

HOW TO PLAY AN ACTIVE ROLE IN YOUR MPN TREATMENT DECISIONS

Program Resource Guide

<h3>ENGAGE IN YOUR CARE</h3> <ul style="list-style-type: none"> ▪ 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. 	<h3>MPN RESOURCES</h3> <ul style="list-style-type: none"> ▪ The Leukemia & Lymphoma Society LLS.org ▪ MPN Research Foundation mpnresearchfoundation.org ▪ PV Reporter pvreporter.com
<h3>SHARED DECISION-MAKING</h3> <p>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.</p>	 <p>question@powerfulpatients.org</p>   <p>@power4patients PowerfulPatients.org</p>
<h3>ELEMENTS OF SHARED DECISION-MAKING</h3> <ul style="list-style-type: none"> ▪ 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 	<h3>LEARN ABOUT CLINICAL TRIALS</h3> <ul style="list-style-type: none"> ▪ Consult with an MPN specialist ▪ Visit The Leukemia & Lymphoma Society: LLS.org ▪ Visit Clinicaltrials.gov
<h3>GOALS OF MPN TREATMENT</h3> <ul style="list-style-type: none"> ▪ 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 	<h3>VISIT THESE RELATED PROGRAMS</h3> <ul style="list-style-type: none"> ▪ What Are the Considerations When Choosing Myelofibrosis Therapy? ▪ What You Need to Know Before Choosing a Cancer Treatment ▪ MPN Symptom or Treatment Side Effect? Know the Difference ▪ Office Visit Planners for MPN Patients and Care Partners

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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.