



**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.

CMTA BOARD

Patrick Torchia
Chairman and President

Robert Kleinman
Treasurer/President Elect

Phyllis Sanders
Secretary

Gary Gasper
Patrick Livney

Steve O'Donnell

Elizabeth Ouellette

Jason Steinbaum

Jack Walfish

Michael Shy, MD

Chairman,

Medical Advisory Board

Robert E. Lovelace, MD

Chairman Emeritus,

Medical Advisory Board

Charles F. Hagins

Executive Director

EMAIL CMTA AT:

CMTAssoc@aol.com

CMTA Funds New Three-Year Grant to Develop Possible Treatment for CMT

One application for a three-year grant of \$100,000 per year was chosen for funding by the scientific review committee of the CMTA's Medical Advisory Board and a vote of the CMTA's Board of Directors. The recipient of funding to begin in the fall is Dr. Steve Scherer, MD, PhD, the William N. Kelley Professor of Neurology, University of Pennsylvania School of Medicine.

Dr. Scherer's grant is entitled, "A high-throughput screen for Kv3.1b antagonists." The purpose of his research is to identify new medications to

treat CMT1A and other demyelinating forms of CMT by looking for drugs that inhibit potassium channels in peripheral nerves. His summary of the work states that:

We have unpublished evidence that a substantial fraction of myelinated axons do not function in the nerves of *Trembler J* mice, a genetically authentic animal model of CMT1A. Furthermore, the function of these axons can be restored with a drug (4-aminopyridine; 4-AP) that

blocks many kinds of potassium channels. We have evidence that a single kind of potassium channel, Kv3.1b, is the main target of 4-AP. Because there are no specific blockers of Kv3.1b, and general potassium blockers like 4-AP are difficult to use

in humans, our results motivate us to search for drugs that inhibit Kv3.1b selectively, and test the effects of these drugs on *Trembler J* nerves.

This study will be supported by the CMTA for three years and we will have periodic reports on the progress of the study. Additionally, of course, the organization is entering year two of our three-year support of both Dr. James Lupski and Dr. Stephan Zuchner. The report from Dr. Zuchner's exciting work to date is found in this issue of the newsletter. *

The purpose of the study is to identify possible medications to treat CMT1A.

CMTA and MDA Co-Fund Ascorbic Acid Clinical Trials to Treat CMT1A

The Charcot-Marie-Tooth Association and the Muscular Dystrophy Association have joined forces to fund the first large-scale clinical trial in North America for the most common form of CMT, CMT1A.

The CMTA has agreed to commit \$550,000 over the three-year period of the clinical trial, which will investigate the potential of high doses of

ascorbic acid to successfully treat CMT.

The research centers in the study will be Wayne State University, MI, the University of Rochester, NY, and Johns Hopkins, Baltimore, MD.

A more detailed description of this clinical trial along with information for interested parties will be presented in an upcoming issue of *The CMTA Report* and on our website. *

INSIDE:

Ten Reasons to Visit Wayne State	5
Getting the Seal of Approval	6
Summer Fundraising	8

Research Funded by the CMT Association Provides Clues About the Role of Protein Synthesis Enzymes in CMT

BY STEPHAN ZUCHNER, DUKE UNIVERSITY

The human peripheral nervous system is composed of cells, called neurons and glial cells, that are responsible for neuronal communication (e.g., between the brain and muscles that control voluntary movement). This process is facilitated, in part, by neurons that originate in the spinal cord and that have very long projections, called axons, spanning long distances to stimulate muscles in the hands and feet. Charcot-Marie-Tooth (CMT) disease represents a broad group of disorders associated with impaired function of the neurons or glial cells in the peripheral nervous system. Patients with CMT have weakness in their hands and feet. In line with this, CMT-associated mutations have been identified in a number of genes with a known or expected function in the peripheral nervous system. One important aspect of CMT research is that, while there are a number of different forms of the disease, understanding the specific cause of any one will

likely provide insights for the group as a whole.

In 2003, mutations in the gene encoding glycyl-tRNA synthetase (GARS) were identified in four families with a specific form of CMT. GARS is a member of a family of enzymes involved in protein synthesis, a process that is essential for all life forms and that occurs in all cells and tissues of the human body. The most interesting aspect of this discovery is that the mutations appear to affect only the peripheral nervous system, and not the myriad other tissues in which the enzyme is needed. This suggests that GARS has a specific role in maintaining a healthy peripheral nervous system. Interestingly, mutations in a gene encoding a related enzyme were recently identified in another group of families with CMT, supporting a role for these protein-synthesis enzymes, called

aminoacyl-tRNA synthetases, in peripheral nerve function.

Funding from the Charcot-Marie-Tooth Association is currently supporting studies aiming to determine how mutations in the GARS gene specifically affect neurons that supply muscles in the hands and feet of patients with CMT. Three major findings

highlight the importance of this research, which is being carried out by Dr. Anthony Antonellis in Dr. Eric Green's laboratory at the National Human Genome Research Institute.

