THE CMTA Report

NOVEMBER/DECEMBER
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.

EMAIL CMTA AT:
info@cmtausa.org

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CMTA Announces Strategic Alliance with Genzyme

A modern miracle of drug discovery is the ability to rapidly test millions of molecules for the potential to treat or cure disease. This process is called high-throughput screening.

The Charcot-Marie-Tooth Association is very happy to announce the formation of an alliance with Genzyme, a Sanofi company, to discover therapies for CMT1A using a Sanofi U.S. high-throughput screening facility. The facility can test over 2 million small molecules.

This agreement is a direct result of the hard work our STAR researchers have been doing to create cell lines and construct tests that work in high-throughput screening environments.

CMT1A is the most common Charcot-Marie-Tooth (CMT) disorder, comprising at least 60 percent of all patients with CMT Type 1. This hereditary neuropathy is caused by a duplication of the gene for Peripheral Myelin Protein 22 (PMP22), located on Chromosome 17, and is inherited in an autosomal dominant fashion.

CMT1A usually presents with progressive symptoms including muscle weakness and atrophy, loss of balance, and sensory loss. There are currently no available therapies to treat either the initiation or progression of the disease, and patients often resort to bracing for ankle support.

"This relationship represents another example of collaboration between Genzyme and a patient association that leverages the relative strengths of the respective organizations. We are excited to have the opportunity to work with the leading scientists of the CMTA to identify potential therapies for patients with Charcot-

(continued on page 2)

A private family fund has offered a generous matching grant to encourage donations from new donors. If you have never donated to the CMTA STAR Campaign, please take advantage of this opportunity. For more information, see page 3.

INSIDE:

GENZYME PARTNERSHIP

(continued from page 1)

Marie-Tooth," said Seng H. Cheng, PhD, Head of Rare Disease R&D at Genzyme.

Under the agreement, a close collaboration will be formed between the CMTA STAR network of investigators and Genzyme that will leverage the Sanofi U.S. high-throughput screening facility in Tucson, Arizona. Assays developed at the University of Wisconsin and the NIH will be used to screen compound libraries that include more than 2 million small molecules. Additional investigative STAR participants include laboratories at the University of Iowa and University of Buffalo, which will participate via the sharing of assays specific to the regulation of PMP22 in peripheral nerves. Preclinical investigation of the in vivo activity of select molecules will be pursued in laboratory models of CMT1A through the CMTA's earlier announced service relationship with Psychogenics (www.psychogenics.com).

The ambitious aim of this consortium effort driven by the CMTA will be to identify small molecule candidate therapies for CMT1A, which can be further advanced into clinical testing in a patient trials network supported by the NIH and the CMTA. ★

For further information about Genzyme visit genzyme.com. For further information about the alliance, please contact Patrick A. Livney, CEO of the CMTA, at Pal@cmtausa.org.

New Calendar Celebrates Our Athletes

From mountaintops to the deep blue sea, on roads and at international shooting ranges, members of the CMTAthlete community have joined together to bring to you a calendar that knows no limits and shares insights and motivations from people who live with, and manage, CMT.

The motivator-in-chief of the CMTAthlete calendar project is Bob Hartdegen, a long-time member of our CMTAthlete community. A little over a year ago someone mentioned the idea of a CMTAthlete calendar. I put out the idea to our Facebook group and got favorable responses. So many people tend to hold back because they feel different or think they can't challenge themselves. Let me tell you something, we ARE all different AND we must challenge ourselves. This calendar is dedicated to all those people—with or without CMT—who refuse to be sidelined by anything that stands in their way.

As you go through the months and turn the pages you will learn more about the incredible people who are a part of the global CMT community.

For every calendar purchased, vital funds will be raised in support of the Charcot-Marie-Tooth Association's community and research programs. —*Donna DeWick*

Calendars are available for purchase directly from the CMTA for $20, which includes the cost of shipping within the United States. (An additional fee will be added for international deliveries.) Please allow a minimum of six weeks from order to delivery. Order your calendar at www.cmtausa.org/2015calendar by December 31, 2014.

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WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

My husband and I have been married for 25 years. We are both in our early fifties. My husband was diagnosed with CMT when he was 17 years old. He has been fine until a few years ago when it seemed like his CMT got worse in a short period of time. The problem is that he does very little around the house, refuses to travel, and never says thank you for all that I do for him. Please know that we love each other, and I don't mind doing more of the chores, but we are too young to act so old and I worry that he feels that our life is over. How do we approach these issues?

David replies:

Part of the answer to this is in your question. This is definitely a "we" issue. It sounds like he is dealing with some depression, which is completely understandable, and like many, he may need to experience a grieving process which will hopefully end in a healthy acceptance of his limitations. He then can lift his head up to see that there is still much to enjoy in life. There is a strong body-mind connection, so getting help with the psychological aspects of CMT can actually help him feel stronger and more motivated to stay active. Some men have a hard time accepting help with this, so he needs to know that depression is real and that there is help out there. More importantly, his attitude is affecting your relationship, which he might be taking for granted.

In any relationship we need to feel appreciated, and part of his resentment at CMT is manifesting in shutting you out and creating barriers to intimacy and love. At the right time a conversation is needed to convey to him that, as much as you empathize with his physical and emotional pain, you do not want to treat him like a child and you want a partner who contributes to the relationship as an equal. There is still much that he can do to help you, starting with an occasional "thank you."

As many of you who read this column know, staying in the moment and not projecting your fears of the future is a vital element in successfully dealing with CMT. As I write this column, I am looking out my window at the sun shining and highlighting the dazzling colors of autumn. Appreciating this kind of beauty helps me feel grateful that beyond our fearful thinking, there is so much to still enjoy. The key is to find ways to quiet our thoughts, become aware of how much we create fearful stories of the future, and learn to appreciate the beauty and stillness of the present moment. Being aware of the constant chatter in our mind without self-judgment or self-criticism is one way to quiet the noise. Just being aware of this habit of ours and remembering to breathe will help us experience more peace and tranquility in our lives. It is a challenge both physically and emotionally to prevent CMT from controlling our lives, but I truly believe that we all have it within us to triumph in the end. ★

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. Write to David at info@cmtausa.org.

Matching Grant Opportunity for First-Time Donors

The CMTA has been challenged by a private family fund: every dollar given by a **new donor** to the CMTA will be matched up to $300,000. If you've never given before, or if you've paid your premium membership dues but haven't given an additional donation, this match applies to you!

This challenge grant and your donation will pay for the CMTA's contribution to our Genzyme alliance, accelerating the pace of drug discovery. Your gift will pay for 2.2 million compounds to be screened in the Genzyme library against CMT1A cells. This screen will find any compound on the shelves at Genzyme that could provide treatments for CMT.

Your first time gift will have a major impact in finding treatments for CMT.

If you are ready to end CMT, let's meet this family's challenge. Your gift will make a difference. That is how change happens—one gesture, one person, one moment at a time.

Stanford CMT Patient and Family Conference Recap

BY PAM PALMER

The Stanford CMT Patient and Family Conference was held Saturday, September 27, 2014. It was an amazing event, and I would like to encourage all persons affected by CMT (patients and family) to attend one of these conferences. There is so much to learn, so many people to meet, and so many questions to be answered; but more importantly, you will know that you are not alone. This is the second conference I have attended and I was amazed not only by the advancements that have been made in the fight to conquer this disease in the past two years, but also by the diversity of the speakers and topics that were presented.

The reception given by the staff at the Stanford Neuromuscular Clinic, who were present to both assist and to speak, was outstanding in so many ways. There was a Meet and Greet the evening before the conference where Dr. John Day of Stanford, Dr. Michael Shy and Patrick Livney spoke about the collaboration between the CMTA and the Stanford Center of Excellence. Next was a tour of the Neuromuscular Clinic where we were able to listen to staff talk about what occurs when someone comes into the clinic for testing. It was very informative, and I felt encouraged to see how they diagnose patients.

On Saturday, the sponsors had displays up and several SAG Facilitators were handing out name tags, bags of goodies, and the agenda. The morning "technical sessions" were about all the advancements in the science of CMT and how STAR is helping to eradicate this disease.

> "You can do anything as long as you are not restricted by your fear of weakness."

Patrick Livney welcomed everyone and gave an overview of where the CMTA is with STAR research. I have heard Pat speak many times, but each time I learn about new advancements from the collaborators working on CMT. Next, Dr. Day spoke about the "Basics of CMT," a talk which was so important for those in the audience to hear. I think it is important for all of us to go back to the beginning so we can understand the updates in subsequent talks. Carly Siskind gave a wonderful presentation on the "Genetics of CMT," including having prenatal testing done. Dr. Shy then talked about STAR and the treatments for the various subtypes of CMT. Dr. Shy is another speaker you can listen to time and again as he continually updates his talks. Jeana Sweeney rounded out the morning with an invigorating talk about "The Time is Now." Her words were inspiring, and she quoted Nora Roberts: "If you don't go after what you want, you'll never have it. If you don't ask, the answer is always no. If you don't step forward, you'll always be in the same place." Jeana got a $5 donation from one of the attendees, and she didn't even ask!

The afternoon sessions were directed at helping those affected by CMT (whether directly or indirectly) to cope. There were two breakaway sessions where attendees could choose from among three presentations. Jeanne Kane talked about the H.E.A.L Program and navigating the educational system for kids. Included were the IEP (Individualized Education Plans) and 504 Plans, as well as guidance for children in the school system. (For more on this topic visit the Articles for Parents section of the Resource Center at www.cmtausa.org. It is a must-read guide if you have children with CMT.)

Sarah Kesty, a special educator who is on the CMTA Advisory Board, opened her fascinating breakout session talk with how she had to start with her shoes to coordinate her outfit for the day. (I related to that.) Her talk was "A Stepping Stone or Stumbling Block … Raising Kids with CMT." As a parent and a teacher, she had both insight and common-sense advice on how to support your

Advisory Board Members Bethany Meloche and Jonah Berger, along with NIH Post-Doc Brittany Wright, worked to give the youth a special outing during the conference weekend.

child with CMT. Whether it is buffering your child with regard to the doctor's diagnosis or dealing with bullying, she was honest and enthusiastic. I looked at her audience and found many attendees nodding their heads as they understood what she was saying. She talked about the difference between Growth Mindset (where one looks forward to life) and Fixed Mindset (where one sees everything as a challenge).

Jonah Berger, another member of the CMTA Advisory Board, spoke about "The Joys of CMT: Choosing Life on the Bright Side." While I decided to attend the two sessions on children, I could hear laughter across the hall while he gave his second talk. Jonah is an absolute bundle of pure love and vitality—so much so that I listened to his talk on the website. Jonah says, "You can do anything as long as you are not restricted by your fear of weakness." He will deny that that he is fearless, but he has accomplished so many challenging physical feats.

The last speakers helped those in the audience with CMT by giving information on how to live with CMT. Peggy Peter gave a talk on the "Genetically Handicapped Person Program," a program for California residents. Janis Kitsuwa-Lowe, an occupational therapist, gave an interesting presentation on all the adaptive equipment available to help make our lives easier. Items such as splints help with mealtime, home management, and leisure. Kristina Zekos-Ortiz, a respiratory therapist, finished the session by leading us through breathing exercises. She reminded us that sometimes we forget to take care of ourselves. Oxygen—we can't live without it—helps our brains, and it is important for us to practice relaxing, whether by deep breathing, yoga, or meditation.

Susan Ruediger, the CMTA Director of Development, closed the conference by thanking the Stanford staff for graciously and enthusiastically hosting the conference. This conference would not have happened without the tireless energy of Elizabeth Ouellette. Susan also wrapped up by pulling together all the parts of our CMTA—the science, the STAR program, and the Support and Action Groups.

I encourage all of you visit the Resource Center on the CMTA website at www.cmtausa.org, and listen to all of the speakers above. The videos in the Patient and Family Conference section are wonderful to watch, and you will learn not only about CMT but also about our terrific organization. I also encourage you to attend a Patient and Family Conference if at all possible. Join a support and action group. Be active. We need you to help us win our fight! ★

STANFORD & LUCILE PACKARD CHILDREN'S HOSPITAL'S FAMILY CLINIC

When: 4th Thursday of each month
Where: 211 Quarry Road, Hoover Building, 2nd Floor, Palo Alto, CA
Questions on how to get an appointment: 650-497-5934

The LPCH/Stanford Neuromuscular Program offers a Family Clinic for patients with two or more family members living with a genetic neuromuscular disorder. The purpose of this clinic is to allow interested families the opportunity to consolidate individual visits into one family clinic visit. This is especially helpful to families traveling long distances for consultation at Stanford and Lucile Packard. The Family Clinic experience can be tailored to any family's needs with individual consultations, group consultations or a combination of the two. Families will be seen by Dr. Day's team of specialists from the multidisciplinary clinic. These team members may include the nurse practitioner, physical therapist, occupational therapist, the respiratory therapist, speech therapist, the social worker and the outreach liaison. Clinic visits may be 2-4 hours long depending on the types of services needed. The Family Clinic is held in the Hoover Pavilion, where the Stanford Adult Neuromuscular Clinic takes place. This is located at 211 Quarry Road, just down the street from the LPCH neurology clinic.

Two and One-Half Years…and, Lots of Tears

My name is Bob DeRosa, and I am the Director of Marketing/Creative for Aetrex Worldwide, a CMTA corporate sponsor. This is where my story begins. It's neither sad, nor blue, but I assure you it's all true. I work for a terrific company and a fantastic family—the Schwartzes. When the company was deciding how best we could make a difference and give back to the community, CMTA Board Chairman Herb Beron approached an old college buddy, Larry Schwartz. From the start, Larry was excited about Aetrex's support and commitment to the CMTA. We felt, as a company, we could make a difference, and being in the shoe business, excuse the pun, it was a great fit.

Two CMTA representatives, Susan Ruediger and Jeana Sweeney, wanted to introduce themselves to Aetrex and hold a focus group to discuss our shoes. I was not required to get involved, but, as it turned out, my associate was out on maternity leave at that time, and we had just hired a wonderful young lady a few weeks earlier. Not wanting to put the burden on her to go it alone, I figured I would step in and help manage the event. We had a conference call with Susan and Jeana prior to them coming to our corporate headquarters in New Jersey. They seemed like two nice older women. (I'm sure they're going to want to hit me for thinking that!) They came to New Jersey, and I politely sat in on their presentation. Well, needless to say, I was amazed by what I heard and saw. First, I had no idea they both had CMT. Their knowledge and their passion about what they were presenting was impressive. Later in the evening, as I got to know them and their stories, I was so touched that I decided that very night that I would take an active role in representing Aetrex and supporting the CMTA.

> After meeting Jeana and Susan, I decided to take an active role in representing Aetrex and supporting the CMTA.

I was invited to the CMTA Support and Action Group Facilitators' Conference in Chicago later that year. The evening we were to leave, we had a snow storm and almost didn't make it out. Life is made up of special moments in time. That was certainly one of them. Meeting so many special, caring and courageous people made me want to be a part of something so important to so many. That weekend, I met a member of the CMTA Board (who will remain nameless). Five minutes after meeting that person, I was again asked what my name was and what I was doing there. Being from New Jersey, I don't do well with being forgotten or slighted. So, my next thought was, you will remember who I am and what I'm doing here!

I do not have CMT, had never heard of CMT, and didn't know of anyone who had CMT, and yet two and a half years later I was given the Volunteer of the Year Award. "The Time Is Now" brochure, Awareness Month website, CMT Survivor's Guide, and even the "Shark-O Marie Tooth" T-shirts were all collabo-

JOHNSTOWN, PA LIGHTS UP FOR AWARENESS MONTH

The Stone Bridge in Johnstown, PA, was illuminated on September 15th for CMT Awareness Month! The impressive bridge had a light show running with CMTA blue, orange and yellow from 8:30 to 9:00 pm. At 9:00 pm, the lights settled into a beautiful stationary array of the blue, orange and yellow. The CMTA, represented by Jeanne Derricott, Jeana Sweeney and her daughters, Hayley and Rylee, were honored to have the Stone Bridge looking beautiful and creating awareness. The visual display was made possible by the Johnstown Area Heritage Association (JAHA).

rations between me and the CMTA team. I have provided a fresh and engaging approach to the CMTA's goals and objectives, all of which have been successful and effective in raising awareness, education and funding.

