deep committment to finding some answers to our disease.

To summarize the survey, persons with CMT were chosen at random from our database and were asked several questions on the types of disabilites that they experience. One part of the survey was taken from a widely used functional disability test developed by J.F. Fries at Stanford University. The bulk of that part of the survey will be reported on in a later issue of The CMTA Report. *This issue contains the part of the survey which consisted of questions composed by myself to ascertain walking ability (or inability) amongst the CMT population and also to ascertain symptoms that are not typically written about in the medical text books,but are heard about in support groups and on the phone at the CMTA office. The type of CMT that the person has (if he/she knew) was also asked.*

It is important to note that all persons selected for the survey were encouraged to reply "Even if you are mildly affected and have few or none of the problems questioned in this survey, your participation is very important." This statement was added to the survey introduction to eliminate skewing of the data toward the more disabled.

If you have any questions about the survey, please contact me through the CMTA office.

1. THE RESPONDENTS

The results were based on 472 respondents. (Some surveys were determined ineligible because of respondent's age (those < 10 years old) and those which were grossly incomplete.)

Some respondents did not answer all questions, in this case the number of respondents are given eg. (n=)

Males:	204 (43.2%)
Females:	268 (56.8%)
Average Age:	49.4 years.

Range 10-89 years.

2. WALKING ABILITY

a. HOW FAR?

- When asked the question "How far are you able to walk without prohibitive pain or fatigue?

Unable to walk	5.1%
Able to walk distances less than 1 block	24.3%
Able to walk distances of between 1 and several blocks	44.0%
Able to walk distances of greater than 1 mile	26.6%

b. PAIN OR WEAKNESS

- "If able to walk, in which areas do you experience pain or weakness?"
(Respondent to check boxes of all that apply)

Feet and Ankles	73.3%
Calves	39.0%
Knees	38.8%
Hips	30.5%
Back	31.6%

Other - the most frequent response was the thigh area.

c. MOBILITY AIDS & DEVICES

- "Please check any aids or devices which you usually use for the activities of walking and/or climbling steps mobility."

Cane	22.5%
Walker	4.7%
Crutches	3.0%
Wheelchair	8.9%
Leg Braces (AFO's)	37.9%
Help from another person	23.0%

3. OTHER SYMPTOMS

Please note that some of these symptoms could be related to other medical conditions. Comparison with age matched controls from the Non-CMT (general) population will be necessary in the final report in order to draw conclusions.

a. BREATHING

- " Do you have any trouble with breathing?" (n=464)

Yes	17.7%
No	82.3%

- "If yes, do you use a respirator or ventilator?" (n=82)

Yes	11.0%

Note: Value represents 1.9 % of all respondents.

No	89.0%

b. VISION

- "Do you have double vision?" (n=463)

Yes	7.6%
No	92.4%

- "Do you have loss of sight that is not remedied by wearing glasses?" (n=466)

Yes	9.7%
No	90.3%

c. HEARING

- "Do you wear a hearing aid and/or are you partially or totally deaf in one or both ears?" (n=467)

Yes	15.2%
No	84.8%

4. TYPE OF CMT

a. "Do you know what type of CMT you have?"
(If unsure, please answer no)

Yes	21.6%
No	78.4%

- "If yes, what type?" (n=102)

Type I	61.0%
Type II	34.3%
Type III	1.0%
Type V	1.0%
X-Linked	2.0%
Other	1.0%

b."Have you had the blood test for CMT Type 1A?" (n=446)

Yes	14.6%
No	85.4%

- "If yes, did the blood test confirm Type 1A?" (n=65)

Yes	33.8%

Note: Many were still waiting for results.

Civil Rights

This article is excerpted from Orphan Disease Update, *a publication of the National Organization of Rare Disorders, Inc. (NORD).*

Under federal law people with disabilities are guaranteed their civil rights under the Americans with Disabilities Act (ADA). Disabled children, who until the late 1970's were often denied a free public education, are now guaranteed a public education under the Individuals with Disabilities Education Act (IDEA). All people with disabilities are provided with job training services under the Vocational Rehabilitation Act. However, all of these laws are under major attack in Congress mostly because our elected officials feel they are too expensive.

