MPN ALLIANCE AUSTRALIA
Empower • Enrich • Enliven

MPN MATTERS

ISSUE 37 - May/June 2026

MPN AA can receive tax deductible donations to support MPN research, advocacy, and patient resources.

The MPN AA is thrilled to advise that we can receive tax deductible donations again. We have established a charitable fund and can now direct donations toward the areas where they will make the biggest difference — funding Australian MPN research, strengthening our advocacy, and expanding the resources and support we offer you, the MPN patient community.

Every contribution helps us continue the important work we've started and brings us closer to our goal of improving outcomes for everyone living with an MPN.

So, if you would like to be part of supporting our brilliant Australian MPN researchers, as well as MPN patients, **please consider making a tax deductible donation.**

MPN AA grant launches breakthrough Australian discovery

A big moment for Australian CALR research has landed — and it's one the MPN Alliance Australia funding helped spark.

At the 2025 American Society of Hematology (ASH) meeting, A/Prof Dan Thomas and Dr Chloe Thompson-Peach unveiled their work, Ultraprecision treatment for myelofibrosis from Type 1 CALR and Type 2 CALR. Dr Thompson-Peach led the study, which showed that Type 1 and Type 2 CALR mutations behave differently — and that if you target those differences properly, you may be able to deliver far better outcomes for patients.

What makes this especially exciting for the MPN community is that this breakthrough had its beginnings in a grassroots effort. Back in 2022, shortly after her diagnosis, MPN patient Sarah Gardner (pictured below) ran a raffle to raise money for MPN research. Her efforts directly funded an MPN Alliance Australia Fellowship grant awarded to Dr Thompson-Peach in August 2022 — early support that helped this project get off the ground.

More information is available on our website.

L to R. Dr Chloe Thompson-Peach, MPNAA's Ken Young & A/Professor Dan Thomas from SAMRI

Sarah in her studio with her daughter. Sarah is an MPN patient who raised funds which supported Dr Chloé-Thompson Peach's early research.

The work by Dr Chloé Thompson-Peach aligns with encouraging early signals from the INCA33989 clinical trial — a monoclonal antibody designed specifically to target mutant CALR.

How can you find a clinical trial?

These new antibodies mentioned in the previous article are just some of the encouraging developments in the clinical trial space for MPNs.
The MPN AA provides an up-to-date clinical trial document for MPN patients, that is carefully maintained by MPN AA team member, Sandra, who checks the trial sites each month to ensure our document is as up to date as possible.
The document can be found on our Australian clinical trials webpage.

Further support for a paradigm shift in PV treatment.

Two haematologists have been using interferon therapy for decades in patients with MPNs. In 2026 they published in the international journal ‘Leukemia’ a review article that with a compelling argument for the early use of pegylated interferon in the treatment of polycythemia vera.
Titled: A paradigm shift in the treatment of patients with polycythemia vera. The initial early use of recombinant interferon-alpha. The article is free to access in full.

They argue for earlier use of interferon because “even low-risk PV patients are at increased thrombotic risk, estimated at 2 to 3 times that of the general population. Moreover, as PV progresses, the development of myelofibrosis is the leading cause of morbidity, perhaps abetted by PHLEB-O (phlebotomy only)”.

More details from this article are available on our website. At times it refers to the more recently developed ropeg interferon, which is not available in Australia. To date, however, as patients, we have not been able to identify substantial differences between the efficacy of the pegylated interferon available in Australia (Pegasys) and ropeg

interferon.
As mentioned, the full article is freely available to access.

Management of menopause in MPNs

Dr Cecily Forsyth has advised of the article ‘The Management of Menopause in Women with Philadelphia-Negative Myeloproliferative Neoplasms (MPNs)’, which reviews what is currently known about how menopause affects women living with an MPN, and how menopause symptoms can be safely managed in MPN patients. The authors provide practical guidance for clinicians on menopause and MPNs.
A patient friendly summary of this article is available on our website.

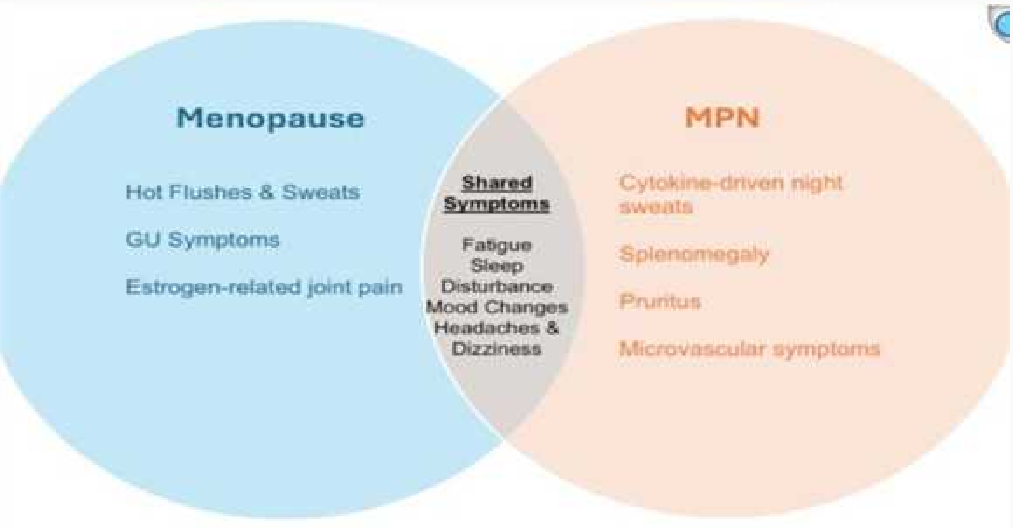


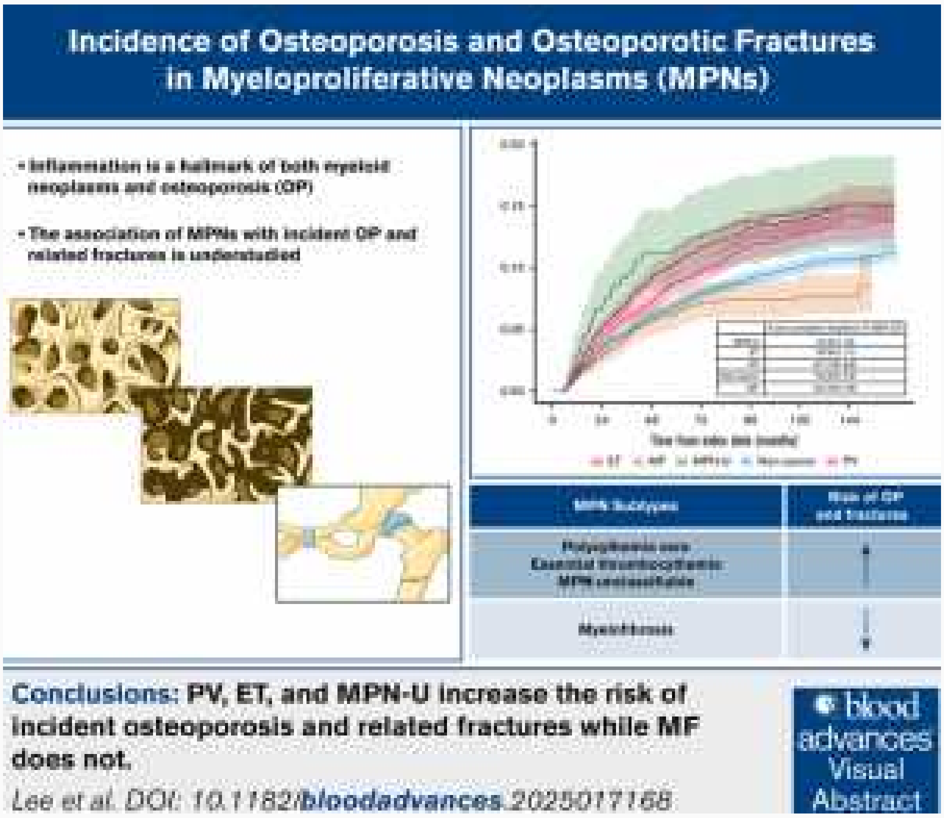
Image: figure 1 from the article.

MPN patients at higher risk of osteoporosis – a research letter in ‘Blood’

MPN patients over the age of 50 who have risk factors for osteoporosis may wish to discuss with their doctor if they should undergo a bone density test (DEXA scan), based on a research letter published January 2026 online in ‘Blood’, titled ‘Myeloproliferative neoplasm subtypes have distinct impact on risk of incident osteoporosis and osteoporotic fractures’.

The full article is available to access from our website.

We have some suggestions for improving bone strength and fitness generally in our new ‘Wellness section’ (below).



Incidence of Osteoporosis and Osteoporotic Fractures in Myeloproliferative Neoplasms (MPNs)

- Inflammation is a hallmark of both myeloid neoplasms and osteoporosis (OP)
- The association of MPNs with incident OP and related fractures is understudied

MPN Subtypes	Risk of OP and fractures
Polycythemia vera Essential thrombocythemia MPN unclassifiable	↑
Myelofibrosis	↓

Conclusions: PV, ET, and MPN-U increase the risk of incident osteoporosis and related fractures while MF does not.

Lee et al. DOI: 10.1182/**bloodadvances**.2025017168

blood advances Visual Abstract

WELLNESS SECTION

Staying well by keeping muscles and bones strong through healthy eating and physical activity

Before embarking on any new exercise program, be sure to check with your GP or haematologist - and start slowly and gently if you have not exercised for some length of time. You might also consider speaking with an exercise physiologist (EP) or a physiotherapist to get a tailored exercise plan. Visits to a physio or EP can be included in a chronic disease management plan from your GP or attract a rebate from your private health fund, reducing costs.

Weight-bearing exercise is valuable for MPN patients. It can help manage symptoms, improve bone strength, and improve overall health. Strong muscles support better balance and reduce the risk of falls.
The type of exercise suitable for MPN patients will depend on the individual's level of fitness and could include: weight-bearing impact exercise, low impact aerobic exercises, and/or balance and flexibility exercises.

Weight-bearing impact exercise: activities performed on your feet that involve firm, rapid landing—eg jumping, hopping, jogging, skipping, stair climbing.

Low impact aerobic exercises: or you may be much more comfortable with gentler activities like walking, swimming, and cycling which are easier on the joints.

Balance and Flexibility Exercises: do you know about the 'Single Leg Stance': Balance on one leg briefly, then switch sides. This exercise strengthens the leg muscles and improves balance. Yoga and tai chi also can improve balance and flexibility, further reducing the risk of falls.

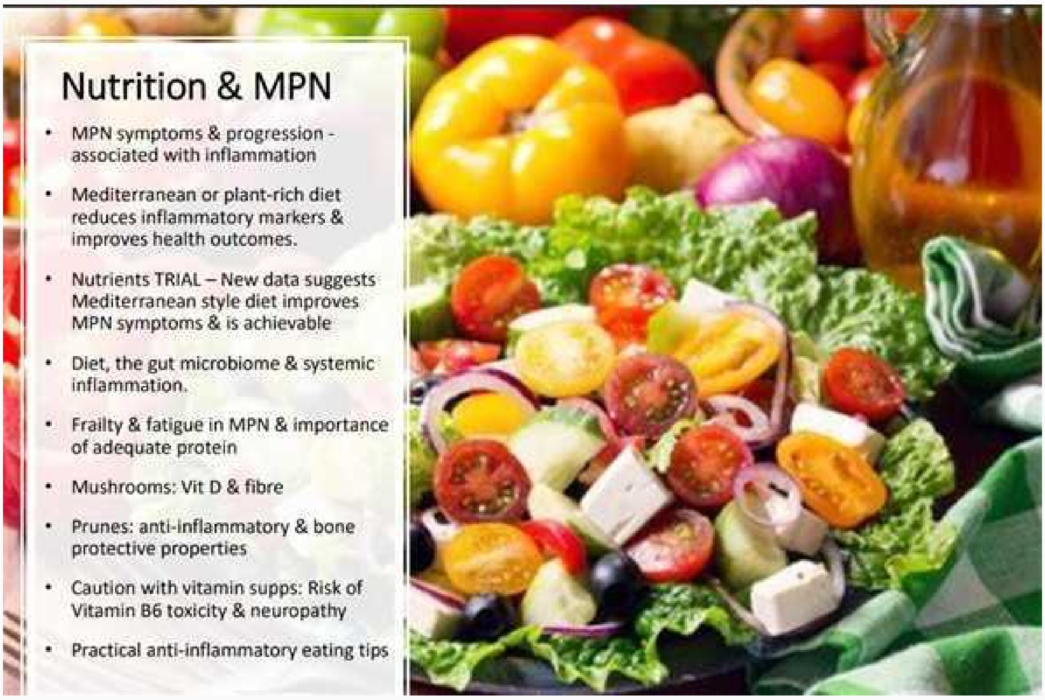
Exercise benefits mental health, quality of life and symptom management

