

THE CMTA Report

MAY/JUNE
2011

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ www.cmtausa.org

STAR Challenge Grant—The Time Is Now!

BY DAVID M. HALL

The CMTA has received an anonymous donation in the amount of \$100,000 in support of the STAR research and drug discovery program. The incredibly generous donation has compelled the CMTA's Board of Directors to issue a new challenge grant. The Board of Directors will match all funds raised between now and August 31, 2011 up to \$100,000—which gives us the chance to turn the initial \$100,000 into \$300,000! Please take this great opportunity to help advance the STAR program—your support is not only greatly appreciated, but also needed now more than ever!

During the past two years, the US economy has experienced a recession the likes of

We can turn
\$100,000 into
\$300,000 with the
help of the CMTA
Board of Directors
and our supporters.

which we haven't seen in decades. During this same time period, the CMTA has initiated several major programs including the Strategy to Accelerate Research (STAR), the national support and action group program, and the launch of the state-of-the-art online community program that includes the CMTA website, CMTA Facebook pages, YouTube Channels, and Twitter feeds.

As a result of these dynamic and innovative initiatives, I could not be happier with the current state of the CMTA along with the future opportunity that we and you have together. Examples of our successes over the past two years are as follows:

- ★ The STAR program has succeeded in producing two robust CMT1A cellular models that have been used

to screen more than 350,000 potential drug candidates, resulting in the identification of four FDA-approved compounds that will be incorporated into advanced drug development programs;

- ★ The CMTA is currently partnered with two global pharmaceutical companies and two global biotechnology companies that are each contributing significant technologies and know-how towards the advancement of the STAR program;
- ★ The CMTA has created a scientific advisory board comprising of 10 world-renowned thought leaders from five countries who are providing invaluable guidance to the STAR program;
- ★ The CMTA hosted a first-of-its-kind global CMT Type 2 research and drug development meeting that was attended by more than 30 scientists from 7 countries;

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SWIMMING AGAIN FOR CMT

The O'Donnell family has been raising money for CMT research for 10 years. Steve and his two children will swim together this year.

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ANONYMOUS CHALLENGE

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- ★ The CMTA's national support and action group program has grown to more than 60 groups in 30 states across the country, resulting in an unprecedented level of local activity promoting CMT awareness and education;
- ★ The CMTA hosted a national support and action group facilitator meeting in Las Vegas, NV in which the national CMTA community was trained and educated on managing fund-raising and awareness initiatives;
- ★ The CMTA launched the first-of-its-kind national CMT Awareness Week, which compelled the CMTA to initiate the first-of-its-kind national CMTA Awareness Month in September 2011;
- ★ The CMTA launched an online community via its corporate website, which has attracted thousands of CMT patients, families, and visitors from dozens of countries around the world. The result is a global exchange of CMT stories and ideas never before seen.

The aforementioned programs and successes are the result of the hard work of many individuals within the world of the CMTA. The CMTA must continue to generate the financial resources required to ensure these programs and projects continue to thrive.

This challenge grant presents us with a significant opportunity to raise much-needed funds. You have been integral in helping us achieve our objectives to date. I sincerely thank you for your past support and ask you to consider helping us now with this unique fund-raising program. ★

CMT Patient & Family Conference

Saturday, July 2, 2011, Washington, DC

REGISTER now until June 10th for the CMT Patient & Family Conference that will be held near Washington, DC on Saturday, July 2. The day-long conference will feature presentations from the world's leading clinicians and researchers, who are gathering for the biennial CMT International Consortium. The conference will focus on topics including the latest research into CMT, the role of genetics, the impact of the disease on children, compensatory strategies, and physical therapy.

Some of the outstanding speakers will be Dr. Steven Scherer from the University of Pennsylvania discussing, "Understanding the Types of CMT." He will be joined by CMTA Medical

Advisory Board Chairman, Dr. Michael Shy, from Wayne State University, talking about "CMT Research: Progress and Promise." Two genetic counselors from Wayne State, Carly Siskind, MD and Shawna Feely, MS, will



explain the genetics of CMT. "Physical Therapy, Orthotics and Activity in Adults with CMT" will be presented by Gita Ramdharry, from Kingston University, London, England. Finally, Dr. Joshua Burns from the University of Sydney, Australia, will discuss "Assessment and Management of Children with CMT."

The conference will be held at the beautiful Bolger Center in Potomac, Maryland, minutes from the nation's capitol. Registration is just \$50 per person and includes continental breakfast and "Lunch with the Experts," at which registrants will be able to meet face to face with the day's presenters. Don't miss this unparalleled opportunity to learn more about CMT and talk with the

world's top minds on CMT. Space is limited, so register now on the CMTA website at www.cmtausa.org/dcpfc. ★

For more information, please contact Jeana Sweeney (jeana@cmtausa.org) or Steve Weiss, support and action group facilitator for Washington, DC Metro (scweiss2001@yahoo.com).

Congressman Bob Dold

A Friend to the CMTA & the National Rare Disease Community

Congressman Dold's support of the CMTA provides a great example for all of us to follow. CMTA Chairman Patrick Livney is a constituent of Congressman Dold and took it upon himself to introduce CMT and the CMTA to the Congressman. It was through Mr. Livney's proactive efforts to promote CMT and CMTA awareness that Congressman Dold has embraced the CMTA's campaign to not only improve the lives of those living with CMT, but also to live in a world without CMT.

A small dose of awareness can go a long way....please contact your US Representative or US Senator and let them know about CMT and the CMTA. For more information, contact the US House of Representatives at (<http://www.house.gov>) and the US Senate at (<http://www.senate.gov>).



The CMTA is sincerely appreciative of the support it receives from Congressman Robert Dold (IL-10) and would like to recognize Mr. Dold for his recent appointment to the Rare Disease Congressional Caucus within the US House of Representatives.

