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The CMTA Report

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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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A Look at the Third International Conference on CMT Disorders

By PAT DREIBELBIS, Director of Program Services

The long-awaited and long-anticipated Third International Conference on CMT disappointed no one. With 53 world-renowned researchers presenting lectures on such topics as "Abnormal Schwann Cell-Axon Interactions in CMT Neuropathy" and "Phenotypic Variability in Hereditary Neuropathy with Liability to Pressure Palsy" and 62 poster presentations on topics such as "A Second Family with Autosomal Dominant Burning Feet Syndrome" and

"Phenotypic Variation of a New P0 Mutation in Genetically Identical Twins," the conference was bursting with information from Thursday morning at 8:30 AM until Saturday night at 9 PM. Excitement filled more than just the conference hall and the poster presentation room. Elevators resonated with conversations among researchers anxious to trade blood samples or to find out about a new breed of trembler mouse or P0-deficient mouse.

continued on page 4



The entire group of participants at the Third International Conference on CMT gathered (in a neat formation...no small accomplishment) in front of the Le Chanticleur Hotel and the beautiful lake that it faces.

Begin with Flynn

By PAUL R. FLYNN, Executive Director

“Make no little plans, for they will not stimulate excitement nor generate the commitment necessary to bring the plans to fruition.”

—Daniel Burnham

1998: A BREAKTHROUGH YEAR

It is fitting that such a productive and accomplishment-filled year should coincide with an anniversary, but it is not coincidental. Celebrating the milestone of our 15th year, the Charcot-Marie-Tooth Association (CMTA) achieved several important goals in the areas of promoting research, generating awareness and financial support, and organizational development. Many years of volunteer service and individual sacrifice were the foundation for a “breakthrough” year.

EXPLOSIVE GROWTH

The CMTA experienced a rapid period of growth, eclipsing 12,000 in membership for 1998. Nearly 2,000 members joined the Association last year, which can be attributed to increased marketing efforts, “Internet traffic,” and more improved and reliable diagnosis of CMT. Another major factor that contributed to the explosive increase in membership, was the medical Q&A column of Dr. Paul Donohue. Twice in 1998, Dr. Donohue wrote responses to reader inquiries about CMT. Readership must be significant for Donohue’s articles, which appear in more than 200 newspapers in the US and Canada, because more than 1,600 people called the CMTA offices after seeing our phone number, 800-606-CMTA.

On a recent visit to his hometown of Kansas City, CMTA member Shawn Sullivan met with Elizabeth Reinert, an art history instructor at the Maple Woods Community College. Elizabeth, who has CMT, was named recipient of the Muscular Dystrophy Association’s 1998 National Personal Achievement Award.



BENEFACTOR LEADERSHIP

CMTA members have demonstrated a commitment to funding research and doing so at a higher level. With the help of remarkable benefactor leadership, the CMTA successfully met two critical research objectives for 1998, the Armington Research Challenge and the Third International Conference on CMT Disorders. Given the scope and importance of these undertakings, the bar was raised significantly for our major donors. Several new and long-time members answered the call for leadership support, including the Buuck Family, Dan Charny, brothers Frank and George Crohn, the Flynn Family, the Freaney Family, Steven E. Khosrova, and the Quinn Family. Additional major support came from the Evenor Armington Foundation, Athena Diagnostics, and the National Institutes of Health.

ARMINGTON RESEARCH CHALLENGE

In 1995, the Armington Research Challenge signaled a turning point for the CMTA and its commitment to advancing research. Original terms required that the CMTA match a \$25,000 challenge on a 1-to-1 basis, terms that were exceeded by almost double in the first 2 years. The goal was renegotiated to reflect a greater ambition and sense of urgency. This year, the CMTA raised more than \$150,000, matching 3 to 1 the Evenor Armington Foundation’s challenge of \$50,000. The \$200,000+ research fund will enable the CMTA to provide three \$35,000 fellowships and several summer internship grants at \$4,000 apiece. Ultimately, the CMTA is positioning itself to fund and direct large grants for multi-year projects.

THIRD INTERNATIONAL CONFERENCE

The CMTA’s mission is to create awareness of CMT disorders within the health care community and the general public, and to be a leading source of information regarding CMT. The Association encourages, promotes, and supports research into the cause, treatment, and cure of CMT. It is the CMTA’s vision to become a recognized world leader in promoting awareness of CMT disorders, and in developing solutions for the effects of CMT—now and for the future.

By convening nearly 150 CMT investigators from around the world, the CMTA took a momentous step toward achieving its vision. The Third International Conference on CMT

Disorders was a collaborative effort between the CMTA and the New York Academy of Sciences. The conference focused on the latest developments in research and clinical aspects of CMT. There was special emphasis on the “cross-fertilization” of ideas and perspectives between clinicians, geneticists, molecular biologists, morphologists, and physiologists. A strong effort was made to integrate basic and clinical research and to highlight important areas for future research and collaboration.

A LAUNCHING POINT

It is estimated that CMT affects 1 in 2,500 Americans, equating to roughly 125,000 people. This estimate is perceived by many to understate the prevalence of CMT disorders, particularly given frequent misdiagnosis and the rising numbers of cases of hereditary neuropathy with liability to pressure palsy (HNPP), a “close cousin” of CMT. While the CMTA has seen a rather dramatic 1-year increase in membership, our mission requires that we reach more people.

Clearly, we have more to do. Thousands of people still do not know that they have CMT and for those who do, too many are unaware of the CMTA. Taken in this context, the accomplishments of 1998 will serve as a launching point for even higher goals. For instance, the Third International Conference must not be a single, isolated event but rather a catalyst for collaborative research and on-going discussions. The CMTA has a preliminary agreement with the CMT European Consortium to work together to sponsor international meetings here and abroad on a regular schedule.

Additionally, the CMTA is entering its final year of the Armington Research Challenge and must not only raise \$150,000 to qualify for the foundation match, but also look ahead to maintaining this “momentum” in subsequent years. Of course, the significant research fund raising goals should not overshadow the real need to further develop our operating capacity, which exists to serve members and achieve organizational objectives.

Finally, the CMTA must enlist and utilize greater volunteer support. Numerous organizations have a cadre of volunteer leaders advancing their missions; so too should the CMTA. The volunteer deficit is not from a lack of willing participants but rather insufficient administrative coordination to provide the stewardship and oversight of volunteers. Addressing this need is a primary goal for the coming year, as it is through volunteer leadership that the CMTA will continue to move aggressively forward.



CMTA MEMBERSHIP/ORDER FORM

Name: _____

Address: _____

Phone Number: _____

Members who are current with their dues are considered “active”.
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		active members \$15 inactive members \$20	
Membership Dues		\$35	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 inactive members \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 inactive members \$7	
CMT Facts III		active members \$5 inactive members \$7	
CMT Facts IV NEW PUBLICATION		active members \$8 inactive members \$10	
VCR Double Tape: Wayne State Conference		active members \$25 inactive members \$40	
VCR Double Tape: duPont Conference		active members \$25 inactive 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			
Shipping & Handling <i>Orders under \$10 add \$1.50, orders over \$10 add \$3.00</i>			
TOTAL			

Check payable to the CMTA (US Residents only).
Foreign residents, please use a credit card or International Money Order.

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.

THIRD INTERNATIONAL CONFERENCE

(Continued from page 1)

From a lay person's perspective, perhaps the most encouraging aspect of the conference was the willingness of the doctors to spend hours at breakfast, lunch, or dinner, in an elevator, or standing in front of a poster to explain the work they are involved with to those of us who found some of the presentations difficult to understand. A more enthusiastic and pleasant group of researchers could hardly be found.

One of the most exciting pieces of news to come from the conference was the decision not to let another 11 years pass before convening a fourth international conference. Plans are currently underway to meet again in 2000 in Belgium. The rationale for that decision is based on the volume of research currently underway and the speed with which breakthroughs are being made. A second very exciting development was the plan to form a consortium in North America similar to the consortium currently operating in Europe. The consortium concept allows for the exchange of information and materials, stimulates collaborative research, encourages the training of young scientists, and encourages the pooling of resources. The European Consortium has been successfully operating since 1991.

An effort as monumental as this conference could not have occurred without a tremendous amount of work and effort. Both Drs. Michael Shy and Robert Lovelace were recognized by the New York Academy of Sciences Director of

Dr. Jim Lupski and Dr. Tom Bird were co-conveners of a session of presentations on the clinical and pathological aspects of CMT.



