The reason you may have received confusing and often contradictory answers to your questions stems from the relative lack of rigorous research on the topic. A recent systematic review of exercise and CMT identified just nine studies on the topic.* Most of the existing studies are small and use varied exercise protocols and design, preventing the possibility of generalizing results to all people with CMT.

But as a whole, the available studies suggest that certain forms of exercise may be an effective tool for improving elements of health and fitness.

With this premise in mind, and drawing from what we know about exercise in the general population, let’s sketch a framework for exercise for people with CMT. We are not focusing on only one muscle or area of the body. We are looking at the person as a whole with the goal of making gains in mobility, independence and overall well-being.

To exercise or NOT to exercise?

If you have received conflicting advice about the role of exercise in CMT, you are not alone! Not a CMT clinic day goes by without my being asked:

- “Will exercise help me get stronger?”
- “Can exercise hurt people with CMT?”
- “What types of exercise are best for me?”
- “How much and how often should I exercise?”

1. BALANCE

Balance problems are nearly universal with CMT. While this problem cannot be easily solved and assistive devices may still be needed, several simple balance exercises exist and can be performed at home. A chair may be used for support. Tai-chi and modified chair yoga have been shown to help with balance in other diseases.

2. STRETCHING

Stretching exercises help prevent pain and loss of range of motion at joints affected by CMT, such as the ankles. Stretching the heel cords should be a daily routine for people with CMT.

DEAR FELLOW CMTERS:

As I sit and pen this letter to you, I’d like to share with you what we have accomplished together this year and what I will commit to you for 2016.

For the last three years, the CMTA has seen improvement in every meaningful metric in our march toward realizing success in our mission for a first treatment and providing help to increase the quality of life for each person with CMT!

On STAR: The CMTA is funding translational projects focused on CMT 1A, 2A, 1B, 2E, 1X, and 4 that cover more than 90 percent of CMT cases. We spent approximately $2 million on this research, another record year. The CMTA enjoys collaborations with several pharmaceutical companies that have bought into the CMTA’s STAR consortium model in our search for a first drug to treat patients. We anticipate milestones and decisions toward drug development to be a reality in the coming year.

On CMT Community: The CMTA added resources this year to continue the exploding numbers of CMTA members. All of our STAR efforts go for naught if we are not successful in identifying as many CMT patients as possible, as well as the type of CMT that affects them. The CMTA branch system has grown to more than 80 branches in 40 states, plus Canada. Together, we raised more than $4 million in 2015, another record for the third year straight!

CMT Centers of Excellence, subsidized by the CMTA, NIH, and MDA, now number 22 globally, providing multidisciplinary touch points for CMT patients and their families under one roof.

My gratitude goes to all donors, the seven-person staff of the CMTA, all branch leaders, the STAR Scientific Board and Therapy Board members for your valuable and treasured participation and contributions for a remarkable and record 2015! I am humbled to be part of this team and community.

For 2016: I’d like to announce my renewed commitment to our mission and challenge all of you to make your New Year’s Resolution count! My 2016 resolution is to challenge myself as much as possible for what is shaping up to be a critical and exciting year!

I hope each and every one of you takes my challenge. Don’t make some trite resolution: Make one that can make a difference.

My best to you and your family for a healthy and prosperous 2016!

Patrick A. Livney
CEO – CMTA
Music City Patient/Family Conference Draws Crowds from Across South

BY BETHANY TONGATE

More than 100 people turned out to hear doctors, researchers and therapists from the Vanderbilt University Medical Center at the CMTA’s Patient/Family Conference on November 14, 2015. The event was the first held in Nashville, home of the Grand Ole Opry and the other CMT—Country Music Television.

Three people from the Vanderbilt CMT Clinic spoke. Noting that more than 80 gene mutations cause CMT, Clinic Director Dr. Jun Li told the audience that, “Saying you have CMT is like saying you have a car. You could have a Toyota or a Mercedes.”

Noting that more than 80 gene mutations cause CMT, Clinic Director Dr. Jun Li spoke. Robin Yawn, RN, the case manager for the clinic, outlined the steps necessary to get an appointment at the clinic: Have a neurologist fax a referral to the clinic at (615)-936-1263 and indicate “Dr. Li and CMT” on the fax. She also suggested that patients bring pictures of other family members who have CMT to help Dr. Li determine how the patient’s CMT will progress and to aid him with his research.

CMTA, and five other pharmaceutical companies are in early testing of compounds believed to have positive effects on CMT1A. Livney also stressed the importance of signing up with the Rare Disease Registry (www.rarediseasenameetwork.org/INC/register) to receive notification once a potential treatment is identified and studies are active.

The day also included lots of practical advice. Dr. Li advised audience members to let doctors know they have CMT, especially in emergency rooms, because CMT can often mimic stroke-like symptoms. A panel on assistive devices covered tools for helping those with CMT function better.

CMTA CEO Patrick Livney updated attendees on the CMTA’s Strategy to Accelerate Research (STAR). Perhaps most excitingly, the CMTA’s partnership with Genzyme, a Sanofi company, has identified a handful of compound series for treating CMT1A, and five other pharmaceutical companies are in early testing of compounds believed to have positive effects on CMT1A. Livney also stressed the importance of signing up with the Rare Disease Registry (www.rarediseasenameetwork.org/INC/register) to receive notification once a potential treatment is identified and studies are active.

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Beverly Wurzel Receives Rebecca Sand Volunteer of the Year Award

On November 7, 2015, CMTA Community Services Director Jeanne Sweeney and Finance Director Kim Magee presented the Rebecca Sand Volunteer of the Year Award to a surprised Beverly Wurzel in honor of her 15 years as leader of the Westchester County CMTA Branch. The presentation took place at the Westchester County CMTA Holiday Luncheon for CMT. People who know Bev won’t be surprised that Jeana hand-carried the award everywhere until the presentation, even the bedroom, knowing that Bev might just be tempted to take a peek into a box of unknown origin.

“Fiery” is a word people use to describe Beverly. Jeana calls Beverly a “fire-cra—cracker,” a one-of-a-kind individual whose faith and devotion to the CMTA are on display every day of the year. Elizabeth Ouellette, vice chair of the CMTA Board of Directors, calls Beverly “an unstoppable ball of fire, sparked into action by her sheer determination to leave this earth a better place, knowing that her hard work and dedication make a treatment for CMT not only a possibility, but a reality.” According to Elizabeth, Beverly is tireless, optimistic, loving, unstoppable, nice, tenacious, energetic, exuberant, and resolute—in short an amazing volunteer.

Born to immigrants in Brooklyn, Beverly remembers her gait. The doctors just shrugged. Beverly went on to attend Brooklyn College until she met and married her husband Frank when she was just 19. Together they bought their first house in Brooklyn for $7,000. They later bought a $24,000 house in Monroe, New York, where they raised their three children. Today, that she leave the hospital in a wheelchair. Beverly’s response was, “Maybe I’ll wheel you out!” When the CMTA came into existence, Beverly switched her allegiance. She began attending CMTA meetings and was eventually asked to lead the group. Amazingly, Beverly was initially reluctant to become a branch leader, feeling that she was too shy for the job.

In the 15 years since then, Beverly has become a role model and an inspiration for all CMTA branch leaders. She says that one of the secrets of becoming a great branch leader is getting to know all branch members on a personal level. Beverly is a fearless fundraiser. She believes in taking advantage of matching donations and when she hears about a match, she contacts all of her members and lets them know about the opportunity to double the impact of their donation. She also believes in doubling down on her asking.

In her own words: “When someone asks me if $25 would be an okay donation, I tell them $50 would be better.” Beverly attributes the tremendous growth in the CMTA to its leadership—people like CEO Pat Livney, Elizabeth Ouellette, and Helen Hayes Hospital when a doctor told her she had Charcot-Marie-Tooth disease. Beverly had no idea what he was talking about but went in to get things checked out. On the day she was finally diagnosed and discharged, a nurse brought her a chair to wheel her out. When Bev asked why, the nurse said that her results dictated that she leave the hospital in a wheelchair. Beverly’s response was, “Maybe I’ll wheel you out!”

But Beverly believes there will be a treatment and a cure, in her lifetime. Until then, the CMTA is grateful to have leaders like Beverly raising funds and awareness for CMT! ***
A NEW YEAR’S WISH FROM HANGER CLINIC, NEW CMTA PARTNER

Happy New Year, CMTA Members!

On behalf of everyone at Hanger Clinic, I am delighted to announce a new partnership with the CMTA. Both of our organizations work to improve the quality of life for those affected by CMT, while still clearly envisioning a world without it. Our combined efforts will allow greater collaboration, communication and success for those in need of our support and services. Hanger Clinic is dedicated to fostering human potential and empowering everyone to live a healthier, happier and more active life. Your stories are incredibly inspiring, and Hanger Clinic is proud to partner with the CMTA’s amazing, proactive leadership.

Everyone wants to live a life without limitations. We are here to help you do just that. Hanger Clinic is the largest provider of orthotic and prosthetic services in the country. We are committed to:

- Quality patient care programs to achieve the highest outcomes possible.
- Exceedingly skilled and educated clinicians (2016 will be busy with a variety of clinical and educational events).
- Convenient access to orthotic and prosthetic clinical care with over 75 locations across the U.S.
- The latest products and technologies, including the innovative low-profile Silicone AFO (SiAFO), available exclusively from Hanger, and
- Recognizing that each individual’s challenges are unique.

We are excited about the potential to help the CMTA make a difference, and we hope to hear from you about the obstacles you’re facing and how Hanger Clinic can help you overcome them. Many of our clinicians have been involved in CMT clinics and with CMTA activities for years, and they will continue to share their experiences and expertise with all of you and other healthcare professionals.

Hanger Clinic believes in this partnership because we share the same optimism, passion for your independence and mobility, and belief in the power of your potential. Most importantly, we want to support your goals and add our voice to yours. To contact us or to learn more, visit www.HangerClinic.com or call 1-877-4Hanger.

Here’s to an empowered 2016!

My very best regards,

Deanna Fish, MS, CPO, Hanger Clinic Vice President, Orthotics

A few years ago, the folks at the CMTA called me with an idea. They had noticed that many young people were attending the CMTA’s Patient/Family Conferences. They had also noticed that the conferences didn’t provide the right environment for young people to connect or to share their experiences with CMT. Youth Outings were born, and Bethany Meloche, the CMTA’s director of social media, and I were asked to lead them.

The concept was simple: After the science and speakers and table sitting of the conference were over, teens would gather, jump (or walk slowly) into a van and head out into the city for an evening of activity and fun. The concept was simple, but the results have been complex and wonderful.

In the last few years, we have taken Youth Outings in Chicago, Los Angeles, San Francisco, Orlando, Boston, Nashville. We have eaten together, bowled, gone to Disney World, quacked through a duck boat tour, escaped from “The Escape Game,” and so much more.

We’re always aware of the physicality when choosing the activities and we keep an eye on each other when choosing the activities and managing the array of reactions they got from their peers. We began to use the dinner portion of the outings to facilitate a discussion about our experiences with CMT. Our staple starter question is: What is the worst part of having CMT and what is the best part of having CMT? The answers we have received over the years are impressive and wonderful. Once the kids got talking, we usually sit back and watch the magic happen. We listen as they complain about

by Jonah Berger

Editor’s Note: Beginning in 2016, the Youth Outings will fall under the new umbrella for all things having to do with CMTers aged 13 to 19—CMTeen!
**CM1A RESEARCH: A View from the Bench**

**BY JOHN SWENEN, PHD**

Last year was a big one for the CMTA, and I want to give you my perspective on how the Strategy to Accelerate Research (STAR) program is reaching the goals that we set for new therapy development for CMT.

As a faculty member at the University of Wisconsin-Madison, I was invited several years ago to participate in the STAR research program dedicated to CMT1A. At that time, my laboratory was interested in trying to do studies relevant to CMT1A but needed help to gather the necessary resources and to develop a plan of attack.

CMT1A was of great interest to me because it is caused by having an extra copy of the PMP22 gene, and we thought that our investigation into genetic control of Schwann cells would give us the tools to identify ways to reduce PMP22 levels and thereby come up with an effective therapy for CMT1A.

Although relatively little was known about regulation of PMP22 at the time, resources provided by the CMTA enabled us to identify regulatory pathways that can be used to downregulate PMP22. Along the way, our collaborations with the laboratory of Dr. James Inglese at the National Institute of Health gave rise to a groundbreaking approach in which we developed and screened a new cell-based assay for CMT1A that utilized recent developments in genome editing.

Genome editing refers to newly developed technology that allows us to "re-write" a cell’s DNA sequence, much like editing a document with a word processor. In our case, we took Schwann cells, which make myelin (the coating around the nerves) in the peripheral nervous system, and inserted a new gene that would allow us to measure the output of the PMP22 gene. Like fiber optic cables that simultaneously transmit many types of data, our cells use light generated by a firefly gene, which emits light indicating the level of the PMP22 gene. Our goal was to use these genetically modified Schwann cells in order to simultaneously test large numbers of compounds to find those that would reduce PMP22 levels and thereby identify candidate compounds for treatment of CMT1A.

