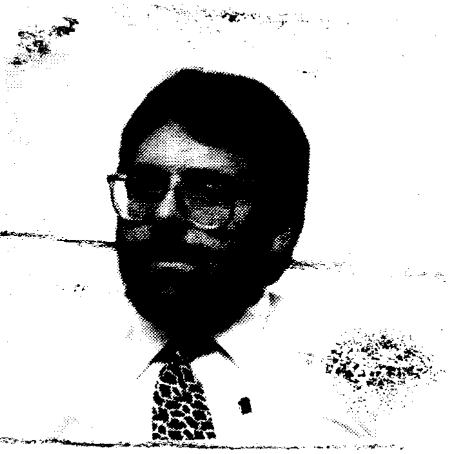
Charcot-Marie-Tooth Association

THE CMTA REPORT

Fall 1991 Vol.6/No.4

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

Scientist Announces CMT Diagnostic Breakthrough



Dr. James Lupski

A simple blood test may now be used in some CMT patients and families for diagnosis. This test was developed at Baylor College of Medicine, Houston Texas, by Drs. James R. Lupski, Roberto Montes de Oca-Luna, Susan Slaugenhaupt, Liu Pentao, Vito Guzzetta, Barbara J. Trask, Odila Saucedo-Cardenas, David F. Barker, James M. Kilian, Carlos A. Garcia, Aravinda Chakravarti, and Pragna I. Patel. The findings were published in the July 26, 1991 issue of the scientific journal Cell. (Editor's note: Dr. Garcia is at Louisiana State University and Dr. Chakravarti is at the University of Pittsburgh.)

These researchers determined that, in the patients studied, CMT is caused by a duplication of deoxyribonucleic acid (DNA) on chromosome 17. According to Dr. Lupski, who is himself a CMT patient, "We now have a direct diagnostic test for one form of CMT." Dr. Patel said, "This kind of early diagnosis can be made in people who have the disease but who have not yet shown any symptoms." Historically, diagnosis of CMT has been done by family history, clinical examinations, sophisticated testing of nerve and muscle function (EMG's and nerve conduction velocities) and sometimes nerve biopsy.

The research involved large families centered in South Louisiana. Genetic material was purified from white blood cells taken from family members. These DNA samples were used to track the chromosomal position of the gene responsible for CMT. What the researchers found was an extra copy of a segment of chromosome 17. According to Natalie Angier writing in the August 6, 1991 issue of The New York Times, "The length of the normal chromosome is about 130 million subunits, or base pairs, of DNA. But somehow in afflicted patients, about 500,000 DNA bases had been duplicated, causing a sort of molecular stutter right in the middle of the upper arm of the 17th chromosome."

Dr. Lupski, who is a member of the Medical Advisory Board of the CMTA, wrote to the CMTA prior to the publication of the article in Cell. About this work he said, "This should very rapidly lead to a DNA based diagnostic test for this disease entity if a patient has the duplication in the family." However, the test is not available now on a commercial basis as Dr. Lupski is continu-

Dr. Pragna Patel

ing to gather data on random samples of CMT patients. If you are interested in being a part of this phase of Dr. Lupski's study there are certain criteria which must be met. He will accept one family member for testing from any

(continued on page 2)

The CMTA is a participant in the **Combined Federal Campaign** (#1031 in the CFC brochure) and in the **United Way Campaign** (Donor Choice # 08823).

IN THIS ISSUE:

CMT Blood Test (cont'd from pg 1)

given family, **after the submission of the required criteria**. If you are interested send a stamped, self-addressed envelope to the CMTA, 601 Upland Avenue, Upland, PA 19015, and we will send a copy of the requirements to you.

What does this discovery mean to you the CMT patient/family? Early and simply obtained diagnosis (including pre-natal diagnosis) is the most obvious benefit in families who have this duplication on chromosome 17. Since Dr. Jeffrey Vance and colleagues' discovery of a CMT gene on chromosome 17, scientists have advised us that the vast majority of CMT families will be found to have this genetic defect. (CMT caused by a CMT gene located on the X chromosome or chromosome 1 is a very rare occurrence.) Additionally, this discovery can lead to a real understanding of the underlying causes CMT. In other words, what has gone wrong? Once scientists understand what is wrong, then they can begin to develop therapies specific for the problem. Ultimately, cures can even come into being. It is to this end that we are all working. We congratulate and laud these researchers for their collective efforts.

