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Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ✻ www.charcot-marie-tooth.org

CMTA

Charcot-Marie-Tooth Association

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.

Members Exceed Expectations in Support of Gasper Challenge!

The Charcot-Marie-Tooth Association is proud to announce that with some extremely generous gifts from our members, the Gasper Challenge of raising $100,000 for the research fund as a match to Gary's gift has been met and exceeded. On July 25, 2005, we had amassed a total of $123,580.

The gifts that helped meet and exceed the challenge were both small and large. Some people could only afford to give $10, but one generous stock gift was valued at $27,343. Most of the 378 gifts fell somewhere in between those extremes. It was, however, a group effort, and the whole membership can be proud of what they accomplished.

> In response to the challenge made by Board Member Gary Gasper, CMTA members contributed over $120,000 towards CMT research.

Since the original three research grants were announced in the last newsletter, the Board of Directors of the CMTA have decided to grant a one-year extension to Dr. Yan Huang, who is working in Dr. Steven Scherer's laboratory at the University of Pennsylvania on the pathogenesis of X-linked CMT. That grant represents another $35,000 commitment.

You have all justified Gary's original faith that our members would match his generous gift. This fundraising effort will allow the CMTA to continue its mission of increased funding and larger three-year grants for research into the causes and possible cures for CMT.

Thank you all. ✻

Congress Acts on CMT Research

June and July 2005 were great months for the CMTA in Washington, DC. Key Congressional committee reports not only mentioned CMT, but expressed strong support for CMT research.

The National Institutes of Health (NIH) funds a great deal of research throughout the country on CMT and other diseases, and in the months ahead, is planning a workshop on peripheral neuropathies. The CMTA was concerned that this workshop, a key NIH tool to advance medical research, might not focus intensively on CMT. Without a focus on CMT, one of the most common inherited neurological disorders, we might miss an important opportunity to advance efforts to find a treatment or cure for CMT.

We therefore asked our friends in the House of Representatives and the Senate to work with NIH to help us

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EMAIL CMTA AT:
CMTAssoc@aol.com

Open Your Address Book for the CMTA

BY SUSAN SCHUELER ELMER

Following a terrible health crisis that was touch and go at the beginning of the year, I got the feeling I was kept here for a purpose. I started thinking of community volunteer work and how I could do something that would help other people. As a former director of a non-profit for people with disabilities, a light bulb flashed in my head that said "fundraiser for CMT research."

I drafted a letter of appeal citing my recent CMT-related health problems (including respiratory and coronary damage) and discussing the need for financial support to fund CMT research. I started with my personal address book and then attacked my Christmas card list. I moved on to my high school graduating class mailing list that I had from two years ago when I organized our 35th reunion. Finally, I did a mailing to doctors, restaurants, and vendors whom I have dealt with for many years. I set a long-range goal for myself of raising $5,000 in three years.

Using her personal address book and holiday mailing list, Sue wrote about the need for financial support for CMT research.

Imagine if every person who gets the CMTA newsletter opened his or her address book for CMT research! What a windfall we would have the power to generate… All it took me was two rolls of stamps, a box of self-sealing envelopes, computer printer paper, and ink, all of which are charitable tax deductions (so save your receipts.)

Having a background in grassroots fundraising, I know people are more willing to respond with a donation if they have a personal connection to the person sending the appeal. Using your own return address label (that you probably get free all year long) will entice the person to open the letter and read your appeal. Often people get appeal letters in official envelopes and toss them out without even opening them. If you feel you can't generate a 200-piece mailing, remember that every little bit helps!

If you worry that you are begging or taking advantage of people, ask yourself this question: isn't CMT research a good cause?

IF YOU WORK FOR THE FEDERAL GOVERMENT... you can make a contribution to the Charcot-Marie-Tooth Association through the Combined Federal Campaign. Our designated number is CFC#2513. This number is only good for the federal campaign, so do not use this number if you are contributing through state government campaigns or through the United Way. Gifts to the CMTA have totaled almost $20,000 through the CFC for the past few years.

CONGRESS ACTS

(Continued from page 1)

ensure that the workshop concentrate substantially on CMT. With the help of Senators Arlen Specter (Pennsylvania) and Judd Gregg (New Hampshire) and Congressmen Eliot Engel (New York) and Curt Weldon (Pennsylvania), language was included in the Senate and House Labor, Health, and Human Services Committee reports.

