

PREPARE FOR YOUR HAEMATOLOGY APPOINTMENTS

1. Bring a list of all your health conditions and the year of diagnosis, including current medications and doses.
2. Bring contact details of other doctors currently involved in your care.
3. Bring a list of questions you wish to ask the doctor, written in order of priority in case you do not have time to ask them all at the appointment.
4. Take other medical reports about general health issues.
5. Establish a timeline of when you started to feel symptoms
6. Take a support person if possible, and ask them to take notes of the consultation for your future reference. It is very easy to forget details otherwise.
7. Let the doctor know if you are pregnant, breastfeeding, or planning to become a parent in the foreseeable future (this applies to men and women). Your treatment plan will need to take this into account.
8. Be prepared for a physical exam including palpation of your abdomen and spleen, and questions about your general health history.
9. Don't be afraid to ask questions, and ask for clarification if you don't understand something. At the end of your appointment, don't be afraid to ask the doctor to sum up the main things you need to take away from the appointment.

QUESTIONS TO ASK YOUR DOCTOR

1. What is my diagnosis?
2. What are my treatment options?
3. If I am to be on "Watch and Wait", what will trigger a change to active treatment?
4. Why would I wait to start treatment?
5. Will I need a Bone Marrow Biopsy? What pain relief will be provided?
6. Do I have one of the 3 major MPN gene mutations – JAK2+, CALR, MPL?
7. What is my risk of thrombosis, and how will you mitigate that risk?
8. How often will I need to have blood tests?
9. How often will I see you in the future?
10. Will I have access to my blood test and other test results?
11. Is there anything I can do to help manage my condition?
12. Are there any symptoms I should watch out for that would require immediate attention?

WHAT YOU CAN EXPECT

- Be prepared for a physical exam including palpation of your spleen and abdomen, and questions about your general health history, and your family history of disease.
- Your haematologist will require a complete medical history and perform a physical examination.
- Blood tests including complete blood counts and biochemistry, molecular testing (JAK2), and possibly CALR, and MPL.
- You will usually be required to undergo a bone marrow biopsy either as part of diagnosis or later in your treatment

SECOND OPINION

You are always entitled to seek a second opinion on your diagnosis and/or treatment. If you feel comfortable to do so, you can ask your haematologist for a referral for a second opinion. Alternatively you can discuss with your GP, and request a referral to another haematologist. If possible and practicable, it is desirable to see a haematologist who treats many MPN patients, or see someone in a major hospital centre.

CONCLUSIONS

- Get involved in your care
- Partner with your physician
- Read quality MPN information, watch MPN videos, and ask questions about your MPN
- Educate your other medical practitioners, dentists, carers etc about your rare condition
- Don't be afraid to seek a second opinion if you have concerns
- Participate in clinical trials if appropriate
- Control what you can ie your diet and lifestyle choices