THE CMTA Report

MARCH/APRIL
2012

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

Charcot-Marie-Tooth Association

OUR MISSION:

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

OUR VISION:

A world without CMT.

EMAIL CMTA AT:
info@cmtausa.org

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"Make a Better Tomorrow"

A Message to the CMTA Community from CEO Patrick Livney

It is with extreme honor that I address you all on behalf of the CMTA for the upcoming year! I have never been more excited about the CMTA and its mission in the six years I've been involved with the organization.

The past five months have been difficult for me as two men I considered heroes have passed away. They are my father, George U. Livney, and Joseph V. Paterno. Both men shared similar core values reflective of an era considered by many to be the greatest generation ever. Family, hard work, the importance of education, and the moral and ethical responsibility of leaving our children a world better than what we inherited were the cornerstones of their beliefs.

The CMTA has much to be proud of in that spirit:

- ★ The CMTA's STAR research program has hit milestones and is expanding its focus to include all forms of CMT
- ★ The CMTA's Support and Action Groups, comprised of dedicated and committed volunteers, now number 58 in 39 states.
- ★ The CMTA's focus on CMT awareness and education has noticeably increased on the local, regional, national, and global levels.

As CEO, I have the privilege to represent a special group of people I consider "family" at the CMTA. A dedicated team, consisting of an invested Board of Directors, a talented Advisory

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Folsom School Kids Get Involved

BY KATHLEEN VANDEVORD

What kind of community service project would impact the students and families in the rural public school where I teach in South Hero, Vermont? That was the question I was challenged with as a first and second grade teacher. Every year, all the teachers in our K-8 school involve our students in helping other people in some meaningful way. I needed a project to introduce to 27 students on Martin Luther King Day. Parents were coming to our school in the morning for breakfast, followed by activities in the classroom. Panic started to set in by Jan. 10 when I still did not

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Mrs. Vandevord explains to her class about Archy and his problems with CMT.

INSIDE:

AN EXCITING TIME

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Board, an energetic and enthusiastic staff, a world-class STAR Scientific Advisory Board, the brightest team of international investigators, and an awe-inspiring network of patients, families, and volunteers touched by CMT are my "family."

We have an ambitious year planned that will require hard work by all. In honor of my heroes, I pledge to lead by example in my effort to make a difference. I simply ask each and every one of you reading this letter to get involved in some tangible way. Tell everyone you know what CMT is and how to help the CMTA; get an article in your local paper; host a fundraiser, or simply "Tweet" or text about CMT and you will help the CMTA get a step closer to achieving its mission: a world without CMT. What a great tomorrow that would be!

With heartfelt thanks. I love and miss you, Dad!

— Patrick Livney, CEO of the CMTA

KIDS GET INVOLVED

(continued from page 1)

have a plan. I wanted a project that would reach outside our local community and help people globally.

I started thinking about my nephew, Yohan Bouchard, who has CMT. I knew from traveling with my sister, Elizabeth Ouellette, to a few conferences and through many conversations, that CMT is not a very well-known disorder. By the next evening, I was on the phone with my sister talking about the possibility of educating as many of my students, parents and co-teachers as possible about CMT as a community service project.

I can honestly say things would not have worked out if it were not for the response from Jeana Sweeney, the CMTA's Director of Community Services. Within minutes of talking with my sister, Jeana called me in Vermont. The next day, we were emailing back and forth. I really needed her help to figure out how to explain CMT to 6- and 7-year-old kids. I wanted them to understand the disorder to the extent that they could explain CMT to their family and friends, and to the general public. By Friday, I was equipped with a fabulous DVD, "Teaching Kids About CMT" made by Elizabeth explaining CMT to Yohan's class when he was in 5th grade. Jeana also sent information about the CMTA's mascot, Archy the Turtle, along with brochures, wristbands, cookbooks, star necklaces, and buttons.

On Martin Luther King Day, I went to school wearing my CMTA shirt. I was a little nervous, but very excited to educate my students. What I thought would be a one-hour introduction stretched out to two. The children watched part of the DVD and then "put themselves in the shoes" of a person with CMT. I used Elizabeth's idea of having the children try to unbutton shirts with socks on their hands. They expressed how hard it was. We discussed what it might be like to have CMT. They said it must be really "frustrating." The most important point they learned was to try to understand differences and accept people the way they are.

> "I wanted to educate students, parents, and teachers about CMT."

I showed them a pair of Yohan's braces, and they couldn't believe that people actually wear them in their shoes. This led to many questions and lengthy conversations. After two hours, the children couldn't have been more excited about being part of the effort to raise money for research.

This was only the beginning for my students. On Feb. 16th, my school held a school-wide celebration of learning. That night, students sat behind a desk that held all the CMT materials. I watched as parents asked them questions and the children collected money to send to "doctors so they can find a cure." On Feb. 23rd, we had a table for CMT at the science fair in our school. All totaled, we are sending the CMTA $160. I am so proud of the first and second graders in my school. They are all stars in my book!

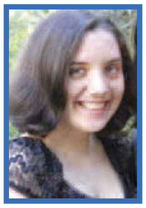
And let's not forget Archy. Archy the Turtle sits in our circle area and attends my morning meetings with the children. Every day, we all say good morning to him as part of our greeting. After all, Archy is one cool turtle whom we all accept as one of us! ★

MORE ADDITIONS TO OUR ADVISORY BOARD

In a continuing effort to provide varied resources to the CMT community, the Board of Directors has added another four "advisors" who can answer questions about occupational therapy, genetics, legal issues, and the issues facing young people who deal with CMT.

TIM ESTILOW, OTR/L, is an occupational therapist at The Children's Hospital of Philadelphia. He provides outpatient-based therapy services and interdisciplinary specialty clinic consultations/evaluations, and he participates in clinical research. His specialty practice includes the use of splinting, dynamic movement orthosis, and aquatic therapy interventions for patients with neuromuscular disease. Tim has participated as an evaluator in clinical trials for CMT and other neuromuscular/neurological diseases. He is currently an investigator in the CMT natural history study, and contributed to the development of the CMT Pediatric Scale (CMTPedS) including the establishment of validity and reliability. His primary interests are improving hand function and balance to improve independence and quality of life for individuals with CMT.

SHAWNA FEELY, MS, CGC is a board certified genetic counselor with a specialty in Neurogenetics and CMT. She was previously an Assistant Professor at Wayne State University (WSU), where she helped to provide genetic counseling services and coordinate the WSU CMT Clinic with Dr. Michael Shy. She has now moved to the University of Iowa (UI), where she is helping to establish a Center of Excellence with Dr. Shy. Shawna has worked with individuals and families who have CMT for the past 6 years, and she has done research in this area with her particular area of research involving CMT Type 2A (CMT2A). She has enjoyed her work with the individuals and families that she has been able to meet in clinic over the years, along with all the wonderful people who are committed to the CMTA. She is looking forward to continuing this work at the UI and as a new member of the CMTA Advisory Board.



