

THE CMTA Report

MAY/JUNE
2012

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



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.

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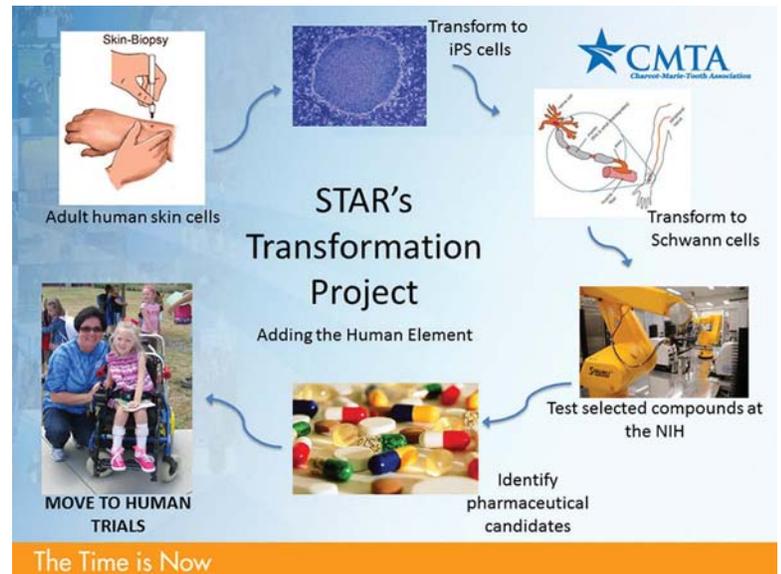
EMAIL CMTA AT:

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CMTA's STAR Initiative Announces the "Transformation Project"

For the first time ever, live adult human stem cells will be used to search for effective compounds to treat CMT. By using cutting-edge technology developed at the University of Wisconsin's Waisman Center, live human skin cells can be transformed into cells that can be tested against pharmaceutical compounds for the purpose of finding candidate drugs for use in human clinical trials. The CMTA has embarked on this ground-breaking STAR research project to rapidly accelerate the drug development process in search of a successful treatment to slow, stop, or potentially reverse the progression of CMT.

In addition to searching for effective CMT treatments, results discovered in STAR's Transformation Project will have potential applications in other closely related diseases such as



ALS, MS, Parkinson's and Alzheimer's.

The cost to fund STAR's Transformation Project is \$100,000. We can't do this alone, so we need your financial support. The CMTA humbly invites you to partner with us in this historical journey by making a donation in any amount

to STAR's Transformation Project.

To learn more about the Transformation Project, go to www.cmtausa.org. There you will find a full description and a budget of the project as written by Dr. Anita Bharttacharyya and Dr. John Svaren at the University of Wisconsin. ★

New Measurement Tool For Clinical Trials to Help Children with CMT Disease

An international study led by the University of Sydney and published in the May edition of the *Annals of Neurology* has the potential to improve the design of clinical trials for the treatment of Charcot-Marie-

Tooth disease, a disorder which affects the peripheral nervous system.

Charcot-Marie-Tooth disease (CMT) is one of the most common inherited neurological

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PEDIATRIC SCALES

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disorders, affecting 1 in 2500 people. Symptoms such as leg weakness, foot pain, trips, and falls develop in the first two decades of life, with some patients wheelchair-bound by 21 years. Currently there is no treatment for any form of this disease, however clinical trials are increasingly occurring.

“While it is very positive that clinical trials are taking place in this area, it is vital that trials are based on appropriately selected patients and carefully chosen outcome measures,” says

Associate Professor Joshua Burns, Chief Investigator from the University of Sydney and The Children’s Hospital at Westmead. “This relies on being able to measure disease severity accurately, and in turn the patient’s response to treatment, which we were previously unable to do in children.”

In response, Associate Professor Burns and colleagues from the USA, the UK, and Italy designed the CMT Pediatric Scale (CMTPedS), a patient-centered multi-item rating scale of disability for children with CMT.

“Rating scales used for adult

patients are inappropriate for children, and since most forms of CMT affect children, there was an obvious need for a new clinical tool. Furthermore it is during childhood that we anticipate that treatments for CMT may be most effective—before the disease progresses and makes repair more difficult.”

During a 14-month test period, the CMTPedS was administered to over 170 children aged 3 to 20 years with varying types of CMT in Australia and internationally via the Inherited Neuropathies Consortium. Analysis of these data supported the viability of CMTPedS as a reliable, valid, and sensitive global measure of disability for children with CMT from the age of 3 years.

The CMTPedS can be completed in 25 minutes and will have broad application in clinical trials of rehabilitative, pharmacological, and surgical interventions.

“There is growing international support for the rating scale to be implemented as the primary outcome measure in studies of children with CMT because the quality of the measure has the potential to influence the outcome of clinical trials and patient care,” comments Associate Professor Burns.

This research was supported by grants from the National Health and Medical Research Council of Australia, NIH National Institutes of Neurological Disorders and Stroke and Office of Rare Diseases, the Charcot Marie Tooth Association, Muscular Dystrophy Association, and CMT Association of Australia. ★

AMY DE SILVA CROWNED 2012 MISS MASSACHUSETTS’ OUTSTANDING TEEN

The Miss Massachusetts Scholarship Foundation announced 16-year-old CMTA member Amy C. de Silva as the winner of the 2012 Miss Massachusetts’ Outstanding Teen pageant, held March 31 at Keith Middle School in New Bedford. Twenty contestants from across the commonwealth competed for the title.

Amy will have the opportunity to compete in the Miss America’s Outstanding Teen pageant to be held in August in Orlando, Florida. As Miss Massachusetts’ Outstanding Teen, she will receive a \$2,000 scholarship and various awards and gifts from pageant sponsors. At the state pageant, she competed as Miss New Bedford’s Outstanding Teen.

Amy is the daughter of William and Catherine de Silva of Dartmouth. She is a 10th grade student at Dartmouth High School, where she has maintained honor roll status, and is a member of the cross country, winter track, and spring track teams.

