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 Bhattacharyya and Dr. John Svanen at the University of Wisconsin.
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.

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

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

BY GARY GASPER

Nearly 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 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 trials, 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 different 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 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 Neuromuscular 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.”
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 convention 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
☐ Thank You ☐ Anniversary ☐ Other

Memorial Gift:
In memory of (name of deceased) __________________________________________________________

Send acknowledgment to:
Name: ____________________________________________
Address: ____________________________________________

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

Gift Given By:
Name: ____________________________________________
Address: ____________________________________________
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 within the definition of the ADA?

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.”

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, 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. 

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:
Ann Arbore
Full Moon Properties LLC
Larry Blewins
Mr. and Mrs. Randy Ronish
Kurt Brun
Ms. Yolette Nussbaum
Betty Chow
Ms. Jean H. Kaung
Ms. Rose H. Yuen
John Cooper
Ms. Christina Kealey
Mr. and Mrs. Joe Rawson
Jeff Gerry
Mr. and Mrs. Allan Lee
Roger Grissier
Mr. and Mrs. Ray Harrel
Crystal Groce
Mr. and Mrs. Larry Levetor
Seymour Helfant
Ms. Marsha Siegel
Mark Hollingshead
Donelson/Jere Baxter
Chapter #197 RAM
Mr. and Mrs. Victor Fregos
Peg Leahy
Mr. James J. Gomez
Harold Levatter
Ms. Lois D. Brown
Mr. and Mrs. David Meyer
Ms. Naomi Rice
Mr. and Mrs. Jerry Schroeder
Ms. Janice E. Thornburg
Emma Leverence
Mr. and Mrs. Donald E. Leverence
Leonard Lietz
Mrs. Granada Lietz
Reta Londoner
Mr. and Mrs. Judah Maze
Arthur Plouffe
Mr. and Mrs. Gregory Mueller
Rensselaer Teachers’ Association
Ms. Paula Rixinger
Mr. and Mrs. Paul Rixinger
Roger Redick
Mr. and Mrs. Gerry Beausang
Mr. Robert F. Carter
Ms. Margaret Carter
Mr. Steve DeCarlo
Mr. and Mrs. Ben Hickok
Ms. Loretta Hunter
Mr. and Mrs. Jordan Locke
Mr. and Mrs. Clarence Root
Mr. and Mrs. Ed Ryment
Mr. Dennis Saucerman
Mr. Jerry Smith
Mr. and Mrs. Rich Vales and Family
Mr. Ralph Vemmer
Mrs. Anca Wass
Mr. and Mrs. Brandon Wilson
Mr. and Mrs. Brian Wittling
Shirley Rumfelt
Mrs. Ada Kay St. John
William “Bill” Steele
Equine Journal Staff
John Wittenmuth
Doris Wittenmuth
Judy Joyce
Mr. Stephen Joyce
Billy Kennerly
Ms. Carolyn Fulghum
Zachary Korowitz
Ms. Elayne Korowitz
Diane Kosik—Happy 60th Birthday
Ms. Lori Gordon
Kim P. Marshall
Mr. and Mrs. Leslie E. Smith
Michael Needleman
Mom and Dad
The Oramdy Family and all of the descendants
Brian Ruediger
Phyllis Sanders
Maier Foundation, Inc.
Kelsey Shinnick
Mr. Joe L. Williams
Clarence and Dee Van Heuvelen—Happy 50th Anniversary
Ms. Carolyne Y. Estelle
Mr. A. Gorlet
Mr. Ralph Hoffman
Mr. Nicholas H. Keegstra
Mr. and Mrs. Robert J. Mais
Mr. and Mrs. Corry Oosterhous
Mr. and Mrs. John Prins
Mr. and Mrs. Dean Van Bruggen
Mr. and Mrs. Marvin Van Heuvelen
Mr. and Mrs. Duane A. Van Solikema
Mr. and Mrs. Harold VanDyken
Heather Winslow
Mr. Brian Allen
Mr. and Mrs. Edward Bousquet
Mr. and Mrs. George Carr
Ms. Danielle Oslack
Mr. and Mrs. Wallace Houghton
Mr. and Mrs. Daniel Prescott
Mr. and Mrs. Patrick Thibault
Mr. and Mrs. Lewis Winslow
Mr. and Mrs. Randall Winslow
Dallas, TX SAG
Mr. Maria Rodriguez
Atlanta, GA SAG
Mr. Zack Williams