An evidence based international study of hundreds of MPN patients showed wellness activities had a pattern of decreased levels of symptom burden, fatigue, depression, and a higher quality of life for MPN patients. Here is the full report of the Survey of Integrative Medicine in Myeloproliferative neoplasms – the SIMM study.

Improving muscle mass

To learn more about nutrition for improving muscle mass, MPN AA's Nathalie Cook OAM, who is an accredited practising dietitian, has authored our website page on diet and how to maintain muscle mass.

Nutrition: Eating for healthy bones



Nutrition & MPN

- MPN symptoms & progression - associated with inflammation
- Mediterranean or plant-rich diet reduces inflammatory markers & improves health outcomes.
- Nutrients TRIAL – New data suggests Mediterranean style diet improves MPN symptoms & is achievable
- Diet, the gut microbiome & systemic inflammation.
- Frailty & fatigue in MPN & importance of adequate protein
- Mushrooms: Vit D & fibre
- Prunes: anti-inflammatory & bone protective properties
- Caution with vitamin supps: Risk of Vitamin B6 toxicity & neuropathy
- Practical anti-inflammatory eating tips

Image: from Nathalie Cook's presentation to the MPN Advocates Network

Bones need nutrients to repair and maintain strength. To help maintain strong and healthy bones, consume foods that are rich in calcium, such as dairy foods (milk, yoghurt and cheese) or calcium fortified soy or other plant milk alternatives. Dairy products contain calcium in a form that is highly bioavailable and more easily absorbed and used to strengthen bones, than calcium from other food sources.

Also, try to eat more vegetables, fruits, and whole grains as they are high in fibre which is important for gut health, and essential vitamins and minerals needed for bone health. They also contain phytochemicals which are substances that can protect against osteoporosis. Protein is also important for bone health. Include protein rich foods at each meal and snack to ensure adequate intake over the day, while limiting added sugar and salt.

Nathalie has prepared extensive evidence-based information about nutrition for MPN patients. Her presentation and video are below.

- 'Nutrition and MPN' presentation from 2022 International MPN Horizons conference.
- PDF of slides from the presentation.

Monash University Connecting for Better Health project survey invitation

The Connecting for Better Health project is a five-year National Health and Medical Research Council funded research project awarded to the Monash University Health Economics Group. The project aims to understand how loneliness and social isolation affect people who are at risk of, or already have, a health condition.

The Connecting for Better Health project team invites you to take part in a survey to tell us which aspects of programs to reduce loneliness and social isolation you do and don't like. You do not have to have used a program to reduce loneliness or social isolation to take part.
We are looking for people who are, or have been, lonely or socially isolated and who also have had a diagnosed health condition for 12 months or more. Examples of health conditions are heart disease, diabetes, mental health conditions (e.g. anxiety, depression), arthritis and asthma.

The survey can be completed by clicking this link:
https://enter.surveyengine.com/r.156e.a4a4.kttq0js13o57movucv79n60lbi1tmpuk73439ldt60m6bajokh5efru3hhuvcbtk7jdmpodjkfv9hlbhcv250

jhk8h009g6v117351demvcbe42sk6747246phuchrs6tkfchard24t03hvo3l85rhv2lviedtakp3ah3djedoo7oifgde5h8ivojai1kfpkeo3nom7jeo130

After completing the survey, you will be given the chance to enter into a draw to win one of ten $50 e-gift cards as a thank you for your time. The survey will remain open until enough responses are received. The prize draw will run after we have checked all responses to ensure they are valid. To be fair to everyone we will remove any duplicate, ineligible or fake responses before the draw. The draw is not expected to take place before August 2026, and winners will be contacted via email.

