

THE CMTA Report

MAY/JUNE
2013

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ www.cmtausa.org

Family Planning for CMT

The Second Article in a Series

BY SHAWNA FEELY, MS, CGC, AND CARLY SISKIND, MS, LCGC

In the last newsletter we presented options that people with CMT have to become biological parents without passing CMT on to their children. These options, such as prenatal testing or preimplantation genetic diagnosis (PGD), can be a good choice for some, but they are not for everyone. Some people considering family planning may not be able to utilize these options because their genetic cause for the type of CMT is unknown. Others may find some of these options cost prohibitive or they may have concerns about ethical issues raised with these choices. For



these individuals, having alternative options for family planning is necessary and is more important than having children that are related genetically. In these situations, options such as adoption or using donors can be the means to start their own family.

ADOPTION

Traditional infant or child adoption has been a long-standing option for many people search-

ing for an alternative way to build a family. There are many different types of adoption, which differ based on where the child is from (domestic or international), how the child is found (using an agency or through a private source), and whether or not there would be a continued relationship of some kind with the biological parents (open or closed adoption). It is important

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Special Education Services for Physically Disabled Students

BY PHYLLIS SANDERS, CMTA BOARD MEMBER

Physically disabled students who enroll in public schools have many services available to them. The special education laws in the United States ensure that the appropriate accommodations will be made for students with physical challenges that impair their ability.

There are specific special education services available to students with physical disabilities. Our laws protect the rights of special education students in the classroom and ensure that

they are provided a quality education despite physical disabilities. The Individuals with Disabilities Education Act of 1975 (IDEA) ensures that all children are offered a free education through their local public schools. There are several categories of physical impairments that are defined under the special education law, and each provides certain accommodations that should be made for students with disabilities in the public school setting. Depend-

ing on the severity of their disabilities, children are eligible for an extensive range of services.

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OUR MISSION:

To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT and, ultimately, to find a cure.

OUR VISION:

A world without CMT.

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Physical Therapy Exercises for Moderate CMT

BY FRANCISCO FERNANDEZ WITH DR. RICK RAPHAEL

I suffer from moderate, slowly progressive peripheral neuropathy (PN) that my doctors believe has a genetic cause (i.e., CMT). My PN affects my legs below the knee and my hands, and it is most visually apparent in my lower leg muscles, which are quite atrophied. I generally cannot stand in place without assistance, and I have an unusual gait and drop foot on both sides. However, I'm mobile and regularly work out with a trainer three times a week to stay in shape. I can perform most exercises in a gym, in particular those that do not require difficult balancing.

Three years ago I noticed that my PN was getting worse. Upon returning from a business trip, I realized for the first time that I could not turn my left foot outward. It was a pretty scary time for me. Since there is no medical treatment for my PN, I started working with my trainer to develop exercises for my lower leg muscles to attempt to get them working again. Together, we developed some basic exercises that did help. After a month of utilizing these exercises, I could turn my left foot again without assistance and even against mild resistance.

Two years later, my trainer moved out of town, and I decided to upgrade my rehabilitation efforts to a physical therapist. Eventually I found Dr. Rick Rafael of SportsFit Physical Therapy of Santa Monica, California. Rick was familiar with CMT, but he did not have prior

experience working with a CMT patient. I explained to Rick my experience of working with my trainer and my view that targeted exercise could help my PN. At first Rick was somewhat skeptical and suggested that I obtain a pair of AFOs. But after a few weeks of working together, Rick could clearly see that the strength and muscle mass in my lower legs was improving. Through trial and error, Rick and I developed a much more expansive regime of rehabilitation exercises and treatments for my PN than those that I had been doing with my former trainer.

In this article, I will share with you all of the exercises that Rick and I developed together. Some of these may not be appropriate for patients with more severe forms of CMT. So, if you decide to try these exercises, I suggest that you work with a licensed physical therapist under close supervision. Also, note that some of the treatments described below (such as muscle stimulation and laser therapy) need to be administered under the supervision of a licensed physical therapist or doctor.

Please keep in mind that these exercises and treatments have helped me, but they may not be effective for all CMT patients. Further, I have no scientific proof that the muscle stimulation and laser therapy described below is effective to treat CMT. I can only say that my functionality has improved from performing the entire regime described below on a reg-

ular basis (twice a week for an hour). Lastly, don't expect miracles. My functionality is perhaps 10–20 percent improved from these exercises and treatments, and I am able to maintain the functionality that I currently have. But I don't expect that this regime will ever put me (or any other CMT patient) back to the functionality of a person who does not have CMT.

1. Resistance Training

While lying flat or seated on a gym mat, your therapist should provide resistance with his or her hand against your foot while you turn your foot in each direction—up, down, left and right. Generally, I do 10–15 reps in each direction and then switch legs. I've found that the best place for your therapist to push against your foot is around the ball of the foot.



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SPECIAL EDUCATION

(continued from page 1)

Children with CMT may be considered orthopedically impaired and entitled under IDEA to receive an Individualized Education Program (IEP) which includes support and orthopedic therapies.

The IDEA specifically states that children with disabilities have the right to a free public education that is offered in the “least restrictive environment.” The Act requires an Individualized Education Program which outlines the specific educational and physical needs that must be met and the support and services to be provided to the student. Through the IEP process, the special education coordinator, teachers, parents and possibly related service providers will meet as a team and decide which services are necessary to provide the best learning environment for the physically challenged student.

Physical therapy and occupational therapy are available to students with physical disabilities in the public school system. Physical therapy focuses on gross motor skills that involve the larger muscles in the body. A disabled child can improve strength, movement, endurance and muscle tone through exercises that are performed with a therapist’s help. School physical therapy treatment helps a student in traveling throughout the school environment, participating in classroom activities, moving around in the classroom as well as managing stairs, restrooms and the cafeteria. Physical therapy also helps with

improving wheelchair mobility. A special needs student may treat with the physical therapist once or twice a week, or, depending on the child’s individual need, the physical therapist can make suggestions to the classroom teacher and/or parents to implement. The degree of involvement will depend on the child’s IEP.

Occupational therapy plays a role in helping students engage in activities of daily living, such as work, play, and social participation in the school setting. When students need assistance with self-help skills such as washing hands, managing clothes for toileting, and tying shoes, a referral for occupational therapy is made. Students with physical disabilities also qualify for occupational therapy services when they have delays with fine motor skills such as cutting with scissors, typing and handwriting. The occupational therapist sometimes works directly with students once or twice a week or may consult with the teachers and parents to make recommendations. The degree of involvement depends on the severity of the disabilities and the IEP Plan.

There are other types of accommodations that can be made for physically disabled children who attend public school. Children who use a wheelchair or who walk with the assistance of crutches, braces or a walker should be given access to a school elevator in a multi-level building. Appropriate accommodations would also ensure that these students have the necessary amount of physical space to maneuver about in a

classroom setting. An aide may be assigned to a severely disabled student to accompany the student throughout the school day.

Remember that if your child has been identified by the public school system as physically impaired, he or she is entitled to be evaluated for one or more of the above-mentioned services and possibly other services as well. If you believe your child meets the criteria to be identified by the public school system as physically disabled, contact your school to begin the identification process. Your child will flourish when given the extra help to which he or she is entitled. ★

PROGRESS ON THE WARFIELD CHALLENGE

The thermometer on the CMTA website showing the donations to the Warfield Family Challenge keeps getting hotter and hotter! By the first of May, the donations stood at more than \$103,000 with time shortening for the chance to be doubled before June 30. This just shows how anyone who knows someone living daily with CMT wants there to be “A World Without CMT!” Remember that the Warfield Family Challenge will match all gifts up to a total of \$150,000. Give, give, give and the Warfields will match, match, match. Thank you, everyone!

