THE CMTA Report

MARCH/APRIL
2011

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ www.cmtausa.org

CMTA
Charcot-Marie-Tooth Association

OUR MISSION:

To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

OUR VISION:

A world without CMT.

EMAIL CMTA AT:
info@cmtausa.org

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A New Year, A New Look, A New Website, A New Opportunity

BY DAVID M. HALL

Did you make a New Year's resolution this year? If so, have you been compliant to that resolution? I know how difficult that can be!

The CMTA made a New Year's resolution, and in fact it was a New Year's commitment—a commitment to expand our community, awareness, and education programs throughout the country. As we all know, previous studies suggest CMT affects 1 in 2,500 people in the United States—that's equal to approximately 125,000 Americans! So, how do we adhere to our New Year's resolution?

Welcome to our new home at www.cmtausa.org! In addition to a new logo and a new look, our new site is updated with improved navigation and search capabilities.

Help Joe Paterno Tackle CMT
Joe Paterno, Head Football Coach at Penn State, and his wife, Sue, have been getting the word out about CMT. ...

"Losing My Grip"
I reached the end of a "plateau" period—those times of varying length we all have when our CMT seems to...

Hope through Surgery
I knew nothing about foot drop. My son Mark was falling a lot in school and finally told me near...

About the CMTA
"A World without CMT": that's the

What Is Charcot Marie Tooth Disorder (CMT)?
Charcot-Marie-Tooth, or CMT, is

Get Involved
Charcot-Marie-Tooth Disorder, or CMT is

STAR: A Strategy To Accelerate Research
For 27 years, the vision of the CMTA

Ascorbic Acid Trial -- Italian/UK Results Just Published
Save the Date!! CMT Clinical Conference
Dallas / Ft. Worth Cruise for a Cure
Video - Still Making A Difference
MDA Awards CMT Research Grant to Johns Hopkins University

The CMTA website doesn't just look different; it offers improved navigation and search capabilities.

The new CMTA website introduces an active, online CMTA Community for patients, caregivers, clinicians, and researchers and provides a safe place where people can come together, share their experiences, learn, have a voice, participate in support groups, and make a difference. It not only features rich content centered on the CMTA's mission to provide everyone affected by CMT with the information and resources they need to improve their lives today, but it also carries a powerful message of hope for the development of treatments in the near future as the CMTA's Strategy to Accelerate Research (STAR) continues to make groundbreaking advances in identifying therapeutic targets. As the CMTA's programs and services continue to grow and evolve, it is clear we must employ the latest web technologies to ensure we are efficiently

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INSIDE:

NEW ADDRESS
The Chester office of the CMTA has closed and mail should now be sent to P.O. Box 105, Glenolden, PA 19036. The toll-free phone number (1-800-606-2682) remains in service and you can reach Kim at extension 105, Pat at extension 103, and Jeana at extension 106. The CEO, David Hall, can be reached at extension 102.

STAR RESEARCH NEWS

Ascorbic Acid Trials Update

HIGH-DOSE TRIAL IN THE US

The high-dose vitamin C treatment of CMT1A will be completed by the beginning of May 2011. A total of 110 patients were enrolled, and 85 to 88 patients will complete the 2-year trial. We anticipate that we will have preliminary results by September 2011. The trial tests the hypothesis that high doses (4 g/day) of vitamin C will slow the progression of CMT1A compared with patients taking placebo. The primary outcome measure is the change in the CMT neuropathy score, and secondary measures include the levels of PMP22 detected in skin biopsy specimens of dermal nerves. The study is being performed at Wayne State University School of Medicine, Johns Hopkins University, and the University of Rochester. The investigators include Drs. Richard Lewis, Michael Shy, Ahmet Hoke, and David Herrmann.

Richard Lewis, MD, Wayne State University School of Medicine

LOW-DOSE TRIAL IN THE UK AND ITALY

Editor's note: Drs. Reilly and Pareyson were the lead investigators in England and Italy and published the results of this study in Lancet. Here they summarize their feelings about the study.

The results of a large trial of ascorbic acid (AA) treatment in Charcot-Marie-Tooth disease type 1A (CMT1A) have just been published in *Lancet Neurology*. This was a placebo controlled study of AA in 277 adults with CMT1A which was run in Italy and the UK. Patients received either 1.5 g daily of AA or placebo. A wide range of outcome measures were used including the CMT neuropathy score (a score developed by Professor Michael Shy and colleagues in Detroit). The results of the study showed the AA had no effect on the development of the neuropathy compared with the placebo.

This result suggests that AA at a dose of 1.5 g daily does not have any effect in patients with CMT1A.

Three issues to consider are whether the outcome measures used were sensitive enough, whether the trial was long enough, and whether the dose of AA was high enough for us to detect an effect. In this trial, as in other studies of CMT1A, the outcome measures did not show much change over the two years even in the placebo group, which may suggest that trials need to be much longer (impractical) or outcome measures need to be improved. This highlights the importance of carefully conducted natural history studies in all forms of CMT and the search for sensitive outcome measures and biomarkers to detect small changes in slowly progressive conditions. The final point as to whether the dose of AA was high enough will be answered by the ongoing US trial (NCT00484510) looking at AA 4 grams daily versus placebo. We look forward with interest to the results of this trial to see if a larger dose of AA has a significant effect on the development of the neuropathy. The US group is using the same outcome measures as the Italian / UK study, so that the two trials can be usefully compared.

Mary Reilly, MD, FRCP, FRCPI
National Hospital for Neurology & Neurosurgery, London, England

We finally have the results of this 2-year trial of 271 CMT1A subjects. Although the results are negative and we found no evidence that vitamin C is effective for adult subjects with CMT1A,

Meet New Board Member Alan Korowitz

My wife Ruth and I became involved with the CMTA shortly after our son Zachary was diagnosed with a still-to-be identified form of CMT in 2008. Ruth immediately became active as a support group leader on Long Island. We have committed ourselves to finding a cure for a disease that affects over 2.6 million people. I am the Executive Vice President of Operations for Clear Channel Radio Sales, the division that handles the national advertising sales for Clear Channel Radio's radio stations and digital properties. My hope in joining the board is simple: to assist in increasing awareness of the disease and the Association so we may raise the necessary funds to finance the important research being done today. By working to grow our base of support in the New York area, I hope to further the Association's ongoing efforts to achieve a cure in the not-so-distant future.

we feel that from other points of view this trial was very successful. Indeed, we are learning a lot from it both for future trials and for a better knowledge of the natural course of the disease.

