



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.

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# GREAT ACCOMPLISHMENTS REQUIRE GREAT EFFORTS

BY DAVID M. HALL, CEO

We are all familiar with the saying, "You reap what you sow." This famous quotation generally refers to the fact that one cannot escape the consequences of one's actions. This certainly applies to the CMTA. We are now happily dealing with the consequences of our actions, which is great news for the CMTA and the national CMT community.

More than two years ago, the CMTA launched the STAR program (Strategy to Accelerate Research) as a strategic effort to find a therapy for CMT Type 1A. Under the leadership of Drs.

Michael Shy and Steven Scherer and the CMTA's Scientific Advisory Board, a world-class team of scientists was recruited to participate in a structured, collaborative research and drug development program. The results to date have been astounding:

- ★ 2 CMT Type 1A cell lines have been created (bio-technology that is used to screen against vast libraries of compounds and drugs)
- ★ 350,000 compounds and drugs were screened against the CMT Type 1A cell lines using robotic, high-throughput screening (HTS)

- ★ 800 "hits" were discovered in the HTS project (drugs and compounds which demonstrated significant promise in reducing the levels of PMP22 within the cell lines)
- ★ 2 additional libraries of chemicals have been employed to identify the "best of the best" within the 800 "hits"
- ★ 1 laboratory animal model has been created for the sole purpose of testing the best CMT Type 1A drug candidates

*(continued on page 2)*



## FOCUS ON FUNDRAISING:

*CMTA members share the ambitious ways they've helped raise money and awareness. Among them is Donna DeWick (pictured left) who has CMT and competes in triathlons.*

*See pages 4-7.*

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EMAIL CMTA AT:

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**GREAT ACCOMPLISHMENTS***(continued from page 1)*

Not only has the STAR project greatly exceeded expectations, but it has also created an intuitive understanding of the processes and technologies necessary to tackle the therapeutic challenges of CMT. And as we plow ahead with the current STAR project, we will utilize this emerging foundation of knowledge to continue to “sow” for the future. For example, I am delighted to inform you that in November 2010, in San Diego, California, the CMTA is convening more than 30 scientists from 7 countries for a strategic CMT Type 2 meeting. The goal of the 3-day gathering is simple—leverage the newfound body of knowledge with the best minds in the world to develop a new STAR project dedicated to CMT Type 2.

What does this mean for the CMTA and the national CMT community? It’s simple. We will simultaneously be driving the only two dedicated CMT drug development projects in the world! The challenge is awesome, but so is the opportunity at hand. Recent scientific and technological advances, including the human genome project, have been uniquely incorporated into STAR. Going forward, we feel it is time to reap even more of what we have sown.

One of the many reasons the CMTA is strategically aligned with the leading scientific and clinical minds in the world is our leadership in managing and sponsoring the Inter-

national CMT Conferences. Every 2 years more than 100 thought leaders from over 12 countries come together with the goal of exchanging new clinical and scientific information and starting or strengthening collaborations between research and patient service organizations. The 4th International CMT Conference is scheduled for June 2011 in Washington, DC, and once again the CMTA will proudly sponsor this dynamic meeting.

We plan to work with the best minds in the world to develop a new STAR project dedicated to Type 2 CMT.

As you know, it is the mission of the CMTA to balance our hope for finding the treatments and cures of tomorrow with the goal of improving the lives of those living with CMT today. Education and awareness campaigns are essential components of our patient advocacy efforts. Through the CMTA’s national network of support and action groups (SAGs), we are collectively making huge strides in building bridges between the clinical and patient communities.

In March 2010, in an attempt to solidify and bolster our patient advocacy efforts, the CMTA hosted the 1st Annual SAG Conference in Las Vegas, Nevada. More than 50 of our national SAG leaders, CMTA staff, directors, and advisors gathered for a weekend-long meeting to develop strategies for enhancing our advocacy efforts. I am very proud to announce

that because of the Las Vegas meeting, we were able to celebrate the 1st Annual National CMT Awareness Week during the week of September 19–25, 2010. The Awareness Week, a true partnership between the CMTA and the national SAGs, along with groups of dedicated parents, patients, doctors, nurses, and health care workers, helped to raise awareness and increase knowledge about one of the most commonly inherited, but little known, disorders in the United States.

We at the CMTA are very proud of our accomplishments to date, yet our work is far from complete. Obviously, the CMTA does not exist, nor do programs like STAR or the national and international meetings, without your continued commitment to the mission at hand. Your generous support has been unprecedented within the world of CMT.

The CMTA is sensitive to the very challenging economic times that we live in today. For this reason, we have not embarked upon multiple fundraising campaigns this year. We understand that budgets are tight, but hopefully you can find it in your heart to continue your generous support of the CMTA’s mission. Your contributions can make a difference like never before.

Please join us in “sowing” so that the rewards we reap will change the lives of those you love. To contribute, visit our website at [www.cmtausa.org/sow](http://www.cmtausa.org/sow). Thank you again for all you do for the CMTA and the national CMT community. ✨

# CMT Awareness Week: A Smashing Success

BY ELIZABETH OUELLETTE

Over the past 4 months, the CMTA has been diligently preparing for the Association's First Annual CMT Awareness Week, September 19–25, 2010. Together with a group of dedicated parents, patients, family members, and friends, our 50+

and increasing funding to support CMT-related treatments and therapies through the STAR initiative.

In addition to the numerous activities and events our exuberant support and action group facilitators (more on this in the November/December

updated, and informed about Charcot-Marie-Tooth disease on many different levels.

Upon entering the micro site, you will meet others, from all walks of life, who are either involved with the CMTA or who have CMT, and are determined not to let CMT define

Visit [www.wearethecmta.com](http://www.wearethecmta.com) to view the Awareness Week posters, photos, and write-ups, and to link to the CMTA's YouTube videos.



support and action group facilitators are skillfully spearheading an exceptional grassroots effort to raise awareness and increase knowledge about Charcot-Marie-Tooth disease (CMT) nationwide. This First Annual Awareness Week will not only put CMT in the public eye, but will also eventually be instrumental in reducing misdiagnosis

newsletter) have been working on, the CMTA has set up an Awareness Week micro website ([www.wearethecmta.com](http://www.wearethecmta.com)), where people all over the world can follow along and participate in Awareness Week happenings. The micro website is an eye-catching and interactive tool for CMTA members and non-members alike to get involved,



their true essence. You will also be able to join our team of health professionals, supporters, and members, by uploading your own pictures and videos to share your personal stories,

*(continued on page 18)*

## The CMT “Circle of Friends”

*“You’re going to do ...what??!!”*

Since we began the CMTA Circle of Friends program, our members have found many new and creative ways to support the work of the CMTA. People who initially began with a simple letter to their friends and family have built upon their success and now hold annual dinners, walks, and tournaments.

Others have met the challenge by finding ways to get their employers and other companies involved through sponsored events and matching gift programs.

Recently, however, CMTers have really been pushing the envelope. We’ve mentioned Ken’s Ride ([www.cmtausa.org/kensride](http://www.cmtausa.org/kensride)) before—in 2011, he’s going to ride from Anacortes, WA, to Bar Harbor, ME—but this month Ellen Welby (pictured here at the relatively tame elevation of 2077m) is taking on Mt. Kilimanjaro, the fourth highest summit in the world at 5,895m or 19,341 ft! Ellen will summit on Uhuru peak on September 22 ([www.cmtausa.org/Ellen](http://www.cmtausa.org/Ellen)).

