

# THE CMTA REPORT

Providing information on Charcot-Marie-Tooth disease (known as Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neurological disease. Contents © 1990, CMTA. All rights reserved.

## WE'VE CHANGED OUR NAME!

### NFPMA IS NOW THE CMTA

The name of the National Foundation for Peroneal Muscular Atrophy has been changed to the **Charcot-Marie-Tooth Association (CMTA)**. This action was taken at the February meeting of the Board of Directors. The Board conducted a survey of neurologists to determine what name he/she routinely called this disorder. By far, CMT was the most common name used with hereditary motor sensory neuropathy being the second most common. Many physicians reported using both names. Less than 10% of the reporting physicians used the term peroneal muscular atrophy. We are pleased with the change and hope this will better enable us to reach the CMT patient/family community. We thank the physicians who answered our questionnaire. Their help is greatly appreciated.

## Boston & Miami CMT Patient/Family Conferences

The CMTA is pleased to announce upcoming CMT patient/family conferences in Miami and Boston. These conferences will feature lectures by medical experts specializing in CMT. There will be ample opportunity to query the doctors and to meet with other CMT patients and families. These will be half-day conferences, and there is no fee for attending.

The Boston conference will be held on May 19th at 1pm. Dr. Frances Dyro, Neurologist at the Veterans' Administration Medical Center and Associate Neurologist at Brigham & Women's Hospital of Harvard

Medical Center, will be the lead speaker. The conference will be at the Veterans Administration Medical Center, 1400 Veterans of Foreign Wars Parkway, West Roxbury, Massachusetts 02132. Further details will be available at a later date.

The Miami conference will be held on April 21, 1990 at 1 pm. Dr. Ram Ayyar, Professor of Neurology at the University of Miami, will be our featured speaker. The conference will be at the University of Miami Medical Center, 1500 NW 12th Avenue, Miami FL 33101. Travel directions: Take I-95 South to Exit #836 (Also Rte. 836). Follow Rte. 836 to 12th Avenue. Exit and follow signs to

University of Miami Jackson Medical Center.

For further information on these conferences contact the CMTA office at Crozer Mills Enterprise Center, 600 Upland Ave., Upland, PA 10915, phone (215) 499-7486. From 4/5/90 - 4/21/90 call (813) 321- 7945.

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### Upcoming Conferences

*Mark your calendars!*

- Miami, FL .....April 21, 1990
- Boston, MA ..... May 19,1990

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# MARY JANE KING GOLF CHAMPION - CMT PERSON

We're on the fourteenth fairway following Mary Jane King at the Hampton golf course during the Peninsula Women's Championship Tournament. Mary Jane is now just one stroke behind the leader and two up on her closest competition.

King blocked her tee shot somewhat and her ball now lies just short of the dog leg on the far right of the fairway. Unfortunately, her ball has settled in a low depression with a stand of trees blocking a straight-in approach to the green.

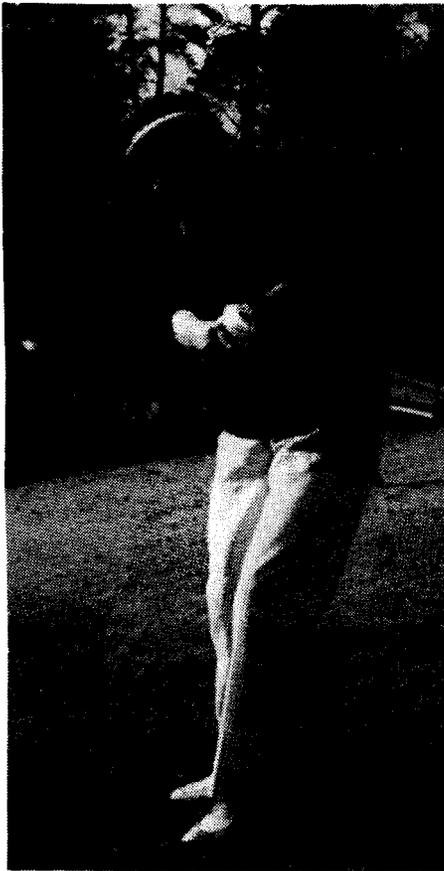
From this point she is about 145 out. It seems that her best bet, and by far the safest, would be a short chip shot out to the center of the fairway leaving her a clean shot at the pin. But, that approach could leave her two shots back behind the front runner.

She's taking her time. It looks like she intends to use her four iron, going to green with a fade shot. If it works she'll be able to par fourteen keeping her only one behind. But, it will require a great touch to pull this off.

She will have to lift the ball out of the depression, yet keep it low enough to stay under the overhanging branches. Or, she can try to lift it some and fade it around the trees.

She did it! What a remarkable shot! She brought the club head on through the ball perfectly. The ball just cleared the branches, fading enough to drop within ten feet of the pin. It was a beautiful shot for any top amateur golfer. For Mary Jane King, who is a CMT patient, it was truly magnificent.

As one of Virginia's top amateur golfers, Mary Jane does not let the physical handicap of this disorder affect her handicap on the golf course. She is an active member of two women's golf groups in the Tidewater area of Virginia, and regularly par-



Mary Jane King

ticipates in the U.S. Senior Woman's Amateur Championship Tournament. In 1985, and again in 1986, she showed her prowess on the links by winning the Virginia Senior Women's Amateur Championship title.

Her love of sports has kept her physically active all of her life. Besides golf, which she began playing in her twenty's, Mary Jane was at one time a highly competitive bowler. She notes that she does not bowl much anymore, preferring to concentrate her efforts on golf. Mary Jane explained "Once the children were in Jr. High school, I became a serious golfer. At that time I also started working with the Junior Golf program. " On non-golfing days, weather permitting, she bicycles five miles a day and participates in water aerobics. Through her very active physical regime she believes the effect of the CMT disease is kept under control.

