1983-2008

WE CELEBRATE 25 YEARS: LIVING OUR VISION OF A WORLD WITHOUT CMT

THE CMTA Report

NOVEMBER/DECEMBER
2008

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

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@charcot-marie-tooth.org

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West Coast Conference Attracts Huge Audience

BY PAT DREIBELBIS

The Palo Alto, California patient/family conference was the largest one ever held by the CMTA, attracting more than 250 attendees. On Saturday, November 8, 2008, the Mitchell Park Community Center welcomed a crowd of people anxious to hear about the latest in CMT research and treatment. They were not disappointed!

The audience was welcomed by organizer and Board member, Elizabeth Ouellette. The conference had been her dream and her mission for the last three months and all her work was rewarded by the fantastic turnout on Saturday.

The program began with a challenge from Chairman of the Board and President, Patrick Livney, to "imagine a world without CMT." He further discussed the three-pronged focus of the organization to fund research, to promote awareness, and to provide support through our network of support groups.

He was followed by the Chairman of the CMTA's Medical Advisory Board, Dr. Michael Shy, who spoke on "Making sense of Alphabet Soup." His mission was to explain the various forms of CMT, their gene locations, and why knowing types could be important to a person. As research zeroes in on correcting specific flaws, it will be crucial for people to know their type in order to know what correction might work for them. Dr. Shy also talked about the Wayne State Clinic, the STAR initiative, and the new Centers of Excellence. His presentation was followed by many questions and answers.

Board member, Steve O'Donnell and actress Julie Newmar (former Catwoman) enjoy the presentations at the West Coast Conference.

The CMTA was delighted to have Julie Newmar, former Catwoman in the Batman TV series, noted for her fabulous legs, in attendance. She greeted

(continued on page 2)

INSIDE:

Ascorbic Acid Trial 3
Skiing with CMT 5
More Transitions 7
Help from a Podiatrist 13

WEST COAST CONFERENCE

(continued from page 1)

the crowd and stayed for the entire conference. She has recently been diagnosed with CMT.

Dr. Paul Billings, President and CEO of CELLectiveDX, explained to the audience how genetic policy affects people with genetic diseases and how important government policy can be in providing equity for all persons facing genetic issues. After a short break, the audience learned about foot and ankle options from Dr. Bill Metaxas, a podiatrist who treats some of the people in attendance. He was followed by Jennifer Kaubish, a physical therapist familiar with CMT, who advocated building up unaffected muscles in order to have them take over some of the work of muscles directly affected by CMT.

Gretchen Glick, founder of the online group CMTUS, concluded the morning's presentations with a brief explanation of what she set out to do 10 years ago in founding the group. Her postings of research findings and her chat room discussions have provided CMT patients with important information for a decade.

After lunch, CMTA Director of Program Services, Pat Dreibelbis, talked about the development of the CMTA over its 25 years. She challenged attendees to all buy and wear a "Be a Star" aqua bracelet for a dollar (like Lance Armstrong's yellow "Live Strong" ones) before the conference concluded. By the time of the closing remarks, not one bracelet remained. The challenge had worked perfectly. Dana Schwertfeger, Director of Member Services, then talked about the "Circle of Friends" campaigns and announced the awarding of a scooter to David Capps.

> The West Coast Conference challenged those present to "imagine a world without CMT."

Genetic counselors Carly Siskind and Shawna Feely, from Wayne State, explained inheritance patterns and the value of doing a genetic history. They even encouraged the audience to do a family tree this year during the Thanksgiving feast when large family gatherings often take place. The final presenter was Sean McKale, an orthotist who also works with the members of the Wayne State Clinic staff. He brought a bag full of possible orthotic corrections for the CMT foot and leg and discussed which type works best for which individuals. He also discouraged people from "jumping" on each new bracing type that comes out without carefully evaluating the likely function gain the device might provide. His presentation provoked questions because so many of the attendees were in braces of one sort or another or were contemplating the need for braces in the future.

The day concluded with a gathering where attendees could ask personal questions of the presenters and enjoy desserts provided by the San Francisco Bay area support group. Throughout the day, attendees were able to enjoy the displays of vendors such as Active Forever, Diablo Prosthetics and Orthotics, Healthy Bare Feet, and the Bay Sleep Clinic. They also could meet and talk with author Jonah Berger, who wrote *He Walks Like a Cowboy*.

All of the presentations, vendor displays, and opportunities to speak with others who have CMT made a full and valuable day for those who were able to attend. Elizabeth hopes to be able to arrange another West Coast conference in two or three years. ✻

Board Member Elizabeth Ouellette and Board Chairman Patrick Livney opened the West Coast Conference with presentations about STAR.

PROGRESS REPORT TO CMT ASSOCIATION

High-Dose Ascorbic Acid Treatment of CMT-1A

Year 2 (October 2007–September 2008)

This is a summary of activities of the High-Dose Ascorbic Acid Trial for the second year of the grant. The grant was funded from 10/1/2006 to 9/30/09.

SEPTEMBER 18, 2008—Overall the trial is progressing nicely, although we are still recruiting patients to reach our total number of 120 patients. The second year of the trial has ended with 90 patients enrolled. Recruitment was rapid in the first 12 months but slowed somewhat until the last month, when it has picked up again. We have made a concerted effort to publicize the trial with announcements in both the MDA and CMTA newsletters. In addition, the physicians have been giving talks locally and nationally to bring awareness to the trial. We should have over 100 patients participating in the trial by January 1, 2009. The first patients will complete the 2-year trial in April 2009, and the 90 patients currently recruited will all complete the trial by September 2010. There have been no major complications, and the adverse event profile has, to the best of my knowledge, been acceptable. Only eight patients have dropped out of the study.

Because of the delay in full recruitment, some of the expenses that were budgeted for the second year were not spent (per patient charges), but the study will need to be extended beyond the original end date of April 2010.

Please contact me if you have any questions.

Richard A. Lewis, MD
313-577-1244
Ralewis@med.wayne.edu

STUDY PARTICIPANTS NEEDED…

CMT RESEARCH STUDY AT UNIVERSITY OF MIAMI

The Miami Institute for Human Genomics at the University of Miami, Miller School of Medicine is looking for individuals and families who would like to participate in Charcot-Marie-Tooth (CMT) research. Stephan Zuchner, MD, and Jeffrey Vance, MD, hope to identify genetic factors that contribute to this disease.

Any individual with a CMT diagnosis, along with selected family members, can participate. Participation is free of charge, and travel to the University of Miami is not required. The research team will perform a family and medical history interview, focused neurological exam, and review of medical records related to CMT. A small blood sample also will be needed. Anyone interested in participating may contact the CMT study coordinators at (877) 686-6444 or by emailing mihgCMT@med.miami.edu. Information is also available at www.mihg.org.

