1983-2003
CELEBRATING 20 YEARS
OF LIVING OUR MISSION

Finding
a Cure

Creating
Awareness

Improving
Quality of Life

The CMTA Report

DECEMBER 2003

Vol. 18, No. 6 ISBN #1067-0181

**Our Mission:**
To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

**Our Vision:**
A world without CMT.

EMAIL CMTA AT:
**CMTAssoc@aol.com**

# U of Pittsburgh, Shadyside, Hosts CMT Patient/Family Conference

Despite the dismal rain on October 4, 2003, approximately fifty people gathered at the Herberman Conference Center of the University of Pittsburgh, Shadyside, PA, to learn more about the characteristics of and treatments for CMT. The conference was arranged by J.D. Griffith, support group leader, and Dr. Neil Busis, a neurologist at the facility. The speakers, all of whom donated their time, were Dr. Neil Busis, Dr. Gauri Pawar and Dr. Robert Chetlin (West Virginia University), Dr. Stephen Conti (Allegheny General Hospital), Amar Kamath (Athena Diagnostics), and Rajiv Sawhney (Allegheny and Chesapeake PT, Inc.).

After a continental breakfast, the group was welcomed by CMTA Executive Director Charles Hagins. His presentation was followed by that of Dr. Busis. Among the information which he shared was the somewhat startling statistic that over 20 million people suffer from some form of peripheral neuropathy. The leading cause of peripheral neuropathy is leprosy and other causes are diabetes, nerve entrapment, toxins, inherited diseases, and inflammation of the nerves.

According to Dr. Busis, CMT patients suffer from negative motor symptoms and positive sensory symptoms. Negative motor symptoms include a loss of function and a loss of sensation. Positive sensory symptoms include too much activity (restless legs), pricking, burning, and neuropathic pain. Occasionally, autonomic symptoms such as fainting, lightheadedness, and excessive sweating have been noted.

Another startling statistic which Dr. Busis presented was the fact that probably 90% of CMT patients don't complain and don't bother to get a firm diagnosis. In many cases, this is because someone in the family is already diagnosed and there are issues with getting or keeping medical insurance.

The presentation by Dr. Busis concluded with the very encouraging statement that, "The peripheral nervous system is much more ripe for genetic therapy than the central nervous system. The peripheral system wants to regenerate if allowed to." This information is exciting for the future of CMT research.

*(continued on page 2)*

*Dr. Stephen Conti (left) and Dr. Neil Busis (right) gave informative and encouraging presentations at the recent Pittsburgh conference.*

## PATIENT/FAMILY CONFERENCE

(Continued from page 1)

Another fascinating presentation was given by Dr. Stephen Conti, orthopaedic surgeon. He began his discussion by saying that to an orthopaedic surgeon, CMT causes a pure mechanical problem. A human being takes 8,000-10,000 steps each day and puts two or three times his body weight on his feet each time he steps. For that reason, when assessing a CMT patient for treatment, it is important to know where he or she is in the continuum of the disease. A patient might be still supple, have weakness, or have weakness with a stiff foot. The goal of the orthopaedic surgeon is to get the patient's foot flat on that ground, because, as Dr. Conti said, "There are only two functions of the body: to pump blood to the brain and to get your foot flat on the ground so it can get you where your brain wants to go."

To that end, the surgeon might suggest bracing, which takes something supple and moves it into the right position and holds it there. If the person is past the point of benefitting from bracing, the goals of surgery become to balance the muscles, to lower the arch, to straighten the toes, and to tighten the ligaments on the outside of the ankle. Initial surgery is best done early while some strength and flexibility remain. There is a high success rate in foot and ankle surgery, but results can deteriorate with time owing to the worsening of the neuropathy and the onset of progressive arthritis.

Finally, Dr. Conti said that the surgery usually takes approximately two hours. The patient will then be on crutches and in a cast for six to eight weeks. He or she will have physical therapy for three months and should expect to reach maximum medical improvement in one year. Even after surgery, people almost always require some orthotic use and prefer comfort shoes, such as sneakers.

*Support group liaison Robert Budde drove from Kentucky to attend the conference and, while there, tried the EZ Gait brace.*

*Dr. Robert Chetlin, from West Virginia University, stayed after the conference to answer questions about exercise programs for patients.*

The final speaker in the afternoon was Rajiv Sawhney, PT, MS, OCS, of the Allegheny and Chesapeake PT, Inc. His presentation centered on the rehabilitation goals and techniques used with CMT patients. For a program to be well balanced, he suggested that it was important to identify the person's impairments, such as reduced range of motion, reduced hand dexterity, or presence of painful contractures. Once the problems are identified, the therapist and patient must set realistic goals and design exercises which will minimize the deformities, maximize function, and be easy enough for the patient to perform at home.

For most patients, energy conservation is key. The therapist suggested learning to pace oneself and using orthotic devices (braces) or assistive devices, such as canes or walkers. In addition, he suggested strength training (especially for the buttocks and thighs) and flexibility training (stretching to the point of discomfort, but not pain!). Finally, he suggested aerobic exercise (repetitive movement), which can burn calories, help cardiovascular conditioning, relieve stress, and promote a sense of well-being. All of these suggestions, of course, should be undertaken after evaluation by a medical professional.

The conference was well received by the patients and families in attendance and the association is already planning more patient/family conferences in the spring of 2004. ★

# Help Us Help You!

Salaries, rent, utilities, and supplies are the basic needs of any business. As a business the Charcot-Marie-Tooth Association has to operate and deal with those issues like any other company—with one major difference—the product we sell is *hope*.

Our efforts provide hope that important research will be funded; that we can help improve the quality of life for those affected by CMT; that some day we will be at the forefront of the efforts which find the cure for this disease; that as an association, we will be able to continue our mission another year, to serve our members.

This year, we are again asking for your financial assistance in providing hope to those we serve. This year's Annual Appeal, along with the funds we raise during the year, will enable the CMTA to continue into its 21st year. Will you help us?

