

THE CMTA Report

JANUARY/FEBRUARY
2014

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



OUR MISSION:

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

OUR VISION:

A world without CMT.

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2013—What a Year for the CMTA!

To My CMT Family,

As we prepare to greet the New Year, I have found myself reflecting on the amazing year we had in 2013! I am continually overjoyed by the abundant support from our community—in awareness efforts, sharing of stories, and financially supporting the CMTA. Your commitment to us has allowed the CMTA to realize successes we only dreamed possible five years ago. When I started writing them all down, I was so proud of what we have done that I just needed to share them with you, our family.

STAR

Because our ultimate vision is a world without CMT, I am especially proud of our scientific progress. This year we reached major milestones, including the following:

- ★ One drug candidate has shown PMP22 down-regulation in a long term CMT1A laboratory study! This could be the first candidate medication making it through the STAR process for potential human trials in 2014.
- ★ We have agreements for collaboration in drug discovery with two major pharmaceutical companies. In 2014, we will continue conversations with three other major companies to help with the research and development of pharmaceutical therapies.

- ★ We entered a relationship with SAGE Labs Inc., which produced new laboratory models of CMT2A.

- ★ We purchased successful laboratory genetic models of CMT1A from the academic developers.

- ★ We developed a testing relationship with PsychoGenics, a leader in preclinical contract research with highly specialized expertise in neurological testing of models.

- ★ We added several world-class investigators to the STAR network, including Dr. Robert Baloh at Cedars-Sinai in Los Angeles and Dr. Mario Saporta at LaNCE in Brazil.

- ★ We now have 17 Centers of Excellence worldwide, including Nemours Children's Hospital in Orlando, Florida.

I am so very proud of our STAR scientific team and their collaborative efforts. Gone are the days of researchers working independently as STAR has brought the world's best CMT researchers together to succeed!

Support and Action Groups

One of the things I have learned this year is how eager people in our community are to connect with one another. We reach our community in person though

our Support and Action Groups and virtually over the internet.

CMTA Support and Action Groups are a vital part of the CMTA community. They are

STAR has brought the world's best CMT researchers together.

mutual self-help groups whose members share stories, experiences and ideas for coping with CMT. During the year, the CMTA took on nine new Support and Action Groups in four new states! To date, the CMTA has 63

Support and Action Groups in 34 states, three groups in Canada and one in Mexico reaching over 10,000 people. This number is growing every month, and new individuals are volunteering every month to join the CMTA Support and Action Group Facilitator team!

Our support groups are about providing the resources to the CMT community but we also take action! The facilitators

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Staying Fit with CMT

BY DAVID OFFERRALL

What do you think about when you hear the word “exercise?” Do you cringe? Do you feel, “I can’t?” Or, perhaps, you do exercise and you feel, and look, great. Whatever the case may or may not be, exercising with CMT raises real questions such as:

- How will exercise benefit me?
- How often should I exercise?
- How intensely should I work out?
- What exercises can I do?
- How long should I work out?
- What challenges will I face, and how do I approach them?
- How can I get the best results?

Before beginning any exercise program you should consult with a supportive doctor.

The book *Muscles: The Magic of Motion* states; “Exercise helps the body inside and out...Muscles exercised regularly do a better job at everything.”

Anaerobic exercise such as lifting weights on a regular basis strengthens your muscles. CMT does not affect the whole body, which means we can work on our large muscle groups and strengthen them. If these muscles are stronger, they will store more sugar and fatty acids and burn them more efficiently. More than that, your body will resist fatigue. That’s a huge consideration.

Aerobic exercise like brisk walking, swimming, or biking promotes overall fitness. Blood flow increases to the muscles; and leads to an increase in ATP, a biochemical in the body necessary for muscle contraction. In

addition, aerobic exercise helps the heart.

How often should I work out?

Dr. Hatfield, PhD, suggests twice a week to maintain the body, three times a week for those just starting out, and five or more times a week for the serious fitness enthusiast.

How intense?

We should train at a high intensity. Since there are real limitations, it is recommended that we partner up with a qualified professional to determine what high intensity is right for you, as every individual is at a different fitness level. A qualified professional can conduct a fitness assessment to test upper body strength levels, lower body strength levels, and run a muscular endurance test.

What types of exercise? It is best to use a wide variety of exer-

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2013

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and community members took fundraising and awareness by storm in 2013! From dinners and walks to minor league baseball awareness events, our communities raised close to \$500,000.

Social Media Efforts

Sometimes the impact of social media can be underestimated. Why is it important for a group like ours to increase our social media presence? One reason is because so many of you feel isolated and alone with CMT. I am here to proclaim that you are no longer alone!

Since we’ve focused on our Facebook page, our fan base has

grown from under 800 to over 12,000! These fans are found worldwide representing over 45 countries. We reach over 4 million friends of fans about CMT, and we have expanded our reach to include “Charcot-Marie-Tooth Association,” “CMTAthletes,” “CMTA Youth Group” and “CMTA Parents.” Join the conversation about CMT on Facebook, Twitter, YouTube and LinkedIn.

Patient-Family Conference

We held an extremely successful Patient-Family Conference in Orlando, Florida, in November with over 200 people in attendance. Over 20 children with CMT enjoyed a day at Walt

Disney World’s Magic Kingdom while their parents were able to attend the conference and learn about the many resources that exist in Florida. Additionally, the community was able to connect with one another, meeting others with CMT and finding local and regional friends.

Awareness Month 2013

September 2013 was the second annual CMT Awareness Month. Over 24,000 people came to visit our website to learn more about CMT, and we held our first live webinar featuring Dr. Michael Shy. During Awareness Month, over \$45,000 was raised by our community members, old and new!

cises and methods to strengthen muscles in affected and unaffected areas of the body.

How long? Thirty to sixty minutes is recommended for beginners. In my case, as an athlete, I train 2-3 hours at a time.

What challenges will I face? You will discover balance and weakness will affect your ability



to exercise. Talk to your doctor about certain braces and exercise accessories that will help you stabilize your body during exercise. I use straps for my hands and braces for my knees when I

leg press. There are also braces for elbow joints.

How can I get the best results? A program consisting of good nutrition, cardio, and resistance training will give you the best possible results. We have discussed the benefits of cardio and resistance. We must also acknowledge that nutrition is key to success.

The Wall Street Journal reports: “On every continent of the globe, even including regions where malnutrition is rife, the number of people who are either overweight or obese is rising at an alarming clip. The major culprit is the same combination of high-calorie diets and sedentary behavior that fuels the epidemic of fat in the U.S.” One professor

of health behavior at the Karolinska Institute in Stockholm, Sweden, said, “There is no country in the world where obesity is not increasing.” We are not exempt from this. Those of us with CMT need to control our weight with good nutrition and exercise. Why? Try picking up 20 pounds of potatoes and going for a walk. What will happen? Mobility will be affected significantly. What is the solution? The book *Fit or Fat* says, “The ultimate cure for obesity is exercise...”

