



**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.

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EMAIL CMTA AT:
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NCAA Coach of the Year Joe Paterno Helps Raise Awareness of CMT Disorder

The Charcot-Marie-Tooth Association will kick off its campaign to raise awareness with Joe Paterno-voiced public service announcements. The Penn State Nittany Lions coach will soon hit the radio airwaves to help raise awareness of Charcot-Marie-Tooth disorders.

Often mistaken for other ailments or undiagnosed, CMT is the most common inherited neurological disorder, affecting one in every 2,500 people. The condition, for which there is no cure, affects the peripheral nervous system, causing muscle deterioration that can lead to problems with balance, walking and fine muscle control.

"I'm used to working with athletes at the height of their physical ability," Paterno says in the announcement. "But I've learned about a serious illness that limits the activities of thou-



Joe Paterno coached the Nittany Lions to an outstanding 2005 season.

sands of Pennsylvanians. The problem is that most people haven't even heard of Charcot-Marie-Tooth disorder."

Charles F. Hagins, Executive Director of CMTA said, "We enlisted Coach Paterno's help in the campaign because his work involves encouraging people to perform at their peak levels. Because CMT is often mistaken for something else and little is known about it, it's important to reach as many people as possible. Because Coach

Paterno is so well known and respected in Pennsylvania, the CMTA is very grateful Coach Paterno could lend his voice to assist in this effort."

"The Pennsylvania General Assembly earmarked \$250,000 in the 2005-06 state budget as a testament to the need for better understanding of CMT," Hagins said. "We hope to secure more funding in the next fiscal year, so that we can continue to increase awareness of this not-so-rare disorder."

In addition to creating general awareness of the disorder, a secondary reason for the radio campaign in Pennsylvania is to encourage Cambria County residents to complete the survey prepared by Conemaugh Health Systems. The study will be the model for an epidemiological study which could then be used throughout the state and country. *

Funding Research Through Awareness—A Personal Journey

BY ELIZABETH OUELLETTE

In the past, I have written about the joys, the struggles, and the overall experiences of parenting a child with CMT. After speaking with other parents of CMT

kids, many would agree that raising a child with different abilities, let's take a progressive neuro-muscular disease as an

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FUNDING THROUGH AWARENESS

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example, can not only be a tough and daunting task, but truly equivalent to working a full-time job!!! However, in light of all the current research findings and the many scientists avidly studying therapies, I often reflect on what I could do on a personal level to make a difference, spread awareness, and participate in funding these promising projects.

Just recently, I happened to pick up the July/August 2005 CMTA newsletter and flipped to the article on fundraising by Susan Schueler Elmer. I was moved by the courage and willingness of just one woman to raise money for CMT-related research by writing her friends and community using her personal address book and holiday mailing list to ask for support.

She continued by writing, "Imagine if every person who gets the CMT newsletter opened his or her address book for CMT research!" This is exactly what I did. I imagined, I thought, I reflected, and I imagined a little more. Then, without prior warning, thoughts began to stream from my brain and the ensuing adrenaline gave me a burst of energy with which I moved into action.

Using the advice given by Susan, I drafted a personal appeal letter by explaining CMT, describing the effects this disease has on Yohan (now 13!!!) and revealing some of his future goals (to climb California's Mt. Whitney one day with his dad). As I wholeheartedly believe in the research efforts funded by the CMTA, I sent this letter to family, friends, and those I know well

in the community asking for monetary contributions so that Yohan and all people affected by CMT might benefit from

advancements within the medical world.

My original goal was to write to 200 people, but suddenly realizing I did not even know 200 individuals, I swept my family up in the excitement. Thanks to my mom and dad, my



Yohan Bouchard

mother-in law in France, and other family members, who all sent between 10 and 25 letters each, I attained my objective of 200 people and exceeded my original goal of raising \$10,000!!!! I am still amazed and deeply thankful to my family for their good will, as, without them, I could not have reached my targets. Moreover, I am profoundly moved by the generosity of my donors, who contributed to a

SEE PAGE 10
for gifts in honor
of Yohan Bouchard.

Board of Directors' Awareness Activities

The Board of Directors of the CMTA has been active in lobbying the state of Pennsylvania and the federal government for funding to raise awareness and to increase our research initiatives. One of the projects being funded by the Pennsylvania Awareness Grant is a census of CMT patients and families in the state. Another project arising from the Pennsylvania grant is the rewriting of the handbook on Charcot-Marie-Tooth disorders. First written as a physician's guide in 1995, the

new edition will be targeted at educating patients on tests, therapies, and genetics of the disorder. Another exciting outgrowth of the Pennsylvania grant is the Hershey, PA, patient-family conference which will occur on May 24th. At lunchtime, the attendees will be bused to the Capitol in Harrisburg, where a rally will be held to recognize the legislators who were instrumental in getting the \$250,000 grant for the CMTA and to impress legislators with the need to continue that funding for next

year. *(See registration form on page 7.)*

All of these projects have been accomplished with the help of Duane Morris Government Affairs, LLC, through the efforts of board members Jason Steinbaum and Gary Gasper.

Also in May, the Board of Directors will hold their quarterly meeting on Capitol Hill in Washington, DC. During their stay in Washington, the board members will host a reception for key federal legislators and CMTA area members. *

cause so dear to my heart.

