

# THE CMTA Report

JANUARY/FEBRUARY  
2012

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ [www.cmtausa.org](http://www.cmtausa.org)

## An Exciting Time!

BY HERB BERON, CMTA CHAIRMAN OF THE BOARD

**H**i Everyone! I just wanted to take a few minutes to tell you about all of the exciting things going on within the CMTA. It's been a whirlwind two months for me since being named Chairman of the Board. I've visited support and action group meetings in Westchester, NY, and Freehold, NJ (thanks,

Beverly and Mark!) and attended Melinda Lang's Art de Cure fundraiser in Albany (which netted \$9,000 for the CMTA). I've spoken with over a dozen Support and Action Group Facilitators and several individuals who have successfully raised money for the organization. My wife and kids

wonder how I'm finding time for everything (my juggling has improved dramatically!), but, all kidding aside, it's been an incredibly fulfilling beginning.

There are so many things to be excited about going on within the CMTA. The Board of Directors has considered our

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## Melinda Lang Receives CMTA Rebecca Sand Volunteer of the Year Award

BY ELIZABETH OUELLETTE

**O**n December 2, 2011, CMTA Chairman Herb Beron presented Melinda Lang, the Upstate New York Support and Action Group Facilitator, with the honorary

Rebecca Sand Volunteer of the Year Award. 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.

This year, the CMTA 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 Melinda Lang, for her remarkable contributions and unwavering commitment to the CMTA.

Melinda's CMT symptoms began in childhood with frequent falls and sprained ankles, but her self-diagnosis was not confirmed until age 47. By that time, she was very weak, struggled to climb stairs, and began most days by

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Herb Beron awarded the Volunteer of the Year honor to Melinda Lang.

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Charcot-Marie-Tooth Association

### OUR MISSION:

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

### OUR VISION:

A world without CMT.

### CMTA LEADERSHIP

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EMAIL CMTA AT:

[info@cmtausa.org](mailto:info@cmtausa.org)

## AN EXCITING TIME

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job to be threefold (fundraising/research, increasing awareness, and patient advocacy), and I'd like to spend a minute to share with you exactly what we are doing in each of these equally important areas. Firstly, our research is ready to enter an important new phase—namely testing FDA-approved compounds on CMT1A-afflicted laboratory models. The high-throughput screening (HTS) that we undertook through our partnership with the National Institutes of Health (NIH) yielded three FDA-approved compounds that were able to downregulate PMP22 levels in cellular assays. The CMTA

Board has approved testing two of these compounds in two doses each at a cost of \$100,000 per dose. We will be updating results as they become available. In addition, we have recently received a large private donation which is earmarked for the launch of STAR's Type 2A program, which includes the creation of cellular assays with Dr. David Chan at Caltech and the creation of a Type 2A animal model at the University of Miami under the direction of Dr. Stephan Zuchner. On the Type X front, the CMTA has approved a pilot program facilitating a study of how Athersys' CMT X iPS cells may affect a CMT X animal model.

Secondly, to further enhance the power of CMT

awareness, Advisory Board member Jason Steinbaum is attempting to have the Obama Administration proclaim September 2012 National CMT Awareness Month.

Lastly, on the patient advocacy side—so much to talk about! We now have 50 support and action groups (with 8 more coming on board), a new PT program by Physiotherapy Associates, ([www.cmtausa.org/url/ptvideo1](http://www.cmtausa.org/url/ptvideo1)), and an expanding Centers of Excellence network. Board Member Elizabeth Ouellette was recently added to the NIH's Patient Advocacy Group committee as a liaison for CMTA. We've expanded our Facebook presence (<http://www.facebook.com/CMTAssociation>), our YouTube channel ([www.youtube.com/user/CMTAssociation](http://www.youtube.com/user/CMTAssociation)), and our Youth Discussion Groups (<http://www.facebook.com/groups/112378272199073>). In addition, we have grown our Advisory Board to include professionals from every aspect that affects our patient community (geneticist, PT, OT, psychologist, orthotist, etc). We want to be able to provide our members with specialists in every area (so if you ever have questions, you can come to the CMTA to help you find answers).

Whew—a lot on our plate! For all we've accomplished thus far, we still have so much more to do. I look forward with great anticipation to what I believe will prove to be a fantastic 2012. Thank you for all you have done (and continue to do) for the CMTA and have a happy new year. ★

## NEW STUDY REVEALS MORE ABOUT THE PMP22 GENE

A new study just published in the journal *Human Molecular Genetics* details the molecular control of the PMP22 gene, which is duplicated in the most common type of Charcot-Marie-Tooth disease, CMT1A. While the most common duplication encompasses approximately 1.4 million bases around the PMP22 gene, two independent groups—the Baas laboratory in the Netherlands and the Lupski laboratory at Baylor—have identified two shorter duplications in patients with mild CMT-like symptoms. The duplicated regions do not affect the PMP22 gene itself, but rather ~150,000 bases directly adjacent to the PMP22 gene. The functional significance of this was explored in the new study, in which specific DNA sequences that activate the PMP22 gene were found within the boundaries of the shorter duplicated region. This study employed analysis of two major proteins that regulate many genes that are induced during myelination by Schwann cells. These proteins are known as EGR2 and SOX10, and novel high-throughput sequencing approaches were used to identify their binding sites in the PMP22 gene.

This work was performed as a collaboration of the John Svaren laboratory at the University of Wisconsin, Waisman Center, and the laboratory of Anthony Antonellis at the University of Michigan. Erin Jones and Rajini Srinivasan in the Svaren laboratory helped identify the new regulatory elements, and Megan Brewer in the Antonellis laboratory was able to show that the newly identified enhancers are also active in the Schwann cells of zebrafish. These results indicate that the shorter duplication probably results in PMP22 overexpression because of increasing the number of positive regulatory elements. Overall, this publication provides a more detailed picture of how the PMP22 gene is regulated, and ongoing efforts are focused on using the regulatory mechanism of PMP22 to identify compounds that would lower PMP22 expression and potentially lead to new treatments for CMT1A. This research was funded by grants from the CMTA and the National Institutes of Health.

