

# THE CMTA Report

SEPTEMBER/OCTOBER  
2014

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



## OUR MISSION:

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

## OUR VISION:

A world without CMT.

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## PROUD and EXCITED

BY HERB BERON, CMTA CHAIRMAN OF THE BOARD

In September 2011, Pat Livney took over as Chief Executive Officer of the CMTA and I took over as Chairman of the Board. At that point, although we had initiated STAR, we had little to show in terms of progress on our research platform. We were expanding our support group network, but were without a plan for its future growth. We had tried to raise awareness, but it seemed a slow process. In a nutshell, we were optimistic about our future but trying to figure out how to bring everything together.

Now, three short years later, I couldn't be prouder of the progress that we have made as an organization. When Pat and I first met to discuss our vision, we knew that the CMTA needed more focus but on fewer areas. At that time, we decided that those three areas of focus going forward would be:

- Delivering the first treatment for CMT, and fundraising with that end goal in mind.
- Bringing more services, programs and information to CMT patients.
- Creating more awareness (both in local communities as well as in the physician community).

In terms of our STAR research program, we are mov-

## CMTA GETS FOUR-STAR RANKING FROM CHARITY NAVIGATOR

We are very excited to announce that the CMTA has just received the highest rating designation possible from Charity Navigator, Four-Star!

Charity Navigator evaluates over 1.6 million IRS registered nonprofits, helping charitable givers make intelligent giving decisions by providing in-depth, objective ratings.

The Four-Star rating demonstrates a high commitment to ethics, accountability, and transparency and is only bestowed on a select few nonprofit organizations.



ing closer to our goal. In the near future, you will be hearing details of our first agreement with a major global pharmaceutical firm which will test its library of drug compounds on the CMT1A cellular assay that we developed and own the rights to! These cell lines were created thanks to the donations that all of us have made to STAR. These assays have been validated by the National Institutes of Health in Washington, with whom we partner. In addition, we have developed laboratory models of several types of CMT, and have begun to use human-derived iPS cells

(taken initially from skin biopsies) to replicate the human element of CMT to be used to test compounds. We have developed teams of scientists who are working on cellular assays and laboratory models for several sub-types of CMT: 2, 4 and X.

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## Contributing to the Solution: Fundraising for a Cure

I have found this to be one of my favorite times of the year. While it certainly doesn't hurt that there is a lot of overlap between baseball, football, hockey and basketball, it is really the experience of the CMTA New York STAR Update and Cocktail Reception that Phyllis Sanders and I host each year in New York City that brings me such great satisfaction.

Once again, on October 27th at the New York Palace, we will gather some of our closest family, friends, business associates and fellow members of the CMTA to raise funds and awareness in our effort to find a cure for CMT. In prior years, Drs. Shy, Scherer and Svaren have shared the progress the CMTA is making in research. Our guests are treated to great music provided by the New York Pops, cocktails, and food, all in a world-renowned New York City venue. And, of course, there are unique, experiential opportunities and highly desirable items that are available for auction. Last year we auctioned a trip to any Monday Night Football game with a tour of the ESPN broadcast set, as well as concert tickets with a backstage meet-and-greet with John Mayer. Through the generosity and support from so many, in our first two years, we have raised well over \$300,000. If you are in the New York area, or can join us on October 27th, I would like to encourage you to meet many caring individuals who share in our goal.

Each of you can, and should, experience the chance to contribute in your own way to the CMTA's effort. By coordinating a fundraising event with your school, church, synagogue or local sports team, or by organizing any other event in which you can engage your family and friends, you, too, can feel the fulfillment of making a difference. The CMTA has people and resources that can help your fundraising event be fun and effective. You will gain a greater appreciation of your circle of friends and family and the support that they will provide you in your effort. And, most importantly, you will have the satisfaction of knowing that being a part of the solution for something that means so much to you is the greatest reward there is.

—Alan Korowitz, CMTA Board of Directors

## PROUD AND EXCITED

(continued from page 1)

With all of our success, our need for continued fundraising grows exponentially as we get closer to the "goal line"—clinical trials are often the most expensive part of the drug discovery process.

The services that we provide to the CMT patient community have also expanded greatly. We now have 76 support groups in 39 states, including two each in Canada and Mexico. Jeana and Elizabeth do a fantastic job keeping the SAGFs up to date with the organization. We are striving to give facilitators even more information to bring to their members. Our recent partnerships with Aetrex, Allard and

GeneDx have opened doors for specialists to attend meetings and share their services. In the last three years, we have also greatly expanded our Advisory Board. I encourage you to look up each of their specialties; we have taken great pains to try and create a group that can answer most (if not all) the questions that our members have. We have

charged these AB members with writing articles in the newsletter and hosting monthly webinars. I hope that you have taken part in these webinars, but if you haven't, they are all archived on the CMTA website for you to

access at your convenience. The patient/family conferences that we sponsor have been greatly expanded and give our members the opportunity to interact further

with specialists and researchers.

