THE CMTA Report

SEPTEMBER/OCTOBER
2011

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

CMTA
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.

EMAIL CMTA AT:
info@cmtausa.org

ISSN #1067-0181 ★ Vol. 26, No. 5

A New STAR Is Born

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.

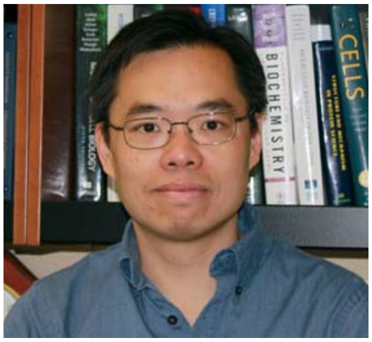
Over the past year, two significant events have paved the way for the CMTA to announce the launch of a new STAR drug discovery project focused on CMT Type 2A:

- 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.

> A generous grant from the Buuck Family Foundation will fund Type 2A research.

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.



Dr. David Chan joins the CMTA's STAR research team to work on type 2A.

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.

OUR NEW EXPERT

David Tannenbaum is a new addition to the CMTA's Advisory Board. He is a psychotherapist in New York City and is a person who deals with CMT every day.

See page 12

THE CMTA CELEBRATES AWARENESS MONTH— SEPTEMBER 2011

See page 2

[SEPTEMBER 2011]

THE WORLD CELEBRATES

BY PAT DREIBELBIS

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-

Support and Action Group Facilitators wrote to mayors, senators, and governors. Here are a few statewide proclamations they received.

STATE OF NEW MEXICO **EXECUTIVE OFFICE** SANTA FE, NEW MEXICO

Proclamation

WHEREAS, CHARCOT-MARIE-TOOTH DISORDER (CMT) IS THE MOST COMMONLY INHERITED PERIPHERAL NEUROPATHY AFFECTING 1 IN 2,500 PERSONS WORLDWIDE, WITH NUMEROUS CITIZENS IN THE GREAT STATE OF NEW MEXICO DIAGNOSED WITH CHARCOT-MARIE-TOOTH DISORDER; AND

WHEREAS, CMT OFTEN MANIFESTS ITSELF IN A SLOW PROGRESSION EXEMPLIFIED BY MUSCLE ATROPHY IN THE EXTREMITIES COUPLED WITH ATAXIA, CHRONIC PAIN, OVERWHELMING FATIGUE AND LOSS OF SENSATION; AND

WHEREAS, PATIENTS WITH CHARCOT-MARIE-TOOTH MUST CONSTANTLY ADVOCATE ON THEIR OWN BEHALF WITH DOCTORS, MEDICAL PROFESSIONALS, EDUCATORS AND ADMINISTRATORS WHO OFTEN ARE UNAWARE OF THE DISORDER, ITS SYMPTOMS OR THE OBSTACLES FACED WHEN AFFECTED BY THIS DISORDER; AND

WHEREAS, GENETIC TESTING IS OFTEN THE BEST WAY TO DETECT THE PRESENCE OF CMT AND THE CHARCOT-MARIE-TOOTH ASSOCIATION'S STAR (STRATEGY TO ACCELERATE RESEARCH) INITIATIVE IS DEDICATED TO CONDUCTING RESEARCH AND DEVELOPING TREATMENTS AND ULTIMATELY THE CURE WHILE FUNDING FOR THIS INTEGRAL PROGRAM IS BASED ON PUBLIC DONATIONS AND CORPORATE ALLIANCES; AND

WHEREAS, THE PURPOSE OF THE CMTA IS TO PROVIDE GRASSROOTS SUPPORT FOR LOCAL CITIZENS FACING THE DAILY CHALLENGES OF LIVING WITH CMT BY ENCOURAGING LOCAL MEMBERS OF THE COMMUNITY TO RALLY AROUND THEIR NEIGHBORS AND MAKE A COMMITMENT TO EDUCATING THE PUBLIC; AND

WHEREAS, THE CHARCOT-MARIE-TOOTH ASSOCIATION IS WORKING NATIONALLY AND INTERNATIONALLY TO EXPAND PUBLIC AWARENESS AND ENCOURAGE ALL RESIDENTS OF NEW MEXICO TO TAKE COGNIZANCE OF THIS EVENT AND JOIN IN THE ENDEAVOR TO SPREAD AWARENESS AND EDUCATE THE POPULACE ABOUT CMT;

NOW, THEREFORE I, SUSANA MARTINEZ, GOVERNOR OF THE STATE OF NEW MEXICO, DO HEREBY PROCLAIM SEPTEMBER 2011 AS

"CHARCOT-MARIE-TOOTH AWARENESS MONTH"

THROUGHOUT THE STATE OF NEW MEXICO.

