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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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CMTA Hires New Executive Director

Vincent J. Bertolino joins the Charcot-Marie-Tooth Association as its new Executive Director. Prior to accepting this position, Mr. Bertolino was a volunteer member of the CMTA Board of Directors in the role of Vice President while functioning as the Neurogenetic Product Manager for Athena Diagnostics. Since 1997,



Mr. Bertolino has been responsible for the promotion of genetic testing for CMT, and championed financial support for the CMTA.

CMTA Board Chair Ann Lee Beyer said, "Vincent is uniquely positioned to drive funding for the cure with his history of working with the CMTA, connections within the industry, and background in marketing and medical research. His acceptance of this new role is a critical part of our plan to make CMT history."

Mr. Bertolino added, "After being on the periphery as a corporate sponsor for four years, I am really excited to be squarely in the thick of things, where making a difference in the CMTA's mission to find a cure is my principal role."

Changes that will help find the cure

At age 19, the CMTA is almost through its adolescence. If the CMTA were a person, this time would mark a change in maturity that could be summed up as "getting serious" about our future. Teenagers mature into "twenty-somethings" and trade jobs for careers, casual dating for commitments, and life with their parents for life on their own. The tumult of the teens is replaced by the daily accumulation of progress toward a goal.

This is the exciting age of the CMTA! This is a time when we have a history, but not too much. We have wealth, but not enough. We have hopes and dreams that will become our goals, and the initiative to make them reality.

Playing a role in the achievements to come at a time like this is a rare blessing. You know that things are about to get interesting and progress will be made in leaps and bounds. You also know that it couldn't have been possible without the hard, and frequently unrecognized, work of those who came before you. You also know that no one can do it alone; it takes a team to keep us moving toward the goal. Everyone, from the one carrying the ball, to the coach, and to the fans in the stadium, is part of that team in some way. Everyone makes some contribution in time, talent, or wealth that helps make victory possible.

Let us join together now, all the members of the CMTA, set our sights boldly upon the goal of curing CMT, and contribute our various gifts to that vision. In this way, each one of us can make a difference and share in the thrill of this age where the world is in front of us and nothing will be beyond our reach.

—Vincent J. Bertolino, Executive Director, Charcot-Marie-Tooth Association

Exciting Advances in CMT Research

The CMTA.... Living our Mission

Mission Statement:
To improve the
quality of life for
people with CMT.

Vision Statement:
Dedicated to
generating hope.

By ANN LEE BEYER

There have been several significant breakthroughs in CMT in the last few months. First, some very good news about our CMTA Fellowship awards. Your research donations do make a difference. In 2000, the CMTA awarded a CMTA Postdoctoral Fellowship to a researcher at Baylor University, Hiroshi Takashima, M.D., Ph.D. The title of his proposal was "Searching for Causes of CMT." This project involved patients who had been diagnosed with Charcot-Marie-Tooth but did not have mutations in the known genes that cause CMT.

The study was indeed fruitful in that it identified, not only one, but two genes that are involved in Dejerine-Sottas. Dejerine Sottas is a severe recessive form of CMT that appears in early childhood. The results of the study appear in "EGR2 Mutation R359W Causes a Spectrum of Dejerine-Sottas Neuropathy" (to be published in *Neurogenetics*, and "Periaxin Mutations Cause Recessive Dejerine-Sottas Neuropathy" [*American Journal of Human Genetics* 2001;68(2):325-333.]

A mutation in the EGR 2 gene had already been found to be responsible for CMT1, but until this research, it had not been linked with the severe form of clinical presentation, Dejerine-Sottas. The Periaxin gene (PRX) mutation is a new discovery and identifies yet another genetic cause of the Dejerine-Sottas phenotype.

We also just received a copy of an excellent study "The Frequency of 17p11.2 Duplication and Connexin 32 in 282 Charcot-Marie-Tooth Families" [*Neuromuscular Disorders* 2001;11:458-463]. The principal author is Dr. O. Duborg. The purpose of the study was to speed up and simplify diagnosis of CMT by estimating the frequency of 17p11.2 duplication and Connexin 32 mutations in different Charcot-Marie-Tooth subgroups, in order to propose a practical strategy for molecular analysis of CMT. The results propose a strategy for molecular diagnosis based on median motor nerve conduction velocities (MCNV) and mode of inheritance, avoiding unnecessary costly and time-consuming analysis. The study was carried out at the Hopital de la Salpetriere, the hospital where the famous Dr. Jean Marie Charcot practiced. Dr. Dubourg was one of our CMTA Summer Fellows in 1997. We are very pleased that she has

Your donations do make a difference—the past year has brought significant advances in our understanding of CMT.

continued working in CMT research.

Then there is the exciting news about the gene for CMT2A, "Charcot-Marie-Tooth Type 2a Caused by Mutation in a Microtubule Motor KIF1Bbeta" [*Cell* 2001;105(5):587-97], which was identified by a group in Tokyo.

This discovery is extremely important, as it not only identifies the genetic cause of CMT2A, but it will also add to our understanding of both CMT2 and CMT1, by showing how axonal transport causes neuropathy.