The Aetrex family has also been committed to helping the CMTA and its members. Our sales team and customer service personnel located throughout the country have been tremendous assets to the CMTA community in showcasing shoes specially selected and designed for individuals with specific foot concerns and problems. Ownership has committed valuable resources in providing free shoes for premium members, as well as supporting the annual Julia's Swim fundraiser that takes place in New Jersey every year.

I am proud to say that I am also now a member of the CMTA Board of Directors. I hope one day to meet all of you. I don't know if that's possible, but I do know one day we will gather together as one to celebrate a new day of discovery where treatment and a cure are a reality. A few years ago my NY Giants had a theme for the season; it was "ALL IN." Well, consider me "ALL IN!" Why would anyone want to sit on the sideline and not be a part of something bigger than he himself is?

Oh, about the tears. They are not tears of sadness, but tears of joy. The friendships I have made and my ability to make a small contribution to an amazing association and its members truly fills me with happiness and joy.

—Bob DeRosa

Thanks for Taking Part in CMT Awareness Month

September CMT Awareness Month 2014 has officially come to a close. Wow! That sure did go quickly … time flies when you are having fun!

2014 Awareness Month was a huge success on many levels thanks to YOU. All of our Support and Action Group Facilitators and so many of our community members stepped up and stepped out to spread awareness of CMT, and we could not be more grateful for all of your efforts. From sharing information on the Facebook page, to passing out brochures, participating in CMT awareness events and putting on fundraisers, we've made great strides in getting the word out about this little-known disorder.

A few fun facts to share:

- ★ 20 States proclaimed September as CMT Awareness Month! Check it out to see if we received one from your state: www.cmtausa.org/proclamations
- ★ The Wear It Loud campaign was a HUGE success. More than 1,250 Shark-O shirts were sold, which, in turn, raised $23,000 for the CMTA! Haven't purchased your Shark-O shirt? It's not too late: www.cmtausa.org/sharko
- ★ The "Bare Your Brace" initiative was re-launched with a brand new website. Bare Your Brace encourages people with CMT who wear leg braces to embrace their differences by "baring" their braces. People from all across the globe sent in photos of themselves "going bare." You can see the fabulous collection of pictures at www.bareyourbrace.com. Join the movement!
- ★ During awareness month, over 2,000 new patients and supporters connected with us.
- ★ We were able to reach hundreds of thousands of people through social media with important information about CMT.
- ★ We announced the exciting release of materials in Spanish! www.cmtausa.org/espanol
- ★ We announced the Sanofi-Genzyme partnership to find treatments for CMT1A! (*See page 1.*)

The CMTA would like to thank you ALL for being part of this month and for supporting the CMTA! And, just because September is over doesn't mean you should ever stop spreading the word about CMT. Together, we can, and will, continue to make an irrefutable difference in the lives of many living with CMT every moment of every day. Until next year!

—Jeana Sweeney and the Whole CMTA Team

Exercising with a Zero-Gravity Treadmill

My name is Neil Rappaport. I was diagnosed with CMT1A in 2011 by a DNA test. I had had CMT for many years, but I treated it as just a slowness of function in my hands and feet. I am now 68 years old and retired.

About three months ago, while on a visit to my neurologist, she suggested that I might consider some exercise for weight loss which has always been a problem for me, largely because of my limited mobility. She suggested trying a zero-gravity treadmill. She gave me a keyword to search on my computer, and I found such a treadmill made by a company called by Alter-G. I hit the locator button and found a location in my neighborhood.

Neil Rappaport tested the zero-gravity treadmill in his physical therapist's clinic and is now using it twice a week to get a cardiovascular workout.

I went to my physical therapist's office and they answered a few questions I had, like have you ever used this for CMT patients before? (Of course, the answer was "no.") Then they suggested a live demo and asked me to try it with my AFOs on for walking.

I thoroughly enjoyed the walking experience and asked if the machine could be turned up for running. They started me off at about a 3.0 mph pace and I saw myself, for the first time in well over 30 years, running. My good friend who looks out for my health and fitness joined me at the appointment. He saw a huge smile on my face and an ecstatic expression of accomplishment. I immediately went back to my neurologist's office, hugged my neurologist ,and requested a prescription to use the zero-gravity treadmill at the physical therapy clinic.

Now I am going twice a week, and each day I have increased my run speed. I'm now up to 5.0 mph and I've reduced the anti-gravity component to 48 percent of my body weight. I am currently running for 15 minutes. My physical therapist helps me with warm-up exercises and balance training.

This exercise device has created a happier, healthier life style for me. I get a great aerobic cardiovascular workout, and I am losing some weight as well. This recent find has made me very enthusiastic, so I want to share this experience and perhaps help others dealing with CMT. Feel free to contact me via email: neilrappaport@me.com ★

Always check with your health care provider before beginning any new exercise program.

4TH ANNUAL FERGUS FUNDRAISER HELD ON SEPTEMBER 28TH

I truly cannot express in words what the event day meant. So many inspiring people participated. The 4th Annual Walk for CMT was held on Sunday, September 28th, at Victoria Park in Fergus, Ontario, Canada. The beautiful, sunny fall day brought out 110 participants who spread awareness to their circles of friends and their families and raised $8,500 for CMT. A big thank you to all of our sponsors this year and to everyone who helped with the event! We look forward to next year! —*Holly Stevens*

CMTA Member Spotlight: Iris Anderson

As a young girl growing up in Queens, New York, Iris Anderson was "clumsy, slow, and not good with a ball." She dreaded gym class. As a teenager, she had trouble with high heels, finding them "painful and difficult." With feet and hands that hurt at times, Iris knew she was different from other children, but chose not to dwell on it.

At the age of 29, Iris visited a Manhattan foot specialist, who instantly diagnosed her with Charcot-Marie-Tooth. Iris was pleased to have a diagnosis, but she was not so pleased when her doctor took her to an event where her feet were photographed and she was placed on a stage while doctoral residents noted the shape of her toes and the curve of her arches.

Once diagnosed, and after a surgical release on each foot, Iris's doctor insisted that she wear leg braces. The braces were made of thick, heavy plastic, with straps in front. They were, in a word, "horrible," and Iris found wearing them very depressing. After a few days of navigating busy New York City in her cumbersome new braces, Iris secretly threw them down the chute leading to the incinerator in her apartment building. She told herself that she could manage without them, and fortunately, she was able to do just that.

In 1979, Iris and her husband moved from New York to Bethesda, Maryland, where Iris worked for a government contractor as an information specialist. Some years later, Iris and her husband bought, and moved into, a 100-year-old Victorian farmhouse in Damascus, Maryland, determined to become loofah farmers. Unfortunately, the loofah didn't fully ripen, the long commutes to their day jobs were exhausting, and the adventure eventually ended in divorce.

After struggling with finances and life as a single woman, Iris found work as a reference librarian at the World Bank/IMF Library in Washington, DC, where she eventually became head of the Research Department. Fearing the loss of her job or her health insurance, Iris remained "undercover" about her CMT for much of her career. When she applied for long-term care insurance at the age of 52, her application moved right along until it was discovered that she had CMT, and they "dropped her like a hot potato." Work as a manager at the IMF was demanding, with long hours and frequent meetings. There were also professional library conferences and travel, and many days Iris would come home from work and "just collapse." But Iris is proud of the work that she did during her career, and she never let her CMT define who she was or what she did. Slowly, as her gait became more impaired, she began to tell a few colleagues about her CMT. None of them had ever heard of it, but everyone was sympathetic.

