

[Subscribe](#)[Past Issues](#)[Translate](#)

MPN Matters Issue 35 - January 2026



---

## MPN MATTERS ISSUE 35 - JANUARY 2026



### **PATIENTS WITH CALR MUTATION - PROMISING CLINICAL FINDINGS TRIAL**

At our MPN symposium in October, Dr Zi Ng spoke about the promising drug INCA033989. INCA033989 is a monoclonal antibody given intravenously designed to treat ET and MF with CALR mutations. It works by selectively binding to the mutated CALR protein on the surface of cancer cells, leading to cell death without harming healthy cells. A copy of her presentation slide is below.

**INCA33989 – monoclonal antibody targeting CALR**  
**Rapid and Durable Normalization of Platelet Counts Observed in Most Patients**

**Doses 24-250 mg<sup>1</sup>**      **Doses 400-2500 mg<sup>1</sup>**

Platelet Count (x10<sup>9</sup>/L) vs Visit

- Of the 31 patients that enrolled with concomitant cytoreductive therapy (hydroxyurea or anagrelide), 20 (65%) discontinued it and remained on study
- Thrombocytopenia was not observed in any patient
- Doses of ≥400 mg produced higher frequency of platelet count normalization

Side courtesy of Claire Harrison

At the December 2025 American Society of Hematology (ASH) meeting, further findings were presented about this trial. The trial is still in phase 1 but findings were sufficiently encouraging that the drug has now been granted breakthrough therapy designation by the US Food and Drug Administration.

Please note that the [clinical trial for drug INCA033989 is actually open in some sites in Australia](#). So if you have a CALR mutation and think the trial might be relevant for you, you may wish to discuss it with your haematologist. However, regardless of clinical trial access, ongoing testing of this drug to ensure its efficacy and safety is occurring around the world. If it continues to prove as promising as it has to date, it will undoubtedly be more widely available in the future.

## CLINICAL TRIALS INFORMATION NOW ON OUR WEBSITE

Based on feedback from our MPN symposium, one of our new team members has now carefully identified and documented all the clinical trials relating to MPN patients in Australia that are currently open and recruiting. She has had great support from haematologist Professor Andrew Grigg in compiling this. The MPN AA would also like to thank Dr Cavan Bennett, Senior Research Officer from the Walter and Eliza Hall Institute, for his help early on in this process.

We hope that the webpage will be useful not only for patients, but also for busy clinicians.

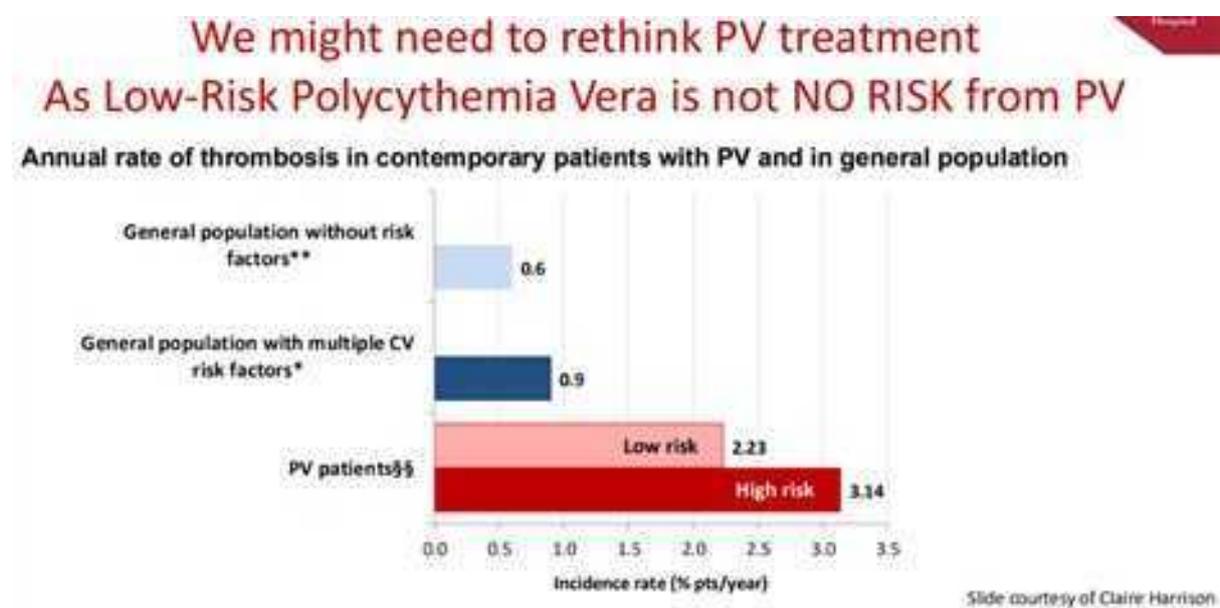
If you identify a clinical trial that may seem relevant to you, please raise it with your haematologist.