PARENTS SOUGHT FOR SURVEY OF GENETIC COUNSELING EXPERIENCES AND GENETIC KNOWLEDGE

A graduate student in the Genetic Counseling Program at the University of Maryland School of Medicine in Baltimore is conducting a large-scale survey of what parents of children with neuromuscular disorders know about the genetic basis of their child's condition and how this information was obtained. The investigators hope to improve parental education in this area. The survey is available online at http://www.surveymonkey.com/s.aspx?sm=px33yKo77QFithmcfY1sag_3d_3d. Contact Jacquelyn Francis at jfran007@umaryland.edu with questions or concerns.

The goal of the study is to determine if parents of children with neuromuscular disorders were offered genetic counseling, how this affects what parents know about the genetic basis of their child's condition, as well as how and when this information was provided and/or obtained within the diagnostic and management process. We anticipate that the results of this study will provide insight into the best mechanism for educating parents of children with neuromuscular disorders about the genetic basis of their child's condition.

Participation in the study involves completion of an online survey and is voluntary and completely anonymous, as no identifying information is requested. The survey takes about 10-15 minutes to complete. Once parents are finished, nothing more will be asked of them. This study was approved by the Institutional Review Board of the University of Maryland School of Medicine in August 2008.

My Experiences with CMT

BY JACK GRAVES

As anyone with CMT understands, balance and walking present the biggest challenges. I recall, as a young child, being teased for the way I ran. One older boy called me "sloofoot," a word he created. Since all the other boys laughed at that and, since youngsters are notoriously fragile when it comes to teasing, I just stopped running. In school, I only ran when it was absolutely required in gym (now physical education) classes. I did not have any hand or leg problems during those years and was unaware that CMT was lurking inside. I simply ran "funny."

The CMT never actually caused serious concerns for me early on. I did have high arches, hammer toes, sprained ankles, and broken ankles on occasion, but the severity only manifested itself years later.

My real concern developed as I entered adulthood. My leg muscles were still visible and strong, I walked without balance problems, and my hands worked as they were designed. However, during Army Basic Training at Fort Ord, California, I had some significant ankle problems during heavy calisthenics and long marches. I ended up at the base hospital three times, and the Senior Medical Officer indicated that my ankles could not withstand the arduous rigors of training, so I was given an Honorable Discharge. I was extremely disappointed because I did want to complete my service during the Korean War. I was too young during World War II.

During college, I took the easiest route for physical education (bowling classes, for example) and managed to get through. After I began my teaching career, I continued to be able to function with no balance problems and all that implies. However, I continued to turn, sprain, and break ankles. It was also a period when I began to feel that my legs were not so strong, and, worse yet, the muscles adjacent to each of my thumbs were disappearing. I decided to see an orthopedic surgeon, and he recommended an operation to stabilize my right ankles. It is called a triple arthrodesis. It worked, and I have not turned that ankle since (30 years ago). However, the surgeon did chat with me a few days after the operation and indicated that he believed I had Charcot-Marie-Tooth disease. I had no idea what that could be. And my! What a peculiar name. He made an appointment with a neurosurgeon and, after the usual examination/tests, he also described my condition as CMT. His diagnosis occurred in 1978.

Since that time, my CMT has continued its attack on my leg muscles. Soon, the muscles below my knee and into my foot/ankle were wasted away. I began to have that awful "foot drop," and my gait became unusual because of it. In addition, the muscles below my elbow and into my hands atrophied, and my thumbs became very weakened. My profession as an educator suffered because my legs tired quickly. However, my emotional state was fine, even though physically the situation was a bit difficult. I was determined to complete my work until retirement, and CMT was *not* going to win the battle. I am proud to state that I did just that.

William, my brother with CMT, began to notice symptoms during his late thirties, and the disease got progressively worse for him as the years went by. He, too, made the personal decision that he would continue working until retirement, and that is what happened. I am quite proud of him as well. Hopefully, young people, in whom the condition might be more visible at an early age, can develop a positive outlook, accept what cannot be changed, and meet any challenges that CMT presents. If my brother and I could do it, I know they can, too.

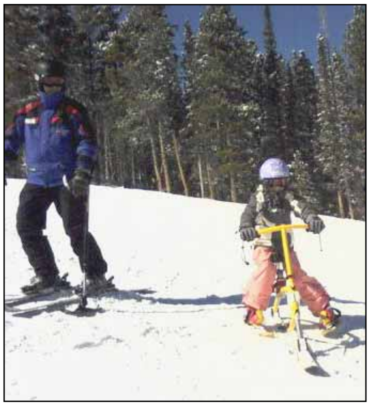
But, in all of this, there was a concern. My walking became worse and my balance suffered significantly. As a member of the CMTA, I receive the Report and in the December, 2002, issue, I read about some braces. The braces described in the article were made by Mitch Warner in his lab. They were Helios orthoses, designed to load energy in their helical uprights and correct deformity at the same time.Carbon-graphic gives the orthoses rigidity for control

Skiing with CMT

My name is Amanda. I'm eleven years old. I have a disability called CMT.

CMT makes stuff that's easy for other people to do a little more difficult for me. I wear AFOs on my legs; I wear them so I can walk. Because of my condition it is hard to do sports that I love, like skiing. Skiing is my favorite sport, but I could only ski for a little bit, and then I would get tired.

While at Breckenridge Outdoor Education Center in Colorado (BOEC), I was taking a ski lesson and they were trying different ways so I could ski longer. First, they tried a different skiing technique. It didn't work out that well. Next, they tried outriggers. They kept sticking to the snow. Finally, we tested a snowbike. It worked perfectly, but it was a little heavy. Then, I got to try a Brenter snowbike. I like this snowbike because it is easy to maneuver and it is light-weight. Another reason that I like the Brenter snowbike is because it's easy to carry on and off the lifts.



Amanda uses her ski bike to allow her to continue skiing with her father.

When I do use the snowbike, I can ski longer than before. I'd rather ski on the snowbike for twenty runs than ski standing up for only two runs, and then be tired.

I would like to thank The Vail Group's Adaptive Ski Program in Breckenridge, Colorado, and Brenter Snowbikes for helping this Florida snow girl tear up the mountain again.

See ya next powder day,

—Amanda, FL

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and also an energy-loading structure to store and release energy. I became interested in these braces, so I drove to his laboratory in Las Vegas.

After an examination, Mitch indicated that he felt he could improve my balance and gait with the Helios orthoses. It took a week for the procedure—making a mold, creating a cast, checking for needed adjustments, and finally making the braces. On Friday morning, the braces seemed fine, so I drove the 475 miles home to California.

Even though I'm not an overly emotional person, when I put on my braces initially and stood up, it was the first time in at least 15 years that I could do so without losing my balance. Tears welled up in my eyes because this was a monumental moment for me. These braces made by Mitch seemed to solve all my balance problems. And, since my ankle was in a rigid position, I no longer had foot drop. It became much easier for me to drive because my foot/ankle joint was not "flopping," and I felt much safer and more confident. Additionally, the braces gave me a greater self-image for I could now walk keeping my head up and my back straight.

