

# MyeNews

Autumn 2022 Issue no 61

Myeloma  
Australia



# Contents

## In this issue

From the President	3
3.8 with a mate Fundraising Awareness Walk	4
My Journey – Terry Bickmore	6
Myeloma and the Mouth	7
Advocacy News	9
In Betty's Garden	10
Charity TV	11
Exercising the Brain	12
New Resources	13
What's Happening (States)	14
News from the Myeloma and Related Diseases Registry (MRDR)	17
News from Australasian Leukaemia & Lymphoma Group	18
News from Australasian Myeloma Research Consortium	19
Medical Corner	20
Calendar of Events	22

MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

Contact MyeNews Coordinator

(03) 9428 7444

[myenews@myeloma.org.au](mailto: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: Wodonga 3.8 with a mate walk. Photo credit: Jos Weemaes*



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 quarterly 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

**How things have changed over the past two years, I'm pleased that we are now able to travel and catch up with family and friends living in other states. COVID has made us think about where we go and even who we go with.**

My wife reminded me that in some ways this is what we did in the period after her stem cell transplant some 25 years ago. Now that most of us are triple vaxed we are starting to feel more confident to go out and enjoy ourselves.

We are also experiencing some significant changes within Myeloma Australia (MA) with some long-serving staff members deciding to move on to new challenges.

Steve Roach who was our CEO for the past 12 years, began when we only had three Myeloma Support Nurses. He helped to build Myeloma Australia to a strong organisation with a team of seventeen Myeloma Support Nurses stationed around Australia. During this time, we have built strong relationships with international myeloma support organisations as well many organisations in Australia. I would like to thank him for the work he put into MA to build it to be one of the major cancer support organisations in Australia.

Hayley Beer our Manager of Programs and Services has been appointed into the Interim CEO role while we find a permanent replacement for Steve. Hayley has been with MA also for about 12 years starting as the Victorian Myeloma Support Nurse. During this period, she has also worked at the Royal Melbourne Hospital and Peter MacCallum Cancer Centre. She has been involved in developing our resources and planning the growth of our nursing team and support services. With the support of all at MA she is settling into her new role.

We have had two other long-serving staff leave MA in the past month. Pina Civitarese was a member of our Support

Services team and Co-ordinator of MyeNews magazine. Pina worked with us for over 12 years and was always a friendly voice on the end of the phone. We are grateful for her dedication to the myeloma community.

Matt Maudlin worked at MA for five years as our Community Engagement and Fundraising Manager. He brought many new ideas and energy to the fundraising team and worked hard to ensure there was opportunity for the myeloma community to get together.

We wish Steve, Pina and Matt all the very best for their future endeavours.

Finally, thank you for all your efforts in participating in the 3.8 with a mate walks on Sunday 27th February. COVID has prevented many charities from holding large events in recent years so we were pleased to see so many events happening around the country. Unfortunately, the devastating floods prevented the QLD and NSW walks from going ahead. These have now been rescheduled to Sunday 29th May 2022 which coincides with the end of National Myeloma Month. The 3.8 with a mate will be a regular event to be held each year. Community fundraising is extremely important to MA as this helps us to continue to provide our support services.



*Brian Rosenzarten*



### 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

For the first time in Myeloma Australia's history, people across the country gathered on Sunday 27th February to take part in Australia's first ever national fundraising and awareness walk. 3.8 with a mate was our way of further supporting the 38mates that are diagnosed with myeloma each week in Australia. We reached out to people across the country, asking individuals, families and community groups to walk together in solidarity, to raise both awareness about myeloma and vital funds for Myeloma Australia.

We can assure you that the inaugural 3.8 with a mate walk has proven to be a huge success, and that is all thanks to you, our community!

As news of 3.8 spread, our modest idea of a handful of walks grew to eighteen events scheduled across the country. That was thanks to the 18 wonderful people from the myeloma community that stepped up to volunteer as event organisers, assisting in running each event across the country and being the key point of contact for all attendees. The drive and enthusiasm of these volunteers ensured each event was an absolute success! In addition, over 600 people registered to participate in the inaugural 3.8 with a mate, to support the services of Myeloma Australia. Numbers that we could have never imagined when we first considered this initiative.



Photos supplied and used with permission

Many new contacts were made leading up to, and on the day of the event, highlighting the importance of myeloma awareness in the community. We have heard of so many positive stories and new friendships being made. Newly diagnosed 38mates and their families expressed their happiness in meeting fellow 38mates and learning about the resources available through Myeloma Australia. Peter Malinauskas, the leader of the SA Labor Party attended our Adelaide walk. We were delighted to see him interview our very own Myeloma Support Nurse Alicia Hopper on his Facebook Live account, raising awareness about myeloma in the wider SA community. Overall, the general feeling was that it was great to meet together as a community and feel a sense of belonging.

People hosting and attending events were creative and innovative, ensuring that everyone had fun while starting conversations about myeloma. Some events were so well

attended that they became a mini festival, with market stalls, sausage sizzles, morning tea, picnics and balloons! For those that didn't live close to a Myeloma Australia organised event, they created their own path, choosing to 'walk where you want'. From Airlie Beach to Bendigo and everywhere in between, Team Myeloma t-shirts were worn with pride!

Finally, our thoughts are with the Queensland and New South Wales communities who have had to postpone their events due to the floods. These walks will now be held on Sunday 29th May 2022 which coincides with the end of National Myeloma Month. If you wish to be part of an event in QLD or NSW, head to the 3.8 page on our website to register.

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 Australia. 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 host so many successful events across the country.*

## My Journey – Terry Bickmore



My myeloma journey began in 1997 at age 46 after being diagnosed with an inguinal hernia. I had taken a redundancy package from my employer of 28 years at age 45 and was doing contract work for an agency based in Adelaide.

My admission to the North Eastern Hospital for this surgery followed and the usual pre-op tests were performed. This included testing a specimen of urine by the nursing staff. The test demonstrated traces of blood and protein and this information was forwarded to my GP.

Everything went well following the surgery but my appetite was not as good as it had been previously and I was always tired.

I visited my GP, who thankfully was very thorough and organised further tests, which were also abnormal and he proceeded to refer me to Dr Tony Clarkson, (renal specialist) at the Royal Adelaide Hospital (RAH).

He performed a kidney biopsy which demonstrated further abnormalities and he referred me on to the haematology clinic.

Further testing was performed, including x-rays and scans, where bony lesions and fractures were found in my ribs and other areas, which explained the pain I had been feeling. I was eventually admitted to hospital for further testing.

On the 26th of May I was diagnosed with multiple myeloma and I began my first round of chemotherapy on the 29th of May. I was in a six bed bay with five other men with the same diagnosis and I was the second youngest at 46. I had been told the average age was 60 for anyone diagnosed with MM at that time. This began a very challenging time in my life and I did not react favourably to one of the three drugs I was being administered with: Vincristine, Adriamycin and Dexamethasone (VAD). I also developed constant hiccupping, and this continued for at least four days until a suggestion was given to try eating cubes of sugar. Success!

Once I was allowed home, there were quite a few trips from Redwood Park in the middle of the night to the RAH. I recall telling my wife to drive faster one night as I was feeling so ill and on top of this our daughter, who was 14 at the time, had a very interesting education sitting in emergency with us watching the usual weekend clientele coming and going.

Eventually it was decided that I would soon be ready for my transplant and as I was using my own stem cells for transplant, I had to undergo further treatment with high dose cyclophosphamide for the donation of cells. I also had several rounds of radiation as well as the “top up” of chemo.

Before my admission I attended the RAH for insertion of a VasCath line. I was very stubborn and wanted my wife to continue with her work and our home life to continue as normal as possible. I caught the bus into Adelaide, had the procedure, went to the pictures and caught the bus home again. I am not sure what the other commuters and patrons in the cinema thought about the tubes coming from my neck, but I enjoyed myself for the first time in a long time.

