THE CMTA Report

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

JANUARY/FEBRUARY
2013

CMTA
Charcot-Marie-Tooth Association

OUR MISSION:

To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

OUR VISION:

A world without CMT.

EMAIL CMTA AT:
info@cmtausa.org

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Join the Warfield Family in the CMTA STAR Pathways $25 Million Campaign

BY MISSY AND SETH WARFIELD

Do you stumble? Are your hands and ankles weak? Do you have high arches? Are your lower legs skinny? These are buzzwords that mean more to those with Charcot-Marie-Tooth disorder than to others. To our family, they reflect three generations of life and struggles with CMT.

It is one thing when the diagnosis is about oneself, but our whole outlook changed when our two children were diagnosed. We joined the CMTA. We supported the CMTA with our donations. Missy wrote articles for the Association's newsletter. When two of our six grandchildren were diagnosed as toddlers with CMT1a, we felt a different call to action. It was an urgent call to do something to help those who daily live with CMT and to encourage more research through donations to find the cure.

> Our whole outlook changed when our two children were diagnosed.

We started a support group for those with CMT and their families and friends who live within 50 miles of our hometown, Easton, MD. We had learned from the CMTA that there are more than 250 people within that area who struggle daily with CMT. People have come to our meetings from Delaware, from over an hour south of us on Maryland's Eastern Shore, and from across the Chesapeake Bay. Only after meeting those who came to the group did we realize that we truly were not alone. We all share the same issues and frustrations. We are all hoping for a miracle for our children and theirs.

As a mother, and one with some guilt for having passed CMT to our children, Missy has always strived to set an example of what can be done. She played tennis until she could not even manage doubles, then she took

(continued on page 5)

INSIDE:

The CMTA's corporate partner Aetrex is offering new members a pair of free shoes. See page 9 for details.

DEAR CMT COMMUNITY:

Since 2012 has drawn to a close, I would like to reflect on the past twelve months and, looking forward, tell you about the promising and exciting new year.

It has been my honor and privilege to serve as the CEO of the CMTA. The women I work alongside (Jeana, Susan, Kim, Pat, and Elizabeth), day in and day out, work tirelessly to educate, engage, and energize the very people who will be essential for making the first treatment of CMT a reality—you. The world-class scientific team, led by Drs. Shy, Scherer, and Svaren, continues to push the translational research which is producing some early promising results. Our accomplishments are nothing short of amazing:

★ Despite a distracting election year, the CMTA surpassed last year's record year in fundraising.

★ STAR (Strategy to Accelerate Research) has identified compounds that downregulate PMP22 both in vitro and in vivo.

★ Support and Action Groups have grown to 53 in 40 States, with Canada and Mexico now aboard.

The CMTA is funding a record amount of research:

★ Two full-time specialists at the NIH focused on high-throughput screening and assay development.

★ Dr. David Chan at Cal-Tech focused on creating Type 2 cellular assays.

★ Dr. Stephan Züchner at the University of Miami focused on creating a Type 2 rat model.

★ Dr. John Svaren at the University of Wisconsin focused on Type 1 and Type 2 cellular assays.

★ Dr. Anita Bhattacharyya at the University of Wisconsin focused on human induced pluripotent stem cell assays.

★ Dr. Klaus Nave and Dr. Michael Sereda at the Max-Planck Institute, Germany, focused on in vivo testing of compounds for Type 1.

★ Dr. Rudolf Martini, University of Wurzburg, Germany, focused on a stem cell pilot rat study for Type X.

★ Dr. Ronald Liem, Columbia University, focused on creating cellular assays for Type 2E.

To complement the ongoing research, the CMTA has added Dr. Lawrence Wrabetz, University of Buffalo, a world-renowned expert on CMT, and Dr. Mark Scheideler, Founder, Humanfirst Therapeutics, to the STAR team. Mark will help guide the CMTA's drug development path forward, helping to forge the necessary partnerships with the pharmaceutical industry in 2013.

Most importantly, the STAR process, namely replicating the various types of CMT in cellular assays suitable for high throughput screening of compounds, followed by animal model confirmation, ultimately leading to an approved treatment drug, has been proven valid by the Cystic Fibrosis Foundation. Their first FDA-approved drug for treatment of a devastating genetic disease went on the market this year, and was discovered using a similar process to the one that the CMTA calls STAR.

I'd like to close by imploring everyone to reach out to all the contacts they have. Talk about CMT. Ask them to make a difference. Spread the word! Contribute to a movement under way that absolutely will be successful and will prove so meaningful to CMT patients around the world.

I hope you all had a great holiday season with your family and friends!

I cannot wait to see what progress is in store for the CMTA in 2013!

—Patrick A Livney, CEO

Be the Change

A Profile of Support and Action Group Facilitator, Joyce Steinkamp

The first time a doctor recommended disability to me was in 1998. As an orthopedic surgeon, he could reposition the forefoot and straighten the toes, but not too much could be done about the arthritic pain. I opted for the surgery and pain medication to keep me on the job. With the orthopedic surgery on my feet, I did much better than anyone ever expected.

I altered my original dream of becoming a nurse because of all the walking involved, and I became a perfusionist. Running a heart-lung machine used for open-heart surgery with my CMT was no easy task. When I found I was slower at assembling the maze of tubing needed for the surgery, I'd get to the hospital earlier and time myself to get faster. When some of the clamps were harder for my hands to open and close, those were the ones I knew I had to take with me to occupational therapy and practice with. Many said I would never be able to do the job: too small, too weak, too quiet. With a reputation like that, I never made it common knowledge that I had CMT. I might have to work harder, but nothing worth having ever came easy. My mom taught me I could do whatever I set my mind to. I figured she ought to know—my mother has CMT, too.

