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THE CMTA Report

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

Hershey Conference Funded by the PA Awareness Grant

On May 24, 2006, the CMTA hosted a patient/family conference at the Penn State Milton S. Hershey Medical Center. The conference was made possible by a $250,000 grant from the state of Pennsylvania as part of a comprehensive awareness campaign throughout the state. Over seventy-five individuals registered for the conference and several "walk-in" attendees arrived after hearing radio announcements about the conference.

A "full house" of patients and family members listened attentively to Dr. Milind Kothari.

After introductions and greetings from Charles Hagins, Executive Director of the CMTA, the audience heard from Dr. Milind Kothari, neurologist at the Hershey Medical Center. His talk was entitled, "CMT Care Overview" and he discussed some of the frequently asked questions, such as "Do I need to have EMGs or NCVs over and over again?" His response was that in type I, NCVs and EMGs do not change significantly over time. So repeated testing is not actually necessary. He also spoke about how they are finding more and more instances of hip disease in CMT brought on by the lower leg muscle weakness and abnormal gait. One of his other insights concerned phrenic nerve involvement, which can cause a lack of oxygenation. He concluded that much of the fatigue in CMT patients can come from poor oxygenation.

> "Find a health care provider who really listens to you!"

The second presenter, Chris Lawall, certified orthotist and prosthetist, discussed the various options in bracing for CMT patients. He stressed that a good relationship between the patient's physical therapist and orthotist can make all the difference in a good therapeutic outcome for CMT. In the best scenario, the PT would make recommendations about the best possible brace and the orthotist would work with the patient to formulate a brace that works well, fits comfortably, and will increase the patient's endurance and performance when performing daily tasks.

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INSIDE:

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.

EMAIL CMTA AT:
CMTAssoc@aol.com

HERSHEY CONFERENCE
(Continued from page 1)

After the morning break, Dr. William DeMayo, Director of the John P. Murtha Neuroscience Clinic and Pain Institute, Johnstown, PA, discussed the multidisciplinary approach to treating patients that is used at the CMT Clinic in Johnstown. The clinic has seen 55 CMT patients since opening in August of 2004 and sees approximately 2.5 new patients each month. The researchers in Johnstown are working on grants to study coenzyme Q-10, heel cord stretching to improve range of motion and weight bearing, and the first CMT patient census in two counties in Pennsylvania as part of the Pennsylvania Statewide Awareness Campaign. One of Dr. DeMayo's interesting insights was that "more important than finding a CMT expert, it is important to find a health care provider who really listens to you."

After lunch, an Athena Diagnostics sales representative, Lynnore Seaton, spoke about genetic testing and answered questions about the process from the audience. Because Medicare now fully covers the DNA testing, it might make sense in many families to have the older patient go through the testing procedure rather than the grandchild, who might have to pay the portion of the testing bill not covered by their insurance.

Dr. Steven Scherer, from the University of Pennyslvania and a member of the CMTA's Medical Advisory Board, spoke about CMT and the research possibilities for the future. He began his presentation by saying that no one can understand the research potential without first understanding, at least superficially, the

News from the Wayne State CMT Clinic

CLINICAL TRIALS FOR CMT1A

Progress has been made in the clinical trial for patients with CMT1A. Researchers in France have found that high levels of ascorbic acid (vitamin C) given to mice seemed to actually improve their condition. The study has been designed and funding has been requested. The trial will operate out of three centers: Wayne State University, Johns Hopkins University, and the University of Rochester, New York. Hopefully, the trial will start by the end of 2006. It is important to stress that there is no evidence that vitamin C helps people who have CMT, and the best way to determine if this is the case is to conduct careful clinical trials. High levels of vitamin C can cause side effects, such as kidney stones, that will require careful monitoring. Therefore, we are not recommending that patients take doses of vitamin C greater than a daily multivitamin. Patients enrolled in the study will have to make 6 to 7 visits over the course of two years to a center to be followed in the study.

LESS INVASIVE METHOD TO LOOK AT NERVE DAMAGE

The doctors at the clinic recently developed a method to look at nerves using skin biopsies, instead of the previously used more-invasive nerve biopsy. The skin has tiny nerves that run through it, and we can better understand how the nerves are affected in CMT by looking at these tiny nerves. This procedure involves taking 2 to 4 tiny pieces of skin (less than the size of a pencil eraser), usually from the fingers. It is done under local anesthetic so it is usually not painful. The information that has been collected allowed the doctors to publish a paper in the journal *Brain.*

NEW GENETIC CAUSE OF CMT FOUND

A new genetic cause for CMT has been discovered. The Wayne State clinic group in collaboration with other labs described CMT6, which is caused by mutations in the same gene that causes CMT2A. In the February edition of *Nature Genetics*, mutations in the YARS gene are described to cause a dominant intermediate form of CMT. There are now more than 33 known genetic causes of CMT, and research continues to discover more.

basics of CMT disease. To that end, he introduced the audience to the idea of axons and myelin by using the Oreo cookie analogy. (The inside is the axon and compares to the icing in a cookie; the myelin is the cookie edge surrounding the icing.)

The research possibilities he alluded to after some basic science instruction included the ascorbic acid trial slated to begin in the US as soon as full funding is provided, the progesterone antagonists, which have shown success in type 1A (but which are not tolerated well by humans), and the potassium channel blockers, which he has been studying at the University of Pennsylvania.

The final presenter of the day was Dr. Paul Juliano, an orthopaedic surgeon from the Hershey Medical Center. He discussed the various operative options to improve stance and gait. In some cases, surgery might involve straightening and pinning toes, lengthening heel cords, or lowering arches. He did say that there is always a right time for surgery and a wrong time, and only the patient, in discussion with his surgeon, can make that decision. Many patients never need surgery because they have had proper interventions along the way, such as bracing and exercise therapy.

