



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.

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TWO FAMILIES MAKE GENEROUS GIFTS TO SUPPORT CMT RESEARCH

\$100,000 Gift Comes From Parents of Adult CMT Patient

The Accelerated Research Collaboration (ARC) to ultimately find a cure for Charcot-Marie-Tooth disorder is getting underway and should be finalized following the CMTA's Board meeting in January, 2008. A couple from State College, PA, has made a major financial gift to assure its success.

John and Joan Chernega made a \$100,000 donation to the mission and the Board Challenge in the name of their son, Jim, who is a CMT patient. The donation will serve as seed money in the effort to raise \$10 million for the program, which hopes to find a cure for CMT within the next 10 years.

"I would like to see it possi-



John, Joan and Jim Chernega hope to jumpstart the Accelerated Research Collaboration (ARC) with their gift.

ble for other families to get good information about CMT and get help in getting through the trying times," said Joan

Chernega, a retired RN. "As a family, we had very little information available to us during

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A Strong Foundation Can Make the Difference

Gilles Bouchard, a former senior executive with Hewlett-Packard and currently the COO of Opnext, a successful fiber optics company, is clearly a man who meets adversity head on. His son

Yohan was diagnosed with CMT seven years ago, and in 2007 Gilles took a year's sabbatical to work closely as a volunteer with members of the Charcot-Marie-Tooth Associa-

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\$100,000 GIFT*(continued from page 1)*

the early years. Even from the doctors we weren't able to get any direction or find support groups or articles to read about CMT. Our son had to do a lot on his own and he struggled learning little by little. I wanted to make sure that by giving money to research and to the CMTA, that other families would be able to have hope and good information."

John Chernega, a retired electrical engineer, agrees with his wife. "In the early days it looked as if Jim had high arches, and we went to specialists who didn't seem to know too much about (CMT)," he said. "We would just like to see some sort of breakthrough in finding a cure and providing new hope for patients. The CMTA has been working hard to get publicity and to fund research. It always takes money to do these kinds of things, and that's why we wanted to make the donation."

There are four children in the Chernega family, and although Jim is the only one who has been formally diagnosed with CMT, his older sister also suffers from mild symptoms. "She's always said she has 'funny feet,' but has never had the problems that Jim has," Mrs. Chernega said. "Nobody else in

Chernega has worn leg braces for the past 15 years, and he has had to leave his job as a purchasing agent because of the deterioration of the muscles in his hands and extreme fatigue. He says he hopes that his parents' donation along with increased awareness of CMT can lead to more sharing among

"We think this is the most exciting time in history to be able to do science and try to develop treatments."

—Michael Shy, M.D.

our immediate family has been diagnosed with CMT, and we've never seen symptoms in our seven grandchildren or in any other family members."

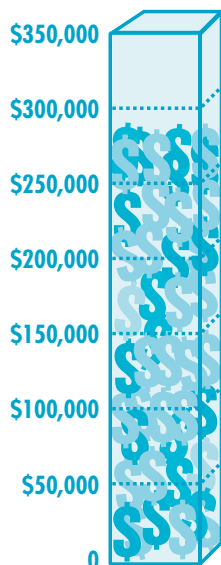
For Jim Chernega, 43, life growing up with CMT was full of challenges and learning to cope. "I really wasn't diagnosed

until my early twenties," he said. "Now looking back with 20/20 hindsight, things are much clearer. As a kid, I wasn't able to do some things, and it was the usual story of being picked last for sports. I was spraining ankles and so-forth, and wondering why. I went through so many specialists who weren't able to identify what was wrong."

other patients of ways to cope with the disorder.

"When people are able to get together and share ideas and strategies for doing things, it's helpful," he said. "Otherwise you might just give up. In my own experience, I had to find alternate ways of getting things done, and one of the great things about the CMTA is that people can get together in groups or online to share their experiences. The leadership of J.D. Griffith of the Johnstown Support Group is an inspiration to newly diagnosed and long-time patients."

The Chernega family hopes their donation will provide an incentive to more families, individuals, and organizations to support the Charcot-Marie-Tooth Association, and the ARC now being designed at Wayne State University under the direction of Dr. Michael Shy. "I think the key word for the ARC is



GETTING CLOSER TO OUR GOAL:

Many thanks to all of you who gave to the Board Challenge. It's not too late to help reach our goal.

Raised in 2007: \$287,840

aggressiveness,” said Dr. Shy. “We think this is the most exciting time in history to be able to do science and try to develop treatments. We are committed to getting the work done by the best people in the fastest way possible, but it needs resources, because we’re not going at this half way.”

Dr. Shy believes that the success of the program will depend on continued financial support. “We need financial support to make this happen, and we expect to be held accountable for the progress that we make,” he said. “It’s very hard to get funding from organizations such as the National Institutes of Health and other sources because many grant requests get rejected. We’re looking at a goal of raising \$10 million to get this done with the idea that we’re pledging to have treatments available in the next five to ten years.

“The challenge for the CMTA and for scientists like myself and my colleagues is to take scientific advances and translate them into treatments for patients, to make them better. And that’s the goal of the ARC.”

For his part, Jim Chernega is touched by the generosity of his parents, and remains optimistic that their donation will make a difference.

“I’m really proud of them for what they’re doing,” he said. “It’s a pretty significant thing and I think it will have a significant impact on helping the CMTA and the research that will eventually help everyone.” *

CMTA Board Elects New Officers

On November 14, 2007, in Mineola, New York, the Board of Directors of the CMTA held a reorganization meeting in accordance with the by-laws.

The Board voted unanimously to elect Patrick A. Livney to a three-year term as President and Chairman. Gary Gasper was elected to a three-year term as Treasurer.

The Board of Directors thanked Patrick Torchia, outgoing President and Chairman, and Robert Kleinman, outgoing Treasurer, for their service to the Association.

—Charles F. Hagins

Livney Assumes Reins of CMTA

After his election as Chairman of the Board and President of the Charcot-Marie-Tooth Association, Patrick Livney unveiled an ambitious plan for his new three-year tenure.

To assist him in his goals of raising \$10 million in the next three years, Livney is organizing an advisory board whose members will help the Board of Directors achieve that goal, primarily through fundraising activities.

The Accelerated Research Collaboration (ARC) is another of Patrick’s priorities. Once the program is fully designed by Dr. Michael Shy and his Scientific Advisory Board, extensive funding will be required to keep the program moving forward. The accelerated program hopes to drastically reduce the time frame required to access the potential of a given course of treatment.

A third focus of Livney is to continue to spread awareness of CMT nationally following the



Patrick Livney begins his tenure committed to elevating CMT research and the CMTA to new levels.

model that has been so successful in Pennsylvania. On a global basis, he hopes the CMTA will be able to pull other CMT organizations around the world into a cohesive unit that more successfully works on research and awareness issues.

Of his three year plan, Patrick said, “I envision an organization which is more substantial in the areas of awareness and funding and which has a global reach.” *

YOHAN CMT RESEARCH FUND*(continued from page 1)*

tion Board of Directors to develop the business objectives and strategic direction for its ground-breaking Accelerated Research Collaboration (ARC).

Gilles' wife, Elizabeth Ouellette, with an M.A. in Counseling Psychology, has devoted countless hours to teaching children and adults the kinds of challenges facing those with CMT by means of a unique educational presentation she developed. Elizabeth joined the CMTA Board two years ago and continues her work with children and CMT support groups around the country.

Gilles and Elizabeth have recently committed \$500,000 to create "The Yohan CMT Research Fund," a Donor Advised Fund designed to sup-

port the critical research being initiated by the ARC. The fund is named in honor of their son, Yohan, who was diagnosed with CMT seven years ago.

"Now is the time to create the financial foundation necessary to support these efforts," Gilles explained. "Creating the fund was very easy, and Elizabeth and I urge others to follow our lead. Working together we can make a difference."

Gilles created the Yohan CMT Research Fund in less than a half an hour over the Internet, at the recommendation of his financial advisor. The fund, which will be managed by Fidelity, is flexible and allows quick and easy distribution of funds to support CMT research and other efforts.

"Creating the fund was a final step in our process of working with the CMTA and the ARC project," Gilles said.

"We have the genetics identified and a practical, yet powerful research plan in place. Now we need money to make it work, and this fund is an easy way to set money aside."

