MPN MATTERS

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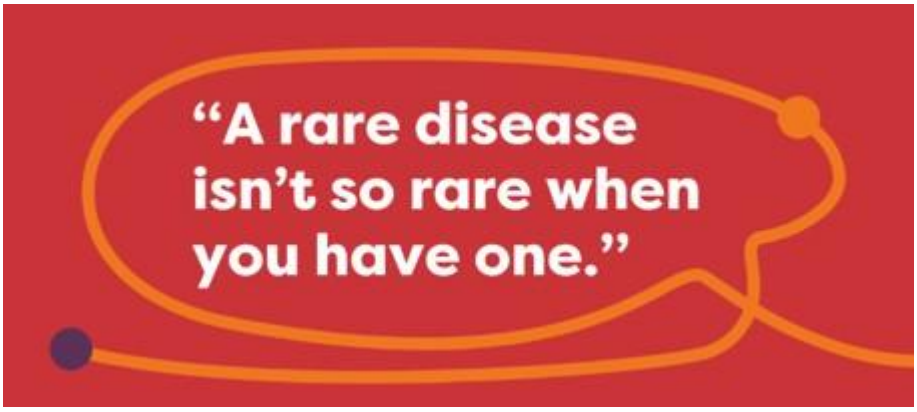
MPN Awareness Day

Shining a light on MPNs this September

10 September is MPN Awareness Day, an opportunity to recognise people living with myeloproliferative neoplasms (MPNs) and to make these rare blood cancers better understood. MPNs can be difficult to recognise because symptoms may be subtle, intermittent or mistaken for other conditions. Greater awareness can help reduce delays in diagnosis, prevent avoidable complications, improve access to specialist care and ensure people receive timely information and support.

MPN Awareness Day sits within Blood Cancer Awareness Month. This wider period of recognition reminds us that blood cancers are often under-recognised, under-funded and under-researched, and that people affected by them need credible information, stronger clinical understanding and a community that does not leave them to navigate diagnosis alone.



Around 1,900 Australians are diagnosed with an MPN each year, an incidence rate of about 7 in 100,000. For people living with an MPN, awareness matters not only in the community, but also across health care. Educating both clinical and non-clinical audiences helps build earlier recognition, more informed conversations and better pathways to care.

The MPN Alliance Australia works to support this progress by educating people about MPNs, supporting the MPN community, and funding research into better treatments and, ultimately, a cure. This MPN Awareness Day, we invite our community to learn, share reliable information, support people affected by MPNs and help strengthen the work needed to ensure MPNs are no longer overlooked.

If you are having trouble explaining your MPN to family and friends, we recommend these 4 straightforward, five-minute “Understanding MPN” video animations.

Clinical trials

High hopes for patients with the CALR mutation

Researchers presented Phase 1 results for Incyte’s INCA33989 mutant-CALR antibody at the European Hematology Association Congress in June, with trial participants in both ET and MF showing encouraging early responses. Australia’s A/Professor David Ross (pictured) from South Australia has prepared an expert review of the findings for patients.

The review includes information on upcoming clinical trials targeting the CALR mutation and offers clear insights into what may be an important step forward in

treating CALR-positive ET and MF.

Read his review to learn why advances in research are looking increasingly promising for patients with the CALR mutation.

Clinical trials for MPN patients

The MPN AA maintains a list of clinical trials available to Australian MPN patients. The list is updated monthly.

An honour shaped by our community

MPN Alliance Australia is proud to have been finalists in the Patients' Choice Awards 2026 (Cancer and Rare Disease Organisation) — a meaningful honour for a patient-led organisation created to support, inform and advocate for people living with myeloproliferative neoplasms (MPNs), and for the families and carers who walk alongside them.

Recognition through a patient-focused award is especially important to us because it reflects the purpose at the heart of our work: helping our community feel less alone, better informed and more confident to speak up about their care.

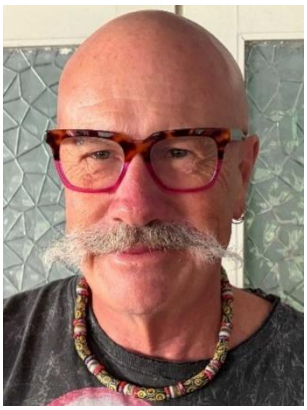
As an organisation led by lived experience, we know how much it matters for patient voices to be heard, respected and included in decisions that affect diagnosis, treatment, support and quality of life.