We succeeded in carrying out an international trial, with an excellent collaboration between centers in different countries, and this is important for future collaborative international trials. We are analyzing now in more detail which are the best scales and clinical items to use to detect the slow changes of the disease over time. One major difficulty is reliably measuring the changes caused by the disease progression and those hopefully produced by treatments.

Regarding the efficacy of vitamin C for CMT1A, although we feel that the dose we used was high enough from a biological standpoint, we cannot exclude that higher doses can be effective. Therefore, we await with great interest the completion of the US trial, which employs higher daily doses. It will also be important to combine the information obtained from all the trials performed in different countries to evaluate whether there is a very small effect of ascorbic acid that can be seen only by pooling data on hundreds of treated subjects.

We are very thankful to the patients' associations in Italy and UK that helped and collaborated in this study.

Davide Pareyson, MD,
C. Besta Neurological Institute,
Milan, Italy

NEW YEAR, NEW LOOK

(continued from page 1)

and effectively communicating and connecting with our global audience. The new website gives us increased flexibility and a framework for quickly delivering fresh information and content. We will continually be making improvements in the days ahead and are looking forward to hearing feedback from everyone. In addition, the CMTA has upgraded its presence on Facebook *(www.facebook.com/CMTAssociation)*, Twitter *(twitter.com/CMTASTAR)*, and YouTube *(www.youtube.com/user/CMTAssociation).*

Through these dynamic resources, it is our hope that a new and vibrant CMT community emerges—a community that not only welcomes CMT patients and their families, but also educates and informs clinicians, public officials, and the general public. Like never before, clinical advances are occurring in the fields of neurology, physiatry, orthotics, and others that directly benefit CMT patients. The historical notion of "nothing can be done to help people with CMT" is just that—historical. Today, more than ever, we owe it to the CMT community to promote these clinical advances to ensure highest standards of care are being delivered to CMT patients, regardless of their zip code.

I invite you to visit online. Join our CMTA Online Community, become our friend on Facebook, follow us on Twitter, and watch us on YouTube. Tell your friends, families, and colleagues. The CMTA has never accomplished anything without the active involvement of our national membership—that is certainly true in this case as well. Please help us promote this wonderful platform of awareness and information.

With your help, this is one New Year's resolution that won't fail! ★

MEMBERSHIP CHANGES TO SUBSCRIPTION FEES

At the CMTA, we're committed to keeping our operating costs low. By delivering our newsletter, *The CMTA Report*, and other premium content online, we will be able to reduce our printing and mailing costs significantly and use the savings to fund research. We'll also be able to get the news to you faster and with greater efficiency. So, with the launch of our new website, we're beginning the process of phasing out our current membership program and replacing it with an online "Premium Content Subscription" plan.

Online: Upon registration on the new website, all active CMTA members will automatically receive a premium content subscription good through the end of their current membership period. New CMTA Community members or existing members will be able to purchase or renew a premium content subscription from the CMTA website for an annual fee of $25. (If the member also chooses to receive a print copy of the newsletter, the cost of the annual subscription or renewal will be $30.)

Via mail: The cost of a purchasing or renewing a subscription through the mail, which will only have the option of delivery of a print copy of the newsletter by mail, will also be $30. No additional premium content will be available to mail-in subscribers. As you can see, we're trying to get as many people as possible to use the online plan. It will not only save us the direct costs associated with mailing newsletters and renewal notices, but it will also save us the effort involved, freeing up valuable time that can be committed to serving the mission of the CMTA. We hope you will join with us in making this transition a success, and we sincerely thank all our loyal members for your cooperation and financial support. We look forward to serving your future needs and receiving your continued financial support through our new premium content subscription program.

CMT Awareness Month, September 2011—*A Fall to Remember!*

Brainstorming sessions, conference calls, and memos have been flying across the country—even across "the pond." Plans for Awareness Month are in full swing and what a great month it's going to be! We wanted to give all of our readers a glimpse of what's in store, and suggest ways that you can help make this September campaign a huge triumph! The following committees have been hard at work formulating concepts, writing letters, and preparing press releases. We are so excited to present them to you:

Let Me Tell You About a Friend of Mine; Chaired by Susan Ruediger

The focus of our committee is to spread awareness of CMT by sending letters to friends of CMT patients and families. This letter can be personalized, but generic letters are available for download if you'd prefer. This grassroots effort will create a buzz about CMT, spread awareness, build the online community data base, and hopefully raise funds through Circle of Friends.

Help is needed to spread excitement about the program and to get commitment from each support and action group facilitator to participate. Our goal is for each support and action group to send out 100 letters. Personalized and local stories from members of your group will help to build a compelling letter to send to the media in addition to friends and family. If you would like to help, please contact Susan at susruediger@comcast.net or call 678-595-2817.

Global Awareness Day; Chaired by Melinda Lang

On September 24, 2011 the CMTA, together with other CMT and/or neuropathy organizations worldwide, will celebrate Global Awareness Day, dedicated to spreading understanding of CMT internationally.

Some of the suggested ways to celebrate this Global Day are to post messages to family and friends on your Facebook/Twitter and other social networking sites. Plan a local event and send press releases to local media. Organize personal interviews with local media and share your story. Make a video showing how CMT affects you or family members and post it on YouTube, Facebook, and on www.cmtausa.org.

Help is needed to research CMT-related organizations in other countries and verify their contact information. The global regions suggested include: Africa, North America, Latin America & Caribbean, Asian & Pacific Far East, North Africa, and Europe/Eurasia. Contact letters are ready to go—we just need the information to personalize them. If you would like to help, please contact Melinda at 518-783-7313 or mlang2@nycap.rr.com.

