WE CELEBRATE 25 YEARS: LIVING OUR VISION OF A WORLD WITHOUT CMT

THE CMTA Report

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

MARCH/APRIL
2009

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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Antwerp to Be Site of the Third International CMT Consortium

Many of the same faces in this 2007 photo from Snowbird, Utah, will be in Antwerp for the Third International Consortium.

In keeping with our evolving tradition of alternating the meeting site between North America and Europe, the Third International CMT Consortium will be held from July 9-11, 2009, in Antwerp, Belgium. Hosted by our friends in the European CMT Consortium, the meeting will again follow the annual meeting of the Peripheral Nerve Society, which will be held in Wurzburg, Germany, from July 4-8, 2009.

The International CMT Consortium will have the same format as the 2007 International CMT Consortium hosted by the CMTA in Snowbird, Utah. There will be oral and poster presentations, with ample time for discussion and interaction. The aim is to exchange new information and, equally importantly, to start or strengthen collaborations between research groups.

> The aim of the Consortium is to exchange new information and to forge collaborations between research groups.

The Snowbird meeting brought CMT physicians and scientists together from all over the world, including the US, UK, Europe, Asia, Africa, South America, and Australia, and, as results of the Snowbird meeting demonstrate, the collaborations formed among these scientists continue to play an extremely significant role in the developments of treatments for CMT.

Most importantly, protocols for the initial project of the CMTA's Strategy to Accelerate

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INSIDE:

8 Hours in Detroit

BY DAVID M. HALL, CHIEF EXECUTIVE OFFICER

My heartfelt thanks go out to everyone in the CMTA community who has been kind enough to reach out to me and welcome me to this great organization. In the midst of all the chaos associated with getting up to speed on all the various issues, it is comforting to read and hear your words of encouragement.

I joined this organization suspecting there were more questions than answers when it came to issues such as research and clinical care, genetic screening, physical therapy, and orthotics. After two months on the job, I must admit I am shocked by the number of people searching for answers about CMT, especially since in many cases those answers do exist. Depending on where you live, you may or may not have local resources available to you that provide care and information—whether they be physicians who specialize in treating CMT patients, MDA clinical centers, or CMTA support groups.

I recently spent a day at the CMT clinic at Wayne State University with Dr. Michael Shy. Thank you to Liz and Danielle for allowing me to shadow them throughout the 8-hour clinical day—as 16-year old Danielle said, I was her "groupie" for the day. For Liz and Danielle and the other families in clinic that day, the Wayne State medical team provided a foundation of care, understanding, and, most importantly, answers to existing questions and to some questions that had never before been asked. As Liz said to me as she prepared to take her daughter home at the end of the day, "it's amazing how 8 hours could change 10 years of life for us."

Equality of care should not be dictated by one's zip code.

I will admit the clinical resources available at Wayne State University are unique relative to most medical institutions in this country. That being said, clinical "best practices" and standards of care do exist within the fields of neurology, orthopedics, and physiatry. These standards are not singular in approach or technique, but represent a strong foundation of clinical experience with the CMT patient.

I consider it a priority of the CMTA to make these resources widely available to families and physicians, so that quality of care is not dictated by one's zip code. For 25 years, the CMTA has been committed to improving the lives of those with CMT. The recent advances in CMT diagnostic and treatment technologies demand that we remain steadfast in promoting a robust campaign of education and awareness.

We are fortunate to have so many loyal support group members and leaders throughout the country supporting the CMTA's mission of education and awareness. It's because of those individuals, who spend countless hours helping their friends and neighbors in their local communities, that we do have the opportunity to improve the lives of those with CMT, regardless of where they live, or what doctor they see.

For Liz and Danielle, it didn't take countless hours. It took 8.

Thank you all for your continued support of the CMTA. ✻

David Hall is working his way through the Support Groups to gather information from patients. In February he visited the Johnstown Support Group.

CMTA Establishes Postdoctoral Fellowship at NIH Chemical Genomics Center

As part of the Strategy to Accelerate Research (STAR), investigators will soon begin high throughput screening at the NIH Chemical Genomics Center (NCGC). The goal of this phase of the STAR initiative, which will utilize the cell line developed by Ueli Suter at ETH Zurich, is to identify compounds that control the overexpression of PMP22 in CMT1A.

In furtherance of this and future studies, the CMTA is establishing and funding a two-year postdoctoral fellowship (extendable to 3-5 years) at the NCGC. The NCGC is an ultrahigh throughput screening and chemistry center which discovers chemical probes of protein and cell functions, develops new paradigms to enable chemical genomics, and develops chemical starting points for new drugs for rare genetic and orphan diseases.

Work will soon begin at the NIH's ultra-high throughput screening and chemistry center.

The postdoctoral fellow will be responsible for development and performance of compound library screening efforts in Charcot-Marie-Tooth inherited peripheral neuropathy. Successful candidates should have experience with cell culture and reporter gene systems, an aptitude for instrumentation, and possess excellent analytical skills.

Applicants should send their CV, including bibliography, and arrange for three letters of reference to be sent to James Inglese, PhD, Deputy Director, NIH Chemical Genomics Center. Email to ncgc@mail.nih.gov. Subject line should read: CMTA Post-Doc. ✻

ANTWERP CONFERENCE

(continued from page 1)

Research (STAR) were formalized at the Snowbird meeting, and, as a result, cell lines are almost ready to be tested at the High Throughput facility housed in the NIH to identify specific medications capable of treating the most common form of CMT.

Secondly, an agreement was made regarding clinical trials for CMT. The ascorbic acid trials in Europe and North America were conceived at the first CMT Consortium in Europe. At the second meeting in Snowbird, Europeans, North Americans, and Australians agreed to continue international collaborations for CMT clinical trials in the future and to work together to develop the treatments for such trials.

Finally, the Snowbird meeting brought together a cohort of young investigators from scientific laboratories and clinical groups around the world. These men and women will be the future leaders in CMT research, and to foster their continued collaboration and advancement, the CMTA will be helping to defray the travel costs for a number of these young investigators attending the upcoming meeting in Antwerp.

Information regarding abstract submission and registration is available for researchers and medical professionals at www.cmtausa.org/antwerp. ✻

Board Issues $350,000 Challenge Again This Year

For the second year in a row, the Board members of the CMTA have offered a challenge to the membership of the CMTA to match every dollar contributed to the STAR campaign, up to $350,000. With work on the Strategy to Accelerate Research (STAR) already well under way, the CMTA is anxious to raise the funds that will allow the work to continue on its path of finding treatments and therapies within three to five years and a possible cure within ten years.

