

# THE CMTA Report

SEPTEMBER/OCTOBER  
2012

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ [www.cmtausa.org](http://www.cmtausa.org)

## CMT Researchers Want to Know How CMT Affects You



### 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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The Inherited Neuropathies Consortium (INC) of the Rare Diseases Clinical Research Network (RDCRN) is conducting a research study looking at what symptoms and day-to-day issues are specifically important to adults with Charcot-Marie-Tooth (CMT) neuropathy. This study will help doctors and researchers develop a scale that will be able to measure CMT more accurately than the general ones currently available. A CMT-specific scale would increase relevance and potentially improve the ability to detect the effects of treatments in research for CMT. This study is called *INC 6606: An Analysis of the Symptomatic Domains Most Relevant to Charcot-Marie-Tooth-Neuropathy (CMT) Patients* (USF IRB#Pro00006746). This study is being conducted by investigators at the University of South Florida and the University of Rochester.

The study involves two surveys: a CMT research survey and a shorter muscle cramps survey. The surveys were written by Dr. David Herrmann and his colleagues at the University of Rochester, in upstate New York, after they asked their patients how CMT affects their daily life and what issues are important to them. Considering the informa-

AWARENESS MONTH 2012 HIGHLIGHTS

### NIGHT AT THE SOMERSET PATRIOTS RAISES AWARENESS

On Saturday August 11, 2012, the Morris County, NJ and Central NJ CMT Support & Action Groups held a fundraiser with minor league baseball team, The Somerset Patriots. Lori Mattheiss, Kate Mattheiss, and Alanna Huber put together a basket raffle with 24 items that drew crowds at the event and raised over \$3,000!

CMTA Board President Herb Beron made an on-field appearance, speaking to the crowd. Julia Beron sang the National Anthem to roaring applause from all in attendance. Carter Huber threw out the first pitch with his Dad, event sponsor William Huber of Panurgy, a leading IT solution provider in the NY metro area..

This successful event brought in \$11,940 and, after expenses, netted over \$9,400 for the CMTA!

tion they collected from their patients at the University of Rochester, they decided to produce the online surveys so that they could collect information from a larger group of people.

An e-mail containing a unique link to the online surveys was sent to all adult members of the RDCRN INC Contact Registry in the middle of July. Those who received an invitation will be able to access the online surveys until the middle of October. The researchers are hoping

that 500 or more members of the Contact Registry complete the study surveys.

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## NEW RESEARCH STUDY

(continued from page 1)

This study is for adults (18 years and older) with CMT who can read and speak English and joined the RDCRN INC Contact Registry prior to July 17, 2012. If you meet these criteria and received an email invitation to join this study, we encourage you to participate in this study and complete the surveys. (If you no longer have the e-mail with the link to the survey and want to participate, please send an e-mail using the e-mail address you have on file with the Registry to the Registry Administrator, Denise Shereff at shereffd@epi.usf.edu and she will send you your unique link.)

If you are not yet a member of the RDCRN INC Contact Registry, we encourage you to

join at [rdcrn.org/INC/register](http://rdcrn.org/INC/register) to be a part of future studies.

The CMT research survey is completed online, and should take about 40 minutes. Since it is possible to save your work and return to it, the survey doesn't have to be done in one sitting.

The muscle cramps survey is a shorter survey asking about muscle cramps in CMT. The researchers are interested in how

muscle cramps vary over a couple of months. Participants will be asked to complete the muscle cramps survey up to three times over a three-month period. For each muscle cramps survey, participants will be asked to keep track of their muscle cramps over a one-week period and then fill in the online survey. The survey should only take about five minutes to complete. ★

### FOR QUESTIONS OR MORE INFORMATION:

- More information on the study can be found at [rarediseasesnetwork.epi.usf.edu/INC/studies/CMT-6606.htm](http://rarediseasesnetwork.epi.usf.edu/INC/studies/CMT-6606.htm).
- More information on the RDCRN INC Contact Registry can be found at [rdcrn.org/INC/register](http://rdcrn.org/INC/register).
- If you have more questions about this study, please feel free to contact the study Principal Investigator, Dr. David Herrmann at (585) 275-1267, or by mail at Univ. of Rochester Medical Center; Department of Neurology, Neuromuscular Div.; 601 Elmwood Avenue, Box 673; Rochester, NY 14642-8673; Email: [care\\_of\\_janet\\_sowden@urmc.rochester.edu](mailto:care_of_janet_sowden@urmc.rochester.edu)
- For questions related to the collection of the study data at the University of South Florida, please contact Denise Shereff, MLIS, AHIP, (813) 396-9557, or by mail at University of South Florida; Data Management and Coordinating Center 3650 Spectrum Blvd., Suite 100; Tampa, FL 33612; Email: [shereffd@epi.usf.edu](mailto:shereffd@epi.usf.edu)

## PREGNANCY AND CMT

A recent article in the *European Journal of Obstetrics & Gynecology and Reproductive Biology* (Awater et al. 2012) has suggested that pregnancy may be a risk for women with neuromuscular disease including CMT. We are concerned about these conclusions with respect to CMT for several reasons. First, the study collectively included women with various forms of neuromuscular disease, so it was not specific to women with CMT. Some of the women in the study had various forms of muscular dystrophies (MD), spinal muscular atrophy (SMA), myotonic dystrophy (DM), and various forms of CMT. All of these disorders represent different diseases and different parts of the nervous system. Additionally, this group of disorders is highly variable in terms of the severity of symptoms, as some of the neuromuscular diseases included can be much more severe than CMT. Thus, it is not certain which diseases are more likely to be associated with problems. Second, we have followed many women with CMT going back as far as 1996. We have not noted problems with the vast majority of women with CMT during childbirth or pregnancy. Therefore, the findings in this study do not reflect our experience. Third, none of the complications listed in the study's table were significantly increased in women with CMT. Finally, this is a retrospective or "chart review" study in which the authors have not examined any of the patients. The study design was based on a review of the medical history and questionnaires that asked women if they experienced deterioration of symptoms after their pregnancy. To the best of our knowledge, symptoms from CMT have not worsened after pregnancy or childbirth, and they have not impaired the health of women during pregnancy. This is based on evaluations performed on patients since 1996 with standardized outcome measures being used longitudinally on all patients.