Global Awareness Day—UK; Chaired by Mark Willis

The CMT UK is also planning a month-long awareness event that coincides with our September campaign. Our small sub-committee is working with the CMT UK to coordinate activities that will work on both sides of the Atlantic. The CMT UK celebrates its 25th anniversary this April with an International Convention being held April 15-17, 2011 in Coventry. If you have any contacts in the UK or would like to lend a hand, contact Mark at: mrwillis@optonline.net

Extraordinary Person Contest; Chaired by Julie Collins

Another idea to help spread awareness is to focus on extraordinary individuals living with CMT. We are asking friends and families to nominate a person who is rising to the challenge of making the most of their abilities on a daily basis despite their CMT. The "I'm A Star!" (Ages 18 and up) and "I'm A Shooting Star!" (Ages 13-17) Awards will be announced during September to coincide with Awareness Month. We need help publicizing the contest and soliciting nominations. There is a press release available for downloading on the Global Support Group site and on the SAGF Support Group site on www.cmtausa.org. We'd really like for this press release to appear in as many publications as possible in addition to any other media outlets you can think of. Please contact Julie at phantomsec4@yahoo.com or call 407-463-7545 to discuss how you can help.

Facebook Profile Campaign; Chaired by Mark Willis

Awareness Week 2010 planted a small seed that grew very large when several members began using the CMTA postcard art as our profile picture or "Avatar." We asked our friends and family to do the same. Soon there were thousands of CMT postcards all over Facebook. This year, we'll have a dedicated version of the official Awareness Month artwork to use. CMT friends and family on Facebook will again be asked to change their profile pictures for the month, and we are taking it global by inviting our international friends to do the same! So many people see your Facebook profile each day whenever you post, you play Farmville, Mafia Wars, Bejeweled Blitz, etc. Imagine how many of those folks have never heard of CMT. The artwork will be popping up everywhere. Questions will be asked about its meaning which provides you with a golden opportunity to educate them about the condition that affects your life or the life of a friend or loved one.

Help will be needed to get the seeds planted on Facebook. Please contact Mark if you are interested in lending a hand. A good way to help right now is to join Facebook so you will be ready to launch for Awareness Month!

Especially exciting will be the launch of a Youth Forum for Teens and Young Adults on our Facebook page—Charcot-Marie-Tooth Association: The Time is Now. By April 1st, kids, teens, and young adults will have a place to communicate, share experiences, and connect with others who have CMT. Watch for updates!

Teen and Youth Awareness; Chaired by Bridget Sarver

The focus of this program during Awareness Month is to encourage youth and teenagers to share information with their peers about CMT and what it's like to live with it. We will attempt to do this via a cell phone texting chain, and to kick it off we are tapping into our own CMTA facilitator families who have youth and teens to invite them to be the first to start the text chain with their family and friends. Have you seen how fast teenagers can forward a text? The news will be out in no time! We've also begun to approach sororities/fraternities to help spread awareness through college campuses.

We've reached out to the World Wrestling Federation and Showtime All-Star Wrestling to ask if they would be willing to display CMTA STAR banners at their venues to promote awareness for research.

Country music stars are being contacted to autograph and donate t-shirts which we hope to auction off. Please contact Bridget at bdsarver81@gmail.com or via phone at Facebook, Bridget Malloy Sarver.

As you can see—September is going to be CMTA-mazing! It takes many people with many talents to plan and implement events for an entire month. We need your help and your support! Just sending one letter, a single text message, or changing your profile picture on Facebook takes but a moment of time and its effect will be felt worldwide. We invite you to do more—call or email one of our chairpersons and get involved in spreading awareness about CMT! Together, we will shine the spotlight on the world of CMT. ★

CMT PATIENT & FAMILY CONFERENCE

Saturday, July 2, 2011, Washington, DC

A day-long conference for people with CMT, their families, and friends will be held near Washington, D.C. on Saturday, July 2. The conference will feature presentations from the world's leading clinicians and researchers, who are gathering for the biennial CMT International Consortium, a meeting of distinguished CMT clinicians and researchers from around the globe. Attendees will hear about topics including the latest research into CMT, the role of genetics, the impact of the disease on children, and compensatory strategies and physical therapy.

The conference will be held at the beautiful Bolger Center in Potomac, Maryland, the site of the consortium meeting and minutes from the nation's capital. Registration is just $50 per person which includes Lunch With the Experts, where registrants will be able to meet face to face with the day's presenters, all-day snack and beverage service, and more. Space is limited, so register now on the CMTA website at www.cmtausa.org/dcpfc. For more information please contact Jeana Sweeney (jeana@cmtausa.org) or Steve Weiss, support and action group facilitator for Washington, DC Metro (scweiss2001@yahoo.com).

PEOPLE PROFILES

Star Researchers

As part of the STAR initiative undertaken by the CMTA, the Svaren laboratory at the University of Wisconsin, Waisman Center, has been engaged in trying to develop and refine new ways to screen for drugs that can be used to treat CMT1A. Our work has been in a line of cells derived from Schwann cells known as S16 cells.


John Svaren, PhD

The first part of the project was designed to screen through the 200,000 bits or "bases" of DNA surrounding the PMP22 gene to find the important elements these bases contain that control how highly the gene is expressed. Our hope is that by finding the few hundred bases that are responsible for regulating the amount of PMP22, we can use the region(s) as an "Achilles heel" of this gene and disease and thereby unlock the secret of how to tamp it down, which will normalize myelin and treat the disease.These efforts have just resulted in a major new publication that is coming out in the *Journal of Neuroscience*, which was largely made possible by support from the CMTA.This work allowed us to improve on the original assay designs supported by the STAR project to create a second generation of assays that more accurately reflect the regulation of the PMP22 gene. As a result, two new cell line assays were sent to the NIH's National Chemical Genomics Center (NCGC) for screening with some of the compound libraries that are maintained there. Initial results with these new assays have been quite promising, and we are assisting NCGC to further test some of the compounds that have been identified so far.

Searching through the large libraries of compounds at the NCGC is a process of developing the best series of assays that can be used for "natural selection" of the few compounds that are most effective at lowering PMP22 levels and treating CMT1A. The better the assay we develop the more likely we are to identify compounds that can treat CMT1A by lower PMP22 levels.

We are collaborating with the National Human Genome Research Institute (NHGRI) to develop and validate new assays that can be used to distill a large collection of compounds to the few with the most promise.

NEW STAR CHALLENGE GRANT!

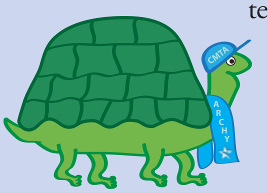
The CMTA has received an anonymous donation in the amount of $100,000 in support of the STAR program. The incredibly generous donation has compelled the CMTA's Board of Directors to issue a new Challenge Grant. The Board of Directors will match all funds raised between now and May 31, 2011 up to $100,000—which gives us the chance to turn the initial $100,000 into $300,000! Please take this great opportunity to help advance the STAR program—your support is greatly appreciated!

