

# THE CMTA REPORT

Spring 1991

Vol.6/No.2

Providing information on Charcot-Marie-Tooth disease (a.k.a. Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neurological disorder. Contents © 1991, CMTA. All rights reserved.

## Financial Options for the Disabled

**Editor's Note:** *The following article was written from a presentation by Jack A. Nolish, Esq. Mr. Nolish, a Southfield, Michigan attorney, was the guest speaker at the February Detroit Area support group meeting. (See Support Group Corner) We would like to thank Mr. Nolish for his counsel, knowledge and time so freely given.*



Jack A. Nolish, Esq.

When a disabled person can no longer work, he/she is confronted with the very real necessity of finding an income source. This was the issue Jack Nolish ably addressed at a recent CMTA support group meeting. There are benefits available which the individual can secure, and those benefits and how to apply for them were explained by Mr. Nolish.

The first benefit source would be the patient's current employer. Some employers have disability pension

benefits. Other sources of this same benefit are unions. In order to qualify, most of these plans will have vesting and a minimum employment term. A less known benefit plan is the "mutual pension." Under this plan the company and the disabled worker come to a mutual agreement and terms for the worker's early retirement. This is a feature of some corporation's retirement plans, and should be investigated by all workers faced with retirement due to disability.

Another source of income is the general assistance programs which are state based and are subject to the current political situation. The application process for this type program begins at the county level, and inquiry to the county social services office should bring the necessary information. These programs do include Medicaid, however there are severe financial restrictions on eligibility. Applying for general assistance will lead to an ap-

plication for Supplemental Security Income or SSI which is done at the local Social Security office.

Under Social Security there are two relevant parts for the disabled person. They are **Social Security Disability Benefits (DIB)**, Title 2 and **Supplemental Security Income (SSI)**, Title 16. SSI is a program for people who have never contributed to the Social Security fund. To qualify for this program, severe financial hardship must be demonstrated.

To qualify for DIB the applicant must meet "earnings" requirements (this would be money paid into the Social System) and be a disabled person. There are also other conditions that can qualify someone for DIB benefits. They include widow's benefits which

(continued on page 2)

### WE HAVE A NEW LOOK!

This issue and the next will be printed on white paper rather than our traditional buff color because we have received a gift of in-kind printing service from the Sun Company.

The Sun Company, of which Sun Oil and Sunoco are two well-known trade names, is headquartered in Radnor, PA, near our own national office. Sun is printing the spring and summer issues of *The CMTA Report* at its print shop in Philadelphia.

We thank the Sun Company for its generosity in sponsoring these two issues of *The CMTA Report*.

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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  
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  
Metronidazole (Flagyl)  
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.**



## TRAVEL POSSIBILITIES

The Society for the Advancement of Travel for the Handicapped offers an enticing array of travel opportunities and lists vacations that are accessible. Their recent newsletter, *SATH News* lists companies that rent vans with lifts and the option of special driving controls; special cruises for people with diabetes; U.S. airports with handicap facilities; travel agents serving clients who are deaf and other useful listings.

For a copy of the newsletter write SATH, 26 Court St., Brooklyn, NY 11242 or call 1-718-858-5483. □

## Benefits (cont'd from pg. 1)

means if you are the surviving spouse of a worker who was covered by Social Security, and you are disabled, you can apply for DIB.

The legal definition of disability is "Unable to engage in substantial, gainful economic activity as a result of medically determinable impairment(s) and that such disability has lasted or can be expected to last for 12 months or to result in death."

Disabled adult children can also qualify for DIB if the condition existed prior to age 18 and was disabling before the age of 22. The applicant must be the child of a parent who works (or worked) and contributed to Social Security. The child can also be the survivor of a parent who was covered by Social Security or the child of a parent who receives DIB. In other words, the disabled child's parent must have worked and contributed to Social Security. Your local Social Security office will explain all of these programs to you. Look in the "Blue Pages" of your local phone book and you will find the closest office.

There are advantages to qualifying for DIB. The recipient is paid as if he/she were 65 years of age and this preserves retirement benefit rates. After two years of DIB qualification, minor dependents (during their minority) and the spouse are eligible for Medicare. Obviously, this is of great benefit.

Benefits can be obtained for numerous periods of time and a person can go on and off benefits. Again, your Social Security representative can advise you.

The Social Security claim application process consists of many steps, and Mr. Nolish's advice was, "DON'T GIVE UP."

The steps involved are:

1. Initial application made by claimant
2. Determination
3. Re-determination
4. Request for Hearing
5. Hearing before Administrative Law Judge
6. Appeal to Appeals Court in Washington
7. Federal Court of Appeals.

The evaluation process by the Social Security includes:

1. Is the claimant working?
2. Does the claimant suffer from medically determinable impairments that meet or equal the regulations?
3. Can the claimant perform his/her past relevant work?
4. Do jobs exist in significant numbers in the region that the claimant can perform based on his/her impairments as well as his/her age, education, background, and skills?

Social Security addresses the functional limitations brought about by various conditions. The diagnosis is important to establish onset for eligibility purposes but the most important question is how the condition affects the ability of the claimant to work. Pain can be a significantly limiting vocational factor, as can medication side effects, emotional reactions, and the need to attend therapy or be recumbent for significant periods.

If you wish to obtain the services of a lawyer experienced in Social Security law we recommend you contact The National Organization of Social Security Claimant's Representatives (NOSSCR) at 1-800-431-2804. They will refer you to appropriate attorneys and legal services in your geographic area who will be able to counsel and assist you in the process. □

## California Conference Thanks

The CMTA wishes to thank the following members of the Association who financially supported the California conferences in Los Angeles and San Francisco. Without the continued support of members such as these, conferences across the country would be impossible.

