

1983-2003  
CELEBRATING 20 YEARS  
OF LIVING OUR MISSION

Finding  
a Cure

Creating  
Awareness

Improving  
Quality of Life

SUMMER 2003

# The CMTA Report

Vol. 18, No. 3 ISBN #1067-0181

## 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.

## Board Members Raise Funds for CMT Research

**C**MTA Board Members Steve O'Donnell, Robert Kleinman, Richard Sharpe, and Patrick Torchia, take fundraising to a whole new level. Each sponsors or participates in an event worthy of special attention.

Steve O'Donnell, for the second year in a row, successfully competed in a group swim across the Chesapeake Bay. The field of competitors swam under the Bay Bridge and covered a distance of 5 miles in water temperatures of 59 degrees. It would be an amazing feat for anyone, but he did it in just over two hours. Wow!

Steve didn't just do it to compete, although he is a serious competitor. He did it to benefit the CMTA by raising awareness and getting donated support. This year's June 8, 2003 endeavor is expected to bring in more than \$50,000 when all the gifts are received. Thank you, Steve O'Donnell, for your sacrifice of six months of training, solicitation of financial gifts, and leadership.

Robert Kleinman, President and CEO of AFA Security Systems, has his company underwrite an exclusive, private golf tournament whose proceeds benefit the CMTA's research fund. This year's event will be held at The Creek on Long Island, New York on July 21, 2003 with an approximate field of 72 golfers.

Thanks to Robert Kleinman and Dick Sharpe, who assists him with the tournament, for 12 months of planning and work that enabled the CMTA to net over \$38,000 last year.

Board Member Patrick Torchia also sponsors a special golf tournament to benefit the CMTA. Patrick personally pulls together ten



*Board Member Steve O'Donnell greeted all of his supporters in attendance at the Bay Bridge swim.*

foursomes to compete in his annual event. This year's third annual tournament will be held on July 25, 2003, at the Sunnehanna Country Club in Johnstown, PA. Thanks to Patrick Torchia for his ongoing commitment of time, talent, and treasury to the CMTA. ★

## CMTA BOARD

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*Executive Director*

EMAIL CMTA AT:  
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## Genetic Testing for Charcot-Marie-Tooth Disease

The identification of genes responsible for CMT has brought forth a new approach to diagnosing the disease. Physicians can now use a simple blood test to determine the cause of the condition in their patients. This has led to considerable advances in the neurology practice, enabling more precise diagnosis and outdating more invasive tests such as muscle and nerve biopsy. In addition, it is now possible to predict the disease in advance of symptoms, allowing patients to take precautions such as avoiding contraindicated medications.

The use of genetic testing does have its fair share of challenges, however. These include technical challenges in developing high-quality tests, interpretation of test results, societal concerns such as discrimination, personal concerns such as anxiety, and inheritance risks. The key to proper use of these tests depends on the ability of physicians and patients to understand the issues and make an informed choice. There is no right or wrong answer in making a choice—it simply depends on the individual's situation.

### WHEN TO DO A GENETIC TEST

One of the key benefits of genetic testing is that it is extremely sensitive and specific. This means that a particular genetic defect will be identified with almost a 100% certainty. However, this is limited to the genes that are commercially available, and in the case of CMT, six genes are currently available. Another benefit of a genetic test is the ability to identify the mutation before the symptoms begin. For example, a child of a parent with CMT may be tested for genetic mutation early in life, so the family can plan for the eventualities and take precautions such as avoiding medications that can cause nerve damage, and avoiding activities that can cause stress on muscles that are at risk.

A genetic test can also help a couple determine their options for having a family. Each genetic mutation has a specific inheritance risk and different options, such as normal conception, sperm or egg donation, preimplantation genetic diagnosis, or adoption, may be considered. In addition, for genes with recessive inheritance (two copies of the mutation needed to have CMT), a carrier status (only one copy of the mutation) may be identified, and may put parents at ease that their children will not be affected. Finally, genetic testing can help identify candidates for treatment and research. As gene replacement therapy, gene regulation therapy, and other such novel mechanisms are explored in treating CMT, a candidate pool of patients with specific genetic mutations will be needed for clinical trials.

### SOCIETAL AND PERSONAL ISSUES OF GENETIC TESTING

**Why me?** This is a normal feeling when a person first encounters a complicated disease such as CMT. In fact, most people feel this way at sometime in their lives about something that has affected them while everyone else seems normal. The important thing to remember is that there are people affected by diseases much more debilitating than CMT, and while CMT is a serious disease, it is manageable. Genetic testing can help determine the cause and put an end to the countless doctor visits. Also, one may be able to avoid painful procedures such as a nerve biopsy and rule out cruel diseases such as ALS.

### *Scarduzio Family Plans Third Annual Golf Outing to Benefit CMTA*

The family of John J. Scarduzio is seeking golfers, corporate sponsors, hole sponsors, and gift sponsors for their third annual golf outing to be held September 8, 2003 at the Rolling Green Golf Club in Springfield, PA (Philadelphia area). Members of the public are invited to play. A total of 92 golfers can play the exclusive club. The cost is \$275.00 per player. Chris and Darlene Scarduzio are chairing the event on behalf of the entire Scarduzio family. Chris is the executive chef at Brasserie Perrier, 1619 Walnut St., Philadelphia, PA 19103.

Contact the CMTA for details at 1-800-606-2682.

The CMTA thanks the Scarduzio family for their all-out efforts in memory of their father, John J. Scarduzio, who had CMT. ★



*The entire Scarduzio family met over dinner to help plan the golf tournament in memory of John J. Scarduzio.*

**Discrimination.** Genetic testing does not change the status of patients that already have a diagnosis of CMT, since CMT is known to be a genetic disease with or without a genetic confirmation. The real question is with predictive testing. The normal children or adults who are found to carry the genetic defect may be at risk for loss of health or life insurance, or employment discrimination. It is important to understand and respect the patient's right to privacy by all concerned parties. Patients could ask that their genetic results not be placed in their medical record. In some states such as Massachusetts, legislations have been enacted to protect the privacy of patients with genetic disorders. Nationally, HIPAA regulations help minimize erroneous disclosure of private medical information.

**Family Issues.** A genetic diagnosis is a diagnosis for the whole family, and sometimes, this may create problems among family members. Some may want to know their status for life planning, while others may not. Some may want to perform predictive testing, while others may choose to wait until symptoms are discovered. Sometimes tests may reveal sensitive issues such as paternity. Everyone has both a right to know and a right to privacy; therefore, individuals that choose to get tested should respect the wishes of those that choose not to know.

## THE ROLE OF A GENETIC COUNSELOR

A genetic counselor may be able to help you with any questions about CMT. To find a genetic counselor in your area, look on the genetic counselor website at <http://www.nsgc.org>. When you go to the genetic counselor website, click on the "genetic counseling" option. You will find the option "How to find a genetic counselor near you." Click on this option. You can then do a search by state and the name of a hospital to find a genetic counselor near you.

Genetic testing for CMT holds a lot of promise. It helps families understand if or why they are affected; it helps physicians and researchers understand the disease better, so appropriate therapies may be developed; it helps people understand their risk of genetic transmission for family planning. As the medical community understands genetics and its implications for CMT better, it becomes each person's responsibility to make informed choices and respect the privacy of all people involved. ★

For more information on the genetics of CMT, please see page 1 of the December 2002 issue of The CMTA Report.

# CMTA MEMBERSHIP/ORDER FORM

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

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

Phone Number: \_\_\_\_\_ Email: \_\_\_\_\_

**Members who are current with their dues are considered "active."**  
If you are unsure as to whether you are current with your member dues, please call the office at 1-800-606-CMTA.