For Mary Jane, incorrect diagnoses of her early bouts with the disease was par for the course. When she was a teenager she was treated by a podiatrist and fitted with steel arch supports to overcome her "foot" problems. Mary Jane related "I was not aware I had a genetic disorder, I knew I had weak ankles and arch problems." After wearing braces for several years she discarded them in favor of physical exercise. Years later, doctors treated her cramping hands, wrists, and legs as effects of arthritis and rheumatism. It wasn't until she reached 56, that her worsening condition was correctly diagnosed as CMT.

Mary Jane's belief that exercise is of major importance in coping with the progressive effect of the disorder is not without support from others. Two experts on the disorder, Dr. Robert Lovelace of Columbia University College of Physicians and Surgeons and Dr. Robert Krebs, III, a physiatrist of the University of Pennsylvania Medical School, subscribe to the "use it or lose it" theory. Dr. Lovelace notes that good muscles may take up the slack for the atrophying muscles. "When I do not exercise I am stiffer, my muscles are weaker, it is harder to get up and down from a sitting position, and I have more muscle cramping in my feet and calves. My thumbs also benefit from exercise" Mary Jane explained.

Beyond displaying her skills with a golf club, Mary Jane is also sharing her knowledge of CMT and golf with others. In 1987, she spearheaded the development of the Tidewater CMTA support group.

This spring Mary Jane will join with Wade Briggs, golf pro from the James River Country Club, to play a "golf marathon." Both golfers will be obtaining pledges for the number of holes which can be played in a non-stop, ten hour feat. Proceeds for the contest will be forwarded to the CMTA.

Additionally, for nearly twenty years Mary Jane has played an active role in organizing and working with junior golf programs in the Tidewater area. In addition to providing the teenagers and subteens with instruc-

(continued, next page)

## LETTERS

We want to hear from YOU!

Write us at:

Letters, The CMTA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

## **MJK's Golf Marathon**

This spring, Mary Jane King and Wade Briggs, the golf pro at James River Country Club, Newport News, Va, will play a golf marathon to benefit the CMTA. They will begin playing at 8 am and will play continuously for 10 hours. Mary Jane and Wade will obtain pledges for the number of holes played. Contributors will pledge to pay a stated amount for each hole played. In a trial run, using a golf cart, Mary Jane played five holes in thirty minutes. *This woman means business!*

We urge you to support Mary Jane's efforts for the CMTA. You may write her here at the CMTA and we will forward your pledge.

**MJK** (continued from pg. 2)

tions on the fundamentals of golf—including rules, techniques, and sportsmanship—she organizes and conducts tournaments for them. Mary Jane feels "working with the young golfers has been a very rewarding experience. We have turned out some very good golfers who can use these skills for the rest of their lives. Golf is a game that you can play alone or with someone. Basically golf is a game between a player and the course." She also organizes and conducts tournaments to benefit the CMTA and other charities.

Being diagnosed as having CMT was not the end of the world for Mary Jane King. For her, the disease was a challenge. She knew that by maintaining her excellent physical and mental condition she would be able to cope with the progression of the disability and extend her active life beyond that which might normally be expected.

Mary Jane King does more than teach youngsters how to address a golf ball, she also shows them how to deal with life when they find themselves in a sandtrap.

— Doug Adams

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*Doug Adams is a writer and an avid golfer living in the Pensacola, Florida area.*

## **Vocational Rehabilitation: What Is It And How To Get It**

*Frequently, people with CMT must tailor their career plans to the limitations of their disability. Career decisions are commonly made in early adulthood, but sometimes the CMT person must change careers in mid-life. There are counselors to assist in making these decisions and there are governmental funds available for vocational training and post secondary education. The following article is in part reprinted from a publication of the HEATH RESOURCE CENTER which is an acronym for Higher Education and Adult Training For People With Handicaps. This agency is a national clearinghouse on post secondary education for individuals with handicaps and is funded by the United States Department of Education. HEATH serves as an information exchange about educational support services, policies, procedures, adaptations and opportunities on American campuses, vocational-technical schools, adult education programs, independent living centers, and other training entities after high school. The Center gathers and disseminates this information so that people with disabilities can develop their full potential through postsecondary education and training if they choose.*

### **What is vocational rehabilitation?**

Vocational rehabilitation is the nationwide federal-state program for assisting eligible people with disabilities to define a suitable employment goal and to become employed. Since education and training at a vocational or technical school, college or university may be part of the plan to reach that goal, vocational rehabilitation agencies often provide both counseling and financial assistance to students with disabilities. Vocational rehabilitation may be referred to as "Voc Rehab" or "VR".

### **Where can I find Voc Rehab offices?**

All states territories, and trust areas have a vocational rehabilitation agency. The nature and scope of services may vary from state to state. Funding for the program is 80% from the federal government and 20% from the state

government. Each state agency has a central or administrative office and district offices that usually are located throughout the state. A list of all state, territorial and trust offices are listed at the conclusion of this article.

### **Contacting the VR office**

It is best to make the first contact with the VR office by phone or letter. From your state office you can learn the name of the closest local office. You are welcome to make a personal visit during normal business hours. If you drop-in, you will be seen by an intake counselor or be given an interview appointment for a later time.