The House report "encourages NIH to focus on CMT in this workshop, with a goal of producing outcomes which will be directly relevant to CMT research." The Senate report emphasized this point and urged that the workshop "lead to a relevant program announcement or request for applications on CMT." (Program announcements or requests for applications are ways the NIH promotes medical research.) The House also requested that NIH report back

I am 55 years old, married 27 years to a great guy by the name of Rich whom I met in 1973 at my first job after graduating from Adelphi University with a B.A. in English. I guess the highlights of my life include my involvement with advocacy for people with disabilities; earning a spot on the USA Disabled Sports Team, where I competed in the 1988 Paralympics in Seoul, Korea; and traveling with my husband to England, France, China, Japan, Hong Kong, Mexico, Bermuda, Canada, and most of the United States.

Although it was quite a few years ago, I spent one year serving on the CMTA's Board of Directors as Recording Secretary. My next goal for the organization is to use my training in peer counseling. I hope to start a CMT support group in Bergen County, New Jersey. Currently, the closest support group is at the Rusk Institute in Manhattan, which is too far for me to drive.

If you are interested in learning more about the fundraising letter, or the support group, you can contact me through Pat at the CMTA office. ✻

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to Congress on NIH research into CMT.

The CMTA also would like to recognize the good work of the Neuropathy Association, which encouraged NIH to conduct the peripheral neuropathy workshop and has worked to guide the workshop in positive directions. ✻

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

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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.

A Salute to Our Volunteers

BY PAT DREIBELBIS

While the summer months might seem to be a time to kick back and relax, our members are always more active in these months than any other. It's a great time to swim or play golf and it's always a good time to ask your friends and families to support something you really believe in. In this issue of *The CMTA Report*, we want to take some time to recognize the people who keep this organization alive and functional.

Not surprisingly, most of our members do their fundraising for the research fund, believing that research into possible cures for CMT is a way to help the future generations as well, perhaps, as themselves.


The O'Donnell family swam across the Chesapeake Bay to raise money for CMT research.

One of the outstanding research fundraising efforts of the early summer was the Great Chesapeake Bay one-mile swim. This year board member Steven O'Donnell was accompanied by his children, Jaime O'Donnell, 11, and her brother, Sean, 9, who competed in the 14 and under age group. They were part of a group of over 350 people who made the swim against some challenging currents. Fortunately, the weather cooperated and the water temperatures were in the mid-seventies, unlike the chilly water that Steve had practiced in with his children early in the week. Steve has been doing the longer 4.4 mile swim for three years, but this year, his children wanted to get into the act and raise money for CMT research, so they swam together in the one mile challenge. Amazingly, although this was the first time the children had swum in open water, Sean won the under 14 age group with a time of 44 minutes and 13 seconds, setting a record as the youngest winner to date for the One Mile Challenge, and Jaime finished seventh. As a family, the O'Donnells have raised $44,043 to date for this year's swim effort.

Another volunteer of note is former board member, Susan Schueler Elmer, who wrote a fundraising letter which she mailed to over 200 friends, relatives, and business associates. The results of her mailing have been coming in for the past few weeks, and she has raised over $965 as of this writing. Sue took on this project because she had experienced a health crisis earlier in the year and, with her new-found energy and enthusiasm, wanted to do something to benefit others. An article that Sue wrote to


Susan Schueler Elmer

encourage others to try her fundraising method is found on page 2 of this newsletter.

In California, Elizabeth Ouellette did something that required only her time and energy. She offered to check, one by one, every name on the California doctor referral list to confirm addresses, phone numbers, and faxes. Now, the list we send out for her state is up-to-date and accurate. The office staff has been working on that project for several weeks, but since we are on the East coast, the time difference had made checking all the California numbers (and there were quite a few) more difficult. Elizabeth was willing to help, and so she volunteered her time to help all CMT patients.


Elizabeth Ouellette


Robert Kleinman

Golf fundraisers have been going full-tilt for more than five years. This year, Robert Kleinman, board member, held his sixth golf tournament at The Creek on Long Island. His company AFA Security underwrites most of the expense of the outing, so the profits are always impressive. This year, unfortunately, his tournament was rained out after only two holes. The golfers will be able to complete the tournament on October 11, 2005. At the golf outing, the CMTA Board members and administration recognized another longtime volunteer, former Board Member Dick Sharpe, with a plaque. Although he was unable to attend, they thanked him for his years of service to the Board of Directors of the CMTA as both treasurer and chairman, and for his assistance in getting the Long Island golf tournament started six years ago.

Also, in July, CMTA Board President Patrick Torchia hosted his fifth annual golf tournament at the Sunnehanna Golf Club in Johnstown, PA. The event was held on Friday, July 22, 2005. CMTA Board members not only volunteer their time to administer and guide the organization, but they are also willing fundraisers and workers on behalf of CMT research.


Executive Director Charles Hagins, CMTA Board President Patrick Torchia, and golfers Robin Cole and Edward Wojnaroski helped make the sixth annual tournament a success.