IN HONOR OF:
Julie Collins
Lake Brantley High School—Congratulations on the Jefferson Award
John Ryland Gravens
Mr. Jack A. Graves
Flora Jones and the CMT Support and Action Group
Ms. Cindy Chesteen

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

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.
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 physical or mental impairment 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 non-disability 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 earning 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.
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 own 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-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 AFOs 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
Dixie 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
209-480-1716

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 Pennnabaker
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
Roni Plageman
352-880-1579

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 Pol伊ya
813-251-5512

GA—Atlanta Area
Atlanta, GA CMT Support and Action Group
Susan Rudiger
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
574-304-9608
Priscilla Creaven
260-925-1488

KS—Wichita Area
Kansas Area CMT Support and Action Group
Karen Smith
316-817-8852

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 Marfield
410-820-0576

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

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

MI—Benton Area
No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MI—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 Albers
601-225-2258

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

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

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

PA—Northwestern Area
Erie, PA CMT Support and Action Group
Joyce Steinkamp
814-262-8427

TN—Savannah Area
Savannah, TN CMT Support and Action Group
Carol Hadie
253-476-2345

WI—Milwaukee Area
Southeasten, WI CMT Support and Action Group
Polly Maziasz
262-439-9099
Margaret Hoepner
414-788-9628

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

WV—Vienna Area
Williamsburg, VA CMT Support and Action Group
Libby Bond
417-845-1883

Groups.
They can be found in the www.cmtausa.org.

* WELCOME TO OUR NEW SUPPORT 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 Squeech 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 something that is a negative. 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.

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.
### CMTA NEWSLETTER SUBSCRIPTION, PUBLICATIONS, AND ACCESSORIES ORDER FORM

**NAME:** ______________________ / ___ / ________________________

**ADDRESS:** ____________________________

**CITY:** ____________________________ **STATE:** _______ **ZIP:** __________

**COUNTRY/POSTAL CODE (IF NOT US):** ____________________________

**DAYTIME PHONE:** ________________ **EVENING PHONE:** ________________

**EMAIL:** ____________________________

***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.***

<table>
<thead>
<tr>
<th>SUBSCRIPTION OPTIONS</th>
<th>NEWSLETTER FORMATS</th>
<th>QUANTITY</th>
<th>COST</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premium Content (with access to more online material and features)</td>
<td>□ PDF only. $25 (must register/purchase online)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Both PDF and print. $30 (must register/purchase online)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mail Only (NO access to online premium content)</td>
<td>□ Print only. $30</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QUANTITY</th>
<th>COST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular Price</td>
<td>Subscriber Price</td>
</tr>
<tr>
<td>The Patients’ Guide to Charcot-Marie-Tooth Disorders (Print Format)</td>
<td>$15</td>
</tr>
<tr>
<td>The Patients’ Guide to Charcot-Marie-Tooth Disorders (CD Format)</td>
<td>$10</td>
</tr>
<tr>
<td>CMT Facts III</td>
<td>$7</td>
</tr>
<tr>
<td>CMT Facts IV</td>
<td>$10</td>
</tr>
<tr>
<td>CMT Facts V</td>
<td>$15</td>
</tr>
<tr>
<td>CMT Facts VI</td>
<td>$15</td>
</tr>
<tr>
<td>My Child Has CMT</td>
<td>$7</td>
</tr>
<tr>
<td>Cooking and Coloring Adventures with Archy</td>
<td>$10</td>
</tr>
<tr>
<td>Teaching Kids about CMT…A Classroom Presentation (DVD set/1 hour)</td>
<td>$10</td>
</tr>
<tr>
<td>CMTA Titleist Hats Quantity and Color: Black___ Blue___ Red___</td>
<td>$25</td>
</tr>
<tr>
<td>CMTA T-Shirts (Blue with white logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___</td>
<td>$15</td>
</tr>
<tr>
<td>CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___</td>
<td>$15</td>
</tr>
<tr>
<td>Be a STAR Wristbands</td>
<td>1-5, $1.50 each 6-10, $1.25 each 11 or more, $1 each</td>
</tr>
<tr>
<td>Be a STAR Necklaces (Includes battery)</td>
<td>1-5, $3 each 6-10, $2.50 each 11 or more, $2 each</td>
</tr>
<tr>
<td>CMTA Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List</td>
<td>FREE</td>
</tr>
<tr>
<td>Donation to the CMTA (100% Tax-deductible)</td>
<td></td>
</tr>
</tbody>
</table>

**Shipping & Handling** (Orders under $10, add $3.50; orders $10 and over, add $7.50)

**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.

---

**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).

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.