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THE CMTA Report

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Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ✻ www.charcot-marie-tooth.org

CMTA

**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:

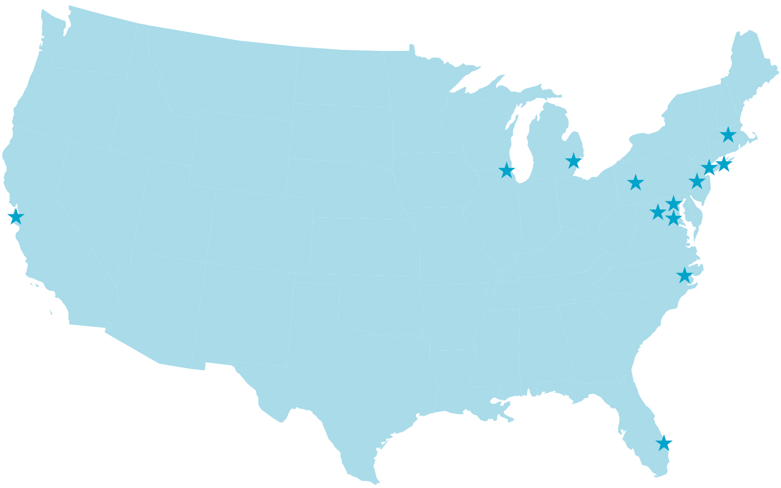
A world without CMT.

EMAIL CMTA AT:
CMTAssoc@aol.com

Westward Ho!

The CMTA Board of Directors Expands

At its last meeting, the standing members of the CMTA's Board of Directors voted to extend membership to two new people, Patrick Livney of Chicago, Illinois, and Elizabeth Ouellette of Los Altos, California Their election enhances the geographic scope of the board by including Midwestern and Western members.



CMTA Board Members...Across the Country

Patrick Livney is the Managing Director at Vanderbilt Capital Advisors, LLC and is the head of Vanderbilt's Structured Product Investment Team. Previously, Pat was a partner at Asset Allocation & Management Company, responsible for marketing. Prior to that, from 1986 through 2000, he worked in institutional fixed income sales on Wall Street, where he specialized in structured financial products. He is a frequent speaker at industry conferences. Pat holds a BS in Industrial Engineering from Roosevelt University in Chicago.

When asked why he chose to become a board member of the CMTA, he replied:

"In our busy personal and business lives it is often difficult to give back to society and make a difference. I spent many years volunteering and fund raising on behalf of MDA. Disenchantment and frustration at the politics within that organization led to my apathy and lack of participation in recent years. Besides my direct time at summer camps, I never felt I knew where the funds I helped raise went.

"I recently met Patrick Torchia, Charles Hagins, and Dr. Michael Shy. What I quickly realized was that there was an organization that was streamlined, focused, and dedicated to finding a cure and treatment for CMT patients, of which I am one. After further meetings, and discussions with them, I became

(continued on page 2)

INSIDE:

Look for an exciting announcement on the cover of our next issue regarding research funding and one of our new Board members!

2006 Annual Appeal Seeks to Help Patients Nationwide

It's time for our annual appeal and this year, you might wonder why we are asking for your support when we have just received a $250,000 grant from Pennsylvania. The answer is that the grant is the capstone to what has been a remarkable year of transition for the CMTA.

That transition began with the redesign of our website, and you can see how that has improved our ability to provide accurate, timely, and relevant information. What's not so apparent is the amount of change that's occurred in our day-to-day office operations.

We've found numerous ways to do more with less, and right now we're converting our database to a new system that will be more accurate and save thousands of dollars over the next several years.

Among other things, those savings have enabled us to change our policy with regard to donations to research. We no longer deduct 10 percent for administrative expenses, so every cent of every dollar donated to research is used to fund research.

But, about that $250,000 grant—it was awarded to create an awareness program within the state of Pennsylvania, not to underwrite our day-to-day office operations. We still need your contribution to gather information, publish *The CMTA Report*, and have people answer your calls to the toll-free number. Will you donate and enable us to continue providing these essential services?

You can make a difference for all CMT patients nationwide.

CMTA BOARD EXPANDS

(Continued from page 1)

convinced that their approach was effective. The organization has made great strides the last two years. Invigorated by their enthusiasm, I hope to assist in any manner that I can to back their efforts.

"I look forward to be able to contribute with fund raising in the future and feel confident the CMTA will pioneer a material breakthrough for all. I am honored to be involved with CMTA and hope my presence and input will be a credit to the solid foundation already in place."

Elizabeth Ouellette is already known to many of the readers of this newsletter as an author of several articles about her son Yohan. She has designed a presentation which she gives to his classmates and teachers each year about his CMT and she has also written about the difficulties of letting kids try things when a parent worries so much about his or her child's health and safety.

When asked about her decision to join the Board of Directors, Elizabeth replied:

"When my son was diagnosed with CMT 1A five years ago, I made a conscious decision to become an active participant in the CMTA, with the goal of making a significant difference in the lives of my son and others affected by this disease. As a certified teacher with an M.A. in French from the University of Vermont, I taught for many years both in the US and France. Upon moving to California, I obtained an M.A. in Counseling Psychology, a course of study and training proving invaluable in the understanding of myself and others, especially in the realm of pain disorders and disabilities.

