

# THE CMTA REPORT

This issue was partially funded by a grant from Edythe Masel in memory of Jacob J. Masel.

Spring 1990

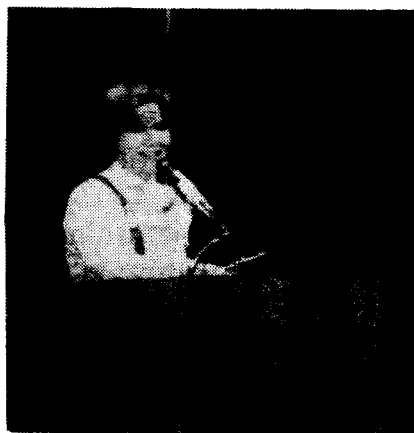
Vol.5/No.2

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

## Conservative Management of the Functional Manifestations of Charcot-Marie-Tooth Disease

by Carol A. Oatis, P.T., Ph.D.

We are extremely pleased to be able to reprint in its entirety this chapter from the recently published book, **CHARCOT-MARIE-TOOTH DISORDERS: Pathophysiology, Molecular Genetics, and Therapy**, copyright (1990) Alan R. Liss, Inc. reprinted by permission of Alan R. Liss. We are able to do this because of the cooperation of the publisher and the author Dr. Carol Oatis. Dr. Oatis is a partner in the Philadelphia Institute for Physical Therapy. An expert on gait problems, she teaches physical therapy at Beaver College, Glenside, PA. Dr. Oatis has spoken at several CMTA patient and professional conferences. Some of the material presented is of a technical nature, but we believe that everyone will benefit from reading the article.



Dr. Carol A. Oatis

Charcot-Marie-Tooth (CMT) disease (peroneal muscular atrophy) is a degenerative disorder of the peripheral nervous system leading to a progressive weakening of the peripheral muscles of the upper and lower extremities. The disease generally involves the most distal muscles first and then progresses in a proximal direction. It is a progressive disease but is generally considered not fatal and there is no known cure (Gilroy and Meyer, 1979). Unfortunately, however, patients are often told that there also is no treatment. Yet, treatment to

alter the physiological course of the disease should not be confused with treatment directed toward relieving the functional deterioration which accompanies the progressive weakness. The purpose of this chapter is to present the conservative treatments which can be utilized to minimize the manifestations of CMT and to optimize the function in patients with CMT. Of course, surgery is also a potential treatment modality but will not be addressed in this chapter.

The goals of conservative management are to:

1. maintain function
2. insure safety
3. maintain comfort
4. protect the weakened joints
5. conserve energy.

These goals can be met by maximizing muscle strength and endurance, minimizing deformities, and by the use of orthotic devices (braces) to compensate for weaknesses or deformities, and adaptive equipment to make activities of daily living easier. How each of these treatments is carried out is discussed in detail in the following sections.

### Maximizing Muscle Strength

CMT is a degenerative disease and there are no means presently available to predict the course of the disease. Some patients may progress to diffuse and profound weakness while others may remain minimally involved. Therefore strengthening exercises will have varying degrees

#### IN THIS ISSUE:

CMT .....	cover
VCR Tape Rental .....	p. 3
Medical Alert .....	p. 4
Letters .....	p. 5
Upcoming Conference .....	p. 6
Group Notes .....	p. 7
CMT Profile .....	p. 8
Remembrances .....	p. 9
Gadgets .....	p. 10
Call for Participants .....	p. 10
Physician Referrals .....	p. 11
Get In Touch .....	p. 11

## **CMT** (continued from page 1)

of success. In some patients the exercises may serve only to retard the rate of weakening while other patients may see a real, measurable increase in strength. Yet both effects will be valuable in enabling the patient to remain functional.

