THE CMTA Report

MAY/JUNE
2014

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

CMTA
Charcot-Marie-Tooth Association

OUR MISSION:

To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.

OUR VISION:

A world without CMT.

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ISSN #1067-0181 ★ Vol. 29, No. 3

The CMT Clinic at University of Michigan:
A New Clinical and Research Center of Excellence


The Burlington Building at the University of Michigan is the home of the newest CMT Center of Excellence.

The Charcot-Marie-Tooth (CMT) Centers of Excellence, funded by both the Charcot-Marie-Tooth Association and the Muscular Dystrophy Association, have been established to provide CMT patients with high-quality medical care, ensure the uniformity of data collection, and give patients the opportunity to have their DNA sample banked for analysis and gene identification. These Centers of Excellence are chosen because of the quality and experience of the doctors who serve as the Primary Investigators.

The CMT Clinic at the University of Michigan at Ann Arbor, a pediatric and adult multidisciplinary clinic, has been recognized as a new Center of Excellence. The University of Michigan CMT Clinic meets weekly on Fridays. Children and adults are clinically assessed by physicians from Neurology (Clinic Director, Dr. Sindhu Ramchandren) and Physical Medicine and Rehabilitation (Co-Director, Dr. Joseph Hornyak), and will also have access to physical and occupational therapists, and orthotists, as well as to genetic testing and counseling. Electrodiagnostic studies to clarify the diagnosis or stratify the disease severity, as well as research studies, are performed later in the afternoon on the same visit. Insurance will be billed for the clinical services provided.

The University of Michigan CMT Clinic is actively involved in clinical research. Participation in clinical research is voluntary and refusal will not affect the clinical care patients receive. The National Institutes of Health (NIH)-funded Inherited Neuropathy Consortium (U54NS065712) is leading efforts to develop new therapies and gathering longitudinal data in children and adults with CMT to develop outcome measures that reflect disease

> Dr. Sindhu Ramchandren is investigating the impact of pain in CMT.

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THANK YOU TO OUR CORPORATE SPONSORS:

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A Journey Through the Years of the CMTA Board of Directors

I am so proud of our Charcot Marie Tooth Association. I have served as a Board Member for approximately 20 years.

I remember the first meeting I attended in Florida. We had a very well-intentioned Board who wanted to make a difference. We were trying to fund some research and do some outreach. We were just like a "Mom and Pop" store existing with few funds and a limited direction. Our Medical Advisory Board was small, and the research projects presented to us may have been academically interesting, but they were not directed to finding a cure as soon as possible.

We went through many transitions within the ensuing years. Our breakthrough into a dynamic organization, in charge of our own destiny, came with our initiation of the STAR Project. Our Strategy to Accelerate Research under the leadership of Patrick Livney has brought us to a new level. Patrick Livney and his team, with a much more full-bodied budget, with funds raised by, and from, people like you, have truly made great strides.

With an international research team, we are screening thousands of compounds to discover what will positively improve CMT patients. We have developed laboratory models to do testing on. We have Schwann cell lines to use in testing. We are working with stem cells. We are working with major drug companies who want to partner with us in the quest for a cure.

Dr. Mike Shy and his team helped develop a standard protocol to measure the results on a patient of any drug we want to test. We have expanded our outreach program and now have 73 active support groups, with the number always growing. Working with the Muscular Dystrophy Association, we have identified Centers of Excellence to ensure CMT patients are provided with high-quality care. Presently there are 13 national centers. We hold patient and physician conferences on a regular basis in different parts of the country. Take a look at our website and see the discussion groups and webinars that we are promoting. See the CMT physicians and specialists listed under the Resources tab on our homepage and their geographic locations. Use the vast array of services we now provide.

We are not a "Mom and Pop" shop anymore! We are a dynamic group with direction and a mission statement with goals that are in reach: "To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT, and ultimately to find a cure." Our vision is "A world without CMT." We look forward to starting clinical trials as soon as possible.

I am proud to continue my service on the CMTA Board of Directors.

—*Phyllis Sanders*

NEW CMT CENTER OF EXCELLENCE

(continued from page 1)

progression for use in future CMT trials. The University of Michigan is a participating site in the Consortium, and Dr. Ramchandren is the site Principal Investigator. Her research focus is on improving patient-centered outcomes, especially pain and overall quality of life.

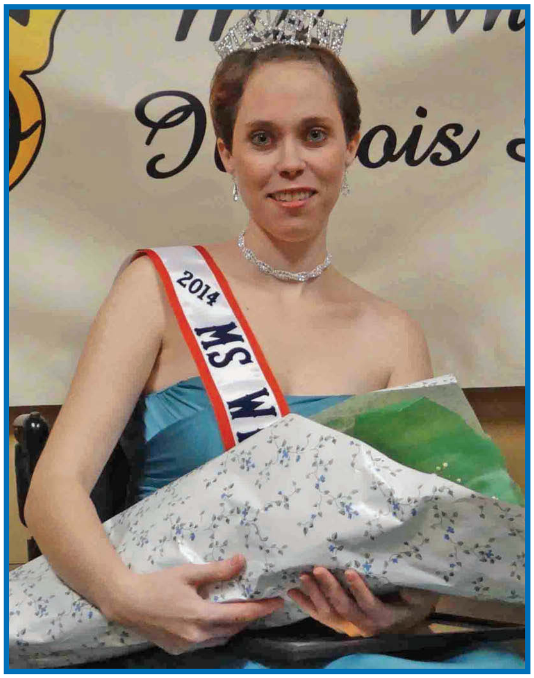
Dr. Ramchandren is also the Principal Investigator of a pediatric CMT Quality of Life instrument development study, funded by the NIH (K23NS072279), and is currently investigating the impact of pain in CMT and other genetic neuromuscular disorders.

