

# THE CMTA Report

JULY/AUGUST  
2013

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



## 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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## Swimming Fundraisers Top \$1 Million!

Back on Father's Day, June 16, 2002, Steve O'Donnell swam 4.4 miles across the Chesapeake Bay for the first time. Back then, Steve's goal was to get people focused on CMT and to raise money for research. Knowing he couldn't run a marathon because of the muscle loss in his lower legs, Steve chose swimming a marathon, which he felt he could train for and then do.

In that first year, when Steve was asked how he could do such a physical task that would be too much for most people, Steve pointed to his heart and said, "It's all in here." Steve's heart is still propelling him forward twelve years later.

Steve's children, Sean and Jaime, joined their Dad in 2005. Then in 2007, Rachel Beron contacted Steve to see if she could swim with him. He said "yes" and "Team Julia" was begun to honor Julia Beron who also has CMT. That year, 325 individuals and organizations contributed to the fundraising efforts. In 2008, Steve's team and seven supporters of Team Julia swam in extreme heat and very choppy waters.

In 2009, the Berons moved their portion of the swim closer to their home. The swim took place in New Jersey at the Lake Valhalla Club. Seventeen swimmers participated with them



STEVE, JAIME AND SEAN O'DONNELL celebrated after this year's Chesapeake Bay Challenge.

that year as over 100 spectators cheered them on.

In 2011, Steve celebrated his tenth year of swimming to raise money for CMT research. He was joined by Donna DeWick who traveled from England to join Steve in the swim. In 2012, Steve went north to New Jersey and joined the Berons at Lake Valhalla for his swim.

This year, his twelfth consecutive swim, Steve returned to the waters of the Chesapeake Bay with his daughter Jaime and his son Sean. It was a beautiful day and the water was not choppy, but there was a very strong current which threatened to pull people off their course.

As of this writing, the efforts of our swimmers have

produced \$1,008,635 for the CMTA's research fund. In the first year that Steve started his swimming fundraiser, we referred to him as a hero. As the years have passed and others have joined his efforts, the description is more appropriate than ever for each and every one of them.

Thanks for all you do. ★

## INSIDE:

Reproductive Options, Part 3 .....	4
Educational Options for Kids with CMT.....	6
A Mother's Reflection .....	8
Awareness Month 2013.....	12

## The CMTA Relationship

BY ALAN KOROWITZ, CMTA BOARD OF DIRECTORS

All healthy relationships are based on giving and taking. My family's relationship with the CMTA is proof of this. As the parents of a child with CMT, we find ourselves having to navigate the challenges and many opportunities that are presented to us. We often turn to the CMTA as an important resource, a source of information, support, partnership and hope. I encourage you to consider how you might get the most out of the CMTA as well.

Our family recently had to turn to the CMTA when my son Zach had an injury unrelated to his CMT. He had to be rushed to the emergency room, where CMT meant nothing more than a country music channel. As they began to discuss the medications they planned to administer, we demanded they refer to the important list of toxic medications on the CMTA website ([www.cmtausa.org](http://www.cmtausa.org)), as well as use it to educate themselves on the effects that CMT has on the

body. The website is designed to provide this information efficiently to medical personnel for just such an occasion.

Just a month prior, we made our annual visit to see the chairman of the CMTA Scientific Advisory Board, Dr. Michael Shy, and Shawna Feely, genetic counselor, at the CMT Clinic at the University of Iowa. Along with their colleagues, they provided a thorough evaluation and details of the progression of CMT with Zach, along with actionable steps that we could

## A Message for All People with CMT Worldwide

return from the 5th International CMT Consortium in Antwerp, Belgium, energized and as optimistic as ever about the prospects of finding the first treatment for CMT! Over three days, as I sat and listened to dozens of 15-minute presentations, digested 80 poster presentations, met the experts investigating the science behind CMT, and met with peer CMT Patient Advocacy Groups from six countries, I couldn't help thinking: Wow! We've come a long way!

I was heartened to see the focus on translational science! We came into the meeting knowing for certain 51 genes cause the various forms of CMT. We came out of the meeting believing 70 genes are now identified as the culprits!

I saw presentations about designing better *in vitro* assays to represent the disease!

I saw discussions on potential compounds that might be beneficial someday as therapeutic options.

I saw presentations about building better *in vivo* models to better observe the benefits/effects of compounds pre-clinically!

I saw advances in the knowledge base of every type of CMT: CMT1, CMT2, CMTX, and CMT4!

And I saw firsthand that this disease knows no boundaries as I met wonderful and eager members of patient advocacy groups from the UK, Belgium, France, Italy, and Australia!

Now, more than ever, please get involved and become part of the solution! Most importantly, spread the word, talk about CMT, educate your circle of friends and community not only about the disease itself but what the CMTA STAR (Strategy to Accelerate Research) and CMT patient advocacy groups around the world are doing in the search for a first treatment for CMT!

A special thanks to Drs. Shy, Svaren, Scherer, and Wrabetz for leading the translational effort on behalf of the CMTA!

—Patrick Livney, Chief Executive Officer, CMTA



LEADING RESEARCHERS AND CMT ADVOCATES gathered in Belgium for the 5th International CMT Consortium.

take home with us to provide a better quality of life.

These are just two examples of how we have turned to the CMTA for vital help. But long term, one of the most important “takings” is the constant comfort of knowing that they are funding and aggressively pursuing research to find a cure for CMT.

But, again, there is the balance in the relationship—giving. Every week there are many efforts made throughout the CMTA support community around the country to raise awareness and money to help maintain these important resources. Last year, along with Board member Phyllis Sanders, we hosted the Third Annual CMTA STAR Gala at the Friars Club in New York City.

This event brought in over \$100,000 for the CMTA. On October 28, 2013, we will once again host a STAR Gala in New York City at the New York Athletic Club, home to an abundance of historic sports memorabilia and a breathtaking view of Central Park. This will be your opportunity to meet the leadership of the CMTA, our medical professionals and, ultimately, to help support our efforts. There will be music, food, and opportunities to win fabulous items and experiences, such as vacations and concert tickets. Information will be posted on the CMTA website, but feel free to reach out to me directly at [alankorowitz@gmail.com](mailto:alankorowitz@gmail.com).

If you, a family member, or someone close to you is touched by CMT, get the most out of your relationship with the CMTA. The CMTA is here for you. Our vision for a world without CMT is a real one. We have dedicated ourselves to it. ★

## ROCK 'N' ROLL FUNDRAISER COMES TO PHILADELPHIA

Join Pat Livney, Jeana Sweeney, and the team from the CMTA in Philadelphia, Sunday, September 15, 2013, at 8am to support Allard USA's Beth Deloria as she runs in the Philadelphia Rock 'n' Roll Half-Marathon. Beth is running to raise awareness and support for the efforts of the CMTA nation-



wide. This event is for runners and non-runners alike.

If you're not running in the half-marathon, come join the CMTA team on the sidelines to show your support. We will have a group along the course and at the finish line to cheer on the runners. The weekend will be full of fun events. Details are coming soon!

Interested in joining Beth in the race? Register online at <http://runrocknroll.competitor.com/philadelphia>

The first 10 runners to register will have their registration fees reimbursed by the CMTA. For registration details and reimbursements, contact Kim Magee at [kim@cmtausa.org](mailto:kim@cmtausa.org) or 1-800-606-2682 x105.

### About *Get Back UP* and Beth Deloria:

In 2004, severe spinal trauma and subsequent surgery left Beth with nerve damage that made her unable to flex her left ankle and raise the front portion of her foot. This condition, known as foot drop, was devastating for the devout distance runner, who had competed in major marathon events from Chicago to Boston.

With the help of the Allard ToeOFF, Beth prevented foot drop from becoming an obstacle in her life. Now she's using her experience to inspire those affected with foot drop to keep it from stealing their quality of life. To underscore her message, Beth started by running in over 20 half-marathons in 2012 as part of the Rock 'n' Roll Marathon Series. But, her journey has not stopped. She is continuing to run in 2013, providing more opportunities to spread her message. ★

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## Responses to Reproductive Options Articles

*In the last two installments of our series about reproductive options, we provided information about ways that potential parents could have children without passing on CMT. In the last newsletter and on Facebook, we asked you to tell us your stories about how CMT influenced your reproductive decision making. We received both heartwarming and heartbreaking stories. Ultimately, these stories prove that these are personal decisions. Every person and each couple has the right to make their own reproductive choices.*

*Due to the number of responses, here we provide just a snippet—ones that capture the essence of the stories and the major points. All are valid and important.*

*—Shawna Feely, MS, CGC, and Carly Siskind, MS, LCG*

### **CMT WAS NOT A FACTOR.**

Not having a child was never an option. I was an uncle at 12 and from that day on could not wait for the day I had my own. God had other plans for me, and it took me until I was in my late 20's to find the love of my life, get married, and try to start a family. When we were finally blessed with our first born, CMT never entered my mind.

