BY DAVID HALL, CMTA CEO

Since 2008, the CMTA STAR program has been focused on collaborating with leading scientists in the world to find treatments for CMT Type 1A. Drug discovery and development are never easy, but the CMTA STAR program has identified new approaches and even new opportunities and partners, and we continue to progress closer to finding drug candidates that can be utilized in clinical trials.

Over the past year, two significant events have paved the way for the CMTA to announce the launch of a new STAR drug discovery project focused on CMT Type 2A:

- Because CMT2 has diverse genetic causes and likely multiple disease mechanisms, the CMTA sought to obtain advice and direction from the most knowledgeable experts in the world. To this end, the CMTA sponsored a CMT2 workshop just prior to the November 2010 Society of Neuroscience meeting in San Diego, CA. The meeting was attended by more than 30 scientists from 7 countries and provided for a dynamic exchange of strategic ideas for future therapeutic initiatives.

As a result of the meeting, the CMTA was able to develop a strategic research and drug discovery plan for CMT Type 2A.

- In June 2011, the CMTA was the recipient of a 2-year $500,000 grant from Gail and Robert Buuck and the Buuck Family Foundation. The grant was provided specifically to launch the CMT Type 2A STAR project.

CMT2A is caused by dominant mutations in both the MFN2 gene and protein. The rationale behind the CMT Type 2A STAR project is that MFN1 can compensate for MFN2 in cell models, and the overexpression of MFN1 can even compensate for the effects of dominant MFN2 mutations. Thus, the goal is to find small molecules that can upregulate the expression of MFN1 in human neuronal cell lines and to determine whether these small molecules can restore the effects of dominant MFN2 mutations.

Leading the initial phase of the CMT Type 2A STAR project is Dr. David C. Chan, a molecular biologist at the California Institute of Technology and an investigator of the Howard Hughes Medical Institute. The CMTA welcomes Dr. Chan as the newest member of the CMTA STAR team.

Learn more about Dr. Chan on page 10.
What began last year as CMT Awareness Week in the United States has grown this year to a full month and a whole world of participants. On September 24th, which is Global CMT Awareness Day, the CMTA will be joined by participants from CMT groups in Japan, the United Kingdom, France, Spain, Belgium, Canada, Malaysia, Italy, Germany, Austria, the Netherlands, Aruba, Brazil, Norway, Switzerland, Australia, China, Korea, Saudi Arabia, Denmark, Greece, Hungary, Iceland, and Portugal. Awareness Month might well be considered a success simply based on how many participants there are in only the second year.

However, the organizers were not content with simply having a much bigger event this year; they wanted to make sure that as many people as possible would know about CMT in September and as many as possible would participate in some event in their community. As David Hall said, “We wanted to dedicate an entire month’s worth of activities to raise awareness for this serious disease. The devoted efforts of the CMTA’s Support and Action Group Facilitators, along with the commitment of the CMT community will help place CMT at the forefront of recognizable disorders in the US.”

Some of the many activities include a fundraising and awareness campaign called “Let Me Tell You ‘Bout” which is a letter writing campaign that can be personalized to tell friends and family about a person with CMT. (The letter to personalize is at www.cmtausa.org/url/write-a-letter-find-a-cure.) On Facebook, everyone has been asked to change their picture to the national Awareness Month poster to help spread awareness (www.cmtausa.org/url/amposter). For the teens who have CMT or know someone who does, there will be a texting campaign where participants will text the Awareness Month poster to everyone they know. This should spread awareness of CMT throughout the teenage population.

Additional efforts include a PSA from Shadoe Stevens which concludes with the sentence “Help CMT Disappear Forever” and which will be broadcast by Clear Channel on radio stations. Another effort is the micro site www.wearethecmta.com where people have uploaded their pictures, under the Share the Expe-
CMT AWARENESS MONTH!

About Our Poster...

You may be wondering who designed the fabulous poster and amazing T-shirt for Awareness Month, 2011. It was actually the collaborative effort of two amazing Lake Brantley High School students in Altamonte Springs, Florida. The concept of holding a contest for students studying Digital Design to create artwork that would be selected to use in our National Awareness Month campaign was presented to Mr. Parker Daniels, the instructor, who posed the challenge to his classes in late 2010. Mr. Daniels encouraged students to explore the CMTA website, learn about the disease and let their creative juices flow. Josh Miller, a senior, and Erik Kopack, a junior, took up the challenge and created these colorful, unique, and informative designs. Josh and Erik studied the literature and the website and worked to develop their individual concepts of spreading awareness about CMT. They presented their ideas to the Awareness Month planning committee and then took feedback and tweaked and honed until the finished products were released.

We are so proud to see the enthusiasm and dedication of these two fine young men. Unaffected by CMT themselves, each realized the importance of helping to spread the word and to provide community service to the CMTA. Thank you to Lake Brantley High School, Parker Daniels, and especially to Josh Miller and Erik Kopack for sharing their time and talents to help make Awareness Month and Global Awareness Day a huge success! Wonder what school will provide us with next year’s artwork? Stay tuned...

About Our Poster...

You may be wondering who designed the fabulous poster and amazing T-shirt for Awareness Month, 2011. It was actually the collaborative effort of two amazing Lake Brantley High School students in Altamonte Springs, Florida. The concept of holding a contest for students studying Digital Design to create artwork that would be selected to use in our National Awareness Month campaign was presented to Mr. Parker Daniels, the instructor, who posed the challenge to his classes in late 2010. Mr. Daniels encouraged students to explore the CMTA website, learn about the disease and let their creative juices flow. Josh Miller, a senior, and Erik Kopack, a junior, took up the challenge and created these colorful, unique, and informative designs. Josh and Erik studied the literature and the website and worked to develop their individual concepts of spreading awareness about CMT. They presented their ideas to the Awareness Month planning committee and then took feedback and tweaked and honed until the finished products were released.