Archy Runs for Office

I'm having a good year in second grade and I made a pretty difficult decision this week. Student council elections for new positions next fall will be coming up in the next two months. I've decided to run even though I know that it will be scary standing in front of the whole school to make speeches and hoping that people will eventually want to vote for me. You can't run for student council until you are in third grade, which is where I will be next year.

One of the biggest problems, as I see it, is my having CMT. I wonder if the other kids running will make it an issue in the election. I watched the presidential elections and the recent ones for governors and senators and they were pretty mean. It seems like they focus on character traits rather than whether the person would make a good representative of the people or not. I worry that they will say that I'm too weak to make a good council member or that I have a "disease" which will make the students sort of afraid of me.

So, I have decided that I have to be the one to make an "issue" of my CMT. If I talk about it first, then the other candidates won't have any ammunition to fight me with. I can tell them about the disorder, the work I do for the CMTA and our hopes for a cure through the STAR program. I actually think it might work in my favor. I don't think there are many other third graders or even fourth or fifth graders who work as a volunteer representative of a national organization or who have travelled to Florida, Las Vegas, and Australia.



Our mascot "Archy" writes about his experiences as a turtle with CMT.

Using the knowledge that we have gained from our study of the PMP22 gene, we have developed a number of sophisticated ways to measure PMP22 levels, and determine the mechanisms by which compounds may affect the gene directly. These tools will help us identify candidate treatments that are specific for CMT1A while causing a minimum of side effects In addition, we are developing a strategy for transitioning from cell-based assays to mouse studies to provide pilot data for subsequent compound testing.

Dr. Patricia Dranchak joined the CMTA STAR project this past December after completing her postdoctoral research in rare diseases of lipid metabolism at the University of Southern California. She earned her PhD at the University of Minnesota in comparative and molecular biosciences where she worked on disease mapping in recurrent exertional rhabdomyolysis. Her addition to the research team at the NIH has already enabled adaptation and optimization of several PMP22-related assay protocols to utilize several of the latest instruments installed at the NIH Chemical Genomics Center (NCGC). This includes the application of high-throughput, high-content imagers that allow visualization of internal structures and interactions within the cells under different conditions.

She is currently developing and optimizing high-throughput assays for screening short interfering RNAs (siRNAs). These small molecules can be custom synthesized to temporarily knock-down specific genes in vitro using the cell's own biology. Screening of siRNAs is one of the latest techniques in target identification and validation in the drug-screening process. This research is an exciting new chapter in the CMT project as it offers a new avenue by which to identify potentially druggable target genes that can then be applied to small molecule chemical screens. This technology also has the potential to further elucidate biological pathways that may be involved in CMT and that may be pursued in future clinical research. Dr. Dranchak has already shown that this technology, using siRNAs to specific control genes, is effective in the cellular model systems currently in use to investigate the pathology of CMT1A. Her next step is to confirm this knock-down phenomenon in known myelination genes, and then move forward with high-throughput screens of several focused siRNA libraries. ★


Patricia Dranchak, PhD

Most of my friends are onboard to help with my campaign. We are trying to think of catchy slogans and bright colors to use on my posters. We've come up with the idea of using some reference to MacDonald's since they are famous for the golden arches and I'm named Archy. Just coincidentally, the new website for the CMTA uses the colors of blue, orange, and a sort of gold, like the arches themselves. I think they will be the colors we use on the posters because they are bright and light and cheery. We have discovered that there aren't many rhyming words for Archy or turtle. Right now, we are thinking of "March forward with Arch...y." Or," If you loved Yertle, vote for this turtle…Archy."

The reason I really want to win this election is because I think the other animals all want silly things that probably would never come to pass. I mean, they want to improve the food in the cafeteria by making it more like a fast food restaurant. The administration would never allow that…parents would be up in arms and there are federal food supplies that would be lost. Some of the kids think we should have more field trips, but I don't think that's logical either because we have so much we need to learn that going to an amusement park seems foolish.

I want to make changes that I think would really work. For one thing, I think that dismissing all the kids at once to try and fight their way to the buses is just plain dumb. If each class were sent to the buses at their own time, then getting on the bus without being trampled would be much easier. I suppose that the kids who can run fast would hate that they might not get the "best" seat, but it seems like safety is a bigger issue. Anyway, I want to run on what seem like "real" issues to me. Stay tuned. We'll see if I'm too idealistic (that's what my sister told me) or if others think like I do. ★

THE CMTA "CIRCLE OF FRIENDS"

If you are interested in creating a fundraising Circle of Friends or want your family or friends to donate money to the CMTA on behalf of your birthday, anniversary or special occasion, please let Jeana Sweeney know! You can email Jeana at: jeana@cmtausa.org Working together, we can create a world without CMT!

DONATIONS WERE MADE TO THESE CMTA CIRCLES:

Anna's Bananas

School District of Springfield Twp, Mont. County, PA

Chris's Run

Mrs. Terri A. Hofstede
Mr. Mike Wodke

Cruise for a Cure

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Donna's Quest

Mr. Paul A. Gribbon
Ms. Laura Porter

Grace's Courage Crusade

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Mr. Joseph Gomez
Ms. Jennifer Kinzel
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Mr. Matthew Walker
Mr. Tegan West
Mr. Stephen Woolley
Mr. Lyle Workman
Zembo Medical Mail Network, Inc.

CELEBRATION BENEFITS RESEARCH FUND

On March 5, 2011, Terry McIntosh celebrated her 70th birthday party at the Sofitel Hotel in Redwood City, California with over 80 of her closest relatives and friends. Instead of birthday gifts, Terry asked everyone to donate money to the CMTA on behalf of the promising STAR initiative. Terry has CMT, as do several of her children, and possibly some of her grandchildren. This celebration presented the perfect opportunity to spread awareness of CMT and to explain to all the invitees what exactly CMT is and how it affects people in their everyday lives. Gilles Bouchard and Elizabeth Ouellette distributed CMT brochures and literature to every guest present. In addition, attendees were given blue glow stars, symbolizing how much hope and promise the STAR initiative holds for the all those with CMT and their families. The CMTA would like to thank Terry and her guests for their generosity and thoughtfulness. Terry's celebration has brought in over $2,000 and the contributions are still coming in! It was a night to remember in everyone's heart and mind!

