THE CMTA Report

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

NOVEMBER/DECEMBER
2011

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.

TRANSITIONS:
A New CEO and a New Chairman

Former CEO Dave Hall began his career with the CMTA in 2008 after being enticed by the enthusiasm and passion of Patrick Livney. “It didn’t take me long to realize how easy a job that was going to be—easy because I represented a staff, a Board of Directors, and a medical team whose commitment to the CMTA’s mission rivaled that of Pat Livney; and easy because the CMTA was fortunate enough to have a national membership comprising people who genuinely cared for one another and were determined to find solutions for the many challenges that existed. Three years later this organization has touched more people than ever before, and has also advanced the scientific understanding of CMT Type 1A to a point where the discovery of real treatments is no longer a dream, but a soon-to-be reality. I have recently made the decision to resign my position as CEO and accept a position in the healthcare investment sector, a business I was in earlier in my career. As many of you know, I am married with three young children, so this career move was something I had to do in the best interest of my family.” Dave has accepted a position on the Board of Directors and will continue his work with STAR and the pharmaceutical companies.

Patrick Livney will direct the CMTA’s efforts as Chief Executive Officer.

Patrick Livney has assumed the CEO role that Dave had. Pat is familiar with this role, having

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CMT Clinic at Wayne State Relocates to University of Iowa

Dr. Shy and the CMT Clinic that has been at Wayne State University in Detroit, Michigan, since 1996 will be moving to the University of Iowa in Iowa City, in February 2012. Dr. Shy and his team are excited about the move, since it will not only allow them to continue the clinic as it has been organized since 1996, but it will also enable the team to serve patients and their families at an even higher level. The clinic will remain multidisciplinary—combining patient care, genetic counseling, physical therapy, occupational therapy, and orthopedic expertise. The clinic will continue to care for children with CMT. It will also continue to focus on research directed toward testing and developing therapies for patients with CMT. Hopefully, patients from all over the United States and the world will continue to visit Dr. Shy at the new location. For the time being, the contact person will remain Lisa Rowe (313-577-1689) at Wayne State. As soon as there is a scheduling person at the University of Iowa, that information will be made available. ★

Doug Allie and his sons in Wisconsin prior to his run of Michigan’s Upper Pennisula. ***See page 10***

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NEW LEADERSHIP

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served as CEO before Dave was hired. He has an in-depth knowledge of the CMTA because he has been with the organization for six years and has served as chairman of the board, president, and a major fundraiser. The CMTA will now have a Chicago address (10 South LaSalle St., Suite 3600, Chicago, IL 60603) that Pat will work out of. He plans to hire one additional staff person in the near future. Pat said, "The CMTA is growing and changing and will continue to aggressively pursue the first treatment for CMT under the STAR initiative!"

Herb Beron has been elected as the new Chairman of the Board of Directors. Herb writes of his new position:" It is with great excitement that I take on the role of Chairman of the Board of the CMTA. My involvement with CMT dates back seven years, when my then four-year-old daughter Julia was diagnosed with CMT Type 2E. We also have a 14-year-old son Joshua who does not have CMT but is in no way unaffected, given his compassion for and understanding of his sister's physical condition.

There was no history of the disease in my (or my wife's) family; we, therefore, needed to do a lot of research to bring ourselves up-to-date with everything happening in the world of CMT. In 2007, my wife Rachael decided to participate in a one-mile swim (swimming is *not* my strong suit) to raise funds for the CMTA. Five years later, "TeamJulia and the Swim for the Cure" has now raised in excess of $400,000 in total donations for the STAR program. I have sat on the Board of Directors for the past four years, and I welcome the opportunity and challenge to lead the Board in taking the CMTA to even greater heights. Our organization has accomplished much in the past four years (dramatic expansion of the support and action group network and awareness campaigns, and tremendous progress with NIH and the pharmaceutical industry in our research initiatives). That being said, there is still much more work to do. I'm hopeful that we can build on the momentum that we've generated in the past four years and take the CMTA to an entirely new level. I look forward to meeting support and action group facilitators and members at meetings throughout the country, and working closely with the new CEO Patrick Livney to raise research dollars to further our goal of finding a cure!" ★


Newly elected chairman and president Herb Beron brings knowledge and enthusiasm to his new role.

Give a Gift; Make a Promise

Rylee, a six-year-old girl, struggles every day because of the symptoms caused by CMT. In our community, these are symptoms we know well: poor balance, weak ankles, general clumsiness, fatigue, and pain. As a person affected with CMT, I know these symptoms well, too.

Rylee and all the children affected with CMT have been the inspiration and driving force behind my motivation to make a difference. Years ago, I was told I would be in a wheelchair by age 30. I have promised Rylee and many others that the "threat" of the progression of CMT won't hang over the heads of tomorrow's generations. Today, there is tremendous hope. Since I joined the Board of Directors six years ago, the CMTA's vision has been a world without CMT. Now, that vision is close to becoming a reality.