We are so proud to see the enthusiasm and dedication of these two fine young men. Unaffected by CMT themselves, each realized the importance of helping to spread the word and to provide community service to the CMTA. Thank you to Lake Brantley High School, Parker Daniels, and especially to Josh Miller and Erik Kopack for sharing their time and talents to help make Awareness Month and Global Awareness Day a huge success! Wonder what school will provide us with next year’s artwork? Stay tuned…

CMT AWARENESS MONTH!

Experience tab, and written personal comments on the “wall.” You can also watch video clips of people relating their CMT stories or post your own video.

One of the highlights of the month was the announcement of the winners of the “I Am a Shooting Star” and the “I Am a Star” contests. People across the country were invited to submit letters detailing the ways in which both young people and adults have risen above the problems of CMT and achieved success. The “I Am a Shooting Star” contest was open to young people aged 3-17 and the “I Am a Star” contest was for adults 18 and up.

Awareness Month is a huge undertaking and would not have been possible without the help of the Support and Action Group Facilitators who willingly wrote to their governors, mayors, and representatives to request that September be recognized as CMT Awareness Month in their cities, towns, and states. Some of the successes are seen in the proclamations on page 2. And Awareness Month would definitely not have been possible without the incredible commitment and energy that Elizabeth Ouellette and Jeana Sweeney devoted to it. Starting back at the end of Awareness Week in 2010, they began strategizing to make sure that an undertaking as big as a full month devoted to awareness activities would succeed. The number of other countries that have joined in the effort shows that they succeeded.

If you are not involved through a local Support and Action Group, you can support the effort by changing your photo on Facebook to the Awareness Month poster or by going to iGive.com and then to Zazzle.com to order T-shirts, new bracelets, which are white with blue lettering, or the CMTA $.44 stamp. Most of all, make sure that the people you love know about CMT and respect what the disorder can do to you and your children. ★
I AM A STAR

I am writing to tell you about a star and hero, my son, Timothy Ward.

Tim was diagnosed with CMT1A on July 24, 2008, at the age of 15. The answer we had searched for for many years was finally ours. See, Tim’s life consisted of doctors, tests, bracings, castings, and surgeries, with no answer why. As a child, Tim struggled with being clumsy, tripping a lot, and never being athletic enough for his peers. His teachers reprimanded him for his “terrible” handwriting and not being as good as he should in gym classes. His peers whispered among themselves and Tim became the kid that they got a good laugh about.

In spite of this, Tim was an inspiration for me because he always managed to look at the glass half full. He always gave people the benefit of the doubt and forgave those who hurt him.

In spite of this, Tim was an inspiration for me because he always managed to look at the glass half full. He always gave people the benefit of the doubt and forgave those who hurt him.

See, Tim never felt sorry for himself. He always found someone to help or something to get involved in. Whether it was playing the guitar at our parish, teaching CCD, or volunteering at the local hospital day care or the summer camp for children with disabilities, Tim was there. Don’t get me wrong: all of this did not come without difficulties because of CMT. Playing the guitar became very difficult. His fingers and wrist would become weak and hurt. What did Tim do? He did occupational therapy instead of giving up his guitar.

We found a wonderful doctor and neuromuscular clinic that not only knew CMT but were experts. Sophomore year right after Tim’s diagnosis he was faced with another surgery. In spite of all the positives, CMT did not go away. This was difficult for Tim to accept.

There was no pill to take, no shot to get, no cure for CMT. He became sad, confused, and angry. We decided to seek someone who could help Tim deal with the emotional part of CMT. After a lot of hard work and support, Tim was able to reach another milestone in his life with CMT.

High school consisted of making the most of his whole person. He continued to volunteer for causes like children with disabilities, school retreats, and debate club, and he became vice president of his senior class. He went to physical and occupational therapy three times a week and was Philadelphia-bound twice a year. One of our proudest moments was at graduation. Tim received “The Most Courageous Student Award” along with “The Seton Hall President’s Award” for being an inspiration and example to others.

Tim now attends Drew University. He continues to volunteer and is an active participant in campus life. His passion for writing will make his dream of someday writing his own book come true. He has learned that the best way to rise above CMT is to recognize it, own it, nurture it, and fight back when necessary. Tim has been a true inspiration to so many people; he selflessly shares his strength, courage, and wisdom. This is why my son, Timothy Ward, is my star, my hero, and an extraordinary person.

Written by Tim’s mother
A SHOOTING STAR

Jacqueline is 7 and is getting ready for 2nd grade at Peterson Elementary. She was diagnosed at age 4 with CMT Type 1. Still able to walk and get around, she lived a normal life with minor limitations. Soon after being diagnosed though, her disease really started to take hold of her little body. We quickly learned the challenges of everyday life.

Starting school in the fall of 2009, Jacqueline was like any other kid, excited, nervous, and a little scared at first.

On her first day of school, Jacqueline walked into class with AFOs and a walker to be used when needed. On her last day, she rolled out in her power chair. Her disease is very progressive with no plateau in sight. Through it all, she smiles, laughs, and carries on like any other 7 year old would. She has a spirit that makes you want to be a better person.

