

The CMTA Report

FALL 1997

Vol. 12, No. 4 ISBN #1067-0181

A resource for information on Charcot-Marie-Tooth disease (Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy), the most common inherited neuropathy.

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New York Academy of Sciences to Co-Sponsor International Conference

The New York Academy of Sciences (NYAS) will join the CMTA in sponsoring The Third International Research Symposium on Charcot-Marie-Tooth disorders. Set for October 23–25, 1998, at the Le Chantecler Hotel in Canada, the symposium will follow the American Academy of Neurology meeting to be held in Montreal.

The partnership of the CMTA and the NYAS represents a powerful collaboration with international reach.

Celebrating its 180th anniversary, the Academy is the third oldest scientific organization in the nation. NYAS has more than 45,000 members in nearly 160 countries, half of them outside the United States. The Academy's programs stress the interdisciplinary applications of science and technology. The Academy has a rigorous, two-stage peer review process.

The proposal for the program of the Third International Research Symposium was first sent to some 12 expert neurologists for review. Their comments were then considered by the Academy's 25-member Conference Committee, which approved the proposal and agreed to co-sponsor the meeting under the Academy's aegis.

Symposium chairman, Dr. Michael Shy of Wayne State University, acknowledged the significance of working with the New York Academy of Sciences. "The prestige of the Academy and their recognized excellence in planning meetings of this nature are a tremendous asset," remarked Shy. "The resulting book is assured the world-wide audience this subject deserves." The symposium proceedings will be published in the *NYAS Annals*, which has a distribution to more than 745 libraries. The *Annals* series is among the oldest (174 years) and the most frequently cited scientific publications—ranked in the top

2% of more than 4,500—and is part of the permanent collections of libraries around the world.

This interdisciplinary symposium will present the latest advances in clinical and pathological aspects of CMT, pathogenesis of demyelination in CMT, genotype/phenotype correlations in CMT, and diagnosis and therapy of CMT and immune-mediated neuropathy. Speaking on behalf of the Academy, Rashid Shaikh, PhD, Director of Science and Technology Meetings, said, "I am sure the meeting will be a great success and the resulting publication will be a landmark, meeting the high requirements of publications of the New York Academy of Sciences."

CMTA members will receive a special discount on the *Annals* when they become available.

ON THE HORIZON...



Drs. Lisa Baumbach and Walter Bradley from the University of Miami will co-host the next patient and family conference in South Florida in late February, 1998.

■ IF YOU GIVE AT THE OFFICE

Federal and some state employees have the opportunity to support the work of the CMTA through payroll deduction in their workplace through the Combined Federal, or state, Campaign. The Charcot-Marie-Tooth Association is listed under Health Charities of America on page 18 of the national directory.

The CMTA can also receive donations in most United Way campaigns. If your area offers donor choice, ask for a donor card and write in The Charcot-Marie-Tooth Association, 601 Upland Avenue, Upland, PA. 19015. We are a federally recognized 501(c)(3) charity and can receive funds through workplace donations.



The Year in Review

1997 Each year this organization makes great strides, but this year was marked by several amazing “firsts.” The CMTA took a huge step forward as an organization by hiring an executive director, Paul R. Flynn, who assumed his duties on the first of September. Even with this important step, the growth and accomplishments of the organization will depend on the work of our volunteers.

Last spring, with the help of the Kansas City support group, the CMTA hosted our first conference in the St. Louis area. Dr. Becky Parks gave an excellent presentation on pain, which many patients feel is the most unrecognized and untreated aspect of CMT. She discussed the drugs and other therapies that she prescribes to treat neuropathic pain. This was the first time that I have heard that pain from CMT can be treated, not just endured.

In the fall, we held a highly successful Patient/Family Conference at Wayne State in Detroit. The conference was organized by Ardith Fetterolf, Board member, and Dr. Michael Shy, Medical Advisory Board member and Program Chair for the Third International Conference on Charcot-Marie-Tooth disorders.

Research funding increased this year, thanks to the many members who contributed in response to the Evenor Armington Research Challenge. The postdoctoral fellowship, awarded to Agnes Jani of Wayne State, and the four summer internships will be reported on in the “Research” newsletter in February 1998.

Another first this year was the “Cycle for CMT I,” conceived and executed by Joe Beernink. Many thanks to Joe, whose fundraising efforts topped \$4000, which will fund a summer intern next year.

For the first time, the CMTA issued membership cards. I encourage every member to make it a priority to pay his or her dues because members provide our entire budget. Our mailing list grew to over 10,000 and the CMTA home page (www.charcot-marie-tooth.org) debuted this year. Please visit and let us know your thoughts.

The “firsts” for the CMTA this year have been many, and they have been significant. We are justifiably proud of what we have accomplished and we look forward to 1998, which will be the 15th anniversary of the organization’s founding. Please become an active part of the

Rod Steele Assumes Chairmanship, Dan Charny, Steve Scofield Join Board

J. Rodman Steele, Jr., senior partner with the law firm of Quarles & Brady, will serve as chairman of the CMTA board. Rod has a long history with this organization, having served previously as Vice President. Ed Butchko, past chairman, had this to say: “My primary goal was to see the CMTA hire an executive director. That being accomplished, I feel secure in my decision to leave the board.” “I am proud to have served the association,” Butchko said, “and applaud the election of Rod Steele, whose leadership skills will be a tremendous asset to the CMTA.” The CMTA gratefully acknowledges Ed’s efforts and commitment, as well as his ability to instill a “business approach” into board functions.

Rod Steele has developed his “consensus” approach to leadership and activism through service in greatly varied settings: the Judge Advocate General’s Corps of the US Army, numerous bar associations, the Ann Norton

Sculpture Gardens, the American Swedish Historical Foundation, the South Florida Science Museum, the Enterprise Development Corporation, and the alumni association of the Dickinson School of Law. As CMTA chairman, Rod is anxious to introduce his South Florida community to the CMTA for the purpose of boosting awareness and raising much needed funds for research. Rod and his family have lived in the Palm Beach area for the past ten years.

Business acumen is certainly a strong point for new board members Dan Charny and Steve Scofield. Dan graduated from the University of Pennsylvania with a degree in electrical engineering, which was followed by four years of service in the US Navy. He went on to work in advertising, marketing, sales promotion, and public relations for such companies as General Electric, IBM, Revlon, ITT, General Motors, and others. After a stint as a math teacher in New



CMTA MEMBERSHIP/ORDER FORM

Name: _____

Address: _____

Phone Number: _____

If you are unsure as to whether you are current with your member dues, please call the office at 1-800-606-CMTA.

	QTY	COST	TOTAL
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		members \$15 non-members \$20	
Membership Dues		\$25	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		members \$3 non-members \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		members \$5 non-members \$7	
CMT Facts III		members \$5 non-members \$7	
VCR Tape: CMT Neurology		members \$15 non-members \$18	
VCR Tape: Physical Therapy & Occupational Therapy		members \$15 non-members \$18	
VCR Double Tape: duPont Conference		members \$25 non-members \$40	
CMT Informational Brochure <input type="checkbox"/> English <input type="checkbox"/> Spanish		FREE	Send Self- Addressed Stamped Envelope
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to Armington Challenge for CMT Research			
TOTAL			

Check payable to the CMTA

VISA MasterCard

Card Number _____ Expiration Date _____

Signature _____

Mail to the CMTA, 601 Upland Ave., Upland, PA 19015

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.

Pat Dreibelbis, Director of Program Services, Krista Hall, RN, CMTA Board of Directors, and Paul Flynn, Executive Director, registered attendees as they arrived at the conference site in Detroit, Michigan. See page 12 for "A Day in the Life" of Pat Dreibelbis.

association by attending a conference, contributing to research, paying membership dues, reading and responding to the newsletter, joining a support group, or offering your expertise in some area of the association's endeavors.

Diane Freaney
President

York City, Dan pursued business interests related to the marketing and manufacturing of computers and peripherals. CMTA members recall Dan's wife, Gloria, a member of the Westchester County Support Group, who was highlighted for her "quilting fundraising" projects that benefited the research fund. Dan and Gloria live in Dobbs Ferry, NY.

Stephen Bruce Scofield hails from Kingsville, TX, where he is an assistant professor in the business school at Texas A&M University. Steve is a certified public accountant and worked as a tax consultant for many years. In addition to the CMTA, his philanthropic interests include board service at the Big Brothers/Big Sisters of Nueces County and the Kiwanis Club of Kingsville. Scofield has a uniquely varied educational background culminating with the Doctor of Business Administration from Louisiana State University. His schooling in the disciplines of psychology, philosophy, and accounting influenced his scholarship, as indicated by his published works, which address the logic and ethics in accounting and business functions.

Members of the CMTA's Medical Advisory Board met during the proceedings of the American Neurological Association in San Diego, California, to discuss recent research findings and to bear a presentation on HNPP. Seated from left to right: Dr. Robert Lovelace, Chairman, Dr. Fran Dyro, Paul Flynn, CMTA Executive Director, Eric Liebler, External Relations, Athena Neurosciences. Standing from left to right: Dr. Linton Hopkins, Dr. Walter Bradley, Dr. Mark Bromberg, Dr. Lefkos Middleton, Dr. John Hsu, Vince Bertolino, Director of Neuro-genetic Testing, Athena Diagnostics, Dr. Phillip Chance, Dr. Ed Ehrman.