Over the last five years, there have been times when one of the braces would rub my leg a bit much. All I had to do was FedEx them to Mitch and let him place some soft material in the appropriate location.

I have now reached the theme of this message, and that is, for any individual with CMT to get assistance in the form of leg braces from some source. The ones I am now wearing are from Ortho Rehab Designs. More information is available at www.ordesignslv.com.

I hope my comments will encourage others with CMT to make an effort to get some help for walking in the form of braces. I would be happy to discuss this topic with anyone. Contact me at jag.syzgy@att.net or by mail at P.O. Box 2337 Turlock, CA 95381-2337. ✻

The CMT "Circle of Friends"

As we give thanks and celebrate during this holiday season, please join us in saying a very special thank-you to everyone who has organized and contributed to a CMTA Circle of Friends.

We are very grateful for your support, and, together with our Strategy to Accelerate Research (STAR), your gifts have brought us closer to finding therapies and a cure for CMT.

You've also demonstrated what a powerful effect we can have when we work together, and you will soon receive a letter from Patrick Livney, the Chairman and President of the CMTA, announcing a new 350K Board Challenge. It's a great opportunity to work together with the CMTA Board of Directors, who will once again match your donations, dollar for dollar, up to a total of $350,000.

Along with Pat's letter, you will also receive a brochure explaining the CMTA Circle of Friends program. We hope you'll consider starting your own Circle.

Working together, can give the gift of a world without CMT.

The CMTA Circle of Friends... Working Together for a Cure!

Tyler's 2nd Annual Thanksgiving Walk & Benefit

We held 'Tyler's 2nd Annual Thanksgiving Walk' on November 15. Although it was a brisk morning, our 60 dedicated supporters didn't mind the chilly weather. They enjoyed coffee and chocolate donated by Starbucks and wonderful baked goods donated by Panera and Tuzik's Bakery. As they walked beside Tyler along the 1-mile path, everyone had a great time laughing and talking, and it was a wonderful sight to see!

Later that night, nearly 200 people also attended a benefit for Tyler at O'Conner's Pub & Grille. CMTA Chairman Pat Livney began by introducing the CMTA and the STAR program, so everyone understood why we needed their help to find a cure for CMT, and then it was time for the fun to begin!

We had plenty of great food and dozens of raffle prizes, and three bands—one headed by Tyler's father—donated their time and talent and rocked us all night long. We were completely overwhelmed by the number of family and friends that came out to support us and by everyone's generous donations. It was a night we will always remember!

Our goal is to hold a bigger and better fundraiser each year. We can't think of a better way to help our son and the organization that gives us so much hope....The CMTA!

—Dale, Dan, and Tyler Lopez

Tyler's Walk

Mrs. Catherine A. Altobelli
Mrs. Felicia A. Alves
Mr. and Mrs. Mark Anderson
Mr. and Mrs. Rich Barton
Mr. and Mrs. Randy Barton
Mr. and Mrs. Todd Blue
Ms. Elaine H. Bowen
Mr. Mel Bramble
Mr. and Mrs. Mike Brown
Mr. and Mrs. David Bufka
Mr. and Mrs. Randy Burkamper
Mr. Tim Casey
Ms. Lorraine M. Connolly
Mr. and Mrs. Steve Crook
Mr. Ronald Dowling – Estate Planning Consulting
Ms. Rae Egan
Mrs. Linda M. Fedro
Ms. Ginny Fisher
Dr. Diane Garrison
Mr. and Mrs. Edward T. Graney
Mrs. Mary Greenway
Ms. Patty Hayden
Ms. Nancy L. Harhen
Ms. Margaret Hermann
Ms. Bernie Hill
Mr. and Mrs. Ed Hill
Mr. Jeff Hill
Mr. and Mrs. Fred Hill
Ms. Lisa Hill
Ms. Natalie Hill
Mrs. Pat Hill
Mr. Micheal Holman
Mr. Donald Jager
Mr. Arnold Kaslofski, Jr.
Ms. Bernice Keenan
Mr. Ronny Keenan
Mr. and Mrs. Pat Kolpak
Mr. and Mrs. Donald E. Krause
Mr. Pat Livney
Mr. and Mrs. Jim Logoni
Mr. and Mrs Daniel Lopez
Mr. Daniel Lopez, Jr.
Mr. Jim Lopez
Mr. and Mrs. Joe Lopez
Mr. and Mrs. Kevin Lopez
Mr. Paul Lopez
Mr. Ron Lopez
Mr. Rory Lopez
Mr. and Mrs. Rubin Lopez, Sr.
Mr. and Mrs. Rubin Lopez, Jr.
Mr. and Mrs. Rubin Lopez III
Ms. Cathy Marose
Mr. Kris Mansour
Mr. Mike McNichols
Ms. Jeanine McNichols
Mr. Wayne A. Meyer
Mr. and Mrs. Douglas Miller
Mrs. Jean A. Moore
Ms. Doreen Moore
Mrs. Harriet Neitzel
Mr. and Mrs. John J. O'Donnell, Sr.
Mr. Kevin Osterloh
Mr. and Mrs. Andy Paciga
Mr. and Mrs. Robert Pesavento
Mr. and Mrs Robert Pierce
Ms. Kym Peters
Prestige Painting & Custom Design, Inc.
Ms. Sharon Prell
Mr. and Mrs. Robert G. Rudolph
Mr. and Mrs. Hazim Saadan
Mr. and Mrs. Tom Sanchez

More Transitions

Dr. Steven Scherer recently joined the Board of Directors of the CMTA. When asked about his new appointment, Dr. Scherer wrote:

"I am currently William N. Kelly Professor of Neurology at the Hospital of the University of Pennsylvania. From the beginning, I have investigated what causes peripheral neuropathy and what can be done about it. For 15 years now, CMT has been my focus. I have grants that enable my students to investigate the causes of CMT from a biological point of view in the laboratory. I see patients who have CMT in my clinic. I teach medical students, graduate students, neurology residents, and patients about CMT. I have written many papers about CMT, for physicians, for scientists, and for patients. My increasing involvement with CMT naturally developed into an ever larger association with the CMTA, and I have always had an excellent relationship with the staff, the board, and the patients that they have referred to me. Our mission is the same—to unlock the secrets of CMT, to provide patients with treatment and effective therapies, and, ultimately to find a cure for CMT—goals which I believe I can help the CMTA accomplish through my participation as a member of the Board of Directors."

Dr. Steven Scherer joined the CMTA Board in late September.