You may wonder if such an undertaking is possible. You may wonder if you can really get fit. The answer is an emphatic “yes!” Just because we have CMT does not mean we can’t get fit and stay fit. With determination, training, proper nutrition, and plenty of rest, we can be confident that we will get fit and stay fit, even with CMT. ★

Financial Success

For the first time in our history, the CMTA has passed the \$2 million mark in donations! Clearly, you believe in the work we are doing to find the first treatments for CMT, to improve the quality of life for those living with CMT and to increase awareness about CMT. We hope to continue to prove our worthiness of your hard-earned dollars. You make a difference in the CMT community.

2014: What a Year to Come!

Believe it or not, 2014 is poised to bring greater success to the CMTA. We know that we will launch a STAR program for CMT Type 1B in the first quar-

ter of the year. We will have our laboratory models ready for candidate drug testing by the second quarter of 2014, and we are confident that we will develop the first human trial for a candidate compound for CMT1A. We will host two Patient-Family Conferences in California and announce new corporate partnerships as we continue to grow.

Thank you for your incredible support! Without you, the members of the CMTA family, we would not have the financial resources to accomplish these significant milestones. You are making a difference in the lives of people with CMT—today through our Support and Action

Groups, social media initiatives and Patient-Family Conferences, and tomorrow, through STAR, our successful and validated research initiative. Thank you for all you have done!

In closing, I urge you to continue to fight for those with CMT. Tell your story about why you are a part of our family, share information via social media about the CMTA, connect locally and nationally with people in our family and continue to provide the support you have. Together, as a family, we will succeed. I look forward to sharing more tremendous success throughout 2014 with you.

My heartfelt thanks,

Pat Livney, CEO

Orlando Conference Underscores Treatment Options, Research and Hope

BY VICKI POLLYEA

When anyone reads a CMT blog, post, chat-list, or Facebook page, he or she always reads how alone people feel and that no one understands CMT and all the issues that someone with CMT copes with. My response to these posts is always the same, “Go to a CMTA patient and family conference or support group.” I never will forget the first time I entered a conference room filled with people who knew what CMT was and who shared many of my issues. From that moment on, I knew I never would feel alone again.

Over the years, I have attended many support groups and CMT conferences, and I still get a rush of emotions when I spot other people who walk like me or who use a pen as I do. Considering the Internet, the many support groups across the country, and patient and family conferences hosted by the CMTA, there is no reason for anyone to feel isolated. The November 11, 2013, conference in Orlando, Florida, was well worth the trip.

Patrick Livney, the CEO of the CMTA, opened the conference by stating the focus of the CMTA. Although there are many things that need to be done, the CMTA decided it would be best to limit the focus to three missions: patient advocacy, increasing awareness, and research.

The STAR initiative has been a huge success, as it has moved the researchers out of isolation in their labs, toward meeting frequently and sharing the steps needed in achieving their mutual goals. This level of accountability and cooperation between scientists has already proven to be a success, and they are ahead on the timeline they established to achieve the goal of finding treatments for CMT.

Patient advocacy has improved as the number of Support and Action Groups has grown from 8 to 65 in the US,

Support and Action Groups reach over 10,000 people affected by CMT.

with three in Canada and one in Mexico. Now, there are over 10,000 members participating in the groups. They have also increased participation in social media, including Facebook and Twitter.

CMT Awareness Week is now Awareness MONTH. There is a new level of cooperation between CMT groups across the globe, with 45 countries participating in Awareness Month activities.

The CMTA has increased the number of members on its Advisory Board. Their fields of expertise include law, orthotics, mental health, education, social

media, physical and occupational therapy, etc., and people can direct questions and issues to the Advisory Board through the CMTA’s website.

The Board of Directors governs the CMTA and, besides providing a foundation for the organization, all members of the Board of Directors have agreed to raise or donate fifty thousand dollars a year to the CMTA.

The first speaker to address the audience at the conference was Richard Finkel, MD, Chief of Neurology at Nemours Children’s Hospital in Orlando. The evening before the CMTA conference, Dr. Finkel and his team hosted a tour of Nemours. This CMT clinic is focused on making children’s time at the hospital fun and less stressful. The physicians and clinicians move from room to room versus having to transport children all over the hospital.

Nemours is the newest CMT Pediatric Center of Excellence. The CMT team includes a pediatric orthopedist, a pediatric physiatrist, an OT, a PT, a nutritionist, and a geneticist. Dr. Finkel and his team assisted in developing and testing the new Pediatric CMT Scale, which evaluates a child’s level of function in a variety of areas, including fine and gross motor skills. This evaluation tool helps document progression and will be useful in evaluating effective-



CMT staff, Advisory Board members and support group leaders attended the Orlando conference. Top row, left to right: Elizabeth Ouellette, Bethany Meloche, Sean McKale, Susan Ruediger, David Misener. Bottom row, left to right: Kim Hughes, Steve Weiss, Jonah Berger, Jeana Sweeney.

ness when treatments become available.

Dr. Finkel stressed that CMT is a treatable condition. Issues that Dr. Finkel believes need more focus include muscle weakness, pain, fatigue, and joint tightness. Changes in the feet and ankles can significantly impact walking and developing other gross motor skills.

As children go through rapid stages of growth, their issues and problems also change, even if their CMT is not progressing. Children might have issues keeping up with peers, participating in physical activities, maintaining muscle balance, and developing age-related fine motor skills. Having a child's CMT medical team work with that child's academic team can help ensure that CMT issues do not keep a child from progressing and being successful at school.

The next speaker, Steven Frick, MD, Chairman of the

Department of Orthopedic Surgery at Nemours, has found that in children with CMT, 10 percent have issues of hand involvement, 10 percent have scoliosis, and 10 percent have hip dysplasia, and that many of the above issues will require surgery. All children need to be evaluated for the above issues as well as the typical foot issues one expects to see in anyone with CMT.

As foot deformities increase over time, the deformities become rigid and more difficult to reconstruct. Before deformities become rigid, he thinks that non-operative interventions are preferred. Shoe orthotics, bracing, and sometimes serial bracing can all be very effective.

When surgery is considered for a child, the goals of the surgery need to be identified and should include stability during weight-bearing and maintaining muscle balance. His opinion is that surgery should be consid-

ered when there is a lack of foot clearance during the swing phase of walking due to foot drop and there is no longer the stability to bear weight.

He stressed that the benefits of any surgery must outweigh the risks. The types of procedures used on feet impacted with CMT have evolved over the years. Often with children, surgical intervention in soft tissue has better results than surgery on bones. What was once considered the standard of CMT surgery, a triple arthrodesis (fusion of the ankle), is no longer a preferred procedure as they have discovered that ankle fusions increase damage to the knees and hips, often requiring further surgery or even replacement of the knees and hips. When consulting with an orthopedist, he thinks the first question everyone should ask is how familiar and experienced with the progressive nature of CMT the orthopedist actually is.