Last year, the organization exceeded the challenge by contributing $362,153, making it our most successful fundraising campaign ever. You have already demonstrated what we can do when we all work together and we hope you will rise to the challenge again this year. Fundraising has been down, due, no doubt, to the economy, and we have raised only $56,095 so far during the challenge campaign. We encourage you to keep the commitment to the STAR initiative by making a contribution to the Board Challenge if you haven't done so yet. ✻

ASK THE DOCTOR

Dear Doctor,

Since I was approximately 7 years old, I have found that I cannot feel electric fences or cattle wires. When I was in the 7th grade, our science teacher had us hold on to two metal rods connected to an old telephone generator. He had me go against several classes to see who could take the electric current the longest and he finally gave up because I always won, hands down. I never could feel the current no matter how hard or how long they would crank the generator. My eldest son, who also has CMT, did not believe me until he tried. We think this is connected to CMT. Why?

The Doctor replies:

There are different types of nerves that respond to various types of sensation, including electricity. The loss of that feeling implies that some of these nerves are selectively under-functioning. Simply slowing the nerve conduction from CMT is not enough; there must also be some loss of function. The sensory nerves affected in most forms of CMT are the types that sense the effects of electricity. True sense of electricity or related magnetic fields is limited to certain specialized animals and not humans, however. Be aware that failing to feel the electric shock does not mean it still cannot do harm.

Dear Doctor,

I was diagnosed with Déjérine-Sottas neuropathy. My feet and hands turn purple and sometimes feel either hot or cold to the touch. Are there any medications available, as it is very embarrassing when noticed by others?

The Doctor replies:

Some neuropathies cause discoloration, owing to involvement of small axons, some of which regulate blood flow. I do not recall seeing someone with Déjérine-Sottas neuropathy have this problem, so it would be relevant to know what mutation produced the Déjérine-Sottas neuropathy. There is another condition, Raynaud's phenomenon (unrelated to D-S neuropathy) that makes the extremities white, then blue, then red; this can be treated with calcium channel blockers in some people.

Dear Doctor,

My doctor has prescribed Niaspan 500 mg/day. I have CMT. Could this cause my CMT to worsen?

The Doctor replies:

All cholesterol- and lipid- lowering agents, including Niaspan, have the potential to affect muscle function and cause some muscle symptoms, but the risk with this agent is quite low and probably lower than statins. It is not known to worsen the neuropathy of CMT or injure nerves. ✻

CMT is No Laughing Matter—Or Is It?

BY SAMUEL SPOONER

A rather-eccentric, old loon called CMT has been diving in and out of our family gene pool for the last six or seven generations. Every patriarch in my direct lineage, at least back to my great-great-great grandfather, has had to deal directly with the old bird to one degree or another. Ironically, until my Dad was officially diagnosed with Charcot-Marie-Tooth disease in the late 1960's, we all believed that the all-too-familiar fowl was unique to our gene pool. To us, the gangly-legged, bird-clawed condition was simply tagged as the Spooner Syndrome—and no one was particularly afraid of it. Despite its eccentricity and unpredictability, it was seen as quite benign, and some of us even came to secretly show it off with a sense of pride—as proof of our membership in an exclusive wing of the family bloodline.

Oh, everybody understood that if a family member had the syndrome, owing to the likelihood of frequent fumbles, he or she probably wasn't the best person to handle the toolbox (although, some of us have even been pretty crafty in that respect). Then, too, there were the tell-tale hammertoes and the recurrent wrenched ankles. Perhaps the most persistent manifestation of Spooner Syndrome, however, was the presence of what we called our enlarged funny bone. It is as though we intuitively recognize that laughter truly is the best medicine and therefore love to laugh! There is no medical explanation for it—but our family CMT circle was and is filled with an all-star cast of pranksters and pun-masters. Often our humor takes the form of good-natured self-deprecation—a gameness to look the old CMT bird straight in the eye and laugh at him as loudly and frequently as possible.

Owing to the span of generations involved, I didn't personally get to meet all of my afflicted kinfolks. Therefore, some of what I'm about to relate may be anecdotal. As stated above, however, the long-standing Spooner sense of humor is well documented. Let me start in the anecdotal department. Despite the fact that my great-great-great grandfather eventually rolled around with the aid of a device which he affectionately dubbed his "wheel chariot"—he is reported to have said: "The only handy cap I'd concede to is this silly red-plaid thing with the ear flaps which I wear to ward off head colds."

By some strange twist of the hand of fate, most of the Spooner family members affected by the syndrome have been males, despite the 50/50 odds involved in the autosomal-dominant transmission of CMT1A—the form of the disease which was eventually documented in my family by genetic testing. Of the eight siblings in my family, for example, I and my three brothers were all visited by the eccentric old loon, while all four of my sisters were free of his foul genetic footprints. Furthermore, proof of the old bird's unpredictability can be seen in the fact that I was the only brother affected by the early-onset form of the disease—a fact that made my childhood quite challenging and often found me up to my skinny elbows in a test involving my ability to fall back on my enlarged funny bone for support.

Our family CMT circle is filled with an all-star cast of pranksters and pun-masters.

As we all know, children can be cruel—especially when confronted by anyone who doesn't conform to expected physical norms. During my early school years, I often fended off cruel encounters with the aid of my trusty sense of humor. Once, during a sixth-grade gym-class outing, while I was, let us say, circumstaggering the track, two young fellows flew up behind me for the third time. "Well, if it isn't Speedo Spooner!" the first jock said as they slowed down to taunt me.

"Do you suppose there's any chance he'll ever overtake us?" the other dude said, running backward as they passed.

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UPCOMING PATIENT/FAMILY CONFERENCES:

April 18, 2009—Erie, PA
To register go to www.cmtausa.org/erie

May 30, 2009—Allentown, PA
To register go to www.cmtausa.org/allentown

NO LAUGHING MATTER

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"Yup!" I said. "I'll be sure to wave as I buzz on by you two lettermen during this afternoon's spelling bee."

One of the few females in the Spooner family to be affected by the disease was my father's sister, my favorite, cane-raising, quick-witted aunt. Late in life, she required surgery to relieve problems caused by deteriorating scoliosis, curvature of the spine often seen in CMT patients. My wife and I visited her in the recovery room soon after she came out of surgery. She was breathing with the assistance of a ventilator and her mouth was filled with a variety of plastic tubes which had been taped into place, leaving her unable to speak. After holding her hand and talking to her for a few minutes, I asked her if there was anything we could get for her. She gingerly shook her head up and down a few inches to indicate that there was definitely something she desired. After a few wild guesses to which she indicated "no" with a slight sideways nod of her head, I thought I'd better come up with a better way to communicate. Walking out to the nurse's station, I mooched a clean sheet of computer paper and a pencil. Returning to the recovery area, I quickly wrote the alphabet in five rows of evenly-spaced, large, capital letters—with the Z tucked onto the end of the last line.