Dr. Rashid Shaikh presents Dr. Michael Shy with a certificate of achievement for his work in organizing the Third International Conference as Dr. Robert Lovelace, co-organizer of the conference, looks on.

Science and Technology Meetings, Dr. Rashid Shaikh, for their enormous efforts in planning and arranging for the speakers and poster presenters. Ann Lee Beyer, Chairman of the Board of Directors of the Charcot-Marie-Tooth Association, recognized the financial and planning efforts of Board members Diane Freaney and Steven E. Khosrova, and the financial contributions of CMTA members Frank and George Crohn.

Probably the most lasting impression that the conference created was one of enthusiasm. Both the Board and staff of the CMTA and the researchers and clinicians who attended the conference were excited by all the work that is currently underway in CMT research and the promise of what is to come. Dr. Christine Van Broeckhoven concluded her presentation by saying, "Research grows from meetings..." With that in mind, we are all looking forward to the year 2000 and the next international conference on CMT.

A Questionnaire About Charcot-Marie-Tooth and Pregnancy

By TED M. BURNS, MD, University of Virginia, Department of Neurology

There is very little published about CMT and pregnancy. We are interested in your experience with pregnancy—both the experiences of those of you whose CMT symptoms did not worsen during pregnancy and the experiences of any of you who might have experienced a worsening during pregnancy. We appreciate your taking the time to fill out this brief questionnaire and returning it to us.

1. How old are you now?
_____ years
2. How old were you when you were diagnosed with CMT?
_____ years
3. Were you diagnosed with CMT during a pregnancy?
 yes
 no
4. At the time of your first pregnancy, did you already have symptoms of CMT?
 yes
 no
5. How was the diagnosis of CMT made? (Mark all that apply.)
 EMG/nerve conduction studies
 Nerve biopsy
 Blood test (DNA)
 Family history (other family members with CMT)

(continued on page 6)

If you are a woman with CMT who has ever been pregnant, please complete this survey and return to Dr. Ted Burns at the address below. Your participation is greatly appreciated.

COMPLETE REVERSE SIDE OF FORM AND RETURN TO:

Ted M. Burns, MD
University of Virginia Health Systems, #394-52
Charlottesville, VA 22908

CMT AND PREGNANCY SURVEY

(Continued from page 5)

6. If you experienced worsening of symptoms during pregnancy, was your worsening due to another cause, such as a pinched nerve, carpal tunnel syndrome, diabetes, or thyroid problems?

- yes (If yes, you are finished.)
 no

7. Did you have considerable worsening of your CMT during a pregnancy?

- yes (If yes, please mark all boxes below that describe your worsening symptoms during each pregnancy.)
 no (If no, you are finished.)

First Pregnancy

Second Pregnancy

Third (or More) Pregnancies

_____ (your age at delivery)

_____ (your age at delivery)

_____ (your age at delivery)

more symptoms in hands

more symptoms in hands

more symptoms in hands

more symptoms in feet

more symptoms in feet

more symptoms in feet

more trouble walking

more trouble walking

more trouble walking

more frequent falling

more frequent falling

more frequent falling

8. If you had worsening with pregnancy, did it improve after the pregnancy?

- no (If no, you are finished.)
 yes

First Pregnancy

Second Pregnancy

Third (or More) Pregnancies

improved completely

improved completely

improved completely

improved almost completely

improved almost completely

improved almost completely

improved only minimally

improved only minimally

improved only minimally

did not improve

did not improve

did not improve

How long did it take to improve?

_____ months

_____ months

_____ months

Comments about pregnancy and CMT:

Meet the President: Jack Walfish

When an opening developed in the office of the President, I volunteered to assume that responsibility. The Board elected me to fill the unexpired term and I value their confidence in me.

I have been a member of the Board of Directors of the CMTA since 1994, previously serving as Treasurer.

I believe that my experience and background make me well suited for this position. I graduated from the US Merchant Marine Academy and served as a ship's officer in WWII. At war's end, I returned to work in the garment industry as a manager. After graduating from the Fashion Institute of Technology, I became a full professor and chairman of the Manufacturing Management Department there. At the same time, I obtained a Professional Engineer's Registration and Certification as a Cost Engineer. I operated my own management consulting practice, Jack Walfish Associates.

What, then, is my attachment to the CMTA? I think it is quite similar to that of others of us who have CMT.

Ever since I was a child, my family knew there was some problem in our family, but we never knew what it was. Some of the family thought it was one of the Middle European Jewish diseases. This was a reasonable assumption because of all the intermarriage of relatives that occurred in the ghettos of Poland, where my family originates. We have, of course, learned differently.

The mystery was unraveled in 1975 when an uncle of mine fell and went to his family doctor who sent him on to a neurologist at NYU. That was the first time the family heard the words, "Charcot-Marie-Tooth." He examined my mother and, since I was along, he examined me, too, telling me that I had the first signs of CMT. That explained why I was having trouble making the Scout sign with my right hand, and why I was having trouble gripping a baseball or starting a nut on a bolt.

I look back, now, and realize that too many doctors and distinguished specialists knew practically nothing about CMT. It was true in those days, and it's still too true today. That comment brings me to the topic of our just-concluded Third International Conference on



*Jack Walfish,
board president,
gets down to busi-
ness at the CMTA
office.*

CMT, and our relationship with all of the researchers and our own Medical Advisory Board.

I wish to express my own personal admiration and gratitude for the work that our MAB has accomplished to date. Their achievement in gathering the largest assemblage of leading authorities and eminent researchers on CMT in Montreal was amazing. At the risk of omitting other deserving candidates for citation for a job well-done, I must recognize both Dr. Robert Lovelace and Dr. Michael Shy.

We have come a long way and we have a long way to go. One positive result of this conference is the initiation of new consortiums to study this disorder, and the exchange of research findings that will result in less duplication of effort. All of this work, is, however, skewed on the genetic side of the problem. In my opinion, we need more specialists, such as podiatrists, physical therapists, and orthotists, working on finding methods of alleviating the problems affecting those people who now have CMT. This will be one of the prime objectives of my tenure in office.

Computer Recycling: Bytes That Benefit

By **CARRIE SMOOT, 1998 The Disability News Service, Inc.**

GIVE

The "Give Button" allows visitors to our website the opportunity to make an instant, online gift to the CMTA via a secure encrypted Web server. Donors can give using their Visa or Mastercard, or they can print the form and mail or fax it with their credit card information.

Please visit our homepage at www.charcot-marie-tooth.org

Upgrading that computer system soon? Don't trash your old machine! Instead, consider donating it. A quality used 386 or 486 could be the inexpensive catalyst for computer literacy, vital communication, or the doorway into the job market for a disabled person who wants a computer but can't afford one. Here's how to find or donate used equipment.

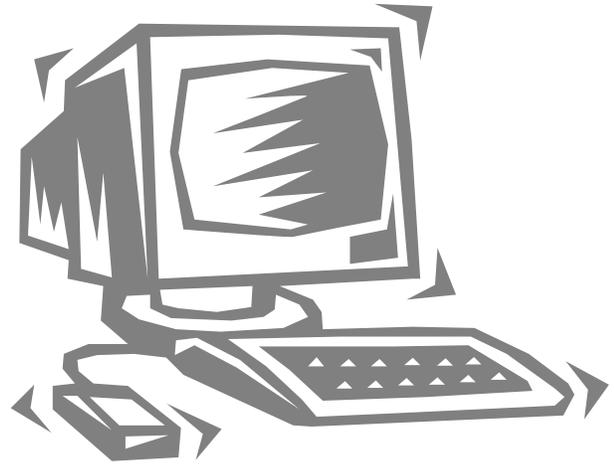
The Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) provided Federal money for 56 state programs—one in every state, commonwealth, and territory of the United States. Although the law doesn't cover direct services and purchase of equipment for individuals, Tech Act projects, such as the Virginia Assistive Technology System (VATS), do provide valuable information for consumers with disabilities.

People with disabilities have a strong sense of the technology solutions they may need, but they struggle with the funding solutions to make this technology a reality in their lives, says Joey Wallace, PhD, the VATS policy analyst. "This is where VATS can help." VATS works on a small scale with community groups to promote computer recycling and donation programs. Director Ken Knorr reports that VATS and its partners distributed more than 300 computers over the past year.

"The demand for low-cost computers is much higher than the supply," Knorr explains. "We found that all we had to do was ask when it came to approaching people for computers," he notes, referring to local businesses and industries that upgrade their systems but don't know what to do with older computers.