If a muscle is able to contract it is theoretically capable of increasing its strength of contraction (Brooks and Fahey, 1985). Thus, if a patient can activate any of the motor units of an involved muscle, that patient has the potential for increased strength. DeLateur and Giaconi (1979) reported increased strength in four patients with Duchenne's Muscular Dystrophy. These patients participated in a program of exercise four or five days per week for six months and were retested monthly for six months following the exercise period and again six and twelve months later. The authors reported modest but not statistically significant increases in strength in the exercised limb, compared to the contralateral unexercised limb continuing for nine months following the cessation of exercise. McCartney, et al (1988) also reported strength gains in patients with spinal muscular atrophy, limb girdle or facioscapulohumeral muscular dystrophy resulting from nine weeks of exercise on a three times weekly basis. These

authors reported increased strength in the exercised limb as well as in the unexercised limb although the latter's increase was less than in the exercised limb. They also demonstrated improved motor unit activation in the exercised limbs but failed to find increased strength of an evoked (electrically stimulated) contraction. These data suggest that the strength gains noted resulted from a neural adaptation rather than from cellular hypertrophy. However, neural learning is an integral element

### **"...even neurologically involved muscles can be strengthened."**

of strengthening according to McDonagh and Davies (1984). These authors suggest that neural learning may result in an increased level of activation of the contractile elements from the same neural stimulus or from an actual increase in the voluntary neural stimulus, or drive, to the muscle. Thus, even in the absence of frank hypertrophy of the muscle, real improvements in strength are possible. Whatever the mechanism, these studies support the concept that even neurologically involved muscles can be strengthened. Therefore, people with CMT may be able to improve function or at least minimize the loss of function through appropriate strengthening exercises.

Even the muscles not involved by the disease should be exercised. Because of the nature of the disease many patients with CMT discontinue vigorous physical activity and become more and more sedentary. This lifestyle results in progressive weakness in normal muscles

## **Upcoming Conference**

New York City ..... October, 1990

and generalized deconditioning. However, compensation for the weakness associated with CMT requires additional physical exertion. In addition, weakness at the distal end of the lower extremity increases postural instability. Thus, strengthening the normal muscles more proximal in the lower extremity will help the patient tolerate the increased stresses applied to the lower extremity in quiet standing and in gait because of the distal weakness. Function will be improved dramatically by establishing a generalized program of strengthening and conditioning exercises.

Some authors have suggested that neurologically impaired muscles may be injured by resistance exercises (Johnson and Braddon, 1971). However, the studies reported above denied any sign of damage to the exercised muscles (McCartney, et al, 1988 and DeLateur and Giaconi, 1979). Excessive resistance and excessive fatigue have been shown to result in injuries to normal muscles. So similar results are possible but are not inevitable in neurologically weakened muscles. Admittedly, the loads and repetitions sufficient to cause injury are likely to be decreased in the abnormal muscles. Thus while there may be no unique deleterious effect of strengthening exercises in patients with CMT, resistance exercise must be carried out cautiously to avoid the damaging effects of overtraining, because injury to an already weakened muscle can further

(continued, next page)

*For your records, our address is:*

The CMTA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015  
(215) 499-7486

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

compromise its performance. A program for strengthening must be directed toward improving the function of the weakened muscles and maximizing the strength in the uninvolved muscles. Even small increases in strength of the impaired muscles can result in a significant improvement in function. Patients have reported an increased tolerance for hand-writing after only one month of hand exercises. One patient reported that he was unable to write a single-page letter without resting his hand to relieve cramping. One month following the inauguration of an exercise program, he stated that he was able to complete two or three pages without discomfort. Another patient reported that prior to beginning exercise, she had difficulty walking her dog because of ankle and knee instability. A program of stretching and strengthening exercises for the lower extremities allowed her to increase her tolerance to ambulation. In fact, she resumed walking a round of nine holes of golf. Neither of these patients returned to normal strength. However, their function was markedly improved in a relatively short period of time.

An appropriate exercise program must also be based on an understanding of the patient's individual level of function. Thus each patient should undergo a complete evaluation by a physical therapist to establish a level of exercise for each muscle group which will result in strengthening without injury. Such a program characteristically will involve active or resistive exercises to the dorsiflexor and plantarflexor muscles and the muscles which pronate and supinate the foot. Exercises to the intrinsic

muscles of the feet are also available. However, these muscles are often so weak that they can no longer be activated by the patient. The hamstrings and quadriceps muscles of the knee may also be involved. They must be evaluated and exercised appropriately. The intrinsic muscles of the hand and occasionally the long finger flexors and extensors are also involved. They too must be evaluated and a program of exercise be established.