The next topic, Orthotic Management of CMT, was presented by two members of our Advisory Board, Sean McKale, CO, LO, and David Misener, CPO. In CMT, there is a sequence of muscle loss that results in classic deformities and causes future issues. An orthotist evaluates if there is a way to accommodate the deformity while providing functional corrections. No orthotist can make a CMT foot "normal," so, the patient needs to work with the orthotist to identify his or her primary issues. Then, an orthotist attempts to improve the biomechanics that will decrease the physical symptoms.

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ORLANDO CONFERENCE

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It was stressed that we all differ in our tolerance for equipment. No one brace is the perfect solution. We need to be our own best advocate and must keep going back until the brace fits and does what was initially decided was the goal. Nearly half of those in attendance admitted to having a brace in their closet that they just gave up on. Sean and David stressed the importance of going back and working with one's orthotist to find a solution.

Thankfully, over the past decade, the materials and designs for AFOs have evolved tremendously. Hard AFOs made out of rigid thermoplastics are very "old school." Even off-the-shelf carbon fiber products such as "Blue Rocker" and "Toe-Off" braces can be customized by an attentive orthotist. Double-action laminated AFOs that have energy return can be very useful. A newer design, "Noodle AFOs," comes in different strut strengths and also can be modified to the individual foot. Silicon AFOs are very soft and can work for those with painful joints and serious issues with calluses.

You might need more than one type of AFO, and it likely will evolve as your condition changes. Working with an interested orthotist is the first step in getting the correct device.

Jeana Sweeney, the CMTA's Director of Community Services, shared her enthusiasm and commitment in focusing on the

goals of increasing awareness and fundraising for the CMTA. Jeana shared that many patients feel frustration that CMT is not more well-known but said that it is up to each of us to increase awareness about CMT. If we don't talk about it and share what CMT is, who will? Make sure that your friends and family know what CMT is and practice explaining what CMT is in 60 seconds or less. Then ask them to help you spread the word. Check out the cmtausa.org web site. If you ever need some encouragement on your awareness or fundraising efforts, reach out to Jeana!

The type of brace you need will likely evolve as your condition changes.

Stephan Zuchner, MD, PhD, Chair of Human Genetics at the University of Miami, shared exciting news regarding the world of CMT and genetics. Dr Zuchner alone has identified over 15 genes that carry CMT, including the one for CMT Type 2B.

With significant improvement in genetic sequencing technology, this area of study has improved 100,000 fold in just the past 10 years. Now it is possible to examine the entire DNA of a person, over 3.2 billion genes.

Now the field of genetics is looking at "exome sequencing" as it is a more efficient tool of measurement and only needs to examine the position of 2,000 genes. The number of genes identified as causing CMT is

significantly increasing; it is now over 73, and Dr. Zuchner expects it to reach 200 genes. He and other scientists suspect that besides the specific genotypes, the understanding of genetic modifiers will be the next important step in understanding the genetics of CMT. Genetic modifiers would explain the wide variability in symptoms, age of onset, and degree of disability within the same family or the same genetic type.

The commercial genetic testing through Athena is limited in the number of genetic types that they can evaluate. It is suggested that your neurologist, in ordering genetic testing, limit the test requested based on whether your nerve conduction velocity reflects axonal or neuronal changes. For those

people who have Type 2, with a sub-type of "unknown variant," it is suggested that you work through a Center of Excellence in getting your DNA sample to a lab such as Dr. Zuchner's.

Michael Shy, MD, Director of the CMT Clinic at the University of Iowa, Chairman of the CMTA's Medical Advisory Board, and co-founder of the CMT International Research Consortium, was the last speaker. Since researchers are exploring treatments for CMT, ways to modify the CMT genes and decrease the PMP22 protein levels seen in CMT1A, Dr Shy focused his presentation on how to measure changes and the impact of future human trials.

One important action for all who have CMT is to register

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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.

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In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
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VISA MasterCard American Express

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Name: _____

Address: _____



James Nussbaum is a member of the CMTA Advisory Board and the Clinical and Research Director of ProHealth & Fitness PT OT, www.prohealthptot.com 212.600.4781

Using Therapeutic Exercise and Physical and Occupational Therapy to Improve Function and Quality of Life

BY JAMES NUSSBAUM, PT, PHD, SCS, EMT

Quality of life (QOL) improvement is the goal of most patients and therefore should be very high on the priority list of goals for healthcare practitioners. Every person has a different hierarchy of the factors leading to improved physical function and QOL; however, there are a few fundamental items reported by many, including independence and comfort in activities of daily living (ADL), mobility, and physical function and control.

Physical function, in general, mobility, ADL, and control over one's life can all be negatively impacted by weakness, pain, joint restrictions, sensory loss, and imbalance. These symptoms and impairments along with others are often seen in patients with a diagnosis of CMT. They all negatively impact physical function and QOL and should be skillfully addressed by healthcare practitioners in an effort to help their patients with CMT.

Patients newly diagnosed or with long-standing CMT typically see neurologists, orthopedists, physiatrists and other medical and healthcare professionals. Unfortunately, rehabilitation specialists, physical (PT) and occupational (OT) therapists, who are the experts in

physical function and dysfunction, are not common (or common enough) members of the healthcare team providing regular skilled care for patients with CMT. *The purpose of this article is to advocate that every patient with a diagnosis of CMT undergo an evaluation and treatment (if warranted) by a PT and OT to help improve physical function and QOL.*

Exercise is often seen as a panacea given its positive effects on so many health-related variables. Numerous medical and public health organizations and even government agencies provide exercise guidelines for their patient and general populations. Recommendations for exercise include cardiovascular exercise, resistance work, and recreational activities that help to keep people active. While exercise is generally thought of as terrific for most, there are instances where it requires more careful guidance. There is a potential danger of exercise in patients with CMT called overwork weakness, a condition described in the medical literature as weakness caused by doing too much. This concept has been spoken about for more than half a century, but it is still not fully understood. Given the fear of overwork weakness and the

other complexities found in patients with CMT, a skilled evaluation by PT and OT, along with carefully prescribed, and at times supervised and monitored exercise, is imperative.

The National Institute of Health's service, MedlinePlus, along with the U.S. Centers for Disease Control and Prevention define exercise as follows:*

Regular physical activity is one of the most important things you can do for your health. It can help

- Control your weight
- Lower your risk of heart disease
- Lower your risk for type 2 diabetes and metabolic syndrome
- Lower your risk of some cancers
- Strengthen your bones and muscles
- Improve your mental health and mood
- Improve your ability to do daily activities and, if you're an older adult, prevent falls
- Increase your chances of living longer

Fitting regular exercise into your daily schedule may seem difficult at first. But even ten minutes at a time is fine. The key is to find the right exercise for you. It should be fun and should match your abilities.

Another definition: Physical exercise is physical activity which overloads the body in some way, or which causes the

* <http://www.nlm.nih.gov/medlineplus/exerciseandphysicalfitness.html>

NEW MEMBER JOINS CMTA BOARD OF DIRECTORS

I was diagnosed with CMT1A when I was eight years old. My experiences growing up with Charcot-Marie-Tooth disease led me to a career in medicine. Prior to medical school, I completed a Masters of Public Health and worked in public health research and health education. I went on to graduate from the University of Rochester School of Medicine and Dentistry. Now, as a board-certified pediatrician and father of three, I appreciate the critical role of the CMTA.

