

THE CMTA Report

SEPTEMBER/OCTOBER
2009

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.

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A Time to Reflect and Say Thanks

BY DAVID HALL, CHIEF EXECUTIVE OFFICER

The national celebration of the Labor Day holiday provides us with an ideal opportunity to reflect upon the significant contributions made by so many members of the CMTA community across the country. CMTA staff, board members, medical advisors, support group leaders and members, along with volunteers have all played major roles in creating a new era of hope and opportunity for patients and families who fight CMT on a daily basis.

Today, the CMTA is proud to support approximately 50 support groups in 29 states across the country, with several more in the formative stages. Support group leaders and members are working hard to promote local awareness initiatives to families, clinical providers, insurance companies, local governments, schools, and community businesses. These efforts are invaluable to our mission of improving the lives of everyone affected by CMT. There is no better symbol for the CMTA than the national support group program, which is led by CMTA board member Elizabeth Ouellette. As our support groups grow and evolve, so will the CMTA.

The CMTA must also rec-

ognize our global team of scientists and researchers who work tirelessly on identifying not only the causes of the disease, but also how best to treat and cure the disease. In addition, our medical team is dedicated to developing clinical protocols and solutions that will assist in the identification and management of CMT—real time answers for problems that those with CMT are dealing with today. At no

The progress made to date can only continue if the CMT community enhances its support of the CMTA.

point in time has there been a higher quantity and quality of dedicated medical professionals focused on CMT.

The CMTA STAR program is indicative of how CMT research is being conducted on a global scale. Biotechnology developed in the United States and Switzerland (CMT1A cell line) is delivered to a CMTA-funded team at the NIH in Bethesda, MD. When the NIH succeeds at finding drug candidates via high-throughput

screening, the compounds that are identified will be sent to Germany for advanced development and modeling. The STAR program embodies the international scale of CMT research today. As such, the CMTA will continue to cultivate a global healthcare community that is committed to our goal of living in a world without CMT.

The progress made to date in all of our programs and initiatives can only continue if the CMT community continues and even enhances its support of the CMTA. We are solely dependent upon the incredibly generous contributions of time, energy, and money made by all of you. As we reflect upon and celebrate everyone's contributions to date, let's be sure we take full advantage of the opportunities that are now before us.

Success breeds success for those destined to succeed. Thanks to all of your support, our destiny is clear. *

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RESEARCHER PROFILE**Dr. Richard Lewis, Wayne State University**

Dr. Richard Lewis has been a member of the Wayne State University CMT Clinic since its inception in 1997. His primary role in the clinic has been to oversee the electrophysiological evaluation of patients and to work closely with Dr. Michael Shy, Clinic and CMT Program Director, in developing new concepts that will help in understanding the various disorders that comprise CMT. In this regard, Dr. Lewis helped in the development of the CMT Neuropathy Score that is now being utilized in clinical trials for CMT and at the CMT Centers of Excellence. He also has been instrumental in understanding the differences in nerve physiology among the different forms of CMT, including HNPP.

In fact, Dr. Lewis' interest in CMT dates back to one of his initial contributions to the field in 1980, when he demonstrated that the conduction abnormalities in CMT-1 (before the genetics were known and in retrospect the patients all had CMT-1A) were uniformly seen in all segments of the nerve. That initial observation has led to a career interest in CMT and demyelinating neuropathies.

His other important paper in the early 1980's, based on work that he did at the University of Pennsylvania during his 5 years as a resident and faculty member, was on a form of inflammatory neuropathy now known as Lewis-Sumner syndrome.



Dr. Richard Lewis is both a noted CMT researcher and a devoted violinist.

He has been at Wayne State University since 1993 and is Professor and Associate Chair of Neurology, co-director (with Dr. Shy) of the neuromuscular program, and Director of Clinical Neurophysiology. After leaving Penn in 1980, he was on the faculty at the University of Connecticut, where he saw many patients with CMT in the Muscular Dystrophy Clinic. He then went into practice in Norfolk, Virginia, where he continued his involvement with CMT.

Dr. Lewis grew up in Jackson Heights, New York City, and is the only member of his family to have gone into medicine. He did his premed under-

graduate work at Union College in Schenectady, New York, and went to medical school at the Medical College of Virginia in Richmond, Virginia. He is married to a psychoanalyst. He has a son in Mountainview, California who has recently left Google to start a mobile application company, Tapjoy, and a daughter in Los Angeles who is completing her PhD in English and is interested in teaching writing and language skills as a way to empower young people.

Dr. Lewis' long-time passion is music, having played the violin since the age of 8. He also enjoys being a not-so-decent golfer, hiking and cooking with his wife and family. ❄

CMT IN THE NEWS

News from Morgantown, Philadelphia, and Detroit

An article in the Dominion Post, Morgantown, WV, reported on Gabrielle Ramirez, of Lewisburg, who had foot and hand tremors from the early days of infancy. Local doctors said it was nothing and would just go away. It never did. By the age of 15, Gabrielle couldn't take it anymore. She was having muscle spasms, affecting her hand writing, her eating, and her drinking, and she would even fall frequently. A doctor in Lewisburg mentioned West Virginia University's Mountaineer Doctor Television. They decided to try it. Gabrielle sat in a studio with a computer and a camera connected via Internet to a studio at WVU's Health Sciences Center. Dr. Margaret Janes, a pediatric neurologist, examined Gabrielle via the Internet connection. She had Gabrielle show her her foot. And Janes had the answer, a neu-

rological disorder called Charcot-Marie-Tooth or CMT.

■ Philly.com reported on Meagan Berry, an Episcopal Academy rower, who fights through both CMT and type 1 diabetes, to compete on her school's crew. She is a senior at the private school and has lettered in swimming, water polo, and one of the most grueling sports on joints, crew. Berry has been told that the combination of CMT and diabetes will likely put her in a wheelchair by the time she is in her 30's. "It's hard for people to believe I have a disease, but I like that because I don't want people thinking, 'poor Meagan.'" She will attend Cornell next year, where she plans to row in the fall. She doesn't want to be defined by CMT, though it puts great stress on her bones and arches, stirring great pain. She can't do many of the cardio workouts other ath-

letes are required to do, like running, but CMT hasn't changed her attitude. And, it won't.

■ The Wayne State University School of Medicine welcomed Joshua Burns, who will spend three months there as a 2009 Fulbright Postdoctoral Scholar. Dr. Burns is a faculty member of the University of Sydney, Australia, the National Health and Research Council and is with the Australian Clinical Research group at the Institute for Neuromuscular Research. He will work with Dr. Michael Shy and other researchers in the Department of Neurology and the Center for Molecular Medicine and Genetics to undertake research on Charcot-Marie-Tooth disease. The ultimate goal of this international collaboration is to dedicate clinical research focus on alleviating the burden of CMT for both patients and society. ✱

A SUMMARY OF THE ASCORBIC ACID TRIALS TO DATE

The trial being conducted in the United States of high-dose vitamin C in patients with CMT1A conducted at Wayne State, John Hopkins, and the University of Rochester completed enrollment in April 2009, and the last patient will complete the study in April 2011. A study conducted in France has recently been reported at the Peripheral Nerve Society meeting in Germany and separately at the International CMT Consortium in Belgium. This study used a low dose of 1 g/day and a higher dose of 3 g/day for 1 year. They did not find significant differences in the CMT Neuropathy Score after 1 year of treatment for either group as compared with the placebo. However, the higher-dose group showed a trend toward improvement that the other groups did not. The study had too few patients and was not conducted long enough given the study design they used. But it was encouraging that the higher dose seemed to do better than the other groups. This points to the importance of our trial utilizing 4 g/day. It is currently the only study looking at a higher dose of vitamin C, and the 2-year trial design seems optimized to obtain meaningful results.

