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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.

Challenged Again!

BY CHARLES F. HAGINS, EXECUTIVE DIRECTOR

It started with a simple handshake and has turned into an amazing challenge which will benefit CMT Research.

CMTA Board Member, Steve O'Donnell's brother Chris is a registered broker with Bear Stearns, New York. While attending a conference, Chris was introduced to Patrick Livney. They shook hands and Chris immediately recognized the CMT grip. "You have CMT!" Chris said to Patrick. "How did you know?" Chris responded, "Because I have it, too."

Chris explained to Patrick that his brother, Steve, was a Board Member of the Charcot-Marie-Tooth Association, located in suburban Philadelphia. Chris told Patrick that the CMTA was the national organization generating resources for research on the disease. Patrick had never heard of the association and was interested in more information.

Chairman Patrick Torchia, Medical Advisory Board Chairman Michael Shy, and Executive Director Charles Hagins immediately traveled to Chicago to meet Patrick and his brother, Roland, and to present to them the goals and hopes of the CMTA.

While attending the CMTA's October, 2005 Board of Directors' meeting in Philadelphia, the Livney Foundation announced their plan to challenge the CMTA to raise matching research funds in the amount of $250,000! Challenges are what make both individuals and organizations stretch and grow. This is the largest single challenge the CMTA has ever received and it will cause us to push ourselves beyond anything we have accomplished in the past.

> Challenges make organizations stretch and grow.

This challenge comes at a perfect time as we anticipate the annual research appeal, which will begin in February/March 2006. This is an important challenge because we have begun funding three-year, $300,000 grants. So far, we have received 15 applications for year 2006's round of funding.

Clearly, this challenge will require every single reader of the newsletter and member of the organization to play his or her part in meeting the match. Already, we are happy to announce that one member, Gary Kauffman, has contributed $20,000 to the challenge.

Let's all get behind the effort to not only match, but exceed, this newest and biggest challenge! We were successful in exceeding Gary Gasper's $100,000 challenge. Are we up to an even bigger challenge? Together, I believe we are! ✻

A SURPRISE DELIVERY FROM SANTA!

See story on page 11

INSIDE:

EMAIL CMTA AT:
CMTAssoc@aol.com

The CMTA in Washington: The Year in Review

BY JASON STEINBAUM AND GARY GASPER

The CMTA hopes to build on the successes of this past year and encourage more national interest in CMT research.

2005 was an exciting year for the Charcot-Marie-Tooth Association in Washington, DC. Not only did our Board of Directors visit Capitol Hill and meet with key legislators, but we continued our success in promoting CMT research at the National Institutes of Health (NIH).

In February 2005, the Director of NIH issued his first ever report specifically on CMT. Coming at the instruction of two Congressional Committees with which the CMTA had worked, the Director reported to the House and Senate on NIH's research efforts on CMT and its plans for the coming year. This report also announced that NIH would begin a workshop on peripheral neuropathy, with a major focus on CMT. If you would like to get a copy of the NIH report, please do not hesitate to contact the CMTA headquarters.

Following the release of this report, the CMTA board met on Capitol Hill. The board briefed key Senators, Congresspersons, and Committees on the status of CMT research and how Congress can help. The CMTA would particularly like to thank Congressmen Curt Weldon (R-

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A Note about Membership, Appeals, and Newsletters

Toward the end of 2005, the CMTA converted and updated its member database. The new software is less expensive to maintain, and it enables us to manage information and communicate more effectively with you. In that regard, please take note of the following:

Each year, in addition to regular membership (which runs for a year from the date dues are received), we make an Annual Appeal (which is issued in November and used to fund operations and program activities) and a Research Appeal (which is issued in March and used to fund research grants).

We categorize and record donations according to the remittance envelopes in which they are received, so some confusion is inevitable, especially when membership comes due in the same month we issue an appeal.

In the past, we've had people call and say, "Hey, I sent in my dues, but I'm not getting the newsletter." When we check, their records show a they made a donation using either an Annual Appeal or Research Appeal envelope, and the donation was credited to one of those accounts, not to membership.

If all that seems a bit confusing, the best way to ensure timely receipt of your newsletter is still to send in regular membership dues in the envelope that comes with your renewal notice. We'll always send you a notice one month prior to your expiration date, so you'll have plenty of time to renew and keep your membership active.

We'd also like to extend a special thank you to those of you who contribute more than $40 when you renew your membership. That helps us provide complimentary memberships to the many people with CMT who are are on disability or have fixed incomes.

(If you are currently receiving a complimentary newsletter,

LOOK FOR THE SEQUEL to last issue's article on AFO fabrication in the March/April issue of *The CMTA Report*

PA) and Eliot Engel (D-NY) and Senator Judd Gregg (R-NH) for their hard work during 2005 to help find treatment and a cure for CMT. Their efforts generated another Congressional request that NIH should explain progress in CMT research. This report should be completed in the next month or two and will hopefully provide new insight into the status of federally funded CMT research.

