THE CMTA Report

NOVEMBER/DECEMBER
2010

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community * www.charcot-marie-tooth.org

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@charcot-marie-tooth.org

Researchers Gather to Discuss CMT Type 2 Direction

BY PAT DREIBELBIS

From November 10-12, thirty-five researchers who specialize in CMT Type 2 met in San Diego, California, to discuss the status of their personal research and to make plans regarding the most likely form of CMT on which to collaborate. The workshop was entitled, "Defining Therapeutic Approaches to CMT2."

The meeting began with a welcome from CMTA CEO David Hall and a brief talk by Chairman and President of the CMTA Board, Patrick Livney, who introduced many of the investigators to the work of STAR, the Strategy to Accelerate Research, and the CMTA's ongoing relationship with NIH and their high-throughput screening lab. The first presenters all discussed axons and axonal degeneration to supply the background needed before possible "corrections" could be considered for the Type 2 forms of CMT.

Stepan Zuchner, from the University of Miami, discussed the pathophysiology of CMT2A in cell and animal models. Type 2A is the most common form of axonal CMT, affecting about 20% of CMT cases. They have indentified mitochondrial fusion factor 2 (MFN2) as a cause for CMT2A. However, the MFN2 knock-out mice they created showed no signs of neuromuscular disease and died in utero. Therefore, the need to create a good mouse model for the axonal neuropathies is imperative. Based on the success of the mouse model for PMP22, a mouse model should lead to promising results for future treatment of the Type 2 forms of CMT.

Dr. Ronald Liem, of Columbia University, discussed CMT Type 2E. Mutations in the neuronal intermediate filament gene, *NEFL*, have been shown as a possible cause for Type 2E. Mutations in this gene are responsible for approximately 2% of all CMT cases. It is believed that inhibitors of neurofilament misassembly will lead to therapies for CMT. Therefore, the goals of Dr. Liem's research group are to identify small molecules that inhibit misassembly and to test their effects in a mouse model of CMT2E.

Another group of researchers discussed less common causes of CMT2 such as GARS, YARS, FIG4, and TrpV4.

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TURTLE LOVERS GATHER IN FLORIDA: ***Jeana Sweeney, dressed as Archy's sister, Tara, posed with the Cooterfest official turtle in Inverness, Florida.***

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CMT RESEARCH DIRECTION

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Finally, Jim Inglese, from the NIH's Chemical Genomic Center, discussed high-throughput screening, and dosage versus gain of function approaches. Then, the group learned about the "Valley of Death" and the challenges of bringing candidate medications to successful therapies.

The final day revolved around summaries from the various investigators and their discussion groups and questions and answers from the attendees as to the probability of success in each strategy. The discussion was lively and probing.

As with most of the consortiums I have attended, the overwhelming feeling of this meeting was that there are amazingly committed and brilliant minds working on CMT Type 2 research. In the elevators, at the breaks, and at the meals, the talk was always about someone's presentation and how an idea they proposed might work in someone else's plan. Consortiums really are a time for devoted researchers to learn about the work of others and to share their discoveries so that the whole world of CMT research can move forward constructively. ✻

Organized by Dr. Michael Shy and Dr. Steven Scherer, thirty three distinguished researchers gathered in San Diego, California, to discuss how best to proceed with research on Type 2 forms of CMT.

RESEARCH ABSTRACT

Reversal of neuropathy phenotypes in conditional mouse model of Charcot-Marie-Tooth disease type 2E

(from Hum Mol Genet. 2010 Jul 1;19(13):2616-29. Epub 2010 Apr 26)

Dequen F, Filali M, Larivière RC, Perrot R, Hisanaga S, Julien JP.
Research Centre of CHUQ, Department of Psychiatry and Neurosciences, Laval University, Québec, Canada.

Mutations in the gene encoding for the neurofilament light subunit (NF-L) are responsible for Charcot-Marie-Tooth (CMT) neuropathy type 2E.

To address whether CMT2E disease is potentially reversible, we generated a mouse model with a conditional doxycycline-responsive gene system that allows repression of mutant hNF-LP22S transgene expression in adult neurons. The hNF-LP22S;tTa transgenic (tg) mice recapitulated key features of CMT2E disease, including aberrant hindlimb posture, motor deficits, hypertrophy of muscle fibres and loss of muscle innervation without neuronal loss.

Remarkably, a 3-month treatment of hNF-LP22S;tTa mice with doxycycline after onset of disease efficiently down-regulated expression of hNF- LP22S and it caused reversal of CMT neurological phenotypes with restoration of muscle innervation and of neurofilament protein distribution along the sciatic nerve.

These data suggest that therapeutic approaches aimed at abolishing expression or neutralizing hNF-L mutants might not only halt the progress of CMT2E disease, but also revert the disabilities. ✻

Joe Paterno Nominated for Presidential Medal of Honor

Senator Robert Casey (D-PA) is seeking the support of his fellow members of the United States Senate to join him in nominating Penn State football coach and CMTA spokesman Joe Paterno for the Presidential Medal of Freedom.

The Presidential Medal of Freedom is a decoration bestowed by the President of the United States and is—along with the equivalent Congressional Gold Medal bestowed by an act of Congress—the highest civilian award in the United States. It recognizes those individuals who have made "an especially meritorious contribution to the security or national interests of the United States, world peace, cultural or other significant public or private endeavors." The award is not limited to U.S. citizens, and, while it is a civilian award, it can also be awarded to military personnel and worn on the uniform.

