MPN Matters Issue 16 - September 2021

MPN MATTERS
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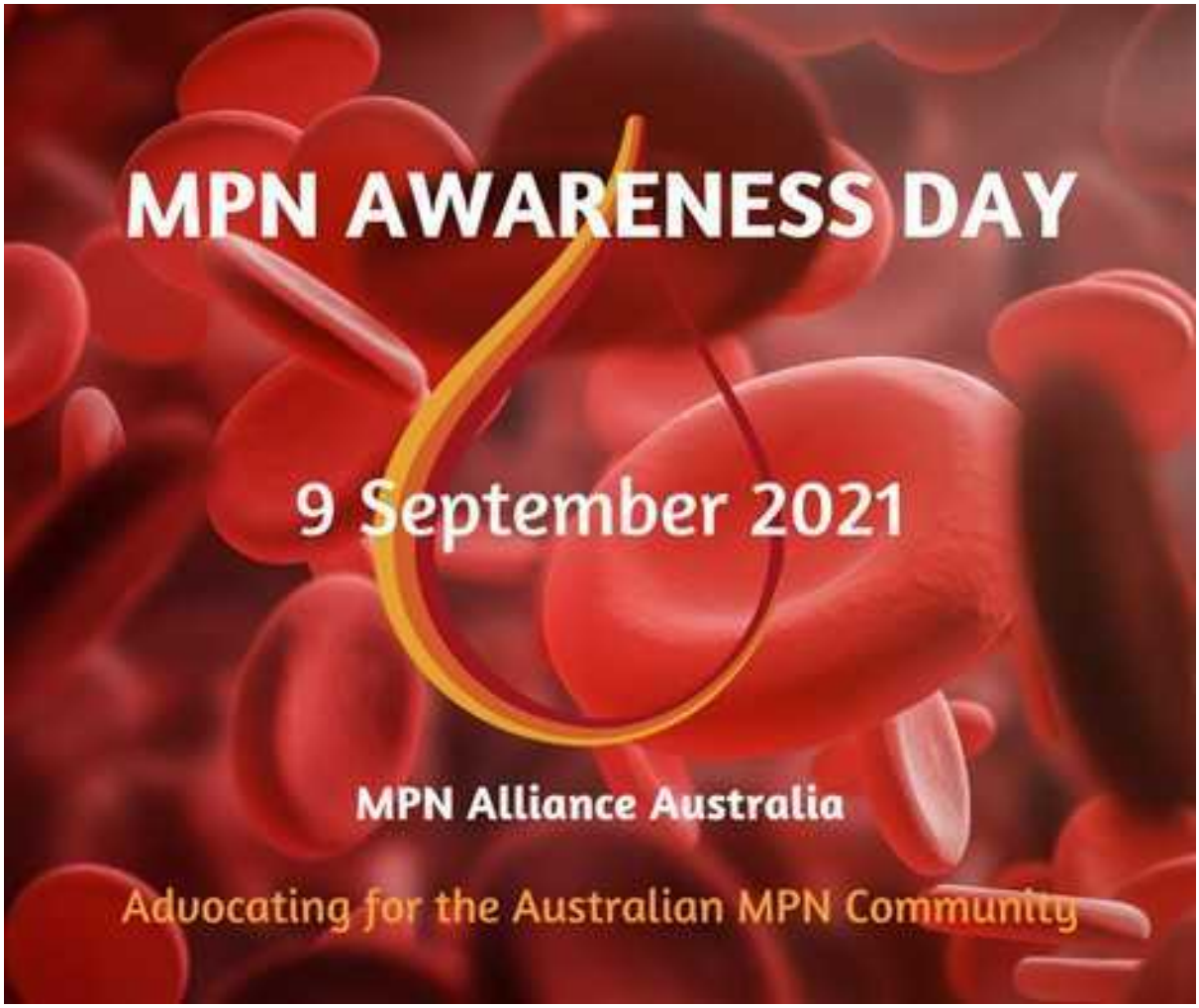


This issue is dedicated to raising awareness of myeloproliferative neoplasms (MPN) on this MPN Awareness Day during Blood Cancer Awareness Month. You will hopefully find some of the information below helpful in explaining your condition to others, and raising awareness of our rare MPNs.

How to Live your best life with your MPN - Leukaemia Foundation Interview with Dr Cecily Forsyth

You may not have read this inspiring interview, in which Dr Forsyth shares tips on how to manage to live well with your MPN. Read the interview HERE

Confused with your MPN?

The language of haematologists is complex. Knowing the lingo can help you find your way in the strange land of MPNs.

When you first learn you have a MPN it can be overwhelming to grapple with a new diagnosis. You might find it difficult to understand what your doctor is telling you, or to grasp what you are reading. People from all walks of life can find haematological terms baffling and this is normal.

What exactly is blood?