House Majority Leader, Dick Armey, called the Americans with Disabilities Act "an abomination" and "the worst written law I have ever seen." But without the ADA, people and businesses will be permitted to discriminate against people with disabilities by denying them jobs, making it impossible to work at inaccessible job sites, and even refusing to allow people with disabilities to enter a store or eat at a restaurant. Other politicians believe that vocational rehabilitation services for people with disabilities should be merged into the normal unemployment system. However, vocational rehabilitation counselors are specially trained to analyze and ameliorate the problems that people with specific disabilities may have in their job performance tasks, whereas unemployment counselors have no medical training.

All of these efforts to weaken protective laws and reduce services and medical care for disabled people are motivated by an effort to reduce government spending. However, without many of these services and civil rights guarantees, people with disabilities will be unable to go to school, work, or become independent, which in the long run will cost our government more money.

Letters to the Editor

Dear CMTA,

If anyone with CMT is interested in snow skiing, I would like to share my technical solutions for problems I have found. Gloves: If you have skinny hands, a warm mitten is essential. The warmest I have ever found is sold by Climb High, Shelbourne, VT (phone: 1-802-985-5055). The mittens consist of a Gore-Tex outer shell and a pile liner. I carry an extra set of liners to change at lunch. Moisture tends to form when your mittens are off for a period of time. Be sure to ask for their warmest mittens, used by mountain climbers. Ski Boots: The best fitter I have found is Earl Middlemiss at the Sport Loft in Salt Lake City, UT. His phone number is 1-801-272-3701. Earl laughingly says that I have the skinniest lower legs he has ever seen. Due to the wide range of wasting and shapes of feet, it is very important to have a person of Earl's ability evaluate each individual's situation. Boot heaters with extra batteries are also nice. Knee Braces: Properly fitted ski boots hold your feet, ankles and lower legs so well that you are not likely to have a problem in this area. A good connection between your thigh and lower leg is essential if you have any wasting or weakness in the lower leg. I would not consider snow skiing without knee braces. The most common ski injuries in people with normal muscles involve the knee. So, why take a chance. I recommend Townsend Design Knee Braces. They are located in Bakersfield, CA and their phone number is 1-805-837-1795. These braces are low profile for bilateral use. They allow you to stand in an athletic position and provide tremendous edge control. I used another type of knee brace for several years and dramatically improved my skiing when I changed to Townsends.

Under the best of circumstances, skiing is a risk sport. Anyone with CMT who is considering snow skiing should give it a lot of thought. In my situation, I have gotten more joy and self-satisfaction from skiing than from any other sport.

I would be happy to talk to anyone who is interested in taking up or improving their skiing.

Lawrence Porterfield

1-616-929-3210

My dear Friends,

Yes, you certainly are my friends! I'm so grateful for all the effort that has gone into creating the CMTA. When I get really frustrated with the shifts and changes that keep occuring as the CMT continues to rob me of strength and vitality, I turn to your publication for information and support.

I'm 70 now, and am one of the lucky ones who has led a very active life right up to four years ago. I didn't even know I had CMT all those years. I just thought that I was a bit clumsy and that spraining my ankles was part of that awkwardness. I was finally properly diagnosed in February of 1991. I started stumbling when I walked and knew my body well enough to realize that something was wrong. Like so many CMT patients, I had to go to 5 different doctors before I finally found out what the problem was.

I now have braces on both legs, and I couldn't walk without them. I'm also experiencing weakness in my hands and forearms. You can see what my writing looks like now from my check. Thank goodness I have a computer. I need a lot more rest than I used to, which is frustrating. But, I still manage to facilitate classes and workshops on a part-time basis, focused on Aging as a Spiritual Journey. As part of the work I do on spirituality, I also talk about hallowing our diminishments... honoring them, and realizing they are part of our spiritual journey.

I even managed to start seminary when I was 60 and graduated with a Master's degree in Divinity when I was 64. Along with an M.A. in Education and Counseling and a Marriage, Family and Child Counseling license I earned in 1973, I feel well equipped emotionally and spiritually to deal with this big challenge in my life. But, there are days when, like everyone else, I get discouraged. And that's when I go straight to my CMT file and read back issues of the newsletter.

I send blessings and love to all of you.