After the report is released, the CMTA board will come back to our nation's capital to talk about future priorities in CMT research. We will ask our friends in Congress to continue to support efforts to place a priority on CMT research and, as always, will fight until we find a treatment or cure for CMT. ✻

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we don't want to deprive you of the information in *The CMTA Report*. Our problem is that undeliverable newsletters are not returned and we haven't heard from many of you in quite a while, so we have no way of knowing if your contact information has changed. We don't want to send newsletters to undeliverable addresses, so beginning this year we will ask you to confirm your address every two years. We'll be mailing you a verification card soon. All you have to do is return it to us by July 1, 2006.)

If you have any questions about your membership status, please call the office at 800-606-2682 or send email to cmtassoc@aol.com. ✻

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

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

*NAME: ____________________/_______/ ________________________________
First MI Last

*ADDRESS: ____

*CITY: ________________________________ *STATE: _______ *ZIP: ________________

*COUNTRY/POSTAL CODE (IF NOT US): ________________________________

*DAYTIME PHONE: ________________________ EVENING PHONE:________________________

EMAIL (Required for website access and PDF newsletter): ________________________

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	
Contribution to CMT Research Fund (100% of contribution is used to fund research)			
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.

Signs of Courage: My CMT Story

BY SCOTT ZOELLER

Editor's note: This essay was written three years ago when Scott was twelve. It won him first place in his school's seventh-grade essay contest. When we first read Scott's story, it seemed a bit unusual because the onset of CMT is typically slower and less dramatic. His mother told us some additional details, however, and her comments are in italics.

Since Scott was in kindergarten, he had had problems with balance and walking properly. He was constantly tripping and falling. I took him to a foot and ankle doctor and he told me that Scott had just gotten into the habit of walking funny and would outgrow it. I always felt something was wrong, but everywhere I turned to try and find out became a dead end.

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One day my friend came over to spend the night and we played around for a long time. The next morning, I was tired but got up anyway. I was more tired than I thought, though, so I lay down on the couch and fell asleep. When I woke up, my Mom was making breakfast, so I tried to get up, but something was wrong. I couldn't even get up. She thought I was kidding.

She started upstairs and told me to brush my teeth. I got on my feet, but as soon as I did, I collapsed. She finally believed me! My friend's father came over and carried me out to the car. I couldn't see anything but a blur and I fell asleep. When I woke up, I was in my doctor's office. He asked me to sit up, and I tried and tried but couldn't do it. By this time, my mother was bawling, so he called an ambulance.

In the ambulance, they gave me at least five shots in the arm and hooked me to an IV. It was starting to get so bad that I couldn't even talk. When we got to the hospital, the doctor put a wrap on me so the IV would stay in place.

I was put in a room and for days, I got MRIs, spinal taps, EEGs, CAT scans and blood work… more than I can count. My grandpa, grandma, my mother's friends, and my karate instructor all visited me.

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We are not sure why he collapsed that day other than the fact that he had been sick for a few days with a viral infection and the doctor had done a strep test earlier that week that was negative at first, but positive on second testing. By the time he was in the hospital, he was very sick, and they ran many tests trying to find out what was wrong. By the end of the week in the hospital they determined that he had CMT.

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When I got out of the hospital, I was really weak. The doctors determined that I had CMT. CMT is a neurological disorder which mainly affects my legs and feet. I don't have as much strength in my legs as most other kids. I have to take physical therapy to try and keep what strength I do have. My uncle Charles has a very severe case, and he has to use a wheelchair to get around. Things that other kids take for granted, I struggle with every day, like walking to and from class, or the mile run in physical education. I think I must have courage because some days are a lot harder than others, just trying to do what everyone else does.

Scott Zoeller finds some days harder than others, just trying to do what everyone else can do.

Because of the love and support from my family, I get the courage I need to go on with each day. This weekend, I'm testing for a red belt in taekwondo, which is one belt away from a black belt. That proves to me that I can do what others do, it just might take me a little longer.

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The neurologist that checked Scott also tested me and determined that I had it as well, just not as severely. I had no idea. My feet are bad (hammer toes) but I just always thought I must have worn shoes that didn't fit properly and they had caused the problems. I have it worse in my hands and I don't have as much strength as I used to.

In Scott, it is very noticeable when he walks and people ask all the time why he walks that way because otherwise, he looks very healthy. He was fitted for AFOs but he doesn't want to wear them and has just dealt with the walking issues in his own way. He goes to a high school with an open campus which involves quite a bit of walking, but he manages quite well. We have made arrangements for him to have an extra set of books which he leaves in his classes so he doesn't have to carry around so much. Scott doesn't want to be singled out, and whenever I suggest doing something that might make things easier on him, he says, "I'm fine, Mom!"

He is a very strong young man and never complains. He has a great attitude about all of it. I'm very proud of him.

BOOK REVIEW

Melodies of My Life

A Disabled Girl's Journey to Womanhood

AUTHORED BY BY DENEDRIA RENEE BANKS, MSW, ACSW

Denedria Banks lives with Charcot-Marie-Tooth disorder, which causes muscle weakness and atrophy in her feet, legs, hands, and forearms. She was diagnosed with the disorder at age nine. Her book is the portrait of a young woman who believes that the question she must ask herself is not "Why me?" but rather, "Why not me?"

