MPN Matters Issue 24 - April 2024

MPN MATTERS
ISSUE 24 - APRIL 2024

EXCITING AUSTRALIAN RESEARCH DEVELOPMENTS FOR MPN PATIENTS WITH CALR MUTATION

A team of researchers in South Australia has made some important breakthroughs for patients with the CALR mutation.
Thanks to wonderful fundraising effort by myelofibrosis patient Sarah Gardner, the MPN AA was able to award a fellowship to Dr Chloe Thompson-Peach.
Dr Thompson-Peach's report from the fellowship for the MPN AA is below.

Dr Chloe Thompson-Peach - SAHMRI

MPN Alliance Australia Fellowship

Lay Report by Dr. Chloe Thompson-Peach, fellowship recipient.

Myelofibrosis is an insidious condition of the bone marrow, which disrupts the normal production of blood cells. It is characterised by painful inflammation, low blood counts and fibrous tissue building up in the bone marrow. In some patients, myelofibrosis can also develop into acute leukaemia over time. The lack of effective therapeutic options for these cancers has led us to the development of a new immune treatment for these individuals.

We have developed a novel immune treatment, a biological therapy, that is a monoclonal antibody directed against the mutant *CALR* gene, which is the second most common cause of myelofibrosis or essential thrombocythemia.

We have shown this to be effective in cell lines and patient cells harbouring pathogenic CALR mutations in the laboratory.
Additionally, our treatment has also been shown to have no effect on cell lines and patient cells that do not carry mutations within the *CALR* gene, suggesting

it is truly selective, which means it will not have side effects.

This was published recently in a major European science journal, EMBO Reports.

EXCITING UPDATE:

We have recently developed a new version of our antibody which is able to be used in humans without being rejected (called antibody humanisation) and demonstrated that the antibody is still effective at eliminating mutant CALR cells, while leaving healthy normal cells unharmed. We have shown that our antibody is able to significantly reduce the live burden of disease, with mutant cells being completely eradicated in pre-clinical in vivo experiments.

Our antibody reduced the number and size of megakaryocytes formed in *CALR* mutant patient samples in the lab, a key cell in driving myelofibrosis.

Additionally, we have shown that this antibody can be combined with Jakafi (ruxolitinib) to completely eradicate mutant *CALR* cells in the lab and re-sensitise cells that are resistant to ruxolitinib therapy alone.

Importantly, our human antibody has shown no signs of toxicity in mice and is in the process of preparation for clinical trial in the near future.

The good news is we have worked out which parts of the mutant CALR protein that causes myelofibrosis can be blocked by the antibody and it looks like we have another antibody that also has activity. We are now using the molecular information we have gained from these antibodies to build new cell therapies (CAR T cell or NK therapies or "bispecific T cell engager" antibodies).

We are hopeful that our research can build a suite of therapies, either to be used on their own or in combination with Jakafi, that will be effective and help move towards demonstration of long-term remission or cure in patients with myelofibrosis, as well as in patients that relapse after a stem cell transplant.

Some of our data was presented at the recent "New Directions in Leukaemia" conference organised by my supervisor Dr Dan Thomas at the University of Adelaide and Stanford University and is under review at a major international journal.

Please stay tuned and thank you for being committed to changing outcomes for patients with MPNs!

Sarah Gardner's patient story is available HERE.

ELEVATED WHITE CELL COUNT - A THROMBOSIS RISK FACTOR IN PV

Findings from a super important study have just been released in 'Blood'. Called REVEAL, the study followed 2510 PV patients in clinical settings in the US.