—John Svaren, PhD

## PHYSIOTHERAPY ASSOCIATES JOINS CMTA TO EDUCATE CLINICIANS

The CMTA has announced an initiative with outpatient physical therapy, occupational therapy, orthotics and prosthetics service provider Physiotherapy Associates, Inc. (PTA). The initiative will focus on developing improved treatments for CMT through educational modules and will be delivered to PTA's clinicians. This shared education and program development arrangement will help patients who are seeking clinical providers for CMT services and treatments. "Physiotherapy Associates

is uniquely positioned to provide services to patients affected by CMT," said Pat Livney, CEO of the CMTA. "Through a committed relationship with Physiotherapy Associates and their clinicians, the CMTA is working to improve the quality of life for CMT patients."

"From my physical therapy treatment background, I see this relationship as a powerful tool to help persons affected by CMT. Our licensed clinicians offer one-on-one care, and, now, those affected with CMT will benefit from an increased

knowledge of this condition," said Pete Grabaskas, PT, COO, Physiotherapy Associates.

Physiotherapy Associates has designated over 55 clinicians to be trained specifically about CMT. A series of educational modules is under development by the CMTA to continue the clinicians' CMT-specific educational training.

To find one of the 55 clinicians, who will be trained, visit the CMTA's website, [www.cmtausa.org](http://www.cmtausa.org). Click "Find A Clinician" and search your state. ★

## Kids "Step It Up" for Third Year in a Row

The kids at the Richland Elementary School in Johnstown, PA, "Stepped it up" for the CMTA for the third year. This year the children raised just under \$8,000!

I go to each grade in the school to educate the kids about CMT by teaching them what CMT is and reading a story about Archy the turtle. Then the children wear pedometers during the school day to "Step It Up for CMT." After wearing the pedometer, the children take a sponsorship sheet, with the number of steps they have taken, to parents, grandparents, friends, and neighbors. The sponsor can choose what they want to give. It could be as little as \$1 or as much as \$20 or more. The children have two

weeks to get sponsors, then they bring the money back to the school, and it is collected by a CMTA representative.

The children are excited to raise money, but they have another motivating reason to participate. Every child who brings in \$1 or more receives a participation gift. Every child who brings in \$30 or more receives a CMTA Archy T-shirt.

There are also grand prizes. At this school, the child who raised the most money was given a bike (donated by Ski Den). He also won lunch for two at any restaurant he wanted. The biggest prize. He got to cut off the school principal's tie!

Two runners up each won a \$50 gift certificate to TJ Maxx, and they got to throw whipped

cream pies at the gym teacher. I also rewarded the classroom that raised the most money. They raised \$850. They won the chance to throw water balloons at the gym teacher. This prize will wait for the warmer weather of spring!

—Jeana Sweeney,  
Director of Community Services

Principal Moran sacrificed his tie as a souvenir to Lucas, who raised an amazing \$350 in the "Stepping It Up" challenge.



*If you would like to learn more about this school program, please contact Jeana Sweeney at 1-800-606-2682 ext 106.*

*"What's on Your Mind... Ask David?" will return in the next newsletter.*

## CMTA'S ADVISORY BOARD GROWS

**B**ecause patient advocacy is one of the missions of the new leadership of the CMTA Board of Directors, an advisory board has been created whose members will offer insights into some of the important, non-neurological, issues facing people dealing with CMT. Our experts come from a wide variety of backgrounds and will be happy to assist CMTA members who have questions in areas in which they would be considered "experts." Below, we introduce you to the current advisory board members.



**JONAH BERGER** is 39 years old and lives in the mountains of Colorado. He is the Program

Director for the Easter Seals mountain camp. He also runs a business called The Rhythm Within, working with kids and adults with special needs. He has been diagnosed with CMTX and has enjoyed an interesting journey of challenge and wisdom. He is the author of *He Walks Like A Cowboy*, a book detailing the life and lessons of the CMT path. He is a proud member of the CMTA community!



**KATY EICHINGER, PT, DPT, NCS**, is a physical therapist in the Neuro-muscular Disease Unit at the Uni-

versity of Rochester. She received her Master of Science degree in Physical Therapy from Springfield College in Massachusetts. She received her Doctorate in Physical Therapy from Upstate Medical University in Syracuse, New York. She also is a Neurological Certified Specialist (NCS).

Dr. Eichinger is involved in the clinical care of adult and pediatric patients with neuromuscular diseases. Additionally, she is part of the neuromuscular research team and is involved in natural history studies and clinical trials involving patients with Charcot-Marie-Tooth disease, myotonic dystrophy, and facioscapulohumeral dystrophy. She has been involved with clinical evaluator training and assisted in preparing the manual for the pediatric assessment for the CMT natural history study. Her interests are in outcome measures, health and wellness, and balance.



**SEAN MCKALE, CO, LO**, is the practice manager of Midwest Orthotic and Technology Center

in Chicago, IL. Sean began as an athletic trainer who decided his love of working with his hands would lead him to making furniture. Fortunately a mentor of his told him about the field of orthotics. He has worked in various clinical settings, but through his time spent at the Rehabilitation Insti-

tute of Michigan and his relationship with Dr. Michael Shy, he has become increasingly passionate about helping patients with neuromuscular involvement. Sean has spoken at numerous national Orthotic and Prosthetic conferences about dynamic AFOs, CMT, unique case presentations, and the management of pediatric patients. He enjoys working with CMT patients because he knows he is really helping improve their daily life.



**CARLY SISKIND, MS, CGC**, is a board certified genetic counselor with a specialty in CMT. She is

currently working at Stanford University and Hospital and Lucile Packard Children's Hospital. She previously worked for four years as a genetic counselor, assistant professor, and clinic coordinator at Wayne State University in the CMT Clinic. She is the project manager of the Inherited Neuropathies Consortium, part of the Rare Disease Clinical Research Network. Her involvement with the CMTA has included speaking at Patient and Family conferences and the CMT. SAG facilitator conference, writing articles for the *CMTA Report*, and being a resource for general genetics questions. She is very happy to be able to lend her expertise as a member of the advisory board.

