

THE CMTA Report

NOVEMBER/DECEMBER
2012

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

STAR Updates Highlight Patient and Family Conference

BY PAM PALMER, ARIZONA SUPPORT AND ACTION GROUP FACILITATOR

OUR MISSION:

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

OUR VISION:

A world without CMT.

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On November 10th, I attended a wonderful symposium on the status of the research aimed at conquering CMT. It was truly amazing to learn how far we have come in such a short time. Patrick Livney, the CEO of the CMTA, gave the welcoming comments and an overview of the day's talks. He is to be commended for being a catalyst—pushing the envelope and creating a new paradigm for our research.

Three leading researchers, Dr. Michael Shy, Dr. Steven Scherer and Dr. John Svaren spoke on “Three Research Strategies: Developing Cell Lines, Testing in Animal Models, and the Human Component.”

Dr. Scherer, a neurologist at the University of Pennsylvania, opened their series with a description of the vocabulary associated with CMT which helped the members of the

“I came away in awe, empowered, and motivated to help continue the fight.”

audience understand the scientific intricacies of CMT, including the clinical aspect of diagnosis. His discussion included the differences between the demyelinating and the axonal neuropathies.

Dr. Svaren, Associate Professor and Director of Cellular and

Molecular Neuroscience at the University of Wisconsin, gave an update on the status of CMT1A clinical trials. He talked about PMP22 and how using Luciferase can help researchers discover which drug compounds will work most effectively to bring down the levels of PMP22 in type 1A patients.

Dr. Shy, a neurologist at the University of Iowa, next discussed how CMT is assessed in patients and the need for a clinical network in which there is uniform evaluation and measurement. He encouraged everyone with CMT to visit the website for INC-RDCRC (Inherited

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Support and Action Groups Brought Awareness of CMT to Their Communities



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The Second Annual Walk for Fergus Fundraiser attracted 80 participants and raised over \$5,600.

CMT PATIENT/FAMILY CONFERENCE

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Neuropathy Consortium—Rare Disease Clinical and Research Consortium) at <http://rarediseasework.epi.usf.edu/inc/> where patients can register under CMT.

The three speakers brought us up to date regarding the STAR initiative as they try to find a remedy that will put CMT into remission.

Sean McKale, CO, LO, of Midwest Orthotic and Technology Center, in Chicago, next spoke about orthotic management for patients with CMT. His group has created an outreach program for schools, targeting children three to four years of age to ensure that they receive appropriate bracing before CMT advances too far. This helps to preserve their ability to walk effectively.

He told the audience that the biomechanics of walking are important and small adjustments to one's bracing can be made to ensure a proper fit. An orthotist's work is not so much about disability as it is about enablement.

Sean talked about the vast number of bracing options. There are AFOs, including Allard's Toe Offs and Blue Rockers) and others such as Phat Braces which are laminated AFOs. He also talked about insurance coverage which varies depending on whether the patient has private insurance or Medicare. I found Mr. McKale to be very knowledgeable and I realized that getting the right fit in the braces you use is what makes the biggest difference in how well you will be able to walk.

The final speaker, Gregory Carter, MD, MS, Medical Director, Regional Neuromuscular Disease Center in Olympia, Washington, discussed "Maximizing Quality of Life in CMT: Strategies to Manage Pain, Fatigue, and Immobility."

He explained that CMT has many phenotypes—many of us are truly different in how CMT presents in us. Even mild genotypes (what our genes look like and how they present) can be a major source of significant disability. He stressed that because of our disabilities it is important to know our rights, especially as given to us by the ADA (Amer-

icans with Disabilities Act).

As a clinician treating CMT patients, he discussed the diagnosis, initial evaluation, weaknesses, exercise precautions, common injuries, walking aids, ulcers, pain and fatigue, medications and other mechanisms for treating nerve pain. Most of us with CMT can relate to that topic, especially.

When the formal presentations were over, we were treated to "Lunch with the Experts." Each table had one of the specialists who serve CMT patients seated with the attendees, including members of the CMTA's Board of Directors and Advisory Board. We were able to ask questions and absorb the knowledge that permeated the room.

I know that I came away in awe, empowered, and motivated to help continue the fight to beat this rare disease that in the moment didn't seem so rare. As several attendees noted, "It is wonderful to be with others who look so much like us, with our "funky" hands and feet. We are not alone."

Spread the word about CMT—the fight is on! ★

THANK YOU TO
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FAMILY FUNDRAISER NETS \$15,000 FOR THE CMTA

The Second Annual Campbell Classic took place on Sunday, October 7th at Minebrook Golf Club in Hackettstown, NJ. The outing was organized by the Campbell Family to raise funds and awareness for CMT research. Rob Campbell and his son Robbie both have CMT, and they are both avid golfers. "The outing is a great way to get our friends and family together for a great day, playing the sport Robbie loves to play, while raising money for CMT at the same time," said Debbie Campbell, Robbie's mother. The whole family, including brothers Kyle and Michael, played a part in planning the event. This year the Campbell Classic raised \$15,000. Shown here are Robbie (left) and his eight year-old brother Michael.



2012 Volunteer of the Year Honored

BY ELIZABETH OUELLETTE

Working tirelessly on behalf of the CMTA, Rebecca Sand was the first to raise her hand to take on new challenges. From spreading awareness and fundraising to championing the rights of persons with disabilities, Rebecca received the CMTA's first Volunteer of the Year Award in the summer of 1990.

Again this year, the CMTA has decided to recognize the outstanding efforts of one individual within the CMTA community who best displays Rebecca Sand's qualities of leadership, service, hard work, camaraderie, enthusiasm, and dedication.

Congratulations to Julie Collins, the facilitator for the Central Florida Support and Action Group. In addition to her work as a support group facilitator, Julie is secretary to the Exceptional Education Department at Lake Brantley High School in Alamonte Springs, Florida. She serves on the school advisory council and is a transition mentor. She is the recipient of the Jefferson Award for Public Service for her committed involvement with the CMTA within the school community. She has owned and operated Phantom Secretary for 18 years, 14 of which were spent concurrently working in education.

She's been married to her husband, Mark, for 26 years. They have two teenaged sons. Ten years ago their eldest, Andrew, was diagnosed with

CMT. The quest began. Her goal was, and is, to learn as much as possible about CMT and its patients and families and to help in whatever capacity needed to try to spread awareness.

In addition, Julie is also a researcher, facilitator, author, and advocate for the CMTA. She writes articles for the CMTA newsletter on a regular basis and systematically takes copious notes for all the support and action group facilitator monthly calls. Julie also has chaired the CMTA's Extraordinary Person contest, which includes the "I'm A Star!" and "I'm A Shooting Star" contest.

Working with the Digital Design instructor at Lake Brantley, Julie helped launch a student-based competition to create artwork for use in the worldwide Awareness Month Campaigns. The CMTA's current national and Global Day posters are a reflection of Julie's hard work and creative spirit.

However, Julie is also well known for her work on the CMTA's Presidential Proclamation initiative. As the CMTA's elected governmental liaison, Julie has worked tirelessly over the past two years on a "Call to Action" to the CMT community, asking our constituents to reach out to Congressional Representatives for support of a Dear Colleague letter, requesting President Obama to declare the month of September as National Charcot-Marie-Tooth Awareness Month. Through email blasts,



Julie Collins, Central Florida SAG facilitator, received the Volunteer of the Year award in Chicago at the SAGF conference.

newsletter articles, personal pleas, and numerous phone calls, we were able to obtain the signatures of 23 members of Congress and the support of one US Senator, Barbara Boxer.