Working in cardiovascular medicine for 13 years was a dream come true. I knew I was doing important work as part of a team that was really good. We worked really well together, learning each other's strengths and weaknesses. I learned that everyone has weaknesses, but that if we worked as a team the weaknesses were almost negligible. And with the occasional adrenalin rush when a life was critically on the line, my physical weaknesses hardly existed at all. I could physically do things I would never dream of attempting routinely.


Joyce has amazing success with her hobby of growing flowers.

It was when administrative changes forced us to do more intricate and risky operations that my career got too difficult. Longer hours in a day, more patients in a day, and more hours worked on call, all increased the stress of an already stressful position. The stress that once gave me an adrenalin rush was more commonplace every day and night; weekends, too. The adrenalin was there, but now I was maintaining myself on it. I found myself in greater pain and with more weakness and clumsiness in my hands. I was forgetting things outside of work as if they never happened at all. I was now only beginning to see what the doctors were talking about.

The big game changer came on September 11th. Yes, that September 11th, 2001. That single event forced many people to look at life differently, and I was one of them. For the two years before that, I was trying to "beat" my CMT. The morning the towers came down in New York, I was in the operating room with a patient on the heart-lung machine. When we were told it was an attack, our department prepared for power outages. But we were okay so we went on to the next patient. When I left for the night, it was the end of another 18 hour day. I fell asleep on the couch as my roommate began to tell me of the day's events. I didn't have any energy to care with. And I hadn't been out of the operating room all day so I didn't even know what she was talking about.

Flights were grounded. No supplies were being flown to us. Surgeons were angry that they couldn't operate because we didn't have what was needed. Every day for a week we did one surgery at a time, while the other team hit the phones to some other hospital within driving distance to lend us supplies. Longer days, even more stress. A week after the tow-

(continued on page 12)

THE CMTA IS EXCITED TO LAUNCH STAR PATHWAYS, a fundraising initiative to deliver the first treatments of CMT. For the first time in history, we have reached major milestones with proven success and the sequential steps to drug delivery are mapped out. The $25 Million STAR Pathways campaign will result in the delivery of real results to the CMT population. For more information, visit www.cmtausa.org

CMTA PATHWAYS

THE WARFIELD FAMILY

We have learned a lot since becoming involved with the CMTA, especially as support group facilitators. I learned that my story is typical of those living with Charcot-Marie-Tooth disorder. My parents had no idea why I couldn't run or why I kept twisting my ankles or tripping. I was diagnosed with CMT when I was a young teenager growing up in Washington, DC.

I was blessed that my orthopedist was a family friend who was Chief of Orthopedics at the George Washington University School of Medicine, Dr. John P. Adams. Over the years, he did all that was then known to offset the muscles weakened by CMT: surgery to transfer tendons in ankles, feet, and knees for stability. All this surgery enabled me to lead a fairly normal, if not athletic, life. The "down times" of surgeries, casts, and crutches seemed endless. Today, very little surgery is done except in extreme cases. Instead, regular stretching and exercise are encouraged.

In time, Dr. Adams sent me to the NIH where, under the guidance of neurologist Dr. King Engle, I was observed and tested by Dr. John Griffin. (Dr. Griffin, then in his neurology fellowship, later rose to become Chief of Neurology at Johns Hopkins University School of Medicine.) He told me to "push" my body, but not to do so to exhaustion. Those are tough instructions for a young mother with children two and five. But "push" I did, often to exhaustion, and today nearly forty years later, I still push! It was Dr. Griffin who diagnosed our two children with CMT1A when they were in elementary school.


Missy and Seth Warfield have issued a generous challenge grant to advance STAR research.

Along the way, as my ankles and legs grew weaker, I went through the trials of orthotics and bracing—some of my own creation! Remember that I was a young mother with growing children who shared many of my CMT issues. I struggled to remain strong and positive so that they would. We all know that we must be our own advocates, and, sometimes, it seemed that none of the doctors "heard" my pleas. Surely, they did not understand how frustrating and exhausting dealing with CMT could be.

Finally our orthopedic surgeon, Dr. Joel Schiffman, sent me to California to be seen by a well-known ankle/foot surgeon, Dr. Roger Mann, who worked with CMT patients from around the country. It was a long and exhausting trip to Oakland, but it was there that they stood me on top of the X-ray table and film plates to finally see how the pressure from my high arches to the balls of my feet really did cause stress. Eureka! It was progress, but it meant going home for more surgery. Although our son also has had major ankle/foot surgery, we vowed that our children would not undergo such pain and anxiety if at all possible.

None of us with CMT runs. Our family sports have been water-oriented. We swim; we love the beach; we sail. Both of our children rowed crew in college, training on "ergs" instead of running. Our son's hobby is cycling, and he rode across the United States on the "Big Ride" to benefit the American Lung Association—from Seattle to the Mall in DC!

CMT STORY

He is a pediatrician who went into medicine because of his interest in CMT. When he can find time as the father of three little ones, he cycles in the Washington, DC, area and recently rode a "Half Century" (50 miles) in the Maryland hills.

