WE CELEBRATE 25 YEARS: LIVING OUR VISION OF A WORLD WITHOUT CMT

THE CMTA Report

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

JANUARY/FEBRUARY
2009

Charcot-Marie-Tooth Association

OUR MISSION:

To generate the resources to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie-Tooth.

OUR VISION:

A world without CMT.

EMAIL CMTA AT:
info@charcot-marie-tooth.org

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The CMTA Welcomes New Chief Executive Officer David M. Hall

David M. Hall joins the CMTA with a background in business and government.

Hello and Happy New Year! 2009 is a new year, and for me it brings an exciting new opportunity as the CEO of the Charcot-Marie-Tooth Association (CMTA). I can't tell you how pleased I am to join the CMTA team, and how impressed I am with the staff and board members I have met over the past months.

I come to the CMTA as someone profoundly interested in healthcare issues, with a background in finance, business, and government. After graduating from the Pennsylvania State University in 1994, I started my career in Washington, D.C. as a legislative aide in the U.S. Senate and completed my Masters in Business Administration at the George Washington University.

Soon after we were married in 1998, my wife Liz and I moved back to our hometown of Pittsburgh to be near our families. Over the next 10 years my career path included corporate banking, healthcare venture capital, and most recently I served as the CEO of a technology company focusing on neurocognitive assessment and concussion management. As CEO, I created and managed relationships with clinics and physicians throughout the county. This invaluable experience will help me as I work with the CMTA's stakeholders to create a national network of clinical infrastructure that will be available to all those affected by CMT.

From a personal standpoint, my family and I know all too well what it is like to feel overwhelmed by healthcare issues and questions. On February 20, 2002 we welcomed our son Brent into the world. A few minutes after he was born, we were told Brent had Down syndrome. The next few months were filled with many uncertainties, overnight stays in the hospital, the beginning of therapy regimens, and eventually open heart surgery to repair a hole in Buddy's heart.

Today, Buddy is almost 7, and my experience as his father has been the most important of my life. I believe that being Buddy's father has in fact been the best preparation for me as I begin my tenure with the CMTA.

> I know all too well what it is like to feel overwhelmed by healthcare issues and questions.

First and foremost, my time with Buddy has taught me

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INSIDE:

DAVID HALL

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empathy for all people facing healthcare challenges. I know firsthand the heartache and frustration they and their families face as they strive to find resources to effectively treat their disability or disease. I have learned how to navigate the healthcare system and advocate for my family and my child. I know this is a challenge all of you face as well. Lastly, I now look at every setback as an opportunity and try to remain positive in the face of adversity. I will never give up trying to improve the quality of Buddy's life, and as CEO of CMTA I will use that same tenacity to not only improve the lives of those dealing with CMT, but also to one day find therapies that manage and hopefully cure this debilitating disorder.

I would like to thank you for your continued support of our national research and education initiatives. We have a compelling opportunity to promote real change for people of all ages through a robust campaign of education, awareness, and clinical care. I very much look forward to working with the CMTA community and I welcome all of your thoughts, ideas, and feedback.

Thank you.

—David M. Hall

Scooter Awarded: "A Life-Changing Gift"

*At the West Coast Conference, I was pleased to announce the award of a brand new Pride Go-Go scooter to David Capps, a resident of Martinez, CA. The scooter, made available to us through our partnership with Scootaround and the Clarence Vincent Foundation, was delivered to David in early December. Here, David describes his first experience with the scooter.—**Dana Schwertfeger, CMTA Director of Member Services***

Scootaround Mobility Services™

Clarence Vincent FOUNDATION

Unfortunately, my van has been out of commission since I received my scooter, so I have to be honest and say that my experience with it thus far has been limited. I had anticipated enjoying a lot of things, such as shopping in stores that don't provide courtesy scooters, making a trip to the pier here in town, and doing various other things I've missed out on.

As soon as my van is fixed, I will be able to do all these things, but I did have an occasion to use the scooter for the first time recently. My closest friend's mother was celebrating her 90th birthday at the church where she's been a part of the congregation for over 45 years. A friend picked me up in her rather small Honda, and because of the ease of disassembling the scooter, I was able to put it in her trunk and take it with me to the party.

The party was a lot of fun—when someone asked, "What's a positive aspect of reaching 90?" she said, "No peer pressure." But something that hadn't even occurred to me made it an enjoyable day for me. The scooter enabled me to circulate among people that in some cases I hadn't seen in years. It was liberating to be able to mingle and visit. For years, I've avoided crowds because of difficulty in walking and lack of balance. Until that day, I hadn't thought of the scooter as a social asset, but it most certainly is.

Again, I must thank the CMTA, Scootaround, the Clarence Vincent Foundation, and everyone involved in arranging for me to have this scooter. This is literally a life-changing gift. ✻

David Capps intends to enjoy the freedom his scooter will provide him.

A Fundraiser's a Fundraiser… *No Matter How Small!*

BY MARYBETH CALDARONE

I know you're out there so please take the time to let me know you're interested. How does CMT impact your life? It has a significant impact on mine and my eight-year-old daughter. We both have CMT Type 2A. I watch my daughter day to day meet with the same frustrations that I did as a child. I hope, as I sit in my wheelchair unable to walk and unable to perform the simplest of tasks with my hands, that this will not be her fate.

I continue to hold out hope that people who have the means to give will understand how important contributing NOW is to helping us find effective therapies and eventually a cure. I don't have the time to sit around and wait for something to happen, so here's what I have done:

Last November (2007), I wrote a letter explaining my story and put together a list and sent it to the CMTA for them to mail out to my "Circle of Friends." All they needed were names and addresses of family, coworkers, neighbors and friends. *You can do this too!*

In January (2008), the middle school where I work had a dress-down day and collected a donation from each of my colleagues. My brother had the same sort of event at his law firm. Imagine a bunch of lawyers in jeans? *Your place of employment can do this too!*

In April, my daughter's school had their annual variety show. This time they decided to donate a portion of the proceeds to CMT research. *Your school can do this too!*

In May, a local restaurant had a day where 20% of each bill was donated to CMT research. We passed out a letter explaining that if you ate at this establishment on this day the restaurant would donate 20% of the bill to CMT. All the patron had to do was show the waiter the letter. We all eat out. *You can find out if a restaurant in your area does this too!*

There isn't a person out there who can't make an impact.

