



**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.

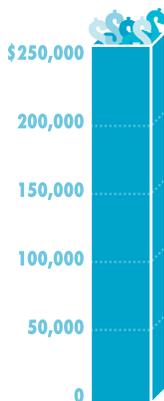
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EMAIL CMTA AT:
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Supporters Match the Livney Challenge!

As of January, income from the Livney Challenge Research Appeal had reached \$255,094. Board Member Patrick Livney who originated the challenge said, "On behalf of the Livney Foundation and Roland Livney, we want to express our deepest appreciation and gratitude to everyone who contributed to match this challenge grant. It is just the beginning!" The monies collected will go toward the funding of clinical trials and research



efforts to find both treatments and possible cures for CMT.

Patrick went on to say that he expects 2007 to be a record year for fundraising at the CMTA, equaling or surpassing our accomplishments this past year.

It took gifts both large and small for the CMTA to raise over \$250,000. Gifts were made by a total of 549 persons. (See letters to the editor for comments from one donor.) This campaign raised the most money for CMT research to date by an individual campaign. It was an amazing accomplishment for the CMTA!

Currently the research grants that this campaign is helping to fund include the ascorbic acid clinical trials, soon to begin in Rochester, NY, Detroit, MI and Baltimore, MD; the investigations of Dr. Stephan Zuchner now at the University of Miami, who is investigating the function of dynamin 2 mutations in CMT; Dr. James Lupski, at Baylor College of Medicine in Houston, TX, who has uncovered the use of curcumin in restoring partial function to mice with more severe forms of CMT; and Dr. Steven Scherer, University of Pennsylvania, who is studying a drug which appears to restore function in the axons of *Trembler J* mice by blocking certain potassium channels. *

New Year's Resolution Number 1: Get the word out!

As 2007 opens before us, we here at the Charcot-Marie-Tooth North American Database are making it our number one goal to ensure that everyone knows about the CMT registry, what it is, why it's here, and how to join. So let's jump right in!

What is a registry? A registry is a place to keep informa-

tion on people who are affected with a particular disorder. Different registries collect various kinds and amounts of information, from basic demographics (age, gender, etc.) to more detailed information that comes from things like physical exams and tissue samples. Registries are used in several different ways.

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CMTA to Begin Scooter Giveaway Program

Beginning in March 2007, in a partnership with Scootaround and the Clarence Vincent Foundation, the Charcot-Marie-Tooth Association (CMTA) will give away four electric scooters each year to people with Charcot-Marie-Tooth disease, an inherited neuropathy that causes muscle wasting and may severely limit a person's mobility.

"We are always looking for ways to offer additional services," said CMTA Executive Director Charles F. Hagins, "and our partnership with the



Clarence Vincent Foundation will give us an extraordinary opportunity to help restore freedom and independence to a

few of the many people severely affected by CMT."

"We understand the needs of an organization with varying levels of resources", said Lee Meagher, President and CEO of Scootaround, "and we are proud to partner with the CMTA and help people affected by CMT move around with added control, comfort and self-confidence."

In 1986, Meagher's father, Clarence William Vincent, suffered a stroke that affected his ability to speak, read and walk.

Jack Walfish Elected to the Emeritus Board of Directors

At their last Board meeting, the Directors of the CMTA announced that they would award Emeritus status to CMTA Board Member, Jack Walfish. He joins Dr. Robert Lovelace who was awarded that status for his years of service on the Medical Advisory Board.

Jack joined the CMTA Board in 1994 and almost immediately began making his presence felt by serving as the Treasurer of the Board. From there, he progressed to the position of President in 1998. He didn't know then, but his volunteer job would soon become an almost day to day responsibility as he shepherded the office through the trauma of recovering from Hurricane Floyd in September of 1999 and the

total destruction of the office in Upland. For weeks, he drove from his home in New Jersey to our old office building (before it was condemned), then continued to work with the staff almost daily to find, and move to, our current headquarters in November of that year.

For three months, the office functioned on card tables and side tables gathered from the homes of staff members and friends, who gave them out of sympathy for our plight. We looked like a ragamuffin group during those days, but we were open every day, partly because Jack insisted that we regain normalcy as quickly as possible. Despite having cataract surgery during that traumatic time, Jack faithfully continued to work with the staff to rebuild

what that natural disaster had almost completely stolen from the CMTA...all its storehouse of information. We, quite literally, could not have recovered without him.

In 1998, Jack wrote an article for this newsletter in which he said, "I look back now and realize that too many doctors and distinguished specialists knew practically nothing about CMT. It was true in those days and it's still too true today. We have come a long way, but we have a long way to go."

Jack's words, although almost a decade old, still ring true.

