

# THE CMTA Report

MARCH/APRIL  
2013

Information on Charcot-Marie-Tooth Disorders for patients, families, and the scientific community ★ [www.cmtausa.org](http://www.cmtausa.org)

## Family Planning for CMT

*The First Article in a Series*

BY SHAWNA FEELY, MS, CGC, AND CARLY SISKIND, MS, LCGC

A common question in genetic counseling is, “Will my kids have CMT?”

Sometimes this question comes after the kids are already grown, in which case the answer is based on the type of CMT someone has. But in other cases, this question comes before someone is pregnant. In these cases, we have a conversation about reproductive options.

If the genetic type of CMT is

known, it is possible to find out if a child will be affected or make decisions to not have a child if he or she would be affected. These are very personal decisions, and what is right for one person or family may not be what is right for others. Our job as genetic counselors is to present the options that are available, and to help the family determine what is best for them.

(continued on page 6)



### OUR MISSION:

To support the development of new drugs to treat CMT; to improve the quality of life for people with CMT and, ultimately, to find a cure.

### OUR VISION:

A world without CMT.

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## Working Through the Social Security Disability Process

BY RAM MEYYPAN, [www.socialsecurity-disability.org](http://www.socialsecurity-disability.org)

Applying for Social Security Disability benefits can be a long and strenuous process.

It is crucial to know, going into the process, how long each step takes and what forms are required. Understanding the process in detail can greatly reduce the stress that so many disability applicants experience. Below are details outlining the requirements for each stage of the disability application process and how long each stage takes, on average.

### The Initial Application Process

When applying for Social Security Disability benefits, the first step of the process is known as the initial application process.

This is when you start your disability application by:

- Filling out the disability application
- Filling out the adult disability checklist
- Providing consent to release medical records
- Providing copies of medical records that you may have in your possession

Depending on your specific circumstances, you may be required to attend a consultative exam. The purpose of this exam is to gather evidence to support or dismiss the fact that you qualify for Social Security Disability benefits from the Social Security Administration (SSA). This exam is in no way intended to

treat your condition. It is only meant to assess the extent of your disability and how it interferes with your day-to-day life.

The initial application process takes approximately 3 to 6 months to complete. If you are not approved for disability benefits during this stage of the

(continued on page 14)

### INSIDE:

“Lucky” with CMT .....	2
Classroom Awareness .....	4
Getting Involved .....	8
Partners Fighting CMT .....	10

## The Lucky Ones

BY JONAH BERGER

I would like to invite you, if I may, to take a moment to consider how lucky we are to have CMT. Don't adjust your newsletter and don't consider getting contacts, you heard me right. I think we are lucky to have what we have.

As I get older with this challenge, I begin to see the blessings in this. The hidden gifts. The pieces of wisdom bestowed to all of us, if we simply allow ourselves to see them. The greatest of these, in my opinion, is humility. I see what a rare quality this can be in our society. True humility. The ability to understand in your very core how fragile we really are. How vulnerable and how reliant. This is a true gift. Because those who

live in denial of these absolute truths are at a far greater risk than any of us. By nature of our condition, we have no choice but to be constantly aware of our weakness. Always focused on our need for help. And ever seeking to work within the unchangeable parameters of our bodies. This is a gift.

Another lucky blessing we all have is the ability to see the greatness in others. Those friends, family, and especially strangers, who ease our challenges with their love and support. I was in Italy this fall. I went to a café and ordered pizza for lunch. All pizzas in Italy come in a small, round, and uncut form. The waitress, who spoke little English, brought my lunch and walked away. I began to cut into it with my non-traditional, sloppy, and, mostly ineffective, cutting style. A few minutes later, the waitress walked over to me and without saying a word, picked up my plate and walked away. I sat there wondering what had just happened and hoping to get my pizza back. Two minutes later she returned. She placed my pizza back down in front of me. Now it was cut into perfect forkable pieces. It was so nice. She didn't say a word. She simply observed that I could use some help and decided to give some. It is moments like that that make me feel lucky to have this challenge. Other patrons at that café might not have had a reason to learn that their waitress was a queen in disguise. Yet, as a result

of having CMT, I got to see her true heart. And I got to connect with a fellow human being. I was blessed.

Recently, I was working at my camp with a group of kids. There was a volunteer working with us for the weekend. She was beautiful, and I was attracted to her. And in the midst of my trying to woo her with my abundance of "cool," I tripped in front of her while carrying a large kettle of hot coffee. It was a mess. I was sprawled out on the floor and looking as un-cool as one can possibly look. And yet, as I walked back to my house to change, I realized that even in this moment I was strangely lucky. I don't get to rely on false machismo to connect to women. I have no choice but to rely on my strength to connect to them; to rely on my ability to fall and get back up; to find myself in an embarrassing situation and choose to keep on going. Hard as moments like this can be, I am lucky to stay grounded in my spirit, and not in my ability to carry coffee with grace.

Don't get me wrong, I don't think that all parts of this CMT experience are delightful. Many of them simply are not. But I challenge you all, as I challenge myself often, to remember that with the hard parts, come some pretty amazing parts. We are better and stronger and more enlightened people as a result of CMT. We understand things now that we never would have without it. And in that regard, color us lucky! ★

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### WE'VE ONLY JUST BEGUN!

Give! Give! Give! And we will match, match, match! Many thanks to all those who have already given to the Warfield Family Challenge in support of the STAR Pathways Campaign. Our family challenge is a hopeful beginning to the overall campaign. That challenge to match up to \$150,000 in donations has only just begun and will last until the end of June. The early donations have come a long way, but there is so much more that is needed.

We, as a family, are asking friends individually to help with this fundraising opportunity to support the research to find the treatment for CMT1A. We appreciate their loving support. They understand well how CMT affects our family.

There are so many families with CMT. We urge everyone who has been touched by someone living with CMT to find a way to give to the CMTA drive to fund the research for a "world without CMT!"