The goals of the Rare Disease Caucus are to bring Congressional attention to the nearly 7,000 known rare diseases that currently have no approved therapies; ensure sufficient funding for research and orphan product development; explore ways to incentivize companies to create new drugs, biologics, and humanitarian use devices; and provide an opportunity for Members of Congress, families, and advocacy groups to exchange ideas and policy concerns. Rare and neglected diseases afflict nearly 30 million Americans, approximately half of whom are children.

For the past five years, Congress has passed legislation in support of CMT research at the National Institutes of Health (NIH). Congressional champions like Representative Dold are

key to ensuring that CMT and other related disorders maintain their priority status within the NIH.

Congressman Dold is serving in his first term in the US House of Representatives and serves on the Financial Services Committee. He is a third-generation resident of the North Shore in the 10th District of Illinois. Prior to being elected to Congress, Congressman Dold ran Rose Pest Solutions, a small

business founded in 1860. It is the oldest pest management company in the United States.

Congressman Dold's educational credentials include a BA from Denison University, a law degree from Indiana University, and an MBA from Northwestern University's Kellogg School of Management. ★

FREE CMT DVD: THE PATIENTS' GUIDE TO CHARCOT-MARIE-TOOTH DISORDERS

Join your local support and action group on the CMTA's new website: www.cmtausa.org and receive a FREE CMT DVD: The Patients' Guide to Charcot-Marie-Tooth Disorders, a \$10 value. How do you receive your free DVD in the mail? Simply join your local support and action group on-line. Here is how:

If you have not already registered on the CMTA's new website, **please go to cmtausa.org and register with the CMTA community, free of charge.** Once registered, please click on **Support and Action Groups**, found on the left side of the home page, under **CMTA Community**. Then, click on the middle tab, **Find and Join a Group**. Join the support and action group closest to you! If there are no groups in your area, please join the Global Support and Action Group Community, where all the CMTA's support and action group facilitators post notes and news from around the country. Once you've joined a group, let us know. Write to info@cmtausa.org and give us the name of the group you've joined, along with your full name and mailing address, and we will send you a FREE Patients' Guide to Charcot-Marie-Tooth Disorders, no strings attached. It's that easy!

Offer good through October 31, 2011, or as long as supplies last.

Athletes Unite to Raise Awareness of CMT

College friends Chris Wodke and Cheryl Monnat are showing that friendship and loyalty extend well beyond college days. Wodke and Monnat met when they both attended engineering school at the University of Wisconsin, Milwaukee.

They have united once again to form Team CMT. The purpose of Team CMT is to raise awareness of Charcot Marie Tooth disease and funds for CMT research.

They are recruiting runners and triathletes to join them on Team CMT.

Wodke got the inspiration when she was diagnosed last August with CMT Type 1A.

"It is very frustrating for those of us with this disease no one knows about. Team CMT's mission is to make everyone



Chris Wodke and Cheryl Monnat have united to form Team CMT and compete in Triathalons to create CMT awareness.

aware of this disease. It is time for those of us with CMT to be visible in the community." She feels very blessed she is able to run and wanted to contribute to a "World without CMT."

Team CMT will be competing in events around the county including the Lakefront Marathon in Milwaukee, the Madison Marathon, and the Marine Corps Marathon in Washington, DC this October. Team CMT will also be competing in many additional triathlons and running events around the country. They already have eight team members in three states.

Wodke hopes to use the Madison Marathon to qualify for the mobility-impaired division of the 2012 Boston Marathon. She needs to finish in 6 hours to qualify for the Boston Marathon and expects to complete the race in about 4:45.

With her CMT she never knows what to expect on race day, so finishing is a major victory.

The Team singlet takes its inspiration from the STAR (Strategy to Accelerate Research) initiative. The teams' dream is a world without CMT. An important step is to raise awareness through efforts like Team CMT. The team runs for many of those with CMT who can't. Hopefully, friends and family of those with CMT will join in this effort. There is no cost for the singlet but the supply is limited.

Monnat will be attempting to qualify for Boston at the Lakefront Marathon in October. Both women plan on running the Boston Marathon in April of 2012. ★

You can learn more about Team CMT, their efforts to raise awareness, and how you can help at their website www.run4cmt.com

KEN'S RIDE FOR CMT AWARENESS AND RESEARCH

When Ken Gomez retires in June, 2011, he is going to ride his bicycle 4200 miles across the country in an effort to create awareness about CMT and raise funds for the CMTA's STAR research initiative. He is planning to start in Anacortes, WA, and end in Bar Harbor, ME. (For more information, or to contact Ken directly go to kgomez@twcny.rr.com.)

Bicycling across the country would be an extraordinary feat for anyone, but it will be an even greater triumph for Ken, who has CMT. So does his son Paul, who is a vented quadriplegic because of his CMT. Many of Ken's relatives also have the disorder, so he has personally witnessed the challenges that people with CMT face, and he is determined to do what he can to make their lives better.

The Paul Flynn Charitable Trust has generously provided \$22,000 in matching funds for Ken's Ride, and there is currently \$3,024 still available to be matched. To donate to Ken's Ride, you can go to www.cmtausa.org/kensride.

THE CMTA "CIRCLE OF FRIENDS"

If you are interested in creating a fundraising Circle of Friends or want your family or friends to donate money to the CMTA on behalf of your birthday, anniversary, or special occasion, please let Jeana Sweeney know! You can email Jeana at: jeana@cmtausa.org. Working together, we can create a world without CMT!