Today, after a 35-year career, Iris is retired, financially secure, happily remarried, and feeling very lucky despite the progression of her CMT. Iris credits yoga, swimming, and water exercise classes for helping her maintain flexibility and strength. She describes her life with CMT as being a series of tipping (and tripping) points as her condition has worsened. In the past two years, she has experimented with braces again and recently purchased a pair of Allard Blue Rocker AFOs with which she is very pleased. She has also added a cane for balance as needed.

Iris confides that her secret weapon for surviving and thriving with CMT is her husband of 24 years, Lynn Thomas. He has been very supportive and has kept her laughing at her mishaps. Prior to the creation of the CMTA, Iris received information and services from the MDA. She joined the CMTA shortly after its formation, and has been a member and strong supporter for more than 10 years.

—Clark Semmes

After decades of dealing with CMT, Iris is enjoying retirement with her supportive husband.

IF YOU KNOW SOMEONE who would be a good subject for a CMTA member spotlight, please contact Clark Semmes at 410-350-4812 or clarksemmes@gmail.com.

CMT Patient Takes Pride in Her Triathlon Triumph

Editor's note: This piece was submitted by Robin Schock, the proud mother of the young woman who posted it on Facebook.

I don't normally write much on Facebook, but I want to share something and hopefully it will reach someone who needs to hear it.

If you were to call me an athlete six years ago, I would have laughed at you and secretly wished inside it was true. A bright light lit up today for me because I completed my first triathlon. I was in a room full of athletes and was overwhelmed. I didn't know my body was capable of such an athletic feat.

Backing up a bit: As a child, I was diagnosed with CMT (Charcot-Marie-Tooth), which is a type of neuromuscular disease. My doctor or my mom could explain it better than I can, but growing up this is how I understood it: My body had to work harder to do simple things like run and do coordinated tasks. I am blessed that physical therapy helped a great deal by putting me in plaster casts to stretch my heel cords. I felt like everyone could see that I was different, and I stuck out every time I tried anything "athletic." I saw being an athlete as a high privilege—to be able to run, jump, dribble, skate, or do whatever physical activity with ease. I envied those who took their athletic talent for granted. As I grew up, I figured out that my jealousy was fruitless, and I should focus on other things. I was a gifted student, musician and artist. Was that enough? Deep down I still had that desire to be fit.

I started small. I entered a triathlon as a part of a relay team in 2008. I did the bike portion. I participated in floor hockey at my university and our team won the championship in 2010. I ran/walked the 5K Teen Challenge charity event in 2012. I ran the whole 5K in the same event in 2013. I decided to up the ante and go all out. I would compete in a triathlon in 2014. I trained from May 2013 to August 2014.


Rachel learned that you don't know what you're capable of unless you try.

Race day arrived. On August 17th, at 7:00 am, I pulled into CONA in Gander, Newfoundland, and took a deep breath. I was actually going to do this—swim 750m, bike 20km and then run 5km. I could do all three separately, but could my body handle the stress of doing all three back to back? Yes it could. Who knew!

I give God all the glory. How many times did I pray for God to give me the strength and the determination to see this goal through? I walked away from the race with one major lesson learned: You don't know what you're capable of until YOU TRY. And I don't mean try to complete a mammoth movie marathon. I mean try something that has the possibility of pushing you to your limit—mentally, physically, and emotionally. What is that for you? Why haven't you done it yet? For me it was an athletic goal that induced fear and overwhelming doubt. My whole childhood could have proved to me that a triathlon was out of the question. God changed my heart and mind by taking me through small goals and dreaming about the unthinkable.

I say none of this to pat myself on the back. I say all of this so you will see yourself in a new light. Where have you been holding back? It's time to make a change. I am an athlete. Who might you be?

—Rachel Schock

GIFTS WERE MADE TO THE CMTA

IN HONOR OF:

MY THREE CHILDREN
Ms. Sommone Ray

MEL & RACHEL BERRY
Ms. Shuli Tor

JONATHAN & LAURI BEY
Ms. Sandra Reid

GRACE CALDARONE
Ms. Katherine Gibson

MARIA CALZADA
Mr. Alberto Ortega

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

Honorary Gift:
In honor of (person you wish to honor)
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Send acknowledgment to:
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Address:________________________
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Occasion (if desired):
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☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____
Send acknowledgment to:
Name:__________________________
Address:________________________
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Amount Enclosed: __________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card #____________________________
Exp. Date _________________________
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Gift Given By:
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★ RAISING FUNDS AND

Peaks Island Walk for CMT

The Second Annual Peaks Island Walk for CMT was held on Sunday, September 21, 2014, on beautiful Peaks Island, Maine. In true New England fashion, the weather was what most would call unpredictable, starting with heavy rain showers all morning prior to the event. Luckily for us, the sun came out and graced us with its presence in time for all of our event walkers to enjoy the delightful ferry ride over to the island and for the excitement to build to walk for CMT!


Megan Webster, Mary Louie and Kathryn Flynn showed off their Peaks Island Walk T-shirts before the event began.

Our event began again at the lovely Inn at Peaks Island under a wonderfully decorated tent where our registrants could check in and get their 2014 Walk for CMT T-shirts and water bottles. They could also see the new custom Aidbands made by the Walk's newest sponsor and local business. The Aidbands promote the Walk and the CMTA in a fun, new way.

The Walk began with quick opening remarks and many "thanks." Our walkers (and some runners!) left the Inn and continued around the Island for four miles where they took in the magnificent views of the Maine coast and its "calendar islands." As walkers returned to the Inn on Peaks after completing the walk, a reception was held with appetizers, cocktails, a silent auction and lots of laughs and excitement.

Our silent auction this year kept with our local theme with lots of wonderful items donated from large and small businesses in the greater Portland area. In only our second year, we nearly doubled the number of registered walkers to 82, and we are proud to say we raised $2,500 to go directly to the CMTA! With each passing year, we continue to gain more and more support from local businesses and individuals who are interested in learning more about CMT and ways they can help, whether through participating and raising money through our Walk or other means. We would like to say thank you to all who supported us and continue to do so as we grow our event each year! We would also love to extend a warm invitation to anyone who would like to join us next year in the gorgeous state of Maine for our Third Annual Walk for CMT. We know it will be another record breaking year for us.

—Mary Louie

The CMTA Fishing Team

Joel LoDolce (Cape Coral, FL), Patty Bolton (North Fort Myers, FL) and Ellen Eagle (Cape Coral, FL) worked hard to put together an idea Joel had for raising awareness for CMT during CMT Awareness Month. On September 20th, we had our 1st Annual CMTA Shark Fishing Tournament.

It rained all week and the skies were ominous. Joel announced that the two boats scheduled to take out our team would not be coming. We tried contacting other fishing captains, but no one was going to go out in the weather. One captain recommended that we cancel and reschedule. Living with CMT, we have learned that quitting is not an option. If anyone knows what it's like to persevere, it's someone with a disability.

A friend came with his team and was able to fit the rest of the men on his boat. Once we had the team out, it was time to set up for lunch and raffles. A half hour after our fishermen and women left, the heavens opened and it rained hard for over an hour. When the skies cleared, we set up for lunch. Several out-of-town guests had heard about our tournament on the CMTA Facebook page. One family had a son, Anthony, age 13, the first person in their family who was diagnosed with CMT. Another couple traveled several hours to support us. Karen was diagnosed a few years ago and her brother and nephew, who also attended the fundraiser, were newly diagnosed as well.

We shared our stories and gave out the CMTA pamphlets and bracelets. Joel took a few landlovers along with our new friend, Anthony, and fished off the bridge. We had over 40 people show up for lunch. Our fishing teams returned wet and hungry. We had lunch, gave out prizes and raffled off some great gifts. No sharks were caught, but it was a great time for CMT friends and family to come together in fellowship and fun. Only having three weeks to put this together, we worked hard to make this happen. It was a glorious day, and we raised over $1,000 to go toward research.

Joel is excited to get started on the 2nd Annual CMTA Shark Fishing Tournament next year.