Please read the Participant Information Sheet before completing the survey. If you have any questions, you can contact me on (03) 9902 4474 or via email: connecting4betterhealth@monash.edu

NOTE: Please feel free to share this invitation with your networks via email, but we ask that you **do not post it on social media** to help prevent fake or automated responses.

Yours sincerely, Sharon Clifford
Project Manager, Connecting for Better Health
Research Fellow, Health Economics Group
School of Public Health and Preventive Medicine
Monash University

Recipe – curried pea soup

This soup is so easy, healthy and delicious.

Ingredients

500pkt frozen peas
40g butter
3 tablespoons flour
2 teaspoons of curry powder
4 cups water
3 chicken stock cubes
½ cup milk
Chopped mint or parsley for garnish

Method

Cook peas and puree them.
In a separate pan, melt butter, add flour and curry powder.
Gradually add water and return to heat.
Add crumbled stock cubes and stir until soup thickens.
Reduce heat and add peas and milk
Mix well and simmer uncovered for five minutes
Serve with chopped mint or parsley

MPN coffee and chats and MPN lunches

We are pleased to advise of some wonderful MPN patients supporting other patients by offering coffee and chats or lunches.
For details, please visit the events pages linked below.

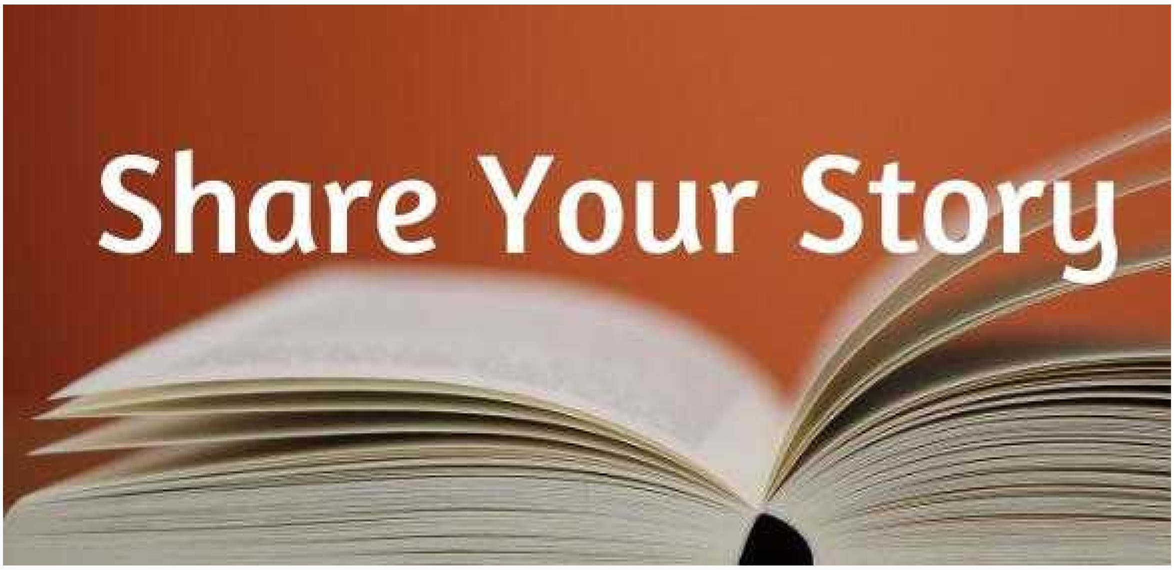
- Brisbane coffee and chat Friday 26 June
- Brisbane lunch Saturday 11th July from 11:30. For details watch our events page.
- Sydney coffee and chat – in the city, date and details to be advised. Please watch our Events page
- Canberra weekly coffee and chat Monday mornings – email mpnaa@mpnallianceaustralia.org.au
- **If you would like to host a coffee and chat in your neighbourhood, we can assist with promoting it on our social and news pages.**

LEUKAEMIA FOUNDATION LIVED EXPERIENCE ENGAGEMENT PROGRAM

The Leukaemia Foundation runs a Lived Experience Engagement Program which may be of interest to some MPN patients. It's about sharing personal experiences to help shape and improve the Leukaemia Foundation's services, programs and advocacy**.** So if you'd like to help improve experiences for people with blood cancer, more information is available **HERE**.

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

Share

Forward to Friend

Website:
https://www.mpnallianceaustralia.org.au

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