## Celebrations and What Comes After



**JASON STEINBAUM** is Minority Staff Director on the House of Representatives Sub-

committee on the Western Hemisphere and Senior Policy Advisor for Foreign Policy to Rep. Eliot Engel (D-NY), the Subcommittee's Ranking Member. In that position, he has carried out congressional oversight of US policy toward Latin America and the Caribbean. Jason has worked in Congress for over 20 years in a variety of positions in the House and Senate.

Jason became involved with the CMTA in 2003. Learning that the disease ran in his family, Jason helped the CMTA establish an active presence on Capitol Hill by generating clear messages that Congress supports extensive research at NIH into CMT.



**DAVID TANNENBAUM** has an LCSW degree and has been a psychotherapist in NYC for the

past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life." David has a column in the newsletter entitled, "What's On Your Mind?" and he will continue to answer questions directed to him at [info@cmtausa.org](mailto:info@cmtausa.org). ★

I don't know about you, but I love the holidays. I think I look forward to them for at least two months and then, when the celebrating is over, I'm always left feeling a little empty. I'm just a kid, but I don't think my reaction is all that unusual.

Around our house, we put up decorations and start baking goodies weeks before the first holiday hits. Our family is a little unusual because we celebrate both Hanukkah and Christmas. My Dad's side of the family is Methodist and my mother's side is Jewish. So, I know I have it good. We light the menorah; we decorate the Christmas tree, and, most of all, we get a lot of presents and we eat all kinds of fabulous food!

When everything is over, we have to undecorate the house and put away all the ornaments and bright lights. It's kind of sad. On top of everything else, after having a nice long vacation from school and homework, it's back to the classroom and all the expectations that my parents put on me. I'm not complaining; I'm just telling you how it is. The fact that it gets dark so much earlier and keeps us kids from playing outside after school is a problem, too. It's just very hard to keep your spirits up when the winter seems endless and there is nothing to look forward to. Of course, I'm still crazy about Tina Turtle so I can focus a little on Valentine's Day and what I will give her. I'll probably make her a card

because the ones they sell never seem to be just right for what I want to say. But, in general, my life is drab and boring in comparison to the holidays.

What I think is interesting is that my Dad says that my feelings aren't unusual at all and that people have the exact same problems with becoming depressed after the holidays. In fact, he told me that for some people, the holidays are actually worse than what comes after. If they

have no family or friends living nearby, they can feel very left out and very alone.

The scariest part of my Dad's story was that he told me that people sometimes

become so depressed that they commit suicide. That is so sad. I feel like we could prevent that from happening if we tried a little harder. I know my Mother always invites an older turtle from our community to have Harvest Holiday dinner with us. I thought she did it to make sure they got a good meal, but now I think maybe it's to make sure they get a little boost to their spirit.

After listening to my Dad talk about the "down" time after the holidays, I decided to look around our neighborhood and figure out who doesn't have a supportive family around them to help them get through the dark days of winter. I'm going to visit them and after I've visited, I'm going to make them a card to help them know that someone is thinking about them. I really hope it helps. ★



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



# GIFTS WERE MADE TO THE CMTA

## IN MEMORY OF:

### Elia Atalla

Mr. Yacoub Atalla

### Arnold Carlson

Ms. Jeanne Corbin

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Ms. Bobbye Driscoll

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Mr. Patrick McGrath

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Mr. & Mrs. Emmett McMahon

Mr. Willard Whitaker

### Uncle Bud

Mrs. Marcia Hoffman

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Ms. Grace Tracy

### Linda Arcuri

Mr. Gerald Arcuri

### Marilyn & Martin Berger –

Happy 45th Anniversary

Mr. & Mrs. Frank Weiss,

Terrie, & Gene

### Julia Beron

Mr. & Mrs. David Beron

Mr. & Mrs. Ira B. Geller

### Madeleine Brown

Mr. & Mrs. Chris Brown

Mr. & Mrs. Mel Ross

### Finn Burke—Pat Driebelbis'

First Grandchild

Mr. & Mrs. Frank Wurzel

### Barbara Castle

Mr. & Mrs. Earl Dudley, Jr.

### Catherine Christensen

Mr. Robert Christensen

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Congratulations on

becoming CEO!

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Mrs. Jennifer Spinney

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The Hill Family Reunion

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Mr. & Mrs. Larry Newsom

## 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: \_\_\_\_\_

\_\_\_\_\_

## A Portrait of Grace

**Beverly O'Free Rooney**  
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Ouellette

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Mr. John Park

**Gwen Redick Dempsey**  
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**Don & Mary Ellen Sharp**  
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Ms. Erin Keene

**Devin**  
Mrs. Alison Childress

**Trace**  
Ms. Geraldine Walker

Like some of you reading this article, I was diagnosed with CMT at a young age. However, the diagnosis was by no means frightening because I was blessed with a courageous role model, my mother, who modeled for me the value of endurance, persistence, and painstaking hard work. By the time I was diagnosed, she had so gracefully faced the many unending challenges associated with living with this disorder in my birth country, Iran. A third-world country ravaged



**Arezoo Aryaee (right) and her mother, Mrs. Roghich Ghadam share a drink and lots of good advice about living well with CMT.**

by political corruption, war, economic devastation, social malaise, and religious fanaticism is hard for anyone to raise a family in let alone a handicapped woman who lacked the support and encouragement of a loving husband. It was during those trying years of my young life that I learned from my mother that the meaning of dignity and self-confidence has very little to do with physical appearance and is conversely intertwined with one's mettle and moral disposition.

My mother's strong spirit, tempered by her kind and generous heart, helped me understand at a very young age the true meaning of grace. She demonstrated the importance of a positive and strong attitude in overcoming life's adversities through her capacity for meeting challenges with fortitude. Today at almost 73, she continues to inspire me daily by her physical, mental, and moral strength to venture, to persevere, and to withstand the difficulties that accompany a life colored by CMT.