### **The application process**

You will be asked to complete a formal application to receive services. You will be assigned to the vocational rehabilitation counselor who serves the area where you live or who specializes in your disability. The counselor will ask you to make an appointment to have a general medical examination. Depending on your particular disability, other evaluations may be required such as vision, hearing, psychological tests or other special studies. If you have had such examinations done recently and reports can be obtained, these will be helpful. Examinations are necessary since VR must have medical evidence that you have a disability, that the disability limits the type of work you can do, and that you will be able to work if VR services are provided. If it is necessary to get new examinations, VR will pay for them.

Other pertinent records such as school transcripts, work history military records, and perhaps social security data, may be requested to help plan an appropriate rehabilitation plan. If you have them, it will be helpful to bring these records with you for your initial interview with the VR counselor, otherwise your counselor will ask you to sign a release so they may be requested directly.

### **Who receives VR services?**

The VR program is an eligibility program, not an entitlement program. This means that the determination of eligibility is an individualized process based on your unique situation. You

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## 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  
 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  
 Nitrofurantoin  
 (Furadantin, Macrochantin)  
 Nitrous Oxide  
 (chronic repeated inhalation)  
 Penicillin  
 (Large IV doses only)  
 Pyridoxine (Vitamin B6)  
 Vincristine

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

#### Voc Rehab (cont'd from pg.3)

are not automatically eligible just because you have a disability. Eligibility is determined by a state rehabilitation counselor based on the criteria in the state approved VR plan.

The Rehabilitation Act of 1973 (P.L. 930-112), as amended, requires the states to give priority to individuals who are most severely handicapped. This applies to the process of determining eligibility and the delivery of services.

**Eligibility for rehabilitation services is determined on the basis of three criteria:**

1. You must have a physical or mental disability.
2. Your disability creates or causes a substantial handicap to employment.
3. There is a reasonable expectation that the provision of vocational rehabilitation services can make you employable.

According to the Rehabilitation regulations, a physical or mental disability means "a physical or mental condition which materially limits, contributes to limiting, or if not cor-

rected, will probably result in limiting an individual's activities or functioning." Also as defined by regulations, a substantial handicap to employment means "that a physical or mental disability (in light of attendant medical, psychological, vocational, educational, or related factors) impedes an individual's occupational performance by preventing, obtaining, retaining, or preparing for employment consistent with his/her capabilities and abilities."

Employability with regard to vocational rehabilitation refers to "a determination that the provision of vocational rehabilitation services will enable an individual to obtain or retain employment consistent with his/her capacities and abilities in the competitive labor market, (such as the practice of a profession), self employment, homemaking, farm or family work (including work for which payment is in kind rather than in cash), sheltered employment, supported employment, or other gainful work."

The determination of eligibility can be more than a simple matter of reviewing data and making a decision in a few days. The state VR program permits an extended evaluation period to determine your eligibility if there is a question about your employability. The process can take up to eighteen months. The application of the eligibility criteria must be made without regard to race, sex, color, creed or national origin. A state may not impose any prior residential requirements as a condition for eligibility. If you are determined to be not eligible for services, you must be notified in writing of this decision, the basis for the decision, your right to appeal the decision, and how to appeal the decision.

#### Who pays for VR?

If you are eligible for VR you will be asked to provide information concerning your income and your expenses. This information is necessary so that the counselor can determine how much you can contribute to your rehabilitation program. In some cases, VR may be able to pay for all services you need if you are not able to contribute. The counselor will fully explain this before you begin a VR program.

Federal regulations require that VR work directly with postsecondary financial aid officers to determine what portions of postsecondary educational expenses will be met in other ways. Before VR can do this, you must apply

for federal student financial aid using the FAF or other standardized national needs analysis required by your school. The primary funding for postsecondary education related expenses is student financial aid, while VR is responsible for disability related costs.

#### IWRP, what is it?

If you are declared eligible for services, you and your counselor will develop an **Individualized Written Rehabilitation Plan**, or **IWRP**, to specify the services to be provided and your employment goals. The IWRP is very important. It becomes the written plan of action between you and the state agency. Modifications and amendments to the original program can be made when there is reasonable and logical justification for so doing. You, as the client, receive copies of the original plan and any changes.

#### When will VR services end?

Your case remains open until you are successfully rehabilitated or a determination is made that you cannot achieve a vocational rehabilitation goal. Under the vocational rehabilitation program, you are not considered "rehabilitated" until the state VR agency determines that you have been suitably and satisfactorily employed for at least 60 days.

#### For more information

HEATH has several publications available and single copies are free to those who request them. You can contact HEATH by calling toll-free at (800)544-3284 or by writing HEATH Resource Center, One DuPont Circle, Suite 800, Washington, DC 20036-1193. Some of the titles available are:

- Access to the Science and Engineering Laband Classroom
- Career Planning and Placement Strategies
- Education Beyond High School—The Choice is Yours
- Education for Employment (vocational education)
- Make the Most of Your Opportunities
- Opportunities After High School for Persons who are Severely Handicapped
- Vocational Rehabilitation Services—A Student Consumer's Guide
- How to Choose a College: Guide for the Student with a Disability
- HEATH Brochure
- HEATH Resource Directory

HEATH materials are also available in computer media for MS-DOS compatible or Macintosh. Please enclose a blank 5 1/4 or 3 1/2 DD/DS diskette.☐

## CMT Patient Job Survey

The CMTA is interested in learning about the career choices of CMT patients. We would appreciate it if you would take the time to complete the following survey and return it to the CMTA office. In a future issue of **The CMTA Report** we will publish the results. Feel free to omit your name if you wish to remain anonymous. Send your survey to: **CMTA, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015.**

