

The CMTA Report

APRIL 2002

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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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Board Member Swims for "The Cure"

To start off the CMTA's annual research appeal with a "splash", Steve O'Donnell, a recent addition to the CMTA's Board of Directors, has decided to do "something big" to bring attention to CMT disorders and to raise money for research. One of Steve's favorite symbols to demonstrate commitment to the cause of CMT is the concept of each person being a caped-crusader. He likes to say that each of us should put on our cape (à la Superman) and get out there and do something to bring the public's attention to our little-known disease. So, six months ago, Steve put on a cape (and a bathing suit) to begin training to take on the challenge of a lifetime.

On Father's Day, June 16, 2002, Steve will swim 4.4 miles across the Chesapeake Bay. The swim is organized by Linmark.com. To understand Steve's commitment, one has only to listen to his training regimen. He gets up at 5:00 AM to be in the pool by 5:30; he swims laps for an hour and 45 minutes; he drives home to be there before his children, ages 6 and 8, awake so that he can kiss them good morning and be to his own job by 8 AM.

On Sunday mornings, Steve has convinced his swimming partners to swim at 6 AM so that he can take his children to the 9 AM church service. He even joined a pool across from his business so that he can get more hours in by taking an afternoon break, swimming, and then returning to work.

Steve's goal is to make the swim in under three hours, but he is aware that the probability of that is dependent on the weather, the effect of ship traffic, and the often rough water conditions. Many swimmers more experienced than



On Father's Day, June 16, Steve O'Donnell will swim 4.4 miles across the Chesapeake Bay—under the Bay Bridge!

he have been pulled from the water when exhaustion set in. He vows not to be pulled out, no matter what.

When asked what would motivate someone with CMT to attempt such a feat, Steve replied that he wants to get people's attention focused on CMT and to raise money for research. He said, quite honestly, "I couldn't run a marathon because of the muscle loss in my legs. This was the biggest thing I thought I could train for and do."

Using the swim as a vehicle to raise money, Steve hopes to add \$100,000 to the CMTA's research fund. His cape is starched and ready for wearing. He needs your help to make his goal a reality.

To make a donation, see form on page 2.

*The CMTA....
Living our
Mission*

Mission Statement:
To improve the
quality of life for
people with CMT
and to find a cure.

Vision Statement:
A world without CMT.

EDITORIAL:

Making the Effort

For many people, CMT demands that they adjust their lifestyle to accommodate progressing symptoms. But, when it comes to going above and beyond the daily struggle, most of us need some kind of inspiration. When that happens, miraculous things occur and hidden abilities emerge.

One example of inspiration is Steve O'Donnell, our Superman. As you see from the article about his fundraising event, this man's inspiration has empowered him to do what many people without CMT will never be capable of doing. No one asked Steve to do this; he volunteered! He chose to go out of his way and make a personal effort to influence the progress of CMT research. Why?

Leading researchers tell us we need a large infusion of money over the next few years. Probably several million dollars, before we can find a treatment and cure for CMT.

What does Steve's example teach us? There is something each of us can do, and there is a

hero in each of us who makes an effort to inspire and be inspired. Board members Robert Kleinman and Patrick Torchia host golf tournaments to raise money for research. Kim Salzberg has encouraged her Welcome Wagon group in Garden City, NY, to devote their fundraising effort to CMT this year; a group of students in Johnstown, PA are hosting a volleyball tournament to raise money in memory of a fellow student, Marah Griffith, who had CMT.

Everyone who becomes a member, encourages their family to join, or teaches his or her physician about CMT is a winner. Everyone who writes his or her congressman or completes the database survey is trying to make a change for a better future for all people with CMT.

Do you have to swim a channel or raise a hundred thousand dollars? No. Within your abilities, all you have to do is make the effort. Together, with all our various gifts, we will find a cure for CMT!

See page 3 for action you can take today.

*Make a
personal effort
to influence
the progress of
CMT research.*

YES! I WOULD LIKE TO SUPPORT STEVE O'DONNELL'S "SWIM FOR THE CURE FOR CMT RESEARCH":

NAME: _____

ADDRESS: _____

PHONE #: _____ AMOUNT OF GIFT: _____

CHECK ENCLOSED VISA MASTERCARD AMERICAN EXPRESS

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SIGNATURE: _____

Mail form to: The CMTA, 2700 Chestnut Parkway, Chester, PA 19013 or FAX to: (610) 499-9267.



Help the Cause... Push Rare Disease Legislation

(Editor's note: Here is an opportunity to "make the effort" for CMT. Everyone affected by CMT—patients, families, friends—can help themselves and make a difference, without it costing more than the price of a phone call or stamp. If you write or call, you should mention that you have Charcot-Marie-Tooth, a rare disease, which will also help get the word out about the disorder.)

On March 20, 2002 two critically important bills were introduced in the House of Representatives to strengthen research programs on rare disorders (like CMT) at the National Institutes of Health (NIH), and the Food & Drug Administration (FDA). The two bills are companion legislation for the Rare Diseases Act of 2001 (S.1379), which was introduced in the Senate August 3, 2001 by Senator Edward Kennedy (D-MA). The House bills separate the two initiatives for the NIH and the FDA by making each a separate piece of legislation.

One bill in the House of Representatives is named The Rare Diseases Act of 2002 (H.R. 4013), which establishes an official Office of Rare Diseases at the NIH. Congressmen John Shimkus (R-IL) and Henry Waxman (D-CA) introduced this bill. The Office will promote and coordinate research on rare disorders, and will create academic centers for research on these conditions. The Office of Rare Diseases would receive \$24 million per year for this program.

The second bill in the House is named The Rare Diseases Orphan Product Development Act of 2002 (H.R. 4014). Congressmen Mark Foley (R-FL) and Henry Waxman (D-CA) introduced this bill. This law would provide \$25 million

per year for the FDA's Orphan Products Research Grant Program, which supports clinical trials of new orphan drugs, diagnostics, medical devices and medical foods. This program received only \$12 million from Congress this year, which is less than the funds appropriated for this research in 1995. To date, 27 new products (24 orphan drugs and 3 medical devices) have been developed (and are currently on the American market), through these grants to academic scientists and small companies.

ACTION NEEDED:

The two bills are critically important to people with orphan diseases who are waiting for new treatments and cures to be developed for their health conditions. In order to enact these important laws, interested people are urged to contact their congressional representatives and ASK THEM TO CO-SPONSOR H.R. 4013 AND 4014. More than half of the members of the House of Representatives MUST sign-on to the bills before the entire House can vote on them. If we want these laws to be enacted this year, this must occur before Congress recesses before the election season this autumn.

It is best to phone your congressional representative either at his state office or their Washington, DC office (phone the Capitol switchboard at 202-224-3121 and ask for your Congressman's office). Remember that mail to Washington is delayed by four or more weeks due to security concerns. If you wish to send a letter, either mail it to your congressman's local state office, or FAX it to his Washington, DC office.

