



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.

Ascorbic Acid Clinical Trials Set to Begin

The CMTA is pleased to announce that participants are now being sought for the high-dose clinical trials

of ascorbic acid to be held at Wayne State University, Detroit, Michigan; the University of Rochester,

Rochester, New York; and Johns Hopkins School of Medicine, Baltimore, Maryland.

Participants must be between the ages of 13 and 70 and have been genetically confirmed as having CMT 1A, or have an immediate family member who has undergone genetic testing and has had confirming

nerve conduction velocities. The genetic tests will not be paid for by the trials. No pregnant women will be considered.

There is no charge to be part of the trial, but transportation to the testing centers is the responsibility of each individual. Participa-

tion will require two visits per year and each person will participate for a two-year period.

Because participants will join at various times, the actual trials are expected to last three years.

The doses will be given by mouth, and 80% of participants can expect to receive the ascorbic acid and not a placebo.

If the results are positive as the trials proceed, all participants will eventually be given the actual high-dose ascorbic acid.

The clinical trials are almost ready to begin. When contact information for each testing facility is available, it will be posted on the CMTA web site. In the meantime, individuals interested in being considered for the clinical trials should call or email the CMTA and register their name and contact information (see info below). It will be kept private and be transferred only to the testing facilities. *

Contact the CMTA via phone:
610-499-9264 or 1-800-606-2682
or by email:
ascorbicacid@charcot-marie-tooth.org

80% of participants receive the ascorbic acid and not the placebo.

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NIH Peripheral Neuropathy Conference Bethesda, MD — October 22-24, 2006

More than 50 renowned scientists, representatives from patient advocacy groups, and directors from the National Institutes of Neurological Disorders and Stroke (NINDS) attended the NIH Workshop on Peripheral Neuropathy.

"We're very excited," said Charles F. Hagins, Executive Director of the Charcot-Marie-Tooth Association. "This workshop brought together many of the top scientists in the field and

encouraged them to identify the most promising avenues of research for the next five years. The collaborations and strategies forged at this workshop should have a tremendous impact on the course of CMT and neuropathy research."

Among those top scientists were three members of the CMTA's Medical Advisory Board: Dr. Michael Shy, (Chairman of the MAB), Dr. Phillip Chance, and Dr. Steven Scherer. (Dr Scherer is also the recipient

of the CMTA's three-year \$100,000 per year grant.)

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CMT in the News

Newspapers around the country feature stories about people with CMT

The *Tuscaloosa News* featured an article entitled, "Ready, willing and able" that discussed tours provided by the Alabama Department of Rehabilitation Services and the American Association of People with Disabilities as part of "2006 Alabama Disability Mentoring Day." One of the highlighted students was Ashley Farr, a student at Shelton State Community College who hopes to obtain a biomedical engineering degree. She visited a health clinic to see how a curt toned defibrillator worked. Farr, who has been diagnosed with Charcot-Marie-Tooth disease, believes that a disability becomes part of who you are, but it doesn't define you. The program is intended to give students a chance to see if a job is right for them, and it gives employers a chance to learn about how people with different abilities can do the jobs they were hired to do.

The Casper Star-Tribune highlighted the unusual contribution of Kassie Brinkerhoff to

her high school's volleyball team. Kassie has Charcot-Marie-Tooth disease but starts for the Rock River varsity volleyball team. She has to! Only five other players are out for the team this year, so for one serve each match, Brinkerhoff stands in uniform near the corner of the court, then comes out as an injured player. Kassie, who is a senior, said that she had a plan to just fill in until they got enough players, but that never really happened. Rock River high school has only 13 girls in grades 9-12. Brinkerhoff had been the team's manager for three years, and, when it was noted that a volleyball team can't gain credit for a victory if they start a game with fewer than six players on the floor, she decided to suit up. Kassie has dreams of teaching elementary school special education, and her teammates are sure she'll accomplish that dream.

The Daily Collegian, the publication of the Pennsylvania



The Joe Paterno ornament is the current best-seller for Georges' Floral Boutique.

State University, did a feature on October 20, 2006, on homecoming and the appearance of Christopher Radko, known for his European-made glass ornaments, at the Bryce Jordan Center, where he autographed purchases of his signature Joe Paterno ornament to benefit the CMTA.

Radko was quoted as saying he was "so psyched to do this." Radko was pleased that royalties normally given to Paterno would be going to the CMTA. Radko said that he hoped his ornaments would help to make a difference in the lives of others. Charles F. Hagins, Executive Director, announced that the royalties would be directed toward awareness and education of CMT.