Editor's note: *When the DNA test for CMT is available either at Baylor or other laboratories, we will advise you in the CMTA Report. There are scientists in other laboratories in the U.S. and abroad who are also working on diagnostic CMT DNA procedures. In Antwerp, Belguim, Dr. Christine VanBroeckenhoven announced in May similar findings as Dr. Lupski on a study of 12 families. The reference for Dr. Lupski's article in Cell is "DNA Duplication Associated with Charcot-Marie-Tooth Disease Type 1A"; James R. Lupski et.al. Cell. July 26, 1991.*

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Professional Help

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

Max Wehr, C. Ped.
Wehr's Shoes and Pedorthic Center
135 S. Cochran
Charlotte, Miss. 48813

CMTA Recognizes The 1991 Rebecca Sand *Volunteer Of The Year*

Sue Tarpinnian
with sisters Marianne & Rayeanne

The CMTA is very pleased to announce that Suzanne Tarpinian, the Detroit area support group leader, has been chosen as the recipient of the 1991 Rebecca Sand Volunteer of the Year Award.

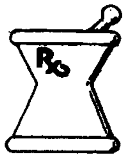
Sue has been an inspiration to all of the staff of the CMTA and the people who belong to her support group. She was instrumental in bringing a regional conference to the Great Lakes Area in September and has worked with the local and national MDA to get CMT patients and their disorder recognized.

When the poster child was chosen, and happened to represent Michigan, Sue went to work informing CMTA headquarters of all the possible avenues for recognition for Adam and for publicity for the organization.

No one gives more willingly or enthusiastically of her time and talents than Sue. If something needs to be done, Sue will do it herself or find the person who can make it happen. "Impossible" isn't in Sue's vocabulary, and she has little time for anyone who uses that word.

A typical support group meeting of Sue's draws 20-25 people and her summer picnic had an attendance of 50. Sue's enthusiasm and up-beat attitude are hard to resist, and her success as a support group leader and a CMTA supporter are the attributes which have garnered her the Volunteer of the Year Award. Congratulations! ¤

MEDICAL ALERT



Certain Drugs Toxic to the Peripheral Nervous System

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

Adriamycin
Alcohol
Amiodarone
Chloramphenicol
Cis-platinum
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Mega Dose of Vitamin A
Mega Dose of Vitamin D
Metronidazole (Flagyl)
Nitrofurantoin
(Furadantin, 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.

The CMTA Report is published quarterly by the Charcot-Marie-Tooth Association, a registered non-profit 501 (C)(3) health organization. The newsletter is co-edited by Karol Hitt and Pat Dreibelbis. The layout is by Chesapeake Bay Design, 48 Henry Court, Hollywood, MD, 20636.

Those Fabulous Crohn Brothers

George and Frank Crohn

Politics, sports, theater, and philanthropy all have their famous families - the Roosevelts, DiMaggios, Redgraves and Duponts.

The CMTA is equally blessed by a family whose members bring reflected honor to our organization by the good they do. In this issue of the newsletter, we highlight two brothers, Frank and George Crohn, whose contributions to the CMTA and to people in general is immeasurable.

Frank and George were born and raised in New York City and each was diagnosed with CMT. Frank has since moved to Boca Raton,Florida, where he is the President of a life insurance company and George has remained in New York as the Executive Vice-President of a company in the jewelry industry. Although they have gone in different geographical directions, a common thread runs dependably through their lives no matter where they go or what they do. Both are firmly committed to helping others.

Both Frank and George were original Board members when the National Foundation for Peroneal Muscular Atrophy was first founded. Both were financial backers of the 1987 Arden House CMT conference and both helped fund <u>CMT FACTS</u>. Each of them has also done some remarkable good not related to CMT.

Frank made a promise in 1990 to some 25 children from the Dixie Manor project in Boca Raton that if they kept up their grades and their good behavior, he would treat them to 10 days this summer at his 10 acre property at Boyden Lake, Maine. They did their part, and he kept his promise!

This vacation was not just a gift to those kids, but, for Frank,a sharing of himself. He went with the 25 inner city kids, a Boca Raton policeman who handles the Dixie Manor beat, and a parent of one of the kids who just happened to be a cook in a Boca Raton restaurant. For 10 days the Dixie Manor kids had an experience so different from their normal existence that most were reluctant to return home. They swam in a brisk lake, paddled a canoe, hiked in the mountains, caught lobsters and toured FDR's summer home. For Frank, the days were not quiet and relaxing as a normal get-away might be, but they were filled with emotion and reward.

As policeman Wayne Barton said on their return to Florida, " This trip has given these kids new life. I keep trying to think how they can show their appreciation to Frank. But everything I think of is not enough. Frank has a great love for these kids. This was a once-in-a-lifetime experience these kids will never forget."

George's contribution to the welfare of others has taken a different tack, with no less success. In 1958, he founded the Dysautonomia Foundation, a group begun to help persons suffering from this rare genetic disorder which affects only Jews from a certain portion of Eastern Europe. His son suffers from both CMT and Dysautonomia. After a few years, he founded and currently serves as the President of an association called the National Foundation for Jewish Genetic Diseases. This organization umbrellas such disorders as Tay-Sachs, Gaucher's Disease, Torsion Dystonia, and Canavan Disease. All of these disorders affect Ashkenazi Jews exclusively. The primary function of this organization is to fund research and to conduct seminars for physicians.