Amy has sung at Fenway Park four times, is the Youth Ambassador for the Charcot-Marie-Tooth Association, and has performed lead roles in many musical productions. For her talent competition, she performed a vocal to the Beatle’s “Let It Be.” Her platform issue is Charcot-Marie-Tooth Disease awareness.

The Miss Massachusetts’ Outstanding Teen includes teenagers from ages 13 to 17.



Amy is crowned by Miss Massachusetts Outstanding Teen 2011, Sydney Levin-Epstein (left) assisted by Molly Whalen, Miss Massachusetts 2011. Thanks to photographer Andrew Gallagher and the Miss Massachusetts Scholarship Foundation for the photo.

Parents, There is Something You Can Do: Donate to Research!

BY GARY GASPER

Early nine years ago this summer, my wife and I received the diagnosis that our son had CMT 1A. My son did not directly inherit the disorder; rather, it was “de novo” or a new occurrence of CMT within our family. Like most parents without the disorder, we knew nothing about what the diagnosis meant to my son and my family. It would be an understatement to say that it changed our lives dramatically.

I immediately went on line to search for as much information as I could about CMT 1A.

While there were many articles of a general nature, and some information on NIH and other websites, what caught my eye was the website and information from the CMTA. I read how they were working with Congress to get language in an appropriations bill that would support CMT research. As someone who works in Washington, DC, I immediately gravitated to the idea that maybe there was something I could do to help the cause.

I quickly contacted the CMTA and became active in the organization, soon joining the Board and becoming Treasurer. This was the early days of CMTA research. Over the years, and particularly in the last 5 years, the CMTA has made enormous strides in the organization as a whole and in the research area in particular.

As new leadership unfolded at the organization, new ideas for research blossomed. The “STAR Program—Strategy to Accelerate Research” grew out of a strategic board meeting in Palo Alto, California, where the Board brought in an expert from the Myelin Repair Foundation to discuss a new approach to research. Rather than funding research projects haphazardly based on traditional grant writing procedures, the new direction would establish a targeted, well-defined

Any contribution to research makes a difference!

approach that would methodically lead to a drug treatment. Thanks to the CMTA medical advisors, a step-by-step plan was put together that led to the ongoing, coordinated work with the NIH and the current successes to date.

As you may know from reading about the STAR Program, we now have a number of FDA-approved compounds that have been shown to reduce PMP-22 in cell lines. For those non-medical folks like me, PMP-22 is the peripheral myelin protein (PMP) that is overproduced in CMT 1A patients. The goal is to reduce the expression of this protein.

The next steps are to test these compounds in animal tri-

als, develop stem-cell-related tests, and then move the process to human trials. All of these efforts, of course, cost money that the CMTA is committed to funding.

The main goal of the CMTA is a world without CMT. The goal inherently involves research efforts that go beyond supporting the status quo. It is only through research discoveries that we can find drug treatments and therapies that will help everyone with CMT.

When I first discovered my son had CMT 1A, I did not know what I could or should do to help. I got involved with the organization and contributed to its efforts. These actions were well worthwhile and gave me a sense of involvement in doing something to help my son.

As each of us worries about what more we could do to help our children with CMT, we may sometimes think about sending in contributions but then dismiss the thought as not really making a difference. I can tell you any contribution to research makes a difference. So as you think about what you can do to help children with CMT, I urge you to make a contribution, no matter what amount, to CMT research and, particularly, the STAR program. We will only get life-changing treatments with your help. ★

Exercising with CMT

BY MIKE O'LEARY, BS CPT

Exercising with a disability is something that scares some of us. What happens if we can't complete a certain exercise, or we get so tired we can't make it home from a walk? How many times have these thoughts entered our heads, and have stopped us from getting up and trying to stay fit? Well, for me, it has been more times than I wish to admit. My whole life I have been active, from playing hockey since the age of 4, winning provincial lacrosse championships, playing college football, to working as a personal trainer. Sports and fitness have always been a part of my life.

The greatest thing about exercising is that it can improve us in every way. Yet, when you have a disease like CMT, you need to look at exercise in a dif-

ferent light. Exercising with a disability can be challenging, but we can remove the roadblocks by creating exercise routines that fit our body and our certain abilities. Many doctors that I have worked with have told me that stretching should be a main component of my life to help keep my muscles loose. Yet, that is only one part of what we need to do.

Exercising can do numerous things to improve our lives. One, exercising improves our mood by stimulating various brain chemicals that can leave us feeling happier and more relaxed than we did before starting exercise. Two, exercise can help keep us away from other diseases, like heart disease, by increasing our "good" cholesterol. And three, exercise boosts self-esteem. We can look in the mirror after exercising and know that we did something good for our body. Now that we know why we should be working out, let's look at some things that people with CMT can incorporate into their life to keep active.

1 Work what is strong. While everyone is affected differently by the disease, we all have areas of our body which are still working quite well and are still

relatively strong. Working these muscles will help us maintain what's strong. Some ideas might be: assisted pushups, wall squats, assisted squats, biceps curl presses, etc.

2 Set realistic goals. Set some goals for yourself with your exercise. It could be exercising three times a week, or walking half a mile. You know your body best and setting a realistic goal for yourself is a good way to start.

3 Replenish the body. While we may think about exercising as just working out and keeping in better shape, we need to make sure that we replenish our body after exercising. When we work out, our muscles are being used and these need to be supported through nutrition. A healthy dose of 20g of protein with a serving of fruit would be a great way to say "Thanks!" to your muscles after exercising. ★

Mike O'Leary is a certified personal trainer who obtained his bachelor's degree in exercise science from Minnesota State University. Mike has worked with clients from professional athletes (NFL and NHL) to the elderly just looking to stay active. Mike is currently taking classes to obtain his PhD in Natural Medicine.

SAMPLE WORKOUT

Day One

Cardio/Bike/Walk/Swim: Set a goal and complete the daily cardio session within your body's abilities. Finish by stretching.

Day Two

Full Body: 10 assisted pushups, 10 stand ups (from chair), 10 curl presses (biceps-shoulder), 10 hamstring curls. (Repeat twice, if able.) Finish by stretching.