Originally, it had been planned that the conference attendees would travel by bus to the Capitol to have a rally and to thank the legislators who had been instrumental in getting the $250,000 grant for the association. Unfortunately, the legislature was not in session, so as a gesture of appreciation, 65 of the attendees signed a letter of thanks to be sent on to the secretary of health stating that the conference in Hershey was a wonderful start to the need for patient and physician education about CMT. ✻

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My "quiet monsters"

Life with Charcot-Marie-Tooth disease

BY LENKA VODICKA

EDITOR'S NOTE:
This article appeared in *The Union*, serving Western Nevada County, CA. It is reprinted with permission of the author.

I know quiet monsters. I meet them in small white-light rooms with faded forest prints beside posters of spinal columns. I am introduced with remarkable calm. The names could be called pretty: Scoliosis, Arthritis, Charcot-Marie-Tooth.

The doctors walk away and I am left holding the hands of these quiet monsters. I will know them. I will become their world, as they become mine.

I was born in their embrace. I walked late, had high insteps, grew up under a cloud of constant weakness and clumsy falls. I marveled at the simple ease of others pulling ahead on trails.

Why didn't my feet land where my eyes told them? I walked on my toes, couldn't walk on my heels, and avoided active sports.

When I was 12, a routine school screening for scoliosis, curvature of the spine, alerted my parents that I should be checked. The doctor held my feet, my Barbie-doll feet with high arches, and he shrugged. The X-rays showed a snaking curve in my spine.

He sent me to specialists at UC Davis. They took one look at my feet and called in more specialists for more opinions. The doctors told my parents that I had a nerve disorder called Charcot-Marie-Tooth. Specialists wanted to involve me in studies, take nerve biopsies to confirm my diagnosis. I was told: CMT is incurable and degenerative.

An entire new world opened before me, with choppy grey waters and cold abysmal depths. I knew one thing…here be monsters.

Symptoms vary intensely among individuals. Thus, it is impossible to predict the progression of the disease. Some people live their entire lives without ever suspecting anything beyond clumsiness. Other people live normal lives and then develop symptoms in adulthood. Some people have multiple surgeries before they are 15.

I considered my symptoms mild.

For the next 17 years, I looked the other way. I earned a teaching credential and taught second grade. I figured I would write in my downtime, though my unending exhaustion meant few stories were ever completed. I married. I visited neurologists about every five years to hear again that I had decreased sensation in my legs, weak muscles, etc.

My children would have a 50/50 chance of inheriting the disorder. Was that a reasonable risk? Would I have wanted never to have been born? Everyone has challenges of one kind of another. What would life be like with a child who might not be able to participate in physical activities?

Perfection is an ideal. We could offer unconditional love, safety and support. The doctors said why I should not have children.

When I was 30 years old, I held my baby daughter Anika. Her bright eyes and clenched fists rubbed into my deepest chasms. From the very beginning, she was strong. She sat up, crawled, and walked along with her friends.

I felt firm earth underfoot again. The path wound before me, with thorns and sunshine, but still a predictable, understood journey. I had everything under control.

I dreamed that if I didn't believe in monsters, they wouldn't believe in me. They would look in my eyes, and if I looked back unseeing, if I refused to call them real, they could not touch me. They were nothing more than ghosts in the mists. I could see right through them.

I was wrong.

I don't remember the first day of pain. The pain gathered, as a wave offshore, moving from occasional annoyance towards a constant undercurrent. By May of 2005, I grimaced every day. Friends insisted that I go to a doctor.

My feet felt as though I had dropped dictionaries on them 10 minutes before. One morning, I was overcome with sore feet. I waited for the doctor's appointment.

Meanwhile, I created treasures. I knitted baby blankets in maroon and indigo yarns. I painted delicate faces on beads for fairy-dolls, crocheting wild hair with aqua eyelash yarn. I gave them away, almost all of them, the blankets, fairies, dolls, inspirations. They seemed endless, a streak of continuing projects that led one into the other over and over again. I had no idea what treasures they were—my creative evenings.

Also in May, 2005, my left pinky finger went numb. At first it annoyed me. I waited for days without change. The sense of fingers being asleep settled in for a long stay. I made appointments with a neurologist who leafed through old files. "So, Charcot-Marie-Tooth," he said. "I don't see that very often."

Soon after, I picked up paperwork qualifying me for a lifetime disabled parking permit due to the deformities caused by CMT.

Was that the official moment? Was I disabled? Was I "rising above my circumstances" or "overcoming daily obstacles" or the hundreds of other catch phrases that attach to the disabled experience?

In late July, I walked into a certified hand therapist's office. My finger had remained persistently numb for the past two months. She held my hand between her own, had me close my eyes while she poked my skin with what looked like stiff fishing wire.

"Tell me when you feel something."

I knew she must be touching me. I felt nothing.

She tested my grip strength. My left and right hand could squeeze 34 and 36 pounds. The chart lists 38 pounds for someone your age," she said.

"So, that's good," I said. "I'm close."

"No, you don't understand. The bottom of the chart is 38 pounds. You're off the chart. You have a compressed ulner nerve. You must rest your hands. Limit activities to a few minutes a day. That's everything…knitting, sewing, anything needing a grip."


Lenka and her daughter Anika

The liberation no longer sounded appealing. I sat on the couch in my imposed rest and struggled with the sense of panicked doom rising up out of the stillness. I had known, in high school, how I might need a wheelchair, how I could have physical limitations. But I never thought about that in reality. I knew my feet were troubled, but I trusted my hands. The therapist showed how muscles were atrophying around my thumb. My joints could all be hyperextended, meaning that what I thought was flexibility was actually weakness, where muscles did not have the ridigity necessary to protect the ligaments. I had to pay attention.