Because computer technology is evolving and changing at such a rapid pace, a brand new computer loses 80% of its value within a year. If the machine works well when it's time to upgrade, donating it could help someone in need and earn a tax deduction for the person making the donation. Some state projects and nonprofit agencies operate computer recycling programs, offering donated hardware and software to disability agencies for distribution.

"Used computers aren't for the technology chasers who want bigger and faster machines,"



cautions Barry Cranmer, founder and president of Share the Technology, a Rancocas, New Jersey, nonprofit 501(c)(3) organization that distributes computers in New Jersey and the Delaware Valley. "But, if I'm a person at home all day, a computer can expand my world." Cranmer recalls a young autistic man who used his donated computer and basic word-processing software to talk with others for the first time in his life.

People with disabilities should work with nonprofit organizations when searching for the right computer. "It takes guts for someone with a disability to call an agency and ask for assistance in obtaining a computer," notes Sally Beers, administrative coordinator for the National Cristina Foundation (NCF) in Stamford, Connecticut. For the call to be effective, Beers suggests that the person outline his or her current situation and be specific about how the computer will help.

NCF distributes used computers only to organizations that train or rehabilitate people with disabilities, such as Easter Seals or United Cerebral Palsy. "We are not a store," cautions Beers. "We don't have warehouse space or the means to repair or ship computers, and it's unfair to ask donors to assume those costs," she says. "Our many partners across the country take care of this for us."

According to Beers, the Foundation encourages businesses to see computer donation as “good for the bottom line,” noting that it is expensive for companies to move or store outdated equipment. For example, when one New York City advertising agency moved to a new office building equipped with new Pentium-processor computers, the company debated transporting and warehousing all its old 486s. Instead, the company worked with an NCF partner to donate the machines. “It was a tremendous savings for them,” comments Beer. “A tax deduction is often the least important reason for donating a computer,” notes Cranmer.

But those who do donate for the IRS deduction sometimes send useless equipment. ReBoot, a computer recycling program located in Stone Mountain, GA, has experienced this frustration. If you plan to donate, make sure your system is in working condition. And don’t forget to send mice, keyboards and power cords (these frequently are in short supply, since people often reuse them with their upgraded system.)

Through Tools for Life, Georgia’s Tech Act project, ReBoot has given away 155 computers to qualified people with disabilities since February 1998. “We couldn’t do any of this without our partners,” says ReBoot project manager Carolyn Phillips. “We work with a lot of different companies and individuals.” Tools for Life has 11 technology resource centers around Georgia that it uses for local distribution. One such non-profit group is Friends of Disabled Adults and Children, which also distributes wheelchairs and

medical equipment to people with disabilities and provides warehouse and office space for all the used equipment. ReBoot also has 35 volunteers and works with a literacy center, community college, and independent living center to repair machines and train recipients to use their new computers.

ReBoot is not just another giveaway program—a detailed training action plan and a specific description of how the computer will be used is required from recipients. Although volunteers train users in basic computer safety and software use, individual recipients must pay shipping costs, additional training costs, and the charges for an needed upgrades. Other organizations provide adaptive devices, such as speech synthesizers. If a computer breaks, the customer can return it to ReBoot for repairs. Participants in the ReBoot program are asked to give at least 20 volunteer hours to ReBoot or another agency to “earn” their new computer. “What we’ve seen is that people give a lot more than 20 hours,” reports Phillips. “They are really dedicated to this project.” Volunteer jobs include data entry, phone work, marketing, as well as teaching computer use and repair. “Few people realize the power of using a computer,” Phillips says. “Our main goal is independence for people with disabilities.”

(Editor’s note: We have available a list of 21 sources of information and advice about obtaining a low or no-cost machine or donating a machine. To obtain the list, please send a self-addressed and stamped envelope to the CMTA office.)

Call for Participants:

I am a clinical geneticist at Southern Illinois University School of Medicine currently doing genetic and clinical research with a large Central Illinois family with CMT and progressive sensorineural deafness. The local family also has another unique feature. The disease appears to be getting worse with each generation. In fact, two babies with CMT have died already from what appears to be complications of the CMT.

I would be very interested in hearing with other families with similar features—either the deafness with CMT or the progressive severity of CMT in their families.

Virginia Kimonis, MD
Southern Illinois University School of Medicine
217-782-4839
217-785-4117 (fax)
vkimonis@wpsmtp.siumed.edu

BOOK REVIEW

Finding The Way Home: A Compassionate Approach to Illness

by Gayle Heiss

Based on the author's personal experiences and those of hundreds of people who have attended her weekly support groups, *Finding the Way Home* is a book of thoughtful reflections on living with illness.

Looking at illness from the inside out, Ms. Heiss reveals distinctions that are profoundly important to those who are ill. She explores the difference between disease (a biological condition) and illness (the individual human experience of it); between curing (the alleviation of symptoms) and healing (the healthy integration of all life experience, including illness); and between pain (physical distress) and suffering (the loss of meaning, connection, and hope in the face of pain).

Anyone touched by health concerns will want to share this book with others. The inner world of illness is portrayed with clarity and compassion. This is a book for anyone trying to live wisely, no matter the state of his or her health.

You can purchase the book from your local bookstore or contact the publisher: QED Press, 1-800-773-7782. The cost is \$24.95; ISBN 0-936609-35-4.



Five Ways to Find Peace with On

By ROBERT J. RONALD, SJ, Operation De-Handicap, Taiwan

(Reprinted from Polio Network News, Vol. 14, No. 4, with permission of Gazette International Networking Institute, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915)

For persons with disabilities like us, three principles are indispensable for peace: first, if I am going to live in peace with myself, then I must learn to live at peace with my disabilities. Second, if others are going to live in peace with me, then they too will have to learn to be at peace with my disabilities. And third, the more comfortable I am with my disabilities, the more others will be comfortable with me.

As I see it, peace with myself is harmony between where I am right now and where I aspire to be. I am not there yet. But I have peace in knowing I am still on the way. Peace with my disability is harmony between life as I want to live it and the demands that the disability makes upon my strength, energy, and endurance. I am always searching for a way of compensating for what I have lost by having goals that are attainable in spite of my losses.

Peace with others with me is harmony between what I do and say and what others expect from me. I should be open and clear about who I am and what I want. And they must not blindly expect me to follow their wishes.

Just how are we going to live in harmony with our disabilities and with others? As a result of my own experiences with disability, I have developed a five-step plan toward this harmony, and each step begins with a letter of the word "peace."

But I am going to start with the letter "A" because it is the most important. "A" is for aim. Aim is the goal, the purpose of our actions. Aim as a verb is the lining up of our actions to reach our goal. Without worthwhile goals to aim for, life has no meaning.

If you want to help me get back on target, aimed again toward peace, there are things that I hope you will do for me and, of course, that I should be doing for you.

Be patient with my anguish and uncertainties. These feelings of mine are founded on real loss and real fears. Be positive and upbeat. Gently draw my attention away from dwelling upon what I have lost to recognizing the powers that remain. In your hopes for me, I can find hope



for myself. Be enterprising and creative. Because I am unable to do the many things I used to do, help me to find a way to go on doing the few things that I can still do. Try to see and feel things from my perspective. Be warm and accepting. Be open and flexible.

If you want me to be at peace with you, don't pressure me to make your goals my goals. Once I have set my goal, even if you think it is wrong, don't reject me or try to block my path. If I fail to reach it, don't say, "I told you so." Just come over, give me a hug, and help me find another path to follow.

In my experience, the people who seem to adjust most easily to their losses are those with strong principles, because they more readily realize that what matters most in life is not what one does but how one does it. And they seem to have an inner power that gives them energy to press on in the face of setbacks.

But what about the times we fail through our own fault—doing something stupid, unkind, lazy, or what we should not have done? Although guilt destroys peace, it also restores us to our senses. Peace is regained not by denying guilt or running away from it, but by acknowledging mistakes, learning from them, and accepting the consequences of our actions. Peace

e's Self and the World

is being able to start again tomorrow regardless of what happened today.

Now the second step uses the letter "P" for powerizing prayer. We need to take time every day to withdraw into our inner selves in silence and attentiveness, making contact with the inner source of our energies.

If you are a believer, find and communicate with your God, the spirit in nature, the universal force. If not a believer, touch and draw on the powers of your inner self. Such prayer takes us into a world where disability doesn't matter. It refreshes our spirits, draws on our inner strengths, and give us renewed purpose and energy. I highly recommend this process as an energizing step toward finding peace in our changing post-polio situations.

