THE CMTA Report

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

NOVEMBER/DECEMBER
2009

CMTA

Charcot-Marie-Tooth Association

OUR MISSION:

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

OUR VISION:

A world without CMT.

Good News...*There's Never Enough of It!*

What a year 2009 has been for the CMTA and for CMT patients and families across the country! Never before has the CMTA been blessed with more members (4011) than we have today; never before have more support groups (44) existed across the country providing invaluable assistance to patients, families, and clinicians; never before have more world-class scientists been focused on finding treatments and cures for CMT; and never before have we been more optimistic that those scientists will find those treatments soon!

What this demonstrates is that together we can not only provide the hope that treatments will be available through our STAR research program, but also focus on the real challenges and issues of today that all CMT patients and families must live with. Maintaining this balance is core to our mission at the CMTA.

We will not rest, however, until all this changes. Having hope and making commitments sounds good and is good. But it is not enough. STAR is a world-class research program that is focused on finding drugs to treat CMT.…We need STAR to find those treatments now. Our national support group program helps families with a variety of health-related matters. We need strong, multidisciplinary clinical programs devoted to CMT patients now. The only way we can do this is with your help. More so than ever, we need to grow the financial support of both STAR and our patient advocacy programs.

The CMTA is fortunate to be led by a board of directors that has financially supported the mission of the CMTA. For the second year in a row, the CMTA Board has offered a challenge to the membership of the CMTA to match every dollar contributed to the CMTA, up to $350,000. Those are funds we simply cannot afford to lose.

Last year, the CMTA membership exceeded the Board Challenge Grant by contributing $362,153, making it our most successful fundraising campaign ever! With your financial support, we can exceed that number this year and truly make 2009 a year to remember.

> Your donation, doubled by the Board, can make a difference like never before.

I hope you will do what you can to support our work. Your contribution, doubled by the CMTA Board Challenge Grant, can make a difference like never before. Thank you again for all you do for the CMTA.

—David M. Hall, CEO

Our Growing Circle of Friends
See page 10

INSIDE:

Family and friends joined Tyler Lopez on a walk around Lake Katherine outside of Chicago.
See page 12.

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

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The CMTA Balancing Act

BY DAVID M. HALL, CEO

I am often asked how the CMTA is able to manage and keep up with all the various projects and programs that we have underway. There are fundraising activities such as the CMTA Board Challenge, the Circle of Friends, benefit races, swims, golf outings, and dinners. There is the national CMTA support group program, which is developing local communities of patients, families, and providers. There is the CMTA STAR research program, which is a global collaboration of scientists focused specifically on finding treatments for CMT1A. And when I add our work with the federal and state governments, considering the CMTA employs a grand total of five people, it makes me scratch my head as well.

Before I answer the question of "how," I think it's more important to understand the "why" behind the projects and programs of the CMTA. I can answer the "why" question with one word—*balance.*

Balance in how we design our strategies for finding the CMT treatments and cures of tomorrow versus the urgent medical and financial needs that CMT patients and families face today. Balance in striving for a world without CMT versus doing everything in our power to improve the daily lives of those living with the disease. Balance in that we expect physicians across the country to help patients with tomorrow's treatments but only when they're able to diagnose and manage the disease today.

How do we keep a balance between our goals for today and those for the future?

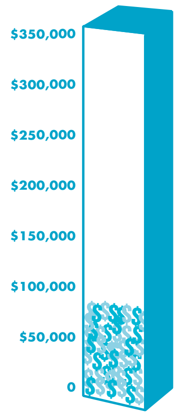
So how do we manage and grow these programs while keeping the balance between our goals for today and tomorrow? The answer is surprisingly simple—we turn to the experts.

With STAR, we are blessed to be partnered with world-renowned geneticists and scientists who have committed their professional lives to understanding the causes of CMT and ultimately unlocking mysteries associated with it. The CMTA has made and will continue to make significant financial investments in our STAR scientists to ensure we accomplish our strategic mission.

But who are the experts we can turn to for guidance in dealing with today's challenges? The answer is *you.* You are at the heart of our national support group program. Through our national support groups, you not only identify the questions we must ask, you help find the answers. You understand best that caring for the CMT patient requires a multidisciplinary approach, a coordinated effort between neurologists, primary care physicians, orthopedic surgeons, physiatrists, and physical trainers. And you know where to find those doctors. You know how to educate clinicians, school teachers, and public officials, and you understand that awareness about CMT must be priority number one.

The CMTA is able to manage the exciting number of programs and projects underway because we have never had so many experts helping us. Our scientific leadership is always looking to add to the STAR team to make sure the progress of our research program never stops. I ask you to do the same. Please don't stop looking for the next expert to add to the CMTA family as we must continue to progress in caring for the CMT patient today. I promise we'll keep them busy. ✻

THE 350K BOARD CHALLENGE: A LONG WAY TO GO!



As of Nov. 10th—$75,211

Fulbright Scholar Visits CMT Clinic at Wayne State University School of Medicine

BY DR. JOSHUA BURNS PHD, B APP SC (POD) HONS, INSTITUTE FOR NEUROSCIENCE AND MUSCLE RESEARCH, CHILDREN'S HOSPITAL AT WESTMEAD, UNIVERSITY OF SYDNEY, AUSTRALIA

I had a wonderful summer. As a Fulbright Postdoctoral Scholar I spent 3 months working with Professor Michael Shy and his team at Wayne State University School of Medicine (Detroit, Michigan) to learn more about the assessment and management of children and adults with Charcot-Marie-Tooth disease (CMT). Professor Michael Shy and his team are world leaders in the evaluation and treatment of people with CMT, and I was fortunate to visit during very exciting times at the Detroit CMT Clinic.

During my stay we worked on several interesting projects. In addition to observing clinics and attending research meetings, we developed the CMT Pediatric Scale, a measure of disease severity for children with CMT. There is a need for accurate, sensitive, and patient-relevant outcome measures for young children through to adolescents with CMT. The CMT Pediatric Scale captures symptoms, foot and ankle involvement, hand dexterity and strength, sensation, balance, and motor function. The CMT Pediatric Scale is intended to be a functionally relevant measure of disease severity in childhood CMT with broad application in natural history studies and clinical trials of therapies, surgery, and medications. In addition, we worked on projects investigating how best to measure health-related quality of life in children with CMT and discussed how new rehabilitative strategies might help with day-to-day activities.

It is hoped that my Fulbright experience will lead to ongoing collaboration between Australia and the United States to improve the care, and enhance the quality of life, of children and adults suffering with CMT. It will allow expansion of our therapeutic research and clinical trials capacity. It will enable us to achieve these goals in a coordinated program across two sites that are international leaders in the clinical and laboratory research of CMT. By collaborating, these achievements will lead to a progressive reduction in the community and healthcare costs by decreasing morbidity, increasing well-being, and increasing productivity of people with CMT.

Dr. Joshua Burns

The team at Wayne state University really welcomed me and ensured an excellent experience. Professor Shy was a gracious host; he is a thoughtful, funny, and caring gentleman. I thoroughly enjoyed my time in the United States.

The team enjoyed my farewell dinner at a local Belgian café in Detroit. ✻

SWINE FLU AND REGULAR SEASONAL FLU INFORMATION

Dr. Michael Shy from Wayne State University offers the following information regarding the safety of flu shots for CMT patients:

"To the best of my knowledge, there is no reason for a CMT patient to avoid the vaccination for the swine flu or other flu. CMT patients are no more likely to have an allergic reaction to the vaccine than any other person. For patients with respiratory problems, the flu can be especially serious. Often patients are worried about Guillain-Barré syndrome, which is a reaction to vaccines or other processes that results in sometimes severe peripheral neuropathies. There is no evidence that this is more likely in CMT patients than non-CMT patients, and it is likely a rare occurrence. As far as I am concerned, there is a greater risk of trouble from contracting the swine flu in compromised CMT patients." ✻

"Top Ten" List for Parents of Kids with CMT

BY ELIZABETH OUELLETTE

I was recently asked to provide the top ten suggestions I would give a parent whose child has CMT. Here is what I have come up with.

