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MPN Matters Issue 28 - December 2024



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Ruxolitinib for some PV patients? Have your say!

We have been notified that the Pharmaceutical Benefits Advisory Committee (PBAC) March 2025 meeting agenda includes a request for consideration to extend the existing approval of Ruxolitinib to include adult patients with PV who are resistant to or intolerant of hydroxycarbamide (hydroxyurea).

This is an opportunity for PV patients who may have previously been unable to access Ruxolitinib, and whose haematologists would support their use of it. If you are unsure, we suggest discussing this with your haematologist.

Consumers are invited to provide comments and the period to provide them closes on 29 January 2025.

Read more and about [how to submit comments](#).



Stem cell donors required

The MPN AA is collaborating with Stem Cell Donors Australia to help publicise how easy it is to register as a stem cell donor and how important it is to do so. It can save lives.

A certain percentage of MPN patients will have to make the choice to undergo a stem cell transplant. If you are an MPN patient needing a transplant, please refer to [the transplant information on the Leukaemia Foundation website](#).

If you know someone interested in helping save a life, please read on.....

There is a huge need to increase the number of registered stem cell donors in Australia, particularly of people from diverse ethnic backgrounds. The age range from which donors are sought for the registry is 18-35.

Registering as a donor – only involves a cheek swab

Registering to be a stem cell donor is really that simple. Most people who register are never actually called upon to donate. But if you are a match, you have the power to save someone's life. And if you match.... the stem cells are simply taken from a blood donation. Imagine how it would feel to be able to save someone's life.

Please help get the message out to your family and friends. The website [Stem Cell Donors Australia](#) explains how easy it is.

MPN Horizons meeting 6-8 September 2024 Warsaw – A personal

reflection from Sharon MacIntyre, MPN AA team member



"Well let's just say it was an honour to attend the MPN Horizons conference this year. There was representation from MPN specialists, many MPN advocacy groups, PV ET & MF patients, pharmaceutical companies and more! The title "Shifting the treatment paradigms of MPN" was very apt. Since I first attended in 2017 sponsors have grown from 3 to now 11! And patient advocacy groups now include Thailand, Korea, and other nations which previously were not represented. It is such a growing global family to address MPN needs. The almost 70 participants in Warsaw Poland were from an amazingly geographically spread 26 countries, including Australia, India, Chile, to Europe, America and Asia! All were very vocal in sharing new developments for MPN from research to trials, to advocacy and patient stories. All sharing a key purpose - to make life better for MPN patients".

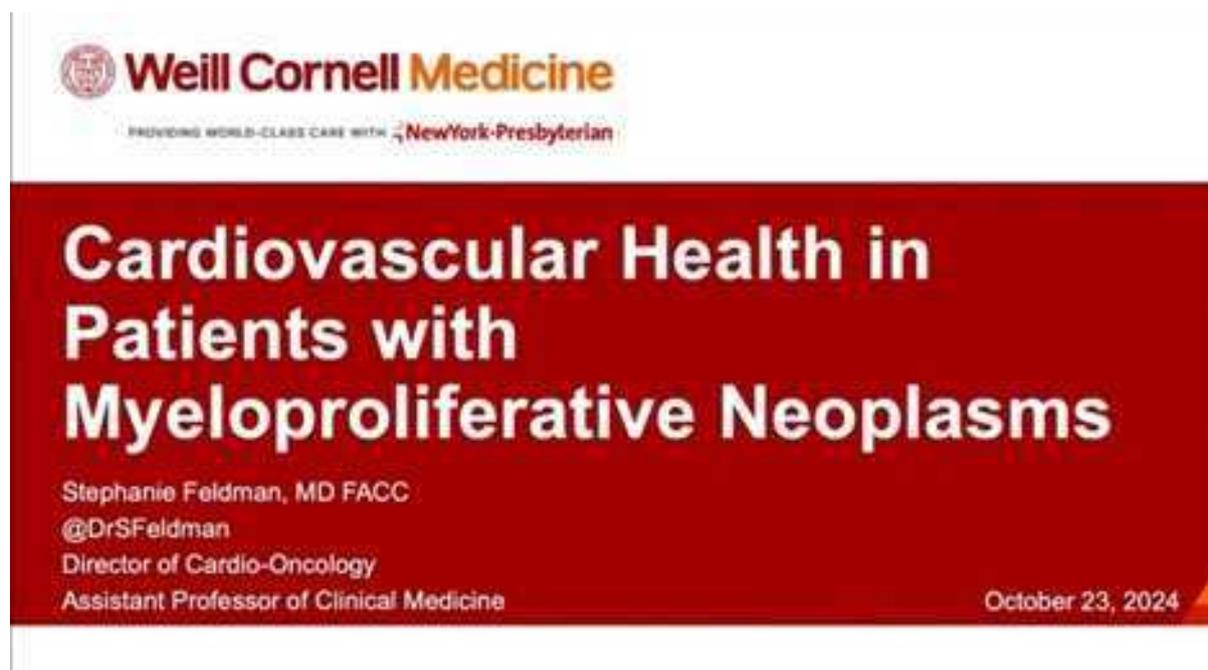
[Read Sharon's full report](#) about her impressions and takeaways from the meeting.