What Is HNPP?

By Maureen Horton,
edited by Dr. Phillip Chance, the CMTA Medical Advisory Board

Editor's note: The CMTA will be working with Maureen to keep our readership updated on HNPP. She has HNPP and first noticed problems during her pregnancies. She was finally diagnosed with HNPP and because information was so difficult to find, she began to teach herself about the disorder. As a nurse, Maureen offers our readers both the personal side of the disorder and medical expertise on the subject.

Hereditary neuropathy with liability to pressure palsies or HNPP is associated with a deletion on chromosome 17p11.2-12. This is the same chromosomal site where CMT1A has been found to have a duplication, and it contains an important myelin gene, peripheral myelin protein-22 gene (PMP22). Therefore, while CMT1A results from having an extra copy of PMP22, HNPP results from the loss of a copy of PMP22.

HNPP is caused by an autosomal dominant gene. HNPP is also a demyelinating form of neuropathy like CMT1A. However, the affected nerves in HNPP are described as having focal regions with "tomaculous" changes or sausage-shaped figures, due to the irregular thickening of the myelin sheath.

HNPP causes episodes of numbness and weakness, similar to an arm or leg going to sleep. But instead of lasting only a few seconds, as it does in a normal person, this numbness and weakness can last from several minutes to months. These episodes may be associated with fairly mild trauma (stretching or pressure on the nerves) that would not ordinarily affect a normal person, such as: leaning on elbows, crossing

legs, cutting with scissors, knitting, kneeling, sleeping in the wrong position, etc. It has usually been described as a painless disorder, although some people do have pain, which is probably a subjective sense of numbness. Most individuals with HNPP have normal strength and sensation, unless experiencing an attack.

Typically, persons who have inherited HNPP will develop symptoms in their teens or twenties, but individuals may be first symptomatic during childhood or late adulthood. Like CMT, there is a wide range in how severely people are affected. For many people, symptoms are so mild that they are unaware that they have a problem. Others develop the symptoms of a more generalized hereditary motor and sensory neuropathy, which on occasion may be misdiagnosed as a form of CMT. Carpal tunnel syndrome is frequently seen in patients with HNPP.

As a hereditary neuropathy, it is progressive, though to what extent it will progress in any individual is unknown. There is no treatment or cure for HNPP. People are usually advised to avoid activities that they have learned cause symptoms to develop. Leg crossing and leaning on elbows is discouraged. AFOs can be used during periods of acute peroneal nerve palsy or for permanent foot drop and/or balance problems.

DRUG INTERACTION WARNING

The November/December 1995 NAMI Advocate warned of a potentially fatal drug interaction.

It involves selective serotonin reuptake inhibitor antidepressants such as Prozac, Zoloft, Paxil and Luvox. Apparently, a drug interaction between these antidepressants and dextromethorphan and/or pseudoephedrine, found in over-the-counter cold remedies, can cause excessive serotonin activity. Signs of this "serotonin syndrome" include changes in mental status, hypertension, restlessness, myoclonus (sudden muscle contraction), hyperreflexia (accentuated reflexes), diaphoresis (profuse perspiration), shivering, and tremor.



CMT, EMPLOYMENT, and THE AMERICANS WITH DISABILITIES ACT

By Peter D. Nugent, PhD, Rockhurst College, Kansas City, MO

THE AMERICANS WITH DISABILITIES ACT 1990

The ADA guarantees equal opportunity for disabled individuals in:

- public accommodations,
- employment,
- transportation,
- state and local government services, and
- telecommunications.

In the area of employment, this law requires employers to make a “*reasonable accommodation*” to *disabled*, qualified individuals who are able to perform the “essential functions” of the job. This applies to both applicants and current employees.

WHO IS DISABLED?

The ADA considers an individual to be disabled when:

- that individual suffers from an impairment that substantially limits major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for one’s self, and working, OR
- the individual has a record of such an impairment, OR
- the individual is regarded by the employer as having such an impairment.

The law does not protect individuals who are **currently** drug users, or alcoholics, or possess sexual identity problems.

WHAT IS MEANT BY “REASONABLE ACCOMMODATION”?

A reasonable accommodation is any modification or adjustment to a job or the work environment that will enable a qualified applicant or

employee with a disability to perform the essential functions of the job.

A reasonable accommodation will vary on a case-by-case basis; what is required in one case might not be in another case.

Examples of such accommodations might include:

- acquiring equipment such as voice-activated computers, large screen monitors, specially designed office equipment, and TDD facilities,
- modifying work schedule,
- restructuring the job,
- modifying existing machinery or,
- modifying the work area.

The employer is NOT required to make an accommodation that would impose an “undue hardship” on the company.

HOW DOES CMT FIT INTO ALL OF THIS?

Individuals with CMT are covered only if the disease substantially limits a major life activity.

Thus, the severity of the disease will determine whether an individual is disabled under the meaning of the Act.

Simply being diagnosed as having CMT is probably not sufficient to meet the requirements of the Act.

PROTECTING YOUR RIGHTS

If you are a victim of employment discrimination because of a disability, you should contact the local office of the Equal Employment Opportunity Commission (EEOC), the federal agency that administers the ADA. They will assist you.

The ADA has a clause that protects you from any retaliation from your employer because you filed a complaint.

If you want the protection of federal and state employment laws, you must take an **active** role.

OF INTEREST

For “designer” canes and walking sticks, call or write the House of Canes and Walking Sticks, 767 Old Onion Mountain Road, P.O. Box 574, Wilderville, OR 97543 (800-458-5920) for a catalog with an extensive collection of shafts made of walnut, oak, ebony, birch, lucite; covered with fabric; handles and knobs made of sterling silver, silver-plated, brass, etc.



Wayne State University Hosts Conference on CMT

A conference on Charcot-Marie-Tooth disorders was held on October 18, 1997 on the campus of Wayne State University in Detroit, Michigan. Ninety-four attendees heard the following presentations: Dr. Steven Hinderer on rehabilitation, Dr. Michael Shy on the neurology of CMT, Dr. William Quinn on surgical and corrective options for CMT patients, Dr. John Kamholz on the historical perspective in CMT research, and Eric Hughes, a representative of Athena Diagnostics, on the DNA test for CMT Type IA, IX, and HNPP.

Breakout sessions also were held on the ethical and genetic issues in CMT testing, moderated by Dr. James Garbern and genetic counselors Ann Greb and Karen Walkowicz. Dr. Dan Duffy and Ms. Karen Gatrell, assisted by Dr. William Quinn, discussed occupational and physical therapy and demonstrated braces and shoe

inserts for CMT patients. Drs. Michael Shy and John Kamholz also led a workshop discussion on new approaches to the treatment of CMT. A final workshop on pain and pain treatment was run by Dr. Richard Lewis.

Over half of the people attending took the time to fill out the questionnaire and some of the comments included, "the high point was interacting with others affected by CMT and meeting really interested and dedicated medical researchers." One person wrote, "The conference was outstanding! Please continue to share practical information regarding exercises, physical therapy, and orthotics." Constructive criticisms were related to presentation content and creating defined roles for volunteers. Although the conference lasted six hours, many participants wished there could have been more time.

A highlight of the conference was the tours

Marilyn, Anna Lucia, and Carlos Troetsch traveled all the way from Panama to Detroit to attend the patient and family conference at Wayne State University.

ABOVE AND BEYOND

Since the concept of an "Above and Beyond" column was formulated, the number of possible subjects has been surprisingly high. This issue we salute a group of doctors who went out of their way to help a couple whose 3¹/₂-year-old daughter had been diagnosed with CMT in Panama, where the disorder is not well known.

Carlos Troetsch called our office, having found the association on the Internet. He was

interested in attending the Detroit conference in the hope of finding out more about the disorder that his young daughter had recently been diagnosed with. During subsequent calls, it was suggested that perhaps it would be a good idea to bring his daughter and wife along so that Anna Lucia could be evaluated by the doctors at Wayne State. When Carlos called Dr. Michael Shy, he was encouraged to do so. Only a week before the conference, Dr. Shy committed to finding the time to examine and evaluate Lucia.

Virtually everyone in this story went "above and beyond" what might normally be expected. Carlos, his wife Marilyn, and their daughter spent six hours stuck in the Miami airport waiting for a repair to their plane so they could make the connection to Detroit. Arriving tired and travel-worn, they got very little sleep and still arrived at Wayne State early Saturday morning. Between presentations, Dr. Shy and Dr. Dan Duffy, a physiatrist, examined Lucia and did a gait analysis. Dr. Duffy wrote a prescription for the family to take back to Panama so that Lucia would get some help with her gait.