At the same time that we announce the addition of a new Board member, we must acknowledge the passing of another, Jack Walfish. Jack served as a member of the Board, and was elected treasurer and later, President of the CMTA. His last few years, he enjoyed status as an Emeritus Board member. His greatest service was in seeing the organization through the flood of the old office at 600 Upland Avenue and the move to our current location. He worked with the staff during the first shaky weeks after our displacement, driving from New Jersey almost every day. He also was the officer who insisted that we begin taking credit cards, and he would be amazed to know, today, how much of our money comes in through Visa, MasterCard and American Express. Jack was a caring and loving man who will be missed by everyone at the CMTA. ✻

Mr. James J. Schaefer
Schmit Laboratories, Inc.
Mr. and Mrs. Kurt Seehoffer
Mr. D. Spada
Mr. and Mrs. Dennis Swatak
Mr. and Mrs. Gary Szparkowski
Ms. Geraldine Szparkowski
Mr. and Mrs. Rick Thompson
Mr. and Mrs. Joe Torregrossa
Mr. and Mrs. Sam Torregrossa
Ms. Peggy Voss
Mr. and Mrs. Robert M. Ward
Mr. and Mrs. Robert Waunn
Mr. and Mrs. Robert Waunn, Jr.
Mr. and Mrs. Darren Waunn
Ms. Janet Winters

Contributors to other Circles:

David Paige's Marathon Swim
Ms. Rachel Brenner
Mr. and Mrs. Alan Korowitz

Erwin Family Circle of Friends
Mr. and Mrs. Kenneth R. Buwalda
Mr. and Mrs. Martin Webster
Mr. and Mrs. Robert A. Winchell

David's Quest
Mr. Robert J. Mitchell

Grace's Race
Mr. and Mrs. Lewis Hassell
Mrs. Eileen A. Patton
Mr. and Mrs. Bradley M. Safford

Reagan's Quest
Ms. Edith M. Barton
Ms. Michelle L. Buza
Mr. James J. Cotey
Ms. Judith K. Nelson
Mr. and Mrs. Rick Olejnik
Mrs. Maryann J. Schaefer
Mr. and Mrs. James V. Smyth

Keara's Quest
Ms. Elizabeth L. Kowalchyk
Mrs. Kim Kuhr
Mrs. Terry S. Peck

Ryan's Quest
Mr. and Mrs. Stephen D. Cook
Mrs. Clarice Corey
Mr. and Mrs. Joseph Godec
Ms. Sue Kardon
Mrs. Joan R. Sullivan
Mrs. Devora Timmerman

Team Julia '08
Merck Giving Campaign
Mrs. Keri Spitz

Holiday Fundraisers

Help spread CMT awareness by buying and wearing a CMTA T-shirt or bracelet...

We are pleased to be able to offer T-shirts, bracelets (like the Lance Armstrong…. Live Strong ones), and postage stamps for purchase. Our teal bracelet says, "Be a STAR," a reference to our research campaign, STAR, the Strategy to Accelerate Research and to our belief that every person is a star in their own right. The white T-shirts have the teal CMTA logo on the front and a pair of teal-colored gears on the back with the statement, "working together for a cure." Each item helps spread the word about CMT and at the same time helps raise money for our research projects.

We sold over 200 bracelets at the West Coast conference and we'd like to sell hundreds more across the US. Both young and old can wear these bracelets and help create a groundswell of attention for the cause of CMT.

The T-shirts come in women's styles, sizes Medium to X-Large. The men's shirts run from Medium to 3X. The cost for each shirt is $10.

To order stamps, visit our website: www. charcot-marie-tooth.org and click on the link "STAR postage stamp." This will bring you directly to Zazzle, online producer of quality customized products. Once there, click on "To create a world without CMT" and choose your valid USPS postage stamp. As an added bonus, Zazzle is currently offering free shipping on all orders of $45 or more.

Help us spread awareness and ultimaely achieve our vision of a world without CMT. ✻

HOLIDAY FUNDRAISER T-SHIRT AND BRACELET ORDER FORM

☐ I would like to order _______ bracelets at $5 for 5.
☐ I would like to order T-shirt(s) at $10/ each *(enter quantity of each size)*:
Woman's ____ M ____ L ____ XL Men's ____ M ____ L ____ XL ____ 2XL ____ 3XL
Shipping/Handling *(orders of $5-$10 add $2.95, orders of $15 and up add $3.95)*

Amount Enclosed: ________________________

☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express

Card #________________________

Exp. Date ________________________

Signature ________________________

SHIP TO:

Name: ________________________

Address: ________________________

____

____

Mail form to: CMTA, 2700 Chestnut Parkway,
Chester, PA 19013; or fax to: 610-499-9267

Coming Back

BY LINDA PHILLIPS

In early 1987, I founded the first New York City CMT Support Group at the Rusk Institute in Manhattan. I was going through a long painful divorce at the time, and my name was Linda Phillips Goldfarb. Most of you are probably too young to remember me.

I was contacted by Dr. Howard Shapiro, the original founder of the NFPMA, National Foundation for Peroneal Muscular Atrophy, (which eventually became the CMTA) and was invited to attend the Second International CMT Conference, at Arden House, in Westchester, NY.

It was an overwhelming experience. I had only learned a year prior that the disorder that I had suffered with since infancy (and had always believed was "The Family Foot Problem"), actually had a name (Charcot-Marie-Tooth) and that my family members were not the only people in the world who had it!

Among the nonmedical experts were a handful of CMT patients. The late Ann Lee Beyer was one of them. I had met Ann a few months prior to that when we were both affiliated with a CMT group that was based in Canada. They had put us in touch with each other. Ann had founded her support group a few months prior to mine and was very helpful in sharing her experiences in leading a CMT group with me. We became friends.

At the Arden House Conference both Ann and I were approached to change our group affiliations to the NFPMA, which we did, very soon after. I lead my group at Rusk for four years. I was also named a member of the Board of Directors of the NFPMA.

I guess my greatest accomplishment with the organization was the psychosocial study that I conducted jointly with Dr. Howard Shapiro. We interviewed 20 men and 20 women each, regarding their childhood and adult experiences and how CMT had affected them from a psychosocial standpoint. I interviewed all of the women and Howard interviewed the men.

We then turned our findings into two papers which we delivered at a conference sponsored by the MDA on "The Psychosocial Aspects of Muscular Dystrophy and Other Neuromuscular Diseases."

Finally, I was divorced and needed to find a part-time job to supplement my income. My twenty-six-year career as a commercial interior designer had ended in 1985 because of my CMT, and I now receiving Social Security Disability and a small amount of spousal support from my ex-husband.

Because of my limited energy, I had to put my CMT work on the back burner, where it basically has remained until very recently.

Late one evening, I was doing some research on club feet. For the heck of it, I decided to take a look at what was happening in the area of CMT as both diseases involve varus deformity.

On the CMTA website, I happened to come across the name of Elizabeth Ouellette. She had written an article about support groups, and it got my attention. So I sent her a very long email. I was not looking to start a support group, but I felt like talking to someone who appeared to be doing what I had been doing 20 plus years ago.


Linda Phillips' history with the CMTA goes back to the early days when we were the NFPMA—more than 20 years ago.

From this I formed a friendship with Elizabeth. I told her that I would be more than glad to help her in any way that involved the computer or the telephone, but that my CMT had progressed to a degree where I have very limited energy.