Remember that we will match gifts to the Warfield Family Challenge and that will double your gift! Thanks for your generous support. —Seth and Missy Warfield

# Fantasy Baseball Camp Fundraiser

Each year around the same time, I find myself pushing my body to limits that rival a professional athlete. This can only mean one thing... Fantasy Baseball Camp time! In all honesty, this happens to be one of the most enjoyable times of the year for me because I am able to participate in a sport that I absolutely love, while at the same time, contribute to a cause that is very dear to my heart.

In January, I was fortunate to be able to take part in a fantasy baseball camp hosted by the San Francisco Giants. I have attended the camp for many years, and this week away from everything really puts things into perspective and allows me to enjoy myself, while being productive as well.

Prior to the start of camp, I sent over 700 letters to friends and professional associates asking them to pledge a

sum of money for the total number of hits that I might get throughout the week. Everyone is also given the opportunity to donate a flat sum for my efforts at camp. Aside from doing my best to rack up a few hits, I also play in the outfield while on the defense (mainly because of my speed... or lack thereof).

There is one option included on the brochure that is called the "Super-Bonus Option." This gives people the chance to make a donation based on my chances of getting a hit during the 'Pros vs. Campers Game.' This year, Vida Blue (six-time All-Star, MVP, and Cy Young Winner) was pitching. I was luckily able to hit a single off of him. Even if he did place the pitch in the perfect spot for me, it still felt great when the bat connected. Apart from this special hit, I was able to total eight hits throughout the week.



From left to right: Vasi's brother Steve, 2010 Rookie of the Year Buster Posey, Vasi's son Will, and Vasi.

Overall, this year's camp was a success and everyone who took part in the fundraiser allowed me raise an amazing amount of money that will be put toward additional CMT research. With everyone's help and generosity over the years, we have been able to raise a tremendous amount of money, in excess of \$120,000 for the charity. —Vasi Vangelos

## DONATIONS WERE MADE TO THESE CMTA CIRCLES OF FRIENDS:

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## Spreading CMT Awareness from Classroom to Classroom

### “STEPPING IT UP FOR CMT” IN JOHNSTOWN, PA

The kids at the Richland Elementary School in Johnstown, PA, “stepped it up” for the CMTA for the fourth year in a row. The children raised just shy of \$9,000!

How the program works: I go to each grade with the goal of educating the kids about CMT by teaching them what CMT is and reading a story about Archy the turtle. This is then followed up by the children wearing pedometers during the school day to “Step it up for CMT.” After wearing the pedometer, the children take a sponsorship sheet home with the number of steps they have taken. They then ask parents, grandparents, friends, and neighbors to be their sponsors. The sponsor has the choice of what they want to give, as there is no designated or mandatory amount of a contribution. It could be as little \$1 or as much as \$20 or more. The children

have about two weeks to get as many sponsors as they can, and then bring the money back to the school, where it is collected by a CMTA representative.

The children are excited to raise money for CMT, but they have another motivating reason to participate. Every child who brings in \$5 or more receives a participating gift. Every child who brings in \$30 or more receives a signature Archy tee shirt.

There are also grand prizes that go along with this program. For this particular school, the child that raised the most money was given a limo lunch! The winner was Maddy, a sixth-grade student, who, by herself, raised \$627! She got to choose two other students to join her at the restaurant of their choice. The biggest prize of all? She got to throw pies in the Principal’s face. Who wouldn’t love to do that to their principal! Thank you, Mr. Smith, for being such a good sport.

The two runners up won a \$50 gift certificate to TJ Maxx, and they got to throw pies at the gym teacher!

I also rewarded the classroom that raised the most money. The class that won was the sixth grade. Their class raised \$848, and the prize was a pizza party. The class gathered and enjoyed their prize and their pizza.

The whole school was also rewarded with an assembly for another job well done.

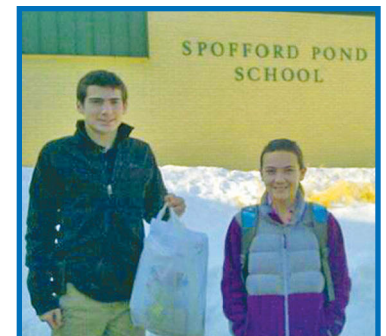
If you would like to learn more about the school program, please contact me at 1-800-606-2682, ext. 106.

—Jeana Sweeney, Director of Community Services

### STUDENT RETURNS TO ELEMENTARY SCHOOL TO TALK ABOUT CMT

I recently had the opportunity to talk about CMT to the students of Spofford Pond Elementary school in Boxford, MA. I attended Spofford Pond in the third through sixth grades. I was in sixth grade three years ago. My sister, Emma, is currently in sixth grade at the same school. She was on student council, which helped organize the event. All twenty-three classrooms participated in the fundraiser, with the most successful class winning a pizza party. My sister and her friends passed out donation envelopes and CMTA rubber bracelets and made posters that were put up around the school, encouraging people to donate.

Limo owner Rick, “stepping” winner Madalynn (third from left) with two of her friends, together with PE teacher Ms. Tinnick and Principal Smith head out for their “prize” lunch.



Vittorio and his sister Emma pose outside their elementary school.



**Vittorio shows the audience the brace he uses to deal with his CMT**

At the end of the week, I came to the school to give a speech, teaching the kids about what they had been raising money for. I told them what Charcot-Marie-Tooth disorder is, how it can affect people, how I am affected, how I was diagnosed, and what I am doing now because of it. My mom was in the audience, attempting to film the entire thing. It was my first time presenting CMT to an audience, but all the kids seemed very interested in what I had to say. I noticed as I was walking through the school that some kids would look down at my feet to see any signs of my disorder.

I went to collect the donation envelopes at the end of the day. When I was there, a little girl recognized me and told me how much she enjoyed the presentation. It was nice. All together, the school raised about seven hundred dollars. I had a great experience going to my old school and meeting all my old teachers and getting to spread awareness about Charcot-Marie-Tooth. I hope to do more presentations in the future.

—Vittorio Ricci

## FRESHMAN SPEAKS UP ABOUT CMT TO EDUCATE CLASSMATES

Hello! My name is Warren Ouellette. I am from Shelburne, Vermont, and I attend Champlain Valley Union High School.