We look forward to the completion of the trial in 2011.

—Richard Lewis, MD, Wayne State University School of Medicine

Ohio State Football Players Hold Video Game Tournament to Benefit CMTA

Craig Pryor was only 21 years old when he began experiencing the symptoms of Charcot-Marie-Tooth disorder. He was already a father, and by the time his son signed to play football at Ohio State, he was in a wheelchair. His son Terrelle says that “it (CMT) was never a big deal in their household. It was just a fact of life.”

On Wednesday, August 5, 2009, the Ohio State’s chapter of Uplifting Athletes showed up at Damon Grill on Olentangy River Road in Columbus, Ohio, to participate in a video-game tournament and raise money for the CMTA. While the football players competed in NCAA Football 2010, fans paid to watch, buy memorabilia, and get autographs.

The event was organized by Kurt Coleman, the president of the chapter of Uplifting Athletes.



Kurt Coleman, Ohio State University representative of Uplifting Athletes (left) and Scott Shirley (right) from National Uplifting Athletes joined CEO David Hall at the video game event. Coleman organized the event.

Kurt approached Pryor about making CMT the cause for this year’s event and he (Terrelle) got the biggest smile on his face.

David Hall, Chief Executive Officer of the CMTA, attended the event and said that the CMTA’s partnership with the Pryor family is a “natural” since Terrelle almost went to Penn State, and Penn State coach Joe Paterno is the CMTA’s national spokesperson. Craig Pryor’s strong relationship with the Penn State staff and Coach Paterno was the main reason his son delayed his college decision, finally deciding on Ohio State.

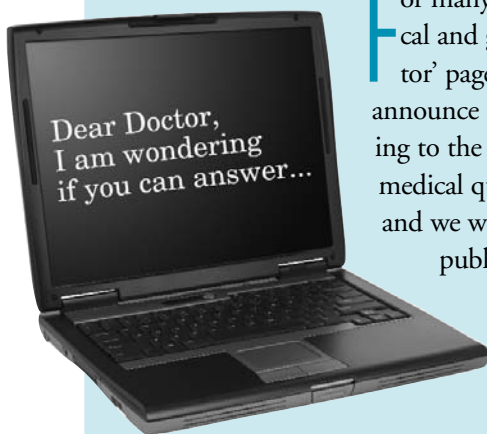
About 60 players turned out for the event, with freshman receiver Duron Carter emerging as the winner of the 16-player bracketed showdown. Pryor was into the game early on, but eventually dropped out because he wasn’t feeling well. *

NEW “EXPERT” JOINS THE CMTA WEBSITE

For many years, questions from our members about the physical and genetic aspects of CMT have filled the ‘Ask the Doctor’ pages of *The CMTA Report*. Now we are pleased to announce that we also have an expert to answer questions relating to the emotional and psychological impact of CMT. As with medical questions, we will observe the strictest confidentiality, and we will not reveal your name to the doctor, nor will we publish your question or the doctor’s answer unless you give us explicit permission to do so.

To submit a question, please email it to asktheexpert@charcot-marie-tooth.org, or address it to: Ask the Expert, CMTA, 2700 Chestnut

Parkway, Chester, PA 19013. *





ASK THE DOCTOR

Dear Doctor,

My brother and I both have CMT. I wore leg braces for several years and underwent years of surgeries. They did tendon transfers and ankle fusions on both legs. I have been able to walk without the aid of braces or crutches since the surgeries. Now, I'm beginning to lose the feeling in my upper thighs and am having more difficulties walking up steps or on land that is not flat. If I am on my feet a lot, they hurt tremendously. I was just told about an over-the-counter drug called trigloxamine. Is this safe for someone with CMT?

The doctor replies:

I had not heard of this supplement before, but found on the company website that Trigosamine contains: hyaluronate in addition to the more common glucosamine and chondroitin. I know of no information that these supplements have either a positive or a negative effect on nerves. They are purported to improve joint function, but this combination supplement has not been tested in a published study. It is doubtful that it will cause harm in conventional amounts. I could not find anything about "trigloxamine."

Dear Doctor,

Both my 14-year-old son and 12-year-old daughter inherited CMT from their father. My son has taken sertraline for 8 years and my daughter has taken it for about 4. When I showed my

daughter's psychiatrist the medical alert form, she took her off of sertraline and put her on citalopram. When I asked our family practitioner to take my son off of sertraline and put him on citalopram, she said they were basically the same. Why would citalopram be okay to take but not sertraline?

The doctor replies:

The medications are very similar from a psychiatric perspective. The association with sensory symptoms in CMT with sertraline was noted anecdotally and in the CMT database review. The drug is not independently associated with causing neuropathy. There was no evidence of nerve injury neuropathy but only that numbness and tingling increased. The association has not been made with the other similar drugs. If the child is already doing fine on sertraline, there is no requirement to change to another agent.

Dear Doctor,

Is it okay to use botox or Restylane when you have CMT?

The doctor replies:

I know of no problems with Restylane, which is hyaluronic acid, a normal component of skin and joints. Some supplements use it as well, but there should be no negative effect on CMT. Botox is another story and must be used with care and judgment. The toxin works by weakening muscles and can weaken nearby muscles depend-

ing on the dose. Obviously, injection of small doses into forehead muscles is quite different from large doses injected into leg muscles. The physician should be aware of the CMT diagnosis and consider the effect of weakening muscles close to the injection site.

Dear Doctor,

Our friend and his sister have CMT. They are both in their eighties. He told us his sister's doctor prescribed primidone for her CMT. Our friend has never heard of primidone, and so he was wondering if it is a drug sometimes used for CMT. Do you know?

The doctor replies:

Primidone has been around for decades and is used for a variety of neurological conditions. There is no association with worsening weakness or neuropathy, but it can cause sedation and changes in muscle tone.

Dear Doctor,

I have just been put on two new medications due to a diagnosis of asthma: Singulair and QVAR 80 mcg (inhalation aerosol). Will either of these medicines cause a problem with my CMT?

The doctor replies:

I know of no problems with either medication. The dose with inhaled medications is small to the general system, but it is still worthwhile to ask. ✱

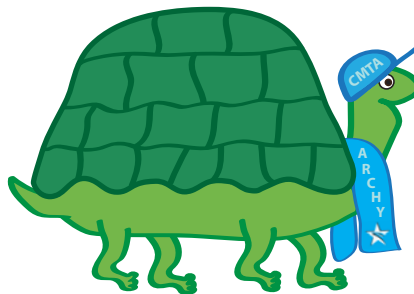
"Archy" Visits the Orthotist

"Archy," our stout-hearted, but high-arched, spoketurtle, writes about his experiences as a turtle with CMT.

I'm not looking forward to today. After school, my mother is taking me to the doctor's to see what can be done about my ankles and feet. I have really high arches in my feet, and when I walk, I tend to turn over on my ankles. I fall if the ground is uneven and my feet hurt if I walk too long. I live near a pond, where the ground is almost all uneven and rough, so falling is a pretty common event. My mother is worried about it because I wind up with bruises and skinned knees. I've even dented my shell from falling down.

Anyway, I made it through the day at school, and when Mom picked me up, she explained about what was going to happen at the doctor's. He was going to watch me walk and

see what could be done to correct my "gait" (that's the way you walk.) Sometimes, I guess they do operations and sometimes they send you to physical therapy and sometimes they make some kind of plastic brace that helps hold your foot and ankle in the right position. I spent the entire drive praying



that I would only have to go to physical therapy, because I've done that before and it's fun. I work in a pool and I do balancing exercises with a rocking board. The thing is, physical therapy has made me stronger and more coordinated, but it hasn't stopped me from tripping and falling.