On September 19th, Chris Wodke will run the Fox Cities Half Marathon ([www.cmtausa.org/Chris](http://www.cmtausa.org/Chris)), and Mary Louie will be walking the 26.2-mile Mount Desert Island Marathon on October 17th ([www.cmtausa.org/Mary](http://www.cmtausa.org/Mary)).

In July, 2011, Doug Allie, who doesn’t have CMT, is planning a 14-day, 355-mile run across Michigan’s Upper Peninsula to help find a cure for CMT, the neurological disorder that affects his son Jacob ([www.cmtausa.org/runacrosstheup](http://www.cmtausa.org/runacrosstheup)).

We’ve also had people Tri for CMT. Donna DeWick, a triathlete from London, England, has been raising funds for CMT research through her Tris and related activities (see “Why I Tri” on page 5).

While we acknowledge that mountaineering, marathoning, tri-ing, and other rigorous athletic activity are not possible for many people with CMT, we hope you appreciate what all of these athletes are doing on behalf of everyone with CMT.

If you would like to take up the challenge to get involved and start your own Circle of Friends, call us today at 1-800-606-2682, email us at [cof@charcot-marie-tooth.org](mailto:cof@charcot-marie-tooth.org), or visit us on the web at [www.charcot-marie-tooth.org/cof](http://www.charcot-marie-tooth.org/cof).

Working together, we can create a world without CMT!



The CMTA reaches new heights as Ellen Welby is set to climb Mt. Kilimanjaro (19,341 feet).



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**Doug Allie will run 355 miles to help raise funds to find a cure for his son Jacob.**

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**Why I Tri**



I've always been interested in health and well-being. In 2003 I decided to sign up for the London Half-Moon midnight walking half marathon, in support of breast cancer-related charities. About halfway through the night my left foot started to ache, which I chalked off to my shoes. I headed for shoe analysis at a trusty well-regarded running shop, where I was told they could not sell me new shoes until I had sorted out my foot roll with good orthotic inserts. About a year later, in 2004, with inserts in hand (or should I say, in shoe), I completed the Full-Moon midnight walking marathon for charity.

The process of sorting out my foot roll also led me to an official diagnosis of Charcot-Marie-Tooth disease. I am lucky in that my CMT is mild, but it does impact me. I have high-arched feet. I can feel extreme fatigue after exercise. And I develop all sorts of aches and pains caused by nerve-compromised biomechanics. But I firmly believe that with the right attitude, nutrition, and activity levels, I can minimize the way that CMT impacts my life.

With this in mind, in 2007 I decided to take on the challenge of a triathlon.

Who knew what I was getting myself into?! I finished the London triathlon sprint distance in 2007, 2008, and 2009, and I stepped up my game and added a second triathlon in 2009. I have started to run again after about 25 years. And through a consistent and constant training program, I was able to complete my first Olympic distance triathlon (1500m swim; 40km bike; 10km run) in 2010.

On [www.myfitnessyear.com](http://www.myfitnessyear.com) and my blog, you can follow my training, details about my approach to managing my well-being with CMT, news on my charity fundraising activities, and of course, the challenges I face while trying to "do it all"—balancing my job, my personal life, and my training!

—Donna DeWick

"I firmly believe that with the right attitude, nutrition and activity, I can minimize the way CMT impacts my life."



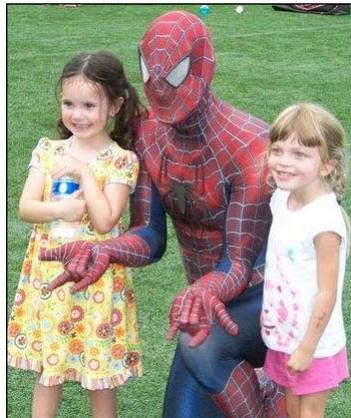
**CMT gears up as triathlete Donna DeWick heads out on a 100km training ride.**

## More Fundraisers for the CMTA

### "FRIENDLY" SOFTBALL IN JOHNSTOWN

The Second Annual CMTA "Friendly" Softball Tournament was held on July 17th and 18th in Johnstown, PA, at the Point Stadium. This event was arranged and managed by support and action group co-leader, Jeana Sweeney. Sixteen teams participated in play this year. To make it fun, all teams were required to choose a name related to feet. A few of the cleverest were Children of the Corns, Foot Fetish, Unde"FEET"ables, 2 Left Feet, and "Toe"rally Awesome. Corporate teams such as Kongsberg Defense, DRS, Pitt Bulls, Richland Rotary, and CTC got involved this year by sponsoring a team for their employees. They all plan to post something in their employee newsletter about their participation in the tournament. Pepsi also did their part by dedicating the month of May as Dress Down Month for CMT; all proceeds from the month

**Diesel Dog, the Altoona Curve mascot, posed with some of the kids who attended CMT night. And Archy was there, of course.**



**Spiderman attended the softball tournament and got "up close" with Mya Derricott and Rylee Sweeney.**

went to the tournament. There were two trophies handed out—one for "The Best of the Worst" which was won by Hammer Toes. The big winners of the tournament were the Loafers, a team sponsored by a local business in Johnstown. The trophy will be displayed in their place of business until next year. It was a great weekend for all who participated (even Spiderman came to support Jeana's efforts).

### RAISING CMT AWARENESS IN ALTOONA

A CMT Awareness Night was held at the Altoona Curve on July 25th with the monies raised from the softball tournament providing the attendees with a ticket to the game, a CMT teeshirt and a barbecue dinner. Wow, what a night! There were 5,666 people in the stands, and they all learned about CMT. Sixty-five people attended who either had CMT or had a loved one with CMT. Everyone had the chance to be involved,

including the throwing of the first pitch, games played during the time between innings and children being named honorary team captains. There was a booth selling CMTA bracelets and T-shirts and giving brochures away. To lure people over to the booth, there was an Altoona Curve Jersey, which was signed by the entire Curve team. This ultimately was sold for \$205. To end the night, a fantastic fireworks display was enjoyed by everyone in attendance. It was truly a great night not only for those who attended, but above all for Jeana Sweeney, who realized her goal of spreading awareness of CMT.

### SWIMMING FOR CMT IN MONTVILLE

On Sunday September 5th at the Lake Valhalla Club in Montville, NJ, a total of 25 swimmers took to the water again to raise money for the Charcot-Marie-Tooth Association's Research Fund in honor of Julia Beron. It was a phenomenal day for the community, as 150 close friends and family cheered on the swimmers and showed their continued support to the CMTA. Specially designed graffiti-style "TeamJulia '10" T-shirts were sold, and local businesses provided baskets and gift certificates that were auctioned off in a silent auction.

A local apparel company also donated Jac Vanek bracelets, which were sold with all proceeds going to the CMTA. All in all, TeamJulia '10 has raised



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25 swimmers participated in the TeamJulia "Swim for the Cure."

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Mr. Steven A. Weill  
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Mrs. Michele Weiner  
Mr. & Mrs. Jeff Weinflash  
Ms. Karen B. Weinstein  
Mr. Adam Weitzman  
Mrs. Patti Wold  
Mr. & Mrs. William L. Yerman  
Mr. Philson Yim  
Mr. & Mrs. Barry H. Zucker  
Ms. Denise Zwerling

in excess of \$50,000 thus far, and the total continues to grow. The picture shows this year's swimmers. There were many newcomers (both swimmers and donors!) and the team will surely grow for the 2011 event.

