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MPN Matters Issue 33 - November 2025



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## MPN MATTERS ISSUE 33 - OCTOBER 2025



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### Australian MPN Symposium – in Perth and online, 25 October 2025

This is a reminder that our wonderful MPN symposium with the theme 'What does optimal management of MPNs look like in 2025' is coming up very soon.

It's not too late to register to attend online.

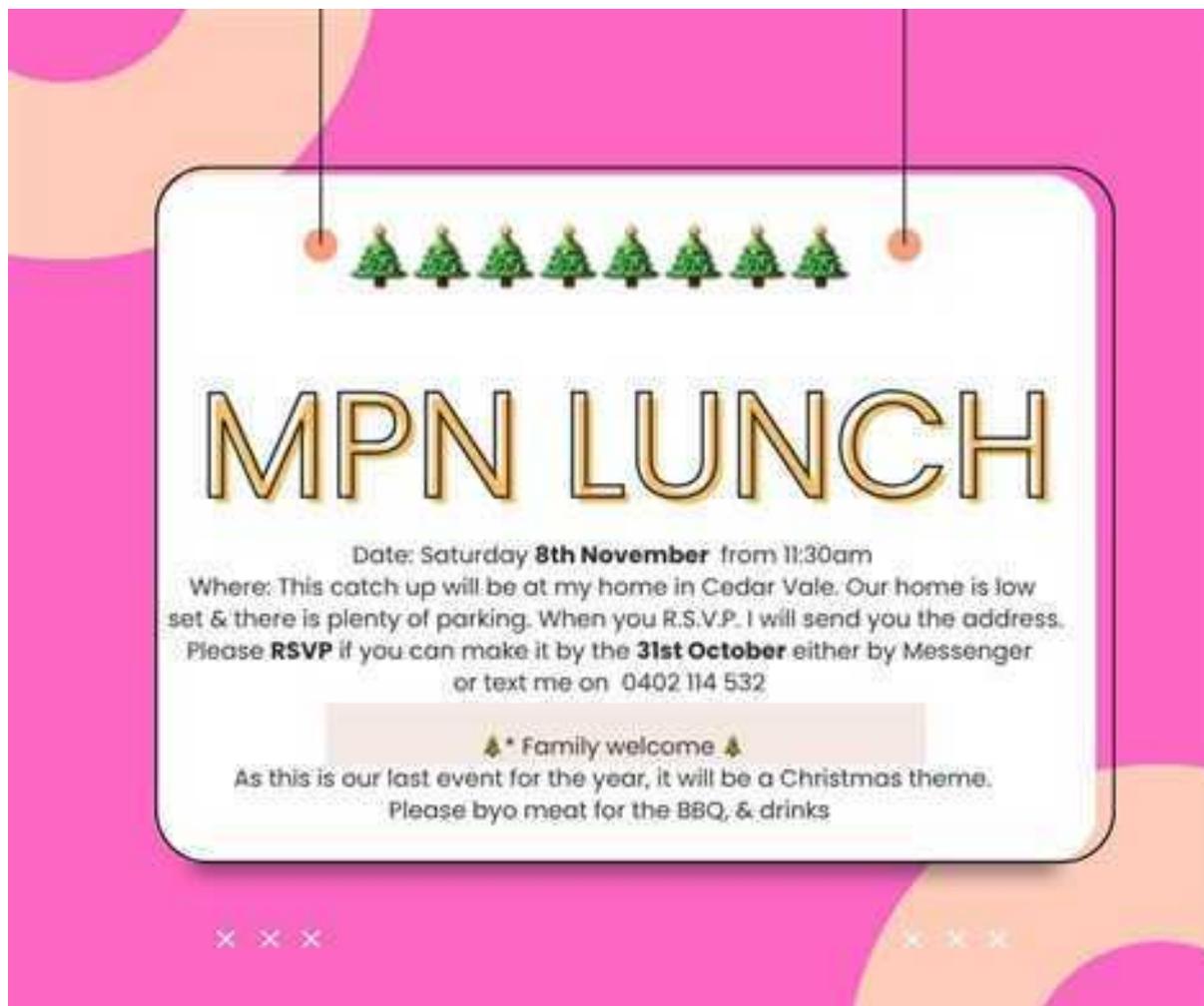
More details on speakers, the program, and how to register, are at <https://www.mpnallianceaustralia.org.au/event/mpn-education-symposium-in-perth/>

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### Christmas Lunch Saturday 8 November for Brisbane MPN patients

Lesley Royle, an MPN AA team member from Brisbane, has very kindly invited MPN patients living in Brisbane and surrounds to the final catch up for the year at her home in Cedar Vale. Lesley has been supporting MPN patients for many years with her regular get togethers.

Thank you so much Lesley!



