

Branch Leader Guide

A Resource Manual



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Foreword

This Resource Manual is a living, breathing document, open to change, discussion and suggestions. If you have ideas or thoughts on how to improve this guide, we would love to hear from you. Please send thoughts and feedback to the CMTA's Director of Community Engagement, Jeana Sweeney - jeana@cmtausa.org.

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Part I - Introduction to CMTA Branches

What Are CMTA Branches?

CMTA branches are mutual self-help groups whose members share stories, experiences and ideas for coping with CMT in an environment of acceptance, empathy and understanding. CMTA branches are valued for their supportive, collaborative and educational aspects, as well as their social and community-building potential. When individuals who share a common experience meet face to face, a world of reciprocal understanding and camaraderie is created. In addition, these meetings pave the way toward personal empowerment by providing a structured forum in which individuals can help and be helped by others, while lifting the burden of isolation.

CMTA branches are not static, but dynamic and vibrant entities, whose members create a unique community of invigorated individuals actively changing the world of CMT, one day at a time. Some of their activities include learning about the CMTA's innovative Strategy to Accelerate Research initiative (STAR), spreading CMT awareness, creating synergy to improve the lives of everyone with CMT and fundraising for much-needed treatments for all types of CMT.

The participation of local professionals who are familiar with CMT is strongly encouraged. Most CMT-savvy experts are more than willing to donate their time and knowledge to educate members about their particular CMT-related specialty. Branch members, the real experts on the disorder, may in turn end up enlightening presenters about the various and distinctive symptoms and challenges of living with CMT.

Leader Requirements

You do not have to be an expert in the field of CMT, nor do you have to be trained in leading groups. The most essential requirements are motivation, a certain time commitment, genuine people skills and sincere dedication to the group and its members. We do ask that you understand, at a basic level, the CMTA's STAR initiative, participate in our annual September CMT Awareness Month, take part in our bi-monthly leader calls, and carry out one fundraiser per year. Remember, you will not be all alone in taking on these endeavors; the CMTA is here to help out.

Recognizing the intrinsic value of our branches, which make a tangible difference in the lives of everyone in the CMT community, we take a very active role in reaching out to them, assisting our leaders and co-leaders, getting them off to a good start and maintaining their success over time.

Thanks to the persistence and determination of so many wonderful leaders across the United States and Canada, hope and optimism for a world without CMT is at hand. Each one of us can and does make a difference, so let's strengthen our roots and multiply. As Margaret Mead once said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

We are very excited to have you on board and look forward to working with you!

Part II - Starting a CMTA Branch: The Basics

Materials Box

You will receive a box of CMTA branch materials. Please keep one of each item for yourself. Many of the included materials can be handed out free of charge to your members, but others are salable items for display only. The display items may be purchased from the CMTA's on-line store at www.cmtausa.org/store/. Please familiarize yourself with all CMTA materials once you have received the box. If you have any questions, contact your regional branch manager.

Choose a Venue

One of the first orders of business is finding a meeting place. Libraries, hospitals, clinics, municipal buildings or your local church/religious facility may allocate rooms for non-profit organizations at no charge. Please make sure that the building is spacious, easy-to-reach, has adequate parking and is handicapped accessible. If the facility asks for a 501c(3) letter authenticating the CMTA's non-profit status, your regional branch manager can provide one.

Set a Date and Time

Once you have a location, choose the date of your first meeting, giving yourself and the CMTA at least **six weeks** to prepare and publicize the meeting. Most groups meet on Saturdays or Sundays, either morning or afternoon, as it is more convenient for working adults and parents with kids to free up time on a weekend.

Frequency and Duration

We ask that our leaders have meetings approximately two hours in duration *at least* three times a year. Many groups meet quarterly and schedule extra time for relaxed summer picnics or holiday get-togethers. Others meet almost every month. As coordinator and leader/co-leader of the group, setting the frequency of the meetings is entirely up to you, based on your schedule and availability. Often, presenters will take up the majority of those two hours, especially when time is allowed for a question-and-answer period, but try to leave 10-15 minutes at the beginning and end for updates, ceremonial activities, branch business and social time.

Many branches meet at regularly scheduled intervals, while others prefer the flexibility to accommodate speakers with busy schedules. Whatever approach you take, at the end of each gathering, try to let attendees know the date or the tentative date of the next meeting. This allows your members to plan ahead and integrate the meetings into their

schedules. When planning meetings, remember to be cognizant of religious holidays and special events like Super Bowl Sunday and Mother's Day.

Signs

Please put up enough well-placed directional signs to show the way to the meeting room. It can be frustrating and exhausting for your attendees to search for your meeting room or building due to a lack of prominent signs. The easier you make it for your members, the happier your group will be.

Publicity

Once you have secured a room and decided on a definite date and time, please let your branch manager know as soon as possible. This way, we can announce your group to the community. We will also mail your first flyer to everyone in our database who lives within a 60-mile radius of your meeting location. The flyer will include your name and contact information (phone number and email address), as well as the time, date and location of your meeting. (A sample flyer can be found in Part VI – Samples and Examples.) Please provide us with this information at least four to six weeks in advance of your meeting to allow for preparation of the flyers and to give enough advance notice to people who may be interested in attending.

You may also want to be proactive by getting your new meeting information in a local newspaper or by putting up flyers in key locations like physicians' offices, prosthetic and orthotic offices, shoe stores or other public facilities serving individuals with CMT. If your meeting location is a hospital, check the hospital's website to see if it has a list of support groups that meet there. If so, contact the hospital's website administrator to get your group added to the website.

Lastly, we can now create ads on Facebook to promote two of your events per year (one meeting and one fundraiser).

First Meeting

The main purpose of your first meeting is to bring people with CMT and their families together to meet you and others living with CMT. In addition to asking everyone to introduce him/herself, this is a great time to ask your group members what they expect from future meetings, what topics interest them most, their ideas for speakers and how they plan on participating in the overall functioning of the group. If you are worried about not having enough materials for the first meeting, you may find it helpful to review some of the pertinent CMTA handouts with your members. Do that and you will have more than enough to discuss at your first meeting.

Member Involvement: Share the Workload

One of the keys to leading a long-lasting, cohesive branch is learning to delegate tasks and getting members involved in any and all ways possible. Realistically, one person cannot and should not bear the entire weight of the branch. By making the group “their branch” as opposed to “your branch,” you are empowering your members to be active participants in a dynamic and growing entity.

*Coming together is a beginning.
Keeping together is progress.
Working together is success.*

~Henry Ford

From the beginning, get your members involved by asking for help with small tasks like making photocopies, setting up the room and getting snacks or drinks, etc. We cannot stress just how important it is to find a way to make your members feel included, needed and integrated in the group, however big or small. By asking members to help out with fundraisers, awareness campaigns, grassroots efforts and organizing meetings, you are not only creating lasting bonds, but also forming a solid and cohesive CMTA community. (For more on the benefits of working together, please see “Lessons from the Geese” in the Appendix or follow this link: [www.aikentdc.org/Lessons From The Geese.pdf](http://www.aikentdc.org/Lessons_From_The_Geese.pdf).)

Promoting Participation

Here are a few ways to get your members involved with your CMTA branch and to promote individual participation.

Call Your Members

One of the best ways to connect with potential new members and to reconnect with regular or former members is to pick up the phone and give them a call. Upon request, your regional branch manager will provide you with a list of people from the CMTA’s database who live in your area.

If you call a brand new person, first tell that person who you are and who you represent (CMTA). Give the time, date, location and speaker information for the upcoming meeting. Talk up the meetings, share your vision for the group and provide reasons why you think this person would enjoy attending your branch meeting. Don’t forget to ask a few questions about the person you are speaking to and give that person time to talk about him/herself. Take notes so you can refer back to details when you meet up in the future.