For my Personal Health class, we had to give a presentation on a disease or illness to our freshman classmates. Since my cousin Yohan has CMT, I decided to do my research and give my presentation on this disorder.

A lot of people in my class chose diseases that many have heard of, like lung cancer and Alzheimer's. I was one of the few that gave a talk on a disease that no one besides one or two teachers had heard of. When I gave the presentation, my classmates were very interested that a disease like CMT existed, and they had never heard about it.

Using all the information I gathered, my classmates learned about CMT and became interested and wanted to know more. I explained about the life situations that people with CMT have to go through every day. CMT affects one's nerves, and people that have severe cases of CMT can't do things like ride a bicycle or skateboard because this disease affects their balance and the way their feet are shaped. People with CMT can have constant pain in their legs and hands, too.

Given these conditions, I am always impressed with how my cousin Yohan stays positive. He is always laughing and having fun whenever I see him.

I feel it is important that more and more people know about this disease as I assume most of you do, too! I am happy I did this and was able to let more people know about CMT. I feel if more people were aware of this disease, it could lead to increased donations, which could lead to a cure.

—Warren Ouellette



**Warren Ouellette chose a less well-known disorder to discuss in school because his cousin is affected.**

## REPRODUCTIVE OPTIONS

(continued from page 1)

### PRENATAL OPTIONS:

If a woman is pregnant, the pregnancy can be tested to determine if it has the familial mutation that causes CMT. This can be done in a few ways:

#### Chorionic Villus Sampling (CVS):

CVS is performed between 10 and 12 weeks of pregnancy. A sample of the placenta is taken, either transabdominally with a biopsy needle or transvaginally with a catheter. The cells are taken and tested for the familial mutation. Complication rates vary by center and expertise of the person performing the test, but are usually quoted at 1 in 100 to 1 in 300. Complications can include miscarriage.

**Amniocentesis:** This test is performed after 15 weeks of pregnancy (second trimester). A sample of the fluid that surrounds the pregnancy (amniotic fluid) is taken, and the cells found are analyzed for the familial mutation. The complication rates for amnio are usually lower than CVS but also vary by center and expertise. These are usually quoted as 1 in 200 to 1 in 1000.

**Non-invasive prenatal diagnosis (NIPD):** This is not readily available for CMT but will be within the next couple of years. A sample of maternal blood is taken through a regular blood draw. The sample is analyzed for cell free fetal DNA, which is essentially DNA from the pregnancy that has passed the placental barrier into maternal blood. The lab would look to see if the familial mutation is present in this sample. If dad is the affected individual, the presence of the

mutation in mom's blood would be very suggestive of an affected pregnancy. If mom is the affected individual, the lab would analyze the proportion of mutation versus non-mutation DNA. This test would likely need to be followed up with one of the invasive procedures listed above for confirmation.

What a family does with the information from this testing is up to them. Some people want to know so they can plan once the child is born. Other people are very adamant that they do not want to have a child with CMT, and would decide to terminate the pregnancy. These are very difficult decisions.

### PRECONCEPTION OPTION:

For a woman considering a pregnancy, preimplantation genetic diagnosis (PGD) is available if someone does not want to have a child affected with CMT and does not want to have to make the decision about terminating a pregnancy. PGD is used in connection with in vitro fertilization (IVF), which is a procedure more commonly used for couples who have difficulty conceiving on their own. In IVF, egg and sperm are combined in a laboratory and grown into embryos. Different labs use different technologies, but once an embryo has a certain number of cells (at least 6), between one and ten are removed by a biopsy, chemically, or by a laser. The DNA from these cells is amplified and analyzed for the familial mutation. At some labs, for an additional charge, they can also look for another feature, such as chromosome number. So, for

example, they can avoid implanting an embryo with an extra chromosome 21, which causes Down syndrome. The lab would choose the best embryos that are not affected with CMT to be implanted back into the uterus of the mother to carry to term.

PGD can be an amazing option for some families, but there are downsides to it. In order to retrieve the eggs from the woman, she must get hormone shots to stimulate the follicles. A surgery must be performed to remove the eggs. A second surgery is then needed to re-implant the embryos. There is no guarantee that the embryo will implant when re-entered into the uterus, so an additional cycle may be needed. Each cycle of IVF tends to run \$10,000 to \$20,000, and not all insurances cover it, and PGD is often another \$3,000 to \$5,000. People who use IVF for non-infertility reasons (e.g., PGD for CMT), however, do have a higher percentage of success per cycle than those who are using IVF because of infertility. Finally, many centers would suggest following up PGD with a CVS or amniocentesis to ensure that the embryo implanted really was free of the familial mutation.

All of these options are available only for people who know the genetic cause of their CMT. Your local genetic counselor ([www.nsgc.org](http://www.nsgc.org)—Find a Genetic Counselor) would be happy to go over the specifics of these options in more detail. These are very personal decisions and only the family can know if one of these options is right for them. ★

## WHAT'S ON YOUR MIND? ASK DAVID.

**Dear David,**

My Mom was diagnosed with CMT a few years ago and is still in denial about the whole thing. She is extremely depressed and alienating everyone. We feel at such a loss as to how to help her. Can you make any suggestions?

*David replies:*

Being diagnosed with CMT as an adult is a shock and does, naturally, include depression as one of the reactions. It certainly can include anger as your comment suggests. But having said that, it seems that your Mom is not moving on with her life and making a healthy adjustment.

So what is a healthy adjustment? It certainly does not mean that one never experiences depression or fear or anger during the course of the journey as our bodies go through changes. It does mean, however, that we try to accept our CMT as well as we can and continue to find peace and joy in any way possible. Family and friends, meaningful work, grati-

tude for what we do have can eventually help put our CMT into perspective and not have us define ourselves by our physical problems.

You ask how the family can help your Mom. Of course, I will state that since you are asking this question you love your Mom and do not want to see her go through this. To have compassion for her struggle without telling her what to do is a start. Let her know that it hurts you to see her so unhappy. I am not sure if she was depressed before the diagnosis. This needs to be figured out because there might be other things as well as her CMT that are causing her depression.