—*Ellen Eagle*

Hartford CT East Support and Action Group Bowling Fundraiser

A fundraiser was sponsored by the Hartford CT East CMT Support and Action Group on September 20th from 2:00 to 4:00 pm at Bradley Bowl in Windsor Locks, CT. Posters advertising the event were distributed to stores and medical facilities around the greater Hartford area, and articles were published in the *Hartford Courant* and *Journal Inquirer* newspapers.

In attendance were 33 bowlers and many CMTA friends and families to cheer them on. The bowling tickets netted $330 for the CMTA. A raffle was held after the bowling for gift certificate prizes donated by 15 local merchants. The raffle netted $160 for the CMTA. Many members and friends of the Hartford CMT Support and Action Group were not able to bowl but generously donated to the fundraiser, resulting in a total donation to the CMTA from all sources of $2380.

The Hartford SAG is especially glad to donate this money to the STAR research initiative in light of the recent announcement of a CMTA partnership with Genzyme to develop a treatment for CMT1A. Besides the money that was raised, this was a fun event bringing many extended family members and friends together in an enjoyable social sport.

My thanks to all who participated, and special thanks to my wife Diana and my co-facilitator Jeff Beyer for their great assistance.

—*Roy Behlke (Facilitator)*

Attendees at the Hartford Bowling Fundraiser came in all sizes and ages and enjoyed both the raffles and the bowling matches.

Individually, we are one drop. Together, we are an ocean.

From our partnership with Genzyme, the CMTA hopes that our investment will generate resources to invest in further research for other types of CMT. And, we are currently exploring partnerships with four other pharmaceutical companies to replicate this model. We will not stop until we have found treatments for all types of CMT!

This is what the future looks like for CMT and the CMTA. This is possible now because our community is funding this work. You, a person with a deep connection to CMT and a current contributor to the CMTA, have helped to fund the research for CMT.

- *You have helped us develop a validated strategy for drug delivery for 90 percent of all CMT.*
- *You have helped us assemble a team of world-class researchers and clinicians.*
- *You have helped us build cellular lines for three types of CMT.*
- *You have helped us build laboratory models for two types of CMT.*
- *You have helped us build human cell lines for 1A derived from adult skin and blood cells.*
- *You have helped us build tools to measure the progression, and the potential reversal, of symptoms associated with CMT.*
- *You have helped us establish 17 CMT Centers of Excellence worldwide.*
- *You have helped us build a patient registry, preparing us for human trials.*

Please drop in your 2014 contribution today....

You are the reason we have reached such significant milestones, and you enable us to realize our dream of providing treatments for CMT! If we rely only upon government funds, large donors' support and academia to fund research, we will wait much, much longer. I haven't waited for someone else to fund CMT research and neither have you. Thank you!

But, we are not done yet. The search for treatments for CMT still needs your help. We still rely upon the financial support of the CMT community to fund our work and progress. **Every gift makes a difference.** Please consider a gift of $8 a month ($100 annually). If every American living with CMT were to make such a commitment, we could dedicate $12.5 million to research, thus dramatically accelerating the pace of drug discovery for CMT!

The CMTA promises to fund projects that demonstrate success and to fund researchers who have a proven track record of success and have shown expertise in their field related to CMT. We promise to fund projects in small increments, ensuring the highest efficiency of your donation. We also promise **complete transparency** in the allocation of all funds. Our 4-star rating by Charity Navigator demonstrates the responsible allocation of every dollar donated to the CMTA.

The leadership of the CMTA personally donates over $1 million every year to the CMTA. Therefore, we promise fiscal efficiency and complete transparency with your investment.

So … if you are ready to end CMT … if you want to change the course of CMT for people living with it today and … if you share our vision of a world without CMT for future generations, please join me in giving to the CMTA in 2014 by either going online to www.cmtausa.org/mygift or by completing and mailing in the attached form with your check.

Thank you for your support!

Patrick Livney

My 2014 Gift to the CMTA

YES! The children and families affected by CMT can count on my tax-deductible contribution to accelerate research for treatment for CMT. Please accept my gift in the amount of:

○ $25
○ $50
○ $100
○ $250
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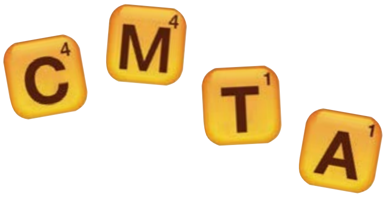
Kyle Thomas and Pam Palmer Score Big in the 2014 CMTA Words With Friends World Cup Tournament!



Congratulations to Kyle Thomas and Pam Palmer for their performances in the 2014 *Words With Friends* World Cup Tournament. Kyle Thomas won the event, beating out 31 other players over the course of three months to claim the championship and the accompanying prizes ($100 Amazon gift card and a Charcot-Marie-Tooth T-shirt). Pam recruited the most new players to the tournament, claiming prizes that included a $50 Amazon gift card and a Charcot-Marie-Tooth shirt of her own.

Kyle Thomas heard about the tournament from his aunt, Iris Anderson, a longtime member of the CMTA. Iris urged Kyle to enter the tournament, believing that Kyle's love of Scrabble and crossword puzzles might give him the skills needed to beat out his competitors. In the championship game with Carol Andrews, Kyle needed all his skills to squeak out a win. His big break came when he laid down the word HASTENED over a triple word space for a total score of 88 points.

Kyle lives in Noblesville, Indiana, and is the proud father of Dominic, who recently celebrated his fifth birthday. When not playing *Words With Friends*, Kyle can usually be found practicing the piano, performing a play or musical, walking dogs for the Humane Society, or on the local trails going for a long-distance run.

In addition to Kyle Thomas and Carol Andrews, participants in the tournament included three members of the Palmer family (David, Pam, and Brandon). Thanks to all these folks, the tournament brought in $800 for Charcot-Marie-Tooth research (STAR), which then was matched by the Star Power Challenge, netting $2400 for the CMTA!

Thank you to everyone who participated, and look for a new *Words With Friends* tournament sometime this winter!

—*Clark Semmes*

2014 Reach for the STARs Walk & Roll for the CMTA

The Chicago Area CMT Support & Action Group sponsored the 5th Annual Reach for the STARs Walk & Roll for the CMTA on Saturday, September 20, 2014.

The walk took place at Lake Katherine's Botanic Gardens & Nature Center, which is a beautiful location with a one-mile scenic walk around the lake.

Every year more members are getting involved in the planning, and we had a great team this year working to make our Walk & Roll a success! Susan Moore, the Southeastern Wisconsin CMT Support and Action Group Facilitator, was part of our team along with some of her support group members. Susan and her husband drove all the way from Wisconsin to the Chicago area for the walk bearing gifts to be used in the raffle. What an awesome sight it was having everyone working as a team, setting up all the breakfast goodies, decorating, selling T-shirts and raffle tickets. (And wow ... did we have the raffle items!) I could not have been happier seeing how many people went out of their way bringing items to place in the raffle! We even had homemade apple pies in the raffle.

When I first started the walk nine years ago in honor of my son Tyler who has CMT, it was just my family and friends. Once I became a CMT Support and Action Group Facilitator, the other members became involved and the Reach for the STARs Walk & Roll was born. It has just been amazing watching it grow each year with all the members involved and now their families and friends.

We were blessed with wonderful weather and an incredible turnout of over 125 people … just too many to count! So many were representing the CMTA, wearing the T-shirts and carrying signs while on the walk. We were all spreading the word! People not affiliated with the walk around the lake were asking about CMT, and we were happy to explain it to them.

Pat Livney joined us and gave everyone an update on STAR and the new partnership that was just formed with Genzyme. Incredible and promising news for us all! We are so fortunate to have him leading the way. I know each and every person appreciated hearing the research news, knowing that drug companies are helping us and supporting our cause.

We surpassed our fundraising goal and have reached $11,000, with more company matches on the way!

Thanks so much to all the wonderful members who were involved and their families and friends. Working together, we can make a difference! —*Dale Lopez*

Participants in the Walk and Roll enjoyed the scenic walk around the lake and raised $11,000 in the process.