"My decision to become a board member is based upon my enthusiasm and dedication to educating kids, parents, and the community as a whole about CMT. Moreover, I have been extremely impressed by the positive outlook, dedication and support of the entire CMTA staff and administration who continuously offer insight, comprehension, up-to-date information and last, but not least, More about that Pennsylvania grant—it's not just the capstone to a year of transition; it's the springboard to the future of the CMTA. Because the grant will also fund the revision of the Patient/Physician Handbook, a curriculum for physicians, a booklet for parents and teachers, and several other projects, it gives us an extraordinary opportunity to broaden the scope of services we provide.

You can make a difference. With your help, we can expand these projects and make the benefits available to CMT patients nationwide.

Watch for your appeal letter in the mail and please donate so you can help the CMTA meet the challenge of improving life for all people affected by CMT. ✻

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unwavering promise. I wholeheartedly believe in the future of this organization and I am proud to be an integral part of it.

"Lastly, through my own writing, school-based presentations, and various fund-raising events, I know that I can not only build continued awareness of this disorder, but also participate in raising the funds needed for continued CMT study and research, until one day, in the very near future, a cure is found and available to all."

Both Patrick and Elizabeth exemplify the dedication and commitment that makes the CMTA Board of Directors such a vital contributor to the accomplishment of the mission and vision of the organization. ✻

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): ____________________

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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
ANNUAL MEMBERSHIP DUES			
Members have the option of receiving *The CMTA Report* in print, PDF via email, or both. Receive newsletter as: ☐ Print *or* ☐ PDF via email		$40	
Receive both Print *and* PDF Newsletters		$45	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		**active members $15** nonmembers $20	
CMT Facts I ☐ English ☐ Spanish		**active members $3** nonmembers $5	
CMT Facts II ☐ English ☐ Spanish		**active members $5** nonmembers $7	
CMT Facts III		**active members $5** nonmembers $7	
CMT Facts IV		**active members $8** nonmembers $10	
CMT Facts V		**active members $12** nonmembers $15	
A Guide About Genetics for the CMT Patient *(No shipping and handling on this item only)*		**active members $4** nonmembers $5	
CMT Informational Brochure		FREE	
Physician Referral List: States: ______ ______ _____		FREE	
Letter to Medical Professional with Drug List		FREE	
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Shipping & Handling *(Orders under $10, add $1.50; orders $10 and over, add $4.50)*			
TOTAL			

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

☐ Money Order ☐ American Express ☐ MasterCard ☐ VISA

Card Number: ____________________ Expiration Date: ____________

Mail to: CMTA, 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.

Wayne State CMT Clinic: October 12, 2005

BY WENDY AND CHARLIE METZGER

In January, 2005, our 5-year-old son, Joe, was diagnosed with CMT. Needless to say, we were shocked. We had so many questions on so many different levels. Within a week we went from thinking our son ran a bit "funny" to setting up appointments with the muscular dystrophy clinic, ordering day and night leg braces and being told there was really nothing we could do. We had never heard of CMT and we had no family history. Joe's CMT, we have come to learn, is the result of a spontaneous mutation.

Although our pediatric neurologist was helpful, optimistic and very knowledgeable, we never really got answers to the questions we had. Specifically, we wanted to know the following: how far along is Joe's CMT? How will CMT impact him when he is 17? 27? 57? What are his limitations? Does he need to wear braces? What do the braces do? How are his hands and when will they begin to deteriorate? What is a spontaneous mutation? Why Joe? Etc. etc. Not knowing the answers left us expecting the worst.

Fortunately, through the CMTA we learned about Dr. Michael Shy at the Wayne State Clinic in Detroit, MI.


Wendy and Joe Metzger

We called the clinic and were informed about their work and how their individual assessments were done. We learned that they see patients from all over the world and patients with all different symptoms and of all different ages. The appointments start early and require a full day. Wayne State is the hub of much of the research and analysis related to CMT. They staff geneticists, pediatricians, neurologists, orthotists, and rehabilitation experts. The patient (and parents in our case) is scheduled to visit with each of these specialists.

When the day came for our appointment we were uncertain, nervous, and a bit scared. We weren't sure we really wanted to know all the facts. We might learn that our fears were justified. We were also concerned about how Joe might react. He is so young and doesn't really understand his circumstance.

NEW WEBSITE HELPS CONSUMERS IDENTIFY TRUSTWORTHY HEALTH SITES

Are you one of the estimated 95 million Americans who search the Internet for health information? With over 10,000 health sites now on the Internet, choosing the most credible and reliable sites for health information can be a daunting task. To help the consumer sort out which websites have their best interests at heart, Consumer Health WebWatch has released ratings of the 20 most trafficked health sites on the Internet. The ratings are available online at: www.healthratings.org

Consumer Reports' panel of experts evaluated the health websites for nine different attributes including identity, advertising and sponsorship disclosure, ease of use, privacy, coverage, design accessibility, and contents. Of the 20 sites rated, six were given the highest rating, "Excellent"; five received a "Very Good"; eight were given a "Good"; and one site was rated "Fair." Sites rated "Excellent" were noted to include unbiased, peer-reviewed content written by health professionals. The six top-rated sites were WebMD Health, National Institutes of Health, MayoClinic.com, MedicineNet.com, KidsHealth, and MedScape. ✻

Would this assessment frighten him? We could not have been more off base.