The CMTA thanks Jack for his years of service and recognizes his incomparable contribution to this organization. *

—Pat Dreibelbis

At the age of 58 he was forced to retire and adapt to his physical limitations. But his family realized the need to get him back to his day-to-day life and got him a scooter. Seeing how the scooter helped her father regain his independence, Lee Meagher created Scootaround, a company designed to make it easier for people with disabilities to rent a wheelchair or scooter. Today, Scootaround operates about 125 locations that serve over 500 cities throughout North America, and rents about 1,000 scooters and wheelchairs every month.

In honor of her father, Meagher launched the Clarence William Vincent Foundation to improve the quality of life for those with limited mobility and to provide the necessary equipment to get them from one place to another.

“This gift of mobility is something that my father would have wanted all of those with impaired mobility to experience,” Meagher said. “I know what a scooter meant to my dad and to my family. A scooter provides more than independence and mobility—it provides a sense of dignity.”

For more information about eligibility for the CMTA scooter giveaway and an application form, please visit www.charcot-marie-tooth.org, send an email to scooter@charcot-marie-tooth.org, or write the CMTA at 2700 Chestnut Street, Chester, PA, 19013. Applications for the March 31, 2007, giveaway must be postmarked no later than March 15, 2007.

For more general information on the Clarence Vincent Foundation and the scooter giveaway program, please visit www.scootaround.com/cvf.

—Dana Schwertfeger

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

(Items marked with an asterisk “*” are required.)

*NAME: _____ / _____ / _____
First MI Last

*ADDRESS: _____

*CITY: _____ *STATE: _____ *ZIP: _____

*COUNTRY/POSTAL CODE (IF NOT US): _____

*DAYTIME PHONE: _____ EVENING PHONE: _____

EMAIL (Required for website access and PDF newsletter): _____

Note: If you are joining now, you may purchase publications at active member prices. ACTIVE MEMBERS have paid dues within the past year. If you are unsure about your membership status, please call 1-800-606-2682.

	QTY	COST	TOTAL
ANNUAL MEMBERSHIP DUES			
Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both. Receive newsletter as: <input type="checkbox"/> Print <i>or</i> <input type="checkbox"/> PDF via email		\$40	
Receive both Print <i>and</i> PDF Newsletters		\$45	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		active members \$15 nonmembers \$20	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 nonmembers \$7	
CMT Facts III		active members \$5 nonmembers \$7	
CMT Facts IV		active members \$8 nonmembers \$10	
CMT Facts V		active members \$12 nonmembers \$15	
A Guide About Genetics for the CMT Patient (No shipping and handling on this item only)		active members \$4 nonmembers \$5	
CMT Informational Brochure		FREE	
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research Fund (100% of contribution is used to fund research)			
Shipping & Handling (Orders under \$10, add \$1.50; orders \$10 and over, add \$4.50)			
TOTAL			

Check payable to the CMTA (US residents only; non-US residents, please use credit card or international money order.)

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

Mail to: 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.



CMT REGISTRY

(Continued from page 1)

We'll go into more detail later about how data are used here at the CMT registry.

The Charcot-Marie-Tooth North American Database was created in 2001 with the goal of furthering research on the causes and treatment of CMT. The database, funded by the Charcot-Marie-Tooth Association, is an endeavor headed by Wayne State University and housed at Indiana University School of Medicine. To date, the registry contains information from about 600 people in 470 families that are affected by any of the various types of CMT.

JOINING THE DATABASE

Who can join the database? The registry is open to any person who has any type of CMT. There are no other requirements!

How do you join the registry? Joining the registry is easy. There are several forms to fill out, all of which can be found on the Wayne State University CMT Clinic website (see inset). You may also request the forms be sent to you by calling (313) 577-5273.

In order to participate in the registry, you will need to fill out:

- a consent form for your information to be collected and stored in the database;
- a consent form that allows your protected health information to be collected;
- a consent form that will allow the researchers at Wayne State University to collect pertinent medical records;
- a symptoms questionnaire;

- a family history questionnaire;
- a physical form with cover letter for you to present to your treating physician if you choose to.

The forms can take several hours to fill out and ask for a lot of information. Understandably, this might not be the most exciting several hours of your life, but it's important for us to get a complete picture of you and your experiences with CMT! If you have problems or questions about any of the forms, you can call WSU at (313) 577-5273.

When you have completed the questionnaires, you will mail

information. In this situation, researchers and clinicians who are interested in conducting research into CMT are required to submit a research request. The request is then evaluated by a panel of experts to ensure both that it is a sound study and that all appropriate measures are in place to protect potential subjects. Once a request is approved, Indiana University searches the database to find the people and/or data that fit the request. We then send an information letter about the study and an informed consent form for that specific study to each person who meets the study criteria.