If you call a regular member, mention just how much his/her participation means to you and to the group, and encourage him/her to attend the next meeting. If you can do all this with genuine enthusiasm, you are bound to have great attendance at your meetings.

After a few meetings, you might consider creating a phone tree, whereby you ask others to participate in calling people to tell them about the upcoming meeting or just to check in. This is just another way to create community and build strong relationships while making individuals feel valued and appreciated.

Appoint a Co-Leader

A co-leader works hand-in-hand with the leader, sharing responsibilities and tasks to keep the group running smoothly. Each leader brings a different set of skills to the table, making the group diverse and interesting for the participants. (Spouses are discouraged from becoming co-leaders.) *To avoid burnout, we strongly encourage you to find a co-leader who can help you with branch planning and duties. This should be someone on whom you can rely to take on some group undertakings, or even the entire meeting, if you need a break, become ill or go on vacation.* Important note about co-leaders: If you have someone you would like to become your co-leader, make sure they go through the branch leader approval process before you add their bio to your branch page.

Reach Out to the Community

Ask someone to be responsible for getting the meeting information into local papers and distributing and posting flyers in the community. Media possibilities include, but are not limited to, radio spots, TV coverage and published articles on CMT-related subjects. Community outreach volunteers can also publicize fundraising events.

Keep Members' Information Current

Put someone in charge of your member database. Have him or her add new member information and modify information about existing members. Also ask this volunteer to encourage members to join the branch on the CMTA website. With access to the member database, a branch secretary could also serve as the branch treasurer, keeping track of money at fundraisers and other events.

Greet New Members

A greeter welcomes new members to the group and makes them feel comfortable by introducing them to other members and answering questions. The greeter is responsible for name tags and collecting new member contact information. Greeters may also create a skills/contact sheet to collect information that could benefit the CMTA either locally or nationally. Find out for example, if a member has personal contacts who may be interested in helping the CMTA on a local or national level. Also find out if a member

has any expertise that could be useful to the branch or the CMTA, like computer skills, media experience or coordinating large events.

Ceremony – Keep Them Coming Back

–CMTA Branch Co-Leader and Advisory Board member Thomas Meloche

Ceremony adds positive emotional energy to meetings and events, improving the participant engagement. Organizations throw events all the time. Most events can be improved through the application of a small amount of ceremony.

The Ann Arbor Michigan CMTA Branch has the following ceremonial structure for our meetings:

First, we formally open the meeting by reading aloud the parent organization’s mission:

Leader says:

“Hello, my name is (insert name), and I am the leader for this meeting of the Ann Arbor CMTA Branch.

Our mission is 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 is a world without CMT.”

This mission statement is projected on the wall as it is read aloud. It is a simple yet powerful way to open the event. It establishes why everyone is there.

Second, we formalize and structure announcements. Each announcement is projected onto the wall as it is made. Most of the announcements introduce those in attendance to CMTA resources. These are repeated at each meeting and are limited to five minutes. Announcements are important, but quick. Announcements that occur at every meeting include signing-up for the eNewsletter, signing up for membership and identifying the nearest CMTA Center of Excellence.

Third, we formally introduce one branch member to the group and have that member do a short five-minute presentation on him/herself or a topic. At large events with lots of people in attendance, it takes emotional energy to have everyone introduce him/herself to the whole group: It takes too long and names are quickly forgotten. Instead, the facilitator introduces him/herself and one person from the group. The person the facilitator introduces is asked to stand up front and answer a few short questions about him/herself. It is personal and special and now the group as a whole knows one

member a little better. To finish the introductions, everyone in the group is asked to introduce him/herself to a neighbor and to ask the neighbor few questions as they have just seen demonstrated. It takes only a few minutes, but begins to bind the group together.

Fourth, we light a candle. Because the group comes together to raise money to look for treatments and a cure we light a candle to remind us of our hope for the future. The candle reminds people of our long-term goals—treatments and a cure for the disease. The candle sits up front and burns through the rest of the ceremony. Lighting the candle signals the shift in our ceremony to our main speaker.

Fifth, we do the program with our special guest speaker, usually in a Q&A format. The leader gathers questions in advance and asks them of the special guest speaker in a conversational manner. Our speakers are not presenting PowerPoint slides, they are having a conversation. As more of the basic questions are asked and answered, the group itself gets more and more involved in dynamically asking questions of the expert. This tends to be a lot more interesting than just watching a PowerPoint presentation.

Sixth, we officially end the program. We announce it is over, mention that we have snacks and drinks, and encourage people to talk to each other, talk to the expert, and enjoy their time together. We also ask for help cleaning up.

This simple structure matters. The difference in how the event feels is palpable. Try it yourself; discover the power of ceremony.

Organize Informal Group Meetings and Outings

Members often want to meet more than just four times a year. Ask someone to set up informal meetings three to four times a year for those who would like more interaction. Picnics, holiday get-togethers and coffee-shop meetings are all wonderful ways to encourage communication, bonding and friendships among members dealing with similar issues. Another idea is to have outside get-togethers based on common themes (parents with children who have CMT, teens with CMT, family support and CMT, parenting issues, concerned grandparents, etc.).

Serve Refreshments

If your venue permits food and drink, the refreshment coordinator asks members to bring snacks and drinks.

Know CMTA Sponsors and Cultivate Others (www.cmtausa.org/corpsponsors)

Find out if any members would be willing to inquire about corporate sponsorship at their places of work, in the community or among friends and co-workers. The CMTA needs corporate sponsors on many levels within the organization. Corporate sponsors could include local businesses to support your local branch, regional businesses that might want to support regional conferences or events and national businesses whose services improve quality of life for those living with CMT. Every corporate partnership is customized to best fit the needs of the business and the CMT community.

If you have contacts or ideas for corporate sponsors, please contact Jeana Sweeney (jeana@cmtausa.org). She can either lead the discussions with the partners or give you the tools and support to develop those relationships.

Many of you may have fewer branch members than job positions. Start small and either combine the roles, or create the volunteer positions you find most useful in the short term. As your branch grows and expands, you can always add additional roles and responsibilities. Look for and nurture potential new volunteers and helpers. If you know that a certain individual would be a perfect fit for a particular volunteer position, don't hesitate to ask him or her privately, in person, by phone or email.

Each position can be filled by one person or by several people if the job is too intimidating for one individual. At first, ask members to sign up for a one-year commitment. If after a year, that individual wants to continue in the chosen role, great. If not, suggest that the person find a replacement when he/she chooses to move on. And don't forget to acknowledge your helpers often and publicly for their time and effort. A nod of appreciation goes a long, long way.

Contact Information Sheet (www.cmtausa.org/leader-toolbox)

At the beginning of the first meeting, don't forget to get everyone's contact information (name, phone, address and email) and *make sure you can read everyone's handwriting before they go home!* (See Part VI – Samples and Examples for a form you can use.) If your branch members agree to share their contact information with other members, offer to send the master list, including names, phone numbers, addresses and emails to every member of the branch. As new members join, update the contact information list to keep it current. This will allow relationships to grow outside of meeting hours and can provide for carpooling opportunities as well. Your regional branch manager will ask you for your member list on a semi-annual basis (January and June). Also ask your members to join your branch on the CMTA website.

Professional Resource List

Please collect the names of local professionals (PTs, OTs, neurologists, physiatrists, orthotists, orthopedic surgeons, etc.) from your members regularly. Before submitting your new resources to the CMTA, please **call** the CMT specialist in question to verify that he/she sees people with CMT. We want to make sure that the CMTA Resource Directory contains CMT-knowledgeable specialists. Please also ask whether they would be willing to give out new patient packets of CMTA information and leave a few “What is CMT” pamphlets in the waiting room.