*—M.W.*

### **YES, CMT STINKS!**

No, we don't want our children having it. Every parent wants a healthy child but there are no guarantees in life. After six years of marriage our desire for a family increased. It was a 50/50 chance that our child would have CMT. Although my symptoms were minimal at that time, I knew the severity of the disease could vary. Our offspring could have much greater debilitating effects. Despite all the questions, odds and possibilities, the desire for a baby *trumped* everything.

*—D.D.*

### **I DECIDED NOT TO HAVE KIDS.**

I married my husband in 2009, and we began to think of our future and children. I am a dedicated Catholic and familiar with the church's teachings. I

have a wonderful husband who would make a great father. However, after many prayers and discussions, we decided not to have children. I have a nephew who is almost a year old and a niece who is four years old. After a day with one or both of them, my pain level greatly increases. Also, I have a difficult time keeping up with my niece when she wants to play rather actively. I truly don't know if I could deal with this daily. I had a rough childhood and would not want a child to go through the same thing I did, even if it has made me the person I am today.

I am lucky to have the support of most people in my life regarding my decision. At times my husband has a difficult time knowing he will never be able to walk a daughter down the aisle, but he is very supportive of me and my CMT. We also have to deal with people who don't support our decisions and this is difficult. My husband's mother has told him that our decision is very selfish on my part. After many tears, I had to remind myself that she hasn't seen my struggles or trials growing up. She also doesn't know my pain.

*—H.H.F.*

### **THOUGHT ABOUT IT...**

Once I knew I had CMT, I was concerned that if I had a child, I could pass this disease on to him or her. Although at the time I was not as symptomatic as I am presently, it was already impacting my life and I had numerous relatives whose function was very compromised by CMT. By the time I remarried, I was in my late thirties and I desperately wanted a baby.

I believe that having a baby is a tremendous leap of faith, and even if my leap was a little limp due to my CMT, my desire to have a baby was stronger than ever. As time went on, my biggest concerns had to do with infertility issues. CMT fears definitely took a back seat to so many tests and so much heartache.

I think I developed magical thinking that if I ever could become pregnant (I was now 41), then everything would work out just fine.

Well, I did become pregnant! The question was whether to test for CMT when I had the amniocentesis, or not. Due to my "advanced maternal age," there were other possible medical and genetic concerns. My doctor and midwife told me about another patient who had CMT and decided not to have the test.

They insinuated that she was in some kind of denial.

I had always thought that I would want to know, but when the opportunity presented itself, I was much more interested in knowing that the baby was healthy and what the sex was.

I weighed the pros and cons. I felt that since there wasn't anything that could be done if the result was positive, and I would not consider an abortion for that reason, then knowing would only create anxiety and worry earlier than necessary. I'm glad I made that decision. I got to enjoy a blissful pregnancy, and when my healthy baby girl was born, there was only great joy. —M.M.

#### WHEN REPRODUCTION FAILED

My husband and I decided that we would try to have a baby,

even though we knew the risk of passing on my CMT. Nobody else in my family has it, and my progression has been very slow, so although I was worried, I thought it might not be too bad if they had the same experience as me. I didn't realize at that time that there can be such differences amongst family members.

Anyway, I was not able to get pregnant alone. I was 36. We tried some reproductive treatments. We were unsuccessful. We did not go so far as trying IVF. I have adopted siblings, and we had agreed early on that this was an option for us.

In the end we did adopt a baby. That was in September 2010. We are now trying to adopt a second child. I will always live with the loss of not having my own biological

child, but ultimately I am glad not to have passed on my CMT, and I think building a family through adoption was the right thing for us. —J.B.

#### TRIED IVF/PGD

I come from a family with five generations of CMT. After years of struggling physically and knowing I was different, my parents shared the family's CMT story with me when I was 17. It explained so much to me.

The night I met my husband, I told him about my CMT. He still asked for a date, and two years later we were married. When we decided to have children in 2002, we knew little of the family planning options, except for the obvious two choices: have children and take

(continued on page 10)

## THE CMTA PROUDLY PRESENTS THE 3RD ANNUAL CHARCOT-MARIE-TOOTH ASSOCIATION'S "I'M A STAR!"/"I'M A SHOOTING STAR!" CONTESTS

All CMT patients are special individuals. They face the challenges of everyday life those without CMT can't begin to imagine. Do you know an extraordinary person living with CMT? Please share that person's story with us and he or she may be selected as the recipient of the Third Annual "I'M A STAR!" Award (ages 18 and up) or the "I'M A SHOOTING STAR!" Award (ages 10–17)

In 500 words or less, please tell us about your extraordinary individual. How old was that person when he or she was first diagnosed? What type of CMT does the person have? How does living with CMT affect his or her ability to have a full and rewarding life, or does it? What does that person do to rise above disability and prove his or her abilities on a daily basis? What does that person excel in?

Any additional information you can provide such as family life, community involvement, mentoring, sports, hobbies, and interests will all be considered in the selection of our winners.

You can submit your entry by emailing your submission to [CMTextraordinaryperson@yahoo.com](mailto:CMTextraordinaryperson@yahoo.com), or by mailing your entry to: CMT Extraordinary Person c/o 200 Tollgate Trail, Longwood, FL 32750.

**All entries must be submitted by email or postmarked by midnight, August 23, 2013.  
Winners will be announced during Charcot-Marie-Tooth Awareness Month in September.**

This contest is sponsored by the CMTA.

Regrettably, please note that employees of the CMTA, Support and Action Group Facilitators, or their immediate family members are not eligible to participate in this contest.

# Educational Options for Children with CMT

BY SARAH KESTY, MA, CMTA ADVISORY BOARD, [www.sarahkesty.com](http://www.sarahkesty.com)

It was just a typical field: grass, two soccer goal posts, and children—34 of them, lined up along the edge of the grass and the blacktop, some talking, some laughing, all staring and waiting. And then there was CMT me, desperately trying to stay upright on my pounding feet and shaking legs, hoping that my teacher would lose count of my laps or lose patience with me and finally call an end to my mile “run.” This was my school’s version of “modified” physical education (PE).

If your child with CMT is in school, chances are this scene has haunted you. PE is an integral part of most school days; many teachers even use extra PE as a class reward. But for a child with CMT, PE and other times requiring physical movement (long writing assignments, for example) can be riddled with shame, embarrassment, and frustration. Information and collaboration are keys to ensuring your child has the best possible experience with PE and in the classroom.

## What can a parent ask of the schools?

As a parent of a child with a disability, you have two main options for developing a plan for your child: a 504 Plan or an Individualized Education Plan (IEP). The goals of both these plans are to ensure all children receive Free and Appropriate Education (FAPE) in schools, and each requires a team of

school professionals and parents to meet yearly to develop and review the plan. Here are the key differences as they relate to children with CMT:

**504 Plans** are available to all individuals who have a documented disability; these plans fall under civil rights law. A child with CMT would absolutely qualify for a 504 plan, at minimum.

504 Plans aim to “level the playing field,” for all children, meaning they require teachers and staff to make accommodations and modifications to ensure children can access the general education curriculum. For example, if CMT greatly impacts your child’s ability to use her hands to write, an accommodation could be receiving copies of the teacher’s notes (rather than writing them all herself) or it could be the use of a scribe for writing assignments.

With regard to PE, a 504 plan would require the teacher to modify or accommodate the PE activities for your child (i.e., require fewer repetitions, allow breaks as needed, limit high-impact movements) but would not ask the teacher to individualize the PE program.

**IEPs** are available to children whose disabilities adversely affect his or her educational performance or ability to benefit from general education. IEPs are protected under the federal statute of the Individuals with Disabili-

ties Education Act (IDEA). A child with CMT that impacts his or her ability to write or participate in PE should be assessed by an IEP team to determine the services necessary to support the child.