Mind you I was not always compliant. I did attend Football Park (commonly known as Pleurisy Park) in the middle of winter for a Crows game with my mate Barry and a hip flask of port. That was my medication!

I was admitted on the 5th of September (Father's Day) and had my transplant a few days later.

My recovery was slow, visitation was limited to my wife and daughter due to infection possibilities. Daily blood test results on the board in my room were gradually heading in the right direction. The only setback I had was an anaphylactic reaction when I was being given my medication through the PICC line. It was due to Vitamin K of all things.

I was eventually discharged home on the Friday before the Crows first grand final which they won.

I had a good incentive to aid in my recovery as our daughter was to be a bridesmaid in her friend's wedding and there was no way I was going to miss it, bald head and all. I returned to work three days a week and continued through my recovery period with no setbacks. During my usual schedule of follow ups with Dr Hui a routine blood test detected that my thyroid gland was underactive and was not producing enough thyroid hormone which is important for controlling my metabolism. The cause was linked to my radiation treatment. Medication was prescribed (thyroxine) and I continue to take it daily.

My health continued to be good and this enabled us to travel overseas at least once a year during which time we went on a number of cruises, two trips to Britain and to the USA to catch up with friends in California and Montana.

In 2011 we retired to Encounter Bay and I had been by then having six monthly trips to the RAH for my regular haematology clinic check-ups. Eventually I was told I was “boring” due to my excellent recovery and would only need to return if there were any signs of the cancer returning.

Fortunately, thanks to the good care provided by my own registered nurse (my wife Sherrill), plus an excellent local GP, I continue to be in remission after 24 years after initially being told I may have three months to live.

*Terry Bickmore*

# Myeloma and the Mouth



By Alissa Jacobs  
Oral Medicine Specialist  
BDSc (UWA), GradDipDPPH (UWA),  
DCLinDent (OMOP) (UWA)

People living with multiple myeloma, can experience changes to their oral health. This could be from the myeloma itself or the medicines used to treat it. This article will focus on the oral complications associated with myeloma and how people can best manage these if they arise.

## Prevention

Much of the effects on oral health that come from treatment, especially in the short term, can be prevented with adequate pre-treatment dental checks. Those living with myeloma should visit their dentist to ensure there are no dental infections of the gingiva or teeth before treatment starts. Ideally any caries (decay) should be removed and restorations smoothed and polished. If appropriate, then a scale and clean of your teeth should be carried out as well.

## Short Term Effects

Side effects vary depending on the treatment regime. People undergoing stem cell transplantation are at a higher risk of significant short-term side effects. Infection, mucositis and pain are the most common side effects noted during therapy.

## Infection

To help prevent infection and to limit the effects of mucositis, an intensified oral hygiene regime is recommended soon after diagnosis. This involves brushing teeth three times a day and flossing daily. An ultra soft toothbrush (eg Curacept or SurgiSoft) is recommended and should be softened in warm water before use. The brush should be allowed to air dry between use and replaced monthly during treatment.

Ideally high fluoridated toothpaste (ie Neutrafluror 5000™) should be used to strengthen the enamel. If discomfort is too great, you can switch to a non-foaming (SLS-free) toothpaste such as Oral-7.

Previously it was recommended to cease brushing or flossing if bleeding occurred. It was thought an infection such as systemic bacteraemia could be caused from the bleeding. Most recent research has confirmed that it is more beneficial to continue teeth brushing even if there is bleeding. Always report excessive bleeding and pain to your treating team.

Local infections from Candida (oral thrush) and recurrent herpes labialis (cold sores) can also occur. However, most people on treatment for myeloma will be taking prophylactic medicines to prevent infections such as these.

## Mucositis

Mucositis is an inflammation of the lining of the digestive tract, often seen as soreness of the mouth. In myeloma we most often see mucositis during autologous stem cell transplants as a side effect of the melphalan conditioning chemotherapy.

There is research to show that having higher plaque levels in the mouth can increase the risk of mucositis. This reinforces the importance of having good oral hygiene before starting treatment. Once mucositis sets in, it can be too painful to brush your teeth.

If mucositis does occur barrier mouthwashes such as a compounded sucralfate mouthwash can be of great benefit as can the compounded mouthwashes.

## Pain Control

Controlling and preventing local infection and mucositis significantly helps reduce pain. However, there are some very effective pain relieving medications that can be used such as opioid and non-opioid pain medications. Additional mouthwash preparations can be made available when required. These often contain varying amounts of antihistamine, mucosal coating agents, antifungals, anaesthetics and corticosteroids. You can rinse with these prior to eating and when pain is significant – up to six times a day.

... continues next page

**DONATE YOUR CONTAINERS**

WE RECEIVE 10 CENTS FOR EACH

**Containers for Change Scheme**

Operating in Western Australia and Queensland we receive 10 cents for the deposit of every eligible bottle and can at Containers for Change recycling centres.

Further details about Containers for Change can be found at:  
<https://www.containersforchange.com.au/>

The QR code you require is the numerical code is:  
**C10356476**

## Long Term Effects

### Medication Related Osteonecrosis of the Jaw

Bone strengthening therapies or bisphosphonates such as Zometa or pamidronate have a small chance of causing osteonecrosis of the jaw. This is where there is an area of exposed bone in the jaw that does not heal properly. It is often due to an invasive dental procedure such as a tooth extraction. If left untreated, it can become quite a nasty complication.

To minimise the risk of developing osteonecrosis of the jaw, it is important to have a dental check up prior to starting bisphosphonate therapy. If you need any invasive procedures, delay the start of bisphosphonates until the area is fully healed. If you need an invasive dental procedure while on bisphosphonate therapy, you may need to take a break from the infusions and only recommence once the area has healed.

If you have any jaw pain or can feel an area of exposed bone, seek guidance from your doctor or dentist. Early detection is vital as conservative measures such as antibiotics and topical antimicrobials are often all that's required.

### Decreased Saliva and Dry Mouth

As saliva is of great importance in preventing dental and oral infections, people with persistent decreased saliva (hyposalivation) will have an increased risk of decay, gum disease and oral mucosal infections. They will need to maintain an intensified oral hygiene regime long term to reduce this risk.

People with dry mouth (xerostomia) may benefit from salivary substitutes that are commercially available (eg Biotene, Oral 7). Some people prefer home made remedies with a mixture of salt, bicarbonate soda and warm water or a rinse with grape seed oil. The use of sugar free lollies and a Saliwell device can also provide relief. In severe cases a medicine can be prescribed to help with salivary flow.

### Taste Disturbances

Both loss of taste (ageusia) and altered taste (dysgeusia) can be attributed to medication, hyposalivation or to a condition called complex oral sensitivity disorder which can occur after treatment. Your dentist or treating haematologist can refer you to an oral medicine specialist if this is suspected for treatment.

### Neuropathic Pain

Certain medications can cause neuropathic (nerve) pain in the mouth this can be managed with pain relieving medication. If the nerve pain is in the head and neck region, pain patches and creams can be used in addition to other medications.

