

MyeNews

Winter/Spring 2022 Issue no 62

Myeloma
Australia



Joyful Moments

Contents

In this issue

From the President	3
3.8 with a mate Fundraising Awareness Walk	4
My Journey – Corinne Brandon	6
Readd aloud for wellbeing during cancer treatment	8
Advocacy News	9
National Myeloma Month	10
Introducing Rosie	10
Joyful Moments	11
Mel's 38km for 38Mate	12
Music for myeloma	13
What's Happening (States)	14
The Rotary Outreach Myeloma Scholarship	17
Exercising the Brain	18
News from Australasian Leukaemia & Lymphoma Group	18
News from the Myeloma and Related Diseases Registry (MRDR)	21
Medical Corner	22
Calendar of Events	23

MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

Contact MyeNews Coordinator

(03) 9428 7444

myenews@myeloma.org.au

If you no longer wish to receive the MyeNews please let us know.

Design & layout: Greg Loveder Graphics

Printed by Eastern Press

Front cover: Joyful Moments launched to shine a light on myeloma and the 38 Australians diagnosed each week.



Find us on Facebook, Instagram, LinkedIn and Twitter

MyeNews is supported by an unrestricted educational grant from Celgene, a Bristol Myers Squibb company



Office Hours: 9am – 5pm Monday to Friday AEST

Head Office: 333 Swan Street, Richmond, VIC 3121 **Post:** PO Box 5017 Burnley, VIC, 3121

T: (03) 9428 7444

MyeNews is published by the Myeloma Foundation of Australia Inc. The information presented in MyeNews is not intended to take the place of medical care or the advice of a doctor. Your doctor should always be consulted regarding diagnosis and treatment. No part of this newsletter may be reproduced in any form without the prior written permission from The Myeloma Foundation of Australia Inc.

Myeloma Foundation of Australia Inc. ARBN 126 035 247 ABN 30 476 390 368

From the President

In May for Myeloma Awareness Month our Myeloma Support Nurses ran a series of seminars both in person and via video links which covered a very large range of topics. These were well supported by our community and the feedback has been that they were very well received. If you missed any of these, they are available on our website along with the series of podcasts which are well worth listening to.

I would like to thank all the Myeloma Support Nurses for the fabulous work they do. I would like to thank both Daniel in Western Australia who is leaving us to change direction in his career and Rachel in Victoria who has resigned to spend time with her growing family. Both Daniel & Rachel will be missed, and we wish them all the very best for the future.

During the month of May, Myeloma Australia launched a new campaign called 'Joyful Moments'. We asked our community to share what makes you feel joyful. We've been overwhelmed by your response and loved seeing and hearing about the activities that bring you joy. We hope you enjoy the montage of photos from our community members on the front cover. Thank you to all those who participated in the campaign.

Thank you to everyone who gave to our End of Financial Year tax appeal. Due to COVID we have been unable to hold a series of fundraising events. We had a fantastic response to the appeal and we are so grateful to our community for getting behind us. Your contributions, no matter the amount, go a long way in ensuring we can continue to have an impact.

We are pleased to announce our new corporate partnership with online travel agency, Luxury Escapes. If you use our code MYELOMA5 when booking a holiday package, 5% of the purchase cost will be donated to Myeloma Australia.



We are currently looking for more corporate partners. If you have a business or know someone looking to add to their Corporate Social Responsibility program, please forward these details to our fundraising team via email; fundraising@myeloma.org.au.

Winter weather has arrived in Melbourne along with the normal colds, influenza as well as COVID still being around. Ros and I are finding it a challenge to go out for our regular coffee fix but staying outdoors rather than sitting inside still. We are still wearing masks when we get into a crowd, and we are limiting our time in shops. Even though, we are still getting the call that someone we were with a couple of days ago, has come down with COVID or the flu. So far, we have been lucky and kept well. I hope that you all are as well.

Lastly, our search for a new CEO is continuing and I would like to thank Hayley for doing such a great job as the Interim CEO.

Brian Rosenzweig



Myeloma Support Line

Monday – Friday 9am – 5pm (AEST)

1800 MYELOMA (1800 693 566)

A confidential service providing those living with myeloma, their family and friends and health professionals access to specialist myeloma nurses. Open to anyone with a question about myeloma or just to have a chat.



Myeloma Australia's first ever national fundraising and awareness walk arrives in NSW and QLD



3.8^{with a}mate



Photos supplied and used with permission

For the first time in Myeloma Australia's history, people across the country gathered on Sunday 27th February to take part in Myeloma Australia's first ever national fundraising and awareness walk. Unfortunately, NSW & QLD suffered severe weather warnings, storms and in some parts of the states flooding. Due to this, the QLD & NSW 3.8 events did not go ahead as planned. Instead of giving in to the weather, teams across both states were determined to be a part of Myeloma Australia's inaugural 3.8 with a mate, and their events did not disappoint, with over 300 people gathering across these states.

Along with family, friends and neighbours participating in their own 'walk where you want' amongst their own communities, larger hosted events took place in Centennial Park Sydney, the Central Coast in Gosford, Newcastle, Southbank Brisbane and Woody Point located north of Brisbane.

The sun was shining and the weather glorious at all of these locations, with burgundy Team Myeloma t-shirts filling the local walking trails, parks and beachfronts. Myeloma Australia support nurses and representatives were available at each event to greet and spend time with participants. It was a wonderful opportunity to see new faces, reconnect with regular support group attendees and meet their family and friends.

We are very proud to be a part of a community that comes together to support each other and raise awareness for myeloma and Myeloma Australia. Thank you to every person that supported, participated in and donated. 3.8 with a mate was bigger than we could have ever imagined, with over 800 people participating across the country, and that is all thanks to you, our community. So, it is with great excitement, that we announce that 3.8 with a mate 2023 will be held across the country on Sunday 5th March, to support International Myeloma Action month, an initiative, created by our friends at the International Myeloma Foundation, to encourage individuals and groups to take actions that positively impact the myeloma community.

3.8 with a mate may have been our first ever fundraising and awareness walk, but you, the community embraced the concept the moment we announced it. We really look forward to seeing this event grow every year.



We would like to acknowledge and thank our myeloma community for sending in these wonderful photos of events held across NSW & QLD. We would also like to thank our volunteers who took the first step towards 3.8 with a mate by becoming Event Organisers. Without these volunteers it would not have been possible to reschedule and host such successful events across NSW & QLD.



I had never heard of myeloma until my son, Scott, was diagnosed with metastatic melanoma in February, 1999. A medical professional said to him "The three M's. Melanoma, Mesothelioma and Multiple Myeloma. They are all very bad news!". Scott

died soon after. Sadly, my first husband from whom I was divorced, also died from melanoma some years later. 21 years later ALL these diseases have much better prognoses with new drugs, targeted treatments and immunotherapies.

Life rolled on and in 2009 my second husband, David and I leased out our home in Alstonville, near Ballina and went off in our Winnebago travelling around Australia and never went home! Such a great life – and very little housework! A great decision, since if we had waited until my retirement age it could never have happened. We travelled until 2013 uneventfully in our motorhome with our little Pomeranian, Tim. He's still going at the ripe old age of 18 and a half.

My blood had always been regularly checked as I had been a blood donor for 44 years. My theory is if you can do some good, do it and what a good way to have a regular checkup (with a milkshake and something nice to eat). I donated in several states over the travel time. In hindsight this could have alerted me that something wasn't quite right. From 2011-13 I often had quite low haemoglobin readings with no apparent cause. I donated plasma at Port Adelaide, SA but was back in NSW when the Blood Service in SA contacted me with the news that my blood was no longer worth bottling, and I needed to see a doctor.

When pressed they said I had MGUS (monoclonal gammopathy of uncertain significance). They also sent me records which showed that the paraprotein level had been around 10 for at least eight years. Naturally I looked up MGUS and was shocked. Ah Google!