NAME (optional) \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

TELEPHONE \_\_\_\_\_

AGE \_\_\_\_\_ AGE AT DIAGNOSIS \_\_\_\_\_

OCCUPATION AND A BRIEF DESCRIPTION OF YOUR JOB \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

DID CMT INFLUENCE YOUR CAREER DECISION? \_\_\_\_\_

IF YES, IN WHAT WAY? \_\_\_\_\_

\_\_\_\_\_  
HOW LONG HAVE YOU WORKED AT YOUR JOB? \_\_\_\_\_

HAVE YOU HAD TO MAKE A CAREER CHANGE BECAUSE OF CMT? \_\_\_\_\_

WHAT IS YOUR NEW CAREER? \_\_\_\_\_

DID EITHER OF YOUR JOBS REQUIRE FORMAL TRAINING? \_\_\_\_\_

DID YOU RECEIVE EDUCATIONAL/VOCATIONAL COUNSELING PRIOR TO MAKING  
YOUR CAREER DECISIONS? \_\_\_\_\_

IF YES, PLEASE COMMENT \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

*Thank you for completing this survey.*

## State Vocational Rehabilitation Offices

### ALABAMA

Division of Rehabilitation &  
Crippled Children Services  
Dept. of Education  
2129 E South Blvd.  
Mail to: PO Box 11586  
Montgomery, AL 36111-0586  
205/281-8780

### ALASKA

Division of Vocational Rehabilitation  
Department of Education  
Goldbelt Bldg., 1st floor  
Mail to: PO Box F, MS 0581  
Juneau, AK 99811  
907/465-2814

### ARIZONA

Rehabilitation Services Administration  
Dept. of Economic Security  
1300 W Washington St, Rm. 930A  
Phoenix, AZ 85007  
602/542-3332

### ARKANSAS

Rehabilitation Services Division  
Dept. of Human Services  
Mail to: PO Box 3781  
Little Rock, AR 72203  
501/682-6709 or 682-6667

### CALIFORNIA

Department of Rehabilitation  
830 K St. Mall  
Sacramento, CA 95814  
916/445-3971 or 322-6606

### COLORADO

Division of Rehabilitation  
Dept. of Social Services  
Social Services Bldg., 4th Fl.  
1575 Sherman St.  
Denver, CO 80203  
303/866-5196

### CONNECTICUT

Governor's Committee on Employment  
of the Handicapped  
200 Folly Brook Blvd.  
Wethersfield, CT 06109  
203/566-8061

### DELAWARE

Governor's Committee on Employment of  
the Handicapped  
Division of Vocational Rehabilitation  
Department of Labor  
Elwyn Delaware Bldg.  
321 E 11th St.  
Wilmington, DE 19801  
302/571-3915

### DISTRICT OF COLUMBIA

Rehabilitation Services Administration  
Commission of Social Services  
Dept. of Human Services  
East Potomac Bldg. Rm. 1111  
605 G St. NW  
Washington, DC 20001  
202/727-3227

### FLORIDA

Division of Vocational Rehabilitation  
Dept. of Labor & Employment Security  
1709-A Mahan Dr.  
Tallahassee, FL 32399-0696  
904/488-6210

### GEORGIA

Division of Rehabilitation Services  
Dept. of Human Resources  
878 Peachtree St. NE, Suite 706  
Atlanta, GA 30309  
404/894-6670

### HAWAII

Commission on the Handicapped  
Dept. of Health  
Old Federal Courthouse, Rm. 353  
335 Merchant St.  
Honolulu, HI 96813  
808/548-7606

### IDAHO

Division of Vocational Rehabilitation  
State Board of Education  
Len B Jordan Bldg., Rm. 150  
650 W State St.  
Boise, ID 83720  
208/334-3390

### ILLINOIS

Dept. of Rehabilitation Services  
623 E Adams St.  
Springfield, IL 62794-9429  
217/782-2093 voice & TDD  
800/233-DIAL voice & TDD

### INDIANA

Dept. of Human Services  
251 N Illinois St.  
Mail to: PO Box 7083  
Indianapolis, IN 46207-7083  
317/232-7000

Child Specialty Services Div.  
State Board of Health  
1330 W Michigan St. Rm 232  
Mail to: PO Box 1964  
Indianapolis, IN 46206-1964  
317/633-0286 or 633-0269

### IOWA

Commission of Persons with Disabilities  
Dept. of Human Rights  
Lucas State Office Bldg., 1st Fl.  
E 12th & Walnut Sts.  
Des Moines, IA 50319  
515/281-5238

### KANSAS

KACEH - Kansas Advisory Committee on  
Employment of the Handicapped  
Dept. of Human Resources  
1430 SW Topeka Ave.  
Topeka, KS 66612-1877  
913/296-1722

### KENTUCKY

Office of Vocational Rehabilitation  
Dept. of Education  
Education & Humanities Cabinet  
Capital Plaza Tower, 9th Fl.  
Frankfort, KY 40601  
502/564-4440

### LOUISIANA

Div. of Rehabilitation Services  
Dept. of Social Services  
1755 Florida Blvd.  
Mail to: PO Box 94371  
Baton Rouge, LA 70804-9371  
504/342-9409

### MAINE

Bureau of Rehabilitation  
Dept. of Human Services  
32 Winthrop St.  
Mail to: State House, Station 11  
Augusta, ME 04333  
207/289-2266

### MARYLAND

Governor's Committee of Employment of the  
Handicapped  
One Market Center  
300 W Lexington St.  
Baltimore, MD 21201  
301/333-2264

Office for the Handicapped Individual  
Office of the Governor  
One Market Center  
300 W Lexington St.  
Baltimore, MD 21201  
301/333-3098