At the CMTA, we are moving rapidly toward human trials for a treatment for those affected with 1A, the most prevalent type of CMT. We are developing a protocol to attack multiple types of CMT, including 2, 4, and X. We are adding new support and action groups around the country to provide a system of support to those in need. We are cultivating new relationships with many different partners including biotech firms such as Genzyme and GlaxoSmithKline as well as service providers like Physiotherapy Associates. These relationships will further the treatments and standard of care for our community.

Of course, these accomplishments need resources to continue to thrive. As you think about your annual giving for 2011, please think about Rylee, your children, your grandchildren, and all the kids you know who deal with CMT daily. Your donation will help the CMTA continue to build upon recent breakthroughs in research and accelerate the discovery of treatments. You can securely donate to the CMTA on-line by visiting www.cmtausa.org or by mailing a check to the CMTA, P.O. Box 105, Glenolden, PA 19036. —*Patrick Livney, Chief Executive Officer*

TWO NEW MEMBERS JOIN THE BOARD OF DIRECTORS

JOHN SVAREN, PhD writes of his background and his reasons for joining the Board:

“I am an Associate Professor in the Department of Comparative Biosciences at the University of Wisconsin, and I serve as Director of the Cellular and Molecular Neuroscience core at the U.W. Waisman Center, where my laboratory is located. Since 2000, I have focused my research program on the genetic basis of peripheral myelination and the disruptions found in peripheral neuropathies such as CMT. I have had the pleasure of working with the CMTA to lead one arm of the collaborative STAR project, which is focused on understanding the regulation of the *PMP22* gene in order to develop novel assays for drug screenings at the National Institutes of Health. During this time, I have been very impressed with the vision, outreach, and leadership of the organization. Although my primary focus has been on CMT1A, I welcome the opportunity to broaden my perspective and help in development and implementation of a multi-front strategy directed at other forms of CMT.”

STEPHEN BLEVIT lives in Los Angeles and is a partner at the international law firm, Sidley Austin LLP, where Stephen practices corporate law. Stephen was previously a member of the board of directors at the Hereditary Neuropathy Foundation. Stephen’s law firm serves as pro bono corporate legal counsel for the CMTA. ★

Awareness Month Leaves a Lasting Imprint

BY ELIZABETH OUELLETTE

From early February through late August 2011, a dedicated committee of CMTA support and action group facilitators worked diligently to create the blueprint for a global CMT awareness month campaign. Together, with the CMTA’s national support and action group facilitators, their members, and the CMTA community worldwide, we successfully put CMT at the forefront of recognizable disorders and increased funding to support critical CMT research through the CMTA’s Strategy to Accelerate Research (STAR) initiative.

To show how effective the CMTA’s Awareness Month campaign turned out to be, here are just a few impressive statistics:

- the CMTA microsite (wearethecmta.com) had more than 17,500 page views
- nearly 80 countries participated in Awareness Month activities
- the CMTA’s YouTube channel registered more than 29,000 video views
- the CMTA’s Facebook Page (Charcot-Marie-Tooth Association: The Time is Now) received 450 new fans.
- an estimated 130,000 people received specific CMTA Awareness Month messages.

This outcome would not have been possible without the hard work of our Awareness Month committee. Allow me to highlight these wonderful individuals as well as just a few of their many achievements:

Jeana Sweeney-PA, the CMTA’s Director of Community Services, presided over all Awareness Month committee activities, acting as advisor, consultant, and organizer. Jeana initiated the CMTA’s Awareness Month texting campaign.

Julie Collins-FL chaired and created the “Extraordinary Person” campaign. She also requested a CMT Presidential Proclamation and authored the verbiage for all the gubernatorial proclamations. Moreover, Julie successfully raised donations for STAR, sponsored an Awareness Month booth, and acted as the liaison for the

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Ken Reesey of The Corner Coffee Shop presents Jeana Sweeney with a check for the Archys they sold.

FOR UP-TO-THE-MINUTE INFORMATION ABOUT THE CMTA AND ISSUES RELATING TO CMT, PLEASE VISIT OUR WEBSITE AT **www.cmtausa.org**

Italian CMT Organization Meets

RICCIONE, ITALY—The weekend of September 23, 2011, I had the pleasure of attending the ACMT-RETE 10th Annual Congress Venue; the ACMT-RETE is the Italian CMT Association. The congress venue was very similar to our patient family conferences. I was invited to present the STAR Program and also what the CMTA has to offer as far as patient advocacy. With the help of an interpreter, I believe that I was able to get out the CMTA's message. For the five days I was in Italy, the ACMT-RETE showed me great hospitality. Special thanks to Filippo Genovese, Managing Group Member for the ACMT-RETE and to my interpreter, Margherita Pelleriti.