For my family, the CMTA serves as a bridge between the science of the disease process and the support and wellbeing of those of us with CMT. The CMTA also represents hope for our children that they may someday benefit from the research supported by the CMTA and the new therapies that result from it.

—Peter I. Warfield, MD, MPH



ORLANDO CONFERENCE

(continued from page 7)

on the Rare Disease Clinical Research Network Inherited Neuropathy Consortium. This is the place researchers turn to develop tools, and where they will look to find people to do human trials. Only 1,500 have registered so far! If you do nothing else, please register at: <http://rarediseasesnetwork.epi.usf.edu/INC/>.

The establishment of CMT Centers of Excellence is now world-wide, and they are found at 17 locations. Besides providing rational approaches to treatments and dealing with current issues of CMT, these centers are developing reliable and repeatable tools for evaluating the progression of CMT and future cures.

The CMT Neuropathy Score is currently being revised. This is an evaluation tool that measures the current status of a person coping with CMT. For the test to be an effective tool, each person is tested exactly the

same no matter who does the testing. It also has to have information reliability (no difference in the testing score between different evaluators).

Recently it was discovered, during MRI imaging, that when muscle cells atrophy due to CMT, they turn into fat cells. Small MRI studies of the thigh muscles are showing promise as a tool to measure loss of muscle function and, hopefully, one day the return of muscle cells after treatment.

Another measurement tool that is being developed is the use of skin biopsies. From a small punch biopsy of the skin, the skin's fibroblasts can be modified to original stem cells and then grown into neurons. Further testing of these neurons can be used to evaluate effectiveness of potential treatments.

In his closing, Dr. Shy shared that another important area that he and others in the world of CMT are identifying and developing is the next generation of neurologists and research leaders.

Pat Livney, in his closing remarks, mentioned how grateful he is to have the support and commitment of all of us in the work of the CMTA. The CMTA is an organization comprised of people who are living with CMT or who have a loved one with CMT. With the great strides achieved through the STAR initiative, this is a time of hope. Knowledge about CMT is increasing significantly every year. What is known now is ten-fold what was known 10 years ago.

Pat then asked how many in attendance met someone else with CMT for the first time that day. A number of hands went up. My hope is that the next time Pat asks this question, fewer hands will go up, as that would indicate we are reaching people and that people no longer feel isolated. If ever there is a CMT Patient and Family Conference near you, I hope you will consider attending. I promise you will learn a lot, feel less isolated, experience the excitement of hope, and eat well. ★

The 2013 Rebecca Sand Volunteer of the Year Award Goes To....

BY ELIZABETH OUELLETTE

"Volunteers don't get paid, not because they're worthless, but because they're priceless."

—Sherry Anderson

Working relentlessly to spread awareness, fundraise and advocate for those with CMT, Rebecca Sand is fondly remembered for her passion, enthusiasm and community outreach efforts. In 1990, Rebecca received the CMTA's first Volunteer of the Year award for her tireless, selfless efforts on behalf of all those with CMT.

This year, the honorary Rebecca Sand Volunteer of the Year Award was given to not one, but two, outstanding individuals for their dedication, commitment and service to the CMTA. Congratulations to Robert DeRosa and Vittorio Ricci for going above and beyond the call of duty to drive the CMTA's mission of a world without CMT forward.

Fate is what brought Robert "Bob" DeRosa, Director of Marketing at Aetrex Worldwide (an invaluable CMTA sponsor), to the CMTA. Bob does not have CMT, nor do any of his family members. So, how did he initially get involved with the Association?

Standing in at the last minute for one of his Aetrex colleagues at a Focus Group, Bob had the opportunity to not only meet members of the CMT community but also witness the passion and dedication of



Vittorio Ricci and Robert DeRosa were honored for their dedication, commitment and service to the CMTA.

CMTA employees Jeana Sweeney and Susan Ruediger. After reviewing a few CMT-related pamphlets and brainstorming ideas, Bob saw an outlet for his creative mind. At that moment, he thought, "Why would I not want to contribute to a great cause, for great people, with the skills I have? From that point on, my involvement with the CMTA has evolved and intensified."

Over the past year, Bob has donated much of his spare time to the CMTA. He's created

everything from the Awareness Month website, posters, postcards, ribbon, and magnets to CMTA pins, flyers, bookmarks, brochures and banners. His contributions are endless, as are his original ideas. He's changed the way the CMTA looks and feels from the inside out, making our messages more widespread, effective and catchy.

Working with the folks at the CMTA has given Bob a great feeling inside, one that encompasses love, family and relationships. "When it is time for me to go, I will leave knowing that I did some really good things for some really good people. Isn't that what it is all about?" he asks.

The feeling is mutual, Bob! Your imaginative genius continues to grab

the attention of our members, spread awareness and fund important research projects. We thank our lucky stars that we have a close and sincere friend in you. 2014 promises to be another year of creativity, which our members will experience with the fresh website designs and billboard messages. To a sensitive, caring soul with a big heart, we thank you for your vital input and on-going inspiration.

When Vittorio Ricci first came on the scene, we knew we had met a special breed of teen;

he's a fighter, a mover, a shaker and he's full of unstoppable determination. CMT is no match for this vibrant and passionate young man, as he has taken this diagnosis by the horns, choosing to deal with it head-on and openly.

Vittorio, backed by his family, joined the CMTA and started a "Circle of Friends" in August of 2012. Vittorio had just been diagnosed with CMT, and this news did not undercut his enthusiasm for life or living, but spurred him on into a flurry of action and activity! In his own words, Vittorio states, "I choose not to waste a minute of my time being upset, because I'll lose a minute of happiness." Seriously folks, what kind of kid writes three articles for the CMTA newsletter, the last one entitled, "Celebrating My First Year with

CMT?" He's simply amazing!

Within that first year, 14-year-old Vittorio has not lost any time spreading awareness of CMT or fundraising for the CMTA. Among his many accomplishments, Vittorio gave presentations about CMT to students at both his former elementary and his current high school. He's been interviewed on TV, lauded as a Hometown Hero for CMT Awareness. He even went to the Massachusetts State House in September, where the Senate signed a Resolution recognizing September as CMT Awareness month.

He's written numerous articles for the CMTA newsletter as well as his home town newspaper. And, Vittorio's "Circle of Friends" (cmtausa.org/url/vittorios-cof) has raised over \$45,000, the cumulative total

for the diverse fundraisers he and his family have hosted.

Vittorio is also an accomplished athlete who loves to mountain bike. He signed up for cross-country, joined the ski team, participated in a triathlon and is very involved with CMTAthletes. As you can see, when Vittorio says, "My life is happening now. I'm going to give it hell." He's not joking around. This guy means business! And he won't stop there. In his last article, he wrote, "There is more to be done and I look forward to my second year of opportunities."

