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MPN Matters Issue 18 - September 2022



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# MPN MATTERS

## ISSUE 18 - SEPTEMBER 2022





**MPN Alliance Australia Fellowship: Engineering and Pre-Clinical Validation of CALR+ directed CAR-T cells**

MPN Alliance Australia is very excited to announce the award of a fellowship grant worth \$30,000 to Dr Chloe Thompson-Peach, an early career researcher with SAHMRI and the University of Adelaide.

Dr Thompson-Peach has previously been involved in research in this area as reported in the article below. The fellowship will enable her to continue researching a therapy for CALR-driven myelofibrosis which has potential to benefit many current and future MPN patients.

To read more about Chloe's planned research, click [HERE](#)

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### **Generous Donation by MPN patient**

The grant to Dr Chloe Thompson-Peach was made possible by a generous donation of \$30,000 from Sarah Gardner following a fundraiser for the MPN cause. Sarah donated the proceeds of her fundraiser to the MPN AA fund via the Leukaemia Foundation. Sarah has been recently diagnosed with an MPN, and has previously raised funds for other important causes. We are extremely grateful to Sarah for making this grant possible, and we are hopeful the research will lead to real change for those patients with CalR mutated MPNs.

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## **Myelofibrosis treatments – evolving and increasingly promising**

Since the discovery of the Jak2 mutation in 2005, and then the Cal R mutation in 2013, research into potential treatments for MPNs has attracted world-wide interest and is flourishing. (And if you'd like to know more about those relatively recent discoveries, the links below will give you more information).

Researchers are increasingly optimistic about the potential to target the CalR mutation (in a similar way to how Chronic Myeloid Leukaemia is now able to be targeted and successfully treated). Work in the CalR MPN space is occurring not only around the world but also in Adelaide, where very promising research is underway. This is the research

showcased at the beginning of this newsletter, and you can read more about it [HERE](#).

In addition to this Australian work on CalR, substantial research and clinical trials are focusing on myelofibrosis both here and overseas. There are a raft of articles and videos available on-line about these developments, but we recommend the video by MPN specialist haematologist Dr Ruben Mesa who provides an excellent overview on the significant evolving therapy in all the classic MPNs. For patients with myelofibrosis (MF), this is especially relevant and important. Discussion of MF therapies starts at 27.42 minutes into the video, which can be viewed [HERE](#). (with thanks to the MPN Education Foundation).

With this wave of research into MPN treatments, availability of clinical trials is also expanding. Already early results are encouraging. While some therapies are not yet approved in Australia, some may be accessible here via clinical trials. If you have MF and think you might be interested in participating in a clinical trial, your haematologist can provide you with more information. Watch this Leukaemia Foundation video to learn more about Clinical Trials for blood cancer [HERE](#).



## **Myeloproliferative Neoplasms - Towards Precision Medicine**

Australian Centre for Blood Diseases - Monash University

13 October 2022

6pm - 7.30pm

Myeloproliferative neoplasms (MPNs) are a rare, difficult to treat group of blood cancers. Understanding the genetic lesions in MPNs can transform diagnosis, prognosis and treatment.

Please join the discussion into the role of genetics and new therapeutic options in MPNs, and how medical staff, researchers and the MPN community can work together towards precision diagnostics for MPN patients.

[Register](#) for this hybrid event to attend in person or online.

For more information, here is the [flyer](#) or watch this [short video](#) introduction

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## MPN AA's News and Events pages

Don't forget to look at our MPN AA website news pages. We try to keep MPN patients up to date with the major MPN research announcements so please regularly check in on our News page on our website to keep up to date. Read the latest news [HERE](#)

Similarly, our Events pages list the Leukaemia Foundation's online blood cancer support groups, webinars and presentations by MPN experts.

Since COVID, we have had less events to inform you about. However, every month, the

Leukaemia Foundation provides a topic specific number of online support groups which are facilitated and cover a range of different topics such as Advocacy, Resilience, Coping, Coping Financially etc. For news of upcoming events, see [HERE](#)

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### Nathalie Cook OAM

MPN patient and MPN AA team member, Nathalie has continued to provide high quality resources for patients with MPNs and other blood cancers. Nathalie was a presenter in the recent Leukaemia Foundation webinar titled "Nutrition and Blood Cancer". In case you missed it, [here is the link](#).

Nathalie also featured in a recent Leukaemia Foundation "Talking Blood Cancer" series podcast. You can listen to Nathalie's fascinating

story [HERE](#).