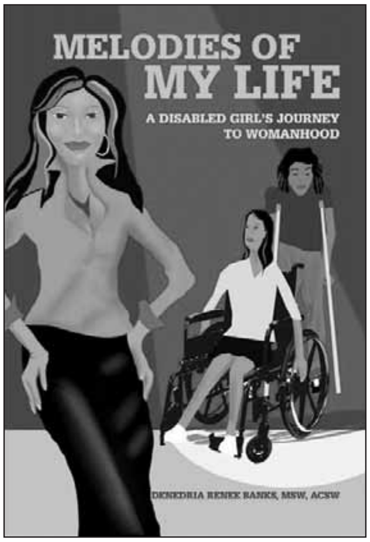
She discusses her life from the position of daughter, sister, friend, public speaker, single, independent Black woman, social worker, and woman with a disability.

While the book is uniquely the story of a female, some of the experiences and feelings she shares transcend her sex. She writes of her seventh-grade year:

> "Life as a teenager was difficult for me. However, because adolescence was coupled with a disability, the difficulties seemed magnified. I felt stuck between two worlds—the able and the disabled bodies. Many days, when I compared myself to others in my peer groups, I felt less than acceptable because I did not feel as if I fit in. I walked around with my head down. I feared, if someone looked into my eyes long enough, they would discover how I felt about myself. When I was in the presence of other children with disabilities, I felt that I did not belong with them either. Looking at children confined to wheelchairs or with facial deformities, I wanted to run in the opposite direction. I was scared of those kids because I feared I would become like them."

Banks gives the reader a rare glimpse into living with CMT. She relates her specific experiences with doctors, horrible recoveries from broken knees and hips, and the rehabilitation process she endured both as a child and later as an adult. While her stories are about *her* life, there are common threads that anyone with CMT will relate to.

I found a few small medical inaccuracies, but overall, I found the book to be an interesting and easy, pleasant read. Books about the CMT experience are few and far between, and this one is a welcome addition to the short list. —*Pat Dreibelbis*



***Melodies of My Life*, ISBN:0-595-35681-8 is 100 pages and sells for $11.95. It can be ordered at www.iUniverse.com, www.amazon.com, and www.bn.com. Denedria Banks can be contacted at dbanks1922@earthlink.net.**

Positive Spirits...Positive Results

BY JOSH DONLEY

CMT has run in my family for many generations. I was diagnosed with CMT when I was a teenager and had my first surgery when I was 17 years old. I had played golf extensively throughout high school on the golf team but started having trouble playing well when CMT hit me. My cousin, Jason Everhart, was a great motivation to me when I was first diagnosed. He was diagnosed with CMT as a child, but determined to stay active in sports and weight lifting despite the disease. He always had a great attitude about his CMT, so I determined I, too, would strive to keep a positive spirit and not let CMT affect my life in a negative way.

Other family members were also a great support system for me. My grandmother, Peggy Jumper, my mother, Cynthia Donley, and others have set positive examples of dealing with the disease. My sister, Angel Donley, is a nurse at Brenner's Children's Hospital, where my surgeries were performed. She can always answer the medical questions that nag me. I've had a triple arthrodesis of the left foot with a posterior tibial tendon transfer and a plantar fascia release. The same procedure was done on my right foot two years later. I also had a procedure to help straighten the toes on my right foot. Dr. Andrew Koman of Wake Forest Baptist Medical Center did all my foot surgeries as well as having operated on three generations of my family.

I began working out with weights in college but did not do much cardiovascular exercise. My wife, Maggie, is an exercise enthusiast who always gives me motivation and strength. She convinced me to start cycling in 2004 to help my cardiovascular endurance. I was hesitant at first, but decided to give it a try. Since then, I have ridden in the Tour to Tanglewood, a ride for MS which was approximately 50 miles, and I rode the first day of Cycle North Carolina, which was a 63-mile ride through the mountains of Asheville, NC. I plan to eventually ride all seven days of Cycle North Carolina, which rides from the mountains, across the state, to the beaches of the Atlantic.

Cycling has helped not only with my cardiovascular fitness, but also with my balance, leg strength, and desire to encourage others to exercise. I feel that, although the limitations are sometimes difficult, CMT has positively affected my character and my life. Amazingly, my outlook on life and my relationships with others have been enhanced because of having CMT. Not only have I surpassed the physical limitations, but I continue to fight the less obvious mental limitations through my faith and my family. I sincerely believe that one can do anything he sets his mind and heart to. Once you have a limitation of this sort, it is much easier to recognize the struggles of others, and be cognizant of ways you can help. The interesting twist is that the people who have inspired me the most (like my wife) say that I have inspired them in different ways. I believe there is a reason that some people are given outward limitations, and I trust that I will not waste the opportunity to use having CMT in a positive way.