Once we got to the doctor's, he made me walk back and forth in front of him. Then, he put me up on a bed and he turned my ankles with his paws. He's a very nice doctor. He's big, and his voice is a little gruff, but he's a bear, so I think that's normal. But he's gentle and kind, and I really trust him because he talked about other animals he knows who have my same problem. The result of his examination was that he thought I needed braces. He called them AFOs which I thought sounded like some alien ship or something, but he said it meant ankle-foot orthoses. They were going to be made for my back legs, and they would keep me from tripping over my own toes and turning my ankles to the sides. He examined my front legs, too, but he said I could just use some splints at night to keep those feet from turning in. That was good, because I have to use my front legs to draw and write, and a brace would have made that harder.

We went right from the doctor's office to the office of this man who makes braces. He's an orthotist, which means he makes these AFOs that I need. He watched me walk, too; then, he put me up on a high table so my legs dangled down. He wrapped them in a cloth and then covered the cloth with some stuff that dried really quickly and got hard. He had to draw lines on the mold where they would cut it to fit me perfectly. It felt a little weird, but it

NEW SUPPORT GROUPS HOPING TO FORM

There are people in the Hot Springs, AR, and the Champagne-Urbana, IL, areas who are interested in meeting other people with CMT and forming a support group. If you live in either area and are interested in attending a support group, please let us know by emailing support@charcot-marie-tooth.org or calling 1-800-606-2682. Be sure to provide your contact information and indicate which area is near you.

You can also let us know that you are interested in attending or starting a support group in any area by visiting us online at www.cmtausa.org/sgsignup.



didn't hurt at all. He used a little electric saw to cut the mold off of me. He warned me that it would sound loud but wouldn't even touch my leg. It didn't. I liked him, too. Like the doctor, he was nice to me and he, too, had made braces for others with CMT. That makes me feel better. Just knowing that there are others with the same problem is kind of comforting, and now that I'm the mascot of the CMTA, I look for others with CMT whenever I can.

He told me my braces would be ready in about two weeks. Because he's a beaver, I actually think they'll be ready sooner because they are known to be really hard workers. I went home feeling pretty good about my experiences and knowing that I should be able to walk better once I get my new braces.

Ten Days Later....

After school today, we are going for my new braces. I'm excited and a little afraid. I don't want

to look different from everyone else at school. Braces will make my problems more visible, and I'm afraid I'll get teased a lot. I want to talk to my Mom and Dad about it, but I'm kind of scared. I know that they are doing what is best for me, and I don't want them to think I don't appreciate it.

The braces felt a little funny at first, but he said that was normal. I would have to get used to walking in them.

We waited in the outer office for a while, and I got to see a lot of other animals with walking problems. One of them, a raccoon, had on braces and used crutches, too. A deer had one artificial leg because of a hunting accident he had been in. I couldn't decide if seeing all of them made me feel better or worse. I think I'm in pretty good

shape right now, but they made me wonder how much worse I might get.

When I finally got in to see the orthotist, Mr. Woods, I was nervous. He showed me the new braces. They were so cool looking. He had made them sort of like camouflage, and they looked like something an army guy would wear. They felt a little funny at first, but he said that was normal. I would have to get used to walking in them. I was only supposed to wear them for a few hours the first two weeks. I was told to pay attention to how they felt and tell him if they pinched me anywhere or if they rubbed my skin. He said I could come back as many times as I needed to until I almost couldn't tell they were on at all.

I'm going to do everything he told me because I really want these to work and make me walk better. I'm tired of falling, and I think these braces are going to help a lot. I'll let you know how I feel in a few weeks! *

New Brace Design Announced

Ortho Rehab Designs has produced a new Helios® Hinged brace. It is custom made and is a range-of-motion, adjustable hinged AFO. It is similar to the standard Helios® brace with the exception of energy-storing uprights. The mechanics of this brace allow for ankle angular adjustability. Features of this brace include:

- Lightweight aerospace carbon fiber
- Correction of alignment and foot deformity
- Helps restore balance and stability
- Custom made for each patient
- Controls drop-foot due to CMT

Ortho Rehab Designs accepts insurance assignment on the Helios® Hinged, with qualifying insurance plans.

For further information about the Helios® Hinged, please contact the company at 702-388-9909, or www.ORDesignsLV.com *





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CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
 Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____ Check Enclosed VISA MasterCard American Express

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____

BOOK REVIEW

Alphabet Kids—From ADD to Zellweger Syndrome

A Guide to Developmental, Neurobiological and Psychological Disorders for Parents and Professionals

REVIEWED BY ELIZABETH OUELLETTE

Over the past 2 decades, Robbie Woliver, New York Time's best selling author and current editor-in-chief of the Long Island Press, has been compiling an invaluable and easy-to-follow resource guide to over 70 childhood disorders. After consulting with world-renowned specialists across the globe (our own Pat Dreibelbis was interviewed!), Woliver assembled *Alphabet Kids*, a comprehensive compendium of ailments affecting our children, ranging from the most readily recognized diagnoses (Down syndrome) to some of the least known (Charcot-Marie-Tooth).

Woliver begins each section with an introduction and heartfelt case history illuminating the everyday struggles of the many kids with varied and often interconnected medical problems. Each alphabet condition (ADD, CMT, ZT) is then followed by a clear and thorough description of the possible signs and symptoms, causes, treatment, and prognoses, providing a clear picture of all the interrelated physical, emotional, and intellectual elements each diagnosis may encompass.

Mr. Woliver contacted the Charcot-Marie-Tooth Association several years ago, requesting more information on CMT. Pat

Dreibelbis, who is quoted in the book (unfortunately misquoted in one instance), spoke with him at length and provided him with detailed medical information on CMT.

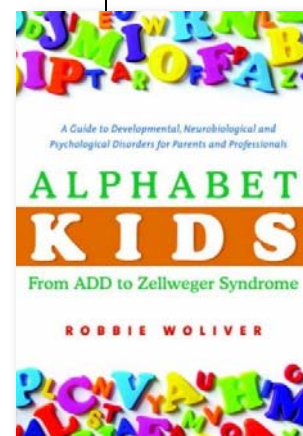
Woliver then contacted me to gather information about how all aspects of CMT affected my son Yohan, who was 14 at the time. After several months of communicating back and forth, I told our story, one which was personal, intimate, and wholeheartedly truthful. It reveals not only the physical symptoms linked to CMT, but addresses the social and psychological aspects of the disease, which are often downplayed or disregarded in pure scientific literature.

Woliver succeeds beautifully in piecing together Yohan's story with a precise and heartfelt rendition of our tumultuous lives from the time of Yohan's diagnosis of CMT1A to the present. Keep in mind that children often react to intruding symptoms through certain thoughts, behaviors and reactions because they do not have the words, or the ability to do any emotional sharing and/or intellectual discussion. Yohan's primary behavioral response to the testing and subsequent diagnosis of CMT became readily apparent through his increasing anxiety, pain, isolation, and bewilderment. As the

years have passed, Yohan's CMT has predictably progressed on a physical plane, but on a social, educational, and emotional level, his growth has been astounding. Today, we are better educated about CMT and have had time to digest the implications of the disorder. Most importantly, Yohan has accepted his own diagnosis of CMT, and he has made a choice to live in the moment, the best he possibly can.