"There's Nothing We Can Do"

BY DANA SCHWERTFEGER

"CMT is incurable and there's nothing we can do." That's absolutely the worst thing any person with CMT could hear, yet in one form or another, it's what one of every three CMT patients I've talked with has been told when first diagnosed.

It's what I was told, too, and coming from a neurologist, those words do hold a grain of truth. I returned to a neurologist five years after I was diagnosed, underwent another EMG, and learned that my nerve function had deteriorated since my first EMG. The prognosis? It would continue to worsen, and there was still nothing they could do.

By then, my toes had curled under to some degree, my arches were higher than before, and the muscles in my lower legs had atrophied to the point where my feet slapped down when I walked. A podiatrist did not recommend surgery to straighten my toes, however. In my case, he said, as long as I was not in pain, surgically straightening my toes would only serve vanity and do little for me as far as mobility was concerned.

An orthopedist also believed surgery was unnecessary. He said my foot was not terribly misshapen, and that bracing would correct my foot drop and allow me to walk fairly well.

My next stop was an orthotist, who made me the first of many pairs of AFOs. Initially, I didn't think the AFOs were such an improvement. They had no padding and the plastic cut into my ankles, creating blisters and calluses. To make them more comfortable, I bought shoes a size larger, put insoles inside the AFOs, and added some padding where they were cutting into my ankles.

> I credit my AFOs with helping me avoid many of the physical deformities that so often accompany CMT.

Now, when I have AFOs made, I have the orthotist flare the plastic out a bit at the ankle, leave a little extra room around my heels so they don't rub, and drill some ventilation holes. Those modifications are a great help, but I've still found it impossible to explain to someone else exactly what will be comfortable and I always wind up doing some fine tuning on my own. I add my own insoles, trim off some excess plastic, and add padding at contact points until wearing the AFOs causes no discomfort whatsoever.

In terms of mobility and personal freedom, I believe having comfortable AFOs has made the single greatest difference in my life. Unless I'm wearing shorts, most people are unaware I wear braces, and I can do just about any daily activity, from walking several miles to working around the house and yard.

I also credit my AFOs with helping me avoid many of the functional deficits and physical deformities that so often accompany CMT. I led an active life before I found out I had CMT, and my AFOs have allowed me to stay active—just in different ways. I no longer run or go spelunking on weekends, but I do walk, cycle, and work out with light weights several times a week.

Stretching has also been part of my routine for many years, though I did not fully appreciate the importance of it with regard to my CMT until several years ago, when I read about something called "contractures."

When I was first diagnosed, I had come across some clinical photographs of CMT patients—the really graphic ones that show claw hands, hammertoes, and pes cavus feet—but I had no idea that the conditions developed from muscular imbalances in the hands and feet. Now I understand that when CMT affects nerves and muscles, it is common for some groups of muscles to weaken while the opposing muscle groups remain strong. Those strong muscles continue to contract, but they are not reflexively stretched by the weakened group opposing them.

When this happens, the muscles and the tendons attaching them to bone lose their elasticity. The result is fingers, toes, and feet that are "locked" into position as if the muscles were contracted, hence the term "contractures." At this point, surgery is necessary to release the contractures and reposition the affected areas.

Even though weakened muscles can no longer contract and stretch the opposing muscles, the stronger muscles can still be relaxed through "passive" or "static-passive" stretching, a type of stretching that uses external force to stretch a relaxed muscle (*see page 11*).

Many people "loosen up" for activity and exercise with passive stretching or use it afterward to relax tight muscles. Done regularly, passive stretching can help conserve the elasticity of unopposed muscles and tendons and maintain flexibility and range of motion, and the activity and exercise are beneficial in their own right, as long as you don't overdo it.

In my case, I believe the combination of bracing, activity, and stretching helped me avoid some of the more serious complications of CMT. I did not have the good fortune to begin managing my CMT with the guidance of a physiatrist (a physician trained in physical medicine and rehabilitation), a physical therapist, and an occupational therapist, but I was lucky to do many of the right things on my own.

What someone with CMT should hear is that there is "something we can do." Treating and managing CMT, especially in the early stages, is extremely important. With conservative management of CMT ("conservative" in this case meaning "to conserve"), many of the functional deficits and deformities typical of CMT may be delayed, minimized, or even prevented.

