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MPN Matters Issue 27 - October 2024



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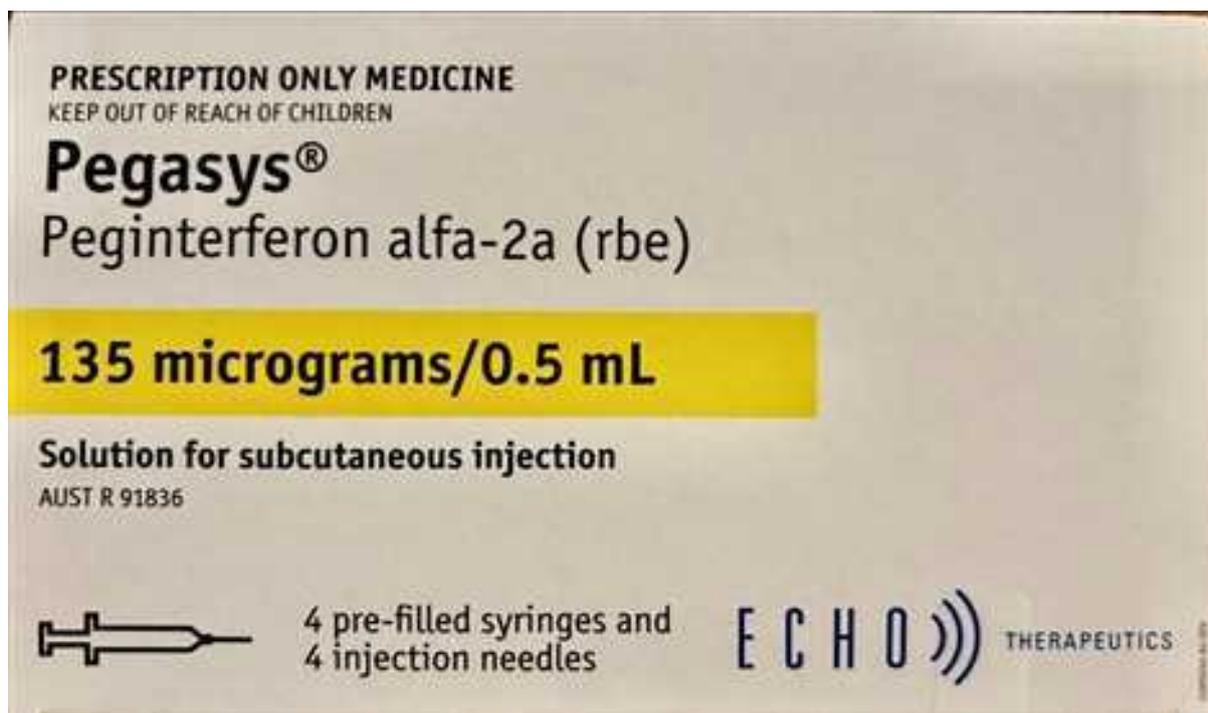


Tereena's story



Tereena was diagnosed with an MPN-like illness at age 15 in 1982, long before the discovery of the Jak2 mutation. At age 27, some 12 years later, she was officially diagnosed with an MPN. She is now 57, and has kindly shared with us her remarkable courageous MPN story - [HERE](#).

Pegasys® change to dispensing arrangements in Australia



Patients using Pegasys® to treat their MPN will know there has been a change to how Pegasys® is being delivered. This measure is temporary. It was put in place rapidly to try to protect the Pegasys® supply for Australian patients as there is a world-wide shortage.

Unfortunately, even with these new delivery measures, there may be a shortage in Australia next year. To ensure fair distribution of available Pegasys® in Australia, the company asks that you please only have one script dispensed at a time - unless there are exceptional circumstances.

A [new cold-chain delivery method](#) has been put in place for regional patients.

[TO ORDER PEGASYS ONLINE, PLEASE USE THIS LINK.](#)

For background and further details, there are [News posts on the MPN AA website](#).

Australians Professor Andrew F Wilks and Dr Chris Burns have received the 2024 Prime Minister's Prize for Innovation for their invention of Momelotinib

Momelotinib is a drug to help treat myelofibrosis. It is now been approved for use by the US FDA. We are hopeful that it will become available to Australian myelofibrosis patients in the future.