The assessment was the best thing we could have done. The doctors were terrific; the environment was non-threatening for Joe and extremely informative for us.

We started the day providing basic background medical information on Joe and our family. Joe went through a full examination with the pediatrician. Dr. Shy met with Joe and analyzed his reflexes and general well-being. We met with the geneticist who gave us a crash course in genetics and how CMT occurs. Finally, we went to the rehab center. At the rehab center we were shown different stretches to help Joe. They provided a different approach for orthotics and recommended shoe inserts. Joe's night braces were adjusted to provide more comfort. We wrapped up the day meeting with Dr. Shy to review Joe's case completely and we were finally able to ask and get answers to the questions we had.

Sometimes the truth is hard to hear, but in this case it was enlightening and comforting. We now know where Joe stands; we have an idea of what we can expect going forward; we are informed about the research that is being done for CMT; and we now have a resource that can help us and direct us. Additionally, our visit is helpful to the Clinic in that it allows them to learn more and track the progress of CMT. We were impressed with Dr. Shy and the group at Wayne State. It was a positive experience. We will plan on making an annual visit. ✻

The CMTA…*Your Organization*

If you are a member of the CMTA, the chances are that you or someone you know has Charcot-Marie-Tooth disorder. Whether the organization gives you medical information or moral support, this association may be one of your safe harbors in one of life's storms.

As the holiday season approaches, one of the best gifts anyone can give you is a donation to CMT Research. As our organization's research challenge grant nears its December 31st end, please consider asking your family and friends to give a gift to the CMTA in your honor.

When you write out your holiday cards this year, consider enclosing a small note asking that the recipient's holiday gift to you be a donation to CMT Research. Checks can be made out to the CMTA and mailed to 2700 Chestnut Parkway, Chester, PA 19013.

My summer address book mailing has generated a little over $2,000 so far. Do any of us really need another well-meant coffee mug to put in our cabinets or another T-shirt to jam into our dresser drawer?

Let's ask people to give a gift that will really count. Share your holiday spirit with the CMTA. —*Susan Schueler Elmer*

Charities Can Benefit from New Tax Law

When Congress was debating a tax relief law to aid victims of Hurricane Katrina, they wanted to provide extra perks to encourage donors to be generous and help the hurricane survivors. They learned, however, that tragedies such as hurricanes, tsunamis, terrorism attacks, earthquakes, etc. often have a negative effect on other charities. When Americans generously help victims of major disasters, they give less money to charities they normally support and who rely on their annual gifts from dependable donors.

So, the hurricane tax package that Congress enacted allows donors who make cash gifts to almost any American charity by the end of this year to deduct an amount from their taxes that is equal to 100 percent of their adjusted gross income. The normal limit is 50 percent. The donation must be made between the time of the hurricane and the end of this year.

Many wealthy donors who understand this unusual opportunity to lower their taxes say they will maximize their charitable giving this year. Donors should contact their tax advisors for details on the Hurricane Katrina tax package. —*from NORD on-line bulletin*

Molded Ankle-Foot Orthoses

Part I: Casting

BY DANA SCHWERTFEGER

When I was diagnosed with CMT at age 22 in 1978, I already had a significant degree of muscle loss in my lower legs. Bracing was recommended to correct my foot drop, and I was given a prescription for molded ankle-foot orthoses, often called MAFOs or AFOs.

MAFOs, like most prescription orthoses, are custom molded—a process that begins with casting to make a "negative mold" and ends with "static" and "dynamic" fitting.

If you don't have any idea what those terms mean, you know about as much as I did when I had my first AFOs made. I asked a few questions, and the orthotist explained what she was doing, but it all seemed very technical to me.

That first time I had no idea what to expect. Should the AFOs be comfortable? Should they enable me to walk fairly well and engage in most day-to-day activities? Initially, it seemed like they would, but after wearing them for 15 minutes, I was in agony. I was still wearing the same shoes, which were now much too small, and there was nothing between my foot and the hard plastic except a sock.

I bought shoes a size larger, and placed an insole between my foot and the plastic. That made a huge improvement, but I soon discovered that if I walked for any distance I would get blisters on my heels and under my toes, and the plastic cut into my ankles.

I made some additional modifications and eventually wound up with AFOs that were comfortable and in which I could do just about whatever I wanted. AFOs, however, have a limited lifespan, so I eventually found myself back at the orthotist going through the process all over again.

AFOs have a limited lifespan, so the process of molding and fitting occurs again and again.

That time, I knew enough to make some suggestions and I wound up with a more comfortable pair of AFOs at the start. I've been through the process several more times since then, and each time I've done just a little better.

I recently broke an AFO (while crossing a busy street, of all places), and when I went to see the orthotist, Pat Dreibelbis came along and brought a camera. People always have questions about bracing, and it seemed like a great opportunity to document the process.

Stockingette prevents the casting material from sticking to the legs.

Frank marks the stockingette for trim lines.

Plaster of paris bandage is used to wrap each leg.

In that regard, many thanks to Frank Gramaglia of Hanger Prosthetics and Orthotics in Havertown, PA. Not only did Frank allow us to photograph my casting, he is planning to arrange for us to visit the fabrication facility, so we'll also be able to show you how the AFOs are made and fitted.