The third step is "E" for engage and enjoy. "E" is for the importance of spending our time engaged in meaningful activities. "E" is for embellishing and emblazoning whatever we do with value and importance. "E" is for getting enjoyment out of whatever we do. Even if the only thing you can do is rest, then enjoy it. Put your heart into it. You have earned it.

Sometimes it is necessary to tramp through mud to get where we are going. So enjoy the squish, squish of the mud; be happier moving instead of being stuck. Be glad you are getting somewhere.

The fourth step is "C" for concern and communication. When we are concerned about others reaching out to them with understanding and warmth, our troubles are lightened and fall more easily into perspective. Joy shared is joy doubled. Sorrow shared is sorrow lessened. Concern for others muffles pain for ourselves.

Peace also comes in fighting for a good cause such as standing up for our rights to protect what is necessary for our well being, particularly in the face of post-polio realities. But even in these situations, more attention to the concerns and needs of our adversaries can make accommodation and peace easier to achieve.

I am reminded of the little boy who once cut his finger and wound up with blood all over the place. But he went calmly into the bathroom to get a Band-Aid. When his mother found him there, she said, "Why aren't you crying? Doesn't it hurt?" He said, "I didn't know you were home."

The little boy knew that crying was futile if no one heard him, so he solved the problem on his own. With his mother's help, though, that boy's finger would have been bandaged much faster, neater, and probably more effectively.

Finally, "E" is for embroidery, representing all types of leisure activities, hobbies, recreation, games, diversions. A peaceful life is a varied life. All work and no play usually adds up to pressure and anxiety and puts a strain on others.

These so-called steps are not steps to be taken one at a time or in any particular sequence; they are five important everyday ingredients for finding peace.

Peace is when the world is falling apart and you are not. Peace is when you are hurting but the pain doesn't make you quit. Peace is when you have to slow down but refuse to stop. Peace is having something to do and doing it with all you've got. Peace is having nothing to do but enjoying it. Peace is when you can enjoy whatever you do without regret for what you aren't doing. Peace is doing well what you would rather not do but have to. Peace is when you have done something wrong and have the courage to admit it and change.

Peace is when you are not afraid to say no when you would rather say yes. Peace is when you stop and commune with your inner self. Peace is doing something right when everything is going wrong. Peace is blowing off steam without burning anyone. Peace is time shared with another. Peace is clearing the tears from your eyes by wiping the tears from the eyes of another. Peace is when you are in conflict and find a friend. Peace is shaking hands with someone you would rather sock. Peace is giving generously when you would rather be taking and receiving graciously when you would rather be giving.

In 1991 in Beijing, at an Asian and Pacific rehabilitation conference, the delegation from Hong Kong brought with them a supply of dolls as gifts. Each doll was egg-shaped without arms and legs. On the front were the words "Keep me down if you can." To show the spirit of rehabilitation, the dolls were weighted to return to the upright position if put on their sides. In this life of ours, we cannot escape being bowled over from time to time, but we can bounce back if we strive for peace with ourselves and those around us.

Reports from the CMTA Summer I

Reports from three of the four CMTA summer grant recipients follow. This research

Julie Cole, Medical Intern

Dr. Gareth Parry, Mentor, University of Minnesota

Phenotypic Variability in Hereditary Neuropathy with Liability to Pressure Palsy (HNPP)

The first step in this study was to obtain and review all charts from the identified patients with HNPP who are followed at the neuromuscular clinic at the University of Minnesota. This chart review was used to develop a questionnaire concerning symptoms experienced by HNPP patients. This symptom questionnaire was further refined in consultation with a nurse who is also an HNPP patient. [Editor's Note: The nurse is Maureen Horton, RN, a CMTA member and frequent contributor to our newsletter. She is a passionate advocate of HNPP research.] After the surveys are completed, the participants will then be asked to undergo a standard neurological exam and an electrodiagnostic study.

To date, we have traced 50 members of one kindred. The results from 42 individuals who have returned the questionnaire are reported.

Results:

1. Sensory Symptoms: Twelve individuals (29%) reported sensory symptoms. Ten complained of intermittent numbness associated with minor trauma and nine (24%) had paresthesias (numbness or tingling). One individual had permanent numbness and paresthesias as

well as intermittent symptoms. Five individuals (12%) complained of significant pain, a poorly appreciated symptom of HNPP. Of the 11 individuals who had intermittent symptoms, 64% noted that episodes lasted less than 12 hours; seven individuals noted that episodes typically lasted less than 15 minutes. The majority of episodes (70%) recovered partially or completely.

2. Motor Symptoms: Nine individuals (21%) reported episodes of weakness. Five had intermittent cramps and one had fasciculations (spontaneous, irregular contractions of a muscle, apparently at rest). Episodes of weakness were more likely to last more than 12 hours; 56% lasted more than 12 hours and half of those lasted for more than 24 hours. Only two patients identified episodes lasting less than 15 minutes. All but two episodes of weakness recovered partially or completely.
3. Initial Symptom: In one individual, the initial symptom was brachial paralysis* that occurred at birth, but the disease was not recognized at that time. He has mild residual weakness in that arm. He subsequently went on to develop multiple episodes of numbness and weakness lasting more than 24 hours. The remaining 11 individuals had the classic presentation of intermittent sensory and motor symptoms, alone or in combination, occurring in association with minimal trauma. Thus, the presenting phenotype was acute brachial paralysis in one individual and recurrent mononeuropathies in 11 individuals. However, the recurrent mononeuropathies were most often purely sensory and the symptoms were short-lived. As a result, the significance of early symptoms was not recognized and diagnosis was delayed for many years.

Conclusions:

Based on the review of this initial family, our hypothesis appears to be confirmed, although a much larger cohort will be needed. Within this single kindred there were two distinct presenting phenotypes and many individuals were oligosymptomatic (having few symptoms), with

The Westerfer family was the subject of a study by Dr. Kenneth Fischbeck of the University of Pennsylvania and Dr. Jeffrey Vance of Duke University in 1990. The family's 50 or so first cousins gathered recently. 75% of them have CMT. This family demonstrates how important large families can be in studying hereditary disorders.



* The brachial plexus is a collection of large nerves from the lower spine down the arm. Paralysis causes loss of movement and sensation in the arm.

nternship Grants

was made possible by CMTA member support of the *Armington Research Challenge*.

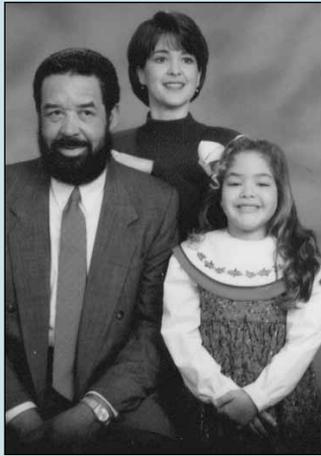
very brief sensory symptoms as the only manifestation. Phenotypic progression from the presenting phenotype to the classic phenotype occurred in the patient whose presenting symptom was brachial paralysis. Furthermore, only 29% of individuals were affected, at least based on symptoms, suggesting an incomplete penetrance of the gene defect. However, symptomatically unaffected individuals will need to be examined to determine whether they have asymptomatic involvement.

Jennifer Anderson, Medical Intern

M. A. Pericak-Vance, Mentor, Duke University

Clinical Phenotype Study of Charcot-Marie-Tooth Type IA: Search for Factors That May Reflect a Modifier Gene to the 17p11.2 Duplication

The Charcot-Marie-Tooth disorders are a clinically and genetically heterogeneous group of disorders. Type IA (CMT1A), the most common inherited neuropathy, involves myelin and Schwann cell abnormalities, observed primarily by decreased motor nerve conduction velocities and muscle weakness and atrophy in the lower extremities. All 57 individuals with CMT1A in our data set composed of several multigenerational families have a duplication of the region 17p11.2, where peripheral myelin protein PMP-22 has been identified (Patel 1992; Timmerman 1992; Valentijn 1992). Although these patients all have the same underlying genetic defect, they exhibit pronounced clinical variability. This study examines the variability and looks for correlation between the components of the phenotype. Gender ratio, mean age of onset, and motor nerve conduction velocity measurements agree with previous clinical studies. Correlation was not found between motor nerve conduction velocity and gender, gender of transmitting parent, age of onset, age at exam, or disease duration. We are currently preparing to gather additional clinical data for the original goal of identifying a modifying gene and also for longitudinal studies. The overall goal of the study is to find components or logical groupings of components of the CMT1A phenotype that may represent effects of a modifying second gene (or genes). Follow-up analyses will involve segregation analysis and genetic linkage analysis.