First, the researchers studied the effect of the human mutations on the function of the corresponding gene in yeast. This was possible because the human and yeast genes are highly similar and perform the same function. To do this, they mutated copies of the yeast gene to bear the mutations found in patients with CMT, and studied the growth of the resulting yeast strains. This revealed that yeast cells carrying most of the human mutations do not grow well compared to those carrying a normal (wild-type) copy of the gene, indicating that the human mutations impair the function of the enzyme. Next, they determined how wild-type and

CMTA-supported researchers hope to provide patients with improved diagnostics and therapeutics.

EDITOR'S NOTE:

A summary of the work to date of Dr. James Lupski, Baylor College of Medicine, will appear in the September/October issue of The CMTA Report. One of Dr. Lupski's studies focuses on a molecule which might be capable of suppressing the overproduction of PMP22 in CMT1A.

mutated forms of human GARS behave in cells by labeling the enzyme with a fluorescent tag and studying it in cultured neurons. These experiments revealed that the wild-type enzyme forms granules (tiny speckles that look like grains of sand), while the majority of mutant forms do not. This indicates that the mutations may cause the enzyme to improperly localize (i.e., go to the wrong part of the cell) in patients with CMT. Finally, they studied the behavior of naturally occurring GARS in the axons of the peripheral nervous system using tissue samples from healthy subjects. This revealed that the enzyme forms similar granules in human axons, including those that supply the muscle groups in the lower legs and feet. Combined, these studies suggest that GARS has a specific function in axons of the peripheral nervous system, with disruption of that function leading to CMT.

Based on the above studies, researchers will have a better ability to determine the precise role of GARS in axons. This will offer two major benefits for CMT research in general. First, it will provide candidate genes for forms of CMT with no known genetic cause. For example, if it is determined that a protein-synthesis defect is responsible for the onset of GARS-associated CMT, other genes with a role in this process can be examined for CMT-associated mutations. Second, it will likely yield insight into how healthy axons function, thus providing new avenues for therapeutic development in types of CMT in which the axons are primarily affected. The major goal of CMT Association-supported research is to provide patients with improved diagnostics and therapeutics to improve patient care. With continued support, these goals should become a reality. *

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.



LIVING WITH CMT

Thanks to Joe Paterno, the Invisible Becomes Visible

BY DANA R. SCHWERTFEGER

Here's a quick quiz. Match the names on the left to their claim to fame:

- | | |
|-----------------------|------------------------------------|
| 1) Michael J. Fox | a.) <i>The Nutty Professor</i> |
| 2) Stephen J. Hawking | b.) <i>Superman</i> |
| 3) Christopher Reeve | c.) <i>Tour de France</i> |
| 4) Lance Armstrong | d.) <i>Back to the Future</i> |
| 5) Jerry Lewis | e.) <i>A Brief History of Time</i> |

I'll bet you scored a perfect 100. (If you didn't, you've either been dead for at least 50 years or you're a teenager, in which case you might not know Eddie Murphy was only two years old when Jerry Lewis made the original Nutty Professor movie.)

Anyway, here's another quiz.

Match those same names with these diseases/disorders:

- | | |
|-----------------------|---|
| 1) Michael J. Fox | a.) <i>Testicular cancer</i> |
| 2) Stephen J. Hawking | b.) <i>Muscular dystrophy</i> |
| 3) Christopher Reeve | c.) <i>ALS/Lou Gehrig's disease</i> |
| 4) Lance Armstrong | d.) <i>Spinal cord injury/paralysis</i> |
| 5) Jerry Lewis | e.) <i>Parkinson's disease</i> |

Scored 100 again, didn't you? Mention Michael J. Fox and I'll bet your first thought isn't of Marty McFly but of Parkinson's. Christopher Reeve gave us the classic Clark Kent/Superman persona, but we'll remember him as the actor who suffered a tragic fall from a horse and waged a heroic battle

against paralysis. We laughed until it hurt at the screwball antics of Jerry Lewis, but he truly entered our hearts as the champion of kids with MD.

I could go on, but you get the idea. Each of these people brings instant recognition to a condition that impacts the lives of thousands of people. This recognition can be a tremendous asset when an organization seeks to raise funds for research and treatment, but there's an equally important benefit to having a well-known spokesperson, one I didn't fully appreciate until several months ago when Joe Paterno agreed to help us raise awareness of CMT in Pennsylvania.

The NCAA Coach of the Year doesn't have CMT, but

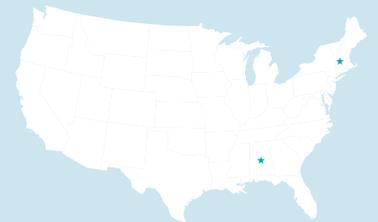
Two New Support Groups Hope to Find Members

Dice K. Lineberry, MD, held the first meeting of a new Alabama CMT support group August 5, 2006 at the Lakeshore Foundation Fitness Center, 4000 Ridgeway Drive, Birmingham, AL, from 10AM-1PM. The first meeting was partly devoted to organizational matters, but a tour of the facility was planned. Lakeshore is a not-for-profit organization that promotes independence for persons with physically dis-

abling conditions and opportunities to pursue active healthy lifestyles.