I thank God for the strength I have to maintain an active lifestyle and the wonderful family I have that is such an encouragement to me. My wife Maggie has been more of a motivation and encouragement to me than she could ever know. I am forever indebted to the wonderful people in my life. I now reside in Walnut Cove, NC with my wife and two dogs. I'm a financial planner in Winston-Salem, NC. My main objective at this point in my life is to stay positive and to encourage others to try and accomplish their dreams. ✻

Josh rode 63 miles in Cycle North Carolina and hopes to complete all 7 days of the ride eventually.

News From NINDS

BY MARY JO HOEKSEMA, CONSULTANT TO CMTA

The National Institutes of Health (NIH) *(www.nih.gov)* is the nation's premiere biomedical and behavioral research agency, funding basic and clinical research both on its main campus in Bethesda, Maryland and at major medical institutions nationwide. NIH is comprised of 27 separate institutes and centers categorized by disease, life stage, or body organ. For example, the NIH includes the National Cancer Institute, National Institute on Aging, and National Eye Institute.

For CMT, the lead NIH research agency is the National Institute of Neurological Disorders and Stroke (NINDS) *(http://www.ninds.nih.gov/)*. NINDS supports a division dedicated to promoting research and research training on neuromuscular diseases. Some of the key CMT-related projects the institute currently supports include research to identify more of the mutant genes and proteins that cause the various CMT subtypes. This research includes studies in the laboratory to discover the mechanisms of nerve degeneration and muscle atrophy, and clinical studies to find therapies to slow down or even reverse nerve degeneration and muscle atrophy.

To educate more CMT members, both from the scientific and lay communities, about research and advisory opportunities the NIH and NINDS are supporting, the CMTA newsletter will include a regular column, "News from NINDS." The objective of this column will be to stimulate more interest in the institute's CMT portfolio and to encourage more involvement in its research and public advisory activities. We hope you find the

(continued on page 8)

RESEARCH OPPORTUNITIES ANNOUNCED BY NINDS

Below is a list of recent research opportunities announced by NINDS that may be of interest to you. For additional information about these announcements, please contact the program official listed in the "contact information" of each announcement.

Exploratory/Developmental Program for Translational Research in Muscular Dystrophy (R21)
(PAR-06-043) National Institute of Neurological Disorders and Stroke and National Institute of Arthritis and Musculoskeletal and Skin Diseases. See announcement at *http://grants.nih.gov/grants/guide/pa-files/PAR-06-043.html,* for application instructions and receipt dates.

Translational Research in Muscular Dystrophy (U01)
(PAR-06-044) National Institute of Neurological Disorders and Stroke and National Institute of Arthritis and Musculoskeletal and Skin Diseases. See announcement at *http://grants.nih.gov/grants/guide/pa-files/PAR-06-044.html,* for application instructions and receipt dates.

Training in Computational Neuroscience: From Biology to Model and Back Again (T90)
(RFA-DA-06-010) NIH Blueprint for Neuroscience Research, Various Institutes, including NINDS. Research application receipt date: March 13, 2006. For application, see *http://grants.nih.gov/grants/ guide/ rfa-files/RFA-DA-06-010.html.*

2006 NIH Director's Pioneer Award Program
The 2006 NIH Director's Pioneer Award program announcement has been published. The award, a key component of the NIH Roadmap for Medical Research, supports exceptionally creative scientists who take innovative approaches to major challenges in biomedical research. The program is open to scientists at all career levels. In September 2006, NIH expects to make five to ten new Pioneer Awards of up to $2.5 million in direct costs over a 5-year period. Applications may be submitted between January 15 and February 27, 2006. See announcement at *http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-06-005.html* for application instructions. For more information, visit the Pioneer Award Web site at *http://nihroadmap.nih.gov/pioneer* or e-mail questions to pioneer@nih.gov.

NEWS FROM NINDS

(Continued from page 7)

news highlights informative, and more importantly, we hope they will encourage you to submit a research application, apply for a public advisory panel, or go to the NINDS or NIH websites to learn more about the critical CMT-related basic and clinical research these agencies support. Without our involvement, the CMT research agenda will not achieve its full potential. Learn and get involved today!

SETTING THE RESEARCH AGENDA

To identify future opportunities in CMT-related research, CMTA has been working with its congressional partners to encourage NINDS to sponsor a scientific workshop. In recognition of both the priority Congress has asked the institute to make CMT research and the unmet scientific opportunities that exist, NINDS will be sponsoring a scientific meeting on peripheral neuropathies in mid-2006. The meeting is expected to focus on issues related to CMT research, and two CMTA Medical Advisory Board Members, Dr. Steve Scherer and Dr. Michael Shy, are serving on the organizing committee. Ideally, the recommendations from this meeting will lead to a future program announcement or request for applications to solicit CMT-related research applications. Stay tuned to the CMT website and future columns for information about the outcome of this important meeting.