Although we have not yet received this Presidential Proclamation, we have spread much-needed awareness throughout the country and among our elected officials. And, Julie will not abandon her efforts or our cause until she succeeds with this very important initiative. In fact, now that the groundwork has been laid, Julie is revving up for 2013, already planning and strategizing for an extensive and energetic program to succeed in our ultimate goal: receiving an official Presidential Proclamation making the month of September CMT Awareness Month. If anyone can bring this home, it will be Julie Collins!

Thank you, Julie, for all of your dedication, commitment and unrelenting efforts on behalf of the CMTA. You embody the spirit of the Rebecca Sand, Volunteer of the Year Award. ★

Support and Action Group Facilitator Conference: Reflections from the Air

BY JULIE COLLINS

Editors note: Julie Collins is this year's CMTA Volunteer of the Year. See story on page 3.



The SAGF group, numbering 75, learned about successful strategies for meetings and enjoyed meeting their colleagues from other states.

I was flattered when asked to write an article about the SAGF Conference held in Chicago,

November 8-11, 2012. How hard could it be? I am writing this while in flight heading back to Orlando. I am afraid that if I don't put it all in writing immediately, my head will explode!

This was my first conference and my first opportunity to meet the majority of the facilitators that I have communicated with over the past three years when I became a SAGE. They are such an incredible and extraordinary group of people.

When my son Andrew and I arrived in the lobby of the hotel, we were greeted by Jeana, Elizabeth, and Drs. Mike and Rosemary Shy. One of the foremost experts and researchers on CMT in the world was welcoming folks to the conference with a big hug and a fabulous smile. You won't find that happening at other conferences!

Sitting at the registration table and welcoming my colleagues, I was struck most by the instant familiarity we had with one another—the ease with which conversations were launched. From the ice breakers that began Thursday evening

during dinner, to the official ice breaker session Friday morning, the sharing of personal stories flowed freely.

The presentations made throughout the conference on Friday were topical, informative, emotional at times, and uplifting all the time. Whether we were discussing building relationships, led by Dave Tannenbaum, or learning ways to employ those concepts within our support groups with Jeana and Elizabeth, we were inspired and motivated.

If anyone thinks that we were resting on our laurels while in Elk Grove Village, fear not! Our laurels were busy from sunup to way past sundown. Even on the breaks between sessions, we were busy learning from our corporate partners at Aetrex and Allard, who brought staff, displays, and samples to demonstrate products customized for CMT patients. We were so very grateful to our corporate sponsors for their encouragement and financial support of this most important event.

The Patient Family Conference is being covered in another

article here in the newsletter, but I would be remiss if I didn't include that meeting support group members from other areas of the country was such a pleasure! Big shout out to our 94-year-old attendee Laverne Stohl. What a delightful young lady!

Every presenter brought something unique to the conference, but what I found so intriguing, even bordering on the mystical, was that while none of us collaborated, a common thread ran through each and every presentation: Missy Warfield, Pat Livney, Mike Needleman, our Advisory Board who held an open panel discussion, Donna DeWick, Tom Meloche, John Paul Mendocha, Steve Weiss, Susan Ruediger, and I spoke about bringing change and about being the change that will help us reach the goal of a world without CMT.

Saying goodbye came too quickly. Oddly enough, some of us reconnected briefly in the airport. We shared a few new ideas, many more hugs and some raucous laughter at the airport. Peo-

ple were amused, and I think jealous of the obvious delight we shared in each other's presence, connected by this bond that so many still don't know about. That's the crux of it right there. We are all connected whether by having CMT or by being a family member of someone with CMT—we get it. No judgement.

I took away so many ideas for how to make my group meetings more interesting: great ideas for fund raising for STAR, tremendous knowledge, and a deeper understanding of where the research is and where it's headed and the resources available through our corporate sponsors.

Reflecting back on these past 72 hours, I see each of the faces of the people that have become family to me. We are united by this awful CMT, but dedicated to being there for our group members. Let's keep the momentum going. Make the effort to be on the monthly conference calls, schedule those meetings and fundraisers. Keep spreading awareness every chance you get!

Well, it's time to turn off all electronic devices, so it's time to wrap this up by reaffirming my deep appreciation to everyone who organized, contributed to, and attended the conference. I am humbled by your service to one another and the CMT community. If you are a member of a support and action group, you are in for a treat at your next meeting. If you are not a member, I urge you to find a group, or start a group in your area. The reward is that you will be a part of the achievement of the greatest goal. A world without CMT! ★

Another Successful CMT Awareness Month

Fall has come and gone, but the month of September will always be a time to remember.

Together, with the help of the CMTA's national support and action group facilitators, their members and the CMTA community worldwide, we have successfully raised awareness and increased funding to support CMT research through the CMTA's Strategy to Accelerate Research (STAR) initiative.

To measure just how effective the CMTA's Awareness Month campaign was, here are just a few impressive statistics:

- the Premium Content Subscriber Special brought in 72 NEW subscribers to the CMTA
- the CMTA's Facebook Page-Charcot-Marie-Tooth Association: The Time is Now received 500 new Facebook fans
- an estimated 173,000 people received specific CMTA Awareness Month messages
- the CMTA's YouTube video channel registered more than 13,000 video views
- the CMTA's Signature Wall raised \$1,200 for the CMTA's STAR Research Initiative

This incredible outcome could not have been made possible without the hard work of our Awareness Month committee: Julie Collins, Mark Willis, Serena Clarkson, Karen Smith, Linda Davis, Elizabeth Ouellette, and Jeana Sweeney

Thanks again to all who participated in Awareness Month. If you would like to become more involved next September, please contact Jeana Sweeney at jeana@cmtausa.org

HOW CMT SUPPORT GROUPS SUPPORTED AWARENESS:

CA—San Francisco Peninsula/ South Bay Area

Many thanks to Terry McIntosh for throwing a wonderful party on September 8th. Terry and her two helpers made enough food for people to take home a meal for the next day. In addition to casual discussion and talk about CMT Awareness Month, we had the pleasure of meeting Dr. John Day, neurologist, who is in the process of building the CMT Center of Excellence at Stan-

ford with genetic counselor Carly Siskind.

DC—Washington Area

The group met on September 23rd. They gathered at the American City Diner in the District and visited with each other over dinner. Special thanks to Jeffrey Gildenhorn, the diner's owner, and a person living with CMT, for hosting us. A portion of the evening's receipts was donated

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CMT Doesn't Stop 14-Year-Old Athlete

BY VITTORIO RICCI

Before I knew what CMT was, I thought I had bad balance and weak legs. I was told that I ran awkwardly. I couldn't stand on one foot too well, and I could only jump a few inches off the ground. I knew something was wrong a year ago when I couldn't lift up my big toe on my left foot. I thought it was a tendon problem. It wasn't. Now that I know why my abilities are limited, I am determined to run a six-minute mile in my leg braces. A year ago I had CMT without knowing it. Now I know, but I choose not to waste a minute being upset because I'll lose a minute of happiness.

I signed up for cross coun-

try with a few of my friends. On our first practice two weeks before school started, coach made us run three miles on the road. My friend Michael and I (both of us had only ever run two miles straight) were navigating our way up hills, through intersections, and across badly paved roads when my friend tried to quit and walk the rest of the way. Despite my own pain, I found myself telling him all about my new CMTA "Circle of Friends" site through great heaving breaths as I ran. I told him about raising money and posting pictures and perhaps filming some Go-Pro videos together for the site. By the time I finished my story, I noticed I was just about done with the run, and my friend had kept running right alongside me despite his clearly visible pain. I learned not to expect less of my athletic ability because of CMT, but to expect more of myself. I was able to run, and that meant I should push myself to my limits to get better, not to take sit-out practices and justify my laziness with a mutated chromosome. Now, both Michael and I are plowing through five-mile runs after half-hour track workouts.