QUICK CONTACTS:

Forms to participate in the CMT Registry can be found at:

http://www.med.wayne.edu/neurology/clin_programs/Labs/CMT/CMTDatabase.htm

For forms, questions, or comments, contact:

Wayne State University, (313) 577-5273

them to Wayne State University (the address is listed on the WSU website). They are then sent to Indiana University, where data are entered into the registry database. This database is protected by a vast number of security measures to ensure that your information is secure and confidential.

What happens once you've joined the registry? Two types of research can be conducted using data from the registry. The first type is simply statistical/demographical research. This request does not involve the use of any identifiable information and can be released to researchers requesting statistical/demographic information.

The second type of research request requires identifiable

No information is released to the researcher without your explicit, written permission to do so. You are never under any obligation to participate in any research project, and if you choose to participate in a study, you can withdraw at any time with absolutely no consequences.

LOOKING AHEAD

From the support groups, the fundraisers, the newsletters, and the considerable response we've already had to the database, it is clear that this is an active, dynamic, involved CMT community. We want to continue our efforts to build a registry that serves you. Together, we can make 2007 a banner year for CMT research! ✨



GIFTS WERE MADE TO THE CMTA

IN HONOR OF

James Arter

Jeffrey Vanetten

Dr. and Mrs. Bruce Bennett

Jason and Rachel Bennett

Yohan Bouchard

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Barbara Whatley & Linda Hudson

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Keith Widdop

I've Just Been Diagnosed: What Should I Do?

BY PAT DREIBELBIS

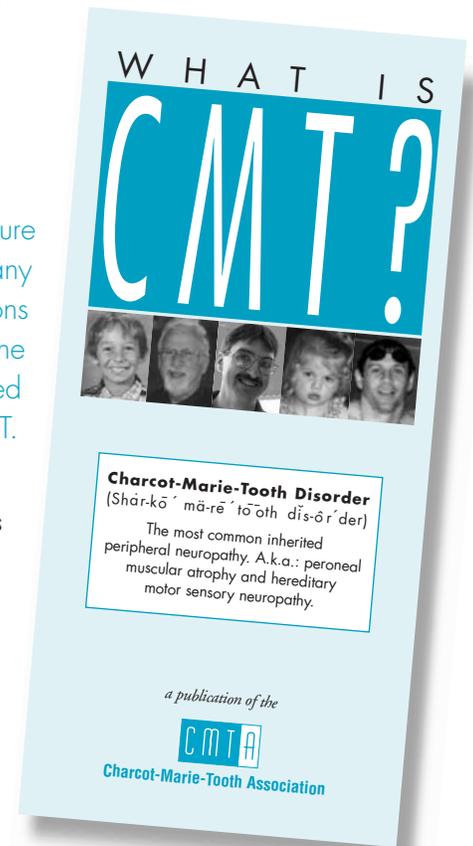
That question was posed to us in an email by a man who had just received a CMT diagnosis. So, what should people do when they first learn they have this disorder?

When people were diagnosed 30 years ago, there wasn't much to do. There was no CMTA, no Internet to access for help, and not many doctors who could even make the diagnosis. Patients were left to look through medical textbooks searching for some insight into what on earth CMT was. For many, the diagnosis came as a complete surprise because they had been very active and sports' oriented. For some it was just the "family curse" that they watched their mother or father deal with. For all of them came

the knowledge that the loss of muscle strength and the awkwardness in their gait weren't going to disappear with exercise, and they were facing something described as "progressive and degenerative."

Back then, worst of all, were the pictures in medical textbooks that made CMT patients look freakish and crippled. It was terrifying for patients to look at them and think about what the future might hold, even though most

The CMT Brochure is just one of many excellent publications that inform the newly diagnosed about CMT.



of the worst-case scenarios presented in medical textbooks weren't what the average CMT patient faced. Still, it was disheartening to have the doctor

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: _____



tell the newly diagnosed patient, “There’s nothing we can do for you. Go home and do what you can because eventually you will be in a wheelchair.”

That was the situation thirty years ago, but how do we answer the person’s question in 2007? We say, “Learn all you can about the disorder.” Today, you have the CMTA, the Muscular Dystrophy Association, the Internet, many excellent publications about the various aspects of CMT, and, if you are lucky, a doctor who knows what CMT really is. Knowledge is power when facing a lesser-known disorder. Some of our members tell us that they still know more than their doctors do. Some of them have bought the handbook for their doctor so he/she can read about CMT. Most of them put the neurotoxic drug list in their patient files.

A person with a “rare” disorder (which is still the category into which CMT falls) has a responsibility to be his/her own advocate when dealing with the health system. So, the more that person knows, the better the care he/she will receive. It’s as simple as that. In addition, the more a person knows, the more likely it is that he/she will be a pro-active patient, using physical therapy and adaptive devices to remain vital.