Our social media presence has also grown exponentially—our Facebook site has grown 900 percent over the last year to over 14,000 "likers," and we are

now also on Twitter, LinkedIn and Instagram! These sites are important. They allow our members to connect with one another and share their stories, successes and challenges, and they are key in reminding each

Our need for continued fundraising grows as we get closer to the "goal line."

of us that “we are not alone!” Pat and I envision even greater expansion of our social media efforts in the future.

Awareness Month has become an annual success story for us. As we often mention, it is important for all of us to be our own advocates, and it is great to see all of the state, city and county proclamations that continue to be amassed by our members and our organization. Oftentimes, it is simply a member of the CMTA who reaches out to his or her elected official and is “teaching” that office about CMT. What a terrific way to get the word out! At our core, we are a grass-roots organization and we need to spread the word community by community. What a job we are doing!

And trust me, the work we are doing is not going unnoticed. On August 1, 2014, we were given a FOUR-STAR rating (their highest) by Charity Navigator, the nation’s largest and most-utilized evaluator of charities! This is a significant event for the CMTA. It shows that we exceed industry standards and outperform most charities in terms of financial health and accountability/transparency.

So, in conclusion, I am so very PROUD of what we have all accomplished so far, but I am even more EXCITED about what is yet to come! The CMTA Board—a group of volunteers who are all passionate about this disease because we all either have it or our children do—continues to work tirelessly on behalf of the CMT community. Please do your part. Together, we will achieve great heights! ★

## iGive.com: The Magical Button

I have some good news and some bad news. The bad news is that fall is upon us and the holiday season will be here before you know it! Soon you will be browsing the Internet and shopping online, trying to find the perfect holiday gifts for your kids, spouses, friends and family. The good news? iGive.com, the world’s first online shopping mall, has turned Internet shopping into a philanthropic activity: a portion of your everyday online purchases is sent to your charity of choice—at no cost to you.



On the iGive.com website, you will find over 1,400 participating merchants, including the Apple Store, Best Buy, Drugstore.com, Eddie Bauer, Enterprise Rent-a -Car, GAP, Hilton Hotels, JCPenney, Kohl’s, Land’s End, L.L. Bean, Macy’s, Nordstrom, Office Depot, Radio Shack, Target, and so many more. Signing up is pain free! In fact, the whole process can be completed within 90 seconds!

Go to <http://www.igive.com>. Choose the Charcot-Marie-Tooth Association (CMTA) as your cause. Install the iGive.com button and start shopping! Between now and October 31st, I will personally send an extra \$5 donation to the CMTA for each person who installs the teensy tiny iGive.com button. The button is an almost imperceptible addition to your browser, and it automatically tells participating stores that you want your shopping to support the CMTA. In fact, statistics show that, “Members with the iGive Button installed raise three times more for their causes than those members without.”

Our Support and Action Group Facilitators are on board with this program, too, creatively sharing this unique program with their members. Roy Behlke, a CMTA Support and Action Group Facilitator, encouraged his members to download this seed-like symbol by writing, “Wouldn’t it be great if you could push a magical button to find a cure for CMT?” Installing the iGive Button is a very good start!

Fundraising for CMT cannot get any easier. To date, we have raised an amazing \$5,408.53 for the Charcot-Marie Tooth Association, but only 77 of our 751 supporters have installed the iGive Button, which is the key to uninterrupted donations.

The bottom line? Go to iGive.com right now, sign up and install the magical button. Tell your friends, co-workers and family members about this wonderful resource. Spread the love! You personally have nothing to lose, and the CMTA has everything to gain. Let’s use the power of iGive to generously support the CMTA today and every day.  
 —Elizabeth Ouellette

**Thank you to these Support & Action Groups who raised \$4,100 by spreading the word about iGive.com:**

- Arizona
- Asheville, NC
- Atlanta, GA
- Boston, MA
- Central New Jersey
- Chicago, IL (South)
- Cleveland, OH
- CMT New Mexico
- Dayton, Ohio
- Denver Area
- Eastern Ontario
- El Paso, TX
- Erie, PA
- Hartford, CT East
- Horseheads, NY
- Johnstown, PA
- Kansas Area
- Lincoln, NE
- Long Island, NY
- Los Angeles, CA
- Los Angeles (South)
- Morris County, NJ
- Naples, FL
- Nashville, TN
- Northern Ontario
- Orange County, CA
- Parkersburg/Vienna, WV
- Portland, OR
- Research Triangle Area, NC
- Portland, ME
- Rhode Island
- San Francisco Peninsula/  
 South Bay, CA
- Sarasota, FL
- Southeastern Wisconsin
- Southern Connecticut
- Southern Ontario
- Space Coast, FL
- Tampa Bay Area, FL
- Washington, DC Metro
- Westchester, NY
- Wilmington, NC



ers first, and he never lets his pain or muscle exhaustion get in the way of helping others.

He keeps himself active through scouting, golf, and weight-lifting. He monitors his food and drink intake to keep his body healthy. He trips, falls, and drops things, but he laughs it off and keeps going.