Lastly, this campaign did much more than raise money and spread awareness for CMT. It served as a tool to share bits of our lives with those who mean the very most. In our daily comings and goings, my husband and I may reference Yohan's CMT in conversations with friends and family but do not make an issue of explaining all the intricate and fine details of this neurological disorder. I do believe that our loved ones desire more information, but bringing up the topic, at the right time, the right moment with the right words, can be quite delicate and uncomfortable. Searching to resolve this dilemma, I not only sent a letter asking for research dollars, but also included an article Yohan had written about his own experience of CMT, providing others with a framework and some knowledge of what this disease means to him and his future.

In response, I received numerous e-mails, comments, and notes from recipients of my appeal, thanking us for opening up and writing about Yohan's little known disease with a funny name. The pressure of perceived secrecy was finally relieved and the support, love, and empathy of our loved ones came shining through crisply and clearly. Reaching out, I held many hands that were always there for me, I just was not able to grasp them. To all those who participated in this fundraising for research campaign, I thank you with my entire being for supporting Yohan's dreams and giving hope to all those who are affected by the same malady. Lastly, I wish to leave you with a very powerful thought: JUST IMAGINE!!! ✨

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

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

*NAME: _____ / _____ / _____
First MI Last

*ADDRESS: _____

*CITY: _____ *STATE: _____ *ZIP: _____

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

*DAYTIME PHONE: _____ EVENING PHONE: _____

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

Note: If you are joining now, you may purchase publications at active member prices. ACTIVE MEMBERS have paid dues within the past year. If you are unsure about your membership status, please call 1-800-606-2682.

	QTY	COST	TOTAL
ANNUAL MEMBERSHIP DUES			
Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both.			
Receive newsletter as: <input type="checkbox"/> Print <i>or</i> <input type="checkbox"/> PDF via email		\$40	
Receive both Print <i>and</i> PDF Newsletters		\$45	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		active members \$15 nonmembers \$20	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 nonmembers \$7	
CMT Facts III		active members \$5 nonmembers \$7	
CMT Facts IV		active members \$8 nonmembers \$10	
CMT Facts V		active members \$12 nonmembers \$15	
A Guide About Genetics for the CMT Patient (No shipping and handling on this item only)		active members \$4 nonmembers \$5	
CMT Informational Brochure		FREE	
Physician Referral List: States: _____		FREE	
Letter to Medical Professional with Drug List		FREE	
Contribution to CMT Research Fund (100% of contribution is used to fund research)			
Shipping & Handling (Orders under \$10, add \$1.50; orders \$10 and over, add \$4.50)			
TOTAL			

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

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

Mail to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013; or fax to: 610-499-9267

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.



Molded Ankle-Foot Orthoses

Part 2: Fabrication and Fitting

BY DANA SCHWERTFEGER

I am sure many of you expected to see an article about the fabrication of AFOs in the last newsletter, but the invitation to visit a fabrication facility of Hanger Orthopedics was apparently rescinded, most likely due to liability issues, and I was unable to complete the article as planned.

I apologize for that, but I also have to say that not being able to visit the fabrication facility was a big disappointment. While I've gone through casting and fitting several times, I've never had the opportunity to see the molding process, and I was hoping to gather evidence to support a personal theory of mine.

Well, two theories, actually. One is that knowing more about the fabrication process would improve my ability to describe the modifications I needed beforehand, and the other is that being able to speak directly to the person molding the brace would improve his or her ability to follow my directions, thus reducing the number of adjustments that would need to be made during fitting.

The latter theory derives from my belief that central fabrication is better left to things which come in standard sizes and not to things requiring a personal touch like custom-fitted AFOs. Nevertheless, large

companies like Hanger cut costs by centralizing fabrication, and many independent orthotists also send casts to another location for molding.

Wherever it is done, vacuum molding involves several basic steps. First, each cast is aligned (the reason Frank made hatchmarks on mine before removing them) and filled with plaster, and a post is inserted. When the plaster hardens, the cast is removed, leaving what is known as a "positive mold."

The orthotist or orthotic technician clamps the post in a vise so that the heel of the mold faces up, and any surface defects are filled and smoothed. Corrections can also be made to the mold at this point. The heel area can be built up, for example, to create a little extra room and prevent the AFO from chafing and rubbing.

Next, a sheet of polypropylene is heated and vacuum formed to the mold.

When the plastic cools, it is rough-cut along the trim lines and removed. The edges are smoothed, Velcro straps are attached, and Aliplast or other cushioning material is glued in place. (If my directions are followed, no padding will be added, ventilation holes will be drilled up the back, and the trim lines at the ankle will be heated and flared outward slightly.)

The AFOs are now ready for the first fitting. I will eventually



FIGURE 1: Frank Gramaglia, of Hanger Prosthetics and Orthotics in Havertown, PA, trims the front of the brace and then grinds the edge smooth.

EDITOR'S NOTE: This is the second of two articles concerning AFOs. The first appeared in the November/December 2005 CMTA Report.



FIGURE 2: Dana points out a troublesome area just in front of his arch.



FIGURE 3: Frank checks the pressure on the back of Dana's legs.

tape in my own insole, but before I do, I want to make sure the area under my fifth metatarsal head is properly cut away. You can see in *Figure 1* how it looks when finished, but the cut-ins weren't quite as deep when Frank first brought me the AFOs.

That was okay. As a general rule, if there's too much plastic, some of it can always be cut away, but you can't add more. The corollary to that is that if you cut away too much plastic, you can't put it back, so don't try and cut everything away all at once. Take a little off here and a little off there until it feels right.

In this case, Frank was able to cut pretty close the first time because he traced the trim lines from my insoles. He still had to cut in one more time, though, and then he ground the edge smooth (*Figure 1*).

Now that I was able to put in insoles—I prefer to use the ones I remove from my New Balance Sneakers because they're comfortable and durable—I could go through my checklist of trouble spots. One is right in the middle of my arch (*Figure 2*). There's a bone there called the navicular, and I have to make sure it won't hit the plastic when I stand up and move around. It's one of the more difficult spots to get right. My arch has to be supported, especially since it's high, to distribute my weight more evenly and avoid stress fractures, but if it's not properly cushioned, my skin can be rubbed raw. Sometimes I have to wear the AFOs for several days before I can be sure it's okay. Here, the problem was actually just slightly forward, and Frank had to heat the plastic and bend it outward just a little.

Next, it was time to put my sneakers on, take a few trial steps, and do a little leaning and twisting. What I've found is that the new AFOs can be almost exact replicas of the old ones, but they'll still feel funny at first. One thing I check for is the degree of dorsiflexion—the angle at which the AFO holds my foot flexed upward. I've found that having between 3 and 5 degrees of positive dorsiflexion is necessary to allow my foot to swing through without raising my knee in classic “step-page gait” fashion. (Standing new and old AFOs side by side is one way to check that the dorsiflexion is similar.)

After walking the length of the hall several times to get a feel for the relative rigidity of the new AFOs, I kept each foot flat
(continued on page 6)

AFOs*(Continued from page 5)*

and leaned forward, bending my knee. Then I kept each foot planted and twisted side to side. Finally, I went up and down a flight of stairs.

What was the point of all this leaning, twisting and climbing? My legs were cast in a fixed position, and the AFOs were molded to a positive mold made from those casts, so they would fit perfectly as long as I stood still. I needed to see how they would fit when I moved.

In *Figure 3*, Frank marks the spot where I could feel the AFO digging into the back of my leg. The orthotic technician had not flared out the trim lines as I had asked, so Frank had to reheat the plastic and reshape it.

The problem with this

approach is that I have some degree of sensory loss, so I can't always tell if the AFOs are pinching. I have to wear them for a while, take them off, and look for red or irritated areas where they have been rubbing. I also had yet to add the padding I put on either side of my heel to keep it from rubbing against the plastic. (Frank gave me some Aliplast, a self-stick foam, but I prefer self-adhesive moleskin. I buy it by the roll from a medical supply house and cut it to fit, but pre-cut shapes can be found in almost any drugstore.)

Meanwhile, the new AFOs (*Figure 4*) appeared to fit fairly well, and I left hoping I would not have to return. That did not turn out to be the case, however. After wearing the AFOs for several hours, I noticed the the AFOs were too tight in the heel.

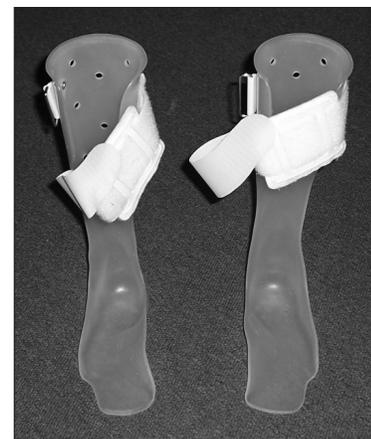


FIGURE 4: The finished AFOs—almost perfect

I made another appointment (at no cost, by the way), and saw an associate of Frank's, who reshaped the heel of each AFO.

Several weeks later, I'm not entirely sure that I won't have to go back for one last tweak, but AFOs that do not allow me to walk without discomfort are unacceptable. *

Research Update: Your Help is Needed!

With the announcement last year of the CMTA's new funding policy of awarding three-year \$100,000 per year research grants, the volume of applications received by the CMTA has increased. This year, fifteen applications were received, and they are currently being reviewed and evaluated by a special committee of the CMTA Medical Advisory Board.

The grant proposals run the gamut from the role of mitochondrial function to the creation of new mouse models for CMT4D, to the identification of a novel CMT2 gene, to a study of the outcome of foot

surgery from a functional gait point of view, to a study of modifier genes which may help explain why patients with the same CMT gene abnormality can vary greatly in the severity of their disease. Additionally, one study hopes to establish an Australian pediatric CMT registry, one will use a fruit fly as a model to study the MFN2 gene defects which can cause CMT2A, and another will search for a novel potassium blocker that might improve function in Trembler J mice (models for CMT1A).

Each of these studies has the potential to result in findings

which will lead to improved knowledge of CMT and the possibility of therapies for the disorder, but only the most promising can be funded. Scientific merit aside, whether the CMTA is able to fund these grants will depend on the response to the new Livney challenge grant.

If the CMTA can raise \$250,000 for research, the Livney Foundation will match that amount dollar for dollar. This is an incredible opportunity to raise money for CMT research, and we urge all patients and their families to contribute to the 2006 Livney challenge. *

The Charcot-Marie-Tooth Association

presents

A One-Day Patient-Family Conference on CMT and a Rally at the State Capitol



Made possible by a \$250,000 grant from Pennsylvania to the CMTA, a patient-family conference on Charcot-Marie-Tooth disorders will be held on Wednesday, May 24, 2006, at the fitness center of the Milton Hershey Medical Center, Hershey, PA.

The conference will begin with registration and a continental breakfast from 8:00 to 9:00 am. There will be morning presentations on topics such as orthopedic surgery, characteristics and diagnosis of CMT, and bracing.

At noon, lunch will be provided at the Capitol in Harrisburg, where there will be a rally and special presentation recognizing state legislative leaders who supported the \$250,000 grant to the CMTA. As the legislature considers the 2006-2007 state budget, it is important for patients and families to urge continued CMT grant funding. Your presence at the Capitol rally will help, and free transportation will be provided.

The afternoon program will continue with presentations on topics that may include physical and occupational therapy, pain management, research findings, and information about the CMT clinic in Johnstown.

There will be time allotted for questions following each presentation.

Registration is free for Pennsylvania residents. For non-residents, the fee is \$15. Directions to the hospital will be sent with confirmation of your registration. Seating is limited, and preference will be given to PA residents, so early registration is recommended. The facility is handicapped accessible.

HERSHEY CONFERENCE REGISTRATION FORM

Name: _____
(First) (MI) (Last)

Address: _____

(City) (State) (Zip)

Daytime phone: _____ Email: _____

Names of additional people attending:

I am enclosing \$15 for each non-resident attendee for a total of \$_____

I am a member of the CMTA.

Please mail or fax registration form to:

Hershey Conference, CMTA, 2700 Chestnut Parkway, Chester, PA 19013; or fax to: 610-499-9267

Questions? Call 1-800-606-2682 or email CMTAssoc@aol.com

News From NINDS

BY MARY JO HOEKSEMA, CONSULTANT TO CMTA

On February 6, 2006, President Bush released the Administration's proposed budget for Fiscal Year 2007. This action marks the first step in the annual appropriations process through which all federal agencies are funded.

The President's budget proposes cutting non-defense discretionary spending for the second straight year. More than a dozen departments and agencies are targeted for reductions, including education, health, housing, transportation, and agriculture programs. The bud-

get also proposes cutting mandatory spending for entitlement programs, such as Medicare, by \$65 billion over five years. Defense and homeland security programs are slated to receive the largest increases under the budget.

The National Institutes of Health (NIH), which includes the National Institute of Neurological Disorders and Stroke (NINDS), the lead federal research agency for CMT, would be flat funded under the President's budget. As a result, the agency would not receive more money in Fiscal Year 2007 than

it did in Fiscal Year 2006—\$28.5 billion. This flat funding proposal translates into an actual cut for the agency, since the rate of biomedical research inflation index is an estimated 3.8% in 2007.

With the exception of NIH Office of the Director and the National Institute of Allergy and Infectious Diseases, all of the NIH Institutes and Centers would receive less in 2007 than they did in 2006. NINDS would be cut 10% below last year's level of funding. To accommodate this cut, NINDS, like most other NIH institutes and centers, will be funding fewer applications, and those that are awarded may endure further reductions.

Despite the bleak funding outlook, NINDS still plans to sponsor its scientific meeting on peripheral neuropathies in mid-2006. The meeting is expected to focus on issues related to CMT research, and two CMTA board members, Dr. Steve Scherer and Dr. Michael Shy, are serving on the organizing committee. Ideally, recommendations from this meeting will lead to a future program announcement or request for applications to solicit CMT-related research applications. Although, again, the funding outlook may affect the institute's ability to fund all of the recommendations this meeting generates.

In its budget submission, NINDS announced plans to

RESEARCH OPPORTUNITIES ANNOUNCED BY NINDS

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

Intervention Research Grants to Promote the Health of People with Disabilities

The purpose of this research program is to develop, implement, and measure the effectiveness of interventions that promote the health and wellness of people with disabilities and prevent secondary conditions across the lifespan. The work should clearly define the precise targeted populations for the intervention program, convey the capacity to identify, reach, enroll, and follow this population; and measure and evaluate the effectiveness of the intervention(s). The application deadline is April 11, 2006.

For more information, go to: <http://grants.nih.gov/grants/guide/rfa-files/RFA-DD-06-004.html>.

Exploratory/Developmental Program for Translational Research in Muscular Dystrophy (R21) (PAR-06-043)

National Institute of Neurological Disorders and Stroke and National Institute of Arthritis and Musculoskeletal and Skin Diseases.

Application Receipt Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PAR-06-043.html>.

begin renewing its strategic plan in 2006. According to the document, "the plan will guide the Institute in balancing research on the hundreds of neurological disorders, common and rare, within its mission; across the many areas of basic, translational, and clinical research that are essential to progress; and between short-term opportunities for modest progress and long-term goals of preventing and curing diseases. The Institute will engage all stakeholders in this process." When NINDS solicits participation and comments from its stakeholders, CMTA will respond and share the information with its membership.

ADDITIONAL WEBSITES OF INTEREST

The NINDS Office of Communications and Public Liaison recommends the following websites for additional information about the NIH and its resources:

- **The NIH Bulletin:** <http://getinvolved.nih.gov/newsbulletins.asp>
- **NIH News in Health** is a monthly newsletter bringing you practical health news and tips based on recent research. It is fully reproducible and available online (and in hard copy format) at <http://newsinhealth.nih.gov/>.
- **The NIH Roadmap** website is <http://nihroadmap.nih.gov/>. Provides information about funding opportunities available through the trans-NIH Roadmap initiative.
- **NIH Director**, Dr. Zerhouni, has a website at: <http://www.nih.gov/about/director/index.htm>.
- **The Neuroscience Blueprint** website is <http://neuroscienceblueprint.nih.gov/>. Provides information about funding opportunities available through the trans-NIH Neuroscience Blueprint initiative.
- **The Medlineplus** website is <http://medlineplus.gov/>. Provides comprehensive health information.
- Clinical trial information is at <http://clinicaltrials.gov>. *

Progress in the CMT North American Database

BY MICHAEL SHY, MD

The CMT North American Database was created to track a large number of well-studied and documented patients with a variety of types of CMT so that they can be available for clinical trials and to provide information about whether certain medications exacerbate CMT, whether pregnancy exacerbates the condition, and whether exercise improves the condition. During this past year, we have added 300 new patients to the database, bringing the total of qualified entrants to 700.

The database is being used or has been used for three major projects this past year. Dr. Louis Weimer, Columbia University Medical Center, New York, used the database to obtain information on which medications have

been documented as having exacerbated (made worse) CMT. His article is now available online and will be published in the March, 2006, edition of the *Journal of the Neurological Sciences*. Much of the data in his

300 new patients were registered in 2005.

paper came from the database and had not previously appeared in the literature. His paper also will appear in modified format in the new edition of *A Patient's Guide to Charcot-Marie-Tooth*, which is being rewritten by members of the CMTA's Medical Advisory Board.

The database is currently being used in a pending grant to

the Muscular Dystrophy Association on developing a clinical trial utilizing ascorbic acid to treat CMT1A. The database will also be a primary source for procuring patients for the clinical trial.

Ed Zahurak of Conemaugh Health Systems in Johnstown, PA, has submitted a request to use the information in the database to help with an epidemiological study of patients with CMT in the state of Pennsylvania.

The database is also being used as a source to identify medications that may prove harmful to CMT patients in addition to those known to be harmful. A recent presentation at a CMT patient fair in Salt Lake City (3/4/06) was largely based on information gleaned from the database. *



GIFTS WERE MADE TO THE CMTA

IN HONOR

Yohan Bouchard*(See story on page 1)*

Mr. Dave Ackerman
 Mme. Jeannine Battentier
 Mr. and Mrs. Tom Beebe
 Mme. Blanche Bouchard
 Ms. Pat Charbonneay
 Ms. Carol Clark
 Mr. Grant Crichfield
 Mr. and Mrs. Brian Croll
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 M. Claude Francois
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 M. et Mme. Max Gayral
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 Mr. and Mrs. Steve Heald
 Mr. Patrick Henry
 Ms. Patricia Hurley
 Mr. Lynville Jarvis
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 Docteur J. M. Melon
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 Mr. and Mrs. Paul Osborn
 Ms. Elizabeth Ouellette and Mr. Gilles Bouchard
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The Friedmann Family

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Peggie Jumper

Joshua R. Donley

Dorothe Knowles' birthday

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Michael Park

Mr. and Mrs. John W. Hardy

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Judy McDonald
 Michael McKenzie

Betty Chow

Jean Kaung

Dorothy Herndon Kiger

Mr. and Mrs. Michael Zimmerlund

Lucille McKendry

Tom and Mame

Burton Martin

Carey McClung

Betty More

Larry Benner
 Jody, Dean, Cach & Kaillyn Blomquist
 Sandy, Joe, Holly, Heathy & Johnny Brozovich
 Janie & Gonk Jacobs
 Dean Look and Family
 Vi, Norm, Deana Lynn & Krista Look
 Mitch, Debbie, Derek, Heather & Randy Rule
 Louise and Stan Snyder
 Darrell and Lyu Stonebrink
 Lila Stonebrink

Lucille Park

Mr. and Mrs. John W. Hardy

Brucie Rowe

Alan Latman

Gloria Wickham

Mr. and Mrs. Frank Gunnison

CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
 Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____

 Check Enclosed VISA MasterCard

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____



The Function of Dynamin 2 Mutations in Peripheral Neuropathies

BY STEPHAN ZUCHNER, MD, DUKE UNIVERSITY

Charcot-Marie-Tooth (CMT) disease is caused by mutations in a number of different genes. One could even argue that all these genes represent different diseases with very similar clinical features. However, researchers believe that the many different CMT genes will uncover more general pathways underlying all CMT forms. We have recently identified mutations in the gene dynamin 2 (DNM2) causing a so-called dominant intermediate CMT form (DI-CMTB).

DNM2 was the first gene in the group of intermediate CMT neuropathies, which are characterized by moderate reduction of nerve conduction velocities. In contrast to many other CMT genes, DNM2 is one of the most intensely studied proteins in molecular biology. It is already well known that DNM2 is involved in endocytosis, which is the internalization of molecules from outside cells. DNM2 is also important for transport of vesicles in cells and for the organization of the cytoskeleton. However, this large amount of knowledge has not yet been applied to the peripheral nervous system, where CMT pathology takes place.

The CMTA recently awarded us a grant that will support research on DNM2. We are specifically studying the effect of DNM2 mutations we found in

CMT families on different cell lines that we grow in Petri dishes. We currently enroll new CMT families that have been tested negative for all the available gene tests and include them into a DNM2 mutation screen (contact: Jeffrey Stajich, stajich@chg.duhs.duke.edu). The identified sequence changes will be modeled in neuronal cell lines. In these cells we are studying cellular functions important to CMT, such as axonal transport of different vesicles and mitochondria, or the organiza-

tion of the cytoskeleton. We already showed that mutant DNM2 lost the capability to bind to certain membranous structures in cells. Thus, one of our aims is to specify in a biochemical assay what exactly impairs membrane binding of DNM2 in CMT. We hope to identify specific alterations that occur in response to DNM2 mutations that cause CMT. Such a mechanism of action in hand would enable a focused search for therapeutic strategies in CMT. *

THE QUALITY OF INFORMATION AVAILABLE ON THE INTERNET

A scientific study was conducted to evaluate the websites accessible to the general public. The study was conducted by doctors from the Department of Orthopaedic Surgery, SUNY Health Science Center of Brooklyn, NY. The study concluded that the information about scoliosis is of limited quality and poor information value. Although the majority of the websites were academic, the content quality and accuracy scores were still poor. The lowest-scoring websites were the nonphysician professionals and the unidentified sites, which were often message boards. Overall, the highest-scoring website related to both quality and accuracy of information was www.srs.org.

This website was designed by the Scoliosis Research Society. The public and medical communities need to be aware of these existing limitations of the Internet. Based on the group's review, the diagnosing physician must assume primary responsibility of educating and counseling their patients. *





SUPPORT GROUP NEWS

Minnesota – Twin Cities

The MN–Twin Cities CMT/ HNPP support group held its quarterly meeting on Saturday, February 4th, at the Ridgedale Library in Minnetonka.

Dr. Gareth Parry, Professor of Neurology from the Dept. of Neurology, University of Minnesota,

spoke to our group and answered our many questions. Dr. Parry has published a number of

papers on CMT and contributed to and edited *Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians*. He serves on the medical advisory board of the Charcot-Marie-Tooth Association. Forty-seven individuals braved frigid weather to attend, socialize and share experiences about their disease.

Available were many articles and information sheets about CMT and HNPP for the participants to take home with them.



Dr. Gareth Parry at the February meeting in MN

A lending library is also available, with books and pamphlets, for the people to check out, read, and return.

Thank you to Jodi Castillo of the regional Muscular Dystrophy Association for all of her help to keep our group going strong. And a special thanks to Dr. Parry, who, not only is a terrific speaker, but was instrumental in the forming of our support group three years ago.

Washington – Seattle

The first Charcot-Marie-Tooth Seattle Informational Group Meeting was a great success. “With only one week of advance notice, attendance exceeded expectations,” said Ruth Oskolkoff, volunteer leader.

Dr. Philip Chance’s Power Point presentation, “CMT 101,” was enlightening. He was entertaining, and he permitted question and answer exchanges during and after his lecture.

The quality of the questions and observations, from those of us who were “students,” left favorable impressions. Dr. Chance fielded all questions with clear, concise answers.

Based on our experience here in Seattle, we would highly recommend the local, community, and information presentation for other regions in our nation.

Our second meeting featured Dr. Thomas Bird, who gave a presentation on the ten most common questions he is asked regarding CMT. He started with question 10, “Is something wrong with my teeth?”

That garnered some laughter among the group and started his discussion on a light note. There were 15 people in attendance who asked a lot of questions of Dr. Bird. His knowledge and good nature made the meeting enjoyable as well as informative.

PA – Johnstown

The Johnstown CMTA support group held its bi-monthly meeting February 24th at The John P. Murtha Neuroscience and Pain Institute. The quest speaker was AJ Stick, PTA. AJ discussed “Exercise: The Art of Adaptation.” He also addressed the importance of research. AJ and research nurse Jan Goodard reviewed the research projects at The John P. Murtha Neuroscience and Pain Institute. One new member came 130 miles to attend—which set a new distance record!

Group leader J.D. Griffith visited Don McLaughlin, the patriarch of the CMT group in Johnstown. He is still on a respirator because of CMT but is in great spirits and looked great. One Sunday afternoon, Don single-handedly assembled 30+ disparate members of his family in Johnstown to allow Dr. Jeffrey Vance and his team from Duke University to draw their blood for genetic analysis. The family’s genes, and genes from six other large families, including families from Russia, Italy, Turkey, and Japan, were used to determine the genetic cause of CMT2A. ✨

A crowd of 47 attended the MN support group meeting.



CMT Support Groups

Arkansas—Northwest Area

Place: Varies, Call for locations

Meeting: Quarterly.

Meetings are not regularly scheduled so call ahead.

Contact: Libby Bond, 479-787-6115

Email: charnicoma57@yahoo.com

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)

Place: Sutter Medical Center of Santa Rosa

Meeting: Quarterly, Saturday, 1 PM

Contact: Louise Givens,
707-539-2163

Email: lbgivens@ix.netcom.com

California—San Francisco Bay Area/Santa Clara County

Place: Location to be determined

Meeting: Bimonthly

Contact: Elizabeth Ouellette,
650-248-3409

Email: elizabetho@pacbell.net

Colorado—Denver Area

Place: Broomfield Public Library, Eisenhower Room

Meeting: Quarterly

Contact: Diane Covington
303-635-0229

Email: dmcovington@msn.com

Florida—Tampa Bay Area

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

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

Contact: Lori Rath, 727-784-7455

Email: rathhouse1@verizon.com

Kentucky/Southern Indiana/Southern Ohio

Place: Lexington Public Library, Northside Branch

Meeting: Quarterly

Contact: Martha Hall,
502-695-3338

Email: marteye@mis.net

Minnesota—Benson

Place: St. Mark's Lutheran Church

Meeting: Occasionally

Contact: Rosemary Mills,
320-567-2156

Email: rrmills@fedtel.net

Minnesota—Twin Cities

Place: Call for location

Meeting: Quarterly

Contact: Maureen Horton,
651-690-2709
Bill Miller, 763-560-6654

Email: mphorton@qwest.net,
wmiller7@msn.com

Mississippi/Louisiana

Place: Baptist Healthplex,
102 Clinton Parkway,
Clinton, MS

Meeting: Quarterly

Contact: Flora Jones, 601-825-2258

Email: flojo4@aol.com

Missouri—St. Louis Area

Place: Saint Louis University Hospital

Meeting: Quarterly

Contact: Carole Haislip, 314-644-1664

Email: c.haislip@att.net

New York—Greater New York

Place: NYU Medical Center/
Rusk Institute, 400 E. 34th St.

Meeting: Third Saturday of every other month, 1-3 PM

Contact: Dr. David Younger,
212-535-4314,
Fax 212-535-6392

Website: www.cmtnyc.org

Email: bwine@acm.org

New York—Horseheads

Place: Horseheads Free Library on Main Street, Horseheads, NY

Meeting: Quarterly

Contact: Angela Piersimoni,
607-562-8823

New York (Westchester County)/Connecticut (Fairfield)

Place: Blythedale Hospital

Meeting: Bimonthly, Jan, March, May, Sept, and Nov; 3rd Saturday

Contacts: Beverly Wurzel,
845-783-2815
Eileen Spell, 201-447-2183

Email: cranomat@frontiernet.net
espell@optonline.net

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)

Place: Church of the Reconciliation, Chapel Hill

Meeting: Quarterly

Contact: Susan Salzberg,
919-967-3118 (evenings)

Ohio—Greenville

Place: Wills Restaurant
405 Wagner Ave, Greenville

Meeting: Fourth Thursday,
April–October

Contact: Dot Cain, 937-548-3963

Email: Greenville-Ohio-CMT@
woh.rr.com

Ohio—NW Ohio

Place: Medical College of Ohio

Meeting: Quarterly

Contact: Jay Budde, 419-445-2123
(evenings)

Email: jbudde@fm-bank.com

Oregon/Pacific NW

Place: Portland, Legacy Good Sam Hospital or Brooks, Assembly of God Church

Meeting: Quarterly

Contact: Darlene Weston, 503-245-8444

Email: blzerbabe@aol.com

Pennsylvania—Johnstown Area

Place: John P. Murtha Neuroscience Center

Meeting: Bimonthly

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

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

Pennsylvania—Northwestern Area

Place: Blasco Memorial Library

Meeting: Call for information

Contact: Joyce Steinkamp,
814-833-8495

Email: joyceanns@adelphia.net

Pennsylvania—Philadelphia Area

Place: Penn Towers Hotel
Conference Room

Meeting: Bimonthly

Contact: Amanda Young,
732-977-9983

Email: astarryoung@yahoo.com

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



LETTERS

Dear CMTA,

I am 36 years old and I have known I've had CMT for over twenty years. I have enjoyed reading *The CMTA Report* through the years and all the information I have received from it. After reading the Jan/Feb articles from Scott Zoeller and the one from Y. Chetty in South Africa, I felt a connection with these two people.

I have experienced similar battles, starting with weak ankles where I'd roll them and fall from stepping on the smallest stone. I've had a few of those embarrassing episodes in my life. When I was fourteen, I had some AFOs made for me. I

never wore them. They just sat in the closet. I was ashamed of those funny-looking things. So, I know how Scott feels. I can also empathize with Y. Chetty, who has thin calves and wears long jeans all the time.

I wanted to write to them and every other man, woman, boy, and girl dealing with CMT. It is tough, but this is what we have. Like Mr. Chetty said, there are always people who are worse off than we are. CMT makes us unique, but stronger, with character.

I've had my ups and downs with life and with CMT. In my twenties, I didn't want to have children, but as my neurologist

said, "what if your parents knew they had CMT and decided not to have you?" Good point. I am married to a wonderful woman now and we are expecting our first baby on July 4th!

Mr. Chetty wrote about joining a gym and feeling good about putting some extra mass in his upper body, but wondered about pushing extra hard to build his leg muscles. Free weights are great, but don't push too hard and overexert yourself. I've done that before and had to pay for it. I think we just have to deal with those thin legs we have.

About the AFOs, Scott, I wear them whenever I am heading out to uneven ground. I love being outdoors, and the AFOs are the best things I've ever bought. They save me a lot of sprained ankles and loss of balance. It's amazing what a pair of baggy jeans can cover up! No one even knows I wear them.