1 **EDUCATION.** The new booklet, "My Child Has CMT," recently published by the CMTA, is the best printed guide to date. It is filled with advice, information, and invaluable resources for parents whose children have CMT. Call the CMTA or order your copy online today. In addition, read about the fundamentals of Charcot-Marie-Tooth disorder and sign up with the CMTA to receive updates on current CMT news. Most forms of CMT can be managed with physical therapy, braces, orthotics, and a fundamental understanding of what CMT is and how it affects each individual differently. The symptoms and severity of two people within the same family, with the same type of CMT, can vary significantly. So, if a parent is in a wheelchair and disabled by the effects of CMT, this does not necessarily mean the child will have the same symptoms or outcome.

2 **ATTITUDE.** The reaction and response of parents towards the diagnosis of a child's CMT will affect that child profoundly. If a parent is very distraught about the diagnosis of CMT, it is important that the parent(s) talk with a professional to eventually embrace the diagnosis. Although it is sometimes difficult to keep emotions intact, a positive outlook and a gentle understanding toward the child, which includes empathy (not sympathy), will help a child with day-to-day struggles much more than an anxiety-ridden household which promotes helplessness and negativity about the CMT.

3 **HOPE.** The CMTA is now working hard on treatments and a cure for CMT through the Strategy to Accelerate Research (STAR) initiative. Learn more about STAR and just how hard our scientists are working to find a treatment and eventual cure for CMT. If there is one message to give your child, it is one of hope and promise for the future.

4 **ACCEPTANCE.** Parents and children will experience a wide range of emotions from sadness and despair to anger then acceptance and back to sadness again. If the parents learn to cope with the diagnosis of CMT, it will be that much easier for the child to "own" his or her personal life process with this progressive neurological condition. In my own personal opinion, I do not believe in hiding or being ashamed of this condition, because we all have differences, and CMT is yet another one of life's challenges to manage and overcome. It is true that many parents feel guilty for having passed the disease on to their children, but feeling guilty serves no one in the end. Every single parent genetically passes many physical, behavioral, and biological traits on to his or her child, and if the CMT gene is included, then so be it. The reality is that changing the past is not an option, so accept the present and teach your kids to live life to the fullest, despite their differences.

5 **ROLE MODELS.** The parent who has CMT can be a wonderful role model for his or her child. Show your children how to confront conflict and adversity by role modeling coping behaviors that you would like to see him or her replicate in the future. You may also find wonderful role models from within the CMT community. Anthony Zhan is a biker who is on the US Paralympics' team and has been very successful in his pursuits and goals, despite his CMT. Jonah Berger is a young man who wrote a book called *Walk Like a Cowboy* about his experiences with discovery and acceptance and of his own CMT. He now works with handicapped kids, playing the drums as a means of personal expression and sharing his talent with others. These are just a few of the many unbelievable individuals who are winning the game with the deck of cards life has thrown their way. Find others who have CMT and share their exploits with your family.

6 **WAYNE STATE AND DR. MICHAEL SHY.** Take your child to the Wayne State CMT Clinic, if possible. When I took my son to Wayne State to see Dr. Shy and his team, it was as if the sun started shining in my shady neck of the woods again. We felt accepted, understood, and supported by every single staff member there. We met others dealing with CMT-related issues and felt that we were not alone any longer. His website is: http://neurology.med.wayne.edu/neurogenetics/about_clinic.php

7 **CMT SUPPORT GROUPS.** I think it is important for parents to attend a CMT support group, if possible. I know there are not support groups in every corner of the US, but we do have quite a few (44 and counting), and the support group communities are a constant source of education and information. Parents hesitate to bring their kids to the support groups, which is understandable. However, if you find other parents at the support group with a child in the same age bracket as your own child, plan a day where the kids or teens can get together around common interests, have dinner, and promote relationship-building.

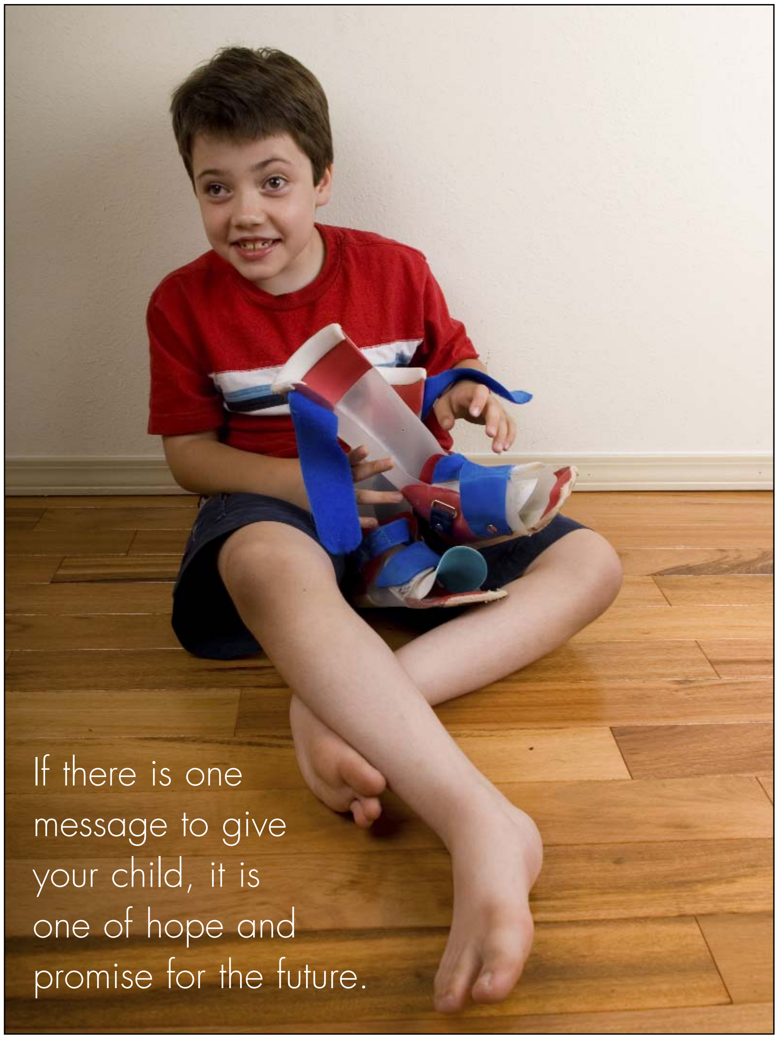
8 **ORGANIZATIONS.** Make sure to join the CMTA and sign up for email updates. Our newsletter, website, and other informational materials provide up-to-date information on all types of CMT.

Register with the Muscular Dystrophy Association (MDA). The MDA provides services to all those who have been diagnosed with CMT. Kids grow especially fast, and those who need yearly bracing and other aides or even physical therapy can provoke financial crisis within a family. The MDA also sends out a free newsletter which may or may not include CMT information, but the focus is both on kids and adults and the struggles they have to face daily. Moreover, the MDA summer camp for kids with all types of MD has been very popular among kids with CMT. Many go on to become counselors to help others with severe disabilities. It's a win-win situation.

Shriners Hospitals for Children will also accept children up to the age of 18 with CMT. Shriners provides a one-of-a-kind international health care system dedicated to improving the lives of children by providing specialty pediatric care, innovative research, and outstanding teaching programs.

9 **MEDICAL ISSUES.** If your child is dealing with physical pain, depression, sleep apnea, or any one of a large number of comorbid conditions related to CMT, bring your child to your general practitioner and request specialist referrals who know about CMT. As your children grow, pay attention to their spines, as scoliosis and kyphosis

(continued on page 6)



If there is one message to give your child, it is one of hope and promise for the future.

"TOP TEN" FOR KIDS

(continued from page 5)

can creep up before you know it. The spine disorders usually worsen during puberty, so keep your eyes open and intervene quickly to avoid further complications in the future. Moreover, we found that alternative therapies like biofeedback and relaxation not only helped with pain, but also helped with the anxiety and/or depression that can come with having a progressive neuromuscular disorder that is not very well understood.