In the June 2001 issue of the *CMTA Report* we printed an article, "The Psychiatric Aspects of Peripheral Neuropathy," based on a presentation to a peripheral neuropathy support group, by psychiatrist Scott Berman, who suffers from chronic demyelinating polyneuropathy. The gist of the article was that "neuropathy often leads to depression, anxiety and fatigue." Most of Dr. Berman's talk was based on his own experience and clinical practice.

We are very aware that CMT can have a profound effect on people's lives and that depression can be a problem for some people with CMT. However, until now, there has been no research to measure its impact.

A recently published and important study from Hamburg, Germany, "Disability and Quality of Life in Charcot-Marie-Tooth Disease Type 1" [*Journal of Neurology, Neurosurgery, and Psychiatry* 2001;70(4):548-50], is the first one to do so. Not surprisingly, it found that CMT has a much greater impact on quality of life than has been previously thought, and that the emotional stress of living with CMT is similar to that of people with stroke and comparable disability.

The study evaluated and compared 50 CMT1 patients with a group of similarly affected stroke patients "without mental deficit," six months after a stroke. Based on the Hauser ambulation index and the Rankin scale,

researchers found that 44% of the CMT patients had significant disability. These interesting results validate what we have known all along. For people with CMT, fatigue, slowness, clumsiness in daily activities, pain, and the need for more than average rest and sleep, are ongoing issues.

However, 18% of the patients with CMT reported that they were also depressed.

What is more interesting and quite significant is that, as people became more disabled and everyday activities became markedly slowed, attitudes toward childbearing changed. Thirty-six percent of those with significant disability voted against having children, as they did not want to have children with as much impairment as they experienced themselves.

Although for many of us these results are not surprising, what this study does is put CMT on the map as being a serious disease, that does indeed have a profound impact on people's lives.

NEW TOTE BAGS AVAILABLE

The CMTA has had a supply of tote bags designed with the logo and 800 number in white on a teal background. The first appearance of the bags was at the Support Group Leaders meeting and they were offered at the Downey, California patient/family conference as well. The bags measure 12" x 19" x 4 1/2" and are made of heavy canvas.

The totes were created to help increase awareness of CMT and the organization. The cost of the tote is \$10.00, plus shipping and handling (see order form, at right).



CMTA MEMBERSHIP/ORDER FORM

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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
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Shipping & Handling Orders under \$10 add \$1.50, orders \$10 and over add \$3.00			
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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.

■ UPCOMING CONFERENCE

There will be a conference in Detroit on September 22nd, at Wayne State Medical Center, from 9 AM to 4 PM. The conference will focus on both clinical and research issues. Registrations will be mailed to members living in Michigan. All other interested members should call the office to have a form sent to them. Wayne State is the site of the first comprehensive CMT clinic in the US.



Continuing Our Patient-Education Program:

By PAT DREIBELBIS

On June 16, 2001, over 85 people attended a well-received conference on Charcot-Marie-Tooth disorders at the rehabilitation center at Rancho Los Amigos in Downey, California. The conference was organized by Dr. John Hsu, a member of the CMTA's Medical Advisory Board.

Karen Krajewski, genetic counselor from Wayne State University in Detroit, Michigan, began the conference with a presentation on the North American Database. She then presented an overview of the new genetics booklet that she co-authored. Following her presentation, she fielded a number of questions about genetic testing and about the importance of knowing which form of CMT runs in one's family.

Dr. Bruce Cristol, a doctor of pharmacology, distributed a chart about the various medica-

tions that might be prescribed for CMT pain. He listed the drug, its dosage, how it works to alleviate pain, what other drugs it interacts with, and any precautions one should be aware of. He closed his presentation with the four "D's":

- 1) Do not take more than the number of pills ordered by your doctor,
- 2) Do take your pills as filled by your pharmacist,
- 3) Do not take a friend's medication,
- 4) Do inform your doctor or pharmacist if you are taking other medications or herbs your doctor would be unaware of.

The final morning presentation was the keynote address by Dr. John Hsu on orthopaedic treatment options for CMT. His most important point was that it is crucial that children be seen as soon as problems occur with their CMT. An orthopaedic surgeon will use noninvasive treat-

Professionals Working for CMT Patients: Dr. John Hsu

(Editor's Note: Dr. Hsu recently hosted the Rancho Los Amigos patient/family conference on CMT and has been a member of the Medical Advisory Board of the organization for over ten years.)

Dr. John Hsu joined the orthopaedic staff at Rancho Los Amigos Hospital and the faculty of the University of Southern California in 1971. He studied medicine at McGill University, graduating with his M.D. degree in 1961. He then took training in General Surgery at the Royal Victoria Hospital, Montreal, Canada, from 1961 to 1964, and entered the orthopaedic residency at Johns Hopkins Hospital, Baltimore, MD in 1964. He became chief resident in 1966 and completed his residency in 1967. In 1970, he became certified by the American Board of Orthopaedic Surgery.