**If you have any questions please reach out to your treating team or call our Myeloma Support Nurses via the Telephone Support Line on 1800 693 566 (1800 MYELOMA).**



SYDNEY CONGRESS HALL BAND AND FRIENDS PRESENTS

## BANDING TOGETHER FOR MYELOMA

A BENEFIT CONCERT



**Sydney Congress Hall 140 Elizabeth Street, Sydney  
Sunday 15th May 2022 at 2.00pm**

**Tickets: Adults \$15 – Concession \$12 Children under 15 years Free  
Purchase tickets at [www.trybooking.com](http://www.trybooking.com) / [www.trybooking.com/BYLFU](http://www.trybooking.com/BYLFU)**





## Myeloma Awareness Month

Around the world, every March, we celebrate Myeloma Action Month, the annual myeloma awareness and advocacy initiative championed by our friends and colleagues in the Global Myeloma Action

Group (GMAN) and the International Myeloma Foundation. This year's theme was MY MYELOMA ACTION and you can see the action from around the world at [www.mam.myeloma.org](http://www.mam.myeloma.org) or on social media via #MYelomaACTION

Locally in Australia, each May, we celebrate the National Myeloma Month with online events, community events and social media awareness. Planning is underway for the program this year so stay updated by subscribing to our e-newsletter at [www.myeloma.org.au/what-is-myeloma/](http://www.myeloma.org.au/what-is-myeloma/) subscribe or following us on @MyelomaAustralia on Facebook, Instagram and LinkedIn.

## Consumer comments open for CAR-T cell therapy funding for myeloma in Australia

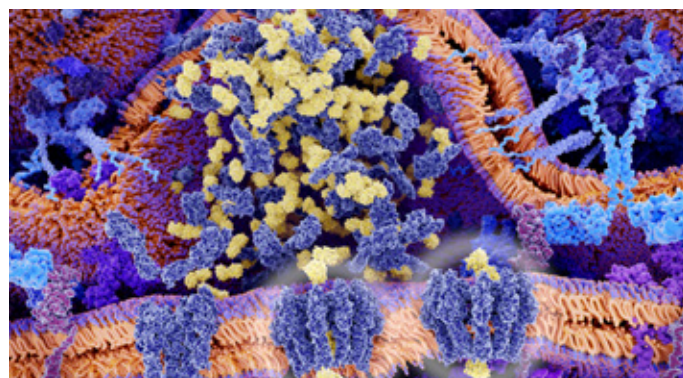
### What is CAR-T cell therapy?

CAR-T stands for 'Chimeric Antigen Receptor T Cell' and is a type of treatment known as an immunotherapy. The treatment works with your own immune system to detect and destroy myeloma cells.

### What are T cells and how does CAR-T work?

T-cells are a type of white blood cell and are part of our first-line immune defense. T-cells are found in the blood and lymphatic systems and circulate to detect and destroy abnormal cells or antigens such as bacteria and viruses. Unfortunately, T-cells are unable to detect and destroy cancer cells, allowing them to survive and multiply.

CAR-T cell therapy involves collecting an individual's T-cells and genetically engineering them by adding a specific



protein onto the T-Cells. The engineered or 'CAR-T cells' are then given to the person with myeloma by an infusion into the bloodstream and they are then able to recognise, bind to and destroy myeloma cells.

For myeloma, the most common receptor targeted by CAR-T cells is called B-cell maturation antigen (BCMA), however other targets are also being explored and trialed.

Currently, CAR-T cell therapy for myeloma is available through clinical trials, this application is the first CAR-T cell product for myeloma to seek funding through Medicare in Australia so far.

### What is the CAR-T product being considered and the indication?

The CAR-T cell product that is being considered for funding is called Ciltacabtagene autoleucel (cilta-cel) and for those with myeloma who have had more than 3 prior lines of therapy. Ciltacabtagene Autoleucel (cilta-cel) is a CAR-T cell product from Janssen Pharmaceuticals and has been studied through the CARTITUDE clinical trials globally and in Australia.

### What is the process of getting funding for CAR-T cell therapy in Australia?

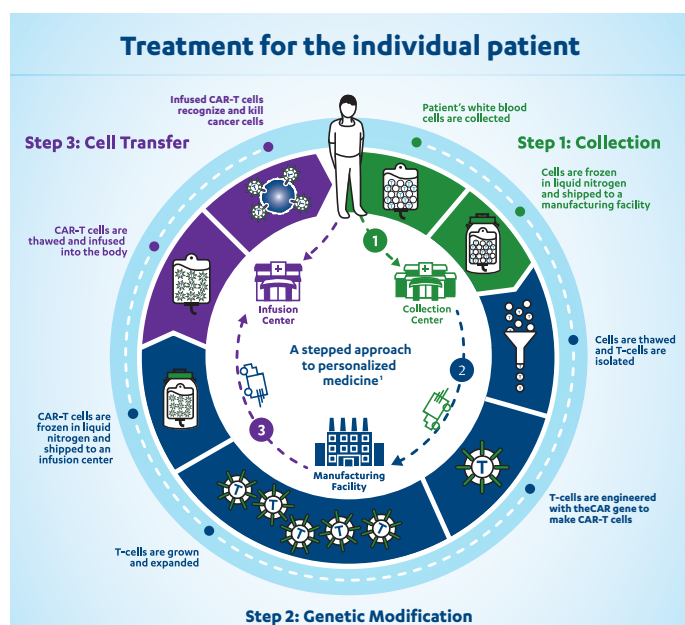
As CAR-T cell therapy is not a 'medicine' as such, public healthcare funding is sought through Australia's Medicines Services Advisory Committee (MSAC) rather than the Pharmaceutical Benefits Advisory Committee (PBAC).

MSAC is an independent committee and its role is to advise the Australian Minister for Health on evidence relating to the safety, effectiveness and cost-effectiveness of new medical technologies and procedures, including CAR-Ts. This informs Australian Government decisions about public funding for medical procedures.

Consumer comments remain an important aspect to the decision-making process and MSAC are currently seeking consumer comments and feedback for the Cilta-Cel CAR-T application for people with myeloma who have received at least 3 prior lines of therapy.

### How do I submit consumer comments to MSAC?

You can positively influence the government's decision to fund CAR-T by making your voice heard. Myeloma Australia and our Medical Scientific Advisory Group (MSAG) have provided feedback for the application already as part of



the MSAC process and now the opportunity for the wider community to provide feedback and comments is available.

As an individual with myeloma, a carer, a friend or a relative it is important that your voice be heard when these decisions are being made. MSAC needs to hear your story, how myeloma has impacted your life and why having this myeloma treatment available is so important to you or your loved one. Further, any individual with lived experience with this treatment via the clinical trial programs are able to provide input.

There are three ways to submit your comments:

1. Email MSAC directly:  
[commentsMSAC@health.gov.au](mailto:commentsMSAC@health.gov.au)
2. Send a letter:  
MSAC Secretariat,  
MDP 960,  
GPO Box 9848,  
ACT 260.
3. Via the **Consultation Survey** form on the MSAC website, details of which are below.

The easiest way to provide consumer comments is via email or letter.

#### Things to include in your letter or email to MSAC:

##### Your Details

Your name and email / phone

Whether you are an individual with myeloma, or a family member or carer

##### Your Story

What is the reality of living with, or caring for someone with myeloma?

What would it mean to you to have access to Cilta-Cel CAR-T therapy for myeloma?

##### **When is the deadline?**

Consumer comments can be made up until June 10th 2022

##### **What are the MSAC application details and where do I find further information?**

The application details are as follows, Application number 1690, Ciltacabtagene autoleucel, a B-cell maturation antigen-directed chimeric antigen receptor T cell to treat refractory or relapsed multiple myeloma

You can download the **Consultation Survey** form at the MSAC website – [www.msac.gov.au/internet/msac/publishing.nsf/Content/1690-public](http://www.msac.gov.au/internet/msac/publishing.nsf/Content/1690-public)

***Myeloma Australia will provide more information about this process in upcoming email communications and social media and if you have any questions please email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)***

## In Betty's Garden

Rebecca Johnson came to Australia from the UK in 2017 to be with her fiancé, Michael. During the many COVID lockdowns, Rebecca began candle making and experimented with lots of different oils and waxes to try and find the perfect combination. It was a therapeutic pastime that became a wonderful distraction from the outside world, which is a feeling that she wants to share with others through the magic of home fragrance.