DONATIONS WERE MADE TO THESE CMTA CIRCLES:

Chris's Run

Ms. Ann Tanis

Cruise for a Cure

Ms. Shelly Adams

Ms. Claril Anderson

Mr. and Mrs. David J. Brewer

Mr. and Mrs. Ray E. Brown

Ms. Cricket Cook

Mr. and Mrs. Shawn Dyer

Mr. Casey Hebert

Mr. Tom Humbert

Ms. Mana Knause

Mr. Stewart Kouba

Mr. and Mrs. Danny Kreps

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Ms. Pam E. Sumrow

Mr. Loyce Tabor

Ms. Marcella Washborn

Ken's Ride

Mr. and Mrs. Thomas Adams

Anonymous donor

Boating Night Buddies

Brewerton Cub Scout Pack 112

Ms. Elizabeth Cox

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Dr. Judith Gomez

Mr. Lawrence Gomez

Mr. Ken Gomez

Mr. Tim Hazlehurst

Mr. and Mrs. Jim Kersting

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Ms. Holly Walsh

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Mr. Chris J. Drouillard

Mr. Tom W. Eastman

Mr. and Mrs. Dan Gauthier

Mr. Brian Greenlee

Mr. Bob Griffin

Mr. Joe Grimoldi

Knieper Wood Floors Inc.

Mr. Erv Kowalski

Mr. Kyle Krebill

Mr. Ethan Perkins

Mr. Timothy F. Schuler

Mr. Joe Selleck

Ms. Simone Simon

Mr. Scott Skinner

Ms. Miranda Stoneman

Mr. Mark Thompson

Ms. Julie Thorn

Mr. Stanley R. Tyler

Tyler's Walk

Mr. and Mrs. Alan C. Kaspar

Vasi's Baseball

Fantasy Camp

The Meyer Levy Charitable Foundation



ASK THE DOCTOR

Dear Doctor,

I have CMT 1A and have been suffering with severe muscle cramps in my calves for years, and it is getting worse. I have tried so many medications, botox, etc. I also have two children with CMT who are starting the muscle cramping a lot earlier than I did. I have been to many doctors with no relief. I have had 65 surgeries. I'm 38 and had my first one when I was 7. I do not sleep the night through and I'm afraid my kids are going to get the severe cramps like me. Have you heard of this or what helps?

Dr. Steven Scherer replies,

Cramps are a frequent problem in patients who have axonal loss,

including people who have CMT. I certainly don't have a good treatment for them, and I doubt that any exist. Quinine might be the most effective medication, but some adverse events have led to the FDA taking action against its use for this indication. Although you may suffer from cramps more than do most people with CMT1A, there is no reason to think that your children will be equally affected in this manner.



Dear Doctor,

I read on the Internet that treatment with cyclophosphamide was followed by marked improvement in strength in both patients this

was given to. It was reported in Annals of Neurology. Is this true?

Dr. Louis Weimer replies,

Cyclophosphamide is a more extreme and reasonably toxic treatment used for some severe forms of autoimmune and inflammatory neuropathy when more traditional treatments fail. The drug is not a recognized treatment for CMT. I am not aware of any paper in *Annals of Neurology* that studied cyclophosphamide and CMT.



Dear Doctor,

My husband first got sick 10 years ago with chronic vomiting. He

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ASK THE DOCTOR

(continued from page 5)

was eventually told it was gastroparesis (a slow stomach). This has led to a never-ending journey. He received a diagnosis of MS last year after they found lesions on his brain and spine. His appearance is that of CMT and a nerve conduction test confirmed that. His mother abandoned him when he was three and she has been given a diagnosis of CMT recently. We know very little about CMT and he is on the medicine, Copaxone, for his MS.

Could this harm him? How likely is it that he has both CMT and MS? He was recently diagnosed with retinitis pigmentosa.

Dr. Louis Weimer replies,

It would be very unusual to have all three separate diagnoses, especially the RP. Copaxone is not known to worsen CMT, however, there are some very rare genetic disorders that have the combination of neuropathy, retinitis pigmentosa, imbalance, and brain changes that can mimic MS. If he is very thin, then NARP, a rare mitochondr-

ial disorder, comes to mind.

Dear Doctor,

Do you know anything about the use of the drug Pristiq for depression and if it would be suitable for a CMT patient to take?

Dr. Louis Weimer replies,

The drug is a newer antidepressant that poses no specific concern for CMT patients that I know. It might provide some symptomatic relief for neuropathic pain, but it is not approved for that indication. ★

Film Benefits CMTA

Tom Townsend is a Baltimore film producer and actor who suffers from Charcot-Marie-Tooth Disease. But he isn't letting that stop him from chasing his dreams. After being diagnosed with the disease two years ago, Townsend didn't even know it existed, and now he wants to create awareness. Tom Townsend is proud to announce that despite the challenges of this disease, he successfully produced and acted in a recently released family feature film

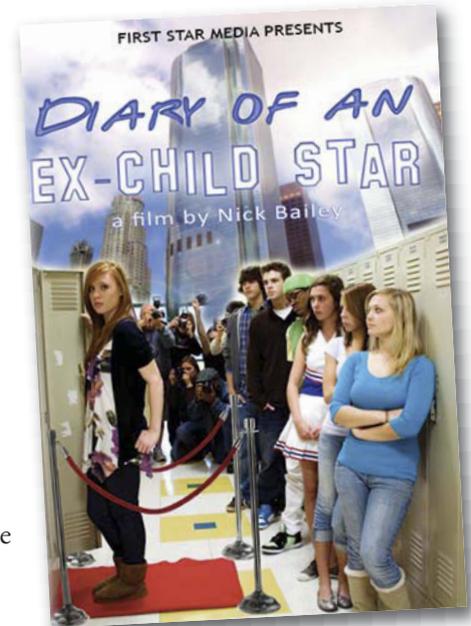
titled "Diary of an Ex-Child Star." The movie follows Peyton Bradford, a television child star, as she is forced to move to a small town following the cancellation of her show. Without even being settled, we follow her

journey as she attends a normal high school and deals with the pressures of being a celebrity teenager outside of Hollywood. Townsend explains that filmmaking is his passion and when he was diagnosed with CMT, he really thought it was over. Once he found the CMTA

Kids think that CMT will ruin their dreams. But, you can be and do whatever you want.

