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# MPN Matters

Issue 1 - May 2017

Historic Australian MPN Patient Education Program



**MPNAA Members from left: Nathalie Cook, Lara Chapman, Ken Young, Sue Taylor, Jolanda Visser, Angela Willett**

Welcome to our first **MPN Matters** newsletter, designed to keep you updated on the latest MPN AA activities.

We trust that you are rested after travelling to The Langham, Melbourne to join us in the first ever MPN specific national patient education program. Thank you for attending and participating in our day. Your support is appreciated.

We would love to welcome new subscribers to our newsletter, as we build our community and reach. Please let others know to send us a message via [mpnaa@mpnallianceaustralia.org.au](mailto:mpnaa@mpnallianceaustralia.org.au)

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### **Why MPN AEI came to Australia!**

By Ann Brazeau, CEO, MPN Advocacy and Education International

MPN Advocacy and Education International hosts several patient/caregiver educational programs per year. Although most take place in the United States, their goal to expand to other countries where MPN groups are interested in partnering to benefit their MPN Communities has been a priority.

Through collaboration with the MPN Alliance Australia, the first patient/caregiver program was held in Melbourne on the 28th April, 2017. MPN specialists from Australia joined U.S. specialists to share up-to-date, relevant information to over 150 patients and caregivers.

Empowering patients with the knowledge they need to better understand the complexities of MPNs, is what MPN Advocacy and Educational International hopes to achieve at these events. Partnerships are essential to the success of these very important programs. Imparting valuable, reliable information to the MPN Communities around the world helps bridge the gap to understanding what is being done, and identifying unmet needs.

In the early days of my work in MPN little was being shared among researchers and academic institutions. Today, it is a common practice. Recognizing the importance and value in collaborating, researchers and clinicians are much more amenable and grateful for opportunities to share their experiences and findings. Thus, a physician/researcher meeting was held the afternoon before the patient event.

A half-day strategy meeting with the MPN Alliance Australia proved to be meaningful and productive. Their dedication and commitment to the patients and caregivers in Australia is evident in the many hours they volunteer each week.

We are proud to have been a part of this experience and were happy to pull this event together with our partners, MPN Alliance Australia.

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### **MPN Patient Program - 28 April 2017**

The Australian MPN community was given a wonderful gift on Friday 28 April by Ann Brazeau and her team from MPN Advocacy and Education International, together with Drs Ruben Mesa, Laura Michaelis, and Raajit Rampal from the US; and Drs Cecily Forsyth, Steven Lane, Kate Burbury, David Ross, and Wendy Erber, and Andrew Lim, (standing in for Prof Andrew Grigg), from Australia.

Months of planning culminated in an outstanding educational event for the group of over 150 Australian MPN patients, caregivers and haematologists.

We all expected great things from the US contingent, and they certainly delivered. We were also extremely impressed by the presentations from our home-grown haematologists. The level of passion, dedication and care for patients was very evident in each and every one of the presentations.

After the formal presentations, patients and caregivers were able to ask questions of the presenters in disease-specific break-out sessions.

I think for patients and caregivers ranging from the newly diagnosed to the old hands, everybody learned something, and valued the opportunity to share with patients and professionals during breakfast, lunch, and the wonderful Mix and

Mingle event at the end of the day. If we didn't finish all that wonderful food, it was only because we were so busy talking!

Given the amount of information which was presented on the day, I am looking forward to seeing the video of the presentations, to have the opportunity to revisit it.

Together with my MPNAA colleagues, I felt privileged to have had the opportunity to listen to the clinicians in their meeting on the Thursday afternoon, as we gained insights into the challenges of diagnosis and treatment of these complex blood cancers.

Thanks so much to Ann and Marina (as well as Kathleen behind the scenes) and the wonderful doctors who were willing to cross the vast Pacific to share their knowledge. Thanks also to all the wonderful clinicians and researchers who came from far and wide across Australia. Together you enlightened, empowered and entertained all those who were lucky enough to be present!

I feel so inspired.

Sue Taylor

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This afternoon MPN Advocacy and Education have released the much anticipated videos from the Melbourne conference. To view, copy and paste this link in your browser, or click on the watch now button.

<http://mpnadvocacy.com/australia-mpn-patient-education-registration/>

**Watch now**

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Dr Ruben Mesa addresses Australian and American haematologists, researchers, and pathologists on the unmet needs of MPN patients, particularly those with Myelofibrosis. He discussed the role of Ruxolitinib, Interferon and clinical trials. He addressed the question of what would constitute failure of Ruxolitinib treatment, and when it might be appropriate to continue Ruxolitinib despite suboptimal symptom or spleen control, or hematological toxicity in this group of patients.

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