Rebecca became inundated with requests from friends and family to share her creations which led to the start of her business in Adelaide, named after her beloved Nan "In Betty's Garden". Rebecca hand pours pure soy candles and wax melts at home in Adelaide and sends these all over Australia. Rebecca was very close to her Nan, who had myeloma, growing up and wanted to recreate the memories they had together in the beautiful English countryside, including wandering through the bluebell woods and picking wild blackberries from the hedgerows. Rebecca supported her Nan, Betty, through her myeloma journey and understands from personal experience the valuable support offered through Myeloma Australia and Myeloma UK.

Rebecca has a beautiful range of natural candles all inspired by Betty and her beloved English garden. Her goal is to recreate these memories for homes across Australia to spread some smiles and connect people to the myeloma community. In Betty's Garden donate a percentage of all sales to Myeloma Australia and very soon will be pouring in the UK too in support of Myeloma UK.

#### Contact details

Contact Rebecca online at <https://inbettysgarden.fws.store> or by email at [inbettysgardenau@gmail.com](mailto:inbettysgardenau@gmail.com) or follow her story on Facebook at [facebook.com/inbettysgarden](https://facebook.com/inbettysgarden) If you are interested in becoming a corporate partner you can contact Deb Cutts directly on 0419 005 191 or via email at [deb.cutts@myeloma.org.au](mailto:deb.cutts@myeloma.org.au)



Photo supplied and used with permission

## Charity TV Global Adventure All Stars

It's been a long time, but our Myeloma Australia Charity TV Global Adventure All Stars have finally experienced their six day adventure! Originally scheduled for August 2021, this adventure was hampered by ever changing border restrictions and delayed travel due to COVID, but we are now excited to say that our All Stars finally got to experience their adventures!

This year, our Adventure All Stars travelled within their own states to ensure safety and to comply with regional travel restrictions. In early February our NSW Charity TV Ambassadors, Alison, Meg & Frankie enjoyed their experience, which they described as a "truly once-in-a-lifetime opportunity".

Travelling to Jindabyne, their base for the week, some of the surprise activities they experienced included rock climbing and abseiling, then ascending a chairlift to experience the glorious views of Kosciuszko, bobsledding, hydrobike riding, eFoil boards, fly fishing and more!

A few weeks later Myeloma Australia's very own Alex Dawson travelled to Lakes Entrance in south east Victoria to enjoy her All Star Adventure! Kicking off the week with camel husbandry followed by a chance to crack a whip and round some sheep. This was followed by Segways and a relaxing yoga session and soothing geothermal springs, with a glorious view over the Gippsland Lakes. There was



even a sailing lesson and race followed by mountain bike riding to test everyone's fitness. Even more adventure was had at an Aqua Park followed in the afternoon by kayaking. The grand finale was a helicopter ride over Lakes Entrance with breathtaking views of the coastline.

Well, what an adventure! We want to give a heartfelt thankyou to our Charity TV Global Adventure All Stars for choosing to raise funds and awareness for Myeloma Australia. Your support and spirit of adventure is appreciated, and the funds raised will go towards helping us support, inform, empower and bring hope to people living with myeloma and their loved ones.

Photos supplied and used with permission



**Buy a Membership to help us raise extra for our fundraising**

For more information please contact:

E: [fundraising@myeloma.org.au](mailto:fundraising@myeloma.org.au)

T: 03) 9428 7444



## Exercising the Brain



## Double Word Puzzle

Unscramble the following list of shuffled words to see the final message!

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.

PLEHTEAN

A horizontal number line with 11 equally spaced tick marks, labeled 0 through 10. The tick mark for the number 3 is highlighted in a light blue color.

GRETNIENTIAN

A horizontal number line with 11 equally spaced tick marks, labeled from 0 to 10. The tick mark for the number 7 is highlighted with a light blue background.

LESTNI

ATAKEL SBB

[illegible]

DRSBEOBA

LATBE

A horizontal number line with arrows at both ends, labeled 0, 1, 2, 3, 4, 5, 6, 7, 8, 9, and 10. A solid dot is placed at the number 9, and another solid dot is placed at the number 6. A curved arrow points from the dot at 9 to the dot at 6, indicating a subtraction of 3.

MRMEOY

THISYOR

LMECOTPE

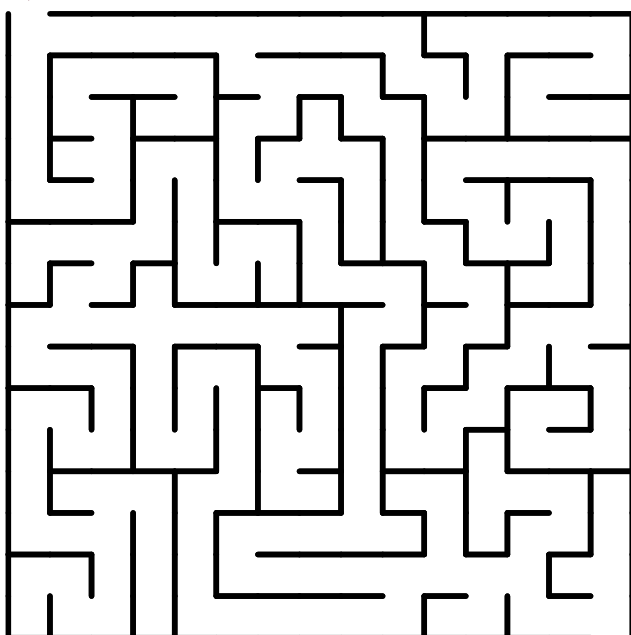


4

1	2	3	4	5

						!
6	7	8	9	10	11	12

**START**



# MazePuzzle

answers on page 23

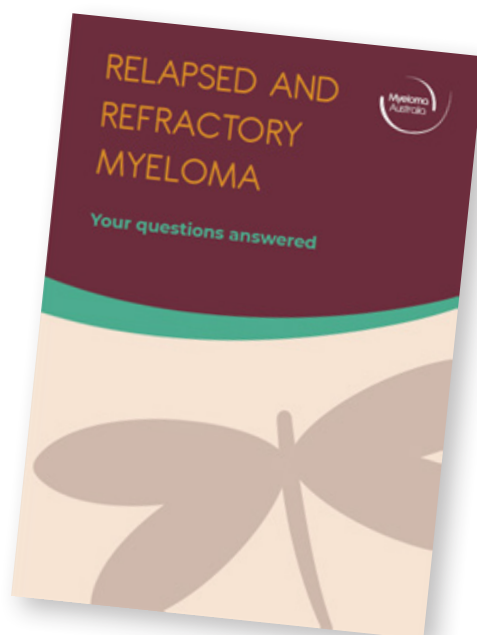
## New Resources

### Relapsed and Refractory Myeloma

There are many questions asked of our Myeloma Support Nurses either through our Telephone Support Line or Information and Support Groups. These include; Why is there no cure for myeloma? Why does myeloma keep coming back or does not respond to certain treatments? What does relapsed and refractory myeloma mean?

These are all really important questions to answer so we felt it necessary to create a new booklet, *Relapsed and Refractory Myeloma – Your questions answered*. This booklet is full of useful information that is written for people living with myeloma as well as their families, carers and friends. Topics include; understanding relapsed and refractory myeloma, making treatment choices, coping with the news, communicating with family and friends and where to find more information and support. Throughout the booklet diagrams have been used to explain some of the more difficult concepts. It also includes quotes from people living with myeloma and their carers and signposts to other information that you might find useful.

If you would like a copy of the booklet you can order it via the shop on our website [www.myeloma.org.au](http://www.myeloma.org.au) or call our Telephone Support Line on 1800 693 566.