10 EXPLAINING CMT. Find easy ways for your child to explain what he or she has to playmates and peers. These explanations should be age-appropriate, so, if for example, you have a seven-year-old with CMT who has a hard time with gym class in school, it may make your child feel better if he or she has words to explain what CMT is. For a seven-year-old, I would recommend saying "my legs don't work quite right and my muscles are not very strong because of CMT," or "I wear braces so that I don't trip." It is the parents' job to educate the teachers and your child's friends. Make sure you let schoolmates know that CMT is not contagious and it will not kill your child. These are real fears that many children have which will cause them to avoid playing or hanging around your kids. The CMTA has a DVD called "Teaching Kids about CMT" which you can use in many ways. You may want to do some of the activities on this DVD for friends and family to help them understand CMT better. Or you may want to give the DVD to your child's teacher so that he or she understands your child's difficulties better. I myself made the program up for elementary school kids to foster understanding of CMT in a fun and educational way. However, make sure your child feels comfortable with the concept, before you go into the classroom to do this presentation. ✻

Fundraisers for the Holiday Season

✻ **To order the special STAR stamps,** visit our website: www.charcot-marie-tooth.org and click on the link "STAR postage stamp." This will bring you directly to Zazzle, an online producer of quality customized products. Once there, click on "To create a world without CMT" and choose your valid USPS postage stamp.

Help us spread awareness and ultimately achieve our vision of a world without CMT.

✻ **An independent beauty consultant** has offered to help the CMTA raise funds for the association's Strategy to Accelerate Research (STAR) initiative by offering customers a 10% discount on their purchases of cosmetics and beauty aids and donating 20% of all proceeds to the CMTA. An additional 5% discount will be given with the purchase of special products such as hand creams, shaving creams, lipstick, and lip gloss. This is a great way to do some holiday shopping and help the CMTA, and all from the comfort of your home, so please invite your family and friends to participate and help the CMTA fund research.

For complete details, please contact Walter Donikowski, at 610-960-1199 or by email at walterdonikowski@hotmail.com (and be sure to include the words CMT STAR in the subject line). ✻

LIVING WITH CMT

Readers Send Suggestions for Shoes and Sneakers

I normally try to make a purchase from a vendor or test a product or idea before passing the information on to you, but that wasn't an option in this case because there are so many styles and shoe stores. So, while I have edited the responses for grammar and brevity, the suggestions and opinions presented here are those of the individuals identified and not of me or of the CMTA. We neither imply nor express any endorsement of the products or merchants mentioned below.

Diana from CA wrote to say that she and her mother looked for years for attractive women's dress pumps that would fit their high arches and stay on their feet, and she has just discovered "Clare Mary Janes" by Croft and Barrow. Available only at Kohl's department stores (www.kohls.com), the shoes have all-leather uppers, low heels, and two thin straps that hold them on. They list for $49.99 and are also available in widths.

"Clare Mary Janes" by Croft and Barrow

For a casual tennis shoe, Lisa, also from CA, loves the Easy Spirit Get Up and Go. "They have a little stretch panel in the side, which appears to give that extra room we need for our AFO's, and the rocker bottom front helps me with rolling up on the toes. At first I was a little tense because they also added an additional inch to the height (which I loved but I was worried about stability) but I never noticed a balance issue. And comfort—*wow!* Even with the AFO plastic under my feet, I could still feel the cushion from the padding in the sole." The Get Up and Go is available in widths and lists for $79.99 from www.easyspirit.com.

EasySpirit "Get Up and Go"

The CMT foot can, of course, present special challenges when it comes to footwear, and Catherine, a DPM, wrote that many CMT patients require an accommodative insert/orthotic in the shoes to offload pressure areas. Catherine also wrote that any pedorthist/orthotist or podiatrist who does "diabetic shoes" can get athletic, casual, dress, and orthopedic shoes that are extra depth and up to 4E width, as well as shoes that are washable and stretch for swelling. However, as a podiatrist, she generally will not sell shoes to people off the street. She likes to see them as a patient at least once to evaluate them and advise them about footcare.

In the Detroit area, Lisa from MI recommends Footwear Footcare in Warren, a family-owned business that carries nice-looking women's shoes by PW Minor, Munro, and Saucony. For hard-to-fit customers, they build up shoes and adjust them as needed. They also have an online store at www.footwearfootcare.com.

In NY, Jerry says Moulded Shoe (http://mouldedshoe.com), a family-owned shop on east 39th Street in Manhattan, is excellent. They will sell from stock or custom build, and they really take care of you, both when you buy and afterward. If you need wide shoes, Jerry likes Hitchcock Shoes (www.wideshoes.com). Primarily for men (sorry, ladies), Hitchcock sells a variety of brands including New Balance and Drew, but they also have shoes in widths up to 6E, made only for Hitchcock.

—*Dana Schwertfeger*

HAVE A PRODUCT SUGGESTION OR TIP FOR MAKING LIFE WITH CMT EASIER?

Email it to: mac@cmtausa.org or mail it to:
Mac's Tips, CMTA, 2700 Chestnut Parkway, Chester, PA 19013

WRITE TO US!
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GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Eleanor Arcieri
Ms. Elaine P. Cooper
Mr. and Mrs. Herman E. Jorgensen

Janice L. Avery
Mrs. Diane B. Brant
Ms. Julie M. Kinsey
Mr. and Mrs. Richard Orwig

John M. Bachkosky
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Elvira Bucceroni
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Mrs. Phyllis Sabo

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The Society of St Vincent de Paul

Jack Walfish
Mr. and Mrs. Jerry Walfish

IN HONOR OF:

Bailey-Sugden Wedding
Mrs. Brandi Sugden

Johnny Bonner
Mr. David Neilsen

Patrick Coles
The Ballweg-Pulju Family

Tim Crosby
Ms. Susan E. DeFonso

Erin Davenport
Mr. and Mrs. Rex Macey

Gail Feeney-Coyle
Ms. Marian J. Bakken

Bishop John Kinney
The Ballweg-Pulju Family

Darin Ramsay
Mr. Gavin W. Ramsay
Ms. Janelle N. Ramsay

Yael Reynolds
Mr. and Mrs. Mark L. Kaufmann

Lauren Olivia Roskopf
Ms. Jennifer H. Roskopf

Jackie Feldman Sachs
Mrs. Louise Potash

Dr. Eugene Sidoti
Mr. Donald R. Flick

Bill and Janet Soinski
Mr. John S. Jones

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 ☐ American Express

Card # ____________________

Exp. Date ____________________

Signature ____________________

Gift Given By:

Name: ____________________

Address: ____________________

____

RESEARCHER PROFILE

Stephan Züchner, University of Miami

Dr. Stephan Züchner is an Associate Professor in the Departments of Human Genetics and Neurology at the University of Miami. He received his clinical training in neurology and neuropathology at the Medical School of the University of Aachen, Germany. In 2003, a neurogenetic scholarship from the German Research Society (DFG) allowed him to spend a year of research in Dr. Jeffery Vance's laboratory, then at Duke University. At Duke University Dr. Züchner discovered his passion for human genetics research, and together with Dr. Vance he identified several genes for CMT and related diseases in short sequence.

In 2007 the majority of the human genetics faculty at Duke University was lured to the University of Miami to start a new, highly interdisciplinary genetic research institute, now known as the John P. Hussman Institute for Human Genomics, which has meanwhile grown to >200 employees and is counted among the most significant genetic institutes in the world. Within the institute, Dr. Züchner is heading the Center for Human Molecular Genomics, and his own research group tackles problems from gene identification to functional characterization of genes and biological pathways.

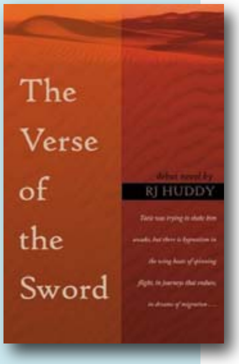
Dr. Stephan Züchner

The CMT research program at the Hussman Institute has grown considerably, and the excitement was further fueled by the most recent NIH-funded project that involves some of the best clinicians in CMT, including Dr. Michael Shy and Dr. Mary Reilly, who will work in collaboration with Dr. Züchner to apply the latest in genomic technology to gene and genetic modifier identification in CMT2 and CMT1A.

Since the original discovery of the CMT2A gene, mitofusin 2, Dr. Züchner's group has been studying the functional aspects of this important protein in cell culture models. He also recently developed a novel transgenic mouse model that will mimic CMT2A neuropathy and will allow studies more closely resembling the situation in CMT patients. These activities have been made possible thanks to funding from the NIH, as well as steady and significant support from the CMT Association of North America.