Congratulations, Vittorio, for all your unwavering determination to make a difference in the lives of many! You are our inspiration, and we look forward to hearing about all your accomplishments in 2014! ★

CPO ART DE CURE GALLERY FOR CMT DEDICATED TO HONOR CHRISTINE A. HOOK

BY MELINDA LANG, UPSTATE NY CMT SAG FACILITATOR

On December 5th at the Starry Night for CMT Art de Cure silent auction, the gallery at Clinical Prosthetics & Orthotics (CPO) in Albany, NY, was dedicated in honor of Christine A. Hook. Christine, a talented artist and member of the Upstate NY CMT Support and Action Group, volunteered as gallery coordinator for a year before her passing last February.

In addition, Christine won the CMTA's "I'm a Star" award last year for her efforts in raising awareness and money for the CMTA through the sale of her paintings at the Art de Cure Starry Night event.

Art de Cure, a 501 (c)(3) formed in 2010, is a collaboration between art and medicine. Art de Cure is a unique concept which brings art to an audience not likely to explore art galleries. Galleries are housed in medical practices and the work of regional artists is on display. The host practice chooses the charity that will benefit, and Art de Cure curates the shows.

Jackie Watsky, president of Art de Cure, presented a plaque at Starry Night that states: "The Christine Hook Gallery to Benefit CMT. This Art de Cure gallery at CPO is dedicated to helping people with Charcot-Marie-Tooth Disease and sharing Christine's love of art."

Along with one of her paintings, this plaque will remain on display in the gallery at the Albany CPO office for patients and the public to enjoy and be reminded of Christine.

The silent auction raised over \$2,300 for the Charcot-Marie-Tooth Association (CMTA), adding to the \$20,000 previously raised (with matching funds from a board member of the CMTA). ★

SAG FACILITATORS SPOTLIGHT:

Vicki Pollyea: My Path with CMT

I always knew there were things my sister and I could not do, or didn't do as easily as other children. Thankfully, we also had parents who sought ways to compensate; when I finally gave up on riding a bike, they found a 4-wheeled pedal surrey that was the hit in our neighborhood. Our parents also never let us quit; if I could not run, I would become a strong swimmer.

They also had to fight some battles that thankfully parents no longer have to fight. Every grading period there would be a meeting about my only failing grade. Even as a child I knew it was unfair to receive a failing PE grade when I tried as hard as I could.

When my mom was in her mid-20s (she was pregnant and I



Vicki Pollyea is the leader of the Tampa Bay Support and Action Group. She gets pleasure from kneading dough and baking bread.

was a 4-year-old) we were misdiagnosed as having a disease that causes dementia, the complete loss of motor skills, and an early death. The fear of that diagnosis stayed with our parents for another six years. I can only imagine what they coped

with; thinking our mother was soon going to decline and leave us, and our dad would be left with two children facing the same outcome.

Thankfully, when I was 10 years old, we were given the correct diagnosis: CMT, a progressive disease, but not one that would impact our mental abilities or cause premature death. I am so thankful that my parents encouraged us to dream and not let anything keep us from our aspirations.

Both my sister and I pursued jobs in the medical field, perhaps because we had spent so much time in the hospital when we were young. I worked as a pediatric occupational therapist, thinking I would remain stronger than the children. However, after complications of

The CMTA Circle of Friends: An Easy Way to Support STAR Pathways

What is a CMTA Circle of Friends? It's an easy way to fundraise without hosting a labor-intensive event. You can create awareness of the disorder, the CMTA, and the campaign we are running to find a treatment and cure for CMT—all without a huge effort.

We like to think of our "Circle of Friends" as a new approach to fundraising, but there's really nothing new in asking one's family, friends, and business contacts to support a favorite cause. The "Circle of Friends" begins with a personal appeal. Each of us has a "circle" of family, friends, people we do business with, places we shop and so on, and by reaching out to them with a personal letter or email, we can greatly enlarge the number of people who support the work of the CMTA.

We will provide you with a dedicated page on our website where you can have friends and family follow your efforts. You can even personalize your campaign with videos and photos.

We'll help you write your letter and provide you with brochures, newsletters and other documents necessary to start your circle.

Please contact Jeana Sweeney (jeana@cmtausa.org) for more information on creating a Circle of Friends. Together, with a little help from your friends, we can conquer CMT.

numerous orthopedic surgeries, the physical demands of working with no significant adaptations were very difficult. This was a year before the ADA was passed.

Also, as an occupational therapist, I realized that other roles in my life were perhaps more important than working part-time and having no energy for anything else. Wife, sister, aunt, friend, neighborhood leader, and godmother were roles as important to me as being a working therapist.

I also was blessed with a positive attitude toward adaptive equipment, thinking of the equipment as a tool for independence. From canes, walkers, AFOs, and my power chair and adaptive van, I can function better thanks to these tools.

I only wish I would have been more aware of how losing hand function would impact my life. I think this is an area that we often neglect until we have

lost too much function. As CMT progresses, loss of strength and function in our hands causes many issues. I wish I would have consulted sooner with hand surgeons to explore ways to maintain or improve strength and function in my hands.

A positive in my life is having a supportive husband who knows that sometimes I need to push myself a little too much, and then is there to help pick up the pieces from the overexertion. Our nearly century old home and garden provide lots of opportunities to try new activities. Now, I often provide the knowledge and guidance on how to do things, and he does the "grunt" work. Together, our home and garden remain a comfortable reflection of how we choose to live. Whether it is fishing, gardening, baking bread or being active in local politics, he is always there to support me when needed. Having a partner

who not only understands CMT, but also grasps the importance of my need to try things independently, is a gift that he gives me every day.

For years, I wrote articles about CMT, was active on chat-lists, and spoke about CMT but resisted leading a support group. Now, I realize how perfect a fit it is for me to be a support group facilitator.

The Tampa Bay Area has a great many people with CMT. New people regularly show up at our meetings, feeling encouraged and relieved to find others with their same issues. Organizing meetings, facilitating discussions, finding insightful speakers and topics, talking to people who are newly diagnosed, helping parents find resources for children with CMT, or supporting the efforts of the CMTA, I now find my role of being a support group leader one of the most gratifying jobs I have taken on. ★

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Mr. Thomas DeVesto
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Mr. & Mrs. Vittorio Ricci
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Building Resilience in Children

BY SARAH KESTY, MA IN SPECIAL EDUCATION

If your child has CMT, you're likely finding yourself coaching your child to continue on in the face of adversity—to pick her/himself up by the bootstraps, sometimes literally! Current research on resilience suggests the bootstrap approach may have it all wrong; those of us who forge paths through challenges never do so alone. Researchers¹ have uncovered several *Protective Processes* that can neutralize the impact of risk factors like CMT or other disabilities. Parents have an incredibly important role in a child's life with CMT! Here are some methods and perspectives on supporting a child who lives with a disability:

1 Take a new perspective on adversity: Feeling, or being perceived, as “different” is frightening for a child, impacting his self-esteem, social interactions, and group acade-

mic work. Your child needs you to help him develop a balanced view on having CMT. Focus on the “can’s” list and approach the “cannot’s” as problems-to-be-tackled, or speed bumps, rather than dead-ends.