Then, please send the CMT specialist’s name, medical degree, specialty (including whether the practice is adult, pediatric or both) address, appointment phone number, office email and website to your regional branch manager who will put it on the CMTA website. We will keep a record of who submitted each listing so that if questions arise, we will know who to contact.

This information can then be collected and compiled and sent to your regional branch manager semi-annually (January and June), and he/she will upload it to the CMTA website.

You may also consider creating a resource document for your specific branch with a list of local CMT professionals and businesses. This is a great job for a group member to take on. This resource document may contain:

- All local CMT-savvy medical professionals (podiatrists, physiatrists, neurologists, orthotists, psychopharmacologists, nutritionists, occupational therapists, physical therapists, etc.)
- Shoe stores
- Information and referral agencies’ crisis lines
- Low-cost mental health clinics
- Mechanics trained to retrofit vehicles, making them handicapped accessible
- National websites selling medical supplies and/or gadgets

For a great example, please refer to the Resource Guide for the Washington, DC area (www.cmtausa.org/leader-toolbox). The template for the Resource Guide can also be found in the Leader Toolbox.

Guidelines and Tips for Conducting Meetings

- ★ Keep what is said in the meeting confidential.
- ★ Listen empathetically when others speak. Thank the person for divulging personal information and show support.

- ★ Keep the meeting positive!
- ★ Do not give out medical advice.
- ★ Do not offer individual or group therapy.
- ★ Prevent individuals from monopolizing the group's time. If one individual talks or asks questions non-stop, speak with that person after the meeting. You may want to explain that although the comments, questions and suggestions made are interesting, important, etc., others are not getting the opportunity to participate. Explain that everyone needs time to express concerns and ask the person to try to keep questions and comments to a minimum.
- ★ Always have CMTA information out and available for members to browse.
- ★ From day one, ask group members to help out. Involvement in the group's functioning will not only bring people closer together, but will also make them feel responsible for the overall success of the group. Include your members in group decision-making and always ask for their input.
- ★ Attendance varies from meeting to meeting. Don't become discouraged if only a few people turn up for a meeting from time to time. Turnout varies due to a number of factors: weather, vacations, interest in scheduled speakers, etc. Don't give up!! There will be ups and downs. If you find attendance consistently low, give your regional branch manager a call to brainstorm on how to re-energize your group.
- ★ Please always write hand-written thank you notes to your presenters. Remember, the speakers take time out of their days, often on weekends, to talk to your branch members. This extra sign of gratitude is very much appreciated.

Ideas for Speakers and Presenters

Ask branch members to get involved in finding speakers for your group. It's preferable that the presenter knows about CMT and is familiar with its symptoms and signs. Here are a few ideas for speakers:

- ★ Neurologists
- ★ Orthotists
- ★ Orthopedists
- ★ Occupational therapists
- ★ Psychiatrists (doctors of physical medicine and rehabilitation)
- ★ Podiatrists
- ★ Physical therapists
- ★ Sleep specialists
- ★ Pain management specialists
- ★ Nutritionists
- ★ Social workers

- ★ Psychologists – (some common themes are depression, grief counseling, pain management, children and chronic illness, etc.)
- ★ Humor therapists
- ★ Social Security/Disabilities representatives
- ★ Representatives from CMTA corporate sponsors (www.cmtausa.org/corpsponsors)
- ★ Canine Partners for Life/Guide Dogs of America
- ★ Representatives from the CMTA

If you live close to a CMT Center of Excellence (www.cmtausa.org/coe), get to know the CMT specialist team. Many centers have CMT experts who are more than willing to speak at a branch meeting.

Please be sure to tell members that the speakers are giving information, not advice, and that they should consult their own physicians before undertaking any health management strategies discussed at the meeting.

Meeting Follow-Up

Following your branch meetings, please write a short summary. It should include the name of your branch, the date of the meeting, how many people attended, and what went on at the meeting. If there was a guest speaker, include the presenter's name, topic and main talking points. Try to encapsulate the single most important idea you took away from the meeting in a short, easy-to-understand sentence. You should also write about anything unusual that occurred or about new ideas that your fellow branch members might find useful. Send the summary to your members and **copy your regional branch manager**. Meeting summaries will not only keep your members current, but will also enable us to feature your groups in *The CMTA Report* and share tips and practices with the entire leader community.

Facilitate Connections: The Spinning Wheel

We will send you information on awareness, research news, and patient advocacy efforts throughout the year via email, including the CMTA Quarterly Report. **Please send this information on to your members as we send it to you.** As a CMTA leader or co-leader, you are the representative and voice of the organization throughout the community. In order for movement, action, and reciprocity to take place, the hub (the CMTA) needs spokes (its leaders) to communicate to the rim (CMTA members) regularly and in a timely fashion. When we send you news, share the love with your members. Keep them updated, involved, and hopeful. They will appreciate your efforts and communications, as will everyone at the CMTA.



The Art of Fundraising

The CMTA is fortunate to have many generous donors and devoted members who sincerely want to make a difference by supporting the CMTA's mission and goals. Within your branch and broader community, you will find generous donors, passionate fundraisers, and strong advocates for CMT awareness. This section of the Branch Leader Guide will provide an overview of the different aspects of fundraising. Please refer to the CMTA's supplemental fundraising guide for detailed approaches and tools for executing successful fundraisers (www.cmtausa.org/leader-toolbox)

Why Is Fundraising Important?

Simply stated, without funds, the CMTA and all of the benefits that it provides to our participants would not exist. What does the CMTA offer the community and its members?

- Articles, educational information and current research news
- The Ask-the-Expert Q & A forum
- Awareness Month activities
- Bi-annual Patient/Family Conferences
- Branch meetings
- A directory of CMT clinicians and Centers of Excellence

- The CMTA Report
- An emotional support group
- Friendly staff members who answer calls and advocate for you
- Fundraising opportunities
- Social media forums
- A state-of-the-art website
- Updated news about the CMTA community through eNews
- Webinars

Perhaps most importantly, the CMTA relies heavily upon the financial support of the CMT community to fund cutting-edge CMT research under the banner of STAR (Strategy to Accelerate Research). STAR is alive and strong because of our volunteers, members and supporters! If every person living with CMT in America were to give annually to the CMTA, we could dramatically accelerate the pace of research. That's why it's so important that branch leaders make a commitment to lead and promote fundraising efforts through their branches and communities.

Fundraisers can be big or small. Every dollar counts! The possibilities are endless. Let your mind wander, and you will be surprised what you come up with!

Leader Giving

We encourage you to give to the CMTA on an annual basis, whatever amount is appropriate for you. Again, the amount of the contribution is less important than the act of giving, which will motivate you and also signal to others your higher commitment and investment in the CMTA.

Participant Giving

It is important that our participants understand why fundraising is so critical to the CMTA (see "Why is fundraising important?" above). Contributions not only keep the CMTA running, they also provide the CMTA and its branch leaders a vote of confidence in its programs and services and allow the participants to lead by example when asking their own networks for support of awareness and fundraising initiatives. Just like leader giving, the amount of the contribution is less important than the act of giving and being invested in the CMTA at some level.

Fundraising Events

First and foremost, there are no bad fundraisers. Keep in mind that you will get better at fundraising with experience. The prospect of planning a fundraiser may sound intimidating, but it's not a sink-or-swim situation. Your regional branch manager will help

ensure your success. We have a lot of experience with fundraisers, and we can help you with every aspect—from planning to executing to promoting your event.

Leader Commitment: One Fundraiser per Year

Aside from the obvious benefit of raising money, fundraisers are also uniquely effective at raising awareness of CMT, a little-known disease. Consider the fact that CMT and multiple sclerosis have approximately the same incidence—one in 2,500 people. But hardly anyone has ever heard of CMT. It's time to change this discrepancy in awareness by providing a method to raise funds from people outside of the CMT community. Your successful fundraiser will motivate branch participants to tackle their own fundraisers. And before you know it, more and more people will catch the fundraising bug.

Community Fundraising: The sky is the limit with our Community Fundraising Pages, which are loosely structured fundraisers that can occur at any time of year. Community fundraisers give you the opportunity to be really creative and plan a fundraiser based on an interest that you are passionate about. Remember, this is a blank canvas, and can include anything, like:

- Birthday wishes
- Graduations
- Weddings
- Retirement parties
- Holidays (ask for contributions in your name instead of gifts)
- Just Because!

For more information on fundraising, go to www.cmtausa.org/fundraising or contact your regional branch manager.

All-Star Events

The CMTA All-Star Events can occur at any time of the year. Choose the format that is most appealing to you: Walk4CMT, Cycle4CMT or Swim4CMT. These events, which are held nationwide, bring the entire community together to raise awareness and critical funds for CMT research. The All-Star Events tend to follow a more structured process for fundraising, but they are also an opportunity for creativity. For a detailed booklet on how to structure a successful All-Star event, check out our All-Star Guide:

www.cmtausa.org/leader-toolbox. A Sample Press Release is included in the Samples and Examples section (Part VI) to use in publicizing your All-Star event in local newspapers or other media outlets.

"Easy as Pie" Fundraising

It doesn't get much easier than these fundraisers. If you shop online, you can help: Don't miss the opportunity to have a portion of the sale proceeds go to the CMTA. EVERYONE in the CMT community should participate in these fundraising opportunities, so please reiterate to your branch participants and network the importance of helping with these programs.

- **Sign up for I-give.** It's fast, simple and free. Go to www.igive.com/cmta. Every time you shop through igive.com, the CMTA will receive a percentage of your purchase.
- **Use Amazon Smile.** If you use Amazon, you should definitely sign up for Amazon Smile. Amazon will donate 0.5 percent of your eligible purchases to the CMTA. Simply go to <https://smile.amazon.com/> and type in Charcot-Marie-Tooth Association.
- **Check for Employee Matching Donations.** Does your company donate to non-profits? Many employers offer an employee matching program. To find out if your company does, visit www.doublethedonation.com/cmta.
- **Use E-Scrip.** Sign up with E-Scrip and you can shop online or dine out and earn money for the CMTA. To sign up go to www.escrip.com. Then go to new sign up and find the Charcot-Marie-Tooth Association. For city, put Chicago, then hit search. When the CMTA comes up, choose us and start shopping!
- **Get Kroger Community Rewards.** Everyone needs groceries right? Did you know that every time you shop at Kroger you can earn money for the CMTA? To get started, sign into your Kroger account and select the CMTA as the organization you would like to support. We currently have the Community Rewards set up in Texas (# 94054), Tennessee (#68720) and Georgia (# 79222). We are working on setting up this profitable program in many other states, too. For more information on participating locations and reward numbers, please go to: www.cmtausa.org/leader-toolbox.
- **Use GoodSearch and GoodShop.** GoodShop works with more 5,000 stores, donating a percentage of each purchase to the CMTA. Plus, every time you search they will donate a penny to the CMTA. To sign up go to www.goodsearch.com and choose the Charcot-Marie-Tooth Association as your charity!

Other Business

The CMTA will make business cards for you with your contact information as well as the address and phone number of the CMTA. These cards also display the CMTA STAR logo and colors. If you are interested in getting business cards, please ask your regional branch manager.

CMTA Membership

As a CMTA branch leader/co-leader you will receive free membership to the CMTA that includes CMTA materials, *The CMTA Report*, discounts on CMTA store products and much more.

As a branch leader we ask that you encourage each of your members to become a paid CMTA member. A subscription membership is \$30/year or \$80/3 years. A STAR membership is \$100/year or \$270/3 years.

Why is Membership Important?

Becoming a CMTA member is critical in helping us provide information and resources to ensure people with CMT and their families get answers and the support they need.

Membership dollars allow us to provide things like:

- A CMT support network through our more than 70 local branches with over 3,000 members
- Literature and educational materials
- *The CMTA Report*
- Free monthly webinars
- Tools and resources to help with branch events
- Stipend checks to all branches to help cover costs associated with running a branch
- A recommended CMT clinician list and much more!

Membership offers additional benefits for people with CMT and their families. With your support, the range of services and support we provide will continue to grow each year.

How Do I Join?

To join please visit our website at www.cmtausa.org and click on the Get Involved tab and then on Become a Member. Here is a quick link: www.cmtausa.org/membership. When your membership expires, we will email you and also mail you a renewal form. To renew your membership, simply log into your CMTA account and purchase and choose the renewal option for your membership.

Expenses

The CMTA annually provides branch leaders a small stipend for miscellaneous branch-related expenses. Many branch leaders use this money for general expenses such as mailings, food and beverages, or for special events like holiday parties or picnics. The amount provided is \$50 per meeting, with a maximum limit of \$250/year. In order to be eligible for the stipend money, you must fill out a form that will be provided by your branch manager bi-annually. Please do not charge admission for your meetings. If you decide to advertise your meetings or events, the CMTA may be able to cover some of the associated costs, but please call us in advance to work out the details.

Bi-monthly Conference Calls

We ask all our leaders to participate in bi-monthly leader conference calls to get updates on current CMTA research and activities. The calls are usually scheduled for the second Sunday of every other month at 8:00 p.m. ET. Call-in details will be emailed to you a week prior to the conference call.

September Is CMT Awareness Month

September is CMT Awareness Month! The CMTA counts on its branch leaders and the general CMT community to make an extra effort to spread awareness during that time.

To help you spread awareness, you will receive a box of goodies/handouts. These are meant for you to pass out to your branch members, local businesses and family/friends, so that they too can participate in this call to action ... creating awareness of CMT!

The CMTA will also have a wide range of AM activities on the website and on the social media front. Every year is a little different, so we'll let you know the theme for the upcoming year well in advance. These activities are planned both on a national and international basis.

Branch leaders and other members of the CMT community are also encouraged to contact their governors to ask them to proclaim September as CMT Awareness Month. To find out how YOU can ask your state for a proclamation, go to (www.cmtausa.org/proclamation). Let's shoot for the STARS and get ALL 50 states to issue proclamations!

And, please don't stop spreading CMT awareness at the end of September. Every day provides opportunities to spread awareness of CMT! Together, we can make a significant difference in the lives of many living with CMT.

STAR (Strategy to Accelerate Research)

Please familiarize yourself with our ambitious STAR initiative. For more information about the CMTA's cutting-edge drug discovery initiative, go to: www.cmtausa.org/research.

Part III: The CMTA Website

Registering on the CMTA Website: (www.cmtausa.org)

If you have not yet registered on the CMTA website, you will need to do so. (If you have already registered, please skip to the next paragraph.) To register on the CMTA web site, click on the “Register” button on the top right-hand side of the home page. This will take you to the Registration Page, where you will be asked to fill out a short form with your email address and a username you will pick. A temporary password will be emailed to you that you can use to log in to the website. To log in, go back to the homepage and click “Login” in the upper right corner. You can log in with your username or email address and your temporary password. You can change your password to something easier to remember in the My Account section.

My Account

The sooner you familiarize yourself with the “My Account” section on the site, the better off you will be! To access this section, when you are logged into the site hover over “My Account” in the upper right corner of the homepage and click on “Account Settings.” Here you can edit your account details and manage your events, fundraising pages and more. This is also a fast and easy way to get to your branch page. You should now be looking at “My Dashboard.” Click the blue “View My Branch” button to go straight to your branch page.

Your Branch Page

Your regional manager will create your branch page for you and schedule a call with you to review it. When other community members visit the website and search for a branch, those who live in your vicinity will be directed to your branch page.

Your branch page is an information portal, with information about your branch, your upcoming events and you—the leader! Your branch page also has a space where people can give you their email addresses to sign up for branch news (email updates from you on upcoming meetings, notes, and events). We encourage you to personalize your page and make it your own.

Editing Your Branch Page

Are you ready to start personalizing your page? Great! Scroll to the bottom of your branch page and click the “Edit Listing” button, located right above the map. This button will only be visible when you’re logged in. This is where you can edit your leader bio and photos, change the photo on your page (we recommend a photo of your branch members at a meeting) and add a personal welcome message (the “Listing Excerpt”). Consider including important information about your branch (for example, you meet on

the first Saturday of every month). We also suggest you to use this page to encourage people to sign up for branch news so that they will receive updates about upcoming meetings and events. When you've made your desired changes, be sure to click the "Submit" button at the bottom of the page.

And about the photos you use: The rule is that you should only use a photo if you KNOW you are not infringing the copyright. How do you know?

1. You took the photo, perhaps at one of your branch meetings or fundraisers.
2. You know who took or owns the photo and they gave you permission to use it. Feel free to use CMTA logos or banners.
3. You used photos that are not under copyright, like those licensed through Creative Commons (search.creativecommons.org) or in copyright-free images found online or in collections.

Also, we'd love to use your photos for our informational brochures, appeals and on our website. Please only send high resolution photos to your branch manager. If using an iPhone, choose the "Actual Size" option when you send. Photos must be clear and in focus.

Creating Events

The "Edit Listing" section is also where you'll go if you want to create, edit or view an event for your branch. If you are on your branch page, scroll toward the bottom and click "Edit Listing" above the map. Toward the top of the page, under "Branch Information" is a blue button that says "Create Branch Event." On the branch event creation form, you'll be asked to fill out key details about your event, including whether it's a branch event or branch meeting. If you are creating an event for one of your regular meetings, select "Branch Meeting Notice." If it's another kind of event, like a special outing or fundraiser, select "Branch Event." If you select branch event, you will be able to add tickets. You will also have the opportunity to create a short link for your event, which is useful for posters, flyers, or social media advertisements for your event.

Managing Your Email List

When people sign up for your branch news via your branch page, their email addresses will go into your email registry. To find your email registry, go to your branch page, click on "Edit Listing," and then click on the "Email Registry" tab underneath the heading "Branch Information." This list will automatically update when someone signs up on your branch page. If you collect additional names and email addresses at your meetings, we suggest you add them to your email registry so you will have one master list. Just click the "Add to Registry" button on this page. When you click the button a new line will populate at the top of the list. Click "Enter name" to edit the name and "Enter email" to

enter the new email address. You can also edit any incorrect names or email addresses in the list by clicking on them, or delete people from the list by clicking the “Delete” button to the right of their email addresses.

When you are ready to send an email about your next meeting or event, visit your branch registry and click the “Export” button to download an excel file of the names and emails. Then just copy and paste the email addresses in the “BCC” field of your email client, and in the “To” field put your own email address. This keeps the email list private.

Facebook Group for Your Branch

Facebook groups are a great tool for your branch. They are another way for you to keep in touch with your members and remind them about upcoming meetings and events. The group is an online location where your members can chat, ask questions, post photos, and stay involved with branch goings-on ranch even when you aren’t together in person!

Having a Facebook group for your branch is entirely optional, and you can decide to start one at any time. If you don’t use or like Facebook, a Facebook group may not be for you! Perhaps you have a Facebook-savvy branch member who would like to volunteer to manage the group.

If you do decide you want a Facebook group for your branch, let your regional branch manager know and a member of the CMTA staff will create your new group for you!

If you are interested in starting any other social media accounts (Twitter, Instagram, etc.) under the name of your branch, please speak to your regional branch manager.

CMTA-Sponsored Social Media Accounts

A large following on our social media accounts increases our ability to reach out and spread awareness and demonstrates to large donors and pharmaceutical companies that we have a large, active community that WANTS A TREATMENT!

Please “Like” or “Follow” the CMTA on all of the social media sites you use, and ask your members to do so as well!

- Facebook: www.facebook.com/CMTAssociation
- Twitter: www.twitter.com/CMTASTAR
- Pinterest: www.pinterest.com/CMTAssociation
- LinkedIn: www.linkedin.com/company/2779868

- Instagram: www.instagram.com/cmtausa
- YouTube: www.youtube.com/CMTAssociation

Facebook Groups

- Branch Leader Group: www.facebook.com/groups/CMTALeaders
- CMTA Group: www.facebook.com/groups/CMTAssociation
- CMTA Parents: www.facebook.com/groups/CMTAParents
- CMTAthletes Group: www.facebook.com/groups/cmtathletes
- Youth Group: www.facebook.com/groups/CMTAYouth
- Spanish Group: www.facebook.com/groups/CMTAespanol

Part IV: Leader Facilitation: Problems and Solutions

By David Tannenbaum, LCSW, CMTA Advisory Board Member

What Is the Difference Between Therapy and Group Support?

Therapy has more to do with observing the reactions people have with other group members and helping them see how they appear to others, which inevitably reflects how individuals get along with people outside the group. Group support, although certainly therapeutic, deals with finding support, safety and love with others who are taking a journey similar to yours and understand firsthand what you might be experiencing. In building this kind of community, you are less isolated and become empowered by the knowledge shared by other members.

The Importance of Community

Several longevity studies have found significant connections between longevity and community. Each branch is a small community in which members can openly discuss the emotions that emerge in dealing with the personal challenges of CMT. Members might not be comfortable talking to their loved ones about these issues. Just because someone is in a relationship doesn't mean that they are talking about what is painful. In fact, their loved ones' reactions to their CMT might be the very issue that needs to be expressed. The branch meeting gives members the opportunity to discuss the emotional challenges within their own families in a safe and nurturing environment.

CMTA Leaders: Qualities, Skills and Understanding

Adept at Listening

Effective leaders listen much more than they speak. They need to know when to listen, how to concentrate on what the speaker is saying, how to minimize their own internal dialogue and how to remember what's been said. Because leaders are models of behavior, the better they listen, the better their members will listen.

Skilled at Communication

When branch leaders speak, their words are noted, both because they don't speak a lot and because of their role in the group. Whether you are comfortable or not with the role of "expert," the role of leader will put you in that position with your group members. It helps to speak plainly, clearly and pointedly. Express feelings as well as thoughts. Be comfortable communicating with all parts of yourself in addition to the spoken word.

Accepting

The importance of a leader being real with the group can't be overstated. It's only when a leader feels free to be himself or herself that group members will feel free to be themselves. If any participants are hiding, withholding or role-playing, group members will not reach the deeper levels of acceptance where they can really trust and support one another. The leader leads the way, not by doing, but by being.

Present

A group feels important and empowered when its leader is fully present. Such leaders bring all aspects of themselves—body, mind, heart and soul—to the experience. They center themselves before the meeting begins, then stay centered throughout the meeting. If their attention starts to drift, they know how to bring themselves back to the moment.

Energetic

Centered leaders bring their own energy and enthusiasm to the group experience. They don't expect the group to energize them, nor do they feel responsible for energizing the group. They take responsibility for their own preparation and look forward to what can happen during the meeting.

Observant

Skilled branch leaders are all eyes and ears, taking in all they can from all participants: what their faces say, what their bodies disclose, and what their inflections reveal. They notice patterns of interaction between individuals and the group as a whole. They also pick up on what people don't say or do.

Co-Leadership: Benefits and Challenges

Generally speaking, two heads are better than one and co-leadership can benefit the leaders, as well as the group members.

Conserving Energy

Facilitating groups can be tiring. Co-leadership provides diversity in voices, presentation styles and energy levels, which can serve to hold the attention of the group while giving each leader time to shine and time to rest.

Maximizing Diverse Resources

No one, regardless of how skilled, knows everything. Working as a team allows each person to contribute his or her gifts, talents and resources.

Capitalizing on Strengths

Co-leadership allows one person to speak while the other observes and supports his/her partner. Partners can share the material in a way that lets them capitalize on individual strengths and have their own moments in the spotlight.

Providing Mutual Support

Anyone can have an "off" day. Perhaps your energy is low or you are preoccupied with something in your personal life. Co-leaders can bring balance to the team. When one leader is off, the other will usually be on. If the co-leaders' behavior is supportive and collaborative, it can also serve as a model for the way participants behave towards one another.

Useful Tips for Working with Leadership Partners

Get to know each other and do what it takes to build healthy, authentic relationships in which honest and compassionate feedback is welcomed and differences are worked through in healthy ways. The relationship you develop as co-leaders will be a silent and tangible teaching model for your group.

Discuss each other's styles of planning and facilitating and share each other's triggers. Verbalize what you feel you are best at and what you are most challenged by.

Talk about whether it is okay to interrupt each other. Decide how to keep track of time. Plan ways to give signals to one another. Strategize how to keep to the original outline and how to switch gears. Divide facilitation of activities fairly. Agree on how to share responsibilities in preparing and bringing up workshop materials and resources. Agree to arrive at the group meeting in time to set up and check in before the group begins. Schedule time after the meeting to debrief.

During the meeting, particularly during a break, check in with one another. Sharing the subtleties of what you see and experience can be invaluable to making corrections and inspiring innovations that can contribute to the health of the group. Support and validate one another and use a lot of eye contact.

Include your co-leader even when you are leading a discussion, for example by asking "Do you have anything to add?" Assert yourself if your co-leader is talking too much and take the initiative to step in if your co-leader misses an opportunity to address something.

Embracing or pointing out a mistake that was made, if done in a gentle way, can actually be an invaluable teaching opportunity if the mistake relates to the context of what you

are discussing. The willingness to admit and look at your mistakes does wonders for bolstering the group's trust in you.

Dealing with Anger

In general, the leader must act as a custodian of the group objectives. As a leader, you are faced with some difficult decisions when your group arrives at a place where anger is being directed from one member to another. Generally, the best course is to use the opportunity to remind members of the central importance of cohesion and support. If issues of anger arise, show the group how to deal with them.

This is generally called the constructive expression of anger, which involves talking about anger rather than being openly angry with someone. It's a way of identifying anger in order to resolve it and get free of it. Remember that anger is just the surface emotion. Fear and pain usually lie underneath anger. It's generally a richer emotional experience to get in touch with those two deep-seated feelings.

Dealing with Silences

Silences are not threatening if they are seen as an alternative way of being together. It can be relaxing to experience silences in a group where trust and tolerance have developed. The members may be just taking time to look at themselves, while drawing on the companionship of the group. However, it is also the role of the leader to judge whether the silences are "good silences" or whether they are motivated by tension, resentment, confusion or some other problem. The group might finish one person's material and might not know what to do next. Sometimes angry outbursts may cause tension. If the members seem stuck, tense or unsure, then from the point of view of preserving safety, it is best for the facilitator to help out by saying something like, "Everybody seems very absorbed in thought. Let's try to make an effort to surface these thoughts and share them with the group" or "I just want to check in with you about what is going on. We've been silent for several minutes."

Before you intervene, check your own motive. Is the silence making you tense, and is it your need to end it? If so, what is bothering you about the silence? Are you being overprotective? Perhaps, in trying to make the group a success, it's hard for you to give the group space to have quiet periods. Don't rush to take over a silence. Silences are normal and reflective of productive group behavior, especially if they lead to useful exchanges. Your aim is to help the group use and tolerate silences. Intervene only when you think silence is putting a member's essential sense of safety at risk or when you feel that the silence is, for negative reasons, going nowhere and could be turned into a useful opportunity for teaching the group more effective behavior.

Leader Self-Care

Leader self-care concerns how we take care of ourselves while leading and taking responsibility for a CMTA branch. Leading these groups is an enormous task that can bring great joy, but may also cause psychological and emotional strains. An effective leader needs to be prepared to be exposed to a wide arrange of emotions from group members. Some of what is brought up in group can touch very close to home, especially if CMT is a challenge in your own life. Having a place to process your own responses to what comes up in group is of the utmost importance. This can be a good friend or another leader who understands what you might be experiencing. Although most members of the group will be grateful for the work you do, there will always be members who provoke feelings of inadequacy. There will always be members who express dissatisfaction, regardless of what happens in the group. Keep in mind at those times that it is not your responsibility to make everyone feel good. These groups are formed around self-help models, and the group shares in the responsibility of helping all its members feel at home. This is another good reason to try to co-facilitate whenever possible.

Group members will often put you in the role of "expert." That is a responsibility you don't want to take on because it simply puts too much pressure on you. You are not responsible for having all the answers, but you can certainly be of help in finding out whom to ask.

Managing the Dominators

The group leader cannot be shy in dealing with dominators in a group. Those who speak too much need active help, first from you and ultimately from the group, to gain a more realistic picture of their effect on others so they can modify their behavior.

Let's say your group members are bonding well. Everyone is engaging in conversation and everyone seems to be enjoying the meetings. But then a new person joins the discussion and starts dominating the conversation. No matter what topic is discussed or what question is asked, this person shares his/her opinion for five, 10, or 20 minutes and no one else can get a word in. Even worse, when someone else starts to answer a question, the dominating person jumps in and talks louder until the first person gives up. At first, it is not a big deal, but after several meetings, some members are clearly getting annoyed.

There are usually understandable reasons for the talker's behavior. Are the interruptions occurring near the start of the meeting? Do they occur in a group with strong tension? Some people talk too much when they are anxious, but regardless of the cause, they are hurting the group. The health of the whole group should be the facilitator's first priority, and one way to make a group feel safer is to take a strong lead.

There are a number of methods for dealing with dominators. First, before each discussion, set the stage by announcing that you would like everyone to share, if possible, and ask the group members to try to limit their sharing to no more than a minute or two. When the dominant personality starts talking, and inevitably goes over the time limit, wait for that person to catch his/her breath or maybe just slow down a bit and say, "That's a really good point." Immediately look at another person in the group, direct your hand toward him/her and ask, "What do you think?" or "What do others think?" Get others involved in the conversation.

If the dominant person interrupts someone who had started to share, hold a hand up and say loudly, "Sorry, XXX, so-and-so was talking first." Then, turn to the person who was interrupted, direct your hand toward him/her and say "Now, what were you saying?"

Another technique that I have found helpful is using your body to direct the discussion. Try standing or turning your body by facing each person who shares. If you face away from the dominators, they can't get your attention. And if they start talking when you're facing away from them, don't turn to face them. When it is their turn to share, face them for a reasonable time and then turn and face someone else in the group, asking "What do you think?"

You can also try humor, but be careful to challenge the behavior rather than the individual. Humor is less likely to be useful than an explicit approach, but it may be appropriate in some groups, particularly where there is a limited capacity or willingness to think about process. You can sometimes use humor with individuals, particularly when your signals to speak have been ignored.

Sometimes, it may be necessary to have a private chat with the dominating person after the meeting, and speak to him/her in a gentle and loving way and say, "I know you have good ideas and you really want to share them, but we need to get everyone involved in the discussion. Please help me get other people talking and sharing in the group by letting at least five people share before you do. That should encourage others to share. It will also help give them some responsibility for the success of the group as a whole."

If that person has been interrupting others, you might add, "You may not have known you were doing this, but you interrupted several people who were talking before you." Usually, the talker will recognize these traits in himself/herself, and your conversation will help that individual realize when he/she is talking too much. It will also get the person thinking about how to involve others. Again, the key here is to talk to the dominator in a gentle way and try to avoid hurt feelings as much as possible.

If the dominating behavior continues after you've tried these ideas and you have spoken with the dominating person privately, continue to divert the conversation away from him/her during that meeting and have another private conversation with him/her, giving a reminder of your earlier conversation and again asking for help and cooperation.

Although the ultimate task is to quiet the person down so that others can speak, the above suggestions are only a stopgap. These techniques may be helpful in the short term, but they will not change the underlying issue of what makes a person speak so much. The dominating person is more than likely to repeat the pattern. If you continue to be the only one to stop the individual from talking, the group is likely to become less free in its responses, in general. The whole group needs to be involved and if your members continue to leave the issue for you alone to deal with, investigate further by becoming curious about why that is.

Overall, dominance is one of the toughest issues for most group leaders. These methods take practice, so don't be discouraged if you don't master them immediately. Each time you practice them, you will become more comfortable and more empowered to look out for the health of the group as a whole.

Depression

We all go through ups and downs in our moods. Sadness is a normal reaction to life's struggles, setbacks and disappointments. Depression is much more than sadness, though. Some people describe depression as "living in a black hole" or "having a feeling of impending doom." However, depression doesn't always manifest as sadness. Some people may feel lifeless, empty or apathetic. Men in particular may even feel angry, aggressive and restless. Depression is different than normal sadness in that it engulfs your day-to-day life, interfering with your ability to work, study, eat, sleep and have fun. The feelings of helplessness, hopelessness and worthlessness are intense and unrelenting, with little if any relief. Symptoms of depression include: inability to sleep or sleeping too much, inability to concentrate, finding previously easy tasks difficult, feeling hopeless and helpless, inability to control negative thoughts, loss of appetite or overeating, irritability, being more short-tempered than usual, consuming more alcohol or engaging in reckless behavior, having thoughts that life is not worth living and self-loathing.

When to Suggest Individual Counseling

Some branch members may appear depressed and seem to take up much of the group's time. Although they receive support from the group, they often give the impression that it is not enough. If allowed to continue, these members can drain the group's energy.

Experiencing periods of depression is not unusual when trying to manage a physical disability: We all go through a grief process as we cope with losses of function. However, if the depression lasts for more than several weeks, affecting work or personal relationships, professional help may be needed. The branch model may not be sufficient for the clinically depressed member, so it is a good idea to recognize the symptoms of depression and not be shy in taking the member aside to gently suggest that private counseling could be extremely helpful. The leader must always keep in mind the needs of the group as a whole.

Suicidal Members

As a branch leader, you may feel helpless and scared when a member expresses suicidal thoughts to you individually or in the group. This rarely happens, but when it does, it can be overwhelming. Keep in mind that many people occasionally have these thoughts, but they are often a symptom of depression and more often than not will pass on their own. If the group member has made the effort to attend the group, you can view this as a plea for help. All comments pertaining to suicide should be taken seriously. Take the time at the end of the group to talk individually to the member and ask a few questions to find out a bit more information about the seriousness of his/her intent. Remember: As a branch leader, you are not a mental health professional, so please do not take on this responsibility alone. Gently inform the member that as much as you would like to help, you are not professionally equipped to provide the necessary help and strongly suggest professional help. Keep a list of counselors and contact information for community health clinics with sliding scale fees. You might need to be firm with a member who insists on speaking only with you. Don't be shy or feel guilty in directing this person to a mental health professional. It is in both your best interests.

Suicide Warning Signs

- Excessive sadness or moodiness
- Long lasting sadness, mood swings and unexpected rage
- Hopelessness: Feeling a deep sense of hopelessness about the future, with little expectation that circumstances can improve
- Sleep problems
- Sudden calmness: Suddenly becoming calm after a period of depression or moodiness may indicate that a person has made a decision to end his or her life.
- Withdrawal: Choosing to be alone and avoiding friends or social activities also are possible symptoms of depression, a leading cause of suicide. This includes the loss of interest or pleasure in activities the person previously enjoyed.
- Changes in personality or appearance: A person who is considering suicide might exhibit a change in attitude or behavior such as speaking with unusual speed or slowness. In addition, the person might suddenly become less concerned about his or her appearance.

- Dangerous or self-harmful behavior: Potentially dangerous behavior such as reckless driving, engaging in unsafe sex and increased use of drugs and or alcohol might indicate that the person no longer values his or her life.
- Recent trauma or life crisis: A major life crisis might trigger a suicide attempt. Crises include the death of a loved one or pet, divorce or breakup of a relationship, diagnosis of a major illness, loss of a job or serious financial problems.
- Making preparations: Often a person considering suicide will begin to put his or her personal affairs in order. This might include visiting friends and family members, giving away personal possessions, making a will or cleaning up his or her room. Some people will write a note before committing suicide; some will buy a firearm or other means like poison.
- Threatening suicide: From 50 to 75 percent of those considering suicide will give someone like a friend or a relative a warning sign. However, not everyone who is considering suicide will say so, and not everyone who threatens suicide will follow through with it. Again, every threat of suicide should be taken seriously. In summary, many of these feelings are experienced occasionally by many of us, but it is the consistency and severity of the feelings that indicate suicidal behavior.

Personal Boundaries for Group Leaders

Occasionally, a group member will latch on to the group leader because of a sense of isolation. This person might be so grateful for the kindness of the group facilitator that he/she will cross some personal boundaries and desire more contact than the group has to offer. Keep in mind that group leaders can help in connecting members to one another, but they are not responsible for "fixing" members' personal problems. The message that a leader doesn't have to be "friends" with a branch member is usually conveyed without words. Try to suggest, in a friendly way, that as much as you would like to be of help, you are not a professional counselor. Suggest that it might be worth bringing up these issues in group and have a few referrals to local therapists on hand. Most communities have a mental health clinic with sliding scale fees. This is one way to protect yourself from "burnout" as a group leader. Having strong boundaries and protecting your own time is extremely important. Most leaders and many health professionals have a hard time saying no or disappointing others, but these are skills worth learning to protect your own mental health.

Part V – Who’s Who at the CMTA?

Amy J. Gray – Chief Executive Officer (agray@cmtausa.org)

Amy brings to the CMTA more than 17 years of management experience in national voluntary health agencies, combined with a strong understanding of mission-driven organizations. Her experiences working for three major non-profit health care organizations—the National Parkinson Foundation (NPF), the Crohn’s and Colitis Foundation of America and the Muscular Dystrophy Association—have shaped her expertise in fundraising, staff development, financial and operational management, strategic planning and community engagement.

Gray was most recently the senior vice president of constituent and community relations for the NPF, responsible for providing the overall leadership, strategy and vision for the foundation’s fundraising efforts, planned giving legacy society and network of chapters. Gray is a graduate of St. Cloud State University in Minnesota and lives in South Florida with her husband and children.

Michelle Hayes – National Branch and Community Relations Manager (michelle@cmtausa.org)

Michelle is the National Manager of Branch and Community Relations for the CMTA. She oversees and is the primary point of contact for more than 73 CMTA branches across the United States. With years of experience in peer-to-peer coaching and customer service, Michelle fuels the growth of the branch network by providing resources, support and strategy to the CMTA’s branch leaders. In her role, Michelle supports patients and families diagnosed with CMT and provides hope and direction to those newly diagnosed.

Additionally, Michelle is a key player in the CMTA’s fundraising efforts. A former business owner, Michelle jumpstarts local fundraisers with creativity and initiative, developing strategies to promote revenue growth and training volunteers in fundraising strategy and management.

Michelle lives in Dallas, Texas with her husband, Sean, and their three children. Her son Carter has CMT Type 2.

Kim Magee – Director of Finance (kim@cmtausa.org)

Kim handles all donations, questions regarding donations, official documents and membership. Kim can be reached at: 1-800-606-2682, ext. 105.

Frank Gaidjunas – Director of Marketing and Communications (frank@cmtausa.org)

Frank has joined the CMTA after 20+ years successfully leading important programs and initiatives in the CPG (Consumer Products Goods) industry. In his new role at the CMTA, he is responsible for overseeing the marketing, communications, and public relations strategies and activities of the organization to ensure delivery of the highest quality mission services to the CMT community.

As a person with CMT, Frank is passionate about the work of the CMTA and wants to help deliver its vision of a world without CMT. He has a strong appreciation for the magnitude of the research, community services and fundraising activities that are required to both manage and cure this disease.

Frank lives in the Chicago area with his wife and two children. He likes to swim, bike and take in the local music scene.

Andi Cosby – National Events Manager (andi@cmtausa.org)

Andi has joined the CMTA to spearhead the Walk 4 CMT, as well as build out additional fundraising events. Andi has more than 15 years of management experience in national voluntary health agencies both on the local and national levels.

Before coming to the CMTA, Andi served in leadership roles at the Crohn's and Colitis Foundation and the Leukemia and Lymphoma Society. Cosby is a graduate of Truman State University in Missouri and lives in Old Greenwich, Connecticut with her husband and three children.

Leslie Nagel – Marketing Coordinator (leslie@cmtausa.org)

As Marketing Coordinator, Leslie manages the planning, execution, maintenance and performance of the CMTA's digital presence as well as other marketing and communication platforms.

With a background in digital marketing, writing and relationship-building, Leslie is passionate about making the CMTA's voice strong through effective communication, analytical problem-solving and teamwork. As someone with a close relationship to CMT, Leslie is thrilled to have the opportunity to work for this cause and community that are close to her heart.

Leslie lives in Michigan and enjoys biking, reading and throwing dinner parties.

Jeana Sweeney – Director of Community Engagement (jeana@cmtausa.org)

Jeana Sweeney, a natural relationship builder, specializes in connecting the community with initiatives and resources at the CMTA. As the Director of Community Engagement, she oversees and creates educational programs, including patient and family conferences, webinars and community outreach events. Co-director of Camp Footprint and manager of the national branch system, Jeana crafts the vision and programming that brings the CMTA into your home.

A dedicated, passionate leader and communicator, Jeana brings to her role over two decades of experience in community services. With a heart for patients, Jeana spearheaded and continues to develop the Walk 4 CMT program, plans our Awareness Month activities and organizes national fundraising events.

Jeana wants every person with CMT to have the answers, support and resources they deserve!

Part VI – Samples and Examples

Sample Press Release

For immediate release

For more information, contact: [xxxbranchleader, be sure to give email and phone]

Xxx CMTA Branch
Announces All-Star xxx for CMT

(Placexxx)—The xx Branch of the Charcot-Marie-Tooth Association (CMTA) announced [xxxdate] that it will hold a [xxxWalk/Run/Swim] 4CMT on [xxxdate] at [xxxplace].

The [Walk/Run/Swim] is one of dozens of All-Star Events being held nationwide to mark CMT Awareness Month, which takes place each September. Charcot-Marie-Tooth is a progressive disorder of the peripheral nerves that causes people to lose the normal use of their feet, legs and hands. CMT affects some 2.8 million people of all races and ethnicities worldwide, though many of them are misdiagnosed or not diagnosed at all. Raising awareness about CMT is particularly important given that so many people are unaware that they have the disease.

CMT symptoms include: Foot deformity (very high arched feet) and foot drop (inability to hold foot horizontal); a slapping gait (feet slap on the floor when walking because of foot drop); loss of muscle in the lower legs, leading to skinny calves; numbness in the feet; and difficulty with balance. Hands and arms may also be affected. CMT is not fatal, but it is currently incurable.

The CMTA is a patient-led association that is aggressively searching for a treatment for CMT, putting together a group of top-flight researchers and experts and directly funding their work. The CMTA launched the Strategy to Accelerate Research, or STAR, in 2008 to capitalize on breakthroughs in genetics and dramatically speed up the pace of CMT research. Since then, the CMTA's STAR Initiative has made great strides toward developing treatments for CMT.

For more information about CMT, please visit www.cmtausa.org.

Sample Meeting Sign-in Sheet

This is an abbreviated version of a sign-in sheet. The full version may be downloaded as a Word document or Excel spreadsheet here: www.cmtausa.org/leader-toolbox.

Meeting Sign-In Sheet

Leader: _____
Place/Room: _____

Date: _____
Time: _____

PRINT NAME	ADDRESS	PHONE	EMAIL	OTHER
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

Sample Branch Flyer

Please Join Us for the Inaugural Meeting of the

Austin, TX CMTA Branch
Thursday, December 2nd from 6:15 p.m. to 8 p.m
Spicewood Springs Library
8637 Spicewood Springs Rd
Austin, TX 78759

The Austin, TX CMTA Branch is for all those who have Charcot-Marie-Tooth disease and their families. The first meeting will focus on getting acquainted and deciding on topics and speakers for future meetings. You'll also meet others in your area who have CMT and be able to share resources, ideas, CMT-related information and personal experiences.

Our meetings will center around CMT education, awareness, research updates, fundraising, advocacy, current events and will include occasional guest speakers.

If you would like information about future meetings or plan to attend please RSVP to Nate Halk at halk@mac.com or call 512-415-6097 or Michele Gonzalez at michelegonzalez@hotmail.com or call 512-626-1275.

Hope to see you there!

Visit www.cmtausa.org to join this branch online.



Appendix – “Lessons from the Geese” – Effective Teamwork

Lessons From The Geese

by Dr. Robert McNeish

(People with disabilities, parents, staff, businesses, etc., all need to work together. Synergy is the concept that when we all work together the end result is greater than if each of us acts independently. There's a great deal to be learned from the teamwork shown in Lessons from the Geese.)



As each goose flaps its wings, it creates an "uplift" for the bird following. By flying in a "V" formation, the whole flock adds 71% more flying range than if each bird flew alone.

Lesson: People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the thrust of one another.

Whenever a goose falls out of formation, it suddenly feels the drag and resistance of trying to fly alone, and quickly gets back into formation to take advantage of the "lifting power" of the bird immediately in front.

Lesson: If we have as much sense as a goose, we will join in formations with those who are headed where we want to go

When the lead goose gets tired, it rotates back into the formation and another goose flies at the point position.

Lesson: It pays to take turns doing the hard tasks and sharing leadership – with people, as with geese, interdependent with one other.

The geese in formation honk from behind to encourage those up front to keep up their speed.

Lesson: We need to make sure our honking from behind is encouraging - not something less helpful.

When a goose gets sick or wounded or shot down, two geese drop out of formation and follow their fellow member down to help provide protection. They stay with this member of the flock until he or she is either able to fly again or dies. Then they launch out on their own, with another formation, or catch up with their own flock.

Lesson: If we have as much sense as the geese, we'll stand by each other like that.

Lessons from the Geese, was written in 1972 by Dr. Robert McNeish of Baltimore. Dr. McNeish, for many years a science teacher before he became involved in school administration, had been intrigued with observing geese for years and first wrote the piece for a sermon he delivered in his church.

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