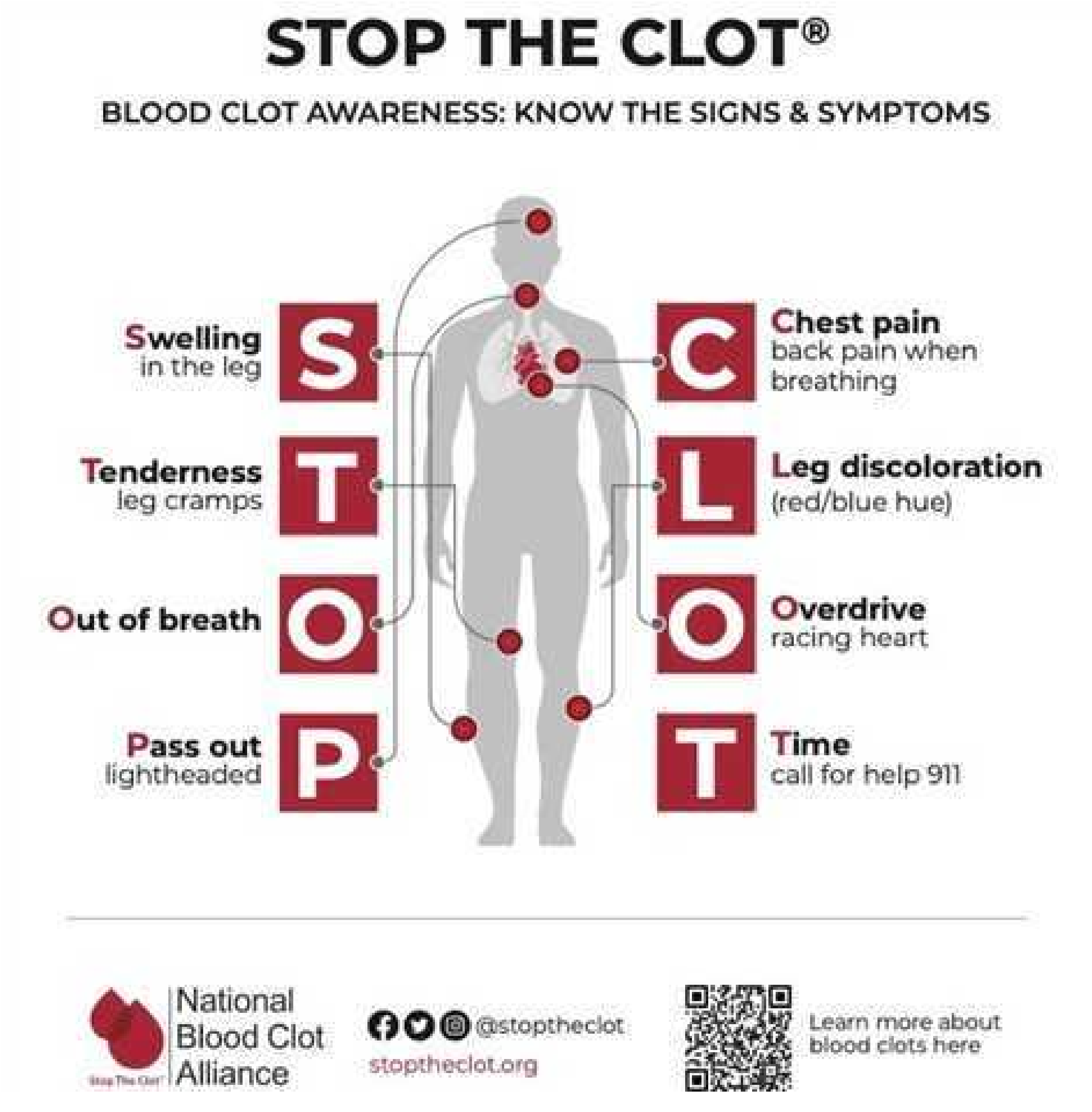
The authors found that leukocytosis (a high white cell count) was an additional risk factor for thrombosis that should be factored into risk stratifications for PV patients.

The study's authors argue that data from REVEAL suggest that two aspects of clinical practice could be changed:

1. classic low-risk patients with persistent leukocytosis could be elevated to the high-risk category and, therefore, be candidates for cytoreduction.
2. normalization of leukocytes should be included as an objective of treatment in patients receiving cytoreduction.'

Our website provides links to more information and the abstracts of the articles HERE.