Dr. Züchner grew up in the city of Dresden in what used to be East Germany. Rather timely, the fall of the Berlin wall allowed him to attend Medical School in Frankfurt and Aachen. He and his family of three daughters moved to the United States in 2003 and now live in Miami. His wife is a trained architect, but works as a freelancing artist and designer. In recent years, he observed that the excitement with genetics has taken over much of his life. When possible, he goes sailing or hiking, but most often he spends his time with his family. ✻

THE VERSE OF THE SWORD, the debut novel by RJ Huddy, a man with CMT, which we profiled in the July/August issue of the newsletter is now available through Amazon.com. A portion of the proceeds from the novel goes to CMT research. The novel has a list price of $17.50. For ordering purposes, the ISBN number is 978-1-59028-237-3. You can read online at www.xpatfiction.com. *The Verse of the Sword* is a love story, an adventure, and a travelogue; a many-layered tale of creeping tension deftly told with insight and surprising humor. ✻



The CMT "Circle of Friends"

Since we began the CMTA Circle of Friends program, our members have found many new and creative ways to support the work of the CMTA. People who initially began with a simple letter to their friends and family have built upon their success and now hold annual dinners, walks, and tournaments.

Others have met the challenge by finding ways to get their employers and other companies involved through sponsored events and matching gift programs.

If you would like to take up the challenge to get involved and start your own Circle of Friends, call us today at 1-800-606-2682, email us at cof@charcot-marie-tooth.org, or visit us on the web at www.charcot-marie-tooth.org/cof.

Working together, can create a world without CMT!

Cousin of Former CMTA Executive Director Paul Flynn Plans Cross-Country Ride for CMT Research

When Ken Gomez retires in 2011, he is going to honor the memory of his cousin, Paul Flynn, a former Executive Director of the CMTA, and ride his bicycle 4200 miles across the country in an effort to create awareness about CMT and to raise funds for the CMTA's STAR research initiative.

Ken is planning to start in Anacortes, WA, and end in Bar Harbor, ME.

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

Ken Gomez, standing, and his son, Paul, will be part of a fundraiser to honor the memory of former Executive Director, Paul Flynn. Ken will ride across the country to raise awareness of CMT and money to support STAR.

We admire Ken's courage and are very grateful for his effort to raise awareness and money for CMT research. Like Ken, his cousin Paul believed that people should strive to do whatever they could despite having CMT, and we are also pleased to inform you that the Paul Flynn Charitable Trust will be supporting Ken's effort by matching up to $22,000 of donations made to Ken's Ride.

If you are as inspired by Ken's effort as we are, please visit www.cmtausa.org/kensride to sponsor him at a penny or more a mile.

Through your support of Ken, you will help the CMTA to continue funding the STAR initiative and bring us closer to finding effective treatments for CMT. ✻

Grace's Courage Crusade

Mr. & Mrs. William Alexander
Ms. Florence L. Allen
Mr. & Mrs. Lincoln D. Almond
Amica Companies Foundation
Mrs. Kathy E. Anderson
Mr. & Mrs. Thomas L. Andrew
Ayco Charitable Foundation
Ms. Sue Leilani Baris
Mr. & Mrs. Ron Barlow
Ms. Kathleen A. Barrette
Mr. & Mrs. Charles Beck
Mr. & Mrs. Robert W. Benjamin
Mr. & Mrs. Paul T. Bernardi, Jr.
Mr. & Mrs. Robert D. Brown
Mr. & Mrs. Robert Caffrey
Ms. Alberta R. Caldarone
Ms. Milva Catallozzi
Mr. & Mrs. Robert Censabella
Charlestown Auto Body
Mr. & Mrs. Joe Clark
Mr. & Mrs. Constantine Clemente
Mr. & Mrs. Francis P. Clossick
Mr. & Mrs. Bernard C. Coghlan
Ms. Karen A. Colicchio
Mrs. Lois E. Crudden
Mr. & Mrs. Dean D'Andrea
Mr. & Mrs. Albert I. Darbey
Mrs. Carolyn Darling
Mr. & Mrs. William de Silva
Mrs. Jane A. Degnan
Mr. & Mrs. Kevin J. DeLoge, Sr.
Mr. & Mrs. Russell Demarco
Mr. & Mrs. John H. Devereaux
Mr. & Mrs. David A. Devine
Mr. & Mrs. Louis DiFante
Mr. & Mrs. Thomas A. Drennan, Jr.
Mr. & Mrs. Leonel J. DuBois
Mrs. Annmarie Durning
Ms. Janet Edmond
Mr. Matthew F. Edwards
Mr. John Fanning
Mrs. Jaclynn M. Ferria
Ms. Pauline H. Fewster
Mr. & Mrs. Jeffrey E. Fischer
Mrs. Donna Fitts
Ms. Mary Anne Flaherty
Mr. Donald Flick
Ms. Lynne Francois
Mr. & Mrs. Andrew F. Gagnon
Mr. & Mrs. Tom Gilligan
Dr. & Mrs. James R. Guthrie
Mr. Dan Hagerty
Mr. John C. Halloran
Mr. & Mrs. Lewis Hassell
Mr. & Mrs. Michael P. Hassell
Mr. & Mrs. Lewis Hassell III & Family
Ms. Megan K. Havener
Mr. & Mrs. James R. Heagney
Ms. Judith A. Healey
Mr. Paul F. Helweg
Mr. & Mrs. David Henry, Jr.
Ms. Lee Ann M. Hooper
Mr. & Mrs. Daniel J. Hughes
Mr. Will Humphrey
Mr. & Mrs. Edward H. Kammerer
Mr. & Mrs. John S. Kanakry
Mrs. Barbara J. Kelly
Mr. Charles W. Killian, Jr.
Mr. & Mrs. Carl S. King, Jr.
Mr. & Mrs. Peter J. Kirwin
Ms. Sarah M. Kirwin
Mr. & Mrs. Donald E. Klein
Mr. & Mrs. Matthew Lang
Ms. Bethany A. Lardaro
Mr. & Mrs. Mark Larned
Dr. & Mrs. A. Laurenzo
Mr. Jeffrey M. Lenihan
Mr. Thomas R. Leto, CFC
Mr. & Mrs. Patrick Livney
Dr. & Mrs. Scott J. Lloyd
Ms. Alicia A. Loffredo
Mr. Joseph A. Lopes
Mr. & Mrs. John D. MacDonald
Ms. Lauren D. Manning
Mr. & Mrs. Herb Mansfield
Ms. Patricia McGauran & Mr. Ken Richmond
Mr. & Mrs. Gerard McLoughlin
Mr. & Mrs. Andrew P. McMahon
Ms. Brenda Medina
Mr. & Mrs. Christopher B. Metcalf
Ms. Debbi A. Miceli
Mr. & Mrs. Joe Miltimore
Ms. Jennifer Morin
Mr. Robert E. Mousseau
Ms. Patricia A. Murphy
Ms. Rose M. Nealon
Mr. & Mrs. James T. Neary, Jr.
Mr. & Mrs. William J. Nee
Mrs. Iris M. Ornberg
Mr. & Mrs. Todd M. Oster
Mr. & Mrs. Robert T. Parker
Ms. Andree J. Rathemacher
Mr. & Mrs. David M. Reddington
Ms. Cynthia Reiser
Mrs. Jennifer A. Ricci
Mrs. Susan E. Rice
Mr. & Mrs. Eugene Rizzo
Mr. & Mrs. David W. Rolin
Mr. Douglas M. Rosie
Ms. Linda A. Ruggieri
Mr. & Mrs. Everett Salisbury
Ms. Amanda L. Santello
Mr. Domenic Scardera
Mr. & Mrs. James P. Sheehy
Mrs. Nancy W. Sherman
Dr. & Mrs. Eugene J. Sidoti
Mr. & Mrs. Mark S. Sidoti
Mr. & Mrs. Peter Sidoti
Mr. & Mrs. Anthony N. Silvestri
Mr. & Mrs. Gary P. Southwick
Mr. & Mrs. Timothy J. Sullivan
Ms. Kitty Tally
Mr. & Mrs. William A. Tavares, II
Mr. & Mrs. Albert R. Vanasse
Mrs. Barbara M. Vigeant
Mr. & Mrs. Henry A. Walker
Washington Trust Co.
Mr. & Mrs. Lawrence A. Webber
Mr. & Mrs. David A. Zartarian
Mr. Gregory M. Zenion
Mrs. Deborah A. Zonfrilli

GRACE'S DINNER PARTY

On September 26th, the second annual dinner party for Grace Caldarone's Courage Crusade was held at the Village Inn Grand Ballroom in Narragansett, RI. Approximately 250 people joined Grace and her mother Mary Beth *(pictured right)*, for dinner and to bid on things like a plasma TV, original artwork, and sports memorabilia. The climax of the evening was a bidding war on cakes that were donated by area bakeries and renowned chefs. Proceeds from the dinner will benefit the STAR research initiative. Chairman of the CMTA Board of Directors, Patrick Livney, discussed research news and read a letter from Dr. Michael Shy regarding how the advances in research will benefit the Caldarones, who have type 2A.