SCIENTIFIC AND PUBLIC ADVISORY PANELS

Recently, CMTA Board Members Jason Steinbaum and Gary Gasper met with the NINDS public liaison officer and NINDS director of communications and public liaison, to learn about the scientific and public advisory committees and organizations the institute and NIH supports. NINDS is constantly seeking dedicated and knowledgeable individuals to review scientific applications and to advise the institute on its scientific research programs and public outreach and communications activities. Below is a summary of the major advisory opportunities.

If you are interested in being involved, please inform the CMT office. We will collect your information and share it with the appropriate NINDS or NIH officials. Nominations are typically solicited in the fall, but CMTA wants to know at any time of your willingness to serve as a potential representative of our organization on these prestigious, crucial panels.

NINDS Board of Scientific Counselors. The Board of Scientific Counselors reviews all projects proposed by researchers participating in the institute's intramural (or on campus) research program. Additional information about the board is available at: *http://www.ninds.nih.gov/find_people/groups/bsc/index.htm.*

National Advisory Neurological Disorders and Stroke Council. The council meets three times a year to review scientific applications recommended for funding by the initial peer review study sections. The council advises NINDS on research program planning and priorities. The 18-member council is composed of physicians, scientists, and representatives of the public who serve four-year terms.

Additional information about the council is available at the following link: *http://www.ninds.nih.gov/find_people/nands/index.htm#Council*

NIH and NINDS Peer Review Study Sections. Both NINDS and the NIH Center for Scientific Review convene peer review study sections to conduct the initial review of scientific grant applications.

Additional information about the NINDS Scientific Review Branch is available at the following link: *http://www.ninds.nih.gov/funding/review_committees/index.htm.*

Additional information about how CSR selects reviewers is available at: *http://cms.csr.nih.gov/PeerReviewMeetings/StudySectionReviewers/*

NIH Advisory Groups. There are three key outside advisory groups managed by the NIH Office of the Director: Council of Public Representatives (COPR), COPR Associates, and the Advisory Council to the Director (ACD).

- Link to background on COPR: *http://copr.nih.gov/application.asp*
- Link to background on COPR Associates: *http://copr.nih.gov/associates.asp*
- Link to background on ACD: *http://www.nih.gov/about/director/acd.htm* ✻

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF

Ann Lee Beyer
Paul Flynn

Thomas Buchanan
Judy McDonald
Kassandra Sawatzky

Henry Friedmann
Agnes Aronsohn

Doris and Jeff Gerry
Dolores Riedinger

Daniel Headrick
Nancy Headrick

Grace Klein
Mr. and Mrs. Lyle Van Vleet

Michael Patak
Mr. and Mrs. Walter Calvert
Denise Corsano
James E. Cumbie
Felice Schachter

Jeanette Reilly
Anonymous

Hope Silvera
Dr. Quick and the Department of OB/GYN

Ellen Walle
Michael and Barbara Wall

IN HONOR OF

Richard Charles Brayshaw
Joyce Wood

Barbara Castle
Dr. Thomas Bird

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Sue Elmer
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Andrew J. Ryan
James H. Ryan

Bernadette Scarduzio
Pathology Group of Doylestown
Michelle Pierangeli

Dr. Robert Stern
Jack Fenton
Alexis Stern
Ryan Stern

Peggy Wolf
Martha Wolf

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: ________________________
____

Pain Relief Possibility for Charcot-Marie-Tooth Feet

BY M. DANIEL SLOAN, SEATTLE, WASHINGTON

High arches, ankle and hammer-toe deformities, dramatic shoe size differences, and protruding veins distinguish Daniel Sloan's feet. Two neuroma surgical scars on his right foot are another footnote to a life-long series of problems.

After enduring 17 months of debilitating pain, I finally bought a pair of graduated cotton compression stockings as an experiment. They cost $27.50. On my drive home, I noticed I could accelerate and brake without experiencing the burning ache of my right foot on fire.

First thing, Monday morning I put my Samson socks back on. Then I walked the half mile to and from my favored lap pool. Today I enjoyed a bike ride. I ran up steps!

As I sit here typing, my feet feel pretty good.

$27.50 compares favorably to the several thousands of dollars in group health medical insurance benefits paid for physicians, x-rays and a bone scan to diagnose my pain. $2.34 in sales tax beats the seven hundred dollars I have paid out of my own pocket for time-consuming podiatrist visits, new shoes that didn't help, and worthless, orthotic cork inserts. Three days of mobility beats the social isolation caused by relentless foot pain.

I am an avowed skeptic. My anecdote is not evidence of either curative or palliative efficacy. But, I am darned happy I tried the experiment. I have no financial interest in Sigvaris or its cotton socks*. In my opinion, they are worth $30.

Up until Sunday I had never been to a medical supply business. I don't know who owns Allcare Medical in Bellevue, Washington. But I am personally impressed with their service. I don't own stock in Strongrem, but their double-strap ankle support seems to enhance the performance of my new socks. As promised by the brochures, my feet just feel better.

Daniel, an avowed skeptic, believes he has found a solution for his painful feet.

