

# THE CMTA REPORT

This issue was funded by grants from The Plastic Bottle Corporation and Sanders, Sanders, and Block, P.C.

Winter 1991

Vol.6/No.1

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

## 16,000 Libraries Receive CMT FACTS

The CMTA is delighted to announce the publication of a sixteen page informational booklet about Charcot-Marie-Tooth disorders. The booklet, entitled CMT FACTS, has been distributed to 16,101 public libraries in the United States to be filed in the libraries as a permanent resource.

This project was funded by David Norcom, Dallas, TX; Philip Norcom, Homeworth, OH; George Crohn, New York, NY and Frank Crohn, Boca Raton, FL. We are deeply grateful to these gentlemen for their financial commitment to this project.

The publication was edited by Jennifer Schoonmaker Hitt and is comprised of seven articles about CMT and therapies for the disorder. Many of the articles have appeared in previous is-



Jennifer Schoonmaker Hitt  
Editor, CMT Facts

sues of the *CMTA REPORT*. All have been reviewed by a medical professional. The titles are: Facts about Charcot-Marie-Tooth Disorders, Genetics of CMT, CMT Children, Physical Therapy and Rehabilitation of the CMT Patient, CMT Foot – Surgical Options, The CMT Hand, and Occupational Therapy.

If you would like a copy of CMT FACTS, please complete the "I Want to be in Touch" panel (see p. 11) and enclose a check or money order payable to The CMTA for \$3.00 to cover printing and mailing costs.

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## CALIFORNIA CONFERENCES COMING THIS SPRING!

Two conferences geared directly to the CMT patient and family will be offered this spring in LOS ANGELES and SAN FRANCISCO. The first conference will be held on Saturday, APRIL 6, 1991 in the Lucas Auditorium at Good Samaritan Hospital, 637 South Lucas Ave., Los Angeles. The second will be held on Saturday, MAY 11, 1991, at Bothin Auditorium, Children's Hospital, 3700 California St., San Francisco.

For each conference, registration will be at 9:30 am with the first session beginning at 10:00 am. The format for each conference will be the same, with two speakers in the morning session, a break for lunch, and two speakers in the afternoon. Each speaker will address his topic for approximately one hour with allocated time for questions from the audience.

Lunch will be provided for a fee at the conference sites and reservations must be made and prepaid for the lunch. However, attendees may choose to bring their lunches or make other arrangements. We urge you to join us for lunch, whether attending one or both sessions. It is an excellent opportunity to meet and socialize with other CMT patients/families and the attending medical professionals. It is also advisable to preregister for the con-

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### Colorado Conference

March 16, 1991

Details were still being finalized at press time... see page 9.

## 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  
Amlodarone  
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)  
Vincristine

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

## 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.

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## CMTA MEDICAL ADVISORY BOARD



## MEETS



The Medical Advisory Board (MAB) of the CMTA met in Atlanta following the annual meeting of the American Neurological Association. The MAB consists of distinguished CMT clinicians and researchers from the United States, as well as several foreign countries. In addition to being an expert in his/her field, these men and women share a commitment to CMT.

The members of the MAB are:

Dr. Shukuro Araki, Kumamoto Medical School, Kumamoto, Japan  
Dr. Barry Aranason, University of Chicago, Chicago, IL  
Dr. Pierre Bouche, Neurologic Hospital of the Salpetriere, Paris, France  
Dr. Thomas Bird, VA Medical Center, Seattle, WA  
Dr. Walter Bradley, University of Miami, Miami, FL  
Dr. Phillip Chance, University of Utah, Salt Lake City, UT  
Dr. J.S. Chopra, Post Graduate Institute of Medical Education and Research, Chandigarh, India  
Dr. Michael Conneally, Indiana University, Indianapolis, IN  
Dr. Peter Dyck, Mayo Medical School and Foundation, Rochester, MN  
Dr. Francis Dyro, VA Medical Center, Boston, MA  
Dr. King Engel, University of Southern California, Los Angeles CA  
Dr. Kenneth Fischbeck, University of Pennsylvania Philadelphia, PA  
Dr. Hans Goebel, University of Mainz, Mainz, West Germany  
Dr. John Griffin, Johns Hopkins University, Baltimore, MD  
Dr. Ludwig Gutmann, University of West Virginia, Morgantown, WV  
Dr. Anita Harding, University of London, London, England  
Dr. Linton Hopkins, Emory University, Atlanta, GA  
Dr. John Hsu, University of Southern California, Downey, CA  
Dr. Victor Ionasescu, University of Iowa, Iowa City, IA  
Dr. Roger Lebo, University of California, San Francisco, CA  
Dr. Robert Lovelace, Columbia University, New York, NY  
~~Dr. James Lupski, Baylor University, Houston, TX~~  
Dr. Harold Marks, A.I. duPont Institute, Wilmington, DE  
Dr. Richard Mayer, University of Maryland, Baltimore, MD  
Prof. James McLeod, University of Sydney, Sydney, Australia  
Dr. Lefkos Middleton, The Cyprus Institute of Neurology & Genetics, Nicosia, Cyprus  
Dr. Robert Miller, University of California, San Francisco, CA  
Dr. Stanley Meyers, Columbia University, New York, NY  
Dr. Carol Oatis, Philadelphia Institute of Physical Therapy, Philadelphia, PA  
Dr. Shin Oh, University of Alabama, Birmingham, AL  
Dr. Gareth Perry, Louisiana State University, New Orleans, LA  
Dr. Jack Petajan, University of Utah, Salt Lake City, UT  
Dr. Irena Hausmanowa Petrusiewicz, Warsaw Medical Academy, Warsaw, Poland  
Dr. Roger Rosenberg, University of Texas, Dallas, TX  
Dr. Marvin Rozear, Duke University, Durham, NC  
Dr. George Serratrice, University of Marseille, Marseille, France  
Dr. Ding Guo Shen, Chinese PLA General Hospital, Beijing, China  
Dr. Thomas Swift, University of Georgia, Augusta, GA  
Dr. P.K. Thomas, Royal Free Hospital, London, England  
Dr. Gerald Weber, New York College of Podiatric Medicine, New York, NY  
Dr. Lowell Williams, Children's Hospital, Columbus, OH  
Dr. Hitsoshi Yasuda, Shiga University of Medical Science, Shiga, Japan

One of the topics discussed at the meeting was current CMT research. (*Editor's Note: See the Research Update in this issue. This was written by Dr. Roger Lebo who is the research liaison for the MAB and is engaged in CMT research at the University of California at San Francisco.*) MAB members will be asked to present current work at the next Board meeting.

Another topic for discussion at the next MAB meeting will be the effect of physical trauma on the CMT patient. This topic was suggested by the CMTA in response to the number of inquiries from CMT patients.

Dr. Jack Petajan, a neurologist and professor at the University of Utah Medical Center, presented a five point program for the management of CMT.

(continued on page 3)

## Patient Profile

Dear CMTA,

I am a 31 year old female who was diagnosed at the age of 13 with CMT. I had previously been diagnosed at age 7 as a cerebral spastic and was put on valium to control the severe muscle cramps in the calves of my legs. Three months later I experienced a 180 degree personality change. Now I am a recovering alcoholic and drug addict. I have had difficulty accepting the fact that I have CMT. I am also adopted and cannot find the identity of my biological parents, since the adoption laws in the state of Missouri were designed to protect the natural parents. After several letters to the judges of Jackson County requesting information because of the unpredictability of my disease, I still remain in the dark. I would like to visit my biological parents to find out if anyone else in my family has CMT. I would like to know how they are dealing with the progressive nature of the disease. Since I had to go into a wheelchair in August of 1990, my desire to find my family has become unquenchable.