My next challenge was a triathlon that I signed up for before my CMT diagnosis. I think my parents were worried, but I knew they wouldn't stop me from having the experience. The triathlon was in honor of a fallen police officer who donated money to our schools for sports

programs. The entire triathlon was a .25-mile swim, 10-mile bike ride, and 1.5-mile run. It started early in the morning and was a cool day, with clouds completely covering the sky. I got all my stuff set up in my designated area: my road bike, biking shoes, running shoes with the leg braces sticking out, a towel, and of course, lots of water. I was a little nervous as I got ready for the start. There were a lot of people, around three hundred. Being fourteen, I was the first group going in the water. I was thinking about how cold the water would be and the snapping turtles I had seen over the summer. But, as I stepped into the unexpectedly warm pond, all my fear melted away. The horn sounded and a dozen kids ran in the water. I remember hands and feet hitting my head as I was trying to follow the course.

The hardest part of the whole race was getting out of the water and running up onto the beach. I swam in as shallow as I could go, but gaining balance on feet that felt the need to turn into fins is not easy. I got up to run and every muscle, tendon, and nerve ending in my body just failed. Spectators cheering, I slowly headed toward my bike. The biking was easy, a nice 10 miles up and down hills. There was nothing exhausting. But it seemed like the entire town passed me on their bikes.

Again, transitioning from bike sneakers to sneakers with my AFOs took a little time—

Vittorio has learned not to expect less of his athletic abilities, but to expect more of himself.



but I was ready for the run. All the cross country training had helped. So even though I was slow in transitioning, I felt confident in the 1.5-mile run. Sprinting to the finish, I knew that I would do this again next year. Who knows, I might even beat my record—now that I have one.

Winter sports are coming up, and so far I have signed up for the High School Ski Team. Skiing is one of my favorite sports because when I wipe out I don't tear myself up. Falling off a mountain bike into sticks is not as painless as plummeting into snow. I prefer freestyle, but Ski Team will be focused on racing. And how convenient that skiing

doesn't require any sort of movement restricted by CMT.

For now, I'm content with running, mountain biking, and skiing, but something else may catch my attention. After doing a triathlon, I am curious to see

"I'm not going to ask if CMT will stop me from a physical activity. I'm just going to go do it."

how I would do in a half marathon. 13.1 miles seems a little daunting, but I won't know until I try. It would be a shame if I missed out on mountain climbing, too. I did a little when I was very young, and lately I've been crawling up trees to satisfy my urge. My dad used to ice climb and that sounds like fun,

too. I'm not going to ask if CMT will stop me. I am going to go do it.

One day at cross country practice, I was running laps with a few kids. One of them asked me, "Do you think you'd be a better runner without those on your legs?" I replied "I don't know." I thought later to myself, "if I didn't have CMT, would

I be better at balancing and jumping and would I have more time in my daily routine?" Probably, but I know I wouldn't try as hard. I have a mutated gene. We all have flaws, and waiting around for what is fair in the universe isn't going to work—for me. My life is happening now. I'm going to give it hell. ★

DONATIONS TO CMTA "CIRCLES OF FRIENDS"

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

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Annual Appeal Features 8-Year-Old Jacqueline

BY SUSAN RUEDIGER, DIRECTOR OF DEVELOPMENT

As a subscriber to the CMTA's newsletter, you know that we are the place where scientific experts, the patient and caregiver community, and the world's best CMT clinicians come to connect. One of the many people who benefit from the services provided by the CMTA is eight-year-old Jacqueline.

She has CMT type 1D, and her symptoms are devastating. Her CMT has caused the complete deterioration of the muscles in her feet, hands, legs, arms and trunk, preventing her from using them. Her lung capacity is severely compromised due to the atrophy of her diaphragm. Her ability to swallow is quickly deteriorating, and her dependence upon her mother and father for daily activities increases weekly. Her grandmother and aunt also suffer from the symptoms of CMT.

Jacqueline and her family



Jacqueline sits with Dallas Support and Action Group facilitator Whitney Kreps who has helped the family understand CMT and find many services in their area.

regularly come to the CMTA to find peer support, updated diagnostic information, and the resources to increase awareness in their community. On the CMTA's website they have found many helpful tools: the informational brochures to help educate her physicians, information about developing an Individualized Education Plan (IEP) for Jacqueline, and access to the CMTA's advisory board to answer ongoing questions and concerns. Through the CMTA, Jacqueline and her extended family found their local support and action group, where they have made friends with others with CMT, found emotional support, and participated in local awareness efforts. Because of the CMTA, Jacqueline and her family better understand CMT and the expected progression in each person. They also have hope for the future—hope that their family's legacy will come to an end in this generation and that no other families

will have to endure the devastating effects of CMT.

As you can imagine, our programs are invaluable to Jacqueline and her family. Providing these programs and research takes significant funding. We need your continued help to make scientific progress and provide continued support to the community. As we end 2012, we have planned 2013 to be another year of significant progress, not only in research, but also in community support and awareness. Our programs will continue to deliver significant benefits to those with CMT: increased patient and caregiver meetings and conferences, increased public and community awareness validating the debilitating symptoms of CMT, and, lastly, the hope that the first treatment is on the horizon.

In order for the CMTA to achieve these goals, we need your continued support. Please join the Board of Directors, the support and action group facilitators, and Jacqueline's family by giving to the CMTA. You can visit the website www.cmtausa.org/donate. Your support will allow us to continue to work toward tomorrow's treatment while providing the resources to improve the lives of those with CMT today.

We in the CMT community can all benefit from a gift to the CMTA, today and tomorrow. We appreciate your continued support and your engagement with our organization. ★

RESULTS OF THE CHASE COMMUNITY GIVING CAMPAIGN

THANK YOU! Your actions made a difference! The CMTA was nominated by the customers and employees of Chase to participate in a Facebook contest in September. The CMTA received over 1300 votes to place 163rd out of 30,000 eligible charities and was chosen to receive a grant for \$10k from Chase Community Giving. Thank you for your participation! Look for us next year and help us earn \$10,000, \$20,000, \$50,000 or even \$100,000! Every person has the ability to achieve the goal of a world without CMT. Proof positive—you are empowered to help us end CMT!

Walking and Rolling for CMT

Chicago Support and Action Group Sponsors Third Annual Fundraiser

The Chicago Area CMT Support and Action Group sponsored the “Reach for the STARS—Walk and Roll for the CMTA” on Saturday, September 8th. This was our third year having the walk and roll.

The walk took place at Lake Katherine’s Nature Center and Botanic Gardens located in Palos Heights, IL. Lake Katherine is a beautiful location with a one-mile scenic walk around the lake. We rented out the Auditorium Room for all our family and friends to have a place to sit and relax and enjoy all the breakfast goodies. Bagels, pastries, homemade cookies, and Starbucks coffee donated by a local store awaited our “Circle of Friends.” The room was decorated with “CMT Awareness Month” posters, and star-shaped balloons were placed on all the tables. A slide show explaining CMT and the progress the

STAR has made was shown. Raffle baskets were made, and items were donated in order to sell raffle tickets to raise more funds for the CMTA.

