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MPN Matters Issue 13 - May 2020



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MPN AA donates \$15,000 to Australian MPN research at UWA

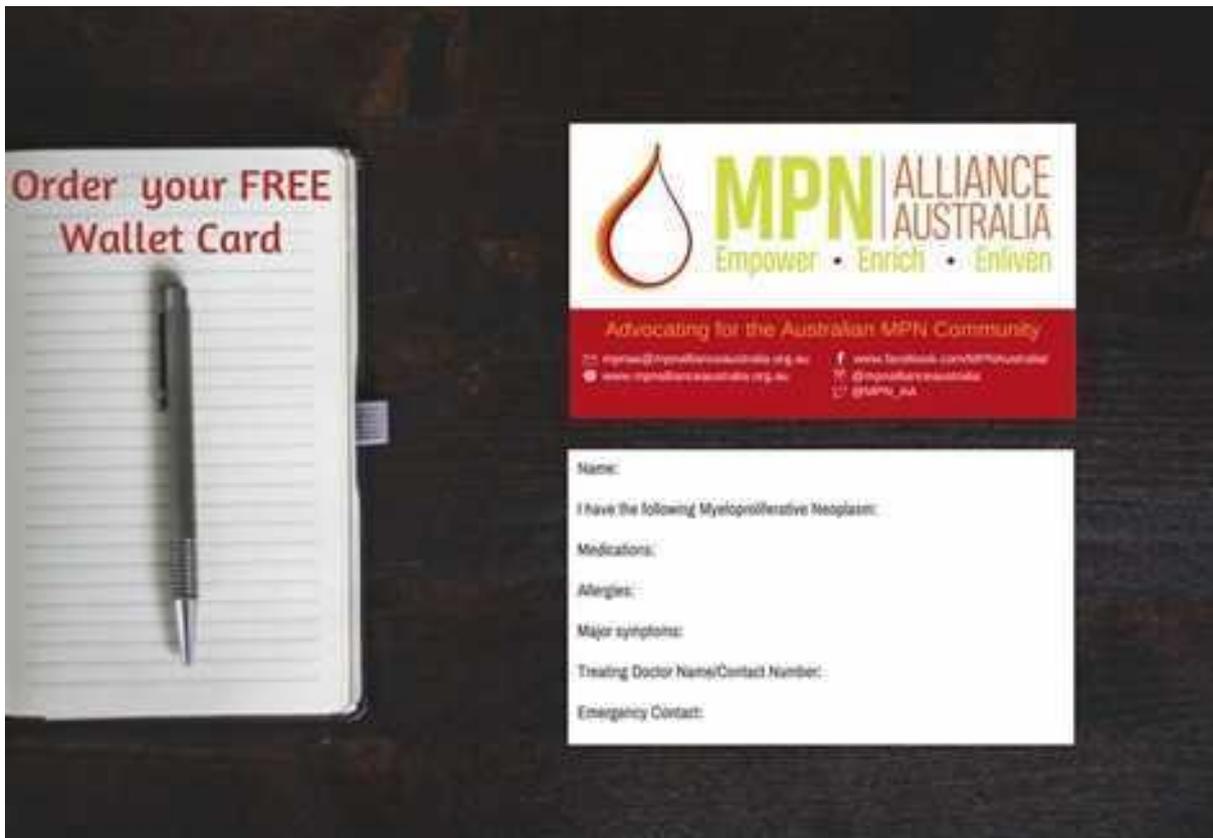
MPN AA is very proud to announce that with the help of our supporters, we have donated \$15,000 for MPN research in Australia to Professor Wendy Erber and her colleagues, Dr Kathryn Fuller, Dr Henry Hui and Dr Belinda Guo at the University of Western Australia. The team are undertaking research on a new technique to see if they can detect which MPN patients may be at risk of progressing to leukaemia or marrow fibrosis. It is hoped this may ultimately provide an alternative to the current method of utilising bone marrow biopsies for the purpose of detecting the first signs of disease escape or progression. Although only a minority of MPN patients are affected, it is not currently known who this might affect or when this will occur. By the time symptoms appear, it is generally difficult to cure. Hence a predictor of progression may assist in providing treatment earlier and possibly providing cures.