Last year, the CMTA formed ARC, an unprecedented collaboration of scientists from around the world, to develop specific therapies for those suffering from CMT disorder. Unlike other genetic disorders, enormous progress has already been made in researching the causes of CMT. To date, 33 specific genes known to cause the disorder have been identified. Now the genetic mutations can be replicated in mouse/rat models which provide opportunities to develop treatments and cures for this disease in the immediate and foreseeable future.

Modeled after a program pioneered by the Myelin Repair Foundation, the ARC bridges

Genetic Discrimination by U.S. Military *From NORD On-Line Bulletin*

In 1999, the U.S. military estimated that 250 service members are discharged annually for genetic health conditions. Disability payments to those people would cost \$1.7 million in the first year and increase thereafter. Thus, military personnel who have positive genetic tests can be dismissed from the service based on test results, even if there is no way to determine if and when symptoms may occur. Military doctors have been discouraging their patients from taking genetic tests to avoid possible dismissal based on this policy.

In 1996, Congress enacted a ban against genetic discrimination by group health insurance, and in 2000 former President Clinton signed an executive order forbidding genetic discrimination against two million government employee, but it does not extend to the military.

Mark Nunes, former head of the Air Force Genetics DNA Diagnostic Laboratory at Keesler Air Force Base in Mississippi, told the Los Angeles Times that the military has had this policy for the past 20 years and will deny disability benefits to service people with con-

genital or hereditary conditions, which "would be illegal in almost any other workplace." Twenty years ago there were few genetic tests available, but today hundreds of hereditary diseases can be identified through tests.

Kathy Hudson, Director of the Genetics and Public Policy Center at Johns Hopkins University, said, "You could be in the military and be a six-pack-a-day smoker and if you come down with emphysema, that's okay...but if you happen to have a disease where there is an identified genetic contribution, you are screwed." *



Gilles, Yohan, and Elizabeth express optimism and hope in dealing with CMT.

the gap between academic researchers and funding sources. A Scientific Advisory Board comprising of senior scientists and CMTA board members, will select the projects to be performed, choose the investigators to perform them, and monitor progress against established targets and desired outcomes.

Fourteen-year-old Yohan Bouchard, diagnosed with CMT1A, is growing progressively worse. Yohan's parents have watched him suffer through muscle pain, deteriorating fine motor skills, sleepless nights, and physical limitations that stand as roadblocks to the normal childhood he deserves.

An intelligent and personable teen, Yohan has suffered quietly through the pain in his shins and calves, the aching feet, the cramped hands, and the fatigue that smothers his ability to run and play like other kids.

Like his parents, Yohan doesn't take adversity lying down: "I love to ride horses, scuba dive, and drive around this very cool electric scooter. And I have made

lots of friends at school thanks to my mom and others."

Yohan was the first member of his family to be diagnosed with CMT. Most commonly inherited, his CMT appeared as a mutation. His Type 1A comprises at least 60 percent of all patients with CMT Type 1. The disorder is caused by a duplication of the PMP22 gene on chromosome 17. Instead of having two copies of the gene (one of each paired chromosome), there are three copies, two on one chromosome and one on the other. PMP22 is a peripheral myelin protein, but its exact function in causing CMT is still not known.

Elizabeth explained how extremely difficult it is to watch her son grow progressively worse. "As he matures, he has developed kyphosis, curvature of the spine that results in a severely rounded back," she said. "He also has developed scoliosis that can cause lower back problems. In addition to his leg braces, he is being fitted for a back brace."

To help overcome his progressive CMT problems, Elizabeth and Gilles have hired a personal trainer to stretch Yohan's tightening muscles. But ever the optimist, he recently told his doctor, "I'm not worried like you all are. I'm a 'now' kind of guy. I try to stay in the present and focus on today."

Optimism and hope also keep Elizabeth and Gilles moving forward. "No manual came with CMT when Yohan was initially diagnosed," Elizabeth said. "But with the help and support of Dr. Michael Shy, Director of the Wayne State CMT Clinic in Detroit and leader of the ARC team, and the wonderful staff and Board of Directors of the CMTA, we are persevering."

"The CMTA projects that the ARC will need around \$10 million to fund research to find effective treatments and ultimately a cure for CMT," Gilles said. "We are so close and the Yohan Fund is our way of 'putting our money where our mouth is' so to speak. You can plan and create the most effective research initiatives in the world, but they need the resources and funds to work."

"The message is clear," he continued. "Elizabeth and I believe strongly in what we are doing, and we encourage others to consider creating a Donor Advised Fund to support research into CMT and the myriad of other diseases that exist today. Financial support is a critical and necessary part of the journey." ✱

For more information on forming a Donor Advised Fund, visit http://en.wikipedia.org/wiki/Donor_advised_funds



ASK THE DOCTOR

Dear Doctor,

This may be of interest to a few of us baby boomers that have CMT. Is there any harmful effect of using Botox or any of the new fillers for the face? I realize there are risks to the general public for Botox, but since it does affect facial nerves, I am concerned about anything to do with relaxing nerve tissue even though it is a very localized use.

The doctor replies:

Botulinum toxin (Botox) is a more complicated problem for CMT patients. In most instances, any weakness produced should be very local to the injection site and temporary in nature. There is some evidence, but not a well-accepted belief, of mild effects on muscles away from the injection site. It's possible that more local weakness than average will be produced in CMT patients, especially when the injections are in the legs. However, the risk is likely very small, depending on which muscles are injected. There is no evidence that injections will worsen the overall CMT condition. One might consider different options considering these small risks.

Dear Doctor,

I am a 35-year-old female with CMT. I was treated for a UTI and given Macrobid. Unknowingly, I took the drug for 5 or 6 days. I began to feel not only nauseous, but also severely weak. I had muscle tremors and muscle cramps and could hardly get out of bed at times. I went to my fam-

ily doctor, who prescribed something different for the UTI that had not improved and he placed me on a low-dose blood pressure medication, since my blood pressure was very high. I also followed up with my neurologist, who gave me the Medication Alert list where I noticed the drug. Since then, my pain medication has been doubled and I notice more weakness in my hands. Can the Macrobid have caused such a response so soon and what possible lasting effects could it have? I am definitely weaker and have more pain, but what are the long-term effects?

The doctor replies:

Macrobid (macrodantin) can cause neuropathy, but usually after more extended use, weeks to months. Rarely certain individuals can have unusual and more immediate reactions. The drug usually affects the sensation (sensory) nerve fibers more than the strength (motor) fibers and the process is relatively reversible if stopped in time. It is difficult to conclude the link in your specific case, but it was certainly prudent to switch antibiotics quickly.

Dear Doctor,

I live in Sweden and have CMT2A. I just had surgery for an inguinal hernia, and as a pain killer after surgery, I took Tramadol Hexal 50 mg. My CMT went over the hills with total loss of sensation in my feet up to my knees and in my hands up to my elbows. This happened after only 2 days of the medication.

I gave the anesthesiologist the Medication Alert list before the surgery and she said that I wasn't given any of the drugs on the list. Did she read the list incorrectly or is Tramadol something that isn't on the list but should be?

We have nothing in Sweden similar to your Medication Alert list and CMT is very rare in Sweden, so the doctors ask me what to do and not to do. Many thanks for the information given on the CMTA site.

The doctor replies:

Tramadol HCL is widely used in the US and other countries. Tramadol is not associated with neuropathy or loss of sensation. In fact, it is most commonly used to reduce unpleasant or painful symptoms in patients with various types of neuropathy. The association here is surprising, and your anesthesiologist did not read the list incorrectly. I would ask about other medications used, including the anesthetic drugs used for the surgery, especially nitrous oxide gas.

Dear Doctor,

Years ago, I was tested and put on the national bone marrow registry list as a possible donor. Someone told me (anecdotally) that because I have CMT, I cannot donate bone marrow. Is this true?

The doctor replies:

Because most kinds of CMT affect only nerves, I cannot think of a logical reason why someone with CMT could not donate his or her bone marrow. ❄

Scooters Make Recipients More Mobile

At the end of 2007, the Charcot-Marie-Tooth Association, in alliance with Scootaround and the Clarence Vincent Foundation, was able to give away two mobility scooters, one to Milda Vizbar, who lives in New York City, and the other to Phillip Kiefer, residing in Colchester, Vermont. I had the good fortune of meeting both Milda and Phillip and felt privileged that I was able to be present when they received their scooters. I would like to thank all involved who support this mobility program for those who can no longer walk due to the effects of CMT. Carol, our first recipient, and now Milda and Phillip will remain forever in my thoughts, and these unique experiences will stay with me for a very long time.