I am 66 and have watched my CMT gradually progress. I have been wearing braces since 1985. I began to use a walker (a cute red one with a seat and hand breaks) 10 years ago.

(continued on page 10)

COMING BACK

(continued from page 9)

Besides all of the more common symptoms of CMT, I went through a period of five years in the 1990's which I think of as "The years of the foot."

I went through a nightmare of serious foot infections, five surgeries to remove the infected tissue, years of being on antibiotics, months at a time in hospitals, and months at home being cared for by home health aids. I spent all of this time in a wheelchair to avoid putting any kind of pressure on my foot as my surgeries healed.

The infection returned, and I had the head of the fifth metatarsal bone removed. Six weeks later, I had to have emergency surgery to remove the entire fifth metatarsal (and attached baby toe) as it had turned into severe osteomyelitis and the bone had turned to mush. I spent another six months to a year in a wheelchair while I recovered.

> I'm proud of my accomplishments over the years as well as my fierce independence.

During that period I lived on my computer and spent a great deal of my time in a chat room. I vowed that when I was fully healed, I was going to get into my car and drive around the entire country, visiting my online friends as well as my real-life friends.

In May 1998, I ventured upon a six and a half-week voyage around the United States. I slept at the homes of my online and real-world friends and many low-cost motels. I had my laptop with me and reported nightly to my chat room.

It was the trip of a lifetime, but something was happening to my body that I didn't like. I was having far more difficulty walking and maintaining my balance and my right hip was in constant pain. By the time I made it to Atlanta, Georgia, I was wishing that I was home.

Shortly after I got home to Santa Cruz, I saw a rheumatologist. I had known for years that I had arthritis in my hips, lower back, and hands.

What I did not know was that I had congenital hip dysplasia, from CMT, and was walking around with basically no hip or hip socket left.

I did a few things as soon as possible. I saw the best orthopedic hip surgeon in the area and scheduled surgery for his first available date, which was six weeks away.

Next I bought a walker, the type I still use with a seat and hand brakes. Then, I bought a mobile home and had an electric lift installed at my side door.

I spent close to a year recovering from the total hip replacement. I was given what was, at the time, a new kind of implant where the bone had to grow back around it.

My latest CMT issues are my breathing, which has been poor for many years, causing shortness of breath and difficulty breathing while lying down. Last year I got a BIPAP machine, which I sleep with every night.

Then my vocal chords atrophied. My voice has become very raspy. At first I thought that it was allergies, but last fall I saw an ENT doctor who told me the cords were atrophied and not moving. My options were either six months of speech therapy or surgery. I completed the speech therapy this summer and the good news is that although they remain atrophied, they are now moving.

I wrote this article mainly to bring out the many unanticipated things that have happened to me as a result of having CMT and secondly to show that one can maintain a happy, self sufficient, independent life despite these many adversities.

As I am typing this, I am going through a fairly new set of frustrations. My nearly rigid thumbs keep hitting keys that accidentally erase what I have typed or send me to other computer actions that I don't want to take. I think it is time to buy a Dragon Speak Freely Program that will do the actual typing for me. There is always a way around just about any issue that gets in my way.

Despite my many limitations, my fatigue, my occasional falls when not in braces, and the other frustrations of living with CMT, I would not want to trade my life with anyone else. I am a unique individual, as we all are, and I happen to like myself a lot. I am very proud of my accomplishments over the years, as well as my fierce independence. ✻

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF

James R. Cargill
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Mr. and Mrs. Gene Garlick
Ms. Helen Innes
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Mr. Vasi Vangelos

Phillip and James Voland
Mr. and Mrs. Craig Voland

During the holiday season, remember those you love with a gift in their honor or memory. You can direct these gifts to the STAR program to support our ambitious research initiatives.

See form on page 13.

Jeff Bingham: The Man behind the Scenes

BY PAT DREIBELBIS

A chance reading of the September-October issue of *Quest* magazine brought me face to face with an article about Jeff Bingham, a man who does technical direction on many major league sports broadcasts. I would have read the article and moved on had it not been for the fact that Jeff Bingham has Charcot-Marie-Tooth and that there was an email address for him at the end of the article.

I emailed him and patiently waited to see if he would answer me. I honestly didn't think he would. How many people respond to emails from people they don't even know? He didn't email me back, but he did pick up the phone and call me. I was very impressed. Jeff has been written about many times and in much bigger publications than this newsletter, but he was delighted by my email and anxious to be an example of how much can be accomplished by just "trying."

Jeff's an example of how much can be accomplished by just "trying."

Jeff was diagnosed around the age of 5 when his kindergarten teacher noticed his "different" motor skills. His mother had CMT and suffered with severe foot drop, so the diagnosis wasn't such a surprise. As a kid, Jeff was very interested in playing baseball, but as that became more and more difficult, he found ways to stay connected to the game. For a while, he videotaped his high school's baseball and basketball teams.

He majored in telecommunications at San Bernardino Valley College and was hired out of college to work at a TV station in Orange County. Then he saw ads in the newspaper for a technical director for the Los Angeles Angels. He now works as an independent contractor and freelancer doing the technical director's job for the Angels, the Lakers, and the Clippers. He controls the images of both the athletes and the fans that flash on the big screens at the stadiums. He works 13-20 games a month at the Staples Center, the Arrowhead Pond of Anaheim, the Home Depot Center, and Angel Stadium.

Jeff has moved from plastic braces to metal braces to a wheelchair as his condition has worsened. He moves his often stiff, curled hands over the buttons and levers that control the images that appear on the screens in the stadium as well as at home. The video console has hundreds of switches that cause the screen to go from a fan cheering to a graphic full of statistics to a commercial. Although it is difficult, he is determined to continue working because when he is behind the control board, he doesn't think of his physical limitations. He just works to give the fans a good show.

If you would like to correspond with Jeff or ask him any questions, he welcomes your emails at tdjeffbingham@yahoo.com. I can testify to the fact that he does respond! ✻

Jeff sits among the Lakers Championship Trophies from 2000-2002.

THE FIRST IN A SERIES OF ARTICLES:

What can your podiatrist do for you?

Charcot-Marie-Tooth disease is a progressive disease, which means it changes over time. Charcot-Marie-Tooth manifests mostly in the hands and feet. In the lower extremity, the disease causes muscle wasting below the knee. Some muscles atrophy, and some do not. This causes one muscle to overpower another, ultimately causing a foot deformity. The muscle wasting and imminent foot deformity cause an unstable foot to walk on.

The foot has 28 bones in it. Each one of these bones moves with each step you take. The shape of the foot molds to the ground so it can become a stable object for your body to walk on. If your foot is not flexible enough to adapt to the ground, it is considered unstable. In Charcot-Marie-Tooth, the shape of the foot and the lack of muscle power prevent your foot from adapting to uneven terrain. This foot construct ultimately causes you to lose your balance.

Often the disease is diagnosed because you can't keep up with others, you lose your balance, and you find yourself tripping often. How can you stop tripping? What can you do to gain balance? What can you do to walk without so much difficulty?