Pasquale is my “shooting star” because while this disease may defeat others spiritually, his heart is big enough to love the world. At the end of the day his friends will say he is really a scout: trustworthy, loyal, helpful, friendly, courteous, kind, obedient, cheerful, thrifty, brave, clean and reverent.

## The “I’m a STAR” Winner Takes Weaknesses and Turns Them into Strengths

*Nominated by Monica Phillips*

I would like to nominate Bob Ernst (age 67), to receive the “I’m A Star” award.

My Dad had an uneventful upbringing, graduating from high school and enlisting in the Air Force. He served stateside and overseas in Okinawa.

Upon discharge from the military, Dad moved his family back to his hometown of Gillette, Wyoming, where he lives today. He worked as a mechanic, which became increasingly difficult for a man with undiagnosed CMT. It was then that he began investigating the odd behavior of his hands and feet and eventually received the diagnosis of CMT.



Bob proudly wears the uniform he worked for years to earn.

Dad always wanted to pursue a career in firefighting, so he applied to the fire department. He threw himself into learning the skills and science of fighting fire. With ever-weakening hands and increasingly unstable ankles, he fought fires in homes, businesses, coal mines, and wild lands. He went back to college to finish his fire science degree, although he couldn't hold his pencil like my sister and I did.

I remember Dad being the first one up in the morning. He made us breakfast and always struggled with cereal boxes, often asking one of us to open them. As a kid, I thought he was impatient. Then came the zip-close bags, plastic wrap, jars, or bottle lids most folks think are just a convenience. Dad did not. He struggled to find new ways to hold his thumbs so his pinch-grip would operate. He placed items between his knees for better hold. As a kid, I thought he was being funny.

In my teens, my Dad showed me how to care for my own car. We spent time together in the garage changing oil, adjusting fluids, rotating tires, or talking about the specifications of one car versus another.

That was when I learned about Dad's disease, his limitations, and how frustrating it was for him. He used tools differently than how they were intended; he adjusted angles so he could reach better, and he strategized repairs around his abilities to optimize his function.

Dad is retired now and has a love for model trains. I'm fascinated with how he gets his hands to function on a smaller scale than in the real world. His hands fumble a lot. His feet still trip him up, so he just looks at every step he takes. He's living with the disease, and he is proof that even a retired guy can be a champion. He's not just my Dad; he's a reminder to all CMT champions to stay strong!

In my 40s now, and I'm learning to do the same as Dad. I'm learning to take my weaknesses and strategize to make them function in my favor. I'm learning to channel frustration into energy for the good of others around me. Dad has taught me to take what I've been given, adapt what I can, throw out what doesn't work, and move forward with a positive attitude—just like he has always done. ★

## What Is a Supra Malleolar Orthosis (SMO)?

BY SEAN MCKALE CO, LO

An SMO is an orthosis that crosses above the ankle bones (malleoli) and controls the joint motion of the foot in the coronal (side-to-side) and transverse (rotational) planes of motion. Technically, an SMO is also an ankle-foot orthosis (AFO); however, it is much shorter and has a unique name because it is not attempting to control the sagittal (up-and-down) plane of motion. It also lacks the normal “lever arm” of a traditional AFO. In more simple terms, an SMO will help to control the ankle and prevent it from rolling and twisting.

The advantage of using an SMO compared to a foot orthotic is that it has a greater amount of leverage because it crosses the ankle. It will also help a person to land the foot with a better heel strike because it is controlling the rotation through the swing phase of gait. This is a good decision for a person who does not have significant weakness but is experiencing poor stability or frequent ankle sprains. With CMT it is important to control motion in these planes to prevent orthopedic injury and to improve balance.

SMO's are often going to be prescribed more for children with CMT than for adults. In some cases, a child may present more with a pronation or rolling

in of the ankle because the foot's intrinsic muscle groups and other muscle imbalances have not yet occurred which will eventually cause a higher cavus foot presentation and lead to supination or rolling outward. This overpronated foot position can also be difficult for children

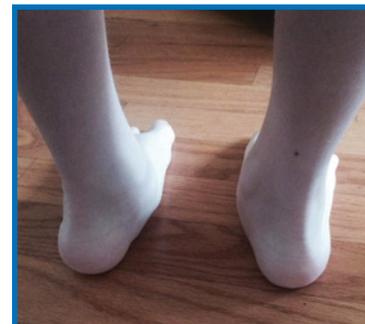
**SMO's are prescribed more for children with CMT than for adults.**

through developmental stages because the poor alignment can make it difficult to create the force production that leads to walking, jumping, and stair

climbing. An analogy I often use to better explain this is that it is a lot easier to pull a hose straight forward versus trying to pull it around the side of your house. At right are some examples of a child who has CMT who is currently presenting as an overpronator and having difficulty with some of those skills. Changing the line of pull can have significant functional mobility changes.