Sounds like a silly question, because we all know that blood is that red fluid that travels around the body, but in fact blood is a complex substance. Blood has many functions, including heat regulation, keeping us healthy by fighting infection and supplying every cell in the body with energy. Blood is made from a watery fluid called plasma. Floating in the plasma are several types of blood cells including red blood cells, white blood cells and platelets.

What do blood cells do?

• Red blood cells carry oxygen throughout the body

• Platelets (the name sounds like “little plates”) are flat cells that stack and stick together to heal cuts or wounds

• White blood cells are fighter cells – they work to fight infections in our bodies

Where do blood cells come from?

Our blood cells are made inside our bones. The marrow in our bones is like a factory that produces blood cells. Special cells called “stem cells” (they’re also called “progenitor cells”) live inside the marrow. These cells grow into the cells that travel through our blood, called red cells, white cells, and platelets. When

the blood cells are mature, they pass right through our bone and into the bloodstream and start travelling through our blood vessels to do their jobs all around the body.

What are MPNs?

MPNs are diseases that affect how blood cells are produced in our bodies. The most common types of MPNs are essential thrombocythemia (ET), polycythemia vera (PV) and myelofibrosis (MF). Sometimes people start with one type of MPN and it turns into another type over time. People can also be diagnosed with one MPN but still have some attributes of another MPN. MPNs are classed by the World Health Organization as blood cancers because the bone marrow is producing blood cells in an uncontrolled way.

Do people with MPNs have more risks than other people?

People with MPNs, where the condition is not controlled, have a higher risk than other people of developing blood clots and these clots can cause harm by blocking off the blood flow.

Why is it bad to have too many blood cells?

People with ET can have too many platelets, and people with PV have too many red blood cells. Having too many blood cells clogs up our arteries and veins. Sometimes the cells stick together to form a clot inside an artery or vein, and this can lead to problems.

What happens if I don’t have enough blood cells?

People with MF sometimes don’t have enough blood cells. This is because the blood cell-making factory in their bone marrow is filled up with fibrous material and the blood cells don’t have enough “space” to grow and because the stem or progenitor cells are diseased and unhealthy. Blood cells deliver oxygen to your body, fight infections and repair any injuries or damage. Your body has a hard time doing these tasks when you have MF.

What is blood “stickiness”?

Doctors sometimes refer to platelets and to other blood cells as being “sticky”. When you cut your finger, platelets in your blood stick together to close the cut and form a clot to stop the body from continuing to bleed after an injury. Clots are useful because they stop bleeding, but they can be a serious problem if they occur in the wrong place in your body and at the wrong times.

Which kinds of clots can be a problem?

There are two types of large blood vessels: arteries that carry blood from the heart to the body, and veins that carry blood from the body back to the heart. Blood clots can occur in either type of blood vessel, Arterial clots: A clot in an artery is called an arterial clot and Venous clots: A clot in a vein is called a

venous clot.

Any clot in a blood vessel can potentially be a problem because the clot is like a roadblock –think of your blood cells as cars whizzing along, then encountering a roadblock preventing them from reaching their destinations further down the road. This also means that the tissue on the far side of the roadblock doesn't receive blood and is damaged as a result. If a clot forms a block in the heart, it can cause a heart attack. If a clot blocks blood flow in the brain, it can result in a mini-stroke (TIA) or a stroke.

What does it mean to be at risk?

Having ET or PV increases your risk of experiencing a blood clot such as a heart attack or stroke.(MF is a little different.) There are several different ways to think about risk: considering risk over time and amount of risk.

Your risk can be low, medium, or high depending on how old you are, how healthy you are, and whether you have any other medical problems. If you are young and generally healthy, you might not need to take any medications for your MPN, other than possibly low-dose aspirin. People who are older or have other health issues can have higher risks of developing a clot and they will need more medication to control their blood counts.

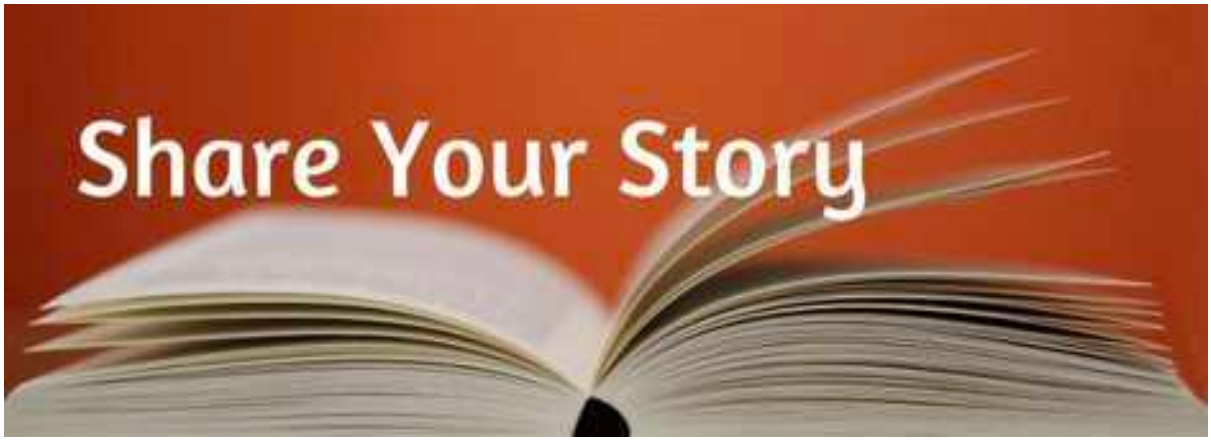
One question to ask your haematologist is whether you are a low-risk, medium-risk, or high-risk - You know you can't diagnose yourself with a google, so please check with your haematologist to get the right advice for you...

