Charcot-Marie-Tooth Association

THE CMTA REPORT

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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 neuropathy.

Service Dog... Joe Ehman's Best Friend

Joe Ehman's story begins as so many do. He was misdiagnosed all through his childhood. He was told that his problems were due to a growth spurt in which his bones grew faster than his muscles, resulting in difficulty walking and running. By age 16, he was unable to run without spraining his ankles and by 17 he had experienced multiple leg operations. He always had difficulty writing, but no one diagnosed that.

He attended Nazareth College in Rochester, NY, majoring in social work and became an adolescent drug and alcohol counselor. In 1988, he bought a private health club and worked as a manager of a popular city night club. He began to notice that as he worked out, his leg and arm muscles never developed, but, rather, seemed to diminish. Chronic pain and fatigue began to bother him and he was forced to give up his business. He developed major problems with walking and began falling more frequently. In 1992, he was finally diagnosed with CMT and fitted with bilateral AFOs.

At present, Joe is considered 100% disabled and he uses a wheelchair for distance. He still suffers with fatigue and pain, but he is definitely not idle. He volunteers for the MDA, the CMTA, TRIADD(he's a public speaker on being disabled) and PADD(Partners in Adaptive Dog Development), the organization that trained both him and Ariel.

Ariel is a New York State Certified Service dog who pulls Joe's wheelchair, retrieves things that he drops and steadies him when he is walking or standing. She helps him up if he falls and she opens doors for him, both figuratively and literally. In the figurative sense, Ariel opened the door of public acclaim for Joe when she almost got them arrested in 1993 at a TCBY store. The clerk told Joe that he didn't look disabled and that the dog could not be in the store. Police arrived and also said that Joe didn't look disabled and that they had never heard of service dogs. The local evening news picked up the story and Joe and Ariel became famous.

Joe Ehman & Ariel

When you talk to Joe, you can hear in his voice that Ariel and Joe are more than "man and dog" They are companions and friends.§

Special Education...

Your Child's Rights

In 1975, the passage of Public Law 94-142 or The Law for the Education of All Handicapped Children Act (EHA),guaranteed that children with disabilities would not be excluded from the right to an education at public expense regardless of the nature or the severity of the disability. A significant part of P.L. 94-142 is the mandate for parent involvement in decision making within the educational process. Before a parent can be an equal participant in developing his/her child's educational program, he/she should know some of the basic laws, regulations and policies about special education for students with disabilities. Recently, the EHA has been renamed the IDEA (Individuals with Disabilities Education Act.)

Special education is instruction and related services provided to students who have the following handicapping conditions according to state and federal criteria: learning disabilities, speech impairments, physical handicaps, mental retardation, emotional disturbance, autism, multiple handicaps, pregnancy,

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Items of Interest

Item 1. If anyone has purchased a "Genetics" tape from the CMTA prior to January 1995, please check it in your VCR to determine if it has audio. Several tapes were found to have no sound. If you have a defective tape, please return it to the office of the CMTA and another will be returned to you immediately.

Item 2. There is a program in the state of Calfornia called the Genetically Handicapped Persons Program (GHPP) which is state funded and coordinates care and helps pay for medical costs for persons with inherited conditions, of which CMT is one. The stated goals of the program are: 1) To help each client achieve the best level of health and functioning possible through : early case finding, preventive and treatment services by highly skilled comprehensive center teams, and maintenance in the home community by qualified providers. 2) To prevent the occurence of GHPP conditions through cooperation with programs responsible for: genetic counseling, public and parent education, and care of high-risk mothers. GHPP pays for medical care in case of loss of private health insurance or Medi-Cal and for some services not covered by other plans. It does not pay for long term care. The annual enrollment fee is determined by income and family size on a sliding scale. For information or to apply write or call: State of California, Department of Health Services, Genetically Handicapped Persons Program, 714 P Street, Room 300, Sacramento, CA 95814, (916)654-0503.

Item 3. The office will maintain a list of Dejerine-Sottas families so that parents can contact one another. We currently have one family in Suffern, NY who have agreed to have their names and phone number released to others who might like to contact them. If you have a Dejerine-Sottas diagnosis in your family and you would like your name listed as well, please drop a note with that information on it to the office.

Item 4. Free Prescription Drugs: The Pharmaceutical Manufacturers Association has a hotline service for physicians that provides information on drug companies that offer free drugs for patients whose doctors certify that they are in need. Patients can urge their physician to call: 800/PMA-INFO.

Item 5. The article in Muscle and Fitness which featured Ben Feen and was reprinted in the last issue of The CMTA Report received a feedback letter in the February 1995 issue of Muscle and Fitness. The letter follows:

My brother Matt's struggle with the little-known, but debilitating, malady called Charcot-Marie-Tooth disease has been very hard. His early teen years were riddled with trials and tribulations brought on by the disease's effects. Only through weight training regularly for the last two years has he been able to battle this disease. As his body has grown, so have his self-confidence and personality. That's why he was so pleased with your Success Story article on Ben Feen. (Septmember M&F) Ben's heroic struggle with CMT mirrors my brother's own efforts. Weight training can change lives if it is coupled with determination and a strong spirit. My brother and Ben are testaments to that.

J.O./ Auburn, AL

Item 6. Another reader responded to a request for wider shoes for women in the last issue of the newsletter and led us to a company called B.A. Mason who offer a fairly wide range of wide shoes for both men and women. We called the company and they sent out a catalogue. (As an editor's note, one of the staff ordered a pair of women's shoes called Walkabouts. They are wide and have a generous toe box.) If you are interested in seeing a catalogue, call B.A.Mason at 1-800-422-1000. §

Call for CMT-X Participants

If you are a CMT-X patient or a member of a CMT-X family, Dr. Michael Bennett, chairman of the Neuroscience Department at Albert Einstein College of Medicine, needs you! Dr. Bennett is conducting research on connexin 32, the malfunctioning chemical compound in CMT-X patients. If you have the diagnosis of CMT-X in your family, contact Dr. Bennett at the Dept. of Neuroscience, Albert Einstein College of Medicine, Bronx, NY, 10461 or call 718/430-2535.