CMT, as with any other disorder or handicap, can, and does, provide an opportunity for personal growth. For me, it has provided a true purpose in life. As a student of psychology, I am constantly reminded of the vast human ability to alter life's trajectory through focused attention and intentional effort, irrespective of physical limitations. I have no doubt that like polio, typhoid fever, and measles, as well as hundreds of other deadly disorders that we have since found cures for, Charcot-Marie-Tooth will be eradicated through the diligent efforts of our scientific community. To this end, it is my hope to be able to support the tireless efforts of our medical community by contributing regularly and religiously to the research fund as set forth by the STAR initiative.

As a tribute to my beloved mother as well as all who carry their cross in life with honor, courage and grace, I pledge to do my part by devoting as much time, treasure, and effort as needed until that sunny day when CMT no longer can cast a dark shadow on the human life experience. Here's to that day!!!!

—Arezoo Aryaee

# You Can Go Anywhere!

## Travel Tips for People with Disabilities

BY PHYLLIS SANDERS

If you are a person with CMT or traveling with a person with CMT, the key to a wonderful vacation is preparation. Think about where you want to go and what you want to see. Then factor in your special needs and do your research before booking the trip.

### GETTING TO YOUR DESTINATION

- ◆ If you use a wheelchair, include that information when booking your tickets.
- ◆ If you walk with a cane, and find walking long distances a problem, ask for wheelchair assistance.
- ◆ If you use a cane, you can ask for disability access to the secu-

rity line at the airport. This will avoid the necessity of standing on long lines.

- ◆ Find out the distance from the landing gate at your destination to the customs or baggage area. Very often the airports are huge and wheelchair assistance may be necessary. Arrange for this assistance when booking your ticket.
- ◆ On many trains in Europe wheelchair accessible seats near handicapped bathrooms are only in the first class section of the



CMTA Board Member Phyllis Sanders has moderately severe CMT, and has traveled to over 50 countries. She has used donkeys, horses, elephants, rickshaws and three-wheeled bicycle carriages to get to where she wanted to be. Here she poses with her husband Stanley on a remote island in Indonesia.

train. You may be able to upgrade to first class without paying a premium for the ticket. Ask.

- ◆ Call or email trains to say that you will need assistance at least 24 hours before your trip. Get to the station early.

- ◆ The Air Carrier Access Act and its amendments resulted in the Department of Transportation issuing new regulations requiring that persons with disabilities who are traveling be treated without discrimination. Carriers are prohibited from imposing charges for extra services that are covered by the regulations. See the Department of Transportation pamphlet “New Horizons for the Air Traveler.”

### WHERE TO STAY

- ◆ If you use a wheelchair, make sure the hotel you choose has an elevator. Some hotels have steps leading from the street into the interior. Check that all the areas of the hotel that you want to use, such as the pool, the restaurant, and the bar, are accessible.
- ◆ If you can walk some steps, but would like a room that is

## NEUROPATHIC PAIN IN CHARCOT-MARIE-TOOTH DISEASE

The debate over how much pain is typical in CMT cases or if any pain at all should be expected continues to rage on in the medical community. Over ten years ago, the question was considered in a study done by, among others, Dr. Thomas Bird, head of the CMT Center of Excellence at the University of Washington and Dr. Gregory Carter, who practices neuromusculoskeletal medicine and physical medicine and rehabilitation in Centralia and Olympia, Washington.

In the abstract of the article they published, they reveal that the participants for the study were recruited from CMT support organizations worldwide. They used the Neuropathic Pain Scale to have patients complete a descriptive nonexperimental survey.

The pain reported in CMT patients was compared to pain afflicting subjects with postherpetic neuralgia, complex regional pain syndrome, diabetic neuropathy, and peripheral nerve injury.

Of 617 CMT subjects, 440 reported pain, with the most severe pain noted in the low back (70%), knees (53%), ankles (50%), toes (46%), and feet (44%). Of this group, 171 reported interruption of the activities of daily living by pain; 168 used non-narcotic pain medication and 113 used narcotics and/or benzodiazepines for pain. Pain was described as hot, dull, and deep.

The conclusion that the study drew was that neuropathic pain is a significant problem for many people with CMT. The frequency and intensity of pain reported in CMT was comparable to the other diseases mentioned above. They noted that further studies would be necessary to examine possible pain generators and pharmacologic and rehabilitative modalities for treating pain in CMT.

To read the full article go to: [www.cmtausa.org/url/painpdf](http://www.cmtausa.org/url/painpdf)  
You must be logged in as a member of the CMTA Online Community.

elevator accessible, be specific when booking.

◆ If your trip involves a resort with rooms located outside the central area, make sure to check the distance and type of path. Many rooms can only be reached by winding paths that have steps with no handrails.

### BOAT TRIPS

◆ Special research must be done when booking cruises on small ships to exotic destinations. Not all ports have a dock. Disembarkation can be done by tenders. This can be very challenging to people with disabilities.

◆ Not all ports are level with the street. Depending on the tide there may be multiple flights of steps. The steps may be irregular and have no handrails. Check ahead with the travel agent or shipping company.

◆ Some small ships have no elevator. Check ahead and evaluate your limitations when planning.

### SEEING THE SITES

◆ Many destinations have rough paths, cobblestones, or uneven surfaces. If you are using a wheelchair, make sure the rubber wheels are in good condition. Cane users should take extra tips. Comfortable well-worn traveling shoes are necessary.

◆ Although some castles and museums do not have elevators, many do. Ask in advance. Very often the elevators are behind closed and unmarked doors. The guard or attendant at the ticket booth can help you. If you are on a group tour, the tour leader may not be the best person to ask. Getting to an elevator can take extra time and your group leader

## *New Facebook Youth Group and a Call to Action*

There's been a noticeable lack of resources and support for teens and young adults with CMT. We at the CMTA sought to fill this gap with the introduction of a Youth Tab on the CMTA's Facebook page (Charcot-Marie-Tooth Association: The Time is Now).