Braces can help. There are so many different types and models of braces that are available to you. The type of brace you need may be different from the type of brace your friend needs. Just because you have the same disease does not mean that you have the same deformity! Each and every person needs to be treated as an individual. Your podiatrist can help educate you on braces that you would benefit from. He/She can also write a prescription for you to get a custom-molded brace. It is important to keep in mind that this brace will not last you a lifetime.

Charcot-Marie-Tooth is a progressive deformity. As your deformity changes, your brace will need to change also. You must keep this in mind if you are considering surgery. There are many surgical procedures that can take away some of your pain and get you back into a regular shoe. I will be writing a series of articles for the Charcot-Marie-Tooth Association's newsletter. My goal is to educate you on the role of a podiatrist and a podiatric surgeon in your life. Stay tuned for the next newsletter!

—Dr. Sara Bouraee
Foot & Ankle Surgery
255 S. 17th Street, Suite 300
Philadelphia, PA 19103

CMTA REMEMBRANCES

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

Honorary Gift:
In honor of (person you wish to honor)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
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Amount Enclosed: ___________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card # ______________________________
Exp. Date ______________________________
Signature ______________________________

Gift Given By:
Name: ______________________________
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____

SUPPORT GROUP NEWS

NEW GROUP FORMING IN BALTIMORE

Be a charter member of a new support group forming in January in Baltimore. Meetings are tentatively planned to be held one Saturday morning each month at Johns Hopkins Medical Center, through the courtesy of the Neurology Dept., which is one of the six national Centers of Excellence for the treatment of CMT. Johns Hopkins is easily accessible with great parking, or by public transportation. To receive future announcements please contact Pat@charcot-marie-tooth.org or Bruce at cmtguy@verizon.net or 410-960-5460.

Colorado – Westminster

On October 25, 2008, Sean McKale, an orthotist from Wayne State, in Detroit, MI, spoke to the group about orthotics and bracing. He works with Dr. Michael Shy and the clinic group from Wayne State and is considered an expert on dealing with CMT. The next meeting of the group will not be until January 10, 2009, due to the holidays.

Georgia – Atlanta Area

Dr. Dale Strasser provided the group with a wealth of information about personal care. His overall message was to be an advocate for yourself, to listen to your body, and to respect what it tells you. He works with patients at a clinic at Emory. He also recommended that CMT patients make sure that their orthotist works closely with a physical therapist for the best fit in orthotics. On December 13th, at 2 PM, we will hear from Sean McKale, an orthotist from the Wayne State Clinic, who works closely with Dr. Michael Shy. He will give the attendees insight into which orthotics work best for the CMT patient.

Illinois – Chicagoland

The next meeting of the Chicago area support group will be January 17, 2009 from 2-4 PM. The speaker will be Dr. Andrea Pappalardo, Doctor of Pediatrics and Internal Medicine. The location of the meeting will be announced at a later date.

Massachusetts – Boston

Forty-three people attended the “kick-off” meeting on September 27, 2008. Mark Boxshus gave a brief introduction of his story and what led him to the CMTA and then he discussed the CMTA’s history, mission statement, and current goals. He then showed the STAR video and introduced Amy de Silva, who sang for the group. After some discussion, it was decided that the group would next meet on January 24, 2009.

Watch for an appeal for your healthy recipes! A CMTA cookbook is on the horizon.

Missouri – St. Louis

The group met on October 18th to hear Pat Dreibelbis and Dana Schwertfeger from the CMTA talk about the STAR initiative and the new things going on with the CMTA. Seventeen people attended, including both long-time members of the group and a new family who had never met anyone other than their own family members who had CMT. Carole Haislip hopes to hold another meeting in the spring of 2009.

New York – New York City

On November 8, 2008, the group was pleased to listen to Dr. Vern Houston, PhD, CPO discuss the newest in state-of-the-art orthotics and what they can do for the CMT patient.

Pennsylvania – Philadelphia Area

On October 18, 2008, the presenter was Dr. Sara Bouraee, a foot and ankle doctor from Philadelphia. Dr. Bouraee showed a PowerPoint presentation on CMT and on the classic foot and ankle deformities she sees in her practice. The group will hold its next meeting on December 13, at Kennedy House on JFK Blvd., in Philadelphia.

Tennessee – Walnut Grove

On October 25, 2008, in a rural community (Walnut Grove), about 18 miles outside the city limits of Savannah, Tennessee, the first CMTA support group meeting was held. We kicked off the evening with a good southern cooked meal. The support group leader and guest speaker, Reagan McGee, spoke about CMT. All 26 people left with more knowledge about CMT than they had before the meeting. The next meeting will be on the last Saturday in January, 2009.

Washington – Seattle Area

The group met on October 25, 2008, to hear Dr. Tom Bird of the Department of Medicine and Medical Genetics, University of Washington, discuss the CMT Center of Excellence opening at the University of Washington in January of 2009. The group also discussed the free year of membership from the CMTA, The Patient’s Guide to Charcot-Marie-Tooth Disorders, and a free CD regarding the STAR research program. ✲

CMT Support Groups

Support Group Liaison: Elizabeth Ouellette, 1-800-606-2682, ext 107

Alabama—Birmingham
Contact: Dr. Dice Lineberry, Calls only
205-870-4755
Email: dkllrl@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: ladyblue123@att.net

California—San Francisco Bay Area/Santa Clara County
Place: San Mateo Library
Meeting: Quarterly
Contact: Elizabeth Ouellette,
650-248-3409 (C)
650-559-0123 (H)
Email: elizabetho@pacbell.net

Colorado—Westminster
Place: Capabilities, Westminster, CO
Meeting: 10 AM – noon, Last Saturday of
every other month
Contact: Diane Covington
303-635-0229
Email: dmcovington@msn.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital,
St. Petersburg, FL
Meeting: Second Saturday
of Feb, May, Nov
Contact: Lori Rath, 727-784-7455
Vicki Pollyea
Email: rathhouse1@verizon.net
v_pollyea@mindspring.com

Georgia—Atlanta Area
Place: Cliff Valley School Library
2426 Clairmont Rd, NE
Meeting: Third Saturday of every
other month
Contact: Sue Ruediger, 678-595-2817
Email: susruediger@comcast.net

Illinois—Chicago Area
Place: Peace Lutheran Church,
Lombard, IL
Meeting: Quarterly
Contact: Alan Pappalardo,
800-606-2682, ext. 106
Email: alan@charcot-marie-tooth.org

Kentucky/Southern Indiana/ Southern Ohio
Place: Lexington Public Library,
Beaumont Branch
Meeting: Quarterly
Contact: Martha Hall, 502-695-3338
Email: marteye@mis.net

Massachusetts—Boston Area
Place: Beth Israel Deaconess
Medical Center
Meeting: Bi-monthly
Contact: Mark Boxshus, 781-925-4254
Email: MarkB_CMTANE@mac.com