BECOME A CMTATHLETE

The CMTAthletes program is for those with CMT and their supporters alike, and those who are athletes today or who aspire to become more active. If you participate in any type of sport (walking, yoga, golf, biking, swimming, archery, etc.), the CMTAthletes program is for you!

Offering support, advice, information, and enthusiasm, CMTAthletes will also help you with ideas so that you can fundraise for the CMTA through the very sports you love the most. Need a unique logo? We'll create it for you. Also, CMTAthletes' sports kits will be made available for purchase so that anyone can buy and visually support the CMTA with their athletic clothing choices.

Come join in on the fun by becoming a member of our team and support the CMTA!

For more information, visit the CMTA website or contact Jeana Sweeney at jeana@cmtausa.org.



MORE ADDITIONS TO OUR ADVISORY BOARD



GREGORY T. CARTER, MD, MS, is medical director of the Regional Neuro-muscular Disease

(NMD) Center and Hospice and Palliative Care Programs for Providence Medical Group in Southwest Washington.

His clinical and research interests center on rehabilitative and palliative care of NMD, focusing on pain, fatigue, and quality of life. He has co-authored over 150 peer-reviewed publications, including the first studies on longitudinal physical performance, phrenic nerve and pulmonary function, and neuropathic pain in CMT.

He holds faculty appointments at the University of Washington and the UC Davis Schools of Medicine. He graduated from Loyola University Chicago, Stritch School of Medicine, followed by a PM&R residency and NMD fellowship at the University of California, Davis, where he also earned a Masters degree in Physiology.



DAVID B. MISENER, BSC (HK), CPO, MBA, is an American Board-Certified Prosthetist and

Orthotist in private practice in Albany, NY. He is one of three owners of Clinical Prosthetics and Orthotics, and their office locations range from Saratoga Springs to Poughkeepsie, NY. Originally from Guelph, Ontario, he received his Bachelor of Science in Human Kinet-

ics from the University of Guelph. He then went onto postgraduate work in Orthotics and Prosthetics at George Brown College, Toronto, Ontario. Since then he has continued his education and has completed his Masters in Business Administration. David has been practicing in Albany, NY, since 1998.

Not only does David provide services to people with CMT, he has CMT. He was born with it, as was his son Ethan. David assisted his family in determining the genetic source by working with the Lupski Laboratory at Baylor College of Medicine. It is an isolated and unique form of CMT1B.

David looks forward to contributing to the CMTA and is excited to be part of a great team.



JAMES NUSSBAUM, PT, PHD, SCS, EMT is the Clinical and Research Director of ProHealth &

Fitness PT OT, a physical and occupational therapy organization in New York.

His career was fueled by his experiences as a physical therapy patient and working for Johnson and Johnson as a health and fitness specialist. James graduated from Touro College with a Masters of Science in Physical Therapy. He later earned a PhD in pathokinesiology, and then board certification as a Sports Certification Specialist.

James has had both his knees and his right ankle reconstructed and personally knows rehabilitation.

Over the past 8 years, James' clinical and research focus has been on the effects of innovative therapy interventions in medically complex patient populations. James has lectured and presented his research around the world, and has a particular interest in finding ways to enhance and document patient improvements in activities of daily living, mobility, balance, function, and, most importantly, quality of life.



SUSAN SALZBERG, OTR/L, MOT is a retired Occupational Therapist who lives in

Chapel Hill, NC. Although in the early years of her practice (1971-1980) she worked in Mental Health and Pediatrics, the majority of her experience has been with adult rehabilitation and acute care, most recently at the Durham Veteran's Affairs Medical Center.

Susan was diagnosed with CMT1A when pregnancy exacerbated the symptoms of her prior diagnosis: "walks like her dad." The diagnosis proved to be an affirming moment, since it explained the problems she had been dealing with since early childhood.

She enjoys photography, swimming, writing, and reaching out to people. In 1990 she started a CMT Support Group in Chapel Hill which moved to Raleigh in 2006. She is a supporter of the CMTA's initiatives and a contributing moderator of the CMTA's discussion forum "OT and CMT." ★

Spotlight on Flora Jones

Mississippi/Louisiana Support and Action Group Facilitator

At a very young age I remember sprained ankles and painful feet, but I tried to run like other kids. At age 13 the surgeries began, and they lasted for five summers to “straighten” both feet. I thought my problems were solved. After two years of college, I worked, got married, and had three children.

After my children were all in school, I went back to work taking care of private patients in hospitals, nursing homes, and homes. About age 45, it became evident that something was wrong, as my legs were getting very weak, and I was losing hand function. In 1982 I was told I had CMT at an MDA clinic. At last I had a name, but what was it and what would happen next?

I could find no one with answers until a family in New Orleans gave my sister information about CMT International. In 1988 we went to a conven-

tion in Toronto, and there were about 200 people who had feet and hands similar to mine! There were many doctors there who learned so much from us. They were surprised to find that 30 of us had breathing problems.

Since I now had access to a lot of information, I began “teaching” everyone in the medical field at every opportunity. About 1993 a family in the Jackson, MS, area organized the first local meeting. They had thought they were the only people with CMT until they saw a person with the “walk.” I learned about the CMTA from this family. The support group meetings and my passion to educate others have been a priority for me, and somehow I became the leader!

Since I now require so much physical help, my daughters or my husband assists with mailings to papers and members, setting up tables, etc. We

have a speaker at some meetings, but many times there seems to be such a need to share things, especially if there is a person who is new to the group. I encourage my members to join the CMTA, and I give out reports and brochures, provide research updates, and encourage giving to STAR.

I am now 75 years old and have not walked for 17 years. I have very little hand function and use a Bi/Pap Avap machine to assist my paralyzed breathing muscles. Talking is often difficult, as my vocal cords are affected. However, when a doctor asks me if I have anything new about CMT today or when one says “I would not have known about CMT had I not met you,” then I know I cannot stop what I do yet!

