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MPN Matters Issue 7 - December 2018



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## MPN Matters

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## **MPN Alliance Australia – Supporting Australian MPN Research**

The MPN Alliance Australia hosted a charity dinner on Saturday 11 August in Adelaide, South Australia. The dinner was a great success and very much enjoyed by the 166 people who attended and danced into the night. The dinner was supported by generous businesses and individuals who donated goods to be auctioned on the night. A total of 73 items were sold via auction, silent auction and raffle. The Grand Ballroom at Tapleys Hill Road in Fullham Gardens was a wonderful venue, and staff went out of their way to make the night such a success. Entertainment during the night was generously donated by the fabulous band Soul'd Out. MPN Alliance Australia was also very grateful to be supported by the Leukaemia Foundation, including the very talented and engaging MC Julia Clarke and assistance on the night from Kerry Lambert.

**Thanks to our very own Jolanda Visser for her extraordinary efforts in organising this event, the generosity of our donors**

**and the guests, the MPN Alliance Australia raised \$23,505. See more below on how these funds are enabling MPN research with renowned Professor Lin Fritschi, cancer epidemiologist.**

Myeloproliferative Neoplasms are group of rare blood cancers and currently available statistics estimate that there are about 5,000 patients living with MPN in Australia. MPN patients however often question the exact number of people living with MPN diagnoses in Australia, and whether the available statistics accurately report the number of cases. MPNs were only officially designated as a cancer about 15 years ago, which means that there is not so much information available on them. In addition, the main mutations which give rise to MPNs have only been discovered relatively recently, and pathology testing was not as widely available in the past.

Epidemiology - accurate information about the incidence and prevalence of various cancers, is used by governments, hospitals and support agencies to plan services, resources and access to medication, and is also used to assist in prioritising funding for research. It is also important to determine the factors which may give rise to the disease, and this requires accurate recording of numbers and location of patients.

**Epidemiological research on MPNs in Australia is in progress.**

The MPN Alliance Australia is working together with Professor Lin Fritschi, a renowned cancer epidemiologist from Curtin University of Western Australia. (You may already know of Lin's work as Chair of 'the International Agency for Research on Cancer's' enquiry on the health impacts of the herbicide glyphosate as featured on the ABC's 'Health Report' recently). MPN Alliance Australia will donate the funds raised from the charity dinner to contribute towards achieving a better picture of the incidence, prevalence and hopefully causal factors in Australian MPN cases. The first stage of this research initiative, which is analysing the data from the national Australian registry has already shown some interesting trends. The next stage is the process of obtaining, analysing and researching MPN data from the cancer registries in a number of different states. This stage is underway and the MPN Alliance Australia is excited to be able to contribute to this research.



Guests enjoying the atmosphere at the Adelaide MPN AA fundraising dinner

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If you would like to support the MPN Community this Christmas, please donate via this link.

**Support MPN - Make a Tax Deductible Donation**

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## **MPN Interferon Initiative Report**

On the 30<sup>th</sup> November, Lara Chapman represented the MPN Alliance Australia as an invited guest, at the 2<sup>nd</sup> Annual ASH Meeting, hosted in San Diego by the MPN Research Foundation. The MPN AA would like to thank our partner organisation MPN RF, for the invitation. We appreciate the opportunity to follow up on the progress being made on behalf of the donors who have supported the MPN AA.

The meeting convened to hear updates on the progress from the Grantees of the

MPN Interferon Initiative. Although, the meeting was very scientific as researchers reported to their peers, the overarching feeling as an observer, was one of positivity and hope for new information and progress being made. As a patient, it was encouraging to witness the sharing of information and respect amongst the scientific community. Project Manager, Mr Richard Winneker, and the MPN RF are to be congratulated on establishing such a positive research environment, and we can only hope that through sharing of resources and information, that greater progress and outcomes will be forged.

The MPN AA contribution to the MPN Interferon Initiative directly supports research here in Australia. Dr Steven Lane's laboratory is based in Brisbane. Dr Lane (QIMR Berghofer Medical Research Institute) collaborates with Dr Ann Mullally (Brigham & Women's Hospital) & Dr Michael Milsom (German Cancer Research Centre).

The aims of their project are outlined in the slide below. Achievements in the first 12 months are:

- \* Validated CRISPR/Cas9 in vivo gene editing studies to develop and validate clinically relevant models of MPN disease progression (published)
- \* Mechanistic understanding of interferon on Jak2 V617F stem cells (completed/ manuscript in preparation)
- \* Acquisition and validation of Ro-pegIFN (experiments ongoing)

An interesting finding was that Ro-pegIFN to date has shown superior durability of action, tolerability and efficacy.

We look forward to hearing more as the project progresses.

## Project Title & Aims

- **Title** - *Overcoming resistance to interferon in MPN stem cells* – Ann Mullally, MD (Brigham & Women’s Hospital) Steven Lane, MD, PhD (QIMR Berghofer Medical Research Institute) & Michael Milsom, PhD (German Cancer Res. Ctr).
- **Aims**
  - **Aim 1:** To uncover the mechanisms which mediate the resistance of MPN stem cells harboring concomitant epigenetic mutations to IFN
  - **Aim 2:** To determine whether MPN stem cells are preferentially sensitized to IFN as a result of elevated DNA replication stress and an aberrant DNA damage response (DDR).
  - **Aim 3:** Use deep molecular analysis of a cohort of IFN-treated MPN patients to comprehensively define the key genetic drivers of resistance to IFN in MPN



## Keeping muscles strong to stay well with MPN

Nathalie Cook APD

As we age, we lose skeletal muscle mass and physical strength in a process called *sarcopenia*. Unfortunately sarcopenia begins from our 30s and after age 50, we can lose up to 15% of our skeletal muscle each decade. Sarcopenia is one of the most important causes of functional decline and loss of independence in older people. MPNs like other chronic inflammatory diseases are risk factors for sarcopenia. Sarcopenia contributes to fatigue and low energy levels experienced in people living with MPN.

Read Nathalie's full article to find out how to minimise loss of skeletal muscle [HERE](#). The article resides on the MPN AA website.

*“Let food be thy medicine and medicine be thy food” Hippocrates*

Nathalie Cook is an Accredited Practice Dietitian with over 20yrs of experience

in the public and private health sectors. She works as an Adult and Paediatric Dietitian at Banyule Community Health in Victoria, is a volunteer member of MPN Alliance Australia and has personal experience with MPN (PV).

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## PLEASE VISIT OUR NEW WEBSITE

[www.mpnallianceaustralia.org.au](http://www.mpnallianceaustralia.org.au)

You will find MPN disease and treatment articles, patient stories and information and support resources to help you live the best life you can with your MPN.



The three colour strands of our new blood-drop symbolise the three classic MPNs, encircling the rarer subtypes. Together we are a community.

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**Send us an email**

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