



**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.

EP Magazine Publishes Parenting Articles by CMTA Board Member, Elizabeth Ouellette

Two articles on parenting by Elizabeth Ouellette were published in the August 2006 issue of *Exceptional Parent Magazine*.

“Teaching Kids About CMT” was originally published in the January-February 2005 issue of *The CMTA Report*, and “Parenting, the Art of Letting Go” appeared in the March-April 2005 issue. You can read those articles on the parents’ page of the CMTA website. You may also view a video of Elizabeth’s presentation to Yohan’s classmates on our web-

site, also in the parents’ section. (The one-hour presentation is in a Windows Media (.wmv) file and may take some time to download.)

We welcome this opportunity to continue spreading awareness of CMT, and we join Rick Rader, EP Editor-in-Chief, and Joseph Valenzano, EP President and CEO, in extending our appreciation to Elizabeth “for the opportunity to publish and share your knowledge in the field of disabilities. Your article has provided vital information and



insights to both parents and professionals in the support of citizens with special needs.” *

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Research Funded by the CMTA Offers Possible Treatment

BY JAMES R. LUPSKI, M.D., Ph.D., BAYLOR COLLEGE OF MEDICINE

In the past year, our research grant from the Charcot-Marie-Tooth Association allowed us to use exciting new techniques in our search for a treatment for CMT disease. We obtained some very promising results suggesting that small molecules (i.e., drugs) may be useful in treating some forms of mutated (abnormal) proteins that cause CMT. Using mouse models, we recently demonstrated that curcumin, a dietary supplement, may potentially have a therapeutic role in

treating selected forms of inherited peripheral neuropathies.

We showed in our experiments that curcumin can apparently reduce the toxic effect of abnormal proteins that cause more severe forms of CMT. Interestingly, when we tested mouse models of CMT, we clearly observed partial improvement of severe CMT in these mice after a daily feeding of curcumin.

Further studies are recommended on other mouse models

to evaluate potential use for therapy in more selected forms of inherited peripheral neuropathies. *

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EMAIL CMTA AT:

info@charcot-marie-tooth.org

Quest Features Article on CMT Surgery and Bracing Options

In the September/October 2006 issue of *Quest* magazine, a publication of the Muscular Dystrophy Association, an article subtitled “Caring for the CMT-affected Foot” discusses the various options one might consider in dealing with the foot malformations typical of CMT.

Dr. Michael Shy, director of the CMT clinic at Wayne State University in Detroit, Michigan, suggests that the first step in correcting foot problems caused by CMT is to use shoe inserts and AFOs to align the foot. Another suggestion in the article is that

CMT patients wear a good walking or athletic shoe with a removable insole to make room for their orthotic. Dr. Steven Hinderer, also from Wayne State, likes New Balance and Brooks shoes to fill that need.

When shoe inserts aren't enough, and the weakening muscles in the front of the lower leg begin to pull the front of the foot back and off the ground, the foot tends to flop down as the person walks, causing him to trip over his own feet. A custom-fitted, plastic AFO with a hinge at the ankle joint (for stairs and driving), is probably

the first device that's prescribed. Dr. Hinderer stresses in the article that the most important thing is that orthotics fit extremely well.

Surgery is certainly not a first-choice option for CMT patients. Dr. Hinderer is quoted as saying that foot surgery is “something people should hold off on, in my opinion, until they've really pursued good orthotic fitting, and, if need be, physical or occupational therapy to supplement that.”

Orthopaedic surgeon, Robert Meehan, of Wayne State University, says in the article that he advises people to put off surgery until their 20s or 30s because muscle imbalances are still evolving over time. The article goes on to discuss the surgical options, including triple arthrodesis (bone fusion to stabilize ankles), tendon transfers, and osteotomies (cuts in bones to put them in a better position), as well as heel cord releases.

The article concludes with a list of “dos” for CMT feet from Drs. Shy and Hinderer.

Protect your feet from blisters and cuts. Examine your feet frequently for injuries if you've lost sensation, and don't wear shoes or orthotics that rub. Wounds that aren't healing need prompt attention.

Avoid scalding yourself. If you lack sensation in your feet, test the bath water with another part of your body.

Avoid broken bones, which can complicate matters. If you're

PLEASE NOTE:

Our email address has changed. The new address is info@charcot-marie-tooth.org

CHICAGO GOLF TOURNAMENT SUPPORTS CMT RESEARCH



CMTA Board Member Patrick Livney (left), host of the Chicago golf tournament, presents his brother Roland with a plaque for his work in support of the research fund of the CMTA. The tournament was a huge success, raising \$133,215.

falling more than once a month, rethink how you are managing your foot problems.