Much of that management will be up to you, however, once you consult with the appropriate health professionals. My experience aside, you should never begin an exercise program without the advice of a physician, and you should be doubly careful of starting a stretching routine on your own. As beneficial as stretching and exercise can be, they can also be harmful if done improperly. If possible, have a physical therapist evaluate your level of ability, demonstrate proper stretching, and suggest appropriate exercises. And then, just do it! ✻

KIDS COMMENT

Having CMT

BY KEENON FORD

Hello. My name is Keenon Ford Werling. I am, for the most part, a normal, fifth-grade boy. I live in Minneapolis, Minnesota, and have a pair of unbelievably great parents, go to an excellent school, and enjoy a good life. Of course, although touching, that is not the reason I am writing an article for The CMTA Report. I am writing this because I have CMT. CMT (I'm sure you all know this by now, but I'll say it anyway for the record) is a neurological disorder that destroys the peripheral nerves.

I don't find CMT that hampering to my life in general. Yeah, I have to put on my AFOs in the morning in order to be able to walk, but that isn't a big problem. I am an introvert by nature, so I don't ever feel inclined to go and run around or play football unless there is nothing else to do (at such times I can play reasonably well but am usually chosen for my strategies, not my running). For this reason I have developed skills that I don't think I would have developed normally (if I hadn't had CMT, that is), but you never know. Some of the skills I have developed include writing, drawing, 3D animation, chess, and acting.

For me CMT is something of a blessing, and at the same time a minor physical obstacle. ✻

ASK THE DOCTOR

Dear Doctor:
I have CMT and recently have been undergoing treatment for breast cancer. After finishing four treatments of Adriamycin, my legs became so weak that I was unable to walk. A nerve conduction study showed no detectable nerves in my lower legs. The neurologist thinks that the Adriamycin worsened the neuropathy that I already had. The oncologist said he had never seen any documented case of this happening. I would appreciate any answers that you could give me.

The doctor replies:
Adriamycin is an agent reported to occasionally cause neuropathy in general, but not with the frequency or severity of some other chemotherapy drugs such as vincristine, cisplatin, suramin, and Taxol. A recent in-depth literature review found no cases going back to 1963 that described an example, positive or negative, of Adriamycin on a CMT patient. The agent was placed on the CMTA drug list based on the experience of other types of patients receiving the drug as part of their chemotherapy. In addition, most of the literature on other medications is based on patients with CMT1A (the most common demyelinating form). We know very little about special risks for patients with less common forms of the disorder.

Dear Doctor,
The physicians in my area don't seem to be very familiar with CMT. I am concerned that the deformities of my feet are just getting worse and that eventually I won't be able to walk. What surgeries are typically done to fix the foot deformities common in CMT?

An orthopaedic surgeon replies:
There are many surgical procedures available for people with CMT, but one that is quite effective is reconstruction of the foot and ankle. Options include the straightening of hammered toes, the repositioning of an inturned heel, and the lowering of the arch. The end result is a foot that is stable and able to stand flat on the ground. As well, tendon transfers on the lateral side of the foot and ankle can provide increased strength and a more normal gait.

You don't say whether you wear orthotic devices (ankle-foot orthoses) to help with stability and balance, but that is always the first option that should be considered before surgery is undertaken.

Dear Doctor,
It was mentioned in the news that people on air flights, particularly long ones, should wear support stockings or socks. Is this advice good for people with CMT? Are there any reasons not to wear these stockings when flying?

The doctor replies:
Unless the person has HNPP, which is typically caused by a deletion of PMP22, then wearing compression stockings should not be a problem. The nerves are not more sensitive to compression for most kinds of CMT.

Dear Doctor,
I have been taking Reglan for intestinal problems while in the hospital. I believe it has caused a serious balance problem for me, and I wonder if it should be on the CMTA drug list. I also take heavy doses of Lomotil for ulcerative colitis.

The doctor replies:
There is no known or reported link between neuropathy worsening with use of either Lomotil or metoclopramide (Reglan), but I am keeping a list of reports in case there are other reports that suggest a pattern. Reglan is associated with other neurological side effects, most commonly types of movement disorders, which are usually recognizable by treating physicians. Some forms affect muscle tone (dystonia), which can disrupt balance, especially if it is abnormal at the outset. It is difficult to sort out which effect is at work in this instance.

Dear Doctor,
I am bi-polar and take 1800 mg of Eskalith (lithium) a day. I was diagnosed with CMT in 1999 and since then I have developed a problem with severe shaking, as if I were really cold. I would appreciate any information you could give me about this.

The doctor replies:
Tremor is one of the more common side effects of lithium.

I would theorize that CMT would enhance this effect, but I am not aware of any association between the two. The tremor is not a permanent effect or a sign of your neuropathy worsening, but you should discuss the problem with your psychiatrist to confirm this suspicion and weigh your options.

Dear Doctor,

A close relative of mine who was found to have CMT, took Lamisil pills for the treatment of a fungus infection on his toes. After three weeks, he got a strange rash and was unable to move his arms and legs. He immediately stopped taking the pills, but after a week, he is still paralyzed.

