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MPN Matters Issue 22 - December 2023



MPN MATTERS

ISSUE 22 - DECEMBER 2023





The MPN AA wishes all MPN patients and their extended families good health and a peaceful festive season.

MPN Horizons conference

The MPN Advocates Network, an international group of MPN patient advocates, has just held an international MPN conference featuring some of the world's leading MPN haematologists and researchers.

Conference presentations and videos are available [HERE](#). We especially recommend:

- **Cardiovascular risk factors.** Explains that all MPN patients are burdened with high thrombotic risk and that managing cardiovascular (CV) risk factors is so important. Fortunately, CV risk factors in MPN patients are modifiable.
- **Special cases: skin cancers and thromboses.** Skin cancer risk is heightened with some MPN treatments. And while MPN patients worry about our MPN progressing, UK specialist MPN haematologist, Claire Harrison, reminds us that our main risk is thrombosis. Even low risk PV

patients are at a much higher risk of thrombosis than the general community.

- **Complementary therapies.** This presentation highlights the benefits of exercise, the value of a mediterranean diet, the importance of stopping smoking and maintaining a healthy weight as well as other insights into how to live well with an MPN.

Important: Haematologists caution to be sure to check with your GP and haematologist before launching on any new exercise program and start slowly and gently if you have not exercised before or for some length of time.

Thrombosis in MPNs – a retrospective German study

And more on the subject of blood clots.....A German study has just looked back at arterial and venous thromboembolic complications in 832 MPN patients. Researchers found a relatively high incidence of MPN-associated blood clots.

The most frequent sites for clots in arteries were strokes and transient ischemic attacks.

The most frequent sites for clots in veins were deep vein thrombosis (with or without pulmonary embolism) and splanchnic vein thrombosis.

Patients with polycythemia vera had a significantly higher risk of a blood clot than the other MPN subtypes whereas patients with a CALR mutation had a significantly lower risk compared with JAK2-mutated MPN patients. The full study is available [HERE](#).

Recognising a blood clot

After all this, if you feel unsure how to recognise a blood clot, just a reminder that the MPN AA has a [webpage on blood clot awareness](#).

And the summary overview below is directly taken from '[Stop the Clot](#)' website.

STOP THE CLOT®

BLOOD CLOT AWARENESS: KNOW THE SIGNS & SYMPTOMS

S Swelling in the leg

T Tenderness leg cramps

O Out of breath

P Pass out lightheaded

C Chest pain back pain when breathing

L Leg discoloration (red/blue hue)

O Overdrive racing heart

T Time call for help 911

 National Blood Clot Alliance

 @stoptheclot
stoptheclot.org

 Learn more about blood clots here

Tell Your Doctor If You Experience Any Of The Signs Or Symptoms Of A Blood Clot.

There are several important signs and symptoms of blood clots. If you can recognize these signs and symptoms, you can save your life or the life of a friend or family member.

Seek immediate attention if you experience these signs or symptoms.

Blood clots can be safely treated.

Benefits of exercise on longevity



Image: MPN patient and partner walking on a warm summer evening

For several years now, the importance of exercise for cancer patients has been recognised. To further reinforce this fact, Melbourne oncologist Dr Ranjana Srivastava OAM, recently explained in *The Guardian Australia* that increased longevity is an additional benefit of exercise for cancer patients: “In addition to standard treatments, exercise really is one of the best daily “pills” cancer patients can take to improve their life expectancy. Indeed, if exercise could be marketed as a pill, it would be an outright blockbuster.”

[“Exercise is the prescription that every cancer patient deserves – and one they’re in control of”.](#)

Ageing and blood cancer

Dr Srivastava also recently presented a Leukaemia Foundation webinar for blood cancer patients titled ‘Ageing and blood cancer’. Her presentation was informative and inspiring, with many ideas to take action to age well. It is available [HERE](#) - with thanks to the Leukaemia Foundation.

If you are interested in more information about ageing, SBS on demand features an intriguing series by Dr Michael Mosley [‘Secrets of the superagers’](#).

MPN symptom burden

Were you aware that there is an internationally used MPN Symptoms Score Card to help monitor MPN patients' disease and treatment?

MPN 10 KNOW YOUR SCORE

Name: _____

Date: _____

Fill out the form below to track the burden of your symptoms.

Symptom: 1 to 10, 0 if absent and 10 being worst imaginable

Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during the past 24 hours

Fatigue										
0	1	2	3	4	5	6	7	8	9	10
(NO FATIGUE)					(AS BAD AS YOU CAN IMAGINE)					

Circle the one number that describes during the past week how much difficulty you have had with each of the following symptoms

Filling up quickly when you eat (early satiety)										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Abdominal discomfort										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Inactivity										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Problems with concentration - compared to before my diagnosis										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Night sweats										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Itching (pruritus)										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Bone pain (diffuse, not joint pain or arthritis)										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Fever (> 37.8°C or 100°F)										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

Unintentional weight loss last 6 months										
0	1	2	3	4	5	6	7	8	9	10
(ABSENT)					(WORST IMAGINABLE)					

To help you get a clear overall picture of how you are feeling, you can add up all your scores to calculate your Total Symptom Score. **Total:**

You can also fill in this form and find more expert information about myeloproliferative neoplasms online at www.spotlightonMPN.com



Novartis Pharmaceuticals Pty Limited, 54 Waterloo Road, Macquarie Park NSW 2113. ABN 18 004 244 160 PH: (02) 9805 3555. For medical enquiries please contact 1800 671 203 (phone) or medinfo.ph@novartis.com.au (email). R-Registered Trademark, AU-0136, NOV3391. Prepared January 2017.