The ACMT-RETE is a very passionate and supportive association. Their CMT community is very tight and very positive. They want to find a cure just like the CMTA, but they also are very focused in treating the symptoms of CMT. They believe in surgery to correct the deformities of CMT and have had good results in doing so. Dr. Gianfranco Caputi, physiotherapist, did a presentation on a taping method that he uses to help in rehab. It was very interesting. I had the pleasure of being taped on my hand and arm. I can honestly say that I felt a difference in my hand control. He did explain that this is something a physical therapist should do, not a CMT patient.

The program was very exciting. Among the many speakers, Dr. Laura Gentile, clinical psychologist, spoke about the "Social Aspects and Interactions for People Living with a Rare Disease." Dr. Carala Taveggia, PhD, presented the "Study of the Mechanisms Regulating Myelination," and Dr. Davide Pareyson, discussed "Clinical Trials in CMT: Results and Perspective." I also found the discussion pertaining to the legislative and political situation of rare diseases in Italy to be very interesting. Their health care system is very different from ours. Right now, physical rehabilitation is limited to two weeks a year in most regions of Italy, and there are no special programs or services for those living with CMT. This was very heartbreaking to me, because I know how important it is to have PT, OT, and other services that are needed for people living with CMT.

Also, the Italians really look to the CMTA to see what is going on in the USA—they made a point to mention that they check our website at least every other day. They consider the CMTA as a role model on how to grow the ACMT, which should make the CMTA community very proud.

I was able to connect with most of the CMT patients who attended the conference, despite the fact I do not speak Italian. We laughed, hugged, and shared our CMT stories through our hands. This shows me that no matter where we live or what language we speak, all of us living with CMT have the same concerns, fears, and the same hope in finding a cure for CMT.

—Jeana Sweeney,
Director of Community Services

Kim Magee and Jeana Sweeney join the members of the ACMT following a day of scientific presentations.

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

What can someone do to remain positive when things that were once easy enough are becoming impossible to do? I am finding it harder and harder to button clothes, clip my finger and toenails, and open jars when working in the kitchen. My family doesn't seem to even notice and they never offer to help me. That makes me feel even more alone and sad.

—D.R.

Dear D.R.,

Thank you for asking a question that many of us with CMT can relate to. If by staying positive, you mean happy, then that is a difficult task when we notice changes in our muscle strength affecting our ability to be independent. Every time we notice something that we can't do as well as before, we go through a sort of grieving process. We sometimes go through a denial process; then we feel angry and possibly fearful and sometimes sad at losing something we could do before. The key here is to allow yourself to experience these feelings without judging yourself or feeling that you are emotionally weak. Eventually after experiencing these normal reactions to loss, you come to a place of acceptance and peace. Talking to someone who is loving and who accepts your feelings often helps.

Sometimes, even our closest loved ones don't notice that we could use some help, so don't wait for them to notice. Asking for help directly does not make you weak or needy. It is a show of courage and strength. Not asking for help can lead to bitterness and loneliness. I have always felt that those who never ask for help may be independent, but they could also be avoiding closeness or intimacy. Showing our vulnerability is about being open and that is a personality strength that allows others to love you.

There are a few companies out there that specialize in devices that help those with grip problems for simple tasks like nail clipping and buttoning. One good one is Active Forever.com and their telephone number is 800-377-8033. They have a catalogue that they will be happy to send you.

Dear David,

I am the mother of a child of 8 who has CMT. She never talks about it and so far, seems to be able to keep up fairly well with her classmates. I feel we should be discussing what is going on because she will probably need leg braces by next year. The problem is that I don't have CMT; her father, who does not live with us, does. His family does not talk about it at all. I don't want to tell her the wrong things and I don't want to scare her. Is this the right time to talk about CMT or is it too soon?

—J.E.

Dear J.E.,

Thank you for a question that concerns many parents of children with CMT. I do not think that eight years old is too young to discuss her feelings about CMT. In some ways, it is the perfect age because kids begin to notice differences amongst one another and begin to ask questions. Keep in mind that facts about CMT can arm her with good information as opposed to her making up stuff filled with fearful fantasies. It is important that your child knows that everyone is different in his or her own way. Some kids have glasses; some kids have allergies, and some kids have weaker muscles in their legs. The sooner she can know that she is loved and cherished for exactly who she is, the more confident she will be out in the world.