10:00 AM approached and our “Circle of Friends” started to arrive for the walk. The weather was absolutely perfect! We had a wonderful turnout of over 100 people coming out to support

The Chicago event has raised over \$10,000 for CMT research.

us. What an awesome sight to see all our family and friends, along with so many new faces this year, finding out about CMT and spreading the word!

CEO Pat Livney joined us and gave everyone an update on STAR and the “Transformation Project” before the walk began. Hearing the progress the CMTA has made since our walk last year was just incredible. Pat’s passion for the CMTA and his

drive to find a cure was evident in every word he spoke. We are so fortunate to have him leading the way. I know each person appreciated hearing the news and knowing that they are helping us with their donations.

Everyone enjoyed each other’s company while completing the one-mile walk around beautiful Lake Katherine. The kids also enjoyed finding turtles and watching the swans swimming along the way. After the walk, the winning raffle tickets were announced. We made an incredible \$930 from selling raffle tickets.

Every year the walk is getting bigger and more people are finding out about CMT. Our goal was to raise \$10,000, and we have already surpassed it.

It’s been a great CMT Awareness Month!

—Dale Christine Lopez,
Chicago Area SAG Facilitator

After their one-mile walk around Lake Katherine, over 100 participants posed happily for their group photo.



CMTA Awards Two Plaques for Outstanding Service

All CMT patients are special individuals. They face the challenges of everyday life those without CMT can't begin to imagine. They are extraordinary people and the Awareness Month Committee encouraged the submission of names and stories of people achieving and living life to the fullest, not being defined by CMT. The Annual CMTA "I'm A Star!" Award is for ages 18 and up and the "I'm A Shooting Star!" Award is for ages 10-17. This year's winners received their awards during Awareness Month.

"I'm A Shooting STAR" Winner

*Nominated by her aunt,
Karen Cisco*

Kelly Cisco is my beautiful, blue-eyed, out-going niece, who is an honor student going into 8th grade at St. Francis School this September. Without any doubt Kelly is a warm, caring, animal-loving young lady who has been diagnosed with

CMT Type 2. When Kelly was just one, our family found out that Kelly had the disease. In her 13+ years of life, through the pain and hardships that the severity of the disease gives her, Kelly has not once let CMT slow her down. Unfortunately Kelly is not alone in our family, as Kelly's mom, Sharon (50), her Uncle Gary (48), and her Grandmother Betty (78), also all have CMT. Uncle Gary was in a wheelchair years before Kelly was born. Her mom is still able to walk, but not without assistance. Kelly's older sister, Kaitlyn (17) and I are the only two who do not have the disease.

Kelly loves life, being around people, smiling, and being a teenager. Recently there is a new love in her young life, the group, 1 Direction, is now a top priority in her life. I recently purchased tickets to go see the band in July, 2013. The tickets were expensive, but I couldn't remember a time when she wanted something so badly, so we made a deal. I would pay for one ticket, and she would pay for one. Within the week, Kelly began paying off her ticket price by working little jobs in the neighborhood and at a local ice cream parlor I co-own.

Last September, Kelly joined another young man,



Thirteen-year-old Kelly Cisco poses with her "I'm A Shooting STAR" Award.

Timothy Ward, and three others at a televised meeting of the Passaic County Freeholder Board. Tim was the principal spokesperson, and Kelly joined him to bring awareness of CMT to the people of Passaic County. In turn, the Board of Chosen Freeholders proclaimed September, 2012, as CMT Month in Passaic County. We are working to have them do so again this year to help educate the residents of Passaic County about this life-altering disease.

Every day is a struggle for Kelly. Though the world has come very far in recognizing people with a disability in the last 50 years, it has much farther to go. It is young ladies like Kelly who will make a positive difference in the lives of the children and adults she meets, whether they have a disability or not. My few words are inadequate to describe the qualities of this special young lady whom I place in nomination for the "Shooting Star" award, but I hope it shows you how special I think she is.

BETHANY MELOCHE JOINS CMTA STAFF



In October, Bethany Meloche joined the CMTA as Director of Social Media. Bethany began working with the CMTA as a volunteer in 2010. As a result of her active participation, she was asked to join the CMTA Advisory Board as a youth liaison.

She has worked as an advocate for youth services within the CMTA.

A member of the social media generation and a student of its trends, Bethany helped edit the book *The Ultimate Guide to Facebook Advertising* published by the Entrepreneur Press. She has also been spotted on one or two occasions hanging out at Facebook headquarters in Menlo Park.

Bethany hopes to use social media as a tool to reach out to people worldwide who are affected by CMT, and foster a community of support, information, and action.

Bethany has CMT1A and runs the blog BareYourBrace.com. Bethany invites all of the CMTA's friends to "Like" the CMTA on Facebook at www.facebook.com/CMTAssociation and follow us on Twitter at www.twitter.com/CMTASTAR

Kelly also works with younger kids with disabilities through the Special Association for Children once a month.

Through school, Kelly set up a Flip-Top Lid Drive for the Ronald McDonald House and collected over 85,000 lids in 2010.

"I'm A STAR" winner: Christine A. Hook

*Nominated by her mother,
Mrs. J. Neil Hook*

I am pleased and proud to nominate my daughter, Christine A. Hook, for the "I'm A Star Award." Christine is now 40 years old and was first diagnosed with a "neurological difficulty" at the age of 13. It was not until she was 25, however, that her primary doctor made the correct diagnosis of CMT. She is currently undergoing testing to determine the type of CMT she has but thinks it is probably Type 2A. For the past 14 years she has been required to wear braces to assist her in walking.

CMT has definitely affected her ability to have a full and rewarding life. Christine has a bachelor's degree in fine arts and two master's degrees—one in

special education and one in literacy. She worked for seven years as a special education teacher but had to give up her teaching duties after suffering a back injury. This, complicated by also having CMT, diminished her ability to work.

For approximately six years she worked part-time as a secretary/receptionist in various medical offices, but earlier this year she was told that it would not be in her best interest to continue working. For some time she has been receiving Social Security Disability benefits, which at the present time are her primary source of income.

Faced with the prospect of not being able to work, she returned to her artistic background. She has again taken up painting and has had several of her works displayed in galleries around the Albany, New York, area. She has become involved with a local movement called Art de Cure which seeks to display local artists' efforts in various medical buildings. This project supports a variety of charities that receive a portion of any proceeds from the sale of the artwork. One of the charities is the CMT Association, and Christine now is the coordinator for that ADC gallery, from which the sale of any art will benefit CMT. Another way she has helped to raise awareness for this disease was to submit her artwork to Artist's World Magazine for their "Expressions Art Challenge for CMT Awareness, 2012." Three of Christine's paintings were chosen for AWM's September edition, along with 14 other pieces of artwork by artists who have CMT or have friends with CMT.

The Road of Struggle and of Hope

By Tony, Easton MD Support Group

They are neither drunk nor woozy,
As they wobble down the street.
They walk a little crazy,
'cause God gave them goofy feet.

Braces, canes and stumbles
Make it hard to "Get and Go."
There's limps and gimps and tumbles,
But no dancers, in this show.

They have educated doctors,
Nurses, teachers, too.
They know more genetic factors
Than lab technicians do.

As kids they couldn't skate or run,
At least, not very well.
They missed out on a lot of fun,
But why? No one could tell.

Embarrassed by their lack of grace
They felt somehow alone.
No others knew the trials they faced
They did it on their own.

But now they're not so lonely.
They've formed a little band.
They know it is not them only,
Each lends a helping hand.

They share their tales of how they cope,
While traveling down the road.
The road of struggle and of hope,
Where CMT's the load.