Exercises are progressed by increasing the resistance used in the exercise or by increasing the number of repetitions. Resistance for foot and ankle exercises can be progressed from lifting only the weight of the limb to lifting the limb and a weight attached to it. Another convenient method for increasing exercises is the use of rubber strips [Theraband: Fitness Wholesale, Inc., 800-537-5512], which the patient can use to tie the limbs together, making it harder to pull apart. Resistance for the intrinsic muscles of the hand can be applied by exercise putty [Exercise Putty: Smith and Nephew Rolyan, Inc., 800-722-0442]. It must be noted that strengthening exercises must be carried out with careful precision. It is quite easy to substitute a strong muscle for the weakened one and thus not obtain the desired effect. Careful guidance by the physical therapist is essential for optimal results.

Resistance should increase the difficulty of the exercise without causing pain or making it impossible to complete the exercise correctly. Repetitions should be increased in small increments to avoid excessive fatigue. For example, a patient may be able to

(continued on page 4)

## Honoraria

In Honor Of	By
Rebecca Sand	Francis Margolis
Rebecca Sand	Ethel Cohn
Rebecca Sand	Frances Doner
Rebecca Sand	Loretta Ress
Rebecca Sand	Anonymous
R. Gordon Bradwick	Faye Bradwick
Sophia L. Bradwick	Faye Bradwick
Paola Caser Sperandio	Fontana Costanza
Henry Eldredge	Susan, Kirt, Lindsey, & Hilary Nead

## VCR Tape Rental

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

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

To order a tape, fill out our "I want to be in touch!" form (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.

## CHARCOT-MARIE-TOOTH DISORDERS: Pathophysiology, Molecular Genetics, and Therapy

This book, from which our lead article was excerpted, may be ordered from:

John Wiley & Sons  
EDC  
1 Wiley Drive  
Somerset, NJ 08875  
Tel: 800-225-5945



## MEDICAL ALERT

### Certain Drugs Toxic to the Peripheral Nervous System

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

Adriamycin  
Amiodarone  
Chloramphenicol  
Cis-platinum  
Dapsone  
Diphenylhydantoin (Dilantin)  
Disulfiram (Antabuse)  
Glutethimide (Doriden)  
Gold  
Hydralazine (Apresoline)  
Isoniazid (INH)  
Mega Dose of Vitamin A  
Mega Dose of Vitamin D  
Nitrofurantoin  
(Furadantin, Macrochantin)  
Nitrous Oxide  
(chronic repeated inhalation)  
Penicillin  
(Large IV doses only)  
Pyridoxine (Vitamin B6)  
Vincristine

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

#### CMT (cont'd from pg.3)

do an exercise and repeat it four times. Perhaps that patient can increase the repetitions to two sets of five in the next week or so taking care to avoid excessive fatigue. Fatigue is excessive if it results in pain or leaves the patient too tired to resume normal activity. Repetitions can be increased gradually from ten to a maximum of three sets of ten. When the patient is ready to increase resistance the number of repetitions should be decreased then gradually increased again to avoid injury to the muscle.

Electrical stimulation has been employed by some clinicians for muscle strengthening. Muscles and nerves can be stimulated by external electricity to elicit a

muscle contraction. This has been shown to result in strengthening when the electricity is strong enough to elicit a visible contraction. This technique was not shown to be more beneficial than voluntary exercise in normal subjects (Currier and Mann, 1983). However, electrical stimulation was found to be more effective than voluntary exercise in producing isometric strength gains in subjects following anterior cruciate ligament reconstruction (Delitto, et al, 1988). No studies have been identified comparing these treatment regimens in subjects with degenerative neuropathies. Further study is required before the usefulness of electrical stimulation in patients with CMT can be determined. However, denervated muscles require more electricity to produce a stimulated contraction. Patients with intact sensation may not tolerate the discomfort associated with this increased intensity. Thus for most patients a program of voluntary exercise remains the most reasonable approach to increasing strength.

In most cases, the patient can carry out this strengthening program at home, requiring only occasional visits to the physical therapist to modify the program based on any functional changes secondary to the disease. Periodic reevaluations will also allow close monitoring of the progression of the disease.

#### *Maximizing Endurance*

Mention should also be made of the generalized conditioning program emphasizing aerobic conditioning. Aerobic exercises are designed to increase the heart rate and sustain that increased rate for approximately thirty minutes. The "target heart rate" for aerobic exercise is

usually a rate (220 minus age). Simple activities like walking have been shown to require more energy to accomplish when the subject has a weakness or limited movement (Winter, 1978). Therefore, walking a city block is generally more fatiguing for a patient with CMT than for a normal subject. However, the sedentary lifestyle of most CMT patients also contributes

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**"benefits of... exercise enable that person to take a more active role in everyday life."**

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to significant deconditioning. So not only is the patient generally required to spend more energy to accomplish a task, he is often less capable of expending that energy. Thus the CMT patient will benefit from improved conditioning. However, such conditioning exercises must accommodate the patient's weakness. For example, walking may be too stressful, so swimming or the use of a stationary bicycle may be more suitable. The benefits of such exercise include those accrued by normal subjects, such as decreased risk of heart disease, decreased body fat, lowered resting blood pressure and increased sense of well-being. However, the most obvious benefit to a patient with CMT is increased muscular and cardiovascular endurance, enabling that person to take a more active role in everyday life. It should be noted that because aerobic exercise involves elevation of the normal heart rate, there are some risks involved. Therefore, no patient should undertake such a program without appropriate medical supervision.

(continued on page 5)

CMT (continued from page 4)

### ***Minimizing Deformities***

The characteristic deformities seen in patients with CMT result from an imbalance between the weakened muscles and the unopposed pull of their antagonists. For example, the dorsiflexor muscles of the feet are often weakened before the plantarflexor muscles which oppose them. As the dorsiflexors become weak, the plantarflexors pull and become tight. The resulting "plantarflexion contracture" makes it difficult for the patient to stand with his/her feet flat on the floor. The patient usually reports that he feels as though he will fall backwards or that he/she is only comfortable in shoes with higher heels.

The disadvantages of such deformities are many. First, the deformity often results in ab-

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**“Careful guidance by the physical therapist is essential for optimal results.”**

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normal pressure on the foot, and consequently, in pain. The resulting abnormal weight bearing may also put an excessive strain on the other joints. In the case of a plantarflexion contracture, the deformity often results in a backward pull on the lower leg and leg and a hyperextension pull at the knee.

Appropriate stretching exercises are useful in minimizing, if not completely avoiding, such deformities. However, as in strengthening exercises, specificity in the stretches is essential. First, the muscle imbalance must be identified since stretching the weaker muscle may increase the imbalance. The stretch also must be performed carefully to insure that the stretch is applied to the intended muscle. So again stretching should be taught by a physical therapist who knows how to isolate individual muscles for stretching and for strengthening.

### ***Orthotic Devices***

When muscle weakness progresses to such an extent that the patient is unable to walk normally or is frequently falling, it is time to consider orthotic devices to support the weakened limb. The most common device of this sort is the ankle-foot orthosis (AFO) to support the weakened ankle. When the dorsiflexor muscles are weak, the patient has difficulty lifting the foot away from the floor when stepping forward during walking. The patient has a tendency to trip over the dangling foot. To prevent stubbing the toes and a potential fall, the patient will bend his hip and knee excessively as he swings his leg forward. This excessive movement causes increased energy expenditure.

An AFO supports the foot and thus decreases the chance of tripping and the increased energy expenditure. The most common such device is a light weight plastic brace molded to the foot and worn inside the shoe. This device can also support the foot in the presence of weak plantarflexors. The disadvantage of the molded AFO is that it is hard and occasionally causes discomfort particularly in the sensitive foot.