We launched another fundraiser in May. It is called "Coins for a Cure." We put a picture of my daughter and a brief explanation of CMT on coffee cans labeled "Coins for a Cure" in local businesses and schools. My daughter's friend explained to his classmates how she struggles and how they could help by bringing in coins. That same little boy had his friends donate money instead of giving him birthday presents. *Does this move you?*

My 13-year-old nephews went door-to-door and collected money for a bike-a-thon they did. They rode 30 miles with their step dad. *30 miles!!! Someone you know can do this too!*

Several family members, friends, and neighbors have had the companies they work for match donations or make significant donations. Others have donated through family trust funds.

These are the easy things. These are things *you can do!*

However, there's more.

On July 25, 2008, we had a spectacular fundraiser. It was a dinner dance with a silent auction, live auction, dessert wars, and balloon sales. Yes, it took lots of planning, dedication, and hard work, but we did it and *so can you!!!*

Our newest campaign is called "Give the Gift of Hope." My friend and I put together a gift certificate and a plea for people to give a gift of hope in honor of someone.

There is definitely more to come. We are working on a dance-a-thon at a local dance studio. We are talking about an all-day music festival. Maybe another dinner dance will happen. Who knows…the possibilities are endless. With a little effort we *can* do this together. There isn't a person out there who can't make an impact.

Please choose to help by contacting Dana Schwertfeger at the CMTA. Dana's email is dana@charcot-marie-tooth.org. He will notify us and we *will help* you, too. ✻

Can You Get Insurance If You Have a CMT Diagnosis?

Editor's note: The idea for this column arose out of an email that Jane sent me in which she said, "Please share with the members of the CMTA that underwriters are no longer rejecting CMT patients, out of hand, for life insurance. If a CMT patient is the owner or key person in a corporation or other entity with more than ten employees, they should be able to get group disability and long-term care without medical underwriting." These tidbits made us think that a column on insurance issues might be beneficial to the readers.

My name is Jane and I have CMT. My family can trace its CMT back to Grandfather Philip. We have 27 cousins with varying degrees of disability and 9 aunts and uncles with abnormal gaits. I have two sons. One son has CMT. The other son has severe learning disabilities from a precipitous birth.

I am a speech therapist by training and taught at Rusk Institute and NYU as an adjunct instructor while running a practice in NYC. Twenty-six years ago I left my profession to start a life insurance practice. By virtue of my background, I am in a position to share important information. My therapy background coupled with the ability to teach and an edcation steeped in various neuromuscular diseases and central nervous system disorders has served me well. Add in my 26 years of getting life insurance, major medical insurance, disability insurance, and long-term care insurance issued, while at the same time utilizing special needs planning for my learning-disabled son and dealing with the special needs of my CMT son, and I am in a unique position to answer questions on how to underwrite insurance for CMT patients.

So let's start with a few basics. The most important rule to remember in fillng out an application is never to withhold information. The more information an underwriter has, the more ability he or she has to understand and give a fair rating. CMT is not a life-threatening disorder for most people. Recently, several insurance companies have recognized the fact that CMT does not affect mortality. Life insurance has become much easier to get issued. It will be issued Standard, not Preferred or Preferred Plus or Elite; which makes it more expensive, but you can control premiums by maintaining the correct height/weight ratio, by not smoking, and by purchasing it at an early age. (Buy it for your children and grandchildren when they are born, before they have a diagnosis.)

Life insurance has become much easier to get issued.

Never give more of an answer than is asked for. For example, if they ask if you have had surgery in the past 10 years, don't tell them about the surgery you had 20 years ago.

Also remember that in today's computer age, what you put down on applications follows you through the Medical Information Bureau. When you are denied insurance, or rated by an insurance company, that is also recorded. One of the things I frequently do with my clients and potential clients is to take a preliminary application so that a rejection or rating never makes it to the general computer, and, therefore, it is not available to the insurance companies years later when you might be healthier.

I will end today's article with some final ideas. A company's underwriter will reevaluate additional medical information one year after the policy is issued to make any changes. The other is that if you are rejected, you can ask your agent to ask the underwriter to go to reinsurance. Finally, you might buy your insurance right before Christmas when insurance companies are trying to close their books and get policies through to make for a more profitable year.

Don't let a family member disclose, if they have no symptoms and no diagnosis, that a genetic disorder is in their family. I had a client that asked me why he should give me a deposit on a $1 million life insurance policy. I answered "because you might have a genetic predisposition to

Progress Report on the STAR Initiative

On November 20, 2008, members of the CMTA Board of Directors met with the principle investigators working on the three projects of the STAR initiative and scientists at the NIH Chemical Genomics Center in Rockville, Maryland, where the high-throughput screening (HTS) will take place once the stable cell line currently being engineered by Ueli Suter and his colleagues at ETH Zurich is ready, perhaps as early as July, 2009.

The meeting, held to review progress thus far and to allow the investigators to coordinate their plans, lasted several hours. In addition to reviewing how the Strategy to Accelerate Research had evolved from recommendations made at the 2006 NIH Peripheral Neuropathy Conference (chaired by Dr. Steven Scherer) and meetings with the Myelin Repair Foundation and NIH scientists, each investigator presented a report on his work. Overall, it was incredibly encouraging to hear of the progress being made, especially as it relates to speeding up the search for therapeutic agents for CMT1A and other forms of CMT. Rather than completing work on one project before beginning the next, the scientists are working simultaneously to develop the cell line for use in screening the compounds in the NIH library, to create a laboratory model for further testing of the compounds identified that reduce the over-expression of PMP22, and to make sure that the reporter/promoter constructs identified in these projects are also usable in clinical trials involving humans.

Dr. Christopher Austin, Senior Advisor to the Director for Translational Research at the NIH, put this in perspective when he used a football analogy to describe the process of developing an investigational new drug (IND). Instead of starting at the 5-yard line, he said STAR will get the ball on the 30-yard line at the completion of the HTS. While that leaves 70 yards to go, the infrastructure the CMTA has already put in place will help cover the remaining distance.

Specifically, Dr. Austin said, the CMTA has already taken appropriate measures to avoid failure. This includes maintaining control over the process of developing "lead compounds" by independently funding both the initial projects of the STAR initiative and the ascorbic acid clinical trial, which has provided the framework for evaluating them. Once the viability of these compounds has been established, funding for clinical trials may be available from other sources, including the NIH and the pharmacological industry.