If you know anybody who might be interested in making a

contribution to TeamJulia '10 and the Swim for the Cure, the website is: [www.cmtausa.org/Julia](http://www.cmtausa.org/Julia).

In 2007 and 2008, TeamJulia participated with Steve O'Donnell in the Chesapeake Bay Swim. In 2009, the first TeamJulia swim was held at Lake Valhalla. In coming years,

it is our goal to turn this great day into a regional or even national event, and we are seeking a swimming celebrity to be a national spokesperson.

Also, if you are on Facebook, you can check out the official TeamJulia '10 site at [www.cmtausa.org/tmjfb](http://www.cmtausa.org/tmjfb) \*

# Aids for Daily Living

RECOMMENDED BY CMT PATIENT, WAYNE ROGERS



## DRESSING AID: MOLDED SOCK AID

Along with zipper pulls, non-slip socks, and elastic shoelaces at Active Forever, the Sock Aid they offer is easy to use, a convenient size, and an affordable price. It is ideal for those who have difficulty leaning down to put on socks or stockings; with the Molded Sock Aid you can complete this task with ease. The versatile Molded Sock Aid features two garters that fasten a stocking to the sock aid so that they won't slip off the aid while being pulled onto the foot.

*Price: \$12.50. Available at [www.activeforever.com](http://www.activeforever.com) or 800-377-8033  
SKU# A16006 01*



## OXO GOOD GRIPS BUTTON HOOK

Most CMT patients could benefit from a button hook. The cushioned grip of the Good Grips Button Hook makes but-

toning clothes easy. The built-up handle features flexible ribbing that adapts to any grip.

*Price: \$7.95. Available at [www.activeforever.com](http://www.activeforever.com) or 800-377-8033  
SKU# A16020*



## LONG-REACH SPRING-ACTION SHOE HORN

This device minimizes bending and stretching and has a flexible shaft and a soft, simulated leather riding-crop grip with hanging strap. It has durable steel construction and is 23" in overall length.

*Price: \$14.99. Available at local Sears Stores or [www.sears.com](http://www.sears.com)*



## PICK UP & REACHING TOOL

Exceptionally helpful around the house, this tool brings ease to everyday living. It reaches items high on the shelf to eliminate the need for dangerous step-stools—lowering boxes, cans,

and such safely to the counter. While you're comfortably seated in a chair, it picks up glassware, remote controls, portable phones, and more from the coffee table or floor. Just squeeze the trigger to close the gripper arms, press the lock, then squeeze again to release the item. You can use it indoors and out. Made from durable, lightweight aluminum with plastic handle. About 31"L; folds to about 16".  
*Price: \$8.00. Available at [www.starcrest.com](http://www.starcrest.com) or 800-551-2843  
Stock# 12-80686-5*



## JAR OPENER TRIO

You can twist lids off effortlessly and painlessly with this jar opener set. Simply squeeze the easy-grip handle as you turn and the nonslip EVA ring clamps tightly to prevent frustrating slippage. You'll avoid straining your muscles. Simply push the handle in one direction to loosen, in the other to tighten. Set of three for large (mayonnaise size), medium (jelly jar size) and small (condiments). Largest is about 7"L.  
*Price: \$3.00. Available at [www.starcrest.com](http://www.starcrest.com) or 800-551-2843  
Stock# 24740*

### STEADY-WRITE PEN

This pen works for either a right- or left-handed person. It is useful for people with a weakened grasp. The pen uses standard ballpoint pen refills. Your hand does not touch the pen, but simply glides the base across the paper.



Price: \$12.50. Available at [www.activeforever.com](http://www.activeforever.com) or 800-377-8033  
 SKU# A15134



### THE MAGNETIC PICKUP TOOL

The tool is heavy-duty and can lift up to 8 pounds. It's most useful for picking up dropped paper clips, tacks, and pins—items which can be difficult for CMT-affected hands. It can also retrieve kitchen utensils which get stuck between the stove and the counter or hardware that gets wedged in narrow spaces.

Price: \$3.00. Available at [www.starcrest.com](http://www.starcrest.com) or 800-551-2843  
 Stock# 10-99546-2

## The Blighted Years

by Doug Hounsome

*Had you* All my blighted years I've had you  
*Loathe you* I loathe you more each day  
*Wrench you* I wish that I could wrench you,  
 wrench you from my soul  
*Throw you* And throw you, throw you miles away

*Weakness* You fill me with your weakness,  
*Feel* I feel you everywhere  
*Spirit* But you cannot, will not, break my spirit  
*Try me* Come on and try me, try me if you dare.

*Heart* This heart is full of music  
*Chance* But you never gave the chance,  
*Feet* For these puny legs and stunted feet  
*Dance* To run or jump or dance

*Sorrow* Sometimes I filled with sorrow  
*Cry* I could hide my face and cry  
*Young* When I was young and you were strong  
*Die* I wished that I might die

*Sterner* But now I'm made of sterner stuff  
*Joy* My life has known much joy  
*Hurt* You cannot hurt the man I am  
*Boy* The way you hurt the boy

*Run* These legs may never run or dance  
*Care* But I no longer care  
*Head* I live a life inside my head  
*There* And you can't get in there

*Joy* My spirit runs and jumps with joy  
*Sing* And dances when I sing  
*Muscles* You don't need muscles in your mind  
*Bells* Nor strength to make bells ring

*Worst* So do your worst, you devil's work  
*Master* You will not master me  
*Strength* Your weakness is my strength, begone  
*Bother* For you don't bother me

## CMT IN THE NEWS

### **STATE COLLEGE, PA—**

#### **Joe Paterno Nominated for Presidential Medal of Freedom**

U.S. Rep. Glenn “G.T.” Thompson, R-Howard, wants Joe Paterno to receive the Presidential Medal of Freedom, one of the nation’s highest civilian honors.

On Friday, Thompson sent to President Barack Obama a letter with 17 additional signatures—from both sides of the aisle—asking that Obama grant the award to Penn State’s head football coach.

In its 65-year history, the medal has “rarely ... been made to someone who has personified sportsmanship on the field of play and academic achievement in the classroom,” the letter reads. “It is our hope that this year the Medal of Freedom does just that by honoring Joe Paterno for his contribution to the coaching of football, his commitment to academic integrity of the young men under his charge, and his deep dedication to education in general.”

Paterno, 83, has been head football coach at Penn State for 44 seasons. He’s about to begin his 45th.

The letter to Obama suggests that Paterno “represents an ideal of what student and college athletics should be.”

“He has amassed nearly 400 wins, more than any other coach in Division I history,” the letter reads. “His program has never been on probation. There has never been an accusation of corrupt recruiting and, in what is depressingly rare, his players stay in school and graduate. Rather than raising money for stadium

skyboxes, as many of his colleagues do, Coach Paterno has personally donated millions and raised hundreds of millions more for libraries and need-based scholarships for Pennsylvanians. He is a strong supporter of the Pennsylvania Special Olympics and serves as a national spokesperson for the Charcot-Marie-Tooth Association.”

### **CEDARTOWN, GA—**

#### **Woman with CMT Receives Award from MDA**

The Muscular Dystrophy Association has named Pam Barfield of Cedartown the recipient of its 2010 Robert Ross Personal Achievement Award for Georgia, according to a press release.

Barfield, 32, was selected for MDA’s highest achievement award in Georgia for her outstanding work on behalf of others with disabilities and for her determination to excel in the face of personal challenges.