The most astonishing example of going "above and beyond" came eight hours after the day had begun for the doctors at Wayne State. After the conference, they took the Troetsch family into the lab and Dr. Richard Lewis donated his time to do a nerve conduction velocity on



of the research facilities conducted during the hospitality reception Friday night and following the conference on Saturday. The current recipient of the Evenor Armington CMTA research grant, Dr. Agnes Jani, was available to discuss her research on Friday night during the tour.

Especially notable was the distance that many people traveled. Several people came from California to attend and one family journeyed all the way from Panama (see “Above and Beyond” below). Attendees from Pennsylvania, Virginia, and many midwestern states further demonstrated the great need for information and the lengths to which people will go.

The next planned conference for patients and family members will be in South Florida late in February, 1998. All members of the CMTA living in Florida will receive a first-class mailing and registration for the conference. Members interested in receiving a registration should call the office (1-800-606-2682), fax: 1-610-499-7487 or e-mail us at CMTA@charcotmarie-tooth.org after the 15th of January.

both Carlos and Marilyn. Since only Lucia seems to have clinical symptoms, the doctors were trying to determine whether she was an example of spontaneous mutation or a different type of recessive CMT Type I. Both parents tested normal.

Dr. John Kamholz then studied the genetic testing results that the family had brought from Panama and decided that the little girl was probably a Type IA patient, but gave the parents an Athena Diagnostics test kit so they could have her blood drawn and sent to Athena when they returned home to Panama.

After all of this, Drs. Kamholz and James Garbern spent time doing genetic counseling with the parents to help them understand that in all likelihood they would not have another child with CMT because their daughter's case was the result of a spontaneous mutation. That information was especially crucial to the parents because they were in the process of deciding whether to have another child.

When the day ended, it was almost 6:00 PM and the doctors had been donating their time to make presentations or run workshops and do the diagnosis for the Troestch family since 8:00 AM that morning. The doctors at Wayne State (Michael Shy, Rich Lewis, John Kamholz, Dan Duffy, and James Garbern) had most definitely gone....”Above and Beyond.”



Beth Troutman, President of the Women's Civic Group of Hershey, PA, and her mother, Shirley McKee, announced at the organization's first meeting that the CMTA would be the beneficiary of their fundraising efforts for the 1997-98 year.

A Gypsy's Menu: A Donut, Chocolate, and Alphabet Soup

By Paul R. Flynn, Executive Director

Twelve cities in nine weeks, a healthy dose of alphabet soup—AAN, ANA, APMA, ASHG, HNPP, NORD, NSFRE, NYAS, MAB, MDA, and PFA (see sidebar page 9), all beginning with a donut and chocolate. Conferences, meetings and networking made for a busy travel schedule in my first two months, which began in a funny way; though I was not laughing at the time. The day after Labor Day and the Jerry Lewis Telethon was my first day—which called for me to speak to the Women's Civic Group of Hershey, PA. Beth Troutman, the group's new president, (see photo above), invited a representative of the CMTA to give a presentation because we would be the beneficiary of her organization's fundraising activities this year. What a great start to my new job...

On Route 78, 40 minutes west of home, my passenger-side, rear tire blew out. The silver lining: it was a warm (hot, actually, as I recall sweating profusely), perfectly sunny day, I was casually dressed with the intent of “dressing for success” upon arrival, and it was the “best” tire to blow out because it was safely on the inside part of the shoulder and the rear is lighter to lift.

But all that glitters is not gold or silver lining for that matter—a big old dark cloud quickly descended. I pulled out the jack, tire iron, and donut and set about my task. As I knelt for better leverage, I felt a large rock under my knee. *Entomologist alert*, pulling out the rock unearthed perhaps the largest ant colony in Clinton, NJ, the inhabitants of which quickly began climbing up my sneakers and pants...swat the ants, crank down the jack, tighten lug nuts, pull car forward, and out of range.

Ultimately, rental car found and a few hundred miles later (God as my navigator and fuzzbuster), I made it just in time, still casually dressed though. Again, let me express my thanks to the women of Hershey, where the lamplights are chocolate kisses and pretenses need not be made.

By comparison, the rest of my time may be viewed as less eventful but certainly productive. I must acknowledge the many well-wishers who bade me good luck, some of whom remarked, “Oh, you're the one holding the baby in the last newsletter...” Yes, and holding my own thus far. I look forward to personally meeting many more members and having the chance for us to work together.

WEB SITES FOR KIDS

Ability OnLine Support Network:
<http://www.ablelink.org>

An electronic mail system that connects young people with disabilities or chronic illnesses to disabled and nondisabled peers and mentors.

Band-aids & Blackboards:
<http://funrsc.fairfield.edu/~jfleitais/contents.html>

This cleverly designed site will help sensitize nondisabled children to what it's like to grow up with a medical problem.

Convomania:
<http://www.mania.apple.com/mania/convohome.htmw>

This web site from Apple computer features bulletin boards, art, chats, quizzes, and more for kids with serious illnesses or disabilities.



A Journey Toward Wellness

By Cynthia Gracey

"My Mama always told me that miracles happen every day. Some people don't think so, but they do."
 —Forrest Gump

When I was a child, I stumbled a lot. Doctors couldn't find reflexes in my legs or arms. Gym and dance were not my favorite classes at school, and finally at 13, after a variety of neurological tests, I had a muscle biopsy and was diagnosed as having CMT. At the time my parents were distraught; my longevity was questioned and my future mobility was assumed to be severely limited. The year was 1966. I was given leg braces to wear at night and certain exercises to do by day, none of which appeared to have any effect. As time went by, I did not appear to get worse and, as there was nothing to be done anyway, my parents and I dismissed the diagnosis. I knew I was never going to be a dancer or an Olympic athlete or a marathon runner, but then, so what? I could still walk, ride, hike, albeit with some difficulty, and not much grace, but I could still do it.

It was not until I was in my mid twenties when I came back from living in Hawaii to rejoin my husband in Philadelphia and started attending law school that my symptoms became more severe. Winter, the stress of law school, an abusive marriage, my family of origin in turmoil, all on top of an extremely stressful childhood, finally took an excruciating toll. My body no longer responded the way I was used to. I felt like I was moving through molasses. Each step was a challenge and each hand gesture a feat of mind over matter. My meditation, my vegetarian diet, my therapy, nothing seemed to be having an impact on the slow, but seemingly inevitable, progression of weakness in my body. Eventually I could no longer ignore my physical deterioration. Thankfully, I had access to what I thought was the best advice that traditional western medicine had to offer in the late 1970's.

After several examinations by a neurologist, an orthopedic surgeon, and a psychiatrist (just in case) the prognosis came back once again, CMT. The treatment they recommended consisted of fusing bones in my ankles for stability, rerouting muscles and nerves...and doing this one leg at a time. They informed me that each leg would be in a cast for several months, after which the leg would require many more months of physical therapy. I was told I might never quite recover

the strength that I had at the present time.

It was hard for me to believe that everyone was serious about this. I remember leaving the room and deciding that I would never do any of what they had so earnestly recommended. Simultaneously I decided I was going to have to do "something" and that the "something" was going to be to follow a different path of healing.

So I did. The first alternative therapy I chose proved very successful. Good fortune, knowledge, intuition, and the need just to do that "something" guided me. My healing journey, through both alternative and traditional terrain, continues to this day.

In the process of discovering healers, teachers, ideas, technologies, and products that really worked, I began to share what was helping me with those who wanted to know. My job became to try to distill and formulate into some system the enormous amounts of experience and data I was processing. I discovered that the basic axioms for healing were truths that had been around a long time. These principles did not just work for healing the physical body, but they worked for creating "wholeness" of body, mind, soul, and spirit.

I found guidance from teachers, techniques, worlds, and experiences, some of which even today I have difficulty writing about. Intense. Alien. Not always culturally acceptable but irresistibly attractive. I continued to learn. I was seeking to heal my body and, in the process, I began to discover my soul.

As my body became stronger and healthier, I began jogging. Equipped with great shoes and an inner vision that it just might be possible, I began running (if you could call what I did running!) at night. At first my night running was so that no one would see me, but it became an adventure to be running in the night, experiencing myself as athletic and vitally alive. I was putting all that I had learned into practice and my dream was coming true. I was running. At my peak, I ran 7 1/2 miles.

There were three important axioms generating the energies of healing and accomplishment at this time in my life. They were:

1. Imagination is more important than the evidence.
2. A developed intuition makes decision-making easier and more effective.
3. The more aligned your life is with your

values, the less friction and stress are generated.

With my newfound energy and vitality, I discovered a desire, a primary value: to contribute. I worked in politics. I co-founded an executive women's group. I managed workshops for healers from around the country. I volunteered my time for hunger and environmental issues. I participated in human development workshops. I practiced law. I dated. I bought a house and renovated it and I eventually I suffered from severe stress, burnout, and inflammation of my connective tissue. Not only could I not run, but just sitting or lying down was painful. I had not listened to my body. I had not honored all my primary values (just the ones that were easy to honor) as I had literally and figuratively ran after my vision of well being.

