



**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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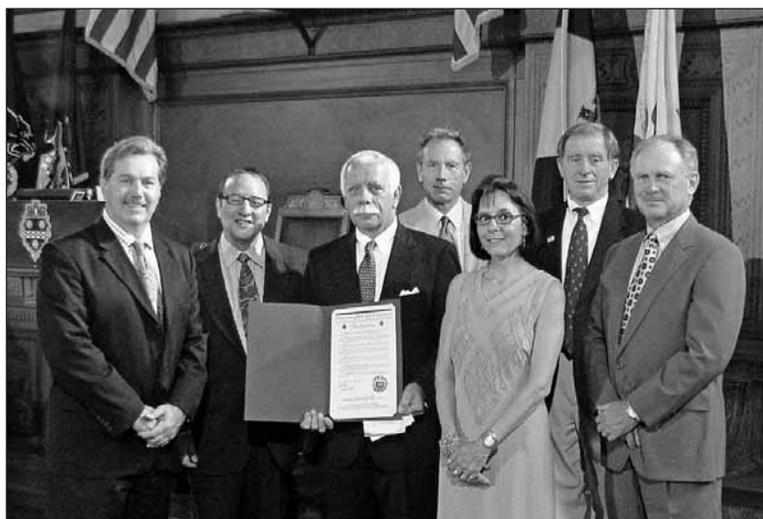
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## Pittsburgh City Council Declares CMTA Awareness Week

**O**n June 19, 2007 at a meeting of the Pittsburgh City Council, Council President Doug Shields sponsored a proclamation declaring the week of June 18, 2007 "CMTA Awareness Week" in Pittsburgh, Pennsylvania.

Pointing out the need for increasing awareness not only among the public, but also among the medical community, Councilman Shields said, "My wife Brigit is affected with the disease but it was misdiagnosed for years."

In thanking the City Council, CMTA Executive Director Charles F. Hagins noted that "The CMTA has adopted a new accelerated research collaboration model to identify com-



**Charles F. Hagins, Pittsburgh City Council President Doug Shields, Dan Merchant, Frank Catanzano, Brigit Shields, Thad Picklo, and Frank Marmion gather to examine the proclamation making June 18, 2007, CMT Awareness Week in Pittsburgh.**

pounds which promise to find therapies and a cure." He also emphasized the importance of grants awarded by the State of

Pennsylvania to help raise awareness of CMT which have enabled the organization to

*(continued on page 2)*

## Swimming the Chesapeake: A Fabulous Fundraiser

**F**or the sixth year in a row, CMTA Board member Steve O'Donnell has participated in the Chesapeake Bay Challenge to raise money for the organization's research fund. This year, Steve was joined by his friends, Dave Ruff, Greg Strait,

and Jim Reed, and his college roommates from the University of Maryland, Thomas O'Grady and Stephen O'Connell. Stephen O'Connell's wife Beth also joined them in making the one-mile swim. All these friends

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## CMT Patient and Family Conference Held in Pittsburgh, PA

On June 9, 2007, the CMTA hosted a patient/family conference at the Holiday Inn in Monroeville, PA.

Approximately 65 people listened to presentations by Dr. Chitharanjan Rao, Dr. William DeMayo, Dr. Mary Louise Russell, Kathi Brandfass, Sandy Thompson, and Scott Osipiak.

Dr. Rao began the meeting with a presentation on the various aspects of the disease, including an explanation of what neuropathy actually is, the various sensory and motor components of the problem, and the amazing gene discoveries which have been made in the last 15

years. He told the audience that only 5 genes were known to cause CMT back in 1993. By 2003, there were 15 known CMT genes, and now in 2007, there are over 30 known locations for the flaws which cause CMT. He also told the audience that although CMT is a genetic disorder, over 20% of all diagnosed cases are now “de novo” or new cases with no family history.

Dr. Mary Louise Russell, who is the Co-Director of the MDA Clinic at the Children’s Hospital of Pittsburgh, discussed the technique and goals of pediatric rehabilitation.

She explained that the goals in dealing with children with

CMT include maximizing their independence and minimizing the burden of care for them. To that end, physiatrists work to prevent or delay complications resulting from sensory loss, contractures, localized weakness, generalized weakness, and the need to remain independent.

Sandy Thompson represented the Muscular Dystrophy Association and provided the audience with a very comprehensive overview of the services provided by the MDA. Scott Osipiak, from Athena Diagnostics, discussed the advances in genetic testing and the help that Athena provides in paying for their testing services.

### PITTSBURGH PROCLAMATION

*(continued from page 1)*

conduct the first prevalence study in the United States. “The prevalence study will drive the statistics which, in turn, will drive the funding,” he concluded.