Does anyone know how I might go about finding my biological parents? I do know I was born on February 25, 1959, at the Willows Maternity Sanitarium in Kansas City, Missouri. My name was Elizabeth Moore and my mother was 16 years old and a freshman in high school. I would be pleased to hear from anyone who has experience with finding their natural parents or anyone who might have known or now know my biological family. Please write to RuieMunson, %CMTA, CMEC, 600 Upland Ave., Upland, PA 19015.

I would also like to caution other patients who are taking Valium or any other mood altering drug to be very careful and to ask for help if they suspect they may be abusing the drug. I was lucky to get into a rehabilitation and recovery program before I drank my life away. I couldn't deal with being disabled and felt I had no one to talk to, so several times I attempted suicide

### LETTERS

We want to hear from YOU!

Write us at:

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



Ruie Munson

because dealing with reality was too painful. Thank God, I got help. Today I am full of life and involved in many positive activities. I love life today! It is still painful to deal with the reality of having CMT, but life is worth all the pain and agony. I am, and will continue to be, an active advocate for disabled rights everywhere and anywhere I can.

Friends among friends,

Ruie Munson

## MAB (continued from pg. 2)

This program is used at the Medical Center in Salt Lake City. The five points of the program are:

1. good nutrition following accepted nutritional standards
2. supervised physical exercise
3. self management by the patient so that the patient has an attitude of being in control of his/her own life (methods include improved communication skills with family and friends, relaxation techniques, and heightening the patient's perception of his/her own disease)
4. accurate information about CMT
5. a support group system run by competent and interested people which is a problem solving situation, fills a social need, and is an information source including professional medical referrals.

The members present reviewed CMT FACTS and then proposed the publication of a professional educational brochure. It was agreed to do this when funding is obtained for the project. There was consensus that the recognition of CMT and the CMTA must be increased.

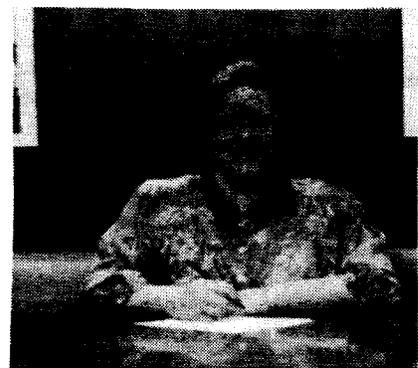
This reporter was impressed with the dedication and interest that the attending members have in CMT and the CMT patient/family. We are indeed fortunate to have these professionals giving their time and knowledge to the CMT community. ☐

## SOMETHING NEW HAS BEEN ADDED

Patricia Dreibelbis has joined the staff of the CMTA as the administrative assistant. Pat is a graduate of Ohio Wesleyan University and a former high school English teacher. Her previous experience in the nonprofit sector has been with school-parent organizations, Lutheran World Hunger Appeal and the Mothers' March of Dimes.

In addition to phone and mail tasks, Pat is conducting an extensive public relations campaign. We must increase the public awareness of CMT. This can be accomplished with media coverage of the disorder.

(Editor's Note: If you are interested in assisting us with public relations in your local area, write us and ask for a



Pat Dreibelbis

public relations kit to use with newspapers, radio and TV.)

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**California Conferences** (continued from page 1)

ference of your choice as seating is limited in both locations. One can register for the morning or afternoon session only for \$ 10.00 or may attend both sessions for \$ 15.00. There is a special rate for families of two or more of \$ 15.00 per session for the whole family or \$20.00 for the entire day. All day parking will be available at each site for a fee.

Please complete the registration form as soon as possible and return it to CMTA with your payment. If space permits, there will be registration on the days of the conferences. If you have any questions, please call 1-215-499-7486 (CMTA).

In LA, Dr. King Engel, a member of the Medical Advisory Board, is arranging for the speakers and the facilities. The first topic of the morning in LA will be "The Neurology of CMT and Research Advances". The second morning presentation will be Dr. John Hsu of Rancho Los Amigos Center, USC, discussing "Orthopedics and CMT". In the afternoon, Dr. Roger Lebo, geneticist from UCSF, will speak on genetics and current research. The final speaker will be Cathy Howell, a physical therapist from Good Samaritan, addressing "Physical Therapy Aspects of CMT".