Here is our [information page about clinical trials](#)

And here is the [document listing the clinical trials currently open](#). It includes information about INCA033989.

## MPN SYMPOSIUM: DO WE NEED TO RETHINK WHAT IS 'LOW RISK' PV?

At our MPN symposium, Dr Zi Ng's presentation was about what's new in PV and ET. She discussed whether 'low risk' PV patients really are low risk, demonstrating that even low-risk PV patients are much more likely to have a thrombotic event than the general population – see slide below.



### Low risk PV – benefits of earlier intervention

Dr Ng highlighted a study conducted with low-risk PV patients and reported in 2021. It had to be stopped early due to superior efficacy of the intervention arm (ropeg interferon) compared with phlebotomy and low dose aspirin alone. Ie, patients on phlebotomy and low dose aspirin alone, fared significantly worse

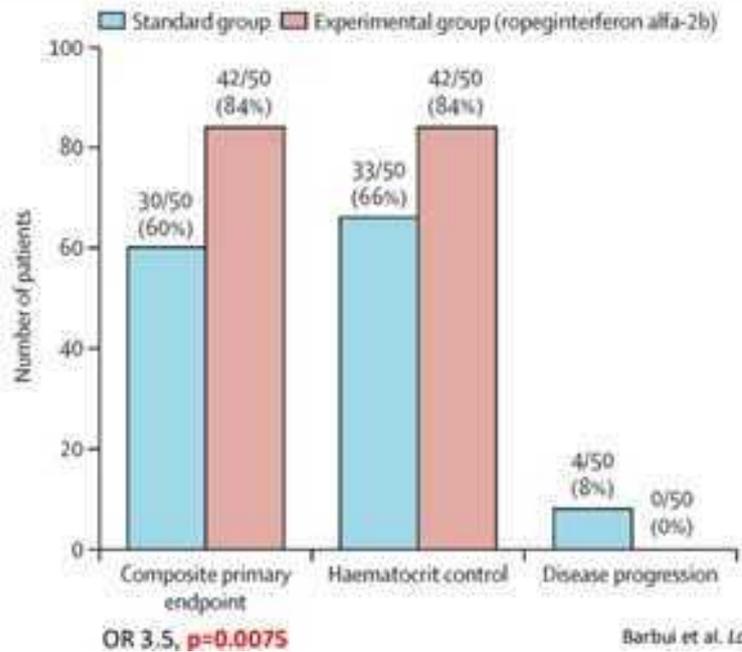
than those on pegylated interferon.

Please note that 'Ropeginterferon' (Besremi) is similar to Pegasys in that they are both forms of pegylated interferon.

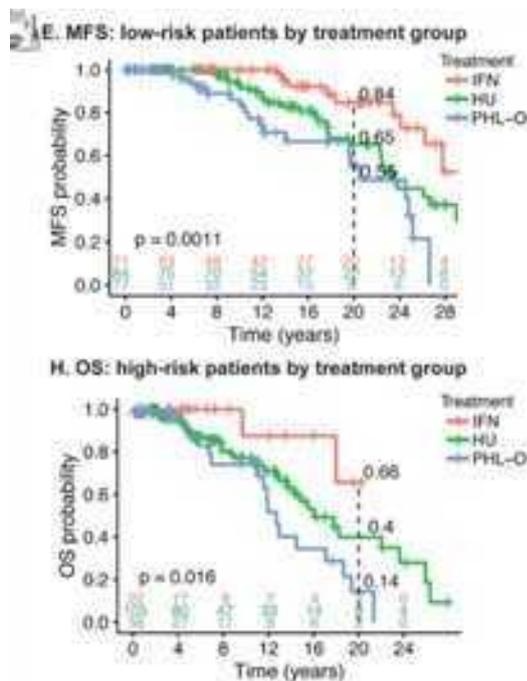
### Low-PV study

↑ efficacy

- 127 low-risk PV pts randomised to either phlebotomy and aspirin +/- ropeginterferon
- Stopped early at 2 years due to superiority of experimental arm
- Composite primary endpoint = maintenance of hct <45%, no progressive disease, vascular or major bleeding complication



Further, a retrospective single-centre study in the US showed superior outcomes for patients on either interferon or hydroxyurea, compared with those on phlebotomy and aspirin alone.