In our lab, we could test hundreds of compounds, but the Inglese lab at NIH had the capability to test multiples more and we initially used these cells to screen a collection of 3,000 compounds. The success of our approach led to using the same modified Schwann cells with partners at NIH and Genzyme, a Sanofi company, to test approximately 450,000 and almost 2 million compounds, respectively, for their ability to reduce high levels of the PMP22 gene.

Those tests were completed last year and we are now in the midst of testing hundreds of promising compounds using independent types of Schwann cells to try to identify those that can reduce PMP22 levels in a safe manner. These efforts have involved collaborations with scientists at other institutions, including Dr. Laura Feltri at the University at Buffalo and Dr. Steven Scherer at the University of Pennsylvania, among others who were part of the early meetings that envisioned the goals of the STAR program.

Finally, these efforts have involved six people in my lab who have worked on various aspects of the project in a CMTA-sponsored collaborative network with other individuals at NIH and Genzyme-Sanofi who are skilled at drug screening and drug development. While we have come a long way, a lot of intense effort remains in order to refine and test our list of candidate drugs using multiple testing platforms. Also, since we do not wish to put all of our eggs in one basket, we work on multiple parallel tracks to identify new ways to treat CMT1A.

This project has been immensely satisfying, not only because of the new scientific insights into the basis of CMT1A, but also because of the support and collaboration we have received from NIH and our pharmaceutical partners. The potential of this project to provide new treatments for CMT1A is a major motivator for everyone involved.

Along the way, the CMTA has fostered all of our initiatives and has supported similar approaches to develop therapy pathways for other major CMT subtypes like CMT2E, CMT1B, and CMT2A.

The ultimate success of these efforts begins and ends with the support and involvement of the CMTA community...

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**CMTA RECEIVES CHARITY NAVIGATOR’S 4-STAR RATING FOR SECOND YEAR IN A ROW**

The CMTA has earned a second consecutive 4-star rating from Charity Navigator. Only 21 percent of the nonprofits rated by Charity Navigator get two consecutive 4-star evaluations, indicating that the CMTA outperforms most other charities in America.

According to Charity Navigator President and CEO Michael Thatcher, receiving four out of five stars indicates that an organization adheres to good governance and other best practices that minimize the chance of unethical activities and consistently executes its mission in a fiscally responsible way.

“This ‘exceptional’ designation from Charity Navigator differentiates the Charcot-Marie-Tooth Association from its peers and demonstrates to the public it is worthy of their trust,” Thatcher said in announcing the award.

“4-star ratings are the pinnacle of our rating system and are awarded to only the best nonprofit organizations in the country,” said Charity Navigator’s Chief Executive Officerijing Chang. “We congratulate the CMTA for achieving this top rating.”

The CMTA’s commitment to excellence is evidenced in its fiscal responsibility rating of 100 percent and its 10 times more charities than its nearest competitor and currently attracts more visitors to its website than all other charity rating groups combined.

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**CMT RESEARCH**

The CMTA is the leading source of information for individuals with CMT, their families, and the medical community. The CMTA funding provides the ability to give drug discovery research a chance to be successful. With your support, CMT patients will have access to needed medical advances.

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**Sam Houston State Bearkats Raise $21K for Research**

Sam Houston State University’s women’s volleyball team hosted its first ever CMT Awareness Night September 15 as the Bearkats took on Texas State. The Bearkats lost the game, but the CMTA won big. The event raised almost $21,000 for CMT research.

The event was conceived in August 2015, just a few short weeks before in her birth. Because there was no CMTA branch in Houston, Director of Community Services Jeana Sweeney and Midwest Regional Branch Manager Michelle Hayes organized what they called a “pop-up meeting” in an effort to kick start interest in this major American city. They sent e-mails, located a meeting room and waited to see who would show up. Happily for the CMTA, Devon Gray did. Her mother was recently diagnosed with CMT Type 2A, and her mother-in-law, Brenda Gray, is the Bearkats coach.

Working on a tight deadline, Devon and a host of volunteers created CMTA STARs—blue and orange cardboard cards with the CMTA logo on a star shape. The stars were sold for $10 apiece (three for $25, $100 for a business). Donors were encouraged to write their names on the stars with encouraging words for the fundraiser took on a life of its own. The event was adver tised on radio, Facebook and in local newspapers.

