# How to Play an Active Role in Your MPN Treatment Decisions

**Program Resource Guide**

## Engage in Your Care
- Educate yourself about your MPN.
- Partner with your healthcare team on care and treatment decisions.
- Include a friend or family member in your appointments.
- Consider a second opinion and/or a consult with a MPN specialist.

## Shared Decision-Making
Process of communication by which **patients and clinicians collaborate** to make healthcare decisions. The process encourages patients to take a more active role in their care and treatment.

## Elements of Shared Decision-Making
- Earn trust by developing a patient-doctor relationship
- Empowering yourself by learning about your MPN
- Discussing what you learn with your doctor
- Partnering with your doctor on your care and treatment decisions

## MPN Resources
- The Leukemia & Lymphoma Society | LLS.org
- MPN Research Foundation | mpnresearchfoundation.org
- PV Reporter | pvreporter.com

## Learn About Clinical Trials
- Consult with an MPN specialist
- Visit The Leukemia & Lymphoma Society: LLS.org
- Visit Clinicaltrials.gov

## Goals of MPN Treatment
- Improvement in lab work and overall monitoring
- Improvement in overall survival and quality of life
- Management of co-morbidities
- Reduction of symptoms
- Patient preference and personal goals

---

© 2021 Patient Empowerment Network, a 501(c)(3) Public Charity  
www.powerfulpatients.org  
Produced by Health Content Collective
### HOW IS MPN TREATMENT EFFECTIVENESS MONITORED?

- Controlled blood counts through regular lab work (CBCs)
- Assessment of the size of spleen and liver
- Absence of blood clots or bleeding
- Good quality of life

### Advice When Starting New Treatment

- Read the package label insert.
- Understand that you may be at a higher risk for infection.
- Listen to your body. Report any side effects or changes to your doctor.
- Discuss medication with your pharmacist.

### More Tools for Empowerment

- Digitally Empowered™
- PEN Powered Activity Guide
- Empowered Blog
- Empowered! Podcast

### GLOSSARY OF TERMS

**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.

**Complete Blood Count (CBC):** Blood test used to evaluate one’s overall health and to detect a wide range of disorders. CBC measures several features of the blood, including red blood cells, white blood cells, hematocrit, hemoglobin, and platelets.

**JAK2 (JAK2V617F) Mutation:** An acquired mutation in the majority of patients with myeloproliferative neoplasms. The mutation is found in approximately 50% of myelofibrosis (MF) and essential thrombocythemia (ET) patients and 95% of polycythemia vera (PV) patients.

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

**Ruxolitinib (Jakafi):** JAK inhibitor therapy currently approved for the treatment of myelofibrosis and polycythemia vera.

**Thrombotic Event:** Formation of a blood clot in a blood vessel that may obstruct the blood flow of the circulatory system.