I am Flora Jones with the Mississippi support group, and I appreciate so much the work each of you does for all of us. ★



Flora Jones, with help from her husband Billy, never fails to tell people about CMT.

CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
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Address: _____



Heads I Win, Tails You Lose

The Americans with Disabilities Act and the “Interactive Process”

BY MICHAEL NEEDLEMAN, ESQ

By now we are, of course, familiar with the Americans with Disabilities Act. The ADA protects against disability discrimination in the workplace, and perhaps most visibly, in places of public accommodation. (We have the ADA to thank for the wheelchair ramp cut-outs on every street corner in every city in America.) While it is easy to see whether disability discrimination has taken place in the context of a public accommodation (consider a baseball stadium with only stairs or a train station with no elevator), discrimination in the workplace is not nearly as easy to spot. In fact, unfortunately, times when overt disability discrimination has occurred, the employee ends up losing the case in court anyway.

The goal of this article is to highlight one important, but often overlooked, requirement of the ADA—participation in the “interactive process.” As will (hopefully) become clear, this aspect of the law is particularly important to those with CMT.

Is CMT a disability?

Before we discuss the interactive process, we should start at the beginning—by asking whether CMT is a “disability” within the meaning of the ADA. The answer to this question seems intuitively obviously “yes,” but it is actually not quite so clear. The ADA strictly defines *disability* by the nature of the condition’s

impact on the affected person, rather than the description of the condition or its potential affects. In other words, someone newly diagnosed with cancer is not, simply because of the diagnosis, disabled. Often, unless CMT has left the affected employee in a wheelchair, it will be necessary to get a note from your physician describing what CMT is, its effect on your hands, feet (or both), and how those symptoms affect a “major life activity.”

Is CMT a disability within the definition of the ADA?

Major life activity is defined as walking, working, performing fine motor skills, and the like. While this is surely most people suffering from CMT, it is at least theoretically possible that a person, who has just been diagnosed with CMT (through, for instance, a blood test) and has yet to display significant symptoms, might not be considered disabled for purposes of the ADA.

What is the interactive process, and when must it be utilized?

As we have all heard, the ADA requires “reasonable accommodations” for disabled employees in the workplace. There is no set definition for reasonable accommodations and what is reasonable may depend on the nature of the job, the size of the employer, the nature of the

requested accommodation, and whether, how, and to what extent other employees may be affected by the implementation of the requested accommodation. Finally, even if the accommodation itself is reasonable, it may nevertheless be refused if it creates an “undue burden.” For instance, in one highly notable case, the US Court of Appeals sitting in Chicago found a public employee’s request to modify a desk chair sufficient to constitute an undue burden, as, theoretically, the municipal employer could never turn down an accommodation request no matter how expensive, as it will simply raise taxes to satisfy the request.

In the ordinary course, an employee with a disability, such as CMT, must notify his or her employer of the disability at the time that an accommodation is requested. (As noted, some medical documentation may be necessary, such as a letter from a physician). Once the request is made, the ADA requires that an interactive process take place. That is, the employer and the employee must have some type of communication to allow the employer to better identify how a reasonable accommodation may be made. This process need not be formal, and can be as short and sweet as a five-minute face-to-face conversation in a plant manager’s office, or as

(continued on page 8)

HEADS I WIN

(continued from page 7)

complicated as a home-based insurance claims adjuster filling out a four-page questionnaire. It is important to bear in mind, too, that the interactive process requires only a “good faith” conversation on the part of the disabled employee and employer to try to come to some reasonable accommodation. If, ultimately, no such accommodation can be found, the employee’s employment could be terminated.

Perhaps most importantly, the interactive process is, for the employee, a game of heads I win, tails you lose. That is, if the employee fails to engage completely and in good faith in the interactive process, the employee will almost certainly be unable to succeed in any future lawsuit against the employer for disability discrimination. The judge will

instruct the jury that if it finds a failure to participate on the part of the employee, it cannot find in the employee’s favor. This is true no matter how intuitively obvious or simple, or incredibly complex, the requested accommodation might be.

On the other hand, if the employer fails and/or refuses to engage in the interactive process, that failure and/or refusal may only be used as evidence of the employer’s discriminatory animus. Typically, the interactive process is triggered when the employee makes a request for accommodation. Employers are not obligated to choose the accommodation that is suggested by an employee, and the employer may choose the accommodation that is most beneficial to the employer; the only key is that the accommodation be effective when implemented. Employers cannot be

found liable for failing to engage in the interactive process, so long as they prove no reasonable accommodation could have ever been made.

As with many of our laws, the ADA works, in practice, much less well than in theory. The bottom line is that for persons affected by CMT, when a reasonable accommodation is needed from your employer, arm yourself with as much documentation as your physician is willing to provide, and be sure to attend every meeting requested by your employer to discuss reasonable accommodations; answer every question posed by your employer; and, finally, have in mind both the accommodation you would ideally want, as well as a back up you can request. Following these steps, you should keep yourself in good stead for purposes of the ADA. ★



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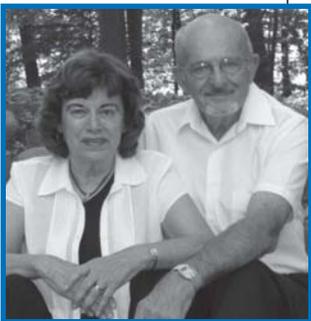
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Clarence and Dee Van Heuvelen celebrated their 50th wedding anniversary. In lieu of gifts, they asked that donations be sent to the CMTA.

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,
CMT runs in my family. My mom has it and passed it on to me. I have a 13-year-old daughter who also has CMT, and I feel terribly guilty that I gave her this horrible disease. What makes matters worse is that she is so angry all the time and outwardly blames me for all her physical problems. Help! I just don't know what to do anymore.

David replies:

I know for sure that all the Moms reading this who have angry teenage kids are saying to themselves, "Yeah, I know what that's like."

So, before we begin to talk about your daughter's anger, let's look at your feelings of guilt about "giving this horrible disease to her." You would never knowingly have given your child CMT, just as your mother would never have "given" it to you. This is not your fault. We do not know why life hands us these challengers, but it happens and how we deal with it makes all the difference in the world.

