



**Charcot-Marie-Tooth  
Association**

### OUR MISSION:

To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

### OUR VISION:

A world without CMT.

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## CMTA Launches Circle of Friends Campaign

BY DANA SCHWERTFEGER

### What is the "CMTA Circle of Friends?"

We like to think of our "Circle of Friends" as a new approach to fundraising, but there's really nothing new in asking one's family, friends, and business contacts to support a favorite cause. Every year, thousands of dollars come to the CMTA from golf tournaments and other events like Steve O'Donnell's "Swim for the Cure."

Steve began doing the swim six years ago and now raises over

the Berons, the "CMTA Circle of Friends" is simply a way for people to help the CMTA fund research and other important projects without having to organize golf tournaments, auctions, or other events.

### How does it work?

The "Circle of Friends" begins with a personal appeal. Each of us has a "circle" of family, friends, people we do business with, places we shop, and so on, and by reaching out to them



There's really nothing new in asking one's family, friends, and business contacts to support a favorite cause.

\$100,000 a year for CMT research. This year, however, he was also joined by members of "Team Julia," which was formed to honor 7-year-old Julia Beron, who has CMT. Through the efforts of Julia's parents, Herb and Rachael, Team Julia raised an additional \$65,000.

People often ask what they can do to help raise funds, but holding a golf tournament or organizing an event is often beyond the scope of what the average person can do—until now. Building on the success of

with a personal letter or email, we can greatly enlarge the number of people who support the work of the CMTA.

Two years ago, CMTA Board Member Elizabeth Ouellette, inspired by Sue Elmer's letter-writing campaign, wrote a letter describing how her son Yohan is affected by CMT. She sent her letter to over 100 family members and friends and raised over \$13,000. When the Berons contacted us, we told them about Elizabeth's appeal. Using her letter as a model, the Berons incor-

porated information about their daughter and Rachael's participation in the Swim and sent the letter, mostly via email, to over 500 family members, friends, and business contacts. (To read their letters and learn more about creating your own letter, visit us on the web at [www.charcot-marie-tooth.org/cof](http://www.charcot-marie-tooth.org/cof).)

Having an easy way for the Berons' Circle of Friends to donate was another key to their success. We created a "Team Julia" webpage just for them. They included a link to that

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**A NEW WAY TO EARN MONEY FOR THE CMTA**  
Board member Phyllis Sanders sent us information about a unique new way to earn money for the CMTA. An organization called Givenik provides tickets for Broadway and off-Broadway productions and returns 5% of each ticket purchased to the non-profit of your choice. You can read more about this fundraising service at [www.givenik.com](http://www.givenik.com).

## CMT, My Scooter, and Me

When I was contacted by the CMTA to tell me I was a finalist for a scooter, I was asked to write a short essay on what I felt a scooter would mean to me—what it would bring to my life. My essay was pretty accurate, and yet the scooter has actually brought me more than I expected.

Yes, it means I can “go for a walk” (go for a scoot) if I want. I can again do local errands for which I had had to make other arrangements. Monday I will take it on our local GoBus to go to a doctor’s appointment. This will be the first of many trips I will be able to do, widening my world. I’m looking forward to at least one Christmas shopping trip. Having my little blue REVO is opening doors that had become closed to me as my CMT has progressed. As time goes on, I will be doing more and more with it.

You might ask why I haven’t done more with it already. That comes under several headings—time, opportunity, health, other responsibilities, practice... I am guardian and caregiver for my husband, who has multiple medical issues and cannot be left alone. This means I have limits on my time and opportunities to get out, and I have to make them count (the scooter helps me do this). My first independent times on my scooter were short practice runs to get used to it. It has speeds from TURTLE to RABBIT, and it makes a difference when you’re riding. RABBIT is great on a flat

straightaway, but bad in a store. The scooter has a built-in governor which won’t allow the scooter to speed up going downhill or slip back going uphill. These are things to get used to.

And then there’s the fact that I had several medical issues to catch up on, the most demanding of which is the hernia repair I had done. You can



Two more scooters will be awarded by the CMTA in November and December.

work around a lot of things, but you just can’t work around your belly. Since my CMT was diagnosed when I was an infant and I am 59 now, I’ve had lots of practice finding ways to work around obstacles. This one has been more challenging than most. There have been some delays in my recovery, but I’m well past the halfway mark of the recovery phase, so my restrictions from it will soon be over.

What I’ve found to be the most valuable effect of my scooter though was unexpected. I projected its enabling effects—the freedom to go independently. I didn’t expect the reawakening of wishes—even dreams. As my CMT and I got older and so much progressed with my husband’s needs, I have become mired in getting through what must be done and just grabbing a few minutes here and there to do something just because I wanted to. I was spending all my energy everyday, but nearly completely on only necessary things. I’d set aside the drive or desire to volunteer on a crisis line and the need to rescue guinea pigs, both of which I had done for years but gave up when my husband’s health was in crisis.

Maybe it happened to be the timing of receiving the scooter when I did, or maybe it’s a coincidence, but I think receiving and beginning to use my REVO reopened doors which I had let close, not only when it comes to running errands or “going for scoots” but also exploring ideas of what else I want to do, what else I can still do, what else I’d like to try. The situation with my husband’s care has improved a little, and with this reawakening of ideas my outlook has brightened considerably.

This is also a freedom my scooter has brought me.

—Carol Simpson,  
Recipient of the first  
CMTA Scooter Giveaway

## CIRCLE OF FRIENDS

(continued from page 1)

page in their email, and for people without email, or for people who preferred not to donate online, we also created a flyer with a stub people could return with their checks to make sure their donation was properly credited to the Berons' Circle.

Acknowledging donors was also important, so we sent Herb a donor list once a week, which he used along with his own list to keep track of who had received his appeal, who had donated, and to whom he had sent a personal thank-you note. We sent each donor a thank-you as well (also useful for tax purposes), and we listed their donors (just names, not amounts) in our newsletter, *The CMTA Report*. We then provided Herb with both print copies and a link to the PDF version of the newsletter so that his donors could read about Team Julia and see their names in the donor list.

That was all there was to it. In a little over two months, the Berons raised \$65,000, and they left us with a model that anyone can use to help the CMTA raise funds.

### Ready to start your own CMTA Circle of Friends? We'll help!

Just call us at 1-800-606-2682 or email [cof@charcot-marie-tooth.org](mailto:cof@charcot-marie-tooth.org). We'll help you write your letter, create a webpage specifically for your Circle of Friends, and provide you with all the brochures, newsletters, and other documents necessary to start your circle.

We'll acknowledge your effort and your "CMTA Circle of Friends" in our newsletter, we'll send each of your donors a thank-you letter, and we'll also send you a weekly donor report so you can track your progress and send your personal thank-you notes.

In addition, we're having the "Circle of Friends" logo imprinted on various items.



When you use them to thank your friends, you'll also be helping to spread awareness about CMT.

More importantly, whether your circle contributes \$500, \$5,000, or \$50,000, every dollar will enable the CMTA to fund research and programs that will make life better for everyone with CMT.

So please contact us today. Together, and with a little help from our friends, we can tackle CMT! \*

## CMT-EH? GOLF TOURNAMENT IN CANADA

On September 9, 2007, the first annual Gord Hamilton Memorial Golf Tournament took place at The Maples of Ballantrae Golf Course in Stouffville, Ontario, Canada. Stouffville is a small town just north of Toronto.

Jeff Hamilton, his wife Sherri, and their friends Eric Langdana, Bruce Edgar, and Steve and Pam Davis, always wanted to do something in memory of Gord Hamilton and came up with this idea. Gord,

Jeff's brother, died as a result of complications from Charcot-Marie-Tooth disorder at the age of 36.

The group worked together to plan and organize the tournament, which included corporate hole sponsorships, prize giveaways, a silent auction, and a 50/50 draw.