website, he learned a lot, including that the disease is something he could learn to live with. "Kids out there with CMT (might) think it will ruin their dreams. You

can be and do whatever you want. The only one that is going to hold you back is you," explained Townsend. The movie, "Diary of an Ex-Child Star" is donating a portion of the proceeds to the CMTA



to help with finding a cure. Please support Tom Townsend and the CMTA by purchasing a copy of this heartwarming family film. Visit the film's website at www.diaryofanexchildstar.com and for just \$15 you can purchase the movie, make a donation, and get free shipping of the film. ★

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Betty Barlow

Mr. and Mrs. William Krejci

Patricia Beechem

Mr. and Mrs. Danny Beechem

Mr. and Mrs. Rob Crook

Ms. Diane M. Sborlini

Betty Chow

Ms. Jean H. Kaung

Ms. Rose H. Yuen

William Finnegan

Mr. and Mrs. Stuart Benson

Aaron Greif

Mr. Michael Grife

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Ms. Billie Rose Palla

Ms. Marie Scherck

Mr. and Mrs. Walter H. Williams

Andrea Hirsch-Demby

Mr. and Mrs. Irwin L. Rhine

Gertrude Lee

Blevins Paint Center Inc.

Mr. and Mrs. Thomas R. Mayo, Jr.

Charles T. Lynch, PhD

Mr. Tom Lynch

Travis L. Nation

Ms. Maria Cowles

Robert Norton

Ms. Margaret Jean Smith

Fran Gomez Owens

Mr. Lawrence Gomez

Mr. and Mrs. Charles S. Owens

Sharon L. Peirce

Ms. Martha M. Johnson

Dennis Reigle

Mrs. Frances Davis

David Reigle

Mrs. Frances Davis

Alexander F. Waier, Jr.

Mr. Gerald Rosicky

Jack Walfish

Mr. and Mrs. Jerry Walfish

Bernard Yabroff

Ms. Shirley S. Feldman

IN HONOR OF:

Carol Albright

Mr. Bryan Albright

Mr. Heithem El-Hodiri

Mr. Ron Phitayakorn

Sherry Brown

Ms. Dona Inamura

Dianne Everhart

Mr. and Mrs. Jason Hill

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Erin Elizabeth Hughes

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Kim P. Marshall

Mr. and Mrs. Leslie Smith

Terry McIntosh

Happy 70th Birthday

Ms. Gloria Casey

Mr. and Mrs. Roman Esparza

Ms. Marsha Kliewer

Ms. Cheri J. Simpson

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, P.O. Box 105, Glenolden, PA 19036.

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 American Express

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____



Passing a Bill at Capitol Hill

SAG Facilitator Beverly Wurzel inspired her granddaughter to lobby on Capitol Hill to encourage NIH to continue its commitment to CMT research as part of her school's Face to Face program.

My name is Jessica Bangel. I will be 17 years old next month, and I live in New Jersey where I am a junior in high school. I am involved in community service and enjoy helping others.

On March 11, 2011, I was fortunate enough to participate in a program that incorporates Judaism and social justice. The name of the program was Panim El Panim which means face to face and is affiliated with B'nai

B'rith Youth Organization. The term "Face to Face" means that we actually go out and face the problems at hand and try to resolve them in person.

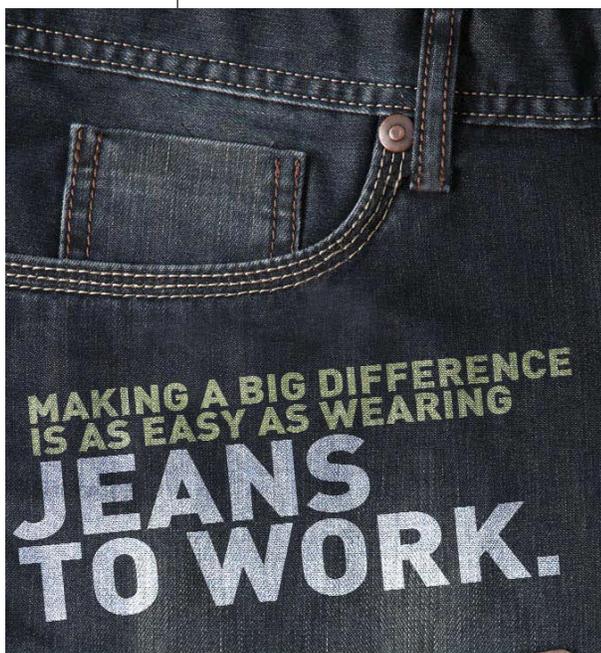
With this program I was fortunate enough to have the opportunity to lobby at Capitol Hill for bill S.3686 in which congress encourages the National Institutes of Health to continue their current commitment to CMT research and outreach.

When I was in Washington, DC, I met with the legislative correspondent to Senator Menendez. I informed her about CMT, which she had never heard of and was eager to learn more about. After my description and explanation of this debilitating disease, she asked some questions,

and then my meeting was over. Before going on a tour of Capitol Hill, I left her the CMT pamphlet which I suggested she look over and pass along to our Senator. As we left Capitol Hill, the legislative correspondent promised that she would discuss this senate bill with Senator Menendez and pass along the information.

My grandmother, Beverly Wurzel, has CMT. I have witnessed first hand the daily challenges that she faces. It is my wish that I can help to assist in passing this bill and in my life time see a cure.

At the very least, I have spread awareness about CMT. I have since followed up and am patiently awaiting a response. ★



Doing something small can make a big difference for a serious disease! By implementing a "Jeans Day" program, your business could raise funds that could lead to better clinical care for Charcot-Marie-Tooth disorder. CMT is a muscle wasting disease that affects one in every 2,500 people and is the most commonly inherited peripheral neuropathy in the world. All proceeds will benefit the Charcot-Marie-Tooth Association's ambitious Strategy to Accelerate Research (STAR™) initiative which is working towards improved treatments for CMT.



CASUAL FRIDAY'S WITH DEEP POCKETS...