Marilyn Abbate	Patti Ault
Neil Brody	Betty Chow
Norman Cool	Jack Graves
Raymond Green	Janice Hagadorn
Elsa Kovacs	Hope Lariosa
Julie Lorenz	Philip Mack
Maureen and Grant Nelson	Gary Oelze
Ronald Riskevich	Margaret Schaefer
Thomas Smalley	Daniel Sifling
Howard and Miyuki Sheppard	Marian Sward
Mark Thomas	Sue Turner
M/M Franklyn Weiss	M/M Robert Welby

**PATIENT PROFILE:**

**JENNIFER HINEBAUGH**

Jennifer Hinebaugh is a sixteen year old girl, typical in her interests and activities, but "special" in the accomplishment of having CMT and still seeming typical.

Jennifer's story is one that is heard too often... a story of misdiagnosis or no diagnosis for many years. Jennifer walked at 10 months, but her mother was told she was "imagining" that Jennifer walked funny. At 2 years, Jennifer fell or stumbled easily and "Mom was just a worrywart." At 4, a doctor said she had weak knees and put her in cable braces. At 6, her parents decided that she had weak legs and started her on an exercise program of their own. Between the ages of 6 and 12, she saw many doctors who told her she was "awkward" because she was tall, that she was having a "growth spurt" and that things would "level out."

Finally in 1988 tests were done by an orthopedic surgeon and Jennifer's disease was given a name... CMT. In June of 1988, Jennifer had tendon transfers in both feet.

Jennifer has had six years of ballet, jazz, tap dance and baton and has marched with a baton twirl team for 2 years. In the summer she swims and walks daily. In winter she uses a treadmill and exercise bike.

Today she wears braces on occasion. She is a member of her high school marching band and performs at halftime functions. She has enrolled in modeling classes and came in first runner up for Queen in the Rainbow Beauty Pageant in Cumberland, Maryland, on February 17th, in spite of the fact that she has the "marionette walk" and slightly drags one foot.

Jennifer's parents have encouraged her to do anything she wants, with the only rule being that once she starts something she must be determined to see it through.



Jennifer Hinebaugh

Both Jennifer and her parents believe that lifelong exercise is a must for CMT patients and both believe that doctors, patients, the public and insurance companies must be made more aware of the existence and nature of CMT.

We, at the CMTA, admire Jennifer's "can do" attitude and see her as a positive example of a CMT patient who meets the challenges of a disability and is still able to live life to the fullest! ☐

***In Memory Of...***

The following note which accompanied several donations in memory of Eric "Mac" Carpenter touched us here at the CMTA and made us feel that he was certainly a special man. We felt the tribute that the note conveyed was worth sharing.

*Please accept these checks donated to CMTA on behalf of Eric "Mac" Carpenter who passed away on January 1, 1991. He wanted to do something to help our daughter Elsa Johnson, age 9, and others coping with Charcot-Marie-Tooth disease. Mac was a very kind and generous person with great wisdom and concern for others. He was a true believer in the zest of life and appreciated the wealth of enjoying the simple things. He will be missed by many friends from all walks of life in the different countries he lived in - England, Africa, and the United States.*

*Sincerely,  
Mark Johnson*

***In memory of "Mac" Carpenter***

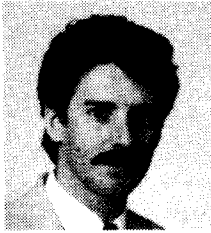
Suzanne Motzenbecker  
Michael Alesi  
Hali Kaufman  
Deborah Leong  
Phyllis Mulligan  
Melissa Piermont  
Mr. and Mrs. Jon Barrett  
Alan and Jean Smith  
Mrs. M.A. Barclay  
M.L. and G.T. Cann

**CMT FACTS**

**AVAILABLE NOW!**

CMT Facts, a 16 page informational booklet about CMT and therapies, may be purchased from the CMTA. To order complete the "I want to be in touch!" panel on page 11.





## The Pedorthic Aspects of Charcot MarieTooth Disease

by Ian Alexander, M.D.

(Editor's note: The following article appeared in the Dec./Jan. issue of *Pedoscope*. With the permission of the Prescription Footwear Association we present it in the CMTA Report in the hope that it could be shown to the CMT patient's pedorthist to help him/her better understand the CMT foot.)

Some of the most difficult treatment problems facing pedorthists fall into two groups of conditions affecting nerves and muscles, which are known as neuromuscular disorders.

When the primary site of damage in these disorders is in the peripheral nervous system, selective muscle atrophy (wasting) may result in motor imbalances which produce secondary limb deformities. Charcot Marie Tooth (CMT) disease, named after the discoverers of this condition, fits into this group.

Damage to the peripheral nerves in CMT results in characteristic wasting of the calves, pes cavus (high arch) and claw toes. Patients with CMT frequently complain of tired legs, foot fatigue, metatarsalgia, ankle instability, trouble fitting shoes, and problems with their balance as a result of damage to sensory nerves that provide position sense. The involvement of both feet, as well as a family history of thin calves and high arched feet, are strongly suggestive of CMT disease as, in most cases, the condition is inherited. Occasionally, the nerves of the upper extremity are involved, producing hand weakness and deformity.

The characteristic foot deformities include pes cavus with a rigid, plantarflexed first metatarsal, resultant forefoot valgus with compensatory hindfoot varus, and clawing of the toes. Muscular atrophy may result in a drop

foot and a resultant tightness of the heel cord.

Early on, the compensatory hindfoot varus and claw toes are flexible. In the late stages, these almost invariably become fixed. Flexibility of the varus hindfoot can be assessed with the lateral block test, which allows the first metatarsal to drop while the lateral rays and heel are supported by wooden blocks of variable height. If the hind foot is flexible, the alignment of the heel will correct with this maneuver. If heel varus persists, the deformity is rigid.

CMT disease is a progressive disorder and any corrective orthosis and shoe modification used to treat the problem needs to be reassessed regularly to be sure that they meet the patient's needs. In the early stages, patients most often complain of metatarsalgia and dorsal irritation of claw toes. A composite orthosis, that both unloads the metatarsal heads and provides impact attenuating materials under the heads, will often alleviate the majority of the forefoot pain if the claw toes are accommodated with a larger shoe toe box. When forefoot valgus and compensatory hindfoot varus cause a feeling of instability (rolling over at the ankle), pedorthic intervention can help considerably. If the hindfoot malalignment corrects with the lateral block test, hindfoot varus can be corrected with a lateral forefoot post on the orthosis and/or the shoe. This lateral build up replicates the mechanics of the lateral blocktest. In patients with rigid hindfoot varus, posting is usually of minimal benefit but a lateral flare on the heel may help alleviate the subjective instability. In neglected cases, a severe equinovarus deformity (fixed ankle plantarflexion with an inturned, higharched foot) may necessitate a custom shoe.

The progressive nature of CMT disease makes this debilitating deformity a possibility in all those affected. At this time, however, it is impossible to predict which individuals are at greatest risk of this severe deformity. This creates a dilemma for both the pedorthist and the surgeon. Is there a point at which pedorthic treatment,

even if successful in alleviating the discomfort, should be aborted to perform surgery to correct the existing deformities? It is possible that this surgery might slow or prevent the development of the rigid equinovarus foot. From the surgeon's perspective, deciding to operate on a deformed but pain free foot is difficult, as even the best conceived and technically performed surgery may lead to a painful appendage.

In summary, the patient with CMT disease challenges the pedorthist due to the severity and progressive nature of the foot deformity in this condition and the additional problem of instability related to neuromuscular imbalance. If this challenge is met successfully by the pedorthist, these patients are most grateful. □

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### Recent Scientific Articles on CMT

A comprehensive article on CMT entitled "Charcot-Marie-Tooth Polyneuropathy Syndrome: Clinical, Electrophysiological and Genetic Aspects" has just been published in *Current Neurology*, Vol. XI, Stanley H. Appel, Editor.

The article is the work of James R. Lupski, M.D., Ph.D.; Carlos A. Garcia, M.D.; Gareth J. Perry, M.D.; and Pragna I. Patel, Ph.D. The book can be ordered from Mosby YearBook, Inc., 11830 Westline Industrial Dr., St Louis, MO 63146 or call 1/800/426-4545. The cost of the volume is \$69.95.

Another recent publication is "Muscular Dystrophy and other Neuromuscular Diseases: Psychosocial Issues" from the *Journal of Loss, Grief and Care*, Vol. IV, issues 3 & 4. Editors are L.I. Charash, R.E. Lovelace, et. al. There is a large section on CMT in the book.

This may be ordered from Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904 or call 1/800/342-9678. The cost of the softcover edition is \$20.00; hardcover edition is \$34.95. □

### LETTERS

We want to hear from YOU!

Write us at:

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

# 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 disorder.

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 please 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.

**California— Los Angeles area  
Burbank**  
Sherry Brown (818)841-8421

**Oxnard-Thousand Oaks**  
Janice Hagadorn (805) 985-7332

**San Bernadino ("Inland Empire")**  
MaryL Michels (619) 246-7807

**Canyon Country - Saugus**  
Sheila Levitch (805) 254-5322  
Denise Miller (805) 251-44537

**California— San Diego**  
Gary Oleze (619) 792-1427

**California— San Francisco**  
David Berger (415) 491-4801  
After 6:00 pm

**Colorado— Denver Area**  
Dr. Gregory Stilwell (719) 594-9920

**Connecticut**  
Linda Friedo (203) 374-8478

**Florida— Orlando Area**  
Mary Beeler (407) 295-6215  
Meets 3rd Saturday, every other month

**Florida— South (Atlantic Coast)**  
George Meyerson (305) 431-3979

**Georgia— Greater Atlanta Area,**  
Molly Howard (404) 333-0597  
or (404) 564-9433

**Georgia— Western**  
Molly Howard (404) 253-5632

**Indiana— Indianapolis**  
Elaine Donhoffner (317) 841-0241  
Robert Birdwell (317) 352-0235



**Massachusetts— Boston,**  
Eunice Cohen (617) 894-9510

**Michigan— Brooklyn**  
Robert D. Allard (517) 592-5351

**Michigan— Detroit**  
Suzanne Tarpinian (313) 883-1123

**New Jersey— Central**  
Janet Saleh (201) 281-6289  
Meets at Princeton Medical Center  
Lambert House, Classrooms #1&2

**New Jersey— Northern**  
Teresa Daino (201) 934-6241  
Meetings: Englewood Hospital  
Clinic Conference Room  
350 Engle Street, Englewood, NJ

**New York City— Manhattan**  
Anne Beyer (201) 391-4624

**New York— Long Island**  
Lauren Ugell (516) 433-5116

**New York— Rochester**  
Neale Bachmann (716) 554-6644  
Bernice Roll (716) 584-3585

**New York— Westchester County**  
Kay Flynn (914) 793-4710

**Ohio— Cleveland**  
Norma Markowitz (216) 247-8785

**Pennsylvania— Delaware Valley**  
Rex Morgan, Jr. (215) 672-4169  
Meetings: Holy Redeemer Hospital  
Meadowbrook, PA

**Pennsylvania— Pittsburgh**  
Garnett McDonald (412) 937-0115

**Texas— Greater Dallas Area**  
Dr. Karen Edelson, D.P.M.  
(214) 542-0048

**Utah— Salt Lake City**  
Marlene Russell (801) 942-8642

**Virginia— Tidewater Area**  
Mary Jane King (804) 591-0516  
Thelma Terry (804) 838-3279

## support group corner



Sue Tarpinian

"It's been tough getting it going" began Sue Tarpinian's story of the Detroit, Michigan support group that she, her mother, and her sister were instrumental in starting. But, it is going now and the successes are measurable with each passing meeting.

