

THE CMTA REPORT

Spring 1992

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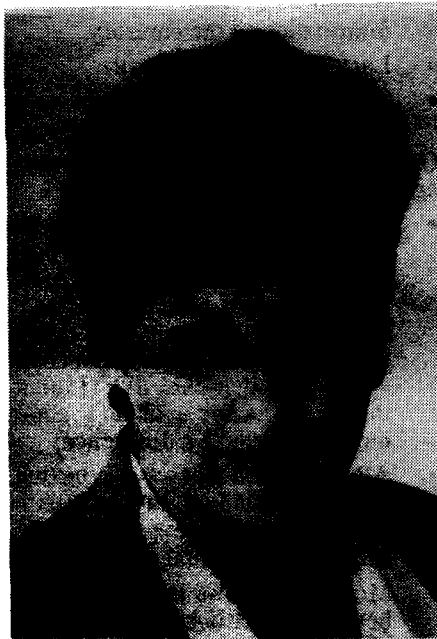
Providing information on Charcot-Marie-Tooth disease (a.k.a. Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neurological disorder. Contents © 1992, CMTA. All rights reserved.

Parenting the CMT Child

As a family therapist over the last twenty years, I have seen that people are basically more alike than different in spite of effects of income, gender, ethnic origin and even disability. We all need essentially the same basic things from life in order to survive and thrive, and we should never forget that this is as true for children as it is for the adults on whom they depend.

The childhood experience requires that we learn and understand certain essential behaviors and skills. This is usually a sequential, incremental and evolving process. Different ages and stages yield certain triumphs and rewards as well as lessons.

I believe any child growing up in today's world has more stress than at any time prior. The fabric of daily life in our country today is constantly more complex, layered and generally threatening



Richy Snowden

to children. Therefore, parenting is an exponentially greater and more difficult task than ever before. It has to be said then, that the added obstacles and problems of development and daily living with Charcot-Marie-Tooth in a young person is very hard indeed for a parent to watch, let alone communicate to and describe for others. It is hard to figure out what to do or when it should be done; it is hard to know whom to trust or turn to. By their own report, parents of CMT children feel that life is a constant "catch 22" of overwhelming proportions.

One goal of this article is to identify some of the major difficulties in CMT parenting. This is important because nothing can be helped or changed until

we are aware of and declare the problem. Another goal is to give some specific ideas about help and creative change. The third goal is to provide family members and professionals with more insight into the disorder in order to create better understanding, more positive intent and to improve the services on which we are forced to depend.

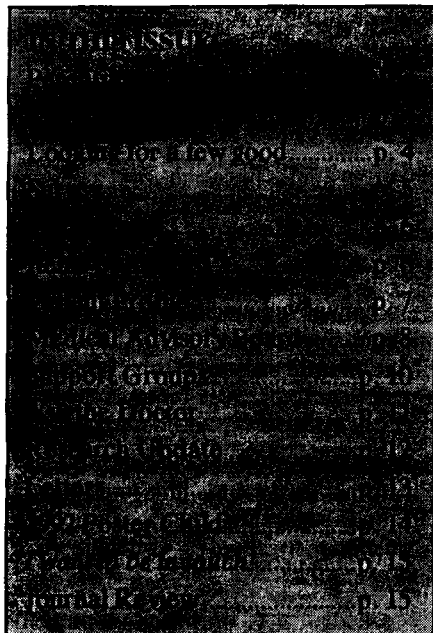
Most important of all is the goal of beginning a process that assists parents and children to connect and communicate. Thereby, we can reduce their feelings that they are isolated or forgotten, especially by those who share the same battles. The help we provide from within is critical to how we eventually derive the best help from others.

Everyone enjoys seeing young children learn and discover through movement and exploration with the senses. They try to touch, grasp, climb, taste, hear, see and smell in order to understand the world.

The child with CMT may be able to do most of these things and attain a level of accomplishment in walking, running, reaching and holding only to be faced with losing these competencies; and we know that too often some of these skills are never experienced at all. Parents I have interviewed unanimously spoke of the constant sense of loss, alienation and frustration. The very nature of CMT means living with an enemy that has no consistently predictable face. This is an enemy that creates anxiety and fear because of ambiguity and daily threat.

(continued on pg. 2)

**Upcoming Conference
Fall 1992
Chicago, IL**



CMT Children (cont'd from front page)

Along with the isolated coping with a little-understood or heard-of disorder, no one in the CMT home gets the luxury of grieving properly. There is always new therapy, preparing for surgery, changing and adjusting to braces or wheelchairs, as well as caring for other children. Paul Cavanaugh of Madison Heights, Michigan puts it this way: "There is just not time to help ourselves or our son grieve sufficiently for the things he must constantly give up."

The non-CMT brother/sister has a unique experience as well. Parenting him/her and giving each enough time is a rigorous challenge. The siblings themselves often lose patience and have difficulty understanding when his/her CMT sibling can't do the same thing today that they could last month.

I heard the same things told in different ways but always with determination tinged by a sense of urgency, indignation and bewilderment. Parents, who themselves have CMT or those whose children are older, are anxious to help those with very young children because they understand that sense of urgency to know.

These parents describe on the "downside":

- A crushing sense of alienation and isolation, as well as indifference to their plight from agencies, the medical profession, insurance agencies and even the extended family.
- Appalling lack of informed medical and educational service personnel.



Do you know of 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.

- Discrepancy in second and third opinions regarding surgery, therapy and school placement.
- Non-existent or sporadic special education programming and transportation options.
- Frustration with professionals' inability to accept, if not comprehend, the implications of the degenerative aspects of CMT; for instance a teacher's unwillingness to accommodate her own expectations to the fact that a child's writing isn't "pretty". Rosemary O'Brien of North Wales, Pennsylvania tells a story of a well-meaning teacher who was convinced that someday her child could jump rope and insisted he try in spite of information to the contrary.
- Lack of monetary support.
- Distance from competent and qualified services.

On the "up-side" the theme was encouraging and inspiring:

- Parents expressed an ever-present awe at the courage and healthy attitudes they saw in their child. Mothers who also have CMT spoke proudly about how much better their children seem to cope at their age than they did. (I think this is an example of how good models can make a difference).
- All are excited that we are starting a dialogue, finding ways to start a CMT parent's network, and the sharing of individual experiences.
- More good news is that there is better information about nutrition, physical conditioning and fitness training. This can relate to family wellness in general and specifically to those with neuromuscular impairment.

One mother says her intuition to take a common sense and total body approach is what aided her daughter's optimal recovery from several weeks in post-operative leg casts. Years later, this teenager is on a competitive rowing team and still works out daily.

There are many stories of empathic care providers, found in the right place at the right time. This encourages us to keep looking until we find those that fit this description. The real lesson here is to decide that you have the right to expect and find doctors that deserve the adjectives "caring and concerned". Moreover, most are happy to learn from you as well. Make sure other parents learn of them. When you find such

a professional recommend him/her to the CMTA for inclusion in its doctor referral list.

More advice about what works...

Be honest, clear and realistic with yourself, your spouse and your children.

Helping each other constantly adapt and cope requires a straight-forward approach. Linda Muhlrig of Millville, N.J. said, "Kids should be told of the nature of the disease." Try to answer all questions using the words that are understandable according to age level.