Don't you relish those days when it's o.k. to wear jeans to work?

An easy and great fundraising idea that requires very little effort from our CMT community is to reach out to local business, even your own employer, via email or in person and propose a Jeans to Work day.

Explain to the prospective participating business that CMT is the most commonly inherited peripheral neuropathy and it affects one in every 2,500 people. Go into as much detail as you feel comfortable in doing. Tell him/her that the donations will go directly to STAR (Strategy to Accelerate Research)!

Permit the employer to determine if they will charge their employees anywhere from \$1-\$5 for the privilege of wearing jeans to work on a designated day of their choice. Then, send me the contact information and I will take it from there!

The CMTA has made it easy for everyone to participate by providing the Jeans to Work poster for downloading from www.cmtausa.org. Go to Support Groups and you will see a group named "Anyone Can Fundraise." The Jeans to Work poster is under the "files" section.

Yes, it is that easy! Contact me at jeana@cmtausa.org for any further information. ★

Steve O'Donnell and Friends Swim the Chesapeake for the Tenth Year

Again in June, Steve O'Donnell, his daughter Jaime and son Sean, along with some loyal friends, will swim the Chesapeake Bay to raise money to find a cure for Charcot-Marie-Tooth disorders. With your support, Steve hopes to make 2011, his tenth year doing the Swim for the Cure, the most successful year ever.

Joining Steve in this year's swim is Donna DeWick. Donna lives in London and is coming across for the challenge.

She has been fundraising for a cure for CMT since 2009. An avid swimmer, since 2010 Donna has sent swim caps to athletes

around the world to help build CMT awareness. You can read more about Donna's efforts on her website, www.beatinglimitations.com

Over the nine years preceding this one, Steve and the others who have done the swim with him have raised an amazing \$773,454. Steve's friends, his family, and the members of the CMTA have been incredibly generous in supporting Steve's efforts.

If you would like to support Steve, his children, and Donna in their efforts to raise money for the STAR initiative, you can go to the website at www.cmtausa.org/swim and donate with a credit card on

line. If you prefer, you can send a check to the CMTA marked for the Bay Swim. The new address for the organization is CMTA, PO Box 105, Glenolden, PA 19036.

Working with the preeminent thought leaders and institutions within the inherited neuropathy community, the CMTA is at the forefront of the advancement of CMT research, the creation of clinical standards of care, and the development of therapies to treat and cure

CMT. Through these strategic relationships and programs, the CMTA is able to not only stimulate the advancement of collaborative

CMT research and clinical care, but also provide essential information for outreach and education to the national CMT patient and health care professional communities. The NIH and Pfizer are among the industry leaders working with the CMTA to develop disease models that will be used to test vast libraries of chemicals in the hopes of finding candidates for drug development initiatives.

With your generous support of the 2011 "Swim for the Cure," you will enable the CMTA to continue funding research by the best scientists in the world and will bring us that much closer to our goal of a world without CMT. ★



Donna DeWick is traveling from England to participate with Steve O'Donnell, his family, and friends, in the Chesapeake Bay swim. She, like Steve, has been fundraising for CMT research and a possible cure for CMT.

NEW TRAVEL CARD AVAILABLE

Based on the style of the new TSA card to be used in airports, the CMTA has developed a card which incorporates the TSA information regarding the reporting of a disability to a TSA officer with the description of the symptoms of CMT. This should make it much easier for patients with CMT to travel without having to spend an inordinate amount of time trying to tell someone exactly what CMT is.

The organization would like to thank Vicki Pollyea for being the driving force behind the creation of the card. She had a similar card from years ago and felt that it would be a worthwhile project to get something created again. The other person who should be thanked is Rick Alber who designed the card and managed to get a great deal of information in a small space.

If you belong to a CMTA support and action group, you can obtain a laminated version of the card from your group facilitator. Not a member of a group? Go to <http://www.cmtausa.org/url/findgroup> to find and join one.

A laminated card will also be included with your thank you letter when you renew your newsletter/premium content subscription, but if you have recently renewed or would simply like to request a laminated card, you can obtain one by sending a stamped, self-addressed envelope to:

TSA CARD, CMTA, PO Box 105, Glenolden, PA 19036.

Traveling soon? You can also print a temporary paper version of the card by going to <http://www.cmtausa.org/cmtraid>.

If you any difficulties or questions about the TSA identification card, please contact Jeana Sweeney at jeana@cmtausa.org or call 1-800-606-2682, ext. 106.

Archy Learns a Lesson or Two

Well, I've learned a valuable lesson. Or, at least, that's what my mother called it. I didn't win the election at my school to be a representative to student council. I thought I had good ideas and something that was realistic and doable as a plan for next year. It turned out that wasn't what the students wanted.

This is what happened. I talked about having CMT and being a representative for the CMTA because I didn't want any of my opponents to use my "difference" against me. They didn't. They never talked about my having CMT as a reason to vote for someone else. What they did do was what my mother called "clever bribing." One of the boys I was up against gave out coupons for French

fried grub worms from MacDougals. That's just about everyone's favorite food. Another one of my opponents, Rachel Racoon, wore cute little skirts and shook her gorgeous tail at the boys, and I'm pretty sure they all voted for her.

In any case, I lost by a fairly convincing number of votes and I learned the so-called valuable lesson that the best candidate is not necessarily the one who gets elected. My mother and my father said that's true in the national elections, too. Sometimes the person with the most money or the one who is popular for some reason or another is the one that wins, while the candidate with the well-thought out plans and the most concern for the good of the people comes in last. I guess it's nice to think it wasn't all about me being unelectable, but frankly, it still feels pretty bad.

My best friends, of course, stood by me and even after the defeat, they told me my speech was good and that they liked my campaign to "march forward with Archy." My teachers were pretty cool, too. They said it was a clean campaign and that I should be proud of the great effort I put forth. I don't know about you, but losing never feels very good no matter how many nice things your family and friends say about it.