Your need to practice self-forgiveness and to replace self-hate with self-love is your most important task. You might also explore if you have any remnants of angry feelings toward your mom as well. These feelings are normal. We sometimes feel guilty for being angry especially towards our parents. Accepting our feelings of anger can help us avoid feelings of shame and guilt. Feelings of fear and sadness are often lurking right under our anger. Again, all

these feelings are normal, but it helps to know and accept what we are feeling before we try to understand the feelings of others. Accepting and truly loving yourself will go a long way in providing an emotionally strong and peaceful presence and role model for your child.

Teens often have the hardest time with their negative emotions. Helping teens realize that their anger is a reaction to another emotion such as guilt, shame, anxiety, or embarrassment will allow them to understand the meaning of their anger, to learn problem-solving skills and develop the awareness that will allow them to maintain composure. It's always helpful to teach teenagers to learn to openly and honestly discuss their thoughts and feelings. More than anyone else, you can empathize and understand what your daughter is feeling. I am sure she is also struggling with her intense need to be soothed by you while being angry with you at the same time. You are the one person she trusts enough to let out her frustrations! Lucky you! When there is a moment of calm, remind her how much she is loved and cherished by you. She might push away and not want to hear it, but remind her anyway. Feeling love from you, regardless of the problems of CMT, will strengthen her emotional foundation and help her develop the tools she eventually needs to love herself. Teaching children some calming exercises, like deeply breathing from the diaphragm, slows the heart rate

and can have a calming effect. Also, some form of exercise can help stimulate the release of endorphins, a brain chemical that can also create a feeling of calm. These are activities that you can do together and help remind her that you are truly in this together. There is also an online chat group for teens with CMT. The site is on Facebook and can be accessed at <http://www.facebook.com/#!/groups/112378272199073/> It might be easier for your daughter to express her feelings with other kids who know exactly what she is experiencing. If you are currently in a CMT support group, please request some time at the beginning of the group to share what you are going through. There is a lot on your plate, and I am sure you feel overwhelmed at times. I know many parents can relate to what you are experiencing. If you need some outside support, please try to find a counselor. Just remember that you deserve the help you need and that you are not alone. ★



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.

WEBSITE FOR COLLEGE STUDENTS WITH DISABILITIES

A college student has created a website called "We Connect Now" to serve college students with disabilities. The website connects and integrates students with disabilities in a virtual community. Since its launch in 2008, the website has been linked to by colleges and universities and groups serving people with disabilities in 50 states and at least nine foreign countries.

Visit the site at <http://weconnectnow.wordpress.com>



New Corporate Partnership: Allard USA

The CMTA is pleased to announce a partnership with renowned orthotic device manufacturer and distributor, Allard International, based in Helsingborg, Sweden and Allard USA, based in Rockaway, New Jersey. Allard International has been a leader in the creation of innovative orthotic devices for over 50 years. Allard USA services North and South America. The partnership combines the philanthropic spirit of the Allard

companies, with the CMTA's mission of improving the quality of life for those affected by CMT.

"Allard provides an innovative line of Ankle Foot Orthoses (AFOs) which has proven successful with many patients living with CMT," said Pat Livney, CEO of the CMTA. "Through a committed relationship with Allard USA, the CMTA is grateful to provide opportunities to improve the

quality of life for CMT patients across the country."

Studies have shown that early intervention through orthotic devices can maintain range of motion on the ankle as well as compensate for muscle weakness and instability. In one study, some patients walked up to 60% faster with braces than without.

The Allard companies distribute the ToeOFF Family of products, offering multiple styles of carbon composite devices, designed to assist with foot drop, ankle instability, and proximal neuromuscular weakness—all symptoms of CMT. Allard also features the KiddieGAIT, a brace specifically developed for growing children as young as 9 months.

"We created the Dralla Foundation, a not-for-profit organization with the mission to provide 'support for better life' for children and adults with disabilities, by helping them to fulfill their dreams or visions," said Peter Allard, President and CEO of Allard International. "Our partnership with CMTA is a major expansion in this evolution to 'give back.' There is no doubt in my mind that this partnership will change many lives—for the better!"

The Allard ToeOFF Family is often recommended for those with CMT. People who use these devices have reported increased endurance while walking, the ability to walk more upright, more ankle stability, and less tripping over their toes. ★

For more information, please visit www.allardusa.com.

allard USA

REPRESENTING THE CMTA IN WASHINGTON, DC

On May 1st in Washington, DC, the President's Council on Fitness, Sports & Nutrition (PCFSN) convened for their annual meeting. The council is co-chaired by Drew Brees, quarterback of the New Orleans Saints and Dominique Dawes, who won a gold medal in gymnastics at the 1996 Atlanta Olympic Games. The mission of the PCFSN is to engage, educate, and empower all Americans to adopt a healthy lifestyle that includes regular physical activity and good nutrition.

In attendance was 12-year-old Julia Beron, daughter of the CMTA's Chairman of the Board Herb Beron. Julia represented CMT patients and the CMTA while participating in the Jammin' Minute Activity (a product of the JAM School Program). The JAM program is a free wellness resource for schools which brings physical activity and health education into the classroom. Julia's specific exercise was "raise the roof" stretches with the members of the President's Council; she then talked about her CMT and asked questions that were specific to CMT and exercise. Afterwards Julia participated in a roundtable discussion with all members about how young people can be leaders to promote a healthy lifestyle. All in all it was a tremendous day for Julia (one that made her parents beam with pride!) and the CMT community. Julia looks forward to continue to be an advocate for children with CMT.

—Herb Beron, Chairman and President of the CMTA

For information on the PCFSN, you can access their website at www.fitness.gov.

For information on the JAMmin school program, visit their website at www.jamschoolprogram.com.

A personal thank you to Deb Vangelos (wife of board member Vasi Vangelos) for introducing Julia and the CMTA to long-time friend Patti Howell (Founder and CEO of Health-E-tips/JAM School Program). Without Deb and Patti, none of this could have happened.