World Congress and Exposition on Disabilities Hosts Website

There is a website for the disability community at www.vwcdexpo.com, which has information on products and services in the special needs arena. The World Congress and Exposition on Disabilities is a leading event for the exchange of information and ideas on important issues for people with disabilities and the new website has created a virtual world in which visitors can interact with national and local organizations and exhibitors. The site also provides a bulletin board to allow participants to receive the greatest number of responses.



CMTA MEMBERSHIP/ORDER FORM

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Address: _____

Phone Number: _____ Email: _____

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 | |
| SPECIAL OFFER FOR ACTIVE MEMBERS ONLY: CMT Facts Series (I-IV) | | active members \$16 | |
| 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 | |
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| A Guide About Genetics for the CMT Patient No shipping and handling on this item only. | | active members \$4 inactive members \$5 | |
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| Contribution to CMT Research 10% will be applied to administrative expenses. | | | |
| Shipping & Handling Orders under \$10 add \$1.50, orders \$10 and over add \$3.00 | | | |
| TOTAL | | | |

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

VISA MasterCard American Express

Card Number _____ Expiration Date _____

Signature _____

Mail to the CMTA, 2700 Chestnut Parkway, Chester, PA 19013 or Fax to 610-499-9267.

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.

SEEKING: PARENTS WITH DISABILITIES AND THEIR TEENS FOR THROUGH THE LOOKING GLASS NATIONWIDE SURVEY

Through the Looking Glass is conducting a nationwide project to learn more about families in which a parent with a disability is raising a teen (11-17 years old). The National Institute on Disability Research and Rehabilitation, part of the Department of Education, funds this project.

What do we mean by disability?

Disability can involve physical, visual, systemic, hearing, cognitive, learning, developmental and mental health issues. Why are we conducting research? Although there are over 10 million families in which one or both parents have a disability, relatively little is known about the experiences of these families.

Who can participate?

Parents with disabilities and deaf parents who have teenagers (children 11 to 17 years of age) living at home. The parent and the teenager are both welcome to participate.

Ways to get involved

- Participate in a national survey of parents with disabilities who are raising teens age 11-17. Your teen can also fill out a survey and receive \$5 in return.
- Surveys are available in a variety of formats: By mail, online and printable at our Website, in Spanish, over the phone, and in a version specific to Deaf parents.
- Local families (SF Bay area) can participate in 12 weeks of solution-focused family therapy in their own home.
- Deaf parents can participate in a face-to-face interview in ASL if you live in or near one of the following cities: San Francisco, Seattle, Santa Fe, Rochester, New York, Kansas City, or Washington, DC.
- Teens of parents with disabilities can participate in our hosted Teen Bulletin Board (www.lookingglass.org).

For more information, contact:

Nancy Freed, MSW, Coordinator
(510) 848-1112 ext. 174

Voice: (800) 644-2666

TTY: (800) 804-1616

Email: tlg@lookingglass.org

Website: www.lookingglass.org

Professionals Working for CMT Patients: Dr. Frances M. Dyro

I am the newly recycled Associate Professor of Neurology and Director of the Neuro-muscular Section at New York Medical College—Westchester Medical Center in Valhalla, New York. I say recycled because thirty years ago I completed my residency in this very program. In those 30 years I had a number of colorful and exciting experiences before returning home.

After my adolescent growth spurt, I realized that a career in Ballet was not an option.

My father was a musician in Portland, Maine where I was born and grew up. He convinced me that a career in the arts required a good solid day job. I think his only regret about me was that I never learned to play the accordion. My mother, who had no formal schooling, thought I should “get a good job with the telephone company.” After high school I went on to the Massachusetts Institute of Technology thinking to become an astrophysicist. I was still clutching my Frank Slaughter MD medical novels. At MIT I found that while astronomy was fun, astrophysics might not be right for me. I had the good fortune

of being exposed to professors making the news in the field of biology. Two later became Nobel Laureates. My psychology professor Ronald Melzack and my physiology professor Patrick Wall were at that time developing the gate-control theory of pain perception. My undergraduate thesis was supervised by Dr. Jerome Y. Lettvin. Jerry had trained as a neurologist but was doing research on the visual system. I was put to work studying ways to modify the neuromuscular junctions of frogs. I went from MIT to the University of Maryland School of Medicine in Baltimore. My physiology professor William J. Adelman was studying how nerve cell membranes conduct signals. He hired me for the summer to be a lab assistant at the Marine Biological Laboratory in Woods Hole, MA. That summer I was co-author of my first paper on nerve function. I

went back to Woods Hole (a big summer camp for scientists) two more summers. I had to decide whether to go on to a Ph.D. or to continue with clinical medicine.

After a year of “rotating” internship in Maine, I spent one year at Johns Hopkins. The chief of neurology was Joseph Magladery who first described the F wave. I moved to New York and finished up at NYMC. I had a six-month interval between my residency and the start of my fellowship. Wanting to do some-

thing useful, I went to Kasganj, Uttar Pradesh, India and worked as a volunteer in a small mission hospital. They were doubtful about what a newly minted neurologist could offer. I proudly declared, “I can do anything. I went to U Maryland and did a rotating internship”. I ended up delivering babies, doing surgery, and even did a one shot angiogram using a spinal tap needle and an antique x-ray machine (then doing a craniotomy on the patient). Those were my wild days.

I did my clinical neurophysiology fellowship at Columbia-Presbyterian Hospital with Dr. Robert Lovelace, who interested me specifically in the



Dr. Dyro became interested in the hereditary sensory neuropathies while working with Dr. Robert Lovelace.

hereditary sensory motor neuropathies. I became proficient in electro-diagnostic testing and in clinical diagnosis of neuro-muscular disorders. In 1973, after another trip to India (they expected me to speak Hindi and return every year), I opened up an office in Portland, ME. I was given a part time job covering the Rehabilitation Service at the Maine Medical Center with Dr. John Lorentz, who got me involved in the Muscular Dystrophy Clinic. I learned that southern Maine has quite a few people with CMT who trace their ancestry back to the original French settler with CMT. My theory is that they are the Acadians who decided to stay in Maine instead of going all the way to Louisiana to become Cajuns. After four years of the full-time practice of general neurology, I got restless to return to teaching.

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PROFESSIONALS WORKING FOR CMT PATIENTS: DR. FRANCES M. DYRO

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I did neuromuscular physiology at Temple University for a year and then moved up to Boston to head up the Clinical Neurophysiology Lab at the VA Medical Center, West Roxbury. I was also an attending at the Brigham and Women's Hospital with an Assistant Professorship at Harvard. While there I organized a day long seminar on CMT for patients. This led to the development of the Boston area support group. I also developed a special interest in the neurology of the bladder and pelvic area (see "Ask the Doctor," page 18).