### Pegylated Interferon (PV)

- Improves myelofibrosis-free survival in low-risk PV patients
- Improves overall survival in high-risk PV patients

Abu-Zeinah et al. Leukemia 2022

Dr Ng then discussed factors haematologists might consider to determine when

low-risk PV patients should be given cytoreductive therapy.

## Which low-risk PV patient should get cytoreductive therapy?

- Strictly defined intolerance to phlebotomy
- Inadequate haematocrit control requiring phlebotomies
- Symptomatic progressive splenomegaly
- Persistent leukocytosis, WCC  $>15 \times 10^9/L$
- Progressive leukocytosis
  - at least 100%  $\uparrow$  if baseline count is  $<10$  or at least 50%  $\uparrow$  if baseline count is  $>10$
- Extreme thrombocytosis, platelets  $>1500 \times 10^9/L$
- Persistently  $\uparrow$  CVS risk
- Persistently  $\uparrow$  symptom burden

Dr Ng's full video and presentations (SESSION 3), are available [HERE](#).

---

### INTERFERON AND MPNs – RECENT VIDEO PRESENTATION AVAILABLE

At an international MPN Advocates Network conference earlier this year, Melbourne haematologist and researcher Dr Joshua Casan presented on 'Interferon treatment in MPN. Inflammation in MPNs and management of side effects.'

#### **Joshua Casan, Australia (Virtual):**

There is an excellent presentation for patients taking interferon or for those contemplating it: [HERE](#).

The video is available: [HERE](#).

---

### AN EXERCISE PRESCRIPTION

Regular readers will know that we often remind patients about the

extraordinary benefits of exercise and of quotes about if exercise were a cancer pill, 'it would be a blockbuster' and 'everyone would be clambering for it to be on the PBS' and so on.

Every year, new studies reinforce these findings and 2025 was no exception. Conclusions from the [CHALLENGE](#) trial, although relating to colon cancer patients, we believe are still of interest to the broader cancer community, including blood cancer patients. And, what seems new from the CHALLENGE trial, is that **an exercise prescription from an exercise physiologist or similar was the factor that had the greatest benefit.**

"The CHALLENGE trial provides robust evidence that regular, structured exercise significantly improves both disease-free and overall survival following curative treatment for colon cancer. This reframes exercise from a supportive measure to an active component of oncological care."

### **What exactly is an 'exercise prescription'?**

The Leukaemia Foundation's website has a whole [SECTION](#) devoted to exercise, including how to [FIND](#) an exercise physiologist. And if seeing an exercise physiologist is not possible for you, your GP could undoubtedly give you guidance.

---

## **HELP FOR MPN PATIENTS WHO SUFFER FROM ITCHING (AQUAGENIC PRURITIS)**

Apart from fatigue, MPN itching is a symptom that distresses MPN patients greatly. One of our haematologists told us that some of his patients couldn't care less about their MPN. All they want is for the itching to stop.

An MPN AA team member has had to cope with pruritis for some time and has developed a few different and innovative strategies that work for her. Her suggestions as well as other anecdotes from patients include:

### 1. Beta alanine\*

Many patients have reported they have found relief using the supplement beta alanine. A small dosage of half a teaspoon a day seems to be adequate, and it can be bought from health food shops.

## 2. Antihistamine\*

Other MPN patients find an over the counter antihistamine is helpful. These are available from chemists.

## 3. Walking after a shower

Our MPN team member finds that going for a walk as soon as possible after a shower, seems to calm her itchy skin and irritation about 15 minutes into the walk.

4. Shorter showers and using a gentle soap-free wash, followed by a rich emollient cream daily (such as an advanced repair cream – fragrance free – for very dry skin), and even a fractionated coconut oil are all helpful. The coconut oil is quickly absorbed into the skin and is non-greasy. As part of a soap free approach, washing hair separately (ie, in the laundry sink, not in the shower) can also help minimise itching.

## 5. A heat pack

This seems very counter intuitive, but our team member finds that a grain wheat heat pack is a great help to calm her itchy skin.

## 6. Histamines in diet

Our team member also finds minimising foods high in histamines helps. And if she has high histamine foods she tries to balance them with low histamine foods.