Have you had any similar problems with this drug and CMT patients? Will his paralysis be reversible? Can we assume that this drug worsened his CMT?

I live in Israel and the doctors' knowledge of CMT is limited.

The doctor replies:

There are no known reports of terbinafine (Lamisil) causing peripheral neuropathy or worsening CMT-related weakness. I performed a brief literature review and checked the manufacturer's information to confirm this fact. A recent review of the North American CMT database uncovered no cases of terbinafine complications, but no patient may have reported using the medication. Rash, however, is a potential complication of any medication. It may be worthwhile to have your physician report this possible complication to Novartis (the manufacturer) to see if they have collected other cases that have not been made public.

Dear Doctor,

You have statins listed on your general drug list, and you have several specific statins listed on your expanded drug table, but rosuvastatin (Crestor) is not listed. Should it also be on the list or is it not known to have any adverse effects?

The doctor replies:

There is no evidence that one statin is any better or worse as a risk factor for neuropathy, so Crestor is part of the group even without a clearly reported case. However, the effect with all of the statins is rare and we are not advising patients to avoid statins, only to be be aware of the association. Statins are clearly superior to the older treatments for hyperlipidemia (elevated cholesterol levels), so each treating physician needs to weigh the clear benefits of the drugs against this small risk in CMT patients. ✻

Do You Have Restless Leg Syndrome?

Restless leg syndrome (RLS) is an overwhelming urge to move the legs constantly, usually in response to uncomfortable or unpleasant sensations in the legs. The sensations usually occur during periods of inactivity, become more sensitive in the evening and at night, are relieved by movement of the limb, and may cause involuntary jerking of the limbs during sleep and sometimes, wakefulness.

Up to 8% of the population may have this neurologic condition. RLS affects people of all ages. Many adults can trace their first symptoms back to childhood, when they were told they had growing pains. Evidence connecting RSL and attention-deficit hyperactivity disorder is growing.

The use of caffeine intensifies RLS symptoms. The consumption of alcohol can also increase the span or intensity of symptoms in most individuals. Just recently, a drug was brought to market to treat restless legs. The drug is ropinirole (Requip). Self-directed activities that can also help control the problem are effective, although temporary, solutions. Walking, stretching, taking a hot or cold bath, massaging the affected limb, using vibration, or applying hot or cold packs may help. When traveling and being forced to stay seated, you may find that reading, performing needlework, or playing video games will help distract you.

If you have CMT and believe you may also suffer from Restless leg syndrome, you should contact the Restless Leg Syndrome Foundation at www.rls.org. They have a great deal of information, including a list of drugs to avoid and suggestions about vitamin or mineral supplements to control the problem. ✻

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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.

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Send acknowledgment to:
Name:__________________________
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Occasion (if desired):
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In memory of (name of deceased)
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Send acknowledgment to:
Name:__________________________
Address:________________________
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Amount Enclosed: ____________________
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Card #____________________________
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Stretching and CMT: Some Basics

The majority of stretching exercises target the body's larger muscles in the shoulders, arms, trunk, hips, buttocks, and legs, but people with CMT must also stretch the smaller muscles in the hands, fingers, feet, and toes.

For the beginner, the terminology associated with stretching can be a bit baffling. Google the word *stretching* and you'll find references to *ballistic*, *dynamic*, *static*, *active*, *passive*, *isometric*, and even *PNF* or *proprioceptive neuromuscular facilitation.*

Ballistic stretching—using the body's momentum to extend beyond the normal range of motion, as when you try to touch your toes by repeatedly bouncing lower and lower—is dangerous and should never be attempted.

Dynamic stretching—using arm and leg swings to gradually reach the limit of range of motion—is much safer. It's good for loosening up before activity or exercise, but it doesn't focus on muscle groups affected by CMT.

As for *isometric* and *PNF* stretching, don't try these at home. They're primarily for serious athletes who are in very good condition.

That leaves *static* stretching, which can be either active or passive. Static-active stretching relaxes one muscle (the agonist) by contracting the opposing muscle (the antagonist), but this requires both muscles to be fully functional and won't be doable for most people with CMT.

Static-passive stretching, on the other hand, uses some type of external force—another muscle group, your body's own weight, a chair, a wall, or some other apparatus—to supply the resistance needed to relax the muscle. One of the most common passive stretches, and one of the most important for someone with CMT, is the calf stretch illustrated here. Figure 1 shows a stretch of the gastrocnemius (right leg), and Figure 2 shows a stretch of the soleus (also right leg). These simple stretches can help prevent tightening of the heel cord (Achille's tendon).

