

Successful Support Groups (KITs or Keep In Touch Groups)

And How to Make Them Happen

Led by Marianne Moyer

(At TMA's Annual Patient Conference, September 14, 2012, in Orlando FL)

Table of contents

Topic or item	Page Number
Table of contents	1
Overview of session	2
Handout: Tips on starting a Myositis KIT-Keep In Touch Support Group	3-4
Handout: Growing your KIT	5-6
Handout: Speaker Suggestions	7
List of Brainstorming questions	8
Brainstorming 1: What is the purpose of a KIT or Support Group?	9
Brainstorming 2: Why do we need KITs?	10
Brainstorming 3: Why do people come to (or back to) KIT meetings?	11
Brainstorming 4: Why don't people come to (or back to) KIT meetings?	12
Brainstorming 5: What is the role of the KIT leadership?	13
Brainstorming 6: What is TMA's role in KITs?	14
Conclusions	15

Successful Support Groups (KITs) and How to Make Them Happen

This conference session was a workshop for people who self-identified as being in one of three groups:

Group 1	Group 2	Group 3
<p>My KIT/Group Needs some Help</p> <ul style="list-style-type: none"> • Irregular meetings • Falling attendance • No newsletter • Leaders struggling • No new members lately 	<p>My KIT/Group Works Pretty Well</p> <ul style="list-style-type: none"> • Regular meetings • Consistent attendance • Newsletter • Gets new members • Leaders are doing 'ok' • Not perfect- always looking to improve 	<p>There is no KIT/Group Active in my area</p> <ul style="list-style-type: none"> • Nearest group >100 miles away • No one willing to be leader • Don't know where to start • Need a mentor

All groups participated in a discussion to identify answers to some of the issues that leaders of support groups face. We provided our input to six brainstorming questions. (See pages 9-12)

After we addressed the six areas, the groups had some time to discuss them. Group 2 which included leaders and participants of several successful KITs were split to join the discussions with Groups 1 and 3. This provided the people who either are interested in beginning a KIT or those whose groups are facing challenges of growth and member participation, with input from those who may have already overcome those challenges.

We circulated a sign-up sheet for those who would like to have another leader as a mentor to them. It also included spaces for those who are willing to be a mentor. As a follow-up to this session, Marianne will put each of the requestors in touch with someone who volunteered to help.

The second sign-up was for those who want electronic copies of the handouts which addressed three areas (and are included at the end of this document).

1. Tips on starting a Myositis KIT-Keep In Touch Support Group – ten suggestions that MAY be used to initiate a new support group. All suggestions are just that; suggestions.
2. Ideas to “Grow” Your KIT – once a KIT is started, it’s sometimes hard to keep it going at its original rate so this document shares some ideas to help maintain the excitement.
3. Speaker suggestions – one way to keep the enthusiasm of members at a high level is to make sure the meetings provide them with value. Good speakers are an easy way to do that. This list is just a start; but it can help with inexpensive meeting topics.

Tips on starting a Myositis KIT-Keep In Touch Support Group
These are ten suggestions that may be modified to meet the needs of the group

Convene three to six people interested in forming and leading the group. Topics to cover might include:

1. Where the group will meet—this is usually a conference facility that is:
 - a. Free of any charges (hospitals, libraries, and churches are a good place to start). The one disadvantage to churches is that they tend to ‘bump’ outside groups if their congregation needs the space
 - b. Able to provide total handicapped accessibility. This means parking lots, halls and elevators, restrooms and the meeting room
 - c. Willing to schedule several months (or even a year) in advance so that you can plan to have your meetings on a regular schedule
 - d. Easy to find, near a major intersection or landmark, or via GPS
 - e. Near a facility where you can purchase food or snacks for the meeting (this is optional)
 - f. As close as possible to the majority of potential members. Note that if a person perceives that they will get value from attending, they are more likely to be willing to drive two or more hours to attend.