Barfield has Charcot-Marie-Tooth disease, a neuromuscular disorder that causes muscle weakness and atrophy; some loss of sensation in the feet, lower legs, hands and forearms; and often, stiffened joints due to abnormal tightening of muscles and associated tissues. She walks with the assistance of leg braces and frequently uses a power wheelchair for mobility.

Barfield volunteers at Cherokee Elementary School, mentoring several students every year. She also helps people who are elderly or disabled file their tax returns, and volunteers at the local animal control shelter, fostering and bottle-feeding kittens.

### **PROVIDENCE, RI—**

#### **Girl with CMT Inspires New Book**

A 9-year-old, Arlene, who suffers from a debilitating nerve disease called Charcot-Marie-Tooth, needs the support of braces to keep from falling. After years of living with CMT, she is losing feeling in her feet and hands. But this year she’ll stand out for another reason: she’s the star of a new book aimed at young readers, modeled on her struggles with CMT.

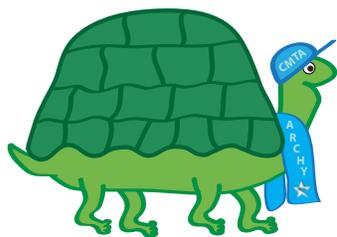
Written by lawyer and family friend Carol Liu, *Arlene on the Scene* tells the story of a fourth-grade girl who runs for class secretary in a Rhode Island school. Like Grace, Arlene suffers from an inherited neurological disorder that could rob her of the use of both her hands and feet and leave her in a wheelchair. There is no cure for the disease, which affects about 2.6 million people.

“My disease is very hard to understand,” explains Arlene in Liu’s first book, scheduled for a September release by the Texas-based Emerald Book Company. “It’s like muscular dystrophy, but not exactly. There’s no big telethon or anything for it. We don’t have posters on buses and we don’t collect change at Halloween in little cardboard boxes.”

Author Liu and Grace’s mother, Marybeth Caldarone, hope to change that. “I want the book to raise awareness of the disease, so that CMT becomes a household word,” says Marybeth, a CMT sufferer who has been wheelchair-bound since high school. \*

(See Book Review on page 13)

# Archy Goes Back to School



*“Archy,” our mascot, writes for the CMTA newsletter about his experiences as a turtle with CMT.*

Well, school is back in session and I’m in my usual blue funk because I am missing all the fun I had this summer. School isn’t bad, mind you, but it can’t compare to having friends over and swimming and just generally fooling around on a hot summer day. Factor in that I went to Australia this summer and you can imagine why going back to school doesn’t seem all that exciting.

I am in a new grade and I have a new teacher. She’s fairly young and she’s very cute. Her name is Miss Nancy Nuttley and she’s a grey squirrel. Her tail just swishes around when she walks and it’s so very cute. All of us boys are sort of in love with her, but I know that will change when we get our first hard test or hateful assignment. We’ve already had to write about our summer vacation and I chose to talk about meeting all the kangaroos in Australia and having my picture taken with some famous people in the world of CMT. Most of the kids in my class know I have CMT by now, but Miss Nuttley is new this year, so I figured I might as well bring it up early in the year and

get it out of the way. In my essay, I also mentioned being part of the “Fresh Air” program that brings city turtles to live with country turtles for two weeks. I mentioned that so that Miss Nuttley would know that I was able to save Vinnie from drowning because I can swim really well in spite of my CMT. I don’t want to go through the year having her think I need to be coddled and kept from all physical activities.

It’s actually pretty hard to find just the right response to my having CMT. On the one hand, I want my teachers to know that it takes me a little longer to get some assignments done because my handwriting is a problem, but I don’t want them to treat me differently in front of my classmates. Kids won’t like me if they think I’m getting away with doing less than they do. And really, I want to do everything that all the other kids do...I just might need a little more time or a little understanding. I can kick the ball out on the blacktop, but I’m horrible at running. I can play chess and checkers better than a lot of other kids my age, but I can’t button the little buttons on my shirt. It’s weird about what I can do and what I can’t. When my Mom is frustrated with me, she says I can do all the things I really love to do and none of the things I dislike. I actually think she’s right, but she’s got the reasoning wrong. The way it really works is that I love the things I can do well, and I dislike the things I can’t do.

So, another school year has begun. I’m sure it will have its high and its lows, but in general, I am looking forward to it. Instead of the old “show and tell” we now can bring in presentations to share with the class and my Dad is helping me make a sort of PowerPoint presentation of my trip to Australia. I’m really looking forward to sharing that with all my friends because the furthest anyone else went this summer was to Wheeling, West Virginia. I’m sure that was a nice trip, but it can’t compare to being in Australia. I’m so proud that I was invited to go along on that trip! \*

## ARCHY CONTINUES HIS “TRAVELS” BY VISITING TENNESSEE



**Support and action group facilitator Reagan McGee took Archy (a bigger, plywood type) to a health fair in her area. Her mother and stepfather created Archy for her.**



## GIFTS WERE MADE TO THE CMTA

## IN MEMORY OF:

**Beverly Czajka**

Dr. Jori Reijonen

**Paul Flynn**

Ms. Catherine E. Daniels

**Hilda Gorman**

Ms. LaVerne Stahl

**Donald Herndon**

Mr. and Mrs. Michael Zimmerlund

**Patrick Joyce**

Ms. Mary Caloway

**Lester Kass**

Mr. and Mrs. Robert Kleinman

**Tommy Kitchens**

Mrs. Juanese Calkins

**Sharon L. LaFontaine**Mr. Robert A. LaFontaine  
Mr. and Mrs. Jerry Mantyk**Herbert Levy**

Mr. and Mrs. Robert Kleinman

**Marvin Napier**

Mr. and Mrs. James Wehner

**William Paschal**Mr. and Mrs. John Paschal-Dixon  
Mr. and Mrs. Wendell Walker**Michael E. Roberts**Mr. and Mrs. Donald Alexander  
Ms. Shirley Bumpus  
Mr. and Mrs. Frank Dosch  
Mr. and Mrs. Mike Higgins  
Mr. and Mrs. Bill Watson  
Mrs. Jodi L. Wolfe**Sarah Wien Robin**

Ms. Leanore R. Cohen

**Donald Robinson**Mr. William F. Maher  
Ms. Margery M. Parker**Rebecca Sand**

Mr. and Mrs. Stephen Sand

**John Slate**Dr. Jill Abell  
Mr. Stephan E. Berry  
Ms. Anne H. Castagno  
Dr. Stephen W. Gulyas  
Ms. Susan W. Howard  
Dr. Bruce Pihlstrom  
Mr. Mark Sterbank  
Task Force on Design and  
Analysis in Oral Health Research**Shirley Tysver**Mrs. Randi Huntsman  
Mr. and Mrs. Tom McManus  
Mrs. Marilyn R. Tranchita**Jim**

Ms. Cynthia A. Huffer

## IN HONOR OF:

**Iris Anderson**

Mrs. Eleanor Anderson

**Trenton Angell**

Mr. Jason Angell

**Dave and Anita Beron**

Mr. and Mrs. Lawrence Hazan

**Christopher Eley**

Anonymous

**John Gatesman**

Mr. Cary S. Chaitoff

**Paul Gomez**

Ms. Catherine E. Daniels

**Theresa Herman**

Ms. Betsy J. Hachfeld

**Raena Korenman**Mr. Manuel Goldberg  
Ms. Rachel Rivlin**Dan Martens**

Mr. William Martens

**Keith Moseman**

Mrs. Dianne Moseman James

**Judy Perkins—Happy 70th Birthday**

Mr. and Mrs. William N. Sharp

**Mr. and Mrs. Derek Queen and Alexa**

Anonymous

**Gary Shepherd**Ms. Jo Lynn Carmichael-Rowan  
Mrs. Dorothy Rarick**Dr. Mike Shy**The Atlanta, GA Support and Action  
Group**Rosemarie and Eugene Sidoti—  
Happy 50th Anniversary**

Mr. and Mrs. Raymond Romatowski

## 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, 2700 Chestnut Parkway, Chester, PA 19013.

**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: \_\_\_\_\_

\_\_\_\_\_

## BOOK REVIEW

## Arlene on the Scene

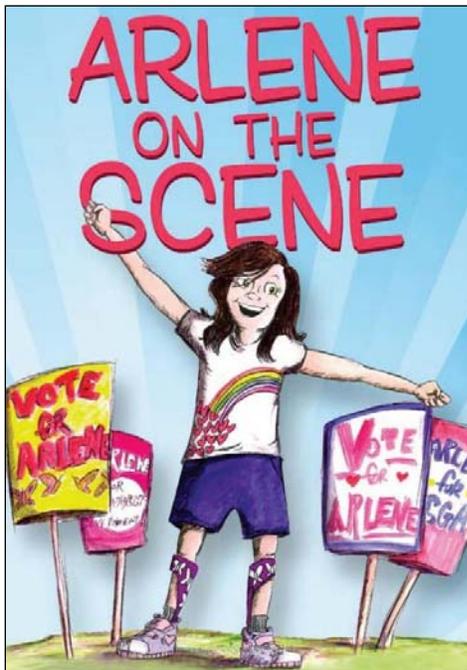
by Carol Liu with the help of Marybeth Sidoti Caldarone

Arlene Harper goes back to fourth grade wearing bright purple leg braces with butterflies on them and immediately feels as though she is “different.” That isn’t what she wants, so she hatches a plan to do something really impressive, like run for Student Council, which is normally reserved for fifth and sixth graders. After convincing her principal to let her try, the story becomes one of how running for election becomes a huge battle between the boys and girls of the fourth grade.

The book is written with humor and a fundamentally wonderful philosophy of life—that the individual parts of a person are important, but they are only a small part of a bigger picture. As Arlene’s Mom says, “You and I have CMT, but that’s not the only thing there is to know about us.” Arlene, herself, realizes one night that CMT might have splashed a big purple stripe across her life, but she was now busy in fourth grade coloring over it one stroke at a time, making the purple stripe a smaller and smaller part of her.

Through all kinds of fourth grade adventures, such as a wildly rolling inflated pumpkin, a leaf fight on the recess field, loose gerbils, and a taco-greased classroom floor, a lesson slowly emerges: that no one should

take one thing about a person and blow it out of all proportion, making it the only thing that person is known for. Just as Arlene did not want to be



known as the girl with the leg braces, her classmates didn’t want to be labeled either, like the jock, the brainiac, or the glamour girl.

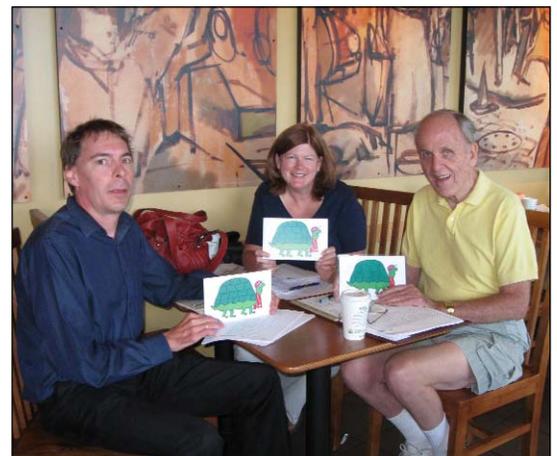
This book was written about Grace Caldarone and her mother Marybeth who have been holding Grace’s Courage Crusade dinners and fairs and runs for many years to benefit the CMTA. The author, Carol Liu, was Marybeth’s college roommate and now is an attorney and a clinical social worker, working with special needs children in the Washington, DC, area.

The book can be ordered from Amazon.com by searching under the book title or the author. The cost of the book is \$7.95. Although the book is clearly written for the age group from about 8–12, I loved reading the book and was totally engaged by the adventures and the discoveries of the kids in the book. (I’m not even close to the appropriate age group!)

—Pat Dreibelbis

## DENVER AREA SUPPORT AND ACTION GROUP LEADERS PLAN AWARENESS WEEK ACTIVITIES

**Ron Plageman, Diane Covington, and Dick Kutz, leaders of the Denver, Colorado, support and action group, had coffee one morning to brainstorm about how to use Archy in their work on Awareness Week and what events would be best for getting out the CMTA’s message that the end of CMT begins today.**





## ASK THE DOCTOR

*These questions were answered by Dr. Steven Scherer, MD, Ph.D.*

### Dear Doctor,

*Is there any reason why people with CMT would have high blood pressure? If CMT affects the autonomic nervous system, "should" it cause problems with blood pressure?*

### The Doctor replies:

In general, "no" is the answer. Hypertension is a common problem, and people with CMT are not immune to having common problems.

Some kinds of "axonal CMT" (recessive or dominant) could result in abnormal blood pressure. The best example is hereditary sensory and autonomic neuropathy type III/familial dysautonomia/Riley-Day syndrome, in which affected people can have attacks that include high blood pressure. But this is a rare kind of CMT.

### Dear Doctor,

*I was born with hammer toes and diagnosed with CMT at the age of 18. At 24, I had toe surgeries*

*and lower calf surgery that permanently left me in braces. Recently, I have been in horrible pain from kidney stones. Do you know if the shock-wave treatment (lithotripsy) affects CMT patients and can cause greater damage?*

### The Doctor replies:

I "googled" lithotripsy and neuropathy, and found a few case reports suggesting that a focal neuropathy is a possible but rare complication. Unless you have HNPP (hereditary neuropathy with liability to pressure palsies),



## LETTER

### Dear CMTA,

We are just back from our trip to Michigan and our visit to the CMT Clinic at Wayne State. Good visit, mixed bag of results. This was our second visit, so it was not quite as long as our first visit—they had all the history and there was little more in the area of education to share. We were told my son needs to start wearing braces and Blue Rockers were prescribed. He tested out a set there and felt they made a huge difference to his ability to walk, and did say that if he got them, he would wear them. He will not have to wear them all the time, and they said he would know when he needed them (he is 16). For me, the prescription was physical therapy for my balance issues. They all said that people have had great results

with improved balance after PT.

We did some of the touristy things while there too, like the Detroit Zoo the next day. Nice place, highly recommended, but warning: it was too much the day after the clinic for my son. He could hardly sleep from pain in the hips, lower back, and legs. He finally found some comfort in a chair in our hotel room, but could NOT get moving for that day's agenda. We had to leave him behind and go with our younger son and then come back to get him for the family BBQ. (There were other family members in the hotel, so we were not abandoning a minor!) Sunday we went to Frankenmuth, a neat Bavarian village a little over an hour north of Detroit. About half way there, we stopped at Great Lakes National Cemetery, which is absolutely beautiful, and is where my in-laws are interred. I

had about all the walking I could do that day. Today was the long drive home. They just have to make Pennsylvania shorter!

So if anyone is thinking about going to a CMT Center for Excellence, I highly recommend it! If you can get to Detroit, I cannot say enough about our experiences. You give, you get when you go. You are a patient and a research subject, just be prepared.

So Detroit is not that bad of a trip to us, and it might be to others, I understand. I have spent the better part of the last 20 years making that flight or drive one or more times a year because my wife grew up there and still has family around the area. Try it! You owe it to yourself to get the best available to you, and you owe to the future generations to help stop this disorder! Imagine a life without CMT! —M.W., Freehold, NJ

### WRITE TO US!

Pat Dreibelbis, Editor,  
pat@charcot-marie-tooth.org

David M. Hall, CEO  
dave@charcot-marie-tooth.org

Dana Schwertfeger,  
Director of Member Services  
dana@charcot-marie-tooth.org

I do not think that the risk of a focal neuropathy is increased.

**Dear Doctor,**

*I am a 59-year-old male. My neurologist suspects I may have CMT but the diagnosis is complicated because I also have bilateral neuropathy due to lumbar stenosis and cervical stenosis plus past lumbar spine injuries due to an accident.*

*I also have an omega or U-shaped epiglottis that causes some swallowing problems with thin liquids.*

*Can the epiglottis malformation and CMT be related?*

**The Doctor replies:**

I do not think that an epiglottis malformation is related to CMT. Some patients with severe CMT do have trouble swallowing. In addition, it should be possible to determine whether you have CMT with clinical electrophysiology. One can distinguish neuropathy from the consequences of lumbar and cervical stenosis.

*Dr. Louis Weimer answered this drug-related question:*

**Dear Doctor,**

*I have been reading about bisphosphonate drugs for bone loss and it reads that there is a chance of moderate to severe muscle pain—especially with the Reclast injection. What can you tell me about this since I have CMT.*

**The Doctor replies:**

Yes, the drugs are associated with transient muscle pain in some patients, but not muscle weakness and not neuropathy worsening to my knowledge. \*

## THE TALE OF A COMET

BY DONNA RENNIE, SUPPORT AND ACTION GROUP FACILITATOR, SAN FRANCISCO, CA

It happened while I was getting a massage. My massage therapist, a nurse, asked me why I wasn't using a little transport chair. I had no idea what she was talking about.

"Do you mean a wheelchair?" I asked with a menacing look.

"Yes," she offered. "They're small, lightweight, and you can put them in your car. You can have full mobility anytime you want it. People use them all the time."

Everything shifted.

At age 59, I was diagnosed with Charcot-Marie-Tooth disease. After four years of not being able to walk more than about 10 minutes without starting to jump from pain, I imagined a way out. Could it be true? Would it be possible to go to a museum again?...take long walks with family and friends?...shop for hours with my daughter?...and, most of all, get rid of all the anxiety about how long I would be stuck on my feet!

So, off I went into the local orthopedic store. They pulled down a little chair called a Nova Comet (no advertising here). I sat in it, lifted it, folded it, loved it. Bought it.

Now, I have complete confidence in my "feet." I don't use it all the time, but when I need it, the Comet is there for me.



What's the big deal anyway? So what if my feet have wheels? So what if my feet have hands? So what if people look at me a little differently? I always smile and wave. They always wave back. In some way I think I might be helping them.

Wheelchairs get a bad rap. They shouldn't. They are just another mode of transportation.

All I had to do was accept what works, shift my thinking a little bit, and ask for a push. Voila. My life came back. I have since found out that my friends and family want to help me. They love me. Everyone has always wanted to push me around anyway! \*

*The Comet comes with a couple different styles of wheels, all adding to the weight. The lightweight one, like mine, is the Comet 327. Shop around, as the prices vary quite significantly. Here are some online resources:*

[www.allegromedical.com](http://www.allegromedical.com)

[www.spinlife.com](http://www.spinlife.com)

[www.bizrate.com](http://www.bizrate.com)



## SUPPORT AND ACTION GROUP NEWS

### California – SF/East Bay Area

For this meeting, we put the chairs in a circle and we put the food table in the middle. It created a casual, friendly, and relaxed atmosphere. Eighteen people arrived.

The agenda was obvious: CMT Awareness Week. We set a goal of making 10 contacts for Awareness Week. People will order their own supplies and keep track of what they give out. Each person will report back their own results and stories. We made a list of possible activities, the usual fare. One member said she would send the Order Supply Form LINK to her brother in Idaho as he works at a farmer's market—a good place to “spread the word.” Spreading the LINK around was a great idea to get new people involved. And who doesn't love a free magnet!

Finally, a bowling fundraiser was explored. The group went wild. As it turns out, bowling brought up a lot of wonderful childhood memories for most support group members. We will continue to get the

fundraiser organized, hopefully for the fall.

People are very excited about Dr. Scherer coming November 13th. There should be an excellent turnout.

### Georgia – Atlanta Area

Dr. Shy was so happy to have 50 people in attendance on August 21st! Dr. Shy spoke for about 1 hour on the physiology of CMT. He gave an update on the STAR program (our research to find treatment and a cure). CMT 1A is the focus of the STAR program for now for two reasons: it is the most common form of CMT (50% of all CMT is 1A), and it is the most understood and replicable by scientists. All of the pharmaceutical trials have completed phase I. Phase II is complete for non-FDA-approved treatments. For FDA-approved treatments, 12 compounds were found to be potential candidates to treat CMT 1A. A second phase must be completed before the trials can move into the laboratory trials. There will be a CMT Type 2 consortium this November to

discuss a strategy to approach treatments designed for Type 2. The outcome of that meeting will be communicated from the CMTA via the newsletter. A question-and-answer session followed his presentation.

After Dr. Shy gave an overview of

CMT, we muddled through the new dataset for CMT. Dr. Shy and his colleagues have produced a three-page summary of CMT symptoms for a patient. The purpose of the dataset is to gather a group of CMT patients to assess eligibility for treatment trials. After the group completed the dataset together, he spent about 5 minutes with any interested person to chat, assess, and answer any questions. Dr. Shy saw about 30 people and spent 6 hours total with our group. Many people left understanding more about CMT, having answers to their particular questions, and feeling a little more at ease with their CMT. We are so grateful to him for his time on a Saturday, his dedication to CMT and his personal approach to each patient.

I spent about 15 minutes giving an overview of CMT awareness week, scheduled for September 19–25. Activities specific to Atlanta are as follows:

Monday–Friday a few folks from the support group will go to local hospitals with a CMT display. We have specifically targeted CHOA- Egelston, Piedmont Hospital, and Gwinnett Medical Center. These were chosen due to contacts I have at each place. I have received permission at CHOA to be there any of those days—I am still waiting to confirm the other two.

We will have a BBQ/pot luck on Saturday, September 26th for lunch. The location is to be determined as we are hop-

*(continued on page 18)*

**Dr. Michael Shy joined 50 people (and 3 Archys) in a photo after his presentations to the Atlanta Support and Action Group.**



# CMT Support and Action Groups

## AL—Birmingham Area

No group currently meeting  
Will accept calls/emails  
Dice Lineberry  
205-870-4755  
sag\_birmingham@cmtausa.org

## AZ—Phoenix Area

Ken Wysocki  
602-606-2805  
sag\_phoenix@cmtausa.org  
Pamela Palmer  
602-343-7033  
sagcf\_phoenix@cmtausa.org

## CA—Los Angeles Area

Ryan Conlon  
310-383-1024  
sag\_losangeles@cmtausa.org  
http://www.cmtla.org

## CA—South Bay Area

Elizabeth Ouellette  
1-800-606-2682 x107  
sag\_southbay@cmtausa.org  
Rick Alber  
650-924-1616  
sagcf\_southbay@cmtausa.org  
http://groups.google.com/  
group/cmtpeninsula

## CA—Sacramento Area

Rashid Thomas  
916-947-5377  
sag\_sacramento@cmtausa.org

## CA—San Diego Area

Steve Gabbert  
619-987-6022  
sag\_sandiego@cmtausa.org  
http://groups.google.com/  
group/sdcmta

## CA—Santa Barbara Area

Gretchen Glick  
805-693-9511  
sag\_santabarbara@cmtausa.org

## CA—Santa Rosa Area

Carol O'Bryan  
707-823-0165  
sag\_santarosa@cmtausa.org  
Ronald Deghi  
707-829-0911  
sagcf\_santarosa@cmtausa.org

## CA—SF/East Bay Area

Donna Rennie  
925-330-2790  
sag\_eastbay@cmtausa.org

## CA—Visalia Area

Melanie Pennebaker  
559-972-3020  
sag\_visalia@cmtausa.org

## CO—Denver Area

Diane Covington  
303-635-0229  
sag\_denver@cmtausa.org  
Dick Kutz  
303-988-5581  
sagcf\_denver@cmtausa.org

## DC—Washington, DC Area

Steven Weiss  
sag\_washingtondc@cmtausa.org  
Kimberly Hughes  
sagcf\_washingtondc@cmtausa.org

## FL—Inverness Area

Ronnie Plageman  
352-860-1578  
sag\_inverness@cmtausa.org

## FL—Orlando Area

Mark Collins  
407-786-1516  
sag\_orlando@cmtausa.org

## FL—Tampa Bay Area

Vicki Polleya  
813-251-5512  
sag\_tampa@cmtausa.org

## GA—Atlanta Area

Susan Ruediger  
678-595-2817  
sag\_atlanta@cmtausa.org  
Jeannie Zibrida  
sagcf\_atlanta@cmtausa.org

## IL—Chicago Area

Dale Lopez  
708-499-6274  
sag\_chicago@cmtausa.org

## KS—Wichita Area

Karen Smith  
316-841-8852  
sag\_wichita@cmtausa.org

## KY—Burlington Area

Pam Utz  
859-817-9338  
sag\_burlington@cmtausa.org

## MA—Boston Area

Mark Boxshus  
781-925-4254  
sag\_boston@cmtausa.org

## MD—Baltimore Area

Bruce Egnew  
410-729-2297  
sag\_baltimore@cmtausa.org

## MD—Hagerstown Area

Jeffrey Martin  
301-582-2401  
sag\_hagerstown@cmtausa.org

## ME—Portland Area

Celeste Beaulieu  
207-284-1152  
sag\_portlandme@cmtausa.org

## MI—Ann Arbor Area

Jori Reijonen  
269-341-4415  
sag\_annarbor@cmtausa.org

## MI—Chesaning Area

Carolyn Koski  
989-845-5731  
sag\_chesaning@cmtausa.org  
Ellen Albert  
810-639-3437  
sagcf\_chesaning@cmtausa.org

## MI—Kalamazoo Area

Jori Reijonen  
269-341-4415  
sag\_kalamazoo@cmtausa.org

## MN—Benson Area

No group currently meeting  
Will accept calls/emails  
Rosemary Mills  
320-567-2156  
sag\_benson@cmtausa.org

## MO—Anderson Area

No group currently meeting  
Will accept calls/emails  
Libby Bond  
417-845-1883  
sag\_anderson@cmtausa.org

## MO—St. Louis Area

Carole Haislip  
314-644-1664  
sag\_stlouis@cmtausa.org

## MS—Mississippi/Louisiana

Flora Jones  
601-825-2258  
sag\_clinton@cmtausa.org

## NC—Triangle Area

Betsy Kimrey  
919-833-3991  
sag\_trianglearea@cmtausa.org

## NH—New Hampshire/Vermont

Margaret Healey  
802-535-2797  
sag\_lebanon@cmtausa.org

## NJ—Central New Jersey Area

Mark Willis  
732-252-8299  
sag\_centralnj@cmtausa.org

## NM—Albuquerque Area

Gary Shepherd  
505-296-1238  
sag\_albuquerque@cmtausa.org

## NV—Las Vegas Area

Diane Cencak  
702-560-3647  
sag\_lasvegas@cmtausa.org

## NV—Reno Area

Ken Smith  
775-233-7788  
sag\_reno@cmtausa.org

## NY—Upstate New York Area

Melinda Lang  
518-783-7313  
sag\_upstateny@cmtausa.org

## NY—Greater New York Area

Dr. David Younger  
212-535-4314  
sag\_nyc@cmtausa.org  
Bob Wine  
212-535-4314  
sagcf\_nyc@cmtausa.org  
http://www.cmtnyc.org

## NY—Horseheads Area

Angela Piersimoni  
607-562-8823  
sag\_horseheads@cmtausa.org

## NY—Hudson Area

Deborah Newman  
845-883-0580  
sag\_cornwall@cmtausa.org

## NY—Long Island Area

Ruth Korowitz  
516-318-3202  
sag\_longisland@cmtausa.org

## NY—Westchester Area

Beverly Wurzel  
201-224-5795  
sag\_westchester@cmtausa.org

## OH—Greenville Area

Dot Cain  
937-548-3963  
sag\_greenville@cmtausa.org

## OR—Portland Area

Debbie Hagen  
503-333-7936  
sag\_portland@cmtausa.org

## PA—Bucks County Area

Linda Davis  
215-943-0760  
sag\_buckscounty@cmtausa.org

## PA—Johnstown Area

J.D. Griffith  
814-539-2341  
sag\_johnstown@cmtausa.org  
Jeana Sweeney  
814-262-8427  
sagcf\_johnstown@cmtausa.org

## PA—Northwestern Area

Joyce Steinkamp  
814-833-8495  
sag\_erie@cmtausa.org

## PA—Philadelphia Area

Dana Schwertfeger  
1-800-606-2682  
sag\_philly@cmtausa.org  
Walter Donikowski  
610-960-1199  
sagcf\_philly@cmtausa.org

## PA—Pittsburgh Area

Christine Miller  
412-341-5749  
sag\_pittsburgh@cmtausa.org

## RI—East Providence Area

Meredith Souza  
401-433-5500  
sag\_providence@cmtausa.org

## TN—Nashville Area

Mark Hollingshead  
615-480-2044  
sag\_nashville@cmtausa.org  
Bridget Sarver  
615-3909-0699  
sagcf\_nashville@cmtausa.org

## TN—Savannah Area

Reagan McGee  
731-925-6204  
sag\_savannah@cmtausa.org  
Melinda White  
731-925-5408  
sagcf\_savannah@cmtausa.org

## TX—Dallas Area

Whitney Kreps  
972-989-5743  
sag\_dallas@cmtausa.org

## VA—Harrisonburg Area

Anne Long  
540-568-8328  
sag\_harrisonburg@cmtausa.org

## VA—Williamsburg Area

Jennie Overstreet  
757-813-6276  
sag\_williamsburg@cmtausa.org  
Nancy Mollner  
757-220-3578  
sagcf\_williamsburg@cmtausa.org

## WA—Seattle Area

Ruth Oskolkoff  
206-293-2204  
sag\_seattle@cmtausa.org  
Yumi Hines  
425-335-0272  
sagcf\_seattle@cmtausa.org

## WA—Tacoma Area

Carol Hadle  
253-476-2345  
sag\_tacoma@cmtausa.org

## SUPPORT AND ACTION GROUP NEWS

*(continued from page 16)*

ing for a fun venue. Details will follow!