Work with specialists who understand CMT, with its unique combination of weakness, loss of sensation, oddly shaped feet, and progressive course. *

Editor's Note: This is just a small portion of the article that appeared in Quest magazine. To read more, visit www.mdausa.org/publications/Quest/q135cmt_foot.aspx or call the national office to receive a subscription to the magazine. They can be reached at 1-800-572-1717. The magazine is not devoted exclusively to CMT, but often features detailed and well-written articles on the disorder.

Clinical Study Offered by NIH

A clinical study examining the experiences of genetics patients with physical anomalies that may be seen by others is being conducted at the National Institutes of Health (NIH). The research team is seeking adults 18 or over who have visible physical differences and who have been to a genetics clinic or seen a genetics professional in the past five years. The study is open to participants with any genetic condition that causes physical anomalies visible to others. Participation involves a one-time interview by phone, which will take approximately 45 minutes. For information, contact Jamie Dokson at the NIH at (866) 294-9078 or at doksonj@mail.nih.gov. *

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

*NAME: _____ / _____ / _____
First MI Last

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TOTAL			

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

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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.



"Blessed" ... A Thank You

BY ARCHIT KHANUJA

They say I'm courageous and brave to take on any challenge despite the physical handicap that I face everyday, every moment in my life. They say I am strong, an independent young woman with good values. They say I'm insightful, perhaps beyond what is expected of my age. I say that I'm blessed.

I am now 18 years old and about to go off to college. I'm not exactly in the real world yet, but I am on the precipice of a vast unexplored sea, on the verge, ready to set sail and hope for the smoothest of currents but prepared for a storm, with an ambition to one day become a significant part of it all. The root of such determination and anticipation, such confidence,

lies not too far behind, but rather as a part of me. Without any doubt, I owe all that I am and will be to my parents, Mintu and Rani Khanuja. They have given me, and still do on many occasions give me, the most precious gift any child can ask for: encouragement.

Looking back at my childhood I am amazed and thankful for the way my parents raised me to become who I am today. It is admirable how they not only overcame but conquered every parent's worst fear. It isn't easy growing up with a physical handicap, or any sort of handi-

cap, and I can only imagine how difficult it must have been accepting, let alone dealing with, the fact that your first and only child must suffer a lifetime ailment with no current cure or remedy. Is one even prepared for that sort of challenge? Honestly, I don't think any parent wants to consider it. Some challenges we choose, and others we have no choice

but to accept. My parents were dealt the latter.

My parents are both strong, independent individuals, and they weren't going to allow me to become any less. My parents gave me everything I needed, and sometimes wanted (hey, I am their only child), however they deprived me of one thing—and that is, sympathy.

They kept me away from it, and they surely never showed me any. And thank God they didn't, because now I don't accept any.

My parents are part of the first generation in our family to immigrate to America from India—a challenge they chose to take on, and a decision that perhaps changed not only their stars but also mine. Part of their reason to stay, even though in their hearts they still longed to live in India, was not the opportunities that were in store for them but instead the opportunities that lay ahead for me, for providing me with a better and more promising life. They have definitely taken advantage of that opportunity by supplying me with the best and never allowing me to feel inferior for any reason, especially for my physical handicap. They nurtured my dreams and desires, even if they were unsure of the possibilities or probabilities. They always presented me

"They never let me feel inferior for any reason, especially for my physical handicap."



Archit credits her parents Mintu and Rani Khanuja with helping her be strong and independent.

Penn State Coach, Joe Paterno, Continues to Support the CMTA

with nothing less than the facts allowing me to form my own opinion. They guided me through the dark and comforted me through the difficult times. They showed me that it is possible to appreciate the good in this world and still make efforts to amend the bad. They protected me and stood their ground no matter how much I insisted, persisted, and yelled. They loved me even when I disappointed them. They recognized my potential and made me aware of it myself with their sincere encouragement. My parents made it certain that I would never have to suffer just because of my handicap. Never have I felt inadequate, weak, or hopeless. And so, only recently have I truly realized their struggle.

My parents sacrificed a lot so that I wouldn't have to sacrifice my happiness in the future. My parents triumphed over their challenges as well as helping me defeat mine. My parents, when faced with a harsh reality, changed their hope for a better future into a commendable present.