"We would have been excited to have raised a few thousand dollars from this event because we only opened it up to 70 golfers, mostly just family and

friends," Jeff said. "However, everyone came with their wallets and their hearts open, and we were able to raise almost \$10,000!"

The group looks forward to doing this as an annual event and hopes to raise even more money for CMT research, next year. \*

Left to right: Jeff Hamilton, Bruce Edgar, Jay Collett, Steve Davis and Eric Langdana at their golf tournament.



*These questions were answered by a physical therapist and specialists at the gait study laboratory at Wayne State University.*

# Wayne State Clinicians Answer CMT Questions, Part III

## 1 What is a gait study?

A gait study can encompass studying aspects of a person's walking abilities. Gait is only one aspect of the study that we are conducting at the Wayne State University Physical Therapy Mobility Research Laboratory. We use the GaitRite instrumented walkway to collect data relating to spatio-temporal variables such as gait speed, step-length, stride-length, step width, % stance, % swing, and double-support time. Participants walk along an 8-meter instrumented "carpet" which interfaces with a computer that collects the data. Those participants that have been prescribed orthotics wear them for data collection purposes.

## 2 What tests do you perform? Why? What data are you looking for?

The natural history of CMT is poorly understood, and few studies have investigated progression of CMT prospectively. There is not much known about progression of such disability factors as ambulation and balance in CMT patient. The overall goal of this study is to gain insight into progression of CMT. Specifically, we wish to identify the multiple physical performance measures associated with progression of CMT, including factors that may increase risk for a fall and thus impact function. The overall goal is imbedded in our broader, long-term objective of deter-

mining which rehabilitation-related interventions are most effective in improving physical function in people with CMT, as well as in people with other neurological diseases. We perform a series of high- and low-tech tests and assessment tools that evaluate the following: muscle strength (particularly of the lower extremities), balance, balance confidence, stepping ability, gait, endurance, and lower-extremity reaction and movement time. We are also interested in the incidence of falls in people with CMT. Adult (18 years and older) participants with CMT keep a record of any falls as they occur during the first year of enrollment in the study. The following is recorded for each fall: date, location, time of day, circumstances (e.g., "what were you doing immediately prior to the fall?"), and fatigue level prior to the fall. Participants mail their falls records to the Mobility Research Lab every 3 months.

## 3 How will the results benefit a CMT patient?

It is hoped that as a result of the study we will have a clearer idea of which physical performance measures (e.g., strength, balance, etc.) deteriorate more rapidly than other measures. This may allow us to design optimal rehabilitation programs for people with CMT by aggressively targeting the measures that deteriorate rapidly. Furthermore, our investigation of falls and the situations

in which they occur may give us insight into ways we can reduce the incidence of falls in persons with CMT.

## 4 What can a physical therapist do for someone with CMT? When should a patient with CMT begin PT? How often/how long should a patient have PT?

Depending on what the person's specific impairments are, physical therapy may certainly be beneficial for people with CMT. For example, if there is weakness in the lower extremities, the PT can prescribe a program of individualized exercises to strengthen the weak muscles and to maintain the strength of muscles that have been less affected. If the person's main problem is balance, then the PT can institute a program of balance training individualized to the person's needs. It is important that people with CMT and other neurologic diseases be evaluated by a PT in order to receive optimal and individualized rehabilitation programs. It is wise to begin therapy early on in the disease process as a means of preventing or minimizing complications such as reductions in strength and joint range of motion. The length of time and frequency of therapeutic sessions is based on many factors including severity of signs and symptoms. Motivation to actively participate in therapy sessions and home exercise programs also affects the amount of

therapy needed on an outpatient basis. Ultimately, the physical therapist will design individualized therapeutic programs most suitable to the needs of the patient.

## 5 Should a patient with CMT exercise?

Just as therapy is designed on an individualized basis to suit the needs of a patient, so too are exercise programs. Most people with CMT should be able to engage in some form of exercise, even though in some cases it may be at a very low level. In any case, physical activity is important for many different reasons including preventing some of the complications of inactivity (e.g., joint stiffness, muscle weakness, etc.). Other benefits of exercise for persons with CMT may include maintenance of flexibility, increasing endurance, improving balance, and more.

## 6 What types of exercise should a patient do or avoid doing?

A patient with CMT should consult with his physician and physical therapist prior to beginning any exercise program. Exercises are likely to include muscle strengthening, particularly of the lower extremity, active and passive stretching, exercises to improve endurance, and balance and coordination activities. Avoid exercises that exacerbate joint symptoms or that cause fatigue. One should always exercise only to one's level of tolerance, which will be different for each person depending on severity and stage of the disease. \*

## In the News

### *Haircuts for Maddie*

Wayne TV coverage in Indiana reported on a fundraiser at the Great Clips hair salons of Georgetown Square, where haircuts were being given to raise money for Maddie Zelt.

For two days employees of the salon donated \$5 per day to be able to wear jeans to work on Saturday and Sunday. The latest fundraiser was conducted after business hours, with the employees donating their time so the proceeds could go to the Maddie Zelt benefits.

Maddie is diagnosed with Dejerine-Sottas disease, a form of Charcot-Marie-Tooth, which causes damage to the lining of the nerves. In Maddie's case, the defect is on gene 35. Maddie has problems with swallowing and eating. She gets her medications and nutrition through a J-G tube. Her special formula alone costs \$1,000 a month. At seventeen months, she still cannot walk or crawl.

Additional fundraisers are planned by the family's Lutheran church to help Maddie and her family with medical costs.

### *CMT Prevalence Study*

*The Pittsburgh Tribune Review* published an article on a prevalence study being done in western Pennsylvania. They reported that this new study is the first of its kind since a study was conducted in Norway in 1974. If their numbers were correct, the Norwegian

study would suggest that about 150,000 Americans have CMT and 2.5 million are affected worldwide. But, the article asserts that the data is outdated and may not be accurate for the United States.

The CMTA, through the John P. Murtha Neuroscience and Pain Institute in Johnstown, PA, is collecting data from eight counties in western Pennsylvania and eventually hopes to expand the study to include the four corners of Pennsylvania, said Executive Director, Charles Hagins.

An article in the *Pittsburgh Tribune Democrat* also reported on the prevalence study in eight Pennsylvania counties. Patrick Torchia, Chairman of the Association, said that although CMT is one of the most common inherited neurologic disorders, it remains little understood.

### *A Reason to Stay Lean*

An article in the Toronto Star called "Post-game Bodycheck" explained how Wendell Clark, the former Toronto Maple Leafs captain, who retired in 2000, spends his retirement. Always a fan favorite, Clark, 41, now does public relations for his former team as well as for some corporations and charities. In retirement, Wendell is working to keep his weight down because his father has Charcot-Marie-Tooth disease, and Clark carries the gene for it as well. For that reason, Clark says, "The less weight I carry, the better." \*

**CANINE PARTNERS  
FOR LIFE**

is a non-profit organization in Cochranville, PA, dedicated to training and placing service dogs with people who have physical disabilities. Visit their website at [www.k94life.org](http://www.k94life.org)

**A service dog brings his owner the phone.**



## Service Dogs...Changing Lives

**H**ave you ever wondered if a service dog could help you? People often have misconceptions regarding what a service dog is, what it can do to help someone who has a disability, and what is involved in getting a service dog. Hopefully this article can help answer some of your questions and show you how a service dog could change your life.

Service dogs are specially trained to assist the person they are partnered with. While many service dogs assist people who utilize a wheelchair (manual or motorized), many others are trained to assist people who have difficulty walking or who deal with fatigue issues.