Metal upright braces also provide support for a weakened foot. However, these braces are considerably heavier and should be used only when the patient cannot tolerate the molded AFOs. There are other variations of orthoses to support the weakened foot. The appropriate device should be determined by the patient, the physical therapist, the physician, and the orthotist, based on the patient's individual needs.

Orthoses are also useful in accommodating foot deformities. In particular, foot orthoses are devices which fit in the shoe and cover the sole of the foot without crossing the ankle. Thus, they may increase foot comfort, but they do not provide ankle stability. These devices are usually prescribed and made

(continued on page 6)

## Boston

The Charcot-Marie-Tooth Association (CMTA) in conjunction with Dr. Frances Dyro of the VA Medical Center and Brigham and Women's Hospital are sponsoring a conference for Charcot-Marie-Tooth (CMT) patients and families Saturday May 19 at 1 PM. The meeting will be at the VA Medical Center, 1400 VFW Parkway, West Roxbury in the physical therapy department. The facility is handicapped accessible and there is ample parking. There is no fee and reservations are not required.

Dr. Dyro, a neurologist, will speak on the general aspects of CMT. Following her presentation there will be time for questions from the audience. The second speaker will be Dr. Joseph Addante. Dr. Addante is the head of the podiatry clinic at the University of Massachusetts and the former president of the American Podiatric Medical Association. He will discuss podiatric care for the CMT patient and also answer questions from the audience. The final speaker is Dr. Bruce Corff. Dr. Corff is a neurogeneticist at Boston Children's hospital. His topic will be the inheritance of CMT and he too will answer questions from the audience.

**Directions:** When approaching West Roxbury on route 128 turn onto route 109. The VA Medical Center is at the intersection of routes 1 and 109.

*Eunice Cohen will be at the meeting and she will be formulating plans for a Boston area support group.*

## CMT (continued from page 5)

by podiatrists or physical therapists. It should be noted that some of the modifications of the foot orthoses can be incorporated, to a certain extent, in the ankle-foot orthoses to provide stability and to increase comfort.

### *Adaptive Equipment*

Adaptive equipment is equipment specially altered to improve its utility for patients with musculoskeletal pathologies. For example, enlarged grips can be used on table flatware to improve the patient's hold on the device. Enlarged handles can also be used to improve the grip on pens and pencils. Special devices are available to make tasks in the kitchen easier. Others provide ease of dressing. There are countless devices on the market today designed to make activities of daily living easier. Much of this equipment is available through catalogues (Fred Sammons, Box 32, Brookfield, IL 60513-0032; ph.800/323-5547). In particularly involved cases or for specific needs, occupational therapists can evaluate patients and make recommendations for adaptive equipment. Such devices can make a marked difference in the quality of life for patients with CMT. Patients with CMT should seek a consultation with an occupational therapist to see if any adaptive equipment would be helpful.

### *Summary*

While there is no known treatment to alter the physiological degeneration characteristic of Charcot Marie Tooth disease, there is treatment available to minimize the manifestations of the disease. Physical and occupational therapy provide

programs utilizing exercises and orthotic and adaptive equipment to maximize strength and endurance, minimize deformities and to improve function. These approaches can help the patient with CMT to conserve energy, function safely, and minimize the discomfort associated with contractures. By doing so, the patient can significantly improve the quality of life and remain hopeful with the realization that he is taking an active part in the treatment of his disease.

□

### *References*

- Brooks GA, Fahey TD (1985). "Exercise Physiology: Human Bioenergetics and Its Application." New York: Macmillan, pp395-425.
- Currier DP, Mann R (1983). Muscular strength development by electrical stimulation in healthy individuals. *Phys Ther* 63:915-921.
- DeLateur BJ, Giaconi RM (1979). Effect on maximal strength of submaximal exercise in Duchenne muscular dystrophy. *Am J Phys Med* 58:26-36.
- Delitto A, Rose SJ, McKowen JM, Lehman RC, Thomas JA, Shibely RA, (1988). Electrical stimulation versus voluntary exercise in strengthening thigh musculature after anterior cruciate ligament surgery. *Phys Ther* 68:660-663.
- Gilroy J, Meyer JS (1979). "Medical Neurology", New York: Macmillan, pp 175-235.
- Johnson EW, Braddon R (1971). Overwork weakness in facioscapulohumeral muscular dystrophy. *Arch Phys Med Rehabil* 52:333-336.
- McCartney N, Moroz D, Garner SH, McComas AJ (1988). The efforts of strength training in patients with selected neuromuscular disorders. *Medicine and Science in Sports and Ex* 20(4):362-368.
- McDonagh MFN, Davies CTM (1984). Adaptive response of mammalian skeletal muscle to exercise with high loads. *Eur J Appl Physiol* 52:239-155.
- Winter DA (1978). Energy assessments in pathological gait. *Physiotherapy Canada* 30:183-191.