	QTY	COST	TOTAL
<b>Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians</b>		active members \$15 inactive members \$20	
Membership Dues		\$40	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 inactive members \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 inactive members \$7	
CMT Facts III		active members \$5 inactive members \$7	
CMT Facts IV		active members \$8 inactive members \$10	
<b>NEW! CMT Facts V</b>		active members \$12 inactive members \$15	
<b>A Guide About Genetics for the CMT Patient</b> <i>No shipping and handling on this item only.</i>		active members \$4 inactive members \$5	
<b>NEW! Golf Shirt</b> Size: <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL <input type="checkbox"/> XXL		\$15	
CMT Informational Brochure <input type="checkbox"/> English <input type="checkbox"/> Spanish		FREE	
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
<b>Contribution to CMT Research</b> <i>10% will be applied to administrative expenses.</i>			
<b>Shipping &amp; Handling</b> <i>Orders under \$10 add \$1.50, orders \$10 and over add \$4.50</i>			
<b>TOTAL</b>			

Check payable to the CMTA (US residents only).  
Foreign residents, please use a credit card or International Money Order.

VISA  MasterCard  American Express

Card Number \_\_\_\_\_ Expiration Date \_\_\_\_\_

Signature \_\_\_\_\_

Mail to the CMTA, 2700 Chestnut Parkway, Chester, PA 19013 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.

# Australian CMT Health Survey Results and Final Summary

*This is the completion of the results published in the last Newsletter.*

**Anthony Redmond, ex-Moore Postdoctoral Fellow of the CMTA (US)**

**Professor Robert Ouvrier, Head, Institute for Neuromuscular Research, Children's Hospital at Westmead, and the CMT Association of Australia**

## BALANCE

One real-world manifestation of impaired sensory function sometimes reported by patients with CMT is altered balance. In this sample, differences in balance capacity during static standing and in walking on flat and uneven surfaces were confirmed by more than three quarters of respondents. Balance was strongly correlated with the severity of leg/foot weakness. People with CMT appear to have particular problems with static standing. The problem is lessened to some degree when walking on the flat, but walking on uneven surfaces causes significant balance problems. Knee bending is a common strategy for improving balance, and nearly two thirds of the CMT sample reported adopting this compensation mechanism.

Of great concern is the number of falls to the ground reported by people with CMT. The risk of falling did not appear to be closely linked to age, but was strongly associated with leg/foot weakness, implying a CMT-specific mechanism. For one quarter of all our respondents, falls to the ground are reported as occurring “often” or frequently. This should cause great concern to doctors.

## DEVICES

Aids and other devices likely to be required by people with worst impairment (wheelchairs, electric scooters, walking frames, etc.) were not used by many respondents. The proportion of our sample using a wheelchair to aid mobility (6%) was actually slightly less than suggested in the anecdotal literature. Singles were more dependent on a wheelchair for mobility than were people with a partner. Dependence on these “high-end” aids was related both to age and severity of weakness. Cane and walker use was again highly age dependent, although leg/foot weakness was also implicated. This suggests that disease-related weakness might add to the increase in dependence on common walking aids normally associated with aging. Kitchen and dressing aids were not widely used and are only considered helpful by those with more significant upper limb weakness.

Over one third of respondents reported using in-shoe orthoses, and 70% reported them to be “quite helpful” or better. In-shoe orthoses are better suited to people with less weakness. Ankle-foot orthoses (AFOs) were used by fewer people than reported using in-shoe orthoses, and were generally used by those with worst leg/foot weakness. AFOs were very unpopular in the age group 21–40 years, and their use in this group was only one fifth of that in the other age groups. Conversely, in the 61–80 age group, the prevalence of AFO use was double that expected. The results suggested that the 21–40 age group also find footwear issues particularly profound and it is possible that the same factors may be implicated, namely a trade-off between social acceptability and the appearance, against the burden of disability imposed by the CMT. The many factors likely to influence success with this treatment should be considered carefully by the doctor/orthotist/podiatrist, etc. when AFOs are being contemplated, and patients need to be honest with their feelings about wearing such devices.

Of the more aggressive nonsurgical therapies, night splinting was generally considered unhelpful and raised difficulties with compliance. Again, the best results were reported by patients with less weakness, but overall, night-splinting did not appear to be a popular treatment. Unsurprisingly, plaster casting was considered more difficult to comply with than removable night splints, but conversely, casting was also considered marginally more effective.

Strengthening of weakened muscles, either weight bearing or non-weight bearing, was considered effective by the majority. Again, this approach appears to be suited better to people with milder weakness. There is little to separate weight-bearing and non-weight bearing regimens, although the weight-bearing approach was considered marginally more effective, perhaps reflecting its improved relevance to real-life activities. Stretching is widely advocated, and had been tried by 70% of the respondents. Stretching exercises are considered easy to use, and are considered effective by half the respondents. Again, stretches were more likely to be reported as effective by people with milder weakness.

## ALTERNATIVE THERAPY

Alternative therapies were widely used, with a variety of approaches reported. Many respondents who had tried one alternative approach also tried other alternative therapies. Massage and chiropractic were the two alternative treatments felt to be most effective by respondents in this sample. Acupuncture was the only other alternative therapy tried by enough respondents to warrant detailed exploration, but was not considered effective by most who had tried it. Alternative therapeutic approaches to managing the symptoms associated with CMT evaluated much more poorly than expected and must, therefore, be viewed with some caution. The more conservative approaches (massage, chiropractic) may be of limited use to some people, but the alternative therapies proved disappointing overall.

## SURGERY

Surgery for CMT is an area of great concern as there are no gold-standard treatments. People with least weakening had the best chance of avoiding surgery, while those with the most weakness tend to undergo arthrodesis. The younger patients in this sample tended to have more tendon transfers at first surgery, although there was considerable overlap between the approaches. Somewhat surprisingly, all the surgical approaches were considered similarly traumatic by the respondents, with joint fusion considered marginally more effective, but tendon transfers marginally more worthwhile. None of the differences were statistically significant. Osteotomies were usually reported as repair procedures, or as forefoot surgeries for toe deformity, and were performed on more females than males.

Given the apparent absence of factors in this survey able to predict allocation to these surgical groups, perhaps the differences are less significant than we currently think.

## QUALITY OF HEALTH

The final part of the analysis was to use a statistical technique to investigate which of the factors in the survey might be used to predict the overall quality of health. Of the general physical health dimensions, leg/foot weakness was the single most influential factor in the analysis, and was linked to the scores in each of the four physical dimensions (more weakness = worse health scores). Age was also linked to reduced physical quality of life scores, as it is in the general population. The amount of pain experienced appeared to be affected more by the presence of cramps than physical factors such as foot deformity, although people who had undergone more inva-

sive surgeries such as arthrodesis and osteotomy also reported worse pain scores. We do not know whether this reflects the outcomes of the surgeries themselves, though, or the choice of more severely affected patients for these procedures.

Foot pain was highly influenced by presence of cramps and by leg/foot weakness, and foot pain was also worse in older people. Foot function was strongly related to leg/foot weakness and age, while a history of more invasive surgeries and the frequency of cramps turned out to be fairly minor factors. This suggests a compounding effect of CMT—related disability over the life span. Problems with footwear were overwhelmingly influenced by gender. It is likely that the mismatch between the female foot and shoe recognized in the general population is even worse in people with a foot pathology related to CMT. Women with CMT may have particular trouble finding and buying suitable footwear from street outlets.

Finally, the importance of leg/foot weakness in predicting the impact of CMT disease on the lower limb is illustrated well in the measure of “general foot health,” which turned out to be highly dependent on the severity of leg/foot weakness.