PUTTING STOCK IN MEMBERSHIP

Aimee F. Williamson (standing) with her husband Lindsey and daughter Chantalle. Aimee, a CMTA member from Greensboro, NC, recently made a generous gift of stock from A.G. Edwards & Sons (her employer) in honor of her daughter. Chantalle has been diagnosed with CMT, which led to the further discovery of CMT in Lindsey's family.

Dr. Elif Yosunkaya, Student

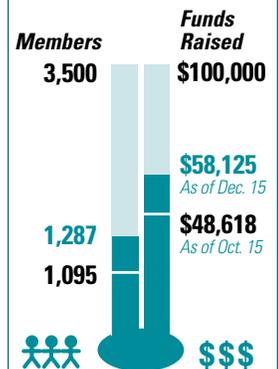
Dr. Roger Lebo, Mentor, Center for Human Genetics

Fetal Gene Therapy of Peripheral Neuropathy

The summer CMTA research funding to Elif Yosunkaya by the CMT Association allowed us to pursue our desire to genetically cure diseases in the fetus to prevent abnormal cell growth prior to birth. This idea began in our laboratory with a chapter comparing the ethics of fetal gene therapy to other forms of gene therapy (Lebo and Golbus, 1991). Delivering genes in fetuses overcomes rejection of foreign genes before the fetal immune system develops, and also delivers genes to spinal nerve cells growing in the fetal limbs so that more genes can be delivered per nerve cell. This fellowship provided us with the resources to study delivered gene expression by analysis of thin tissue slices at the same time we optimized fetal surgery during gene delivery to mouse fetuses. While all pregnant mice initially failed to recover from surgical procedures used routinely in nonpregnant mice, our improvements in anesthesia and gene delivery allowed the last 8 of 8 mothers to survive after gene delivery into multiple fetuses each of them carried. The relatively impure injected genes clearly expressed the reporter gene in selected tissues of one mouse fetus. Current studies are using purified viral vectors to determine how much gene expression can be improved in all fetuses. Thus, we have moved one small step closer to gene therapy in fetuses.

STRENGTH IN NUMBERS

OUR 1999 MEMBERSHIP GOALS



■ ALTERNATIVE MEDICINE EXPOSÉ

From *NORD (National Organization for Rare Disorders) On-Line Bulletin*

The *Los Angeles Times* ran a week-long series of articles about the alternative medicine industry, and particularly nutritional supplements. This is an \$18 billion per year industry, and the National Institutes of Health (NIH) is spending \$14.5 million annually on testing alternative remedies. The 1994 Dietary Supplement Health and Education Act, "gave manufacturers of vitamins, minerals and herbs wide latitude to market products without having to prove them safe and effective," says the *Los Angeles Times*.

Since many nutritional supplements are widely used, the *Los Angeles Times* tested some of them and found that there is an apparent lack of quality controls. For example, they tested several different brands of St. John's wort, which is widely used as an antidepressant, and found that none of the pills contained the labeled amount of active ingredients. They also tested "ethnic patent medicines" and found that some contain arsenic, Valium, and other potentially dangerous substances.



A Journey Toward Wellness, Part IV: Body Work

By CYNTHIA GRACEY

I have often wondered what I would have done if my first serious attempt to address the symptoms of CMT with an alternative therapy had not worked. Would I have continued looking for alternative ways to enhance my vitality and mobility? Would I have become so discouraged that I would have gone back to traditional modalities and surgery? No telling, as my first foray into the then, almost mystical, land of holistic healing was a fantastic success, so I have never had to look back.

When I left the doctors who were suggesting surgery, which I knew was not for me, I remembered that I had heard about a type of deep massage therapy that was designed for people who had been injured. It was supposed to re-sculpt the body and to realign it. I thought to myself if there was ever a body that needed a sculptor to do some re-sculpting, it was mine. My legs were weak; my arches were high; walking was painful; my back and pelvis were twisted from overcompensating for my feet and lower legs; my neck was strained and my shoulders and jaw were tight. I was not the image of grace and alignment. I thought I fit the definition of "injured" if anybody did.

So, I went into my research mode (remember, I was in law school at the time and we certainly learned how to research... if nothing else!). All I could find was a small pamphlet and the name of someone who did this thing called Rolwing who was located within half an hour of where I lived. I felt I had no choice but to try it. My first Rolfer was a woman who worked out of her home. She explained that the first course of Rolwing took ten sessions, but that I might want extra sessions on my feet. I thought to myself, "Yeah, like a hundred extra sessions," but I tried to keep my critical mind out of the process while maintaining a discerning awareness of what was going on.

I noticed a difference after the first session. My feet felt more firmly planted on the ground. Rather than walking with my weight forward, I was walking with my weight centered, more toward the midline of my body. It actually took some time getting used to this shift in my center of gravity. But I was excited. I knew this was going to work, and work it did! Over 15 years, I have had probably 100+ rolwing sessions; some

years doing ten sessions; some years going back for tune-ups of one to five sessions. Often I have had immediate and positive results. This is not to say all the sessions were relaxing; some of the sessions on my feet were painful, but the results were always worth it. Since my wonderful friend and Rolfer, Lucy Bissell, left the area 2 years ago, I have been half-hearted in looking for another person to work with. Recently my body has been urging me to get more of the work done. I discovered a listing on the web, which can fill in all the details about Rolwing, how it works, and also a list of people who do the work, their level of certification and where they practice. Check it out at www.rolf.com.

So, Rolwing stabilized my body and allowed me the experience of what standing and walking from a centered space felt like. My next great therapeutic bodywork experience was with a nurse at the MDA. I had gone to the clinic to see if they had Rolfers, massage therapists, and body workers who would be specifically trained with knowledge about CMT. I should have known that I was dreaming.

I was told that I would likely need leg braces and a wheel chair within the next 5 years, so I might as well sign up now. After all, they were free. I was furious and said I had no intention of being in a wheelchair in 5 or 10 years, and they had no right to share their negative beliefs or fantasies about me, with me. I was clearly not popular, but as I was leaving one of the nurses came up to me and said that she was studying a new form of therapy that was having great results for some people. The therapy was called cranial sacral therapy, and she was learning it from the man who developed the technique, a Dr. Upledger in West Palm Beach. She wondered if I would like to try it. Having become a firm believer that my next step in my healing process is always offered clearly and usually in unexpected ways, I began to work with her. I am embarrassed to say that I have forgotten her name. I felt so wonderful after the work with her that I paid for, bartered, did what ever I could do, to continue having sessions with her. While Rolwing helped on a very physical level, cranial sacral work felt like it was going deeper... almost into my emotional and spiritual neurology, if you will. While I did not experience the dramatic physical effects of the Rolwing, I did have dramatic results on other levels.

I found cranial sacral therapy was like a gentle fine-tuning, encouraging my body, mind, and spirit to embrace this body of mine and to wake up and do the healing work that was necessary. Cranial sacral therapy is very much about waking up one's own innate ability to heal and developing the ability to trust in that process. I experience an expanded sense of well-being, vitality, and joy after sessions of cranial therapy. I definitely have an altered perception of my energy and the energies of others after each session.

The wonderful news for people interested in cranial therapy now is that there is now an institute and clinic in Palm Beach Gardens, Florida. Thousands of people (from newborns to the elderly, from people with tennis elbow to those with spinal cord injuries) have received assistance, been trained to work on themselves and others, and become certified in a variety of levels of cranial sacral therapy. At the institute, they also offer a variety of other therapies which may be helpful to a person with CMT. For example, they offer something called Muscle Energy, which helps correct muscle dysfunction and improves range of motion. They also utilize the St. John's method of neuromuscular therapy that helps to alleviate pain and dysfunction through-

out the body. This is just a sampling of their offerings. For those interested, contact Dr. Russell Bourne at 561-622-4706 and discuss the possibilities with him.

For those of you who would like to dive into the world of these complementary therapies, the Upledger Institute and I are going to host a joint, intensive, two day journey into the world of complimentary therapies. This will probably take place in February for a limited group (probably no more than 20.) The agenda will include cranial sacral therapy, breathwork, your healing personality type, connecting with your inner physician, and more. We are working on the agenda now. It will be a fundraiser for both the CMTA and the Upledger Institute and it will be a first for both organizations. If you are interested in participating, please let me know as soon as possible.

Until the next time, in spirit, hope, and the adventure of it all.