—Elizabeth Ouellette

MILDA VIZBAR

I am an artist with a disability, living in lower Manhattan. I use crutches to walk due to problems with mobility. My primary use for my scooter is to be able to shop for food, which had been impossible since the summer of 2006 after I had surgery for breast cancer. My best friend and partner died suddenly the day before my surgery. He used to do the food shopping. I was devastated and at a loss as to how I could survive and maintain some degree of indepen-

dence without him. I truly don't have time for cancer. I have too many art projects in the works! As you can see, based on my situation, a scooter for me is about survival and will make an enormous impact on my life.

PHILLIP KIEFER

When I was five years old and had a biopsy performed on my calf, the doctors informed my parents that I would be crippled in my twenties. Furthermore, I



Recipients Milda Vizbar and Phillip Kiefer demonstrate their new scooters.

was the only one in my extended family with any symptoms. The doctors were not sure what I had.

In my fifties the symptoms accelerated, mainly affecting my feet and legs. After a neurological consult, I was diagnosed with Charcot-Marie-Tooth disease.

An auto accident occurred forty years ago when someone rear-ended me, resulting in whiplash. My frequent falls continued to aggravate that neck injury. Being a caregiver for my wife for two years before she passed away also took a toll on my CMT. All the typical symptoms got worse. This resulted in my exploring cervical spine

surgery. In the midst of all the doctors' visits and tests, I received a call from CMTA telling me I was a finalist for a scooter.

I didn't really believe it (I have not won anything in sixty years), but after the second telephone call I came to believe it. I was presented a Pride Go-Go Ultra X scooter on December 21st. What a wonderful Christmas gift!

For five years I have volunteered at the local rehab hospital helping people who are worse off than I am. I had been thinking of quitting because my symptoms were getting worse. Now with my new scooter, I am still able to help, which is very important to me.

I am really looking forward to increasing my trips to the Mall after the holidays to practice on my new scooter.

My new scooter is also enabling me to plan for a trip in the spring. I have not been able to dream, let alone plan, an extended vacation for a long time.

Recently I have had to acquire assistance in my home. This has been a big help mentally and physically, but getting out is very important to me. Maintaining the independence to do my own errands is essential.

Thank you CMTA and Scootaround for giving me back my freedom. *

A Pain-Free Window Into Painful Neuropathies

BY TOM RICKEY, SENIOR SCIENCE EDITOR, UNIVERSITY OF ROCHESTER MEDICAL CENTER

Scientists have demonstrated a new technique for detecting a painful nerve condition known as neuropathy, which affects millions of people with diabetes and many other patients as well.

The painless technique focuses on tiny structures in the skin known as Meissner corpuscles, which encapsulate the endings of microscopic nerves in our hands, feet, and other areas. When someone tickles your feet, or lightly brushes the palm of your hand, or gives you a kiss, it's Meissner corpuscles that are detecting the touch. The tiny structures act like little sensors, allowing us to feel light touch and pressure.

Now a neurologist at the University of Rochester Medical

Center, working together with scientists from Lucid Technologies in Rochester, N.Y., has demonstrated a new way to monitor the structures, which offer a direct window into a condition known as peripheral neuropathy. The team showed that reflectance confocal microscopy, a technology for looking just beneath the surface of the skin, can be used to see and count the number of the structures in a person's fingers and hands. The work gives doctors a noninvasive way to detect and monitor the progression of nerve damage in patients.

The research appears in the December 4 issue of the journal *Neurology*.

Doctors have known that the number and density of Meissner

corpuscles in a person's hands and feet offer a snapshot into the degree of a patient's nerve damage. As nerves degenerate and die, the corpuscles disappear. The difficulty has been actually visualizing and counting them.

Currently, doctors take a small biopsy of the skin, freeze and stain the tissue, and then count the structures. Neurologist David Herrmann, MBBCh, the lead author of the *Neurology* paper, helped develop and popularize skin biopsy about 10 years ago as a way to keep close track of the condition of nerves in patients. At the time, for some forms of peripheral neuropathy, it was a big improvement over previous methods, which required a much larger biopsy of a large nerve.

SAFETY OF NITROUS OXIDE ADMINISTRATION IN PATIENTS WITH CHARCOT-MARIE-TOOTH DISEASE

The *Journal of the Neurological Sciences* published an article which studied the safety of nitrous oxide as an anesthesia. The abstract of the report follows:

Nitrous oxide is routinely administered to children and adults with Charcot-Marie-Tooth disease (CMT) as anesthetic for procedures such as nerve conduction studies and maintenance for general anesthesia. However, it is listed as a

“moderate to significant” risk of potential toxicity and worsening neuropathy in people with CMT by the CMT Association (USA), CMT Association of Australia, CMT International (Canada) and CMT United Kingdom. We performed a systematic review focusing on the use of nitrous oxide in patients with CMT to help clarify its safety. This identified 11 studies reporting 41 exposures to therapeutically

inhaled nitrous oxide as maintenance for general anesthesia with no reports of adverse effects or worsening of CMT neuropathy. In the absence of a single case in the literature reporting worsening neuropathy in CMT patients receiving nitrous oxide, this review provides good evidence that nitrous oxide should be considered a safe agent for use in children and adults with CMT. *

Even so, “Taking a small piece of skin is not ideal,” said Herrmann, associate professor of Neurology and of Pathology and Laboratory Medicine. “It can be painful for the patient; the processing can be time-consuming; and it’s impossible to measure the exact same area of skin year to year to track the progression of the disease.”

A few years ago Herrmann met a scientist from Lucid, a medical device and information company that is creating tools for physicians based on innovative technologies such as confocal microscopy. The technology uses light to actually look beyond the surface of skin tissue into the layers of skin below. The technology is being used more and more to track skin cancers and to look at tissue samples in the operating room.

Herrmann and the Lucid team began a study of some of the tiniest nerves in our body, those that reach into the furthest reaches of our hands and feet. Damage to those nerves leads to a variety of troublesome symptoms for the millions of Americans who have some type of peripheral neuropathy. Symptoms in the feet and hands can include numbness, burning, tingling, weakness, and pain.

While diabetes is the most common cause of neuropathy, it’s caused by a variety of other conditions as well. Patients with HIV are prone to getting it. Excess alcohol consumption can bring it on, as can some vitamin deficiencies, cancer treatments, and dozens of inherited disorders, most notably Charcot-Marie-Tooth disease.

“These patients are often dismissed, and many really suffer,” said Herrmann. “Diagnosis is often difficult. The small nerves in the skin are basically invisible to standard techniques for checking the function of a person’s nerves, such as conduction tests.”

So Herrmann lined up 15 little pinkies—well, 15 research subjects willing to put their little pinkies under the microscope. The group included 10 healthy people, and five who had neuropathies from various causes, such as diabetes or HIV.

The researchers found, as expected, that the healthy volunteers had many more Meissner corpuscles in the tip of the pinkie finger—about 12 such structures per square millimeter, compared to a mean of 2.8 in people with neuropathy. Patients with neuropathy also had fewer of the structures at the base of the thumb.

While the results were not surprising, attaining them so easily was. Volunteers simply held their pinkie finger under a microscope for a few minutes. No pain, no blood, no tissue preparation.

In an editorial about the research, Peter J. Dyck, MD, of the Mayo Clinic wrote in the journal, “The approach may find use as the gold standard of tactile sensation and of large fiber sensorimotor polyneuropathy.” But he also pointed out some limitations of the work. Dyck said the technique needs to be tested in greater numbers of people, pointed out that the equipment needed for reflectance confocal microscopy is expensive, and mentioned the need to differenti-

ate between healthy and abnormal Meissner corpuscles.

An advance in screening would be appreciated by millions of patients. More than half of people with diabetes will eventually develop neuropathy. Most of them won’t feel pain—they’ll simply lose sensation in their feet, making them vulnerable to wounds that can result in severe infections. Oftentimes sensation slips away so gradually that patients don’t even notice. A new screening tool would help doctors monitor patients more closely so that both they and patients are aware of nerve damage and can do everything they can to prevent further damage.