Senator Casey's letter *(right)* will be sent to every member of the United States Senate seeking their support. We need your help—please contact your senator (email, letter, phone) and ask him/her to support Coach Paterno's nomination. You can find your senator's contact information at the following link (www.senate.gov).

Coach Paterno has been a tireless advocate for charitable causes during his legendary career, and the CMTA is honored to have him as our spokesman. ✻

President Barack Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

We are writing to request that you consider Penn State University football coach Joe Paterno for the Presidential Medal of Freedom given his substantial contributions to collegiate athletics, higher education and American society.

Coach Paterno's accomplishments on the football field are nothing short of legendary. His 396 career wins, amassed during his 44-year tenure at Penn State, are more than any other coach in Division I history. He has coached five undefeated teams, two national championships teams, won three Big Ten conference championships, and has been named "Coach-of-the-year" five times by the American Football Coaches Association.

While these numbers are unrivaled, his contributions to society beyond the field of play are even more noteworthy. Under Coach Paterno, Penn State's football program is consistently ranked by the NCAA as among the best in the nation for graduation success rate. Fifteen Hall of Fame Scholar-Athletes, forty-four Academic All-Americans, and 18 NCAA Postgraduate Scholarship winners are evidence of his dedication to helping his players excel in both athletic and academic endeavors.

Coach Paterno and his family have also made monetary donations to the University that have benefited all students at Penn State. These contributions, which total more than $4 million, include their donations to the University Library, which named a wing in their honor. It is common for a university to name a field of play after a coach that has contributed immensely to that institution's athletic program. Coach Paterno's name is on the library because he has contributed immensely to academics at Penn State.

Coach Paterno's dedication to charitable causes is also remarkable. He has contributed to the State College community in substantial ways, including a $1 million donation to Mount Nittany Medical Center for the construction of a new 42,000-square-foot wing. Coach Paterno is a strong supporter of the Special Olympics of Pennsylvania, and he and his wife Sue were inducted into this organization's Hall of Fame in 2008. Coach Paterno worked closely with Bob Casey, Sr. in the 1970s to support Easter Seals' efforts to help individuals with disabilities and special needs. He is also a national spokesman for The Charcot-Marie-Tooth Association. This organization raises awareness about Charcot-Marie-Tooth (CMT) disorders, which is the most commonly inherited neurological disorder.

Awarding the Presidential Medal of Freedom to collegiate coaches is not unprecedented. Two coaches with comparable success in their sport have been awarded the medal: Paul "Bear" Bryant and John Wooden. Joe Paterno's celebrated accomplishments on the field and his significant contributions off of it make him worthy of joining these coaches as recipients of the highest civilian award of the United States government.

We recognize that this award recognizes meritorious contributions to the national interests of the United States. Coach Paterno's work exceeds this standard by a considerable degree. Throughout his time at Penn State, this man has shown tremendous character and loyalty to which we all can aspire and has remained committed to reaching goals without sacrificing the ideals that are central to higher education. The content of his character, along with his contributions to college athletics, higher education, and charitable causes, make Joe Paterno deserving of the Presidential Medal of Freedom.

Thank you for your consideration of this matter.

Awareness Week 2010: Our Volunteers Shine

BY ELIZABETH OUELLETTE

The breeze, the trees, the honey
bees—All volunteers!
—Juliet Carinreap

Members and friends of the Albany, NY, Support and Action Group helped raise money with a fundraising event at TGI Friday's restaurant. From left to right: Cheryl Traeger, Rich Piche, Donna Piche, Joe Pingielski, Kathy Pingielski

The idea of an awareness week was planted during a May 2010 conference call with the CMTA's support and action group facilitators (SAGFs). We were discussing our frustration about the lack of knowledge and basic understanding of CMT among the general public and health professionals alike. "What about a CMT Awareness Week?" one of our leaders inquired. With that one comment, the seed was planted and the idea rooted, blossoming into the first National CMT Awareness Week, September 19-25. It will become a perennial event, changing the face of the CMTA for years to come.

From May 2010 through September 2010, our network of nation-wide SAGFs worked with undeterred passion and commitment to create a CMT awareness campaign from start to finish. Planning innovative and creative programs to successfully spread CMT education and understanding during the designated week in September, our CMTA team (CEO David Hall, SAGFs, CMTA family and friends, CMTA staff, and our publicity firm, Gatesman, Marmion, Drake, and Dave) went into a full strategizing mode with energy and enthusiasm.

In addition to creating a CMT Awareness Week micro-website (www.wearethecmta.com), where members uploaded their pictures, signed the signature board, and interacted with the week's on-line events, we also came up with CMTA Awareness Week posters, postcards, and flyers for distribution. We mailed out CMTA personalized items (STAR necklaces, balloons, bracelets, Archy stickers, and buttons), available to both CMTA facilitators and members, to draw attention to CMT, this little-known disease, affecting so many people, in so many different ways.

What our members and friends accomplished, under the guidance of our team of SAGFs, before, during, and after Awareness Week is truly commendable. In honor of Awareness Week, our association sent out more than 2600 posters, 7000 postcards, and 15,000 brochures. Our committed facilitators took charge, not only making sure these materials were posted and distributed for public consumption, but also organizing a wide-array of activities: fundraisers, information booths at local health care centers, media-related events, letter-writing campaigns to state representatives, and school outreach programs.