Perhaps the most important lesson I've learned from my parents is the importance of good parenting, and I just hope one day (just not any day soon) I too can inspire my own children to become courageous, strong, self-sufficient, and insightful individuals. I hope one day I can provide my own children with the blessings that my parents have provided me. *

Coach Joe Paterno is donating the royalties from the sale of a Christmas ornament featuring his likeness to the Charcot-Marie-Tooth Association. The ornament has been designed by the well-known maker of exclusive glass ornaments, Christopher Radko. The ornament is being sold by George's Floral Boutique, 482 East College Ave., State College, PA. It may also be ordered online at www.georgesfloral.com, or by calling 1-800-301-2722 or 1-814-237-2722. Mitch Ballas, owner of George's Floral, has chosen to provide additional publicity for the CMTA by putting an insert about CMT in the ornament package and putting a

scroll with CMTA information in their TV ads.

During Homecoming Weekend, October 21, 2006, Christopher Radko will be appearing at the Bryce Jordan Center and signing ornament purchases prior to kickoff of the Penn State-Illinois game. Executive Director, Charles F. Hagins, will also be on hand to answer questions about CMT and to provide further information about the organization.*

Editor's Note: The CMTA wishes to thank Joe Paterno, his wife, Sue, and Mitch Ballas for their generous and thoughtful help in spreading awareness of CMT and supporting the work of the CMTA.)



The front of the Radko Ornament features the likeness of Coach Paterno and the back shows Beaver Stadium, the home of Penn State football.

It's All Happening Too Quickly

My name is Latifa Daud. I am a 13-year-old girl from New Zealand. Earlier this year, I wrote this speech for my class. It's entitled "It's All Happening Too Quickly!" and it tells the story of how I learned I have CMT.

Imagine yourself, one week, you're playing in the playground with your friends, running around having a good time. The next week, you're going from doctor to doctor trying to figure out what's wrong with you.

Well, this is exactly what happened to me two years ago. It all started, when I was 10 and my dad noticed that it was harder for me to move easily. Actually, my sister thought something was

up way before that but nobody paid attention to her.

So, anyway, dad suggested going to the doctor. Even though we didn't think anything was wrong, we went to the doctor just to be safe. The doctor thought it was a lack of calcium so he made me get a blood test.

Honestly, that was a complete waste of time. The blood tests showed nothing. The next step was to go to a paediatrician, but he said he wasn't the right guy for the job, so he referred me to an orthopaedic surgeon, who also said it wasn't his department.

I went to a neurologist next, and FINALLY, he was the right guy! After that, life changed quickly. I had blood test after blood test. It was hard getting used to all those needles in and out of my arm, but still nobody knew what was wrong with me.

Two years went by, and things were gradually getting worse. It finally hit me that life would never be the same again. There I was, with a scooter and people constantly asking me what was wrong and all I could do was say, "I don't know." It was tough.

And then there is my family. There's my dad who makes me take at least 10 pills every morning. And my mum who makes me go to all these people who she thinks are going to help.

Thank God, my sisters are just normal about everything.

Then, in June, 2005, the doctor said I should have a nerve biopsy. A few days after that appointment, I was in the hospital. I couldn't eat anything that morning because otherwise the anaesthetic would make me sick.

Time went so fast and before I knew it, the operation was over and I was waking up in the recovery room with all these people around me. I couldn't get any rest at all with all these people surrounding me. And I was in a room

People constantly asked me what was wrong. All I could say was, "I don't know."

with 6-year-olds!

The section of my nerve went straight to Sydney for this professor to examine. He found out that I had Charcot-Marie-Tooth, a disorder that affects the nerves that control my muscles.

It causes foot-drop, foot bone abnormalities, problems with balance, problems with hand function, occasional lower leg muscle cramping, loss of some normal reflexes, curvature of the spine, and, sometimes, breathing difficulties.

All this happened in just one year. If you asked anyone I went to primary school with, they would say I was perfectly normal. It just goes to show how much your life can change in a really short time. But, even after everything that's happened, I'm getting on with my life, and nothing's stopping me. *

—Latifa Daud



In the course of two years, Latifa went from running around with her friends to using a scooter.

GIFTS WERE MADE TO THE CMTA

IN HONOR OF

Barbara Bernstein

Eileen M. Eller

Dr. & Mrs. Robert Berris

Robert & Barbara Berstein

Sandy Chaplin

Mr. Robert G. Chaplin
 Mary Lindsay

Mr. & Mrs. Richard Davis

Mr. & Mrs. Skip Davis

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 Murray Schechter
 Donald & Marie Tsouhnikas

Adam Gelman

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Mary Rehm

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Helen A.L. Snyder

Bill & Lois Kesack

Chuck Sohnen

Belle Sohnen

Dr. Howard Weiner

Mr. & Mrs. Jack Shaffer

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: _____





SUPPORT GROUP NEWS

Alabama—Birmingham

Dice K. Lineberry, MD, plans to hold the second meeting of a new Alabama CMT support group several months from now at the Lakeshore Foundation Fitness Center, 4000 Ridgeway Drive, Birmingham, Alabama. As soon as more information is available, the exact date and time will be published on our website.