Sincerely,

T.B. Palo Alto, CA

Dear CMTA,

I am hoping that my letter will bring responses, for I very much need them.

I have been living with CMT for nearly 25 years. I am 50 years old, and when I was about 27, I started to develop walking problems. To make a very long and difficult story short, ever since I've been the patient of various podiatrists and have used various orthotics. It was not until several years ago, that I found out a name for my problem. For over 20 years, I suffered both personal, medical and societal isolation for having this deteriorating foot problem, but not having a name for it.

It has been a real godsend to know that I have CMT,to have a name, at long last, even if CMT is unknown to most people. I am a member of the association and find the newsletter interesting. Nevertheless, I have always had a nearly impossible time finding shoes that will accomodate my orthotics and my feet (I wear a size 7, which is very hard to find, and I need a very wide shoe.)

I now own over 80 pairs of shoes, only one of which is wearable by me! I can no longer afford this kind of expense, not only financially, but emotionally and psychologically. Several times, I have tried to have custom shoes made, but with no success.

I am desperate, depressed, and basically without a sense of the future. If I do find a pair of shoes, like the New Balance running shoes, I have to remake the interior with a sockliner, etc. I am very worn out with this repeated activity. I hope you can help me with some concrete advice, or suggestions.

Please write: Jeffrey Weidman, c/o CMTA, 601 Upland Ave.Upland, PA 19015

Dear Editor,

I have been reading with interest the letters of persons afflicted with CMT. I, too, am a patient with this disease. I have suffered limited use and atrophy of my hands since birth and of my legs and feet since about the age of twelve.

I wish to pass along some help that I have found that makes life easier and more comfortable. I was very fortunate to be able to graduate from college and become,of all things, a shop teacher. I taught in public schools for 37 years and continued on in a university for 7 more.

(continued on next page)

I tell you this for I was constantly on my feet, walking and visiting each student as I taught them woodworking, machine shop and drafting. I needed comfortable shoes in order to work.

I found Murray's Space Shoes in Bridgeport, CT, had the answer with moulded shoes that fit one's feet. The shoes were made to fit the feet and not the feet made to fit the shoe. Most doctors that I visited were opposed to my investing in these shoes because they claimed that my feet would atrophy. That had already happened, so I went ahead and invested in them, and found that they were the answer to my terrible discomfort. I'm sorry to say that these shoes were expensive; however, the first pair lasted 20 years with some repairs along the way. I'm sorry also that the Murray Space Shoe company has ceased operations, but there have been some spin-offs, one of which is Comfort Moulded Shoes, made in Monroe, CT, 06612.

Since I have moved to Charleston, SC, I needed to find a new source. My podiatrist did the moulds, which I sent to Jerry Miller I.D. Shoes, 3158 Main Street, P.O.Box 584, Buffalo, NY 14214. This last pair cost $ 385.00 and seemed heavier than any previous pair I have had made. They are comfortable, however.

I'm sure that without this type of shoe, I would not be walking today. Yet, I can walk even though I am now 73 years old. My balance is poor and I walk much slower than normal, but I am comfortable. Several surgeons have said that surgery could answer some problems. In 1957, I had triple arthrodesis on both feet, but after some time, the feet returned to the deformed state that they had been in before the surgery. Since that time, I have discovered the moulded shoes. I would not recommend surgery.

I must say that the shoes are not very attractive as fas as style is concerned. Who cares? Comfort comes at a high cost in this case, not only the money, but the vanity one must give up. To me, it has been a blessing.

I have been blessed with good health despite my deformed appendages and have been able to earn several graduate degrees, including ordination in the Episcopal Church, and I have made a comfortable wage and can now enjoy some retirement time.

Sincerely,

J.L. Charleston, SC

(The CMTA does not endorse any medical treatment and presents the following letter only for your information.)

Dear Editor,

As a Doctor of Chiropractic who is currently treating a patient with CMT, I am writing to encourage others who suffer from this disease to consider the benefits of chiropractic care as an adjunct to other forms of treatment. Treatment of one of my patients has included spinal adjustments, a specially designed workout program which allows for anaerobic and aerobic conditioning without irritating the patient's feet, and a low fat, low sugar diet which includes vitamin supplements. This particular patient's history includes several foot surgeries, lethargy,and slight obesity. The patient was initially seen three times a week for four weeks. His visits consisted of spinal adjustments followed by a one hour workout session.