To schedule an appointment with Dr. Ramchandren or learn more about the clinic, visit: www.med.umich.edu/neurology/clinical/cmt.htm, or contact Kim Creamer (clinic coordinator) at 734-647-3863 or creamerk@med.umich.edu.★

Ms. Wheelchair IL Advocates CMT Awareness

My name is Pearl Gannon and I'm Ms. Wheelchair Illinois 2014. I am currently 27-years-old. At the age of eight, I started having symptoms of a neuromuscular disorder, but the doctors could not put a definitive name on it. It wasn't until I was 26 that I received the diagnosis of Charcot-Marie-Tooth. I'm not sure what type of CMT I have, but it causes not only the "normal" symptoms but also hearing loss. I wear bilateral hearing aids, and I have trouble with swallowing and digesting, so I have a feeding tube to help with nutrition.

I am very active in wheelchair sports such as wheelchair basketball, adaptive wake boarding, and adaptive skiing. I've tried many other sports, but these are the three I stick with. Even while playing these sports I am pursuing a double major in college. I take American Sign Language classes at two separate colleges while also studying social work for early childhood intervention.


Pearl Gannon is Miss Wheelchair Illinois for 2014 and will compete for the national title in August.

For the next year I will be using my title to raise awareness about various disabilities. I will also be educating society when it comes to various disability-related issues. I will be focusing on the disabled to advocate for positive mental health, personally interacting with as many people as possible to make a difference. Within the next year, I will be visiting schools to bring hope and direction to our youth and also help teach what being disabled is all about, from both an athletic and a personal perspective. I will be attending different expos to bring awareness to the Ms. Wheelchair Illinois pageants and also attending many different sports events, both adapted and able-bodied.

In early August, I will be traveling to Long Beach, California, to compete for Ms. Wheelchair America 2015. I will meet 28-30 other crown-holders from various states, all competing for the same title. I'm very excited to even have the opportunity to meet these other amazing and inspiring women who are all making a difference in their states, advocating for their passions. ★

YOUR GIFT TODAY IS TRIPLY SIGNIFICANT!

Through STARPOWER, two generous families have each agreed to match contributions to the CMTA's Strategy To Accelerate Research (STAR) up to $500,000, for a total of $1.5 million for CMT research.

That means every research dollar we raise will be matched not once, but twice. Act now and make your contribution so we can TRIPLE its impact in pursuit of our ultimate goal—a world without CMT.

In a few short years, STAR has reached major milestones on the way to finding treatments and cures for several types of CMT. We have made significant progress in research for five types of CMT. We have one agreement in place with a very large pharmaceutical company and are in discussions with four others. These collaborations will accelerate the drug development process!

So far, through the efforts of our supporters, we have raised over $110,000. Thank you to all who have already pledged their support.

We have 60 days left to meet our matching challenge. The time is now to give to the CMTA to accelerate research by turning $500,000 into $1,500,000!

To give today, go to www.cmtausa.org/starpower, call 800-606-2682, ext. 105, or send a check to PO Box 105 Glenolden, PA 19036.

Visit www.cmtausa.org/research to learn more about the progress we've made and to watch a video about our STAR initiative. Thank you for all of your support!

WHAT'S ON YOUR MIND? ASK DAVID.

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at info@cmtausa.org.

Dear David,

I am a 35-year-old male with CMT. No one else in my family has CMT, and although I look okay and function pretty well, I am really depressed when I see others who appear to be more severely affected. My doctor says it progresses very slowly, but my fears of being disabled are affecting my entire life. What can I do to control my anxiety about the future? I have a girlfriend who says she loves me, but I find that my concerns about myself are causing me to push her away.

David Tannenbaum answers:

It is quite common with many of us with CMT to allow our fears and anxiety to define our life. We forget that our CMT, although imposing some limitations, does not have to dictate whether our life is fulfilling or not. When we take ourselves away from the present and project stories into the future, that can create enormous stress and make us miserable, and it can also negatively affect our muscle strength.

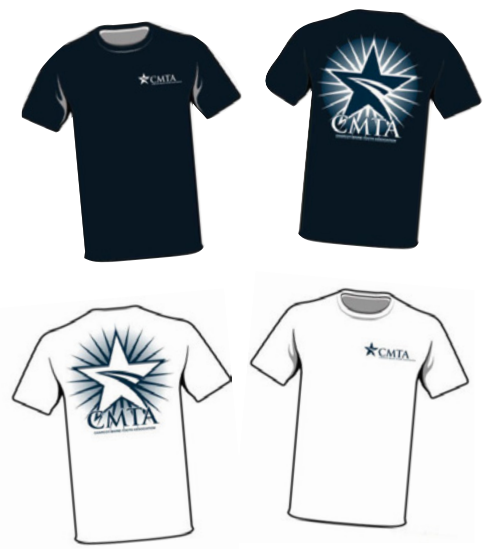
Your greatest challenge, if you want to take it up, is to try to grow emotionally and spiritually by making a commitment that you are going to be happy despite life's events. Okay, so how do you do that? The answer is not about living in denial and pretending that everything is fine when inside it feels differently. That is simply being inauthentic. I am talking about keeping your heart open to whatever is going on and allowing the different feelings you experience to simply "show up" and then pass through. Keeping your heart open allows you to experience the feelings and release them in a few moments. The trick is to notice the feeling at its onset before it takes hold and becomes a block to the loving energy that is underneath. That loving energy is there all the time, even when you are not feeling it. It is similar to the analogy of the sun always being behind the clouds. We know it is there whether we see it or not.

Suffering is caused by resistance to life's events. It is caused by allowing life's upsets to block that loving energy that is always present underneath those negative and fearful stories everyone makes up in their minds. Yes, there might be people who have a more severe form of CMT, but that doesn't mean that they lead less meaningful or less fulfilling lives. I know people who will be miserable all day long if they miss their train in the morning. Be the one who is aware of your feelings. Be the witness to your feelings. Be the part of you that watches your feelings come and go because the part of you that is the watcher is quite peaceful. From this place of observing and of neutrality you can experience your life much more calmly.

The greatest form of happiness is peace. The expression "it is what it is" is more profound than it initially appears to be. It is a statement that reminds us not to judge or be critical or compare our experience to anything else. Just accepting what is can be very freeing. It takes practice. Remind yourself that opening up to your girlfriend's love can be unbelievably healing on so many levels. Your girlfriend is showing you the love that you carry inside your heart at every moment. Stay open to it. It will be a gift you give yourself. ★

SPREAD AWARENESS WITH STAR T-SHIRTS

New blue and white tee shirts have been designed to highlight the CMTA's STAR campaign to find treatments for CMT. T-shirts are $12 for CMTA members and come in adult sizes from small to 3X. To order yours, use the form on page 15, or visit the CMTA store on our website.



Managing Neuropathic Pain

BY STEVEN SCHERER, MD, PHD, CMTA BOARD OF DIRECTORS

Why does peripheral neuropathy cause pain?

Peripheral nerves are a collection of nerve fibers that originate from many different kinds of neurons. Motor fibers originate from motor neurons that are located in the spinal cord. Sensory axons originate from neurons that are located outside the spinal cord in large clusters called ganglia. The ganglia that contain the sensory neurons for the leg are located in the low back region (called the lumbar and sacral levels); those for the arm are located in the neck (called the cervical region). Each of these ganglia contains many thousands of sensory neurons.

Every sensory neuron has two ends. One end is connected to a tissue in the body (a piece of skin, muscle, bone, etc.), and the other end is connected to the spinal cord. Under normal circumstances, sensations are generated only upon stimulation of the end of the nerve fiber that is in the body. Then, sensory nerve fibers relay this information to the spinal cord, and cells in the spinal cord, in turn, relay this information to the brain.

There are many kinds of sensory neurons. This is why we can perceive so many different sensations. All of us can appreciate many of these sensations, such as heat, cold, light touch, pin prick, vibration, and movements of the hairs on our skin. Other sensations are less obvious, such as the ability to determine movements of our arms and legs. Each kind of sensation, including pain, is conveyed to the spinal cord by certain kinds of sensory neurons.

So what does this have to do with pain? It is likely that some kinds of neuropathy damage the sensory fibers that convey pain, causing them to be hyperactive even in the absence of stimulation. In other words, damaged “hyperactive pain fibers” trick the brain into perceiving a painful stimulus even though none is present. The hyperactive fibers may not even be properly connected to their tissue, thereby accounting for why people can experience pain in their “numb” feet or legs.

> To manage pain effectively, there has to be a partnership between patient and physician.

It should be clear that not all pain is caused by neuropathy, even in people who have peripheral neuropathy. The pain of arthritis or headache, for example, are conveyed, but are not caused, by sensory fibers. Even the pain caused by one of the foot deformities caused by neuropathies is not caused by damaged sensory fibers; the sensory fibers are merely conveying the information to the spinal cord. Conversely, not all people who have peripheral neuropathy have painful symptoms. Pain is a common symptom in some kinds of neuropathy, such as diabetic neuropathy, in which small sensory fibers may be disproportionately affected. Among people who have inherited neuropathy, pain is much less frequent in the demyelinating forms than in the axonal forms affecting small sensory fibers.

What are the principles of treating painful peripheral neuropathies?

If neuropathy causes pain that is diminishing the quality of life, then this symptom should be treated. In my view, to manage pain effectively, there has to be a partnership between the patient and the physician. The patient needs to understand their pain—when it occurs, how well the drugs work, the side effects of the medications (particularly how troubling they are)—and they need to communicate these things to the physician. The physician needs to know the

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If you are already an Amazon.com user, you will use the same account on Amazon.com and AmazonSmile. On your first visit to AmazonSmile, select the Charcot-Marie-Tooth Association before you begin shopping, which will allow the CMTA to receive donations from your purchases. Amazon will remember your selection, so every eligible purchase you make on AmazonSmile will result in a donation to the CMTA. Go to: https://smile.amazon.com/

Thanks for continuing to support the CMTA! Your help makes us SMILE!