I had the chance to travel to many countries. I spent more time volunteering in India and Nepal. I lectured in France, Sri Lanka, and Czechoslovakia. In 1993 I "retired". This retirement lasted 6 months before I went to spend four months working on a project in the Urology Department at Emory. I was also working with World Development Group, Inc. This is an organization helping to restructure economies and health care delivery systems in emerging countries. I enjoyed

Dyro will be starting up an MDA-CMT clinic to serve Westchester County.

performing in musicals such as the Gilbert and Sullivan productions. Sorry, no accordion playing. A year or so ago, the need to teach came over me, and I succumbed when approached by Dr. Brij Singh Ahluwalia, the Chief of Neurology at NYMC. We had been co-chief residents many years before. He gave me the opportunity to build a neuromuscular section and to develop a strong training program in clinical neurophysiology. In the near future we will be starting up an MDA-CMT Clinic to serve Westchester County. The Neurology Department here is particularly collegial in that three of the six of us trained together. I feel as though I have come full circle. I have already found a place to sing here.

I am particularly proud to be an Altrusan for nearly thirty years. Altrusa International, Inc. was the first business and professional women's service organization. We say, "Like Rotary, but better". I have recently been appointed a Non-government Organization Delegate to the United Nations representing Altrusa International, Inc. My next goal is to establish an Altrusa Club in Westchester County. I am also proud to be a member of the CMTA's Medical Advisory Board. I look forward to serving patients with CMT here at NYMC.

CMTA Remembrances

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
- Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____

- Check Enclosed VISA MasterCard

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

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The New Medicine

(Editor's note: We receive many calls in the office about alternative therapies. The information presented here is for information only. The CMTA does not endorse any of the therapies mentioned below. The information is excerpted from Guide to Good Health, published by Independence Blue Cross and Blue Shield.)

ACUPUNCTURE:

We can thank Richard Nixon for drawing attention to acupuncture. Among the press corps accompanying Nixon on his landmark visit to China in 1972 was the *New York Times*' James Reston, who underwent an emergency appendectomy in Peking. To his amazement, instead of pumping him full of painkillers after the operation, the local doctors stuck needles all over him. And it worked. On his return home, Reston wrote glowingly about his experience.

Acupuncture has become one of the most popular alternative therapies. The World Health Organization recognizes more than 40 medical problems, from allergies to arthritis to AIDS, that it can help. Nationwide there are nearly 7,000 practitioners and 50 schools. The American Association of Acupuncture and Oriental Medicine reports that 15 million Americans had acupuncture treatments in 1991. The needles hurt no more than tiny pins and the sensation they give is one of mild tingling. Afterward you're likely to feel relaxed.

Why acupuncture works is something of a mystery. It's rooted in a concept of energy, and to understand that, it's necessary to change the way we're accustomed to looking at sickness. Western medicine is based on complex electrical and chemical interactions that regulate metabolism. When something in the body goes askew, we search for the imbalance with laboratory tests—checking glucose levels, electrolytes, T-cell counts and the like. Then we try to correct the problem with drugs. By contrast, Eastern medicine barely measures symptoms. It views metabolism as a life force called Qi (“chee”) that can't be quantified in a test tube.

Qi circulates through the body along a dozen pathways called meridians, which do not correspond to any physical map we learned in high school biology. The other key in the Oriental concept of disease is yin and yang, the interdependent, opposing forces of nature. The trick in all of life is to maintain the proper balance between yin and yang so that Qi can flow naturally.

Illness occurs when Qi is blocked. Health returns by restoring harmony, and that's where acupuncture enters the picture. The acupuncturist, who knows hundred of points along the meridians, inserts three- to four-inch-long hair-thin needles at key places to stimulate or sedate the system. The needles help release whatever is obstructing Qi so that the body can heal itself.

What's even more confusing is that there are different schools of acupuncture—traditional Chinese medicine, Five Elements, medical acupuncture, electro-acupuncture—all with somewhat different approaches to diagnosis and treatment. And don't ask for proof in the form of standard medical studies, because there isn't much. There's no placebo for a needle. But there is overwhelming anecdotal evidence that acupuncture is capable of some pretty remarkable things.

Acupuncture should not be used in place of standard medical examinations, nor should you expect it to cure diseases like cancer. In choosing an acupuncturist, find out if he or she attended an accredited school and is licensed or has been approved by the National Committee for the Certification of Acupuncturists. Make sure that only disposable, pre-sterilized needles are used. The American Association of Acupuncture and Oriental Medicine has a referral list of certified acupuncturists and lots of free information (919-787-5181).

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The acupuncturist inserts 3- to 4-inch-long needles at key points to stimulate or sedate the system.



THE NEW MEDICINE

(Continued from page 7)

HOMEOPATHY:

Homeopathy was developed 200 years ago by a German doctor, Samuel Hahnemann, for whom Hahnemann University Hospital in Philadelphia is named. Distressed by the barbarian medical practices of his day, he started experimenting with natural medicines and formed a theory that became known as the law of similars: The same substance that in large doses causes an illness can cure that illness in small or infinitesimal amounts. This is like the fight-fire-with-fire idea behind vaccines and allergy shots, which use a speck of virus or allergen to produce an immune reaction.

The thing about homeopathy that drives scientists crazy isn't his like-cures-like principle, but its other core belief: Less is more. Hahnemann taught that the smaller the dose of the remedy, the stronger its effect. The 1,500 remedies in the *Homeopathic Pharmacopeia* (considered nonprescription, loosely FDA-regulated

drugs) are so diluted that they frequently contain nothing more than a memory of their original ingredient. Nevertheless, more and more people are flocking to homeopaths, who have regained much of the stature they enjoyed at the turn of the century.

The movement never lost steam in Europe. The Queen of England has a homeopath on her staff. In France, a third of family physicians practice homeopathy; in Germany, one out of every five. The resurgence in the United States dates to the early '70s, spurred by disaffected young doctors who wanted less toxic and more individual ways to treat their patients. Today, an estimated 2,000 physicians in America use homeopathy.

Because the medicines used in homeopathy are nontoxic, people are encouraged to become educated in self-treatment. The goal is to shift the emphasis from the doctor to the patient and to educate people about the remedies, as well as their limitations. People worry that they have to make a choice between allopathic and homeopathic medicine, but they're really complementary. Most people are perfectly capable of handling minor health problems—stuff like

Trager Therapy... A Success Story

(The following testimonial was provided with the hope that information about heel stretches might help the CMT population. We have written about Trager therapy in the past and this discussion is an attempt to explain how one person benefitted from the therapy.)

By **MEGANWIND EOYANG, CMT, CTP**

Margaret Fingerson was diagnosed with CMT in her 60s and it is now 20 years later. She used to have burning pain in her calves, hands, arms and occasionally her face. She rarely feels these pains anymore. Margaret came to me because she was suddenly having a very difficult time with her balance, especially when turning to the side. Margaret wears leg braces and uses a cane or walker, depending on her balance and strength that week. I have been working weekly with Margaret in California for several years, using Trager movement education, as well as stretching and balance exercises, which she does in my office and at home.

