THE CMTA Report

JULY/AUGUST
2009

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

CMTA
Charcot-Marie-Tooth Association

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

OUR VISION:
A world without CMT.

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

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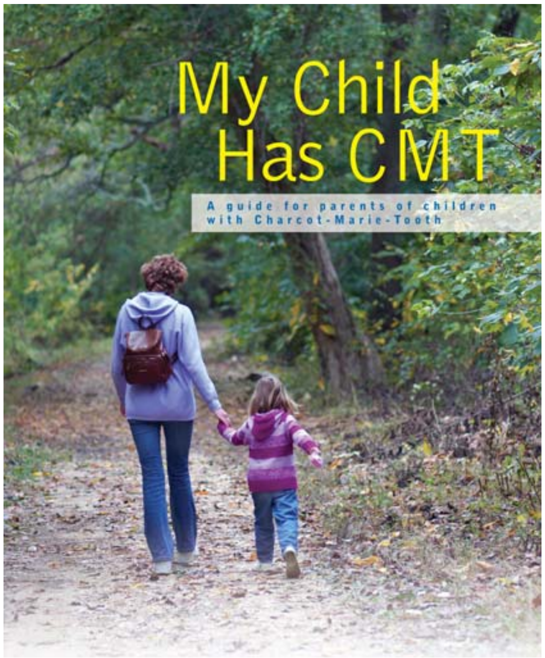
New Pediatric Publication Available Now


My Child Has CMT
A guide for parents of children with Charcot-Marie-Tooth

The CMTA has published a new booklet entitled "My Child Has CMT: A guide for parents of children with Charcot-Marie-Tooth." This publication was a year-long effort made possible by a grant from the Pennsylvania Department of Health. The booklet contains a section on "When a Child is Diagnosed with CMT," a long question and answer section of the most commonly asked questions following a new diagnosis answered by Dr. Mena Scavina, pediatric neurologist and Co-Director of the MDA Clinic at the A.I. DuPont Institute in Wilmington, Delaware, an essay from a father called "When We Found Out Our Daughter Had CMT," a chapter called "How to Keep a Medical History for your Child," a dictionary of the "Medical Terminology Common in the Diagnosis and Treatment of CMT," and a final section of resources for CMT patients and family members.

The booklet is 32 pages in length and is printed on high-quality glossy paper with photos in full color. It's a very attractive publication and one that contains lots of useful information for parents and caregivers.

We are offering the booklet for $5 for our members and $7 for non-members. ✻

Allentown, PA, CMT Conference Draws Huge Crowd

BY PAT DREIBELBIS

On May 30, 2009, 133 patients, family members and friends gathered at the Lehigh Valley Health Network Kasych Pavilion for a conference on CMT disorders. The agenda was packed with medical experts in the fields of neurology, orthotics, physical therapy, foot and ankle surgery, and occupational therapy. Representatives of the CMTA were also there to make presentations and to register and welcome the huge crowd.

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INSIDE:

ALLENTOWN CONFERENCE

(continued from page 1)

The morning began with a presentation from Glenn Makin, MD, who is the Director of the Neuromuscular Division of the Lehigh Valley Hospital and Health Network. He did a thorough job of explaining what CMT is, how it is inherited, and what research is going on that offers hope for cures and therapies in the future. A favorite line from his presentation was "CMT doesn't get the respect it deserves" from doctors and the public in general. Almost everyone in the audience related to that comment.

Dr. Makin was followed by David M. Hall, Chief Executive Officer of the CMTA. He energized the group by talking about the research of the STAR initiative and the fact that Phase Two is ready to begin at the NIH. He urged every person present to get involved in one way or another to promote awareness of CMT and to help raise the funds necessary to finance the STAR's ten million dollar cost.

After a break, the third presentation was made by Gary Michalowski, an orthotist/prosthetist from Wilmington, Delaware. He brought a bag full of sample braces and explained that the brace that's right for one person is not necessarily the one for someone else. He talked about the reasons why one would use an articulated brace (one that bends at the ankle) versus a more standard fixed brace. He was bombarded with questions following his presentation, demonstrating the importance of bracing to the majority of CMT patients.

Lunch was a nice break and allowed attendees to ask personal questions of the presenters. All three of the morning speakers stayed on and spoke to people right through their own lunchtime. After lunch, Allyn Danni, a physical therapist from the Lehigh Valley Health Network, Trexlertown, talked about the need for exercise in keeping muscle and limiting functional loss. Her presentation also provoked a lot of questions.

CEO David M. Hall urged every attendee to promote awareness of CMT and to raise funds for the STAR program.

The next presenter, Dr. Sara Bouraee, an ankle and foot surgeon from the Philadelphia area, encountered some computer problems and had to begin her presentation without benefit of slides. She did a great job and once a new computer was up and running, she finished with lots of explicit (read that as gory) slides showing ankle surgeries and tendon transfers. Although the slides were graphic, the audience liked them and really appreciated all the questions she was able to answer for them. She did remind everyone that although she was a surgeon, surgery should never be the first choice for how to handle CMT deformities and pain. She urged everyone to explore the option of bracing before resorting to surgery, where the outcome is never guaranteed.

The final presentation was on occupational therapy. Betsy Green, an occupational therapist from the Lehigh Valley Health Network, demonstrated hand splints and other devices to help control the loss of muscle between the thumb and forefinger. She answered questions about ways to help kids with school work if they have hand problems and she did her entire presentation without benefit of slides because of the ongoing problem with the main computer.

All in all, this was an excellent conference, full of information and enthusiasm. The venue was one of the most perfect we have ever had with drop-down screens, portable microphones, an excellent AV system, and comfortable chairs with large tables. Dr. Glenn Mackin, who was the lead presenter, stayed for the entire conference and was still answering questions at 4:30 when we were packing up to leave. Sharon Bartz, the conference organizer from the LVHN, also was in attendance for the entire day and was an invaluable resource for all of us. Special thanks go to Margaret Eighen, a nurse who volunteered her time as part of a class she is taking while working on her Masters' Degree. Her help with registration and the selling of books and bracelets was a lifesaver (mine). In the surveys we collected, the day was described as "uplifting and encouraging" and that's a perfect summary of the conference. ✻

Join the Fight: Washington, DC, Is a Place to Make CMTA History

Many of you have had the memorable experience of taking your family on a sightseeing trip to Washington, DC. The history of the city itself along with the history of our great nation makes Washington, DC unlike any city in the world. If you were like me on my first recreational visit, you probably asked yourself "where do I begin and what should I visit first?" The various monuments, museums, and national treasures can be overwhelming to almost anyone.

The sightseeing analogy is appropriate when describing the CMTA's recent outreach efforts to the federal government. The National Institutes of Health, the Centers for Disease Control and Prevention, the Department of Health and Human Services, the Office of Orphan Products Development, the House of Representatives, the United States Senate—"where do we begin and what office should we visit first?"

Each of the aforementioned agencies and branches of the federal government can play a pivotal role in assisting the CMTA in reaching its goals pertaining to research, drug development, clinical protocols, education, and awareness. But in order for that to become a reality, we must be committed to an advocacy campaign to ensure that key leaders in these various public offices are aware of what Charcot-Marie-Tooth disease is and how it effects tens of thousands of families across this country.

The advocacy campaign in the halls of Washington, DC (and state governments!) is not a one-time, static event. It is a dynamic process of relationship management and education that will never cease to be a top priority of the CMTA. However, just like with all the other CMTA programs and projects, we will only be successful in leveraging public resources if we have the proactive support from our members and friends throughout the country. The democratic system in this country ensures equal representation for all of us. We all have one Congressman and two senators in Washington, DC. We all have state representatives and state senators. We all have governors. And we all have a president. Reach out to each of them via letter, email, or phone and tell them about CMT and the CMTA, and tell them we need their help in not only improving the lives of those who live with the disease, but also with meeting our ultimate goal of curing CMT.

At right is a copy of correspondence I use when contacting members of congress and agency directors who might be of assistance to you when contacting your local or federal representatives. Please feel free to use all or parts of the letter as you see fit. Your local or federal representative may never have heard of CMT, but after hearing from you, I'm willing to bet they'll never forget.

As you'll read throughout this newsletter, your continued support of the CMTA has allowed us to make remarkable progress over the past several years. We should all be proud, but not complacent. Now's the time to work harder than ever. Now's the time to realize our goals are within reach.

Please don't hesitate to contact us to learn more about our programs. I hope all of you have a safe and enjoyable summer.

—David M. Hall

Dear Congressman,

It is my sincere pleasure to write you today regarding an opportunity to dramatically improve the lives of the more than 2.5 million people worldwide afflicted by Charcot-Marie-Tooth (CMT) disease, the most commonly inherited peripheral neuropathy. As Chief Executive Officer of the Chester, PA-based Charcot-Marie-Tooth Association (CMTA), I am extremely proud to introduce you to our global strategic research program, the Strategy to Accelerate Research (STAR). The goals of STAR are ambitious. We expect to develop therapies for the three most prevalent types of CMT within the next three years and to be able to reverse symptoms in some patients within seven years. These goals are attainable, though it will take an extraordinary effort from our scientists and staff along with the corporations, foundations, and families that support the CMTA throughout the country. CMT is little known to the general public and poorly understood by much of the medical community. In order for STAR to become a reality for those living with this disabling disease, it is incumbent upon the CMTA to initiate and execute a national educational campaign targeting the patients, families, and clinical providers. It is only through a structured educational program that we can promote a collaborative relationship between CMT patients and their providers to ensure people are being properly diagnosed and treated with the latest standards of care.

To this end, it is the goal of the CMTA to not only serve the needs of affected individuals in the U.S., but also to serve as a model for organizations and countries around the world. I believe with your assistance, the CMTA can make this a reality. For the past 25 years, the CMTA has taken the lead in creating awareness about CMT and funding CMT-related research. I look forward to working with you to ensure CMTA can meet its next aggressive goal—a world without CMT.

STAR UPDATE:

CMTA Postdoctoral Fellow Scheduled to Begin Work at NIH in July

In the May/June *CMTA Report*, we announced the completion of Phase 1 of the STAR program. A CMT1A cell line, created by Dr. Ueli Suter in Zurich, Switzerland, has been sent to the NIH Chemical Genomics Center (NCGC) in Rockville, MD, where it has been undergoing a necessary period of growth in preparation for high-throughput screening (HTS).

This month, we are pleased to announce the appointment of Sung-Wook Jang to a three-year term as a CMTA postdoctoral fellow at the NCGC. Sung-Wook, who has a PhD in Cellular and Molecular Biology from the University of Wisconsin in Madison, will work closely with scientists at the NCGC and be responsible for the development and performance of screening efforts using the NIH compound library to find therapies for Charcot-Marie-Tooth inherited peripheral neuropathy.

Sung-Wook's initial work, scheduled to begin later this month, will involve conducting biological assays using the CMT1A cell line. (A biological assay, or bioassay, is a test performed to measure the effect of a substance on living matter, e.g., the CMT1A cells.) What's remarkable about HTS is that it will enable Sung-Wook and his NCGC colleagues to conduct bioassays using the more than 350,000 drugs and other compounds in the NIH chemical library as reagents.

The NCGC Chemical Compound Library: Some of the 350,000 compounds stored here may become treatments for CMT.

We don't know yet how many promising compounds will be identified, but it's vitally important that we have a way of determining which of those compounds are likely candidates for further testing.

This is one key reason the CMTA chose to do the HTS at the NIH. Over the next several months, Sung-Wook and the NCGC scientists will perform sophisticated informatics analyses within and among screens and use other advanced techniques to optimize their understanding of the activities of these compounds in biological systems.

It's also why the CMTA initiated work on two other crucial projects in the STAR program. One, currently being undertaken by Klaus Nave at the Max Planck Institute for Experimental Medicine in Gottingen, Germany, is focused on developing a laboratory model of the disease because we need to know if the effects we observe in HTS will also be observable in animals.

The other, being pursued by John Svaren in his lab at the University of Wisconsin at Madison, where Sung-Wook also studied, is designed to further our understanding of how PMP22 is expressed and regulated and to tell us whether the same constructs will be observed in humans.

These two studies will ultimately help us determine which compounds will be the best candidates for laboratory and clinical trials, and the fact that we

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WHAT ARE "CELL LINES" AND WHY ARE THEY SO IMPORTANT IN CMT RESEARCH?

Cell lines are cells that have been taken from a tissue (such as Schwann cells from peripheral nerves), and that have then been "immortalized" by fusing them with a cancer cell line.

If done properly, these "immortalized" cells will have many of the same properties as myelinating Schwann cells but can be grown up in a culture dish indefinitely.

For the current phase of STAR, Ueli Suter has also genetically engineered our CMT1A cell line to express fluorescent markers every time the PMP22 gene is expressed. The crucial factor in doing so, however, was to also make certain that the elements in the cell line that regulate PMP22 expression are as close as possible to the regulatory elements in the Schwann cells in nerves.

LIVING WITH CMT

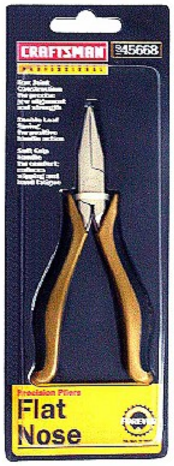
MacGyver Gets a Lesson

No, he didn't blow up or burn down the house while fiddling in the garage, but he did spend a weekend at the home of someone with CMT2A, a type of CMT that often affects people severely. She is unable to walk, has very little use of her fingers, and can only hold objects by pressing them between her hands or against her body. With a power chair equipped with a joystick, she is able to maneuver around the first floor of her house, but she can only get to the finished basement in good weather by going out and around to the back. She doesn't drive, either, but she can ride as a passenger in a modified van.

She is also an avid reader of *The CMTA Report*, and one of the first things she told me was that she thought it was great that people were sharing ideas about living with CMT. They just weren't of much use to her.

If you think that's a plea for sympathy, you're wrong. She wouldn't want it. Despite her limitations, she is a very independent, hard worker, and over the weekend it became apparent that all the gadgets in the world can replace neither a devoted and supportive spouse who leaps into action without being asked, nor other family members and friends who take the time to help.

It also helps to remember that everyone's situation is different, and that the ideas and solutions we share here won't always work for everyone.



On that note, needlenose pliers (especially the spring-loaded type) appear to be the tool of choice for handling credit cards at gas stations and ATMs. G.O. from NC recommends mini flat-nose pliers from Craftsman (available at Sears/Kmart). He keeps one pair in his car and another in a cellphone case that he clips to his belt, and he uses them for opening salt/pepper packets in restaurants and as a zipper pull. C.T from TN also suggests using rubber finger tips, which can be purchased at any office supply store and used for page-turning and other tasks.

Meanwhile, does anyone remember gas station attendants? Good luck finding one willing to clean the windshield, but in NJ and OR, they have to pump the gas for you. In other states, if you have a handicap placard, L.P. from CA suggests asking for help.

On the subject of buttoning jeans, J.H. from CA suggests enlarging the buttonhole slightly, and several people have written to suggest removing the button and replacing it with Velcro or with a slide-and-hook. Velcro closures also work on everything from sneakers to jackets, but they can be troublesome if there isn't enough material at the end to grab, as anyone can attest who has ever had a strap on an AFO cut too short.

—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

THEY'RE NOT JUST BEAUTIFUL!

Amy de Silva, far left, competed in the Miss Massachusetts Outstanding Teen contest on a platform of CMT awareness entitled "It's Okay to Be Different." The contest was for girls aged 13-17, with Amy being the youngest competitor at 13.

Getting the Right Shoe

BY ELIZABETH OUELLETTE

Adam Kemist, a Board-Certified Pedorthist, spoke at the San Mateo support group meeting and offers these thoughts about shoes, CMT feet, orthotics, and more.

Asics shoes are one of the brands that Adam Kemist recommends.

THE ANATOMY OF A WALKING/RUNNING SHOE

- **The bottom of the shoe or outsole** comes in direct contact with the ground. Certain outsoles provide more traction than others, depending on the materials used. With changing technologies and materials, the bottom of your shoe is no longer used as the sole indicator of whether a shoe needs to be changed or not. Often times, the midsole is worn down, while the outsole remains unaffected by everyday use.
- **The midsole** is the layer of the shoe providing stability, flexibility, and cushioning. Again, this area usually wears out before the outsole shows major signs of wear. When a midsole of a shoe loses functional stability and cushioning, more stress is put on the foot, increasing the risk of injury. The grayer the materials, the more support you will have. The lighter the color on the midsole, the more flexibility and cushioning your shoe will have.
- **The upper** is everything on the shoe above the sole—the laces, the tongue, the toe box, etc. The upper is usually the most flexible part of the shoe. Today, most sport shoes offer breathable, synthetic materials for everyday use.
- **The insole** is the removable part of the shoe, which essentially is there to protect your feet from the sewn-in seams on the inside of the shoes. The insoles provided in most shoes do not add that much extra support or cushioning. A podiatrist or pedorthist can make custom orthotics or arch supports, if needed.

SHOES AND CMT

- Many people with CMT tend to over supinate, or walk on the outer edges of the feet, rolling outwards during the gait cycle.
- You may also be aware of the term over pronation, or excessive rolling inwards of the foot. In the general population, pronation is a much more common problem than supination.
- In general, the heel in walking shoes is built to be 10 millimeters higher from back to front, whereas running shoes are made to be 12 millimeters higher from heel to toe.
- If you wear orthotics, which most of us do, they should not

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Robert Adams
Mrs. Flora K. Jones

Kenneth P. Bemiller
Mr. & Mrs. Jim Cramer

Milt Birt
Mr. & Mrs. Myron Martenson

Pauline Jacoby Dinges
Mr. & Mrs. Michael D. Gorka

Staff Sgt Travis Hunsberger
Mr. & Mrs. Jim Cramer

Lulu Kassover
Mr. & Mrs. Robert Kleinman

John Klover
Mr. Oliver D. Musat

Catherine Liccione
Mr. William Broderick

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The Farissier Family

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Mr. & Mrs. A. Hart Wurzburg

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Doris Dubuc
Mrs. Michaela Langlais

Gail & Gaellyn Feeney-Coyle
Ms. Mary Ellen Feeney

Sabrina Forth
Mrs. Maria C. J. Forth

Curtis Hayter
Mr. Andrew Monaghan

Dr. William Hopkinson
Mr. Michael Imrisek

Lynda Jensen
Delta Theta Tau Sorority, Inc. Omicron Zeta Chapter

Jenny Lopez
Mr. Al Jephson

Miriam & Bryce Maples
The Brown Family

Dan Martens
Mr. William Martens

Andrew Moody
Mr. Mitchell Moody

Coach Joe Paterno
Mr. & Mrs. Robert Johnson

Clem & Mary Petschel
Mr. & Mrs. Donald Graveman
Mr. & Mrs. William Perkins

Doug Sieg & Family
Ms. Joan Binstock
Mr. David Silvers

Vasi Vangelos
Miss Rebecca Vangelos and Friends

change the type or construction of the shoe you normally wear. Orthotics simply replace the manufacturer's insoles and provide additional support for the wearer.

- Since there are no universal sizes in the world of shoes, every company has its own individual standards for narrow, wide, extra wide or extra extra wide shoes. A "D" size in Saucony is most likely different from "D" sized Nike shoes.

S1 VS. S2

Most running shoes are coded S1 or S2. Look on the heel section of the insole of your shoe. S1 shoes will have the same bottom or base, which is relatively narrow, with little added depth. S1 shoes do come in extra widths, but it is *not* the base of the shoe that changes, but the material in the upper that increases, leading to more room in the toe box and around the outside of the upper's foot. An S2 shoe will provide a different bottom, which is actually a wider version of the same S1 shoe. S2 shoes offer true width changes in the bottom of the shoe as well as a generous toe box. So every company will have its own unique form shape and base, which remains consistent within the designated brand.

After working with Adam, I realized I was purchasing New Balance XX wide sneakers for Yohan, but in an S1. He compensated for the lack of width by purchasing shoes that were one or two whole sizes too big for him. Now I know that an S2 shoe will better accommodate a wide foot and that extra long shoes will not make up for lack of depth or width.

If you are looking for shoes for everyday use, a running shoe is not a bad choice. Adam recommends that you first look towards Asics and Brooks. For dressier shoes, Mephisto and Ecco seem to have a wide variety of shoes that are nice-looking with the added room needed for braces and orthotics.

Most importantly, go to a store whose staff is familiar with all the different aspects of the running/walking shoes made with today's technology. ✻

STAR UPDATE

(continued from page 4)

have already begun these projects has allowed us to not only increase our chances of success, but to also significantly shorten the time involved in the drug development process.

We're projecting that it will take between three and five years to develop a treatment for CMT1A, when, on average, it takes two to four years of work and $10 million to move a drug through the preclinical process alone. Then it can take years and millions more to bring it to the marketplace. With the risk involved, it's no wonder pharmaceutical companies seldom get involved in the development of drugs for rare or orphan diseases like CMT that affect fewer than 200,000 people in the United States.

That means that while STAR has enabled us to advance the timetable, you and the CMTA have had to fund the research. We expect that we will benefit from that in the long run, especially when it comes to funding research for other forms of CMT, but we are also optimistic that a new program announced by the NIH will greatly increase our ability to develop therapies for CMT.

It's called the Therapeutics for Rare and Neglected Disease program, or TRND, and, according to Christopher Austin, the director of the NCGC, one goal of the program is to "de-risk" drug development projects sufficiently in the preclinical phase to make them adoptable by private industry.

TRND will work closely with disease-specific experts, using in-house scientific capabilities to carry out much of the development work, and it will also work to find a company willing to help carry out clinical trials if a drug successfully passes the preclinical phase. (For more on TRND, visit www.nih.gov/news/health/may2009/nhgri-20.htm.

Although the CMTA began work on STAR well before the announcement of TRND and built a solid foundation for successfully identifying and shepherding a potential treatment for CMT1A through the preclinical process, we are still in an excellent position to benefit from a program like TRND as we begin the HTS phase of our preclinical work.

Meanwhile, as you can see, your continued support of the CMTA STAR is essential in helping maintain the progress being made in our compelling research program. ✻

GCC's Rock 'n Run for CMT Research

BY DANA SCHWERTFEGER

The first annual 5K run in honor of Grace Caldarone took place on Sunday, June 28, at Ninigret Park in Charlestown, RI, with 115 entrants competing for the top prize of $100.

After the race, everyone was invited to a family festival, which featured live bands all day until 5:00 p.m. In addition to popcorn, cotton candy, Del's Lemonade, and great food, kids of all ages were able to take part in a variety of activities including face painting, dunk tank, moon bounce, and police tank rides.

The day before, Grace's parents, Chris and Marybeth, took me on a quick tour of Narragansett to show me the future site of Grace's Second Annual Dinner Party, but the entire coastline was shrouded in thick fog, and showers were in the forecast. We spent an anxious evening making final preparations and watching weather reports, hoping that months of work wouldn't be spoiled by rain.

Fortunately, it wasn't, and everyone had a great time! ✻

Chris Caldarone looks on as Grace presents 1st place award.

For more information about Grace's Dinner Party, September 26, at The Village Inn in Narragansett, visit www.cmtausa.org/Grace or call Tonia at (401) 782-3574.

Grace and Marybeth with event organizer Tonia Hassell.

The CMT "Circle of Friends"

Started as a CMT "Circle of Friends," Grace's Courage Crusade has grown to include a Rock 'n Run and an annual dinner party. Donors to all three, and to Reagan's Quest, appear below.

Grace's Courage Crusade

Mr. and Mrs. Ronald P. Babineau
Ms. Michelle D. Barber, LMT
Ms. Linda E. Beaudry
Mr. and Mrs. Irwin M. Birnbaum
Mr. Troy M. Boucher
Mr. Jason Caldarone
Ms. Milva Catallozzi
Charlestown Mini-Super
Mr. James B. Creighton
Mr. and Mrs. T. G. Crotty
Crotty & Sons Body Works
Mr. and Mrs. David Crowley
Ms. Deborah D. Dauray
Mr. and Mrs. James A. Dunham
Ms. Donna Dyson
Ms. Nancy H. Fallon
Mr. and Mrs. Glenn E. Faubert
Mr. and Mrs. Robert E. Gaudet
Mr. Henry J. Grills
Ms. Karen E. Grimes
Grimes Auto Body
Mr. James A. Harrington
Mr. and Mrs. Kevin P. Harrington
Mr. and Mrs. Robert A. Haughney
Mr. Owen Haynes
Mr. and Mrs. Vincent J. Joyce
Mr. and Mrs. Odd Larsen
M & M Oil, Inc.
Ms. Eileen Montalto
Mr. and Mrs. Wayne J. Morgan
Mr. James F. Noonan
Ms. Deborah Izzo Ostrowski
Ms. Heather L. Paliotta
Mr. and Mrs. Robert T. Parker
Pat's Power Equipment, Inc.
Ms. C. C. Peduzzi
Mr. and Mrs. Gregory Quirk
Mr. and Mrs. Gary W. Schipritt
Mr. Dana R. Schwertfeger
Mr. and Mrs. David Sfreddo
Mr. and Mrs. Douglas M. Snow
Mr. and Mrs. Dean E. Soderberg
Mr. and Mrs. Timothy J. Sullivan

Reagan's Quest

Mr. and Mrs. Dana Castilla

"Archy" Gets a Diagnosis

For a long time, I've struggled with my walking. I've walked on my toes; I've walked on the outside of my ankles; I've fallen more than I've walked sometimes. So, it wasn't a surprise to me when my mother told me I had an appointment with a new doctor.

When Tina had approached me about being a mascot for the CMTA, the topic of her disorder and my strange-looking feet had come up. My mother was very surprised to know that there was a name for my problem because we always thought I had the Turtlebaum feet. My mother's father had feet like mine and while my mother walked perfectly well, she always mentioned that my feet looked like her father's. Still, we thought it was just a Turtlebaum problem, and the idea that I might have something that thousands of others had was pretty amazing.

Not necessarily good, but amazing all the same. So, on a Tuesday, I missed school so that I could go see a new doctor, a type called a neurologist. He was a snake (I don't mean that to sound like name calling; he really was a snake) who had studied under some really famous neurologists in a place called Detroit, and he knew exactly what CMT was.

He rather matter-of-factly checked out my reflexes by hammering on my knees, and my reflexes were totally lacking. Then he watched me walk and pronounced that I needed an EMG and an NCV (some scary-sounding tests that send little electrical signals down my legs) to determine if I had CMT and which type it was, if it was CMT.

I'm a fairly brave turtle, but the machines he hooked me up to were not pleasant looking. There were lots of wires and beeping sounds and, frankly, I was scared. But, my mother stood right by me and held my hand, and Dr. Pythonic explained about the little jolt I was going to feel when they sent the current down my legs. It sounded worse than it really was. I wouldn't necessarily want to have it done again, but the pain was not that bad and it was over quickly.

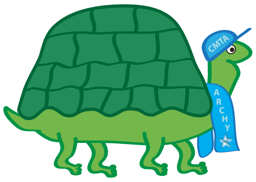
My results told them I did, in fact, have Charcot-Marie-Tooth disorder, and it was a demyelinating form. I have no idea what that means, but my mother seemed to be following the doctor's explanation. She said that the myelin around my nerves (kind of like insulation around an electrical wire) was breaking apart and that kept the signals from getting down my legs properly.

The type you have is important to know for reasons related to research and possible cures, but otherwise, everyone with CMT looks pretty much the same and deals with the same problems. In my case, my biggest problems right now are walking and falling. The doctor has something in mind to fix those problems, according to my mother.

Dr. Pythonic's nurse was a real fox (again, not name calling—she was a fox named Ms. Redd) and she gave us some papers to read that explained about CMT. It was weird, but one of them was all about the CMTA, the group that I'm going to be working with. I felt pretty important when I thought about how much good I could do by telling my story and being a role model for others who get diagnosed with CMT. I'm hoping that I won't get a lot worse if I do everything the doctors and therapists tell me to so I can continue to do all the activities I enjoy.

My sister didn't get the Turtlebaum feet, so I feel a little special. I know that my PopPop handles his bad feet and legs pretty well, and I'm going to be like him. He doesn't let anything stop him from doing what he always has. I know he doesn't climb up on the roof of his house anymore, but, frankly, I haven't ever wanted to do that. He takes care of his pets and he does the gardening, and I know he's a great swimmer like I am. So, we have lots in common and that is pretty special because I love my PopPop a lot.

All in all, going to the doctor's wasn't as bad as I had feared, and now that I have a name for what's wrong with me, I feel more like I'm part of something bigger and more important than just my life in the pond. I have a feeling I might wind up doing something great. Stay tuned. ✻



"Archy" our stout-hearted, but high-arched, spokesturtle will write about his experiences in future issues of the newsletter.

FUNDRAISING

Small Events Make a Big Difference

BY ELIZABETH OUELLETTE

As a frequent customer of Jamba Juice, (a chain that sells nutritional fruit smoothies in 30 states, the District of Columbia, and the Bahamas), I had just ordered my "Bright Eyed and Blueberry" drink when I noticed a flyer explaining Jamba Juice's community outreach program geared towards raising money for nonprofit groups supporting kids of all ages. Pam Higgins, the manager of Jamba Juice in my area (Los Altos, Ca) explained how Jamba Juice's very popular in-store fundraising program worked: on a selected date, when friends and family drop by the store with a preprinted announcement flyer, 20% of all sales are donated directly to one's organization of choice.

The idea sounded simple enough. So Pam and I chose a Saturday in April, from 11-4, for the first CMTA fundraiser. I asked for volunteers among my Bay Area support group members to help me promote the event by e-mailing an announcement flyer to families and friends, urging them to participate in one of two ways: either by visiting Jamba Juice on our specified CMTA day, or by spending an hour or two with me, manning a table in front of the store, asking potential customers to mention the CMTA before ordering (a necessary detail for the CMTA to receive the 20% credit).

That morning in April, I set up a table, and a few chairs and put out our CMTA brochures and the CMTA flyer announcing the 20% contribution on the part of Jamba Juice, if the word CMT was mentioned before placing the order. Every time a potential Jamba Juice customer approached its doors, we quickly, but politely, asked them to mention the CMTA before ordering. Most people took well to my request, despite the fact that the majority had no idea

Frank and Harriet Weiss helped man the table in front of the Jamba Juice store.

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:________________________
____

what CMT was, or why I was asking them to repeat three seemingly unrelated letters of the alphabet to the cashier. Many customers asked for CMTA brochures to have something to read while waiting for their order. If anyone wanted further information about the CMTA, CMT, or STAR, a support group member remained at the table to answer questions.

Nevertheless, there were a few people who cunningly slid by me (not an easy endeavor). Some ran into the store, eyes lowered, just repeating "no thank you, no thank you" and a confused minority just stared back at me blankly. Most people complied and willingly mentioned the CMTA to the Jamba Juice employees. If not, the Jamba Juice staff was good about consistently asking most customers if they were there for the CMT event.

This initial Jamba Juice event turned out to be not only a fundraiser and a community awareness activity, but also a unifying experience for all my members who participated on that particular day. We ended up raising approximately $350 for the CMTA's STAR program and decided to repeat the experience on a Saturday in June.

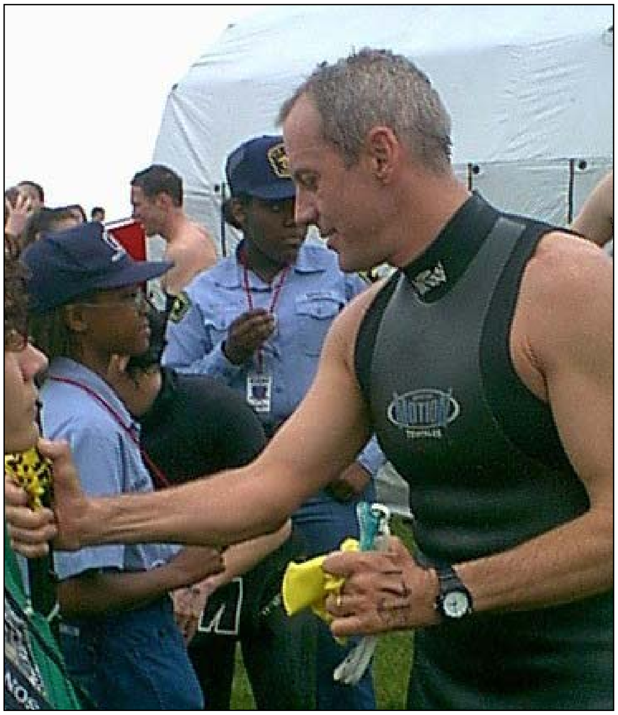
On June 6, we once again convened in front of Jamba Juice in Los Altos, but this time we split the shifts among the support group members into 1 1/2 hour blocks of time. To catch the customer's eye, I plastered bright yellow and orange posters all over the store and entranceway which read: "Just Say STAR" before ordering. The difference in explaining that CMT means Charcot-Marie-Tooth disease vs. STAR, our research initiative to find a cure for CMT was a key factor in easily conveying the fundraising format to unsuspecting customers. To show our gratitude, we all thanked each customer for being a STAR for the CMTA.

Our Jamba Juice efforts were very successful in both raising money and local awareness. The second event netted a grand total of about $325, but that $325 quickly turned to $2,000 plus dollars with the help of my Bay Area support group members and the CMTA board members. How? For those who were not able to physically participate at the event, I asked each member to consider making a small monetary donation (even a $5 donation goes a long way) to the Board Challenge for STAR research. My original goal of doubling the $325 was quickly surpassed the first day. By the end of the week, we raised an additional $875 for the CMTA through individual, tax-deductible donations. To sum it all up, the original $325 turned into $1200 thanks to the generous support of my support group members, and in turn, this $1200 was transformed into a total gift of $2400, thanks to the CMTA Board of Directors, who have promised to match each dollar up to $350,000.

These smaller fundraising events, if replicated in our communities and across the country, could raise the money needed to advance STAR research beyond CMT1A to other types of CMT, sooner rather than later. Why not approach your local Jamba Juice, Starbuck's, Pizza Hut, etc. and ask about their community outreach programs? Many businesses welcome fundraisers, as everyone benefits, making each new affair a win-win situation for all those involved. Just think, if just 10 individuals took the initiative to raise $300 through similar programs, just four times a year, $12,000 additional dollars could easily be raised for CMT treatment and cure-related research while better informing our communities about CMT.

Better yet, if one person from each of our 40 support groups replicated the above exercise quarterly, well, you do the math. The sky is the limit! Help us reach for a STAR, the CMTA's STAR, promising a better future for all. ✲

EIGHT SUCCESSFUL SWIMS!



Board Member Steven O'Donnell completed his "Swim for the Cure" in the Chesapeake Bay again this June. He was joined by his daughter, Jaime and her friend, Cecily. The trio has raised $61,259 to date for CMT research.

SUPPORT GROUP NEWS

California – Northern Coast
The next meeting will be on August 1, 2009, from 1-3 pm. The topic will be bracing with a presenter from Hanger Prosthetics. After the presentation, we will have a discussion on topics important to the group members.

California – Santa Barbara
The first meeting of the Santa Barbara group was held on June 28th and was attended by representatives of four Southern California counties. We enjoyed a healthy brunch while discussing everything from traveling, to successful surgeries, work/careers and personal stories. Denedria Banks, author of *Melodies of My Life*, joined us and spoke about her book and autographed copies. Our next meeting is planned for August 8 at 1 pm at the Alisal River Grill in Solvang.

California – San Francisco
The third annual picnic will take place on August 23, 2009. Then, on September 12, 2009, Dr. Rosemary Shy, from the Wayne State Clinic in Detroit, Michigan, will speak on kids and teens with CMT.

Colorado – Westminster
The group met on June 27th from 2-4 pm at Capabilities in Westminster. The guest speaker was Jonah Berger, author of *He Walks Like a Cowboy*. He founded and runs a business called “The Rhythm Within,” a therapeutic mentoring service for children and young adults with special needs. Following Jonah’s presentation, there was a discussion of each attendee’s perspective on living with CMT.

Florida – Inverness
Our last meeting was held on June 20, 2009. We had ten people in attendance, with two new members. We chose dates for the remainder of the year and discussed speakers. On October 24th, the speaker will be Dezra Brown from Athena Diagnostics. On January 23, 2010, we will have Dr. Jeff Miller, a physical therapist from Oviedo, FL.

We also discussed the cook book, the possible bike ride going through the area, and the braces that the members are currently using. Our speaker, Dr. Raynor, a podiatrist in Inverness, explained how CMT is diagnosed and how it affects different people.

Florida – Tampa
The next support group meeting will be on Saturday, September 12, 2009, at St. Anthony’s Hospital from 10:30 am to 12:30 pm. The meeting will include a discussion about future plans for the group as well as a speaker, Oscar Hernandez, an acupuncture physician at Lumina Health Center. For more information, contact interim leader, Vicki Pollyea at 813-251-5512 or v_pollyea@mindspring.com.

Georgia – Atlanta Area
The August 15th meeting featured Lynn Deal, a certified Pilates instructor. She presented “Pilates at home, a CMT patient’s guide to building core strength.” The next meeting is scheduled for October 17, 2009, with featured speaker, Pat Livney, CMTA Board Chairperson. He will speak about updates from the CMTA and the STAR initiative.

Illinois – Chicago
The next meeting of the group will be August 15th at 11 am in the Oak Lawn Public Library in meeting room C on the lower level. The speaker will be Marijo Pesavento, physical therapist and pediatric clinical specialist from Advocate Hope Christ Hospital. For more information, contact Dale Lopez, 708-499-6274 or email tyraylow1@comcast.net

Minnesota – Minneapolis
The group met on August 1, 2009, at the Ridgedale Library and heard from Dr. Gareth Parry, neurologist from the University of Minnesota. The next meeting after that will be November 7, 2009, and will feature M. Margolis, who is a physical and occupational therapist.

Mississippi/Louisiana
The group has had meetings in March, with a speaker from the MDA, in June, where the STAR DVD was shown and a discussion was held. The next meeting is on September 5th, with scheduled speaker Dr. Alan Freeland, a hand specialist from the University Medical Center, Jackson, MS.

New Hampshire/Vermont
The New Hampshire/Vermont support group had its second meeting on Saturday, June 27, 2009, at the Dartmouth-

(continued on page 14)

Margaret Healey and Elizabeth Ouellette at the meeting of the New Hampshire-Vermont support group in June.

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—Los Angeles
Place: Fred Hesse, Jr. Community Park, Fireside Room
Meeting: Quarterly
Contact: Ryan Conlan, 310-541-8114

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

California—Santa Barbara
Place: TBA
Meeting: Quarterly
Contact: Gretchen Glick, 805-693-9511 (between 3-5 pm, PDT)
Email: gfijig@yahoo.com

Colorado—Westminster
Place: Capabilities, Westminster, CO
Meeting: 10 AM – noon, Last Saturday of every other month
Contact: Diane Covington, 303-635-0229
Email: dmcovington@msn.com

Florida—Iverness Area
Place: Citrus Memorial Hospital - Historical School Bldg
Meeting: Quarterly
Contact: Ronnie Plageman, 352-860-1578
Email: cmtasg_ivernessfl@charcot-marie-tooth.org

Florida—Orlando Area
Place: Ability Rehabilitation, Oviedo, FL
Meeting: Call for schedule
Contact: Jeff Miller, 407-579-1005
Email: jeffmillerDPTMOT@gmail.com

Florida—Tampa Bay Area
Place: St. Anthony's Hospital, St. Petersburg, FL
Meeting: Second Saturday of Feb., May, Sept., Nov.
Contact: Vicki Pollyea, Interim Leader
Email: v_pollyea@mindspring.com

Georgia—Atlanta Area
Place: Cliff Valley School Library
2426 Clairmont Rd, NE
Meeting: 3rd Saturday, every other month
Contact: Sue Ruediger, 678-595-2817
Email: susruediger@comcast.net

Illinois—Chicago Area
Place: Peace Lutheran Church, Lombard, IL
Meeting: Quarterly
Contact: Alan Pappalardo, 800-606-2682, ext. 106
Email: alan@charcot-marie-tooth.org

Kentucky—Burlington
Place: Boone County Public Library, Main Library
Meeting: Quarterly
Contact: Pam Utz, 859-817-9338
Email: pamutz@insightbb.com

Massachusetts—Boston Area
Place: Beth Israel Deaconess Med. Center
Meeting: Bi-monthly
Contact: Mark Boxshus, 781-925-4254
Email: MarkB_CMTANE@mac.com

Michigan—Ann Arbor
Place: Great Lakes Regional Training Center
Meeting: Monthly
Contact: Tammy Mayher, 734-216-1347
Email: a2.cmtagroup@yahoo.com

Minnesota—Benson
Contact: Rosemary Mills, calls only 320-567-2156
Email: rrmills@fedtel.net

Minnesota—Twin Cities
Place: Call for location
Meeting: Quarterly
Contact: Bill Miller, 763-560-6654
Email: wmiller758@msn.com

Mississippi/Louisiana
Place: Baptist Healthplex,
102 Clinton Parkway,
Clinton, MS
Meeting: Quarterly
Contact: Flora Jones, 601-825-2258
Email: jonesflora4@gmail.com

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

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

Nevada—Las Vegas
Place: West Charleston Library,
6301 West Charleston Blvd.
Meeting: Email for dates 1-3 PM
Contact: Mary Fatzinger
Email: cmt_suppgroup_lvnv@yahoo.com

New Hampshire/Vermont
Place: Dartmouth-Hitchcock Medical Center, Auditorium A
Meeting: Bi-monthly
Contact: Margaret Healey, 802-535-2797
Email: margaret_ healey@hotmail.com

New Jersey—Mountainside
Place: Children's Specialized Hospital, Auditorium A
Meeting: Quarterly
Contact: Rachel Beron, 973-316-0058
Nicole Fulmino, 908-421-3595
Email: cmtasg_mountainsidenj@charcot-marie-tooth.org

New York—Greater New York
Place: NYU Medical Center/
Rusk Institute, 400 E. 34th St.
Meeting: Second Saturday, 12:30-2:30 PM
Contact: Dr. David Younger,
212-535-4314
Fax 212-535-6392
Website: www.cmtnyc.org
Email: david.younger@nyumc.org

New York—Horseheads
Place: Horseheads Free Library on Main Street, Horseheads, NY
Meeting: Quarterly
Contact: Angela Piersimoni, 607-562-8823
Email: amtcp36@aol.com

New York (Westchester County)/ Connecticut (Fairfield)
Place: Blythedale Children's Hospital
Meeting: Bimonthly, Jan, March, May, Sept, and Nov; 3rd Saturday
Contacts: Beverly Wurzel, 201-224-5795
Eileen Spell, 732-245-0771
Email: craneomatic@verizon.net
espell@optonline.net

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)
Place: Raleigh, NC
Meeting: Quarterly
Contact: Susan Salzberg, 919-967-3118 (afternoons)
Email: nabosmom@gmail.com

Ohio—Greenville
Place: Brethren Retirement Community
Meeting: 4th Thurs. of April, July, Oct.
Contact: Dot Cain, 937-548-3963
Email: Greenville-Ohio-CMT@woh.rr.com

Oregon—Portland
Place: Midland Library,
805 SE 122nd, Portland
Meeting: Quarterly
Contact: Debbie Hagen, 503-333-7936
Email: hagen84@yahoo.com

Pennsylvania—Johnstown Area
Place: John P. Murtha Neuroscience Center
Meeting: Bimonthly
Contacts: J. D. Griffith, 814-539-2341
Jeana Sweeney, 814-262-8467
Email: jdgriffith@atlanticbb.net, cjsween@verizon.net

Pennsylvania—Northwestern Area
Place: Blasco Memorial Library
Meeting: Call for information
Contact: Joyce Steinkamp, 814-833-8495
Email: joyceanns@roadrunner.com

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

Pennsylvania—Philadelphia Area
Place: CMTA Office,
2700 Chestnut Pkwy.,
Chester, PA
Meeting: Bi-monthly
Contact: Dana Schwertfeger, 800-606-2682
Email: dana@charcot-marie-tooth.org

Tennessee—Savannah
Place: East End Sports Complex
Meeting: Bi-monthly
Contact: Reagan McGee, 731-925-6204
Email: janesgang@bellsouth.net

Texas – Dallas
Place: Fieldwork Dallas
Meeting: Bi-monthly
Contact: Whitney Kreps, 971-989-5743
Email: WhitneyKreps@gmail.com

Virginia—Harrisonburg
Place: Sunnyside Retirement Community, Sunnyside Room
Meeting: Bi-monthly, Second Sat. 1-3
Contact: Anne Long, 540-568-8328

Virginia—Williamsburg
Place: Williamsburg Library, Room C
Meeting: TBA
Contact: Jennie Overstreet, 757-221-3245
Nancy Mollner, 757-220-3578
Email: jlover@wm.edu
holymoley2@cox.net

Washington—Seattle
Place: U of Washington Medical Center, Plaza Café—Conference Room C
Meeting: Monthly, Last Saturday, 1-3 PM
Contact: Ruth Oskolkoff, 206-598-2765 work
Email: rosk@u.washington.edu

Washington—Tacoma Area
Place: Moore Library
Meeting: Quarterly
Contact: Carol Hadle, 253-476-2345
Email: cmtasg_tacoma@charcot-marie-tooth.org

SUPPORT GROUP NEWS

(continued from page 12)

Hitchcock Medical Center in Lebanon, NH. Elizabeth Ouellette, CMTA Board member, accompanied by her son, Yohan, was our guest speaker. We went around the room and introduced ourselves and mentioned what we wanted Elizabeth to speak about. Topics included CMT symptoms, pain medication, coping strategies, and braces. Elizabeth explained what the CMTA is doing in the field of research. There were lots of questions about the STAR (Strategy to Accelerate Research) program. Elizabeth encouraged us to get the word out about CMTA and talked about the Jamba Juice fundraising that she does. Our group is going to approach Ben and Jerrry's about doing a fundraiser at their store in Waterbury.

New Jersey – Mountainside

Our meeting was held on Sunday May 17th at Children's Specialized Hospital in Mountainside, NJ. We had approximately 35-40 attendees. As it was our first meeting, after going around the room and introducing ourselves, we talked about each of our issues dealing with CMT, what we were looking for from a support group, and ideas/suggestions for what everybody would like for future meetings.

After that, Lauren Bakuna, PT, spoke to the group. It was very informative, as Lauren discussed the different stretches and exercises that she does with Julia (the Beron's daughter). Lauren took questions after that. Some of the ideas for future meetings included Dr. Martin Diamond (a physiatrist at Children's Specialized), or one of the doctors on the CMTA's Medical Advisory Board. Our next meeting is preliminarily scheduled for mid-September

Pennsylvania – Johnstown

The group met on June 20, 2009, to enjoy a class on water aerobics and waking walking. The meeting was held at the YMCA where attendees could choose to actually get in the water (the recommended choice) or simply listen to the benefits as they were described and demonstrated. Documented benefits of water aerobics are to manage weight, to strengthen and firm muscles, to reduce and eliminate pain, and to combat problems such as high blood pressure, diabetes, high cholesterol, etc.

Pennsylvania – Pittsburgh

The last meeting was on June 20th with 25 people in attendance. The guest speaker was Michael DeGregorio from Phoenix Rehabilitation. He gave a talk on both the necessity and the benefits of physical therapy in helping to alleviate pain. He also talked about the new technologies and materials used in bracing. Another guest discussed home health care providers and the ways to obtain funding for this care.

Texas – Dallas

The first Dallas area support group meeting was held on June 20th. We had CMT patients from 24 months old to 80 years old. We had over 30 people in attendance with a large number of people responding that they were unable to attend this meeting but would in the future. We intend to meet every two months and hope to have Dr. Gil Wolfe, head of neurology at UT Southwestern, as our next speaker.

Members of the Johnstown Support Group enjoy the benefits of pool time.

Virginia – Williamsburg Area

A new group is forming in this area and will hold its first meeting on September 19, 2009 from 2:30-4:30 pm. The group will meet in Room C of the Williamsburg Library, 515 Scotland St. Williamsburg, VA 23185. The co-leaders are Nancy Mollner and Jennie Overstreet. The meeting will be a "meet and greet" and will be a discussion of meeting times, topics to be discussed, and involvement in the planned bike ride from Florida to Boston.

Washington – Tacoma Area

The next support group meeting is scheduled for August 15th, at 3 pm in the Moore Library. The presenter will be Bryan Roehr, LCPO, from Hanger Prosthetics and Orthotics. He is going to share how braces are made from beginning to end, the different types of braces for people with CMT, and all the pros and cons of wearing braces. ✻

WRITE TO US!

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

David Hall, CEO
dave@charcot-marie-tooth.org

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

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.

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

ALSO AVAILABLE:

Circle of Friends T-Shirts

Be a STAR Wristbands

MEMBERSHIP APPLICATION/PUBLICATIONS ORDER FORM

NAME: ______________________/________/ ______________________________
First MI Last

ADDRESS: ____

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COUNTRY/POSTAL CODE (IF NOT US): ______________________________

DAYTIME PHONE: ______________________ EVENING PHONE: ______________________

EMAIL: ______________________ USER NAME: ______________________
Required for PDF Newsletter/Website Access *Required for Website Access*

Note: If you are joining now, you may purchase publications at active member prices.	QTY	COST	TOTAL
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	
CMT Facts I ☐ English ☐ Spanish		**active members $3** nonmembers $5	
CMT Facts II ☐ English ☐ Spanish		**active members $5** nonmembers $7	
CMT Facts III		**active members $5** nonmembers $7	
CMT Facts IV		**active members $8** nonmembers $10	
CMT Facts V		**active members $12** nonmembers $15	
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.

THE CMTA Report

CMTA

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www.charcot-marie-tooth.org

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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.