# 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 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.

## **San Diego, California**

Contact: Gary Oleze (619) 792-1427

## **San Francisco, California**

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

## **Greater Dallas, Texas Area**

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

## **Parsons, Kansas**

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

## **Indianapolis, Indiana**

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

## **Detroit, Michigan**

Contact: Marrienne Tarpinian (313) 883-1123

## **Chicago, Illinois**

Contact: Carol Wilcox (312) 445-2263

## **Cleveland, Ohio**

Contact: Norma Markowitz (216) 247-8785

## **Boston, Massachusetts**

Contact: Eunice Cohen (617) 894-9510

## **Central New Jersey**

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

## **Northern New Jersey**

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

## **Connecticut**

Contact: Linda Friedo (203) 374-8478

## **Long Island, New York**

Contact: Lauren Ugell (516) 433-5116

## **Westchester County, New York**

Contact: Kay Flynn (914) 793-4710

## **New York City**

Contact: Ann Beyer (201) 391-4624

## **Rochester, New York**

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

## **Delaware Valley, Pennsylvania**

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

## **Pittsburgh, Pennsylvania**

Contact: Garnett McDonald (412) 372-2853

## **Tidewater, Virginia Area**

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

## **Greater Atlanta, Georgia**

Contact: Molly Howard (404) 253-5632

## **Western Georgia**

Contact: Molly Howard (404) 253-5632

## **Orlando, Central Florida Area**

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

## **South Florida (Atlantic Coast)**

Contact: George Myerson (305) 431-3979

## CMT Profile

### Larry Wechsler: An Appetite for Life

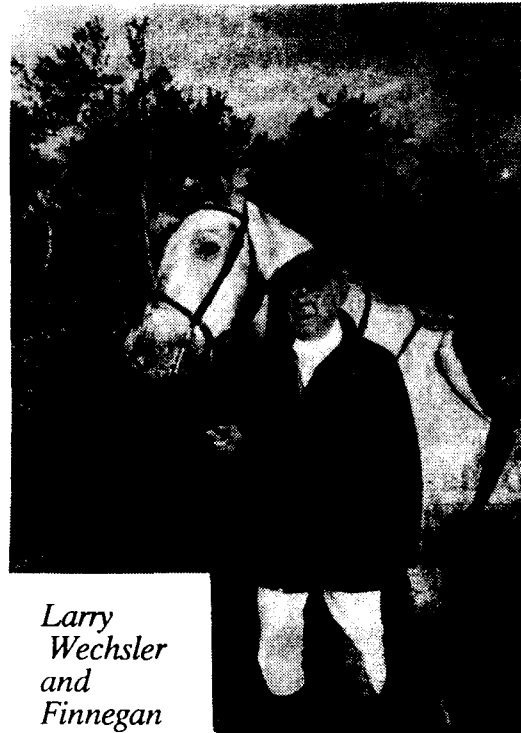
In his office at Revlon's headquarters in Manhattan, Larry Wechsler gets on his feet and assumes The Stance. Placing his weight on his right foot, he slowly moves his hands and arms through the air, delivering imaginary blows in a series of graceful, deliberate movements.

Now if someone in a neighboring building across Madison Avenue happened to spy this, they might think that Larry had seen one too many kung fu movies. But actually he is demonstrating the ancient martial art of Tai chi, a gentle, rhythmic form of exercise which provides relaxation and body conditioning. An activity performed by millions of Chinese for centuries, it is a pastime gaining popularity in the West as well.

