THE CMTA Report

MARCH/APRIL
2014

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

Charcot-Marie-Tooth Association

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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PATIENT-FAMILY CONFERENCE

CMTA Partners with Cedars-Sinai

BY STEVE FOX

Robert Baloh, MD, PhD, Bethany Meloche, CMTA Director of Social Media, Glen Pfeffer, MD, Rudy Parada, CPO, Tara Funari, MS, CGC, Richard Lewis, MD, Lynn Kuttnauer, PhD, and David Cooney, PT, CPO, formed the panel for the question and answer period.

The CMTA has established a significant presence in Southern California with a highly successful patient and family conference hosted February 15th in conjunction with the recently established Charcot-Marie-Tooth/Hereditary Neuropathy Center at the renowned Cedars-Sinai Hospital in Los Angeles.

An appreciative audience of some 175 attendees heard presentations by experts in a wide range of medical disciplines, including Robert H. Baloh, MD, PhD, Director of Neuromuscular Medicine in the Cedars-Sinai Department of Neurology and a noted CMT researcher; Richard Lewis, MD, FAAN, Director of the EMG (electromyography) Laboratory and Co-Director of the Neuromuscular Clinic in Cedars-Sinai's Department of Neurology and also a respected CMT researcher; and Glenn B. Pfeffer, MD, a highly experienced surgeon who is Director of the Foot and Ankle Program at Cedars-Sinai's Orthopedic Center.

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Standing Ovation for Bethany Meloche

Meloche ignited the audience at the LA patient/family conference with her moving and amusing stories.

There were a number of informative presentations at the recent Southern California conference, but the one that brought the house down was a simultaneously hilarious and inspiring talk by Bethany Meloche, the CMTA's Director of Social Media.

Mixing wry observations with personal tales of struggles and awkward moments familiar to those with CMT, Bethany put forward her five rules for dealing with the disease under the heading of *Tumbling Forward*:

1. **My disease does not define me.** Citing President Franklin Roosevelt and theoretical physicist Stephen Hawking as examples, Bethany said CMT patients should accept themselves as valuable, not disabled.
2. **Be willing to change my path.** Sometimes a new direction can lead to a stronger, better place.
3. **Believe in the future.** "I want to open myself to whatever adventure awaits me."
4. **Face my fears.** "Our fears can limit us; when we share them, they unite us."
5. **Challenge myself.** Bethany certainly has, recently, by completing a seven-mile fundraising walk that raised about $10,000, and by scheduling a 14-mile walk for this summer. ★

INSIDE:

PATIENT FAMILY CONFERENCE

(continued from page 1)

CMTA Chief Executive Officer Patrick Livney kicked things off by noting that the CMTA is currently focusing on three areas—research, awareness and patient advocacy—with great strides being made in each. Research fostered by the CMTA has engaged some of the best peripheral nerve researchers and clinicians in the world and generated active interest among several pharmaceutical companies, bringing us continuously closer to the day when drug treatments will be available for CMT. Awareness of the disease is also growing. For example, there are now 66 active CMTA Support and Action Groups in North America, including seven in California. Five years ago, there were just 15 cohesive SAGs in the country. As it always has, the CMTA is also working hard on patient advocacy.

The estimated 5,000 CMT patients in the Greater Los Angeles Area will find what Dr. Baloh described as "one-stop shopping" at the new Cedars-Sinai clinic, which is a collaborative effort by the hospital's departments of neurology, pediatrics, orthopedics, and medical genetics to provide state-of-the-art diagnosis and advanced treatment. Orthotic services and occupational/physical therapists are also available, with each patient receiving the most current and comprehensive treatment available. Dr. Baloh urged CMT patients to visit the center once a year, emphasizing that the understanding and treatment of the disease is advancing rapidly.

Dr. Lewis presented a broad overview of the causes of CMT, explaining that while the disease has more than 70 variations, each caused by a different genetic mutation, the underlying problem is degeneration of the peripheral nerves (those outside the brain and spinal cord). He urged patients to contact the Global Rare Diseases Patient Registry and Data Repository (GRDR), a pilot project of the National Institutes of Health intended to help researchers understand and develop treatments for rare diseases, including CMT. (See https://rarediseases.info.nih.gov/research/pages/43/global-rare-disease-patient-registry-and-data-repository.)

The conference also provided plenty of practical advice. Dr. Pfeffer discussed reconstructive foot surgery. Physical therapist Dawn Hageman offered advice on stretching and exercise. (It may be helpful, but patients were warned not to overdo it, either. You can't eliminate CMT with exercise.) Orthotic specialists David Cooney and Rudy Parada provided helpful information on the latest options in bracing. (Every patient is different; treatment should be individualized.) And Tara Funari, a genetics expert, provided an overview of the hereditary aspects of CMT. (Most people with the disease have a 50 percent chance of passing it on with each pregnancy.)

Research into CMT treatment has entered an exciting stage, Dr. Baloh noted, with three main areas of focus—drug therapy, which may help protect nerve axons and the myelin sheath that surrounds them; gene therapy, which someday may allow scientists to repair or even replace the defective genes that trigger CMT; and cell therapy, which may enable scientists to produce Schwann cells to aid in producing healthy myelin. Research into a treatment for CMT has reached the stage where initial human pharmaceutical trials are on the horizon, with the CMTA playing a major role in funding and coordinating that research.

Fundraising was the topic of Jeana Sweeney, CMTA Director of Community Services, whose energetic presentation highlighted the STAR (Strategy to Accelerate Research) program and the work of California Support and Action Groups. The CMTA, which committed $1 million to milestone-driven CMT research in 2013, is striv-

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THANK YOU TO OUR CORPORATE SPONSORS:

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College student Yohan Bouchard volunteered to man the CMTA information booth.

Our Star is About to Shine Brighter Than Ever: The $500,000 STARPOWER Challenge

Last November, a family came to the CMTA to offer their support. They have been witnessing the success of our STAR Initiative (our Strategy to Accelerate Research) and they have been overwhelmed with our success. Like most of us with CMT, they have one goal, one vision—a cure for CMT. In order to achieve that goal, they pledged $500,000 toward STAR!

This is the largest gift ever given to the CMTA in one year by one family. They want to challenge our community to match their donation, dollar for dollar. If one family can give $500,000 toward treatments for CMT, what can you give?

