

**Successful Support Groups (KITs or Keep In Touch Groups)  
And How to Make Them Happen  
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**Tips for a Myositis KIT-Keep In Touch Support Group  
Ten tips to start or re-energize a group**

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

- Where the group will meet—this is usually a conference facility that is:
- 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
- Able to provide total handicapped accessibility. This means parking lots, halls and elevators, restrooms and the meeting room
- Willing to schedule several months (or even a year) in advance so that you can plan to have your meetings on a regular schedule
- Easy to find, near a major intersection or landmark, or via GPS
- Near a facility where you can purchase food or snacks for the meeting (this is optional)
- 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.

When the group will meet—usually three or four times a year on a regular schedule:

- Allow at least three hours:
  - One hour for a speaker or topic of the day
  - One hour for either breakouts by disease or a general discussion for all
  - One hour for lunch, socializing and announcements

How to handle finances—especially if you plan to have a lunch or snacks

- 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
  - Some KITs ask you to bring your own food
  - There are other expenses to be covered: nametags, handouts, etc.
  - Some KITs open a checking account for this purpose
  - TMA will provide up to \$200 per year to help defray reasonable expenses
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- 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.

How responsibilities will be split—you need a person or persons to be accountable for:

- Being the group leader (two people are recommended). They will:
  - Be listed on TMA's website as the contact(s) for the group
  - Communicate with TMA on the group's activities
  - Coordinate as appropriate with other KITs
  - Arrange for meeting space for meetings (set up, clean up, etc.)
  - Maintain a list of members with contact info
- 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.
- Communicating with the group (see #4 above)
- Preparing and distributing news releases for meetings, Myositis Awareness Day, etc.
- Ensuring that meetings are entered onto TMA's events calendar. This should be done right after each meeting.
- Deciding on food and ordering
- Maintaining records of finances
- Miscellaneous duties that can include doorprizes, speaker gifts, signage, etc.

Some other things to consider;

- 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.
- Writing a welcome page for TMA's website, for your KIT
- Social committee to handle things like a holiday party
- Some KITs have a team to provide beverages for the meetings
- Some KITs have a team to provide desserts for the meetings
- Having a photographer to record special events and to take members' picture (one KIT uses this when they send around a card for someone, to remind people of who the members are.)
- How communications will be handled—usually e-mail for the majority
  - The group should receive at least four e-mails a year, announcing the next meeting.
  - 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'.
  - 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.
  - Members must be asked to not use KIT mailing lists for any purpose except the KIT.
- Ask TMA to connect your group's leaders with another KIT leader who can mentor you through any challenges that arise. (Talk about Mentor Program here).
- 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.
- **Don't hesitate to call on TMA if you have questions or concerns.**

## **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, contact name and phone number. Try to include parking, cost if there is one, speaker or topic.

Post a meeting notice in local senior centers and your doctorss offices.

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.

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, 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 a 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.

## 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](http://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

## **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
- 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
- Caregiver support

## **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
- They can share doctor and other resource information
- They feel they get special attention
- They can get their questions answered (an anonymous question box is a good idea)
- Members share information about trials and other medical information

## **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

## **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
- Provide structure and consistency for members
- Letting members know what to expect (calendar, speakers, etc.)
- Delegating tasks to spread the work load



## **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

**What Alternatives Are There to KIT Support Groups?**  
**(New topic)**