In addition, a few facilitators took on special projects: Dick Kutz (CO) created a SAGF collage, Gretchen Glick (CA) took on Awareness Week organization and various community outreach projects, Susan Ruediger (GA) managed the popular email chain letter, Karen Smith (KS) rallied members around the Archy the Spokesturtle contest, and Mark

Willis (NJ) undertook Facebook's profile picture initiative. Moreover, a round of applause is in order for radio personality Shadoe Stevens, who graciously volunteered his time to be the voice of the CMTA throughout the week. Thanks to Ruth and Alan Korowitz, the CMTA partnered with Clear Channel, who aired the Shadoe Stevens public service announcement across the country and ran CMT Awareness Week banner ads on each of its radio station's websites.

On the following pages, you will read more about the people who took action, uniting across the country toward one common goal: a world without CMT. The CMTA is fortunate to work with such a dynamic and passionate group of individuals, willing and able to make the world a better place for all those with CMT. Personally, I would like to send my profound gratitude and a sincere thanks to each and every one of our facilitators, members, and friends who gave contributions of time and energy, successfully bringing the first national CMT Awareness Week to fruition.

As Vicki Pollyea, a SAGF from Florida recently wrote in a well-crafted letter to her state Senator, Representative Kathy Castor, "Of course the goal is for a world without CMT but first we have to make the world aware of CMT! Perhaps with this ongoing grassroots campaign, we can change peoples' *awareness* of what CMT is."

And we've only just begun. The foundation has been set. In 2011, CMT organizations from around the globe will join the CMTA to dedicate the month of September to CMT awareness. My hope is that you will join the 2.6 million people worldwide who have CMT, giving the world's most commonly inherited peripheral neuropathy the recognition it deserves. ✻

The Support and Action Groups that went above and beyond the call to promote CMT Awareness were:

California – Santa Barbara and the Tri-Counties

Awareness Week included six days of harvest wine tasting at Bella Cavalli Farms and reached nearly 600 people. A "Glee for CMT" fashion preview sold out to 200 people for the second rehearsal. At the final performance, an anonymous donor pledged $25,000 if Macy's will match that. Gretchen Glick spoke to three Rotary groups and contacted 15 independent radio stations who agreed to air a public service announcement for two weeks.

California – Los Altos

The group held a very successful garage sale at leader Elizabeth Ouellette's house. They placed collection jars in local stores with the tag line, Time for Change, Fund STAR. They also walked around their neighborhoods putting up Awareness Week posters.

California – Visalia

Melanie Pennebaker contacted local newspapers and ended up getting articles in four local papers. She sent the CMTA press release, pictures of her family, and a picture of the CMTA poster, as well as her personal story of living with CMT.

Colorado – Denver Area

In conjunction with Awareness Week, the support group held a fundraiser at Chad's Grill in Lakewood, CO. Diners who brought the CMTA's flyer with them, had 20% of their purchases contributed to the STAR program to continue the goal of creating a world without CMT. Additionally, the *Times Call* published a story about a group member, Marianne Nyman, who related her journey with CMT and the journey of getting a diagnosis. Diane Covington, the Denver CMT SAGF, also contributed to the article by describing the loss of sensation and how it resulted once, in a dark movie theater, of her stumbling and falling right into an unknown man's lap. They also wrote to the governor informing him about Awareness Week and had one member, Jonah Berger, compete in a triathlon, along with orthotist, Sean McKale.

Florida – Tampa Bay Area

Group leader Vicki Pollyea had two articles about CMT published in the Tampa Bay Area. She also was able to get a

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Support Groups participate in Awareness Week

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In North Carolina, Susan Salzberg, Jeanne Gresko, and Lee Lichtenwalter staffed a booth at a local shopping center to raise awareness and educate people about CMT.

response from her Representative, Kathy Castor, who read into the United States House of Representative's Congressional Record information about Awareness Week and CMT which Vicki had written for her. Representative Castor finished her presentation to the House by saying, "Raising awareness about CMT through CMT Awareness Week will help to educate communities about this disease and help to find a cure for this disorder."

Georgia – Atlanta Area

The group started by visiting doctors' offices and leaving Awareness Week posters and support group postcards. Five doctors chatted with members about CMT. On Thursday, group members set up an information booth at Children's Heathcare of Atlanta. Many nurses, parents, patients, and caregivers stopped by for information and a STAR necklace. Several nurses who came by were excited to be able to share CMT information with their doctors. The week ended with a group picnic attended by 20 members. The group enjoyed a BBQ lunch and good conversation about each other and CMT.

Illinois – Chicago Area

The Walk and Roll for the CMTA took place on Saturday, September 25th. Before the walk started, we enjoyed donated doughnuts and bagels, and coffee and hot chocolate served by Starbucks. The pavilion was decorated with balloons and CMT awareness posters. CMTA Chairman Patrick Livney gave an inspiring speech before the group headed out, and a physical therapist put the group through stretching exercises. The walk was through a beautiful paved wilderness area. After the walk, hot dogs were barbecued along with Polish sausages. Dan Lopez played the guitar while people enjoyed the barbecue.

Kansas – Wichita Area

Karen Smith, the facilitator of the group, held a balloon launch to bring attention to Awareness Week. The group also manned an information booth and distributed posters throughout the area.

Kentucky – Burlington Area

Pam Utz did outreach to area schools by using the CMTA T-shirts and other awareness materials to help her explain about her daughter's CMT. She also provided information that would help the schools know more about having a student with CMT in the classroom.

Maryland – Hagerstown Area

Jeff Martin and his group planned and held a scrapbooking event to raise funds for the CMTA. He promoted the event on Facebook and encouraged people in his area to support the event. The group also handed out Awareness Week materials and hung posters in local stores and hospitals.