Will your employer match your donation to the CMTA?

It’s easy now to find out. Simply visit www.doublethedonation.com/cmta.php and type in your company name. If your company is listed, you can fill out the forms and submit them right online.

If your employer is not listed, ask your HR department if your company has a matching program or would be willing to consider one. You can then “Add Your Employer” (on the page following the search page).

Every gift we receive is significant in funding our fight to find treatments for CMT; doubling your gift means we can move even faster in our efforts to find those treatments.



TELL YOUR STORY

For the third and final part in our series about reproductive options and CMT, we are asking for stories from people who have used CMT as the central part of their family planning decisions. If you knew about your CMT before beginning a pregnancy and decided to use PGD, prenatal diagnosis, adoption, or a donor, or if you decided to have children without any of these interventions, we would like to hear your story. We will choose the most representative stories to publish in the next newsletter, or we will use pieces of several submissions to tell a representative story. Please email your story to familyplanning@cmtausa.org by June 20, 2013.

REPRODUCTIVE OPTIONS

(continued from page 1)

for a family considering adoption to do the research and identify all of the pros and cons for each of these choices.

It is also important to know that things like the age of the child, location, and source can all impact the overall costs and fees that are associated with the adoption process. Although there are grants and sliding scales that are available depending on the type of adoption, the overall cost associated with this process can quickly add up when including fees, legal representation, travel costs, etc., resulting in expenditures that often range from \$10,000 to \$40,000. There are a lot of agency websites that can be found online, but the best place to start research on the adoption process is through national organizations such as the National Adoption Center (www.adopt.org) or AdoptUSKids (www.adoptuskids.org [adopting foster children]).

Embryo adoption is a relatively new method of adoption in which the adopting parents get to be involved from the start of pregnancy. With embryo adoption, couples who have created embryos using in-vitro fertilization (IVF) donate embryos to the adopting parents. The embryo is then implanted in the uterus of the adoptive mother in the hope that she will become pregnant and ultimately give birth. Because the embryos are donated from couples who no

longer wish to use them, the cost of embryo adoption can be much lower than alternatives, such as using egg donation, in which the donor woman typically gets paid (see below). However, there are still costs associated with the transfer of the embryo to the adopting mother and agency fees.

Depending on state and agency regulations, people considering embryo adoption may still have to go through a homestudy, just like traditional adoptive parents do, which can

The overall cost associated with the adoption process can quickly add up.

also add fees to the process. A homestudy is the process of assessing a family's suitability to adopt a child or embryo by ensuring that the

child's needs would be met by that family and that they are prepared for the adoption process. With homestudy fees and procedure fees, the average cost for embryo adoption is \$10,000 to \$15,000, and this does not ensure a successful pregnancy. As with all of these options, it is important to do thorough research and weigh all the pros and cons. A good place to start is the Embryo Adoption Awareness Center (www.embryoadoption.org).

USING A DONOR

For men who have CMT and are considering family planning options, using donor sperm is an option. There are a variety of ways to both obtain donor sperm and to use it for insemination. The most common process is to start with a reputable sperm bank that allows

couples to review the histories of possible sperm donors and make selections based on characteristics such as physical descriptions, ethnicity, age, career, education, personal interests, and personality traits. Typically, sperm banks are helpful and safe to use as they will run routine screening for things like STDs and genetic conditions that are common in the population. Reputable sperm banks will also monitor how many people use a particular donor within a certain population, and they may even keep track of successful pregnancies to ensure that the donated sperm is successful in yielding a pregnancy as well as identifying possible genetic conditions.

Some people opt for using private donors, like family members or close friends. These are not necessarily screened as thoroughly as sperm bank donations, but they allow for a closer relationship with the donor, or, if a family member is used, a genetic relationship within the family will be maintained. In general, the process of using sperm donation and insemination can cost up to \$1,000, depending on a variety of factors including where the sperm is obtained and whether the insemination process is achieved at home or in a doctor's office with assistance.

For women who have CMT and are considering family planning options, using egg donation is a possibility. Similar to sperm banks, there are facilities that can help link willing donors to couples, and donor selections can be made based on characteristics such as physical descriptions, ethnicity, age, career, education, personal inter-

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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, P.O. Box 105, Glenolden, PA 19036.

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Address: _____



PT EXERCISES

(continued from page 2)

2. Balance Board

A balance board can be used in two directions—forward and back and side to side. Try two sets of 60–90 seconds in each direction. The goal is to maintain your balance with as little movement as possible. Your therapist can help you to balance if you cannot initially balance on your own.



3. Bosu Ball Squats

Standing on an upside down Bosu ball, do squats for 10–15 reps, two to three sets. Again, your therapist should help you to balance, at least initially.



4. Step-Ups

This requires little explanation. Step up one leg at a time for 10–15 reps and then repeat with the other leg. Do two sets for each leg. Try to hold your balance after each rep.



5. Stability Disc

Stand with one foot on a stability disc and perform 10–15 heel raises per leg. You're probably going to need to balance yourself against a wall, or your therapist can help you to balance. Do two to three sets on each leg.



6. Seated Heel Raises

While seated on a bench with your foot resting on a small platform 2–3 inches off the ground, place a dumbbell (I use 12.5 lbs) on your knee and do 10–15 reps per leg. Do three sets on each leg. When I first started doing these exercises, I put a towel under my foot to make sure that I was actually using my calf muscle and not my hip flexors to move my leg. After months of training, I no longer need to use the towel.



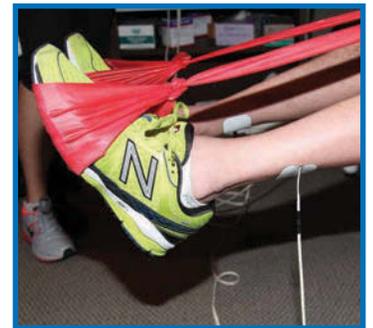
7. Leg Press Heel Raises

Use a leg press (hip sled) machine to do three sets of 20–40 reps of heel raises with both feet. I use a very light weight (20 lbs) and try to concentrate on pushing with my calf muscles rather than cheating and using my upper legs.



8. Neuromuscular Electrical Stimulation (NMES)

NMES can be used to help activate targeted muscle groups where the patient has difficulty activating the muscles on his or her own. The NMES causes the targeted muscles to contract, which improves strength and helps the patient learn to use muscles that the body has forgotten. I use NMES to target two muscle groups: (i) the calf muscles (gastrocnemius, soleus, and posterior tibialis) and (ii) the anterior tibialis. The NMES machine is set by my therapist to cause contraction in



one leg for 10 seconds and then switch to the other leg while the first leg is resting. In each case, I actively try to recruit the muscles that are being stimulated. For example, when stimulating the calf muscles, I use a set of Therabands to perform a plantarflexion exercise against resistance. When stimulating the anterior tibialis, I perform a dorsiflexion exercise by lifting up my feet and toes. (Your therapist can also provide resistance with his or her hand while performing this exercise.)