*\* You must seek the advice of your haematologist/GP before trying either of these anecdotal remedies to relieve your pruritis symptoms in case there is any contra-indication in your particular circumstances.*

For more information about other MPN symptoms, please see our website:

<https://www.mpnallianceaustralia.org.au/understanding-mpn/mpn-symptoms/>

---

**THIS MONTH'S HEALTHY RECIPE:  
WHITE BEAN AND BROCCOLI PASTA.**



This is a recipe from MPN AA team member and accredited practising dietitian, Nathalie Cook, OAM. Nathalie advises that it is quick and easy to prepare and is budget friendly at less than \$10 for 2 generous serves. The beans provide a great high fibre source of plant protein and the garlic, broccoli and tomatoes are great sources of vitamins, mineral and anti-inflammatory flavonoids. This meal also provides a good amount of protein at 30gm per serve. Enjoy!

### **Ingredients**

- 1 can crushed tomatoes
- 1 can white beans (borlotti or cannellini)
- 2-3 tbsp extra virgin olive oil 50ml +20ml
- 3 gloves garlic, crushed

- 1 head of broccoli, chopped
- Pasta – 250gm
- 40gm Grated parmesan or crumbled feta to serve
- Extra virgin olive oil to serve

Optional additions or changes:

Add fresh or dried herbs - chilli, parsley, oregano, basil, paprika etc

Try kidney beans, four bean mix or lentil instead of white beans

Add other vegetables to the sauce such as zucchini, capsicum, rocket or spinach

### **Method:**

1. Heat oil in a pan and add garlic. Cook for a couple of minutes, stirring to prevent burning. Add tomatoes and tin of beans and mix.
2. Cover the pan with a lid and turn down heat to low and simmer for 20-30 minutes.
3. heat a large pot ½ full of water. When boiling add pasta of your choice.
4. Halfway through pasta cooking time, add the chopped broccoli.
5. When pasta and broccoli are tender, drain, reserving 1/2 cup of pasta liquid.
6. Toss pasta and broccoli through the tomato and bean sauce and loosen with extra pasta water if necessary.
7. Serve topped with cracked black pepper and grated parmesan cheese or feta and a drizzle of olive oil. Enjoy with a green salad.

---

## **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

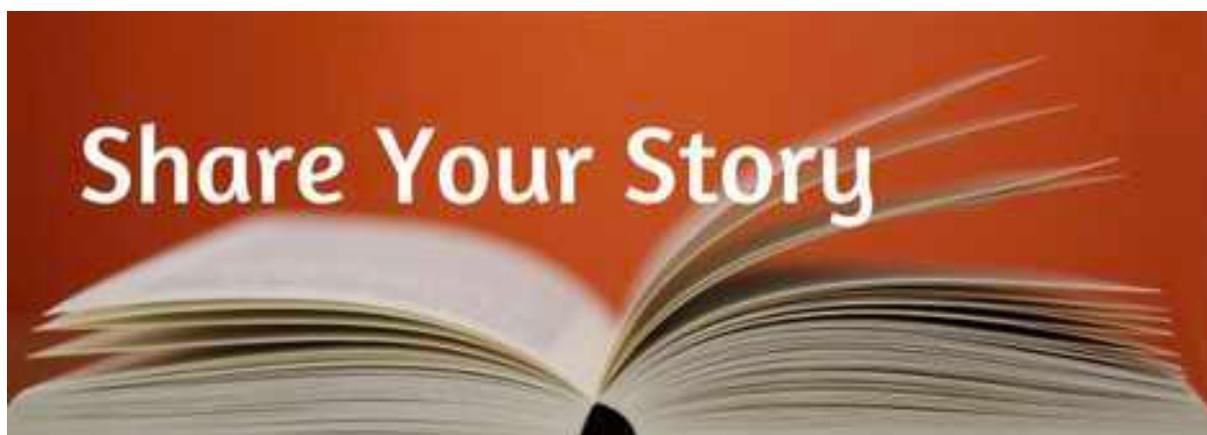
with blood cancer, more information is available [HERE](#).

---

## 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**

---





*Copyright © 2017 Myeloproliferative Neoplasms Alliance Australia (MPN AA), All rights reserved.*  
You are receiving this email because you registered to attend the MPN Patient Education Program in Melbourne on 28 April 2017, or because you have subsequently signed up to receive them.

**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

Want to change how you receive these emails?

You can [unsubscribe here](#)

---

This email was sent to <<Email Address>>

[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)

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