In addition to his commitment to his own genetic organization, George still finds time to serve on the Board of Directors of the CMTA as the Chairman of Long-Term Development.

The CMTA is justifiably proud of the Crohn brothers for whom helping others is "first" nature.

Honoraria

In Honor Of	**By**
Dr. Roger Lebo	Gary Oelze
Carter Thompson	William H. Thompson
T. Smalley	James Held
Geoffrey Clarkson	Elizabeth Clarkson
Rebecca Sand	Mike, Diane, Jay, Marc
Martin Stallone	Laurie Stallone
Rebecca Sand	Rose Freed
Debra Czarnecki	Carol Fink

We need an upgrade!

Since 1986 we have been using a donated, used IBM PC XT. Due to the age of the system and the growth of the CMTA we urgently need to upgrade our system. Our computer friends tell us we need an IBM (or clone) 386 SX, 2 MB RAM, 80 MB Hard Drive, 3 1/2 and 5 1/4 floppy drives, VGA monitor and controller. If you can help us obtain this system, please contact us.

Ask the Doctor

We regret we can not answer all letters we receive which pose medical questions. We chose letters that ask questions which we feel would be of general interest to our readership. We have no doctors on staff at our office, and questions are sent to physicians who serve on our Medical Advisory Board. Due to the volume of mail we receive, we are unable to respond to all letters.

Dear Doctor,

I am a 44 year old female who was diagnosed two years ago with CMT. My brother and nephew were diagnosed with CMT six months before me.

Our father probably had CMT from birth, along with club feet and many other symptoms. In his early 40's his walking got harder for him and he ended up in a wheelchair, unable to walk or use his hands and fingers. He died at the age of 54 not knowing that CMT is an inherited disease. He suffered from backaches, which I recently found out that many close relatives of his also had.

My children were tested two years ago using the electromyogram. They were ages 20, and 17. Even though my son and my daughter had foot problems as infants, the neurologist said they don't have the disorder. He said they were safe to have children in the future without worrying about passing the CMT to their children. I told my sister-in-law, who talked to another neurologist who said that CMT could still show up after 30. Which is true? Our family wants to know if they could still develop CMT.

The Doctor answers:

Yes, one or both of your children may have inherited CMT. Sometimes clinical weakness doesn't show up until after 30. They would need a nerve velocity conduction study and EMG and I could not make a further judgement without seeing those results.

I also want to mention my sister. She was given the electromyogram and her doctor told her that she doesn't have CMT, but because of a slow reaction, she has to go back for check-ups on her feet once a year. Should CMT be able to be ruled out if she has had the nerve tests? Why would the neurologist need to see her once a year?

Ask the Dr. (cont'd)

The Doctor answers:

CMT should probably be able to be ruled out by nerve conduction studies; however, it could depend on the type. In Type II nerve times are normal or slightly long and these patients must have an EMG done on all four limbs. Sampling one or two muscles or nerves would not be adequate.

Another question I have is could I have hypertrophic type of CMT as the doctor said, or is it possible to have both the hypertrophic and the neuronal types together? Can one family member have one type and another family member have the other type?

The Doctor replies:

Both types are not usually found in one family. Someone would need to work up all family members to acquire more data. I would suggest that this family go to an MDA clinic for a thorough evaluation.

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support group corner

A Special Lady

This issue's support group leader profile was prompted by a letter from one of our readers who recommended her support group leader as one worthy of notation.

She writes," Mary is a very "special" lady who started the Orlando area support group on Saturday September 17, 1988 and has held a meeting every other month since that time. Attending these meetings has been of such help to my husband and myself and also to my granddaughter and her parents who live in Rhode Island. My enthusiasm and reports of how wonderful CMT people are and of how well they cope has been very encouraging to all of them."

Mary Beeler

The "Mary" of whom she writes is Mary Beeler,the Orlando support group leader who began the group after attending the Orlando Patient/Family conference in 1988. Her first meeting had 17 in attendance and she now averages 20-25 at the meetings held in her church. Mary says she could not do all she does if it were not for her husband, Frank, and the many friends at her school who support her efforts.

Mary was diagnosed with CMT at the age of 7 and her father also had the disorder. Mary left high school in the eleventh grade because a teacher said to her, " This is not a school for cripples. Go find a special school." Although these thoughtless comments devastated her at the time, they probably resulted in her eventual determination to get her GED at the age of 40, then attend college and now to work as a resource teacher with the exceptional education department in Orange County.

The letter that recommended Mary concluded, "She now works in the school system in special education and is I'm sure, a role model for all 'special' people" (Mary's name for CMT patients).

She calls those not affected people "plain people." She is bright, cheery, well-organized and has a tremendous sense of humor."

The CMTA is fortunate to have such "special" people as Mary Beeler, who serves as an inspiration to the members of her support group and to everyone who knows her.

