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MPN Matters Issue 23 - February 2024



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American Society for Hematology Dec 2023 meeting: updates for patients

This patient-friendly summary about MPNs is available thanks to a series of video interviews (and transcripts) with Dr Catriona Jamieson produced by Patient Power in the US.

They cover the latest thinking, treatment insights and developments for MPN patients.

Dr Jamieson stresses the importance of early and correct diagnosis, how early intervention can improve life expectancy and how it's important that patients monitor their own symptoms and give feedback to their haematologist to help in the monitoring of their MPN. The interviews cover:

[ET: updates and risks](#)

[PV: what to do if your PV is progressing](#)

[MF: myelofibrosis should be running for cover](#)

International guidelines recently updated for ET and MF

Essential thrombocythemia:

- [2024 update on diagnosis, risk stratification, and management](#)

Myelofibrosis:

- [Diagnosis and evaluation of prognosis of myelofibrosis: A British Society for Haematology Guideline;](#)
- [The management of myelofibrosis: A British Society for Haematology Guideline \(a companion guideline\);](#)

The management guidelines for MF includes detailed advice on:

- Management of myelofibrosis-associated anaemia
- Management of thrombocytopenic patients
- Role of splenectomy in myelofibrosis
- Myelofibrosis in paediatric, teenage and young adult population
- Myelofibrosis and pregnancy
- Allogeneic stem cell transplantation for myelofibrosis

Significant advance in blood clot treatment



Photo courtesy of ABC website.

As MPN patients are at higher risk of blood clots than the general population, this news item from the ABC is of particular interest.

'Inside the 'game-changing' blood clot treatment pioneered by Wollongong surgeon Laurencia Villalba' discusses a revolutionary treatment by Dr Villalba for dissolving pulmonary embolisms. It involves inserting a catheter through a patient's groin. "Then we deliver medicine ... through multiple holes in the tip of the catheter. "[It's] like a spray that destroys the clot and simultaneously dissolves it. All up, it takes about 20 minutes."

The New South Wales government has since asked Dr Villalba to teach the technique to other vascular surgeons. "And hopefully, in a few years' time, this is going to be standard of care." The full article from the ABC website is available to read [HERE](#).

Further evidence about exercise reducing cancer risk



Image: yet another study has shown the benefits of exercise

As MPN patients are still vulnerable to other cancer diagnoses, the message about exercise remains very relevant.

New research led by Australia's Cancer Council has 'estimated that more than three times as many cancers are attributable to physical inactivity than previously reported, reinforcing the importance of creating environments that support and promote physical activity in Australia.'

For more information, here is the media release about the study "[New research shows more than three times as many cancers are attributable to physical inactivity than previously](#)"

And exercise has great mental health benefits as well. Other ideas are on our [LIVING WELL](#) pages.

Harvard Happiness Study



whichImage: good relationships keep us healthier and happier

Haematologists sometimes remind MPN patients about the importance of living well. Apart from other previously recognised factors which can increase wellbeing, we wanted to highlight findings from the world's longest study on human flourishing - that good relationships keep us healthier and happier. There is a great interview on the ABC's Life Matters program [HERE](#).

And if you'd prefer to read rather than listen, or read about how to help put some of this into practice, [this article](#) has several suggestions.



Leukaemia Foundation upcoming events

1. Webinar – creating meaning in the face of uncertainty

The Leukaemia Foundation has just held a webinar about creating meaning in the face of uncertainty. It will be available shortly to watch on their youtube channel.

<https://www.leukaemia.org.au/webinar-videos/>

2. "Watch and wait" support group

The focus in March for support groups is living with uncertainty. Of particular interest for MPN patients is the support group session on 14 March which will be aimed at those of us on 'Watch and Wait'.

As this is likely to be a popular session and numbers are limited, you may want to register early.

<https://www.mpnallianceaustralia.org.au/event/watch-and-wait-support-group-living-with-uncertainty/>

3. World's greatest shave – March 2024

This is the main fundraising initiative of the Leukaemia Foundation.

‘Every year, thousands of Australians step up to Shave, Cut, or Colour their hair. It's the ultimate act of support for people facing blood cancer.’
The money you raise will help ‘power Australia's brightest research minds, bringing us closer to our goal of zero lives lost to blood cancer by 2035.’
For more information on how you may participate, [see here](#).

Recipe - Hellenic Republic's Cypriot grain salad



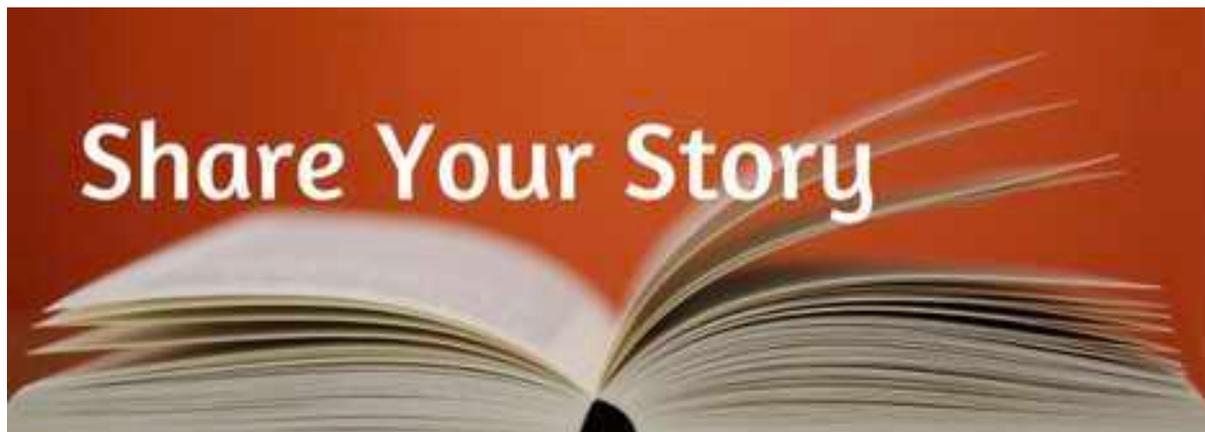
Image of Hellenic Republic's Cypriot grain salad courtesy of the SMH 'Good food guide'

Everyone seems to be talking about how delicious Cypriot Grain Salad is and we have to agree.

[This version is wonderful and is included here from the Good Food Guide](#)

How to quickly de-seed a pomegranate.

Did you know there's an easy way to remove the seeds from pomegranates? Simply use a large and deep bowl (such as the salad spinner bowl without the insert), cut the pomegranate in half, turn it seed side down and bash with a rolling pin. The seeds come out quite quickly and easily. There will be a few little pieces of white pith in with the seeds so just gently remove those.



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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