Michigan—Ann Arbor
Place: Great Lakes Regional
Training Center
Meeting: Monthly
Contact: Tammy Mayher, 517-451-8471
Email: themayhers@verizon.net

Minnesota—Benson
Contact: Rosemary Mills, calls only
320-567-2156
Email: rrmills@fedtel.net

Minnesota—Twin Cities
Place: Call for location
Meeting: Quarterly
Contact: Bill Miller, 763-560-6654
Email: wmiller758@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: carole.haislip@sbcglobal.net

Nevada—Las Vegas
Place: West Charleston Library,
6301 West Charleston Blvd.
Meeting: Email for dates 1-3 PM
Contact: Mary Fatzinger
Email: cmt_suppgroup_lvnv@yahoo.com

New York—Greater New York
Place: NYU Medical Center/
Rusk Institute, 400 E. 34th St.
Meeting: Second Saturday, 12:30-2:30 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
Email: amtcp36@aol.com

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Children's Hospital
Meeting: Bimonthly, Jan, March, May,
Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 201-224-5795
Eileen Spell, 732-245-0771
Email: craneomatic@verizon.net
espell@optonline.net

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Raleigh, NC
Meeting: Quarterly
Contact: Susan Salzberg,
919-967-3118 (afternoons)
Email: nabosmom@gmail.com

Ohio—Greenville
Place: Brethren Retirement Community
Meeting: 4th Thurs. of
April, July and October
Contact: Dot Cain, 937-548-3963
Email: Greenville-Ohio-CMT@woh.rr.com

Oregon—Portland Area
Place: 1008 NE Division, Suite B
Gresham, OR
Meeting: Quarterly
Contact: Debbie Hagen
Email: hagen84@yahoo.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@roadrunner.com

Pennsylvania—Philadelphia Area
Place: CMTA Office, 2700 Chestnut Pkwy.,
Chester, PA
Meeting: Bi-monthly
Contact: Pat Dreibelbis
800-606-2682
Email: info@charcot-marie-tooth.org

Virginia—Harrisonburg
Place: Sunnyside Retirement
Community, Sunnyside Room
Meeting: Bi-monthly, Second Sat. 1-3
Contact: Anne Long,
540-568-8328

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

COMING SOON: Baltimore, Maryland

ASK THE DOCTOR

Dear Doctor:

I suffered a fractured patella in February and am still having nerve-type pain through the knee and now the entire leg, even though the facture is now healed. Is this most likely due to the CMT or nerve/other damage sustained during the fall? My CMT was diagnosed at 30 and I'm now 39. I was not having CMT-related problems with the knee/leg before the fracture.

An orthopedic surgeon replies:

Because I have not been able to examine this person or review their radiographs, I can only speak in general terms. The continued pain is most likely to be a consequence of the fracture and any related injuries to the surrounding soft tissue. The pain is less likely to be related to your CMT.

Dear Doctor:

I had an HSV test and it came back positive with a score of 1.29, normal being 1.08. I wonder if CMT could cause this positive test result since I am in a monogamous relationship and have been for years. My wife does not test positive. Have you ever heard of CMT causing a false positive?

The doctor replies:

Sorry, but I don't think you can blame the slightly positive test on CMT. However, the test does not determine when the exposure occurred or what serotype of the virus you have. The exposure could have happened years ago. Note that common cold sores are also caused by HSV. Your results need to be interpreted by your local physician in the proper context.

Dear Doctor:

I am looking for a daily vitamin that does not have properties that are on the list of things that CMT patients are not supposed to take….like iron. Any information would be helpful.

The doctor replies:

Multivitamins in general are not dangerous and probably are beneficial unless the ingredients cannot be verified. They are generally considered to be supplements and not drugs, so they do not receive the same scrutiny. Most contain conventional quantities of various supplements. Almost anything can be hazardous in excess, including iron. It is generally good to ask your physician if extra iron is better to include or exclude from a vitamin pill. Many people need supplements for low blood counts, but most do not. Problems of various types can arise from an excess of several vitamins, including A, E, K, C, B6, Iron, Zinc, and others. In some cases, such as vitamin C, huge doses are required before it's a problem.

Virtually all reputable commercial vitamins contain conventional doses of differing components. Always beware of unlabelled or very expensive "Special" concoctions.

Dear Doctor:

I was recently put on fish oil instead of Lipitor and then, a day later, an ophthalmologist put me on flaxseed oil for dry eyes. Are these supplements okay to take? I have been experiencing neuropathic burning pain in my legs, which has only occurred once previously when I was on an antibiotic similar to something on the neurotoxic drug list.

The doctor replies:

To the best of my knowledge, flaxseed oil would not be expected to cause neuropathy or neuropathic pain. Fish oil would not have that effect, either. On

(continued on page 19)

WRITE TO US!

Pat Dreibelbis,
Editor,
pat@charcot-marie-tooth.org

Dana Schwertfeger,
Director of Member Services
dana@charcot-marie-tooth.org

Having CMT… My Thoughts

CMT is not so bad. Focus on what is good in life. Focus on the positive things and not the negative. Also, focus on the things that are good about CMT. CMT makes me compassionate. It can make you compassionate, too. I don't make fun of anyone if they can't do something. CMT can make you special because you have something that someone else doesn't. Every day I feel proud of myself because of the challenges I overcome.

You should be proud of yourself like I am. Like I said, CMT is a very special thing to have.

—Robbie Campbell, 9 years old

Kyle, Robbie and little brother Michael celebrate a family birthday.

CMT FACTS VI


CMT FACTS VI

Vol. 6, 2008 ◆ A resource for information on Charcot-Marie-Tooth disease ◆ www.charcot-marie-tooth.org

Facts VI is a collection of articles from our newsletter, *The CMTA Report*, published from 2002 to 2007, by the Charcot-Marie-Tooth Association or CMTA. The CMTA was founded in 1983 to provide a source of information and support for those dealing with CMT—patients, families, medical professionals, research scientists and others. The CMTA educates by publishing a newsletter, sponsoring patient and professional conferences, and serving as an information source on CMT issues. It also coordinates support groups, provides physician referrals, advocates for patients and funds research directed at therapies and a possible cure for CMT.