In September 2010 Jacqueline started cheer leading and has since performed with her cheer team, “Heaven’s Angels” at the Dallas Cowboys stadium where they were interviewed and featured on the local news. That same month Jacqueline attended The Night of Superstars, a local program that gives children with physical disabilities a night to feel like they are a superstar. Ever since, her confidence has soared. We have since attended another Night of Superstars, where she was honored as a veteran. She is not afraid of who she is and what she has.

You ask her what’s wrong and she will tell you, “My legs don’t work right.” That’s how a 7-year old sees this. Not like I do as her mother. She lives for today, for the here and now. So her legs don’t work, but her chair, “Casey” as she calls it, has turbo and goes to the speed of 5. She is also a member of Rise Adventures based out of Dallas, a group that encourages people with physical disabilities to go out and live life to the fullest.

On our first encounter with Rise, Jacqueline and I went sailing, and it was nothing short of amazing! Positivity is her motto and it has kept us all going through the past 3 years of consistent negative change in her physical abilities. I tend to have more bad days than she does. She is not worried about tomorrow. She is just looking forward to today.

“Shooting star” Jacqueline Dyer and her teacher Mrs. Cain enjoy the last week of school.

PUMPING UP CMT AWARENESS

On June 15, a fundraising/awareness event for Hayley Nilsen and CMT was held at “Pump It Up” in Eden Prairie, Minnesota. Pump it Up is a play area with a variety of inflatable slides and jumping castles. They charged admission for each guest and we received 60% of the profits. We did an Evite with emails from the school directory. Fifty of Hayley’s first grade classmates came for an evening of play, pizza, and a chance to learn more about Hayley’s CMT. Over $600 was raised by the evening’s activities. Hayley and her family would like to thank everybody involved in making this event a success.
ALBANY NY SAG ENJOYS BASEBALL WITH THE VALLEYCATS

On August 12, the Upstate NY support & action group’s CMT Awareness Night All-You-Can-Eat Picnic Benefit with the ValleyCats baseball team was a great success, raising $2,000 for the CMTA’s STAR initiative, which will be doubled by the challenge grant.

The ValleyCats made an announcement over the PA and recognized the CMTA group on the scoreboard. Also, SouthPaw, the mascot, tossed CMTA T-shirts into the crowd.

The weather was perfect. We enjoyed great food and time with family, friends, and co-workers as the ValleyCats swept their second doubleheader in three days at Joe Bruno Stadium in Troy, NY.

Support and Action group members and friends won the fun raffle baskets, which Melinda Lang, facilitator, put together with donated and purchased items including a wine lovers basket, scrap booking basket, BBQ lovers basket, Catsmont Adventure Park tickets, A Day at the Track in Saratoga, Girl’s Night Out basket with Saratoga Performing Art Center tickets, Rumor’s Salon facial certificate, wine and chocolate, a sportsman’s basket and the Grand Prize, round trip air fare tickets worth up to $800 with Southwest.

In addition, Melinda obtained many items for the silent auction such as an autographed NY Jets football, autographed Nets basketball coach photograph, gift certificates for chocolate-dipped fruit, Nuns of New Skete cheesecake, a golf putter, autographed books from the Monks of New Skete including, “How To Be Your Dog’s Best Friend,” a bus trip, and various gift cards.

They were very fortunate to have Elizabeth Ouellette, Support and Action Group liaison, join them. She immediately went to work selling raffle tickets, and her son, Yohan, volunteered to help by handing out programs.

TOE-TALLY AWESOME SOFTBALL BENEFITS CMTA

The Third Annual CMTA “Friendly” Softball Tournament was held on July 16th and 17th at the Point Stadium in Johnstown PA. This event was arranged and managed by Jeana Sweeney. Sixteen teams participated again this year and they all came back with the same crazy names! A few favorites this year were Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet. Many companies participated by sponsoring a team for their employees such as CFO Strategies, HF Lenz, Pitt Bull, and Kongsberg Defense. There were two trophies handed out—one for the “The Best of the Worst,” which went to Bunion Bridges, “ST”inky Feet, The Gout Laws, and Sweet Feet.
CMT AWARENESS WITH THE ALTOONA CURVE

For the second year in a row, CMT Awareness Night was held at the Altoona Curve on August 14th with a corporate sponsorship from Laurel Medical Supply and Golden Orthotics. The money raised from the softball tournament provided the attendees with a ticket to the game and a barbecue dinner. The CMTA was able to spread the word about CMT to a little over 5,000 people. In the stands there were also 105 people either living with CMT or who had loved ones with CMT. Everyone had the chance to be involved, including throwing the first pitch, playing games in-between innings, and being named honorary team captains... There was a booth selling bracelets and handing out information on CMT. To draw in people to the booth, there were two very special items, a signed autographed football by Joe Paterno and an Altoona Curve Jersey, signed by the entire team. The football went for an amazing $1000.00 and the jersey went for $165.00. The end of the night went off with a bang with a fantastic fireworks display!

TAKE ME OUT TO THE BALL GAME... NEW JERSEY STYLE

On July 19th, the Central New Jersey Support and Action Group hosted CMT Awareness Night at the Somerset Patriots, a minor league baseball team in Bridgewater, NJ. While it was the hottest day of the year to that point, we had the sun on our side and we found ourselves in the shade by the time the game started.

Before the game, we had a 10-minute on-field presentation. We arranged for a video on the big screen, and Dave Hall, CMTA CEO, gave a speech from the field. There were attendees involved in every on-field activity. Jacob Matteis threw the ceremonial first pitch; Julia Beron was rolled up in a red carpet, and the whole crew of kids were welcomed in the dugout and on the field before the game started. Another bunch of our group got to go on the field during the 7th inning stretch to sing “Take Me Out to the Ballgame.”