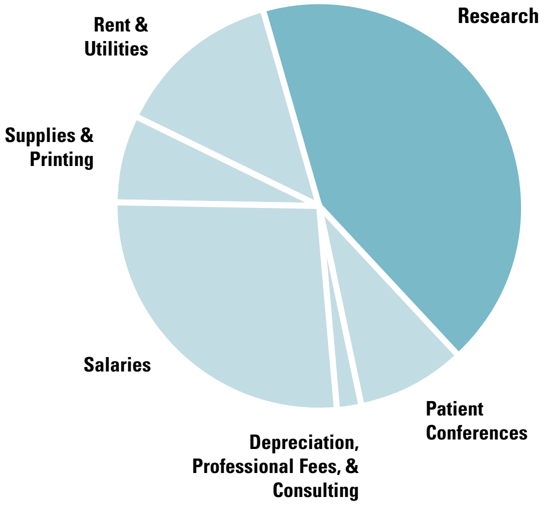
As an Annual Appeal donor, you will be pleased to know that we continue to operate with a minimal staff of two full-time and two part-time employees. Our experienced team enables us to maintain our operating expenses below budget, while we continue to serve our 3,000 paying members and several hundred who cannot afford to help us financially.

Please examine the adjacent pie chart detailing our fiscal year expenses so you can see how your money is prudently allocated.

Help us continue to help you and others affected by Charcot-Marie-Tooth disease by sending your tax-deductible donation today and take advantage of the year-end tax benefits.

*—Charles F. Hagins, Executive Director*

## WHERE THE MONEY GOES...



# CMTA MEMBERSHIP/ORDER FORM

Name:________________________________________

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:**<br>**A Handbook for Primary Care Physicians** | | *active members* $15<br>***inactive members* $20** | |
| Membership Dues | | $40 | |
| CMT Facts I ☐ English ☐ Spanish | | *active members* $3<br>***inactive members* $5** | |
| CMT Facts II ☐ English ☐ Spanish | | *active members* $5<br>***inactive members* $7** | |
| CMT Facts III | | *active members* $5<br>***inactive members* $7** | |
| CMT Facts IV | | *active members* $8<br>***inactive members* $10** | |
| **CMT Facts V** | | *active members* $12<br>***inactive members* $15** | |
| **A Guide About Genetics for the CMT Patient**<br>*No shipping and handling on this item only.* | | *active members* $4<br>***inactive members* $5** | |
| **Golf Shirt** *Size:* ☐ M ☐ L ☐ XL ☐ XXL | | $15 | |
| CMT Informational Brochure ☐ English ☐ Spanish | | FREE | |
| Physician Referral List: States: ____ ____ ____ | | FREE | |
| Letter to Medical Professional with Drug List | | FREE | |
| **Contribution to CMT Research**<br>*10% will be applied to administrative expenses.* | | | |
| **Shipping & Handling**<br>*Orders under $10 add $1.50, orders $10 and over add $4.50* | | | |
| **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.*

# Two Exciting Research Announce

## NEUROTROPHIN-3 SHOWS PROMISE FOR CHARCOT-MARIE-TOOTH DISEASE

A pilot trial of recombinant human neurotrophin-3 (NT-3), a growth factor being developed by Regeneron Pharmaceuticals, Inc., yielded statistically significant improvements in nerve regeneration and sensory function in four patients with Charcot-Marie-Tooth disease, Type 1a, researchers reported at the American Neurological Association meeting on Tuesday, October 21, 2003.

Dr. Zarife Sahenk of Ohio State University presented the findings of the study, which was sponsored by the Neuropathy Association and Regeneron.

Dr. Sahenk's group randomized eight patients to 150 micrograms/kg of NT-3 or placebo three times a week for 6 months. The primary outcome was myelinated nerve fiber regeneration in sural nerve biopsies, which were taken at baseline and after treatment. In addition, patients were monitored using the Mayo Clinic Neuropathy Impairment Score and quantitative muscle testing.

At follow-up, the four patients who received recombinant NT-3 demonstrated an increase in the mean number of small myelinated fibers in the second biopsy ($p < 0.0001$), as well as elevation in solitary myelinated fibers independent of Schwann cell processes ($p < 0.0002$), Dr. Sahenk reported. In contrast, none of the control patients demonstrated any improvement.

"Though [NT-3] was only tested in four patients, it was very encouraging to see the nerve regeneration," Dr. Sahenk said.

The NT-3 group also had improvements in neuropathy impairment scores and on a sensory gradation scale, which assessed response of distal limbs to stimulation by pins, vibration, and cold temperatures. In contrast, the sensory response of the control group deteriorated at 6 months, according to the researchers.

NT-3 is the first clinically significant treatment for Charcot-Marie-Tooth disease, Dr. Sahenk's group concludes, and may also benefit patients with other inherited neuropathies.

The first human trials for CMT nerve regeneration by using injections of NT-3, are almost complete.

NT-3 stands for neurotrophin-3, a bio-engineered chemical. The first human trials will stand against a 53% background rate of success for NT-3 nerve regeneration in mouse models.

There have been eight people in the study. All eight tested DNA positive for CMT 1A. Each patient needed to have a nerve biopsy before and after taking NT-3. The men had to have a prostate exam while the women were required to have a Pap smear. Anyone with a history of cancer was disqualified from the program. The cost of NT-3 was free to the clinic, but the clinic had to pay for the expensive packaging.

The eight research subjects gave themselves three injections of NT-3 each week over a period of 6 months. The study was a double-blind study, meaning the doctors, nurses, and the eight participants do not know who was given NT-3 or a placebo. Dr. Sahenk is counting and measuring each nerve fiber herself, a slow, yet extremely accurate process.

## RESEARCHERS FIND NEW WAY TO SLOW NERVE DISEASE

**By RANDOLPH SCHMID from the Associated Press**

A new method of slowing the most common inherited nerve disease may point the way for novel treatments for nerve disorders. Researchers working with rats retarded the progression of CMT, which gradually reduces the ability to use the arms and legs and affects about one in 2,500 Americans.

The team found success using a chemical that blocks a protein associated with more than half of all cases of CMT. People with the most common form of CMT have a genetic defect that causes overproduction of that protein.