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CMTA Announces New Additions to MAB

The CMTA is pleased to announce the addition of two doctors to the Medical Advisory Board. The newest members of the Board are Jan Korthals, MD, PhD, a Professor of Neurology at the University of South Florida College of Medicine and Kieran Mahan,D.P.M., F.A.C.F.S.,Vice-President for Academic Affairs and Dean Associate Professor of Podiatric Surgery at the Pennsylvania College of Podiatric Medicine in Philadelphia.

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"When one is sick, two need help"

That motto serves as the basis for the Well Spouse Foundation, a non-profit organization which serves to offer emotional support to the husbands and wives of the chronically ill. The group also advocates for change in insurance coverage and new programs to help families deal with chronic illness. The message of the group can be found in a book by Maggie Strong called Mainstay. Or, you may contact the President Barbara Drucker at 619-673-9043 for further information.

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VCR Tape Rental

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

Single lecture tapes (1 hr., 15 min.) rent for $10, and the double lecture tapes (2 hr., 30 min.) rent for $15. The rental fee includes prepaid return postage. To order a tape, fill out our "I want to be in touch!" form (see page 11) and send it to us with a check or money order payable to: The CMTA, 601 Upland Ave., Upland, PA 19015.

Support Group Notes

A primary goal of the CMTA is to become a truly successful advocate for those with CMT. Its message must reach the patients, their families, and the medical and research communities. Patient family support groups, a growing and vital part of the CMTA program, inform and support anyone who must deal with CMT.

There are already several CMTA support groups. These chapters are spirited and growing stronger, but more groups are needed in other parts of the United States. The CMTA will gladly help you to set up a chapter in your area. For information please contact the CMTA by mail or call (215) 499-7486.

Perhaps there is a chapter meeting near you. You are cordially invited to join these groups in their upcoming events.

California– Los Angeles Area

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

San Bernadino ("Inland Empire")
Mary'L Michels (619) 246-7807

Canyon Country - Saugus
Sheila Levitch (805) 254-5322
Denise Miller (805) 251-4537

California– San Diego
Gary Oleze (619) 792-1427

California– San Francisco
David Berger (415)491-4801
after 6:00 pm

California–Santa Rosa
Freda K. Brown (707) 573-0181

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

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

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

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

Georgia– Western
Molly Howard (404) 253-5632

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

Massachusetts– Boston,
Eunice Cohen (617) 894-9510

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

Michigan– Detroit
Suzanne Tarpinian (313) 883-1123

New Jersey– Central
Janet Saleh (908) 281-6289
Somerset Medical Center
Sommerville, NJ 08876

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

North Carolina–Eastern
Susan Salzburg (919) 967-3118
(919)286-0411 (x6586) days
Durham Medical Center

Ohio– Cleveland
Norma Markowitz (216) 247-8785

Pennsylvania– Delaware Valley
Rex Morgan, Jr. (215) 672-4169

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

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

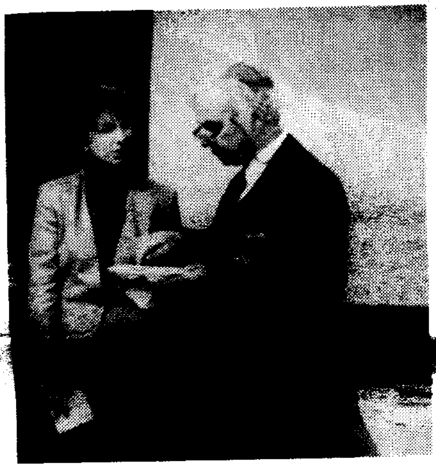
Virginia– Tidewater Area
Mary Jane King (804) 591-0516
Thelma Terry (804) 838-3279

Virginia–Richmond Area
Dennis Breckenmaker (804) 748-9021
Steve Firestone **(804)** 745-4123

1991 In Review

This has been a productive and good year for the CMTA. Early in the year the CMTA published CMT FACTS, a handbook about CMT for the lay person. CMT FACTS was mailed to over 16,000 public libraries in the United States making the information available to the general public. Additionally, the handbook can be purchased for a nominal fee from the CMTA by anyone. (See page 11 for order blank.)

CMTA Conferences



a quiet chat with a doctor...

In April at the annual meeting of the Board of Directors, the following officers were elected: Karol Hitt, President; Rodman Steele, Jr., Vice-President; Diane Freaney, Treasurer; Donald Perrella, Corresponding Secretary; and Rex Morgan, Recording Secretary. Other members of the Board are Howard Shapiro, Robert Lovelace, George Crohn, Jr., Ann Beyer, Larry Williams, and Lawrence Wechsler. At the meeting Diane Freaney reported that the CMTA is in sound financial condition. (Anyone wishing a financial report may receive one by writing the CMTA. We are an IRS tax-exempt charity.) Since the mission of the CMTA is not to make money, but to assist the CMT patient/family and the medical community with a multi-faceted program, the Board voted to establish a CMT Research Fund. The Board further voted to make the first donation to that fund.