We had a CMT table on the main concourse and we had representatives at the table all night to sell 50/50 tickets, talk up our silent auction items, sell bracelets and STAR necklaces, and hand out brochures. Our 50/50 prize was $263 and was won by a friend of one of the group members. The team jersey signed by the team members sold for $155, and a football signed by Coach Joe Paterno sold for $500!

The most rewarding part of the night was when a gentleman and his wife approached the table and told us he had CMT and never knew there was a local group! He was touched and happy to meet us.

Special thanks to those who traveled to be with us for the event, including Pat Livney, Chairman of the Board of the CMTA; Dave Hall, CEO of the CMTA and a great spokesperson for us all; Jeana Sweeney and her family; and Kim Magee and her family. Kim’s daughter Noel and her friend Katie were our STAR 50/50 ticket sellers. The CMTA STAR logo was shown so many times, and the CMT name was said so many times, 4,400 people left that game knowing about CMT.
### GIFTS WERE MADE TO THE CMTA

#### IN MEMORY OF:
- Robert Ahlvers
- Mrs. Janelle Lea Pearl
  Danville High School Class of 1955
- Emil Barlow
  Mr. and Mrs. William Krejci
- Constance Carver
  Mr. and Mrs. William Krejci
- Harvey "Mitch" Fisher
  Mr. Dennis Bowers
  Mr. and Mrs. Guy O. Daniels
  Ms. Joan D. Engle
  Mr. and Mrs. Leroy R. Fisher
  Ms. Joy Kern
  M-D Truck Sales and Service, Inc.
  Mr. and Mrs. Ronald Smith
  Ms. Joyce G. Taylor
  Mr. Bernard A. Thome
  Ms. Jody Weaver
- Robert Kalstrom
  Lake Brantley High School
- Robert Kitchens
  Ms. Juanese Calkins
- Walter Konstalid
  Mr. and Mrs. Kenneth Konstalid
- George Livney
  The Livney Foundation
  Mr. and Mrs. Anthony Matthews
  Mr. Gilles Bouchard and
  Ms. Elizabeth Ouellette
- Frederick Luepke
  Mr. and Mrs. Charles Hoffmann
  Mr. and Mrs. Robert Moen
  The Silva Family
- Mickey McNamar
  Mr. and Mrs. Bill Seabolt
- Carmen Pappalardo
  Beneficience, Inc.
  Mr. Jeff Cardwell
  Mrs. Renee Copeland
  Mr. and Mrs. Bill Donnelly
  Ms. Amy Keller
  Mr. Lawrence Levin
  Mr. and Mrs. Jack Lubinski
  Ms. Laura Marotzke
  Mrs. Shelly Meracle
  Mr. and Mrs. George Oleskievicz
  Mr. and Mrs. Ram Padmanabhan
  Mr. Melvin E. Pearl
  Mrs. Camille Richco
  Dr. Rita and Richard Rossi-Foulkes
  Mr. and Mrs. Tad Sieck
  Ms. Annette Slovick
  Ms. Erin Spear
  Mr. and Mrs. Herbert Wander
  Ms. Maryann Waryjas
- Velma Pasch
  Ms. Joan Boniface
  Mr. and Mrs. Herb Persons
  Mr. and Mrs. Yoshiai Tsuji
- James Quarner
  Mr. and Mrs. Ye Caplan
  The Heller Family
  Mr. and Mrs. Harold J. Hettelman
  Mr. and Mrs. Marshall Layton
- Ms. Barbra McLaughlin
  Mr. and Mrs. William Pittler
  Mrs. Geraldine Quarten
  Ms. Amy Resnikoff
  Ms. Eileen Sherman
  Mr. and Mrs. David Wirthsheter
- Althea Scott
  Mr. Ronald Scott
- Latrice Slaughter
  Mr. and Mrs. Paul Slaughter
  and Family
- Gennaro A. Smeglin
  Mr. and Mrs. Frank Esposito
  Mr. and Mrs. Gary Thompson
  Williamstown Medical
  Associates
  Ms. Marion Zorn
- Ruth T. Wallace
  Ms. Cheryl Ellis
  Mr. and Mrs. Ricardo Johnston-Garcia
  Mr. and Mrs. David M. Robbins
  Mr. and Mrs. Jack L. Thomas
  Ms. Betty Wallace
- Donna M. Webb
  Ms. Victoria O’Malley
- Sarah Wien Robin
  Ms. Leonore R. Cohen

#### IN HONOR OF:
- Riley Ashe
  Mr. John McCarthy
  Mrs. June McCarthy
- Marilyn and Martin Berger
  Mr. and Mrs. Frank Weiss
- Dr. Robert Chetlin
  Ms. Joyce Kelly
- Lindsay Conn
  Mr. and Mrs. Frank Weiss
- Steven Weiss and
  Kim Hughes
  Mr. and Mrs. Frank Weiss
- Coach Morgan Johnson
  Ms. Joyce Kelly
- Julie Leonard—
  Happy Birthday
  Ms. Shirley Weiner
- Patrick Livney
  Mr. Peter Silverman
- Jacob Mattheis
  Mr. Wayne R. Clevin
  The Moms Club of
  Long Hill NJ.
  Ms. Charlotte Novak
- Eugene and Terrie
  Rosenzor
  Mr. and Mrs. Frank Weiss
- Jeana Sweeney—
  Happy Belated Birthday
  Mr. Rick Alber
- Frances Torone
  Mr. John Fitzgerald
- Richard and Jill Weiss
  Mr. and Mrs. Frank Weiss
- James P. Whitten
  Ms. Janice Flower
- Robert Zawideh
  KempKlein Law Firm

---

### 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: _______________________________
My name is Katie Ayala and I currently train a client who has had Charcot-Marie Tooth disease for 44 years. His name is Richard Cook. I am writing to you today to tell you how amazing Richard is. He, to this date, has completed 2 half marathons and a full marathon. His next endeavor is a 100-mile Lakes and Grapes bike ride. He has been training all summer long and we are excited for him. He has also chosen to complete another full marathon in Richmond, November 12th.