SMO's can be fabricated in many different ways but should be used to:

- Improve ankle stability at a younger age, which should help to inhibit lateral ankle instability by utilizing rear foot posting, forefoot posting, or by using compression to maintain a midline position.
- Prevent forefoot drifting into adduction/abduction at the mid-tarsal joints by the plastic borders.
- Limit shortening of the longi-



A view of an overpronated and uncorrected foot.



The foot corrected by an SMO.



The front view of the SMO.

tudinal arch by maintaining elongated foot positioning in standing.

All of these changes have the goal of improved function and the avoidance of orthopedic injury and surgery. ★

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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: \_\_\_\_\_





David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. Write to David at [info@cmtausa.org](mailto:info@cmtausa.org).

## WHAT'S ON YOUR MIND? ASK DAVID.

**Dear David,**

*I have a fourteen-year-old son who is having a hard time with his CMT. He understands that he has something that is making it tough for him to keep up with the other boys his age. He is not good at sports, and he gets tired easily. What can my husband and I do to help him accept his limitations? His brother and sister are not affected, and they excel in athletics.*

*David Tannenbaum answers:*

Your son is fortunate to have parents who are sensitive to his emotional state. It is tricky with teenagers because more often than not they are nonverbal, particularly if there is something bothering them. Being able to praise him for the skills that he

can do well is a good place to start. There is a fine line between validating his strengths and overpraising him, creating an unrealistic view of the world. Taking the time to ask him how he is doing and being patient and aware of creating a safe and loving environment will be important in helping him verbalize his emotional state.

There are numerous factors that contribute to a child's self-esteem. Some things are out of your control, but helping him to learn to verbalize how he is feeling without judgment will help him to develop the skills he will need to make it in the world. It is particularly important for you and your husband to teach him that athletics is

just one of many ways for a boy to feel masculine and strong in the world.

Teaching him that there is a difference between power and force is vital. Force is about aggressiveness, whereas power is about wisdom. True power has nothing to do with physical strength. It is about feeling good about oneself regardless of limitations. It is about learning that we all have something to contribute regardless of our physical attributes. Although it is hard for parents to watch their kids struggle, children need to work through their insecurities to develop effective coping skills. Loving him unconditionally will go a long way in helping him develop true strength. ★

### A Special Thanks to All Federal Employees

Thank you very much for your past support of the CMTA through the Combined Federal Campaign. Your 2013 contributions allowed us to continue to accomplish our mission every day. As you know, the CMTA has three focus areas: improving the quality of life for those with CMT by providing resources and information, increasing awareness about CMT, and funding research for the development of treatments for all types of CMT. Our progress includes:

- Creating 76 Support and Action Groups throughout North America, providing local resources for those with CMT.
- Building our social media presence and interacting with over 15,000 people through Facebook, Twitter, LinkedIn and Pinterest.
- Spreading the word about CMT to physicians and clinicians through trade magazines and partnerships.
- Gathering a robust Scientific Advisory Board, identifying experts in the industry, and forging partnerships to develop protocols and pathways for 90 percent of all types of CMT—1A, 1B, 2A, 2B, 2E and X.

Your generosity has helped us achieve these major milestones.

In the coming weeks, the CFC will open again for the 2015 giving year. The CMTA has been named as one of the *Best In America* as certified by *Independent Charities of America* and has received a Four-Star rating from *Charity Navigator*, the premier non-profit rating organization. The CMTA is also approved as a national charity for the 2015 giving year. Our CFC number is 10597.

Thank you for all of your support! We are very grateful to you!



## Meet Eoin, Tau, and Lia O'Sullivan

BY CLARK SEMMES

*A family battles to have their daughter diagnosed with CMT and then battles even more to give her the best life possible.*

**V**avatau Kalikau Halafihī (Tau) grew up the youngest of 11 children on the Island of Tongatapu (northeast of New Zealand) in the Kingdom of Tonga. Her parents worked hard to support their large family, and her older siblings helped raise the young ones. When Tau was just 16, her father passed away from lung cancer, and soon thereafter she followed her brother and his family to the United States. Tau describes herself as a “good girl,” who as a teenager could always be found in one of three places: home, school or church.

Literally on the other side of the world, Eoin O'Sullivan was growing up in Farran, Ireland (outside of Cork City). Eoin was studious and loved to read and draw. Awarded a work placement in California while in college, Eoin fell in love with the state and soon became a resident.

A few years after arriving in the states, Eoin was in Reno, Nevada, for a friend's bachelor party. Playing poker in a casino at 3:00 am, he looked up to see a tall, exotically beautiful woman standing nearby. In his mind, he had hit the jackpot. When she left, he literally ran after her. They stayed up talking all night, and although Tau lived in Sacramento and Eoin was in San Jose,

they began seeing each other every weekend. Four years later, they tied the knot.

A few years after their marriage, Tau gave birth to a beautiful baby girl they named Sesilia Deirdre O'Sullivan (Lia). For the first six months of her life, Lia seemed to be growing and developing in a normal fashion. When Lia showed no signs of walking at 12 months, her parents began to grow concerned. Although her doctors at Kaiser Permanente insisted she was fine, Eoin and Tau were not convinced. In addition to not walking, Lia also showed signs of hyper-flexibility and had a twitch in one eye. These conditions drew the doctor's attention, and eventually Lia was given a nerve conduction test. Genetic testing confirmed that Lia had CMT Type 1B. According to her doctors, there is only one other person in the world with Lia's exact mutation.