My daughter, her husband and their small daughter lived in Parramatta at that time so David and I, using their address, went to a local doctor for a referral to Westmead Hospital Haematology and were extremely lucky to see a wonderful young haematologist. Young, smart and friendly. I cried when she said "This is incurable....". I barely heard "but it is treatable".

So, lots of blood tests, bone scans and the dreaded bone marrow biopsy, twice..and they said it wouldn't hurt! Maybe in some other universe!

In 2014 we knew that we'd never go back north, so we bought a place at Point Clare on the Central Coast as my diagnosis meant we were "in the system" there. For 18 months I was monitored at Westmead Hospital. In 2015, David convinced my daughter, Leonie and her husband, Daniel to

move up to the Central Coast and buy a place in Point Clare. It turned out to be a wonderful decision. While David was my support then, I didn't know what the future was to bring.

From 2013 to 2015 my paraprotein and light chain levels were monitored, although they were heading upwards very significantly, and I now had smouldering myeloma.

Saturday September 5th, 2015 I was helping David, holding tight to a nut with a spanner. I yanked – and yelped as I felt a rib suddenly give me intense pain. The next day I saw my local doctor and when I explained my pain and that I had smouldering myeloma she asked if there were any other spots which hurt. "Oh, yes, the back of my shoulder near my collarbone, but it's probably just a muscle". On x-rays it turned out to be a lytic lesion on my fourth rib and another on my 10th rib as well as a broken eighth rib. It was suddenly very real and there was now a starting point for treatment.

On the 29th September I started twice weekly hospital visits at Westmead Hospital for bortezomib subcutaneous injections. I also took cyclophosphamide and dexamethasone tablets as was the standard upfront treatment for myeloma at the time and valaciclovir and Bactrim to prevent shingles and pneumonia.

I felt lousy and had the usual diarrhoea and constipation, upset tummy, fatigue. I did two cycles at Westmead. I was then transferred to Gosford Hospital under the care of a young and very knowledgeable haematologist. Two more cycles of chemo and then it was decided that an autologous stem cell transplant would be done.

For the stem cell transplant many factors are considered. Age, state of health and underlying issues. They did a series of tests to check for any issues in my blood, lungs and heart. Turns out that except for a touch of cancer I was in very good shape!

By Christmas 2015 I had finished chemotherapy and had a break before I started the process to collect stem cells for an ASCT (mobilisation). First, on the 7th of January, 2016 was a high dose infusion of cyclophosphamide. I then self-administered Neupogen injections to encourage stem cell growth.

On Friday 15th January I was given platelets because my count was too low. On Saturday 16th David took me to emergency at Gosford Hospital because I had become so sick overnight. My compromised immune system had allowed gut bacteria (E-coli) to take over. I was admitted to Gosford Hospital spiking 40-41 degree temperatures.

But the show must go on. Once you've started on the transplant journey nothing can get in the way. So while I spent the next eight days in hospital I still had Neupogen while being treated for the infection. I felt SO sick. Fever and dreadful sweats and always the bone crunching headache. I lived for a week like a mushroom in a dark room.

My stem cells were then harvested, twice, since the first lot didn't seem quite rich enough in stem cells. I found the five hours of immobility quite daunting and very boring. Both arms are needed for the procedure so you can't do much!



Finally, I went home and I asked David to shave my hair off since it was falling out everywhere. What was unexpected was how I felt minus the scalp covering. Naked, silly, embarrassed. I cried when I showed my daughter but no one seemed worried but me!

From then until the stem cell transplant I stayed home getting better and stronger which was vital since the treatment had worn me out in the preceding months of chemo, mobilisation and stem cell harvesting. I had a Hickman catheter put in on the 11th February. This was for the regimen of drugs needed for the transplant.

I went into hospital for the transplant on the 16th February, 2016. Unfortunately, the Hickman catheter site had become infected so that had to be treated before I could have melphalan to nuke what was left of my immune system. On the 19th February I had the stem cell transplant. Very low key and rather anticlimactic! It makes your body smell odd (fishy or of corn) because of the preservatives they use. Then you wait! The process is horrible and I felt sick for days as my white cells dropped. Nausea, vomiting, pains and aches – but it's short term, even if it feels like forever at the time. Then the magic begins and the immune system starts to reboot. A fortnight in hospital but a new beginning for me.

It took six weeks to get over the chronic nausea, tiredness and general weakness.

Then David said "It's time to pump up your bike tyres". So, I was back on my pushbike and regaining strength. It took months for the weakness in my legs to improve. It felt as if my calf muscles had melted, but it resolved in time with plenty of exercise.

In June, 2016 I started twelve months of thalidomide (the maintenance treatment on offer then). I started on a smaller dose and found when it came to double it I could not cope. It gave me peeling skin and itch. It gave me a great nights sleep but it eventually caused some peripheral neuropathy in my feet. I also had monthly infusions of Zometa, for 20 months, for bone strength. My final result was a paraprotein of 9 and light chains of about 60. Then it was over, Rover, except for regular monitoring, scans for any bone problems and regular blood tests.

David had been there for me while I had been sick and then he was diagnosed in February, 2017, with an awful and fast debilitating form of Parkinson's disease. Mentally sharp but he was effectively immobilised within about 18 months and never complained. A real trooper. So for a while it was my turn to do all the "looking after" for David who needed 24/7 care. In July, 2019 David died at home in bed! The best way to go. He had been my rock and best buddy while I was sick and it was my privilege to support him as his health failed. How lucky we were that these things hadn't happened while COVID-19 was raging.

Life remained static until early 2021 when the blood count readings started increasing rather rapidly. At that point the haematologist decided that six months treatment was a good option, using the same drugs, bortezomib (a weekly subcutaneous injection for six months) and dexamethasone (tablets) and the newer daratumumab (an infusion by cannula in my arm). It has been a "walk in the park" except for the side effect of sleeplessness and then a crash (from the dexamethasone) and the neuropathy in my feet is a bit worse. For some people, including me, daratumumab can cause a reaction in the first dose, but thereafter it's fine. My current paraprotein level is around 4, the lowest it has ever been. Light chains 33. Soon I will be having a single monthly infusion of daratumumab for twelve months and will be back in a holding pattern.

I don't know how long the status quo will hold. I know that daratumumab can halt progression of disease for a couple of years, however, with myeloma being considered a chronic disease now, my future looks amazingly bright. I have just turned 70. I have my daughter and son in law and my now TWO grandchildren, Milly 12, and Jacob 6, close by. As good as it gets, I think.

A few fun facts. I've learned to keep a diary of EVERYTHING! Appointments, what medication I had, how I felt, even what I ate. (As I read diaries for this article I realised how much I'd forgotten.)

I keep moving! Exercise is great for physical and mental health.

I read all about it! Information is a wonderful thing. And things change all the time. For the better!

I am a real "Pollyanna" positive person. We know that this is no longer "the worst case scenario" so I LIVE! I am eternally grateful that I live in Australia where our health system is truly wonderful.

Read aloud for wellbeing during cancer treatment



During my years working in public libraries in central Victoria, I noticed a pattern of regular readers losing their ability to read for pleasure while undergoing cancer treatment. I am now

in Adelaide, undertaking a PhD with the University of South Australia, investigating this phenomenon, which is a common manifestation of cancer-related cognitive impairment (CRCI). This impairment can start as early as diagnosis and become dramatically worse with treatment, especially chemotherapy. People describe it in all sorts of ways, but its impacts are frequently frustrating and often upsetting. The area of the brain most affected by cancer treatment is the frontal lobe, responsible for many attention, processing and organisational functions, but it is also the area we use when we read (visually) to ourselves.