If your child isn't talking to you about it, then gently bring it up and find out what she is thinking. Her father could be helpful and supportive if you feel that he is a positive influence and she has a loving relationship with him. I am also thinking that the teachers or counselors in her school could help you prepare a presentation in her school about CMT and possibly include your child if you feel she is ready. Kids can be harsh with someone who is slightly different, so her self-acceptance could go a long way in helping her navigate through some tough situations. When it is time for her to get her braces, then make it a "cool" thing as opposed to something she needs to be ashamed of. You play an important role in her ability to love herself. Verbalizing how terrific she is and how lucky you feel to be her Mom goes a long way in helping her develop a positive view of herself. ★

David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at info@cmtausa.org.)

The Faces of CMT…

Paul Bailey, who was diagnosed with CMT when he was only 3 years old, has never let it get in the way of his living his life and doing what he wants. He tells his story in a new blog, “The Faces of CMT” at **facesofcmt.blogspot.com**, to help create awareness about CMT.

Paul lives in Grand Ledge, Michigan with his wife, Diane, her two kids whom he adopted, Ian and Amanda, and his son, Adam. To describe him, you would use words like outdoorsman, comedian, family man, stubborn, and inspiring. One might even call him a hero for the way that he has never let CMT get in the way of his living his life and doing what he wants.

Paul and his wife, Diane, were married in 2000, but Paul talked about how hard dating was for a while. He said that every girl just seemed to get to a point where they wanted to be friends because they couldn’t deal with CMT. He and Diane met on the Internet first and talked a lot before they ever met face to face. “I remember before we first met, I told her that I had a neuromuscular disease that made me walk with a bad limp. She said to me, ‘Since we are being honest, I have a mole on my cheek.’ I kind of knew then that she was different.” Diane added, “When Paul came into our lives, there was laughter in our house every day.”

Paul Bailey tells his story in our new blog spot.

If you go to the blog, you can read much more about Paul, his extended family with CMT, their trips to Wayne State, and his philosophy about dealing with the problems that CMT can present.

Katie, a photographer and writer living in Buffalo, NY, who is the creator of “Faces,” describes the project:

“It started out as just an idea—a thought that people with CMT needed to connect with each other; that families needed to connect with other families; that telling the personal stories of people with CMT would be the best way to create awareness. ‘The Faces of CMT’ was born.

“With backing from the CMTA, we will be interviewing people from all over the country who are living with CMT. We will be telling their stories and their families’ stories, through pictures and their own words. Each month, a new person or family will be featured with a blog post each week, talking about their lives.”

If you are interested in telling your story, visit **facesofcmt.blogspot.com** to contact Katie. This project will continue indefinitely. ★

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:__________________________
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Occasion (if desired):
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☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased)
____
Send acknowledgment to:
Name:__________________________
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Amount Enclosed:__________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
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DONATE STOCK!

To make a stock donation to the CMTA, please contact The Schwartz Group at 1-800-526-9075 and tell them you are giving your stock gift to the CMTA.

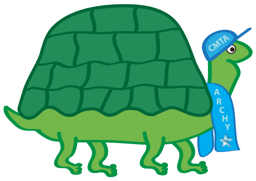
A Turtle's Quandary

We don't celebrate Thanksgiving like you guys do, but we do have a holiday that revolves around the changing of the seasons and the bounty of the harvest. It's an animal thing, I guess. Anyway, we were having the dinner at our house this year, and my Mother was doing all the work—which is the way it always is, much like in human homes.

She was doing a lot of the preparation in the days leading up to Harvest Holiday, and I noticed she was complaining a lot about how tired she was and how much her legs hurt. That's not the way my Mom usually is. She is endlessly energetic (or it seems that way to me), and she always gets everything done. This year, though, was different.

The weird thing is that I was pretty sure I knew what was wrong, but no one else said a word about it. My Mother has CMT. It's just that she is the carrier of the X-linked form that my Grandfather Turtlebaum passed on to her and which I have. She has always chosen to believe that she has no symptoms of CMT, but I notice her unsteadiness and how she likes to lie in the pond and just wiggle her legs after she works on her feet all day. For some reason, though, it is a forbidden topic with her. I know she is upset that she passed the condition to me, but she always encourages me to do anything I want and to keep after tasks until they are completed and to never let CMT get the better of me. So, why won't she concede that she has a similar problem? I think it would make us closer. We could compare notes and tell each other things that work to make tasks easier. But she simply won't discuss how CMT impacts her.

So, here we were trying to get ready for this huge gathering and Mom was so tired and her feet and legs so sore that she really couldn't keep working. My Dad, my sister, and I had a meeting and decided that, rather than confront her about acknowledging her CMT, we would just take over and do a lot of the work. It was a good idea, but it turned out that none of us could really do the cooking the way my Mom always does. My sister was the best because she has always enjoyed watching my Mother in the kitchen; my Dad was good at the heavy lifting and moving of furniture; and I was useless. I mean, I could help set the tables and I could wash the lettuces and carrots and all the yummy herbs, but I had never paid any attention to all the work that went into one of these get-togethers.



