

MPN SUPPORT GROUP GUIDE



FOR PEER FACILITATED LOCAL GROUPS



COMMUNITY FOR PEOPLE LIVING WITH A MYELOPROLIFERATIVE NEOPLASM

Dear MPN Support Group Coordinator,

The compassion and support MPN patients share with one another is truly remarkable. Over the past 13 years, I have worked with local peer-led MPN support groups, helped patients create new groups, and I lead a group in Michigan. I have experienced the encouragement, frustrations, small wins, and big losses with many courageous people. I'm humbled to be part of this community.

While people are living many decades with an MPN diagnosis, newly diagnosed patients continue to receive misinformation. Social media, grassroots outreach and educational programs often provide better information than the standard Google search.

Yet, there is something special about the in-person connection. That is why peer-facilitated local MPN Support Groups will remain an important part of the patient experience. We need both. Providing an intimate, safe place for patients and caregivers to share their experiences, ask for help, or simply listen, has been invaluable.



Our local support group coordinators are as varied as the MPN symptoms. Many are diagnosed with a MPN and others have the support/caregiver role of a MPN patient. Still others work in the blood cancer or MPN field and share their skills with MPN patients and their families in this special way. All are volunteers who share their time, energy and resources to help foster a sense of community among people living with MPN.

At a gathering of MPN Support Group Coordinators in September, 2016, we discussed the value of sharing ideas and best practices of our support groups. This is the first edition of the MPN Support Group Guide. A special thanks to Marina Sampanes Peed for taking on this assignment. She co-leads the Greater Atlanta MPN Support Group and remains active in the MPN community since her successful Stem Cell Transplant in 2013. Marina joined our small but mighty team at MPN Advocacy & Education International and has proven to be a great and positive force.

This guide includes the fundamentals of creating a peer-led support group and many best practices shared by seasoned support group coordinators from several countries. I'm sure you will pick up an idea or two to add to your support group toolbox. There is something for everyone here.

Please remember: as a support group leader you have a solemn obligation to protect the privacy of the people who join the support group. Some have not shared the information with their employers, neighbors, friends, or even family. Additionally, there are laws that govern the protection and privacy of patients. Together, we strengthen the community for people living with a Myeloproliferative Neoplasm.

Thank you for your continued stewardship.

Ann Brazeau, CEO

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What is a Peer Support Group?



Let's start with a few definitions:

Peer: a person who is of equal standing with another in a group.

Peer Support: a deep understanding and empathy through shared experiences; to listen with compassion and without judgment, to connect with another who “gets it”.

Peer Support Group: It is a system of giving and receiving support, information, and guidance founded on principles of respect, shared responsibility, and mutual agreement.

Talking to people with the same questions and challenges helps; learning from others who have lived with the health issue helps a lot.

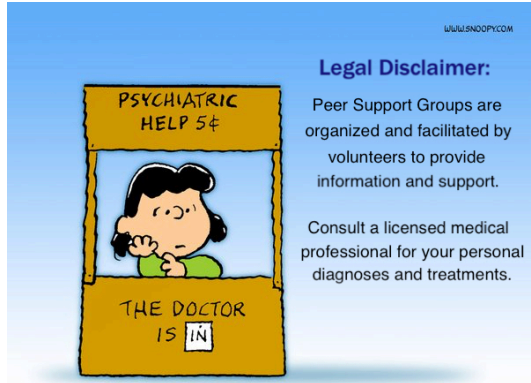
Purpose

MPN Support Groups offer the latest information, MPN education, and encouragement for people living with MPN. Patients and their loved ones meet others living with the same disease in a supportive, positive environment. *These groups do not provide therapeutic counseling or patient-specific diagnoses nor licensed medical advice.* There is no fee to the participants.