In February, 22 people attended the meeting which featured an attorney whose specialty is disability income and an attorney who is a specialist in the rights of the handicapped.

At the March meeting, an 8 year old who was having trouble with how to stand up to the meanness of children without using his fists, left the meeting saying that he would say to kids who teased him about what he can and can't do, "That's just what I've got (CMT) and if you don't like how I do things that's just too bad!"

One member of the support group could barely get around because of the weakness in her legs. Through the group she learned of the MDA and had braces fitted for her. When last seen, she was jitterbugging for the first time in many years!

The April meeting is yet to occur (at this writing) and will focus on AFO's and braces with presentations by an orthopedic service company and a man who makes custom designed shoes.

Sue is working with the CMTA in planning a CMT patient/family regional conference in Detroit this Fall. Details will be announced in the Summer CMTA Report.



## Ask the Doctor

Dear Doctor,

I am writing about my son. He was diagnosed as having Charcot-Marie-Tooth disease about 2 years ago. He is 25 years old and has worked since he was 17. He has been on his feet a lot. In 1990 he broke a bone in his left foot and was off work till January 2, 1991. He was on crutches for 4 weeks and then was put in an air cast. He went back to work and worked until January 28 and another bone broke in his left foot. He stepped on something and turned his foot and heard the bone snap. Is this common with this disease?

I and one of my daughters have this disease also, but have never had any bones broken. My daughter has a real high instep and sprains her feet a lot. I don't have much trouble with my feet anymore, only on the balls of my feet.

Please help me with any information that you can.

E.F. Joplin, Mo

**Editor's note:** Two experts from the CMTA's Medical Advisory Board answered this patient's letter with the result that there is a great deal of excellent and learned information given to the patient. We thank these medical specialists for their counsel.

**ANSWER:** *The skeletal structure of an active young person with CMT disease should not be significantly different than that of a normal person. The disease itself does not weaken the bones. If a person with CMT persists in breaking their bones, this person should have a generalized medical examination by a family physician. This examination should also include the necessary blood tests to rule out any other condition or a metabolic bone disease. Persons with CMT who have weak ankles or deformed feet including feet with high arches may have difficulty balancing. Thus, sprains or fractures can occur more readily. When these injuries are severe enough, they may require immobilization. With immobilization, demineralization can occur. Thus, the bones can become weaker from the immobilization and disuse. It is important to follow the advice of your doctor with regards to postfracture care and use of an injured extremity.*

**ANSWER:** *Though this particular scenario may not be common, there is indeed a predisposition for situations such as these to occur. As muscles become affected by CMT, a muscle imbalance invariably follows. Since muscles attach to bones, an irregular or uneven distribution of body weight is likely to develop in CMT patients as they walk, even in patients who never previously sustained an injury. The existence of an underlying muscle imbalance therefore creates an increased risk of stress, pressure and other abnormal forces which could induce fractures or other foot impairments. Once a fracture has occurred in a CMT patient, he/she may not be able to absorb full stress or other pressures until it is fully healed (which may consume many months). During this period while the bone is still healing (though perhaps no longer requiring a cast) there is a tendency for further alterations in body weight and function of the foot, causing other bones and structures to inherit excessive forces which previously they did not endure. As a result these additional factors place an increased risk for further damage (such as fractures) of the foot to evolve. Furthermore, the patient who is recovering from a fracture may subconsciously favor how they walk and aggravate adjacent foot structures. CMT should not have a primary or direct affect upon weakening the bones of the foot. However, as a result of the muscle imbalance as described in response to question one, as well as a late secondary affect of sen-*

*sory nerve involvement, supporting structures to the bones will become compromised. Once again the result will cause abnormal stress (and other forces) on the bones of the foot. Appropriate physical therapy, orthotic intervention and perhaps bracing may be required to reduce the advent of compensatory factors which will place the patient at risk for further injury.*

**Editor's note:** The CMTA can refer you to medical specialists. For information see page 11.

Dear CMTA:

I am 27 years old and have CMT plus scoliosis. Is this very common? I would like to hear from you.

D.S., MN

Dear D.S.

*Dr. Harold Marks of the A.I. duPont Children's Hospital found in a study of 81 children that 44.7% of Type I CMT children had scoliosis and 62.3% of Type II CMT children had scoliosis. This is in contrast to a study by Drs. Anita Harding and P.K. Thomas of London who found rates of 1.4% and 3.6% for Types I & II. Dr. Marks attributed the significant difference to the fact that A.I. duPont is an orthopedic children's facility and only treats such problems. The Thomas/Harding study was conducted in the general CMT population. In his survey, Dr. James Lupski found scoliosis was present in 8.6% of the surveyed CMT patients.* □

### WELCOME!

### CMT ASSOCIATION OF AUSTRALIA

The CMTA is pleased to welcome the newly formed CMTA of Australia to the network of organizations whose purpose is to provide information on CMT to patients, families, and medical professionals. President Karol Hitt of The CMTA was contacted back in 1988 by David Fennell for advice on how to start an association devoted to CMT. His organization began as a support group and in the summer of 1990 was granted official status as a registered Australian charity. The group publishes a quarterly newsletter and in their second issue printed a letter of congratulations and encouragement from Karol.