I rethought my process. I began to really look at my values and began to ruthlessly extricate myself from those things I knew were not honoring my inner-most self. Through trial and error, I discovered that living more "on purpose" made life easier. There was less stress and friction in all aspects of my life. Healing on many levels, including the physical, began to occur. There also seemed to be an abundance of unexpected support from likely and unlikely sources. It seemed that God or life was more than willing to empower my journey as I walked more and more in alignment with my core orientation. I continued my alternative healing and spiritual journeying. It took me two humbling years to get my body back to walking and sitting without pain and discomfort. I was miserable in the world of business, politics, and finance and felt more comfortable in the world of mystics, healers, visionaries, and artists. I left the practice of law. I married a gentle and compassionate man, and we had two beautiful and healthy children (after being earnestly counseled by a traditional doctor that I probably did not have CMT and that it would not affect my children in any event!). Nothing in life prepared me for how much I have learned about love and kindness, joy and caring, from my husband and my two sons. Through my boys, I daily experience a new and profoundly deep kind of nurturing love.

At this juncture in my journey I discovered two other important axioms: 1. Develop the ability to listen to your body, and healing happens. 2. The combined experience of safety, love, and nurturing accelerates the healing process.

Again I feel healed, well, vital, and whole. And daily I have to address what that means and how to maintain and enhance this experience. I continue to shape my career as a consultant. I develop workshops, evening lectures, orchestrated experiences, and retreats all based on what I am most passionate about: "that which heals, that which enhances vitality, and that which encourages alignment with one's inner self."

I no longer run, but I work out gently in the gym. Sometimes I take those running shoes out and wonder about putting them on again, especially as the nights start earlier and the temperature is dropping from sweltering to cool....

I remember something my mother taught me: Focus your will, your desire, and your intentions on a dream and let the angels take care of the rest... and I do (when I remember).

In future articles I will be sharing some of the teachers, doctors, and alternative practices that have been most helpful and some that were not. These articles will hopefully give you some guidance as you set out to incorporate any of the wide range of body, mind, and spirit practices into your well being journey. I will be delighted to address any questions that you might have. Send them to Cynthia Gracey, c/o the CMTA or email me at pathcg@aol.com.

The Starfish... author unknown

One child came upon another child on the beach one day. The second child was walking along, looking down, then every few feet would bend down, pick something up out of the sand, and toss it into the ocean. The first child asked what kind of game this was.



The second child replied, "I'm saving starfish."

The first child was incredulous. "Are you kidding? There are too many! What are you going to do? Spend all day and night out here, tossing starfish back into the ocean? You'll never save them all. And anyway, in the grand scheme of life, they're just starfish. It doesn't matter if they live or die."

The second child scooped another starfish from the sand, considered it briefly, then hurled it back into the ocean.

"It mattered to that one."



**YOU CAN REACH
CMTnet
ON THE INTERNET**

@URL<<http://www.ultranet.com/~smith/CMTnet.html>>

ALPHABET SOUP ...

AAN = American Academy of Neurology

ANA = American Neurological Association

APMA = American Podiatric Medical Association

ASHG = American Society of Human Genetics

HNPP = Hereditary Neuropathy with Liability to Pressure Palsies

NORD = National Organization of Rare Disorders

NSFRE = National Society of Fund-Raising Executives

NYAS = New York Academy of Science

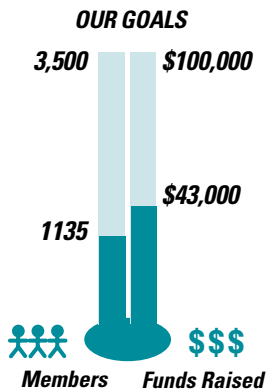
MAB = Medical Advisory Board

MDA = Muscular Dystrophy Association

PFA = Pedorthic Footwear Association

A Day in the Life...

HOW WE'RE DOING:



Pat Dreibelbis, Director of Program Services, began working for the CMTA in 1990, part-time, and has since become a full-time employee, the CMTA's first. Many members benefit from her empathic ear and informed judgement. She serves not only as the backbone, but also as the front line, of the CMTA; the first, and oftentimes, only person callers speak to. Pat balances numerous tasks but always manages to put people first. As the "broker" between the CMTA's various subsets (board, members, support groups, medical professionals, etc.), she facilitates nearly all activities and serves as our institutional knowledge.

Pat taught English in the high schools of Reading and Hershey, Pennsylvania, for 11 years before retiring to raise her two children. With her children nearly grown (one daughter, a junior at Hamilton College, and one son, a freshman in high school), Pat has taken on more responsibilities and travels to conferences and meetings throughout the country. In her seven years of work with the organization, Pat has seen the organization grow from 2,000 members to well over 10,000 and the research into the causes and treatments of CMT "take off" in ways that she could never have imagined.

It's 8:30 AM. The first call today is a woman from California devastated because her young daughter has been diagnosed with Charcot-Marie-Tooth and she had never heard of the disorder, never had anyone in the family diagnosed with it, and was totally unaware of what her daughter might be facing. She was given a dismal prognosis from the pediatric neurologist and was devastated by the speed with which her dreams for her child's future had seemed to vanish. For the next

hour Pat explains the disorder, giving her the names of doctors to contact, and perhaps most importantly, giving her lots of reasons to feel optimistic again about her daughter's future.

The phone rings early, but it also rings often. At 10:00 this morning a call comes in about what side effects one might expect from taking a "neurotoxic" drug. A man has been prescribed Zoloft and although it is listed as "take with caution," he needs reassurance that he can begin the treatment and he needs advice as to what he should look for if he has any reaction to the medication. Pat tells him about paying attention to his body and watching for exacerbation (worsening) of his imbalance, his tingling, his numbness, and a host of other possible reactions. Individuals react differently to drugs, so Pat urges him to contact his neurologist. A quick call, this one lasts only a few minutes.

A break from the phone... announcements must be sent about two new support groups forming. The flyer must be formatted and printed and labels must be generated. Then, the envelopes can be stuffed and stamped. That task completed, on this day, there is also the Detroit conference to attend to. Registration forms must be designed and printed. Again, the task of mailing to hundreds of members of the CMTA is interrupted by the phone.

It's now close to noon on the east coast and this call is from a man whose granddaughter has just been diagnosed. The family is distraught. Only he is in enough control to place the call. The family fears the worst. They believe the little girl's life might be shortened by the CMT. It takes a long time to explain the disorder in lan-

BROKEN RECORD PLAYS ON

My apologies to Ringo Starr and Pat Dreibelbis, Director of Program Services. While Ringo may not like his lyrics (*You know it don't come easy*) being used in this manner, at least he doesn't have to listen to me over and over talking about membership dues. Pat does.

Dues fuel the CMTA, enabling us to serve you through our newsletter, 800 number, Internet service, doctor referrals, etc. The \$25 membership dues signifies your most basic level of support and is essential for us to continue to serve you.

So I ask you to send your check today and help me change my tune... Please, *Just Due It*. For Pat!—Paul Flynn

◀ Poor Pat, stuck inside of Upland with the member dues blues again.



guage that lay persons can understand, but it takes even longer to assuage fears and make sure that someone has actually "heard" what has been said. The conversation ends with the promise that a packet will be sent out immediately by first-class mail. The caller concludes the conversation by saying, "My wife is at home and needs to talk to you. She's very upset and you can really help her. I'll have her call you."

The phone rings 15 minutes later. It is the grandmother who needs the information and the reassurance. This conversation ends with her saying that her daughter and son-in-law need to hear this, as well.

Lunchtime has come and gone. A hot bowl of soup was sacrificed to the caller from Washington state.

It's 1:00 PM and there are letters from the day's mail that need answers. Two requests are simple. The first person needs a doctor to examine her young son and Dr. Harold Marks, in Wilmington, DE is the perfect choice; the second wants to be seen somewhere in Texas... Baylor and its experts are offered. One letter is a "Dear Doctor" question that will have to be sent out to someone on the Medical Advisory Board. One person has retold his life story and really only needs someone to listen. Still, a response must be written.

There are packets to fill, books to mail, and videos to be packaged. But the phone rings again. It's 2:30 PM and a doctor is operating on a patient with CMT and wants to have the neurotoxic drug list and the article on anesthesia faxed to him before he begins. His request is filled right away.

A call about membership. Someone just gave \$25 before the membership campaign began. Can they have a membership card? Absolutely!

The day is winding down, but the phone never rests. Someone has just found the organization through the Internet and has questions about almost everything. Thirty minutes later, she has had many questions answered and has learned enough to have created even more questions. After dealing with CMT for 20 years and having no idea that this organization existed, she is excited to have found us. A packet is filled and addressed almost before the conversation ends.

It's 4:30 PM and the computer needs to be backed up before the office closes for the day. There are still conference registrations to finish tomorrow and packets to mail and thank you's to be written, but there is no more day left in which to do them. They will wait... the people could not.