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

The event went off without a hitch mostly because my Mother got her "second wind" as she calls it and was able to finish up what we had not done and she was able to allow things to be less perfect that she normally likes them. What was disappointing to me, though, was the fact that my Mother is ashamed of having CMT and won't even talk about it with me, of all turtles. I know so much from working with the CMTA and I feel like she would actually be better off if she could just get to the point of admitting that, at times at least, she can't do certain things anymore because of her CMT.

My quandary? Talking to my Mother about this problem. What do you think ? ★

T.J. MAXX IN JOHNSTOWN, PA GETS INVOLVED!

For the past two years, I have held a "Step it Up For CMT" school program (a program that educates children about CMT, brings awareness in the community, and raises funds for CMTA) at the Richland Elementary School in Johnstown, PA.

After my second year at the school, a student's father contacted me because he wanted to learn more about CMT. After understanding more about CMT and the mission of the CMTA, Mr. Ira Strahl took his interest one *step* further. Ira is the manager at the T.J. Maxx Store in Johnstown, PA. He reached out to the T.J. Maxx Foundation to ask if the CMTA would qualify for a grant. Well, I am pleased to announce that the T.J. Maxx Foundation granted the CMTA $2000 to support my Teaching Kids about CMT Program!

I hope this will encourage you all to get out there and spread the word about CMT, because you never know what doors will open for you.

—*Jeana Sweeney*

Meet a Shooting STAR: Jacqueline Dyer

BY WHITNEY KREPS

On June 20, 2009, a beautiful child with golden blonde pigtails and large blue eyes slowly walked into my life with the assistance of her family and some incredibly cool pink AFOs. Her smile was bright enough to light up an evening sky. Two years later, Jacqueline Dyer continues to share her contagious smile without regard to her declining condition caused by CMT.

> Life, like CMT, is about the choices you make.

The history of this hereditary disease has haunted Jacqueline's relatives as far back as her great-great-grandmother, great grandfather, her grandmother, and her aunt. Yet regardless of the effects CMT has challenged her family with, they have maintained grace and class. Each member of her family continues to display an amazing and courageous smile.

Over the past two years, Jacqueline's disease has progressed rapidly causing her to rely on a wheelchair and constant care from family, who assist with everything from eating to brushing her hair. CMT has stripped Jacqueline of every ounce of strength, beginning with her thin arms that no longer allow her the ability to lift or move them. Yet the courageous spirit that Jacqueline possesses has not only given her confidence and optimism, but has allowed her to bestow hope, joy, and inspiration on all she comes in contact with.

On September 2, 2010, Jacqueline was admitted to Cooks Pediatric ICU for two weeks with a collapsed left lung, and pneumonia. The respiratory distress as well as weakness caused by Charcot-Marie-Tooth had become life-threatening and continues to cause concern.

Amanda Dyer, Jacqueline's mother, has shared an enormous amount of encouragement and enthusiasm, allowing both of them to live each day to the fullest. Merely two weeks after being released from the hospital Jacqueline was honored at the 2010 Night of Superstars, where she was treated like a star and even strolled down the red carpet. That same month Jacqueline started cheerleading with Cross Timbers Gym in Argyle, Texas and has since performed at the Dallas Cowboys Stadium and even had a feature on the local news station!

There are so many reasons that Jacqueline qualified as a contender for the Shooting Star Award and the statements above are simply a few. When I was informed that she would be awarded the honor at our September 2011 meeting, I was overwhelmed with emotion. Above all, I was filled with joy knowing that out of the hundreds of thousands of amazing people who live with and suffer daily with CMT, this inspirational child was going to leave our meeting with the understanding that she truly makes a difference in the lives of countless people each and every day.

As I presented Jacqueline with the award, my voice began to shake and the words I had prepared simply would not find their way out. Tears began to slowly make their way down my cheeks, and as I looked up, I saw that the room was filled with emotion and no one, with the exception of Jacqueline, had a dry eye. Her face was filled with excitement and surprise. This was such a special moment that her mother and I wanted to extend this deserving honor to her in front of our support and action group and chose to keep

(continued on page 15)

Amanda Dyer helps her daughter Jacqueline accept her plaque and flowers as a "Shooting Star."

Fundraising for CMT

SWIM FUNDS CMT RESEARCH

TeamJulia grew to over 30 swimmers this year, all supporting the CMTA's research initiative.