9. Laser Therapy

Infrared laser has been shown to promote circulation. This technology improves blood flow to the targeted regions and therefore improves oxygenation and nutrient delivery, enhances recovery and facilitates improved healing. My therapist will use the infrared for about 2–3 minutes per leg during each session.



10. Massage

Similar to the laser therapy treatments, the goal of massage is to get some blood flowing in these atrophied muscles. My therapist will massage both lower legs at the same time for about 5–10 minutes.



The information in this article is provided for educational purposes only. The CMTA neither endorses nor recommends any of the above exercises or treatments. Always consult with your physician before beginning any exercise program or treatment regime.

Social Services to the Rescue!

When I was growing up, I often wondered why I could not do things as well as the other kids. Then, after years of sprained ankles and pain in my feet, legs and hands, I was diagnosed with CMT.

Finally, everything made sense. Not that I was excited about inheriting a neuromuscular disease, but it helped just to know that all the problems I had encountered throughout my life were not in my head, like most doctors kept telling me.

At the time of the diagnosis, which took several years of going from doctor to doctor, I needed to use a walker to maintain my balance when standing. Five years after that, a power chair was needed. All the while I was trying very hard to continue working and not let this horrible disease beat me.

This is what leads me to this article. I am hoping that the following information will help just one person, if not many.

By the time a power chair was needed, I was faced with giving up and applying for disability or finding a solution and continuing to work. I was determined to do the latter, so my search began. We all know that you have to have a way to transport the power chair and a way to get the chair in and out of your home to even go to work, which creates the high cost of modifications.

On one of my visits to the neurologist, a nurse mentioned that I should give the Social Services Department a call. She said they do provide help to a lot of

people who are working or in school to maintain their status by providing them with a wheelchair or powerchair, as well as van and home modifications.

My search had ended. I found not only what I needed to keep me working, but to make my life a little easier in functioning with this disease. I not only received all three services above, but also a bathtub lift for easy access in and out of the tub and multiple gadgets that help me around the house because of my having weak hands.

In the last few months I had a friend, who also has CMT, contact the Social Services Department. He called me the other day after the appointment with great news. He is a 56-year-old man and now will enroll in business school because Social Services will pay for it. That was something he wanted to do but just couldn't afford. Now, he can go.

I urge anyone with a disability who is in school and needs assistance or wants to go to school, or someone who is working or wants to go to work, to contact their state's Social Services Department (Rehabilitation Services section) for more information.

It has been 15 years since my diagnosis. Not only did I continue to work, but I made it to retirement four months ago after working for the Department of Revenue for 33 years. It has been a struggle and continues to be, but hopefully there is still a lot of fight left in me.

—Suzanne Turner



David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at info@cmtausa.org.

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

I have a 3-year-old son, and my CMT (1A) has gotten a lot worse since he was born. I don't know how to physically manage the responsibilities of parenthood anymore, and I'm honestly scared of what's to come, and I need some tips and strategies that have worked for others in the same boat. For example, when my son gets mad and runs off, I am incapable of running after him—even if he's running toward a busy road. It's terrifying when he does that. As a less dramatic but more frequent example, I can only hold him in my right arm (because my left side is too weak), which can be pretty tiring. "Healthy" parents can switch their kid from one side to the other to prevent fatigue, but I'm right-handed, so I have to put him down if I need to use my right hand. I don't have time to feel like a bad mother because, while I'm in my pity party, he still needs me to show up for him in a very

real and responsible way. I need help to do that. How do you creatively keep your kid(s) safe and feeling loved despite your physical limitations?

David answers:

Thanks for reaching out and asking a question that many parents can relate to. Let me just say that no week goes by when a mom who is perfectly able bodied fails to express her insecurity about being a good parent. That fear seems to be universal, especially in today's world where there is so much pressure to be perfect. Ease up a little on yourself because I can tell from your letter that you love your child dearly and want the best for him. That desire for him to thrive is something that I am sure he can feel, which will nourish him in ways you cannot even imagine.

Your physical limitations will not deprive him of what is most important for him: to feel safe and cared for. I might be

stating the obvious, but here in NYC I see parents using child harnesses to keep their kids from getting too far ahead of them. I know that sometimes kids are just spontaneous and one never can tell when they're going to run. Don't be shy about asking for help when you can. Being honest with another parent about your need for a little assistance is perfectly okay.

It might also be a good idea to ask a competent occupational therapist about the best way to conserve energy when using your muscles to hold your child. As you become more accepting of your limitations and imperfections, your child will grow up with a more relaxed mom who loves her child with everything he's got. He will feel safe in that love and comfortable in exploring the world. Knowing that limitations eventually can be a strength and not a weakness helps us grow in other ways and can be a great lesson for any child. ★

REPRODUCTIVE OPTIONS

(continued from page 4)

ests, and personality traits. The woman who is providing the egg, however, goes through a more complex process than men go through to donate sperm. To donate eggs, women must have a series of hormone injections in order to produce more than one egg at a time, and outpatient surgery is required in order to harvest the eggs. Because this process is more involved and more invasive than sperm dona-

tion, the financial compensation is higher, costing from \$15,000 to \$50,000. As with sperm donation, it is possible to use a friend or family member as the egg donor.

It is important to remember to research the pros and cons thoroughly before making any decision in order to select an option that is right for you and your family. A genetic counselor in your area may be able to help you get started or guide you through the process

(www.nsgc.org [Find a Genetic Counselor]).

Whether it is through prenatal testing, PGD, adoption, using donors, or the old fashioned way, having children and building a family is every person's right, and no one should tell you not to have children just because you or your partner have CMT. We hope these options have provided possibilities to families who would like to have children, but who do not want to pass on CMT. ★

New Therapeutic Targets for CMT1B

BY LAWRENCE WRABETZ, MD, HUNTER JAMES KELLY RESEARCH INSTITUTE,
UNIVERSITY OF BUFFALO SCHOOL OF MEDICINE

An article has just been published in the April 1, 2013 issue of *Journal of Experimental Medicine* that describes a potential treatment strategy for CMT1B neuropathy. CMT1B neuropathies are associated with mutations in the Myelin Protein Zero (P0) gene. Myelin is the insulation around the wires, called axons, in our nerves. It helps nerves to conduct electrical impulses normally. Myelin is also what is damaged first in many CMT neuropathies, even if later there is secondary damage to the wires (axons) that actually causes the disabilities in patients. So, it is important to try to treat the myelin problem early.

P0 is the most abundant protein in myelin in the peripheral nerves. P0 is very sticky and glues the wraps of myelin together. This increases myelin's electrical insulating properties and also helps to keep it from breaking to pieces.

Although some CMT1B mutations interfere directly with the 'stickiness' of P0, most actually turn P0 into a kind of poison for the Schwann cell—the cell that makes myelin in nerves. For example, all proteins need to be folded into the proper shape in order to do their work. When a protein is misfolded or unfolded, it can poison a cell. Several mutations in P0 associated with CMT1B lead to misfolding and a big headache for the Schwann cells. Most times, the misfolded P0 gets

stuck inside the cell and never even arrives to myelin. Worse yet, this creates a problem of garbage disposal for the Schwann cell—how to get rid of the misfolded P0 protein.

I am a member of the CMTA Board of Directors, and I work at the Hunter James Kelly Research Institute (HJKRI) at the University at Buffalo. Several years ago, my laboratory found a CMT1B mutation in P0—called P0S63del—that causes this kind of misfolding. We had previously characterized the P0S63del protein in a mouse model into which we introduced the authentic human mutation that causes this form of CMT1B. In this S63del mouse, we showed that the misfolded P0S63del protein never arrives to myelin, but remains stuck in the inner part of the Schwann cell where it causes toxicity. The big surprise was that the toxicity did not kill the Schwann cell, but caused myelin to break down.