Reading has long been acknowledged as having benefits to physical and mental health. A plethora of studies now confirm bibliotherapy, or reading for therapy, has a real place in the suite of treatments offered for mild to moderate mental health conditions, including anxiety, depression, coping ability, eating disorders, OCD and sleep problems. It has been successfully trialled in cases of chronic pain where escapism and solace are the key themes; the same themes which arose from the psychological distress associated with COVID-19, where reading has been seen to help. Bibliotherapy comes in many guises, but the tools employed are generally either cognitive based therapeutic self-help books or fiction and poetry. With societal values driving our thirst for information and life-long learning, the concept of reading for simple pleasure, even escapism, is often seen as an inferior reason to read. Yet reading fiction has more proven benefits to our health and personal development than reading non-fiction or newspapers. The intention of this program is not to educate people affected by cancer about their disease or treatment, nor to use self-help books to directly address emotional issues, but rather to use fiction chosen according to individual participant's preferences as a mechanism to boost emotional wellbeing.

People have been finding ways to tell each other stories for eons. Storytelling has strong cultural and educational ties. Some adult storytimes have been trialled in a handful of libraries around the world. A program in Melbourne was particularly successful and went on to be conducted in the Peter MacCallum Cancer Centre. Proposing stories be listened to rather than read silently for this study was initially based on anecdotal evidence of cancer patients struggling with their reading but nevertheless enjoying hearing stories, but the evidence around how the brain processes stories does support this concept. Auditory input is processed by the temporal lobe (which is significantly less affected by treatments than the frontal lobe) then projected to a wide region of the prefrontal cortex where different prefrontal

networks can be activated, even shifted, according to attentional demands. This gives a level of confidence for the usefulness of the idea of reading aloud.

We are seeking participants about to commence, currently undergoing, or up to 12 months post treatment for this weekly 6-week read-aloud program, delivered one-to-one in participants' homes, local libraries, UniSA campuses or via Zoom where required. Reading material is chosen according to participants' interests, and participants do not have to be regular readers, will not be asked to do any pre-reading before sessions, nor any reading aloud themselves during sessions and they will not be asked questions about what is read. The job of the participant is to sit back, relax, and enjoy listening to some stories being read to them, chosen especially for them. Two standard wellbeing questionnaires will be completed by participants at the first and last sessions. Short one-on-one interviews will be conducted following the conclusion of the program, so we can learn more about the participants' experience of it. The relationship between the emotional wellbeing of people undergoing cancer treatment and read-aloud programs has not been previously examined.

The joy of reading can be denied to those undergoing cancer treatment. CRCI can mean concentrating sufficiently to read to oneself can become frustrating then impossible. When reading is abandoned, the reader is denied its health benefits. Hearing a story, having it read to you rather than having to read it to yourself, offers a way to restore the joy of reading, or to introduce it to new readers. Integrative oncology employs complementary therapies such as art, music, yoga, exercise and mindfulness training. However, there is also a potential place for bibliotherapy in integrative oncology and read-aloud programs may offer some relief from the emotional distress, anxiety and depression of cancer diagnosis and treatment. This research seeks to explore the extent to which read-aloud programs are associated with improvements in the emotional wellbeing of people undergoing cancer treatment.

We are now recruiting research participants Australia-wide. For more information please see <https://www.unisa.edu.au/research/research-volunteers/are-you-undergoing-about-to-undergo-or-completed-cancer-treatment/>

Media release (including short video)
<https://www.unisa.edu.au/media-centre/Releases/2022/in-reality-escapist-fiction-could-be-what-the-doctor-orders/>

Elizabeth Wells
PhD Candidate
UniSA STEM
Email elizabeth.wells@mymail.unisa.edu.au
Phone (08) 8302 3737



Myeloma Australia is involved in advocacy programs on both local and global levels. The aim of these programs is to improve the lives of people living with myeloma and work towards a cure by increasing awareness of myeloma and the lived experience, building community, and together working to improve access to care, treatments, and education both locally and globally and this last quarter has been a busy period in these areas.



Global Myeloma Action Network (GMAN) Summit: 20th to 22nd May 2022, Milan Italy

As guests of the International Myeloma Foundation (IMF), Interim CEO Hayley Beer and NSW State Manager and Senior Myeloma Nurse Jacqui Keogh travelled to Milan, Italy to represent Myeloma Australia at the 2022 Global Myeloma Action Network (GMAN) Summit.

GMAN is a group consisting of representatives from myeloma advocacy groups from over 30 countries and this was the first opportunity we had been able to get together in person for this meeting since the start of the pandemic.



After a long journey to get to the meetings, Hayley and Jac got straight into the packed agenda and were warmly welcomed by our friends at the IMF, CEO Yelak Biru and GMAN director Serdar Erdogan who also presented a wrap up of the 2022 Myeloma

Action Month held in March this year around the theme of 'Take Action' with a reach of over 30 million people this year and growing each year. For more information visit the webpage www.mam.myeloma.org

The agenda was packed to the brim with project workshops with other GMAN members, presentations from the other myeloma advocacy organisations and some great updates from International Myeloma Working Group (IMWG) members about the latest advances in myeloma, a CAR-T therapy and Covid-19 related updates specific to the myeloma population.

Thank you to the IMF who invited us and hosted us at the meeting. As always it was a fantastic experience and opportunity to connect with our international friends in the advocacy space and we are excited about our involvement in the projects and look forward to connecting again with the group later in the year.

Local Advocacy

Pharmaceutical Benefits Scheme (PBS) Update

After a positive recommendation at the July 2021 Pharmaceutical Benefits Advisory Committee (PBAC) meeting, as of May 2022, the combination of elotuzumab, lenalidomide and dexamethasone is now available on the PBS for those with relapsed or refractory myeloma. Elotuzumab is a monoclonal antibody that targets the SLAMF7 receptor on myeloma cells and if you would like to know more about this treatment, please download our treatment fact sheet on elotuzumab on our website at www.myeloma.org.au/resources or discuss with our myeloma support nurses.

Outcomes of the March PBAC Meeting

The March 2022 PBAC meeting was very busy on the myeloma front with multiple submissions on the agenda for considerations.

The PBAC gave their recommendation to two combinations for myeloma, firstly carfilzomib, lenalidomide, dexamethasone (KRd) for the treatment of relapsed refractory multiple myeloma and secondly, selinexor with dexamethasone, for those who have received at least four prior therapies and are refractory to the prior therapies on the PBS.

Unfortunately, two applications were not recommended by the PBAC at this time: ixazomib, lenalidomide and dexamethasone (IRd) and selinexor, bortezomib and dexamethasone (XVd) combinations, both in the relapsed and refractory setting. It is not uncommon to have treatments not recommended at the PBAC the first time they are submitted, and we will continue to advocate for future submissions to ensure the best access to myeloma treatments in Australia.

Medicines Services Advisory Committee (MSAC)

Australia's Medicines Services Advisory Committee (MSAC) is currently considering funding the CAR-T cell product called Ciltacabtagene autoleucel (cilta-cel) for those with myeloma who have had more than three prior lines of therapy.

Thank you to all our community who got involved in our 'My Future, My Life, My Say' campaign and took the time to submit your feedback. We have heard that there was a record response from the myeloma community. The consumer consultation period has now closed, and we will report on the decision as soon as we hear.

If you would like to be involved in any of our advocacy programs, please contact advocacy@myeloma.org.au

National Myeloma Month

With the world starting to open again and everyone adapting to living the 'new normal' with COVID, here at Myeloma Australia, we wanted to refocus on how we can empower you to live well with myeloma, so our theme for National Myeloma Month this year was 'Wellness and Possibility'. Alongside education about myeloma the disease and its treatments, we wanted to provide our community with expert information on some of the topics that are commonly brought up in our support groups and on our telephone support line across Australia. We know myeloma and its treatments can sometimes have a significant impact on your everyday life and the lives of your loved ones. We wanted to be able to give you some information and strategies that may improve your overall wellbeing and open the door to new possibilities or help make some of the things you enjoy possible again!