Our daughter and her husband have three energetic girls, ages 9 to 14. We worry that one of them will be diagnosed with CMT one day. They now play soccer and softball, and one is a year-round swimmer. Only time will tell. Their Mom plays no sports, but has walked the Avon Walk for Breast Cancer from Baltimore to Washington, DC (60 miles!). In addition to walking three miles daily, she walks benefit 5Ks and does her part as a stroke-and-turn judge for swim meets. She also rallies the elementary school children as the costumed school mascot, in spite of her past knee surgeries.

I have progressed from orthotics to SAFOs to Toe-Off Blue Rocker (knee high) braces. They enable me to walk with less effort and fatigue and are made so that I can wear my own, fairly lady-like, flat shoes. I use a cane for balance on uneven surfaces, longer walks and in crowds. Our little "grands" wear orthotics in their shoes, but neither our son nor our daughter wears any bracing. Sadly, I fear that their day will come.

Our faith rests on the CMTA-funded Centers of Excellence at teaching hospitals across the country and the research funded through its STAR program to help us all out of the mire. We all hope for a world without CMT.

—*Missy Warfield*

Heather (Warfield) with her husband Ron and their three girls joined Amy and Peter Warfield and their two children in 2011 for a race for charity.

WARFIELD CHALLENGE

(continued from page 1)

up golf until that was not feasible. She pushed to set a "can do" example. Her mantra has been that she and our children may have been hampered by weak legs and hands, but they have been given a multitude of other gifts: good minds, a great spirit, and a loving family.

Our hearts broke when our children could not play sports in school—they "managed" teams to stay with their friends, but it was not the same. Instead they made us proud as class leaders and student government officers. They led, and they participated. We travel; we volunteer; we live normal lives, and we are blessed. But, it is not always easy!

Now, we want to pave the way for those who have been, and may someday be, diagnosed with CMT. We have learned that it is possible that with a bankroll of $25 million the CMTA can fund the final necessary research to cure CMT1a within the next three-to-five years. Already, there are advanced projects in the works at the NIH and around the world.

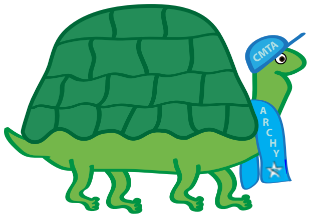
Because of this exciting forecast, we have decided to make a pledge of $150,000 to the CMTA. We will match donations up to that amount and challenge others to build on it from now through June 30, 2013. We want to fulfill the CMTA's mission and our dream of "a world without CMT." We ask that you join us! To donate, please go to www.cmtausa.org/url/warfieldchallenge. ★

Hitting the Skids!

Usually at this time of the year, I talk about all the fun and festivity of the holiday season. But, this time, I have a real problem that I've been dealing with that I think might affect all of you who read my articles. We had the horrible hurricane or "storm" Sandy around here in the middle of October. We are still trying to get our homes back together after that disaster, and we were lucky enough not to suffer as much damage as some of the people in New York and New Jersey.

But, hot on the heels of that problem has come the winter we never seemed to get last year. We have already had freezing rain and icing problems, and that's what I want to talk about. I have four feet, so you would think that I would be pretty gifted at walking on icy patches….but you would be SO wrong.

If anything, it seems like the two extra feet just give me more of a sliding potential. In winter, I feel like I'm trying to steer a toboggan without the protection of actually having one under me. Since my mother is noticing more and more issues with her CMTX, we decided to get some advice on how to stay upright rather than becoming airborne when walking on icy paths.



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

The first piece of advice, which I got at a local support group, was to avoid wearing my sneakers when the potential for slipping presents itself. Apparently, sneakers are especially slippery when wet. One suggestion for still being able to wear your sneakers in the winter would be to buy something like a "crampon" which is a traction device to improve mobility on snow and ice, sort of like the old chains that humans used to put on their car tires in the winter to keep them from sliding. With them, you can, according to their manufacturers, walk across glaciers, ascend snow slopes, and climb frozen waterfalls. Since none of those are things we really need to do, we need a more simplified version. Ultra Snow and Ice Cleats are sold at Amazon.com, and they just pull on over your regular shoes. They fit all flat-heeled casual shoes and sneakers. They only cost $17 from Amazon and they can be lifesavers in icy weather.

The other option for walking more safely is to use a cane or some kind of walking stick. While I prefer not to use such devices because I don't walk upright and because I'm kind of young to need that type of support, lots of older animals in Greenwoods use them. When it comes to safety, we should try not to be too vain because falling and breaking bones is a real threat to our health. They do have some very cool types of canes, and one of the big dogs in the neighborhood has a cane with cat pictures all over it. I think that's what my English teacher would call "irony."

My mother tries to make me wear lots of extra clothing to pad me if I do fall in bad weather, but that just makes me look really goofy. So, this year, I'm going to get good boots with traction on the bottom and a pair of snow and ice cleats to keep in my locker at school so I'm safe no matter when the storms hit. I hope you will, also, take care at this time of the year. ★

LAWRENCE WRABETZ JOINS BOARD OF DIRECTORS

Dr. Lawrence Wrabetz is Professor of Neurology and Biochemistry and Director of the Hunter James Kelly Research Institute at the University at Buffalo. His research laboratory has worked for over 20 years on the formation and repair of myelin. He is particularly interested in how different disease genes cause inherited demyelinating neuropathies, and his lab has developed and characterized multiple mouse models of Charcot-Marie-Tooth Type 1 neuropathies. By introducing authentic CMT mutations from patients into these mice, they strive to reveal the mechanisms of disease, to investigate potential avenues of therapy, and to create the opportunity to test resulting medicines in preclinical trials for CMT. Dr. Wrabetz has also diagnosed and treated children with diseases of myelin, and his experience with these children has motivated him to find better ways to translate his lab's research into therapies as rapidly as possible—the very same goal the CMTA has.