I swim and when I come in second or third or last, my coach always tells me I put great effort

into my heat or that I will win the next time. I think there must be some manual somewhere that tells adults what to say when their child or student loses. The problem is, I don't have a book to tell me how to feel about the loss. I'll tell you guys the truth. I went home and cried and then felt sort of sick to my stomach for days. I had worked so hard and I had my hopes up and then....nothing.

Thank goodness there are exciting things happening at the CMTA that I can be involved with. They are already working on

Awareness Month....that's right, not Awareness Week this year but Awareness Month. That's a sign of how much we want the public to understand and recognize what CMT is. I'm working on some ideas to use during Awareness Month here in Greenwood. I'm planning a swim to raise money for the STAR program (swimming is still my best sport) and I'm hoping to do as well as the Berons and Steve O'Donnell. They are my heroes for doing swims to support the work of STAR. I hope you can all find something to do to celebrate Awareness Month and to support the work of STAR. They are getting close to medications that might improve the lives of those with Type 1A. That's not me, but one day the work will be about x-linked and I'll be in line to do everything I can to get that research funded, too. ★



Our mascot "Archy" writes about his experiences as a turtle with CMT.

This poem was the winner in a contest run by "Grading Girl" newsletter. The challenge was to write a poem about a young boy living with CMT

UNWRAP ME

by Stefanie Dell'Aringa

Scout's honor, this is my life:
I feel like an Egyptian mummy
being wrapped in slow motion from the feet up
My insides are like pottery breaking
As the python cloth squeezes
Unwrap me, please, and let me be a boy again
Because my ankles are tired
And I don't like the word "prosthetic"
If Star Wars were real, I'd light saber myself
Out of this mess
Hurry, and find me a cure
Until then, I'll go outside
I'll blow hot, angry air into my trumpet
I'll eat cake. Sweet!
I'll decide I can wait
And then I'll go to bed and dream
Of a ladder made of Legos
That reaches straight to heaven
and it doesn't hurt to climb it



SUPPORT AND ACTION GROUP NEWS

CA – SF/East Bay

The East Bay meeting was held on March 26, 2011. The guest speakers were Nathan and Cheryl Sherman, World Travelers. Nathan and Cheryl are amazing and truly inspirational! They engage the audience by asking people where they have been and where they want to go. Cheryl and Nathan talked about everything from logistics, luggage, wheelchair access, fatigue, planning, testing, attitude, pacing, rest, and relief for spouses and or friends. Their approach to travel is to save energy while traveling! According to Nathan and Cheryl, "...with positive attitude and determination you can turn CMT into an Adventurous Disability." Special thanks to Tim Phillips, for helping group members with the new CMTA website. The next meeting will be in May.

CA – Peninsula/South Bay

Many thanks to Harriet and Frank Weiss for lending their house as a meeting place for the March 12, 2011, support and action group meeting. The speaker was Julie Forbes, PhD, who specializes in stress reduction and mindfulness practice. She conducts several classes at Kaiser Permanente, El Camino

Hospital, and the Palo Alto Medical Foundation. Julie thought it might be helpful to the group members to know about different ways to reduce stress with such techniques as mindfulness, meditation, and qi gong and to learn about the mind/body connection.

Julie educated the group on how stress can and does cause and/or exacerbate chronic health issues. She led us through several exercises, including: Mindfulness of the Breath, Progressive Muscle Relaxation and Breathing Exercises

CA – Los Angeles

The first meeting of the year was held on March 26, 2011. They were delighted to have 23 in attendance, including Elizabeth and Jeana from the CMTA. Elizabeth spoke about the STAR initiative and gave the group updates. Jeana talked about the new website and how important it is for everyone to register and join the online support group to enhance communication. Jeana also talked about fundraising and how easy it can and should be. Both women

showed their knowledge and commitment to the CMTA. The group will meet again in June.

GA – Atlanta

The group met on April 16, 2011. They had 25 people who came with five new faces. The speaker for the group was Ruthann Lacey. She is an attorney who specializes in elder law. She spoke about laws which affect the aging population, including wills, long-term care options, trusts, estate management, and all things Social Security related. She also spoke about Social Security benefits, retirement income, supplement-

(continued on page 12)

SUPPORT AND ACTION GROUP FACILITATOR DEBBIE HAGEN, with the help of SAGF Julie Collins from Florida, made an inquiry requesting a proclamation from the Governor of Oregon in recognition of CMT Awareness Month in September. Julie wrote the official language and submitted it online. The approval came with the proclamation itself. This is the first official declaration of CMT Awareness Month and there should be more to come.



SUPPORT AND ACTION GROUP NEWS

(continued from page 11)

tal security income (SSI), and disability insurance. The next meeting will be May 21st at 2 pm at St. Martin in the Fields Episcopal Church (www.stmartins.org).

MI – Kalamazoo Area

The Southwest Michigan Group had their meeting on March 17, 2011. The new MDA Health Care Services Coordinator for the area, Melinda Howard, visited the meeting. Ms. Howard spent some time discussing her background and her new role with the MDA. The attendees

discussed orthotic bracing, insurance issues, diagnosis of CMT, and recent STAR developments. During the meeting, Ms. Howard surprised Jori (support group facilitator) by presenting her with two awards from the Muscular Dystrophy Association, The Robert Ross Personal Achievement Award for their Chapter and the Robert Ross MDA Personal Achievement Award for the State of Michigan “for outstanding achievements and demonstrated success in overcoming the challenges of muscle disease.”