Dr. Hsu feels that he was very fortunate to have had the opportunity to take a U.S. Public Health Service-supported fellowship in the basic sciences between 1967 and 1971. During that time, he was based at the Johns Hopkins Medical Institutions and was able to take graduate studies and participate in research in muscle physiology. As part of his continued clinical

experience, he was a clinician in the muscular dystrophy clinic, which had recently been established by Daniel Drachman, M.D. Patients were examined by clinic members and reviewed by a team of medical experts in neurology, pediatrics, and pathology. Treatment programs were established. When Dr. Hsu came to Rancho, together with Dr. Ralph Perry, Jr., a pediatrician, they established a muscular dystrophy clinic and used these principles as well as the skills of allied health professionals (physical therapists, occupational therapists, psychologists and orthotists) to further manage the disabled child. Dr. Hsu continues to be the clinic director with Dr. Irene Gilgoff, a pediatrician who took over from Dr. Perry when he retired.

One of the main interests of the Child Muscle Disease Clinic is maximizing the patient's functional abilities despite muscle weakness. Utilizing experience gained from the care of severely disabled persons with polio, spinal cord injury, severe joint diseases, and contractures, the clinic's first goal was to mobilize a bed-ridden or wheelchair-dependent child. Criteria and techniques for spinal fusion to control the development of spinal curves

A Conference at Rancho Los Amigos

ment early in the course of the disorder and can often delay the need for surgery if a child is seen before bony deformities occur. After his presentation, Dr. Hsu had personal consultations with many of the adults in attendance. Men were seen with their shoes off walking across the room so Dr. Hsu could assess their gait and discuss their shoes and/or orthotics.

After lunch, where attendees interacted with each other and the doctors, a Shriners' representative discussed the services they provide for children and adults with CMT. There are 19 specialized hospitals run by the Shriners that provide orthopaedic care for children. Admission to Shriners is based on medical need and there is never a charge to the patient or family. Treatment at Shriners focuses on a "family-centered" care environment. This philosophy stresses that,

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Berkeley, California area support group leader, Ruth Levitan (left), chats with another attendee following the conference.

(scoliosis, kyphosis, kyphoscoliosis) were developed for the child with muscular dystrophy and spinal muscular atrophy.

Another goal is to keep children with muscle weakness and imbalance standing and walking. Orthoses (braces) are often used, necessitating structural changes to the foot and ankle.

Tendon transfer operations are also used. Dr. Hsu developed a surgical technique* so that surgical trauma was minimized and the patient could be allowed to bear weight on his or her legs shortly after surgery and thus, stand and walk. This would lessen muscle atrophy from disuse.

The posterior tibial tendon transfer is an operation that is most suitable for a child with Charcot-Marie-Tooth disease where this muscle causes the pull into varus and contributes to the pes cavus (high arch). Thus, using this operation, Dr. Hsu has been successful in rebalancing the muscle pull on the ankle and feet and preventing permanent contractures and deformities. Also, with his interest in support of the ankle and foot, lightweight orthoses were developed and used. These procedures were reported at meetings involving the Charcot-Marie-Tooth Association and at CMTA Medical Advisory Board meetings. This type of surgical treatment gives a certain degree of comfort and relief for persons so afflicted, allowing them to maintain their activities.

In 1995, Dr. Hsu participated in the publication of *Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians* by writing the chapter on orthopaedic considerations. Rancho Los Amigos National Rehabilitation Center has been the host of two regional meetings of the CMTA in 1998 and 2001.

*Reference: Hsu JD, Hoffer MM. Posterior tibial tendon transfer anteriorly through the interosseous membrane. *Clinical Orthopaedics and Related Research* 1978;131:202-204.

Patients surround Dr. Hsu to ask questions about foot deformities following his presentation at the Downey Conference.



RANCHO LOS AMIGOS CONFERENCE

(Continued from page 5)

while medical care might heal the child's body, tending to the child's sense of well-being is equally important.

Dr. Sara Mulroy, a physical therapist and researcher at Rancho Los Amigos, discussed their gait analysis lab and the work they are doing with CMT patients. She encouraged attendees to consider being analyzed by the lab for their on-going study.

Finally, Donna Clark, of Gollihar's Shoe Store in Versailles, Missouri, provided both valuable information and an injection of humor into the day's presentations. She, too, stressed the need for people to be seen and treated for foot deformities and gait problems before the situation is so severe that therapeutic intervention is impossible. The humor in her presentation came from her suggestion that patients take a large club or stick with them to see their pedorthist or orthotist and that they freely suggest that they will not settle for a shoe or device that causes them pain. (The stick is intended to subtly suggest that the power lies with the patient, not the professional.) Mrs. Clark reviewed some of the custom-molded shoes that can correct the



Conference attendees question genetic counselor Karen Krajewski about genetic testing and inheritance patterns.

problems of drop-foot and the need for extra depth and the use of flairs to keep the ankle from rolling over and twisting.

The conference concluded at 4:00 PM, with many attendees remaining to talk with one another and with the presenters and the representatives of the organization.

Hints on shoes and braces

By **DONNA CLARK, Pedorthist**



My name is Donna Clark. My husband and I have been studying feet for almost 30 years, trying to help people. In our Certified Pedorthist practice, we have many clients who are troubled with CMT. We have noticed that many of the CMT clients have had different appliances made to make their feet feel better and allow them to walk with ease. Many of these items have been very successful, but, unfortunately, many have not.

Here's some helpful advice from years in the business. As a client, you should not settle for painful appliances just because the people who design the things to help you do not care enough about their work. As a client, you should not just put the painful shoes or braces in your closet—you should complain. If someone is taking your money or the money of your insurance company, the item he gives you should help.