Anyone who is interested in this new group should contact Dr. Lineberry at (205) 870-4755 or dkllrl@yahoo.com. (Dr. Lineberry does not treat patients with CMT; however, he does have CMT.)

A second new group is trying to form in Amherst, MA. Ellen Panzer plans to hold her first meeting on August 31,



2006, from 7-9 PM at the Bangs Community Center, 70 Boltwood Walk, Amherst, MA, 01002. Interested persons should contact Ellen at CMT_support_MA@yahoo.com or by calling (413) 256-0189.*

shortly after the TV and radio spots featuring the Penn State coaching legend hit the airwaves, we began getting calls from people all over Pennsylvania telling us how wonderful it was to have someone as famous as Coach Paterno spreading awareness about CMT.

When one woman called and I asked how I could help her, she said, “Oh, you can’t help me. I just want to say thanks for getting Joe Paterno to speak about CMT.” Another said, “I am so happy someone like Joe Paterno is doing ads for the CMTA,” and she went on to describe how, for the first time, people she knew suddenly appreciated the serious nature of her condition.

As many of us well know, CMT can be practically “invisible,” and it’s not uncommon for someone to be told, “What do you mean you can’t do it? There’s nothing wrong with you.” But our limitations are very real, and the implication that we are shirking or playing for sympathy can be very hurtful, especially when it comes from someone close to us.

We can abide it when complete strangers fail to understand our limitations, but when a spouse, close friend, or co-worker expects us to function as though nothing is wrong, that can leave us feeling as though the people who should know us best don’t really know what it’s like to have CMT.

The phone calls I’ve received show that simply making the invisible visible can make a remarkable difference in the lives of people with CMT. On behalf of all of us, I’d like to say, “Thanks, Joe. You have made a very valuable contribution, and it is greatly appreciated.” *

Ten Reasons to Visit the Clinic at Wayne State

BY CMTGUY (by email)

I recently made my second visit in 3 years to the Wayne State University CMT Clinic in Detroit, Michigan. I spent the day with Dr. Michael Shy and his team of geneticists, physiatrists, technicians, interns, and researchers who are working hard to help people with CMT. I want to offer these top ten reasons why everyone with CMT should consider making the visit and not pass up this great resource and opportunity.

- 1 You will be contributing to the overall research effort and helping to build the database of nerve and strength test results.
- 2 You will be seen and tested by the experts – professionals who see enough CMT to know what the different symptoms mean and who can give you good practical advice and a realistic prognosis based on their experience of seeing hundreds of CMT patients.
- 3 You can stay in the nearby and affordable International Guest House accommodations and eat in the nice cafeteria at the medical center, both only 3 minutes from the Detroit airport.
- 4 You will meet CMT interns and have the opportunity to encourage these young medical professionals to pursue their interest in CMT studies to help future generations of patients.
- 5 You will see a physiatrist at the rehab center and get his expert advice about AFOs, orthotics, exercise, and other helpful resources for accommodations.
- 6 Instead of a rushed 10-minute appointment with a doctor who is unfamiliar with CMT, you will have all day in a relaxed, pleasant, and private setting with knowledgeable people.
- 7 You will have a chance to contribute to the North American CMT database and may be able to participate in DNA studies of different types of CMT.
- 8 You will meet other people with CMT, something I have never been able to do where I live.
- 9 You will access by email to make inquiries and get advice in the future as a follow up to your visit.
- 10 You will see a map on the wall showing how many CMT patients the Clinic has seen from all over the country, and you will realize you are not the only one with CMT.

Traveling and flying aren’t always easy, but I guarantee you this trip is worth it! *

EDITOR'S NOTE:
Phyllis gave this speech to the attendees of the AFA Golf Tournament.

Thoughts from the Heart

BY PHYLLIS SANDERS, CMTA BOARD MEMBER

Last week, the *Wall Street Journal* published an article which said that in order for a rare disease to attract research attention it had to have a tissue center and a database.

The CMTA already has participated in the funding of the North American CMT Database. It was established to provide case material for CMT research. So, we have passed one of the criteria for attracting researchers to our rare disease.

At this point, though, I'm not sure that CMT is such a "rare" disease. It is the most common inherited peripheral neuropathy, with one in 2500 being affected. As awareness of the disease grows, more and more diagnoses are being made and more and more people are finding out the actual name of the problems they have dealt with for years.

To enhance and continue the growing awareness, our organization is participating in a campaign in the state of Pennsylvania. Through lobbying efforts, the legislature awarded the CMTA a \$250,000 grant to educate medical professionals and the general public about CMT.

Through national lobbying efforts, congress wrote legislative language encouraging NIH to put more effort into funding research on peripheral neuropathy and inviting researchers to submit study proposals on CMT and other neuropathies.