Julia Beron participated in an exercise program and answered questions about CMT.

You May Be Entitled To Social Security Disability Benefits

BY PHYLLIS SANDERS

The Social Security Administration oversees a program that provides for payment of disability benefits to individuals who have contributed to the Social Security Fund through taxes on their paycheck. To be eligible for Social Security Disability benefits, the applicant must have a work history of five of the last ten years. The Social Security Administration has rules for determining whether a person is disabled. The applicable regulations define disability as the inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months. Social Security Disability benefits are not intended for short term disability.

A medically determinable physical impairment is one which results from physical or psychological abnormalities which can be demonstrated by medical evidence consisting of signs, symptoms, and laboratory findings. Very often a disability finding can be based on a combination of both physical and mental components. A list of subjective complaints without medical treatment and diagnosis will usually not be sufficient to prove a disability.

Under the guidelines you are considered disabled if you can no longer perform any type of work for which you are suited based upon your health, your

age, and your educational background. Please note that you will not be eligible for benefits if there is any type of work that you can do. You do not have to be able to perform your usual and customary work as long as there is some work you can do. Even when it seems clear cut that a person is entitled to receive disability benefits, the Social Security Administration may deny benefits, based on its assessment that the applicant can perform a job in the workplace.

The most efficient way to apply for benefits is by filing an application at your local district office. You may also apply by phone or mail. Once your application is filed, the Social Security District Office will screen it to determine that you meet the nondisability requirements under the regulations. The District Office will review whether you have worked long enough and recently enough to qualify for benefits.

If it is determined that you meet the eligibility requirements to receive benefits, your application will be forwarded to a Disability Determination Officer. It is at this point that your claim is evaluated by a physician or psychologist and a disability specialist. Medical report forms will be forwarded to your treating doctors. The completed forms will be analyzed and a determination made. Upon approval, your first check will include benefits dating back to six months from the date that your disability began. The amount of benefits you will

receive is based upon your earnings covered by Social Security.

If you are denied benefits you can apply for reconsideration. This process takes place in the same office as the original evaluation. If you are denied again, you can file an appeal. Appeals are heard before an independent administrative law judge. He or she will review the papers and the original findings. An actual hearing may be scheduled. You should consider consulting with an attorney to represent you in the appeal process. Typically the contingent fee is 25% of the retroactive benefits up to a maximum of \$6,000. ★

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:

GET'N WIGGY FOR CMT

Mr. Bryan J. Albright
Dr. Eric Pickering
Mr. Steve Reynolds
Mr. and Mrs. Michael and
Melanie Streng
Mrs. Donna Widmer

EVERY PENNY MAKES A DIFFERENCE

Ms. Casey Ewing
Ms. Susan Ward

CLIMBING FOR CMT

Mr. Tom Anderson
Mr. Miguel A. Avellaneda Rivera
Ms. Allesen Cann
Ms. Mary Castellucci
Mr. Olivier Collignon
Mr. Ashish Goyal
Mr. Jack Guedj
Mr. Deepak Gupta
Mr. Peter Halpin
Ms. Dana Harrold
Mr. Edward Hieatt
Mr. Derek Hill
Mr. Jasper Jackson
Mrs. Agnieszka Jacquet
Mr. Rob Mee
Ms. Meta Mehling
Mrs. Kerri Mesa
Mr. Neale Minch
Mrs. Elizabeth Ouellette and
Mr. Giles Bouchard

Ms. Vikki Pachera
Ms. Shauna Peterson
Ms. Beverly Rooney
Mr. Thomas J. Scannell
Mr. Samir Shah
Ms. Eva Shepherd

DI BILLOCK'S 10K FOR THE CURE

Mrs. Angela Billick
Ms. Karen Huizenga
Dr. Paul Sommer

SWIMMING FOR THE CHILDREN

Leyhane & Associates, Ltd.
Mr. and Mrs. Daniel Lopez

TOM AND SERENA'S SOUTH DAKOTA CIRCLE OF FRIENDS

Ms. Angela Graham

SARVER FAMILY CIRCLE OF FRIENDS

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Ms. Colleen Malloy

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Bernstein & Bernstein, Inc.
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Ms. Nathalie Blossom
Mr. and Mrs. Mark Deitch

Sigrid H. Desoi
Ms. Kasey Devarenes
Ms. Maristela Dunn
Mr. and Mrs. David Ellis
Ms. Kay C. Fields and Family
Mr. David M. Frank
Mr. and Mrs. Steven C. Freedland
Ms. Laura Goldwasser
Mr. and Mrs. Robert J. Gould
and Family
Ms. Lisa Gutman
Hidden Hills Community Assn.
Mr. and Mrs. Howard Horowitz
Ms. Lucia M. Jacobson
Mr. William J. Koch
Mr. and Mrs. Michael Kotal
Ms. Andrea Shankman-Lascoe
Mr. and Mrs. Robert Lopata
Ms. Janet L. Markowitz
Ms. Jeanne Ann Moore
Ms. Lisa Moriarity
The Nairin Family
Mr. and Mrs. Ralph Peris
Mr. and Mrs. Jeffrey Rome
Mr. Theodore Rosenquist
Mr. and Mrs. Craig Shandler
Mr. and Mrs. David M. Shulman
Mr. Scott Silveira
Mr. and Mrs. David G. Stanley
Ms. Jodi Lee Tenenbaum
Ms. Camille Treacy
Ms. Kimila Ulrich
Mr. and Mrs. William Vangelos
Ms. Debbie Wolf



SUPPORT AND ACTION GROUP NEWS

CT—North Haven

The group met on March 29th.

The speakers for the meeting were two doctors and a kinesiologist from the Connecticut Children's Medical Center, who answered questions from the group members. Everyone shared their personal CMT stories and talked about what kind of speakers they'd be interested in having for future meetings.

DC—Metro Area

The group met on March 31th.