Playing Football for CMT Awareness

BY ALAN KOROWITZ

The idea for the fundraiser stemmed from CMT Awareness Week. At that time, my wife Ruth approached Coach Charlie Mazzocchi and discussed doing something to support CMT during the week. Timing was difficult because there was very little time from when we made the decision to when the season started. The coach thought it would make sense to do something later in the season. The event was originally going to be the work of a few teammates that needed to fulfill some community service work for their church, but it turned out to be truly a team effort—with everyone getting involved. The team met at Coach Charlie's house to plan the event and assign responsibilities. The following weekend, many of the kids met early Saturday morning to begin making banners, signs, and donation boxes. What was probably most impressive was a 25-foot banner that the two teams ran through to kick the game off. Our family joined the football team and some of the parents to solicit local businesses to provide gift certificates. We also had a printer donate 1500 color flyers to hand out. The CMT Charity Game had two games: the first game was between two of the younger-aged kids from the Plainview PAL football program and the second game was between Plainview's team and a neighboring town—Farmingdale.

Coaches, some parents, and most importantly, Zach and his teammates arrived at the field—a balmy 30 degrees, at 8:00 am. Many tables were set up. Ribbons, signs, and banners were all over the Plainview JHawks' football field. Most of the kids on the team brought different baked goods for sale. Prizes to be raffled were sprawled out all over the bleachers on the tables next to the baked goods. There were airline gift certificates, Broadway show tickets, many electronic games and accessories, Hershey Park tickets, and many local business certificates. Prior to each game, two teammates of Zach got on the public address system to talk about Zach and CMT. Everyone was asked to donate $5 (optional) to watch the game. There were many things for sale—including CMT bracelets, and t-shirts. Zach scored a touchdown and had many opportunities to run the ball as a fullback. There was even our regular food vendor selling food and drinks, and donating a hot dog and drink to every player that participated. After the final game, all the prizes, roughly 40, were raffled off.

Zach has been involved in the PAL football program for 5 years. He began playing prior to knowing he had CMT, and while we did not know why he struggled with some of the drills, he never gave up; he never complained. There was one drill, the crab walk, where players cross a field on all fours—feet and hands, no knees touching. This was virtually impossible for someone with CMT, but someone who didn't know he had CMT—like Zachary—made every effort to do it. And the teammates cheered him on every step of the way. Runs during practice, naturally, were equally difficult. We're not sure which was more inspiring, Zach's refusal to give up, or his teammates there to cheer him on.

Zach and his teammates raised awareness and funds for CMT research.

PAL football has been a great experience for Zach. We are fortunate to have a great program director Jack Young, and many coaches like Charlie Mazzocchi. Football commitment is practicing two days a week plus a third day for the game. One important thing we learned is not to let CMT limit what Zach does. I am not sure that we would have considered allowing Zach to play full contact, tackle football if we had known he had CMT. The fact is, he is very good at it. He's established strong bonds with his teammates and he's made progress educating our community about CMT. He loves it, and it's great for his confidence. At many of the games, parents will approach me and comment how they are inspired by Zach and his performance on the football field. ★

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Patricia L. Beechem
The Charles Beechem Family
Mr. Jim Bull
Mr. Robert Eads
Mr. John C. Garvey
Mr. & Mrs. Raymond L. Hovis
Mr. & Mrs. Rob Hovis-Stephenson
Mr. Jerri Lamson & Family
Mr. & Mrs. Steven Gluckstern
Mr. & Mrs. Dennis Hodgson
Ms. Cathy Langsner
The Lish Family
Mr. & Mrs. Charles Luria
Mr. Alan J. Malman
Ms. Elizabeth M. Nuss
Ms. Lucille Zinman

John S. Bradley
Mrs. Janet R. Bradley

Millie Checki
Mr. & Mrs. Walter Sorensen

Arlene & Bill Conrad
Mr. & Mrs. William N. Sharp

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Mrs. Joanne E. Fatur

Dorothy R. Jacobson
Ms. Leanore R. Cohen

Mimi Levy
Mr. & Mrs. Robert Bernstein

John J. Slate
Ms. Wanda H. Dalling

Florence Spooner Vinson
Mr. Samuel Spooner

Bernard Yabroff
Mr. & Mrs. Andy Feldstein

IN HONOR OF:

Carol Albright
Ms. Brenda Gardner
Mr. Joseph Hiestand
Mr. David Hooie
Mr. Eric Pickering
Mr. and Mrs. Michael Streng
Mr. and Mrs. Jason Widmer

DeeAnn Alongi
Ms. Claudia K. Alongi

Lessia Bemmel
Mr. Vincent Bemmel

Andrew S. Brooks
Mr. Scott C. Brooks

Cathy Brooks
Mr. and Mrs. Kenneth Dunham

Sherry Brown
Ms. Jana Benham
Mr. Mark Hodgin

Joy W. Colby
Mr. Robert H. Colby

Irene Cross
Ms. Elizabeth Ouellette

Mr. and Mrs. Harry Lee Cross, III
Mr. and Mrs. Harry Lee Cross, IV

Amy de Silva
Mrs. Marcella M. Costa

Frank S. Dingwerth
Ms. Sherry Brown

Jacqueline Dyer
Ms. April Capps
Mr. Jonathan Carpenter
Ms. Tiffany Crabb
Mr. and Mrs. Scott Dyer
Ms. Linda Saldana
Ms. Stephanie White

Amy Hodge
Mr. and Mrs. Ashley Hodge

Cynthia Hodges
Ms. Ellen Bunting

Gayl S. Johnson
Mrs. Jane K. Fairbanks
Pamela Kleinman
Mr. Donald D. Capelin
Ms. Maureen Wipf

Zachary Korowitz
Mr. and Mrs. Richard J. Allen
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Stewart Kouba
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The Sarver Family
Mr. and Mrs. James W. Ott

Cody Thomas
Ms. Katy Thomas

Harriet Weiss
Ms. Erica J. Berger

Terry McIntosh—Happy 70th Birthday
Mr. and Mrs. Ronald W. Albers
Mr. Gilles Bouchard and Ms. Elizabeth Ouellette
Mr. and Mrs. Richard A. Bertoldi
Mr. Mario Ceja
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Ms. Pamela A. Cronin
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Ms. Catherine Dittmar
Mr. and Mrs. Edward Flank
Ms. Debora Gonzalez
Mr. Travis Hastings
Mr. Arnold Manrubia
Mrs. Carol Manrubia
Mr. Stephen Manrubia
Ms. Jan McFarland
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Mr. and Mrs. Rico Morini
Ms. Dolores Neal
Mr. and Mrs. Will Ortega
Mr. and Mrs. B. J. Rodondi, Jr.
Mr. and Mrs. Raymond Rosenthal
Mr. Hal Schuette

Lisa Weiner—Happy Birthday
Ms. Mary Elliott
Mrs. Carolyn D. Lyon

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, P.O. Box 105, Glenolden, PA 19036.