The CMTA has been funding studies by giving \$35,000 grants to qualified and vetted applicants for over ten years. By doing this, we have encouraged young scientists to study CMT. Last year we began funding three-year, \$300,000 grants which are larger in scope and

which we believe can provide valuable information in our search to find the ultimate cure for CMT. By understanding what goes wrong in a cell affected by CMT, researchers will be able to take the next step to either prevent the damage or reverse it.

This year, we are very excited to be participating in funding a major clinical trial being conducted at Wayne State University, Johns Hopkins, and the University of Rochester. Dr. Michael Shy, among others, will be conducting a study to test the hypothesis that massive doses of ascorbic acid (vitamin C) given to CMT patients with Type 1A, could result in the remyelination of peripheral nerves, hence slowing or halting the progression of the disease.

We are pleased that so many scientists are interested in studying our disease. We sponsor a bi-annual consortium where world-wide CMT specialists in various disciplines can come together to exchange ideas and research findings. Their work has application not only to CMT patients, but to those suffering from related disorders such as diabetes, AIDS, Alzheimer's, and many other neurological disorders which have neuromuscular effects.

We must continue to encourage them with support and funding. Help us help them. One hundred percent of what is given to our research fund goes directly to help us in finding the cure. *

CMTA Receives Seal of Approval

The Independent Charities Seal of Excellence is awarded to the members of Independent Charities of America and Local Independent Charities of America that have, upon rigorous independent review, been able to certify, document, and demonstrate on an annual basis that they meet the highest standards of public accountability, program effectiveness, and cost effectiveness.



These standards include those required by the US Government for inclusion in the Combined Federal Campaign, probably the most exclusive fund drive in the world. Of the 1,000,000 charities operating in the United States today, it is estimated that fewer than 50,000, or 5 percent, meet or exceed these standards, and, of those, fewer than 2,000 have been awarded this seal. *



ASK THE DOCTOR

Dear Doctor,

I am a 63-year-old patient with CMT. I've had several foot surgeries in adulthood. Last week, I had surgery for lengthening my right Achilles tendon. At present, I have dressings and splints. I am scheduled to have a cast put on next week. Is there anything that can be done to lessen the atrophy which occurs with casts?

Whenever my legs have been in casts, I've experienced severe pain in the affected leg. It might be called ventriculation.

Can anything be done to reduce or prevent this? I am able to tolerate only low dose and infrequent pain medications.

An orthopaedic surgeon replies:

Given this person's situation and being postoperative (i.e., part of a planned event), I don't think there is anything that can be done to lessen the atrophy which occurs while in casts. I am sure that the patient is aware that after the lengthening surgery, the tendon needs to heal. Depending on whether the lengthening was done percutaneously or by open technique, there is a certain amount of time that is required for healing. Thus, after the dressings and splints used postoperatively, the cast is needed to keep the ankle immobilized so that the tendon, which may or may not have been repaired with sutures, can heal and become whole again.

I am not familiar with the term "ventriculation", but in all cases, pain is a very individual and personal matter. The use of

medication for pain, its tolerance, especially when prescribed postoperatively, needs to be discussed between the patient and his/her physician. The prescription, its quantity, strength, and period between dosages needs to be carefully adjusted and monitored via patient feedback.

Dear Doctor,

Recently, there has been a lot written about law suits against the manufacturer of Lipitor because it causes peripheral neuropathy. Do you think this is a problem that CMT patients should consider?

The Doctor replies:

This topic is quite controversial. Over the years, Lipitor or other statins have been suspected of causing neuropathy in a handful of cases, but no one thought the issue was very important. This new round of concern is based on a single large study in Denmark that found that people with neuropathy of no known cause were more likely to be taking a statin. Others have argued that they could not be sure that there were no other explanations for these neuropathy cases, such as metabolic syndromes or mild diabetes. Unfortunately, lawsuits do not demand proof. The statins are on the CMTA's drug list, but I think that people with CMT and high cholesterol would be negatively affected by avoiding Lipitor or other statins, if they truly need them. If they appear to worsen after starting a statin, the issue should be addressed with their physician. Muscle

complications are still probably a more important and sometimes overlooked problem with statin drugs.

Dear Doctor,

I'm a 75-year-old woman and have been taking Evista for arthritis and now the doctor wants to change my prescription to Actonel. Will that be okay for me since I have CMT?

The Doctor replies:

As far as we know, there are no neuromuscular complications associated with risedronate (Actonel). The same thing is true for the former medication, ibandronate (Evista.)

Dear Doctor,

Would having an MRI using contrast dye show nerves as abnormal for someone with CMT Type 1?

The Doctor replies:

MRIs have shown that nerve and nerve roots are enlarged in patients who have CMT Type 1 and other more severe kinds of inherited demyelinating neuropathies such as Dejerine-Sottas neuropathy. I do not think that contrast dye enhances nerves or nerve roots in CMT patients, but it has been reported that nerve roots enhance in patients with Dejerine-Sottas.

Gadolinium is an inorganic salt that is used to provide enhancement on MRIs. Gadolinium enhancement is usually taken as evidence of a breakdown in the "blood-nerve barrier" which is likely the result of inflammation. *

WRITE TO US!