The meeting concluded with an opportunity to tour the HTS facility, which houses an impressive array of robotic equipment, and it was impossible not to come away with a feeling of confidence in the process after seeing how the screening will actually be performed. ✲

Editor's Note: The report on page 7 was written by Dr. Steven Scherer and provides a more detailed and scientific report of the meeting.

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some disorder." The policy was issued. He had not given me the deposit and had gone to check to see if he had the family genetic disorder for a clotting factor. He did and was taking Coumadin and I could not give him the policy.

Let me know what direction you would like to see this column take and how I may best help the CMT community. If you wish to have a personal question answered, please indicate and I will try to accommodate.

This is not a solicitation or an offer to sell insurance. Please understand that I am restricted by license to sell only in the states that I am licensed in, and I prefer to meet with my clients face to face. There is no CMT Association insurance available and there is no intention to develop any such program. I just want my knowledge and unique experience to benefit others. Please consult your own insurance advisors, attorneys, accountants, and doctors. Do not rely solely on the information in this or any future column. ✲

LIVING WITH CMT

Aids for Daily Living Make Dealing with CMT Easier

BY DANA SCHWERTFEGER, AKA MACGYVER

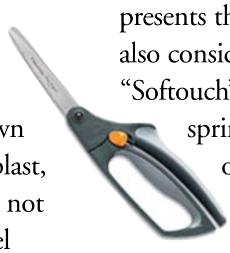
By day I'm known as the mild-mannered CMTA Director of Member Services; but after work I become MacGyver, the resourceful super spy. Well, okay, let's leave out the super spy part, but I do become an inventor of sorts when I enter my garage workshop, and my gadgets have earned me the nickname MacGyver, after the TV character from the 80's known for working his way out of sticky situations with his spur-of-the-moment inventions.

I've done everything from trimming down my AFOs to fashioning my own thumb splints from Aquaplast, but I'm also smart enough not to try to reinvent the wheel when it comes to the helpful products that enable us to overcome our limitations and perform many of the routine activities of daily life that would be impossible without one of these gadgets.

One of my favorites is something called a button hook/zipper pull. At about $7.00, the combination tool enables me to put on and button a sport or dress shirt and pull up (or down) a zipper. I still haven't figured out how to undo the top button of a dress shirt without help—and I don't mind asking for it—but zipping up my fly in a public restroom is another matter altogether. (For emergencies, MacGyver recommends keeping a large paper clip in your wallet that you can bend out and use to catch the tab of your zipper.)

For picking up and manipulating other small objects, MacGyver keeps a pair of needle-nose pliers handy, and tweezers (the kind with the extra grip) are a great addition to your travel kit. Magnetized screwdrivers are also useful—just not around your computer.

If you struggled wrapping presents this year, you might also consider a pair of Fiskars "Softouch" scissors. They have a spring-loaded handle that opens the blades after each cut, making cutting easier and reducing the wear and tear on your thumb.



All Oxo Good Grips utensils are worth their weight in gold, and Oxo also makes a jar opener that eliminates the stressful twisting motion of removing a stubborn lid. (MacGyver knows you can also easily open most jars by holding the lid under hot water for a few seconds, or you can turn the jar upside down and tap it on the counter to loosen the vacuum.) You can also use a rubber pad or damp towel to get a better grip, but no matter how you do it, the important thing is not to put so much stress on your hand that you dislocate a finger or thumb or tear a ligament.

Speaking of twisting and turning things, levers make great replacements for those old round door knobs, but if you're still dwelling in the MacGyver era, get a T-handle tool. It's great for door knobs and other things that are hard to grip and turn.

And the one place you don't want to lose your grip is the bathroom. A non-skid bathmat is essential for either the bath or shower, and don't think the rod holding up the shower curtain is a good thing to grab if you lose your balance and start to fall. In most cases, you, the rod, and the curtain will all wind up on the floor. Installing fixed grab bars is a good idea, but if you don't know what you're doing, MacGyver recommends hiring a pro and avoiding costly water and structural damage. Another option is using a portable grab bar—just make sure it has good-quality suction cups and that it is firmly attached. You won't have to drill into your bathroom walls and you can take it with you when you travel, but it's always a good idea to put some weight on a grab bar and test it before you're actually falling and grabbing it in earnest. ✻

These are just a few of the many products available to make your life easier and safer. Those pictured here are from the www.Active-Forever.com catalog, though similar products can be purchased from a number of retail and medical supply stores. However, if you visit www.ActiveForever.com or call 1-800-377-8033 and enter or mention the promo code "CMT" at checkout, you will receive a 5 percent discount and the CMTA will also receive a contribution from Active-Forever equal to 5 percent of your order.

NIH MEETING ASSESSING THE PROGRESS OF STAR

BY STEVEN SCHERER, MD, PHD

The CMTA held a meeting at the NIH Chemical Genomics Center in Rockville, Maryland, on November 20, 2008, to review progress and plans for the STAR initiative. The attendees included board members (Patrick Livney, Gary Gasper, Herb Beron, Robert Kleinman, Phyllis Sanders, Dr. Michael Shy, and Dr. Steven Scherer), a member of the STAR Scientific Advisory Board (Dr. Lawrence Wrabetz), the STAR scientists (Drs. Ueli Suter, Ned Mantei, Klaus Armin-Nave, and John Svaren), members of the Chemical Genomics Center (Drs. James Inglese and Christopher Austin) and the National Institutes of Health (Drs. John Porter and Amelie Gubitz), and members of the CMTA staff (Pat Dreibelbis and Dana Schwertfeger).

CMTA Chairman Patrick Livney and Dr. Michael Shy reviewed the history of the STAR initiative. Key points included the recommendation, from the NIH Peripheral Neuropathy Conference in 2006 (http://www.ninds.nih.gov/-news_and_events/proceedings/10_2006_NIH_Peripheral_Neuropathy_Conference.htm), to use high-throughput screening, and meetings between the CMTA board, members of the Myelin Repair Foundation, Dr. John Porter (Program Director at the National Institute for Neurological Disorders and Stroke; NINDS), and Dr. James Inglese (Deputy Director of the Chemical Genomics Center). Drs. Michael Shy, Steven Scherer, and Lawrence Wrabetz, in consultation with the investigators of the individual projects, then refined a plan that ultimately became the three current projects of the STAR initiative.