Alphabet Kids is a comprehensive manual for all parents on the wide array of emotional, physical, or developmental issues our kids may have to deal with at some point in their lives. Woliver explains that one in every 100 children will be affected by one or more of the acronymic diagnoses contained within these pages. I highly recommend this guide as resource material for all parents, teachers and professionals alike, especially those who are in the midst of trying to unravel the complicated and often interconnected symptoms of so many childhood conditions. *Alphabet Kids* is a worthy investment, one which you will want to keep handy for years to come. *

Alphabet Kids is available on Amazon for \$19.77



International CMT Consortium Meets in Belgium

Once again, the CMTA was a proud sponsor of the Third International CMT Consortium Meeting which was held in Antwerpen, Belgium from July 9 to 11, 2009.

Following the format of previous international CMT meetings, participants had the goal of exchanging new clinical and scientific information and starting or strengthening collaborations between research and patient services organizations.

The CMTA was represented at the meeting by CEO David Hall and Medical Advisory Board members Dr. Michael Shy and Dr. Stephen Scherer.

Joining the CMTA team were more than 100 clinicians and investigators from 12 countries around the world, along with representatives from CMT

patient organizations in the United Kingdom, Holland, Belgium, France, Czech Republic, Italy, and Australia. Fifty lectures and fifty posters were presented that focused on the clinical, diagnostic, and basic research of CMT neuropathies. (Visit www.cmtausa.org/2009abstracts to download the program, abstracts, and list of participants.

At the conclusion of the meeting, Dr. Michael Shy announced that the CMTA will be hosting the Fourth International CMT Consortium Meeting in 2011 in Washington, DC.

The CMTA remains committed to partnering with international organizations and researchers to ensure a global commitment to our core mission—A world without CMT.

The European Neuromuscular Centre (ENMC) will be

hosting an international meeting of 20 invited CMT researchers in the Netherlands from September 18 to 20. The goal of the meeting will be to review and improve outcome measures used by physicians and scientists for studies involving patients with CMT. David Hall, the CEO of the CMTA, has been invited as the representative of patient support groups in the U.S. Dr. Michael Shy, Chair of the CMTA Medical Advisory Board, is one of the four organizers of this meeting. The other organizers are Dr. Mary Reilly from the National Hospital of Neurology and Neurosurgery, London UK; Dr. Davide Pareyson, from the C. Besta Neurological Institute, Milan, Italy; and Dr. Francesco Muntoni, from the Institute of Child Health, London, UK. ✱

CMT researchers gathered together at the Belgium consortium to share research findings and goals.



The CMT "Circle of Friends"

This issue, congratulations and special thanks go out to newlyweds Zane and Alex and those who donated in their honor for rising to the challenge of coping with CMT, getting involved, and helping us fund the CMTA Strategy to Accelerate Research.

If you have what it takes to get involved and start a Circle of Friends, call us today at 1-800-606-2682, email us at cof@charcot-marie-tooth.org, or visit us on the web at www.charcot-marie-tooth.org/cof.

Working together, we can create a world without CMT!

Aly's Circle

Mrs. Lynn T. Van Horn

Glenn's Quest

Mrs. Nancy DiBonaventura
 Ms. Gertrude M. Flynn
 Mr. & Mrs. Rudolph Moritz
 Mrs. Carolyn A. Von Mechow
 Mr. Andrew C. Woehrel, III
 Ms. Ruth A. Woehrel

Grace's Courage Crusade

Mr. & Mrs. Albert Alba
 Mr. & Mrs. Lincoln D. Almond
 Mr. & Mrs. Joseph Brian
 Ms. Julie A. Casey
 Dr. & Mrs. Anthony Catuogno
 Dr. & Mrs. Vincent Ciaramella
 Mr. Joseph Creedon

Ms. Emma DiSano
 Mr. & Mrs. Charles Dumberger
 Mr. & Mrs. Richard Esposito
 Mr. & Mrs. Leo H. Fox
 Mr. George S. Gorman
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 Mr. & Mrs. Carol Liu
 Mr. & Mrs. John D. McNeill
 Mr. & Mrs. John W. Miller, Jr.
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 Mrs. Pamela E. Murphy
 Ms. Tonia C. Papitto
 Mr. & Mrs. Robert M. Parrillo
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 Mr. & Mrs. Everett Salisbury
 Dr. & Mrs. Eugene J. Sidoti
 Mr. Eugene J. Sidoti, Jr.
 Dr. & Mrs. Paul A. Sidoti

Mr. & Mrs. Robert Smith
 Ms. Ann Snell
 Mr. & Mrs. Douglas M. Snow
 Mr. & Mrs. Timothy J. Sullivan

Kayla's Circle

Mr. Mathew Mandeltort
 Ms. Kimberly Tschida

Ryan's Quest

Mrs. Stacey A. Espe

Zane & Alex's Wedding Circle

Mrs. Fatma Demirbas
 Mrs. Patricia Macritchie
 Ms. Maureen A. Minor
 Ms. Elizabeth Peterson



Swimming for Julia and for CMT Research



On Sunday, September 6th at the Lake Valhalla Club in Montville, NJ, a total of 17 swimmers (including six swimmers between the ages of 9 and 14) took to the water to raise money for the Charcot-Marie-Tooth Association's Research Fund in honor of Julia Beron. It was a truly incredible day. In attendance were approximately 120 close friends and family who cheered on the swimmers and

showed their support to the CMTA.

We were lucky to be joined by Ttxtlktees, a newly formed apparel company which designed, printed, and sold souvenir tee shirts specifically made for the swim (and donated 100% of all profits to TeamJulia). As a surprise, an impromptu lemonade and cookie stand was set up by some children in attendance (which raised \$20 for the CMTA!) All in all, TeamJulia09

TeamJulia09 swimmers pose by the edge of Lake Valhalla before their swim. Julia is front and center in her mother Rachel's arms. Over the past three years, TeamJulia has raised more than \$200,000 for CMT research.

has raised approximately \$50,000 thus far, and the total continues to grow.

See above picture of the swimmers from TeamJulia09. We've already been approached by double this number of people eager to train and participate in the 2010 swim!

If you know of anybody who may be interested in making a contribution to TeamJulia09 and The Swim for the Cure, the website is: <https://secure.charcot-marie-tooth.org/teamjulia.php>.

This is the Beron's first year to hold their own swim. Previously they participated in Steve O'Donnell's Chesapeake Bay Swim for the Cure. *



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"FGHT CMT" T-SHIRTS

In addition to the T-shirts made specifically for the swim, Ttxtlktees made some with their special logo and the message, "FGHT CMT." (*Editor's note: Text messagers drop their vowels to make shorter messages, so FGHT is really Fight in text lingo.*) The image on the T-shirt is shown at left, and the shirts can be ordered by calling 877-898-8551 or by visiting the website at Ttxtlktees.com/cmta. ALL proceeds from the sale of these shirts will be given to the CMTA's research fund. *