Bicyclists Explore Vermont in First Annual Cycle 4 CMT™

The fall foliage was peaking on October 11th as more than 40 bicyclists gathered in the picture-perfect town of Richmond, Vermont, for the First Annual Cycle 4 CMT. Organized by Chris and Mia Ouellette in honor of their nephew, Yohan, the Cycle 4 CMT offered a choice of bicycle routes (5, 20, 45 and 55 miles), allowing folks at every level of fitness to enjoy the gorgeous Vermont countryside while raising money for CMT research.

Bikers from left to right: Clark Semmes, Steve Weiss, Steve O'Donnell, Sherri O'Donnell and Gene Rosengarden

Nestled in the rolling hills of beautiful Northwest Vermont, the tiny town of Richmond, with its round church and abundant bakeries, embodies every romantic notion of small-town America. With the rolling hills painted in autumnal tones of red and orange, the town and its surrounding hills set the perfect backdrop for a day of cycling. Gathering throughout the day at the Cochran Ski Lodge just outside of town, small packs of cyclists departed at various times to enjoy the foliage and the out-of-doors. Well-marked trails wound through well-kept farms and the rolling hills that draw cyclists to this area from near and far in the fall.

Following the morning's outdoor recreation, cyclists and supporters returned to the ski lodge for an afternoon of barbecue, live music, and camaraderie. Well-packed goody bags, courtesy of a long list of sponsors, ensured that no one went home empty handed. The highlight of the afternoon was the surprise appearance of Yohan Bouchard. Told that the guest of honor was home in California studying for a test, Yohan hid behind stage until his mother cleverly announced his presence. Striding from his hiding place, Yohan's presence underlined the theme of family love and generosity that ran through the entire weekend and brought almost everyone in the room to tears.

Dedicated to Yohan Bouchard, the Cycle-4-CMT hopes to raise funds for CMT research so that people like Yohan who suffer from CMT will one day be able to enjoy all of the outdoor activities so many of us take for granted. Thanks to the efforts of the Ouellettes, the Cochrans, and all the cyclists and supporters, the First Annual Cycle 4 CMT raised over $50,000 for the Strategy to Accelerate Research (STAR) program and the CMTA. Based on the success of this event, plans are already underway for next year's ride. —*Clark Semmes*

GRILLIN' AND CHILLIN' FOR STAR

On a beautiful September evening, more than 125 people gathered for the Southern Connecticut SAG's "Grillin' and Chillin' Fundraiser" benefiting the CMTA's STAR program. As the sun set beyond the 18th hole, family and friends enjoyed BBQ and craft beer on the New Haven Country Club's patio while listening to lively tunes provided by two local musicians.

Several people attending won some great raffle prizes—an iPad mini, suite tickets for the circus, an overnight stay at the Mohegan Sun Hotel, tickets to the University of Connecticut vs. Yale University men's basketball game and a J. Crew gift card. In addition, silent auction items up for bid included tickets to a NY Jets game, a Yankees/Red Sox game at Yankee Stadium, a Red Sox game at Fenway Park and a round of golf for four at the New Haven Country Club. One family went home $350 richer when they won the 50/50 raffle.

The event was a terrific way to celebrate CMT Awareness Month, and the best part was that it raised $10,000 for STAR! —*Lynne Krupa*

THE CMTA "CIRCLE OF FRIENDS"

Start the new year by creating your own fundraising Circle of Friends! Have your family and friends donate money to the CMTA on behalf of a birthday, anniversary, or special occasion. Need help getting started? You can email Jeana Sweeney at: jeana@cmtausa.org. Working together, we can create a world without CMT!

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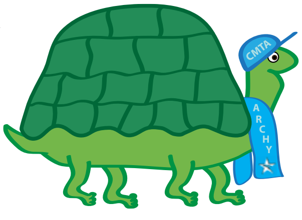
Tis the Season

Our English teacher is well known for her campaign to make us all more civilized in our thoughts and behavior. To that end, she decided to teach us the meaning of altruism and to then require us to put the principle in motion in our own life.

So, do you remember what altruism means? My parents said there used to be an award at their high school at the end of the year for the most altruistic student. Well, simply defined, altruism is selflessness or the practice of showing concern for others. Some philosophers say that service to others is the justification of life and that generosity and good deeds are what make life worthwhile.

I understand the premise of this concept, but the problem for me was how exactly I would put it into practice in my own life. This is definitely the season of giving, but most of us give to a charity or cause that is somehow connected fairly directly to our own life. For instance, my parents give to the CMTA and to the American Cancer Society because my Dad's father died of pancreatic cancer and, of course, I have CMT.

I wracked my brain to come up with some worthy deed that would allow me to remain anonymous because good deeds that are done completely unselfishly are those that are done without any praise or compliment coming back to the giver. We have a deer in our class at school who was shot in the woods last fall. She can't walk up the steps to her house anymore and so I decided that constructing a ramp for her would be a good deed.



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

It's probably important to reveal that I'm not good at wood shop and that I am not very dexterous. That being said, I am good at talking people into doing things to help me and so, my shop teacher, Mr. Beaverton, said he would get a group together to get the job done. I got her family to go on a weekend trip to visit her grandparents by convincing her grandparents to help with the plan. I told you … I'm good at talking people into things.

On the appointed weekend, we were blessed with pleasant weather, and the crew my shop teacher assembled were good workers. My job was to take tools to people and to get snacks and drinks for everyone. In just two days, we had a very nice-looking ramp assembled and installed at the Elkhart's home. We dutifully disappeared without any evidence of our having been there other than the new ramp.

The family was very surprised and did their best to find out who had done the work, but no one said a word. I discovered that the philosophers are right: good deeds and altruism are absolutely the elements of a worthwhile life. Not being publicly thanked, but knowing how much the ramp means to that family has made me feel incredibly good. Give altruism a try! ★

INTRODUCING THE CMTA STAR BANGLE

Show your support for CMT research by wearing a custom CMTA STAR Bangle! The Rhode Island CMT Support and Action Group worked with custom jeweler Magnetros to create a one-of-a-kind bracelet to raise money for the STAR research program. The bracelet features blue beads in honor of CMT awareness, spacers with the words "Courage" and "Strength," and three special charms: a dragonfly for prosperity and perseverance, the CMTA STAR, and an anchor for hope. The bracelet is finished off with a special stone for rejuvenation. The bangle comes in three sizes—small, medium, and large.

These bracelets are not only beautiful, but they are a great way to raise awareness and support our STAR (Strategy to Accelerate Research) program. Magnetros is generously donating 50 percent of the proceeds of each sale back to the CMTA.

Please visit www.magnetros.com/custom-designs/cmta.html to order your bangle!

Rethinking Dressing

BY SUSAN SALZBERG, ADVISORY BOARD MEMBER AND FORMER OCCUPATIONAL THERAPIST

"The only constant in life is change."
—Heraclitus

You can count on change! In my experience, the most effective way to deal with change is by adapting. Every living being must adapt to the decline in ability that inevitably takes place over the years. Having CMT means we must deal with this change at a younger age and in more specific ways. Our specific areas of decline include limited mobility and weak hands (and arms). To counteract these limitations, we need to adapt our actions and our environment so that we do things more efficiently. In the field of Rehabilitation Medicine, these adaptations are referred to as "Work Simplification and Energy Conservation."

The topic of Work Simplification and Energy Conservation deals with multiple areas of our lives: organizing our home, doing daily household chores, attending events outside the home, and perhaps even sleep hygiene. I will discuss adapting clothing and dressing.

Appearance is a matter of personal taste. How we achieve the "look" we present to the world often involves long-standing habits and routines. But if our manual dexterity and strength diminish so that self-care becomes more difficult, we may need to rethink the methods by which we accomplish our personal hygiene and dressing. If some of these suggestions seem radical, perhaps they are not for you. They are meant to spark your thinking about your particular situation and give some insight into how you weigh your priorities. How you balance the time and effort it takes versus the outcome you hope to achieve is up to you, but the bottom line is, "Is it worth it?"