On September 4, a large contingency descended upon Lake Valhalla Club in Montville, NJ to participate in the fifth "Swim for the Cure" to benefit the CMTA's STAR campaign. "TeamJulia" was formed in 2007 by Herb and Rachael Beron, whose 11-year-old daughter Julia has CMT Type 2E. Back in 2007, the only swimmers were Rachael and her sister Cathy Bailey; however, each year the swim team has grown, and this year there were over 30 swimmers (half of them being between the ages of 9 and 15!). Approximately 125 friends and family came out to witness the event. For the second year, a silent auction was held while the swimmers engaged in their one-mile event. Among the highlighted items auctioned off were visits to the studio sets of "Modern Family," "The Ellen DeGeneres Show," "Wipe-Out," and CBS Sports' "NFL Today," as well as several signed sports memorabilia items. In addition, souvenir "TeamJulia '11" T-shirts were designed by one of Julia's best friends and sold during the event. In every way, this year has been the most successful in the swim's history—not only did the event attract the greatest number of swimmers and spectators, but it also raised $130,000 to date and donations are still coming in! If you'd like to contribute to TeamJulia, please go to www.cmtausa.org/Julia. In the five years since "TeamJulia" was launched, it has now raised in excess of $400,000 for STAR. Herb Beron, the newly appointed Chairman of the Board of the CMTA, has a goal to turn the swim into a regional or even national event. Please feel free to reach out to Herb at hberon@optonline.net if you'd like to discuss putting together a swim team to participate in Swim for the Cure 2012!

360-MILE RUN ACROSS MICHIGAN'S UPPER PENINSULA RAISES FUNDS FOR CMTA

In an effort to raise awareness about his son's rare disorder, Doug Allie took on a run of about 360 miles over a two-week period. The run across the Upper Peninsula of Michigan equates to approximately a full marathon per day. Doug had prepared by running 80 miles per week to build up his lungs and muscles.

Doug's 10-year-old son, Jacob, was diagnosed with CMT, and Doug felt that he had to personally do something to help push the research along. Since there currently is no cure, he felt that raising money and awareness would be a worthwhile goal.

Both of Doug's sons, Jeremy, 15, and Jacob, 10, accompanied him on the trip. In their cases, it was a two-week vacation to the Upper Peninsula, although Jacob watched his father complete the 350-mile run because he was proud of what his father did for him.

To date, the run has raised $13,800.

WALK AND ROLL FUNDS CMT RESEARCH

The Chicago Area support and action group sponsored their "Reach for the STARS Walk and Roll" for the CMTA on Saturday, September 10th. The walk took place at the Wolfe Wilderness Refuge located in Oak Lawn, IL. The pavilion was decorated with Awareness Month

The Chicago area turned out in huge numbers to participate in the "Reach for the STARS" fundraiser.

posters and STAR balloons. Raffle tickets were sold and T-shirts were for sale.

More than 100 people participated this year. A personal trainer and PE teacher started everyone off with stretches before the walk started. It was a beautiful sunny day and the walk was enjoyable.

After the walk, brats and hot dogs were grilled and many people made a day of the fun. As a group, our goal is to raise $10,000.

SINGING CONTEST AND DISCO PARTY SUPPORTS CMT RESEARCH

On July 28th the Acclaimed Idol Singing Contest and Disco party was held at the Boogie Café in Ferndale, Michigan, to raise money for the CMTA. Speaking on behalf of the CMTA, Patricia Santer, RN, talked about her own CMT and how the disorder has affected her and her family. Patricia's involvement with the CMTA has helped to raise awareness in southeastern Michigan, especially among healthcare professionals. One of the sponsors of the event was Acclaimed Home Care.

On September 19th, Pat accepted the check for $5,300 for the CMTA. Coincidentally, the day was also Pat's birthday. ★

Patricia Santer, RN, (right), accepted the check on behalf of the CMTA from Alice Salazar, RN, and Karen Katko from the Acclaimed Family of Companies.

RUNNING A MARATHON FOR CMT

When I was in second grade, there was a race on the playground at lunchtime. I could run like the wind. The race started—one lap around the asphalt playground. Somehow I intuitively knew about pacing, and I saved a burst of speed until I hit the last turn. It was exhilarating, and I've been running ever since.

Now, some 47 years later, after running track in high school and completing marathons, I was content to call it a day. But, there was something gnawing at me. I have a nephew, Michael Gene, who several years ago (when he was six or seven) began to walk with an awkward gait. There was something about it that troubled me. His gait was reminiscent of a boy I grew up with who had Duchenne muscular dystrophy. I became afraid that Michael Gene might have that affliction.

Over a period of time, Michael Gene was taken to various doctors and medical experts. It was thought that he had an orthopedic condition, and that surgery could correct the problem. I was relieved by the news because I felt that they could "fix him." As time went on, however, and the debate proceeded about whether or not he would have the surgery, I confided in my wife that I didn't think Michael Gene's problem was orthopedic in nature because of the way it was obviously progressing.

Finally, it was determined that Michael Gene had CMT. Like many people, I had never heard of CMT, even though it affects one in every 2,500 Americans. I discovered that patients slowly lose normal use of their extremities as nerves degenerate and muscles weaken because the nerves no longer trigger motor function.