Coordinated by volunteers (often patients or allies), support includes:

- Sharing the latest (professionally vetted) discoveries and treatments
- Guest speakers to share helpful information
- Connect MPN patients and their primary support to others for mutual support
- Coping & self-advocacy strategies
- Emotional and moral support
- Sharing resources





Participant Benefits of Support Groups

Recent studies demonstrate significant value to patients participating in support groups related to their specific illness. Essential Thrombocythemia, Polycythemia Vera, and Myelofibrosis, behave differently among the people with the diagnoses.

As “rare diseases” most hematologists do not have a large MPN patient population; this hinders local knowledge of the variations of symptoms and signs

experienced by MPN patients. Patients benefit from learning more about the disease and coping strategies from other patients.

Here are just some of the benefits of MPN Support Groups:

- 1) Reduce feelings of isolation by joining a caring MPN patient community & social networks
- 2) Improve sense of confidence and empowerment in how you live with the MPN
- 3) Learn more about the illness from expert speakers and ask questions (outside a medical setting)
- 4) Get practical advice and information about living with a MPN and the signs & symptoms
- 5) Improve your coping skills and confidence in living with the MPN
- 6) Talk openly and honestly about your thoughts and feelings about how your life has changed with people who live with MPNs
- 7) Improve your self-advocacy with your medical care team, insurance, family by learning from others who have gone through similar challenges
- 8) Reduce distress, anxiety, depression by sharing, listening, learning, and receiving support from others who live with MPNs
- 9) Feel affirmed by others who “get it”
- 10) Encourage and support others who are going through similar issues
- 11) Laugh with other MPNers at the crazy things the illness brings

Who Can Participate

Most MPN Support Groups in the United States are open to all people living with a Myeloproliferative neoplasm (Essential Thrombocythemia, Polycythemia Vera, Myelofibrosis) either as a patient or a direct care giver/loved one of the patient. Given the rarity of these diseases, support groups include members of all ages, genders, and experiences with the diseases.

In larger groups, it may be possible to create special time or space that is specifically focused:

- Gender specific
- Age-specific
- Just for patients, just for caregivers / family, or a combination
- By diagnosis (PV, ET, MF, going through stem cell transplant)

Recruiting Members

There are many ways to create a new MPN Support Group in your local community. Do what works for you. We all have special skills, talents, and interests. Ask someone to help you will strategies that you'd like to implement but are outside your comfort zone. Here are some suggestions:



1. Find another MPN person to help get the group started, if possible. It's helpful (and more fun) to work on this with a small team. More ideas, more contacts, more hands to do the work.
2. Create a flyer or cards with the name of your Support Group (typically "city/region MPN Support Group" or "MPN Support Group of city/region") and an invitation to contact you for more information. Include your name, contact info.
3. Distribute the cards and flyers to blood cancer patient serving organizations, including hematologists, hospitals, infusion clinics, Leukemia & Lymphoma Society local chapter, Cancer Community Support, American Cancer Society local chapters, etc.
4. Use your personal Social Media accounts (e.g., Facebook, LinkedIn, Google+) to announce your new MPN Support Group and invite people to contact you and learn more. Invite people to "share" your news with others.
5. Create a social media group on Facebook, Google Groups or Yahoo! Groups as a means for members to share information, pose questions, etc.

Name your "Group" with the city/region in the group name so it can be easily found during a search.

When creating a Group page, you must decide on privacy settings. In Facebook, for example, decide whether it will be “Public” “Closed” or “Secret.”

Public Facebook Group: Some local groups are set up as “Public” and use the page simply for announcements and sharing the latest news and on-line resources. Anyone can see the group, its members and their posts.

Closed Facebook Group: Most MPN groups are set up as “Closed” groups. Anyone can find the group and see who’s in it. Only members can see posts. This means that one must ask to “join” the group. Administrator(s) can interact with the requestors to screen out non-MPN population and prevent marketers and insurance companies from checking out the people who visit the page. This requires more action on the part of Administrators.

Secret Facebook Group: Only members can find the group and see posts. We are not aware of any MPN support groups using this category.

A few comments about Facebook:

- Do not rely on Facebook solely as your marketing plan. Many people are not on Facebook or do not check it frequently.
- Some people create a pseudonym Facebook account for the purposes of masking their identity from employers, insurers, marketers, etc. on social media. They may let you know that when they choose to join the group.

Start small. Word of mouth is powerful in the MPN community. The experience, how people feel during the interaction, is important to building a welcoming, thriving support group.

Adding New Members

MPN patients and caregivers may find you through a variety of ways, depending on the outreach you do. For example, each Coordinator’s contact info is posted on the website of MPN Advocacy & Education International and others. Hematology offices may also refer MPN patients to a local group. Leave our MPN booklets with the offices and be sure your contact information is included, (there is space on the back of the booklets to place a sticker with your contact information).

Remember that this is a shocking and confusing diagnosis. Anything you can do to paint a picture of understanding and support can ease anxiety.

Here are some suggestions for welcoming new members:

- When contacted by a new patient, listen to their story and the questions they have. When were they diagnosed and by whom? Current treatment, how they are feeling.
- Describe your support group, when and how meetings are run.

- Clarify any financial aspects of the meetings. For example, if meetings are held at restaurants are meal purchases required? Is there a cost for parking? Is it a potluck?
- Invite them to join your support group social media group (e.g., if you have a Facebook page).
- With their permission, you can post a “join me in welcoming Polly Vera to the group. Polly, when you are ready, please share a bit about yourself” to the page.
- Offer to connect them with a member of the group whom you believe will be a helpful contact. Always ask for permission to share their name and information first.

Administration / Management

Create a contact list for your support group. Remember to keep it updated. When a member dies, his/her loved one often requests to have their email removed from the list. Sometimes a spouse/partner/parent/adult child of someone with a MPN will join the group. The key information you need:

- Name
- Is this person the MPN Patient? Relationship to patient?
- Email address
- Phone
- Diagnosis / Diagnoses of patient
- Address (at least city or general geography)

Email Tip:

An easy way to do emails is with the free service by MailChimp (in the US).

<https://mailchimp.com/>

Once you add your contacts to your free account, they can “unsubscribe” if they no longer wish to receive notices. The email addresses may remain private to recipients if you choose that option. You can make the emails attractive and stand out from the others in the mail Inbox.

MailChimp is a second step from traditional emails from a traditional Google or Outlook account. An advantage is that people on the list do not get the sometimes annoying “reply-all” messages for notices that are for information purposes only.

Privacy:

MPN Support Group coordinators are guardians of their members’ privacy. Coordinators are charged with protecting the confidentiality of all privileged information and respecting the privacy of all individuals. Do not give, sell, rent, or otherwise distribute the names, contact information, nor health issues of Support Group members to third parties.

If a third party wants to market its products or programs to our members, they may provide you with the information. You can review it and determine if its purpose is to sell or endorse a

product. If you choose to share the information with your groups we advise that you remain neutral and transparent and allow individuals the option to receive, attend, or participate.



Support Group Culture/Environment

The MPN Support Group is a warm, respectful, safe, space for participants to share their experiences, ask questions, give and receive encouragement and support. Members are at varying stages of living with MPN, from newly-diagnosed to managing disease for 20+ years. We learn from one another

and share changes in our health status with others who live under the cloud of chronic blood cancer.

Ground rules or guidelines may help remind everyone of the expectations and responsibilities we share. Most coordinators of long-established support groups say that a formal set of ground rules isn't needed in their groups. Their group norms are established and they encounter few, if any issues.

For new groups or growing groups, a brief statement of how we are together may help set the tone. Here are some *examples* of the types of expectations your group may adopt:

- ☐ Our meetings start on time and end on time. Socializing may continue beyond the official meeting.
- ☐ We maintain confidentiality, courtesy, and respect toward others, even if we don't agree.
- ☐ We accept people as they are, and avoid making judgments.
- ☐ Everyone is welcomed to speak or simply listen, as they choose.
- ☐ We listen to others and avoid side conversations.

Don't assume new people know the expectations of your group. Especially if the group is new or experiencing growth in membership.

Enthusiasm, frustration, disappointment, and fear can cause someone to steer a discussion off course; the ground rules help the group get back on track.

Casual and Friendly

Support groups are meant to be a place where one can exhale and feel safe and among friends. There is no need for strict formalities or Robert's Rules of Order. Don't let yourself get stressed about organizing the meetings. People are glad someone else put it together!

Member Expectation of Privacy

Invited guests may participate in general education sessions of our meetings; however patient and care giver discussions are private, regardless of any outside sponsors of the gathering.

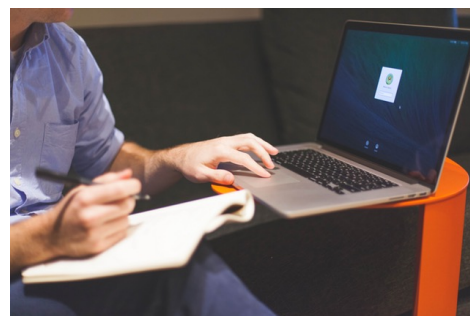
For groups that have been together for several years, it is helpful to ask: How do we welcome newly diagnosed people to the group? Are we flexible in meeting time, location, topics to the newly-diagnosed?



Note: If a support group has become tight-knit and participants are comfortable as it is, that is okay. Just be open and supportive of the creation of a new support group for newly-diagnosed patients in your broader community.

Communication Between Meetings

MPN Support Group meetings function differently from traditional support group meetings facilitated by a licensed social worker or psychologist. Instead of meeting weekly for a fixed period of time, most MPN peer support groups meet 3-5 times per year.



It is helpful to keep in touch between meetings so members remember the group and stay connected.

Communication Content Ideas

1. Information about upcoming seminars and conferences run by MPN organizations and cancer support organizations that might be of interest.
2. Links to studies, reports, interviews, news that would be of interest to the members.
3. Questions, news from/to members.

Planning Local Meetings

Based on feedback from MPN Support Group coordinators across the United States and other English-speaking countries, most group meetings operate within this framework. There are variations according to the size of the group, the geography a group serves, the demographics of the attendees, and the length of time the group has been together.

Feel free to adapt what you see here to a format that works for you!

Frequency:

Regular connections over time help people to feel connected and comfortable sharing with others. You may be familiar with support groups that meet weekly or monthly for a specific period of time. The experiences of MPN support groups in the United States tend to be far less frequent.



Most groups meet 3-5 times per year. Many augment the meetings with Facebook or other social media group to share information. Remember that many people do not use Facebook (yes, it's true!), so send reminders by email or text.

As a local group forms, ask participants for their preferences. If there is active interest, a local group may choose to meet monthly.

Schedules:

Some coordinators schedule 12 months, rolling (so the next 4 meetings are booked and publicized). Some schedule topics and have to change dates based on speaker availability. Some coordinate calendar with members (smaller groups).

When:

Most support groups meet for **2-3 hours on Sunday afternoons**, to make participation easier for widest range of patients. This also gives people time to travel to and from the meeting. Many patients drive as much as 2 hours each direction to attend a meeting.



Weekdays are difficult not only for those who are employed, but also anyone who must tangle with rush hour traffic.

Saturdays are difficult because many people have family and community commitments.

Where:

If you are starting a new group, ask your doctor to let other MPN patients know and allow he/she to share your contact information. We recommend email.

Consider your attendees. A location that is easy to access – by transit if in a metro area or near a major highway for distance travelers. In urban areas, free parking is also helpful. Groups meet in meeting spaces in medical facilities, Cancer Support Center, college campus, churches,

member's homes, private room in local restaurant. Some groups move locations around a metro geography to appeal to broader member base.

Participation Levels:

This varies by group. Based on experience of many MPN support groups, typically 25-30% of people on the local distribution list attend (with group lists of 40+ people).

Ask for RSVPs. The act of responding to a meeting announcement increases the likelihood of attendance.