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KFC GOLF TOURNAMENT

In August, the Tristate Kentucky Fried Chicken team donated the proceeds from their annual golf tournament to the CMTA's Board Challenge. Special thanks go to Barry and Doug Knipp for their generous gift.

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GE AVIATION'S CHARITY GOLF EVENT

GE Aviation in Durham, NC held a Charity Golf Tournament for the CMTA on Friday October 23rd. Every fall the Aviation Facility picks a cause to raise money for; with the help of Jeana Sweeney's brother-in-law (who works there), this year they chose Charcot-Marie-Tooth disease. Jeana had the pleasure of attending this event, not to golf but to network and raise awareness. There were over 65 golfers, and, since she was selling CMTA bracelets and 50/50 tickets, she got to meet all of them and explain or answer their questions about CMT.

Thanks go to Joe Sweeney, Gary Weber, and Doug Mclean for making this event happen. Not only did the event raise money, but 65 more people now have an understanding of what CMT is.

Not only did GE promote awareness for CMT in NC, but three young ladies who are GE employee family members reached out to help. They took time to go around their neighborhood and sell the CMTA bracelets. Thanks to Tiffany Sweeney and Kylie and Jamie Doyle for their work.

CMTA Circles of Friends (cont.)

Erwin Family COF

Mr. James Askew

Ken's Ride

Ms. Margaret S. Accordino
Mr. John B. Agati
Mr. & Mrs. John J. Agosta
Ms. Janis M. Gomez Anderson
Ms. Brenda Berger
Ms. Elaine V. Bolton
Mrs. Marian Budnar
Ms. Christine Cafasso
Mrs. Dolores Cafasso
Mr. Paul W. Culligan
Mr. Anthony Finizio
Mr. & Mrs. Richard C. Flaherty
Mr. & Mrs. Leonard Freeman
Mrs. Diana L. Fritzen
Ms. Danielle Gomez
Mr. Joshua Gomez
Mr. Ken Gomez
Mr. & Mrs. Jim Gulley
Mrs. Linda Hickey
Mr. & Mrs. Robert Homyak
Mr. Charles J. Keeley
Mr. Malcolm O'Malley
Mr. Thomas Ribson
Mr. John F. Vetter
Ms. Danielle Jo White
Mrs. Victoria M. White

Reagan's Quest

Mr. & Mrs. Steve Franczyk
Mr. Archie Livingstone
Ms. Kristin S. Mackert
Mr. Joel D. Mendelsohn
Mr. & Mrs. Rick Olejnik
Mrs. Rosamond G. Savage
Mr. & Mrs. Wesley C. Stultz
Mr. & Mrs. Mark R. Stultz
Mrs. Susan M. Taylor
Mr. & Mrs. Eric Thomas

Team Julia '09

Mr. Steve Alper
Mr. & Mrs. Cliff S. Berliner
Mr. & Mrs. Steven Bernstein
Mr. & Mrs. David Beron
The Big Screen Solution
Mr. & Mrs. Jonathan Bloom
Dr. & Mrs. Jeffrey T Brodie
The Estate of Mildred Burg
Mr. & Mrs. Yale H. Caplan
Mr. & Mrs. Michael Carver
Mr. & Mrs. Frank Coppola
Mrs. Lois Davis
Mayor Frank De Bari
Ms. Lauren Eras
Mr. & Mrs. Brian E Fleisig
Mr. & Mrs. Ron Geffner
Mr. & Mrs. Steven G. Grossman
Mr. & Mrs. Sanford A. Heumann
Mr. Alan R. Katz & Mr. L. Jimmy Katz
Morgan Stanley
Mr. & Mrs. Clifford R. Neukrug
Mr. & Mrs. Brian Olson
Mrs. Diana I. Ortiz
Mr. & Mrs. Christopher Pompeo
Mr. Joel L. Rauchberg
Ms. Donna L. Bass-Reichman
Mr. Robert M. Reilly
Ms. Fran Reinstein
Mrs. Amy Resnikoff
Mr. & Mrs. Richard Schatzberg
Ms. Berylin Tancer Schwab
Mrs. Meryl J. Sieradzky
Mr. & Mrs. David E Slavitt
Mr. & Mrs. Michael Sonnabend
Mr. & Mrs. Mark Tabakin
Txttlktees LLC
Mr. & Mrs. Theodore Vagias
Mrs. Ellen B. Walker
Ms. Elizabeth Wallace
Mr. & Mrs. Robert E. Weiner
Mr. & Mrs. Jeff Weinflash
Mr. & Mrs. Bernard Wolfeiler

Tyler's 3rd Annual Benefit & Walk

Mrs. Debra A. Alyinovich
Mr. Kerry L. Barton
Mr. & Mrs. Richard Barton
Mr. & Mrs. Todd Blue
Mr. Douglas G. Bridwell
Mr. & Mrs. David Bufka
Mrs. Jill A. Cano
Mr. James W. Cockerill
Mrs. Bridget Dickinson
Ms. Rae Egan
Mrs. Linda M. Fedro
Mr. Michael Figiel
Ms. Virginia M. Fisher
Mr. & Mrs. Frank Gaidjunas
Dr. Diane Garrison
Mr. & Mrs. Edward T. Graney
Ms. Marion Gray
Ms. Carolyn M. Grela
Ms. Jennifer A. Gricus
Mr. Amit Hasak
Ms. Margaret Hermann
Mr. David M. Hall
Ms. Bernadine A. Hill
Mr. & Mrs. Edward C. Hill
Mr. & Mrs. Frederick Hill
Mr. Donald Jager
Mr. George Karson
Mr. Arnold Kaslofski, Jr.
Mr. & Mrs. Donald E. Krause
Ms. Sharon Krengel
Ms. Nancy A. Langosch
Mrs. Patricia Longanecker
Mrs. Julie Andersen Lopez
Ms. Nitzia Lopez
Mr. Paul Lopez
Mrs. Ramona Lopez
Mr. & Mrs. Ron Lopez
Mr. Rory J. Lopez
Ms. Cathy Marose
Mr. Michael McNichols
Dr. Elsbeth F. Meuth
Ms. Marita R. Moniger
Mrs. Jean A. Moore
Ms. Kathleen M. Murray
Mrs. Harriet Neitzel
Mr. Kenneth L. Olson

Zelenowski's Quest

Mr. & Mrs. Robert C. Embleton
Mr. & Mrs. Harry Fairclough
Mrs. Karen Huntley
Mr. & Mrs. John V. Ingari
Mrs. Kristin D. King
Mr. & Mrs. Joseph Lankowski
Mrs. Patty Pearce
Mr. & Mrs. Jack R. Scheatzle
Mr. Robert Scoda

fundraisers

ELLERBE FOUNDATION DINNER

On October 9th, the Elizabeth Necole Ellerbe Foundation held its second annual black tie dinner in honor of seven year old Lizzy, who has type 2B CMT. The event was held at the Downingtown Country Club in Downington, PA and featured a buffet dinner and music by a local rock gospel band. Pat Dreibelbis, Director of Program Services, discussed the latest research findings and the news that a type two mouse has recently been developed.