In Australia, at the University of Sydney, there is significant molecular genetic research being conducted by Professor James McLeod, an internationally known authority on recessive forms of CMT. Dr. McLeod is a member of the medical advisory board of our American CMTA.

We encourage our members from Australia and New Zealand to consider joining the CMTA of Australia if they have not already done so. The secretary's address is: Association Secretary, 30 Glenarvon St., Strathfield, Australia, 2135.



# CMT PATIENT HISTORY AND SYMPTOM QUESTIONNAIRE

Once again, you, the CMT patient, are being asked to participate in a survey. This survey was formulated by Dr. Gerald Weber, a professor at the New York College of Podiatric Medicine. Only you can provide this information to the medical community, enabling them to improve your care and therapy. Please take the time to complete the survey and return it to the CMTA.

DATE: \_\_\_\_\_ AGE: \_\_\_\_\_ SEX: \_\_\_\_\_

Please check the appropriate space:

1. At what age were you first diagnosed?

- 7-12                       31-40
- 13-20                      41-50
- 21-30                      After age 50

2. What type of doctor first recognized or suspected you of having CMT?

- Orthopedist                       Neurologist
- Other                                 Podiatrist
- Internist/Family Physician

3. Does anyone else in your family have CMT? If so, who?

- Mother                       Father                       Brothers
- Sisters                       Sons                       Daughters
- Grandparents                       Cousins

4. At what age did any discomfort begin in your feet/legs?

- Never                       21-30
- 8-12                       31-40
- 13-20                       Over 40

5. Have you ever had any of the following symptoms:

A) Weakness or Instability?                       Yes                       No

If Yes:                       Right                       Left                       Both

At what age did it begin? \_\_\_\_\_

Does it affect your:

feet                       hands                       ankles                       legs

B) Recurrent ankle sprains:

If yes:                       Right                       Left                       Both

At what age did it begin? \_\_\_\_\_

C) Numbness, pins and needles or tingling sensation:

If yes:                       Right                       Left                       Both

Where?                       Toes                       Ball of the foot

Entire foot                       Foot and legs

At what age did it begin? \_\_\_\_\_

D) Pain: If yes, where?

Toes:                       Right                       Left                       Both

Ball of the foot:  Right                       Left                       Both

Heel:                       Right                       Left                       Both

Ankle:                       Right                       Left                       Both

Shin:                       Right                       Left                       Both

Calf:                       Right                       Left                       Both

Knee:                       Right                       Left                       Both

At what age did it begin? \_\_\_\_\_

6. Do you have any of the following:

A) High arch foot

If yes:                       Right                       Left                       Both

B) Contracted (bent) toes

If yes:                       Right                       Left                       Both

1-2 toes                       3-6 toes

8 toes                       All toes

C) Corns on your toes

If yes:                       Right                       Left                       Both

D) Callouses (Hardened skin)

If yes, where?

Under ball of foot:  Right                       Left                       Both

Side of big toe:  Right                       Left                       Both

Heel:                       Right                       Left                       Both

E) Recurrent ingrown toenails

If yes:                       Right                       Left                       Both

1-2 toenails                       3 or more

Did they become infected?                       Yes                       No

F) Skin breakdowns ( sores, ulcerations )

If yes, where?

Top of toes:                       Right                       Left                       Both

Tip of toes:                       Right                       Left                       Both

Ball of the foot:  Right                       Left                       Both

Side of the foot:  Right                       Left                       Both

Heel:                       Right                       Left                       Both

Ankle:                       Right                       Left                       Both

7. Do you have excessive shoe wear

If yes, where?                       Right                       Left                       Both

Heels                       Tips

Inner (toward the big toe)

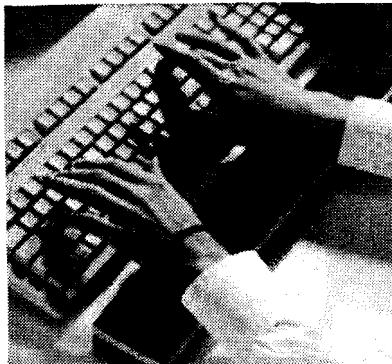
Outer (toward the little toe)

**Thank you for your participation in this survey. Please send your completed forms to:**

CMTA, 600 Upland Ave., Upland, PA 19015

## GADGETS

Two devices for use at the typewriter or computer keyboard are found in the March/April issue of *Taking Control of Your Health*. The first device is called a keyboard wrist support.



keyboard wrist support

The catalogue's description follows:

If you work long hours at a computer keyboard, you'll find this "Keyboard Wrist Rest" relieves tension in your hands and arms. The "Keyboard Wrist Rest" elevates your wrists to just the proper height and gives them a place to rest without strain. Made of hightech Temperfoam (developed by NASA) sandwiched between a soft nylon top and a nonskid neoprene base, the "Keyboard Wrist Rest" molds gently to the shape of your wrist then springs back into shape. To find the proper size, measure the height of the front edge of your keyboard then add 1/2". If you're concerned about hand pain, you owe it to yourself to try it. Make your desk ergonomically correct without spending hundreds of dollars.

1" A1523 Keyboard Wrist Rest \$27.00

1-1/2" A1524 Keyboard Wrist Rest \$27.00

## VCR Tape Rental

The CMTA has available for rental four lectures which were taped at patient conferences sponsored by the CMTA. 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 (see page 11) 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 second device is a wrist support/brace and the catalogue description follows:

Carpal tunnel syndrome candidates or other sufferers: this support lets your fingers and thumb move freely. The "Freedom USA Wrist Support's" perfect fit allows for full range of movement. Wrist circumference: XS(4.5-5.5"), S (5.5-6.5"), M(6.5-7.25), L (7.25-8"). 100% nylon webbing attractive enough for everyday wear. Aluminum stay.