When you see any sign that worries you or isn't clear, check it out. Talk with your child. Discuss concerns with doctors, therapists, counselors and teachers regularly. Even if they have no answers, you are raising his/her consciousness about CMT. Maggie Malone of Travis Air Force Base, comments that she is constantly asking questions in hopes that the professionals will keep trying to help her answer them.

If parents know child development principals thoroughly they can avoid being too protective or unrealistic in expectations. It is important to acknowledge that all children have to experience disappointment and frustration. Maintaining perspective is important. All teenagers have trouble accepting loss and disappointment. In this respect CMT teen-agers are more like their peers than they are different.

Child development knowledge and behavior management skills are also beneficial to balancing attitudes in other children in the family.

Find creative ways to build and maintain self-esteem in all members of the family.

Power struggles between child and parent or between brothers and sisters may seem unusually intense in the family of a disabled person. Children at certain ages are manipulative anyway, but these "power games" are magnified by the many powerless feelings implicit in CMT. Family members are bound to transfer some of these feelings through anger or passivity.

Inevitably extra expenses and job complications, as well as, family demands burden the marriage relationship. Seek counseling to resolve conflicts in a timely manner.

(Continued on page 3)

Improve personal and parent power through a good parenting course, assertiveness training and advocacy groups. A parenting course teaches communication and organization strategies, conflict resolution, and basic child psychology principles. Popular programs available are S.T.E.P. (Systematic Training or Effective Par-

...encourage everyone to share emotions.

enting); P.E.T. (Parent Effectiveness Training); and Active Parenting. S.T.E.P. and Active Parenting are available on audio-cassette and video cassette. Local school systems and many churches use these materials. Check your local library for these and other suggestions.

Assertiveness training is available through many community education programs at local high schools and colleges. Toastmasters of America offers a good way to help build confidence and overcome shyness through practice in public speaking as a member of a small, familiar group. These classes and meetings can be structured as short-term experiences since time is always of the essence.

Learn good stress and time management techniques.

It is very difficult, if not impossible, for parents to keep their objectivity. Let a child be her/himself but look for balance and keep things in context. A family therapist or pastoral counselor may be excellent help in validating you and comforting you and the child during stressful episodes. Good stress and time management tapes and books are also available at the library.

Forgive yourself regularly. Wanting everything to be as easy as possible for those you love in itself makes you irritable and impatient. The same is true for your child. Let your child express his/her feelings with the guidance that anger, fear, etc. are ok to feel and express. However, it's how one expresses them that often creates problems. Insist that no one takes out frustration on someone else. Do encourage everyone to share emotions. They can pound pillows when angry. They can cry together when a favorite physical therapist takes another job. They can yell together when new braces hurt or break; or pray together out of fear when results of

surgery are so unpredictable. Always validate frustration, as in situations where one doctor wants to operate and others disagree. Say "I understand" when a teenager yells he hates the band leader for dropping him out of the marching band with no apology.

Use tapes and books often. Some of the best I have found for help in handling feelings are:

Between Parent and Child
by Haim Ginott

Between Parent and Teen-Ager
by Haim Ginott

The Family by John Bradshaw

The Road Less Traveled by Scott Peck

Traits of a Healthy Family
by Delores Curran

Stress and the Healthy Family
by Delores Curran

TA for Teens by Alwyn Freed

Self Esteem: A Family Affair
by Jean Illsley Clark

Born to Win by Muriel James

Find and Create Support Systems

In addition to parent education groups and community education experiences, church and school organizations may offer special help. In fact, organizing a parenting group through any of these would be especially helpful to other parents of the disabled regardless of diagnosis.

Look into support groups that may already exist. Call the CMTA office. If an existing group is not close enough, the CMTA office has instructions on "How to Start A Support Group". You may wish to start one for parents and/or children. Don't hesitate to recruit a volunteer to do this for you since time and energy must always be conserved. Call or write other CMTA parents frequently. A list of parents who contributed appears at the end of this article. You are invited to contact them.

Know your rights and your child's rights.

Study or attend seminars that explain existing laws. Contact advocacy groups. Insist on proper services such as Individual Education Programming (IEP) and adequate transportation. Educate the public at every opportunity.

Ivy Collier of Baltimore, MD is a coordinator for the County Board of Education Parent Information Center. She recommends the book, "Negotiating the Special Education Maze," by Anderson, Chitwood, and Hayden. It is published by Woodbine House. Ivy insists, "Know this book backwards and forwards and stand up for what you child needs." Ivy also teaches a six hour seminar for parents of the developmentally disabled and will be happy to share her materials with other parents. Ivy urges parents to know the special education personnel at the state, county and local levels. She encourages a team approach for mainstreaming. For example, before each new school year, Ivy and her daughter meet with the new teacher. When school starts they present a program about CMT to the class and discuss Sarah's wheelchair, physical characteristics and limitations. They explain that CMT is not "catching". If leading this type of discussion doesn't feel comfortable, provide the teacher with the proper information and ask her assistance. Subscribe to Exceptional Parent Magazine. Ask your local library to subscribe also.

Contact the CMTA office whenever you have a question (215/499-7486). The following are representative of a variety of national information networks which are available for additional assistance and advocacy suggestions of many kinds:

National Health Information Center
1-800-336-4797

National Association for Youth and Children with Disabilities
1-800-999-5599

Estate Planning for Parents of the Disabled 1-800-448-1071

IBM Special Needs Information Center
1-800-426-2133

Another option is ChildFind/Child-Serve through you State Department of Education Division for Exceptional Children. When you contact them, also ask about Parent Information and Training Centers or Learning Resource Centers. These may be county or regional in scope.

States usually have advocacy offices in the capitol city. Call the state government information line or directory assistance.

This is only a beginning for meeting the challenge of giving the best support to our CMT children.

(continued on page 4)

CMT Children (continued from page 3)

Please let us hear from all of you interested in networking a parenting question and answer column, a pen-pal list and any other ideas that will help us strengthen our efforts.

Many thanks to the following parents who provided information and inspiration for this article.

Paul & Julie Cavanaugh
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Maggie Malone
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Travis Air Force Base, CA 94535
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About The Author Richeleen Snowden, M.S.

"Richy" Snowden has a diverse professional background which includes experience as a entrepreneur, family therapist, corporate consultant and human service program developer.

Over the last two decades she has served on several national, state and local health and human service program development task forces. She has been in private practice for twenty years. She worked toward a Ph.D. in Organizational Development at Emory University where she was also a visiting lecturer. Richy was named a 1989 Outstanding Woman of DeKalb County (Georgia) and has also appeared in "Outstanding Educators of America" and "Who's Who in the South and Southeast."

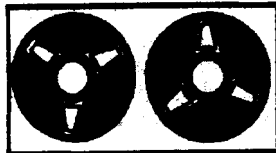
VCR Tape Program Changes

For the past several years the CMTA has rented VCR tapes of lectures about various aspects of CMT. These tapes were made at CMT patient/family conferences and cover CMT neurology, genetics, physical therapy, and orthopedic surgery.

The tape program has been a great success, and we now are offering the tapes for sale instead of rental. The cost of each tape is \$15.00 and this includes postage and handling. The available tapes are: Dr. John Griffin, Johns Hopkins Medical Center, discussing "CMT Neurology"; Dr. Orest Hurko, Johns Hopkins Medical Center and Dr. Fred Gilbert, Cornell Medical Center, discussing "CMT Genetics"; Dr. David Thompson, Johns Hopkins Medical Center and Dr. Robert Clark, Columbus Children's Hospital discussing "Orthopedic Surgery and CMT"; and Dr. Carol Oatis, the Philadelphia Institute of Physical Therapy, and Kelly Koch, OTR, Columbia University Medical Center, discussing "Physical Therapy for the CMT Patient" and "Occupational Therapy for the CMT Patient" respectively.