### MASSACHUSETTS

Rehabilitation Commission  
Executive Office of Human Services  
Fort Point Pl.  
27-43 Wormwood St.  
Boston, MA 02210-1606  
617/727-2172 or 727-6744

### MICHIGAN

Commission on Handicapper Concerns  
Dept. of Labor  
Market Sq.  
309 N Washington St.  
Mail to: PO Box 30015  
Lansing, MI 48909  
517/373-8397 voice or TDD

### MINNESOTA

Council on Disability  
Metro Square Bldg. Rm. 145  
7th Pl. & Jackson St.  
St. Paul, MN 55101  
612/296-6785

### MISSISSIPPI

Div. of Vocational Rehabilitation  
Dept. of Rehabilitation Services  
932 N State St.  
Mail to: PO Box 1698  
Jackson, MS 39215-1698  
601/354-6825

### MISSOURI

Governor's Committee on  
Employment of the Handicapped  
1904 Missouri Blvd.  
Mail to: PO Box 1668  
Jefferson City, MO 65102  
314/751-2600  
800/392-8249 (MO)

## State Vocational Rehabilitation Offices

### NEBRASKA

Governor's Committee on  
Employment of the Handicapped  
Dept. of Labor  
550 S 16th St.  
Mail to: PO Box 94600  
Lincoln, NE 68509  
402/475-8451

### NEVADA

Rehabilitation Division  
Dept. of Human Resources  
Kinkead Bldg. 5th Fl.  
505 E King St.  
Mail to: Capitol Complex  
Carson City, NV 89710  
702/885-4440

### NEW HAMPSHIRE

Governor's Commission for the Handicapped  
Executive Office of the Governor  
Park Plaza  
85 Manchester St.  
Concord, NH 03301  
603/271-2773  
800/852-3405 (NH)

### NEW JERSEY

Division of Vocational Rehabilitation Services  
Dept. of Labor  
Labor & Industry Bldg., Rm. 1005  
Mail to: CN 398  
Trenton, NJ 08625  
609/292-5987

### NEW MEXICO

Developmental Disabilities Bureau  
Behavioral Health Services Division  
Health & Environment Dept.  
Harold Runnels Bldg.  
1190 St. Francis Dr.  
Santa Fe, NM 87503  
505/827-2573

### NEW YORK

Office of Vocational Rehabilitation  
State Education Dept.  
One Commerce Plaza, Rm. 1907  
Albany, NY 12234  
518/473-4595  
518/474-2714

### NORTH CAROLINA

Governor's Advocacy Council for Persons with  
Disabilities  
Dept. of Administration  
1318 Dale St., Suite 100  
Raleigh, NC 27605-1275  
919/733-9250

### NORTH DAKOTA

Office of Vocational Rehabilitation  
Dept. of Human Services  
State Capitol  
Bismarck, ND 58505  
701/224-2907

### OHIO

Rehabilitation Services Commission  
400 E Campus View Blvd.  
Columbus, OH 43235-4604  
614/438-1210

### OKLAHOMA

Governor's Office of Handicapped Concerns  
Employment Div. or Technical Assistance Div.  
4300 N Lincoln Blvd., Suite 200  
Oklahoma City, OK 73105  
405/521-3756

### OREGON

Dept. of Human Resources  
Public Service Bldg., Rm 318  
Capitol Mall  
Salem, OR 97310  
503/378-3034

### PENNSYLVANIA

Division of Vocational Rehabilitation  
Dept. of Labor & Industry  
Labor & Industry Bldg., Rm 1300  
7th & Forster Sts.  
Harrisburg, PA 17120  
717/787-5476

### RHODE ISLAND

Vocational Rehabilitation  
Community Services Division  
Dept. of Human Services  
Gardner Bldg., 2nd Fl.  
40 Fountain St.  
Providence, RI 02903  
401/421-7005 or 401/227-3182  
401/421-7016 (TDD)

### SOUTH CAROLINA

Vocational Rehabilitation Dept.  
1410 Boston Ave.  
Mail to: PO Box 15  
West Columbia, SC 29171-0015  
803/734-4300

### SOUTH DAKOTA

Dept. of Vocational Rehabilitation  
Richard F. Kneip Bldg.  
700 Governors Dr.  
Pierre, SD 57501  
605/773-3125

### TENNESSEE

Division of Rehabilitation Services  
Dept. of Human Services  
Citizens Plaza Bldg., 15th Fl.  
400 Deaderick St.  
Nashville, TN 37219  
615/741-2019

### TEXAS

Rehabilitation Commission  
118 E Riverside Dr.  
Austin, TX 78704  
512/445-8108

### UTAH

Utah State Office of Rehabilitation  
250 E 500 South  
Salt Lake City, UT 84111  
801/538-7530

### VERMONT

Dept. of Social & Rehab. Services  
Human Services Agency  
Osgood Bldg.  
Waterbury Office Complex  
103 S. Main St.  
Waterbury, VT 05676  
802/241-2211

### VIRGINIA

Dept. of Rehabilitative Services  
4901 Fitzhugh Ave.  
Mail to: PO Box 11045  
Richmond, VA 23230  
804/257-0316  
800/552-5019 (VA)

### WASHINGTON

Division of Vocational Rehabilitation  
Dept. of Social & Health Services  
Office Bldg. 2  
12th & Franklin Sts.  
Mail to: Mail Stop OB-21C  
Olympia, WA 98504  
206/753-0293, or  
Special Programs 206/753-5472, or  
Field Services 206/753-0291

### WEST VIRGINIA

Division of Rehabilitation Services  
State Board of Rehabilitation  
Program & Planning Bldg.  
West Virginia Rehabilitation Center  
Institute, WV 25112  
Mail to: State Capitol Complex  
Charleston, WV 25305  
304/766-4601; 766-4603; 766-4604