The CMTA PSA was played on the Coliseum’s big screen, and Michelle spoke to the crowd. The response was tremendous and plans are in place to make it an annual event.

The CMTA gives a big Texas-sized thank you to Devon Gray, Brenda Gray, the entire Gray family, the Sam Houston State University, and the city of Huntsville, Texas! Go Bearkats!
WHAT’S ON YOUR MIND?  Ask David.

Dear David,

I was diagnosed about 10 years ago with CMT (while in my mid-thirties), and this last year it feels like it has gotten a little worse. As far as I know I am the only one in my family with CMT, I am married with three children in their late teens who show no symptoms. My question has to do with the daily struggle I have with living with all the uncertainty. My husband and I are ambivalent about getting the kids tested at this time. They are smart kids but show little interest in knowing. Do you have some tips for handling uncertainty in general? I am anxious and depressed much of the time even though there is much to be grateful for in my life.

David replies:

Although having CMT shows uncertainty in our faces, uncertainty is a good challenge to master. Focusing on what-if this-happens or what-if-that-happens can keep you in a state of anxiety that will paralyze you and lead to depression. I know because I did it myself for years. I used every little change in my body to justify all my worst fears. Ninety-nine percent of this worry was my imagination. I knew I had to find a way to manage my fears because of the very real connection between my anxiety and feeling physically weaker. I wish I had those years back because if I knew then what I know now, I would not have suffered so and maybe could have just enjoyed my young adulthood.

Allison Carmen wrote a great little book called “The Gift of Maybe.” The concept of “maybe” helps you stand in the moment and also gives you an opening to recognize that things can always change. In your moment of feeling hopeless, negative or frightened, identify what you are feeling and say it out loud. Take a deep breath and wait a few minutes until you begin to notice a small shift. Allow these feelings to slowly pass away, notice what’s left and then ask yourself: OK, what’s next? Be mindful that life is filled with possibilities, even if you can’t feel it in the moment. The idea of “maybe” allows you to have these feelings but will not let you get stuck in this place of negativity. “Maybe” offers you an opening of hope that you can move into naturally when you are ready. We get so stuck in the way we think our life should be that we can’t see what is really in front of us. That is called linear thinking, linear thinking makes us believe that there is a right way and wrong way for our lives to unfold. Joseph Campbell said, “We must be willing to let go of the life we have planned, so to accept the life that is waiting for us.” Arguing that things should be different from what they are is like banging your head against a closed door.

As we embrace the idea of “maybe,” our thoughts dissipate and all the negative stories we tell ourselves about the future dissolve into the past. The goal is to try to sit comfortably in the present without our stories, knowing that the future can unfold in many ways and just maybe not turn out as badly as we have imagined. Be curious and open to all possibilities!

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. “My CMT has been my greatest challenge and my best teacher in life,” says David.

NO, NO, THANK YOU!

Now it’s our turn to be grateful! You responded to our Thanksgiving drive by raising $100,000 in just 40 days. In total, the CMT community raised almost $2 million for CMT research in 2015, more than $1.2 million of it for CMTA research. You’re the reason why STAR is working! To read more about STAR, see page 10. For a recap of progress on all disease states, see page 5.

MEMBER SPOTLIGHT: Deaf and Blind, Artist with CMT Creates, Inspires

Artist Christian Markovic

Christian inherited CMT from his mother. When his parents divorced, Christian was raised by his father, Bob Markovic. After Christian came down with the flu at the age of 13, Bob began noticing that he was experiencing walking issues, including occasional collapses. The deterioration of his eyesight soon followed.

Despite his health issues, Christian maintains a sunny disposition. According to his father he is always smiling and lives by the adage “Never Give Up!” Always artistically inclined, Christian received good grades at the Savannah College of Art and Design, and his creative abilities are on clear display in his artwork and the line of greeting cards and clothing incorporating it.

To create his drawings, Christian works on a Macintosh computer using a zoom program that enlarges his work 10 times. His work has been shown at the Credit Suisse Gallery in New York City and the Pierro Gallery in South Orange, New Jersey. He is also one of the primary artists at Arts Unbound in Orange, New Jersey. Some of Christian’s corporate customers are Harlem Day Charter School, Bright Horizons Day Care Centers and the United Way Foundation.

