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MPN Matters Issue 26 - August 2024



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## MPN MATTERS ISSUE 26 - AUGUST 2024



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### **PV patient shares her success in improving her bone density**



Libby was diagnosed with polycythemia vera (PV) in 2016 but has also had to combat osteoporosis and breast cancer. Her PV is now well managed, and her

breast cancer is in remission. However, her osteoporosis has been of concern, especially as it can be exacerbated by the hormone reduction therapy she must take for ongoing breast cancer treatment.

So, feeling uncertain as to what her best options were, Libby embarked on improving her bone density naturally. And she has achieved this by weight bearing exercise, walking, and most importantly, increasing her daily calcium intake. Libby has managed to do this through diet without eating mountains of dairy every day.

Libby's experience is relevant and important for many of us. She has kindly agreed to share her story. Read Libby's story [HERE](#).

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### Doing all we can to stay well with our MPN



*Image: Sit ups can be done anywhere!*

Developing a blood clot is a risk for MPN patients. We are also at a slightly higher risk of developing a secondary cancer.

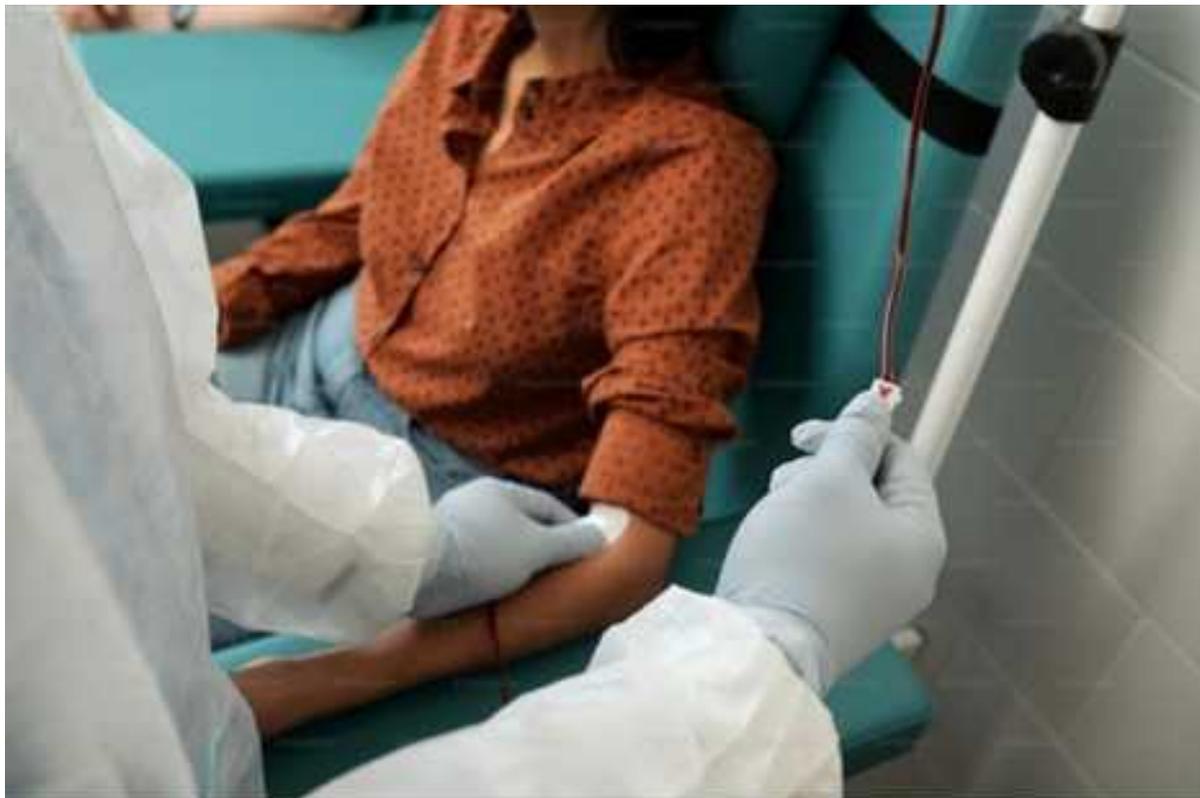
Being aware of these issues is great motivation to do all we can to stay healthy and manage these risks, as well as increasing our general quality of life. The MPN AA has prepared some **living well** pages outlining what we can do to help ourselves.

A summary is below:

- **Don't neglect your general health.** It is a good idea to have regular physical checkups, including eye health examinations.
- **Have your regular screening tests** for mammograms, cervical cancer and prostate cancer.
- **Have regular and vigilant skin checks**, especially if you are taking ruxolitinib or hydroxyurea.
- **Make sure your cardio vascular risk factors are well managed:**
  - Managing cholesterol
  - Eating healthily
  - Maintaining a healthy weight
  - Exercising regularly (after checking with your doctor if you haven't exercised for some time)
- **Maintain your muscle mass.** More and more this is being found to be an important factor and there is a great deal you can do that is not too onerous. Again, our [living well pages](#) have more information on all these topics.

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**Momelotinib for myelofibrosis – patient input to PBS consultation sought – due date 25 September**



Australia's Pharmaceutical Benefits Advisory Committee (PBAC) is currently considering the inclusion of Momelotinib (known as Omjjara) onto the Pharmaceutical Benefits Scheme (PBS), so it is affordable for all eligible patients.

Momelotinib is already approved and available to patients in the US and Europe, but has not been formally registered in Australia by our regulatory agency, the Therapeutic Goods Administration (TGA). We understand this is being progressed at the moment.

Momelotinib is a new-generation oral therapy originally developed in Australia that inhibits the JAK proteins (similar to Ruxolitinib, which is the existing standard of care). Momelotinib has also been shown to tackle the issue of anaemia.

The Federal Government is being asked to include Momelotinib on the PBS if used 'for the treatment of intermediate or high-risk primary myelofibrosis, post-polycythaemia vera myelofibrosis or post-essential thrombocythaemia myelofibrosis **in patients with moderate to severe anaemia who are JAK inhibitor naïve or have been treated with ruxolitinib.**'

To help the Government in its considerations, the PBAC is now taking

consumer comments until 25 September:

- from those who have some lived experience with myelofibrosis either as a patient or a carer, or
- from people involved in support groups.

So, if you fit either of these categories, you may like to make a submission.

[Use this link for further information and how to make a submission.](#)

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## **US patient guidelines for myeloproliferative neoplasms updated for 2024**

The National Comprehensive Cancer Network in the US has just released its **patient guidelines** for myeloproliferative neoplasms. They are based on the latest clinical practice guidelines in the US.

[\*\*The 2024 NCCN Guidelines for Patients®: Myeloproliferative Neoplasms\*\*](#) is available on the NCCN website and is free to download.

These US patient guidelines are also available in Arabic, Chinese, French, Portuguese, Spanish Hindi, and Russian – see [HERE](#).

And don't forget that [\*\*Australian MPN 'Optimal Care Pathways'\*\*](#) have also recently been released for Australian patients. A much more detailed version is available for practitioners on that same link.



## High Protein baked oat breakfast puddings



*Image: Nathalie's high protein baked oat breakfast puddings*

### **Benefits**

This recipe is a great way to increase your daily protein intake and was provided to us by our own Nathalie Cook, OAM, Accredited Practising Dietitian.

To keep our muscles strong and help prevent age related muscle loss, it's important to include adequate protein in our diet each day. People living with MPN need to be extra careful to ensure they consume enough protein in their diet each day because chronic inflammation associated with MPN can accelerate muscle loss.

Adults should aim to consume 20-30gm of protein per meal or 75-90gm per day. Foods high in protein include dairy foods, meat, chicken, fish, eggs, legumes, nuts and seeds. Protein also helps keeps us feeling full for longer and high protein foods provide a range of other important nutrients too.