We held three live webinars throughout May with a variety of expert guest speakers. Topics included the following:

- Myeloma Disease Overview
- Interpreting Tests and Investigations
- Travel and Myeloma
- New Treatments
- CAR-T cell therapy
- Cancer Related Cognitive Impairment
- Sleep
- Intimacy and Relationships
- Caring for the Carer
- Patient and Carer Interview

Our speakers were from a range of different professions including medical, nursing, pastoral care, research/librarian, and myeloma community members. We would like to take this opportunity, to again, thank our guest speakers for donating their time and sharing their expert knowledge with our community. We had some great questions from our live audience and your feedback and comments on the evaluation forms was much appreciated.

If you were not able to join us live for these webinars, or if there is a topic you would like to watch again, all three of our webinars are available for playback on our website www.myelomaaustralia.org.au (link for online version: <https://myeloma.org.au/national-myeloma-month>). If you have any further questions about any of these presentations, please don't hesitate to contact one of our Myeloma Support Nurses on our support line:

1800 MYELOMA (693 566)

In addition to our online webinars, we also held face-to-face events in each state across the country. Community members gathered for morning tea followed by Q&A sessions and presentations with local haematologists, myeloma clinical nurse specialists, naturopaths, exercise physiologists and wellbeing sessions with art therapists, music therapists and guided meditation. It was uplifting to be able to gather in person again after being 'online only' for the most part of the beginning of the year. Thank-you to all of you who attended, and we hope that you enjoyed myeloma month this year!



Introducing Rosie

Hello, my name is Rosie Robinson and I am the new Support Services Administrator at Myeloma Australia. My previous position was Administration/ Customer Service for a transport company called Allied Express Transport, where I worked for the last 17 years.

I am very happy to have been given the opportunity to work with the lovely people I have met so far within the myeloma team. I think I will get a lot out of working for Myeloma Australia as I have had relatives with cancer, and I feel this is a little way to give back to people in need and help support them.

Just a little bit about me; I live in Melbourne, Victoria and I am a mother to four Children – a son, 40 years old and a daughter, 34 years old and I also have twin daughters who are 31 years old. I have 14 grandchildren ranging in age from two years to 21 years and I love them all dearly. I am a very lucky person to have a good relationship with my children and all my grandchildren.

I enjoy spending time with my family, love having sleep overs with my grandchildren, although I think five to seven at one time is enough! I also enjoy reading books, movies, spending time with my siblings, walks along the beach and bush walking. I think I just enjoy the simple things in life.

Thank you to everyone within the myeloma community for the warm welcome.



Last year we launched our first official awareness campaign '38 Mate' shining a light on myeloma and the 38 Australians diagnosed each week. This year we introduced you to a new campaign 'Joyful Moments'. This campaign was all about celebrating YOU and the things that you and your loved ones enjoy doing. Myeloma can have an impact on the things you love to do, however sometimes it's possible to still do the things you love just in a slightly different way. Throughout National Myeloma Month in May we asked you to complete the sentence 'I'm a 38 mate and I love...' or 'I care for a 38 mate, and I love...' and for you and your loved ones to send through photos or videos doing whatever it is you love to do. The submissions we received were of our community enjoying a range of activities including swimming, walking, art classes, time with pets and loved ones, bike riding, yoga drumming and even a surprise wedding! We would like to say thank-you to everyone who submitted their photos and videos and look forward to celebrating more joyful moments with you.



Photos supplied and used with permission

Mel's 38km for 38Mate

On May 19th this year Melissa McMurray, and her friends Dan and Christine Carter, did something not many people ever do in their lives – they walked 38km to raise money and awareness for Myeloma Australia, specifically to go towards our new Bob Moran Research Fund. Mel was diagnosed with myeloma seven years ago at the age of 48. She has endured three stem cell transplants, radiation, and numerous lines of treatment.

12 months ago, Mel could only walk 10 minutes due to some severe lesions in her hip. As she got on top of her pain, she decided that she needed an exercise goal and so with the help of Dan, another person living with myeloma and his wife Christine they came up with the plan of walking 38km for 38Mate. Over six months, despite floods, record rain falls, radiation treatment, regular therapy and hospital visits, they trained. Mel's background is in physiotherapy so she knew just how to build up her fitness in a safe and manageable way.



Mel wrote about what she wanted to achieve below:

- Walk 38km because approximately 38 people get diagnosed with myeloma each week in Australia
- Raise awareness of myeloma and to raise funds for Myeloma Australia to be put towards myeloma related research
- Give others some insight into what it's like living with myeloma because people see you as looking 'good' and so think that you must be 'good'
- Improve my fitness, because being in the best physical condition, I think, helps you cope with treatment and improves your quality of life
- Encourage and motivate others and especially those living with myeloma, to start getting active
- It took me 650km of training walks (not including incidental walking) to get there with a few interruptions with radiation treatment and COVID.

"I achieved everything I wanted to and so much more!

Christine, Dan and I, and later Cass (and Odes) had so much fun training for this event.

We met a bunch of lovely people along the way which gave us the opportunity to spread more awareness about myeloma, this incurable blood cancer."

"Thanks to you for your generous support, for following our journey and for all the words of encouragement. You made such a difference!"



Music for myeloma

As the community begins to return to social activities across the country, we are honoured that several musical groups chose to perform concerts for myeloma, donating their time and all proceeds to Myeloma Australia. These performances took place during National Myeloma Month, a wonderful addition to support the continued education and support amongst the myeloma and greater community.

Women in Brass

On Saturday 7th May, *Women in Brass*, an all-female ensemble of over 30 players from all over Australia, performed at the Old Museum Brisbane. The talented Marissa Clarke of *Blow Woodwind and Brass* came up with the concept of bringing together female musicians and band leaders from across the country to form *Women in Brass*. The ensemble was under the musical direction of Maureen Cameron, performing to a sold out theatre, with over 300 people in attendance! In addition to this one night only performance, a raffle was also part of the proceedings, with all the funds being generously donated to Myeloma Australia. Thank you to the *Women in Brass*, not only did you help raise awareness about myeloma, but you also raised an amazing \$4,952 for Myeloma Australia.



Banding Together for Myeloma

On Sunday 15th May, *Banding Together for Myeloma* was held at the Sydney Congress Hall. Three ensembles came together, donating their time and musical talent to Myeloma Australia. A total of 120 musicians performed with an audience of 350 people. A highlight of the afternoon was a trumpet solo by Dominic Longhurst called *Song of Hope*, arranged for Ryan Anthony from the Dallas Symphony Orchestra by Peter Meechan, to support his fight against myeloma. This performance had significance at the concert, as a member of Dominic's extended family was in the audience and is currently living with myeloma. You can see the performance here: https://www.youtube.com/watch?v=nC3_KSbvpdg

Thank you to the following ensembles:

Cameraygal Wind Symphony, Music Director Gavin Staines
Central Coast Brass – Music Director Darren Jones
Sydney Congress Hall Band & Friends- Music Director Dominic Longhurst

For donating your time and talent, and to our very own Rob O'Brien who was also the concert producer on the day. *Banding Together for Myeloma* raised \$4,200 for Myeloma Australia.

Thank you all so much, we look forward to more musical events just like these.





New South Wales/Australian Capital Territory

We had a very busy National Myeloma Month in NSW. In Newcastle, Juliet and Tina both chaired our online seminars as well as hosting a national myeloma month morning tea, with Dr Wojit Janowski giving a wonderful myeloma update and Q&A session. This is becoming an annual event and our Newcastle myeloma community thoroughly enjoy listening to Dr Janowski's knowledge of myeloma.

We have also been able to resume our support group for the Nepean/Blue Mountains area and we look forward to meeting more people in this area as this group evolves.