We told the man who asked the question to learn everything he could, and he would be well prepared to deal with having CMT in his life. ✱

Hope vs. Expectations

“Hope vs. Expectations” is the first in a series of articles for the newsletter. Each article will be a step-by-step guide to enjoying life while living with physical limitations.

BY PAT MEUTH LCSW, COUNSELOR

Just as everything in nature is intertwined and connected, with one situation affecting the other, so it is with our lives. For instance, if it has been a very dry summer, and then we have a wet spell, plants or trees may become nurtured and survive, even though they once appeared dried out and lifeless. So it is with human beings. When we have physical and/or emotional complications in our lives, sometimes just a few changes can make a difference in how we feel and how we function. Perhaps a change in our outlook, our attitude, or our perception can make our lives easier. When life gets easier, we have more fun, we are more optimistic, and we function more closely to our optimum potential.

A pitfall of society today is the attitude of “expectation.” Often, “expecting” a person to act a certain way, feel a certain feeling, or think as we expect him/her to think has become a way of life. We can become very rigid in our dealings with ourselves, or our interactions with others. We set up ourselves and others for failure. When a doctor’s appointment doesn’t turn out the way that we had “expected,” or when a person doesn’t act or feel or think the way that we “expect,” we become trapped in the consequences of assuming a specific result will happen. When our “expectations” are not met, disappointment, anger, anxiety, and depression are usually high. Acceptance and serenity are usually very low. This way of thinking is a rut that is difficult to get out of.

I teach about “hope” and “hopefulness”—learning to be hopeful about what may happen instead of “expecting” results. Being hopeful is a very different way of living. When we are hopeful, we are much kinder to ourselves, and others. Our outlook about life is very different. No matter the outcome of a situation, disappointment, anger, anxiety, and depression are lower. Acceptance and serenity are higher.

When we are “hope-full,” we may look forward to, or “hope” for, a certain outcome, but we are also prepared for different results. Those results are easier to accept, and we cope better with the results. When our coping is better, we are healthier and happier.

I encourage you to look for ways to be kind to yourself, to be full of hope and passion for life. Look to those who love and support you for help while you are on your journey of discovery. ✱

Pat Meuth LCSW is a counselor in Brighton and Westminster, Colorado. If you would like to schedule a counseling appointment, please call 720-635-9366. If you have a suggestion for a future article in the newsletter, please email Pat at p_meuth@yahoo.com

The Helios® Thermoplastic Brace: A New Option in CMT Bracing

BY MITCHELL WARNER, CPO, ORTHO REHAB DESIGNS

After many months of development and careful consideration of design, we have developed a new thermoplastic version of the standard Helios® orthosis.

The original Helios and Helios® E/I are made with carbon fiber and Kevlar throughout the orthosis. Our newest Helios design is made from thermoplastic material. However, carbon fiber reinforcements can be added to sections of the brace on a case-by-case basis.

WHY PLASTIC AND NOT CARBON FIBER?

When considering any patient's needs for an orthosis, weight, activity level, age, and severity of the progression of CMT all must be taken into consideration from the clinician's point of view. Sometimes, from the patient's point of view, there is a need for something less expensive; also, traveling considerations may be a factor. The reason we have designed the Helios thermoplastic is to give



The foot plate of the new Helios® brace

patients more options when considering brace costs and materials. We will always help any patient make a decision based on what is more appropriate for them regarding an orthosis, and their specific needs.

The Helios thermoplastic is actually more appropriate for a patient of lower activity level, or a combination of a lower activity level and greater body weight. Also, the severity of foot deformity and balance loss would have to be very low to mildly moderate. When dealing with moderate to severe foot deformity, laxity of the joints, and severe balancing problems, the Helios that is made out of full carbon fiber and Kevlar will always be a better option as it offers more control.

THE THERMOPLASTIC HELIOS VERSUS OFF-THE-SHELF DEVICES

Though the thermoplastic Helios is not carbon fiber, it can be reinforced in areas with carbon-fiber. It will still produce more superior results than any off-the-shelf brace. Since this brace is taken from an actual leg mold, it is custom-designed and modified with the typical Helios design corrections. A custom fit, with proper alignment and correction for balance, will give the wearer more benefit than any off-the-shelf, and many standard custom, plastic designs that are currently available.



A view of the entire Helios® brace in thermoplastic

Because this new version of the Helios is made in thermoplastic and not carbon fiber, the procedure for fabrication and the cost of materials is considerably lower. The cost of it would be approximately 50% less than the Helios E/I (eversion/inversion) model. Of course that is always dependent on the severity of the patient's condition and what needs to be done as far as clinical corrections.