The group participated in an informative discussion about living with and caring for people with CMT. Many thanks to Erica Berger for leading the meeting. One focus of the discussion was the CMTA's travel card that informs airport security and others about CMT. They also discussed the list of health care resources for people in the DC metro area with CMT. The group was encouraged to ask their members of Congress to sign a letter urging President Obama to officially designate September as National CMT Awareness Month.

FL—Inverness Area

The group met on April 28th.

The speaker was Susan Reeder, PhD. Dr. Reeder is a licensed psychologist with a clinical practice in Citrus County since 1993. She spoke about the psychological management of pain and the impact of chronic illness on the family.

FL—Tampa Bay Area

The group met on March 10th.

The group discussed the recent Alternatives to Pain Management Therapies Seminar. Topics

included meditation, healing touch, acupuncture and a presentation on attitude and activities as tools for coping. They also discussed all of the activities and goals of the CMTA and the moderated discussion groups on the CMTA website.

MI—Southwest Michigan

The group met on March 22nd.

The group discussed recent developments in CMT. They also spoke about and genetics and genetic testing.

NC—Triangle Area

The group met on March 24th.

The guest speakers were Patrick Livney and Jeana Sweeney. Pat spoke about the research being done (STAR Initiative). He explained that there are two scientists at NIH whose salaries are paid for by the CMTA who are working on research specifically aimed toward finding treatments for the various types of CMT. They are zeroing in on two compounds (already approved by the FDA) that may provide a treatment for CMT 1A. Jeana spoke about "painless ways" of fundraising, including the Circle of Friends on the CMTA website, www.igive.com, and designating your donation if you donate through United Way. There are a lot of ideas on the website's "Anyone Can Fundraise" Group.

NY—Upstate NY

The group met on March 17th.

The guest speakers included Ken Cornell, Vice President of Cornell O & P; David Misener, CPO, and Glen Case, CPO of Clinical Orthotics & Prosthetics and Laurie Lasky, RFM, North-

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.*

east District Manager of Allard USA, worldwide leader of innovative orthotic devices. Mr. Cornell gave a very informative presentation on CMT and demonstrated some of the types of AFO that are available. At the conclusion of the presentation, attendees were invited to try on some of the braces, and all of the guests stayed to answer questions.

WA—Tacoma

The group met on March 10th.

The group discussed cannabis from a more personal level rather than the medical perspective. Those that take medicinal medicine spoke of a decrease in prescription medication and an overall better well-being. Muscle relaxation, a calming effect, and a good night's sleep were some of the top reasons people spoke with their doctor and got a prescription for marijuana. It was highly recommended that everyone speak with their doctor before starting or stopping any medications.

Canada—Southern Ontario

The group met on April 28th.

The group members were welcomed for the 1st CMTA meeting in Canada! The group was presented with the CMTA marketing piece and publications and was updated on Awareness Month. The group also discussed the upcoming fundraiser that is being held on September 30th. ★

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—Stockton

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

CA—South Bay Area

San Francisco Peninsula/
South Bay CMT Support and
Action Group
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area

San Diego, CA CMT
Support and Action Group
Steve Gabbert
619-987-6022

CA—Santa Rosa Area

Santa Rosa, CA CMT
Support and Action Group
Carol O'Bryan
707-823-0165

CA—Visalia Area

Visalia, CA CMT Support
and Action Group
Melanie Pennebaker
559-972-3020

CO—Denver Area

Denver Area CMT Support and
Action Group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—North Haven

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

DC—Washington, DC Area

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

FL—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

*IA—Great Lakes

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

IL—Chicago Area

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

IN—Fort Wayne Area

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

KS—Wichita Area

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

KY—Burlington Area

Pam Utz
859-817-9338

MD—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
410-820-0576

ME—Portland Area

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

MI—Chesaning Area

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

MI—Kalamazoo Area

Southwest Michigan CMT
Support and Action Group
Jori Reijonen
269-341-4415

MN—Benson Area

No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area

No group currently meeting
Will accept calls
Libby Bond
417-845-1883

MS—Mississippi/Louisiana

Clinton, MS CMT Support
and Action Group
Flora Jones
601-825-2258

NC—Triangle Area

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

NJ—Central NJ Area

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

*NJ—Morris County

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

NM—Albuquerque Area

CMT New Mexico CMT
Support and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area

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

NY—Upstate NY 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
Shari Loewenthal
631-254-8960

NY—Westchester Area

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

OH—Cleveland Area

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

OH—Greenville Area

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

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

SD—Hartford Area

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

TN—Nashville Area

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

TN—Savannah Area

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

TX—Dallas Area

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

UT—Orem Area

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

VA—Harrisonburg Area

Anne Long
540-568-8328

VA—Williamsburg Area

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

WA—Seattle Area

Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WA—Tacoma Area

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

WI—Milwaukee Area

Southeastern, WI CMT
Support and Action Group
Polly Maziasz
262-439-9009
Margaret Hoepner
414-788-9628

WI—Brodhead Area

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

*WV—Vienna Area

Parkersburg/Vienna WV
Support and Action Group
Rebecca Knapp
304-834-1735

GROUPS IN CANADA AND MEXICO

*CAN—Ontario

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

*CAN—Montreal

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

*Mexico

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

VIRTUAL/DISCUSSION GROUPS

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

**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.**

Problems with No Solutions

I think I'm a very clever turtle and that I can figure my way out of most problems. What I have come to realize recently, though, is that I can't solve other people's or animal's problems. I thought I would do something altruistic (not because I'm necessarily so thoughtful,) but because I'm hoping to win the

award at the end of fifth grade for community service. In any case, I thought it would be easy enough to start a Dear Archy column in our school newspaper, *The Screech Owl Gazette*, where I would answer questions about health issues, social problems, and just regular old complaints about school.

When the column was first announced, it was met with some fairly rude comments and laughter. I don't think my classmates thought anyone would actually write in. That was not the problem. The problem was what they wrote about.