Since the release of the Youth Tab in August, young people from around the world have come together to connect with others who are affected by CMT. It soon became clear that a tab alone could not meet the vital need to communicate, discuss, and share information, so a new group was born.

I am the moderator of the new Facebook group, CMTA Youth Discussion. This group is open to everyone—teens and adults alike—but is focused on youth-related discussions.

This is my call to action. Young people around the world: we are the future of CMT, and the CMTA. Let's come together to learn and support one another. If you want to know how you can contribute and make a difference, contact me! As with the tab, I expect, and hope, that this is only the beginning.

*Bethany Noelle Meloche*  
*bethany.meloche@gmail.com*

may not have the time or knowledge to direct you. If there is no elevator, you may still want to see the grounds and the main floor.

- ◆ Do not waste your time standing on lengthy lines. Ask for disability access.
- ◆ Bring your disability parking tag. It is recognized internationally.
- ◆ Many museums and other sites have wheelchairs available for use within their facility. If you are tired, ask for one.

### TRAVEL SMART

- ◆ Follow the tips for all travelers as well as the tips for disabled travelers.
- ◆ Pack light.
- ◆ Carry your meds and other important items in your hand luggage.
- ◆ Leave ample time for you to

get to your destination. Allow yourself sufficient personal time to adjust to the time zone, the climate, and the altitude.

- ◆ Check with the Communicable Disease Control Center for any necessary immunizations you may need.
- ◆ Check with your doctor to verify that you are well enough to be immunized. Age and other factors make certain immunizations contraindicated.

To travel with a disability, you need a sense of adventure, a sense of humor, and perseverance. When things do not go exactly as you planned, you must be flexible enough to try another approach. Most people are kind and will help you if you ask. Keep these tips in mind, and *you really can go ANYWHERE.* ★

## FUNDRAISING FOR CMT

**THE FIRST ANNUAL CAMPBELL CLASSIC GOLF OUTING** took place in October at Minebrook Golf Club in Hackettstown, NJ. Organized by Debbie Campbell, whose husband Rob and son Robbie both have CMT, the outing raised over \$16,000 for the STAR program. “We wanted to do something to raise funds and awareness for CMT. My husband and son both love to play golf, so the outing seemed like the perfect way to do this.” The Campbells plan on having another outing next year. “Everyone had such a great time, and it was such a fun way for us to do our part to raise money for CMT research.” In attendance were 72 golfers, joined by an additional 50 people for the dinner. Dinner included door prizes, 50/50, golf awards, raffles, a tricky tray, and silent auction items.

**“STARRY NIGHT,”** the Art de Cure gallery reception at Clinical Prosthetics and Orthotics in Albany, NY, on December 2nd was a great success, raising over \$9,000 to benefit the STAR initiative for CMT research.

Art de Cure Gallery is a not-for-profit collaboration between art and medicine showcasing art in the community to benefit a charity in their search for a cure. The reception and silent auction of original artwork by regional artists featured complimentary wine, food, and live music provided by guitarist Mary Grace Barada.

Friends donated hand-made jewelry, quilts, painted



Golfers for the Campbell Fundraiser gathered before the Tee-off.

glassware, and knitted baby clothes for the silent auction. Fiber Artist and Art de Cure curator, Susan Rivers, contributed hand-made silk scarves, which quickly sold out. The Monks of New Skete donated books and DVDs, and Susan Salzberg contributed hand-made note cards.

“The innovative concept behind Art de Cure is to partner art with medicine while supporting a cause. A further advantage is that it brings art to a cross section of the community. Patients, staff, and everyone who comes to the office have an opportunity to enjoy the artwork,” stated Dr. Jay Watsky.

Herb Beron, Chairman of the Board of Directors of the CMTA, presented the “Rebecca Sand Volunteer of the Year Award” to Melinda Lang, RPH, founder of the Upstate NY support and action group, for her dedication and outstanding accomplishments.

Project committee members Jackie Watsky, President of Art de Cure, Susan Rivers, board member of Art de Cure, Elizabeth Misener and Teresa Cietek from CPO, Christine

Hook, Upstate NY CMTA group member, Melinda Lang, SAGF Upstate NY, along with volunteers Lora Bonaker and Tina Grant worked seeking sponsors and donations and planning for the event.

Sponsors included Ossur, M&T Bank, PEL medical supplies, Spinal Technology, together with food donations from Fresh Market and Hannaford. Event volunteers were Amy Cherkosly, Carol Angela, Carmona Olds, Anne Pape, Jeffrey Sammons, Elizabeth Sammons, Jessica Cameron, Melissa Barada, and Nora Mulvey.

The following artists contributed their work to benefit the CMTA: Nancy Gardner, Linda Starr, Pat Hoffmeister, Christina Hook, Deb Carpenter, Enid Watsky, Carol Warburton, Gary Larsen, Donna Peirce, Marilyn Ramsdale, Paula Bossert, Marjorie Olsen, Susan Rivers, and Melinda Lang.

The CTMA hopes to continue collaborating with Art de Cure, setting up galleries in other areas across the country, with Melinda Lang as the liaison to other support group leaders. ★

# A Race for Erin

BY LIZ SULLIVAN

It's been almost 4 years since my niece, Erin Hughes, was diagnosed with Charcot-Marie-Tooth Syndrome. Watching this disease progress with Erin has been very difficult for our entire family. However, none of us can fully understand how difficult it is and has been for my sister, Monica, and her husband, Dan. Realizing as a parent that your child has a debilitating condition that you can't stop makes you feel helpless. For the first time, Monica and Dan had to come to terms with not being able to protect and help Erin achieve all her goals. This disease was going to run its course and there was nothing they could do about it. Or so they thought.