We have discovered that if she does negative heel stretches before going to bed at night, she has more strength in her legs and better

balance the next day. I believe this is because the braces hold the Achilles tendon at a single length the entire time they are worn, which could contribute to weakening and atrophy. By stretching the Achilles tendon, she both lengthens the muscle fibers and enlivens the nerve messages to the Achilles tendon and in the calf muscles. When more of the muscle and tendon fibers are flexible, it strongly increases her ability to feel and find her balance.

HOW TO DO NEGATIVE HEEL STRETCHES:

Getting Ready: Negative heel stretches are done standing with the balls of the feet on the edge of a step or a very big book (like a telephone yellow pages or a dictionary). Be sure to hold on to a banister or wall, counter or chair for balance. When doing this exercise, keep your focus on stretching and strengthening the muscles and tendons of the heel and calf. Do not try to balance: hold on to something. (The better balance comes from greater strength and flexibility in the Achilles tendon and the calf). Margaret says this negative heel stretch also

colds, flu bugs and sprains. They want to be in control of our lives.

Much, but not all, of the evidence of homeopathy's efficacy is anecdotal. However, in 1991 the *British Medical Journal* reviewed 107 clinical homeopathic studies and found that 81 showed positive results, although the methodology of some of the research was questioned. A double-blind study published in *The Lancet* found that a homeopathic remedy significantly reduced hay fever symptoms. Another study showed that flu sufferers taking *Oscilloccinum* had a quicker recovery than a control group given a placebo.

"We have plenty of clinical and anecdotal evidence that homeopathic remedies work, but we don't have a unifying theory why," says Jay Borneman, whose great-grandfather, grandfather and father were homeopathic pharmacists. "Still, the lack of an explanation doesn't make the phenomenon cease to exist." Borneman is vice president of Standard Homeopathic Company, the largest homeopathic drug firm in America.

Nobody disputes its safety. But people might be hurt by discontinuing useful drugs in favor of

homeopathic remedies. There is something going on in all these cases of cures, but the answer isn't in quantum physics. It may be in the mind/body connection. The lack of proof of how the process works is one reason health insurers do not endorse homeopathy and typically do not cover homeopathic services and supplies.

SHIATSU:

Shiatsu is a Japanese term for finger pressure. Using the hands and feet, the practitioner applies gentle but deep pressure along the same pathways as the acupuncturist and with the same goal: to balance and harmonize the movement of Qi. Shiatsu can reduce the excesses and replenish the deficiencies. It's done without oils because they would interfere with the flow of energy, and the client wears light cotton clothing because it's a good energy conductor. Advocates of shiatsu believe that in addition to affecting the muscular and skeletal system, it regulates biological functions like digestion and circulation.

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helps almost eliminate "restless legs" at night, and reduces leg cramping for her.

With the balls of your feet on the edge of a step (or book), first stand with your heels lower than the step, only as far as you can *comfortably* stretch. It is important not to overdo with this exercise. During a slow inhaling breath, as smoothly and steadily as you can, rise up on the balls of your feet. The heels will now be higher than the step. Then on a very slow exhaling breath, as smoothly and steadily as you can, let the heels sink down below the level of the step again. Repeat this 4-10 times depending on your strength that day. If you are feeling good, you might enjoy doing this both on waking and just before sleep.

ABOUT TRAGER MOVEMENT EDUCATION:

Margaret was referred to me by a holistic health referral service specifically because she mentioned that she was dealing with a degenerating nerve condition. Trager movement education was developed about 75 years ago by Milton Trager, MD specifically to address issues of limitations created by various neurological conditions. For the first 50 years of practicing this work, he worked exclusively with people coping with neurological challenges, for instance, multi-

ple sclerosis, cerebral palsy, polio (before vaccines were discovered) and post-polio sequelae, muscular dystrophy, stroke, Parkinson's disease, and many others.

The work Dr. Trager created uses gentle rocking, swinging and stretching movements to communicate to the nervous system that it is safe to relax. Dr. Trager taught his students that for every physical restriction in the body, there is an unconscious (nervous system) pattern holding it. Through easy, almost playful movements, none of which hurt, the nervous system learns new, easier, freer, more effortless ways of moving. Some of this work is done with the client covered, partially clothed, on a massage table. Some of it is independent movement called *Mentastics*, which are designed to recreate that feeling of easiness and effortlessness clients feel during the tablework. In my practice, I also incorporate various strengthening movements and stretches from t'ai chi ch'uan, chi gung, yoga, and physical therapy.

FURTHER INFORMATION:

If you would like to find a Trager practitioner in your area, you may call the United States Trager Association at (216) 896-9383; e-mail them at US-Trager@trager.com; or, check their website at www.Trager.com.

THE NEW MEDICINE

(Continued from page 9)

ROLFING:

Rolfing, also known as structural integration, is designed to improve posture and repair the emotional and physical trauma trapped within our bodies. Created by Dr. Ida Rolf, who had a Ph.D. in biochemistry, rolfing stretches and separates major muscle groups and the soft tissue that connects them. Rolfers reorder the head, shoulders, chest, pelvis and legs into vertical alignment, which results in proper posture and minimizes the negative effects of gravity. Upon completion of a typical ten-session program, people report feeling physically, emotionally and spiritually enhanced. The cost, \$800 to \$1,000, is not covered by insurance.

REFLEXOLOGY:

For pure pleasure, nothing beats reflexology. There are some 7,000 nerve endings in the foot, which reflexologists view as control panels to the rest of the body. By applying gentle pressure to certain points (which supposedly connect to various organs), the practitioner disperses metabolic waste that's clogging the circulatory and nervous systems. Reflexology reduces stress, cleanses the body of impurities and revitalizes the immune system.

Stretching is an integral part of the Alexander Technique geared to relieving muscle tension.



THE FELDENKRAIS METHOD:

The Feldenkrais Method, developed by an Israeli engineer/physicist, rests on a complicated brain-body theory that connects muscular movement with the entire nervous system. It retrains the brain to unlearn the muscles' bad habits. The "teacher" gently moves and lifts parts of the body in a way geared to free them from the stress of gravity. Those who have tried the method, especially dancers, actors and athletes, report feeling light and graceful afterward—it purports to be helpful for MS and stroke patients.

THE ALEXANDER TECHNIQUE:

The Alexander Technique evolved around the turn of the century from the work of a Shakespearean thespian interested in the principles underlying movement. Many of its current adherents are actors. During the nearly hour-long sessions, a certified instructor coaches participants on exploring their movement history, identifying its problems and improving coordination. Supposedly that leads to less muscle tension and stress.

PILATES:

Some exercise techniques transcend body-building and are considered holistic health programs by their proponents. One is Pilates. It's done on a spring-loaded platform bed that looks like a cross between an exercise machine and a torture rack. Pilates promises increased strength, flexibility and endurance, plus improved posture, alignment and balance.

HELLERWORK:

Hellerwork is a method developed by aerospace engineer Joseph Heller, a student of Ida Rolf. He felt that rolfing lacked a strong mind-body connection, so he combined many of its physical principles—proper posture, balance and muscle manipulation—with a focus on self-actualization.

TRAGER:

Trager is the creation of a physician who believed that if there's tension in your body, it's because your emotions are holding your muscles hostage. It uses gentle rhythmic body massage to carry the mind to a relaxed, meditative state. Practitioners claim it's helpful for physical problems related to nerve impairment like multiple sclerosis, muscular dystrophy and Parkinson's disease. *See article on page 8.*

And the Survey Says...

By PAT DREIBELBIS

As of this writing, 507 surveys were returned to the CMTA office. Because we appreciate all of you who took the time to answer the questions, we wanted to give you some feedback as to how our members responded to the questions.

At a rate of almost 2 to 1, respondents said they have never accessed our home page. Of those who have visited it, the ratings averaged out to a rating of between 3-1/2 to 4, out of a possible 5. Very few people made comments or suggestions, but one suggestion was to put more links on the home page to other related sites. Another respondent asked where the questions for the experts were and we want you to know that area is now active. So, check our "Ask the Expert" if you haven't been there recently. Another comment was that the new site is better than the previous one and the only improvement would be to list where clinical trials were being conducted.

Only about 1/3 of the respondents have ever called the toll-free number, asked for a physician referral list for their state, or requested the letter to medical professionals with the drug list on it. That letter is intended for patients to give their doctors for inclusion in their medical files and is most useful for non-CMT related professionals such as dentists, gynecologists, and primary care doctors.

Ninety-nine percent of the surveys were returned by patients or family members, rather than professionals. An overwhelming number of the respondents are current subscribers to the newsletter or have seen it in the past. Happily, most of the comments about the newsletter were positive. Here are some of the comments:

- I especially like learning about books or alternative therapies that can help with symptoms.
- I like questions by others with CMT and doctor answers.
- I like articles on disability and quality of life, pedorthic management of CMT. (I actually have liked the last few newsletters more than previous ones.)
- I would like more questions and answers and less asking for money. (*Editor's note: The CMTA has only two fundraisers, one operations and one research.*)
- I appreciate learning about the latest in orthotics and physical therapy—anything to add ease and quality of day-to-day living. I enjoy hearing about people's successes despite their handicaps.

One criticism was that the medical articles are too difficult to understand and should be written more in layperson's terms. The subject matter interests the reader who made this comment, but the medical terminology makes understanding the information almost impossible.

Only 5% of the respondents are currently involved in a support group, although many people said they would be interested in joining one if it were located closer to their home. Others remarked that caring for an elderly parent or seriously disabled spouse makes joining a group impossible.

65% said that a children's newsletter would be of little interest or applicability to them. Several people who would be interested in such a publication listed topics of interest such as how to cope with peer rejection, how to help a child have confidence, and how to escape the fear of how the progression of their child's disorder might go.

The final question on the survey was "what other programs, publications or comments would you like to talk about or wish the CMTA would provide?" Below are some of the comments that were made:

- Educate all types of doctors and nurses about CMT, also the public.
- What kind of therapy (weight-lifting, strength training) should I do?
- Orthotics and everyday things to help me perform in life.
- I would love to see the CMTA have an aggressive fundraising program so that research and positive treatments could progress more rapidly.
- More on rehabilitation and practical day-to-day coping.
- What universities are studying CMT and when they have lectures or conferences.
- It would be great if CMTA pens were those big fat ones, since they're easier to write with.
- Sources for *attractive* shoes that I can wear.
- Send information to general practitioners to familiarize them and enable them to make early diagnosis.

The CMTA thanks all of you who took the time to reply to the survey and gave us your valuable opinions. The selections used in this article are a small proportion of all that were received. We will read all of the surveys and respond to those that asked a specific question.

DOLPHIN THERAPY

Island Dolphin Care, Key Largo, FL, is a not-for-profit organization which provides dolphin-assisted therapy to critically ill, disabled and special needs children from all over the world. Island Dolphin Care offers 5-day therapy programs which allow children an opportunity to work one-on-one with a skilled therapist and to enjoy amazing interaction and swimming with dolphins.

If you are interested in receiving brochures/ applications for the program, call 1-305-451-5884 or check out the website at www.islanddolphin-care.org.





VISIT OUR HOMEPAGE

at

www.charcot-marie-tooth.org

Understanding HNPP Phenotypes

(Editor's note: The following discussions of two of the phenotypes of HNPP are a follow-up to Maureen Horton's article on HNPP, which appeared in the December 2001 issue of the newsletter.)

CLASSIC HNPP PHENOTYPE OF HNPP

Five-year-old Molly has had several episodes of foot drop that come and go. After much testing, her neurologist finally checked for HNPP. Her genetic test was positive. Then he began questioning and testing her parents.

Kate, at age 24, developed severe carpal tunnel syndrome during her eighth month of pregnancy. Up until then, she had no problems or reason to think she had any neurological problem. But after cutting out material for 45 minutes, she developed profound numbness and weakness in her hand. She could not hold a pen, open a jar or even make a fist, let alone diaper her baby. Her obstetrician told her that it sounded like carpal tunnel syndrome, a fairly common problem in pregnancy. Still having problems six weeks after delivery, she was sent to a neurologist. Her EMGs showed not only carpal tunnel syndrome, but problems with the ulnar nerve at her elbow too. Nerve conductions were almost equally slow in both arms. The neurologist wanted to first take a 'wait and see' approach. Six months after delivery, she had surgery on both hands. But two years later, she was back seeing the neurologist. The carpal tunnel syndrome had returned.

Both of the above are examples of the classic phenotype of HNPP. Classic HNPP was the first identified phenotype of HNPP and, as its name suggests, is the most common form. Essentially, describe pressure palsies (PP) and you have described the classic phenotype: painless, recurring episodes of numbness, tingling and/or weakness in an arm or leg.

While pressure palsies, in general, are described as ranging from mild to severe, the pressure palsies of the classic phenotype typically are the severe ones. They are severe in both duration and symptoms. This group may have some mild PP in addition to their severe ones. But it is the severe episodes that get their attention and send them off in search of medical help. And quickly. A few may try to wait a day or two and self treat, but these episodes are not going away

that fast and can be quite alarming at first.

A pressure palsy in the hand can result in not being able to: make a fist; hold a pen, much less write; hold a bar of soap; dress, or any number of fine motor activities. Shoulder involvement may make an arm almost totally useless. Or maybe one has some use of the hand, but can't do any movements without the elbow tucked firmly at one's side—thus ruling out activities like eating, dressing, reaching, etc. A leg palsy can cause foot drop (unable to bring toes up while walking so foot clears floor) and/or leg weakness, making walking, driving or climbing stairs nearly or completely impossible. Dragging a leg during a palsy is not uncommon.

These classic pressure palsies are the ones which may last many days, weeks or months. Six weeks to three months is a pretty common duration of a "long" pressure palsy, but 6-12 months is not unheard of either; the longer-lasting episodes tend to resolve incompletely. These episodes are often recurring, though not always in the same limb. The numbness and weakness may gradually go away or it may remain severe for quite some time and then rapidly get better. And sometimes the numbness and weakness may only partially improve, meaning there is permanent nerve damage. There is no way to tell at the beginning of a pressure palsy whether there will be noticeable permanent damage or not. With a pressure palsy, only time will tell. The amount of time the nerve is compressed seems to play a role in the severity of symptoms.

Over a lifetime, the number of pressure palsies this group might experience ranges from only one or two to too many to remember.

Many times cause the of these episodes can be identified. And the cause is usually something that puts pressure on or stretches the nerve and would not affect a healthy person. Many individuals wake up to find an arm or leg weak and numb simply from sleeping in a wrong position. Examples of activities that cause symptoms of numbness, tingling and weakness are:

- crossing legs at the knee
- leaning on elbows
- sitting with legs crossed
- kneeling
- gardening
- carrying anything by the handle (purse, suitcase, grocery bag)
- using scissors

- knitting
- working with hand power tools
- holding the telephone in one position too long
- tying shoes too tight or tight shoe straps, wearing high heels can make toes numb
- painting too long (holding brush or roller)
- walking too long (more than an hour)-advanced HNPP
- lifting weights
- using a mouse at the computer
- typing

Classic phenotype subtypes include, but are not limited to:

- Only arm involvement (or hand, elbow or shoulder)
- Only leg involvement (or foot)
- Only right side
- Only left side

ACUTE BRACHIAL (ARM) PARALYSIS OR BRACHIAL PLEXOPATHY PHENOTYPE OF HNPP

Tim had been on the wrestling team for all of junior high and senior high. While in his junior year, he was pinned. His arm was over his head and his opponent really leaned on his shoulder area hard. Tim knew right away that something was wrong. He could barely move his arm. Luckily there was no pain.

Ann woke up one morning and could tell there was something wrong with her right arm. She could barely raise the whole arm, but could use her hand and forearm if she kept her elbow next to her body. Some of her arm was numb. She could hold a cup of coffee, but she couldn't get the cup out of the cupboard, nor pour or drink the coffee with her right arm.

The two cases mentioned above are examples of the acute arm paralysis phenotype or brachial plexopathy or brachial plexus neuropathy. The brachial (arm) plexus (network of nerves) is a network of nerves running between the neck and the shoulder/arm pit. In this area, the nerves from the cervical spine come close together before branching out to supply the muscles and skin of the shoulder, arm, elbow, wrist, and hand. (A good picture of the brachial plexus can be found at <http://www.tos-syndrome.com/newpage2.htm>.)

The examples sound exactly like the classic phenotype pressure palsies—painless episodes of numbness and weakness. And they are, with two exceptions: This phenotype involves only the brachial plexus, while the classic phenotype involves many different areas (brachial plexus, shoulders, elbows, wrists, legs, etc.). In addition, it is unusual for these episodes to recur, while in classic HNPP they frequently recur.

This may seem like splitting hairs, but remember the phenotyping is a way for doctors to recognize the different ways they may see this disease when the patient comes into the office. Acute brachial paralysis occurs with enough frequency to warrant its own phenotype.

In classic HNPP, one may have one or several episodes of acute arm paralysis, but these would be in addition to pressure palsies at other sites. Like classic HNPP, the cause of acute arm paralysis may be some minor trauma, as well as more substantial trauma like getting pinned in a wrestling meet. Activities that involve repetitive or sustained overhead use of the arm, sleeping with arms overhead, forward reaching, or excessive weight on the shoulder can cause symptoms. Episodes can also occur spontaneously. Although there may be some numbness and weakness, there is no pain. And recovery occurs over several weeks and is usually complete or nearly complete.

In acute brachial paralysis, any or all of the arm muscles may be suddenly involved in varying degrees of weakness, from slight to completely paralyzed (and unable to be moved by the individual). Symptoms can be variable depending on the part of the plexus that is compressed. The injury may involve only the shoulder area, only the upper arm or the entire arm and hand. The more areas involved, the longer it will take to heal. In addition to the weakness, there may be a lack of muscle control in the shoulder area, upper arm, wrist and hand, and lack of feeling or sensation in the arm or hand. If the entire arm and hand are involved, the arm may be almost totally useless until some healing takes place. If the arm is very weak, but still moveable, a frequent scenario is the ability to do light activities with the hand as long as the elbow is supported. But activities which involve reaching or lifting the arm to eat, or over the head, for instance, to shampoo hair are impossible to do.

(In the next issue of the newsletter, we will describe more of the phenotypes of HNPP.)

OF INTEREST

The **National Patient Travel Helpline** provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available through the Angel Flight America Network. Visit their website at www.Patient-Travel.org or call their helpline at 1-800-296-1217.



New Source for Products for the Lower

A member of the CMTA told the office about a website called FootSmart, which sells many useful products for the feet and lower body at prices that are quite competitive. The address is www.footsmart.com, and if you don't have access to the Internet, they can be reached at 1-800-870-7149. They offer a catalogue as well as a newsletter about foot and leg health issues. Some of the products which are available from their website are shown here.



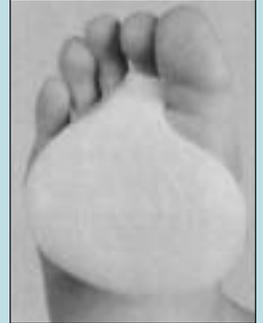
Village Walker for men



35° Below Socks



Added-depth Women's Bloom



Silicone cushions for troubled feet

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Irene Askins

Myron & Dianne Martenson

Pearl Daniels

Linda Simpson

Jessie Dezern

Donald & Marion Bean

Richard Bean

Phyllis Erickson

Myron & Dianne Martenson

Sam Gaastra

Eric & Clarice Hillstrom

Joan Price

Marah Griffith

Margaret Burke

Brad de Vries

Marsha & Kent Dykstra

Mark & Margaret Garrison

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David & Gale Kunkel

Ann Mardis

Billie McClintock

Rapp Family

Colleen Reffner

Barbara McEvoy & Michael Stibich

Karen & John Wozniak

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Frank & June Gunnison

Howard Keister

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Dan Moser

Mr. & Mrs. Jack Applebee

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Galen & Caroline Pentecost

Norma Pentecost

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Resources Management

Directorate & Police & Security

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Body



Adjust-to-me slippers for men or women



Microwaveable footwarmers

Francis Robison

Mrs. R. F. Boquet
Helen Edsinger
Mr. & Mrs. Robert Edsinger
Charles & Elsie Morris
Francis & Marie Snowden
Becky von Ashton

Clyde Taylor

Donald & Marion Bean

Bessie Whitt

Dorothy Womble

IN HONOR OF:

Margaret Davis

F. A. & Patricia Davis

Samantha Lynn Sheriff

Dan & Nancy Headrick

Ophir Trigalo

Mr. & Mrs. Sam Chiprin

CMT in the News

The *Lexington Massachusetts Minuteman* featured an article on German Ordonez, 18, who has been in this country on a medical visa since September 2001 after having been brought to the US to have surgery on his feet. Moran is a teacher at a mission in Flores, Honduras. He was 11 when symptoms of his problem began to appear. But doctors in Honduras were unable to identify his problem and so he had no idea what was wrong.