A press release from the University of Miami's Miller School of Medicine announced, "Two of the World's Top Geneticists are Coming to Miami." The two geneticists are Dr. Jeffery Vance and his wife, Dr. Margaret Pericak-Vance, formerly of Duke University. Jeffery Vance, MD, PhD is the

Workplace Giving Campaigns

If you work for the federal government, please remember that you can make a workplace contribution to us by choosing number 2513, the Charcot-Marie-Tooth Association. If your place of business has a United Way campaign, you can fill in our name on the line for designating your contribution. We have a different number in every United Way campaign, so it is best to simply write in our name. We are the recipient of funding from many of the United Way campaigns, and those gifts help us continue our mission of finding a cure and educating medical professionals and the public about CMT. *



associate director of the Duke Center for Human Genetics, professor of medicine, and director of the Morris K. Udall Parkinson Disease Research Center of Excellence at Duke. His lab has found and studied genes that contribute to diseases including Parkinson's, Alzheimer's, and one of the most common inherited neurological disorders, Charcot-Marie-Tooth disease. (He is also a member of the CMTA's Medical Advisory Board.)

Several other investigators from the Duke team will also move to South Florida. "We're a very integrated group and we work together on a daily basis," Jeffrey Vance said. "Miami is just a tremendous opportunity to continue to grow, and to begin to translate some of these genes that we're finding into actual practice. That's the ultimate goal."

The *Centre Daily Times* published a front page article entitled, "JoePa's Support Brings Hope to Local Family." The story features a 40-year-old woman who "wishes she could meet Joe Paterno so she could personally thank him." As the article explains, she isn't a football fan and she didn't graduate from Penn State. She is "thrilled" that the football coach has taken to the airways to talk about CMT, from which she suffers. The article also mentions the sale of the Christopher Radko ornament. The owner of George's Floral Boutique, Mitch Ballas, said that 600 ornaments have been sold already, putting it on pace to be the store's best-selling ornament. The article highlights the fact that Joe Paterno is donating his royalties from the sale of the ornament to the CMTA. *

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

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



NIH CONFERENCE

(Continued from page 1)

The workshop was an outgrowth of the effort spearheaded by the CMTA and the Neuropathy Association to have Congress and the NIH recognize the peripheral neuropathies as important targets for research. They were represented at the workshop, as were the Muscular Dystrophy Association, the Juvenile Diabetes Association, and the Neuropathy Research Foundation.

“It is very encouraging to have the NIH and patient advocacy organizations working together to promote this research,” said Pat Dreibelbis, CMTA Director of Program Services.

Sunday evening’s session included a discussion by Dr. Peter Dyck, from the Mayo Clinic in Rochester, MN, and also a member of the CMTA’s Medical Advisory Board, of what has been done in developing therapies for peripheral neuropathy and what still needs to be done. He observed that

while peripheral neuropathy is extremely common, more so than stroke, there is no effective treatment for any of the inherited neuropathies that can be caused by any one of more than 100 gene abnormalities.

Dr. Dyck conceded that while symptoms such as neuropathic pain can sometimes be controlled, severe pain usually responds only to narcotics, and patients can’t function on narcotics. The challenge, he concluded, is to find effective means of both prevention and treatment, and a necessary first step will be an epidemiologic study to determine the frequency and severity of peripheral neuropathy.

Another interesting presentation entitled “From Cone Snail Venoms to Therapeutics for Pain” was made by Dr. Baldomero Olivera, Distinguished Professor of Biology at the University of Utah. He and other researchers have discovered that there are over 700 species of cone snails, all of which are venomous, and that the peptides found in their venom have

implications for pain relief in humans. One—the “shaker peptide”—is now produced as Prialt, a drug used for intractable pain. He left the group with the admonition that researchers need to look more often to the animal world to find drugs to control neuropathic pain.

On Monday, October 23, 2006, the day began with welcomes and introductions from John Porter, PhD, Program Director of NINDS, Story Landis, PhD, Director of NINDS, and Steven Scherer, MD, PhD, chairman of the peripheral neuropathy workshop.

- Presentations were then given on the following topics:
- Disease mechanisms: axonal neuropathies
- Disease mechanisms: demyelinating neuropathies
- Disease mechanisms: neuropathic pain
- Diagnosis and biomarkers
- Therapeutic development
- Clinical trials

Between three and five speakers addressed each topic, and the floor was open to questions and comments

One participant offered up the somewhat disappointing truth that most therapies to date have failed and have cost a lot of time and money in the process. In some cases this was due to a poor choice of targets, candidates, or models and strategies. This led another to observe that the therapy chosen must be linked to the actual disease mechanism, and that success is most likely when patients are identified at a sufficiently early stage in the disease process.

The topic of pain in peripheral neuropathies also produced a lengthy discussion centered around the paradox of how patients can lose function and sensation and yet experience pain. Almost all patients with one of the peripheral neuropathies experience burning sensations, feel unpleasantly cold, have lancinating (stabbing)



Dr. Steven Scherer, Executive Director Charles F. Hagins, and Medical Advisory Board Chairman Dr. Michael Shy were participants at the “Demyelinating Neuropathy” table.



Dr. Vincent Timmerman, Dr. Kurt Fischbeck, and Dr. Phillip Chance take an infrequent break during the conference.

pain, or suffer allodynia (pain from stimuli not normally considered painful). Antidepressants, anticonvulsants, and opioids are often used to treat these types of pain, but it was observed that the treatment effect is often not sufficient to control the pain, and there are also side effects and cost problems to be considered.