It was back in the spring that my sister called me and asked if I would run a marathon with her. I knew I couldn't say no. Monica is not someone who asks for things, and she is always the first to help when you need it. I said yes and then started persuading the rest of my siblings to join us. Once we all decided to commit to this race, we started talking about how we could make it more meaningful. My brother suggested we run for Erin and raise money for CMT. In a very short period of time, this race took on a life of its own.

I am one of five siblings. We are a close-knit family. We have been very blessed over the years and have come together on numerous occasions to support each other in many different

events. However, I have never felt the strength, love, and family unity I experienced over the last 6 months. We started brainstorming on how we could raise the most money in a short period of time. Many of us started email and letter campaigns informing our friends and family about Erin, her condition, and our cause. The outpouring of support, cards, letters, and, most importantly, money was unbelievable.

One month before the marathon, we decided to hold a fundraising event at my house. My family and I started strategizing how we could hold an event that would raise money, bring awareness to the community about CMT, and, at the same time, help Erin accept her condition a little more. This event turned out to be a huge success on so many levels. Local vendors came together to donate food, supplies, raffle items, inflatables, and so much more. Friends, family, neighbors, and coworkers came out to support our family. Erin walked around the party wearing a tiara, smiling, laughing, and talking with people about CMT. It was her day and we were all together to let her know she is not alone in her fight. When all was said and done, we were able to raise over \$7,500.

On October 15th, seven of us competed in the Baltimore marathon. We ran as "Erin's Runners." Raw Threads created shirts for us with a design that

Erin had drawn. It was hard to believe this day had actually come. We all made our way through the 26.2 miles to the sounds of people cheering for us, yelling "Go Erin's Runners." There were many points where we had to push our way through the pain. However, keeping Erin and her fight on our minds



Erin and "Erin's Runners" posed after completing the Baltimore Marathon.

made it easier. When we went through the gates of Camden Yard to the finish line, Erin was there waiting for us. We grabbed her hands, and three of us crossed the finish line as a united team. The rest of our family was there cheering us on. I looked down at my niece and over at my sister holding each other's hands, smiling from ear to ear. It was such a powerful and emotional moment for me. I realize that Erin has a long and hard road ahead of her filled with many challenges. However, in that moment, I saw a little girl holding her Mom's hand and laughing. She was happy. I will hold that memory in my heart for as long as I live. ★



## SUPPORT AND ACTION GROUP NEWS

### CA—San Francisco Peninsula/ South Bay

*The group met on December 2, 2011.*

Bethany Meloche (*see page 9*), our 20-year-old youth leader spoke about her life experiences with CMT. She did a fabulous job discussing her journey thus far, living with CMT. Also, Jeana Sweeney, the CMTA's Director of Community Services, spoke

about her own CMT and how she copes with the fact that her 6-year-old daughter, Rylee, also struggles with CMT.

### MI—Southwest Michigan

*The Group met on November 17, 2011.*

The group speaker was counselor and pastor Rob Cook. The topic for the evening was "Coping with Pain." Cook spoke about

coping with pain from a psychological and spiritual viewpoint.

### NJ—Central NJ

*The group met on December 10, 2011.*

The group speakers were Meagan and Mike from the Health and Fitness Center. They spoke about the benefits of exercise and the services that the center can provide. They also had a special guest, Herb Beron, Chairman of the CMTA Board.

**O**n November 19, the Upstate NY CMT support and action group met at the East Greenbush library for a presentation from three occupational therapists: Celeste Freeman, OT, CHT (Certified Hand Therapist), Karen Pahl, OT, CHT, and Nancy Clemente, OTR from The Hand Rehabilitation Center at Albany Memorial Hospital. After the presentation the therapists showed different types of equipment/adaptive devices such as computer mice that your hand can rest in, key turners, special comfort grip kitchen tools, automatic mini choppers, zippers and button gadgets, various splints for thumbs and wrists, and pen holders.

### SOME TIPS TO PRESERVE HAND FUNCTION:

- Avoid pressure against the thumb side of your fingers.  
*Example:* Use bag holder for plastic bags.
- Keep your joints in a "neutral" position.  
*Example:* at night wear hand splints to hold hands in closed, straightened position.
- Use the largest joint possible to accomplish the task.  
*Examples:* stir holding the spoon with a fist grip and using shoulder motions. Use a purse with a shoulder strap.
- Avoid moving fingers/wrists at angles at your joints.  
*Example:* hold handles straight across your palm, never diagonally (knife, hammer, pan, spoon, iron). Turn doorknobs sideways to the door and use wrist motion.
- Slide objects whenever possible or transport in a wheeled cart.  
*Example:* slide a pan along the counter from the sink to the stove.
- Utilize both hands with palms up to lift items.  
*Example:* use both hands when removing a pan from the oven.
- Add leverage (through additional length) to reduce the stress when turning, grasping, or pulling with your hands.  
*Examples:* lever style facets, knob turner, tab grabbers, zipper pulls.

The therapists recommended the following website for adaptive and splinting devices: <http://www.pattersonmedical.com/>

### NY—Westchester

*The group met on November 5, 2011.*

The group speakers were the new Chairman of the CMTA Board Herb Beron and Jeana Sweeney, Director of Community Services. Herb and Jeana gave an update on the STAR program.

### WA—Tacoma

*The group met on December 3, 2011.*

The support and action group in Tacoma was honored to have none other than CMTA's finest, Elizabeth Ouellette and Jeana Sweeney. The ladies' presentation included but was not limited to the STAR program and research updates. There was an emphasis on, "A world without CMT: start with me." The group was encouraged to learn there is no such thing as a small amount when it comes to awareness and fundraising. Even the least amount of effort makes a big difference. Also in attendance was Thomas Bird, MD, Professor of Medicine, Neurology, and Medical Genetics at the University of Washington, and Research Affiliate, Center on Human Development and Disability. ★

# 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—Stockton

Stockton, CA CMT Support and Action Group  
Nina Anselmo

## 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  
Steve Gabbert  
619-987-6022

## CA—Santa Rosa Area

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

## CA—SF/East Bay Area

San Francisco/East Bay CMT Support and Action Group  
Donna Rennie  
925-330-2790