Christine is also a talented writer. About two years ago, she began to write a blog called Grace Lines (accessible by going to atticusmom1.blogspot.com) in which she discusses her life with CMT along with a variety of other topics and issues. She has a remarkable sense of humor that shines though even though she has had to deal with this debilitating disease. Christine continues to raise awareness for CMT through her artistic efforts and her writing.

I am proud to nominate Christine A. Hook for the "I'm A Star Award." ★



Christine Hook (right) with her support group leader, Melinda Lang.



ASK THE EXPERTS

Dear Doctor,

We follow a patient with suspected CMT in our genetics clinic. DNA testing to date is negative, but he has enrolled in Dr. James Lupski's research study looking for additional CMT genes. We have reviewed with him the list of medications to avoid. We wanted to ask specifically about his medications to see if there are any known contraindications. His medications are:

- 1) Triamterene/HCTZ
- 2) Quinapril
- 3) Omeprazole

Dr. Louis Weimer replies:

The Accupril (Quinapril) and HCTZ combination drug are not recognized causes of neuropathy. There were a very small number of patients with suspected omeprazole neuropathy about 8 years ago, but no further cases were reported; millions take this medication worldwide. It carries doubtful risk.



Dear Doctor,

I had genetic testing for CMT and it returned "abnormal variant" on HSPB1. The doctor who ordered the test phoned me with the results and just said she couldn't help me. Can you explain the significance of this? In my reading it seems that this is an indicator of CMT2F.

Carly Siskind, MS, CGCL, a genetic counselor, replies:

People who have a disease-causing mutation in HSPB1 do indeed have CMT2F. Most people with mutations in this gene have predominantly motor

symptoms (problems with walking, with the hands) but fewer or no sensory symptoms (numbness, burning, tingling). What the abnormal variant means is unclear based on the information provided. It could mean that it is a known disease-associated mutation, in which case the answer to your question would be yes—this is an indicator of CMT2F. However, it could also be a variant of uncertain significance, in which case it may be a bit of an odyssey to determine if it is what is causing the CMT in the family. It may be reasonable to speak with a genetics professional in your area about the results. Genetic counselors can be found through the look-up feature at www.nsgc.org.



Dear Doctor,

My son had testing done and the doctor called me and said he had two changes in the gene that caused Dejerine-Sottas syndrome, but they researched it and said that the two changes were benign. Has anyone ever had this happen? My husband has CMT3.

Shawna Feeley, MS CGCL, a genetic counselor answers:

CMT 3 (also known as Dejerine-Sottas syndrome) was previously used to describe patients who have a form of CMT which causes more severe symptoms, typically starting in childhood. When genetic testing became available, we were able to determine that there are many different forms of CMT that can have

a severe presentation starting in childhood. Therefore, CMT3 or Dejerine-Sottas syndrome is not a specific disease; it describes the symptoms of a group of conditions. In order to have a specific diagnosis of CMT, you need to have both a number and a letter that tells you which gene is causing the symptoms. An example is CMT1A: the 1 tells you the problem is in the myelin, and the A tells you which gene and which chromosome are causing the problem. So, we know everyone with CMT1A has an extra copy of the PMP22 gene, which is found on chromosome 17.

For CMT3, as I mentioned, this is a group of many types of CMT, so it is not a specific diagnosis of CMT. When people have genetic testing, many physicians order a "genetic panel" of many different genes. There is a "Dejerine-Sottas panel," so I am sure this is what the doctor ordered here. They may have found what is called variants of unknown significance. These may or may not actually cause disease. The variants have to be researched to know if they are actually causing a person's symptoms. This is a difficult process, and it is usually best to work with an expert in CMT to figure this out.

**"What's on
Your Mind?
Ask David"
will return in
our January
Issue.**



What is a 504 Plan?

Schools in the U.S. that receive federal funding must adhere to the provision in Section 504 of the Federal Rehabilitation Act of 1973. Section 504 guarantees individuals with disabilities equal access to education as a civil right. Educational plans based on Section 504 are referred to as 504 Plans.

In order to qualify for a 504 Plan, a person must have a physical or mental impairment that causes significant limitations to one or more areas of life activities. Recent clarification of the definition of “disability” has broadened the application of 504 Plans to students who may not have previously qualified.

These plans can address a number of different areas, including the physical assistance a student needs to attend school, adaptations needed to perform academically, and equipment/technology needs. The plan can also specify services such as physical therapy, speech therapy, or occupational therapy.

Unlike an Individualized Educational Plan (IEP), the 504 Plan does not address the need for specialized instruction. Students who qualify for special education services will receive services as specified through an IEP rather than a 504 Plan.

The 504 Plan differs from an IEP in other ways as well. While an IEP requires a formal written plan, a 504 Plan does not. Unlike the IEP process, parents are not required to be part of the planning process. In practice, however, parents are often involved in formulating 504 Plans, and these plans often have written documentation. Schools do not receive additional federal funding for services given under a 504 Plan.

If parents do not feel that their child’s needs are being met by the school, the parent does have the right to file a complaint with the Office for Civil Rights at the US Department of Education. Parents have the right to review records and request a

hearing if they feel that there has been discrimination against their child.

During the hearing process, the school selects the hearing officer. The school, along with the hearing officer, sets the details of the hearing process. Parents are not required to be present for the hearing and are not required to provide consent. Parents must, however, be given the option to participate in the hearing and to have legal counsel.

While most students with neuromuscular disease have physical disabilities, they less often have learning disability or cognitive delay. Many students with neuromuscular disease will not qualify for special education services through an IEP. However, these students may qualify for 504 Plans even though they do not qualify for special education services.

—Jori Reijonen, PhD,
Southwest Michigan SAG Leader,
Previously published at
www.bellaonline.com

CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
 Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____ Check Enclosed

VISA MasterCard American Express

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____



Spotlight on Denver

Support Group Leaders Ron Plageman and Dick Kutz

Ron Plageman was blessed with a very active childhood growing up in the Tampa Bay area of Florida, constantly at play with his close brother and neighborhood friends with Little League baseball, swimming, and general boyhood play. Always aware of his “odd” way of walking, the conditions of CMT did not slow him down a lot, even through two surgeries on his feet by the time he entered high school. Increasing difficulty and frustration, as well as the nagging social stigma

of his gait, allowed him the opportunity to discover cycling. He took to it immediately, and even competed nationally for several years. Ron has remained active with cycling, having completed several organized rides through the foothills of Boulder, CO, and beyond this past year, and attributes cycling in part to his physical and emotional well-being.

After college and a move to New York City to enter the publishing world, Ron remains an active, and employed, advo-

cate of the printed word. Moving to Denver in 1992, he finally visited a recommended podiatrist to see if anything could be done to help with the foot pain, calluses, and increasing incidents of tripping. This began his close relationship with the podiatrist and his love of the life his orthotics have allowed. This first visit was the first he recalled hearing the term CMT.

Ron was introduced to the Colorado CMT Support and Action Group through his father, a SAG facilitator with



GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Anna Mae C. Berlin
Ms. Colleen Becker

Stella Bialek
Mr. & Mrs. Gary Walker

Sandra K. Davidson
Ms. Beverlee Nix
Ms. Wanda Spigener

Gerard Donovan
Ms. Lois Bolgunas
The Fitzgerald Family

Sara C. Fuhrman
Ms. Colleen Becker

Sheila Hatch
Ms. Donna Byrnes

Mark Hollingshead
Ms. Sheran Boyte
Mr. & Mrs. Richard Brown
Mr. & Mrs. Joe Bush
Mr. & Mrs. James Chatham
Crystal Nails
Mr. & Mrs. C. A. Demonbreun, Jr.
Mr. D. Randall Early
Ms. Mary Harrington
Hendersonville Health Mart
Indian Lake Animal Clinic
Mr. & Mrs. Robert Mingle
Mr. & Mrs. Richard Vrabcak

Jack Jones
Mr. Garold F. Crayton

Lewis G. Lynch, Jr.