SIGNED AT THE EXECUTIVE OFFICE THIS 15TH DAY OF JULY 2011.

WITNESS MY HAND AND THE GREAT SEAL OF THE STATE OF NEW MEXICO.

SMartinez
SUSANA MARTINEZ
GOVERNOR

ATTEST:
Dianna J. Duran
DIANNA J. DURAN
SECRETARY OF STATE

STATE OF OREGON
PROCLAMATION
OFFICE OF THE GOVERNOR

WHEREAS: Charcot-Marie-Tooth Disorder (CMT) is the most commonly inherited peripheral neuropathy affecting 1 in 2,500 persons worldwide; often manifesting itself in a slow progression exemplified by muscle atrophy in the extremities coupled with ataxia, chronic pain, overwhelming fatigue and loss of sensation; and

WHEREAS: Patients with Charcot-Marie-Tooth must constantly advocate on their own behalf to doctors, medical professionals, and educators who are often unaware of the disorder, its symptoms, or the obstacles faced when affected by this disorder; and

WHEREAS: The Charcot Marie Tooth Association's (CMTA) STAR (Strategy to Accelerate Research) Initiative is dedicated to conducting research, developing treatments and ultimately the cure while funding for this integral program relies on public donations and corporate alliances; and

WHEREAS: The purpose of the CMTA is to provide grassroots support for citizens living with the daily challenges presented by CMT by encouraging local members of the population to rally around their neighbors and make a commitment to educating both the public and medical communities at large.

NOW, THEREFORE: I, John A. Kitzhaber, M.D., Governor of the State of Oregon, hereby proclaim **September 2011** to be

CHARCOT-MARIE-TOOTH AWARENESS MONTH

in Oregon and encourage all Oregonians to join in this observance.

IN WITNESS WHEREOF, I hereunto set my hand and cause the Great Seal of the State of Oregon to be affixed. Done at the Capitol in the City of Salem in the State of Oregon on this day, April 27, 2011.

John A. Kitzhaber, M.D., Governor

Kate Brown, Secretary of State

COMMONWEALTH OF PENNSYLVANIA
OFFICE OF THE GOVERNOR
HARRISBURG

THE GOVERNOR

GREETINGS:

I am pleased to extend my support and encouragement to all Pennsylvanians who are suffering with Charcot-Marie-Tooth (CMT) disease, and the devoted members of the Charcot-Marie-Tooth Association (CMTA) who endeavor to raise public awareness of this condition, help people living with CMT disease, and support research into its cause, cure, and treatment.

I applaud the CMTA's commitment to fighting this progressive neurological disease as well as to helping those adults who are coping with its effects. Your work has helped to educate the public about CMT, advocate for CMT patients and caregivers, and support CMT research — making a dramatic impact within the medical community and improving the lives of countless individuals with this disease. I hope you will continue to find success in your mission of advancing CMT patient care and that a cure will soon be found.

On behalf of all Pennsylvanians, I commend the Charcot-Marie-Tooth Association, as well as those who have joined in the effort to raise awareness of CMT and its effects, on your remarkable dedication to the health and welfare of our citizens. Best of luck in your CMT Awareness campaign and all of your future endeavors.

Tom Corbett
TOM CORBETT
Governor
September 2011

STATE of WISCONSIN
OFFICE of the GOVERNOR

Proclamation

WHEREAS; Charcot-Marie-Tooth (CMT) Disorder, the most commonly inherited peripheral neuropathy, is a disease of the nerves that control muscles; and

WHEREAS; this disorder, named after the three physicians who discovered it in 1886 (Jean-Martin Charcot, Pierre Marie, and Howard Henry Tooth), is slowly progressive, causing loss of normal function and/or sensation in the lower legs/feet and hands/arms, and can be severely disabling; and

WHEREAS; approximately 2,262 Wisconsin citizens have CMT disorder; and

WHEREAS; the mission of the Charcot-Marie-Tooth Association (CMTA) is to educate patients and physicians, create awareness about CMT, promote research and, ultimately, find a cure; and

WHEREAS; through public awareness, CMTA and the State of Wisconsin seek to minimize the disabling effects of Charcot-Marie-Tooth disorder;

NOW, THEREFORE, I, Scott Walker, Governor of the State of Wisconsin, do hereby proclaim September 2011, as

COT-MARIE-TOOTH DISORDER AWARENESS MONTH

throug the S f Wisconsin, and I commend this observance to all of our citizens.