[Watch a video](#) of Professor Wilks and Dr Burns discussing their invention. Read more about this award [HERE](#).

MPN genetics and impact on prognosis

An important study of genetic mutations in MPNs and their impact on prognosis has just been released in 'Leukaemia', titled "*Characterization of myeloproliferative neoplasms based on genetics only and prognostication of transformation to blast phase.*"

The authors state "By conducting a thorough genetic analysis, we've developed

a model that relies on 12 genetic markers to accurately stratify MPN patients. The model can be simplified into a decision tree for routine use.”

“Our data suggest to perform a broader genetic screening at diagnosis and also at clinical progression, as driver mutations may change and the MPN-driver mutations present at diagnosis may disappear.”

Their conclusion is “Consequently, expanding genetic analysis beyond *JAK2*, *CALR*, and *MPL* at diagnosis is crucial for accurate MPN classification, early high-risk patient identification, and timely intervention.”

This study can be freely accessed [HERE](#).

Possible clinical trial opportunity for MPN patients with high platelets

A new clinical trial for essential thrombocythemia (ET) patients or other MPN patients with thrombocytosis (high platelets) has been brought to our attention.

The clinical trial is an international Phase I/II clinical trial. It aims to evaluate a first-in-class, orally administered treatment for patients with ET and other MPN patients with thrombocytosis.

[Details of the trial are HERE](#).

If you are interested and think you might be eligible, you would need to first discuss this with your haematologist.

If you'd like to understand more about clinical trials and what phases I,II and III involve, please visit [the clinical trials page](#) of our website.

MPN Advocates Network conference – 2024 in Warsaw



The MPN Horizons conference featured some of the world's leading MPN haematologists and researchers, including zoom presentations from Australians A/Prof David Ross and WA researcher Dr Belinda Guo.

It was a patient focussed conference and topics included:

- State of the art treatments for myelofibrosis, polycythemia vera and essential thrombocythemia
- Emerging therapies and treatment strategies, including predicting factors for relapse and progression
- The future – eg use of patient reported data in MPN research, potential new technologies for diagnosis, future treatments in myelofibrosis.

Video presentations from this 2024 conference will soon be available [HERE](#).



Elevated dementia risk for MPN patients identified – but there is

much you can do

A September 2024 article in the European Journal of Haematology reported that MPN patients may have an elevated risk of dementia, thought to be related to vascular inflammation. The full article, is free to access at this link '[Myeloproliferative Neoplasms and Dementia Risk: A Population-Based Cohort Study](#)'.

Encouragingly, however, [another recent study published in *The Lancet*](#), found that nearly half of all dementia cases in the general population could be delayed or prevented altogether - by addressing a range of possible risk factors. These risk factors include:

- hearing loss
- hypertension
- smoking
- obesity
- depression
- physical inactivity
- diabetes
- excessive alcohol consumption
- social isolation
- untreated vision loss
- high LDL cholesterol.

Whilst not all related to MPNs, clearly there is much for MPN patients to take and do from this list of modifiable dementia risk factors. The MPN AA has some suggestions:

- i. Exercise – see article on [the benefits of exercise](#).
- ii. [Healthy eating](#) by Nathalie Cook OAM accredited practising dietician - anti-inflammatory diet
- iii. Talk to your GP and seek a checkup and chronic disease plan or if you need help in giving up smoking, are concerned about your mental health, hearing loss or vision impairment.
- iv. Start an MPN walking/coffee and chat group
A weekly walking/coffee and chat support group is a fun and wonderful supportive way to improve your physical activity, mental health and social connection. This is especially relevant for MPN patients who are retired.

And we know it works because every week, a group of Canberra MPN patients and their partners meet for a walk, and/or a coffee and chat. We all learn from, and support each other by sharing our health updates, worries, perspectives and questions and answers

So if you'd like to meet MPN patients in your local area, it's a simple thing to start up your own group, especially if you just meet at a local café. If you'd like more information, please [contact us](#).