As Helios braces are currently only available in Las Vegas, the stay for a thermoplastic Helios will be approximately 1-3 days with 2 days as the average. To compare, a Helios that is made out of 100% carbon fiber and Kevlar would require a 5-day stay in Las Vegas from the time of leg molding, to getting

TO LEARN MORE ABOUT HELIOS® BRACES CONTACT:
Mitchell Warner, CPO
Ortho Rehab Designs
2578 Belcastro St.
Suite 101
Las Vegas, NV 89117
Phone:
702-388-9909
Website:
www.ORDesignsLV.com

the device, and then follow-up. With the thermoplastic Helios, there are no test braces made, as required in the case of a carbon fiber Helios where we must fabricate a set of prototype braces first.

WHICH OPTION IS MORE APPROPRIATE? THE HELIOS THERMOPLASTIC OR THE HELIOS CARBON FIBER?

I designed the Helios thermoplastic to make more options available to the CMT patient. With this brace's lower cost, less time needed to fabricate, and less time needed to stay in Las Vegas, more options are now

available to patients to make decisions as to what is appropriate for themselves based on their physiological profile and deficits due to CMT. I believe in giving options to patients and letting them make an informed decision as to what is better for them, and what they want. I am always glad to help my patients in this decision-making process.

VIDEOGAIT EVALUATION

As with the carbon fiber Helios, I still offer video evaluation at no cost for the thermoplastic Helios. To participate in this process, any patient can visit www.ORDesignsLV.com, and click on the VideoGait

button. There he/she will find printable and easy-to-follow videotaping instructions and an information form. This should be sent to Ortho Rehab Designs for evaluation to see if a thermoplastic Helios or a carbon fiber Helios is suitable. We do not charge the patient to evaluate the videotape. This process helps us learn what the patient may need or may not need, and whether or not he/she would benefit from Helios style bracing. Before a patient makes a decision to come to our clinic, we want to make sure that the Helios would be an appropriate choice. *

LETTERS

Dear CMTA,

My husband and I would like to contribute to CMT research in response to the 2006 Livney Challenge. I'll tell you why.

I was diagnosed with CMT when I was a teenager growing up in Washington, DC. Over the years, I've had tendons transferred to keep my patellas from dislocating; osteotomies and tendon transfers to stabilize my feet and ankles. My hammertoes were fused and eventually I had a triple arthrodesis of my left ankle and foot. All this enabled me to lead a fairly normal, if not athletic, life.

My two children were diagnosed with CMT. As a mother, and one with some guilt for having "given" CMT to my children, I have always strived to set an example. My mantra has always been that we have been

hampered by our legs, but that we've been given a multitude of other gifts—good minds, a great spirit, a wonderful husband and father, and a life of privilege.

We all know that one must be his own advocate, doing research and networking to find the best care. Now, as grandparents, we want to help pave the way for the research that will make the lives of our grandchildren, and the lives of so many others, healthier and easier because of the inroads made through research to cure CMT.

With this gift as a contribution to the Livney Challenge, we hope you will be able to make significant grants to lead to improved knowledge of CMT, and ultimately a cure. Please keep us informed on the grant recipients, their goals, and progress.

—R.W., Maryland

Dear CMTA,

I would like to tell all your readers about a wonderful experience I have had with pool walking. I have tried many exercise machines over the years and have had some, but limited, success in building any leg muscles. When I developed a hip problem, water exercise was suggested. In the weeks that I've been walking in a lane of my local rehabilitation center's pool, I have actually seen improvement in my lower leg muscle strength. Not only that, but my balance seems to have improved as well. I intend to make pool work a permanent addition to my exercise regimen and recommend it to any CMT patient who can still walk with minimal aids.

—L.P., Tennessee

WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Pkwy.

Chester, PA 19013

or

info@charcot-marie-tooth.org

5-Minute Fundraising: iGive.com

BY ELIZABETH OUELLETTE

Do you or someone you know own a computer? Have you, a friend, or any member of your family ever made a purchase on-line? Would you like a donation to go to the CMTA, automatically, every time you buy an item from an on-line shop at no cost to you? If you answered yes to any of the above questions—read on!

The Charcot-Marie-Tooth Association is fortunate to have many generous donors and devoted members who want to make a difference in the lives of others by giving and raising money to advance research, increase awareness of CMT, and support this organization's missions and goals. Many individu-

als go above and beyond the call of duty by planning fundraising activities, like bake sales and classroom donations, golf tournaments and formal dinners. But, let's keep in mind that despite the best of intentions, not everyone can put together a fundraiser! Our lives tend to be overly busy and often times downright hectic. We have families, jobs to go to, kids to pick up, errands to run, and the list goes on and on. Moreover, there are a great number of people with CMT who have a difficult time just getting through a normal day because of CMT-related fatigue and disability.