BETHANY NOELLE MELOCHE is 20 years old and lives in the California bay area. At the age of 12 she was diagnosed with CMT1A. Since then she has set out to learn everything she can about CMT. She believes that armed with knowledge and determination, you can still live a happy and full life—CMT or not! Bethany is a passionate patient advocate and has pioneered the CMTA's first youth-focused group on Facebook. She hopes that this group will be a stepping stone toward the creation of a Youth Committee, focused on reaching out to teens and young adults with CMT.

If you are interested in youth services, contact Bethany at bethany.meloche@gmail.com, and find the Youth Group at https://www.facebook.com/groups/112378272199073/ or search for "CMTA Youth Discussion" on Facebook.

MICHAEL NEEDLEMAN has been practicing law in Pennsylvania and New Jersey for about 9 years, and is awaiting admission to the Washington, DC bar. He is licensed to practice in the United States District Courts for the District of New Jersey, the Eastern District of Pennsylvania, the Western District of Pennsylvania, and the United States Court of Appeals for the Third Circuit. He has developed a speciality practice in the employment discrimination area, and within that, of handling disability discrimination claims. He also concentrates on insurance coverage issues, which he hopes to be able to use to benefit CMTA members. In terms of his personal involvement with CMT, he and his brother both have confirmed diagnoses, and there is a fairly extensive family history. His brother first starting showing signs at 11 or 12, while he was diagnosed at 22. ★

HAVE QUESTIONS about the congressional letter? Please contact Julie Collins at phantomsec4@yahoo.com.

A Call for Action for Awareness Month

YOU CAN MAKE A DIFFERENCE IN A BIG WAY!

The soil has been tilled, and the seeds planted. A seedling is sprouting, but growing it strong until it bears fruit is a monumental task that will require all the nurturing we can muster. Together. We have to work together. There is power in numbers.

I am excited to announce that there is currently a "Dear Colleague" letter being circulated on the floor of the United States Congress asking for endorsement to present a letter to President Obama requesting that he declare September as National Charcot-Marie-Tooth Awareness Month!

Why am I so excited?

The issuance of a Presidential Proclamation would be groundbreaking for all patients living with CMT. The endorsement of the "Dear Colleague" letter by your House of Representatives and Senators will propel the request directly to the Oval Office. I can't think of a better way to promote Awareness Month!

This truly is a "Call to Action." All I ask is that you set 15 minutes aside to contact your U.S. Representative by phone and tell him/her about the "Dear Colleague" letter and ask him/her to cosign it. It's that simple. By visiting www.opencongress.org, clicking on "Representatives" and/or "Senators" across the top bar, and entering your zip code, you will be immediately redirected to the names and contact numbers for all of your Congressional Representatives and Senators. Make the call. Explain to the staff member that you are calling about a Health Care Initiative, (a Presidential Proclamation), and that as a constituent you believe it is of vital importance for him/her to cosign the letter. Ask to speak directly to the Congressman/Senator if at all possible.

You may be asked questions about the initiative, and you can be prepared to answer them by remembering: 1. That this letter has no political agenda. It is being sponsored on a bipartisan level. 2. The letter we are asking to have signed has no request for funding. 3. It has absolutely no legislation attached to it. It is simply a request submitted respectfully by a nonpolitical, charitable health organization (CMTA) to promote awareness about the disease. 4. If you are asked when the letter will be closing, simply explain that time is of the essence.

In order to get the required signatures, it's up to each and every person of voting age to contact their U.S. Representative's office via phone, email and snail mail and implore his/her to seek out the Dear Colleague letter and sign it. Ask your friends and family to do the same. It doesn't matter where they live. They can reach out to their own districts through the opencongress.org website.

> Help ask Congress to endorse the request to make September the national CMT Awareness Month.

Once directed to the contact information, you will observe that you can visit your Representative's website. When you visit the website, click on "contact" and you will find a listing to email that individual. I urge you to send an email as well. For your convenience, I have drafted a letter that you can cut and paste directly into the message box. Should you decide to print it out and mail it via U.S. Postal Service, please make sure to include your name, address, and telephone number on all correspondence. You can find that letter on the CMTA website. It's quick and it's easy.

—Julie Collins, SAGF, Central Florida

In Memory

We are saddened to inform you that Mark Hollingshead, who founded the CMTA's Nashville, TN Support and Action Group, passed away suddenly on February 19, 2012. Mark will be remembered for his keen sense of humor, his laughter, and his quick wit. There was never a dull moment in his presence! He was also very dedicated to the CMTA, always fundraising and spreading awareness of the disorder throughout his community. He was an important and integral part of our CMTA family and we will all miss him deeply.

What if I didn't have CMT?

Let's just say I find a lamp in the woods. And I pick it up and rub it. And all of a sudden, smoke comes out and a genie appears. The genie looks remarkably like Jerry Lewis. I ask him what is going on and he says to me that he has the power to take me back in time and erase my CMT. He asks me if I would like to see how my life would turn out without this disease. I accept his offer and with the wave of his hand and the sound of the tympani, back I go. I am standing at second plate. It is gym class, third grade, and my current self shivers from the memory of how hard gym class was to survive. The ball is hit a few feet from me. I remember this moment, I remember my teammates screaming at me to get it, and I remember not being able to move fast enough to make the play. But in this moment, I watch my eight-year-old self dart over, scoop up the ball, and swiftly throw the runner out at first. With a wide smile, I decide I'm gonna like this exercise. So I look at the genie and I ask him to show me more.

Poof! I am at summer camp. Fifteen years old, and I am about to walk into the dance to see Jody Brown. And instead of tripping on the pavement and skinning my knee and being laughed at by several friends, including her, I walk gracefully into the dance, and young love flourishes to "Open Arms" by Journey.

On to climbing Mt. Elbert, where I see my 30-year-old self climbing it in 7 hours flat, instead of the 14 hours it really took me. And there I am competing in the triathlon. I come in 10th place instead of last. I cross the finish line, and people are clapping, but they don't have the magical inspired look in their eyes that they did when I crossed the finish line last and in leg braces. In fact, they barely see me.