But it all begins with casting.* The accompanying photos show how the "negative mold" is made. The first thing Frank did was put cotton stockingette over my feet and lower legs. The stockingette, which is cut off a roll and open ended, served two purposes. It kept the casting material from sticking to and ripping the hair off my legs, and it allowed Frank to mark the location of the malleoli (the protuberances on both sides of the ankle joint), the navicular (one of the bones prominent in the longitudinal arch), and the metatarsal head (which forms the ball of the foot).

These markings, made with a wet colored pencil, will bleed to the casting material and then to the plaster used to make the "positive mold." Along with the measurements Frank took of the circumference of each calf and the height of each AFO, the markings will later serve as guides for cutting the trim lines.

In the next photo you can see Frank beginning to wrap my right calf with plaster of paris bandage. Before doing that, he taped a piece of felt to the back of my heel. That way, when he wrapped the bandage, it would automatically leave a little extra room in the heel of the AFO. I always ask for that because my heel will move up and down slightly with the action of walking, and without that room the plastic rubs my heel raw and eventually causes a bony growth on my heel.

He also taped a rubber hose to the front of my leg. When the plaster hardens, orthotists often use an oscillating saw to cut through the cast, and the hose makes it easier to cut cleanly through the plaster. It also functions as a protective strip, even though the oscillating saw will not break the skin, a fact one orthotist once demonstrated to me by placing the saw blade against his palm.

Frank, however, uses a utility knife. Children, he said, are often frightened of the noisy saw, and he also uses it with adults because he doesn't have to wait for the plaster to fully harden before removing the cast.

Frank holds the legs straight while the cast stiffens.

When the casts are removed, Frank uses the marks for alignment.

The old AFO—note the flare at the ankle and the trim of the bottom plate.

Before he cut the cast, Frank held my foot in position for several minutes while the plaster stiffened somewhat. Then he used his colored pencil to make a series of lines across the front of the cast. I knew why he had made the other markings, but I didn't see the reason for this, so I asked. It's simple, Frank explained. Before he fills the cast with plaster to make the positive mold, he uses the marks to line up the cast and get it straight.

After Frank removed the casts, I had some final instructions. First, I showed him the bottom of the AFO and pointed out how the plate only came out

(continued on page 9)

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* What I describe here is the way most orthotic casting and fitting is currently done. Frank used plaster of paris bandage, but there are elastic synthetic casting materials such as those that use fiberglass fabric and polyurethane resin. Digital topography is also emerging as a hi-tech alternative to casting.

Hand Controls: An Option to Consider

BY RUTH LEVITAN

My adventure with hand controls started with the realization that the numbness in my feet had progressed until I could no longer feel the pedals when I was driving. With the loss of the sense of proprioception in my feet, it became harder to judge the distance between the brake and accelerator pedals, and on a few occasions when I was diagonal parking, my feet missed the brake pedal and I hit the curb with a thump. What if I had hit another car, I thought. What if I should miss the brake and hit a pedestrian? My anxiety drove me to wonder if I should give up driving, but someone at a CMT support group meeting suggested I consider having hand controls installed.

A trip to the phone book led me to Mobility Systems in Berkeley, a company with a wide range of van conversions, scooters, and other mobility aids. They showed me how hand controls work. The control was simply a lever installed to the left of the steering wheel, with a rod leading down to the brake and another to the accelerator. Pushing the lever forward with my left hand would cause the rod to push down on the brake, pushing the lever downward would do the same to the accelerator. With only my right hand to steer with, I would be unable to turn the wheel hand-over-hand as I usually did, but with a knob installed on the steering wheel, I could turn the wheel in a full rotation with one hand.

But that was just the beginning. I knew I would need instruction in using the new apparatus. I called many driving schools without success until I came across the 49er Driving School in South San Francisco. Dr. Frank McNees was a skilled and patient instructor. He came to my house, and we got started. He got behind the wheel and drove us to Golden Gate Fields, our local race track. In a parking lot that was empty except for some hay bales and horse trailers, I took the driver's seat and he coached me on how to ease up a tiny bit on the brake so that the car began to roll forward, then to press the lever slightly down to accelerate, then up again and forward to brake. With my heart in my mouth I went forward while he gave me directions such as "go forward and stop when you get to that stack of hay bales." Learning to turn was the next assignment, and it wasn't easy to coordinate the left hand controls with turning the wheel using the knob. Gradually my turns became smoother as my brain formed new synapses, and my hands learned to do what my feet used to do.

> "I'm grateful
> I had the courage
> to switch
> to hand controls."

On our third session, after we had practiced for a while in the parking lot, he instructed me to drive through the gate and onto the street. It was a white knuckle trip, but under his tutelage I learned to drive down San Pablo Avenue, change lanes, and practice left and right turns. Eventually, on about our fourth session, he had me enter the freeway. I got on, drove a short distance, and took an exit ramp, grinning at my own successful daring.

There were still obstacles. I continued to be awkward at parallel parking, but my control increased until I was able to get it right on the first try. Well, on the third try, anyhow. It was much like learning to drive for the first time, but, as for any student, actions that at first were awkward and took conscious concentration began to be automatic. The first time I drove across the Bay Bridge into San Francisco was a great milestone, and I realized that I would not have to give up the convenience and independence of driving. The cost of the hand controls and six driving lessons was well worth it.

