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MPN Matters Issue 5 - February 2018

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The MPN AA thanks Ryan Eckert, MPN Research Program Co-ordinator for permission to share these interesting news summaries from the UT Health San Antonio/Arizona State/Mayo Clinic Partnership (i.e., MPN Quality of Life Study Group).

Thank you to our guest writer, Christine Donaldon, for her valuable contribution to this newsletter.

## **MPN NUTRIENT trial**

The world's first study investigating the impact of diet on MPN symptoms and disease progression, the NUTRIENT trial (NUTRitional Intervention among myEloproliferative Neoplasms Trial) lead by MPN researchers and physicians Dr Robyn M. Scherber, (Oregon Health and Science University and Mayo Clinic, Arizona) and Dr Angela Fleischman, (assistant professor in the department of Medicine, Division of Hematology/Oncology at UC Irvine) commenced in the USA in 2017 and is ongoing.

This study aims to identify dietary patterns associated with increased symptom burden and inflammation in MPN. So far, the study has collected self-reported data on MPN patients' dietary habits and food preferences via an online survey, however results of this study are not yet available.

Data from this study will be used to develop dietary interventions to assess the impact of various foods and dietary patterns on MPN patients' symptoms and biomarkers of inflammation. The goal on the study is to develop evidence-based dietary recommendations for MPN patients to follow to help reduce symptom burden, improve quality of life and hopefully delay progression of the disease.

Until we learn the outcomes of the NUTRIENT trial, MPN patients should aim to eat mostly minimally processed, high fibre plant foods and lean protein foods from the five food groups (vegetables, fruit, dairy, protein foods and grains), and include vegetables oils, nuts and seeds daily, to obtain healthy fats and antioxidants.

Recent research confirms high fibre plant-based diets encourage growth of beneficial intestinal bacteria (the gut microbiota), which helps reduce inflammation throughout the body. These effects may also benefit MPN symptoms.

Consistent with general healthy eating advice, MPN patients should limit intake of foods high in added sugar, salt and saturated fats (including soft drinks, cakes, sweet biscuits, confectionary, chips, fried takeaway foods) to occasional treats, eaten only sometimes and in small amounts. These foods lack fibre and nutritional value and when eaten regularly, can displace healthier foods in the diet. Moreover, these so called 'sometimes foods' adversely effect the gut microbiota and increase systemic inflammation, which may worsen MPN symptoms.

Further updates on the findings of the NUTRIENT trial will be reported here as the study progresses.

Nathalie Cook, Accredited Practising Dietitian

### **American Society of Haematology (ASH) Annual Meeting 2017: Updates in MPN Research**

Many haematology researchers and clinicians from around the world came together in December at the 2107 ASH Conference in Atlanta, Georgia.

Noteworthy updates for MPN patients included the work of Dr Dueck (Mayo Clinic) on the Phase II trial of pegylated interferon alpha 2a in hydroxyurea-resistant, high-risk ET/PV patients. The trial began with 115 patients, with 15% discontinuing due to side effects and 10% dropping out. For those who continued there were reported improvements in total symptom burden, fatigue, dizziness, numbness and weight loss. Of those patients who could tolerate the treatment, their QOL was not affected negatively despite the side effects of treatment (flu-like symptoms, injection site irritation, blurry vision). Further research is needed to identify those who are most likely to tolerate this treatment, especially among those who are resistant or intolerant to hydroxyurea.

Stem cell transplantation is a potentially curative therapy for high-risk MF patients, but as we know, carries many risks and potential complications. Dr Jeanne Palmer (Mayo Clinic) examined pre-transplant predictors of survival in 87 patients who underwent stem cell transplantation between 2005 and 2016. These patients had a survival rate of 66% at 2 years and 57% at 5 years, a treatment-related mortality rate of 29% and a relapse-related mortality rate of 9%. Predictors of mortality were found to be the need for a red-blood cell transfusion pre-transplant and the use of an unrelated stem cell donor. The use of antithymocyte globulin (ATG) was associated with increased overall survival. It was noted that the findings of this study will need to be confirmed in future research.

### **MPN Symptom Burden & Quality of Life**

The complex relationship between patient-reported symptoms, quality of life and MPN diseases was highlighted in the work of Drs Leslie Padrnos, Allison Scotch and Blake Langlias (Mayo Clinic) and Dr Kristina Gowin (Salish Cancer Centre). Their combined efforts were reported on at ASH and included findings from 1087 MPN patients. Of those surveyed 41% reported depressive symptoms and 23% met the criteria for a diagnosis of clinical depression. Depressive symptoms were found to be associated with increased symptom burden and were also believed to be related to the MPN disease itself rather than pharmacologic treatment. These findings were not unexpected as depression has also been found to be up to three times more common in cancer patients than non-cancer patients. The relationship of stress to a cancer diagnosis and then to depression has been found, with findings that a chronic diagnosis of greater than three years is associated with higher stress levels, less knowledge of how to manage stress and higher fatigue levels. The importance for clinicians and researchers of managing the stress and fatigue associated with a chronic MPN diagnosis was noted. This was also supported in additional findings by Dr Blake Langlias, indicating that depression and fatigue are symptoms especially likely to reduce QOL. While standard pharmacologic therapies (medications, phlebotomy, stem cell transplant) are associated with reduction in some areas (early satiety, abdominal discomfort, night sweats and weight loss), they are also

associated with increased fatigue and a reduced QOL. The impact of non-pharmacologic strategies (yoga, exercise, meditation, counseling) on QOL warrants more research.

Christine Donaldson

## **National Comprehensive Cancer Network Releases MPN Patient Guidelines**

On the 19th October 2017 the NCCN - a non-profit alliance of 27 leading cancer centres, published MPN-specific patient guidelines.

These 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:**

<https://www.nccn.org/patients/guidelines/content/PDF/mpn.pdf>

## **MPN Quality of Life Study Group – A Quarterly Report for MPN Patients The SIMM (The Survey of Integrative Medicine in Myeloproliferative Neoplasms) Study: Use of Integrative Medicine**

This 2016 study survey, developed by the Mayo Clinic in collaboration with Arizona State University, aimed to investigate Integrative medicine and its potential for improving the symptom burden of MPN patients. This was driven by both patient and provider dissatisfaction with unmet symptom burden. Patient use of complimentary treatment methods in conjunction with standard medical therapy was surveyed. Many of these strategies were found to be associated with lower symptom burden, improved quality of life, reduced depression and/or fatigue. These included aerobic activity (walking, jogging), massage, yoga, strength training, meditation, breathing exercise and support groups.

This research has led to further investigations, including the effects of diet and

meditation on MPN patient symptom burden and quality of life.

Those who attended the inaugural MPN Conference in Melbourne in April, 2017 may remember that Dr Ruben Mesa mentioned an Online Yoga Study for MPN Patients. In this Pilot Study the prescribed participation was 60 minutes per week for 12 weeks. The findings included improvement in MPN symptom burden, particularly in depression and quality of life as well as TNF-a (Tumour necrosis factor-alpha). This has led to further research to investigate the effects of online yoga for MPN patient symptom burden and quality of life. Feedback from the initial participants has also led to study of the effects of meditation on MPN patients, as they reported that the meditation aspect of the yoga was particularly helpful when falling asleep at night. Something we could all do with from time to time!

Christine Donaldson

Principal Investigator on the MPN Yoga Study, Dr Jennifer Huberty, participating in the filming of an online yoga video with Udaya Inc.

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**Do you have half an hour spare or love writing? We would love to hear from you! The MPN AA is seeking helpers for small tasks. Our advocacy work is growing. In order to provide the best service to the MPN community we are seeking volunteers in any capacity. Thank you!**

**Send us an email**

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We had a tremendous response to the Inaugural MPN Charity Art Exhibition. MPN Alliance Australia member, Lara Chapman, has raised \$14,788.53 to go toward supporting research into MPN!

Lara Chapman donated her own painting and Suzette Brander from the MPN community kindly donated a painting as well. In all, 52 artists donated paintings, of

which 31 sold. The MPN Charity Art Auction not only raised much needed funds, but also helped raise awareness of MPNs amongst the broader community.

Thanks to Lara for giving of her time to help the MPN community.

Watch this space as we grow this event into the future.

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Rare Disease Day is the 28th February. As a partner of Rare Voices Australia, the MPN Alliance Australia supports equitable access to treatments. Improved access to treatment options is 1 of Rare Voices Australia 6 Strategic Priorities.

To help the MPN AA support MPN research, consider making a tax deductible donation at [www.leukaemia.org.au/mpn](http://www.leukaemia.org.au/mpn)

**Donate Now**



**PBAC has recommended the government change the listing for PEGASYS to UNRESTRICTED ACCESS.**

Roche phoned me recently to announce the Pharmaceutical Benefits Advisory Committee (PBAC) recommended in it's November 2017 meeting that the Government change the PBS listing for Pegasys to UNRESTRICTED ACCESS, to enable MPN patients to obtain Pegasys on the PBS (and also other blood

cancers, such as myeloma and lymphoma.) The PBAC Nov meeting recommendations were published today online. (See page 13). <http://www.pbs.gov.au/.../.../recommendations-pbac-november-2017>.

The next step in the process is for the PBS and Roche to negotiate and agree on a price for the Australian Government to pay Roche for Pegasys to be on the PBS for MPN. Once this agreement has been finalised, Pegasys will be listed on the PBS for MPN and patients will pay \$36.00 per script instead of about \$1800.00 per script. Roche were unable to give me an exact time frame for when we can expect to have Pegasys listed on the PBS for MPN, but I was reassured Roche and the PBS are working hard towards this end. Given the time of the year, it's likely to be a couple of months delay over the holiday period until this work can resume, and then a bit longer to wait until it is actually on the PBS.

I have been campaigning to have Pegasys on the PBS for MPN since 2011 by contacting Roche Products, my local MP, Josh Frydenberg, the Health Minister and the PBAC. In Nov 2016 I wrote a submission to Prof. Andrew Wilson, Chair of the PBAC after meeting him in Canberra at the Rare Cancers Australia forum earlier that year, and explaining to him the unmet need of MPN patients to treat their disease with Pegasys. Following this meeting, I wrote my PBAC submission on Pegasys for MPN, (which included extensive references to published literature on Pegasys for MPN). Before logging my PBAC submission, I sought advice from several haematologists who reviewed my submission. The Health Minister and Prof. Wilson wrote back to me in early 2017, advising my submission had been accepted for consideration. The issue was then considered at the March, August and Nov 2017 PBAC meetings. In the meantime, I have been in contact the Roche Products throughout the process. Thank you to all who submitted consumer comments via the PBAC online portal, in support of my submission to Prof. Wilson, Chair of the PBAC. Our voices have been heard and history has been made! Hurray!!!

Specialists in Australia will be able to prescribe Pegasys for their MPN patients via the PBS, and patients will only need to pay the PBS amount of \$36.00 per script.

Kind regards,  
Nathalie Cook



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