After the first month of care, the patient has reported that he has never had as much energy as he now feels, and has never felt as good about himself. Additionally, he reports he now feels more stable on his feet, and has a much better sense of balance. At this point in time, the patient will continue to workout in our rehabilitation center on a regular basis and maintain his diet. The frequency of his chiropractic spinal adjustments will be decreased as his spine continues to function properly. Prior to receiving the aforementioned treatment, this patient had not been instructed in the role of the nervous system and its proper functioning,nor had he been informed of the steps he could take to contribute to his overall health.

I hope this letter will encourage other CMT patients to consider that chiropractic treatment, combined with proper nutrition and exercise, may hold tremendous benefits.

Dr. Larry Plotkin
7925 Crain Highway
Glen Burnie, MD 21061

Dear CMTA,

I am 52 years old and lived with CMT for 20 plus years before diagnosis. My lack of balance and "funny walk" was blamed on polio which I contracted during the epidemic in Texas in 1947. I suffered only a mild case and was considered very lucky.

However, it was difficult growing up: always the last one picked for sporting events. I couldn't run fast, jump high, or excel at any physical event. However, we do reach adulthood and these physical attributes diminish in importance. I married and after my first child, I noticed that my balance worsened. High heels became yesterday's products. After my second child was born, I noticed that the muscles in my lower leg began to ache again at night. It brought back those many nights as a child that I lay in bed and couldn't get to sleep because of cramping. Polio seemed to me to be something one has to live with forever.

When my second child was three and still walking on her tip-toes, I wanted to know why. We were fortunate to go to an orthopaedic doctor who instantly became suspicious and thought there might be a connection. He sent us to Children's Hospital in DC and CMT was confirmed. IN BOTH OF US !

My daughter is 29 and because of years of braces, therapy, and a life filled with physical activities, i.e. horseback riding, swimming, running,etc., if you met her you would never know she has CMT. Those early days of wearing braces at night that pulled and stretched her tendons and the grueling daily therapy to strengthen the muscles are all in the past and her life is good and relatively free of CMT deficiencies. She still has her horse and rides regularly, competes in triatholons, runs several times a week, and works out with weights.(Note: My second daughter is the only one of three to have CMT.)

Having none of the benefits of childhood prevention against CMT progression, my adulthood has been what most of you would expect. I have had several major surgeries, including triple arthrodesis on my left ankle at age 31. Looking back, I wish I had done the triple arthrodesis on my right as well. But, pain and recuperation from the surgery held my desire to a minimum and somehow it never happened.

Two years ago, I also had the hammer toe next to my big toe straightened on each foot. The hammertoes were so curled that the top of my toe reached the bottom of my foot. These toes had become extremely painful and it was next to impossible to find shoes. The surgery cut out

(continued on next page)

sections of bone and inserted a plastic rod through the remaining bone. In two weeks, I was back in normal shoes with straight toes and no pain. It was a miracle! In fact, I never had any pain from this surgery. My balance is tremendously improved and my trip/fall episodes have almost completely disappeared. I am wearing normal shoes(with no more than a two inch heel) and it is wonderful to walk into a shoe store and have a chance of finding comfortable shoes.

Not long ago, someone wrote in complaining of leg cramps at night. Try taking one Vitamin E (400 mgs.) before going to bed. My physician suggested this potential remedy for me and it worked. Withing a few days, the cramps disappeared and have not returned. Remember to take only one. This was something he stressed when offering the suggestion to me.

The future...well, I take it one day at a time. Twenty years ago, they told me I would be in a wheelchair by now. Guess what? I'm not. It's important not to feel sorry for yourself. I never have. I have a stressful full-time job, do my own housework, rigorous gardening in spring, summer and fall, and try to walk as much as possible. The malls are good places to go regularly, not to shop,but to walk. Keep as active as you possibly can. And remember, you don't have to do anything fast...just consistently.

For those of you with children with CMT, it is not something to hide or be ashamed of. It is only another challenge for you as a parent. Children adjust to anything. It's the parent who sets the stage.

G.S.
Bethesda, MD.

