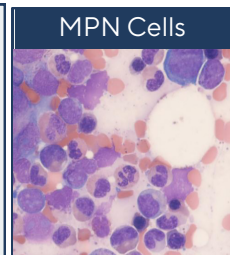


[ACT]IVATED MPN

RESOURCE GUIDE

An [ACT]IVATED patient is informed, empowered, and engaged in their care.

- ✓ Get information about choosing an MPN specialist or treatment center
- ✓ Discuss your treatment options and make the decision that best fits your personal needs
- ✓ Ask your doctors if clinical trials would benefit your type of MPN
- ✓ Talk openly with your doctor about your fears or concerns
- ✓ Determine if financial assistance is available
- ✓ Find an in-person or online support group to connect with others living with an MPN



MPN & YOUR RACE/ETHNICITY

- If an MPN patient is younger, they do have a higher risk of thrombosis over time, but there was no difference in risk if the patients were white, Hispanic, or African American.
- More research is being done on the biologic hereditary differences of MPN patients in order to improve outcomes. For example, almost half of African Americans have less than 80 percent of genes of African descent, which means there are biological differences that are related to their experience here in America and in the Western Hemisphere. It also means they have a more diverse gene pool, which may contribute or not contribute to cancers and other diseases.
- High blood pressure and diabetes puts patients at a higher risk of complications associated with MPNs. 2 out of 5 African American males have high blood pressure and Hispanics are twice as likely to be diagnosed with diabetes than Caucasians. *If you have these risk factors, work with your doctor to improve your diet and exercise.*

THE IMPORTANCE OF BONE MARROW REGISTRIES FOR MPN PATIENTS

- Currently, the only defined curative therapy is a bone marrow transplant.
- African Americans, Hispanics, and Asians have lower chances of finding a fully matched donor compared to white Americans. The chances of the patient relapsing after the bone marrow transplant and the rates of graft-versus-host disease are significantly higher if there is a lower level of match.
- In order to increase donors from specific ethnic groups, we encourage people to register at Be The Match, a registry where you can donate bone marrow or stem cells if you end up being a match based off of your genes for a patient. You may just save a life!

FUTURE TREATMENT OPTIONS FOR MPNS

- Researchers are looking at curative drugs that are not as intense as a bone marrow transplant but still eradicate the underlying cells that drives this disease.
- Immunotherapy: Drugs that can target the signals that drive MPN cells to divide and multiply within the bone marrow.
- Clinical trials that target the underlying disease as opposed to treating symptoms.

MPN EXPERT TIPS

[ACT]IVATION TIP: "If you have an MPN with some specific complications, and there are treatment options offered to you, I would ask your provider if there are any differences in outcomes related to if you are a Hispanic female, or a Black male, or an Caucasian female. I think it's important to understand if there are potentially differences in the outcomes related to the treatments, and then you can tailor your treatment specifically to your ethnicity and sex." - Dr. Idoroenyi Amanam

[ACT]IVATION TIP: "Check with your doctor if you have a risk or you do have diabetes, high blood pressure or high cholesterol. If so, ask how can you improve that diagnosis in order to decrease your risk or complications related to your MPN." - Dr. Idoroenyi Amanam

[ACT]IVATION TIP: "Make sure you get a clear expectation with your diagnosis as to what that means for you specifically and what the treatments will do for you short-term and long-term." - Dr. Idoroenyi Amanam

[ACT]IVATION TIP: "...if you see high platelet counts, high white blood cell counts or high red blood cell counts on a routine blood check, you should ask your doctor to delve a little bit deeper to try to get an answer as to why your counts are presenting in that fashion." - Dr. Idoroenyi Amanam

MPN FACTS

- MPNs (myeloproliferative neoplasms) are a closely related group of progressive blood cancers where the bone marrow overproduces one of the mature blood elements
- Mostly afflicts people in their 60s or older
- There is no known cure, but stem cell transplants may offer relief for myelofibrosis patients

Source

MPN RESOURCES

- [ACCC](#)
- [CancerCare](#)
- [Cancer Grace](#)
- [Family Reach](#)
- [Lazarex Cancer Foundation](#)
- [MPN Research Foundation](#)
- [Cancer Support Community](#)
- [LLS](#)
- [Triage Cancer](#)
- [MPN Advocacy & Education](#)