Researchers led by Klaus-Armin Nave of the Max Planck Institute of Experimental Medicine in Goettingen, Germany, called the finding a "proof of principle" that they had located a promising target for therapy in CMT, which is not as well known as other nerve disorders such as ALS—Lou Gehrig's disease.

Although the treatment did not cure the disease, "it improved motor performance," according to the team's report, made public in the online issue of the journal, *Nature Medicine*.

# ments Made about CMT

Their work was welcomed by Craig Blackstone, chief of the cellular neurology unit of the U.S. National Institute of Neurological Disorders and Stroke.

“They’ve done what we hope to do with other disease genes,” Blackstone said. “They figured out how a gene works and developed an animal model that mimics the disease—and then they came up with a new, novel way to treat the disease.”

There are several forms of CMT. The most common form, CMT 1, accounts for more than half of all cases and involves overproduction of the protein PMP22. That protein is a vital part of the myelin coating that surrounds nerves. When it is over-produced, the result is an abnormal nerve sheath.

Production of PMP22 is stimulated by the hormone progesterone, so Nave’s team used onapristone, a progesterone blocker originally developed for use in breast cancer. In Nave’s experiment, the rats treated with onapristone had a 65% improvement in muscle holding ability after five weeks, compared with rats with CMT left untreated.

Blackstone said that onapristone can have side effects, so it probably would not be useful in humans with CMT. But other drugs in the same class may work without the side effects. The important thing, he said, is that they have shown a different method to attack the disease, “something we wouldn’t have thought to do.” ★

## AN UPDATE ON THE NORTH AMERICAN CMT DATABASE

**By MICHAEL E. SHY, MD**

Currently, there are over 400 patients who are enrolled or in the process of being enrolled. Of this group, 238 have their data completely enrolled in Indiana and the database has begun to receive queries from researchers, such as the one from Dr. Louis Weimer from Columbia University, who is trying to identify drug interactions which have affected CMT patients.

We had hoped to have over 1,000 patients by now and we do not have this number. Most of the data collected is useful, but there are some dialogue boxes which are too vague and need to be made more specific. We will be working to improve data acquisition.

As of this date, there are 169 males and 236 females enrolled or in the process of being enrolled. Of these numbers, for the males, there are 3 Asian, 1 American Indian, 1 Black, 1 Hispanic, and 5 listed as Other, with the majority, 158 Whites, completing the information. In the female responses, 2 are Asian, 2 are Black, 4 are Other, and 228 are White. ★

### FREQUENCY OF CMT MUTATIONS BY SEX IN THE NORTH AMERICAN DATABASE

| | Males | Females | Total |
|---|---|---|---|
| CMT1A | 22 | 52 | 74 |
| CMT1B | 3 | 6 | 9 |
| HNPP | 7 | 9 | 16 |
| CMTX | 7 | 8 | 15 |
| Possible type 2 | 15 | 13 | 28 |
| Unknown | 115 | 142 | 257 |
| Other | | 3 | 3 |
| CMT point mutation | | 3 | 3 |
| **Total** | **169** | **236** | **405** |

# GIFTS WERE MADE TO THE CMTA:

## IN MEMORY OF:

**Sterling Campbell**
Elsie Mann
Faculty & Staff of Shelton High School

**Georgia Cutler**
Dorothy Maltby
The News Herald
Mr. & Mrs. Edward Szuter

**William Demers**
Frank Booker
Louise Booker
Harold & Myrtle Davidson
Francis & Marian Kaczynski
Mr. & Mrs. Edward Ovian
John & Mary Ellen Stansky
Zymark Corp.

**Frank Eckman**
Frank & Debbie Tamburello

**Genevieve Eggers**
Roger & Marie Friewer
Larry & Karen Fultz
Ted & Jody Hill
Kathy & Tim Landess
Mr. & Mrs. Donald Miller
Dorothy Muenchow
Janet Newman
Mr. & Mrs. Karl Pauzar
Mr. & Mrs. Neil Perkins

**Carole Felt**
Mr. & Mrs. Walter Denio
Herman & Sylvia Foster
Marianne Harris
John & Christine Kirk
Mr. & Mrs. John Marakas
Maureen Nicholson
Neal & Lee Patterson
Kirk & Lauren Townsend
James & Frances Vorhes
Vicki Vorhes

**Millie Holterman**
David & Kathleen Cull

**Keith Oates**
Kay Flynn

**Dwight Pace**
Doris & James Cramer

**Rich Reid**
Doris & James Cramer

**Kathleen Smith**
Benetech
Robert & Rosemary Bezzo
Lee & Jean Bjorklund
Ann M. Burch
Martin & Dorothy Civin
Yvonne Dean
Gordon & Irene Dick
T. R. Fisher
Ed & Erva Hance
Harry & Esther Immer
Suzi Jones
Doris & Reuben Klammer
Thomas Lopp
Laurence McGilvery
Margaret & Alfredo Naranjo
Florence & Louie Osborne
Frank & Ann Rosa
Ethel Mae Rutledge
Carol Salgot
Benjamin Seymour
Canfield & Georgene Smith
Verbeck Smith
Leon & Karin Snyder
Ben & Edith Swisher
Marilyn & Alan Swisher
Walter Van Horn
Dean & Darlene Weston
Patricia Wolf
Lillian Zeigler

**Orville Stocker**
Mr. & Mrs. Coleman Smith

**Ken Takayama**
Margie Kusumoto

**Lee Tullock**
Nancy Jeanne Alward
Fay & Antonio Armenante
Dr. Ronald Cally
Carl & Daisy Davis
Barbara Eaton
Mary Ferrare
Mary Gillette
Carol & Karl Muster
Maureen Schiraldi
Richard Swarm
Roy Tarvin
Wayne & Patricia Yankus