Go back to the person who made the devices or braces for you and demand comfort or your money back. In our practice, we offer a money-back guarantee. Hurting someone cannot be the aim of the professional and you have the right to expect modifications to be made without complaint.

A person with CMT has special needs and one of them is that the person making orthotic devices should understand the disease fully. So please start by asking the professional if he understands CMT and the ramifications of the deterioration. The person making your devices must understand CMT. If he does not, it is your job to educate him before your work is done. Use the handouts from the CMTA when you make your initial contact. Provide videos taken of you walking or even still photos so that he understands how you walk and stand. A gait lab is a great help in determining how your device needs to be made.

The most important goal is that you receive real help—not just a reduction of your bank account. Do not be afraid to say “This hurts and I need it to feel good and work.”

Physical and Occupational Therapy and the CMT Patient

(From a presentation by Sue Edwards at the Annual General Meeting of the CMT United Kingdom which appeared in the Summer 2001 Issue of ComMenT.)

Doctors often say that “nothing can be done” for people with CMT, as the condition is incurable. This negative attitude is dispiriting, especially since physical therapy can play an important role in ameliorating the secondary effects that the condition causes.

Hereditary Motor and Sensory Neuropathy is the name more commonly used by the medical professional to describe CMT. As the name implies, the disease involves both motor and sensory loss. This is important to keep in mind when planning a therapy program.

Sensory loss, while not usually being as marked as motor problems, plays an important part, effecting both proprioception and balance. Proprioception is the ability to know where you are in space, i.e. where your feet or legs are at any time. Lack of proprioception causes loss of balance, which to some extent is compensated for by vision (looking down or fixing one's gaze to regain balance.)

For most people, motor loss (causing wasting and weakness in the affected muscles) is much more evident than sensory problems. The rate of progression and the severity of the loss cannot be accurately predicted as there is enormous individual variation. Because of this variation, it is vital that everyone be individually assessed and that a personal program of exercise be determined. However, while the severity is variable, there is a predictable sequential pattern to the progression of muscle weakness. Feet and legs are affected before hands and arms, and the intrinsic (small, fine) muscles are lost first.

The peroneus longus, along the outside of the calf, is one of the first muscles to be affected. This muscle gives balance and stability. The eviators, which control the outside of the leg and ankle, become weak and adversely affect the stability of the ankle, leading to sprains and falls. The dorsiflexors which pull up the foot, and the toe extensors which pull up the toes are the next, followed by calf muscles.

This progressive weakening of specific muscles results in an imbalance with opposing muscle groups. The strong muscles exert a disproportionately greater pull, causing foot

deformities such as clawing of the toes and changes to the arch of the foot. The shortening of the calf muscles, because of the weakness of the dorsiflexors, causes shortening of the Achilles tendon.

“Normal” people constantly, and subconsciously, make adjustments to keep their balance, using the muscle of their feet and legs. This normal postural sway is affected by the competence of the lower leg and foot muscles. Because these very muscles are the ones affected by CMT, people with the condition cannot make these anticipatory postural adjustments. This reduced balance and postural control has obvious consequences and is exacerbated by the additional loss of sensory input already described.

Muscles work reciprocally—when some muscles weaken, everything is thrown out of balance. Maintaining balance involves using various strategies, using ankles and hips, or a “stepping gait” for instance. If distal (the feet) control is compromised, secondary effects move upwards causing greater pressure on the hips and buttocks. These progressive compensatory strategies may lead to further detrimental effects. The proximal muscles (those closer to the body) become tired and over-used and may cramp.

The difficulty bringing one's weight forward over the foot can lead to hyperextension of the knee, flexion of the hip, anterior tilt of the pelvis with increased lordosis (inward curvature of the spine), and weakness of the abdominal muscles.

As a rule, the hands are affected by CMT much later than the feet and legs. There is progressive weakness of the intrinsic muscles leading to impaired opposition of the thumb and fingers. This results in gross flexion instead of an effective pinch grip. Immobilization of the hands (splinting) can help prevent contractures. Good hand function is crucial to one's independence and dignity. As with the feet and legs, stretching exercises can help maintain the range of function. If the “pinch” grip has been lost or is very weak, a thumb opposition splint can be custom-made, which can restore function and can be worn when writing. Thumb opposition splints are usually made by an occupational therapist.

No exercise program or therapy should be started without a personal assessment and the advice of someone who understands CMT. Ask the therapist how many people with CMT he or she sees.

■ SCAM ALERT!

We have received a warning from another organization that people have been scamming older patients with CMT, playing on their sympathy by claiming to also have CMT and being in need of money for various reasons, including surgery, bracing, relative's funerals, etc. Please do not respond to anyone who approaches you wanting your help with financial issues unless you know them well. This organization does not give the names of its members to ANYONE, but in the age of the Internet, information about individuals is all too easy to find. Be careful.

WARNING!



VISIT OUR HOMEPAGE

at

www.charcot-marie-tooth.org

Groundbreaking Lawsuit: Genetic Testing in the Workplace

By MAUREEN P. HORTON, R.N.