I would suggest getting as much information as possible about CMT because so many of our reactions are based on fear and misinformation. Try encouraging her to attend a support group, if possible. It could be a real blessing for her to know that there are others like her who are alive and well and able

to have a full, active, life with CMT. CMT is not the critical limitation; it is our fears that stop us from enjoying life.

If your Mom is uncomfortable talking to family members, then I would suggest talking to a counselor for a while. Your Mom's reactions, although upsetting to the rest of the family, are understandable. She feels alone and scared, so letting her know in a gentle way that you love her and recognize her suffering goes a long way. Maybe you can go with her to a support group, if she will agree. CMT is a family issue because it affects everyone close to her. If she is not ready, try to attend a group yourself because there are often family members that attend the support groups for their loved ones who are not quite ready. It is not easy for you to see your Mom go through this, so it would help you to get support as well. Don't give up on her, because deep down, she will see that her family really cares about her.



David Tannenbaum has an LCSW degree and has been a psychotherapist in New York City for the past 30 years. He has specialized in helping others with the task of growing emotionally and spiritually through physical challenges. "My CMT has been my greatest challenge and my best teacher in life," says David. Write to David at [info@cmtausa.org](mailto:info@cmtausa.org).

## CMTA REMEMBRANCES

Your gift to the CMTA can honor a living person or the memory of a friend or loved one. Acknowledgment cards will be mailed by the CMTA on your behalf. Donations are listed in the newsletter and are a wonderful way to keep someone's memory alive or to commemorate happy occasions like birthdays and anniversaries. They also make thoughtful thank you gifts. You can participate in the memorial and honorary gift program of the CMTA by completing the form below and faxing it with your credit card number and signature or mailing it with your check to: CMTA, P.O. Box 105, Glenolden, PA 19036.

**Honorary Gift:**

In honor of (person you wish to honor)

\_\_\_\_\_

Send acknowledgment to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

**Occasion (if desired):**

- Birthday     Holiday     Wedding  
 Thank You     Anniversary     Other

**Memorial Gift:**

In memory of (name of deceased)

\_\_\_\_\_

Send acknowledgment to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Amount Enclosed: \_\_\_\_\_  Check Enclosed

VISA     MasterCard     American Express

Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

**Gift Given By:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_



## Archy “Steps” up for CMT

I really thought that I was going to go insane living through the dark, gray days of winter until my Physical Education teacher announced that we were going to participate in a program called “Stepping It Up for CMT.” The program is run by the CMTA, and I had read about it in the newsletter, but I never imagined that we would be doing it at Greenwoods Elementary.

As soon as we learned about the cool pedometers that we would be wearing while we did some “stepping” work in class, everyone who knows me wanted

to know what the program was all about. I’m ashamed to say I hadn’t really ever learned much about the program, so you can imagine my surprise (and all the other animals that know me) when Jeana Sweeney arrived to do an assembly, and she talked about “Archy” the mascot turtle of the association and how he has CMT. She explained that the point of the program was to raise money for research to help find treatments and possibly a cure for kids like me.

I almost died of pride and a little embarrassment. I try to keep a rather low profile regarding the problems I have associated with my CMT. Of course, my close friends and classmates know, but I never wanted the older kids to know because I was afraid they might pick on me. Well, Jeana spoke so glowingly of me and my accomplishments as a spokesturtle for the CMTA, that everyone was impressed with me and wanted to talk to me about what I do and where I get to travel for the CMTA. I think they actually were a little jealous of my opportunities.

The way the program worked was that we were all given pedometers while we were in gym class, and we recorded the number of steps we took. Needless to say, no matter how many legs we had, we could only count the steps of two legs

to make it fair for everyone. Once you completed the stepping, you took your sheet with the steps you had taken home and to neighbors to ask for contributions. The contributors could either give a set amount, or they could pledge an amount per step. My parents just sent a check for \$100 for me because they were so proud.

The animals were anxious to possibly win one of the top three prizes for most money raised. I don’t think you will be surprised to learn that

one of the fifth-grade rabbits was the grand prize winner. He just hopped and hopped and hopped almost without end and won easily for most steps and, consequently for most money sent in support of his efforts.

While the program was going on, there were posters of me on the walls and bulletin boards all over school. The local news even did a story on what our school was doing called, “Kids Helping Kids.” I was really proud of how well the other students supported this effort. I honestly felt like they got involved because they actually knew someone with CMT. It made me proud.

I’m really hopeful that all the research, especially the STAR Pathways program that we learned about, will one day make CMT a problem of the past. I want to make that happen. Don’t you? ★



## GET INVOLVED WITH THE CMTA COMMUNITY

The CMTA is currently looking for dedicated and committed individuals to step up as CMTA Support and Action Group facilitators. Support and Action Group facilitators organize and run local CMT meetings. We ask each Support and Action Group facilitator to:

- Be a member of the CMTA
- Have basic knowledge of CMT and the CMTA
- Have basic computer and organizational skills
- Involve group members in one fundraising event per year (the CMTA will offer guidance and structure)
- Monitor on-line activities on the CMTA’s website

Join our growing team of CMTA volunteers! The CMTA is currently looking for volunteers to:

- Spread the word by distributing CMTA brochures in your community
- Put a simple ad in your local paper
- Put on a fundraiser
- Participate in September’s CMT Awareness Month
- Share your unique skills with CMTA
- Be a CMTA social media advocate

If you are interested in one or more of the above activities, or, if you have other ideas on how to help the CMTA achieve its goals and mission, please contact Jeana Sweeney at: [jeana@cmtausa.org](mailto:jeana@cmtausa.org).