2 Become his inner voice: Talk through his challenging times and acknowledge that they stink. Teach him go-to self-talk phrases to say or think to himself when he's challenged. Some examples:

- “Everyone has something. Mine is CMT.”
- “I’m having a bum moment, but by this time tomorrow, I will feel better.”
- “I have lots of great ways to get around this challenge.”

3 Coach the class and teacher: Your child is assuming a mix of others' opinions of him and meshing them into his own opinion of himself. Be sure your child's peers and teachers share your perspectives on CMT. The CMTA has presentations on CMT, or you can use the “Everyone Has Something” PowerPoint from my website, sarahkesty.com. Be sure the information you present explains the challenges of CMT but does not cause pity. The ideal result is a group of students who understand that everyone has a challenge of his own and who

recognize growth and strength in themselves and others.

4 Find a mentor: Pair your child with someone older with CMT who is doing well and is willing to share advice. These mentoring experiences often give children a vision of how amazing overcoming and thriving can be—a beacon of light they can look to in difficult times.

5 Keep the safety net strong: Experiencing your child struggling can drain a parent! Be sure to avoid “compassion fatigue” by replenishing yourself from time to time.²

6 Don't avoid the physical: Be sure to heed advice from your child's doctor, but do not steer your child away from physical activities for fear of pain or embarrassment. Confidence and social success come from sports, training, and other exercise. Werner (et al 2001)¹ found that children needed to have experiences giving them a sense of mastery. The lesson with these experiences is simple but profound: when we try hard and don't give up, we'll reach our goals. In contrast, a lack of mastery experiences (i.e., the denial of the chance to face a challenge and prevail) often leads to lower self-expectations.

RESOURCES FOR YOUR RESILIENCE JOURNEY:

- **CMTA Archy** at www.cmtausa.org/archy
- **Everyone Has Something:** book and blog for creating positive, empathetic classrooms at www.everyonehassomething.com
- **Peace builders:** Classroom lessons for empathy and acceptance and anti-bully tools at www.peacebuilders.com
- **Why Try:** visuals and information for resilience at school and in the workplace at www.whytry.org
- **A lighthearted look at the parent experience** at www.shutupaboutyourperfectkid.com
- **Eye to Eye:** Mentors for different thinkers at www.eyetoeyenational.org

¹ Werner, E. E., & Smith, R. S. (2001). *Journeys from childhood to midlife: Risk, resilience, and recovery*. Ithaca, NY: Cornell University Press.

² Figley, C. R. (1995). Compassion fatigue as secondary stress disorder: An overview. Compassion fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized (1-20). New York: Brunner/Mazel.

7 Remember the turning point is experiences. Your child may toil with his disability for years, but don't lose hope. He is growing in body and mind, and life has many turning point experiences in store.

For me, one of my experiences is watching my students soften when I tell them about

my surgeries (usually in response to a gasping, "What happened to your foot?"). Our classroom "family" is empathetic and kind, and I'm thankful to have had the turning point experience of sharing my own challenge.

Your child has a wonderful team: his/her family! Remember

that developing these "Protective Factors" is both immensely important and something that will build over time.

Enjoy the learning and growth that comes with facing a challenge—and overcoming it! We are the CMTA community, and we can change this world! ★

Brightening Up the Dismal Days of Winter

No matter how hard I try, I just can't seem to get my spirits up once all the excitement of the holidays is over. The weather doesn't help at all, either. It gets dark too soon to play outside after school and the darkness makes me feel tired even if I'm not. My mother and father both try to cheer me up because they can see that my lack of enthusiasm really affects my school work and my social life.

This year, my mother was watching some show on television that was discussing how people in nursing homes and hospitals at this time of the year really suffer from a type of depression. So, she got it into her motherly mind that I would benefit from doing some volunteer work at the local hospital. I wasn't really on board to do this because I'm not really outgoing when it comes to meeting new folks. But, my mother is relentless and so I found myself scheduled in to the Helping Hands program after school.

My first "meet and greet" was with an elderly turtle like me who was dealing with a dis-

ease called Friedrich's Ataxia. He had problems with balance and weakness in his legs just like I do. But, he also had problems in the central nervous system, so he was much more disabled than I was. We talked for two hours my first day there, and I realized that sometimes it helps to get perspective on your own situation.

While you are alone and worrying about your problems, you tend to think they are insurmountable and simply "horrible." When you can talk with someone else who has different problems and sometimes, worse ones, you realize that you really aren't as bad off as you might think.

My second encounter was with a little girl squirrel who had Cystic Fibrosis. She was very small and fragile and I realized, again, that I was talking to someone who had more significant problems than I do. We wound up playing Candy Land, and she enjoyed it. I had to be careful not to get her too excited or make her laugh too

much or she would start coughing and couldn't stop. It was truly scary to watch the nurses pound on her back to help clear her lungs. She hugged me when I had to

leave and I actually

had a lump in my throat about her being alone once I was gone. (You probably won't

be surprised to know that I went

back to visit her even though I wasn't scheduled there again.)

I've kept up with my volunteer work even though I could have stopped a month ago. I'm not sure if working at the hospital has lightened my mood or if it simply gives me something else to think about other than my own problems. What I do know is that, just like always, my mother knows what's best for me. I'm not going to tell her that, of course, or it would upset the delicate balance of difficult child versus caring mother. All you teens and preteens know exactly what I'm talking about. ★



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



SUPPORT AND ACTION GROUP NEWS

• AZ—Phoenix Area

Patrick Livney served as guest speaker at the November 16th meeting. The attendees found out first-hand what advances are being made by the CMTA for people with CMT! He told them how close we are to finding a treatment and even, possibly, a cure for so many of us. The questions and answers that followed were informative for all and showed the desire that each of us has to reach the goal of defeating CMT.

• CA—South Bay Area

Thanks to everyone who came to our last support group meeting, featuring Animal Planet's Patrick Major and his adorable dog, Sammy Davis. What a fantastic meeting with raw, heartfelt discussion following Patrick's Animal Planet video and presentation. Patrick, Sammy Davis, Sabrina, and Chris shared tender moments of truth, honesty and emotion, leaving a lasting impact on everyone in the room.

• CT—North Haven

There were 13 in attendance at the November 19th meeting. They watched the documentary "Bernadette" and shared their thoughts and own experiences afterwards. One group member spoke about her positive experience at the Orlando CMTA Patient and Family conference.

• DC—Washington, DC

Thanks to everyone who was able to attend the meeting. We had a great discussion with Steven Srebnick, from Aetrex, who explained the benefits of Aetrex shoes for people with CMT. Thanks to everyone for

your efforts in support of this great group.

• FL—West Palm Beach

Dr. Verma served as guest speaker for the October 27th meeting. One of the most amazing items discussed was the fact that there are now 60 genes found to cause CMT. Although there are many mysteries that surround CMT, Dr. Verma is very encouraged by the depth of what is now available to work with, and he believes that real progress will be made over the next five years.