MANAGING NEUROPATHIC PAIN

(continued from page 5)

medications and the relevant information about them—their duration, common side effects, potential interactions with other drugs, and whether a patient has other complicating medical problems—and communicate these things to the patient.

The goal is maximize the patient's quality of life. In practical terms, the patient should take the amount of medication that effectively manages the pain, but that does not cause unacceptable side effects. In the ideal case, the patient would be pain-free without any side effects. In the worst case, the patient has intolerable side effects at a dose that produces no pain relief whatsoever. In the typical case, however, there is a dose of a medication that provides some pain relief but that also causes some side effects. It should be clear that only the can patient know whether a medication works and whether it has acceptable side effects.

A key point is to know if the pain varies reliably according to the time of day. Many patients have their worst pain after getting home from work, or at night. For these patients, one can try to match the dose of shorter acting medications to the time of day that the pain is worse. Another related point is that each medication has a certain duration of action that usually corresponds to the number of times per day that one takes it. Thus, medications that are typically taken every 4, 6, 8, 12, or 24 hours typically are effective for 4, 6, 8, 12, or 24 hours, respectively.

What medications are used for treating painful peripheral neuropathies?

Many medications have been reported to work for painful peripheral neuropathies (Mendell & Sahenk, 2003; Wolfe & Trivedi, 2004). Most have been studied in clinical trials, such as gabapentin (Lesser, Sharma, LaMoreaux, & Poole, 2004), desipramine (Max et al., 1992), oxycontin (Gimbel, Richards, & Portenoy, 2003), and Lyrica (pregabablin) or Cymbalta (duloxetine HCl) for painful diabetic neuropathy, but FDA approval (a long and *expensive* process) for this "indication" (namely, painful diabetic neuropathy) has been granted only for Lyrica and Cymbalta. That does not mean that the other medications don't work; it means that physicians are forced to prescribe medications that have not been FDA approved for treating painful neuropathies. To make matters worse, many insurance companies *will not pay for* Lyrica or Cymbalta (even Oxycontin) unless the patients have exactly what the FDA approved—a painful neuropathy caused by diabetes.

Which medication to try first is an important question. In one recent consensus statement of pain experts (Dworkin et al., 2007); but also see the editorial (Cherny, 2007), "certain antidepressants (i.e., tricyclic antidepressants and dual reuptake inhibitors of both serotonin and norepinephrine), calcium channel a2-d ligands (i.e., gabapentin and pregabalin), and topical lidocaine" were considered first-line treatments, with opioids as "generally second-line treatments." "Third-line treatments that could also be used as second-line treatments in some circumstances include certain antiepileptic and antidepressant medications, mexiletine, N-methyl-D-aspartate receptor antagonists, and topical capsaicin." What this expert panel is saying is to try first-line medications first, second-line medications second, and so on, but also that, "Medication selection should be individualized, considering side effects, potential beneficial or deleterious effects on comorbidities, and whether prompt onset of pain relief is necessary."

Regardless of the medication, the logic I use is the same:

- Introduce one medication at a time. Changing the doses of two medications simultaneously makes it difficult to determine which medication is responsible for any given effect (especially a side effect).
- Use a gradually escalating dose of one medication until either good pain relief is obtained or intolerable side effects occur. This is the key concept; too often I have seen patients who have been taking potentially effective medications but at doses that neither alleviate the pain nor cause significant side effects.
- If one medication fails, try another one. ★

To read the full article by Dr. Scherer and see the list of medications that may be used to alleviate neuropathic pain, please visit this webpage: www.cmtausa.org/scherermanagingpain

Children Spread Easter Cheer to Nursing Home Residents with Daffodil Giveaway

The 17th Annual CMT Daffodils for Seniors was held Saturday, April 19, 2014, at Arbutus Park Manor, Johnstown, PA. Each spring children pick, arrange and hand out thousands of daffodils, much to the delight of the nursing home residents.

The daffodil giveaway is conducted by the Johnstown, PA CMT Support and Action Group and is done in honor of Facilitator J.D. Griffith's daughter, Marah, who died at sixteen from respiratory arrest on Christmas Day, 2001. Marah was instrumental in the concept of children giving daffodils to seniors. Marah loved organizing the event and working with the children, and she particularly enjoyed the pleasure the event gave to the nursing home residents.

Jeana Sweeney organized the children for this year's event.

WTAJ, the local CBS affiliate, covered the event on the 6:00 and 11:00 pm news, and the giveaway was mentioned in the local Johnstown paper. ★

Some of the participants in the nursing home visit: *Left to right, back row*: Jeana Sweeney, Nina Griffith, Brenda Griffith, Hayley Sweeney, Cody Shaw, Ausha Shaw. *Left to right, front row*: Rylee Sweeney and Ireland Bradley.

CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank-you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, P.O. Box 105, Glenolden, PA 19036.

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

Send acknowledgment to:
Name:______________________________
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____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
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Send acknowledgment to:
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Address:____________________________
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Amount Enclosed: ___________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card #______________________________
Exp. Date ___________________________
Signature ___________________________

Gift Given By:
Name:______________________________
Address:____________________________
____

HOBBY TURNS INTO A FUNDRAISING OPPORTUNITY

I wanted to learn to knit because I thought it would be good therapy for my son's hands. However, he wasn't too interested in knitting. I enjoyed it though, so I continued doing it.