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

The CMTA reserves the right to edit letters for space.

Summer Sizzles with Fundraisers

Summer means jumping in the water to cool off or getting out on the fairway to assert man's (and woman's) superiority over the little white ball. Members of the CMTA use those common interests to get out and raise money for the many projects of the organization.

On June 11, 2006, Steve O'Donnell and his two children, Jaime and Sean, swam the Chesapeake Bay Challenge to raise money for research. This is the fifth year Steve has done the swim and the second year his children have joined him. They

call their effort "The Swim for the Cure" and dedicate their fundraising efforts to helping to support the research grants chosen by the CMTA's Medical Advisory Board. This year, to date, they have raised \$63,748.00!

On July 18, 2006, Robert Kleinman hosted the seventh annual AFA Protective

Systems golf tournament. This year the event was held at the exclusive Meadowbrook Club in Jericho, NY. A limited field of eighteen foursomes played golf during a true summer heat wave. Because AFA underwrites the cost of the club, the entire amount donated by the participants goes to the research fund of the CMTA.

In that same week, on July 21, 2006, Patrick Torchia held his sixth annual golf tournament at the Sunnehanna Golf Course in Johnstown, PA. This year, former Pittsburgh Steelers Louis Lipps and L.C. Greenwood participated. His tournament supports the activities of the CMTA, including aspects of the Pennsylvania Awareness Campaign.

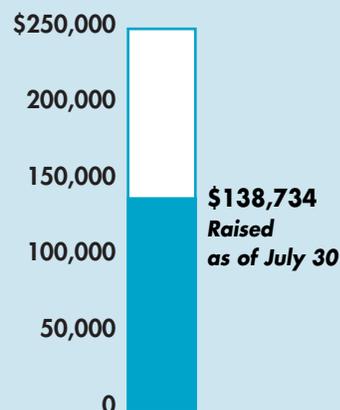
For the first time this summer, Patrick Livney will host a golf fundraiser at the Merit Club in Libertyville, IL. The First Annual CMT Golf Tournament will be held on August 14, 2006. All proceeds will go to



Sean, Steve and Jaime O'Donnell once again met the challenge of the Chesapeake Bay successfully.

LIVNEY CHALLENGE PROGRESS

Because of the generosity of both large and small donors, the challenge is over halfway to reaching its target. Thanks to all of you who have supported our campaign to end the legacy of CMT. If you have not yet given, your gift would be greatly appreciated.



CMT research to help find a cure for the disorder. Participation is limited to twenty foursomes and the first prize is \$10,000 cash. Hole-in-one prizes include cars, cash, and other great prizes.

Another new entrant into the fundraising field is the charity golf tournament and dinner being run by Mike Farrugia. His event is being held on October 14, 2006, at the Far View Golf Course in Avon, NY. The proceeds will be divided between two charities: Hunter's Hope, a charity which honors the infant son of Buffalo Bills Quarterback Jim Kelly and his wife Jill and supports research into Krabbe Leukodystrophy and the Charcot-Marie-Tooth Association. Mark is still in need of volunteers to help on the day of the event. If you are interested in playing or helping, call Mark at 585-519-1917 or you can email him at goldenbenefit@aol.com. *

GIFTS WERE MADE TO THE CMTA

IN HONOR OF

Yohan Bouchard

Warren Ouellette

Amanda M. Cohen

Selah N. Mapes

Richard Davis' Birthday

Mr. and Mrs. Skip Davis

Amy Hodge

Mr. and Mrs. Thomas Chang

Warren Ouellette

Candis P. Kjelleren
Dr. Christine A. Murray
Beverly Rooney

Richard & Kathleen Stees

Mary Stees

Leah Vaknin

Leon Gelman

Rachel Weil's 21st birthday

Melody Misiaszck

Yohan and Warren

Mrs. Amy S. Kinneston

IN MEMORY OF

Dale Craig

Maureen Sheffield

Andrew Ettelson

The Messer Family

William R. Graves

Jack Graves
John Graves
Jean Morris

Charles Hathorn

Juanese Calkins
Delores Houston
Joseph and Donna Whitacre

Michael Wade Johnson

Joan Taylor

Mildred Kleinman

Beth & Don Capelin
Annette Kroll
Riverside-Nassau North Chapel
Diane Sandler
Gloria and Dr. Jerry Zuflacht

Charles E. McCabe

Port Huron High School

Frank Michenzi

Scott & Jennifer Bialek

John F. Pulicare, Jr.