Special Education - cont'd from p. 1

visual handicaps or hearing impairments. To receive special education, students must be at least 3 years old but under 22 on September 1 and need the services of special education to progress through school. The public school provides these services at the preschool,elementary and secondary levels at no cost to parents. Every child has a right to these services in a setting with children who are not in special education to the maximum extent appropriate. This is known as the least restrictive environment. (LRE)

One of the purposes of the laws about education for handicapped children is to assure that the rights of students with a disability and their parents are protected. The law says the school district must give parents written notice of their rights and must explain all of those rights when a student begins the referral process. The notice must be given by someone in the district and must be in the primary language a parent speaks at home. If a parent cannot read or write, the school must give the notice orally, or on cassette tapes or in braille. These rights, known as procedural safeguards, include:

The right to receive general notice which must be:

- A full explanation of all rights throughout the educational process
- In writing at the time of referral and whenever updated
- Explained by school personnel.

The right to receive specific notice which must:

- Be given in writing in the primary language of the family
- Be received at least five school days before the action takes place
- Include all of the following
  - a description of the action proposed or refused
  - an explanation of why the agency proposes or refuses to take the action
  - a description of any options the agency considered
  - the reasons those options were rejected
  - a description of each evaluation procedure,test, record or report the agency uses as a basis for the proposal or refusal

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George Grams... Suffering in Silence

George Grams (second from left) and the Sixth Ohio Volunteer Cavalry

by Mark Robinson

Your typical basketball career, it was not. But then, George Grams isn't your typical man - in stature or in substance.

The first 7-footer to play in the Big Ten Conference, Grams lettered at Purdue in 1964 and '66. He was the first Caucasian to play on the all-black Harlem Magicians comedy basketball team, a spinoff of the Globetrotters. He's a Civil War reenactment enthusiast and rubbed elbows with the stars when he served as technical consultant during the filming of the epic "Gettysburg."

All the while he endured pain unimaginable and intolerable to most. Now 50 years old, Grams suffers from Charcot-Marie-Tooth Syndrome (CMT), a neuromuscular disease where the toes curl up under the balls of the feet. Until it was diagnosed in 1984, he didn't even know what the affliction was. All he knew was that it was at times excruciating and that it ate away at his health and mobility.

But,he refused to let the affliction get the best of him. Grams considers CMT a hindrance, not a roadblock. That's the message he conveys to the groups of physically challenged he addresses, children in particular.

"My basic theme to the people that I've talked to is I don't believe in the word 'handicapped' and I barely believe in the word 'disability,'"explains Grams. "We all have our cross to bear. Each one of us has some limiting factor. A form of muscular dystrophy is just another form of a limiting factor."

"So, you need to forget about the limiting factor; we all have one. Let's figure out what the positives are and go on from there," he adds.

That's how Grams has lived his life.

Playing With Pain

As a high schooler in Grand Rapids, MI, he was all-city, all-state,all-American, all-everything. Colleges didn't just wear a path to his door, they paved it for easier access. But Grams settled on Purdue.

"Purdue was the only school that talked to me about what would happen after I got out of school and about academics," Grams says."The other schools talked about what a great basketball program they had, all the places they were going to play and what a great gymnasium they were going to build.

"Purdue said, 'Look, there's going to come a time when you quit playing basketball and you need to be prepared for that. Here's how Purdue's going to prepare you for that,"he continues. "They kept me forward-looking and gave me more things to think about than just my next game and how much it was going to hurt."

Hurt it did, though Grams didn't let on to anyone. Not coaches, not teammates, no one. In great part, he kept his painful secret in ignorance.

"It was tough," he admits." Trying to tell somebody it wasn't tough would be a lie. If you can imagine every game or every practice, having somebody grab hold of your toenails with a pair of pliers and trying to pull them off."

"There was no particular reason to pass it on. I just thought everybody had some level of problems. You just dealt with them and went on. That was stupid, but that's what I did."

Grams endured through a mainly uneventful Purdue career, playing in the shadows of Dave Schellhase and Mel Garland. In 41 games, he averaged 4.6 points and an equal number of rebounds.

Facing His Future

Grams may not have put up big numbers at Purdue, but NBA teams are always looking for big men with potential, so he was selected in the third round of the 1966 draft by the Los Angeles Lakers. After witnessing him play first-hand in rookie camp, Lakers officials knew that Grams wasn't ready for the NBA so they arranged for him to get some seasoning with the Harlem Magicians, a team in the mold of the Globetrotters headed by former 'Trotter' Marques Haynes.

Experience Grams gained, all right. But it wasn't limited to the basketball court.

"I learned an awful lot about a culture that was different from mine,and it was by total immersion," says Grams. "Later on I went to Saudi Arabia and spend several years over there. The culture adaptation things I learned with the Magicians really helped me out over there."

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Good Grips... a Good Name and a Useful Gadget

In 1989, Betsey and Sam Farber were supposedly in retirement, he from a cookware company that he had founded and she from her job as an architect. They rented an ideal vacation cottage for two and began cooking, a favorite hobby of both. Sam was a pie maker and Betsey was a soup inventer.

tools

Mixing, chopping, and tasting up a storm, they discovered that ordinary kitchen gadgets hurt their hands: painful scissor loops, rusty metal peelers and hard skinny handles on lots of tools. Betsey's arthritis flared up and Sam got sore hands. They searched for comfortable tools and couldn't find them anywhere.