## CONCLUSIONS

In summary, this survey has given us valuable insight into the effects of CMT, and for the first time, enough information to be able to draw some conclusions about the links between the symptoms and the clinical signs. The amount of weakness appears to tell us much about the type and severity of problems likely to be encountered. Estimation of weakness tells us a lot, even without detailed clinical measurements, because the patients’ own perspectives seem highly relevant. Very few people in this survey reported needing to use mobility aids, and the incidence of wheelchair use was lower than often quoted, and related as much to age and marital status as CMT. Conversely the “minor” symptoms (such as tremor, pins and needles, etc.) might have been underreported in medical studies and could be more common than previously thought. Cramps make a more significant impact on the quality of life measures than had been recognized before and are probably over-trivialized currently. Poor balance is an issue in the CMT community, as we know, and the consequent problem with increased risk of falling should, perhaps, be given more consideration also. Conservative treatments are most effective for people with mild weakness, and alternative therapies did not appear as effective as might have been expected. Surgical treatment remains as mysterious as ever. ★

## RESEARCH APPEAL

The 2003 Research Appeal has been mailed out and should have been received by CMTA members. Please remember that we are in the midst of a \$30,000 challenge pledge from the Gallagher family and hope to raise as much as \$250,000 to help fund our postdoctoral grants, the CMT North American Database, and our consortiums. No gift is too small, and we appreciate the ongoing support of our membership. Designate your gift.

# IF YOU HAVE CMT, YOU COULD HELP MAKE A DIFFERENCE



## HOW:

Participating in a study about the exercise habits among persons with CMT located at:

<http://www.mdausa.org/research/ctrials.html>

## WHO:

Any person diagnosed with CMT

## WHAT:

Filling out a questionnaire that will take less than 15 minutes to complete

## WHEN:

Any time from now through November 2003

### For more information please contact either:

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SO...LOG ONTO THIS WEBSITE NOW AND TAKE THE SURVEY!

<http://www.mdausa.org/research/ctrials.html>

# Abby's Adventures...

## A book series about a heroine with CMT

Several years ago, *The CMTA Report* featured an article about Pam Walls, an author with CMT who was just getting into the children's book market and had written her first book in a series about Abby, a young girl who faces amazing challenges in 1837 in the South Pacific. Now, eight books later, Pam is facing her own challenges with CMT and was recently profiled in her local paper.

Pam suffers from the extreme fatigue often seen in patients with CMT, but despite that has authored eight children's books in only two years. Most people don't write eight books when the doctor tells them to get rest, but Pam says she isn't most people and she has always had a certain enthusiasm and inner drive. "Subconsciously, you just push really hard," she says. "You have to; there's no other choice."

Pam has lived her entire life with CMT, although she was not diagnosed until she was 33. Others in her family, including her father, have the disease. CMT's physical effects aren't remarkably obvious on Pam, but with a closer look, one sees hands and legs which she describes as "really skinny." She describes her feet as "little horsey hooves." As a child, she constantly fell and scraped her knees because of her decreased muscle strength.

Writing was always her first love and she received a degree in science writing and co-authored a book while at the University of California, San Diego. After getting married and having two daughters and various writing jobs, Pam decided to pursue her long-time dream of writing children's books and attempting to get published.

The inspiration for the South Seas adventures came from her own daughters and the stories she



would tell them before bedtime. Targeted at kids aged 8 to 13, the books are based loosely on Pam's own life. The personalities of the two main characters were modeled after her children. The series follows Abby and her friend Luke through the South Pacific in 1837. In each book, they end up in different geographic regions, such as China, Tahiti, even California. Walls uses her life experiences in backpacking and sailing in the books and relates her disease as well. Abby is tormented by CMT, but because the disease wasn't discovered until later, she merely has weak legs, presumed to be inherited from her mother.

Abby is constantly faced with immense challenges, such as a dragon pit, being trapped in a runaway hot air balloon, or being attacked by sharks (none of which come from Pam's life experiences!), but each time Abby finds a way to beat the odds. At the end of each volume, Pam wrote about herself and her lifetime struggles with CMT. She says that readers often write to her, mostly children who are struggling with something themselves.

Pam has achieved her dream of being published as an author of children's books and in typical fashion has begun work on new dreams. She is working on an adult novel and is substitute teaching at the high school level so she can remain close to kids. She often speaks at schools and writers' conferences. She's a very productive woman in spite of her fatigue! ★

*Pam Walls has realized her dream of being a published children's book author.*



## PERSONAL EXPERIENCE

# My Cross-Country Bicycle Trip

By FRED S. ETHERIDGE

This is my story of training for and completing a 4,000-mile cross-country bicycle ride in 1982, in the summer after I graduated from college. I have seen similar stories in the CMTA Report from others with Charcot-Marie-Tooth (CMT), and thought this might be of interest.

### Medical History

I have the demyelinating type of CMT (Type I). I was diagnosed with it at a young age. I learned to walk late and, once I did, I tripped often as a child, as I had foot drop even then. I had triple arthrodesis surgery performed on both feet when I was in eighth grade, as well as surgery to straighten out hammer toes after my second year in college. So my feet have seen their share of staples, pins, and stitches, with the staples from the triple arthrodesis surgery still in my feet to secure the fusions.

In grade school I dreaded PE, because I could not run well and could jump barely at all, having very weak calves. At the same time I am very athletically minded. By that I mean I love

to exercise, to move, sweat and work to see what I can do. Being athletically minded while having CMT is a frustrating combination, as you find yourself wanting to run, but having legs that cannot carry you where you want to go. For example, I can remember playing basketball with friends in high school. I am trying to turn left to drive to the basket; my hips and shoulders are leaning left toward the hoop, so I'm ready to go, but my legs aren't following. They are too weak; it is as though my feet are glued to the ground. It wasn't that I wasn't trying; I could give all I had, but it just didn't work, having CMT-weakened legs and trying to run and jump with those who had a full set of functioning motor neurons and muscles.

As exercise was so important for me, I searched for some physical activity that did not involve running and jumping that I could actually do well. I found it in bicycling. While I had grown up riding a bicycle around the neighborhood, that was always a one-speed child's bike with a limited range. It wasn't until I got a 12-speed road bike in college that I really began to ride.

### Training

I started riding a few times a week on a bike path that went from campus toward Santa Barbara. I would ride 2 miles down the bike path, turn around and ride the 2 miles back to campus. Next time I went a little farther, maybe 3 miles out, then 3 miles back, and so on, gradually increasing my range. It was a flat bike path, so it was a good starting ground. I gradually built up strength. Having no car, I also rode a bike to and from campus (about a mile) and from class to class. Because my bike was my way of getting around, I had a base level of fitness from which to start my slightly longer bike rides.

I was fortunate to have friends who liked to ride, and I slowly expanded the length of my rides when I went riding with them. We would ride to a beach maybe 5 miles from campus, eat lunch there, then ride back. We also went up the coast to El Capitan beach (12 miles away) to swim, eat, then ride back, then later we did the same at Gaviota beach (24 miles away), and so on. I continued to increase my range and riding

*Fred Etheridge trained for and completed an amazing bicycle journey twenty years ago.*



## Seeking a Few Good Men and Women

**T**he CMTA is seeking qualified individuals to serve as volunteers on our Board of Directors. This is a three-year commitment. Travel is involved. Kindly forward a letter of interest with a phone number so that the Executive Director can contact you. He can be reached at 1-800-606-2682, option 6.

The Board of Directors of the Charcot-Marie-Tooth Association met in Trenton, NJ, on May 28, 2003 (see photo, right). Steve O'Donnell and Ann Lee Beyer were absent. Ann is currently on a medical leave of absence from the Board. Everyone wishes her a speedy recovery. ★



strength. Bicycle riding is an excellent aerobic exercise because it tones your body and—important for me at the time, busy with a full class load and working—provides a healthy outlet for stress. And, it also can be done while sitting, an important consideration for someone with CMT who finds running-based sports difficult.