Delegate: You may not need adaptations if you have someone available at home to help you dress and groom.

Use tools: Try using dressing aides such as buttonhooks, Velcro, zipper pulls, shoe horns, etc., but be mindful that for some of us, these devices may be difficult to handle or require more energy than they are worth.

Redesign:

- *Zippers:* Try wearing elastic-waist pants.
- *Buttons:* Sew your shirt closed except for the top few buttons and wear your shirt as a pull-over.
- *Pullovers:* If you have difficulty, see if the next larger size will meet your needs. Consider knits or other stretchable fabrics.
- *Shoes:* Velcro is the obvious answer here. Check out "soft" shoes that are marketed to diabetics—Propet is one brand—but be aware that the foam insoles on some of these shoes may make your balance worse.
- *Earrings:* For pierced ears, try wearing a simple loop that can stay in for a while—in my case for months!

Eliminate: As a person whose goal is to be as close to no-maintenance as possible, this is my favorite method.

- *Hair:* Keep it as short as is feasible for you and your sense of style. If you don't need to, don't dye it.
- *Bras:* If no one can tell, you don't need to wear one.
- *Underpants:* Again, if no one can tell, do without.
- *Dresses:* Think of a dress that hangs from the shoulders or bodice. If it is made of a substantial material, it may be the only item of clothing you need (except for footwear).
- *Athletic Clothing:* Sweatsuits are ideal for cool weather. Men's swim trunks have built-in mesh underwear and can be worn instead of traditional shorts.
- *Shoes:* If you spend most of your day in a wheelchair, decide whether it is important to wear shoes or if soft footwear (slippers or slipper socks) will do.

If this topic is interesting to you, please join the OT and CMT group on www.cmtausa.org and add your comments and suggestions! We can all benefit from each other's experience.

"I don't know where I'm going from here, but I promise it won't be boring." —David Bowie

Splinting Options for CMT

BY TIM ESTILOW, OTR/L

The hand is very complex in its structure and function. There is a delicate balance between the large extrinsic and smaller intrinsic muscles which work together to allow for precise movement of the thumb and digits. In CMT, it's these small intrinsic muscles of the hand that are impaired, disrupting the balance within the hand and impacting intricate thumb and digit movement, limiting the ability to complete activities of daily living (ADLs) such as: buttoning clothes, zipping a jacket, picking up money, writing, opening containers, grasping snacks for self-feeding, tying shoes, and fastening jewelry. In a recent survey, 97 percent of adults with CMT reported having weakness of the hand and fingers,[1] and it's been shown that ADLs often rely on hand strength[2] and functional dexterity.[3] This weakness is often present in early childhood as well. Children spend a large proportion of the school day (up to 60 percent) engaged in fine motor activities[4] and most ADLs require fine motor manipulative skills.

The progressive nature of CMT combined with the risk of disuse atrophy makes it important to identify ways to maintain soft tissue integrity and utilize intact muscles during daily life. Participation in therapeutic activities to strengthen muscles, mobilize joints, and refine sensorimotor control is important throughout the patient's lifespan and may be combined with the use of upper extremity splints to prevent further deformity/contracture, improve positioning, and enhance hand function for ADLs. Upper extremity splints can serve many purposes, and it's important to discuss the options with an occupational or certified hand therapist to identify the appropriate orthotic for a patient's specific needs. Splints can be custom-molded out of a thermoplastic material or measured and custom-fabricated from neoprene. They can also be ordered as "off the shelf," but everyone's hands are unique, and it's preferred to have a custom-molded/measured device to meet a patient's needs whenever possible.

Figure 1: Nighttime splinting

Nighttime splinting of the lower extremity for heel cord contracture is common in CMT, and similar options exist for the upper extremity. Nighttime splinting may be effective to position the wrist and fingers to prevent contracture, overstretching of muscles, and maintain soft tissue integrity. The intrinsic plus splint *(Figure 1)* positions the hand with the wrist extended, MCP joint flexed, PIP and DIP joints extended, and the thumb in opposition. This prevents shortening of the wrist flexors (common in wrist drop) maintains flexion of the MCP joint (most stable positon for the joint), prevents overstretching of the intrinsic muscles (occurs during clawing position), and maintains the thumb in opposition to reduce risk of web space contracture. The splints can be worn overnight, as the hands are not needed during sleep, but should not be used during the day, as they prevent movement of the hand. If contractures are already present at the wrist or

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[1] Johnson NE, et al. Quality-of-life in Charcot–Marie–Tooth disease: The patient's perspective, Neuromuscul Disord (2014), http://dx.doi.org/10.1016/j.nmd.2014.06.433

[2] Selles RW, van Ginneken BT, Schreuders TA, Janssen WG, Stam HJ. Dynamometry of intrinsic hand muscles in patients with Charcot-Marie-Tooth disease. Neurology 2006; 67:2022–7.

[3] Miller MJ, Williams LL, Slack SL, Nappi JF. The hand in Charcot–Marie-Tooth disease. J Hand Surg [Br] 1991; 16:191–6.

[4] McHale K, Cermak SA. Fine motor activities in elementary school: preliminary findings and provisional implications for children with fine motor problems. Am J Occup Ther 1992; 46:898–903.

[5] Videler AJ, Beelen A, van Schaik IN, Verhamme C, van den Berg LH, de Visser M, et al. Tripod pinch strength and thumb opposition are the major determinants of manual dexterity in Charcot-Marie-Tooth Disease type 1A. J Neurol Neurosurg Psychiatry 2010; 81: 828–833.

fingers, serial casting is an effective intervention to reduce the degree of contracture, and a splint can be fabricated following casting to help maintain the newly gained range of motion.

In addition to maintaining soft tissue integrity with a nighttime splint, there are some good options to help facilitate functional hand use during the day. There are various splint options that can place the hand and digits in a more biomechanically appropriate position, block positions of deformity, and facilitate grasp patterns that are otherwise unable to be performed. For wrist drop, a basic wrist cock-up splint *(Figure 2)* can help maintain a neutral to slightly extended wrist position which allows for improved grip strength to maintain grasp on objects for ADLs. Ulnar clawing *(Figure 3)* increases the risk of PIP flexion contractures, limits the ability to fully open the hand in preparation for grasp, and impacts the ability to flex the ring and small fingers at the MCP joint for activities such as typing, playing musical instruments, and grasping bottles, cans, and other large objects. An ulnar claw splint *(Figure 4)* blocks the MP joint into flexion, preventing hyperextension, and redistributes the force to allow for full PIP extension *(Figure 5)* for grasp and manipulation of objects while reducing risk of PIP joint contractures.


Figure 2: Wrist cock-up splint

Limited thumb mobility and strength is very common in CMT, and the inability to oppose the thumb is a strong determinant of manual dexterity[5] and can severely limit hand function. The thumb provides an opposing force to the fingers to maintain grasp on a cup, to shift keys around in the hand when searching for the car/house key, to type text messages on a cell phone, and to grasp and manipulate tools and other common objects. The Benik and Mckie splints *(Figure 6)* allow the thumb to be positioned in varying degrees of abduction and opposition to improve grasp and manipulation and have been shown to improve occupational performance as well as satisfaction with quality of life.[5]

When considering upper extremity orthotics, it's important to consult with an occupational therapist or certified hand therapist. The presence of contractures, the ability to actively move the wrist and fingers, and the patient's grasp/pinch strength and manual dexterity are all factors that need to be considered to select the appropriate positioning, material, and type of splint. In addition, it's extremely helpful to have specific goals in mind for the therapist (for example, maintain grasp on a crochet hook, open hand to catch a basketball, stabilize a bottle in hand to twist off the cap, etc). This will allow the therapist to consider unique needs and to possibly even test the splint to see how it enhances function and improves the quality of life with everyday tasks. ★


Figure 3: Ulnar clawing


Figure 4: Ulnar claw splint


Figure 5: Ulnar claw splint


Figure 6: Thumb splints

SUPPORT AND ACTION GROUP NEWS

• AZ – Phoenix Area
The group met on September 20th and had 18 in attendance, including Jeff Smith from Allard, USA. The group welcomed Matt and Paulette Hunt, Cliff and Matt Sooter, and Liz Ramadan as new members. Topics discussed included webinars, CMT updates, the conference at Stanford, iGive, and future meetings.