## 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

## DC—Washington, DC Area

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

## FL—Inverness Area

West Central Florida CMT Support and Action Group  
Ronnie Plageman  
352-860-1578

## 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

## GA—Atlanta Area

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

## IL—Chicago Area

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

## KS—Wichita Area

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

## KY—Burlington Area

Pam Utz  
859-817-9338

## MD—Hagerstown Area

Hagerstown, MD CMT Support and Action Group  
Jeffrey Martin  
301-582-2401

## MD—Easton

Easton, MD CMT Support and Action Group  
Missy 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/emails  
Libby Bond  
417-845-1883

## MS—Mississippi/Louisiana

Clinton, MS CMT Support and Action Group  
Flora Jones  
601-825-2258

## NC—Triangle Area

Triangle, NC CMT Support and Action Group  
Betsy Kimrey  
919-833-3991

## NH—New Hampshire/Vermont

New Hampshire/Vermont CMT Support and Action Group  
Margaret Healey  
802-535-2797

## NJ—Central New Jersey Area

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

## 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  
Diane Cencak  
530-414-0432

## NY—Upstate New York Area

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

## 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  
Ruth Korowitz  
516-318-3202

## NY—Westchester Area

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

## OH—Greenville Area

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

## OH—Zanesville Area

Zanesville, OH CMT Support and Action Group  
Tara Boehke  
740-297-4940

## OR—Portland Area

Portland, Oregon CMT Support and Action Group  
Debbie Hagen  
503-333-7936

## PA—Bucks County Area

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

## PA—Johnstown Area

Johnstown, PA CMT Support and Action Group  
J.D. Griffith  
814-539-2341  
Jeana Sweeney  
814-262-8427

## 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

## TN—Nashville Area

Nashville, TN CMT Support and Action Group  
Mark Hollingshead  
615-480-2044  
Bridget Sarver  
615-3909-0699

## 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

## 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—Milwaukee Area

Southeastern, WI CMT Support and Action Group  
Polly Maziasz  
262-439-9009  
Margaret Hoepner  
414-788-9628

## WI—Brodhead Area

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

## \* WV—Vienna Area

West Virginia CMT Support and Action Group  
Rebecca Knapp  
304-834-1735

## VIRTUAL/DISCUSSION GROUPS

Anyone Can Fundraise

Archy and Friends Discussion Group

Boston South Shore Voice Discussion Group

CMT and Fatigue Discussion Group

CMT and Pain...Share Your Experience Discussion Group

CMT Creates: Music Project Discussion Group

Global Support and Action Group Community

Hand and Finger Struggles with CMT Discussion Group

Insurance and Benefits Discussion Group

Marijuana and CMT Discussion Group

Parents with CMT Who Are Raising Kids with CMT Discussion Group

The CMT Outdoorsman Discussion Group

Trigger Points Discussion Group

**Most Support and Action Groups, Virtual Groups and Discussion Groups can be accessed at [www.cmtausa.org](http://www.cmtausa.org). They can be found in the CMTA Online Community under Support and Action Groups.**

**\* WELCOME TO OUR NEW SUPPORT GROUP: WEST VIRGINIA**

**TAKE ACTION: If there is no Support and Action Group in your area, consider becoming a facilitator! If you are interested, please contact Jeana Sweeney at [jeana@cmtausa.org](mailto:jeana@cmtausa.org).**

**MELINDA LANG**

(continued from page 1)

tripping and falling. After leaving her career as a pharmacist, because of health concerns, she decided to make a difference in her own life and the lives of others by founding the Upstate NY CMTA support and action group and getting involved with the CMTA.

Emphasizing the CMTA's three major goals of fundraising/research, increasing awareness, and patient advocacy, Melinda's efforts have been strikingly successful. Her achievements include talking to physical therapy students about CMT, writing a CMT awareness blog, "Living Well with CMT" and participating in many CMT Awareness Month activities, including the launching of

CMT Global Day. Melinda was interviewed on television, submitted CMT articles for her local newspapers, organized fundraisers (Valley Cats Baseball and Art de Cure's Starry Night event), set up a CMT exhibit table at the American Pain Foundation, and created the CMTA's product line in our Zazzle store.

Melinda emphasizes her belief that "you can live a full life, even though you have CMT." Remaining active and dedicated to self-care is essential to her well-being. Daily physical therapy and swimming have improved her quality of life. Her husband of 28 years and her loving mom, Melanie, also provide an essential support system for Melinda.

To live fully in the world, Melinda is committed not only

to overcoming her CMT but also her shy nature. Facilitating a group was initially a daunting task for Melinda, but she is conquering her inhibitions through determination and unrelenting passion. In addition, her desire to help others through supportive empathy and informative activism makes her a commendable facilitator and a wonderful individual.

The CMTA is forever grateful for all of her efforts and contributions today, which will positively impact the generations of tomorrow. To quote 19th Century Universalist Minister, Edwin Hubbel Chapin, "Every action in our lives touches on some chord that will vibrate in eternity." We thank Melinda for the permanent gifts and indelible mark she has left on the CMT community! ★

**THE CMTA "CIRCLE 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](mailto:jeana@cmtausa.org). Working together, we can create a world without CMT!