At this point I'm able to drive wherever I want to for shopping, visiting, and recreation. I'm grateful that I had the courage to switch to hand controls, I'm grateful to the people at Mobility Systems and to Frank McNees of the 49er Driving School for his patient encouragement and expert teaching. ✻

AFO CASTING

(Continued from page 7)

to the ball of my foot. On my early AFOs, that bottom plate had extended all the way out under my toes, and I was prone to getting really ugly blisters under my big toes. I asked an orthotist if I really needed the bottom plate to extend that far, and he said no, the insole and the shoe would support my toes. I still occasionally get a blister if I walk four or five miles, but the shorter plate has pretty much solved the problem.

I also showed Frank how the area of the plate under the fifth metatarsal was cut away. My metatarsal pad has deteriorated and I get a callus there, which is quite painful when I stand or walk on hard surfaces. Cutting out that small area of the plate allows me to stand and walk virtually pain free, and it doesn't have any noticeable affect on the leverage or stability of the AFO.

Next, I showed Frank where the plastic was flared slightly outward at the ankles. Again, that doesn't reduce the strength or stability of the AFO, but it does keep it from pinching and binding at the ankle.

I also asked to have holes drilled in the back of the AFOs for ventilation, about 20 of them on each brace, beginning five inches or so above the ankle. Wearing calf-high socks keeps the plastic away from my legs, and the holes help keep them dry.

Last but not least, I asked Frank if he was going to add any padding or insoles. He said he could, but I told him I preferred that he didn't. At various times, orthotists have glued down insoles made of PPT or polyurethane foams like Aliplast, but I've found that the AFOs always outlast the glued-down material.

I've tried a variety of insoles, including a silicone gel type that slid all over the place and left a gooey mess, but I prefer using the removable insoles from my New Balance sneakers. I've also found that cloth athletic tape works best to secure them in place, but I'll write more about this and how I use self-adhesive moleskin in the article dealing with fitting. ✻

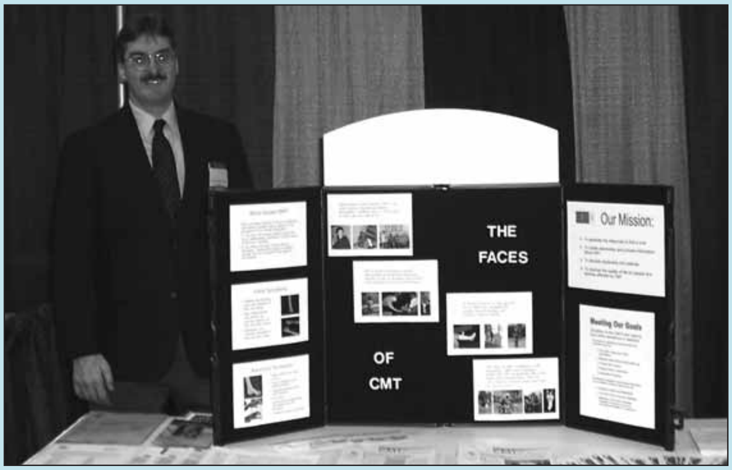
Next Issue—The Fabrication Process: How AFOs are Made

CMTA Attends Neurology Expo in Atlanta, GA

Dana Schwertfeger and Pat Dreibelbis represented the CMTA at the Neurology Expo in Atlanta, GA. The full-day event in October probably did not draw as many participants as the American Academy of Neurology might have hoped. However, the CMTA booth was visited by twelve patients and their families, and numerous other attendees expressed interest and took the brochures, newsletters, and other literature we provided to spread awareness of CMT.

While the numbers may seem small, being at the Expo gave the CMTA staff the unparalleled advantage of speaking face-to-face with concerned parents, grandparents, and teenaged patients. We discussed approaches to dealing with pain, conservative management, and exercise, but virtually everyone had questions about bracing, including one couple who had traveled from Australia to inquire about alternatives in bracing, which are unknown in their home country.

In the afternoon, we briefly attended a presentation by Susan Wheeler, Executive Director of the Hereditary Neuropathy Foundation, but it was our personal interaction with people with CMT that made the Expo a successful and rewarding experience. ✻



Dana shows off the CMTA's new conference displays.

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF

Ann Lee Beyer
Her husband Ron & their 5 children & spouses

Diane Chase
Jeanell & Robert Haynie

Betty Chow
Jackie Henney
Jade & Gene Lew

Frank Eckman
Frank & Debbie Tamburello

James Eller
Barbara & Robert Bernstein

Shirl Gerlach
Walter & Anita Cressler
Robert & Molly Keenan
Kay Leistikow
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Greater Harrisburg Pigeon Club

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Nancy Sanson
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Susan, Chris, Marie, Heather, & Ann

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IN HONOR OF

Yohan Bouchard
North End Express Deli

Mr. & Mrs. Martin Chetlin
Mr. & Mrs. Charles Freed

Amanda Cohen
Selah Mapes

Skip Davis
Richard & Margaret Davis

Susan Elmer
Luz D'Silva
Joseph Satta

Mr. & Mrs. Ford Farabow's Wedding
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Jean Maase

Gigi Osten
Mr. & Mrs. Charles Freed

Bernadette Scarduzio
Dr. Peter Sottile

Jason Steinbaum
Sheila & Norman Steinbaum

Mia Vaknin
Leon Gelman

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:________________________
____