Depending upon your disability and your needs, your dog may be trained to provide support while you are walking, retrieve something as small as a dime on a concrete floor, carry a lunchbox or briefcase, turn

light switches on/off, open/close all types of doors, pay cashiers, roll you over in bed, help you get up from the ground or transfer, operate elevator buttons/power strips/door openers, alert to your seizures before they happen, go get help within the home or work,



**Carrying things, opening doors, and retrieving items are tasks a service dog can perform.**

tug the laundry basket, put laundry into or pull it out of the washer/dryer...and much, much more!

Service dogs are generally trained to assist people who have mobility-related disabilities, difficulty using their hands/arms, balance disorders, or seizure-related disabilities. If a person needs a service dog and is also blind or deaf, a service dog can additionally be trained to perform guide work or hearing alert work.

There are a number of service dog schools across the country. Each school operates differently, and has a different cost per dog and a varying waiting list. It doesn't have to be difficult to get a service dog. One of the best places to begin your research is the Assistance Dogs International website, [www.adionline.org](http://www.adionline.org). Don't just pick the organization closest to you! Do your homework and find the organization that best

meets your expectations and needs. Ask how long the organization has been operating, is it an accredited voting member of Assistance Dogs International (this is important to ensure quality), what is the follow up/support program that the organization provides, how is funding provided for the dog, and does the organization provide ideas where that funding may be obtained. Visit the organization if possible and make sure that the environment is nurturing and feels good to you.

Service dogs may be placed with people of all ages, disabilities, and financial means. Don't assume that you are too disabled—or not disabled enough. Go exploring today to find how a dog might change your life. Independence, unconditional love, and a partner may be right around the corner. \*

*Provided by: Canine Partners For Life (see info at left).*

# Imagine the possibilities

BY WENDY GODMERE

"Stoney" Stone has accomplished many impossibilities: a master martial artist, movie and stunt coordinator, life and success coach, lead vocalist for a classic rock band, author and there is more to come.

On December 6, 1949, Marjorie Louise Perry and Robert William Stone had a child who would change their lives and countless lives after them.

On that day, there was an added celebration in the Stone household—twins! Lawrence Donald came first, followed fifteen minutes later by Terrance Ronald. A double blessing for their family!

By the age of five, Larry, the eldest of the twins, was still not walking. Medical investigation showed a congenital hip condition. This was just the beginning of a life of physical struggle. Larry suffered through painful operations and extensive hospital stays.

After graduating from high school Larry attended the Bulova School of Watchmaking, acquiring watch repair skills that could provide him with a sound, secure career. The only problem was the three-piece suit chafed at the free spirit confined inside.

While in high school, Larry had been the lead singer in several rock bands, and it was this life that called to him. Music was his love, and a series of jobs provided the stability he required to meet his daily needs.

While Larry worked and sang in a number of rock bands, he also pursued a hobby in martial arts, first attending a dojo, then starting his own school. He is a Martial Arts Master, and was inducted into the Martial Arts Hall of Fame in 2000. Stoney dedicated himself to helping people explore their own power, helping them identify the things that make them unique, and helping them understand the difference each of us can make in the lives of others.

Stoney, now 58, is experiencing further physical challenges. He has been diagnosed with CMT, a degenerative nerve disease that, in time, may leave him in a wheelchair. He also believes that the many muscle and nerve problems that he dealt with as a young man were simply a missed diagnosis, now being properly diagnosed as Charcot-Marie-Tooth. The symptoms of CMT that Stoney deals with on a daily basis involve hands that just don't want to work, which can be frustrating. The strength it takes to do the simplest of things like opening a bottle of water, zipping up his coat, pulling socks on in the morning, or simply wiping his nose when it is cold outside contributes to the perseverance that Stoney displays to those around him. CMT, along with the lack of circulation in his feet, has become a threat to his mobility, causing him to fall frequently. For the last few years, Stoney has relied on crutches to

get around. The muscles in his hands, legs, and feet continue to deteriorate.

Today Stoney travels between the United States and Canada doing motivational seminars and book signings. Stoney is living out his dream teaching young and old alike that, instead of just imagining the possibilities in life, they can accomplish them by simply making a choice to live their dream. He is driven by the fact that his niece Shannon Stone and other members of his family live with the realities of CMT. Shannon is 31 years old; she is the eldest daughter of Stoney's twin brother Terry. Shannon, who has CMT, also has the passion to raise awareness. Shannon's sheer determination to educate the world as to the plight of those with CMT has caused her to stand beside her Uncle Stoney as a strong team. Shannon, Stoney, and his company LIVE NOW INC. (a company of motivational and inspirational speakers) hope you will join them in their quest for public awareness about CMT and the CMTA.

You can purchase Stoney's book, *Imagine the Possibilities... Live Now!* on his website [www.livenowgroup.com](http://www.livenowgroup.com) or by calling toll-free 1-866-534-6094. For each purchase, \$5.00 will be donated to the CMTA. \*

**"What defines us is how we rise up after we have fallen..."**





## ASK THE DOCTOR

**Dear Doctor,**

*I have CMT and was recently prescribed vandazole for a bacterial infection. When I read the warnings, I noticed that it said side effects could include peripheral neuropathy. I called the doctor and she changed the medication to metronidazole 250 mg. I saw this medication on the moderate-to-significant risk list but only with prolonged use. Would it be okay to take the metronidazole for 7 days?*

**The Doctor replies:**

Metronidazole (Flagyl) is a commonly used antibiotic and an underappreciated cause of toxic neuropathy, but virtually all cases develop after many weeks and usually several months of treatment at the highest usual dose (500 mg, three times per day.) The risk from one week at the lowest dose is probably very low. There is no reliable information available about treatment differences in CMT patients, but the risk from a short course of treatment should be the same as reported for patients with other causes of neuropathy.

**Dear Doctor,**

*My mom is 85 and has CMT Type 1A, which has now paralyzed her diaphragm and compromised her breathing. (She sleeps with a ventilator at night.) Additionally, she was diagnosed with a low grade B-cell lymphoma in 2001, but due to her age and her compromised breathing status, she has not received any chemotherapy.*

*My question is this, my Mom's Alzheimer's disease symptoms of*

*hallucinations, combativeness and depression have worsened recently despite the use of Aricept. Our family doctor has suggested placing her on a daily dose of half a pill of Risperdal at bedtime.*

*Are there any contraindications when using Risperdal in elderly CMT patients, especially in light of my Mom's past history of compromised breathing and B-cell lymphoma?*

**The Doctor replies:**

Risperdal is not associated with causing or worsening neuropathy, including CMT. However, there are other side effects that should be considered, including light sedation. This drug is generally less sedating than many other medications used to suppress hallucinations and Alzheimer's disruptive thoughts, due to disease.

**Dear Doctor,**

*I have been taking Nexium recently and Aciphex before that, and I believe that I had a neurotoxic response to each of them. Are there any known problems with either of these drugs?*

**The Doctor replies:**

The neuropathy risk with proton pump inhibitors like Nexium (esomeprazole) is not yet clear. Aciphex (rabeprazole) is a related but different drug. There are a small handful of cases that appear to have developed neuropathy soon after starting the drug, but millions more who did not. At present, the rare risk is considered a possible association. However, if someone expe-

riences worsened CMT symptoms after starting one of these agents, the possible link should be taken seriously. There is no clear link with older ulcer medicines such as Zantac and Tagamet, but they are generally less potent and have other concerns but are still effective. There is also no known risk with antacids. For CMT patients already successfully using Nexium or Aciphex, the risk appears to be extremely low.