A1519 Freedom USA Wrist Support (Specify XS, S, M, L and Left or Right Hand) \$22.00.

We asked the advice of Joanne Cassidy, the head of occupational therapy at Jefferson Medical Center in Philadelphia, with regard to the usefulness of these devices. Her comments were as follows: "The first device is helpful for individuals with weak shoulders and neck. It has been associated with causing pressure on the nerves at the wrist."



Freedom™ USA Wrist Support

"The second device is an excellent product. It is especially good for people with carpal tunnel syndrome or weak wrists. It works best with individuals with minimal atrophy. If a person's wrist is stiff or they have visible wasting of the muscles, they should not use this."

To order one of these items or to request a catalogue, write: SelfCare Catalog, 349 Healdsburg Ave., Healdsburg, CA 95448, or call the toll free number 1/800/345-3371 from 6am to 6pm, Pacific Coast Time. ☐

## Call For Participants

In the Spring '90 issue of the *CMTA Report* we published a CALL FOR PARTICIPANTS for Dr. Bruce Sangeorzan of Seattle, WA. We have contacted Dr. Sangeorzan and he is still conducting the study and needs CMT patients for his project. Dr. Sangeorzan is interested in neuromuscular diseases that affect the foot and ankle. He is seeking CMT patients to become involved in a preliminary study collecting data about factors that affect walking and standing balance.

Dr. Sangeorzan is looking primarily for patients who have not had any kind of surgical procedure on at least one of his/her two feet. The study involves walking back and forth across a computer-linked force plate built into the floor of a gait lab. The procedure takes 20-60 minutes.

The information will be used to help guide bracing and surgical treatment and provide the basis for a federally funded research project. Since no money is available for this preliminary study, the participant must be able to fund his/her own transportation. If you can be a part of this study, contact Dr. Sangeorzan at:

Department of Orthopaedics  
Harborview Medical Center  
325 Ninth Avenue, ZA-48 6S21  
Seattle, WA 98104  
206-223-8053

We urge you to be a part of this study if it is at all possible. This preliminary study could become the basis for funding of a major project which could directly benefit you. Please, contact family members who would qualify for the project and advise them of the study. We will keep in contact with Dr. Sangeorzan and report the results of the study in the *CMTA Report*. ☐

### Memorials

In Memory Of	By
Jack Goldman	Ruth & Lawrence Linker
Charlie Dezern	Mrs. E.A. Jumper
Irving Finkelman	the Finkelmans
Mollye Schwartz	Michael Schwartz
Lois Willingham	Anonymous
Howard Myrick	Dr. Karen Edelson
Daniel Guertin	Joan & Clarence Vater
Cathy Porter	Gene Dreher



# If fate throws a knife at you, there are two ways of catching it... by the blade and by the handle.

## 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.

With that quotation as its theme, the pamphlet, Living Well with Chronic Illness by Gayle Heiss presents an uplifting, hopeful message about keeping a good self-image and maintaining a positive attitude while living with illness.

The author, herself, suffers from Sjogren's Syndrome, an autoimmune, connective tissue disorder and brings her own personal experience with disease as well as her work with persons suffering from chronic illnesses to bear in the pamphlet.

standards as before. Still another reaction is to make the job of curing oneself and investigating all healing methods an obsession. Finally, the best reaction to illness, Gayle points out, is to "Accept the challenge of the present physical limitations and learn from it lessons about attachment, letting go, control and vulnerability."... "Set priorities... find the balance."

Healing means both healing the wound left by the loss of your "invulnerable" body as well as healing the actual disease or its symptoms.

*The CMTA Report* is published by the Charcot-Marie-Tooth Association, a tax exempt not-for-profit corporation.

Layout by:

**Chesapeake Bay Design**  
48 Henry Court  
Hollywood, MD 20636  
Tel. 301/373-5912

Inquiries welcome.

One section of the pamphlet is called "Responses to Illness" and here, condensed, is a portion of that section. The responses do not necessarily occur in any order and, in fact, often occur simultaneously.

One response is to give up and experience only a sense of loss. Another response is to act as if nothing has changed--trying to continue with the same activities and meeting the same

The treatise is easy to read and might make an interesting subject of discussion at a support group meeting or other self-help meeting.

Copies are \$2.00 plus \$.60 postage and handling from:

Gayle Heiss  
P.O. Box 210  
Mendocino, CA 95460

## 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.*

**In honor of:** (person(s) you wish to honor) \_\_\_\_\_

**In memory of:** (name of deceased) \_\_\_\_\_

**Send acknowledge to:** Name: \_\_\_\_\_

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

**Occasion:**

- |                                      |                                    |
|--------------------------------------|------------------------------------|
| <input type="checkbox"/> Birthday    | <input type="checkbox"/> Holiday   |
| <input type="checkbox"/> Wedding     | <input type="checkbox"/> Thank You |
| <input type="checkbox"/> Anniversary | <input type="checkbox"/> Other     |
| <input type="checkbox"/> Memorial    |                                    |

**Amount Enclosed \$** \_\_\_\_\_

**Gift given by:** Name: \_\_\_\_\_

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

Check if you would like the amount of your gift to be revealed.

Help Perpetuate The CMTA'S Work...

### *Remember the CMTA in Your Will*

You can give hope to thousands of CMT patients by extending your support of the CMTA's programs beyond your lifetime. Whether your legacy is small or large, you can support our programs of education, service and research by remembering the CMTA in your Will.

To make a bequest of cash or other property to the CMTA, your Will (or supplemental codicil if you do not wish to write a new Will), should state:

"I give and bequeath to the Charcot-Marie-Tooth Association, a not-for-profit corporation, organized under the laws of the Commonwealth of Pennsylvania, and having its principal office at Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015, the sum of \$(\_\_\_\_\_) or (\_\_\_\_\_) percent of the rest, residue, and remainder of my estate to be used for general purposes of the Organization."