For the past five years Larry had made Tai chi a part of his regular morning exercise routine. As a result, he's enjoyed some newfound physical benefits—increased flexibility and better balance, both problem areas for CMT patients. "Before I began practicing Tai chi, I couldn't do this," he says, swinging his leg around to change his stance. "More often than not, I'd lose my balance and topple over. Now I have more control over it. With Tai chi, you use different parts of your body, as well as your mind, and things I could not do before, I can do now."

In addition to Tai chi, Larry plays golf, shoots skeet, rides horses and works out regularly in a midtown gym. After a thirty year absence he recently took up playing the saxophone again. Needless to say, he likes to keep physically active. Not only does he find it healthy and fun, but he also firmly believes that it's the best way to combat CMT. "I feel like I'm missing something if I don't exercise," he says. "If I let myself go for any length of time I know I'm doing a disservice to myself and my body."

Perhaps Larry's greatest passion is horseback riding. He and his wife Jan took up the sport 15 years ago on a whim. "It wasn't an easy thing to learn," he recalls. "you have to keep your heels down in the stirrups and, physically, that is difficult for me to do. In the beginning I fell off a few times and banged up some ribs." But he hopped right back on and now regularly hits the trails with a riding club near his weekend home in



*Larry  
Wechsler  
and  
Finnegan*

Millbrook, N. Y., about a 90 minute drive north of Manhattan.

Larry's office at Revlon reflects his taste for the equestrian life. It looks more like the living room of a fine country home than your standard corporate digs. The walls are decorated in a tasteful floral print and several 19th-century equestrian prints hang about the room. There's a comfortable couch and arm chair along with a pleasant conference area. Larry is Executive Vice President at Revlon, Inc., overseeing the marketing and advertising efforts for the cosmetic giant. He's been with the company since 1961, working his way up the ranks to become one of its top officers. His story is the classic case of "Brooklyn boy makes good." Born and raised in the borough and educated at Brooklyn College, he first worked at the War Information Office during World War II. That experience led to a job in advertising, which in turn led to a career in the cosmetic field. He's worked alongside some of the top names in the cosmetic industry, notably Helena Rubinstein, Elizabeth Arden and Charles  
(continued, next page)



**CMT People (cont'd from pg.8)**

Revson. Today he is a member of the board of the Fragrance Foundation as well as other industry organization. (More recently, he joined the Board of Directors of the Charcot-Marie-Tooth Association.)

What has been key to his success? "Appetite," he says after pondering the question for a moment. "I don't quite know where it comes from or why, but I've always had an appetite for everything I do. There's a wonderful assortment of things to do in life and I like to try them all."

- Rex Morgan □

**FAME ... FAME ... FAME**

**ATTENTION  
CMT PATIENTS,  
FAMILIES AND FRIENDS**

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..

**LETTERS**

**We want to hear from YOU!**

Write us at:  
Letters, The CMTA  
Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

**Memorials**

<b>In Memory Of</b>	<b>By</b>
Phillip Krieger	Natalie Roth
Jacob J. Masel	Edythe Masel

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**CMTA Remembrances**

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards 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.*

<p style="text-align: center;"><b>Honorary Gift</b></p> <p><b>In honor of:</b> (person(s) you wish to honor) _____</p> <p><b>Send acknowledge to:</b> _____</p> <p><b>Name:</b> _____</p> <p><b>Address:</b> _____</p> <p>_____</p> <p><b>Occasion:</b></p> <table border="0"> <tr> <td><input type="checkbox"/> Birthday</td> <td><input type="checkbox"/> Holiday</td> </tr> <tr> <td><input type="checkbox"/> Wedding</td> <td><input type="checkbox"/> Thank You</td> </tr> <tr> <td><input type="checkbox"/> Anniversary</td> <td><input type="checkbox"/> Other</td> </tr> </table>	<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	<p style="text-align: center;"><b>Memorial Gift</b></p> <p><b>In memory of:</b> (name of deceased) _____</p> <p><b>Send acknowledge to:</b> _____</p> <p><b>Name:</b> _____</p> <p><b>Address:</b> _____</p> <p>_____</p> <p><b>Amount Enclosed:</b> \$ _____</p> <p><input type="checkbox"/> Check if you would like the amount of your gift revealed.</p> <p><b>Gift Given By:</b></p> <p><b>Name:</b> _____</p> <p><b>Address:</b> _____</p> <p>_____</p>
<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						