Since scientists have been able to identify disease-causing genes, medical ethicists, legal experts, and scientists have pondered both the positive and the negative aspects of having this information available. “Big Brother–like” questions have been raised as to who is entitled to know this information, how and when it can be shared, and other aspects of patient and employee privacy rights. Chromosome 17, the chromosome responsible for CMT1A and HNPP, has been one of the first to test this question in the legal system.

On February 9th, 2001, U.S. Equal Employment Opportunity Commission (EEOC),* along with the Brotherhood of Maintenance of Way Employees Union, filed separate lawsuits chal-

lenging the use of genetic testing in the workplace. According to an EEOC news release, the “EEOC had sought a Preliminary Injunction against Burlington Northern Santa Fe Railway (BNSF) to end genetic testing of employees who filed claims for work-related injuries based on carpal tunnel syndrome.” According to EEOC’s petition, Burlington Northern’s genetic testing program was carried out without the knowledge or consent of its employees, and at least one worker was threatened with termination for failing to submit a blood sample for genetic testing. This is the first court action, by EEOC, challenging the use of workplace genetic testing under the Americans with Disabilities Act of 1990 (ADA). Specifically, BNSF was testing its employees for HNPP.

The story broke nationally and was picked up by magazines as well as local union newspapers. *60 Minutes* did a story on it. As the story broke, the HNPP website, which had been averaging 1 to 200 hits a month, had over 1300 hits in a matter of days!

While the action by the EEOC is remarkable in itself, even more intriguing is that BNSF did the testing without their employees’ knowledge or consent. *The Union Advocate*, the official publication of the Saint Paul (Minnesota) Trades and Labor Assembly, AFL-CIO wrote:

Bruce Glover, general chairman for the Maintenance of Way Employees in the Twin Cities, said the union discovered the testing thanks to Janice Avery, wife of injured worker Gary Avery, of Nebraska. Glover said Janice Avery, a registered nurse, questioned why her husband was asked to go to an unknown doctor as part of the company medical exam of his injury. “He got a letter,” Glover said, “saying the medical department had reviewed the information in his claim. They couldn’t tell if his injury was duty related, so they wanted further testing at the below-named doctor.” The letter also reminded him of Rule.26.3, that he is subject to any testing the company thinks is necessary. Janice Avery called the doctor’s office in January. Glover said, “They told her they needed blood for laboratory tests.” She asked a few more questions, and they

Keeping Genes Private

President Bush has joined the cause of longtime advocates of a law against “genetic discrimination,” the use of genetic tests to deny people access to jobs or health insurance. The President addressed the need for protection from abuses of this information, stating it amounts to “medical speculation” because a genetic predisposition to a condition does not mean it will develop.

A genetic privacy bill, written by Rep. Louise Slaughter (D-NY), has the endorsement of scientists Francis Collins and J. Craig Venter, the decipherers of the human genome. Her bill would bar employment discrimination based on gene tests and forbid insurance companies from using genetic information to deny coverage or adjust premiums. More important, no one could be forced to take a genetic test for either employment or insurance purposes. Some insurers are reported to have denied coverage merely because someone took a genetic test, the sort of overreaction that drives people away from taking the tests at all. A bipartisan bill would extend significant protection to millions of people.

causally mentioned that the purpose of the blood was for genetic testing.

A 2/19/01 article in the *Amarillo Globe* by Matt Curry, A.P., states:

After Avery refused to take the test, the company informed him that he would be investigated for failing to cooperate. A railroad spokesperson says BNSF doesn't require workers to submit to genetic testing but that "some employees were asked to take a test."

Three days after the law suits were filed, BNSF voluntarily suspended its testing. In their February 2nd press release, BNSF explained what genetic testing they had done:

As part of the rail industry's safety rules and negotiated union agreements, BNSF may require its employees to take a medical examination as a method to evaluate a range of employee injury claims. In March 2000, BNSF included in this examination a genetic factor only for some employees who claim work-related carpal tunnel syndrome.

By the time of the April 16th court date, the EEOC had reached an agreement with BNSF. Burlington Northern agreed to stop requiring genetic testing, not analyze any blood previously obtained, and not retaliate against anyone who was opposed to the testing or aided EEOC in the proceedings.

Had BNSF not settled with the EEOC, this would have been a landmark lawsuit. Because the EEOC has settled with BNSF, the EEOC's position on how the ADA bans such genetic testing remains untested in the court. This means there is no precedent for any future lawsuits involving genetic testing by an employer.

While EEOC, the courts, media and employers have focused on this case, their objective has clearly been the general concept of employer-mandated genetic testing. What disease, exactly, the genetic test was testing for, seems to matter little. It has been referred to as "the genetic test," a DNA test for chromosome 17 deletion—which is claimed to cause carpal tunnel syndrome in rare cases." To date, only one source has been identified as naming it HNPP. With an estimated 90% of those with HNPP yet to be diagnosed, it seemed like a perfect opportunity to get some media attention for this disease. But all requests to the media, to include a few sentences in a side-bar, have been ignored.

In our next newsletter, we will look at this lawsuit from the HNPP/CMT community perspective.

RESEARCH UPDATE

Recent Findings on Coenzyme Q10

A brief article in the *Washington Post* reported on a small study on the usefulness of Coenzyme Q10 (CoQ10) for patients with the rare genetic condition that affects nerves and muscles, hereditary ataxia.