Sam took the creating of comfortable kitchen and gardening tools as a mission and with designers and experts on gerontology and arthritis, he invented Good Grips. Since their invention, Good Grips have won design awards from the Arthritis Foundation and the Industrial Design Society of America.

The handles of Good Grips are made of Santoprene, a plastic rubber that insulates against heat and cold. The smooth plump shape feels natural and you don't have to tense the muscles in your hands to get a good grip. The ends are flexible and the tool can actually bounce on its end. That resilience protects the carpal bones in the wrist. The tools also have fins which bend to cushion your fingers where you push the hardest. They also protect against slipping.

Pictures illustrate the common tools of the kitchen, the vegetable peeler, a small knife and the jar opener. If you are interested in Good Grips, by OXO, they are found in most kitchen stores, such as Lechters and in catalogues such as Willams-Sonoma, or you can call 1-800-545-4411 for help in finding a store near you.

jar opener

(Editor's Note: As so often is the case, the information for this article came from an observant member of the CMTA who saw these kitchen tools, bought a few, and was thoughtful enough to tell us about them.)§

George Grams - cont'd from p. 3

All the while, the disease continued to cause Gram intense pain and it slowly deteriorated his physical capabilities. But it would be nearly two decades until it was correctly diagnosed. When a neurologist finally deciphered the problem and told Grams and his wife, Nancy, it was more of a relief than anything.

"He brought me and my wife into a darkened, solemn office and said, 'Mr. Grams, we have our results back and I'm afraid the results are not good news for you. You have a form of muscular dystrophy, CMT.'" He explained what it was.

"When he finished, he said, 'I understand this is really bad news. Are there any questions I can answer?' I looked at him, smiled and said, 'There's no bad news here, as far as I'm concerned. Now I know the reason I couldn't rebound worth a flip.'"

Grams, who earned his undergraduate degree at Purdue in physical therapy and later added an MBA from Drake University, gets around today with the aid of leg braces. But it hasn't slowed him a step.

George Grams and Eleanor Hayes

Since being diagnosed with CMT, he became involved with the Muscular Dystrophy Association. He co-hosted the Youngstown, Ohio, broadcast of the 1992 Labor Day telethon and earned the 1993 Northeastern Ohio MDA Chapter's Personal Achievement Award.

In the past two years alone,George and Nancy have lived in Ohio, Iowa and San Antonio, Texas, where George works in personnel for the dispatch office of Wal-Mart.

While living in Ohio, Gram's dentist got him interested in Civil War reenactments. Grams helped found an annual reenactment near Cleveland that's already one of the largest contributors to battlefield preservation in the nation. Gram's knowledge of horses and the Civil War landed him the position of cavalry coordinator on the set of the 1992 movie,"Gettysburg."

"I worked closely with Sam Elliott and with Martin Sheen and Tom Berenger," he says with name-dropping pride. "Sam and I go fishing on a pretty regular basis."

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The Possibilities of Tissue Donation

The Brain and Tissue Bank for Developmental Disorders at the University of Maryland was funded in 1991 by the National Institutes of Health to serve two different but closely linked groups of people. People from these two groups have much in common because they are working towards the same goal and hoping for the same things, but they rarely communicate. These two groups are families and individuals affected by developmental disorders and the researchers who are working in laboratories and hospitals across the country to solve the perplexing medical mysteries represented by these same disorders.

As individuals ask themselves why and how these disorders come about, they often question when research will find the answers. Support groups for particular disorders become involved in assisting research by raising funds or campaigning for increased research grants. The Brain and Tissue Bank is offering yet another way in which individuals can further research and that is through the donation of tissue at the time of their death. The precious gift of their tissue is one of the most effective ways to fight these disorders. Although some research can proceed through the use of animal models, many of these debilitating disorders are not reproducible in animals. The solutions to these disorders lie in examining human tissues.

The Brain and Tissue Bank works with individuals and families interested in donating tissue by coordinating all aspects of tissue donation. And, the Brain and Tissue Bank works for researchers by ensuring proper retrieval, storage and handling of all tissues, and, after screening the quality of their research proposals,supplying them with the donated tissue without which their research could not go forward.

The Brain and Tissue Bank interacts with potential donors through a National Registry. The Registry provides, at a moment's notice, such facts as the nearest hospital to the donor and what pathologist may be available to help us with the retrieval of the tissue. The rapid recovery of tissue is essential in order for a donation to be of significant value in research. A donor's prior registration is what enables the Brain and Tissue Bank to accomplish a successful donation in less than 24 hours,even across the country.

Please contact the Brain and Tissue Bank, at 1-800-847-1539 if you are interested in becoming a registered donor or if you have any questions concerning the donation process.

Another tissue donation program is the "Gift of Hope" which is administered by the National Neurological Research Specimen Bank at the VA Wadsworth Medical Center in Los Angeles, CA. If you are interested in becoming a tissue donor through this program, contact the CMTA and a packet of information will be mailed to you.§

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.

Grams- cont'd from p. 4

When he's not working for Wal-Mart or angling with the stars, Grams finds time to serve MDA, speak to groups and even volunteers as a coach in the sport that helped mold the mountain of a man he is today.

"The game is just a game, but there are so many things it parallels in life," he says. "It's a great teaching device. I've got an awful lot out of basketball in terms of my own esteem, my ability to go to school. My whole life has been pushed and led by basketball. I'd like to return that gift."

Sounds as if he has many times already.§

(Editor's note: This article is reprinted with permission of The Purdue Alumnus *magazine.)*

Special Education - cont'd from p. 2

  - a description of any other factors which are relevant

The right to give or refuse consent in writing for:

- Testing for the first time
- Placement in special education for the first time
- Release of records to someone outside the school system

The right to see and have copies of all "personally identifiable" records collected, used or maintained and to make amendments or deletions to those records.