If you are not hearing from people, consider calling a few members to invite them personally. The personal touch also boosts participation. You may also learn they would like to attend but lack transportation. Perhaps someone nearby can carpool.

Expect 10% of the respondents to miss the meeting. Things happen.

Meeting Formats*:

Customize the meeting format to your community. You and the group will figure out what works best for the group. The Sample Meeting Agendas are simply here to give you ideas. Timing of each section will vary based on the size of your group.

An agenda, whether on paper or on a wall, provides attendees with comfort of knowing how the meeting will proceed.

To help foster the feeling of being part of a strong group, some coordinators ask each member to bring a beverage, appetizer, or dessert to share. It's not a requirement for participation, but most people want to do something to help. Members come into the event with something and feel a part of it. The food is also a great conversation starter among members.

Coordinators usually bring water and a snack or cookies to be sure there is something available.

Typical meetings are 2-3 hours with featured topic with Speaker, Q&A, Discussion, News & Announcements, and Social Time.

Provide handouts for take-aways (even if just the Agenda with announcements of upcoming events) so they always leave with something in hand.

"After the member gets his/her nametag (where they write their first name, which MPN they have, and when they were diagnosed), they put their food on the community table and start to meet people standing near the food area. They can tell instantly if they have something in common, if they are new to the disease or if they are the older wiser one."

Everyone enjoys this social break after a long car ride. We then let them know that the program is about to start so they can use the facilities." ~ Susan K.

Sample Meeting Day With Guest Speaker

Preparation

- 1:15 pm** **Set up meeting space:**
 Welcome table with sign-in sheet, nametags & pens, agenda, handouts
 Set up water, snacks, or potluck table
 Make sure speaker's A/V needs are met
 Know where nearest restrooms are located
- 1:30 pm** **Volunteers arrive; give assignments**
- 1:45 pm** **Early birds arrive**
-

Sample Meeting Schedule with Speaker*

- 2:00 pm** **People sign-in, nametags with Name, their MPN, date of diagnosis.
 Go to community food table, greet one another**
- 2:40 pm** **Introduce Guest Speaker**
- 2:45 pm** **Speaker presents on topic of the day**
- 3:15 pm** **Questions & Answers, Thank the Speaker (who leaves the meeting)**
- 3:30 pm** **Group Member Introductions & Check-In**
 Start with new members. Name, diagnosis, share a question, concern, or
 experience while other members give support.
- 4:45 pm** **Wrap-up. Announcements**
- 5:00 pm** **Adjourn Meeting, Social time continues**
-

After the Meeting

1. Write down the items you will follow up on for participants, speaker, etc. (it's easy to forget)
2. Pack up materials.
3. Send "thank you" follow up to speaker

Sample Meeting Day With No Guest Speaker

Preparation

- 1:15 pm** **Set up meeting space:**
 Welcome table with sign-in sheet, nametags & pens, agenda, handouts
 Set up water, snacks
 Know where nearest restrooms are located
- 1:30 pm** **Volunteers arrive; give assignments**
- 1:45 pm** **Early birds arrive**
-

Sample Meeting Schedule – No Guest Speaker*

- 2:00 pm** **People sign-in, nametags with Name, their MPN, date of Diagnosis**
Go to community food table

- 2:30 pm** **Welcome, Introduce self, Briefly state our purpose, ground rules**
Invite each person to share their name, whether a MPN patient or care giver/partner, and diagnosis since ...

- 3:00 pm** **Patient Conversations or**
Small Groups – break out by Disease, Symptoms, Challenges:

The size and composition of the group will determine how many small groups you may make. Ask the group to decide which small groups to create (see suggestions below). Each group appoints a note taker and another to report out. The note taker records the major issues discussed and suggestions offered. The reporter will share with those highlights with the entire support group.

Disease: ET / PV / MF / SCT / Care giver/partner

Symptom: Fatigue / Joint pain/inflammation / Foggy brain / Sweat & Itch /
 Insomnia / Libido / Fertility & Pregnancy / Women's Health

Impact on: Work / Parenting / Family & Friends / Marriage/Partner / Identity

- 3:45 pm** **Reconvene as full group. Each small group reports out and shares tips.**
- 4:00 pm** **Wrap-up. Announcements**
- 4:15 pm** **Adjourn Meeting, Social time continues**
-

After the Meeting

1. Write down the items you will follow up on for participants, speaker, etc. (it's easy to forget)
2. Pack up materials.
3. Send "thank you" follow up to speaker

Sample Meeting Agenda

This sample agenda shows a time assigned to each section of the meeting. Many people find it helpful to keep the meeting on track. Even with a printed agenda, you can review it with the group and decide to allocate your time together differently.

MPN Peer Support Group of _____

Meeting date
location

AGENDA

- | | |
|---------|--|
| 2:00 pm | Sign-in, name tags,
Community food table, greet one another |
| 2:55 pm | Welcome & Introduce topic and presenter: _____ |
| 3:00 pm | <i>Topic of the Day</i>
<i>speaker name, title, organization -- contact info if speaker is willing to share</i> |
| 3:45 pm | Questions & Answers |
| 4:00 pm | Member Introductions & Check-In |
| 4:45 pm | Wrap-up, Announcements |
| 5:00 pm | Adjourn, Social Time continues |

Reminder:
Tell your hematologist about this group.

_____, MPN Support Group Coordinator
Cell: _____ or email: _____
for more information.

Upcoming Events

List next support group meetings

Conferences or events about MPNs,
blood cancer, insurance, topics of interest
to the group

Popular Topics for Meetings

At recent meeting of MPN support group coordinators, several topics and expert speaker types were shared as popular with local groups:

1. The Bone Marrow Biopsy: a Pathologist shares what they look for in a BMB, terms and definitions used in the reports, and show visual examples of BMB slides.
2. Blood Basics – the CBC: a hematologist or laboratory expert explains the elements of blood, how they are measured in a Complete Blood Count, and which values are most important to track for MPN patients.
3. Scientific Research: a researcher shares how they go about discoveries in basic science that contributes to understanding MPNs or research specific to the MPN disease.
4. Alphabet soup of Genetic Mutations (JAK2, TET2, CAL-R, MPL, Exon 12...). Learn about the latest understanding of genetic mutations, how they are different, what they have in common, and what is yet to be understood.
5. Understand & manage symptoms (insomnia, fatigue, foggy brain, itches, night sweats, joint/bone pain, inflammation, low libido, depression). Palliative care professionals trained in cancer treatment can provide helpful strategies.
6. Control What You Can: How to deal with the uncertainty and ambiguity of MPN. Strategies for self care (movement, meditation, pacing, healthy eating, good sleep hygiene).
7. Clinical Trials: overview, what you need to know, questions to ask, insurance, costs to participate.
8. Accessing Treatments: when prescription medications are out of financial reach.
9. Insurance: understanding what's covered; how to appeal; how to get to a MPN expert.
10. Financial Issues: ways to help with financial loss due to MPN (loss of income, increase in expenses).
11. Latest MPN News from American Society of Hematology (ASH), World Health Organization (WHO), patient conferences.
12. MPN changing landscape: Latest resources, guidelines, treatments, and policies.
13. Caregivers: what patients need to know; what caregivers need to know.
14. Stem Cell Transplantation & the Window of Opportunity: a transplant physician explains the allogeneic transplant process for patients with myelofibrosis, the risks, and why timing is important and how determining the most opportune time is determined.
15. Living with MPN over time: Planning for and coping with changes (physical, mental, financial, etc.) that occur with chronic MPN.

Collaboration & Networks

You do not have to organize the group alone. These resources can help – with space, speakers, materials, and promote your meetings:

- MPN Advocacy & Education International – help secure speakers, educational materials
- MPN Research Foundation – speaker ideas, share materials
- MPN Education Foundation – speaker ideas, share materials
- Local hospitals, research centers – local expert speakers, meeting space
- US Department of Defense – local bases promote meetings to employees, families
- Leukemia & Lymphoma Society (LLS) – local chapter, First Connection program
- Cancer Support Center – provide meeting space, share resources with group

Market the Meetings

Because of the private health issues discussed at the meetings, coordinators must do their best to ensure only invited speakers, members, and new/prospective members attend the meetings.

To *publicly* promote upcoming meetings, announcements or flyers often have the date, time, and topic announced with the Coordinator's contact info to get more information (meeting location is usually NOT included). People must then RSVP to the coordinator to learn the location. This allows the coordinator to talk with new people interested in the group and discern their reason for interest.

When meeting locations are publicized, simply make sure those who attend are not trying to sell products to or access contact information of the members. This only happens occasionally, yet members rely on our maintaining their privacy to the extent possible.

To your current support group members:

- Send e-mails to members with a PDF flyer attached. Ask them to share with their physicians to help get the word out.
- Post to your Facebook group or Google Group page.

To prospective new local support group members:

Ask members to help share meeting info with related patient organizations such as:

1. local hematology offices
2. local hospitals
3. local Cancer Support Community
4. local LLS chapter
5. MPN Advocacy & Education International
6. All the virtual support groups (MPN-NET listserv, various Facebook support groups, MPN Chat, community.lls.org and mpnrcommunity.org).

Optional Fun in Meetings

Everyone enjoys winning. Bring more smiles to the meeting with unexpected prizes. The thought is more important than the cash value.

MPN BINGO

Hand out BINGO sheets with commonly used terms in the MPN world (examples are provided in the toolkit). Hand out candy or treat for each winner.

Free Raffle

Give each person a ticket or slip of paper with a number or MPN word (and put duplicate ticket or paper in a bowl). Draw for winner(s) of small gift you have around the house or can get donated (see ideas below).

Superlative Prizes

It is nice to acknowledge people for any number of reasons. Mix up the superlatives so different people “win” each meeting. Shout out to someone who:

- Drove the farthest to attend the meeting
- Has lived with ET / PV / MF the longest
- Was most recently diagnosed
- Achieved a milestone (retired, qualified for Disability, got a job, pregnancy, wrote a book)
- Shared something courageous
- Celebrated a birthday this month
- Plays the piano / saxophone / violin...
- Speaks 2 or more languages
- Ran a marathon / half-marathon / 10k / 5k (or similar athletic feat)
- Got MPN Support Group information placed in his/her hematologist office

Prize ideas

Invite your friends and others in the group to bring items for meeting prizes.

Remember, you don't have to give them all out at one meeting. Here are some no/low-cost suggestions:

- Handmade item (scarf, jewelry, pottery, bread, jam, salsa...)
- \$10 gift card for coffee, gas
- Favorite inspiring book you've read and are willing to share
- CD of your favorite music
- Gift certificate from a local business
- Bundle of favorite healthy recipes
- Recycle a trophy from another activity



Sign “Thinking of You” card(s)

If there is a member of the group who could use a boost, bring a greeting card to the meeting and invite everyone to sign or add a message. Have it addressed and stamped so all you have to do is seal it and drop it in the mail after the meeting.

Support Group Coordinator -- Job Description

If you are a MPN patient or care partner of one with a MPN, it is important to be realistic about **why** you want to lead a group and **the time and energy required** to do it well.

Also, be sure you will **be objective** and **not promote a certain belief system or way to cope** with cancer. MPNs afflict people of all ethnic, racial, religious, and socioeconomic backgrounds. The coordinator must create a culture of acceptance and respect for all, who already may feel isolated due to the illness.



Responsibilities

1. Main point of contact for people seeking a local support group. Introductions by phone call or email are typical. Check out inquirers to ensure they are patients/caregivers
2. Maintain up-to-date contact information of local support group members.
3. Organize meeting schedule.
4. Engage others to help with the meetings, communications of the group.
5. Be mindful that many people are on tight budgets when planning events.
6. Be mindful that many people are private about their illness.
7. Respect the privacy of members. Do not share someone's condition (e.g., asking for thoughts & prayers, support on social media or elsewhere) without his/her permission.
8. Connect new MPN patients to members who have common interest and are willing to be a MPN buddy.

Duties

1. Set the tone / culture of the group: warm, friendly, respectful, safe, welcoming.
2. Ensure each meeting is organized and runs on time (may enlist volunteers to secure speaker, snacks, welcome area, meeting agenda and supplies, locations, etc.)
3. Ensure each meeting has a facilitator who fulfills the responsibilities and duties described in the Support Group Facilitator job description. The Coordinator may fulfill both roles, or may engage another person to serve that role.

Desired Skills & Qualifications

- Understanding of Myeloproliferative neoplasms, education opportunities, patient resources
- Ability to communicate through electronic mail, social media, telephone, and in person.
- Good listener, positive attitude.
- A "people person," comfortable meeting new people, and enjoys creating a hospitable environment.

Volunteer Support Group Facilitator – Job Description

This role may be filled by the Support Group Coordinator or another volunteer at each meeting. The facilitator ensures the meeting progresses smoothly, participants engage, information is shared, and community is formed.

Responsibilities

1. Set the tone / culture of the group: warm, friendly, respectful, safe, welcoming.
2. Create and maintain a safe space at group for participants to share their feelings, experiences, etc.
3. Build community among participants.
4. Raise awareness and refer participants to other appropriate resources.



Duties

1. Establish and maintain group rules including confidentiality among participants.
2. Review agenda with the group. Keep the meeting flow on schedule. Should a significant event occur to throw off timing, check in with the group and agree on the change.
3. Facilitate sharing from all participants by respectfully monitoring speaking time and encouraging input from all present.

Desired Skills & Qualifications

- Ability to effectively present information to groups
- Ability to lead a group by primarily listening and supporting group members
- Ability to synthesize group discussions and wrap up a meeting
- Training and experience in group facilitation

Potential Challenges for Support Group Coordinators

Every now and then you will encounter one of these issues. It is to be expected. The group looks to the facilitator to keep things moving.

Member Requests

Some people may want you to assist them beyond your role as a Support Group Coordinator. Maintain personal boundaries; offer suggestions they can follow up with. Some examples:

- Patients ask you for a ride to the meeting. You are not obligated to provide transportation. Suggest connecting with another member who lives nearby.
- Patient asks for direct service help (making phone calls, raising money, rides to appointments).
- Patient calls you regularly for a sympathetic ear and the conversations are one-sided. Be clear at the beginning of the call that you have 5 /10 minutes (whatever you choose) and then will have to go. Suggest s/he find a counselor for professional support in managing life.

Member Dies

This is a sad element of our support groups. When a member of the group is deceased, acknowledge the death with the group and share funeral/memorial information. You may choose to send a card to the family on behalf of the group.

Coordinator Wants to / Must Relinquish Role

Some people are reluctant to lead a support group because they fear it will be a lifelong commitment. It is helpful to discuss a succession plan for the Coordinator. Ask 1-2 people to assist with organizing the meetings. This helps with hands-on experience. And lightening the load makes the work more fun!

During Support Group Meetings

Uninvited Visitors

To respect the privacy and candor among patients, you may request that people who are not patients or direct caregivers leave the meeting at any time. Particularly if the visitors work for a company that sells products (pharmaceuticals, insurance, legal services) to patients, they must disclose their relationship.

Sometimes guests may enter after introductions, for the invited speaker portion of the meeting and then leave immediately following.

Meeting Sponsors

Sponsorship of a meeting (e.g., providing space, food, etc) should not be contingent upon their presence throughout the meeting. Sponsors should not be given the names or contact information of people in attendance. Again, we protect the privacy of our members.

Support Group meetings should not involve any kind of monetary exchange. We encourage the coordinators to be mindful and to not rely on third party funding.

