

Thriving With an MPN | Self-Advocacy

- [Educate yourself](#) about MPNs.
- Ask your doctor if you have had [essential testing](#).
- Participate in [shared decision-making with your healthcare team](#).
- Communicate regularly with your provider, make use of your patient portal.
- Write down questions before and include a care partner at your appointments.
- Consider a second opinion and/or a consult with an MPN specialist.

Advice for MPN Symptom Management

- Communicate any [issues you are experiencing](#) to your doctor.
- Evaluate where/why the side effect is happening.
- Discuss possible dose interruption, dose reduction, or a treatment holiday.

Considerations for Choosing MPN Therapy

- Set treatment goals with your provider.
- Medication type.
- Pre-existing health issues or comorbidities.
- How treatment is administered or delivered.
- Financial impact.

Glossary Terms

Anemia (iron deficiency anemia): A condition that develops when the body lacks sufficient red blood cells. Symptoms of anemia may include fatigue, weakness, and shortness of breath, among others.

Ropeginterferon alfa-2b (BESREMI): FDA-approved treatment for patients with polycythemia vera (PV).

Genetic Testing (molecular profiling or biomarker testing): Laboratory testing that identifies certain gene mutations, proteins, chromosomal abnormalities and/or other molecular changes that are unique to an individual's disease. In cancer, it may be used to evaluate treatment or to make a prognosis.

Interferon Therapy: A type of therapy that interferes with the ability of viruses to reproduce and also boosts the immune system.

JAK Inhibitors: A class of therapy that interferes with the activation of the JAK-STAT pathway.

Momelotinib (Ojjaara): JAK inhibitor therapy approved by the U.S. Food and Drug Administration (FDA) on Sept 15, 2023 for the treatment of intermediate- or high-risk myelofibrosis, in adults with anemia.

Phlebotomy: Removal of blood from the veins in order to lower blood volume and to reduce excess red blood cells.

Pruritis: Severe itching of the skin, a common and challenging symptom for patients with PV.

Watch & Wait (or Active Surveillance): The period of time before treatment begins in which a patient is monitored for disease progression and symptoms.

MPN Educational Resources

- American Cancer Society: cancer.org
- MPN Advocacy & Education International: mpnadvocacy.com
- MPN Research Foundation: mpnrf.org
- The Leukemia & Lymphoma Society (LLS): lls.org
- MPN Voice: mpnvoice.org.uk



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