**Harry Wagner**
Honey & Carl Adelsheim
Shelley & Irv Blumenfeld
Eileen Cook
Ruth & Saul Feldman
Cheryl & Jeffrey Ferdarko
Norton & Adrienne Freedel
Marlene & Sonny Gelman
Grace & Kal Ghoshhajra
Clara Goldberg
Joel Harris & Nancy Hoffman
Cheryl & Ron Kaufman
Barbara & Mel Landay
Renee & Gene Lichter
Dr. & Mrs. Kenneth Pakman
Morton & Irmalee Perl
Dave & Carole Pfefferle
Ruth & Paul Reifman
Barbara Rosenzweig
Natalie Schwartz
Sophie & Bob Shapiro
Meredith & Peter Silberman
Morris & Barbara Tufton
Shirley & Irwin Weiner
Barbara & Michael Wollman
Al & Shirley Zionts

**Henry Webb**
Ralph & Deb Militello

# *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:______________________________
______________________________

# *Diagnosis*

*(Editor's note: This was written by a 12-year old named David who was diagnosed at age 6. He lives in Illinois and wrote this for a classroom assignment.)*

I was in kindergarten and my small motor skills were developing horribly. My teachers were worried about how I could write only a few letters and everyone else could write most of the alphabet. My teachers had a meeting with my mom. I ended up seeing a muscle therapist who diagnosed me with upper body muscle weakness, then recommended another doctor who performed tests. He decided to do an electrical one on me. He told me it wouldn't hurt, so I knew it would. He asked me to lie down on the bed and pulled out an object with wires attached to it.

"We'll start out easy. This won't hurt," he said.

A jolt. I went rigid.

"Okay," he said. He attached something to my back and to my arm. "Okay, this might hurt." I went rigid. No pain. "Next one will hurt a lot, okay?" I nodded and wondered if I was six years old, lying in a hospital bed, about to feel a lot of pain. The jolt. I trembled. No pain.

The doctor stood up from the chair and asked, "Would you like some Tylenol?" Then in a more apologetic tone, "I couldn't give you anything during the test because it would interfere with it."

I shook my head and said, "No, it didn't hurt."

He laughed. "Stop trying to be brave. Would you like some?"

I said, "No, I'm serious, it didn't hurt."

Two weeks later I was diagnosed with CMT.

My life has been pretty abnormal since then. Try explaining to a bunch of kids at your summer camp that you can't play basketball because of medical reasons that nobody there can see or has heard of. But, at least, school can be easy because most of it is not physical except for writing, which can be a real killer. Because I can't play sports or other physical activities, I turn to the computer world. On a PC I can get as close as I ever can to playing sports like basketball or baseball. I always hated it when other kids played sports and I had to watch, but I am used to it now and can play some sports like floor hockey or dodge ball. I can't balance on things like bikes or skates. CMT is turning out to be not the huge, horrible thing I thought it was and it does not limit every part of my life. I'm not trying to say it's a good thing, but it's not entirely bad for it has given me a different view on the world; because I am not fully disabled, I have a foot in both camps, that of the disabled and that of those who are not. ★

## IN HONOR OF:

**Barbara Berstein**
Betty & Robert Berris
Sylvia Ginsburg
Nikki Jersin
Adele Lewis

**Yohan Bouchard**
Henry's Diner

**Robert & Phyllis Budde**
Martha Hall
Roger & Nancy Hopwood
Kentucky Support Group
William & Elaine Shaw

**Dr. Robert Chetlin**
Melinda Freed

**Susan Chetlin & Michael Heydt**
Honey & Carl Adelsheim

**Mr. Skip Davis**
Mr. & Mrs. Richard Davis

**Mrs. Skip Davis**
Mr. & Mrs. Richard Davis

**Gail & Gaelyn Feeney-Coyle**
Lara Backas
Marian Bakken
Kathy Bebee
Bonita Bock
Pat Bollacker
Carol Brown
Cynthia Cano
Julie Coyle
Patrick Coyle
Jean Eiss
Cindy Eley
Catherine Feeney
Mary Ellen Feeney
Teddy Adler Finney
Midge Foust
Barbara Froula
Jean Gall
Ledy Garcia-Eckstein
Gene Gardner
Joan Hall
Deborah Harrington
Tricia Huth
Celeste Jeffries
Nikki Jones
Jose Lara
Mary Ludwig
MaryAnne Markham Lynzmeyer
Dot Markham
Margaret Markham
Chris McGuire
Margie Miller
Elizabeth Montgomery
Shirley Moore
Jean Murawski
Katharine Nanda
Dr. Francine Pokracki
Diana Roca
Celeste Rossmiller
Mary Kay Seckinger
Pat Markham Stallings
Graciela Sullivan
Ruth Van de Witt
Melanie Walters
Chris Wells
Mark Westlund
Mary & Vic Williams
Susan Youtz

**Judith Grocott**
Robert Hawkes

**Herbert Holly**
Dorothye Knowles
Mr. & Mrs. Grant Swick

**Harold Seybert**
Carol & Sidney Henner

**Jack & Ethel Walfish**
Linda & Jerry Walfish

**Bernice & Ed Zeller**
Phyllis & Milton Meisner

# Taking on the Challenge...

## *When your child is diagnosed with a progressive neuromuscular disease*

**By SYLVIA McGRIFF, a therapist and teacher with a masters degree in clinical psychology**

*(This excerpt is from a publication of the Muscular Dystrophy Association entitled,* Learning to Live with Neuromuscular Disease.*)*

A stress reaction is the body's response to a challenge. It's a state of heightened physical tension that prepares you to take action to deal with the challenge. A little stress is helpful at times of threat. It can keep you alert and on your toes. But, stress can get out of hand and become overwhelming, so that it prevents you from coping with the very threat that has produced it. Headaches, nausea, insomnia, muscle stiffness, accidents, and inability to work can all be signs of too much stress. Severe or prolonged stress can make you vulnerable to a number of serious illnesses. To safeguard yourself and your family in the days ahead, it's crucial for you to bring your stress down to a manageable level so that you have the energy to sustain the intimate emotional relationships we all need.

When we believe we lack the resources to cope with a serious problem, intense anxiety results. People handle that anxiety in different ways. Many distort the situation to relieve their distress.

Sometimes, for example, parents will not accept the diagnosis of progressive neuromuscular disease for weeks or even months. This flight from reality is one way people try to ward off painful feelings—by refusing to face the truth.