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Wisconsin to be affixed. Done at the Capitol in the City of Madison this [illegible] day of July 2011.

SCOTT WALKER
GOVERNOR

By the Governor:
Douglas La Follette
DOUGLAS LA FOLLETTE
Secretary of State

CMT AWARENESS MONTH!

rience 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. ★

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…

[SEPTEMBER 2011]

AWARENESS ESSAY CONTEST

The first-ever STAR and SHOOTING STAR essays recognize two individuals, one in New Jersey and one in Texas who both exhibit an unfailing spirit.

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.

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.

Board member Herb Beron presented the I AM A STAR award to Tim Ward.

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 unselfishly 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

[CMT AWARENESS MONTH]

WINNERS

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.

Baseball, Apple Pie, and Raising Awareness

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, Catamont 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.

Melinda Lang, team mascot Southpaw, and Cheryl Traeger created CMT awareness at a baseball game in upstate New York.

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 Ouelette, 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. Team Sweet Feet (Sweeney's team) did make it to the championship game this year, but could not come up with the win. Maybe next year! The winner of the tournament was the Marching Arches, a team sponsored by a local business in Johnstown. The championship trophy will be displayed in their place of business until next year. Thanks to all who participated and special thanks to the sponsors!

During a break at the softball game in Johnstown, kids showed off their dance moves.

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 firework display!

▲ To help create awareness of CMT, the Altoona Curve baseball team posted a CMTA banner on their scoreboard.

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 gamed 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 Matteiss 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.

A few well-known faces were in the crowd at the Sommerset Patriots game (Patrick Livney and Herb Beron). ▼

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
Benefitdecisions, 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 Oleskiewicz
Mr. and Mrs. Ram Padmanabhan
Mr. Melvin E. Pearl
Mrs. Camille Ricchio
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. Yoshiaki Tsuji

James Quartner
Mr. and Mrs. Yale Caplan
The Heller Family
Mr. and Mrs. Harold J. Hettleman
Mr. and Mrs. Marshall Layton
Ms. Barbra McLaughlin
Mr. and Mrs. William Pittler
Mrs. Geraldine Quartner
Ms. Amy Resnikoff
Ms. Eileen Sherman
Mr. and Mrs. David Wirtshafter

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. Leanore 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 Mattheiss
Mr. Wayne R. Clevin
The Moms Club of Long Hill NJ.
Ms. Charlotte Novak

Eugene and Terrie Rosendarden
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:________________________
____

Richard Cook: Defying the Odds

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:

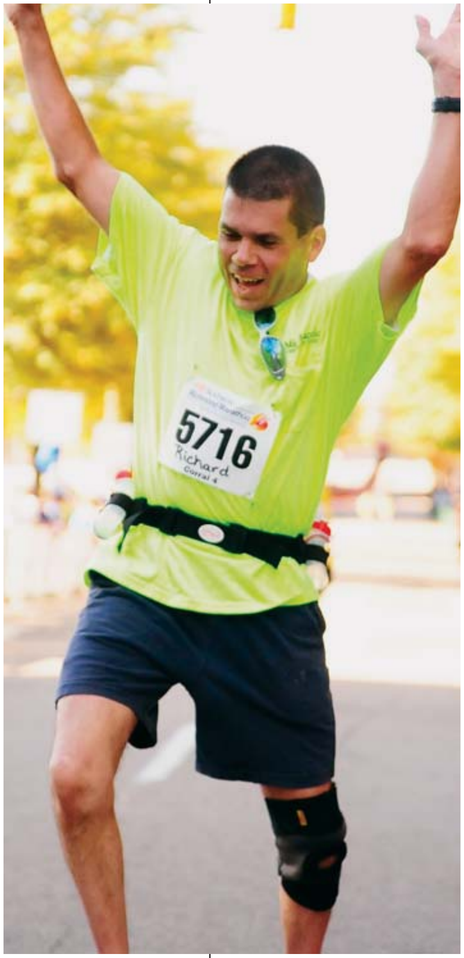
When Richard was in 4th grade, the gym teacher first noticed that he might have some foot issues. Since Richard's older brother, Mike, was already undergoing treatment for CMT at Crippled Children's Hospital, he started going there, too. As time progressed, the issues of hammer toes, high arches, weak 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)



Richard Cook completed the Marine Corps Half Marathon on May 15th.