John Pulicare

Mary Rehm

Marian Budnar
Ursula & Mathias Forberger
James Gomez
Patricia A. Klosterman
Francine Phillips
Planet Earth Projects, Inc.
Carolyn Schmeltz
Ann & Joe Tartaro
Mary M. Thompson

David & Dennis Reigle

Mr. & Mrs. John N. Garns

Mary S. Risser

Mary Azrael
Madeline Brandon
Mr. & Mrs. Donald Brown
Helen Fultz
Harriet & Herb Goldman
Mr. & Mrs. John S. Risser
The Randolph Stroup Family
Brian & Karen Teaman

Hoyt Springer

Winona Springer

William (Bill) Westerfer

Brenda & James Blackmore
Reese & Marion Crowe
Skip Henry
Cathy & Mick Iacovelli
John, Fred, and Friends at
"The Imaging Group"
Ave & William Kelly, Jr.
Marge Kelly
The Krimm Family
Joan McManus
Carol Stairiker
Denise & Michael Westerfer
Donald and Dyane Westerfer

Myron Widdop

Keith Widdop

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: _____



A Very Special Birthday Party

BY ELIZABETH OUELLETTE

My nephew, Warren Ouellette, is a bright, outgoing, funny, and gregarious kid who lives in Shelburne, Vermont with his parents and his sister Lila. He turned 8 on July 20th and like most kids his age, he was looking forward to celebrating this very special day with his family and friends.

This year, Warren decided to invite his buddies to a Vermont Lake Monster's baseball game where they had oodles of fun eating hot dogs, drinking soda, and indulging in ice cream cake, topped with 8 sparkling

candles. Moreover, at the top of the fourth inning, his entire group was invited to the middle of Centennial field for solo pictures with Champ, the Lake Monster's endearing Mascot (Champ is a mythical sea monster who supposedly lives in Lake Champlain) and the entire crowd sang a melodious "Happy Birthday" in honor of Warren and his eight years of life. After hours of festivities, the game came to an end, the lights dimmed, and all the kids went home with party favors in hand and happy memories of this exciting event.

Why all the fuss about an 8-year-old's birthday party? Well, the difference between this birthday celebration and those of most kids I know is Warren's decision to forego any and all traditional presents. In lieu of gifts, he asked his friends to make donations to the CMTA in honor of his 13-year-old cousin, Yohan, who has CMT.

No, Warren was not coerced, cajoled, or coaxed into performing this selfless act of giving; this came straight from the heart. In recent months, several parents of children who attend Warren's school felt unsettled by the sheer quantity of toys, games, and other play items their children seemed to have accumulated over the years. With newer and better goods constantly put on the market, today's youth are bombarded with the message that the more you buy, the happier



Warren poses with Champ, a mythical monster from the depths of Lake Champlain.

you become. If we take all the kid-friendly publicity and commercials boasting the latest fads, computer games or electric 4-wheeled vehicles into consideration, can we blame our children for the pull toward consumer abundance?

With so much unused "stuff" piling up in each family's home, some moms and dads became resolved to teach their children about the broader needs of the community. For example, at one birthday party, Warren's peer asked that canned goods be brought to the Vermont Food Shelf. Another child wanted his birthday gifts in the form of donations to the Vermont Children's Trust Foundation.

So, when Mia, Warren's mom asked him if he would like to give to a charity or organization of his choice instead of gifts, his answer came out determined and decisive. With his hazel eyes aglow with enthusiasm and a bright smile, he



Warren proudly shows off the CMT poster which features his cousin Yohan.

looked sincerely at his parents and ebulliently proclaimed, “I want my friends to give to the CMTA to help Yohan so that he can get better soon!” And this is exactly what he set out to achieve.

His mom made up cute and informational invitations for the baseball game party detailing Warren’s request for gifts to the CMTA. Warren, who has always shown a keen interest and understanding of CMT and its effects, went about educating his friends and many adults about this disease of which they had never heard. From the moment Warren chose to raise funds for CMT, not once did he waver in his decision to support this organization, nor did he ever utter a word of regret for loss of potential presents. In fact, he could not wait to tell Yohan of his idea, not for praise or thanks, but so that his brother-like cousin may sense his support, love, and commitment toward finding a cure for CMT.

To close, I would like to thank Warren’s parents, Mia and Chris for empowering Warren with the knowledge that even at 7, 8, 9, or 10 years old, small gestures of selflessness can and do make an impact in the hearts and minds of many. But of course, my hero in this story is my nephew Warren, who never stops to amaze me. We are all moved by Warren’s altruism and empathic nature in all aspects of his life. Thank you for giving hope to many CMT-afflicted individuals all around the world and brightening Yohan’s days by letting him know just how much you care. You are the best! ❄

Journal Devotes Two Volumes to Charcot-Marie-Tooth Disorders

A special 2-volume edition of *NeuroMolecular Medicine* is devoted exclusively to Charcot-Marie-Tooth disorders.

The two volumes contain 18 articles on CMT written by the world’s leading researchers and scientists.

Through the generosity of Board of Director Gary Gasper, an electronic version of the journal was purchased for the association to post on our website.

One chapter discusses CMT1, the demyelinating form of Charcot-Marie-Tooth, which is characterized by median motor conduction velocities below 38 meters per second and pathologically by demyelination. Autosomal dominant CMT1 is the most common form of CMT, except in specific ethnic groups. There is a wide spectrum of severity, from classical CMT, which is usually mild to moderate, to the more severe forms such as Dejerine-Sottas and congenital hypomyelinating neuropathy (CHN). All of these forms are discussed in detail in the fourth chapter of the journal.