Drs. Ueli Suter and Ned Mantei (ETH-Hoenggerberg, Zurich, Switzerland) reviewed their group's progress in Project #1—to genetically engineer stable Schwann cell lines to express a form of the PMP22 gene that expresses a fluorescent "reporter" molecule. These cells lines will be used for high-throughput screening, which is an automated way of testing large numbers of compounds (even more than 1 million) for their effects on PMP22 expression. They have successfully made several cell lines that stably express their construct—a long (10,000 base-pairs) piece of the mouse PMP22 promoter, fused to the reporter ("green luciferase"). These cells could be screened now according to Dr. James Inglese, but Drs. Suter and Mantei are trying to make further refinements that will enable non-specific toxic effects of the compounds used in the high-throughput screen to be evaluated.

Dr. Klaus-Armin Nave (Max-Planck-Institute of Experimental Medicine, Goettingen, Germany) reviewed how he and his colleagues generated a rat model of CMT1A, and how progesterone antagonists were used to decrease PMP22 expression, thereby improving motor function and diminishing the severity of demyelination in these rats. In Project #2, his group will generate transgenic rats that express a very large (77,000 base-pairs) fragment that contains the entire human PMP22 gene. The human PMP22 gene will be modified to introduce a reporter ("green luciferase") in place of part of the PMP22 gene.

Dr. John Svaren (University of Wisconsin) reviewed the data that a combination of binding sites for two different transcription factors, Sox10 and EGR2, regulate the expression of several myelin-related genes. In Project #3, his group has found two such Sox10/EGR2 binding sites in the human PMP22 gene, and has evidence that at least one of these sites is active in regulating PMP22 expression. Continuing analysis of the human PMP22 gene is key for properly designing the next generation of PMP22 promoter/reporter constructs.

Dr. James Inglese (Deputy Director of the NIH Chemical Genomics Center) and Dr. Christopher Austin (Senior Advisor to the Director for Translational Research) outlined the pathway for developing new drugs. According to this outline, the STAR initiative has done the first step, identifying the target (PMP22 overexpression), and is currently engaging the next step—finding compounds that properly affect this target (diminish PMP22 expression). Typically, this is an iterative process that requires refining the "positive hits" found in a high-throughput screen to generate an active "lead compound" with the proper features to be used as a drug in humans. This refinement will likely benefit from the approach used at the Chemical Genomics Center—they use dose-response curves (they look at the effects of compounds over a range of concentrations), and use this data in compiling and analyzing "positive hits" of the high-throughput screen.

The next step is testing the lead compound(s) in appropriate biological models, like myelinating co-cultures and animal models with PMP22 overexpression; historically, ~90% of compounds have failed this step. These initial steps, however, are relatively cheap and fast compared to the subsequent clinical trials involving human subjects, which are expensive and have a high failure rate (~90%). Repurposing already approved drugs can potentially bypass much of the time and expense of clinical studies, as these drugs have already been shown to be safe in humans. The Chemical Genomics Center has been putting together a chemical library of drugs that have been approved in the US or abroad (Britain, Canada, Japan, and other countries) for just this reason.

Dr. John Porter (Program Director at the NINDS) emphasized that it is important to preselect criteria for preclinical trials (endpoints, randomization, properly powered studies), and to consider outsourcing preclinical studies to a professional preclinical trial organization. He will continue to advise the CMTA of granting opportunities as the research develops.

Dr. Michael Shy (Wayne State University) reviewed the history supporting the use of ascorbic acid to treat CMT1A. There are three ongoing clinical trials, one in North America (supported by the CMTA and the MDA) and two in Europe. All three trials are using the CMT Neuropathy Score as an endpoint; this should facilitate the comparison of the data from the trials. Dr. Shy also helped to establish six CMT Centers of Excellence (funded by the CMTA and the MDA) for the purpose of having CMT patients evaluated by peripheral neuropathy specialists and recording the resulting clinical data in the CMT database. These data will also be useful in generating a list of eligible participants for future clinical trials. ✻

The CMT "Circle of Friends"

Although we credit the efforts of Susan Elmer, Elizabeth Ouellette, and the Berons with giving us the foundation for the Circle of Friends program, we don't include the money they have raised in the program's official total, which has grown to $169,974 since it began in October of 2007. But if we did, the total would more than double to just over $350,000.

That's pretty amazing, given that when Susan Elmer first wrote about opening her address book for the CMTA in the summer of 2005, she set the rather modest goal of raising $5,000 in three years.

Just imagine how much closer we could be to finding therapies and cures if more of you got involved!

To learn more about starting a Circle of Friends call us today at 1-800-606-2682, email us at cof@charcot-marie-tooth.org, or visit us on the web at www.charcot-marie-tooth.org/cof.

Working together, can create a world without CMT.

The CMTA Circle of Friends...
Working Together for a Cure!

Dave's Marathon Swim

Mr. and Mrs. Timothy Dye
Mr. Will Freeman
Mr. and Mrs. Erik Simpson

Grace's Courage Crusade

(Includes Grace's Race and Gifts of Hope)

Mr. and Mrs. Alfred R Abbatiello
Mr. and Mrs. Milton S. Abrams
Ms. Lisa Ackerman
Albert Ranallo Plumbing & Heating
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Dear Circle of Friends,
Our heartfelt thanks for each donated dollar as nothing could mean more. The day will come when we have answers for the cure and treatment of CMT and all of you have a part in being responsible for that. God will smile on each of you. Thank-you from the bottom of our hearts.
Love and Prayers, Carol and Jim Ris
and son Ryan Whitman

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SOCIAL SECURITY TO BE THE FIRST GOVERNMENT AGENCY TO USE NATIONWIDE HEALTH INFORMATION NETWORK

Beginning in early 2009, Social Security will be the first government agency to utilize the Nationwide Health Information Network (NHIN) and begin to receive medical records for some disability applicants electronically through the NHIN gateway.

Through the NHIN, Social Security will have instantaneous access to medical records. This will significantly shorten the time it takes to make a disability decision and make the process more efficient. The NHIN will help ensure records are received timely by making it easier and less labor-intensive for medical professionals to submit records.

Social Security is working with MedVirginia, the North Carolina Healthcare Information and Communications Alliance, and Kaiser Permanente to implement the NHIN. In early 2009, the first real-world use of the system will begin between Social Security and MedVirginia.

The NHIN is an initiative of the Department of Health and Human Services and is supported by multiple government agencies and private sector entities. Please go to www.hhs.gov/healthit for more information. ✻

Memories of a Support Group Leader

BY ROSEMARY MILLS

I was the first support group leader in Minnesota. I'm not saying this to brag, but to encourage others to start one in their state. I live in a small community. The town I held my meetings in is six miles from our home and boasts a population of 3,500. I held meetings at our church because it is handicapped accessible. My husband and I paid a small price for the room we met in and considered it an offering to our church and a donation to help the CMTA reach people.