Figure 1:
GASTROCNEMIUS STRETCH—keeping right leg straight, lean forward into wall until you feel a slight pull at the top of your calf.

Figure 2:
SOLEUS STRETCH—bend right leg and lean forward until you feel a slight pull just above your ankle.

Another useful stretch for the heel cord involves standing with the ball of the foot on a step and the heel over the edge and gradually increasing the amount of body weight on the foot. (AFOs limit your range of motion, by the way, so take them off before stretching.)

Toes can be stretched by sitting on the floor, bending one knee up, grasping your toes and gently pulling them upward. A simple finger stretch involves placing the hands palm-to-palm (as if in prayer) and pushing first one way with the fingertips and then the other. You can also place just your fingertips on a table or desk and push gently downward.

Before stretching, you should always warm up for a few minutes by engaging in low-to-moderate activity. Then, when you do passive stretches, the goal is to extend the relaxed muscle until you feel a mild pulling sensation, never pain, and hold that position for 10 to 30 seconds, repeating 3 to 5 times and gradually increasing the range of motion each time *as long as you feel only mild discomfort.*

You must be very cautious, however. Even for people with normal neurologic function, stretching must be done with care to avoid injury, but extra precautions apply for someone with impaired sensory feedback. If you cannot feel the pulling sensation or pain, it is extremely unwise to stretch without the assistance of a trained health professional. It is also unwise to begin stretching without having a physical therapist evaluate you and demonstrate proper technique. ✻

SUPPORT GROUP NEWS

New Jersey—Bergen County

Former Board member, Susan Schueler Elmer is interested in restarting the support group that once functioned in Northern New Jersey. If you are in that area and would like to join such a group, call or email the CMTA's office and give us your name and a contact number. We will forward the information to Sue and then she will contact people regarding an inaugural meeting.

New York—Westchester/ Fairfield County, CT

The support group held its annual spring brunch to say goodbye for the summer. Meetings will resume on Saturday, September 17, 2005.

Michael K. Geake discussed the value of PrePaid Legal Services with today's rising legal costs.

Michael K. Geake gave a presentation on PrePaid Legal Services, Inc. He was able to explain how the need for an attorney has grown and most people cannot afford one. PrePaid Legal Services are especially useful for enforcing rights under the Americans with Disabilities Act.

Jennifer Taylor, a long-time friend of the group, attended and announced that she has been promoted to District Director of the Westchester MDA office. Former support group leader, Diane Kosik, and her husband attended from Prescott, AZ.

The group participated in the MDA's Spring Stride and Ride events at the Palisades Center Mall and raised funds for their causes. ✻

(Editor's note: The New York item should have appeared in the May/June newsletter, but was inadvertently overlooked.)

Opportunities for Adaptive Sports Activities

The Adaptive Sports Association (ASA) provides fun outdoor sport and recreational activities for people with disabilities. Their activities are provided regardless of financial limitations and their goal is to create an atmosphere for learning and enhancing self-esteem.

The ASA is a volunteer-based nonprofit based in Durango, Colorado. It was founded as a winter ski program in 1983 by a man who had lost a leg to cancer, but had taught himself to ski on one leg.

Now, 20 years later, the winter program offers lessons for adults as well as children with every type of disability. With adaptive equipment to suit every level of disability and a core of exceptional instructors, this program enables students to find an appropriate and safe way to slide down the hills. Two-track, three-track, four-track, mono-ski, bi-ski, dual-ski, and snowboarding, and ski biking are all taught at the center's mountain headquarters.

Their summer program is now in its eighth season of fun in the sun. The main draw for the summer is whitewater rafting on the Animas River, which runs through downtown Durango. In addition to rafting, the summer program includes canoeing and kayaking on area lakes and fishing in a flatwater section of the Animas river.

ASA strongly encourages family involvement in their activities. For more information about ASA's programs, go to www.asadurango.org or contact the program at 970-259-0374 (summer program) or 970-385-2163 (winter program). You can also email them at asa@frontier.net ✻

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
Email: charnicoma57@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
Email: pcmobley@mac.com

Colorado—Denver Area
Place: Glory of God Lutheran Church Wheat Ridge
Meeting: Quarterly
Contact: Marilyn Munn Strand, 303-403-8318
Email: mmstrand@aol.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital, St. Petersburg, FL
Meeting: Quarterly, 2nd Saturday, 10:30 AM
Contact: Lori Rath, 727-784-7455
Email: rathouse1@msn.com

Kentucky/Southern Indiana/ Southern Ohio
Place: Lexington Public Library, Northside Branch
Meeting: Quarterly
Contact: Martha Hall, 502-695-3338
Email: marteye@mis.net