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 ☐ American Express

Card #___________________________

Exp. Date ________________________

Signature ________________________

Gift Given By:

Name:__________________________

Address:________________________
____

PEOPLE WITH CMT

Nancy Foster-Mills Finds Joy in Breaking Things

(from The News Tribune.com)

Usually it's a stack of 1-inch pine boards. Other times it's concrete, ice or watermelon.

The 44-year-old has a first-degree black belt in tae kwon do and has held the United States Breaking Association's women's record for the most boards—11—broken with an elbow since 2008.

She also is tied for first place for the women's USBA record for breaking the most boards—nine—with a fist.

Foster-Mills took up martial arts five years ago almost on a whim and despite the fact that she suffers from a genetic degenerative neurological disease that likely will cause her to use a wheelchair someday.

"I...was looking for a way to get some exercise, something that wasn't boring," she said.

She discovered there is nothing boring about how her instructor, Wes Lewallen, owner of Pacific Kicks in Kennewick, Washington, teaches tae kwon do. Foster-Mills also discovered she had an aptitude for breaking objects.

Lewallen said his students often show a preference for one part of the sport over another.

"Some do weapons, but breaking really sparked her," he said. "which is unusual. Females don't usually take to breaking as much as guys."

And Foster-Mills, who is product line manager at the Environmental Molecular Sciences Laboratory in Richland, does it in spite of genetic degenerative neurological disease, called Charcot-Marie-Tooth, or CMT.

People with CMT slowly lose normal use of their lower legs and hands as nerves to the extremities degenerate and muscles become weakened due to a lack of stimulation, affecting their balance and strength. Six people in her immediate family have the disease.

Foster-Mills wears sturdy elastic braces on her feet.

"I'll eventually need sturdier plastic braces, then a cane and finally a wheelchair," she said. "But not now. I do have problems with my balance, and I can't do high kicks, but I can still break boards and do most everything everyone else can do."

Breaking, Foster-Mills said, "requires power, technique, focus and confidence. Strength helps but it's really a combination of all those that allow you to break." For her, taking up martial arts was about being courageous. "You don't know what you can do until you try. If you fall down, you pick yourself up and keep going. That first day I thought, 'This won't work, my knees will be killing me.' But you'd be surprised what rubberized floor mats, anti-inflammatory drugs and braces will do," she said.

To achieve championship status, Foster-Mills competed in tournaments, which mainly are held in Ohio, Texas, and on the East Coast. She earned points at each one for a first-place win.

You can see videos of Nancy Foster-Mills in action on YouTube.

"The more tournaments you attend, the more points you can earn," she said. Points are totaled at the end of the year and the championships awarded. It's fun, she says, but expensive. Her out of pocket expenses for each tournament run about $1,500.

Part of her expenses are the boards and cement blocks she breaks. The blocks are standard. But the 9-by-12-inch boards, 1/2 inch or 1 inch thick, have to be special ordered. To ensure all the boards being used at a tournament are equal, they have to come from the same lot.

Between buying materials, travel, entry fees and ongoing tae kwon do classes as she works on her second degree black belt, Foster-Mills said "it's not a cheap sport." But she loves it. ★

SUPPORT AND ACTION GROUP NEWS

CA – Visalia Area

The Visalia SAGF had their second meeting since starting the group, on Feb 28th. Four members attended and were very happy to have a local physical trainer show them how to do some stretches and myofascial release. The trainer had been working with Melanie (group facilitator) for over a year. There was also a local nutrition company that shared some information. The next meeting is planned for sometime in May.

FL – Inverness

The group met on January 29th. Their guest speaker was Mr. John Spang, owner of Visiting Angels in Ocala, Florida. He covered the many types of in-home or assisted living in the area. John covered what private insurance, Medicare, or Medicaid might possibly cover. He went into how to determine, financially, whether in-home care or assisted living is best long term. It was very informative. The next meeting will be April 30th. The speaker will be John Messer, owner of Kidder Orthopedic Laboratories.

FL – Orlando

The group met on February 5th. The group focused on the plans for Awareness Month, a brief update on STAR, and an explanation of the new website and how to join the group on the site. Members were encouraged to join or renew their membership to CMTA. Discussions included one member demonstrating her new AFOs, with others talking about the pros and cons of getting genetically diagnosed and the impact on securing health insurance. They concluded the meeting by announcing Jeana Sweeney's upcoming visit to the May 5th meeting.

FL – Tampa Bay Area

The group met on Feb. 19th. They had nearly 50 people attending, including a few 'snow-birds' who only come to one or two groups a year. The speaker was Dr. Jason Bottoms, DPM, of the Ankle and Foot Centers, who discussed the variety of surgical procedures available and the need for a podiatrist's involvement based on the degree of severity of the CMT. He covered specific surgical procedures and when each was indicated based on the degree of deformity and flexibility in the foot. The group will meet again May 21st.

MI – Kalamazoo Area

The group met on January 20, 2011. Unfortunately, bad weather was threatened (and did arrive by the end of the meeting!), and there were only five attendees at this meeting. They had a chance to meet and welcome the new MDA Health Care Coordinator for our area, Brian VanKley. They also discussed the medical and insurance concerns that one of our members has been having. The next meeting will be in March.

NJ – Central New Jersey Area

The group met on January 29th. The speaker was Tara Schmidlen, MS, CGC, from the Coriell Institute for Biomedical Research. She spoke about the NIGMS Human Genetic Cell Repository. The group also reviewed the successful fundraiser they held for awareness week last year; they raised $1,768. Mark gave an update on the STAR Program and he encouraged everyone to visit the new web site and join his group. The group will meet again in March.