Unfortunately, for many of us, the fun in fundraising is not the first thing that pops into our minds when considering the possibility of hosting a charitable event. As for me, dreadful images of past experiences where frantic planning, organizing, and running around dominate my thinking. Furthermore, when I looked up fundraising in an on-line encyclopedia I found: "fundraising is the process of soliciting and gathering money or other gifts in-kind, by requesting donations from individuals, businesses, charitable foundations, or governmental agencies."

I enjoy fundraising for the CMTA. Of course, raising money is an art, and once in a while, when attempting to be innovative, my "ideas" do not turn out quite the way I had envisioned.

Last summer, my mother and I brainstormed fundraising ideas at length. In addition to a raffle, we decided to sit on the main pedestrian street in Burlington, Vermont with the hopes of informing the public about CMT by passing out flyers and collecting donations for the Association. What a disaster! The pedestrians avoided us like the plague, and we collected all of \$4, half of which my mother put in the donation pail at the start of the day. In retrospect, this was not the best tactical plan, since most people do not like to be approached for money, especially by unknown women for some unknown disease. Nevertheless, I've chalked this adventure up to one of those learning experiences, It was a great bonding and eye-opening experience, one which still generates laughter whenever that fateful day is mentioned.

In this light, let me re-emphasize that the "fun" in fundraising is there for some very good reasons. Raising money does not have to be an all-consuming, energy-zapping activity. It can be gratifying and easily accomplished by all. If you, a friend, or family member have access to a computer and shop on-line, the solution to your fundraising desires is—[www.iGive.com!](http://www.iGive.com)

iGive.com has partnered with many businesses to help non-profit organizations raise money. They are currently contracted with over 600 well-



Bev Rooney stands on the mall in Burlington, VT, trying to raise money for CMT.

known stores, including eBay, flower and gift basket vendors, JC Penny, Circuit City, Lands' End and many more. Through iGive, each store offers anywhere from 0.4% to 26% of your total purchase directly to the CMTA, at no cost to you! The best news is that it only takes five minutes to sign up. When you download the iGive shopping window, every time you shop at one of the stores associated with iGive, a window pops up and the donation happens automatically. You may also go right to the iGive site and browse merchants, view the percentages donated, and keep track of the money you have raised for your particular cause.

I have used this service over the past two years, personally raising over \$300 for the Charcot-Marie-Tooth Association, all without effort! You may think \$150 per year does not sound like much, but just imagine if every member, their families, and friends joined today. That \$150 could turn to \$15,000 or more in no time! Our potential is unlimited. In addition, when you tell a friend about iGive, a \$5 bonus goes immediately to the CMTA. If you would like to view the step-by-step instructions for iGive, go to <http://www.charcot-marie-tooth.org/PDF/iGive.pdf>, found on the CMTA website. When you sign up, feel free to send me an e-mail at elizabetho@pac-bell.net. I would love to hear from you learn about your experience and answer any questions.

We need your continued support to serve you, to spread awareness, and to continue our

A TOOL FOR PARENTS: *Your Child's Health and Wellness Record*

Karen Melnick, R.N, sent a copy of her document organizer and health recorder to our office. It is called "Your Child's Health and Wellness Record" and consists of two books, one a notebook in which you can store a report from a neurologist or podiatrist or something like an IEP (Individualized Education Program) for your child's year in school and the other a book in which you can record things like medications, diagnostic test results, and physician's names and their diagnoses.



If you think that you will naturally remember all these things without keeping a record, you might be amazed at how much there is to remember and how valuable this information could be to your child when he/she is no longer a child and you are not available to ask questions of.

The two publications are beautifully presented with pictures, all in black and white, of children in various stages of growth. Additionally, Karen has thought of some categories that you might not even think of. She suggests gathering information on all blood relatives, illnesses, and conditions that have affected other family members, any natural remedies or vitamins your child is using, and any operations your child has had, even if they are unrelated to the disease you are currently dealing with.

Just about everything related to helping you help your child through his/her health challenges and keeping detailed records of that journey is included in this two-volume organizer. Karen has even included a section in the notebook to keep receipts for any medical bills you pay "out of pocket." This could certainly help you at income tax time.

All in all, the organizers seem very well thought out and would be a wonderful gift for a first-time mother or a seasoned veteran.

For further information about these products, you can visit www.healthandwellnessrecord.com. Or, you can call the publisher HR Press at 705-721-4981. *

quest for treatments and cures. By joining iGive, you feel good about your continuing contributions, and you also know that you are playing a very important role in the future of the CMTA

and its accomplishments. You have nothing to lose and the CMTA and its members have everything to gain. So, spread the news and don't delay—join iGive today! *



SUPPORT GROUP NEWS

California – San Francisco Area

We had between 15 to 20 members at the January 6, 2007, meeting. Dr. Michael Shy, Chairman of the CMTA's Medical Advisory Board, and head of the CMT clinic at Wayne State in Detroit, MI, was our speaker. He presented 10 slides which covered the basic biology of CMT. Then he described the two major types, 1 and 2, and the type X which is a variant form of type 1. He also explained rarer forms of CMT and answered many questions from the members in attendance. Also present was Charles Hagins, Executive Director of the CMTA, who talked about the work going on in research, in spreading awareness of CMT, and in providing client services to members of the association.