In his remarks, Dan Merchant, chief development officer, outlined his plans to raise \$10 million in the next two to three years. “We can see the light at the end of the tunnel. With proper funding and through the use of the new research model, we believe we can find therapies within five years and a cure within ten years.”

Briget Shields, wife of the City Council President and herself a CMT patient, spoke during the ceremony. She thanked

the CMTA for “giving me a great amount of strength and hope.” Mrs. Shields also mentioned the importance of the CMTA website as the vehicle that “enables people from all over the world to come together through the forums to share their hope and to keep abreast of progress in finding a cure for this disease.”

Also present were Frank Marmion, Frank Catanzano, and Thad Picklo of Gatesman, Marmion, and Drake, the communications firm that represents the CMTA.

The proclamation was co-sponsored by Pittsburgh council members Len Bodack, Twanda Carlisle, Dan Deasy, Darlene Harris, Jeffery Koch, Jim Motznik, Tonya Payne, and Bill Peduto. \*



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



Kathi Brandfass, a neuro-physical therapist, kept the attendees busy with exercises they do from their chairs as well as discussing with them the importance of being evaluated by a professional and receiving a personal profile assessment. Physical therapists should discover which muscles are weak, and also what tasks the person needs to do each day. She promoted the idea of energy efficiency so that whatever you do, you do in the best way possible. She taught everyone that resistance training will accomplish muscle fiber architectural change; stretching will increase connective tissue (tendons and ligaments); posture will help with balance; and cardio-vascular work will improve stamina and endurance.

The day ended with a presentation by Dr. William DeMayo who is the Medical Director of the CMT Programs at the Conemaugh Health Systems Neuroscience Center in Johnstown, PA. He explained the program that is used for the CMT clinic at his facility, which includes many alternative procedures, such as massage and water therapy in addition to the usual neurological and orthopedic evaluations.

Each person present received the CD version of the new Patients' Guide to CMT as well as a printed copy of the book. The production of this new book was made possible by an awareness grant provided by the Pennsylvania Department of Health. Currently, the book is being reprinted to include colored pictures rather than the black and white ones used in the first printing. The CD is currently available for purchase and the book can be ordered now and will be mailed as soon as it becomes available. \*

## EXERCISING WITH CMT

# Why the Pool?

BY SARA KITTELL, MSPT

Charcot-Marie-Tooth disease was discovered in 1886 and continues to be a cause of progressive mobility limitation to those affected. Nearly 150,000 Americans suffer from the degeneration of peripheral nerves associated with Charcot Marie Tooth disease, leading to decreased muscle function and altered sensation. It is then more difficult to carry out daily activities, such as dressing, bathing, and walking, as gravity adds extra resistance to the work required to achieve these tasks.

Exercise has long been an integral component in maximizing function in people with neurological diseases, including Charcot-Marie-Tooth disease. In order to strike an effective balance, exercise must not cause excessive strain or fatigue. The pool provides an excellent medium for exercise that follows these guidelines.

The pool decreases the amount of effort required for movements that are challenged by gravity when on land, which allows for greater range of motion, thanks to buoyancy, and is less painful. Buoyancy, in an opposing yet beneficial manner, also challenges balance, by forcing core stabilization through the trunk anytime a limb is moved through the water. Core stabilization is imperative to a person with Charcot-Marie-Tooth disease,

since balance reactions closer to the feet are impaired due to nerve degeneration. Adaptive yoga positions in the pool or Tai Chi are excellent options for further increasing stabilization. The opportunity to train these muscles in an upright position, even if the person leans against a wall, can reap great benefits for standing activities at home.

Increasing speed when moving a limb through the water not only challenges core stability, it also increases resistance on that limb, and promotes strength. Research has shown that muscle mass can be improved with low-to-moderate resistance training, provided that significant weakness is not present in the respective muscle groups. The more quickly a person “pushes” his hand through the water, for example, the greater his resistance will be. There should not be any weakness suffered as a result of low-to-moderate resistance training, as long as the muscles being worked are not significantly weak to begin with. Devices such as paddles or foam barbells can be used to increase the amount of resistance while exercising.

In addition to strength training, aerobic exercise is also important, as it promotes endurance, reduced fatigue, and improved mood. In the pool, this can be accomplished by walking, riding a stationary bike, or in the deep water while suspended by a foam floatation

device, such as a foam noodle, for example. If possible, it is best to walk for as long as tolerated, to also promote postural strength while doing endurance training, and follow up with deep water exercise as able.

The final component of an exercise plan, either on land or in the pool, is stretching. The heel cords, or “achilles tendons,” need to be a point of focus in a person with Charcot-Marie-Tooth disease, as the foot can commonly be flexed downward due to nerve degeneration causing drop foot. Stretching is also fundamental to avoid formation of muscle contractures which can further limit mobility.