If you prefer to listen as you learn, we have also developed a podcast in our MyeConversations series called Relapsed and Refractory Myeloma. Our Interim CEO, Hayley Beer chats with Professor Andrew Spencer from the Alfred Hospital in Melbourne. Professor Spencer gives a recap on the basics of myeloma then moves into more detail about relapsed and refractory myeloma. Within the podcast he also explains how drugs become reimbursed on our Pharmaceutical Benefits Scheme (PBS) and explains what the treating team consider when making treatment choices with their patients. He also explains how myeloma behaves over time, clinical trials and the logistics to support patients on

clinical trials that live in a regional or rural area of Australia. To listen to this episode of MyeConversations, head to [www.myeloma.org.au/podcast](http://www.myeloma.org.au/podcast) or search MyeConversations on all major podcast streaming platforms.

Additionally, if you have any further questions about relapsed and refractory myeloma please don't hesitate to contact our Myeloma Support Nurses on the Telephone Support Line 1800 693 566 or email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)



Find our podcast series at  
**[www.myeloma.org.au/podcast](http://www.myeloma.org.au/podcast)**  
or through your favourite  
streaming platform



## What's Happening



### New South Wales/Australian Capital Territory

Finally after another uncertain year we were able to hold our Christmas catch ups face to face. Team NSW/ACT made trips around the state to be with our groups in Canberra, Orange, Central Coast, Liverpool, Westmead, Newcastle and Tamworth. It was fantastic to see you all in person, conversation flowed, and it was wonderful to sit around the table and relax with friends. While our local groups were face to face, our NSW cuppa and catch up continues monthly via Zoom. This continues to be a great forum to discuss all things myeloma and we welcome anyone who considers joining, to jump on and say hello.



Our 2022 groups have seen great numbers, with topics covering exercising, eating well, bone disease and bisphosphonates, interpreting blood results, and a discussion on sleep with sleep scientist Kerri Melehan from RPA. March will see the commencement of a new online group specifically for partners and carers and if you would like more information about this group please contact Diana Yun.

Our Newcastle Myeloma Support Nurses Tina and Juliet are soon to be a regular sight around The Calvary Mater Newcastle hospital, based onsite from March. Our Myeloma Australia nurses will be available in a support role for patients visiting the hospital for clinic or treatment appointments. If you would like to see one of the nurses please tell your treating team. Alternatively, if you would like to refer a myeloma patient please email either Juliet or Tina – our email addresses are available on our website.

Unfortunately, our first ever “3.8 with a mate” was postponed in NSW due to the wet weather. We are now please to announce that a new date has been confirmed, with 3.8 with a mate in NSW now scheduled for Sunday 29th May 2022. While NSW was rained out, Team ACT had a wonderful turnout in Weston Park Canberra. It was so wonderful to see our Myeloma community coming together. Thank you to our participants who flew the flag in ACT.

Also, we are busily preparing for our Myeloma Month seminars and morning teas in May so watch this space.

*Jacqui Keogh, Cath Bowley, Juliet Hill, Tina Gordon & Diana Yun*  
Myeloma Support Nurses NSW



### Queensland

Here in Queensland, we were very lucky to catch up with a few of you just before Christmas in Lismore, Buderim, Coorparoo, Red Hill, North Lakes and the Gold Coast. All going well, most of our groups will re-commence in person, in April so keep an eye out for your emails or in the online Events Calendar.

You may receive an invitation to attend some of our national specialised groups, the ‘Younger Persons’ and ‘Smouldering Myeloma’ groups. If you are interested in these groups, please give our Telephone Support Line a call (1800 693 566)

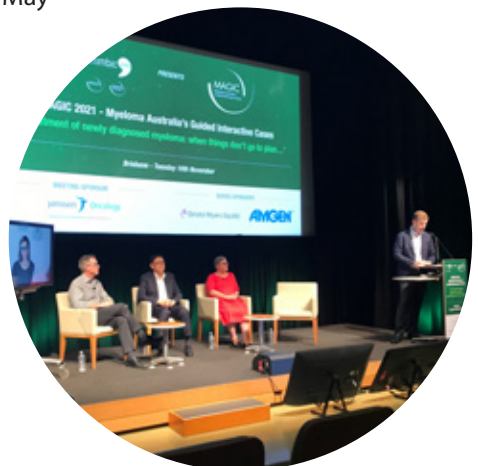
Thank you to everyone involved in the lead up to our inaugural ‘3.8 with a mate’ walks. Unfortunately, due to the extreme weather we had to postpone our state events to Sunday 29th May 2022.

#### Spotlight on a Qld Information and Support Group:

Each MyeNews this year, we would like to shine a light on a local group and the unique benefits it brings to its regular members. This month we successfully introduced our NEW online ‘Partners and Carers Group’ catering for those family members and loved ones caring for someone with myeloma. We have given our local group the nickname, COGs (carers only group) as they are often instrumental in keeping the wheels turning in day-to-day life with myeloma. We have had great discussions with our COGs, about the unique challenges they face and a few laughs as well. If you are a carer or partner, please join us next time.

If you would like to hear about any topic that's close to you or would like to start a local group, please get in touch with Megan or Tash via phone or email.

*Megan McDowell and Tash Clarke – Myeloma Support Nurses QLD*



Photos provided and used with permission



## South Australia/Northern Territory

It's been an interesting start to the year in SA with us all learning to live in a COVID-positive environment. While initially our support groups were moved back to an online format only, we are pleased to announce that from the 1st of March we have returned to our usual hybrid model combining the option to attend face to face or online. Several of our local groups have met online already this year with some great topics and conversations. In February, our Fullarton support group hosted the amazing Dr Jess Hafner, RAH Neurologist who gave very generously of her time to present and answer questions about peripheral neuropathy. It was a wonderful discussion, and everyone present appreciated the time and effort she took for us.

The rest of the year is shaping up to be a big one with many events planned. We are looking forward to going on a virtual tour of the SAHMRI myeloma research facility in April and our next Partners & Carers support group will be hearing from Carers SA and their work. Please all save Wednesday 4th May for our South Australian seminar and morning tea in honour of Myeloma Month.

Finally, a huge thank you to everyone who came out for our inaugural '3.8 with a mate' walk on the 27th February. It was amazing to see so many people all in their Team Myeloma shirts raising awareness and funds. The sense of community was just wonderful! A huge thank you to event organizer, Paul Hoskin who went above and beyond in making the event the success it was. See you in 2023 for the next one!

*Alicia Hopper & Jo Gardiner*  
Myeloma Support Nurses



## Tasmania

Hi, and welcome to 2022! The year started with Tasmania 'opening up' which meant greater restrictions and returning to online support groups. We had a joint northern/north-west group and a southern group both via Zoom. Luckily, we are able to re-commence face-to-face groups from March, with our next gathering at the Howrah Community Centre in the south.

We had two events in Tasmania for the '38 mate, 3.8 with a mate' fundraiser on Sunday February 27th: a walk from the Launceston Yacht Club to Peppers Silos Hotel in the north organised by Bev Ernst and in the south a walk around Risdon Brook Dam. A great big thank you to all those who joined in and for the funds raised. Awesome effort!

We have expanded our members' base in the north of Tasmania since the start of the year and are looking forward to meeting new participants at our upcoming information and support groups. As requested by our northern myeloma colleagues, we will experiment holding one group for the north-west and this will be held at the Penguin Football Club every two months.

I encourage people to listen to any or all of the podcasts that have been developed by staff at Myeloma Australia. Our podcast series 'MyeConversations' can be accessed through our website and every major podcast platform. There are (and will be more) some very interesting topics to listen to. Likewise, National Myeloma Month (May) isn't far away and if you have any ideas for speakers here in Tasmania, please don't hesitate to let us know.

*Deborah Thompson*  
Myeloma Support Nurse



## What's Happening



### Victoria

We hope everyone was able to stay safe, see family and friends over the summer period and enjoyed the warmer weather. There has been a lot of changes in the way we're living with Covid during this time and we are looking forward to being able to hold face to face events again. We have all been busy taking on more in our other clinical roles to support our hospitals in this time of increased demand on the healthcare system. We now hope that this wave is behind us as we see hospital admission rates decrease each week.