Dear Friend,

In your winter newsletter, under the "Items of Interest" section there was a response to an inquiry pertaining to wide shoes. I believe we can be of some assistance in this area.

Eneslow, The Foot Comfort Center, specializes in the "pedorthic" management of conditions which affect the foot (diabetes, CMT, etc.). We employ eight board certified pedorthists who are specifically trained to handle such cases. Eneslow has a large selection of ready-made extra depth footwear, in widths up to 6E in certain styles. In the event that ready-made shoes are inappropriate, Eneslow features a custom shoe and orthotic lab on site. We are an ideal source for the footwear needs of your members.

You can reach Eneslow at 1-212-477-2300. They are located at 924 Broadway (at 21st), New York, NY 10010.

(The CMTA does not endorse any medical or therapeutic treatment and presents the following opinion only for your information.)

Dear CMTA,

I am a 40 year old podiatric surgeon who has CMT and has been in private practice since 1984. I have had a keen interest in nutritional therapy of CMT for myself and my patients. It has been frustrating to me to see people with CMT started on steroids, high dose anti-inflammatories, and neurotoxic drugs in hopes of providing the patient with some measure of relief of pain, weakness, or in an attempt to stop progression of this disease. Many of the traditional, well-respected authorities in the US have very little to say except "eat a well-balanced diet" or take a good multi-vitamin, as long as you don't overdue it.

After a significant amount of research, I found a company with the products I had been looking for. Dr. William Sheppard is a researcher who has introduced his ideas to the holistic health arena through a company called Momentum, based in Colorado.

Exciting articles are published every day in major magazines, journals and newspapers regarding the efficacy of prevention and treatment with food supplements, vitamins, and anti-oxidants. Compounds such as phytochemicals can boost your immune system. Yet, it is sometimes difficult to separate the truth from the hype since some companies produce or sell such products without the stringent quality control standards which are necessary. Dr. Sheppard's company stands above the crowd in that department.

Some products which I believe hold promise for CMT patients are:

- Evening Primrose Oil. This helps in repair of the myelin sheath and can help some of the neuritic symptoms.
- Shark Cartilage. Can help damaged nerves find new attachments and helps with protein, calcium, and phosphorus supplementation.
- Deep Rxn. Natural herbal remedy for depression, stress, and nervousness.
- Body Mgr. Amino Acid. Vitamin, mineral and herbal product for building muscle growth, aids in endurance and recovery.

There are many other products which I've found helpful for those people with poor circulation, diabetes, or pain. If you would like to talk to me about nutritional strategies, I can be reached at 719-594-9920.

Dr. Gregory Stilwell

The Physician's Handbook

The publication and mailing of CHARCOT-MARIE-TOOTH DISORDERS:A Handbook for Primary Care Physicians has been delayed by production problems. If you have already ordered a copy, you should expect delivery by the third week in October. If you have not yet ordered a copy, you may do so by completing the form below and returning it to the office of the CMTA. The book is a compilation of information about the genetics of CMT, the surgeries available to correct deformities, and the therapies commonly prescribed for CMT patients. The book has been written by ten experts on CMT, members of the advisory board of the organization and is both well written and technically correct.

To order, fill out the following form:

ORDER FORM: THE PHYSICIAN'S HANDBOOK

Name ____________________________________

Address __________________________________

____

Phone number (during the day) ______________________

Number of books ordered ________________________

Check enclosed for (amount) ________________________

The cost of the book is $15 for current members of the CMTA;
$20 for non-members and $22 for foreign orders
(please remit in US funds.)
The cost includes all shipping and handling charges.

____

Please allow 4-6 weeks for delivery.

Make your check out to CMTA and mail your order form to:
CMTA, 601 Upland Ave, Upland, PA 19015.