Foot pain and a withering left calf drove me to the Charcot-Marie-Tooth disorder web site in September. Their home page slide show drew me in. "Hey. That looks just like my left leg!" I read articles.

I learned my hand tremor is called Roussy-Levy syndrome. I have a pretty good idea why my mother always complained about her feet and lived a sedentary life. I learned I am not the only person who has experienced life-long balance problems.

I have always had the ability to fall down for no reason without warning; others do too. I learned neuropathic pain often seems to have no cause. It responds poorly to standard pain treatment and may get worse instead of better over time. I learned some patients are extremely sensitive to the cold or even to temperatures a few degrees lower than normal. Just like me. I learned more about peripheral vascular disease than I care to know.

I learned I do some things right. I swim three to four times per week. I practice yoga and lift light weights to stay in shape, improve my flexibility, balance, and strength. Even when I travel on business I swim laps, lift light weights and do moderate yoga. (Yoga headstands and the "plow" are out of bounds for excellent biomechanical reasons.)

I am trim and have an appropriate weight and body fat percentage for my height. At 55, I am clearly not getting younger, but there is nothing I can do about that. I never smoke. I don't drink any alcohol. I love biking the 60 miles around Lake Washington. With some luck and these new cushioned, com-

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* The cotton socks mentioned in the above article may be found at *http://www.sigvarisusa.com/Prod_web%5Cen-uslocaldb.nsf/vw_framesetprofile/Profil?Opendocument&fm_HeaderAnwenderinfo*startdefaultsite*

pression socks, I might be able to bike that 100 miles per week regularly again. Shoot, I'd be thrilled with 50 miles.

The Charcot-Marie-Tooth Association's web site has helped me come to grips with the fact that I am not the only amateur athlete who can no longer participate in activities I love(d). The grieving process is serious. Knowing about it helps me work through it.

My 15-year-long, twenty-mile-per-week jogging routine, kicking soccer balls with my son, surfing, and mini-triathlons were the first casualties of my CMT. Whacking tennis balls isn't much fun without the lateral movement required to return shots. Telemark downhill cross-country skiing is impossible. I miss Mount Baker by moonlight.

Boogie boarding is more fun than surfing; getting May-taged inside a wave is more fun than wiping out and getting hit on the head by my board. Water numbs my feet. No pain and lots of gain.

But, scuba rules. I am grateful for neutral buoyancy. Underwater adventures in the Puget Sound, Costa Rica, Brazil, California's Channel Islands, British Columbia's Sunshine Coast, and Nanaimo wrecks have been a blast. I am counting the days to my upcoming Solomon Islands trip. Floating over a coral reef all day makes my feet feel great.

Cascade and Canadian Rocky backpacking, winter camping, and snow caves are out of the question. Maybe my socks will get me back on a day hike or the slopes for downhill runs in Utah before climate change eliminates these sports entirely.

I am pretty sure I will take a walk through the Meadowbrook wetlands tomorrow to see what the beavers, herons, Mergansers, muskrats, and ducks are up to. I can walk today. What a rush! ✻

Christmas Prayers Answered

Elaine Newcomer's prayers for an electric wheelchair were answered Thursday, December 22, at 1:00 PM in the Atrium of The John P. Murtha Neuroscience and Pain Institute, 1450 Scalp Ave, Johnstown, PA.

On Saturday afternoon while she was attending the Charcot-Marie-Tooth Association support meeting at The John P. Murtha Neuroscience and Pain Institute, J. D. Griffith, support group leader, asked if anyone needed a Jazzy Power Wheelchair. Elaine raised her hand and asked the price. When J.D. made the sign of a zero, Elaine was ecstatic. She is a cancer survivor with heart problems, wears braces, and severely restricted mobility. She had been unable to find funding and, in desperation, had recently entered a contest to win a power wheelchair.

The $6,000 power wheelchair was donated by Lena Ciabattoni whose brother, Nick Scarfo, died this August in Pittsburgh of respiratory failure related to his CMT. He had asked that his barely used wheelchair and a new lift chair be given to someone in need who had CMT. Lena contacted J.D. and support group member Ann Bootman's husband Charlie drove to Pittsburgh to pick up the equipment and stored them in his basement.

The lift chair will be given to CMT support member Joyce Miller's 82-year-old father, Vernon Yoder. Vernon wears braces and also has serious breathing issues as a result of CMT.

Channel 8 (Fox) News opened their December 22 10:00 PM News with coverage of the presentation of the Jazzy Power Wheelchair. The local newspaper, The Johnstown Tribune Democrat, also had a color picture of Elaine, Charlie Bootman, and J.D. ✻

Charlie Bootman, Elaine Newcomer, and support group leader J. D. Griffith try out Elaine's new electric wheelchair.

SUPPORT GROUP NEWS

Colorado – Denver Area
Our first meeting was small but productive. We met November 19, 2005, and the topic was footwear. The information gathered from that meeting will be available at our future meetings. One of our plans from that meeting was to ask each support group member to take a copy of the flyer I have made to their neurologist's office or their podiatrist or whomever they see for their CMT. The key is to make the newly diagnosed and the long-time diagnosed aware of our group.