The CMT "Circle of Friends": Team Julia '09

Dr. Robert Adamenko
Ms. Stephanie Alexander
Mr. & Mrs. Jon Alin
Mr. & Mrs. Leslie S. Ash
Mr. & Mrs. Charles August
Mr. & Mrs. Brad Bailey
Ms. Nancy Bailey
Mr. & Mrs. Scott Bailey
Mr. Fred H. Barrows, IV
Mr. & Mrs. Gregory Bauer
Mr. John Bautz
Mr. & Mrs. Jeffrey Becker
Mr. & Mrs. Terry Becker
Ms. Nancy M. Berkley
Mr. & Mrs. Alan S. Bernstein
Mr. & Mrs. David C. Beron
Dr. Elisabeth Beron & Mr. Evan Supcoff
Mr. & Mrs. Herbert Beron
Mr. & Mrs. Michael Beron
Mr. & Mrs. Larry Blake
Mr. & Mrs. Keith Blicht
Ms. Elaine M. Blitz
Ms. Wendy Block
Mr. & Mrs. Jonathan Bloom
Ms. Marcy Bloom
Ms. Susan Bloom
Mr. & Mrs. Sidney D. Bluming
Dr. Janice & Bruce Bolten
Mr. Robert D. Bortecq, Esq.
Mr. & Mrs. Marc Bortniker
Mr. & Mrs. Andy Boyer
Brahman Capital Corp
Ms. Joan Brock
Ms. Marlene G. Brown
Mr. & Mrs. William D. Bruen, Jr.
Mrs. Rhoda Burkholz
Mr. & Mrs. Dan Carus
Mr. Michael Carus
Mr. & Mrs. Michael Carver
Mr. & Mrs. Stanley Charlow
Mr. Eran Chen
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Mr. & Mrs. Tom Chiodi
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Mr. Thomas Dattoli
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Mr. Scott T. DeCanio
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Dr. & Mrs. Gary Drillings & Family
Mr. & Mrs. Karl Feaster
Mr. & Mrs. Jon Feinstein
Mr. & Mrs. Jesse A. Ferro
Mr. & Mrs. Allen Fleisig
Mr. Todd M. Foreman
Ms. Nicole Fulmino
Mr. Gary Gasper
Mr. & Mrs. Ron Geffner
Mr. & Mrs. Ira B. Geller
Mrs. Roberta Ginsberg
Mr. Jay Glickson
Mrs. Barbara J. Glucksman
Mr. Michael Goldenberg
Mr. Richard Goldschmidt
Mr. & Mrs. Alan D. Goldstein
Mr. Edward H. Gollob
Mr. & Mrs. Joseph S. Goodstein
Mr. & Mrs. Sterling A. Gordon
Mr. & Mrs. Don O. Gorman
Mr. & Mrs. Rick Greenebaum
Ms. Blanche J. Greenfield
Mr. Mitchell Haberman
Mr. & Mrs. Mark Haft & Family
Mr. W. Drew Hawkins
Mr. Lawrence Hazan
Mr. & Mrs. Abe Heller
Mr. & Mrs. Brad Horowitz
Ms. Rochelle Hyman
Mr. Daniel Indek
Ms. Jill Jaclin
Mr. & Mrs. Roland A. Jacobus III
Ms. Valerie J. Jakubowski
Mr. & Mrs. Scott Karp
Mr. & Mrs. Herbert S. Kasoff
Mrs. Abby Kastin
Mr. & Mrs. Mitchell Katz
Ms. Susan B. Katz
Mr. & Mrs. Brian J. Kelly, Jr.
Mr. & Mrs. Hyman F. Kleinman
Mr. & Mrs. Bill Kolodner
Mr. Lee Kornbluh
Mr. James M. Kostell
Mr. Frank Kovar
Mr. Randy Krupnick
Ms. Chia Yuen Ku
Mr. Gary Lancz
Mr. Sean Lang
Mr. Rocco Lavista
Ms. Barbara Ann Lazar
Ms. Daysi M. Leiva
Mr. & Mrs. Steven Lerner
Mr. Steven Lessans
Ms. Jill Levine Popkin
Mr. & Mrs. Lisa Levine
Ms. Dana Z. Levitan
Mr. Joshua Levy
Mr. Michael B. Levy
Mr. & Mrs. Ronald Liebowitz
Lipkin Family Foundation
Ms. Wendy Lipp
Mr. & Mrs. David London
Mr. & Mrs. Robert Lowenfish
Mr. & Mrs. Gary Mach
Mr. & Mrs. Jonathan Mach
Mr. Paul Mallen
Mr. & Mrs. Jeffrey G. Marcus
Mr. Kenneth Marcus
Mr. & Mrs. Christopher Maurizi
Mr. & Mrs. Larry May
Mr. & Mrs. Bob Mayer
Mr. & Mrs. David Mazie
Mr. & Mrs. Seth Mendelson
Mr. & Mrs. Andrew J. Merkin
Mrs. Robin Miller
Ms. Joann Minardi
Mr. John Minicucci
Mr. Mike Minwell
Ms. Jennifer M. Miscia
Mr. John Moran
Ms. Renee R. Morgan
Dr. Steven E. Morganstein
Mr. Jason Nazmiyal
Mr. John A. Nidds
Mr. & Mrs. Joel Orris
Mr. Robert V. Papaleo
Mr. Glenn M. Parker
Mr. Eric Paulen
Mr. & Mrs. Mike Pearlman
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Mr. & Mrs. Marc Platinsky
Mr. Jonathan Posner
Mr. Bruce Evan Prescott
Mr. & Mrs. Stephen Press
Mr. & Mrs. Craig A. Pruett
Mr. & Mrs. James H. Quartner
Dr. Jeffrey L. Quartner
Mr. & Mrs. Jonathan H. Quartner
Mr. & Mrs. Mark Reichman
Mr. Robert M. Reilly
Mr. & Mrs. John Reynolds
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Mr. & Mrs. Glenn Robinson
Mr. & Mrs. Mark D. Robinson
Mr. Tom Rogers
Mr. & Mrs. Albert Ross
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Mr. Steven Sachs
Dr. Ron Sadler
Mr. K. Safian
Mr. & Mrs. Daniel Sauer
Jen & Rich Schatzberg
Mr. Steven M. Scheine
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Mr. Ita M. Schenkel
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Mr. Ted Segal
Mrs. Zhanna Sheykhet
Dr. Vivian Shnaidman
Mr. & Mrs. Jeff Shupack
Mrs. Fran Simmons
Mr. Scott Sklar
Mr. & Mrs. Marc Sokobin
Mr. & Mrs. Michael Sonnabend
Mr. & Mrs. John Spielberg
Ms. Joan R. Spindel
Mrs. Lisa C. Stathis
Mr. & Mrs. Michael Stefani
Mr. & Mrs. Richard Steinberg
Ms. Jennifer Stone
Mr. & Mrs. Mitchell Storch
Mr. Herb Subin
Mr. Baehyun Sung
Mrs. Bonnie Tarlowe
Mr. Adam J. Taub
Ms. Tamara Telesko
Mr. & Mrs. Daniel Tellem
Ms. Maureen Torcivia
Ms. Ann Trainor
Mr. Lee Tsukroff
Mr. & Mrs. Nancy S. Tuckman
Mr. & Mrs. Richard Tull
Ms. Wendy Turnbull
Mr. Tim Tynan
Ms. Stacey Vinder
Mr. & Mrs. Kenneth N. Vostal
Mr. Matthew Wasserman
Mr. Steven A. Weill
Mr. David S. Weinerman
Mrs. Jenifer Wirtshafter
Mr. & Mrs. Joel Wolff
Mr. Philson Yim
Mr. & Mrs. Barry H. Zucker

Prince and the Scooter

BY ROSEMARY MILLS, FORMER MINNESOTA SUPPORT GROUP LEADER

My story begins this past spring when our dog Princess got run over. It was a Saturday. My husband Ron was home and had just gone out to work in the barn. Princess was walking along with him, getting petted, of course. All of a sudden, she took off and Ron thought she was just going after a bird. She liked to do that...chase the birds. They would be high up in the air and she would still be going after them. She even ran into a tree once, doing that.

Ron heard her yelp even before he got all the way to the barn. He saw her lying by the side of the road. When he got to her, she was already dead. He brought her up to the yard and buried her out in back of the trees. When he came in, he said, "I don't think I can stand to bury another friend. It hurts too much."