The right to disagree and voice that disagreement by:

- Following the chain of command at the local level, such as:
  - meeting with the person responsible for the situation to discuss possible solutions or actions (document the meeting), and/or
  - writing a letter to the person responsible to express concerns and requests
- Meeting with responsible persons to negotiate
- Meeting with someone "higher up" on the chain of command at the local level, such as the Superintendent or the Board of Trustees
- Sending a complain to state or federal agencies
- Requesting mediation
- Requesting a due process hearing
- Filing a suit in civil court

All parents have the right to participate in and approve the individualized education program (IEP) developed for their child. When children are placed in private schools by state or local education systems to receive an appropriate education, it must be done at no cost to the parent. Additional services such as transportation and special aids must also be provided at public expense.

Additional information on relevant sources of assistance in your state, the rights of children with disabilities and their parents, appeal procedures, and general advocacy information in the education field is available from:

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Ask the Doctor

Dear Doctor:

I was diagnosed with CMT at the age of 2 and my condition progressed rapidly with my need for a wheelchair by age 12. I am presently 36 years old. My wheelchair use has led to contractures in both knees at about 130 degrees. Over the years, I have had several brief physical therapy sessions which included stretching but little results. My last physical therapist told me I was wasting my money. I would like to know if there are any interventions, surgical or otherwise, that can improve my contractures as I feel them tightening more and limiting the mobility I still have.

The Doctor replies:

Although seen, rapid progression in patients with CMT to wheelchair use is not common, and, if not done so, I would suggest that the diagnosis be confirmed by physicians familiar with neuromuscular disorders.

While regular stretching exercises can help in preventing contractures, these are less likely to correct severe contractures that have existed for such a long time. Maintenance of range of motion is of benefit for facilitating transfers, for ease in dressing and to decrease the likelihood of pressure points leading to the development of decubitus ulcers. Aside from manual stretching, other means of treating contractures are serial casting - which is often uncomfortable and time consuming, and surgical releases. Sometimes the surgical release can be done under local anesthesia (eg. percutaneous hamstring tenotomy). Splinting (night and/or day and maintanence range of motion exercises will usually be necessary post-operatively to prevent recurrence of the contractures. Also, one should not spend the whole day in the wheelchair with knees flexed. If surgery is contemplated, the possible effects of tendon releases on other joints (positioning and function),especially if ambulatory, should be considered prior to surgery.

Dear Doctor:

My husband requires almost two days of rest to recover from sexual intercourse. It is almost as though he has fallen and must rest to regain his strength. He is 52 years old and has what seems to be a moderate case of CMT. Is this fatigue to be expected? Is this recovery period predictable in middle-aged men with CMT?

The Doctor replies:

This is essentially a question about excessive fatigue following physical activity. The first issue is whether or not this is to be expected in middle-aged persons with CMT. The answer is probably not. Some persons with CMT complain of excessive fatigue but the majority do not. This is a highly individual issue and differences between individuals cannot presently be easily explained. I know CMT patients who play soccer and tennis and go backpacking without unusual difficulty. However, no one has done a detailed systematic study of sexual activity in CMT patients, so a precise answer to this exact question is not known. In any case, I would not write off this problem as simply being a result of CMT.

Second, does the man really have CMT? Could there be some other cause of his neuropathy? No details of the diagnosis are given in the letter. This would be a legitimate question to ask a neurologist.

Third, could there be some other physical cause for the excessive fatigue? Does the man otherwise receive sufficient sleep and rest? Could there be an undiscovered additional physical problem such as anemia or thyroid deficiency? These are questions to ask your family physician.

Fourth, are there any unrecognized psychological factors? For example, is the man worried that exercise and/or sexual activity may cause physical damage or somehow worsen his CMT? These are reasonable questions for the couple to discuss.

Finally, if no additional explanation can be discovered, then the best strategy would be to attempt to schedule and pace all physical and sexual activity in order to maximize endurance and comfort.

Dear Doctor:

What can be done about bone spurs that occur on the heel of the foot and seem to be worsened by AFOs which rub that area?

The Doctor replies:

If the bone spurs are on the bottom of the heel (plantar), and the bottom of the brace is rubbing them, causing discomfort, then an injection of an anesthetic steroid can be used in the foot and ankle area. If the bone spur is on the back of the heel, it is often less responsive to steroids. It might need to be surgically removed by a process called exostectomy. This is the removal of redundant bone by abrasion. The patient would be out of his braces for approximately two weeks and then could return to normal usage.

Dear Doctor:

I have Charcot-Marie-Tooth,and I wonder if you can answer a question for me. For the past seven years, I have been suffering with bouts of vertigo. I am 68 years old and my doctor sent me for an MRI, a cat scan, and MRA for my arteries, a series of ear tests and the doppler test. Everything proved negative, but I am still getting the vertigo with unsteadiness in my legs. Can this vertigo be caused by the CMT that I have? Do you have any cases where someone has CMT and vertigo?

The Doctor replies:

Vertigo, which is defined as a sensation of rotation or movement of one's self or of one's surroundings, is not associated with CMT. Vertigo is frequently used erroneously to mean any form of dizziness. True vertigo can be produced by different disorders, including auditory disease(Meniere's), ocular(eye) disease, labyrinthine or vestibular(internal ear) disease, etc. These disorders are best evaluated and treated by an Ear, Nose, and Throat specialist. There is a form of vertigo called benign paroxysmal vertigo that can easily be treated at home by bedside positional exercises of the head. Dizziness, which is defined as a sensation of unsteadiness, a feeling of movement within the head, or a disturbed sense of relationship to space is a frequent complaint after the fifth decade, and in most cases, the cause of this symptom is never found. Dizziness is not associated with CMT, and most cases of dizziness respond to symptomatic medication. In essence, CMT is not the cause of your symptoms. In our large population of CMT patients, this complaint is rare. §

Letters to the Editor

Dear Editor,

I am a CMT Type II patient and have recently been involved in a slip and fall due to gross negligence on the part of my former apartment complex. I have a law suit in process and am interested in hearing from anyone who has had a similar experience. If you have had an accident causing your condition to get worse and you have had successful litigation, please write to Chris Fitzpatrick, 590 Lower Landing Road, TH152 Blackwood, NJ 08012.

