MPN Matters Issue 34 - November 2025

MPN MATTERS
ISSUE 34 - NOVEMBER 2025

AUSTRALIAN MPN EDUCATION SYMPOSIUM 25 OCTOBER 2025
Recordings now available to view

‘What does optimal management of MPNs look like in 2025’

Image: Panel discussion, pictured from LEFT: Researcher Ruby Hamilton, Prof Andrew Perkins, Dr Cecily Forsyth, A/Prof David Ross, Dr Ashlyn Chee, Dr Zi Ng and Michelle Nelson (MPN AA)

In collaboration with UWA School of Biomedical Sciences and Royal Perth Hospital the MPN AA held a hugely successful MPN Education symposium in Perth on 25 October 2025.

We were treated to excellent presentations from MPN specialist haematologists as well as MPN researchers and not forgetting Professor Claire Harrison, an MPN specialist who joined online from the UK.

Along with thanking the wonderful presenters, the MPN AA cannot thank enough Dr ZI Ng, Dr Belinda Guo and our own brilliant team member and MPN patient, Michelle Nelson, for organising the symposium in its entirety!

We urge you to find the time to watch each of the presentations as they are a treasure trove of expert, evidence based and up to date information about your MPN.

This newsletter highlights a snippet of important issues raised at the symposium. We plan to feature issues from a second tranche of these wonderful presentations in our next newsletter.

Videos and PowerPoint presentations are now available HERE.

FRANK'S STORY

Frank attended the MPN symposium and kindly offered to share his MPN story with other patients. Read his story HERE.

We are very grateful to Frank and we think you will enjoy reading his story.

New coffee and chat group offered in Brisbane

New MPN AA team member Sandra has kindly offered to start a new coffee group to connect with other MPN patients in Brisbane. Sandra thought it could be helpful to those patients who live in the eastern and inner-city suburbs of Brisbane, which is nearer to her home.

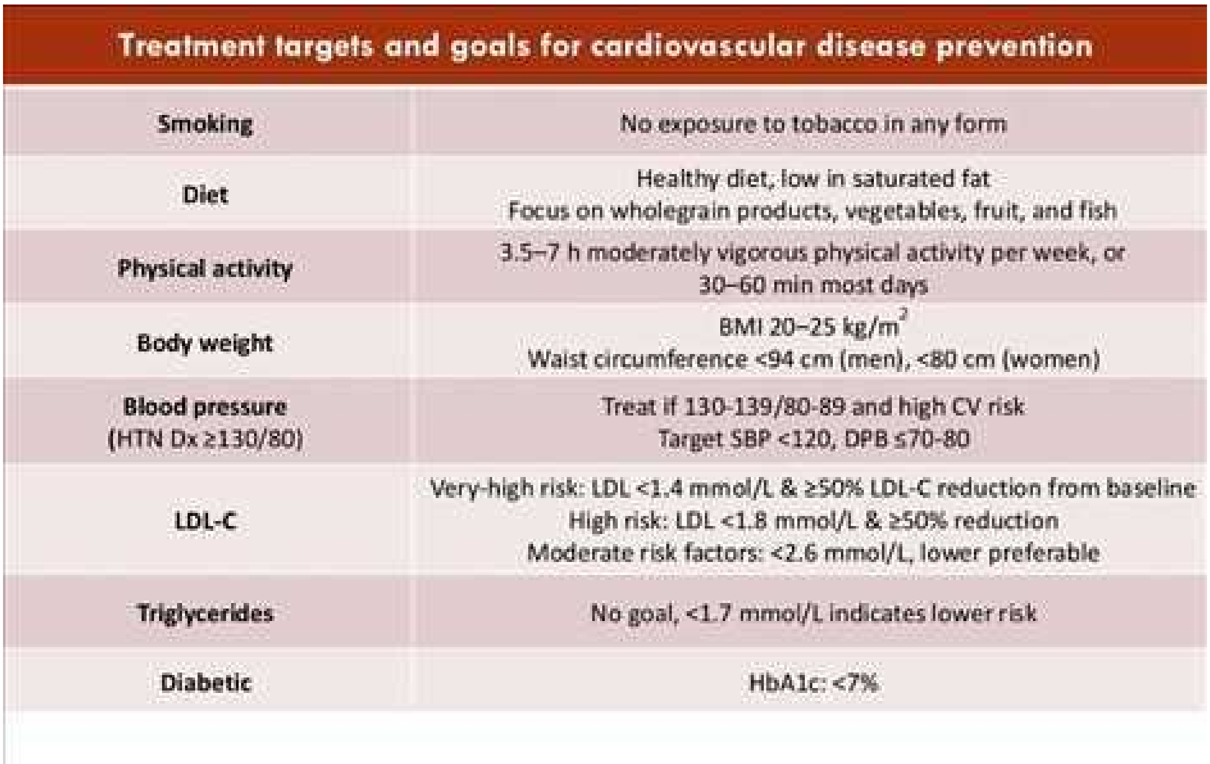
If you would like to connect, please email the MPN AA at mpnaa@mpnallianceaustralia.org.au.