So, I thought that was the end of our having dogs. I understood. After all, Ron had all the work when we had outside dogs...feeding, watering, and picking up after them. I tried not to mention another dog, but as summer went on, once in a while I would see dogs listed in the paper and dream of another one. One day, I mentioned this to Ron and he said, "Oh, what kinds were there?" I had already thrown the paper away, but I realized then that he was softening to the idea of another dog.

One summer day, Ron took

a vacation day. One of the things we did that day was to go to Home Medical to get his sleep machine tested. While we were there, Ron saw a scooter and became quite interested in it. He thought I would enjoy it so much. I wasn't sure we should even think about it because I have an electric chair.

But, we got the papers on the scooter and took them home with us. The more we talked about it, the more we could see the advantages of a scooter for both of us....being

able to take it out into the yard for me and loading it in the van for Ron.

After talking over the idea, we decided to buy a scooter. I can't tell you what a difference it has made in my life! I go out into our yard almost every day. I hadn't realized how much I had missed that. I cried with joy the first two days I was out. Now, when I go out, I ride over all three acres Ron has mowed, just because I can and for the pure joy of it.

And then, along came Prince. It happened like this. I heard about some dogs on the radio, but I didn't mention it to Ron. One day, they were talking about some Border Collie/short hair German Shepherd pups for sale. I copied down the phone number, but then threw it away. That evening, I couldn't help mentioning them to Ron. He said, "That would be a really good mix." He asked if they had

a male puppy. I told him I had thrown away the phone number.

The next day was our 43rd wedding anniversary. I got a bright idea. I called the radio station and got the number for the dogs. I called and found out they had one male puppy left. I sent a check to hold the puppy and told them we would pick him up on Sunday after church. That evening, I told Ron I had bought him a puppy for his anniversary present. He was happy and excited.

I can't tell you what a difference a scooter has made in my life!

On the way to pick up the puppy, Ron asked what we should name the dog. I said that since we

had had a Princess, maybe we should have a Prince. I thought we would know when we saw him if that fit. Well, he was a Prince! He was chocolate brown and white with golden eyes.

Now, almost every day, Prince and I take the scooter and run around the yard together. He likes to get up on my lap and sometimes, he puts his paws up on the handlebars and beeps the horn. Ron has a mess to clean up almost every day because Prince is a pup and likes to chew and dig. But, Ron adores him as much, or perhaps more, than I do.

P.S. As Prince has gotten older, I can open up the scooter and he and I can race. It feels so good. It's as if I'm running with him. I never could run well, so this feels so freeing. ✨

LIVING WITH CMT

Mac Needs Info on Shoes/Sneakers

Day in and day out, I wear New Balance sneakers. I love them because they have easily removable insoles and come in 4E sizes with roomy toe boxes. They accommodate my AFOs well, can be worn comfortably for long periods, and provide a reasonably stylish option for casual footwear. My orthotist loves them because they are made on an SL-2 last (a model specifically designed for high-arched, cavus feet) and have roll-bars that provide medial and lateral stability.

I can't wear sneakers with a suit, though, so my alter ego MacGyver occasionally takes a good pair of Rockports out to the garage and uses all manner of tools to extract enough of the glued-down insoles and under-soles to allow me to get my feet and AFOs inside. The results haven't always been pretty on the inside, but they have been comfortable.

And I've also learned that New Balance and other sneakers can give new meaning to the phrase "slippery when wet," to which I'd also add snowy and

icy, so I have a pair of shoes with Vibram soles made by P.W. Minor. They look like something I borrowed from Herman Munster, but the Vibram soles allow me to stomp around on just about any terrain without worrying about my feet skidding out from under me (except when I'm foolish enough to venture out onto bare ice).

Then there is my closet, where failed experiments reside,



New Balance sneakers have removable insoles to provide extra depth.

gathering dust and waiting for a second chance, as in, "Gee, these looked like they'd be so comfortable...maybe if I just wear them a few more times until they're fully broken in." The reality is more like, "Okay, I can't take these back because I ripped out the insoles, but I paid good money for them, so I'm not just throwing them away."

I'm also a hoarder—when I find a pair of good-looking shoes that are comfortable, my first impulse is to go right back and buy three more pair just so I'd have them if they stopped selling them.

I can only imagine what the odyssey must be like when it



Dunham shoes are available in a wide range of widths.

comes to buying women's shoes, but J.W. from Ontario sent me the link, www.drcomfortdpm.com/WomensAll.htm, and she also recommends www.boothuggers.com for socks and all sorts of cool stuff to keep you warm.

A personal favorite of mine is www.nbwebexpress.com (where they have New Balance and Dunhams), but I'm sure many of you have your own favorites. Email suggestions to me! (See address at right.)

—Dana Schwertfeger

HAVE A PRODUCT SUGGESTION OR TIP FOR MAKING LIFE WITH CMT EASIER?

Email it to:
mac@cmtausa.org
or mail it to:
Mac's Tips
CMTA
2700 Chestnut Parkway
Chester, PA 19013



Look for the Vibram soles from P.W. Minor for extra protection from slipping.

Come Join the CMTA on Facebook

Facebook, the ever-popular social networking site, is gaining more and more popularity among our members. There are quite a few sites dedicated to CMT, but I have created a group called *CMTA Support Group Leaders, Members and Friends* to stimulate discussion on CMT-related issues outside of support group meetings. If there is not a CMTA support group in your area, consider this on-line group a virtual gathering of individuals with CMT, their families, and friends. Let's create a nationwide community committed to spreading awareness, fostering education, and getting to know one another a bit better, despite the distance. Everyone's invited, so I look forward to becoming your friend!

—Elizabeth Ouellette



SUPPORT GROUP NEWS

California – San Diego

A new group met for the first time on September 13th to “meet and greet” each other and make plans for future meetings. The group is lead by Steve Gabbert and meets at the Mission Hills Branch Library in San Diego. For more information about this group call Steve at 619-987-6022.

California – San Mateo

The group met on September 12th to hear pediatrician Dr. Rosemary Shy, who practices at the Wayne State Clinic in Detroit, speak about children and CMT. Some of the questions she addressed involved how kids can tell other kids about CMT and what kinds of concerns should a parent have about their child taking regular physical education classes.

Colorado – Denver Area

On August 29th, the group heard from Bernadette Mascarenas, who is an exercise coach. She spoke about movement therapy to incorporate simple stretching and strengthening exercises into a daily routine. The next meeting will be held on October 17th and will feature Dr. Marc Treihaf, a neurologist with the Colorado Neuromuscular and Peripheral Nerve Disorders Center in Englewood, CO.

Illinois – Chicago Area

The meeting took place on August 15th and despite the extreme heat, 22 people were in attendance. The speaker was

Marijo Pesavento, Physical Therapist and Pediatric Clinical Specialist from Advocate Hope Children’s Hospital. Her topic was “Fitness for All Ages.” Marijo has been a therapist for 37 years and has worked with CMT patients. She demonstrated a few exercises for stretching and low impact. The group also discussed adding information to the CMTA Resource Directory. Members will bring lists of valuable CMT experts to the next meeting or will email that information to leader, Dale Lopez.

Massachusetts – Boston Area

The group will meet on October 3rd at their new site, the Brookline Library’s Hunneman Hall, a state-of-the-art meeting and performance hall, from 1 to 3 PM. One of the main attractions of the new site is the free parking in an attached garage. The group will have an open-forum type of meeting where members can share their personal stories of living with CMT.

Missouri – St. Louis

The next meeting will be October 24, 2009, at St. Louis University Medical Center Cafeteria from 10 AM to noon. Dr. Florian Thomas will be the featured presenter and will field all questions regarding CMT. Dr. Thomas is a member of the CMTA’s Medical Advisory Board and a noted CMT expert.