Nevada – Las Vegas Area

The Archy Train, driven by Jerry Cross, appearanced at area fairs and festivals. Additionally, the group participated in the MDA's Stride and Ride and took part in the Pahrump Fair and parade.

New Jersey – Central NJ Area

The highpoint for the group was the Dine to Donate night. Applebee's in Bridgewater, Flemington, and Lacey, the T.G.I. Friday's in Freehold and Marlboro, and the Stirling Diner in Stirling, provided a percentage of each dinner ordered to the STAR program. The members were able to reach hundreds of people and raise funds as well. Members also mailed postcards to their own medical communities and hung posters in medical centers, supermarkets, and libraries. Lastly, Archy the turtle did a lot of sightseeing around New Jersey and New York.

New York – Upstate Area

The upstate New York group raised $885 from a T.G.I. Friday's Awareness Week fundraiser for STAR. They had an informational table set up where they handed out brochures and sold magnets, bracelets, and STAR necklaces. They distributed posters to 30 hospitals and pharmacies. Letters were written to medical practitioners, local newspapers, health journals (one was published), and local radio stations. Melinda Lang has spoken about living with CMT to a class of physical therapists at a local college for the past three years.

North Carolina – Triangle Area

The members of the North Carolina group set up an information table at The Shops at Eastgate and had CMT brochures to hand out along with an easy CMT quiz for people to take. Nearly 40 people stopped by in the three hours they were there. A man who worked at an adjacent Rite Aid store stopped by and said that CMT runs in his family and he was looking for resources.

Heidi Welch, Whitney Kreps, Stewart Kouba, and Patti Bennett volunteered at a booth at the University of North Texas during Awareness Week.

Pennsylvania – Johnstown

To kick off Awareness Week in Johnstown, the support group and Jeana Sweeney did a balloon release at the top of the Johnstown Incline Plane. They also set up a booth at the Conemaugh Neuroscience Center where they handed out CMT brochures and free items from Awareness Week. Many local radio stations broadcast information about CMT. During the week, Jeana attended her daugther's preschool and handed out postcards and STAR necklaces for the children to wear during the week.

Tennessee – Savannah Area

The group had a booth at the Trail of Tears motorcycle event. They also had tables at the ECM and Helen Keller hospitals. During the entire week, they had a display at Sunset Trust Bank to help raise understanding of CMT.

Texas – Dallas Area

The group headed by Whitney Kreps set up a two-day event at the University of North Texas. Three group members teamed up with Alpha Kappa Delta (an international honor society for sociology) and spoke to hundreds of students, professors, and other college employees, educating them on CMT. By selling freshly baked cookies, wrist bands and T-shirts, the group was able to raise $250.

Virginia – Williamsburg Area

The group distributed PSAs to local radio stations. They also got articles in several local daily newspapers. They also did a classroom presentation on CMT to an elementary school. ✻

The CMT "Circle of Friends"

As you can see, the past several months have been a busy time for the CMTA Circle of Friends program.

Chris Wodke ran the Fox Cities Half Marathon (www.cmtausa.org/Chris) on September 19th, and Ellen Welby reached the summit of Mt. Kilimanjaro on September 22nd (www.cmtausa.org/Ellen).

Grace's Courage Crusade held their 3rd Annual Dinner Party on September 26th, and, to help celebrate CMT Awareness Week, several other "Chicago STARs" joined Tyler's Walk, which was also moved up to the 26th and renamed the "Reach for the STARs Walk & Roll" (www.cmtausa.org/chigagostar).

Next up, Mary Louie walked the 26.2-mile Mount Desert Island Marathon on October 17th (www.cmtausa.org/Mary), and then it was time for Tyler's 4th Annual Benefit on November 5th.

And there's more to come. In 2011, Ken Gomez is going to ride from Anacortes, WA, to Bar Harbor, ME, and up to $22,000 in sponsoring gifts will be matched by the Paul Flynn Charitable Trust (visit www.cmtausa.org/kensride for more info).

Also in July, 2011, Doug Allie, who doesn't have CMT, is planning a 14-day, 355-mile run across Michigan's Upper Peninsula to help find a cure for CMT on behalf of his son Jacob (www.cmtausa.org/runacrosstheup).

Whether you walk, run, or climb or would just like to help raise funds for CMT research, you can take up the challenge and start your own Circle of Friends. It's easy. Just call us today at 1-800-606-2682, email us at cof@charcot-marie-tooth.org, or visit us on the web at www.charcot-marie-tooth.org/cof.

Working together, we can create a world without CMT!

DONATIONS WERE MADE TO THESE CMT CIRCLES:

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CIRCLE OF FRIENDS TRIUMPHS

CMTA Member Completes Half-Marathon

BY CHRIS WODKE

I am a triathlete and long-distance runner. On September 19th I lined up with 1500 other runners for the Community First Fox Cities Half Marathon. Because I was running to raise funds and awareness for CMT, I was chosen as one of the 20 "Inspiring Women of the Race" and given a special pink singlet to wear. As I toed the line, I had worries like no other runner because I also have CMT.

Chris Wodke participated in a half marathon and came away with a medal.

When I was diagnosed with CMT this year, it was actually a relief to put a name to symptoms I have had my whole life. I was always a horrible runner as a child, ridiculed for being slow. Gym class was a nightmare because I couldn't do things that other kids could do easily. When I was in college, I began to run and enter races. I loved the challenge and the competition. I took on the challenge of training for my first marathon. I began to win medals and finished four marathons. For the first time in my life, I felt like an athlete.