Others defend themselves with another kind of distortion—inappropriate anger. They may get angry with the physician who made the diagnosis or with the doctors who failed to make it earlier. Their anger may be directed at a world, at a universe, in which a disease like this can be visited on a child, or even at a Supreme

---

# *Ask the Doctor*

**Dear Doctor,**

I have CMT associated with the duplication on chromosome 17. In considering family planning, I am looking for information on genetic transmission of CMT. Specifically, I want to know if my eggs can be tested for CMT rather than an embryo.

**The expert answers:**

Yes, it is possible to test eggs for the CMT1A mutation, rather than an embryo. However, there are still very few locations in the U.S. that offer this service. The best thing to do is to contact a genetic counselor in your area (visit http://www.nsgc.org/resourcelink.asp). If you cannot find a genetic counselor, you can try an IVF (in vitro fertilization) facility in your area.

**Dear Doctor,**

I'm traveling out of the country and some of the medications that have been recommended are mefloquine, doxycycline and ciprofloxacin. Are these dangerous for CMT patients?

**The expert answers:**

Mefloquine is not an innocuous medication. Patients have reported dizziness and occasionally motor neuropathies (e.g., paresthesia, tremor, ataxia). Also, muscle weakness, muscle cramps, and myalgia have been reported. Moreover, if you choose to be innoculated with typhoid vaccine, this should be completed at least three days before the first dose of mefloquine (if you begin this prophylactic regimen).

Central nervous system symptoms, such as dizziness, sedation, vertigo, paresthesia, and muscle weakness, have been reported in patients using doxycycline.

Ciprofloxacin is also not without its problems. What comes to mind is tendon rupture. Considering the gait problems of CMT patients, it is advisable to avoid this medication. Other associated adverse effects include (seldom): dizziness, fatigue, and paresthesia.

Therefore, you will have to weigh the prophylactic benefits of these medications with their possible adverse effects.

Being who allows such a misfortune to occur. Or they may become angry with themselves and/or their spouses for bringing a child with neuromuscular disease into the world. This response channels the force of their feelings away from the actual problem in order to cut off unbearable anxiety and fear.

You will have taken a giant step toward coping if you are able to realize in your innermost self that the stress you are experiencing can be managed…that you have the capability to do it…that there is a network of support available to help you do it. As a start, test yourself. Recall difficult times in your life when you have coped successfully, although it had often seemed you would not be able to. Make a list of friends, relatives, and other individuals you have been able to count on in past crises, and in this present one add the Muscular Dystrophy Association as a firm source of support.

Also begin now—in your mind's eye—to create images of coping, visualizing how it would be to break through your feelings of despair. Your inner conviction about this will act as a self-fulfilling prophecy. You will cope if you believe you can. ★

---

## UNDERSTAND INFORMED CONSENT

**From Dr. John Hsu**

CMT patients need to understand "informed consent" before undergoing any treatment. Know or provide the following:

1) Name of responsible physician/surgeon doing the procedure. (This is very important in teaching hospitals where a resident may actually be doing the procedure.)
2) Nature of procedure/treatment (in medical terms and in layman's terms).
3) Risk/complications if procedure is performed.
4) Risk/complications if procedure is *not* performed.
5) Alternative methods/treatments available.
6) Location where the procedure will be performed (clinic/surgical center/hospital/operating room/etc.).
7) Signature of physician performing the procedure with date and time.
8) Signature of patient/family.
9) Signature of witness or interpreter, if necesssary.

---

### FROM THE CAPITOL

## Genetic Nondiscrimination Bill Passes in Senate

U.S. Senator Mike Enzi, R-Wyo., and Senate colleagues passed legislation that encourages people to seek genetic services by reducing fears about the misuse or unwarranted disclosure of genetic information.

The Genetic Information Nondiscrimination Act of 2003, S. 1053, passed the Senate by a vote of 95-0. The bill prohibits discrimination on the basis of genetic information for health insurance and employment and protects the privacy of that information.

Enzi, a member of the Senate Health, Education, Labor and Pensions Committee and co-sponsor of the bill, has worked continuously with Senate colleagues to pass genetic nondiscrimination legislation.

Genetic nondiscrimination legislation has also been introduced in the House.

Senator Enzi presented the following statement:

*"Fifty years ago, James Watson and Frances Crick discovered the structure of the DNA molecule—the blueprint of life. Their discovery laid the foundation for predicting and treating the hereditary diseases that threaten us.*

*The completion of the Human Genome Project in April, 2003 was a significant step towards this goal. Because of the work of these scientists, we now are able to decipher the exact sequence of the genetic code. This knowledge will allow earlier detection and more effective treatment of genetic illnesses.*

*However, genetic information brings challenges along with promise. The Genetic Information Nondiscrimination Act will ensure that the promise of genetic information is not hindered by fears about its misuse. This legislation will protect individuals from discrimination in health insurance and employment on the basis of genetic information.*

*I want to thank my colleagues on both sides of the aisle for crafting a bill that fairly and effectively protects people against genetic discrimination. In doing so, we have been mindful of existing discrimination and privacy laws and regulations.*

*While the issue is complex, our objective is clear—to encourage people to seek genetic services by reducing fears about the misuse of unwarranted disclosure of genetic information.*

*Today, we mark the 50th anniversary of Watson and Crick's historic discovery with the passage of the Genetic Information Nondiscrimination Act. With each new advance in genetic science, the significance of this legislation grows. By allaying fears about genetic discrimination in health insurance and in the workplace, this legislation will save lives now and in generations yet to come."* ★

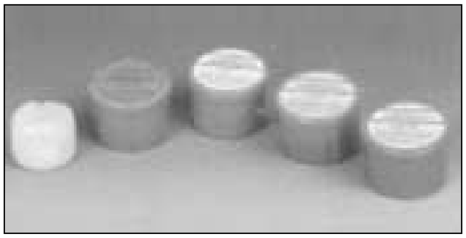
## PRODUCTS THAT WORK

# Soothing Sore Feet and Hands

*The following items are available at www.PainReliever.com or 1-888-498-8587.*

**Bauerfeind MalleoLoc Ankle Stabilizing Brace**
This brace is suitable for teenagers or those who remain physically active with CMT.
It is perfect for playing basketball, volleyball or other activities. The MalleoLoc ankle stabilizing brace increases ankle stability without reducing mobility. This stabilizing ankle brace is specifically contoured to increase stability without restricting mobility. It fits in front of the outside ankle bone and behind the inside to limit outward rolling of the ankle joint that is common in so many injuries. Its unique design leaves front of the foot free for natural stabilization and full plantar and dorsiflexion. This brace is made of lightweight thermoplastic that is heat-molded to provide a custom fit to any shoe. Individually adjustable, color-coded Velcro straps stay secure even with activity.

*Price: $42.95*



**Thera-Putty**
Using Thera-Putty can help rehabilitation of your fingers, hands, and forearms by strengthening the muscles of the hands and wrists. Thera-Putty will not harden and comes in five color-coded resistance levels ranging from XX-Soft to X-Firm.

*Price: $9.95*

*The following items all may be found at www.VermontCountryStore.com or by calling customer service at 1-802-362-8499.*

**Socks Provide Extra Comfort for Sensitive Feet**
These smart socks from Wigwam were designed for diabetics, arthritics, and those who have sensitive feet, but truly are for anyone who's concerned with comfort and maintaining healthy feet. They feature a patented moisture-control system and a cushiony sole so your feet stay dry, blister-free, and cushioned from daily pounding. Non-binding leg and welt top. Machine wash and dry. 45% Olefin, 30% Lumiza, 25% acrylic. USA.

*Price: $11.95*

**Women's Adjustable Booties**

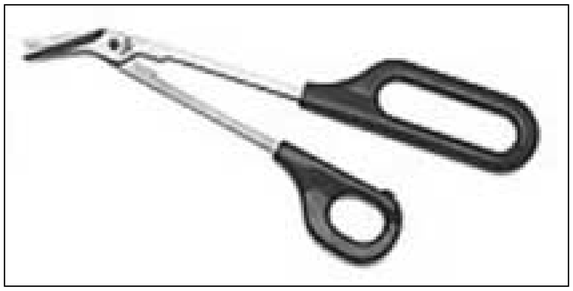
Jack Frost may nip at your nose, but your feet are off limits thanks to these cozy adjustable Berber booties. They're lined with chill-chasing fleece for maximum warmth and the Velcro closure lets you wrap them around your feet as tightly or as loosely as you like—ideal for people whose feet are prone to swelling. And they're so light and comfy you may forget you even have them on. Cushiony insole. Indoor/outdoor skid-resistant sole. All colors are trimmed with gray. 100% polyester. Imported.

*Sizes: 7-10*
*Price: $24.95*

**Natural Cream Warms up Chronically Cold Hands and Feet**

If you suffer from cold hands and feet when you're outdoors, rub this Vermont-made natural cream into your hands or feet and in about 10 minutes you'll feel a pleasant warmth coursing through your fingers and toes that will last for hours. Made with the amino acid L-arginine, which stimulates circulation by naturally relaxing blood vessels. Also contains vitamins A and D and aloe.

*Warm Cream, 2 oz. $22.95*
*Warm Cream, 4 oz. $39.95*



**Long-Handled Toenail Scissors**

If bending over to cut your toenails has become more difficult, it's time you tried our long-handled toenail scissors. They measure approx. 8" in length, allowing you to effortlessly reach your toenails. Feature an easy-grip handle made of durable plastic for safe, sure-handed cutting. The scissors are forged from stainless steel.

*Price: $14.95*

**Shearling Slippers**

These slippers are fully lined with shearling sheepskin, so they're not only soft, warm, and luxuriously comfortable, they're actually good for your feet, too. Why? Because shearling has a naturally high lanolin content that helps keep your feet soft, and wicks moisture away from your skin. Feet are healthier and more comfortable year around. Supple tan suede uppers have a nonskid synthetic indoor/outdoor sole. Imported.

*Sizes: 8-15 (Half sizes order next size up)*
*Price: $49.95*

# Support Group News

### ■ New York - Horseheads

At our November Support Group Meeting, we had a clinical dietitian from a local hospital as speaker. It turned out to be one of our most lively meetings. The group kept him engaged in discussions for approximately 45 minutes! The group was in fine fettle. All seemed quite upbeat in spite of many ongoing problems. Several have recently been approved for disability and another member is facing very serious brain surgery to correct problems with cerebrospinal fluid leaks and hydrocephalus. The surgery will be done in Philadelphia. We ask that everyone keep Ernie in their prayers.

As an interesting anecdote, I saw one of our older pens at a football game in the area. My grandson was playing and someone in the bleachers needed a pen. Before I could get one to them, someone else produced one of our aqua and white ones! I knew it was one of ours. Unfortunately, I was unable to get to speak to the person re: CMT. Do wish I could have because I am certain he is not registered with our group.

### ■ Ohio - Northwest

William Lloyd will be the speaker at our January, 2004 Northwest Ohio Support Group meeting. We had 5 folks at our October meeting.

William uses a 5½ foot tall "standing stick." He says, "It isn't useful for walking, but when standing, it allows me to lock my knees, which lets me rest my leg muscles. I use it almost exclusively at four local county fairs. It allows me to visit activities where often there is no convenient place to frequently sit down and rest. It has two knobs, about chest high, that keeps my hands from slipping. The wearing of gloves also helps in that respect."

Some of our topics for January will be:

1) Do other CMT people bite their tongue while chewing? I do on a weekly basis.
2) Did they grow up as a child with "leg ache" like I did?
3) Does anyone have leg pain? I, occasionally, only suffer sharp pain in my left big toe.
4) Does anyone have cracked skin at the corners of their fingernails? I do and it's worse in winter.
5) I find that using the hot (104-degree) tub at the health club to be weakening. Are there any known contraindications? Anything known about steam cabinet usage?
6) Does anyone here choke on foods often while eating? I seem to, and must be very careful. Looking up is the worst case scenario.
7) Do you normally wake up rested? What is your average sleep time? I frequently wake up tired after seven hours of apparently uninterrupted sleep.
8) Are your lower legs (one or both) normally cold? My right leg runs cold.
9) Do you find one side of your body weaker? My right side is weakest (leg, arm, and shoulder).
10) Does anyone have shoulder pain? I overstressed my right shoulder and now it is almost always painful, especially when trying to use it.