Richard in motion is awesome to watch. He never quits; he always tries, and he doesn’t let CMT limit his capabilities. He has grown stronger and he has gained more confidence. He is super humble and has inspired many of my other clients and fellow racers to set goals and accomplish them. Watching him cross the finish line brings tears to your eyes.

Richard is a perfect example of a CMT success story. Ever-determined, NOTHING can stop him from accomplishing what he wants out of life. We love him dearly. Since September is CMT month, I just wanted to share his story with you so that maybe he could inspire other people with CMT. He has definitely defied what medicine has told him he cannot do.

Richard’s wife Ruth writes:

When Richard was in 4th grade, the gym teacher first noticed that he might have some foot issues. Since Richard’s older brother, Mike, was already undergoing treatment for CMT at Crippled Children’s Hospital, he started going there, too. As time progressed, the issues of hammer toes, high arches, weak ankles, “dropped foot” syndrome, and loss of muscle tone in feet, legs, and hands continued. When Richard was in the 8th grade, he underwent his first surgery to reconstruct his right foot. Later that year, reconstructive surgery was done to his left foot. A few years later, he had surgery on both of his feet—which made for an interesting time for a teenager with casts on both feet!

During high school, Richard lived as much of a “normal” live as he could. He could not play sports for school because he was unable to run a 7-minute mile. However, casts, crutches, and CMT did not stop him from playing “backyard” sports with his friends, playing on a church league for softball and volleyball.

Richard was told that CMT was a degenerative, slowly progressing disorder and it was never going to get any better. He was told that the surgeries on his feet should be able to get him to his late 30’s to early 40’s. Orthopedic surgeons have since suggested inserts and orthotics to help with the pain and with his gait.

“Running/walking” half marathons and marathons had never crossed his mind, because he would say “these legs don’t run.” In January, 2010, I joined a training team for the Marine Corps Half Marathon. Since he was not sure if he could maintain the minimum 18-minute mile, Richard began to “secretly” train outside. After about a month, he finally “broke down” and teamed up with me for weekly training sessions with Katie. His times out from the gym were faster than he ever thought they would be. Our son William joined us in the Marine Corps Half Marathon on May 16, 2010. As Richard and I came near the finish line, William and Katie (who had already completed their race) came running up to greet us. William “ran again” across the finish line with his Dad. Richard’s time was 3:06:32. Once that race was under his belt, he began to train for a full marathon.

Richard finished the SunTrust Richmond Marathon on November 13, 2010, with a time of 6:01:37. This year, the entire family participated again in the Marine Corps Half Marathon on May 15, 2011. Richard’s goal this time was not to beat his previous time—as many participants have that goal—but was to be a pace partner for another Off Da Couch Training member so she could

(continued on page 15)
Meet David C. Chan, MD, PhD

Dr. David Chan has joined the CMTA’s STAR research team to work on Type 2A. See page 1.

I was born in Hong Kong and immigrated to the US when I was 2 years old. I attended Harvard College for undergraduate studies, earning a degree in biochemical sciences. Upon graduation, I enrolled in the MD-PhD program at Harvard Medical School. I then devoted my studies to biomedical research and received further postdoctoral training in biophysics at the Whitehead Institute at the Massachusetts Institute of Technology. In 2000, I began my faculty appointment at the California Institute of Technology, where I have been ever since. In 2008, I was appointed an Investigator of the Howard Hughes Medical Institute.

My lab’s main interest is to understand the role of mitochondrial dynamics in cellular function and human physiology. Mitochondria are dynamic organelles that have many important functions in cells, including energy generation, metabolism, and regulation of cell death. A key feature of mitochondria is that they undergo cycles of fusion and fission, and our lab is trying to understand the role of these processes in controlling their function. In addition, several human diseases arise from a perturbation of these processes. In recent years, my lab has been particularly interested in how MFN2 mutations cause the peripheral neuropathy of CMT2A.

RDCRN: A Valuable Resource for CMT Patients

The former CMT North American Database, which had information on 800 CMT patients, has joined forces with the NIH (National Institutes of Health), which is working to establish clinical research networks and specialized treatment centers for rare diseases. One of NIH’s networks is called the Inherited Neuropathies Consortium Rare Disease Clinical Research Network (RDCRN). All CMT Centers of Excellence are part of the RDCRN.

What does all this mean for the CMT patient? Researchers believe that more studies of patients are needed to record progression and symptoms that occur with each specific genetic type. Understanding the differences between the various types can improve the effectiveness of clinical trials and help the development of targeted treatments. Identifying which genetic type a person has helps doctors provide more information about medical management and discuss inheritance patterns for family planning.

Dr. Michael Shy has been instrumental in establishing this international network and in training physicians to evaluate patients the same way.

Researchers would like everyone with CMT to go to one of the sites listed below for evaluation and to provide biological samples (blood, skin biopsies). These sites are all MDA clinics as well, and MDA will pay for the evaluations and sample collections for all MDA-registered patients.

If you go to rarediseasesnetwork.epi.usf.edu and click on the link for the Inherited Neuropathies Consortium, you can learn about the current studies. If you want to stay informed regarding these studies, join the Patient Contact Registry, and you might be invited to participate in any clinical trials that grow out of the studies.