**Dear Doctor,**

*I am 73 years old and I was diagnosed with CMT at 43 years of age. I broke my left tibia and fibula on August 16, 2007. The tibia fracture is a spiral fracture. I spent four days in a hospital, and 25 days in a rehab facility working with OTs and PTs. I have excellent upper-body strength, which helps compensate for my weak leg strength.*

*On October 8, 2007 I was cast with a straighter cast so I could start weight bearing, walking up to 50% on a walker. My next appointment with my orthopedic surgeon was on October 23, 2007. At nine weeks now, the ortho doctor said there is not much healing and indicated he feels the CMT is the main contributor to the lack of healing along with my age. We decided to continue with the weight-bearing walking along with my upper-body and leg exercises for four more weeks. At my next appointment on November 16, 2007 the ortho doctor will suggest again that the tibia should have a rod*

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# A French Girl Learns the Joy of Volunteering

BY JULIE DANJOUX

This past summer, I spent 5 weeks in the US, where I stayed in Vermont and California, with my friends Gilles, Elizabeth, and Yohan, who has CMT. Before I left France, I knew I would learn a lot during my travels, but never in my wildest dreams would I have imagined just how much or what I would take back with me.

I have known Yohan since he was born. After he moved from France to California, at the age of 2, I had heard something about him having a type of neurological disorder, but what it was or how it affected him was unknown to me.

These 5 weeks gave me the opportunity to discover his world, bear witness to his everyday life, and learn more about how CMT affects Yohan and others with the disease. Just observing how many balls he has to juggle every day of his life made me reflect on his situation, a lot. CMT affects the entire family too; not just those who have the disease! Yohan's parents are always by his side, and make enormous efforts to help him lead a "normal" life, which is not always an easy task, given his medications, chronic fatigue, pain, and multiple doctor appointments.

These are just some of the reasons why, when Elizabeth asked me to volunteer my time to help her out with a summer eBay project, I readily agreed. As I reflect upon those weeks, I am

very happy to have had this wonderful experience. I was able to use my skills and add a personal touch to the creation of the flyers, posters, and banners which we hand-delivered to individuals' houses

At first, this eBay undertaking seemed pretty easy and straightforward, but once we really got into the heart of the matter, it took a lot of time, energy, and hard work. Our goals were to inform people



**Julie Danjoux learned first-hand about volunteering during her stay in America.**

about CMT, and then ask them to contribute to the CMTA by donating unwanted household items to be sold on eBay. One-hundred percent of the profit would then directly go to the CMTA.

Then, the real work began! We gathered up the various sellable goods, and I took pictures of each object, found detailed information on each item, and finally priced everything we had to sell. All this took a solid week of non-stop work between the

two of us, but we laughed a lot and had fun, too!

Before I spent this summer in the US, I knew absolutely nothing about CMT or the CMTA. Now, I realize that many people are affected by this disease worldwide. The worst of all is that there are still no treatments to make the disease better.

In no way did my CMT efforts stop when I left California. To this day, I continue to talk about CMT with my friends, their parents, and my family. My goal is to make people more aware and interested in this disease so that they, too, may one day get involved in the fight against CMT.

I feel grateful to have been given the chance to take part in this fundraising effort. I admire Yohan and his courage to meet each day and Elizabeth's efforts to advance CMT research, awareness, and understanding of the disease. Thanks to Yohan and his family, I experienced a deep desire to spend my free time on this worthy cause, with the hopes of making a difference in someone's life.

The concept of volunteer work is not widespread in French culture, so at 17 years old, I gained first-hand experience about the rewards and personal satisfaction of selflessly helping others. I hope I will tangibly have the opportunity to help Yohan and the CMTA, despite the distance.

Good luck to everyone; you deserve the best. ✨

## SPOTLIGHT ON SUPPORT GROUP LEADERS

**Diane Covington**

**H**aving been asked by Elizabeth Ouellette to write something about myself, I sit at my computer thinking of the best way to write about my life with CMT. Hopefully, this bio will tell you something about me and inspire you. I think that by being open and talking about it, I can help people in my life feel more comfortable with my CMT. Along those lines, I lead a support group in the Denver area. I find it very uplifting to attend meetings and have friends who know first-hand what I'm experiencing. It's one thing for a partner or husband to sympathize, but it's entirely different when you're speaking with someone who can empathize with having numb feet.

One of the most recent contributions I've made to my support group is to publish a resource directory which includes all kinds of information useful for other people living with CMT. It includes names of doctors who are knowledgeable about CMT, shoe stores in our area that can fit people who wear AFOs, exercise suggestions, information on organizations that focus on individuals with disabilities who want to participate in outdoor activities, and much more. It's grown to 16 pages, and I add information monthly as members email or call me with something that's worked for them. Various members in my support group have had great luck with

supplements, socks that can be worn with AFOs, a place where a van can be made wheel-chair accessible, etc. It's been a labor of love because I hope that the directory will encourage folks to live their lives to the fullest in spite of having some difficulties. As time goes on, Elizabeth and I intend to publish a national directory along the same lines as my local directory.

I'm 51, and I work part-time (21 hrs/week) for a wholesale tile and stone importer. I assist customers in the design of



**Diane Covington published a resource directory for her support group members.**

their kitchen, bathroom, entry-way, etc. It's a lot of standing, but so far I am able to maintain the stamina needed for this job. My hobbies include reading, scrapbooking, mosaicing, and enjoying many friendships.

When I was 28, it became obvious that I was limping. Coworkers often asked if I had hurt my leg. I knew my gait was "off" but couldn't figure out why. I gradually had to buy lower-heeled shoes for work, eventually needing to wear shoes with no heel whatsoever. Finally, I made an appointment with my

family doctor. He referred me to a neurologist. After an examination and some blood work, the doctor scheduled me for an EMG. He did not prepare me in any way for the discomfort of that test. I arrived at my appointment with no idea of what the procedure was going to entail. Needless to say, it was uncomfortable. Once the whole thing was over, the pain subsided, but I remember to this day just how excruciating it was. (Since then, I've had two other EMGs within the past three to four years and they were much less painful. I attribute that to the fact that I have much less feeling in my legs now!) My neurologist gave me the diagnosis of CMT, which I had never heard of. I didn't feel too upset about it at the time because I was able to lead a fairly normal lifestyle. I had a third child after the diagnosis, and it never occurred to me or my husband to consider genetic counseling.

My children are now 18 (son), 23 (daughter), and 28 (daughter). At this point, I would venture a guess that my son may have CMT. My oldest daughter is clumsy and trips a lot, but I'm not sure if that's just the way she's built or if it's possibly caused by CMT. My middle daughter shows no signs of any impairment. I have suggested to all three children that they have the Athena testing to know for certain whether they have CMT. All three have declined. Since

*(continued on page 16)*

# CMT Support Groups: Looking for Leaders!

BY ELIZABETH OUELLETTE

The CMTA is expanding in membership, research, public awareness, and fundraising efforts. In light of these encouraging events, there is a need for more CMT support groups across the country. Our offices receive many calls and e-mail requests for information on support groups in virtually every state in the US. The demand is much greater than the supply, so I am personally reaching out to each and every one of you to consider facilitating a CMT support group in your area.

Starting a support group may seem to be an overwhelming task. At least, this is how I felt when Dana Schwertfeger approached me with the idea of starting a group in the Bay Area. My knee-jerk response was: "Why me? I don't know the first thing about leading a group! How much time will it take to start and continue the group? Where do I find attendees? Who do I call for a conference room?" After my questions were answered, I let the idea simmer for a while and decided to give it a whirl, assured that the benefits would greatly outnumber the disadvantages.

What does the CMTA require of those interested in starting a CMT group? You do not have to be an expert in the field of CMT, nor do you have to be trained in leading groups. The most essential requirements are motivation, a certain time commitment, people skills, and

sincere dedication to the group and its members. Remember, you will not be all alone in taking on this endeavor; the CMTA is here to help out. Recognizing the intrinsic value of such groups for our members and communities, the CMTA is reaching out to our groups, assisting the leaders to get off to a good start, and maintaining success over time.

Once you decide to start a group, contact the CMTA and I will walk you through the orga-

donate their time and knowledge to educate members. In turn, the participants are also given the opportunity to enlighten the presenter about the distinctive traits of CMT.

At the time of my first meeting, 2 years ago, I had only met 2 people with CMT and my son, Yohan, had never met a single soul with the disorder. Now, in my second year as support group "leader," I remain fiercely committed to the individuals who comprise our group.

The demand for support groups is much greater than the supply.

nizational steps and answer any questions you have. The Association will help publicize your first meeting through e-mail or a written letter, and will announce all the details on our web site.

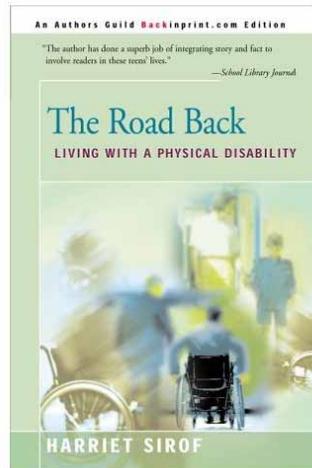
A CMTA support group provides a valuable service by teaching coping skills, educating, socializing, and informing. When individuals who share a common experience meet face to face, a world of reciprocal understanding and camaraderie is created. A group of this nature allows for the exchange of insightful experiences and life stories, not to be found elsewhere. In addition, these meetings provide a structured forum where individuals can help and be helped by others.

Secondly, local professionals familiar with CMT are willing to

Most of our group leaders across the US have been at this task far longer than I, and along the way, I have gained great respect for these people who forge ahead, personally making these groups happen. Groups make a difference by serving individuals, the community, and society at large.

After reading this article, my wish is that some of you will pick up the phone with the intent of putting a CMT group together. The rewards, both personal and social, are immeasurable. Each one of us can make a difference, so let's strengthen our roots and multiply. As Margaret Mead once said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." \* ❄️

## BOOKS WORTH A LOOK



## The Road Back: Living with Physical Disability

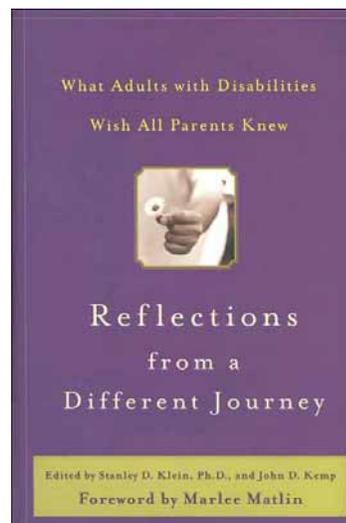
By Harriet Sirof  
List price: \$12.95  
ISBN – 0595090710

The book looks at three teenagers who become disabled and the obstacles they overcome in adjusting to school, friends, and family. One girl, Tricia, 14, was injured in a car accident; Steven, 16, injured his spine in a skate-boarding accident and has to adjust to life in a wheelchair; and Christopher, a high school senior, has multiple sclerosis. Using these three examples, the author shows how rehabilitation takes place in the hospital, as an outpatient, or in a rehab center. She introduces the professionals, explaining therapies, schooling, and the laws that serve the disabled. The three students join a support group to help them adjust to their changed lives and deal with the practical aspects of daily living, the reactions of their family and friends, and the choices that all young people have to make.

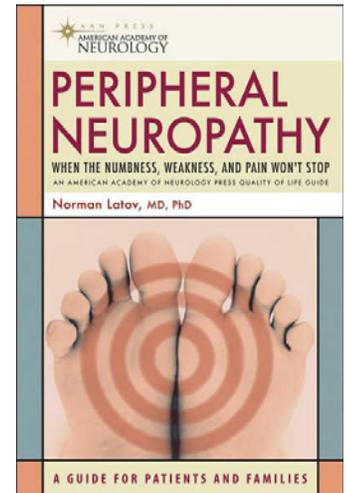
## Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew

By Stanley D. Klein and  
John D. Kemp  
List price: \$8.95  
ISBN – 0071422692

This book presents 40 stories by successful adults who grew up with disabilities. They provide insights into what it is like to persevere in the face of prejudices and what it takes for families and children with disabilities to work together to find fulfillment.



This is one of the first books to help parents raising children with disabilities to learn from people who have “been there” and to help children face the unique challenges and rewards of growing up with a disability. The book is generally quite encouraging.



## Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop

By Norman Latov  
List price: \$19.95  
ISBN – 193260359x

This essential guide explains what is known about peripheral neuropathy, including its causes and manifestations, and what can be done to manage it. Topics include drug therapy for the condition and its symptoms, interventional therapy, alternative medicines, caring for the feet, and much more. (This book was written by the doctor who started The Neuropathy Association and while not specifically directed to CMT patients, information in it might be helpful in dealing with some of the common problems of neuropathy such as numbness, burning, cold feet, and so on.)

## American Icon and Medical Enigma

An article by Ronald J. Anderson, MD, Associate Professor of Medicine at Harvard Medical School, explores the possible physical disabilities of one of America's iconic images in art, Christina of *Christina's World* by Andrew Wyeth. The painting depicts an apparently crippled woman in an open field looking up toward a house and barn on a New England hillside.

Christina Olsen, the subject of the painting, lived her entire life in the farmhouse depicted in the painting. She had a progressive crippling disorder, apparent from childhood. By the age of fifty, she had lost the ability to walk. The painting was done in 1948 by Wyeth who saw Christina crawling in the field to pick blueberries and care for her parents' grave.

Wyeth maintained that he was not purposely depicting Christina as crippled, but rather was attracted to her because of her dignity. He actually used his

own wife, Betsy, as the model, so the painting was his perception rather than a reproduction of Christina's anatomical features. Nonetheless, Dr. Anderson points out that she has long been a symbol in the disabled community, and many have conjectured about her disease.

Christina was noted to have a clumsy, waddling gait at age three, and her mother constructed knee pads for her in grade school to protect her against falls. All available photos of her appear to demonstrate muscle atrophy rather than arthritic swelling. She, apparently, never complained of joint pain.

Descriptions of her crawling along the ground using her thigh and shoulder muscles seem to exclude myopathies with proximal weakness, according to the author of the article. In her later years, she fed the wood stove in the farmhouse by grasping the logs with her wrists rather than her hands.

Christina's niece, Jean Olsen

Brooks, a little girl in the early 1940's while Christina could still walk, describes her as having a "slapping gait" characteristic of foot drop seen in peripheral neuropathies. Descriptions of her decline in function mention a loss that was always symmetrical and distal.

What evidence the author could find leads him to a diagnosis of a primary motor sensory neuropathy in the spectrum of disorders known as Charcot-Marie-Tooth disease. The available evidence and clinical course are most like type

1, since features of this form have onset in childhood, predominantly affect motor nerves, and are compatible with a normal lifespan.

Sadly, the author concludes that therapy for this condition is essentially no better today than it was in Christina Olsen's lifetime. \*



## CMTA REMEMBRANCES

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

### 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

Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

### Gift Given By:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_



**Board member Elizabeth Ouellette visited Mary Fatzinger's Las Vegas support group to talk about the work of the CMTA and how thoughts affect one's sense of well-being.**



## SUPPORT GROUP NEWS

### California – San Francisco Bay Area

On Saturday, October 6, 2007, the group heard an informational overview of hereditary neuropathies presented by Sean McEvoy from Athena Diagnostics. Sean went over information on inheritance patterns in CMT, upcoming treatments, and details of the testing protocol. For more information, Sean mentioned [www.athenadiagnostics.com](http://www.athenadiagnostics.com) and [www.genetests.org](http://www.genetests.org), a site sponsored by the National Institutes of Health.

The group's next meeting will be December 16th for a holiday party.

### Colorado – Westminster

Group leader Diane Covington has moved the meetings to a store in Westminster, Colorado.