They want to inspire our community to hope the way they do. They want to galvanize all people with CMT to one mission, one cause—to find treatments which will slow, stop or reverse the cause/symptoms of CMT.

It's our time to believe in STARPOWER!

It's time to challenge our community to fund research to find the treatments.

It's time to challenge our doubters with proven success.

It's time to challenge those without hope for their future, for their children's future, to take action!

It's time to organize an event, to ask friends and families, to give yourself—whatever you can!

We have reached major milestones in CMT research, and we are on the brink of the first human pharmaceutical trials for CMT. We have galvanized our researchers and accelerated the pace of research. We committed $1 million to research in 2013 alone, and, with your help, 2014 will reach beyond that record.

Treatment for CMT is within reach. Our research dollars are being spent wisely. We are funding projects that are poised for success with proven methods of research and which are milestone driven. No one gets paid unless successful milestones are met.

Last year, the Warfield Family offered their support by giving $150,000 toward STAR. In their match alone, they raised over $350,000 for the CMTA, allowing us to fund $1 million in research in 2013. They inspired this second family to "up the ante," and this family has, indeed, stepped up!

The donor family will ask their friends and family to support this match. They will inspire others to do the same. With this kind of success, the CMTA will deliver the first treatments for CMT, preparing for continued success until we cure all types of CMT.

We are on our way. We have major support from families who can offer it. But we need everyone's support to realize our dream, as we cannot rely solely upon our larger donors. Your donation matters!

Every dollar you give will be matched, dollar for dollar up to $500,000, the CMTA's largest matching grant ever!

Give today to the STARPOWER Challenge at www.cmtausa.org/STARPOWER. With your help, our STAR is going to shine brighter than ever. We are going to prove that CMT has met its match! Now let's match the $500,000 STARPOWER Challenge! ★

PATIENT FAMILY CONFERENCE

(continued from page 2)

ing to surpass that figure in 2014 with the help of a very generous family that has pledged $500,000 in matching donations. You can help—learn about the STARPOWER campaign on the www.cmtusa.org website!

Of course, until a treatment is found, CMT patients must live with their disease. Lynn Kuttnauer, PhD, a psychologist and psychoanalyst who spoke about the emotional and social aspects of CMT, urged patients to learn more about the various ways people cope with chronic diseases and to be open about sharing their feelings and fears. Her presentation was followed by a wide-ranging Q&A session, with the assembled medical experts providing advice on how best to deal with CMT.

Closing the conference on an upbeat note in remarks titled "The Future Is Ours," Pat Livney urged CMT patients and their loved ones to put their hearts and —and cash—into finding a treatment for the disease and helping all those affected by it. He emphasized that the STAR program is making great strides and deserves everyone's support.

The CMTA has scheduled a Northern California Patient and Family Conference to be held September 27th in the Bay Area. Hope to see you there! ★

Be a part of CMTAthletes!

Race with Donna DeWick and join the team from the CMTA at one of two events this summer: in Austin on Monday, May 26, 2014, at the USA Paratriathlon National Championships, or in Chicago on Sunday, June 29, 2014, at the International Triathlon Union World Triathlon.

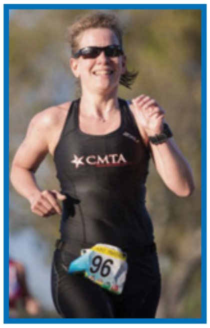
Even If you're not racing in the sprint distance triathlon, come join the CMTA team to cheer on those racing and show your support. We will have a group along the course and at the finish line to cheer on the triathletes. The weekend will include events, with full details to be announced soon.

If you are interested in racing and joining other CMTAthletes who will be participating in the event, register online at:

For the Austin CapTex triathlon: http://www.captextri.com/
For the Chicago ITU World Triathlon: http://chicago.triathlon.org/

The registration fees for up to five triathletes at each event will be paid by the CMTA. Contact Kim Magee for registration and reimbursement details at kim@cmtausa.org or by calling 1-800-606-2682 x105. If you would like to join as a supporter and cheer on the athletes, please email Jeana Sweeney at jeana@cmtausa.org.

About CMTAthletes: The CMTAthletes program is for those with CMT and their supporters, alike, who are athletes today or who aspire to become more active. "If you have a body, you are an athlete" is the group's philosophy, and with the support of the CMTA its members seek to support an active and healthy lifestyle as a means of managing CMT. For more about CMTAthletes, visit the CMTAthletes Facebook page at https://www.facebook.com/groups/cmtathletes.



About Donna DeWick: Donna DeWick has been an active supporter of the CMTA since 2009, having received her CMT diagnosis in 2004. Donna turned to triathlon as a way to manage her health in 2007 and, since then, has completed numerous triathlons, open water swims, cycling and running events. Donna believes that exercise and healthy living are the best ways we have today to manage CMT and helped to form the CMTAthletes group as a means of sharing information and ideas among members of the CMT community. Donna was named by Triathlon England as one of the London region club paratriathletes for the year in 2013 and writes about her journey at www.beatinglimitations.com. ★

RESTAURANT HOSTS “TASTING” FUNDRAISER

CMTA Board Member Steve O’Donnell, Support Group Facilitator Missy Warfield, and event organizer Clark Semmes joined in at the restaurant fundraiser.

On January 26th, Latitude 38 restaurant in tiny Oxford, Maryland, held a “tasting” to raise funds for the CMTA. Despite cold temperatures and competition from the Grammy Awards, the event was a huge success. Latitude 38’s Chef Seth created a stunning array of dishes that included curried butternut squash bisque served in a fluted glass, pork tenderloin on sweet potato biscuits with cranberry, and duck confit wrapped in phyllo, all served banquet-style before a roaring fire. Restaurant owner Wendy Palmer was both welcoming and gracious.

Some of those in attendance at the tasting fundraiser were CMTA board member Steve O’Donnell, Easton Support and Action Group Facilitator Missy Warfield, and new CMTA member Clark Semmes. After cocktails and food tasting, Steve O’Donnell spoke about the CMTA, the progress it has achieved over his 13 years with the organization, and the crucial role that fundraising plays in funding the development of a drug treatment for CMT. Missy Warfield spoke movingly about her own experience with CMT, and the importance of raising CMT awareness and growing CMTA membership. Clark Semmes described his own experience with CMT, the formation of the STAR initiative, and his confidence that this initiative would find a treatment and ultimately a cure for all types of CMT.