Please note that this new coffee and chat group will be offered at different dates to complement the longstanding wonderful quarterly meet ups run by Lesley Royle. See the photo below of the recent Christmas Lunch at Lesley's home.

MPNs and cardiovascular risk factors

The more patients the MPN AA meets, the more we realise that many aren't aware of the increased cardiovascular risk faced by MPN patients. Dr Cecily Forsyth's presentation at the Symposium highlighted the importance to MPN patients of managing cardiovascular risk factors. See the video of the presentation HERE – her session starts at 35min 40s.

Below is an extract from the presentation.



Treatment targets and goals for cardiovascular disease prevention

Smoking	No exposure to tobacco in any form
Diet	Healthy diet, low in saturated fat Focus on wholegrain products, vegetables, fruit, and fish
Physical activity	3.5–7 h moderately vigorous physical activity per week, or 30–60 min most days
Body weight	BMI 20–25 kg/m^2 Waist circumference <94 cm (men), <80 cm (women)
Blood pressure (HTN Dx ≥130/80)	Treat if 130-139/80-89 and high CV risk Target SBP <120, DPB ≤70-80
LDL-C	Very-high risk: LDL <1.4 mmol/L & ≥50% LDL-C reduction from baseline High risk: LDL <1.8 mmol/L & ≥50% reduction Moderate risk factors: <2.6 mmol/L, lower preferable
Triglycerides	No goal, <1.7 mmol/L indicates lower risk
Diabetic	HbA1c: <7%

To add further weight to Cecily's presentation, in Denmark, a retrospective study 'showed that of the 538 patients with ischemic stroke, 61 (11.3%) had JAK2V617F mutation. There were no differences in patient demographics or cerebrovascular comorbidities between the patients with and without mutations.'

There was also a recent article about atrial fibrillation and MPN patients with the Jak2 mutation which may be of interest.

Predict Blood Tool

Predict Blood

Predict Blood is an online tool to help health professionals see how a person's blood cancer (known as myeloproliferative neoplasm, or MPN) might develop given their age, gender, health and any information that is known about genetic variations that they carry.

While there was so much to learn and remember from the Symposium, we would like to highlight the **online prognostic tool PREDICT BLOOD**.

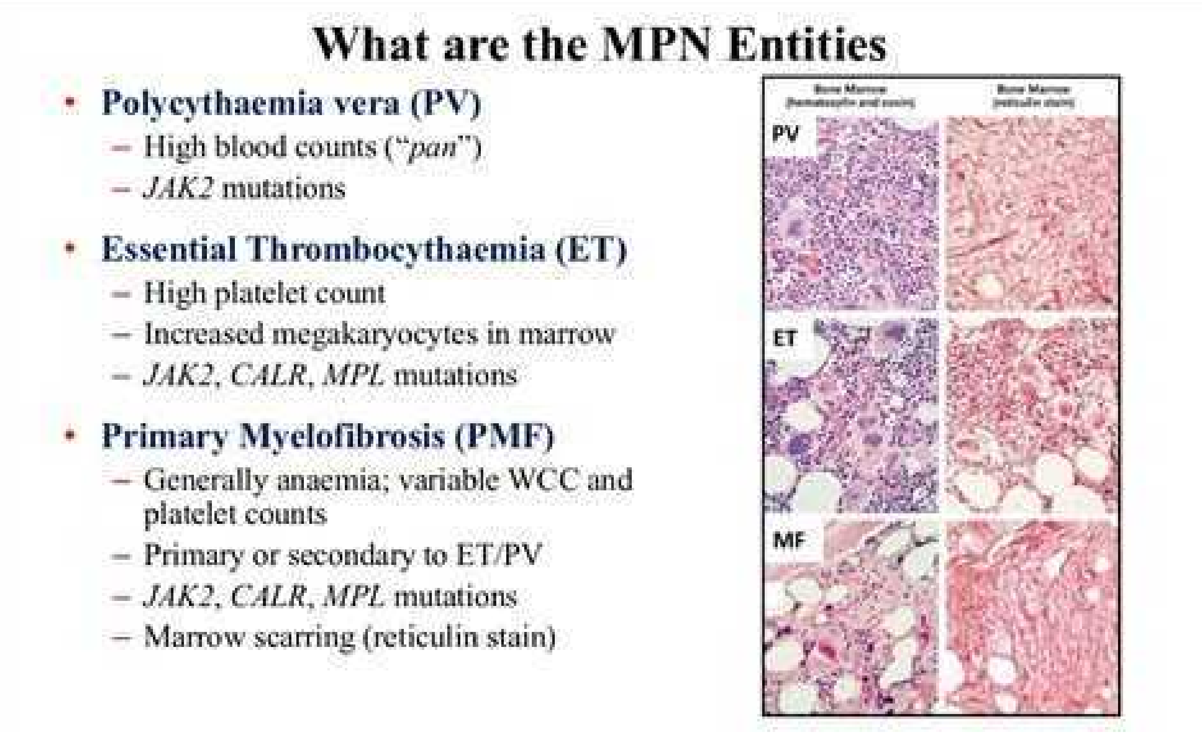
The Predict Blood website explains that 'Predict Blood is an online tool to help health professionals see how a person's blood cancer (known as myeloproliferative neoplasm, or MPN) might develop given their age, gender, health and any information that is known about genetic variations that they carry.'