### WISCONSIN

Division of Vocational Rehabilitation  
Dept. of Health & Social Services  
Wilson Street State Office Bldg.  
One W Wilson St., Rm. 850  
Mail to: PO Box 7852  
Madison, WI 53707  
608/266-1281  
608/266-2168  
608/266-9852 (TTD)

### WYOMING

Division of Vocational Rehabilitation  
Dept. of Health & Social Services  
Hathaway Bldg., Rm. 347  
2300 Capitol Ave.  
Cheyenne, WY 82002  
307/777-7389

### GUAM

Dept. of Vocational Rehabilitation  
122 Harmon Plaza, Rm. B201  
Mail to: PO Box 2950  
Harmon Industrial Park, GU 96911  
011-671-646-9468 & 9469

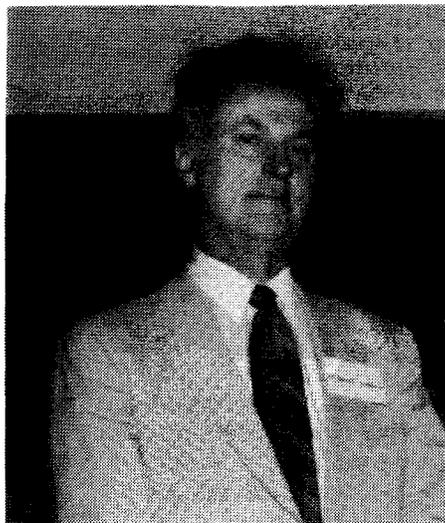
### PUERTO RICO

Office for the Handicapped  
Office of the Governor  
916 Chardon's St.  
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### VIRGIN ISLANDS

Special Services Section  
Disabilities & Rehabilitation Services  
Dept. of Human Services  
Barbel Plaza South  
St Thomas, VI 00802  
809/774-4775

## Ask The Doctor



Dr Robert E. Lovelace

*I am writing concerning my CMT. I am now 43 years old. As a child my twin brother and I, as well as father, grandfather, and numerous other family members, were diagnosed as having Charcot-Marie-Tooth disease. Up until about April of 1989 my symptoms have been the classic ones of general muscle weakness and occasional transitory episodes of numbness and tingling (sometimes cured by a week or two of Xanax or Tranxene). However, commencing April 1989 I have developed a constant burning in my hands and forearms spreading up to my elbows. Also my elbows are now very sensitive in the "funny bone" area. Although any strenuous hand activity involving concussion or vibration (hammering, lawn mowing, etc.) could cause temporary symptoms, the problem has never lasted this long and would go away by itself or with medications as I already mentioned. Also, in my prior episodes the sensations were confined to my hands only and not up my forearms. Now, even while just sitting I have discomfort in my arms, especially when my elbows are merely touching my lap or the sofa or chair arms. I have trouble sleeping because I cannot find a position that does not aggravate my arms, and I often awake with the aforementioned symptoms. As far as I know no one else in my family has had this severe a problem.*

*My family doctor originally felt that anxiety might be aggravating the CMT and he put me on Xanax. My neurologist at first diagnosed bilateral carpal tunnel syndrome. He did an EMG which verified by abnormally slow nerve conduction, but he said that*

*considering my already damaged nerves the tests were not conclusive enough to identify carpal tunnel, and that I would probably not find a doctor who would consent to trying carpal tunnel surgery. He also suggested Xanax, which works fairly well to ease the symptoms. However, I have now been on Xanax since April and I cannot go more than a day without having to take it. My concerns are these...I would like a more clear picture of CMT in an effort to determine whether that alone is the cause of my increasing physical problems, or if anxiety or some other treatable condition is at work. Also, for 18 years I have been a computer programmer for AT&T, and this job requires at least five hours a day typing at a computer terminal. How much effect could this have had on my hands and arms? I have read in several books and magazines that carpal tunnel is a common disorder among typists. Even though carpal tunnel (as I understand it) affects just the wrists and fingers, is it possible that I do indeed have this condition and that with my CMT damaged nerves the carpal tunnel symptoms have spread up my arms? If so, is surgery a consideration or would it result in even more damage? Is it possible that I have a nerve compression problem in by elbows, similar to carpal tunnel at the wrists? Or is it simply that my burning sensations are common to CMT? Are there other medications besides Xanax that might be more effective? The impressions I get from the professionals I have consulted is that they just don't know. Frankly, I am annoyed and discouraged by their attitude of "sorry, but you just have to learn to live with it".*

*Can you help me locate a CMT specialist in the Chicago area who could help me resolve my concerns and answer questions definitively? I would be most grateful for any contacts of CMT related literature that you can give me. Thank you very much.*

*M.S., IL*

The above letter was given to Dr. Robert E. Lovelace for his reply. Dr. Lovelace is a professor of neurology at Columbia University College of Physicians and Surgeons and co-director of the Neuromuscular Diseases Clinic. Additionally, he is Chairman of the Medical Advisory Board of the Charcot-Marie-Tooth Association.

From the description above, this gentleman would appear to be suffering from the slow conduction or hypertrophic peroneal muscular atrophy commonly called Charcot-Marie-Tooth Disorder Type I (aka hereditary motor sensory neuropathy type I [HMSN I]). The most recent account of this disorder, which in this patient's case would appear to be of autosomal dominant hereditary type, was published in the Clinics in Pediatric Medicine and Surgery, January, 1990 (1). This reference also contains references to other key articles.

