



MPN | ALLIANCE AUSTRALIA

Empower • Enrich • Enliven

Who Are We & What Do We Do?

MPN AA was founded in 2015 by a group of MPN patients, motivated by a shared lived experience.

Volunteer run by this team of patient advocates, MPN AA has become a space for raising awareness & understanding of MPNs, through our website we offer support for existing and newly diagnosed patients, and speak up for the Australian MPN community.

Sharing information & important connections to MPN resources, organizations, and support to MPN patients from evidence based resources.

All of the team are volunteers, and do not receive any funding.



MPN AA Achievements

- Provision of input to government reviews of policies on funding for medications and next generation sequencing (NGS) testing for MPN patients.
- Donated over \$150,000 to support Australian MPN research
- In 2018, after the Australian Government agreed to consider adding Pegasys to the PBS for people with MPN, MPNAA encouraged MPN patients across Australia to provide personal submissions to demonstrate the need for the medication.
- A curated Website with science based information & health & well being advice.
- Translated treatment documents in 3 community languages
- Quarterly newsletter to 900 subscribers.
- Contributed to MPN Optimal Care Pathways for doctors and patients, Australia's first MPN guidelines approved by state and territory governments.
- Provide MPN wallet cards to patients across Australia on request.
- Co-organised the first MPN patient program in 2017 with speakers from Australia and the US, thanks to MPN Advocacy and Education International.
- Ongoing Advocacy contribution to the MPN Advocates Network.
- Hosted a meeting for MPN patients with the Leukaemia Foundation, joined by doctors, a psychologist, and a social workers.
- Ongoing MPN walking/coffee and chat support group in Canberra.
- Individual team members contributed as patient representatives on different MPN research funding proposals as required in grant applications.
- Provided some funding and worked with Prof Peter Baade and team at CCQ on the Australian Cancer Atlas enabling MPNs to be included for the first time. Also gave feedback from consumers for version 2 of the Atlas.
- Ongoing work with all the state cancer registries aiming to improve MPN incidence data collection
- Contributed to the Leukaemia Foundation's blood cancer taskforce and final report leading to the National Strategic Action Plan for Blood Cancer.

Our Mission

We aim to increase awareness and understanding of MPNs, to support MPN patients, and to advocate on behalf of the Australian MPN community. By sharing information and providing vital links to MPN resources, organisations and support we aim to benefit newly diagnosed and existing patients and their families. MPN patient quality of life is central to everything we do. Together, we strive to advocate for access to emerging treatments and research to aid in the search for answers and a cure.

***“Alone we can do so little;
together we can do so much.”***

— Helen Keller

Hopes & Dreams for the future

- Improving our social media on all platforms to drive more visitors to our website. Focusing on engaging younger patient groups, especially women getting ready to start a family.
- Ongoing work with the Australian Cancer Atlas team and Australian cancer registries to ensure all MPNs are reported
- Working to ensure all MPN patients are aware of best practice guidelines and receive best care and treatment for their MPN.
- Running an Australian MPN patient conference in the next 1-2 years.
- Supporting & advocating for more MPN clinical trials in Australia to help patients get access to new drugs.
- Closer collaboration with researchers to help inform patients about their work and potentially provide further ideas for their research directions.
- Building connections with international MPN patient organisations.
- Continued work & advocacy to update Optimal Care Pathways by incorporating the latest research and other MPN developments.