A bequest to the CMTA is fully deductible for estate tax purposes. Additionally, you will be providing hope to CMT patients and families now and in the future. You may wish to learn about other gift giving opportunities by consulting your attorney, accountant, and/or tax or estate planning specialist.

## Letters...



## to the editor

Dear CMTA,

I just received your fall 1990 Report on surgical options for the CMT foot. Your summer 1989 edition was on hand surgery and I showed it to my orthopedic hand surgeon. He has already done surgery on my left hand on December 20, 1990, and the results so far are fantastic! He will do my right hand this spring.

After my hands are done, I am thinking of having my feet done. I would like a list of orthopedic foot surgeons who are familiar with the CMT foot and the surgery mentioned in your report.

Thank you for all the information you have sent me.

R.R., California

Dear CMTA

I have a 19 year old daughter who has CMT as well as scoliosis. When she was in the 8th grade, her school nurse talked her into seeing Shriners with her illness. She agreed before seeing them to do whatever the doctors wanted and to accept what was coming.

The Shriners were great! Sandra learned that there is always someone who is worse off than she. The weeks she was there for tests and evaluations she grew up and as a family we welded together behind her. She has gained an inner strength which makes me very proud of her.

Shriner's Hospital of St Louis is an excellent orthopedic hospital. The staff is very helpful to everyone. It is also a teaching hospital and nothing is done to any child without discussion and planning. The welfare of the child always comes first.



Do you know anyone famous who is a CMT patient? Do you know anyone famous who would advocate for CMT? The CMTA is looking for a well-known person to be a spokesperson for CMT. If you know of such a person, contact the CMTA; we will do the rest.

I am very aware of the frustration that CMT causes, but physical therapy and occupational therapy do help. I have found that if the patient and the therapist have a good relationship much can be accomplished. I think that a working relationship with the patient helps both parties involved. I think a therapist can teach the patient to learn how to do things in a different way so that it lessens the frustration that comes with CMT.

I have learned a lot about CMT and I have learned of the ignorance of most people about CMT. I know that CMT is not easy to spot until it has progressed too far without treatment. We need to make people and doctors aware of CMT before therapy is unable to help them maintain independence.

I hope this letter will encourage families that there is help out there.

J.T.

P.S. My daughter wrote a paper last year for school about CMT.

(Editor's note: We receive many requests from students at all academic levels for information on CMT for school projects and papers. We are always happy to provide whatever help we can.)

Dear CMTAA,

I wish I had known as a child that I had CMT and was not just dumb because I couldn't run or sit on my haunches. How I hated the running races at Sunday School picnics! The only time I did not come in last in a race was when the child coming in second tripped and fell. What's more, when everyone else crossed the finish line, I was only halfway down the track! I did not know that I had tight achilles tendons which prevented me from having any spring in my ankles. I survived my school days by accepting the fact that I was not athletically inclined and concentrating on being a good student.

My CMT disability did not worry me in adulthood until I got into my 50's when I found I was struggling to open our double garage door and my arms and legs were aching from carrying the shopping for a family of five up the steps from the garage into the house.

Then I started swimming in Ryde indoor pool every week and what a difference that has made! From being able to manage only half a length without stopping, I soon built up to 32 lengths in 35 minutes. I have been doing this once a week for four years now. Not only has it strengthened the muscles in my arms, legs, and back, but it has given me greater flexibility in my joints. An arthritic pain in one knee, which I had for five years, has simply disappeared.

At the first CMT seminar, I mentioned how much swimming had helped me. One of the doctors at the seminar suggested that I try walking a few lengths with my heels down and my feet flat on the bottom of the pool. I now start by doing four laps of walking with my heels down. I have discovered that this stretches my Achilles tendons and the muscles in my calves to such a degree that I no longer have to jump out of bed two or three times a night because of cramps in my legs - something I had done all my life.

I still can't run, but I enjoy bush walking in easy stages as long as there are not too many steep hills.

I am thankful that I am only slightly incapacitated by CMT. Nevertheless, the quality of my life has been greatly improved by swimming - making me feel stronger and fitter. I can recommend it to others who have weak muscles from this disease.

S.W., Australia

(This letter appeared in the most recent issue of the Australian CMT newsletter.)

### Honoraria

In Honor Of	By
Frank T. Crohn	Dr. & Mrs. David Sachor
E.B. Hummel	Lani Hummel
Lorenz Sulzenfuss	Laurie Sulzenfuss
Patti Murphy	Michael Murphy
Christy Wagne	Pam Gatfield
Wanda Kelley	Pola Kelley
David Salaman	Rebecca Sand
Rebecca Sand	M/M Irwin Whitman
Audey Kincaid	E.B. Hummel0
Elissa Maxwell	Joan Lisinski
James Gomez	Elizabeth & James Gomez
Ruth Horowitz	Rebecca Sand

## Referrals Available From The CMTA

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 of pedorthists. 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 any of these referrals send a stamped self-addressed envelope indicating the geographic areas needed to: CMTA, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015.

For referrals for a hand surgeon contact the American Society for Hand Surgery, 3025 South Parker Road, Suite 3025, Aurora, CO 80014, phone 303-755-4588.