"Now," I said, holding the letter chart close to her right hand, "let's try this again. What is it that you would like us to get for you? Just spell it out by pointing to the correct sequence of letters. If there's more than one word, take a short pause between them."

She glanced at the chart and almost immediately pointed to the "P."

"Starts with P?" I said.

She nodded affirmatively and proceeded to tap the letters in sequence with the tip of her old, CMT-crooked, right index finger—tap, tap, tap. P-I-Z-Z-A.

"You want us to smuggle in your favorite food? You want pizza?" I said, trying to suppress an out-loud guffaw in deference to other folks in the recovery area. "I don't believe your doctor would be willing to prescribe pizza right now—maybe next week!"

She was obviously in high spirits, yet unable to smile due to the tangle of tubes filling her mouth, and unable to express her full range of emotions using the severely limited scope of her head movement. I looked directly into her eyes—eyes which had always been as blue and mischievous as the jays that wintered in her backyard. They were bubbling with laughter.

Oddly enough, it was my Dad's definitive CMT diagnosis that ultimately resulted in a temporary sea change in the family's outlook toward the old loon in our gene pool—the syndrome about which we had previously been almost unflappable. My Dad was in his late 60's at the time he was diagnosed—and was experiencing rapid decline due to arthritic complications superimposed on his advancing neuromuscular disease. Our abrupt realization that the syndrome had an actual medical name, that it was loose in the general population, that it could appear in a wide range of manifestations—from mild to very severe—even within a single family, and that each child born into a CMT family had a high degree of likelihood of inheriting it, had a sudden, sobering effect on the Spooner family. At least temporarily, our funny bones shrank dramatically. If it could strike any child born to us, sometimes severely, CMT was no longer a laughing matter.

> If CMT could strike any child born to us, sometimes severely, CMT was no longer a laughing matter.

As a result, my wife and I made a firm decision not to have any more children. Although our son didn't present with any of the symptoms early on, many years passed before we were certain that our only child had escaped the potential for karmic calamity associated with our one genetic gamble—that is, that he was free of the old loon in the gene pool. We have four healthy grandkids now, and another on the way. My brothers have not been so fortunate. CMT has spread to the seventh generation in some branches of the family tree.

Once the family had assimilated the initial shock regarding the wider implications of the Spooner Syndrome, a.k.a.,

LIVING WITH CMT

Aids for Daily Living: Product Suggestions from Our Readers

In his last column, my alter ego MacGyver offered several product suggestions, and he has since received a number of suggestions from people who have found their own solutions to the zipper problem.

ZIP GRIP

Although he needs help getting them on the zipper tab, T.L. from Michigan uses split rings that he buys in the jewelry section of a hobby shop. T.L. also suggests Zip Grips, available from http://www.life-solutions-plus.com (1-877-785-8326), where a package of 6 is $3.95.

Split rings might work on jeans, but J.W. from Ontario emailed to tell Mac about a solution she found for the tiny "invisible zippers" used on women's clothing. Clear zipper pulls, available from http://www.colonial-medical.com (1-800-323-6794), have a monofilament loop that can be tucked out of sight. A 3-pack is $7.95.

SPLIT RINGS

And little did Mac know when he suggested that using spring-loaded scissors could make dealing with gift wrap easier that 3M actually makes a cutting tool specifically for use with gift wrap. P.S. from Norway has one. Mac found it and other handy 3M tools at http://solutions.3m.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, or mail it to Mac's Tips, CMTA, 2700 Chestnut Pkwy., Chester, PA 19013.

—*Dana Schwertfeger*

CLEAR ZIPPER PULLS

CMT, most of the afflicted members experienced a sudden, sense-of-humor renaissance. Relatively speaking, even during the worst of times, I'd never picked up a mental block when it came to toying with words. At a family congregation, soon after our funny-bone reformation had commenced, I was presented with a plaque (with some obvious apprehension that the accolade might spin me off into a whole new cycle of wordplay) declaring me the Prince of Punland. I doubt that I'd be out on a limb to opine that my flair for sliding puns into conversational breaches is probably related to my bent for slipping my somewhat unshapely legs, AFO's and all, into my altered jeans.

I'm in my early 70's now and (probably because most CMT patients with the early-onset form of the disease experience rapid decline in later life) for the last few years, the old loon has made it extremely difficult for me to find his antics amusing. Nevertheless, as I hope this missive to our gene-pool misfit illustrates, I can still stare the old bird in the eye and chuckle now and then. If I've coaxed even the smallest smile from anyone who's braved this brief chronology of the Spooner Syndrome, I urge you, while you're still in good humor, please make a generous donation to the CMTA STAR (Strategy to Accelerate Research) Program—so that some day soon we can all share one long, last laugh as we watch dedicated scientists shoo the old loon from our gene pools altogether.

CMTA Announces New Cookbook:

Alphabet Soup: The ABC's of Comfort Food for Shattered Nerves

Tie on your aprons, fire up your ovens, and get out your favorite, comforting recipes! The CMTA is pleased to announce the compilation of a new cookbook to raise funds for research, and we need your help.

You must have a few favorite recipes that warm the heart and comfort the soul, and we'd like to know all about them.

Spearheaded by New England Support Group Leader Mark Boxshus, the Alphabet Soup cookbook project will include your favorite crowd pleasers in a keepsake edition created by you and your fellow CMTA members.

One lucky member will also win our Grand Prize and have a Special Feature Page about his or her award-winning recipe, so please use the "Note/Story" section of the submission form to tell us what is special about your recipe, or what memories or thoughts it brings to mind.

Your recipes and stories will help make *Alphabet Soup* a meaningful and enduring memento, and you will want to display it proudly in your kitchen or pass it along to other family members. You may even want extra copies available for gift-giving occasions all year long.

We also encourage you to solicit recipes from your family members and friends, as well as any celebrity acquaintances or culinary luminaries you know. We currently have agreed upon participation by a few culinary icons and are hopeful that many more will get involved as our project evolves. If you are good friends with the Obama family, by all means ask them for a recipe or two! If the chef at your favorite restaurant is amongst the Who's Who in the food world, ask them for a recipe or two.