The first meeting in the new location, October 27, 2007, featured a presentation from Martin McCorkle, the author of *Walk with Me*, the story of Martin's personal trek through California on the Pacific Crest Trail. His topic for the meeting was "Staying Active with Life Passions." Future meetings will be from 10 AM to noon. The next scheduled date is January 5, 2008.

### Nevada – Las Vegas

In September, Elizabeth Ouellette, one of the CMTA's Board members, spoke in Las Vegas to the support group. The heart of the presentation focused on the way thoughts and attitudes can create feelings and behaviors. The entire group explored various inaccurate thinking styles and learned how to restructure

thought processes in order to create a more positive experience of daily life. In addition, Elizabeth discussed some of the CMTA's exciting new and reformulated research strategy. The group is working at raising awareness for the CMTA and doing a great job.

### New York – Greater New York City

The group is now meeting on the second Saturday of every other month from 12:30-2:30 PM. The next meeting is November 10. They also have a web site at [www.CMTnyc.org](http://www.CMTnyc.org) which offers more information about the group.

### Pennsylvania – Philadelphia Area

On October 20, 2007, Dr. Michael Shy flew in from Detroit to speak to the group regarding the typing of CMT and the ascorbic acid trial. In explaining the different types, Dr. Shy first spoke about the most common variety, CMT IA and then the other autosomal varieties. Over 35 people were in attendance and the session lasted until almost 3 PM, with many good questions and responses.

The next meeting of the group will be December 8, 2007, at 10 AM, when orthotist, Gary Michalowski, C-Ped, BOCP, CFO, from Lawall Prosthetics and the A.I. DuPont Institute, will discuss the appropriate time to brace and the type of brace that is best for each foot and ankle deformity. ❄



## GIFTS WERE MADE TO THE CMTA

### IN MEMORY OF

#### Irene Ausherman

Mrs. Linda Skiftun

#### Mrs. E. Inez Bachman

Mr. Edward Bachman

#### Betty Chow

Ms. Jean Kaung

Ms. Rose Yuen

#### Eugene Earl Cosner

Patsy Ann Parker

Mr. & Mrs. Scott

Mitchell

#### Frank T. Eckman

Mr. & Mrs. Frank

Tamburello

#### Gail Lynn Feeney-Coyle

Ms. Mary Ellen Feeney

#### Gail Marie Feeney-Coyle

Ms. Mary Ellen Feeney

#### Paul Flynn

Mrs. Arla Van Almen

Mr. & Mrs. Richard

Van Almen II

#### Irma Jaffe

Ms. Julia Leonard

#### Joseph Janner

Ms. Virginia S. Kobarg

#### James P. Jones

Robert May

#### Ruth Linker

Mr. Lawrence Linker

#### Elaine Valenti

Mr. & Mrs. William

Sharp

#### Annie Vater

Mr. & Mrs. Robert

Tretheway

David & Shirley Hutchins

### IN HONOR OF

#### Yohan Bouchard

Josie Mallette

Ms. Jennifer Schust

#### Harvey Ducharme

Mr. & Mrs. Craig Voland

#### Dr. Michael Shy

Mrs. Arla Van Almen

#### Reagan Stultz

Mr. James J. Cotey

#### Dr. Florian Thomas

Mr. & Mrs. James

Haislip

Mr. W. Morris Young

# CMT Support Groups

*Support Group Liaison:* Elizabeth Ouellette, 650-559-0123

## Alabama—Birmingham

**Contact:** Dr. Dice Lineberry, 205-870-4755

**Email:** dklrl@yahoo.com

## Arizona—Phoenix Area

**Place:** MDA Office, S. 51st St, Phoenix

**Meeting:** Bi-monthly, Thursday  
6:30-8:30 PM

**Contact:** Marilyn Hardy or  
Aisha Hackett, 480-496-4530

## California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)

**Place:** Sutter Medical Center of  
Santa Rosa

**Meeting:** Quarterly, Saturday, 1 PM

**Contact:** Louise Givens,  
707-539-2163

**Email:** lbgivens@ix.netcom.com

## California—San Francisco Bay Area/Santa Clara County

**Place:** Menlo Park Library

**Meeting:** Quarterly

**Contact:** Elizabeth Ouellette,  
650-248-3409 (C)  
650-559-0123 (H)

**Email:** elizabetho@pacbell.net

## Colorado—Westminster

**Place:** Capabilities, Westminster, CO

**Meeting:** 10 AM – noon, Last Saturday of  
every other month

**Contact:** Diane Covington  
303-635-0229

**Email:** dmcovington@msn.com

## Florida—Tampa Bay Area

**Place:** St. Anthony's Hospital,  
St. Petersburg, FL

**Meeting:** 2nd Sat of Feb, May, Aug, Nov

**Contact:** Lori Rath, 727-784-7455

**Email:** rathhouse1@verizon.net

## Illinois—Chicago Area

**Place:** Peace Lutheran Church,  
Lombard, IL

**Meeting:** Quarterly

**Contact:** Alan Pappalardo,  
800-606-2682, ext. 106

**Email:** alan@charcot-marie-tooth.org

## Kentucky/Southern Indiana/ Southern Ohio

**Place:** Lexington Public Library,  
Beaumont Branch

**Meeting:** Quarterly

**Contact:** Martha Hall, 502-695-3338

**Email:** marteye@mis.net

## Michigan—Detroit Area

**Place:** University Health Center, Wayne  
State University School of Medicine

**Meeting:** Call for schedule

**Contact:** Lainie Phillips, 248-890-1529

**Email:** familiaphillips@sbcglobal.net

## Minnesota—Benson

**Place:** St. Mark's Lutheran Church

**Meeting:** Occasionally

**Contact:** Rosemary Mills, 320-567-2156

**Email:** rrmills@fedtel.net

## Minnesota—Twin Cities

**Place:** Call for location

**Meeting:** Quarterly

**Contact:** Bill Miller, 763-560-6654

**Email:** wmill758@msn.com

## Mississippi/Louisiana

**Place:** Baptist Healthplex,  
102 Clinton Parkway,  
Clinton, MS

**Meeting:** Quarterly

**Contact:** Flora Jones, 601-825-2258

**Email:** flojo4@aol.com

## Missouri—St. Louis Area

**Place:** Saint Louis University Hospital

**Meeting:** Quarterly

**Contact:** Carole Haislip, 314-644-1664

**Email:** c.haislip@att.net

## Nevada—Las Vegas

**Place:** West Charleston Library,  
6301 West Charleston Blvd.

**Meeting:** Email for dates 1-3 PM

**Contact:** Mary Fatzinger

**Email:** cmt\_suppgrp\_lvnv@yahoo.com

## New York—Greater New York

**Place:** NYU Medical Center/  
Rusk Institute, 400 E. 34th St.

**Meeting:** Second Saturday,  
12:30 -2:30 PM

**Contact:** Dr. David Younger,  
212-535-4314,  
Fax 212-535-6392

**Website:** www.cmtnyc.org

**Email:** bwine@acm.org

## New York—Horseheads

**Place:** Horseheads Free Library on Main  
Street, Horseheads, NY

**Meeting:** Quarterly

**Contact:** Angela Piersimoni,  
607-562-8823

## New York (Westchester County)/ Connecticut (Fairfield)

**Place:** Blythedale Hospital

**Meeting:** Bimonthly, Jan, March, May,  
Sept, and Nov; 3rd Saturday

**Contacts:** Beverly Wurzel, 201-224-5795  
Eileen Spell, 732-245-0771

**Email:** cranomatic@verizon.net  
espell@optonline.net

## North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)

**Place:** Raleigh, NC

**Meeting:** Quarterly

**Contact:** Susan Salzberg,  
919-967-3118 (afternoons)  
Betsy Kimrey

**Email:** judae@bellsouth.net

## Ohio—Greenville

**Place:** Various locations.

**Meeting:** Fourth Thursday, April–October

**Contact:** Dot Cain, 937-548-3963

**Email:** Greenville-Ohio-CMT@woh.rr.com

## Ohio—NW Ohio

**Place:** Medical College of Ohio

**Meeting:** Quarterly

**Contact:** Jay Budde,  
419-445-2123 (evenings)

**Email:** jbudde@fm-bank.com

## Pennsylvania—Johnstown Area

**Place:** John P. Murtha Neuroscience  
Center

**Meeting:** Bimonthly

**Contacts:** J. D. Griffith, 814-539-2341  
Jeana Sweeney, 814-262-8467

**Email:** jdgriffith@atlanticbb.net,  
cjsweeney@ussco.net

## Pennsylvania—Northwestern Area

**Place:** Blasco Memorial Library

**Meeting:** Call for information

**Contact:** Joyce Steinkamp,  
814-833-8495

**Email:** joyceanns@roadrunner.com

## Pennsylvania—Philadelphia Area

**Place:** CMTA Office,  
2700 Chestnut St., Chester, PA

**Meeting:** Bi-monthly

**Contact:** Pat or Dana, 800-606-2682

**Email:** info@charcot-marie-tooth.org

## Virginia—Harrisonburg

**Place:** Sunnyside Community Center

**Meeting:** Quarterly

**Contact:** Ann Long, 540-568-8328

## Washington—Seattle

**Place:** U of Washington Medical  
Center, Plaza Café—  
Conference Room C

**Meeting:** Monthly, Last Saturday, 1-3 PM

**Contact:** Ruth Oskolkoff, 206-598-6300

**Email:** rosk@u.washington.edu

**DIANE COVINGTON***(continued from page 10)*

there is no treatment, the knowledge could have a negative impact, and there's really no need to know until symptoms develop.

I've had the Athena test, and I have CMT2A. Over the years, I saw various neurologists. All concurred with my CMT diagnosis, and I find some consolation in knowing for certain what my disorder is. I'm really glad that I had the Athena blood test. My insurance did pay for a large part of the testing, but Athena has a patient advocate program, and they were great about working with my insurance company to get the testing covered. I didn't have much out of pocket expense in the end.

My daily life now is definitely impacted by having CMT, but I live peacefully with it. I do regret not being able to do things like skiing or hiking, especially since I live in beautiful Colorado. I've come to accept my limitations and make the best of the situation. I feel fortunate that I don't have any pain, but I do have tingling sensations. My feet are always freezing, but as long as I wear socks, I'm OK. My biggest concern at present is leg bracing. In the past 26 months, I've been through about eight sets of braces as I attempted to find the best option for me and my lifestyle. My original orthotist was very talented at making custom braces, but we finally settled on a toe-off type of brace that wasn't custom-made. Eighteen months and four sets of braces later, it became apparent

this type of brace wasn't going to be a long-term solution, as the shank that went into my shoe kept breaking. My orthotist said I was more "active" than most of his clients. I had a different kind of brace made by another orthotist this past June, but it wasn't a viable solution either. I went to a board-certified pedorthist to get fit for shoes and discovered the brace made finding shoes an impossible task. This new brace was extremely bulky with hinges at the ankle, and there wasn't a shoe in the entire store that would accommodate the brace! Most recently, I've been a patient at Hanger Orthotics,

I've come  
to accept my  
limitations and  
make the best of  
the situation.

and I've been fit with a pair of wonderful rigid plastic AFOs. We tried the carbon braces, but the plastic ones were the answer for me. After 26 months, I'm confident I've found the best bracing option to accommodate the weakness and drop foot problem I'm experiencing. Braces have been a lifesaver for me. Without them, I wouldn't be able to work or even grocery shop very efficiently. In the short time I've been wearing braces, they've allowed me to be much more mobile, and I'm grateful for that.

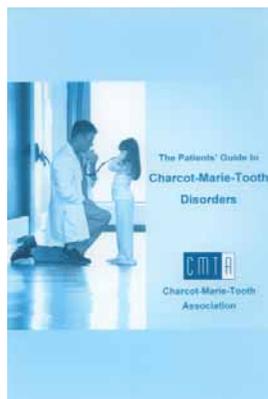
Two years ago my husband and I separated and divorced. Having re-entered the dating

world recently, I discovered that having CMT isn't as much of an obstacle as I'd feared it might be. Not every man I've dated was totally accepting of my somewhat weird gait and ugly shoes, but who'd want to have a relationship with someone who is that insensitive and shallow anyway? Fortunately, most of my dates were fine with my CMT and it didn't seem to influence those relationships negatively. This summer, in the best of all possible scenarios, I met a wonderful man whom I've fallen head over heels for, and he with me. I know that my guy loves me for who I am and isn't concerned about the few things I can't easily do. If you're single and reading this, I hope you'll feel encouraged to look for a partner regardless of any disability you may have. I've learned that I am not defined by CMT; I am simply a woman who has CMT but who has a full life in every respect.

The only advice I can offer is to learn to accept yourself. About five years ago, I finally got a handicapped tag for my car. Before I got braces, shopping at the mall was out of the question. I have a cane, but I only use it on occasions when I know I'll really need it, for example, walking long distances when traveling. I do feel a bit self-conscious, but I'm trying to get past that. I've considered that it's a lot less embarrassing to use a cane than to fall over because I've lost my balance! Truly, acceptance is hard to come by, but I'm learning that being comfortable with my CMT and living a full and productive life are entirely possible. ✨

*Patients' Guide to CMT...*  
**Is Now Available**

**in print...**



**and CD...**



The long-awaited update to our *Handbook for Primary Care Physicians* is now available in both print and CD format. Each chapter in the book has been written by a leading CMT expert and is directed at a more lay audience than the previous text.

Topics include the clinical features of CMT, electrodiagnostic evaluations, genetics, CMT in children, orthopaedic considerations, new treatments, physical exercise, genetic counseling, toxic medications, and resources for CMT patients and their families. The new book is 178 pages and features full color photos of many conditions and treatments.

The CD, which contains the entire text of the *Patients' Guide*, also contains a slide show by Dr. Steven Scherer, neurologist, University of Pennsylvania, which is intended for doctors who would like a quick overview of CMT and another slide show by Dana Schwertfeger, Director of Member Services, which is intended for patients and families who might need a fuller understanding of CMT.

We are currently offering the CD to anyone new who joins the CMTA before year's end or anyone who renews their membership before then.

We pride ourselves on being the best source for up-to-date information on CMT, and these two publications are our latest accomplishments in that area.

## MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

(Items marked with an asterisk "\*" are required.)

\*NAME: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
First MI Last

\*ADDRESS: \_\_\_\_\_

\*CITY: \_\_\_\_\_ \*STATE: \_\_\_\_\_ \*ZIP: \_\_\_\_\_

\*COUNTRY/POSTAL CODE (IF NOT US): \_\_\_\_\_

\*DAYTIME PHONE: \_\_\_\_\_ EVENING PHONE: \_\_\_\_\_

EMAIL: \_\_\_\_\_ USER NAME: \_\_\_\_\_

*Required for PDF Newsletter/Website Access*

*Required for Website Access*

**Note: If you are joining now, you may purchase publications at active member prices. ACTIVE MEMBERS have paid dues within the past year. If you are unsure about your membership status, please call 1-800-606-2682.**

	QTY	COST	TOTAL
<b>ANNUAL MEMBERSHIP DUES</b>			
Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both. Receive newsletter as: <input type="checkbox"/> Print <i>or</i> <input type="checkbox"/> PDF via email		\$40	
Receive both Print <i>and</i> PDF Newsletters		\$45	
<b>NEW!</b> The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		<b>active members \$10</b> nonmembers \$15	
[CD Format]		<b>active members \$7.50</b> nonmembers \$10	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		<b>active members \$15</b> nonmembers \$20	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		<b>active members \$3</b> nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		<b>active members \$5</b> nonmembers \$7	
CMT Facts III		<b>active members \$5</b> nonmembers \$7	
CMT Facts IV		<b>active members \$8</b> nonmembers \$10	
CMT Facts V		<b>active members \$12</b> nonmembers \$15	
A Guide About Genetics for the CMT Patient (No shipping and handling on this item only)		<b>active members \$4</b> nonmembers \$5	
<b>NEW!</b> Teaching Kids about CMT...A Classroom Presentation (1 hour DVD)		<b>active members \$7.50</b> nonmembers \$10	
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# *The CMT Facts Series:* **An Indispensable Collection of Articles about CMT**



## *CMT Facts 1*

- Facts about professionals who treat patients
- Genetics
- CMT and physical therapy
- CMT foot: surgical options
- The CMT hand
- Occupational therapy



## *CMT Facts 2*

- ADA overview
- Hope and fear
- For parents
- Anesthesia
- Adaptive gadgets
- Rehabilitative medicine
- Vocational rehabilitation
- Orthotics and orthotists
- Disability profiles
- Tremor



## *CMT Facts 3*

- Incurable, not untreatable
- CMT and pregnancy
- Prenatal testing
- Q & A about living with chronic illness
- Exercise & sports for children with CMT
- Patient services
- CMT hand surgery
- Special education
- Health insurance



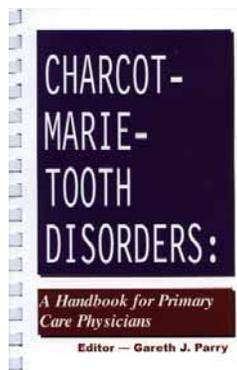
## *CMT Facts 4*

- Treatment of familial neuropathies
- Pulmonary function
- HNPP
- Orthotics survey
- Pulmonary function
- Managing pain
- Orthopedics and children
- Shriners hospitals
- Employment/ADA
- SSI



## *CMT Facts 5*

- AFOs and foot issues
- Emotional issues
- Pain and CMT
- Pregnancy
- Social Security
- Vitamins and herbs
- Physical therapy
- Occupational therapy
- Genetic testing
- Medical terminology
- Special section on HNPP

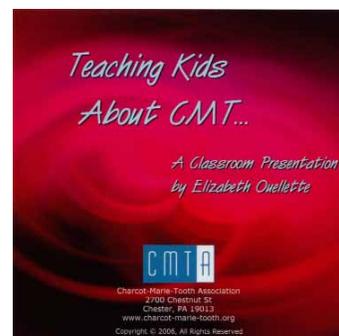


## *Handbook for Primary Care Physicians*

1995/130 pages

Edited by Dr. Gareth J. Parry, Professor of Neurology at the University of Minnesota, the *Handbook for Primary Care Physicians* is an excellent source of information about the causes, symptoms, and treatment/management of CMT. Patients will also want to read it.

**Nonmember Price: \$20.00**  
**Member Price: \$15.00**

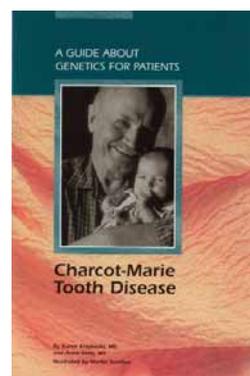


## *Teaching Kids about CMT... A Classroom Presentation*

2006/DVD 1 hr.

This hour-long DVD of an actual classroom presentation demonstrates a number of games and other exercises to teach classmates of children with CMT about the disorder.

**Nonmember Price: \$10.00**  
**Member Price: \$7.50**



## *A Guide about Genetics for Patients*

2000/21 pages

Illustrated with easy-to-understand diagrams, this booklet outlines the basics of genetic inheritance and CMT.

**Nonmember Price: \$5.00**  
**Member Price: \$4.00**



## LETTERS

**Dear CMTA,**

I'm finally able to contribute toward your research fundraising. My husband has been out of work for a year and just recently went back to work, so money is still scarce. But your efforts in finding treatments and a cure are close to our hearts since our daughter and I both carry CMT1X. I am passing along your letter about research projects to family and friends.

Thanks for all you do.

—L.J.

**Dear CMTA,**

We live on 50 beautiful acres that need to be kept cleared from time to time each year. A couple of years ago, the weakness reached the point where it became too dangerous for me to safely climb up onto our farm tractor while I was alone. Our son, who lives in his own house about 100 yards from ours, wouldn't let me take the tractor out unless he was present. If I needed to use it for one job or another, I had to wait until he was present in the barn with me.

However, this year, he

designed and built for me a platform at the height of the deck and seat of my tractor, along with a ramp attached to it. Now I ride up the ramp on my 3-wheeled scooter, onto the platform. Then, all I do is step across onto my tractor and into the driver's seat. I am now able to take the tractor out whenever I want. He restored a level of independence that I thought I had lost two years ago. I can still operate the tractor alright, always have been able to. I just couldn't climb onto it by myself. I owe him a debt of gratitude.

—W.S.

**DEAR DOCTOR**

*(continued from page 8)*

*inserted, which as he says will enhance healing along with stabilization, of course.*

*I am not so sure the rod is the best answer for healing even with CMT. Also the possibility for infection is there as well.*

*My question: Can a person with CMT achieve normal healing and calcification with time albeit longer than normal compared to a younger person without CMT?*

**An Orthopedic Surgeon replies:**

There are multiple factors that influence fractures and their healing in people with hereditary neuropathies, such as Charcot-Marie-Tooth disease. These include muscle weakness, muscle atrophy, osteoporosis, and deformity.

People who have paralysis or muscle weakness in the legs are more prone to falls and

therefore more likely to have a fracture. Fracture healing depends on the blood supply to the bone. Much of this blood supply comes from the surrounding muscles. If the muscles are atrophied (shrunken in size), then there is less blood flow to the bone to assist with healing. This is a common scenario with leg fractures in persons with CMT.

Another factor that promotes bone healing is to have a compression force across the fracture which pushes the bone ends together. This compressive force is provided by the surrounding muscles. When the muscles are weak and atrophied then there is less of a compressive force across the fracture to promote healing.

Persons with hereditary neuropathies, such as Charcot-Marie-Tooth disease, commonly have osteoporosis. There are a few studies that show delayed bone healing when osteoporosis is present. This has also been my

clinical experience. In addition, osteoporosis makes the surgical stabilization of fractures more technically challenging. With osteoporosis, the bone is thin and fragile. It does not hold fixation devices, such as screws, as firmly as normal bone does.

Deformity can also influence healing. If the foot is not well aligned, this places abnormal mechanical forces on the leg during standing or walking. These misdirected forces can result in a fracture moving excessively even in a cast or with surgical fixation. It is important to be certain that the foot be positioned well.

When the fracture is well aligned, either by casting or surgery, and the foot is positioned as normally as possible, then fractures in persons with CMT will heal, but it generally takes longer than in people who have normal muscle strength.

*Mary Ann Keenan, MD  
Chief, Neuro-Orthopaedics  
University of Pennsylvania*

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## CMT PATIENT MEDICATION ALERT:

### Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

### Moderate to significant risk:

Amiodarone (Cordarone)  
Bortezomib (Velcade)  
Cisplatin and Oxaliplatin  
Colchicine (extended use)  
Dapsone  
Didanosine (ddl, Videx)  
Dichloroacetate  
Disulfiram (Antabuse)  
Gold salts  
Leflunamide (Arava)  
Metronidazole/Misonidazole (extended use)  
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)  
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)  
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)  
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  
Fluoroquinolones  
Glutethimide  
Lithium  
Phenelzine  
Propafenone  
Sulfonamides  
Sulfasalazine

# What is CMT?

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

## THE CMTA Report



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