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CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, P.O. Box 105, Glenolden, PA 19036.

Honorary Gift:
In honor of (person you wish to honor)
____
Send acknowledgment to:
Name:____________________________
Address:__________________________
____

Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____
Send acknowledgment to:
Name:____________________________
Address:__________________________
____

Amount Enclosed: __________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card #____________________________
Exp. Date _________________________
Signature _________________________

Gift Given By:
Name:____________________________
Address:__________________________
____

Youth Outing at the Chicago Patient/Family Conference

My name is Mike Pepoon, and I am a 25 year old from Chicago living with CMT Type 2A. I recently had the great pleasure to go on a CMTA sponsored outing with other young people who also have CMT like myself. This outing took place immediately following the conclusion of the CMTA Patient and Family Conference on November 10th, 2012, in Chicago, Illinois. I have to say that I was very much looking forward to this event since I have not had many opportunities before to meet other young people who also are affected with CMT.

We first set off to a local video arcade where we all had a splendid time playing games with one another. Afterwards, we all decided to sample some traditional Chicago-style pizza at a restaurant nearby.

Marko, Sean, Jonah, Mary, Andrew, Mike, Flannery, Bethany, Reagan, Tyler, Thomas, and Matt at Lou Malnati's Pizzeria in Chicago, IL.

Being a native Chicagoan, I was very glad to see everyone enjoying the sights and sounds that my hometown had to offer.

During the outing we all had a chance to share our personal experiences and to address the challenges we've all faced coping with our disability. It was quite reassuring and comforting to discover in our conversations that we had all come across very similar difficulties and obstacles in our lives in dealing with our condition. We discussed topics ranging from relationship and dating concerns to issues surrounding school and family life. It was such a dream come true to finally be in the company of other people my age who understood what it was like to struggle with CMT each and every day. Unlike many of my non-disabled peers, they all could relate to the hardships that come along with having a physical disability such as CMT. That was so refreshing for a change.

When it eventually came time to say goodbye to my new-found friends, I was a bit downcast since everyone would be returning to their separate parts of the country. But, I knew that we all had wonderful memories from the time we spent getting to know each other on that day.

I would certainly encourage other young people with CMT to participate in, and get involved with, their local CMT support groups. I hope to see the CMTA continuing to promote different activities and programs that are focused on young people with CMT with the goal of helping them connect and build long-lasting friendships. If anyone would like to contact me, I can be reached at Mike1987010@yahoo.com

Lastly, I would very much like to thank Bethany Meloche who helped organize and make this event possible. ★

NEW CALIFORNIA CLINIC OPENS

Cedars-Sinai Medical Center, Los Angeles, California, will open a multi-disciplinary clinic for the evaluation and treatment of patients with Charcot-Marie-Tooth Disease (CMT) and other inherited neuropathies in February 2013. Under the direction of neurologists, Robert Baloh, MD, PhD, and Richard Lewis, MD, and orthopedic surgeon, Glenn Pfeffer, MD, the clinic will include a physical therapist, genetic counselor and orthotist. Patients and families will be evaluated for diagnosis, treatment, and counseling. Patients of all ages can be seen and multiple family members can be seen at the same time.

Appointments can be made at 310-423-4CMT (4268). **Inquiries** can also be sent to clinic coordinator: Tami Kendra-Romito at tami.kendra@cshs.org or Dr. Lewis at Richard.lewis@cshs.org

ELIZABETH'S BIRTHDAY WISH: A DREAM CAME TRUE

In November, I set up a Birthday Wish Challenge Match on Facebook, where my husband Gilles and I promised to match all donations up to $50,000. Thanks to so many of you, news of this fundraiser spread throughout the CMT community. I sent out the original post and a video with a reminders to give to CMTA research (STAR), and you all stepped up to the plate, making this the most successful fundraiser in which I've taken part. I not only received many wonderful comments, emails, Facebook shares, posts and one beautifully written song, but also donations ranging from $10 to $10,000 came rolling in from supporters across the globe.

Thanks to the participation of friends, family, dedicated Support and Action Group facilitators and members, my Birthday Wish did indeed come true! I am thrilled to report that we surpassed the original $50K goal and exceeded all expectations by raising more than $100,000 (with our match) for the STAR initiative!

As you have read in this newsletter, Missy and Seth Warfield are kicking off the New Year with a generous matching gift campaign of their own.

The outpouring of generosity, participation and support has been overwhelming, and I would like to express my sincere appreciation to all who donated their time, energy and money to my campaign. Thank you for ending 2012 on such a positive and upbeat note.

The New Year brings promise as STAR is making remarkable progress. As the CMTA continues advancing research and spreading awareness, you, our members, are the shining stars of this Association.

—*Elizabeth Ouellette*

New CMTA Membership Policy

The CMTA is pleased to announce that a new Premium Membership has replaced the previous Premium Content Subscription Plan. The fee for Premium Membership is $30/year.

Thanks to the generous support of Aetrex Worldwide, we are able to offer an exciting promotion in 2013. Every NEW Premium Member in 2013 will receive a free pair of Aetrex shoes! If you purchase your Premium Membership online, a coupon for a free pair of shoes will be emailed to you. If you become a Premium Member by calling the CMTA, a coupon will be mailed to your home address.