CMT FACTS

AVAILABLE NOW!

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

The CMTA conference program produced seven regional CMT patient/family conferences in 1991. Beginning in March, Dr. Greg Stilwell organized and hosted a meeting in Colorado Springs. This meeting was so successful that he repeated it in September. In April, working with Dr. King Engel, the CMTA hosted CMT patients/families in Los Angeles. San Francisco was the location of a May meeting hosted by Dr. Robert Miller. In September, we worked with Dr. Danny Lisak in Detroit, and in October cooperating with Drs. Roger Rosenberg and Susan Iannoccone we met in Dallas. Baltimore will be the location for our final 1991 meeting and there we are working with Dr. John Griffin. We are deeply indebted to all of these dedicated physicians and their institutions. Without them this conference program would not be possible. Because of them hundreds of CMT patients/families and medical personnel have received accurate and timely information about the disorder, research, and therapies. Additionally, the support received from others in like circumstances and the medical personnel is invaluable. These conferences are not grim dreary gatherings, but rather occasions of learning and sharing.

CMTA Conferences

an opportunity to socialize...

This would be an appropriate time to report on the CMTA's Medical Advisory Board (MAB). The MAB consists of 44 scientists from the United States and several foreign countries. These men and women are a mix of clinicians and research scientists and share a common interest in CMT. They are a wonderful resource for the CMTA, and without them we would be unable to provide you with learned accurate information. We laud and thank them for their time and knowledge so freely given. The MAB met in April in Boston and again in October in Seattle. The proceedings of these meetings have been reported upon elsewhere. Dr. Robert Lovelace is chairman of the MAB, and Dr. Roger Lebo is the research liaison.

1991 In Review

CMT Poster Child - Adam Cavanaugh

(continued from page 6)

In June, the CMTA was pleased to announce the winner of the first CMT Poster Child contest. Adam Cavanaugh, an 8 1/2 year old from Michigan was chosen to represent the organization this year. To date, Adam has represented the CMTA at the Great Lakes Area Regional Conference, a Detroit Lions Football game and a Detroit Tigers baseball game where he had his picture taken with Sparky Anderson.

As part of our outreach program the CMTA exhibited at the meetings of the American Academy of Neurology in Boston in April. Boston support group members assisted us at the meetings. In October at the American Neurological Association's annual meeting in Seattle the CMTA again was an exhibitor.

Late in 1990 the work load dictated and our finances allowed the half-time employment of Pat Dreibelbis. Pat's duties are many and varied, and if you call on Monday, Wednesday, or Friday, Pat will tend to your needs. Pat is our only paid employee. The rest of the program is done by volunteers. However, as we grow, we will need to increase our staff.

In October we moved to a larger office within this complex. We would like to thank our neighbors, the staff and the administration of Crozer Mills for their assistance and support. We continually "pick the brains" of the various businesses who are in this facility.

A major part of our program is providing information to the CMT community. As we become known to more and more CMT patients and families, there is a corresponding rise in the number of phone calls answered and information packets distributed. This is wonderful and the reason for the existence of the CMTA. We are here to serve, but are truly frustrated by not serving more. Help us to spread the word and reach the CMT patients in your community. You can do this in a variety of ways through press releases (write us for a standard press release), speaking appearances at school, church, etc; or just telling your neighbor about CMT.

We thank all who have helped us this year, and you are many. Our support group leaders have earned our admiration for their efforts. We have a crew of mailers who assist us in getting out large mailings; they do this task willingly as well as competently. We frequently call upon one of our computer experts to answer our computer problems. Pat and I are definitely computer illiterates, but thanks to George Debolt, Harrison Stone, Gerry Hitt and Dean Dreibelbis we accomplish our tasks.

1991 has been busy and fruitful. The CMTA has grown and extended its program. We have met and worked with people who have taught us and enriched us. Much remains to be done and with your help we will accomplish our mission. The mystery of CMT ultimately will be unraveled and therapies and even cures will be found.

On a personal level, I feel that you, our membership whether CMT patient, family or professional, are an amazing group of people with whom I am honored and delighted to associate.

– Karol B. Hitt, President

CMTA Australia Comes to America

Mary Jane King & David Fennell

In June David Fennell of Sydney, Australia, president of the Charcot-Marie-Tooth Association of Australia visited the United States for several weeks. While on the East coast David visited at the home of Gordon and Marjorie Bradwick in Urbana, VA. During his stay he attended and addressed the Tidewater, VA support group meeting. The Tidewater group is led by Mary Jane King and Thelma Terry. The attendees learned of the Australian group's corresponding and differing problems.

During his visit David conferred with CMTA president Karol Hitt. David has been in contact with the CMTA since he founded an Australian CMT support group several years ago. Last year that group incorporated and are now the CMTA of Australia. They are a recognized tax-exempt Australian charity and are carrying out a full program for the CMT patient/family and professional community. David and CMTA Australia are to be commended for their work.