Researchers from Columbia University's College of Physicians and Surgeons reported in the journal *Neurology* that high daily doses of CoQ10, normally found in nearly every human cell, reversed ataxia symptoms in six patients. Some who had been using wheelchairs were able to stand and move using walkers. Participants took from 300 milligrams to 3,000 milligrams daily, with no reported side effects.

But, the study, which was funded by the National Institute of Neurological Disorders and Stroke (NINDS) and the Muscular Dystrophy Association, should not give a green light to widespread use of CoQ10, said the lead author of the journal report, Salvatore DiMauro, professor of neurology at Columbia University. The findings do hold promise for the treatment of hereditary ataxia and a few other neurological diseases.

* U.S. Equal Employment Opportunity Commission (EEOC) is the federal agency responsible for enforcing Title I of the ADA, which prohibits discrimination against qualified individuals with disabilities, including prohibiting an employer from seeking disability-related information not related to an employee's ability to perform his or her job.

In addition, EEOC enforces Title VII of the Civil Rights Act of 1964, which prohibits discrimination on the bases of race, color, religion, sex or national origin; the Age Discrimination in Employment Act, which protects workers age 40 and older; and the Equal Pay Act, which prohibits sex-based differences in compensation. Further information about EEOC, including its ADA policy guidances, is available on the agency's website at www.eeoc.gov.

Working to get the Word Out: CMT and Art Combine

Joe Thomasson lives in Sherwood Shores, Texas and became familiar with CMT through an accidental meeting with a CMT patient. He had become disabled in 1995 with bipolar disorder and went back to school full-time for drafting, even though he really wanted to be an artist. After eighteen months of working in the drafting market, he found himself back on disability. It was about this same time that he met Amanda Dedmon.

He saw her in a café in Oklahoma and was drawn to two aspects of her. She was very pretty and she had a very distinctive walk. She seemed to have a hinged hip, leading with one leg, twisting her hip, then dragging her other leg around to finish the step. The ball of her right foot didn't seem to rise above the parallel line from the floor as her other foot had done. Joe isn't a doctor, but he knew there was something unusual about her gait, so he asked her what medical problem she had. She told him all about Charcot-Marie-Tooth.



Right: Amanda and her daughter posed for Joe's camera.

Below: Amanda's profile became the first in the series of watercolors that Joe has done to illustrate the positive images of her life.



Amanda writes: "My story is like a million others I'm sure. I feel silly even writing any of it. I found out that I had CMT neuropathy in 1996 from a Denison, Texas, neurologist. I don't want pity or to be looked at with sad eyes. I just want to get through life with my pride still intact and have a great 'quality of life.'"

"I have a disease, but my disease is not who I am. I am a great mother (I have three children, ages nine, seven, and three). I am a daughter, a girlfriend, a singer, and a hard worker. I am a terrific woman and I can do almost anything.

"When I first found out that I had CMT, I went through denial and severe depression. Now, I understand my handicap as a handicap only. I continually make goals and achieve my goals most of the time. I live a positive life."

Joe asked Amanda to model for his artwork so that he could show the positive aspects of her life for others to see. To his surprise, she agreed and they have been working together in a partnership which allows the sale of paintings to help them both. They had their first showing in June and now hope to be seen in galleries in north Texas and the Dallas area.

Each of his pieces of artwork has the following label on the back; *Modeling is Amanda Dedmon. Amanda has Charcot-Marie-Tooth neuropathy. This watercolor was painted in partnership with Amanda to help with her medical costs.*

Joe likes the words of the philosopher Lu Hsun, who wrote: "Hope cannot be said to exist, nor can it be said not to exist. It is just like the roads across the earth. For actually there were no roads to begin with, but when many people pass one way, a road is made." As Joe says, "Each of us has one handicap or another, either known or unknown, and it is only when we begin to share with others the positive aspects of our living that we can rise to the greatness that God would be pleased with."

Membership solicitation changes

Beginning in June of this year, the organization began a membership renewal program based on the month in which a member joins or pays his or her renewal dues. With the new program, a person who joins the organization in June 2001 will receive a renewal reminder in June of 2002. This change from all membership renewals being solicited in the summer months will allow a steady flow of income from membership throughout the year and will guarantee that each member will receive a full year of membership benefits before being asked to renew.



In June, all members who had allowed their membership to lapse were sent reminders along with the members who had paid in June of the previous year. This was a large mailing, but as we get through the first year of this new program, the number of members in each month should even out.

We want to thank the members who include a little extra in their membership gift. This allows us to grant "scholarship" membership to people who write and tell us of their financial difficulty in paying the yearly dues. One 84-year-old woman wrote about how much the newsletter meant to her, but said she was cancelling because she receives only \$400 per month from Social Security. We were able to write and tell her she would continue to receive her newsletter because of the generosity of other members.

Two New Products: Help for CMT Patients

ETONIC SYNERGY SHOES

If you are looking for a shoe that will provide both therapeutic benefits and athletic design, you might consider the Etonic Synergy Series from the Drew Shoe Corporation. The footwear line was designed for patients who wear orthotics and enjoy more athletic pursuits.