More recently, this work has been expanded, beginning at San Raffaele Scientific Institute in Milan, Italy, where I worked until 2011, and then later at HJKRI in Buffalo, and supported by grants from the National Institutes of Health, Telethon Italy, and the European Community. One of my research associates, Maurizio D'Antonio, has now found high levels of a protein called Gadd34 that is increased in cells by mis-

folded proteins. When we eliminated Gadd34 from the Schwann cells in S63del CMT1B mice or the same mice treated with a research drug that inhibits Gadd34, we were surprised to find much less myelin damage and, as a result, improved nerve conduction and muscle function.

This finding is intriguing as misfolded proteins are associated with a myriad of diseases including Alzheimer's and Parkinson's, Multiple Sclerosis, diabetes and cancer. In addition, another member of the CMTA Board of Directors, Dr. Michael Shy at the University of Iowa, has recently published on another CMT1B mutation in P0, R98C, that also causes misfolding. Finally, other disease genes associated with CMT1, such as PMP22, also have mutations that cause protein misfolding.

Although the research drug that we used in this study is not safe for use in patients, we are collaborating with chemists to develop related medicines that we hope will block the effects of Gadd34 and reduce the toxicity of misfolded proteins. More work is already underway to understand how many of the more than 120 known CMT1B mutations cause misfolding of P0, and to test these new medicines in preclinical trials with mouse models like S63del. We hope this could eventually pave the way for clinical trials in patients. ★

CMT and Your Feet

BY HAL ORNSTEIN, DPM, FASPS, AND GREGORY STILWELL, DPM, FACFAS

The key for people with CMT is to view all foot problems as potentially dangerous, to prevent them if possible, and to seek podiatric care as soon as possible if they occur.

Neuropathy can cause numbness, burning pain, and less ability to feel pain, heat or cold. Heating pads are notorious for causing severe burns that were never felt as they were occurring. When decreased sensation is present, serious problems, such as ulcers and gangrene, can occur without pain. Infection may go unnoticed and appropriate care may be delayed until it is too late; amputation may be necessary to save the person's life. Daily observation of the feet is necessary by those with CMT or by a trusted guardian.

Deformities are very common in the ankles and feet of those with CMT because of progressive muscular weaknesses, causing imbalance of opposing muscle groups. Either surgical

realignment or bracing with orthoses can work well. Many times, simple extra-depth shoes with soft inlays provide relief. Exercise, stretching, and massage can maintain flexibility and as much strength as possible. Custom-molded braces and in-shoe orthotics are commonly used as well. Surgery has become much more common and effective when performed by a qualified foot and ankle surgeon. From straightening toes to lowering the arch and realigning the ankle joint, new techniques have greatly improved many patients' mobility and agility. To treat the tripping commonly experienced from a foot drop deformity, carbon fiber lightweight braces fit into most shoes and are easy to fit around the calf. Surgical transfer of muscles to help stabilize drop foot is an effective proce-

sure. Physical therapy is commonly prescribed to help develop a Home Exercise Program and speed up healing after surgery.

Ulcers can be caused by lack of blood circulating to the foot, lack of soft tissue protection, excessive callous tissue, infection, and pressure points caused by deformities. Some causes of

injury and ulcers are wearing ill-fitting shoes, performing "self" surgery, applying electric heating pads or hot water bottles, and using ingrown toenail and corn remedies. If the circulatory response is adequate, most ulcers can be healed

if diagnosed and treated early.

Skin changes in the foot can be caused by CMT. Dehydration is common since those with CMT can have less natural lubrication. Fissures and cracks in the skin develop, and, often, itching can become severe. Scratching can cause breaks in the skin that may become infected. Dryness can be helped by using a good skin cream daily on every part of the foot except between the toes.

Cuts, scrapes, blisters and puncture wounds can cause serious problems. To prevent such injuries, people with CMT should always wear some kind of footwear. While going barefoot, especially in sand or soft grass, is a wonderful treat, it is dangerous

(continued on page 19)



COMMON FOOT TYPES SEEN IN CMT:

Pes cavus: The most typical type, a high-arched foot with a rigid "cave" under the instep. Calluses are common on the balls of the feet. Chronic ankle sprains and foot drop are common as well. Hammer toes, claw toes and corns on the toes are typical. The muscles within the foot itself (intrinsic muscles) atrophy and cause the toes to curl up. Treatment ranges from wearing insoles to surgery.

Paralytic Flatfoot: A less common foot type, which usually requires some type of fusion in the arch to stabilize the progressive breakdown.

Foot Drop: Weakness in the muscles of the front of the calf cause foot drop; those with stronger muscles in the calf are better able to lift the front of the foot up. Bracing can be effective, and rocker bottom shoes and surgery to move stronger muscles to the top of the foot are all helpful.

IMPORTANT FOOT CARE FOR THOSE WITH CMT:

1 Be very careful walking barefoot; thoroughly inspect the toes and bottoms of your feet if you do walk barefoot, especially if you have been outside.

2 Open toes or heels on shoes are dangerous. Wear some type of water sandal to the pool or lake that will protect your feet from injury.

3 Wear shoes that allow room for your toes, yet still support your heel and arch. There should be inch (a thumb's width) between your longest toe and the end of the shoe. A rounded "toe-box" is recommended; the upper portion of the shoe should be soft and flexible. The lining should be smooth and free of ridges, wrinkles and seams.

4 Don't wear the same shoes two days in a row, and use a "shoe tree" (available at most discount stores) in the shoe to maintain that new shoe shape.

5 Break in new shoes gradually and wear them only a few hours at first to prevent blisters and sore spots. Check your feet for red areas indicating too much pressure.

6 Check inside your shoes daily for sharp edges and foreign objects.

7 Be careful soaking your feet. Many foot soaks overly dry the feet; some create too much moisture between the toes. Many fine herbal foot soaks are available that can condition skin and help with aching in the feet. Be aware of too much moisture between the toes and athlete's foot that can occur.

8 When drying your feet, remember to get in between all your toes.

9 For calloused or extra dry areas, use an oil like

coconut, jojoba, or shea butter to moisturize the area and keep it from cracking. Do not apply between toes.

10 Be aware that loose pieces of skin can be signs of something dangerous, and have a podiatrist check out what is causing the skin to peel.

11 Change your socks at least once a day, and minimize cotton and nylon in them. Look instead for wicking fibers that also provide cushioning to the soles of the feet.

12 Inspect your socks daily for stains, blood, or other drainage which would indicate an open sore that you may not realize you have because you cannot feel it.

13 Keep your toenails trimmed. If you have reduced feeling, nerve problems or circulation problems, it is recommended that you coordinate with your podiatrist's office to get a trained technician to trim your nails. This will help reduce the risk of cutting yourself, preventing a potential infection and many other problems.

14 Corns and calluses are signs of excess pressure and should be evaluated and treated by your podiatric specialist.

15 OTC/commercial brand corn and wart remedies contain harmful acids that are very dangerous for people with CMT. Please do not use them!

16 Avoid extremes, such as cold or heat, and if your feet are cold, wear warm boots. Never use hot water bottles or heating pads.

17 Be aware that the tops of some socks can act as a tourniquet around your calf or

ankle; if your legs swell, ask your podiatrist for a recommendation for a support hose. Always avoid wearing anything tight around your legs or ankles that may in any way reduce or cut off the blood supply to your feet.

18 Do not smoke! Smoking constricts the blood vessels and directly affects the blood supply to your feet.

19 Crossing your legs can decrease circulation; keep feet and legs moving!

20 Do not expose your legs to prolonged sunlight.

21 Do not apply adhesive material such as moleskin or adhesive tape to the skin of the feet without first consulting your podiatrist.

22 Most importantly, examine your feet daily, including between your toes. Using a mirror can help you to see challenging spots. If you have a difficult time seeing your feet, have a family member or friend do the inspection. If you find any sores, cuts, redness, swelling, pus, or blisters (*even if you have no pain*), make an appointment to see your podiatrist immediately.

23 It is very important for everyone, of any age, with CMT to establish a relationship with a podiatrist. There is a saying that goes "the time to fix a leaky roof is when it is sunny." In other words, do not wait to fix it when it is raining. APMA.org has a list of podiatrists in your area. Your family doctor is often familiar with good podiatric specialists in your area.

Please remember, *prevention is the best medicine!* Please share this information with your family members.

A Physician's Journey

BY DR. FRANCIS ABDOU

My journey with neuropathy began eight years ago. The first thing I noticed was my feet hurting at the end of a day. I didn't pay much attention to this. I am an anesthesiologist, and I spend most of my day on my feet walking on a hard surface. It's not unusual to walk the equivalent of 4–5 miles in a day. I told myself that it was probably normal to have pain, especially as I got older. I bought new sneakers, tried various commercial shoe inserts, and finally got a pair of orthotics. Everything worked for a short time, but the pain kept returning. It progressed and began to affect my life outside of work. I began noticing pain when standing for prolonged periods or walking on softer surfaces. Family trips and recreational activities became more difficult and required advanced planning to minimize the pain.

In retrospect, there were other, more subtle signs that accompanied the pain. Playing basketball with my son, I couldn't jump as high and my lateral movement was impaired. I had trouble running when playing softball and my golf swing began to change. Again, I attributed all this to getting older and decided I just needed to get in shape. While running on a treadmill, I noticed I was making loud noises from my feet

slapping on the treadmill. Balance became a problem when performing certain weight training exercises.

In the fall of 2009, I ruptured a disc in my lower back during a weight training routine. During my medical evaluation, my doctor noticed that my reflexes were absent on both legs. With conservative treatment, the disc healed and I started working out again. This time, I began to notice tightness in my feet. I rested, but the

I attributed all the pain and physical loss to getting older.

tightness returned every time I worked out.

In January 2010, I was making dinner and felt a strange, warm sensation going down my right leg. This was soon followed by violent shaking and numbness in both feet. I immediately called my neurosurgeon, who prescribed oral steroid medications and ordered a repeat MRI. This time the results came back normal. I had no explanation for what had happened. It was suggested that I see a neurologist.

I was evaluated near my home by two different neurologists. I had the proverbial "million dollar work-up," including many blood and urine tests and a nerve conduction and EMG study. It was then that I was diagnosed with CMT. I questioned this conclusion because there was no history of CMT in my family and no evi-

dence of the disease in my youth. The physicians were convinced of their diagnosis, so I accepted the diagnosis and made peace with my future.

It was then that I became involved with the CMTA. Over the past few years, I have had the pleasure of meeting Elizabeth Ouellette, Jeana Sweeney, Pat Livney and Herb Beron. All are incredibly warm, wonderful people dedicated to finding treatments and cures for CMT. Each of them encouraged me to visit Dr. Michael Shy to better evaluate and treat my disease. Having accepted my diagnosis, I didn't see a need to travel to Iowa since there was nothing more that could be done. My disease, however, continued to progress, and I noticed increasing weakness and fatigue. So, I made arrangements to see Dr. Shy in early February to see if he had anything to offer.

Dr. Shy and his team do a complete, day-long evaluation. In addition, Dr. Shy does a complete history and physical exam. At the conclusion of the evaluation, Dr. Shy sits down, summarizes the evaluation, and designs a treatment plan and follow-up. I was seen by a physical therapist, a genetics counselor, an orthotist, and an occupational therapist, and I had a nerve conduction study.

The result of my evaluation was quite a surprise. Dr. Shy did not agree with the CMT diagnosis I had been given. Instead, he believed I was dealing with

Chronic Inflammatory Demyelinating Polyneuropathy, or CIDP. It's an acquired immune-mediated neuropathy in which the body's immune system begins attacking the myelin covering of the peripheral nervous system. The wonderful news for me was that it's a treatable form of neuropathy. Dr. Shy prescribed a treatment course of IVIG, which I began in early March. The early results have been encouraging.

The takeaway from my experience is that it's imperative to get a correct diagnosis and treatment. As a physician, I had access to the best physicians in my area and could get their opinions anytime I wanted. No one, including me, picked up on the multiple signs of neuropathy along the way. Even after neuropathy was correctly diagnosed, the etiology was wrong. Neuropathies are very complex disease processes and require experienced and knowledgeable physicians and health care providers to provide proper diagnosis and treatment. For me, this could only be obtained by visiting a Center of Excellence. I encourage everyone given a diagnosis of neuropathy to find these centers and arrange for an evaluation.

Finally, I want to encourage everyone reading this to support the CMTA in any way they can. This organization is on the path to finding significant treatments and potential cures for this disease. Only through your support will they be able to continue the exciting progress that has been made. The CMTA changed my life and, with your support, it will change others. ★

PATIENT FAMILY CONFERENCE IN ORLANDO, FL

The CMTA is thrilled to announce a CMT Patient and Family Conference to be held on Saturday, November 9, 2013 in Lake Buena Vista, Florida! We are offering a Patient Family Conference happening at the beautiful Royal Plaza, a Downtown Disney Resort Area Hotel. The Central Florida Area has never hosted an event like this one! You can't afford to miss it!

Patrick Livney, CEO of the CMTA, will kick off our exciting program with some research news, which will be followed by

presentations from some of the prominent minds in the fields of CMT research and treatments. We are excited to present Michael Shy, MD, Richard Finkel, MD, Stephan Züchner, MD, PhD, and Sean McKale, CO, LO among our featured speakers.*

This event provides a tremendous opportunity to not only hear but to interact personally with these experts. Registration is just \$50 per person (non-refundable) and includes "Lunch with the Experts," during which you will have time to talk with the presenters and other leading CMT authorities, including Support and Action Group Facilitators and CMTA Board Members while enjoying a delicious lunch. Don't delay. Register now for this informative and interactive conference. You can do it online or you can mail a check made payable to the CMTA and designate Orlando PFC on the memo line. The deadline for registration is November 1st.

If you plan to stay at the hotel for the conference and you have registered to attend with the CMTA, call the hotel at 1-800-248-7890. Be sure to mention the CMTA Patient Family Conference to take advantage of the reduced room rate! Please have a credit card ready as you will need to guarantee your reservation at the time you make it. These special room rates are extended 3 days prior to and 3 days after the November 9th conference. (This is a 3-day weekend!) Come early, stay after and enjoy what Central Florida has to offer. (The cut-off date for booking hotel rooms at the special rate is October 5th.)

The Patient Family Conference will also feature exhibitors offering valuable information and a variety of suggestions and products to assist with mobility, alternative pain management, and exercise for people affected by CMT.

Register your family and friends now at www.cmtausa.org/url/orlando-pfc. It's a conference you don't want to miss!

**Speakers/venue/exhibitors are subject to change.*



Drive the Boat!

Everyone here is anticipating summer and all the fun activities that come with the season. I'll be attending summer camp again this year, and I was a little depressed thinking about all my friends playing softball and me slinking off to go swimming or to just play word games. I like to do all the things that my friends do, but I just can't.

I have two strikes against me. I'm a turtle, naturally slow and not very sports-oriented, and I have CMT. Together, they make almost everything except swimming a frustration. I was spending a lot of time with my head hung down and my spirits a little deflated. My friends were all encouraging me, saying I could just pinch hit or something, but it wasn't making me feel any better.

Then, one glorious morning a woman who works at the

CMTA told a story about some advice she got that seemed to hit home with me. She had always hoped to be a water skier, but despite trying very hard, she just couldn't do it on her weakened CMT ankles and legs. A well-known orthotist who works with a lot of CMT patients told her that the secret was to learn to "drive the boat." She would be with her family and friends and not miss out on a single accomplishment of her daughter and her husband. She has embraced the advice and is content with water skiing vicariously.

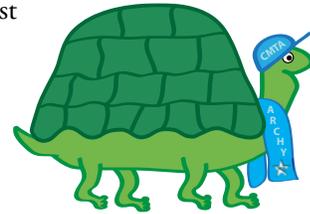
So, I decided after hearing her story that I needed to "drive the boat" with my friends and softball. I approached the coach

and asked if I could be a first-base coach or a statistic-keeper. He was very open to my working with him since he knows I follow sports very closely and would learn anything I needed

to know to do a good job. What a difference that little story has made in my life!

Now I can be with my friends no matter what activity they choose to do. I just have to figure out how

I can "drive the boat." I am looking forward the end of school and the start of summer vacation. I'm always happy that classes are almost over, as are my friends. But now, I'm really looking forward to being with my best friends all summer and being a part of the team. ★



Our mascot "Archy" writes about his experiences as a turtle with CMT.

NEW ADVISORY BOARD MEMBER: SARAH KESTY



SARAH KESTY has worked with individuals with a range of disabili-

ties for over ten years. She has a Masters in Special Education from Sacramento State and two teaching credentials. Sarah is a passionate advocate for people with disabilities. She has experience teaching kindergarten through high school-aged students and

coaching Special Olympics. She has received numerous grants, most recently to launch a mentor program and create a disability-awareness and executive functioning curriculum for middle school students.

Sarah has spoken to groups of teachers, parents, and students about disability awareness, advocacy, and maximizing life satisfaction. Her speaking has taken her all the way to Belize, where she taught a seminar on behavior management to a group of 150 teachers.

Sarah writes for several publications, including *The Special Edge*, a publication for California's special educators. She shares inspiring stories on her website (sarahkesty.com) and has recently written a book for children, available in July 2013. Sarah has CMT and can deeply empathize with both students and parents navigating the school support systems.

She is honored to help CMTA members make the best of their children's school experiences. ★

Unlocking Potential: Mark Miller

BY ELIZABETH OUELLETTE

Mark Miller, Stericycle's Executive Chairman, is no stranger to success. A computer-science graduate of Purdue University, Mark began his career as a computer programmer at Abbott Laboratories in 1976. By May of 1992, Mark had worked his way up the corporate ladder, serving as Abbott's Vice-President of the company's international operations for the Pacific, Asia and Africa and was well-positioned for a bright and glorious future. In an about-face, Mark put an abrupt end to his secure and promising executive career at Abbott by joining Stericycle, Inc., a small, struggling and unprofitable medical waste management company. Today, with Mr. Miller's leadership, vision and expertise, Stericycle has become an S&P 500 company and an extremely successful, prominent and global leader in its field.

When the CMTA's CEO Patrick Livney met Mark Miller at the Merit Golf Club in 2005, Mark had never heard of the CMTA. However, after participating in Pat's annual golf fundraiser for CMT research, Mark was impressed with the passion, energy and planning behind the CMTA's strategic research program, STAR (Strategy to Accelerate Research).

Mark's philanthropic tendencies have benefited many reputable non-profit organizations, but he admits that his, "contributions to the CMTA are greater by several orders of mag-

nitude than to other non-profit organizations." And being the visionary he is, Mark knows a sound and worthwhile investment when he sees one. To illustrate this point, Mark has donated over \$500,000 to the CMTA's STAR initiative over the past 5 years!

When considering charitable donation requests, Mark weighs "the impact of the donation, the other sources of income, and the fiscal need of the charity in question." STAR, funded uniquely by the CMTA, is focused on utilizing existing compounds to try to find applicable treatments. Mark fully understands that "the potential to change the lives of hundreds and thousands of people in a short amount of time is a rare and worthy opportunity." With his pharmaceutical background, Mark attests that "the cost of clinical trials is high, but if we get lucky and find an effective compound, we can have a huge and meaningful impact on the lives of hundreds and thousands who live daily with this progressive neuromuscular disorder."

Unfortunately, "rare disease states like CMT often get overlooked by pharmaceutical and biotech companies who are more interested in blockbuster hits that will bring in multibillion-dollar sales." But Mark is not deterred by stark realities. In fact, he could not be keener on championing our little-known disorder or more eager to unlock possibilities through underwrit-



Mark Miller has donated over \$500,000 to the CMTA's STAR initiative over the past 5 years.

ing groundbreaking clinical trials and continued drug discovery initiatives.

When I asked Mark about his success in business, he boiled it down to two key factors: "working with smart and competent people, and good luck. Good luck finds those who try hard and long enough to come to know it." In the same spirit, Mark notes that "the CMTA's STAR initiative has brought together the brightest minds in the fields of academia, business and research to work on finding treatments for CMT, a disorder that is currently incurable." With a lot of determination, effort, execution and luck, Mark intuitively knows that one day in the very near future "the CMTA will produce tangible outcomes, forever changing the lives of those with CMT on a global level."

Mark Miller, on behalf of the entire CMTA community, I thank you for your unwavering support of our vision! ★



SUPPORT AND ACTION GROUP NEWS

• CA—San Diego Area

We welcomed a new member, Jordan Thomas. Topics included the Facebook page, CMTAthletes, the possibility of Jordan becoming the new group facilitator, and the Bare Your Brace campaign.

• CA—South Bay Area

Bethany Meloche, the CMTA's Director of Social Media, served as guest speaker, sharing her "Tumbling Forward" presentation with the group. Bethany shared her limitations and the challenges she faces due to CMT, as well as how she works to overcome them and move forward. Thanks to co-facilitator, Rick Alber, for videotaping the presentation.

• CT—North Haven

The group welcomed Jeana Sweeney, the CMTA's Director of Community Services, to its meeting. Jeana gave a very thorough presentation on CMT and the latest STAR accomplishments. She was also a guest speaker at a SAG member's Rotary Club meeting earlier in the day, where she gave an overview of CMT and asked a few participants to demonstrate how something as simple as buttoning a shirt can be difficult for a person with CMT.

• DC—Washington, DC Area

Thanks to everyone who participated in our meeting. We had 20 people in attendance, who contributed to a valuable discussion about resources and tips for people living with CMT.

• FL—Naples

The group had a successful first meeting at Naples Community

Hospital. There were 17 attendees. Jeana Sweeney, the CMTA's Director of Community Services, gave a PowerPoint presentation on the research gains and resources available through the CMTA.

• IL—Chicagoland

The group held their first meeting and had 12 in attendance. Thanks to Dale Lopez for taking time to offer her support. Also, thanks to Rick Lusiak for offering his expertise on Allard's various products.

• IN—Ft. Wayne Area

Dr. Michael Shy, Chairman of the CMTA's Medical Advisory Board, served as guest speaker for the April 6th conference, "A Conversation with Dr. Shy." Fred Price, CEO of DeKalb Health, welcomed our 65 guests and introduced Dr. Shy. Dr. Shy discussed research, genetics, types of CMT, and advances in science that relate to CMT. Thanks to sponsor Ross Toenges of Fred Toenges Shoes and Pedorthics of Fort Wayne and Muncie, Indiana, and friends of co-facilitator Aimee Trammel for helping fund the event. Dr. Bob Hall, Karen Belcher, Dave and Rosetta Harth, and Lou Metelko helped in the event planning and presentation. Mary Ann Ketzenberger and Hilda Kennedy also helped register the guests.

• MD—Easton

The group met March 16th. There were 21 in attendance. Three experts served as guest speakers: Jayme Brendle of Allard USA demonstrated the various braces they make, including the Toe-Off Blue Rocker; Steve Sreb-

nick of Aetrex Shoes told the group how shoes should be fitted and what types of shoes work best with orthotics and bracing; and Magdalena DiZebba, orthotist/prosthetist, of Dankmyer, Inc., told us what to expect when taking a prescription to be fitted at the orthotist for custom inserts and various types of bracing. In addition, there was discussion about the various insurance regulations, including Medicare, for prescribed appliances. The meeting ended with a plug for the Warfield Family Challenge (*see page 3*).

• MI—Kalamazoo Area

Four members were present for an open discussion of topics including genetic testing, the diagnosis of CMT, and avoiding falls.

• NJ—Central New Jersey

The meeting was held on April 22nd. The topics included bracing, medications, general health issues, affected family members, and Aetrex shoes. Mark summarized topics from the SAG conference call. He also updated the group on the upcoming Lakewood BlueClaws event. Other topics discussed included fundraising ideas, an explanation of the Hereditary Neuropathy Foundation, and the status of the "Berns Life" film.

• NY—Long Island Area

The meeting was held on March 5th. There were eight people in attendance. Roy spoke about various types of braces available and described which would fit each individual's need. It was great to share challenges and dis-

(continued on page 18)

BREAKING NEWS IN CANADA!!!

The Southern Ontario CMT Support & Action Group is pleased to announce that it has declared September as "Charcot-Marie-Tooth Disease Awareness Month" in Canada effective April 1, 2013. We are convinced that this recognition will provide the stepping stones for establishing a network of resources, services, funding and support. We are positive this will foster awareness and help all Canadians afflicted by this disease to realize that they are not alone.

CMT Support and Action Groups in Your Community

AL—Birmingham Area

*No group currently meeting
Will accept calls*

Dice Lineberry
205-870-4755

AZ—Phoenix Area

Pamela Palmer
480-926-4145

CA—Santa Barbara Area

Steve Fox
805-627-8225

CA—Stockton

Nina Anselmo
209-460-1716

CA—South Bay Area

Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area

Laurel Richardson
814-404-8046

CA—Santa Rosa Area

Carol O'Bryan
707-823-0165

CA—Visalia Area

Melanie Pennebaker
559-972-3020

CO—Denver Area

Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—North Haven

Lynne Krupa
203-288-6673

DC—Washington, DC Area

Steven Weiss
Kimberly Hughes
301-962-8885

FL—Naples

Roy Behlke
239-455-5571

FL—Orlando Area

Julie & Mark Collins
407-786-1516

FL—Tampa Bay Area

Vicki Pollyea
813-251-5512

FL—West Palm Beach

Phil Lewis
561-630-3931
Eileen Martinez
561-777-8471

GA—Atlanta Area

Susan Ruediger
678-595-2817

IA—Great Lakes

Daniel Bachmann
507-399-0592

IA—Iowa Area

Jeffrey Megown
319-981-0171

IL—Chicago Area

Dale Lopez
708-499-6274

*IL—Norridge Area

Charles Barrett
224-628-5642

IN—Fort Wayne Area

Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

*IN—Lafayette

Connie Chance
574-595-0674
Lawane Lord
765-474-4000

KS—Wichita Area

Karen Smith
316-841-8852

KY—Burlington Area

Pam Utz
859-817-9338

*LA—Baton Rouge Area

Kathleen Douglas
985-215-3926

*MA—Boston

Mimi Works
617-913-4600

MD—Easton

Missy Warfield
Seth Warfield
410-820-0576

*ME—Portland Area

Mary Louie
207-450-5679

MI—Chesaning Area

Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area

Jori Reijonen
269-341-4415

MN—Benson Area

*No group currently meeting
Will accept calls*
Rosemary Mills
320-567-2156

MO—Anderson Area

*No group currently meeting
Will accept calls*
Libby Bond
417-845-1883

MS—Mississippi/Louisiana

Flora Jones
601-825-2258
Cindy Chesteen
601-668-5439

NC—Durham Area

Susan Salzberg
919-967-3118

NJ—Central New Jersey

Mark Willis
732-252-8299
Jacqueline Donahue
732-780-0857

NJ—Morris County

Alanna Huber
973-933-2635

NM—Albuquerque Area

Gary Shepherd
505-296-1238

NV—Las Vegas Area

Jerry Cross
775-751-9634
Virginia Mamone
702-343-3572

NY—Horseheads Area

Angela Piersimoni
607-562-8823

NY—Long Island Area

Shari Loewenthal
631-254-8960

NY—Manhattan Area

Amanda Imbriano
516-680-2981
Barbara Abruzzo
212-473-4157

NY—Upstate New York

Melinda Lang
518-783-7313

NY—Westchester Area

Beverly Wurzel
201-224-5795

OH—Cleveland Area

Heather Hawk Frank
440-479-5094

OH—Greenville Area

Dot Cain
937-548-3963

PA—Bucks County Area

Linda Davis
Mitch Davis
215-943-0760

PA—Johnstown Area

J.D. Griffith
814-539-2341
Jeana Sweeney
814-269-1319

PA—Northwestern Area

Joyce Steinkamp
814-833-8495

RI—East Providence Area

Meredeth Souza
401-433-5500

SD—Hartford Area

Serena Clarkson
605-215-8853
Tom Clarkson
605-370-7595

TN—Nashville Area

Bridget Sarver
615-390-0699
Gwen Dempsey
256-655-0391

TN—Savannah Area

Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area

Whitney Krepes
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Merissa Lovfald
214-394-8907

UT—Orem Area

Melissa Arakaki
801-494-3658

VA—Harrisonburg Area

Anne Long
540-568-8328

VA—Williamsburg Area

Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area

Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WA—Tacoma Area

Carol Hadle
253-476-2345

WI—Brodhead Area

Molly Hawkins
608-921-0032

WI—Milwaukee Area

Polly Maziasz
262-439-9009

WV—Vienna Area

Rebecca Knapp
304-834-1735

GROUPS IN CANADA AND MEXICO

CAN—British Columbia

Melanie Bolster
250-888-7713

CAN—Montreal

www.cmtausa.org/ur/montreal/sag

CAN—Ontario

Kelly Hall
519-843-6119

MEXICO

(This group is in Spanish.)

Gina Salazar
Gina_oviedo@hotmail.com

Most Support and Action Groups can be accessed at www.cmtausa.org. They can be found in the CMTA Online Community under Support and Action Groups.

*NEW SUPPORT GROUPS

SUPPORT GROUP NEWS

(continued from page 16)

cover creative ways to adapt our lives to fit our needs.

• NY—Manhattan Area

The meeting was held on April 13th. There were nine members present. The group had an informal discussion on how CMT affects each individual and what coping mechanisms they found helpful. Fundraising ideas were shared, with a final decision to have a letter-writing campaign sent to family and friends to ask for donations.

• NY—Upstate New York Area

The March 23rd meeting was attended by 35 people, including six new people. Dr. Andrew Dubin, a psychiatrist who is Board Certified in Physical Medicine and Rehabilitation and Electrodiagnostic Medicine, spoke about neuropathic pain. Treatment options for nerve pain were discussed, such as non-steroidal anti-inflammatory drugs and antidepressants. Ways to manage pain and reducing stress were other topics discussed.

• OH—Cleveland Area

The March meeting had 13 people in attendance, including two new members. Heather shared the Aetrex catalogs and new CMTA literature. Also discussed was the possibility of creating a Cleveland group t-shirt. She shared bookmarks and posters for sale with CMT poems. They spent time talking about how to use humor to cope with CMT.

• RI—East Providence Area

Jeana Sweeney, the CMTA's Director of Community Services, served as guest speaker for the March 9th meeting. She discussed the CMTA Pathways, the

funds needed to move forward and the importance of each person doing their part to reach the goal. Also, Jeana discussed ways to get involved in the "Party for a Cure" fundraiser, the Warfield Challenge, "iGive.com" online shopping, and becoming a premium member with the CMTA and receiving a free pair of Aetrex shoes. Everyone left with such hope and excitement and a willingness to help.

• SD—Hartford Area

The group had 10 people in attendance. Rick Lasik, from Allard USA, served as guest speaker. Serena handed out Aetrex catalogs, talked about the Warfield challenge, the CMTA Premium Content with Aetrex

sponsorship, STAR updates, and three upcoming fundraisers that have been planned.

• WV—Vienna Area

The March 23rd meeting had 24 in attendance. Our thanks to Dr. Bonnie Buchman, RN, from Integrative Holistic Health, and Jane Burdette, a well-known advocate for disabilities in the area, for serving as guest speakers. Many topics were discussed, including the "change for change" fundraiser, the Warfield Challenge, Aetrex shoes, the benefits of naturopathic and holistic treatments, mainstreaming of disabilities in public areas, and how we can be more involved in our communities to raise awareness of CMT. ★

"STARSTRUCK" JEWELRY RAISES AWARENESS AND FUNDS

Riverbank Handworks is proud to introduce a new line for the CMT community called **CMT starstruck!**



When one of our artists, 15 year old Emily, was diagnosed with CMT2 this year, we were driven to help. Emily's love of handcrafted artistry has been hampered by her CMT symptoms, but she inspired us by creating nearly all of the **CMT starstruck** line.

Besides being a beautiful way to show support and raise awareness, there is a funding benefit to the CMTA. Riverbank Handworks has committed to donating 100% of the net profit on every **CMT starstruck** piece to the CMTA.

Every two months, we will be offering featured pieces—some of which are original designs. We have many more items that are in the **CMT starstruck** line, so please take a look by visiting www.cmtausa.org/url/starstruck

If you have any questions, would like to special order any **CMT starstruck** piece or need a different size or clasp style, please contact us at cmtstarstruck@riverbankhandworks.com.

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If you are a member or are joining now, you may purchase publications and accessories at discounted prices. (Some exclusions may apply.) To check your membership status, please call 1-800-606-2682, ext.105.

JOIN THE CMTA :				
Premium Membership (formerly "Premium Subscription," includes access to more online material and features)	Newsletter Formats (check one or both) <input type="checkbox"/> PDF <input type="checkbox"/> Print	Premium Membership Cost (includes Newsletter): \$30		
	QUANTITY	COST		TOTAL
		Regular Price	Member Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		\$15	\$12	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]		\$10	\$8	
CMT Facts III		\$7	\$5.60	
CMT Facts IV		\$10	\$8	
CMT Facts V		\$15	\$12	
CMT Facts VI		\$15	\$12	
My Child Has CMT		\$7	\$5.60	
Cooking and Coloring Adventures with Archy		\$10	\$8	
Teaching Kids about CMT...A Classroom Presentation (DVD/1 hour)		\$10	\$8	
CMTA Titleist Hats Quantity and Color: Black___ Blue___ Red___		\$25	\$20	
CMTA T-Shirts (Blue with white logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
Be a STAR Wristbands		1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each		
Be a STAR Necklaces (Includes battery)		1-5, \$3 each 6-10, \$2.50 each 11 or more, \$2 each		
NEW! Unframed Sunflower Poster		\$5		
NEW! Sunflower Bookmarks		1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each		
CMTA Brochure & Neurotoxic Drug Card		FREE		
Donation to the CMTA (100% Tax-deductible)				
Shipping & Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
ORDER 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, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267

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

CMT FOOT CARE

(continued from page 10)

for people with decreased "protective sensation." If a foreign body such as a splinter punctures the skin, it can lead to an infection and cause drastic consequences if a podiatric surgeon doesn't appropriately open the wound and extract the foreign body.

Ingrown toenails press on the surrounding skin, and if a person doesn't have adequate sensation to feel the pressure, an infection can quickly develop. To treat the problem, a podiatric surgeon will drain the infection to relieve the pressure, prescribe an antibiotic, and recommend special home care to help the infection heal. A permanent surgical procedure can be done in the office to prevent recurrence.

Athlete's Foot is a fungal infection commonly seen in people with CMT. This can affect nails as well, making them thick and painful. Many easy preventative solutions such as correct socks and OTC creams can be highly effective. However, if not treated, secondary bacterial infections that require vigorous treatment with antibiotics may develop.

Structural changes in the feet and ankles typically occur with CMT. As the nerves are affected by CMT, muscles become weak, and the bones those muscles control start to shift and cause bone and joint deformities. Again, if a person doesn't have normal sensation, he or she may not feel the added pressure over bony prominences and develop a sore, an infection, or a full-fledged ulceration. A podiatric specialist can help prevent complications from CMT-caused foot and ankle deformity. ★

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)
Eribulin (Halaven)
Gold salts
Ixabepilone (Ixempra)
Leflunomide (Arava)
Metronidazole/Misonidazole
(extended use)
Nitrofurantoin (Macrochantin,
Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of
Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Fluoroquinolones (Cipro)
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
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

THE CMTA Report

The Charcot-Marie-Tooth Association
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WHAT IS CMT?

- ▶ CMT is the most commonly inherited peripheral neuropathy, affecting approximately 150,000 Americans.
- ▶ CMT may become worse if certain neurotoxic drugs are taken.
- ▶ CMT can vary greatly in severity, even within the same family.
- ▶ CMT can, in rare instances, cause severe disability.
- ▶ CMT is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ CMT is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ CMT causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ CMT does not affect life expectancy.
- ▶ CMT is sometimes surgically treated.
- ▶ CMT 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).
- ▶ CMT has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ CMT 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.
- ▶ CMT Types that can now be diagnosed by a blood test include 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN.
- ▶ CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.