My first failure was a question from one of the rabbits in fourth grade. He has a form of ataxia. (I had to look that one up, and he has terrible balance problems.) He wanted me to tell him how to be a rabbit without being able to hop. I think that question must be a lot like the ones humans encounter when CMT makes it impossible for them to do the very job that defines who they are. How do you answer them when they are so dejected? With humans, you can tell them to try to switch from the really demanding physical job into something a little more intellectual or go for vocational rehabilitation. But how do you tell a rabbit not to hop? I made a mess of that one.

Then, I got a letter from a little girl squirrel. Her tail was not the tail of a typical squirrel.

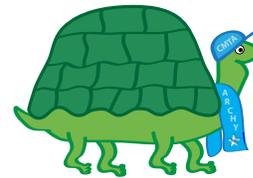
I know it's wrong to put too much emphasis on appearance, but a squirrel's tail is what makes it a squirrel. Hers was so thin and limp that she didn't do any swishing when she walked, and it couldn't keep her warm on really chilly days. She was being picked on and bullied. I was teased when I first got my AFOs, but once I

explained that they were braces like other kids had on their teeth, everyone just sort of dropped it. How could she take the

attention off of her skinny tail? I did suggest that she find something that she was really good at—maybe running or storing nuts or doing math problems. The best way not to get teased is to do something that others admire and which will take the attention off the thing that is a negative.

Then, the worst question of all came from another turtle who wanted to know how to tell someone that you like them without actually coming out and saying it. The reason that's the worst question is because she was asking about telling *me*, and I didn't have any idea how to answer her. I have a girlfriend, but I didn't want to hurt her feelings.

So, here's my advice—don't give advice. It's a horrible task. Lucy, in the Peanuts cartoons, might have been able to charge 5 cents and do well, but it's certainly not my strong suit, even if I think I'm pretty clever. ★



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

CHANGES IN THE NEUROTOXIC DRUG LIST

For the first time in five years, new drugs have been added to the list which was originally compiled by Dr. Louis Weimer in 2007. The two new drugs are used in the treatment of cancer, while the other change involves a reclassification of antibacterial medications.

The first drug class is the fluoroquinolones including the most commonly prescribed ciprofloxacin (Cipro). Cipro is used to prevent infections that are proven, or strongly suspected, to be caused by bacteria. Before taking this drug, it is suggested that you tell your doctor about any nervous system problems, such as a peripheral neuropathy. It is frequently prescribed for urinary tract infections. The class will move up on the list from negligible or doubtful risk to causing uncertain or minor risk.

The next drug is ixabepilone, marketed with the trade name, Ixempra. It is used in the treatment of metastatic or locally advanced breast cancer. The drug can cause decreased sensation, numbness, and tingling in the hands and feet. Some patients have difficulty walking. The problems may continue as long as the therapy is continued. It is on the list under the heading, moderate to significant risk.

The final drug is eribulin which is marketed under the name, Halaven. It is advised that patients tell their doctor if they have impaired blood circulation before beginning this treatment. It is a treatment for patients with breast cancer who have tried at least two other types of anti-cancer medicines. This treatment may cause numbness, tingling, or burning in the hands and feet. Peripheral neuropathy is the most common side effect causing patients to discontinue taking Halaven. It appears on the neurotoxic drug list under the heading, moderate to significant risk.

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If you are a subscriber or are subscribing now, you may purchase publications and accessories at discounted prices. (Some exclusions may apply.) To check your subscription status, please call 1-800-606-2682, ext.105.

Grand Re-Opening of the CMTA Online Store!!

The CMTA Store is back and ready for business! When the new CMTA website launched in March 2011, the CMTA Store was unavailable. But, as of December 2011, the store is up and running. Take advantage of the store to get all of your CMT needs, including publications, multimedia products, and accessories to help raise CMT awareness. Also, with the opening of the store, we have added some fun new products!



NEW! CMTA T-shirts

Buy one for you and don't forget your family members! The t-shirts are available in blue and white.



NEW! CMTA Titleist hats

People will go out of their way to ask you where you got this cool-looking cap! The hats are available in blue, red, and black.



NEW! Light-Up Star Necklace

Show your support for the STAR Initiative with this light-up necklace. Includes battery and cord.

ONLINE DISCOUNTS

- Community members will receive 10% off each item (to be able to receive this discount be sure you are logged in on the website).
- Premium Content members will receive 20% off each item (to be able to receive this discount be sure you are logged in on the website).

Visit our store at <http://www.cmtausa.org/url/store>.

SUBSCRIPTION OPTIONS		NEWSLETTER FORMATS			
NEWSLETTER	Premium Content <i>(with access to more online material and features)</i>	<input type="checkbox"/> PDF only.	\$25 <i>(must register/purchase online)</i>		
		<input type="checkbox"/> Both PDF and print.	\$30 <i>(must register/purchase online)</i>		
	Mail Only <i>(NO access to online premium content)</i>	<input type="checkbox"/> Print only.	\$30		
		QUANTITY	COST		TOTAL
			Regular Price	Subscriber Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]			\$15	\$12	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]			\$10	\$8	
CMT Facts III			\$7	\$5.60	
CMT Facts IV			\$10	\$8	
CMT Facts V			\$15	\$12	
CMT Facts VI			\$15	\$12	
My Child Has CMT			\$7	\$5.60	
Cooking and Coloring Adventures with Archy			\$10	\$8	
Teaching Kids about CMT...A Classroom Presentation (DVD set/1 hour)			\$10	\$8	
CMTA Titleist Hats Quantity and Color: Black___ Blue___ Red___			\$25	\$20	
CMTA T-Shirts (Blue with white logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___			\$15	\$12	
CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___			\$15	\$12	
Be a STAR Wristbands			1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each		
Be a STAR Necklaces <i>(Includes battery)</i>			1-5, \$3 each 6-10, \$2.50 each 11 or more, \$2 each		
CMTA Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List			FREE		
Donation to the CMTA (100% Tax-deductible)					
Shipping & Handling <i>(Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)</i>					
ORDER TOTAL					

Check payable to the CMTA *(US residents only; non-US residents, please use credit card or international money order.)*

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

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

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

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

THE CMTA Report

The Charcot-Marie-Tooth Association
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www.cmtausa.org

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WHAT IS CMT?

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