The chapter following the one on Type 1 discusses the axonal form of CMT or Type 2. CMT2 has normal nerve conduction velocities, but decreased motor conduction amplitudes. Type 2A, caused by a flaw in the gene mitofusin 2 (MFN2) has been established as the most prevalent axonal form, comprising up to 20% of CMT2. This makes it second only in frequency to the PMP22 duplication (CMT1A) on chromosome 17 as a cause of the CMT phenotype.

Among the other chapters are ones on X-linked CMT, animal models, molecular genetics, clinical aspects of CMT, electrodiagnostic studies, and some rarer forms of inherited neuropathies. The final chapter, “Therapeutic Strategies for the Inherited Neuropathies” by Medical Advisory Chairman, Michael Shy, MD, offers practical advice and information on living with the disorder.

In order to read more about the journal articles, go to www.charcot-marie-tooth.org/Physicians/NMM_Articles.php ❄





SUPPORT GROUP NEWS

Colorado – Denver Area

Our April meeting involved the topic of bracing. Our speaker was Paul Henderson, an expert in orthotics and prosthetics. It was helpful for all the members who wear braces to see other options. A meeting was held on June 24th and the next one will be on August 26, 2006, at the Capabilities Store in Westminster, CO at 10 AM.



Paul Henderson shows the Denver group one of the many bracing options he discussed at the meeting.

New York (Westchester County) – Connecticut (Fairfield)

At a recent support group meeting, Sandy Levy, of Hawley Lane Shoes, a board-certified pedorthist, showed each person in attendance how to properly fit his or her shoes.

The next meeting featured a presentation by Gopi Shah, a representative of "Lifeline," a personal response service available 24 hours a day, 365 days a year, with just a press of a button.

In April, the "Charcot Crusaders" participated in the "Stride and Ride" event, spon-

sored by the Muscular Dystrophy Association. Thanks to Frank Porter and his enthusiastic team, we raised over \$1,100. We had posters, music, and floats and were honored with an award for Team Spirit.

We ended our regular year with a potluck brunch and will meet again in September.

Our group meets every other month at Blythesdale Children's Hospital, Valhalla, NY. New members, family, and friends are always welcome.

Pennsylvania – Johnstown

JD Griffith and Jan Goodard research nurse at The John P. Murtha Neuroscience and Pain Institute, reported on the excellent and informative CMT Patient Family Conference for the support group members. The conference, held May 24th at the Hershey Medical Center, was sponsored by the CMTA. Thank you for a great day. Jan reviewed the morning speakers and JD the afternoon.

If you are a resident of Cambria or Somerset Counties please go to <https://www.conemaugh.org/> or call 1-888-606-0139 to participate in the CMT patient census. It is important to be a part of this survey as it may help determine future funding for CMT.

The members were excited about the CMTA TV ads featuring Pennsylvania's beloved Coach Joe Paterno. Also, the group has a free, like new, lift chair available for someone from the area.

Pennsylvania – Philadelphia Area

A meeting is tentatively scheduled for August 19, 2006, from 10 AM to noon at the office of the CMTA, 2700 Chestnut St., Chester, PA. All interested persons are invited to attend and help plan the schedule for the fall. ✨



Some proud members of the Westchester Support group show off their "Team Spirit" award at a recent meeting.

EDITOR'S NOTE:
Please see item on page 4 about two new support groups in search of members.

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: CMTA Office, 2700 Chestnut St. Chester, PA

Meeting: Bi-monthly

Contact: Pat or Dana, 800-606-2682

Email: CMTAssoc@aol.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

Senator Specter Urges Political Pressure for Research Funding

Senator Arlen Specter (R-PA) is chairman of the Senate Appropriations Labor-HHS-Education Subcommittee that is responsible for the budgets of the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC). At a recent Senate hearing on the FY2007 budgets for both NIH and CDC, two dozen disease advocacy groups testified that recent reductions of government research funding are having a devastating impact on the biomedical research field.

Congress doubled the budget of NIH from 1999 to 2003.

However, since 2003 budget cuts and inflation have reduced NIH funding by 11 percent. The budget this year alone represents a \$66 million cut from FY2005, and the President's proposed budget for FY2007 asks for the same funding next year.

At the Senate hearing, Senator Specter asked the patient organizations to do more than they are doing now to increase government funding for medical research. The Senator suggested that advocates should stage a million-person march in Washington, DC, with "enough people to be heard in the living quarters of the White House."

He also suggested that the groups should hold protests against the 27 senators of his own political party who voted against an increase for NIH funding. "You ought to march on them in their cities," he said. "This is a battle that has to be waged by the 110 million Americans that are suffering from these illnesses."

Senator Specter has survived a brain tumor, heart surgery, and lymphatic cancer, and has continued to work after surgery and through chemotherapy. He is a firm believer in the importance of biomedical research.