We are very proud of Nathalie who was awarded an OAM earlier this year for her services to dietetics.

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## What can you do about MPN symptoms and fatigue?

If you suffer from MPN symptoms, you are encouraged to raise these with your haematologist. While some studies show that a large percentage of MPN patients are symptomatic, especially with fatigue, many MPN patients are relatively symptom free once their blood counts are well controlled.

MF patients however may be more likely to experience symptoms so don't forget to keep a record of your symptoms so you can remember to mention them at your appointment.

Managing your symptoms is best achieved by a combination of medical management and taking control to improve your own lifestyle. Research has shown that participating in appropriate physical exercise, yoga, meditation and getting involved in pleasurable activities with others can really improve well-being.

There is more information and many ideas to improve your wellbeing on our website on our [Living Well](#) page.

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## DELICIOUS PEAR CAKE

This is a simple, delicious, and moist cake which is easily mixed by hand in one bowl. It is perfect for a special treat for dessert or morning or afternoon tea. Any left-over cake can be frozen in individual wedges and gently warmed in a microwave.

### Ingredients:

- 1 ½ cups self-raising flour
- 1 cup sugar (raw sugar or white sugar or mixture of both)
- ½ teaspoon baking soda
- 1 teaspoon cinnamon
- ¼ teaspoon salt
- 1 ½ cups diced pear (plus 2 pears cut into narrow wedges to decorate base of cake tin as per photo)
- 1 large egg (lightly beaten)
- 1 teaspoon vanilla
- Grated rind of 1 lemon
- ½ cup of light oil (light olive, rice bran, sunflower etc)

### Method:

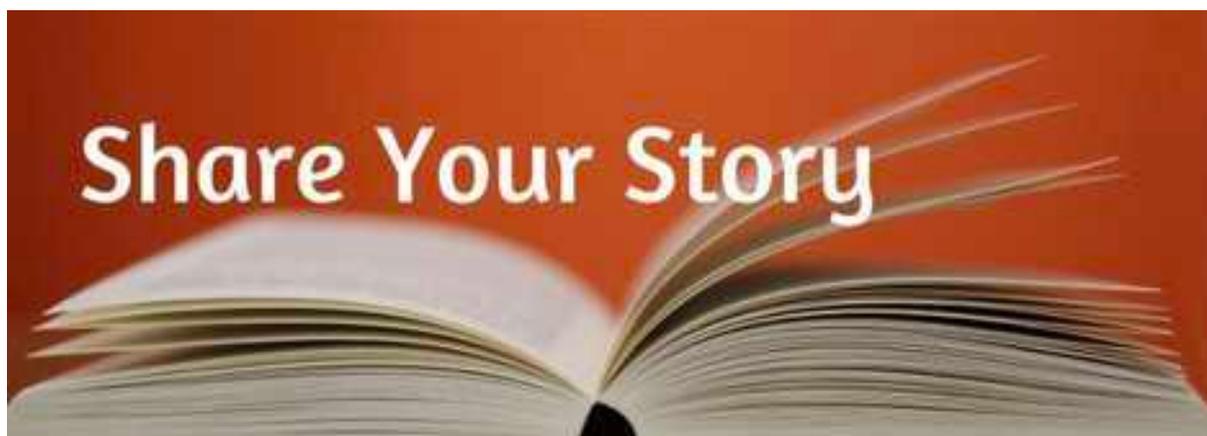
- Sift flour, baking soda, cinnamon, and salt into a large bowl.
- Add the rest of the ingredients (excluding the extra pear wedges) and mix thoroughly with a wooden spoon. Mixture will feel rather dry.
- Prepare a 23 cm round cake tin by greasing and lining with baking paper.
- Line the base of the prepared tin with pear wedges.
- Pour the cake mix carefully into the tin on top of the pears.

Bake in a pre-heated 180 deg C for approximately 40 minutes. Cake is cooked when a skewer comes out clean.

Invert once cooled to display pears and dust with icing sugar.

**Variations:**

Pears can easily be replaced by apples or nectarines or similar types of fruit. For a simpler version, leave out the decorative pear wedges at the bottom of the tin.



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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**Website:**

[www.mpnallianceaustralia.org.au](http://www.mpnallianceaustralia.org.au)

**Our mailing address is:**

Myeloproliferative Neoplasms Alliance Australia (MPN AA)  
Post Office Box 111  
Sandringham, Victoria 3191  
Australia

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