I made everyone I knew dishcloths and then graduated to infinity scarves. After a couple of scarves, the idea of making them for people and requesting a donation to the CMTA occurred to me. This also brings people an awareness of CMT when they go to the website to donate.

I can knit while watching TV or in what downtime I do have and still contribute something. If I won the lottery tomorrow, I would make a huge contribution to the CMTA, but until then, I will just knit....

—*Alison Childress*

Alison concentrates as she works on another knitting creation to help raise awareness of CMT for her friends and neighbors.

DONATIONS WERE MADE TO THESE CMTA CIRCLES OF FRIENDS:

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SAG FACILITATORS SPOTLIGHT:

Central NJ Facilitators Work to "Spread the Word"

The Central NJ CMT Support and Action Group is a group of about 95 members from towns as close as Freehold and as far away as Little Egg Harbor to the south and Jersey City to the north. The group first met in May, 2009, under the leadership of Herb and Rachael Beron. When facilitating the group was becoming too much for the Berons because of Herb's increasing responsibilities on the Board of the CMTA and their very successful TeamJulia Swim for the Cure annual event, Mark Willis stepped in to take over the group and started holding the meetings at CentraState Medical Center in Freehold. After attending the first-ever Facilitator's Conference, the group became the Central New Jersey CMT Support and Action Group. The group held events a little further north, like the, now annual, Somerset Patriots Baseball event. Eventually, that spurred the creation of the Morris County CMT Support and Action Group.

Mark has CMT Type 1A. Mark and his family have traced CMT back to his maternal great grandfather. Aunts, cousins, even his sister, have it. Mark has two sons. The oldest has CMT, and they know one of his nieces has it, and recently, her four-year-old son was diagnosed. So, Mark is determined to spread the word and find a cure. "I'll never forget my first meeting," said Mark. "I was scared beyond words—what did I know about doing this? However, we were freshly back from our first visit to see Dr. Michael Shy when he was at Wayne State, and I came away from that experience knowing I had to do more and be a part of the change."

Originally the group met quarterly, but with the increased attendance and so much information to be communicated and discussed, they began meeting every other month. Speakers have included Ken Cornell from Cornell Prosthetics and Orthotics, David Singer from Singer Stress Management, and a host of others whose expertise meant something to each of the members in their CMT journey. A few times a year the group changes the meeting format and holds BBQs, restaurant luncheons or catered holiday parties.

The co-facilitator of the group is Jacky Donahue. She has CMT1A and is concerned about passing it on to her daughters, ages 23 and 25. A few years ago, Jacky Donahue joined the group from the Philadelphia area SAG. "I was driving an hour to Philadelphia area SAG meetings when I heard that there was a central NJ group 10 minutes from my home in Farmingdale. I joined and when I saw the time and effort that went into organizing these meetings, I offered to help out. I am detail-oriented and have some writing and organizational skills to bring to the table. Mark has experience, an established network of CMTA contacts, and the ability to keep one eye (sorry for the pun, Mark, who has just had eye surgery) on the big picture. We complement each other, so it works out well. But I have to admit that nothing matches Mark's enthusiasm and determination. When meeting details take a detour or a fundraiser flops, he finds that silver lining. Recently, a speaker cancelled at the last minute, but Mark plowed ahead. The room was full to capacity, including seven new members, and there wasn't a dry eye in the room after a very open and moving round table discussion."

Jacky Donahue and Mark Willis complement each other as SAG facilitators.

According to Mark, "These meetings are so much more than coffee and donuts. There is so much that happens that can't be documented. Friends are found, strength is shared, and hearts are healed. And in the end, no one really cares if we followed the agenda or not." ★

Archy Visits Facebook Headquarters

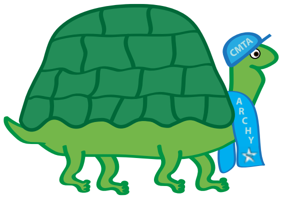
After the winter we've had here at Greenwoods, it was a wonderful treat to be invited to travel to California to go the headquarters of Facebook in Menlo Park. I stayed with Elizabeth Ouellette, and we went to Facebook with Bethany Meloche, whose fiancé works there.

I was so in awe of this place! The grounds were very accessible and there was an air of fun and happiness even though it's a place of work. There was an arcade and a tiny yellow brick road like in the Wizard of Oz with a miniature house and the legs of the Wicked Witch sticking out and lots of people playing street hockey. (You did have to watch out for flying objects.)

The Facebook campus was enormous, but we only toured one of the buildings. A programmer showed us around and talked about things that were way beyond my understanding. His personal desk had two huge monitors on it and the screens were filled with computer code … rows and rows of computer code.

What impressed me was the fact that in the back of all the buildings was a long walkway where people of all ages raced around on foot, on bikes and on skateboards. People just whizzed by me, who as you can guess, was moving much more slowly than the average employee. Apparently, there have been instances of people walking and into the walls while looking at their iPhones and iPads, so there were signs everywhere that said, "Look up!"

There were lots of individual offices in the buildings and most of the doors were closed, so we could see the signs on the doors. The phrase on each door was a palindrome. (Remember that term from English class?) Two examples we saw were "Rats live on no evil star" and "No melon, no lemon." They don't have any hidden meaning; they just show the creative side of the employees at Facebook.



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

Bethany Meloche, Elizabeth Ouellette and Archy posed in front of the "Like" sign outside of Facebook headquarters.