—Michael Shy, MD; Shawna Feely, CGC; Steve Scherer, MD, PhD

# Aetrex Worldwide, Inc. Hosts a Focus Group Specifically for the CMT Community

BY SUSAN RUEDIGER, DIRECTOR OF DEVELOPMENT

On August 29, Aetrex Worldwide, Inc., a partner of the CMTA, welcomed 18 members of the tristate area CMT community to their corporate headquarters in Teaneck, NJ. The product development team, the staff certified orthotist, and members of the marketing team spent two hours introducing their product lines and discussing features and benefits of their footwear that are relevant to the CMT community.

Significant time was spent on three product lines in particular:

The Edge Runners, an athletic shoe, features a wide toe box, few interior seams for foot comfort, high-quality yet removable insoles, and a lock down strap at the heel for easy AFO access. The heel has a wide base of support to increase the wearer's stability. The shoes are very lightweight, making them less cumbersome for the wearer.

The Berries are a line of comfortable casual shoes for women made of flexible material with significant give. Many of the Berries come with Velcro straps for easy manipulation and adjustability throughout the day. They come in a variety of attractive colors and have a stylish appeal. The Berries line also features extra depth, comes in a variety of sizes as low as women's 5, and has widths as wide as EE.

The Gramercy collection is made for men who wish to wear a leather lace-up or slip-on. These shoes have a removable memory foam insert that cushions the foot while providing support. If needed, it can be removed to accommodate a custom in-shoe foot orthotic and/or an AFO. There is also an attractive fisherman's sandal with adjustable Velcro openings and a padded tongue. These shoes start at men's size 7 and have widths as wide as EEE.

Another unique product from Aetrex that was discussed was the Lynco orthotic. These can be used by many people with CMT to provide extra support and comfort. The Lynco can fit into any shoe, increasing the duration of the wear.

For more information about these featured lines or any Aetrex products, please visit [aetrex.com](http://aetrex.com). Remember that Premium Subscribers of the CMTA will receive 50% off their first purchase from Aetrex. To find a retailer, please visit [aetrex.com](http://aetrex.com) and click on Store Locator. Retailers are not able to offer the discount at this time, but may be helpful in fitting shoes through Aetrex's iStep technology, and finding the correct insole.

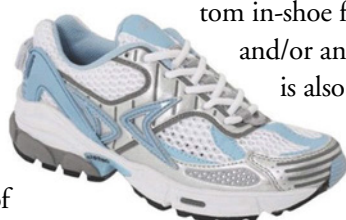
Members of the focus group were asked about desired features, current challenges, and visions for future products. Aetrex enthusiastically noted the comments and hopes to incorporate some of the desired features in future products.

In the immediate future, a Buyer's Guide for those with CMT will be published in collaboration with the CMTA and Aetrex Worldwide, Inc. This guide will offer

footwear options as well as features and benefits that are relevant to CMT patients.

We hope that this will enhance the shoe-buying experience and help people find just what they are looking for.

A special thank you to Alanna Huber, Mark Willis, Beverly Wurzell, and Lynne Krupa for coordinating attendance from their support group members. ★



The Edge Runner sneaker and Berries Mary Jane are two of the Aetrex styles that may work well for people with CMT.

## AWARENESS MONTH 2012 HIGHLIGHTS

### CMTA SUBSCRIPTION DISCOUNTS!

In celebration of Awareness Month 2012, the CMTA is pleased to offer an annual Premium Subscription Special to all new and renewing Premium Content Subscribers: \$15 for a one-year subscription or \$20 for a one-year subscription including printed issues of *The CMTA Report*. Don't delay! Even if you have just renewed, this offer will allow you to extend your subscription for a year after your next renewal date. Subscribe now, take advantage of these incredibly low prices, and stay connected with the organization that is working so hard for you.

Simply follow this link and use coupon code AM2012: [cmtausa.org/url/premiumcontent](http://cmtausa.org/url/premiumcontent). Offer good now through October 31st. If you prefer to mail in your renewal, simply send your check clearly marked for membership and include the coupon code.



# Swimming for a Cure

## 6th Annual TeamJulia Swim

There's always a mixture of excitement, nerves, and anticipation as we get ready for our annual swim fundraiser. There's an incredible amount of planning that goes into the day—the solicitation of donations is only a small part of the work that surrounds the day. On Sunday, September 2nd, more than 30 swimmers took to the waters at the Lake Valhalla Club in Montville, NJ, for the sixth annual TeamJulia Swim for the Cure. In 2007, when we first began our fundraiser, we traveled to Baltimore to swim in the Chesapeake Bay with fellow CMTA Board member Steve O'Donnell. Now six years later,

"Team O'Donnell" made the trek up I-95 and the New Jersey Turnpike to join forces with TeamJulia! Also in attendance was CMTA CEO Pat Livney, as well as Aetrex CEO Larry Schwartz. As I have highlighted, Aetrex is an important corporate partner of the CMTA (and the official sponsor of TeamJulia!). Larry even braved the waters himself and finished the one-mile swim in a very respectable time!

This year, we were able to secure approximately 50 fantastic items for our silent auction, including NFL on CBS and NCAA Basketball set visits, VIP tickets to the Rachael Ray and Kelly Ripa shows, and signed sports memorabilia by NBA star Jeremy Lin, New York Rangers

captain Ryan Callahan, hockey hall of famer Steve Yzerman, and baseball great Willie Mays.

As I have said repeatedly, the Board of Directors of the CMTA has narrowed our focus to concentrate on three main areas—fundraising for research, creating awareness, and providing services to the patient community. Our swim has been successful from a fundraising standpoint. (TeamJulia has raised over \$450,000 since we began.) However, of greater importance to my wife and me is the awareness that has been created in our community for CMT. Julia is growing up in a town that is well aware of her needs, and it is this sort of "grass-roots" effort that we as an organization need to continue to

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TeamJulia swimmers gather in front of Lake Valhalla in Montville, NJ.

build upon, telling our story one town and one community at a time.