## Call For Participants

We have been contacted by Dr. Bruce J. Sangeorzan, an orthopaedic surgeon at the University of Washington. Dr. Sangeorzan is interested in neuromuscular diseases that affect the foot and ankle and is currently looking for patients with CMT. He is seeking CMT patients to become involved in a preliminary study collecting data about factors that affect walking and standing balance.

He 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 from 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 its existence. We will keep in contact with Dr. Sangeorzan and report the results of the study in the **CMTA Report**.

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

## Gadgets...Gadgets...Gadgets



A patient in Virginia sent in a picture of his new door handle to solve the problem of grasping the handle. It is obvious why this handle works well for the CMT hand. He purchased the mechanism from a regular hardware dealer.

ABLEWARE has several hand helper items which could be of great benefit. One is a *doorknob extension*, a finished metal extension handle which fits onto round door knobs from 1 3/4" to 2 3/4" in diameter. It provides the same leverage as the pictured doorknob.

Another aid is the *big lamp switch*. This big three spoked knob replaces small rotating knobs which are a problem for people with limitations of the hand and fingers. It installs in minutes without requiring tools.

The *key holder* is another useful tool for the CMT hand. It is made of strong plastic with a brass screw. This two key holder has a tightening lever to hold keys snugly when used. By loosening the lever, the keys may be retracted into the handle. The handle fits comfortably

in the palm of the hand to provide a good grip and excellent leverage for turning keys in locks.

How about a pair of *elastic shoelaces*? Once tied you need not untie and retie them. These laces allow you to slip your shoes on and off without fussing with the laces.

Another dressing aid is the *combination button aid/zipper pull*. This double-duty dressing aid is made of a wood and rubber handle with a wireform buttoning aid at one end and a brass hook at the other end for pulling zipper tabs.

These and many more gadgets are available from ABLEWARE, a division of Maddak, Inc., Pequannock, NJ 07440-1993. This company does not sell directly to the consumer, but if you call 800-541-3311 they will refer you to the closest dealer who handles their products.

For foot comfort, a patient in Michigan suggests products from COMFORTABLY YOURS, 61 West Hunter Avenue, Maywood, NJ 07607-1005, (201)368-0400. She particularly cited the toe cushions for pain relief from hammer toes. The toe cushion is made from the softest suede leather and supports toes that curl under. It prevents corns from forming on tips of bent toes. A cotton covered elastic loop secures 2nd, 3rd, and 4th toes. They are sold by the pair and are sized for men and women. A call or letter to the company will bring a copy of their catalog to you.

■

## Physician Referrals Available from the CMTA

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

### Pedorthist Referrals

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

## 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                |   |

Fill out this form and return it today!

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)                  |  |

## 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.

### October CMTA Patient/Family Conference

The CMTA is planning a patient/family conference in New York City in October. Final plans for this meeting will be announced in the next issue of the CMTA Report.

### For the CMTA

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

### Attention CMT Patients!



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

## Call for Articles

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

The following back issues of *The CMTA Report* are available at \$2.50 a copy:

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

Write or call the CMTA  
(215)499-7486

### CMT...

- .....is the most common inherited neurological disease, affecting approximately 125,000 Americans.
- .....is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- .....is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of the foot/lower leg and hand/forearm.
- .....causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- .....causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, occasional partial sight and/or hearing loss problems and scoliosis (curvature of the spine) is sometimes present.
- .....does not affect life expectancy.
- .....has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.
- .....is sometimes surgically treated.
- .....is usually inherited in an autosomal dominant pattern and could affect half the children in a family with one CMT parent.
- .....may become worse if certain neurotoxic drugs are taken.

# 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

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