The next meeting will tentatively be on the first Saturday in March.

Massachusetts – Amherst Area

The recently formed support group in Amherst, MA, will not be holding a meeting on March 2nd, 2007, as previously announced. The former leader, Ellen Panzer, has been informed that she does not have CMT, so she is giving up the leadership of the group. If any of the members are interested in assuming the role of support group leader, please contact the CMTA office and we will be happy to assist you. We thank Ellen for all her hard work and wish her well.



Attendees at the Johnstown Support Group Meeting in December enjoyed homemade cookies and other caloric delights.

Pennsylvania – Johnstown

The Johnstown, PA, CMTA support group held its annual Christmas party Saturday afternoon, December 16, 2006. The event was well attended with lots of festive high-calorie fare and great conversations. The highlight was the arrival of Jeana Sweeney, co-leader, who brought her two beautiful young daughters, Halley and Rylee (who had been missing because of illness). We had some new members attend from Hanover, PA, a three-hour drive away.

Pennsylvania – Philadelphia Area

The group met on January 20, 2007, in the community room of the Chestnut Ridge Assisted Living building. Bruce Goodman, C.O. from Harry J. Lawall & Son, Inc. Prosthetics and Orthotics, answered all kinds of questions about the various

types of braces available for CMT patients. Different attendees walked in order to have a visual gait analysis done and almost every person at the meeting who wore braces took his/hers off to engage in "show and tell." Fifteen persons attended and the group shared valuable information regarding doctors, physical therapists, and orthotists from whom they had received excellent care.

The next meeting is tentatively scheduled for March 24, 2007.

Nevada – Las Vegas

A new group met for the first time on January 22, 2007, from 1-3 PM at the Whispering Pines Community Center in Las Vegas. If you would be interested in attending future meetings, please contact Mary Fatzinger at cmt_suppgrp_lvnv@yahoo.com. *

CMT Support Groups

Alabama—Birmingham

Place: Lakeshore Foundation
Fitness Center
Meeting: Call for schedule
Contact: Dice Lineberry, 205-870-4755
Email: dklr1@yahoo.com

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.net

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

Nevada—Las Vegas

Place: Whispering Pines Community Center
Meeting: Email for dates 1-3 PM
Contact: Mary Fatzinger
Email: cmt_suppgroup_lvnv@yahoo.com

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)

Place: Various locations in Raleigh
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (afternoons)
Email: judae@bellsouth.net

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

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: info@charcot-marie-tooth.org

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



ASK THE DOCTOR

Dear Doctor,

I am concerned that my oncologist wants to put me on vinblastine, a drug I feel might be related to vincristine. Should I be concerned?

The doctor replies:

Vinblastine is closely related to vincristine. Although there are no specific reports of vinblastine toxicity in CMT, it likely is a very high-risk agent, especially if you have CMT1A. Vinblastine also causes neuropathy in individuals without existing neuropathy. If you have another form of CMT, the risk is less clear, but certainly your oncologist should consider whether equivalent drugs are an option.

Dear Doctor,

I recently had an endoscopy and was told to start taking Aciphex for my gastritis and duodenitis. Is this a safe medication for CMT? I see that Prilosec is on the list. Is Aciphex a similar compound?

The doctor replies:

Aciphex (rabepazole) is in the same class of drug as Prilosec (omeprazole) and Prevacid (lansoprazole), both of which have very rarely been associated with causing peripheral neuropathy. Even this association is still preliminary and not well accepted, however. I know of no cases associating Aciphex with neuropathy to date, but neuropathy is listed in the company information as a very rare association (less than 1/1,000) from its clinical trials conducted before drug release. It is not known

whether Aciphex also carries the same small risk as the other drugs in this class, but it is possible. There is no information on whether CMT patients are at greater risk than others. The small risk must be weighed against the drug indication. Definite gastritis or duodenitis is a much stronger reason for use and for potential benefit than simple uncomplicated heartburn.

Dear Doctor,

I have a question for the experts. Are there nutritional supplements and/or herbal supplements that should be avoided by a person with CMT? Can increased doses of magnesium citrate cause neurotoxicity? My chiropractor has me taking MyoCalm PM as needed for muscle tension which contains magnesium citrate 150 mg and calcium lactate 75 mg as well as other herbs. I reviewed the list of toxic drugs and did not see any mention of supplements.