Courteney LaChey Bolton-Johnson, Lovette Ellerbe, and Elizabeth (Lizzy) Necole Ellerbe *(pictured above)* spearheaded the black tie dinner-fundraiser on behalf of Lizzy and CMT.

fundraisers

TYLER LOPEZ: DINNER & WALK

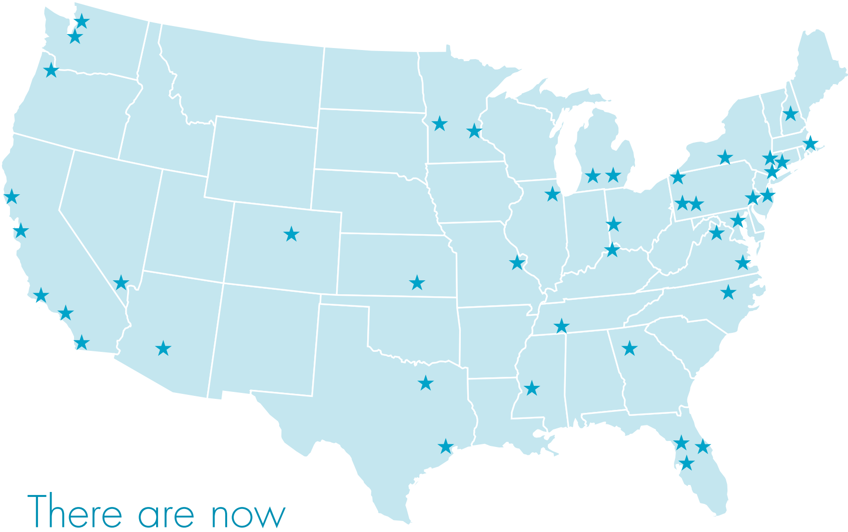
On November 6th, Tyler's Third Annual Benefit for the CMTA and Research, was held at 115 Bourbon Street in Chicago, IL. Over 250 people attended the dinner and were treated to musical entertainment by Tyler's father's band, The Beaters. In addition, the attendees bid on silent auction items and purchased chances to win any one of the many baskets of goodies that were offered. Then, on November 8th, on an unseasonably warm day, family and friends of Dan, Tyler, and Dale Lopez *(pictured below)* gathered at the Lake Katherine Nature Preserve in Palos Heights to walk in honor of Tyler and to raise money for the research fund of the CMTA.

Attending a Support Group Meeting—Is It For You?

BY SUSAN RUEDIGER

You may have noticed by reading the bimonthly newsletters that there are 41 support groups in the United States with 3 more in development. You have probably looked in your region to see if there was one in your general vicinity. You've looked at the meeting times and dates and thought that perhaps one day you might attend one. You are a little reluctant. What would it take for you to talk about your disability? What could you possibly benefit from attending a meeting? What would everyone think of you? Could there possibly be that many others with CMT who share your challenges?

In Atlanta there are 77 people who have expressed an interest in the support group. The membership includes seniors, young adults, children affected by CMT. It includes spouses and important family members who are interested in learning more about living with CMT. It also includes medical service providers including doctors, nurses, physical therapists, and orthotists. On average 25 people attend each meeting, some with greater regularity than others. The support group has met 10 times since April 2008. Topics have included visits from Dr. Michael Shy, CMTA Chairman, Pat Livney, Sean McKale, a leader in CMT orthotics, our local physiatrist, a physical therapist, a psychologist, and a representative from the MDA. As a leader of the support group, I have wondered what impact the meetings were making on the CMT community in Atlanta.



There are now 44 CMT support groups across the country. Consider being part of your local CMT community by joining one of them.

At our most recent meeting, I was overwhelmed by the many people who spoke of improvements to their lives. Three families have visited Dr. Shy's clinic in Detroit. Two more are scheduled to visit in the next three months. Three people have found a correct orthothic device, solving discomfort and loss of strength concerns. Five people have found a local doctor and physical therapist and feel supported by the medical community. Two have acquired new scooters, which they learned about at a meeting; both scooters were free. Two have sought additional psychological assistance for coping with a CMT diagnosis. Three people have changed or modified their exercise regimen to benefit their bodies rather than cause additional stress.

Many members have expressed a sense of belonging and comfort within the group. We feel safe in sharing concerns and troubles associated with CMT. We are inspired by the research and hope for CMT patients. We leave happy, supported, and inspired to share our stories. We are talking about CMT with peers and medical professionals positively impacting the world of CMT. Won't you consider being a part of the CMT community? ✻

SUPPORT GROUP NEWS

California—Los Angeles
The group met on October 3rd. It was their first meeting in the new location, the Hilltop Community Church in El Segundo. About 45 people attended and listened to a presentation by Keith Vinnecour, CPO, from Beverly Hills Prosthetics-Orthotics. Keith presented some of the different bracing options and the pros and cons of various models. The next meeting will be January 16, 2010, when the speaker will be Dr. Glenn Pfeffer from Cedars Sinai Medical Center. The meeting will take place at Cedars Sinai.

California—San Mateo
Dr. Rosemary Shy spoke to the group on September 12th on the subject of CMT and kids. On December 5th, new CMT employee, Cheryl Sherman, Director of Community Development, will talk about how to get involved with the work of the CMTA. Group leader Elizabeth Ouellette will give a Power Point presentation on STAR.

California—Santa Barbara
The group met on November 8th and discussed how to manage pre-holiday stress while sharing a white elephant exchange. Brunch/lunch was included. Members discussed how to lighten stress levels, such as shopping on line, having potluck meals, and using a scooter when shopping in malls. The group will meet again on January 10th to discuss the importance of maintaining a low body weight with CMT.

Florida—Inverness
The group met on October 24th and heard a presentation from Ms. Draza Brown of Athena Diagnostics. She answered questions about genetic testing and what the results mean and gave everyone a brochure that further explained the various tests. The next meeting will be in January with guest speaker Jeff Miller, a physical therapist.

Florida—Tampa
The group met on a stormy Saturday, September 12th, to present retired leader Lori Rath with a plaque and the thanks of the group. Lori has handed the leadership over to Vicki Pollyea. The group has reassigned work for the meetings so that some people will be phone buddies, some will bring refreshments, and others will greet any new members who attend. The next meeting is scheduled for November 20th.

Georgia—Atlanta Area
The support group met on October 17th and heard a presentation from Patrick Livney, Chairman of the CMTA Board of Directors. He discussed the three facets of the CMTA—the research, the support groups, and the advocacy efforts. Pat also described the STAR initiative and the strides they are making toward finding a treatment for 1A patients. The group members was inspired by the visit and were left with a clear understanding of how each member can positively impact the CMT community. The next meeting will be on January 16th when Lynn Deal, a certified Pilates instructor, will speak about Pilates movements.

Illinois—Chicago Area
The group met on October 24th and were treated to a presentation on STAR by Elizabeth Ouellette, CMTA Board Member. She discussed where we are in the research process, who is working on it, and how we can support the program. We also discussed parenting issues and physical therapy and exercise. We met new employee Cheryl Sherman, who will be heading up support group work.

Massachusetts—Boston Area
The group met for the fourth time in a new location at the Brookline Public Library. The group enjoyed an “Open Forum and Show and Tell” format which enabled everyone to discuss his or her life with CMT. Attendees showed off AFOs and battle-scarred legs.

New Hampshire/Vermont
The group met on November 21st and shared strategies for coping with CMT. Members brought tools and gadgets they have bought to make things easier. They also shared ideas on where to buy shoes and what brands work best.

New York—Hudson Valley
The kick-off meeting on September 26th was a great success with 22 people in attendance. Members of the Westchester

(continued on page 19)

THREE NEW GROUPS HAVE FORMED:

Phoenix, AZ
under the leadership of Ken Wysocki

Hagerstown, MD
under the leadership of Jeffrey Martin

Kalamazoo, MI
under the leadership of Jori Reijonen

CMT Support Groups

Director of Community Development: Cheryl Sherman, 916-969-8226
Board Member Support Group Liaison: Elizabeth Ouellette, 1-800-606-2682, ext 107

Alabama—Birmingham
No support group
Will accept phone calls/emails
Contact: Dr. Dice Lineberry, calls only 205-870-4755
Email: cmtasg_birminghamal@charcot-marie-tooth.org

Arizona—Phoenix Area
Place: Cronkite School of Journalism, Arizona State Univ., Room 125
Contact: Ken Wysocki, 602-606-2805
Email: cmtasg_phoenix@charcot-marie-tooth.org

California—Los Angeles
Place: Hilltop Community Church
Contact: Ryan Conlon, 310-383-1024
Website: cmtla.org
Email: cmtasg_losangeles@charcot-marie-tooth.org

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: Sutter Med. Cen. of Santa Rosa
Contact: Louise Givens, 707-539-2163
Email: cmtasg_northcal@charcot-marie-tooth.org

California—San Diego Area
Place: Mission Valley Branch Library
Contact: Steve Gabbert, 619-987-6022
Email: cmtasg_sandiego@charcot-marie-tooth.org

California—San Francisco Bay Area/ Santa Clara County
Place: San Mateo Library
Contact: Elizabeth Ouellette, 1-800-606-2682 ext 107
Email: cmtasg_sanfran@charcot-marie-tooth.org