This second meeting will be partly devoted to organizational matters, but there will also be presentations on one or more topics related to CMT and possibly a tour of the Lakeshore Foundation facilities. (Lakeshore Foundation is a not-for-profit organization that promotes independence for persons with physically disabling conditions and opportunities to pursue active healthy lifestyles.)

Anyone seeking more information or planning to attend is asked to contact Dr. Lineberry at (205) 870-4755 or dkllrl@yahoo.com.

California—San Francisco

A meeting was held on September 16, 2006, and the discussion centered on one member's orthosis—the SAFO, or silicone ankle foot orthosis. It was very comfortable looking and primarily controls foot drop. It was expensive but insurance paid some of the cost, and Muscular Dystrophy Association chipped in \$2000. More information can be obtained at the manufacturer's website at (www.safo.eu.com). In California, the SAFO can be obtained from Keith Taylor of

Taylor Shoes. Contact keith@tayloredshoes.com or 707-429-1054.

Another discussion at the meeting focused on a new voice-activated software called Dragon Naturally Speaking, Version 9. The patient using it reported that the accuracy is very high and she has found it to be ten times better than previous versions.

The next meeting will be November 4, 2006. The speaker will be Martin McCorkle, author of the book, *Walk with Me: The Story of One Man's Life*

with Muscular Degeneration and His 1700-mile Walk Through California. Hikers and non-hikers will benefit from the presentation of his struggles and triumphs in dealing with CMT.

Colorado—Denver

The group is currently meeting at a new address. They met in August at the First National Bank board room, 12009 Sheridan Rd., Broomfield, CO. They will meet there again in October on the 28th to hear a presenta-

(continued on page 10)

A FAMILY EFFORT SUPPORTS THE CMTA



Beverly Rooney (right) and her family, including Elizabeth Ouellette and Yohan Bouchard, held a CMT fundraiser this summer in Burlington, Vermont, to raise money for the CMTA's operations fund. They gathered gift certificates from area businesses and then sold raffle tickets with the gift certificates as prizes. They collected over \$2000 for the CMTA and held a buffet dinner for the drawing of the prize winner. Pat Dreibelbis and Dana Schwerfeger represented the CMTA at the dinner and were warmly welcomed and impressed by the amount of support and interest in CMT the attendees demonstrated.

An Unusual Book Review: *The Family That Couldn't Sleep: A Medical Mystery*

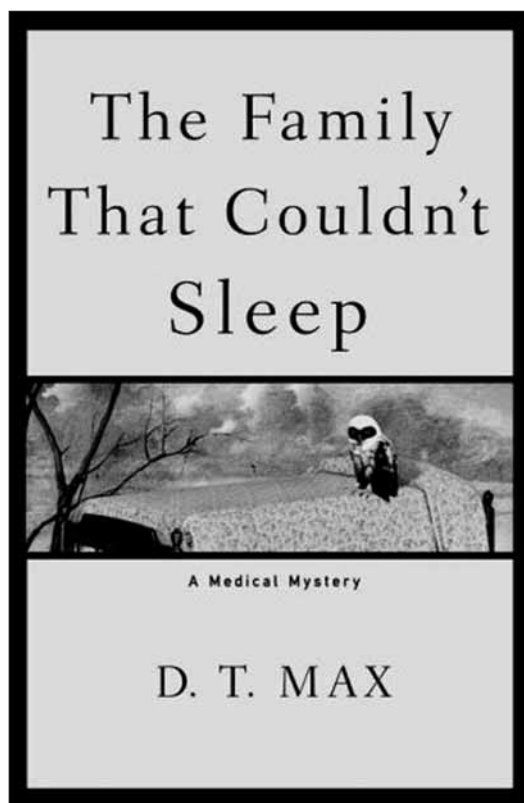
By D.T. Max, Published by Random House, 2006

Random House sent us a book a few days ago by D.T. Max and wrote in the note that we might be interested in the last chapter. That seemed curious enough to make me read on. The book itself is about a real family in Italy, cursed with a fatal disease that prevents them from falling asleep. They go days without sleeping and they are exhausted. After weeks like that, they begin to see their bodies deteriorate. After months, they fall into a coma and die.