Pennsylvania – Philadelphia

The next meeting will be on October 3, 2009, when the

group will hear from Wendy McCoy, a physical therapist who specializes in hand therapy and has been treating hand problems for patients for 14 years. She has a Masters Degree from the University of Pittsburgh and has lectured to community organizations and colleges about physical therapy and hand therapy exercises.

Tennessee – Savannah

Our fourth meeting of the year featured David Hall, CEO of the CMTA. It was held on Saturday, July 18th. Dave flew in from his home in Pittsburgh and was able to answer many of our questions. He also helped us understand how important community support and community education is. We had a family join us from Illinois. Because many of the group members do not have access to the Internet, the meetings are extremely important in getting out the information that the patients need to understand their problem and improve their daily living.

Texas – Dallas Area

The group had a successful “meet and greet” meeting and made plans for their future meetings. The next time they met was September 19th to hear Dr. Susan Iannacone from the University of Texas Southwest, who will be leading the CMT Center of Excellence there and is a nationally recognized pediatric specialist. The next meeting, October 24, 2009, will feature Dr. Gil Wolfe, who will speak about CMT and pain issues. ✨

CMT Support Groups

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

Alabama—Birmingham

No support group
Will accept phone calls/emails
Contact: Dr. Dice Lineberry,
calls only 205-870-4755
Email: cmtasg_birminghamal@
charcot-marie-tooth.org

California—Los Angeles

Place: Hilltop Community Church
Contact: Ryan Conlon, 310-383-1024
Website: cmtla.org
Email: cmtasg_losangeles@
charcot-marie-tooth.org

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

Place: Sutter Med. Cen. of Santa Rosa
Contact: Louise Givens, 707-539-2163
Email: cmtasg_northcal@
charcot-marie-tooth.org

California—San Diego Area

Place: Mission Valley Branch Library
Contact: Steve Gabbert, 619-987-6022
Email: cmtasg_sandiego@
charcot-marie-tooth.org

California—San Francisco Bay Area/ Santa Clara County

Place: San Mateo Library
Contact: Elizabeth Ouellette,
650-248-3409 (C)
650-559-0123 (H)
Email: cmtasg_sanfran@
charcot-marie-tooth.org

California—Santa Barbara

Place: TBA
Contact: Gretchen Glick, 805-693-9511
(between 3-5 pm, PDT)
Email: cmtus@yahoo.com

Colorado—Westminster

Place: Call for location
Contact: Diane Covington,
303-635-0229
Email: cmtasg_colorado@
charcot-marie-tooth.org

Florida—Iverness Area

Place: Citrus Memorial Hospital
Contact: Ronnie Plageman,
352-860-1578
Email: cmtasg_ivernessfl@
charcot-marie-tooth.org

Florida—Orlando Area

Place: Metro Church, Winter Springs
Contact: Jeff Miller, 407-579-1005
Email: cmtasg_orlando@
charcot-marie-tooth.org

Florida—Tampa Bay Area

Place: St. Anthony's Hosp.,
St. Petersburg
Contact: Vicki Polyea, 813-251-5512
Email: cmtasg_tampa@
charcot-marie-tooth.org

Georgia—Atlanta Area

Place: St. Martin's Episcopal Church
Contact: Sue Ruediger, 678-595-2817
Email: cmtasg_atlanta@
charcot-marie-tooth.org

Illinois—Chicago Area

Place: Oak Lawn Public Library
Contact: Dale Lopez, 708-499-6274
Email: cmtasg_chicago@
charcot-marie-tooth.org

Kansas—Wichita Area

Place: Independent Living Resource
Center
Contact: Karen Smith, 316-841-8852
Email: cmtasg_wichita@
charcot-marie-tooth.org

Kentucky—Burlington

Place: Boone County Public Library
Contact: Pam Utz, 859-817-9338
Email: cmtasg_burlingtonky@
charcot-marie-tooth.org

Maryland—Baltimore Area

Place: TBA
Contact: Bruce Egnew, 410-729-2297
Email: cmtasg_baltimore@
charcot-marie-tooth.org

Massachusetts—Boston Area

Place: Hunneman Hall, Brookline
Public Library
Contact: Mark Boxshus, 781-925-4254
Email: cmtasg_boston@
charcot-marie-tooth.org

Michigan—Ann Arbor

Place: Great Lakes Regional Training Ctr.
Contact: Tammy Mayher, 734-216-1347
Email: cmtasg_annarbor@
charcot-marie-tooth.org

Minnesota—Benson

No support group
Will accept phone calls/emails
Contact: Rosemary Mills, 320-567-2156
Email: cmtasg_bensonmn@
charcot-marie-tooth.org

Minnesota—Twin Cities

Place: Call for location
Contact: Bill Miller, 763-560-6654
Email: cmtasg_twincities@
charcot-marie-tooth.org

Mississippi/Louisiana

Place: Baptist Healthplex, Clinton, MS
Contact: Flora Jones, 601-825-2258
Email: cmtasg_clintonms@
charcot-marie-tooth.org

Missouri—St. Louis Area

Place: Saint Louis University Hospital
Contact: Carole Haislip, 314-644-1664
Email: cmtasg_stlouis@
charcot-marie-tooth.org

Missouri

No support group
Will accept phone calls/emails
Contact: Libby Bond, calls only
479-752-7112 after 7pm weekdays;
any time on weekends

Nevada—Las Vegas

Place: West Charleston Library
Contact: Mary Fatzinger, 702-369-6095
Email: cmtasg_lasvegas@
charcot-marie-tooth.org

New Hampshire/Vermont

Place: Dartmouth-Hitchcock Med. Cen.
Contact: Margaret Healey, 802-535-2797
Email: cmtasg_lebanonnh@
charcot-marie-tooth.org

New Jersey—Mountainside

Place: Children's Specialized Hospital
Contacts: Rachel Beron, 973-316-0058
Email: cmtasg_mountainsidenj@
charcot-marie-tooth.org

New York—Greater New York

Place: NYU Med. Cen./Rusk Institute
Contact: Dr. David Younger,
212-535-4314
Website: www.cmtnyc.org
Email: cmtasg_nyc@
charcot-marie-tooth.org

New York—Horseheads

Place: Horseheads Free Library
Contact: Angela Piersimoni,
607-562-8823
Email: cmtasg_horseheadsny@
charcot-marie-tooth.org

New York—Hudson Area

Place: St. Luke's, Cornwall Hospital
Contact: Deborah Newman,
845-883-0580
Email: cmtasg_cornwallny@
charcot-marie-tooth.org

New York (Westchester County)/ Connecticut (Fairfield)

Place: Blythedale Children's Hospital
Contacts: Beverly Wurzel, 201-224-5795
Email: cmtasg_westchesterny@
charcot-marie-tooth.org

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

Place: Raleigh, NC
Contact: Susan Salzberg,
919-967-3118 (afternoons)
Email: cmtasg_chapelhill@
charcot-marie-tooth.org

Ohio—Greenville

Place: Brethren Retirement Com.
Contact: Dot Cain, 937-548-3963
Email: cmtasg_greenvilleoh@
charcot-marie-tooth.org

Oregon—Portland

Place: Midland Library
Contact: Debbie Hagen, 503-333-7936
Email: cmtasg_portlandor@
charcot-marie-tooth.org

Pennsylvania—Johnstown Area

Place: John P. Murtha
Neuroscience Center
Contacts: J. D. Griffith, 814-539-2341
Jeana Sweeney, 814-262-8467
Email: cmtasg_johnstown@
charcot-marie-tooth.org