“Neuropathy is very difficult to treat, and part of the reason is that currently, we usually identify it too late, after there has been significant damage,” said Herrmann, director of the Peripheral Neuropathy Clinic at Strong Memorial Hospital. “Treatments might be more beneficial if we could detect the condition earlier.”

“The idea is to move from an invasive biopsy for monitoring nerve endings, to noninvasive, painless approaches. A person could have this technique done as frequently as is necessary, for instance. That’s an attractive notion for tracking the condition of nerves in patients,” said Herrmann, who is now assessing the technique in 75 people, with funding from the National Institute of Neurological Disorders and Stroke. ✱

Editor’s note: Dr. Herrmann is the lead investigator on the CMTA’s ascorbic acid clinical trials at the University of Rochester.

"CIRCLE OF FRIENDS"

Tyler's Thanksgiving Walk

Our son Tyler is 12 years old and was diagnosed with Charcot-Marie-Tooth (CMT) disorder three years ago. Since we were unable to receive information about CMT from the doctors we had seen, I headed to the Internet for help. I was very fortunate to find a wealth of information from the Charcot-Marie-Tooth Association. Reading the articles on the website and receiving the newsletters sent us in the right direction to help our son.

We have taken Tyler to see Dr. Michael Shy, at Wayne State University, for the last two years and plan on going there once every year. We are so happy that we found someone so knowledgeable who could give us answers and explain Tyler's condition. This summer we were able to attend a golf outing and fundraiser for the CMTA held

by Patrick Livney. Luck was on our side and the board members of the CMTA also attended the golf outing along with Dr. Shy.

One of the board members, and now my friend, Elizabeth Ouellette took us under her wing and introduced us to all of the board members. The drive and dedication that each one of the board members has for the CMTA is unbelievable. We left the fundraiser filled with so much hope just knowing how hard the board members are working to find a cure and to make life better for individuals with CMT. I wish everyone had the opportunity to meet the board members—you couldn't help but feel the same way we did. The Charcot-Marie-Tooth Association has become our lifeline for information, support, and hope.

We have always talked about having a fundraiser to support the CMTA, but both

my husband and I work full time and it is hard finding the time to get started. When I read about "Circle of Friends" on the CMTA website I knew this was our answer. I thought people would be more responsive to the fundraiser if they were sponsoring Tyler on a walk, so in the spirit of the holiday "Tyler's Thanksgiving Walk" was created. I called the CMTA and the Director of Member Services, Dana Schwertfeger, was very helpful and sent me everything I needed to get started. I created a letter for Tyler's Thanksgiving Walk using a template from the CMTA, and I entered in the names and addresses of my Circle of Friends. The name-and-address listing was then forwarded to Dana. He created the webpage for online donations and printed the envelopes that would be mailed to my Circle of Friends. Once I received



Family and friends turned out to support Tyler in his Thanksgiving Walk.

the printed envelopes back, all that was left to do was to fill the envelopes and mail them out. With minimal effort we were on our way to help Tyler, the CMTA, and everyone affected by CMT.

Tyler's Thanksgiving Walk took place at 10:00 a.m. on November 17th, and he walked a 1-mile path around Lake Katherine on a brisk fall day. A few local businesses were very generous and donated bagels, coffee, and water. Our Circle of Friends started to arrive and before we knew it almost thirty of our friends and family were there to support Tyler's walk. Everyone was excited to be a part of the walk and to be able to help in any way they could. We were very touched by the caring and support we received that day. The walk was a big success and everyone really enjoyed it. The members of our Circle of Friends who were unable to be there for the walk have been just as supportive with donations letting us know how much they care. Our Circle of Friends continue to ask how they can help when we do this again next year and remind us not to forget about them whenever we need help.

So far Tyler's Thanksgiving Walk has raised \$6,000 for the CMTA, but this is just the beginning. I'm hoping next year to make it bigger and better and possibly have other families affected by CMT in the Chicago area join me with their Circle of Friends. If you are interested, please email me at tyraylow1@comcast.net. If we all try to help in our own small way, we can make a difference.

—Dale, Dan, and Tyler Lopez

The CMTA Circle of Friends

Our heartfelt thanks to Tyler, Dale, Dan and the entire Lopez family and their Circle of Friends. They have made an important contribution that will benefit all of us as we work to find a cure for CMT.

More than that, they have shown that our goal of raising \$10,000,000 for research is within reach!

Ten million sounds like a huge amount of money, but think about it: Tyler's Walk raised over \$5,000. If you start a Circle of Friends and raise \$5,000, we'll only need 1,999 other people to do the same and we'll have that \$10,000,000 in no time at all.

Do you believe that's possible? We do, and we'll do whatever it takes to help you with your Circle of Friends. But we can't do it unless you're willing to help, so please call us today at 1-800-606-2682, email us at cof@charcot-marie-tooth.org, or visit us on the web at www.charcot-marie-tooth.org/cof and get started!

TYLER'S CIRCLE OF FRIENDS:

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Mr. and Mrs. Todd Blue	Mr. and Mrs. Bruce Longanecker
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BOOK REVIEW

Augie's Quest: One Man's Journey from Success to Significance

REVIEWED BY ELIZABETH OUELLETTE

Augie Nieto, the fitness buff, is known in health clubs as the man who revolutionized gyms across the world with his popular Lifecycle. With time, his company, Life Fitness, Inc. expanded to Asia and Europe, becoming the largest exercise equipment supplier in the world.

Augie was a driven, hard-working individual who gave most of his time and energy to his blossoming business. Consumed by work, he paid little attention to his wife and children. After 8 years of marriage and two children, he was faced with divorce.

Picking up the pieces of his shattered personal life, Augie worked hard to understand his "failure." Two years later, in 1995, the new Augie, more family-oriented, married his high school sweetheart, Lynne. Life was good, if not great, for a while, but thirteen years later, Augie's existence was to unalterably change.

Athletic, robust, and healthy, Augie began to experi-

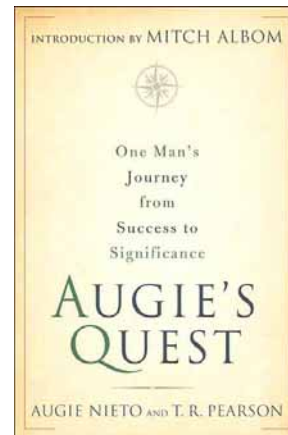
ence unusual back pain followed by decreasing strength. The medical tests provided him with the grim diagnosis of ALS, also known as Lou Gehrig's disease.

This once strong and fit man was slowly withering away. In amyotrophic lateral sclerosis (ALS), motor neurons progressively degenerate over the course of 2 to 5 years. The brain and intellectual functioning remain fully intact and alert, but the body gradually loses muscle function, becomes paralyzed and eventually succumbs to death. The bottom line in this disease is: there is currently no cure. ALS is a death sentence.

Initially, this diagnosis threw Augie over the edge, leading to severe depression and an attempted suicide. Nevertheless, the spirit that kept Augie afloat throughout his life kicked in, providing him with the wisdom

to accept the disease along with the resolve to be instrumental in finding a cure.

Augie's Quest, written by Augie and T.R. Pearson, gives an intimate look into the life of a man who, in light of slowly losing all motor function, has found the strength and courage to keep fighting for a cure, spreading inspiration and hope to ALS patients and their families.



ALS, like CMT, is considered an orphan or rare disease, one that affects less than 200,000 people in the US. Approximately 1 in 250,000 Americans are afflicted with ALS while 1 in 2,500 people have CMT.

As Augie studied developments in ALS research, he was disheartened to discover just how little was scientifically known about ALS. More importantly, he realized that the way research was being conducted was less than optimal for the ALS patient. ALS researchers worked in isolation, rarely collaborating or uniting to advance research. Until recently, these words rang true for CMT research as well. In most research facilities, scientists are affiliated with universities and seek

(continued on page 15)

CMT RESEARCH STUDY

If you have CMT, you may be eligible to participate in a research study that will address pain, weakness and fatigue associated with CMT. For details, you can call Jan Goodard, RN, at 1-800-587-5875. This study is sponsored by Memorial Medical Center and funded through the Department of Defense. The study will be conducted by the John P. Murtha Neuroscience and Pain Institute in Johnstown, Pennsylvania. You can also read more about it by going to www.clinicaltrials.gov. *



GIFTS WERE MADE TO THE CMTA

IN HONOR OF

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Nick D. Avanzo

Mrs. Kathleen J. Byram

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Dee

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GIFTS WERE MADE TO THE CMTA

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Jack Veatch

Mr. and Mrs. Jeffrey Kingsley

Myron W. Widdop

Mr. and Mrs. Keith Widdop

AUGIE'S QUEST*(continued from page 12)*

research grants through the National Institutes of Health or nonprofit organizations. Moreover, the orphan diseases are often bypassed by pharmaceutical companies due to the low number of people diagnosed with the disease, and the lack of potential profit.

Augie, like those at the CMTA, quickly realized that there had to be a more efficient way to come up with a cure. Augie is first and foremost an entrepreneur, and he was going to treat ALS research as a business, thereby considering his donors as investors.

Once the word got out that Augie had this life-threatening and incurable disease, he and his wife Lynne reached out to friends, supporters, clients, and colleagues to raise money through fundraisers, speaking engagements, and awareness campaigns. News of his illness spread through the exercise communities and soon the media

STOCK DONATIONS

When making a donation of stocks or bonds, please email, fax or call the CMTA office to inform us of your gift. At the end of 2007, we received several generous stock donations that were processed through our broker with no name connected to them. We are unable to issue proper thank you letters for income tax purposes because we do not know who made the gifts. If you are one of the people who donated stock at year's end and have NOT received a thank you letter, please contact our accounting supervisor, Kim Magee, as soon as possible. She can be reached at 1-800-606-2682, ext. 105. *

blitz covered his story and the plight of all ALS patients.

Eventually, Augie partnered with the MDA and chose to financially support specific ALS research projects. He also has invested in the ALS Therapy Development Foundation, a nonprofit biotech company which has the capability to test many pharmaceuticals in ALS mouse models, with the primary goal of accelerating research and finding a drug that may benefit ALS patients. Augie and his wife choose how their money is spent and only fund research projects

they believe to be promising.

Augie's Quest is a heart-wrenching story of a man who refuses to surrender, despite the inevitable. It also brilliantly outlines the inherent problems with traditional academic research, proposing a different approach to curing now incurable diseases.

This sort of business model is the wave of the future. As heart-breaking and touching as this story may be, heroes like Augie are the ones who will change the lives of many in the years to come. *

CMTA REMEMBRANCES

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

Honorary Gift:

In honor of (person you wish to honor)

Send acknowledgment to:

Name: _____

Address: _____

Occasion (if desired):

- Birthday Holiday Wedding
 Thank You Anniversary Other

Memorial Gift:

In memory of (name of deceased)

Send acknowledgment to:

Name: _____

Address: _____

Amount Enclosed: _____

Check Enclosed VISA MasterCard

Card # _____

Exp. Date _____

Signature _____

Gift Given By:

Name: _____

Address: _____



CMT In the News

Haunted house fundraiser

The Enterprise from Oconomowoc, Wisconsin, printed an article on a haunted house hosted by Kathy Stultz to raise awareness and funds for the Charcot-Marie-Tooth Association. Her daughter, Reagan, was just diagnosed with CMT in February of 2007. About 150 children from Park Lawn Elementary School, Reagan's Brownie Scout troop and the neighborhood attended the event, raising \$2,600 in donations. Kathy said, "This event was one way to get the name (of CMT) out and increase awareness."



Reagan was the focus of her parents' fundraising efforts.

Discrimination corrected

An English police officer who served on the Lincolnshire force for 30 years won a claim for disability discrimination against his employers. Paul Weaver took the Lincolnshire Police to an employment tribunal after his application to continue working past the normal retirement age was denied. He was diagnosed with CMT in 2000 and was placed on restrictive duties. In the six years since, he had taken no sick days. He became eligible for retirement when he reached 30 years of service, but chose to apply for a program called 30 Plus, which is designed to let experienced officers stay on beyond retirement age. He was

turned down based on the fact that he was on restricted duty and was likely to remain so. The tribunal upheld his complaint of disability discrimination and awarded him an undisclosed sum.

Focus on Lori Rath

Support group leader, Lori Rath, was featured in a publication by Westcoast Brace & Limb. The article briefly discussed the problems caused by Charcot-Marie-

Tooth and the typical characteristics of the disorder. It also discussed the fact that Lori had problems with falling and was sent to Westcoast Brace & Limb for ankle foot orthoses. The publication called "Making Her Mark" highlights the fact that Lori found little support for her problem and decided to start a support group in her area with the aid of the CMTA and the MDA.

"Songbird" does it again

Amy deSilva was the featured performer at the Massachusetts State House on November 16, 2007. She sang *The National Anthem*, *God Bless America*, *Over the Rainbow* and a special song, entitled "American Tears" which she is recording for the Troops. Her project W.A.T (Wiping American Tears) is designed to lift the spirits of soldiers who are physically or emo-

tionally challenged. Amy has CMT and her project should raise awareness of CMT, but she hopes, more importantly, that it will let the troops know they are heroes to her.

Move to Miami completed

The Miami Herald announced the opening of the Miami Institute for Human Genetics. The institute will focus on the genetic origins of multiple sclerosis, age-related macular degeneration, amyotrophic lateral sclerosis, and Charcot-Marie-Tooth, as well as cardiovascular disease, neurodevelopmental disorders, and cancer, according to the article. The institute is led by the husband-wife team of Margaret Pericak-Vance and Dr. Jeffrey Vance (a member of the CMTA Medical Advisory Board), who were recruited from Duke University along with 20 of their fellow researchers. "We believe genomic research will change the course of medicine and the University of Miami will be the leader," Vance said. "But we must first identify and explain the genetic contributions to human disease."

Fighting fatigue

An article by Dr. Greg Carter of the University of Washington reported on the use of Modafinil to reduce fatigue in CMT1A. The wasting of the intrinsic muscles of the feet and the peroneal muscles results in marked reduction in functional aerobic capacity during exercise, and fatigue is commonly reported.

Modafinil is traditionally used to treat the symptoms of fatigue and excessive daytime sleepiness in narcolepsy. Dr. Carter reports on four patients with genetically confirmed Charcot-Marie-Tooth disease who had significant fatigue that was almost completely relieved by Modafinil.

Focus on CMT

An article in the *Pittsburgh Post Gazette* was entitled “Finding out the truth about Charcot-Marie-Tooth” and featured the story of Briget Shields, wife of Pittsburgh City Council President Doug Shields. As a kid, Briget had skinny legs, weak ankles, and terrible leg cramps, but no one thought too much about them. Three years ago, more things went wrong, including leg cramps, twitches, burning, and loss of balance. The story reports on the journey she took to find a diagnosis. At first, she thought it might be Lyme disease because she is a fly fisherman. Then they thought it was multiple sclerosis, or ALS or lupus. They were all ruled out and an EMG produced a diagnosis of CMT. “Once you’re diagnosed, there are things you can do and it makes you feel you’re not a hypochondriac,” Ms. Shields said. “I was actually grateful when I was diagnosed with CMT.”

Ms. Shields has chosen to be proactive in dealing with CMT and has a goal to help raise awareness among doctors, physical therapists, and especially, pediatric neurologists. She hopes to start a support group in the Pittsburgh area. *

STEP BY STEP WITH PAT

Listening and Learning

BY PAT MEUTH, LCSW, COUNSELOR

When I received the most recent *CMTA Report*, I read and re-read the article “Imagine the Possibilities” by Wendy Godmere. Stoney Stone is a striking and admirable role model. His philosophy of “What defines us is how we rise up after we have fallen...” certainly is an admirable and achievable model for living.

Stoney’s struggle feels very familiar to anyone with CMT. Since my last article about listening and learning in life, several people have asked me how to listen. While there are certainly many approaches to listening, I will describe a process that my counseling clients have used with much success.

Listening and learning with an open mind is a difficult yet very rewarding process. When we listen, we bring all of our past experiences, decisions that we have made, and people and events that have influenced us, into the situation. Our past can cause us to filter what we are hearing. If we allow this to stop us from listening and hearing, we miss out on new opportunities, suggestions, or ideas that may be helpful.