Having an IEP affords a student the opportunity to have specialized support. He or she may receive support from a Physical Therapist (PT), Occupational Therapist (OT), Adaptive PE teacher (APE), Resource Specialist (RSP), or counselor/psychologist. An IEP will also include individualized, yearly goals generated from assessments of current levels and in support of the child’s progress toward grade level standards. Many IEPs also outline accommodations and modifications similar to those in 504 Plans. Changes to IEPs may not be made without parental consent, and you must agree to, and sign, the IEP before services can begin/change. If you disagree with the school’s findings, you may request that private assessments be completed and financed by the school district.

Be aware that the services outlined in the IEP will most likely be provided during the school day; your child will miss part of his or her class time to work with the specialist(s), however many minutes per week are written in the IEP. Due to budget constraints, you may find some districts resistant to offering some services; stay the course and continue to provide

the team with information about CMT and how it affects your child. Even experts can be lured into assuming that because a disability is mostly “invisible” it does not present great needs.

### Things to keep in mind

Advocacy and information are key. Ensure the professionals working with your child are well aware that your child is giving his or her best effort. “Try harder” is a damaging remark too commonly said to students with mostly invisible disabilities like CMT. Ensure the school staff celebrates your child’s efforts and successes.

In addition, be sure that the modifications put in place do not socially isolate your child (i.e., having him or her practicing dribbling a ball alone while others play basketball). Many state standards for PE denote the development of teamwork and

social skills as they relate to games. Your child deserves this opportunity as well.

Beware of sidelining: watching peers play, picking up the cones on the field as others run, or keeping score are not acceptable modifications for your child. Your child should be offered low impact games, played with others, that practice skills related to the PE games, if/when he or she is unable to play the games.

Assessments for PE are changing, as the majority of states are transitioning to the Common Core Standards, which omit standards for Physical Education. (States currently have PE standards and yearly testing associated with them.) It’s still a good idea, however, to check in each spring with your school team to ensure the modifications and accommodations for assessment will be in place.

You also have the right to request that your child be excused from the state testing for PE; make this request in writing, and be sure to receive a response from the school.

This process is bound to be frustrating. You know and love your child best, yet you have to work as a team to plan for his or her success. The team members may not always agree with or offer what you would like, and you may feel trapped between working together and getting exactly what you want. The best advice is to trust your gut and listen to your child. Most professionals in the schools are there to promote success for all children, but they are human and may need further information to be able to relate to your perspective. This is your opportunity to inform others about CMT and create a more compassionate world. ★

## ASK THE DOCTORS

### Dear Doctor,

*My question involves nerve regeneration in CMT1A after having a nerve cut during jaw surgery. I wonder if my CMT will keep the nerve from healing properly.*

### Dr. Steven Scherer replies:

One might expect that peripheral nerve fibers will regenerate less well in people with CMT1A. I suspect that the jaw surgery may have injured the inferior alveolar nerve, which runs in the jaw bone. If the inferior alveolar nerve is cut, then the chance of full recovery is low even in people who do not have

CMT1A. This nerve, however, does not perform any critical functions; to the best of my knowledge, one may be left with a “numb chin”—the clinical finding of such a nerve injury.

### Dear Doctor,

*I have been taking TSH (thyroid stimulating hormone) for hypothyroidism for about one year. This has caused a noticeable decrease in leg strength. I have CMT2A and have been treated for it for about 14 years. I exercise at a wellness center 4 times a week. I have done that for over 20 years beginning prior to the onset of CMT. So, I*

*know there is a definite strength reduction. Is the TSH the cause? I take no other medications and my diet has not changed.*

### Dr. Louis Weimer answers:

The issue is complicated. Thyroid conditions are very rare factors in neuropathy, but both an over- and under-functioning thyroid is a factor in muscle strength and development. My usual advice is to keep the thyroid function in the optimal range. I know of no specific problems with the medications, only their help with overall thyroid status and function.

# A Mother's Reflection on Living with CMT

BY ELIZABETH MISENER, CMTA ADVISORY BOARD

**M**y hope in writing this article is to share my reflections on being the mom of a young son who has CMT. I can only give you a glimpse into our lives, but I am hopeful that the more we share our stories the less isolated we might feel.

I am a social worker by training and my area of expertise is depression and anxiety. I have spent many years building my skills in teaching people how to shift their thoughts to shift their feelings, and I know it works. I am also a wife and mother. My husband of 20 years has CMT1B and one of our sons was also born with CMT1B. We did not know right away, but when he did not meet milestones, we had his blood work done and it was confirmed for us. Most of the time, I can handle his having CMT.

With the passage of time, we adjusted—I carried him until he was two years old and loved it. At three, we placed him in a Montessori school that has

helped him every day. As he is developing, I can see in him the characteristics I love about his father ... kind-hearted, strong-minded, determined to always find a way to do what he wants, and such sharp thinking. I attribute these qualities to his daily challenges with CMT. Everyone I have met who has CMT demonstrates these, and so many more, amazing traits.

There have been a handful of times that I have struggled with my sadness about his CMT—wanting to protect him in life. But there are some days I can not ignore the reality. In the past year, I have had two such days. One was when we had him assessed for foot surgery, and I realized the torture he might have to endure due to the CMT. I had to use all the skills I teach others and re-teach myself how to process and refocus. (I have all the skills; I am a social worker, and I know how to change my thinking so my behavior will change. I work with clients all the time with

these skills.) But it was not easy. However, I knew that for my son I had to shift my thinking and not get stuck in my sadness for too long.

I like to operate from facts, so after many conversations with my husband—some harder than others—we made an appointment with an orthopedic surgeon. He told us both feet will need two surgeries within a two-week period. This was too much for me, so we took some time off from thinking too much about the surgery. But as the year has gone by, we have continued to gather data about the surgery, and it has become easier for me to think and talk about it. To get here we have:

- Read all the research articles we could find. Unfortunately, there are not many and no clear answers.
- Talked to many amazing parents and people with CMT and heard their stories.
- We have since had four consults with orthopedic surgeons and all said that

Here is a “cognitive restructuring” exercise you can use to help “rewire” your thinking:

Event	Thinking	Feeling	Re-thinking	Re-Feeling
Birds poops on head	I always have bad luck!	Angry for the rest of the day	Great luck! The chance of this happening is so small, I must be lucky!	Rest of day: look for other great luck.
Wearing braces	I don't like my braces. Everyone is looking at me.	Self-conscious and miserable; do not want to leave home	I can walk longer distances, and my feet are straighter.	Uplifting and accomplished
I have CMT	You fill in the blank on what you think of your CMT.	How do you feel?	Now think: what is one thing that you are grateful for that CMT has brought you?	How do you feel now?



surgery is recommended. The question is when? Two recommended surgery now and two recommended waiting until he is done growing.

The bottom line is, as of now, there is no clear pathway. We are still in the process of having appointments with experts, and we can keep you posted. For me, this is one of the hardest challenges with CMT because the answers to my questions are not clear. There is still so much unknown about CMT and the surgeries associated with it. Still, I have been inspired by how many people have shared their stories.

The second difficult day was when my husband and I took him to another specialist to have his spine looked at for scoliosis, an abnormal curve of the spine, which can also be related to CMT. His father has it and had major surgery for it. The spine orthopedist was amazing. He gave us practical advice, and our son was thrilled because he told us to focus on what he does have and to strengthen it. So, we were told to get a Wii and have him play “standing-up” games. Our son said he is glad he has CMT so he could finally get a Wii. It was also recommended that he swim each day, so our son asked when we are getting a pool because the doctor told us he needs one. Not any time soon, we told him.

At that appointment we were told he has a nine-degree curve. Ten degrees is considered scoliosis, and 30 degrees means surgery. I could not ignore this. When I work with clients, I encourage them to go the dark place, so they can walk through

and come out the other side. I did this in the privacy of my car. I was angry that he might have to suffer a major surgery. I was angry at CMT. I was so sad that I might not be able to do my job as a mother and protect him from pain. I cried and felt the pain. It was hard, but liberating. After some time I was able to walk through that dark place, face my fears, and focus on what I can do now to be present in the moment. We were told to measure him each month, and if he grows more than an inch, to take him back to the spinal orthopedist. At least I had a task I could focus on, and I felt I could do something to help prevent more surgeries.