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Ralph H. Binford
Marilynn Dodge

Samuel C. Cantor
Eddy Cantor

Henry Clesen
Charles & Janice Schult

Alvin A. Chiri
Mr. & Mrs. Frank Gunnison

Margaret "Pat" Crawford
Betty Breitengross
John & Irene Bruecker
Leslie L. Crawford
Mr. & Mrs. Earle L. Deaner
Mr. & Mrs. James E. Farrell
Nancy Gothier
Ross & Gesa Kearney-Clark
& Dr. Patrick Kearney
John & Norine Madden
MaryLou & David Maudsley
Marie C. McCalmon
Norine Miller
Mrs. Berniece E. Rhoda
The Greve & Selvassio
Families
Jerry Sharp
Vivian V. Teague
Gloria & Jack Thoner
Martha & Clifford Williams

Peter W. DeJong
Bob & Mary Williams

Nora Hawley Gibbons
The Robert Shreve Family
David & Joan Tompkins
Richard & Pearl Young
Linda Vogel

Lillian "Bunny" Greenberg
Stuart Bindeman
Jeff & Phyllis Brenner
Mrs. Sally Ellis
Nancy & Howard Finkelman
& Family
Faye First
Mr. & Mrs. Robert Footlick
Esther Fort
Dorothy & Ben Frauwirth
Mr. & Mrs. I.E. Friedlander
Ann & Joel Friedman
Jeanette Garber
Mr. & Mrs. Jerome
Greenberg
George & Gloria Harris
Mr. & Mrs. M. Holzman

Lillian Hurowitz
Sheila Kosman &
Ruth Finkelman
Susan & Norman Finkle
Ina & Morty Goldstein
Mr. & Mrs. Robert Lachin
The Lavitt Family
Olga Levin
Selma & Philip Levin
Jutta & Harold Levy
Sissie & Herb Lipton
Terrie & Jeff Manchester
Mr. & Mrs. I. R. Mollen
Linda & Larry Nissenbaum
The Pollan Family
Marion F. Poms
Mr. & Mrs. Ernest Robertson
Harriette & Bob Rosen
Marjorie & Charles
Rosensweig
Mrs. Diane Weinfeld
Ann & Richard Young

Kathleen Hall
The Complin Family, Gordon
& Rebecca
Marmion Complin
Mike & Aloha Lee Grant
Mrs. Phyllis C. Higginson
Mr. & Mrs. W. D. Pringle
Mr. & Mrs. Dennis Pringle

Barbara Liek Hawkes
Robert W. Hawkes

Kevin Hoar
Robert W. Chirillo
Friends of Palm Shores
Robert W. Hawkes
Terrie W. Hoar
Cathy Mafra
Sylvia Maliga
Palm Shores Social Club
Evelyn Smithem
Vaughn & Eileen Stancage
The VanGorder Family
John & Joan Wilhelm

Landa Hoy
Mr. & Mrs. Richard Hill

Peter LaPorte, Sr.
Stacey Bahian
Margaret E. Boyd
Don, Nancy, Katie & Annie
Edelman
Mr. & Mrs. John Ferri
Mr. & Mrs. William J. Hill

Marion Newhouse
Marie M. Kroninger

**Dr. Abraham Sand &
Rebecca Sand**
Mr. & Mrs. Mark Sand

Edna Seendermann
Elsie Crawford
Ron & Norma Urban

Arlene Shapiro's son, Kenny
Harriet and Frank Weiss

Maurice A. Silver
Gisa Indenbaum

Thelma Smith
Wallace & Jerry Taylor

Florence Spooner Vinson
Sam & Joan Spooner

Kevin Wales
Greg & Beverly Bates
Ron Crowe Family
Mrs. Arlene Ratliff & Family
David & Jean Vess
Kenneth & MaryLou Wales
Jared & Lynn Walker
Guy & Betty Woodward

IN HONOR OF:

**Kay Flynn's receiving the
Volunteer of the Year Award**
Kay O'Leary

Lydia Musgrave's Birthday
Jo Wilson

**Terrie Rosengarden &
Marilyn Berger &
Abbe O'Donnoghue**
Harriet Weiss

**Catherine Salerno's
90th Birthday**
Dr. & Mrs. James Trezza

**Alexandra
Segal's Birthday**
Helene Segal

Our apologies to Percy H. Sand and Pearl A. Sand, who were listed incorrectly in the last issue of the newsletter under contributors to the research fund.

NOTES TO FINANCIAL STATEMENTS

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Operations

The Charcot-Marie-Tooth Association (the Association) was established to create awareness of Charcot-Marie-Tooth (CMT) disorders within the health care community and the general public, and be a leading source of information regarding CMT disorders. The Association encourages, promotes and supports research into the cause, treatment and cure of CMT. The Association also facilitates education and support for persons affected by CMT.

Basis of Presentation

The organization follows Statement of Financial Accounting Standards (SFAS) No. 117, Financial Statements of Not-for-Profit Organizations to prepare its financial statements. Under SFAS No. 117, the organization is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Restricted and Unrestricted Support

The organization follows SFAS No. 116, Accounting for Contributions Received and Contributions Made in recording contributions received. Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence and/or nature of any donor restrictions.

Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the Statement of Activities as net assets released from restrictions.

Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires the use of estimates based on management's knowledge and experience. Accordingly, actual results could differ from those estimates.

Functional Allocation of Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefitted.

Charcot-Marie-Tooth Association

INDEPENDENT AUDITOR'S REPORT

To the Board of Directors
Charcot-Marie-Tooth Association
Upland, Pennsylvania

We have audited the accompanying statement of financial position of Charcot-Marie-Tooth Association (a Pennsylvania nonprofit corporation) as of June 30, 1997, the related statements of activities, cash flows and functional expenses for the year then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free

of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Charcot-Marie-Tooth Association at June 30, 1997, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.



July 24, 1997

STATEMENTS OF FINANCIAL POSITION

JUNE 30, 1997 WITH COMPARATIVE TOTALS FOR JUNE 30, 1996

ASSETS	1997	1996
CURRENT ASSETS		
Cash	\$169,216	\$136,460
Accounts receivable - grant	169,216	161,460
EQUIPMENT—Net of accumulated depreciation of \$9,411 and \$6,189	18,044	5,104
OTHER ASSETS	265	265
TOTAL ASSETS	<u>\$187,525</u>	<u>\$166,829</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 5,005	\$ 3,104
Accrued expenses	250	250
TOTAL LIABILITIES	5,255	3,354
NET ASSETS		
UNRESTRICTED		
Operations	88,132	92,410
Board designated for research grants and education	14,179	14,179
	102,311	106,589
TEMPORARILY RESTRICTED	79,959	56,886
TOTAL NET ASSETS	182,270	163,475
TOTAL LIABILITIES AND NET ASSETS	<u>\$187,525</u>	<u>\$166,829</u>

STATEMENTS OF CASH FLOWS

JUNE 30, 1997 WITH COMPARATIVE TOTALS FOR JUNE 30, 1996

	1997	1996
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 18,795	\$ 48,360
Adjustments to reconcile change in net assets to net cash provided by operating activities		
Depreciation	3,223	1,832
(Increase) decrease in assets		
Accounts receivable - grants	25,000	(25,000)
Other assets	-	(100)
Increase (decrease) in liabilities		
Accounts payable	1,901	1,038
Accrued expenses	-	(177)
Net cash provided by operating activities	48,919	25,953
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase of property and equipment	(16,163)	(4,871)
NET INCREASE IN CASH	32,756	21,082
CASH - BEGINNING OF YEAR	136,460	115,378
CASH - END OF YEAR	<u>\$169,216</u>	<u>\$136,460</u>

The accompanying notes are an integral part of these financial statements.

Financial Report as of June 30, 1997

NOTES (cont'd.)

STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 1997
WITH COMPARATIVE TOTALS FOR JUNE 30, 1996

	1997			1996 TOTAL
	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL	
SUPPORT AND REVENUES				
Contributions	\$125,540	\$76,994	\$202,534	\$200,280
Conference fees, net	3,238	-	3,238	-
Return of unexpended research grant	6,854	-	6,854	-
Interest income	7,524	-	7,524	5,261
Miscellaneous	162	-	162	16
	<u>143,318</u>	<u>76,994</u>	<u>220,312</u>	<u>205,557</u>
NET ASSETS RELEASED FROM RESTRICTIONS				
Satisfaction of program restrictions	53,921	(53,921)	-	-
TOTAL SUPPORT AND REVENUES	<u>197,239</u>	<u>23,073</u>	<u>220,312</u>	<u>205,557</u>
EXPENSES				
Program services	191,036	-	191,036	146,051
Management and general	2,793	-	2,793	3,123
Fundraising	7,688	-	7,688	8,023
TOTAL EXPENSES	<u>201,517</u>	<u>-</u>	<u>201,517</u>	<u>157,197</u>
CHANGE IN NET ASSETS	(4,278)	23,073	18,795	48,360
NET ASSETS - BEGINNING OF YEAR	<u>106,589</u>	<u>56,886</u>	<u>163,475</u>	<u>115,115</u>
NET ASSETS - END OF YEAR	<u>\$102,311</u>	<u>\$79,959</u>	<u>\$182,270</u>	<u>\$163,475</u>

The accompanying notes are an integral part of these financial statements.