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LETTERS

We want to hear from YOU!

Write us at:

Letters / The CMTA
601 Upland Avenue
Upland, PA 19015

Referrals Available From The CMTA

The CMTA has compiled a list of neurologists, orthopedists, physiatrists (a physiatrist is a physician trained in physical medicine and rehabilitation) and podiatrists who have a special interest in CMT. We can also access respiratory specialists. Additionally, we have listings of pedorthists. A pedorthist is a practioner 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, 601 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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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, 601 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.

Why the CMT Patient Might Be Taking a Neurotoxic Drug

In our educational program for the CMT patient community, the CMTA continually publishes a list of drugs which can be neurotoxic. These drugs possibly can cause a worsening of CMT in an afflicted person. CMT patients should consult with his/her physician before taking any of these drugs. The list was compiled by neurologists and is continually monitored by them for additions and corrections.

To further clarify the use of these drugs we have listed each drug and the condition(s) for which it is prescribed. The information source was the 1991 edition of <u>Drug Information for the Health Care Professional</u>. We are indebted to Dr. Robert Miller for his editing of this article. Dr. Miller, a neurologist and member of our Medical Advisory Board, is at Children's Hospital of San Francisco. Names in parenthesis are brand names, other names are generic.

alcohol - no medical usage

adriamycin-(Doxorubicin)leukemia/cancers;

amiodarone - heart arrhythmias

chloramphenicol - eye infections, antibiotic

cis-platinum (Cis-platin) cancers

dapsone - antibacterial, antiprotozoan, antifungal, antileprosy and dermatitis herpetiformis suppressant

diphenylhydantoin (Dilantin) - anticonvulsant, epilepsy, heart arrhythmias, trigeminal neuralgia

disulfiram (Antabuse) - used to help maintain sobriety in the treatment of chronic alcoholism

glutethimide (Doriden) - sedative, hypnotic

gold - rheumatoid arthritis

hydralazine (Apresoline) high blood pressure

isoniazid (INH) -antibacterial, tuberculosis

mega dose of vitamin A [Editor's Note: a megadose is defined as 10 times or more of the recommended daily allowance (RDA)]- no usage

mega dose of vitamin D - no usage

metronidazole (Flagyl) - very specific bacterial and protozoan infections, amebic infections, bone infections, endocarditis, genitourinary infections, pneumonia, skin infections, vaginal infections, giardiasis, antibiotic associated colitis, inflammatory bowel disease

nitrofurantoin (Furadantin, Macrodantin) - urinary tract infections

nitrous oxide (chronic repeated inhalation) anesthetic

penicillin (large IV doses only) -antibacterial

pyridoxine (vitamin B 6) - very rare vitamin deficiency and as an adjunct to hydralazine or isoniazid. Pyridoxine (vitamin B 6) in doses above 200 mg/day may cause worsening of CMT or other neuropathies. Lower doses of pyridoxine are probably safe, there is no evidence that they are beneficial to CMT patients.

vincristine - cancers/leukemia

Suddenly, we find that our address has changed!

The Post Office has changed our address...
from 600 Upland Avenue to 601 Upland Avenue.
However, we are still doing business in the same building...

Capital Area Patient/Family Conference: November 9, 1991

The third fall regional conference sponsored by the CMTA will be held at The Johns Hopkins Medical Institution, Baltimore, MD, on November 9, 1991 from 9:30am to 4:00pm.The conference will follow the usual format with two presentations in the morning and two presentations following lunch. The conference is being arranged by Dr. John Griffin, Assistant Director of the Department of Neurology at Johns Hopkins. Dr. Griffin will speak first at 10:15am on "The Clinical Features of CMT." The second speaker will be Dr. Orest Hurko, Assistant Professor of Neurology speaking on "The Genetics of CMT."

After the first two presentations and their question and answer periods, the group will have lunch together. Following lunch, Dr. Thomas Crawford, Assistant Professor of Pediatric Neurology, will discuss, "CMT in Children." The finally presentation will be "Surgical and Rehabilitational Approaches to CMT" by Dr. David Thompson, Assistant Professor of Orthopedics.

The cost of the conference, which includes lunch, will be $20.00 for the first person in the family who attends, and $15.00 for each additional member.

Applications will be due in the CMTA office by November 4th. Confirmation of your reservation will be returned to you by mail along with a detailed map of the Baltimore streets.

Baltimore/Johns Hopkins CMT Conference Registration

name(s) of attendees ____________________

address state zip ____________________

telephone number ____________________

Fee for one person	$20.00
Fee for each additional family member	$15.00

Fees include morning coffee, lunch, afternoon refreshments and all postage and mailings.

Number of persons attending ______

Amount enclosed $_____

Return by Monday November 4,1991 to :

Pat Dreibelbis
CMTA
601 Upland Ave
Upland, PA 19015

You will receive confirmation and a street map by return mail.