2. When the group will meet—usually three or four times a year on a regular schedule:
 - a. Saturdays are usually the best, around lunch time. This allows working folks to attend.
 - b. Allow at least three hours:
 - i. One hour for a speaker or topic of the day
 - ii. One hour for either breakouts by disease or a general discussion for all
 - iii. One hour for lunch, socializing and announcements

3. How to handle finances—especially if you plan to have a lunch or snacks
 - a. Some KITs order the food based on people who made reservations to attend and this requires charging a nominal amount like \$15/person or \$25/couple
 - b. Some KITs ask you to bring your own food
 - c. There are other expenses to be covered: nametags, handouts, etc.
 - d. Some KITs open a checking account for this purpose
 - e. TMA will provide up to \$200 per year to help defray reasonable expenses

4. How communications will be handled—usually e-mail for the majority
 - a. The group should receive at least four e-mails a year, announcing the next meeting.
 - b. This is also a good way to provide a summary of what happened at the last meeting so that those who missed it can still feel ‘in the loop’.
 - c. Someone must be accountable to contact those who don’t have e-mail; phone calls or snail mail must be made in a timely fashion.
 - d. Members must be asked to not use KIT mailing lists for any purpose except the KIT.

5. How responsibilities will be split—you need a person or persons to be accountable for:
 - a. Being the group leader (two people are recommended). They will:
 - i. Be listed on TMA’s website as the contact(s) for the group
 - ii. Communicate with TMA on the group’s activities
 - iii. Coordinate as appropriate with other KITs
 - b. Arranging for the meeting space for each meeting (room set up, cleanup, etc.)
 - c. Maintaining the list of members (name and contact information)
 - d. Arranging for speakers or selecting a topic for discussion. This is important so that there is value in attending and the meeting is not just a free-for-all discussion.
 - e. Communicating with the group (see #4 above)
 - f. Preparing and distributing news releases for meetings, Myositis Awareness Day, etc.
 - g. Ensuring that meetings are entered onto TMA’s events calendar. This should be done right after each meeting.
 - h. Deciding on food and ordering
 - i. Maintaining records of finances
 - j. Miscellaneous duties that can include doorprizes, speaker gifts, signage, etc.
6. Some other things you may want to consider;
 - a. Cards to send to members who are sick or have other problems that prevent their attending. Send these around at a meeting so everyone can write a greeting.
 - b. Writing a welcome page for TMA’s website, for your KIT
 - c. Social committee to handle things like a holiday party
 - d. Some KITs have a team to provide beverages for the meetings
 - e. Some KITs have a team to provide desserts for the meetings
 - f. Having a photographer to record special events and to take each member’s picture (one KIT uses this for when they send around a card for someone, in order to remind people of who the members are.
7. If regularly scheduled meetings are not possible, plan an alternative like a conference call which TMA can set up for you. If you do this, be sure the call has a specific topic to address and that someone is willing to be moderator to keep the call on track.
8. Ask TMA to connect your group’s leaders with another KIT leader who can mentor you through any challenges that arise.
9. Be sure to ‘share the load’. It’s important that whether the leader has myositis or is a family member, that they not become overwhelmed with these duties. This is a fun job if you have others to share it.
10. Don’t hesitate to call on TMA if you have questions or concerns. Once the new Member Services Manager is in place, s/he will be able to guide you through whatever you need to make your group a success.

Ideas to “Grow” Your KIT

Most newspapers have a section on community meetings or health happenings. E-mail to the paper at least two weeks before the meeting, basic information: meeting name, time, date, place and room. Include a contact name and phone number. Additional helpful information includes parking, cost if there is one, speaker or topic and something that lets everyone know they are welcome.

Post a meeting notice in local senior centers.

Post a meeting notice in your doctor’s office.

Be sure your welcome page on TMA’s website is truly welcoming. Go to the Colorado’s group page with a zip code of 80207. Or SW FL with zip 34209.

Use TMA info cards to remind all your doctors of your KIT’s existence. If he or she refers someone, be sure to thank them.

Tell your doctors’ nurses, physician assistants and office managers about your KIT. Leave TMA brochures and your cards with them.

Be sure to follow up with new members who join via TMA.

If you haven’t heard from someone in a while, call, e-mail or send a card to them.

Hold awareness events on Myositis Awareness Day. This may generate press, radio or TV coverage. If you don’t want to hold an event, use MAD as a reason to contact the media and propose an article.

If you meet in a hospital, ask their PR office to issue a press release. They get credit for doing this sort of community service.

When you hold your meeting, place signs all around the building so people see the word ‘Myositis’.

Send an invitation to the meeting via e-mail about 30 days before the meeting. For non-computer users, send the same invitation via snail mail. Keep an accurate list of your members.

After the meeting, be sure to follow up with a newsletter or report on what happened. Send this to all members so they know what they missed. Hopefully this will also inspire them to want to come to future meetings.

Ensure that members get some sort of communication from the KIT at least four times each year. This goes for active members and those you’ve never seen.

Keep in touch with TMA, sending updates on KIT leader information, activities, newsletters, etc.

Consider an annual party apart from regular meetings. Examples would be a summer picnic, holiday luncheon or 'field trip' to a local research facility or even an evening out.

Create a "New Member Welcome Package" with info about your KIT, contacts and resources like TMA's website and forum. It will make people feel part of your group and encourage them to return.

Other ideas: (this space was for participants to help one another with new ideas)

Speaker Suggestions for KIT meetings

- Rheumatologist
- Neurologist
- A good source for a specialist if you can't find one to speak to your group is to go to TMA's website for Medical Advisory Board members. Go to www.myositis.org. You may need to negotiate with the doctor or TMA regarding how their expenses will be covered.
- Dermatologist
- Physical Therapist
- Speech Therapist mainly to address dysphagia
- Pulmonologist
- Travel Agent conversant with disabled travel requirements
- Red Cross to address if a disaster occurs, how disabled must plan to go to shelters
- IVIG providers like Walgreen's
- Financial Planners to address how to plan for eventual needs
- Estate Planners to ensure paperwork is in order
- Equipment providers to address canes, walkers, wheelchairs, scooters, and when you need them
- Real Estate agent to talk about preparing your home for sale if you plan to move to assisted care
- Assisted Care Facility representative to address how to plan when you may need them
- Family counselor to address caregiver and emotional aspects
- Pain management specialist
- Home repair person to address how to modify your home for grab bars, ramps, etc.
- Acupuncturist and other alternative methods of treatment like herbal aids
- Nutritionist
- Group discussion after annual conference to tell those unable to attend, what they missed
- Session about on-line services like TMA's website, Facebook, GoodSearch, etc.
- Someone to address stress reduction (could be a shrink or doc or?)
- Someone to address depression both for patients and caregivers
- Caregiver network group representative
- MDA representative to discuss what they do to support myositis patients
- VA representative to discuss benefits
- Art or music therapist
- Yoga and meditation

Brainstorming Sheets About KIT Leadership

1. What is the purpose of a KIT or Support Group?
2. Why do we need KITs?
3. Why do people come to or back to KIT meetings?
4. Why don't people come to or back to KIT meetings?
5. What is the role of the KIT leadership?
6. What is TMA's role in KITs?

(At the bottom of each sheet are some comments from Marianne which supplement or explain the bullet items).

What is the purpose of a KIT or Support Group?

- **Provides emotional support to members and their families**
- **There is transfer of information between speakers and attendees**
- **Members and families have a chance to share what is important to them**
- It provides for a uniting of the three myositis disease groups
- Meetings help us humanize our disease
- Attendees can brainstorm ideas and activities
- **Patients and caregivers can receive practical tips for dealing with myositis**
- KITs may participate in fundraising for their KIT or for TMA
- **KITs can raise awareness in their community about myositis diseases**
- We can participate in lobbying efforts locally and nationally
- **Members can enjoy socializing and fellowship**

Comments:

I have '**bolded**' the text of the suggestions that seem to be the most important. All support groups have slightly different goals and it's up to that group to decide where their priorities lie.

Here is just a word about 'fundraising'. It is not a primary goal of KITs to fundraise for TMA. They may however want to consider efforts to raise money for their group so that they can fund speakers' expenses, special meals, parties or other activities. There are a number of easy and successful ideas that other KITs are willing to share. If your group wants to fundraise for TMA, either for the general benefit of the organization or for a special area like PM, DM or IBM research, this can be a fulfilling and uniting effort. Again, there are other KITs who can provide suggestions on what has worked (and not worked) for them.

Contact TMA or look over the information on the website, under KIT Leaders.

Why do we need KITs?

- **Participating in a KIT combats the feeling of aloneness**
- At a KIT meeting our feelings can be validated
- We can help to raise our doctors' awareness of these diseases
- KIT meetings can be inspiring
- Members can leave a meeting with a feeling of self-value and self-worth
- KITs can provide members with a view of the future of myositis
- There is strength in numbers
- **KITs are a great source of education**

Comments:

I have '**bolded**' the text of the suggestions that seem to be the most important. Actually, I could have bolded all these bullets. I'll comment more on these areas on subsequent pages.

The important bullet which says that KITs combat the feeling of 'aloneness', has been proven over and over. Almost every time a first-time member attends a meeting, they say they have never spoken to another myositis patient. They felt alone. But at the end of the meeting, they can say they know others who relate to their feelings. This also encourages members to make contact with one another, outside the KIT meetings.

Finding out about myositis is not just getting technical medical information. It includes finding aids that others use in their daily challenges. Everything from scooters and walkers to the best kind of protein shake are the kinds of things members are happy to share and are a vital link in our efforts to help each other.

Why do people come to or back to KIT meetings?

- They come to be with their KIT friends who become their KIT family
- KIT meetings provide a feeling of “belonging”
- Members can feel they are really ‘understood’
- **There is great ‘value received’ from most meetings**
- People actually listen and talk with one another
- We learn acceptance of one another and our caregivers
- **There is support for our caregivers**
- We can ask the hard questions
- We can effect change
- **There is an opportunity to share feelings**
- **They learned something**

Comments:

I have **‘bolded’** the text of the suggestions that seem to be the most important.

Our KIT has proven, and I’ve heard from other successful groups, that there are two main benefits people want from their meetings and these are the last two bullets. People want to be able to share what they are experiencing, both as patients and as caregivers. Also, they want to learn something. Learning doesn’t necessarily have to be about myositis per se. It can be about nutrition, travel, humor, or other topics that will make our lives better. It’s about providing value to them.

When a KIT member starts describing their group as a ‘family’ you will know your group is a success.

Why don't people come to, or back to KIT meetings?

- **As patients get weaker or sicker, travel becomes difficult, especially by car**
- One or two people may dominate the meeting (or conference call) and this discourages others
- If the meeting is more than a few hours away, the distance becomes very difficult
- Patients, either newly-diagnosed or longer-term, may be in some form of denial about their disease
- **Meetings that aren't well planned can be boring**
- Patients in remission feel they don't need the group anymore
- Some meetings can become just a social hour
- Logistics like room layout, parking, and restrooms can be a problem
- Meetings may be depressing if patients fear they may become like others whose disease is more advanced
- **There is no follow-up for new members**
- There is poor leadership of the group

Comments:

I have '**bolded**' the text of the suggestions that seem to be the most important. This is a difficult area to address and is not meant to be a criticism of leaders whose groups are struggling. There is not much we can do about patients who decide not to attend for reasons of increasing weakness or attitudinal decisions. However, we as the leadership of KITs, should do all in our power to avoid providing a meeting that is not valuable. Allowing one or two people to dominate discussions, poor logistics and lack of follow-up should not be allowed to occur. If these problems plague your group, find another KIT leader who can mentor your group to prevent further erosion of your membership.

Follow-up is very important. When a new member joins and/or attends, they should receive some form of follow-up either via e-mail, phone or card, welcoming them to the group and letting them know you are glad they joined. It should also provide them information on TMA and where they can go for more information.

The last bullet, poor leadership is most often a function of leaders who are overwhelmed and need help. Fixing this is relatively easy if the leader(s) will just ask for others to become involved. We don't need to ask for new "leaders"; we need to ask for more leadership.

What is the role of the KIT leadership?

- **Communicating with:**
 - **Members**
 - **TMA**
 - **Other leaders**
- **Facilitating meetings**
- **Listening to what members want to see, do and hear**
- **Polling members for their input**
- **Be encouraging; and a cheerleader to the group**
- Outreach and awareness advocate in the community
- Networking

Comments:

I have **'bolded'** the text of the suggestions that seem to be the most important.

I believe communicating with members is the most crucial role of the leadership. The key term here is "leadership" and not just 'leaders'. Many leaders in the past have felt that the one or two people who agreed to 'lead' their group had to do everything. This is not so; and in fact can be the downfall of the group. Each KIT needs at least three or four people to be the leadership of the group, sharing duties and filling in for one another when conditions warrant. Refer to the handout "Tips on Starting a Myositis KIT" on page 3 and 4 of this document, for a list of some duties that can be spread between your group's leaders.

A newsletter does not have to be professionally created. A simple letter with a few paragraphs about what happened at the last meeting and what to expect at the next one, plus any news of note, can be created and sent via e-mail or snail mail. All members should receive some sort of communications, at least four times a year. This lets them know they really are a part of your group.

Listening to what your members have to say about meetings, activities and communications is crucial to ensuring your KIT is responsive to members' needs. Simple comment sheets after meetings or one or two questions at the end of a newsletter can let members know the leadership is interested in providing the best quality group experience possible.

In addition, ensuring that your leadership keeps TMA informed of your activities is another way to recruit new members. TMA will then help steer new members to the KITs.

What is TMA's role in KITs?

- **Help leaders find speakers and suggested meeting topics**
- Giving leaders and members hope
- **Providing a potential member list**
- Producing and delivering media contacts and help
- Communicating medical updates including trials and studies
- Helping with funding
- Lobbying for us
- **Keeping in Touch with other group leaders**
- **Providing website access that is user friendly for people to access**
- **Providing ways for KITs to post on TMA's website**

Comments:

I have '**bolded**' the text of the suggestions that seem to be the most important.

Speaker suggestions are included as one of the handouts from this session and are on page 7.

When TMA receives information about a new member, they will notify that KIT's leaders to contact the individual. When KITs receive new members, they should also suggest to that person that they should join TMA too.

TMA's website is under revision now and KIT leaders must currently ask TMA to update their information for us. This process is currently under review and may change over time.

Conclusions

This conference session brought together a diverse group of leadership and potential leadership of one of the most vital of TMA's members, the KITs. KIT stands for Keeping in Touch and conveys the primary purpose of our support groups. Having a myositis disease can be very lonely and our groups strive to provide a connection between members and TMA.

Traditionally KIT leaders were the one or two people who took on the entire task of starting and maintaining their group. Often that person had a myositis disease and as they became sicker or weaker, running the KIT became a burden instead of a joy. As a result, the KIT met less often or had less valuable meetings. Others were reluctant to step up to help because they did not want to find themselves in the same position of 'failing' in the future.

It's easy to prevent this! A group of people who are willing to split duties and step in for one another can make a support group not only succeed but thrive. It takes some communications, sometimes some suggestions from other KIT leaders, and a lot of faith that this can work.

I wish all KIT leadership, both current and future, the joy that I have felt in being part of my KIT's leadership. And if there is anyone out there who wants to be a part of continuing this discussion, I invite you to contact me.

Thank you,

Marianne Moyer

Marianne.moyer@verizon.net

September 17, 2012