



HOW TO START AN MPN PATIENT SUPPORT GROUP

MPN RESEARCH FOUNDATION



How to begin...

1. Find Potential Group Members

- The first step to take in establishing a support group is to get the word out to MPN patients in your area. This can be accomplished in a number of ways:
- Ask the MPN Research Foundation to inform the patients in your area of your upcoming meeting. We can do this via regular, through e-mail and on social media.
- Word of mouth at doctor's offices
- Customize patient brochures with labels and information to advertise your group
 - Ask your hematologist if you can place your brochures in the waiting room
 - Drop off brochures in area hospitals, clinics & cancer centers
- Place an advertisement in your local newspaper or through your local radio and television stations. (Public Service Announcements are free)
- Post a notice or a flyer in local pharmacies and grocery stores
- Contact your local blood cancer support groups

2. Plan the meeting

- Select and reserve a meeting space with a capacity that is a little higher than your anticipated attendance at a local church, library, community center, hospital, social service agency or a restaurant with a private space. Try for a convenient, central location that's conducive to open conversation with chairs arranged in a circle to avoid a lecture room setting.
- Determine the date & duration of meetings. Most groups meet 3-4 times per year. Generally, allow for a 2 1/2-hour meeting. Keep in mind that it is impossible to accommodate everyone all the time and all you can do is the best you can.
- Create an agenda so that you can stay on top of the time and give everyone a chance to speak if they want to.
- Send meeting reminders via email, phone call or snail mail with an agenda one week and then one day in advance.
- Plan to arrive at the meeting site with one or two other members, no less than half an hour before the meeting time to set up the chairs/tables and to put out the literature, sign in sheet, name tags, pens, etc.
- Prepare a sign-in sheet to get contact information for future use but be aware that privacy is important. Add a space for people to check if they want their information private.

3. Consider Inviting a Speaker

- Many support group leaders enjoy having a speaker attend each meeting. Speakers are typically someone with a medical background who can discuss updates in MPNs, but you may also consider inviting speakers with a background in social work, nutrition, etc.
- Many find it most efficient to allow the speaker to present at the start of the meeting so that an informal discussion with questions may follow at the end.

4. After the Initial Meeting

- Get feedback from attendees on the meeting site, including format and input for future locations and venues. Use this information to determine a regular meeting site or plan to rotate host duties that can accommodate the budgets and locations of all attendees.
- Keep the MPN Research Foundation updated as to your meeting time & dates and we will post announcements on our website www.mpnresearchfoundation.org and our social media.
- Consider recruiting a second person to be a co-coordinator to be an additional point of contact and assist you with planning.
- Prepare an initial membership list and enlist one other patient to assist you in compiling contact information & with meeting logistics.
- Make sure to get the full name, address, phone number and email of all new attendees and begin each new meeting with words of welcome to the newcomers.
- Ask attendees to suggest possible topics and/or guest speakers for future meetings. The MPN Research Foundation can assist with speaker procurement.
- Encourage attendees to bring fellow MPN patients in the future.

The MPN Research Foundation receives and maintains up to date information about myeloproliferative disorders and is dedicated to increasing awareness of MPNs and educating patients, health care professionals, family members and the general public. Please contact our office if you need educational materials or updates on current research.

We are happy to assist in obtaining speakers for your support group meetings. You can contact us by phone at 312-683-7249 or by sending an email to Lexi Moore at lmoore@mpnrf.org

How MPN Research Foundation Can Help You

1. **Recruit Attendees:** MPNRF has an extensive database of contact information for MPN patients, caregivers, doctors, etc. We can spread the word about your meeting or event to our community via postal mail, email and/or social media.
2. **Find Event Speakers:** Having a physician or medical professional at your meeting helps keep people focused and prevents the spread of misinformation. If you can't find a local doctor or nurse to speak, consider having them dial in to the meeting.
3. **Provide Fliers:** A great way to attract people to your group is to spread the word at your local libraries, community centers, clinics, hospitals, etc. MPNRF can help by providing you with an informational flyer about your event you can hang at these locations and more.
4. **Provide Educational Handouts:** MPNRF is happy to provide educational resources for you to handout at your event/meeting. These resources may include but are not limited to information for caregivers, facts myeloproliferative neoplasms broken down by each disease, material about how MPN Research Foundation can be used as a resource, directions on how to join our online patient registry, myMPN, and more.
5. **Keep you connected:** It's important to know how other support group leaders handle their responsibilities. Even when we can't meet in person, we are happy to keep all the coordinators in the loop about what's going on in the MPN patient community and how that might impact their group.
6. **Utilize Social Media:** We are happy to utilize our social media following across various platforms to help you publicize your group and your meetings.

Contact Lexi Moore at 312-683-7247 or lmoore@mpnrf.org for help with any of the items listed above.

Program Ideas for Support Group Meetings

Potential Speakers and Talking Points

MPN Researcher:

- Research updates / New Discoveries
- Ongoing studies
- Updates from clinical trials.

Hematologist or MPN Specialist:

- What are the current treatment options for MPNs?
- Side effects and how to manage or prevent them.
- How to maintain a healthy lifestyle through exercise and nutrition

Healthcare Professional:

- What are my rights as a cancer patient?
- Navigating the healthcare system.
- Are there any financial relief/assistance options for MPN medications?

Possible Meeting Topics

Just Diagnosed?

- What are the first steps to understanding more about ET, PV, and MF?
- What local resources should I be aware of?
- What online forums, groups or communities should I be a part of?

How to find the right hematologist

- What qualities are important?
- What services to expect from you physician.
- Questions to ask before engaging in a permanent doctor / patient relationship
- When should I seek a second opinion?
- Available resources to help find a hematologist that's right for me.

Everything you need to know about clinical trials

- What does "double-blind", "placebo", "control group" etc. mean?
- When will I find out what group I am in (experiment or control)?
- What are the risk factors?

Emotionally coping with an MPN diagnosis

- Network and build connections with your MPN community
- Learn how other people cope with their disease
- Having a rare disease no longer means you have to feel isolated