• IL—Chicago Area

Since this was the first meeting since CMT Awareness Month and the fundraiser, "Reach for the STAR's-Walk & Roll for the CMTA," Dale gave an update on the success of both. There were over 100 people that attended the walk. She thanked everyone involved for helping them reach their fundraising goal! The special speakers for the meeting were Shawna Feely and Tiffany Grider, who are both genetic counselors working with Dr. Shy at the "CMT Center of Excellence" in Iowa. There were over 50 members, along with their families and friends, who came to hear Shawna and Tiffany. They took turns explaining their PowerPoint presentation. The last 30 minutes of the meeting were open for questions/answers.

• MI—Kalamazoo

The group met on November 21st. Four members were present, with one new member attending. They had an open

discussion regarding many aspects of living with CMT, including pain control, physical therapy, bracing, and dealing with the cold and avoiding falls during the winter.

• NJ—Central NJ

Fourteen members gathered on November 24th for a wonderful buffet. They had only a short, formal discussion, which included a brief overview of the Orlando Patient and Family Conference. Mark got to share big news with the group! Following their first year as a Community Partner with the Lakewood BlueClaws, BlueClaws Charities offers grants to their Community Partners. The Central NJ CMT Support and Action Group was awarded a \$1,000 grant! The purpose of the grant will be to host a "Day with the Doctors." Mark will work with the CMTA to arrange for Dr. Shy and maybe Dr. Scherer to come to and spend a day with them and any practitioners they can gather to educate their local community on CMT! Karen Sarageno won the children's book *Everyone Has Something* by Sarah Kesty. Sarah has CMT and is an educator, motivational speaker, and author. She kindly autographed the book for them. Dr. Marvin Selzer and Don Donahue won copies of Jonah Berger's *He Walks Like a Cowboy*. Jonah also autographed these books with a personal inspirational message. Nicole Cardillo and Leilani Gardner each won gift cards to The Cheesecake Factory!

(continued on page 18)

CMT Support and Action Groups in Your Community

AL—North Florence

North Florence, AL CMT Support and Action Group

Tina Smith
256-757-9250

AZ—Phoenix Area

Arizona CMT Support and Action Group

Pamela Palmer
Jim Blum
480-272-3846

CA—Santa Barbara Area

Los Angeles, CA CMT Support and Action Group

Steve Fox
805-647-8225

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

Jordan Thomas
619-549-0872

CA—Santa Rosa Area

Santa Rosa, CA CMT Support and Action Group

Carol O'Bryan
707-823-0165

CA—Visalia Area

Visalia, CA CMT Support and Action Group

Melanie Pennebaker
559-972-3020

CO—Denver Area

Denver Area CMT Support and Action Group

Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—Hartford

Hartford, CT East CMT Support and Action Group

Roy Behlke
239-682-6785

CT—North Haven

North Haven, CT CMT Support and Action Group

Lynne Krupa
203-288-6673

DC—Washington, DC

Washington, DC CMT Support and Action Group

Steven Weiss
Kimberly Hughes
301-962-8885

FL—Naples

Naples FL CMT Support and Action Group

Roy Behlke
239-455-5571

FL—Sarasota Area

Sarasota, FL CMT Support and Action Group

Racel Rivlin
941-870-3326

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
Eileen Martinez
561-777-8471

GA—Atlanta Area

Atlanta, GA CMT Support and Action Group

Susan Ruediger
678-595-2817

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

IL—Norridge Area

Chicagoland (North) Support and Action Group

Charles Barrett
224-628-5642

IL—Springfield Area

Central IL CMT Support and Action Group

Eileen Parn
217-787-8658

IN—Fort Wayne Area

Fort Wayne, IN CMT Support and Action Group

Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

IN—Lafayette

Lafayette, IN CMT Support and Action Group

Connie Chance
574-595-0674
Lawane Lord
765-474-4000

KS—Wichita Area

Kansas Area CMT Support and Action Group

Karen Smith
316-841-8852

KY—Burlington Area

Burlington, KY CMT Support and Action Group

Pam Utz
859-817-9338

LA—Baton Rouge Area

Louisiana CMT Support and Action Group

Kathleen Douglas
985-215-3926

MA—Boston

Boston, MA CMT Support and Action Group

Mimi Works
617-913-4600
Jill Ricci
(978)887-1014

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

Mary Louie
207-450-5679

MI—Chesaning Area

Chesaning, MI CMT Support and Action Group

Carolyn Koski
989-845-5731

MI—Kalamazoo Area

Southwest Michigan CMT Support and Action Group

Jori Reijonen
269-341-4415

MS—Mississippi/Louisiana

Clinton, MS CMT Support and Action Group

Flora Jones
601-825-2258
Cindy Chesteen
601-668-5439

NC—Durham Area

North Carolina CMT Support and Action Group

Margaret Lee
919-359-6003

NC—Wilmington Area

Wilmington NC Support and Action Group

Laurel Richardson
(814)404-8046

NJ—Central New Jersey

Central New Jersey CMT Support and Action Group

Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NJ—Morris County

Morris County, NJ CMT Support and Action Group

Alanna Huber
973-933-2635

NM—Albuquerque Area

CMT New Mexico 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, NY CMT Support and Action Group

Amanda Imbriano
516-680-2981
Barbara Abruzzo
212-473-4157

NY—Upstate New York

The Upstate NY CMT Support and Action Group

Melinda Lang
518-783-7313
Richard Piche
518-331-2020

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

PA—Bucks County Area

Bucks County, PA CMT Support and Action Group

Linda Davis
Mitch Davis
215-943-0760

PA—Ephrata, PA

Ephrata, PA CMT Support and Action Group

Rachel Weaver
717-344-6063

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
Raymond Souza
401-433-5500

SD—Hartford Area

Hartford, SD CMT Support and Action Group

Serena Clarkson
605-215-8853
Tom Clarkson
605-370-7595

TN—Nashville Area

Nashville, TN CMT Support and Action Group

Bridget Sarver
615-390-0699
Gwen Redick
256-655-0391

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

Michelle Hayes
972-539-0905

TX—El Paso

El Paso, TX CMT Support and Action Group

Veronica Gallegos
915-852-2273

UT—Orem Area

Orem, UT CMT Support and Action Group

Melissa Arakaki
801-494-3658

VA—Harrisonburg Area

Harrisonburg, VA CMT Support and Action Group

Anne Long
540-568-8328

VA—Shenandoah Area

Northern Shenandoah Valley CMT Support and Action Group

Teresa Frederick
540-336-4496

VA—Williamsburg Area

Williamsburg, VA CMT Support and Action Group

Nancy Mollner
757-220-3578

WA—Seattle Area

Seattle, WA CMT Support and Action Group

Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WI—Milwaukee Area

Southeastern WI CMT Support and Action Group

Susan Moore
414-510-8736

WV—Vienna Area

Parkersburg/Vienna, WV CMT Support and Action Group

Rebecca Knapp
304-834-1735

GROUPS IN CANADA AND MEXICO

CAN—British Columbia

Victoria, BC CMT Support and Action Group

Melanie Bolster
250-888-7713
Neville Tate
250-656-2547

CAN—Ontario

Eastern Ontario CMT Support and Action Group

Robin Schock
613-389-1181

Southern Ontario CMT

Action and Support Group

Kelly Hall
519-843-6119

Mexico

(This group will be in Spanish.)
México CMTA Grupo de Apoyo y Acción

Gina Salazar
Gina_oviedo@hotmail.com

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

SUPPORT GROUP NEWS

(continued from page 16)

