



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.

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One Devoted Family Plus One Worthy Cause Equals Fundraising Success

For the fourth year, the Scarduzio family gathered at the Rolling Green Golf Club on September 13, 2004, and put forth an enormous effort to raise money for the CMTA research fund. This annual golf tournament held to honor the memory of John J. Scarduzio, the family patriarch, who died at the age of 48, after suffering his whole life from CMT, grossed over \$65,000 this year. It was their most lucrative year to date and demonstrates what one family can do when they are motivated and committed.

Chris Scarduzio, Executive Chef at the exclusive restaurant, Brasserie Perrier, in Philadelphia, led the family in arranging for donors and sponsors and finding the location and golfers for the tournament. His wife, Darlene,



Della Scarduzio, Chris Scarduzio, Darlene Scarduzio, holding Mia, Bernadette Scarduzio, John Scarduzio, Johnny Scarduzio. Front row: Christopher Scarduzio, Maryanne Lucidi and Anthony Scarduzio

his sister-in-law Bernadette, his sister Mary Ann, his brother John, and other members of his immediate family provided

much of the "detail" support. For some of them, their efforts meant picking up donated items, *(continued on page 4)*

CMT Clinic Becomes A Reality in Johnstown

Jeanna Sweeney doesn't let her CMT get her down, but she'll be the first to admit that the neurological condition does present some challenges when it comes to getting around. That is why she, and so many clients at the John P. Murtha Neuroscience and Pain

Institute, are excited about the Institute's new location.

"The Institute houses physical therapy, occupational therapy, bracing and so many other important services that we used to have to travel to different facilities to receive,"

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NEW JOHNSTOWN CLINIC

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says Sweeney. "The staff is wonderful. Everyone is so knowledgeable."

"Our programs, particularly CMT and Post-Polio Syndrome, really draw people in from all over the area; many times even from other states or countries," says Barbara Duryea, Director of Research and Development for the John P. Murtha Neuroscience and Pain Institute. "That is why this location works so

well. It is right off of a major highway with easy access to other major routes and public transportation. There are a number of hotels and restaurants around for patients who need to travel to get here. It is very convenient and that is a real plus for our patients."

In addition to diagnostic testing, invasive pain relief procedures and high-tech treatment rooms, the bright and spacious Neuroscience Institute has a community room for balance therapy and yoga classes as well

as community support groups. "The Neuroscience Institute provides an ideal space for us to hold our regular CMT Association support group meetings," says J.D. Griffith, Support Group Leader for the Charcot Marie Tooth Association. "Not only can people have their treatment here, but they will also find support and a network of people who really understand their condition."

Working with the local and national chapters of CMTA has been a priority for the Cone-

United States Congress Acts on CMT Research

In an historic move, on September 9, 2004, the United States House of Representatives passed legislation that calls upon the National Institutes of Health (NIH) to find ways to increase federal research on Charcot-Marie-Tooth disease (CMT) and CMT-related disorders and report their efforts back to Congress by March, 2005. CMT is one of the most commonly inherited neurological disorders in the U.S. and cuts across all aspects of the age spectrum.

The report accompanying the "FY 2005 Labor, Health and Human Services, and Education Appropriations" bill specifically states that Congress is "concerned about the prevalence of this disease and its effect on people across the age spectrum and recognizes the value of CMT research for advancing understanding into other neuromuscular disorders. The Committee encourages

NIH to identify new research opportunities on CMT that could lead to a relevant program announcement or request for applications."

Patrick Torchia, Co-President of the CMTA, said, "This important development goes a long way to raising awareness and providing significant research funding for a serious neurological disorder that affects approximately one in 2500 people in the United States."

CMT affects approximately 150,000 Americans and is found world-wide in all races and ethnic groups. It was discovered in 1886 by three physicians, Jean-Martin Charcot, Pierre Marie, and Howard Henry Tooth. CMT patients slowly lose normal use of their feet/legs and hands/arms as nerves to the extremities degenerate. The muscles in the extremities become weakened because of the loss of stimulation by the affected nerves.




This Congressional action dramatically increases the awareness of CMT in the legislative arena and can be expected to lead to increased attention at NIH. Such focus should accelerate funding to search for a cure or treatments for CMT and CMT-related disorders.

The legislation will soon be considered by the Senate, where similar efforts to include language on CMT research are already underway. As an appropriations measure that provides annual funds for NIH, the bill will be enacted into law in some form before the end of this year. ✨

maugh Health System. This collaboration led to a CMT conference in May that drew more than 130 participants from throughout the United States and Canada.

Charles F. Hagins, Executive Director of the CMTA states, "This is an important and exciting development for CMT diagnosis and clinical therapy. We will communicate with and encourage people who suffer from CMT in the Northeast to take advantage of Conemaugh's services. We believe Conemaugh has the potential to become a CMT Center of Excellence."

Currently under construction at the John P. Murtha Neuroscience and Pain Institute is a genetics laboratory that will allow researchers to look for genetic ties to CMT, headaches, stroke, back pain, and other neurological conditions. The research will be done in collaboration with the Conemaugh Health System's military partners including Walter Reed Army Medical Center, National Naval Medical Center, and the Uniformed Services University of the Health Sciences.

"Our vision is to significantly reduce the incidence of acute and chronic disabling neurological diseases and pain syndromes through cutting-edge clinical care and research," says Dr. Richard Salluzzo, CEO/CMO of the Conemaugh Health System and Memorial Medical Center. "We're excited to see our vision take shape, and we look forward to future success in identifying, evaluating, and refining new treatment methods for neurological disorders." *


CMTA MEMBERSHIP/ORDER FORM

Name: _____

Address _____

Phone Number: _____ Email: _____

Members who are current with their dues are considered "active." If you are unsure as to whether you are current with your member dues, please call the office at 1-800-606-CMTA.

	QTY	COST	TOTAL
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		active members \$15 inactive members \$20	
Membership Dues		\$40	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 inactive members \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 inactive members \$7	
CMT Facts III		active members \$5 inactive members \$7	
CMT Facts IV		active members \$8 inactive members \$10	
CMT Facts V		active members \$12 inactive members \$15	
A Guide About Genetics for the CMT Patient <i>No shipping and handling on this item only.</i>		active members \$4 inactive members \$5	
Golf Shirt Size: <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> XXL		\$15	
CMT Informational Brochure <input type="checkbox"/> English <input type="checkbox"/> Spanish		FREE	
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research <i>10% will be applied to administrative expenses.</i>			
Shipping & Handling <i>Orders under \$10 add \$1.50, orders \$10 and over add \$4.50</i>			
TOTAL			

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

VISA MasterCard American Express

Card Number _____ Expiration Date _____

Signature _____

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

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

PATIENT PROFILE

Bishop Works to Break Down Barriers

In St. Cloud, MN, a local bishop is working to create more access to churches for people with disabilities. The accessibility issue is important to Bishop John F. Kinney not only because he was recently diagnosed with Charcot-Marie-Tooth disease, but also because he knows that the problems of steps, lack of railings in churches, and absence of ramps in some facilities affect far more people than just himself.

To compensate for the loss of feeling and sensation in his fingers, Bishop Kinney has requested that the diocese provide him with thicker communion wafers because the thin wafers have become difficult for him to handle. He also has asked that some churches combine ceremonies so that he can reduce the number of parishes he must visit.

Kinney, who is 67, was just diagnosed with CMT in May, 2004. He remarked that it isn't easy for him to ask for help since he still thinks he can do what he did at 25 or 30. "I'm going to need some railing assistance, elevator assistance, or a helping

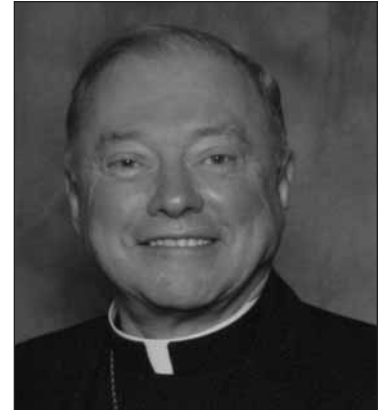
hand to get into sanctuaries and churches."

He has no intention of retiring early because he loves his work and his diocese, but he acknowledges that his walking has become more erratic and climbing stairs is more difficult because he can't tell where his foot is in relation to the steps. He wears braces and may soon use a walking stick as well. He commented that "Many of our churches are beautiful, but the front steps look like the Alps."

In August, 2004, Kinney wrote this column, A Shepherd's Care, for his concerned parishioners:

"I would rather not draft this column. Perhaps it is a matter of pride with me or an unwillingness on my part to admit that I am getting more diminished as the years go by. Something in me wants to pretend that I am still many years younger than my date of birth verifies.

I know many of you have been concerned about my health over these past months. Some of you have written cards and letters to me, and I am very grateful for them and for your



Bishop John F. Kinney

prayers. Over the past years, I have been noticing a pronounced weakness and numbness in my ankles, feet, and fingers. At first I blamed it on a broken ankle in my youth and then, to a family history of arthritis. When my walking became more erratic and climbing stairs more tenuous for me, I consulted our local physicians. On their recommendation, I sought the opinion of the medical staff at the Mayo Clinic. After a battery of tests, they diagnosed me with Charcot-Marie-Tooth disease, so named after the three doctors who first identified it.

"This summer, I was fitted with ankle and leg braces to give

SCARDUZIO FAMILY'S GIFTS

(Continued from page 1)

keeping lists of the golfers, the sponsors of holes, food, and auction items, staffing the table on the day of the event, and selling raffle tickets and "mulligans." For all of them it was a labor of

love in memory of John J. Scarduzio. The tournament also honors the members of the family who are currently suffering from the disease.

This family demonstrates how much can be accomplished by a small group that is driven by a desire to bring an end to the

suffering caused by CMT. Whether a family member provides "sweat equity" or signs a large check, each contributes in a real and tangible way. Their combined effort provides major support for the Charcot-Marie-Tooth Association's mission to fund the research to find a cure. ✨

me greater stability in my walking. You will notice them as I travel around the diocese. Sometimes the use of a cane or “walking stick” is helpful to “ground me” with the earth under my feet, especially on uneven or unfamiliar surfaces. Fortunately, my bishop’s staff also serves to steady me as well.

“I write this not to garner sympathy, but because over the past months, I know my walking patterns have dramatically changed. I find climbing and descending stairs to be more of a challenge than in the past. I now look for sturdy railings for support or the availability of ramps or elevators. Accessibility questions in our churches and schools have suddenly taken on a whole new importance for me. Sad to say, it took my own disease and incapacity to wake me up to what many of you have been burdened with for a long time, as you struggled to get into our Alpine-stepped churches.

“The good news is that CMT is not life-threatening. While currently there is no cure for the disease, I am assured it progresses slowly, which I interpret to mean I have many good years of ministry left as bishop of our diocese.

“Over the past years, I have watched with you the increased frailty of Pope John Paul II. I am always amazed at his grace and stamina in the midst of illness. Now I find that I am called to some increased diminishment in my own life. I pray that I will be as filled with grace and strength as he has been.”

*John F. Kinney
Bishop of Saint Cloud, MN*

Athena Announces New Tests

AMAR KAMATH

Athena Diagnostics announced the clinical availability of two new molecular assays to help diagnose hereditary neuropathy patients starting July 31, 2004.

LITAF/SIMPLE DNA SEQUENCING TEST FOR PATIENTS WITH DEMYELINATING CMT

Patients with mutations in their LITAF/SIMPLE gene present with a demyelinating CMT phenotype referred to as CMT1C. Studies have shown that the LITAF/SIMPLE gene is induced by a variety of cellular signals and may play a role in protein degradation pathways. Therefore, it is suspected that mutations in this gene may cause a significant proportion of CMT1 cases. Patients with mutations in this gene present with classic symptoms including distal muscle weakness and atrophy, reduced deep tendon reflexes and sensory impairment, and are, therefore, indistinguishable from patients with other genes causing demyelinating CMT.

MFN2 DNA SEQUENCING TEST FOR PATIENTS WITH AXONAL CMT

Patients with mutations in their MFN2 gene present with an axonal CMT phenotype referred to as CMT2A. In a study by Zuchner et al, 19% of families (7 out of 36 studied) with an axonal CMT phe-

notype were found to have mutations in the MFN2 gene. Therefore, MFN2 analysis may be helpful in confirming the diagnosis in a significant proportion of patients with an axonal neuropathy.

Mutations in these genes are not specific to any race or gender and are known to segregate in an autosomal dominant manner. Patients with a confirmed molecular diagnosis may benefit from genetic counseling to understand the inheritance implications for themselves and their family.

LIMITED FINANCIAL LIABILITY FOR PATIENTS

Because we recognize that insurance companies do not always cover the full cost of advanced laboratory testing without extensive medical justification, we have established Access Athena. Through this program, Athena limits the patient’s financial liability to 20% of the amount billed. If the insurance company pays more than 80% of the amount billed, Athena will refund the excess amount to the patient. In addition, Access Athena includes convenient blood draw services through a local hospital or a home draw company.

If you have any questions on the new testing services of Access Athena, please call our customer service team at 800-394-4493, ext. 2. *

Making Your Internet Purchases Count

SHOPPING THROUGH THESE SITES CAN HELP THE CMTA

Using iGive.com

Open your Internet browser and type igive.com on the address line. Click “go.”

When the iGive.com page opens, enter your e-mail address in the field beneath “Join Here” and click “Join Now.”

A new page will allow you to find a cause to support. Type Charcot in the search field and click “search.” When the results appear, scroll down and click on the link for the Charcot-Marie-Tooth Association.

Next, you’ll be required to enter your first and last name, type and retype a password, and enter your zip code, but you can choose whether you want your name revealed, how you want your donations used for tax purposes, and whether you want to give them your gender and birthdate.

When you’ve entered that information, scroll down and click “submit.” (If you’ve left a required field blank, you’ll have to go back and fill it in before continuing.)

The next page will ask if you want to download the iGive.com Shopping Window. I’d suggest doing this, because you can shop directly from any company’s website, and the Shopping Window will automatically activate iGive.com if that company is an iGive affiliate. If you don’t download the Shopping Window, donations will be made only if you shop by going to iGive.com and finding the company you want to



make a purchase from on the iGive site.

To download the Shopping Window, click “submit.” When the next box appears, click on the box to “always trust content from Top Moxie Inc.” and click the “Yes” button. When the program finishes downloading, close all open browser windows. To make sure your settings are saved, you should also shut down and restart your computer.

That’s all you need to do to get started, but there are several things you should look at to make sure you’ve registered and that the Shopping Window is working properly.

First, when you type iGive on the browser address line, the opening iGive page should greet you by name, show your e-mail address, and say you’re logged on and supporting the Charcot-Marie-Tooth Association. It will also show the amount of your donation to date. (iGive recognizes you by planting a cookie, so if you’ve removed cookies or are on a different computer, you will be greeted as a “guest.” Click on LOGIN, type your e-mail address and password, and you should be greeted by name. You will also need to LOGIN to access more than one iGive account on the same computer.)

Next, check your e-mail.

You should have two confirmation messages from iGive.com. One is from “Betty” and will give you additional details about shopping through iGive.com. The other will give you information on how to make sure the Shopping Window is working. You’ve already closed and reopened your browser, so just type landsend.com into the address line and click “go.” The Shopping Window should open, stay on your screen for a few seconds and disappear. (One final note about the Shopping Window: It will only work on the computer to which it was downloaded. If you make a purchase using a different computer, you will have to go to iGive.com to find the company.)

Before shopping, you should also spend some time exploring the iGive site, but these are some of the features I’ve found to be helpful.

To view a list of company links by the category of business, click on the “Shopping” tab. Under the “Mall Directory” the number of companies is listed in parentheses, and clicking on a category brings up a list and brief description of those companies.

To view a list of all the companies that donate through iGive, click on the “Shopping” tab. If you click under “Our Merchants,” the list shows the percent donated and can be arranged either alphabetically or from greatest to least percentage. You’d do better, however, to click on “Merchants” on the left

I Wish There Were Some Way I Could Help...

DANA SCHWERTFEGER

I wish I had a nickel for every time I've heard that one.

Most people really do want to help, but all too often they don't know what they can do or how big an impact they can have.

The good news is that there's an easy way to help the Charcot-Marie-Tooth Association raise funds for operations and research, and it takes very little time and effort. You can even get your friends and their families to help.

If you or your friends make purchases on the Internet, it's easy. Suppose, for example, you were to purchase \$100 worth of merchandise at Eddie Bauer. If you had registered at iGive.com and identified the Charcot-Marie-Tooth

Association as your cause, the CMTA would have received 2 percent of your purchase. You would have donated \$2 to the CMTA, and it wouldn't have cost you anything.

Eddie Bauer is just one of the 551 companies that support iGive.com. Some give less than 2 percent, but many give much more. Next time you buy ink cartridges, think 00Inkjets.com. They give a whopping 14.4 percent!

That's such a good deal, you'd think more people would be supporting the CMTA by registering at iGive.com. The truth is, however, that since the CMTA was first listed there in 2001, it has received less than \$350 from iGive.com and

there are only 91 current supporters.

Okay, so you didn't know. Now you do. The accompanying article has step-by-step instructions to make it easy to register at both iGive.com and at GreaterGood.com, another site linked to companies that make automatic donations to the causes you identify.

Oh, and did I mention that you should ask your friends to register, too? It only takes a minute and when participating companies offer special deals or discounts, they'll be able to take advantage of them as well.

Thanks for your help, and I'll keep you posted on how those nickels are adding up! *

of the Shopping page. Not only can you use a search field to search for a particular company, but you can open the link to a company or find out more about the rate by clicking on it. That's really useful when "special rate" is listed. AOL's special rate, for example, is a \$10 donation for each new sign-up.

To view other special rates and discounts offered by various companies, click on the "Specials" tab.

To view your stats and edit your personal settings, click on the "My iGive" tab.

To view information on the donations made to the CMTA, click on the "My Cause" tab and then on "Cause Stats."

To send an e-mail to a friend and tell him or her about shopping at iGive.com, click on the "My Cause" tab and then the "Tell Friends" link. For each person you get to join, \$1 gets donated to the CMTA.

To make all of this work, however, you have to shop on line. Please take a minute and think of all the things you shop for on line already, or all the things you and your friends could shop for on line. Then think of how much money your purchases could generate for the CMTA. You really can help!

Using GreaterGood.com

Unlike iGive.com, which has the Shopping Window to identify

affiliated merchants, you must always begin by registering at GreaterGood.com in order for a percentage of your purchase to be donated to the CMTA. GreaterGood also gives you access to less information about your account and your cause, but it is somewhat easier to register. Here's how to register for the first time.

Type www.greatergood.com on your browser's address line and click "go."

When the first page appears, click on "Register." Next, you'll have to enter your e-mail address, your first and last name, and a password. After retyping your password, scroll down and

(continued on page 8)

ONLINE GIVING*(Continued from page 7)*

look at the options. The check boxes are already checked, so you'll have to click on the box of any feature you don't want. (Leaving the e-mail checked is okay, and so is sharing your name with us, but the e-mail alerts can be a pain so I'd uncheck that box.) When you've done that, click "enter."

The next page, which shows a number you can enter at Gear That Gives to get \$5 off any purchase of \$30 or more, also allows you to edit and send an e-mail to your friends and tell them about Greater Good. We'll always appreciate your help in signing up additional people, but you can skip that page by clicking on the "find a cause" link.

Whether you send an e-mail or not, you have to click on "find a cause" before you shop. Type Charcot-Marie-Tooth Association in the "Name" field and Chester in the "City" field.

The "State" is PA and the Zip is 19013. Click "search."

You should see that one match has been found. Click on the link to the Charcot-Marie-Tooth Association. The next page will welcome you back and notify you that your on-line shopping is supporting the CMTA.

The same page will show you merchants by category of business. Clicking on "more" in



any category brings up links to, and descriptions of, all merchants in that category, or you can scroll down and view the complete list by clicking on "see all merchants."

Clicking on the link to any merchant opens a new browser window and takes you directly to that company's website. To select another merchant and continue shopping through GreaterGood.com, you can

either close or minimize that browser window, or you can click on the taskbar button (usually located at the bottom of your screen) that appeared when you first went to GreaterGood.com. (The taskbar button most likely reads "Shopping Directory...")

Once you're registered, clicking on the "find a cause" link allows you to edit your personal information by clicking on "your account" and entering your e-mail address and password. You'll also receive a confirmation e-mail from memberservices@greatergood.com.

One last detail: If you shut down or log off your computer, the next time you go to GreaterGood, check to make sure it greets you by name and says you're supporting the CMTA. If it doesn't, click on register, enter your e-mail address and follow the directions to "click here" if you're already registered.

Thanks again for your support! *

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: _____



ANN LEE BEYER: A Memorial Tribute

In the two decades that I had the honor of knowing former CMTA president and chairperson Ann Beyer, she was the most impressive and dedicated force in the advancement of the cause of the Charcot-Marie-Tooth diseases. Having met her just prior to the Second International Conference held at Arden House, it was stimulating that she wished, with so much enthusiasm, to attend. Not surprisingly, within a year or two she was giving her own paper on "Families and CMT," published in a book about the psychosocial aspects of neuromuscular diseases sponsored by Columbia University. A mere ten years later she was giving a remarkable welcoming address as President of the CMTA to the Third International Conference in Canada, Laurentians.

From the moment she joined the CMTA, she became a powerhouse on the Board and rose to become the President and Chairperson. Sensing the need for a strong Medical Advisory Board, Ann gave special attention to this area, during which time our MAB grew to nearly 40 members representing the world. At this time, CMT was a disorder much under-recognized in matters of care and research. She also worked very hard so that we would increase our fledgling fellowship program, as training and research form the basis of developing future clinical researchers and scientists. In this way, not only



Ann Lee Beyer was involved with the CMT from its inception.

are we paving the way to find mechanisms and cures for the various forms of CMT, but by facilitating interaction between the various groups around the world, we are speeding up this process. Eventually, she planned that we should join together, with the North American and European Consortia, leading the way. Already in Antwerp last month we were talking about an Australian or Asian Consortium meeting in 2005.

Ann Beyer's other main concern was to involve government in this process, as well as the private sector, and she spent a great deal of time in her last few years doing this. In this way, we hope to get funds to support research projects and Centers of Excellence. She fully realized the importance of money in this venture, and managed organization funds well. She was generous and would strongly support giving funds where and when needed, as well as becoming

involved in fundraising and negotiations with donors. As mentioned in the earlier memorial, we became close friends over the years and would frequently discuss these plans. It was not unusual for me to be on the phone with Ann about a deserving young doctor or research scientist and the need for support of their projects and have her come up with an answer promptly, followed by funds, when appropriate. Many budding projects have been saved this way. The results of this support is well illustrated by not only the referenced articles, but also the inspiring reports that have appeared in *The CMT Report* over the past decade.

Elizabeth and I knew Ann and Ron very well and we had many cultural and family (with five children and nine grandchildren) interests, with their joys and sorrows. It is, therefore, with deep sorrow that we mark the passing of Ann, but with the joy of having known her and her vibrant and interesting, multifaceted personality. Together, the four of us enjoyed many events, particularly fine food and great music. I remember one balmy evening in Capri, after the CMT2 Conference, when the musicians singled out Ann in the restaurant and came over and serenaded her. She enjoyed it, and this is how we wish to keep her in our memories.

—Robert E. Lovelace, MD
Chairman Emeritus
of the MAB

Reflections on Attitude

ROSEMARY MILLS, BENSON, MN SUPPORT GROUP LEADER

Having a physical challenge has caused me to reflect on attitude more than once. Someone told me that they think people have a “nasty” attitude toward physically challenged people. I’ve never found this to be the case, so I started to reflect on why that might be. I remembered before I ever used a wheelchair that I would try to smile at people in one. They seemed to reflect the attitude that I pitied them, which was not the attitude I intended to convey. It has since been my experience that if I’m using a cane, walker or wheelchair, that if I greet people with a smile, I get one back. Of course, there are those people in the world that don’t smile at all, no matter how friendly you are.

So many times when I’ve needed assistance, a good soul seems to appear to help me. I’ve talked to many others who have found the same to be true. Do we get in life what we are looking for? Or, does God reward a joyful spirit? Either way, a joyful spirit is truly a blessing unto itself.

I’d like to share one of my most recent experiences in being well taken care of by God and the good souls he sends to help me. It was after the “Alice in Wonderland Tea” at the local library. I went out to my van to leave and, for some reason, I turned slightly as I passed the passenger side. My intention was to use my key pad to unlock the doors. That’s all it took to throw

off my balance and there I was on the pavement. Pretty flow-ered dress, big white hat, braces...there I was. What to do? Should I wave down a passing vehicle for help? It really wasn’t long before a van noticed me and came to my rescue. A man jumped out and asked, “Are you hurt?” I told him, it was only my pride that hurt. Then, I proceeded to explain the best way to pick me up (I’ve had a lot of experience) and he did a great job of it. He had a teenage son with him. They were both great and asked again and again if I was okay. I assured them I was. They waited with me until I was safely in the van. I was shaken. I thanked God that I didn’t get hurt and that I didn’t know this man and his son (which meant they didn’t know my husband, so no one would tell him and worry him.) Just then, another lady from the tea came out of the library and I

thanked God that she hadn’t seen my mishap. Pride problems, again!

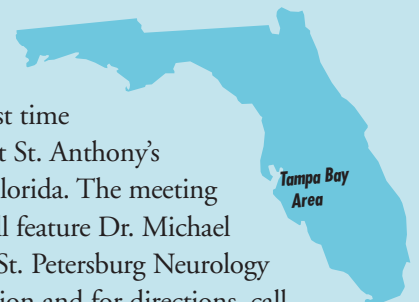
Two week later, at an appointment with neurologist, I owned up to the number of falls I’d been experiencing. He suggested that I use my walker with my braces and make an appointment with another specialist who might have a better answer for me and my safety.

The other day I was walking with a friend and she said it was too bad I had to give in and use a walker. I said, “Oh, I just look at it as another tool to use so I can go on living life.” Yup, Attitude... that’s where life is really lived. *

(Editor’s note: Rosemary received an award from the Muscular Dystrophy Association for her outstanding achievements and demonstrated success in overcoming the challenges of a neuromuscular disease.)

New Support Group Forming!

A group is forming in the Tampa Bay area of Florida. They will meet for the first time on November 20, 2004, at St. Anthony’s Hospital, St. Petersburg, Florida. The meeting will begin at 9AM and will feature Dr. Michael Franklin, a neurologist at St. Petersburg Neurology Clinic. For more information and for directions, call Lori Rath at 727-784-7455. *



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—Berkeley Area

Place: Albany Library, Albany, CA
Meeting: Quarterly
Contact: Gail Whitehouse
Email: gwhite@earthlink.net

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)

Place: 300 Sovereign Lane, Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Freda Brown, 707-573-0181
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

Kentucky/Southern Indiana/Southern Ohio

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

Massachusetts—Boston Area

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

Minnesota—Benson

Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156

Minnesota—Twin Cities

Place: Call for location
Meeting: Quarterly
Contact: Maureen Horton, 651-690-2709
Bill Miller, 763-560-6654
Email: mphorton@qwest.net, wmillier7@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 each month from 1-3 PM of each month
Contact: Dr. David Younger, 212-535-4314, Fax 212-535-6392
Website: www.cmtnyc.org

New York—Horseheads

Place: Horseheads Free Library on Main Street, Horseheads, NY
Meeting: Quarterly
Contact: Angela Piersimoni, 607-562-8823

New York (Westchester County)/Connecticut (Fairfield)

Place: Blythedale Hospital
Meeting: 3rd Saturday of each month, excluding July & August
Contacts: Beverly Wurzel, 845-783-2815
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, odd months
Brooks, Assembly of God Church, even months
Meeting: 3rd Saturday of the month (except June and Dec.)
Contact: Jeanie Porter, 503-591-9412
Darlene Weston, 503-245-8444
Email: jeanie4211@hotmail.com or blzerbabe@aol.com

Pennsylvania—Johnstown Area

Place: Crichton Center for Advanced Rehabilitation
Meeting: Bimonthly
Contact: J. D. Griffith, 814-539-2341
Email: jdgriffith@mail.charter.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

LIVING WITH CMT

"What I Did on My Summer Vacation"

DANA SCHWERTFEGER

When you live in an apartment, you don't have to do much in the way of maintenance and yardwork. That changed for me this summer when I stayed with a friend while looking for a job. Suddenly, I was in a house with five bedrooms and an enormous yard.

Part of the deal was that I would help my friend put things in order in exchange for room and board while I waited to see if a job with a publisher was going to come through. But was I really up to the task?

My family built our own house when I was seven—okay, so I spent most of my time nailing down particle board and fetching things, but I did pick up some rudimentary skills with a hammer and saw. After I started college, though, the only use I had for tools was when I had to adjust the trim of my AFOs so they fit better.

The first thing I discovered was that my friend didn't have much use for tools, either. Whenever I asked if she had a specific tool, her answer was that she used to have one, but it had probably been sold at a yard sale. I don't want to sound sexist, but women just don't have the tool gene—the one that makes men acquire every tool in the universe. We're never sure what we might use all those tools for, but when we need a quarter-inch masonry bit or a cold chisel, we

want to be able to reach in the tool box and get one.

Well, as luck would have it, not only was my Y-chromosome intact, but a tool company was having a grand-opening sale nearby. A couple of hundred dollars later, I had a selection of screwdrivers, pliers, and wrenches, a vise, a circular saw, a jigsaw, and an electric drill. I wasn't sure what I was going to do with the jigsaw, but it was such a good deal...

Then this past weekend, I found myself shoring up and cementing the wall in the garage. The floor had settled, and mice had been enjoying easy access to the family room and the rest of the house. The cats weren't amused by the sudden decline in the rodent population, but once I closed off that route, I figured I'd better do something about the hole in the furnace-room wall, too. The duct cover was there; I just had to affix it to a piece of plywood and attach the whole thing to the wall. (Tools used: circular saw, jigsaw, screwdriver, drill and, yes, that quarter-inch masonry bit! No need to point out, however, that I have yet to use the 50 or so other drill bits I bought at the same time.)

Before any of you men with a repressed Y-chromosome and



Dana survived his summer with fingers intact.

CMT head for the garage, I should mention that using power tools is dangerous even for someone with no physical deficit who knows what he's doing. It can be treacherous for someone with poor manual dexterity, so take the time to learn how to do things prop-

erly and never attempt something that might leave you short a finger or two.

I'd also advise caution when climbing ladders to clean windows and gutters. I was able to do it, but I was very aware of how different being on a ladder is when you're wearing AFOs.

Taking on the yard presented challenges, too. Parts of it were pretty overgrown with vegetation, particularly honeysuckle. It took me two days to clear out the worst corner of the yard. Then I planted some juniper and rhododendron and mulched. In all, I think I spread about 20 bags of the stuff where I dug out all the weeds around the house.

It was hard work, but did I enjoy myself? You bet I did! Inside and outside, the house looks like it got an extreme makeover. And while my CMT occasionally caused me to fumble around and get frustrated trying to start screws or nails, there's a certain satisfaction to finishing up a project, especially when it involves using tools! ✨



GIFTS WERE MADE TO THE CMTA

IN MEMORY OF

Ann Beyer

Frank Crohn
Mary Haicken
Robert & Elizabeth Lovelace
Vicki & Michael Molinari

Virginia Coombs

Elna Crook & Jenny Klatt

Sidney Dicker

Margaret Traub & Phyllis
Dicker Fund of Stonewall
Community Foundation

Katherine Meier

Saint Louis University
F. A. A. Gondim
L. J. Kinsella
Y. Pan

Katherine Meier (cont.)

C. V. Rao
F. P. Thomas

Tex Newman

Ron & Anita Beesley
Frances Harden
Hubert & Martha Newman
Mr. & Mrs. J. M. Newman
Joyce Wood

Mary Price

Myron & Dianne Martenson

Rebecca Sand

Rhoda & Stephen Sand

Belle Singer

Dr. & Mrs. David Edgar

Sheldon Solodar

Barbara & Scott Goldstein

Carol Stuller

Doris Cramer

James E. Tupper

Mary T. Kennedy

IN HONOR OF

Betty Baptiste

Mrs. Lee Gasper

Margaret & Richard Davis

F. A. & Patricia Davis

Sandra Ettelson

Mike & Joan Wald

Ruth Gelman

Leon Gelman

George Kendrick

Robert Bloom

Social Security Disability Information On-Line

A resource for individuals dealing with the issue of social security disability can be found at www.disabilitysecrets.com. The website provides a very complete explanation of the process and the problems in applying for disability. The website was set up by a man who was a social security disability examiner and he has attempted to provide applicants with sample questions and answers that they might not typically have answered for them at the social security office during the process. Topics covered on the site include:

- Should you get an attorney or representative for your case?
- When should you apply for social security disability (SSD) benefits?
- How do I apply for disability benefits offered by social security?
- What evidence is used to decide a SSD case?
- What does an attorney or representative do to assist a claimant?
- If my disability claim is denied, what advice is there for what to do next?
- How do I appeal my SSD denial?
- How lengthy are SSD appeals?
- How do you qualify medically for social security disability?
- Why is the SSD process so long?
- What SSD cases win?
- How good are the approved chances for disability?
- When should you decide to get representation?
- Why do SSD cases take "forever"?
- Is it better to appeal or start over on a case?
- Is there a time limit to file an appeal?
- Who makes the SSD decision?
- Does social security deny everyone the first time they apply?
- Does social security deny you a certain number of times before you're approved?
- How much does a representative charge to handle a case?
- Can certain medical conditions or problems get you automatically approved?
- Can you win a SSD case if you've used alcohol or drugs?
- Does social security give backpay to everyone approved for disability?
- Will VA approval help my SSD case?
- What is the purpose of the medical exam that social security sends you to?
- Should I use an attorney or non-attorney to provide representation? *



LETTERS

Dear CMTA,

I just received my July/August issue of The CMTA Report and have been continually amazed at how early so many of your readers were diagnosed with the disease. I have been complaining for years to my doctors about my symptoms, and not one of them ever considered this disease. Because I have severe shooting pains, I have asked over and over again what could be the cause and basically their attitudes have been the same, acting like I am crazy, etc. My mother and grandmother both had the symptoms and died never knowing what they had.

Since learning what I have (finally at the age of 64), I have found out that I have four cousins with the disease, and their fathers, my uncles, had the disease. These people live in Colorado and Kentucky. Because I live in California, one of the most progressive states in the U.S., you would think I would have been able to get a diagnosis long before I reached the age of 64. When I did find out, it was only a fluke. One of my daughters was going to UCLA for another problem and while answering various questions about her family history, the doctor became interested, and I was tested. Finally, after all of these years, I found out I was not crazy. I really do have something that has a name. We have since found out that one of my daughters and my son also has the disease.

I am now quite disabled, cannot walk without a walker or

wheelchair, and have received Tramadol for the pain. You cannot imagine how distressing it has been over the years knowing that something terrible was going on with my body and not being able to get a single doctor to take me seriously. *Why is this disease so secret that general practice doctors have never heard of it?*

How in the world is it possible that so many young people who write to your magazine have been diagnosed at an early age, and I couldn't get anyone to listen to me?

I even had one doctor tell me (when I was having shooting pains in my left foot), that if I would lose some weight, I wouldn't have the pain. She never even considered that all of my other symptoms could mean that I had a disease.