As the visions continue, the genie shows me countless mornings, where I wake up and tie my shoes with ease. And the whole process takes 10 seconds. In fact, everything is happening faster. And I am noticing that I am doing things physically without appreciating them. And I also notice that I am acting differently. I don't seem to have the same care for myself and for others. In fact, I seem a bit cocky, never having been made humble by the experience of weakness. And there is my girlfriend. She seems to like me but isn't in love with how I deal with my challenge, because I don't have one. We don't share the challenge together, and there is something missing because of it.

I decide that I don't like this. CMT isn't so bad. It has carved me into who I am—a physically challenged, hard-headed, frustrated, sensitive, caring, empathetic, appreciative, aware human being. I turn to the genie to scream that I want out and—*Poof!*—I awake in my bed. I look down and there are my amazing curled up toes. My hands are stiff; my braces are at the foot of my bed; a day of challenge is ahead of me, and a smile is on my face. I have CMT, and while it is a difficult path to walk, it is an interesting and unique one as well! It takes things away, and it gives important things to fill the spaces. I get up, happy to be me. And I go grooving and stumbling into my day…

—Jonah Berger, Advisory Board Member

SPOTLIGHT ON CMTA SUPPORT AND ACTION GROUP FACILITATOR:

BEVERLY WURZEL

I was enrolled in ballet class when I was 5 years old. It was my dream. After 2 months, I was told ballet was not for me.

Throughout my school years, I dreaded going to gym class. I could not run, hop, or even jump. It made me sad. I remember going to many different doctors because I walked funny, but not one doctor knew why.

I am older now and my walking has become more awkward and difficult. My balance is not good at all, and I get tired much sooner than in years past. Over time, however, I have learned to live with the challenges of CMT.

It was not until I went to the first Support and Action Group Facilitators conference, met the doctors and researchers, and listened to them speak, that I realized how hard they were working to find a cure for all of us. I felt hopeful and wanted to help, to make a difference, but I didn't know where to begin.

I am a wife. I am a mother of three and a grandmother of five. I am certainly not a fundraiser. As time went on, however, I started to write personalized letters to everyone I knew—family, friends, and acquaintances. I also asked my Support and Action Group members for their help. I took advantage of matching incentives, such as "Ken's Ride" and the "Board Challenge." I always responded with a hand written thank you for every donation I received.

It takes time and effort, but you can get great results. I will continue to write letters and stay committed to my goal of a world without CMT in my lifetime.

My name is Beverly Wurzel, and I am a facilitator for the Westchester, New York support group. *Together we can raise money for CMT research.*

Does a "Variant of Uncertain Significance" mean you have CMT?

BY CARLY SISKIND, ADVISORY BOARD MEMBER

Many people have had genetic testing ordered that has been returned announcing a "Variant of Uncertain Significance" (VUS). The question is what to do with that information. Some people, including some physicians, are inclined to automatically dismiss the variant as non–disease causing or, conversely, automatically accept it as disease causing. In most cases, however, the answer is not clear-cut. Here are some general ways to tell if a particular variant may or may not be disease causing.

Does the VUS change an amino acid?

In order to answer this question, a short primer on genetics is in order. Our genetic code is made up of four "letters" that together make short three letter "words," similar to the letters A, C, and T making up the word CAT. Each of these three-letter words in the DNA codes for an amino acid (AA). AAs are the building blocks of proteins—these proteins then come together to make muscles or organs or other parts of the body. The AAs usually are arranged in a very specific order. In order for the correct AA to be made, the letter code needs to be correct. However, there is some room for error within the three-letter code, usually in the third letter. Using an English example, CAR and CAB are both modes of transportation, even though they are spelled differently. In the same way, even though the letters in the gene may be changed, the AA may still be the same as expected. When looking at a VUS, the first question should be "Does it change an amino acid?" If the answer to that is no, this variant is not likely to be a cause of CMT. However, if the answer is yes, more searching to discover if it is disease-causing is in order.

Has the variant been reported?

Variants must be screened in order to tell if they are disease-causing or not. There is quite a bit of active research being done to identify if variants do indeed cause CMT. There is a database, the Inherited Peripheral Neuropathies Mutation Database (IPNMD), located at http://www.molgen.ua.ac.be/cmtmutations/Mutations/Default.cfm, which has chronicled the variants found through 2007 and reported in the literature whether or not the variant was thought to be disease-causing. When you enter the gene of interest, you get an output that looks like the table below.

While this is not a ton of information, it does provide many important details that can help narrow down what the VUS means.

- **Mutation:** This is at the "letter" level of the DNA. The number means which place the letter is that was changed. In the table, #10 is translated as the 36th letter into the *PMP22* gene

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EXAMPLE OF THE INFORMATION THAT IS PROVIDED WHEN A SPECIFIC VARIANT IS QUERIED USING THE IPNMD DATABASE *(PMP22 IN THIS CASE)*

	MUTATION	ALIAS	PHENOTYPE	CITATIONS
1	CMT1A duplication	CMT1A duplication	CMT1	Lupski et al, 1991 Raeymaekers et al, 1991 Wise et al, 1993 Nelis et al, 1996
2	HNPP deletion	HNPP deletion	HNPP (+ CNS involvement)	Chance et al, 1993 Nelis et al, 1996 Sanahuja et al, 2005
3		Reciprocal translocation t(16;17)(q12;p11.2)	HNPP	Nadal et al, 2000
4	Partial deletion of coding region	Partial deletion of coding region	HNPP	Van de Wetering, 2002 Sutton et al, 2004
5	c.-141C>G	-	- (polymorphism)	Nelis et al, 1998
6	c.-134G>A	-	- (polymorphism)	Numakura et al, 2002
7	c.-40G>A	-	- (polymorphism)	Numakura et al, 2002
8	c.11delT	Leufs	HNPP	Muglia et al, 2007
9	c.19_20delAG	Leu7fs	HNPP	Nicholson et al, 1994
10	c.36C>A	His12Gln	DSS	Valentijn et al, 1995

WHAT'S ON YOUR MIND? ASK DAVID.

Dear David,

I was diganosed back in 1978 with CMT. I was wondering if you could give me any ideas on how to handle the depression from not being able to do something that I was able to do say a month ago? Thank you for any help that you can give me.

—*C.C.*

Dear C.C.,

Thanks for asking a question that affects so many of us dealing with the challenge of CMT. The progressive nature of CMT is so erratic that it is stable for a long time, and then it seems like suddenly we have to deal with yet another change in our physical body. In some ways we are faced with dealing with loss more often than most. As with most forms of loss, there is a period of grieving that follows. This is absolutely normal. Within this grief reaction there is depression that manifests in a variety of symptoms: sadness, anger, depression-related fatigue, lack of purpose, and a feeling of hopelessess. We also tend to feel anxiety when we notice a limitation we hadn't noticed before, often experiencing a panic reaction and imaging worst-case scenarios. Many of us are quite creative with the stories that we make up about what we think can happen in the future. I often remind myself to stay in the present. Learning to simply observe your fear-based thoughts in a nonjudgmental and noncritical way can be helpful in reducing your fear and anxiety. Eckarte Tolle's book, *The Power of Now*, gives very simple and clear tools for how to stay in the present, reducing the suffering we create with our thoughts. Remember that our true identity is so much more than our thoughts, our emotions, or our bodies.

It is very understandable to feel depressed when we notice these changes. These are human reactions. If the depression lasts longer than several weeks, it can be extremely helpful to speak to a counselor. If there is a loved one close to you who is compassionate, it is invaluable to share your feelings. When we keep these fearful thoughts and emotions to ourselves, we feel isolated, which just adds to our pain. Remember that our vulnerability and openness are powerful strengths, leading to intimacy with ourselves and others. Intimacy creates health on so many levels.

There have been many scientific studies that show the link between sharing our emotions and increasing physical health.

Another tool that I have found helpful is reminding myself that my self-worth is not dependent on whether I have a strong body. I am reminded that health is about a feeling of aliveness regardless of whether we can climb stairs or button up easily. My greatest challenge is not only managing the limitations of CMT, but handling these limitations emotionally. Reminding myself on almost a daily basis of what there is to appreicate in life often helps to lift my mood. I am referring to simple things like opening my eyes in the morning, enjoying a beautiful day, listening to a moving piece of music, playing with my dog, or seeing the smile of a loved one. It is not always easy to remember the beauty of life itself when you are in a dark place. Be kind and patient with yourself. Allow yourself to feel what you feel, and then nudge yourself gently to do this excercise. The more things you can find to be grateful for, the better you will feel. ★

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.)

CHICAGOLAND PATIENT AND FAMILY CONFERENCE, SATURDAY, NOVEMBER 10, 2012 *REGISTER TODAY*

In conjunction with the upcoming Support and Action Group Facilitator conference, the CMTA is excited to announce a CMT Patient & Family Conference on November 10, 2012, from 9 AM to 2 PM. The conference, which is the first such event to be held in the Chicagoland area in years, will feature a few of the most prominent CMT clinicians and researchers, including Michael Shy, MD; Steven Scherer, MD, PhD; John Svaren, PhD; Gregory Carter, MD; and Sean Mckale, LO, CO.

This event provides an opportunity to hear from the most prominent minds in the fields of CMT research and treatment. Registration is just $50 per person and includes "Lunch with the Experts," during which you will have time to talk with the presenters and other leading CMT authorities, including the CMTA's Advisory Board members. Space is limited, so please register early by visiting http://www.cmtausa.org/url/chicago-pfc.

Questions? email us at info@cmtausa.org.

Register before May 1, 2012, and receive a $10 discount on admission

WAYNE STATE CMT CLINIC MOVES TO IOWA

The Wayne State CMT Clinic is excited to announce its move to the University of Iowa, in Iowa City IA. We hope to be opening our doors in Iowa the first week of April. We are sad to be leaving Detroit, which has been home to the CMT clinic since the fall of 1996. We greatly appreciate all the patients and families that have come through the clinic in Detroit over the past 15 years. We could not have come this far in the world of CMT research without all of you. However, it is our hope that we can do an even better job at the University of Iowa in terms of both research and patient care.

The clinic will be housed in a lovely Clinical Research Unit that is supported independently by the NIH. It is a state-of-the-art facility that offers us the potential to grow, with more space and new equipment. We also will have access to a world-renowned group of neuromuscular scientists and excellent pediatric neurologists. Iowa City is the home of the University of Iowa Hospitals and Clinics. It is easy to navigate for patients and families, and there are many wonderful places to stay in the area.

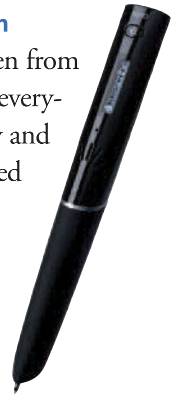
Shawna Feely, one of our genetic counselors from Detroit, will be heading up the genetic counseling component of the clinic. The Iowa CMT clinic will continue to provide multidisciplinary care for people with CMT. We will provide multiple assessments during the clinic evaluation, including physical therapy, occupational therapy, and physiatry. We hope to be able to expand into new areas such as exercise physiology, pulmonary function, and bone density studies as we utilize other departmental expertise within the University of Iowa Hospitals and Clinics. We are still in the process of assembling the entire Iowa team, but we hope that the team will be in place by the end of March, including a contact and scheduling person.

All the research programs that were in place in Detroit will be continued in Iowa. We hope that our long-time friends who visited us over the years in Detroit will be able to continue to visit us at the University of Iowa CMT Clinic.

AIDS FOR DAILY LIVING

Several members of the CMTA have suggested the following items as being very useful in managing the problems often associated with CMT.

The Echo Smart Pen



The Echo Smartpen from Livescribe records everything you hear, say and write in a specialized notebook, linking your audio recordings to your notes. Just tap the pen anywhere on your hand-written notes, and the recording picks up where you left off. Never miss another word of a presentation or lecture! Then, upload and save your notes to your computer, where you can make edits and send to others through email, Facebook, Google Docs, etc. The Smartpen facilitates taking comprehensive, handwritten notes. You can purchase the Echo Smartpen, on Amazon, at Staples, Best Buy or www.livescribe.com, $99.

Universal Lid Jar Opener

This is an easy twist/universal jar opener. It can open anything from soda bottles to large jars. You can get it in a variety of different designs at Amazon, starting at $5.99.

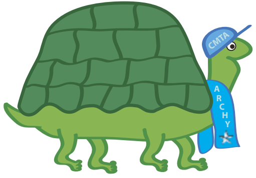
OXO Good Grips Button Hook

Get a secure, cushioned grip on hard-to-hold buttons. The cushioned grip of the Good Grips Button Hook makes buttoning clothes easy. The built-up handle features flexible ribbing that adapts to any grip. Available at www.activeforever.com or 800-377-8033, $7.95.

Luck Is What You Make of It

I think I'm lucky to be a turtle, CMT and all. Let's face it. The expectations on turtles are much less than on human kids. First of all, turtles as a species all move really slowly so my awkward gait is not noticeable. Then, I go to a school where all the animals are so different that there aren't really any expectations in that area either. Human kids might be teased for not being good at baseball, but turtles are always the last chosen for that game because we're too close to the ground to be good at pitching, or throwing out a stealing player. We don't roller blade or ride bicycles very much, but the fleet, athletic animals don't really think we should be able to do those things, so they don't tease about those inabilities, either. We are fabulous swimmers and we don't mock the raccoons and skunks, who aren't especially gifted in that department. All in all, I think diversity is quite handy when it comes to avoiding being picked on.

If you think I am always happy and that nothing ever goes wrong, let me assure you that is not the case. Instead of getting better at keeping up with the other kids, I think I'm getting worse and they are noticing. So far, they haven't really teased me about my slowness in getting ready to go out for recess or how long it takes me to pass out the test papers. But, I see them look at each other and smile, and somehow in the deep recesses of my heart, I know it's not a smile of support.



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

I've talked to my best friends about all my inabilities and they always reassure me that no one notices and that I do so many things so well that it doesn't matter. But, why does it feel so bad? Parents and friends can be as supportive as possible and I still think I'm not good enough. I need to develop a thicker skin…that's one of those old fashioned sayings that's particularly silly for a turtle since I clearly have very thick skin and a rock hard shell. Of course the saying is about my insides needing to be less susceptible to harm, but it's one of those weird sayings. I guess the idea is that if your skin is thick enough, the hurt can't get in to the heart area. It just doesn't work for a turtle very well.

So, I started out thinking I was lucky to be a turtle and I ended up feeling sorry for myself. That's not good. I really am lucky. I just need to remind myself of that. I have a wonderful family and great friends. I go to a good school where I am generally well-liked. I have a grandfather who is the perfect model of how to not just survive, but thrive, with a disease like CMT. What more could I ask? Okay, that's a bad question because all of us want whatever we don't or can't have. I'm no different. I wish I were fast and tall and physically impressive, but I'm left with smart and thoughtful and kind and a good swimmer. All in all, I think I'm lucky to be a turtle, CMT and all. ★

THE CMTA "CIRCLE OF FRIENDS"

If you are interested in creating a fundraising Circle of Friends or want your family or friends to donate money to the CMTA on behalf of your birthday, anniversary, or special occasion, please let Jeana Sweeney know! You can email Jeana at: jeana@cmtausa.org. Working together, we can create a world without CMT!

Donations were made to these CMTA circles:

VASI'S S.F. GIANTS FANTASY BASEBALL CAMP
Mr. & Mrs. Craig Aaronson
Mr. Shawn Antin
Mr. Carter Armstrong
Ms. Kelly Austin
Mr. Jay Ayers & Mr. Matt Walker
Band From TV
Mr. & Mrs. Jeff Beal
Mr. David Bell
Broadcast Music, Inc.
Mr. Paul B. Broucek
Mr. William L. Brown
Mr. Michael Brunner, D.C.
Mr. Thomas Cavanaugh
Mr. Andrew Cipes
Mr. George Clinton
Mrs. Michelle Conwisar
Ms. Suzanne Cortney & Mr. John Spiegel
Mr. Bo Daniels
Mr. & Mrs. Jamie Daugherty
Mr. Patrick Dowd
Ms. Maristela Dunn
Feitler Family Fund
Mr. Jay Ferguson
Mr. Roger Feusier & Ms. Jane Feusier
Ms. Kay C. Fields & Family
Mr. & Mrs. Howard Fink
Mr. & Mrs. Michael Fottrell
Mr. Mark Friedgen
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Mr. Ken Fuchs
Mr. Robert Gasper
Mr. & Mrs. Jeff Gaspin
Mr. Randy Gerston
Gold & Gold
Mr. Charles Goldwasser
Mr. & Mrs. Burton H. Greenberg
Mr. David M. Greenberg
Ms. Isobel Griffiths
Mr. Randy Grimmett
Mr. Andrew Gross & Ms. Gieri Kelly
Mr. & Mrs. Francis Gyermek
Mr. & Mrs. Paul Haslinger
Mr. & Mrs. Richard Heller
Hertz & Lichtenstein, LLP
Mr. Jeff Huang
Mr. Rich Jacobellis & Ms. Moanikeala Nakamoto
Jacobson Insurance Agency Inc.
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Ms. Laura Karpman
Mr. Vaughan Kastor
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Mrs. Nanette Klein
Mr. Jeffrey Korchek
Mr. & Mrs. Thomas Kuhny
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Mr. & Mrs. Robert Messinger
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Ms. Denise Morello
Mr. & Mrs. Michael Morris
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Mr. David Newman
Mr. Steve Newman
Mr. Michael O'Brien
Mr. Kevin O'Connor
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Mr. David Schwartz
Shenfeld Law
Mr. Clinton Shorter
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Worldwide Production Agency
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Zembo Medical Mail Network, Inc.

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Ms. Angela Pistilli

NEW MEXICO CHALLENGE
California Pizza Kitchen, Inc.

TEAM MGF
Greenrock Corporation
Vivendi Holding Corp.

VUS

(continued from page 1)

was changed from a C to an A.

- **Alias:** This is the "word" or amino acid (AA) level. The number means which place the "word" is that was changed. For #10, the 12th AA is expected to be a His (histidine) but has been changed to a Gln (glutamine).
- **Phenotype:** This is the general presentation of CMT in the cases where the mutation was found. CMT1 = demyelinating CMT. HNPP = hereditary neuropathy with liability for pressure palsies. DSS = Dejerine Sottas syndrome (early onset, severe CMT). Polymorphism = does not cause CMT.
- **Citations:** Here, the papers that reported this variant are listed so a researcher can look up the study and find out more information.

The IPNMD has a fairly complete listing of variants through 2007. However, many VUS have been reported since then. The next place to look is in PubMed (pubmed.gov), a medical science library of peer-reviewed journal articles. It is possible to search PubMed by title, keyword, or author. However, not all articles are available free to the public. You may want to have a doctor, genetic counselor, or other researcher who has free access through their institution help you with this literature search.

Finding patterns

Even if your VUS has not been reported, it may be possible to infer whether it is disease causing. For example, if it is in an area of a gene where every alias around it with an AA change causes disease, it is more likely that your VUS is also causing CMT. There are some genes where all AA changes have caused disease, such as *GJB1* (which causes CMT1X). If there is an AA-changing variant in this gene, it is very likely to be disease causing. That is different from the gene *PRX*, where even AA-changing variants do not always cause CMT.

Another way to provide evidence for a VUS to be disease causing is to see if it tracks with the family. Do all the people in the family with CMT have the VUS? Is there anyone without CMT who has the VUS? Is there anyone without the VUS who has CMT? If the VUS follows the pattern of the family, there is more weight toward it being the cause of the family's CMT.

Even going through all these steps it may not be possible to figure out if a VUS is the cause of the CMT in your family. Hopefully, though, this information will arm you and help you to be more informed about the genetics in your family. ★

GIFTS WERE MADE TO THE CMTA

IN MEMORY OF:

Janet Birdsall Bance
Mr. & Mrs. Keith Bance

Larry Christopher Blevins
Mrs. Dorene Ronish

La Rue Fatur
Ms. Lisa Rohrbacher

Anita Flynn
Mr. & Mrs. Richard Budnar
Mr. & Mrs. William D. Rehm

Jeffrey Gerry
Ms. Betty C. Gerry

William Gerry
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Mr. & Mrs. Steven O'Donnell

Mary Elizabeth York
Ms. Betty J. Fletcher
Ms. Cathleen Smith

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Mr. & Mrs. Warren Gutting

Riley Ashe
Mr. John McCarthy

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The Capital Group Companies Charitable Foundation

Jacqueline Dyer
O. A. Peterson Leadership Assoc & Safety Patrol

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Mr. Timothy Trankina

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Ms. Martha Clark

Tyler Lopez
Mr. Alan C. Kaspar
Mrs. Jean A. Moore

Carolyn Mann
Ms. Tammy Mann

Elizabeth Ouellette
West Chester Area Support & Action Group

The Parrott Family
Ms. Martha Clark

Elaine Peck
Mr. Allen Peck

Julian Rome
Mr. & Mrs. Jeffery Rome & Family

Ellen Schleifstein
Ms. Diane Gross

Frank Showalter
Mr. Christopher Hood

Rylee Sweeney
Dr. Jack A. Graves

Deborah Vangelos
Mr. & Mrs. Jeffery Rome & Family

Alexander Vangelos
Mr. & Mrs. Jeffery Rome & Family

West Chester Area Support & Action Group
Mr. Robert Price

Making Changes:

MY JOURNEY WITH CMT AND MY HOPES FOR STAR AND IMPROVED DISABILITY LAWS

My name is Vikki Vance and I am a 27-year-old from Columbia, MD. I am a dog lover, crafter, and caffeine and pinterest (an online pinboard where you can share and organize things you love) addict. My likes and interests aren't much different from those of other people my age.

My life, goals, and dreams, however, are quite different from most.

I was three years old when I was diagnosed with CMT, but at the age of 12 I was diagnosed with hip dysplasia. My initial surgery took place a month after my diagnosis, and things got progressively worse. I had four failed hip replacements in 18 months. Twice I was infected with MRSA (Methicillin-resistant *Staphylococcus aureus*), and once I went septic and feared I would lose my leg. The fancy reconstruction that was done on my pelvis has only been done to about 50 people in the entire world. With only one hip, I am literally a case study. You should see the x-rays. Years ago my mother said something that will stay with me for the rest of my life: she told me, "You can either let it beat you, or you can pick yourself up and keep going."

Living with CMT, my eyes have been opened to a ton of things that need to be changed in public facilities. For those of us who use wheelchairs or have physical limitations, public facilities can be grossly subpar in terms of accessibility. There are thousands of nice people out there, but we shouldn't have to rely on the kindness of strangers. Even though it is not intentional, we are discriminated against, and that needs to change.

While the ADA laws are extensive, there are some aspects of them that need to be updated, and some aspects that should be better enforced.

The top priorities for me are:

- Any door that allows entrance and exit to a building needs to have either a push button to open the door or an automatic sensor to open it.
- Doors also need to be the correct size. An XL wheelchair should be able to fit through comfortably, without the wheelchair owner's knuckles being whacked against the frame (I know some of you know exactly what I'm talking about!).
- There is a need for more handicap parking spots, and better policing of these spots.
- Ramps and crosswalks need to be placed in areas nearby handicap spots, as well as near entrances and exits. Ramps don't have to be fancy—they just have to work and be safe.
- Inside establishments, the aisles should be clear. There should be enough space to move easily between racks of clothes and displays in grocery stores, for example.

There should be consequences when establishments don't follow the ADA rules. One thing that I think business owners don't realize is that when an establishment is not handicap accessible, they are cutting out a huge group of potential buyers, and a huge source of potential revenue. A great idea would be to offer grants for building owners who want to make their facilities handicap accessible.

The STAR program is in desperate need of funding and support. I have recently decided to start fundraising by selling the crafts that my friends and I make, with the proceeds going to the STAR program. We will be making jewelry, paintings, vases, bags, boxes, and more. I'm going to have craft parties at least once a month. I would absolutely love it if you would join me, and make this effort nationwide, with craft groups in every state. Since this will start on a small level, I'm going to sell our crafts at church fairs, work, etc. If we are able to get this off the ground (I'll need your help), I will start a page on Etsy (an Internet site where you can buy and sell handmade items). I'd love your input on this idea and the above-mentioned thoughts on changing disability laws. Please feel free to contact me through the CMTA at victoria@cmtausa.org. ★

Vikki Vance hopes to support the STAR program by making and selling her crafts and by encouraging others to do the same.

SUPPORT AND ACTION GROUP NEWS

CA—San Francisco Peninsula

The group met on February 25, 2012

The speaker for the group was Carly Siskind, MS, CGC. Carly is a board-certified genetic counselor with a specialty in CMT. She is currently working at Stanford Hospital and Clinics in Palo Alto, CA. She spoke to the group about Genetics and CMT. You can hear what Carly had to say at vimeo.com/37636725

CA—Santa Rosa

The group met on February 4, 2012

The group talked amongst themselves and covered a lot of topics. They plan to have a hand therapist at the next meeting.

FL—Inverness

The group met on January 28, 2012

The speaker for the group was Dr. Horn. Dr. Horn is a practicing chiropractor, and he also practices acupuncture. He spoke about the different types of equipment and procedures that he uses with his patients. The members felt that some of the things that were discussed could give patients with CMT some pain relief.

GA—Atlanta Area

The group met on January 21, 2012

Buzz Hanie from Allard spoke about the different types of AFOs that they make and offer. He also spoke about the benefits of the Allard AFOs. They help with foot drop, and the AFOs encourage the heel to strike the ground first, which in turns allows the foot to roll through the ground giving the foot an extra swing up. The AFOs also aid in the high steppage gait so commonly seen in CMT. According to Buzz, most insurance will pay for Allard products, just be sure it's coded as an AFO and not a foot orthotic, which most insurance companies do not pay for. Allard doesn't sell their AFOs to the public, only through orthotists.

IL—Chicago Area

The group met on January 28, 2012

The speaker for the day was Pat Livney, CEO of the CMTA. It was a wonderful opportunity for everyone to be able to meet Pat and hear him talk about all the wonderful opportunities that are in front of the CMTA. He spoke about the progress that has been made through the STAR program. He also shared the new CMTA Marketing PowerPoint presentation with the group. After Pat's presentation, the group had a much better understanding of the research process and how the CMTA runs their operations.

MD—Easton Area

The group met on January 7, 2012

It was only the second gathering and the group is growing, and so is overall community interest and awareness. It is also reassuring to note that the group is becoming more comfortable chatting amongst themselves. It was nice that Steve O'Donnell, from the CMTA Board, could join the group. He gave the group a better understanding of what the CMTA is doing and what is happening in the search for a treatment.

NY—Westchester

The group met on March 3, 2012

Motivational speaker Matthew Castelluccio was the guest speaker. Matthew is a mentor and adaptive sports coordinator at Helen Hayes Hospital in West Haverstraw, NY. He focuses on what he can do and is a true inspiration.

NY—Upstate Area

The group met on January 14, 2012

The group chatted about what speakers would interest them. They also discussed various supplements people have found to be helpful. For example, some are taking CoQ10 for energy. Also, hydrochloride tablets were recommended by a member as an aide for digesting protein, and treating bloating, gas, and acid reflux.

NM—Albuquerque

The group met on February 11, 2012

Gary (facilitator) discussed what's been going on in CMT research and the need to redouble our fundraising efforts, since the next phase of research is going to be costly. Then the group viewed the video that Elizabeth Ouellette's group made in California of a talk by Jonah Berger (author of *He Walks Like a Cowboy.*) Everyone responded very positively to Jonah's anecdotes and commentary on his life in dealing with CMT.

RI—Providence

The group met on February 25, 2012

The group discussed their last guest from Athena Diagnostics, the CMTA partnership with Physiotherapy Associates, and the strides that STAR is making with the possible treatment of CMT1A, CMT2A and CMTX. They also talked about the upcoming fundraiser, "Party For A Cure!" ★

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

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
Arizona CMT Support and Action Group
Pamela Palmer
480-926-4145

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
Steve Gabbert
619-987-6022

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

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

FL—Inverness Area
West Central Florida CMT Support and Action Group
Ronnie Plageman
352-860-1578

FL—Orlando Area
Central Florida CMT Support and Action Group
Julie & Mark Collins
407-786-1516

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

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

IL—Chicago Area
Chicago Area CMT Support and Action Group
Dale Lopez
708-499-6274

***IN—Fort Wayne Area**
Fort Wayne–Indiana CMT Support and Action Group
Aimee Trammell
574-304-0968
Priscilla Creaven
260-925-1488

***KS—Lawrence Area**
Lawrence, KS CMT Support and Action Group
Dudley Crow
785-760-3568

KS—Wichita Area
Kansas Area CMT Support and Action Group
Karen Smith
316-841-8852

KY—Burlington Area
Pam Utz
859-817-9338

MD—Hagerstown Area
Hagerstown, MD CMT Support and Action Group
Jeffrey Martin
301-582-2401

MD—Easton
Easton, MD CMT Support and Action Group
Missy Warfield
410-820-0576

ME—Portland Area
Portland, ME CMT Support and Action Group
Celeste Beaulieu
207-284-1152

MI—Chesaning Area
Chesaning, MI CMT Support and Action Group
Carolyn Koski
989-845-5731
Ellen Albert
810-639-3437

MI—Kalamazoo Area
Southwest Michigan CMT Support and Action Group
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
Clinton, MS CMT Support and Action Group
Flora Jones
601-825-2258

NC—Triangle Area
Triangle, NC CMT Support and Action Group
Betsy Kimrey
919-833-3991

NH—New Hampshire/Vermont
New Hampshire/Vermont CMT Support and Action Group

NJ—Central New Jersey Area
Central New Jersey CMT Support and Action Group
Mark Willis
732-252-8299

NM—Albuquerque Area
CMT New Mexico CMT Support and Action Group
Gary Shepherd
505-296-1238

NV—Las Vegas Area
Las Vegas, NV CMT Support and Action Group
Jerry Cross
775-751-9634

NY—Upstate New York Area
The Upstate NY CMT Support and Action Group
Melinda Lang
518-783-7313

NY—Horseheads Area
Horseheads, NY CMT Support and Action Group
Angela Piersimoni
607-562-8823

NY—Long Island Area
Long Island, NY CMT Support and Action Group
Ruth Korowitz
516-318-3202

NY—Westchester Area
Westchester, NY CMT Support and Action Group
Beverly Wurzel
201-224-5795

***OH—Cleveland Area**
Cleveland, OH CMT Support and Action Group
Heather Hawk Fran
440-479-5094

OH—Greenville Area
Greenville, OH CMT Support and Action Group
Dot Cain
937-548-3963

OR—Portland Area
Portland, Oregon CMT Support and Action Group
Debbie Hagen
503-333-7936

PA—Bucks County Area
Bucks County, PA CMT Support and Action Group
Linda Davis
215-943-0760

PA—Johnstown Area
Johnstown, PA CMT Support and Action Group
J.D. Griffith
814-539-2341
Jeana Sweeney
814-262-8427

PA—Northwestern Area
Erie, PA CMT Support and Action Group
Joyce Steinkamp
814-833-8495

RI—East Providence Area
Rhode Island CMT Support and Action Group
Meredeth Souza
401-433-5500

***SD—Hartford Area**
Hartford, South Dakota CMT Support and Action Group
Serena Clarkson
605-838-2331

TN—Nashville Area
Nashville, TN CMT Support and Action Group
Bridget Sarver
615-390-0699

TN—Savannah Area
Savannah, TN CMT Support and Action Group
Reagan McGee
731-925-6204
Melinda White
731-925-5408

TX—Dallas Area
Dallas, TX CMT Support and Action Group
Whitney Kreps
972-989-5743

***UT—Orem Area**
Orem, UT CMT Support and Action Group
Melissa Arakaki
801-494-3658

VA—Harrisonburg Area
Anne Long
540-568-8328

VA—Williamsburg Area
Williamsburg, VA CMT Support and Action Group
Jennie Overstreet
757-813-6276
Nancy Mollner
757-220-3578

WA—Seattle Area
Ruth Oskolkoff
ruth.oskolkoff@gmail.com

WA—Tacoma Area
Tacoma, WA CMT Support and Action Group
Carol Hadle
253-476-2345

WI—Milwaukee Area
Southeastern, WI CMT Support and Action Group
Polly Maziasz
262-439-9009
Margaret Hoepner
414-788-9628

WI—Brodhead Area
Southern, WI CMT Support and Action Group
Molly Hawkins
608-921-0032

***WV—Vienna Area**
Parkersburg / Vienna WV Support and Action
Rebecca Knapp
304-834-1735

GROUPS IN CANADA

***CA—Ontario**
Southern Ontario CMT Action & Support Group
Kelly Hall
519-843-6119

***CA—Montreal**
Montreal (Canada) CMT virtual support group
www.cmtausa.org/url/montrealsag

VIRTUAL/DISCUSSION GROUPS

Anyone Can Fundraise

Archy and Friends Discussion Group

Boston South Shore Voice Discussion Group

CMTAthletes

CMT Speaks

CMT and Fatigue Discussion Group

CMT and Pain...Share Your Experience Discussion Group

CMT Creates: Music Project Discussion Group

Global Support and Action Group Community

Hand and Finger Struggles with CMT Discussion Group

Insurance and Benefits Discussion Group

Marijuana and CMT Discussion Group

Parents with CMT Who Are Raising Kids with CMT Discussion Group

The CMT Outdoorsman Discussion Group

Trigger Points Discussion Group

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

**** WELCOME TO OUR NEW SUPPORT GROUPS!***

TAKE ACTION:* *If there is no Support and Action Group in your area, consider becoming a facilitator! If you are interested, please contact Jeana Sweeney at jeana@cmtausa.org.

Developing Resilience

Resilience has been defined by psychologists as the ability to adapt well to the difficulties in our lives including all kinds of adversity and stress. This ability decreases the risk for development of post-traumatic stress disorder. Resilience can help those of us who are coping with significant health challenges like dealing with neuromuscular disease.

Research suggests that humans are actually quite resilient.

Research suggests that humans are actually quite resilient. Resilience does not suggest, however, that a person does not experience distress, but instead that they find ways to cope and adapt. Strong supportive relationships strengthen resilience. Other factors include skills such as planning, communication, and problem-solving, self-control skills, and a healthy self-image.

While personal characteristics influence resilience, the ability to adapt well to difficulty can be strengthened. General categories for building resilience include: building positive relationships; cognitive strategies related to how one views one's self, problems and life changes; positive growth and goal directed behavior; self-care behavior, including maintaining life balance and flexibility; and spiritual practices. The best strategies for a particular person will depend upon that person's individual characteristics.

Resilience can also be strengthened through looking at and learning from the past. Considering times when an individual has had difficulties meeting challenges and times when challenges have been successfully met can help one to learn how to overcome future obstacles.

Parents can help their children develop the skills that they will need to build resilience through teaching them the types of strategies discussed above. Additionally, family characteristics such as family closeness, positive rituals, listening and communicating well, providing a safe and nurturing environment, and promoting skills such as empathy and perspective-taking can aid children in developing resiliency.

Many people will need assistance in dealing with the challenges of life. Along with support from our family and friends, sources for help can include self-help and support groups and informational resources. For some individuals, counseling from a licensed mental health professional can be beneficial.

Research has shown that people can learn to be resilient and to face adversity well. For those of us coping with neuromuscular disease, strengthening resilience can enhance our ability to cope and thrive.

—Jori Reijonen,
Michigan SAGF

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:_________________________
____

Grand Re-Opening of the CMTA Online Store!!

The CMTA Store is back and ready for business! When the new CMTA website launched in March 2011, the CMTA Store was unavailable. But, as of December 2011, the store is up and running. Take advantage of the store to get all of your CMT needs…including publications, multimedia products, and accessories to help raise CMT awareness. Also, with the opening of the store, we have added some fun new products!

NEW! CMTA T-shirts
Buy one for you and don't forget your family members! The t-shirts are available in blue and white.

NEW! CMTA Titleist hats…
People will go out of their way to ask you where you got this cool-looking cap! The hats are available in blue, red, and black.

NEW! Light-Up Star Necklace
Show your support for the STAR initiative with this light-up necklace. Includes battery and cord.

ONLINE DISCOUNTS

- Community members will receive 10% off each item (to be able to receive this discount be sure you are logged in on the website).
- Premium Content members will receive 20% off each item (to be able to receive this discount be sure you are logged in on the website).

Visit our store at http://www.cmtausa.org/url/store.

CMTA NEWSLETTER SUBSCRIPTION, PUBLICATIONS, AND ACCESSORIES ORDER FORM

NAME: ____________________/______/________________________________
First MI Last

ADDRESS: ____

CITY: ______________________________ **STATE:** _______ **ZIP:** ____________________

COUNTRY/POSTAL CODE (IF NOT US): ________________________________

DAYTIME PHONE: ______________________ **EVENING PHONE:** ______________________

EMAIL: ____

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

	SUBSCRIPTION OPTIONS	NEWSLETTER FORMATS		
N E W S L E T T E R	**Premium Content** *(with access to more online material and features)*	☐ **PDF only.**	**$25** ***(must register/purchase online)***	
		☐ **Both PDF and print.**	**$30** ***(must register/purchase online)***	
	Mail Only ***(NO access to online premium content)***	☐ **Print only.**	**$30**	

	QUANTITY	COST		TOTAL
		Regular Price	Subscriber 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 I ☐ English ☐ Spanish		$5	$4	
CMT Facts II ☐ English ☐ Spanish		$7	$5.60	
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	
West Coast Patient-Family Conference *(2-DVD set/5 hours)*		$20	$16	
Teaching Kids about CMT…A Classroom Presentation *(DVD set/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		
CMTA Brochure, Neurotoxic Drug Card, and Letter to Medical Professional with Drug List		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.

THE CMTA Report

The Charcot-Marie-Tooth Association
P.O. Box 105
Glenolden, PA 19036
1-800-606-CMTA FAX (610) 499-9267
www.cmtausa.org

CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):
Vinca alkaloids (Vincristine)

Moderate to significant risk:
Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddI, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Lefluonamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrodantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse)
Perhexiline (not used in US)
Pyridoxine (mega dose of Vitamin B6)
Stavudine (d4T, Zerit)
Suramin
Taxols (paclitaxel, docetaxel)
Thalidomide
Zalcitabine (ddC, Hivid)

Uncertain or minor risk:
5-Fluouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
Gemcitabine
Griseofulvin
Hexamethylmelamine
Hydralazine
Ifosfamide
Infliximab
Isoniazid (INH)
Lansoprazole (Prevacid)
Mefloquine
Omeprazole (Prilosec)
Penicillamine
Phenytoin (Dilantin)
Podophyllin resin
Sertraline (Zoloft)
Statins
Tacrolimus (FK506, Prograf)
Zimeldine (not in US)
a-Interferon

Negligible or doubtful risk:
Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Fluoroquinolones
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

WHAT IS CMT?

- 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 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN can now be diagnosed by a blood test.
- CMT is the focus of significant genetic research, bringing us closer to solving the CMT enigma.