JAK2V617F mutation is highly prevalent in patients with ischemic stroke

[A Danish study has reported that the Jak2 mutation was found in 11% of stroke victims,](#)

This finding further underlines the importance of MPN patients managing their cardiovascular risk factors, in conjunction with their haematologist.

At an October 2024 MPN symposium, US cardiologist Stephanie Feldman explained how to manage our cardiovascular health. She also gave a quick 'cardiology 101' explanation of how our heart works - "plumbing, pump and electricity issues" - and what MPN patients need to be aware of. Her excellent presentation is freely available to watch [HERE](#).



MPNs and inflammation

Another excellent presentation from that same MPN Symposium is from Dr Hans Hasselbalch from Denmark. His topic was 'MPNs and inflammation' and

he covered:

- the huge numbers of undiagnosed MPNs around the world,
- the significant impact of chronic inflammation in MPN patients, heightening cardiovascular risk along with other risks,
- research showing the possibility of targeting and eliminating the Jak2 mutation in its early CHIP stage with statins,
- the increased risk of inflammatory bowel disease in MPN patients,
- the benefit of early intervention treatment with interferon, and
- an evidence-based potential role for statins for MPN patients.

Dr Hasselbalch's presentation is available [HERE](#).

Message for patients taking Anagrelide

The MPN AA has become aware of a warning placed on the MPN treatment Anagrelide.

Haematologists are aware that anagrelide must not be suddenly stopped, but we wanted to highlight this issue for patients taking anagrelide. Patients must not stop anagrelide suddenly and should contact their haematologist if they'd like to stop taking it. The warning states:

SPECIAL WARNING AND PRECAUTIONS FOR USE

Do not stop using anagrelide suddenly without checking first with your doctor. Rather you may need to slowly decrease your dose before stopping it completely. Stopping suddenly will cause the platelet level in your blood to increase quickly. It should be noted that there is risk of thromboembolic events during this rebound phase which may lead to potentially fatal thrombotic complications, such as cerebral infarction. Platelet counts should be monitored closely when anagrelide is ceased.

[The relevant page of our website has been updated, as has the printable PDF treatment document Anagrelide \(in English\).](#)

Christmas Prawns - Sri Lankan inspired Issa Thel Dala

One of our team members, Sharon, is of Sri Lankan heritage and has kindly provided us with this gorgeous recipe



Ingredients

- . 500g raw green or banana prawns in their shells
- . sprig of curry leaves (or 14 individual leaves)
- . ½ red onion, finely chopped
- . a red chilli or two (optional or to your taste)
- . 3 cloves of chopped garlic
- . 1 level teaspoon turmeric
- . 1 level teaspoon cumin
- . 1 level teaspoon cinnamon
- . ½ teaspoon chilli powder (optional if you can handle the heat)
- . salt to taste
- . 1/2 red capsicum, chopped
- . 1/2 punnet cherry tomatoes, chopped

Method

1. In a wok on medium heat drizzle some oil.
2. Add in 1 sprig of curry leaves (or 14 individual leaves) stir until the oil is

infused with curry leaf flavour.

3. To this add half a finely chopped red onion, a red chilli or two, and 3 cloves of chopped garlic. Add about a small teaspoon each of turmeric, cumin, cinnamon (chilli powder if you can handle the heat) & salt.

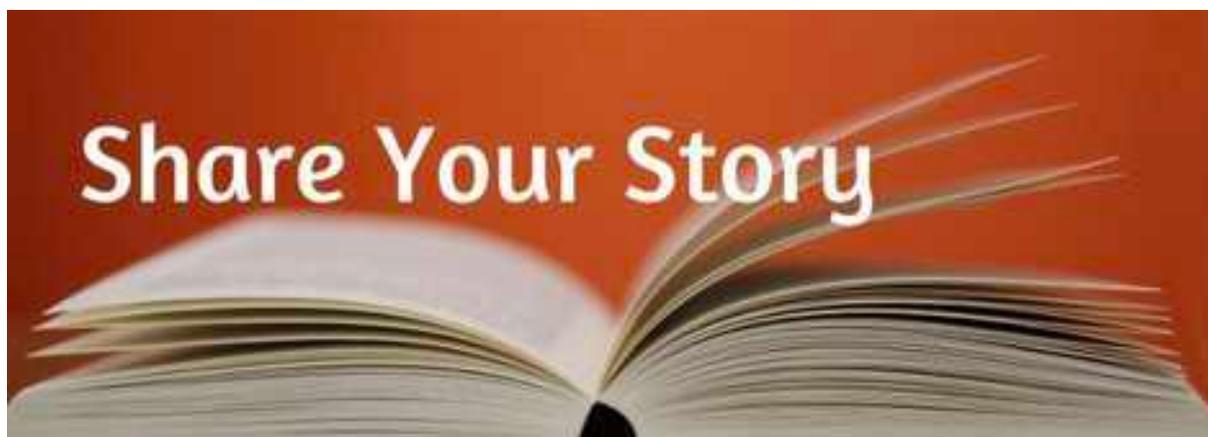
5. Stir this until fragrant.

6. Add the raw green banana/tiger prawns with some chopped red capsicum and chopped cherry tomatoes.

7. Stir fry until prawns are just cooked.

8. If you like it creamier - add half cup of coconut milk.

9. Enjoy with salads & or basmati rice.



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



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