### ■ Kentucky/South Ohio/South Indiana

The Fall Meeting of the Ky/SO/SI CMT Support Group was held on Saturday, November 1, 2003, at 10:30 a.m. at the Northside Branch of the Lexington Public Library, 1737 Russell Cave Road. We were fortunate to have two presenters: Linda Clark, an Occupational Therapist from Cardinal Hill Hospital in Lexington, and Bill Messer, an orthotist from Wright & Filippis, Detroit, Michigan. He is affiliated with the CMT Clinic in Detroit.

At a previous meeting we were reminded of the importance of vitamin B-12 on nerves and how a B-12 deficiency can be treated only by injections. We also shared information from Dr. Florian Thomas from St. Louis on what to watch for in surgery, to avoid nitrous oxide, especially if there is a vitamin B-12 deficiency, and to avoid compression of the nerves during a long surgery.

We are taking suggestions for names for our CMT Newsletter. Ideas include "Wired" (unless it's already been used by National Public Radio), "Impulse," "Nervy," "Numb News," "Numb News Is Good News," "Shocking," "No Feelings," "My Line" (myelin), "My Line Sheet" (sheath), "Rebuilding My Line," etc.

# CMT Support Groups

**Bob Budde, Support Group Liaison, 859-255-7471**

### Arkansas—Northwest Area
**Place:** Varies, Call for locations
**Meeting:** Quarterly. Meetings are not regularly scheduled so call ahead.
**Contact:** Libby Bond, 479-787-6115
**E-mail:** charnicoma57@yahoo.com

### California—Berkeley Area
**Place:** Albany Library, Albany, CA
**Meeting:** Quarterly
**Contact:** Gail Whitehouse
**E-mail:** gwhite@earthlink.net

### 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:** Martha Hall, 502-695-3338
**E-mail:** marteye@mis.net

### 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

### Minnesota—Benson
**Place:** St. Mark's Lutheran Church
**Meeting:** Quarterly
**Contact:** Rosemary Mills, 320-567-2156

### Minnesota—Twin Cities
**Place:** Call for location
**Meeting:** Quarterly
**Contact:** Maureen Horton, 651-690-2709
Bill Miller, 763-560-6654
**E-mail:** mphorton@qwest.net, wmiller7@msn.com

### Mississippi/Louisiana
**Place:** Baptist Healthplex,
102 Clinton Parkway,
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 bimonthly
**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:** 2nd Thursday of each month
**Contact:** Dr. David Younger, 212-535-4314,
Fax 212-535-6392
**Website:** www.cmtnyc.org

### New York—Horseheads
**Place:** Horseheads Free Library on Main Street, Horseheads, NY
**Meeting:** Quarterly
**Contact:** Angela Piersimoni, 607-562-8823

### New York (Westchester County)/ Connecticut (Fairfield)
**Place:** Blythedale Hospital
**Meeting:** 3rd Saturday of each month, excluding July & August
**Contacts:** Beverly Wurzel, 845-783-2815
**E-mail:** cranomat@frontiernet.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

### Ohio—NW Ohio
**Place:** Medical College of Ohio
**Meeting:** Quarterly
**Contact:** Jay Budde, 419-445-2123 (evenings)
**E-mail:** jbudde@fm-bank.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@hotmail.com or blzerbabe@aol.com

### Pennsylvania—Johnstown Area
**Place:** Crichton Center for Advanced Rehabilitation
**Meeting:** Bimonthly
**Contact:** J. D. Griffith, 814-539-2341
**E-mail:** jdgriffith@mail.charter.net

### Pennsylvania—Northwestern Area
**Place:** Blasco Memorial Library
**Meeting:** Call for information
**Contact:** Joyce Steinkamp, 814-833-8495
**E-mail:** joyceanns@ adelphia.net

### Pennsylvania—Philadelphia Area
**Place:** Penn Towers Hotel Conference Room
**Meeting:** Bimonthly
**Contact:** Amanda Young, 215-222-6513
**E-mail:** stary1@bellatlantic.net

### Pennsylvania—State College
**Place:** Centre County Senior Center
**Meeting:** Call for information
**Contact:** Katia Skovrinskie, 717-608-1081
**E-mail:** skov@psu.edu

**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.*

# Letters

**Dear CMTA,**

This letter is written in response to an article titled "CMT: For some it is a breath-taking reality" by Susan Wheeler in the August 2003 edition of a newsletter entitled, *CMT...Today*. We thought it would be of interest to your readers, too.

This hit home, as our father died at age 72 in July from a paralyzed diaphragm caused by his CMT. He had struggled with the typical symptoms of lost muscle tone in his extremities since his mid 30's and then started having shortness of breath the last couple of years. It was only three months prior to his death that he was diagnosed with paralysis of the diaphragm. He started using a biphasic positive airway pressure ventilation machine at night, but unfortunately, it was a little too late.

We wanted everyone to be aware that this is not just a disease affecting the extremities, but in some cases it can affect the diaphragm and, possibly, the heart. As a precaution, it would be a good idea to have your $CO_2$ levels checked periodically if you have CMT.

*—H.F. Seattle, WA*

■

**Dear CMTA,**

I felt I had to share with others who have CMT the near miracle (at least I think so) that has occurred since I had braces made by Mitch Warner of Ortho Rehab Design in Las Vegas in early September.

I had seen the description and pictures of these braces in The CMTA Report about a year ago. I showed the article to my husband who is both an engineer and an inventor of medical devices and he was certain they would improve neither my gait nor my balance as they claimed to be able to do. I was wearing an AFO on my left foot and though I could walk, it was difficult, tiring, and slow. However, the AFO did nothing to improve my balance and that was getting significantly worse. I could not stand for even a moment without holding on to someone or something and so decided to go to Las Vegas for the necessary 5 days to have the braces filled and made. I won't go into all the details, but I can now walk quickly with an "almost" normal gait and can stand without any assistance, indefinitely. My husband said he was never happier to be wrong.