We ate lunch in a Mexican restaurant for free! And, as if that weren't great enough, they provide all the free candy anyone could ever want for their employees. They also have a wall of Legos where anyone can make designs on the wall, so I've decided that I want to study computer programming and work at Facebook one day, although I'll have to assume that when I'm older, I won't overeat the candy like I did on our visit. I felt a little sick afterwards.

I only had one little complaint. There were no ponds or flowing water on the whole campus. I will have to take that up with the "powers that be" if I really do apply for a job with them one day. I wasn't sure how I felt about the foxes, either. There was a sign that read, "No photos with the foxes." There is apparently a family of foxes who have moved in at Facebook, and they even have a Facebook page dedicated to them.

Before we left, we finished our busy day with a photo at the famous "Like" sign. No self-respecting boy turtle could pass up the chance to be photographed with two fabulous women. ★

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

ROY V. BEHLKE
Mr. & Mrs. Roy F. Behlke

HARRY BLUM
Mr. Jim Blum
Maria-Victoria Boucugnani
Dr. Lynda Boucugnani-Whitehead

DUDLEY BOWLBY
Ms. Dawn Orr

MARY BRUGGEMANN
Mr. Louis Maresca

BETTY CHOW
Mr. & Mrs. Gene Lew

WILLIAM CLEMENT
Mr. & Mrs. Ray Cahill

RENIA COLE
Mrs. Donna Boe
Mr. & Mrs. Dale Hassinger
The Krumm Family
Midwest Disability PA

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Dr. Catherine Hoyt Drazen

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REGINALD DURDEN
Ms. Sara Gray

EUNICE FAIMAN
Mr. Robert Faiman

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Mrs. Judith Ruehl

CHRISTINE HOOK
Dr. & Mrs. Richard Bossert

MARGARET HULMES
Mr. & Mrs. Jack Fitts
Mr. & Mrs. Paul Anziano
Belchertown Little League
Mr. Ron Besancon
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Mrs. Janine M. Connor (Besancon)
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Kaplan/Stewart Attorneys at Law
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Mr. & Mrs. Paul Gosiewski
Mr. & Mrs. William Helmer
Ms. Gayle E. Huffman
Mr. & Mrs. Steve MacCabe
Ms. Mally K. Miceli
Mr. & Mrs. Keith Parr
Mr. & Mrs. Seymour Rabens
Mr. & Mrs. Roger Seely
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Ms. Sandra Spriester Markowitz
Mrs. January Van Dyke

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Mr. & Mrs. Arnold Levine
Ms. Norma Sims

ANNE MONDEL
Mr. & Mrs. Fred Hirschenfang
Ms. Barbara Toms

PAUL NAPPER
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Mr. Felix Robles

RICHARD ROTHMAN
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The Bristol Lioness Club
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Ms. Terry Forstrom
Mr. & Mrs. Eric Forstrom
Mr. & Mrs. Arthur Geller
Interval Management Corp
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Ms. Linda Lu McMullen
Ms. Kim Moebus
Mr. & Mrs. Al Rogalla
Mr. & Mrs. Jack Tranter

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Mr. & Mrs. Carl Dupes, Jr.
Mr. & Mrs. Ralph Fisher
Mr. & Mrs. Thomas Fisher & Family
Mr. & Mrs. Paul Gallo
Ms. Wendy Juodikis
Mr. & Mrs. Dennis Schmidt
Mr. & Mrs. Wayne Smeal
Mr. & Mrs. James Tyson
Mrs. Jennifer White
Mr. & Mrs. David Willey

WERNER SIEBERT
Ms. Marion Schmidt

SAMMY J. SMITH
Ms. Betty Aultman
Clinton, MS CMT Support Group

JAMES SNOW
Mr. & Mrs. John Gallichio
Ms. Nina Rose Jawnyj
Mr. & Mrs. Jeffrey Jelm
Mr. & Mrs. Steve Kante
Mr. & Mrs. Randall Kowalewski
Mr. Joe Lightcap
Mr. Jeff Musur
Ms. Lynn Nelson
Mr. Mark Richardson
Mr. & Mrs. Richard Schwarzbach
Mr. & Mrs. Thomas Selzer
Mrs. Susan Snow

BEE & STANLEY SOLES
Ms. Cynthia Heier
Ms. Eleonora Jedrysek

HARRISON WELLS
Mr. & Mrs. William Bollenberg

FENELON WHITAKER
Mr. & Mrs. Gerald Federici

IN HONOR OF:

DONALD ABRUTYN
Mr. Robert Schechner

MARILYN & MARTY BERGER
Mr. & Mrs. Kenneth Handel
Mr. & Mrs. Richard Hayman
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Ms. Lori Gold

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Ms. Stephanie Powers

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Mrs. Judith Kubesh

SURVEY OF DISEASE BURDEN IN GENETIC NEUROMUSCULAR DISORDERS

Researchers at the University of Michigan are interested in collecting patient impressions of how genetic neuromuscular disease affects their lives, particularly issues such as pain, depression, fatigue, sleep and cognitive problems. If you are an adult who has been diagnosed with a genetic neuromuscular disorder, such as muscular dystrophy, inherited neuropathy or Charcot-Marie-Tooth disease (CMT), etc., you are invited to participate.