RDCRN SITES

Wayne State University, Detroit
Johns Hopkins University, Baltimore
University of Washington, Seattle
Children’s Hospital of Philadelphia, Philadelphia
Hospital of the University of Pennsylvania, Philadelphia,
University of Rochester, Rochester
Vanderbilt University, Nashville
National Hospital for Neurology and Neurosurgery, London, UK
Children’s Hospital at Great Ormond St, London, UK
Children’s Hospital Westmead, Sydney, Australia
C. Besta Neurological Institute, Milan, Italy

YOU CAN STILL CONTRIBUTE TO THE BOARD CHALLENGE

The Board Challenge has come to its original end with a total of $90,000 being added to the CMTA’s fund. If you have not yet contributed and would like to, a special Awareness Month campaign has been added. You can still be part of the Board Challenge by making an on-line donation through the Let Me Tell You ’Bout link. You can access it at www.cmtausa.org/url/let-me-tell-you-bout-campaign. The deadline for these contributions is October 31st.

You can still contribute to the Board Challenge by making an on-line donation through the Let Me Tell You ’Bout link. You can access it at www.cmtausa.org/url/let-me-tell-you-bout-campaign. The deadline for these contributions is October 31st.
New CMT Center of Excellence

BY PAT DREIBELBIS

The Vanderbilt Charcot-Marie-Tooth Disease clinic serves patients with inherited neuropathies from Tennessee and across the Southeast. They offer a multidisciplinary approach that includes clinical neurology, electrodiagnostic testing, genetic counseling, physical therapy, and consultation regarding orthopedic surgery. They also have an active research program as well as a basic science laboratory which help advance their mission of better understanding and treating CMT.

The director of the clinic is Jun Li, MD, PhD who has specialized in inherited neuropathies for over ten years. In 2000, Dr. Li joined the faculty at Wayne State University, School of Medicine, as an Assistant Professor of Neurology. He was promoted to Associate Professor in 2002 and was recruited to Vanderbilt in 2009.

The first visit will occur on a Thursday. When you come to the clinic, the CMT specialist will meet with you to learn more about your medical history. You will receive a physical exam as well as one or more of the following tests:

- **Nerve conduction study:** This measures the speed of electrical signals that travel through nerves. The test feels a bit like the static electricity when you take off a sweater.

- **Hand grip strength assessment:** This test measures your grip strength using a hand dynameter. This is a painless test to evaluate hand function and strength.

- **CMT neuropathy/disability score:** This is a simple questionnaire that assesses your motor and sensory functions for daily living. This score allows the clinic to track changes in your nerve function across time.

- **Physical therapy assessment:** The physical therapist is available to see patients on Thursday afternoon. The therapist can help with bracing and walking issues.

- **Surgery consultation:** If a patient needs to see an orthopedic surgeon, clinic staff will set up an appointment.

- **Skin biopsies:** A patient may be asked to provide a biopsy (sample of skin). This procedure can be declined after asking questions about its use and pain.

- **Blood samples:** Many patients choose a genetic test because it is the most certain way of diagnosing CMT. They will draw a blood sample and send it to a lab for the DNA testing. Your blood can be archived in Vanderbilt’s lab to help with further treatment and research.

The CMT Clinic is part of the Muscular Dystrophy Association clinic. Each patient will benefit from the coverage that MDA usually offers. Your clinic visit and clinical evaluation will be free. Because they do not want to exclude anyone from their clinic, they will see patients who do not have insurance or whose insurance will not cover the visit. The cost of medical devices (braces, wheelchairs, etc.) will not be covered.

Dr. Jun Li will head up the new Center of Excellence located at Vanderbilt University.

Walk for a Reason

Philadelphia, PA

Join Team Yunkers as they raise money for the CMTA in a 5K Walk/Run in Manayunk.

Sunday, October 16th, 2011
Starts at 9:00 a.m.

Registration starts at 8 a.m.
Course: Approx. 3.1 mi. from Umbria and Fountain Streets to the Canal Towpath, along the path, and back up the steps

FOR MORE INFORMATION about this event and a registration form email Vickie Remolde at Vick916@aol.com

PROCEEDS BENEFIT THE CMTA
Dear David,

I have CMT 1A. I am a 35-year-old female who has been married to a great guy for the past 5 years. We don’t have children. Over the past 2 years, my CMT has progressed to the point that small chores are exhausting and I need to take frequent naps. In addition to some foot drop, I’ve also developed burning foot pain, which makes standing and walking difficult. But, I am not a complainer and I keep trying to carry on, despite my CMT. However, my family just does not understand what I am going through. I’ve tried to explain how my CMT affects me, but when I say I am tired or cannot do a certain task, I am met with disparaging remarks and impatience. How can I help my family understand the effects of CMT on me? They think I am a whiner and I am doing my best! Help!

Hi—

If your family has labeled you a “whiner,” this could indicate a few different issues. First, let me say that one of the problems for those of us who have CMT is that we often look very able-bodied and our challenges are simply not that apparent to even our close circle of loved ones. That does not excuse your family from cutting you some slack when you feel you just need a little rest. I have found that sometimes they truly do not understand our limitations.