A comprehensive aquatic exercise program for a person with Charcot-Marie-Tooth disease can best be designed by a physical therapist, in cooperation with a treating physician. This way, specific needs will be identified to meet goals that will help to improve function, and gradual progression will be directly supervised. Aquatic exercise classes are another option, but may include less direct instruction. A patient can speak with his or her doctor, who can advise on performing aquatic exercise in physical therapy versus a class setting, and refer to an appropriate facility. The earlier exercise is begun, the greater the benefit will be in a person with Charcot-Marie-Tooth disease. Exercising in the pool is a great way to do it! ✨

## SWIMMING THE CHESAPEAKE

*(continued from page 1)*

of the O'Donnells joined in the swim this year to help Steve generate more awareness of the disorder and to increase the monies that could be raised.

For the first time this year, another CMTA member, Rachael Beron, swam the challenge in honor of her daughter, Julia, who has CMT. Rachael's comments following the swim were: "Wow, what an incredible day! Who could have guessed that just four months after I had originally emailed Steve O'Donnell (just to inquire about The Swim for the Cure!) that it would have been such an unbelievable success? When I crossed the finish line, I was actually disappointed that it was over. TeamJulia is already getting excited for the 2008 Swim, and we've been approached by three other friends who've expressed interest in joining our team. Many thanks go out to our



friend Steve Grossman, who immediately upon hearing of our cause, jumped on board and was a great swim partner! Also, I want to thank Steve O'Donnell for welcoming our family—you are truly an inspiration! And lastly, our heartfelt thanks to all of our supporters (numbering 234 and counting!)"

The swim, which is basically the effort of individuals, is the

largest fundraising event of its type. This year, including pledges, the swim has raised an amazing \$189,353. It is the dream of Steve O'Donnell to reach \$200,000 for this event, so anyone who wishes to help him achieve his goal may send a contribution to the CMTA and mark the gift for the swim. All money raised goes directly to the research fund. \*

**Successful swimmers pictured are (kneeling) Rachael Beron and (standing) Dave Ruff, Jim Reed, Tom O'Grady, Steve O'Donnell, Greg Strait and Steve Grossman. Steve O'Donnell, who has CMT, has found swimming to be an excellent sport and exercise program.**

## LETTERS

**Dear CMTA,**

I have chosen to donate to your association for my mitzvah project called, "Tzedakah."

Tzedakah is a project where a person gives money to a fund that means something to them. I chose your association because I have CMT. I was diagnosed when I was about four years old and now that I'm twelve, I am going to have a bat mitzvah. In conservative and reformed Judaism, a bat mitzvah is when a Jewish girl of 12-14 years of age is considered

an adult who is responsible for moral and religious duties.

I am donating \$500 because I would like to help find a cure or help the people who are diagnosed, like I am, with CMT. I hope this money can help with the goal of finding a cure for CMT.

—Alexandra, MI

**Dear CMTA,**

I just wanted to pass along some information on a pair of shoes that I think will help people with CMT. They are called Dickies.

I discovered them by accident in a boot store. My hus-

band and I were getting ready for a tour of Italy and I knew I would need a "good pair of shoes" for the trip. The girl said they were sort of like a tennis shoe, but with a hard steel plate in the bottom of the shoe for support.

I made it through the rough terrain roads of Rome, Venice, Florence, and Pisa and the steps we had to climb...wow, these shoes supported me with such stability I could not believe it. I do not wear AFOs but I believe the shoes are deep enough to accommodate them.

—Lisa, FL

# Wayne State Clinicians Answer CMT Questions, Part II

*This is the second article of a three-part series. These questions about genetic counseling were answered by Karen Krawjewski, MS, Certified Genetic Counselor and Assistant Professor of Neurology at Wayne State University. The next CMTA Report will feature questions and answers about gait analysis and orthotics.*

## 1 Who are genetic counselors and what exactly do they do?

Genetic counselors are health care professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. Most enter the field from a variety of disciplines, including biology, genetics, nursing, psychology, public health, and social work.

Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence, and review available options with the family. Genetic counselors try to help families make

decisions that are based upon the family's beliefs, values, and individual situation.

Genetic counselors also provide supportive counseling to families, serve as patient advocates, and refer individuals and families to community or state support services. They serve as educators and resource people for other health care professionals and for the general public. Some counselors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counseling.\*

## 2 What is genetic counseling?

Genetic counseling involves education about conditions that may run in a family. This process can also help people deal with problems that occur when there is a genetic condition in the family. Genetic counselors can help to connect people with appropriate resources and help them to make decisions about their future and reproduction.