These tapes were made at CMT conferences, and this did present some technical problems that are reflected in the tapes. There are minor blips in the tapes for example; slides the speaker was showing are occasionally not quite clear and sometimes a question asked by a patient in the audience is difficult to hear. However, the information contained on the tapes is excellent. The speakers are all highly qualified and experts in CMT.

The CMTA changed from a rental to a sale program because of the popularity of the tapes, and the problems associated with rental. There were the inevitable lost in the mail tapes and tapes that were never returned. The ownership program allows a family member to share the tape(s) with family members, teachers and medical professionals. To order a tape see the order blank on page 15.



Attention: → CMT PATIENTS

Charcot-Marie-Tooth Disorder (CMT) is a unique neuromuscular disorder and, unlike ALS and Duchennes muscular dystrophy, it is not life threatening. However, the disorder does present a variety of physical and emotional adjustments. Dr. Rhonda Jones, a member of the adjunct faculty of the University of Rochester Medical Center and a clinical psychologist, is interested in chronic illness and life adjustments. Therefore, she has prepared this questionnaire (on the facing page), and we once again ask you, the CMT patient, to assist a researcher. Dr. Jones will publish her findings in the Fall or Winter issue of the CMTA Report.

We Are Looking For A Few Good Men And Women

The military's slogan is very applicable to the CMTA. The Board of Directors of the CMTA needs additional members. Currently, the Board consists of twelve men and women, and we have a few vacancies we would like to fill with interested, capable people.

If you have experience with public relations, fund raising, corporate relations, administration, writing, or any other applicable talent/experience and are interested in serving on the Board of Directors, please contact the CMTA.

The Board meets 2-3 times per year, usually in Central New Jersey. We have tried to secure a location that is convenient for the majority of members. However, as this organization grows it is obvious that other geographic areas of the country need to be represented.

For consideration for Board membership please submit a letter citing your background, including work experience, and your interest in CMT. Most of our current Board members are either CMT patients or family members, however, this certainly is not a requirement for membership. Please send your letter to Karol Hitt, CMTA, 601 Upland Avenue, Upland, PA 19015.

Circle or mark your responses. Please attach a separate sheet if you need more space to answer any of the questions.

Age _____ Sex _____ Age at Diagnosis _____

1. What was the first physical sign of CMT you noticed?

foot & ankle weakness clumsiness lack of endurance hand weakness

2. Who first noticed you had one of the above problems?

I did Someone else

3. If someone else was it:

a CMT blood relative Other relative Doctor or nurse Athletic instructor Dance teacher
Shoe salesperson Other (please explain)

4. If you were the first to notice you CMT symptoms, did you have knowledge about CMT at that time? Yes No

5. If yes, how did you learn about CMT? A blood relative had CMT Someone else I know had CMT

From the media (TV, magazines, etc.) From my readings in medicine, nursing, podiatry, etc.

Other (please explain)

6. If your diagnosis was prior to age 21, did you try to excel in any of the following ways to compensate for any self-consciousness you may have had about your CMT symptoms? (Answer all that apply.)

Academics friendships music art school clubs
other organization sports other talent job helpful at home

other (explain)

7. After receiving your diagnosis, how did you feel over the first few months? (Answer all that apply)

angry hopeless expected it sad accepting nervous/worried
depressed did not want to believe it other (explain)

8. If you were angry, with whom were you angry? (Check all that apply)

myself my CMT parent my non-CMT parent siblings with CMT
siblings without CMT doctors people in general who do not have CMT
gym teachers/coaches everything/everyone God or religious figure

other (explain)

9. If you were depressed, how did you feel? (Check all that apply)

poor thoughts about myself depressed mood sleep problems eating problems
lowered interest in activities I usually enjoy lowered interest in sex difficulty concentrating

10. Did you react to the diagnosis with any of the following behaviors? (Check all that apply)

Tantrums increased drinking of alcohol other drug abuse
withdrawal from others sexual acting out trouble with the law trouble at school

11. How severe are your present CMT symptoms? slight moderate severe

12. What are your present physical symptoms?

thin legs hammer toes thin hands foot drop bent fingers
high arch foot flops when I walk foot rolls over to the side

13. Have you had surgery on your feet? yes no

14. Have you had surgery on your hands? yes no

If you have not had surgery please skip to question 17. If you have had surgery, please continue with the next question.

15. Do you feel the surgery was helpful? yes no somewhat

16. If surgery was helpful, did it help your movements? Yes No

And did it help your feelings about yourself? yes no

17. Regarding your CMT, have people said or done things that have hurt your feelings or made you angry? Please give specific examples.

18. Regarding your CMT, have people said or done things which you found to be helpful and supportive? Please give specific examples.

Thank you for completing this survey. Please return this survey to: The Charcot-Marie-Tooth Association
601 Upland Ave.
Upland, PA 19015

Items of Interest



ITEM 1: Prudential Insurance Company is offering a companion policy to most new life insurance contracts. It is called "Charity Plus" and has been approved for sale in 43 states. As reported in *The NonProfit Times*, the new policy allows customers to purchase \$2500 to \$10,000 of low-priced coverage payable directly to a charitable organization. Premiums can be tax deductible if the designated charity is given policy ownership.

ITEM 2: From *NORD On-Line*: Some insurance policies contain a "terminal liability clause" which enables a person who becomes disabled while they were insured to retain their insurance for a period of time after the policy is canceled by their employer.

We saw a Blue Cross/Blue Shield contract that allowed a patient to retain her insurance for one year after her husband's employer changed insurance carriers. Another Aetna policy also covered a patient for up to twelve months while a Provident Life Policy could be extended for three months.

To qualify, a person must be "totally disabled" when the insurance policy ceases. According to these policies, this means a person is not working for pay or profit, or if a dependent child, the child cannot engage in normal activities of a healthy child of like age and sex.

If you have lost health insurance because your employer changed insurance carriers and the new insurer won't cover your pre-existing condition, read your old policy to see if it has a "terminal liability clause."

ITEM 3: The CMTA would like to produce high quality note cards to sell as a fund raiser for research. We would like to feature the artwork of one or more members of the association on the front of the cards, with the Association's name and address, along with the credit to the artist on the back.

These cards would be blank inside and would be suitable for members as well as the general public to buy. Hopefully, support groups would sell these cards as a way of building the research fund.

If you are a professional artist, or skilled amateur, we would like to see a

sample of your proposed card design by June 1. Please consider this request. You can help make a major contribution to furthering CMTA research and know that your artwork will be seen throughout the country. Children are welcome to submit designs as well. Send your sample to the office of the CMTA, 601 Upland Ave, Upland, PA 19015.

ITEM 4: In *Business Week* (October 7), an article on page 152 describes data bases once accessible only to medical professionals and skilled computer users that can now be used by consumers. Check out your public library and health-resource libraries, clinics, and hospitals to determine if they have installed THE HEALTH REFERENCE CENTER, a hardware system by Information Access of Foster City, CA. It provides consumers free use of a PC to locate and print out disease-specific articles. Other companies will search for a fee.