When I was first diagnosed with CMT, I was 50. I'm now soon to be 63 and have decided to retire from being a support group leader, but not from supporting those who have CMT. We have another support group in our state now, and it's headed by a man, younger than I, who came to many of our support group meetings. He was encouraged by Dr. Gareth Parry to start a group in the Minneapolis-St. Paul area. More people can be reached there and it was always my dream to reach as many people with this disease as possible. Dr. Parry graciously asked me if I minded that Bill was starting a new group and I said, "NO." I was excited and overjoyed to see the large number of people at the first meeting there. I have received an award from the MDA, for outstanding achievements and demonstrating success in overcoming the challenges of a neuromuscular disease. I don't feel I did quite all that, but I appreciate being nominated for the award.

When I was diagnosed, I didn't know about the CMTA and the doctor who diagnosed me apparently didn't either. This was in Wilmar, MN. I found out that their medical library had no information on the disease, either. Of course, they do now, because I gave it to them as I received it from the CMTA.


Rosemary is retiring as a group leader but not from helping those with CMT.

Soon after my diagnosis, I was in my local pharmacy and I mentioned to the pharmacist that I had been diagnosed with CMT. He seemed familiar with the disorder, so I asked him where he had learned about it. He said it was when he studied at the University of Minnesota. I went to my local librarian and asked her to get me information on CMT from the University of Minnesota library. In no time at all, she had the information and the most important part was the information on the CMTA. I subscribed to the newsletter right away. I still wasn't comfortable with having the disease, but I wanted to learn all I could. I saw that the CMTA had one contact person listed for the state of Minnesota, so one day, when I was feeling brave, I called her. I told her my story and she told me about doctors and about riding a stationary bike. Apparently I got emotional and she said, "misery loves company." That wasn't what I felt or what I needed to hear that day, so I decided to volunteer to be a support person for the CMTA. I hoped I could help others feel their way through the disease and I knew they would help me and we could learn from each other.

About a year after I started being a support person for the CMTA, I received a letter from them asking if I would start a support group. I didn't know if I could do it, but they said they would help me. Ardith Fetterolf was the person in charge when I started my group and she sent all the things that kept the group going.

At my first meeting, I had only four people in attendance…myself, my brother, his wife, and the speaker, a physical therapist. I hadn't realized that the CMTA would send out a mailing and invite people to my group. They did that and the next meeting I had about a dozen people. That's about what I have continued to average over the years. At my third meeting, I decided to ask people to tell their CMT story. It was a wonderful experience for us all. I continued this practice. If you were new, you told your CMT story. Otherwise, you shared what had happened to you since the last meeting.

This being Minnesota, we voted to meet in the spring after the ice and in the fall before the snow. Most of my people came a distance, traveling two to three hours to attend.

Dr. Parry blessed us with his presence two different times through the years. When he came, the group would swell to 20-25 people. One meeting, we had a young couple from Chile come from Chicago. They had come on visas to the US to learn more about the disease. Both the young man and his brother had the disease. I know the CMTA worked with them and I hope our group helped them, too. My goal for every meeting was that everyone would go away with some new knowledge or understanding, or just feel better about themselves and the disease.

I've mentioned some of the highlights of the years of being a support group leader Others were a trip to St. Louis and meeting Ann Beyer, then Chairman of the CMTA Board and a delightful person. She's gone now, but not forgotten. In St. Louis, I met other support group leaders from around the country. One of my warmest memories was when a man who attended one of my meetings made a gift in my honor to the CMTA.

I've decided to retire from being a support group leader but have agreed to be a contact person for the CMTA. So, if you want to laugh or cry about the disease, give me a call and you'll find a listening ear and an understanding heart. ✻

CMT IN THE NEWS

Southern Methodist University Mustang band drummer Ricardo Leon went from performing at halftime of football games to rock star status overnight. Drumming since he was 10 years old, Leon is not the usual marching drummer in the Mustang band. Leon was born with Charcot-Marie-Tooth Disease, a form of neurological disorder under the heading of muscular dystrophy. Scoliosis has him drumming from the seat of his wheelchair. Leon's drumming skills were required when his "Make a wish request" was granted at the beginning of December. He said the Make a Wish Foundation provided everything, including putting Leon up in a presidential suite in his Denver hotel. He had asked to play with Coldplay, the alternative rock band. The jam session took place at the Pepsi Center just blocks from his hotel, but Leon said that the foundation still provided a limousine for the short trip. Leon said when they first got to the Pepsi Center he was taken on stage and was admiring the band's instruments when the foursome came on stage.

Ricardo Leon got his wish to "jam" with Cold Play.

"All day before I got there I was extremely nervous, I mean I was about to meet one of the biggest rock bands in the world," Leon said. "Once they got on stage I forgot they were rock stars, and they seemed really normal; it was so surreal that they were just talking to me like a member of the band." After some introductory chatting, lead singer Chris Martin asked Leon which song he wanted to play first and was surprised to find his choice "Politic" was the favorite of Martin. After finishing the song, Leon thought his wish was filled and the jam session with one of his favorite bands was over, but soon after the song ended Martin turned and asked what he wanted to play next. The band went on to play some of their bigger hits with Leon including "Scientist," and "Chinese Sleep Chant," Martin's favorite song from the band's most recent recording Viva la Vida. Leon was provided tickets to the night's concert and came back to listen to his jam session mates of a few hours prior. He said that throughout the concert lead guitarist Jonny Buckland would wave at Leon after songs; and lead singer Martin gave him a shout out during the last encore song. Leon is grateful for his time he got to play with his favorite rock band, and is happy to find that there are still good people that would never be too famous to help a guy like him. ✻

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Donations made in honor of Stanley Gumson's 80th Birthday will appear in the 2009 March/April issue of the newsletter.

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:______________________________
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Occasion (if desired):
☐ Birthday ☐ Holiday ☐ Wedding
☐ Thank You ☐ Anniversary ☐ Other

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Send acknowledgment to:
Name:______________________________
Address:______________________________
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Amount Enclosed:__________ ☐ Check Enclosed
☐ VISA ☐ MasterCard ☐ American Express
Card #______________________________
Exp. Date ______________________________
Signature ______________________________

Gift Given By:
Name:______________________________
Address:______________________________
____

Parents: There Is Hope

BY JEANINE SKOOG

My son was diagnosed with foot drop (which is a neurological disorder). The doctors say that puts him in the category of having CMT.