## 3 What happens during a consultation with a genetic counselor?

Genetic counseling sessions can vary depending on why the person is being seen and their major concerns. Typically time will be spent going over the person's family history in great detail. This will include gathering information about each person in at least three generations of the

family including their ages, major medical conditions, age, and cause of death if applicable, and whether or not they have any symptoms of the condition in question. Information will also be collected on the ethnic background (German, Italian, etc.) of the patient as well as any history in the family of people with mental retardation, learning disabilities, babies that were still-born or died in infancy, children who died young, woman with multiple miscarriages, and any intermarriage (cousins who marry each other, for example). Some of the questions asked may not seem directly relevant to the condition being evaluated but sometimes small details can give clues important for making a diagnosis and it is important to also consider the impact of other conditions that run in a family.

There are many questions that may be addressed during a counseling session, including:

- What are the chances that my children or relatives will develop symptoms like mine?
- Can this condition be detected before birth?
- Is there a way to prevent any children from getting this condition?
- Can my children be tested?
- How will genetic testing impact my or my family's ability to gain employment or get insurance coverage?
- How will genetic testing in one family member affect the rest of the family?

\*Parts Adopted by the National Society of Genetic Counselors, Inc. 1983

- Should everyone in the family be tested?
- Can this condition “skip” generations?
- What are the pros and cons of genetic testing for my family and me?
- What information will genetic testing tell me?
- What are the possible results of testing?
- Is there any way to delay or prevent the onset of symptoms?

#### 4 Why should I see a genetic counselor if I am diagnosed with CMT?

There are many different types of CMT, each caused by changes (called mutations) in different genes. There are different types of inheritance for these conditions and depending on the gene involved and the inheritance, the chance for a person’s children and/or other relatives to be affected could range from almost no chance up to 50%. Genetic counselors can help to figure out which genetic tests are most appropriate based upon the person’s family history and their findings on examination. They can also help to interpret the results, which are not always straightforward, and help identify options for family planning.

#### 5 If my type of CMT has not yet been determined, can a genetic counselor still be of help to me?

Yes, based on the family history, it may be possible to determine the chance that other family members could be affected or could pass the condition to their children. Genetic counselors also

may have access to the latest testing. New genes are being identified at a rapid pace and new tests for CMT become available fairly frequently. They may also be able to coordinate testing on a research basis when appropriate.

#### 6 What are the benefits to making a genetic diagnosis?

There are several reasons why making a genetic diagnosis is important. First, a definite diagnosis clears up any doubt about often unusual and confusing medical symptoms. Second, it often allows a more accurate prognosis to be made. This can be helpful in predicting complications so that appropriate measures can be taken to prevent or minimize their effects. Beginning a physical therapy program early on may help to extend a patient’s normal activities and abilities. Third, a diagnosis allows people to know for certain their chance of passing on a genetic disorder to their children. Options for prenatal testing (testing a pregnancy) and/or preimplantation genetic diagnosis (testing embryos before implantation) may be available once a person has a genetic diagnosis. Fourth, as genetic and other medical advances occur, it will be possible to treat or prevent these diseases from developing. Since each of the different types of CMT is caused in different ways depending on the gene involved, early clinical trials may be limited to people who have a certain genetic type of CMT. This has already happened with the vitamin C trials

for CMT1A. A clear understanding of one’s neurogenetic condition often removes misunderstanding and allows people to feel some control over their condition.

#### 7 Will genetic counseling prove conclusively that someone does or does not have CMT?

A genetic counselor may be able to help arrange testing that will lead to a conclusive diagnosis. For many people it may be possible to say with certainty that they have CMT, but, because of the current limits of genetic testing, not make a genetic diagnosis. Hopefully as further research is done, more of the genetic types will be able to be easily diagnosed.

#### 8 Is genetic testing expensive? Who pays?

Genetic testing can be expensive. However, it is not usually necessary to test a person for every possible CMT-causing gene. Based on a person’s family history, their medical history and their nerve conduction testing, it is often (but not always) possible to narrow down which genes are most likely to give a positive result. The amount that a given person will have to pay is largely dependent on their type of insurance. Many people with private insurance will only have to pay at most about 20% of the full cost of the test and for some people the cost is covered in full. A genetic counselor can help to determine the out-of-pocket expense and help develop a testing scheme that is most cost-effective. \*

## Nona Leatherwood Maxwell: Creative Inventor

**M**y name is Nona Leatherwood Maxwell. I am 53 years old. I am a wife, mother, grandmother, canemaker, and avocational archeologist. Recently, the title of inventor was added to my portfolio, not by design but by happenstance. In 2006, I was honored with Oklahoma's Muscular Dystrophy Association (MDA) Personal Achievement Award for my work.

I was raised on an Oklahoma farm, and I am proud to be a farmer's daughter.

I recall the difficulties my father had being a farmer with CMT. Walking across a plowed field, turning a bolt, or climbing on the tractor was never easy. I also recall the determination and dignity of his drive and desire to

always "find a way" to accomplish tasks that would be difficult for anyone with CMT.

I was diagnosed with CMT in my early 20s. By my late 20s, I was prescribed AFOs—which I did not want to wear. I was also advised to use a walking cane—which I did not want to do either.

But much more, I wanted to be able to stand on my own without having to hold on to someone's arm or lean against a wall. I also wanted to continue hiking and going on archeological digs. I did not want to give up anything because of my CMT. I just had to find ways around my CMT and like my dad, try to "find a way."



**The white AFO liner makes braces more comfortable.**

with disabilities, but my canes are an invitation to conversation. They invite interaction while breaking an uncomfortable barrier.

### LESS PAIN, COOL, COMFORT, AND FASHION IN AFOs.

I loved the stability and energy that my AFOs gave me, but I did not like that they were

unappealing and they were hot. But I wore them anyway. I put a knee sock on to buffer the AFO from my skin and then put on a second sock to cover them up completely. They were hot and the sock bands caused my legs to ache even more.

As my sister, who also wears AFOs, and I

sat at our mother's table talking of the difficulties we had wearing our AFOs, it became clear. Most of our problems would be solved if we didn't have to wear socks under our braces.

So I developed the AFO Liners. The AFO Liners are a comfortable cushioning sleeve for the AFO. With an AFO Liner on the brace, I no longer have to wear socks. Therefore, I am able to stay cool in sandals, or wear tennis shoes with anklets. The AFO Liners come in colors of tan, white, and black. Dressing for business and evening is now possible with a skin tone AFO Liner on the brace and sheer hosiery. I hadn't

**Nona shows off some of her intricately beaded canes.**



### I WANTED A CANE THAT WAS FUN AND BEAUTIFUL.

I was too young and too vain to use a generic cane. A friend gave me a cane with feathers painted along the shaft. I used it for years until it was badly worn, and then searched for another but couldn't find one that I liked. One night I had a dream about a blue, beaded cane. It was then that I began making my canes. I made them not only for myself but for others who needed a cane and couldn't find one that made them feel better about having to use a cane. People tend to shy away from others

worn sheer hosiery in over 20 years until now. (See my website, [www.afoliner.com](http://www.afoliner.com) for more information.)

My desire is to be able to fit as many AFOs as possible and especially children's AFOs. AFO Liners can make the AFO experience a lot easier. The current line of AFO Liners fit many sizes and shapes of AFOs, and we will work to develop new products as AFOs change and evolve.

### HEALTH BENEFITS OF AFO LINERS

AFO Liners come in white Coolmax, tan polyester, or black polyester/X-STATIC fibers. The liner wicks moisture away from the wearer's legs, keeping them drier. The yarns are "corespun" around Lycra, providing the unique benefits of less wrinkling and an ability to conform to various shapes of AFOs. Core-spun yarns also offer greater strength and superior rebound. All three provide antimicrobial benefits, making the AFO Liner more hygienic.

I have no idea what my life would have been like had I not had CMT. But my life with CMT surely has been no less exciting and challenging. And just like my father, I am always looking to "find a way." When one door closes, another door opens.

Because of organizations such as the CMTA, one day AFOs and walking canes will not be necessary. But until that day comes, I'm going to continue to step out with my "good medicine" walking canes and dress in comfort and style in my AFOs. \*

## The CMTA Mourns the Loss of Its First Executive Director

BY PAT DREIBELBIS

**O**n Monday, June 25, former Board member, Jack Walfish, called the office with the unbelievable news that Paul Flynn, only 39 years old, had died of congestive heart failure the previous week. Paul had been a member of the Board of Directors, then had been chosen as the association's first paid Executive Director. Both Jack and I worked with Paul during his years of service and for each of us, the news was devastating.

Paul was an energetic visionary who imagined all the possibilities that an organization like the CMTA might achieve. There were no limits to what he imagined. He designed fundraisers using his grandmother's support group to help with the Westchester Broadway Theater; he had a group called Kids In Business design note cards for the CMTA to sell; and most importantly of all, he spoke to anyone and everyone about CMT and demonstrated by his own life how much a person with CMT could accomplish.

When Paul left the CMTA, he began his work for the city of Newark. He ran an unsuccessful campaign to gain an at-large city council seat, but that did not stop his determination to serve the city and its children. He worked for the Gateway Northwest Maternal Health Care Consortium and his

job was creating awareness about lead poisoning among city children.