I, too, have never met anyone else with CMT. It would be nice to share our experiences. I would be happy to correspond with anyone and can be reached at plubberts@yahoo.com.

—Paul Lubberts, NY

WRITE TO US!

Pat Dreibelbis, Editor
The CMTA Report
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2700 Chestnut Pkwy.
Chester, PA 19013
or
CMTAssoc@aol.com

The CMTA reserves the right to edit letters for space.

Support Group Liaison Retires

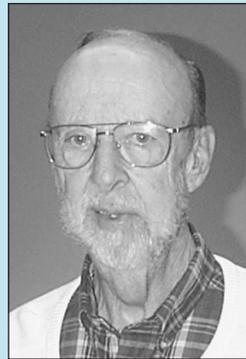
Robert Budde, who first began his service to the Charcot-Marie-Tooth Association as the leader of the Kentucky support group, became the liaison for all support group leaders almost four years ago. At the time that he was asked to take over this newly created position by Chairman Ann Lee Beyer, he agreed with the stipulation that he would do it for one year until someone else could be found.

Now, three years later, Bob has stepped down and is turning the reins over to board member, Elizabeth Ouellette. Some of Bob's accomplishments include talking to potential support group leaders, sending out the "How to Start a Support Group" information and answering questions about finding speakers, keeping members active, and announcing meetings.

Elizabeth is planning to work on keeping the support groups active, creating children's programs, and increasing membership in the national organization.

All of the support groups received a survey several weeks ago that asked questions intended to help the national organization better serve our groups and better communicate with them. If any support group has not returned the completed survey, we ask you to do that as soon as possible so that planning can begin on how to address the needs of our groups and to improve our relationship with them.

The CMTA thanks Bob for his efforts for the last few years and for being a dependable and concerned proponent for CMT support groups throughout the United States. ✨



Bob Budde

Dear CMTA,

I read my newsletter cover to cover. I am always hoping for some miracle to happen and where better to announce anything connected to CMT than in your newsletter. I found my dynamic braces when Jean-Paul Neilsen did an article back in 2000, and my life has totally changed because of this kind of

brace. I am also pleased to get updates on the North American Database to which I contributed my information.

There was an article on Zetia, which I am going to show my primary care physician because no matter what I eat (and I do eat low fat, low cholesterol, low everything), it seems my cholesterol keeps creeping up. Both of my sisters are on Lipitor, so I figure it's familial.

You probably don't get enough thanks. For ten years I did a newsletter for my building and got, maybe a dozen people who commented they were happy to get the newsletter. But the other 80 households never said a word. When I retired last fall, I received three rounds of spontaneous applause, so I guess

there were more people who just never said a simple thanks. Thanks.

—A. W., NY

Dear CMTA,

I had a pair of orthotics made by Mitchell Warner in June of 2005. I am 64 years of age, and my balance was becoming an issue. I called the CMTA office and asked about the braces made by Mitchell. I was told that they were worth trying if I could get to Las Vegas for evaluation and fitting. The results have been life changing! I have tried several types of orthotics over the past 30 years and always went back to the type I started with. They worked fine and were comfortable. But those orthotics did not allow me to

stand up straight because they pushed me slightly forward.

I am now aligned properly, which allows my skeletal system to hold me in a neutral position. Work and desire were required for the first several months. I have only fallen once, and that was because a chair leg in my den tripped me! Mitchell goes to aeronautical conventions to learn more about issues of weight and strength for his orthotics. He continues to work on new designs.

His assistant, Michelle, hounded my insurance company until they gave up and paid. I can be reached at 423-929-3210 and would be happy to answer questions of anyone interested in these orthotics.

—Lawrence Porterfield, TN

ASK THE DOCTOR

Dear Doctor,

I am 68 and am currently seeing a urogynecologist for a nervous bladder condition. Part of the therapy involves tibial nerve neuromodulation using an acupuncture needle above the ankle to incorporate the electrical stimulation. I understand that each stimulus to the brain and toe continues until the big toe jerks. My question is: can strong stimulation of the nerves weaken and damage them to cause an increased neuropathy to my feet and legs?

My legs have been the strong part for me. I walk 1 1/2 miles each morning, but this past year I have slowed down considerably and am not able to move very fast. This is why I do not want

anything that might cause the neuropathy in my feet and legs to increase.

The Doctor replies:

Electrical currents of the intensity that are used in medical therapies or diagnosis are not harmful to nerves, so there is no contraindication to this treatment.

Dear Doctor,

I am a 76-year-old woman. My doctor has recommended that I take Actonel for osteoporosis. I have CMT and feel that I am experiencing some muscle weakness in my lower legs when I take this medication. Have there been any studies or is there information

available to let a CMT patient know if this is a safe drug?

I have done quite well over the years. I work with a physical therapist and am faithful about doing my exercises every day. I am starting to have some drop foot and balance problems. So, I don't want to take a medication that is going to weaken what I have worked so hard for over the years.

Thanks for your organization and all you are doing to push for research and answers to CMT.

The Doctor replies:

As far as I know, there are no neuromuscular complications associated with risedronate (Actonel) or the newer treatment for osteoporosis, Boniva.

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CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

Moderate to significant risk:

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

Uncertain or minor risk:

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

Negligible or doubtful risk:

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

What is CMT?

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

THE CMTA Report



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