If this is the case, we can begin by giving them some of the literature that has been written on CMT so they can become truly educated in the challenges of living with CMT. Sometimes our loved ones react with impatience or irritability when in truth they are covering up their own fears and anxieties around our condition. Anger is often an emotion that is more accessible than fear or sadness. Those of us who live on a daily basis with CMT often cannot tell the difference between being physically tired or being a little depressed. Keep in mind that when we are a bit depressed or sad or anxious our emotions speak directly to our muscles and will reflect how we feel at any given moment. Those of us with CMT are pushed to form a very intimate relationship with our bodies and our emotions. This can actually be a positive thing in that we get to know ourselves and grow in self-awareness. Often what we experience as limitations helps us grow in other areas. If your response to your family is being perceived as whining, then perhaps your own work is to get in touch with the stronger feeling of anger around feeling misunderstood and a certain insensitivity that your family is displaying towards your daily challenges. In other words, STAND UP for your right to sit down!

Dear David,

One of my three children has CMT. Like most families, all my kids have chores and responsibilities around the house. My 12-year-old with CMT often tells me he is too tired or in too much pain to do some of the chores, like taking out the garbage or putting the dishes in the dishwasher. I understand that between school, friends, and the demands put on kids these days, he may be worn out at the end of the day, but some days, I feel like he is using his CMT to get out of doing certain tasks.

Of course, this causes conflict with his siblings, too. Should I ignore his complaints and insist that he do what is asked of him? Or, should I cut him some slack and relieve him of his responsibilities around the house?

Hi—

This is a dilemma that parents of children with CMT often face. On one hand you want to be sensitive and understanding of your child’s limitations. On the other hand your child can be playing you big time. If you are too pampering, he grows up feeling he or she is less capable than other kids and this could affect his self-worth. It is most important that your child feel that in spite of his being a little different, he has just as much to contribute to the family and to others as well. If he is complaining to you about being too tired to do certain chores, why don’t you involve him in choosing what chores he feels he is capable of doing. Explain to him that he is an important part of this family orchestra even if he is not playing first violin. ★
CMT Support and Action Groups in Your Community

**CMT Support and Action Groups in Your Community**

**Support and Action Group**

- **205-870-4755**
  - Ronnie Plageman
  - West Central Florida CMT Support and Action Group

- **661-433-2533**
  - Kimberly Hughes
  - Steven Weiss
  - Washington, DC CMT Support and Action Group

- **303-988-5581**
  - Dick Kutz
  - Denver Area CMT Support and Action Group

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

- **707-829-0911**
  - Ronald Deghi
  - San Francisco Peninsula/CMT Support and Action Group

- **661-433-2533**
  - Nina Anselmo
  - Stockton CA CMT Support and Action Group

- **661-433-2533**
  - Bill Wilkens
  - Central Florida CMT Support and Action Group

- **661-433-2533**
  - Janice Zippe
  - floridacmt@gmail.com

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

- **707-829-0911**
  - Donna Rennie
  - San Francisco/East Bay CMT Support and Action Group

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

- **661-433-2533**
  - Nina Anselmo
  - Stockton CA CMT Support and Action Group

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

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

- **661-433-2533**
  - Nina Anselmo
  - Stockton CA CMT Support and Action Group

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

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

- **661-433-2533**
  - Nina Anselmo
  - Stockton CA CMT Support and Action Group
Back to School!

Every year there is both excitement and dread when the first week in September rolls around. I’m worried that no one will like me…that no one will even know who I am….that I will not be able to write an acceptable “What I Did This Summer” essay. Or, worse than no one knowing me, what if someone knows me and hates something I’ve said or done? I work myself into a proper state of anxiety each and every year. My Mom keeps telling me that it will get better, but it really doesn’t.

On the other hand, I look forward to meeting some new kids in my class, going on awesome field trips, being smart in some subject that I might not ever have had before, and learning new things. Yes, school really is cool…once you get over the rough patches.

So, this year I’m in the third grade and my teacher is Ms. Annabelle Armadillo. She moved to the Greenwoods from Arizona and she’s been telling us all about the deserts and the cacti and animals that we never see around here. I like her.

Unfortunately, I also have Samuel Skunk in my class. I think he’s been held back and he’s just not a nice student. When I tell my family about him, they say that he probably doesn’t feel good about himself and that’s why he says nasty things to the rest of us. That’s all well and good, but when he is taunting me about losing the election at the end of last year, it’s very hard to remain cool and collected. I guess, if there is a good side to his attacks, it is that everyone else sympathizes because they have also been his victim. Miss Armadillo talks to the class in general about thinking about how we make other people feel (because she wouldn’t single out Samuel), but I think he’s the only one who doesn’t really listen. I think this is an example of that “preaching to the choir” thing that the pastor always says in church. He lectures about how we need to attend services and contribute to the upkeep of the church, but we are the ones there doing just that.

I’m on the swimming team again and that makes me feel good. I’m not super fast, but I’m really dependable, and the coach says I’m a team player. I guess it’s just something older people say to make kids feel like they belong.

I wasn’t sure if I was going to write about this or not, but I’ve decided that I can because none of you will be talking to my classmates.

There’s a new little girl turtle at the school. Her name is Tiffany and she’s exceptionally cute and nice. Ok, I’m saying it: I think I have a crush on her. She makes my shell turn pinkish brown when she looks at me. Sometimes she’ll tell me that I’m so smart or clever, and I can’t stop stammering or blushing. I’m hoping to take her to the Harvest Festival and maybe even have her over to my house to study some afternoon. Keep good thoughts for me—I don’t want to mess this up!

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. Working together, we can create a world without CMT!