While I am so blessed to be able to run, the CMT does cause complications. I have extremely high arches and almost no flexibility in my legs. I have been told I don't have enough flexibility to walk properly, much less run long distance. With every stride I land on the ball of my foot and this can be very painful, especially over long distances. The foot drop I have means I must concentrate on every step to avoid tripping. Sometimes I am so profoundly tired at the end of the day that I want to go to sleep, not go out and train.

A friend recently asked me why I run. I run to preserve the athlete inside of me. For all the challenges of running, it brings me great joy. Running is a lot like life, sometimes it's painful but I can't sit on the sidelines. I run to raise money and awareness for CMT. I run to inspire others to do whatever their CMT permits. I run to find a cure because my 20-year-old niece with CMT wears braces. No young man or woman should have to wear braces.

I was able to complete the half marathon in 2 hrs and 12 minutes—20 minutes slower than I could run one only a few years ago. Sometimes I am sad because of what I am losing, but I have to remember how blessed I am to be able to run when so many with CMT struggle with everyday tasks. I am inspired by them to keep going. My next goal is to run the Boston Marathon in 2012 again to bring awareness of CMT to a wider audience. I will be training to qualify for this event over the next year. My running and other fitness activities have kept me strong. I will need this strength as I strive for my goal to qualify and run the Boston Marathon. ✻

A Final Act Raises Money for the CMTA

Mona Steward of Hernando, Florida, spent her life following her passions and doing for others. One of her goals was to honor her friends from The Thunder Inn, a biker's haunt, with a collection of their favorite recipes. The proceeds were designated to benefit the Charcot-Marie-Tooth Association.

Mona had CMT, along with congestive heart failure and cancer. She kept going despite her medical problems, but succumbed on August 22, 2010. She was very proud of the fact that she lived long enough to see the cookbooks turn a profit of $1,000. The leftover cookbooks were sold at Cooterfest in Inverness, FL in late October.

Mona was a member of the Inverness Support and Action Group, headed up by Ron Plageman, and she worked hard on the cookbook so she could leave memories of herself and bring awareness of what she suffered from. She was born in upstate New York and attended Oswego College, intending to be a math teacher. She loved the arts and often painted and photographed sunrises and sunsets. She spent her professional life with the Xerox Corporation as a graphics illustrator in New York and California.

Her mother and sister wrote of her: "Mona will always be in our hearts. She touched many with her generosity, her infectious smile, and her great sense of humor. Think of her when you see a beautiful sunset or hear a motorcycle in the distance." ✻

CIRCLE OF FRIENDS TRIUMPHS

Doing the Impossible: Climbing Mt. Kilimanjaro

BY ELLEN WELBY

I've wanted to climb Mt. Kilimanjaro since 2006. That's when I hiked to base camp on Mt. Everest and thought, what's next? But the road to Kilimanjaro has been a rocky one; plantar fasciitis, ankle surgery, and an eventual diagnosis of CMT 1B last year. If I was going to climb Kilimanjaro, my best chance of success was *now!*

The first step was finding the right route. Most tour companies take the Marangu or "Coca Cola" route in about 5 to 7 days. The day before reaching the summit you hike to the highest camp, rest for a few hours, and then get up at about 11:00 pm to hike through the night to arrive at the summit around sunrise. Then you hike back down the mountain the same day. That sounded way too grueling so I found a company that took the Lemosho /Western Breach route in 9 days. It's a bit further, and technically the most difficult route, but this route gives you more time to acclimatize, and the summit day starts at 5 am instead of 11 pm the night before. It's still a 12-mile day, but that's an improvement.

Now the hard part—training for the climb. My approach to CMT is "keep what you have strong." I don't have control over what I've lost or will lose, but I do have control over keeping what I have left strong. I work with a personal trainer twice a week. We focus on balance and core strength. I also take yoga once a week. And walk. Even if it's just a mile walk during my break, two miles after lunch, or a 6- to 8-mile hike on the weekend. I have foot drop, twist my ankles, and can trip over nothing. Hiking poles have been the best aid I've used yet. They don't completely prevent falls, but they have helped a lot.

I was fitted for leg braces before the trip and planned to take them with me, but all my test hikes caused major blisters on my heels. So I ended up leaving them at home.

I made arrangements with the tour company to have a "tough guy" porter or guide to hike with me and carry my day

---

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"Flat Archy" and Ellen made it to the summit of Mt. Kilimanjaro.

pack on the two hardest days of the hike; the day we climbed the Western Breach and the day we reached the summit. But the third day into the trip was actually the most difficult for me. It was a relatively easy day, only 7 miles and the trail was flat or very gradual incline. The elevation wasn't very high either, at around 12,000 to 13,000 feet. But my legs felt weak and shaky. Fortunately my guide took my raingear into his pack to lighten my load, and stuck with me for the hike. With every difficult step, I was thinking of all my friends and family who made donations to CMTA in support of my climb and that really helped me keep going. In the end, I arrived at camp just about 10 minutes behind the rest of the group. And I felt much stronger on subsequent days.

Many people with disabilities have successfully climbed Mt. Kilimanjaro. According to *Kilimanjaro—A Trekking Guide to Africa's Highest Mountain* by Henry Stedman:

"Every year there is at least one group of blind trekkers who, incredibly, make it to the top by using the senses of touch and hearing alone. And in January 2004 four climbers who had been disabled on previous expeditions on other mountains all managed to make it to the summit. The party consisted of Australian Peter Steane, who has permanent nerve damage and walks and climbs with the help of two leg braces; his compatriot Paul Pritchard, who has limited control over his right side; Singaporean David Lim, partially disabled in his right leg and left hand after contracting the rare nerve disorder Guillain-Barré Syndrome; and Scotland's Jamie Andres, an amazing man who had to have his hands and feet amputated after suffering severe frostbite during a climbing expedition near Chamonix, France in January 1999, and yet who made it to the top of Kilimanjaro with artificial limbs and prosthetic arms."