If you already had a Premium Content Subscription, you are now a Premium Member. You are eligible for a 50% discount on every pair of Aetrex shoes. Go to aetrex.com or call 1-800-526-2739 and give them the coupon code of CMT50.

If you need help finding shoes, Aetrex has created a catalog specifically for the CMT community at www.cmtausa.org/aetrexcatalog. If you prefer to talk with someone, the entire customer service department has been trained about CMT, so feel free to talk to them about your shoe fitting needs. If you have family or friends who are not Premium Members, tell them about the great offer from Aetrex and the benefits of being a Premium Member of the CMTA.

Thank you for being a part of our community! If you have any questions, please call Aetrex at 1-800-526-2739 or send an email to info@cmtausa.org. ★

Unregistered site visitors, registered members, premium members, and professional members will have access to the following content on the CMTA website as indicated:	Membership Level			
	Unregistered	Registered	Premium	Professional
	FREE	FREE	$30	$100
General content, including:				
• News	✓	✓	✓	✓
• Resource Directory	✓	✓	✓	✓
• CMTA Store	✓	✓	✓	✓
• Latest Research	✓	✓	✓	✓
• CMT Clinicians	✓	✓	✓	✓
• I Have CMT	✓	✓	✓	✓
• My Child Has CMT	✓	✓	✓	✓
• About the CMTA	✓	✓	✓	✓
• What Is CMT?	✓	✓	✓	✓
• Centers of Excellence	✓	✓	✓	✓
• Medications List	✓	✓	✓	✓
• Diagnosing CMT	✓	✓	✓	✓
• Ask the Experts	✓	✓	✓	✓
• Helpful Products	✓	✓	✓	✓
• Share Your Story	✓	✓	✓	✓
• eNews Alerts	✓	✓	✓	✓
The CMTA Online Community, including:				
• CMT Support and Action Groups		✓	✓	✓
• Discussion Groups		✓	✓	✓
• Circles of Friends Groups		✓	✓	✓
• CMT Athletes Groups		✓	✓	✓
Free Info Kit		✓	✓	✓
Member Downloads		✓	✓	✓
Premium Content, including:				
• *The CMTA Report* (PDF)			✓	✓
• The CMT Facts Series (PDFs)			✓	✓
• CMTA Therapy Videos			✓	✓
The CMTA Report (printed copy via mail)			✓	✓
Editable Resource Directory Listing				✓

Starry Night Art de Cure Gallery Reception Raises over $9,000 for CMT

The Upstate NY Support and Action Group held its second Starry Night Art de Cure gallery reception on December 7, 2012, hosted by David and Elizabeth Misener at Clinical Prosthetics and Orthotics in Albany, NY. Guests enjoyed complimentary wine, cheese, appetizers, and desserts, while browsing through original art including acrylics, framed photography, watercolors, mixed media, and oil paintings. There was also a silent auction of quilts, hand-crafted jewelry, silk scarves, gift cards, wine baskets, baby blankets, books, an autographed Giants football poster, and more!


Art de Cure volunteer Nichole Alonzo with her husband and grandson.

In addition, four Disney World Hopper tickets were raffled off along with a 50/50 raffle. Carey Ahner of *The Bear Bones Project* entertained with his guitar. To help create CMT awareness, there was a poster for the event along with a large sign that read “Funny Name...Serious Disease—Charcot-Marie-Tooth disorder,” with copies of *The CMTA Report* and CMTA brochures on tables decorated with blue stars and balloons.

Friends, family, and neighbors came out on a cold, rainy night to support the event. Organizers announced the winner of the Disney raffle, Laurie Leal, and lucky bidders headed home with their loot. The group had hoped to match last year’s total, and we exceeded that amount, with matching funds for Elizabeth Ouellette’s birthday wish.

We want to thank our sponsor M&T bank and our corporate donors, Fresh Market, Price Chopper, and Cascade Orthopedic Supply. Also, thanks to the artists, families, and friends, who contributed items for the silent auction and our volunteers: Donna & Rich Piche, Nicole Alonzo, Joanne Van Genderen, Miranda Rand, and Jessica Cameron. Lastly, thank you to group member, Christine Hook, gallery coordinator, Jackie Watsky, and all of Art de Cure for making this event possible.

Art de Cure, a collaboration between art and medicine, showcases art in the community to benefit a cure. Galleries are housed in medical practices, where the work of regional artists is on display. The host practice chooses the charity that will benefit.

To find out more about setting up an Art de Cure gallery in your area visit: www.artdecure.org

—Melinda Lang,
Upstate NY SAG Facilitator

EVERY DOLLAR COUNTS


Jason Wurzel

Master Paul Kim and staff at the United Tae Kwon Do Center in Manhattan, New York work hard to help their students build self-esteem, respect for each other, and the desire to help those less fortunate. Prior to every class, the students chant the Tae Kwon Do (TKD) Code which includes; helping one another and standing by the weak. In order for the younger children to understand this, Master Kim gives each child $1.00 at his or her belt ceremony. He explains why helping is so important, and that each child should donate the $1.00 to a charity (and not use it for toys). Jason Wurzel, age 9, has chosen to donate his money to the CMTA. He hopes that children with CMT will be able to attend such wonderful programs as United Tae Kwon Do. He sees first-hand how CMT impacts one’s daily life, as his grandmother, Beverly Wurzel, lives with CMT. He hopes that future research can include the impact of TKD programs for children diagnosed with CMT.

