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MPN Matters Issue 19 - December 2022



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# MPN MATTERS

## ISSUE 19 - DECEMBER 2022





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### **Reflections on the 2022 MPN Horizons meeting, Netanya, Israel from Ken Young, MPN AA team member**

For the past 20 months I have been a Steering Committee member of the MPN Advocates Network (MPN AN) which is constituted as an independent steering committee within its parent organisation, the Leukaemia Patient Advocates Foundation, registered as a non-profit organisation in Switzerland.

This year Nathalie Cook and I were able to attend the first meeting since COVID. This "hybrid" meeting was face-to-face in Netanya, Israel and also available online. The conference theme was "to Learn, Share and Grow". It was attended by patient advocacy group representatives from around 20 countries. It was inspiring to connect with other patient advocates and discuss common and unique strengths and barriers. I will reflect on general themes here, and a link to all the presentations appears below.

Firstly, at the 2022 Horizons there were patient representatives from first, second and third world countries. For second and third world countries access to medication, genetic testing and drug trials was a significant issue. An Armenian haematologist gave the example that he can only access

Hydroxyurea for his patients - Pegasys or other treatments are completely unavailable. Whereas in a number of European countries MPN patients can access latest treatments such as Besremi at highly subsidised cost. I was impressed with The Max Foundation which delivers medication, technology, and services to patients facing cancer and other critical illnesses, focusing on those who no one else is helping. I recommend you watch the presentation by Lyat Granati Espinosa, from the Max Foundation in Chile.

The second observation is there is a very strong camaraderie between patient organisations to Learn, Share and Grow. Johannes Hoogland reported on an initiative from the MPN Stichting, Netherlands, which has developed a private and secure social media platform for MPN Patients which will be made available to MPN advocacy groups globally. You can watch Johannes's presentation for more detail.

Thirdly, there are interesting partnerships developing between some patient groups and pharmaceutical companies. This may be controversial but I found the Advocacy Session 4: Patient organisation's collaboration with pharma very interesting.

Finally, Dr Gabby Hobbs, the MPN AA's Nathalie Cook OAM and Dr Ruben Mesa presented in Medical Session 3: Effective complementary therapies for MPNs which I recommend that you look at.

On our last day in Israel, Nathalie and I joined Felice Bombaci and his wife from Italy, to visit Bethlehem and Jerusalem.



Ken Young watches on whilst Nathalie Cook presents at the November 2022 MPN Horizons Conference in Netanya, Israel.

Here is the link to the videos from [MPN Horizons Hybrid Conference 2022](#)

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## ASH 2022 MEETING

The recent American Society of Haematology (ASH) meeting featured many presentations relating to MPN research findings. This demonstrates just how much is happening in the world of MPN research, and should give us all hope for the future of MPN management.

Perhaps the most exciting news was that the discovery of a CALR monoclonal antibody which has proven very successful in the laboratory is expected to commence patient clinical trials in the coming year. The CALR mutation is responsible for roughly 30% of ET and MF cases. A measure of the importance of this breakthrough is that the research was featured in a plenary session at the conference.

Some other research report highlights:

- . The trial drug Momelitinib is continuing to show benefit for selected MF patients, and is likely to commence the approval process in the US
- . There were reports of many combination trials where different drugs are tried in combination with JAK inhibitors to address such disease symptoms as anaemia and splenomegaly in myelofibrosis, with the aim of improving quality of life.
- . For PV patients, the drug Rusfertide is showing promise to help keep HCT under control.
- . A Phase 2 clinical trial of the LSD1 Inhibitor Bomedemstat (IMG-7289) for the treatment of Essential Thrombocythemia (ET). This is an agent that is being trialled for ET patients who are intolerant or have failed other conventional treatment. This clinical trial includes some Australian researchers.

For more information on some of these advances, you can read the article below, thanks to MPN-Hub:

<https://mpn-hub.com/medical-information/ash-2022-abstracts-whats-hot-in-mpn>

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**MPN treatment information for patients is now available in English, Arabic, Mandarin and Vietnamese at the MPN Alliance Australia website**

The MPNAA is proud to advise that MPN treatment information is now available in three languages as well as English: Arabic, Vietnamese and Chinese. Many thanks to the accredited translators who undertook this work.

[This information is available in printable PDF format.](#)

The MPNAA would like to particularly thank Dr Cecily Forsyth for revising and updating these treatment documents which also take account of COVID antivirals.

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### **Pregnancy and MPNs**

As awareness about MPN increases amongst doctors, younger women are more often being diagnosed with MPNs. This has seen the development of best practice recommendations for the management of MPN in pregnant patients. The MPNAA has put [a link to this information](#) on our website with thanks to MPN Hub.

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### **The Latest Information about MPNs is continually updated on our website**

The MPNAA website has links to the latest MPN guidelines from the USA, the British Haematology Society, the European Haematology Association, as well as guidelines for management of specific situations in MPNs such as pregnancy, splanchnic vein thrombosis, peri-operative management. You can find this information [here](#).

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### **Support groups/walking group**

The Leukaemia Foundation runs monthly online support groups for blood cancer patients and their families with a different topic each month. Groups are free but [you need to book](#) as numbers are limited. [Events](#) are also listed in our website.

Canberra MPN patients are welcome to join a weekly walking group. The group meets at 9.30 each Monday morning and for those who would just like to meet for a coffee and chat, are welcome to join the group at about 10.30 at the Yarralumla Play station café. [Send us an email](#) if you are interested.

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### Spicy Red Lentils with Capers and Currants

This [Recipe Winners SALAD](#) is so simple but absolutely delicious. It's a super healthy and protein-packed. It keeps for several days in the fridge.

#### Variations

Omit capers and instead add roast beetroot and capsicum, chopped into fairly small chunks, and add chopped feta cheese.



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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**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

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