Pennsylvania—Northwestern Area

Place: Blasco Memorial Library
Contact: Joyce Steinkamp,
814-833-8495
Email: cmtasg_eriepa@
charcot-marie-tooth.org

Pennsylvania—Pittsburgh Area

Place: St. Simon and Jude Church
Contact: Christine Miller, 412-341-5749
Email: cmtasg_pittsburgh@
charcot-marie-tooth.org

Pennsylvania—Philadelphia Area

Place: CMTA Office, Chester, PA
Contacts: Dana Schwertfeger,
800-606-2682
Walter Donikowski,
610-960-1199
Email: dana@charcot-marie-tooth.org
walterdonikowski@hotmail.com

Tennessee—Savannah

Place: East End Sports Complex
Contact: Reagan McGee,
731-925-6204 evenings
Email: cmtasg_savannahtn@
charcot-marie-tooth.org

Texas—Dallas

Place: 13154 Coit Rd, Suite 101
Contact: Whitney Kreps, 972-989-5743
Email: cmtasg_dallas@
charcot-marie-tooth.org

Texas—Houston Area

Place: Park Place Regional Library
Contact: Brady Gibbs, 409-692-0493
Email: cmtasg_houston@
charcot-marie-tooth.org

Virginia—Harrisonburg

Place: Sunnyside Retirement
Community, Sunnyside Room
Contact: Anne Long, 540-568-8328

Virginia—Williamsburg

Place: Williamsburg Library, Room C
Contacts: Jennie Overstreet,
804-693-5806
Nancy Mollner,
757-220-3578
Email: cmtasg_williamsburg@
charcot-marie-tooth.org

Washington—Seattle

Place: U of Washington Med. Center
Contact: Ruth Oskolkoff,
206-598-2765
Email: cmtasg_seattle@
charcot-marie-tooth.org

Washington—Tacoma Area

Place: Elmer's Restaurant
Contact: Carol Hadle, 253-476-2345
Email: cmtasg_tacoma@
charcot-marie-tooth.org



LETTERS

Dear CMTA,

On the first weekend in August, for the last 15 years, our family reunion has taken place in a small town in Nekoosa, Wisconsin. Over a hundred family members and close friends come from all over the states to meet up on that one weekend to celebrate a wonderful tradition.

This year, the family took it upon themselves to have a fundraiser honoring our son,

Tyler, who was diagnosed with CMT four years ago. Our family and friends have become familiar with the disease from the "Circle of Friends" fundraiser we have been having for the last three years. I was thrilled and very touched that they would go out of their way to do this for Tyler without any intervention on our part.

The first night of the reunion everyone gathered for the fundraiser and a chance to sample "Tyler's Tasty Tornado," a wonderful martini drink the family created, and some wonderful appetizers. I was able to pass along an update on the STAR program to some of the family. Many of the family members receive the CMTA newsletter, so they were telling me what they had read.

The last night of the reunion a silent auction was held with items the family had donated. When the reunion was over, the total amount raised by the family was \$1000 for the STAR research fund. The power of family and friends is amazing!

—*The Lopez Family*

Dear CMTA,

The month of June was a memorable one for me. I reached 90 years of age, and I renewed my Texas drivers' license so I can continue driving my minivan around the state to see friends and relatives. I live on the tenth floor of a retirement community and have my own one-bedroom apartment in the independent living section. I've worn plastic AFOs for the past 15 years and

walk with a cane, but I go everywhere I want to go as long as there are not too many stair steps involved.

The good news about the success of Phase 1 of the STAR project is most encouraging. I will never see the day when CMT is cured, but I have hopes for future generations.

Consequently, I am enclosing a small donation for the STAR project with the hope that it in a small way will help make a bright light truly visible in the tunnel.

—*A.M., Houston, TX*

Dear CMTA,

I just thought I would pass along my experience with vitamin C. I had read in your magazine that trials were being conducted on large doses of vitamin C. I have CMT Type 1A. I called the trial point of contact but was turned down because I am also a diabetic.

After I spoke with my doctor, I started taking a 2000-mg dose: 1000 mg in the morning and 1000 in the evening. I can honestly say I never really noticed a difference. That is until I stopped. Within two weeks, I started noticing both feet were feeling very numb in the morning. I had less feeling in my feet and in turn, less control.

Needless to say, I am starting back on my vitamin C today.

Thanks for the information. It has been very helpful and created great results for me.

—*J.M., Williamsport, MD*

Next Please

Who is in charge here?

I have a request

A mistake has been made

This model is broken at best.

What happened to quality?

The customer is always right,

Production has made a mistake

I'm trying to be polite.

The warranty you say?

You know how I must feel?

No more in stock?

I'll just have to deal?

The work it takes

To live day to day

The aches, the pain

The strength I have,

wasting away.

Fine, you know what?

I think I agree

Nobody could handle this body

Anything like me.

—*Jennifer Rusball*

WRITE TO US!

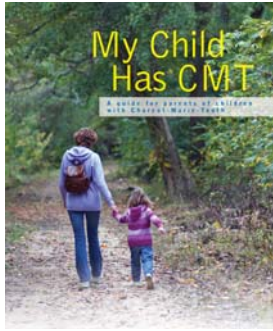
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MEMBERSHIP APPLICATION/PUBLICATIONS ORDER FORM



New Pediatric Publication Now Available

My Child Has CMT is a 32-page booklet with full color photos and topics such as "When We Found Out Our Daughter Had CMT", questions and answers from Dr. Mena Scavina, A.I. DuPont Institute in Wilmington, DE, "How to Keep a Medical History for Your Child," and a dictionary of common medical terminology. A list of resources and organizations helpful to families with CMT is the final chapter. The booklet is only \$5 for CMTA members and \$7 for non-members.

ALSO AVAILABLE:



Circle of Friends T-Shirts



Be a STAR Wristbands

NAME: _____ / _____ / _____
First MI Last

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

COUNTRY/POSTAL CODE (IF NOT US): _____

DAYTIME PHONE: _____ EVENING PHONE: _____

EMAIL: _____ USER NAME: _____
Required for PDF Newsletter/Website Access *Required for Website Access*

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

	QTY	COST	TOTAL
MEMBERSHIP Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both. Receive newsletter as: <input type="checkbox"/> Print or <input type="checkbox"/> PDF via email Receive both Print <i>and</i> PDF Newsletters		\$25 \$30	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		active members \$10 nonmembers \$15	
[CD Format]		active members \$7.50 nonmembers \$10	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 nonmembers \$7	
CMT Facts III		active members \$5 nonmembers \$7	
CMT Facts IV		active members \$8 nonmembers \$10	
CMT Facts V		active members \$12 nonmembers \$15	
CMT Facts VI		active members \$12 nonmembers \$15	
A Guide About Genetics for CMT Patients <i>(No shipping and handling on this item only)</i>		active members \$4 nonmembers \$5	
Teaching Kids about CMT...A Classroom Presentation <i>(1 hour DVD)</i>		active members \$7.50 nonmembers \$10	
NEW! My Child Has CMT, A Guide for Parents		active members \$5 nonmembers \$7	
Be a Star Wristbands (Pack of 5)		\$5	
Women's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL		active members \$9 nonmembers \$10	
Men's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL ___2XL ___3XL		active members \$9 nonmembers \$10	
West Coast Patient-Family Conference <i>(5 hours—2-DVD set)</i>		active members \$15 nonmembers \$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 <i>(Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)</i>			
TOTAL			

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

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

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

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



CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

Moderate to significant risk:

Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddl, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, 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-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
a-Interferon

Negligible or doubtful risk:

Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Fluoroquinolones
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

THE CMTA Report



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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.