These are just a few of the amazing people who have climbed Mt. Kilimanjaro with major disabilities. And persons with disabilities can apply for permits that give them more time to climb the mountain. ✻

STEPPING IT UP FOR CMT

BY JEANA SWEENEY

Last week I was invited back to the Richland Elementary to do "Step it up for CMT." I left again with a great feeling of accomplishment. All the children remember me and my buddy Archy, but the greatest thing is the children were actually saying the words Charcot-Marie-Tooth Disorder and they explained CMT to me this time!

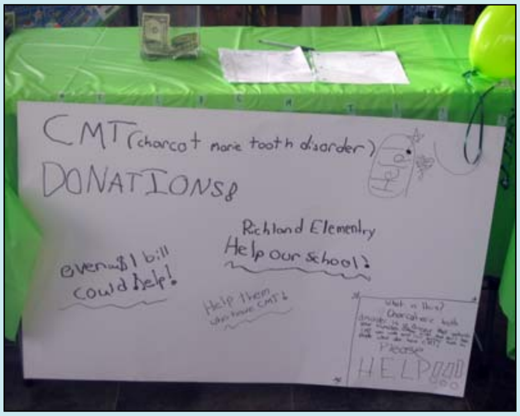
Within the last two days, I have heard three different stories about the children at Richland. A young girl approached J.D. Griffith's daughter in a store asking her for a donation for the CMTA. The school called me about a 14-year-old child going to area businesses looking for donations, and then another phone call came in about two 10-year-old girls who had set up a CMTA booth at a local store to raise money for CMT *(see picture below)*.

Keep in mind that these children had not even started stepping! These are *kids*. It's amazing to me that three different kids are giving a whole new meaning to "Stepping It Up," and who knows what the other children have planned. I wanted to share this with all of you, because it shows no matter how big or small, we can all make a difference!

I also would like to share with you some of the other things that I have been up to.

I had the pleasure of visiting three schools this month, one of them being in Kansas. I was truly honored to be asked to bring the stepping

(continued on page 18)



Archy Goes to Cooterfest

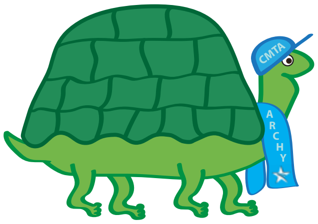
Jacqueline Dyer and Kaitlyn Mattheis (and her cat, Theo) pose with a stuffed Archy that they won in the Flat Archy photo contest.

Wow! I just got back from Florida, where it was hot and humid, but there were so many turtles! I was in heaven. I've never been so appreciated in my life. This kind of adoration could go to a small turtle's head!

We were invited to Inverness, Florida, by Ronnie Plageman, who is the support and action group facilitator down there. He began talking about going to Cooterfest when we were in Las Vegas for the Support and Action Group Facilitator's conference. Elizabeth Ouellette and Pat Dreibelbis wondered what on earth a "cooterfest" might be, and only after reading the website did they realize that it was a celebration of a turtle who saved the animals that lived on the shores of Lake Tsala Apopka.

It seems that there was a very noisy gator who had been making a terrible ruckus and keeping the animals awake. They nominated Turtle to handle the problem because he was a perfect choice (he could swim and he had a hard shell to protect him). When he swam out to meet the gator, Turtle was gobbled up, encased safely in his shell, before he could even talk to the alligator. When he thought it was safe, Turtle peeked out and saw a sharp spike from a trout's fin embedded in the side of Gator's stomach. Turtle pulled the spike out and a great roar resounded around him. Then he was thrown from the belly into the lake.

Gator felt so much better that he returned Turtle to the shore on his back, promising friendship and quiet forever. Turtle was cheered by the animals and called "Courageous Turtle" by Possum. Baby Mouse couldn't quite say that so he called him "cooter." And that was the name that stuck. Now, the Great American Cooterfestival in Inverness celebrates the little turtle with the big heart.



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

Jerry Cross drove my "Archy" train all the way from Nevada to Inverness so that the kids at the festival could ride and he could raise money and awareness about CMT. He is such a nice man! I really loved him, mostly because he really loves me and that's pretty hard to resist. He was helped by his wife Irene and his brother-in-law, Ralph. Without all of them, the festival would have been boring for the little kids. The train was a huge hit…some kids wouldn't get off the train and rode 7 times in a row.

My sister Tara came with me and she was another big hit. She's really cute and all the other bigger turtles at the fair wanted their pictures taken with her. She took the tickets when the kids got on the train ride and the little kids were really in awe of her.

Jerry Cross drove the Archy train all the way from Nevada to Florida to be able to spread awareness and provide fun for all the little kids who took a ride during Cooterfest.

CIRCLE OF FRIENDS TRIUMPHS

"Chicago STARs" Walk and Roll for CMT Research

Organized by Dale Lopez, Chicago Area support and action group facilitator, this year's Walk and Roll brought out a crowd of supporters and participants. With the help of the Chicago support and action group members, the walk raised $7,678 for CMT research.

Walkers *(green italic)* ***& Their Sponsors***

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Hill Family Reunion

I think she enjoyed being there as much as I did. Lots of people learned what CMT is from Elizabeth and Dana and Pat, who worked at the ticket booth. We even went to a support and action group meeting Sunday before the fair started and met a lot of nice people and talked a lot about CMT and what's going on with the STAR program.