The nomination also recognises the many people who make this work possible — volunteers, committee members, supporters, clinicians, researchers, donors, families and, most importantly, the MPN patients who continue to share their stories and help shape better understanding of these rare blood cancers.

MPN AA committee members Ken Young and Nathalie Cook (pictured) had the privilege of being alongside organisations at the 2026 Patients' Choice Awards and rub shoulders with the individuals working to improve patient experience and outcomes across Australia.

We are grateful for this recognition, and even more grateful to the MPN community for continuing to guide and inspire everything we do.

Andrew's MPN story



Volunteers are the driving force behind everything we do at the MPN Alliance. One of our new team members, Andrew (pictured), has shared his story, which highlights the challenges associated with delayed MPN diagnosis.

Andrew, was diagnosed with PV after more than three years of debilitating aquagenic pruritus, a common MPN symptom that is now managed.

This is Andrew's story

Raising MPN awareness among GPs

Many MPN patients, once diagnosed, feel they have probably had their MPN for years. The reality is that MPNs can be difficult to recognise. MPNs are rare, and the mutations that cause them, especially JAK2, may arise in early childhood, early adulthood or even in utero, then develop slowly over time. This seven-minute video from haematologist Dr Jyoti Nangalia explains the origins of MPNs.

Symptoms can creep up gradually and may be missed by doctors and patients

until a serious event occurs. Sometimes an MPN is detected through a routine blood test when the person has no symptoms.

The MPN AA is working to raise awareness of MPNs among General Practitioners (GPs). We have developed an information page to help GPs navigate the world of MPNs.

Could you help to raise awareness?

Ask your own GP to help raise MPN awareness with their colleagues.

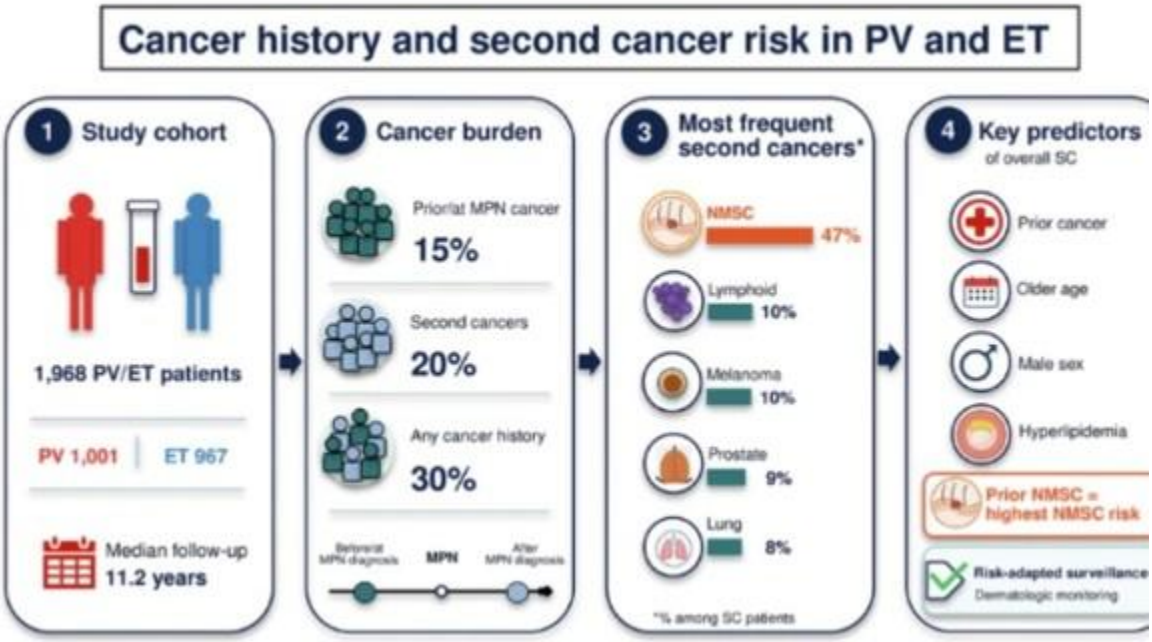
Share the link to our GP-focused webpage:
https://www.mpnallianceaustralia.org.au/understanding-mpn/general-practitioners-information/

Research updates

Recent research is improving understanding of how MPNs develop, progress and respond to treatment — knowledge that can support earlier diagnosis, better monitoring and more informed care.