Cultivating the Qualities You Want in 2013

Psychotherapist David Tannenbaum writes the column "What's On Your Mind? Ask David." Rather than answering questions this issue, he writes about his own plans to improve himself in the New Year. His column will return in the next issue. Write to David at info@cmtausa.org.

I'm not much for resolutions because it's such a bummer when I can't quite discipline myself enough to follow through on them. But I was thinking about what I could improve within myself, and I came up with a few things. First and foremost, I would like to stay more in the moment and project less into the future. I need to catch myself when I begin to make up stories about what might or might not happen to me. I want to be less critical of myself when I do make the stories up, and just smile and make the observation that I'm doing it again.

I hope to breathe more deeply. I especially need to breathe more deeply so I can tell myself that nothing is that important in the long run. I want to catch moments of beauty when I can and get out of my head so I can recognize those moments.

I plan to tell people I love them more, and, of course, feel small moments of gratitude whenever I can. Like today, I caught a taxi immediately and didn't have to wait a second! That's something to be grateful for.

I want to excercise more, eat better, and stay active, and stop complaining! Above all I want to be kind not just to the people who I am close to but everyone I come in contact with. Okay, I think I have some stuff to work on for 2013!! What about you? ★

DONATIONS TO CMTA "CIRCLES OF FRIENDS"

If you are interested in creating a fundraising Circle of Friends or want your family or friends to donate money to the CMTA on behalf of your birthday, anniversary, or special occasion, please let Jeana Sweeney know! You can email Jeana at: jeana@cmtausa.org. Working together, we can create a world without CMT!

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Ms. Laura Davis
Electronic Office Products, Inc.
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JOYCE STEINKAMP

(continued from page 3)

ers collapsed, so did I.

It had been two years since I was first advised to leave perfusion. I had tried a few different positions in patient care at the hospital, but there was always some physical obstacle I just couldn't overcome.

September 17th I collapsed in the O.R. director's office. I told him there was so much work to do and nobody else to fill in—we all were working 18 hour days on a regular basis. And I told him I was not coming to work the next morning so I could examine my options as far as full-time disability because of my worsening CMT.

In the weeks that followed I learned more about the attacks our country had sustained. The crash at Shanksville, PA was not far from where I grew up and where my family still lived. But, when I wasn't working, I was literally too exhausted to enjoy friends, family, or even vacations away from work. It was through that tragedy and so many testimonials about the vulnerability of that one day that I realized money and status as a "success" didn't matter much if you didn't have the capability to take care of your health enough to enjoy your life.

I would be giving up my life's dream. Was I letting CMT win? I was sure that would be my mother's view. I was sure my family would be disappointed. I wanted more than anything to find just one person who was around my age (35) with CMT who could really understand where I was in my life and what I was considering.

I had many doctors' appointments to try and get as much information about my future as possible. But doctors frequently don't understand enough about CMT to predict its future course in their patients. I learned a great deal about stress and its deleterious effects on a healthy nervous system, and more so on my CMT-compromised nervous system. I ultimately decided to leave my career, apply for disability, and focus on gaining back my health.

> September 11th forced many people to look at life differently, and I was one of them.

It would be a good nine months before I could say I no longer felt exhausted and felt compelled to do something with myself. I had attended a CMT support group in Johnstown, PA, which was a three and a half hour drive from Erie, and met many people with CMT, some of whom were like myself. It was amazing to see so many people just like me willing to talk about CMT and ask questions! I started to realize that I had a great deal of experience with CMT and surgery, and my difficulties at work, and applying for disability. I had experience with much of the information people were asking about.

It would be a few weeks before I called the facilitator of that meeting, JD Griffith, on the phone, to ask about how to even start a support group. He was so easy to talk to, and held so many of the same ideas and opinions that I had. He encouraged me to contact the CMTA to find out if there would be enough people with CMT in my area to form another support group in Pennsylvania. I sent an email to Pat Dreibelbis, and she and I worked on the zip codes of the areas that I wanted to serve with my group. She would conclude that there were indeed enough people in the CMTA's database that it should be successful, and she recommended announcing it in the newspaper and distributing flyers to doctors' offices.

Slowly I began receiving phone calls from people who were interested. One such call came from a 37-year-old woman who actually lived only five blocks away from me! We met for dinner, and spent three hours just amazed at how alike we were. She encouraged me to form the group, offering her help in whatever I needed to get it going. In our conversation I learned that she was originally from Johnstown, PA! The planets were all coming in line for the formation of a CMT support group in Erie, PA.

We had about 35 people attend our first meeting, which included a Power Point presentation on CMT by JD Griffith. People were so anxious to learn about this disease they had. JD brought a young woman with him named Jeana Sweeney, and the two of them presented the information together. Our first meeting was a great success, and Erie now had its own CMT support group.