Our January meeting focused on stretching and strengthening. We not only discussed exercises that are particularly helpful, but we practiced some, as well. The next meeting will be held on April 22, 2006.

Pennyslvania – Johnstown
The Johnstown CMTA Support Christmas Party was held as always at The John P. Murtha Neuroscience and Pain Institute. The meeting was well attended and we were all overfed—the cookies were awesome—thanks to Jan Goodard and Ann Bootman. Jeana Sweeney, co-leader, was back and her baby, Rylee, is doing fine. Members offered advice and support for a new member applying for disability and generally enjoyed themselves.

Christmas came early when J.D. asked if anyone needed an electric wheelchair and Elaine Newcomer raised her hand. She asked how much, and J.D. gave the sign of a zero. Elaine had been desperately trying to get coverage or funding for one. It was a very emotional moment for the group, and it made Christmas not only for Elaine but for everyone.

Dr. William DeMayo, Medical Director, The John P. Murtha Neuroscience and Pain Institute, will be the guest speaker at our February 18th meeting.

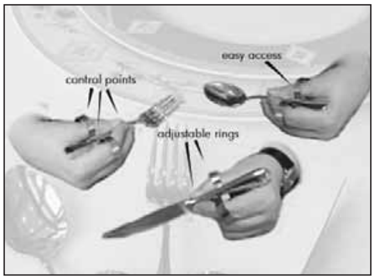
Washington – Seattle Area
The first meeting of the newly formed Seattle CMT Support Group will be held on January 28, 2006, at the Unversity of Washington Medical Center. The group will meet in the Plaza Café, Conference Room C. The topic will be "CMT 101 – The Basics" presented by Dr. Phillip Chance, Chief, Division of Genetics and Development, Pediatrics. There is free parking behind the center after noon.

The next meeting will be on Saturday, February 25, 2006, and future meetings will be held on the last Saturday of every month, except May, November, and December. ✻

NEW AND NOTEWORTHY PRODUCT

Dining with Dignity Flatware

When Pat Dreibelbis and I toured the expo at the World Congress on Disabilities in Philadelphia in November, one stop we made was at "Dining with Dignity," an exhibit that caught our eye because of the silverware on display. The forks, knives, and spoons had adjustable rings on either side of the handles.



The utensils were designed by Bob Bayton, a chef who was left paralyzed after an auto accident. His limitations made normal eating impossible, and he dreaded going to public restaurants, so he decided to do something about it.

Bayton and a friend, Joe Janes, began experimenting with utensils that could be used by people with limited dexterity. Using a simple pattern made by Oneida Silverware, they attached stainless rings that fit over the thumb and forefinger. The rings are pliable and can be adjusted for a comfortable fit.

Bob says the utensils make it possible to stab food rather than push it around the plate and scoop it up. I have some hand involvement, so I know what he means. I'm able to hold forks and knives, but I've had my fingers slide down the handle when I try to spear or cut something that doesn't yield easily. I can only imagine the difficulty someone with a weaker grip would have.

Individual pieces are priced from $22-25, and a three-piece set is $55. A fork and spoon set is also available in a children's size for $35.

—Dana Schwertfeger

**For more information contact: Dining With Dignity, 101 Deerwood Drive, Williamsburg, Virginia 23185
757-565-2452, fax 757-345-0731, diningwithdignity@cox.net, www.diningwithdignity.com**

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: 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
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: 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:

I am a 53-year-old female with CMT. I was recently given a prescription for Amerge 2.5 by my neurologist, and the medicine made me feel like I couldn't move my legs. I also had severe cramps in my lower extremities. Are those side affects related to the medication?

The Doctor replies:

Naratriptan (Amerge) is a commonly prescribed migraine treatment in the triptan class and is similar to Imitrex (sumatriptan). These agents may have a variety of side effects complicated by the fact that most who take the pill already suffer from an acute migraine. Common and infrequent reactions include nausea, odd numbness, chest tightness, dizziness, drowsiness, and fatigue. There is no evidence, however, of true worsening of weakness or sensory function. Muscle cramps are rarely seen but could be more common in patients prone to cramps, such as patients with CMT.

Dear Doctor:

One of the side effects listed for Prilosec which should be reported to a physician is numbness and tingling of the hands and feet. Since I already have numbness and tingling of the hands and feet, I'm not sure if I should continue taking it. Is there anything on record to the effect that Prilosec is contraindicated for people with CMT?

The Doctor replies:

Numbness and tingling are listed as side effects for a wide variety of medications, but only a small number have been linked with causing or worsening neuropathy. Prilosec (omeprazole) has been reported to cause neuropathy and/or myopathy (muscle disease) in a very small number of patients, but not enough to know if the effect is real or not. It is not known whether CMT patients are affected differently or why some patients are affected and not others—none of the reported patients had CMT. The related drug lansoprazole was reported in 2005 to cause neuropathy in one patient. This fact should be brought to the attention of your treating physician.

Dear Doctor,

How common is it for a person with CMT to develop breathing problems?