NM – Albuquerque

The group met on April 9, 2011. Thanks to the California

CMTA support group, the New Mexico group had access to DVDs from a patient/family conference. At the last group meeting they heard parts of the DVD in which Dr. Scherer gave his lecture on CMT. This time they continued with Dr. Scherer answering questions in a number of areas such as genetic testing, insurance issues, CMT and exercise, CMT and dizziness, and a host of other valuable things. They also heard from a brace practitioner. He discussed bracing in general and several types of bracing in particular. If anyone in the New Mexico group missed either of these meetings, please contact Gary

(continued on page 14)

Chicago Area SAG Wins Fundraising Challenge

On Saturday, April 9th, some of the CMT support and action group members in the Chicago area, who were responsible for raising funds last year and won the CMTA Fund Raising Challenge, were treated to a wonderful lunch by Pat Livney, chairman and president of the CMTA.

The lunch took place at the ‘Weber Grill,’ which is well known for their flamed seared food cooked on authentic Weber grills. The food was delicious, but the company and conversation were even better. What a wonderful opportunity for all of us to hear, from Pat Livney, the

latest news on the STAR and events that are taking place at the CMTA. It is always inspiring and motivating to hear Pat as he discusses the efforts of the STAR initiative.

Our fund raising efforts were never put in place to try to win a challenge, but the special lunch was greatly appreciated. The challenge we all work towards is to spread awareness about CMT and to help the CMTA raise funds for the STAR. We met that challenge last year and plan on doing the same this year during CMT Awareness Month. It’s a wonderful feeling knowing that we have made a difference!

—Dale Christine Lopez,
Chicago CMT Support and
Action Group Facilitator

Members of the Chicago Area Support and Action Group were treated to lunch out with Chairman and President Patrick Livney as a reward for their successful fundraising during last year.



CMT Support and Action Groups

AL—Birmingham Area

No group currently meeting
Will accept calls
Dice Lineberry
205-870-4755

AZ—Phoenix Area

Arizona CMTA Support Group
Ken Wysocki
602-606-2805
Pamela Palmer
480-926-4145

CA—Los Angeles Area

SoCalSupportGroup
Dottie Zagar
661-433-2533

CA—South Bay Area

San Francisco Peninsula/
South Bay
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area

San Diego CMTA Support Group
Steve Gabbert
619-987-6022

CA—Santa Rosa Area

Santa Rosa Support Group
Carol O'Bryan
707-823-0165
Ronald Deghi
707-829-0911

CA—SF/East Bay Area

San Francisco/East Bay Support
and Action Group
Donna Rennie
925-330-2790

CA—Visalia Area

Visalia California SAG
Melanie Pennebaker
559-972-3020

CO—Denver Area

Denver Area Support &
Action group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

DC—Washington, DC Area

Washington DC Metro
Steven Weiss
Kimberly Hughes

FL—Inverness Area

West Central Florida
Ronnie Plageman
352-860-1578

*FL—Jacksonville Area

Jacksonville, FL Support Group
Bill Wilkins
904-268-4530

FL—Orlando Area

Central Florida Support and
Action Group
Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area

FL Support Group
Vicki Pollyea
813-251-5512

GA—Atlanta Area

Atlanta Support Group
Susan Ruediger
678-595-2817
Jeannie Zibrida

IL—Chicago Area

Chicago Area Action &
Support Group
Dale Lopez
708-499-6274

KS—Wichita Area

Kansas Area CMT Support
Group
Karen Smith
316-841-8852

KY—Burlington Area

Pam Utz
859-817-9338

MD—Hagerstown Area

Hagerstown Maryland
CMT Support Group
Jeffrey Martin
301-582-2401

ME—Portland Area

Portland, ME Support and
Action Group
Celeste Beaulieu
207-284-1152

MI—Chesaning Area

Chesaning, MI Support
and Action Group
Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area

Southwest Michigan Support
Group
Jori Reijonen
269-341-4415

MN—Benson Area

No group currently meeting
Will accept calls
Rosemary Mills
320-567-2156

MO—Anderson Area

No group currently meeting
Will accept calls/emails
Libby Bond
417-845-1883

MS—Mississippi/Louisiana

Clinton, MS Support and
Action Group
Flora Jones
601-825-2258

NC—Triangle Area

Triangle, North Carolina
Support and Action Group
Betsy Kimrey
919-833-3991

NH—New Hampshire/Vermont

New Hampshire/Vermont CMT
Support and Action Group
Margaret Healey
802-535-2797

NJ—Central New Jersey Area

Central New Jersey Support and
Action Group
Mark Willis
732-252-8299

NM—Albuquerque Area

CMT New Mexico Support
& Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area

Las Vegas CMT Support
and Action Group
Diane Cencak
702-560-3647

NY—Upstate New York Area

The Upstate NY CMTA Support
& Action Group
Melinda Lang
518-783-7313

NY—Greater New York Area

Greater New York CMT
Support Group
Bob Wine
212-535-4314

NY—Horseheads Area

Horseheads, NY Support Group
Angela Piersimoni
607-562-8823

NY—Hudson Area

Hudson Valley CMT
Support Group
Deborah Newman
845-883-0580

NY—Long Island Area

Long Island Support Group
Ruth Korowitz
516-318-3202

NY—Westchester Area

Westchester Support Group
Beverly Wurzel
201-224-5795

OH—Greenville Area

Greenville OH Support and
Action Group
Dot Cain
937-548-3963

*OH—Zanesville Area

CMT Crusader Support
Group of Ohio
Tara Boehke
740-297-4940

OR—Portland Area

Portland Oregon Support and
Action Group
Debbie Hagen
503-333-7936

PA—Bucks County Area

Bucks County Support Group
Linda Davis
215-943-0760

PA—Johnstown Area

Johnstown, PA Support
and Action
J.D. Griffith
814-539-2341
Jeana Sweeney
814-262-8427

PA—Northwestern Area

NWPA CMT Support and Action
Group-Erie, PA
Joyce Steinkamp
814-833-8495

PA—Pittsburgh Area

Pittsburgh Support Group
Christine Miller
412-341-5749

RI—East Providence Area

Rhode Island Support Group
Meredeth Souza
401-433-5500

TN—Nashville Area

Nashville Support and
Action Group
Mark Hollingshead
615-480-2044
Bridget Sarver
615-3909-0699