The durable leather design of the footwear reduces foot fatigue, allowing the feet to breathe. The line features a rocker toe, padded tongue, removable insoles, heel support and supportive

medial and lateral midsoles. The footwear series is available in 16 styles and five different widths.

For more information on stores which supply the shoe, or how to order the shoe, call 1-800-837-3739.

GEEN DIABETESOX

DiabeteSox are designed to minimize pressure on the leg and foot and are suited to diabetics, but also are suitable for anyone seeking the comfort of pressure-free socks. They are constructed with no constricting welt and have a unique ankle "hinge" which is designed to prevent uncomfortable folds and creases. The hand-linked toe seam is flat, comfortable and nearly imperceptible, thus avoiding pressure points on the toes.

They come in both a plain and a padded version. The plain sole is excellent as a dress sock and the padded sole has a terry cloth layer for added warmth and cushioning.

These socks come in black, navy blue, white, gray and sand and sizes small through X-large. For information, or to order, call 1-888-254-1149 (Garnet Maple Design, Ltd.)



Support Group News

■ Arkansas - Northwest Area

The group has changed their meeting location because of accessibility issues and informs their members before each meeting of the date and location. In June, the group met in Bentonville, Arkansas at the Benton County Extension Room. The presentation concerned the work of orthotic technician Allam Dalati, who volunteers his time to travel to Syria and Damascus teaching doctors there about CMT. He distributes the physician's handbook on CMT and the "What is CMT?" pamphlets from the association. He serves as the sponsor of the support group in Arkansas and mails their newsletter and meeting announcements.

The next meeting will be an end of summer cookout with a wound care specialist from North West Medical sharing information about the proper care of wounds for CMT, diabetes and Charcot foot.

Information about this group can be found at www.geocities.com/charcot_marie_tooth

■ Colorado - Denver Area

Marilynn Munn Strand, who attended the national support group leaders' conference in April, created a bulletin board for her group featuring pictures from the conference and information about the North American Database. On the database board, she affixed printouts of a microscope, DNA helix, test tube and nerve as

well as family member names, such as grandmother, sister, cousins, etc. She did this to draw attention to the very important project and reports that it must have worked because everyone in the group took a database packet.

■ New York - Westchester County/Connecticut (Fairfield)

Westchester leader, Kay Flynn, sent in an article about one of her group's members, Tom Garrick, who was recognized in a local paper for his artistic talent and a recent showing of his work. Tom was diagnosed with CMT in 1985 and was forced to leave his teaching job in New York City in 1995. He now lives in Hyde Park and continues his painting. Although his CMT has caused a deterioration of his hand and lower leg muscles, making him unable to stand or grip for long periods of time, he has not given up his passion for painting and his works cover his barn, which he uses as a studio.

Garrick and his friend, John Lewis, are in the grassroots stage of planning a conversion of the barn into a school for disabled artists. Tom hopes to resume his role as an educator in the visual arts while helping others overcome their disabilities through art.

His show in Woodstock represented 23 years of his work, beginning when he was 14. The self-taught painter has no specific style to which he adheres.

BOOK REVIEW:

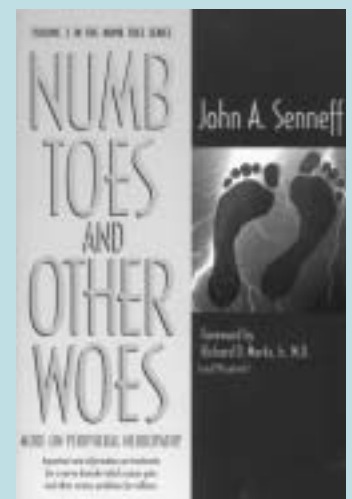
Numb Toes and Other Woes: More on Peripheral Neuropathy

This is the second book in a series written by John Senneff, a retired attorney who suffers from peripheral neuropathy. The first book, *Numb Toes and Aching Soles*, was a timely look at the symptoms of neuropathy and the treatments available at that time. There were first-person comments from patients as to what had worked for them and what had not.

This follow-up is more like a text than a first-person narrative. Mr. Senneff has done exhaustive research into the various pain medications available and what new clinical studies have shown with regard to the problems of aching hands and feet, weak muscles and shooting pains. In addition to discussing what one would call "standard" medications, he also provides a quantity of information on nutrient supplements and alternative and complementary therapies.

If you read current articles about nerve growth factors, gene therapy or stem cell research, you can find explanations of each in this new book. In addition, Mr. Senneff reviews the use of nerve stimulation machines and other options such as magnets, massage therapy and biofeedback. If one thing could be said about this book, it would be that it is exhaustive in the topics that are covered in its pages.