And just a reminder, the following pictorial courtesy of 'Stop the Clot' provides a useful overview. We also have a webpage with further information about blood clots.



strength to give.

BONE MARROW REGISTRY – EASY TO REGISTER

The only potential cure for a myeloproliferative neoplasm is a stem cell transplant for suitable patients. Some MPN patients with myelofibrosis have had transplants and others may need one in the future.
This is a reminder to family and friends of MPN patients. Please consider going onto the bone marrow register. It's simple and registration only involves providing a cheek swab!
It may help save someone's life.

The Australian bone marrow donor registry is pleading for support from Australians to register as donors. They are especially in need of male donors aged from 18 to 35 years and those from diverse backgrounds. Currently, many stem cell donations for Australians needing life-saving transplants must come from overseas. We can do better as a nation.
Imagine how you would feel knowing that your kindness has saved someone's life.
The Strength to Give campaign explains how easy it is to register, and provides more information about stem cell donation.

PLEASE CONSIDER SUPPORTING AUSTRALIAN MPN RESEARCH

The work done by Chloe Thompson-Peach as part of her MPN fellowship is to be celebrated and we again congratulate Chloe and thank Sarah Gardner for her extraordinary personal fund raising.
So please consider donating directly to MPN research! There are brilliant MPN researchers in Australia, who are following leads in a range of directions.
This is a list of what we are aware of, but we will continue to give you more details in future.

https://www.mpnallianceaustralia.org.au/mpn-aa-fund/

If it's hard for you to decide, you may wish to choose to support MPN researchers in your own state or territory.

Postscript: The MPN AA is sometimes asked if we are still accepting donations for research. We'd love to say yes but managing this is too much for our small team of volunteers. But please don't let this stop you donating directly to MPN research.

Recipe

For this newsletter, we have a real treat for you. It's a healthy, simple to make, delicious recipe with huge thanks to Celia, one of our Canberra MPN patients. Perfect for nibbles .

SAVOURY SEED BISCUITS
(with parmesan)

Ingredients:

½ cup pumpkin seeds
½ cup sunflower seeds
2 tablespoons sesame seeds
200 gms grated parmesan
½ teaspoon cayenne pepper (*or paprika, or a mix of both*)

Method:

Preheat oven to 180 degrees
Mix all ingredients in a large mixing bowl.
On a baking tray, covered with baking paper, place one heaped teaspoon per biscuit and pat down gently.
Bake for 10-15 minutes but after 10 mins check them carefully
Remove from oven when lightly browned
Allow to cool before storing
Makes about 30-40 biscuits.

Leukaemia Foundation upcoming events

The Leukaemia Foundation has upcoming virtual support groups with the topic being 'Tricky Conversations'.
The Leukaemia Foundation tells us that ‘Sharing the news of a blood cancer diagnosis can be challenging & confronting. This initial news will be one of many tricky conversations you & those around you will be faced with after a diagnosis. Despite the challenges, there are ways to manage these conversations. Together, we will discuss the group’s experiences, share strategies to ease the discomfort & build confidence in having these conversations.’

1. Men’s virtual support group – ‘Tricky conversations’
7 May 2024, 2-3pm

Group sizes are limited so registration is essential.

To register and for more information – see HERE.

2. General Blood Cancer virtual Support Group - 'Tricky Conversations'
8 May 2024 11am-12.30pm

This group is for all blood cancer patients.

Group sizes are limited so registration is essential.

To register and for more information – see HERE.

3.General Blood Cancer virtual Support Group - 'Tricky Conversations'
22 May 2024, 6.30pm - 8.00pm

This group is for all blood cancer patients.

Group sizes are limited so registration is essential.

To register and for more information - see HERE.

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

Share Forward to Friend

You are receiving this email because you registered to attend the MPN Patient Education Program in Melbourne on 28 April 2017, or because you have subsequently signed up to receive them.

Website:
www.mpnallianceaustralia.org.au

Our mailing address is:
Myeloproliferative Neoplasms Alliance Australia (MPN AA)
Post Office Box 111
Sandringham, Victoria 3191
Australia