Dr. Kurt Fischbeck, an NIH scientist, discussed what is being done to find possible cures for the hereditary demyelinating

factor treatment using NT3 to promote nerve regeneration and produce sensory improvement in 1A mouse models has been tried at Ohio State. Finally, he mentioned the use of curcumin, a derivative of curry, to correct protein misfolding as seen in myelin protein zero or CMT 1B.

The workshop concluded Tuesday morning with a breakout session in which the meeting attendees were divided into groups. The mission of each group was to address one of the

neuropathies. He mentioned that both onapristone and ascorbic acid are being tried to “downregulate” the overexpression of PMP 22 in CMT 1A, and that neurotrophic

seven topics presented on Monday and make a list of broad research objectives that warrant emphasis in a five-year window of activity. Each group then had a representative present their list of objectives, highlighting those considered to be “hot” topics. The whole group then agreed, disagreed, or simply asked questions about the list. Ultimately, the workshop organizers will collect the edited lists, transcribe them, and provide them to the attendees.

“What was most impressive,” said Pat Dreibelbis, “was the intensity and focus of these scientists. Even during the brief coffee and bathroom breaks, they were seen grouped in the hallway, following up on what someone had just said at the meeting. Everyone who suffers from the peripheral neuropathies or who works in the health professions should be heartened and inspired by their dedication and effort to find treatments and cures.” *

CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone’s memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

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Raising Children with CMT— Our Parents are Precious!

BY ELIZABETH OUELLETTE

Last week, I purchased a brand-new cell phone with enough options to bedazzle even the most technologically gifted. Some of the features were intuitive enough that I disregarded the instruction manual altogether. To my dismay, I soon discovered that a good number of even the simplest functions were complicated, puzzling, and downright impossible to comprehend without the handy user's manual, a never-to-be lost guide, with everlasting value.

Realizing my dependence on this pamphlet of how-to's, I reflected upon the parenting guides I have bought over the years, all dealing with every imaginable aspect of the child: the terrible twos, sleeplessness, anxiety, positive discipline, the emotional lives of boys, raising self-confident girls, tolerating teens (I am reading a lot of these books lately!), and so on. However, the one book I have yet to come across is called "THE MANUAL" a how-to, step-by-step instruction guide on parenting children from 0-18 and older. It was not included in my take-home packet from the hospital when Yohan was born almost 14 years ago, and I still fantasize about getting my hands on a copy of this nonexistent source of knowledge.

Parents can, and do, influence their children, by modeling behaviors and values.

Initially I learned to care for my bundle of joy by asking questions, reading a few of those parenting books I mentioned above, taking advice from others, and relying heavily on my own maternal instincts. Through trial and error, my husband and I strived to raise and nurture our

child to be a resilient human being who would hopefully be happy, successful, empathic, friendly, confident, etc. None of these attributes are ever guaranteed, but parents can and do influence their chil-

dren to a very large degree by modeling behaviors and values, including empathic listening, acceptance of the whole child, unconditional love, compassion, and positive discipline.

Born with unique dispositions and temperaments, each child will integrate what he or she witnesses, observes, and experiences to form a personality, which is in a state of constant flux, molding to, and shaped by, the surrounding environment. Raising children is truly a humbling adventure, where perfecting parental skills comes through valiant efforts on the part of the parents to do the best they can at any given moment.

Just to keep us on our toes, life has this nasty habit of throw-

ing wrenches into our well thought-out and admirable plans and dreams, forcing us to change directions or reroute our journey through life over and over again.

For instance, when parents are told that their apparently healthy and precious child has a progressive neurological disease called CMT (or any other chronic illness or disability), the world as they know it comes to an abrupt halt. For a while, time just seems to stop as the shock of reality works its way through to the senses. With no current treatment or cure, CMT is a group of diseases whose effects vary greatly from one person to the next, even among members of the same family. The fear of an uncertain future for our beloved child creates a chaos so disruptive, parents inevitably experience and re-experience a whole gamut of feelings ranging from grief, rage, disbelief, depression, anxiety, sadness, hopelessness, guilt, and disappointment. This flurry of varied emotions is absolutely normal in the face of such devastating and unwelcome news.

We immediately wonder what this diagnosis means for our child's future—will she be able to play the piano, have children, and fulfill her dreams as an actress? Will his legs remain strong, what about his basketball career, and just how much will my son be affected? Will he/she

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GIFTS WERE MADE TO THE CMTA

IN HONOR OF

- Sandy Chaplin**
William R. Bergquist
- Linda Kleingartner**
Lynn Tichenor
- Marie Reilly Heed**
Anonymous
- Howard Parker**
Anonymous
- John Parker**
Anonymous
- Lisa Stetler**
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IN MEMORY OF

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Daisy Goo
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- Frank T. Eckman**
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- Robert Parker**
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- Jeanette Parker Reilly**
Anonymous
- Betty J. Walker**
Richard & Dorene Ronish

Help Tackle CMT: The 2007 Annual Appeal

DANA SCHWERTFEGER, DIRECTOR OF MEMBER SERVICES

Within the next week or so, you will receive the CMTA's 2007 Annual Appeal. This year, it begins with a message from Penn State coaching legend Joe Paterno urging you to do your part to help tackle CMT.