It was developed at Cambridge and can be used for all MPN patients.
https://blood.predict.nhs.uk/

Professor Andrew Perkins also mentioned that it was his favourite MPN predictive tool.

The importance of MPN patients having a bone marrow biopsy

At the Symposium Professor Wendy Erber provided a wonderful explanation of MPN bone morphology. She emphasised her view about the importance of MPN patients all having a bone marrow biopsy as part of our diagnostic workup. She explained that this provides a baseline for our haematologists to manage our disease.
One of her slides below shows examples of bone marrow differences between the three main MPN entities.



What are the MPN Entities

- **Polycythaemia vera (PV)**
  - High blood counts ("*pan*")
  - *JAK2* mutations
- **Essential Thrombocythaemia (ET)**
  - High platelet count
  - Increased megakaryocytes in marrow
  - *JAK2, CALR, MPL* mutations
- **Primary Myelofibrosis (PMF)**
  - Generally anaemia; variable WCC and platelet counts
  - Primary or secondary to ET/PV
  - *JAK2, CALR, MPL* mutations
  - Marrow scarring (reticulin stain)

MYELOFIBROSIS GUIDELINES COMMENTS SOUGHT

Public comment is open on draft recommendations for new guidelines on myelofibrosis

The treatment landscape for myelofibrosis has been evolving over the last decade and there are so many treatments available although sadly still no cure except for a stem cell transplant.

Professor Andrew Perkins alerted us at the Symposium that the American Society of Hematology (ASH) is seeking public comment on their draft recommendations for new guidelines on myelofibrosis.

Comments are due by 24 November which doesn't give you much time and we apologise for the late notice. Here is a link to further information.

Focaccia Recipe

This recipe is from MPN AA team member, Sharon.

Ingredients

☐ 600 grams of Caputo flour
☐ 480ml of water
☐ 7 grams of dry yeast
☐ 15 grams of table salt
☐ 2 tablespoons of olive oil

Method

1. Mix the flour and yeast in a bowl and add the water tempered
2. Mix to almost all flour is absorbed, then add salt and olive oil
3. Knead in your bowl until all flour is dissolved and keep kneading for a couple of minutes. It will be sticky, and that is perfect.
4. Drizzle olive oil over the top, cover with a damp tea towel and set aside for 30 minutes.
5. After 30 min, stretch and fold all four sides – that is, pinch the side, pull up and fold on top. Do this 4 times i.e. stretch and fold, wait 30 mins, repeat four times. This stretches out the gluten and creates air pockets
6. For maximum flavour, put in your fridge covered overnight to let the gluten form, just add more olive oil over the top and spread so it doesn't dry out
7. Pull out of fridge, wait an hour, then transfer carefully to your baking tray - metal non-stick is preferred.
8. Heavily oil your tray first!- Cover again and let it rest for an hour
9. Cover with olive oil and kosher salt, dimple it with your fingers and add to the oven on 220 degrees fan forced for 22-25 minutes
10. Take out of your tray onto a wire rack and let it sit for 30 minutes to continue baking, before slicing- slice in quarters, cut your quarter in half, length ways (like a sandwich) and load it up with porchetta or similar! Enjoy :)

NB Sharon advises she uses Caputo pizzeria 00 flour from Coles. ‘It's the best I've found and makes for a great focaccia!’

Leukaemia Foundation Lived Experience Engagement Program

The Leukaemia Foundation runs a Lived Experience Engagement Program which may be of interest to some MPN patients. It’s about sharing personal experiences to help shape and improve the Leukaemia Foundation’s services, programs and advocacy**.** So if you’d like to help improve experiences for people with blood cancer, more information is available **HERE**.

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

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

Send us an email

Leukaemia Foundation

Share Forward to Friend

Website:
www.mpnallianceaustralia.org.au

Our mailing address is:
Myeloproliferative Neoplasms Alliance Australia (MPN AA)
Post Office Box 111
Sandringham, Victoria 3191
Australia