

GETTING MYELOFIBROSIS CARE IN A RURAL AREA

- If you live in a rural area, it's important to advocate for yourself to get connected to experts from an MPN center of excellence. This could involve traveling to see a myelofibrosis specialist while still having your local doctor manage your care.
- Utilize telemedicine services, if possible. This can ensure you receive expert advice and treatment plans without extensive travel.
- Join a support group for emotional and practical support. These groups or networks can help you feel connected and informed.

PATIENT [ACT]IVATION TIPS

[ACT]IVATION TIP: "Increase your awareness of specialties and expertise in the region where occasionally you might have to travel or seek attention from an MPN center of excellence in order to get the care that you deserve and need." - Dr. Abdurraheem Yacoub

[ACT]IVATION TIP: "Keep up with the field through reliable sources of information that give updates on clinical trials or by keeping up with clinicaltrials.gov, which is a federally funded website that lists active and enrolling trials at any part of the country. Patients can look up their state or ZIP code and find clinical trials that are available to them in that area. Be proactive at seeking these options." - Dr. Abdurraheem Yacoub

[ACT]IVATION TIP: "You have to understand that your cancer is a disease you're going to partner with for the rest of your life. And the more skilled and knowledgeable you are, the more you can get the best care you deserve and advocate for yourself and be able to communicate your challenges with your doctors and be a participating partner in your own care." - Dr. Abdurraheem Yacoub

[ACT]IVATION TIP: "I like to involve a dietitian early on in our patients, although there is no specific diet that is uniquely specific for myelofibrosis (MF), but there are certain interventions that are globally of benefit to patients to be healthier. I also advocate for mental health and involve our oncology psychologists to be partners with us on patient care and to tackle the challenges that they have to cope with as they live with a chronic cancer. Lastly, I also endorse exercise as a method of improving functionality, strength, and emotional well-being, and also as a tool to battle fatigue and musculoskeletal pains." - Dr. Abdurraheem Yacoub

[ACT]IVATION TIP: "Patients who know that they have myelofibrosis can help teach their primary care providers about their journey in MF care, thereby increasing knowledge and letting providers know how far myelofibrosis care has come. Often, primary care physicians want to be able to partner with specialists in the care of complex conditions." - Dr. Michael Grunwald

[ACT]IVATION TIP: "Do not be scared of pursuing a second opinion and/or involving a specialist in your healthcare. Partnership between a specialist and local hematologist-oncologist and/or primary care physician can be beneficial for patients. Occasionally, there can be community physicians who are taken aback by that request, but more often than not, I find they appreciate the partnership and the extra set of hands in the patient's care and that it ends up being a good relationship all around." - Dr. Michael Grunwald

[ACT]IVATION TIP: "While there can be regulatory limitations on certain uses of telemedicine, patients should take advantage of telemedicine when it's possible." - Dr. Michael Grunwald

[ACT]IVATION TIP: "While one cannot trust everything one learns online, oftentimes online communities can point patients toward helpful questions that enrich the conversations they have with their providers. Write or type down questions and bring them with you to your appointments." - Dr. Michael Grunwald

MYELOFIBROSIS CHECKLIST

- 1. **Activate Your Care During Your Initial Appointment.** Discuss diagnosis, stage, and treatment options.
- 2. **Establish Your Treatment Team.** Find treatment centers experienced with treating myelofibrosis with an individualized approach.
- 3. **Maintain Open Communication:** Discuss fears and concerns openly. Do not hesitate to seek 2nd or 3rd opinions.
- 4. **Research Financial Support.** Explore financial assistance options as well as other community financial support options.
- 5. **Explore Clinical Trials.** Discuss your suitability with your doctor to weigh benefits and risks.
- 6. **Seek Emotional Support.** Talk openly with loved ones, consider talk therapy, and connect with relevant support groups.
- 7. **Strive for a Healthy Lifestyle.** Maintain a balanced diet, moderate exercise, and stress management.
- 8. **Stay Informed.** Learn about myelofibrosis through trusted resources, ask questions, and remain updated on advancements.

RESOURCES

- [Patient Empowerment Network](#)
- [American Cancer Society](#)
- [CancerCare](#)
- [Cancer Support Community](#)
- [Clinicaltrials.gov](https://clinicaltrials.gov)
- [The Leukemia & Lymphoma Society \(LLS\)](#)
- [MPN Advocacy & Education International](#)
- [MPN Cancer Connection](#)
- [MPN Research Foundation](#)
- [National Cancer Institute](#)
- [National Comprehensive Cancer Network \(NCCN\) Guidelines for Patients](#)
- [National Organization for Rare Disorders](#)

MYELOFIBROSIS FACTS

- Myelofibrosis is one of a related group of blood cancers known as myeloproliferative neoplasms (MPNs). It leads to abnormal development and functional of blood-producing cells, resulting in fibrous scar tissue formation.
- MF affects both men and women, usually diagnosed in people over the age of 50.
- Often develops slowly, and some people may live symptom-free for years. Symptoms include anemia, fatigue, and enlargement of the spleen and liver.
- MF can occur independently (primary myelofibrosis) or as a progression of other MPNs, such as polycythemia vera and essential thrombocythemia.
- MF develops when a genetic mutation(s) occurs in bone marrow stem cells. Between 50-60% of people with MF have a mutation of the Janus kinase 2 gene (JAK2), and 25% have a mutation of the calreticulin gene (CALR). The exact cause of these mutations is unknown.

Source