# GIFTS WERE MADE TO THE CMTA

**IN MEMORY OF:****Donna Collins**

Dr. Catherine Hoyt

**William Cooper**Mr. & Mrs. Gene Rosengarden  
Mr. & Mrs. Franklyn Weiss**James Downs**Mr. & Mrs. Ron Mauru  
Mr. & Mrs. Art Rose  
Mr. & Mrs. Norman Voelliger**Catherine Ebersole**

Ms. Lori Karnuk

**Carolyn Erwin**

Mr. &amp; Mrs. William Sharp

**Herbert Fey**Mr. & Mrs. David Baker  
Mr. & Mrs. Darryl Behrmann  
Ms. Adele Bradley  
Mr. & Mrs. David Brinton-Robkin  
Mr. & Mrs. Timothy Carr  
Catholic Parents Network  
Ms. Kathy Cipriano  
Mr. & Mrs. Frank Conrad  
Ms. Eleanor Crowley  
Mr. & Mrs. Darren Crozier  
Mr. & Mrs. Michael Dean  
Mr. & Mrs. David DeLellis  
and Family  
Mr. & Mrs. Todd Dhavale  
Ms. Melin Fey  
Ms. Heidi Fey  
Mr. David Fey  
Mrs. Margaret Frey  
Mr. Williams Gibbons  
Mr. & Mrs. Fred Greim  
Mr. & Mrs. James Hanahan  
Mr. & Mrs. Robert Hauck  
Mr. Vincent Malandra  
Ms. Tina Maida Masington  
Mr. & Mrs. Neil McDevitt  
Mr. & Mrs. Thomas McGarrityMr. & Mrs. Scott Patterson  
Ms. Mary Powers  
Mr. & Mrs. Ronald Rice, Sr.  
Mr. & Mrs. James Ricigliano  
Ms. Phyllis F. Sexton  
Mr. & Mrs. William Sheneman  
Mr. & Mrs. Donald Sills  
Mr. Ferol Y. Smith  
Mr. & Mrs. Edward Smith  
Ms. Beverly Warner

**Shirley Friedman**  
Mrs. Eileen Meltzer

**Mark Hollingshead**  
Ms. Gail Harber  
Mr. Skip Helm

**Christine Hook**  
Dr. & Mrs. Richard Bossert  
Ms. Jill Brass  
Mr. & Mrs. Jim Brown  
Ms. Margaret Byrne  
Mr. Paul Conahan  
Mr. & Mrs. Howard Domfort  
Ms. Sandra Fratianni  
Granny Squares of All Saints  
Catholic Church  
Mr. & Mrs. W. David Hains  
Ms. Carolyn Harris  
The Kateri Lay Ministry Class  
at St. Joseph's North  
Ms. Melinda Lang  
Mrs. Margaret Martin  
Ms. Mary McKeon  
Mr. David Misener  
Mr. & Mrs. Kevin Pighetti

Mr. & Mrs. Philip Salm  
Mr. & Mrs. J. Robert Sheehan  
Mr. & Mrs. Edward Solomon  
St. Michael's Church  
Mr. & Mrs. Larry Stewart

**Dollye E. Johnson**  
Ms. Elaine Tockston

**Marilyn Kasro**  
Mr. Robert O. Erickson  
Mr. Tom Thomas

**Bernard Kunen**

Mr. & Mrs. Helen Friedenberg  
Mr. & Mrs. Brian Gold  
Ms. Mayra Gonzalez  
Mr. & Mrs. George Helwig  
Mr. & Mrs. Irving Kramer  
Mr. & Mrs. Samuel Laitman  
Mr. & Mrs. Burt Seletsky  
Ms. Barbara Shevrin  
Mr. & Mrs. Mark Tanz  
Mr. & Mrs. Howard Udoff  
Ms. Shari Udoff

**Edward H. Leverage**  
Mr. Donald Leverage

**William Lloyd**  
Mrs. Marian Lloyd

**Charles Lynch**  
Mr. J. C. Julian

**Audrey Mae MacDonald**  
Mr. Spencer MacDonald  
Ms. Dawn MacDonald  
Mr. Douglas MacDonald  
Ms. Crystal MacDonald  
Ms. Heather MacDonald  
Ms. Deandra MacDonald  
Mr. Vaughn MacDonald

**Linda Myrick**  
Mr. Jeremiah Lamson  
Ms. Carol Mason  
Ms. Betty Mulkey & Family

**Kunjala "Kala" Patel**  
Mr. & Mrs. Michael Atkins  
Ms. Sally Boucher  
Ms. Dorothy Craig  
Mr. & Mrs. Kanak Desai  
Mr. David Fischer  
Mr. Nish Patel  
Ms. Yash Patel  
Mr. & Mrs. Kirti Patel  
Ms. Mrunal D. Patel  
Dr. Margaret Vanwyk

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Ms. Patricia Draper  
Ms. Alice Sechrist Markley  
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**Bill Steele**  
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**Mary Ellen Werner**  
The Ted Kissel Family  
Ms. Roxane Myers  
Ms. Penny Parker

**John B. Whitaker**  
Mrs. Helen L. Whitaker

**Stephen**  
Ms. Margaret Schaefer

**IN HONOR OF:**

**Riley Ashe**  
Mr. Vince McCarthy  
Mr. & Mrs. John McCarthy

**Atlanta Support and Action Group**  
Mr. Zack Williams

**Ralph and Vedia Bacchus – Happy 25th Anniversary!**  
Mr. & Mrs. Michael Anderson

Mr. & Mrs. Ihab Badra  
Mr. & Mrs. Andrew Giglio  
Mr. & Mrs. Michael MacMorris

Ms. Carmen Mitchell  
Mrs. Per Nabavi  
Ms. Nelly Perez  
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Ms. Stephanie Meletis

**Bethany Meloche**  
Mr. Joshua Watzman

**Andrew Moody**  
Mr. Mitchell Moody

**Margaret Mullery**  
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**Ashley Pomykala**  
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**Billy Richards**  
Ms. Valerie Sharp

**Karla Sandman**  
Mrs. Darcy Andrade

**Mikey Sayward**  
Ms. Jo Anne F. Morgan

**Bruce Spackman**  
Ms. Jodi McCuiston

**Vasi Vangelos**  
Mr. & Mrs. Jeffrey Rome and Family

**Xavier Virola**  
Mr. & Mrs. Al Wester

**Luc and Jacob Wessel**  
Mrs. Anita Wessel

**IN MEMORY: CHRISTINE HOOK**

Christine A. Hook, 41, daughter of Deacon Neil and Carol Hook, died unexpectedly at her residence on Friday, February 8. This past September Christine received the "I'm a STAR" award from the CMTA for her work in raising awareness of CMT through her blog "Grace Lines," which inspired many with her wonderful sense of humor, and for her fundraising efforts in the sale of her artwork with Art de Cure at Clinical Prosthetics and Orthotics in Albany, NY.

She was a graduate of Guilderland High School, and after attending the Junior College of Albany, she received her Bachelor of Fine Arts degree from Alfred University. Then she earned two Masters Degrees in Literacy and Special Education from the Sage Colleges. Christine taught a special education class in the Cairo-Durham Central Schools, but had to leave teaching due to a back injury. Then, she worked part-time in several medical offices until her CMT forced her to retire.

After retirement, she took up her art work again. Last year, after selling her paintings at Starry Night for CMT, she became the gallery co-coordinator and has several paintings in the Broadway Art Center in Albany, NY. Christine Hook was a talented artist, gifted writer, and a kind and caring friend who will be sorely missed.

In her blog "Grace Lines," Christine wrote:

*Hold Your Loved Ones Close*

*Time speeds by, sometimes in a flash. Before you know it the years have passed; the children you've held in your arms are cradling you now, in theirs...roles are reversed, and there is never enough time. Never, EVER enough time.*

*.....hopefully hold our loved ones closer and give thanks that they are still here.*

*We appreciate who we have in our lives all the more, realizing how precious and how short life can truly be. And tomorrow a new day starts, and we do our best to move forward.*



## Partnering in the Fight Against CMT

*A Profile of Washington DC Metro SAG Facilitators Steve Weiss and Kim Hughes*

**HE SAID:** I was diagnosed with CMT nearly 40 years ago. An unknown condition had been in my family for generations, and my parents had long suspected that the condition was affecting me. I was late in walking as a toddler, and I frequently tripped as a young boy. I had very shallow arches as a kid and wore orthotics in grade school. In high school, I had tendon transfer surgery on my left foot, and shortly after college I began to wear braces. It was one of the hardest things I've ever had to do, because wearing braces meant there was no denying that I was different from everyone else. I spent my childhood and teenage years trying to be as "normal" as possible—always participating in P.E. and trying to be as active as my friends. But being different took a lot of getting used to. It still does.

**SHE SAID:** Growing up, I didn't know anyone with a physical

disability, but my brother had a speech-language impairment. When we were young, I used to help him with his speech homework, playing the role of school teacher. As an adult, I served as a tutor in an "adopt-a-school" program and felt drawn to help people with special needs, so I went to graduate school to study speech-language pathology. I was glad to be in a new career where I could serve others—my heart has always been open to that.

**HE SAID:** I was 29 when I met Kim at a job in Washington, DC. I had recently quit my old job and gone backpacking through Europe alone for a month—one of the best things I've ever done. I fell 3 or 4 times on that trip and was very nearly pickpocketed one night in Paris, but I had a great time. Just doing the trip alone was enormously empowering. I don't think I had explained CMT to any date or girlfriend before, but I told Kim everything on our first date. She took it in perfect stride, which made me realize that I probably should have been more open about it to others in the past—and also that Kim was the right person for me. I had always expected my CMT to be a big deal—and not necessarily a good one—in a relationship, but it wasn't with Kim. To her, CMT was no bigger a part of me than any other trait—endearing or annoying.

**SHE SAID:** Steve told me about his CMT on our first date. Apparently, this was a big deal

because he hardly ever told anyone. I had noticed the difference in his gait, and his handshake felt different, but I didn't know why. He explained that the gene causing CMT could be passed on to his children. I remember shrugging it off and saying it didn't matter. Over our years together, it's been my honor to button his shirts and open tricky packaging. I've seen him trip and fall at times, but I've also seen him climb huge mountains on our honeymoon, shovel snow, and change diapers despite the physical challenges.

**HE SAID:** By the time we were ready to have kids, we knew that I had CMT Type X. As a man, I knew that if we had a daughter, she would also have CMT, while a son would not. Some family members and friends asked if we would try to identify the gender of the fetus early on—I guess as a way to "get ready" for what was to come. We decided to leave the baby's gender a mystery until birth. Our first child was a boy, Mason. Our second was a girl, Campbell. We know that Campbell has CMT, though she shows almost no signs of it so far. Both kids are well aware that I have the disease—they like to help me put my braces and shoes on, and they know what activities I can do with my braces that I can't do without them. They're learning invaluable lessons early in life about living with a disability.

**SHE SAID:** The kids are extremely sensitive to the needs

Married couple Kim Hughes and Steve Weiss have come together to fight CMT.



## Sunflowers Represent Strength, Beauty, and Perseverance

Tony Severn, a member of the Easton, MD, Support and Action Group shared a poem he had written with support group members. Tony's poem was given rave reviews, so, with the creative help of Robert DeRosa, Marketing Director at Aetrex Worldwide, the CMTA is able to share this poem with you.

Tony's poem can be purchased as bookmarks: beautiful full-color front and back with protective lamination on extra heavy card stock.

Quantity	Price
1-5	\$1.50 each
6-10	\$1.25 each
11 or more	\$1.00 each

Or, you can purchase a poster: beautiful full-color 8.5"x11" art with a special soft touch finish. Frame not included. Cost: \$5.00

The poster and bookmark would make great gifts for birthdays, an anniversary, or "just thinking of you." Bookmarks and posters are available at [www.cmtausa.org/url/bookmark](http://www.cmtausa.org/url/bookmark).