Donations were made to these CMTA Circles:

- Chris’s Run
  Mr. Kevin Klein
  Tasha Kutzkhals
  Mr. Thomas A. Peterson

- Ken’s Ride
  Mr. James Glisson

- Running the UP
  Mr. Tim Bauer
  Ms. Susie Bawks
  Mr. David M. Becker
  Ms. Elizabeth Began
  Mr. John Converse
  Ms. Terry Doherty
  Mr. Alan Dolley
  Ms. Betty E. Doyle
  Ms. Dawn M. Eccles
  Ms. Kristine Ertman

- Fraternal Order of Orioles
- Mr. Mike Gormline
- Mr. Mark Hardy
- Mr. Paul Heidecker
- Ms. Janet Heminger
- Mr. Chris Hoag
- Mr. & Mrs. Jeremy Holbrook
- Mr. & Mrs. Jeremy Holbrook
- Mr. Scott Kintopf
- Mr. David J. Landon
- Ms. Stacey Barta Lee
- Mr. Chuck Leight
- Ms. Linda Mattes
- Mr. Dean B. Mazzolini
- Ms. Beverly McCulloch
- Mr. Rodney Palmer
- Mrs. Diane Ross
- Mr. Paul Schluckebier
- Shiawassee Conservation Association
- Mr. Gary Smith

- Ms. Holly M. Thompson
- Ms. Cathy Thorne

- Swim for the Cure
  Mr. & Mrs. Thomas M. Carbotti
  Ms. Heather A. Kormanik
  Ms. Grace Reusing
  Mr. & Mrs. Thomas S. Waxter

- West Chester, NY SAG, STAR Research Challenge
  Mr. Ben Berry
  Mr. Hershey Berry
  Mr. Joshua Berry
  Mr. Melvin Berry
  Mr. Jim Hall
**SUBSCRIPTION AND PUBLICATIONS ORDER FORM**

**NAME:** ______________________/_______/ _________________________________________________________

**ADDRESS:** __________________________________________________________________________________

**CITY:** ___________________________________________  **STATE:** _______ **ZIP:** _______________________

**COUNTRY/POSTAL CODE (IF NOT US):** ______________________________________________________________

**DAYTIME PHONE:** ________________________________   **EVENING PHONE:** ___________________________

**EMAIL:** _______________________________________________________________________________________

<table>
<thead>
<tr>
<th>QTY</th>
<th>COST</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Online subscription with PDF newsletter</td>
<td>$25 (MUST REGISTER ONLINE)</td>
</tr>
<tr>
<td></td>
<td>Online subscription with printed newsletter</td>
<td>$30 (MUST REGISTER ONLINE)</td>
</tr>
<tr>
<td></td>
<td>Mail subscription only with printed newsletter (no access to online premium content)</td>
<td>$30</td>
</tr>
<tr>
<td></td>
<td>CMT Facts I [English]</td>
<td>$5</td>
</tr>
<tr>
<td></td>
<td>CMT Facts II [English]</td>
<td>$7</td>
</tr>
<tr>
<td></td>
<td>CMT Facts III</td>
<td>$7</td>
</tr>
<tr>
<td></td>
<td>CMT Facts IV</td>
<td>$10</td>
</tr>
<tr>
<td></td>
<td>CMT Facts V</td>
<td>$15</td>
</tr>
<tr>
<td></td>
<td>CMT Facts VI</td>
<td>$15</td>
</tr>
<tr>
<td></td>
<td>Teaching Kids about CMT…A Classroom Presentation (1 hour DVD)</td>
<td>$10</td>
</tr>
<tr>
<td></td>
<td>My Child Has CMT, A Guide for Parents</td>
<td>$7</td>
</tr>
<tr>
<td></td>
<td>Cooking and Coloring Adventures with Archy</td>
<td>$7</td>
</tr>
<tr>
<td></td>
<td>Be a Star Wristbands (Pack of 5)</td>
<td>$5</td>
</tr>
<tr>
<td></td>
<td>Women’s Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL</td>
<td>$10</td>
</tr>
<tr>
<td></td>
<td>Men’s Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL ___2XL ___3XL</td>
<td>$10</td>
</tr>
<tr>
<td></td>
<td>West Coast Patient-Family Conference (5 hours—2-DVD set)</td>
<td>$20</td>
</tr>
<tr>
<td></td>
<td>CMT Informational Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List</td>
<td>FREE</td>
</tr>
<tr>
<td></td>
<td>Physician Referral List: States: ______  ______  ______</td>
<td>FREE</td>
</tr>
<tr>
<td></td>
<td>Donation to the CMTA (100% Tax-deductible)</td>
<td></td>
</tr>
</tbody>
</table>

**Shipping & Handling**  
(Orders under $10, add $3.50; orders $10 and over, add $7.50)

**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

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.
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, 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.

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)
- Gold salts
- Leflunomide (Arava)
- Methotrexate/ Misoprostol (extended use)
- Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
- Nitrous oxide (inhalation abuse)
- Perhexiline (not used in US)
- Pyridoxine (mega dose of Vitamin B6)
- 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
- Hexamethylenemelamine
- Hydralazine
- Ifosfamide
- Infliximab
- Isoniazid (INH)
- Lansoprazole (Prevacid)
- Metformin
- Omeprazole (Prilosec)
- Penicillamine
- Phenelzine
- Pilocarpine (Dilantin)
- Podophyllin resin
- Sertraline (Zoloft)
- Statins
- Tacrolimus (FK506, Prograf)
- Zimeldine (not in US)
- a-Interferon

Negligible or doubtful risk:
- Allopurinol
- Amitriptyline
- Chloramphenicol
- Chloroquine
- Cimetidine
- Clioquinol
- Clofibrate
- Cyclosporin A
- Enalapril
- Fluoroquinolones
- Glutethimide
- Lithium
- Phenelzine
- Propafenone
- Sulfonamides
- Sulfasalazine

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA FAX (610) 499-9267
www.cmtausa.org