

**MAY/JUNE  
2009**

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community \* [www.charcot-marie-tooth.org](http://www.charcot-marie-tooth.org)



**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.

## ONE STEP CLOSER Phase 1 of STAR Now Complete

BY DAVID M. HALL, CHIEF EXECUTIVE OFFICER

In 2008, the CMTA launched the Strategy to Accelerate Research (STAR™) as a three-step strategic research program to maximize breakthroughs in genetics and dramatically speed up the pace of CMT research. The goals of STAR were and remain ambitious, yet doable:

- 1) within 5 years, introduce effective therapies for the three most common types of CMT; and
- 2) within 10 years, reverse symptoms of the disorder.

The opportunities associated with STAR stem from the fact that Charcot-Marie-Tooth disease is unlike other neuromuscular disorders because its causes have been pinpointed, leading to the identification of 40 specific gene defects. More importantly, the fact that these genetic mutations can be replicated in laboratory models and grown as tissue cultures opens an extraordinary window of opportunity to develop treatments and cures for CMT in the immediate and foreseeable future.

Less than one year after the start of the STAR program, the CMTA, in conjunction with its world-renowned team of scien-



**A robot at the NIH Chemical Genomics Center (NCGC) holds a 1,536 well plate similar to the ones to be used in the STAR high-throughput screening.**

tists, is proud to announce the completion of Phase 1 of the STAR program. A CMT1A cell line, grown by Dr. Ueli Suter in Zurich, Switzerland, has been sent to the NIH Chemical Genomics Center (NCGC) in Rockville, MD. The NCGC will conduct extensive testing of the CMT1A cell line using a technology known as high-throughput screening (HTS). The use of HTS technology will allow the NIH scientists to study hundreds of thousands of medical compounds to determine which

ones may be effective treatments for CMT. So, within a very short period of time, we should

*(continued on page 2)*

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**EMAIL CMTA AT:**

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**STAR PROJECT  
BEGINS PHASE 2***(continued from page 1)*

have some indication as to which compounds hold promise for treatments and a cure for those with CMT1A.

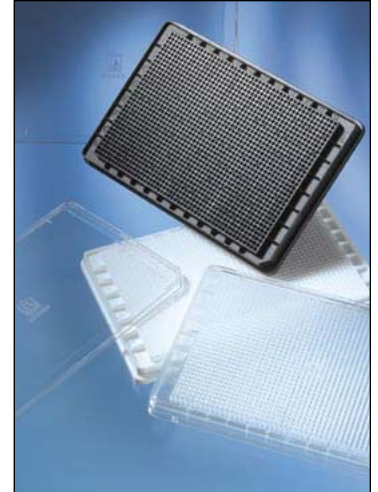
STAR Phases 2 and 3 will test the candidate medicines from Phase 1 in both laboratory and animal models and then in clinical trials that will be designed to test drug efficacy on individuals with CMT1A. After the completion of these projects, the CMTA STAR program will aggressively work to pursue any potential treatments arising from these trials, as well as foster new strategies for treating other forms of CMT, including 1X, and Types 2 and 4.

As you know, STAR is the most important initiative ever

undertaken by the CMTA. The incredible success to date of the STAR program only increases the urgency with which the scientists, staff, Board of Directors, support group leaders, and partners of the CMTA must act to ensure STAR continues at full speed.

To maintain the success of the STAR program, we will need to raise \$10 million over the next five years. The financial support we've received from government entities, corporate partners, support group leaders, and individuals has been amazing and is why we're able to report such fantastic news today!

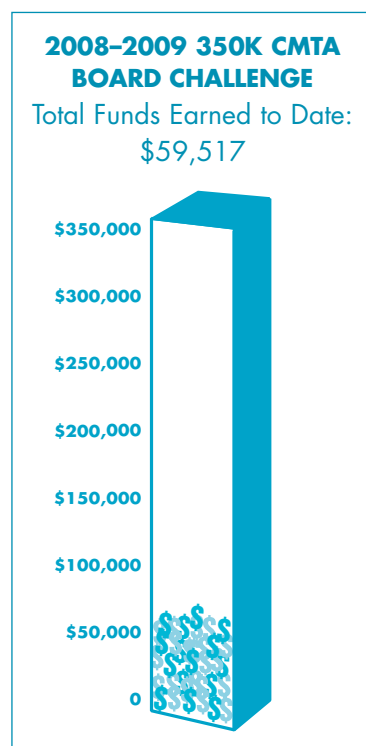
But our work is far from being done and our future success is dependent upon the continued financial support from all of you. Please help us in any way



**The stabilized cell line for PMP22 will be inserted into these plates, which will then run through the robots to complete the high-throughput screening phase of the STAR program.**

you can to support the STAR program and be a part of changing the face of CMT forever. ✨

## CMTA Board of Directors Challenge Grant



The CMTA is fortunate to be led by a Board of Directors that has financially supported the vision of the CMTA. That vision of finding treatments and a cure for CMT is much clearer today than it ever has been thanks to the thrilling success of the STAR program. More so than ever, we need to enhance the financial support of STAR to ensure we adhere to our mission of living in a world without CMT.

Launched in 2007, the CMTA Board of Director Challenge Grant matches your donations on a one-to-one basis up to \$350,000. The Challenge Grant has generated significant

funding for the CMTA and the STAR program. Your generous contributions will not only contribute to advancing the scientific understanding of CMT, but will also help us to immediately raise an additional \$350,000 from our Board of Directors. As you can see from the graphic at left, we have a long way to go to meet our goals this year and maximize the financial contribution of the Challenge Grant. Your financial support is greatly needed and appreciated.

We will be sending you a contribution notice soon, but you can also make a donation to the challenge online at [www.cmtausa.org/350K](http://www.cmtausa.org/350K). ✨

## CMTA Doubles Membership; Reduces Annual Dues

In May of 2008, the CMTA began celebrating its 25th anniversary year with an offer of free membership to anyone who joined by April 30, 2009.

In addition to rewarding current members for their loyalty and support with an automatic renewal for a free year, we also hoped to double our membership—and we have! The CMTA now has 5197 members and counting—but we're still not satisfied.

We can't be, not when there are an estimated 2.6 million people with CMT worldwide.

Whether we're talking about research, access to health care, or anything that has an impact on our situation, we have no stronger advocates than ourselves—our membership. That's why we're going to continue our effort to increase our membership in 2009.

At the same time, it's also

important that everyone who joined during the past year continue to be a supportive member of the CMTA, so we've reduced our annual membership dues from \$40 to \$25.

When you receive your renewal notice, please return it as soon as you can so you don't miss any of the news about STAR and other exciting developments at the CMTA.

—Thanks!

## CMT IN THE NEWS

- Abbey Umali will return for a second term as National Goodwill Ambassador for the Muscular Dystrophy Association.

During her first term, Abbey, who has CMT, traveled the country with her parents, speaking about MDA's programs of research and services. Abbey walks with the help of leg braces. She and her parents have appeared on the Labor Day Telethon five times in the past three years.

- Quest* magazine reported on the cooperation between the MDA and the CMTA in funding the North American CMT Network to provide an infrastructure to help CMT researchers locate potential participants for clinical studies. An early goal is to establish scoring systems for functional evaluations in children with CMT. Patients will have the opportu-

nity to be evaluated at six CMT centers of excellence and have their DNA samples banked.

- An on-line article featured Tom Mumper, who has crafted over 4,600 pieces of functional wooden art. Tom is 80 years old and uses a combination of chain saw, bandsaw, lathe, and disc sander to turn raw hunks of wood into bowls, vases, lamps, and platters. Tom retired from his management job at a large gunpowder manufacturing firm 20 years ago when he was diagnosed with CMT. That's when he decided to fine tune his wood crafting skills. Mumper's works have won top honors at museums and shows.

- Co-support group leader, Jeana Sweeney was chosen as one of the most beautiful people in Johnstown, PA and graced the cover of the maga-



zine and an interior page. Jeana used her interior paragraph to talk about her daughter, Rylee, who has CMT, and her passion for raising money and awareness about CMT. Jeana not only co-leads the Johnstown area support group, but she also volunteers at the John P. Murtha Neuroscience Center and the Conemaugh CMT clinic by leading a program known as "Healthy Living with a Chronic Condition." \*



## 2nd Annual “Honor a Star—Be a Star” Gala Generates Over \$350,000 for CMT Research

*Event Honoring Joe and Sue Paterno in New York City Raises Money for STAR Initiative*

The Charcot-Marie-Tooth Association’s second annual “Honor a Star—Be a Star” Gala recognizing Joe and Sue Paterno for a lifetime of achievement raised a record amount of over \$350,000 at the Mandarin Oriental Hotel in New York City on April 29. Proceeds from the Gala will be used to support the CMTA’s Strategy to Accelerate Research (STAR™), an ambitious initiative that has been created to develop new treatments for CMT.

Nearly 200 people were in attendance as Hall of Fame Football Coach Joe Paterno and his wife Sue were honored for their generous contributions to the CMTA. Joe Paterno has

**The gala was also an opportunity for friendships old and new. When she wasn’t performing, Amy de Silva (left) became “Best Friends Forever” with Julia Beron.**



**Sue Paterno and CMTA CEO Dave Hall look on as “Joe Pa” tells our guests, “We can cure it. It will take a little money... The good news is we have the money. The bad news is it’s in your pocket.”**

served as national spokesperson for the CMTA over the past several years.

“The CMTA is proud to have Joe as its official spokesperson,” said David M. Hall, Chief Executive Officer of the CMTA, “and we’re extremely grateful and appreciative of all that Joe and Sue have done not just for the CMTA, but for countless other organizations and communities.”

Highlights of the evening included opening and closing vocal performances by 13-year-old CMT patient Amy de Silva, a moving video tribute, and the presentation of the 2009 “Honor a Star—Be a Star” Award to the Paternos.

Guests also received the latest scientific updates on medical advances in CMT from leading STAR researchers Drs. Michael Shy and Steven Scherer, who

*Sponsors for the 2009 Gala included the Livney Foundation, the Putnam Foundation, AFA Protective Systems, Gary Gasper, Kemark Financial Services, Pamela and Robert Kleinman, and the Sanders Firm.*



announced that the first STAR project—the creation of a cell line for use in high-throughput screening at the NIH—has been completed, and that the cells have been delivered to the NIH.

We were also fortunate, through the generosity of our sponsors, to be able to invite several support group leaders and CMTA members from the greater NY area. One member, attending his first CMTA event, captured the enthusiasm generated by the Paternos and the STAR news when he said, “What you are doing here is remarkable, and I am definitely going to be involved from now on.” \*



**Special thanks to CMTA Board Members Robert Kleinman (pictured here with Joe Paterno) and Phyllis Sanders, who both sponsored and chose the venue for the Gala.**

## RESEARCH NOTE: ASCORBIC ACID STUDY

*The following is a condensed version of Dr. Michael Shy's reply to the results of an ascorbic acid study published in the June, 2009, issue of Lancet Neurology. The complete reply may be read at [www.cmtausa.org/aa](http://www.cmtausa.org/aa).*

In the current issue of *Lancet Neurology*, Burns and colleagues report on a study evaluating 81 children with CMT1A in a double-blind, placebo-controlled 12-month trial with escalating doses of ascorbic acid ranging from 375 mg/day in younger children to 1.625 mg/day in older children. Although the authors concluded that ascorbic acid was well tolerated at these doses and that there was no improvement in conduction velocity, or in strength, function, or quality of life, issues in

their study raise concerns about how clinical trials in CMT1A and other inherited neuropathies are designed.

The first is how best to measure clinical impairment of children with CMT. This is not to say that the choice of outcome measures in the current study was inappropriate. Rather, at present, it is to say that there are not yet good outcome measures for children with CMT, and this limits the ability of trials in children to detect what might be milder, but still important benefits, from candidate treatments. Even if benefits seem mild during a brief period, they may prove quite significant over a young patient's lifetime.

A second issue for this and other trials involving patients with CMT1A is the number

of patients in the study and the length of time the patients are evaluated. Analysis of the data suggests that a two-year study involving more patients would be needed to detect a reduction in progression. Clearly, if a therapy cured or dramatically improved impairment, these numbers would not be an issue. However, if a therapy such as ascorbic acid simply slows progression of CMT, this effect could easily be missed in trials such as this one that are not maximally powered based on natural history data gathered over at least a two-year period.

Accordingly, we encourage anyone participating in an ascorbic acid clinical trial to complete the drug regimen and evaluations as scheduled in the study design. \*

## Meet Archy: Our Newest Member

**M**ore than 3,000 people have joined the CMTA in the past year, but Archy, the most recent member of the CMTA, is a bit different. Actually, he's a turtle.

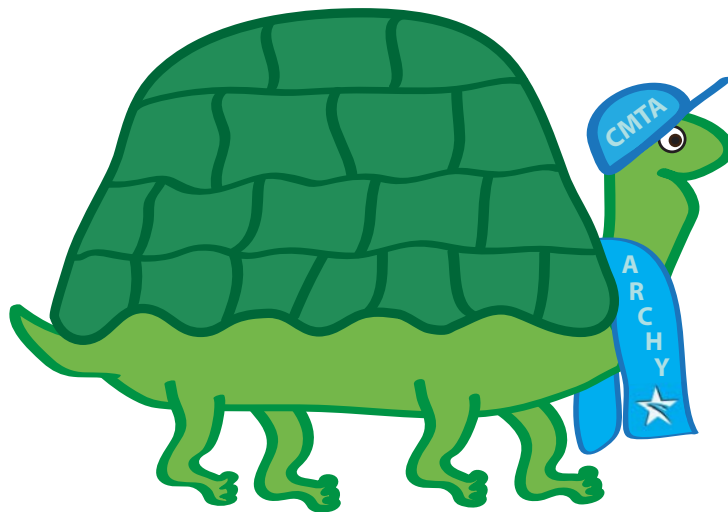
Our thanks to Tina Marie Thomas, who made the initial drawing and asked if we would like to use Archy. Tina drew him with high-arched feet, hence the name "Archy," and thought he would be a great mascot for CMT.

We thought so, too, but we have even grander plans for Archy. We think Archy will be a great way to help parents talk to kids about CMT, and we're already working on *The Adventures of Archy*, a series of stories that explain how Archy copes with CMT in a variety of situations from going to school to going to the doctor to getting braces.

And, while we don't think there's anything funny about CMT, we do think that it's important to appreciate the joy and humor in life, so most of all, we want Archy to provide kids of all ages with a way to look at themselves, accept their differences, and smile as they cope with the challenges they face because of their CMT.

Archy's adventures will be coming soon, but you can get a first look at Archy on our Kids' page. Here's his first story.

My name is Archy. I'm a turtle, but I'm a little different. My mother says that makes me special, but sometimes I just feel different. My feet are shaped



**Archy is a very proud turtle since he became a mascot for the CMTA's Kids' Page.**

funny with a high arch (that's why my Mom named me Archy) and I walk on my toes. Most turtles are really flat-footed and kind of thump down when

Win when you can;  
lose if you must,  
but always  
try your hardest.

they walk. I can't get my heels down, so I get teased for being a sissy and walking on my toes. When you're little, it's not fun to be different. I'm not sure if it's ever going to be fun to be different, but my parents tell me it will get better. I sure hope so.

The one place I really feel like I'm special is in the water. When I swim, no one can tell I'm different. In fact, I think my arched feet actually make me go faster. I'm on our school's swim

team, and I can even dive pretty well, so no one teases me when I'm in the water. I'm also fairly smart, so the teachers are nice to me and even let me take a little longer to get from one place in school to another. I do all my homework and really study hard to make my parents proud of me. If I can't be a superstar athlete, I can be a superstar student.

Still, none of this makes it any easier to deal with the bullies in our school. You might think all turtles are quiet and well-behaved animals, but it's not true. The biggest and the dumbest of us are bullies. I get abused on the school bus and during recess. I don't mean physically abused, but they do call me names and they pick on me and anyone that befriends me. It's very hard to take. Sometimes, I get pretty upset about it all. I pull my head inside my shell and won't come out for a

long time. I have to get up my courage to come out of my shell and face the kids again. The only reason I can face up to my bullying is that my Mom and Dad are really great and they really love me. So does my older sister, Tara. They remind me that I'm a special kid and that I can do great things. In fact, they make me feel sorry for the turtles who bully me because they point out that they aren't great students and they don't have loving families. So, I get reminded of how lucky I am, in spite of my weird feet, to be so loved.

Just the other day something really special happened! I met a lady named Tina, and she thought my funny-shaped feet were so great. She was really

happy that I had these high-arched feet because she said she does, too! Can you imagine? Well, she has something called Charcot-Marie-Tooth disorder and that makes her feet pull up into a high arch just like my feet do. Even better was the fact that she wanted me to be the mascot of the kids' page of the CMTA. Suddenly, I really was going to be special. My face was going to be on a web site and no one would think my feet were silly; they would have the same kind of feet. This is by far the best thing that has ever happened in my life.

So, here I am now, sitting on the web site (and appearing in the newsletter) and catching the eye (or so I hope) of kids, who,

like me, are a little different. I guess I really want kids to know that it's okay to be different and it's okay not to like being different, sometimes. I work hard at doing what I can do really well and not worrying too much about the things I can't do. I'm slow, but I'm steady. You've all seen that story about the tortoise and the hare...well, I'm very much like the tortoise. I won't win any races of pure speed, but when smarts come into play, I'm a sure winner. That's okay with me. "Win when you can; lose when you must; and always try your hardest." That's the lesson my parents taught me, and I'm sharing it with you. I hope it serves you well in life. It works for me. ✨

## You Can Take It with You: Medical Alerts and Data Tags

Since 1956, the engraving on the back of MedicAlert® bracelets has provided a way to inform first-responders and other medical professionals about patients' drug allergies and other medical conditions, and the services provided by the MedicAlert Foundation ([www.medicalert.org](http://www.medicalert.org)) now include a 24-hour emergency response center that stores detailed information for members, including Advanced Directives, Do-Not-Resuscitate orders, medical device instructions, and more.



Along with the proliferation of companies allowing people to create and manage Electronic Medical Records (see, for example, [www.ihealthrecord.org](http://www.ihealthrecord.org)), the Staff of Aesculapius is now appearing on "data tags"—USB flash memory devices designed to allow patients to carry their medical records and emergency contact information with them.

These devices typically come with software to manage the patient's records, and, in the event of illness or injury, the information can be easily accessed by EMTs and physi-

cians. W.D. from PA showed us the device pictured here (available from [www.utagus.com](http://www.utagus.com)), but similar products are available from [www.sosalertproducts.com](http://www.sosalertproducts.com) and other vendors. ✨



**Data tags allow patients to carry medical records and contact information with them at all times.**



## April Patient/Family Conference in Erie Was a Success

BY PAT DREIBELBIS

**T**he patient/family conference at the Shriners Hospital in Erie, PA, didn't come off without a hitch, but it was still a huge success.

Even though Dr. Michael Shy was stuck in an airport in Dallas and was late in arriving, and even though Dr. William Schrantz was stuck in Philadelphia and could not make it at all, the attendees were delighted with the time allotted for questions and the extra time Dr. Shy took once he arrived. Special thanks go to Mandy Anderson and Bobby Rainey for being flexible and fitting their presentations in where blank time existed.

The meeting was opened with a welcome by Pat Dreibelbis, who encouraged the attendees to become members while there was no fee because of the 25th anniversary. She also encouraged attendees to submit recipes for the cookbook project and to buy a "Be a Star" bracelet to support the STAR (Strategy to Accelerate Research) initiative.

Pat then introduced David M. Hall, Chief Executive Officer, who told the audience about plans for the CMTA to become more involved with lobbying efforts and the plans to apply for money to allow the PA Awareness Grant to be replicated across the country. He also showed the

Seventy-five people enjoyed a day of information and advice sharing at the Erie conference.

STAR video to help the audience members feel more connected to the research initiative.

Mandy Anderson, OT, came with a bag full of goodies, otherwise known as adaptive devices, that could make certain activities of daily living easier for patients with CMT. She showed key turners and door knob handles and explained how success-

ful adaptive devices move the pressure of the activity from the smaller joints up to larger ones. So, a jar opener which is a flat pad fits under the palm and allows a person to open a jar primarily with the wrist rather than the fingers. She showed the audience the catalogue of Sammon, Preston, and Royton and told them about the availability of many adaptive devices to make working around the house a little easier.

Mandy was followed by Bobby Rainey, DPT, who discussed physical therapy regimens, bracing, and what patients should and shouldn't do. There was lots of interaction with the audience and many suggestions about which socks work best with bracing, water therapy, and what shoes are deep enough to accommodate braces. It was a wonderful segment for learning all kinds of things from all of the people who were there.

Lunch provided a break from the learning and gave attendees a chance to speak to one another about support groups, things that work for them, and where to find good doctors.

During the end of lunch, Dr. Michael Shy began his presentation on the ABC's of CMT and how the various types of CMT are genetically different. One of his best comments and his favorite "joke" involves how the Y chromosome is much

**Chief Executive Officer David M. Hall told the capacity audience about the CMTA's ambitious lobbying efforts to gain more government funding.**





## LIVING WITH CMT

# MacGyver Needs Solutions for Credit Cards, Blue Jeans, and Razors

Ever notice that many of the so-called “modern conveniences” aren’t so convenient when you have CMT? Take TV remotes, for example. In the incredible shrinking universe of electronic devices, not only do I have no idea what half of the 600 buttons on mine do, but I have to hold this masterpiece of ergonomic design in one hand and push them with the other. Cell phones with tiny buttons are also not very CMT-user friendly, but the real bane of my existence is becoming the type of credit-card reader that requires me to insert the card and remove it in the blink of an eye.

I can still swipe a card, but getting a card in and out of one of those readers at the gas station is an ordeal any time and nearly impossible on a cold, windy day. I have problems with removing hotel key cards, too, but those generally



Hackle pliers from [www.flyshack.com](http://www.flyshack.com)

work even if I take more than a split second to remove them.

S. A. has the same problem and asks if there is anything on the market that can be used to hold a card while inserting and removing it. Well, if it’s out there,

I can’t find it. I spent an hour with Google and didn’t come up with anything specifically designed to hold credit cards.

My alter ego Mac thought about punching a small hole in the card and inserting a ring or string, but he really didn’t want to mutilate his cards, not to mention that it would be difficult to put them back in his wallet. Pliers, especially those with rubber tips, are always useful gripping aids, but if you want something small enough for a pocket or purse, Google “hackle pliers.” They’re used by fly fishermen, also come with rubber tips, and can be purchased for under \$5.



Rolling Razor from [www.rollingrazor.com](http://www.rollingrazor.com)

K.O. from OK is also looking for a way to make buttoning blue jeans easier. Actually, what K.O. is thinking of is a two- or three-inch post that will replace the button and that can be inserted through the buttonhole and bent to

the side to fasten her jeans. Mac also wonders if something can’t be made to just slide over the button and fold back...?

Finally, A.H. from HI has a suggestion for people who have difficulty holding and using a conventional razor. It’s called a “Rolling Razor,” and it’s available in men’s and women’s styles at [www.rollingrazor.com](http://www.rollingrazor.com).

If you have a product suggestion or tip for making life with CMT easier, Mac would like to know. You can email it to [mac@cmtausa.org](mailto:mac@cmtausa.org), or mail it to Mac’s Tips, Charcot-Marie-Tooth Association, 2700 Chestnut Parkway, Chester, PA 19013.

—Dana Schwertfeger

smaller than the X and basically contains, according to his wife, only the genes for beer drinking and football viewing. That commentary always leads into his discussion of the X-linked version of CMT. He answered all kinds of questions from the audience about the genetics of

CMT, the characteristics of CMT, and how CMT is inherited in an individual’s family. He also graciously gave out his email address so that patients could send him their DNA test results and get an analysis of their diagnosis.

The day ended with a panel

discussion featuring David Hall, Dana Schwertfeger, and Pat Dreibelbis, along with Erie support group leader Joyce Steinkamp. More questions were fielded and more suggestions were made by members of the audience. The day was really informative and enjoyable. ✨

# David's Quest to Strike out CMT

BY GAIL-MARIE LORANDEAU

Two years ago, David was diagnosed with CMT. We weren't really surprised: his dad, uncle, and paternal grandmother all have CMT. There were signs as he was developing that led us to believe he had it, but our pediatrician advised against testing him because there was "nothing that could be done about it." Then David went to school and started falling. There was trouble with his fine motor skills as well. We had him tested, and even before



**David Corley begins his approach during the "Help David Strike Out CMT" bowling event.**

we had the results, we learned there were things that could be done. True, there is no treatment or cure, but there is therapy. David has been happily attending physical and occupational therapy. He rides horses with an instructor who has experience

with disabled children. He also loves karate. All these things have made David more and more confident and coordinated.

We have also found a wonderful physiatrist who has equipped David with a Benik vest to improve his kyphosis and bi-valves to wear at night for heel-cord lengthening. The bi-valves are removable casts, and according to his physical therapist, they have made a big difference in his flexibility. And for the record, we defied the pediatrician and had our little girl tested for CMT as an infant; she is negative. We have this blessing that she is spared from the CMT, but she still needs special attention. Most of her three years, she has spent waiting in doctors' and therapists' offices for her brother.

I have to stay positive about David's condition if I want him to have a positive outlook. I truly feel we are doing all we can for him. Being proactive is my cure. Last year we started a Circle of Friends mailing for David and raised about \$1000. This year we had a bowling fundraiser called "Help David Strike Out CMT." Even in this economy, we raised twice as much as last year, about \$2000. This helps the CMTA, and in a real way

helps us to feel like we can make a difference.

This is not to say I walk around at peace every day. David was also diagnosed with a food allergy to tree nuts about a year ago. I have to say that is when I started asking big questions. Standing around in the hospital waiting to see how bad his reaction was going to be, I was just asking aloud, "Why him? Why this too? He has enough on his plate."

But like with the CMT, he has risen to the challenge. On the few occasions I forget to read a label, he's on it. He reminds me when I have touched a potentially dangerous food.

David is a blessing. He has inspired the adults in our family with CMT to seek therapy for themselves, to address the disease instead of just living with it. He inspires us every day with his willingness to do exercises every night, to wear his devices, and to just take care of himself.

We take it one day at a time in our family. I can't get all wrapped up in what the future will be for him, because all we have is right now. I have hope that with the CMTA and the work they are funding, he will have a future better than I can imagine. ✨

*I have to stay positive about David's condition if I want him to have a positive outlook.*

## The CMT "Circle of Friends"

We are proud to have David Corley and his family in our Circle of Friends. Not only have they risen to the challenge of coping with CMT, but they have gotten involved and are helping us fund the CMTA Strategy to Accelerate Research.

If you have what it takes to get involved and start a Circle of Friends, call us today at 1-800-606-2682, email us at [cof@charcot-marie-tooth.org](mailto:cof@charcot-marie-tooth.org), or visit us on the web at [www.charcot-marie-tooth.org/cof](http://www.charcot-marie-tooth.org/cof).

Working together, can create a world without CMT!



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

### David's Quest

American Kempo Karate Academy  
Mr. and Mrs. John Babich  
Ms. Dausha Campbell  
Children's Creative Learning Center, LLC  
Mr. Pat Coakley  
Mr. and Mrs. Michael J. Collins, Jr.  
Mr. Tom Connolly  
Mr. Richard D. Conti  
Mr. David C. Corley  
Ms. Nancy Corley and Mr. Alfred Eisan  
Ms. Susan B. Cunningham  
Ms. Melania Dzedzic  
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Mr. John McMillan  
Mr. Robert J. Mitchell  
Mr. Carlos I. Moniz  
Mr. and Mrs. Edward J. Neary  
Mrs. E. Marie O'Meara  
Ms. Gail M. O'Meara  
Ms. Patricia O'Meara  
Ms. Nellie K. Powell  
Mr. and Mrs. William T. Raleigh  
Ms. Corina Howe-Shea  
South Coastal Demolay  
Chapter 220008

Mr. Roger Stamper  
Ms. Dana Hansen-Stork  
Mr. Paul David Stuart  
Mr. and Mrs. James Sugarman  
Sullivan and Folan, LLC  
Mr. Aldan Tague  
Ms. Wendy Walsh  
Ms. Colby Weron

### Grace's Courage Crusade

American Express Foundation  
Mr. and Mrs. Thomas D. Argiriou

Mr. and Mrs. Brendan T. Murphy  
Mr. and Mrs. Eugene Rizzo  
Dr. and Mrs. Eugene J. Sidoti  
Mrs. Elaine Synan

### Keara's Quest

Girl Scout Troop #48746

### Ryan's Quest

Mrs. Carol Ris  
Mr. Don Gregoire

## Taking the Plunge

For the eighth year in a row, Board member Steve O' Donnell will take on the chilly, choppy waters of the Chesapeake Bay to raise money for CMT research. Steve's "Swim for the Cure" has raised an astonishing \$516,262 in the previous seven years. The swim will take place on June 14, 2009, and Steve will be joined by several friends and by his daughter, Jaime, in making the swim. Still more friends will support the swimmers by staying back on shore and "guarding the ribs" an important task that protects the pork spare ribs that the swimmers and their families and friends will enjoy after the swim.

When Steve, who has CMT, first took on this challenge back in 2002, we called him a "hero" for trying to do something that a totally healthy person would find difficult to do. But, back then, Steve said that it was his heart that made the task possible, not to mention the amazing amount of time he spent training for the swim. His heart will propel him again this year in his mission to spread awareness of CMT and to raise funds for the STAR research program.

If you would like to support Steve and his daughter, you can send a check to the CMTA, 2700 Chestnut Parkway, Chester, PA, 19013 and mark it for "Swim for the Cure" or go to [www.cmtausa.org/swim](http://www.cmtausa.org/swim). Even in this tough economy, Steve hopes to continue his incredible support for CMT research and the cure he hopes is right around the corner. ✨



**Jaime O'Donnell and her friend Cecily McIntyre will join Steve O'Donnell in swimming the Chesapeake Bay.**



## ASK THE DOCTOR

### Dear Doctor,

*I have read that stem cells might offer a cure for CMT sometime in the future. Can you explain how they would work?*

### The Doctor replies:

The current fame of stem cells raises the possibility that they might effectively replace cells in various diseases. This possibility is based on their special ability to differentiate into specialized cells, including nerve cells (neurons) or myelin-producing cells (Schwann cells). Thus, if stem cells transplanted into a diseased nerve could somehow restore that nerve or even improve its function, then this could be an important therapeutic advance.

To date, however, there are

no compelling data that support the use of stem cells for the treatment of any kind of peripheral neuropathy, including CMT. The typical experimental approach has been to inject stem cells into a nerve of a rat or mouse, but this has not produced much functional improvement. The reasons for this lack of an effect are not clear—perhaps stem cells fail to receive proper “instructions” to become myelin-producing cells and/or the cells don’t migrate far enough to do much good.

### Dear Doctor,

*Three years ago while pregnant, I was prescribed Prometrium once daily for about 3 months because I had a history of miscarriage. I*

*did not know then that I had CMT1A. My symptoms, mild then, really worsened after taking it. I have read the studies on progesterone in rats, and I am concerned about the safety of Prometrium. What do you think?*

### The Doctor replies:

There is no proven or highly suspected link between progesterone-containing hormones and the worsening of CMT, but the issue has not been specifically studied. I know of no published reports of worsening after these types of hormones, but that is not proof that there is no effect. There are ongoing animal trials on the beneficial effects of a progesterone antagonist on a model of CMT1A. \*

### WRITE TO US!

Pat Dreibelbis,  
Editor,  
pat@charcot-marie-tooth.org

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

## CMT Daffodils for Seniors Day Held in Johnstown

The 12th Annual CMT Daffodils for Seniors Day was held Saturday, April 4th, at Arbutus Park Manor in Johnstown, PA. Every spring children pick, arrange, and present thousands of daffodils to nursing home residents. The year’s event was another success because even though the daffodil supply was down, the child count was up. The event raises awareness of CMT for the children, the residents, and the public. The appreciation of the residents is overwhelming. Many get few, if any, visitors and a spring bouquet delivered by a cute kid truly makes their day. We did not have TV coverage this year but got a huge picture in the local paper. The CMT daffodil giveaway is a great affair for everyone involved and could be expanded across the country. If anyone would like to get involved, my e-mail address is; jdgriffith@atlanticbb.net



The daffodil giveaway is in the name of Charcot-Marie-Tooth Disease (CMT) and in honor of JD Griffith’s daughter, Marah, who died at sixteen on Christmas Day, 2001. Marah was instrumental in the conception of children giving daffodils to seniors. Marah loved organizing the event and working with the children. She particularly enjoyed the pleasure the daffodils gave to the nursing home residents. \*

# Filling the Void

## How the Book *Chasing Normal* Came To Be

BY DINAH CHAUDOIR FEDERER

It is said that the universe does not allow a vacuum. Whenever there's an empty space, the universe will promptly fill it. Much to my husband's chagrin, this is absolutely true in our household. Thanks to me, our closets and previously empty spaces are full, always! I'm the space filler in our relationship.

When Editor Pat Dreibelbis asked me to discuss why and how I wrote the book *Chasing Normal—A Guide for the Newly Disabled and for Those Who Love Them*, I thought "Well, it was meant to fill what I perceived as a void or a hole in the rehab system." I have "atypical" CMT. I grew up walking with assistance of some kind—walking along walls and furniture, holding onto a friend's arm, using crutches, etc. So, as I've said in the book, I grew up chasing normal.

At 35 I was diagnosed with trigeminal neuralgia bilaterally. It's an intense, actually torturous, electrical shock type of facial pain. The medication given for this pain is anti-seizure in nature. So, give someone with a neuromuscular challenge a drug that relaxes muscles and nerves and the result is life changing weakness. Suddenly I was dealing with severe chronic pain and a body that wasn't behaving the way it had for 35 years!

As a veteran vocational rehabilitation counselor for the state, you'd think I'd have been better prepared to deal with loss of functioning, grief, doctors

who wouldn't believe the meds were causing weakness, etc. But, it's one thing to counsel people through loss and quite another to journey through it yourself.

The knowledge in your brain doesn't stop the pain in your heart! During those initial years I would have liked to have been able to talk to someone else who was not just surviving but thriving, through pain, weakness, and loss. I looked on Amazon.com and didn't see much that felt applicable.

I remembered what kinds of things I said to my newly disabled clients as a way of supporting their journey, and I tried applying it personally. I returned to my job after my initial diagnosis and the medication change that allowed me to walk again and found myself repeating the same things to my new clients. They were the things I had said to my clients before my world collapsed. They were the things I wished someone had said to me. I was finding myself wondering why these things were not in print.

Ahhh, now we've come full circle. We're back to the void!

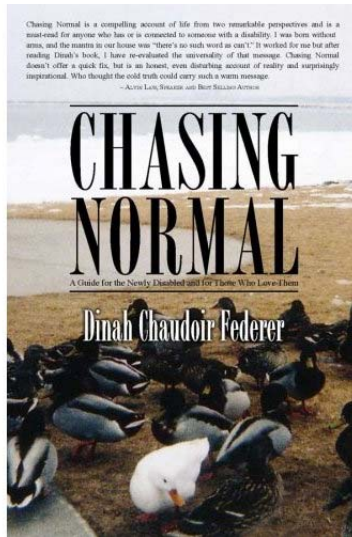
There's another old expression, "as within, so without!" We see in the world that which exists within us. I perceived a void in the rehab system and I intended to fill it.

Remember, I'm the empty space filler! And as a result of aiming for the space "out there," I filled the void in my heart that made me wonder why I'd been given two disabilities. I reminded myself of the truths I believe in. My goal of

helping others with new disabilities to see that life really could be worth living helped me convince myself of that very thing.

So, if you're a newly disabled person, I wrote *Chasing Normal* for you. If you're a friend or family member of someone with a disability, I wrote it for you. If you're a medical or rehab professional serving people with disabilities, I wrote it for you. And by writing for all of you, I gained peace of mind and heart for myself! May peace surround your journey, too! ✨

*Editor's note: Chasing Normal can be purchased either as an ebook or in paperback form at [www.chasing-normal.com](http://www.chasing-normal.com) or at [Amazon.com](http://Amazon.com)*





## GIFTS WERE MADE TO THE CMTA

### IN MEMORY OF:

**Robert M. Adams**

Mr. and Mrs. Richard W. Kershaw

**Bettie Appleyard**

Ms. Ann M. Lyman  
Mr. John Lyman

**Cliff Bjork**

Mr. and Mrs. William N. Sharp

**John S. Bradley**

Mrs. Janet R. Bradley

**Patrick A. Bright**

Mrs. Victoria White

**Lyn Carmichael**

Mr. and Mrs. Michael Gorman

**Don Crandall**

Mr. and Mrs. Myron B. Martenson

**Richard Creel**

Mr. and Mrs. Steven J. Narro  
Mr. and Mrs. Ken Oldham

**Arthur Davis**

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**Kathleen Dannemiller**

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Mrs. Fleeta Lynch

**Aaron Greif**

Ms. Nina Bernstein

**Helen Gardner Hardison**

Mr. Tommy Weigle

**Dorothe Knowles**

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**Arnold Lande**

Ms. Linda Phillips

**Ruth Linker**

Mr. Gregg Linker

**Virginia MacDonald**

Mr. Daniel MacDonald

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Mr. and Mrs. Robert T. Roet-cisoender

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Mr. and Mrs. Gregory Schilcher

**Mark Schnitzler**

Ms. Vera Stremick

**Raymond Sifling**

Mr. James Sifling

**Rita Sohnen**

Mrs. Marla Carr  
Mrs. Belle Sohnen

**Isabella Torna**

Dr. and Mrs. Eugene Sidoti

**Shirley Wegener**

Mrs. Ardis G. Coslo

**Lawrence A. Werner**

Ms. Patricia J. Hardcopf

### IN HONOR OF

**Biology II Class—5th hour**

Mrs. Sandy B. Hearron

**Rev. Msgr. John Halloran**

Dr. and Mrs. Eugene Sidoti

**Marcelle E. Hreiz**

Mr. and Mrs. David Lugara

**Joseph Inger**

Ms. Ann M. Inger

**Carol Keeley**

Ms. Elizabeth Beers

**Robert and Pamela Kleinman**

Mr. and Mrs. Harry Beeker

Mr. and Mrs. Raymond

Greenberger

Mr. and Mrs. Stephen Hess

**Pamela Kleinman**

Mr. Mark D. Levy

**Dr. Richard Lewis**

Mr. Vasi Vangelos

**Kate Lin Bittner**

Mrs. Jane L. Bittner

**Patrick Livney**

Mr. Vasi Vangelos

**Tyler Ray Lopez**

Mrs. Jean A. Moore

**Amy Doremus Mackay**

Mrs. Amy Mackay

**The Neary Family**

Mr. and Mrs. Thomas G. Wipf

**The Pulicare Family**

Mrs. Susan Pulicare

**Linda Robinson**

Mr. and Mrs. George Nkwonta

**Phyllis Sanders**

Maier Foundation, Inc.

Mr. and Mrs. C. Glenn Schor

**Dr. Michael Shy**

Mr. Vasi Vangelos

**Jeronimo Turrent**

Mr. Armando Turrent

**Dan Vangelos**

Mr. Vasi Vangelos

**Rosemary Werner-Mills**

Ms. Patricia J. Hardcopf

**Erika B. Wiltenmuth, PhD**

Mr. and Mrs. John P. Wiltenmuth, Jr.

**Rita Womer**

Ms. Valerie Baxter Womer

**Grace's Gift of Hope:**

Julie Ann Sgobbo

Mr. and Mrs. Eugene Rizzo

## 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: \_\_\_\_\_

\_\_\_\_\_



## COMING SOON... *The Verse of the Sword*

*This article will introduce you to an author and his soon-to-be published first novel. When the book is available (probably in July), we will follow up with more details and information on where to purchase the book.*

### THE AUTHOR WRITES:

My name is RJ Huddy and I'm from rural eastern Kentucky—Hillbilly country as we proudly say. I was diagnosed with CMT rather late in life...when I was about 30.

One doctor (who shall remain nameless) designated my condition as "severe" and told me I'd be in a wheelchair by the time I was 50. I decided two things:

- 1) I wanted to see the world while I had the chance; and
- 2) He was dead wrong about the age 50 prediction.

My 60th birthday is about seven weeks away, and I plan to celebrate it with a 25K walk down a nature trail south of Paris, a "coulee verte." I'll be wearing my AFO's and using my cane, but I'm still a keen walker and have been in training for this, so smart money says I'll make it. I plan to finish the day with a nice French meal and a glass of champagne.

So, over the past 30 years, I've lived in several countries, including Morocco, Thailand, Japan, and Saudi Arabia. I've visited perhaps 50 countries. My legs are weakening noticeably now, and my hands are growing weaker, but when I'm rocking on my front porch someday, I'll

have nice memories to keep me company.

My first novel, called *The Verse of the Sword*, will be published this summer. It's the story of a romance gone wrong, a suicide letter with lasting consequences, religious warfare in North Africa, and the ties of love that break or fold under the extremes of human conflict. Here's the back cover blurb:

*You've always avoided emotional entanglements; you knew what the results would be. But a hard gust of wind on Cape Cod knocks you overboard and the next thing you know, you are looking up at a nurse. Her face floats far above you, as if you were lying at the bottom of a clear lake and she were snorkeling on the surface searching for you. Now the door is open to love and to crippling heartbreak.*

*You help an Algerian graduate student order a hamburger in a West Virginia restaurant and suddenly you've stumbled into a lifelong friendship—and into the hell of religious warfare.*

*When a time of calamitous change sends societies and entire religions into upheaval, what awaits the innocents caught up in revolution? Some succumb to the turmoil; some ride it out. Some special ones find space within the whirlwind to reinvent themselves as people they never imagine they could be. But, some become the people they always knew they were meant to be.*

Intrigued? The book will be available in July and we will publish more about it in the next newsletter.

### A JOURNALIST WRITES:

Because of my association with the author, I had the chance to read an advance copy of his "The Verse of the Sword." Not only was the writing exquisite, the intriguing plot held the reader's attention and the characters were clearly developed and easily stirred the reader's emotion. His juxtaposition of Muslim culture and Appalachian culture provided a rich experience for the reader along with the opportunity to think and learn.

Lee Ward  
Lifestyles Editor  
*The Independent*  
Ashland, KY USA

### STILL TIME TO SHARE YOUR BEST RECIPE

It's not too late to submit your favorite recipe for inclusion in the CMTA's cookbook, *Alphabet Soup: The ABC's of Comfort Food for Shattered*

*Nerves*. Mark Boxshus is still looking for some good appetizers, side dishes, main dishes and desserts. If you are a cook or you have your mother's most famous recipe in a drawer somewhere, jot it down and see it published in our cookbook. You can download a recipe form by going to [www.cmtausa.org/recipe](http://www.cmtausa.org/recipe) or you can call the office at 1-800-606-2682 and request a printed form by mail. Please help with this ambitious fundraiser. If each of you reading this reminder would submit one recipe, the cookbook would be full to overflowing. That's what we need! \*





## SUPPORT GROUP NEWS

### California – San Francisco Bay Area

On Saturday, March 28th, Jamba Juice, in downtown Los Altos, hosted the CMTA in a fundraising event. Twenty percent of all purchases made from 11 am to 4 pm was donated to the CMTA's STAR initiative. Elizabeth Ouellette and members of her support group had a small table in front of Jamba Juice, where there were stacks of CMT pamphlets and flyers explaining the event. The volunteers asked people to mention the CMTA before ordering. The staff at Jamba Juice also helped out by asking customers if they were there for the CMT fundraiser. In all, the event raised \$350 for the STAR initiative and spread awareness of CMT throughout the community. This event will be held bi-monthly and the group hopes that others will replicate their efforts at Jamba Juice or other companies throughout the country. Special thanks go to Harriet and Frank Weiss, Margarita Carson, Rita Takahashi, and Joelle Gernez and her daughter Ceclie.

The support group met on May 23rd to hear Adam Kemist, CPed and owner of Healthy Bare Feet, talk about specialty shoes for the CMT foot. He also discussed orthotics and custom insoles that he creates for clients' shoes. The meeting on September 12th will feature Dr. Rosemary Shy, a pediatrician who works with the CMT kids at the Wayne State Clinic in Detroit.

### California – Los Angeles

The first meeting of the new Los Angeles group will be on July 11th from 11 am to 1 pm at the Fred Hesse Jr. Community Park in Rancho Palos Verde. The meeting will be held in the Fire-side Room.

### Colorado – Westminster

The Denver CMT support group meeting took place on Saturday, April 25th. The featured speakers, physical therapists Mark Kahl and Kristy Kelly from Anchor Physical Therapy in Broomfield, talked about proper movement and maintaining balance with CMT issues in mind. They also discussed building core strength and demonstrated ways to maintain a healthy back.

Group members volunteered specific topics of interest that they'd like to see included in future meetings and were introduced to the cookbook project being spearheaded by Mark Boxshus.

### Florida – Orlando Area

Our last meeting was Saturday, May 2nd. Dr. Bryan Reuss (an Orlando orthopedic surgeon) spoke about shoulder pain and rotator cuff syndrome in individuals with CMT. We now have an online forum and social coordinator! Our November speaker is already booked (PhD in exercise physiology and physical therapist).

### Illinois – Chicago Area

The group met on April 25th under the leadership of Dale

Lopez. About 20 members heard a presentation from Matt Okon, a Certified/Licensed Prosthetist and Orthotist from Scheck & Siress. He is the orthotist for Dale's son, Tyler, and has designed an AFO for him which still allows Tyler to play sports. The presentation sparked many questions and Matt provided many answers. The group also heard from Pat Livney, Chairman of the CMTA Board, who gave an update on the STAR research projects. The group plans to meet again in August.

### Kentucky – Burlington

Pam Utz held her first support group meeting on May 30th. It was a meet and greet so that people could introduce themselves and help choose topics for future meetings.

### Massachusetts – Boston Area

On May 2nd, Elizabeth Ouellette, support group liaison and CMTA Board member, spoke to the group about STAR and the recent dinner in New York City honoring Joe and Sue Paterno for their charitable work, especially on behalf of the CMTA. The group also discussed the fact that more recipes are needed for the cookbook project.

### Minnesota – Twin Cities

The MN/Twin Cities CMT/HNPP support group meetings have been set for the rest of the year. On Sunday, May 3rd, the group toured the Courage Center, Golden Valley, MN to learn about the services

*(continued on page 18)*

# CMT Support Groups

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

## Alabama—Birmingham

**Contact:** Dr. Dice Lineberry, Calls only  
205-870-4755

**Email:** dklrl@yahoo.com

## California—Los Angeles

**Place:** Fred Hesse, Jr. Community Park,  
Fireside Room

**Meeting:** Quarterly

**Contact:** Ryan Conlon, 310-383-1024

## California—Northern Coast Counties

(Marin, Mendocino, Solano, Sonoma)

**Place:** Sutter Medical Center of Santa Rosa

**Meeting:** Quarterly, Saturday, 1 PM

**Contact:** Louise Givens, 707-539-2163

**Email:** ladyblue123@att.net

## California—San Francisco Bay Area/ Santa Clara County

**Place:** San Mateo Library

**Meeting:** Quarterly

**Contact:** Elizabeth Ouellette,

650-248-3409 (C)

650-559-0123 (H)

**Email:** elizabetho@pacbell.net

## Colorado—Westminster

**Place:** Capabilities, Westminster, CO

**Meeting:** 10 AM – noon, Last Saturday

of every other month

**Contact:** Diane Covington, 303-635-0229

**Email:** dmcovington@msn.com

## Florida—Iverness Area

**Place:** Citrus Memorial Hospital -  
Historical School Bldg

**Meeting:** Quarterly

**Contact:** Ronnie Plageman, 352-860-1578

**Email:** cmtasg\_ivernessfl@

charcot-marie-tooth.org

## Florida—Orlando Area

**Place:** Ability Rehabilitation, Oviedo, FL

**Meeting:** Call for schedule

**Contact:** Jeff Miller, 407-579-1005

**Email:** jeffmillerDPTMOT@gmail.com

## Florida—Tampa Bay Area

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

**Meeting:** Second Saturday of Feb., May,  
Sept., Nov.

**Contact:** Lori Rath, 727-784-7455

Vicki Pollyea

**Email:** rathhouse1@verizon.net

v\_pollyea@mindspring.com

## Georgia—Atlanta Area

**Place:** Cliff Valley School Library  
2426 Clairmont Rd, NE

**Meeting:** 3rd Saturday, every other month

**Contact:** Sue Ruediger, 678-595-2817

**Email:** susruediger@comcast.net

## Illinois—Chicago Area

**Place:** Peace Lutheran Church, Lombard, IL

**Meeting:** Quarterly

**Contact:** Alan Pappalardo,

800-606-2682, ext. 106

**Email:** alan@charcot-marie-tooth.org

## Kentucky—Burlington

**Place:** Boone County Public Library,  
Main Library

**Meeting:** Quarterly

**Contact:** Pam Utz, 859-817-9338

**Email:** pamutz@insightbb.com

## Massachusetts—Boston Area

**Place:** Beth Israel Deaconess Med. Center

**Meeting:** Bi-monthly

**Contact:** Mark Boxshus, 781-925-4254

**Email:** MarkB\_CMTANE@mac.com

## Michigan—Ann Arbor

**Place:** Great Lakes Regional Training Center

**Meeting:** Monthly

**Contact:** Tammy Mayher, 734-216-1347

**Email:** a2.cmtagroup@yahoo.com

## Minnesota—Benson

**Contact:** Rosemary Mills, calls only

320-567-2156

**Email:** rrmills@fedtel.net

## Minnesota—Twin Cities

**Place:** Call for location

**Meeting:** Quarterly

**Contact:** Bill Miller, 763-560-6654

**Email:** wmilller758@msn.com

## Mississippi/Louisiana

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

**Meeting:** Quarterly

**Contact:** Flora Jones, 601-825-2258

**Email:** jonesflora4@gmail.com

## Missouri—St. Louis Area

**Place:** Saint Louis University Hospital

**Meeting:** Quarterly

**Contact:** Carole Haislip, 314-644-1664

**Email:** carole.haislip@sbcglobal.net

## Missouri

**Contact:** Libby Bond, calls only  
479-752-7112 after 7pm  
weekdays; anytime on weekends

## Nevada—Las Vegas

**Place:** West Charleston Library,  
6301 West Charleston Blvd.

**Meeting:** Email for dates 1-3 PM

**Contact:** Mary Fatzinger

**Email:** cmt\_suppgroup\_lvnv@yahoo.com

## New Hampshire—Vermont

**Place:** Dartmouth-Hitchcock Medical Center,  
Auditorium A

**Meeting:** Bi-monthly

**Contact:** Margaret Healey, 802-353-2797

**Email:** margaret\_healey@hotmail.com

## New Jersey—Mountainside

**Place:** Children's Specialized Hospital, Audi-  
torium A

**Meeting:** Quarterly

**Contact:** Rachel Beron, 973-316-0058

Nicole Fulmino, 908-421-3595

**Email:** cmtasg\_mountainsidenj@

charcot-marie-tooth.org

## New York—Greater New York

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

**Meeting:** Second Saturday, 12:30-2:30 PM

**Contact:** Dr. David Younger,

212-535-4314 Fax 212-535-6392

**Website:** www.cmtnyc.org

**Email:** david.younger@nyumc.org

## New York—Horseheads

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

**Meeting:** Quarterly

**Contact:** Angela Piersimoni, 607-562-8823

**Email:** amtcp36@aol.com

## New York (Westchester County)/

## Connecticut (Fairfield)

**Place:** Blythedale Children's Hospital

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

**Contacts:** Beverly Wurzel, 201-224-5795

Eileen Spell, 732-245-0771

**Email:** craneomatic@verizon.net

espell@optonline.net

## North Carolina—Triangle Area

(Raleigh, Durham, Chapel Hill)

**Place:** Raleigh, NC

**Meeting:** Quarterly

**Contact:** Susan Salzberg,

919-967-3118 (afternoons)

**Email:** nabosmom@gmail.com

## Ohio—Greenville

**Place:** Brethren Retirement Community

**Meeting:** 4th Thurs. of April, July, Oct.

**Contact:** Dot Cain, 937-548-3963

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

## Oregon—Portland Area

**Place:** Midland Library, 805 SE 122nd,  
Portland

**Meeting:** Quarterly

**Contact:** Debbie Hagen, 503-333-7936

**Email:** hagen84@yahoo.com

## Pennsylvania—Johnstown Area

**Place:** John P. Murtha Neuroscience Center

**Meeting:** Bimonthly

**Contacts:** J. D. Griffith, 814-539-2341

Jeana Sweeney, 814-262-8467

**Email:** jdgriffith@atlanticbb.net,

cjsweeney@ussco.net

## Pennsylvania—Northwestern Area

**Place:** Blasco Memorial Library

**Meeting:** Call for information

**Contact:** Joyce Steinkamp, 814-833-8495

**Email:** joyceanns@roadrunner.com

## Pennsylvania—Philadelphia Area

**Place:** CMTA Office, 2700 Chestnut Pkwy.,  
Chester, PA

**Meeting:** Bi-monthly

**Contact:** Pat Dreibelbis, 800-606-2682

**Email:** info@charcot-marie-tooth.org

## Tennessee—Savannah

**Place:** East End Sports Complex

**Meeting:** Bi-monthly

**Contact:** Reagan McGee, 731-925-6204

**Email:** janesgang@bellsouth.net

## Virginia—Harrisonburg

**Place:** Sunnyside Retirement

Community, Sunnyside Room

**Meeting:** Bi-monthly, Second Sat. 1-3

**Contact:** Anne Long, 540-568-8328

## Washington—Seattle

**Place:** U of Washington Medical Center,  
Plaza Café—Conference Room C

**Meeting:** Monthly, Last Saturday, 1-3 PM

**Contact:** Ruth Oskolkoff, 206-598-2765 work

**Email:** rosk@u.washington.edu

## Washington—Tacoma Area

**Place:** Moore Library

**Meeting:** Quarterly

**Contact:** Carol Hadle, 253-476-2345

**Email:** cmtasg\_tacoma@

charcot-marie-tooth.org



**SUPPORT GROUP NEWS***(continued from page 16)*

the center provides. Courage Center is a Minneapolis-based rehabilitation and resource center. Group leader Bill Miller uses their therapeutic swimming pool 2 to 3 times a week. Eighteen members attended and shared with each other what is happening in their lives—both triumphs and struggles with CMT and HNPP. On Saturday, August 1st, from 10 am to noon, the group will hear a presentation from Dr. Gareth Parry of the U of MN, Department of Neurology. Finally, on November 7th, from 10 am to noon, Marcia Margolis, PT and Caroline Portoghese, OT from Fairview Hospital will discuss exercises and activities that can be beneficial for CMT patients.

**Nevada – Los Vegas Area**

The group held a fundraiser during a Blue Grass Festival at the VFW in Pahrump, NV, which is about 50 miles from Las Vegas. There was a raffle for a handmade bird house and handmade Civil War statues. They also sold tee shirts and wrist bands. The proceeds of over \$300 were sent to the CMTA. The group had a regular meeting on May 16th with the CMTA's new Chief Executive Officer, David M. Hall.

**New Hampshire – Vermont**

The next meeting of the group will be on June 27, 2009, from 10 am to noon. The speaker will be Elizabeth Ouellette, Board member and support group liaison. Elizabeth will update the attendees on the progress of the

STAR initiative and other work that the CMTA is undertaking. The group meets at the Dartmouth-Hitchcock Medical Center, Auditorium G.

**New York – Greater New York**

On Saturday, May 9th, the group discussed “Why Me? And What Now?” with moderator Bob Wine at the helm. They discussed how to deal with finding out about having CMT and what can be done about it. Caregivers, relatives, and friends were welcomed and gave an alternative perspective on the questions. The group meets at the New York University Medical Center.

**North Carolina – Triangle Area**

The group met at The Center for Independent Living in Raleigh, NC on Sunday April 26th. The speaker was Krissy Profio, the new MDA Healthcare Services Coordinator. She discussed MDA services available in their area. After her presentation, the group saw the presentation by Dr. Michael Shy from the Palo Alto conference. Susan Salzberg, the original group leader, who began the group in 1990, was presented with a plaque of appreciation and a gift certificate from the group. The new leaders are Betsy Kimrey and Gary Orsen. The next meeting will be on the last Sunday in July.

**Oregon – Portland**

The Portland Support Group met on April 7th, at the Midland County Library. It was a great informative meeting with guest speaker Clarisa Walcott, OT. She

provided us with hand-outs of how to help with fatigue. There were about 10 people there. We are hoping for a bigger turnout for the July meeting.

**Tennessee – Savannah**

The last meeting in April was short and sweet. We had a cook-out and discussed the new cookbook. Our next meeting in July will be with David M. Hall, Chief Executive Officer, coming down to speak to us. We are planning on having a yard sale in the next couple of months. All the money will go to STAR.

**Washington – Seattle**

The last meeting was on April 25th at the University of Washington Medical Center. The speakers were Charity Ranger and Mary Beth Lum, staff members of the Alliance of People with Disabilities. They discussed their program to keep people living independently and the group enjoyed a pot-luck luncheon with the main course provided by the CMTA. The group will meet again on June 27, 2009. ✨

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**CORRECTIONS**

- When you have a dorky disease” was incorrectly attributed to Carole Haislip. It was, in fact, written by her daughter, Lisa Minzer. We apologize for that mistake.
- An article entitled “My Experiences with CMT” by Jack Graves appeared in the Nov/Dec 2008 issue of the newsletter. We had his email incorrectly listed at the end of the article. His correct email address is jag.szygy@att.net.



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

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

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

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

**ALSO AVAILABLE:**



**Circle of Friends T-Shirts**



**Be a STAR Wristbands**

**MEMBERSHIP APPLICATION/PUBLICATIONS ORDER FORM**

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**Note: If you are joining now, you may purchase publications at active member prices.**

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<b>NEW!</b> CMT Facts VI		<b>active members \$12</b> nonmembers \$15	
A Guide About Genetics for CMT Patients <i>(No shipping and handling on this item only)</i>		<b>active members \$4</b> nonmembers \$5	
Teaching Kids about CMT...A Classroom Presentation <i>(1 hour DVD)</i>		<b>active members \$7.50</b> nonmembers \$10	
<b>NEW!</b> Be a Star Wristbands (Pack of 5)		\$5	
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<b>NEW!</b> West Coast Patient-Family Conference <i>(5 hours—2-DVD set)</i>		<b>active members \$15</b> nonmembers \$20	
CMT Informational Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List		FREE	
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Check payable to the CMTA *(US residents only; non-US residents, please use credit card or international money order.)*

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**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.*



## CMT PATIENT MEDICATION ALERT:

### Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

### Moderate to significant risk:

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

### Uncertain or minor risk:

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

### Negligible or doubtful risk:

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

# 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.

## THE CMTA Report



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