After about a year of gradually increasing my distance on flat rides to about 50 miles a day, I was looking for something more; I wanted hills. The Santa Ynez Mountains border Santa Barbara, and I soon began trying the roads of those mountains. I started on a pass road that crests the mountains at 2,200 feet. Mountain roads are a different animal than the flats, as they are steep, with twisting switchback turns, exposed to the full heat of the sun. I took a lot of water and some food with me on my bike.

I used the same gradual approach in the mountains as I had with the flat bike path. I started slowly, going a little way up the road, turning around and going back. The next weekend I went a bit farther up the road, turned around and went back down, and so on, until a few months later I was able to climb far enough to reach the pass.

After I felt comfortable doing the pass, I switched to other, steeper roads that climb the Santa Ynez. The toughest of those mountain roads climbs to nearly 4,000 feet in just a few miles. There was nothing I liked better than working my way up a twisting mountain road on my bike, pushing down through the pedals,

rocking the bike from side to side, in rhythm with my breathing, switchback after switchback, as the beach slowly dropped away behind to become a tiny postcard image. When you climb a mountain and reach the summit, you know that you got there solely on your own; no one drove you, pushed you, or carried you. It is yours.

### **The Trip**

In my last year of college I talked to a couple of friends about doing some type of trip after graduation. We didn't have much money, but also felt we needed to go on some sort of big trip after finishing college. We ultimately decided on a cross-country bicycle trip, taking a northern route through the Canadian Rockies, as we wanted to ride in cooler weather rather than across the Midwest or south in the midst of summer.

As training, we went on two, one-night bike trips. This got us used to riding a fully loaded bike (tent, sleeping bag, stove, and other camping equipment, plus clothes). But my real training was my mountain rides in the Santa Ynez. I didn't know it at the time, but those Santa Barbara roads were tougher than anything we saw in the Rockies; if you could climb the Santa Ynez Mountains, ride around the valley on the backside, and ride back over to Santa Barbara, you were ready for the Rockies.

We started our trip in Victoria, British Columbia, fully loaded with panniers (the bike

*(continued on page 10)*

## MY CROSS-COUNTRY TRIP

(Continued from page 9)

bags that slide into a rack, holding gear), tent, sleeping bags, and pads. We rode up Vancouver Island, crossed on a ferry to Vancouver, then up the Fraser and Thompson River valleys. We then passed Mt. Robson, the point on our trip that was the farthest north, and from there headed down into Jasper, Banff, and Kootenay National Parks.

We rode the width of Montana, from the northwest to southeast corners, across South Dakota, Minnesota, Wisconsin, the upper Peninsula of Michigan, back into Canada at Sault Ste. Marie, dropping down into upstate New York and across Vermont and New Hampshire to Portland, Maine, where we rode our bicycles into the ocean. (Not so good for the bikes, but it was a once in a lifetime trip, so we thought it a fitting end).

We rode a total of 58 days over the summer, with a few days off here and there, averaging about 70 miles a day. Some days in the Rockies were so beautiful we stopped early after only 40 or so miles just to camp in a well-situated campground. But, then on other days, when the weather and winds were good, we rode over 100 miles.

We would usually get up early, have breakfast, break camp, and go. Generally, we would ride about an hour, stop and eat, ride another

hour, eat some more, ride another hour, then stop for lunch, then continue the same pattern through the afternoon before stopping later in the afternoon to camp. We ate a lot, as bicycle touring will literally double or triple your appetite. (We could eat five to six sandwiches each, plus fruit for lunch, then get back on our bikes and ride, not gorged but feeling ready to go.)

The hardest thing we had to deal with wasn't the Rockies, but the headwinds. There were times on the Montana plains where the east winds were so strong we could be headed downhill from a small rise, and if we ceased pedaling, we would be stopped by the wind, whereas usually we could coast down such a hill. Riding eight to nine hours a day into a headwind and making slow progress is discouraging.

We also hit our share of weather, including rain almost every day in British Columbia, near-freezing temperatures in Marquette, Michigan (in August!), and torrential rain in Ontario, but those times were counter-balanced by views of the lakes in Jasper and Banff Parks, emerald green from glacier melt, or the exposed rock faces of the Rockies, layer upon layer of rock uplifted and twisted by eons of geologic time; the crystal-clear waters of the Georgian Bay, Ontario, and the start of fall color in New England.

We stayed on small country roads to the extent we could, as they were quieter and led us to small towns across the continent. Each town had its own flavor, from the small ranching towns of western Montana, farm towns in the Midwest, to wooded towns in upper Michigan, Canada, and New England. Bike touring is one of the best ways to get a true sense of a place and its people, as you are going slow enough to get a flavor of the landscape and it is easier to talk to people at stops than if you are inside a car.

### **CMT and Riding**

We did not race; instead we toured, keeping a steady, easy cadence and averaging about 12-14 mph. This made it easier on my body, though I did have problems with my knees. In the Rockies, and later again in New England, my knees hurt. I think this was due to not having enough easy gears on my bike (this was in 1982, before 18+ speed bicycles were available; I had only 12 speeds, and my easiest gear wasn't easy enough for me and my 20-30 pounds of clothes and equipment to pedal up grades or into headwinds without straining my knees). My sore knees were also due to CMT. I had imbalances in my leg muscle strength from CMT, so that at times my legs did not travel in a clean downstroke on the pedals, but would instead shift slightly from side to side. The lack of a clean downstroke meant my knees weren't tracking

## Symposium Honors Dr. Robert E. Lovelace

The Columbia University College of Physicians and Surgeons, Department of Neurology, honored Robert Lovelace, M.D., F.R.C.P for his clinical and academic career at Columbia with a special symposium. Dr. Lovelace practiced and taught at Columbia from 1963 to 2003. The Symposium was held June 12, 2003, from 1 to 5 PM at the Neurological Institute Alumni Auditorium. The topic of the Symposium was "Advances in Neuromuscular Medicine." Some of the speakers were Walter Bradley, D.M, F.R.C.P., Jack Petajan, M.D., Ph.D., and Michael Shy, M.D., all members of the Medical Advisory Board of the CMTA, which Dr. Lovelace chairs. ★



properly, but were instead grinding, causing painful knees. When that happened, we would take a day off and I was then able to go on the next day.

I also had to make adaptations in my riding style due to CMT. Most serious riders will use their calves in riding to help turn the pedals. But, as my calves were weak from CMT, I was unable to do that, instead having to rely on my quadriceps and glutes to generate power. I also have long legs and that leverage helped, as well. The main thing I did was to listen to my body. If I was sore I backed off and if I felt good I would open up some more. In the entire trip I never really rode fast—Lance Armstrong I wasn't—but I was persistent.

### **My Current Exercise Program**

I ride only short distances now (a few miles) and only attempt slight inclines, as I do not have the leg strength I had 20 years ago. I do swim three times a week, as I find swimming provides a similar full-body workout, is great cardiovascular exercise, and is easy on joints. That last point is important because some of my joints do not have a full set of musculature surrounding them to protect against side tension injuries that could result from traditional land-based sports. Swimming also helps keep me fit for those rare occasions when I go body boarding (on small surf only!) in the ocean.

From my standpoint, physical exercise is a vital component of healthy life, both mental and physical. We humans were made to move and, unfortunately, CMT can hinder what would otherwise be best for our bodies. But, that doesn't mean we should just give up and sit. I would recommend working with your doctor and physical therapist to develop an exercise program that fits you. Start slowly and listen to your body; it can tell you things no medical



practitioner can determine. Gradually develop and adjust your exercise program to fit your body's needs. I am convinced that the only way I was able to ride over 100 miles a day or climb mountains was that I was young and started with a low-distance ridden per day (1-2 miles), and very slowly and gradually built upon that.