I knew nothing about foot drop. My son Mark was falling a lot in school and finally told me about it near the end of the school year. My husband and I took Mark to the doctor, where he was diagnosed with foot drop. The doctor could see this as soon as he walked. He always walked on the balls of his feet as a baby and we thought nothing of it. He also walked with a big gait, picking up his feet very high. The bigger he grew, the more he could not hold up his big frame, so he kept falling. (He is a big kid—6'2", 200 pounds and only 14 years old.)

We then went to Children's Hospital and had a lot of testing done. Although the tests did not show why he had foot drop, the doctors knew that is what he had. The doctors said if Mark was a smaller kid they might not have detected the foot drop so early, but since he is a big kid he couldn't keep up his big frame.

Meanwhile we had to find something for Mark to use to help him from falling. We tried what they call the "Easy Gait" brace made by Walk Right, Inc. in Waxhaw, NC. The brace pulled Mark's foot up just enough so he didn't fall. It worked but it was only a temporary fix. The doctors also wanted Mark to wear a removable cast only at night to help him keep his foot in the upright position while he slept. That really didn't work.

The Easy Gait brace worked when he wore it, but the doctors said it would only work for a short time and Mark's foot drop would get worse They said the best thing for Mark would be to have surgery. The surgery would consist of taking a tendon from the side of his foot and putting it on top of his foot so he would be able to pull his foot up when he walked. It also consisted of lengthening his Achilles tendon by 2 inches. His total stay in the hospital was two days. He was in a cast for 10 weeks—the first 6 weeks in a cast putting no pressure on the foot, then 2 weeks in a removable cast, still putting no pressure on it, then in a walking cast for two weeks.

I think 10 weeks in a cast is a small price to pay for the successful outcome of the surgery. Mark needed surgery on both feet. He had the first surgery last year and the other surgery this year in July. The surgery on the first foot was a success. Mark has not fallen at all. He picks it up enough to walk normally without falling. Mark still has his cast on from the July surgery but is expected to have it off by the end of September. The doctor said the surgery was very successful.

I would definitely recommend this surgery to anyone who has foot drop who is in my son's situation. I would also highly recommend his doctor at Children's Hospital in Boston. He is outstanding in what he does. He not only does the surgery but is a caring doctor who works in helping all involved in the casting department, the therapy department, and the nurses. I am so thankful to have found a doctor like him.

I want parents to know who have children with foot drop that there is help out there. My son will soon be playing golf again this fall and can't wait to go snowboarding.

My message to parents is: Have faith. Do not give up. There is hope. ✻

There Is Hope…

Hi. My name is Mark. I am 14 years old. I have a foot dysfunction they think is CMT, but they don't really know for sure. It all started when I was falling a lot in school and in my backyard.

I went to a doctor and he said I had foot drop. I tried a bunch of supporting braces, but only one worked—the "easy gait" brace. I used the brace for a while, but I was still having problems.

My doctor said if I waited any longer to correct my foot, my hips and back would be bad. So he recommended surgery on my Achilles tendon and a tendon transfer from the side of my foot to the top. He said it's the only good fix for what I have.

It was a pain in the neck going through all the casts but at the end it was all worth it. I can play sports with no restrictions. I can do anything I could do before and more. I highly recommend this surgery to anyone who has this problem.

The one place they treat you right and do a good job is Childrens' Hospital in Boston. They successfully did the surgeries, and the doctors and nurses are very nice. Now, after 10 weeks, I am already on the golf course!

—*Mark Skoog*

When We Found Out

BY HERB BERON

"The blood test came back positive—your daughter has CMT." These were the words told to us by our daughter's physiatrist. Julia had developed physically later than most children, not walking until after her second birthday. After a year of in-home physical therapy, we were strongly encouraged to take Julia to a prominent local physiatrist (doctor specializing in physical medicine and rehabilitation). We had received *so* many different opinions from our various doctors, and we really felt that we needed to put our trust in one doctor (who could help us to "quarterback" her therapy/treatment schedule). It was this doctor who had ordered the blood work after seeing the results of her EMG.

The Beron family celebrates Julia's 9th birthday together.

When we first received the diagnosis, we didn't really know what to think. What is CMT? Is it life-threatening? Can it be cured? There were so many questions. Looking back, I remember that our heads were spinning and that we didn't know exactly what to think. On one hand, we were scared and saddened to hear that Julia did indeed have a disease; maybe subconsciously we were hoping that she was just physically "slow." On the other hand, we were indeed relieved that there was a specific diagnosis for her. For us, this was of utmost importance—as we could now begin to ascend the steep learning curve about her disorder. We read tirelessly as much information as we could (both on the Internet and in the literature we received from the CMTA). I also consulted with an old college friend who is now a prominent orthopedist. I specifically remember him telling me, "If I had to pick one disorder for my child to have—it would be CMT." There was something very soothing about hearing those words.

My wife and I have always believed that for check-ups and garden-variety sicknesses (i.e. ear infections, colds, etc.) that our children come down with, we would use our local pediatrician. However, for more serious and more unusual issues, we have always sought out the *best* specialists. The search is never an easy process. My wife and I did extensive research, spoke to countless physicians, and eventually found the specialists who had the most experience dealing with CMT, and, importantly, in whom we had the most confidence and trust. We now had to put a plan in place for Julia. Besides her semi-annual visits to her physiatrist (who was located at the same facility as her orthotist), we began a regular routine of appointments with her physical therapist, neurologist, and orthopedist—as her foot was getting worse and we knew that surgery was an eventuality. Julia's surgery (tendon transfer, heel cord lengthening) was performed in October, 2008, and she is now well on her way to recovery.

The CMTA has made enormous strides in the past several years in terms of increasing the flow of information to patients, and there is real hope that scientific breakthroughs can occur in the not-too-distant future. I would encourage all patients (and their families) to do their best to keep up with all of this information—as the support groups, medical advisory commentary, and general news are all invaluable input. To steal a phrase from one of my daughter's favorite songs, I truly believe that "we're all in this together"; and with the work currently being done, we have the wherewithal to make a difference not just for this generation of patients, but for generations to come. ✻

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STUDY PARTICIPANTS NEEDED

CMT RESEARCH STUDY AT THE JOHN P. MURTHA NEUROSCIENCE AND PAIN INSTITUTE

The John P. Murtha Neuroscience and Pain Institute in Johnstown, PA is currently recruiting subjects for a study using Coenzyme Q10 (CoQ10) for CMT subjects with symptoms of pain, weakness and fatigue. After supplementation with 600 mg of CoQ10 a day, changes in weakness, fatigue, and pain will be monitored and compared with blood levels of the CoQ10. 300 mg of CoQ10 as a chewable wafer are taken twice a day for 6 months.