Christian points out that regardless of his diagnosis and loss of function, he is still a contributing member of society. He fights his CMT every day by staying active with physical therapy and going to the gym. He also continues to flex his creative muscles and recently took up sculpting.

“It’s important for me to share my story, especially with others who have a similar diagnosis,” Christian says, adding, “I want everyone to see my accomplishments in business and use that as inspiration.”

Christian sells his screened cards and other products from his website, www.fuzzywuzzysdesign.com, as well as his ETSY store, which is located at www.etsy.com/shop/fuzzywuzzys4u.
Rachel Rivlin inherited her height and her love of sports from her father, who played professional basketball in Maine. From her mother, she inherited CMT. While her mother was never officially diagnosed, Rachel remembers that she had high arches, tripped a lot and staggered when she stood up from a chair. Doctors said her mother had arthritis and maybe Parkinson’s disease.

Rachel was an all-around athlete in her youth. She was a swimmer and played basketball, softball and volleyball. Later, she was a professional belly dancer with paying gigs in restaurants and at private parties. Shifting from physical to mental concerns, Rachel became an attorney and ran the legal department at a large insurance company. She also served on a number of professional associations and chaired committees of the American Bar Association.

In her late forties, Rachel began noticing numbness in her balls of her feet. She told her doctors that there was something wrong with her feet, but they mostly ignored her. One orthopedist told her she had tunnel syndrome and that he could perform surgery, but when she asked if it would help, he said probably not.

Always up for some fun, Rachel sprayed her hair blue this past September as part of the Go Blue 4 CMT campaign.

Branch Leader Spotlight: Rachel Rivlin, Sarasota, FL

Frustrated with the lack of a diagnosis, Rachel finally went to one of the top neurologists in Boston. He had no more insight into the cause of her symptoms than anyone else, but eventually he did a nerve biopsy, taking a chunk of nerve out of her left leg. Weeks later he called with results. The good news was that Rachel did not have ALS or MS, as the neurologist had feared. The bad news was that she had CMT. When she asked her neurologist for more information about Charcot-Marie-Tooth disease, he handed her a two-page pamphlet with little real information.

Curious about Rachel’s diagnosis, her partner, Manuel Goldberg, went online and began researching CMT. He quickly found a large website and began reading about the disease. It was soon obvious that Rachel’s high arches, ankle problems and foot drop as the neurologist had feared. Rachel realized she needed help immediately. She immediately applied to disability and began hearing back. It was a long battle, but once she received her disability, she turned her life around. Her reaction to retirement was emotional, it ultimately proved a great relief. Her fatigue lessened to manageable levels. In 2004, she was on disability from her job. The realization of her work life was over hit Rachel hard. She remembers becoming very emotional and crying at the doctor's office. While she had always tried to prepare for that day, she still found herself unready when it finally arrived. She was 59 years old when she went out on short-term disability thanks to insurance purchased years earlier through her work. She never thought she would have to use it, but it got her through.

While Rachel’s immediate reaction to retirement was emotional, it ultimately proved a great relief. Her fatigue lessened to manageable levels. In November 2005, she and Manuel began spending winters

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Curious about Rachel’s diagnosis, her partner, Manuel Goldberg, went online and began researching CMT. He quickly found a large website and began reading about the disease. It was soon obvious that Rachel’s high arches, ankle problems and foot drop as the neurologist had feared. Rachel realized she needed help immediately. She immediately applied to disability and began hearing back. It was a long battle, but once she received her disability, she turned her life around. Her reaction to retirement was emotional, it ultimately proved a great relief. Her fatigue lessened to manageable levels. In 2004, she was on disability from her job. The realization of her work life was over hit Rachel hard. She remembers becoming very emotional and crying at the doctor's office. While she had always tried to prepare for that day, she still found herself unready when it finally arrived. She was 59 years old when she went out on short-term disability thanks to insurance purchased years earlier through her work. She never thought she would have to use it, but it got her through.

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by the diagnosis, Ori initially hid his condition from all but a few close friends and family members, but eventually decided that being open about it was the better path. In time, he joined the San Francisco branch of the CMTA and later took over branch leadership from CMTA Board Member Elizabeth Ouellette.

Ori first got his braces in 2009. Abby was rescued by an Asian Humane Society that brought her and her littermates from the Taiwanese countryside. Ori says she almost single-handedly lifted him from the depths of depression. Thanks to those Helios braces, Abby is now getting significantly longer walks.