____

CMTA Contacts

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

**denotes support group leader*

Alabama / Greater Tennessee Valley
*Bill Porter 205/386-6579W
205/767-4181

Arizona
Lavon Little 602-516-0539

California
*Janice Hagadorn 805/985-7332 after 5
(Oxnard/Thousand Oaks)
*Sheila Levitch 805/254-5322
*Denise Miller 805/251-44537
(Canyon Country/Saugus)
*Freda K. Brown 707/573-0181
(Santa Rosa)
Gary Oleze 619/944-0550 after 6pm
Eda Adams, will return calls
916/677-6460
Jeanne Amour 408/749-1661(Sunnyvale)
Clair Bumgarner 209/874-4963
Sandra Huntley 310/597-3728
Felice Gail Viggers, 805/492-2840
Verna M. Sabo, 818/892-6706
Mary Micalizzi, after 6pm
619/441-2432
Bob Hedge, 9am-5pm 310/645-2761

Colorado:
*Dr. Gregory Stilwell 719/594-9920
(Denver area)
Roberta Cummings, 719/846-5611

Connecticut:
Mary Rehm 203/744-2786
(Danbury)
*Kay Flynn 914/793-4710
(Fairfield)

District Of Columbia:
*Lorraine Middleton, 6pm-9pm
202/362-4617

Florida:
William Brady 904/443-6271
Mary Beeler, 9am-8pm 407/295-6215
Harold Wilson 407/465-3656
Pat Ports, M,W, F, 4pm-9pm,
407/965-3691
Joe Ellenbogen 305/921-4660
Edward Carhart, 9:30am-5:30pm
305/567-1066
Beatrice Bannister 407/737-3267
Robyn Cohen 407/622-5829
8pm-9:30pm M-F, weekends anytime
Erika Stilwell 305/232-9066
*Walter Sawyer 407/336-8624

Georgia:
Nancy Lee McCutchen 404/925-1020

Kansas:
*Ardith Fetterholf (Eastern Kansas)
816/763-2176
voice mail 816/756-2020

Louisiana
Bobbie Marberry 504/872-0895

Maryland
Jean Iler 410/987-5432
Linda Ember Miller 410/882-4019
Robert Kight 410/668-3054

Massachusetts
Wayne Cardillo 413/298-3156
*Donald Hay 9am-7pm, 617/444-1627
(Boston)
Jim Lawrence 508/460-6928
Jennifer Brelsford 413/538-9579

Michigan
Robert D. Allard 517/592-5351
Debbie Clements 616/956-1910
(Grand Rapids)
*Suzanne Tarpinian 313/883-1123
(Detroit)
Laurie Vasquez 517/893-4125

Mississippi
*Julia Prevost 601/885-6482
*Henry & Brenda Herren 601/885-6503
(Jackson)
Mae Blackledge 601/763-5151 (Southern)

Minnesota
Grace Wangaard 612/496-0255

Missouri
*Ardith Fetterholf 816/763-2176
voice mail 816/756-2020
Allan Degenhardt 816/942-1817

New Hampshire
Mary Nightly 603/598-5451

New Jersey
*Janet Saleh 908/281-6289
(Sommerville)
Linda Muhlig 609/327-4392
Gary Orson, Mon-Fri 6pm-10pm
& weekends 609/584-9025
Russell Weiss 908/536-6700

New Mexico
Jesse Hostetler 505/536-2890

New York
Joe Ehman 716-442-4123
Internet:KOLOB@Multicom.Org
*Diana Eline 201/861-0425 before 9pm
(New York City)
*Abby Wakefield 212/722-8052 (NY)
*Lauren Ugell 516/433-5116
(Long Island)
*Bernice Roll 716/584-3585 (Rochester)
*Kay Flynn 914/793-4710
(Westchester County)
Amy Gander 518/373-9907
Angela Piersimoni, after 2pm
607/562-8823
Sharon McAvey, afternoon & evening
718/380-3792
William Carrington, 4pm-11pm
718/486-6953

North Carolina
Diane Rodden 910/584-3655
*Susan Salzberg (Durham)
5pm-9pm 919/967-3118
Raymond Woodie 910/838-3221

Ohio
Roger Emmons 216/286-6485
Suzanne Lammi 513/339-4312
Norma Markowitz 216/247-8785
(Cleveland)

Oklahoma
Leah Holden 405/255-4491

Oregon
*Mary Elizabeth York 503/246-4939
(Portland)

Pennsylvania
*Dennis Devlin 215/269-2600 work
610/566-1882 home
(Delaware Valley)
Patricia Zelenowski 717/457-7067
Camille Walsh 215-747-5321
Janet Fierst 412/487-0757
Mary MacMinn 215/322-1073
Carol Henderson 215/424-1176