As always I will be delighted to address any questions that you might have on any of the above. Send them to Cynthia Gracey, PATH consulting, 1109 Harbor Drive, Delray Beach, FL 33483, phone me at 561-243-0000 or email me at pathcg@aol.com.

GIFTS WERE MADE TO THE CMTA:

IN MEMORY OF:

Mary Bastone

Kay Flynn

Norma Jeanette Bloom

Tom Bloom
Clayton and June Koontz

Mr. Boxer

Marilyn Prashker

Andrew Chilton

Madeline Snarski

Roy Gadd

Gail C. Gadd

Fabius Gwin

Mr. and Mrs. Robert Nussmeier
and Family
James and Peggy Voelz

Stanley Hull

American Legion Auxilliary, Unit 851
Theresa Bates
Mary and Howard Bowe
Delaware Twp. Senior Citizens Club
Connie and Joel Gravina
Hometown Abstract Company
Ray and Eleanor Kubik
Bob and Sandy Maher
Mattamoras Seniors
Elvin and Olive Middelton

Marie and Cliff Oxland

Dolores and Irving Shampner
Tilghman Angle Smith
Kim Stevens

Stan and Linda Tashlik

James and MaryJane Whitesell
Sheila Wootton
Joseph J. Viet, Jr.

Gene Langsam

Marilyn Prashker

Elinore Lawrence

Patricia and David Dwyer
Lennox and June Harris
IAG Federal Credit Union
Barry Pasternack
Dr. Barbara Powers
Tom and Kris Powers and Family

Bruce Lee

John C. Bernot
Anne and Garth Docherty

Carmella Mirabella

Mr. and Mrs. Sam DiCara

James F. Murdoch

Beacon Financial Group

Elizabeth Murphy

Mrs. Edward Hayes
Mr. and Mrs. William Heisler
Mr. John Zies

Janet Ruppel

Clifford Holforty

Harold Voelz

James and Peggy Voelz

Alan Wechsler

Margie Farrell
Hearst New Media and Technology

IN HONOR OF:

Stephanie DiCara

Mr. and Mrs. Sam F. DiCara

Grace Kestler

Patti Burns
Mr. and Mrs. Robert Nussmeier and
Family
James and Peggy Voelz

Mr. & Mrs. Robert Klausner's 50th Anniversary

Mr. and Mrs. Robert Bernstein

Emily Louer

Mr. and Mrs. Arthur B. Mayers

Mr. Lou Miller's 90th Birthday

Mr. and Mrs. Robert Bernstein

While a great deal of effort has been made to make these lists as accurate as possible, we apologize for any omissions or misspellings that may have occurred.

CMTA Support Group News

Upper right: Michelle Mechsner, Kristy Daniels, and Daryl Earp attended the first meeting of the Dallas/Ft. Worth Metroplex CMTA support group meeting. A cake, donated by Barbara Davis, peeks from behind Daryl.

Lower right: Al and Marilyn Kent pose in their gift shop with some of the bears that will be auctioned off to benefit the CMTA at the North Broward Medical Center on March 14, 1999.

■ California - Berkeley Area

Ruth Levitan reports that her last meeting in November had 16 people in attendance and featured a physical therapist, who gave great information and answered questions. Ruth calls the Physician's Handbook the "Red Bible" and has been very successful in selling the book to members of her group and her own health care professionals. Miriam Diaz, her co-leader, has returned from Florida and is working on a support group for kids.

■ Florida - Miami/Ft. Lauderdale

Al and Marilyn Kent, leaders of this new support group, report that Dr. Howard Petusensky, a podiatrist, spoke to an enthusiastic group of



attendees at their first meeting. They will meet again in January at the North Broward Medical Center. If you are interested in attending, call either Marilyn or Al at 954-742-5200. Plans are underway for the Kents to host a "Teddy Bear" auction to help raise funds for the CMTA on March 14, 1999, at the North Broward Medical Center in Pompano Beach, FL.

■ Texas - Dallas/Ft. Worth

The first meeting of the Metroplex CMTA support group was held at Harris Methodist HEB Hospital in Bedford, TX. Approximately 40 people attended. The group met for a second time in October and the attendance was, again, very high. The group's co-leaders are Shari Clark and Greta Lindsey.



CMT Children's Clinic Held at Scottish Rite Hospital

The first CMT children's clinic was held at Scottish Rite Hospital on November 25, 1998. The clinic was sponsored by pediatric neurologist, Dr. Susan Iannaccone, Director of Neuromuscular Diseases and Neurorehabilitation. Eleven families attended this first session. A representative of the CMTA Board of Directors, Ardith Fetterolf, was in attendance, as was Greta Lindsey, support group leader from Dallas. The clinic will meet every other month and children can be seen at no charge if they are referred by their physician.

Iris Welch, RN, and Dr. Susan Iannaccone of the Scottish Rite Hospital, venue of the recent CMT children's clinic.

CMTA Support Groups

Alabama/Greater Tennessee Valley

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

Arkansas—Northwest Area/ Springdale

Place: Harvey and Bernice Jones
Center for Families,
Springdale
Meeting: 3rd Saturday of each month
Contact: Libby Bond, 501-795-2318

California—Berkeley Area

Place: West Berkeley Library
Meeting: Quarterly
Contact: Ruth Levitan, 510-524-3506

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,
561-336-8624

Florida—Miami/Ft. Lauderdale

Place: North Broward Medical
Center, Pompano Beach, FL
Contact: Al Kent,
954-742-5200 (daytime) or
954-472-3313 (evenings)

Kentucky/Southern Indiana/ Southern Ohio

Place: First United Methodist
Church, Lexington, KY
Meeting: Quarterly
Contact: Robert Budde, 606-255-7471

Massachusetts—Boston Area

Place: Lahey-Hitchcock Clinic,
Burlington, MA
Meeting: 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

Michigan—Flint

Place: University of Michigan,
Health Services
Meeting: Quarterly
Contact: Debbie Newberger/Brenda
Kehoe 810-762-3456

Minnesota—Benson

Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156

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 Ctr.
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664

New York (Horseheads)

Place: NYSEG Meeting Room, Rt. 17
Meeting: Quarterly
Contact: Angela Piersimoni,
607-562-8823

New York (Westchester County)/ Connecticut (Fairfield)

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

North Carolina—Archdale/Triad

Place: Archdale Public Library
Meeting: Quarterly
Contact: Ellen (Nora) Burrows,
336-434-2383

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

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

Ohio—Greenville

Place: Church of the Brethren
Meeting: Fourth Thursday,
April-October
Contact: Dot Cain, 937-548-3963

Oregon—Willamette Valley

Place: Brooks Assembly of God
Church
Meeting: Monthly
Contact: Marianne Destefano-Hill
(503) 585-3341 or Regina
Porter (503) 591-9412

Texas—Dallas/Ft. Worth

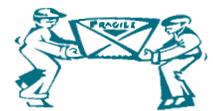
Place: Harris Methodist HEB
Hospital
Contact: Greta Lindsey
(817-281-5190) or Shari
Clark (817-543-2068)

West Virginia/North Central

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

ARE YOU MOVING???

If you're moving or have moved already and this issue has been forwarded, PLEASE notify the office of your new address. It costs the CMTA a few hundred dollars with each issue to get updated addresses from the post office, along with the additional postage to resend the newsletter. Thank you for your help in "containing costs."



Charcot-Marie-Tooth Association

INDEPENDENT AUDITORS' 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, 1998, 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, 1998, and the changes in its net assets and its cash flows for the year then ended, in conformity with generally accepted accounting principles.