In September 2015, Ori and his Co-Branch Leader Tas O’Sullivan organized the Palo Alto Walk for CMT, which raised approximately $55,000 for the CMTA. Ori plans to contribute to the CMTA in raising both funds and awareness. In particular, Ori hopes to assist the CMTA in identifying large donors, corporate sponsors and strategic partners.

ORI BASH TAKES REINS OF WEST COAST BRANCHES

BY CLARK SEMMES

Ori Bash, the CMTA’s new West Coast Regional Branch manager, brings a wealth of knowledge and the perfect skill set to his new position. If CMTA members are to continue to grow, motivation and tenacity. Ori embodies all three.

Ori, who also worked in fundraising, was born in Israel and raised in the San Francisco area, where his parents immigrated in their late 30s in pursuit of the American dream. Ori says his parents won the green card lottery thanks to the sponsorship of his uncle, who lives in Berkeley. The first few years were tough, but they persevered and built a great life in the United States. Ori attributes his strong work ethic and courage to the example his parents set in their times of adversity.

Ori attended business school in Chicago in pursuit of a finance career as an investment banker specializing in mergers and acquisitions. Dissuaded by the stress and values of life as a Wall Street banker, Ori decided to leave the business world and return to the community of his birth.

At the age of 28, Ori began to notice that he was tripping frequently and having trouble lifting the front of his feet. A podiatrist tested his reflexes and immediately sent Ori to a neurologist who confirmed that he had CMT. Ori’s diagnosis led to the discovery of CMT in both his father and his brother. In 2007, genetic testing narrowed the diagnosis to CMT1A. Stunned and fatigued and began to feel hopeless about his declining state. In September 2014, Ori decided to take a gamble and ponied up $13,500 for a pair of Helios braces. After a battle, his health insurance company reimbursed him 70 percent of the cost. Ori says the Helios braces have been a “game changer” for him in terms of increasing his quality of life and allowing him to be much more active with more confidence. “They have given me renewed hope,” he says.

Another thing that gave Ori hope in his very darkest hours was his rescue dog, Abby, a Foisenese Mountain Dog he adopted in 2009. Abby was rescued by an Asian Humane Society that brought her and her littermates from the Taiwanese countryside. Ori says she almost single-handedly lifted him from the depths of depression. Thanks to those Helios braces, Abby is now getting significantly longer walks.

At the December 13, 2015, meeting, sharing stories and tips on their orthotics and orthodontics, genetic testing, and insurance. They all said that they see value in having a group north of the Golden Gate Bridge, even if it is a small one. Attendees were encouraged to donate in any amount to the CMTA so that they can get your name in the database and can be contacted for clinical trials and take advantage of all the other help offered. The next meeting will be in March, with a yoga instructor who specializes in chair yoga and adapting yoga for different ages and physical abilities/limitations.

The branch welcomed a guest speaker from the state’s Muscular Dystrophy Association at its last meeting of the year on December 7, 2015. Nicole Ginnell, health care services coordinator, provided information and answered questions about services available for those with CMT. Those services include four Connective MDA clinics, a loan closet with durable medical equipment that can be delivered free of charge, an equipment repair fund, a summer camp for children ages 6 to 17 and a therapy session not covered by insurance.

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WESTCHESTER, NY

The branch held its third annual luncheon and fundraiser to raise money for STAR Awareness. The event raised more than $7,000 which was matched dollar-for-dollar, so that over $14,000 was raised for research. Branch Leader Bev Wurzel says they have already started the process of looking for a bigger venue for next year’s event.

PORTLAND, OR

Members discussed speakers, transportation and Awareness Month at the October 15, 2015 meeting. Everyone present expressed an interest in having speakers at meetings. Members also discussed how to get members from outlying areas to the meeting location, either through carpooling or providing rides to those who need them. Warren Bless pointed out the branch’s (CMT) Project thin Ankle looking at the wonderful research that’s going on, efforts 1A, 2A, 4. Branch Leader Debbie McGahey shared a terrific fundraising idea with the group—a birthday party fundraiser for her husband Peter’s 70th birthday that raised over $4,000 (and counting) for the CMTA. The next meeting will be held on January 21, 2016.

NASHVILLE, TN

Guest speaker Teresa Blake from GeneDx gave a wonderful presentation on genetic testing. Penny Powers, a physical therapist from the NIH Beta-Pri Rehabilitation Institute at Vanderbilt Medical Center, and Dr. Renne Brown, Chair of the School of Physical Therapy at Belmont University, gave an update on their research project involving walking and said that they will be able to see from children in the age of 8 and up. The group agreed to have next year’s Awareness Month Walk on September 23, 2016, at the same location—Long Hunter State Park.