We also have received access to MASS facts, a publication specifically for Atlanta doctors, to publish an article about CMT. We are waiting for the national media packet to send their article. I will also send the media packet to CNN as a leap of faith!

The October meeting is scheduled for October 23rd at 2 pm at St. Martin in the Fields Episcopal Church. This is a change in weekend as the school/church carnival is the 16th, our published meeting date. Coming in October, we hope to have a physical therapist come to give recommended exercises to those who deal with CMT.

### Illinois – Chicago Area

The CMT action and support group meeting for the Chicago area took place on Saturday, August 28th, at the Oak Lawn Community Pavilion with sixteen people in attendance.

It was the first meeting without a scheduled, outside speaker. I had asked one of our members, Wayne, who has given me information in the past on products he finds helpful, to bring some to show the others. Wayne not only brought the gadgets, he talked about each one and supplied us with information about where to purchase the products. It was really great and very useful to all the members.

Our fundraiser 'Reach for the STARS—Walk & Roll for the CMTA' will be taking place on September 25th at 10:00 AM. An update on the walk took place. We have been

able to get donations of coffee/hot chocolate from Starbucks, bagels from Einstein Bakery, donuts, and water. This is our group-wide project for CMT Awareness Week.

### Tennessee – Savannah Area

We worked at a Health/Educational fair at our local hospital. They were nice enough to let me set up a booth and hand out information on CMT. My mother and stepfather made me an Archie out of wood for my displays. Not one person knew a thing about CMT except for the CEO of the hospital. I got a lot of people to stop and listen, but some others did not want to even take part in my discussion. There is a county fair coming up in September and a huge motor cycle ride called the trail of tears coming to this area. I've got a lot more people to reach! ✨

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## CMT AWARENESS WEEK

*(continued from page 3)*

thereby creating a platform of solidarity, unity, and cohesion.

Let's not forget the CMTA's own YouTube channel video (<http://www.youtube.com/user/CMTAssociation>) or the social networking going on today, as CMTA Facebook fans are replacing their personal profile picture with the CMTA's image for CMTA's Awareness Week, spreading ongoing messages about Awareness Week to other members, family, and friends. This has been an incredibly suc-

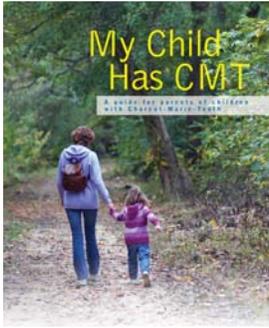
cessful initiative, spreading awareness to thousands of people across the globe.

The finalized Awareness Week schedule includes a planned, interactive podcast with Dr. Michael Shy, new and ground-breaking research updates from our STAR team, a prerecorded message from our CEO, David Hall, bringing you up to date on all the CMT news from Capitol Hill, an announcement naming the winners of the ongoing Archy the Spokesturtle contest, as well as the opportunity to meet our dedicated and determined support and action

group facilitators.

For me, September 19–25 is a week is about hope, recognition and education. Drawing attention to one of the most commonly inherited peripheral neuropathies in the world is no longer an option but an obligation, because public awareness begins with you. Declared within the pages of our Awareness Week website, "The Time is NOW. This is where the end of CMT begins." What better time to get involved and make a difference? Come join our team and help us put an end to CMT: [www.cmtausa.org](http://www.cmtausa.org). ✨

# MEMBERSHIP APPLICATION/PUBLICATIONS ORDER FORM



## Pediatric Publication Now Available

My Child Has CMT is a 32-page booklet with full-color photos and topics such as "When We Found Out Our Daughter Had CMT," questions and answers from Dr. Mena Scavina, A.I. DuPont Institute in Wilmington, DE, "How to Keep a Medical History for Your Child," and a dictionary of common medical terminology. A list of resources and organizations helpful to families with CMT is the final chapter. The booklet is only \$5 for CMTA members and \$7 for non-members.

### ALSO AVAILABLE:



### Circle of Friends T-Shirts



### Be a STAR Wristbands

NAME: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
First MI Last

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CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

COUNTRY/POSTAL CODE (IF NOT US): \_\_\_\_\_

DAYTIME PHONE: \_\_\_\_\_ EVENING PHONE: \_\_\_\_\_

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*Required for PDF Newsletter/Website Access* *Required for Website Access*

**Note: If you are joining now, you may purchase publications at active member prices.**

	QTY	COST	TOTAL
<b>MEMBERSHIP</b> Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both. Receive newsletter as: <input type="checkbox"/> Print or <input type="checkbox"/> PDF via email Receive both Print <i>and</i> PDF Newsletters		\$25 \$30	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		<b>active members \$10</b> nonmembers \$15	
[CD Format]		<b>active members \$7.50</b> nonmembers \$10	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		<b>active members \$3</b> nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		<b>active members \$5</b> nonmembers \$7	
CMT Facts III		<b>active members \$5</b> nonmembers \$7	
CMT Facts IV		<b>active members \$8</b> nonmembers \$10	
CMT Facts V		<b>active members \$12</b> nonmembers \$15	
CMT Facts VI		<b>active members \$12</b> nonmembers \$15	
A Guide About Genetics for CMT Patients <i>(No shipping and handling on this item only)</i>		<b>active members \$4</b> nonmembers \$5	
Teaching Kids about CMT...A Classroom Presentation <i>(1 hour DVD)</i>		<b>active members \$7.50</b> nonmembers \$10	
<b>NEW!</b> My Child Has CMT, A Guide for Parents		<b>active members \$5</b> nonmembers \$7	
Be a Star Wristbands (Pack of 5)		\$5	
Women's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL		<b>active members \$9</b> nonmembers \$10	
Men's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL ___2XL ___3XL		<b>active members \$9</b> nonmembers \$10	
West Coast Patient-Family Conference <i>(5 hours—2-DVD set)</i>		<b>active members \$15</b> nonmembers \$20	
CMT Informational Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List		FREE	
Physician Referral List: States: _____		FREE	
<b>Donation to the CMTA (100% Tax-deductible)</b>			
<b>Shipping &amp; Handling</b> <i>(Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)</i>			
<b>TOTAL</b>			

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, 2700 Chestnut Parkway, Chester, PA 19013; or fax to: 610-499-9267**

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



## CMT PATIENT MEDICATION ALERT:

### Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

### Moderate to significant risk:

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

### Uncertain or minor risk:

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



2700 Chestnut Parkway  
Chester, PA 19013  
1-800-606-CMTA FAX (610) 499-9267  
www.charcot-marie-tooth.org

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## What is CMT?

- ◆ is the most common inherited neuropathy, affecting approximately 150,000 Americans.
- ◆ may become worse if certain neurotoxic drugs are taken.
- ◆ can vary greatly in severity, even within the same family.
- ◆ can, in rare instances, cause severe disability.
- ◆ is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ◆ is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ◆ causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ◆ does not affect life expectancy.
- ◆ is sometimes surgically treated.
- ◆ 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).
- ◆ has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ◆ 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.
- ◆ 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.
- ◆ is the focus of significant genetic research, bringing us closer to solving the CMT enigma.