August 7, 1998

STATEMENT OF FINANCIAL POSITION

JUNE 30, 1998 WITH COMPARATIVE TOTALS FOR JUNE 30, 1997

ASSETS	1998	1997
CURRENT ASSETS		
Cash	\$210,391	\$169,216
Unconditional promises to give	101,662	-
	<u>312,053</u>	<u>169,216</u>
EQUIPMENT - Net of accumulated depreciation of \$13,831	17,925	18,044
OTHER ASSETS	1,627	265
TOTAL ASSETS	<u>\$331,605</u>	<u>\$187,525</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 10,093	\$ 5,005
Accounts payable - research grant	35,000	-
Accrued expenses	250	250
TOTAL LIABILITIES	<u>45,343</u>	<u>5,255</u>
NET ASSETS		
UNRESTRICTED		
Operations	76,396	88,132
Board designated for research grants and education	14,179	14,179
	<u>90,575</u>	<u>102,311</u>
TEMPORARILY RESTRICTED	195,687	79,959
TOTAL NET ASSETS	<u>286,262</u>	<u>182,270</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$331,605</u>	<u>\$187,525</u>

STATEMENTS OF CASH FLOWS

JUNE 30, 1998 WITH COMPARATIVE TOTALS FOR JUNE 30, 1997

	1998	1997
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$103,992	\$ 18,795
Adjustments to reconcile change in net assets to net cash provided by operating activities		
Depreciation	4,420	3,223
(Increase) decrease in assets		
Accounts receivable - grants	-	25,000
Unconditional promises to give	(101,662)	-
Other assets	(1,362)	-
Increase in liabilities		
Accounts payable	5,088	1,901
Accounts payable - research grant	35,000	-
Net cash provided by operating activities	<u>45,476</u>	<u>48,919</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase of property and equipment	(4,301)	(16,163)
NET INCREASE IN CASH	<u>41,175</u>	<u>32,756</u>
CASH - BEGINNING OF YEAR	<u>169,216</u>	<u>136,460</u>
CASH - END OF YEAR	<u>\$210,391</u>	<u>\$169,216</u>

The accompanying notes are an integral part of these financial statements. See page 20.

Financial Report as of June 30, 1998

STATEMENT OF ACTIVITIES

YEAR ENDED JUNE 30, 1998

(WITH SUMMARIZED FINANCIAL INFORMATION FOR THE YEAR ENDED JUNE 30, 1997)

	1998			1997 TOTAL
	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL	
SUPPORT AND REVENUES				
Contributions	\$189,309	\$316,687	\$505,996	\$202,534
Conference fees, net	-	-	-	3,238
Return of unexpended research grant	-	-	-	6,854
Interest income	8,517	-	8,517	7,524
Miscellaneous	-	-	-	162
Donated equipment	4,300	-	4,300	-
	<u>202,126</u>	<u>316,687</u>	<u>518,813</u>	<u>220,312</u>
NET ASSETS RELEASED FROM RESTRICTIONS				
Satisfaction of program restrictions	200,959	(200,959)	-	-
TOTAL SUPPORT AND REVENUES	<u>403,085</u>	<u>115,728</u>	<u>518,813</u>	<u>220,312</u>
EXPENSES				
Program services	364,970	-	364,970	191,036
Management and general	26,105	-	26,105	2,793
Fundraising	23,746	-	23,746	7,688
TOTAL EXPENSES	<u>414,821</u>	<u>-</u>	<u>414,821</u>	<u>201,517</u>
CHANGE IN NET ASSETS	(11,736)	115,728	103,992	18,795
NET ASSETS - BEGINNING OF YEAR	<u>102,311</u>	<u>79,959</u>	<u>182,270</u>	<u>163,475</u>
NET ASSETS - END OF YEAR	<u>\$ 90,575</u>	<u>\$195,687</u>	<u>\$286,262</u>	<u>\$182,270</u>

The accompanying notes are an integral part of these financial statements. See page 20.

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED JUNE 30, 1998

WITH COMPARATIVE TOTALS FOR JUNE 30, 1997

	PROGRAM SERVICES	MANAGEMENT AND GENERAL	FUNDRAISING	1998	1997
				TOTAL EXPENSES	TOTAL EXPENSES
Salaries and benefits	\$ 67,095	\$17,000	\$ 7,500	\$ 91,595	\$ 39,627
Publications and supplies	68,862	285	12,574	81,721	57,196
Occupancy and office expense	20,238	5,059	-	25,297	13,744
Research fellowships	121,000	-	-	121,000	51,000
Conference expense	72,441	-	-	72,441	29,816
Special event	-	-	3,672	3,672	-
Consulting	12,019	-	-	12,019	-
Professional fees	-	2,656	-	2,656	6,911
Depreciation	3,315	1,105	-	4,420	3,223
TOTAL FUNCTIONAL EXPENSES	<u>\$364,970</u>	<u>\$26,105</u>	<u>\$23,746</u>	<u>\$414,821</u>	<u>\$201,517</u>

The accompanying notes are an integral part of these financial statements. See page 20.

CHARCOT-MARIE-TOOTH ASSOCIATION NOTES TO FINANCIAL STATEMENTS—JUNE 30, 1998

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 Association 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 Association 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 Association 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.

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 Association is registered as required with the Pennsylvania Bureau of Charitable Organizations.

In-kind Contributions

Volunteers have donated their time to the Association'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 \$4,300 and is reflected in the Association's funds.

Unconditional Promises to Give

Unconditional promises to give represent payments due in future periods for awards recorded as temporarily restricted support and revenue.

Prior-year Comparative Data

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended June 30, 1997, from which the summarized information was derived.

NOTE 2 - CONCENTRATION OF CREDIT RISK

The Association maintains a cash account balance at a bank located in Philadelphia, PA. The balance is 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, 1998, 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, 1998, the uninsured balance at this financial institution was approximately \$160,000.

NOTE 3 - UNCONDITIONAL PROMISES TO GIVE

In 1997, a private foundation authorized a grant of up to \$100,000 to be paid over the years 1997 to 1999. The annual contribution of \$25,000 to \$50,000 is contingent upon the Association's ability to match from \$75,000 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, subject to the above minimum and maximum. The contribution is recorded as the Association meets the matching requirement each year. The contribution receivable was \$43,562 at June 30, 1998.

NOTE 4 - TEMPORARILY RESTRICTED FUND

At June 30, 1998, the temporarily restricted fund had a balance of \$195,687 comprised of monies for research grants, the Third International Conference and education.

NOTE 5 - LEASES

The Association leases its office premises on a month-to-month lease. Total rent expense was \$5,454 for the year ended June 30, 1998.

Ask the Doctor

Dear Doctor:

My mother has been diagnosed with CMT. I have had an examination and an EMG that showed peripheral neuropathy. My neurologist said that I showed random deficits that did not follow the Charcot pattern. Further, he said that I couldn't have CMT because I didn't get any symptoms when I was in my 20's or 30's. The result of my neurological work-up showed that I had vitamin B-12 deficiency secondary to a history of atrophic gastritis. I have been taking shots for 6 months and some of my symptoms have improved, but most remain. Is there any benefit to my spending money on the DNA testing to confirm whether I, too, have CMT? I have no children to worry about passing it on to.

The doctor replies:

The atrophic gastritis is a wasting of the lining of the stomach that makes it impossible to absorb B-12, hence the treatment with B-12 shots should help some symptoms improve. We would emphasize that B-12 shots are essential for treating neuropathy and spinal cord disease related to this deficiency. The dose may need adjustment.

However, the key to finding out whether you have CMT will lie with having your mother tested first. She is the key person. Since you remarked that both of you had onset later in life, it's possible that your family has Type II CMT and would not have a positive response to the current DNA testing available through Athena Diagnostics. If she were tested first, since she has a positive diagnosis of CMT, you would know whether your taking the test would give you any useful information. If her test result is negative, you know that your family does not carry the defect currently measured in the DNA tests. Testing yourself, then, would be pointless. If her test result is positive, however, you could be tested and would know from a negative result that you do not have CMT. A positive result, of course, would mean you did inherit the disorder.

Dear Doctor,

My son was found to have CMT about 5 years ago. His feet are the primary problem. I have heard that bee stings have provided help for some health problems. Are you aware of any benefits for CMT patients from bee stings?

The doctor replies:

There is no known value for CMT patients from bee stings. It is a "hot" alternative medical treatment, but its real benefit has never been demonstrated over time. The question of hypersensitivity

and/or allergy to bee stings should be evaluated by an allergist before proceeding with this alternative medicine.

Dear Doctor:

I have CMT. In 1997 I was diagnosed with focal segmental glomerular sclerosis with nephritic range proteinuria. Do other CMT patients have this kidney disease?

The doctors reply:

Every CMT specialist who was contacted with this question replied that there was no connection between CMT and kidney diseases as far as they knew.

Dear Doctor:

I noticed that the FDA just approved the first ever drug testing using antisense therapy. Antisense therapy uses synthetically designed chains of DNA that are intended to block the production of disease-related proteins. Since we have a problem with our peripheral myelin protein (PMP-22), would this therapy be useful to us?

The doctor replies:

There are possible implications for CMT patients, but there is nothing being done so far with regard to this therapy and CMT disorders. As soon as research gives more details about the production of disease-related proteins, this approach can be considered.

Dear Doctor:

I am troubled by excessive sweating and often, a nearly constant feeling of being overheated. Could this be related to my CMT? With my hands and feet always cold, it seems ironic that I feel hot in other parts of my body.