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, 601 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:

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

Gift given by:

Name: ____________________

Amount Enclosed $________

Address: ____________________

____

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

Memorials

In Memory Of	**By**
Elizabeth Mattingly	Records Office University of Maryland
Elizabeth Mattingly	Admin. Computer Center University of Maryland
Dr. Joseph Bittenbender	Mrs. Harold Lewis
Sophia L. Bradwick	R. Gordon Bradwick
Sophia L. Bradwick	Karol Hitt
Harry Rohlfing	Rebecca Brezel
Clarence Kluener	Edna Kluener
Panzy Reither Pflughaupt	Joy Brindle
John Joseph Dolinsky	Irene Dolinsky
Edward Bachman	Neale Bachman
Sheelaugh VondenDriesch	Albert Von den Driesch
Mollye Schwartz	Michael L. Schwartz
Irv Finkelman	Sheila Koemin
Lillian Truesdale	Myrtle Brimhall
Roslyn Lustig	M/M Sam Goldblatt
G.T. Broin	Margaret Ode
Andrew Galomb	Karen Gabel
Steven Sware	Gerald Weder
Miriam Wolfe	Mrs. Harold Lewis
Richard Galland	Willam Galland
Alfreda Gomez	Kay Flynn
Ann Rehm	Kay Flynn
Vetal Thibodeau	Emily Nuzzo

Letters... to the editor

Dear CMTA Members,

I am a CMT patient who was able to exercise by running until I had a very bad fall. I have noticed the rapid and extensive acceleration of my disorder since my accident and am very interested in corresponding with other CMT patients who have suffered some trauma which seems to have worsened their CMT.

If you would be interested in comparing notes with me, please write me:

James McFellan c/o CMTA
601 Upland Ave.
Upland, PA 19015

Dear CMTA Report Editor,

I received a copy of the CMTA Report, Summer 1991, from a cousin in Colorado. An item of particular interest to me was the fact that Dr. Jeffrey Vance of Duke University was one of the speakers at your Medical Advisory Board Meeting in Boston.

Since 1987 my family has participated in the research program that Dr. Vance has been conducting in cooperation with the University of Sydney,New South Wales, and the University of Utah, Salt Lake City. Through those efforts, the linkage of CMT Type 1a to chromosome 17 has been discovered. We have a very large family. Dr. Vance, Dr.Charles Stewart and physician's assistant Jeffrey Stajich have made three trips to Elkins, WV to interview, take blood samples and conduct EMG tests on numerous family members. It elates me to realize that we made a contribution to this major breakthrough.

J.P. Elkins,WV

Dear Editor,

I recently learned of a clever somewhat-new device called PROSTRETCH which, with gentle exercise motion, helps to maintain the calf muscles and foot movement.

The idea, I'm told, came from an auto "brake shoe" device. I ordered one and the movement actually makes the leg feel good. Numerous times I've read in your literature that exercise helps those with CMT to feel better. After consultation with his/her physician, those with CMT may wish to try the device. It does seem to help me!

Information about PROSTRETCH can be obtained by calling 908-229-3539 or writing to them at 125 Broadway, Long Branch,NJ 07740.

M.M. Staten Island, NY

Dear CMTA,

Although I am not diagnosed as having CMT, I have similar symptoms as some of the people you highlight in your newsletter. I wish to continue to receive your newsletter because it is informative and helps me keep up my confidence and encourages me to overcome obstacles.

D.D

Dear Friends,

I enjoy every little bit and piece I read about CMT. My mother had it and I've got it. It has progressed way past the knees. My hips have the burning sensation when touched. The skin specialist told me to pat it dry and when I pat all of my legs dry, it does seem to help.

Since most of us older folks in advanced stages of the disease can't go to support groups, I wonder if there is any way we could get in touch with each other by mail. I know it helps to know someone else who have CMT. My mother worried about the unknown. Her doctors thought she had had little strokes. She wasn't satisfied with that because lots of her friends had had strokes and there wasn't anyone exactly like her to compare notes with.

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

I haven't found anyone else with CMT. I would like to correspond with someone who has it and compare or exchange tips - like cutting the toes out of slippers to reach the stubborn toes that roll back under.

Keep up the good work and renew my membership.

CMT friends can write to me:

Joy Brindle
c/o CMTA
601 Upland Ave.
Upland, PA 19015

Dear CMTA,

I wanted to thank you for putting together a wonderful conference in Los Angeles in April.

As a result of going to that conference, I met some of the very top researchers for CMT. The information I received was far beyond what I had heard thus far.

I was most impressed with the work done by Dr. Roger Lebo, University of California, San Francisco, with his continuing search for the CMT genes.

Dr. Lebo and I got together for about 4 hours last week after our local group meeting and discussed what we could do to further the research process for CMT.

We thought it would be great if we could identify some well known people who have CMT, living or not. I was excited to tell him my great-great uncle was President McKinley. Unfortunately, that was on my non-affected side of the family tree two generations up. If you know of anyone famous, please let CMTA know!