The author investigated the literature on this disease and this extended family and found that prions were at fault. Prions are unnatural brain proteins that are infamous for causing some of the most bizarre and unsettling illnesses in history, including this familial insomnia and mad cow disease. Recent research has shown that Parkinson's and Alzheimer's, along with many other neurodegenerative diseases, are the result of a form of protein-misfolding, similar to prion diseases.

The author examines the history and consequences of these proteins that threaten human and animal health

worldwide. Max combines medical history; topical concerns such as public health, food safety and livestock con-



troversies; and the harrowing life stories of people whose lives have been changed by prion disease.

So, where is the connection to CMT? It is certainly not a prion disease. The connection, which is indeed found in the last chapter, is that D.T. Max has a disorder similar to CMT and SMA. He writes: "I first noticed something was wrong in my late twenties. My left foot

had begun to drag. Then, one day, I felt the ground shifting. In a moment, balancing had become a conscious act. After

that, I couldn't simply walk; I walked and balanced. I shook hands and balanced. I talked and balanced. It was as if I were always standing on a water bed."

He also makes an interesting observation about doctors who diagnose CMT. He says, "I believe the reason no one looks you in the eye during a neurological exam is shame – the neurologist's shame. The fact is that the neurologist can diagnose you, but he can't cure you. For him, it is still 1860. Almost 150 years later, he still has nothing more to offer than the accuracy of the clinical gaze."

Would I recommend buying this book? If you are a science buff or someone with a medical background, you would probably enjoy the book. I do think it would be worth a trip to the public library to read the chapter about the author and to learn more about his journey in dealing with a neuromuscular disease—similar to CMT, but a form not yet identified.

—Pat Dreibelbis

SUPPORT GROUP NEWS*(Continued from page 8)*

tion by Dr. Dianna Quan from the MDA clinic at the University Health Science Center.

Massachusetts—Amherst

Ellen Panzer held the second meeting of a new CMT Support Group on September 28.

Anyone interested in attending future meetings may contact Ellen (*see page 11 for contact information.*)

Pennsylvania—Philadelphia

A small group met on Saturday, August 19, 2006, in the office of the CMTA to see a presentation on the diagnosis and characteristics of CMT prepared by Director of Member Services, Dana Schwertfeger. In addition to

watching the PowerPoint presentation, the group shared their experiences with surgeries, bracing, and the finding and fitting of shoes. The group consisted entirely of men, so the information on how to find a comfortable and lightweight dress shoe was particularly helpful. New Balance has purchased an English shoe company and now offers dressy shoes in a wide range of sizes to fit the CMT foot. One of the attendees has purchased the shoes and could testify to the light weight and comfort of the shoes. (Go to NBwebexpress.com to see the new line of dress shoes.)

The next meeting on October 28th will feature a presentation by CMTA Medical Advisory Board Member Dr. Carol Oatis. Dr. Oatis has long

been a leading expert on physical therapy for CMT patients and has authored articles and a chapter in the Physician's Handbook on the conservative management of CMT.

Florida—Tampa Bay

November 2006 will be the second-year anniversary of the CMT Support Group meeting in the Tampa Bay area. This past year we have had a variety of speakers, who have stirred good discussion among our members.

Our next presentation on November 11, 2006 will be on the interesting topic of "Emotional Perspectives of Coping with Loss Related to CMT." The guest speaker will be Sheryle Baker, MA., Executive Director of The LIFE Center of the Suncoast, Inc.

On February 10, 2007, Dr. Michael Franklin, local neurologist, will update us on research and news. This will be the third time Dr. Franklin has shared his great interest in CMT with us. His presentations are always very well attended, as Dr. Franklin has much current and exciting information to share with us.

Washington—Seattle Area

The Seattle Informational Group met on Saturday, September 30, 2006, from 1:00 to 3:00 p.m., in the Plaza Cafe, Conference Room C, at the University of Washington Medical Center in Seattle.

The topic was "CMT and the Practice of Yoga, Tai Chi, and Other Exercise."

For more information or directions, contact Ruth Oskolkoff at (206) 598-6300 or rosk@u.washington.edu. *

**RAISING FUNDS AND AWARENESS
IN BURLINGTON, VERMONT**

For several years, Brad Martello and Jan White of the North End Express Deli in Burlington, VT, have been promoting awareness of CMT with posters, brochures, and a jar with the CMTA logo in which customers can place their change. They do this to honor Yohan Bouchard, who has CMT and whose family Brad and Jan have known for years.