A big welcome back to Laura Jones from maternity leave in February after bub number two, it is great to have her back on the team. We welcome back our regular support groups for the year which have started off online but hoping to be back to face to face in the not so distant future. We are pleased to announce we have expanded our information and support groups in 2022. We look forward to getting to know the community in Swan Hill and Portland. Additionally, a very special new support group for carers and partners. We recognise that carers and partners provide such an important role and have their own unique supportive needs. If you are interested in being involved in any of the new groups, please contact the support line on 1800 693 566 or email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

We are looking forward to seeing you all in person again and thank all our members for attending our groups online.

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



### Western Australia

It was so hot leading up to and over the Christmas period here in WA, that heat records were broken, and we really appreciated everyone that ventured out to our various support groups, seminars and Christmas catch up.

In November, we travelled south of Perth to Busselton to host a support group for members of the myeloma community in the south of WA where we were able to discuss fatigue and fatigue management. Our final younger persons group for the year was held in late December with the impetus in place to help our colleagues develop a series of national seminars for 2022, specifically curated for younger people with myeloma.



November saw us host our final seminar for the year, with haematologist Dr Bradley Augustson holding a Q and A on myeloma tests, investigations, and imaging, then Dr Vidisha Vaidya – consultant radiologist, discussing imaging techniques in myeloma. At our Cottesloe home base, participants were treated to engaging presentations and discussion, as well as Daisies famous sausage rolls.

Narelle and Dan have been busy planning the program for 2022 and are pleased to let you know that they have started two new groups, one in the eastern suburbs of Perth in Bassendean and the other in the south suburb of Melville. Please contact Narelle and Dan if you are interested in attending any of these groups

At the end of February, we hosted our first seminar of the year. The Health, Wellness and Exercise in Myeloma Seminar, initially planned as a face-to-face event, was adapted to be delivered in an online format. We had two expert speakers, Debbie Cooper – Accredited Exercise Physiologist, and Clemency Nicolson – Accredited Practising dietitian

presenting their expertise in an online and interactive format and the recording of the seminar can now be viewed on the Myeloma Australia website.

# News from the Myeloma and Related Diseases Registry (MRDR)

The MRDR now has over 5000 patients registered and 55 approved sites, with 5 new sites joining the registry last year. In 2021 registry sites recruited a total of 852 patients - we send a big thankyou to patients and staff at participating hospitals and clinics for your continued support.



## Publications

We are pleased to report three registry-based journal publications for 2021 thanks to the valuable data provided. These include an investigation of the impact that the number of cycles of therapy received has on survival in newly diagnosed patients treated with bortezomib, who are not for autologous stem cell transplant (ASCT). The other two papers provide comprehensive analyses on the myeloma 'landscape' in Australia and New Zealand: patient demographics, clinical characteristics at diagnosis, treatment and outcomes; and the utilisation of ASCT in multiple myeloma.



## Research

Alongside the publication output, the MRDR had a year of solid research growth in 2021 with several investigator-initiated analyses at different stages of development. Studies range from the evaluation of zoledronic acid use in myeloma patients with renal impairment, to an analysis comparing New Zealand Māori and Pacific Islanders with myeloma

to other ethnicities – the latter was recently submitted for publication. A number of studies using Myeloma 1000 Biobank samples are also in progress. We welcome further proposals and look forward to providing information on the outcomes of these projects.



## Project progress

The IMPROVE study has now completed data collection. This is a sub-study of the MRDR funded by the National Blood Authority to investigate immunoglobulin use and infections in Australian patients with myeloma to improve national immunoglobulin stewardship. The data analysis is well underway, and we look forward to reporting results. The FRAIL-M trial has now recruited over 60 patients between Australia and New Zealand. This trial identifies which bortezomib or lenalidomide-based treatment options are more appropriate in transplant-ineligible myeloma patients according to frailty status.

*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.*

**To contact the MRDR**  
**E: [sphpm-myeloma@monash.edu](mailto:sphpm-myeloma@monash.edu)**  
**P: 1800 811 326**  
**W: [mrdr.net.au](http://mrdr.net.au)**

# News from Australasian Leukaemia and Lymphoma Group (ALLG)

The ALLG is the only not-for-profit collaborative clinical trial group in Australia and New Zealand, delivering research projects focused on blood cancers. We are a for-purpose organisation dedicated to delivering clinical trials to achieve better treatments and better lives for patients with blood cancer.

The ALLG membership includes more than 900 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 and 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 Myeloma Trials

### MM24 – leading doctor Dr Simon

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

The MM24 trial will evaluate a new treatment for relapsed/refractory amyloid patients.

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 is a Phase II study with the Intergroupe francophone du myelome (MM24) evaluating isatuximab in combination with pomalidomide and dexamethasone in patients with AL amyloidosis either relapsed or with a suboptimal response to therapy.

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

The trial is in activation stages now for our four sites in Australia – Box Hill Hospital VIC, Princess Alexandra Hospital QLD, Royal Adelaide Hospital SA and Fiona Stanley Hospital WA.

### MM23 SeaLAND – leading doctor Professor Hang Quach

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



Better treatments...  
Better lives.

The SeaLAND trial is a Phase III randomised study evaluating a new treatment option called Selinexor in maintenance therapy, versus the standard maintenance therapy for post-autologous stem cell transplant patients. This is the only study globally assessing this new treatment option for adult patients who has been newly diagnosed with multiple myeloma and are eligible for an autologous stem cell transplant.

It is hoped that this research will help determine whether this treatment prolongs the progression free survival for patients, and what kinds of side effects/complications may occur with this treatment.

MM23 opened 17 sites across Australia and New Zealand in 2021, and the investigating team is excited to work with all of the investigators and ALLG clinical trial site teams at the participating sites, working together towards improvements in therapy for multiple myeloma.

Recruitment is going very well. We have 98 participants, and we are targeting 232 patients to join the trial.

#### Current Recruiting Hospitals

VIC – St Vincent's Melbourne, Austin Hospital, Alfred Hospital, Geelong Hospital, Monash Health, Peter MacCallum Cancer Centre, Sunshine Hospital

NSW – St Vincent's Sydney, Concord Hospital, Orange Health Service, Border Medical Oncology, Lismore Hospital; SA – Royal Adelaide Hospital

QLD – Townsville Hospital, Princess Alexandra Hospital

WA – Fiona Stanley Hospital; TAS – Launceston Hospital. More hospitals to open in coming months.

## What's New

Dr Georgia McCaughan is working with Prof Hang Quach to establish a platform trial that will assess a combination of pomalidomide and selinexor in myeloma patients. This trial will aim to give more patients with myeloma greater access to new treatments.

The trial will be developed over the course of 2022 with the aim to open in 2023.

## 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/](http://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.

# News from Australasian Myeloma Research Consortium (AMaRC)

Despite being slowed down by the surge in COVID cases this summer, AMaRC has continued to recruit patients and open new sites in our existing studies (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 in the first half of 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 – 2 new sites**

##### **Australia**

- o VIC – Alfred Hospital, Sunshine Hospital, Latrobe Hospital, Northern Hospital (**new**)
- 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 (**new**)

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 – 3 new sites**

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

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 – 2 new sites**

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

## Upcoming Studies

1. **IBIS study - Prof. Andrew Spencer** – The IBIS study explores a combination of Ixertin, Isatuximab, and Dexamethasone to treat patients with functional high-risk multiple myeloma. This study is expected to open in the first half of this year and will be recruiting patients at Alfred Hospital and other sites across Australia.