• NM—Albuquerque

The group met on November 2nd with 11 in attendance. Gary began the meeting by handing out a list of current research projects sponsored by the CMTA. He then emphasized using the website IGIVE.COM. Gary next welcomed Dr. Zachary Haas of the Albuquerque Associated Podiatrists. Dr. Haas gave an informative presentation on CMT that included many x-rays and CMT-related photos. He discussed nonsurgical approaches used in treating CMT symptoms as well as both ligament and bone-related surgeries that may be valuable in certain circumstances.

• NY—Westchester

The group held their Holiday Luncheon on November 2nd, with 46 people in attendance. Whole Foods donated a gift card. Starbucks and Super Cuts donated items for the raffle, and Pas Tina's donated a gift certificate to their restaurant. Other raffle items were donated by the members. They raised \$1,560 for STAR. It was a very successful event and everyone had a wonderful time.

• PA—Ephrata Area

Mike from CPRS Physical Therapy served as guest speaker at the November 16th meeting. He answered a lot of questions that the members had. Two new members attended.

• TX—Dallas Area

The group meeting was held on November 16th. This meeting

was primarily focused on future meetings. Members talked about a regular time and place and having guest speakers. They also touched on advertising future meetings in local papers to increase awareness and attendance. There was also a lot of interest in fundraising. They will be doing one large fundraiser a year for the CMTA. Starting a Facebook page for more support in between meetings was also discussed.

• WI—Milwaukee

The November meeting included sharing stories and ideas and getting to know each other better. They were delighted to have a new member and to welcome back someone they hadn't seen for a while. That's why they keep going! ★

QUALITY OF LIFE

(continued from page 8)

body to physically work with a level of intensity causing a short-term and, at times, a longer-term change. Short-term changes may be fatigue, increased blood flow, elevated heart rate, and increased temperature, among others. Longer-term changes may be gains in activity tolerance, improved strength, increased range of motion and flexibility, enhanced balance, healthier body composition, and improved function. There are many types of exercise and one may participate for a variety of reasons.

Physical and occupational therapists use many modalities when treating their patients, including therapeutic exercise and activities, neuromuscular re-

education and manual therapeutic techniques to improve independence and physical function. Understanding each individual patient's medical history, complexities, personal goals, impairments, and current functional deficits enables a skilled therapist to identify a plan of care to achieve short- and long-term goals and improve function and QOL.

Starting with an evaluation, the therapist will identify baseline function using numerous outcome measures, clinical and functional tests. If the therapist feels that skilled therapy is warranted, she/he will send the Plan of Care to the patient's physician(s) for certification and begin treatment. Treatment will often include therapeutic exercise which will be carefully prescribed

and monitored to ensure safety. Patients with CMT are not typically counseled by their physicians to minimize movement, take it easy, and be on bed rest. Yet, they are not often enough counseled and prescribed skilled therapeutic interventions to promote better function. Better communication between healthcare providers could lead to improved outcomes for patients. Much more in terms of research needs to be done, and the way to start is by having patients participate in skilled supervised interventions and to study them.

Who better than PTs and OTs to help patients with CMT improve their physical function, address their deficits and impairments, and skillfully use therapeutic exercise to attain their goals? ★

CMTA NEWSLETTER SUBSCRIPTION, PUBLICATIONS, AND ACCESSORIES ORDER FORM

New Items in the CMTA Store

Greeting Cards—\$1

(Set of 3)

Maureen Raisch, a CMTA community member, shared her beautiful talent with the CMTA and now we are sharing it with you. What better way of sharing your thoughts than with these hand-drawn cards? The stars represent the CMTA's STAR research program and all proceeds will be donated to STAR.

Cards measure 4.25" x 5.5"



#1

The boy with his binoculars:

"See what mysteries are hidden within the star."



#2

The girl pointing to the star:

"Reaching toward the star to reveal its magic."



#3

The stars as cookies on the plate:

"Share in celebrating how our wishes upon the star are coming true."



Washable CMTA Tattoo—\$1

(Pack of 5)

What kid big or small doesn't like a washable tattoo? What a fun way to create awareness! At 5 for \$1.00, these tattoos make great giveaways at parties, fundraisers, and social events! Oh and adults ... we know you'll love them too!



CMTA Pin—\$3

Why not put on a little bling! This pin is a classy way to show your support of the CMTA. Wear it everywhere—to work, to social events, to church—and make CMTA awareness happen!

NAME: _____ / _____ / _____
First MI Last

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

COUNTRY/POSTAL CODE (IF NOT US): _____

DAYTIME PHONE: _____ EVENING PHONE: _____

EMAIL: _____

If you are a member or are joining now, you may purchase publications and accessories at discounted prices. (Some exclusions may apply.) To check your membership status, please call 1-800-606-2682, ext.105.

JOIN THE CMTA:				
Premium Membership (formerly "Premium Subscription," includes access to more online material and features)	Newsletter Formats (check one or both) <input type="checkbox"/> PDF <input type="checkbox"/> Print	Premium Membership Cost (includes Newsletter): \$30		
	QUANTITY	COST		TOTAL
		Regular Price	Member Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		\$15	\$12	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]		\$10	\$8	
CMT Facts IV		\$10	\$8	
CMT Facts V		\$15	\$12	
CMT Facts VI		\$15	\$12	
My Child Has CMT		\$5	\$5	
Teaching Kids about CMT...A Classroom Presentation (DVD/1 hour)		\$10	\$8	
CMTA Titleist Hats Quantity and Color: Blue___ Lt. Blue___ Black___ White___		\$25	\$20	
CMTA T-Shirts (Blue with white logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
Be a STAR Wristbands		\$1.50 each*		
Be a STAR Necklaces (Includes battery)		\$3 each*		
Unframed Sunflower Poster		\$5 each		
Sunflower Bookmarks		\$1.50 each*		
Greeting Cards (Set of 3)		\$1 per set		
Washable CMTA Tattoo (Pack of 5)		\$1 per pack		
CMTA Pin		\$3 each		
CMTA Brochure & Neurotoxic Drug Card		FREE		
Donation to the CMTA (100% Tax-deductible)				
Shipping & Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
*Quantity discounts for these items available online				ORDER TOTAL

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

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

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

CMT PATIENT MEDICATION ALERT:

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

**Moderate to
significant risk:**
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (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
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA FAX (610) 499-9267
www.cmtausa.org

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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 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.