The football analogy and the "help tackle CMT" slogan is new, but the need for teamwork in the struggle against CMT is not. We've often said, "You are the CMTA," and that's as true today as it ever was.

For some of you—like Coach Paterno—being part of the CMTA "team" involves volunteering your time to raise awareness, run a support group, or write an article for the newsletter.

As valuable as those efforts are, keeping our team on the field requires the ongoing sup-

port you provide through the annual appeal. As Coach Paterno wrote, however, many of us don't realize what that involves.

I was a bit taken aback to learn, for example, that our basic operating expenses for last year were almost \$375,000. Then I began looking at the costs associated with what we did on a day-to-day basis throughout the year, and I realized that for an office with four full-time employees and the newsletter, the website, and other programs, our operating expenses were really quite low for all that we accomplished.

And yet, as you'll read in the appeal, each of us wants to do even more! We hope you will give generously in support of our effort. As a team, we can tackle CMT! *

A MESSAGE FROM PENN STATE COACH JOE PATERNO...

A year ago, I had never heard of Charcot-Marie-Tooth disease. I had no idea how many people it affected, how it changed their lives, or what I could do about it.



Clearly, I was not alone. That lack of awareness is a huge problem, and getting information into the hands of doctors and patients, as well as the general public, remains one of the most important services provided by the CMTA.

It's also a service that, more often than not, is taken for granted. Many of us don't stop to think about the resources or the staff it takes to get the job done.

But I know that teamwork is the key to success. That's true whether you're on the football field or working to defeat a serious disease like CMT.

I'm proud to be on the CMTA team doing what I can to raise awareness about CMT, but there is so much more to be done.

I hope you will decide to do your part. Please contribute and help us tackle CMT.

Sincerely,
Joe Paterno

A Profile in Courage: Jesse Seale

BY TOM LOACH FOR THE CROZET GAZETTE, CROZET, VIRGINIA

Walk into any firehouse in America and more than likely you'll find at least one firefighter wearing a T-shirt representing one of the companies of the New York City Fire Department. There are two reasons for this. First is the universal respect firefighters have for those who serve with the FDNY, especially since 9/11. The second is that many of the fire companies sell T-shirts to raise funds for the 9/11 families. For the fire service, 9/11 was the high water mark that exemplifies the courage displayed by firefighters every day throughout

America. It was a day when uncommon courage was common.

But courage comes in many forms and in Chief Bubba's and Hubba's firehouse, courage can be found in the form of Jesse Seale. In a world that seems to have too many rotten apples, Jesse is one of the good guys. Anyone who starts something new in their life remembers the nervousness and uncertainty of those first steps and the relief you felt when you met that first friendly face whose eyes told you everything was going to be all right. On my first day walking into the firehouse, that face was Jesse.

Jesse has one of those easy-going southern personalities that could have been plucked right out of central casting for the Andy Griffith Show. Yet despite Jesse's disarming smile, when you meet him, you know immediately that something's different about him. His arm and leg movements are not smooth, but appear somewhat uncoordinated. I found out later that Jesse has a disease called Charcot-Marie-Tooth disease or CMT.

CMT is the most commonly inherited neurological disease, affecting approximately 150,000 Americans. CMT patients slowly lose normal use of their feet/legs and hands/arms as nerves to the extremities degenerate and the muscles in the extremities become weakened because of the loss of stim-

ulation by affected nerves. Many CMT patients also have some loss of sensory nerve function. CMT forced Jesse to retire from his job as a tool and die maker. His disease got so bad that even the activities of daily living require assistance from others.

At this point, many people would have given up, but Jesse's not the giving-up type. He underwent delicate neurosurgery to put in a neurological pacemaker that helps control his unnatural movements. Thankfully, the surgery gave Jesse some relief and I'm sure that once he was up and around after this surgery the first place he went was the firehouse. Not only did he show up, but he got right back up on the engine and started answering calls. Jesse went on to serve on the Board of Directors and as department quartermaster. Jesse's a 24-by-7 firefighter, meaning you're just as likely to see him at 3 in the morning as you will at 3 in the afternoon. I'm always glad to see him hoisting himself into the cab ready to go.

If Jesse's not a profile in courage, then I don't know who is. So, if you think you'd like to serve in an organization with members the likes of Jesse, stop by the firehouse some evening and if you see someone with a big smile and an easy-going way, then say hello to Jesse. And if his gait appears a little peculiar, just remember...that's courage walking. ✨

EDITOR'S NOTE:

This article was reprinted with the permission of the publisher and was sent to us by Guy Larry Brown, who wrote that "Jesse introduced me to AFOs, which gave me a new lease on life this past spring."



Firefighter Jesse Seale

OUR PARENTS ARE PRECIOUS!*(Continued from page 6)*

become more or less disabled than me, than my mother, than other family members? As concerned parents, we all have a tendency to get ahead of ourselves by asking a million questions about the fate of our children, wondering and inquiring about what the future has in store, trying to predict what cannot be foreseen.