In the ACT there has been a welcome resumption of the face to face support group in Canberra with some interesting speakers joining us. We celebrated national myeloma month with a morning tea and an interactive session with Tubi Oyston, a wellbeing coach, whose focus and passion aligned perfectly with our theme of "wellness and possibility".

Diana, Cath and Jacqui were thrilled to attend the "Banding together" event in Sydney (see Robert O'Brien's report) and look forward to these community events becoming annual events.

Sunday 29th May saw the completion of NMM activities with several "3.8 with a Mate" walks at Warners Bay foreshore, Centennial Park Sydney and the Gosford waterfront Central Coast. We had a fabulous turn out and were rewarded with amazing weather. It was great to see some new faces and to meet some of the extended families and friends of our regular support group attendees.

It is so wonderful to see our myeloma community coming together to raise awareness. Thank you to everyone who took the time to attend these events.

Jacqui Keogh, Cath Bowley, Juliet Hill, Tina Gordon
Myeloma Support Nurses NSW



Queensland

Holy Moley Queensland! What a month? Tash and I, have been overwhelmed by the Queensland community appetite to get myeloma out of the shadows and into the spotlight. It has been quite fitting for our myeloma month theme this year in capturing joyful moments. We have been delighted by the amount myeloma awareness projects starting to build in the sunshine state.

Our first event a wonderful "Women in Brass" concert organised by the very talented musician, Marissa Clarke from Blow Woodwind and Brass in Red Hill, Brisbane. See community engagement page for details.

At our local Myeloma Month event, we heard from A/Prof Peter Mollee, Director of Haematology at the Princess Alexandra Hospital who gave our members much hope for the future of Australian treatments in myeloma. Our guests were then serenaded by the incredible Soul Song Choir in a flash-mob style performance. The room was filled with smiles and tapping feet. Jac, the choir director, invited anyone who is interested in joining the group either in person or via zoom. You are all very welcome, no matter your singing skill level. Find out more <https://www.soulsongchoirs.com.au/>

Mel's 38km for 38mate as documented on the community engagement pages. Megan and I are in awe of the effort of Mel McMurray, Dan and Christine Carter put in training and coping with rain, floods, COVID and dealing with myeloma on a daily basis. Thanks guys.

Our inaugural Queensland 3.8 with a mate walks in Southbank and Woody Point were a roaring success. We had perfect weather and a sea of burgundy snaked through the bustling footpaths on the 29th of May. Thank you to everyone who joined us to support the cause. Checkout all the photos from the day on the website or above. We can't wait to go bigger and better next year.

Megan McDowell and Tash Clarke – Myeloma Support Nurses QLD





South Australia/Northern Territory

As always May is a busy month at Myeloma Australia. Pleasingly, SA was able to hold its first face-to-face seminar in three years. Over 50 members of the community joined us at the Walkerville Town Hall where Jo compared a Q&A session with Dr Noemi Horvath (RAH haematologist), Ms Sophie Wilson (Myeloma Nurse Consultant, RAH) and Alicia. It was an interesting discussion, especially hearing Dr Horvath discuss her early years as a junior consultant and what the treatment landscape looked like back then. It was also wonderful to see so many people able to mingle and talk with each other.

Our support groups continue to be well attended both in person and via zoom. In April at Fullarton, we heard from Dr Kate Vandyk, Dr Melissa Cantley and associates about the amazing research they are undertaking at SAHMRI. We have also held many discussions about CAR-T cell therapy in our support groups in light of the recent application to the federal government to fund the procedure. Many thanks to all in SA who took the time to make an application to the approval committee. We look forward to bringing you more speakers and educational events in the second half of the year.

*Alicia Hopper & Jo Gardiner
Myeloma Support Nurses*



Tasmania

Here in Tasmania, we held a very successful seminar for National Myeloma Month at the Howrah Community Centre. Dr Nick Murphy, Clinical Haematologist at the Royal Hobart Hospital, gave an overview of myeloma and talked about new treatments. His expertise, knowledge and personable manner was, as always, very much appreciated by guests. Andrew Bonsey, an exercise physiologist and Director of HT Health, gave an animated talk around exercise and myeloma which again was very well received by the audience. After lunch (and some seriously yummy jam donuts), our third speaker was naturopath, Monica Francia, who is well acquainted with myeloma and who shared an abundance of information around complementary and natural therapies and how they can safely sit alongside clinical treatment in consultation with your myeloma team.

In April we held a combined north-west support group at the Penguin Football Club, a great venue, with everything laid on to assist in running a meeting. It was really lovely to catch up with familiar faces and welcome new participants and many laughs were had. That same day we also held the Launceston Information and Support Group. Again, it was terrific to catch up with regular myeloma participants and meet people who joined us online to hear about fatigue and myeloma. When heading north again, I am planning to catch up with staff at the Mersey and Burnie Hospitals and share some of what has been happening in 'Myeloma Tasmania'. Until next time...

*Deborah Thompson
Myeloma Support Nurse*



What's Happening



Victoria

It was wonderful to see so many new and familiar community members, as we returned briefly to face-to-face groups and events in Victoria. Watching the conversation flow in these spaces so naturally has been truly wonderful.

Our groups have once again moved online, and the team thank you for your dynamic and flexible commitment to connection as we navigate risk again. We realise the many months online last year took its toll on some of our groups, and we are committed to working with local communities in helping these groups re-establish themselves. If you've been thinking of returning to, or joining a new group, now is a wonderful time to do so. We encourage you to RSVP to groups, so we can forward plan and ensure our efforts are most impactful. If you are interested in being involved, please see our events tab on our website, contact the support line on 1800 693 566 or email nurses@myeloma.org.au

Rachel and Laura enjoyed this year's National Myeloma Month community event which focused on wellness. The attendees were treated to a Q&A with Dr Carrie Van Der Weyden and Dr Chloe Tang, then had the opportunity to partake in either an art therapy, music therapy, or mindfulness meditation session. We thank those who attended and our speakers.

The Victorian nursing team has again provided education to the nurses in the community which has increased growth in collaborative efforts in supporting you as best as we can.

We end on some happy yet sad news, as we said goodbye to our colleague Rachel in July, as she is getting ready to welcome her first baby. We wish her luck in her future endeavours in the Warrnambool area. Rachel has really appreciated the connections she has made with the myeloma communities in both NSW and VIC over the last 3.5 years and will very much miss working with you all. Keep cosy Victoria, Laura, EJ, Rachel and Emma.

Emma Huybens, Laura Jones, Rachel McCann & Emma-Jane Furphy
Myeloma Support Nurses



Western Australia

After two years Western Australia opened to the rest of the country and the myeloma community in Western Australia have been operating in a virtual way holding support groups and catch ups via Zoom since our COVID numbers began to rise. Thank you to everyone for attending these groups and for keeping our community going during this challenging time.

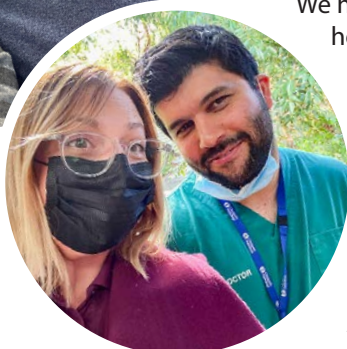
It was fantastic to be able to hold our National Myeloma Awareness Month morning tea in person. This was held at the Cancer Wellness Centre in Cottesloe. Consultant Haematologist Dr Hasib Siddiqi attended for a casual Q&A session with some delicious food also enjoyed.

Our Information and Support groups are always accepting new members. Please get in touch with me if you would like to know more.

We have an amazing myeloma community here in WA and we would love to see anyone interested in attending a group in the coming months.

Lastly, some sad news from WA. Our amazing Myeloma Support Nurse, Daniel Berk, has sadly left the organisation, to further his studies. We are sad to see Daniel go, but he remains a great friend and supporter of Myeloma Australia. All the best Daniel.