The unframed poster of Sunflowers is available at the website store ([www.cmtausa.org/url/bookmark](http://www.cmtausa.org/url/bookmark).) or by using the order form in this newsletter.

of others, especially younger children, and are genuinely compassionate. They know how to be gentle when pushing their grandmother's wheelchair. Campbell is part of a Buddy Program at her school, where she eats lunch periodically with special-education students. She is learning that these interactions can sometimes feel awkward, but she also is learning how to face her fears of hanging out with others who are different. She is learning about both the challenges and blessings that come with having a disability.

**HE SAID:** We were visiting my parents near San Francisco a few years ago, and mom said she really wanted to take us to their local CMT support group. I hadn't been involved in a CMT support group before, and wasn't much interested in joining one then, but we went. Two memories stand out more than any other: one, Elizabeth Ouellette, the group facilitator, had more

energy and passion for the fight against CMT than anyone I had ever known and, two, all the group members who were the first in their families to have CMT. They had no relatives who could relate to their experience, and those whose symptoms first appeared a few years into their lives had been suddenly burdened with a strange and debilitating disease. I hadn't met people like Elizabeth or her members before, and I decided that we needed a group for people with CMT in the Washington, DC, area.

**SHE SAID:** Elizabeth and I snuck into her dining room, and I told her I wanted to start a group. At that point, she approached Steve, who was already thinking the same thing. We just needed a jump-start and who better to give us the push we needed! Thank you, Elizabeth!

**THEY SAID:** The CMT Support and Action Group for the Washington DC metro area has been

going strong for almost three years. We have a dedicated group of people who attend our quarterly meetings on a regular basis, and we have new members at every meeting. The support group has helped us as much as it has our members. They represent different age groups and various types of the disease. Some are significantly impacted by CMT, some less so, and others live or are friends with someone who has CMT. All of them seek information, camaraderie, and support from others living with the disease. Thanks to the CMTA, these people and so many others across the country and around the world get all that and more. Some day soon, we will all benefit from the medical research that the CMTA is supporting. We look forward to celebrating that day with Support and Action Groups here and abroad. ★



## SUPPORT AND ACTION GROUP NEWS

### AZ—Phoenix area

*The group met on January 26th.*

Pam gave a STAR update, followed by Dr. Timothy Peace, a naturopathic doctor, who spoke on supplements. They also discussed possible topics and speakers for 2013.

### CA—San Diego Area

*10 members attended the meeting on January 12th.*

Many shared their CMT story and valuable information. Thank you to Bruce for his information about the in-depth gait analysis that he had done at Scripps Encinitas.

### FL—West Palm Beach

*26 members attended the meeting on February 17th.*

Jennifer Levenson, a professional trainer and wellness coach, presented an interactive workshop. She also discussed wellness and nutrition. Dr. Diana Rogers, a foot and ankle surgeon, and Dr. Kevin Christie, who has a chiro-

practic practice, will speak at the March 24th meeting.

### IL—Chicago Area

*20 members attended the meeting on January 19th.*

The guest speaker was Rick Lusiak, District Manager for Allard USA. He brought samples of the Toe Off and BlueRocker Braces for members to try.

### MI—Kalamazoo Area

*6 members attended the meeting on January 17th.*

Topics discussed were STAR, CMT research, and genetic testing.

### NJ—Central New Jersey

*20 members attended the meeting on January 27th.*

Michael Needleman, an attorney and CMTA Advisory Board member, was the guest speaker. Following Michael's presentation, Jacky gave a summary of the last SAG conference call. Mark gave details on Elizabeth's birthday challenge and the upcoming challenge by Missy and Seth Warfield. He also shared information from the STAR PowerPoint and STAR Pathways presentation.

### NJ—Morris County

*The group met on January 6th.*

Dr. James Nussbaum, PT, SCS, EMT, the Clinical and Research Director of Pro Health and Fitness PT OT, was the guest speaker. The group was updated on the STAR initiative. Alanna also spoke about testing at the NIH, the status of the Transformation Project, and the 51 known types of CMT. Pain management was discussed, as presented by Dr. Gregory Carter. The group is looking forward to David Tannenbaum, LCSW from the CMTA Advi-

sory Board, to serve as guest speaker at their next meeting.

### NM—Albuquerque Area

*The group met on February 9th.*

Gary reviewed CMT research and fundraising. Three graduate students from the University of New Mexico Occupational Therapy Department presented findings on a project to determine if a questionnaire can successfully predict the outcome of physical hand dexterity tests for those with CMT. Fifteen members of the NM CMTA have participated. Jeffrey Smith, a regional manager for Allard, and Deane Doty, an Albuquerque orthotist, were also guest speakers.

### NY—Manhattan Area

*10 members attended the meeting on February 2nd.*

David Tannenbaum was the guest speaker. The group talked about being able to ask for, and receive, help and how that could increase intimacy with others. The group also discussed feeling useful and having a sense of purpose, which contributes to longevity. The group had meaningful discussions on living with CMT. They will be brainstorming how to support the STAR initiative via a fundraising event at their next meeting.

### NY—Upstate New York Area

*The group met on January 26th.*

Stress relievers were discussed, including laughing, meditation, saying "no" when needed, connecting with family and friends, journaling, and music. Financial issues, difficulty applying for, and qualifying for, assistance and what to do if you don't have a

(continued on page 15)

### "CIRCLE OF FRIENDS": AN EASY WAY TO SUPPORT STAR PATHWAYS

What is a Circle of Friends? It's a way to fundraise for the CMTA without hosting a labor-intensive event. It's also a way to educate your friends and family about the disorder. You can create awareness of the disorder, the CMTA, and the campaign we are running to find a treatment and cure for CMT. The "Circle of Friends" begins with a personal appeal. Each of us has a "circle" of family, friends, and people we do business with and by reaching out to them with a personal letter or email, we can enlarge the number of people who support the work of the CMTA.

We will provide you with a page on our website where you can have your friends and family members follow your efforts. We'll help you write the letter and provide you with all the brochures, newsletters, and documents necessary to start your circle. Please contact Jeana Sweeney (jeana@cmtausa.org) for more information on creating a Circle of Friends. Together, with a little help from your friends, we can conquer CMT.



## SOCIAL SECURITY

(continued from page 1)

application process, you will receive a notice of denial from the SSA. You have 60 days from the date you receive this notice to appeal the SSA's decision. This appeal is the next stage of the disability application process.

### The Request for Reconsideration

If you live in a state that requires a request for reconsideration to be filed prior to requesting a disability hearing, this will be the next stage of the disability claim process. It is important to understand that the majority of these requests (greater than 80 percent) are denied by the SSA. It is, however, a necessary step to take in order to request a disability hearing.

To file a request for reconsideration, you, or your attorney, must submit form SSA-561. This is the form that notifies the SSA that you are

requesting a reconsideration. It will take anywhere from eight weeks to four months for this request to be processed. Chances are that you will be denied this appeal and will have to go on to the next stage of the application process.

### The Disability Hearing

Once you receive notice that your request for reconsideration has been denied, you have 60 days to file the next step of the appeal process. This is the step where you request a disability

hearing before an administrative law judge.

To request a hearing before an administrative law judge, you, or your attorney, must file form HA-501-U5. This is the form that notifies the SSA that you wish to have your case heard by an administrative law judge.

The bad news is that it can take in excess of one year to be scheduled for a hearing from the date that you file this request. The good news is that the majority (nearly two-thirds) of disability applicants are granted benefits as a result of this hearing.

### Legal Representation at Your Disability Hearing

It is important that you go into such a hearing with legal representation. Statistics have shown that applicants who obtain legal representation are more likely to be awarded benefits than applicants who try to represent themselves.

Fortunately disability attorneys work on a contingency basis, meaning that you only pay if your case is awarded to you. These attorneys collect 25 percent of the back pay that you are awarded by the SSA, up to a maximum limit of \$6,000. This means that nearly everyone can afford the services of a disability lawyer without any up-front cost.

### The Appeals Council Review

If your disability hearing is not decided in your favor, you may further appeal your case to the

SSA's Appeals Council by submitting a request for an Appeals Council Review.

In order to request an Appeals Council Review, you must submit form HA-520 to the SSA within 60 days of receiving notice of your hearing denial.

Once you submit your case to the SSA's Appeals Council, they will review the way in which the judge decided your case and will do one of three things:

- Deny the request
- Grant the review and evaluate the case themselves
- Remand the case back to another administrative law judge

This process normally takes two to four months. If you again are notified that your case was denied, you and your attorney have a further appeal option and can take your case to the Federal District Court.

### The Federal District Court

If your appeal to the Appeals Council was not decided in your favor, you have the option of furthering your appeal at the federal district court level. If you do decide to file a case in the district court, it is time to hire a disability attorney if you have not yet done so. You will want an attorney representing you during this complex legal process.

The length of time that this stage of the appeal takes will depend on how quickly you are able to obtain a court date. It is important to note that there are filing fees associated with this stage of appeal, as you are technically filing suit against the SSA for denying a claim that you believe you are entitled to. ★

Don't be discouraged. You may have to apply for benefits more than once.

# CMTA NEWSLETTER SUBSCRIPTION, PUBLICATIONS, AND ACCESSORIES ORDER FORM

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CMT Facts III		\$7	\$5.60	
CMT Facts IV		\$10	\$8	
CMT Facts V		\$15	\$12	
CMT Facts VI		\$15	\$12	
My Child Has CMT		\$7	\$5.60	
Cooking and Coloring Adventures with Archy		\$10	\$8	
Teaching Kids about CMT...A Classroom Presentation (DVD/1 hour)		\$10	\$8	
CMTA Titleist Hats Quantity and Color: Black___ Blue___ Red___		\$25	\$20	
CMTA T-Shirts (Blue with white logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
CMTA T-Shirts (White with blue logo) Quantity and Size: S___ M___ L___ XL___ 2XL___ 3XL___		\$15	\$12	
Be a STAR Wristbands		1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each		
Be a STAR Necklaces (Includes battery)		1-5, \$3 each 6-10, \$2.50 each 11 or more, \$2 each		
<b>NEW!</b> Unframed Sunflower Poster		\$5		
<b>NEW!</b> Sunflower Bookmarks		1-5, \$1.50 each 6-10, \$1.25 each 11 or more, \$1 each		
CMTA Brochure & Neurotoxic Drug Card		FREE		
<b>Donation to the CMTA (100% Tax-deductible)</b>				
<b>Shipping &amp; Handling (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)</b>				
<b>ORDER TOTAL</b>				

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

Money Order  American Express  MasterCard  VISA

Card Number: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

**Mail to: CMTA, P.O. Box 105, Glenolden, PA 19036; or fax to 610-499-9267**

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

## SUPPORT GROUP NEWS

(continued from page 12)

pension as you face retirement were mentioned as major stress factors for the majority of the group. Starry Night, a fundraiser, raised \$10,000.

### New York—Westchester

The group met on March 2nd.

David Tannenbaum a member of the CMTA Advisory Board, facilitated a discussion focusing on coping with the challenges of CMT. "CMT has been my greatest challenge and best teacher," says David. He has a column in the CMT newsletter entitled "What's on Your Mind." We had a great turnout, great participation, and a great meeting overall.

### PA—Bucks County Area

3 members attended the meeting on January 19th.

Planning for awareness month and fundraising were discussed. Linda presented each member with a bag containing a car magnet, a refrigerator magnet, an "Ask Me about CMT" button, a bracelet, and a star necklace, to be used in helping spread CMT awareness in the coming year.

### TN—Nashville Area

The group met on February 9th.

Another meeting was set for February 23rd, when updates on the efforts to get Governor Haslam to sign a Proclamation for Awareness Month and information from the February 10th conference call were discussed.

### TN—Savannah Area

The group met on January 26th.

Melinda and Reagan spoke of their experiences at the Chicago conference. Reagan showed a video she made from pictures taken at the conference. Also discussed were bracing, shoes, medicines, vitamins, Dr. Jun Li, and fundraising for STAR. ★

## CMT PATIENT MEDICATION ALERT:

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

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

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

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

# THE CMTA Report

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

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## WHAT IS CMT?

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