BOOK REVIEW

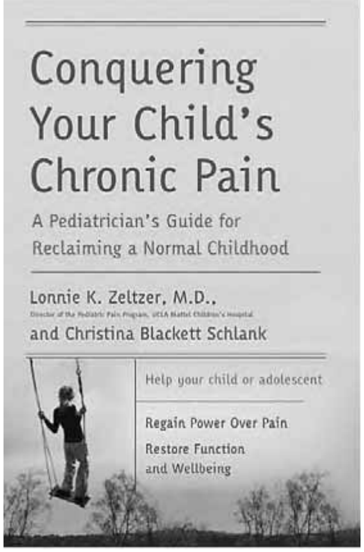
Conquering Your Child's Chronic Pain: A Pediatrician's Guide for Reclaiming a Normal Childhood

AUTHORED BY LONNIE K. ZELTZER, MD, AND CHRISTINA BLACKETT SCHLANK

As the director of UCLA's Mattel Children's Hospital, Dr. Lonnie Zeltzer, an expert in the field of pediatric pain management, and Ms. Schlank have co-authored a book providing a basic guide to the treatment of chronic pain in children. Not only do they detail the appropriate uses and efficacy of prescription medications, but also explore the many non-drug options currently employed to reduce pediatric pain.

Although Zeltzer does not mention CMT, her experience in pain management is certainly applicable to every family whose child endures chronic pain on a daily basis. This book offers a mind-body approach linking the biology to the psychology of pain and outlines the many alternative and complementary techniques available today aimed at helping kids control pain. Since Dr. Zeltzer is so familiar with a wide spectrum of complementary and holistic therapies which have been effective in treating pediatric and adult pain, she presents a thorough look at everything from acupuncture to biofeedback and hypnotherapy to therapeutic yoga.

Parents will discover how to interpret the unique behaviors often manifested by a child living with constant pain, and learn to help that child feel in control of uncomfortable, sometimes intolerable, pain perceptions. Moreover, she clearly explains that pain has been scientifically proven to be influenced by other life factors such as anxiety, stress, depression, and/or a feeling of helplessness; information which may prove invaluable to a parent who is befuddled with an increasingly unhappy, non-responsive child.



Therefore, hoping to provide parents and families with some tools with which to support their children, Zeltzer includes some step-by-step techniques which teach breathing, relaxation, and mindfulness. Once learned by the parent, these strategies are meant to be shared and practiced with the child, providing lifelong skills to address and manage chronic, pain. As a bonus, she provides a useful guide to pain terminology, a list of various pain programs around the country, as well as selected readings, making Dr. Zeltzer's book a valuable resource for every family struggling with the potentially devastating effects chronic pain can have on their children.

Published by HarperCollins and copyright in 2005, this book (ISBN number 0-06-057017-2) may be purchased on line at www.harpercollins.com or at most large book stores. ✻

—Elizabeth Ouellette

DIAGNOSTIC GENETIC TESTING NOW PAID BY MEDICARE

Medicare now covers CMT tests through Athena Diagnostics, so Medicare patients will not be charged for CMT testing. On the poverty program, Athena evaluates each case specifically for financial situation and offers discounts so that the patient's responsibility is dramatically reduced. The specific discounts vary from 35% to 100%, depending on the patient's financial situation. To use this program, patients need to complete Athena's financial assistance form available at: http://www.athenadiagnostics.com/site/pdf/Athena%20Pt%20Asst%20Program.pdf. Patients can also call Athena's reimbursement department at 800-394-4493. ✻

SUPPORT GROUP NEWS

California—Northern Coast
The November meeting was held at Freda Brown's home. She was recuperating from a broken leg but insisted on hosting the meeting despite that. The speaker was Laura Chenault, Health Care Service Coordinator for the MDA in San Francisco. She discussed the services provided by the MDA, including financial assistance for equipment and necessary services, *Quest* magazine, and updates on research.

The group lost its long-time member, Paul Mobley, who had organized the local meetings and kept us informed of all research information.

The next scheduled meeting will be February 4, 2006.

California—San Francisco
A new group will be forming under the leadership of Elizabeth Ouellette. The meeting place is not yet established, but the group hopes to meet bimonthly. Interested persons should contact Elizabeth at 650-248-3409 or elizabetho@pacbell.net. For readers of the newsletter, Elizabeth has written about her son Yohan and the program she set up at his school to educate his peers and his teachers about his capabilities and limitations.

Colorado—Denver Area
The group is being reorganized under the leadership of Diane Covington. The first meeting was held on November 19, 2005 at 470 Golden Eagle Drive in Broomfield, CO. Topics included finding an agreeable future meeting place, setting an appropriate day of the week to meet, and deciding on speakers of interest. Next meeting is Jan 21, 2006 at the Broomfield Public Library, Eisenhower Room.

New York—Horseheads
The group met on November 9, 2005 and had twelve people in attendance. Two new people attended and said they were pleased to have found us and will continue to attend. Our speaker was unable to attend, so we each discussed how we were diagnosed, symptoms in the years leading up to diagnosis, and what symptoms have appeared in the later years. The groups' ever-present frustration is the lack of knowledge about CMT on the regional level, although the disorder seems to have presented differently in each member, making diagnosis a challenge.