Rhode Island:
Robert Matteucci 401/647-9154 PM

Texas
Dr. Karen Edelson, D.P.M.
214/542-0048
M,T,Th, 8:30am-5pm, 214/542-0122
Tony Collette, 1pm-8pm, 713/699-8432
Ken Kerby 817/282-9329

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

West Virginia
*Joan Plant 304/636-7152 after 6pm
(central)
L.Ben Simmers 304/693-7731
Beverly Simmers 304/364-5309
Ronald & Rebecca Sampson,
304/636-7449 24 hours
Barbara Compton 24 hours
304/636-5456

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

Call for Participants

Dr. Francis X. Palermo, a physiatrist (a physician trained in rehabilitation and physical medicine), is conducting a study of the effect of electric stimulation on CMT patients. The procedure is patterned electric stimulation of the legs and is gentle and non-painful. The electric stimulation unit is placed in the participant's home, although some professional monitoring will be required. Dr. Palermo is looking for patients with either type 1 or type 2 CMT. Results from CMT patients currently in the study indicate some restoration of function, greater endurance, and increased balance. There is some cost to the participant, as well as, minimal travel to New Haven, CT. For more information contact: Dr. Francis Palermo, Gaylord/Yale Rehabilitation, One Long Wharf, New Haven, CT 06511, phone 203-624-3140.

Membership/Order Form

Name: ______________________________

Address: ______________________________

____

Phone Number: ______________________________

Tell us about yourself:

☐ CMT Patient ☐ Medical Professional

☐ Interested Supporter ☐ CMT Family Member

Enclosed is:

☐ $25 ☐ $50

☐ $100 ☐ other

for my membership in the CMTA (newsletter included in membership)

☐ At this time I cannot contribute to the CMTA but would like to receive mailings.

Publications and Tapes available from the CMTA

(Check to order)

☐ VCR Tape - CMT Neurology ($15)

☐ VCR Tape - Physical Therapy & Occupational Therapy ($15)

☐ VCR Tape - CMT Genetics ($15)

☐ VCR Tape - Orthopedic Surgery & CMT ($15)

☐ Handbook (16 pp.) - CMT FACTS I ($3)

☐ Handbook (24 pp.) - CMT FACTS II ($5)

☐ Handbook (24 pp.) - CMT FACTS III ($5)

☐ Transcript - San Francisco CMT Conference ($5)

☐ Letter - to Medical Professionals regarding the drug list (free to members with self addressed stamped business envelope)

☐ List - Physician Referrals (by state)
(please send SASE)
please list states:________ ________ ________

☐ CMT Informational Brochure (gray brochure)
(one copy free with self addressed stamped business envelope)

☐ CMT Informational Brochure (gray brochure) in Spanish
(one copy free with self addressed stamped business envelope)

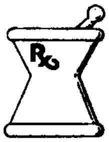
☐ Physician's Handbook ($15 members, $20 non-members $22 foreign)

Contributions are tax deductible.
Please make checks payable to the CMTA.

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.

MEDICAL ALERT

Certain Drugs Toxic to the Peripheral Nervous System



This is a list of neurotoxic drugs which could be harmful to the CMT patient.

Adriamycin
Alcohol
Amiodarone
Chloramphenicol
Cis-platinum
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Mega Dose of Vitamin A
Mega Dose of Vitamin D
Mega Dose of Vitamin B_6 (Pyridoxine)
Metronidazole (Flagyl)
Nitrofurantoin (Furadantin, Macrodantin)
Nitrous Oxide (chronic repeated inhalation)
Penicillin (Large IV doses only)
Perhexiline (Pexid)
Taxol
Vincristine

Lithium and Misomidazole can be used with caution.

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

5/94

Blood Test Available

The blood test for diagnosing CMT Type 1A found on chromosome 17 is available from Athena Diagnostics. They can be reached by calling 1-800-394-4493, ext. 106. Ask for Sarah Quiry, customer service representative. A physician must order the shipping kit. The cost of the test is $395.00. §

CMT...

.... is the most common inherited neuropathy, affecting approximately 125,000 Americans.

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

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

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

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

.... may become worse if certain neurotoxic drugs are taken.

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

.... can, in rare instances, cause severe disability

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

.... Type IA 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

Call 1-800-606- CMTA

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