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. ★

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.

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 Ormand St, London, UK
Children's Hospital Westmead, Sydney, Australia
C. Besta Neurological Institute, Milan, Italy

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.


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

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. ★

THE VANDERBILT CMT CLINIC

ADDRESS:
1161 21st Ave. South
Nashville, TN 37232

PHONE:
615-322-7246

WEBSITE:
http://www.vanderbilthealth.com/clinicalneurosciences/35306

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

WHAT'S ON YOUR MIND? ASK DAVID.

Our new expert, David Tannenbaum, has an LCSW degree and has been a psychotherapist in NYC for the past thirty 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," says David. Write to David at info@cmtausa.org.)

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

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—Los Angeles Area
South Californa CMT
Support and Action Group
Dottie Zagar
661-433-2533

CA—Stockton
Stockton CA CMT Virtual
Support and Action
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—Santa Rosa Area
Santa Rosa, CA CMT
Support and Action Group
Carol O'Bryan
707-823-0165
Ronald Deghi
707-829-0911

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—Jacksonville Area
Jacksonville, FL CMT
Support and Action Group
Bill Wilkens
904-268-4530

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

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
702-560-3647

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
Eastern 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—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

Virtual Groups*

Dave Hall's Virtual Support and Action Group

Global Support and Action Group Community

Virtual groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups. Click on Find a Group and choose either Global or Dave Hall's Virtual Support and Action Group.

TAKE ACTION: **If there is no support group in your area, consider becoming a facilitator!**
If you are interested, please contact Jeana Sweeney at jeana@cmtausa.org.

★ The CMTA welcomes four new support groups!

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.

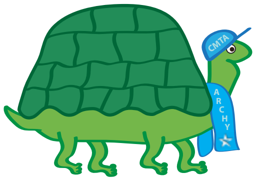
On the other hand, I look forward to meeting some new kids in my class, going on awesome field trips, being smart in some subject that I might not ever have had before, and learning new things. Yes, school really is cool…once you get over the rough patches.

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 cactuses 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! ★



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

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
Tashua Kurtzhals
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 Gorsline
Mr. Mark Hardy
Mr. Paul Heidecker
Ms. Jan Heminger
Mr. Chris Hoag
Mr. & Mrs. Jeremy Holbrook
Mr. Scott Kintopf
Mr. David J. Landon
Ms. Stacey Barta Lee
Mr. Chuck Leigh
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. Hershel Berry
Mr. Joshua Berry
Mr. Melvin Berry
Mr. Jim Hall

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

RICHARD COOK

(continued from page 9)

meet her goal. They crossed the finish line in 3:28:26.

Soon after the marathon, the staff of Hanger Orthotics was able to build a set of orthotics that he could insert into his running shoes. The orthotics have made his gait more stable and have helped him better accomplish his training goals. Since running/walking puts a strain on his knees, hips and ankles, Richard started to ride a road bike with a group from our church. Earlier this year, he was told about a Century ride (100 miles) and that became a new goal. Once he has completed that goal, he will finish training for another full marathon on November 12, 2011.

Richard is really looking forward to December 7th! Thanks to the link to doctors on the CMTAUSA website, Richard was able to find Dr. Zimmer in Richmond, Virginia. Dr. Zimmer will be doing surgery on his left foot on that date. This surgery will straighten out all five toes. There will be pins in the smaller toes and a screw in the big toe. There will be a wedge taken out of the top of his high arch to allow his foot to bend properly. The achilles tendon will be cut and lengthened and his heel will be straightened. Tendons will be rerouted to make his foot look and respond like "normal." If all goes as planned, in late 2012, Richard will have surgery on his right foot. The prognosis is excellent. After about 10 weeks off his foot, Richard should be ready for the "spring" season, as he is a self-employed lawn/landscaper. ★

SUBSCRIPTION AND PUBLICATIONS ORDER FORM

NAME: ______________________/________/ ______________________________
First MI Last

ADDRESS: ____

CITY: ______________________________ STATE: ________ ZIP: ______________

COUNTRY/POSTAL CODE (IF NOT US): ______________________________

DAYTIME PHONE: ______________________ EVENING PHONE: ______________________

EMAIL: ____

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

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
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, 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-Fluouracil
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)
a-Interferon

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

THE CMTA Report

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

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.