Pennsylvania—Johnstown
The Johnstown, PA Support Group held its bi-monthly meeting October 22, 2005. Dr. Brian Ahlstrom, board-certified neurologist and an expert on CMT, was our guest speaker. Dr. Ahlstrom discussed electrodiagnostic studies as well as other CMT issues.

The next meeting is December 17th, which is the Christmas Party, and the February meeting is the 18th with guest speaker Dr. William DeMayo, Medical Director of The John P. Murtha Neuroscience and Pain Institute.

If you live in West Central Pennsylvania please contact J.D. Griffith or Jan Goodard, (814-269-5288), at The John P. Murtha Neuroscience and Pain Institute. The group is also working with the CMTA and The John P. Murtha Neuroscience and Pain Institute to determine the prevalence of CMT in the Johnstown area.

Also, Lena Ciabattoni donated a Jazzy scooter, and a lift chair (both like new) that belonged to her brother. He died from respiratory complications related to his CMT and specified that they were to go to someone with CMT. If you are interested and can pick up these items, please contact the group.

Washington—Seattle
A new group is forming under the leadership of Ruth Oskolkoff. She plans to schedule the meetings for the last Saturday of the month beginning in January. She will have a two-part meeting with a presentation for 45 minutes followed by a coffee hour and socializing and interacting. The time period will be 1-3 PM. The group will meet at the University of Washington Medical Center, Plaza Café, Conference Room C. She has already enlisted Dr. Philip Chance and Dr. Thomas Bird, members of the CMTA's Medical Advisory Board, to speak. If you are interested in attending this group, contact Ruth at 206-598-6300 (daytime) or at rosk@u.washington.edu. ✻

CMT Support Groups

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

Arkansas—Northwest Area
Place: Varies, Call for locations
Meeting: Quarterly. Meetings are not regularly scheduled so call ahead.
Contact: Libby Bond, 479-787-6115
Email: charnicoma57@yahoo.com

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
Email: pcmobley@mac.com

California—San Francisco Bay Area/Santa Clara County
Place: Location to be determined
Meeting: Bimonthly
Contact: Elizabeth Ouellette, 650-248-3409
Email: elizabetho@pacbell.net

Colorado—Denver Area
Place: Broomfield Public Library, Eisenhower Room
Meeting: Quarterly
Contact: Diane Covington
Email: 303-635-0229

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: rathouse1@verizon.com

Kentucky/Southern Indiana/ Southern Ohio
Place: Lexington Public Library, Northside Branch
Meeting: Quarterly
Contact: Martha Hall, 502-695-3338
Email: marteye@mis.net

Minnesota—Benson
Place: St. Mark's Lutheran Church
Meeting: Quarterly
Contact: Rosemary Mills, 320-567-2156
Email: rrmills@fedtel.net

Minnesota—Twin Cities
Place: Call for location
Meeting: Quarterly
Contact: Maureen Horton, 651-690-2709
Bill Miller, 763-560-6654
Email: mphorton@qwest.net, wmiller7@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

New York—Greater New York
Place: NYU Medical Center/ Rusk Institute, 400 E. 34th St.
Meeting: Third Saturday of every other month, 1-3 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, 845-783-2815
Eileen Spell, 201-447-2183
Email: cranomat@frontiernet.net
espell@optonline.net

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: Wills Restaurant
405 Wagner Ave, Greenville
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

Oregon/Pacific NW
Place: Portland, Legacy Good Sam Hospital or Brooks, Assembly of God Church
Meeting: Quarterly
Contact: Darlene Weston, 503-245-8444
Email: blzerbabe@aol.com

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience Center
Meeting: Bimonthly
Contact: 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@adelphia.net

Pennsylvania—Philadelphia Area
Place: Penn Towers Hotel Conference Room
Meeting: Bimonthly
Contact: Amanda Young, 732-977-9983
Email: astarryoung@yahoo.com

Pennsylvania—State College
Place: Centre County Senior Center
Meeting: Monthly
Contact: Rosalie Bryant
Email: rab296@psu.edu

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

ASK THE DOCTOR

Dear Doctor,

Is the prescription drug Requip safe to take with my CMT? My primary care physician thought that Requip would help my restless legs at night, but I want to make sure it is safe. I also have severe pain in my feet if I am on them for only a short time. What pain medications are safe to take with CMT? My feet and legs sometimes hurt really badly at night and I cannot fall asleep due to the pain. ibuprofen and Tylenol are not strong enough. I have taken Vicodin ES, which helps the pain and helps me to sleep. Do you have any other recommendations? I do not want to take something that could be addictive. Also, is the antidepressant Lexapro safe to take with CMT?

The doctor replies:

Requip is a useful drug for patients with Parkinson's disease and appears to help many others with restless leg syndrome, but it is not particularly helpful in treating pain. However, there is no suggestion that it affects CMT neuropathy for better or for worse. There is also no evidence of worsening CMT neuropathy from narcotics or related medications, but these drugs have other concerns if taken long term, which you mention. Antidepressants are increasingly used to treat pain and some have proven more useful than others. I have no experience using Lexapro for pain treatment, but there is no literature which suggests it is harmful to CMT patients. The only SSRI type of antidepressant medication with several (but undocumented) reports said to worsen neuropathy is Paxil (paroxetine). The only antidepressant medication which is FDA-approved to treat neuropathic pain is Cymbalta (duloxetine); however, this is because it is the only drug that braved the long and extensive approval process. Several others likely work as well or better.