Minnesota—Benson
Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156
Email: rrmills@fedtel.net

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

Mississippi/Louisiana
Place: Baptist Healthplex, 102 Clinton Parkway, Clinton, MS
Meeting: Quarterly
Contact: Flora Jones, 601-825-2258
Email: flojo4@aol.com

Missouri—St. Louis Area
Place: Saint Louis University Hospital
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664
Email: c.haislip@att.net

New York—Greater New York
Place: NYU Medical Center/ Rusk Institute, 400 E. 34th St.
Meeting: Third Saturday of every other month, 1-3 PM
Contact: Dr. David Younger, 212-535-4314, Fax 212-535-6392
Website: www.cmtnyc.org
Email: bwine@acm.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: Bimonthly, Jan, March, May, Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 845-783-2815
Eileen Spell, 201-447-2183
Email: cranomat@frontiernet.net
espell@optonline.net

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: Wills Restaurant
405 Wagner Ave, Greenville
Meeting: Fourth Thursday, April–October
Contact: Dot Cain, 937-548-3963
Email: Greenville-Ohio-CMT@woh.rr.com

Ohio—NW Ohio
Place: Medical College of Ohio
Meeting: Quarterly
Contact: Jay Budde, 419-445-2123 (evenings)
Email: jbudde@fm-bank.com

Oregon/Pacific NW
Place: Portland, Legacy Good Sam Hospital or Brooks, Assembly of God Church
Meeting: Quarterly
Contact: Darlene Weston, 503-245-8444
Email: blzerbabe@aol.com

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience Center
Meeting: Bimonthly
Contact: J. D. Griffith, 814-539-2341
Jeana Sweeney, 814-262-8467
Email: jdgriffith@atlanticbb.net, cjsweeney@ussco.net

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

Pennsylvania—Philadelphia Area
Place: Penn Towers Hotel Conference Room
Meeting: Bimonthly
Contact: Amanda Young, 732-977-9983
Email: astarryoung@yahoo.com

Pennsylvania—State College
Place: Centre County Senior Center
Meeting: Monthly
Contact: Rosalie Bryant
Email: rab296@psu.edu

LETTERS

This letter was sent to the Wayne State Clinic and Dr. Michael Shy:

"Andrew and I want to express our appreciation to you and your staff. Andrew was recently diagnosed with CMT, and we were not sure where to start or turn for the best help. The CMTA and our own research pointed us in your direction. We do not believe we could have found any better place than your organization. All of your staff were competent, professional, helpful, and very kind to us.

We very much appreciate the time you took with us and the fact that you informed us each step of the way during your thorough examination and testing. The doctors we met with at the end of the day at the Rehab Center and the insight they provided were also of great value.

We are very grateful for all you are doing to help people with CMT."

—*AB and MB, VA*

Dear CMTA,

I read the article written by E.M. in the Nov/Dec *CMTA Report*, regarding Mitch Warner of Ortho Rehab Designs in Las Vegas, NV. I also obtained a copy of an article that had been written by him in 2002.

I am 69 years old and live in Palm Springs, CA, during the winter. I have many of the same symptoms described by E.M. My calf muscles are deteriorating. I cannot stand without holding on to something and my legs get very tired after use.

I have an identical twin brother who lives in Oklahoma City. The two of us went to see Mitch in February of 2005. We were impressed with him and were convinced he could help us. However, the price tag was $10,000 per person and Medicare would reimburse approximately half of that.

We each decided to check in our home areas to see if there were similar orthotics at lesser prices.

I contacted Desert Prosthetics in Cathedral City, CA. They agreed to work with me until the orthotics helped me. What they made looks similar to Mitch's, but mine are hinged at

WRITE TO US!

Pat Dreibelbis, Editor
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Chester, PA 19013
or
CMTAssoc@aol.com

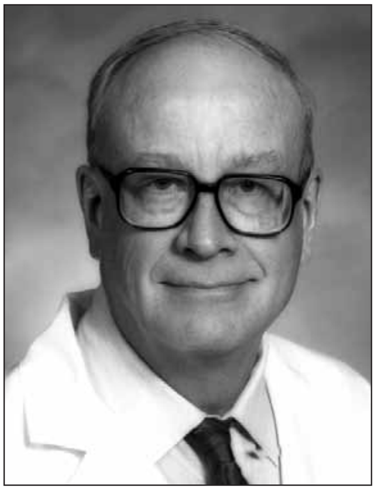
The CMTA reserves the right to edit letters for space.