✕

## I want to be in touch!

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

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

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

*Tell us about yourself:*

- |   |   |
|---|---|
| <input type="checkbox"/> CMT Patient          | <input type="checkbox"/> Medical Professional |
| <input type="checkbox"/> Interested Supporter | <input type="checkbox"/> CMT Family Member    |
| <input type="checkbox"/> Other                |   |

*Please check the appropriate boxes:*

- |  |  |
|--|--|
| <input type="checkbox"/> Put me on the mailing list!                                 | <input type="checkbox"/> CMT Genetics - \$10       |
| <input type="checkbox"/> CMT Neurology - \$10  | <input type="checkbox"/> Orthopedic Surgery - \$10 |
| <input type="checkbox"/> Physical Therapy - \$10                                     |  |
| <input type="checkbox"/> Physical Therapy/Orthopedic Surgery - \$15 (on one tape)    |  |
| <input type="checkbox"/> Neurology/Genetics - \$15 (on one tape)                     |  |
| <input type="checkbox"/> Send me a copy of the informative booklet "CMT Facts" - \$3 |  |

### Join the fight against CMT!

*Enclosed is my check for:*

- \$25 Member  
 \$ \_\_\_\_\_ other

*Contributions are tax deductible.*

*Please make checks payable to the CMTA.*

## Professional Help

The following pedorthists have become members of the CMTA and are interested in and knowledgeable about the foot problems of the CMT patient. If you visit their facility, please tell them that you found them through the CMTA newsletter.

**MR HAROLD CANTOR**  
Soble And Cantor Inc  
1621 E Wadsworth Ave  
Philadelphia, PA 19150

**JEAN SEARS, C. Ped.**  
Cantilever Shoe Stores, inc  
3427 Houma Blvd  
Metairie, LA 70006

**FRED TOENGES**  
F.W. Toenges And Sons Inc  
2415 Hobson Rd  
Fort Wayne, IN 46805

**BOB LOTZ, C. Ped.**  
Marshfield Clinic  
1000 N. Oak Ave  
Marshfield, WI 54449

**CHARLES BROWN, C. Ped.**  
Zimmermann's Shoes  
227 W. Saratoga St  
Baltimore, MD 21201

**SUSAN HELLER**  
Bio-Ped Shoes  
102 Wyndham St  
Guelph, Ontario  
Canada N1H4E8

**A.R. MENZIES AND SONS, LTD**  
33 Rookwood Ave  
Fredericton, New Brunswick, Canada  
E3B2L8

**A.J. ALAIMO**  
ACOR Orthopaedic Inc  
18530 South Miles Parkway  
Cleveland, Ohio 44128

**MARTIN BACON**  
Van Dyke And Bacon  
5851 York Rd  
Baltimore, MD 21212

**HARRIET CAVANAH DART, C. Ped**  
Dart Services, Inc  
674 Milwaukee Ave  
Prospect Heights, IL 60070

**JAMES V. GANLEY, JR**  
The Shoe Stop, Inc  
236 Egypt Road  
Jeffersonville, PA 19403

**MARVIN KINNE**  
Kinne Shoe Repair  
238 James St  
Utica, NY 13501

**CHARLES EHRING, C. Ped.**  
L&E Comfort Shoes  
8026 Frankford Ave  
Philadelphia, PA 19136

**DOMINGOS NOBILE, C. Ped.**  
Nobile Shoes  
420 US 1  
North Palm Beach, FL 33408

**TURNPIKE ORTHOPEDIC SHOE**  
186-06 Union Turnpike  
Flushing, NY 11366

**JOHN QUIGLEY**  
Lakeshore Orthopedic and  
Prosthetic Service  
233 East Erie St # 405  
Chicago, IL 60611

**LOUIE WINSKOWSKI**  
Northwestern Artificial Limb And Brace  
510-8 25th Ave.  
No. St. Cloud, MN 56303

**ALAN R. BURKE, Pres.**  
Aljan Company  
2008 Fish Hatchery Rd  
Madison, WI 53713

**RICHARD A. PENN, PEDORTHIST**  
LEes Comfort Shoes  
101 Medallion Center  
Dallas, TX 75214

**JOHN MC MAHAN, C. Ped.**  
Mc Mahan Shoes  
1809 E 7th St  
Charlotte, NC 28204

**RICK OVERMAN**  
CFI Prosthetics-Orthotics  
43 N. Cleveland  
Memphis, TN 38104

**JERRY'S SHOE COMFORT AND  
PEDORTHIC CENTER**  
251 S Tamiami Trail  
Venice, FL 34285



## 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 CMTA Report* are available at \$2.50 a copy:

Winter '91  
Fall '90  
Summer '90  
Spring '90  
Winter '90  
Fall '89  
Summer '89  
Spring '89  
Winter '89  
Spring/Summer '88  
Summer/Fall '87  
Spring '87  
Winter '87

Write the CMTA (address below)

## CMT...

- ..... is the most common inherited neurological disease, affecting approximately 125,000 Americans.
- ..... is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of foot/lower leg and hand/forearm muscles.
- ..... causes degeneration of muscles of foot, lower leg, hand and forearm.
- ..... causes foot drop walking gait, foot bone abnormalities (high arches and hammer toes), problems with hand function, balance problems, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, occasional partial sight and/or hearing loss problems and in some patients may cause scoliosis (curvature of the spine).
- ..... may produce chronic pain and fatigue.
- ..... does not affect normal life expectancy.
- ..... has no effective treatment, although physical therapy and moderate physical activity are beneficial.
- ..... is sometimes treated surgically.
- ..... is usually inherited in an autosomal dominant pattern, which means if one parent has CMT there is a 50% chance of passing it on to each child.
- ..... is present in the world-wide population, with no apparent link to any one ethnic group.
- ..... may become worse if certain neurotoxic drugs are taken.
- ..... can vary greatly in its severity, even within the same family.
- ..... is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

# THE CMTA REPORT

*information on Charcot-Marie-Tooth disease from the*

## Charcot-Marie-Tooth Association

Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

TO:

Non-Profit Org.  
U.S. Postage Paid  
Glen Mills, PA  
Permit #10