For Eoin and Tau, learning that Lia had CMT was almost a relief. While they were concerned that CMT was serious and degenerative, there were other possibilities that would have been far worse, even fatal. Searching CMT online, Eoin and Tau found the CMTA website and soon went to their first CMTA Support and Action Group meeting, led by SAG Facilitator and CMTA Board Member Elizabeth Ouellette. At two years of age, Lia was by far the youngest person at the meeting, but the welcome was warm and the group was “lovely.” As chance would have it, one per-

son at the meeting was Dr. John W. Day from Stanford University Hospital. Stanford is a Center of Excellence for the treatment of CMT, and Dr. Day soon became Lia's neurologist.

While Eoin and Tau received great support from the CMTA, their battles were not over. When it was time for Lia to attend preschool, they were told she would have to attend special education classes, populated for the most part with developmentally disabled students with mental impairment. Because Lia is a particularly bright and social young girl, Eoin and Tau feared special education classes would restrict her educational and social opportunities. With the help of friends who provided guidance and helped them learn their rights, Eoin and Tau were able to have Lia reassessed and then reassigned to a standard classroom environment.

Today, Lia is three years old and attends standard preschool classes with a state-provided aide

(continued on page 11)

**Tau, Lia and Eoin  
enjoy a dinner  
together.**



## Things Were Changing ... and Not for the Better

Well, school is back in session and I've been faced with the problems of middle school. No one is picking on me. I have too many friends for that to happen. But, I've met the devil and he is "note-taking." In elementary school, not much had to be written down quickly. Teachers handed out printed versions of almost everything you needed to study or it was simply in your text book. That's not the case in middle school.

So, why is that so horrible? I am steadily losing my pinch and my hand control. I just can't write with any speed and not even well enough for me to know what I've written, let alone anyone else. They let me use computers in many situations, but I don't type fast either. So, note-taking is almost impossible.

I never wanted to have an aide. I always felt as though it would be a concession to the fact

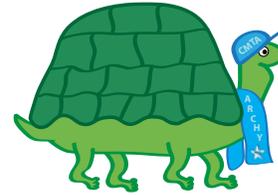
that I was really handicapped. I imagined the aide would be some sweet white-haired older female, and everyone would laugh at me. After just one week of struggling and failing at keeping up with all the details of the class lectures, I decided I had to give in to my mother's suggestion that we take on a school aide, supplied by our school district.

Imagine my surprise and delight when I met HIM. Just the fact that I got a male aide was a huge help to my sagging ego and then, on top of that, he is very athletic and has been showing my classmates some of his karate moves.

I know that not everyone who needs an aide is going to luck out and get one who fits his or her "wish list." But, having

someone around (not a parent) who can help with taking notes, carrying heavy books and keeping the surging hordes from trampling me is a true blessing.

I guess what I've learned so far this year is that it's not smart to ignore problems. They need to be faced head-on and conquered. Not everything will work out the way we want, but just having a solution to a problem is so much better than just hanging on to that problem. I wasn't sleeping well. I wasn't being my old jovial self and my friends were noticing (and not liking) the sad and grumpy turtle I'd become. Now, I feel as though a giant weight has been lifted from me and having an aide hasn't been a concession to my CMT; it's been an improvement to my life. ★



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

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Mr. & Mrs. C. Frederic Young

## COF FUNDRAISER HELD IN MASSACHUSETTS

On August 23rd, my family hosted our second annual CMTA fundraiser at the Cape Ann Marina in Gloucester, MA. Family, friends and CMTA Director of Community Services Jeana Sweeney joined us under a white tent by the ocean. This year, with help from the DeVesto family matching donations for the night up to \$5,000, our event raised over \$22,000. We had 10 door prizes that included Amazon, iTunes and Dunkin' Donuts gift cards; some of the 16 auction items were an autographed Celtics' basketball, a weekend on Martha's Vineyard and Patriots' tickets. We also held a 50/50 raffle that raised \$850. Like last year, we cooked burgers and sausages on a big grill and had pasta and salads.

When it was time for my speech, my Mom introduced me with the "Black Keys" song playing, and it really upped the energy in the room. Everyone was asking me how I was going to top last year's speech, to which I replied, "Just watch." My friends and I made a gymnastic pyramid last year, which we achieved again this year.



Vittorio and his guests posed for a giant "Selfie."

My sister and her friends sold t-shirts, passed out shark-shaped candy, and stuffed toy shark animals for the little kids. Three little girls ate an entire bucket of gummy sharks in under an hour. I had made a video of all the past events we had done, which played on a projector throughout the night.