TN—Savannah Area

Savannah, TN Support
and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area

Dallas Support and
Action Group
Whitney Kreps
972-989-5743

VA—Harrisonburg Area

Anne Long
540-568-8328

VA—Williamsburg Area

Williamsburg VA CMTA
Support Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Tacoma Area

Tacoma, WA CMTA
Carol Hadle
253-476-2345

*WI—Milwaukee Area

Southeastern WI CMT
Support Group
Polly Maziasz
262-439-9009
Margaret Hoepner
414-788-9628

*WI—Brodhead Area

Southern Wisconsin
Support Group
Molly Hawkins
608-921-0032

Virtual Groups

Dave Hall's Virtual Support
and Action Group

Global Support and
Action Group Community

If you would like to contact one of the support groups, you can do so by visiting www.cmtausa.org. All of the CMTA support groups are listed on the website under the CMTA Community.

If there is no support and action group listed in your area, you may want to think about becoming a support group facilitator! If you're interested, please contact Jeana Sweeney at jeana@cmtausa.org.

*New group

SUPPORT AND ACTION GROUP NEWS

(continued from page 12)

Shepherd (support group facilitator) so that you can borrow the DVDs. Gary mentioned several things in a report from the national CMTA office: STAR update, vitamin C trial, \$100,000 challenge, and Awareness Month in September. The next meeting will be on Saturday, June 11, from 11-12 AM at the Multi Generational Center in Albuquerque.

NJ – Central New Jersey Area

The group met on March 26, 2011. The guest speaker was Melissa White, Health Care Coordinator for the Tinton Falls office of the MDA. Melissa covers Monmouth, Ocean, and Middlesex Counties in NJ, and part of Staten Island, NY. Melissa spoke of the tie between CMT and Muscular Dystrophies, which fall under the umbrella of 43 different neuromuscular diseases covered by the MDA. She spoke of the local clinic, what a typical visit is like, and the wide range of services available to registered members of the MDA. Following Melissa's presentation, the group had sharing time. They spoke about upcoming events: The International CMT Consortium Meeting, Baseball Night July 19th at the Somerset Patriots game, and Awareness Month!

NV – Las Vegas

The meeting was held on Saturday, March 5, 2011. The items discussed were CMT Community Webpage, Dr. Shy's article, CMT disease subtypes and

"PARTY FOR A CURE" HELD IN RHODE ISLAND

On April 30, 2011, Meredith Souza, Support and Action Group Facilitator, held her first fundraiser at the Knights of Columbus, Bishop Hicky Council, in Riverdale, RI. The event started at 7:00 PM with approximately 120 people in attendance. There was a buffet dinner at 7:30, followed by three door prize drawings at 8:00. At 9:00, the Chinese auction began. There were 50 items to auction off. Then, the party began with dancing, karaoke, and lots of laughing. This was intended as a family event, so people of all ages were in attendance. One teenage girl said she couldn't remember having so much fun on a Saturday night. When the event was over, it had raised about \$2,000.

genetic testing strategies. They also discussed Archy Train Travels in 2010. It was a successful year for Archy, so he is hitting the road again September 15-18, at the Pahump Fall Festival. If you are in the area, stop by and take a ride on the Archy Train!

PA – Bucks County

The group met on Saturday, March 19, 2011. The group discussed stress and its effects on someone with CMT and the Awareness Month plans for the group. Two members provided information about upcoming community events at which the group could have an awareness booth. They also had a general discussion about the recent changes in the CMTA and what has been happening in their lives in relation to new braces and mobility devices.

PA – Johnstown

The Johnstown PA Support group held its bimonthly

meeting on Saturday April 23, 2011 at the John P. Murtha Neuroscience Center. Guest speaker, Jennifer Lemasters from Athena Diagnostics, educated the group about CMT genetics and genetic testing. Jennifer also discussed the costs and insurance coverage of the testing. Jeana talked about CMT night at the Altoona Curve and the STAR Program.

TN – Nashville Area

The Nashville group met on April 9, 2011. Guest speaker Jeana Sweeney from the CMTA was present and gave an informative PowerPoint presentation on Charcot-Marie-Tooth. After her



Jeana Sweeney and members of the Nashville, TN, support and action group discussed the STAR program and possible fundraising activities.

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CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		\$7	
CMT Facts III		\$7	
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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, P.O. Box 105, Glenolden, PA 19036

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.

presentation, Dr. Li from Vanderbilt University Medical Center and his nurse Robin gave a short talk on how he is working toward making his clinic a center of excellence in the Nashville area. He asked the people present to get the word out that there is now a doctor in the area that specializes in Charcot-Marie-Tooth. Facilitator Mark Hollingshead provided a large selection of pamphlets on everything about CMT. Publix grocery store in Hendersonville provided a superb selection of food and beverages for the group. The next meeting will be taking place on May 20th at Hermitage United Methodist Church.

TN – Savannah

The last meeting was held on April 9, 2011. There were two new folks that made it to the meeting. The guest speaker was Jeana Sweeney from the CMTA. She gave an update on STAR and spoke about how important it is to fundraise and raise awareness. We also had a family from the Nashville Support Group (co-leader Bridget and her husband & son). There were 20 in attendance. It was truly an exceptional meeting!

WI – Milwaukee

The group met on April 28, 2011. This was the first time this group met, and the evening was magical for all who came. They had 24 people attend the meeting. The two hours flew by, and everyone was so happy to talk to others who understand their problems. The next meeting is on the calendar for June 23rd. ★



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
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:

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

Negligible or doubtful risk:

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

THE CMTA Report

The Charcot-Marie-Tooth Association
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www.cmtausa.org

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WHAT IS CMT?

- ▶ CMT is the most common inherited neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT 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).
- ▶ CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ CMT 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.
- ▶ CMT Types 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN can now be diagnosed by a blood test.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.