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MPN Matters Issue 31 - June 2025



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### European Haematology Association (EHA) congress 2025 MPN sessions

MPN Hub Steering Committee members have provided their recommendations for the top abstracts relating to MPN research and treatment from the recent 2025 EHA congress. These include a number of presentations relating to myelofibrosis, exciting developments in CALR, and also research on MPL-mutated ET. See here to browse and read these important [EHA 2025 MPN abstracts](#).

This link provides [more coverage of the 2025 EHA Congress](#) MPN presentations from the MPN Hub website.

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## An often unknown risk for MPN patients - Cardiovascular Health in Patients with Myeloproliferative Neoplasms



MPN patients are generally aware that we're at a much higher risk of blood clots such as in the legs, lungs, or even in unusual sites such as the spleen or surrounding veins. But there seems to be less awareness that having an MPN also puts us at higher risk of a heart attack or a stroke (ie a cardiovascular) event.

**In fact, the very first point in the 2025 MPN treatment guidelines from the US's National Cancer Care Network is to 'manage cardiovascular risk'.** So it is super important for MPN patients to do all we can to improve our cardiovascular health.

We have included this excellent video presentation from US cardio-oncologist Dr Stephanie Feldman in a previous newsletter. As we regularly have new subscribers, we feel we can't emphasise this issue enough. Dr Feldman explains how MPN patients can best manage our cardiovascular health. The presentation is 28 minutes long. If you're really pressed for time, the HOW TO part starts at 14 minutes 55 seconds.

The presentation is available [HERE](#).

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## New MPN Treatment options on the horizon in Australia

The Australian government, guided by recommendations from the Pharmaceutical Benefits Advisory Committee (PBAC), has shown strong support for listing new treatment options for MPN patients.

The government **recently listed momelotinib (Omjjara)** on the Pharmaceutical Benefits Scheme (PBS). This drug, originally developed by researchers in Melbourne, is anecdotally already showing promising improvements for myelofibrosis patients with anaemia. You can find the drug company's treatment brochure for Omjjara on the MPN AA website [HERE](#)

Additionally, at its March meeting, the **PBAC recommended ruxolitinib** be added to the PBS for polycythemia vera patients who are intolerant or resistant to hydroxyurea. While this is still subject to a final approval before any listing, a PBAC recommendation is a crucial first step.

The PBAC also recently considered **fedratinib** for myelofibrosis patients for inclusion on the PBS, and their recommendation from that meeting is eagerly awaited.

The dedicated, small team at MPN AA has provided submissions to the PBAC for all these treatment options. We thank any patients who also submitted their own valuable input.

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## Brisbane MPN "Lunch Catch-Up"

We are very happy to let you know about an MPN lunch catch up in Brisbane on Saturday 19 July. See flyer above or read here for [further details](#).

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## A new tool for MPN patients to summarise their medical history

An Australian MPN patient has developed an innovative information tool that other patients may find useful. She's called it an information graphic or 'infographic' and has kindly agreed to share it with other MPN patients. It's intended for patients who are very informed about their medical history and collective records and especially those with more than one health condition.

While it aims to provide background for an initial haematologist appointment, it can also be used for informing future consultations and to facilitate discussion.

In the example provided, it summarises 10 years of medical history, with key health events and the blood tests that have been consistently abnormal i.e. clotting history and low blood counts. When it was actually used at the appointment, the infographic helped to quickly identify trends, patterns, and possible relationships between health events and test results. By “talking to the infographic” it enabled the patient to talk to key information, explore all relevant issues with the haematologist, and help ensure that important issues were not overlooked or incorrect assumptions were made.

The [infographic is available on the MPN AA website](#) with many thanks to the MPN patient who has developed it!

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### **International series of articles about ‘Prevention, diagnosis and management of myeloproliferative neoplasms’ in "*Haematologica*"**

For patients keen to delve deeper into the latest MPN treatments and research, this international series on MPNs is excellent. It includes papers by Australian researchers and haematologists and was published in April this year in *Haematologica*. Papers are free to access [HERE](#).

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### **Healthy Recipe - Easy high protein vegetable slice**



This recipe makes 4 generous serves. Each serve provides 22g protein, 30g carbohydrate, 280mg calcium and 5g fibre and is packed with vitamins and minerals. You can vary the vegetables depending on what you have. It's delicious served warm with a salad or vegetables.

### Ingredients

- 2 medium carrots, grated
- 2 medium zucchinis, grated
- 1 medium onion, chopped
- 1 tablespoon olive oil
- 2 slices of shortcut bacon, fat trimmed off and chopped
- 5 eggs, beaten
- 1 cup of grated tasty cheese
- 1 cup whole meal self raising flour
- Chopped fresh herbs such as parsley, chives, coriander.
- 1 tomato thinly sliced
- 1 capsicum finely sliced
- Cracked pepper

### Method

Preheat oven to 180C. Fry chopped bacon in oil until golden. Cool. Mixed

together carrots, zucchini, onion, eggs, flour, chopped herbs, bacon and grated cheese until combined. Spoon mixture into a greased baking dish (I used a Pyrex dish measuring 19 x 15cm) and smooth the surface. Top with tomato slices and chopped capsicum. Bake for about 35-45 minutes until golden and slightly risen.

*Thanks to Nathalie Cook OAM, accredited practising dietitian*

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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!

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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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