The San Francisco conference is being arranged by Dr. Robert Miller of Children's Hospital. He will be the first speaker on Saturday morning addressing the topic of "The Neurology of CMT". The other morning speaker will be Dr. Frederick Bost, an orthopaedic surgeon, and he will speak on orthopaedics and CMT. Dr. Roger Lebo will speak in the afternoon on genetics and research, and the afternoon will conclude with Michelle Mendoza, a Physical Therapist at Children's and Sandra Baker, an Occupational Therapist at Children's Hospital.

The wealth of information and the expertise of these specialists make these conferences invaluable to the CMT patient and family. If you live in the Los Angeles or San Francisco area, or can be there on April 6 or May 11, plan to join us. ☐

**CONFERENCE REGISTRATION FORM**

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

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

I will be attending (please check):

- Los Angeles Conference \_\_\_\_\_
- San Francisco Conference \_\_\_\_\_

Number of lunch reservations: (\$8.50 each) \_\_\_\_\_

Number of people attending:

- 1. Morning session only @ \$10. \_\_\_\_\_
- 2. Afternoon session only @ \$10 \_\_\_\_\_
- 3. Both sessions @ \$15.00 \_\_\_\_\_

Discount rates for family of two or more

(Note how many persons will attend from your family)

- 1. Morning session only @ \$15.00 \_\_\_\_\_
- 2. Afternoon session only @ 15.00 \_\_\_\_\_
- 3. All day @ 20.00 \_\_\_\_\_

TOTAL \$ Enclosed \$ \_\_\_\_\_

Registration for Los Angeles must be received by the CMTA before March 31, 1991. Registration for San Francisco must be received by the CMTA before May 4, 1991.

**The Search Is On**



The CMTA is looking for a child aged 5-12 who is a CMT patient and who would like to be the 1991 poster child. In addition to being featured in an upcoming newsletter, the child will be the focus of local and national publicity on behalf of the Association. In order to be considered, the family must complete the following application and return it to CMTA by May 1, 1991, along with a clear photograph of the child. (e.g. school photograph)

**Poster Child Application**

Child's full name \_\_\_\_\_

Age \_\_\_\_\_

Mother's name \_\_\_\_\_

Father's name \_\_\_\_\_

Brothers \_\_\_\_\_

Sisters \_\_\_\_\_

Age of diagnosis of CMT \_\_\_\_\_

Number of afflicted family members \_\_\_\_\_

Hobbies, activities, sports, interests, groups and organizations: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Briefly write why your child would be a good choice as 1991's CMT poster child. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If chosen, my child and I would be available for newspaper, magazine or television promotions as CMTA's representatives and at CMTA's expense.

Parent's signature \_\_\_\_\_

Date \_\_\_\_\_



**Conference Travel**

The CMTA has arranged with USAir for a special conference discount on airfare. USAir will discount 5% off the lowest fare you choose or 45% off full coach fare. When making a reservation call USAir's convention desk at 800/334-8644 and he/she will request the GOLD FILE #. The GOLD FILE # for LA is 381702; for San Francisco it is 381703.

Lodging is available in LA at the Weingart Guest House at the Good Samaritan Medical Center for \$45 per room per night. Reservations may be made at 213-482-8020. ☐

## 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- Burbank**  
Sherry Brown (818)841-8421

**California- San Diego**  
Gary Cleze (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) 253-5632

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

**Illinois- Chicago,**  
Carol Wilcox (312) 445-2263

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

**Kansas- Parsons**  
Tammy Taylor (316) 421-5268  
Meets at Labette Community College  
Parsons, KS

**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



Kay Flynn

The newly formed West Chester County support group under the leadership of Kay Flynn meets bimonthly at the Blythedale Children's Hospital, Bradhurst Ave., Route 100, Valhalla, N.Y. 10595, in the Phoebe Stein Conference Room. The group meets to share experiences, feelings and concerns in a mutually supportive atmosphere. The group is also making an effort to get CMT recognized for funding and research.

At the last meeting, Kay brought home-made chocolates as a treat for the members and then auctioned off a box to cover the cost of the stamps and envelopes she used to announce the meeting.

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### FLASH!

### COLORADO CONFERENCE TO BE HELD IN MARCH

Dr. Gregory Stilwell, Denver area support group leader and a practicing podiatrist, is organizing an all-day CMT patient and family conference for March 16, 1991. Details were not available as we went to press. For further information call the CMTA at 1-215-499-7486 or Dr. Stilwell at 1-719-594-9920.



## Ask the Doctor

Dear Doctor,

My husband has recently been diagnosed as having CMT and we have several specific and serious questions concerning the progression of the disease.

1. "At what rate can we expect this disease to progress...he is now 100% disabled... with the loss of the use of his left arm?"

2. "He has muscle spasms, cramps, and weakness in the hands, arms, calves of his legs, hips and back. Are these part of the symptoms of the disorder?"

3. "He has scoliosis. Will the CMT effect his back muscles?"

4. "So little information is available. What plans should we be making for his future needs?"

*A member of the CMT Medical Advisory Board responds:*

1. The typical rate of progression in CMT is slow but inexorable. Complete disability for activities of daily living is extremely rare, but 100% disability for work occasionally occurs, depending on the nature of the usual employment. It is quite unusual for CMT to be asymmetrical and the implication of the question is that there has been loss of the use of the left arm but not the right. If there really is a significant asymmetry from side to side, this would raise serious questions about the correctness of the diagnosis.

2. The major symptom of CMT is progressive weakness. Muscle spasms and cramps also quite commonly occur. All symptoms are most prominent in the hands and the lower legs and feet, but occasionally involve the thighs and upper arms. Any of these symptoms involving the hips or back are unusual in CMT, and, again, raise significant questions about the diagnosis.

3. Scoliosis can occasionally occur in association with CMT. However, the disease seldom directly affects the back muscles. Secondary weakness of the back muscles is much more likely to be due to other neurological diseases, such as spinal muscular atrophy.

4. There is so much variation in the disease from individual to individual that it is difficult to predict what the future holds for one person. However,

(continued, next column)

the degree of disability described suggests that the disease is quite severe and progressively worsening function is to be expected. A great deal of information is available through the Charcot-Marie-Tooth Association. The Muscular Dystrophy Association provides information and direct patient services such as braces, wheelchairs, etc. The patient can contact the MDA and arrange for an evaluation at their nearest clinic. I hope this information is useful to the individual involved.

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### 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.

## CALL FOR PARTICIPANTS

The CMTA has been asked to come to you, the CMT patient, for your assistance. Dr. Joseph Jankovic, Professor of Neurology at Baylor College of Medicine, is interested in the clinical features of Charcot-Marie-Tooth disorders. Accordingly, in this issue of the CMTA Report we have published Dr. Jankovic's survey.

We strongly urge you to participate in this study and complete the form. Current and future research into causes of and therapies for CMT depend on not only funding, but the cooperation of the CMT community. Only you, the CMT patient, can provide the necessary information to the medical community. We encourage you to now take a pen/pencil and complete Dr. Jankovic's questionnaire. Send the completed form to: Dr. Joseph Jankovic, Department of Neurology, Baylor College of Medicine, 6550 Fannin, Suite 1801, Houston, TX 77030.

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## AMERICANS WITH DISABILITIES ACT

*The following article is reprinted from INFORMATION FROM HEATH, Vol. 9, No. 2.*

The Americans with Disabilities Act (ADA), signed into law by President Bush on July 26, 1990, has been called one of the country's most important pieces of legislation. Others have described it as the most far-reaching civil rights legislation since the Civil Rights Act of 1964, and an "emancipation proclamation" for people with disabilities in America. The ADA prohibits discrimination against people with disabilities in the areas of private employment, public accommodations and services, transportation, and telecommunications. Regulations implementing ADA are expected to be issued in the next few months. The following are the key elements of ADA, as the law pertains to:

### Businesses

- becomes effective within two years of enactment
- covers businesses employing 25 or more persons (in 1992) and those employing 15 or more persons (1994)
- protects applicants and employees who are "qualified individuals with a disability"
- requires covered employers to make "reasonable accommodations" (but excludes such accommodations which would impose "undue hardship")

### Public Accommodations and Transportation

- becomes effective within eighteen months of enactment
- covers private entities which provide public services and accommodations, such as hotels, restaurants, bars, theaters, stadiums, convention centers, grocery stores, shopping centers, museums, libraries, parks and schools.

**Editor's note:** For a free information packet on U.S. disability policy produced by the Senate Subcommittee on Disability Policy write for "AN OVERVIEW OF THE AMERICANS WITH DISABILITIES ACT." The address is: the Labor and Human Resources Committee, 113 Hart Senate Office Bldg, Washington, DC 20510.



10. Have you ever tried any other treatments for your tremor/shaking? Yes      No  
If so, describe \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

11. Does alcohol make your tremor/shaking:      better              worse              has no effect (Circle one)

12. Which treatments for your tremor/shaking have been most effective? (list)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

13. Is there a history of any other neurologic problems in your family? Yes      No  
If yes, please indicate disease and relatives affected

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

14. Please write (in cursive) "Today is a nice day."

15. Draw a spiral:

right hand

left hand

**Mail completed survey to:**

Dr. Joseph Jankovic  
Department of Neurology  
Baylor College of Medicine  
6550 Fannin, Suite 1801

*Thank you for taking the time to complete this survey.  
Your participation in this study is important!*

## CMTA Job Survey Nets Interesting Results

As a part of the 1990 Winter Issue of the CMTA Report which focused on vocational rehabilitation, we enclosed a survey to find out about the career choices of CMT patients. Since then we have received 43 responses and compiled the results. Although admittedly a small study, it yielded some interesting facts about the working lives of CMT patients.

First, the survey showed that CMT patients have jobs in a variety of fields. There are people in the professions—doctors, lawyers, engineers and accountants. There are also factory workers, teachers, bookkeepers, retail clerks, real estate agents, salesmen, etc. There is a policeman and a fireman. There is a professional comedy writer. There is even—very appropriate to the survey—a job counselor.

The survey asked at the top: "Did CMT influence your career decision?" A majority answered "No." A few people wrote that they were diagnosed with CMT later in life, well after they had chosen their career path. A Chicago man in data management writes: "I

knew that physically demanding work like carpentry or construction was out, so I went into a field where the demands are greater on the mind than on the body."

When asked "Have you had to make a career change because of CMT?," most also wrote "No." Those few who said "Yes" typically mentioned CMT-related physical problems as the reason behind the change. A CMT patient who worked retail sales is now studying to be a psychotherapist in part because: "As I got older, it became harder and harder for me to stay on my feet all day."

Finally, when asked "Did you receive educational/vocational counseling prior to making your career decision?," three people mentioned that they sought help at their state vocational rehabilitation office. One wrote that "Nobody know what Charcot-Marie-Tooth disease was, but they found out and were very helpful."

The CMTA would like to thank all those who participated in the survey, and we would still enjoy hearing from more CMT patients about their careers.

— Rex Morgan

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

Published & distributed by:  
**Educational Marketing Services**  
 P.O. Box 760  
 Hoarce Harding Station  
 New York, NY 11362  
 Tel. 718/279-8516  
 Fax. 718/428-0498

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

Inquiries welcome.

### 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.

### Memorials

In Memory of	By
Laurel Hopkins	Karol Hitt
Milton R. Prickett	Grace & Arthur Wangaard, Jr.
George Phy	Janet R. Phy
Leo Breeden	Drucilla Lake
Irving Finkelman	Sheila Kosmin
Irving Finkelman	Ruth Finkelman
Harry Brezel	Karen Edelson
Robert Keegam	Marilyn McCormack
Harold Lewis	The Hankinsons
Hascal Feen	Plastic Bottle Corporation
Bell Robison	Mary Francis Hardy
Janice Jones	M/M R. Firestone
Robert G. Bradwick	Karol Hitt

### Free Information

NICHY, a governmental agency concerned with children has produced an excellent booklet for parents of handicapped children. This booklet is entitled "LIFE AFTER SCHOOL FOR CHILDREN WITH DISABILITIES: Answers to Questions Parents Ask About Employment and Financial Assistance." It is written in question and answer format, is easily understood, and contains excellent information. For a free copy request the booklet by name from: NICHY, P.O. BOX 1492, Washington, DC 20013 or call 1-800-999-5599

## Letters...



Dear CMTA:

I have sent to you the LUPSKI/CMTA questionnaire. I've added a few documents that might interest you in this context. I hope my letter will reach you early enough, so that my questionnaire will help you. You know I am not a recipient of the *CMTA REPORT* myself. My uncle (a CMT patient) lives in the USA and he gets the Report from the CMTA. He reads it and sends it to my mother (a CMT patient) who reads it and sends it to me, also a CMT patient. So one paper is very useful to our whole family, but it takes a lot of time before I get it. Maybe your investigation is finished already, but I'll try.

I think this investigation is very useful, since much more money is spent to build tanks and cannons than to build hospitals and medical laboratories. Many more scientists, clerks and workers are engaged in destroying the world than in healing the people. We must try to help ourselves. So, I'm glad that you are collecting information and researching about this mysterious disorder for the benefit of future generations.

You know, I have two sons. They were born a long time ago before I knew anything about CMT especially about me having CMT. They have no symptoms at all, but they are confronted with the possibility of having inherited CMT from me. Maybe, a quick progress in CMT diagnosing and treating CMT could prevent them from sharing my fate.

So I thank you for your idea to undertake this investigation. I wish you all the best for your work.

K.K., Germany

**Editor's note:** *The CMTA Report is now being sent to this family in Germany.*



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.

## Research Update:

### Charcot-Marie-Tooth Results Presented The American Society of Human Genetics Conference Cincinnati, Ohio, 1990

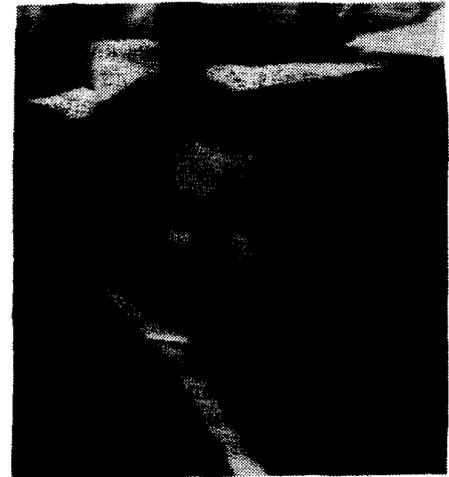
Eight abstracts were presented by five research groups about Charcot-Marie-Tooth disease. Dr. James Lupski's group (Baylor University) reported finding a series of overlapping chromosome deletions in Smith-Magenis disease in the same general chromosome region as the chromosome 17 slow nerve conduction form of Charcot-Marie-Tooth disease (CMT1A). He proposed that these deletions will help map DNA fragments in both disease gene regions.

Dr. Jeffrey Vance (Duke University), who found the CMT1A gene, reported the results of further linkage studies that confirmed the localization of the CMT1A gene to the short arm of chromosome 17. Dr. Roger Lebo (University of California, S.F.), working with Dr. Philip Chance (University of Utah), presented the precise physical ordering of eight adjacent probes by a new procedure called multicolor in situ hybridization. This procedure labels one location red and a second location green on a blue stained chromosome. Dr. Chance has identified common polymorphic markers detected by these probes which make them very helpful in the next stage of isolating the CMT1A gene.

After these presentations, Dr. Kenneth Fischbeck (University of Pennsylvania) organized and chaired a CMT group meeting at the invitation of Dr. P. Michael Conneally (Indiana University), scientific director of the Muscular Dystrophy Association. Nearly all geneticists interested in Charcot-Marie-Tooth disease attended including representatives from Duke, Baylor, Salt Lake City, Seattle, Winnipeg, Philadelphia, and San Francisco. Three important issues were discussed.

First, probes would be made available by Drs. Chance and Lebo after the scientific reports are accepted for publication, but months before the general scientific community reads them. Dr. Lupski and Dr. Pragna Patel (Baylor University) offered their probes described in reports already accepted for publication.

Second, Drs. Patel and Lupski had data indicating the CMT1A gene was in the



Dr. Roger Lebo

next more distant chromosome band from the centromere than Drs. Lebo and Chance had found. Dr. Lebo explained the strong evidence that his assignment was correct.

Third, Dr. Vance presented his continuing concern that a CMT1B gene on chromosome 1 may not really exist. Although Dr. Lebo reported that CMT1B resides on chromosome 1 with a likelihood of 5,000,000 to 1, and Dr. Arthur Hayes (Columbia University) found CMT1B and CMT1A have different abnormal nerve structures, Dr. Lebo had not proven that CMT1B could not reside at the same place as CMT1A. Although substantial effort had been uninformative, Dr. Vance still wanted this issue answered to remove any residual doubt. Since then, further experiments in Dr. Lebo's laboratory have excluded CMT1B from chromosome 17.

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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.

## 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 for 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.

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## 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.

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.

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### Honoraria

In Honor Of	by
James F. Howard	Snadra Howard
M/M Henry Eldridge	M/M Douglas Moody
Lea & Irving Rosoff	Lydia & Harold Servetnick
Gabriel Mark Shipon	Lydia & Harold Servetnick
R. Gordon Bradwick	Faye Bradwick
Sophia L. Bradwick	Faye Bradwick
Craig Haynie	Jeanell Haynie
Meme Plageman	Janice Vaughan
Mrs. Nellie Gill	Mae Boss
The Sand Family	Rebecca Sand
Norma Goldblatt	Mr. & Mrs. Eisenstat
Percy Sand	Lilyan Cantor
Rebecca Sand	Rose Freed
Rebecca Sand	Janet Sand
Rosaline Morgenstern	Steven Firestone
Eileen Perrella	M/M John David Murphy
Frank Crohn	Edward Simon
Percy Sand	Clara Braslow

### SHOES AND MORE

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 his/her facility please tell them that you found them through the CMTA Report.

- Curtis McMahan  
McMahan Shoes  
3903 Gaston Ave.  
Dallas, TX 75246
- Herman Hittenberger  
Hittenbergers Surgical and Orthopedic Appliances  
1117 Market Street  
San Francisco, CA 94103
- Robert Meyers  
Archfame Inc.  
125 East 87th Street  
New York, NY 10128



## 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:

Fall '90  
Summer '90  
Spring '90  
Winter '90  
Fall '89  
Summer '89  
Spring '89  
Winter '89  
Spring/Summer '88  
Winter '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 also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- .....is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of the foot/lower leg and hand/forearm.
- .....causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- .....causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, occasional partial sight and/or hearing loss problems and scoliosis (curvature of the spine) is sometimes present.
- .....does not affect life expectancy.
- .....has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.
- .....is sometimes surgically treated.
- .....is usually inherited in an autosomal dominant pattern, affecting half the children in a family with one CMT parent.
- .....may become worse if certain neurotoxic drugs are taken.

# THE CMTA REPORT

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

## Charcot-Marie-Tooth Association

Crozer Mills Enterprise Center  
600 Upland Avenue  
Upland, PA 19015

Non-Profit Org.  
U.S. Postage Paid  
Ronkonkoma, NY  
Permit # 1390

TO: