THE CMTA Report

JANUARY/FEBRUARY
2010

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

The CMTA Applauds Congress for the Creation of the National CMT Resource Center

BY DAVID HALL

The CMTA applauds Congress' action to create a National CMT Resource Center which will provide a national platform of education, awareness, and treatments for patients and families who live with CMT disease.

Thanks to the leadership of Senator Arlen Specter (D-PA), Congress has allocated $1,000,000 to launch the National CMT Resource Center in conjunction with The Centers for Disease Control and Prevention's National Center for Birth Defects and Developmental Disabilities (NCBDDD).

The funding, which was provided within the 2010 Federal Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill (LHHS), will support a national initiative to promote a collaborative relationship between CMT patients and their providers and ensure people are being properly diagnosed and treated with the latest standards of care. Senator Judd Gregg (R-NH) also provided significant support for the funding request.

The creation of the National CMT Resource Center will provide the foundation for what has always been at the core of the CMTA's mission—improving the lives of those with CMTA.

> The National CMT Resource Center should ensure the proper diagnosis of more CMT patients.

In 2007, the CMTA launched a strategic research initiative known as the Strategy to Accelerate Research (STAR). STAR is designed to support focused research that will develop effective treatments for CMT within five years, and a cure within 10 years. STAR researchers are already able to replicate the disorder in the laboratory and, in doing so, can soon begin testing new treatments that will ultimately lead to clinical trials in people. In addition, the translational science used in the research could have major implications for the treatment of a host of related neurodegenerative disorders including multiple sclerosis, muscular dystrophy, and ALS.

The creation of a National CMT Resource Center will greatly assist the CMTA's efforts in ensuring that more CMT patients be properly diagnosed and that the hoped-for treatment and cure for CMT will reach patients in the shortest possible time. ✻

INSIDE:

★★★★
CHARITY NAVIGATOR
Four Star Charity

In December, Charity Navigator, America's premier independent charity evaluator, awarded the CMTA its highest 4-star rating for sound fiscal management.

Charcot-Marie-Tooth Association

OUR MISSION:

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

OUR VISION:

A world without CMT.

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

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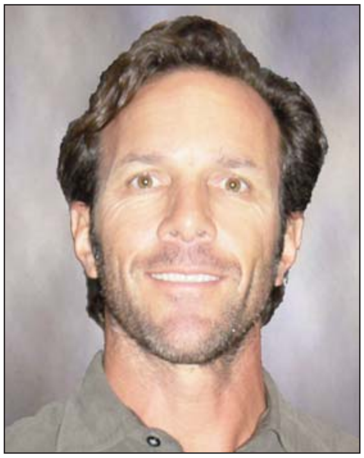
Two New Board Members Join the CMTA

In November, Doug Sieg joined the CMTA's Board of Directors. He is a partner at Lord Abbett, an investment firm, and lives in New Jersey with his wife and daughter. He became interested in working with the CMTA because of two important influences in his life: his mother and Penn State Coach Joe Paterno. Doug's mother has CMT and is often the person referred to as the friend of Joe who caused him to become interested in supporting the CMTA. Doug also played football with the Nittany Lions from 1987 to 1992 and respects Coach Paterno and all that he stands for. He hopes his involvement with the Association will help with the ambitious goals of finding treatments and a cure for CMT.

Vasi Vangelos is the founder of First Artists Management, a talent agency specializing in composers and music supervisors for film and television. He has Charcot- Marie-Tooth (CMT) disease. He writes, "Although this is the most commonly inherited peripheral neuropathy—affecting 1 in 2,500 people—medical science is still striving to develop a cure. Recently, I have been thinking about how I could help support the efforts put forth by the Charcot-Marie-Tooth Association beyond my personal contributions. I joined their board in April 2009 and have decided to share my involvement with my own circle of family and friends as well as my business associates within the Hollywood community. I've recently formed an annual fantasy baseball camp fundraiser on behalf of CMTA with the goal of raising a generous sum of money for research and development as well as educating those unacquainted with this illness. In addition to bringing focus, I hope to create the village it takes to divide and conquer this debilitating disease." ✻

Doug Sieg



Vasi Vangelos

The CMTA Welcomes a New Director of Community Development

In October, Cheryl Sherman joined the CMTA staff as Director of Community Development. Her responsibilities include managing and growing support groups nationally as well as creating grass roots fundraising initiatives at the support group level.

Cheryl has CMT 1B and received the diagnosis 13 years ago. She wears AFOs and went through extensive foot surgery in 2001 and 2002. She believes in living a full life and not letting this condition stop her from pursuing her dreams and goals.

The daily challenges of dealing with this condition and now seeing the signs of progression in her hands give her an understanding of what others with CMT are going through. Cheryl is driven to provide support for everyone who suffers with this condition and to help fund the STAR initiative to stop this disease.

If you are interested in fundraising or starting a support group in your area, please email Cheryl at cheryl@charcot-marie-tooth.org or call her at 1-800-606-2682 x106. ✻

An International Conference on Transitional Medicine in Inherited Neuromuscular Diseases

BY CHERYL SHERMAN

I had the pleasure of attending the first international conference organized by Treat-NMD (Neuromuscular Diseases) and the National Institutes of Health (NIH) entitled “Bringing Down the Barriers in Translational Medicine in Inherited Neuromuscular Diseases.” This conference was held from November 17 to 19, 2009 in Brussels, Belgium, the home of the European Commission. The European Commission has funded the establishment of Treat-NMD and many other initiatives to improve the quality of life for all its citizens. In partnership with the NIH, Treat-NMD is ensuring that the European Commission recognizes the need to look beyond Europe and address issues globally through international collaborations for the benefit of all.

The aim of the conference was to bring together experts, opinion leaders, and the neuromuscular community to collaborate on ways to tackle the key issues that need to be addressed if we are to see new and promising therapies and treatments delivered rapidly to patients all over the world.

The conference had approximately 340 people in attendance with 27 countries being represented. They assembled a stimulating program to discuss progress in translational medicine and map the future collaborative agenda to ensure care and therapy development is driven forward between clinicians, scientists, patients, and industry for the benefit of the neuromuscular community. Participants gave presentations on the current ‘state of the art’ in their respective areas as well as participating in expert panel discussion sessions and poster presentations.

Dr. Michael Shy from Wayne State University and Chairman of the CMTA Medical Advisory Board gave a wonderful presentation on “The STAR Initiative: Partnering between the CMTA, Academia and Government to Develop Therapies for CMT.” His presentation included an update on what the STAR initiative is and what progress has been made to date.

John Porter, Program Director at the National Institute for Neurological Disorders and Stroke (NINDS) at NIH gave a presentation on “Attaining Symbiosis for Therapy Development Efforts in Neuromuscular Diseases.” He discussed how the industry has been working in isolation in terms of research and treatment options. This strategy does not work and ultimately will fail, therefore collaboration and better communication across all neuromuscular diseases are necessary. He highlighted the fact that Michael Shy, the CMTA, and STAR are one example where collaboration is occurring and working well.


Cheryl Sherman, our new Director of Community Development, attended the Treat-NMD conference in Brussels in November.

This conference gave me a good sense of the vast number of scientists, researchers, clinicians, patient advocacy groups, and other industry professionals working on finding therapies and treatments for all CMT and neuromuscular disease patients. It also gave me a renewed sense of hope hearing about the progress that scientists are making and knowing that they are working hard on therapeutic discoveries and the sharing of their discoveries. All of this collaboration, in my opinion, will create the momentum necessary to find successful therapeutic treatments in the not too distant future! ✻

It Takes a Clinic to Tackle Charcot Marie Tooth Disease

It may have an unusual name, but Charcot-Marie-Tooth (CMT) disease is the most common inherited neurological disorder, affecting one out of every 2,500 people. So, Johns Hopkins recently established a clinic that specializes in the care of patients with CMT.

Neurologists begin by determining whether the patient does, in fact, have CMT—or another disorder that shares some of the same symptoms. At least half of the patients neurologist Ahmet Hoke sees at the CMT clinic have been misdiagnosed, he says. Patients with CMT typically present with muscle weakness in the feet, which can later progress to the legs, hands, and forearms, and be accompanied by a loss of sensation. A signature of CMT is foot drop, which results from weakened dorsiflexors, and a high-stepped gait.

The disease, which is named for the three doctors who identified it in 1886, results from mutations in the genes that code for proteins found in peripheral nerve axons or their myelin sheaths. Defects in these proteins cause peripheral nerves to degenerate gradually, with subsequent weakening and atrophy of associated muscles. But not every patient with such symptoms has CMT, says Hoke. Some patients, for instance, are referred with foot deformities that resemble those that can occur in CMT, but the underlying cause turns out to be an orthopedic abnormality.

Many other patients are referred with an initial diagnosis of CMT but turn out to have a different form of peripheral neuropathy. Clinic physicians—Hoke, David Cornblath, Charlotte Sumner, and Thomas Lloyd—diagnose CMT through physical exam, family history, and nerve conduction studies.

Finally, genetic tests can reveal which mutation underlies a patient's disease. "There's been a big explosion in the field of the genetics of CMT, especially in the last five or six years," notes Hoke. "Genetic testing is useful to help predict the prognosis for patients (since different types of CMT progress differently) and helps us in counseling the family about their chances of passing the disease genes to their children."

For patients diagnosed with CMT, the clinic provides a range of specialty services, including physical therapy, occupational therapy, and orthotic specialists. Many patients are fitted for special splints called ankle-foot orthoses that can stabilize gait and prevent patients from tripping and falling. Attentive foot care can help patients reduce the chances of developing ulcers and Charcot joints, potentially painful deformations of the foot and ankle joints.

The Johns Hopkins CMT clinic is one of five centers participating in the North American CMT Registry funded by the CMT Association and Muscular Dystrophy Association. The aim of this registry is to document the natural history of uncommon forms of CMT and identify new genes in CMT patients with no known genetic defects.

The clinic is also participating in a three-site clinical trial to test whether high-dose vitamin C can prevent some nerve degeneration in patients with one genetic subtype of CMT. The results of the study, which is no longer enrolling patients, are expected in February 2011. CMT may not yet have a cure, says Hoke, but small changes can help patients significantly improve their quality of life.

For information, call 410-955-2227. ✻

Article reprinted courtesy of Johns Hopkins Medicine.

A thorough neurological exam helps neurologist Hoke weed out CMT misdiagnoses.

CMT IN THE NEWS

Flag Football League Gives Area Youngster the Chance to Play Football Despite His Rare Illness, *By Joe Amick, reprinted from The News-Herald*

The yellow flags are slung around his waist and the mud coats his shoes and sweatpants. And 11-year-old Spencer Slaght also wears a smile on Saturday mornings. He gets to play football. Until this year, Spencer has never been able to play because of Charcot-Marie-Tooth disease, a neurological disorder that causes muscle weakness and atrophy, and a loss of feeling in the hands and below the knees.

The nerve cells that carry electrical messages between Spencer's brain and spine and his muscles and skin are missing key proteins. Without these, the electrical messages either travel very slowly or at a much-reduced strength. CMT is generally not life-threatening. CMT makes tackle football too high-risk for Spencer.

The solution for the Slaght family was to sign Spencer up for the Lake County Youth Flag Football League. Spencer gets to play football, but his parents don't have to worry about injury because there is no contact. Doctors have encouraged the Slaghts to have Spencer play sports to combat muscle atrophy. "He's been asking for years to play, but tackle (football) is too high-risk," said Spencer's father, Whitney. "He loves the game. One of the real big draws for him is to play on a team and be accepted by the team."

The Mentor-based United States Flag & Touch Football League runs the youth league, which is in its second year. There are 157 players on 18 teams in three age divisions. Spencer's team, Chaos, is in second place in the 9- to 12-year-old division. Spencer was 3 years old when he was diagnosed with CMT. "He's been through a lot. He's overcome quite a bit," said his mother, Arlene. "He's doing much, much better physically than doctors thought he would."

"He's got a fabulous attitude and wants to do his personal best. He doesn't quit," said Whitney. That attitude is evident in other sports Spencer participates in.

This summer, Spencer was on a swim team at the Cleveland Yacht Club. The team held a fundraiser for leukemia as kids took pledges and a certain amount was donated for every lap they swam. "He said, 'I'm gonna swim 100 laps.' In an Olympic-sized swimming pool. He did 50 on Friday and 50 on Saturday," Arlene said. "By the end, he was more sinking than swimming. But he didn't quit," said Whitney.

Spencer is a touch slower than the other kids on the team and he tires a little faster, but plays every play of the half-hour games. "[Spencer] comes out here with a great attitude. He hustles," said one of Spencer's coaches, Mike Champa.

Spencer's parents say the highlight for them has simply been watching how much their son is enjoying himself. How much does Spencer like playing? "A lot," he said after one wet Saturday morning win. "I wanted to play tackle, but my mom wouldn't let me." After that statement, Arlene and Whitney just chuckled with their muddy, happy son.

International Day of Persons with Disabilities Declared

In December, the United States joined the United Nations Convention on the Rights of Persons with Disabilities (see press release below). 650 million people live with disabilities worldwide. ✻

THE WHITE HOUSE
Office of the Press Secretary

For Immediate Release December 2, 2009

INTERNATIONAL DAY OF PERSONS WITH DISABILITIES, 2009
- - - - - - -
BY THE PRESIDENT OF THE UNITED STATES OF AMERICA
A PROCLAMATION

This year, in an effort to renew our global commitment to human rights and fundamental freedoms for persons with disabilities, the United States became a proud signatory of the United Nations Convention on the Rights of Persons with Disabilities. This treaty represents a paradigm shift, urging equal protection and benefits for all citizens, and reaffirming the inherent dignity and independence of the 650 million people living with disabilities worldwide. Today, as we commemorate the International Day of Persons with Disabilities, we celebrate the skills, achievements, and contributions of persons with disabilities in America and around the world. We recognize the progress we have made toward equality for all, and we rededicate ourselves to ensuring individuals with disabilities can reach their greatest potential.

Despite our increased efforts, persons with disabilities continue to face barriers to their full participation in society. In the United States, Americans with disabilities still experience discrimination in the workplace and in their communities. In developing nations, 90 percent of children with disabilities do not attend school, and women and girls with disabilities are all too often subjected to deep discrimination. If we are to move forward as a people, both at home and abroad, all individuals must be fully integrated into our human family.

The International Day of Persons with Disabilities is a time to renew our commitment to the principles of empowerment, dignity, and equality. The United States has co-sponsored and joined consensus on the United Nations General Assembly Third Committee's resolution titled, "Realizing the Millennium Development Goals for Persons with Disabilities." We must continue to embrace diversity and reject discrimination in all its forms, and insist on equality of opportunity and accessibility for all. Let our efforts remind us that when we work together, we can build a world free of unnecessary barriers and include every member of our international community.

NOW, THEREFORE, I, BARACK OBAMA, President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States, more do hereby proclaim December 3, 2009, as International Day of Persons with Disabilities. I call on all Americans to observe this day with appropriate ceremonies, activities, and programs. IN WITNESS WHEREOF, I have hereunto set my hand this second day of December, in the year of our Lord two thousand nine, and of the Independence of the United States of America the two hundred and thirty-fourth.

BARACK OBAMA

CMT IN THE NEWS

Swimming Coach Deni Gillespie, of Jensen Beach, FL, Has Maintained Her Career Despite a Lifetime's Worth of Obstacles Thrown in Her Way

By Bill Meredith, reprinted from The Palm Beach Post News

When swimming coach Deni Gillespie was diagnosed with Charcot-Marie-Tooth disease in 1992, she also found out that she'd had it her whole life.

Named for the French and British scientists who discovered it, the progressive nerve and muscle disorder is caused by a genetic defect in the peripheral nerves.

The Jensen Beach resident, now 56, also found out that she'd passed it on to her son Casey, now 21 and a junior at the University of Central Florida. He hasn't yet experienced the same amount of pain and muscle weakness and atrophy as his mother. But the two share a sympathetic bond.

"He actually feels worse for me," Gillespie said. "He said, 'I feel really bad that you didn't know what was wrong when you were younger. You must've been wondering why you couldn't do certain things.'"

The disease has impacted more than just Gillespie's swimming ability.

The protective pads at the bottom of her feet are worn down, causing her to use a motorized wheelchair and wear special shoes. The move to South Florida from New Jersey 12 years ago has helped, because cold made her symptoms worse.

Gillespie says that her condition worsening has caused her to lose jobs, and be passed over for others, despite a stellar coaching record she started at age 20.

"That's how I put myself through school at Rutgers," the New Jersey native said.

She has been both a college assistant coach and a high school head coach. She also started the Swim Strong Aquatic Club with Casey four years ago.

Swimming coach Deni Gillespie, of Jensen Beach, has maintained her career despite a lifetime's worth of obstacles thrown in her way.

Before the Port St. Lucie Pool closed during non-summer months because of budgetary concerns this year, Gillespie offered lessons to Treasure Coast children who normally might not consider swimming — including minorities and those who were overweight, or suffering from autism or attention-deficit disorder.

Another specialty is her "stress-less swimming" lessons through her Jensen Beach Swim Gym.

Fort Pierce resident Jeff Brodzinski, 39, started training with Gillespie before his first triathlon. Brodzinski, who operates Finishing Touch carpentry business, was pleasantly surprised at the immediate results.

"My first triathlon was the Loggerhead in August," he said, "and I did another one in Melbourne in October. I'd grown up around water and swam all my life, but Deni showed me I wasn't swimming properly.

"She emphasized breathing techniques, and conserving energy by gliding, and I finished seventh in my beginner class at the Loggerhead Triathlon in Jupiter. In Melbourne, I finished eighth in the age 34-39 group."

Gillespie says that some of those training methods were frowned upon as she led a successful Jensen Beach High School program from 2004-2007.

"Jim McCombs, who's coached Martin County since 1995, didn't think much of my breathing techniques," Gillespie said. "He was my nemesis."

"I don't consider her a nemesis," McCombs responded. "I consider her a colleague."

Gillespie would instruct more students if her CMT didn't also impact her driving, and she'd give more lessons at her pool if she could afford to repair its heater. This and other home improvement needs have her offering "skill swaps," in exchange for swimming lessons. ✻

iGive.com: Fundraising at Your Fingertips

BY ELIZABETH OUELLETTE

Do you ever shop on-line? Do you know anyone (friend, family member, neighbor) who ever purchases gifts, books, flowers, or other miscellaneous items through the Internet? Would you like to support the CMTA without depleting your bank account or even leaving your house? If you answered "yes" to any of the above questions, iGive may be the answer to your charitable giving desires—read on!

$4,580,822.27 donated to causes...
48,912 causes...
607,901 members...
One community...
Doing good...

"I love using igive.com. I use it at work and at home. At work I have to make hotel and plane reservations. With most my purchases at work I can help JCCARE - Japanese Chin Care And Rescue. Thanks igive.com."

- Becky McMahon

Select your cause to start iGiving:
Start typing your cause name to see results...

iGive is a free service which enables our members to earn money for their favorite cause whenever they make an online purchase or search the web.

It's that simple...

Search the web and earn 2¢ for your cause:

Performing fraudulent searches will result in removal of your cause from this program.

Shopping through iGive makes every online purchase an extra gift to the CMTA.

iGive.com is an Internet company, established in 1997, to promote philanthropy through everyday consumer on-line purchases. On the iGive website, you will find over 700 of the web's most poplar on-line stores, including Amazon, eBay, Petco, Staples, Netflix, AT&T, HP, and many more. When you shop through iGive, a percentage (anywhere from 0.2 to 26%, depending on the merchant) of your total purchase is automatically donated to your charity of choice (CMTA), at no extra cost to you or to the CMTA!

All you have to do is go to the iGive website and register for a free account. First, select your cause (Charcot-Marie-Tooth Association) and fill out the short form with your name, e-mail address, and password. Once you submit this information, I strongly encourage you to download the iGive toolbar, which makes it harder to forget iGive when shopping on-line, while enabling you to easily track your purchases and contributions. Nevertheless, you can also skip the iGive toolbar step altogether and simply go through the iGive website before shopping, but if you forget to go through iGive, your account will not be credited and the opportunity to support the CMTA will be forever lost.

Moreover, if you make an on-line purchase within the first 45 days of your registration, iGive will give an additional $5 to the CMTA. Better yet, on iGive's homepage, there is a section where you can "Tell Friends about iGive.com!" If a CMTA member convinces just two people to register with iGive, an extra $10 will automatically be donated to the CMTA. If 100 members took on this challenge, the CMTA would receive an additional $100 in effortless donations, and, of course, if 1000 people made the effort to recruit two or more new iGive supporters, the CMTA would receive a minimum $1000 or more in iGive donations. These $5 bonuses are, of course, an additional perk to the money raised on every on-line purchase throughout the year. Those $5 donation add up quickly, so do not underestimate the power each and every one of you holds to support the CMTA and its many programs benefiting those with CMT.

The bottom line? Go to iGive.com right now, sign up, and invite at least two friends to join. Tell your friends, co-workers, and family members about this wonderful resource. You personally have nothing to lose, and the CMTA has everything to gain. The power to make a tangible and lasting difference lies in your hands—right at the tips of your fingers. ✻

LIVING WITH CMT

Losing My Grip

MacGyver's struggles with 21st-century packaging

Not on reality, fortunately, but I did come to the realization the other morning that I had reached the end of a "plateau" period—those times of varying length we all have when our CMT seems to be fairly stable and not noticeably progressing.

I was performing my morning ritual of removing the coffee filter basket (the conical variety) and dumping the grounds, and instead of just the filter and the grounds going into the trash, the filter basket ended up there, too.

I checked to see if my hand was wet (it wasn't) and several instant replays later, I was convinced that something about my left-handed grip had changed, so I set off on a round of experimentation to see just what else might have become more difficult to do. I didn't have any problem holding a water glass, but anything larger was suddenly in danger of slipping out of my hand and crashing to the floor, which means that I now have to be more careful when picking up things that don't easily close in my grip. (Unfortunately, the handle of a snow shovel still does, so I had to deal with the two feet of snow that piled up in my driveway last weekend.)

I was also able to uncrate and assemble a recumbent exercise bike in about three hours, a task I probably could have done in half that time if the bolts and washers hadn't been shrink-wrapped to a piece of cardboard, which brings me to my current rant: *packaging*.

Small snack bags like this one can be almost impossible to open with hands affected by CMT. Mac says "Keep a scissors handy."

Most modern packaging, whether it's intended to deter tampering or theft, or whether it's just the easiest and cheapest way to bottle or wrap something up, can challenge even someone without CMT. Small electronic devices, for example, are usually impossible to extract from the plastic casing without scissors and/or pliers, and pull-tabs are often anything but. If they're not flimsy and impossible to grip, like the half-moon tabs on ketchup bottles (which I poke a knife or fork through and pull off), they can be extremely rigid, like the ring-tabs on beverage and other cans, which are often next to impossible to lift up

OOPS…ERROR AT MAILING COMPANY CAUSES MIX-UP IN LABELS FOR NOVEMBER-DECEMBER NEWSLETTERS

Due to a processing error by the company that creates the mailing labels for *The CMTA Report*, you may have received the November-December issue with someone else's name on it.

A postcard was sent out at the expense of the mailing company, notifying you that you could email your name and address to support@charcot-marie-tooth.org or call 1-800-606-2682 x105 and request a replacement copy if you did not receive any newsletter.

A PDF version of the newsletter is also available at www.cmtausa.org/novdec.

Our apologies for any inconvenience, but please be assured that the information in our database was not affected by this error, and that the list will be verified before future mailings to prevent it from happening again. ✲

without hurting the tips of your fingers or breaking a nail. (Using the blade of a knife or the handle of a spoon or fork to pry the tab at least part-way up can be a real finger-saver.)

I can usually still open large pull-apart bags of chips, but the smaller the bag, the harder it gets to get a grip, so it helps to keep a pair of scissors handy to snip off a corner. Scissors also work on salad dressing and other condiment packs, but if I don't have them handy, I can usually make do by sticking the tine of a fork through the packet. (And let's not overlook the obvious: If there's someone next to you, just ask them for help.)

Pull-apart and resealable bags are a different story, especially the kind that have no sliding tab. Even if the tear strip works (and it often doesn't), I can't grip the flaps that usually extend only a half-inch or so above the zipper, so if I can't unseal the bag by grabbing the sides and pulling it apart, I have to cut between the top and the zipper. I can't reseal the bag by pinching along the zipper, either, so I place it flat on the counter and press it together (often with varying degrees of success).

Toothpaste tubes can represent a real challenge. A tube roller like this one can be used on a variety of tubes.

Shampoos that come in pump bottles are great, but if yours doesn't, consider a shampoo dispenser for your shower, like this one, available from Amazon.com.

And then there are cosmetics. Lotions and shampoos that come in pump bottles are generally easy to use because you can press the plunger with the palm of your hand. Aerosols can be a little more challenging, depending on the size and shape of the buttons, but deodorants that screw up from the bottom (like Gillette clear gels) can be extremely difficult to use by anyone with a weakened opposable pinch. I can still squeeze toothpaste and other tubes, but I generally look for a brand like Colgate that has a flip-top cap and not just a screw-on cap. (You can also get a toothpaste dispenser or a tube roller, like the one pictured here from www.alwaysbrilliant.com, that can be used on a variety of tubes.)

You'll notice that I haven't mentioned make-up (eye shadow, lip gloss, etc.), an area in which I have no experience, so I'm hoping you will have some suggestions for dealing with those items.

FOOTNOTES:

JP from MD sent two women's shoe suggestions from www.healthyfeetstore.com: the Erika, an extra-depth women's shoe with an adjustable strap from P.W. Minor, and the Zoey, a shoe with Mary-Jane styling, also from P.W. Minor.

CH from WA also suggests www.shoebuy.com. Shoebuy has an extensive selection of wide shoes and pays the shipping both ways. After your first order, you also receive a discount on future orders.

Two foot-friendly women's shoes from P.W. Minor: Erika (top) and Zoey

—The CMTA's "MacGyver"
a.k.a. 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

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The Power of a Great Idea! How Far Can It Go?

BY JERRY CROSS

In *The CMTA Report*, May/June 2009 issue, there was a article that had a great idea. It was called "Meet Archy." This article explained how Tina Marie Thomas had a great idea. She made the initial drawing of Archy, a turtle with high-arched feet, to be the mascot for CMT. This inspired another great idea. The Adventures of Archy stories were started on the CMTA's Kids' page to help parents talk to their kids about CMT. Excellent idea, but it doesn't stop there. Let me explain!

After years of doing special events, I have learned many things. For example: people want to be entertained, and the best way to stop parents from passing by your display is to get their kid's attention. So I put on a tutu, wings, wig, and had a magic wand and went dancing through the crowd. After being released by the policeman with no sense of humor, my wife told me that hairy legs scare kids. After that, we started using antique motorcycles to stop the crowd.

Anyway, this article got me thinking. Archy is a great tool to communicate with kids. Why not create games with our Archy mascot? And, thus began the Archy bean bag toss and the Archy ring toss. While the kids are playing the games, the parents are getting information on "What is CMT?" Success! But that's not enough.

> The best way to stop parents from passing your display is to get their kid's attention.

Again, looking back to the past for ideas for the future, I remembered that trains always drew attention. I remembered there was a train that was different. It was called the ladybug express. It was made of wheelbarrows upside down, painted like ladybugs. A great money maker. Idea!! Brainstorm!

The "Archy Express" is almost completed. It is 10 upside down wheelbarrows painted like Archy and with a tow engine, it is about 60 feet long. It took a lot of talking and convincing to prove that Archy and I were not ready for the funny farm. Thanks go to corporate sponsors like Home Depot and Rod Paulson, Inc., both in Pahrump, NV, and family and friends who believe in CMT research and the need to promote our need for a cure.

I had another idea! Why can't a child in a wheelchair enjoy a train ride?

The CMT Express will be an open boxcar that will be wheelchair accessible. It will be ready in the summer of 2010. The Archy Express will be seen in spring 2010.

The power of a great idea is unlimited in length and direction. One good idea will generate many more. What's on your mind? Think, talk, Put it to work. You'll know when it is right. P.S. Tutu's don't work!

As one with CMT, I know the limitations we face in everyday life. As a husband, father, grandfather, friend, indeed I

All Aboard! The Archy Express will roll out this spring.

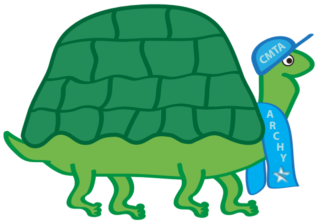
Archy…The hero?

My best friend in first grade is probably Timmy (he's a turtle, too, so we have a lot in common), but I am also really good friends with several other first graders, among them Bruce beaver who is a fabulous Lego builder. We have lots of fun making pretend villages and big trucks and airplanes. He has an older sister just like I do. Her name is Becky and she's the subject of this day's adventure.

Apparently, Becky had to have some work done on her teeth and she came back to school with braces. That made her the immediate talk of the fourth-grade classroom and the object of several unkind comments. Some of the rougher classmates, notably Samuel Skunk and Richard Raccoon, were teasing her in a very mean-spirited way about how she looked with the metal braces on her teeth. At one point, she broke down and cried because she was already embarrassed about the braces and the teasing just made things worse.

I happened to come upon them all out in the woods where we play during lunch break. Since I have recently gotten leg braces of my own, which I have kept hidden under my pants, I knew exactly how she felt. I had gone to great lengths to avoid having anyone other than my best friends know that I had gotten AFOs, or braces, to help me walk. Still, seeing her crying made me rethink my secrecy.

I walked up to Sammy and Ricky and said, "There's nothing wrong with braces. See, I have some on my legs to help me walk. Becky has them on her teeth to help straighten them. All kids have something they need help with and braces are just a way to get help. "If I remember correctly, you needed help with your school work, Sammy. You had a tutor. She was like a brace for you—supporting you until you understood the math problems better."



"Archy," writes for the CMTA newsletter about his experiences as a turtle with CMT.

"Uh, well, yeah. I guess that's true," Sammy said. A few others in the crowd chimed in with comments about how Ricky had needed help with his school work, too. In fact, kids all started mentioning things that they needed help with: Someone mentioned training wheels on bikes and before long, no one even remembered that Becky had gotten new braces on her teeth. Some of the boys did notice my new braces, but they were admiring the cool camouflage coloring and weren't teasing me at all.

When class started again after lunch, Bruce thanked me for defending his sister. Our teacher went so far as to say I was a hero for standing up to the older boys, but I think that's going too far. I really just could "feel" Becky's embarrassment, too, and I wanted to put a stop to it—for her and for me—and apparently I did. What a good day this turned out to be! ✻

THE CMT EXPRESS

(continued from page 10)

know. I also know that the brain, not like the hands and legs, still runs at 110%. Knowledge is a powerful tool that is yours to use. Statements like: I can't! I don't know how! Let somebody else do it! are not acceptable. Your brain is telling you: Yes You Can! You can find someone who knows how! Your family and friends will help you do it. Most people are willing to share knowledge and lend a hand if asked. Try It.

2010 is already here. However, if we stand together and talk about our ideas, we can make wonderful things happen. You think your idea is silly? Try 10 wheelbarrows, upside down going down the road with kids riding on them. Yes, that is silly, but it works. What's your idea? Remember: Yes I Can! I will ask questions! I will do this (whatever it is)! And most important: I will smile & be happy! ✻

ILRC Employee Karen Smith Takes the Independent Living Philosophy to Heart

ILRC (Independent Living Resource Center) located in Wichita, Kansas is all about helping people with disabilities find the services and support they need to be more independent. They have classes to teach people how to be an advocate for themselves and for others. Their mission is to empower people to help themselves rather than do things for them.

Karen Smith, who has worked as an office support specialist at ILRC for nine years, is an example of someone who takes ILRC's mission of empowerment seriously. When she couldn't find a support group to meet her needs, she started one herself.

Karen has Charcot-Marie-Tooth disease, and so do several members of her family.

The idea to start a support group came to Karen when her family gathered at the hospital, to visit her grandmother. Karen's grandfather was diagnosed with CMT when she was young. Her father had it and his eight brothers and sisters did, too. Each of Karen's three brothers has it. Both of Karen's children have CMT. She was diagnosed herself within the past ten years.

At the hospital, family members compared symptoms and realized the disease affects different people differently, even within one family. It got her to thinking about the value of belonging to a support group.

"I just sent an e-mail asking the CMTA asking where the closest support group was," Karen said. "The closest was in St. Louis."

Karen began working with the CMTA to set up a support group in Wichita.

Wichita's CMTA support group held its first meeting on Sept. 24. Eight people attended, ranging in age from 18 to 63. Some had attended other types of support groups but none had attended a group specifically for CMT. One woman came because both her husband and son have the disorder. Participants were in various stages of the disease.

Karen plans to invite speakers to some of the meetings. She'd also like to go to the YMCA to be shown exercises members could do in the water, to help with strength. Karen says water aerobics is one of the best activities for maintaining use and flexibility of extremities.

For more information, e-mail cmtasg_wichita@charcot-marie-tooth.org or call 316-841-8852. ✻

Article excerpted from the Independent Living Resource Center Newsletter.

CMTA REMEMBRANCES

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

Honorary Gift:
In honor of (person you wish to honor)
____

Send acknowledgment to:
Name: ______________________________
Address: ______________________________
____

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: ______________________________
____

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Elia Atalla
Mr. & Mrs. Yacoub E. Atalla

Janice Avery
Ms. Marie Hopkins
Mr. & Mrs. Ben Wingo

John Bachkosky
Mrs. Helen Bachkosky
Mr. & Mrs. George Back
Mr. & Mrs. David Fox
Mrs. Elaine M. Slusark

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Mr. & Mrs. Leonard P. Wishart
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Jacob Walfish
Mr. & Mrs. Paul Dann

Ellen Wall
Mr. & Mrs. Michael B. Wall

Herman Whatley
Ms. Barbara Whatley

Ida Whatley
Ms. Barbara Whatley

Lynn Whatley
Ms. Barbara Whatley

IN HONOR OF:

Agnes Aronsohn
Ms. Esther Friedmann

Doug Auld
Mr. Vasi Vangelos

Herbert A. Beron
Mr. Vasi Vangelos

Johnny Bonner
Mr. David Neilsen

Yohan Bouchard
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Dr. & Mrs. Tom Bird

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Ms. Cathy Sandford

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Mr. Colin D. Coates

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Mr. Vasi Vangelos

Emily Louer
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Benjamin Machado
Ms. Stephanie Powers

Kimberly J. Magee
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Mrs. Cindy B. Forney
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Ms. Sharon E. Thorndale

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Elizabeth Ouellette
Mr. Vasi Vangelos

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Mr. Christopher Palermo

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Ms. Janelle N. Ramsay

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Mr. Vasi Vangelos

Kellie Faulkner Towers
Ms. Joann Duvall

Franklyn Weiss
Mr. Andrew Rosengarden

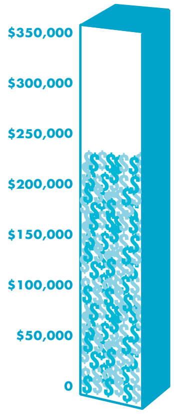
Karen West
Mr. Steven West

Sung Wook Jang
Mr. Vasi Vangelos

Robbie
Ms. Deborah Campbell

Deborah & Karissa
Mr. & Mrs. Felix Zelenowski

Thank you to all of you who have contributed to the Board Challenge. To date, we have received over $232K, but we still have $120K left to reach the $350K Board Challenge. If you have not yet contributed, please do so today. We do not want to lose our matching funds.



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—even haunted houses—like Wes and Kathy Stultz, who have opened their home each year at Halloween after trick or treat and have had family and friends go through a "haunted house" in their basement while they raise money for the CMTA.

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!

Grace's Courage Crusade

The Barrett Family Foundation
Mr. and Mrs. James Brauer
Mr. and Mrs. Bruno E. Brugnatelli
Mr. and Mrs. Constantine Clemente
Mr. and Mrs. Patrick Costaregni
Ms. Dora M. Forte
Mr. and Mrs. Christopher M. McLoughlin
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Mr. Anthony Finizio
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Reagan's Quest

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Mr. and Mrs. Robert Yovish
Ms. Karissa Zelenowski
Mr. and Mrs. Felix Zelenowski

CIRCLE OF FRIENDS SPOTLIGHT:

Reagan's Story

BY KATHY STULTZ

> "We would joke about Reagan's clumsiness because her middle name is Grace."

Our story with CMT is like many others I have heard. Our daughter, Reagan, was born without complications. However, she never had any reflexes at her doctor appointments. Our pediatrician wasn't bothered at all by this. I told him at every visit that Reagan seemed to fall more than other kids. He told me "Not everyone is an athlete." After that statement I came to terms with the fact that I had a "clumsy" kid. We would even joke about it because Reagan's middle name is Grace.

In kindergarten her gym teacher told me that she felt that Reagan didn't have much muscle tone, and that we should enroll her in some sports. I enrolled Reagan in baton and a dance class. Unfortunately, there was a lot of walking in parades and she fell often so we eventually quit.

I thought walking through the zoo would be a good way of getting exercise, but I always had to bring the wagon because Reagan would tire too quickly, and she couldn't walk the whole time. I actually said to her once," Do you see any other 5-year-olds in wagons?" I feel guilty now for saying that. I couldn't figure out why she would tire so quickly; however, I still didn't think there was anything wrong. I thought it was from lack of exercise.

When Reagan was 8, she began having more difficulty getting up from the ground. She would go onto one knee and then use her hands to get up. This is when I realized there was something wrong. I thought she had a problem with her hips. Perhaps her hips were tight, and this was why she fell and couldn't run like the other kids.

We made an appointment with a doctor to address some of her issues. We took her to our new pediatrician, who found no reflexes. He ordered a CT scan and gave us a referral for Children's Hospital. We couldn't get an appointment for months, which was fine by us. In the fall during parent teacher conferences, the gym teacher wanted to talk to us. He was concerned with how Reagan was walking and the fact that she couldn't run like the other kids. He really felt strongly that she had a neurological problem. When he told us, we believed him. I called Children's Hospital, and told them what the gym teacher told

(continued on page 19)

Reagan (third from left) and other Halloweeners enjoyed the haunted house that her parents built in their basement.

SUPPORT GROUP NEWS

Arizona—Phoenix

The group met on November 21st. It was their first meeting, with about 32 people in attendance. All were able to give a brief introduction to the group and plenty of connections were made. A neurologist, Dr. Mulley from Barrow's Institute, also spoke to the group.

Florida—Orlando

The group met on November 7. Dr. Lisa Chase spoke to us about what to expect in regard to selecting appropriate exercise for the feet, calves, upper legs, and lower back. She gave excellent suggestions for maintaining flexibility, strength, and balance and avoiding the risk of falls. Dr. Chase emphasized the importance of doing something, however insignificant you may think it is. It is still better than doing nothing when it comes to maintaining a healthy body. She also stressed the importance of not overdoing exercise routines.

Florida—Tampa Bay

The group met on November 21st with 30 people in attendance. Juli Kaplan, a doctor of acupuncture, was the guest speaker. She did a fantastic job explaining the basic tenets of traditional chinese medicine (TCM) and the concept of 'chi' or life energy. She shared her background and the history of what is now called acupuncture. She then explained how disease in Western medicine is viewed by providers of TCM as a disruption of chi.

Georgia—Atlanta

The group met on October 17th. Pat Livney, the president of the CMTA Board of Directors, came to speak about the many efforts of the CMTA. He discussed the three facets of the CMTA—research, the support groups, and advocacy. He spoke of the importance of advocacy and awareness of CMT to the medical and general community. Pat also described the STAR initiative and the great strides they are making toward finding treatment for CMT 1A patients. The group was very inspired by his visit. In addition, members took the opportunity to speak of their personal challenges and triumphs regarding CMT. Members left feeling inspired and supported in their CMT journey.

Maryland—Hagerstown

The group met on November 21st. It was the first meeting, with about 19 people in attendance. It was a "share CMT experiences" meeting. Refreshments were served. There was a short wrap up at the end that included scheduling the next meeting for the last Saturday in January. Leftover donuts and bagels were dropped off at a senior citizen center just down the street.

Michigan—Ann Arbor

The Southwest Michigan CMT Support Group met on January 21st. They had time for open discussion as well as a presentation and question and answer period. The presentation topic was "An Overview of CMT." In May, Dr. Lazar of the Lazar Spine Care center in Ann Arbor, MI, will discuss, "How to Beat Stress and Live Your Life."

Michigan—Kalamazoo

The group met on November 19. It was their first meeting, with about 15 people in attendance. People came from all over Michigan, some driving as long as 1½ hours. There was time to share personal stories and experiences and then there was a discussion of services available. Michelle Genigeski of the Grand Rapids MDA office also attended.

Nevada—Las Vegas

Roger Beihl, an orthotist, spoke to the group on November 21st. There were 10 people in attendance including a member from

(continued on page 18)

NEW SUPPORT GROUP LEADER NEEDED FOR ST. LOUIS, MO, GROUP

Carole Haislip, the current support group leader for the CMT support group in St. Louis, MO would like to find another person to take over leading the support group. If you are interested in being a support group leader or co-leader, please contact her at 314-644-1664 or by email at cmtasg_stlouis@charcot-marie-tooth.org. ✻

SIX NEW GROUPS HAVE FORMED:

EAST BAY, CA under the leadership of Donna Rennie

SACRAMENTO, CA under the leadership of Nathan Sherman and Rashid Thomas

CHESANING, MI under the leadership of Carolyn Koski

ALBUQUERQUE, NM under the leadership of Gary Shepherd

LONG ISLAND, NY under the leadership of Ruth Korowitz

BUCKS COUNTY, PA under the leadership of Linda Davis.

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

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

California—East Bay Area
Place: Lafayette Orinda Presby. Church
Contact: Donna Rennie, 925-330-2790
Email: cmtasg_eastbayca@
charcot-marie-tooth.org

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

California—Sacramento Area
Contacts: Nathan Sherman, 916-969-7379
Rashid Thomas, 916-947-5377
Email: cmtasg_sacramento@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 Mateo/Bay Area
Place: San Mateo Library
Contact: Elizabeth Ouellette,
1-800-606-2682 ext 107
Email: cmtasg_sanfran@
charcot-marie-tooth.org

California—Santa Barbara Area
Place: Alisal River Grill, Main Clubhouse
Contact: Gretchen Glick, 805-693-9511
Email: cmtasg_santabarbara@
charcot-marie-tooth.org

California—Santa Rosa Area
Place: Sutter Med. Cen. of Santa Rosa
Contact: Louise Givens, 707-539-2163
Email: cmtasg_northcal@
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: Hampton Inn and Suites
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: Susan 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 Area
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: Brookline Public Library
Contact: Mark Boxshus, 781-925-4254
Email: cmtasg_boston@
charcot-marie-tooth.org

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

Michigan—Chesaning Area
Place: Trinity United Methodist Church
Contact: Carolyn Koski, 989-845-5731
Email: cmtasg_chesaning@
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 Area
No support group
Will accept phone calls/emails
Contact: Rosemary Mills, 320-567-2156
Email: cmtasg_bensonmn@
charcot-marie-tooth.org

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

Mississippi/Louisiana Area
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—Anderson Area
No support group
Will accept phone calls/emails
Contact: Libby Bond, 417-845-1883
Email: cmtasg_andersonmo@
charcot-marie-tooth.org

Nevada—Las Vegas Area
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, 732-252-8299
Email: cmtasg_centralnj@
charcot-marie-tooth.org

New Mexico—Albuquerque Area
Place: Mesa Multigenerational Center
Contact: Gary Shepherd, 505-296-1238
Email: cmtasg_albuquerque@
charcot-marie-tooth.org

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

New York—Horseheads Area
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—Long Island Area
Place: Plainview Public Library
Contact: Ruth Korowitz, 516-318-3202
Email: cmtasg_longisland@
charcot-marie-tooth.org

New York—Westchester Area
Place: Blythedale Children's Hospital
Contact: Beverly Wurzel, 201-224-5795
Email: cmtasg_westchesterny@
charcot-marie-tooth.org

North Carolina—Triangle Area
Place: The Ctr. for Independent Living
Contacts: Susan Salzberg, 919-967-3118
Gary Orson, 919-467-5485
Email: cmtasg_trianglearea@
charcot-marie-tooth.org

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

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

Pennsylvania—Bucks County Area
Place: Emmaus Road Lutheran
Contact: Linda Davis, 215-943-0760
Email: cmtasg_buckscounty@
charcot-marie-tooth.org

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience and
Pain Institute
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
sgcldr_philly@
charcot-marie-tooth.org

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

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

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

Washington—Seattle Area
Place: U of Washington Med. Center
Contact: Ruth Oskolkoff, 206-293-2204
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

SUPPORT GROUP NEWS

(continued from page 16)

California. It was a wonderful get-together with plenty of sharing.

New Hampshire—Vermont
The group had its meeting on November 21st with 10 people in attendance. The focus of the meeting was information-sharing for coping with CMT. There was a discussion on the best places locally to buy shoes, the brand of shoe that works, what type of braces are available and what works best, learned about a website that sold fashionable canes, and got a recommendation for a physiatrist.

New Jersey—Central NJ
The group met on November 15th with close to 40 people in attendance. Dr. Steven Scherer was the guest speaker. He gave a detailed presentation and answered many questions. One of the members has also started a practitioner referral list for group members (including doctors, therapists, shoe outlets, and service dog organizations).

Pennsylvania—Philadelphia
The group met on December 12th with about 15 people in attendance. They had David Tannenbaum, a psychotherapist, as their guest speaker, who discussed some of the emotional and psychological issues of having CMT. There was lots of sharing among the group members, and it was a wonderful opportunity to feel truly heard. The group plans to meet again in March, following the support group leaders' conference in Nevada.

Pennsylvania—Pittsburgh
The group met with about 20 people in attendance. They had Gavin Hassell, a director of orthotics and prosthetics, as a guest speaker. He brought a variety of braces to show, regarding the new materials and styles of braces that are now available. ✻

REAGAN'S STORY

(continued from page 15)

us. We got an appointment for the next week.

The first doctor we saw asked Reagan to do all kinds of exercises. I was shocked to see that Reagan couldn't walk on her heels, and she couldn't get up without using her hands. That doctor thought she had a muscle disease and sent us to see the neurologist. The neurologist knew quickly that this was a neuromuscular problem. Reagan had foot drop, and that was why she fell all the time. Her legs had muscle wasting (I thought they were just skinny.) We had a nerve conduction test, which was our final diagnostic tool. According to the nerve tests, the neurologist thought she had CMT type 2. However, the DNA test didn't show any variant genes. We then tested for type 1, which showed a variant gene, however the results are not conclusive.

Reagan was ultimately fitted with AFOs which dramatically changed her life. She could finally walk without falling. She could walk fairly fast and not tire. She had so much more energy when she wore her splints. She also went through physical and occupational therapy. She now is 11 and has new "toe off splints." She is doing well, but does show signs that the disease is progressing. She is unable to button her pants and her handwriting is almost unreadable. Our stairs are becoming more difficult for her too. Getting up from the ground is a real challenge for her now, and unfortunately she is falling more.

I think back at all of the times that I spoke to our first pediatrician about Reagan's clumsiness and how he dismissed me. I am not mad at that doctor, however. I am actually glad for that doctor's lack of diagnosis. We were able to have a "normal" life until she was 8 without ever knowing about CMT. We didn't have all of the worries we now have. We try to ignore CMT as much as we can. But, its symptoms are hard to ignore. Reagan's attitude is unbelievable. Everyone who knows her loves her. We have started having fundraisers every October during Halloween. We open our home after trick or treat and have family and friends go through a haunted house in our basement. We collect money for the CMTA all night. We have been able to raise a lot of money that way. If everyone with CMT could do a fundraiser, imagine how much money could be raised for research! ✻

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

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MEMBERSHIP Members have the option of receiving *The CMTA Report* in print, PDF via email, or both. Receive newsletter as: ☐ Print *or* ☐ PDF via email		$25	
Receive both Print *and* PDF Newsletters		$30	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		**active members $10** nonmembers $15	
[CD Format]		**active members $7.50** nonmembers $10	
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CMT Facts V		**active members $12** nonmembers $15	
CMT Facts VI		**active members $12** nonmembers $15	
A Guide About Genetics for CMT Patients *(No shipping and handling on this item only)*		**active members $4** nonmembers $5	
Teaching Kids about CMT…A Classroom Presentation *(1 hour DVD)*		**active members $7.50** nonmembers $10	
NEW! My Child Has CMT, A Guide for Parents		**active members $5** nonmembers $7	
Be a Star Wristbands (Pack of 5)		$5	
Women's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL		**active members $9** nonmembers $10	
Men's Circle of Friends V-Neck T-Shirt Quantity and Size: ___M ___L ___XL ___2XL ___3XL		**active members $9** nonmembers $10	
West Coast Patient-Family Conference *(5 hours—2-DVD set)*		**active members $15** nonmembers $20	
CMT Informational Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List		FREE	
Physician Referral List: States: ______ ______ _____		FREE	
Donation to the CMTA *(100% Tax-deductible)*			
Shipping & Handling *(Orders under $10, add $3.50; orders $10 and over, add $7.50)*			
TOTAL			

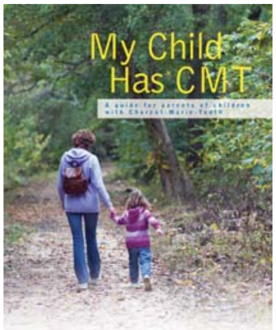
☐ Check payable to the CMTA *(US residents only; non-US residents, please use credit card or international money order.)*

☐ Money Order ☐ American Express ☐ MasterCard ☐ VISA

Card Number: ______________________________ Expiration Date: ______________

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

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



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.

ALSO AVAILABLE:

Circle of Friends T-Shirts

Be a STAR Wristbands

THE CMTA *Report*

CMTA

2700 Chestnut Parkway
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.