### **Sharon MacIntyre represents the MPN AA at the 50th birthday celebrations of the Leukaemia Foundation in Brisbane**

MPN AA was recently honoured to be invited to attend the Leukaemia Foundation's 50th anniversary celebrations in Brisbane. Our Brisbane-based team member Sharon MacIntyre was very excited to be able to attend. 'It was a wonderful celebration at Government House. I met the founder of the Leukaemia Foundation - it started in Queensland in 1976. He was so lovely. Dr Steven Lane was there and we chatted. He asked about the Perth MPN

## Symposium and plans to attend.

The amazing Barbie Hartigan was present too. She would coordinate coffee catch ups for the MPN community to meet at Jindalee Hotel each season. This was how I first ever met another mum (same age with a toddler) like me diagnosed young with an MPN! I want to advocate to bring this back.

A lot of guests were shocked that I was diagnosed (with an MPN) at such a young age and have been symptomatic for over 36 years.

I spoke with Chris Tanti, CEO of the Leukaemia Foundation regarding 'Light the Night' (a previous fund raising event for the Leukaemia Foundation) and how awareness and community togetherness was achieved through this. We discussed perhaps bringing it back on a smaller (less expensive) scale.

We also discussed social media and communication going forward and the possibility of graduates or interns for modern revamping /app development.

The highlight though was meeting the Governor and Humphrey B. Bear!

The sunshine was on display and it was a wonderful celebration of a great achievement of 50 years!





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### **World Thrombosis Day, 13 October**

As MPN patients are at a higher risk of blood clots and bleeding, the MPN AA is really pleased to be able to promote thrombosis awareness via World Thrombosis Day on 13 October.

While many MPN patients know that they are at higher risk of a blood clot, they may be unaware that this includes risk of a heart attack or a stroke. That is, we are at higher risk of both arterial and venous thrombosis. The infographics below are prepared for the general public, but provide a good overview of MPN patients' risk factors for blood clots.

**FROM HEAD TO TOE, TAKE CONTROL: PREVENT THROMBOSIS, PROTECT YOUR HEALTH**

**WORLD THROMBOSIS DAY 18 OCTOBER**

## UNDERSTANDING THROMBOSIS: TYPES AND WARNING SIGNS

### Arterial Thrombosis

- Ischemic Stroke**  
Sudden weakness, vision problems, speech difficulty, limb paresthesia/paralysis
- Myocardial Infarction (Heart Attack)**  
Chest pain, shortness of breath, nausea
- Peripheral Arterial Thrombosis**  
Sudden limb pain, cold or pale skin, numbness or tingling, weak or absent pulse, muscle weakness, blue or mottled skin

### Venous Thrombosis

- Deep Vein Thrombosis (DVT)**  
Swelling, pain, warmth, redness
- Pulmonary Embolism (PE)**  
Shortness of breath, chest pain, rapid heart rate
- Cerebral Sinus Venous Thrombosis (CSVT)**  
Severe headache (often the first symptom), vision problems, seizures, nausea or vomiting, stroke-like symptoms (weakness, difficulty speaking, confusion)
- Abdominal Vein Thrombosis (AVT)**  
Abdominal pain, bloating, nausea, vomiting, blood in stool, swelling in abdomen, fever

WorldThrombosisDay.org

Seek medical attention if you have one or more of these signs.

**FROM HEAD TO TOE, TAKE CONTROL: PREVENT THROMBOSIS, PROTECT YOUR HEALTH**

**WORLD THROMBOSIS DAY 18 OCTOBER**

## UNDERSTANDING THROMBOSIS: TYPES AND RISK FACTORS

### Arterial Thrombosis

- Ischemic Stroke**  
High blood pressure, smoking, diabetes, high cholesterol, obesity, family history, advanced age, atrial fibrillation
- Myocardial Infarction (Heart Attack)**  
High blood pressure, smoking, diabetes, high cholesterol, obesity, family history, advanced age, coronary artery disease
- Peripheral Arterial Thrombosis**  
High blood pressure, smoking, diabetes, high cholesterol, obesity, family history, advanced age

### Venous Thrombosis

- Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)**  
Prolonged immobility, prior history of clots, chronic medical conditions, surgery, injury, inherited clotting disorders, family history of blood clots, pregnancy, hormone therapy, cancer
- Cerebral Sinus Venous Thrombosis (CSVT)**  
Hormonal contraceptives, pregnancy, infection, inherited clotting conditions, cancer
- Abdominal Vein Thrombosis (AVT)**  
Blood clotting disorders, cancer, liver disease, abdominal infections, pregnancy, birth control pills, recent surgery

WorldThrombosisDay.org

Seek medical attention if you have one or more of these risk factors.