I have made a significant adjustment in my own exercise program, switching from my high school efforts at basketball—which weren't too fruitful—to bicycling, and now focusing primarily on swimming, with some light bicycle riding in between. I do miss serious hill climbing on my bicycle because I loved the challenge of it. I would rather have ridden up a mountain than down it, as there is nothing like working your way up a peak. But, I am glad I was able to climb the mountains I did and to ride cross-country. It was one of the best things I've ever done and I would not trade it for anything. ★

## **PATIENT FAMILY CONFERENCE TENTATIVELY SCHEDULED FOR OCTOBER**

**O**n October 4, 2003, the University of Pittsburgh, Shadyside, will host a patient-family conference on CMT from 8 AM to 5 PM. The conference will begin with a continental breakfast from 8 to 9 AM, with presentations beginning at 9. Dr. Neil Busis, neurologist, will speak first on the neurology of CMT. Amar Kamath, Athena Diagnostics, will discuss genetics and the role of genetic testing. Other topics may include pain management, orthopaedic surgery options, exercise and CMT, physical therapy, and bracing and splinting choices. All presentations will be followed by a question and answer period.

Details and a registration form will be in the next issue of the newsletter and will be mailed out to members who live in the general area of the medical center. ★



## WORKPLACE GIVING

The CMTA benefits annually from the Combined Federal Campaign. This campaign is based in the workplace of government employees and the gifts received through the CFC are a major portion of our income. In past years, we have received over \$25,000 from this campaign. If you are a government employee or have a family member who is, we hope you will choose our organization for your annual giving. Look for our ad in the CFC brochure at your workplace and remember the CMTA when you designate your gift.

# GIFTS WERE MADE TO THE CMTA

## IN HONOR OF:

**Yohan Bouchard**  
Patron's of Henry's Diner

**Mrs. Skip Davis**  
Mr. & Mrs. Richard Davis

**Ruth Gelman**  
Leon Gelman

**Debbie Militello**  
Edna Cook

**Missy Post**  
Katie & Gregg Brown  
David Kibbee  
R.M. & D.M. Mirando  
Robert & Amie Potter  
Donald & Aine Thorogood  
Roy & Jan Woods

**Mrs. Charles Ratcliffe, Jr.**  
Mr. & Mrs. Richard Davis

**Samantha Sheriff**  
Myer & Mary Headrick

**Minna Wurzburg**  
Julie Baer  
Mary Jean Field  
Jane & George Frank  
Jeanne Gidwitz  
Mr. & Mrs. James Goldsmith  
Marjorie Grodin  
Mary Lawton  
Sis & Joseph Lelewer

## Minna Wurzburg (continued)

Harry & Elsa Levi  
Mr. & Mrs. Robert Logan  
Lois Lurie & Bill Zack  
Mr. & Mrs. Milton Minkin  
Hortense Mintzer  
Roslyn Orlin  
Dick & Elaine Rieser  
Ann & Fred Ullman

## IN MEMORY OF:

**Madelyn Alderson**  
Lucinda Parrett

**Irving Bank**  
Les Meltzer & Family

**Donald Campbell**  
State Pre-School Program Teachers

**Janet Colwell**  
Laverne & Gerald Collinge

**Maurice Cabbage**  
Maurice's Siblings

**Harold Fines**  
Mabel Fisher

**Henry Friedmann**  
Pete Friedmann & Karen Laner

**Ralph Hall**  
Arthur & Kathleen Benedict

**Daniel Headrick**  
Myer & Mary Headrick

**Eliza Johnson**  
Jeanette Keim

**Charles Louis Koenig**  
Chester & Jill Drash  
Mr. & Mrs. Joe Hanson  
Mr. & Mrs. Lee Kiper  
Betty Savage  
Royce, Tommie, Judy & Peggy Shofner

**Charles Lynch**  
Frank Blair  
J. C. Julian  
Co-workers of Christopher Lynch  
Tom, Jean & Chris Lynch

**Amy Nakasko**  
Gene & Jade Lew

**William Peirce**  
J. D. & Elsie Ruby

**Brucie Rowe**  
Clay Battle

**Percy Sand**  
Evelyn & Paul Becker

**Jerry Shulman**  
Richard & Lois Dennis  
Michelle Etkins & Family

**Edward Smith**  
Carmita Smith

**Lois Thomas**  
Doris & Jim Cramer

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

\_\_\_\_\_



## RESEARCH STUDY REPORT

# Dreams of People with Physical Disabilities

By **CHERI F. PEREZ**, University of Houston-Clear Lake

The purpose of this investigation was to gain a better understanding of how people with physical disabilities perceive their bodies in their dreams. There has been very little research on the dreams of people with disabilities. The few studies that have been conducted have focused largely on people who are blind, deaf, or have a learning disability. There is a large gap in the research regarding dreams of people with physical disabilities that affect mobility and/or movement.

In a pivotal book on dreams, Hall and Nordby (1972) proposed the continuity hypothesis, in which a person's dreams are a continuation of their waking life (i.e., problems, wishes, fears). In line with Hall and Nordby's hypothesis, Newton (1970) found that men who recently acquired their disability had more kinesthetic (muscle sensation) content in their dreams than men with a longer-term disability. Similarly, Ryan (1961) found that people with disabilities have dreams consisting of denial of incapacity and anxiety with their new body image.

The current study investigated the dreams of people with physical disabilities that affect movement or mobility.

The specific focus was on the following characteristics of their dreams: do they have their disability, what is their movement like, are they stronger or weaker, and are they younger or older. Congenital versus adventitious disabilities were also considered.

The most interesting finding from this study is that 88% of the participants do not see their disability in their dreams. This suggests that even people who have had their disability since birth do not see their disability in their dreams (the 88% includes five of the six participants who have a congenital disability).

This is in line with the prior research in this area. The results reflect Hall and Nordby's (1972) continuity hypothesis that individual's

dreams are a continuation of their wishes and thoughts from their waking lives. It also fits Newton's (1970) hypothesis of maintenance of body image in dreams, and possibly Ryan's (1961) finding of denial of incapacity in dreams.

The relationship between various factors and body characteristics in dreams also reflects the prior findings. Participants who were more distressed about their disability saw themselves as younger in their dreams. Participants with a longer-term disability saw themselves as weaker in their dreams. Participants that acquired their disability later in life appear stronger in their dreams. These results reflect Newton's findings that individuals with a longer-term disability (who are possibly better adjusted) may see their body image as more realistic in their dreams.

The finding that as current age increases participants appear younger in their dreams may be a reflection of Hall and Nordby's (1972) continuity hypothesis. However, it may not be related to having a disability, which was the focus of the current study.

Regarding movement in dreams, the majority of the participants who do not see their disability in their dreams are walking or running. Those par-

ticipants who do see their disability in their dreams reported moving the same as in their waking life. No statistic was reported on this information as it was based on detailed dream descriptions versus quantifiable data.

All of the participants who do see their disability in their dreams saw their bodies the same as in their waking lives. Based on the prior research, this would seem to indicate that they are better adjusted to their disability than those who do not see their disability in their dreams.

Although gender was not a primary focus of this study, the fact that there were no significant findings regarding gender and dreams of people with physical disabilities is surprising. ★

### Bibliography

Hall, C & Nordby, V. (1972) *The individual and his dreams*. New York: New American Library

Newton, P.M.(1970) Recalled dream content and the maintenance of body image. *Journal of Abnormal Psychology*, 76, 134-139.

Ryan, J.H. (1961) Dreams of paraplegics. *Archives of General Psychology*, 5, 286-291.

88% of study participants do not see their disability in their dreams

**CORRECTION**

Due to a typographical error, the price of the Easy Gait brace was incorrectly listed as \$305 in the last issue of the newsletter. The brace is correctly priced at \$395. We apologize for any inconvenience or confusion that this error caused.

# Helpful Ideas for Things that Work

By J. D. VEATCH

**H**ere are things that work for me and might for you. We all have different manifestations of our neuropathy; so not all of these products and devices will suit you. But they may spark an idea for an alternative that will allow you to function more comfortably and efficiently.