Content with thanks to MPNVoice

COVID-19 VACCINATIONS

Many MPN patients have questions about COVID-19 and vaccinations.

The MPN Alliance Australia website has a useful webpage titled COVID-19 Resources for MPN patients which contains evidence-based articles, explaining the need for vaccinations and addressing many of the concerns which are expressed by blood cancer patients. If you are yet to be vaccinated, please view the webpage.



To help raise awareness of Myeloproliferative Neoplasms and to support other newly diagnosed MPN patients, we are seeking patient stories for the MPN Alliance Australia website. If you feel you would like to share your MPN journey, we would be very pleased to hear from you via our Contact email

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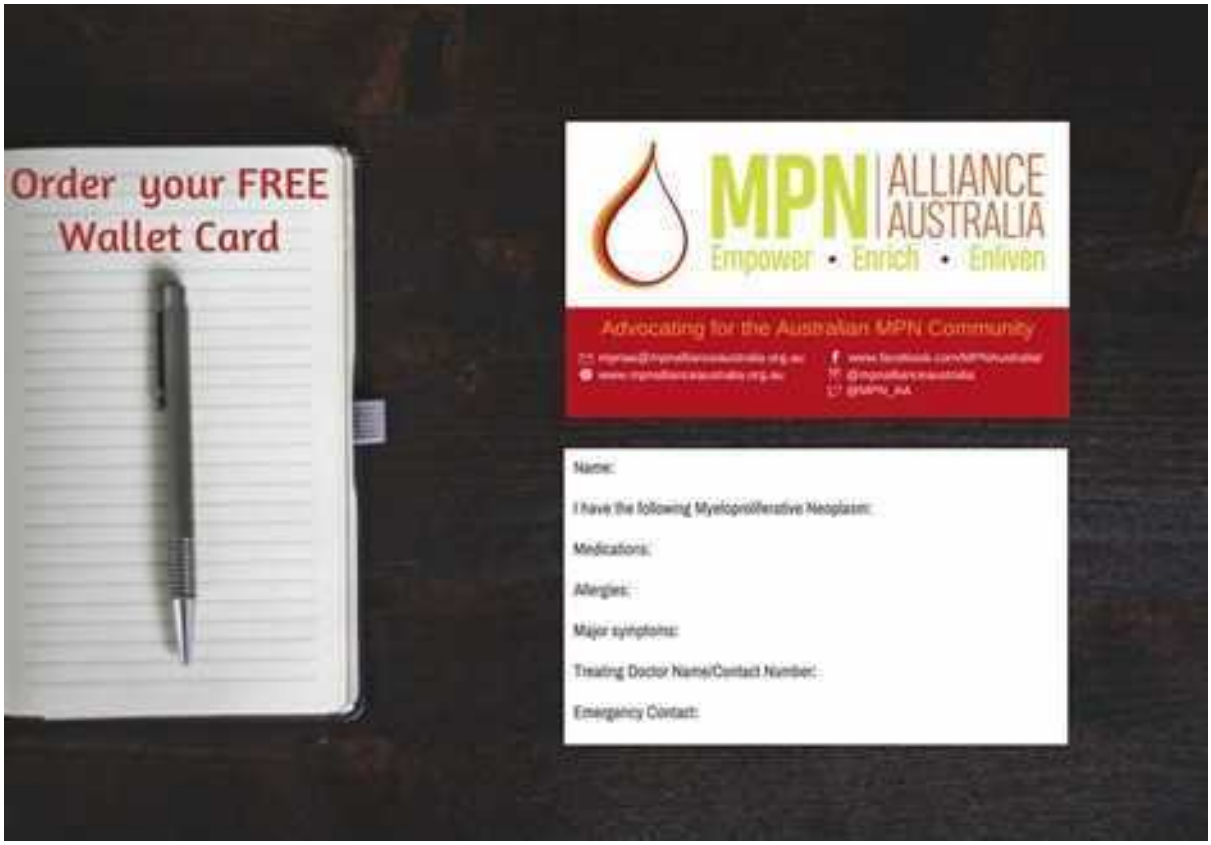

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