MPN AA Social media presence renewed

The MPN AA now has a more up to date social media presence thanks to our new young MPN AA team member Charlie. Although she has myelofibrosis, Charlie is still kindly working wonders posting updates onto our Instagram and Facebook accounts. Charlie's own MPN story is [HERE](#).

So please visit our Instagram and Facebook pages! And let us know if there is more information that you'd like to see on our posts. [Contact us](#).

And don't forget [our website](#) for the latest MPN information, guidelines and articles.

Coconut Baked Salmon



Preparation for this recipe takes under five minutes, and it's healthy and delicious.

The recipe is available at the Aldi website - we have copied their photo and recipe.

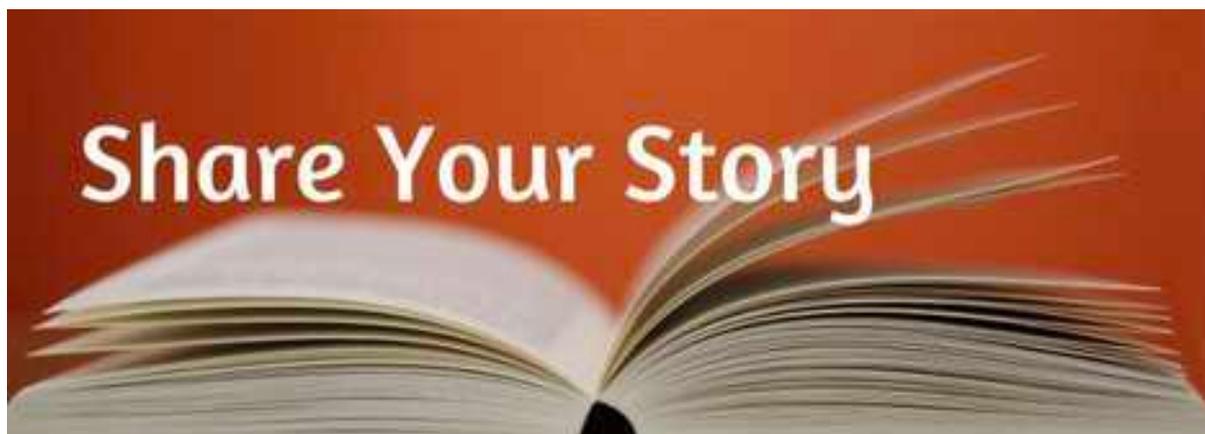
Ingredients

- 4 salmon fillets, skin on
- 3 tspns soy sauce
- 2 tbspsns sweet chilli sauce
- 1 cup shredded coconut
- 1 lime, zest grated, cut into wedges
- Extra sweet chilli sauce for serving
- Coriander to garnish (optional)

Method

1. Preheat oven to 180°C (160°C fan-forced). Line a baking tray with baking paper.
2. Place soy sauce and sweet chilli sauce in a bowl and combine. Place the shredded coconut in another bowl.
3. Coat the salmon in the sauce mixture and then roll in the coconut. Place

- on prepared tray.
4. Bake for 9-14 minutes or until salmon is just cooked and the coconut is golden. (Bake for longer if you prefer salmon well done).
 5. Sprinkle with the lime zest.
 6. Serve salmon with sweet chilli sauce and lime wedges. Garnish with coriander leaves (optional).
 7. We also suggest serve with broccolini or a green salad.
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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](#)

**Leukaemia
Foundation®**

Leukaemia Foundation upcoming patient support events

The Leukaemia Foundation runs regular online patient support groups and webinars.

Men's Blood Cancer Support Group: Topic is "Surviving and Thriving with

blood cancer"

12 November - 1.30pm - 2.30pm (NSW/ACT/VIC/TAS)

Venue: Online via Zoom

Places are limited and [Registration](#) is essential

Caregiver Blood Cancer Support Group: Topic is "Self Care"

19 November - 11.30am - 12.30pm (NSW/ACT/VIC/TAS)

Venue: Online via Zoom

Places are limited and [Registration](#) is essential.

These are among a number of other upcoming patient support events for October to December.

[Further information and registration details are available using this link.](#)

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