The method the team will use is their own invention, and the one that won a Eureka Award (affectionately known as the “Oscars of Science”!) in 2018 (<https://www.youtube.com/watch?v=-AvLxCLkAJc>). As you will see from the Youtube video it is a flow cytometry method that enables the study thousands of cells to see if the cell-of-interest has the chromosome change that may predict progression.

We wish Prof Erber, and Drs Kathy Fuller, Henry Hui and Belinda Guo every success with their research and look forward to sharing their progress in the future.

COVID-19 INFORMATION

The MPN AA shares the concerns of MPN patients about the impact of COVID-19 on our physical and mental wellbeing. We hope that you are managing as well as you can be during these difficult circumstances. In order to provide patients and carers with some quality information relating to COVID-19, we have put together a page of links to trusted sources on our website. For access to these resources, [use this link](#).



This card is designed to fit into your purse or wallet, and can be completed with your own details to assist you at medical and other appointments and in times

of emergency. Use this link to [order your card](#).

MPN PATIENT EDUCATION SEMINAR - PETER MACCALLUM CANCER CENTRE, VICTORIA - 18 FEBRUARY 2020

Peter Mac has kindly made available to patients the videos from the MPN Patient Education Seminar held on 18 February 2020. We are very grateful to everyone involved in putting on this seminar for MPN patients.

The event included the following sessions:

- MPNs, what are they? - Assoc Prof Dr Kate Burbury, Haematologist
- Fatigue Management - Elizabeth Pearson, Occupational Therapist
- Keeping well with MPNs - Nathalie Cook, Accredited Practising Dietitian
- How to get a good night's sleep - Dr Oliver Holmes, Psychologist

The link to the videos is [here](#).



Nourishing Chicken, Vegetable and Barley Soup

Eating mostly Five Food Group foods (grains, vegetables, fruit, protein and dairy/alternatives), is one of the best ways to maintain a healthy immune system. This delicious soup is quick and easy to prepare and is packed with high fibre, anti-inflammatory vegetables and spices. The chicken provides high quality protein for strong muscles. Barley is a great source of fibre to feed the

gut microbiome and keep it healthy and lime juice adds Vitamin C. Enjoy with wholegrain bread for a nourishing and comforting winter meal. Serves 8-10 people. Leftovers can be stored in the fridge for up to three days or frozen for up to three months. Enjoy!

Ingredients

2-3 Tbsps olive oil
2 leeks finely sliced, (green part discarded)
1 large onion, peeled and finely chopped
3 sticks of celery, finely sliced
4 carrots, peeled and finely diced
2 tsps crushed garlic
2 tbsps freshly grated ginger
3-4 tsp turmeric
500gm chicken fillets, skin off
2.5 L water,
2-3 tsps chicken stock powder or 3 chicken stock cubes
1/2 cup pearl barley
juice of 1 lime
chopped parsley
cracked pepper and salt to season

Method

1. Heat oil in a large pot and add chopped onions and leeks. Stir until soft and lightly browned. Add garlic, ginger, diced carrots, celery, turmeric and stock and stir through.
2. Add water, chicken and barley. Bring to boil and turn down heat and simmer gently for 60mins or until barley is soft. Add extra water as required, as soup thickens.
3. When chicken is soft and well cooked, remove from pot and shred using two forks. Return shredded chicken to the soup. Season with cracked pepper and salt.
4. Serve topped with chopped parsley and a squeeze of lime juice.

Nathalie Cook is an Accredited Practising Dietitian (APD) and works at Banyule Community Health in Melbourne's north. She is a volunteer member of MPN AA

and lives with polycythaemia vera.

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