- A *Cancer Discovery* paper, published in May 2026, found that MPN progression may be "genomically encoded years before clinical transformation", with different pathways leading to leukaemia or myelofibrosis. It also reinforces that transformation in MPN appears to be driven mainly by the disease itself, rather than any drug treatments. Read more on our website.

- A study published in *Nature* in July this year highlights the importance of routine cancer checks, particularly skin checks for people with PV and ET (see image below). Sun protection and regular skin checks are sensible for everyone living with an MPN, and are especially important for people taking treatments known to affect skin sensitivity or skin cancer risk, including ruxolitinib or other JAK inhibitors, and hydroxycarbamide (Hydrea). Read more about second cancer risk.



- Also published in July, a paper by a group of French researchers highlights the need for more evidence to guide treatment choices such as pegylated interferon. Read more about interferon and autoimmunity.

Upcoming events

Peter MacCallum: Work and Cancer monthly peer support groups

Melbourne's Peter MacCallum Cancer Centre is running a monthly peer support group on work and cancer, available in-person and online. The group brings together people affected by cancer to share experiences, practical strategies and support for navigating work and cancer.
More details and registration information are available on our website.

MPN coffee and chats and MPN lunches

MPN AA team members and fellow patients support others by organising coffee and chats or lunches.
For details and up to date information, please visit the events page.

- Sydney MPN get together – 2 pm Saturday 26 September
- Newcastle MPN lunch – 12 noon Saturday 10 October.
- Brisbane coffee and chat – 10 am Monday 26 October
- Melbourne coffee and chats. We've just had the very successful first one, with further dates to be advised.
- Canberra weekly coffee and chat: every Monday morning at Yarralumla Play Station– email mpnaa@mpnallianceaustralia.org.au to RSVP and for more details.
- Brisbane lunch, every quarter (next lunch expected to be Saturday 14 November. Please watch our Events page)

If you would like to host a coffee and chat in your neighbourhood, we can help promote it on our social and news pages.

Recipe: Thai pumpkin soup

This recipe is simple and delicious. We have featured it before, but we are pleased to share this even healthier version. It is based on a Donna Hay recipe with a couple of tweaks. While you may be tempted to add extra vegetables — we have previously tried adding zucchini and potatoes — it tastes best when pumpkin is the only vegetable used.

Ingredients

- 1 tablespoon red curry paste (Ayam brand is perfect)

- 1 kg pumpkin, peeled and chopped (Kent is especially rich and flavourful)
- 4-6 lime leaves (optional)
- A lemon grass stalk chopped into small pieces (optional)
- 6 cups chicken stock
- Fresh coriander or any herb (or even a sliver of chilli) to garnish.

Method

- In a large saucepan, fry the curry paste over medium heat for 30 to 60 seconds.
- Add the peeled and chopped pumpkin, stock, lime leaves and chopped lemongrass, then cook until the pumpkin is tender.
- Blend with a stick blender.
- Sprinkle with coriander or another herb to garnish. Some recipes also add pomegranate seeds.

We'd love to hear your thoughts?

Please let us know if you have any suggestions or questions about our newsletter or website. We are always looking for ways to improve. Comments and suggestions can be sent to mpnaa@mpnallianceaustralia.org.au.

Would you like to help?

We welcome all volunteers. We are looking for help in the following areas:

- Website design and maintenance
- Newsletter writing and editing
- Volunteer management

If you think you can help in any of these areas, please send your skills and availability to mpnaa@mpnallianceaustralia.org.au.

Thank you for your generous donations

A heartfelt thank you to everyone who has given generously to the MPN AA fund in recent weeks.

Your support helps fund important Australian-based research into better treatments and potential cures, while also strengthening education and support for people living with MPNs.

We gratefully accept one-off gifts as well as small ongoing donations — even $5 a week, which is less than the cost of a cup of coffee, can make a meaningful difference when combined with the generosity of others.

All donations are tax deductible and can be made through our giving portal.

Donate now

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Share your story

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.

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

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