CoQ10 is an integral part of the electron transport chain in the mitochondria, or the energy production centers of cells. There has been expanding interest in the potential benefits of CoQ10 supplementation on a variety of neuromuscular diseases, some of which involve mitochondrial dysfunction such as CMT. Daily supplementation may have cytoprotective and neuroprotective properties, which may improve symptoms of weakness, fatigue, and pain, as well as increase quality of life among persons with CMT.

For more information, this study can be found on the clinicaltrials.gov website, using search words CoQ10 or CMT, or contact Janet Goodard, RN, BC, BSN at 814-269-5288, e-mail at jgoodard@conemaugh.org, or Dr. Sharon Plank at 814-269-5204, e-mail at splank@conemaugh.org.

SUPPORT GROUP NEWS

California – San Francisco
The group met on January 17, 2009, at the San Mateo Library's Laurel Room. The featured speaker was Beth Weiss, Hand Therapist and Occupational Therapist. Beth attended the Palo Alto patient/family conference and offered to inform people about how to manage the CMT hand.

Colorado – Westminster
The group met at Capabilities, on January 10, 2009. The guest speaker was Christina Neal from the MDA. She answered questions about the MDA's function and the support they provide for CMT patients. Everyone was reminded about the CMTA's free membership for the 25th anniversary year, which concludes in May, 2009. The next meeting will be February 28, 2009.

Florida – Orlando Area
Jeff Miller held his first meeting on February 7, 2009 at Ability Rehabilitation, Oviedo, FL. To contact Jeff, call 407-579-1005 or email jeffmillerDPTMO@gmail.com.

Massachusetts – Boston
The New England group met on January 24, 2009, at the Beth Israel Deaconess Hospital in the Trustman Boardroom. The presenters were Dr. Naven Duggai, CMT foot and ankle specialist, and Mike Bonnar C.O., from the National Orthotic and Prosthetics Company. The men discussed the latest cutting-edge orthotics, bracing, and other supportive devices available to assist CMT patients. Leader Mark Boxshus also discussed the new fundraising project, a CMTA cookbook.

Michigan – Ann Arbor
The group met on January 31, 2009, from noon to 3 pm. The presentation was on preimplantation genetic diagnosis (PGD) and the presenter was Dr. Jonathan Ayers of IVF Michigan. Each attendee brought a snack or dish to pass around. Drinks were provided. The meeting was held at the UA Great Lakes Regional Training Center in Ypsilanti. For more information, contact Tammy Mayher at a2.cmtgroup@yahoo.com.

New York – New York City
The group met on January 10, 2009, at the New York University Medical Center. The group heard a presentation from Alan Jordan, who specializes in massage therapy for people with neuromuscular diseases. He discussed what people should expect at a massage session and what contraindications there might be for a patient with CMT. Lunch was provided.

Oregon – Portland
The group met on January 8, 2009. The gathering was very informative, with presentations by Dr. Zarelli, a neurologist, and Nancy Richman, a physical therapist. Both presenters emphasized the importance of maintaining flexibility with exercises which they demonstrated. The next meeting is tentatively scheduled for April 7, 2009.

Pennsylvania – Johnstown
The group held its annual Christmas party on Saturday, December 30, 2008. Jon Goodard and Sharon Lehman, from the John P. Murtha Neuroscience and Pain Institute, discussed their CMT research. Their study is about the effects of Coenzyme Q10 on CMT and they are currently recruiting patients. J.D. Griffith presented a brief program on the CMTA's STAR initiative. The food was wonderful and everyone had a good time.

Pennsylvania – Philadelphia
The next meeting will be on February 28, 2009. The program will concern shoes and the basic guidelines for buying shoes. The speaker will be Maureen Donohoe, PT, DPT, PCS, from the A. I. du Pont Institute, who recently was a presenter at the Muscle Summit in Wilmington, DE. Both patients who wear orthotics and patients without will learn some important facts about shoes, comfort and function.

Tennessee – Savannah
The new group met on January 31, 2009, at the East End Sports Complex in Savannah, TN. The guest speaker was Justin Rowe, a physical therapist. Not only did guests learn important information about staying active and healthy, but they were treated to a spaghetti dinner, as well. ✻

NEW GROUP FORMING
A new support group will be forming in the Pittsburgh, PA, area in the spring. The group will meet on April 25, 2009, at the St. Simon & Jude Church Hall in Greentree, PA. The new leader will be Chris Miller. You can call her for more information at 412-341-5749.

Libby Bond is willing to answer questions weekdays after 7 pm and on weekends for patients living in Missouri. Her number is 479-752-7112.

CMT Support Groups

Support Group Liaison: Elizabeth Ouellette, 1-800-606-2682, ext 107

Alabama—Birmingham
Contact: Dr. Dice Lineberry, Calls only
205-870-4755
Email: dkllrl@yahoo.com

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: Sutter Medical Center of
Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Louise Givens,
707-539-2163
Email: ladyblue123@att.net

California—San Francisco Bay Area/Santa Clara County
Place: San Mateo Library
Meeting: Quarterly
Contact: Elizabeth Ouellette,
650-248-3409 (C)
650-559-0123 (H)
Email: elizabetho@pacbell.net

Colorado—Westminster
Place: Capabilities, Westminster, CO
Meeting: 10 AM – noon, Last Saturday of
every other month
Contact: Diane Covington
303-635-0229
Email: dmcovington@msn.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital,
St. Petersburg, FL
Meeting: Second Saturday
of Feb, May, Nov
Contact: Lori Rath, 727-784-7455
Vicki Pollyea
Email: rathhouse1@verizon.net
v_pollyea@mindspring.com

Georgia—Atlanta Area
Place: Cliff Valley School Library
2426 Clairmont Rd, NE
Meeting: Third Saturday of every
other month
Contact: Sue Ruediger, 678-595-2817
Email: susruediger@comcast.net

Illinois—Chicago Area
Place: Peace Lutheran Church,
Lombard, IL
Meeting: Quarterly
Contact: Alan Pappalardo,
800-606-2682, ext. 106
Email: alan@charcot-marie-tooth.org