NY – Upstate New York Area

The group met on February 12th. Their guest was Don Paul Shannon, a licensed clinical social worker, who for over 20 years has provided counseling and support to patients and families who are confronted with a serious medical diagnosis. He started off the meeting by encouraging everyone to say a little bit about themselves. Each person talked about being diagnosed with CMT and how it effects him or her now. After a short break Don Paul demonstrated what he calls sounding. Everyone tried some deep belly breathing exercises as he encouraged the group to make various sounds: humming, singing, whatever we felt like. He demonstrated different tones to either wake us up (as in alleluia after a sermon) or to relax as in meditation. The group discussed all the exciting things that the CMTA has planned for awareness month. They were also encouraged to help fundraise and help with awareness month. They will met again on April 23rd.

(continued on page 14)

CMT Support and Action Groups

AL—Birmingham Area
No group currently meeting
Will accept calls
Dice Lineberry
205-870-4755

AZ—Phoenix Area
Arizona CMTA Support Group
Ken Wysocki
602-606-2805
Pamela Palmer
480-926-4145

CA—Los Angeles Area
SoCalSupportGroup
Dottie Zagar
661-942-4501

CA—South Bay Area
San Francisco Peninsula/ South Bay
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—Sacramento Area
Rashid Thomas
916-947-5377

CA—San Diego Area
San Diego CMTA Support Group
Steve Gabbert
619-987-6022

CA—Santa Rosa Area
Santa Rosa Support Group
Carol O'Bryan
707-823-0165
Ronald Deghi
707-829-0911

CA—SF/East Bay Area
San Francisco/East Bay Support and Action Group
Donna Rennie
925-330-2790

CA—Visalia Area
Visalia California SAG
Melanie Pennebaker
559-972-3020

CO—Denver Area
Denver Area Support & Action Group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

DC—Washington, DC Area
Washington DC Metro
Steven Weiss
Kimberly Hughes

FL—Inverness Area
West Central Florida
Ronnie Plageman
352-860-1578

FL—Jacksonville Area
Jacksonville, FL Support Group
Bill Wilkins
904-268-4530

FL—Orlando Area
Central Florida Support and Action Group
Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area
FL Support Group
Vicki Pollyea
813-251-5512

GA—Atlanta Area
Atlanta Support Group
Susan Ruediger
678-595-2817
Jeannie Zibrida

IL—Chicago Area
Chicago Area Action & Support Group
Dale Lopez
708-499-6274

KS—Wichita Area
Kansas Area CMT Support Group
Karen Smith
316-841-8852

KY—Burlington Area
Pam Utz
859-817-9338

MD—Hagerstown Area
Hagerstown Maryland CMT Support Group
Jeffrey Martin
301-582-2401

ME—Portland Area
Portland, ME Support and Action Group
Celeste Beaulieu
207-284-1152

MI—Chesaning Area
Chesaning, MI Support and Action Group
Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area
Southwest Michigan Support Group
Jori Reijonen
269-341-4415

MN—Benson Area
No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area
No group currently meeting
Will accept calls/emails
Libby Bond
417-845-1883

MO—St. Louis Area
Carole Haislip
314-644-1664

MS—Mississippi/Louisiana
Clinton, MS Support and Action Group
Flora Jones
601-825-2258

NC—Triangle Area
Triangle, North Carolina Support and Action Group
Betsy Kimrey
919-833-3991

NH—New Hampshire/Vermont
New Hampshire/Vermont CMT Support and Action Group
Margaret Healey
802-535-2797

NJ—Central New Jersey Area
Central New Jersey Support and Action Group
Mark Willis
732-252-8299

NM—Albuquerque Area
CMT New Mexico Support & Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area
Las Vegas CMT Support and Action Group
Diane Cencak
702-560-3647

NV—Reno Area
Ken Smith
775-233-7788

NY—Upstate New York Area
The Upstate NY CMTA Support & Action Group
Melinda Lang
518-783-7313

NY—Greater New York Area
Greater New York CMT Support Group
Bob Wine
212-535-4314

NY—Horseheads Area
Horseheads, NY Support Group
Angela Piersimoni
607-562-8823

NY—Hudson Area
Hudson Valley CMT Support Group
Deborah Newman
845-883-0580

NY—Long Island Area
Ruth Korowitz
516-318-3202

NY—Westchester Area
Westchester Support Group
Beverly Wurzel
201-224-5795

OH—Greenville Area
Greenville OH Support and Action Group
Dot Cain
937-548-3963

OR—Portland Area
Portland Oregon Support and Action Group
Debbie Hagen
503-333-7936

PA—Bucks County Area
Bucks County Support Group
Linda Davis
215-943-0760

PA—Johnstown Area
Johnstown, PA Support and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-262-8427

PA—Northwestern Area
NWPA CMT Support and Action Group-Erie, PA
Joyce Steinkamp
814-833-8495

PA—Pittsburgh Area
Pittsburgh Support Group
Christine Miller
412-341-5749

RI—East Providence Area
Rhode Island Support Group
Meredeth Souza
401-433-5500

TN—Nashville Area
Nashville Support and Action Group
Mark Hollingshead
615-480-2044
Bridget Sarver
615-3909-0699

TN—Savannah Area
Savannah, TN Support and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area
Dallas Support and Action Group
Whitney Kreps
972-989-5743

VA—Harrisonburg Area
Anne Long
540-568-8328

VA—Williamsburg Area
Williamsburg VA CMTA Support Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area
Ruth Oskolkoff
206-293-2204
Yumi Hines
425-335-0272

WA—Tacoma Area
Tacoma, WA CMTsag
Carol Hadle
253-476-2345

WI-Milwaukee
Southeastern WI CMT Support Group
Polly Maziasz
262-439-9009
Margaret Hoepner
414-788-9628

Virtual Groups

Dave Hall's Virtual Support and Action Group

Global Support and Action Group Community

If there is no support list in your area you may want to think about becoming a support group facilitator! If you're interested please contact Jeana Sweeney at jeana@cmtausa.org. Other online groups you may want to consider are Global Support and Action Community and Dave Hall's Virtual Support and Action Group.

