

Shared Decision-Making

Shared Decision-Making (SDM): 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.

Essential PV Testing

- **Bone Marrow Biopsy:** A procedure that involves collecting a small sample of bone marrow, usually from the hip bone, in order to be examined by a laboratory. This procedure is used to confirm an MPN diagnosis and may be used to monitor the disease over time.
- **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.
- **Cytogenetic Analysis (karyotyping):** Testing of blood, bone marrow, or tissue in order to identify changes in chromosomes.
- **Molecular Testing (genomic 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.
- **Next-generation sequencing (NGS):** Technology to sequence DNA or RNA to identify genetic variations associated with diseases or other biological phenomena.

Common PV Therapies

- Aspirin
- Phlebotomy
- Hydroxyurea (Hydrea)
- Interferon
 - Ropeginterferon alfa-2b (BESREMi)
- JAK Inhibitor
 - Ruxolitinib (Jakafi)
- Hepcidin Mimetic
 - Rusfertide (Mimrylo)
- Clinical trial options

Treatment Plan Questions

- Is my PV diagnosis confirmed?
- Is my PV considered low-risk or high-risk?
- Are there mutations present that impact my care plan?
- What treatment do you recommend for my care goals?
- Are there treatment side effects I should be aware of?

Glossary Terms

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, and 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.

Lovenox (Enoxaparin sodium): A medication used as an anticoagulant (blood thinner) to prevent and to treat deep vein thrombosis (DVT), pulmonary embolism (PE), and blood vessel complications.

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.

Splenomegaly: Enlarged spleen which can cause pain or fullness in the upper left side of the abdomen, feeling full after eating small amounts of food, or abdominal discomfort.

Thrombotic Risk: The risk of developing blood clots, which can block blood flow and lead to complications, such as a heart attack, stroke, or deep vein thrombosis. In PV, the increased number of red blood cells can make the blood thicker, raising the risk of blood clots.

Polycythemia Vera Support and Resources

Blood Cancer United: bloodcancerunited.org

MPN Research Foundation: mpnresearchfoundation.org

Patient Empowerment Network (PEN): powerfulpatients.org



Elevate Polycythemia Vera (PV) is brought to you by the Patient Empowerment Network. It is sponsored by PharmaEssentia, and through generous donations from people like you.