My Grandpa took Jeana on a quick sight-seeing tour of Gloucester Harbor to get a picture of the Fisherman's Memorial. Also, this year, members from the Boston Support and Action Group were in attendance with their families. A good friend of mine (Drew Brockelman) filmed the whole event, and I will share the video on the CMTA site. At the end of my speech, I raised a ski pole-mounted GoPro camera and asked everyone to gather

around for a giant "Selfie."

To promote this event, my mother and I were interviewed in the Gloucester *Daily Times* and talked about how much the CMTA does for my disease. We hope the interview reached the local restaurants that donated gift cards to our Fundraiser.

I also announced at the fundraiser that I recently had an essay published in *Neurology Now* for the August/September issue. That was a perfect way to celebrate September Awareness Month! (Funny how things work out.)

Compared to the previous weekend in which I rode my bike with my Mom for 8 hours and 44 minutes to achieve a 100-mile Century Ride, the fundraiser was a breeze. But, I do like to *give it hell*.

—Vittorio Ricci

## LIA O'SULLIVAN

(continued from page 9)

who assists her with tasks and looks out for her safety. She also goes to weekly physical and occupational therapy sessions. Lia wears braces (AFOs to her ankles) and has a walker—although when she wants to get

somewhere fast, the walker is often abandoned. She has visited Tonga and Ireland several times. Every four to six months, Lia sees Dr. John Day and the entire team at Stanford.

Lia's favorite book is *Everyone has Something*, by CMTA Advisory Board Member Sarah Kesty. She has a signed copy and

insists on having it read to her almost every night. Having CMT has never slowed Lia down. In the words of her father, "Lia is the most determined kid you will ever meet. She has never made a fuss about falling. She just dusts herself off and gets moving. Her spirit is incredible." ★

## SAG FACILITATORS SPOTLIGHT:

## Katerina Marks, Atlanta

**M**y name is Katerina Marks and I am the newest co-facilitator with the Atlanta Support and Action Group. I'm 28 years old, and I was born showing symptoms of CMT. I was delayed in all the milestones and had a very weak grip. It was actually my *Abuelita* (little grandmother) who encouraged my Mom to take me to the doctor, saying, "There is something wrong with her! You have to take her." It took two and a half years, several tests, and one muscle biopsy to properly diagnose me at the age of three.

When I was little, I was able to walk 15 steps without AFOs. Around the age of 10, I started falling a lot and one of my teachers suggested I start using a wheelchair. I've always been a stubborn person and at that age I knew I wasn't going to use a chair ... or a walker ... or a cane, but when you hit your head so hard that you see stars, you have to admit the adults might be onto something, right? So, I gave in and started using a wheelchair. Just to be clear, though, I only used it for long

distances. I wasn't fully wheelchair-bound until the age of 15. By that time I was over feeling weird about it because I had friends who knew about my "floppy feet" and braces—ok, the whole school knew!

I've asked my Mom many times what her experience was like when I was finally diagnosed, and she always tells me, "I only really remember what the doctor told me: 'Now, Mom, this is the worst disease.' He wrote something on the board. 'Katie doesn't have this one. She has this.' And he wrote Charcot-Marie-Tooth. 'It's up to you if she grows up to go to college and does something meaningful or winds up selling burgers, because she doesn't have the worst disease.'"

Growing up, my CMT was never an excuse for me, my family or my friends. I went to sleep-overs and did very clumsy gymnastics. I've shaken pom-poms, and I've been skiing, camping and fishing. I've traveled to Chile. I've done and, continue to do, the things I want to do. The most important



Support and Action Group member, Mary Driscoll, and Katerina pose after the Fueling the Cure fundraiser.

thing I've done was to pursue a degree in art, which has always been my passion. Where most people in my area go to Emory University for pre-med, I attended classes where I created life in collages and paintings!

I still paint. I run my own business and volunteer for the CMTA. Part of this piece is to explain my path to the group and my decision to facilitate. I honestly hadn't really paid attention to the CMTA until the email this past winter about the promising breakthroughs. It was a light-bulb moment for me because I'd never really addressed my CMT. It's always been the "beside the point" thing for me. Anyway, I went to the March meeting (with three family members and my best-friend), met some really awesome people, and when Susan said she needed help with things, all I wanted to do was say, "Okay." ★

## UPGRADE TO A PREMIUM MEMBERSHIP

If you have not already become a Premium Member, please remember that with your first thirty-dollar membership contribution, you will receive a coupon for a free pair of shoes provided by the CMTA's partner, Aetrex. If you are already a Premium Member, we thank you for your support and remind you that if you renew your membership, you will continue get 50 percent off shoe orders from Aetrex. These offers run through the end of this calendar year and are redeemable online or by phone only.