Julia is an incredible girl—she truly touches everyone whom she comes into contact with. I recently reconnected with old friends from high school (after seeing them at my 30th reunion). To my surprise, they showed up at the swim and were truly taken aback by Julia. They are starting their training now for TeamJulia '13! That is just the type of person that our daughter is. She has surrounded herself with a terrific group of friends who are there to help her deal with any physical challenges that she may have. Although we are her parents, Rachael and I often feel that Julia teaches us just as much as we teach her.

Although the swim is over, the TeamJulia donation link is still receiving contributions every day. The link to donate is [cmtausa.org/julia](http://cmtausa.org/julia). If you are on Facebook, make sure to “like” the TeamJulia official Facebook page at: [facebook.com/pages/Team-Julia-Swim-for-the-Cure/114692531914190?ref=hl](https://facebook.com/pages/Team-Julia-Swim-for-the-Cure/114692531914190?ref=hl)

—Herb Beron

### We Are All In This Together

Whether it is donating money, participating in a support group, or creating CMT awareness, every effort helps make things better for those in the CMT community. I was blessed when I had the honor of traveling to Montville, NJ, to join TeamJulia for the swim in Lake Valhalla. What an amazing event! People of all ages traveled from near and far to support the swim. The energy, compassion, and dedication of family, friends, and participants warmed my heart and impressed upon me that we are making a difference in people's lives. Thank you to all who participated, organized, attended, and donated to the event.

I have been a longtime Board member, and the effort to find a cure, help raise awareness, and support those affected by CMT has never been more intense. We need to keep the momentum going. Contribute the best way you can. We are all in this together.

—Steve O'Donnell

Over the past 10 years, these two swims have raised almost \$1,175,000 for CMT research.

## CMTA AND CORTLAND RUN TOGETHER IN CHICAGO

Twenty-three employees from Cortland Capital Market Services participated in the 2012 JPMorgan Chase



Corporate Challenge®. Runners and walkers completed the 3.5-mile event in summery conditions with race time temperatures in the 80's. The event marked not just a successful inaugural experience for Cortland, but also a spirited affirmation of the importance of fitness and team-building in the corporate workplace. “Being a first-time participant, we were excited by the turnout. From walkers to marathoners, every level of runner at Cortland participated,” said Becky Godbey Cortland.

Cortland and several of its employees are proud supporters of the CMTA STAR Program. “Having the CMTA STAR on our backs provided additional inspiration,” said Lora Peloquin of Cortland. “The entire team completed the race and had a wonderful time celebrating afterwards.” Since inception in 2005, the Company has actively participated in the annual CMTA Golf Challenge.

JPMorgan Chase Corporate Challenge® in Chicago brought together a near-record crowd of 23,030 participants from 628 companies to benefit the Greater Chicago chapter of the American Red Cross and Chicago Run.



Participants from Cortland Capital Marketing Services pose proudly before their run.

# Improving Balance for CMT Patients

BY KATY EICHINGER, PT, CMTA ADVISORY BOARD

Individuals with CMT often report imbalance and falls. In a study of 222 individuals with CMT, 89.4% reported falls. (Ramdharry et al., 2011) As a physical therapist working with individuals with Charcot-Marie-Tooth disease (CMT), I often find myself explaining the mechanisms of balance. Good balance abilities are essential in order to optimize safe mobility and improve quality of life.

Balance is the state of maintaining your center of gravity over your base of support, in other words, being able to keep your hips over your feet. Balance, or postural control, is a result of several interacting systems. Information regarding an individual's position in space is collected via several sensory systems, the visual system (eyes), the vestibular system (located in the inner ear), and the somatosensory system (joint position, muscle tension, and touch sensation). This information is processed and compared in the central nervous system, specifically, in the cerebellum of the brain. The central nervous system then initiates signals to the motor or muscular system to make adjustments in a person's position. This process takes place both during movement as well as in an anticipatory manner. For example, when an individual visually sees a change in the surface he is walking on, like an icy or wet surface, the brain sends signals that help him change the way he is walking.

As you can imagine, in individuals with CMT, there are balance systems that may be impaired. The most commonly impaired system is the somatosensory system. Individuals with CMT often have decreased joint position sense and sensation in their feet, ankles, and even further up their leg. This involvement of the sensory system can result in incorrect or insufficient information sent to the central nervous system, resulting in impaired balance abilities. Research has shown that deficits in somatosensory input have a significant impact on postural stability in patients with CMT. (Van der Linden et al., 2010) Additionally, the musculoskeletal system may also be affected in patients with CMT. Decreased strength and range of motion (joint flexibility) at the foot and ankle are impairments seen in the musculoskeletal system that may make it difficult for a person to make postural adjustments that help maintain balance.

Treatment of balance deficits involves an assessment, often by a physical therapist, of the balance systems individually as well as assessing their interaction. Treatment often involves retraining of the various systems to compensate for the loss in the somatosensory and musculoskeletal systems or using adap-

tations /devices to improve balance abilities. Specific balance training has been shown to significantly increase balance in patients with hereditary sensory motor neuropathy (Matjacic and Zupan, 2006.) Additionally, stimulating and challenging different sensory inputs (vestibular, visual, and somatosensory systems) can help to improve balance (Hu and Woollacott, 1994). Other times, the use of additional sensory input, which can be accomplished with the use of a

cane or walking stick, can help compensate for decreased sensory input from the foot and ankle (Ashton-Miller et al., 1996). Addressing musculoskeletal limitations may also assist in balance abilities. For example, stretching of the calf muscles, which are often tight in individuals with CMT, can help restore the range of motion (Radford et al., 2006). Performing strengthening activities for the muscles of the abdomen, back, and legs may also help improve stability.