To top it off, in the midst of this traumatic news, unsettled parents must return home to their children, bearing the intolerable news that will inevitably change the lives of every member of that family. How hard it is to remain calm, in control and at ease after you've been hit with the CMT hammer! In these delicate situations, we need to remember that children are savvy readers of parental anxiety, tension, and stress. They are influenced by our attitudes, opinions, and expressions as they learn a great deal about themselves by watching, listening, and absorbing all the subtle messages in conversations. They definitely do not wish to see us devastated by their disease (even if we are) and need most of all to be comforted, supported, and understood.

So, when a parent unintentionally acts out his or her intense sadness, despair, and anxiety in front of his children, the child is sure to take it all in. If our children receive messages confirming that their own situation is hopeless and the future bleak, he or she will surely feel out of control and helpless in the face of upcoming and ongoing adversity. However, if our kids are met with reassurance

and optimism, they will be more likely to cope adequately, if not conquer the hurdles that are bound to appear throughout their lives. So, the quicker we as parents learn to “deal effectively” with the challenges presented by CMT, the quicker our children will build the necessary coping skills and resilience to live well despite this disease.

Let me qualify the expression “dealing effectively with CMT,” which takes on a different meaning for each and every one of us. Coming to terms with your child's progressive disease and limitations takes a lot of time and energy, and as you already know, this does not happen overnight, if ever at all.

There are still moments when I am angry at this disease and obstinately think of Yohan's CMT as the ultimate definition of unfair lots in life, followed by a pathetic, “Why me?”, “Why him?”, “Why us?” I usually manage to calm down (at least by the time I pick him up from school), by focusing on what he can do, by living in the present moment, and by appreciating the gifts of today. I also fervently practice replacing my negative and catastrophic thoughts with a more positive and realistic perspective.

The brutal reality is that I cannot control his disease or make it go away. However, we as parents are far from impotent, or without resources. On the contrary, by sharing an unwavering hope for the future, demonstrating coping mechanisms such as

humor, optimism, and faith while remaining connected to others for support, we are fostering resiliency and courage in our children, traits on which they will rely heavily today, tomorrow, and the days to come.

Let me reiterate that as parents, we have the capacity to guide and support our children, despite the absence of that darn “manual.” There are always silver linings to black clouds; you may just have to look for them. Hurdles and stumbling

blocks exist to a greater or lesser extent in everyone's life, and, many times, these challenges will bring families closer together or even offer a deeper, more

meaningful purpose to life itself. Whatever afflicts us or our loved ones, no matter how severely, life is truly what we make of it. By planting the seeds of hope, confidence and self-assurance, we are offering our children the right to a bright and fruitful future.

Whether it be CMT or some other uninvited disease, our children will have acquired the tools with which to triumph over whatever may befall them, because WE, as parents, have given them the means. No one ever said that parenting is an easy job, but hard work, time, and patience will make a marked difference in the minds and lives of your children and the generations to come. Manual or no manual, your kids will be forever grateful, which I deem the best award a parent could ever receive. ✨

Children are savvy readers of parental anxiety, tension, and stress.



SUPPORT GROUP NEWS

Alabama—Birmingham

Plans are underway for a second meeting of this new group on Saturday, December 10, 2006 at 10 AM at the Lakeshore Foundation in Birmingham, Alabama. Plans include the showing of a PowerPoint presentation on CMT, an organizational session, and an orthotist speaking on bracing options. Interested parties should contact Dice Lineberry at 205-870-4755 or dklrlr@yahoo.com.

California—San Francisco Area

On Saturday, November 4th, Martin McCorkle, author of the book, *Walk With Me: The Story of One Man's Life with Muscular Degeneration and His 1700 Mile Walk Through California*, spoke to the group about "Staying Active and Fighting Discouragement." Martin, currently the pastor of his church in Dixon, California, is a charismatic, upbeat, and outgoing individual who knows how to engage a group. His motivational stories, positive outlook, and spontaneous laughter were contagious, making a long-lasting impression on those who were present.

His key message to those with CMT was to "bind together the things that you love with the things you can do." As discouraging as it might be to witness decline in the physical body, there are still many things in life to enjoy. Moreover, Martin made the point that he is very grateful to all the researchers working diligently to find treatments and a

cure for this disease. However, he emphasized that life flies by and every moment is precious. If we are putting our life's goals and ambitions on the back burner, while waiting for science to take away our CMT, we are wasting our short time here on Earth. First, find activities you love and are able to do, and then enjoy them with gusto. Many of us feel stuck when we realize that our abilities are limiting our lives, but as Martin points out, if we can broaden our perspectives and enlarge our scope, there are many alternatives and solutions to add passion to everyone's life.

Missouri—St. Louis

A meeting was held on November 18, 2006, at the St. Louis University Medical Center cafeteria. It was a gathering of old and new members with guest speaker, Dr. Florian Thomas, who presented information on a new gene discovery and answered questions about CMT. For information about this support group contact Carole Haislip at cmtcarole@att.net.