# CMT Support and Action Groups in Your Community

## AZ—North Florence

North Alabama CMT Support and Action Group

Tina Smith  
256-757-9250  
Todd Oyen  
256-810-6582

## AZ—Phoenix Area

Arizona CMT Support and Action Group

Pamela Palmer  
ppalmeraz@gmail.com  
Jim Blum  
480-272-3846

## CA—Los Angeles Area

Los Angeles, CA CMT Support and Action Group

Steve Fox  
805-647-8225

## CA—Los Angeles

Los Angeles (South), CA CMT Support and Action Group

Alani Price  
310-710-2376

## CA—Orange County

Orange County, CA CMT Support and Action Group

Jessica Wells  
714-333-8031  
Amber Biddle  
714-343-3041

## CA—South Bay Area

San Francisco Peninsula/South Bay CMT Support and Action Group

Elizabeth Ouellette  
1-800-606-2682 x107  
Rick Alber  
650-924-1616

## CA—San Diego Area

San Diego, CA CMT Support and Action Group

Jordan Thomas  
619-549-0872

## CA—Santa Rosa Area

Santa Rosa, CA CMT Support and Action Group

Carol O'Bryan  
707-823-0165

## CA—Visalia Area

Visalia, CA CMT Support and Action Group

Melanie Pennebaker  
559-972-3020

## CO—Denver Area

Denver Area CMT Support and Action Group

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

## CT—Hartford

Hartford, CT East CMT Support and Action Group

Roy Behlke  
239-682-6785

## CT—North Haven

Southern CT CMT Support and Action Group

Lynne Krupa  
203-288-6673

## DC—Washington, DC

Washington, DC CMT Support and Action Group

Steven Weiss  
Kimberly Hughes  
301-962-8885

## FL—Naples

Naples, FL CMT Support and Action Group

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239-455-5571

## FL—Sarasota Area

Sarasota, FL CMT Support and Action Group

Rachel Rivlin  
941-870-3326

## FL—Tampa Bay Area

Tampa Bay, FL CMT Support and Action Group

Vicki Pollyea  
813-251-5512

## FL—West Palm Beach

South FL CMT Support and Action Group

Phil Lewis  
561-630-3931  
Eileen Martinez  
561-777-8471

## GA—Atlanta Area

Atlanta, GA CMT Support and Action Group

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678-595-2817  
Katerina Marks  
404-372-3158

## IA—Iowa Area

Iowa City, IA CMT Support and Action Group

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319-981-0171

## IL—Chicago Area

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## IL—Norridge Area

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Central IL CMT Support and Action Group

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Priscilla Creaven  
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## IN—Indianapolis Area

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Patricia Wood  
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Jill Ricci  
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Seth Warfield  
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Chesaning, MI CMT Support and Action Group

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989-845-5731

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Southwest Michigan CMT Support and Action Group

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269-341-4415

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Cindy Chesteen  
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## NC—Durham Area

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Margaret Lee  
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## NC—Wilmington Area

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## NE—Lincoln Area

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402-641-0443

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Central New Jersey CMT Support and Action Group

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Jacqueline Donahue  
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Melissa Adams  
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Jerry Cross  
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## NY—Horseheads Area

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## NY—Long Island Area

Long Island, NY CMT Support and Action Group

Shari Loewenthal  
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## NY—Manhattan Area

New York, NY CMT Support and Action Group

Amanda Imbriano  
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## NY—Upstate New York

The Upstate NY CMT Support and Action Group

Richard Piche  
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## NY—Westchester Area

Westchester, NY CMT Support and Action Group

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Frank Wurzel  
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## OH—Cleveland Area

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Joyce Beals  
971-832-8272

## PA—Bucks County Area

Bucks County, PA CMT Support and Action Group

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Mitch Davis  
215-943-0760

## PA—Ephrata, PA

Ephrata, PA CMT Support and Action Group

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## PA—Johnstown Area

Johnstown, PA CMT Support and Action Group

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814-539-2341  
Jeana Sweeney  
814-269-1319

## PA—Northwestern Area

Erie, PA CMT Support and Action Group

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814-833-8495

## RI—East Providence

Rhode Island CMT Support and Action Group

Meredeth Souza  
Raymond Souza  
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## SD—Hartford Area

Hartford, SD CMT Support and Action Group

Serena Clarkson  
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Tom Clarkson  
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## TN—Nashville Area

Nashville, TN CMT Support and Action Group

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Gwen Redick  
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## TN—Savannah Area

Savannah, TN CMT Support and Action Group

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Melinda White  
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## TX—Lubbock Area

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Pam Downing  
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Orem, UT CMT Support and Action Group

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## VA—Harrisonburg Area

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## VA—Shenandoah Area

Northern Shenandoah Valley CMT Support and Action Group

Teresa Frederick  
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## VA—Williamsburg Area

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Nancy Mollner  
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## WI—Milwaukee Area

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Susan Moore  
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## WV—Vienna Area

Parkersburg/Vienna, WV CMT Support and Action Group

Rebecca Knapp  
304-834-1735

## GROUPS IN CANADA AND MEXICO

### CAN—British Columbia

Victoria, BC CMT Support and Action Group

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

### CAN—Ontario

Eastern Ontario CMT Support and Action Group

Robin Schock  
613-389-1181

Northern Ontario CMT Action and Support Group

Brenda Spencer  
705-788-0408

Southern Ontario CMT Action and Support Group

Kelly Hall  
519-843-6119

### Mexico

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

Gina Salazar  
Gina\_oviedo@hotmail.com

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

## Caring for a Parent with CMT

BY CHUCK BARRETT

Howdy, howdy, (my mother's favorite greeting). My name is Chuck Barrett and I have CMT1X that I inherited from my mother. We have all read stories written by people with CMT or parents of children with CMT who wanted to share their experiences, but I cannot recall many, if any, stories about a son or daughter who provided assistance to a parent who has CMT. So, I feel compelled to share my somewhat unique experience with other CMTA members.

CMT1X significantly affects males, but my mother, Bernice Barrett, has it too. On September 22, 2007, after she fell and



Bernice Barrett knows she is lucky to have her son provide daily care for her.

broke her hip, I became my mother's primary caregiver. I am one of six children in our family, and the only one who has CMT. So, I guess this made me a natural candidate to assist my mother because I understand the

condition more than my siblings. My mother also has some memory issues—she will tell anyone who asks, “Honey, I don't have any problems; everything is wonderful”—that I think may have been caused by various surgeries and some mini strokes attributed to stress, thus requiring some assistance with daily living. None of the stress was from living with CMT; it was the stress of living alone.

After the fall, which required a partial hip replacement, I had to communicate with various health care providers such as doctors, nurses, physical and occupational therapists, as well as anyone who would be involved

### We are the Lucky Ones!

I'm not inclined to hero worship. As a matter of fact, in my estimation, heroes are not sports figures, actors, or the beautiful people. They are not people who gain fame through acts or high-profile lives. They are the people who find a niche, an area of interest that contributes to the betterment of the lives of the little guy. In this case, the little guy is the one with CMT. We are the little guys; we who have Charcot Marie Tooth; we who have the disorder with that weird “shark-o” name. Yes, that's us.

So, how did Charcot and Marie and Tooth—those French and English guys—become interested in us way back when? I guess someone could do a doctoral dissertation on that question, but there's no need. We who have CMT got lucky. For us, for now, Dr. Michael Shy, of the University of Iowa came along.

I think that he found an interest in our anomalies. Mike, as he first introduced himself to me, is dedicating his life to the study and support of CMT patients. I know that we're all special to him and his team, but I like to think that it's because of my family (affectionately dubbed, “Carly's Family” because of Carly Siskind, who worked with Dr. Shy at Wayne State University, and her support of my family). Of course we stand out because of our sparkling personalities, but I think it's more likely because there are so darn many of us with CMT 2E.

Regardless, we are lucky. All of us with CMT are lucky. We have so many professionals, so many friends and family, who have taken an interest in CMT—in us as individuals and families. I feel blessed. Thank you to all. Thank you for making all of my birthday wishes from the last umpteen years begin to come true. Oh, dear. I just revealed my wishes. I hope they'll still come true! —Denise Morris Snow

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

in my mother's care. I also have had to provide the list of medications that my mother cannot have and explain that she needs special care because of her CMT.

For example, with physical therapy—three sessions were required—the expectations for someone with CMT will certainly be different than from someone who does not have it. Most health care professionals are receptive to information and really want to assist their patients in the best way possible. Sometimes this required a print copy or an encouragement to go to the CMTA website, or even just going to the Internet and entering "CMT." Most of the health care providers with whom I have communicated with in assisting with my mother's care have either had limited or no knowledge of CMT, so this has been a learning experience for them as well. Sometimes I look at this experience as not only helping my wonderful mother who has done so much for her family, but also spreading the word about this very rare disorder that that many of us live with on a daily basis.

My mother wears ankle supports and uses a walker to get around, and after several sessions of physical therapy, Mom could probably walk a half mile or so. A few years ago on an indoor track Mom used to walk a mile on a regular basis, using her walker the whole time. I do believe that if my mother did not have CMT, she would be able to walk without any aids. Recently due to a couple of falls, my mother had to relocate to a unit that provided more assistance with mobility issues. Mom is a positive person and always sees the glass as half full, and I am very thankful that I am able to be my mother's health care advocate. ★

## CMT PATIENT MEDICATION ALERT:

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

**Moderate to significant risk:**  
Amiodarone (Cordarone)  
Bortezomib (Velcade)  
Cisplatin and Oxaliplatin  
Colchicine (extended use)  
Dapsone  
Didanosine (ddI, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Eribulin (Halaven)  
Gold salts  
Ixabepilone (Ixempra)  
Leflunomide (Arava)  
Metronidazole/Misonidazole (extended use)  
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)  
Nitrous oxide (inhalation abuse)  
Perhexiline (not used in US)  
Pyridoxine (mega dose of Vitamin B6)  
Stavudine (d4T, Zerit)  
Suramin  
Taxols (paclitaxel, docetaxel)  
Thalidomide  
Zalcitabine (ddC, Hivid)

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

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

# THE CMTA Report

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## WHAT IS CMT?

- ▶ CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- ▶ CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ CMT is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- ▶ CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.