An individual's ability to maintain balance is a result of many interacting systems. Limitations in balance abilities for individuals with CMT can result in the fear of falling and impaired mobility. Assessment and treatment of balance deficits may be able to improve an individual's safety, functional abilities such as walking, and quality of life. ★

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## ? WHAT'S ON YOUR MIND? ASK DAVID.

**Dear David,**

My CMT is "invisible" How can I make family members, who do not have CMT, understand what I am going through (pain, fatigue, contractures, etc.)? I just want to be understood.

*David replies:*

When our CMT is "invisible," it doesn't necessarily mean that we go through any less mental turmoil. I know that personally I spent many years watching myself walk while passing my reflection in shop windows hoping that I wouldn't see a strange gait. I am not saying that your family shouldn't be more sensitive about your CMT, but I am thinking that sometimes we give off mixed messages. Part of us doesn't want anyone to notice that we have a problem, and part of us longs for empathetic understanding. Keep in mind that some members of our family prefer denial rather than accepting that there is something not quite right about you. Their way of

avoiding their own fears and anxieties about your CMT manifests in their not saying anything or pretending that it doesn't exist. In general, this is not a healthy coping style. I know it is not easy, but take the risk in sitting down with each one of them or call a family meeting and express to them that you are not looking for sympathy but just a little understanding from them. Let them know that just because you look OK doesn't mean that sometimes you are not in discomfort. Have some pamphlets that the CMTA provides ready, and ask each of them to read about CMT. It takes a lot of courage to speak up to our own families, but become a fearless warrior in asking for what you need.

**Dear David,**

It's going to be 90 degrees and humid on our boat to NYC, but I'm planning on wearing jeans to cover up my leg braces. I just got fitted for new braces and now I need one for my "good leg."

I know I shouldn't care what I look like. It's more important that I can walk without falling. But I have to wear bigger, wider shoes that make me noticeably taller, and I already tower over my shorter friends. For someone who is shy and prefers to blend in, this makes me very uncomfortable. I'll try to get in my awareness spreading mode and wear my braces proudly.

*David replies:*

Just participating in what sounds like a great day on your boat with friends should offset your discomfort showing your braces. As has been mentioned before, you might never feel completely comfortable showing your braces, but honestly that's OK. As for your height and wanting to blend in, sometimes just shifting your focus on what is around you and the good work you do can help you think less about how you look. I am sure that your friends and loved ones actually "look up" to you. ★



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](mailto:info@cmtausa.org).

## 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: \_\_\_\_\_



## Our Summer Adventure: A Trip to the CMT Clinic in Iowa

Over the summer, my son Yohan and I ventured out of California to visit Dr. Michael Shy and his team at his new CMT clinic at the University of Iowa in Iowa City. When I learned Dr. Shy was moving from Michigan to Iowa, my first thought was, “Out of all the places he could set up shop, why Iowa?” As I thought about Iowa a bit more, visions of corn popped into my mind: ears of corn, stalks of corn, fields after fields of corn! Then I wondered how easy it would be to fly there.

Well, Kayak unceremoniously announced that there are no direct flights to Cedar Rapids, so the sketchy puddle jumper from Chicago would be part of the deal. Despite all my initial misgivings, we made an appointment with Dr. Shy (who

we would travel to see even if he chose to practice on the planet Mars) and booked the flight.

Burning with curiosity, I did a little research into the Hawkeye State (a tribute to chief Black Hawk) whose capital and largest city is Des Moines.

Frequently referred to as the “Food Capital of the World,” because of its location in the Corn Belt, Iowa has a population of approximately 3,000,000 people and was recently listed as one of the safest states to live in.

On July 12, Yohan and I left San Francisco at 6 am and arrived in Cedar Rapids late in the afternoon. The Cedar Rapids airport is small and manageable, with the rental car area in the lot

right outside the building (no pesky shuttles). There are a large variety of hotels to choose from, many of which offer discounts to those who have clinic visits. If you want to stay downtown, featuring a quaint tree-lined pedestrian walkway with specialty shops, local eateries, and entertainment, I would recommend the

Hotel Vetro or the Sheraton, but book early because Iowa City is a vibrant and dynamic locale and these hotels fill up quickly, depending on the season.

Dr. Shy’s CMT clinic is held on Thursdays, all day. You will receive a packet of information well in advance of your visit. My friend and colleague Mark Willis and his kids met up with Yohan and me for our clinic visits on Thursday morning at 8 am. Not knowing what to expect, we made our way through the hallways and easily found the CMT clinic. We were cheerfully greeted at the admissions desk and were asked to wait in a comfortable and clean waiting area, equipped with a lounge chair, TV, and comfy chairs.

Soon thereafter, I walked Dr. Michael Shy, Dr. Rosemary Shy (a pediatrician who implements the CMT Pediatric Scale [CMTPedS] at the clinic with children who have CMT), and Shawna Feely, the clinic’s veteran genetic counselor. They gave us a warm welcome before showing each family to its separate and

private examination rooms. Yohan spent the remainder of the day undergoing a battery of tests, discussing orthotic-related issues with the clinic’s very knowledgeable and helpful orthotist, Kristian Kittelson, and

meeting with the on-site orthopedic surgeon, Dr. Frederick Dietz. At the end of the day, Dr. Shy spoke at length with Yohan, giving much-

needed feedback and suggestions to help him with his day-to-day life with CMT, especially during his transition to college.

Lastly, since Yohan and I stayed a few extra days to attend the clinic’s Patient Fair, we were invited to take a tour of Dr. Shy’s state-of-the-art research facilities and meet many of the researchers who are devoting their time and energy to finding treatments for CMT. At the Patient Fair, I also had the pleasure of meeting Jeffery Megown, Iowa’s first CMTA Support and Action group facilitator!

What did I learn over these four fun-filled days? The Iowa City area has much more to offer than corn fields. In fact, it has distinctly delicious cuisine, a popular downtown area, top-rated research facilities, wonderfully warm people, a large selection of Herky the Hawkeye mascot paraphernalia, and now a CMT clinic featuring one of the world’s best CMT clinicians, Dr. Michael Shy, and his team. It does not get much better than that!