ITEM 5: One patient reports relief from pain by the use of a regular massage therapy program. The American Massage Therapy Association has a list of certified massage therapists which you can access by calling 1-804-272-1015. The Griffiths (who are CMTA members) have the certified therapists on their database and will help you find someone near your home.

ITEM 6: One member's 6 year old son was originally denied busing for the handicapped. She called us and requested information on how to pursue this issue. After talking to the office, she took on the school board, and armed with information from the CMTA, she won her case. Her son is now provided with special busing by his local school district.

ITEM 7: The CMTA is offering a letter addressed to all medical professionals that a patient would see for treatment. The letter addresses the issue of the neurotoxic drug list and is intended to be given to each doctor to place in the CMTA patient's file. The letter is available for each member of the organization at no cost; however, we do request that you send a self-addressed stamped business-sized envelope for the return

MEDICAL ALERT



**Certain Drugs
Toxic to the
Peripheral
Nervous System**

This is a list of neurotoxic drugs which could be harmful to the CMTA 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, Macrochantin)
Nitrous Oxide
(chronic repeated inhalation)
Penicillin
(Large IV doses only)
Pyridoxine (Vitamin B6)
Vincristine

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

mailing. The letter begins "I have been diagnosed with Charcot-Marie-Tooth Disorder..." and is to be signed by the patient, so please do not send doctors' addresses. The letter should be taken or sent by you, the patient, when you next visit your various medical professionals.

ITEM 8: Dr. Gerald Weber, a member of the CMTA Medical Advisory Board, has just been appointed editor-in-chief of a prospective medical journal entailing foot orthopedics and interdisciplinary medicine effecting the foot and leg. The journal is tentatively entitled, "The Functional Leg and Foot" and is expected to publish its first issue in two years. The journal will be investigative in nature and will often focus on CMT issues. Dr. Weber is a DPM practicing in New York City.

Patient Profile:

Don Hay, a Boston area member of the CMTA, has a life history that is all too familiar to many CMT patients and their families. His story is one of misdiagnosis, frustration at the many "systems" that one must deal with, and finally, some small, but important, victories.

Don was born in 1940 and was "leveled" in 1948 with a diagnosis of polio. He was flat on his back for 6 months, unable to do anything.

Upon recovering, he worked in the pool to build himself up and over the years he never knew that his mother had been told that he might have either CMT or Friedreich's Ataxia. He went through 12 or more operations over the years, unaware of what was really wrong with him.

In 1980, a visiting relative, who was also a nurse, saw his son, Richard's, walk and said that both of them should be seen by a doctor. After the nerve conduction tests, both of them were diagnosed with CMT.



In 1990, while working as a service engineer, Don fell on ice in a customer's parking lot and tore the ligaments in his left foot. The foot never completely healed, perhaps because the doctor that Don first saw recommended putting an ace bandage on it and returning to work. Eventually, because the foot never improved, an operation was recommended and Don began the battle of the "systems".

The first system he ran up against was the insurance company. The doctor wanted to be paid his "customary and usual fees" and the insurance company

Adversity Overcome



Don Hay

wanted to pay just \$350.00 of a \$450.00 operation. It was two months of calls back and forth before Don won and they approved the operation. Then it was another 5 months before the operation could actually be scheduled. He went into physical therapy following the recovery period and found that the machine they wanted to use to stimulate his muscles would not work for him because his nerves couldn't conduct the stimulation.

On July 2, 1990, Don was placed on total disability. Again he encountered the frustration of the system, as his insurance argued that they should not have to pay any disability claim because the fall did not cause his disability, but the pre-existent CMT did.

Currently, Don receives only Social Security and Workman's Compensation having lost the battle with his insurance company. He is covered by the COBRA plan from his former employer, but when that runs out, he faces a problem in getting reinsured. Blue Cross has told him that he will have a three year wait to be covered for his pre-existing condition.

While Don continues his own battles, he also fights and wins victories for his son.

Richard was 4 years old when he was diagnosed with CMT in 1980. He is now 15 and has had three major operations. He has Harrington rods in his back and has had a spinal fusion because his back was 67% out of alignment. After Richard's latest operation, which kept him

in the hospital for 15 days, Don went to the school district to argue for his son's placement in a special school for the handicapped.

He was told someone would be able to speak to him in about a month.

The school system continued to dodge Don until he threatened to call a lawyer because Richard was being denied an education. The district then offered to place the boy in the state school which Don describes as dark and bleak. Instead, again after months of arguing and hundreds of phone calls, Don won placement for his son in a private school in Lexington with classes of only 3 to 4 and with programs that anyone would envy. He is currently an excellent student and is doing very well in the alternative school.



One of the things Don does to keep busy is to design and install adaptive devices for Richard. Richard is pictured holding a cedar mailbox post that Don altered to be used as a handrail. The cost of the cedar post was \$18.00. An iron railing was estimated at \$400.00. In another picture, Richard, who also suffers from severe asthma, is using a hose which Don adapted. He installed a regular faucet that turns off and on to replace the squeeze sprayer which Richard could not press. The cost was around \$6.00.

Don Hay is typical of the kind of CMT patient that this organization is pleased to profile. He has many reasons to be frustrated and to consider giving up or giving in, but he chooses, instead, to take each frustration as a challenge and to continually fight for his and his son's rights.

Golf Tournament Raises \$1300 for Research

On November 8, 1991, the Virginia (Tidewater) CMTA Support Group ran a women's golf tournament in memory of Mrs. Winnie Sorenson, a dear friend of the support group leader Mary Jane King.

Winnie was an inspiration to all the golfers who knew her. She began playing golf at the age of 55 and played her last game at the age of 90 just before she became ill with cancer. She never lost her love for the game and her desire to get back on the golf course. In her last two years, she participated in putting tournaments held at the nursing home where she lived. Although Winnie did not have CMT, she was a perfect example of how one should find an exercise that is suitable and should keep as active as possible. Proper diet and the right amount of exercise keep the mind and body in the best possible condition.

The golf tournament was a success! The format was a two person select shot. Twenty-eight teams of lady golfers braved the cold weather and high winds at the Hampton Golf and Tennis Center in Hampton, VA to conclude the golfing season in Tidewater.

The people responsible for running the tournament were Mary Jane King, Thelma Terry, Shirley Redding and numerous local sponsors.

Everyone who participated is to be thanked for the check for \$1310.00 which was donated to the growing CMTA Research Fund.