(continued on page 15)

CMT Support and Action Groups in Your Community

AL—Birmingham Area
No group currently meeting
Will accept calls
Dice Lineberry
205-870-4755

AZ—Phoenix Area
Arizona CMT Support and Action Group
Pamela Palmer
480-926-4145

CA—Santa Barbara Area
Ventura-Santa Barbara, CA CMT Support and Action Group
Steve Fox
805-627-8225

CA—Stockton
Stockton, CA CMT Support and Action Group
Nina Anselmo
209-460-1716

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
Laurel Richardson
814-404-8046

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—North Haven
North Haven, CT CMT Support and Action Group
Lynne Krupa
203-288-6673

DC—Washington, DC Area
Washington, DC CMT Support and Action Group
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Orlando Area
Central Florida CMT Support and Action Group
Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area
Tampa Bay, FL CMT Support and Action Group
Vicki Pollyea
813-251-5512

FL—West Palm Bach
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
Susan Ruediger
678-595-2817

IA—Great Lakes
Iowa Great Lakes and SW MN Regional Virtual CMT Support & Action Group
Daniel Bachmann
507-399-0592

IA—Iowa Area
Iowa City, IA CMT Support and Action Group
Jeffrey Megown
319-981-0171

IL—Chicago Area
Chicago Area CMT Support and Action Group
Dale Lopez
708-499-6274

IN—Fort Wayne Area
Fort Wayne—Indiana CMT Support and Action Group
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

KS—Wichita Area
Kansas Area CMT Support and Action Group
Karen Smith
316-841-8852

KY—Burlington Area
Pam Utz
859-817-9338

MD—Easton
Easton, MD CMT Support and Action Group
Missy Warfield
Seth Warfield
410-820-0576

ME—Portland Area
Portland, ME CMT Support and Action Group
Celeste Beaulieu
207-284-1152

MI—Chesaning Area
Chesaning, MI CMT Support and Action Group
Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area
Southwest Michigan CMT Support and Action Group
Jori Reijonen
269-341-4415

MN—Benson Area
No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area
No group currently meeting
Will accept calls
Libby Bond
417-845-1883

MS—Mississippi/Louisiana
Clinton, MS CMT Support and Action Group
Flora Jones
601-825-2258
Cindy Chesteen
601-668-5439

NC—Durham Area
North Carolina CMT Support and Action group
Susan Salzberg
919-967-3118

NJ—Central New Jersey Area
Central New Jersey CMT Support and Action Group
Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NJ—Morris County
Morris County, NJ CMT Support and Action Group
Alanna Huber
973-933-2635

NM—Albuquerque Area
CMT New Mexico CMT Support and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area
Las Vegas, NV CMT Support and Action Group
Jerry Cross
775-751-9634
Virginia Mamone
702-343-3572

NY—Horseheads Area
Horseheads, NY CMT Support and Action Group
Angela Piersimoni
607-562-8823

NY—Long Island Area
Long Island, NY CMT Support and Action Group
Shari Loewenthal
631-254-8960

NY—Manhattan Area
New York, New York CMT Support and Action Group
Barbara Abruzzo
212-473-4157
Amanda Imbriano
516-680-2981

NY—Upstate New York Area
The Upstate NY CMT Support and Action Group
Melinda Lang
518-783-7313

NY—Westchester Area
Westchester, NY CMT Support and Action Group
Beverly Wurzel
201-224-5795

OH—Cleveland Area
Cleveland, OH CMT Support and Action Group
Heather Hawk Frank
440-479-5094

OH—Greenville Area
Greenville, OH CMT Support and Action Group
Dot Cain
937-548-3963

PA—Bucks County Area
Bucks County, PA CMT Support and Action Group
Linda Davis
Mitch Davis
215-943-0760

PA—Johnstown Area
Johnstown, PA CMT Support and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319

PA—Northwestern Area
Erie, PA CMT Support and Action Group
Joyce Steinkamp
814-833-8495

RI—East Providence Area
Rhode Island CMT Support and Action Group
Meredeth Souza
401-433-5500

SD—Hartford Area
Hartford, South Dakota CMT Support and Action Group
Serena Clarkson
605-838-2331

TN—Nashville Area
Nashville, TN CMT Support and Action Group
Bridget Sarver
615-390-0699

TN—Savannah Area
Savannah, TN CMT Support and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area
Dallas, TX CMT Support and Action Group
Whitney Kreps
972-989-5743
Merissa Lovfald
214-394-8907

UT—Orem Area
Orem, UT CMT Support and Action Group
Melissa Arakaki
801-494-3658

VA—Harrisonburg Area
Anne Long
540-568-8328

VA—Williamsburg Area
Williamsburg, VA CMT Support and Action Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area
Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WA—Tacoma Area
Tacoma, WA CMT Support and Action Group
Carol Hadle
253-476-2345

WI—Brodhead Area
Southern, WI CMT Support and Action Group
Molly Hawkins
608-921-0032

WI—Milwaukee Area
Southeastern, WI CMT Support and Action Group
Polly Maziasz
262-439-9009

WV—Vienna Area
Parkersburg /Vienna WV Support and Action
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

CAN—Montreal
Montreal (Canada) CMT Virtual Support Group
www.cmtausa.org/url/montrealsag

CAN—Ontario
Southern Ontario CMT Action & Support Group
Kelly Hall
519-843-6119

CAN-Montreal
Montreal (Canada) CMT Virtual Support Group
www.cmtausa.org/url/montrealsag

MEXICO
(This group will be in Spanish.)
México CMTA Grupo de Apoyo y Acción
Gina Salazar
Gina_oviedo@hotmail.com

VIRTUAL/DISCUSSION GROUPS
Anyone Can Fundraise
Archy and Friends Discussion Group
Boston South Shore Voice Discussion Group
CMTAthletes
CMT Speaks
CMT and Anger Discussion Group
CMT and Fatigue Discussion Group
CMT and Occupational Therapy Discussion Group
CMT and Pain...Share Your Experience Discussion Group
CMT Creates: Music Project Discussion Group
CMT1x or Cx32
Emotional Support For CMT Discussion Group
Genetics and CMT
Global Support and Action Group Community
Hand and Finger Struggles with CMT Discussion Group
Insurance and Benefits Discussion Group
Marijuana and CMT Discussion Group
Musicians with CMT
Parent with CMT who are raising kids with CMT Discussion Group
The CMT Outdoorsman Discussion Group
Trigger Points Discussion Group
Walking assistive devices

Most Support and Action Groups, Virtual Groups, and Discussion Groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups.