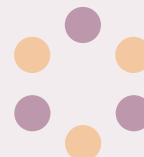
If you would like to know more about our trials or have an interest in working with AMaRC as an investigator or patient representative, please contact us at [amarc@alfred.org.au](mailto:amarc@alfred.org.au)

#### **AMaRC contact:**

**Website:** [www.amaronline.org](http://www.amaronline.org)

**Email:** [amarc@alfred.org.au](mailto:amarc@alfred.org.au)

**Twitter:** @amarconline





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)

**Impact of achieving a complete response to initial therapy of multiple myeloma and predictors of subsequent outcome Marcella Kaddoura et al; American Journal of Haematology; 03 January 2022  
<https://doi.org/10.1002/ajh.26439>**

Achievement of a complete response (CR) in multiple myeloma (MM) correlates with improvement in survival outcomes; however, its impact on prognostic variables at baseline outside of clinical trial settings is not well described. We sought to determine the impact of achieving a CR within 2 years from diagnosis, its effect on the prognostic value of fluorescence in situ hybridization (FISH) and International Staging System (ISS) risk and examined additional predictors of outcome among those achieving a CR in a routine clinical setting.

We evaluated 1869 newly diagnosed MM patients who had  $\geq 2$  myeloma protein studies in the blood and urine available within 24 months from diagnosis, categorizing those with  $\geq 2$  negative blood and urine immunofixation tests as achieving CR. At 24 months, median progression-free survival (PFS) for CR versus non-CR patients was 29.8 versus 20.9 months; median overall survival (OS) was 104 versus 70 months. The impact of achieving a CR was retained after adjusting for FISH (cytogenetics), ISS, sex, transplant status, and involved heavy chain (paraprotein). Baseline FISH and ISS stage were not associated with PFS or OS among patients achieving a CR. The following variables were found as predictors of inferior OS within the CR cohort: age  $> 75$  years, male gender, hypoalbuminemia, and non-immunoglobulin G involved heavy chain. Our study confirms that achievement of CR within 2 years from diagnosis is associated with improvement in survival outcomes and neutralization of the impact of FISH and ISS risk, thereby confirming observations from the clinical trial setting among a clinical practice cohort.

**The development of a home-based therapeutic platform for multiple myeloma; Hayley Beer et al;  
Published online: 07 Jan 2022;  
<https://doi.org/10.1080/17474086.2021.2022471>**

Peter MacCallum Cancer Centre and Royal Melbourne Hospital's combined Clinical Hematology Unit has collaborated with their Hospital in the Home departments to develop several innovative programs for myeloma patients to receive treatment at home and maximise time away from hospital-based settings which is a key preference for patients receiving anticancer therapies over long periods of time.

We have enabled large numbers of patients to receive complex therapies in their own home and the COVID-19 pandemic has increased the pace of the roll out without any compromise in safety. We anticipate that the next raft of immunotherapies will be able to transition into the @Home treatment setting in the coming years.

**Diagnosed with myeloma before age 40; Ola Landgren, Dickran Kazandjian; Blood (2021); 138 (25): 2601–2602;  
<https://doi.org/10.1182/blood.2021013539>**

In this issue of Blood, Caulier et al report clinical epidemiology data from a retrospective cohort of 214 patients diagnosed with multiple myeloma in France before the age of 40. The median patient age was 37 years (range 18–40), and 64% were men. In the United States, the average age at diagnosis with multiple myeloma is 69 years with 95% of newly diagnosed patients are  $\geq 50$  years. The study describes baseline disease characteristics and prognostic factors of overall survival in these patients.

When comparing baseline characteristics to older patients, consistent with previously reported smaller cohorts, the authors found that almost half of the patients diagnosed before age 40 had low-risk disease (International Staging System, stage 1), which is in sharp contrast to older patients. The authors speculate that this finding likely contributed to the greater overall survival (median 14.5 years) and the observed 84% 5-year overall survival rate. The lower rate of comorbidities and the greater ability to tolerate treatment side effects also likely contributed to a better overall survival of younger patients.

The current study is important in many ways. Although the average age of onset for multiple myeloma is close to 70 years, the study emphasizes the fact that multiple myeloma can present at younger ages. These patients have significantly different life challenges compared with older patients. Based on experience from our own clinics, for example, younger patients with multiple myeloma face different hurdles such as childcare, pregnancy, career challenges, and other life circumstances that cause additional stress. There is need for more research focusing on younger patients with multiple myeloma and their needs, including clinical management, exploration of differences in disease biology, social support, drug development, and long-term follow-up of therapies.

**Consensus guidelines and recommendations for infection prevention in multiple myeloma: a report from the International Myeloma Working Group; Noorpur S Raje, et al; Lancet Haematology (2022); 9(20): 143–161  
doi: 10.1016/S2352-3026(21)00283-0  
<https://pubmed.ncbi.nlm.nih.gov/35114152>**

Infection remains the leading cause of morbidity and mortality in patients with multiple myeloma because of the cumulative effect of disease, treatment, and host-related factors. Given that infectious risk is cumulative through the course of the disease, preventing infections is paramount. Optimal preventive strategies include vaccination against common pathogens, antimicrobial prophylaxis, infection control measures, and immunoglobulin replacement in a small subset of patients; however, there are no universally

accepted guidelines for infection prevention. This Review provides a consensus statement from a panel of 36 experts with global representation, which was convened by The International Myeloma Society to review existing literature and current guidelines, address issues associated with the risk of infection and prevention of infectious complications in multiple myeloma in the context of emerging therapies, and offer recommendations for preventing these complications.

#### **Experience with denosumab (XGEVA) for prevention of skeletal-related events in the 10 years after approval**

**Benoit Cadieux a, Robert Coleman b, Pegah Jafarinasabian a, Allan Lipton c, Robert Z. Orlowski d, Fred Saad e, Giorgio V. Scagliotti f, Kazuyuki Shimizu g, Alison Stopeck h**

**Journal of Bone Oncology 33 (2022) 100416**

Skeletal-related events (SREs) are complications of myeloma bone disease. Denosumab is a receptor activator of nuclear factor- $\kappa$ B ligand (RANKL) inhibitor approved for SRE prevention in patients with multiple myeloma and patients with bone metastases from solid tumors. In phase 3 trials, denosumab showed superiority to the bisphosphonate zoledronate (Zometa) in reducing the risk of first on-study

SRE by 17% (median time to first on-study SRE delayed by 8.2 months) and the risk of first and subsequent on-study SREs by 18% across multiple solid tumor types, including some patients with multiple myeloma. Denosumab also improved pain outcomes and reduced the need for strong opioids. Additionally, a phase 3 trial showed denosumab was noninferior to zoledronate in delaying time to first SRE in patients with newly diagnosed multiple myeloma. Denosumab has a convenient 120 mg every 4 weeks recommended dosing schedule with subcutaneous administration. Rare but serious toxicities associated with denosumab include osteonecrosis of the jaw, hypocalcemia, and atypical femoral fracture events, with multiple vertebral fractures reported following treatment discontinuation. After a decade of real-world clinical experience with denosumab, we are still learning about the optimal use and dosing for denosumab. Despite the emergence of novel and effective antitumor therapies, there remains a strong rationale for the clinical utility of antiresorptive therapy for SRE prevention. Ongoing studies aim to optimize clinical management of patients using denosumab for SRE prevention while maintaining safety and efficacy.