CMT Support Groups

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: Sutter Medical Center of Santa Rosa

Meeting: Quarterly, Saturday, 1 PM

Contact: Louise Givens,
707-539-2163

Email: lbgivens@ix.netcom.com

California—San Francisco Bay Area/Santa Clara County

Place: 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
303-635-0229

Email: dmcovington@msn.com

Florida—Tampa Bay Area

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

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

Contact: Lori Rath, 727-784-7455

Email: rathhouse1@verizon.net

Kentucky/Southern Indiana/ Southern Ohio

Place: Lexington Public Library, Northside Branch

Meeting: Quarterly

Contact: Martha Hall,
502-695-3338

Email: marteye@mis.net

Massachusetts—Amherst Area

Place: Bangs Community Center

Meeting: Call for dates

Contact: Ellen Panzer, 413-256-0189

Email: CMT_suppgroup_MA@yahoo.com.

Minnesota—Benson

Place: St. Mark's Lutheran Church

Meeting: Occasionally

Contact: Rosemary Mills,
320-567-2156

Email: rrmills@fedtel.net

Minnesota—Twin Cities

Place: Call for location

Meeting: Quarterly

Contact: 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

Pennsylvania—Johnstown Area

Place: John P. Murtha Neuroscience Center

Meeting: Bimonthly

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

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

Pennsylvania—Northwestern Area

Place: Blasco Memorial Library

Meeting: Call for information

Contact: Joyce Steinkamp,
814-833-8495

Email: joyceanns@adelphia.net

Pennsylvania—Philadelphia Area

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

Meeting: Bi-monthly

Contact: Pat or Dana, 800-606-2682

Email: info@charcot-marie-tooth.org

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

A Visit to the Doctor

BY PAT DREIBELBIS

Most CMT patients know that the responsibility for their health rests directly on themselves. Because CMT is relatively unknown, finding a doctor who truly understands and can actively treat CMT is rare. So, what can make the whole process easier?

First, you need to put some effort into understanding your disorder and the basics of good care for it. To that end, reading information on the Internet and attending seminars and support groups can be very useful. Ignorance is not bliss. It's just ignorance, and it can be dangerous. Our parents were brought up to respect doctors and regard them as infallible. Today, we understand that we need to respect them, but we also need to question what they tell us and seek second and third opinions when

surgery and invasive procedures are recommended.

One of the classic mistakes that patients often make is to go to a doctor's appointment alone. In many instances, having someone else there to answer questions or listen to what the doctor is suggesting can make a huge difference. When our own health is in jeopardy, we tend to hear only partial comments and can come away from the appointment unclear as to what was really suggested. Having a partner or friend with you allows an impartial witness to hear what is being said and take notes if necessary.

Another rule to remember is to tell the truth, the whole truth,



Consult your pharmacist for information about drug interactions and side effects.

and nothing but the truth. When a doctor asks how far you can walk without discomfort, it's not helpful to exaggerate and say it's a mile if you haven't tried walking a mile in five years. It's also in your best interest to tell the doctor about anyone else in the family with similar problems, even if CMT hasn't been diagnosed officially. Making a diagnosis is a lot like solving a crime, and if you don't give the doctor some accurate clues, he's not likely to solve the mystery.

With regard to drugs, one of a patient's greatest sources of information can be his/her local pharmacist. Most pharmacies have access to technology that can answer drug interaction questions, and pharmacists frequently know whether other patients on a certain medication have reported side effects. Additionally, they have no fees connected to their advice, so they

(continued on page 15)

Thanks for Nine Great Years!

Sadly, the office learned on October 6, 2006, that Darlene Weston would be giving up the leadership of the Portland, Oregon, support group. Darlene has headed the group for nine years, initially sharing the job with her daughter, Jeannie Porter. When Jeannie's health prevented her from being a support group leader, Darlene continued the work alone.

Darlene recently suffered the loss of her husband and her father but tried to keep the work of the group going because her husband, Dean, who, along with Jeannie, had CMT, was so proud of what Darlene had accomplished in helping others.

At this time, no one from the group has volunteered to assume the leadership, so the group will no longer meet. If anyone is interested in continuing the group, they may contact the office at 1-800-606-2682 for information and assistance. *

The Key to the Closet Is the Key to the Kingdom

BY FREDERICK S. KAPLAN, M.D., *excerpted from The NORD Orphan Disease Update, Fall 2006*

Nearly twenty centuries ago, the Roman poet, Juvenal, wrote in *The Satires* about “a rare bird comparable to a black swan.” The notion of rarity enticed the mind in antiquity, and continues to do so in modernity—in medicine and in our daily lives. What are the lessons of rarity and specifically of rare diseases?