Pennsylvania—Johnstown Area

The Johnstown, PA CMTA support group held its bimonthly meeting Saturday, October 28th at The John P. Murtha Neuroscience and Pain Institute. The guest speakers discussed various aids including walkers, wheelchairs, and scooters and how to pay for them.

The group also talked about the exciting CMT awareness ads

with Joe Paterno that the CMTA is sponsoring. CMT, thanks to these ads and other efforts, is no longer an unheard of disease in our area.

Jan Goodard covered the progress of The John P. Murtha Neuroscience and Pain Institute's CMT prevalence study. We discussed how difficult it has been to motivate CMT patients and family members to participate in the survey.

Pennsylvania—Philadelphia Area

Despite howling 40-mile an hour winds, 26 intrepid people attended the October 28th meeting to hear Dr. Carol Oatis discuss conservative management of CMT. As a physical therapist and researcher, Carol has many years of practical experience in dealing with CMT and knows the value of stretching and strength training. Her PowerPoint presentation was interspersed with questions and comments from the attendees, and many useful suggestions were made about the kinds of work that every person needs to do to build unaffected muscles, strengthen slightly affected muscles, and conserve energy so that fatigue does not unnecessarily impact daily life. The meeting lasted more than the scheduled two hours because everyone was so interested in the presentation. Dr. Oatis has promised to return again because she also believes in the value of support groups as arenas for the exchange of valuable information. ❄

CMT Support Groups

Alabama—Birmingham

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

Massachusetts—Amherst Area

Place: Bangs Community Center
Meeting: Call for dates
Contact: Ellen Panzer, 413-256-0189
Email: CMT_suppgroup_MA@yahoo.com

Minnesota—Benson

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

Minnesota—Twin Cities

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

Mississippi/Louisiana

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

Missouri—St. Louis Area

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

New York—Greater New York

Place: NYU Medical Center/
Rusk Institute, 400 E. 34th St.
Meeting: Third Saturday of every other month, 1-3 PM
Contact: Dr. David Younger, 212-535-4314,
Fax 212-535-6392
Website: www.cmtnyc.org
Email: bwine@acm.org

New York—Horseheads

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

New York (Westchester County)/Connecticut (Fairfield)

Place: Blythedale Hospital
Meeting: Bimonthly, Jan, March, May, Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 845-783-2815
Eileen Spell, 201-447-2183
Email: cranomat@frontiernet.net
espell@optonline.net

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

Place: Church of the Reconciliation, Chapel Hill
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (evenings)

Ohio—Greenville

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

Ohio—NW Ohio

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

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

Some Bracing Thoughts

BY ROSEMARY MILLS

I am 61 years old and have CMT. I'm on my third pair of braces. My daughter is 37 years old. She also has CMT and she is on her second pair of braces. We have learned a lot from having these braces and I'm writing this in the hope that our experience will help others.

Both my daughter and I have high arches and have been lucky that our braces have not needed adjustments, but you'll see as our story unfolds, things have not all been as rosy as one would hope when being braced.

My first pair of braces seemed like a miracle. I had much better balance when wearing them and could walk much faster. However, I soon found out that the faster I walked, the faster I tired out. I have been very lucky because I can wear braces for many hours at a time.

After four years or so, I felt as if I was sometimes carrying the braces around instead of

them helping me to get around. They seemed heavier than before. Of course, I was getting weaker. I saw the man who had ordered the braces, but he gave me minimal time and said they seemed fine. I decided to persist and ended up at a bracing

establishment closer to home. There I met Warren. He listened to me for half an hour as I told him how the braces were making me feel and what kind of life I still intended to lead. I also mentioned how I wished I could wear a smaller shoe size. My foot is a size 6 and I was wearing size 9 and 9½ shoes. (My braces went way under my toes.)

When I went back to get my new braces and tried them on, it was so neat. They were lighter and a bit thinner under the toes, but still supported me very well. I now can wear a size 8½ shoe and I no longer feel as though my braces are sapping my strength.

In the last two years, my falls have been occurring more frequently. Thankfully, I haven't broken any bones. But since my arms are to the point I can no longer pick myself up, it means that when I fall, I have to call my husband home from work. His employer is very understanding, but the falls are no fun for him or me. I have purchased a transfer belt from the local

nursing home which has been a huge assist to both of us when I fall. After my last fall, I realized my left foot was not picking up as well as it had.

So, I went back to talk to Warren. He said, "I can help you with that!" When I went back to pick up my new brace and tried it

on, I was overjoyed. Warren had added a strip of plastic right above the heel to the back of the brace and cut them down by ½ inch so the weight remained the same. He told me that as a person gets weaker, carbon can be added to the plastic to make the braces even lighter. The left leg and foot felt so good that I asked him to make one for my right foot. I have not fallen since these adjustments and now realize that many of my falls might have been prevented if I had had these braces sooner.