By early August, I knew a small peace. I finished the last of my physical therapy appointments for my feet. I walked around the county fair all day without trouble. I had feeling in my fingers again. I joined a health club so I could swim regulary. Renewed optimism replaced the dread.

Then school started.

Within two days, the pain returned. The numbness flared up. After working to get the class ready, I collapsed into underwater naps, feeling like a stone falling into deep water, rising up disoriented, unaware of the day of the week.

In mid-October, I visited my hand therapist for the last of the insurance approved visits. She registered improved sensation. "You need to think long and hard about your future,"she said. "You need to stop focusing on surviving day to day. Instead, make of list of what you would like to do in 10 years. Do you want to ride bikes with your daughter? Because you need to make careful choices. Your energy

(continued on page 7)

CMT in the News

PAUL DONOHUE

Dr. Donohue, who writes a medical question and answer column that appears in syndicated newspapers across the country, answered a woman's question regarding her son's diagnosis of CMT in late April. He was adopted and so she was interested in confirming the diagnosis through some form of testing.

Dr. Donohue replied to her:

"CMT is not one illness. It's a group of illnesses with somewhat similar signs and symptoms, but often different patterns of inheritance. The most common form usually begins before age 20 and starts as weakness in the feet and lower legs. The first warning sign is often tripping because the leg muscles are too weak to lift the feet off the ground. In addition, the feet often have very high arches. Tingling and burning sensations might be felt in the feet and toes. Later on, the process can involve the hands and forearms. As the illness progresses, reflexes (the body's reaction when tendons are tapped with a rubber hammer) are absent.

There are special tests for CMT. Nerves can be checked for transmission of electric impulses and genetic tests are also available. Your son and all CMT patients should contact the CMTA at (800) 606-2682 for the latest information on the illness.

Dr. Donohue's column resulted in a flood of phone calls to the office. We sent out almost two hundred brochures and packets to the people who inquired after reading his article.

CHARCOT-MARIE-TOOTH AWARENESS WEEK IN PENNSYLVANIA

House Resolution 737 proclaimed the week of May 22-26, 2006, as Charcot-Marie-Tooth Awareness" week in Pennsylvania. The proclamation read:

Whereas, Charcot-Marie-Tooth is the most common inherited neurological disorder, affecting approximately 150,000 persons in the United States; and

Whereas, the Charcot-Marie-Tooth Association in Chester, Pennsylvania, has educated and served this Commonwealth for more than twenty years; and

Whereas, while there is no cure for CMT, physical therapy improves the muscle strength and endurance of persons with CMT; and

Whereas, the CMTA is leading the charge for educational programs dedicated to training doctors at medical colleges in this Commonwealth to identify and treat CMT symptoms; and

Whereas, the CMTA is celebrating "CMT Patients' Day" at the Penn State Milton S. Her-

House of Repre
Commonwealth of Pennsyl
Office of the Speaker

In the

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medical colleges in this Commonwealth to identify and treat CMT symptoms; and

Whereas, The CMTA is celebrating "CMT Patients Day" at the Penn
Hershey Medical Center in Hershey, Pennsylvania, on May 24, 2006; therefore

Resolved, That the House of Representatives designate the week of May 22 thro
"Charcot-Marie-Tooth Association Awareness Week" in Pennsylvania.

I certify that the foregoing is a true and correct copy of House Resolution No. 737,
Representatives Wojnaroski, DeWeese, Lederer, Youngblood, Bishop, Cruz, Sai
Mustio, Fabrizio, Nailor, George, Caltagirone, Melio, Staback, McGill, Hershey,
B. Smith, Frankel, Pallone, McIlhattan, Gingrich, Kotik, LaGrotta, Walko,
Hutchinson, Cohn, Markosek, Shaner, Leh, Phillips, Reichley, Millard, Tang
Scavello, Civera, Ross, Geist, Parker, Baldwin, and adopted by the House of Represen
the Commonwealth of Pennsylvania.

John M. Perzel
John M. Perzel, Speaker

Commonwealth of Pennsylvania
Office of the Governor
Harrisburg

The Governor

GREETINGS:

I am pleased to extend my support and encouragement to all Pennsylvanians who are suffering with Charcot-Marie-Tooth (CMT) disease, and the devoted members of the Charcot-Marie-Tooth Association (CMTA) who endeavor to raise public awareness of this condition, help people living with CMT disease, and support research into its cause, cure, and treatment.

I applaud the CMTA's commitment to fighting this progressive neurological disease as well as to helping those adults who are coping with its effects. Your work has helped to educate the public about CMT, advocate for CMT patients and caregivers, and support CMT research — making a dramatic impact within the medical community and improving the lives of countless individuals with this disease. I hope you will continue to find success in your mission of advancing CMT patient care and that a cure will soon be found.

On behalf of all Pennsylvanians, I commend the Charcot-Marie-Tooth Association, as well as those who have joined in the effort to raise awareness of CMT and its effects, on your remarkable dedication to the health and welfare of our citizens. Best of luck in your CMT Awareness campaign and all of your future endeavors.

Edward G. Rendell
EDWARD G. RENDELL
Governor
May 24, 2006

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AMY DE SILVA HIGHLIGHTED IN *SOUTH COAST TODAY*

Amy de Silva is a ten-year old with CMT who makes every effort to help others despite her own limitations. "I can't raise my wrists. I have a little bit of weakness in my feet, and my legs give out a lot," says Amy. But she puts all of her challenges aside to walk for MS and raise money for the National Multiple Sclerosis Society. Many people in her family are affected by MS and she walks for them. Her mother, Catherine de Silva, says that Amy refuses to use a scooter or bicycle. "She gets fatigued easily, but she said she would finish, no matter what."

Amy proudly shows off her beautiful long hair.

To start the event, Amy will sing the national anthem, a challenge even for seasoned performers. Amy says she sings from her heart, knowing that when she sings, she feels good, like she can do anything. That optimism is something that Amy applies to everyday life.

In keeping with her goal of helping others, Amy recently donated her long hair to Locks of Love, which provides custom wigs to children who have lost their hair battling cancer. Amy said, "It makes me feel really good that I am doing this for someone and it's going to make them happy, and no one will make fun of them. I know what it's like to be made fun of, and it's not fun at all." ✻

Amy's selfless gift to kids with cancer leaves her even more beautiful.

"QUIET MONSTERS"

(Continued from page 5)

is valuable. Most people with your challenges last about ten years with active jobs like yours. How long have you been teaching?"

"Nine years."

I knew I could no longer teach school at that point.

Part of me would like to be the Hollywood hero conquering all obstacles through indomitable and absolute spirit, who inspires others by demonstrating that being held back doesn't mean being stopped, showing that sheer force of will can overwhelm all worldly setbacks. Part of me would like to climb to those heights, talk about the gifts of my challenges.

But a greater part of me listens. It wants to honor the differences that set me apart. It wants to hold changes sacred, wants to slip into the gentle space with these quiet monsters and leave worldly expectations behind. Part of me sees society as flawed, pushing me into an able/disabled choice with nothing to accommodate the path set before me.

As I sit here with the monsters settled into my skin, I think perhaps they are not monsters at all, but the problem is in forcing them to conform to a narrow world, a world of fast-paced, self-sacrificing, money grabbing success. I now question everything; take nothing for granted. I research the intricacies of disability benefits.

Perhaps the challenge is not in forcing the monsters to adapt to the outside world, but in helping the outside world understand the monsters. Perhaps the demands to make them conform to my expectations are misguided. Instead of struggling to stay away from the gray oceans labeled "here be monsters" I should swim right into the depths. Perhaps I should ask what they want. Perhaps I should listen. Dance with them instead of suffocating them. Perhaps then they will not be monsters. They will simply be a part of the whole of who I am. ✻

Two Campaigns Raise Interest in and Funds for CMT Research

The 2006 Livney Challenge

Everyone wants a cure for CMT; everyone imagines a future without CMT; everyone hopes we will find that cure in his or her lifetime and end the legacy of CMT.

This hope—and the promise of a cure or an effective therapy—is kept alive by research.

At the CMTA, we have a long-standing commitment to funding significant research.

Each year we ask you to be generous in giving to the research fund, and this year we are extremely fortunate to have the support of the Livney Foundation and Patrick Livney, a CMTA Board Member.

The Livneys share our commitment and believe so strongly in the viability of our research efforts that they have pledged to match $250,000 of what you and other friends and supporters of the CMTA donate in response to the challenge.

We hope you, too, will believe in our effort and give generously. Every dollar you donate to the Livney Challenge will enable the CMTA to fund this important research by the world's leading CMT scientists.

Of course, no one wants to believe in the value and future success of CMT research more than the kids and parents who face an uncertain future and must live with the disorder right now.

Many of them have shared their stories with us. A few are featured here, but please remember CMT affects thousands and give what you can to help end the legacy.

Sincerely,
Charles F. Hagins, *Executive Director*

Yohan...
Yohan is only 13, but living with a progressive neuromuscular disorder has taught him many of life's lessons the hard way. Chronic pain, daily medications, severe fatigue, limited endurance, and leg braces are part of his daily struggle with CMT.

For the most part, he just wants to be a normal teenager. Believing that a cure is in the near future, he has constructed dreams and goals, one of which involves climbing Mount Whitney with his dad.

When you help the CMTA meet the Livney Challenge, you fund the research that may allow Yohan and others with CMT to achieve their dreams. The next generation is counting on your gift. Please don't let them down!

Molly...
Molly's dad has CMT, as does her grandmother. Though her dad's symptoms are not readily apparent, her grandmother is wheelchair bound. At 8, Molly has classic symptoms of CMT, but because of her sensitive nature, her parents have chosen to downplay these indications. She is only 8, with her entire life before her.

With your contribution, we may be able to offer the hope of a cure for Molly before her CMT progresses much further. CMT families are waiting for researchers to provide answers and offer solutions. These top scientists need our financial support to carry out their cutting-edge research into ascorbic acid and other potential therapies.

Gina...
Gina, a spirited and determined 11-year-old, realized her CMT symptoms were worsening rapidly. She could not walk without dragging her toes and falling. After foot surgery, she was fitted with leg braces which gave her the freedom to walk safely. Although she still tires easily, frequently relies on a wheelchair, and uses the elevator at school, her goal is to ascend stairs unaided by the end of the year.

Will you support Gina in her fight to once again walk, run, and ride her bike? Her future is in your hands! Give generously.

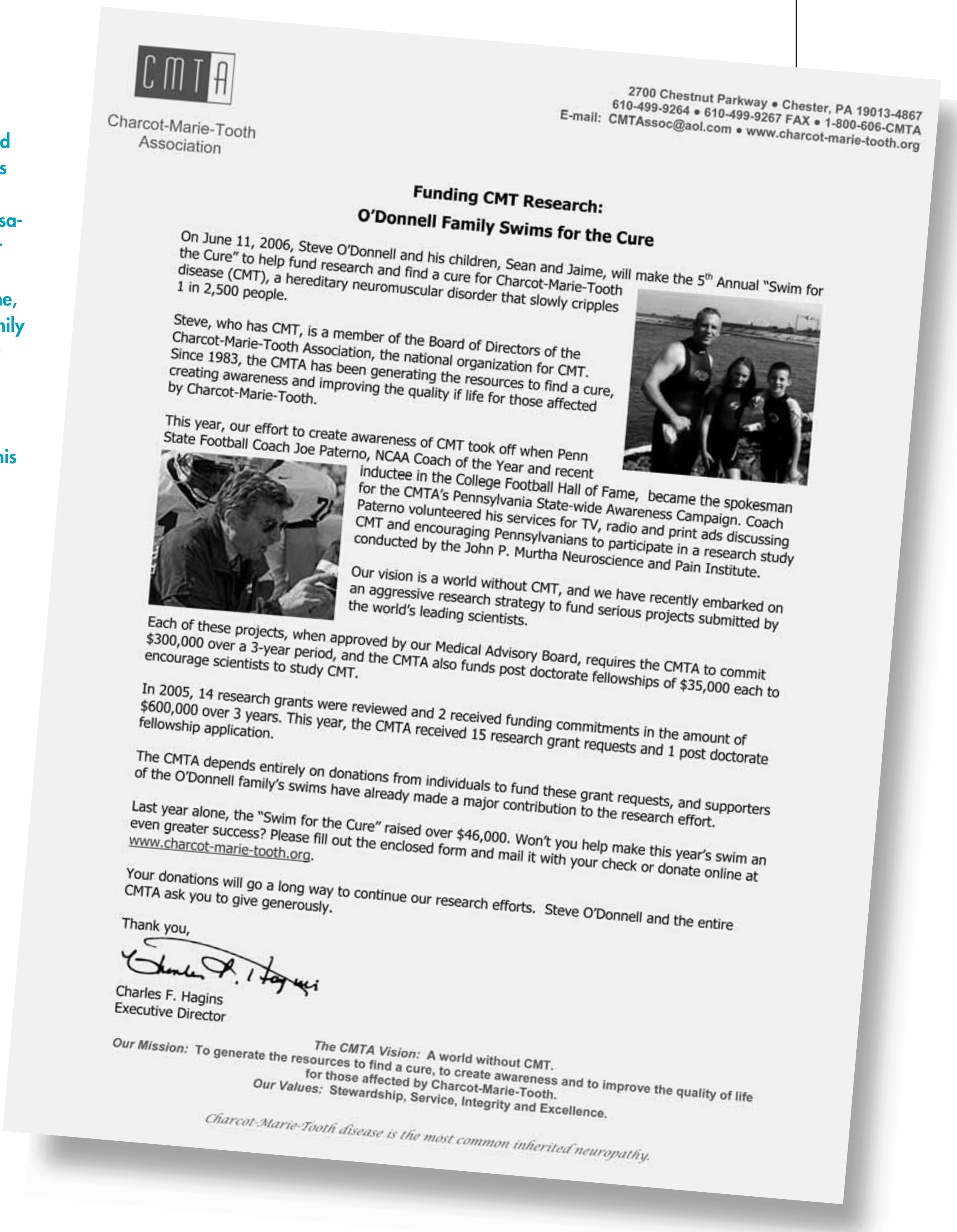
Joe...

Joe's parents were stunned to learn that their 5-year-old son had CMT resulting from a genetic mutation. They had never heard of this condition. Their concern and anxiety know no bounds.

How will Joe function at age 10, 17, 25? Will he need leg braces, pain medication, surgery? How will they ever explain to him that he has an incurable disease and how will he react?

Joe has a full life in front of him. Please remember him and all the others with CMT when deciding how much you can give to the Livney Challenge. We need your continued commitment and generosity to make CMT a disease of the past. Together, we can end the legacy of CMT. ✻

EDITOR'S NOTE:
For the past four years board member Steve O'Donnell has used his participation in the annual swim across the Chesapeake Bay to raise funds for CMT research. Last year, his two children, Sean and Jaime, joined the effort and the family raised a whopping $46,000 for research. This year the O'Donnell family will once again "Swim for the Cure," and they created and sent this flyer to their mailing list to collect pledges.



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Funding CMT Research:
O'Donnell Family Swims for the Cure

On June 11, 2006, Steve O'Donnell and his children, Sean and Jaime, will make the 5th Annual "Swim for the Cure" to help fund research and find a cure for Charcot-Marie-Tooth disease (CMT), a hereditary neuromuscular disorder that slowly cripples 1 in 2,500 people.

Steve, who has CMT, is a member of the Board of Directors of the Charcot-Marie-Tooth Association, the national organization for CMT. Since 1983, the CMTA has been generating the resources to find a cure, creating awareness and improving the quality if life for those affected by Charcot-Marie-Tooth.

This year, our effort to create awareness of CMT took off when Penn State Football Coach Joe Paterno, NCAA Coach of the Year and recent inductee in the College Football Hall of Fame, became the spokesman for the CMTA's Pennsylvania State-wide Awareness Campaign. Coach Paterno volunteered his services for TV, radio and print ads discussing CMT and encouraging Pennsylvanians to participate in a research study conducted by the John P. Murtha Neuroscience and Pain Institute.

Our vision is a world without CMT, and we have recently embarked on an aggressive research strategy to fund serious projects submitted by the world's leading scientists.

Each of these projects, when approved by our Medical Advisory Board, requires the CMTA to commit $300,000 over a 3-year period, and the CMTA also funds post doctorate fellowships of $35,000 each to encourage scientists to study CMT.

In 2005, 14 research grants were reviewed and 2 received funding commitments in the amount of $600,000 over 3 years. This year, the CMTA received 15 research grant requests and 1 post doctorate fellowship application.

The CMTA depends entirely on donations from individuals to fund these grant requests, and supporters of the O'Donnell family's swims have already made a major contribution to the research effort.

Last year alone, the "Swim for the Cure" raised over $46,000. Won't you help make this year's swim an even greater success? Please fill out the enclosed form and mail it with your check or donate online at www.charcot-marie-tooth.org.

Your donations will go a long way to continue our research efforts. Steve O'Donnell and the entire CMTA ask you to give generously.

Thank you,

Charles F. Hagins
Executive Director

The CMTA Vision: A world without CMT.
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 Values: Stewardship, Service, Integrity and Excellence.

Charcot-Marie-Tooth disease is the most common inherited neuropathy.

Scooting Around in Washington, D.C.

BY ELIZABETH OUELLETTE

Planning a trip to an unknown city, state, or country, especially when physical limitations are an issue, is a time-consuming and challenging endeavor. CMT families often consist of members with differing abilities, and finding activities to suit the needs of everyone can turn out to be an organizational nightmare. When endurance, pain, and fatigue are a daily part of your routine, vacation planning is not always easy, and can turn out to be downright challenging at times.

What a difference a scooter can make, increasing endurance and making sight-seeing more pleasant.

So, when I recently traveled to Washington, D.C., for a CMTA Board meeting, I wanted to bring my son Yohan along for the cultural experience. He has spoken many times about seeing the White House, "for real," visiting the Lincoln Memorial, the World War II Memorial, the Washington Monument, the Vietnam Veterans' Memorial and The Smithsonian, where the Air and Space Museum is located.

I wondered how in the world I was going to placate his abounding curiosity and interests. He has CMT, fatigues easily, has little stamina, especially in the heat, and can only walk about 10 minutes without pain in his feet and legs. What to do, what to do?

Determined to find a solution, I surfed the internet and discovered the site www.DisabilityGuide.org, where I found "The Washington D.C. Access Guide 2005-2006." This valuable $5 pamphlet offers all sorts of detailed accessibility information for all D.C. attractions, including maps of the Metro Subway System, the top ten accessible restaurants, nightspots and hotels, available sightseeing, tours as well as places to rent wheelchairs and electric scooters. Scanning the words Electric Scooters, my interest was piqued, and I suddenly had hope that this service might be the solution to our mobility issues.

In the past, when visiting amusement parks and/or zoos, I have tried to rent an electric scooter for Yohan, but the age

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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.

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:____________________
____

limit of 16 to 18 stopped that dream dead in its tracks. However, when I called Scootaround, I was elated to discover that they were able to accommodate Yohan though he was slightly underage. When I told him about the great news, he simply smiled and said, “Awesome.” When I told my mom I was renting one for her too, as I thought it would be more fun to scoot in pairs, she unenthusiastically replied, “Uuhhhh…we’ll see.” Having never used a wheelchair or electric vehicle, she was a little nervous about this new adventure!

I cannot even begin to express how much satisfaction and gratitude I experienced when I met up with Yohan late in the afternoon, still exploring the National Air and Space Museum after 5 hours. Normally, a museum visit of this nature would be utterly impossible due to his physical limitations. When he zoomed by me, he shouted “I need just another 30 minutes, because I haven’t done everything yet!!” My mom’s skills improved rapidly once she got the hang of it, but I was wondering how practically every employee of the Museum knew her, or should I say of her? While Yohan mixed in with the crowd, hardly noticeable, my mom, with her orange hair and orange jacket became an endearing spectacle. Not only did she enjoy using the scooters, but made a reputation for herself (I guess she and Yohan had a few races along the way.) We rented the scooters for the three days we were in D.C., and honestly, this was one of the most enjoyable trips with Yohan ever to be had. We saw all the major sites and attractions one could possibly see in such a short amount of time. When it came time to fly back to California, I must admit I was exhausted and a little cranky, but Yohan (and my mom) still had wide grins on their faces. I will never, ever forget those smiles, as for me, they represented satisfaction, achievement, equality, and, most of all, the very positive impact Scootaround had on my son’s life.

I urge you to check out Scootaround’s website (www.scootaround.com) or call 1-888-441-7575 for more information. They serve 500 locations across the country, offer scooter tours, and rent not only mobility scooters, but manual and electric wheelchairs as well, all deliverable to your location. After speaking with Mr. Gerald Adams, Director of Media Services, I also learned that they have begun to work with Avis, in an exclusive arrangement that allows you to rent a motor vehicle, complete with scooter, all ready for use, right in the trunk of your car. In addition, Mr. Adams also graciously offered a 10% discount on your next Scooter rental, when you mention the CMTA and this article. If indeed you choose Scootaround for your next get away, we would love to hear of your experiences. In the meantime, have fun and Happy Scooting!!! ✻

GIFTS WERE MADE TO THE CMTA

IN MEMORY

Herbert Bernsteen
Mayfield Heights Republican Club

Thomas Buchanan
Tina M. Veliotis

Betty Chow
Brandon and Armida Chow
Henry Chow

James Elam
Norma Martin

Andy Ettelson
Nancy and Bob Fraiman

David Goacher
Marjorie Goacher
Virginia Wissehr

Ruth Linker
Gregg Linker

Charles McCabe
Rose and Harry Burgess

Frank Michenzi
Stella Bialek
Karen and Gary Walker
Frances Zarzeczny

Betty More
Janice and Tom Thompson

Ted Nordby
Howard Mourn

Mary Rehm
Donald and Rose Brandt
Jeanette Brunner
Margaret Crelius
Virginia DiNinzio
Empire Post 375, VFW
Kay Flynn
Rosemary Flynn
Cathy and Lenny Freeman
Margaret Leahy and the Leahy cousins
Westchester/Fairfield County CMTA Support Group

Anne Whelan
Surgical Trauma/ICU Staff
Hahnemann Hospital

Myron Widdop
The Widdop Family

IN HONOR

Yohan Bouchard
Bruno Bessin
Craig Jeong
Pete Kanas
Regis Rinjonneau-Cretin

Tyler Lopez
Mrs. Dale C. Lopez

The Sand Family
Nancy and Joel Weisberg

Bernadette Scarduzio
Dr. Peter Sottile

SUPPORT GROUP NEWS

California – Northern Coast Counties

For the next three meetings, (Nov. 4, Feb. 3 ’07, and May 5 ’07) the group will meet at Sutter Medical Center of Santa Rosa, CA in the Vesalius Room from 1 to 3 PM.

The change in meeting location is a result of Freda Brown’s fall and slow recuperation. She still requires assistance in getting around and can no longer have the meetings in her home. She has shared her home and her gracious hospitality for many years.

For more information about the group, contact Louise Given at lbgivens@ix.netcom.com or call 707-539-2163.

California – San Francisco Bay Area

The last meeting was held on April 1, 2006. The discussion centered on voice-recognition computer programs and vertical PC mice to decrease energy expenditure. We also discussed applying for disability. The handouts for the meeting were on energy conservation while doing housework, shopping, or community activities. We also shared catalogues which sell daily living aids for people with physical challenges.

The next meeting will be June 3, 2006, from 2 to 4 PM.

Colorado – Denver Area

On Saturday, April 22, 2006, the group met to hear John Burgett discuss orthotics and bracing. The group is also working on a flyer which each group member will be taking to their neurologist, podiatrist, or other medical professional to make the newly diagnosed aware of the support group’s existence. The MDA has offered to help patients become aware of the group’s meetings.

Pennsylvania – Johnstown Area

Janet Goodard, RN, BC BSN, CCAP, from The John P. Murtha Neuroscience and Pain Institute, presented a program on aromatherapy. Besides being a nurse at the CMT Clinic, Jan is also a certified clinical aromatherapist. Aromatherapy is a term coined by French chemist René Maurice Gattefossé in the 1920s to describe the practice of using essential oils taken from plants, flowers, roots, seeds, etc., in healing. In most cases, the oil is rubbed onto the skin or ingested in a tea or other liquid. Jan, with the help of her daughter, discussed the healing powers of essential oils and demonstrated how to use this natural therapy to help to relax, sleep better, and reduce muscle, arthritic, and other types of pain. We were able to sample a large variety of blends and fragrances.

Haley Sweeney gives a bouquet of daffodils to a nursing home resident.

Also in Johnstown, the 7th annual “Daffodils for Seniors” took place at Laurel View Village, Johnstown, PA. Children pick, arrange, and distribute thousands of daffodils at no cost to residents of nursing homes every spring.

The daffodil giveaway is in the name of Charcot-Marie-Tooth Disease (CMT) and in honor of Marah Griffith, daughter of Johnstown support group leader, J.D. Griffith, who died at sixteen, December 25, 2001. Marah was instrumental in the conception of children giving daffodils to seniors. Marah loved organizing the event and working with the children.

Pennsylvania – Philadelphia Area

The Philadelphia area group is reorganizing and met at the offices of the CMTA in Chester on April 8, 2006, to hear Dr. Steven Scherer of the University of Pennsylvania do a Power Point presentation on CMT, the diagnosis, the symptoms, the treatments, and CMT research which offers hope for the future. Dr. Carol Oatis, author of many articles on the conservative management of CMT, has committed to doing a discussion on physical therapy at a future meeting.

For information about the group, call either Pat or Dana in the CMTA office at 1-800-606-2682. ✻

CMT Support Groups

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: Sutter Medical Center of Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Louise Givens, 707-539-2163
Email: lbgivens@ix.netcom.com

California—San Francisco Bay Area/Santa Clara County
Place: Location to be determined
Meeting: Bimonthly
Contact: Elizabeth Ouellette, 650-248-3409
Email: elizabetho@pacbell.net

Colorado—Denver Area
Place: Broomfield Public Library, Eisenhower Room
Meeting: Quarterly
Contact: Diane Covington 303-635-0229
Email: dmcovington@msn.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital, St. Petersburg, FL
Meeting: 2nd Sat of Feb, May, Aug Nov
Contact: Lori Rath, 727-784-7455
Email: rathhouse1@verizon.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: Occasionally
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
Contacts: 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: CMTA Office, 2700 Chestnut St. Chester, PA
Meeting: Bi-monthly
Contact: Pat or Dana, 800-606-2682
Email: CMTAssoc@aol.com

Washington—Seattle
Place: U of Washington Medical Center, Plaza Café—Conference Room C
Meeting: Monthly, Last Saturday, 1-3 PM
Contact: Ruth Oskolkoff, 206-598-6300
Email: rosk@u.washington.edu

LETTERS

Dear CMTA,

This is in response to a letter in the Ask the Experts question regarding Fosamax and stress fractures.

I am a late 50s male with CMT2 which manifested about five years ago. I was given Neurontin for neuropathic pain and about 18 months later was discovered to have osteoporosis, which developed out of nowhere. I read that there might be a connection between Neurontin and osteoporosis, so I stopped the Neurontin. I repeated the bone density scan a year after stopping the Neurontin and my osteoporosis was markedly improved. Now I'm on Fosamax to hasten the improvement. I still need the Neurontin but don't take it because I would rather have the pain than risk the fractures. Replacing the Neurontin with Pamelor, Cymbalta, and Lyrica has not been successful.

—*B.E.*

Dear "Walking Challenged",

I am blessed that pain is not a problem for me. Balance and walking are and have continued to worsen since those symptoms appeared some 15 years ago. Until recently, my activity level of travel, yard work, and other physical activities had declined. For many, at age 75, my activity might seem high, but I have always tried to make the best of what I have by keeping fit with daily workouts.

Aside from the usual calisthenics and stretching, I have tried acupuncture, acupressure, chiropractic treatments, muscle reprogramming, physical therapy, Feldenkrais, and tai chi. They have all helped me in one way or another.

Several years ago, one of my therapists told me that if my foot drop became troublesome, there were devices that could help me. While total foot drop occurred infrequently, I didn't realize that I had a degree of foot drop at all times. It affected my gait, the distance and speed I could walk, and the amount of time I could stand comfortably. Standing always required something to touch for balance, usually my wife of 49 years.

One day in April of this year, I observed a friend walking like me. As we chatted, he mentioned how an ankle-foot orthosis (AFO) had helped his walking tremendously. He wasn't wearing it at that moment, but his endorsement of bracing reminded me that a therapist had mentioned it years ago.

That therapist had recommended a CPO (Certified Prosthetic and Orthotic Technician) in Charlottesville, Virginia, near where I live. My physician wrote me a prescription and I was fitted for two Ossur dynamic braces. They are designed for patients with foot drop. This is the web address for those who would like to see what the AFOs are like: www.ossur.com/template110.asp?PageID=731

The impact on my walking has been dramatic and immediate. It was as though my body reverted to my body of more than ten years ago—at least my walking body. My balance also improved, but only slightly. What joy I experienced! Among the changes they have made in my lifestyle is my ability to do

WRITE TO US!

Pat Dreibelbis, Editor
The CMTA Report
CMTA
2700 Chestnut Pkwy.
Chester, PA 19013
or
CMTAssoc@aol.com

The CMTA reserves the right to edit letters for space.

A BITTERSWEET MOMENT…

About two months ago I talked to my wife's childhood friend, who also happens to have CMT. She had picked up her AFOs just a week before. I quizzed her extensively about the comfort, the embarrassment, the usefulness, and, most importantly, her energy. She told me that her ability to get things done increased dramatically. Her statement to me was that it was "a life-changing event."

With that in mind, I started the process. All the while knowing that today would be a difficult moment in my life.

I don't like seeing myself as different. We all know that AFOs are a badge of some type and tell everybody that we are different and somehow unable to meet life's challenges without assistance. I wonder if I have given in, or given up. I wonder if I'm just not strong enough emotionally. I know this is just my pride talking.

At the same time I am also elated. As I put on the AFOs for the first time, I was shocked at how comfortable they were. As I stood up, I felt stable for the first time in years. As I took my first steps, I felt incredible joy simply because my feet rolled from heel to toe correctly for the first time in my life.

The doctor warned me not to walk too far today. It's hard. I feel as though I've been set free. It is ironic that the badge that labels me as disabled is so enabling. —*M.N., via Internet* things I gave up a decade ago; like using a large chain saw to cut trees on very steep slopes. I even accompany my wife to shop and walk so fast that she has to concentrate to keep up with me. She was so accustomed to my plodding along.

The main reason for writing this letter is to alert others with foot drop that braces may help them as well. I could have been helped years ago. Why only one of dozens of specialists I've seen mentioned that braces might be the solution is a puzzle. This is one guy who can attest to their worth!

—G.L.B.,
Charlottesville, VA

Dear CMTA,

I enjoyed reading Paul Lubberts' letter to the editor in the April *CMTA Report*. I am happy he put in his email address so that we could correspond.

I am a 63-year-old male with CMT and have lots of CMT information to share. I wear AFOs and have for several years. I have been married for 41 years and have three sons aged 31, 35, and 37. They are all about Paul's age. None of them show signs of CMT so far, but they may in the future. I didn't have serious signs until age 40. I had always been a slow runner and had sprained my ankles in baseball and football.

Just recently, I tripped and fell over an extension cord outside, landed funny on my foot and AFO and ended up breaking my foot. The AFO survived fine. That left ankle healed up okay by December, 2005. Then in January, I stepped into a hole in a parking lot and broke my right ankle. Again, the AFO survived fine, but the ankle needed surgery, a metal plate, and ten screws. (I think they took a few loose screws out of my head to fix the foot!)

The bottom line is that CMT people have to watch where they are walking…literally.

—Buzz, via internet
(buzzvan40@sbcglobal.net)

ASK THE DOCTOR

Dear Doctor,

I'm a 37-year-old male with CMT and Crohn's disease. I take Remicade treatments for my Crohn's. My symptoms are rapidly getting worse. Can the Remicade have an effect on the CMT?

A member of the Medical Advisory Board replies:

Infliximab (Remicade) is a newer and highly promising agent to treat a number of autoimmune disorders including rheumatoid arthritis and Crohn's disease. A small but growing number of cases of neuropathy that began during infliximab treatment have been reported over the past 2 years. The neuropathies seen are often those considered to be immune-related and may respond to other immunosuppressive treatments. Some of the conditions treated with infliximab can independently cause peripheral neuropathy; this distinction must be made but can be difficult in some cases: is the worsening caused by the treatment or the underlying disease? Having underlying CMT in addition to these two concerns provides added complexity, but CMT patients may be more vulnerable if they are already weak. The pattern of neuropathy often differs with these three problems (CMT, Crohn's neuropathy, infliximab-induced neuropathy). If strength is clearly worsening, then these issues should be addressed by the treating physician to determine which is the most likely possibility. Overall, infliximab-induced neuropathy appears to be a quite rare but valid concern.

Dear Doctor,

Is there any information on Evista (raloxifene) and side effects it can have on persons with CMT?

A member of the Medical Advisory Board responds,

There is no known direct effect of Evista (raloxifene) on CMT patients or peripheral neuropathy. However, deep venous thromboembolism (DVT) is one rare but potential side effect of the treatment. CMT patients with severe weakness, especially those who are wheelchair bound with limited leg movement may be at higher risk and should discuss the treatment with their physician to see if other precautions or preventative treatments are needed. ✻

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
Lefluonamide (Arava)
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)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
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
Fluoroquinolones
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.
- is sometimes surgically treated.
- 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 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), 1E, 1F, 1X, 2A, 2E, 2I, 2J, 2K, 4A, 4E, 4F, HNPP, CHN and DSN 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*

CMTA

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