—Elizabeth Ouellette

Michael Shy remains committed to his CMT patients in his new location. To make an appointment with Dr. Shy at the CMT clinic at the University of Iowa, please contact Anna Sorey at [anna-sorey@uiowa.edu](mailto:anna-sorey@uiowa.edu)





# What Do Occupational Therapists Really Do?

BY SUSAN SALZBERG, OT, CMTA ADVISORY BOARD

I have always had to explain my profession to others. Occupational therapy is one of the allied health professions. We work with PTs, psychologists, and vocational rehabilitation specialists. After realizing I am not going to get them a job, a new client will most often confuse me with physical therapy: "I'm already doing exercises. I don't need you!"

The roots of modern PT and OT are both about 100 years old—emerging around the time of World War I. Physical therapy's roots are orthopedic: exercise and the use of massage and gym-type activities in helping injured soldiers regain mobility. OT's roots are based in mental health and the treatment of shell shock, now known as PTSD. PT's precursors were nurses. Occupational therapists were reconstruction aids: people who used crafts to help veterans recover their mental equilibrium.

Both professions have evolved over the past century and

now may overlap in such areas as hand therapy and fall prevention. OTs work as part of treatment teams in a wide variety of settings from hospitals, schools, and rehabilitation centers, to prisons and homeless shelters.

What defines OT as a unique profession? It is the term occupation that causes so much confusion. The term occupation refers to the activities that give structure, focus, and meaning to our lives. These include:

- Basic activities of daily living (ADL): dressing, washing, grooming, toileting, and eating
- Instrumental ADL or IADL refers to ADL that involve environmental interaction: housekeeping, grocery shopping, menu planning, budgeting, writing checks, reading a bus schedule, using the phone
- Leisure activities
- Job performance improvement, such as modification of the workspace.

The fact that meaningful activities ("occupations") pro-

mote wellbeing is the core of OT practice. The founders of OT realized that having a skill-set in ADL and IADL is a fundamental need, and that restoration of these skills is therapeutic.

OT focuses on developing, recovering, or maintaining ADL, IADL, and work and leisure skills of clients who have physical, mental, or developmental conditions. Intervention may focus on improving foundation skills such as strength, dexterity and flexibility and/or on adapting the environment, modifying the task, and teaching alternative methods.

In the same way a physician's assistant extends the services of your MD, a certified occupational therapy assistant (2-year degree) extends the services of your occupational therapist (4-year degree). Both OT and COTA have a license to practice based on passing an exam and fulfilling continuing education requirements.

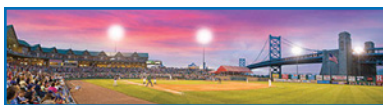
How do you spot an OT who will meet your needs? As with all professionals, there are many areas of specialization and levels of proficiency. During your first session, your OT should provide an appropriate evaluation and help you define your goals—tasks you wish to return to doing for yourself. Your OT should be holistic: able to consider how all aspects of your life affect your goals. We hope to help you increase your proficiency in the areas you choose and allow you to have a more satisfying quality of life. ★

## AWARENESS MONTH 2012 HIGHLIGHTS

### RIVERSHARKS EVENT SPREADS CMT AWARENESS

With the help of Michael Needleman, CMTA Advisory Board Member, the CMTA held a fundraising event at Camp-

bell's Field, home of the Camden Riversharks, on July 21, 2012. It turned out to be a beautiful night at the ballpark, as the home team won a close game in the bottom of the ninth. There was an amazing fireworks show after the game, and—best of all—the CMTA raised money from ticket purchases and table sales! We were also able to educate many people about CMT and what the CMTA does. We sincerely hope you will join us next year for the Second Annual CMTA Night at the Riversharks.



## Bracing Myself to Write

BY PATRICIA NEWMAN

I make my living with my imagination. I am a children's author with seven published books, five more under contract, hundreds of magazine credits, and dozens of presentations to schools, libraries, and conferences. Publishers rejected my first book, *Jingle the Brass*, 16 times. At school visits, I unroll the rejection letters taped end-to-end with a flourish to the gasps of hundreds of children and teachers. I figure it this way—if I'm not going to let the publishing industry intimidate me, there's no way I'm going to let CMT stand in my way.

CMT affects my legs and arms, but I am happy to report that my imagination rocks on! Ideas for books and magazine articles practically assault me. They're everywhere: my kids, the news, memories, vacation. The trick is finding the time to work on them.

Writing for children takes discipline, and discipline requires stamina—one of the many facets of our lives that CMT erodes. After my diagnosis in 2007, I changed the way I worked because quitting was not an option. (You writers out there will know what I mean—we write because we have to, correct?) Here's the surprise: the changes I made to my work habits actually helped my writing! Those frequent breaks to



Patricia tells school children about one of her books but also her long string of rejection letters that preceded her seven published books.

avoid stiffness and cramping? My subconscious continues to churn away on story problems (and often solves them) even though I'm not at the computer. And working out at the gym? My neurologist claims that my daily exercise, although not a cure, has slowed CMT's progression. Additionally, the gym is a vital component of my success at school visits—a monumental test

of strength and endurance even without CMT.

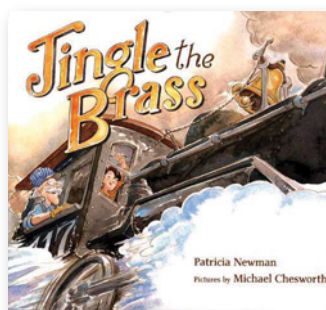
School visits are the grand prize of writing for children:

I meet my readers! From the moment I arrive

at the start of the school day, I'm on my feet performing multiple assemblies, writing workshops, small group readings, and lunch with students or faculty. My mantra is literacy—read, read,

read—and my goal is to make reading fun and rewarding for the students. They help me with demonstrations and skits. They eagerly respond to questions. I share what it was like interviewing Navy and Air Force pilots for *Nugget on the Flight Deck* or a railroad engineer for *Jingle the Brass*. The children and I explore aircraft carriers and trains, the seasons, and the science of movement. I sign books and pose for pictures. Occasionally, I'll even get down on one knee to show kids how the guy on the flight deck launches a jet off a carrier.