Please note, that heart attack symptoms can be different for women. To find out what they are click here <https://www.heartfoundation.org.au/your-heart/risk-factors-for-women>. Thanks to the Heart Foundation for this information.

## Warning signs of a heart attack in women



**Chest pain is the most common heart attack symptom in both women and men**

However, women are more likely than men to have non-chest pain symptoms, including:



If you're experiencing any of these symptoms, tell someone. If symptoms are severe, or getting worse, or last for more than 10 minutes, call Triple Zero (000) immediately.

If you'd like to know more, [the World Thrombosis Day website has loads more resources, including brochures in a number of languages.](#)

### "MPN 101" - excellent video resource

This excellent video clearly explains the basics and beyond of MPNs. It has been sent to us by the MPN Advocates Network which is about to hold its annual MPN Horizons meeting. The video is presented by Martin H. Ellis MD, Haematology and Blood Bank, Meir Medical Centre, Sackler School of Medicine, Tel Aviv.

[WATCH the video](#)

### MPN patient brochures now available

We have recently produced a brochure for MPN patients, with a particular focus on 'What can I do to help myself', as well as links to treatment information and where to get support. The electronic version is available to download [HERE](#).

### Ruxolitinib (Jakavi): three updates

## 1. Final Results: Phase 4 Study of Ruxolitinib for myelofibrosis

A study was released in July 2025 in the European Journal of Haematology about the real world impact of ruxolitinib treatment in myelofibrosis patients in Germany.

Titled, '[Final Results From a Large, Non-Interventional, Phase 4 Study of Ruxolitinib for the Treatment of Myelofibrosis in Clinical Routine](#)' it has reassuring findings.

## 2. Ruxolitinib – now available for some polycythemia vera patients

From 1 September 2025 the Jak inhibitor Ruxolitinib (Jakavi) became available on the Pharmaceutical Benefits Scheme for polycythemia vera (PV) patients who are resistant to, or intolerant of, hydroxyurea. This is a valuable outcome to provide an additional treatment option for PV patients. The MPN AA is proud to have made a submission supporting this PBS listing.

## 3. Ruxolitinib - need for regular vigilant skin cancer checks

Despite all the good news about the impact of ruxolitinib as a treatment for myelofibrosis and now polycythemia vera, this is a timely reminder that regular and vigilant skin cancer checks are needed for patients taking ruxolitinib, especially as we live in Australia with one of the highest incidences of skin cancer in the world.

Read more in a letter published in *Blood*, in January 2024 from UK haematologists and dermatologists titled [Outcomes and characteristics of nonmelanoma skin cancers in patients with myeloproliferative neoplasms on ruxolitinib](#)

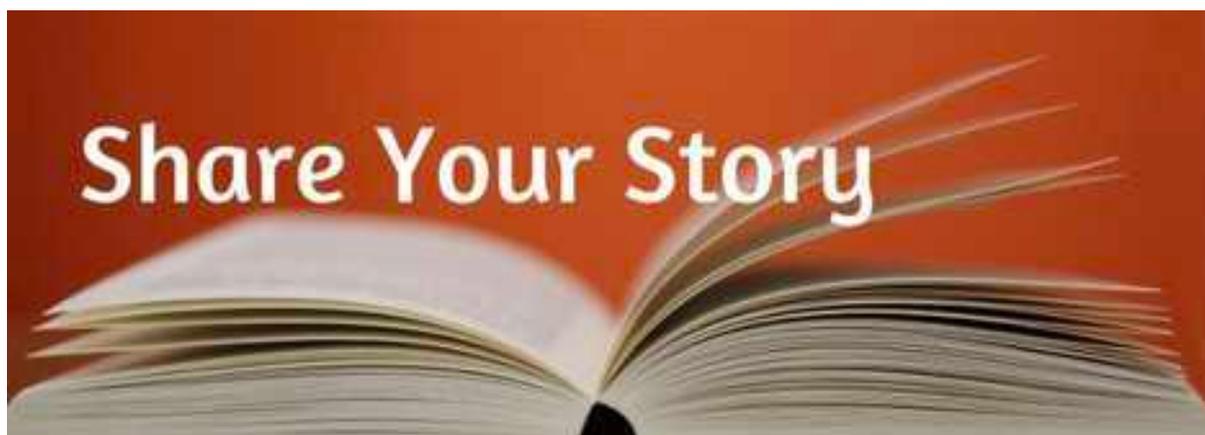
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## Leukaemia Foundation patient information and support events

The Leukaemia Foundation runs Online Support Groups and Webinars throughout the year. They are open to all blood cancer patients. Details of the events and how to register are [HERE](#)

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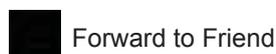
And if you have ideas and suggestions as to how to further support Australian MPN patients, please don't hesitate to contact us on the email link below!



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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**Send us an email**



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