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

Massachusetts—Boston Area
Place: Beth Israel Deaconess
Medical Center
Meeting: Bi-monthly
Contact: Mark Boxshus, 781-925-4254
Email: MarkB_CMTANE@mac.com

Michigan—Ann Arbor
Place: Great Lakes Regional
Training Center
Meeting: Monthly
Contact: Tammy Mayher
Email: a2.cmtgroup@yahoo.com

Minnesota—Benson
Contact: Rosemary Mills, calls only
320-567-2156
Email: rrmills@fedtel.net

Minnesota—Twin Cities
Place: Call for location
Meeting: Quarterly
Contact: Bill Miller, 763-560-6654
Email: wmiller758@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: carole.haislip@sbcglobal.net

Nevada—Las Vegas
Place: West Charleston Library,
6301 West Charleston Blvd.
Meeting: Email for dates 1-3 PM
Contact: Mary Fatzinger
Email: cmt_suppgroup_lvnv@yahoo.com

New York—Greater New York
Place: NYU Medical Center/
Rusk Institute, 400 E. 34th St.
Meeting: Second Saturday, 12:30-2:30 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
Email: amtcp36@aol.com

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Children's Hospital
Meeting: Bimonthly, Jan, March, May,
Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 201-224-5795
Eileen Spell, 732-245-0771
Email: craneomatic@verizon.net
espell@optonline.net

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Raleigh, NC
Meeting: Quarterly
Contact: Susan Salzberg,
919-967-3118 (afternoons)
Email: nabosmom@gmail.com

Ohio—Greenville
Place: Brethren Retirement Community
Meeting: 4th Thurs. of
April, July and October
Contact: Dot Cain, 937-548-3963
Email: Greenville-Ohio-CMT@woh.rr.com

Oregon—Portland Area
Place: 1008 NE Division, Suite B
Gresham, OR
Meeting: Quarterly
Contact: Debbie Hagen
Email: hagen84@yahoo.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@roadrunner.com

Pennsylvania—Philadelphia Area
Place: CMTA Office, 2700 Chestnut Pkwy.,
Chester, PA
Meeting: Bi-monthly
Contact: Pat Dreibelbis
800-606-2682
Email: info@charcot-marie-tooth.org

Virginia—Harrisonburg
Place: Sunnyside Retirement
Community, Sunnyside Room
Meeting: Bi-monthly, Second Sat. 1-3
Contact: Anne Long,
540-568-8328

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

COMING SOON: Baltimore, Maryland

ASK THE DOCTOR

Dear Doctor,

Because of pain, my doctor had me take some blood tests. He now believes I have polymyalgia rheumatica. I see a rheumatologist on Friday. I would be on a low dose of prednisone for 1-2 years. I have taken one 10-mg tablet per day for the past 4 days and it does seem to help the pain, although I have had a headache all afternoon today. What is the feeling about prednisone for such an extended period of time with my CMT?

The doctor replies:

The positive and negative effects of long-term prednisone are too complex to discuss in detail, but this steroid is used to treat many different conditions. It can suppress a number of disorders that cause muscle or nerve pathology, but does not likely affect CMT or nerve function directly. Longstanding use can affect muscle size and strength. This muscle effect is one that must be weighed when deciding on use. The effects depend on the dose and the risk is lower with lower doses.

Dear Doctor,

I'm a pediatrician and would like to know if there is any formal recommendation or contraindication to giving an 11-year-old boy with CMT his booster immunizations, including the Tdap(Boostrix) and Meactra (meningococal) vaccines. I gave him his flu shot, but because CMT is a progressive disorder of the peripheral nerves, I gave a second thought to the Tdap and Meactra. Is there any recent literature on the safety of giving these? I am having trouble finding a definite answer so I thought I would check with you.

The doctor replies:

The concern is very prominent in many patients' minds, but there is no clear problem with any of the specific vaccines. There is a very small and controversial risk in the general population of triggering an immune neuropathy following vaccination, but the numbers are very similar to spontaneous rates. There is no compelling scientific evidence to support withholding recommended vaccinations and there is certainly clear evidence of the benefits of most of the contemporary vaccines, including the Tdap.

Dear Doctor,

I have tested with high B6 levels. My CMT is progressing. I don't take B vitamins except what is in a multiple vitamin. My neurologist told me to stop the multivitamin. Do other patients with CMT have high B6 levels? Is there any harm in taking 5-HTP (hydroxytryptophan) or 1-theanine? These were prescribed by an MD.

The doctor replies:

Both are good questions. There are some patients that have elevated B6 levels even though they only take a multivitamin that contains a small amount of B6 (1-3 mg). We normally associate a high dose with at least 100 mg, if not 200 mg or more. The significance of a mildly elevated blood level is uncertain, but most consider it prudent to avoid extra B6, if possible. The hydroxytryptophan issue is much more complex. There was an epidemic of muscle/nerve pathology in the mid-90's with L-tryptophan that traced back to a contaminent in one manufacturer in Japan. Hydroxytryptophan is a normal brain chemical that actually relies on B6 for one reaction. The safety of this compound has not been challenged, however. I have no information on the effects of theanine, but I know of no problems with weakness or neuropathy.

Dear Doctor,

My daughter has just found out that she is pregnant. She takes Neurontin for pain from her CMT and is worried that it might affect the fetus. Can you tell us if there is a problem in continuing with Neurontin?

The Doctor replies:

Neurontin is in the common pregnancy classification grade C. This grade means that there is insufficient or unreliable information or studies about its safety in pregnancy. In other words, there are no data indicating that the medication is either safe or dangerous to the fetus. About two thirds of all medications fall into this class. The best approach is to weigh the small risk of using the drug against the treatment benefits. You should consult with your prescribing doctor to help decide how much the Neurontin is helping your condition and the consequences of stopping it. ✻

WRITE TO US!

Pat Dreibelbis, Editor,
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Dana Schwertfeger, Director of Member Services
dana@charcot-marie-tooth.org

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

The 2008 West Coast Patient-Family Conference is now available on DVD!

The two-DVD set has more than five hours of video from the conference held in Palo Alto, California on November 8, 2008.

In addition to Dr. Michael Shy's presentation on the CMTA's Strategy to Accelerate Research, the set features presentations on CMT and foot care, genetics, orthotic management, and physical therapy.

The cost is $15 for members and $20 for non-members.

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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.

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-Flouuracil
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)
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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