Your responses are anonymous, and there are no costs to taking part in this survey, which should take you about 20 minutes to complete. To get started, please visit this webpage: https://www.surveymonkey.com/s/UMNeuromuscularSurveyCMTA

SUPPORT AND ACTION GROUP NEWS

- **AZ – Phoenix Area**

The group had a good turnout for their February meeting. Carly Siskind, a genetic counselor from Stanford University, served as guest speaker. This was one of the most informative lectures the group has had.

- **DC – Washington DC**

More than 30 people heard Jeana Sweeney talk about CMT, the work of the CMTA, ways to get involved, fundraising, and more. Very special thanks to Jeana and her daughter Rylee for making the trip from Pennsylvania. Congratulations to Lynn Thomas for knowing the answer to Jeana's quiz question: "What does STAR stand for?" The winning answer was the Strategy to Accelerate Research, which is making progress on several CMT types and will soon result in human trials for a potential drug treatment for CMT1A.

- **FL – Sarasota**

On May 3rd, members of the group met to hear Chris Toelle, orthotist and manager of Hanger Clinic, give an excellent presentation about CMT and AFOs. He showed the group many of the latest types of AFOs, spoke about emerging advances in AFO design, and answered questions from the group while Jack Devine of Hanger Clinic, Sarasota, FL, assisted with the presentation and distributed "goody bags" to our members. The group was made aware of the CMTA webinars and many other resources on the CMTA website. The group was also updated on fundraising, how each person can be a part of the STAR initiative, and the potential benefits to us and successive generations. One couple developed several ideas for possible educational/media events that might be held in the fall, and one couple volunteered to hold a social event for our members at their home later this year. The group is really energized! Our next meetings will be August 2 and November 15.

- **FL – West Palm Beach**

Thank you to Jonathan Shochat and "Arch O & P" for visiting with the group for their March 16th meeting. Jonathan brought to the group a depth of knowledge regarding orthotics, AFOs, and braces. He showed examples of AFOs and braces while answering questions regarding individual equipment with regard to Medicare billing. This was a breath of fresh air for those group members who have had poor to reasonable experiences with securing these walking aids. Also, a special thanks to group member Kurt Weiss for having the vision to know the positive impact that this professional would have on the group.

- **MA – Boston**

The group met at Jill and Vittorio Ricci's home on March 12th. Stories of CMT and HNPP, the diagnosis and the treatments were shared. They also discussed STAR research, the Massachusetts Challenge fundraising effort, and the Massachusetts General Hospital Center of Excellence.

- **MD – Easton**

The group met on March 8th, with 16 in attendance. They shared their handy gadgets, the best canes, the best shoes, how they get up off the floor after falling, what exercises they do and what braces work for them. It was an energetic program with show-and-tell. The most fun was when everyone pulled up their slacks to show their various braces. The program was intended to allow attendees to share their successes and they really did! They hope that their discussion inspires others with CMT and other groups to do the same. They were a reassured group when they left the meeting.

- **NJ – Central New Jersey**

There were 18 people, including 8 new members, present for the

(continued on page 15)

DR. MICHAEL SHY SPEAKS IN ONTARIO

The Southern Ontario CMT Support and Action Group hosted their first-ever CMT Conference with Dr. Michael Shy on Saturday, March 1, 2014, at Victoria Park Seniors Centre in Fergus, Ontario, Canada. It was a huge success! Dr. Shy led two sessions on hot topics in the field of CMT. The first session was for medical professionals and the second one was for patients, families and caregivers. There were 14 medical professionals who attended and over 70 patients, family members and caregivers. All those in attendance were grateful for the opportunity to meet Dr. Shy and have an opportunity to ask questions and get concrete answers. The conference raised $1,000 for the CMTA.

CMT Support and Action Groups in Your Community

AL—North Florence
North Florence, AL CMT Support and Action Group
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Todd Oyen
256-810-6582

AZ—Phoenix Area
Arizona CMT Support and Action Group
Pamela Palmer
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CA—Los Angeles Area
Los Angeles, CA CMT Support and Action Group
Steve Fox
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CA—Los Angeles
Los Angeles (South), CA CMT Support and Action Group
Alani Price
310-710-2376

CA—Stockton
Stockton, CA CMT Support and Action Group
Nina Anselmo
209-460-1716

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

CA—San Diego Area
San Diego, CA CMT Support and Action Group
Jordan Thomas
619-549-0872

CA—Santa Rosa Area
Santa Rosa, CA CMT Support and Action Group
Carol O'Bryan
707-823-0165

CA—Visalia Area
Visalia, CA CMT Support and Action Group
Melanie Pennebaker
559-972-3020

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

CT—Hartford
Hartford, CT East CMT Support and Action Group
Roy Behlke
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CT—North Haven
North Haven, CT CMT Support and Action Group
Lynne Krupa
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DC—Washington, DC
Washington, DC CMT Support and Action Group
Steven Weiss
Kimberly Hughes
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FL—Naples
Naples, FL CMT Support and Action Group
Roy Behlke
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FL—Sarasota Area
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Rachel Rivlin
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FL—Tampa Bay Area
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Vicki Pollyea
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FL—West Palm Bach
South FL CMT Support and Action Group
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Iowa City, IA CMT Support and Action Group
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Dale Lopez
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Charles Barrett
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IL—Springfield Area
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IN—Fort Wayne Area
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Priscilla Creaven
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IN—Lafayette
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Neville Tate
250-656-2547

CAN—Ontario
Eastern Ontario CMT Support and Action Group
Robin Schock
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Southern Ontario CMT Action and Support Group
Kelly Hall
519-843-6119

Mexico
(This group will be in Spanish.) México CMTA Grupo de Apoyo y Acción
Gina Salazar
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hotmail.com

Most Support and Action Groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups.

