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MPN Matters Issue 8 March 2019



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MPN Matters

Issue 8 - March 2019



Connections between people diagnosed with a MPN, families, carers and support organisations such as the Leukaemia Foundation, provide vital support and information. In this issue, read about the Canberra MPN coffee and chats that have become a mainstay for those that attend. Future coffee and chats are advertised under the Events page of the MPN Alliance Australia website.

In February, MPN AA collaborated with the Leukaemia Foundation to host a very successful patient information day at Royal North Shore Hospital. Included in this issue is the link to videos of the presentations by Dr Cecily Forsyth and Dr Renee Eslick.

With increasing awareness of the role that inflammation plays in the disease process, enjoy the Grilled Salmon with Rainbow Salad recipe provided in this issue.

Best Wishes MPN AA Team

Canberra MPN coffee and chats have become regular events, meeting every 4-6 weeks and have around 15-20 MPN patients and partners who are able to attend.



You are welcome to join the group on a regular basis or attend from time to time. One couple drive up from the south coast (a three hour journey) which is a huge effort but one that we really appreciate.

The aim of the get-togethers is to provide mutual support, understanding and share our own MPN experience and knowledge.

Members of our group have the three major types of MPNs – MF, PV and ET. We have all learned much from each other by sharing our histories, our ups and downs, as well as our own perspectives and insights. Our disease has manifested itself in different ways. We have varying levels of bone marrow fibrosis, some have high platelets, others high red or white cell counts, others too much iron and some, not enough. Similarly, our symptoms vary from almost no symptoms to debilitating headaches, fatigue and a number of other symptoms ranging in severity. Fortunately, once correctly diagnosed, we have mostly seen substantial symptom improvement yet our treatments have also varied - from watch and wait, daily low dose aspirin, venesections, or some form of cyto-reduction therapy. And most encouragingly, one of our group has had an allogeneic transplant and is able to provide us with constant optimism and wisdom.

I believe our get-togethers have given us reassurance, knowledge and perspective, as well as a level of comfort in not feeling alone in having this rare blood condition. We understand and can empathise with each other, not only about our symptoms and treatments, but especially our anxieties and hopes about remaining well, long into the future.

Jenny Myers (MPN Alliance Australia) and the Canberra MPN support group
March 2019

The next Coffee and Chat will be advertised on the MPN AA website under 'Events', as well as our MPN Alliance Australia facebook page, Ken Young's MPD-oz Email Support Group (mpd-oz@mpd-oz.org) and Josie Muller's MPN Australia & and NZ Myeloproliferative Neoplasm Support Community Facebook page.

MPN patient information event held at Royal North Shore Hospital in Sydney on 23 February was attended by 60 patients and family members.



Dr Cecily Forsyth presenting at the MPN Sydney Education Day

MPN AA initiated a collaboration with Leukaemia Foundation to host a patient education day. MPN AA is very grateful on behalf of MPN patients for the great job done by Greg Zotos from the Leukaemia Foundation, and also Madeline Thompson on the day.

The presentations were great – firstly Dr Renee Eslick spoke very informatively about “Diagnosis of MPN”. Sue McConaghy, psychologist, spoke on the topic “This is Not the Life I Ordered”, providing ideas about tools we could use to help manage unwelcome and unplanned events in our lives – relevant to all of us at times! We then broke for a lovely afternoon tea, and reconvened to hear Dr Carmel Sullivan speak about how yoga could enhance our physical and mental health and quality of life. Dr Cecily Forsyth followed, and spoke on the topic “Optimal Management of MPN in Australia”, about the latest research on how MPN patients should be managed, going through the 3 main MPN

subtypes in order, but acknowledging the shades of grey that exist, and the need to treat each patient as an individual.

Patients seemed to be very engaged, and there was lots of chat in the afternoon tea break, and also some constructive to and fro between patients during the question time.

Videos of the presentations by Cecily Forsyth and Dr Renee Eslick are available for viewing, as well as copies of the PowerPoint slides. Slides of the presentations by Sue McConaghy and Dr Carmel Sullivan are also available, by clicking on the link below.

Event Videos

Eat a Rainbow to Fight MPN Inflammation



MPN symptoms are linked to increased inflammation. There is growing evidence that plant food based diets high in fruits, vegetables, legumes, and whole grains that also include fish, nuts, olive oil, low-fat dairy products and small amounts of lean red meat, reduce inflammatory markers and confer health benefits. Flavonoids and other phytochemicals (plant chemicals) in plant foods help reduce inflammation and plant fibre feeds the beneficial microbes in our intestine, that produce anti-inflammatory by-products, called short chain fatty acids.

Dr Robyn Scherber, MD Assistant Professor of Haematology and MPN expert at Mays Cancer Center in San Antonio, Texas is currently studying the link between diet, MPN symptoms and inflammation.

Anti-inflammatory foods to eat daily include:

- * Colourful fruits and vegetables
- * Whole grains and legumes
- * Extra virgin olive oil, sunflower, canola and peanut oils
- * Nuts and seeds
- * Oily fish (salmon, tuna, sardines), eggs, lean meat and low fat dairy products
- * Fermented foods including yoghurt, sauerkraut, kimchi etc.

Pro-inflammatory foods to avoid or limit include:

- * Refined carbohydrates- white breads, pastas, commercial cakes, biscuits and pastries.
- * Processed and cured meats – sausages, hot dogs, fried takeaway foods.
- * Packaged processed snacks - chips, crackers and confectionary.
- * Sugar sweetened beverages.
- * Saturated fats such as butter, coconut oil.

“A healthy diet is beneficial not only for reducing risk of chronic diseases, but also for improving mood and overall quality of life.” Dr Frank Hu, professor of nutrition and epidemiology in the Department of Nutrition at the Harvard School of Public Health.

A Family Favourite Recipe

Grilled Salmon with Rainbow Salad

Serves 4

- 4 x 125g salmon fillets,
- 1 punnets of cherry tomatoes halved
- 1 avocado, diced
- ½ of each a red, green and yellow capsicum, diced
- 1/2 cucumber, diced
- 2 spring onions, finely chopped
- Bunch of coriander, chopped 1 punnet of blue berries
- 1 mango, peeled and dices
- 2 cooked corn cobs, kernels cut off
- 1 tbsp extra virgin olive oil
- 1 tbsp lemon juice
- 1 tsp lemon zest
- cracked pepper

1. Grill salmon on each side for 2-3 minutes or until golden.
2. Mix chopped vegetables, mango and blueberries with olive oil, stir through lemon juice, zest and pepper.
3. Spoon salad into bowls and top with salmon fillets. Enjoy!
4. If you do not have the fruit and vegetables listed above, use your own colourful combination.

Nathalie C. Cook, APD, AN

Accredited Practising Dietitian

BAppSc, MNutrDiet, GradCertPaedNutrDiet

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



Newly Diagnosed?

The National Comprehensive Cancer Network MPN Patient Guidelines discuss testing for and treating the “classic” MPN types, including essential thrombocythemia, polycythemia vera, and myelofibrosis. Additionally, the guidelines discuss making treatment decisions from the patients perspective, including questions to ask your physician and the importance of support and seeking second opinions where appropriate.

Click on the following link to view the PDF of these guidelines:

[NCCN MPN Patient Guidelines](#)

If you would like to support the MPN Community and research please consider making a donation via this link.

[Support MPN - Make a Tax Deductible Donation](#)

PLEASE VISIT OUR WEBSITE

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 blood-drop symbolise the three classic MPNs, encircling the rarer subtypes. Together we are a community.



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Website:

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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