Most experience would tend to downplay the frequency of arm sensory complaints in this disorder, and indeed sensory complaints in the arm or leg are rarely reason for the patient first presenting to the doctor. However, with accumulating experience similar to our understanding of CMT progression in pregnancy and the development of involvement in very young children and babies, we now realize that sensory complaints may play a greater role as the disease progresses. Frank numbness and paresthesia (tingling or "pins and needles") are the commonest complaints, but pain and burning sensations have certainly been described. They may be severe enough to merit not only the tranquilizer group of drugs such as the patient has been taking, but also frank nerve depressant medication such as Dilantin (diphenylhydantoin) or Tegretol (carbamazide), physiotherapeutic or, in extreme cases, surgical measures. This should be done under the guidance of a physician, preferably one versed in CMT and its management. To facilitate this we are currently compiling a Medical Advisory Board of such experts from the United States and abroad. The reason for informed medical advise is that sensory symptoms may necessitate revising the diagnosis or clarifying additional disorders which may have developed. This was quite correctly considered in the above patient's case when carpal tunnel syndrome, the commonest nerve entrapment syndrome, was mentioned and for which there is no specific treatment. However, the more general burning complaints the patient has, and particularly extending up to the elbow can represent a nerve lesion at the wrist, the elbow, the neck plexus of nerves, the neck

(continued, page 9)

**Ask The Doctor** (cont'd from pg.8)  
 (cervical) spine and its nerve roots, or even in the central nervous system (brain and spinal cord).

For this reason a neurological evaluation is important. This may include a neuromuscular electrodiagnosis (EMG) and/or nerve conduction studies, imaging procedures (magnetic resonance, CAT scan or X-rays) of the nerves, plexuses, neck, spine and even head. It is also very important to exclude metabolic disorders such as diabetes, thyroid disease (especially low thyroid), and deficiency disorders such as a vitamin B 12 deficiency and the much rarer vitamin E deficiency. There may be disease in other body systems such as the lungs and alimentary (digestive) tract which may give rise to peripheral neuropathy, and in particular special immunological tests should be done on the blood proteins to rule out the group of diseases called the paraproteinemias or gammopathies (from their gammaglobulin abnormalities). Even infections such as a Lyme disease and inflammations of the peripheral nerve blood vessels called vasculitis may need to be considered for which specific treatment is available. On the

whole the semi-invasive procedures of spinal tap (lumbar puncture) and muscle and/or nerve biopsy may not be needed except in the last mentioned cases when a tissue diagnosis is important.

Addressing the problem of entrapment neuropathies such as carpal tunnel syndrome this is usually idiopathic (no clear cause) in young middle age and middle age women. It can also occur from new occupational stress such as retirement gardening, house painting or construction repairs. Other associations are hypothyroidism (low thyroid), pregnancy, rheumatoid arthritis and diabetes (neuropathy), with the rare disease of amyloid disorder which can also be hereditary. CMT disease, although possibly predisposing to carpal tunnel, is not necessarily one of the commoner associations. A very careful evaluation of the electrodiagnostic studies (nerve conduction) would be to be sure that the median nerve was selectively involved at the wrist. On this predisposition basis it is possible that CMT typists and computer keyboard operators may exacerbate this disorder more frequently with their wrist movements. As with carpal tunnel in

diabetics, surgical decompression at the wrist is less successful in patients with a predisposing neuropathy such as CMT. Surgery is more successful in the idiopathic form of carpal tunnel syndrome. It may however, have to be considered in the individual case, but the trial use of forearm-hand night splints may be assessed first.

It is to be emphasized that all of the above should be done with the management skills and advise of a neurologist, rehabilitation physician, orthopedist or other suitable doctor.

*Robert E. Lovelace, M.D., F.R.C.P.*

Reference: Robert E. Lovelace, Hereditary Induced Peripheral Neuropathies. Clinics in Podiatric Medicine 7: 37-50, 1990.

*At the CMTA through our Medical Advisory Board we are very interested in hearing about the different varieties of sensory complaints which CMT patients may have. This will help us in better understanding this aspect of the disease and hopefully lead to therapeutic and treatment consideration. You may write to Dr. Lovelace at the CMTA. Sensory complaints are tingling sensations (pins and needles), numbness, pain, burning and electric shock sensations. ☐*

## CMTA Remembrances

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards sent in honor of or in memory of will be mailed by the CMTA on your behalf. These donations 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 mailing it with your check to:

**CMTA, Crozer Mills Enterprise Center, 600 Upland Ave., Upland, PA 19015.**

### Honorary Gift

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## Support Group Notes

A primary goal of the CMTA is to become a truly successful advocate for those with CMT. Its message must reach the patients, their families, and the medical and research communities. Patient family support groups, a growing and vital part of the CMTA program, inform and support anyone who must deal with this often overlooked disease.

There are already several CMTA support groups. These chapters are spirited and growing stronger, but more groups are needed in other parts of the United States. The CMTA will gladly help you to set up a chapter in your area. For information contact the CMTA by mail or call (215) 499-7486.

Perhaps there is a chapter meeting near you. You are cordially invited to join these groups in their upcoming events.