CMTA Medical Advisory Board

Shukuro Araki, M.D., Kumamoto Medical School, Kumamoto, Japan
Barry Arnason, M.D., University of Chicago, Chicago, IL
Pierre Bouche, M.D., Neurologic Hospital of the Salpetriere, Paris, France
Thomas Bird, M.D. VA Medical Center, Seattle, WA
Walter Bradley, M.D., F.R.C.P. University of Miami, Miami, FL
Phillip Chance, M.D., University of Utah, Salt Lake City, UT
J.S. Chopra, D.C.H., F.R.C.P., Ph.D., F.A.M.S., Post Graduate Institute of
Medical Education and Research, Chandigarh, India
Michael Conneally, M.D., Indiana University, Indianapolis, IN
Peter Dyck, M.D., Mayo Medical School and Foundation, Rochester, MN
Francis Dyro, M.D., F.A.A.N., VA Medical Center, Boston, MA
King Engel, M.D., University of Southern California, Los Angeles CA
Kenneth Fischbeck, M.D., University of Pennsylvania Philadelphia, PA
Hans Goebel, Ph.D., University of Mainz, Mainz, West Germany
John Griffin, M.D., Johns Hopkins University, Baltimore, MD
Ludwig Gutmann, M.D., University of West Virginia, Morgantown, WV
Anita Harding, M.D., F.R.C.P., University of London, London, England
Linton Hopkins, M.D., Emory University, Atlanta, GA
John Hsu, M.D., University of Southern California, Downey, CA
Victor Ionasescu, M.D., University of Iowa, Iowa City, IA
Roger Lebo, Ph.D., University of California, San Francisco, CA
Robert Lovelace, M.D., F.R.C.P., Columbia University, New York, NY
James Lupski, M.D., Ph.D., Baylor University, Houston, TX
Harold Marks, M.D., F.A.A.N., F.A.A.P., A.I. duPont Institute, Wilmington, DE
Richard Mayer, M.D., University of Maryland, Baltimore, MD
James McLeod, M.D., University of Sydney, Sydney, Australia
Leftos Middletown, M.D., The Cyprus Institute of Neurology & Genetics,
Nicosia, Cyprus
Robert Miller, M.D., University of California, San Francisco, CA
Stanley Meyers, M.D., Columbia University, New York, NY
Carol Oatis, P.T., Ph.D., Philadelphia Institute of Physical Therapy,
Philadelphia, PA
Shin Oh, M.D., University of Alabama, Birmingham, AL
Gareth Parry, M.D., F.A.A.P., Louisiana State University, New Orleans, LA
Jack Petajan, M.D., Ph.D., University of Utah, Salt Lake City, UT
Irena Hausmanowa Petrusiewicz, M.D., Ph.D., Warsaw Medical Academy,
Warsaw, Poland
Roger Rosenberg, M.D., University of Texas, Dallas, TX
Marvin Rozeau, M.D., Duke University, Durham, NC
George Serratrice, M.D., University of Marseille, Marseille, France
Ding Guo Shen, M.D., Chinese PLA General Hospital, Beijing, China
Thomas Swift, M.D., University of Georgia, Augusta, GA
P.K. Thomas, M.D., D.Sc., Royal Free Hospital, London, England
Gerald Weber, D.P.M., New York College of Podiatric Medicine, New York, NY
Lowell Williams, M.D., Children's Hospital, Columbus, OH
Jan Korthals, M.D., Ph.D., University of South Florida, Tampa, FL
Kieran T. Mahan, D.P.M., F.A.C.F.S., Pennsylvania College Podiatric Medicine,
Philadelphia, Pa
Hitsoshi Yasuda, M.D., Shiga University of Medical Science, Shiga, Japan

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, 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.

New Support Group Forms!

A new support group called the Greater Tennessee Valley CMT Support Group is forming under the leadership of Bill Porter. The group will have its first meeting on May 9, 1992, in the ECM Hospital in Florence, AL. Interested persons should call Bill at home 205-767-4181 or at work 205-386-6579. A neurologist will speak at the first meeting and further information about this inaugural meeting will be mailed to CMTA members in Bill's area. Get out and support Bill's efforts.

CMTA Medical Advisory Board

The Medical Advisory Board (MAB) of the CMTA meets twice a year to discuss CMT research and clinical topics. The MAB is currently investigating the effect of trauma upon the course of CMT. Trauma is defined as surgery, accident and/or pregnancy. At the CMTA we have spoken with many CMT patients whose CMT appears to have gotten worse after such physical trauma. If you have not completed Dr. Roger Lebo's trauma survey form and wish to do so, send a stamped, self-addressed envelope to the CMTA, and we will mail a form to you. (The survey is the goldenrod colored form originally mailed in June, 1991 and mailed in new patient kits since then.)

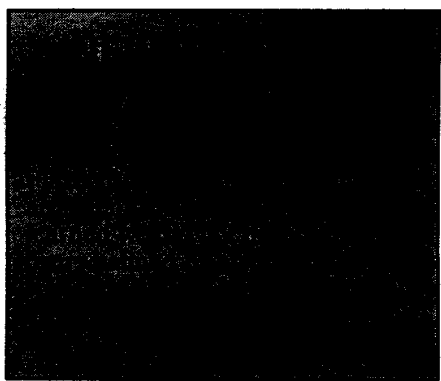
Dr. Lebo has been very pleased with the response of nearly 600 CMT patients, many of whom have responded positively to the idea of diagnostic and pre-natal testing for CMT. The diagnostic test for CMT is not yet available to the public commercially, but its availability will be announced in the *CMTA Report* later in 1992.

The results of the questions regarding trauma and CMT will be discussed at the May meeting of the MAB. The CMTA is very proud of the men and women who serve on our MAB. They are all skilled, dedicated professionals who represent the research and clinical communities. The MAB is chaired by Dr. Robert E. Lovelace, Columbia University College of Physicians and Surgeons. The members of the Board are listed on page 8.



Members of the CMTA MAB gathered at the ANA meeting in Seattle, 9-91. Left to right: J. Petajan, J. Hsu, R. Mayer, J. Chopra, W. Bradley, CMTA President K. Hitt, L. Hopkins, L. Williams, O. Hurko, G. Weber, T. Bird.

Honoraria	
In Honor Of	By
Meme Plegeman	Janice Vaughan
Clyde Goodrich	Joyce Rowe
Judy & John Grocott	Robert Hawkes
Rebecca Sand	Simon & Lyna Levin
Rebecca Sand	Sybil Whitman
Sam Goldblatt	M/M Ron Catalan
Elliott Levitch	Felice & Ed Viggers
M/M Henry Eldredge	Douglas Moody
Emily Ellis	Cheryl Ellis
Henry Friedman	Pete Friedman & Karen Laner
Hon. Judge Albert Scarduzio	Mabel Anderson
Iris Golmetz	Karen Gabel
Kim & Jay Lamar	Judith Lamar
Dr. Greg Stilwell	Charlotte Stilwell
Marjorie Cowan	Charlotte Stilwell
Pat Dreibelbis	Martha Yohe
Mark, Leah, & Ben Willingham	A Friend
Steve Jumper	Mrs. E.A. Jumper
M/M Larry Linker	Doris Goldman
Elsa Johnson	M/M Lawrence Healy
Ruth & Larry Linker	Jonathan Goldman



Memorials	
In Memory Of	By
Mildred Winchell	Phyllis Warren
Hy Berry	Samuel Berry
Lillian Kinney	Margaret Berre
Mariano Realmuto	Tina Realmuto
Harry Brezel	Dr. Karen Edelson
Harry Brezel	Rebecca Brezel
Sophia Bradwick	Faye Bradwick
Clarence Kluenner	Edna Kluenner
Mollye Schwartz	Michael Schwartz
Barney Bernard	M/M James Chandler
Barney Bernard	Theodore & Marwella Lokke
Anthony Farin	Vincent Farin
John Davis	Ruth Davis
Irving Finkelman	Stacy & Robert Finkelman
Edward Bachman	Betty McEvers
Joseph Stein	Estelle Bandler
Nancy Holmes	Karol Hitt
Beverly Fetterman	Robert Warner
Elsie Watkins	Ken Watkins
George Phy	Rebecca Phy
George Phy	Janet Phy
Mary Malriat	Margaret DeStefano

For your records, our address is:


The CMTA
Crozer Mills Enterprise Center
601 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.