I wear the braces from the moment I arise until the moment I go to bed and have never had any irritation on my feet or legs. Mitch is a superb craftsman. He even made the braces thin enough to fit in shoes I am willing to wear such as lightweight sneakers, sandals, and Mary Janes.

The braces, the plane trip, and the stay in Las Vegas were pricey, but I have now pushed my CMT disabilities back five years. Steps are difficult, and probably will not get too much better, but everything else is great. I feel like a new person and I'm 73 years old.

If anyone would like to discuss these braces with me, please e-mail me at mfischell@comcast.net.

*—M. F.*

■

**Dear CMTA:**

For my 50th birthday celebration I had 50 women in my home for a wine and cheese party and in lieu of cards and gifts asked them to bring a contribution to CMTA in honor of both myself and my 18 year old daughter, Gaelyn, who also has CMT. Well, what a wonderful gathering indeed! After mailing invitations in Denver, as well as around the country to dear friends and family, I collected $2,000.00. Many husbands, I may add, added their own separate checks as support. I want to share this idea as I am so proud of my wonderful friends and family. I could think of no other way I wanted to celebrate such an important birthday. It served as a terrific way to educate others about CMT. Everyone was so touched by this effort and so loving and generous in their support of CMTA.

I hope that others will think of a similar way to honor themselves or another and help the cause of CMT.

*—G. F.-C., Denver, CO*

■

**Dear CMTA,**

Just a quick note to thank you for sending information when I called your office and for referring me to your website and to Shriners Hospital for help for my child. So many of my fears and worries were alleviated by this information. Your discussion forum was especially useful—learning about other people's experiences with raising children with CMT has helped me a lot.

*—M.S., Tampa, FL*

**The CMTA Report** is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization.

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.

Photos on pages 9 and 15 by Ian Britton, courtesy of FreeFoto.com.

# Learning to Type—at 46

**By DANA SCHWERTFEGER**

A recent move and change of jobs left me with some extra afternoon hours to fill. Call it a midlife crisis—I'm 46—but what to do?

My inner child urged me to rediscover my youthful athleticism, but my wife quickly steered me away from mountain bikes, snowboards, and other potentially lethal playthings. (I've written before about how it's important to know your limitations when you have CMT, but I sometimes need to be rescued from my own folly.)

Instead of in-line skates, I wound up buying pants with "A skootch more room in the rear" that would be comfortable on my daily walks. Midlife can be humbling, no question about it, and re-inflating my ego would require mastering something new.

Well, how about learning to type? As much as I write, being able to type faster would definitely be a plus. But could I? I'd been "typing" ever since college, where I produced my term papers on a Smith-Corona Classic 10. I didn't have any noticeable hand involvement then, but I still couldn't strike the keys hard enough with my pinkies, so I gave up and became a two-finger typist.

Electronic keyboards enabled me to use a few more fingers and pick up some speed, but I wasn't striking the right keys with the right fingers. And even if I could now use my pinkies, who had time to stop working and learn how to type? I could type as fast as I could think—ha, ha, very funny—and that was good enough for me. Besides, I was also noticing some hand involvement, and the fact that my fingers didn't always do what I commanded gave me a convenient excuse not to try and learn to touch-type.

While I am not above occasionally invoking my CMT in order to avoid distasteful and onerous tasks, was my CMT a legitimate excuse or was I malingering? I called Pat Dreibelbis at the CMTA, who said she knew of several people whose CMT didn't seem to affect their ability to type. Aha! Was that a challenge, or what? If they could do it, so could I. I said good-bye and started the typing software on my computer.

The first drills involved learning the "home keys"—ASDF for the left hand and JKL: for the right. Most keyboards have little ridges or raised dots on the "F" and "J" keys to make them easy to find. I couldn't feel them, though, so it took me a while to be able to return to the home row.

In the program I used, the letters to be typed scrolled across the bottom of the screen, and I was able to tell whether I was keeping up with the word-per-minute goal I had set by watching to see whether I stayed ahead of a little guy in a rowboat. At first, he easily rowed off the screen ahead of me, but I eventually managed to keep him in sight. (Okay, so I had it set at 10 wpm, but who's counting?)

Along the way, I had to deal with three problems. The first was unlearning my bad typing habits and learning to use the correct fingers. I made lots of mistakes and called the computer nasty names, and I'm still liable to goof if I don't concentrate.

The second problem was my wandering pinkies. I knew I could no longer make Spock's live-long-and-prosper sign, but now I've discovered that while my fore, index and ring fingers remain together, my pinkies wander off by themselves. To correct for their tendency to splay outward, I rotate my elbows out a little and curve my hand in. It works but it takes some getting used to. (By the way, did you know that the Qwerty keyboard was designed to place the most frequently used letters under the weakest fingers? In the era of manual typewriter, that slowed down typists and prevented keys from jamming, but what a cruel twist of fate it has turned out to be for CMT typists!)

Finally, there are yips, involuntary muscle twitches that produce unintended results. Just when I get cruising along, yip! A random letter appears. I haven't figured out how to control yips yet, but I'm thankful for spell-checkers and the ability to preview documents before printing.

I'm also glad I took up the challenge of learning to type. There are things I know my CMT prevents me from doing and that would be dangerous if I tried, but I also try not to use CMT as an excuse for avoiding things I actually can do if I make the effort.

You may not see me whizzing by on a snowboard any time soon, but *at leats I cqn tupe*. ★

## 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, 1D (EGR2), 1X, HNPP, 2E, 4E, and 4F 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*

Non-Profit Org.
U.S. Postage Paid
Glen Mills, PA
Permit No. 10

CMTA

**2700 Chestnut Parkway**
**Chester, PA 19013**
**1-800-606-CMTA FAX (610) 499-9267**
**www.charcot-marie-tooth.org**