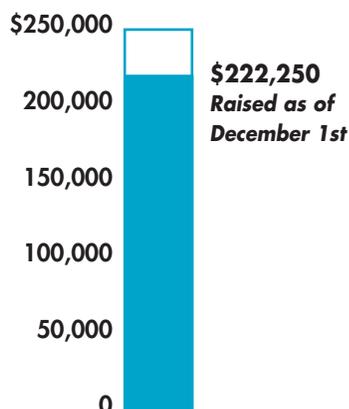
My daughter's experience was slightly different. She got her first pair of braces and I noticed they were thinner, more like my second pair. Other than that, I didn't really take note of them. They were her braces, and she was happy with what they did for her. She doesn't wear her braces as much as I do because she lives in a townhouse and it is not easy to go up and down the stairs with them.

After three years, she began having trouble with her feet. She doctored them, and then

Many of my falls might have been prevented if I had had these braces sooner.

LIVNEY CHALLENGE PROGRESS

Board member Patrick Livney has issued a \$250,000 challenge to the members and friends of the CMTA to match his gift in support of CMT-specific research. Please consider a year-end gift to the challenge to help us reach our goal.



decided to try a new brace person. She got blessed as I did. The man said it was no wonder she was having foot problems. She has very high arches and her first braces had no real arch at all! She now has a new pair and can really tell the difference.

How does something like this happen? All we can figure out is that someone in the process wasn't paying attention. How sad when a mistake like that affects someone's life as it has my daughter's.

So, I'm writing this to help others who have braces or will be getting them in the future. Both my daughter and I have custom-made braces. That simply means they take a cast of your foot and leg so the brace will be exactly fitted for you.

Should my daughter have realized her braces needed an arch because she had such a high one? Perhaps, but she went to a clinic attached to a major hospital where there is a neurologist who understands CMT. She felt

they were professionals and therefore, knew what they were doing. That's another reason for my writing. Don't be afraid to ask what may seem like a silly question and don't be afraid to tell the professionals you deal with exactly what you need. If you don't feel you are getting what you need from the first orthotist, seek someone else. You might find your "Warren."

If you have questions or comments, please email me at rrmills@fedtel.net. *

A Singer "in the House"

BY AMY DE SILVA

My name is Amy de Silva and I am ten years old. I have lived with CMT all my life. I have CMT mostly in my hands, not allowing me to raise my wrist and do daily activities like opening water bottles, buttoning my pants, or even putting in my earrings. But, my parents have always told me that when there is a downside to your life, there is an upside, too. My upside is my voice. This summer I was invited to sing during the seventh inning stretch of a Red Sox home game! I was so happy I cried.

The day of the game, we got field passes to go on the field and meet some of the players. It was so cool! When I got back to my seat, I could see everything that went on. Before I knew it, it was the seventh inning, so I walked out onto the field and sang "God Bless America."

At first, I was a little nervous, but it was just so much fun. When I got back to my seat, everyone cheered and said I did a great job. It felt so great! People even ran over and hugged me.

When everything settled down, I could finally watch the game again. I got an ice cream to hold me over until dinner. For dinner, I went to Game On, which is a sports pub right across from Fenway Park. My parents had rented a skybox and all of my family and friends met there after the game. It was a lot of fun. We ate and partied all night long and there was even a DJ. The DJ heard there was a "singer" in the house, so he wanted me to sing again. I did and again, everyone said I did a great job.



By now, you might be wondering how I have typed this. I type using a program called Reach. It allows me to type by clicking on letters and the words that make sense will pop up on the screen, and you just click on the word you want. That is how I type. How do you? Do you have to use a special program like me, or do you use the keyboard? For a while, it was hard for me to type because using my fingers is hard for me to do. But now I am starting to get the hang of it.

Sometimes it is hard not being able to do things and having to ask for help in front of friends. I do get embarrassed. But, I always say to myself that I shouldn't get all worked up about having CMT because life moves on. That philosophy is how I live with CMT. *



ASK THE DOCTOR

Dear Doctor,

I have reviewed the Medical Alert list and the Frequently Asked Questions and have not seen information about Effexor being associated with neurotoxicity. Is it safe for a person diagnosed with CMT?

The doctor replies:

Venlafaxine (Effexor) is a popular and widely used antidepressant that is also used to treat neuropathic pain, especially well studied in patients with diabetic neuropathy, although the drug has no current specific FDA indication for this use. It has not been associated with worsening CMT neuropathy. The drug does have a variety of side effects and unusual complications that should be considered before use or withdrawal of use. The drug appears to have an increased risk of neuroleptic malignant syndrome and possibly serotonin syndrome, emergent conditions that affect muscle, but this risk is not further increased, to my knowledge, by having CMT.

Dear Doctor,

My 18-year-old daughter has CMT 1A with relatively mild-to-average symptoms of CMT. She took a meningococcal vaccine and a flu vaccine, which are recommended for freshman college students staying in dorms. (She has been taking the flu vaccine for the past several years with no adverse reactions.) Nine days later, she started having extreme tingling sensations in her hands, feet, and tongue; as well as severely increased weakness. She fell six times while walking one block. I

took her to the ER. They ran several tests and couldn't find anything wrong in the blood work or in the urinalysis. Could the vaccine have caused these symptoms in a CMT 1A patient? If so, how long should the symptoms last? They started five days ago, with some slight improvement. She still has the tingling sensation in her feet and occasionally in her hand. She is now able to walk short distances with some assistance.