All proceeds from Alphabet Soup will support CMT research, so get involved today and start digging out those recipes! We can't wait to share them with the rest of the world and bring us closer to a cure for CMT! If you don't have the time to submit a recipe but would like to make a financial donation toward the funding of our cookbook project, we will gladly publish your name in our Sponsor's section of the book.

Submissions will be accepted until May 31, 2009, and all selected recipes will be tested thoroughly to ensure specified results.

To download a form you can complete on your computer and submit via email, go to www.cmtausa.org/recipe. ✻

CMTA COOKBOOK RECIPE SUBMISSION FORM

"Alphabet Soup: The ABC's of Comfort Food for Shattered Nerves"

Your Name: ______________________________

Phone______________________________

E-mail______________________________

Recipe Title and Subtitle: ____________________

____

____

____

Difficulty of Recipe:

☐ Easy ☐ Moderate ☐ Difficult

Preparation Time:

____day(s) ____hour(s) ____min(s)

Cooking Time:

____day(s) ____hour(s) ____min(s)

Servings or Units:

(For example, 8 people, 24 cookies, 2 loaves of bread, etc.)

____

Category:

☐ Starters/Appetizers
☐ Side Dishes
☐ Main Dishes
☐ Sweets & Treats
☐ Breakfast/Brunch
☐ Lunch
☐ Sauces, Condiments & miscellaneous accompaniments
☐ This, That & the Other

Attach a separate sheet of paper with the following information:

1. Ingredients

Please list all of the ingredients used in your recipe, each on a single line, in the order in which they are used. Also specify measurements accurately (Omit terms such as "pinch", "dash", "splash.") Specify ingredient sizes or compositions accurately. This makes a big difference in recipe formulations. Do not use abbreviations.

2. Directions

Please write recipe instructions in paragraph form. Do not number your paragraphs. Use a separate paragraph for every step in the recipe. Specify whether or not your oven settings are in degrees Celsius (°C) or Fahrenheit (°F).

3. Note/Story

Please tell us about this recipe, what special memories or thoughts it brings to mind.

We thank you for your recipe and hope that you have the "winning" entry. Best of luck to all of you, and keep cooking up those wonderful, comforting dishes!

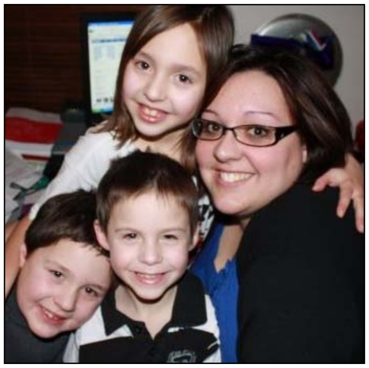
SEND YOUR RECIPE TO:
Mark P. Boxshus
CMTA Cookbook Recipes
24 Standish Avenue
Hull, MA 02045

I Am Just a Mom!

BY SARAH STRONG

I'm a mom—just a mom—and that's ok with me. I have a child—just a child—and that should be ok with everyone else too. But I see the stares, and I hear the comments. "Mom, what's on that kid's legs?" I see the older folks who give me sly looks when my big 7-year-old son pleads with me to zip his coat for him, and I stand there and say, "Honey, you just need to try to do it yourself," knowing in my mind that they have no idea the daily struggles he goes through and how much I don't want him to give up yet. I hear the white-haired ladies sitting together on a bench at the mall whispering, "Isn't he a little big for her to be doing that for him?" I see the looks of pity when I take him to Kids Yoga and the other parents notice him taking his leg braces off to participate. But that is me, the mom. The child, Wyatt, doesn't notice these things and that makes him one GREAT kid!

Wyatt thinks his braces are cool. He just got brand new bright yellow and orange "solar" designed AFO's. He thinks that Jason, the guy from our local prosthetic business, is one really cool guy who can do magic on his braces. He can't wait until summer when he can wear shorts outside so everyone else can see how cool they are. A highlight of Wyatt's week is going to PT and hanging out with his friend Emily, his therapist who lets him play with a Gameboy while she gives him an awesome massage and then plays really cool exercise games with him. This is what Wyatt sees. Wyatt also sees that other kids don't hurt the same way he does. Wyatt knows that other kids don't have to struggle so much just to put a coat or boots on or simply go to the bathroom. Wyatt knows that he isn't the fastest kid on the block and he knows why. Wyatt knows he has CMT, and it still makes him one GREAT kid!


Sarah and her three great kids

Wyatt was diagnosed a little over a year ago by our pediatric neurologist at the Mayo Clinic in Rochester, MN. We were pretty lucky. We already knew that his grandfather had CMT, so we got the blood test, waited the very long month that it took to get the results back, and then got the official word. This is why. This thing called CMT is why he has struggled.

By the time we got the results from the bloodwork back, he had already broken in his first pair of AFOs. He had just turned 6 years old and he needed details. Wyatt likes details. So I turned to the CMTA website and found some awesome resources that helped me explain what CMT is to him.

One of his first questions was, "Why do I have to wear things on my legs if this disease is about my teeth?" That made us all laugh once we explained where the name came from. I have to agree: it's a pretty silly name for a disease.

Wyatt understands CMT better than I could have ever imagined he would. Wyatt doesn't get angry the way I get angry. Wyatt doesn't feel the stares, only I do. Wyatt's heart hasn't broken yet the way mine has for him. I'm his mom. I get angry at CMT. I feel helpless and disabled, not Wyatt. The great thing is that if I don't let this monster called CMT attack me, then that monster does not get a chance to attack my son.

I may hear the whispers, and see the stares, but I am a mom, I can ignore them. I am determined to ignore them. Therefore, they don't even phase Wyatt. If I get excited over new braces, Wyatt gets excited over them. If I love Emily the therapist, then Wyatt loves Emily. If I make it fun to go to kid's yoga, then who cares what those other parents think, those parents who have no idea what it's like to wear AFOs or need help zipping a coat. I have a superpower. It's called being a mom. I am just a mom, and I'm ok with that. ✻

From Devastation to Determination—
The Erwin Family Circle of Friends

This is Evan. He is five and he has CMT. Evan is helping his dad, Chris, who also has CMT, build a wedge for his physical therapy. Evan's therapist at Children's Health Care of Atlanta recommended this wedge to help stretch his heel cords and the tendons in his feet. He spends five to ten minutes two to three times a day standing on his wedge while he watches TV or listens to his mom or sister read one of his favorite books. This is only one exercise in a routine of therapy activities he does regularly.

It is also just one of the ways Brooke and Chris Erwin are meeting the challenges a recent—and unexpected—diagnosis of CMT has given their family.

Although Chris had been experiencing leg and foot pain for 15 years, none of his doctors had mentioned CMT. Then, in November 2006, Brooke took their daughter, Gretchen, who was also having pain in her feet and legs, to a new doctor who evaluated her, diagnosed her, and wanted to schedule surgery—all in the first five minutes of their appointment.

On their family website, Brooke writes that "her head was spinning" and that she was devastated. "How could this be? What was CMT? How did she get it?" However, as Brooke continued to research CMT, she realized why the doctor had asked who else in her family had foot pain. Suddenly there was an explanation for Chris' symptoms, those of his mother, and now those of young Evan.

Brooke's devastation has since been replaced by a fierce will and determination to not only manage the immediate medical needs of her family, but to also get involved and help raise funds for CMT research.

She and her family have become members of the CMTA support group in Atlanta, and in August of 2008, Brooke began doing a Circle of Friends to help the CMTA fund STAR. She hopes the research will benefit her family and thousands of other people affected by CMT.

For more on the Erwin family, visit www.freewebs.com/theerwinfive. ✻

The CMT "Circle of Friends"

We are proud to have the Erwin family in our Circle of Friends. A diagnosis of CMT changed their lives, but they are fighting back and doing what they can to help fund the CMTA Strategy to Accelerate Research.

To learn more about starting a 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!

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

Dave's Marathon Swim

Mr. Paul R. Bellora
Mr. and Mrs. Randolph Brush
Ms. Heather A. Dean
Mr. and Mrs. Christopher H. Hunter
Ms. Katie B. Lau
Mrs. Martha M. Inman-Paige
Mr. Nicholas M. Smith

David's Quest

American Kempo Karate Academy
Ms. Susan B. Cunningham
Mr. and Mrs. Michael G. Grant
Ms. Debra Hewitt
Mr. and Mrs. Robert Krug
Mr. and Mrs. Richard P. La Grassa
Mr. F. A. Langone and Ms. Y. M. Pimentel
Ms. Maureen M. Lappen
Mr. John McMillan
Mrs. E. Marie O'Meara
Ms. Nellie K. Powell

David's Quest (continued)

South Coastal Demolay Chapter 220008
Mr. and Mrs. James Sugarman
Sullivan and Folan, LLC

Grace's Courage Crusade

Ms. Susan Allen
Mr. and Mrs. John Anderson
Mr. and Mrs. Gary W. Anderson
Mrs. Kathy E. Anderson
Mr. Salvatore J. Augeri
Mr. and Mrs. Glen C. Beauchemin
Mr. and Mrs. Louis D. Boccardi
Ms. Margery A. Boyer
Ms. Catheleen M. Caddick
Chariho High School District
ChevronTexaco
Mr. and Mrs. Constantine Clemente
Ms. Dorothy A. Cummings
Mrs. Susan C. Davis
Mr. and Mrs. Bruce D. Downer
Ms. Marianne Dussault
Mrs. Jaclynn M. Ferria
Mr. and Mrs. John B. Gest
Mrs. Evelyn Ghiorzi
Mr. and Mrs. Christopher J. Greene
Mr. and Mrs. Edward Haik, Jr.
Ms. Kathleen J. Harrington
Ms. Vivian D. Julier
Ms. Mary Klehm
Mr. and Mrs. Richard J. La Magna
  and Family
Mr. Robert J. LaMagna and
  Ms. Nicole Shute
Mrs. Gail MacDonald
Ms. Jeanette Marley
Ms. Brenda Medina
Mrs. Iris M. Ornberg
Ms. Marianne Papi-Roque
Pfizer Inc.
Mr. and Mrs. Keith Renner
Ms. Margaret Pilkington Riley
Mr. Raymond G. Romatowski
Mr. Frank J. Rossi
Mr. and Mrs. Lennon J. Schroeder
Mrs. Nikki G.Scott
Mr. and Mrs. Robert Shawver
Rev. John P. Soares
Mr. and Mrs. Jeffrey Sparfven
Dr. and Mrs. George A. Sprecace
Mr. and Mrs. Anthony Teolis
Mr. and Mrs. George H. Travis
Mr. and Mrs. H. Winfield Tucker

Kayla's Circle

Mrs. Kathleen C. Brenner
Mrs. Debbie Earley
Mr. and Mrs. Bruce Frederickson
Mrs. Jennifer J. Perez
Ms. Kelly B. Price
R & W Food Service Sales, Inc.
Roisum Elite
Ms. Kimberly Tschida

Keara's Quest

Ms. Elizabeth L. Kowalchyk
Mrs. Kim Kuhr
Mrs. Terry S. Peck
Mr. and Mrs. Christopher Sonntag

Raising Money for Research

Stan Gumson celebrated his 80th birthday on February 17th surrounded by family and friends at Benvenutos in Boynton Beach, Florida. The invitations mailed to all the attendees requested them to send donations to the CMTA in lieu of gifts. His wife Corinne welcomed everyone and explained that the CMTA was conducting research into the causes of Stan's inherited neuromuscular disorder and were working on finding treatments and cures for CMT. More than $800 was raised for the research fund, and a good time was had by all!

Stanley Gumson's 80th Birthday

Mr. and Mrs. Bernard Bluestein
Mr. and Mrs. Marvin Bressler
Mr. and Mrs. Marvin Byer
Ms. Celia Chalfy
Mr. Donald D'Argenzio
Mr. and Mrs. Gilbert N. Fine
Ms. Francine Garnes
Mr. and Mrs. Alan Guttman
Dr. and Mrs. David H. Katz
Mr. Morris J. Katz
Mr. and Mrs. Howard Keer
Mr. and Mrs. Harold Levitt
Mr. and Mrs. Victor Lubin
Ms. Robin Miller
Mr. and Mrs. Stewart Miller
Ms. Stacy L. Miller
Dr. Albert Levine and
  Ms. Dorothy Delman
Mr. and Mrs. Howard Nagelberg
Mr. Carmine Pacileo
Mr. and Mrs. Dave A. Rothfarb
Mr. Marty Samuels
Mr. and Mrs. Irving Zeitlin
Mr. and Mrs. Asher Zelin

Stanley and Corinne Gumson celebrated Stan's 80th birthday surrounded by family and friends.

LETTERS

Dear CMTA,

I am a new member, but I have been a CMT parent for almost 30 years. In the beginning, there were not many people who could help support a young family as they coped with this disease. I'm glad there is so much more assistance now, and the growing research developments are so impressive.

My daughter is now 35 and was diagnosed at about age seven. I always encouraged her, but she has always been a gifted child. She was always at the top of her class and succeeded at anything she tackled. Denedria completed both a BS and an MSW degree in Social Work, has written a book used in college courses, hosted a radio web broadcast, performs research, and does speaking engagements.

Her life, however, has not been without incident, as her form of CMT affected all quadrants of her body, not later in life, but early. This has been a rollercoaster ride at times.

I did not write the above to brag, but to encourage any parent or person who must deal with this disorder and wonders what type of life can be had: a full one!

—*V. B. Long Beach, CA*

Dear CMTA,

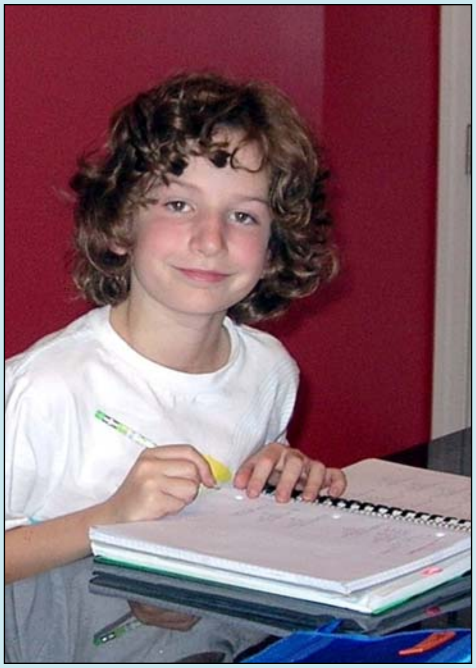
I saw your association mentioned in a medical column this AM and I thought you might like to know the following: My aunt, Christina Olson, was the subject of artist Andrew Wyeth's famous painting, "Christina's World, " the crippled lady lying in the field with a huge New England family home in the background. I was prompted to write a manuscript and later a book about her because so much false was written about her and her brother. Thereafter, three doctors contacted me with lots of questions about my aunt and her physical handicap. Over several years, there were many phone calls back and forth with all three. Eventually, one doctor came to visit me in Maine. After years of studying sketches of her limbs and Wyeth's numerous paintings of her, he felt he had arrived at a likely diagnosis. You see, the family never knew what her disease was. It became apparent at age three that something was wrong. For the next 71 years, it progressed very, very slowly. The doctor described the disease to me and the description fit her like a glove. After the press, speakers, authors all claiming she had polio, MS, rickets, severe arthritis, etc., I finally felt confident that CMT was most likely to have been what she was afflicted with all those years.

—*Jean Olson Brooks*

WRITE TO US!

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

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



A Donation for Yohan

My cousin Yohan has CMT, a disease that I'm sure nobody wants. He lives in California and I live in Vermont. Every year he comes for Christmas and summer vacation, and I dream of him coming to Vermont without CMT.

This year, I remembered I hadn't written a letter to Santa Claus. When I started writing, I remembered Yohan was coming and my dream to see him without CMT. I wrote "Dear Santa, All I want for Christmas this year is $300 to donate to the C.M.T.A. to help find a cure for CMT so I can see my cousin come to Vermont without that disease."

He came with CMT, but we had a lot of fun together. My favorite time was playing with him in the snow. A little while later when he left, I accomplished my goal of donating $300!

I raised the money by taking all the money I got for Christmas and keeping track of how much I received. I added it all up and there was $289! So I took $11 out of my piggy bank to reach my goal of $300 to send to the CMTA.

I know it will take a while to find a cure for this disease, but I know that there is a possibility that I can see Yohan without CMT. —*Warren Ouellette*

Working with Families with CMT

BY CARLY SISKIND, MS

Since I began working in the CMT Clinic at Wayne State University, I have seen over 500 patients and families. Many have come to the clinic with genetic or clinical diagnoses. Others have come questioning whether or not they have CMT. I have had the responsibility of informing countless numbers of people that they, their child, or their spouse, has this genetic condition. It's often the "genetic" part that causes grief—the possibility that this person, newly diagnosed with CMT, can pass on the condition to their children. This is a letter to the newly diagnosed.

1. You are not alone. CMT affects one in every 2500 people. That's the size of my high school. If you cannot find anyone in your community with CMT, there is a large, active online network of people with CMT who can help answer questions and guide you through the tough time of receiving a genetic diagnosis. Charcot-Marie-Tooth.org and CMTUS.com are good places to start.

2. Support groups don't only connect you with other people who have CMT, they often bring in renowned speakers who are experts in dealing with some aspect of CMT. They are a great way to learn more about your condition and to pick the brain of someone who has a unique perspective.

> It's often the "genetic" part that causes grief—the news that CMT can be passed onto their children.

3. CMT is passed down through a family by chance. When the egg and sperm are being made, mistakes occur. Everyone has 8 to 10 changes in their DNA. Some cause disease; some don't. There is nothing you can do to make it happen, and nothing you can do to prevent it from occurring. As a genetics professional, I hope that there is no blame or guilt associated with having or passing on the condition. A child is made up of 50% of the genes from mom, and 50% from dad. The good looks, the great personality, the delightful sense of humor – 50% is mom, 50% is dad – and who would want to change that?

4. Having a chronic condition of any kind can be draining. While the mental ability of a person with CMT is unaffected, losing physical agility can be frustrating and, often, depressing. We encourage people to talk to a therapist if they are having difficulty coping with any complicated life situation. Sometimes being able to talk about it in a safe environment lets a person perform better in everyday life.

5. I have met lots of people who have taken the challenge of CMT head-on. These are people with CMT who do things I would never do—run marathons, bike across Iowa, play professional tennis, swim competitively, win baking contests, and the list goes on. There are ways to chose ability in the face of disability. That is the challenge of every person with CMT who finds success every day in performing the basic functions of living.

6. Get involved. Reading *The CMTA Report* is a good start. Join the Circle of Friends. Go to a support group meeting. If there isn't a support group in your area, start one. Consider being a part of clinical trials as they come up (and there will be several within the next 5 to 10 years). The CMTA envisions a world without CMT, but this cannot come to be without the help of people like you. Help yourself and help others—contribute to research.

I have been lucky to work with people with CMT in my career. I have met people who have inspired me to be a better person and who have melted my heart with their stories. I thank those of you who have trusted your care to me and the others at the CMT Clinic. I hope I have helped you just a fraction of how much you have helped me. ✻

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF

Robert M. Adams
Ms. Diane M. Godwin
Mrs. Christina Palmer

Bettie T. Appleyard
Mr. De Vere O. Appleyard
Mr. and Mrs. Morton Feldberg
Ms. Judy Schiltz
Mr. and Mrs. Foster Tolliver
Mr. and Mrs. Robert Vessey

Alan Arcieri
Mr. and Mrs. Herman Jorgensen

Betty Chow
Mr. and Mrs. Gene Lew

Bernard Dorin
Ms. Olga Slavich
Mr. and Mrs. Richard Watkins

Donald E. Driscoll
Mrs. Bobbye Driscoll

Susan Elmer
Mrs. Karen De Spirito

Marvin Frost, Jr.
Mr. and Mrs. John T. Baker
Central California Wood Carvers
Ms. Judy Douglas
Mr. and Mrs. Dwight G. Harder
Mr. and Mrs. Terry Huntsman
Mr. Robert E. Miranda

Robert E. Jackson
Mr. and Mrs. Jack D. Carpenter
Mr. Earl Sampson

Richard W. Jones
Mr. and Mrs. Douglas A. Thomae
Mr. and Mrs. Stanley A. Torstenson

Jay Lamar
Ms. Judith M. Lamar

John Pacholoau
Ms. Halina D. Kusnierz

John A. Scarduzio
Mr. and Mrs. Ronald W. Schmoyer

Myrtle Sutherland
Mr. and Mrs. Joseph Bevacqua
Mr. and Mrs. William T. Caple
The Cook Family
Freedom Baptist Church
Tommy and Percilla Little
Mr. and Mrs. Ashleigh M. Lucas
Ms. Joan M. Monti
Mr. Charles A. Nance
Terry, Debbie, and Catherine Sexton
Mr. and Mrs. Joe Williams
Ms. Edith L. Williams

Isabel Teixeira
Mr. and Mrs. T. Lester Jackson

Dean Weston
Mrs. Darlene A. Weston

IN HONOR OF

Denedria Banks
Ms. Cheryl D. Ellis

Yohan Bouchard
Warren Ouellette
Ms. Nancy Walsh

Matthew and Marcus Davis
Ms. Tina J. Jones

Jerry Donovan
Ms. Elaine Donovan

Denise Falsetto
Ms. Mary A. Shumaker

Zachary Heigle
Mrs. Marian J. Pleyel

Carol Keeley
Ms. Elizabeth Beers

Ruth Levitan
Ms. Flora R. Schultz

Robert Mirvis
Mrs. Sheryl Markowitz

Peter Sidoti
Mr. Frank J. Rossi

Jason Steinbaum
Dr. and Mrs. Herbert S. Kleiman

Dottie Zagar
Ms. Catherine Zagar

Sadie Zanzuri
Ms. Jane Vayman

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:________________________
____

Valentine's Beef and Beer for CMT and the Stair Lift Fund for Alex Joyce

BY KRISTIN JOYCE

Valentine's Day this year was a real chance for our family, friends, and many generous strangers to SHARE THE LOVE. Recently my 17-year-old step-daughter, Alex, came to the decision that she was ready to have a stair lift installed in our home. We had been worried about her safety going up and down the stairs for many months, but we let her decide in her own time when she was ready for help. Over the years, as her CMT has progressed, she has had to accept the fact that there are things that she used to be able to do on her own, that she now needs assistance with. Alex is a determined person and she has not accepted these things without a fight, but when the time comes to do what she needs to do, she does it with grace and a positive attitude.

The day she said she was ready I called the insurance company to find out what would be covered, only to find out that insurance does not cover stair lifts at all. With my husband out of work, we did not have the means to buy the stair lift right away, and it was gong to take some time for us to save the money we needed. A co-worker of my sister-in-law, Karen Sulecki, called that same week and said she would like to arrange a Beef and Beer to raise money for Alex. She had learned about Alex when we did a 50/50 fundraiser to raise money for Canine Partner's for Life and for Alex to get a service dog. Karen works closely with a local caterer and organizes functions on a regular basis. When she called us, we could not help but think it was serendipity. We accepted her help and decided to use the Beef and Beer as an opportunity to also raise money and awareness for CMT.

The only date the hall had available for the Beef and Beer was February 14th. It turned out to be the perfect day and gave us an instant theme "SHARE THE LOVE." The CMTA graciously sent out our invitations to everyone on their mailing list in our area. We had a few CMTA members attend and several other people generously sent us contributions. Alex was stunned by the response. My husband's many sisters and brothers sold tickets to all their friends, neighbors, and co-workers and all of my family members, including aunts, uncles, and cousins, came out to support Alex. Before we knew it, the tickets were gone and we had to start a waiting list. This was also the first time the hall had sold out a Beef and Beer.

The caterer (DiMichele Catering), Christiana Fire Hall, and the D.J. (Rockin Rudy) all cut their prices to help us raise more money from each ticket sold. The CMTA staff, Dana, Pat, Kim, and Kim's husband Dan, came down and brought their brochures, bracelets, and t-shirts, and Pat briefly spoke to the crowd. We also had a 50/50 raffle, and the winner, a young girl named Keely, tried to donate all of her winnings back to us, but we insisted she take some of her winnings and accepted her generous donation of more than half of her share of the 50/50. We raised enough money to install the chair lift just four days after the Beef and Beer, and Alex has been zipping up and down the stairs with ease instead of struggling. We also raised enough money to make a donation to CMT, which we were very happy about. Everyone said it was the best Beef and Beer they have ever been to, and they are encouraging us to make it a yearly event and we are giving that some thought. ✲

Alex Joyce and her Canine Partner for Life, Deedee, enjoyed the February 14th event.

SUPPORT GROUP NEWS

California – San Francisco
The next meeting will take place on March 21, from 2-4 pm at the San Mateo Public Library. David Hall, the CMTA's new and dynamic CEO, will talk about his exciting plans for the future regarding members, national growth, and research issues. He is genuinely interested in how to better the CMTA to meet your needs, so your thoughts and input are required.

Colorado – Westminster
The group met on February 28, 2009 and heard presentations from Dorothy Miller, Terry Ford, and Bob Bauer, all of the Neuropathy Association of Denver. They spoke about the causes of peripheral neuropathy, as well as its symptoms and treatments. The group will meet next on April 25, 2009.

Florida – Tampa Bay Area
The last meeting was held at St. Anthony's Hospital on February 7, 2009, in the auditorium. Forty people were in attendance. The guest speaker was Dr. Paul MacCabee from the State University of New York Downstate College of Medicine, Brooklyn, NY. He spoke about his research studies for CMT on nerve excitation using neuromagnetic stimulation. The audience had many questions about his interesting research. The group will hold their next meeting on May 9, 2009. The speaker will be a representative from Care and Share Independent Living.

New Hampshire/Vermont
A new group is meeting for the first time at the Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire on Saturday, March 28, 2009. The group will meet from 10 am-noon. The presenter will be Dr. Jeffrey Cohen, Associate Chief, Neurology, at the Dartmouth-Hitchcock Medical Center.

Pennsylvania – Johnstown
The new CEO of the CMTA, David Hall, was the guest speaker. Co-Leader Jeana Sweeney opened with a short talk on "Healthy Living with a Chronic Condition," followed by an impassioned plea for members to participate in CMT studies in general, and in particular the ongoing CMT prevalence and CoQ10 study.

David asked for questions and comments and they came in a torrent for the next two hours.

JD started the questions by raising the issue of breathing problems and CMT. He spoke of his 16-year-old daughter's death from respiratory arrest as a consequence of CMT. Don McLaughlin, the patriarch of the Johnstown group, was in attendance, on a respirator because of diaphragm weakness caused by CMT. JD also mentioned two other members who are on BiPap machines and could not attend.

Other members commented on their breathing problems and then we discussed everything from genetics to the MDA.

Pennsylvania – Philadelphia
The group met on February 28, 2009, to learn about shoes and bracing from physical therapist Reenee Donohoe of the A.I. duPont Institute in Wilmington, Delaware. She discussed proper fitting and how to find the shoe that best suits a person's needs whether they wear braces or not. The next activity of the group will be the "Jazzed for the Cure" fundraiser at the Villanova Convention Center on March 14, 2009.

Washington – Seattle Area
The group met on January 31, 2009. The guest speaker was Dr. Thomas Bird, Professor of Neurology in the Department of Medicine and Medical Genetics at the University of Washington. His topic was "The CMT Center of Excellence at the University of Washington." All people in attendance received a free CD from the CMTA on the STAR research program. The next few meeting dates will be February 28th, March 28th, and April 25th. Lunch was provided courtesy of the CMTA. ✲

NEW GROUP FORMING IN NORTHERN NEW JERSEY
Rachel Beron is starting a group in Mountainside, New Jersey, at the Children's Specialized Hospital. The first meeting will be May 17th, 1–3 pm.

Members of Reagan McGee's Tennessee Support Group gathered following their last meeting.

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: dkllrl@yahoo.com

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)
Place: Sutter Medical Center of
Santa Rosa
Meeting: Quarterly, Saturday, 1 PM
Contact: Louise Givens,
707-539-2163
Email: 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 – 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, 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

Massachusetts—Boston Area
Place: Beth Israel Deaconess Medical
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
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: wmiller758@msn.com

Mississippi/Louisiana
Place: Baptist Healthplex,
102 Clinton Parkway, Clinton, MS
Meeting: Quarterly
Contact: Flora Jones, 601-825-2258
Email: flojo4@aol.com

Missouri—St. Louis Area
Place: Saint Louis University Hospital
Meeting: Quarterly
Contact: Carole Haislip, 314-644-1664
Email: carole.haislip@sbcglobal.net

Missouri
Answers to questions only, no meetings.
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—Lebanon
Place: Dartmouth-Hitchcock Medical
Center, Auditorium A
Meeting: Bi-monthly
Contact: Margaret Healey, 802-353-2797
Email: margaret_ healey@hotmail.com

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: bwine@acm.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
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,
206-598-6300
Email: rosk@u.washington.edu

When You Have a Dorky Disease

BY CAROLE HAISLIP

"Oh yes, you have CMT." Perusing my chart, my doctor looked decidedly embarrassed. "Remind me again just what that is?"

It was nothing new. Charcot-Marie-Tooth disease (CMT) is a subject most physicians cover briefly in medical school and never encounter in actual practice.

CMT affects about 150,000 Americans and is the most common inherited neuropathy. It affects the peripheral nerves — those in the lower legs and feet, but sometimes the arms and hands, too. There is no cure. The nerves become progressively damaged, which causes the muscles to deteriorate and shrink.

My mother was born with this condition, along with several of her 12 siblings. She generously passed it on to all seven of her children.

We were all pretty dorky as kids. All seven of us had painfully thin ankles, highly arched feet, and severe physiological foot drop (where the foot tends to point downward). These combined traits made us pitifully slow runners, and we had a weird way of walking. In order to keep from stubbing our toes while walking, we would forcefully lift our knees with each step and slam down our heels. It resembled marching and was extremely loud. People could recognize the Haislip kids from a block away because of this distinct, noisy gait.

Trips to visit my mother's family in Wisconsin each summer were comforting as a child, because we were among fellow dorks. We could hang out with aunts and uncles and cousins who walked and ran as we did, and no one told us we looked strange. Our family reunions must have been quite a sight for passers-by.

As kids, we were pitifully slow runners, and we had a weird way of walking.

The funny thing is, we never knew it was a disease. None of us had ever heard of CMT. It was just the way we were.

In 1995, our family received its first diagnosis of CMT. First a brother, then my mother, then me. In time all of us were properly diagnosed and we discovered that this was a real, actual disease.

There were fancy medical explanations for all of our odd qualities. Our thin ankles and high arches were caused by muscle wasting and shrinking. Our funny walk is what medical experts call a slapping gait. We learned that it was hereditary, and that it would get worse.

We also learned that there were others out there like us. There is a national association for CMT sufferers, the CMTA. We found out that CMT was one of several neuromuscular conditions sponsored by the Muscular Dystrophy Association–Jerry's kids. My mother founded a local support group and has become a resource for fellow CMT patients in our area.

The high incidence of CMT in my immediate and extended families caught the attention of Dr. Florian Thomas of the Department of Neurology at St. Louis University. At his urging, our families volunteered to take part in a research study of CMT conducted by him and several of his associates around the country.

In the past few years we have repeatedly surrendered blood and even tissue samples and undergone often uncomfortable nerve testing. All this in order to locate the genetic flaw that causes CMT and possibly lead to a cure.

During the course of his study, Dr. Thomas discovered that our family has a form of CMT that has never been seen before, save for a single family in Bulgaria. The research study is still in progress, but in the meantime, much has been learned about this condition and its etiology.

It's enough to make a family feel needed and important.

And definitely not dorky. ✻

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

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.

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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 (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
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Cytarabine (high dose)
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Gemcitabine
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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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