Thanks for your help.

Dear Editor,

I have CMT and have been using a Sherlock walking staff by Cascade Designs, Seattle, WA, for the past year in place of a cane to help with my poor balance. Attempting to hold a cane previously resulted in cramping and muscular spasms in my CMT-crippled right hand. The walking staff has a wrist loop, like a ski pole loop, so the staff does not need to be tightly gripped to hold it, and if you do lose your hold, it doesn't fall to the ground. I like the idea of having it up at the height shown in the drawing.

It is available in outdoor sports shops with other mountaineering and camping equipment.

Cascade Designs,
Inc.
4000 1st Avenue S.
Seattle, WA 98134

P.D. Eliot, ME.

Dear Editor,

Please tell L.D. from Grand Forks, ND, that she might be able to wear Easy Spirit shoes because they come in a variety of widths and lengths and the leather sneaker style (called Mach 1) is very wide, very supportive and very comfortable. I have high arches and wide feet,too, and I don't even need the widest width they make. The company who makes Easy Spirit shoes is the U.S. Shoe Corporation. I wear these shoes every day even with a blazer, silk blouse,dressy rayon skirt and black tights. I can't function when I'm in pain and losing my balance and falling down, so I sacrifice high style to comfort and practicality. I wear the same style for casual wear, too. The shoes are not cheap. They generally cost $72 per pair, but they go on sale every summer, usually in July, and cost about $ 59 then. Also, New Balance makes sneakers for all different widths of feet,so she might like to check those out in a sporting goods store or a sneaker store. Also, I use a cane for stability and I have an ice and snow attachment which I use when necessary. It attaches to the cane and can be flipped up out of the way when you reach dry ground or go inside. It cost me $ 10.00. I grew up in rural Minnesota and my mother grew up in North Dakota, so I know that it is harder to find certain things there than it is in New York City.

(Editor's note: If anyone would like help with finding any of these items, please write to the CMTA office and we will forward your request on to Jean.)

J.R. New York

Dear CMTA,

Ever since I was in the first grade, I remember tripping over my own feet and on curbings while walking home from school. I never made it home without ripping a hole or two in my tights. I was pidgeon-toed and was always twisting my ankles. At camp one summer I was told I ran like a stork. Why couldn't I ice skate and roller skate like my four sisters could?

I've always been self-conscious about the way I walked or ran. In high school, I would wait for the other kids to go up the stairs before me because I didn't want to trip in front of them. In gym class I was always the last one chosen for teams. I couldn't run the entire track without stopping to rest and I was embarrassed to run the bases when playing co-ed baseball. I hated the day we had physical fitness tests, having to do squat thrusts and jumping jacks in front of everyone while the teacher timed us. I was good, however, at water polo and swimming.

No one in my school ever made fun of me to my face, but I had no friends. I wanted to hide the way I was and act normal. I was voted "most shy" in my senior graduating class because I didn't want to draw attention to myself by having friends and being popular. I would have liked to have been voted "most likely to succeed" since my grades were all A's and I graduated 17th out of 252 students in my class.

After attending college for four years and meeting my future husband, I took a job as a clerk typist and worked my way up the ranks to Senior Customer Service Representative in a local insurance agency. No one seemed to recognize my awkwardness at the office. I was still quiet and kept to myself in fear of someone's saying something about the way I walked. After nine years in this type of work, I began having problems with my hands. A quick EMG test revealed that I had carpal tunnel syndrome - from all the typing and data entry work I did. Three surgeries later, I still had problems. My fingers would cramp when typing and my wrist burned when writing. My hands and arms fell asleep on me at night, and I had trouble grasping items. The doctor ordered another EMG..this time from a neurologist.

The neurologist took one look at my high arches and thin lower legs and knew right away that I had CMT disease. After a series of tests at the MDA clinic, I was diagnosed with CMT Type II. So, there was a name for this after all. I wasn't just clumsy. When I revealed this diagnosis to my family, I was told that my father's mother and brother both had CMT. I couldn't understand why they had never told me this. I thought my uncle walked with a cane because of a car accident and my grandmother had high arches, but I didn't see anything wrong with the way she walked. My father is symptom free. So far, I am the only one of seven children in the family with a problem.

I was forced to leave my job and go on long-term disability. After being out of work for almost a year now, I must decide what to do with the rest of my life. I could finish my master's degree in education and be a reading teacher (a very sedentary job) or I could purchase a computer and do medical transcription work out of my home. I was trained on a voice activated computer these last few months as part of a job retraining program I applied for. I don't know how far this disease will progress and whether I would be able to endure a six hour day at school. I tried working in a day care center and couldn't button the kids' jackets for them when we went out to play. I don't want

(continued on next page)

Two Support Groups Lose Valuable Leaders

Robyn Cohen is stepping down as leader of the Florida support group because of the impending birth of her third child. She would be happy to co-chair the group with anyone who would like to help it continue. If you have been part of Robyn's group or would like to become active in a group in the Palm Beach Gardens area as a leader, please call Robyn at 407-622-5829.

Teri Daino has also given up the leadership of the Northern New Jersey support group after several years in that position. She, too, would like someone who has been a member of the group to consider taking over that job. Teri has created, in the Northern New Jersey group, one of the largest and most loyal support groups in the country.