## **Common Abbreviations used in Medical Corner**

**Adverse events:** any untoward medical occurrence in a patient receiving treatment. It may or may not have a causal relationship with the treatment

**ASCT:** autologous stem cell transplantation

**BM:** bone marrow

**CA:** cytogenetic abnormality

**Consolidation:** short duration of treatment given after ASCT to intensify response

**CR:** complete response (no abnormal blood or urine myeloma markers, disappearance of any soft tissue plasmacytomas and < 5% plasma cells in BM)

**IMiD:** Immunomodulatory drug (ie lenalidomide, thalidomide, pomalidomide)

**Induction:** first line treatment after diagnosis for fast disease control with minimal toxicity

**R-ISS stage:** Revised International Staging System to stage myeloma at diagnosis (Stage 1, 2, or 3)

**Maintenance:** long term treatment given after induction +/- ASCT to maintain response from induction

**MoAB:** monoclonal antibody (ie: daratumumab, elotuzumab, isatuximab)

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

**PI:** proteasome inhibitor (ie bortezomib, carfilzomib)

**Phase 1 trial:** accrue small numbers (tens) of patients to evaluate safety (a safe dose range and identify side effects)

**Phase 2 trial:** accrue larger numbers (hundreds) of patients to determine if the study drug/s work as intended (efficacy)

**Phase 3 trial:** accrue large numbers (thousands) of patients to compare the new drug to standard of care therapy

**PR:** partial response to treatment (>50% reduction in myeloma markers)

**PD:** progressive disease (increase of > 25% from lowest response value of myeloma markers)

**Prospective study:** real time study accruing patients as they are diagnosed or relapse

**Randomised study:** Grouping patients at random to compare two or more different interventions

**Retrospective study:** one that looks back at cohorts of patients with similar characteristics

**RR/MM:** relapsed or refractory to therapy multiple myeloma

**sCR:** stringent complete response (as for CR plus normal blood light chain ratio and absence of clonal cells in bone marrow)

**Tandem transplant:** 2 ASCT performed one after the other to intensify treatment

**Triplet:** 3 drugs used in combination

**VGPR:** very good partial response (>90% reduction in myeloma markers)



# 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/>

All at Myeloma Australia are so relieved to see restrictions easing around the country and communities being able to get together in our new 'COVID-normal' environment. Where possible, our Myeloma Support Nurses are working hard to put COVID-safe plans in place to allow face-to-face get-togethers with our Information and Support Groups.

We thank everyone for their patience and for embracing the online groups via Zoom. We plan to move forward making the most of both face-to-face and online gatherings to allow as many people as possible to connect with each other and our team.

Listed below are the current locations of our Information and Support Groups being held across the country. To find out specific Zoom login details for each group, or if they are being held face-to-face, please visit our website.

**[www.myeloma.org.au/events](https://www.myeloma.org.au/events)**

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

## Information and Support Groups ACT

- Canberra
- ACT / NSW Cuppa & Catch Up

**For enquiries please contact**

**Catherine Bowley**

**E:** [catherine.bowley@myeloma.org.au](mailto:catherine.bowley@myeloma.org.au)

**M:** 0426 404 766

## Information and Support Groups National

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

**For enquiries, please contact:**

**Myeloma Support Nurses**

**E:** [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

**M:** 1800 693 566

## Information and Support Groups NSW

- Central Coast
- Liverpool
- Mid North Coast
- Nepean / Blue Mountains
- Newcastle
- NSW / ACT State Cuppa & Catch Up
- Orange
- Partners & Carers
- RPAH
- Tamworth
- Westmead
- Younger Persons

**For enquiries, please contact**

**Jacqui Keogh**

**E:** [jacqui.keogh@myeloma.org.au](mailto:jacqui.keogh@myeloma.org.au)

**M:** 0426 404 230

...continues next column

## Juliet Hill

**E:** [juliet.hill@myeloma.org.au](mailto:juliet.hill@myeloma.org.au)

**M:** 0433 511 554

## Catherine Bowley

**E:** [catherine.bowley@myeloma.org.au](mailto:catherine.bowley@myeloma.org.au)

**M:** 0426 404 766

## Diana Yun

**E:** [diana.yun@myeloma.org.au](mailto:diana.yun@myeloma.org.au)

**M:** 0452 027 765

## Tina Gordon

**E:** [tina.gordon@myeloma.org.au](mailto:tina.gordon@myeloma.org.au)

**M:** 0405 135 310

## Information and Support Groups QLD

- Gold Coast
- Inner North Brisbane
- Inner South Brisbane
- North Lakes
- Partners & Carers
- QLD State Cuppa & Catch Up
- Sunshine Coast

**For enquiries, please contact**

**Tash Clarke**

**E:** [natasha.clarke@myeloma.org.au](mailto:natasha.clarke@myeloma.org.au)

**M:** 0416 019 585

## Megan McDowell

**E:** [megan.mcdowell@myeloma.org.au](mailto:megan.mcdowell@myeloma.org.au)

**M:** 0416 019 022

## 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](mailto:tsg@nswcc.org.au)

## Information and Support Groups SA

- Partners & Carers
- Fleurieu Peninsula
- Fullarton (Central Adelaide)
- Kapunda (Mid-North)
- Marion (Southern Adelaide)
- Parra Hills (Northern Adelaide)
- South-East

**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

- Launceston
- North-West
- Southern Tasmania

**For enquiries, please contact**

**Deborah Thompson**

**E:** deborah.thompson@myeloma.org.au

**M:** 0433 511 689

## Information and Support Groups VIC

- Albury / Wodonga
- Bairnsdale
- Ballarat
- Beaumaris
- Bendigo
- Berwick
- Coburg
- Geelong
- Horsham
- Kew
- Mildura
- Mornington Peninsula
- Partners & Carers
- Portland
- Ringwood
- Shepparton
- Sunshine
- Swan Hill
- Traralgon
- VIC State Cuppa & Catch Up

...continues next column

**You can also follow us on...**



[www.facebook.com/MyelomaAustralia](https://www.facebook.com/MyelomaAustralia)



[twitter.com/MyelomaAust\\_MFA](https://twitter.com/MyelomaAust_MFA)



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



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

- Wangaratta
- Warragul
- Warrnambool
- Younger Persons

**For enquiries, please contact**

**Emma-Jane Furphy**

**E:** EJ.Furphy@myeloma.org.au

**M:** 0426 404 233

**Laura Jones**

**E:** laura.jones@myeloma.org.au

**M:** 0416 129 267

**Emma Huybens**

**E:** emma.huybens@myeloma.org.au

**M:** 0451 404 203

**Rachel McCann**

**E:** rachel.mccann@myeloma.org.au

**M:** 0433 511 606

## Information and Support Groups WA

- Bassendean
- Cottesloe
- Kalamunda
- Melville
- Partners & Carers
- Regional WA
- Rockingham
- South West
- Wanneroo
- Younger Persons

**For enquiries, please contact**

**Narelle Smith**

**E:** narelle.smith@myeloma.org.au

**M:** 0426 404 280

**Daniel Berk**

**E:** daniel.berk@myeloma.org.au

**M:** 0426 404 310

**Solution to word game on page 12**

PLEHTEAN 

E	L	E	P	H	A	N	T
---	---	---	---	---	---	---	---

3

GRETNIENTIAN 

E	N	T	E	R	T	A	I	N	I	N	G
---	---	---	---	---	---	---	---	---	---	---	---

7

LESTNI 

S	I	L	E	N	T
---	---	---	---	---	---

8

10

ATAKELLSBB 

B	A	S	K	E	T	B	A	L	L
---	---	---	---	---	---	---	---	---	---

DRSBEOBA 

A	B	S	O	R	B	E	D
---	---	---	---	---	---	---	---

2

11

LATBE 

T	A	B	L	E
---	---	---	---	---

9

6

MRMEYOY 

M	E	M	O	R	Y
---	---	---	---	---	---

5

THISYOR 

H	I	S	T	O	R	Y
---	---	---	---	---	---	---

1

LMECOTPE 

C	O	M	P	L	E	T	E
---	---	---	---	---	---	---	---

4

H	A	P	P	Y
---	---	---	---	---

E	A	S	T	E	R	!
---	---	---	---	---	---	---

1

2

3

4

5

6

7

8

9

10

11

12

# 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](http://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](mailto:nurses@myeloma.org.au) W: [www.myeloma.org.au](http://www.myeloma.org.au)**