• CA – Orange County
The September 27th meeting was incredibly informative. Meredith Jones and Kathy Hall from UCI Health and Shawn Panich from GeneDx served as guest speakers. They provided a 2-hour overview of genetic counseling and testing options. Two new families joined the meeting along with three returning attendees from the July meeting.

• CT – North Haven
The group welcomed Carolyn Ball, a neurology product specialist from GeneDx, to their September 4th meeting, and the presentation she gave was very informative. The group learned about GeneDx's testing panel for CMT and the insurance issues related to it. Carolyn answered many questions from the members in attendance. On September 26th, the group's Grillin' & Chillin' fundraiser was held at the New Haven Country Club. More than 100 people enjoyed BBQ, beverages and some great music. The amount of money collected was in excess of the $5,000 goal set.

• FL – Tampa Bay Area
There was a nice turnout for the meeting on September 27th, including two new members. Marc Savelis, a GeneDx neurology product specialist, arrived with new information about CMT genetic testing and an array of tasty snacks to fuel attention. Reasons why it is important to find your genetic sub-type included: helping avoid move invasive testing, such as muscle and nerve biopsies to diagnose CMT, assisting in understanding the prognosis of CMT, helping avoid certain medications, offering family members choices in family planning, and helping when treatments are developed. Dr. Rosario, a neurologist at St. Anthony's Neurology Clinic, made a surprise visit. He shared his eagerness to work with CMT patients. He just completed a neuromuscular fellowship at Duke University and is knowledgeable about all types of neuromuscular diseases, including CMT. Also discussed were the yoga class, CMT webinars, the Bare Your Brace community on Facebook, and the International Patient Registry.

• GA – Atlanta Area
Susan Ruediger discussed CMT Awareness Month, plans for the picnic, news regarding the iGive website, and the new pediatric neurologist at Scottish Rite who is interested in the CMTA and helping children manage the transition from pediatric to adult care. She also described how research is underway at the University of Miami. The feature presentation was given by David Keane of GeneDx. He noted that GeneDx testing covers 29 known CMT genes and discussed why genetic testing is important, the importance of gathering as much family history as possible, and insurance coverage.

• MA – Boston
The CMTA's CEO, Patrick Livney, spoke at the Boston SAG meeting for September Awareness Month at Brigham & Women's Faulkner Hospital. Lynne Krupa, facilitator for Connecticut, and Mary Louie, facilitator for Maine, joined many of the Boston members for an informative and fun night. Mr. Livney spoke about the STAR projects, the effectiveness of the CMTA's consortium of clinicians and researchers and the new CMT Center of Excellence at Mass General Hospital. Also joining the meeting was Dr. Vera Fridman, a neurologist working at the CMT Center of Excellence, and Dr. Chris Chiodo, an orthopedic surgeon at Brigham & Womens Hospital. Special thanks to Linda Burgoon for helping with all the details and the beautiful conference room.

(continued on page 27)

CLIMBING MOUNTAINS TOGETHER TO RAISE MONEY FOR THE CMTA

On September 27th, the Las Vegas Support and Action Group, along with many caring hikers, traveled northwest of Las Vegas to Mt. Charleston to hike the Mary Jane Hiking Trail to raise money and awareness for the CMTA. This was the very first "Climbing Mountains Together for CMT" event, and the group hopes to make it an annual event. After 20 hikers climbed the trail, they met at the Cathedral Rock picnic grounds for a nice lunch. It was a great day with a group of hikers and friends traveling all the way from Los Angeles, California, to attend this event.

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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.

In memory of Rick Alber, the family requests that donations be made to the Charcot-Marie-Tooth Association, PO Box 105, Glenolden, PA 19036 or via their website www.cmtausa.org/donate2star. Please indicate that the donation is in memory of Rick Alber.

IN MEMORIAM

Rick Alber, Volunteer and Friend


Rick Alber volunteered as the co-facilitator of the San Francisco Area Support and Action Group and as the "techie" who fixed audio and video problems at patient/family conferences.

It is with extreme sadness that I announce the passing of my good friend and colleague, Rick Alber, whom I knew for close to 10 years. In fact, he was the first person I came into contact with when my son, Yohan, was diagnosed with CMT at age seven. Meeting in a CMT chat room, Rick offered his support by sharing his story and offering to help me and my husband, Gilles, in any way possible. Like Yohan, Rick's daughter, Flannery, was diagnosed with CMT1A at an early age, with no family history of the disease.

Rick, a long-time member of the CMTA, and I first met in 2006 at the newly formed Bay Area Support and Action Group. His willingness to jump in and make a difference was essential to the success of the group. Rick contributed his technical knowledge of web design, online services and video production to enhance the quality of our local support group. He was also instrumental to the success of the CMTA's webinar series, which has created a library of knowledge from experts in the field of CMT. His soothing voice, calm demeanor and moderation skills will be sorely missed, as he was committed to extracting the most pertinent information from each presenter to benefit the general public.

Rick co-facilitated the San Francisco Peninsula/South Bay Area CMT Support and Action Group with me. He was always there for me and all our support group members. Rick was our rock. He took potential problems in stride and never overreacted when facing stressful situations. For example, when we did not have an audio connection 10 minutes before a very important and well-attended CMT conference, Rick coolly commented, "I've got it." And voila, at 9:00 am, we had sound, right in the nick of time. Rick and I complemented one another's skills, which was the key to our successful interaction and work product. He liked being in the background, did not want credit for his achievements, and was happy to stand behind a camera all day long, especially if it meant producing quality material for the CMTA. He was not in the game for himself, but he fought daily to help speed up the discovery of a cure or treatment for people with CMT.

Rick was slated to receive the CMTA's Rebecca Sand Volunteer of the Year Award in December, an award celebrating the efforts of one hardworking individual who stands out as an example of exceptional dedication to the CMTA and the CMT community. Rick Alber was that selfless individual who gave so much to so many. Although he will not be present to receive this award in person, his family will know just how much he meant to every single person he touched.

Our hearts go out to Rick's wife, Maureen and his two children, Jack and Flannery. May you be comforted by the outpouring of love surrounding you.

—*Elizabeth Ouellette*

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

SUPPORT GROUP NEWS

(continued from page 24)

- **NJ – Central NJ**

The group met on September 28th at the CentraState Medical Center. Mark opened the meeting with highlights of CMT Awareness Month and news from the CMTA. Adam Hammaker and Brian Klieberg of Hanger Clinics served as guest speakers. Adam presented a wide range of AFOs, and Brian explained how they go about evaluating patients and recommending the best braces for them. Following the presentation, they moved outside to the patio for a lunch arranged by co-facilitator Jacky Donahue. The group had a surprise for Mark. They had all signed a card and gave him a bunch of balloons with a gift for five years of being the facilitator of this group and giving so much of his time to everyone.

- **OH – Cleveland Area**

The group held its annual Awareness Month picnic on September 6th. Around twenty people were in attendance. The group enjoyed a lot of good food and great company. The picnic ended with Awareness Month materials being given out and people being challenged to spread awareness throughout the month. One group member held an awareness night later in the month by showing a CMT video and having various CMT challenges.

- **RI – East Providence**

Ellynn Koelsch, MSPT, from Performance Physical Therapy, served as guest speaker. She talked to the group about hand therapy, including exercising, bracing and adaptive devices. A big thank you to Ellynn for all of her helpful advice and answering all of the questions, as well as showing the group how to do some hand exercises properly. ★

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THE CMTA Report

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www.cmtausa.org

CMT PATIENT MEDICATION ALERT:

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

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Eribulin (Halaven)
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Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
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Suramin
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Etoposide (VP-16)
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Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
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Podophyllin resin
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a-Interferon

Negligible or doubtful risk:
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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.