On another note, I wanted to mention that any research donations made to MDA can be designated for CMT research specifically. Of course, the CMTA has a research account now too. The speed of research is directly proportional to the amount of research money.

Keep up the good work!

Gary Oelze
San Diego Support Group Leader

Dallas, Texas
October 12, 1991

CMT Patient/ Family Conference

(Editor's Note: This conference announcement might arrive after the date of the meeting. We regret this, but due to the timing of the conference and the newsletter publication dates it was unavoidable. However, we sent a first class announcement to everyone on our mailing list in Texas and contiguous states. Also, press releases of the meeting were sent to the media.)

The Charcot-Marie-Tooth Association (CMTA) and The Texas Scottish Rite Hospital for Children in conjunction with the Neurology Department of the University of Texas Southwestern Medical Center at Dallas (UTSWMC), are sponsoring an all day conference for CMT patients, families and medical professionals. The meeting will be in the Auditorium of the Texas Scottish Rite Hospital for Children, 2222 Welborn Street Dallas, TX.

Registration will begin at 9:15 A.M., and the program will start at 10 o'clock. The first speaker (and conference program director) will be Dr. Susan Iannaccone, Director of the Neuromuscular and Neurorehabilitation Clinics at Scottish Rite. Her topic will be, "What is CMT?" Dr. Roger Rosenberg, Professor of Neurology at the University of Texas Southwestern Medical Center, will follow with "The Genetics of CMT". A discussion of "EMG/Nerve Conduction" by Dr. Ralph G. Greenlee, Associate professor of Neurology and Neurosurgery at UTSWMC will conclude the morning session.

Following lunch, Deanna Carman, P.T., Physical Therapy Research Coordinator at Scottish Rite, will discuss, "Exercise and the CMT Patient". Dr. John Birch, Medical Director of Ambulatory Care at Scottish Rite, will speak about "The Role of Orthopedic Reconstructive Surgery in CMT"

The program will conclude with a presentation from Janice Nance, R.D., L.D., a pediatric clinical dietitian at Scottish Rite. Her topic will be, "Nutrition and the CMT Patient". The speakers will allow time in his/her presentation for questions from the audience.

The fee for the conference is $21.00 and includes lunch. For Category 1, Continuing Medical Education credit contact: Freddie Heitman, Division of Continuing Medical Education, University of Texas Southwestern Medical Center, 5323 Harry Hines Blvd, Dallas, Texas 75235-9035 or call 214-688-2166. Registration must reach the CMTA by October 5, 1991 (See form on page 10). Patient/family registrations will be accepted by telephone. Call the CMTA at 215/499-7486.

¤

I want to be in touch!

Name: ______________________________
Address: ______________________________
____
Phone Number: ______________________________

Tell us about yourself:

☐ CMT Patient
☐ Interested Supporter
☐ Other
☐ Medical Professional
☐ CMT Family Member

Please check the appropriate boxes:

☐ Put me on the mailing list!
☐ CMT Neurology - $10
☐ Physical Therapy - $10
☐ CMT Genetics - $10
☐ Orthopedic Surgery - $10
☐ Physical Therapy/Orthopedic Surgery - $15 (on one tape)
☐ Neurology/Genetics - $15 (on one tape)
☐ 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.

Dallas Area Registration Form

name(s) of attendees ______________________________
address ______________________________ state ________ zip ________
telephone ______________________________

Fee for one person: $21.00

Fees include lunch.

Number of people attending: _______
Amount enclosed: $______

Return by October 5, 1991 to:

Patricia Dreibelbis
CMTA
601 Upland Ave.
Upland, PA 19015

You will receive confirmation of your reservation by mail.

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:

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

Write the CMTA (address below)

CMT...

..... is the most common inherited neurological disease, affecting approximately 125,000 Americans.

..... is slowly progressive, causing deterioration of peripheral nerves which control sensory information and muscle function of foot/lower leg and hand/forearm muscles.

..... causes degeneration of muscles of foot, lower leg, hand and forearm.

..... causes foot drop walking gait, foot bone abnormalities (high arches and hammer toes), problems with hand function, balance problems, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, occasional partial sight and/or hearing loss problems and in some patients may cause scoliosis (curvature of the spine).

..... may produce chronic pain and fatigue.

..... does not affect normal life expectancy.

..... has no effective treatment, although physical therapy and moderate physical activity are beneficial.

..... is sometimes treated surgically.

..... is usually inherited in an autosomal dominant pattern, which means if one parent has CMT there is a 50% chance of passing it on to each child.

..... is present in the world-wide population, with no apparent link to any one ethnic group.

..... may become worse if certain neurotoxic drugs are taken.

..... can vary greatly in its severity, even within the same family.

..... is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

THE CMTA REPORT

information on Charcot-Marie-Tooth disease from the
Charcot-Marie-Tooth Association
601 Upland Avenue
Upland, PA 19015

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TO: