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MPN Matters Issue 29 - February 2025



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FEDRATINIB (Inrebic) - a new drug option for myelofibrosis patients available in Australia? PBAC consultation now open - closes 26 March 2025

There remains an important need in Australia for more treatment options for myelofibrosis (MF) patients. Fortunately, the Pharmaceutical Benefits Advisory Committee (PBAC) is now calling for submissions on the inclusion of Fedratinib for MF patients onto the PBS.

The PBAC is particularly interested to learn about MF patients' lived experience of our disease: how it affects daily life, how it impacts work, family, how current treatment affects us, any side effects and so on.

Overseas experience and clinical trial data show that Fedratinib (also known as Inrebic) is a particularly valuable treatment option for MF patients with low platelets.

If you have myelofibrosis, please consider writing to the PBAC. The process of making a submission is simple.

Submissions will close on 26 March 2025. The link is available [HERE](#).

If you would prefer to provide comments for inclusion in the MPN AA's submission, please email us at mpnaa@mpnallianceaustralia.org.au.

New treatment to overcome need for phlebotomies presented at the American Society of Hematology (ASH)

We are thrilled to announce that findings from clinical trials of a new drug with the potential to eliminate the need for phlebotomies was presented at the December ASH meeting by haematologists and researchers including Walter and Eliza Hall Institute's Dr Indu Raman.

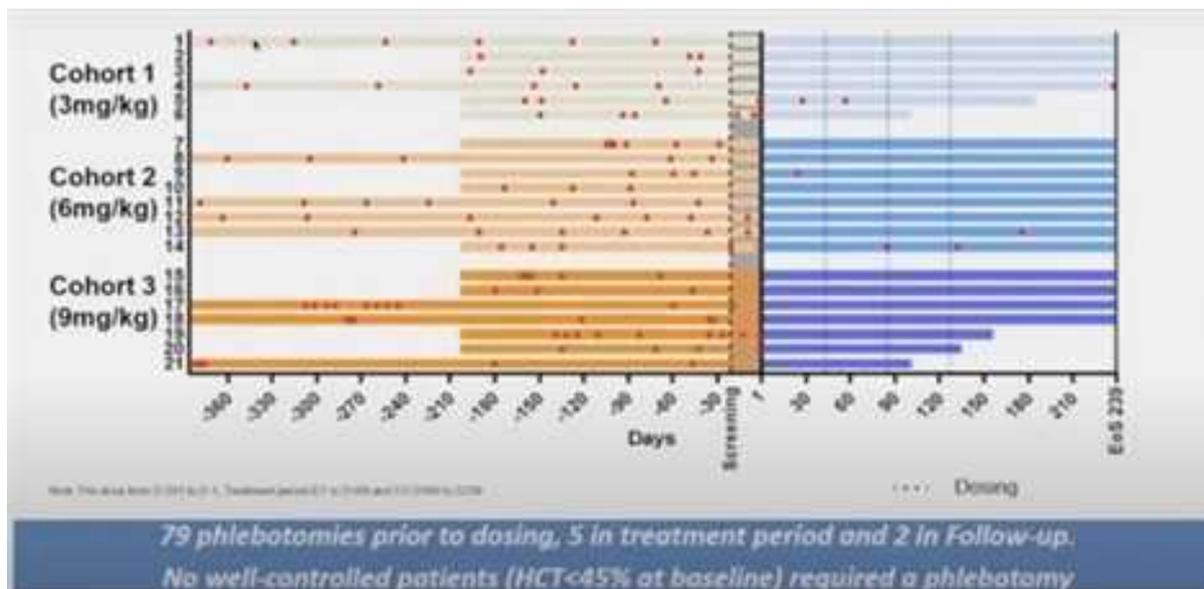
Divesiran is the name of this newly developed drug. It 'increases hepcidin and is being developed for treatment of PV. Phase 1 preliminary results suggest that divesiran is safe and well-tolerated. Importantly, divesiran clearly decreased the need for phlebotomy with a convenient dosing regimen (every 6 weeks) suggesting it serves as a potential effective treatment to control erythrocytosis in PV. These findings support further development of divesiran in PV.' (ASH abstract)

Below is a snapshot from the presentation at ASH showing how the need for phlebotomy was almost eliminated – PV patients required 79 phlebotomies before treatment with divesiran and only 5 phlebotomies during treatment and 2 in follow up. This is really promising for PV patients who often have to tolerate ongoing phlebotomies for many years.

The preclinical studies for divesiran were conducted at Melbourne's Walter and

Eliza Hall Institute by Dr Cavan Bennett and Prof Sant-Rayn Pasricha's team. You can read about how divesiran works in our previous article, [here](#). To learn more about the pre-clinical research you can read Dr Bennett's article published in *Blood*, [here](#).

If you have any questions for Dr Indu Raman or Dr Cavan Bennett please send them to mpnaa@mpnallianceaustralia.org.au.



Travelling with Pegasys Syringes



Many Australian MPN patients are now using Pegasys as their MPN treatment. Patients often ask how to keep their Pegasys syringes at the right temperature when they travel, particularly long-distance. We thought we'd let you know about a travel pack that one of our Canberra patients has successfully used on an extended trip to Europe.

It's called 4 ALL FAMILY Voyager (see image above). It maintains the temperature between 2-8 degrees Celsius with its USB charger and has an inbuilt thermometer. The USB charger can be used on the plane to maintain the temperature indefinitely, assuming your seat has a USB charging port. Or it also comes with a freezer pack which the product information states can maintain the correct temperature for 30 hours. The pack as shown above is 3.3" (8.1cm) in diameter and 8.9" (22.6cm) in height.

For more details, please see [the product website](#).

We have also previously suggested another cool pack along the lines of '[Fridge to Go](#)'. This is a more affordable option and their website advises their products will keep medications cool for up to 8 hours. It relies on a freezer block which once defrosted will no longer keep the contents cold, so you need to decide

what will work best for you based on your own travel plans.

We would love to hear of other solutions which we can also publicise for other patients. Please contact us by email to share your knowledge.

New year and another new study promoting exercise's wider benefits

You may have already seen various articles we've posted about exercise. For example, if '[exercise could be marketed as a pill, it would be an outright blockbuster.](#)'

However a new study from Stanford in the US was recently released and has revealed additional benefits from exercise: '....changes in the kidney, in the adrenal gland, in the intestine, in the brain..... reducing the risk of heart disease by 50 percent, reducing the list of many cancers by 50 percent and more, reducing the risk of back pain. People sleep better. They have better mood. They're able to breathe better. There are just so many ways in which exercise helps.'

The full video interview (with transcript) is available [HERE](#).

However, please be sure to check with your GP or haematologist before launching on any new exercise program and start slowly and gently if you haven't exercised before or not for some length of time.

The SIMM study: Survey of integrative medicine in myeloproliferative neoplasms

Once again as it is the beginning of a new year, we thought it would be useful to remind you about the Survey of Integrative Medicine Study of MPN patients. It was first published in 2020 but still highly relevant today.

Integrative medicine refers to wellness activities such as: yoga, aerobic activity, strength training, meditation, massages, support groups, improved nutrition etc.

An international study of hundreds of MPN patients showed wellness activities had a pattern of decreased levels of symptom burden, fatigue, depression, and an improved quality of life for MPN patients.

The full study is available [HERE](#).

One important take away for us was the contribution of MPN support groups to a higher quality of life. So if you're interested and have some spare time, why not start up a regular coffee and chat in your local area? In Canberra, a couple of MPN AA members run a weekly walk and/or coffee and chat and it has been a great way to support each other.



Canberra MPN support group enjoying coffee and chat after a walk

3 video presentations on highlights from the December ASH meeting in the USA

You are probably aware that the American Society of Haematology (ASH) holds an important conference each December to showcase world haematology developments in research, treatments and general information sharing of clinical trials etc. We have linked three separate presentations from the recent meeting for you if you're interested.

1. An extensive [presentation by Dr Claire Harrison and UK colleagues](#), courtesy

of MPN Voice in the UK explains their main take aways from ASH. It is a long presentation at 90 minutes but if you have the time to watch it, it's extremely informative. The last 30 minutes are a Q and A session and the haematologists address many of the questions we see asked by MPN patients.

2. Courtesy of Ann Brazeau of MPN Advocacy and Education International, a second much briefer but great overview from Dr Ruben Mesa (and of a very different selection of presentations from ASH) is available [HERE](#)

3. And if you're really keen, a third MPN overview (15 minutes) with international haematologists courtesy of VJHEMONC is available [HERE](#).

Vitamin B6 in supplements can cause peripheral neuropathy

ABC news recently featured a warning from the Royal College of Pathologists of Australasia about the amount of vitamin B6 in some vitamin and other supplements commonly sold in Australia. What was quite noteworthy was that high amounts of B6 are often included with other supplements such as magnesium. The excess B6 has been found to be responsible for cases of peripheral neuropathy.

Advice from the Therapeutic Guidelines of Australia (TGA) is [HERE](#) and the January 2025 ABC news article is [HERE](#).

This latest warning echoes information that the MPN AA's Nathalie Cook has been presenting for some time. Below is an image from a 2022 presentation she gave to the MPN Advocates Network Conference.

Nathalie has recently been made aware that **Kombucha tea has very high levels of Vitamin B6** after one of the GPs at her clinic had a patient recently with peripheral neuropathy who was drinking a couple of litres of kombucha per day, but was not taking any supplements with added B6. It turns out kombucha is extremely high in B6 due to production by the bacteria during fermentation of the product.

And in addition to being mindful of your vitamin B6 intake, no matter what

supplements you may consider taking, please remember to first check with your haematologist and GP as many supplements can interact with, or are contraindicated with, MPN treatments and other medications.

Caution with Vitamin B6/pyridoxine supplements: Potential for dose-related toxicity - peripheral neuropathy (tingling, burning or numbness in hands & feet)

The infographic displays several Vitamin B6 supplements: a large white bottle of Optifast, a box of Optifast Shake Assorted, a green bottle of Nature's Own Vitamin B6 200mg, a box of Nature's Own Magnesium, and a box of Nature's Way Magnesium. A flowchart on the right contains three blue boxes with white text:

- Box 1: "Vit B6 is found naturally in many foods. Food sources have not been reported to cause adverse effects."
- Box 2: "Vit B6 toxicity has occurred at a daily dose of >50 mg a day. • (Rec. Dietary Intake = 1mg/d)"
- Box 3: "Vit B6 can accumulate from: Vit B6 eggs (multivitamins, magnesium etc.) • Long term ingestion of foods or drinks fortified with B6 (Energy drinks, breakfast cereals, meal replacement shakes)"

In Australia products with >50mg Vit B6 have a label warning:

"WARNING - Stop taking this medication if you experience tingling, burning or numbness and see your healthcare practitioner as soon as possible. (Contains vitamin B6)" (Currently under TGA review)

© NatHelle-Cook O&M RPD (2022)

Crunchy high protein muesli recipe



The following recipe is from accredited practising dietitian Nathalie Cook, OAM. Nathalie advises that this is an approximate recipe that can be varied depending on what ingredients you have on hand. On this occasion she used:

Ingredients

- 3 cups rolled oats
- 1 cup oat bran
- 1/2 cup desiccated coconut
- 2 cups mixed seeds and nuts (sunflower seeds, chia seeds, sesame seeds, flax seeds, pumpkin seeds and chopped walnuts, almonds, pistachios etc)
- 1/2 cup skim milk powder
- 1 tsp cinnamon
- 2 tbsps honey
- 2 tbsp olive oil
- 3 egg whites, lightly beaten
- 1-2 cups dried fruit (such as sultanas, currents, chopped dates and chopped figs)

Method

1. Warm the honey in the microwave and stir in oil.
2. Add honey and oil mixture to rest of the ingredients, except the egg whites

and dried fruit.

3. Mix in the egg whites until everything is well combined.
4. Spread mixture over a large oven tray and break up any large chunks.
5. Bake at 160C, for about 30 -45 minutes, stirring every 10 minutes until evenly toasted.
6. Remove from oven and allow to cool before stirring through the dried fruit.
7. Once the muesli is completely cool, store in airtight containers.

Enjoy with Greek yoghurt and fresh or stewed fruit.

Note: The dried fruit is added after toasting the muesli to prevent it from burning. The milk powder and egg whites increase the protein content and add crunchiness.

Enjoy!

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



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