Pedorthist

The following pedorthist is a member of the CMTA and is familiar with, and interested in, the CMT patient.

Michael Marmer, C.Ped.
Marmer's Pedorthic Cen
2371 Kemper's Lane
Cincinnati, OH 45206



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 many 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.

Alabama - Greater Tennessee Valley
Bill Porter 205-386-6579W; 205-767-4181
Meeting at ECM Hospital, Florence, AL

California - Los Angeles area
Oxnard-Thousand Oaks
Janice Hagadorn (805) 985-7332

Adelanta (High Desert)
MaryL Michels (619) 246-7807

Canyon Country - Saugus
Sheila Levitch (805) 254-5322
Denise Miller (805) 251-44537

California - San Diego
Gary Oleze (619) 944-0550

California - San Francisco
David Berger (415) 491-4801

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

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

Florida - Orlando Area
Carole Wray (407) 788-7427
Meets 3rd Sat. every other month
Metro West Church of the Nazarene
Orlando, FL

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) 304-1652

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

Missouri - Kansas City
Sandra Toland (816) 926-4213

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 Jersey - Millville Area
Linda Muhlig (609) 327-4392

New York City - Manhattan
Anne Beyer (201) 391-4624

New York - Long Island
Lauren Ugeil (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 Salzberg (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

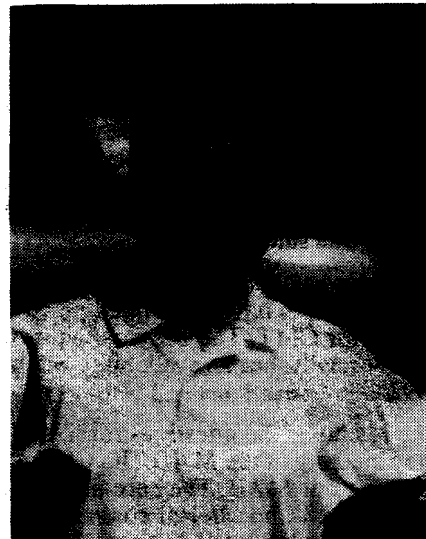
Texas - Greater Dallas Area
Dr. Karen Edelson, D.P.M.
(214) 542-0048

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 (814) 748-9021
Steve Firestone (804) 745-4123

support group corner profile



Susan Salzberg, the leader of the eastern North Carolina support group, is not only an occupational therapist, but more recently is a published author. Susan wrote an article entitled, "Living with CMT - Helping Patients Cope" which was published in the February 28th edition of Occupational Therapy Forum. The article discusses in part, Susan's own discovery of her disorder after symptoms from a difficult pregnancy didn't clear up.

Susan has been the leader of the North Carolina group since its inception in September of 1991. The group meets at the Durham VA Hospital and has a membership of approximately 30 people.

Away from her job, Susan enjoys swimming and photography and has been married for 20 years. She and her husband have a 16 year old son who is mildly affected by CMT and an 8 year old adopted daughter from Korea.

Population density in the Durham area is low and attendance at support group meetings is less than Susan would wish, but it is her goal to continue and to focus on education of the CMT patient.





Ask the Doctor

Dear Doctor:

I have been diagnosed with type II CMT. My grandmother died in 1974 after spending her last 20 years in a wheelchair supposedly with osteoarthritis. My mother died of a stroke and complications of Cushings syndrome at age 54. All of the members of my family have cavus left foot. I am the only member diagnosed with CMT.

In the second generation there has been a male child in each of my brother's and sister's families with neurological problems, mental retardation, dyslexia, and attention deficit syndrome. In addition, my fourth child, also a male, is showing attention deficit syndrome and dyslexia. He also has a cavus left foot, but his EMG and nerve conductions are marginal.

Is there any documented evidence that these problems are related to CMT? I would like to communicate with anyone doing research on this.

Sincerely,
E.B.T. Salem, OR

This question was sent to a pediatric neurologist who is a member of the CMTA Medical Advisory Board.

The Doctor Answers:

To have asymmetrical involvement in patients with CMT is not unusual. I am often referred a child with reported unilateral cavus foot who on careful examination demonstrates mild involvement on the opposite foot and on EMG and nerve conductions demonstrates bilateral sensory motor polyneuropathy and is eventually diagnosed with CMT. To have the same asymmetry in all family members is interesting and, to my knowledge, unique to your family.

In regards to the association between CMT and mental retardation, dyslexia, and attention deficit disorder, I feel there are two possible explanations. One is that you have two common genetic disorders running in the same family. Dyslexia and attention deficit disorders are often familial and more common in males than in females. The other possibility is that you have a neurogenetic disorder which includes a sensory motor polyneuropathy, and, in

fact, you do not have CMT. I recommend that if not done, you and your family be evaluated at a large medical center with experience in diagnosing CMT and metabolic diseases.

I don't know of anyone researching the association between dyslexia/attention deficit syndrome and CMT. Dr. James Lupski in Houston is interested in doing chromosome studies in families with CMT and another genetic disorder. You could contact him through the CMTA.

Dear Doctor,

I am a 35 year old female who was diagnosed with CMT one year ago. I am currently wearing AFO's and have a lot of muscular atrophy in my hands.

Last month I attended a Muscular Dystrophy seminar at which there was a doctor speaking on CMT. I told him that I worked for the police department and was required to change shifts every 28 days. My question to him was, "Will the constant shift changes advance the progression of my disease?"

He suggested that I get on a permanent shift if possible.

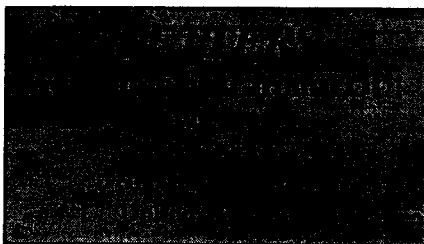
What is your opinion? I am scared that I may be doing harm to my body.

Sincerely,
C.H. Roselle, IL

A Member Of The Medical Advisory Board Replies:

Changing shifts would not directly affect your CMT but could affect your adaptation to CMT. As with any stressful situation, it is a disadvantage to constantly change your sleep patterns—times and amount. Therefore, while there is no direct effect, it will affect the quality of your life and the way you handle your disorder.

✕



The following letter was received by the Northern New Jersey CMTA Support Group after they wrote to Dr. James Lupski, Baylor College of Medicine, regarding his molecular genetic research into DNA duplication on chromosome 17 in some CMT patients. (See CMTA REPORT, Fall 1991).

Dear Members,

I want to thank you very much for your letter of October 12, 1991, expressing your appreciation and support of our research efforts concerning Charcot-Marie-Tooth disease. I can assure you that we will continue to...put forth our best effort to understand the molecular basis of Charcot-Marie-Tooth disorders. It is important for you to be aware that without the cooperation and interests of patients with CMT disease it would be impossible to perform our studies. We have been very fortunate to have voluntary families who have willingly given their time, blood and consent to nerve conduction velocity studies in order to enable us to perform our research. It will only be through the continued efforts of patients and families that we will be able to understand these inherited peripheral neuropathies.

I also want to state that I believe it is very important to have support groups for patients and families with Charcot-Marie-Tooth disease. It is through these support groups that families and patients learn how to deal with this disease. Through my experience as a medical geneticist dealing with families with other inherited conditions and other chronic diseases the patient support groups can be very important. Although, as you stated, it is very frustrating that CMT remains a mystery to the general public and sometimes to the medical community, I feel it is incumbent upon us to educate ourselves and the medical community about this important disease entity.