All in all, I would say that the trip to Florida was pretty excellent. I didn't get eaten by an alligator (I was a little worried about that), and we accomplished a lot.

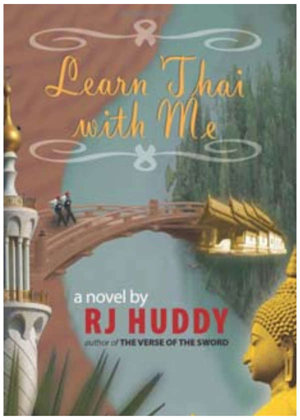
Now, I'm going to do something that I usually don't do. I'm going to ask you all to consider buying my cookbook for the kids you know. Jeana Sweeney gathered the recipes and Dana and Pat worked to get out *Cooking and Coloring Adventures with Archy* so they would be ready for the Cooterfest and the holidays. The books sell for $7 and are 75 pages in length. There are pictures of me to color and a crossword puzzle and word search that I made up all by myself. The cookbooks are on the order form in this newsletter and on the website, as well. I'll really appreciate anything you can do to help us raise money for our research efforts. ✻

Holiday Gift Ideas

Gifts that give back to the CMTA

Long-time CMTA member Jack Graves has just published a book of juvenile fiction called *One More Time* that should appeal to children in the primary grades. Allison, the "star," is a third grader who can't seem to control the urge to do some questionable activities, "just one more time." Generally, the results of her not stopping when told to are somewhat calamitous. The book is in a large format, has brightly colored pages and because of the repetition of the phrase "just one more time," it should be a good "read aloud" book. The book is available from major booksellers. The cost is $17.95.

Another CMTA member with the pseudonym R.J.Huddy, has written a second book, *Learn Thai with Me*. This book follows his previous publication, *The Verse of the Sword*. In this book, two teachers arrive in Saudi Arabia to work together at the same school. Placed as roommates, they develop a bond of friendship that eventually takes them around the world during 1980 with the newly discovered AIDS epidemic and US-backed insurgents in Afghanistan fighting to oust the Soviet Empire. The book is available from Amazon.com for $12.00.



The CMTA has available a Pandora-like bead that features the STAR for our research initiative. The bead is $20 and can be sent to you in time for holiday giving. See the website, www.cmtausa/bead for more information. This STAR bead was commissioned by the De Silva family and is also available on Amy De Silva's Facebook page, as well as directly from us.

Conceived by Jeana Sweeney, a cookbook called *Cooking and Coloring Adventures with Archy* is now available for purchase and is geared toward kids who can easily help prepare the recipes that are included. The cost is $7 and the proceeds will go to the STAR program. Lots of cool pictures of Archy to enjoy and to color are found in the book.

See the order form at the back of the newsletter.

If your fancy runs to T-shirts, mugs, stamps, and shopping bags, then you might want to visit Zazzle at www.zazzle.com/cmtaatzazzle to find those items. Designed by Jennifer Gaidjunas, the items will return a portion of the purchase price to the CMTA. Increase the amount the CMTA earns by signing up for igive.com before you shop. Zazzle gives 10% to the CMTA, but signing up for igive increases our percentage to 18%. All of these purchase help the CMTA continue to fund the STAR initiative.

Just a friendly reminder to sign up for and use igive.com, a website that sends donations to the CMTA whenever you make a qualified online purchase at no additional cost to you. Also, please tell your friends and family about igive.com. When you sign on to igive.com, choose the Charcot-Marie-Tooth Association as your charity of choice. Then, whenever you shop online, at any one of the many stores iGive features, a percentage of your purchase automatically goes to the CMTA, and it costs you nothing. It is easy, it is free, and the CMTA benefits enormously. If you are not familiar with iGive, go to: http://www.charcot-marie-tooth.org/PDF/iGive.pdf to learn more.

Happy holidays and thanks for supporting the CMTA. ✻

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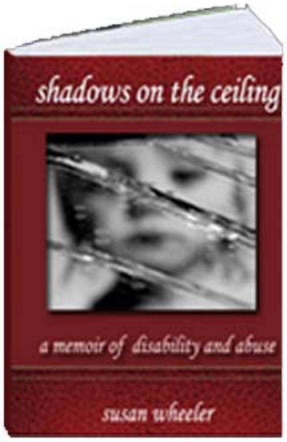
BOOK REVIEW

Shadows on the Ceiling—a memoir of Disability and Abuse

by Susan Wheeler



For many children, shadows on the ceiling created by the smiling man in the moon or night lights mean comfort, protection, and safety. Susan Wheeler, however, was not so lucky. Not only was Susan diagnosed with Charcot -Marie-Tooth neuromuscular disease, but she found no comfort, security or protection in the "shadows" she saw. Family secrets were burdensome for this child and developed unspeakable responsibilities. Driven by an inner grace, Susan forged ahead, inspired by a strong will and a deep inner light.

In her memoir, *Shadows on The Ceiling*, Susan writes with clarity of resilience against all odds in her life. Alcoholism, betrayals, physical disability, and sexual abuse at age eleven colored her world, in which a palate of "secrets" was always kept. The greys, the browns, the blackest darkness and despair left Susan struggling in an adult world, while she was still so small.

This is a brilliantly written, unforgettable story of the life of a physically disabled and abused child, determined to claim her own destiny against impossible odds. Susan's narrative discusses a life with shocking secrets that offers a glimpse into the dark recesses of our human culture.