I practice the skills I teach everyday with myself and my son. When he is angry at the CMT, we sit on the floor and cry together. When he dreams about his future, I dream with him. When he tells me that his

teacher showed him how to hold his pencil a different way the other day—he told her that people with CMT do things differently because it works for them—I am so proud. It is these moments I want to remember and focus on. Some days are easier than others, but I know that our brain is a powerful tool in directing how we think about life, and how we think about something can change our feelings and our behaviors. Usually, we cannot control an event; but we can have a choice about our thinking; which will, in turn, lead to our feelings and how we react. I cannot control that my husband and son have CMT, but I do have a choice in the way I view it, and I make the choice to see it as a blessing as they are both such loving, determined, open-hearted people. They remind me each day to focus on what I am blessed with. ★

## BOWIE BAYSOX WELCOME CMTA FRIENDS

The first ever CMT Awareness Day with the Bowie (MD) Baysox was a big success. Despite rain in the morning, we had a beautiful day, a great game, and a lot of people who were interested in learning more about CMT. Through our raffle, T-shirt sales, and ticket sales, we raised roughly \$800 for the CMTA, an amount that was generously matched through the Warfield Family Challenge. Congratulations to Jean Maase, a member of our group who won the grand prize of half the pot and decided to contribute her winnings to the CMTA. Thanks Jean! The best part of the day was the pre-game ceremony honoring our own Vikki Vance, who worked hard to make it down to the field despite recent surgery on her leg.

Special thanks go to John Logue, founder of Gait Dynamics ([www.gaitdynamics.com](http://www.gaitdynamics.com)), and CMTA Board Member Gary Gasper, whose financial contribution helped make the day possible. We were also fortunate to have representatives from the CMTA on hand—Bethany Meloche, Elizabeth Ouellette, and Jeana Sweeney. It was great to have them there.



Kim Hughes, Bethany Meloche, and Steve Weiss' children, Mason and Campbell, spend time with Louie, the mascot for the Baysox.

## RESPONSES

(continued from page 5)

the chance of passing along CMT, or choose not to have children at all. Because I was glad my mother chose to have children knowing about her CMT, and because I knew that I wanted a large family of my own, the choice was clear. We chose to have our daughter without testing or interventions. We knew that we could test for CMT prenatally but since we weren't going to make any decisions based on the results, we chose not to test.

Six months after my daughter was born, my grandmother with CMT passed away. All of our relatives came to the funeral, many with CMT. After the service we were gathered in her living room where my mother's cousin was talking about the new technology called PGD. He and his wife had just completed a cycle of *in vitro* fertilization using PGD to screen for CMT, and they were expecting a baby girl who did not have CMT. My family's eyes quickly turned to me—had I known about this option?

The following weeks were spent researching PGD and the options in my town. For the first time, I felt empowered to plan my family with the likelihood that CMT would end with me. I also felt very responsible for any future baby's health. If I could keep a child from suffering as I did, it was my responsibility to raise the healthiest baby possible. We spent the next few months exploring local fertility clinics, getting genetic testing and preparing ourselves for the journey of *in vitro* fertilization.

*In vitro* means getting pricked for blood weekly, getting examined regularly, mandatory psychotherapy for the couple to prepare emotionally for the many challenges, manipulating hormones into forced periods, forced fertility times, forced false pregnancies to “trick” your body into building the uterine lining, all of which brings many mood swings. And, then, the shots—every day, given by my husband. Oh what fun!

Conversely, it's really fascinating! The conversations we had with the doctors were stimulating to our quasi-scientific minds. I watched my ovaries mature ... 18 eggs in the course of three weeks. We had photos of the conception of each embryo—12 in all. We watched each embryo develop from one cell, to two to eight in a matter of days. The miracle of life was right before our eyes!

We successfully created four embryos without CMT that survived to the transfer stage. We chose to transfer one embryo and freeze the rest to avoid the

(continued on page 13)

## CMTA FUNDRAISER AT THE CAMDEN RIVERSHARKS

On June 8, 2013, we held CMTA Night at the Camden Riversharks. We sold tickets to the game to raise money (\$5 of every CMTA-designated ticket went to the CMTA) and we held a special raffle. Kurt Coleman, starting free safety for the Philadelphia Eagles, was our special guest. Kurt was drafted out of the Ohio State University (why that's important later) in 2010 by the Eagles. He threw out the first pitch and gave an excellent talk to the crowd about the signs and symptoms of CMT and the need to get checked out if any of them are present.

Kurt was also generous enough to sign autographs for fans, who had a chance to bid on items signed by him: a number 42 home Philadelphia Eagles game jersey, a Camden Riversharks home jersey, and game-worn cleats. We are pleased to say we had a great turnout, and hundreds of fans lined up to get an autograph and shake Kurt's hand. (A lucky few got photos!) More importantly, those fans got to know what CMT is while they were waiting in line.

A special acknowledgement to CMTA Board Member Alan Korowitz's son, Zachary, a big Ohio State University fan, who won the game-worn autographed cleats!

In all, we raised almost \$1,000 for the CMTA, and we will be back at it next year!

Special thanks to Jeana Sweeney for her tireless support and help with this fundraiser. It could not have happened without her.

—Michael Needleman



Julian Needleman got to meet Philadelphia Eagles' safety Kurt Coleman at the Riversharks' baseball game.

## SAG FACILITATORS SPOTLIGHT:

*Aimee Trammell and Priscilla Creaven, Fort Wayne, Indiana*

**A**imee Trammell lives in a small country town in northern Indiana. Aimee is a wife, mother, fitness instructor and co-facilitator for the CMTA support group. Along with managing four kids (two of her own and two step-children) ages 6-17, Aimee loves to teach yoga, strength training and tabata classes at a local gym. Aimee also has a love for baking, which she does for small events and for her friends and family. Aimee and her husband love to travel to the Caribbean, specifically the Dominican Republic. Aimee has CMT1A and also EDS (Ehlers Danlos Syndrome) which is a connective tissue disease affecting every part of her body where connective tissue is found.



**Aimee and Priscilla work together to run the Fort Wayne Support and Action Group.**

Priscilla Creaven is the co-facilitator of the Fort Wayne, IN Support and Action Group. Priscilla grew up in New England. Retired as a clinical social worker and therapist, she

received her MSW from the University of Connecticut.

She is active in local arts events and lives in Auburn, Indiana. This summer (2013), she is chairing "Pianos on the Square," a six-week free outdoor event featuring decorated pianos which are available to play 24 hours a day, as well as concerts, recitals, lectures, film series, etc., with the piano as the star.

She lives with her "car-nut" significant other, who takes her and his 1954 Triumph to car shows all summer long.

Priscilla had signs of CMT for years, but remained undiagnosed for a long time. Her brother also has been recently diagnosed with CMT. ★

## 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: \_\_\_\_\_

\_\_\_\_\_





## Awareness Month is Almost Here!

**T**his year Awareness Month takes a new and fun approach to spreading CMT awareness. We're ready, and we know you will be, too!

For each and every day during the month of September, the CMTA has come up with an idea, a suggestion, a hint, a unique fact, a video to watch, a webinar to participate in and all sorts of fun



and exciting things to do to help you learn more and to help you help others learn about Charcot-Marie-Tooth Disorder. The goal this year is to Help Build a Better CMTA. How?

By spreading as much CMT Awareness as you possibly can.

We are continuing what has become a beloved tradition, so we will be looking for your nominations for the "I'm A Star!" and "I'm A Shooting Star!" awards for those who go above and beyond expectations in

their lives despite living with CMT. There will also be exciting news from our CMTAthletes.

If you can't be involved every day, don't worry. We have taken everyone's busy schedule into consideration and have developed a list of five easy things you can do to help make Awareness Month a huge success!

**1.** Change your Facebook Profile Picture to the CMTA's Awareness Month Ribbon: [www.cmtausa.org/url/am\\_ribbon](http://www.cmtausa.org/url/am_ribbon).

**2.** Spread the Word: Tell five people about CMT. Send them the facts: [www.cmtausa.org/url/cmtfacts](http://www.cmtausa.org/url/cmtfacts).

**3.** Visit our store and buy your CMTA Awareness Month kit today: [www.cmtausa.org/url/amkit](http://www.cmtausa.org/url/amkit).

**4.** "Like" us on Facebook: Charcot-Marie-Tooth Association: The Time is Now: [www.facebook.com/CMTAssociation](http://www.facebook.com/CMTAssociation).

**5.** We always need volunteers. Interested? Email our Director of Community services, Jeana Sweeney ([jeana@cmtausa.org](mailto:jeana@cmtausa.org)) or visit [www.cmtausa.org/url/volunteer](http://www.cmtausa.org/url/volunteer) to learn more.

Keep visiting the website and check your inbox for upcoming events to be a part of the excitement that surrounds CMT Awareness Month! ★

we're this close to helping millions

### September is CMT Awareness Month

Charcot-Marie-Tooth or CMT is a neuromuscular disorder affecting over 2.6 million people worldwide.

Our Wish is for a World Without CMT.  
Make a Difference by Showing Your Support.

Please visit [www.cmtausa.org](http://www.cmtausa.org) to find out how you can make a difference.



## RESPONSES

(continued from page 10)

possibility of multiples. Ten days after the transfer I received the call, no pregnancy. After 60 days, we decided to try again. One transferred with no pregnancy. Four months later, another transfer, still no pregnancy. Then, I had the joy and pain of a natural pregnancy, which miscarried after nine weeks.

Well, there is only so much heartbreak a girl can take. Six years later, our fourth embryo is still frozen and we have decided to stay a family of three.

I often wonder if by choosing to manipulate the genetics of my family I missed out on the love of a larger family. I didn't get the family of four kids I wanted. I feel guilty for playing "god" with my family and wonder what my family would look like if we hadn't heard of PGD or chosen it. Before I get too melancholy, I think of my daughter and the great kid that she is, the love she brings to me and my husband. She is our only child and I am so grateful to have her. —S.R.

### TWO CYCLES OF IVF AND PGD

I'm 35 years old with CMT1A. I live in Sydney, Australia. I've always known I had CMT since I was young enough to understand it. My paternal grandmother had it, three out of her four children have it including my dad who passed it on to me and my two brothers. We all have varying degrees of it.

Having CMT has affected me emotionally as well as physically since my earliest memories.

Although I could walk quite well and had no major balance issues, it affected my coordination and strength. I struggled to keep up with other kids and couldn't do many of the physical things they could. My parents spoke to my teachers about CMT and my physical limitations, but this didn't seem to matter to many of my teachers. They still forced me to take part in activities even though they'd been told I wouldn't be able to do them. This, in turn, affected my self-esteem and self-confidence.

I am very lucky to have a wonderful family. My parents

"I respect everyone's right to an opinion, but no one should force their views and opinions on others."

are very supportive and assist us financially and emotionally. I was lucky to find a very understanding, loving and caring husband. He has stood by me through thick and thin.

My 9-year-old niece has CMT, and she struggles every day to do the simplest tasks like tying her shoelaces or doing up buttons. Seeing her cry when she doesn't want to go to school because the other kids laugh at the way she walks or because she always comes last in running races breaks my heart, and I don't want my children to go through this because they inherited this disease from me.

All of the above are the reasons we decided to try IVF and PGD. We first heard about the procedure at the national annual CMT conference in Sydney. As IVF and PGD is so expensive in

Australia, we weren't sure if we'd be able to afford it, especially since it's a gamble as to whether or not we would have healthy embryos at the end of the cycle. We didn't really think about it further until my neurologist mentioned there was a financial assistance program that would fully cover two cycles. We applied for the program and received it for this year. We were very excited. We had the PGD gene testing done while we were waiting for the results of our application so we were ready to go once we received approval.

We told some friends we were thinking about doing IVF and PGD, and they told us it was immoral and wrong, so we decided to only share it with family and very close friends. While I respect

everyone's right to an opinion, no one should force their views and opinions on others, especially when they have no idea what my life is like.

We didn't realize at the time how emotionally and physically draining IVF is. Our first cycle commenced in January. At egg collection we had six eggs. This was a little disappointing as my doctor was expecting at least 11 eggs. Only four fertilized and none grew strong enough for the testing stage. We were devastated. I'd gone through weeks of injections, ultrasounds, bloating and being very emotional (from all the hormones in my system) to receive no embryos for testing. It took me a few weeks to get over it. It felt like we had miscarried.

We started our second cycle at the end of March. We had

(continued on page 18)

## Archy Joins the Team

I have always been involved in swimming, which is sort of a team sport, but each swimmer has his own responsibilities and can do really well even if the “team” isn’t very good. So, when you swim, you miss all the team-related lectures and the catchy phrases ... like *“There’s no I in team.”*

This summer I was part of a baseball team in the role of baseline coach. For the first time I got to experience all the good things about being on a team and all the problems that can occur. From my experiences I have created a list of the do’s and don’ts of teamwork:

- ★ Never point out the failures of others ... like our left fielder, who frequently had some problems getting the ball in from the outfield, but who blamed the problems on the inability of the shortstop and second baseman to handle his throws. Good people (or animals) don’t try to make

themselves feel better by making others feel worse.

- ★ Be happy for the successes of others. If you strike out, but your catcher hits a home run, tell him how impressed you are that he could handle the pitcher’s curve ball.
- ★ Offer to help people who need your help. I was lucky enough to have a few friends on the team who had played before, and they made me a better coach by teaching me some of the intricacies of the game.
- ★ Remember that conflict and disagreement within the team doesn’t have to end up in an argument. Disagreements give team members the chance to explore differences and see problems from different vantage points. In a team,

no one “wins” an argument. It’s a win-win situation.

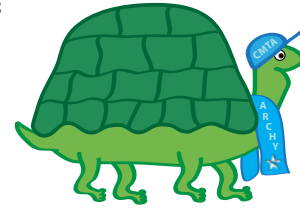
- ★ Be proud of the success of the team as a whole. You could have a bad game or a bad year, but if the team does well, you need to be grateful and you need to express your happiness at the accomplishments of the whole group.

A feeling of being part of a successful team isn’t

matched by much else. I’ve won ribbons for my swimming, but nothing ever made me feel as good as the trophy that my baseball team won this year. I didn’t even play, but my teammates made me feel like they won, in part, because I was a good coach.

While I’ve written about a baseball team, the do’s and don’ts can be applied to any team situation. At the CMTA, there are numerous teams that make the work of the organization more successful. Whether it’s the staff team, or the Support and Action Group facilitators or the Scientific Advisory Board, each team works to utilize the talents of the group’s members and to make a unified effort more successful than any individual effort could ever be. So, my motto is, *“Team: Together Everyone Achieves More.”*

I’ve already been asked to return as a coach for next year’s baseball team, and I’m excited and looking forward to the experience. I had a great summer and I learned a lot! ★



Our mascot “Archy” writes about his experiences as a turtle with CMTA.

## ARCHY TRAIN CHUGS ON... FOR A NEW PURPOSE

Jerry Cross, who designed, built and painted the Archy the Turtle train with the help of friends and family, has had to give up his long-time project of making kids happy with a train ride and letting adults know about CMTA and the CMTA.

We, at the CMTA, want to thank Jerry for his years as an ambassador for the CMTA and an unabashed lover of all children. Happily, the train is moving on to make more children happy by going to another charity that serves children in Nevada.

Archy has never had a better friend than you, Jerry ... and neither has the CMTA.



THE ARCHY TRAIN gave rides to hundreds of children at Cooterfest in Florida.



# GIFTS WERE MADE TO THE CMTA

## IN MEMORY OF:

**Joan Austin**  
Mr. and Mrs. David Jones

**Francis Basquill**  
Mr. Mark Pino

**John M. Dietz**  
Mr. and Mrs. James Mousner  
Mr. Henry Dietz  
Mr. William Dickinson  
Ms. Florence McDaniel  
Ms. Helen Dietz

**Charolette DuBois**  
Ms. Karla McIntire

**Susan Duzac**  
Mr. Lou Duzac  
Ms. Laura Fanella

**Virginia Hoak**  
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Ms. Arlene Trask  
Ms. Mary Cummings

**Christine Hook**  
Mr. and Mrs. J. Neil Hook

**Eleanor Kelly**  
Mr. and Mrs. Ed Razzis  
Mr. and Mrs. Phillip Krepps  
Mr. and Mrs. Russell Booth  
Mrs. Mila Krepps

**Ruth Macey**  
Mr. and Mrs. Steve Siref

**Rene Thirion**  
Mrs. Roberta Williams

**Robert W. Wolf**  
Queen Anne Senior Citizen's Club

## IN HONOR OF:

**Trudance Anderson**  
Ms. Hillary Smallcomb

**Riley Ashe**  
Mr. Vince McCarthy

**William Brady**  
Mr. Daniel Brady

**Madeleine Brown**  
Mr. and Mrs. Bernard Squirrell, Jr.  
Mr. and Mrs. Christopher Brown  
Mr. and Mrs. Mel E. Ross

**Dianne Everhart**  
Mrs. Veledia Jones

**Sheila and David Levine**  
Mr. and Mrs. Ken Willoughby

**The Long Family**  
Ms. Nicole Mohrmann

**Tyler Ray Lopez**  
Ms. Jean A. Moore

**Benjamin Machado**  
Ms. Stephanie Powers

**Alan Neuwirth—  
Happy 80th Birthday!**  
Ms. Janis Berman

**Leslie Nordman**  
Ms. Rachel Nordman

**Sherri E. O'Donnell—  
Happy Birthday!**  
Ms. Lelia H. West

**Karen Pixley**  
Rev. Justin Sellers

**Robert Thornley**  
Dr. John Thornley

**Adalie Tuman**  
Mr. and Mrs. Dan Tuman

## TO THESE CMTA CIRCLES OF FRIENDS:

**Bethany Walks**  
Mr. Micheal Barton  
Mrs. Janet Bengel  
Mr. Kevin Buckingham  
Mr. Robert Chan  
Ms. Mary Chiz Chisholm  
Ms. Karen Hoffman  
Ms. Diane P. Justusson  
Ms. Terry McIntosh  
Mrs. Renee G. Meloche  
Mr. and Mrs. Jim Stetor

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Ms. Melissa Freeman  
Mrs. Nicole Hill  
Mrs. Heather Hossie  
Mrs. Angela Siewert  
Mrs. Barbara Welch

**Funding a Cure to CMT**  
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Mr. and Mrs. Jack Hulmes  
Mr. Craig Johnson  
Mr. and Mrs. Brett Joseph  
Mr. and Mrs. Rick Lavoie  
Mr. and Mrs. Dave Miles  
Mr. Alan F. Murray, CPA  
R. W. Hyde Construction,  
Inc.  
Ms. Lina Storm  
Mr. and Mrs. Terence and  
Teresa T. Sullivan  
Mr. William F. Tracia

**Soul of a Chef**  
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Mrs. Sandy Poznanski  
Ms. April Russell  
Mrs. Heather Ryan

Ms. Abby Sarhan  
Ms. Madhoo Seth  
Ms. Doris Steiger

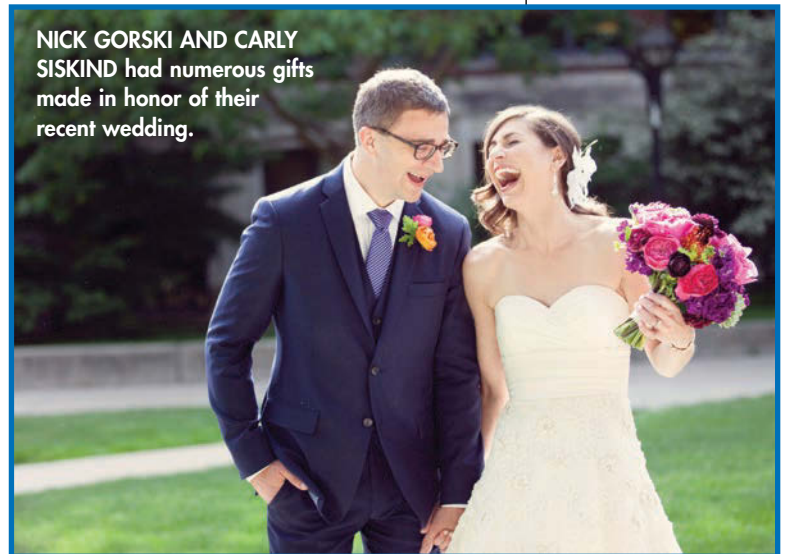
## IN HONOR OF THE WEDDING OF CARLY AND NICK:

Mr. and Mrs. Justin Landis  
Ms. Shawna Feely  
Mr. Adam and Dr. Jessica Bookman  
Ms. Kate Bush and  
Mr. Daniel Montingelli  
Mr. Daniel Freeman and  
Ms. Rebecca Zylberman  
Mr. Andrew Sinkov and  
Ms. Alina Liberman  
Mr. Jason Gatoff  
Dr. Jonathan Sorg and  
Dr. Kristen Wendorf  
Ms. Miranda Chen  
Mr. and Mrs. Theodore Martens  
Mr. Charles Stauffer  
Dr. Mary O'Keefe and  
David Benson  
Mr. Mark Ayzenshtat and  
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Drs. Mike and Rosemary Shy  
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Mr. Jeffrey Bell  
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and Ms. Rebecca Grekin  
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Dr. Robert and Mrs. Joan Cody  
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Mr. and Mrs. Marvin Siskind  
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Ms. Jeni Nudell  
Mr. Jeremy Nudell and  
Ms. Jessica Hunter  
Mr. Bradley Nudell  
Mr. Leon Gabinet  
Mr. John Siegel and  
Ms. Sarah Gabinet  
Mr. Nathan Siegel  
Mr. and Mrs. Ira Kroo  
Mr. and Mrs. Joshua Kroo  
Ms. Gavriella Kroo and  
Mr. Daniel Semaya  
Mr. Ari Gabinet and  
Dr. Christina Paxson  
Mr. Nicholas Gabinet  
Benjamin Gabinet  
Dr. and Mrs. Steven Flicker  
Mr. and Mrs. Glenn Steinberg  
Dr. Michael Flicker  
Mr. and Mrs. Paul Rutenberg  
Mr. and Mrs. Lawrence Kiel  
Mr. Richard Kiel  
Mr. Jeffrey Singer and  
Ms. Ashley Hanson  
Mr. and Mrs. Charles Kiel  
Dr. and Mrs. Daniel Panush  
Mr. and Mrs. Erik Friedman

Drs. Stephanie and  
Jordan Dubow  
Mr. Jonathan Panush  
Mr. and Mrs. Martin Weitz  
Mr. and Mrs. Andrew Weitz  
Ms. Jayme Weitz  
Mr. and Mrs. William Eisenberg  
Ms. Julie Eisenberg and  
Mr. Steven Norrod  
Mr. Brian Eisenberg  
Dr. and Mrs. Kim Margolis  
Mr. and Mrs. Gary Cohen  
Mr. and Mrs. Bruce Steintal  
Mr. Kenneth Steintal and  
Ms. Kelly Nelson  
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Ms. Amanda Miller  
Mr. and Mrs. Seymour Bressler  
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Mr. Adam Mitzner  
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Mr. and Mrs. Michael Fetcenko  
Dr. Nicholas Gorski and  
Ms. Carly Siskind  
Dr. and Mrs. Christian Fierro  
Mr. and Mrs. Matthias Kuegele  
Mr. and Mrs. Irving Tuckel  
Mr. and Mrs. Joe Turner

**NICK GORSKI AND CARLY  
SISKIND had numerous gifts  
made in honor of their  
recent wedding.**







## SUPPORT AND ACTION GROUP NEWS

### • CA—San Diego Area

The group had a fantastic meeting with 15 people in attendance! The guest speaker was chiropractor Jim Wagner. He went through several exercises for improving balance and stretching using a stick. He also recommended working out with the TRX System or the Jungle Gym System. The group welcomed Beth Lovison and her mother, Ruth. Thanks to Brenda and Larry's grandchildren, Alyssa and Jaden, for joining. Lawrence shared the name of his therapist,

Steve Moxy, who is one of two therapists in the area who are certified to train Olympic athletes. Jordan Thomas will be taking over as Support Group Facilitator.

### • CO—Denver Area

The group held their meeting on June 8th. Jay Willey served as guest speaker. He demonstrated Nordic walking. There was interest from the group in learning more about Nordic walking, and Jay agreed to hold a class for those interested.

### • CT—North Haven

The group met on May 20th and had 11 members attend. Cheryl Schechter, a physical and pool therapist, spoke about the benefits of aquatic physical therapy. Pool therapy is a great way for those with CMT to exercise, reap cardiovascular benefits and reduce pain.