Thank you for your letter of support.

Sincerely,
James R. Lupski, M.D., Ph.D.,
F.A.A.P.
Institute for Molecular Genetics and
Department of Pediatrics

RESEARCH UPDATE

CMT RESEARCH - Central Nervous System Project

by Dr. Jane Frith

The following article is reprinted, with permission, from The Journal of the Charcot-Marie-Tooth Association of Australia. Dr. Frith is a post-doctoral research fellow at the University of Sydney.

Charcot-Marie-Tooth is a disease that affects the peripheral nervous system. That is, it affects the nerves after they have left the spinal cord and as they travel to the hands and feet. The peripheral nerves have two parts (see figure 1):

- the inner part is the nerve fibre itself called an axon
- the outer part or insulating material called myelin

There may be an abnormality of either part of the peripheral nerve giving rise to the two major types of Charcot-Marie-Tooth disease. In the more common Type I, the myelin sheath is affected and in the less common type II, the axon is affected (see figure 2). Generally families "breed true". That is to say that all members of a family who have CMT will have either Type I or Type II disease, but Type I and Type II tend not to occur within one family.

Recent research suggests that the genetic abnormality responsible for the most common form of CMT is a duplication of a small segment of chromosome 17. It is still not known how this genetic abnormality translates into the disease that we see. Research now needs to be directed toward this area. Since 1967 we have been aware that some CMT people have abnormalities in some nerve tracts within the spinal cord and the optic nerves as well as within the peripheral nervous system. Several authors have examined small numbers of CMT people to see if there are abnormalities of nerve conduction in the central nervous system (brain and spinal cord), but the results have been inconclusive.

This has become our area of interest at the Department of Medicine, Sydney University. A study has been designed to answer the question "are there abnormalities in central nervous system conduction in people with Charcot-Marie-Tooth disease?". To investigate this, we are performing a clinical examination, a vision test (visual evoked potentials) and a hearing test (brainstem evoked potentials) on 100 CMT people.

If we find there are more CMT people with abnormalities of central nervous system conduction than we would expect by chance, then we intend to ask a second question: "are the central nervous system conduction abnormalities more common in people with CMT Type I or CMT Type II?". Answering this question is important for identifying the mechanisms of CMT.

Currently we have already examined forty people with CMT in this research project.

Editor's note: *We will report the results of this project when they are published.*

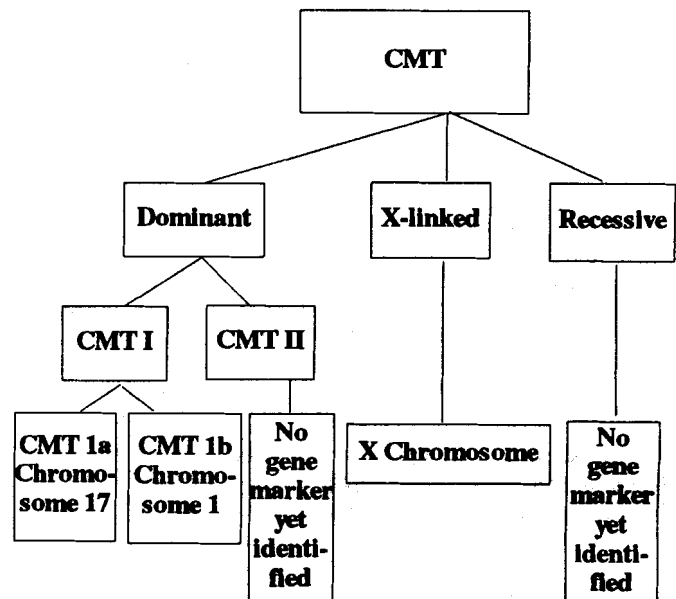


Figure 2 - Types of CMT

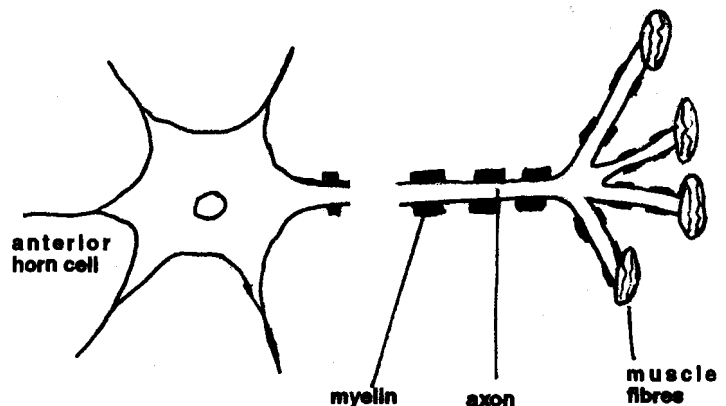


Figure 1 - lower motor neurone

Letters...



to the editor

Dear Editor,

Mine was a spontaneous instance of CMT; no one else in the family had the slightest health problem. After I proved the diagnosis of muscular dystrophy wrong, by living, my neurologist determined I had CMT.

I'm 38. I am healthy, but I still have my problems. I've been hospitalized four times in the last five years for illnesses exacerbated by my condition. I've had four operations on my feet since I was a teenager, and although walking is hard, I am mobile.

I have been treated all over the country. I was fortunate to have the best medical care that money could buy. But there were other problems I've never seen addressed in your newsletter. To this day, my mother and father who began taking me to doctors when I was two years old refer to my health as "your problem" or "bad feet." All my life I was told that I could help myself if I really wanted to: all I had to do was pray and believe.

When I was a child, I was told, despite medical opinions to the contrary, "children don't get tired." When I had leg cramps that kept me awake for hours, I was told I needed to eat more bananas for potassium. When we went on vacation, I was fussed at for not keeping up when we went on walks. When I started having nausea after I got tired, I was told, "it's nerves."

I took a job which proved to be stressful, but exhilarating. I loved it and worked around the clock, oftentimes seven days a week. After a year of this, I began to get sick. I announced my decision to do something less difficult and was told by my parents, "you were not raised to be a quitter." I continued the pace for another six months until I collapsed. My parents decided I had had a nervous collapse. Thank God, for my sanity, my neurologist told me I was suffering acute fatigue.

When you grow up with a "problem" and see a doctor for a 10 minute visit, you get very little explanation. The assumption is someone else has already told you what you need to know. I found, as a young adult, doctors were suspicious when I complained about non-orthopedic matters. One of the last times I saw a neurologist was 6 or 7

years ago to tell him about feeling extraordinarily shaky and tired.

It never occurred to me to tell the physician that two months earlier I had begun drinking a glass of wine a day as a result of a study that showed wine in moderation prevented heart disease. The physician told me after a 3 minute interview and examination that I was probably depressed.

The first time I read the *CMTA REPORT* last year, I was transformed. Until that time, I did not know that I had a legitimate claim to feeling lousy. Thanks to the information your newsletter provides, I felt so very good about feeling so very bad. The nausea, the falls, the feet, the issue, the symptoms, are very legitimate problems. I've had a good year to work through receiving a lifetime of "misinformation" and I can say that I'm only relieved to know the truths of CMT disease. My parents were so worried about their little girl. Their fear was probably compounded by a lack of information available at that time. It seems the impact of CMT is far more than physical and the CMT patient is oftentimes not the only affected one.