Although no specific mention is made of CMT, again, as with the first book, there are valuable pieces of information contained in the text that make it a valuable addition to one's reference shelf. —Pat Dreibelbis



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@home.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: St. Louis University Medical Health Center
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) 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
E-mail: CMT@woh.rr.co

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: jeanie421@yahoo.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

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Marguerite Baker

Katherine & Bernadine Serena

LaVerne Bass

Richard & Barbara Wagner

Paul Budde

Betty McMacken
Mrs. Virgil Mills

William Clark

Steven & Joanne Koenig

Cecil Gustafson

Rita Teresi
Curtis Wiehle

John David Hill

Harper Family
William & Elaine Hickerson
Barrie, Peggy, Kara, Paul & Jay
McDonald
Audrey Trautman
Joyce & Robert Watson

Luther Holly

Richard & Barbara Wagner

Shirley Hubbard

Samuel Hubbard

Grace Klein

Lyle & Marian Van Vleet

Mary Meltzer

Jerry & Debra Bank

George Tutuska

Blue Circle Cement
Mr. & Mrs. Edward Day
A. G. Edwards Company
Hildegard Griffiths
Peter Miceli
Jennifer Milan & David Glick
Andrea Shenocca-Budd
Adrianne Sicoli
Allen & Loreen Steinfeld

GENEROUS BEQUESTS RECEIVED

The CMTA is the recipient of bequests from the estates of Howard Scott Foley and his wife, Sigrid Pederson Foley. Mr. Foley had Charcot-Marie-Tooth disorder and died in 1991, naming the CMTA in the trust he established for his wife and other remaindermen. When she died in December of last year, we were informed of her husband's gift of \$7,500 and 35 shares of Merck. Mrs. Foley also remembered the association in her will and the organization will receive \$15,000 from her estate. The Foleys had no children and no close relatives and were very generous in bequeathing money to a number of non-profit organizations.

IN HONOR OF:

Carol L. Keeley

Office of Public &
Congressional Affairs-FBI

Ruth Wendkos

Estelle Bandler

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: _____

Address: _____

Letters to the Editor:

Dear CMTA,

I want to praise your organization and the column in our daily paper by Dr. Donahue. It was his article on CMT that put me in touch with your 800 phone number.

I had numbness in my feet for years, thinking it was just tight shoes. My podiatrist told me I had a form of club foot and sent me to a neurologist who diagnosed with CMT. I eventually had a DNA test which confirmed that I had type 1A. It was relief to be diagnosed because one night while watching TV, I had the scare of my life. My feet cramped, both legs, calves, thighs and both hands, all at the same time. I thought I had MS. After about five minutes the muscles relaxed, but I was very sore.

The only relief I get now is from custom-made shoes which cost \$430 a pair and which are not covered by insurance. I can't walk barefoot at all. My neurologist says I have a fairly mild case of CMT, but I can't imagine having it any worse. My only regret is that my grandmother and my father are not alive to know about CMT because they both had the clawed feet and hammer toes. When I saw the picture in your brochure, I thought you had taken a picture of their feet.

I would like to read more about how others treat their CMT. I am in my 50's and know it will get worse. My hands cramp up at times when I'm working in the kitchen or crocheting. Thanks to the CMTA, I know what it is.

Thanks again. Keep up the good work trying to find a cure and informing the public.

—S.R., Elba, NY

Dear CMTA,

I would like to share with all your readers a little about the people and work at Wayne State. I am very impressed with the work that Dr. Shy and his group are doing. If I were a betting man, I would say they have as good a chance as anyone to find us a treatment or cure. They are working specifically on OUR problem and I couldn't ask for anything more. They are not only trying to help us, but Karen Krajewski, Dr. Shy, and all his associates are the nicest and most considerate medical types you'll ever meet.

I know a brother and sister who have CMT, are elderly and live together in Indiana, near Ft. Wayne. They drove to Kentucky to attend the support group meeting and I told them about the work going on at Wayne State. They had their first visit to the clinic back in February and

couldn't say enough good things about Karen, Dr. Lewis, Dr. Shy and others. They loved them all and were happy to have had the experience. I suspect there are a lot of us who feel the same way about the work being done in Detroit and we need them to know that we really do appreciate all they do.

—W.S., (by email)

Dear CMTA,

I need your help.

Has anyone been involved in an industrial injury accident or personal injury accident or a court case where the other party is trying to place the blame specifically on your CMT?

If you could share your experience with me (even results of a court case, favorable or unfavorable), it would be greatly appreciated as I am having difficulty trying to prove it is not my CMT, but their negligence that has caused the accident and has accelerated the deterioration of my CMT. They are trying to say that my new disabilities are not caused by the accident but by my CMT.

Please send your responses to Barbara at CMTA, 2700 Chestnut St. Chester, PA 19013.

—B.G., Las Vegas, NV

Dear CMTA,

I have been reading about tremors as part of CMT and I wanted to tell you what I have discovered. I get fairly bad tremors, but they seem to be related to the temperature, fatigue, my degree of nervousness or my doing something which requires concentrated hand control.

For instance, if I am very cold, I notice a shaking in my hands which is impossible to control. Only once my hands warm up can I stop the shaking. The same is true if I get very tired. Then, the shaking is extremely noticeable and disturbing. I can drop things or be unable to pick up items that are small. The day I got married (nervousness!), my hands were shaking so badly that my wife held them to still the tremors.

Finally, if I try to hold something out in front of me for any period of time (no matter how limited) the shaking will begin and run up my entire arm.

I'm not sure how many other people have these problems, but I wonder if this is the tremor they called Roussy-Levy or whether this is just the norm for people with CMT.

—D.S., New York



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.

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.

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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Chester, PA 19013
1-800-606-CMTA

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