Narelle Smith
Myeloma Support Nurse WA



The Rotary Outreach Myeloma Scholarship

Rotary Clubs to recognise and celebrate regional cancer treatment centres.

The Rotary Outreach Myeloma Program, ("ROMP") is a community service venture of the Rotary Club of Camberwell in inner-eastern Melbourne. ROMP brings together many Rotary Clubs in country Victoria to support the work of Myeloma Australia by building awareness of myeloma and encouraging support for regional and remote myeloma communities.

Begun in 2018, ROMP is based upon two simple propositions. "Every myeloma patient needs and deserves the same support that is available in Melbourne" and "no myeloma patient is to live more than one hour from a Myeloma Australia support group". Country Rotarians have offered their assistance to Myeloma Australia nurses and are ready to be called upon to assist in creating new myeloma support groups and supportexisting groups.

Camberwell Rotarians visit regional clubs to promote their program and the Camberwell club holds regular online forums to reinforce the myeloma program. Now, in a major new addition to ROMP, Rotary Clubs will work together to recognise and celebrate the invaluable work of the many Victorian regional cancer centres that treat and support myeloma patients, other cancer patients and many, many more. A number of Rotary activities are in planning and will roll out in due course. Meanwhile, the first of these is the launch of *The Rotary Outreach Myeloma Scholarship* from 1 July, 2022



Camberwell ROMP Team members at work spreading the word.
Left – Adrian Campbell,
Right – Peter Allen.



The new scholarship is offered to selected registered nurses currently employed in rural and regional cancer centres or clinics in Victoria. The successful candidate will complete a Graduate Certificate in Cancer Nursing conducted by Melbourne University in the 2023 university year. The course is conducted online, over one year, part time. It is anticipated that additional scholarships will be added during 2023 for the 2024 academic year

Registered nurses and others interested in the *Rotary Outreach Myeloma Scholarship* are invited to seek more information from –

**The Secretary, Rotary Outreach Myeloma Committee,
Rotary Club of Camberwell,
Email – atholwood1943@gmail.com**



LUXCOMMUNITY

in partnership with



SUPPORTING YOUR COMMUNITY THROUGH TRAVEL

Treat yourself to the holiday you deserve and give back at the same time!

Use promo code **MYELOMA5** and 5% of every accomodation purchase on Luxury Escapes goes directly to supporting Myeloma Australia

www.luxuryescapes.com



LUXURY ESCAPES
THE WORLD'S BEST HOLIDAYS

Exercising the Brain



One of the most common effects of myeloma and associated treatments on the body is impaired cognition, otherwise known as chemo brain or brain fog. This can present as difficulty concentrating, short term memory loss, impaired ability to find words in conversation, difficulty learning new skills and mood swings. These symptoms can be even further compounded by the fatigue that is also caused by both myeloma and its treatment. Some strategies to improve cognition include daily gentle exercise, adequate food and fluid intake and exercising the brain with puzzles, craft projects or learning a new hobby. If cognitive impairment is having a significant impact on the ability to function, a psychologist can help by way of cognitive rehabilitation.



Words List

Berlin	Beijing	Canberra	Sofia
San Jose	Prague	Ottawa	Zagreb
Havana	London	Paris	Athens
New Delhi	Jakarta	Dublin	Rome
Tokyo	Amsterdam	Lima	Manila

Sudoku

				6				
						4		5
			7	4	8			
				7	6			
6					9		5	
1		9					2	
							1	
		5				7		2
		8	6			5		4

Capital Cities

Solve the following puzzle by finding all the hidden words!

I	G	H	T	A	T	R	A	K	A	J	F	S	O	S
H	N	R	R	E	A	A	M	S	T	E	R	D	A	M
L	E	N	A	T	A	H	N	N	O	D	N	O	L	E
E	S	T	W	H	I	P	T	S	G	A	G	A	B	E
D	E	A	A	H	E	H	A	N	P	A	R	I	S	B
W	N	T	T	N	G	L	O	R	I	A	D	J	A	B
E	B	H	T	V	O	Y	A	R	R	E	B	N	A	C
N	T	E	O	R	K	G	N	I	B	N	T	P	U	D
N	G	N	H	O	U	K	A	G	N	I	J	I	E	B
E	Z	S	T	E	O	A	V	A	L	I	N	A	M	S
M	H	A	I	F	O	S	A	E	S	O	J	N	A	S
O	G	T	G	R	A	L	H	N	T	A	T	F	A	I
R	N	I	E	R	E	T	N	A	I	W	M	J	O	T
I	A	A	A	A	E	E	O	B	E	R	L	I	N	E
I	A	I	D	E	A	B	N	I	L	B	U	D	L	S

answers on page 23

News from Australasian Leukaemia and Lymphoma Group (ALLG)

The Australasian Leukaemia & Lymphoma Group (ALLG) is the only not-for-profit collaborative clinical trial group in Australia and New Zealand, delivering research projects focused on blood cancers.

As a for-purpose organisation dedicated to delivering clinical trials to achieve better treatments and better lives for patients with blood cancer, all funds raised for ALLG go directly to the research.

The ALLG membership includes more than 1,000 physicians and haematologists, nurses, scientists and professional support staff, from across Australia and New Zealand, with clinical trials taking place at 93 accredited hospital sites and cancer centres across the country.

Our members include many of the world's, Australia's and New Zealand's pre-eminent experts in haematological malignancies; all of whom are looking for ways to better treat blood cancers through clinical research. Our Life Members include true pioneers in the field of haematology.

Current ALLG Trials for Myeloma

MM23 SeaLAND

– leading doctor Associate Professor Hang Quach

Prof Hang is the ALLG Myeloma Scientific Working Party Co-Chair and is on the Myeloma Scientific Advisory Group (MSAG) for Myeloma Australia.

The ALLG MM23 SeaLAND trial is evaluating a new medicine for patients called Selinexor in the maintenance treatment stage, after having have had a stem cell transplant.

This is the only study globally assessing this new treatment option for adult patients who have been newly diagnosed with multiple myeloma and who are eligible for an Autologous Stem Cell Transplant – a procedure in which a patient's healthy stem cells (blood-forming cells) are collected from the blood or bone marrow before treatment, stored, and then given back to the patient after treatment.



**Better treatments...
Better lives.**

This research aims to determine whether selinexor can prolong survival, and what kinds of side effects may occur with this treatment.

MM23 is open in 17 hospitals across Australia and New Zealand.

We have 116 participants and are aiming to recruit a total of 232 participants to join the trial over the next 18 months.

MM24 IsAMYP – leading doctor Dr Simon Gibbs

Dr Simon Gibbs is a member of ALLG's Myeloma Scientific Working Party and a member of Myeloma Australia's Medical and Scientific Advisory Group.

The ALLG MM24 trial is evaluating a new combination of medicines for patients with AL amyloidosis.

It's an international Amyloidosis trial, in collaboration with the French Myeloma Group IFM. Dr Simon Gibbs will lead ALLG's first collaboration with France in AL amyloidosis.

This international trial (MM24) is evaluating three drug combinations, isatuximab with pomalidomide and dexamethasone, in patients with AL amyloidosis who have either relapsed or are not better after any previous treatments.

The ALLG is proud to bring this important international trial to Australian patients.

There are four hospitals in Australia that are now operating this trial – Box Hill Hospital VIC, Princess Alexandra Hospital QLD, Royal Adelaide Hospital SA and Fiona Stanley Hospital WA. Two participants have already joined the trial and we are planning to recruit another 10 over the next 12 months.

For More Information

For more information about the ALLG and myeloma clinical trials, please visit

www.allg.org.au/clinical-trials-research/current-clinical-trials/

You can also speak with your treating physician to find out more about ALLG trials.

VISIT OUR
ONLINE
SHOP

Limited edition
tea towels available
on our online shop.