So where are we today? I have a wonderful nephew who is in the seventh grade and has his whole life ahead of him. He never complains as he puts on his leg braces, and he laughs and smiles as he talks about fishing and his other passions, and he does not mention the numbness that he occasionally experiences. He does all that he can do seemingly without a care in his heart, but he gets tired and welcomes the fact that his handicapped parking pass is available to him. He looks at my surfboard and asks to learn, and he watches his cousins play soccer while these things are moving beyond what he can do. Those of us who love him watch and wait. We hope that the disease won't progress, and that it won't hit his hands.

In an effort to help him, on Sunday, November 20, 2011, I will run the Philadelphia Marathon as a fundraiser for the CMT Association. The researchers are getting close, and they need all of our help to get there. So, please,, in the name of Team MGF send a tax deductible donation to: CMTA, P.O. Box 105, Glenolden, PA 19036.

Visit the following YouTube link to view a little video that Michael Gene and I made to support our fundraising efforts: **youtube.com/watch?v=U_2ShhbKLYM** —*Charlie Norris*

AWARENESS MONTH

(continued from page 3)




Mark Willis, Julie Collins, Melinda Lang and Susan Ruediger were some of the outstanding participants in Awareness Month.

CMTA's Awareness Month poster and T-shirt artwork.

Mark Willis-NJ led the Facebook campaign charge, by not only asking individuals on Facebook to change their profile picture to the Awareness Month poster, but also by posting daily CMT-related messages. Mark also received two CMT proclamations and presented the "I Am a STAR" award at the TeamJulia Fundraiser, where he managed the CMT info table.

Melinda Lang-NY built the pathway to global CMT awareness by contacting national and international CMT organizations, inviting them to participate in Global Awareness during the month of September. Melinda also organized a CMT Awareness Night benefit, reaching approximately 5,000 fans and raising $2,000 for STAR. In addition, Melinda created a blog, created the CMTA Zazzle items, and received proclamations from both New York State and the mayor of Albany, NY.

Susan Ruediger spearheaded our Awareness Month's "Let Me Tell You 'Bout" fundraising campaign. She also wrote the article, "The Benefits of Exercise" and produced a video which demonstrated simple exercises for all those with CMT. In addition, Susan hosted a picnic, which raised over $2,500 for the CMTA.

My sincere gratitude goes out to Steve Weiss, DC Metro Area facilitator, for his help spreading CMT awareness through his Twitter activities and his article describing the role and function of the CMTA's support and action groups. I would also like to thank both Vicki Pollyea-FL for her informative OT article entitled, "Occupational Therapy and Charcot-Marie-Tooth Disorder," and Dick Kutz-CO for designing the CMTA's facilitator collage.

Awareness Month would not have been possible without the efforts of Kim Magee, who mailed *all* Awareness Month letters and packages to members and facilitators.

Last but not least, I would like to congratulate all our CMTA support and action group facilitators and members nationwide, as well as Beth and Shannon from our PR firm GatesmanMarmion+Dave for their free-flowing creativity and phenomenal service to the CMTA throughout September's Awareness Month. Together, we've left an indelible imprint on the world, one which has changed and will continue to change the range, scope, and face of CMT worldwide. ★

THE CMTA "CIRCLE 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!

DONATIONS WERE MADE TO THESE CMTA CIRCLES:

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Mrs. Catherine A. Altobelli
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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—Los Angeles Area
Southern California CMT
Support and Action Group
Dottie Zagar
661-433-2533

CA—Stockton
Stockton, CA CMT Virtual
Support and Action
Nina Anselmo

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—Santa Rosa Area
Santa Rosa, CA CMT
Support and Action Group
Carol O'Bryan
707-823-0165
Ronald Deghi
707-829-0911

CA—SF/East Bay Area
San Francisco/East Bay CMT
Support and Action Group
Donna Rennie
925-330-2790

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

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

FL—Inverness Area
West Central Florida CMT
Support and Action Group
Ronnie Plageman
352-860-1578

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

GA—Atlanta Area
Atlanta, GA CMT
Support and Action Group
Susan Ruediger
678-595-2817
Jeannie Zibrida

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

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

KY—Burlington Area
Pam Utz
859-817-9338

MD—Hagerstown Area
Hagerstown, MD CMT
Support and Action Group
Jeffrey Martin
301-582-2401

MD—Easton
Easton, MD CMT
Support and Action Group
Missy Warfield

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/emails
Libby Bond
417-845-1883

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

NC—Triangle Area
Triangle, NC CMT Support
and Action Group
Betsy Kimrey
919-833-3991

NH—New Hampshire/Vermont
New Hampshire/Vermont CMT
Support and Action Group
Margaret Healey
802-535-2797