The CMTA wishes to thank both of these women who have contributed so much of their time and energy and have provided a valuable service to the members of their groups. It is with regret that we bid farewell to Robyn and Teri.

Write us:

Letters - CMTA

601 Upland Ave.
Upland, PA 19015
Ph. 610/499-7486

Just the fax.

Is your office upgrading and replacing your current fax machine? We have a need for an auxiliary fax machine to be used off site. Of course, the donation would be a charitable contribution.

Letters - cont'd from p.10

to sit at home and collect a disability check for the rest of my life.

Until recently, my life seemed void... something was lacking. That's when my husband and I adopted a Guiding Eye dog and raised him from a puppy, realizing that one day he would have to leave us to work with the blind. As luck would have it, our dog,Yale, didn't make the program and was released to us permanently.

Yale has been the friend I never had as a girl. If it weren't for Yale, I would never get out of the house for walks. Even though my knees hurt when walking, Yale and I go to the park every day and walk for an hour. I have come to love the outdoors and I look forward to walking with Yale. He has lifted my spirits and allowed me to find a love for animals that I never knew I had. With Yale, my disability seems to be almost non-existent.

A.N. New York

Dear CMTA,

First of all, I'll introduce myself. I am the mother of a child with CMT. We live in a small town close to Madrid, Spain. Three years ago, my son started to turn his right foot in, so we took him to an orthopedist who prescribed an EMG. He was diagnosed with CMT then, at the age of 8. He is 11 now.

It's been very difficult for my husband and I to learn about the disease since there is not much here in Spain written about it. Only a few lines in medical books are all there is. One day not too long ago, I read in a newspaper about some research being done by the University of Wisconsin. I got their address and wrote for some information. In the response was a newsletter and a CMT Facts from your organization. I was thrilled. My excitement was such that I left everything I was doing and read, read, read. I can't say that I'm happy to hear that there are so many people suffering with CMT, but I'm relieved that my son is not the only one in the world.

I believe his CMT is the recessive type since we don't have it (we've been through an EMG also) but my husband and I are cousins. We have not heard of anyone in the family suffering from CMT, and we have information on our ancestors back to 1675.

In October 1992, a tendon lengthening was done on my son's right foot. He had to wear a four-week cast and at the beginning it seemed to work out fine. As time goes by, his foot continues in its deformity so that it is turning in again. His left foot is worse now and some months ago, his orthopedist talked to us about trying an osteotomy. We were not clear about the benefits and postponed the decision. This week, another orthopod saw him and suggested that it was better to wait for the osteotomy until the child's foot has grown competely. He proposed doing the same thing to his left foot..a tendon lengthening. We have also read in your reports that osteotomy is not recommended before 12 or 13, or even older when foot bones stop growing.

I think that in Spain the knowledge of the disorder is very little. After reading some of your articles I've come to the conclusion that many people with CMT are never diagnosed. Some people without severe discomfort and a little clumsiness grow to old age thinking that the reason for their problems is precisely that..."old age." When the disease shows up at a younger age, it's easier to be recognized, like the case of my son.

We would like to be a member of the CMTA. We would like to receive the gray brochure in Spanish since my husband does not speak English. I have translated the most interesting articles for him so far. You have been a ray of hope for us and feel the warmth of being together fighting against the same enemy.

M.F. Spain

§

Special Education - concluded

National Information Center
for Children and Youth with Disabilities
P.O. Box 1492
Washington, DC 20013-1492
1-800-999-5599

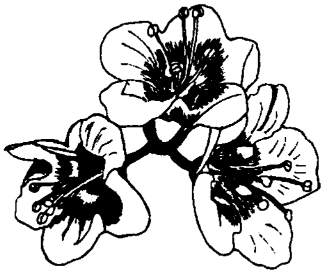
(Editor's note: The information in this article was obtained from a publication entitled, The Pocket Guide to Federal Help for Individuals with Disabilities. This free guide can be obtained from the Clearing House on Disability Information, Office of Special Education and Rehabilitative Services, US Department of Education, Room 3132 Switzer Building, Washington, DC, 20202-2524. In addition to information on educational rights, the booklet discusses and gives valuable phone numbers for vocational rehabilitation, financial assistance, tax benefits, housing, transportation, and the Americans with Disabilities Act.) §

Memorials

In Memory of	by
Bill and Rose Wolter	Betty Roemig
Willie G. Goodrich	Clyde Goodrich
Roy D. Krause	Stuart and Audrey Krause
Leo K. Breeden	Drucilla Lake
William A.Mayer	Shirley Hubbard
Martin Edelheit	Ruth Edelheit
Sophie Jacobson Adler	Ruth Edelheit
Alice Marie Moore	Central Ohio Bag & Burlap,Inc
William North	Shirley Hubbard
Julia Franklin	Technical Services Dept Fireman's Fund Insurance
Blanche Reeder	Jean Ann Marshall
Andrew Geary	John Geary
Kathleen Chute Hausman	Martha Bowman
Marian Evans	Mrs. Harold Lewis
Edith McCormick	Margaret Wegehoft
Bernard Londner	Rita Londner
Sophia Bradwick	Marcia Bradwick
Hilda and Marty Siegel	Reeva Sterling
Josephine O'Grady	John O'Grady
Ada Kinnaman	Mr.and Mrs. Jack Rapp
Ed Miller	Corinne Faschan
Jack Goldman	Doris Goldman
Sandra J.LaPointe	Barbara Elms
My father	Reeva Sterling
Benjamin Wechsler	Larry Wechsler
Hope Isaacs	Paul & Charlotte Brieff
Esther Suskin	Paul & Charlotte Brieff
Mollye Schwartz	Michael Schwartz
Bev Hudson	Jack & Mary Alice Rapp
Albert Sapone	Mr. & Mrs. Joseph Faletti,Jr.
Jack Goldman	Ruth & Larry Linker
Iris Golmitz	Karen Gabel
Milton Meltzer	Janice Keswin
In honor and memory of several McDonalds in the US and Canada with CMT	Frances Hill
Shafiqa Atalla	Yacoub Atalla
Roy Krause	Debra Nelsen
Elizabeth Douglas	Mr.& Mrs.R.L. Eckhardt
Bill Meltzer	Jerry & Debra Bank
Kay Sherrod	June Gunnison
William Hickle	Mrs. Nancy Hickle
Rosemary Petersen	Gilbert Petersen
Jerome Rothman	Sarah Rothman
Catherine Rihn Kruth	Product Safety Dept. PPG Industries
Thomas H. Lee, Jr.	Karol B. Hitt

