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 issues 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.
**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.

- Adenamycin
- 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.

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**VCR Tape Rental**

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

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

To order a tape, fill out our "I want to be in touch!" form (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 Aransson, 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 Connelly, 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. Limon Hopkins, Emory University, Atlanta, GA
- Dr. John Hau, University of Southern California, Downey, CA
- Dr. Victor Ionesescu, 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 Lupska, Baylor University, Houston, TX
- Dr. Harold Marks, A.L. duPont Institute, Wilmington, DE
- Dr. Richard Mayer, University of Maryland, Baltimore, MD
- Prof. James Meloed, University of Sydney, Sydney, Australia
- Dr. Lefkos Middletown, 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. Irene Hausmanowa Petrykowsicz, 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 Marseilles, 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. Hirosi 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 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)
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 Ruie Munson, %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 discovery 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.

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

---

**LETTERS**

We want to hear from YOU!

Write us at:

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

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

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.

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**CMTA Report, page 3**
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)

<table>
<thead>
<tr>
<th>Poster Child Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's full name</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Mother's name</td>
</tr>
<tr>
<td>Father's name</td>
</tr>
<tr>
<td>Brothers</td>
</tr>
<tr>
<td>Sisters</td>
</tr>
<tr>
<td>Age of diagnosis of CMT</td>
</tr>
<tr>
<td>Number of afflicted family members</td>
</tr>
<tr>
<td>Hobbies, activities, sports, interests, groups and organizations:</td>
</tr>
</tbody>
</table>

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.

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.
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 Olcze (619) 752-1427

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) 592-5531

Michigan— Detroit
Suzanne Tarpinian (313) 883-1123

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

New Jersey— Northern
Teresa Diano (201) 594-6241
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
Garrett 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
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 affect 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, 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.

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.

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.

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.
Charcot-Marie-Tooth Disease Questionnaire

Name: ___________________________ Telephone: (______) _________

(last) (first)

City, State: ___________________________ Sex: M F

Age: _________ Age at diagnosis: _________ Age at onset of symptoms: _________

Occupation: ___________________________

1. First symptom (describe): ___________________________

2. Symptoms since diagnosis: (circle)

loss of sensation  weakness  difficulty walking
fatigue  trouble talking/eating  tremor/shaking
scoliosis  foot deformity  loss of balance
dizziness/vertigo  nausea/vomiting  hearing loss

3. Was your condition diagnosed by biopsy (surgery)?

Yes  No

4. Has anyone on your family been diagnosed with CMT?

If yes, please indicate relationship and number affected.

mother  father  grandparent (maternal/paternal)
aunts/uncles (# affected)  (maternal/paternal)
brothers  sisters  cousins
sons  daughters  grandchildren

5. Do you or anyone on your family have:

you (please check)  relative(s) (indicate relationship)

tremor/shaking  _______
memory loss  _______
hearing loss  _______
scoliosis  _______
foot deformity  _______
abnormal posture or deformity of: hands  _______
feet  _______
toes  _______
neck  _______
walking difficulty  _______

6. If you have tremor/shaking what part of your body is affected? (please circle)

head  jaw  tongue  voice  hand
arm  foot  leg  trunk

7. Age of onset of tremor/shaking: _________

8. Has the tremor/shaking: _________  _________  _________ (Circle one)

increased  decreased  remained the same

9. Have you ever taken medications for your tremor/shaking?

Yes  No

If yes, please list

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

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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:  

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 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

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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 acknowledgement to: Name: ________________________________
Address: ________________________________

Occasion:

☐ Birthday ☐ Holiday
☐ Wedding ☐ Thank You
☐ Anniversary ☐ Other
☐ 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 Robinson 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

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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.

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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 Lupsiki’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 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.

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.

I want to be in touch!

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Tell us about yourself:

- [ ] CMT Patient
- [ ] Medical Professional
- [ ] Interested Supporter
- [ ] CMT Family Member
- [ ] Other

Please check the appropriate boxes:

- [ ] Put me on the mailing list!
- [ ] CMT Neurology - $10
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- [ ] Send me a copy of the informative booklet "CMT Facts" - $3

Join the fight against CMT!

Enclosed is my check for: $_______

Contributions are tax deductible.

Please make checks payable to the CMTA.

[ ] $25 Member
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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
  Hittenberger's Surgical and
  Orthopedic Appliances
  1117 Market Street
  San Francisco, CA 94103

- Robert Meyers
  Archframe Inc.
  125 East 87th Street
  New York, NY 10128

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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:
- 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/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

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