There is another thing patients with the disease might want to think about. Several years ago, before I knew what I had, I had total knee replacement surgery. After the surgery I was never able to regain the strength in that leg. Of course, I know now it was because of the CMT. My right knee needs to be replaced now; however, I am very reluctant to have it done because I fear that it will mean I will lose what little remains of the strength in this leg.

Note to others out there with the symptoms of this disease—don't try and get a diagnosis from any doctor in California.

What on earth can be done to educate the public about this debilitating disease? Can't the asso-

ciation get booked on Dateline, 48 Hours or something to get the message out there? There must be many people who have this disease and do not know it.

Thank you for your wonderful magazine—it has been a real source of comfort learning that I am not alone.

—E.H., Oakview, CA

Dear CMTA,

I would like to respond to "I" in the Mar/April CMTA Report, Website Bulletin Board article. "I" talks about the benefits of tendon transfers for the CMT foot drop and wonders if anybody else has had that operation. I am happy to say that I did in 1963 as a teenager. It has served me well for over 40 years. I am starting to notice foot drop somewhat and suspect that I will have to address it one of these days. My surgery was well worth an inconvenient summer of casting 40 years ago.

—J.T., by e-mail

Dear CMTA,

Several weeks ago, I participated in MDA's "Fill the Boot" fundraiser. The firefighters worked in shifts standing at the four corners of a main intersection. Several motorists dropped in \$50 bills. How I wish I could do fundraising like that for CMT!

Our bowling event raised only \$1,700, but I had the pleasure of having someone with CMT from another county come and bowl. He is a retired school teacher who was misdiagnosed and bowls pretty well in

WRITE TO US!

Pat Dreibelbis, Editor
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The CMTA reserves the right to edit letters for space.

spite of wearing AFOs. He bought a donated gift certificate. Another person with CMT, Lynn Upton, helped collect money and sorted gift certificates for me. We didn't collect a lot of money, but I think we did raise awareness of CMT.

—Betty Chow

Dear CMTA,

Just a note to thank you for keeping us informed about new products on the market. In a recent bulletin, someone wrote

about a product called Foot-UP from Innovation Sports (www.isports.com). I found two products to my liking that have helped me. One is the Foot-UP that is simple to put on and works great. No more tripping because it keeps my foot up. It was \$120 for one, but I think it was well worth it. I only needed one because my left foot is not as bad. The second one was called a V-lock stabilizer that I bought for my right ankle when I golf.

Thanks again for letting me know about this source.

—By e-mail

CORRECTION

In our July/August 2004 issue, the author of the Pilates article was misspelled. The correct spelling is Lavinia Magliocco. Additionally, the second picture that accompanied that story was incorrectly identified. It shows an exercise for stretching, not for strengthening.

ASK THE DOCTOR

Dear Doctor:

What is the current opinion on the use of regional anesthesia in the pregnant patient with CMT? Is a labor epidural contraindicated? Is a spinal anesthetic contraindicated for a caesarean section? Is lidocaine, which is thought to be neurotoxic, contra-indicated for a spinal or epidural?

The Doctor Replies:

There have been a number of reports of successful regional and epidural anesthetic exposures for pregnant CMT patients, but the literature is not extensive. I am not aware of any credible complications or worsening of neuropathy with the conventional local or epidural agents, including lidocaine. Other important considerations include the general health of the patient and any other medical problems, especially of the heart or lungs, and any family history or anesthesia reactions, especially malignant hyperthermia (mostly associated with inherit-

ed muscle) (not nerve) disorders. The patient, however, should discuss the pros/cons with the treating anesthesiologist prior to consenting to any procedure.

Dear Doctor:

I am a soon-to-be 57-year-old male. Though I was symptomatic in my mid-teens, I was not diagnosed with CMT (spinal type) until almost 20 years later. One question I have at the moment is as follows: An endocrinologist who is treating me for diabetes has asked me to inquire if it would be appropriate to administer a statin-based cholesterol drug with my history of elevated CPKs (generally 350-500 range).

The Doctor Replies:

Mildly increased CK values are not a primary reason to withhold a statin drug, but muscle symptoms and CK values should be checked while on the drug. The risk of worsening the neuropathy appears to be very small,

but incompletely known, while the benefit of the drugs is well established. Raised CK levels, in general, are not common with CMT.

Dear Doctor:

Can you tell me if the sleep aid "Ambien" is harmful to those who have CMT? I started taking Ambien a few months ago and I have noticed a dramatic change in leg strength over the past few weeks.

The Doctor Replies:

There is no known link between zolpidem (Ambien) and neuropathy or worsening of the neuropathy of CMT. The drug can cause sleepiness or sedation, which is its primary useful effect, and can make some motor tasks more difficult for CMT patients. However, if there has been a notable decline in strength, then attention by a local physician should be considered to look for potential causes other than the Ambien. *

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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 (ddl, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Leflunomide
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, 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-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
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, 1D (EGR2), 1X, HNPP, 2E, 4E, and 4F can now be diagnosed by a blood test.
- ◆ is the focus of significant genetic research, bringing us closer to solving the CMT enigma.

THE CMTA Report



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