### ***Protein powder is an ingredient***

This recipe uses 3 tablespoons of protein powder which many of you may never have used. Protein powder can be readily bought from supermarkets or pharmacies. It is important to buy a quality protein powder that does not have a high iron content as PV patients are not able to have iron supplementation. Nor should it have other vitamins or minerals added.

While protein powder comes in an abundance of flavours and different sources (collagen, whey, pea), I used an unflavoured soy-based protein powder (Nature's Way Instant Natural Protein, available in major supermarkets) with no added iron, in this recipe. You could use milk powder as an alternative to protein powder, to boost the protein content of this recipe.

This recipe makes 6 puddings. (22 gm protein each)

### ***Ingredients***

1 cup rolled oats

2 -3 tablespoons muesli

2 weetbix/vita brits crushed

3 tablespoons protein powder (or milk powder)

2 extra large/ jumbo eggs

2 cups lite milk

1 cup cottage cheese

1 tablespoon each of- hemp seeds, linseeds, chia seeds. (any combination of seeds and/or nuts can be used)

1 dessertspoon psyllium husk (available from health food section of supermarkets or health food stores)

1/2 teaspoon cinnamon

1 teaspoon vanilla

Chopped fruit (2-3 medium apples or pears, or berries). You can leave the fruit unpeeled for extra fibre and nutrients.

Optional: Add 1-2 tablespoons maple syrup or sugar of your choice.

**Method**

Blend eggs, milk, cottage cheese, vanilla and protein powder (or milk powder). Mix with dry ingredients. Pour evenly into 6 oiled ramekins or mugs (250ml capacity). Top with fresh or frozen fruit. Bake for about 30 minutes at 180C, until lightly golden.

Keep in the fridge for up to three days or freeze in snap lock bags. Warm in the microwave topped with some added milk. Enjoy!

Other variations include sliced banana, plums, peaches, dried fruit and chopped nuts.

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**Leukaemia Foundation upcoming patient support events**

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

There are two upcoming webinars featuring excellent guest speakers:

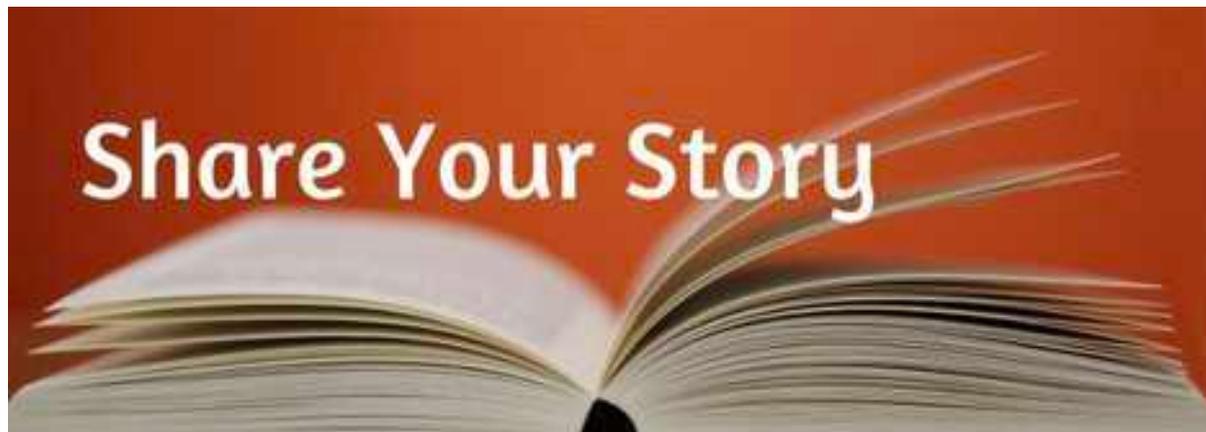
25 August - Return to work

5 September - Empowering conversations (guest speaker Dr Ranjana Srivastava)

These are among a number of other upcoming patient support events for August and September.

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

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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](#)

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**Send us an email**



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