## AFOS

I've evolved to the lightest, thinnest, most flexible plastic that will withstand nearly unrestricted and constant activity. I've snapped and had to replace six different orthoses since 1995, but the flexibility and minimal weight of my current pair far outweigh their relative fragility. And, I've managed to salvage two back-up pairs, one for each of our homes.

After struggling with heavy, bulky buckles to secure the AFO around my calf, I specified 2-inch Velcro tape only, with the catch piece on the back of the AFO. I thread a felt pad onto the tape crossing my shin to avoid contact with and abrasion of the skin. In addition to being easy to secure and remove, the Velcro becomes almost invisible under over-the-calf socks. In fact, at least in my mind's eye, the slight bulge of this fastening system simulates the appearance of well-developed calf muscles.

I wear the thinnest, synthetic fabric quarter sock to keep my feet from sticking to the PPT cover on the foot pad. I've found Wal-Mart/K-Mart tube socks to be the ideal, inexpensive outer sleeve for my AFOs, but turn to soccer or over-the-calf, wool dress socks when I want color variety. I wear shorts in Florida most of the year and don't feel overly conspicuous in my knee socks. I occasionally affect a slight British accent to complement the ensemble.

Three clever tips from a *CMTA Report* article by Dana Schwertfeger that appeared a couple of years ago have resulted in immeasurable improvement in my AFOs. Molding the plate of the AFO to the contours of the bottom of my feet has virtually eliminated chronic and painful metatarsal calluses, and drilling ventilation holes in the back of the braces has made them much more comfortable in hot weather. Cutting off the footplate just behind the toes allows me to wear a full half-size smaller shoe. This places the ball of my foot in a more correct, forward position in the shoe and does away with clown shoe flap.

## FOOTWEAR

Blucher style Rockport dress shoes have served me well, although in retirement I'm favoring L.L.Bean's Blucher Moc in walnut nubuck. The flat, beveled-edge sole and absence of an elevated heel make them surprisingly stable for a relatively shallow shoe. For some reason the walnut nubuck model is much softer and more flexible than the brown model.

They're not great for long walks, but fine for less-than-formal evenings that involve minimal walking and standing. A thin insole makes them even more comfortable.



My favorite everyday shoe is the New Balance 810 Walking Shoe. This shoe is light, flexible, and deep and wide enough to accommodate my AFO. When new, I remove the insole for more break-in room, but replace it when the shoe begins to feel too roomy. I may be the only guy in the world who puts shoe trees in his sneakers, but I've found that they maintain the needed width and original shape.

The most comfortable and accommodating footwear I've come upon in years are L.L. Bean's Moosehide Soft Sole Mocs. I wear them exclusively in and around the house without my AFOs. As advertised, they are truly "buttery soft" and mold immediately to the shape of one's foot. They have no tacky/sticky, sharp edged sole to catch on carpet or tile joints and don't impede the slide/drag gait common to many people with CMT.



I make mine even more comfortable by inserting the best insole on the market, SPENCO Everyday or Thin Soles. The slipper's "Soft Sole" becomes very sticky when wet and will stain light-colored carpet. I wear through the sole about once a year, but could get better wear if I removed them before taking my daily saunter down the driveway for the newspaper.

Because we spend a lot of time on our ocean beach, I tried a number of department and drugstore water/beach shoes that were consistently ill fitting and more of an impediment than an aid. I finally found a light, mesh body and rounded/beveled rubber sole water shoe at my REI, Inc. store in Northern Virginia. Unfortunately, REI advises that they are no longer carrying "my" shoe, at least on their website, and I'll have to wait until we return to Virginia to determine whether they are still in the store,

The surprise bonus these beach/water shoes provide is that they are great for light lawn chores, gardening, and car washing. I put a pair of those wonderful SPENCO insoles in them and find that I can get around the property or the car without my AFOs. These are tight-fitting water shoes that stay on in the surf and are difficult to pull over my high instep when new. I stretch the elastic mesh instep panel with a pair of old baseballs until I can comfortably pull them on. I'm confident that you can find similar water shoes at any good outdoor sporting goods or diving store.

## EMERGENCY WADING STAFF

What? That's what Orvis calls it because it was designed to assist trout fishermen wading in fast rushing, slippery-bottomed mountain streams. My wife calls it my "pokey stick" (I'm always lagging behind and/or she gets an occasional nudge in the backside), and it's the best thing I've ever used for long walks, walking over uneven terrain, climbing steps with no railing, waiting in long, slow-moving lines, standing in museums admiring the works on display, and even standing at cocktail parties. Mine has six black anodized aluminum sections that automatically lock in place with spring cord tension. It's easy to break down and comes with a leather holster with a belt loop. It's a great aid for maintaining balance and provides an extremely effective



leveraged boost for climbs. It's much more comfortable than a cane and has a lot more panache.

It's not cheap (about \$130), but I've had mine for over 12 years and it snaps in place just like it did on day one. A note of caution: it comes in two sizes, 50" for under 6' and 59" for over. I inadvertently sent my 5'8" brother the longer model and he called me asking if I was suggesting he take up pole vaulting. You'll be a lot more popular with your friends who have hardwood floors if you add a rubber tip, because it comes with a sharp tungsten-carbide tip. It'll fit in a large fanny pack, which is sometimes more convenient and secure than the holster.

## GARDEN KNEELER

This terrific, versatile kneeler-stool caught my eye in the Improvements catalogue about a year ago and I've used it several times a week ever since. It has a sturdy steel frame that locks in place with spring-loaded catches and a double-sided rubberized cushion. The steel frame arms/legs form a hand-hold at the top and are the perfect height for raising yourself back to a standing position. Flipped over, it becomes a comfortable stool for chores like scrubbing car wheels and rocker panels. It is advisable to sit down gingerly when using it as a stool. If you plop down, you will, more than likely, go over backwards...only embarrassing in the middle of the yard but potentially painful in the driveway or on the deck.



## RESOURCES

All of the brand names I've mentioned have easy-to-navigate websites that can be accessed by searching with the name. To see the "pokey stick" on the Orvis site, you have to enter the slightly haughty "Wading Staff" in their Search box. You can see the beach/water shoes on [www.deepseeinc.com](http://www.deepseeinc.com), a wholesale distributor. Click on "Boots" and then "Beachwalker." I've asked DeepSee for the name of retail stores and Internet sites, but haven't received a reply yet.

If you have questions or want amplification, e-mail me at [jdveatch@ucnsb.net](mailto:jdveatch@ucnsb.net). Keep pushing. Stay active. ★

## An Improved Walking Device: the Sure Foot Cane

Rebecca Rush, the President of Trillium Wellness Programs, LLC, contacted the CMTA with information about a series of canes which should be valuable to patients with CMT who are seeking a more stable form of support. Her uncle who recently died had experienced walking problems because of both diabetes and CMT.

Ms. Rush sent the cane to Krista Hall, RN, a former member of the CMTA's Board of Directors, for her evaluation and use. Krista, who has CMT, stated that the cane should be a good product for many people with CMT. One customer said that she hadn't been able to go down a ramp for years and now, using the all-terrain Sure Foot, she could.