### San Diego, California

Contact: Gary Oleze (619) 792-1427

### San Francisco, California

Contact: David Berger (415) 491-4801  
After 6:00 pm

### Greater Dallas, Texas Area

Contact: Dr. Karen Edelson, D.P.M.  
(214) 542-0048

### Parsons, Kansas

Where: Labette Community College  
Parsons, KS  
Contact: Tammy Taylor (316) 421-5268

### Indianapolis, Indiana

Contact: Elaine Donhoffner (317) 841-0241  
Robert Birdwell (317) 352-0235

### Detroit, Michigan

Contact: Marianne Tarpinian (313) 883-1123

### Chicago, Illinois

Contact: Carol Wilcox (312) 445-2263

### Cleveland, Ohio

Contact: Norma Markowitz (216) 247-8785

### Boston, Massachusetts

Contact: Eunice Cohen (617) 894-9510

### Central New Jersey

Where: Princeton Medical Center  
Lambert House  
Classrooms #1&2  
Contact: Janet Selah (201) 281-6289

### Northern New Jersey

Where: Englewood Hospital  
Clinic Conference Room  
350 Engle Street  
Englewood, NJ 07631  
Contact: Terry Daino (201) 934-6241

### Long Island, New York

Contact: Lauren Ugell (516) 433-5116

### Rochester, New York

Contact: Neale Bachmann (716) 554-6644  
Bernice Roll (716) 584-3585

### Delaware Valley, Pennsylvania

Meeting: Holy Redeemer Hospital  
Meadowbrook, PA  
Contact: Rex Morgan, Jr. (215) 672-4169

### Pittsburgh, Pennsylvania

Contact: Garnett McDonald (412) 372-2853

### Tidewater, Virginia Area

Contact: Mary Jane King (804) 591-0516  
Thelma Terry (804) 838-3279

### Greater Atlanta, Georgia

Contact: Molly Howard (404) 253-5632  
Sue Saye (404) 565-5950

### Orlando, Central Florida Area

Contact: Mary Beeler (407) 295-6215  
Meeting: Third Saturday of every other month

### Fort Pierce Area, Florida (Atlantic Coast)

Contact: Dorothy Stefanovich (407) 461-1016

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## VCR Tape Rental

The CMTA has available for rental four lectures which were taped at patient conferences sponsored by the Foundation. The tapes are for play on a VHS VCR. Beta tapes are not available. The speakers are authorities in their fields and lecture topics include: Neurology, Physical Therapy, CMT Genetics, and Orthopedic Surgery.

Single lecture tapes (1 hr., 15 min.) rent for \$10, and the double lecture tapes (2 hr., 30 min.) rent for \$15. The rental fee includes prepaid return postage.

To order a tape, fill out our **I want to be in touch!** form and send it to us with a check or money order payable to:

The CMTA  
Crozer Mills Enterprise Center  
600 Upland Ave.  
Upland, PA 19015.

## The CMTA Report

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*If you are moving, please send us your change of address and enclose a mailing label from a previous NFPMA or CMTA Report. Thanks.*

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Name: \_\_\_\_\_  
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 Neurology/Genetics - \$15 (on one tape)  
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## Physician Referrals Available from the CMTA

The CMTA has compiled a list of neurologists, orthopedists, and psychiatrists (a psychiatrist is a physician trained in physical medicine and rehabilitation) who have a special interest in CMT. We can also access hand surgeons and respiratory specialists. To receive information, please send a stamped self-addressed envelope and note what geographic area is convenient for you.

### Pedorthist Referrals

A pedorthist is a practitioner who provides care to the patient by fitting orthopedic shoes and devices, at the direction of and in consultation with physicians. To receive a referral for a pedorthist send a stamped self-addressed envelope and note what geographic area is convenient for you. She/he will be working in an orthopedic shoe store. Send both requests to the CMTA, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19105. ♣

## Memorials

<b>In memory of</b>	<b>By</b>
Jack Goldman	Doris M Goldman
Eleanor Lowy	Gemstone Sales Co.
Naomi Baumgardner	Morris Woolman
Naomi Baumgardner	Loretta Woolman
Stanley Sonntag	Joy Brindle
Mathew McNeil	Ruby LaFranchi
Mathew McNeil	Alan J. McMurry
Mathew McNeil	Dr./Mrs. Albert Newton
Mathew McNeil	Brice & Frances Martin
Mathew McNeil	M/M J.W. Churchill
Mathew McNeil	Richard Princen
Mathew McNeil	Lolly Bienenfeld
Sylvia Ugell	Natalie Roth

## Honoraria

<b>In honor of</b>	<b>By</b>
M/M Henry Edredge	Douglas Moody
Frank T. Crohn	Dr. David Sachar
Meme Plageman	Janice Vaughn
Susan Mayer	Rebecca Brezel
Rebecca Sand	Rose Freed
Cari Hook	Cynthia J. Cilwik
Rebecca Sand	Ida & Maurice Sand

## For the CMTA

This material is presented for educational purposes only and is not meant to either diagnose or prescribe. While there is no substitute for professional medical care for Charcot-Marie-Tooth Disease, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.

## Attention CMT Patients!



Dr. James Lupski, of Baylor Medical Center, requests that CMT patients who have a second inherited condition contact him. Please, when you write give the name of the second condition. Also, CMT patients who have a known chromosomal anomaly are asked to contact Dr. Lupski at the CMTA, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015. (215) 499-7486.

## Call for Articles

### ***THE CMTA REPORT***

welcomes your ideas and article suggestions. For example, you may submit a human interest story telling of your experience of living with CMT. Also, medical professionals can forward articles of a clinical or medical nature that would be of general interest to our readership.

The following back issues of ***THE NFPMA REPORT*** (now ***The CMTA Report***) are available at \$2.50 a copy:

Fall '89  
Summer '89  
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Fall '88  
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Write or call the CMTA  
(215)499-7486

### **CMT...**

- .....is the most common inherited neurological disease, 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 hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, occasional partial sight and/or hearing loss problems 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, affecting half the children in a family with one CMT parent.
- .....may become worse if certain neurotoxic drugs are taken.

# ***THE CMTA REPORT***

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