Honoraria

In Honor of	By
Daniel Clay	Janice Clay
Megan Knuth	Rudolph & Shirley LaSogga
Elsa Johnson	Mr.& Mrs. Lawrence Healy
W.Z.Schenck	Mr.& Mrs.A.K. Schenck
Betty Lou Smith	Drucilla Lake
Mr.& Mrs. Henry Eldredge	Mr. and Mrs. Douglas Moody
Margaret DeStefano	Joseph DeStefano
Francis Heinrich	William & Linda Melville
Don Beck's speedy recovery	Michelle and Ron Catalan
Lou Jakell	William Makin
Marilyn Dodge	Margaret Binford
Mrs. Anne Bernstein	William Bernstein
Judy & John Grocott	Robert Hawkes
Emily & Bob Louer	Susan Louer
Anthony Nutile	Ronald Schlee
Rex Morgan, Jr.	Luella Morgan
Charles, Tom, Chris, & Helen Lynch & Jean Julian	Helen Lynch
Henry Friedmann	Agnes Aronsohn
Megan Knuth	Ellen Knuth
Clyde Goodrich	Joyce Rowe
Susan & Peter Schwab	Ann Ruebenacker
Rebecca Sand	Barbara Alexander
Rebecca Sand	Sylvia Pearl
Diane Kosik	Joseph Higgins
George Smith & Cecilia Thorp	George H.Smith
E.B. Hummel	Lani Hummel
Eric Schwab	Deborah Bull
Rebecca Sand	Judith Goldman
Mark Horan	Joseph Moore
Kris Groyich	George Groyich
Elia Atalla	Yacoub Atalla
R. Gordon Bradwick's birthday	Faye Bradwick
Rebecca Sand	Elizabeth Levy
Rebecca Brezel	Dorothy Kesilman
Rebecca Sand	Ada Hyams
Charles Bergmann	Sarah Bergmann
Rodger Harrington	Beth Benson
Robert Cuchetto	Andrea Cuchetto
Judy Cuchetto	Andrea Cuchetto
Margaret Boyd	Boyd Nation
E. Gordon Rossiter	Elizabeth Grant



CMTA Contacts

Following is a list of CMTA contact persons and support group leaders. There are many CMTA support groups, but more groups are needed. The CMTA will help you set up a group in your area. For information about forming a group or being a local contact person please inform the CMTA by mail or call 610-499-7486.

**denotes support group leader*

Alabama / Greater Tennessee Valley
*Bill Porter 205/386-6579W
205/767-4181

California
*Janice Hagadorn 805/985-7332 after 5
(Oxnard/Thousand Oaks)
*Sheila Levitch 805/254-5322
*Denise Miller 805/251-44537
(Canyon Country/Saugus)
*Gary Oleze 619/944-0550
10am-5:30 pm 619/436-2116
(San Diego)
*Freda K. Brown 707/573-0181
(Santa Rosa)
Eda Adams, will return calls
916/677-6460
Jeanne Amour 408/749-1661(Sunnyvale)
Clair Bumgarner 209/874-4963
Felice Gail Viggers, 805/492-2840
Verna M. Sabo, 818/892-6706
Mary Micalizzi, after 6pm
619/441-2432
Bob Hedge, 9am-5pm 310/645-2761

Colorado:
*Dr. Gregory Stilwell 719/594-9920
(Denver area)
Roberta Cummings, 719/846-5611

Connecticut:
Mary Rehm 203/744-2786
(Danbury)
*Kay Flynn 914/793-4710
(Fairfield)

District Of Columbia:
*Lorraine Middleton, 6pm-9pm
202/362-4617

Florida:
William Brady 904/443-6271
Mary Beeler, 9am-8pm 407/295-6215
Harold Wilson 407/465-3656
Pat Ports, M,W, F, 4pm-9pm,
407/965-3691
Joe Ellenbogen 305/921-4660
Edward Carhart, 9:30am-5:30pm
305/567-1066
Beatrice Bannister 407/737-3267
Robyn Cohen 407/622-5829
8pm-9:30pm M-F, weekends anytime
Erika Stilwell 305/232-9066

Georgia:
Nancy Lee McCutchen 404/925-1020

Kansas:
*Ardith Fetterholf (Eastern Kansas)
816/763-2176
voice mail 816/756-2020

Louisiana
Bobbie Marberry 504/872-0895

Maryland
Jean Iler 410/987-5432
Linda Ember Miller 410/882-4019
Robert Kight 410/668-3054

Massachusetts
Wayne Cardillo 413/298-3156
*Donald Hay 9am-7pm, 617/444-1627
(Boston)
Jim Lawrence 508/460-6928
Jennifer Brelsford 413/538-9579

If you live in the central Massachusetts area and are interested in joining a support group for CMT, please contact Laurie Seymour at 508/885-9813.