ASK THE DOCTOR

Dear Doctor,

Have there been any reports of worsening of the neuropathic pain of CMT with the use of Rivastigmine (Exelon Patch) for treatment of early-stage Alzheimers Disease? An 81-year-old female patient diagnosed about 10 years ago with CMT (symptoms primarily neuropathy in lower legs and hands) had considerable increase in pain and impaired walking after increasing her dose of Rivastigmine (having started on lowest dose three months ago). I did not see this drug listed on the CMT list of toxic drugs. Her condition is improving upon stopping of the higher dose.

Doctor Louis Weimer replies:

I don't have too much experience with this patch. It could cause some tingling and muscle twitching but should not injure nerves or worsen CMT.

Dear Doctor,

I have been on bisphosphonates for quite a while until I developed an ulcer. Now I am in need of returning to some medication to help with my bone density issues. I wonder if Reclast or Prolea would be helpful. I am worried that the injection of Reclast would be too strong for my body to handle. Also, I wonder about Boneva or Fosomax. Are any of these drugs better choices for someone with CMT and severe bone density issues?

Dr. Weimer replies:

I know of no neurological problems from any of these treatments. I'm certainly not knowledgeable enough about the differences between treatments to recommend one over the other for medical reasons. Obviously bone health in general is important for all CMT patients.

Dear Doctor,

I have a nine-year-old daughter with CMT1A who is also autistic. She is showing early signs of puberty, and I'm trying to get information about how birth control can affect her CMT. I am considering the birth control for the autism due to statistics that show that monthly cycles come with seizures. The birth control would be one that would stop the cycle, therefore eliminating the seizures.

Dr. Weimer replies:

The issue is not clear, but there is no established link. Some progesterone inhibitors are experimental targets for CMT treatment, but I know of no reports of birth control pills worsening neuropathy or CMT weakness.

MICHAEL GRIFE WINS FIRST CMTA WORDS WITH FRIENDS TOURNAMENT!

The game's lead slipped back and forth many times on the night of March 26th. Sometimes Mike was in the lead, other times Matt was behind. But the tide finally turned when Mike laid down the word "inked," boosting the value of his tiles with a triple word score. In the end, sometime after midnight, the game concluded with the score Mike 421 and Matt 386. Mike Grife claimed the title of First CMTA Words with Friends Tournament Champion.

While Mike may have won the trophy, everyone in the CMTA was a winner. The players agreed that they had a wonderful time, and the tournament raised $800 for CMT research. The tournament was such a success that the CMTA launched a bigger, better WWF tournament on April 15th. You can sign up for CMTA eNews and receive updates on future Words with Friends Tournaments at www.cmtausa.org/url/enews.

When not playing Words with Friends, Mike Grife lives peacefully in Boca Raton, Florida, with his wife, Alyssa. This year he founded the Grife Law Firm, focusing on serious personal injury. Mike has been named a Rising Star by Florida Super Lawyers and is rated 9.1 (excellent) by Avvo, a legal rating organization. In addition to being an avid supporter of the CMTA and the STAR initiative, Mike is an animal lover and supports the Tri County Humane Society and ASPCA.

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SUPPORT GROUP NEWS

(continued from page 12)

March 23rd meeting. Topics discussed included braces, AFOs, orthotics, podiatrists, the Aetrex shoe offer, STAR, the STAR-POWER Challenge, and the "Easy Thousand" fundraising ideas.

- **NC – Durham Area**

There were 15 people present at the April 12th meeting. The first guest speaker was marathon runner Beth Deloria. She is sponsored by Allard USA, and she has drop foot, which left her in need of braces in order to walk and run in marathons. Their next speaker was Jayme Brendle, the Allard Mid-Atlantic District Manager. She brought many different sizes and styles of Allard braces. She answered many questions and welcomed people to try on the brace she thought would fit them best.

- **NY – Westchester**

Ken Cornell, CO, FAAOP, gave a presentation on the orthotic management of CMT at the April meeting. Ken demonstrated bracing options and several members were evaluated individually. Laurie Lasky, Northeast District Manager of Allard USA, was also in attendance.

- **PA – Ephrata, PA**

Although the meeting was brief, the group shared stories of their successes and failures and learned a lot from each other.

- **WI – Milwaukee Area**

Thirteen members gathered at AccessibleWear, a new retail store for those that need adaptive clothing, accessories, and shoes. The group welcomed two new members. The owners of the company demonstrated some of the products they had to offer. This was one of the best meetings yet. Everyone left smiling. ★

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THE CMTA Report

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CMT PATIENT MEDICATION ALERT:

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

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

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones (Cipro)
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
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

WHAT IS CMT?

- CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- CMT may become worse if certain neurotoxic drugs are taken.
- CMT can vary greatly in severity, even within the same family.
- CMT can, in rare instances, cause severe disability.
- CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- CMT does not affect life expectancy.
- CMT is sometimes surgically treated.
- CMT 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).
- CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- CMT 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.
- CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.