When a group of Lexingtonians traveled to help at the mission in Honduras last year, they met Ordonez and became interested in him and his situation. The high schoolers on the trip were upset that he was not being treated for what they thought might have been club foot. The discussion was made to bring him to the US for treatment and when he was examined at Shriners' Hospital in Springfield, MA, he was told he suffered from Charcot-Marie-Tooth.

After nearly five months in the US, and major surgery on both feet, Ordonez' dream of walking normally has come true. He walks on the soles of his feet with the aid of leg braces. When the time came for Ordonez to return to Honduras, members of the community and new friends he had made along the way celebrated their time with him at a party. Along with authentic Honduran food and mingling with his new friends, it was easy to see the sadness in the teenager's face. Each time someone took him aside for a hug or to say "we'll miss you," the tears filled his eyes leaving him speechless. Many paid tribute to the boy they would never see again, but were able to help for a lifetime.

The *Buffalo News* published a short article on George J. Roberts of Williamsville, a records clerk for the Amherst Police Department, who was diagnosed with Charcot-Marie-Tooth disease in 1982. He was named recipient of the MDA's 2002 Personal Achievement Award for the Buffalo Chapter of the association.

Roberts, 44, a graduate of Grover Cleveland High School and Bryant & Stratton in Buffalo and the Simmons School of Mortuary Science in Syracuse, is co-owner of Dohn Funeral Home and technical adviser for his brother's business, the D. Tonken Crematory.

He was a member of the Elmwood Businessmen's Association and the Erie Niagara Funeral Directors Association when he was diagnosed with CMT in 1982. When his physical condition deteriorated, which prevented him from participating in the physical aspects of his funeral directing work, he changed careers and began working as a clerk in the Amherst Police Department in 1991.

He is an adviser to his son's Explorer Troop 123 at the Eggertsville Hose Company, where he has been an active member since 1984. He has served as recording secretary for four years and line clerk for three years in addition to his regular volunteer firefighter duties.

Roberts has a general-class ham radio license and is registered with the American Red Cross as a volunteer ham operator.

Initiated in 1992, the national awards program recognizes the accomplishments and community service of people with disabilities caused by any of the neuromuscular diseases in the association's program. Association officials cited Roberts for not hiding his disability or using it as an excuse in his dealings with the community and for learning to adapt as his physical capabilities change.

Support Group News

■ California - Berkeley Area

In September, the group watched films on CMT and the Paulo Vinci boot, an alternative to AFOs developed by Larry Clark of Versailles, MO. The discussion that followed the films focused on the problem of pain. Most of the members reported some degree of foot and leg pain and the conclusion was that no one remedy works for everyone. In January, the presenter was Allen Ling, PT, who is a board-certified specialist in orthopaedics and has been doing aquatic therapy since 1989. He spoke on water exercise and demonstrated the use of taping as an alternative or adjunct to the use of AFOs.

■ California - North Coast Counties

The support group has a new email address: pcmobley@mac.com. Their most

recent meeting was March 2, at which time they discussed the surprises and discoveries of having CMT. One person's strategies for coping help another as they face the same problems. They will meet again in July and the November meeting will feature a presentation by Dr. Jerome Chinn, neurologist.

■ Colorado - Denver Area

The Denver Area support group celebrated two years together on February 4. It was their annual meeting at which they discuss ideas for future meetings, including speakers, videos, fun times and sharing. Their previous meeting in December featured Janet Mentgen, founder of Healing Touch, who gave a slide presentation and outlined the many advantages of seeing a Healing Touch practitioner.

Carrying the Torch... John Snurka's Dream Comes True

John Snurka was part of the Torch Running Relay for the Winter Olympics in Salt Lake City. John lives in Littleton, CO, and has hereditary neuropathy with liability to pressure palsies (HNPP). He wrote of his experience, "I did it! I ran with the Olympic flame and have my three minutes of fame. Talk about an awesome experience. I ran about half of the way before the significance of what I was doing hit me. I really had to choke back some tears at that point. But, I was able to finish the last 3 blocks with an easy jog and then passed the flame on to the next person.

It couldn't have been a more perfect night. Even though the flame was over an hour late, none of us cared much. The weather was cold and it was snowing, as you can see in the photo. There were close to a hundred people along my route who came out to just see me and it was moving to see all that support. There were a total of about 150 people along my segment of the run. I would have thought more might be there, but I think the lateness and the cold probably kept them away.

I received the flame from a cancer survivor and then handed it off to an amputee who competes in the winter Para Olympics. Talk about inspirational people. My wife had known how much I had always wanted to carry the flame and she submitted my name for consideration. I was privileged to be selected.

The day after I carried the flame, I went to see the flame carried three more times and then I went to my mother's school where she's the principal. I took the torch to all of the classrooms for a sort of "show and tell." It was an awesome 48 hours."



John Snurka had his three minutes of fame as he carried the Olympic torch through the night in Colorado.

CMTA Support Groups

Arkansas—Northwest Area

Place: Varies, Call for locations
Meeting: Quarterly
Contact: Libby Bond, 501-795-2240
E-mail: charnicoma57@yahoo.com

California—Berkeley Area

Place: Albany Library, Albany, CA
Meeting: Quarterly
Contact: Ruth Levitan, 510-524-3506
E-mail: rulev@pacbell.net

California—Los Angeles Area

Place: Various locations
Meeting: Quarterly
Contact: Serena Shaffer,
 818-841-7763
E-mail: CMT_losangeles@yahoo.com

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
E-mail: pcmobley@mac.com

Colorado—Denver Area

Place: Glory of God Lutheran Church
 Wheat Ridge
Meeting: Quarterly
Contact: Marilyn Munn Strand,
 303-403-8318
E-mail: mmstrand@aol.com

Kentucky/Southern Indiana/ Southern Ohio

Place: Lexington Public Library,
 Northside Branch
Meeting: Quarterly
Contact: Robert Budde,
 859-255-7471

Massachusetts—Boston Area

Place: Lahey-Hitchcock Clinic,
 Burlington, MA
Meeting: Call for schedule
Contact: David Prince, 978-667-9008
E-mail: baseball@ma.ultranet.com

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: Flora Jones,
 601-825-2258
E-mail: flojo4@aol.com

Missouri/Eastern Kansas

Place: Mid-America Rehab Hospital,
 Overland Park, KS
Meeting: First Saturday bi-monthly
Contact: Lee Ann Borberg,
 816-229-2614
E-mail: ardi5@aol.com

Missouri—St. Louis Area

Place: Saint Louis University Hospital
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664
E-mail: c.haislip@att.net

New York—Greater New York

Place: NYU Medical Center/
 Rusk Institute, 400 E. 34th St.
Meeting: Monthly
Contact: Dr. David Younger,
 212-535-4314,
 Fax 212-535-6392

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
E-mail: alma622@worldnet.att.net

North Carolina—Archdale/Triad

Place: Archdale Public Library
Meeting: Quarterly
Contact: Ellen (Nora) Burrow,
 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
E-mail: Greenville-Ohio-CMT@
 woh.rr.com

Oregon/Pacific NW

Place: Portland, Legacy Good Sam
 Hospital, odd months
 Brooks, Assembly of God
 Church, even months
Meeting: 3rd Saturday of the month
 (except June and Dec.)
Contact: Jeanie Porter, 503-591-9412
 Darlene Weston, 503-245-8444
E-mail: jeanie4211@attbi.com or
 blzerbabe@aol.com

Pennsylvania—Philadelphia Area

Place: University of PA, Founders
 Building, Plaza Room A
Meeting: Bimonthly
Contact: Amanda Young,
 215-222-6513
E-mail: stary1@bellatlantic.net



WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Pkwy.