The Sure Foot orthotic canes are the only canes that stand by themselves, provide the correct walking gait, and have up to 18 times greater continuous traction than a standard or quad cane. The Sure Foot canes walk like a typi-



*Users of the Sure Step (top) and Sure Foot F/A (bottom) demonstrate that the canes are particularly useful on uneven terrain.*

cal foot does: heel first, then toe, providing two to three steps. To use the Sure Foot, one places it on the surface 12 to 15 inches forward of the foot. It is placed heel down and the spring system then cushions the movement. As weight is placed on the Sure Foot, it remains flat on the surface to ensure maximum support. As the person walks past it, the cane foot remains flat, enabling continued stability. After walking past the cane foot, the person places the Sure Foot forward, heel down again, and continues the walk. ★

- ★ The Sure Foot and Sure Step Canes are lightweight, weighing just over 1 lb.
- ★ The Sure Foot and Sure Step Canes are available in pediatric sizes (21½" to 29")
- ★ The Sure Foot and Sure Step Canes are adjustable with a single snap button.
- ★ Sure Foot can support up to 400 lbs. with normal use.
- ★ Sure Foot forearm crutch canes can benefit people with neurological conditions which cause weakness of the hands, wrists and forearms.

*For more information or to order, contact Trillium Wellness Programs at 1-866-637-2659 or order online at [www.nescohelpscaregivers.com](http://www.nescohelpscaregivers.com)*

## Letters to the Editor

Dear CMTA,

On behalf of the brothers of Alpha Phi Omega-Phi Chapter, a co-ed service fraternity at Syracuse University, we would like to donate a check for \$1,000 to help benefit CMT research. The brothers of APO organized a tee-shirt sale naming the CMTA as the beneficiary and have been hard at work raising money for the cause. We hope this donation will enable CMTA to further their efforts.

—Rebecca Hasskamp, Alison Reinhardt, and Adam Ritchie

Dear CMTA,

Thank you so much for all your help and for sending information so quickly. I called MDA as you suggested and have been put on their waiting list to see their MDA specialist, plus their “brace man” for a new pair of AFOs so I can walk. Praise God for all of you and your excellent and persistent work for us with this disease!

I'm enclosing an order, plus membership, and will order more as I can afford.

Thank you again and may God bless you all!  
—E. B., Greensburg, IN

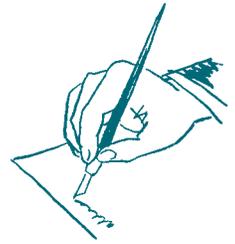
Dear CMTA,

I've been getting your newsletter since 1995 and have gotten useful suggestions from Letters to the Editor. So, here's mine:

I was diagnosed at age 25 with CMT IA, when an ankle injury would never heal. I was referred to a neurologist and my father went with me. He was also confirmed as having CMT. I've lived with it for ten years now and have had two babies and seen a lot of atrophy in both legs and hands. At age 33, I was fitted for AFOs and only wished I had gotten them sooner. I had my AFOs cut shorter than normal. I wanted to wear my shorts and cover them with my socks. It worked.

I have always been physically active with aerobics and working out with weights. When I could no longer do those things, I turned to the water. Water aerobics has helped me tremendously. You can do anything in the water: jump, run, hop on one foot, do jumping jacks. You don't have a disability in the water. It's great therapy for your mind, body, and spirit. I highly recommend a water aerobics tennis shoe (Ryka). The shoe is heavy, but in the water, it doesn't matter.

I hope that this letter gets someone in the water and moving! —C. S., Powder Springs, GA



### WRITE TO US!

Pat Dreibelbis, Editor

The CMTA Report

CMTA

2700 Chestnut Pkwy.

Chester, PA 19013

*The CMTA reserves the right to edit letters for space.*

## Ask the Doctor

Dear Doctor,

*My 11-year-old daughter had a visit with her orthopaedic surgeon a few weeks ago and he mentioned surgery to fuse the bones on the top of her foot. Can you tell me what you might know about this surgery and how successful it is with CMT patients? I have a very active 11-year-old who, in the past year, has fallen many times and has had sprains and fractures. This happens often and I would like to know if this surgery would help her.*

—A. W., Greensboro, NC

### The Doctor Replies:

Eleven-year-olds should be and are expected to be very active. Most are: they have their activities, play sports, dance, etc. However, they don't get a LOT of sprains and fractures of the foot. Are the sprains in the ankle? If they are sprains, what has been done about it besides having the orthopaedist suggest surgery?

If the problem is due to clumsiness because of

a high arch and turning in of the foot and ankle, then something needs to be done. A manual muscle test to determine the strength of the posterior tibial, anterior tibial, and peroneal muscles would be useful. The foot may need to be balanced. If the sprain is at the ankle, then high top shoes and their support would be helpful and would not require fusing the bones on the top of the foot.

If the problem is otherwise (including being extremely overweight or heavy), I would need to know specifically which bone is fractured. The fracture or underlying problem itself may need to be addressed.

In any case, the foot of an 11-year old is still under development (growing). Doing surgery can interfere with the growth and cause secondary deformities, shortening, and scarring and not solve the problem. The orthopaedic surgeon should be a pediatric orthopaedic surgeon or someone very experienced in the care of deformities of the child's foot—not only fractures.

# Support Group News

## ■ New York - Horseheads

The quarterly meeting of the Horseheads, NY CMT support group was held on May 13 at the Free Library. Joy Miller, PT, instructor in aquatic therapy, spoke to the group about that mode of exercise. Following her presentation, the group had a lively discussion concerning issues pertinent to individual problems. The group all felt that more effort needed to be made to acquaint neurologists and other physicians with CMT and the problems it causes so that patients could have better care closer to home.

## ■ Pennsylvania - Northwestern Area

The Erie support group had a good first meeting and all those in attendance were interested in continuing with the group. Thirteen people with CMT were there, plus spouses and friends. Others who could not attend the first meeting but remain interested have contacted Joyce Steinkamp by phone and email. J. D. Griffith and Meghan Stahl from the Johnstown, PA, support group presented an informational Power Point presentation they developed on CMT. The next meeting was held on May 30, 2003.

## ■ Pennsylvania - Johnstown Area

The Johnstown CMT Support Group held its bi-monthly meeting May 30th, at the Myron C. Williams Conference Room at the Conemaugh Medical Center.

Lori Murphy, P. T., from The John P. Murtha Neuroscience Institute at the Conemaugh Health System, gave an excellent presentation on CMT, muscle imbalance, and exercise. Lori graphically explained, using a skeleton, how muscle imbalance occurs and its effect on the structure and function of our feet and hands. She also demonstrated a variety of helpful exercises.

Jeana Sweeney, co-leader, reviewed the "Healthy Living with a Chronic Condition" program, developed at Stanford University, which she recently completed at the Conemaugh Health System. The program included exercises, relaxation techniques, nutrition suggestions and tips on how to talk to doctors. She recommended that all our members enroll.

"Look around the room, we all appear normal," Jeana said to the group. "Others see us as normal and can't understand that we live with disabilities." This is good news and bad news. The good news is society accepts us as ordinary; the bad news is we aren't, and face a daunting task eliciting sympathy and raising awareness. CMT is a serious disease with a funny name and desperately needs our help.

Contact: J. D. Griffith at 814-539-2341 or by e-mail at [jdgriffith@mail.charter.net](mailto:jdgriffith@mail.charter.net) or Jeana Sweeney at 814-262-8427 or by e-mail [jchcs6@cs.com](mailto:jchcs6@cs.com).

## ■ Pennsylvania - State College

The State College, PA, CMT Support Group held its initial meeting May 20th at 7:00 PM at the Senior Center, 131 Fraser St. in State College. The meeting was well organized and led by Katia Skovrinski, a recent graduate of Penn State. Katia is to be commended for her efforts; she does not have CMT, but donated her time not only to organize the initial meeting but also to continue as group leader. J. D. Griffith, from Johnstown, PA, gave an informative presentation and discussion on CMT. The meeting was well attended.