SUPPORT AND ACTION GROUP NEWS

(continued from page 12)

NY – Westchester Area

Thaddeus E. Drygas, CPO, FAAOP of Care Crafters Prosthetics and Orthotics Inc., attended the March 5th meeting of the Westchester Support and Action Group. He discussed the Allard Family of orthotics. Allard's product line of carbon fiber floor reaction AFOs do more than just support drop foot. They enhance knee stability, balance, stamina, and comfort. You can go to www.allardusa.com to get information on these AFOs. The group will meet again in May.

PA – Johnstown

The Johnstown support group held its bimonthly meeting at the John P. Murtha Neuroscience and Pain Institute. The subject was the current CMT research at the Institute. Lisa Pasierb and Jan Goodard presented an informative show on the progress of their PA eight-county prevalence and CoQ10 studies. The prevalence study is going well, but the problem is getting folks with CMT to participate. The CoQ10 study has enlisted support members and participants from outside our area but needs more. These are important studies, and if anyone is interested, please go to: http://www.conemaugh.org/, type CMT and click on Clinical Research Studies.

RI – East Providence Area

The group met on January 22nd. This was the second time the group met. They talked about fundraising ideas. The group is planning a fundraiser party for the end of April. They also talked about awareness month and things they can do to spread awareness. They then talked about what has been going on in their own lives. Their goal is to build relationships within the group. Their next meeting will be held on April 30th.

ASK THE DOCTOR

Dear Doctor,

I am a member with CMT1A. In the Jan/Feb CMTA report, your Dear Doctor re: Adie's pupil was of interest. I have also been diagnosed with Adie's pupil and bilateral hearing loss, and my sister was diagnosed with optical neuropathy and CMT1A. Her symptoms are feeling off balance and having cloudy, tired eyes. Have you heard of patients with type 1A having these problems?

Dr. Steven Scherer (U of PA) replies:

There is no clear association between CMT1A (caused by the PMP22 duplication) and Adie's pupil, hearing loss, or optic neuritis.

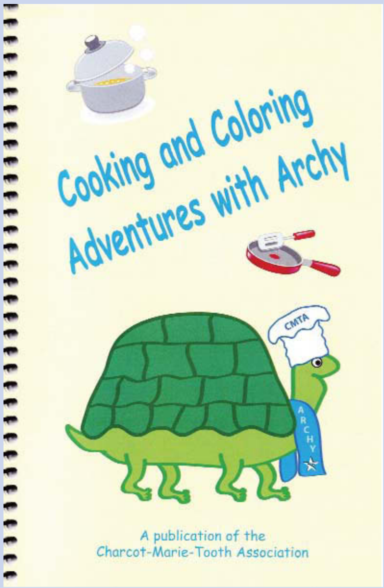
Dear Doctor,

I saw an ad saying that there's a lawsuit against the companies that make Fixodent and Polygrip. I researched it because my father wears dentures and uses Fixodent. It reports that the high levels of zinc have been found to cause peripheral neuropathy, balance issues, weakness, numbness, etc. I wondered if there is a link to zinc levels in people with CMT because it sounded like I was reading about a person with CMT when I was reading about the lawsuit.

Dr. Louis Weimer (Columbia U) replies:

I know of no special link between zinc and CMT, but it is true that excessive amounts of zinc cause the body to lose copper. Copper deficiency is a cause of sensory loss, imbalance, neuropathy, and leg stiffness. All of these problems will interfere with function in CMT patients and potentially worsen the degree of neuropathy. However, a significant amount of extra zinc is needed to produce the problem. Eating coins, especially pennies, is one way to ingest excessive doses, but few people have that urge. Excessive supplements are also an issue, but large doses are needed. People with the dental adhesive exposure used quite a bit more than the manufacturer recommended. One simple question is how long a tube of adhesive lasts. Many affected patients used 1 or more tubes a week to secure poorly fitting dentures; one tube should last at least 4 to 6 weeks. However, I believe that the latest formulations have the zinc removed. If there is any doubt, copper and zinc levels are easily tested in the blood.

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



COOKING AND COLORING ADVENTURES WITH ARCHY

is a new publication which combines fun recipes that parents and kids can do together with puzzles and objects to color on many pages. It's an easy book for a child to make his/her own.

Archy has written the foreword to the book in which he remarks that the best thing about cooking is that it gives him the time to be with his family working together. Some of Archy's favorite recipes from the book include Shoo-fly pie, Ants on a log, Archy's favorite salad, and Archy's not-so-favorite, Mock Turtle soup.

The book is 8 inches by 5 inches and contains 75 pages. It sells for $7.00 and has a glossy wipe-off cover.

SUBSCRIPTION AND PUBLICATIONS ORDER FORM

NAME: ____________________/______/ ______________________________
First MI Last

ADDRESS: ____

CITY: ______________________ STATE: ______ ZIP: ______________

COUNTRY/POSTAL CODE (IF NOT US): ______________________________

DAYTIME PHONE: ____________________ EVENING PHONE: ____________________

EMAIL: ____

		QTY	COST	TOTAL
NEWSLETTER	Online subscription with PDF newsletter	$25 (MUST REGEGESTER ONLINE)		
	Online subscription with printed newsletter	$30 (MUST REGEGESTER ONLINE)		
	Mail subscription only with printed newsletter *(no access to on line premium content)*		$30	
	The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		$15	
	[CD Format]		$10	
	CMT Facts I ☐ English ☐ Spanish		$5	
	CMT Facts II ☐ English ☐ Spanish		$7	
	CMT Facts III		$7	
	CMT Facts IV		$10	
	CMT Facts V		$15	
	CMT Facts VI		$15	
	Teaching Kids about CMT…A Classroom Presentation *(1 hour DVD)*		$10	
	My Child Has CMT, A Guide for Parents		$7	
	Cooking and Coloring Adventures with Archy		$7	
	Be a Star Wristbands (Pack of 5)		$5	
	Women's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL		$10	
	Men's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL ___2XL ___3XL		$10	
	West Coast Patient-Family Conference *(5 hours—2-DVD set)*		$20	
	CMT Informational Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List		FREE	
	Physician Referral List: States: ______ ______ _____		FREE	
	Donation to the CMTA *(100% Tax-deductible)*			
	Shipping & Handling *(Orders under $10, add $3.50; orders $10 and over, add $7.50)*			
	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, P.O. Box 105, Glenolden, PA 19036

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.

THE CMTA Report

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
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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 (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
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, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, 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.