The event was attended by approximately 25 people, many of whom drove almost two hours from either Baltimore or Washington, DC. Following the tasting fundraiser, some guests ventured across town to view the sunset over the Tread Avon River. It was a beautiful sunset over a mostly frozen tributary of the Chesapeake Bay, and it proved to be a perfect cap to a wonderful afternoon. During the dining, a number of potential future CMTA fundraising ideas were discussed, and events including a Words with Friends tournament, an eastern shore horseback ride, an Oxford/St. Michael’s bike race, and the formation of a Baltimore workout group may be expected in the near future. We are happy to report that this event raised approximately $2000 for the CMTA. —*Clark Semmes*

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Want to Go Out with Me and My Braces?

DATING AND CMT

BY JONAH BERGER, CMTA ADVISORY BOARD

JONAH: Can I ask you a question?
GIRLFRIEND: Sure …
JONAH: How do you feel about my disability?
GIRLFRIEND: Uh *(crickets chirping)*

That was the very conversation that occurred between the girl I was dating and me when I was 18 years old. I remember the feeling I had while the crickets were chirping away. I felt in the spotlight. I felt disconnected. I admitted to myself that I hadn't communicated with her about CMT and that keeping it to myself and springing that question on her was totally unfair. And, I felt a profound piece of wisdom come over me that was years beyond my chronological age.... *The only way to connect with someone special about CMT is to be direct, open, and honest.*

There may be some of you who are asking yourselves why you should be taking dating advice from a 41-year-old single man, but I would point out that since I have been single and dating for a long time, I am chock full of experience and wisdom from the front lines. So, judge not, dear friends, simply read on!

I have come to see that there are certain helpful tips when it comes to working your disability into your dating life. I call them my ...

5 Steps to Freedom!

STEP 1: *Dispel the myth.*

Having a disability is not the excuse or reason for having a less-than-satisfying dating life. I think our society and, at times, we, ourselves, make it an issue. But I am here to tell you that with the right attitude and the right communication, you can have all of the joys, stresses, and delights of a normal dating path!

STEP 2: *It is our responsibility to communicate our special needs.*

I have met so many people with CMT who are shy about discussing it, especially with those who don't have it. Let's face it, anyone who sees us can tell that something is out of the ordinary. So, why keep them curious? Why make them guess or fill in the blanks with answers that are probably further from the truth. Just tell a date or interesting person about your CMT. There is no easy way to broach the subject, so just throw it out there. Your forthright style will: 1) Ease their ignorance and put them in the know, and 2) Show them that you are on top of your situation and care about explaining it to others who matter. I suggest practicing explaining CMT to the mirror or to friends. And make sure it is simple to understand. Director Cameron Crowe once said, "It's interesting that the parts of my movies that people connect to the most are the parts that are most personal to me." People want to know each other's truths. Life is short. Be brave and be honest, and if they can't handle it, you probably don't want to be dating them.

Let's face it, anyone who sees us can tell that something is out of the ordinary.

STEP 3: *You accept it, they will accept it. You deny it, they will deny it.*

With most things in this life, others will take the direction from us, as we do from them. If we are closed off and quiet about any one topic, the object of our desire will probably shy from that topic as well. Yet, if we are honest and open about it, they will feel that comfort. A quote from the movie *A Beautiful Mind* hits this point well: "Maybe that's how it is with our nightmares and our dreams. You have to feed them to keep them alive." This tells me that if you deny your CMT, then the negative emotions of fear and shame are fed and will grow; whereas, if you accept your CMT, the emotions of confidence and self-assuredness are fed and will grow.

STEP 4: *Pick the right person to date.*

This may seem an obvious one, but I assure you, it's not. I have dated in the past and not been intentional about picking an accepting and true-hearted female, and I have felt the negative effects of those choices. On the other hand, I have chosen to date someone based on the content of their heart and their character and that has led me to my current girlfriend, Megan. She brings with her an absolute and complete acceptance of my disability and seems to inspire in me a consistent state of smiling.

STEP 5: *Everyone has special needs.*

Last but not least, please remember that every single person walking this earth has special needs. Those needs are special to them. They are needs they are sensitive about, needs they are nervous to put out there, and they make us thankful when their needs receive understanding. We are not the only ones on ANY date with unique situations. So I say, take the lead, stand up proudly (and wobbly) and put yourself out there. Let people know your real and total self. Those who respond well to you are the ones to show your braces to! Good luck and happy dating! ★

What do those of us living with CMT want most? *A treatment for CMT!*

As you know, the CMTA has an amazing drug discovery program called STAR (Strategy to Accelerate Research). STAR is our future, our children's future and our grandchildren's future. STAR provides hope and promise, and, soon, STAR will deliver our first treatment for CMT.

So, how about helping the CMTA accomplish its mission: A world without CMT?

The CMTA has lots in store for 2014, and we need your help! So, here is your call to action: We are putting together a team—not a baseball team, but a fundraising team called TEAM STAR!

Did you know that the CMTA relies solely on private donations and community fundraising dollars? STAR is alive because of our members and supporters!

We are looking for dedicated individuals to fundraise for the CMTA's STAR initiative. The fundraiser you choose to do is up to you! The CMTA is here to guide you along the way, from brainstorming ideas to providing marketing materials.

Some of you at home might be thinking—fundraiser? I am not sure I can ask people for money, or I am much too busy to put an event together! These thoughts and questions are perfectly normal! But, let's look at it this way. If we, as individuals living with CMT don't get involved, who will? This project is about helping the organization that is helping us!

Fundraisers can be big or small. Just know that in the end, every dollar counts toward funding STAR! Plus, the possibilities are endless when it comes to fundraising. Let your mind wander, and you will be surprised what you might come up with!

If you join Team STAR and raise $5,000 or more for the CMTA, you will receive a signature TEAM STAR t-shirt and will be spotlighted in *The CMTA Report.*

Some people have a natural gift for fundraising. Once they get started, they love it. The person with this natural gift may be you. The best way to discover it is to try!

To join, please contact me today at www.cmtausa.org/team.