Mr. & Mrs. John Bratton
Mr. & Mrs. Ralph Brower
Ms. Marilyn Buckler
Mr. & Mrs. Richard Doyle
Mr. & Mrs. S. Jonathan Emerson
Mr. & Mrs. Nick Hagoort
Mr. & Mrs. George Kitts
Mr. Charles Lynch
Mrs. Suzy Lynch & Family
Mr. & Mrs. Robert L. Lynch & Family
Mr. & Mrs. Richard J. Ruth
Mr. & Mrs. M. B. Schreiber
Mr. & Mrs. Charles W. Sowers
Mr. Richard Tierney
Ms. Jackie L. Westbury
and Family

Horace S. Powell
Mrs. Brenda Brubaker

Joseph Rath
Mrs. Heather Brown

Anthony Romeo
Ms. Marguerite Shaffery

Rebecca Rosenfeld
Mr. & Mrs. David Porter
Mr. Ian Thomson

Clair Wester
Ms. Julie Bowers
Mr. Kevin Mullins
Mr. Mark Musial
Schaumburg Athletic Assoc.

IN HONOR OF:

Iris Anderson
Ms. Shirley Meddaugh
Dr. Myrna Teck

Yohan Bouchard
Mrs. Andrea Summers

**Sorlee Chetlin—
Happy 80th Birthday!**
Mr. & Mrs. Charles Freed

Alison Childress
Mr. Alan Taylor

Carter Huber
Mr. Michael Holutiak

Flora Jones
Ms. Cindy Chesteen

Katherine Kramer
Mr. David Heuvelman

Meryl Lemeshow
Mrs. Judy Siref

Jeff LePage
Mrs. Peggy LePage

Andy Levine
Ms. Ellen Greenwald

Sheila Levine
Ms. Ellen Greenwald

Joseph McCallion
Mr. & Mrs. Dennis O'Connor
Mr. & Mrs. Dennis Woisin

Marissa Moran
Mrs. Gail Moran

Gabriel Orozco
Mr. Ned Connolly

Carmen Pignone
Mr. & Mrs. Steven Schloss

**Sophia Rome—
Happy 3rd Anniversary
of Your Bat Mitzvah!**
The Rome Family

Rebecca Rosenfeld
Mr. Ian Thomson

Susan Ruediger
Mr. Todd Bailey
Arefa & Murtaza Cassoobhoy

Frank Showalter
Ms. Liz Cullens

**Vasi Vangelos—
Happy Birthday!**
The Rome Family
Mr. & Mrs. A. J. Vangelos

Harriet Weiss
Dr. & Mrs. Dale Minkin

Mark & Jackie Willis
Mrs. Karen Sarageno

Karen Zaremborg
Mrs. Beverly Barnes

My Beloved Family
Ms. Marcia Hoffman

the Inverness, FL group. Like Dick, Ron was happy to fill in where he could help, and here he is today as a co-facilitator. Ron emphasizes an integrative approach to living and thriving with CMT, combining both focused physical maintenance and general activity along with emotional health. Ron attempts to approach life looking at what one can do, not what one cannot.

Dick Kutz grew up in southern Wisconsin, attended Wisconsin State University-Whitewater and spent four years in the USAF as part of a Minuteman missile team. After that, he began a career in information systems as a programmer/analyst, (including 15 years with the Coors Brewing Company in Golden, CO). He continued employment in this field until his retirement in 2002.

Three years later, at age 65, he went to his PCP complaining of “numb feet, 24/7.” In an oft-told story, the doctor ran a sharpness test starting at his toes and moving upward. “Let me know when you can feel this” he said. “I can’t feel it” was my reply and the doctor’s referral to a neurologist led to the eventual diagnosis of CMT.

Sometime later he joined Diane Covington’s Denver SAG where he met Ron Plageman, his present co-facilitator. Ron and Dick joined forces to head up the group when Diane, after five years of guiding the group, had to give up the leadership of

the SAG due to a new job opportunity. Diane’s continuing contributions, support, and input remain a valued asset.

Diane was preceded by Marilyn Strand who started the group in 1998.

Dick was his high-school PE teacher’s worst nightmare, but he remains mobile to this day.

Dick’s journey with CMT has been a mixed bag. While going through what now seems to be the norm of being less than fantastic at sports, walking on his toes as a

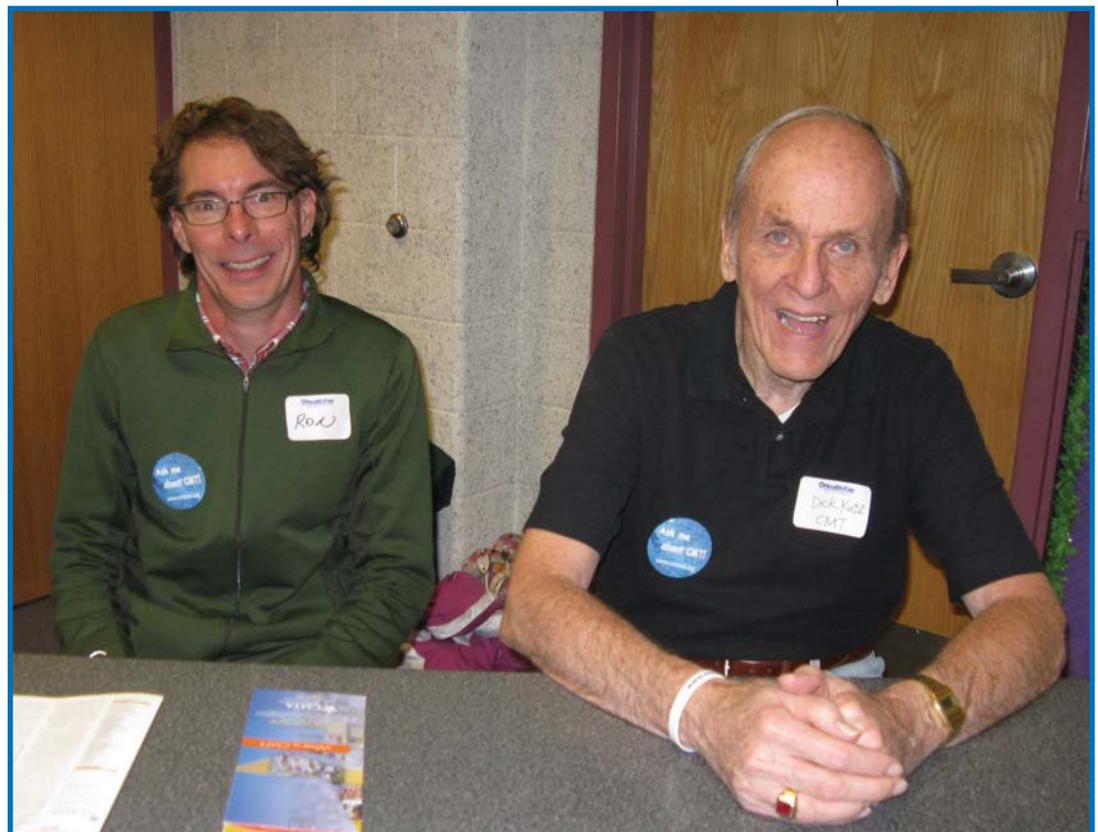
youngster and being his high school P/E instructor’s worst nightmare, he somehow escaped being severely disabled at an early age and, so far, has not needed orthoses. He feels humbled by this lack of severe symptoms in comparison with others

who endure so much more on a daily basis.