CHEAPEAK, VA

Dr. Eric Jeffries, DPM, FACFAS, a podiatrist from Atlantic Orthopedics-Specialties, was the guest speaker at the branch’s November 6, 2015, meeting. She had a number of suggestions for members, including:

• Use light weights to strengthen your muscles. Repetition is important.
• Heavy-duty strength training is NOT recommended.
• Stand at your kitchen sink/counsellor with your toes propped up on a mat or rolled towel. This strengthens the muscles and relieves stress on the balls of the feet.
• Consider physical therapy every three years as your feet continue to change.

This will help you learn how to walk on your “new” feet.

• Wearing support hose/socks helps provide information to the brain, helping to stimulate the nervous. Shoe inserts that “bring the floor up” to your foot also provide the brain with additional information as do gloves.

RICHMOND, VA

This new branch met for the first time on November 17, 2015. Founder David Collins encouraged everyone to join the CMTA to gain the benefits of the newsletter and other resources. One of the branch’s goals is create an active Resource Directory to share information about various providers with CMT expertise. David also reminded members that during the holiday season they can make “automatic” donations by designating the CMTA as the recipient when making purchases through smile.amazon.com, iggle.com and Goodsearch.com.

SOUTHEAST WISCONSIN

Ten members, including three new ones, gathered on December 5, 2015, to hear Stacey Hank, health care services coordinator for the Southern Wisconsin Muscular Dystrophy Association. According to Stacey, the Wisconsin branch sponsors summer camps for kids, has a lending “library” of durable medical equipment and has MDA-sponsored clinics in Madison, Milwaukee, Green Bay and Marshfield, it can also help with fuel and repairing medical equipment.

RACHEL RIVLIN

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in Florida. After buying a house in Sarasota County, they spent five months painting it, sold their house in Boston, and moved to the Suncoast State for good weather. Shortly after moving, Manuel found a CMTA support group in nearby Tampa Bay that they attended for four years. It was a wonderful thing to do all day, but they both enjoyed attending the meetings led by branch leader Vicky Polyoca.

After four years, Rachel began thinking it would be nice to have a support group closer to home and started a branch. She hosted the first meeting of the Sarasota, FL CMTA Branch on February 22, 2014. They now go to 25 people at each meeting, depending on the season. On November 14, 2015, Rachel helped organize the First Annual Sarasota, FL CMT Walk and Roll. The event featured a walk across the beautiful Ringling Bridge. Unfortunately, there were 40 mph wind gusts on the day of the walk and while some were able to walk across, some of the folks on scooters could not. The 2015 walk was held on November 7 at the Sarasota Square Mall, where wind was not an issue. With the help of a branch matching challenge, the event raised almost the entire amount raised last year, which was $12,000 for the CMTA.

Rachel has enjoyed being a branch leader. She has met many people and has learned a lot. On October 27, 2015, she was interviewed on the Sarasota ABC affiliate television station before the branch’s Walk and Roll. Now she is a bit of a local celebrity with strangers stopping her and exclaiming that they saw her on TV.

Thank you Rachel for all that you do for the CMTA and CMT Awareness!*

THE CMTA REPORT

CMTA BRANCH NEWS

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THE TRIBE OF THE THIN ANKLES

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There’s a new volume on the CMT bookshelf. Written by Baltimore Branch Leader Clark Semney, “The Tribe of the Thin Ankles” is a compilation of profiles of individuals who are doing amazing things despite their CMT. Available on Amazon.com, the book includes profiles of Pat Livney, Jeana Sweeney, Elizabeth Ouellette, O’Donnell James, Cynthia Zain and lots of other CMT activists, athletes and scientists.

One customer reviewer on Amazon said, “If 1 in 2500 people have CMT, then 1 in 2500 people—plus their families and friends—would benefit from this book. Semney’s collection of stories of people living with CMT is inspirational without being maudlin and conveys some complex information in a way that is easily understood. “The Tribe of the Thin Ankles” is written with humanity and humor, and I highly recommend it for any one touched by CMT”.

All profits from sales of “The Tribe of the Thin Ankles” will go to the CMTA. Those not wishing to make purchases on the internet can contact Clark directly at ClarkSemney360@gmail.com.
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.