MPN Matters Issue 21 - October 2023

# MPN MATTERS
# ISSUE 21 - OCTOBER 2023

## Polycythemia vera – game changing drug to combat iron deficiency now in clinical trials

*Dr Cavan Bennett (R) is pictured in the lab with Nathalie Cook OAM (a PV patient) from the MPN AA who is part of the WEHI patient consumer program **

A game changing new drug for polycythemia vera (PV) patients is now in clinical trials in Australia, Malaysia and the US. The drug (known as SLN124) has been developed by a team of research scientists in Melbourne.

This newly developed SLN124 has the potential to be a huge step forward in PV treatment. It aims to stop overproduction of red blood cells. This would also overcome the need for regular venesections which by design make PV patients increasingly iron deficient. While iron deficiency slows down the bone marrow from making too many red blood cells it has its own adverse effects. And iron supplements are rarely a solution for PV patients. They can rapidly increase hematocrit, forcing the need for more venesections and resultant further iron deficiency.

This new drug works thanks to a simple principle. It restricts the bone marrow accessing iron from the blood rather than removing iron from the body, limiting iron deficiency. By stopping overproduction of red blood cells, venesections would no longer be needed. Principal researcher Dr Cavan Bennett, said that restricting iron access to the bone marrow could reduce the disease severity of PV and was a gamechanger.

More detailed explanations from the researchers as to how this new drug works are available in two separate media items HERE and HERE.

This significant discovery also featured in the ABC’s internationally renowned Health Report with Norman Swan. Podcast and transcript available HERE.

If you have PV and need regular venesections, you may be eligible to participate in the clinical trial. Please discuss with your haematologist.

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## Link between haemochromatosis and PV

*WEHI researchers (L-R): Dr Victoria Jackson, Professor Melanie Bahlo, Dr Cavan Bennett and Professor Sant-Rayn Pasricha**

While developing this new drug SLN124, researchers made a further significant discovery. They uncovered a link between haemochromatosis and PV. This was made possible by the use of many thousands of patient records in the UK and in Finland.

“This saw us further discovering that the genetic mutations which cause hemochromatosis are one of the strongest risk-factors for diagnosis of PV – an insight that will help the research field better understand this rare disease.”

Professor Melanie Bahlo.

A fuller explanation of this and its implications is available HERE.

The MPN AA cannot thank enough these and other Australian researchers who are working in the field of myeloproliferative neoplasms. The researchers from the WEHI involved in this study were: Cavan Bennett, Victoria Jackson, Anne Pettikiriarachchi, Thomas Hayman, Gemma Moir-Meyer, Katherine Fielding, Ricardo Ataide, Danielle Clucas, Andrew Baldi, Alexandra Garnham, Connie Li-Wai-Suen, Warren Alexander, Melanie Bahlo, Ashley Ng and Sant-Rayn Pasricha

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## Myelofibrosis drug Momelotinib approved by the US FDA

Here is an Australian news item about the US FDA approval of Momelotinib, a new drug for Myelofibrosis. This is significant as there are few treatment options for those with myelofibrosis, and this is another option for those for whom other therapies are unsuitable. We would love to see it made available to Australian patients in the future.

## Newly diagnosed patients

The MPN AA has put together an extensive page of information for patients who are newly diagnosed. Even MPN patients diagnosed for years or decades might also find it a useful reminder of the support and information available to you.
The "Newly Diagnosed" page on the MPN AA website is linked HERE.

## COVID-19

Unfortunately COVID-19 is still amongst us. A member of our team has just recovered from it. Here is the latest advice from ATAGI regarding vaccination boosters (dated 1 September 2023).

## Leukaemia Foundation online support groups

The Leukaemia Foundation offers a variety of online support groups. We try to keep them up to date on the EVENTS section of our website and you can also find details directly via the Leukaemia Foundation's website HERE.

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## Upcoming webinar 13 October

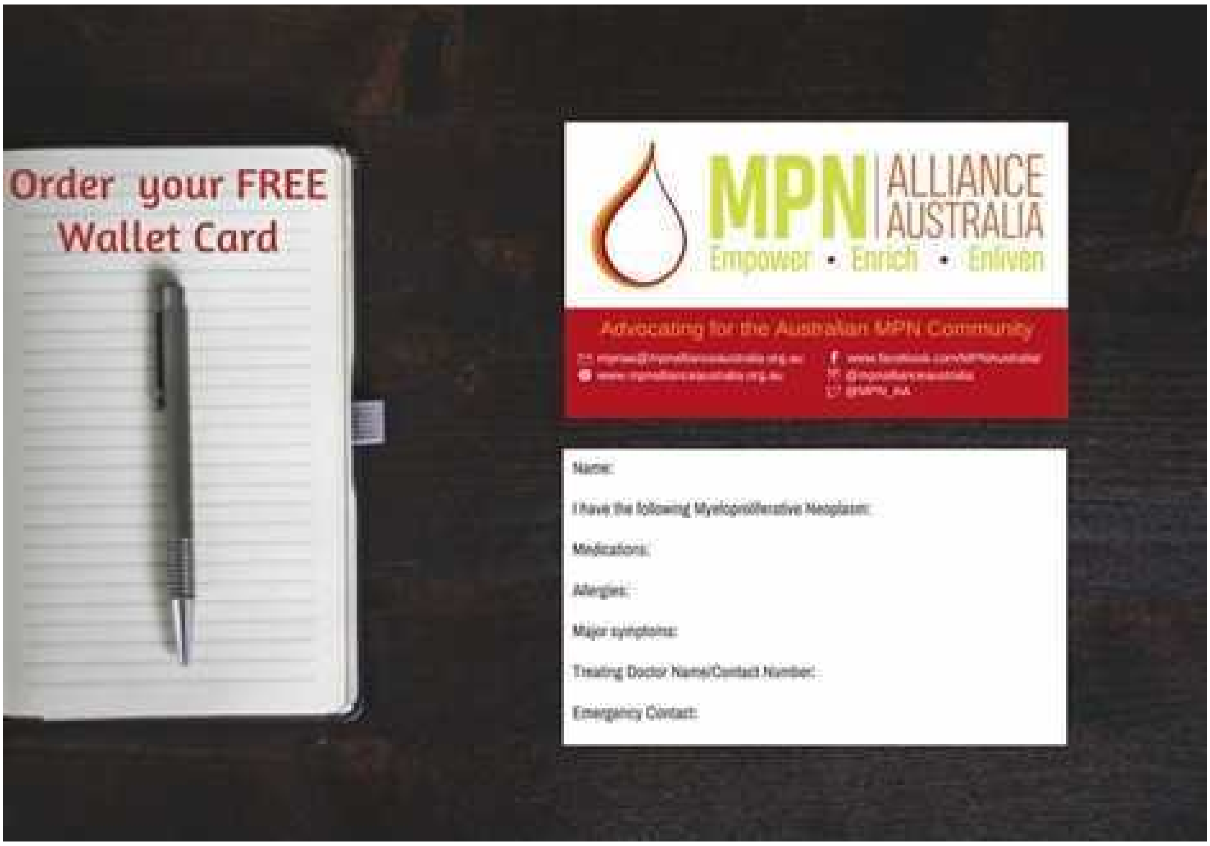
### Ageing with blood cancer/blood disorders

The Leukaemia Foundation is running this webinar 'Ageing with blood cancer/disorders' on 13 October at 11.30am (AEDT). For Queensland, NT, SA and WA, please check the time in your state.

The guest speaker for this webinar is oncologist Dr Ranjana Srivastava OAM. 'Most people diagnosed with a blood cancer or disorder are over the age of 65. As we age, we are likely to have other medical conditions. It is important to have a good understanding of your health needs to advocate for your health and wellbeing. This webinar will provide you with the information, skills and confidence to help you manage this and live as well as possible.'
In this webinar you will hear about:

- Key medical considerations
- Being proactive in your own health care
- Promoting health & wellbeing
- Where to find information & the help you need
- Planning future care needs & end of life considerations

More details about the webinar including how to register are available HERE.



## MPN AA Wallet Card

Do you have an MPN wallet card? If you are an Australian resident, you can order your free card to complete with your own details. These cards are useful to show to medical providers, dentists and other people who need to know about your MPN. Send us an email, and don't forget to include your postal address.

## Living well with an MPN

### Vitamin D

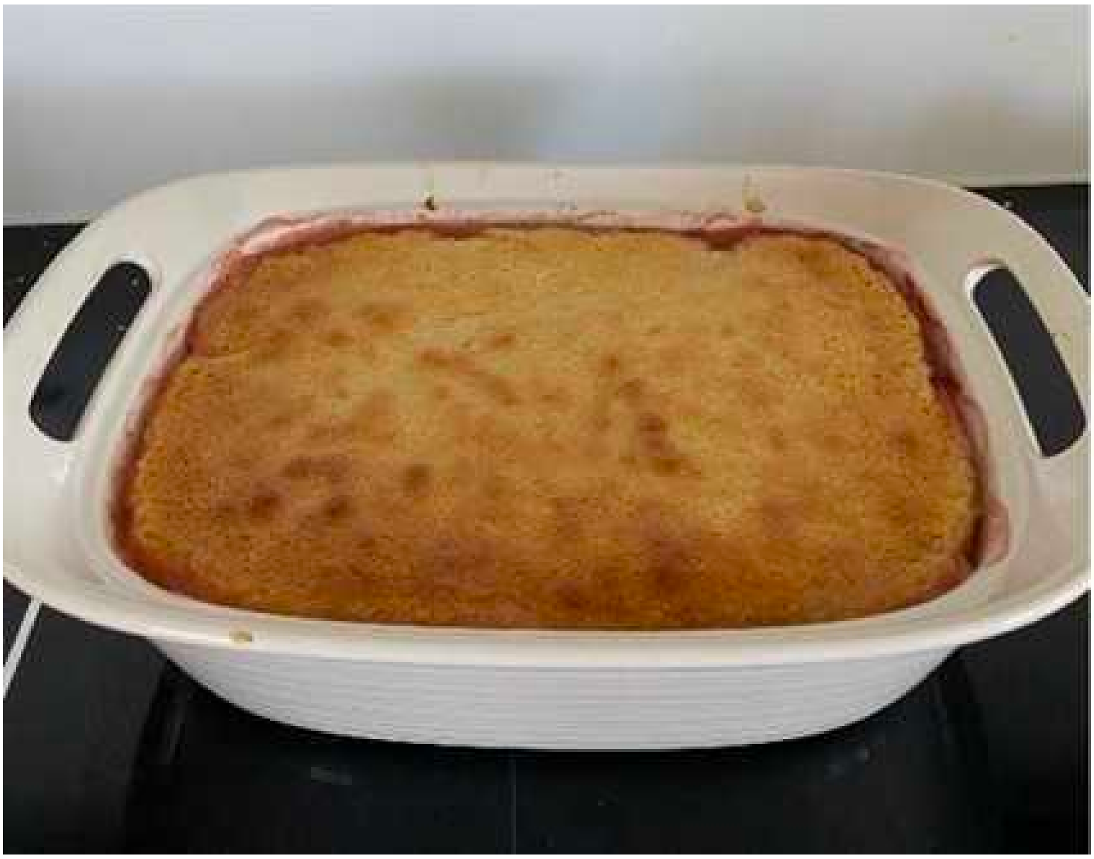
Adequate vitamin D is important for good health. It’s ideally best to obtain vitamin D through safe sun exposure and eating vitamin D rich foods. Mushrooms are rich in vitamin D and via a simple tip, you can supercharge the amount of vitamin D in those mushrooms.
Put the mushrooms in the sun, gill side facing the sun, for about 15 minutes.
This article explains it in more detail.

### Improving your Balance

Another living well tip is to work on improving your balance.
This article in ‘The Conversation’ explains the benefits and how easy it can be.

If you find these helpful, the MPN AA has many pages about living well with an MPN.

## Apple and strawberry sponge



One of our Canberra team members recommends making this recipe with freshly stewed apples and lightly poached strawberries. This is a great way to include fruit in your diet, and serving it with custard or yogurt adds a serve of dairy for strong muscles and bones.

**Ingredients**
125g butter
3/4 cup sugar
2 eggs
1/2 cup milk
1 ½ cups self raising flour
1 tsp vanilla essence
2-3 cups of stewed fruit (2 cups of apples and 1 cup of strawberries are a

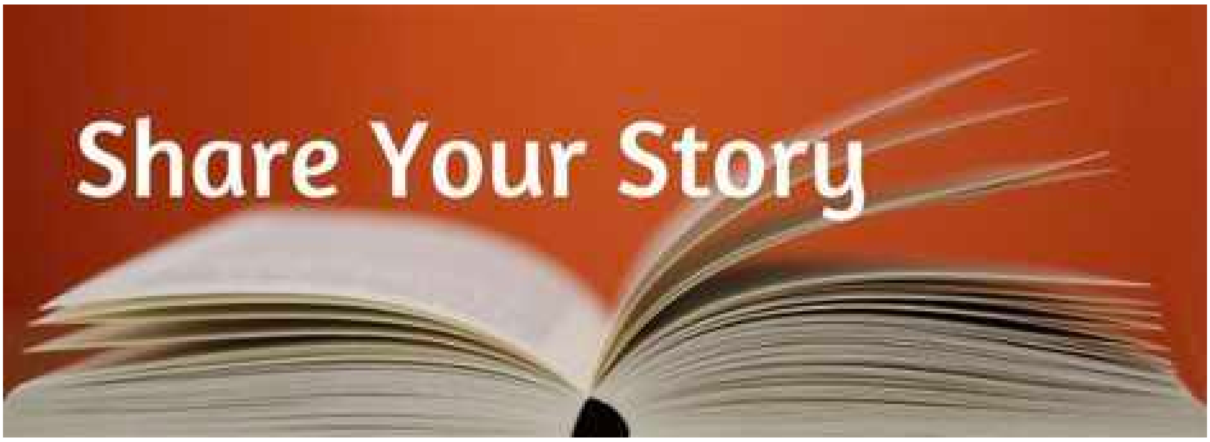
delightful combination with a quarter of a cup of sugar, or less to taste. Frozen strawberries are fine to use)

**Method**

Heat oven to 180 C (160 fan forced).
Cream the butter and sugar together until fluffy.
Add eggs and beat until combined.
Slowly add the flour and milk and beat until smooth.
Spoon mixture onto stewed fruit and cook for 30-40 minutes, until browned and topping springs back when lightly touched.
Serve while hot, but it still tastes great cold.
Serve with yoghurt or custard.

***Variation***

Any stewed fruit is fine to use and you can try cutting back on sugar for both the fruit and topping to taste.
You could always substitute almond meal for the flour or gluten free SR flour for a gluten free alternative.



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**

Share Forward to Friend

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