California—Santa Barbara
Place: Location varies, call for info
Contact: Gretchen Glick, 805-693-9511
Email: cmtasg_santabarbara@charcot-marie-tooth.org

Colorado—Denver Area
Place: Lutheran Church of the Resurrection
Contact: Diane Covington, 303-635-0229
Email: cmtasg_colorado@charcot-marie-tooth.org

Florida—Inverness Area
Place: Citrus Memorial Hospital
Contact: Ronnie Plageman, 352-860-1578
Email: cmtasg_invernessfl@charcot-marie-tooth.org

Florida—Orlando Area
Place: Metro Church, Winter Springs
Contact: Mark Collins, 407-786-1516
Email: cmtasg_orlando@charcot-marie-tooth.org

Florida—Tampa Bay Area
Place: St. Anthony's Hosp., St. Petersburg
Contact: Vicki Pollyea, 813-251-5512
Email: cmtasg_tampa@charcot-marie-tooth.org

Georgia—Atlanta Area
Place: St. Martin's Episcopal Church
Contact: Sue Ruediger, 678-595-2817
Email: cmtasg_atlanta@charcot-marie-tooth.org

Illinois—Chicago Area
Place: Oak Lawn Public Library
Contact: Dale Lopez, 708-499-6274
Email: cmtasg_chicago@charcot-marie-tooth.org

Kansas—Wichita Area
Place: Independent Living Resource Ctr.
Contact: Karen Smith, 316-841-8852
Email: cmtasg_wichita@charcot-marie-tooth.org

Kentucky—Burlington
Place: Boone County Public Library
Contact: Pam Utz, 859-817-9338
Email: cmtasg_burlingtonky@charcot-marie-tooth.org

Maryland—Baltimore Area
Place: Johns Hopkins Outpatient Ctr
Contact: Bruce Egnew, 410-729-2297
Email: cmtasg_baltimore@charcot-marie-tooth.org

Maryland—Hagerstown Area
Place: Washington County Free Library
Contact: Jeffrey Martin, 240-217-5746
Email: cmtasg_hagerstownmd@charcot-marie-tooth.org

Massachusetts—Boston Area
Place: Hunneman Hall, Brookline Public Library
Contact: Mark Boxshus, 781-925-4254
Email: cmtasg_boston@charcot-marie-tooth.org

Michigan—Ann Arbor
Place: Great Lakes Regional Training Ctr.
Contact: Tammy Mayher, 734-216-1347
Email: cmtasg_annarbor@charcot-marie-tooth.org

Michigan—Kalamazoo Area
Place: Richland Bible Church
Contact: Jori Reijonen, 269-341-4415
Email: cmtasg_kalamazoo@charcot-marie-tooth.org

Minnesota—Benson
No support group
Will accept phone calls/emails
Contact: Rosemary Mills, 320-567-2156
Email: cmtasg_bensonmn@charcot-marie-tooth.org

Minnesota—Twin Cities
Place: Call for location
Contact: Bill Miller, 763-560-6654
Email: cmtasg_twincities@charcot-marie-tooth.org

Mississippi/Louisiana
Place: Baptist Healthplex, Clinton, MS
Contact: Flora Jones, 601-825-2258
Email: cmtasg_clintonms@charcot-marie-tooth.org

Missouri—St. Louis Area
Place: Saint Louis University Hospital
Contact: Carole Haislip, 314-644-1664
Email: cmtasg_stlouis@charcot-marie-tooth.org

Missouri
No support group
Will accept phone calls/emails
Contact: Libby Bond, 417-845-1883

Nevada—Las Vegas
Place: West Charleston Library
Contact: Mary Fatzinger, 702-369-6095
Email: cmtasg_lasvegas@charcot-marie-tooth.org

New Hampshire/Vermont
Place: Dartmouth-Hitchcock Med. Cen.
Contact: Margaret Healey, 802-535-2797
Email: cmtasg_lebanonnh@charcot-marie-tooth.org

New Jersey—Central NJ Area
Place: Centra State Medical Center, Star and Barry Tobias Health Awareness Center
Contact: Mark Willis, 732-915-8501
Email: cmtasg_mountainsidenj@charcot-marie-tooth.org

New York—Greater New York
Place: New York University, Langoni Medical Center
Contact: Dr. David Younger, 212-535-4314
Website: www.cmtnyc.org
Email: cmtasg_nyc@charcot-marie-tooth.org

New York—Horseheads
Place: Horseheads Free Library
Contact: Angela Piersimoni, 607-562-8823
Email: cmtasg_horseheadsny@charcot-marie-tooth.org

New York—Hudson Area
Place: St. Luke's, Cornwall Hospital
Contact: Deborah Newman, 845-883-0580
Email: cmtasg_cornwallny@charcot-marie-tooth.org

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Children's Hospital
Contacts: Beverly Wurzel, 201-224-5795
Email: cmtasg_westchesterny@charcot-marie-tooth.org

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: The Center for Independent Living
Contact: Susan Salzberg, 919-967-3118 (afternoons)
Gary Orson, 919-467-5485
Email: cmtasg_chapelhill@charcot-marie-tooth.org

Ohio—Greenville
Place: Brethren Retirement Com.
Contact: Dot Cain, 937-548-3963
Email: cmtasg_greenvilleoh@charcot-marie-tooth.org

Oregon—Portland
Place: Midland Library
Contact: Debbie Hagen, 503-333-7936
Email: cmtasg_portlandor@charcot-marie-tooth.org

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience Center
Contacts: J. D. Griffith, 814-539-2341
Jeana Sweeney, 814-262-8427
Email: cmtasg_johnstown@charcot-marie-tooth.org

Pennsylvania—Northwestern Area
Place: Blasco Memorial Library
Contact: Joyce Steinkamp, 814-833-8495
Email: cmtasg_eriepa@charcot-marie-tooth.org

Pennsylvania—Pittsburgh Area
Place: St. Simon and Jude Church
Contact: Christine Miller, 412-341-5749
Email: cmtasg_pittsburgh@charcot-marie-tooth.org

Pennsylvania—Philadelphia Area
Place: CMTA Office, Chester, PA
Contacts: Dana Schwertfeger, 800-606-2682
Walter Donikowski, 610-960-1199
Email: dana@charcot-marie-tooth.org

Tennessee—Savannah
Place: East End Sports Complex
Contact: Reagan McGee, 731-925-6204 evenings
Email: cmtasg_savannahtn@charcot-marie-tooth.org

Texas—Dallas
Place: Journey
Contact: Whitney Kreps, 972-989-5743
Email: cmtasg_dallas@charcot-marie-tooth.org

Texas—Houston Area
Place: Park Place Regional Library
Contact: Brady Gibbs, 409-692-0493
Email: cmtasg_houston@charcot-marie-tooth.org

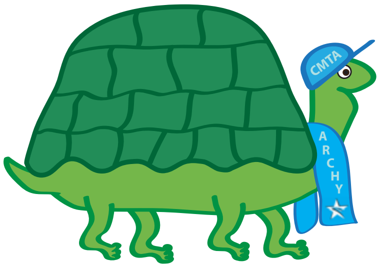
Virginia—Harrisonburg
Place: Sunnyside Retirement Community, Sunnyside Room
Contact: Anne Long, 540-568-8328
Email: cmtasg_harrisonburg@charcot-marie-tooth.org

Virginia—Williamsburg
Place: Williamsburg Regional Library
Contacts: Jennie Overstreet, 804-693-5806
Nancy Mollner, 757-220-3578
Email: cmtasg_williamsburg@charcot-marie-tooth.org

Washington—Seattle
Place: U of Washington Med. Center
Contact: Ruth Oskolkoff, 206-598-2765
Email: cmtasg_seattle@charcot-marie-tooth.org

Washington—Tacoma Area
Place: Elmer's Restaurant
Contact: Carol Hadle, 253-476-2345
Email: cmtasg_tacoma@charcot-marie-tooth.org

"Archy" at the Zoo



"Archy," our stout-hearted, but high-arched, spokesturtle, writes about his experiences as a turtle with CMT.

I could hardly sleep last night. I was so excited about today's trip to the zoo. I wasn't sure how hard it might be for me to walk around all that space, but I really wanted to see the other animals. I go to school with lots of different animals, but not the kind you see at the zoo. My classmates are rabbits and deer and skunks and raccoons and tortoises and snails and others like that. But, we don't have any lions or tigers or monkeys or polar bears. I'm most excited about seeing polar bears because I love to swim and when I see pictures of them, I think they love swimming even more than I do! My other favorite is the otters. They are swimmers, too, and they look so sleek when they slide down rocks and play among themselves.