—*from NORD
ON-LINE BULLETIN*

Social Security Administration to Implement New Disability Process

In late March, the Social Security Administration announced new regulations that will establish a new disability determination process. The agency hopes the new process will shorten the time it takes for obviously disabled people to receive benefits.

Agency commissioner Jo Anne B. Barnhart said the changes would ensure "that we make the right decision as early in the process as possible." The new process will be implemented in the six-state New England region beginning in

August. SSA said it will wait at least one year before phasing in the system nationwide.

Highlights among the new procedures include:

- A faster determination process for people who are obviously severely disabled. The process is intended to resolve such cases within 20 days.
- Establishing a national network of medical, psychological and vocational experts to make accurate timely disability determinations.
- A new position—a federal reviewing official—will review state agency determinations when requested by the claimant. This will replace the reconsideration step of the current appeals process.
- Administrative law judges will have a goal of setting a time and place for a hearing within 90 days after receiving a hearing request.

A Decision Review Board, which will replace the current Appeals Council, will review and correct decisional errors. *



LETTERS

Dear CMTA,

Thank you for the great Hershey conference! The speakers were excellent. I especially enjoyed Dr. Scherer's presentation. It was very informative, answered some of my questions, and expanded my understanding.

If the State Capitol event is rescheduled, please let me know, as I live in the area and would like to attend.

Congratulations on the excellent production of the TV and radio public service announcements. People are seeing and hearing them—and remembering them. I was just diagnosed with CMT in November and many of my friends and acquaintances are just now learning about my situation. When I mention Joe Paterno's spot on radio and TV, a light bulb immediately goes off, making it much easier for me to explain what is happening in my body.

Thanks also for *The CMTA Report*. Each issue has very interesting and informative articles.

Keep up the good work.

—C.M., Mechanicsburg, PA

Dear CMTA,

Thank you for all the wonderful reading material you sent me today.

As I'm retired, I can't send \$40.00 this month, but after paying my rent in July, I will write a check for membership to the CMTA.

By being on the shy side, I'm just now learning about CMT through articles in the *MDA magazine* (once in awhile)

and now through your newsletter and brochures. I wish I had written to you before.

From the picture in your pamphlet, I realize I used to walk like that. I was diagnosed back in 1974.

Not having a computer, I can't receive emails nor look for information on the computer, so I'm glad I finally mailed off a letter to you.

—D.H.

Dear CMTA,

Our seventh and eighth graders organized and carried out a Valentine's Day Candy Gram fundraiser and a car wash to raise money for your organization. One of our students, Anna den Boef, is affected by this disorder and her classmates took it upon themselves to support her and your efforts. We hope this donation can make an impact on the research to find cures and assistance for others.

On behalf of Holy Family Catholic School, I would like to present to the CMTA a check in the amount of \$1,816.80.

—D. H., Teacher,
Holy Family Catholic School

Dear CMTA,

I've always been unable to pay for my membership, yet you have been kind to send me the newsletter. I'd like you to know it has helped me so much, since I have CMT.

I'm now 65 years old (or should I say, "young") and I've been living with this illness all my life. I've come this far and

still will not give up, but continue to do the best I can.

—J.M., West Palm Beach, FL

Dear CMTA,

In a recent *CMTA Report*, you had a brief article about Restless Legs Syndrome, which, in common with Charcot-Marie Tooth disorder, is widely spread and often not recognized as a serious neuropathy.

A friend and neighbor of mine, Robert Yoakum, who suffers from RLS, has just had a book published called *Restless Legs Syndrome: Relief and Hope for Sleepless Victims of a Hidden Epidemic*. This informative and substantial book of 239 pages is available through Simon and Schuster for \$14.95.

(Editor's note: I found it on Amazon.com for \$10.46.)

—E.M., CT

Dear CMTA,

Please let your readers know that the Charcot-Marie-Tooth United Kingdom has just published an updated version of their "Practical Guide." The revised edition was researched and written by John Islitt and it updates the original publication we did in 2000. It is available on CD and can be ordered on our website at www.cmt.org.uk.

—Secretary,
CMT United Kingdom

(Editor's note: Some of the information is specific to health care in the United Kingdom, but other information is general enough to be of interest to any CMT patient.)

The CMTA Report is published by the Charcot-Marie-Tooth Association, a registered non-profit 501(C)(3) health organization. © 2006, The CMTA. All rights reserved under International and Pan American Copyright conventions. No part of this newsletter may be reproduced in any form or by any electronic or mechanical means, including information storage and retrieval systems, without permission in writing from the publisher. The opinions expressed in the newsletter are not necessarily those of the Charcot-Marie-Tooth Association. The material is presented for educational purposes only and is not meant to diagnose or prescribe. While there is no substitute for professional medical care for CMT disorders, these briefs offer current medical opinion that the reader may use to aid and supplement a doctor's treatment.



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



2700 Chestnut Parkway
Chester, PA 19013
1-800-606-CMTA FAX (610) 499-9267
www.charcot-marie-tooth.org

Non-Profit Org.
U.S. Postage Paid
Glen Mills, PA
Permit No. 10