In 1657, a letter arrived at the home of Dr. William Harvey, the discoverer of the circulatory system. The letter was from a Dutch physician and concerned the case of a man with a rare affliction of the urinary bladder. Dr. Harvey was old and in failing health, but he recognized the value of such a noble pursuit. In his reply letter, Dr. Harvey wrote one of the most prophetic passages in the history of medicine:

“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of nature by the careful investigation of cases of rarer forms of disease. For it has been found in almost all things, that what they contain of useful or of applicable nature, is hardly perceived unless we are deprived of them, or they become deranged in some way.”

More recently, Francis S. Collins, M.D., Ph.D., Director of The National Human Genome Research Institute said, “While many of the genes we will initially be pursuing are responsible for rare disorders, what we learn from rare disorders often has profound consequences for our understanding of more common conditions.” Why are rare conditions so instructive of more common ones?

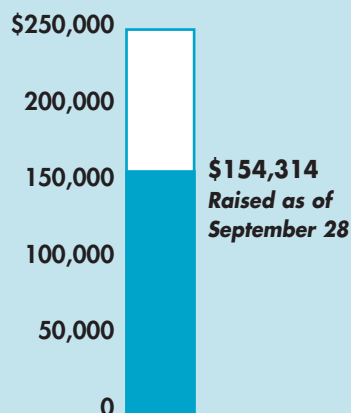
To begin, rare diseases provide robust insight into the complexity in biological systems. The specificity of the rare disease often permits a causative genetic factor to be isolated in a complex regulatory network, thus identifying and defining the network itself. Nature does not use different genes, molecules and pathways for common conditions than it does for rare ones. Rather, it is often the rare disease that actually reveals what gene, molecule or pathway nature highjacks in its common infirmities. The key to the rare disease is often the key to the common one. The key to the closet is often the key to the kingdom.

In an essay in 1928, Sir Archibald Garrod states, “We may feel sure that, in the future as in the past, there will be many who will try to solve the problems of the commoner diseases, the control of which is of vital interest to the community at large. Let us hope there will

always be some who will seek to guess the riddles and to learn the lessons of rare maladies.” The implication, of course, is that in doing so, one may provide the clues to solve the more common conditions as well. How ironic and fortuitous that nature would construct such a universal key and place it not in the hands of the king, but in the hands of the custodian. The key to the closet is (indeed) the key to the kingdom. ✨

LIVNEY CHALLENGE PROGRESS

Board member Patrick Livney has issued a \$250,000 challenge to the members and friends of the CMTA to match his gift in support of CMT-specific research. We still have some ground to cover so please consider a year-end gift to the challenge to help us reach our goal.





ASK THE DOCTOR

Dear Doctor,

I know that “statin” drugs are used for cholesterol control. I have been taking the anti-fungal drug nystatin for years to control Meniere’s disease. Is Nystatin a member of the statin family or is it just an accident of name?

The doctor replies:

Because of the addition of so many new medicines over recent years, name similarities are inevitable. The statin class of cholesterol drugs inhibits a critical enzyme in cholesterol production. Nystatin is a completely unrelated antibiotic drug that long predates statin cholesterol drugs and is primarily used to treat fungal infections; nystatin is NOT associated with neuropathy.

Dear Doctor,

I’m having surgery and will be given Versed. I read somewhere about being careful with Versed. I have CMT 1A and am wondering if that medication will be okay.

The doctor replies:

I know of no special concerns with Versed and CMT unless it is used for an extended period of time, unlike the brief exposure for anesthesia before surgery.

Dear Doctor,

I was just diagnosed with macular degeneration. The specialist told me there is a new treatment. They inject Avastin into the eye. This is a cancer drug. I read in

the newsletter that some cancer drugs were harmful to CMT patients. Do you know anything about this drug that would help me make a decision?

The doctor replies:

The new and promising drug Avastin (bevacizumab) is not known to cause or worsen neuropathy, but the drug has not been in use very long. Many of the cancer trials used the drug in combination with other chemotherapy drugs that often cause neuropathy, but studies did not find a further increase with Avastin. There are no reports of neuropathy and Avastin in association with macular degeneration applications. Despite the list of chemotherapy drugs that cause neuropathy, there are many others that do not.

Dear Doctor,

I recently read in Parade Magazine about a new vaccine against shingles, Zostavax. Patients 60 years of age and older are advised to have this. Is there any evidence that a person with CMT should not take this?