### • FL—West Palm Beach

The group held its regular monthly meeting on May 26th. There were 16 in attendance. They discussed suggestions on neurologists for new members and the benefit of identifying neurologists who could help in supporting a local awareness program for CMT. They also discussed fundraising ideas. Pam Goldberg demonstrated a calf/Achilles heel stretching platform that her husband, David, made for her. He also built three additional units and offered them to members for \$30 each. Two units were quickly spoken for. A discussion also took place around the "new" blood test for CMT, and the prospect of having the testing lab send a

working unit to a CMT meeting where many could participate at the same time. Thanks to Eileen Martinez for the great food and drinks she prepared.

### • LA—Baton Rouge Area

The group held their first meeting and it was a huge success. Thanks to everyone for coming. Jeana took the time to come down and talk with us. Finally, thanks for all the support and love from my family that made this meeting so successful.

### • MA—Boston

The Boston support group held their first meeting on April 27th at the Boston Public Library. Jeana Sweeney served as guest speaker. She spoke about CMT, including symptoms, diagnosis, and current research.

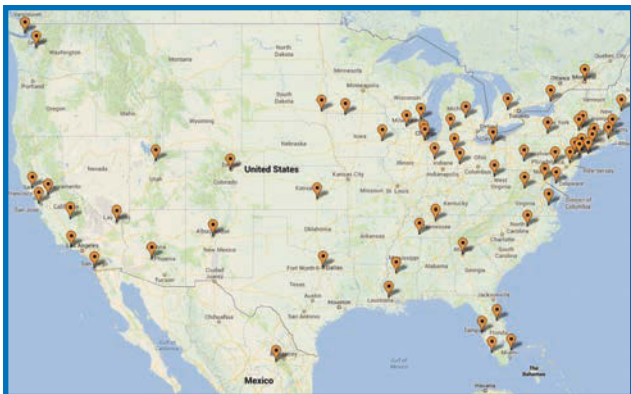
### • NJ—Central New Jersey

The May 18th meeting went well, with 19 in attendance, including four new members. Bernadette Scarduzio, star of the documentary "Bernadette," served as guest speaker. She gave a history of how the film came about and took the group through the 3-year filming experience and how it affected her and her family. She took questions from the group and an open discussion followed with topics such as, pain management, bracing, hypobaric oxygen therapy, and dealing with the emotional aspects and shame of having CMT. Mark shared information about the upcoming BlueClaws event and asked the group to support the event by selling tickets or getting sponsors.

(continued on page 19)

## NEW INTERACTIVE SUPPORT & ACTION GROUP MAP

Have you always wanted to attend a CMTA Support and Action Group, but you are not sure about meeting locations and dates? Problem solved! With ZeeMaps, we've created an interactive, visual map of all our support groups in North America, including three in Canada and one in Mexico. Just visit <http://bit.ly/18vFoCW> to view the map, get information on all our groups, calculate the distance from your home to the meeting site, and meet our fabulous facilitators. The CMTA is working hard to make our Support and Action Groups available to everyone, but if there is not a group in your area, and you would like to attend or facilitate a new group, please contact the CMTA's Director of Community Services, Jeana Sweeney: [jeana@cmtausa.org](mailto:jeana@cmtausa.org).





# CMT Support and Action Groups in Your Community

## **AL—Birmingham Area**

No group currently meeting  
Will accept calls  
Dice Lineberry  
205-870-4755

## **AZ—Phoenix Area**

Arizona CMT Support  
and Action Group  
Pamela Palmer  
480-926-4145  
Jim Blum  
480-272-3846

## **CA—Santa Barbara Area**

Ventura-Santa Barbara, CA CMT  
Support and Action Group  
Steve Fox  
805-627-8225

## **CA—Stockton**

Stockton, CA CMT Support  
and Action Group  
Nina Anselmo  
209-460-1716

## **CA—South Bay Area**

San Francisco Peninsula/  
South Bay CMT Support  
and Action Group  
Elizabeth Ouellette  
1-800-606-2682 x107  
Rick Alber  
650-924-1616

## **CA—San Diego Area**

San Diego, CA CMT Support  
and Action Group  
Jordan Thomas  
619-549-0872

## **CA—Santa Rosa Area**

Santa Rosa, CA CMT Support  
and Action Group  
Carol O'Bryan  
707-823-0165

## **CA—Visalia Area**

Visalia, CA CMT Support  
and Action Group  
Melanie Pennebaker  
559-972-3020

## **CO—Denver Area**

Denver Area CMT Support  
and Action Group  
Ron Plageman  
303-929-9647  
Dick Kutz  
303-988-5581

## **CT—Hartford East**

CMT Support and Action Group  
Roy Behlke  
239-682-6785

## **CT—North Haven**

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

## **DC—Washington, DC Area**

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

## **\*FL—Naples**

Naples FL CMT Support  
and Action Group  
Roy Behlke  
239-455-5571

## **FL—Orlando Area**

Central Florida CMT  
Support and Action Group  
Julie and Mark Collins  
407-786-1516

## **FL—Tampa Bay Area**

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

## **FL—West Palm Beach**

South FL CMT Support  
and Action Group  
Phil Lewis  
561-630-3931  
Eileen Martinez  
561-777-8471

## **GA—Atlanta Area**

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

## **IA—Great Lakes**

Iowa Great Lakes and  
SW MN Regional Virtual CMT  
Support and Action Group  
Daniel Bachmann  
507-399-0592

## **IA—Iowa Area**

Iowa City, IA CMT Support  
and Action Group  
Jeffrey Megown  
319-981-0171

## **IL—Chicago Area**

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

## **\*IL—Norridge Area**

Chicagoland (North) Support  
and Action Group  
Charles Barrett  
224-628-5642

## **IN—Fort Wayne Area**

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

## **\*IN—Lafayette**

Lafayette CMT Support  
and Action Group  
Connie Chance  
574-595-0674  
Lawane Lord  
765-474-4000

## **KS—Wichita Area**

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

## **KY—Burlington Area**

Pam Utz  
859-817-9338

## **\*LA—Baton Rouge Area**

Louisiana CMT Support  
and Action Group  
Kathleen Douglas  
985-215-3926

## **\*MA—Boston**

Boston MA CMT Support  
and Action Group  
Mimi Works  
617-913-4600

## **MD—Easton**

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

## **\*ME—Portland Area**

Portland, ME CMT Support  
and Action Group  
Mary Louie  
207-450-5679

## **MI—Chesaning Area**

Chesaning, MI CMT Support  
and Action Group  
Carolyn Koski  
989-845-5731

## **MI—Kalamazoo Area**

Southwest Michigan CMT  
Support and Action Group  
Jori Reijonen  
269-341-4415

## **MN—Benson Area**

No group currently meeting  
Will accept calls  
Rosemary Mills  
320-567-2156

## **MO—Anderson Area**

No group currently meeting  
Will accept calls  
Libby Bond  
417-845-1883

## **MS—Mississippi/Louisiana**

Clinton, MS CMT Support  
and Action Group  
Flora Jones  
601-825-2258  
Cindy Chesteen  
601-668-5439

## **NC—Durham Area**

North Carolina CMT Support  
and Action Group  
Susan Salzberg  
919-967-3118

## **NJ—Central New Jersey**

Central New Jersey CMT Support  
and Action Group  
Mark Willis  
732-252-8299  
Jacqueline Donahue  
732-780-0857

## **NJ—Morris County**

Morris County, NJ CMT Support  
and Action Group  
Alanna Huber  
973-933-2635

## **NM—Albuquerque Area**

CMT New Mexico CMT Support  
and Action Group  
Gary Shepherd  
505-296-1238

## **NV—Las Vegas Area**

Las Vegas, NV CMT  
Support and Action Group  
Jerry Cross  
775-751-9634  
Virginia Mamone  
702-343-3572

## **NY—Horseheads Area**

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

## **NY—Long Island Area**

Long Island, NY CMT  
Support and Action Group  
Shari Loewenthal  
631-254-8960

## **NY—Manhattan Area**

New York, New York CMT  
Support and Action Group  
Amanda Imbriano  
516-680-2981  
Barbara Abruzzo  
212-473-4157

## **NY—Upstate New York**

The Upstate NY CMT  
Support and Action Group  
Melinda Lang  
518-783-7313

## **NY—Westchester Area**

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

## **OH—Cleveland Area**

Cleveland, OH CMT  
Support and Action Group  
Heather Hawk Frank  
440-479-5094

## **OH—Greenville Area**

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

## **PA—Bucks County Area**

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

## **PA—Ephrata, PA**

Ephrata, PA CMT Support  
and Action Group  
Rachel Weaver  
717-344-6063

## **PA—Johnstown Area**

Johnstown, PA CMT Support  
and Action Group  
J.D. Griffith  
814-539-2341  
Jeana Sweeney  
814-269-1319

## **PA—Northwestern Area**

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

## **RI—East Providence Area**

Rhode Island CMT Support  
and Action Group  
Meredeth Souza  
401-433-5500

## **SD—Hartford Area**

Hartford, South Dakota CMT  
Support and Action Group  
Serena Clarkson  
605-215-8853  
Tom Clarkson  
605-370-7595

## **TN—Nashville Area**

Nashville, TN CMT Support  
and Action Group  
Bridget Sarver  
615-390-0699  
Gwen Dempsey  
256-655-0391

## **TN—Savannah Area**

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

## **TX—Dallas Area**

Dallas, TX CMT Support  
and Action Group  
Whitney Kreps  
972-989-5743  
Merissa Lovfald  
214-394-8907

## **UT—Orem Area**

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

## **VA—Harrisonburg Area**

Anne Long  
540-568-8328

## **VA—Shenandoah Area**

Teresa Frederick  
540-336-4496

## **VA—Williamsburg Area**

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

## **WA—Seattle Area**

Ruth Oskolkoff  
ruth.oskolkoff@gmail.com

## **WI—Brodhead Area**

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

## **WI—Milwaukee Area**

Southeastern, WI CMT Support  
and Action Group  
Polly Maziasz  
262-439-9009

## **WV—Vienna Area**

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

## **GROUPS IN CANADA AND MEXICO**

### **CAN—British Columbia**

Victoria, BC CMT Support  
and Action Group  
Melanie Bolster  
250-888-7713

### **CAN—Ontario**

Eastern Ontario CMT Support  
and Action Group  
Robin Schock  
613-389-1181

### **Southern Ontario CMT Action and Support Group**

Kelly Hall  
519-843-6119

### **Mexico**

(This group will be in Spanish.)  
México CMTA Grupo de  
Apoyo y Acción  
Gina Salazar  
Gina\_oviedo@hotmail.com

**Most Support and Action  
Groups can be accessed  
at [www.cmtausa.org](http://www.cmtausa.org).  
They can be found in the  
CMTA Online Community  
under Support and  
Action Groups.**

**\*NEW SUPPORT GROUPS**

## RESPONSES

(continued from page 13)

egg collection last week and this time we had eight eggs. I was very upset because based on my last ultrasound, we should have gotten 21 eggs. Seven fertilized, but, sadly, only two embryos grew strong enough for testing. It will take four weeks for the results to come back, so the waiting begins. There is a lot of waiting in IVF, which takes its toll emotionally.

While two embryos are better than none, with a 50/50 chance of the embryo carrying the infected gene, our chances of having a healthy baby have been cut dramatically. We were also hoping for some backups in case I don't get pregnant the first time or even to have a second healthy baby.

I'm not sure what we will do if we don't get any healthy embryos from this last cycle.

My parents have offered to pay for a third round, but I'm not sure I could go through the whole process again. I don't think people can truly understand how difficult IVF is for everyone involved unless they've been through it.

All I've ever wanted is to be a mother. When I was little I'd carry my dolls around and look after them. I dreamed of the day

I'd have my own baby, and knowing there's a chance this may never happen has me frightened and upset. —C.F.

### DECIDING NOT TO PASS ON CMT

I decided at a young age that I would not pass on my CMT.

I know that I am not strong enough and it would kill me with guilt watching my child in pain and disabled, especially when I know I could have stopped it.

I have been unable to walk for 10 years now and am in a wheelchair. My husband is incredibly supportive and feels the same way I do. We understand that the child could be mildly affected or be even worse than me.

My husband and I started looking into IVF PGD last year. They tried five different tests to establish a test for PGD but we found out two months ago that our genes are too similar to map and we cannot do PGD. They said this is a very rare case and just bad luck.

So now we are about to start trying naturally. We have a plan that at 11 weeks we will have CVS, which takes a week for results. If the test comes back

positive, we will have to abort straight away. I realize that sounds cold but I have to be clinical about this until we get a negative result and can share our happy news with the world. This is an extremely hard decision to make, but we both know that we couldn't live with ourselves knowing we could have avoided unnecessary pain and limitations for our child.

There is a silver lining though. If our first try is positive and we have to abort,

they can use those cells to make a test for PGD. So we could use IVF and PGD with our second try. Of course we are hoping that the dice roll in our favor the first time and we won't have to worry about the bad stuff.

We are not telling many people about our decision as I have found everyone has an opinion and this brings up morals, values and religion.

I know this is going to be extremely hard, carrying a child for 11–12 weeks knowing there is a 50 percent chance it will be aborted. But we want to be parents and we have so much love to give. —S.M.

"There's a lot of waiting in IVF, which takes its toll emotionally."

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## ALLARD PRODUCTS SOON ARRIVING TO THE CMTA STORE!

As a part of our continuous relationship with Allard, the CMTA store will soon offer select accessories from Allard, including replacement straps and pads for the ToeOFF and the Blue Rocker. Prices are below retail, and the items will be shipped directly to you! Visit our store in the Resource Center at [www.cmtausa.org](http://www.cmtausa.org)

*Thank you to everyone who contributed their thoughts and stories about this important topic. This is a small piece of a larger issue that should be discussed, debated and deliberated. These decisions were not without emotional conflict, but ultimately it seems that the choices were made in the best interest of the family.*

—Shawna and Carly

# CMTA NEWSLETTER SUBSCRIPTION, PUBLICATIONS, AND ACCESSORIES ORDER FORM

## SUPPORT GROUP NEWS

(continued from page 16)

### • NM—Albuquerque Area

The group met on May 12th and had seven members in attendance. The group reviewed the latest research presentation and discussed fundraising, emphasizing the challenge ending in June. They also discussed CMT Challenges and Solutions, and much data was added to the database. Once more research is completed, the database will be uploaded to the CMTA so everyone in the worldwide CMT community can benefit from what is there.

### • NY—Westchester Area

The group met on May 4th. They enjoyed a pot luck brunch. They had a nice turnout and focused on discussing fundraising ideas.

### • PA—Ephrata

The meeting on June 8th went well. The group introduced themselves and got to know each other.

### • SD—Hartford Area

There were six members in attendance. Micah, from Orthotics and Prosthetics, served as guest speaker. He talked about Allard, insoles, and various types of bracing. The group discussed BioNess, a nerve stimulator that is put on the knee by a machine that stimulates the nerves. Micah stated that you need to consult a neurologist to ensure this would be beneficial to you because they cost around \$20,000.

### • CAN—Eastern Ontario

The group had a successful first meeting. They had a small turnout but are hoping to have more at the next meeting. They shared stories with each other and looked at many of the CMTA's publications. ★

NAME: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
First MI Last

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

COUNTRY/POSTAL CODE (IF NOT US): \_\_\_\_\_

DAYTIME PHONE: \_\_\_\_\_ EVENING PHONE: \_\_\_\_\_

EMAIL: \_\_\_\_\_

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

JOIN THE CMTA:				
Premium Membership (formerly "Premium Subscription," includes access to more online material and features)	Newsletter Formats (check one or both) <input type="checkbox"/> PDF <input type="checkbox"/> Print	Premium Membership Cost (includes Newsletter): <b>\$30</b>		
	QUANTITY	COST		TOTAL
		Regular Price	Member Price	
The Patients' Guide to Charcot-Marie-Tooth Disorders [Print Format]		\$15	\$12	
The Patients' Guide to Charcot-Marie-Tooth Disorders [CD Format]		\$10	\$8	
CMT Facts IV		\$10	\$8	
CMT Facts V		\$15	\$12	
CMT Facts VI		\$15	\$12	
My Child Has CMT		\$5	\$5	
Teaching Kids about CMT...A Classroom Presentation (DVD/1 hour)		\$10	\$8	
CMTA Titleist Hats Quantity and Color: Blue___ Lt. Blue___ Black___ White___		\$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</b> (Orders under \$10, add \$3.50; orders \$10 and over, add \$7.50)				
<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.

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