The doctor replies:

The story of vaccinations and neuropathy is a long and controversial one. Some vaccinations in the past (swine flu vaccine in the 1970s) have prompted concerns of certain vaccines triggering an immune-mediated abrupt neuropathy in otherwise normal people, but most associations have not been proven after larger scrutiny. Neither the meningococcal, or current flu vaccines are specifically associated with neuropathy, but the flu vaccine is different every year. There is no evidence that vaccines affect the CMT genes directly, but the issue has not been studied. But, if an immune attack on nerves is triggered in a CMT patient, any nerve damage may be additive to the underlying neuropathy. The process, in general, lasts for 1–4 weeks and then improves depending on the severity of the process. Guillain-Barré syndrome (GBS) can occur in CMT patients; it is controversial whether the incidence is higher than for the general public. If it does occur, the diagnosis and treatment are the same, but the

CMT makes the diagnosis more difficult. It is suspected but unknown whether a mild version of the process commonly occurs because these patients tend not to go to a doctor; however, a mild form of GBS in a patient with underlying neuropathy from CMT could lead to the symptoms presented.

Dear Doctor,

I have been on Prevacid for years. I switched to Prilosec recently. I then found out they were on the Medical Alert list. I told my doctor and she switched me to Protonix, which is not on the list. However, she said it is in the same class of drugs as the two on the list. Why would that happen?

The doctor replies:

There is very little information about this issue, especially noting the large number of patients taking these drugs. The two mentioned are the only ones reported on in the literature, but you are correct to observe that there is no reason why the others should not have a similar risk even though the association has not been noted.

Dear Doctor,

My mother and I both have CMT. She passed away last June and was debilitated for several years prior. My condition has been worsening at an enormous speed.

After her death, I pored over some of her books (she was a psychiatrist) and found that benzodiazepines are very effective in treating pain. I am currently taking Klonopin and Cymbalta.

I haven't seen anything in recent literature about benzodiazepines. Has research changed those earlier findings?

As far as the shooting pains, Cymbalta has almost completely taken them away. Is there a generic form being developed?

The doctor replies:

Cymbalta (duloxetine) is one of the few medications that went through the lengthy process to receive FDA approval for neuropathic pain, specifically for diabetic neuropathy, but is generally used for any type of neuropathy-associated pain. The drug was approved in 2004, so it has quite a while to go before legal generics can be sold in the US. Duloxetine is an antidepressant and not a benzodiazepine, but the drug has been studied to treat anxiety as well. Klonopin is a benzodiazepine.

Dear Doctor,

Are the combination of Verapamil and Avapro as blood pressure medications considered neurotoxic? I take the above medications and my symptoms appear to be worse.

The doctor replies:

I know of no evidence that either of those drugs produces worsening of neuropathy either alone or in combination.

Dear Doctor,

I am a 25-year-old who was diagnosed with CMT by EMG. My doctor also diagnosed me with Charcot joint, osteoarthritis, and lumbar disc syndrome. I have a severe crippling disease that has gotten progressively worse. I have had numerous fractures and sprains throughout my lifetime,

and a few years ago I had a deformed bone taken out of my right foot and screws put in to tighten my ligaments.

My doctor has me on 20 mg of methadone for long-acting pain relief and Vicodin for breakthrough pain. I also take Valium for anxiety. The pain has gotten a lot less, but since starting the methadone, I have been waking up with numbness in my hands, and my hands in a clawed position. The doctor says that in order to stop this medication, I must be slowly weaned off of it. Could the medication be making my CMT progress, and how safe are narcotic treatments for long term use? I have tried Neurontin with little or no relief.

The doctor replies:

Contrary to public opinion, except in the case of overdose, oral narcotics such as methadone are some of the safer medications in use. I know of no evidence linking their use to worsening or causing neuropathy, abnormal muscle cramps, or muscle spasm; however, the timing raises the question in this case. Your physician is correct that too rapid of a withdrawal can cause unpleasant symptoms. Intravenous heroin has very rarely been linked to nerve injury, but almost certainly because of toxic and unintended side products in the injections used by some addicts. Methadone and Vicodin pills have no such concerns. Certainly, the underlying problems of CMT, Charcot joint, arthritis, and spine disease must also be considered by your physician. Simple carpal tunnel syndrome is common and treatable in patients with neuropathy of any

cause, including CMT. There are other medications not mentioned that can possibly cause the described symptoms, especially certain nausea medications and some others. Having your physician see the clawing and examining the hand is needed for specific recommendations, but the narcotics would be a highly unlikely underlying cause.

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 drug list. Is aciphex a similar compound?

The doctor replies:

Aciphex (rabeprazole) 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 neuropathy with Aciphex 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 more 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. ✨

WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Pkwy.

Chester, PA 19013

or

info@charcot-marie-tooth.org



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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