The doctor replies:

The new herpes zoster vaccine (Zostavax), intended for adults over 60, was recently FDA approved, but there is still somewhat limited experience with it. However, the published results in the *New England Journal of Medicine* last year are very promising. The vaccine was studied in about 38,500 adults, half of whom received the vac-

cine; the subjects were followed for an average of 3 years. Subjects who received the vaccine were half as likely to get shingles (herpes zoster) and much less likely to develop postherpetic neuralgia (PHN)—the painful form of neuropathy limited to the region of the shingles. It appears that everyone who developed PHN actually had true shingles, despite the vaccine and not because of a vaccine reaction. There is no evidence that CMT patients would fare differently than others, and PHN can be particularly painful for these individuals. There is no mention of whether any CMT patients were included in this large trial.

Dear Doctor,

Is there any reason why a patient with CMT should not take antimuscarinics? In particular, antimuscarinics to treat overactive bladder, such as Versicare?

The doctor replies:

Antimuscarinic medications such as Versicare are not known to cause or worsen neuropathy. Other types of neuropathy, especially from diabetes, often impair autonomic nerve fibers, and these types of drugs can cause an exaggeration of some expected and predictable side effects, such as dry eyes and mouth; however, most CMT patients have minimal or no autonomic impairment and they should not have concerns any different from those of patients without CMT.

WRITE TO US!

Pat Dreibelbis, Editor
The CMTA Report
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Chester, PA 19013
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Dear Doctor,

My 9-year-old son was diagnosed in July with CMT Type 2, x-linked, with central nervous system demyelination. So, in addition to the regular CMT findings, he also was found to have white matter lesions on the brain MRI.

We are still very new to this diagnosis. Prior to the CMT diagnosis, my son was being treated for ADD. We had taken

our son off *Focalin XR*, 20 mg, in mid-June for a summer rest. The initial CMT episode happened three weeks later on July 9th.

Is this type of medication contraindicated with CMT?

The doctor replies:

Dexmethylphenidate (*Focalin*), approved in 2001, is chemically similar to *Ritalin*, a drug famil-

iar to many. X-linked type CMT 2 is an unusual form; CNS demyelination is also seen, but unusual as well. This class of medication is not known to affect CMT or cause neuropathy and is not contraindicated in CMT in general. It can decrease appetite and lead to weight loss. It may also enhance the risk of seizures in susceptible individuals. *

VISIT TO THE DOCTOR

(Continued from page 12)

are the last real bargain in medicine today. You should also make certain that the neurotoxic drug list is on file in your records so that nothing on that list is prescribed without your knowledge and approval. (This is especially important if you go into the hospital, where you might not be fully aware of what is going on around you.)

If you have testing done to determine if you have CMT or not, don't just sit back and wait for someone to call you with the results. Find out how long the normal wait is and then begin calling to get your results once that time period has passed. Records frequently come in and sit unattended until someone pushes for the results. It's not being annoying. It's being attentive and concerned.

When you are contemplating surgery to correct a foot deformity or to have a hip or knee replaced, find the surgeon who performs the majority of those procedures in your area. Any orthopaedic surgeon can do these procedures, but you want the one who does more tendon

transfers or hip replacements than anything else. Practice does make perfect, or at least better, and surgeries done by doctors who are proficient in one specific procedure typically result in fewer complications for the patient.

Finally, don't be afraid to ask questions and to ask them over again if you don't understand the answer. If necessary,

ask the doctor to write down what he is suggesting so you can discuss the options with your family before proceeding. More important than a doctor who has hundreds of CMT patients is one who cares enough about you to learn everything he can and to listen to what you have to say about your disorder and your problems. *

Treatment Options: A Guide for People Living with Pain Just Published

The American Pain Foundation has just published a book, entitled *Treatment Options: A Guide for People Living with Pain*.

The table of contents lists:

- Mapping a Treatment Plan
- Pharmacotherapy (Drug Options)
- Psychosocial Interventions
- Physical Rehabilitation for Pain Management
- Complementary & Alternative Medicine
- Injection and Infusion Therapies
- Implantable Devices and Surgical Interventions
- Looking Forward with Hope

Treatment Options was written to try to answer all questions related to pain care. At the end of the book, there is section with common pain terms and their definitions. A comprehensive list of resources for finding a pain specialist follows the glossary of pain terms. The book is over 70 pages in length and can be obtained by calling the American Pain Foundation.

You can download the PDF version of the book at the website www.painfoundation.org. If you are not linked to the Internet, you can contact the organization at 1-888-615-7246. *

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CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

Moderate to significant risk:

Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddl, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Leflunomide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:

5-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in U.S.)
a-Interferon

Negligible or doubtful risk:

Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Fluoroquinolones
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

What is CMT?

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

THE CMTA Report



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