Order now before
we sell out!

www.myeloma.org.au/shop



LIMITED
EDITION

Myeloma
Australia

An abstract submission with data analysis of the first 10 evaluable patients in Prof. Hang Quach's BelaCarD study was accepted as poster for EHA 2022 taking place this winter. We will be posting a link to the poster on our website once it becomes available. AMaRC has continued to recruit patients and open new sites in our studies currently recruiting (see below). We are also looking forward to the development of new projects, and currently have several new projects in the works. One of which, IBIS, we are hoping to open for recruitment this year.



Currently Recruiting Trials

1. **FRAIL-M (MM22) study – Prof. Andrew Spencer**

This study aims to look at use of lenalidomide and/or bortezomib based on a patient frailty (weakness) score to identify optimal treatment for myeloma patients.

The FRAIL-M study is a collaboration with the Australasian Leukaemia & Lymphoma Group (ALLG) and funded by the Australian Government's Medical Research Future Fund (MRFF).

Recruiting hospital sites

Australia

- o VIC – Alfred Hospital, Sunshine Hospital, Latrobe Hospital, Northern Hospital
- o NSW – Concord Hospital, Nepean Cancer Care Centre, Tamworth Hospital, Calvary Mater Newcastle
- o QLD – Princess Alexandra Hospital, Sunshine Coast University Hospital, Townsville Hospital, Toowoomba Hospital
- o SA – Royal Adelaide Hospital, Queen Elizabeth Hospital
- o TAS – Royal Hobart Hospital
- o NT – Royal Darwin Hospital

New Zealand

- o Middlemore Hospital, Dunedin Hospital, North Shore Hospital, Christchurch Hospital

2. I-RIL study – Prof. Hang Quach – This study explores the addition of isatuximab in specific cases to improve treatment for patients already receiving lenalidomide and dexamethasone to treat newly diagnosed myeloma.

Recruiting hospital sites

- o VIC – Alfred Hospital, St Vincent's Hospital, Epworth Freemasons, Goulburn Valley Hospital
- o NSW – Calvary Mater Newcastle, Border Cancer Hospital, Concord Hospital, Nepean Cancer Care Centre, Lismore Base Hospital
- o SA – Flinders Medical Centre
- o TAS – Royal Hobart Hospital, Launceston General Hospital
- o WA – Fiona Stanley Hospital

3. BelaCarD study – Prof Hang Quach – The BelaCarD study explores a combination of belantamab, carfilzomib and dexamethasone to treat patients with relapsed/refractory myeloma.

Recruiting hospital sites – 1 new site

- o VIC – Alfred Hospital, St Vincent's Hospital Melbourne, Geelong Hospital
- o NSW – St Vincent's Hospital Sydney, Concord Hospital, Calvary Mater Newcastle, Border Medical Oncology
- o SA – Flinders Medical Center, Royal Adelaide Hospital
- o QLD – **Townsville Hospital (new)**

4. PRO-DVd – Prof. Andrew Spencer – The PRO-DVd study explores patient reported outcomes in patients receiving daratumumab, bortezomib, and dexamethasone for relapsed multiple myeloma.

Recruiting hospital sites

- o VIC – Alfred Hospital, Peter MacCallum Cancer Centre
- o NSW – St Vincent's Hospital Sydney

Upcoming Studies

1. IBIS study – Prof. Andrew Spencer – The IBIS study explores a combination of iberdomide, isatuximab, and dexamethasone to treat patients with functional high-risk multiple myeloma. This study is expected to open soon and will be recruiting patients at Alfred Hospital and other sites across Australia.

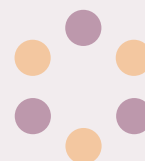
If you would like to know more about our trials or have an interest in working with AMaRC as an investigator or patient representative, please contact us at **amarc@alfred.org.au**

AMaRC contact:

Website: www.amarconline.org

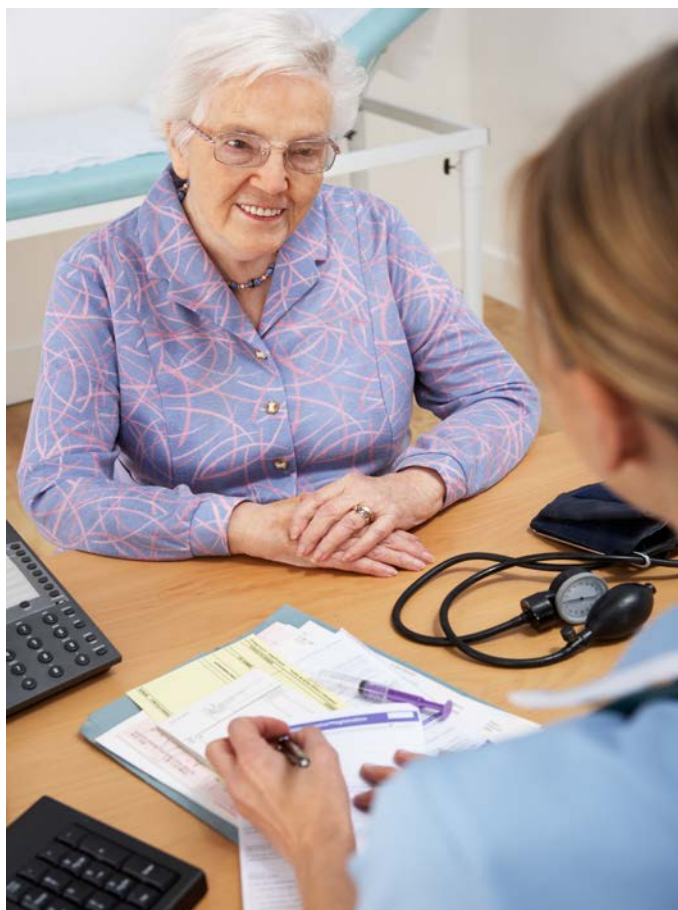
Email: amarc@alfred.org.au

Twitter: [@amarconline](https://twitter.com/amarconline)



News from the Myeloma and Related Diseases Registry (MRDR)

The MRDR now has over 5300 patients registered and 56 approved sites. All Australian states and territories are represented in the registry, along with a strong representation in New Zealand. Thanks to all patients and sites for your support.



before their clinical visits, and this will be fed back to their treating clinician before the visits. This timely information on how patients are responding could help to detect and treat potential emerging symptoms, optimise time on therapy, and lead to better outcomes.

Publications

We are pleased to report a recent registry-based publication thanks to the valuable data provided. It uses MRDR data to compare Māori and Pacific Peoples with multiple myeloma in New Zealand to other ethnicities in NZ. The paper which was published in Clinical Lymphoma Myeloma and Leukemia in April presents some intriguing findings and can be accessed with this link: doi: 10.1016/j.clml.2022.04.004.

Conferences

The MRDR has been active in conferences in 2022. A case-control study investigating tandem autologous-allogeneic stem cell transplant in transplant-eligible patients with relapsed myeloma was recently presented at the European Society for Blood and Marrow Transplantation conference. The MRDR was also represented at the European Haematology conference in June with a presentation on infection prophylaxis and outcomes in patients with myeloma in the ANZ and Asia-Pacific MRDR. We are pleased to put this valuable data to work!

If you are interested in participating in the registry, ask your treating specialist if your hospital contributes data to the MRDR and if you are eligible to participate. If so, you will receive information about the registry including how to opt out if you change your mind.

