How can you take ownership of monitoring your MPN?

What are MPNs?

Myeloproliferative neoplasms (MPN) are a group of disorders in which the stem cells in the bone marrow grow and reproduce abnormally. In MPN abnormal stem cells produce excess numbers of one or more types of blood cells (red cells, white cells and/or platelets). MPNs are sometimes described as being clonal blood stem cell disorder, resulting from a change, or mutation, in the DNA of a single blood stem cell.¹

There are three main types of MPNs:2

- Myelofibrosis (MF): when the bone marrow is exhausted by making too many blood cells and is replaced by scar tissue. This results in a lack of production in normal blood cells.³
- Polycythemia vera (PV): occurs when the body makes too many red blood cells, responsible for carrying oxygen through the body. Too many can cause the blood to become thicker which may cause other problems.⁴
- Essential thrombocythemia (ET): occurs when the body makes too many platelets, the part of the blood needed for clotting.⁵



Many people have no symptoms when they are first diagnosed with an MPN. When symptoms do occur, they develop gradually over time and might be the ones pictured above.

Other symptoms experienced in MPN are a result of the affected cell involved with the MPN.

Monitoring your disease

It is important to monitor your MPN regularly. Keeping a record can help you identify any changes in your health and guide conversations with your healthcare professional.



SCAN THE QR-CODE

or visit the website: https://mpntracker.com/de-CH/

MPN10 Symptom tracker⁷

When living with a chronic condition like MF, PV or ET, it is important that you take an active role in monitoring your symptoms and discussing changes with your healthcare provider. You can use MPN10 Symptom Tracker to assess the severity and progression of the most common symptoms you may experience. Tell your healthcare provider if any of your symptoms become worse or more challenging for you, since this may indicate the need for care-management approaches.

Polycythemia vera patients can additionally prepare for conversation with healthcare professional using the following tools:

Blood count tracker

Your blood counts, particularly haematocrit (HCT), white blood cells (WBCs), haemoglobin (Hgb), and platelets, offer important information about the status of your polycythaemia vera (PV). Actively track your blood counts, and discuss with your healthcare provider how your individual blood results compare with your target blood levels after each blood test.

Phlebotomy tracker

Phlebotomies can be an effective intervention to help manage HCT levels. Track the date and blood volume after each phlebotomy procedure. You may want to discuss your management plan with your healthcare provider if there has been an increase or a decrease in phlebotomies or if procedures are becoming inconvenient for you or you are experiencing any side effects.

References:

- 1. Leukaemia Foundation. What is MPN? Available at https://www.leukaemia.org.au/disease-information/myeloproliferative-disorders/ Accessed Nov 2020;
- Cancer Support Community. What are Myeloproliferative Neoplasms (MPNs)? Available at https://www.cancersupportcommunity.org/ myeloproliferative-neoplasms Accessed Nov 2020;
- Cancer Support Community. What is Myelofibrosis? Available at https://www.cancersupportcommunity.org/myeloproliferativeneoplasms#tab4 Accessed Nov 2020;
- Cancer Support Community. Polycythemia Vera (PV). Available at https://www.cancersupportcommunity.org/myeloproliferativeneoplasms#tab2 Accessed Nov 2020;
- Cancer Support Community. Essential Thrombocythemia (ET). Available at https://www.cancersupportcommunity.org/myeloproliferativeneoplasms#tab3 Accessed Nov 2020;
- 6. Lab Tests Online. About Myeloproliferative Neoplasms. Available at https://labtestsonline.org/conditions/myeloproliferative-neoplasms Accessed Nov 2020;
- 7. Emanuel RM, Dueck AC, Geyer HL, et al. Myeloproliferative neoplasm (MPN) symptom assessment form total symptom score: prospective international assessment of an abbreviated symptom burden scoring system among patients with MPNs [published correction appears in J Clin Oncol. 2012 Dec 20;30(36):4590. Ferarri, Maria L [corrected to Ferrari, Maria L]]. J Clin Oncol. 2012;30(33):4098-4103. doi:10.1200/JCO.2012.42.3863