According to the “1 in 2,500” statistic, there are approximately 1,000 in the Denver metro area with CMT (and 2,000 in Colorado as a whole). Ron and Dick are excited when they have more than 25 at a SAG meeting. Although they make every attempt to attend outside functions such as bike rallies sponsored by an area hospital or a neurological clinic to raise awareness, more work remains to be done.

Currently, because of the new website, we have online members from both Wyoming and Nebraska. We are heartened by how the new website has provided access for these members. We continue to work to encourage more support groups in other parts of Colorado. ★

Ron Plageman and co-facilitator Dick Kutz are working constantly to raise awareness of CMT in Colorado.



SUPPORT GROUPS CELEBRATE AWARENESS

(continued from page 5)

to the Strategy to Accelerate Research (STAR) program.

FL—Tampa Bay

In lieu of their usual CMT group meeting, they set up a special event. A member, Ed Linde, is an avid bowler and set up an event with the help of his local lane and the American Wheelchair Bowling Association. The AWBA also provided financial assistance so our members got discounted prices, and everyone got the chance to play at least a game. Especially heartwarming was seeing parents with CMT having the chance to actively play with their children.

FL—West Palm Beach Area

On October 6, 2012, the first South Florida Support and Action Group was a great success. We packed the conference room with 44 patients, family, and friends, including several teenage patients who were all

captivated by a presentation given by Jeana Sweeney. People made new friends, exchanged contact information, offered up their personal stories, and left more informed and uplifted.

GA—Atlanta Area

On Saturday, September 15th, the group gathered at Stone Mountain Park for the 2nd Annual CMT Awareness Picnic. The kids had scooter races and enjoyed the attractions of Stone Mountain Park while the adults got to know each other better and really bond. The day brought our community closer together while raising \$2,000 for the CMTA.

IA—Iowa Area

Saturday, September 15th, the Iowa City CMT Support and Action Group held their first meeting. We were lucky to have in attendance—Dr. Mike Shy, Dr. Rosemary Shy, and Shawna Feely. A wide variety of CMT-related topics, plus some unrelated, but fun, topics were discussed.

MD—Easton Area

The group met on Saturday, September 9th. Awareness Month material was handed out to those who attended the meeting. Missy Warfield shared the proclamation from the county council, a newspaper article telling about the first year of the group, and about Awareness Month (and including a picture of Steve O'Donnell). She also strongly urged members to donate to the CMTA.

OH—Cleveland Area

The Cleveland Support and Action Group had a picnic on September 8th to celebrate CMT Awareness Month. Heather announced information about the Microsite and encouraged members to visit. She also spoke about the Presidential Proclamation and encouraged members to join the CMTA.

NJ—Morris County

The group met on September 15th, 2012, in celebration of Awareness Month. Support group member Kelly Cisco was presented with the "I'm A Shooting Star" Award (*see article on page 10*). The group also discussed STAR, the Transformation Project, and Aetrex.

NY—Long Island Area

On October 3rd the Long Island, NY, CMTA Support and Action Group held their first meeting. They had a full agenda and discussed all the updates and events going on within the CMTA community. They also discussed fundraising ideas. We look forward to meeting more

(continued on page 18)

Members of the Tampa Bay SAG enjoyed an evening of bowling provided by the American Wheelchair Bowling Association.



CMT Support and Action Groups in Your Community

AL—Birmingham Area

No group currently meeting
Will accept calls
Dice Lineberry
205-870-4755

AZ—Phoenix Area

Arizona CMT Support
and Action Group
Pamela Palmer
480-926-4145

*CA—Santa Barbara Area

Ventura-Santa Barbara, CA
CMT Support and Action
Group
Steve Fox
805-627-8225

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
Laurel Richardson
814-404-8046

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—North Haven

North Haven, CT CMT
Support and Action Group
Lynne Krupa
203-288-6673

DC—Washington, DC Area

Washington, DC CMT
Support and Action Group
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Orlando Area

Central Florida CMT
Support and Action Group
Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area

Tampa Bay, FL CMT
Support and Action Group
Vicki Pollyea
813-251-5512

*FL—West Palm Beach

South FL CMT Support
and Action Group
Phil Lewis
561-630-3931

GA—Atlanta Area

Atlanta, GA CMT Support
and Action Group
Susan Ruediger
678-595-2817

IA—Great Lakes

Iowa Great Lakes and
SW MN Regional Virtual CMT
Support & Action Group
Daniel Bachmann
507-399-0592

IA—Iowa Area

Iowa City, IA CMT Support
and Action Group
Jeffrey Megown
319-981-0171

IL—Chicago Area

Chicago Area CMT Support
and Action Group
Dale Lopez
708-499-6274

IN—Fort Wayne Area

Fort Wayne—Indiana CMT
Support and Action Group
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

KS—Wichita Area

Kansas Area CMT Support
and Action Group
Karen Smith
316-841-8852

KY—Burlington Area

Pam Utz
859-817-9338

MD—Easton

Easton, MD CMT Support
and Action Group
Missy Warfield
Seth Warfield
410-820-0576

ME—Portland Area

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

MI—Chesaning Area

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

MI—Kalamazoo Area

Southwest Michigan CMT
Support and Action Group
Jori Reijonen
269-341-4415

MN—Benson Area

No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area

No group currently meeting
Will accept calls
Libby Bond
417-845-1883

MS—Mississippi/Louisiana

Clinton, MS CMT Support
and Action Group
Flora Jones
601-825-2258
Cindy Chesteen
601-668-5439

NJ—Central New Jersey Area

Central New Jersey CMT
Support and Action Group
Mark Willis
732-252-8299

NJ—Morris County

Morris County, NJ CMT
Support and Action Group
Alanna Huber
973-933-2635

NM—Albuquerque Area

CMT New Mexico CMT
Support and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area

Las Vegas, NV CMT
Support and Action Group
Jerry Cross
775-751-9634
Virginia Mamone
702-343-3572

NY—Horseheads Area

Horseheads, NY CMT Support
and Action Group
Angela Piersimoni
607-562-8823

NY—Long Island Area

Long Island, NY CMT
Support and Action Group
Shari Loewenthal
631-254-8960

*NY—Manhattan Area

New York, New York CMT
Support and Action Group
Barbara Abruzzo
212-473-4157

NY—Upstate New York Area

The Upstate NY CMT
Support and Action Group
Melinda Lang
518-783-7313

NY—Westchester Area

Westchester, NY CMT
Support and Action Group
Beverly Wurzel
201-224-5795

OH—Cleveland Area

Cleveland, OH CMT
Support and Action Group
Heather Hawk Frank
440-479-5094

OH—Greenville Area

Greenville, OH CMT Support
and Action Group
Dot Cain
937-548-3963

PA—Bucks County Area

Bucks County, PA CMT
Support and Action Group
Linda Davis
Mitch Davis
215-943-0760

PA—Johnstown Area

Johnstown, PA CMT Support
and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319