The Doctor replies:

The first thing to stress is that this is very rare. There are two possible causes for breathing difficulties. The first is that involvement of the nerves to the diaphragm (the phrenic nerves) can cause weakness of the diaphragm. This can present as breathlessness, particularly when lying flat, but may also present with excessive daytime sleepiness—the reason for this is accumulation of carbon dioxide due to inefficient breathing. The second problem can be paralysis of the vocal cords—this impairs air entry and breathing can be very noisy. Vocal cord involvement is said to be most common in CMT type 2C but probably can occur in other types.

Dear Doctor,

I have had a significant amount of surgeries done to correct my foot deformities. I keep having problems with pin tract infections. I have been told numerous ways to care for the pin sites. What is the standard of medical care when a pin site becomes infected? I have already been diagnosed with osteomyelitis in my tibia and would like to avoid that again in the future.

An orthopaedic surgeon replies:

Assuming this is an adult and the surgeries are in the tibia to correct a fracture which has united the bones so that the bone is not straight or has trouble bearing weight, the osteotomy (cutting the bone) was made to straighten things out. In this instance, which we will call scenario A, the pins were inserted to hold the fragments together. If this is not the situation, scenario B would be that the pins were used for a frame to stabilize the fragments.

He mentions that he has osteomyelitis (an infection in the bone) in the tibia at the region of the fracture rather than the pin site. This is probably an infection in the region where the osteotomy was done to correct the bone deformity.

Generally, when a pin site becomes infected, the pin is removed, if possible.

In scenario A, if the pin is removed and the fragments become unstable, then the pin should be reinserted somewhere else if possible, so that the new

WRITE TO US!

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The CMTA reserves the right to edit letters for space.

pin can hold the fracture or osteotomy fragments.

In scenario B, if the pin is removed and the frame no longer gives support, then it needs to be remade. This may involve moving several pins, removing them and reinserting them to take the frame away from the area that is infected.

In all instances, the person must take meticulous care of the pin-skin interface, which should have been part of the instructions from his orthopaedic surgeon. That is part of the standard of care.

Dear Doctor,

I know that statins are listed on the drug watch list for their possible effect on muscles. I have CMT type 1A and have been taking Zetia prescribed by my doctor to lower my cholesterol.

It has worked as expected, but how do I know if Zetia is having a negative effect on my muscles? I have always experienced general muscle discomforts and pains, especially a lifetime of back problems and compound scoliosis. How can I tell if the Zetia is contributing to my already evident problems?

The Doctor replies:

Ezetimibe (Zetia) is the first of a new class of antihyperlipidemic agents, the cholesterol-absorption inhibitors. It is known that most lipid-lowering therapies, including statins, fibrates, and niacin, may cause muscle toxicity and Ezetimibe is touted as an alternative. The studies by the manufacturer did not seem to uncover cases of muscle problems, but there are now a handful of reports, though not well documented, with this drug as well. Some theorize that drugs that interfere with fat metabolism may disrupt normal muscle function in a small percentage of patients ranging from 1 in a 100 to 1 in 1000 depending on the agent. Given the current knowledge, this drug is still probably a good bet if lipid therapy is needed. The combination of this drug and a statin may have added toxicity, but this fact is not well established. There is no known link with this drug and neuropathy or a specific link to CMT, but any cause of muscle weakness can hamper function in CMT patients who have weakness as part of their condition. ✻

LETTER

Dear CMTA,

I live in Richard's Bay, South Africa. I am 31 years old. When I was 19, I started experiencing problems with my balance and walking. I was told that I have CMT by a doctor in Durban. I was very disappointed because I was a good athlete. I soon noticed that I could not stand on my toes and I could not run. Even walking became an effort. I then went back to the doctor who prescribed foot splints, which help a lot. I still experience problems with my toes, which are very close together and itch a lot. The worse part is that I wear boots at work for 9 hours a day. I have to take a taxi most of the time because it is more comfortable with the splints. I have very thin legs and barely any calf muscles, so I wear long jeans all the time.

I got married five years ago and am not sure whether to have children or not. I know, in my heart, that my wife would like to have a child, but she always says we should wait.

People tell me that they know what I am feeling, But do they? I feel like I am all alone with this CMT disease and I have not noticed anyone else in Richard's Bay who has it. I try not to let my condition affect my way of life, but it is only natural that it sometimes gets to me. I don't have anyone to talk to who really knows what it is like living with CMT. My wife is very supportive, but I feel that having someone to talk to face to face would be so good.

I joined a gym about a month ago and I feel good. I noticed that I am putting on a little extra muscle in my upper body. It gives me a good feeling to be shaping up, but I worry that my leg muscles are not getting any bigger. I wonder if pushing myself extra hard to build my legs will help.

I sometimes feel like sitting down and crying, but, if I think about it, I know there are people worse off than me. Please let me know about any new information regarding CMT disease.

—*Y. Chetty, South Africa*

The CMTA Report is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization.

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
Lefluonamide (Arava)
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)
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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