When someone is giving you some new information, I encourage you to be discerning and discriminating while listening to your inner self, to determine whether or not the advice is appropriate to you and your needs at that moment in time. It is partly about being in the moment, being able to really hear

both what the other person is saying and what your inner knowing is telling you in response to the new ideas that you are hearing.

When you are listening, if you automatically discount the person or what is being said, if you immediately feel angry or upset, or immediately feel a sense of resistance, this is a sign that you are not being open. The old lions that controlled you in the past are creeping in. Sensing that you are automatically shutting down is a great insight and wonderful guide for you to use. Always celebrate your new insights—they are gifts that you give yourself!

If you notice that you are feeling some resistance, I encourage you to look at what may be getting in the way of your listening and learning. Often, people are resistant because they are unsure of the person who is offering the new ideas, or perhaps don’t understand its meaning. You can ask yourself the question “Is there something that I need to know or learn in order to be less resistive?” It is wise to ask questions and educate yourself before making the decision.

Advice is free! Listen to it, discern if it is helpful, brainstorm with others about it, and then use the part that is helpful and discard the rest! You may just imagine a new possibility that will help you more fully seek out your passions, and live them with determination and vitality. *



SUPPORT GROUP NEWS

California – San Francisco Bay Area

For the holidays, Terry McIntosh invited the group to her home for a party. Terry and her daughter, Cindy, did a wonderful job of providing lots of delicious food, drink, and good cheer. Everyone had a great time thanks to Terry's hospitality.

The group will meet on January 26th from 2 to 4 PM. The speaker will be Dr. Jorge Aranibar, who has treated a member of the support group. He is a chiropractor who has his educational background in exercise rehabilitation, sports science, physical therapy, and biomechanics. His goal is to relieve pain through means other than conventional pain killers and anti-inflammatory drugs



Ray Fisher demonstrated his new three-wheel walker to the Johnstown Support Group.

Colorado – Westminster

The January 5, 2008, meeting featured a presentation by Rosi Mauch, a representative from Athena Laboratories. She educates patients and families about genetic testing available to help in the diagnosis of CMT. There are currently almost 50 different mutations that can cause CMT and Athena is currently offering tests for ten of those mutations.

Illinois – Chicago Area

The next meeting will be at 1:00 PM on February 23, 2008 and the featured speaker will be Dr. Michael Shy from the CMT Clinic at Wayne State. His presentation on CMT and the genetics of CMT is easy to

understand and extremely informative. The next meeting after the February one will be May 17, 2008. The group plans to meet every three months.

Kentucky – Lexington

The last meeting was November 10th and fifteen members and spouses attended. The presentation was made by one of the members who had recently been seen through the Wayne State Clinic in Detroit. The next meeting is tentatively scheduled

Support Groups
are growing
in number and
involvement.

for March 1, 2008. The winter months are difficult because many members travel over 60 miles and the ice on the roads makes the trip dangerous.

Michigan – Detroit Area

The group met for the first time in November and had 58 people in attendance. The meeting was an open discussion of the many issues faced by people with CMT. Between meetings, the group members will communicate by means of a blog. The next face-to-face meeting will occur in early March. Anyone who would like to be added to the Detroit list should contact Lainie Phillips at familiaphillips@sbcglobal.net or 248-890-1529.

The group will meet again on March 1, 2008, from 2 to 4 PM. Both Dr. Michael Shy, from the Wayne State Clinic, and Sean McKale, an orthotist, will give presentations.

Minnesota – Benson

The Minnesota support group was honored to have Dr. Michael Shy visit from Wayne State University in Detroit, MI. He did a very thorough, but easy to understand, explanation of how CMT works. He told the group how lucky they were to have a disorder whose process is so well understood, since that makes the likelihood of finding a substance to help correct the problem much easier. Work is going on in several different countries on various substances (like ascorbic acid).

Nevada – Las Vegas

The November meeting featured Dr. Kelly Woods, who spoke on the problems with the foot and how it relates to CMT. Mary Fatzinger, the leader, introduced the group to the new Patient's Guide to CMT and got 8 orders from interested attendees.

The group will meet on January 12, 2008, from 1 to 3 PM at the West Charleston Library. The guest speaker will be Dr. Santos Yu, from the Neurology Center of Nevada. After the presentation, there will be time for questions and answers. For further information, contact Mary at 702-369-6095.

(continued on page 23)

CMT Support Groups

Support Group Liaison: Elizabeth Ouellette, 650-559-0123

Alabama—Birmingham

Contact: Dr. Dice Lineberry,
205-870-4755

Email: dklrl@yahoo.com

Arizona—Phoenix Area

Place: MDA Office, S. 51st St, Phoenix

Meeting: Bi-monthly, Thursday
6:30-8:30 PM

Contact: Marilyn Hardy or
Aisha Hackett, 480-496-4530

California—Northern Coast Counties (Marin, Mendocino, Solano, Sonoma)

Place: Sutter Medical Center
of Santa Rosa

Meeting: Quarterly, Saturday, 1 PM

Contact: Louise Givens,
707-539-2163

Email: lbgivens@ix.netcom.com

California—San Francisco Bay Area/Santa Clara County

Place: Menlo Park Library

Meeting: Quarterly

Contact: Elizabeth Ouellette,
650-248-3409 (C)

650-559-0123 (H)

Email: elizabetho@pacbell.net

Colorado—Westminster

Place: Capabilities, Westminster, CO

Meeting: 10 AM – noon,
Last Saturday of
every other month

Contact: Diane Covington
303-635-0229

Email: dmcovington@msn.com

Florida—Tampa Bay Area

Place: St. Anthony's Hospital,
St. Petersburg, FL

Meeting: Second Saturday of Feb,
May, Nov, with other special
meetings throughout the year

Contact: Lori Rath, 727-784-7455

Email: rathhouse1@verizon.net

Illinois—Chicago Area

Place: Peace Lutheran Church,
Lombard, IL

Meeting: Quarterly

Contact: Alan Pappalardo,
800-606-2682, ext. 106

Email: alan@charcot-marie-tooth.org

Kentucky/Southern Indiana/ Southern Ohio

Place: Lexington Public Library,
Beaumont Branch

Meeting: Quarterly

Contact: Martha Hall, 502-695-3338

Email: marteye@mis.net

Michigan—Detroit Area

Place: University Health Center,
Wayne State University
School of Medicine

Meeting: Call for schedule

Contact: Lainie Phillips,
248-890-1529

Email: familiaphillips@sbcglobal.net

Minnesota—Benson

Place: St. Mark's Lutheran Church

Meeting: Occasionally

Contact: Rosemary Mills,
320-567-2156

Email: rrmills@fedtel.net

Minnesota—Twin Cities

Place: Call for location

Meeting: Quarterly

Contact: Bill Miller, 763-560-6654

Email: wmiller758@msn.com

Mississippi/Louisiana

Place: Baptist Healthplex,
102 Clinton Parkway,
Clinton, MS

Meeting: Quarterly

Contact: Flora Jones, 601-825-2258

Email: flojo4@aol.com

Missouri—St. Louis Area

Place: Saint Louis University Hospital

Meeting: Quarterly

Contact: Carole Haislip, 314-644-1664

Email: c.haislip@att.net

Nevada—Las Vegas

Place: West Charleston Library,
6301 West Charleston Blvd.

Meeting: Email for dates 1-3 PM

Contact: Mary Fatzinger

Email: cmt_suppgrp_lvnnv@yahoo.com

New York—Greater New York

Place: NYU Medical Center/
Rusk Institute,
400 E. 34th St.

Meeting: Second Saturday,
12:30-2:30 PM

Contact: Dr. David Younger,
212-535-4314

Fax 212-535-6392

Website: www.cmtnyc.org

Email: bwine@acm.org

New York—Horseheads

Place: Horseheads Free Library
on Main Street,
Horseheads, NY

Meeting: Quarterly

Contact: Angela Piersimoni,
607-562-8823

New York (Westchester County)/ Connecticut (Fairfield)

Place: Blythedale Children's Hospital

Meeting: Bimonthly, Jan, March, May,
Sept, and Nov; 3rd Saturday

Contacts: Beverly Wurzel, 201-224-5795
Eileen Spell, 732-245-0771

Email: craneomatic@verizon.net
espell@optonline.net

North Carolina—Triangle Area (Raleigh, Durham, Chapel Hill)

Place: Raleigh, NC

Meeting: Quarterly

Contact: Susan Salzberg,
919-967-3118 (afternoons)

Betsy Kimrey

Email: judae@bellsouth.net

Ohio—Greenville

Place: Various locations.

Meeting: Fourth Thursday, April–October

Contact: Dot Cain, 937-548-3963

Email: Greenville-Ohio-CMT@woh.rr.com

Pennsylvania—Johnstown Area

Place: John P. Murtha Neuroscience Center

Meeting: Bimonthly

Contacts: J. D. Griffith, 814-539-2341

Jeana Sweeney, 814-262-8467

Email: jdgriffith@atlanticbb.net,
cjsweeney@ussco.net

Pennsylvania—Northwestern Area

Place: Blasco Memorial Library

Meeting: Call for information

Contact: Joyce Steinkamp, 814-833-8495

Email: joyceanns@roadrunner.com

Pennsylvania—Philadelphia Area

Place: CMTA Office,
2700 Chestnut St., Chester, PA

Meeting: Bi-monthly

Contact: Pat or Dana, 800-606-2682

Email: info@charcot-marie-tooth.org

Virginia—Harrisonburg

Place: Sunnyside Retirement
Community, Community Center

Meeting: Quarterly

Contact: Anne Long, 540-568-8328

Washington—Seattle

Place: U of Washington Medical
Center, Plaza Café—
Conference Room C

Meeting: Monthly, Last Saturday, 1-3 PM

Contact: Ruth Oskolkoff, 206-598-6300

Email: rosk@u.washington.edu

Washington—Tacoma

Place: Moore Library, 215 S.56th St.

Meeting: Bi-monthly

Contact: Carol Hadle

Email: heandme@q.com

DEALING WITH CMT:

Jamie's Story

I am a 16-year-old boy and I live in Cambridgeshire in England. I have had CMT since I was born. It's always been a pain. Even in primary school all the other kids used to make fun of me and laugh at me. I was always picked last for sports such as football due to my inability to run well. I have been in and out of the hospital since I was little. I have had about six operations on my feet. When I was in primary school, I had to have braces made for my feet. Everyone used to laugh at me wearing them, even the teachers. I stopped wearing them because I got really upset about all the comments.

When I went to secondary school, I knew that things weren't going to get any easier. I wasn't, and still am not, able to write for a long time because I experience quite a lot of pain in my hands (although I have found that the more I write, the easier it gets). I have been given a computer to help me keep up with my work. Much like the braces I had in primary school, the computer aid makes people laugh and make fun of me. So, I have decided to try and fit in and write like everyone else.

All throughout school I have fallen over, many times from people pushing me. I have always been very tall, and at the

age of 16, I am about 6 feet. Since I'm taller, I find it harder to keep my balance.

I have always tried to fit in with the popular people in school. I went through a rocky patch where I self harmed and I started smoking weed. I found that this seemed to make an improvement in my feeling sad, but the next day and for a long time afterward, I felt a lot sadder. So, I've stopped all that.

My girlfriend has helped me through all of this, and she is very understanding of my condition and how sad I sometimes get. I have been with her for nearly 2 years now, and I am so happy.

Your website has helped me a lot, especially in understanding about low

self-esteem and depression, as well as relationships with others.

"Any disabling condition can affect the way people think and feel about themselves, but having a chronic illness like CMT, which is often unseen, places stress on individuals and often causes depression. People with CMT can suffer from low self-esteem, and relationships with others can be affected"

Also, I wasn't aware that CMT could affect breathing. Since 14, I have had trouble with breathing. It seems to only happen when I am sad or under stress. My mum and

step-dad didn't think anything of it. It was my Nan that was really worried. She eventually persuaded my mum and step-dad to take me to the doctors. The doctor couldn't find out why I was experiencing breathing difficulties, even though they were aware of my CMT condition

Throughout my life, I have felt like I have had it hard. My mum and my dad split up before I was born. They never got on after I was born and eventually, due to my dad refusing to pay any child support money, my mum stopped me from seeing him. The last time I saw him properly was when I was 11 or 12.

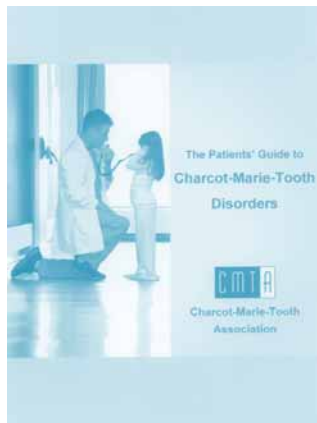
My life has been very hard, especially living with CMT. True friends are few and far between as many people are nasty about my condition. I try to hide my true feelings by always joking around. My friends have always said that I have a really good sense of humor and I make them laugh. Although they help me, your website is a godsend. It gives me a chance to talk to people who really understand just how it feels to have CMT. How hard it is. I find it really hard to get around due to the pain in my feet. My ankles are slowly turning over. I am always aware that my feet look different and I find it very hard to wear shorts or go swimming due to people staring at my feet. All I have is hope that life with CMT will get easier. ✨



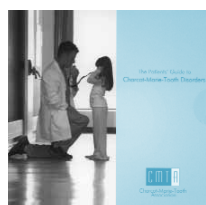
Jamie finds help on the CMT website.

Patients' Guide to CMT...
Is Now Available

in print...



and CD...



The long-awaited update to our *Handbook for Primary Care Physicians* is now available in both print and CD format. Each chapter in the book has been written by a leading CMT expert and is directed at a more lay audience than the previous text.

Topics include the clinical features of CMT, electrodiagnostic evaluations, genetics, CMT in children, orthopaedic considerations, new treatments, physical exercise, genetic counseling, toxic medications, and resources for CMT patients and their families. The new book is 178 pages and features full color photos of many conditions and treatments.

The CD, which contains the entire text of the *Patients' Guide*, also contains a slide show by Dr. Steven Scherer, neurologist, University of Pennsylvania, which is intended for doctors who would like a quick overview of CMT and another slide show by Dana Schwertfeger, Director of Member Services, which is intended for patients and families who might need a fuller understanding of CMT.

We are currently offering the CD to anyone new who joins the CMTA before year's end or anyone who renews their membership before then.

We pride ourselves on being the best source for up-to-date information on CMT, and these two publications are our latest accomplishments in that area.

MEMBERSHIP APPLICATION/ PUBLICATIONS ORDER FORM

(Items marked with an asterisk "*" are required.)

*NAME: _____ / _____ / _____
First MI Last

*ADDRESS: _____

*CITY: _____ *STATE: _____ *ZIP: _____

*COUNTRY/POSTAL CODE (IF NOT US): _____

*DAYTIME PHONE: _____ EVENING PHONE: _____

EMAIL: _____ USER NAME: _____

Required for PDF Newsletter/Website Access

Required for Website Access

Note: If you are joining now, you may purchase publications at active member prices. ACTIVE MEMBERS have paid dues within the past year. If you are unsure about your membership status, please call 1-800-606-2682.

	QTY	COST	TOTAL
ANNUAL MEMBERSHIP DUES			
Members have the option of receiving <i>The CMTA Report</i> in print, PDF via email, or both. Receive newsletter as: <input type="checkbox"/> Print <i>or</i> <input type="checkbox"/> PDF via email		\$40	
Receive both Print <i>and</i> PDF Newsletters		\$45	
NEW! The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		active members \$10 nonmembers \$15	
[CD Format]		active members \$7.50 nonmembers \$10	
Charcot-Marie-Tooth Disorders: A Handbook for Primary Care Physicians		active members \$15 nonmembers \$20	
CMT Facts I <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$3 nonmembers \$5	
CMT Facts II <input type="checkbox"/> English <input type="checkbox"/> Spanish		active members \$5 nonmembers \$7	
CMT Facts III		active members \$5 nonmembers \$7	
CMT Facts IV		active members \$8 nonmembers \$10	
CMT Facts V		active members \$12 nonmembers \$15	
A Guide About Genetics for the CMT Patient (No shipping and handling on this item only)		active members \$4 nonmembers \$5	
NEW! Teaching Kids about CMT...A Classroom Presentation (1 hour DVD)		active members \$7.50 nonmembers \$10	
CMT Informational Brochure and Letter to Medical Professional with Drug List		FREE	
Physician Referral List: States: _____		FREE	
Contribution to CMT Research Fund (100% of contribution is used to fund research)			
Shipping & Handling (Orders under \$10, add \$1.50; orders \$10 and over, add \$4.50)			
TOTAL			

Check payable to the CMTA (US residents only; non-US residents, please use credit card or international money order.)

Money Order American Express MasterCard VISA

Card Number: _____ Expiration Date: _____

Mail to: CMTA, 2700 Chestnut Parkway, Chester, PA 19013; or fax to: 610-499-9267

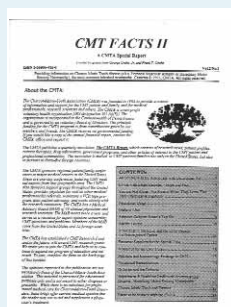
A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling, toll-free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

The CMT Facts Series: **An Indispensable Collection of Articles about CMT**



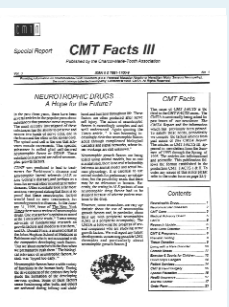
CMT Facts 1

- Facts about professionals who treat patients
- Genetics
- CMT and physical therapy
- CMT foot: surgical options
- The CMT hand
- Occupational therapy



CMT Facts 2

- ADA overview
- Hope and fear
- For parents
- Anesthesia
- Adaptive gadgets
- Rehabilitative medicine
- Vocational rehabilitation
- Orthotics and orthotists
- Disability profiles
- Tremor



CMT Facts 3

- Incurable, not untreatable
- CMT and pregnancy
- Prenatal testing
- Q & A about living with chronic illness
- Exercise & sports for children with CMT
- Patient services
- CMT hand surgery
- Special education
- Health insurance



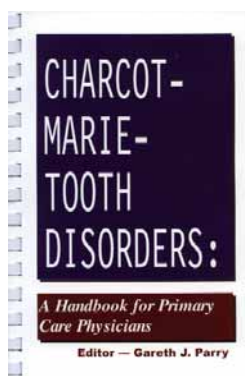
CMT Facts 4

- Treatment of familial neuropathies
- Pulmonary function
- HNPP
- Orthotics survey
- Pulmonary function
- Managing pain
- Orthopedics and children
- Shriners hospitals
- Employment/ADA
- SSI



CMT Facts 5

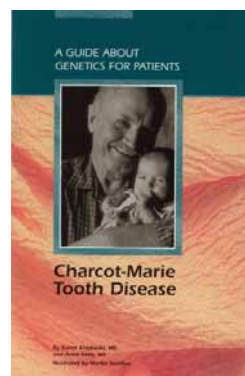
- AFOs and foot issues
- Emotional issues
- Pain and CMT
- Pregnancy
- Social Security
- Vitamins and herbs
- Physical therapy
- Occupational therapy
- Genetic testing
- Medical terminology
- Special section on HNPP



Handbook for Primary Care Physicians 1995/130 pages

Edited by Dr. Gareth J. Parry, Professor of Neurology at the University of Minnesota, the *Handbook for Primary Care Physicians* is an excellent source of information about the causes, symptoms, and treatment/management of CMT. Patients will also want to read it.

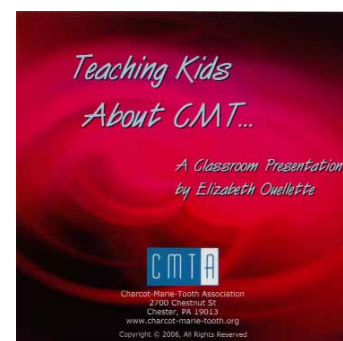
Nonmember Price: \$20.00
Member Price: \$15.00



A Guide about Genetics for Patients 2000/21 pages

Illustrated with easy-to-understand diagrams, this booklet outlines the basics of genetic inheritance and CMT.

Nonmember Price: \$5.00
Member Price: \$4.00



Teaching Kids about CMT... A Classroom Presentation

2006/DVD 1 hr.

This hour-long DVD of an actual classroom presentation demonstrates a number of games and other exercises to teach classmates of children with CMT about the disorder.

Nonmember Price: \$10.00
Member Price: \$7.50


Dear CMTA,

I just took the time to review the *Patient's Guide to CMT Disorders* that you sent with my membership renewal.

Thank you for taking the time and using your resources to produce the CD. I was diagnosed with CMT 1A about 35 years ago and have done much reading on the subject. I don't enjoy the scientific aspects but

do try to read them as well. This is one of the most comprehensive and easy-to-understand documents that I have ever encountered.

I hope that this becomes widely circulated to affected families and medical professionals. Everyone will benefit.

—J.W., Ontario, Canada

Dear CMTA,

I have purchased every single publication the Association has put out and have enjoyed each one. I am especially impressed

by the new *Patients' Guide* and the CD, which I have given my doctor so that everyone in the office can learn more about my disorder. Each item contains a wealth of information. Thank you for continuing to update the CMT community with the newest information and research on CMT. Any chance there will be a *CMT Facts VI* coming out in the near future?

—B.R., Vermont

Editor's note: We hope to publish Facts VI in 2008.

SUPPORT GROUP NEWS

(continued from page 18)

New York – Westchester

The group met on September 15th, after a lengthy summer break. They heard from Catherine Kazienko, who presented a program on balance, fall prevention, and issues related to agility and fitness.

In November, the group held their holiday pot luck brunch. There was a large turnout and a lot of fun was shared.

Pennsylvania – Johnstown

The Johnstown support group held its annual Christmas party on Saturday, December 15, 2007, at the John P. Murtha Neuroscience and Pain Institute. Attendance was down from last year, but food consumption was up! It was nice to have children join in the festivities. Ray Fisher showed off his new three-wheeled walker—an amazing device that is covered by insurance. It has left and right wheel brakes, which make it incredibly

maneuverable. The walker has a nice tote bag and folds flat. The walker is helping to keep him out of a wheelchair.

The next meeting will be February 16, 2008, at 1:00 PM. The group has tried holding meetings on Wednesday evenings without much success, so they are returning to the Saturday afternoon format.

Pennsylvania – Philadelphia Area

The December 8, 2007, meeting featured a presentation by Gary Michalowski, C-Ped, BOCP, CFO from Lawall Prosthetics and Orthotics, Inc. Not only did he discuss the various types of orthoses available to help CMT patients, but he analyzed the current braces used by several of the attendees. He also showed some of the members how the height of walkers and canes can affect gait in a negative way by causing the person to lean over and be out of balance. (He adjusted two walkers and suggested that two other members get taller canes.)

The next meeting will be on February 16, 2008 and will feature a presentation by Canine Partners for Life. The nonprofit organization will bring several service dogs who will demonstrate what they have learned to do to assist their owners.

Washington – Seattle

The February 23, 2008 meeting will feature a presentation by Support Group Liaison Elizabeth Ouellette. The meeting will be from 1 to 3 PM in the Plaza Café of the University of Washington Medical Center.

Washington – Tacoma

The first meeting of this new support group was February 2, 2008 from 3 to 5 PM in the Moore Library, Tacoma, Washington. The leader is Carol Hadle. The group plans to meet bimonthly and you can get more information about this group by emailing Carol at headme@q.com or by calling the support group liaison, Elizabeth Ouellette at 1-800-606-2682, ext. 107. ✱

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CMT PATIENT MEDICATION ALERT:

Definite high risk (including asymptomatic CMT):

Vinca alkaloids (Vincristine)

Moderate to significant risk:

Amiodarone (Cordarone)
Bortezomib (Velcade)
Cisplatin and Oxaliplatin
Colchicine (extended use)
Dapsone
Didanosine (ddl, Videx)
Dichloroacetate
Disulfiram (Antabuse)
Gold salts
Leflunamide (Arava)
Metronidazole/Misonidazole (extended use)
Nitrofurantoin (Macrochantin, Furadantin, Macrobid)
Nitrous oxide (inhalation abuse or vitamin B12 deficiency)
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)
a-Interferon

Negligible or doubtful risk:

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

What is CMT?

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

THE CMTA Report



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