The doctor replies:

There is very limited information about nutritional and dietary supplements and peripheral neuropathy. I know of no suspicious or theoretical problems with magnesium citrate or calcium lactate. There were a few reports of sudden neuropathy with St. John's Wort in the late 90's, but very little since then. Podophyllin resin is clearly neurotoxic and is contained in certain roots used in Chinese herbal remedies, but no longer in Western supplements since the 1980s. One problem is that

the full ingredient list in some herbal supplements is not available, accurate, or required.

Dear Doctor,

Can you help me figure out the risk factors of taking Zetia and having hepatitis C?

The doctor replies:

There are no reports to date of ezetimibe (Zetia) and neuropathy or nerve toxicity, but, as with all cholesterol-lowering treatments, muscle toxicity can occasionally occur. The drug works differently from the statin class of drug, although Vytorin contains both ezetimibe and a statin. Hepatitis C, on the other hand, is a common and important cause of neuropathy.

Zetia can cause toxicity to the liver, especially in patients who already have liver problems, such as chronic hepatitis C. An internist or gastroenterologist would be better to consult about these hepatic (liver) issues. I do not know the relative risk in this setting, which appears to be separate from CMT.

Dear Doctor,

I noticed on your medical alert page that you put amitriptyline in the negligible to doubtful risk category. I definitely had a very bad reaction to it. To date it was the worst of any other meds I have taken for CMT nerve pain.

I have CMT and have tried many medications to ease the neuropathic pain. I have had little success. Vicodin is the most manageable without any major side effects or thought-process disrupt-

tion. Neurontin caused me to break out with very painful cysts on my face and did little to ease the nerve pain.

I recently was prescribed amitriptyline. The very first dose of 5 mg caused some weakness in my legs and increased back pain. On the fourth day, when I increased the dose to 10 mg, I suffered such severe back and leg pain that my daughter took me to the emergency room. By the time I returned home (7 hours later), my pain had eased quite a bit, so I went ahead and took the amitriptyline as prescribed when I went to bed. Within an hour I was in horrific pain again, lasting about 6 hours. Needless to say, I will not be taking this drug again.

The doctor replies:

The painful reaction experienced is a very unusual reaction to amitriptyline (Elavil). The drug is on the negligible list only because of some very old and unconvincing reports from the 1970s. There are other common side effects attributable to predictable blocking of autonomic nerve signals that cause dry eyes and mouth and bladder complaints; increased pain and weakness are not typical side effects. Drowsiness is also common. The drug is still frequently used to treat the symptoms of neuropathy as long as the common side effects are tolerable; there are other similar drugs available with fewer side effects. However, the drug appears to be intolerable to this patient and probably best avoided. I have found no other similar reports of this kind in a review of the North American CMT database registry. *

My New Toy: Voice Recognition Software

BY J.D. GRIFFITH, JOHNSTOWN SUPPORT GROUP LEADER

I am writing this piece without hands! I'm using Dragon NaturallySpeaking 9 software to convert my voice into text. It is weird to talk and see what you just said appear as sentences on the computer screen. I bought the software a few weeks ago, and I'm finally getting the process down. This software may be quite useful for people with CMT who have problems with their hands or folks like me who just can't type. My general practitioner had been using the medical version with considerable success for years.

You talk into a noise cancellation microphone headset, which comes with the software, and what you say magically (most of the time) appears as text in your document. You can also write e-mails, enter data in spreadsheets, and navigate the Internet using your voice. The software learns how you speak and the accuracy improves the more you use it. However, you must speak distinctly and enunciate into a properly positioned microphone. Dragon can type 160 words per minute and does a good job at recognizing multisyllabic words. Dragon advertises that the software achieves up to 99% accuracy, but my present level is probably around 80%. You can also correct mistakes, replace words, spell words, and navigate around your documents and programs, using your voice. Also (and this is important!), don't forget to turn the microphone off when someone comes into the room—the consequences could be disastrous. (I just had to delete a couple of pages of gibberish.)

There is a fairly steep learning curve to this software, but I am finally beginning to think it really is pretty neat—even though I still have a way to go. Out of the box, it reminded me of dealing with DOS commands 20 years ago. For those of you who are not familiar with DOS commands, they are not a particularly intuitive combination of keys that you press to make a PC do what you want it to. I was convinced that this computer stuff was for nerds, and would never catch on.

This software really is amazing. To take sounds and convert them into words that make sense is no small feat and requires considerable computing power. The minimum system requirement is a Pentium 4/1 Gigahertz, 512 MB RAM, 1 GB free hard disk space and Windows XP. Dragon NaturallySpeaking Preferred 9.0 retails for \$200 (\$97 after rebates at Amazon), and the standard version retails for \$100. The package comes with a noise cancellation headphone that works well but is designed for people with extremely small heads. Despite some complaints, this software can be very useful for people once they learn how to use it. *



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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 (Arava)
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)
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



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