PA—Northwestern Area

Erie, PA CMT Support and
Action Group
Joyce Steinkamp
814-833-8495

RI—East Providence Area

Rhode Island CMT Support
and Action Group
Meredeth Souza
401-433-5500

SD—Hartford Area

Hartford, South Dakota CMT
Support and Action Group
Serena Clarkson
605-838-2331

TN—Nashville Area

Nashville, TN CMT Support
and Action Group
Bridget Sarver
615-390-0699

TN—Savannah Area

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

TX—Dallas Area

Dallas, TX CMT Support and
Action Group
Whitney Kreps
972-989-5743
Merissa Lovfald
214-394-8907

UT—Orem Area

Orem, UT CMT Support and
Action Group
Melissa Arakaki
801-494-3658

VA—Harrisonburg Area

Anne Long
540-568-8328

VA—Williamsburg Area

Williamsburg, VA CMT
Support and Action Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area

Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WA—Tacoma Area

Tacoma, WA CMT Support
and Action Group
Carol Hadle
253-476-2345

WI—Brodhead Area

Southern, WI CMT Support
and Action Group
Molly Hawkins
608-921-0032

WI—Milwaukee Area

Southeastern, WI CMT
Support and Action Group
Polly Maziasz
262-439-9009

WV—Vienna Area

Parkersburg /Vienna WV
Support and Action
Rebecca Knapp
304-834-1735

GROUPS IN CANADA AND MEXICO

CAN—Montreal

Montreal (Canada) CMT
Virtual Support Group
www.cmtausa.org/url/
montrealsag

*CAN—British Columbia

Victoria, BC CMT Support
and Action Group
Melanie Bolster
250-888-7713

*CAN—Ontario

Southern Ontario CMT
Action & Support Group
Kelly Hall
519-843-6119

*CAN—Montreal

Montreal (Canada) CMT
Virtual Support Group
www.cmtausa.org/url/
montrealsag

MEXICO

(This group will be in
Spanish.)

México CMTA Grupo de
Apoyo y Acción
Gina Salazar
Gina_oviedo@hotmail.com

VIRTUAL/DISCUSSION GROUPS

Anyone Can Fundraise

Archy and Friends Discussion
Group

Boston South Shore Voice
Discussion Group

CMTathletes

CMT Speaks

CMT and Anger Discussion
Group

CMT and Fatigue Discussion
Group

CMT and Occupational
Therapy Discussion Group

CMT and Pain...Share Your
Experience Discussion Group

CMT Creates: Music Project
Discussion Group

CMT1x or Cx32

Emotional Support For CMT
Discussion Group

Genetics and CMT

Global Support and Action
Group Community

Hand and Finger Struggles
with CMT Discussion Group

Insurance and Benefits
Discussion Group

Marijuana and CMT
Discussion Group

Musicians with CMT

Parent with CMT who are
raising kids with CMT
Discussion Group

The CMT Outdoorsman
Discussion Group

Trigger Points Discussion
Group

Walking Assistive Devices
Discussion Group

Most Support and Action
Groups, Virtual Groups,
and Discussion Groups
can be accessed at
www.cmtausa.org.

They can be found in the
CMTA Online Community
under Support and
Action Groups.

If there is no support group in your area, consider becoming a facilitator!
If you're interested please contact Jeana Sweeney at jeana@cmtausa.org.

***WELCOME TO OUR NEW SUPPORT GROUPS!**

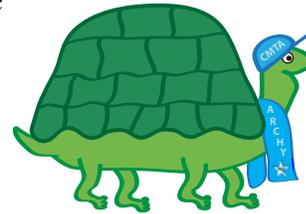
Being Thankful and Making Wishes

Who doesn't look forward to the holidays? I mean once fall arrives, we have Halloween and then Thanksgiving and Christmas and Hanukah. It's hard not to get excited about all the celebrating. But, this year I was not so happy about our family get-together for Thanksgiving, or Harvest Festival as we often call it.

My mother has three sisters and one brother. Since we are an x-linked family, her brother did not inherit CMT from his father. That causes problems all its own. His kids are a little quick to criticize me for doing things slowly or not at all. Their parents always step in to correct them, but frankly, the hurt feelings don't go away so easily.

This year one of her sisters was coming with her family. Her sister inherited the CMT as did all the girls and she has two boys who also inherited it like I did from their mother. Initially, I thought the visit would be more fun because we would all share the same problems and would be able to do all the same activities. What I learned was something completely unexpected.

My cousins live in an area of the country that is not as filled with medical experts as where I live in Greenwoods.



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

When Tommy and Teddy arrived, I was astonished to see how disabled they seemed to be. They didn't wear AFOs and their walk was very unsteady and awkward. It was pretty obvious that they simply didn't know much about how CMT should be treated. We found out that they had never been evaluated. When they started having problems, their mother, Aunt Tess, just assumed they had the same problems as Grandpop Turtlebaum. Without an official diagnosis, they were not getting any special accom-

SUPPORT GROUPS CELEBRATE AWARENESS

(continued from page 16)

members and hearing from people who were unable to attend this first meeting.

NY—Manhattan Area

The New York, NY, CMT Support and Action Group had its first meeting on October 6th, 2011. Those who attended shared their experiences with, and resources for, CMT. All expressed gratitude that there is now a SAG in NYC! Next meeting is December 8th, when Jeana Sweeney, Director of Community Services, will be our guest speaker.

NY—Upstate Area

On September 15, National Support Group day, support group member Christine A. Hook was presented with the CMTA's "I'm A Star" Award (*see article on page 11*). Christine has raised funds for the CMTA through the sale of her art work at the Art de Cure gallery for CMT.

TN—Nashville

The group met on September 22nd at Buffalo Wild Wings in Mount Juliet for lunch and discussion. Bridget Sarver, the facilitator, opened the meeting with the exciting news that CMTA had been awarded \$10,000 from Chase Community Giving. Also discussed was the Star Transfor-

mation Project, the President Proclamation, and fundraising.

Canada—Southern Ontario

The group met on September 22nd. Kelly Hall, the support group facilitator, explained the CMTA's STAR Initiative, as well as the Transformation Project. She also explained to the group that she is continuing to contact and network with professionals to further develop the group's medical resource database. They also held the 2nd Annual Walk for CMT Fergus Fundraiser on September 30 at the Victoria Park in Fergus, Ontario (*see photo on page 1*). There were 80 participants, and they raised over \$5,600!

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modations at school, and they were not registered with their local MDA for help with testing and physical therapy.

When I tried to talk to Tommy and Teddy about CMT and all the things I've learned since working with the CMTA, they really weren't interested. Their philosophy seemed to hinge on ignoring the problems and hoping they would go away at some point. I mean, they didn't even seem to understand that their CMT would get worse, for sure, if they didn't work to prevent that. I invited them to go swimming with me, and they said that they weren't very good at that. They had avoided doing exercises of any kind for so long that they really didn't have much muscle left in their legs. Frankly, it scared me. Even their mother didn't seem terribly interested in all the information that my Mom tried to give her and tell her about.

Not only did this experience make me feel terrible for my cousins, but it made me think about families that live in more rural, or less populated areas where the medical care is not as good as I can take advantage of. It's difficult to deal with CMT. Period. But, if you add in trying to deal with it on behalf of your children when there is no one who understands how the disease will manifest and what preventive measures should be taken, it's much worse.

So, in this season of celebration and Thanksgiving, I am so grateful that I know as much about CMT as I do and that many wonderful people care for me and advise me. What I wish for is that everyone would take advantage of all the information that exists about CMT so that their care would be the best that is possible. ★

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

CMT PATIENT MEDICATION ALERT:

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

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

Uncertain or minor risk:
5-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
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

THE CMTA Report

The Charcot-Marie-Tooth Association
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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 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN can now be diagnosed by a blood test.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.