Dear Doctor,

I have had CMT for over 20 years. I also have diabetes and have been on kidney dialysis. I am going to have a kidney transplant soon and would like to know if the drugs are going to affect my CMT? Also, I have had a NCT and they still can't distinguish if my hand problems are from CMT, carpal tunnel, or diabetes because the symptoms are so similar.

The doctor replies:

The issue is complex with CMT, kidney failure, and diabetes, all of which can cause neuropathy. There are a few drugs that rarely cause neuropathy, but there is not enough experience to recommend avoidance or a special susceptibility by CMT patients. The first is tacrolimus (FK506, ProGraf) that rarely causes a neuropathy with demyelinating features, probably by triggering an immune reaction. The drug is also under investigation for supporting nerve growth, so the issue is complex. The vast majority of patients have no problems with neuropathy on this drug, but if you use it, the degree of neuropathy-related weakness should be monitored. Cyclosporin A can cause the same problem, but even more rarely. However, immunosuppression is a required treatment in order to prevent rejection of the transplant, so the issue and relative risks and benefits should be discussed with your local physicians. This is probably an example where the benefit is great and the risk is small.

The situation with your hands was not really a question, but clearly, with so many problems, it will be difficult to determine which problem is the source of your poor hand function.

Dear Doctor,

I have a problem with food sticking and being uncomfortable when I eat. Is this something that CMT can cause, or is it likely to be something else?

The doctor replies:

I do not think that swallowing problems are commonly related to CMT. There are no convincing reports in the literature to that effect, and I have never seen it. Swallowing problems related to the esophagus are very common and this is probably a chance association.

Dear Doctor,

I have been diagnosed with distal spinal muscular atrophy, which I was told was a form of CMT. I have never seen mention of it in the literature. Can you help me?

The doctor replies:

Distal SMA is like CMT and is often called distal hereditary motor neuronopathy. The major

WRITE TO US!

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difference is that there is no involvement of the sensory nervous system in distal SMA. Three of the recent gene discoveries reported to cause distal SMA also cause three different forms of CMT2. Distal SMA is much less common than CMT. There is no specific treatment and it is usually inherited in an autosomal dominant pattern.

Dear Doctor,

Will weight training cause my CMT to increase in severity?

The doctor replies:

Research into exercise in neuromuscular conditions has shown that there is no increase in weakness with low to moderate intensity weight training. The benefits of exercise far outweigh any risks of "over-work" weakness. Risks can be minimized by exercising at low to moderate level as advised by a physical therapist, not exercising to exhaustion, and cutting back on the exercise if you experience excessive muscle soreness longer than 48 hours after exercising.

Dear Doctor,

I have been taking Tylenol Arthritis Pain formula, but the directions say it should not be taken for more than 10 days. The same direction applies to Aleve, and there are now concerns that Advil and other NSAIDS may lead to complications similar to those caused by Celebrex and Vioxx.

Is there a recommended drug for control of chronic pain due to arthritis that would not cause undue complications for someone with CMT?

The doctor replies:

Pain control with the recent Vioxx concerns is a problem for all patients, not just those with CMT. The issue really needs to be discussed with each treating physician to weigh the risks of these drugs against the need for long-term pain control. Each case must be considered independently. The risks are for many things, but not for the worsening of neuropathy. Unfortunately, there are no easy answers or a preferred agent to switch all patients to. For inflammatory causes of arthritis there are other agents used to suppress the arthritis, but they do not directly affect pain signals. ✻

LETTERS

Dear CMTA,

I agree with J.K of GA when she says that fatigue is certainly a part of CMT. I have suffered from fatigue, although mine was probably not as severe as hers. Everyone is different in the way he or she experiences CMT and how well his or her body can adapt to the symptoms. I found with the right medication (for me), Cymbalta, and my wonderful braces, that I now do not have that kind of fatigue.

Stress, pain, and concentrating on trying to do something like walk without tripping, falling, or losing one's balance can all create fatigue. I suffered incredible exhaustion when I tried to wear even the softest contact lenses. I was absolutely worn out at the end of the day and returned to wearing my glasses—and that was just fatigue from my eyes. Pain medication can also play a part in fatigue.

—K.K. Marysvale, UT

Dear CMTA,

My 13-year-old son Alex would like to make a donation in memory of his great bass guitar teacher Dave Page who passed away unexpectedly, at the age of 50. Dave suffered from this disorder, but had a happy and wonderful spirit. He was a very accomplished musician, as well as being gifted in many other ways.

We marveled at his many talents, but especially as a bass teacher. Dave was quite humble and yet, a wonderful inspiration to Alex and his other students. We are so honored to have known and worked with him.

—G., S., and A. D.

(Editor's note: See the in memory page for more donations to his beloved music teacher.)

Dear CMTA,

Thank you for putting out such a great resource as The CMTA Report. As the mother of a newly diagnosed 13-year old who has just started learning about CMT, the information is priceless. Keep up the great work!

—C.H.

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Leflunomide
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, 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-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Mefloquine
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in U.S.)
a-Interferon

Negligible or doubtful risk:
Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
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.
- 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 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, 1C, 1D (EGR2), 1X, HNPP, 2A, 2E, 4E, and 4F 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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