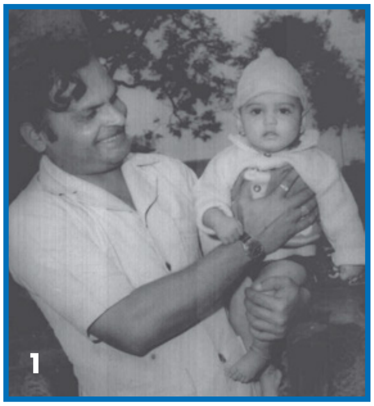
Together, we can, and will, make a difference!

—Jeana Sweeney, Director of Community Services, CMTA

Life with CMT in India

BY ANAND PATKI, KOLHAPUR, INDIA

My name is Anand Patki. I am from India. I have had symptoms of CMT for the past 26 years. I'd like to tell you how my life is affected by CMT. Please look at the picture below.



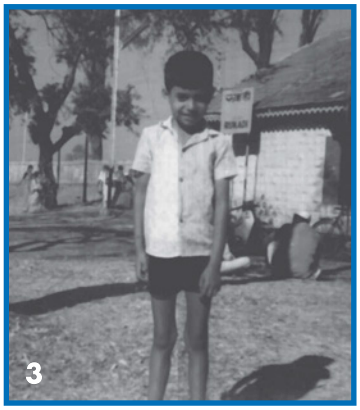
1

As you can see, I was born as a normal child. I was one year old and looked very quiet and excited to know about my new world. My father was happy and smiling at me, but he did not know that one day I would be affected by a rare disease.

In the next picture *(below)*, I was about six years old. You can see that CMT had already begun to affect both legs. But still, my legs appeared very steady and I was able to stand without support.

2

In the next picture *(below)*, taken by my brother's friend, I was ten years old at that time. I remember that he insisted that I stand still for two seconds to take this picture. But I was unable to stay steady for more than two seconds. But you can see my hands are totally normal. Even at that time, I was able to run and play outdoor games like cricket and football.



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The next picture at my sister's engagement party *(facing page, top left)* was when I was 15 years old. You can see I was unable to hold my hands comfortably. At that time, I was unable to write my exam papers continuously.

I was unable to walk for long distances. My right leg curved inside while walking.

The fifth picture *(facing page, top right)* was taken when I was honored by "Social Justice and Empowerment Management for the Disabled" because I received the second highest grades in HSC board exam. I remember I could have had a writing assistant for the exam, but I decided to complete the entire exam paper myself for three hours straight. At this time, I was unable to stand without support. In the sixth picture *(facing page, middle right)*, you can see my hands are badly affected by CMT. At that time, I was 18 years old.

When I was 20 years old, I was correctly diagnosed for the first time in my life. My neurologist told me that I had a degenerative disease called CMT. Doctors told me, "There is no treatment and you will become weaker and weaker." My parents were shocked and very upset at that time. My mind accepted that I had CMT, and I decided to fight with CMT. Whenever I saw other normal children playing cricket or football, I felt very sad because I could not play like them. But one day, I met parents who had a mentally disabled child. That child was crying. Suddenly, he stopped crying and started laughing. I felt very awkward. His parents told me that due to his cognitive impairment, he really did not know what he was doing. He also had no sensation. I realized that this child had more problems than me. His parents had more challenges than mine. Can you imagine the life of a person with severely limited mental capacities? To me, this is like a computer without a microprocessor. I changed my attitude and started to think more positively.

On January 29th, I celebrated my 32nd birthday. For


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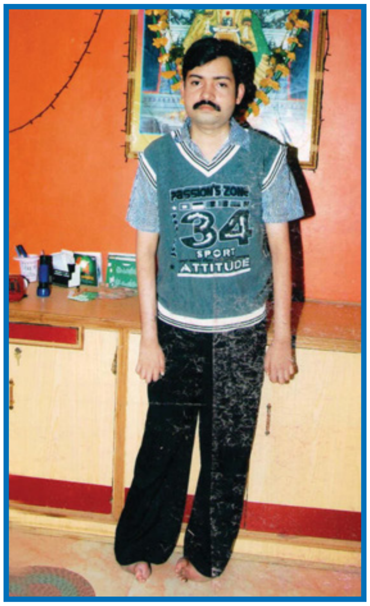
the past six years, I have been working as a computer operator in the Postal Department in India. I have to work continuously for more than eight hours without a single break. Since I am not able to enter the data fast enough, I am not allowed to go to the bathroom. In addition, there are no disabled-friendly toilets in my office. But, I am happy with my work. I am enjoying my job. At this stage, I cannot walk without support on hard surfaces. I am facing a lot of problems performing my day-to-day tasks like buttoning my shirts, wearing my shoes, counting cash, handling vouchers, inserting paper in the printer, etc. I also have had a chronic ankle injury for the past five years. But, I am happy in my life. I have no complaints with my God.


Despite his difficulty walking and writing, Anand holds down a job as a computer operator.

As you can see, I am getting weaker and weaker physically, but becoming stronger and stronger mentally. I cannot tell you that you will be victorious over your CMT, but you can manage the degeneration process of CMT by following these steps:

Always think positively. To train your mind to think always positively is essential. I believe in God and I also believe there are positive waves in nature. So, you can change your life with positive thinking.

Remain hopeful. Don't feel sad in your life. Our scientists and researchers are doing a lot of experiments on CMT. I know in the next five years, we will get very close to making a world without CMT.

Don't think you are a disabled person. You are "specially-abled." I know we cannot do much about our physical capacity, but you have a normal brain. Use it with your full capacity. Be honest and work hard in your job or field and try to become "specially-abled."

Thank God. Don't curse your God because God has gifted you with a super brain. Use it as your sixth sense. God has gifted you with normal eyes. Use them to see beautiful and good things in your life. Be satisfied and happy with what you have. Do not feel badly about what you don't have.

The most important thing is to maintain your physical capacity and try to improve it with proper exercise. For me, Yoga is the best option to improve my muscle flexibility.

The doctors say that my handicap is severe. My feet have turned in and I have no balance. I cannot use a cane or a walker because there is no strength in my hands. Many people suggest that I use a wheelchair, but I have decided against using a wheelchair. I know that one day, I will become 100 percent fit. ★

CMT Guide for Schools

BY MICHELLE HAYES, FACILITATOR FOR THE DALLAS SUPPORT AND ACTION GROUP
AND SARAH KESTY, CMTA ADVISORY BOARD

INTRODUCTION

- ★ Charcot-Marie-Tooth Disease (CMT) is the most commonly inherited neurological condition, affecting 1 in 2,500 people in the U.S. and 2.8 million people worldwide.
- ★ Due to damage to the nerves, it causes progressive weakness and wasting of muscles in the lower arms and legs. It is hereditary and there is no cure.
- ★ It is important for a teacher to be familiar with how CMT can affect a child's school experience.
- ★ Being aware of CMT and its effects can help teachers and parents support the child's school involvement, making it easier on the child and the school.
- ★ CMT does NOT cause learning difficulties; however, a child may experience a variety of symptoms such as limitation in coordination, fatigue, pain, tremors, anxiety and emotional factors related to having a disability.

Effects of Muscle Weakness

CMT looks different in every child. Some effects you may notice include:

- ★ The way the child walks and apparent clumsiness.
- ★ Use of orthotics or leg braces.
- ★ Frequent falls, tripping over their feet, sometimes fall-related injuries.
- ★ Trouble negotiating stairs/ramps and keeping up with their peers in physical activities.
- ★ The need for mobility aids such as a wheelchair or crutches.
- ★ The rate of CMT's progression varying from one month to another or from year to year.

Due to CMT's progressive nature, it is very important to note any changes in a child's ability to do various activities and make accommodations accordingly.

What to Expect

- ★ Lack of muscle and dexterity in the fingers and hands may make holding a pen/pencil difficult. This can lead to teachers perceiving the child's handwriting as merely "messy."
- ★ Difficulty with fine motor skills such as buttoning, tying, opening objects and zipping.
- ★ Hand weakness, tremors and cramping may make it difficult for some students with CMT to take notes quickly and write for long periods.
- ★ Slowness, or difficulty, in rising from a seated position on the floor or from a chair to standing position.
- ★ Inability to move from classroom to classroom as quickly as typically expected.
- ★ Inability to keep up with peers in physical activities such as, but not limited to, running, jumping, squatting, walking, climbing, balancing and heel to toe movement.

Helpful Devices & Equipment

- ★ Foam and/or pencil grips that fit over pencils to make it easier to grasp them
- ★ Laptops, tablets or computers to use instead of writing
- ★ DragonSpeak or other assistive speech-to-text software
- ★ Devices to aid in buttoning and zipping

Classmates

- ★ Discuss with the child and parents their feelings about sharing the child's disability with their classmates. Every family is different, and we need to respect their decisions.
- ★ Some children do not want their classmates to know about their disability, so always make sure the child is involved in the decision.
- ★ If the child and family are open to sharing the child's disability, it would be beneficial for everyone to know about CMT and the way it affects the child's abilities, appearance, and/or behavior.
- ★ With the open approach, peers can better understand their classmate's disability, which can lead to less teasing

and taunting. It can also help as the disease progresses.

- ★ Avoid embarrassing the child by going at the student's pace.
- ★ Be sensitive to issues such as getting up off the floor, buttoning shirts, and poor performance in PE.

How Teachers Can Help

- ★ An informed, perceptive, and concerned teacher can make a world of difference to the student and his/her family.
- ★ Writing assignments for class and homework can cause great fatigue, frustration and pain. Providing notes for the student and allowing the student to type assignments instead of writing them is helpful.
- ★ Timed tests and long written assignments are difficult for a child who is unable to write quickly or write for long periods of time. Providing extra time, verbal tests, or use of a teacher's assistant can be very helpful.
- ★ Provide the child extra time to get books, paper, and other materials ready.
- ★ Encourage the use of a laptop, tablet, or computer.
- ★ Allow extra time to get to and from classrooms and allow the child to use an elevator pass instead of negotiating the stairs.
- ★ Remember low grades on assignments may be due to inadequate time to complete an assignment. Be mindful of whether the grade reflects lack of knowledge vs. lack of ability to finish.
- ★ Giving advanced notice on projects and big assignments will allow the student to pace him or herself and not tire so quickly.

School Services

- ★ Each child should receive adequate services based on measured, rather than assumed, capabilities.
- ★ A 504 Accommodations plan or an IEP may be put in place to ensure the student's needs are met and the playing field is "leveled" when considering the disability's impact on the child's school experience.
- ★ Information from physiotherapists should be taken into consideration to enable an adaptive physical therapy program and/or physical therapy to be provided as part of PE. Physical therapy programs can prevent contractures that can lead to further disability and are essential to slow down progression of the disease, especially during the growth spurts associated with puberty.
- ★ Heavy doors, stairs, and long distances can be cumbersome, so provide accommodations for maneuvering around the school grounds.
- ★ Providing an elevator pass can be extremely helpful along with handrails on stairs that cannot be avoided.
- ★ Rather than requiring the student to carry a heavy backpack, provide a locker or storage space to keep books and binders at an easy, accessible, and central location.
- ★ Consider wheelchair access for a child recovering from surgery or a child more severely affected by CMT.

Physical Education

- ★ For children with CMT, PE is often the class they dread the most.
- ★ For classes requiring students to change into PE clothes, allow students extra time. Keep in mind they may have braces to contend with and difficulty with buttons and zippers.
- ★ Provide suitable, accessible changing facilities with seating to allow the child to sit while dressing and undressing.
- ★ Allow the child to participate in all activities he/she wants to, but let the child "self-limit." If the child is unable to complete the activity, let him/her sit out. If the child can do it, let him/her!
- ★ Never single out the child as weak or a "whiner" if he/she can't complete a task or takes a longer time to complete it. CMT is not a matter of choice or effort.
- ★ Adapt games and activities by allowing the child to take more time, sit out an activity, keep score, or be an assistant instead of forcing him/her to try and complete something beyond his/her physical capability. This only leads to humiliating the child.
- ★ Remember children are often scared of being teased, taunted or humiliated, especially when they have a physical disability.
- ★ Always encourage the child and make him/her feel good.
- ★ Evaluate the child for his/her efforts, not his/her skill level.

For more information visit www.cmtausa.org

My History with CMT

BY CAROL SIMPSON

Anyone with a bit of knowledge about CMT knows it most often shows symptoms around puberty or later into life. However, I was diagnosed just before I was 18 months old though it took years to refine the diagnosis and to finally determine which type I have. I went into full-length leg braces without knee joints just before I was two and learned to walk in them just before I was three. About the time I was diagnosed, a baby brother was born with a severe birth defect and died. About a year later, a healthy sister was born, and my parents' dreams of a family were back on track.

Carol Simpson has succeeded in living as fully and independently as possible, despite her CMT.

My parents resolved to raise me to be as able to function in the "normal" world as possible. I did my share of the chores, and I transferred to regular public school at the start of junior high, learning how to achieve the desired goals, while improvising how to do things differently when needed. My parents' goal for me became my own—to live as fully and independently as possible, despite my CMT.

I graduated from high school and completed my Associate's Degree at Community College, followed by my BA in English and MLS In Library Science. I worked as a librarian for three years after that, and then held other jobs—telemarketing, accounting clerk, etc.

In 1974, I met a man who had significant learning disabilities, but we made a great team—each filling in the areas the other was weak in. We married. Even then we were told that our chances of having a child with CMT were no different than anyone else in the general population. Our daughter was born in 1977—a normal birth and a healthy baby. When she was almost two, we were informed that CMT is, in fact, a genetic disease, and we were offered checkups for our daughter, as often as deemed needed. She continued to be fine. My CMT continued to progress very slowly.

In the early 1990s, I connected with the CMT Clinic in Detroit, where my history was taken and a whole battery of tests were done. Genetic testing was offered. The first test didn't define my genetic error, so samples were sent to the research facility at Baylor. They finally found it. Like a typo in an important document, there is a point mutation in the DNA making my myelin. I have CMT1B. We were offered the opportunity to have other family members tested against my results to see if any had it, too. My mother, four of my five sisters, my brother and my daughter were checked. No one else has it. I can live with being the first and last in my family with it.

Our daughter grew up, earned her BA in Biology, emphasizing wildlife and habitat. She's married and lives in California. My husband developed mental illness, and I began caregiving for him in 1988. In 2006, he was further diagnosed with vascular dementia, and my caregiving duties increased. I've had knee injuries due to falls and am now in full length KAFOs. I also use crutches, and during the last year I have begun using a power chair more and more. I've had toe-release surgery so my toes would stretch

SAVE THE DATE!

In conjunction with the CMTA-designated Center of Excellence at Stanford, a Patient and Family Conference will be held on Saturday September 27, 2014, from 9:00 am-4:00 pm. The conference will provide an extremely valuable opportunity to hear from some of the most prominent CMT clinicians and researchers, including Dr. Michael Shy, Dr. John Day and genetic counselor Carly Siskind. More information will be coming soon! Please keep an eye on your CMTA eNews for updates and announcements.

WHAT'S ON YOUR MIND? ASK DAVID.

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.

Dear David,

I have visited my siblings out of town about once a year for many years. I am the only one with CMT, and they have known this for many years. Is it wrong for me to be so disappointed and angry that no one in my family actually asks me how I'm doing with my CMT? They are intelligent and fairly warm people, but it boggles my mind that they never mention it.

David Tannenbaum answers:

You have touched a chord close to home. I also have the same experience visiting my family. For years I just figured they were so self-centered that it just didn't occur to them to ask about me. Then I had a thought that it might make them uncomfortable or sad to ask me about CMT. I decided that it doesn't really help being angry because I don't like holding on to that feeling, and I know that any negative feelings like that can't be good for my overall health. I think that it is important to be mindful of what you are feeling and not judge yourself for a natural response to feeling invisible.

Of course, feelings are always more magnified when it has to do with our family since we all carry some baggage growing up. If you are brave enough to bring it up and risk their feeling defensive or guilty, then by all means take the chance and let them know that it would mean a great deal to you for them to ask you, on occasion, how you're doing. I don't think we need sympathy or pity, just a little common heartfelt concern.

I have also decided that "modeling for others" by showing caring and concern can also go a long way in educating them about what it means to be human. Again, many people avoid asking because it would bring up vulnerable feelings, and most people, unfortunately, avoid those feelings at all cost. The sad thing about this is that they miss an opportunity for both of you to feel closer and more loving. And isn't that what family ideally should be about? ★

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out and not be rubbed by my shoe. I broke a foot getting up from a fall. All this and more has gone on while caring for my husband at home.

In January 2012, my husband had medication problems and went to the hospital. While trying to deal with that, other problems developed and he was placed in a nursing home, where three shifts of workers could monitor his care much better than I could have done alone at home. The additional problems proved to be a second terminal condition—aortic stenosis, causing congestive heart failure. The cardiologist said we might have a year. I lost him on July 8, 2012.

Our lives are like a book. Mine starts with my childhood with CMT and extends through college and my early adult years. It then covers my 38 years with my husband and the raising of our daughter. It now continues, as I live out my new chapters as an independent widow. CMT has been with me for 65 years. It has had an influence, but it has not prevented me from achieving or doing anything I wanted to do badly enough. I just have become good at thinking outside the box. What is the goal and how do I get there?

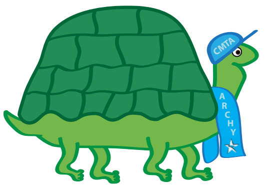
I believe CMT has done too much damage for me to see a cure, but if they find a way to arrest it and stop any further progression, I'll be first in line. I still have a lot of things to do, places to go, and people to meet. ★

(Editor's Note: Putting her words into action, Carol is assembling friends and family to participate in a fundraiser called the Fifth Third Riverbank Run later this year.)

The Tormented Years … Archy Turns 13

I remember hearing my mother talk about the "terrible twos," but I don't actually remember being that age. Apparently, I asserted my independence by saying "no" to every single thing my mother and father asked me to do. Included, I've been told, were really dumb things like playing with electrical wires even though I had been told that I could get electrocuted if I kept doing that. Eventually, I apparently, figured out that I would have a longer and healthier life if I followed a few of the rules.

Now, I'm living through what my mother calls the "tumultuous teens." I can remember every single day of this period of time, and I don't like it any more than my parents do. I never feel right. I'm always angry about something, and it's weird, because I used to be a very calm and happy kid. I'm also always worried, and the worst part of the worry is that I can't even figure out what it is that worries me so much. I just have this sick feeling in my stomach when I have a few minutes by myself.



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

I've always loved picking on my big sister, but now I just say horrible things to her that she really doesn't deserve. I feel like I'm some kind of bomb just waiting to explode. I think that some of my issues involve my age … which seems to lead to all kinds of "foreign" thoughts and feelings, but I also think some of the anger is directed at my CMT which gets a little worse every year. What seemed like a simple stumbling block (sorry for the pun) when I was younger has turned into an issue that makes me so different from my friends, who are getting bigger and stronger and more athletic while I stay the same size and lose more and more of my abilities.

Another problem for me is that I can't really talk about how I feel around my parents because my mother already feels like it's her fault that I have CMT. My father, on the other hand, doesn't share any of my problems, so it's hard for him to totally understand what I'm experiencing. Besides, I'm not sure either of them can remember being 13. They're pretty old.

As it turns out, there is a place for me to go where people will understand the problems of being a teen as well as having CMT. A CMTA Board Member, Elizabeth Ouellette, told me about this site where teenagers can "meet" to talk about these issues that bother them or about wonderful things that are happening in their lives. The site is www.cmtausa.org/fbyouthgroup. I've already visited and have compared concerns with other teens.

Since my problems are, by necessity, also problems for my parents, I have suggested that they might want to visit www.cmtausa.org/fbparentsgroup where they can connect with other parents of kids with CMT and share problems and successes.

I guess the one big lesson I've learned so far is that it's difficult and unnecessary to go through this life without the help of others. Now that I've connected with others who share my experiences, I am less angry. I still worry about my future, but I think that's probably something that all teenagers deal with. Now my worry is more about whether I should study to become an architect or a doctor. Both of them seem appealing. ★

ASK THE DOCTOR

Dear Doctor,

I'm 57 and have been told that "Reactive arthritis" is possibly the cause of some of my pain. What is this? My symptoms had gone into remission in the 14 months that I waited for the appointment with the doctor, so he didn't have much to work with. He ordered a Lyme test and because I wasn't notified that it was positive, I am assuming that it wasn't. Are these proximal symptoms an expected part of CMT? Do others suffer from them?

Dr. Steven Scherer responds,

I can only address your issues in the broadest way. At age 57, you would be expected to have osteoarthritis, which could manifest as pain in various joints of the body. CMT certainly causes people to move differently, and I have seen many patients with severe OA in the ankles, knees, hips, and low back, which I have attributed in part to their CMT. If the pain is from arthritis, then it should respond to non-steroidal anti-inflammatory medications, physical therapy, and time.

GIFTS WERE MADE TO THE CMTA

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

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: __________________________
____

SAG FACILITATORS SPOTLIGHT:

Rick Alber

Rick Alber is a Support and Action Group Co-Facilitator and acts as moderator of the monthly webinars featuring members of the CMTA's Advisory Board.

Rick Alber discovered CMT when his 3-year-old daughter Flannery was diagnosed with CMT1A in 1994. No other members of his family have CMT. Rick is an ex-lawyer and tech enthusiast who was a senior director for Yahoo Groups in 2001, when Gretchen Glick started the first online CMT support group at http://groups.yahoo.com/neo/groups/CMTUS/. Rick still co-moderates that group, which has about 2500 members worldwide.

Rick has been a long-time member of the CMTA but didn't really get involved with the organization until he met Elizabeth Ouellette in early 2006. Her infectious drive, vision and confidence inspired him to help her build the San Francisco Peninsula CMT Support and Action Group.

"I've committed to helping the CMTA and Elizabeth in any way I can in order to speed up the discovery of a cure or treatment for generations of people like my daughter," says Rick. His daughter Flannery is now 23 and, fortunately, is only mildly affected by CMT.

Since 2006, Rick has contributed his technical knowledge of web design, online services and video production to help the support group. In recent months, he's organized the CMTA webinar series, which is accumulating a great library of CMT knowledge explained by leading scientists, technicians, therapists and other experts on CMT. The webinars, held monthly, enable CMTA members to get live answers to their questions and concerns. All webinars are recorded and transcribed, then posted at the CMTA webinar page at www.cmtausa.org/webinars.

Rick will continue assisting Elizabeth and the CMTA for as long as they ask him to. ★

SUPPORT AND ACTION GROUP NEWS

- **CA—South Bay Area**

The group had a wonderful meeting with Sarah Kesty, CMTA Advisory Board Member, as guest speaker. Sarah, author of *Everyone Has Something—Together We Can*, spoke about growing up with CMT and how her early experiences with the disease shaped her life and perspectives. She shared how she has learned to embrace her CMT, forging new paths and directions towards self-discovery and empowerment. She read her book to the group, which speaks to kids and adults alike. Everyone participated in the group discussion, to the enjoyment of all. Thanks to all 30 members who attended.

- **FL—Naples**

The Naples FL SAG met on January 29th with 17 members present. Alan Boiko, Sales Manager of Aetrex Shoes for Florida, was the guest speaker. Alan gave a great talk about the technology of shoe manufacturing and the importance of proper fitting. He showed samples of the Aetrex and Apex shoe lines and gave out brochures. Roy Behlke gave a report on the CMTA research advances in 2013 and plans for 2014. He also gave highlights of Dr. Shy's webinar. Members Rosemary Buck, Jessica Diamond, Don Kincaid and Roy Behlke gave their impressions of the CMTA November Patient and Family Conference in Orlando. All agreed that having access to the major CMT researchers and hearing their reports firsthand was a highlight.

(continued on page 18)

CMT Support and Action Groups in Your Community

AL—North Florence
North Florence, AL CMT Support and Action Group
Tina Smith
256-757-9250

AZ—Phoenix Area
Arizona CMT Support and Action Group
Pamela Palmer
ppalmeraz@gmail.com
Jim Blum
480-272-3846

CA—Santa Barbara Area
Los Angeles, CA CMT Support and Action Group
Steve Fox
805-647-8225

CA—Los Angeles
Los Angeles (South), CA CMT Support and Action Group
Alani Price
310-710-2376

CA—Stockton
Stockton, CA CMT Support and Action Group
Nina Anselmo
209-460-1716

CA—South Bay Area
San Francisco Peninsula/ South Bay CMT Support and Action Group
Elizabeth Ouellette
1-800-606-2682 x107
Rick Alber
650-924-1616

CA—San Diego Area
San Diego, CA CMT Support and Action Group
Jordan Thomas
619-549-0872

CA—Santa Rosa Area
Santa Rosa, CA CMT Support and Action Group
Carol O'Bryan
707-823-0165

CA—Visalia Area
Visalia, CA CMT Support and Action Group
Melanie Pennebaker
559-972-3020

CO—Denver Area
Denver Area CMT Support and Action Group
Ron Plageman
303-929-9647
Dick Kutz
303-988-5581

CT—Hartford
Hartford, CT East CMT Support and Action Group
Roy Behlke
239-682-6785

CT—North Haven
North Haven, CT CMT Support and Action Group
Lynne Krupa
203-288-6673

DC—Washington, DC
Washington, DC CMT Support and Action Group
Steven Weiss
Kimberly Hughes
301-962-8885

FL—Naples
Naples, FL CMT Support and Action Group
Roy Behlke
239-455-5571

FL—Sarasota Area
Sarasota, FL CMT Support and Action Group
Racel Rivlin
941-870-3326

FL—Tampa Bay Area
Tampa Bay, FL CMT Support and Action Group
Vicki Pollyea
813-251-5512

FL—West Palm Bach
South FL CMT Support and Action Group
Phil Lewis
561-630-3931
Eileen Martinez
561-777-8471

GA—Atlanta Area
Atlanta, GA CMT Support and Action Group
Susan Ruediger
678-595-2817

IA—Iowa Area
Iowa City, IA CMT Support and Action Group
Jeffrey Megown
319-981-0171

IL—Chicago Area
Chicago Area CMT Support and Action Group
Dale Lopez
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MD—Easton
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CAN—Ontario
Eastern Ontario CMT Support and Action Group
Robin Schock
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Southern Ontario CMT Action and Support Group
Kelly Hall
519-843-6119

Mexico
(This group will be in Spanish.)
México CMTA Grupo de Apoyo y Acción
Gina Salazar
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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.

SUPPORT GROUP NEWS

(continued from page 16)

Roy also took a poll of the neurologists used by those in attendance to determine if CMTA could endorse one, as there is no neurologist within 137 miles listed on the CMTA web site. He will pass on the names of the two who were recommended.

• GA—Atlanta Area
The group met on January 18th with about 30 people in attendance. Physical therapist Melissa Bloom talked about balance training. She believes balance can be significantly improved through the re-education of the signals between the muscles and nerves. Other updates included the success of the CMTA in 2013 and where the CMTA is with research. The CMTA $500,000 matching challenge grant was also discussed.

• IL—Chicago Area
There were 21 members and family present for the February 22nd meeting. Garrett Hartman, MA and LPC, who is a professional counselor at The Center for Identity Potential, served as guest speaker. Jenny Nilsen, who is also a professional counselor specializing in family counseling, attended. Garrett's presentation provided an overview of some of the issues that affect individuals with a disability or chronic illness and their families and how the family can create the best atmosphere for growth of the entire family. He discussed how to explain a disability to your child, challenges for siblings, caretaker fatigue, and feelings of hopelessness, depression and identity development. It was an informative meeting for everyone!

• MI—Chesaning Area
There were 17 in attendance, including 5 new members, at the February 23rd meeting. Good food and sharing of information and feelings about the CMTA were enjoyed by everyone. Carolyn Koski and Ellen Alberts handed out information and responded to everyone.

Support group meetings often feature neurologists, counselors and physical therapists who offer advice on living with, and beating, CMT.

• MI—Kalamazoo Area
The SW Michigan SAG met on January 16th with 8 in attendance. Dr. Dustin Nowacek, a new physician in the area, answered questions about living with, and treating, CMT. He recently finished his residency in neurology with a specialty in neuromuscular disease. The group asked many questions. Also, Colleen, from the regional MDA office, visited the meeting. She reviewed the programs available through the MDA, highlighting the equipment loan program. The STAR program and recent research developments in CMT treatments were also discussed.

• NJ—Central New Jersey
Because of an email blast, the group had several new people attend. A new family had found out about the group through the CMTA website. One lady who attended the meeting also happens to work in the building in which the meeting was held, so she was able to introduce a few co-workers and share with them about her disease. The group had an amazing meeting.

• NM—Albuquerque Area
The CMT New Mexico SAG met on February 8th with 7 members in attendance. Gary presented an update on current research efforts. Their scheduled speakers were called away on short notice, so the group instead watched the excellent physical therapy webinar by Michael Nussbaum. There was a lot of lively discussion about who is doing what exercise and whether it is actually possible for exercise to be of benefit for the CMT condition (as opposed to just improvements in overall health, which are certainly valuable). The group was also introduced to the $500,000 matching fund grant as well as the "fast thousand" opportunity.

• NY—Upstate New York
The group met on January 18th. Guest speaker, Pat Pfeifer, MDA Health Care Service Coordinator for NENY and Vermont, shared information on healthcare services offered by the MDA. Services offered include clinics, summer camp, advocacy, and durable medical equipment.

• PA—Ephrata, PA
The group met on January 11th. David "Ask David" Tannenbaum talked about the

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emotional part of having CMT and how it is important to have people who care and understand your condition and having at least one person you can share with. The meeting was very helpful.

- **SD—Hartford Area**

The group met on December 14th with 4 in attendance. Discussion included building a web page for their 5K fundraiser and ideas for sponsors for the t-shirts, as well as prizes. They watched the STAR update with Pat Livney. Subway donated cookies. They also talked about snacks for those eating gluten free and those on diets.

- **TX—Dallas Area**

The group met on January 18th. Thanks to Hilary, group secretary, for taking such great notes for everyone. Michelle gave the introduction, discussing CMTA information for schools and Carter's Challenge. Bill Messer, certified orthotist, served as guest speaker. Bill is the only ABC Certified Orthotist in the DFW metroplex with specialty training in the fabrication of carbon-fiber orthotics, which allows the brace to be much lighter and user-friendly. In fact, Bill's method of carbon-fiber fabrication is so revolutionary that he was given an official patent by the U.S. Patent and Trademark Office and has a another patent for his carbon-fiber AFO (Ankle Foot Orthosis).

- **WI—Milwaukee Area**

There were 10 members who attended the January 29th meeting. In spite of the snow, they had 5 new members. Suzi shared information about STAR Research. Suzi and Frank shared their experience at the MDA Muscle Summit. ★

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

THE CMTA Report

The Charcot-Marie-Tooth Association
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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)
Eribulin (Halaven)
Gold salts
Ixabepilone (Ixempra)
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)
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

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.