Approved form (Novartis) 4/16/17 11:27 AM. Only a part of the form is shown.

This scorecard is available for download at: [MPN10 Symptom Score Card](#)
Further details are available from [The haematologist.org](http://Thehaematologist.org)



Image: pruritis (itchiness) can be a debilitating symptom for many MPN patients.

If you would like more information about MPN symptoms and symptom management, see [HERE](#).

Starting out on Pegasys – new explanatory video available

A new video is available on the MPN AA website which explains all you need to know before starting on pegylated interferon (Pegasys). It complements an existing video, kindly prepared by an MPN patient.

Even for those of us who have been injecting Pegasys for several years, it's been a useful reminder of best practice in using the medication.

It's available [HERE](#) to watch (scroll to about halfway down the Interferon page).



Venesection leaflets translated into Arabic, Chinese and Vietnamese

The MPN AA website provides printable PDFs of the main MPN treatments available in Australia - in English, Arabic, Chinese and Vietnamese. The latest set of translations is now available for venesections. And if you are someone who needs venesections, you may find [reading the venesection leaflet](#) helpful to refresh your knowledge about staying hydrated etc.

Healthy recipe: Colourful beef soba noodle salad



Our wonderful team member and accredited practicing dietitian, Nathalie Cook OAM, has kindly provided us with a recipe for this newsletter. Nathalie has explained that this dish is packed with colourful vegetables that provide a range of vitamins, minerals and anti-inflammatory compounds and the meat is a great source of iron, zinc and protein.

Ingredients

300g steak barbecued and cooled then thinly sliced
1 medium carrot, peeled and cut into julienne sticks
1/2 red capsicum thinly sliced
2-3 spring onions finely sliced
1/4 red onion finely sliced
1/3 Lebanese cucumber cut into julienne pieces
300g cherry tomatoes, halved
1 cup of snow peas, sliced diagonally

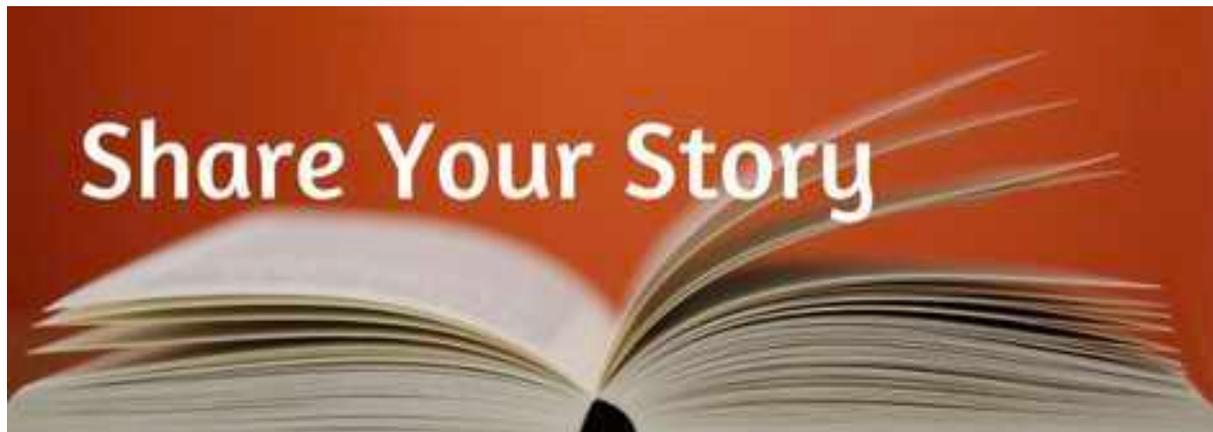
1/2 cup coriander, chopped
200 soba noodles, cooked according to packet instructions

Dressing

1-2 tbsp soy sauce
1-2 tbsp Thai dressing (A mango Thai dressing was used in this recipe but any Thai dressing is ok)
2 tsp sesame oil
1-2 tsp lime juice
1/2 tsp crushed garlic
Freshly ground black pepper

Combine all ingredients. Add dressing ingredients and mix well. Add extra soy sauce or Thai dressing to individual taste.

Serves 2-3



To help raise awareness of Myeloproliferative Neoplasms and to support other newly diagnosed MPN patients, we are seeking patient stories for the MPN Alliance Australia website. If you feel you would like to share your MPN journey, we would be very pleased to hear from you via our [Contact email](#)

Send us an email



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