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 1997
WITH COMPARATIVE TOTALS FOR JUNE 30, 1996

	1997			1996 TOTAL EXPENSES
	PROGRAM SERVICES	MANAGEMENT AND GENERAL	FUNDRAISING	
Salaries and benefits	\$ 39,627	\$ -	\$ -	\$30,386
Publications and supplies	49,508	-	7,688	54,365
Occupancy and office expense	13,301	443	-	12,101
Research fellowships	51,000	-	-	35,000
Conference expense	29,816	-	-	18,232
Professional fees	4,561	2,350	-	5,281
Depreciation	3,223	-	-	1,832
TOTAL FUNCTIONAL EXPENSES - 1997	<u>\$191,036</u>	<u>\$2,793</u>	<u>\$7,688</u>	<u>\$201,517</u>
TOTAL FUNCTIONAL EXPENSES - 1996	<u>\$146,051</u>	<u>\$3,123</u>	<u>\$8,023</u>	<u>\$157,197</u>

The accompanying notes are an integral part of these financial statements.

Equipment and Depreciation

Equipment is recorded at cost. Depreciation is provided on a straight-line basis over the estimated useful lives of the assets.

Tax Status

The Association is incorporated in the Commonwealth of Pennsylvania and is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. The organization is registered as required with the Pennsylvania Bureau of Charitable Organizations.

Reclassifications

Certain 1996 balances have been reclassified to conform to the 1997 presentation.

In-kind Contributions

Volunteers have donated their time to the organization's program and administrative services and its fund-raising campaigns. The value of this contributed time is not reflected in these statements since it is not susceptible to objective measurement or valuation. The Association occasionally receives donations of property and equipment. The value of these assets is not considered material and is therefore not reflected in the Association's funds.

NOTE 2 - CONCENTRATION OF CREDIT RISK

The Association maintains a cash account balance at a bank located in Philadelphia, PA. The total of these balances are insured by the Federal Deposit Insurance Corporation up to \$100,000. During the year, the Association may have a cash balance in its financial institution in excess of the limit. At June 30, 1997, there was no uninsured amount. The Association also maintains uninsured money market cash balances at a financial institution located in Philadelphia, PA. At June 30, 1997, the uninsured balance at this financial institution was approximately \$160,000.

NOTE 3 - CONDITIONAL PROMISES TO GIVE

A private foundation has authorized a grant of up to \$100,000 to be paid over the next two years. The annual contribution of \$25,000 to \$50,000 is contingent upon the Association's ability to match from \$100,000 to \$150,000 in contributions from the general public. The Association will receive \$1 from the foundation for every \$3 the Association raises for the research budget. The contribution is not recorded in the current year, but will be recorded as the Association meets the matching requirement each year.

NOTE 4 - TEMPORARILY RESTRICTED FUND

At June 30, 1997, the temporarily restricted fund had a balance of \$79,959 comprised of monies for research grants and education.

NOTE 5 - LEASES

The organization leases its office premises on a month-to-month lease. Total rent expense was \$4,373 for the year ended June 30, 1997.

TIPS FOR EASIER DRESSING

Dealing with Buttons

- Use a button hooker, a handle with a wire hoop, so the button can be pulled through the hole.
- Cut the buttons off and sew small Velcro patches where the buttons were, and sew a matching Velcro patch under the button hole. Then re sew the button on top of the button hole.

Tying neckties

- Cut neckties in two at the side of the neck and sew on a Velcro splice.



Thoughts on Being a Patient with CMT

By Dana Schwertfeger

Editor's note: Dana was diagnosed with CMT over twenty years ago. He believes strongly in the necessity of exercise and walks between 5 and 10 miles each week, in addition to doing push-ups and sit-ups each day. He's the only CMT patient that his primary care physician sees; hence, he feels the need to be proactive and as well-educated as he urges in this article.

BE PRO-ACTIVE

When I first began treatment for my CMT, I had a fairly simple idea of how the doctor-patient relationship ought to work. I'd grown up accepting that when you went to a doctor, you placed your trust in the doctor's knowledge and expertise. From the examination, you expected to learn exactly what treatment was needed, either from your response to questions or by the results of a physical exam. Then you took the medicine prescribed and got well.

Of course, managing your CMT requires an entirely different approach. Here, the ideal foundation of the doctor-patient relationship shifts from merely trust and obedience to communication and cooperation. From the very beginning, you need to take an active role, becoming involved in your treatment and recognizing the ways in which you can help your doctors treat you.

EDUCATE YOURSELF

I advocate learning as much as you can about your CMT. The actual genetics may interest some of you, but I recommend at least familiarizing yourself with the medical terms used to describe the physical characteristics of the disorder. Reading the *CMT FACTS* series and the *Physician's Handbook* is a great place to start, but you might want to have *Proof of Facts* (a medical dictionary) and a basic text on anatomy and physiology around to look up terms. Don't be intimidated. You'd be amazed what you can learn.

Educating yourself about CMT will make it easier for you to discuss your condition with your doctor, but there's also a secondary benefit. There are a lot of unknowns, especially when you first begin to deal with your CMT, and having no idea what's happening to you or why can be very frightening. The word "progressive" is particularly unsettling, and no matter how hard you press your doctor, he simply can't tell you how severely you'll be affected in 5, 10 or 20 years. You won't be able to tell

either, no matter how much you learn.

Nor, unfortunately, are you likely to alter the course of your CMT, so the fact that it is a progressive disorder means that adjusting to it will be a lifelong process. Personally, I've always felt that learning about CMT and taking an active role in my treatment has made that adjustment easier, both physically and psychologically. I've had up days and down days—which is understandable—but I think it's easier to cope with something you know than with something you don't. CMT is an adversary I no longer fear.

SPEAK UP

Don't hesitate to tell your doctor your problems, even if it seems like your list of complaints is endless. Any doctor will tell you that an unknown problem can't be treated, and that one of the best sources of information about your problems is your own description of them. CMT seldom affects two patients in precisely the same way, so you can't assume that your doctor will ask all the right questions or learn everything from a physical examination. Also, keeping a "health journal" will help your ongoing treatment and understanding.

You cannot assume that your doctor will tell you everything you can do to make your CMT easier to live with. Your doctor's focus may be the treatment of a particular symptom, and unless there is a clear relationship to that symptom, the doctor may not discuss other things. Diet and exercise, for example, are important lifestyle factors, which, in addition to improving cardiovascular fitness, can also help control your weight and maintain muscle strength. This, in turn, can increase your mobility.

Before you belly up to the salad bar or head for the gym, however, check with your doctor to make sure that what you intend to do is appropriate and won't be detrimental or result in injury. In fact, when visiting a doctor, I prepare a checklist of issues or questions. It may seem unnecessary, but this way I'm assured to remember and it's also a good way to track "how I'm doing" over a period of time.

Newspapers, health and fitness magazines and the CMTA newsletters are excellent sources of useful information. The challenge is in determining whether something you've read might be worthwhile. If you're unsure, you can always ask your doctor.

WHAT'S RIGHT FOR ME?

Deciding whether to undergo treatment, or choosing among treatments is another process related to having CMT. Would a tendon transfer restore function in your hand, or would it be only a short-term solution and not worth the expense? Which is the better option: ankle fusion or bracing? How do you decide?

Your doctor will have an opinion, but it is wise to seek other opinions as well. Doctors, tend to have "favorite" ways to solve particular problems, and treatments also go out of fashion. Prefrontal lobotomy, you may recall, was once a preferred treatment for certain types of personality disorders, but no one would dream of performing the procedure today. So, before you decide to have an ankle fusion or other procedure, determine whether it's the right treatment for you.

Additionally, you'll find it helpful to speak with people who've had the procedure. Did it achieve the desired result? Were there complications? While everyone's situation is different, you will gain insight from talking with others. It's a good idea to contact a support group, write to the CMTA, or participate in one of the Internet discussion groups.

KNOW YOUR RIGHTS

Every person in the work force should be aware of what the Americans with Disabilities Act is, what protections it offers, and what accommodation it requires employers to make. (See article on the ADA on page 5.) This is especially true for parents who have school-age children with CMT.

In addition to legal rights, you should also be aware of various groups and state or federal agencies that offer financial or other assistance to CMT patients. The Muscular Dystrophy Association will pay for neurological workups, PT and OT evaluations (one each year), and braces or a wheelchair (every three years). The MDA bills your insurance, if you have any, for the amount it will cover and then picks up the remainder. Coverage also may be available through SSI disability insurance, and the Shriners' organization is the best source of free care for children.

PLEASE SHARE

Last but not least, help keep the rest of us informed. We can all benefit from each other's ingenuity. You might want to consult a patent attorney before sharing your inventiveness, but if you've got an idea that can make life easier or more comfortable, do speak up.

