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MPN Matters - Issue 3 - September 2017 - EOFY & MPN Conference wrap up, How to Inject Interferon Video, EHA Conference summary

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MPN Matters

Issue 3 - September 2017

What an amazing response to our EOFY campaign!!!! THANK YOU to all those who supported the MPN Alliance Australia by donating and/or sharing our link.

With your support, we raised \$11,189. Every cent will benefit the MPN Community.

Please continue to share the donation link www.leukaemia.org.au/mpn amongst your networks to help MPN Alliance Australia raise the voice of the MPN community.

We can make a difference.

MPN AA member, Jolanda Visser, gratefully accepted a generous \$1,000 donation from the Big A Boutique Op Shop, Colonel Light Gardens Church of Christ in South Australia. The Big A boutique regularly donates part of their proceeds to charities and organisations that want to make a difference by supporting the community.

After accepting the donation, Jolanda Visser was able to present a talk on MPNs, how patients' quality of life is affected and how the MPN AA is trying to make a

difference through advocacy and support.

Cecily Forsyth (haematologist) attended the European Haematology Association (EHA) Conference in Madrid from 22nd to 25th June 2017. Dr Forsyth kindly provided the MPN Alliance Australia with a myeloproliferative neoplasm update from the conference.

The update covers the following:

- PEGINVERA study which evaluated the tolerability and safety of Ropeninterferon Alpha 2b in Polycythaemia Vera
- PROUD PV study which compared Hydroxycarbamide with Ropeninterferon Alpha 2b
- RESPONSE 2 update which was an 80-week update on therapy with Ruxolitinib versus best available therapy in Hydroxycarbamide-resistant/intolerant patients with PV without splenomegaly
- SIMPLIFY 1 study which tested the non-inferiority of Momelotinib versus Ruxolitinib therapy in patients with primary myelofibrosis, post-polycythaemia vera or post-essential thrombocythaemia myelofibrosis who had not previously received a JAK inhibitor.

For a full summary of results from the studies, please visit our website mpnallianceaustralia.org.au and go to the MPN News section.



INTERFERON – if you are about to start using interferon, this “How to Inject” video may help. Also have a look at the Interferon Pamphlet on the MPN Alliance Australia website (www.mpnallianceaustralia.org.au) on the Understanding MPN tab.

On 28th April 2017, MPN Advocacy & Education International and the MPN Alliance Australia co-hosted the first ever MPN-specific conference in Australia. Ann Brazeau and her team brought together International and local MPN specialists for a wonderful day of learning and sharing for 153 Australian MPN patients, caregivers and haematologists.

Presentations were given by Drs Ruben Mesa, Laura Michaelis and Raajit Rampal from the US and from Drs Cecily Forsyth, Steven Lane, Kate Burbury, David Ross, Wendy Erber and Andrew Lim (standing in for Professor Andrew Grigg) from Australia.

Conference Empowers MPN Community

- Enabled MPN patients to connect with others with a MPN diagnosis
- Brought together Australian MPN experts – made them visible for patients attending
- Helped build relationships
- Attended by many newly diagnosed patients who were exposed to up to date

information and medical experts upon diagnosis and not years down the track

- Round table discussion between Australian and international haematologists pathologists and researchers to share and discuss their area of expertise
- Empowered MPN patients to ask for a second opinion, seek a bone marrow biopsy or ask for next generation sequencing
- Enriched patients lives by showing them that they can help themselves by living well with an MPN

MPN Advocacy & Education International organised to record all the presentations and these have been released via YouTube. To view, copy and paste this link into your browser, or click on the watch now button.

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

WATCH NOW



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You are receiving this email because you registered to attend the MPN Patient Education Program in Melboiurne on 28 April 2017, or because you have subsequently signed up to receive them.

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