Moments of lightness pervaded her young life with her friend "Muggle," but Susan knew that her favorite doll should not see the darkness coming and would hide Muggle for his own protection. No one, absolutely no one, could protect Susan. She was left on her own to find a job to support herself before she was legally able to work. With true grit and determination, Susan rises to the challenge of that first job and the others that follow with courage, grace, and persistence to protect herself, thus developing a deep inner reliance to move forward and honor her feelings of despair.

—*Gretchen Glick*

This book is available at www.shadowsontheceiling.com
The author's website is www.susanwheeleronline.ca

CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

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Happy 50th Anniversary!
Flora and Billy Jones

Olivia
Mrs. Rosemarie K. Burda

NJ CMT SAG
The Stirling House Diner

In Appreciation for all you do! Dr. Michael Shy, Carly Siskind, Lindsey Miller, Shawna Feely
Jonah Berger, Marilyn Berger, Steven Weiss, Harriet Weiss

STEPPING IT UP FOR CMT

(continued from page 11)

program to Kansas. Up until the family met me, they had never met anyone else with CMT, so my being there not only brought awareness in their community, but also comfort to their family.

GE Aviation in Durham, North Carolina held their Second Annual CMTA golf outing. More than 80 employees of GE golfed this year, and many put their own money into the lunches, prizes, and gift bags. I had the pleasure of attending this outing with Dave Hall.

I would like to point out that there is no CMT in the GE Aviation plant. They are doing this because one of their employee's family members has CMT (my brother-in-law). So remember it can never hurt to ask your employer for a little love.

ASK THE DOCTOR

Dear Doctor,

Currently I have an off and on again very irregular heart beat. Testing shows mildly refluxing mitral and tricuspid valves by ultrasound, PACs by event monitor, and a normal cardiolite stress test to a heart rate of 84 bpm. I also have GERD and severe varicose veins with valves that also reflux. My question is twofold: Can CMT (my type CMT 1 A) cause valves in numerous body systems to reflux? And do conduction issues in the heart relate to my kind of CMT.

Dr. Steven Scherer answers:

To the best of my knowledge, there are no cardiac (or stomach) problems associated with CMT1A.

Dear Doctor,

My neurologist is thinking about having me try Ampyra for my CMT. Are others using this drug?

Dr. Louis Weimer answers:

Ampyra is the brand name for the drug, 4-aminopyridine (4-AP) that blocks a subset of potassium channels. Although there are theoretical reasons why 4-AP might help conduction in other demyelinating diseases besides multiple sclerosis (the disease for which it was recently approved), such a benefit was not found in the one paper that investigated this possibility.

Dear Doctor,

My daughter just had soft tissue surgery of the left foot for CMT. The anesthesiologist recommended a nerve block as part of her anesthesia and sent her home with ropivacaine 0.2% administered by peripheral nerve catheter. He said it was safe and would help control her pain, which it did. It stayed in for 48 hours. Is it really safe? Are there any long-term effects we need to look for?

Dr. Louis Weimer answers:

The nerve block should have no higher complication rate in CMT patients than in others. I am not quite sure what she means by the peripheral nerve catheter—it might be an epidural anesthesia. The anesthetic is not a significant concern, assuming that there is proper care of the catheter itself.

Dear Doctor,

My wife has been prescribed injections of Boniva. Since she has taken two shots, she has not been feeling well. Is there something in the shot that is bad for her CMT?

Dr. Louis Weimer answers:

We have had many questions about Boniva. There are no CMT-related problems, but there are many side effects of taking the drug and those should be addressed with her treating physician.

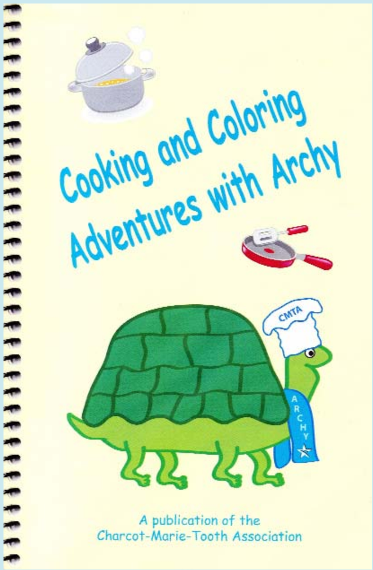
Dear Doctor,

This year the flu shot is combined with the H1N1 shot. Is that safe for CMT patients to take?

Dr. Louis Weimer answers:

The flu shot is a common question that is problematic to answer fully. The shots are more of a concern in patients with acquired immune neuropathies such as CIDP. My opinion for CMT patients is generally that the flu is a real concern and is potentially harmful. Also, the bedrest associated with the flu can cause muscle disuse that can set patients back considerably. However, the risk of worsening from the vaccine is very small. Thus, the small risk is heavily outweighed by the significant benefit.

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



NEW!

Cooking and Coloring Adventures with Archy is a new publication which combines fun recipes that parents and kids can do together with puzzles and objects to color on many pages. It's an easy book for a child to make his/her own.

Archy has written the foreword to the book in which he remarks that the best thing about cooking is that it gives him the time to be with his family working together. Some of Archy's favorite recipes from the book include Shoo-fly pie, Ants on a log, Archy's favorite salad and Archy's not so favorite, Mock Turtle soup.

The book is 8 inches by 5 inches and contains 75 pages. It sells for $7.00 and has a glossy wipe-off cover.

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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)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

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

Negligible or doubtful risk:
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Amitriptyline
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Lithium
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What is CMT?

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