Paul earned a Bachelor's and Masters degree from Seton Hall and was founding director and past president of Jersey Cares, an organization that helped provide volunteers for projects throughout Newark.

As Executive Director of the CMTA, Paul often stayed at my



Paul Flynn

home because he drove from Newark and staying at a hotel would have been costly, using association money in a way he considered unnecessary. To "pay" me for letting him stay in my house, he offered to mow my lawn. I have a very large yard, with

an annoying hill in the front. After completing the arduous task of mowing both my front and back yards, with his face covered in sweat, Paul remarked, "Boy, that was fun!" No one before or after Paul has ever described the job with that term! But, the anecdote clearly illustrates the way Paul looked at everything in life. He saw the fun, the joy, and the possibilities when others saw only the work involved.

The Charcot-Marie-Tooth Association grieves the tremendous loss of Paul Flynn and sends its sympathies to his mother, Anita, his father, Raymond, his grandmother, Kay, his brothers and his sister and all his extended family. \*



# GIFTS WERE MADE TO THE CMTA

## IN MEMORY OF

### John Bradley

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Wholesale  
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Jerry & Helen Thummel

# On the Joy of Speaking at a CMT Support Group

BY MARTIN MCCORKLE

I was diagnosed with CMT as a young child after I had one of those nasty EMG tests.

So, I've lived my whole life with CMT.

My doctor told me back then that CMT was rare, and he was right. I was in my mid-forties before I met another person with CMT.

I vividly remember meeting him. He worked at a printing shop. His hands looked like mine. He walked just like me. He was struggling to maintain his stamina and energy. Just like me.

There was an instant sense of connection. We were fighting the same battles.

After the publication of my book, *Walk with Me*, about my 1,700-mile hike through California, Elizabeth Ouellette, the leader of the Bay Area support group in California, contacted me and asked if I would speak at her group. I was certainly excited about meeting more people with CMT. I prepared a session on how to let your loves and passions help keep you active. I looked forward to being with the group, and I was not disappointed.

I had such a great time! I'll mention four things that I liked about speaking at this CMT support group.

The first thing I enjoyed was encouragement. What a great and awesome privilege to sit with such courageous people,

people who get up every day and deal with CMT.

I met a man who drove all the way from southern California just to be with our group. And for those of you who don't how big California is, he drove a LONG WAY to get there. I was impressed by his independence and capability.

People (with CMT) are making it through this life and doing fine!

I met two young ladies involved in the arts. One of them was a painter, and we talked about her love for painting and how she could lean on that to stay active. Another young woman was involved in theatre. I was "jazzed" by her willingness to take risks and be a public person.

In addition to encouragement, I also reaped the benefit of clarity. It's so helpful for me to think through how to present an idea, write down what I'm thinking, and then actually bring it to a group. As we discussed how to let your loves and passions keep you active, I gained so much more insight than I would have just sitting around on my own.

I talked with Elizabeth, her husband, Gilles, and their son,

Yohan, who has CMT. We hit on such things as the search for a cure, how to maximize the energies of those seeking to help people with CMT, and just stuff know about life.

I left with a greater sense of what was happening in the world of CMT and with a keener understanding of the material that I myself presented.

The third thing that I received was hope. Having CMT is hard. We all know that. But people are making it through this life and doing fine. Kids are getting through school. People are pursuing the things they love. We find a way to make it through.

And at those times when life becomes overwhelming, there are people I've met who know exactly how I feel.

Lastly, I enjoyed the participation of parents who have kids with CMT. How I wish that my own parents had had a chance to talk with and connect with other parents of kids with CMT! To be able to hear their point of view and share the road with them was great.

So thanks to all the leaders who organize these groups. Your work is deeply appreciated. The connection that flows from these groups is extremely precious.

I'll be at the Las Vegas support group later this summer and am looking forward to sharing my life's story, once again, with an awesome group of people. ✨



## SUPPORT GROUP NEWS

### California – San Francisco

On June 9th, we had a picnic with a live magic show and a bubble blowing “contest.” Attendees also played with group leader, Elizabeth Ouellette’s hairless cat, and had one-on-one conversations. The next meeting is tentatively scheduled for September 29th, from 2-4 PM in the Menlo Park Library. Meetings will now be held on a quarterly basis rather than the current bi-monthly schedule.

### Colorado – Broomfield

Dr. Michael Shy spoke to over 50 attendees at the support group meeting. His presentation was informative and well-received. The audience members came away with a better understanding of what CMT is and how to cope with the problems it causes in their lives. Dr. Shy stayed past the meeting time and graciously answered every question the audience had for



Members of the San Francisco group watch the magic show at their summer get-together.

him. Support group leader, Diane Covington, described Dr. Shy as “charming, funny, and completely down to earth.” The group’s next meeting will be on August 25th at 10 am at the First National Bank in Broomfield, CO.

### Nevada – Las Vegas

On September 15th, the group will have guest speaker, Elizabeth Ouellette, member of the CMTA Board of Directors and support group liaison, speaking about the Second International CMT Consortium held in July in Snowbird, Utah. Elizabeth will also discuss pain manage-

ment, depression, and stress and ways to alleviate them through cognitive behavioral techniques. The meeting will take place from 1-3 PM in the Whispering Pines Community Center.

### Pennsylvania – Philadelphia

Fourteen people attended the June 16th meeting and received the new Patients’ Guide to Charcot-Marie-Tooth Disorders and the accompanying CD which also includes a slide presentation for patients and their families by Dana Schwertfeger, Director of Member Services, and a slide presentation for primary care physicians by Dr. Steven Scherer of the University of Pennsylvania. Members discussed many of the pieces of information on the CD which they viewed, including bracing, shoe fitting, and possible therapies they might try to improve their function. The next meeting will be a “picnic” in the comfort of an air-conditioned room on August 18th. \*

## Detroit needs a CMT Support Group!!!

**A**re you enthusiastic, people-oriented and curious?  
Looking for support, community, and updated information on CMT disorders?  
Ready to get involved in CMT-related events by bringing medical professionals and CMT patients together?

The CMTA is looking for a dedicated and committed individual(s) to lead or co-lead a CMT support group at Wayne State University. Groups usually meet quarterly, on a weekend, for a duration of 2 hours.

The CMTA will offer assistance in getting your group up and running, as well as provide topics of interest and help finding CMT specialists and speakers.

If you are interested, please contact Elizabeth Ouellette, CMTA Support Group Liaison, at 1-800-606-CMTA (ext:107).

# CMT Support Groups

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

## Alabama—Birmingham

**Place:** Lakeshore Foundation  
Fitness Center

**Meeting:** Call for schedule

**Contact:** 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

## Arkansas—Northwest Area

**Place:** Varies, Call for locations

**Meeting:** Quarterly  
*Meetings are not regularly  
scheduled so call ahead.*

**Contact:** Libby Bond, 479-787-6115

**Email:** charnicoma57@yahoo.com

## 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:** Location to be determined

**Meeting:** Bimonthly

**Contact:** Elizabeth Ouellette,  
650-248-3409 (C)  
650-559-0123 (H)

**Email:** elizabetho@pacbell.net

## Colorado—Broomfield

**Place:** First National Bank

**Meeting:** Bi-monthly on the  
fourth Saturday

**Contact:** Diane Covington  
303-635-0229

**Email:** dmcovington@msn.com

## Florida—Tampa Bay Area

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

**Meeting:** 2nd Sat of Feb, May, Aug, Nov

**Contact:** Lori Rath, 727-784-7455

**Email:** rathhouse1@verizon.net

## Kentucky/Southern Indiana/ Southern Ohio

**Place:** Lexington Public Library,  
Northside Branch

**Meeting:** Quarterly

**Contact:** Martha Hall, 502-695-3338

**Email:** marteye@mis.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:** Maureen Horton, 651-690-2709  
Bill Miller, 763-560-6654

**Email:** mphorton@qwest.net  
wmiller7@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

## New York—Greater New York

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

**Meeting:** Third Saturday of every other  
month, 1-3 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 Hospital

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

**Contacts:** Beverly Wurzel, 845-783-2815  
Eileen Spell, 201-447-2183

**Email:** cranomat@frontiernet.net  
espell@optonline.net

## Nevada—Las Vegas

**Place:** Whispering Pines Community  
Center

**Meeting:** Email for dates 1-3 PM

**Contact:** Mary Fatzinger

**Email:** cmt\_suppgrp\_lvnv@yahoo.com

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

**Place:** Various locations in Raleigh

**Meeting:** Quarterly

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

**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

## Ohio—NW Ohio

**Place:** Medical College of Ohio

**Meeting:** Quarterly

**Contact:** Jay Budde,  
419-445-2123 (evenings)

**Email:** jbudde@fm-bank.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@adelphia.net

## 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

## 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

# Detroit: A Great Place to Visit

BY YOHAN BOUCHARD, AGE 14

In February, my mom took me to see Dr. Shy, a neurologist, and his team at the Wayne State Clinic in Detroit, Michigan; all experts in CMT. We decided to go there to get advice and information on how to manage my CMT, and hopefully get new braces which would not cause blisters and pain.

We arrived the night before the appointment, and since many planes were cancelled because of snowstorms, we were lucky to arrive on time! Too early the next day (I had jet lag), we found the right building, went up an elevator, and found the CMT clinic. Dr. Shy was kind of busy, so we had to wait 10 to 15 minutes for him to see us. Shortly, Dr. Shy

came out to greet us and brought us back into a normal-looking hospital room. Dr. Shy examined me and then he introduced me to his colleague, Dr. Lewis, who was to perform an EMG study on me, to examine how fast or slow my nerves were conducting.

For fun, I call this test “shock treatment” because the nerve stimulation feels like jolts of electricity going through parts of my body. It sounds painful, but he did not use any needles, and I did not think it was all that bad. The best part is when I asked Dr. Lewis to shock my mom a couple of times, just so

she would know how I felt—and he agreed!

We saw a lot of people that day, including Karen, a geneticist, who explained what CMT was and how it was transmitted. She also asked me to do a series of hand manipulation exercises to test my strength. Before leaving Dr. Shy’s clinic, I added a



Yohan "enjoys" his "shock treatment" from Dr. Richard Lewis at Wayne State.

colorful pin to a huge map of the world to show where I came from. I actually got to stick two pins in, one in Grenoble, France, where I was born, and the other in California, where I live.

Then, we met up with Dana Schwertfeger, who I know from the CMTA, and Dr. Shy brought us through a complicated series of underground tunnels to see Sean, the orthotic guy. I have not had much luck with braces over the years, because they usually cause blisters, sores, red marks, and pain on my feet and legs. However, Sean convinced me he could make a pain-free pair of

braces for me, so I let him mold my feet and make a cast. In the meantime, he gave me a pair of night splints to wear when I was playing computer games or watching TV to stretch my feet and legs until the new braces were made. By this time, it was very late and my mom, Dana, and I were exhausted. Sean gave

us a ride back to our hotel and even stopped at a store for us so my mom could buy snacks. He was really nice.

The next day, we went back to the hospital, to a different clinic, where I met Allon, who tested my gait (the way I walk), my balance, strength, and endurance. At first, Allon did not realize how strong I am, but when he

asked me to push down on his hands with my foot, I nearly knocked him off the chair. I think I gave him a good workout!

After a long two days, we said goodbye to Dr. Shy and his team and thanked them for their help. I was to return to Detroit two months later to get my new braces.

My dad, Gilles, took me to Detroit the second time around. It was nice to see Detroit in the spring because we could walk outside and enjoy the city.

In Detroit, the only way we were able to go places was in

taxis, and most of the taxis my dad hailed were all beat up and full of holes. Some of the taxi meters were not even working and many had thick glass separating the driver and passengers. The drivers were all very nice, but the cars they used were pretty junky. Maybe I was just paying more attention to detail, but in my opinion, I think my mom must have paid more money for better taxis and my dad did not care and did not want to waste the money.

The following day (jet lag never changes), we went back to see Sean for my braces. I could not believe they actually fit well, probably because Sean knew how to make and adjust them properly. I wore them for a day and when I started to get a blister, Sean made another adjustment. I have not had any problems since. They are much more comfortable than any of my other braces and more flexible so that I can play sports. Dr. Hinderer, the physiatrist, even said that my gait was better and I

would be less tired because I would not have to use so much energy to walk and lift my feet.

My dad and I decided to stay a couple extra days to enjoy Detroit and to meet up with some old friends. I didn't think there was anything to do in Detroit, but we went to the Detroit Science Center, where they were featuring an educational exhibition, "Our Body: the Universe Within." The exhibits were fun and very entertaining, especially since it featured real human bodies, without skin! After taking a freight elevator with 20 other people down to the exhibit floor, I learned a lot about my own body and human anatomy through the human specimens on display. For example, we saw muscles, bones, and the digestive tract, and how scientists were able to take out all the veins of the body and keep them intact. Towards the end, there was a real human body sliced vertically and horizontally and the last exhibit showed unraveled human skin

all by itself. It was fascinating and really cool.

Lastly we met up with some old friends who live in Toronto. We first met them a couple of years ago on a vacation in the Galapagos Islands. We spent the afternoon together talking about world and personal events of the last two years. We walked around downtown Detroit where there was a Techno Music Festival (not my favorite) going on. The afternoon and evening went very quickly and we had a lot of fun catching up. After dinner we finally had to say goodbye and go back home to California early the next morning.

I am so glad I went to Detroit to see Dr. Shy and his team because now I understand CMT a little bit better and I have great braces. Despite the shock treatment and run-down taxis, it was well worth the trip. As an additional treat, we got to see our friends, enjoy the city, and see a very unique exhibition. I look forward to going back next year!!! \*

## 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)

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Signature \_\_\_\_\_

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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  
Lefluonamide (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 U.S.)  
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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