Are you getting the picture? There's no room for CMT at a school visit! I am on stage for seven hours looking into the eyes of a child who admits to reading *Jingle the Brass* 17 times, or a child who tells me she never liked to write until I visited her school. Sure, my braces support my legs, but they are usually



### PATRICIA NEWMAN'S CHALLENGE:

Kids with CMT: Let's chat! Visit my website ([patriciamnewman.com](http://patriciamnewman.com)) and send me an email. Tell me what having CMT is like for you. I'll post your emails on my blog so we can help educate the world!

hidden under a flight suit or railroading overalls—my school visit costumes. I hide my unsteadiness with near-constant movement. Yes, my hands cramp during autographing sessions, but how can you say no to the kindergartner who is missing recess to get his book signed by the author? That's where the gym comes in—greater strength means greater endurance for me.

Technology comes to my rescue, too. I connect with readers through a program I developed called Kids On KidLit. Again, I'm spreading the mission of literacy, but via the Internet rather than personal visits. Kids read a book of their choice and send me a short review, which I post on my blog. Every month I select one winner to receive a free age-appropriate book. Kids On KidLit and I have been able to inspire children who are ill and children who read reluctantly.

Skype, another technological miracle, often replaces the in-person author visit for cash-strapped schools. But they are a boon for me as well. I can reach more students and spread the importance of literacy from the comfort of my desk chair (no leg braces required).

Granted, the changes I made probably won't wow the blogosphere or go viral on YouTube, but I discovered the same discipline that forces me to write (even without looming deadlines), helps me make the necessary changes so I can be comfortable and productive for longer stretches of time despite CMT. For me, it's all about attitude. Every day I wake up and say, "I can!" ★

## BARE YOUR BRACES!

Some people have nightmares of finding themselves naked in front of a group of people.

My nightmares were of people seeing me in my braces.

I got my first pair of leg braces when I was 15. Tears were shed. To me, they represented my greatest fears: disability, progression, defeat, and a life-time without cute shorts, dresses, and skirts.

Four years later, now 19, I have come to appreciate my braces. They offer me support and mobility and actually help me blend into a crowd.

But I still hide comfortably behind my long pants. And no one has questioned that. My loving family, ever supportive, even helps me come up with ways to hide them. That is until I met my current boyfriend.

It wasn't long before the badgering began. Our conversations went like this:

*Me: It's so hot out!*

*Him: You should wear shorts!*

*Me: I can't.*

*Him: Why not?*

*Me: Because of my braces.*

*Him: Why not?*

*Me: ...because people would see my braces.*

*Him: So?*

After having similar conversations for the millionth time, with him continually breaking down my logic, I knew that I needed to conquer this.

Weeks passed. One day I finally mustered up the courage and grabbed the shorts buried in my dresser. Shorts on, I went for a walk downtown.

And you know what happened?

Nothing. Absolutely nothing.

And it was amazing.

The pants had been holding me back this whole time. I realized that I had never truly come to accept myself and my disability. If I couldn't accept myself, how could I expect anyone else to?

This is why I created BareYourBrace.com. I have bared my braces to the world and am encouraging others to bare their braces and share their stories. My boyfriend jokes that it is a website devoted to his being right. And as much as I hate to admit it, he is right. My braces are not something to be ashamed of. They are not ugly. And they do not mean a life-sentence in long pants.

Awareness Month may be coming to an end, but one of the ways to make people most aware is to cease to hide—our CMT, and our braces. When you "bare your braces," every month is CMT Awareness Month.

This is why I go bare. I hope you will join me.

—Bethany Noelle Meloche, CMTA Advisory Board

### HELP BETHANY'S CAMPAIGN:

If you would like to be featured on BareYourBrace.com, you can send your story and a picture of you "Going Bare" to Bethany at [bethany.meloche@gmail.com](mailto:bethany.meloche@gmail.com).





## SUPPORT AND ACTION GROUP NEWS

### NJ—Morris County

*The group met on June 30, 2012.*

This was the first time the Morris County Support and Action Group met. The group talked about the CMTA and the Transformation Project. The group also discussed the importance of fundraising. Chairman of the Board for the CMTA, Herb Beron, joined the conversation by introducing himself, his family, and his daughter Julia. He shared their CMT story and was able to elaborate on the efforts of the CMTA, STAR and the Transformation Project. Herb also discussed Aetrex's footwear (see story on page 3) and the company's partnership with the CMTA.

### NM—Albuquerque

*The group met on July 28, 2012.*

The speaker was Anaclaire Hunter, who joined them from the University of New Mexico

Occupational Therapy Department. She came to the meeting to talk about a "CMT Hand Function Study" that they are conducting. The goal is to see if the answers to a particular questionnaire can correlate to results from actual hand function tests. The subjects fill out a pre- and post-questionnaire, and then take a battery of hand function/timed tests. The group also discussed Awareness Month and the Transformation Project and its importance along with fundraising ideas.

### NY—Upstate

*The group met on August 4, 2012.*

Two members of the group were fitted for Allard Toe-Off Braces and Orthotics with positive feedback. Members reported that they were able to walk with a normal gait, and their balance was greatly improved. They discussed plans for CMTA Aware-

ness Month in September. Members were encouraged to hand out posters, speak with people about CMT, and use Facebook or Twitter to spread the word. Members were asked to download the CMTA Awareness month poster to use as their Facebook profile picture. They were also encouraged to check out the CMTA's new partner, Aetrex, and their comfortable shoes available online. The "Starry Night" Art de Cure fundraiser will be held on Friday, December 7th, 5-9:00 pm at CPO South Lake Ave, Albany, NY. Complimentary wine and light fare, live music by Doug Yoel, and a Silent Auction with original art, jewelry, books, Disney tickets, Giants memorabilia, silk scarves, knitted baby clothes, note cards, and more will be available. Volunteers are needed! ★



## GIFTS WERE MADE TO THE CMTA

### IN MEMORY OF:

**Rosary "Pat" Blau**  
Mr. Thomas Burke

**Ivor Dartnall-Smith**  
Ms. Alison Kittle

**Gerard Donovan**  
AEHF/MCS Co-workers  
American Legion Post 926  
Mr. & Mrs. Barry Cahill  
Ms. Camille E. Deberardinis  
Mr. & Mrs. Hugh D. Donovan  
Mrs. Betty Fortunato  
Mr. & Mrs. William Friel, Jr.  
Mr. & Mrs. Anthony Giampietro  
Mr. & Mrs. James Gourley  
Mr. William H. Joos  
Monsignor Bonner H.S.  
Baseball  
Ms. Michele Samsel  
Mr. & Mrs. Stephen M. Shrader  
Ms. Donna Welsh  
Mrs. Rosemary Winterbottom

Mr. & Mrs. John Winters, Jr.  
Mr. & Mrs. Cyprian Yost

**Mark Hollingshead**  
Ms. Martha L. Cone Beck

**Jack D. Jones**  
Mr. Carl J. Croft  
Ms. Barbara Deas  
Ms. Dolores Friedman  
The Fudger Family  
Mr. Jerry Morris  
Mr. & Mrs. Harry Watkins

**Robert Kalstrom**  
Ms. Jean Ebert

**Laura Lauer**  
Mrs. Marilyn Redick

**Robert Lightcap**  
Mrs. Henrietta Cook

**Ruth Linker**  
Mr. Lawrence Linker  
LaCreshia Nation  
Mr. Garrett McKone  
Ms. Crystal McKone  
Mrs. Sara Jane McKone

Mr. & Mrs. Tim Mosley  
Mrs. Johanna Pettit  
Mrs. Brook Rozen

**Carmen Pappalardo**  
Mrs. Arlene Pappalardo

**Joseph Rath**  
Mr. Hank Andringa  
Ms. Tracy Curley  
Mr. Herbert Eiss  
Ms. Penny Greul  
Mr. & Mrs. Dan Holeva  
Mr. & Mrs. Robert Lewis  
Mrs. Vicky Pollyea  
Mr. Kyle Rath  
Ms. Lisa Scott  
Mr. & Mrs. Matthew Stern

**Anthony Romeo**  
Mr. & Mrs. William L. Boone  
Mr. & Mrs. Frank Melillo

### IN HONOR OF:

**Richard Bales, Jr**  
Ms. Tamara Carless

**Yohan Bouchard –**  
**Good Luck in College**  
Mrs. Vicky Pollyea

**David Buck**  
Mr. Henry Norwood

**Jayne Burrow**  
Mr. James Fulmer

**Flora Jones**  
Ms. Cynthia J. Chesteen

**Judy & Arthur Lipton –**  
**Happy 50th Wedding Anniversary**  
Mr. & Mrs. Frank Weiss

**Patrick Livney**  
Mr. John (Yogi) Spence

**Dan Martens**  
Mr. William Martens

**Joseph McCallion –**  
**Happy 70th Birthday**  
Mr. Regis Beneville  
Mr. & Mrs. Joseph Bilotta

Dr. Philip Cea  
Ms. Maria Conte  
Mr. & Mrs. Paul Coppinger  
Mr. & Mrs. John Dee  
Mr. & Mrs. R. Dougherty  
Mr. & Mrs. Mario Federici  
Mr. & Mrs. Tony Formichelli  
Mr. & Mrs. Kenneth C. Fuller  
Mr. & Mrs. Gregory Harris  
Mrs. Rosemarie Keating  
Mr. & Mrs. Neil Klar  
Mr. Michael Kropp  
Ms. Valerie A. Mangan  
Mr. Francis McCallion  
Mr. & Mrs. Martin McConnell  
Mr. & Mrs. Patrick Nealon  
Mr. & Mrs. Nicholas Piccinini  
Mr. & Mrs. Joseph Reynolds  
Mr. & Mrs. Richard Schielke  
Mr. & Mrs. Jeremiah Sullivan  
Mr. & Mrs. Edward Walsh  
Ms. Veronica Walsh

Mr. Kenneth Woisin  
Mr. & Mrs. Thomas Woisin

**Marissa Moran**  
Mrs. Gail Moran

**Ruth Moway –**  
**Happy 90th Birthday**  
Mr. & Mrs. Alan Neuwirth

**Alex Ramsey**  
Mr. Earl Ramsey

**Scott Sandford**  
Mrs. Jane McElroy

**Patricia Seeburg**  
Ms. Susan Delaplaine

**Donika Sterling**  
Ms. Cheng Ying Chung  
and fans of SHINee  
Ms. Dominique Jack

**Reagan Stultz**  
Mr. & Mrs. Rick Olejnik

**Ruey Warfield**  
Dr. Peter Warfield

# 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  
Laurel Richardson  
814-404-8046

## CA—Santa Rosa Area

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

## CA—Visalia Area

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

## CO—Denver Area

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

## CT—North Haven

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

## DC—Washington, DC Area

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

## FL—Orlando Area

Central Florida CMT  
Support and Action Group  
Julie & Mark Collins  
407-786-1516

## FL—Tampa Bay Area

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

## FL—West Palm Beach

West Palm Beach, FL CMT  
Support and Action Group  
Phil Lewis  
561-630-3931

## GA—Atlanta Area

Atlanta, GA CMT Support  
and Action Group  
Susan Ruediger  
678-595-2817

## IA—Great Lakes

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

## IA—Iowa Area

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

## IL—Chicago Area

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

## IN—Fort Wayne Area

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

## KS—Wichita Area

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

## KY—Burlington Area

Pam Utz  
859-817-9338

## MD—Easton

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

## ME—Portland Area

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

## MI—Chesaning Area

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

## MI—Kalamazoo Area

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

## MN—Benson Area

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

## MO—Anderson Area

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

## MS—Mississippi/Louisiana

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

## NJ—Central New Jersey 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—Horseheads Area

Horseheads, NY CMT Sup-  
port and Action Group  
Angela Piersimoni  
607-562-8823

## NY—Long Island Area

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

## NY—Upstate New York Area

The Upstate NY CMT  
Support and Action Group  
Melinda Lang  
518-783-7313

## NY—Westchester Area

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

## OH—Cleveland Area

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

## OH—Greenville Area

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

## PA—Bucks County Area

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

## PA—Johnstown Area

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

## PA—Northwestern Area

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

## RI—East Providence Area

Rhode Island CMT Support  
and Action Group  
Meredeth Souza  
401-433-5500

## SD—Hartford Area

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

## TN—Nashville Area

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

## TN—Savannah Area

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

## TX—Dallas Area

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

## UT—Orem Area

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

## VA—Harrisonburg Area

Anne Long  
540-568-8328

## VA—Williamsburg Area

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

## WA—Seattle Area

Ruth Oskolkoff  
ruth.oskolkoff@gmail.com

## WA—Tacoma Area

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

## WI—Brodhead Area

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

## WI—Milwaukee Area

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

## WV—Vienna Area

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

## GROUPS IN CANADA AND MEXICO

### CAN—Montreal

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

### CAN—Ontario

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

## MEXICO

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

## VIRTUAL/DISCUSSION GROUPS

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

Most Support and Action  
Groups, Virtual Groups,  
and Discussion Groups  
can be accessed at  
[www.cmtausa.org](http://www.cmtausa.org).  
They can be found in the  
CMTA Online Community  
under Support and  
Action Groups.

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

**WELCOME TO OUR NEW SUPPORT GROUPS!**

## CMTA SUPPORT GROUP FACILITATOR SPOTLIGHT

## Jori Reijonen



In the summer of 2009, Jori Reijonen from Richland, Michigan was diagnosed with CMT. She was not prepared for this diagnosis and knew of no one else who had CMT or who had even heard of this disease. She very quickly realized, however, that she was meant to use this diagnosis to help others with CMT and to become involved in advocacy and education about CMT and neuromuscular disease.

Her work, education, and life experiences prepared her well for this new role. She had studied clinical psychology, and earned a PhD in 1996. Dr. Reijonen teaches college and practices psychology as a fully licensed psychologist in the state of Michigan.

Working with the Charcot-Marie-Tooth Association and the Muscular Dystrophy Association, she started the Southwest Michigan Support and Action Group in November 2009. This group remains

active, meeting bimonthly, and has about 20 members. Last year, Dr. Reijonen was honored to receive the Robert Ross MDA Personal Achievement Award for Michigan.

A writer at heart, Dr. Reijonen has been published in professional journals, by a textbook publisher, and in online children's magazines. More recently, during the summer of 2010, she began to use her talents as a writer to write and edit the Neuromuscular Diseases site at BellaOnline.com. Since then,

## Conquering Cramps

I'm going back to the doctor's. I have been having horrible cramps in my legs since returning from camp this summer. They are especially bad at night when I lie down to sleep. My legs cramp so badly that my foot actually gets deformed and I can't get it back to the normal position. Besides that, these cramps really hurt.

I'm not sure what the doctor can do for me. I'm afraid that the cramping is just part of having CMT and I can't get better. Still, I'm hoping that I'm wrong and that he will have a way to fix the problem. My mother is genuinely worried about me. I'm not really a complainer and I tried to just keep this problem to myself because I know every time I have a new

symptom she thinks about the fact that I inherited my CMT from her. In any case, she is the one who is taking me to the neurologist. You probably remember him. He's Dr.

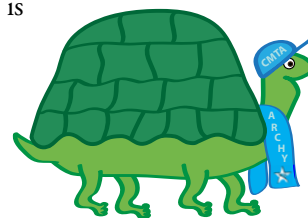
Pythonic, a snake who practices not far from our pond. I actually like to go see him because his nurse, Ms. Redd, is a real fox in all the ways that word is used.

So, I went to see the doctor, and he thinks that I need to exercise more, drink more water, and maybe even eat a banana before I go to bed. He is reluctant to give me any

drugs because I'm still pretty young and small. I know I can do all the things he advises, but I'm still anxious about another cramp "attacking" me in the night. It's really scary because I feel like I can't do anything about it.

I can't really massage it out and the usual advice, to walk around to make it go away, simply doesn't work. I'm in so much pain that I can't stand up, much less walk.

I'm happy to report that it's now been four days since the doctor visit, and I have made it through the nights without any problems. Now what wakes me



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



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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.

she has published almost one hundred articles on the site, hoping to help others with neuromuscular disease to better cope and thrive and to educate the public. The site can be found at [bellaonline.com/site/NeuromuscularDiseases](http://bellaonline.com/site/NeuromuscularDiseases).

Recently, Dr. Reijonen turned her attention towards fundraising for the CMTA. Her Circle of Friends site, Help Cure CMT, can be found on the CMTA website.

Dr. Reijonen has lived in the Southwest Michigan area since 1990 with her husband and their three children. She enjoys spending time with her family, writing and journaling, volunteering at church, reading and studying, exercising, and singing in a choir. ★

up is the fact that I need to go to the bathroom because I'm drinking so much water. I'm pretty conscientious, but my mother keeps pouring me glass after glass of water while I'm working on my homework. I feel like I'm going to float away!

I'm really happy that these little "fixes" seem to be working because I was going to school exhausted every day. I can't afford to be less than my best now that I'm in fourth grade. It's noticeably more challenging than the lower grades were. If you ever watch that TV show, "Are You Smarter Than A Fifth Grader" and you think that it seems like the stuff they know is awfully complicated, I'm here to tell you that kids are actually learning that stuff earlier and earlier. So, I need to be my best each and every day because my intellectual accomplishments are something that will never be diminished by my having CMT. ★

## 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 CMTAReport

The Charcot-Marie-Tooth Association  
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Glenolden, PA 19036  
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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.