Monthly meetings are planned. Katia may be contacted at 717-608-1081 or by e-mail at [skov@psu.edu](mailto:skov@psu.edu). Or contact J. D. Griffith at 814-539-2341 or by e-mail at [jdgriffith@mail.charter.net](mailto:jdgriffith@mail.charter.net). ★

## SUPPORT GROUP LEADER NEEDS

**C**harcot-Marie-Tooth patients in the USA are estimated to number somewhere between 150,000 to 250,000 persons at this time. Our CMT Association has fewer than 3,000 dues-paying members. The Association is trying to fund and find a cure for "our" disease with the support of a tiny percentage of persons affected with CMT. We have 20 support groups that serve a few hundred active members four to six times per year on average. Do all the people who attend support group meetings pay dues to the CMTA? If not, they are taking advantage of all that the organization does for its members without helping to fund the work. We are seeking to begin more support groups, but we are also seeking to have all support group members be paying members of the CMTA.

With a few exceptions, the major metropolitan areas are devoid of organized support groups. We are looking for ideas for a solution to the lack of leaders and groups. Any city of 150,000 or more should be a candidate for a support group.

Please give this problem some thought and contact me with any ideas or methods that would result in growth. The Internet and our home page might be one possibility. Each patient's doctor is another piece of the solution, as are each of us. Tell me what you think and how you would like to help.

—Bob Budde  
Support Group Liaison Leader

# CMT Support Groups

Bob Budde, Support Group Liaison, 859-255-7471

## Arkansas—Northwest Area

**Place:** Varies, Call for locations  
**Meeting:** Quarterly  
**Contact:** Libby Bond, 501-795-2240  
**E-mail:** charnicoma57@yahoo.com

## California—Berkeley Area

**Place:** Albany Library, Albany, CA  
**Meeting:** Quarterly  
**Contact:** Gail Whitehouse  
**E-mail:** gwhite@earthlink.net

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

**Place:** 300 Sovereign Lane,  
Santa Rosa  
**Meeting:** Quarterly, Saturday, 1 PM  
**Contact:** Freda Brown, 707-573-0181  
**E-mail:** pcmoble@mac.com

## Colorado—Denver Area

**Place:** Glory of God Lutheran Church  
Wheat Ridge  
**Meeting:** Quarterly  
**Contact:** Marilyn Munn Strand,  
303-403-8318  
**E-mail:** mmstrand@aol.com

## Kentucky/Southern Indiana/ Southern Ohio

**Place:** Lexington Public Library,  
Northside Branch  
**Meeting:** Quarterly  
**Contact:** Martha Hall,  
502-695-3338  
**E-mail:** marteye@mis.net

## Massachusetts—Boston Area

**Place:** Lahey-Hitchcock Clinic,  
Burlington, MA  
**Meeting:** Call for schedule  
**Contact:** David Prince, 978-667-9008  
**E-mail:** baseball@ma.ultranet.com

## Michigan—Flint

**Place:** University of Michigan,  
Health Services  
**Meeting:** Quarterly  
**Contact:** Debbie Newberger/  
Brenda Kehoe, 810-762-3456

## Minnesota—Benson

**Place:** St. Mark's Lutheran Church  
**Meeting:** Quarterly  
**Contact:** Rosemary Mills, 320-567-2156

## Mississippi/Louisiana

**Place:** Baptist Healthplex,  
102 Clinton Parkway, Clinton,  
MS  
**Meeting:** Quarterly  
**Contact:** Flora Jones, 601-825-2258  
**E-mail:** flojo4@aol.com

## Missouri/Eastern Kansas

**Place:** Mid-America Rehab Hospital,  
Overland Park, KS  
**Meeting:** First Saturday bimonthly  
**Contact:** Lee Ann Borberg, 816-229-2614  
**E-mail:** ardi5@aol.com

## Missouri—St. Louis Area

**Place:** Saint Louis University  
Hospital  
**Meeting:** Quarterly  
**Contact:** Carole Haislip,  
314-644-1664  
**E-mail:** c.haislip@att.net

## New York—Greater New York

**Place:** NYU Medical Center/  
Rusk Institute, 400 E. 34th St.  
**Meeting:** 2nd Thursday of each month  
**Contact:** Dr. David Younger,  
212-535-4314,  
Fax 212-535-6392  
**Website:** www.cmtnyc.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:** 3rd Saturday of each  
month, excluding  
July & August  
**Contacts:** Diane Kosik, 914-937-2013,  
Beverly Wurzel,  
845-783-2815  
**E-mail:** DianeK319@optonline.net or  
cranomat@frontiernet.net

## North Carolina—Archdale/Triad

**Place:** Archdale Public Library  
**Meeting:** Quarterly  
**Contact:** Ellen (Nora) Burrow,  
336-434-2383

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

**Place:** Church of the Reconciliation,  
Chapel Hill  
**Meeting:** Quarterly  
**Contact:** Susan Salzberg,  
919-967-3118 (evenings)

## Ohio—Greenville

**Place:** Church of the Brethren  
**Meeting:** Fourth Thursday,  
April–October  
**Contact:** Dot Cain,  
937-548-3963  
**E-mail:** Greenville-Ohio-CMT@  
woh.rr.com

## Oregon/Pacific NW

**Place:** Portland, Legacy Good Sam  
Hospital, odd months  
Brooks, Assembly of God  
Church, even months  
**Meeting:** 3rd Saturday of the month  
(except June and Dec.)  
**Contact:** Jeanie Porter,  
503-591-9412  
Darlene Weston,  
503-245-8444  
**E-mail:** jeanier4211@attbi.com or  
blzerbabe@aol.com

## Pennsylvania—Northwestern Area

**Place:** Blasco Memorial Library  
**Meeting:** Call for information  
**Contact:** Joyce Steinkamp,  
814-833-8495  
**E-mail:** joyceanns@adelphia.net

## Pennsylvania—Philadelphia Area

**Place:** University of PA, Founders  
Building, Plaza Room A  
**Meeting:** Bimonthly  
**Contact:** Amanda Young,  
215-222-6513  
**E-mail:** stary1@bellatlantic.net

## Pennsylvania—Johnstown Area

**Place:** Crichton Center for Advanced  
Rehabilitation  
**Meeting:** Bimonthly  
**Contact:** J. D. Griffith,  
814-539-2341  
**E-mail:** jdgriffith@mail.charter.net

## The CMTA Report

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The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Association. The material is presented for educational purposes only and is not meant to diagnose or prescribe. While there is no substitute for professional medical care for CMT disorders, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.

Photos on page 6 and 11 by Ian Britton, courtesy of FreeFoto.com

## MEDICAL ALERT:

***These drugs are toxic to the peripheral nervous system and can be harmful to the CMT patient.***

Adriamycin  
Alcohol  
Amiodarone  
Chloramphenicol  
Cisplatin  
Dapsone  
Diphenylhydantoin (Dilantin)  
Disulfiram (Antabuse)  
Glutethimide (Doriden)  
Gold  
Hydralazine (Apresoline)  
Isoniazid (INH)  
Megadose of vitamin A\*  
Megadose of vitamin D\*  
Megadose of vitamin B6\* (Pyridoxine)  
Metronidazole (Flagyl)  
Nitrofurantoin (Furadantin, Macrodantin)  
Nitrous oxide (chronic repeated inhalation)  
Penicillin (large IV doses only)  
Perhexiline (Pexid)  
Taxol  
Vincristine  
Lithium, Misomidazole, and Zoloft can be used *with caution.*

**Before taking any medication, please discuss it fully with your doctor for possible side effects.**

\*A megadose is defined as ten or more times the recommended daily allowance.



# 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).
- ... 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).
- ... does not affect life expectancy.
- ... has no effective treatment, although physical therapy, occupational therapy and moderate physical activity are beneficial.
- ... is sometimes surgically treated.
- ... 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, 1D (EGR2), 1X, HNPP, 2E, 4E, and 4F can now be diagnosed by a blood test.
- ... is the focus of significant genetic research, bringing us closer to answering the CMT enigma.

## The CMTA Report

*Information on Charcot-Marie-Tooth Disorders from the Charcot-Marie-Tooth Association*



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