Michigan
Robert D. Allard 517/592-5351
Debbie Clements 616/956-1910
(Grand Rapids)
*Suzanne Tarpinian 313/883-1123
(Detroit)
Laurie Vasquez 517/893-4125

Mississippi
*Julia Prevost 601/885-6482
*Henry & Brenda Herren 601/885-6503
(Jackson)

Minnesota
Grace Wangaard 612/496-0255

Missouri
*Ardith Fetterholf 816/763-2176
voice mail 816/756-2020
Allan Degenhardt 816/942-1817

New Hampshire
Mary Nightly 603/598-5451

New Jersey
*Janet Saleh 908/281-6289
(Sommerville)
Linda Muhlig 609/327-4392
Gary Orson, Mon-Fri 6pm-10pm
& weekends 609/584-9025
Russell Weiss 908/536-6700

New Mexico
Jesse Hostetler 505/536-2890

New York
Joe Ehman 716-442-4123
Internet:KOLOB@Multicom.Org
*Diana Eline 201/861-0425 before 9pm
(New York City)
*Abby Wakefield 212/722-8052 (NY)
*Lauren Ugell 516/433-5116
(Long Island)
*Bernice Roll 716/584-3585 (Rochester)
*Kay Flynn 914/793-4710
(Westchester County)
Amy Gander 518/373-9907
Angela Piersimoni, after 2pm
607/562-8823
Sharon McAvey, afternoon & evening
718/380-3792
William Carrington, 4pm-11pm
718/486-6953

North Carolina
*Susan Salzberg (Durham)
5pm-9pm 919/967-3118

Ohio
Roger Emmons 216/286-6485
Suzanne Lammi 513/339-4312
Norma Markowitz 216/247-8785
(Cleveland)

Oklahoma
Leah Holden 405/255-4491

Oregon
*Mary Elizabeth York 503/246-4939
(Portland)

Pennsylvania
*Dennis Devlin 215/269-2600 work
610/566-1882 home
(Delaware Valley)
Patricia Zelenowski 717/457-7067
Camille Walsh 215-747-5321
Janet Fierst 412/487-0757
Mary MacMinn 215/322-1073
Carol Henderson 215/424-1176

Rhode Island:
Robert Matteucci 401/647-9154 PM

Texas
Dr. Karen Edelson, D.P.M.
214/542-0048
M,T,Th, 8:30am-5pm, 214/542-0122
Tony Collette, 1pm-8pm, 713/699-8432
Ken Kerby 817/282-9329

Virginia
*Mary Jane King 804/591-0516
(Tidewater)

West Virginia
*Joan Plant 304/636-7152 after 6pm
(central)
L.Ben Simmers 304/693-7731
Beverly Simmers 304/364-5309
Ronald & Rebecca Sampson,
304/636-7449 24 hours
Barbara Compton 24 hours
304/636-5456

Blood Test Available

The blood test for diagnosing CMT Type 1A found on chromosome 17 is available from Genica Pharmaceuticals. They can be reached by calling 1-800-394-4493, ext. 106. Ask for Sarah Quiry, customer service representative. A physician must order the shipping kit. The cost of the test is $395.00. §

¿ Habla usted Español?

The CMTA announces the publication of a Spanish edition of our CMT Informational brochure (gray brochure).For a copy check the block on the order form on page 15. For multiple copies contact the CMTA office.

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.

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The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Associaton.The material is presented for educational purposes only and is not meant to diagnose or prescribe. While there is no substitute for professional medical care for CMT disorders, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.

CMTA Membership/Order Form

Name: ____________________

Address: ____________________

____

Phone Number: ____________________

Tell us about yourself:

☐ CMT Patient ☐ Medical Professional

☐ Interested Supporter ☐ CMT Family Member

Enclosed is:

☐ $25 ☐ $50

☐ $100 ☐ other

for my membership in the CMTA (newsletter included in membership)

☐ At this time I cannot contribute to the CMTA but would like to receive mailings.

Publications and Tapes available from the CMTA

(Check to order)

☐ VCR Tape - CMT Neurology ($15)

☐ VCR Tape - Physical Therapy & Occupational Therapy ($15)

☐ VCR Tape - CMT Genetics ($15)

☐ VCR Tape - Orthopedic Surgery & CMT ($15)

☐ Handbook (16 pp.) - CMT FACTS I ($3)

☐ Handbook (24 pp.) - CMT FACTS II ($5)

☐ Transcript - San Francisco CMT Conference ($5)

☐ Letter - to Medical Professionals regarding the drug list
(free to members with self addressed stamped business envelope)

☐ List - Physician Referrals (by state)
(please send SASE)
please list states:________ ________ ________

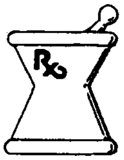
☐ CMT Informational Brochure (gray brochure)
(one copy free with self addressed stamped business envelope)

☐ CMT Informational Brochure (gray brochure) in Spanish
(one copy free with self addressed stamped business envelope)

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

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

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)
Perhexiline (Pexid)
Pyridoxine (Vitamin B6)
Taxol
Vincristine

Lithium, Misomidazole and Zoloft can be used with caution

Before taking any medication please discuss it fully with your doctor for

Referrals Available

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 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 business-sized 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 Surgery of the Hand, 6060 Greenwood Plaza Blvd., Suite 100, Englewood, CO 80111-4801, Ph.303/771-9236. §

CMT...

.... is the most common inherited neuropathy, 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, 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.

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

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

.... can, in rare instances, cause severe disability

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

.... Type IA can now be diagnosed by a blood test.

THE CMTA REPORT

information on Charcot-Marie-Tooth Disorders from the

Charcot-Marie-Tooth Association
Crozer Mills Enterprise Center
601 Upland Avenue
Upland, PA 19015

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TO: