

THE CMTA Report

JANUARY/FEBRUARY
2011

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



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.

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The Neuropathy Association Hosts a Neuropathy Summit

BY PAT DREIBELBIS

From December 3–5, the Neuropathy Association hosted a conference on “Probing the Paradoxes of Neuropathic Pain” at the Washington Hilton Hotel in Washington, DC. After the welcomes and general overviews of the conference, Dr. Marc Treihaft, Colorado Neurological Institute, presented a discussion on “Living with Neuropathy, Diagnostic Tools and Symptom Assessment.” Dr. Treihaft discussed the usual diagnostic tools (nerve conduction velocities, EMGs, and, for some types of neuropathy, metabolic studies). He made some interesting general statements such as problems with sleep being typical for patients with neuropathies. And, in response to the questions about alcohol and neuropathy,

he replied that one glass of wine for women and two glasses for men is considered the safe limit for drinking.

Another interesting topic was “Partnering with Your Doctor: Asking for Help” presented by Dr. Mazen Dimachkie, of The University of Kansas Medical Center. An important concept in talking to your doctor involves the fact that a person with neuropathy can have allodynia, pain from normally painless stimuli, such as bed sheets or ceiling fans. It is crucial to understand that coping with pain is a dynamic process and you must always keep your doctor apprised of new health issues. Trust is the foundation of a good relationship with your doctor. At the first visit, realize you will be emotionally charged, so be prepared and organized. Give a

THE CMTA REPORT GETS COLOR

Thanks to advances in print technology, we've been able to add color to our newsletter without increasing our production costs. We hope you enjoy our new look!

chronological history, provide your medical records, and have a list of questions. Exchange your expectations with your doctors. One of you might wish for a “cure,” but the other may be delighted with an improvement in comfort. If there are any changes in your health, such as a change in the pain you experience, the falls or imbalance you are having, any new weakness, or a sudden rapid progression, you must let your doctor know about these new problems.

Dr. Alan Berger of the University of Florida, Shands,

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20 YEARS OF SERVICE

Pat Dreibelbis has been a key participant in the CMTA's growth over the past two decades.

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Thank You, Pat Dreibelbis, for 20 Years of Commitment and Dedication!

BY ELIZABETH OUELLETTE

Mentor, historian, author, event planner, speaker, comedian, and close friend are just a few of the words that come to mind when I think of Pat Dreibelbis, CMTA's Director of Program Services, who officially celebrated her 20th anniversary with our association in November, 2010.

Pat began her tenure at the CMTA in 1990, as a part-time employee. Then president Karol Hitt hired her as a writer to add substance and flair to the CMTA newsletter, essentially a scientific journal at the time.

As the CMTA's first officially paid employee, Pat not only redesigned and jazzed up the CMTA newsletter, but also took it upon herself to learn more about Charcot-Marie-Tooth disease both from a medical standpoint and a patient's point of view.

In the 1990s, the CMTA was so small and intimate, Pat came to personally know most of the 400 to 500 donors, and many of the 1,200 members. By 1991, Pat became the CMTA's first full-time employee, whose responsibilities expanded rapidly to include everything from compiling data entry, planning patient/family conferences, attending scientific meetings, answering patient questions, and writing articles about CMT to representing the CMTA nationally when she took over the role of editor of *The CMTA Report*.

An accountant was hired to handle all the data entry and book-keeping, and Pat finally enjoyed the companionship of another full-time employee.

Looking back, Pat reflects on where the CMTA is today, compared to 20 years ago, "At the November, 2010, consortium in San Diego, where world-renowned researchers came together to discuss therapeutic options for CMT Type 2, I simply could not stop thinking about just how far the CMTA has come over the years. To experience, first hand, the power, scope, and magnitude of our current association is both amazing and slightly surreal."

Indeed, with a staff of five full-time employees, a very involved board of directors, a collaborative external scientific advisory board, and approximately 60 support and action groups nationwide, the CMTA has grown and matured immeasurably in the realms of patient services, research through the STAR initiative, and overall recognition as a unique and valuable entity.

Today, Pat's title is Director of Program Services, but her job responsibilities are as eclectic and as varied as ever. One of her recent projects has been assuming the persona of the CMTA's mascot, Archy the Turtle. Tina Thomas, Archy's creator, willingly gave the Archy design to the CMTA to be used as a mascot for the kids' page. But Pat felt that Archy needed to be put into



Pat Dreibelbis wears the diamond star that she was given to commemorate her twenty years of service to the CMTA.

context, given a family, a home, and adventures. Archy's stories can now be found in the CMTA newsletter and on Facebook (<http://www.facebook.com/pages/Archie-the-CMTA-Turtle>), where he chats with "friends" from all over the world about CMT-related issues.

Pat also spends a good part of her day answering phone calls from people who have CMT-related questions. Some need information, and some need a shoulder to cry on, a few gentle words, or a hand to hold. Pat is always ready to listen with an open heart and an open mind; she is the heart and soul of our organization.

Asked what she most admires about those with CMT, Pat responded with, "...their determination, hope and unrelenting curiosity." To all those

living with CMT and their families, Pat's message is one of hope and promise: "The future is bright and hopeful, so never, ever give up. There are so many adaptive ways of living life to the fullest, despite your CMT, so don't ever give up your dreams."

Pat also wanted to give a special shout-out to Dr. Robert Lovelace, Chairman Emeritus of the CMTA's medical advisory board. Now in retirement, Dr. Lovelace, a neurologist, used to see CMT patients at Columbia Presbyterian in New York City. "Dr. Lovelace is the perfect embodiment of a caring, competent, and inquisitive human being. He spent innumerable volunteer hours working with the CMTA to help the association gain

recognition, growth, and success. Though no longer practicing medicine, Dr. Lovelace's unquenchable thirst for knowledge and answers has not dwindled in the least. I am forever indebted to him for all he has

"I simply cannot stop thinking about just how far the CMTA has come over the years."

taught me over the years and all that he has accomplished on behalf of the CMTA."

Reflecting on how she would sum up her job experience at the CMTA over the past 20 years, she cautiously remarked that, "For me, the more things change, the more they stay the same." She went

on to explain that, "Despite the positive and rapid evolution of the CMTA, my job of connecting with people on many different levels is still one of the things that gives me enormous satisfaction, and also keeps me motivated, involved, and enthusiastic."

On behalf of all our members, friends, staff, and the entire board of directors, I'd like to acknowledge Pat for being an instrumental source of inspiration and success throughout 20 years of service to the CMTA. Her impact on our association is immeasurable and her tenure extraordinary. The CMTA would not be where it is today without her. We are eternally grateful for her personal contributions to our success. ★

NEUROPATHY SUMMIT

(continued from page 1)

Jacksonville spoke about neuropathic pain treatments that are currently available. For symptomatic treatment, the doctor must first find the exact cause of the pain. He or she must differentiate between neuropathic pain, muscle weakness, gait imbalance, sensory loss, or mood dysfunction before the appropriate medication can be found. The vicious cycle of pain begins with the actual pain, followed by sleeplessness, and finally mood impairment. Pain will change in quality from one day to the next.

Another difficulty in finding appropriate medication is the

fact that response to medication is highly individualized and difficult to predict. The doctor should titrate medication strength upward according to the effect and considering possible adverse reactions. It is important to avoid premature discontinuation because a slightly higher dosage might be the perfect solution to a medication that didn't seem to be working well. It's even possible that a drug combination will be the solution. The patient and doctor need to have a dialogue regarding expectations. In reality, a 40% reduction of pain is a good outcome, but a patient might be expecting a complete relief of pain.

Current neuropathic pain medications that were part of the

presentation include gabapentin, pregabalin, Cymbalta, amitriptyline, tramadol, Lidoderm patches, capsaicin, and opioids. Nonpharmacological pain management options include transcutaneous electrical nerve stimulation (TENS), massage, heavy socks, proper shoes, rest, and management of activities.

In general, the participants seemed to universally express a concern for the lack of knowledge about neuropathies in general and about the treatment options for neuropathic pain in particular. A quotation from Senator Edward Kennedy summed up the message of the meeting, "The work goes on, the cause endures, the hope still lives, and the dream shall never die." ★

THE CMTA "CIRCLE OF FRIENDS"

As can see, the past several months have been a busy time for the CMTA Circle of Friends program.

And there's more to come. In 2011, Ken Gomez is going to ride from Anacortes, WA, to Bar Harbor, ME, and up to \$22,000 in sponsoring gifts will be matched by the Paul Flynn Charitable Trust. (Visit www.cmtausa.org/kensride for more info and keep up with Ken on Twitter at <http://twitter.com/KensRide>.)

Also in July, 2011, Doug Allie, who doesn't have CMT, is planning a 14-day, 355-mile run across Michigan's Upper Peninsula to help find a cure for CMT, which does affect his son Jacob (www.cmtausa.org/runacrosstheup).

Whether you walk, run, or climb or would just like to help raise funds for CMT research, you can take up the challenge and start your own Circle of Friends. It's easy. Just call us today at 1-800-606-2682, email us at cof@cmtausa.org, or visit us on the web at www.cmtausa.org/cof.

Working together, we can create a world without CMT!

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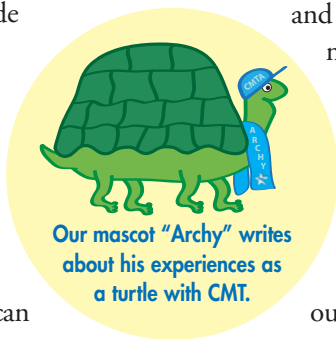
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Archy Contemplates Heredity

I had a wonderful holiday vacation with my family. I hope you all did, too. We stayed home and my grandparents on my mother's side visited us. My grandfather, Ralph Turtlebaum, and my grandmother, Esther Turtlebaum, live close enough that they can visit more easily than my father's family. His family, the Shelleys, are a state away and as slowly as turtles travel, it's just too far to go in the winter.



The reason the Turtlebaum's visit was important is because it's that side of the family that has CMT type 1X. My PopPop Turtlebaum has really obvious signs of CMT just like I do, but my mother, who got it from her father, really hasn't had many problems yet. She does get really tired from standing on her feet too long when she's cooking holiday meals or shopping, but so far, she hasn't needed braces or even physical therapy. My PopPop was trying to explain to all of us how X-linked CMT works. The one thing I got out of his "talk" was that I could have boy turtles without worrying about passing on the CMT, but all of my daughters would have it on one of their X chromosomes. I am really far from thinking about having children, but I thought that was an interesting point anyway. People who have other forms of CMT can pass it on to either their boys or their girls.

The reason my mother doesn't have very serious characteristics of CMT (yet) is because she has another X chromosome and it can be dominant, making the X with the CMT less of a problem. My PopPop's mother, who had CMT and passed it to him, developed more serious issues as she aged.

Eventually, she needed a walker to get around. I don't remember her, but my mother said she was pretty weak before she passed away.

If this discussion doesn't seem like a very good holiday event, it really was. Lots of my cousins and aunts and uncles were around, and it was the first time that all of them knew what I had that made me walk funny and how the inheritance worked

in our family. My PopPop said that holiday gatherings are actually great places to bring up CMT and to make sure that no one in the family is ignorant of the fact that it is genetic and that in our X-linked family it can seem to skip generations when it really isn't doing that.

On a personal note, I think some of my more aggressive cousins treated me with a little more respect this year. They were actually curious about my orthoses and a little jealous of how cool my camouflage pair really is.

I want to start the New Year by thanking everyone at the CMTA for a fabulous 2010. I got to travel to so many conferences and fundraisers that I felt very special. For a little turtle like myself, it can be overwhelming, but exciting, nonetheless. Here's to an equally great 2011! ★

TRACKING KEN'S RIDE ACROSS AMERICA FOR STAR

NORTHERN TIER
LEWIS & CLARK UNDERGROUND RAILROAD
TRANSAMERICA
GREAT RIVERS SOUTH
AS YET UNMAPPED

Ken Gomez plans to ride 5,000–6,000 miles across America from Anacortes, WA to Bar Harbor, ME in June 2011 in support of the Star Research Initiative.

Learning to live with CMT: *A mother's mission, a young man's journey*

Reprinted from the Los Altos Town Crier, January 6, 2011

BY MARY BETH HISLOP

One in every 2,500 people is born with Charcot-Marie-Tooth disease (CMT), an inherited peripheral neuromuscular disorder that afflicts more than 2.5 million people worldwide—approximately as many as suffer from multiple sclerosis.

Los Altos resident Elizabeth Ouellette learned 10 years ago that CMT has nothing to do with teeth.

Ouellette emigrated from France to the Bay Area with her husband, Gilles Bouchard, and son Yohan, then 3 years old. A fairly typical toddler, Yohan was walking—but he was navigating on his tiptoes.

“We knew intuitively there was something wrong,” Ouellette said.

A pediatric exam uncovered tight muscles in the Achilles’ heels, and the doctor recommended physical therapy. Three years later, when a pediatrician discovered Yohan had no deep-tendon reflexes, he recommended that Yohan see a pediatric neurologist.

Dr. John Sum diagnosed CMT through a DNA blood test when Yohan was 7. Although there are 40 types of CMT, Sum discovered the needle in the haystack after one test—the most common form, CMT1A. The diagnosis of an obscurely known disease and its type answered

some questions about Yohan’s symptoms but offered no hope.

“There are no treatments and no cures,” Ouellette said. “And it’s progressive.”

Living to learn

The Ouellette-Bouchard family would learn much about CMT in the ensuing months, but it wouldn’t be through local support groups—there weren’t any for Charcot-Marie-Tooth.

Because CMT affects the nerves, doctors suggested a muscular dystrophy support group, which couldn’t offer much information on Yohan’s affliction.

Three years later, Ouellette learned of the Charcot-Marie-Tooth Association, a non-profit organization founded in 1983 to support patients and family, educate the public and promote research for treatments and a cure.

Discovered in 1886 by three physicians—Jean-Martin Charcot, Pierre Marie and Howard Henry Tooth—the disease is a progressive deterioration of the peripheral nerves that control sensory information and muscle functions of the lower leg, foot, hand and forearm. It crosses all racial, ethnic and geographic borders.

In layman’s terms—the duplication of the gene in CMT1A prompts an overproduction of protein that causes the deterioration of myelin, the insulation surrounding nerve fibers. As the myelin deteriorates, exposing the nerve fibers, those begin

to deteriorate as well, resulting in nerve impulses no longer able to transmit efficiently.

The disease can affect reflexes and the feet—bone abnormalities, high arches, hammertoes—and contribute to muscle loss, balance problems, decreased hand function and clawed fingers, arm- and leg-muscle cramping, spine curvature and, at times, breathing difficulties.

First symptoms include leg weakness, frequent tripping and loss of balance. Anyone whose parent has CMT has a 50 percent chance of inheriting the disorder, which may not be diagnosed until well into middle age. The severity of the disease varies greatly, even among those in the same family with the same type of CMT.

“[Doctors] don’t understand why,” Ouellette said. “It’s just the way it is.”

What perplexed Ouellette and her husband was that neither has CMT—nor does anyone in the family. Yohan’s disease was caused by an inexplicable, spontaneous mutation of a gene now encoded in his own DNA.

“For Yohan, there will be a 50-50 chance his children will have CMT,” she said.

Ouellette dove into the association’s mission to educate the health-care community and the public—and, more importantly, to help support the growing numbers affected by the disorder, expanding national support groups from 16 to 50 across the country; establishing a

local support group that meets quarterly at the Los Altos main library; convening a CMT summit in Palo Alto for patients, family and health-care providers; and accepting a position on the association's board of directors.

Sept. 19-25 marked a coup for Ouellette and CMT—the first CMT Awareness Week. After a visit to Congress, Ouellette hopes to convince legislators that September should be CMT Awareness Month.

Learning to live

A mere 7 years old, Yohan was equally confused about doctors' CMT diagnosis.

"At first, no one knew what to do with it," Yohan said. "They told us it would just go away."

But CMT doesn't go away, though physical therapy, corrective orthopedic surgery, leg braces and other devices can alleviate symptoms. Still, no one warned Yohan that classmates could be so cruel.

Yohan's years at Oak School were filled with taunts and humiliations inflicted by fellow students. Prone to tripping often and slower on his feet than others, his peers didn't understand that he was challenged by a debilitating disease.

"It was brutal," said Yohan, now 17. "I couldn't do all the physical activities."

Ouellette visited the school to make a special presentation on CMT so that children would understand the disease and what Yohan was experiencing. Their attitudes changed—"People apologized," he said.

Now enrolled as a junior at Palo Alto Preparation High School, Yohan loves English, his-

tory and math (calculus, mind you), enjoys computers, archery and soccer—"I try to play every day"—and challenges competitors in the popular trading-card game Magic: The Gathering. Shelves lined with books in his room attest to late nights of reading.

While he tries not to let CMT limit his activities, Yohan continues to suffer from the disease's effects—tiredness, sleep apnea, heat intolerance and hand tremors.

"My handwriting's pretty bad, but I'm pretty lucky," he said. "Some people can't grip and can't write."

He also can't stand for long periods of time, which makes his

small school an ideal place for him in moving from class to class—along with its flexibility.

"I have lots of doctor appointments," Yohan said. "Otherwise, I try not to think about (CMT)."

A STAR is born

In 2008, the association launched Strategy to Accelerate Research (STAR) to fund the CMT-related studies of international researchers searching for understanding and a cure for the disease.

Because scientists have identified CMT's causes and pinpointed more than 33 gene defects associated with the disorder, it has become easier to

(continued on page 14)



NORTH CAROLINA SUPPORT GROUP MEMBERS TOUR GE AVIATION

After hosting the Second Annual CMTA Golf Outing, GE Aviation in North Carolina reached out to the area support and action group. Joe Sweeney, one of the event coordinators, invited the support group members to tour GE's facility. The thought behind the invitation was to create more awareness for the employees and to have the employees meet some of the people that they raised funds for. The support group members felt very welcomed and pleased that people other than those directly affected by CMT showed interest in helping people with CMT. Thanks to GE Aviation for another successful event!



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Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013.

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Mr. & Mrs. Mark Miller
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Mrs. Jennifer S. Spinney

Emily Louer

Mr. Arthur B. Mayers

Tom Lynch

Ms. J. C. Julian

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Kim P. Marshall

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Elizabeth Ouellette—Happy 48th Birthday

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Ms. Carol Bomberger
Mr. & Mrs. John Chernega
Mr. Jim Chernega
Ms. Catherine Dhayer
Monson
Mr. J. Dual
Mr. James Fitzgerald
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Ms. Catherine Gannage
Mr. Frank Ghali
Mr. Randy Haldeman
Mr. Richard W. Hanzel
Mr. & Mrs. Said E. Hassan
Ms. Tracy Larocque-Dorey

CORRECTION/OMISSION

In the November/December issue of the newsletter, we reviewed a new children's book called *One More Time*, by Jack Graves. We did not note that the book can be purchased at discount on Amazon.com or Barnes&Noble.com. Also, Mr. Graves has just informed us that all royalties he receives from the sale of the book will be given to the CMTA.



Ms. Yazmin Martinez
Ms. Terry Ann McIntosh
Mrs. Beverly O'Free Rooney
Mr. Chris Ouellette
Mr. Richard C. Rekoon
Ms. Sandy Sans
Dr. Steve Scherer
Mr. Neal B. Schirle
Ms. Emily Slichter
Ms. Kathleen Vandevord
Mr. Vasi Vangelos
Mr. Frank Weiss
Ms. Gail A. Whitehouse
Mr. & Mrs. Linn B.
Winterbotham
Mr. Wesley Wright
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Anna Maria Park

Mr. John Park
Joe & Sue Paterno
Mrs. Cynthia Ault

Barbara & Kaye Pearce

Dr. Beth A. Bauer

Merrie & Terrie R.

Mrs. Caroline D. Rosengarden

Debbie Rannie

Mr. Mike Rannie

Mr. & Mrs. Dean Reynolds

Mr. Nehemiah Hasak

Kathy Roberts

Ms. Joann Stephan

Beverly O'Free Rooney

Mr. & Mrs. Christopher
Ouellette

Mr. Justin Ross—Happy Birthday

Julie Ross

Deborah M. Rozanski

Mr. Andrew G. Volovar

Stephen J. Schaefer

Ms. Margaret G. Schaefer

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Dr. Jean Schott-Wagner

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Ms. Emily Sharp
Mrs. Linda Sharp
Mr. Donald Sharp

Kelsey Shinnick

Mrs. Amy Shinnick

Catherine Howett Smith

Ms. Catherine M. Howett

Rebecca Stern

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Grayson Thomas

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Mr. & Mrs. Robert J. Elliott

Vasi Vangelos

Mr. Matthew Walker
Harriet Weiss
Ms. Erica J. Berger

Steven Weiss

Mr. Gene Rosengarden

Karen West

Mr. Steve West

James P. Whitten

Ms. Janice Flower

Betty Williams

Ms. Judy L. Williams



ASK THE DOCTOR

Dear Doctor,

I have mild Reynaud's disease, which seems to be worsening as my CMT 1B worsens, and I'm wondering if Reynaud's is common among people who have CMT since the nerves in the hands and feet are affected. I've read that some people who have Reynaud's have diseases that affect the nerves in their hands and feet that in turn affects the blood flow.

Dr. Michael Shy replies,

I don't recall seeing Reynaud's per se in our CMT1B patients. However, particularly when there is a lot of atrophy, hands have been cold and pale, with substantial sensory loss.

Dear Doctor,

I recently went to a Pain Clinic in town and to add to a regimen of pain meds the doctor suggested a "lidocaine infusion" treatment. This would involve an IV push every 2 weeks, in the hospital. Each appointment would be 2 hours and last approximately 14 weeks. The suggestion did not come from my primary physician but a doctor in the pain clinic. This is only the 2nd time I have seen him but he has a strong grasp of my history [because I clearly conveyed that]. I am not sure why but he and his team were eager to sign me up. Naturally, I hesitated because I wanted to 1) run it past my primary physician, 2) do my own research, and 3) check in with other people with CMT. My quick research on lidocaine shows that it's a simple drug that is typically used for temporary relief at dentist

appointments. I found very little on this in the area of infusion, CMT, and/or neuropathy pain.

Dr. Louis Weimer replies,

Lidocaine is a commonly used anesthetic and is very safe when administered locally on the skin or by low-dose local injection. Intravenous lidocaine is a serious treatment that has potential anti-heart arrhythmia and other effects. There is no evidence that it is more dangerous in CMT patients, but adequate justification and adequate monitoring are needed during the treatment. I have not heard of its use for neuropathic pain in this manner.

Dear Doctor,

I searched the Ask the Expert section and did not find any mention of atrial fibrillation. One of the drugs used to treat atrial fibrillation is a rhythm-control medication called amiodarone (Cordarone) which is on the CMT Medical Alert list. I would like to know if the next generation of that drug, dronedarone (Multaq), which is supposed to be much safer than amiodarone, poses the same risks or if it would be safe for a person with CMT to take to treat atrial fibrillation.

If possible, I would also like to know if the incidence of atrial fibrillation or cardiac arrhythmias, in general, differs in people who have various forms of CMT compared to people who don't have CMT.

Dr. Louis Weimer replies,

Yes, the drug amiodarone poses a significant risk of neuropathy

and may increase the neuropathy of CMT patients. It also has a very long half-life, meaning that it stays in the body for a considerable period after stopping the drug. The new drug, dronedarone (Multaq) seems to have considerably less neurotoxicity, including neuropathy. There are no clearly reported cases of neuropathy in patients taking the drug: however, the drug is relatively new. Most forms of CMT do not affect the heart and atrial fibrillation does not seem to be more common in CMT patients.

Dear Doctor,

I have read the data base and there is little information about testosterone shots. Can you comment? My muscle strength is rapidly failing because of age and CMT. Local doctors not well versed in the possible improvement provided by testosterone shots only quote negatives, such as prostate danger. I would like to weigh the good and the bad.

Dr. Louis Weimer replies,

Testosterone treatment is not a currently recognized treatment for neuropathy-based muscle weakness. However, weakness is a complication of low testosterone levels and may add to CMT-based weakness. The testosterone level is easily measured and should be tested for you, appropriately.

Dear Doctor,

I have CMT1A. I experience severe pain in my adductor,

WRITE TO US!

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CARD ISSUED FOR AIR TRAVELERS WITH DISABILITIES

The US Department of Homeland Security has issued a notification that should make commercial air travel a little easier for people with disabilities.

The blue, wallet-sized card allows people to discreetly notify security personnel of a disability, medical condition, or medical device that might affect the screening they're required to undergo before boarding a plane.

The government agency says the optional cards serve the dual purpose of protecting passenger privacy and facilitating the screening process. Although the card doesn't allow the user to skip the screening, it states that "alternative procedures which provide an equivalent level of security screening are available and can be done in private."

The card can be downloaded as a PDF file and printed on a home computer, then filled in with the user's personal information. The link to the PDF is <http://quest.mda.org/news/card-issued-air-travelers-disabilities>. ★



quadriceps, and hamstring muscles. My gait has been altered due to the instability and deformities in my feet and lower legs. I have been treated for trigger points and tendinopathy in some of the aforementioned muscles. I have extreme weakness in these muscles and limited flexibility. The muscles stay taut and I have continuous pain especially where my adductor fascia attaches to the pelvis. My question is, "Is it possible to develop spasticity because of CMT?" Also, I am looking into medication to help relieve some of the chronic pain I am experiencing. I am considering Zanaflex or indomethacin. Would either of these be appropriate for me?

Dr. Steven Scherer replies,
CMT1A does not cause "spasticity," using the strict definition of this word, and would likely mask it. If you have spasticity, CMT 1A is not the cause, and a thorough evaluation is needed. If you have spasticity, then

Zanaflex would be an appropriate medication.

One would expect that the muscles below the knees are weak, but it would be unusual to have weakness in your thigh muscles, and I cannot deduce why you experience "severe chronic pain" in your adductor, quadriceps and hamstring muscles.

I would suggest that you been seen by an experienced neuromuscular physician.

Dear Doctor,

I have CMT 1B with a gross mutation, whatever that means. I also have Adie's pupil. My mother, grandmother, two uncles, three cousins, and two of my children also have been diagnosed with the disease and they all have Adie's pupil. Is this common with other CMT patients?

Dr. Steven Scherer replies,
There are some MPZ mutations that cause a form of CMT1B in

which Adie's pupil is a characteristic finding. If you send me the information regarding your mutation (the genetic test and the EMG results), I may be able to give you more advice.

Editor's note: Adie's pupil is a neurological condition of unknown origin with an unusual, asymmetric presentation known as anisocoria, an inequality in the size of the pupils of the eyes. It is believed to be a result of damage to the nerve innervating a muscle of the eye known as the ciliary body.

Dear Doctor,

Are there any subtypes of CMT1 that are known to cause a vitamin B12 deficiency the way multiple sclerosis (MS) does?

Dr. Steven Scherer replies,
The question is worded incorrectly. B12 deficiency can cause a neuropathy and mimic some aspects of MS. Neither MS or CMT causes a B12 deficiency. ★



SUPPORT AND ACTION GROUP NEWS

AZ – Phoenix Area

The group met in November to celebrate their one-year anniversary as a group and shared a potluck lunch. The meeting was held at the Arizona State University Walter Cronkite School of Journalism, where space has generously been provided all year. Thirteen members heard a presentation on occupational therapy. Tammy Marano from St. Joe's Hospital had hands-on demonstrations with equipment that makes it easier to perform activities of daily living.

DC – Washington DC Area

The DC metro area support and action group held its third meeting in early December. More than 30 people attended to hear a presentation from Dr. Thomas Lloyd, Assistant Professor of Neurology and director of the CMT Clinic at Johns Hopkins University about the CMT Center of Excellence. The next

meeting will be in March 2011 and will be a discussion format with several members sharing their experiences with CMT.

FL – Tampa Bay Area

The November meeting was attended by 36 people, several of whom were new and several who were welcomed back after a long absence. Two representatives from Walgreens discussed the flu shot partnership with the MDA. An attorney discussed patients' rights and the issue of advocacy. Vicki Pollyea reported on her attendance at Cooterfest and the success of the Archy train, which Jerry Cross brought from Nevada. After a discussion of what the group members want for the new year, it was decided that for the immediate future, the group would work on reaching out to new members, having a speaker or presentation and then time for open discussion and support.

LEADERS WANTED!

We are looking for people who would be interested in taking over the support groups in Boston, Baltimore, and Houston.

MI – Kalamazoo

The November meeting had 17 attendees. There were 4 new members in that group. A speaker had been scheduled, but failed to arrive, so the group had a discussion about CMT treatment and research. They also discussed products they used to make life easier. Despite the absence of the planned speaker, it was quite a good meeting.

NY – Upstate NY Area

The group met on December 4th with 29 in attendance. Seven were new people who called after reading an Awareness Week article that Melinda Lang wrote for the local newspaper. Each new person who called Melinda spent 15-30 minutes telling their stories. All were delighted to find the group and to finally meet someone else with CMT. A physical therapist from Columbia Physical Therapy talked about aquatic exercises using one of the members as an example. The discussion also centered on where to buy good shoes locally and online to fit over AFOs. Melinda mentioned Smartknit seamless AFO socks which are very comfortable and Cosysoles to help keep feet warm. The next meeting will be February 12, 2011. ★

THE 4TH INTERNATIONAL CMT CONSORTIUM

The CMTA is pleased to announce that we will be hosting the 4th International CMT Consortium at the Bolger Center in Potomac, Maryland, from June 29 through July 1, 2011.

The Consortium, which will follow the Peripheral Nerve Society meeting at the same location, will have the same format as previous International CMT Meetings and will allow participants to exchange new clinical and scientific information and, equally important, to start or strengthen collaborations between research and patient services organizations.

We will provide information about registration soon, but abstract submissions are due by April 1, 2011.

We believe that the 4th International CMT Consortium will be our most exciting meeting yet, and we once again look forward to the participation of the world's foremost CMT scientists and clinicians. Although the consortium is not open to the general public, the CMTA is planning to hold a patient-family conference in conjunction with the meeting. We will publish details and registration information as soon as it becomes available. ★

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YOHAN

(continued from page 7)

replicate lab models to develop treatments, test the effectiveness of available medications, experiment with other medications and test possible cures.

But it's the association's team-effort strategy that enables communication among separate research groups, Ouellette said.

"We have a medical advisory board to help the collaboration," she said. "It's more like a business program—and it's working."

Ouellette said the National

Institutes of Health is sharing its compound laboratory with CMT researchers, who have already identified several FDA-approved drugs for other diseases that show promise in treating CMT.

With the automated testing accomplished by robots, which is speeding up research, scientists are tickling the interests of pharmaceutical companies.

"This is the most hopeful time for families with CMT," Ouellette said. "Now we're working with drug companies to use their libraries."

To date, researchers have

identified two potential medications for CMT—vitamin C and onapristone—as effective in reducing the proteins that attack the myelin.

"It sounds like they'll discover a cure in my lifetime," Yohan said.

But Yohan and his family aren't waiting for a cure in order to seize the day—he has an impressive list of countries he has visited, with upcoming travels planned to Spain, Portugal and Morocco.

"Why not live in the moment?" Ouellette asked. "That's what Yohan has taught us." ★

 **LETTERS**

Dear CMTA,

I am over sixty years old. For the last 10 years, I have been unwilling to use AFOs. I am a working woman who is engaged in many charitable activities. My husband and I love to travel. We enjoy exploring new places and walking through museums. My appearance is very important to me. Although I was never able to wear shoes with high heels, I have an extensive collection of attractive flats. I viewed AFOs as bulky and unattractive.

Recently as my CMT progressed, I no longer had the option of refusing AFOs. I needed them to help me walk. I had a pair of the orthotics custom-fitted even though I was not sure I would ever wear them. When I finally got them, it took over a week before I was ready to deal with them. I decided that I would wear an opaque knee-high stocking so

the plastic would not be visible. I put the stocking on top of the orthotic device. I then purchased a pair of lightweight sneakers. The brace fit in and I was able to walk much better.

I did not want to wear sneakers for my business and professional activities. I certainly did not want to wear sneakers with an evening gown! I went to a large shoe store at a time when I knew it would not be busy. The shopkeeper assisted me by bringing out a variety of different style shoes in different sizes. I found a ballerina flat that worked very well.

I walked about a mile in my AFOs and new shoes this weekend. I felt steadier and more secure than I had in years. I had a better stride and was able to keep up with my companions. I attended a formal dinner and no one knew I was wearing AFOs besides my husband.

I am sorry I did not get AFOs when they were originally prescribed. It is possible to

accommodate vanity and do what is medically appropriate at the same time.

—Anonymous, via Facebook

Dear CMTA,

I read the newsletter from start to finish. Soon after being diagnosed, receiving my leg braces and needing appropriate shoes, I discovered Propet. Their shoe styles suited my feet beautifully and they have become my favorite brand.

My favorite styles are the Mary Jane Wash and Wear sport shoe and the Ortho Walker III sandal. The Mary Jane has a wide opening and is very easy to get my foot into. The Ortho Walker III has excellent heel support. The hook and loop closures on both pairs make them easy to put on and make adjustments as the day progresses.

—C. M. Mechanicsburg, PA

Editor's Note: The shoes can be found at www.footsmart.com (1-800-707-9928) and other on-line shoes sources.

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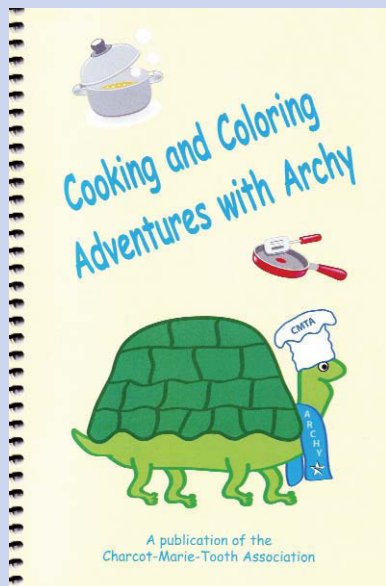
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COOKING AND COLORING ADVENTURES WITH ARCHY

is a new publication which combines fun recipes that parents and kids can do together with puzzles and objects to color on many pages. It's an easy book for a child to make his/her own.

Archy has written the foreword to the book in which he remarks that the best thing about cooking is that it gives him the time to be with his family working together. Some of Archy's favorite recipes from the book include Shoo-fly pie, Ants on a log, Archy's favorite salad, and Archy's not-so-favorite, Mock Turtle soup.

The book is 8 inches by 5 inches and contains 75 pages. It sells for \$7.00 and has a glossy wipe-off cover.

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

Uncertain or minor risk:

5-Fluorouracil
Adriamycin
Almitrine (not in US)
Chloroquine
Cytarabine (high dose)
Ethambutol
Etoposide (VP-16)
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)
α-Interferon

Negligible or doubtful risk:

Allopurinol
Amitriptyline
Chloramphenicol
Chlorprothixene
Cimetidine
Clioquinol
Clofibrate
Cyclosporin A
Enalapril
Fluoroquinolones
Glutethimide
Lithium
Phenelzine
Propafenone
Sulfonamides
Sulfasalazine

THE CMTA Report

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WHAT IS CMT?

- ▶ is the most common inherited neuropathy, affecting approximately 150,000 Americans.
- ▶ may become worse if certain neurotoxic drugs are taken.
- ▶ can vary greatly in severity, even within the same family.
- ▶ can, in rare instances, cause severe disability.
- ▶ is also known as peroneal muscular atrophy and hereditary motor sensory neuropathy.
- ▶ is slowly progressive, causing deterioration of peripheral nerves that control sensory information and muscle function of the foot/lower leg and hand/forearm.
- ▶ causes degeneration of peroneal muscles (located on the front of the leg below the knee).
- ▶ does not affect life expectancy.
- ▶ is sometimes surgically treated.
- ▶ causes foot-drop walking gait, foot bone abnormalities, high arches and hammer toes, problems with balance, problems with hand function, occasional lower leg and forearm muscle cramping, loss of some normal reflexes, and scoliosis (curvature of the spine).
- ▶ has no effective treatment, although physical therapy, occupational therapy, and moderate physical activity are beneficial.
- ▶ is usually inherited in an autosomal dominant pattern, which means if one parent has CMT, there is a 50% chance of passing it on to each child.
- ▶ Types 1A, 1B, 1C, 1D (EGR2), 1E, 1F, 1X, 2A, 2B, 2E, 2F, 2I, 2J, 2K, 4A, 4C, 4E, 4F, 4J, HNPP, CHN, and DSN can now be diagnosed by a blood test.
- ▶ is the focus of significant genetic research, bringing us closer to solving the CMT enigma.