In Memory of Jack Hougen Petajan, MD, PhD

Dr. Petajan was a valuable and vibrant member of our Medical Advisory Board for over 15 years and will be very much missed. After two years of a debilitating illness, he passed away in Salt Lake City on June 22nd at the age of 75 years. He was honored at a Festscrift Symposium in his department just over two years ago, with colleagues and trainees attending from all over the country to praise him. The proceedings will be published shortly in the *Journal of Neurological Sciences.*

Dr. Petajan's professional life was dedicated to his patients, neurological diseases, and research. He was a wonderful teacher and mentor. Truly he was a renaissance man, with many other interests including music, travel and the outdoors. He began with basic science in physiology and zoology. He fathered two families, and his four children do him credit. All the time he remained not only very concerned about the cares and tribulations of his extended family, but he also offered his love and his attention to his fellows and many friends.

Our close personal and professional friendship began 33 years ago when we joined the laboratories of Dr. Edward Lambert as post-doctoral fellows at the Mayo Clinic. Dr. Lambert was not only one of the modern 'fathers of Charcot-Marie-Tooth Disorders,' co-authoring significant publications with Dr. Peter Dyck in the 1960s, but he was an also inspiration in furthering our understanding of neuropathy.



Jack Hougen Petajan, MD, PhD

Dr. Petajan attended most of our Medical Advisory Board meetings and was an incredibly productive member of the Felthe ankle. Mine are a clear plastic and go under the bottom of the foot and up to just below the knee. My brother had custom-fit orthotics made for him in Oklahoma that are similar.

I am very pleased. My legs do not get as tired and I can maneuver better. My balance has improved greatly. The cost for my orthotics was $1,738. Medicare paid $1,302 and my supplemental payed $325. My brother's cost a little more.

CMTA members and the association should conduct research to determine the effectiveness of various orthotics and what they might cost. It is possible to find something less expensive and just as functional with a little effort.

—B.B. CA

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lowship Selection Committee of the CMTA; he could always be counted on to make a detailed evaluation of each candidate. He also chaired the committee working on the physicians' manual revision, a task he worked on diligently until the last moment. In fact, it was because of his early interest in the toxic neuropathies in the 1970s and 1980s that he began the MAB's interest in the effect toxins could have on the natural progression of CMT. This resulted in the creation of the neurotoxic drug committee now chaired by Dr. Weimer.

His passing has created a great absence in my life, but I have lasting memories; he was a dear friend and always a willing right-hand man.

—Robert E. Lovelace,
MAB Chairman Emeritus

What is a Physiatrist?

A physiatrist is a doctor who treats medical conditions that can cause pain or limit function. Also called physical medicine and rehabilitation (PM&R) physicians, physiatrists provide a full spectrum of care—from diagnosis to treatment and rehabilitation—to restore maximum health and quality of life.

SOME CONDITIONS PHYSIATRISTS TREAT:

- Arthritis
- Back and/or neck pain
- Brain injury
- Carpal tunnel syndrome
- Cerebral palsy
- Chronic pain
- CMT
- Multiple sclerosis
- Spinal cord injury
- Sports injury
- Stroke rehabilitation
- Workplace injury

Physiatrists see patients of all ages experiencing a wide range of problems—from sore shoulders to muscle weakness—that may make it difficult to function at home, in the workplace or during recreational activities. Successful treatment of these symptoms requires accurate diagnosis. As specialists, physiatrists use techniques ranging from detailed medical histories to nerve conduction studies to diagnose a multitude of medical conditions.

Physiatrists treat people, not just symptoms. By evaluating the impact of a condition on the whole person—medically, socially, emotionally, and vocationally—physiatrists help their patients understand and take control of their health.

Physiatrists listen to their patients and work with them to develop a customized course of treatment. This may include one or several nonsurgical treatments, such as:

- Medications
- Therapeutic exercise
- Injections
- Assistive devices, such as braces or artificial limbs
- Heat and cold therapy
- Massage
- Biofeedback and electrotherapies

If surgery is necessary, physiatrists work with patients and their surgeons beforehand and coordinate their care afterward. Physiatrists help patients achieve a successful recovery by working with other physicians, such as neurologists and orthopaedic surgeons, and health professionals, including physical and occupational therapists, speech pathologists, and psychologists.

Physiatrists treat conditions of the bones, muscles, joints, brain, and nervous system, which can affect other systems of the body and limit a person's ability to function. Their goal in treatment is to restore the maximum possible function to their patients. ✻

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

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Leflunomide
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Mefloquine
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in U.S.)
a-Interferon

Negligible or doubtful risk:
Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

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).
- does not affect life expectancy.
- 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).
- 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, 1C, 1D (EGR2), 1X, HNPP, 2A, 2E, 4E, and 4F can now be diagnosed by a blood test.
- is the focus of significant genetic research, bringing us closer to solving the CMT enigma.

THE CMTA *Report*

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