I am grateful for the resources the Charcot-Marie-Tooth Association provides.

Name withheld upon request.

Dear Editor,

The newsletter has been a great source of information for us, but it is not enough. We met you at the CMT conference in San Francisco last year and we found the conference informative. We were the people with the baby with CMT. We feel very alone with this condition. It seems that babies just don't have CMT and nobody knows much about how to help us help him. He is getting rapidly worse. We want to get to know parents who are now struggling with this horrible condition. We cannot afford to "wait and see." We want to know what is available now in the way of therapy, bracing, exercise, surgery, support, and education for a young child with CMT. Clay is now 3 years old.

You have our permission to give our name and address to anyone - doctors, therapists, counselors, educators, and parents who would be interested in



Geoffrey Clarkson

Editor's note: This picture arrived too late to accompany the account of Geoffrey's Himalayan climb. Since you saw the mountain he climbed, we thought you would like to see the man.

helping us deal with this CMT toddler. We would be extremely grateful for any help you could provide.

Sincerely,

Maggie Malone
107 Michigan
Travis AFB, CA 94535

(Editor's note: We do not usually print patient's names and addresses in the newsletter, but here we provide Maggie's address for other parents who might offer her some help by way of their experiences with CMT children.)

Dear Friends,

I've found a way to ease the numbness and burning in my feet from CMT. Each night I massage my feet and legs with a moistening cream. After recent surgery for the implanting of an artificial right shoulder, I didn't do the massage and the discomfort grew, especially at night. Naturally, I have resumed the regular rubbing and things are getting better again. I hope such a regimen can help others.

O.M. Waukesha, WI

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 1992'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 _____

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, 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:

- | | |
|--------------------------------------|------------------------------------|
| <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: _____

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 1992 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 June 1, 1992, along with a clear photograph of the child. (e.g. school photograph)

Letters... continued

Dear Friends,

I am 87 years old and live in the Grove Manor Nursing Home in Western Pennsylvania. I have been there since March 1, 1986. I make the daily announcements over the intercom and take part in activities such as exercises, current events, and painting when they are scheduled. I use a wheelchair mostly, along with spring wire braces on my shoes. I have had two cataract operations.

I was an apprentice at the Westinghouse Chemistry Lab while I attended night school at Carnegie Tech. I then completed one year of chemistry studies at the University of Pittsburgh and earned my mining engineering degree from Penn State in 1929.

I worked in coal mining operations in Shenandoah and Ashland, PA, before leaving mining engineering to help my father in his store.

In 1925, I became the postmaster of Potts Grove for the next 38 years. My wife was a schoolteacher and my daughter was a nurse. I have two grandsons.

My hobbies include crafts and reading, particularly about nutrition. My wife and I use to enjoy belonging to the Ramblers Club and traveling across the US and Canada.

Charles Rishel

Grove Manor Nursing Home
 435 North Broad St
 Grove City, PA 16127

(EDITOR'S NOTE: Charles writes to the office frequently and is always anxious to receive mail. Please take a minute and drop him a note if anything in his past or present life is something that interests you as well. He is a delightful man.)

Letters... (continued)

Dear CMTA,

I have had CMT for a number of years and my daughter, who is 29, is also affected.

I enjoy the newsletter so very much and have learned so much about this disease from you. My daughter and I attended the Los Angeles conference last April. My daughter's foot was getting quite bad and one of the speakers, Dr. John Hsu, an orthopedist was able to see my daughter in his Whittier office. He then did surgery on her leg and foot in August. The results are more than we had dreamed they would be. We are very thankful that we attended the conference and met Dr. Hsu. He is a wonderful doctor and very well informed on this disease.

Thanks again for the newsletter. May this year be good for everyone.

E.K. San Gabriel, CA

To the Editors of the CMTA REPORT,

I want to start this letter by thanking the CMTA for all the information you have given me which I have made copies of and given to the many military doctors that see my husband. Many don't know much, or anything, about this disease.

Next, I want you to know that I bought an infra-red muscle relaxer to see if it might help my husband with his muscle pain. It did not seem to help. Then I bought Goose Bumps Massage Balls. They work on the acupuncture idea. My husband says that they help a lot. In fact, he can do some spots for himself. Because the bumps on the ball are long, they do exert a definite pressure which helps.

My husband has just retired from the military. The military would not give him a disability because his CMT is a pre-existing disease, but the Veterans Administration will be providing him with a disability. We are just waiting to find out the exact percentage.

Thanks for all your help and information.

P.S. Portsmouth, VA

I want to be in touch!

Name: _____

Address: _____

Phone Number: _____

Tell us about yourself:

- CMT Patient
- CMT Family Member
- Medical Professional
- Other

Please check the appropriate boxes:

- Put me on the mailing list!
- Send me a copy of "CMT Facts" - \$3

I would like to purchase VCR tape(s):

- Orthopedic Surgery and CMT - \$15
- CMT Neurology - \$15
- CMT Physical Therapy/Occupational Therapy - \$15
- CMT Genetics - \$15

Join the fight against CMT!

Enclosed is my check for:

- Membership (\$25) _____
- Purchases _____

Contributions are tax deductible. Please make checks payable to the CMTA.

Total..... \$ _____

Review of Current Scientific Literature

REVIEW: " Scientific and Ethical Considerations in Human Gene Therapy" by Roger Lebo and Mitchell Golbus. This article appears in Clinical Obstetrics and Gynaecology, Vol.5, Number 3, September 1991.

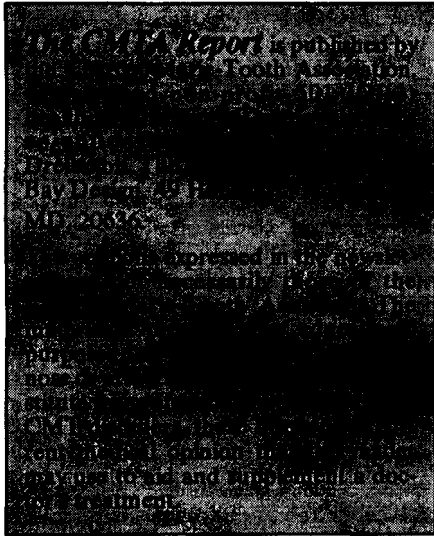
This thought provoking, technical article is an overview of the ethical issues raised by our ever-expanding knowledge of the human genome and the mechanisms of gene manipulation and therapy. Among the topics discussed are: somatic cell gene therapy, prenatal gene therapy, germline gene therapy, enhancement genetic engineering, eugenic genetic engineering and ethical constraints. The authors conclude their essay, " In conclusion, we believe human gene therapy experiments should proceed cautiously following review and approval of the complete

scientific protocol by medical scientists, ethicists, and theologians. We have suggested that some categories of gene therapy previously designated enhancement or eugenic therapy could be redefined as human genetic disease therapy on a case by case basis. As investigations proceed with(it is hoped) positive results with lethal genetic diseases, debate will continue to define, construct, and refine an applicable code of experimental gene therapy ethics. This code will provide a framework for discussing new options prior to approval or disapproval."

With the evolving genetic knowledge of CMT, the ethics of gene therapy does indeed become relevant to the CMT community. For a complete copy of this article, send \$ 2.00 to the CMTA requesting the Lebo/Golbus reprint.

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.



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.
- can vary greatly in 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

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