Chester, PA 19013

The CMTA reserves the right to edit letters for space.

Ask the Doctor

Dear Doctor,

I read somewhere that there is a type of CMT that involves not only the peripheral nerves but the phrenic nerve of the diaphragm as well. My question is twofold: Can this phrenic nerve involvement affect breathing and speech? And Is there anything that can be done to help this condition?

The Doctor replies:

CMT affects the phrenic nerve (which innervates the diaphragm) and the recurrent laryngeal nerve (which innervates the larynx). These nerves are rarely clinically affected unless the patient has a severe neuropathy. I recommend seeing a pulmonary specialist for the breathing problems and an ENT physician for the speaking, as I doubt that CMT is actually causing the problems.

Dear Doctor,

My mother has CMT and I had heard that alpha lipoic acid might help her nerve deterioration. Is this true? She also has diabetes. She is doing great, but her lower body is getting weaker and weaker. She has had surgery and wears a brace. Now we are trying to find something to prevent the nerves from deteriorating more.

The Doctor replies:

I believe that alpha lipoic acid is a non-FDA-approved drug that is available in health food stores. It is used in some European countries for the treatment of diabetic neuropathy, but I do not endorse its use for the treatment of any neuropathy.

Dear Doctor,

I am an orthopaedic surgeon in Peterborough, Ontario, Canada. Recently a 13-year-old girl presented to me with previously diagnosed CMT (I don't know which type) and a second episode of patellar dislocation. While I'm aware of lower extremity weakness in CMT patients, I can't find any information on treatment of recurrent patellar dislocation in CMT patients. Are you aware of any publications on this problem?

The Doctor replies:

Without any further details and assuming that this child does not have congenital anomalies or growth development problems: the dislocation of the patella (which is generally laterally) to the outside is usually not related to CMT disease, but does happen quite frequently in girls, because of

the positioning of the patella (kneecap) in its "groove" or "track" as it extends the knee.

Girls, especially those who develop early, may be obese, and have kneecaps that "track" towards the outside and with a bit of trauma or with a "trick" movement, can dislocate it. Once that happens, the dislocation can occur more frequently. A pediatric orthopaedic surgeon should easily recognize this problem and if a "brace" does not work, it may need surgical repair.

Dear Doctor,

I'm taking medicine for depression. The label says I shouldn't stop taking it without my doctor's advice. What could happen?

The Doctor replies:

The major concern about stopping an antidepressant is that you might not be ready to do so. Most doctors recommend that you continue taking an antidepressant for 4-6 months after you feel better to reduce the risk of your depression returning.

Once you and your doctor decide to stop the medication, the dose should be gradually reduced over a few weeks to avoid the chance of unpleasant effects, or withdrawal symptoms from suddenly stopping the drug. Some experts recommend tapering the dose over 6-8 weeks if you've been on the drug for 6-8 months, as a rule of thumb. During this time, you and your doctor should be watching for evidence of withdrawal symptoms or a depression recurrence.

Older antidepressants like tricyclic antidepressants and monoamine oxidase inhibitors have been known to cause discontinuation effects. The most common effects seen in the case of tricyclic antidepressants such as Tofranil and Elavil are upset stomach and nausea, flu-like symptoms, anxiety, low mood, and sleep disturbance. In the case of stopping monoamine oxidase inhibitors, such as Nardil, you may experience disorientation, confusion, mild movement disturbances, and even hallucinations.

It is also becoming increasingly evident that the newer class of antidepressants, called selective serotonin reuptake inhibitors, or SSRIs, such as Paxil and Zoloft, also have discontinuation effects. The most common are dizziness, lightheadedness, weakness, headache, stomach upsets, sleep disturbances, and anxiety. Problems have also been described with some even newer antidepressants, such as Effexor.

Dear Doctor,

I have never seen this question addressed in the CMTA Report or any other CMTA periodicals.

Have you had anyone diagnosed with CMT1B complain about bladder sensory problems? My urologist recently indicated that my CMT1B problem was preventing my brain from receiving sensations of the need to void my bladder, resulting in several bladder infections. I now have to catheterize myself four times a day to empty my bladder.

I would like to know if this is a common problem among CMT patients?

The Doctor replies:

CMT1B, like any neuropathy that involves motor and sensory nerve fibers, if advanced enough, can cause bladder dysfunction in two ways. The sensory nerves supplying the bladder can lose their ability to conduct signals about bladder filling to the spinal cord center that controls blad-

der function. The nerve fibers that supply the muscle in the bladder wall can malfunction. This results in the bladder getting very full without the person being aware of it. Then the person is not able to contract the bladder muscle to expel the urine once he is aware. The muscle at the base of the bladder (the sphincter) can lose its nerve supply to make matters worse. Not only will the person have a lot of urine left in the bladder (high residual urine) after voiding, but there may be leakage with exercise, coughing, laughing, etc. High residual urine is an invitation for bacteria to breed. Intermittent catheterization helps cut down on recurrent urinary tract infections. Involvement of sensory nerves to the penis has been known to produce impotence in some CMT patients. The incidence of bowel and bladder dysfunction in the varieties of CMT has not been studied. I invite readers of this newsletter to complete the short questionnaire below and return it to me anonymously.

SURVEY QUESTIONNAIRE

AGE: _____ SEX: _____ TYPE OF CMT: _____ IF FEMALE, # OF CHILDREN: _____

If female, describe any difficulty with delivery: _____

Nature of bladder problem: _____

Nature of bowel problem: _____

Nature of sexual dysfunction: _____

How long problem has existed: _____

PLEASE RETURN THE QUESTIONNAIRE TO: Frances M. Dyro, MD, Dept. of Neurology, New York Medical College, Mungler Pavillion, 4th Floor, Valhalla, NY 10595. Thanks for your help. E-mail: fmadyro@pol.net

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, Macrodantin)
Nitrous oxide (chronic repeated inhalation)
Penicillin (large IV doses only)
Perhexiline (Pexid)
Taxol
Vincristine
Lithium, Misomidazole, and Zoloft 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, 1B, 1X, HNPP and EGR-2 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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