If there is no support group in your area, consider becoming a facilitator!
If you're interested please contact Jeana Sweeney at jeana@cmtausa.org.

Avoiding Falls in the Hospital

BY BRUCE EGNEW (FORMER MARYLAND SUPPORT AND ACTION GROUP LEADER)

On several occasions, for non–CMT related hospitalizations, I have given this little handout to Admitting, Pre-op, doctors, floor nurses, and others, and made sure they provided it to the Recovery Room staff. It usually triggers a conversation like "I've never heard of that. "Tell me more about it." "How did you get CMT?" They are very grateful for the information. Teachable moments help build CMT awareness within the medical community. They take CMT into consideration when treating me, and I have a safer and better outcome. I prepare this handout ahead of time. It is unique to my situation, but each person can prepare something similar and feel more secure about his or her hospital stay.

MY NAME and DATE OF BIRTH
NAME OF PRIMARY DOCTOR and HOSPITAL
DATE OF PROCEDURE and NAME OF PROCEDURE

1. I am a FALL RISK.
2. I have Charcot-Marie-Tooth disorder (CMT).
3. CMT is a progressive neurological disorder that causes me to have:
   a. Peripheral neuropathy and pain in the extremities
   b. Irregular and unsteady gait
   c. Poor proprioception
   d. Poor balance
   e. Weakness in feet, ankles, calves, and thighs
   f. No reflexes and very little sensory feedback in the feet and ankles
   g. Very slow transmission of signals from brain to extremities
   h. Extremely cold feet (not legs, but FEET)
4. Because I am tall and have poor ankle and leg strength, I should be in a bed that is at least 26", and preferably 28", above the floor. I am more at risk of falling from a low bed than from a high bed because I don't have the strength to lift myself off of a low bed.
5. I will be slower than most patients to walk after waking up. Anesthesia and pain medications delay my ability to resume normal mobility.
6. I should not walk until I am alert enough to tell you that I am ready to walk. I know when the signals are transmitting to my legs and feet. I will not attempt to walk unless I feel steady enough.
7. I will walk with an unsteady shuffle and a slap step and will have difficulty turning in different directions or navigating around equipment, doors, curtains, etc.
8. I cannot walk with both an IV pole and a cane. I will fall. I need one hand free to steady myself. I am a "wall walker."
9. Please keep my feet very warm. Not my legs, my FEET.
10. CMT does not affect blood pressure, respiration, or pulse, and does not cause dizziness or fainting.

Attached you will find a summary description "What is CMT Disorder" and "Medications List", both from www.cmtausa.org, which has other helpful information about CMT.

SOCIAL WORKER JOINS ADVISORY BOARD

ELIZABETH K. MISENER, PHD, LMSW, is a licensed master social worker in New York State. She provides coaching on a wide range of issues such as depression, stress management, anxiety, life-work balance, and relationships. As a trained social worker, she supports individuals on their journey of self-discovery through self-reflection and goal setting.

Among Elizabeth's areas of specialization are helping people to improve relationships, reduce stress, encourage personal growth, enhance parenting skills, facilitate decision making, manage time, bolster motivation, clarify objectives, and develop concrete, attainable goals. She has been trained in the technique of Problem Solving Therapy, which is an evidence-based short-term intervention for people struggling with depression.

Elizabeth and her husband David are the proud parents of two young boys aged 8 and 6. Her husband was born with CMT 1B, and many of his immediate family members also have CMT 1B. Ethan, her 8 year old, was also born with CMT 1B. She is excited to be part of the CMTA community.

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JOYCE STEINKAMP

(continued from page 12)

That was 11 years ago, and we're still meeting bimonthly at the public library on Erie's bayfront. Our attendance varies and seems to be greater when we have a speaker making a presentation. In the past it has been difficult to get professionals to speak at our group. But that has significantly changed with the commitment of the CMTA, for which I am immensely grateful. This past year we secured a grant from our local Sam's Club so that we could cover the expenses to bring Dr. Shy to one of our meetings. That was my support group dream-come-true, and it was, not surprisingly, very well attended.

We have our handful of regulars, and generally our attendance is small in number. But in 11 years, I have yet to have any meeting where no one showed up. I have learned that on the occasion where only one person came, that person had something on his mind that he would not have otherwise shared and gotten feedback on. I am constantly amazed at the way things "fall together" to give us the information we need just when we seem to need it most. And that goes for me as a facilitator as well; I get just as much support from our group as I hope each of our members gets from our meetings.

Two things always guide me as a facilitator for a CMTA Support and Action Group—Ghandi's quotation that we must be the change we want to see in the world, and the belief that the things that make us most different are our gifts to the world. A world without CMT is the change we ultimately want to see, and sharing our CMT differences is how we will get there.★

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THE CMTA Report

The Charcot-Marie-Tooth Association
P.O. Box 105
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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)
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
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

WHAT IS CMT?

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