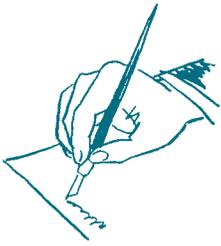
The doctor replies:

Although not proven, there is some belief that CMT can affect the autonomic nervous system; thus, sweating could be related to the disorder. Also, it well known that the body must perspire to reduce body temperature. When the extremities are impaired and sweating cannot occur there, profuse sweating can occur in other regions of the body. A person paralyzed from the waist down often finds that he then sweats profusely from the head and upper body.

Specific testing is available for small fiber and autonomic nerve disease and may be useful. This problem (of abnormal sweating) is a common involvement in diabetic neuropathy, and diabetes and other causes of neuropathy should be excluded even if you have CMT.



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



WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

601 Upland Ave.

Upland, PA 19015

The CMTA reserves the right to edit letters for space.

The CMTA Report

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The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Association. 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.

Letters to the Editor:

Dear CMTA,

Does anyone have any information about sleep-away summer camps for CMT children? My son is 11 years old and ambulatory, but can't compete in sports and just doesn't seem to fit in. He has been to a Maine camp for the past two summers, but now the camp's size and hills limit his choice of activities. He's not being included with his bunkmates.

Please email me at LRRTI@aol.com or send a response to the CMTA office in care of R.Cohen.

(Editor's note: We did mention the camps operated through Shriners to this mother. If you have other suggestions, please respond.)

Dear CMTA,

Thank you for the Physician's Handbook. I have found the book most informative and have lent it to a general practitioner. I am interested in pen pals in the US. I had a letter printed in the local Australian newsletter and have had two replies so far. I met an 8-year-old boy in our area recently and he has had a lot of surgery to his feet already. My son, who is 35, is quite severely affected. He just arrived home from a 3-month band tour of Germany. He finished the tour off by playing in Luxembourg at a Grand Prix car race. Quite a few people commented to him on his ability to play the drums with his disability. He has severe hand involvement from the CMT, but he doesn't let it get him down in any way.

I would like to wish all CMT "friends" a safe and happy holiday season. May 1999 be filled with health and happiness.

—Lenore McLean-Jones
10 Waterworks Rd

North Ipswich, Queensland, Australia 4305

Dear CMTA,

I am 81. I began active bicycling at the age of 63. I twice bike-toured across America via the 4500-mile Transamerican Bike Trail after the age of 65. I had my first encounter with CMT in 1986, when I began to walk with a "clump."

I directed a letter to The Mayo Clinic Health Second Opinion. I described my foot problem. The doctor suggested that it sounded like foot drop and that I should contact a neurologist. I saw a doctor who immediately diagnosed my problem as hereditary peripheral neuropathy... later CMT.

The doctor was aware of my cycling experience. I asked if cycling would be a benefit to

maintaining muscle mass and leg strength. He assured me it would.

I have never stopped cycling. Because of a 1993 bicycle accident, I live with a steel ball in my right hip. Even though I have poor balance when walking, I maintain excellent balance on the bike. My weak ankles do not hamper my ability to manage low-grade hills. Because I have retained upper leg strength, bicycling is not tiring. The doctor was right! I virtually stopped the atrophy of my calf muscles.

—W.S. Aptos, CA

Dear CMTA,

Just a note to tell you that I have found some great comfortable shoes that will accommodate my orthotic insert. I called around and found that a shoe store in Yuba City, CA, carries SAS shoes. They are called Free Time and come in several colors. They cost nearly \$90 (which curdled my Scotch blood), but they are well worth it. They are comfortable and did accommodate my insert just fine once I removed the foot bed.

I appreciate the quarterly magazine and wanted to pass this information along to others.

—D.H. Biggs, CA

Dear CMTA,

I want to thank you for including me on your mailing list even though I cannot afford to support the CMTA on a regular basis.

I just received the Fall issue of the newsletter and I feel like I could have written the article on "The Invisible Heroes of CMT" by Dana Schwertfeger. I even use toenail clippers instead of fingernail clippers as she [Ed: Dana is actually a man] does simply because their size makes them easier to use.

I've never felt like a hero, but anyone living with CMT does heroic deeds everyday by "just coping with obstacles" and "trying to live as normal a life" as possible. "Putting on a cheerful face" takes more energy some days than others, but as Dana writes, there is the matter of self-respect, pride, and a great deal of stubbornness. Maybe, the mule would be a good mascot for us who are challenged by CMT.

Again, thanks for all the information.

—D.W. CMT-challenged and incredibly stubborn

Dear CMTA,

I am on a personal campaign in my local area to bring CMT awareness to the public eye! It's time to open some eyes and come out of the

closet. It's up to us to educate the medical community to the fact that we aren't that rare! I have sent out over 20 letters, with "What is CMT?" brochures from the CMTA, my personal story, and an announcement of our first CMT support group meeting in Northwest Arkansas. I have an interview with an area newspaper to do a story at the same time the announcement of our support group meeting will be printed in the paper.

I am also handing out information to be posted in libraries, Walmart Supercenter stores, health food stores, clinics, and doctor's offices. I've sent other letters to chiropractors and massage therapists, neurologists, physical therapists, and rehabilitation centers, as well as other newspapers.

I urge you to do something in your area to be heard and noted. Sometimes, we must be our own advocate to get the ball rolling. Together, we can and will make a difference!

—Libby Bond, Arkansas

Dear CMTA,

I enclose my check for general membership. I was diagnosed with CMT over 20 years ago. My father had it; my twin brothers and I have it. They each have at least 2 children that have it and grandchildren that have it. My son and one daughter have it and one of my granddaughters has it, so we have obtained a lot of information about it.

My nephew, Reverend Neale Bachman, was a contact person for your organization in central New York. He died of a heart attack in 1997.

I read one of Dr. Donohue's letters in the paper and heard CMT mentioned on the Jerry Lewis Telethon a few years ago. We are spreading the word. I carry the back page of your newsletter with me and have doctors or nurses read it and make a copy for my file and to keep for their information.

I have a cousin in Idaho whom I had never met, only corresponded with. She was in her 70's and described to me her trouble with her toes and foot drop. I had told her about our CMT and she told her doctor. He asked if I would send him all the information I had so he could copy it for his files. (I had saved every newsletter I had ever gotten.) I sent it all to him and it was not long before he returned it and had diagnosed my cousin with CMT. When she told her daughter in Georgia (an RN) about it, she discovered she also had it.

My daughter, who has CMT, is married to a man whose brother had it. She had a triple

arthrodesis several years ago and may have to have it done again. Her feet have caused her a lot of problems since she was in her teens and they are getting worse. She's in her 50's now.

I've had AFO's for many years and my hands don't function very well, but I have no pain, just a burning sensation in my feet at night. We all have CMT1A, diagnosed by blood samples sent to a doctor in Iowa City, IA. [Editor's Note: Dr. Victor Ionasescu, now retired.] I'm 77 and on a limited income, but I will try to support you.

—B.M. NY

Dear CMTA,

I am sorry that I have not been able to send in my membership sooner than this. I was without a job for a while and then it took quite some time to get caught up financially. I'd like to thank you for sending me the newsletters even though I had not paid my membership.

All the information I have received from you has been so helpful. My 6-year-old son is now receiving much-needed help from Shriners' Hospital in Massachusetts thanks to an article you ran in your newsletter.

Thank you so much.

—V.W. NY

Dear CMTA,

I am responding to the mother of the young child who is being teased by other children written about in the Fall 1998 issue. My father has CMT1X and when I was growing up, he was already crippled by the disease.

There were a lot of cruel children in the school I attended, too, who used to tease me because my father walked differently from other people. The best advice I can give the mother is to tell her child what disorder you have and that if kids are cruel because of their mother's handicap, those kids are not worth associating with.

Someday, I will have the same problem because I was diagnosed with CMT1X also and I have two small children (who have been tested, but we are still waiting for the results.) My only advice it to tell the child to ignore those cruel children and just walk away. Don't give in to taunts and teasing. Tell the child that if those kids can't accept his handicapped mother, then they can't accept the child. The child is better off without those children in his life.

Sincerely,

—A.R. PA

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 150,000 Americans.
- ... 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 also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ... is slowly progressive, causing deterioration of peripheral nerves that 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, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- ... Types 1A, 1X, and HNPP can now be diagnosed by a blood test.
- ... is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

The CMTA Report

Information on Charcot-Marie-Tooth Disorders from the Charcot-Marie-Tooth Association



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