CMT Support Groups

Alabama/Greater Tennessee Valley

Place: ECM Hospital, Florence, AL
Meeting: Quarterly
Contact: William Porter, 205-767-4181

California-Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)

Place: 300 Sovereign Lane, Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Freda Brown, 707-573-0181

California-Napa Valley

Place: Sierra Vista Convalescent Hospital, Napa
Meeting: Quarterly
Contact: Betty Russell, 707-253-0351

Florida/Boca Raton to Melbourne

Place: Columbia Medical Center, Port St. Lucie
Meeting: Quarterly
Contact: Walter Sawyer, 561-336-7855

Massachusetts/Boston Area

Place: The Lahey-Hitchcock Clinic, Burlington, MA
Meetings: Every other month, the first Tuesday
Contact: David Prince, 978-667-9008

Michigan/Detroit Area

Place: Beaumont Hospital
Meeting: Three times each year
Contact: Suzanne Tarpinian, 313-883-1123

Mississippi/Louisiana

Place: Clinton Library, Clinton, MS
Meeting: Quarterly
Contact: Betty Aultman, 601-825-5626
Julia Provost, 601-825-6482

Missouri / Eastern Kansas

Place: Mid-America Rehab Hospital, Overland Park, KS
Meeting: First Saturday each month except January, July, and September
Contact: Ardith Fetterolf, 816-965-0017, fax: 816-965-9359

Missouri/St. Louis Area

Place: St. Louis University Medical Health Center
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664

New York (Westchester County)/ Connecticut (Fairfield)

Place: Blythedale Hospital
Meeting: Monthly, Saturday
Contact: Kay Flynn, 914-793-4710

North Carolina/Triangle Area (Raleigh, Durham, Chapel Hill)

Place: Church of the Reconciliation, Chapel Hill
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (evenings)

West Virginia/North Central

Place: VFW Conference Room, Elkins, WV
Meeting: Quarterly
Contact: Joan Plant, 304-636-7152 (evenings)

New Interest in Support Groups

There's been a resurgence of interest in support groups. The new Boston-area group held their first meeting on October 7, 1997, and were overwhelmed when 47 people attended. They heard a presentation on exercise and the CMT patient by Dr. Deborah Riester.

By the time this newsletter reaches its audience, two more groups will have held their first meetings. On Thursday, November 6, 1997, a group will gather in Horseheads, New York, to hear Dr. Mulki Bhat, a neurologist. This group is being organized by Angela Piersimoni. If you would like to be informed of future meetings of this group, call Angela at 607-562-8823.

Another group will have met for the first time on November 8, 1997, in Benson, Minnesota. This new group is being organized by Rosemary Mills who can be reached at 320-567-2156. The presenter at the first meeting will be Mary Nessel, an occupational therapist.

In addition to these three new groups, there are groups in the formative stages in Portland, Maine, Pittsburgh, Pennsylvania and Washington, DC/Baltimore, Maryland. If you have any interest in helping to get these groups "up and running," please call the office at 1-800-606-2682 and leave your name and phone number.



Members of the CMTA's Medical Advisory Board answer questions from readers.

Ask the Doctor

Dear Doctor,

I have problems with callouses that form on the bottom of my feet and seem to be worsened by my AFO's (ankle-foot orthoses). I usually use a razor blade to scrape them off, but I've been warned by my wife that I could get infections from doing that. I wonder if you have any ideas about how these callouses might be controlled.

A podiatrist replies:

Callouses (hyperkeratosis) are the natural way the skin defends itself against pressure. Internal (bone) or external (braces or shoe) pressure can cause the skin to thicken, which protects more sensitive underlying structures. If the pressure continues, the callous can become painful. The solution is to relieve the pressure. Sometimes this is easier said than done. Conservative relief begins with foot soaks and/or emollient creams to soften the skin and make it easier to remove problem callouses. Removal of the callous can be accomplished by periodic use of a pumice stone or callous file. If this does not help, sharp (razor) debridement can be considered. Caution needs to be taken with this method and a consultation with a podiatrist may be beneficial. Adjustment to the bracing may be the only action needed. If the brace is not fitting perfectly, it may need to be adjusted or just simply padded to prevent the high-pressure area from occurring. All adjustments should be done by the orthotist who made the brace or the doctor who ordered the brace. These simple steps can relieve the majority of pressure problems. Only in rare instances should surgical or medical intervention be considered.

Dear Doctor,

We were blessed with a beautiful baby girl named Megan on Christmas Day in 1996. Since her birth, she has had to overcome a number of struggles and now at nine months, we have a probable diagnosis for her. It's called Hereditary Sensory Neuropathy Type II (a very rare autosomal recessive genetic disorder) and the symptoms that led to this diagnosis include: absence of reflexes, no measurable sensory velocity on an EMG, low muscle tone, a nerve biopsy that revealed myelin problems, a moderately severe sensorineural hearing loss bilaterally, and seemingly high thresholds to pain and other sensory input.

At birth Megan suffered from miconium aspiration and was hospitalized; it was then that we

learned that she has other problems as well. She had feeding problems (difficulty with sucking) and due to the absence of a gag reflex, she received a feeding tube. At that time, it was also discovered that she had reflux, so a Nissan wrap was performed as well. Since that time, a swallowing test revealed that she could protect her airway and we began attempting feeding by mouth. Megan did well and within a few months, the feeding tube was no longer needed. Megan is involved in early intervention programs and is receiving help from an occupational therapist, physical therapist, speech therapist, and aural rehabilitation specialist. She is progressing in all areas but does have developmental delays, primarily in her gross motor skills. She began rolling over both ways at about 8 months and her head control is improving but not well enough to enable her to sit unsupported.

This summarizes Megan from a medical and physical standpoint, but I would like to mention she has a wonderful disposition and is a very happy child. It's amazing considering all of the medical procedures she has had to undergo. We are proud of her progress and want to do everything we can for her.

Any help you could provide would be tremendously appreciated.

—C.Z., Milford, OH

A pediatric neurologist replies:

Megan's symptoms of low tone (hypotonia), seemingly high threshold to pain and other sensory inputs, and moderately severe sensorineural hearing loss are compatible with diagnosis of hereditary sensory neuropathy Type II. The nerve conduction study that demonstrated absent sensory velocity is also compatible with this disease. In children with HSN2, nerve biopsy usually reveals almost complete absence of myelinated fibers. From information you sent, it is not clear whether this was the finding on the nerve biopsy. Although the condition starts at birth, most children are not diagnosed until later.

This condition is similar to Charcot-Marie-Tooth (CMT) disease in that it is a neuropathy (illness of peripheral nerve). It is different from CMT disease in that CMT involves neuropathy of both the motor and sensory nerve, while in HSN2, it involves only sensory nerves.

I would suggest that the family get a second opinion and speak with someone who has great expertise with this disorder: Dr. Felicia Axelrod, Department of Pediatrics, NY University Medical Center, New York, NY.

Dear Doctor:

I have been diagnosed with CMT. I am 73 years old and have known for 6 or 8 years that I have the disease. It has most affected my legs and back. I use a cane and am able to keep house.

One of my biggest problems is finding shoes that fit and are comfortable. My arches are very high, so I need the arch supports and whenever I go to a shoe store the salesmen will always try to sell me smaller shoes than I know I can wear. I used to wear a size 5 and am now up to a 6 1/2. Why does one with this disease have this problem? Even with the larger shoes, sometimes by the end of the day, my hammer-toes are hitting the end of my shoes. Bless the summer when I can go in my barefeet or stockings.

Also, I saw a report on TV about a drug called myotrophin. Those who have Lou Gehrig's disease (ALS) say it helps them. It is supposed to replace the lining around the nerves. Could that help those of us who have CMT Type I?

A Podiatrist and a Neurologist answer:

The podiatrist replies: I have been asked to help with your questions concerning your CMT and shoe-fitting problems. As a podiatrist and a person with CMT, I am acutely aware of these problems. High-arched feet with hammertoes are not only painful, but sometimes difficult to find relief for. Orthotics (arch supports) can help, but often cause shoe-fitting problems with regular shoe store shoes. If you have tried to solve this problem and failed, it is now time for you to seek the professional help of a pedorthist. A pedorthist can properly evaluate your feet and your arch supports and recommend the best shoe gear. Most have a full line of extra-depth shoes available and can also custom-make shoes if necessary. There should be a listing in the phone book for pedorthists in your area.

The neurologist replies: The drug myotrophin has not clearly been shown to help ALS patients, yet. It is still in the trial phase. Something like myotrophin, which affects the muscle directly, might not have any likely affect for CMT patients at all. More interesting for CMT patients are the nerve growth factors being tested at the Mayo Clinic and the University of Miami.

Dear Doctor:

A new drug for treating urinary tract infections was discussed in American Health and Time magazines. It is called Monurol and is a one-dose antibiotic recently approved by the FDA. Is there any side

effect that you know of and would the medicine be considered toxic?

A neurologist from the MAB answers:

The generic name of Monurol is fosfomycin, which is a phosphonic acid. It is unlike any other antibiotic used for urinary tract infections. It has minimal side effects and has an incredibly short half-life. It is out of the system within 14 hours. It is listed as having a protective effect on the kidneys because of its rapid movement through the body. For these reasons, it should pose no problems for CMT patients.

Dear Doctor:

I have been taking a supplement called creatine for about a month. My husband takes it before working out or jogging and he says it helps him a lot. Creatine is reputed to create muscle and is used by body-builders. The only negative side effect associated with creatine, according to an article on the muscle builder, is the threat to the kidneys. Can you comment?