CONTENTS

General Information

Who Named It and Why . . . 2
Selecting a Physician . . . 3
A Visit to the Doctor . . . 4
Neurotoxic Drug List . . . 5
Epidemiology of CMT . . . 5
I've Just Been Diagnosed . . . 6
Numbness in CMT Disorders . . . 7

CMT: An Overview

Hereditary Neuropathy Overview . . . 8
Answers to General CMT Questions . . . 10

Genetics

Questions About Genetic Counseling . . 12
Understanding HNPP Phenotypes . . . 14
Genetic Testing for CMT . . . 16

Diagnosis and Treatment

Clinical Features of CMT . . . 17
Advances in the Diagnosis of CMT . . . 19
CMT: A Clinical Perspective . . . 20
A Visit to the Wayne State Clinic . . . 22
Wayne State: Day Two . . . 24
Current Therapy for CMT . . . 27

Therapies and Therapists

Questions About Gait Analysis and Physical Therapy . . . 28
Physiotherapy and CMT . . . 30
Exercise: Is It Worth the Effort? . . . 32
Occupational Therapy and CMT . . . 34
Exercise: Why the Pool? . . . 35
What is a Physiatrist? . . . 36

Bracing

Molded Ankle-Foot Orthoses . . . 37
Silicon Ankle-Foot Orthosis . . . 41
Energy Loading Brace for CMT . . . 43

CMT and Children

Keeping a Medical History . . . 45
CMT in Children . . . 46
Understanding the Student IEP . . . 50
Scoliosis . . . 51
Quality of Life for Children with CMT . . 52

Ask The Doctor

Questions and Answers . . . 53
Order Form . . . 63
Publications . . . 64

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is now available...

The sixth and newest edition of the CMT Facts Series has just been published and is available for purchase. It is 64 pages in length and is divided into sections on general information, genetics, diagnosis and treatment, therapies and therapists, bracing, CMT and children, and "Ask the Doctor."

The compilation of articles goes back as far as 2002 and captures the most significant articles from The CMTA Report from then to the present. Some of the more interesting articles involve numbness in CMT, HNPP phenotypes, current therapies for CMT by Dr. Michael Shy, exercise options, various types of bracing, IEPs for children, and the interesting and diverse questions posed to members of our Medical Advisory Board and answered by them in a ten-page section of the publication.

The cost for members is $12 and for non-members, $15.

(Please see next page for the entire CMT Facts series and other publications.)

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Note: If you are joining now, you may purchase publications at active member prices.

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CMT Facts I ☐ English ☐ Spanish		**members $3** nonmembers $5	
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- HNPP
- Orthotics survey
- Pulmonary function
- Managing pain
- Orthopedics and children
- Shriners Hospitals
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CMT Facts 5

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- Emotional issues
- Pain and CMT
- Pregnancy
- Social Security
- Vitamins and herbs
- Physical therapy
- Occupational therapy
- Genetic testing
- Medical terminology
- Special section on HNPP

The Patients' Guide to Charcot-Marie Tooth Disorders

2008/178 pages—Now available in print and CD formats

The Patients' Guide is an excellent source of information and resources for patients, family members, and physicians. Topics include CMT in children, genetics and genetic counseling, orthopedic considerations, exercise, and current and prospective treatments for CMT.

Bonus features included on CD: *Charcot-Marie-Tooth Disease: An Overview* and *Charcot-Marie-Tooth Disease: A Guide for Physicians.*

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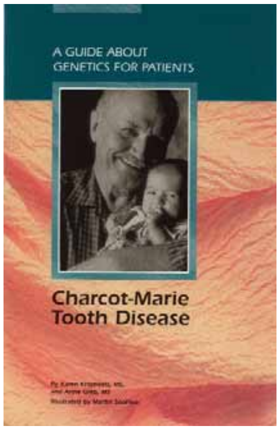

A Guide about Genetics for Patients

2000/21 pages

Illustrated with easy-to-understand diagrams, this booklet outlines the basics of genetic inheritance and CMT.

Nonmember Price: $5.00
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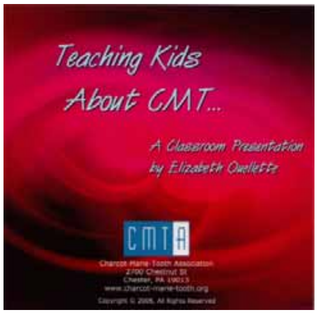

Teaching Kids about CMT...

A Classroom Presentation

2006/DVD 1 hr.

This hour-long DVD of an actual classroom presentation demonstrates a number of games and other exercises to teach classmates of children with CMT about the disorder.

Nonmember Price: $10.00
Member Price: $7.50

ASK THE DOCTOR

(continued from page 16)

the Internet, both fish oil and flaxseed oil are commonly touted as being good for a number of things, including neuropathy and neuropathic pain, although I doubt that they have been studied in that regard.

Dear Doctor:
I am an 80-year-old woman who has been diagnosed with CMT. I was just diagnosed with atrial fibrillation. The doctor has prescribed diltiazem, 120 mg twice daily. I am having pains in both legs and am wondering if it is the medication or just CMT. I did not see this drug listed on your medical alert card and would appreciate knowing if the medication is a problem for someone with CMT.

The doctor replies:
Diltiazem should not cause a problem for patients with CMT, nor should it cause muscle weakness.

Dear Doctor:
I had some routine blood work done which was flagged by the doctor because of the elevated lupus ANA test. I was negative on the lupus test. I have CMT. Do you know of any correlation between CMT and an elevated lupus ANA blood test?

The Doctor replies:
I know of no relationship between any kind of CMT and any autoimmune disease, including lupus.

Dear Doctor:
I am a 62-year-old male with CMT. I am still in very good health and am handling CMT quite well. I have, in the past year, noticed my feet getting numb from time to time. I see a podiatrist who treats a lot of patients with diabetes. Although she said she does not normally recommend supplements, she has found that a supplement called Metanx has been helping diabetes patients with numbness caused by neuropathy. My concern is that CMT patients have to be concerned about megadoses of B6. The ingredients in Metanx are 25 mg of pyridoxal phosphate, 2.8 mg of L-methylfolate and 2 mg of methylcobalamin. Do you feel I would be at risk taking this supplement?

The Doctor replies:
We have been asked about this supplement before. The 25 mg of B6 is probably fine, but it would be wise to first check your blood level of that vitamin to see if it is elevated. The other components are fine.

Dear Doctor:
I am an RN. I have CMT inherited from my father. I have the obvious lower extremity weakness and hand weakness. I exercise daily by swimming, stationary cycling, or weight training. I am 63 and planning a face lift. My surgeon uses a procedure which lifts the fascia vs the skin. What is the risk that the surgical trauma or postoperative swelling will damage facial nerves?

The doctor replies:
Except for the condition known as HNPP (hereditary neuropathy with liability to pressure palsies), I don't think that CMT nerves should be any more susceptible to injury than normal nerves.

Having CMT…
How do you look at it?

When I was five years old, other people made fun of me because I had CMT. I still get made fun of, but I say, "even though I have CMT, I am like any other person." I try to live my life to the fullest…and I do. When I was younger, I was always being told that I could not do things like running and jumping and rock climbing and that I was not like other kids. I think that any person with CMT, no matter how bad their CMT is, can do anything they really want to. The things that I do are very challenging for me, but I know they are good for me in battling my CMT. If anyone were to come up to me and say that I could not play football, I'd say "I can and I will!"

I think that having CMT has changed my life and if I had not been born with CMT, I would not stand out in the world. I like to stand out….in a good way. CMT can be a bad thing if you think of it that way, or it can be a good thing if you look at it that way. It can also just be something you have that you can't do anything about. I choose to think of it in a good way.

—William Welsh

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

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

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