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

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
Diane Cencak
702-560-3647

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

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
Ruth Korowitz
516-318-3202

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

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

OH—Zanesville Area
Zanesville, OH CMT
Support and Action Group
Tara Boehke
740-297-4940

OR—Portland Area
Portland, Oregon CMT
Support and Action Group
Debbie Hagen
503-333-7936

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

PA—Johnstown Area
Johnstown, PA CMT
Support and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-262-8427

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

TN—Nashville Area
Nashville, TN CMT
Support and Action Group
Mark Hollingshead
615-480-2044
Bridget Sarver
615-3909-0699

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
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Whitney Kreps
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Virtual/Discussion Groups

Anyone Can Fundraise

Archy and Friends
Discussion Group

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Voice Discussion Group

CMT and Fatigue
Discussion Group

CMT and Pain—Share
Your Experience Discussion
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CMT Creates: Music Project
Discussion Group

Global Support and Action
Group Community

Hand and Finger Struggles
with CMT Discussion Group

Insurance and Benefits
Discussion Group

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.*

The CMTA is looking for facilitators for Pittsburgh—PA, San Diego—CA, and Jacksonville—FL.

TAKE ACTION:* *If there is no support and action group in your area, consider becoming a facilitator! If you are interested, please contact Jeana Sweeney at jeana@cmtausa.org.

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

ASK THE DOCTOR

Dear Doctor,

My question is about pain medication. Both Aleve and Celebrex are effective for my knee pain at the present time. However, both have drawbacks. Aleve can cause bleeding in the gastro intestinal tract and there has been some research about Celebrex and heart attacks. Do either of these have an effect on my CMT and is one better than the other?

Dr. Louis Weimer replies,

The side effects listed are correct. I know of no extra concern for CMT patients unless you have one of the rare types with coincident heart involvement.

Dear Doctor,

I have a son that is a year old. I was interested to figure out if there have been any issues or problems connected to giving an infant his shots if he has CMT. CMT runs in my family through many generations and I also carry the trait. I have been in the progress (which means on a waiting list) of getting my son tested to see if he carries CMT, but have been worried about him receiving all of the infant shots and how it could affect him if he has CMT. Have there been any signs of these shots affecting an infant with CMT?

Dr. Louis Weimer replies,

There is some debate about vaccines in neuropathy patients in general but mostly concerning patients with immune or inflammatory neuropathies and mostly flu shots and HPV vaccine; the evidence, even in these cases, shows no clear link. Hereditary neuropathies, such as CMT, have a much lower concern. The probable risk of these vaccines is very low, but the complications of infections the vaccines are designed to prevent (polio, measles, diphtheria) are quite dangerous, especially to CMT patients. I know of no pediatric or neurologic authority that discourages or questions vaccinations at this age.

Dear Doctor,

I have a child with Charcot-Marie-Tooth disease and would like a clarification. I was reading the directions for using secnidazole and metronidazole for genital infections and found that they are dangerous for those with problems such as sensory-motor polyneuropathy. If my daughter were to need to make use of these products what should I do? Can she take them?

Dr. Louis Weimer replies,

Although both can potentially cause sensory neuropathy, the problem is usually after extended use, namely more than 1-2 months of continual use. The typical 7-10 day course for routine infections carries minimal risk. ★

MORE CMTA "CIRCLE OF FRIENDS"

CONTINUED FROM PAGE 12

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SHOOTING STAR

(continued from page 9)

it a secret. As she was presented with a plaque, flowers, and a cake, she cruised in her wheelchair with grace and style. An enormous smile lit up her face the entire meeting, and no words can describe the sentiment that was flowing through the members of our group.

Amanda concluded the award ceremony by humbly stating, “Our life is not easy. There are no answers no matter how many doctors you see. We never do anything fast—slow is how we roll! There is never a day where we are not stared at or a day we don’t hear a whisper or two as we walk by. But we keep our heads held high, smiling all the way. When we are stared at, we smile back, and when we hear a whisper we say ‘Hi!’ Life, like CMT, is about the choices you make. You can wake tomorrow thinking about how bad off you are or you can wake up thanking God for all the good in your life. Everything happens for a reason though we may never know why.” She continued by saying, “If you are not moved by the story I have shared with you, please spend a moment or two with my little girl. I promise you will have a different point of view!”

Despite Jacqueline’s condition, she carries herself with poise and purpose. She is wise beyond her seven years of age and continues to teach all those she encounters that there is purpose in pain and that regardless of what each day may bring, a positive outlook as well as a warm heart full of hope can overcome all circumstances including those of a debilitating disease. ★

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

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)
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THE CMTA Report

The Charcot-Marie-Tooth Association
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1-800-606-CMTA FAX (610) 499-9267
www.cmtausa.org

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.