

THRIVING WITH MPNS: YOUR ROLE IN MANAGING YOUR TREATMENT AND CARE

Program Resource Guide



Classic Myeloproliferative Neoplasms		Expert Advice to Thrive With an MPN	
<ul style="list-style-type: none"> ▪ Primary Myelofibrosis (MF) ▪ Essential Thrombocythemia (ET) ▪ Polycythemia Vera (PV) 		<ul style="list-style-type: none"> ▪ Educate yourself about your MPN. ▪ Consider a second opinion. ▪ Be honest about your symptoms and side effects. ▪ Inquire about available clinical trials. 	
Common MPN Symptoms			
Inflammation-Related Symptoms	Microvasculature-Related Symptoms	Symptoms of Enlarged Spleen	
<ul style="list-style-type: none"> ▪ Fever ▪ Night sweats ▪ Weight loss ▪ Fatigue 	<ul style="list-style-type: none"> ▪ Headache ▪ Visual changes ▪ Numbness and tingling in the hands and feet ▪ Painful rash 	<ul style="list-style-type: none"> ▪ Feeling full sooner during meals ▪ Discomfort or pain in the left upper quadrant 	
Therapies to Manage Anemia		Therapies Being Studied to Manage Anemia	
<ul style="list-style-type: none"> • Erythropoietin (EPO) <ul style="list-style-type: none"> ○ Epoetin alfa (Procrit) ○ Darbepoetin alfa (Aranesp) • Danazol (Danocrine) • Lenalidomide (Revlimid) 		<ul style="list-style-type: none"> ▪ Momelotinib: JAK inhibitor being studied in clinical trials for the treatment of myelofibrosis. ▪ Luspatercept (Reblozyl): Medication used to manage and to treat anemia in myelodysplastic syndromes, primary myelofibrosis, and beta thalassemia. 	
Possible Indicators of MPN Progression			
<ul style="list-style-type: none"> ▪ Sudden drop in blood counts ▪ Enlarged spleen ▪ Increased white blood cell count ▪ Blasts of greater than 20% in the peripheral blood 			

THRIVING WITH MPNS: YOUR ROLE IN MANAGING YOUR TREATMENT AND CARE

Program Resource Guide



Glossary 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.

Doxepin (Silenor/Prudoxin/Zonalon): A potent antihistamine drug used orally or topically in many pruritic conditions.

Gabapentin (Neurontin): Commonly used to treat chronic neuropathic pain.

Hematocrit (hct): The volume percentage of red blood cells in the blood.

Hydroxyurea (Hydrea): Oral chemotherapy agent used as a cytoreductive therapy in myeloproliferative neoplasms (MPNs) to control the number of white blood cells, red blood cells, platelets, and to reduce spleen size.

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.

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

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

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

Stem cell transplant (Bone marrow transplant): Procedure in which healthy blood stem cells are used to replace damaged or diseased bone marrow. This procedure can be used to treat certain types of blood cancers.

MPN Support & Resources

- Canadian MPN Network
- CancerGRACE
- Cancer Support Community (CSC)
- MPN Research Foundation
- MPN Voice
- National Organization for Rare Disorders (NORD)

MORE TOOLS FOR EMPOWERMENT

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



Thrive MPNs is brought to you by the Patient Empowerment Network. Funding is provided by an unrestricted educational grant from AbbVie, Inc., AceCancer, Incyte, and through generous donations from people like you.



question@powerfulpatients.org



[@power4patients](https://twitter.com/power4patients)



PowerfulPatients.org