So, I woke up extra early this morning and spent lots of time deciding what to wear. It's pretty warm out today so I had to decide whether to wear shorts or not and if I was going to wear shorts, was I going to wear my orthoses. I love my orthoses, but I hate for other people to see them because I think they make me look crippled and that's not how I see myself. But the reality is that I walk much better when I wear them and I don't get as tired—at least not as quickly. So, I decided that it only made sense for me to wear my braces and skip the shorts. That's sort of the best of both worlds. I might get hot, but no one will know about my braces and I will walk a lot better.

The school bus came right on time and we kids all piled in. The buses are made special to accommodate the different sizes and shapes of us animals. I was seated near the front where they have dirt and small pools for the animals that need water. My friends were there with me and we talked the whole way to the zoo. We were making a plan for where we wanted to go first and what we wanted to see. The first grade teacher is a rabbit, but she is very nice and said she would walk slowly so we could all keep up. One good thing about being a turtle with a slow walk is that all turtles move pretty slowly, so I don't stand out too much.

We piled off the bus and got special badges to show we were with the Greenwoods Elementary School. That was so, if we got lost, we could be returned to our group. We knew we had to stay with our little group, though, because it was much safer that way. We've heard stories about how little ones get stolen from their families and none of us want anything like that to happen, so we're going to stay close to our teacher.

By a vote of five to one, we decided to go to the otters display first. They were brown river otters and they looked so cool and so athletic. I can swim pretty well, but they are amazing as they practically slide through the water and up and down over rocks and waterfalls. I was doing pretty well, because I could sit down occasionally and that kept me from getting too tired. When I go on trips with my mother, she gets a special sort of wagon that I can ride in when I get tired of walking. But I didn't want to have to use anything on the zoo trip that would make me seem different from my classmates.

My best friend Timothy, who is also a turtle, knows about my problems, but he doesn't care. We can still do all the things we really like to do. We love word games and chess and I'm as good at that as Tim is, so we get along great together. He's not a real athlete, either, and so roughhousing and running around isn't his idea of a fun time. He always walks really slowly so that I can keep up and no one thinks much of it because they figure we are just busy talking and not thinking about moving fast.

When we left the otters, we went to the polar bear enclosure. They just love to swim, but they also like to play with balls and roughhouse with each other. I think I would make a better otter than a polar bear, although I think I'm best at just being myself.

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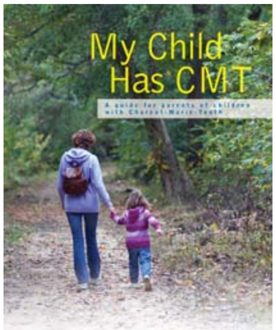

New Pediatric Publication Now Available

My Child Has CMT is a 32-page booklet with full color photos and topics such as "When We Found Out Our Daughter Had CMT", questions and answers from Dr. Mena Scavina, A.I. DuPont Institute in Wilmington, DE, "How to Keep a Medical History for Your Child," and a dictionary of common medical terminology. A list of resources and organizations helpful to families with CMT is the final chapter. The booklet is only $5 for CMTA members and $7 for non-members.

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The Patients' Guide to Charcot-Marie Tooth Disorders

2008/178 pages—Now available in print and CD formats

The Patients' Guide is an excellent source of information and resources for patients, family members, and physicians. Topics include CMT in children, genetics and genetic counseling, orthopedic considerations, exercise, and current and prospective treatments for CMT.

Bonus features included on CD: *Charcot-Marie-Tooth Disease: An Overview* and *Charcot-Marie-Tooth Disease: A Guide for Physicians.*

PRINT FORMAT:
Nonmember Price: $15.00
Member Price: $10.00

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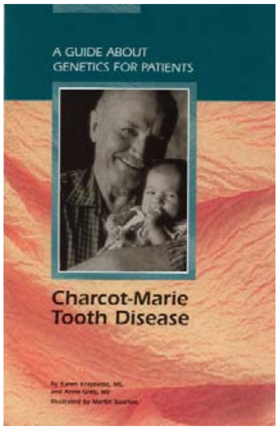

A Guide about Genetics for Patients

2000/21 pages

Illustrated with easy-to-understand diagrams, this booklet outlines the basics of genetic inheritance and CMT.

Nonmember Price: $5.00
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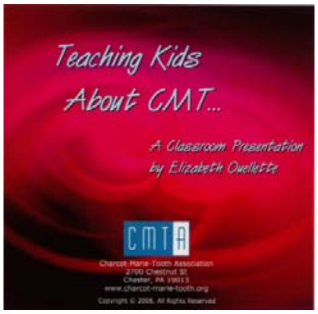

Teaching Kids about CMT...

A Classroom Presentation

2006/DVD 1 hr.

This hour-long DVD of an actual classroom presentation demonstrates a number of games and other exercises to teach classmates of children with CMT about the disorder.

Nonmember Price: $10.00
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SUPPORT GROUP NEWS

(continued from page 14)

County support group came to show their support for the new group. Also in attendance was Ron Beyer, husband of the late Ann Lee Beyer, who was instrumental in pushing for aggressive research into CMT. The group sent a check for $50 to support the STAR initiative.

New York—New York City
On November 14th, the group heard a presentation by Dr. Paul Betschart, whose specialties are podiatric surgery and podiatric orthopedics. The group met in the NYU Langone Medical Center in Alumni Hall B. Lunch was provided.

Pennsylvania—Philadelphia
On October 3rd, Wendy McCoy, a certified hand therapist for 14 years, presented a talk on the advantages of exercises for the hands of CMT patients. She gave print-outs of suggested hand exercises and demonstrated many of them to the audience. The next meeting will be on December 12th when the group will enjoy a holiday party and a presentation from David Tannenbaum, a psychotherapist.

Pennsylvania—Pittsburgh
The group had Dr. Michael Shy as their guest on August 22nd and everyone present was delighted with his presentation on the STAR research initiative and the genetics of CMT. He answered many questions and the group is hoping to invite him back for a second visit in the next year.

Texas—Houston
The group held its first meeting on October 18th at the Park Place Regional Library. It was a meet and greet under the leadership of Brady Gibbs.

Virginia—Williamsburg
On September 19, 2009, the group held its first meeting. There were twenty in attendance, including two children. After introductions, the members discussed how and when each of them was diagnosed. They also had a "show and tell" of AFOs in use. The group has decided to meet every other month.

Washington—Tacoma
On October 10th, the group met and heard a presentation from Bryan Roehr, CPO, from Hanger Prosthetics and Orthotics. He discussed how braces are made, their differing purposes, and the importance of proper shoes and proper fit. Three group members all had different braces on, and it was enlightening to learn why we each needed a different solution to our gait problems. ✻

ARCHY AT THE ZOO

(continued from page 16)

We ate lunch after the polar bear exhibit, and that's when I really relaxed and didn't worry about keeping up. I can eat as fast as the next turtle and my mother always packs my favorite things for lunch. So I enjoyed some vegetables and a thermos full of delicious water from our local pond. It was getting pretty hot by lunchtime, but I stayed under the trees and reminded myself that it was worth being hot to have on my braces so I wouldn't fall.

We saw lions and tigers and bears, oh, my, and they were impressive. They are really, really big and sort of scary. Then we went inside to see small mammals and reptiles. They have their own "houses," but I like my house much better. I know they are well taken care of and all, but they don't get to leave and go on field trips like we do. I think it's good to see how other animals live so we can appreciate our own lives more.

We left around 3 o'clock, and I was really glad to get home and see my Mom and my sister. We all went in the pond and cooled down and just floated around while I told them about my adventures. I had bought my sister a stuffed turtle so she could add him to her collection of stuffed animals. We always laugh at how they make the turtles seem so perfect, which we aren't in real life, but I think they are like dolls are to people—not very realistic, but sort of fun to pretend with.

I was tired from my day at the zoo, but I felt good. I had made a good decision to wear my braces and I had managed to do the whole trip without needing any special help. I also felt good because being at the zoo reminded me of how lucky I am to have a nice family and a comfortable home. ✻

THE CMTA *Report*

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

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

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

Negligible or doubtful risk:
Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Fluoroquinolones
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

What is CMT?

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