Research: MY-PROMPT-2

This MRDR-based trial is in preparation phase and should be ready to begin recruitment later this year. It aims to improve the treatment experience, and as a result, duration on therapy, for patients with relapsed myeloma receiving commonly used treatments. Patients will complete questionnaires assessing symptoms and quality-of-life

To contact the MRDR
E: sphpm-myeloma@monash.edu
P: 1800 811 326
W: mrdr.net.au



Please note the following information references some data, and medicines and/or the use of medicines that are not approved in Australia and/or New Zealand. For further information use the reference provided or ring our Myeloma Nurses on 1800 MYELOMA (1800 693 566)

CAR-T cell therapy:

Ciltacabtagene Autoleucel, an Anti-B-cell Maturation Antigen Chimeric Antigen Receptor T-Cell Therapy, for Relapsed/Refractory Multiple Myeloma: CARTITUDE-1 2-Year Follow-Up

Thomas Martin et al; DOI: 10.1200/JCO.22.00842 Journal of Clinical Oncology; Published online June 04, 2022.

CARTITUDE-1, a phase Ib/II study evaluating the safety and efficacy of ciltacabtagene autoleucel (cilta-cel) (CAR-T cells) in heavily pre-treated patients with relapsed/refractory multiple myeloma, yielded early, deep, and durable responses at 12 months. Here, we present updated results at 2 years including analyses of high-risk patient subgroups.

Eligible patients had relapsed/refractory multiple myeloma, had received ≥ 3 prior lines of therapy or were double refractory to a proteasome inhibitor and immunomodulatory drug and had received prior proteasome inhibitor, immunomodulatory drug, and anti-CD38 therapy. Patients received a single cilta-cel infusion 5-7 days after lymphodepletion. Responses were assessed by an independent review committee.

At approximately 28 months medium follow up, patients treated with cilta-cel maintained deep and durable responses, observed in both standard and high-risk subgroups. The risk/benefit profile of cilta-cel remained favorable with longer follow-up.

Journey of a Patient With Multiple Myeloma Undergoing Autologous Stem Cell Transplantation

Carrie Y. Chong; Clinical Journal Oncology Nursing 2022, 26(3), 252-256 DOI: 10.1188/22.CJON.252-256

Although there are multiple lines of available therapies and ongoing clinical trials for multiple myeloma, autologous stem cell transplantation (ASCT) remains the central option for prolonging durations of remission and improving overall survival. This case study demonstrates how oncology nurses play a critical role in patients' journeys before and after autologous stem cell transplantation.

Conclusion: During the journey of ASCT, patients may encounter physical and psychosocial challenges. Physical distress, fatigue, anxiety, depression, and cancer-related distress are common among patients. Oncology nurses provide patient-centred care during the journey through physical assessment, side effect management, and patient education.

Myeloma patients' experiences of a supervised physical activity programme: a qualitative study

Joanne Land et al; Supportive Care in Cancer; 11 April 2022; <https://doi.org/10.1007/s00520-022-07062-x>

The Myeloma "Advancing Survival Cancer Outcomes Trial (MASCOT)" tested the impact of a supervised exercise programme on fatigue, clinical, and patient-reported outcomes in multiple myeloma [MM] patients.

Conclusions: A post-treatment exercise intervention for MM patients was a positive experience, which enhanced participants' physical and psychological wellbeing. Tailored gym and home-based exercises, a specialist cancer physiotherapist, and sustained support were perceived to be important for success.

Implications for cancer survivors: Exercise support for MM patients, ideally with physiotherapist supervision, should be incorporated into survivorship care to qualitatively improve patients' quality of life, self-efficacy, and mental wellbeing.

How We Approach Smoldering Multiple Myeloma

Iuliana Vaxman and Morie A Gertz; Blood editorial, Tracking no: BLD-2021-011670R2

Conclusions : The current standard of care in smoldering multiple myeloma (SMM) is close surveillance, outside of a clinical trial, irrespective of risk status. Participation in clinical trials is highly encouraged. Two large randomised clinical trials have demonstrated benefit for early intervention in high-risk SMM, but the definition of high-risk is different among clinical trials and the discordance between those definitions is high. We believe that the data published so far does not justify lowering the treatment threshold.

We believe it is reasonable, outside a study, to monitor a patient closely before committing to treatment. Research identifying more accurate genomic markers that would enable us to assign individual risk more precisely is ongoing.



Calendar of Events 2022

Groups / events are subject to change at short notice.

Please check the website for a more up to date schedule. <https://myeloma.org.au/event-calendar/>



There are many Information and Support Groups around Australia. These are being held online for the foreseeable future to keep our community safe from the many viruses in circulation. We look forward to seeing many faces on Zoom as we aim to stay connected.

You are welcome to join any group online. For information about individual groups dates and times, please see our calendar of events. www.myeloma.org.au/events

For further information or help joining a group via Zoom, please contact your state's Myeloma Support Nurses via the contact details below

Information and Support Groups ACT

- Canberra
- ACT / NSW Cuppa & Catch Up

For enquiries please contact

Catherine Bowley

E: catherine.bowley@myeloma.org.au

M: 0426 404 766

Information and Support Groups National

- Smouldering Myeloma
- Younger Persons' Group
- Telephone Support Group (Cancer Council NSW & Myeloma Australia)

For enquiries, please contact:

Myeloma Support Nurses

E: nurses@myeloma.org.au

M: 1800 693 566

Information and Support Groups NSW

For enquiries, please contact

Juliet Hill

E: juliet.hill@myeloma.org.au

M: 0433 511 554

Catherine Bowley

E: catherine.bowley@myeloma.org.au

M: 0426 404 766

Diana Yun

E: diana.yun@myeloma.org.au

M: 0452 027 765

Tina Gordon

E: tina.gordon@myeloma.org.au

M: 0405 135 310

Information and Support Groups QLD

For enquiries, please contact

Tash Clarke

E: natasha.clarke@myeloma.org.au

M: 0416 019 585

Megan McDowell

E: megan.mcdowell@myeloma.org.au

M: 0416 019 022

Information and Support Groups SA

For enquiries, please contact

Jo Gardiner

E: jo.gardiner@myeloma.org.au

M: 0447 331 165

Alicia Hopper

E: alicia.hopper@myeloma.org.au

M: 0426 716 165

Information and Support Groups TAS

For enquiries, please contact

Deborah Thompson

E: deborah.thompson@myeloma.org.au

M: 0433 511 689

Information and Support Groups VIC

For enquiries, please contact

Laura Jones

E: laura.jones@myeloma.org.au

M: 0416 129 267

Emma Huybens

E: emma.huybens@myeloma.org.au

M: 0451 404 203

Information and Support Groups WA

For enquiries, please contact

Narelle Smith

E: narelle.smith@myeloma.org.au

M: 0426 404 280



You can also follow us on...



www.facebook.com/MyelomaAustralia



twitter.com/MyelomaAust_MFA



[myelomaaustralia](https://www.instagram.com/myelomaaustralia)



[Myeloma Australia](https://www.linkedin.com/company/myeloma-australia)

NATIONAL TELEPHONE SUPPORT GROUP (CANCER COUNCIL NSW)



Telephone Support 2nd & 4th Monday every month.

Available to those with myeloma

1.30 pm – 2.30 pm (AEST)

Cancer Council NSW with MA NSW

Cancer Council NSW

1300 755 632

E: tsg@nswcc.org.au

Solution to Sudoku on page 18

8	2	4	9	6	5	1	7	3
9	7	6	2	1	3	4	8	5
5	3	1	7	4	8	2	9	6
2	8	3	5	7	6	9	4	1
6	4	7	1	2	9	3	5	8
1	5	9	3	8	4	6	2	7
3	6	2	4	5	7	8	1	9
4	9	5	8	3	1	7	6	2
7	1	8	6	9	2	5	3	4

Myeloma Australia is the only myeloma specific support organisation in Australia



Call our **Myeloma Support Line** for advice, and emotional support **1800 693 566**



Learn about myeloma from experts and meet others at our **patient and family seminar workshops**



Find your nearest **myeloma support group** to meet other people



Visit **www.myeloma.org.au** to download the latest information, find support and seminar events etc

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

Mon – Fri 9am – 5pm AEST

E: nurses@myeloma.org.au W: www.myeloma.org.au