A member of the MAB responds:

Creatine is made naturally in the body and there should be no need to take it as a supplement. It is not clear how easily it is metabolized and it definitely is a problem for people with bad kidneys. If one eats a healthy diet, the body will have plenty of creatine. It is found most abundantly in fish and red meat. It is not found in poultry products. I would advise that it is better to let your body make creatine and not to take it as a supplement.

Dear Doctor:

I was diagnosed with Parkinson's disease and I was put on the drug, Sinement, which was changed a year and a half ago to Sinement CR. It has suddenly caused a toxic reaction in my system. It causes the left half of my face, my left hand and my forearm to go to sleep. I tried not taking this drug, and it leaves me incredibly weak. I tried going cold turkey and when that didn't work, I diminished the dosage slowly over a period of time. Without the drug, I become so weak I am unable to get out of bed or walk, which is unacceptable. I also have CMT.

A neurologist from the MAB replies:

The numbness you are experiencing on the left side sounds like a cerebral problem and not a peripheral nerve problem. I would suggest you go to your Parkinson doctor and discuss this. Sinement is not known to adversely affect CMT.



WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

601 Upland Ave.

Upland, PA 19015

Letters to the Editor:

Dear CMTA,

I am a mother of a 14-year-old young lady. We have been told that she has CMT. How do we, as parents, tell a beautiful 14-year-old girl that she has CMT? How do we tell what is ahead for her future? We understand what CMT is and what it affects and how someone gets it, but how does it start to affect the quality of her life? Does it gradually affect the way she will do everyday things? I, myself, am afraid of what CMT could do to her. The day we found out that she had CMT, the doctor did not tell me anything about it. I called the 800 number and you sent us information about it. After reading it, I started to cry. Is my young daughter going to be in a wheelchair and crippled for life... and when will all of this start to happen? We are still unsure of how and when to tell her. I do not know if I can tell her without crying. I love her so much and would give my very life for her if I could take away the pain and anger that she is going to feel when told about CMT. I want to do everything that I can to help her get through all of this, but what do I do?

I work at a nursing home and we have a lot of women with MS. I see what it has done to each one of them. I look at them and wonder, is this what my daughter is going to be like? I see them suffer from so much pain and depression that it breaks my heart. My emotions are on such a roller coaster ride when I think about how this is going to effect my daughter. I know that I have to be strong for her, but how do I overcome my fears? I have no one to talk to who understands what I'm going through and can talk with. Yes, I have family, but they do not really understand what I am feeling right now. One day my baby is fine, and the next she is falling down.

I would love to hear from a mother who is or has gone through the same things that I'm going through right now. Please write to me at the CMTA office: Lori Love, CMTA, 601 Upland Ave., Upland, PA 19015.

Thank you.

Dear CMTA,

I have read the *CMT Handbook for Primary Care Physicians*, which is excellent. Since being diagnosed with CMT in 1987 while being tested for carpal tunnel syndrome, my arms and hands have gotten worse.

During those times, my legs, ankles, and feet bothered me once in a while, but I never gave it a thought. The pain would usually subside in a day. In the past year or so, my legs, feet, and ankles hurt so much and sometimes the pain doesn't let up for weeks. The pain can be unbearable. I've seen my MDA doctor, who says I'm not that bad and I need to learn to live with the pain. I've also been experiencing so much fatigue that my primary care doctor is having me tested for sleep apnea.

About two years ago, I reported my employer for discrimination because I needed accommodations. I got them, but now they have shown me that they want me out. I've been under stress and anxiety every day of work and am missing work owing to pain, fatigue, and depression.

The question I have is how does this affect my CMT? My MDA doctor says stress and fatigue and pain have nothing to do with worsening the CMT. I am being treated with anti-depressants and valium for the anxiety and leg and neck spasms and cramps.

Please help me as I know this will probably go legal. Anyone who has experienced this or has knowledge of such cases, please write: L.L. at the CMTA office. (See address above.)

Dear CMTA,

I just received the information that you sent me. I found out about the CMTA through my daughter who has CMT. Her doctor gave her your address.

The reports are very informative and interesting. In our hometown little is known or if it is known, it is not discussed. We are searching for any and all information we can find about our disease.

Generations before us just seem to have accepted it as a weakness and dealt with it in their own way.

I was affected in my early 20's, but was only able to find help in Charlotte, NC, when I was about 45 or so. I was diagnosed and AFO's were made for me. Today, I am 64 and would not be able to walk except for about an hour if I didn't have the braces.

My two daughters, age 41 and 43, are now showing signs of inheriting CMT, for which I am sorry, but hopefully they can accept it and, with aids, can live and lead a good life.

I am so thankful for my AFO's because without them I would be in a wheelchair much of the time.

—D.U., North Carolina

Dear CMTA,

I am a certified orthotist and have been receiving *The CMTA Report* for approximately 8 months and routinely use the report as a reference guide as well as an information database for new CMT patients seeking answers.

In response to a letter to the doctor regarding the use of dorsiflexion splints recommended by the therapist, I believe that an orthotist should be included in the support team for this particular situation. The orthotist has the experience and expertise to select the correct materials and closures for a patient's lifestyle needs or limitations.

—David Burnett, C.O.

Here are two responses to the letter from A.Z., who wrote of her negative experience with Dr. Frank Palermo's electrical stimulation in a letter that appeared in the Summer 1997 CMTA Report:

Dear CMTA,

I am a 56-year-old man who was diagnosed with CMT in 1993. It has progressed to a sloppy gait with a floppy left foot. I also have knee and hip problems caused by favoring my floppy foot.

In October 1996, I attended a conference on CMT at Gaylord Rehabilitation Center in Wallingford, CT. At this time, I spoke to Dr. Palermo about my condition, but I chose not to begin treatment. Approximately 7 months later, my condition had progressed to an unbearable point. Therefore, I got in contact with Dr. Palermo and began undergoing electrical muscular stimulation treatment. I am very happy to say that 5 treatments later, I feel like a new person. At this point, I can walk nearly perfectly and my floppy foot has been under control since the treatments began.

In response to A.Z.'s letter, I have nothing but good things to say about Dr. Palermo's electrical muscular stimulation treatment. I feel like it has given me a new lease on life. Under Dr. Palermo's continued supervision, I have maintained this new and improved quality of life.

—R.O., Massachusetts

Dear CMTA,

I also attended the meeting and visited Dr. Palermo subsequent to the meeting. I also embarked on the program of electrical stimulation. I am pleased to report that it has made a remarkable difference in my life. I have increased muscle strength and energy and it only gets better over time. Please print this reply in your next newsletter. I would hate to have only a one-sided view of Dr. Palermo's work presented.

—R.B.K., via email

Dear CMTA,

Remember when your mother used to say "there's always someone worse off than you?" It was meant to give you some comfort. If you get down from time to time, recognizing other people's misfortune can give you a boost.

It's not politically correct today, but it's not like you really wished any true misfortune on anyone. I remember when Oscar Levant said that for exercise he could simply enter a room, trip, and fall into a coma... compared to him, I was in great shape. I also like to read about ice storms in New York while I'm basking in the Southern California sunshine (don't tell me that New Yorkers don't gloat when we have earth tremors).

My sister-in-law's Christmas letters recite how her kids made Valedictorian, received trophies, or got promoted to Vice-President. I would rather have heard that her kids were having as many problems as mine were (preferably more!). Similarly, it seems that the only people who take the trouble to write articles for this newsletter are those that walk for miles, do 100 push-ups and bike more than 20 miles.

I exercise, too. I can do maybe 3 push-ups and walk a couple of blocks... then I'm exhausted. It's not notable, but perhaps some others with CMT can feel good about themselves compared to me.

So, tell us how you can't catch a ball, hit a pitch, rollerblade, use a ballpoint pen, stand unassisted, walk without concentrating on your feet, or find shoes that ever feel right. Tell us how you walked into a crowded lobby, tripped, and fell on your face with everyone looking at you.

For my final boost: remember, somewhere in this world, there's someone who isn't better off than anyone... Be glad that's not you!

—R.K. CA

The CMTA Report

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MEDICAL ALERT:

These Drugs Are Toxic to the Peripheral Nervous System and can be harmful to the CMT patient.

Adriamycin
Alcohol
Amiodarone
Chloramphenicol
Cisplatin
Dapsone
Diphenylhydantoin (Dilantin)
Disulfiram (Antabuse)
Glutethimide (Doriden)
Gold
Hydralazine (Apresoline)
Isoniazid (INH)
Megadose of vitamin A*
Megadose of vitamin D*
Megadose of vitamin B6* (Pyridoxine)
Metronidazole (Flagyl)
Nitrofurantoin (Furadantin, Macrochantin)
Nitrous oxide (chronic repeated inhalation)
Penicillin (large IV doses only)
Perhexiline (Pexid)
Taxol
Vincristine

Lithium, Misomidazole and Zolofit can be used with caution.

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

*a megadose is defined as ten or more times the recommended daily allowance.



What is 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).
- ...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 and CMTX 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
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Upland, PA 19015
1-800-606-CMTA**

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