**DONATIONS WERE MADE TO THESE CMTA CIRCLES:****KEN'S RIDE**

Ms. Heidi A. duPont  
Ms. Janis M. Gomez

**DONNA'S QUEST**

Mr. Sean Connolly

**ERIN'S RUNNERS**

Mr. & Mrs. Dean M. Accettura  
Adventus, Inc.—Sender Training  
Ms. Mary L. Alexander  
Mr. & Mrs. Ronald A. Altieri  
Mr. William Aubuchon IV  
Ms. Maria R. Avery  
Mr. & Mrs. Frederick C. Barone  
Mr. & Mrs. William R. Bates  
Bill & Sam's Diner  
Mr. & Mrs. Douglas M. Broad  
Mr. & Mrs. Terry T. Bushka  
Mr. & Mrs. William F. Carr  
Mr. & Mrs. Dennis S. Carruth  
Ms. Catherine Chambers  
Ms. Marlene Cossette  
Ms. Anne Crimmins  
Ms. Kathleen P. Culkin  
Mr. Kevin J. Cyr  
Mr. & Mrs. James Dashukewich  
Mr. & Mrs. Gerald G. DePolo  
Mr. & Mrs. Elmer R. Deschaine  
Mr. & Mrs. Patrick J. Dillon  
Mr. & Mrs. Mark Dimond  
Mr. & Mrs. Edward Dooling, Jr.  
Ms. Kristine A. Doucette  
Ms. Joan D. Driscoll  
Mr. & Mrs. William Dubauskas  
Ms. Season DuBois  
Mr. Craig A. DuBois  
Ms. Mary DuBois

Mr. & Mrs. Louis P. DuBois  
Dr. Richard A. Dvaskas  
Ms. Katharine S. Eismeier  
Mr. & Mrs. Leonard W. Elias  
Mr. Samedin Elmazi  
Mr. & Mrs. Francis L. Falgiano  
Mr. & Mrs. Thomas Fava  
Mr. & Mrs. Carter E. Figueroa  
Ms. Terese P. Filippone  
Mr. & Mrs. James F. Flynn  
Ms. Elizabeth Fontaine  
Mr. John W. Fontaine  
Mr. Scott A. Francolini  
Mr. John C. Frantzis  
Ms. Marcia S. Fritz  
Mr. & Mrs. Michael W. Gallagher  
Mr. & Mrs. Keith W. Gavigan  
Mr. & Mrs. Peter M. Gavin  
Mr. & Mrs. John M. Geary  
Mr. & Mrs. Jonathan Genz  
Mr. Jeffrey M. Gilbert  
Mr. & Mrs. William D. Goebel  
Mr. & Mrs. Douglas E. Gordon  
Mr. & Mrs. Frank Haggard  
Ms. Erin Lee Hayes  
Ms. Andrea C. Homewood  
Mr. & Mrs. Joseph T. Hosey  
Industrial Paper & Plastic  
Prod Co Inc.  
John F Kelley Memorial  
Scholarship Fund  
Mr. & Mrs. Joseph D. Joyce  
Ms. Joan P. Kane  
Mr. & Mrs. James E. Kane  
Mr. & Mrs. William A. Karmen  
Mr. & Mrs. Roy R. Kiazim  
Mr. & Mrs. John Kiely  
Ms. Maureen F. Lange  
Mr. & Mrs. Keith M. Lavigne

Mr. & Mrs. Ronald H. Lavigne, Sr.  
Mr. Kenneth M. Lavigne  
Mr. & Mrs. Andrew M. Lawlor  
Ms. Margaret J. Lawlor  
Mr. James J. Lawlor  
Ms. Lynn F. Lawson  
Mr. & Mrs. Jack B. Levine  
Mr. & Mrs. Walter S. Marek  
Mr. David Marshall  
Mr. & Mrs. Alfred E. Mayer  
Mr. William M. McCarthy  
Ms. Dita S. McKinney  
Mr. David F. McLoughlin  
Mr. & Mrs. James M. Mead  
Mr. & Mrs. James K. Mellon  
Ms. Lisbeth A. Miller  
Mr. & Mrs. Vincent J. Miraglia  
Ms. Christine B. Monroe  
Ms. Pamela M. Morey  
Ms. Carole D. Moschella  
Mr. Brendan M. Mullaney  
Ms. Frances J. Mullaney  
Mr. & Mrs. Stephen M. Mullaney  
Mr. & Mrs. George F. Mulligan  
Mr. & Mrs. Sean M. Murphy  
Mr. & Mrs. Christopher G. Navin  
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The CMTA Store is back and ready for business! When the new CMTA website launched in March 2011, the CMTA Store was unavailable. But, as of December 2011, the store is up and running. Take advantage of the store to get all of your CMT needs...including publications, multimedia products and accessories to help raise CMT awareness. Also, with the opening of the store, we have added some fun new products!



### NEW! CMTA T-shirts

Buy one for you and don't forget your family members! The t-shirts are available in blue and white.



### NEW! CMTA Titleist hats...

People will go out of their way to ask you where you got this cool-looking cap! The hats are available in blue, red, and black.



### NEW! Light-Up Star Necklace

Show your support for the STAR initiative with this light-up necklace. Includes battery and cord.

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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 (ddl, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Gold salts  
Lefluonamide (Arava)  
Metronidazole/Misonidazole  
(extended use)  
Nitrofurantoin (Macrochantin,  
Furadantin, Macrobid)  
Nitrous oxide (inhalation abuse)  
Perhexiline (not used in US)  
Pyridoxine (mega dose of  
Vitamin B6)  
Stavudine (d4T, Zerit)  
Suramin  
Taxols (paclitaxel, docetaxel)  
Thalidomide  
Zalcitabine (ddC, Hivid)

**Uncertain or minor risk:**

5-Fluorouracil  
Adriamycin  
Almitrine (not in US)  
Chloroquine  
Cytarabine (high dose)  
Ethambutol  
Etoposide (VP-16)  
Gemcitabine  
Griseofulvin  
Hexamethylmelamine  
Hydralazine  
Ifosfamide  
Infliximab  
Isoniazid (INH)  
Lansoprazole (Prevacid)  
Mefloquine  
Omeprazole (Prilosec)  
Penicillamine  
Phenytoin (Dilantin)  
Podophyllin resin  
Sertraline (Zoloft)  
Statins  
Tacrolimus (FK506, Prograf)  
Zimeldine (not in US)  
α-Interferon

**Negligible or doubtful risk:**

Allopurinol  
Amitriptyline  
Chloramphenicol  
Chlorprothixene  
Cimetidine  
Clioquinol  
Clofibrate  
Cyclosporin A  
Enalapril  
Fluoroquinolones  
Glutethimide  
Lithium  
Phenelzine  
Propafenone  
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# 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.