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. We would like to thank Mr. Nolish for his counsel, knowledge and time so freely given.

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 application 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)
**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
- Amlodipine
- 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, Macrodantin)
- Nitrous Oxide
- (chronic repeated inhalation)
- Penicillin
- (Large IV doses only)
- Pyridoxine (Vitamin B6)
- Vinca

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. Nosh'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
- Neil Brody
- Norman Cool
- Raymond Green
- Elsa Kovacs
- Julie Lorenz
- Maureen and Grant Nelson
- Ronald Riskevich
- Thomas Smalley
- Howard and Miyuki Sheppard
- Mark Thomas
- M/M Miyuki Weiss
- Franklyn Weis
- Maurene and Grant Nelson
- Maureen
- Jack Graves
- Janice Hagadorn
- Hope Larossa
- Philip Mack
- Gary Oelze
- Margaret Schaefer
- Daniel Sifton
- Marian Sward
- Sue Turner
- M/M Robert Welby

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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.

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!

Jennifer Hinebaugh

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. We 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 Marie Tooth Disease

by Ian Alexander, M.D.

(Edited 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, planatarflexed 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 block test. 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.

Recent Scientific Articles on CMT


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 MosbyYearBook, 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.
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) 251-4453

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

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.

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.
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 sensory nerve involvement, supporting structures to the bones will become compromised. Once again the result will cause abnormal stress (and otherforces) 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.
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.

**CMT PATIENT HISTORY AND SYMPTOM QUESTIONNAIRE**

**DATE:** ______  **AGE:** ______  **SEX:** ______

Please check the appropriate space:

1. At what age were you first diagnosed?
   - 7-12
   - 13-20
   - 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
   - 8-12
   - 13-20
   - 21-30
   - After age 50

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:
   - Ball of the foot:
   - Heel:
   - Shin:
   - Calf:
   - Knee:
   - 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:
   - Side of big toe:
   - Heel:
   - Ankle:
   - Shin:
   - Knee:
   - Did they become infected? Yes No

   **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:
   - Tip of toes:
   - Ball of the foot:
   - Side of foot:
   - Heel:
   - Ankle:
   - 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.

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 high-tech 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 your wrist then springs back into shape.

1” A1523 Keyboard Wrist Rest $27.00
1-1/2” A1524 Keyboard Wrist Rest $27.00

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 (6.5-7.5”), 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.

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.

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, 2A-48 6821
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

Jack Goldman        Ruth & Lawrence Linker
Charlize 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

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

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.

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 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 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

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 opportunities by consulting your attorney, accountant, and/or tax or estate planning specialist.
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 surgical option for the CMT foot. I have a 19 year old daughter who has CMTA. She has learned that there is help out there. She has gained an inner strength which makes me very proud of her.

Shriners' 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 that 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 CMTA,

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.)

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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 Wynham St
Guelph, Ontario
Canada NIG4E3

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

A.J. ALAIMO
ACOR Orthopaedic Inc
1850 South Miles Parkway
Cleveland, Ohio 44128

MARTIN BACON
Van Dyke and Bacon
5551 York Rd
Baltimore, MD 21212

HARRIET CAVANAUGH 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 & T 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
L.E. Esh 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
C.F. Prosthetics-Othotics
43 N. Cleveland
Memphis, TN 38104

JERRY’S SHOE COMFORT AND PROTHESIS CENTER
521 S Tamiami Trail
Venice, FL 34285

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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: