

# MyeNews

Summer 2021 Issue no 60

Myeloma  
Australia



# Contents

## In this issue

From the President	3
Myeloma Australia National Partners and Carers Information and Support	4
38mate Recognised	5
Advocacy News	6
Brian's Story	7
Staff Profiles	9
Exercising the Brain	10
Introducing MyeConversations Podcast	11
Comments from the Community	12
What's Happening – Community Engagement and Fundraising	13
What's Happening (States)	14
News from Australasian Leukaemia & Lymphoma Group	17
News from Australasian Myeloma Research Consortium	18
MRDR	19
Medical Corner	20
Calendar of Events	22

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Design & layout: Greg Loveder Graphics  
Printed by Eastern Press

*Front cover: Victorian Nurses getting into the Christmas spirit.  
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MyeNews is supported by an unrestricted educational grant from Celgene, a Bristol Myers Squibb company



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



## From the President

**This November is my wife's 25th anniversary from when she was diagnosed with myeloma. She is really a very lucky lady as one doctor told her that she had about two or three years to live. How wrong he was.**

She is keeping very well and is proving that doctor very wrong. Even though, like most with myeloma, there are the regular visits to your treating doctor, during COVID-19 these have been by telehealth, but now we are getting back to the visits in person.

The past 20 months have been very different for us all, especially if you live in Melbourne. It has been very hard for anyone living by themselves or those with young children. Thankfully it looks as if we will slowly be getting our freedom once again. Though we are being very cautious when going out, this reminds me of the time after the stem cell transplant, being very careful to avoid getting sick.

As per my letter that went out as part of our donation drive, due to COVID-19 and an inability to hold any fundraising events, our finances were being eaten away, so thanks to all of you for digging deep in making that extra donation and for those of you now planning a fundraising event. We hope, now with the warmer weather and the reduced fear of COVID-19, all your fundraising events are very successful.

I would like to thank Ian Driver and wish him and his wife all the very best for the future. Ian was the Chairperson of Myeloma South Australia when Myeloma Australia was formed and with the merger, he joined the Myeloma

Australia Board. He has decided to stand down from the Board after our AGM in November. He has been a valuable member during this time, and he will be missed. He has always been active in the Fullarton Support Group, and he plans on continuing his role there.



I am excited by the continual advances in new therapies for myeloma. Each time the Pharmaceutical Benefits Advisory Committee (PBAC) now meets, there are applications for new myeloma treatments. Thanks to all of you who make submissions, as the PBAC take these into account. The latest change is that Daratumumab can now be given subcutaneously which means that people do not have to stay in the day wards all day as they have been doing.

I again thank our fabulous team of Myeloma Support Nurses for the work they do in the support and education of our community. We are very lucky to have such a dedicated team.

As we approach the festive season, I wish everyone all the very best and may next year be full of joy.

*Brian Rosenzarten*

## Myeloma Australia Christmas Dates

Myeloma Australia will close at midday on Thursday 23rd December 2021 and reopen at 9:00 am on Monday 10th January 2022

The Telephone Support Line will close from Thursday 23rd December 2021 and reopen on Monday 3rd January 2022

From all of us at Myeloma Australia, we thank you for your support this year and wish you all a safe and happy festive season and look forward to seeing you in 2022.



# National Partners and Carers Information and Support Group Program

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Partners and Carers of people living with myeloma form a large and important part of the Australian myeloma community. Our myeloma support nurses have been busy working on a project aimed at understanding the specific needs of carers and developing the first of many support services and resources for those in these vital roles. The first support service available will be an online Partners and Carers Information and Support Group commencing in most states and territories in early 2022. This article aims to explain the steps the myeloma support nurses took to better understand the experiences and support needs of partners and carers in the myeloma community, and how this informed the development of the National Partner and Carers Information and Support Group program.

Myeloma Australia is known for providing support, information and education through its many services delivered to the Australian myeloma community. These services and supports are available to people living with myeloma, their loved ones and health care professionals. However, as an organisation, we were aware that the needs of partners and carers of people living with myeloma are unique and different to those of the person living with the disease. Carers are often present for a lot of the challenging and difficult times that someone who has myeloma experiences, leading to feeling helpless or experiencing high levels of distress. They often have practical and emotional

unmet needs and, experience coping difficulties that at times may exceed the challenges faced by the person living with myeloma themselves.

The Myeloma Support Nurses planned to understand the needs of partners and carers by asking them about their experiences. A survey was sent to the Myeloma Australia database inviting people who identified themselves as a carer take part. Demographic information and the length of time respondents had been in a partner or carer role was collected. The survey also explored the feelings and experiences of being a carer, aiming to identify any specific unmet needs and preference for a carer specific information and support group was established.

There was an overwhelming response to the survey with 147 completed surveys nationally. Geographically, 60% of respondents lived in metropolitan areas and 40% were residing regionally. The largest percentage of respondents had been in a caring role for more than five years and more than 70% expressed interest in attending a carer specific support group. Survey results indicated that partners and carers were equally interested in either a face-to-face or online support group.

Due to COVID-19 restrictions, initial support groups will be offered using an online format. We anticipate there may be the opportunity to offer these groups in a face-to-face format in the future.

Responses from the survey provided some insight into the experience of being a carer for someone living with myeloma and how respondents felt about being in the caring role. When asked to list some words to describe how it felt to be a carer, there were clear themes shared. Some words expressed the challenging aspects of the role, such as worried, sad, exhausted and helpless. Positive words such as privileged, loving, caring, hopeful and grateful also featured, highlighting the complexity of the caring role.

The survey asked further questions about what carers might expect to gain from attending a carer specific support group. Some frequently expressed expectations included gaining information, support, understanding and sharing experiences. One carer shared, "at times I felt overwhelmed due to fatigue. We had no family support throughout that process, and it would have been good to have someone who touched base with me on odd occasions, especially someone who understood the journey".

Pilot online Partner and Carers Information and Support Groups were held in Western Australia and South Australia.





Based on feedback from participants, it was clear that not all participants see themselves as a 'carer' and the suggestion to change the name to partner and carers group was important to acknowledge the varying and changeable nature of the role.

The pilot groups were facilitated by at least two Myeloma Support Nurses with input from a pastoral carer within the myeloma community, who is also a partner of someone living with myeloma and an experienced support group facilitator. These pilot groups were held every two months and ran for two hours. There were small numbers of attendees, allowing time for each group member to share their experiences and connect with each other. There was also the opportunity for partners and carers to speak one on one with a facilitator at the end of each group about concerns raised during the session.

The pilot support groups were evaluated by group members and facilitators following each meeting and at the completion of the pilot phase. One attendee shared his experience of attending one of the support groups;

"I didn't go with much expectation other than a hope to share the experience of our journey, but I received so much more [including] understanding, empathy and practical knowledge and hope".

Myeloma Australia's support nurses in all states are looking forward to adding these groups to their existing information and support group program.

Myeloma Australia is also working on developing further resources and support services for partners and carers. Based on feedback from our surveys and support groups, a resource page for carers will be added to our website and there are plans for carer specific seminars and wellness events.

If you are a partner or carer of someone who is living with myeloma, get in touch with your local myeloma support nurse about a partner and carer specific Information and Support Group in your area.



## RECOGNISED

We are so excited and honoured to announce that Myeloma Australia has received the 'Most Outstanding Patients Campaign' award for the inaugural 38mate awareness campaign!

On 3rd December 2021 the Australian Patients Association held their annual awards night for the health sector. The awards are based on nominations by patients and their families throughout Australia, making the award even more special to us.

We would like to thank you all for supporting the 38mate awareness campaign and thank the Australian Patients Association for recognising our efforts in raising awareness of myeloma and the 38mates that are diagnosed each week in Australia.

We look forward to continuing to raise awareness and supporting those living with myeloma and their loved ones.

*Marlene Katz (Board Member of APA – Australian Patients Association), presenting award to Steve Roach accepting on behalf of Myeloma Australia.*



### Meet Henry

Henry became a 38mate in 2015



"I don't want others to go through what my family and I went through. Hearing about myeloma for the very first time when you're diagnosed."

### Meet Natalie

Natalie became a 38mate in 2016



"Being a mum of two young boys I was really overwhelmed and scared. I knew if this was going to be my life I needed to focus on all the good stuff I already had as a base."

### Meet Kiri

Kiri became a 38mate in 2019



"I have learnt that through sheer strength, determination, amazing medicine and a very positive mindset you can surprise yourself with how strong you really are when faced with adversity!"

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.

### Pharmaceutical Benefits Scheme (PBS) Update

On November 1st 2021, daratumumab was listed for reimbursement on the PBS as a subcutaneous (SC) injection (into the skin). This is in addition to the already available intravenous (IV) infusion that can be given at first relapse in combination with Velcade and dexamethasone. Giving daratumumab via SC injection reduces the chance of an infusion related reaction and the time of administration is only five mins compared to at least four hours for the IV infusion.

### Global Myeloma Action Network (GMAN) Summit: 25th and 26th September 2021

Four members of the Myeloma Australia team attended the 2021 Global Myeloma Action Network (GMAN) Summit which was held virtually for another year running. With members from over 30 countries, it was a fantastic opportunity to meet with members of the global myeloma communities and myeloma support organisations. As always, the agenda was packed full of inspiring and interesting presentations from around the globe.

After a warm welcome from International Myeloma Foundation (IMF) CEO Susie Durie, Sedar Erdogan (IMF Europe and Middle East) gave us an overview of the 2021 Myeloma Action Month (MAM) advocacy campaign, it was wonderful to hear that collectively the campaign reached 25 million people, raising awareness of myeloma across 36 countries. Keep an eye out for the 2022 campaign in March next year!

We heard from our friends from Armenia and Argentina present about their projects initiating new and inventive ways to provide support to their myeloma communities during the COVID-19 pandemic. The Argentinian group implemented a transport reimbursement program for people with myeloma who would usually take public transport to and from hospital appointments, allowing them to take a taxi or car and maintain safe social distancing. The Armenian group implemented a national telehealth program for people with myeloma which was endorsed by the ministry



of health. They also arranged and sent PPE to people with myeloma and hospital staff when national supplies were limited due to the pandemic. Two examples of the amazing work these organisations do every day to support people with myeloma in their respective countries.

As always, Dr Brian Durie and other members of the International Myeloma Working Group (IMWG) gave informative presentations about the latest research and breakthroughs presented at the recent conferences and meetings. From The University of Iceland, Dr Sigurdur Kristinnsson presented the iStopMM project which is an interesting large screening study aiming to prevent myeloma developing. It is doing this by looking at the blood samples of 80,000 adults to identify the earliest signs of myeloma; monoclonal gammopathy of undetermined significance (MGUS) and smouldering myeloma. Those identified are then offered the opportunity to participate in a trial to establish the best strategy for treatment and monitoring. If you would like to learn more about this study please go to <https://www.myeloma.org/black-swan-research-initiative/istopmm>

If you would like to be involved in any of our advocacy programs, please contact [advocacy@myeloma.org.au](mailto:advocacy@myeloma.org.au)





### Before I knew multiple myeloma even existed!



That's me on the right, many years ago, before multiple myeloma. My name is Brian, and I was born in England in 1946. At 15 I left school and started a four-year apprenticeship as an electrician, then at 17 I emigrated with my family to New Zealand and completed the last two years of my apprenticeship there. I went on to become a motor mechanic but after a few years I was ready for a more exciting challenge. I had always wanted to fly, and by chance, while in Te Anau, the local aero club was advertising for people to try for their pilots licence. I didn't know how I was going to fund it, other than through hard work to pay for it all, but I did. I took my private pilots licence on fixed-wing aircraft to help with deer hunting in the mountains of the South Island, New Zealand. Later, I moved to Sydney and divided my time between working as a mechanic and towing gliders from a nearby airfield. I really wanted to buy my own plane, but realised I would never be able to afford one. So instead, I decided to use the money I'd saved to take out a commercial helicopter licence, returning to New Zealand to do this.

As a helicopter pilot I first worked on some of the outback stations in New Zealand and then moved to the top end of Australia. I was employed by a charter company in Darwin which specialised in aerial buffalo mustering. It is similar to mustering with a horse, but in a helicopter you can climb high enough to see the whole of the mob and see leads among the cattle developing much more easily than the stockmen on the ground can. You also need to be able to understand the animals' psychology, especially if you are working the cattle by yourself.

Whilst working in the Top End, I got the opportunity to meet Kerry and Jamie Packer and fly them into Arnhem Land. Another time I met the comedian Dave Allen (see photo above). I flew Dave out to the Bungle Bungles, orange and black rock formations likened to giant beehives in the Kimberley, Western Australia. Being Dave Allen and always the joker, he commented, "Aptly named because God made a bungle bungle."

I have only ever had one accident in all my hours of professional flying and that was when I had a mechanical failure in New Zealand and the helicopter fell into the side of a mountain. I scrambled out, then watched the machine roll 200 metres downhill.

After mustering and living in Darwin for 15 years, my wife Cathy and I decided to move to Tasmania. This was in 1993. Before doing so, we sold everything and cycled for six months through Alaska, British Columbia and down the west coast of America. What an incredible trip, and we managed to do it pretty cheaply by taking our own tents and camping gear along.



*A younger version of me beside my helicopter.*

Moving to Tasmania was a complete change. I no longer wanted to fly helicopters and was looking for something different. I saw 'Tassie Cycles', a bike shop, for sale. I thought, "Well I kind of know a thing or two about bikes having spent six months on the road on one", so I mustered up the courage and became a bike shop owner, helped along by the existing young mechanic already working there. It was probably the only bike shop in Hobart where you would find the owner playing a guitar between jobs. My first band was formed in that bike shop. People would come in and say they played the drums etc. and voilà. We would practice in the shop's basement. Although I loved being a bike shop operator, after 15 years (and cycling around Tasmania three times) I decided to sell and retire.

Retirement was good. I was playing guitar in, and still am, a band called '3 Floorz Up', but then came the biggest challenge of my life. I remember I was working on a car at the time when I got severe pains in the middle of my back which didn't go away. I firstly saw a chiropractor which only made the pain worse. My GP ordered x-rays and saw 'cracks'



*Flying 'Swamp Dog' (name I gave the helicopter).*


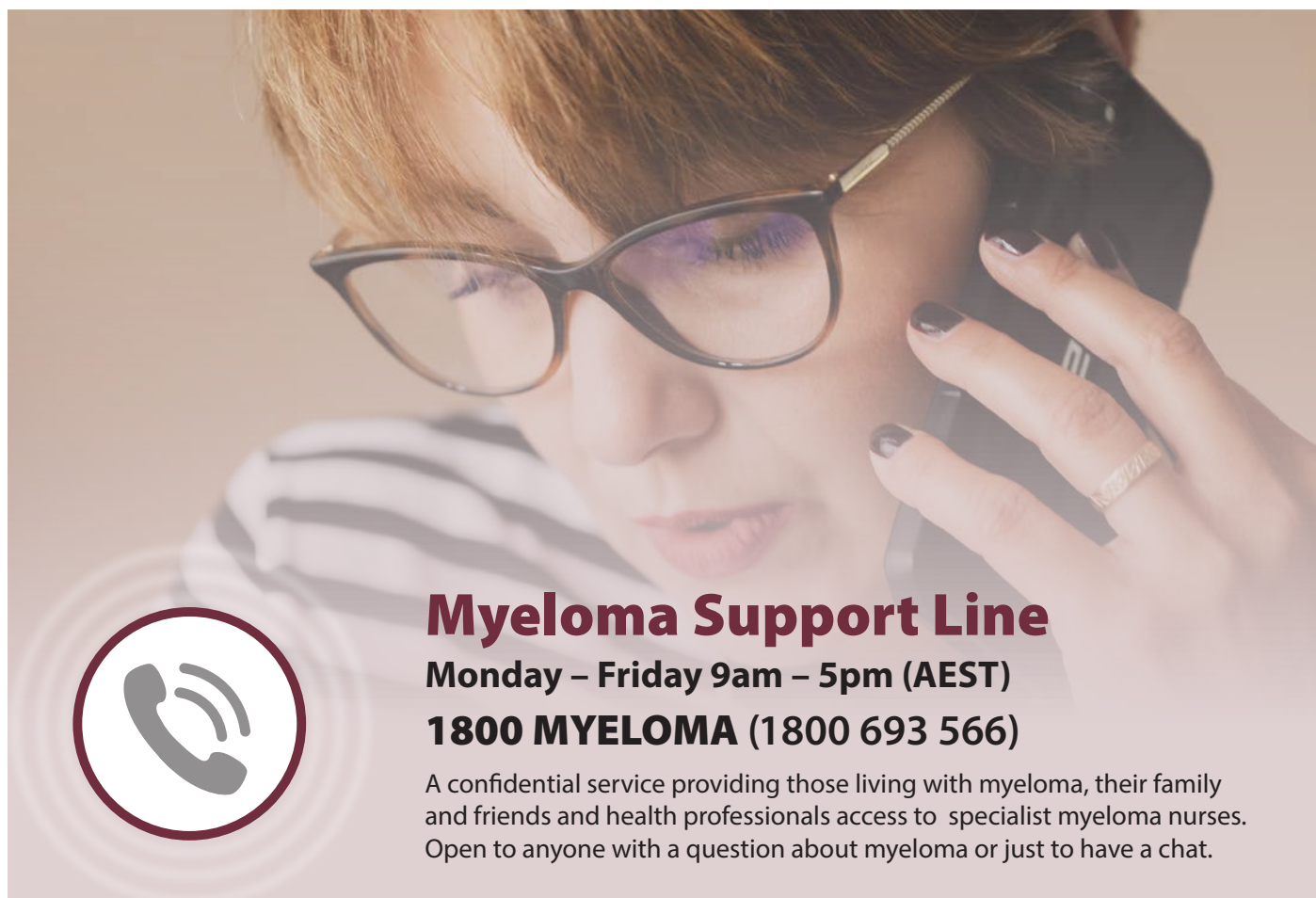
in my spine. I was referred to the Royal Hobart Hospital and after more tests and scans I was diagnosed with multiple myeloma. That was in August 2018. At the time I remember thinking, "Well I've had a great life and you hear about cancer all the time, why not me?" It didn't stop me feeling dejected and hopeless though. Fortunately help came in the form of great doctors and nurses like my GP Dr Roffe, my haematologist Dr Nick Murphy and Deborah Thompson, a haematology and myeloma support nurse, who introduced me to a support group. My outlook soon changed. I am so grateful today to these people and everyone else who has seen me through my diagnosis.

I am now 75 and living a pretty healthy, happy life. I had a stem cell transplant two and a half years ago and fortunately things are stable. I've seen some of the world and life has given me some great opportunities and adventures. I thoroughly enjoy playing with mates in '3 Floorz Up'. We play a range of pop, dance and country & western music at local venues around Hobart. Cathy and I get to spend quality time at our shack at Lake Sorell, in Tasmania's central highlands. And last, but certainly not least, I enjoy catching up with, and having the support of others with myeloma, at the regular groups held here in Hobart.

*Brian Mansfield  
Hobart*



3 Floorz Up.



## **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.



## Staff Profiles

### Deb Cutts

#### Relationship Manager Philanthropy

Deb Cutts has joined the Fundraising Team as the Relationship Manager Philanthropy to engage with trusts and foundations, major donors and develop corporate partnerships.

Deb has worked in the not-for-profit market for the past 30 years. After completing a science degree majoring in pharmacology, she worked with an international pharmaceutical company in medical education and clinical research. A career change from the corporate sector to a community agency opened opportunities in media, communication, grant writing, education, and fundraising. Deb worked in women's health for 15 years and then she was approached by the Prostate Cancer Foundation of Australia (PCFA).

There are numerous synergies between Myeloma Australia and PCFA including the need to raise awareness, an active network of support groups, telephone support and online resources. Whilst at PCFA, with support from the key clinicians Deb supported the set-up of a National Scientific Advisory Committee (SAC) very similar in purpose to MSAG (Medical & Scientific Advisory Group).

Photo © Matt Maudlin



After a few years at Walter and Eliza Hall Institute of Medical Research, Deb ran fundraising at the Eye and Ear Hospital. Deb is very excited to join the Myeloma Australia Team and looks forward to meeting the myeloma family.

### Tina Gordon

#### Myeloma Support Nurse in Newcastle

Hello, my name is Tina Gordon and I am the new Myeloma Support Nurse in Newcastle working alongside Juliet Hill. I have been a haematology nurse at Calvary Mater Newcastle for 18 years. I work in the inpatient ward and the outpatient unit and am also an apheresis operator. In my time at the Mater, I have cared for many people living with myeloma and their families. What interests me most about myeloma is the vast array of treatment options available in this area. I look forward to supporting and connecting with the myeloma community and am very eager to learn from the highly skilled Myeloma Australia team.

Outside of work, I enjoy travelling (pre-COVID), catching up with family and friends and spending time outdoors with my 5-year-old son. On a day off you'll find me supporting one of the local coffee shops and following my son on a scooter, bike or skateboard adventure in beautiful Newcastle. He's starting kindergarten in a few months – we're all very excited but anxiously hoping home schooling is a thing of the past by then.

I am excited to have been given the opportunity to work for Myeloma Australia and continue to strengthen relationships

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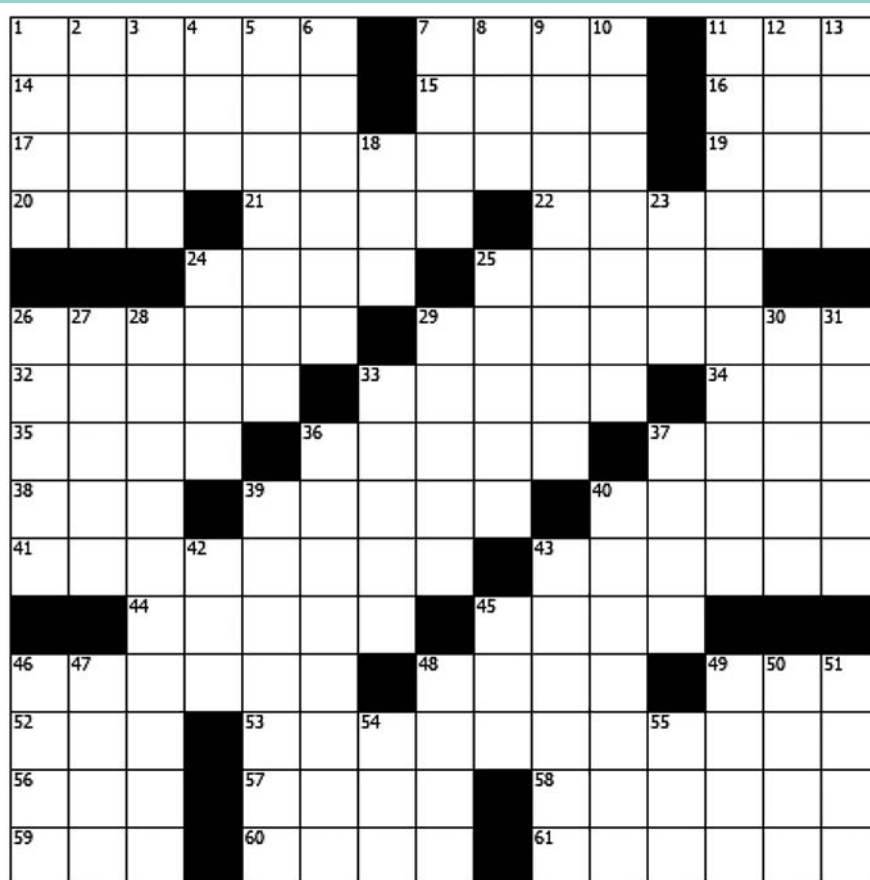


with the myeloma community. Please feel free to get in touch and let me know if there is anything we can do to further support your journey.

# 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.



## ACROSS

1. Book copier of old
7. Poet laureate Nicholas
11. Numbers person
14. Where gladiators performed
15. Bank offerings, for short
16. Was published
17. Read them and giggle
19. Op or pop
20. Abbr. after a telephone number
21. Finish finish?
22. Japanese battle cry in WWII
24. Kind of organ
25. -night (unscrupulous)
26. Hero of a Virgil epic
29. Word with knee or riding
32. Rough-mannered
33. TV pioneer, John Logie ---
34. Touted sort of bran
35. "Gilligan's Island" constructions

36. Teaspoonfuls, sometimes
37. Jason's boat
38. Suitable to the occasion
39. Jockey's wear
40. One deep in thought
41. Some beauty parlor employees
43. Napoleon locale
44. Office subs
45. Is repentant
46. You'll get a face full of it on a cruise
48. Billions of years, geologically
49. Petal-plucker's word
52. "Deck the Halls" words
53. Partner of Merrie Melodies
56. Biblical verb ending
57. Tel---
58. Adversaries in Risk
59. Litmus, essentially
60. Count (on)
61. Bottle cap?

## DOWN

1. Sound's partner
2. Vital point
3. Popular Broadway musical
4. Quaint hotel
5. Cookery seasoning
6. Catches sight of
7. Opportune
8. Assayer's specimen
9. Singing birds
10. Put to the test
11. Revered Sioux chief
12. Legal lead-in
13. Start to freeze
18. "Tea--- Sympathy"
23. Seinfeld network
24. Arbiters of plays
25. Sautes
26. Turkish military leaders
27. Explode
28. Peanut brittle has it
29. Soaks up the sun
30. Like a beaver
31. News feature
33. Frankenstein monster features
36. Refute
37. Web-footed diving birds
39. Alike
40. Toscanini and Iturbi
42. This may be turned into a golf course
43. He had a blue ox
45. Lobster eggs
46. Luge, for one
47. Crossword category
48. Object of desire?
49. Scissors cut
50. Callous cad
51. Latin for to be
54. Change it regularly
55. He keeps a clean plate

answers on page 23



## Introducing MyeConversations Podcast

During lockdown we have been busy working on a brand-new resource for people living with myeloma, their family and friends. We are so excited to announce our new podcast show - MyeConversations. In these podcasts, Myeloma Australia's support nurses chat to people living with myeloma, interview experts in the field and deliver educational material on elements of this often-confusing blood disorder. These podcasts aim to support, inform and empower those living with myeloma, their families, friends and health care professionals. If you have a particular topic that you would like discussed, please email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

The first episode of MyeConversations will be available very soon on all major podcast platforms and on the Myeloma Australia website. Each new episode will then be released every month for you to listen to at your own convenience.

Some of the platforms you will find MyeConversations on include:

Apple Podcasts, Spotify, Google Podcasts, Stitcher, iHeartRadio, TuneIn, Alexa, Overcast, PocketCasts, Castro, Castbox, and Podchaser.

To download any of these apps to your smartphone please visit:

**Android:** [play.google.com/store/apps](https://play.google.com/store/apps);

**Apple:** [www.apple.com/au/app-store/](https://www.apple.com/au/app-store/)



Whilst the advice and opinions of our guests is welcomed these podcasts provide general information and are not intended to replace medical care or the advice of your treating team. Please talk to your doctor if you have any questions about your diagnosis or treatment. Your doctor can answer your questions, talk with you about your treatment goals, and provide you with extra support.

Please share this exciting new resource  
with your family and friends.

## Daratumumab (Darzalex®) Treatment

We have been receiving lots of questions from people who are about to start treatment with daratumumab.

***Our Myeloma Support Nurses are ready and waiting to provide you with information and support.***



**Please contact us via our Telephone Support Line – 1800 693 566  
or email – [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au) to learn more.**



## COMMENTS from the Community

We always appreciate hearing from the myeloma community. Whether the feedback is good or bad, we take it seriously and use it as an opportunity to improve our services. Here are a few of the lovely comments we have received recently. If you have some feedback for Myeloma Australia, please send it through to email: [support@myeloma.org.au](mailto:support@myeloma.org.au) or phone: (03) 9428 7444.

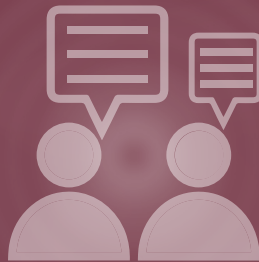
*"Our WA nurses (Narelle & Daniel) are amazing people and extremely dedicated and generous with their knowledge and time. I can't thank them enough."*

*"Please continue your wonderful support of the myeloma community. Together with so many others, I really value and appreciate it."*

*"My husband had myeloma for 15 years and your organisation was a great support"*

*"Everything I have learnt or know about myeloma is because of Myeloma Australia."*

*"You do the most wonderful job of providing support through your nurses. When my husband was diagnosed with myeloma at first the nurses were an absolute lifeline and still are."*



*"It was lovely meeting you and listening to someone who is so very intelligent and well versed in multiple myeloma. Meeting other people (in support groups) living with myeloma and hearing their stories was very helpful too. If you are able, I would like you to pass on my thanks to them as well."*

*"To all at Myeloma Australia  
– Love your work!!!"*

*"The nurses are so amazing; the resources are fantastic and the support groups too."*

*"Keep up the great work!!! You guys are amazing. My wife was diagnosed 11 years ago and is still in complete remission, so we have a lot to be thankful for. You have been a great source of information over the years for us and continue to be so."*

*"Just a brief note to thank you very much for organising and giving your time up for the Zoom chat today. It is wonderful that you do this, we found it very interesting not only to hear of the situation others are in, but to hear your comments in response to the various questions. Most informative."*



## What's Happening

### Community Engagement & Fundraising

It has been quite wonderful to watch and work alongside members of the myeloma community as they have rallied around the 38mate Fundraising Appeal over the past couple of months. We have seen SUCH creativity, bravery and enthusiasm deployed as community members have got busy raising much needed funds for Myeloma Australia. To all of you who supported or participated in any number of these events which included runs, bike rides, hair and beard cuts, baking, triathlon, DJing, dinners, other social gatherings, walks, raffles, toenail painting and 38mate cap wearing... THANK YOU!

We have recently launched the sale of raffle tickets for the People's Choice Community Lottery. The draw for this raffle is 3rd March 2022. Each and every cent of the \$2.00 cost of each ticket sold from this site comes to Myeloma Australia: <https://myeloma.org.au/fundraise-for-us/peoples-choice-community-lottery/>

In addition to the raffle, our well-established fundraising projects of The Entertainment Book and Containers for Change continue to raise funds for us too.

Now a date for your diary! The next iteration of 38mate occurs on Sunday 27th February 2022. On this day we are encouraging the myeloma community nationwide to gather for The Myeloma Australia '3.8 with a mate' walk. In short, the 3.8 is an awareness and fundraising event in which we are encouraging members of the myeloma community to walk (although other activities are encouraged too!) 3.8km together as a local community to raise awareness of myeloma, build community with one another and raise funds for Myeloma Australia. We are keen for walks to be held in as many cities, towns and regions around Australia as possible! If you are keen

to organise a walk for the myeloma community where you live, do please reach out to me!

Our fundraising team recently welcomed Deb Cutts as our Relationship Manager, Philanthropy, Major Gifts and Corporate Giving. Deb joins us with a wealth of experience in the charitable sector and it's wonderful to have her join Myeloma Australia.

Rob in our NSW Community Engagement & Fundraising Executive in Sydney, is continuing his great work and I know that Rob is keen to hear from any folks in NSW with community building and fundraising ideas; do please reach out to him: [robert.obrien@myeloma.org.au](mailto:robert.obrien@myeloma.org.au)

And finally, as always, do please reach out to me (and to Rob if you're in NSW, ACT, QLD or NT) with your community engagement & fundraising ideas. We are here to help, and love helping you establish successful events.

It is fair to say that 2021 has been a challenging year on the community engagement & fundraising side of the Myeloma Australia operation. Yet despite the difficulties, it has been so encouraging to see members of our community continuing to reach out to me with their fundraising ideas and to see these ideas become reality. Rob and I are greatly looking forward to all that 2022 holds on the community engagement & fundraising front!

I wish you and yours a safe, happy and healthy holiday season and I very much look forward to touching base with you all in early 2022.



Matt Maudlin

Community Engagement & Fundraising Manager  
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## COMMUNITY LOTTERY

**Ticket sales close 24th Feb**

**100% of ticket sales come to  
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Prizes:

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**People's Choice**

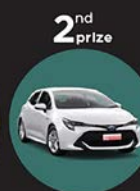
COMMUNITY LOTTERY

## COMMUNITY LOTTERY

**Tickets  
\$2  
each**



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(RRP \$59,537)



Toyota Corolla  
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(RRP \$31,610)



Harvey Norman  
Grand Home Package  
(RRP \$25,330)



## New South Wales/Australian Capital Territory

With Christmas rapidly approaching, we are busy planning Christmas catch ups for a few of our support groups. Invites will be sent out once details are finalised. We have welcomed a new member to our NSW team – Tina Gordon. She started four weeks ago and will work with Juliet in Newcastle. We are excited to have her on board and cannot wait for you all to meet her! In October Juliet and Nella hosted Myeloma Australia's first online Smouldering Myeloma Q&A event with Dr Wojt Janowski who is a haematologist based at Calvary Mater in Newcastle. The event was well received, with plans to start a support group for the smouldering myeloma community.



Cath at the beach  
with her 38-mate hat

We will continue to run our support groups online and the fortnightly telephone support groups for the rest of 2021 to stay connected with the myeloma community. The state-wide NSW cuppa and catch ups on Zoom will continue till the end of 2021 and will be reviewed for 2022. The state – wide cuppa and catch ups are held on the last Thursday of the month, so come join us for a chat with people living with myeloma from all around the state. With COVID 19 restrictions easing, we aim to resume face to face support groups in 2022.

Our NSW team will be meeting up soon to discuss and plan for 2022. We will be planning projects and events, and finalising seminar content for next year. Please contact us if you have any ideas or suggestions of topics or areas of interest.

Stay safe and relax at the beach when the weather warms up.

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



## Queensland

At this stage we plan on getting back to normal with face-to-face groups while keeping our fingers crossed that COVID doesn't get in the way. While we really want to get back to seeing one another in person, we also want to keep our vulnerable community safe so watch this space.

Thank you to all of those who joined us online for our 3rd Clinical Workshop. We were lucky enough in Brisbane to set up a "Base Camp" in our new office. We were joined by our local MSAG member Dr Nick Weber. Nick was very busy all day switching between our patient seminar and chairing the health professional meeting being held concurrently. We had 100's of attendees to both events in the comfort of their own homes.



Townsville © Danny Poole



Nicholas Weber

Tash had the pleasure of visiting Townsville in October for a health professional education session on myeloma. She had a great chance to meet with the fabulous team from haematology in Far North Queensland. She met with Jodi Marsh the Haematology Nurse Practitioner at Townsville University Hospital, Dr Hock Chai, Director of Haematology as well as other key nurses and practitioners. We look forward to further cementing our relationship with our North Queensland myeloma members with the hope to start support groups locally in 2022 (COVID willing!).

*Megan McDowell and Tash Clarke*  
Myeloma Support Nurses QLD





## South Australia/Northern Territory

It's been a busy few months since our last report. Due to the challenges of COVID it has been two years since one of our team was able to go to Darwin. In September Alicia was successfully able to cross the border, avoid visiting the Howard Springs quarantine facility and run support groups and healthcare professional education sessions in Darwin. It was wonderful to

finally have a physical presence in the NT and we are hopeful that more regular visits can occur in 2022 and beyond. In addition, Jo and Alicia have continued to engage their nursing colleagues in myeloma education sessions in hospitals across SA and the NT.



*Fleurieu Peninsula SG meeting*

Our SA support groups have also continued to be well-attended and it's pleasing to see that members are enjoying having the choice of attending in person or via Zoom. We have had a focus on physical and practical support recently for our members, with excellent and engaging presentations from physiotherapists Glenys Williams and Chelsey Rothall at the Victor Harbor and South-East support groups respectively. Occupational therapist, Jess Church also attended the Northern Adelaide group to discuss practical ways to stay independent in the home. We appreciate the time and support of Dr Akash Kalro (haematologist) who finished off our year on a high note with his presentation at the final Fullarton meeting, talking about the new PBS drugs for myeloma treatment.

Wishing everyone a safe and happy holiday season, we look forward to seeing you all in 2022.

*Alicia Hopper & Jo Gardiner  
Myeloma Support Nurses*



*Alicia presenting Darwin*



## Tasmania

We've been having some terrific face-to-face groups here in Tasmania. In September, Dr Anna Johnston talked about managing bone disease and transplants in myeloma.

It was a very relaxed, round the table chat, and we had a great turn-out to hear Anna.

David Carter, a manager of physiotherapy services in the northwest, spoke at the Burnie Support Group (SG) in October. He spoke at length about the importance of exercise, the benefits, and how best to incorporate it into our daily routine, being mindful of fatigue and other symptoms those with myeloma can experience.

Unfortunately, we were not able to hold the Launceston support group at the Cancer Support Centre in October due to flooding, so instead we met at the Apricus Café in Norwood (see photo). What a lovely setting it was too; with a small lake, loads of birdlife and 'Old McDonalds Farm'. It was also wonderful to welcome new members.



*The Launceston SG at Apricus Cafe Norwood*

In southern Tasmania, End of Life Doula, Tracey Rusden and Bec Lyons, spoke at the meeting about the help & assistance they can provide to ensure our end-of-life wishes are carried out, working closely with the medical team, allied health and other health practitioners involved in a person's care. The talk included information on 'Daisy Boxes' and 'Peace Pods', which are brand names of cardboard coffins, the latter made here in Tasmania, which can be made up like any cardboard box (and obviously much cheaper than a traditional coffin)!

Our fundraiser for the '38mate, 3.8 with a mate' campaign on Sunday February 27th next year will be a walk at Risdon Dam followed by a picnic. Everyone is welcome and encouraged to bring family members and friends along

*Deborah Thompson  
Myeloma Support Nurse*

# What's Happening



## Victoria

Finally, freedom came and Victoria was out of lockdown after a long three months! We cannot wait to see you at our seminars and information and support groups in 2022.

The most recent topics we have covered in our information and support groups focused on; 'Chemo Brain' cognition and cancer and fatigue which brought about a lot of conversation around personal experiences and management strategies. We are always amazed at the support and information you provide each other, we as nurses learn too from your experience!

Our national younger persons support group enjoyed, guest speaker Cara Woods from Camp Quality, an amazing organisation supporting children of families affected by cancer. If you would like information on their services, please visit: [www.campquality.org.au/](http://www.campquality.org.au/) Our next group will be held in December with guest speakers from CANTEEN.

In late November we held the annual La Trobe Myeloma Update, led by Professor Miles Prince. This was again delivered online nationally. Professor Prince gave a clear and informative overview of myeloma and updated us on current and future treatments. We had great questions from the audience in the Q&A session. If you missed out on the seminar it is available for playback on our website.

We have continued to run online healthcare professional education for the staff at Epworth Richmond, Hamilton, Portland and Albury Wodonga Hospitals.

Next year we will be launching a new support group for partners and carers of people living with myeloma. If you would like to express your interest in joining the group please reach out via email or phone one of the Victorian support nurses.

We look forward to catching up with the members of the myeloma community and wish you all a Merry Christmas and Happy New Year with plenty of much needed time with loved ones.

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



Victoria Nurses



## Western Australia

A lot has been happening in WA for the myeloma community as we have been

lucky enough to hold most of our events face to face. We held an information morning at the end of August where Consultant Haematologist Dr Collin Chin spoke about breakthrough therapies for myeloma from a WA perspective and Dr Carolyn McIntyre shared an in-depth presentation on the hot topic of exercise as medicine.



Throughout October, Daniel was busy sharing his myeloma nursing expertise at several health sites in the Perth metro area as well as presenting some education to the new haematology nursing team in the Midwest. Daniel and Narelle are planning to travel to Geraldton to provide further health professional education and information and support to the myeloma community in the first half of 2022. Get in contact with Daniel or Narelle if you would like further information.

The primary topic for our information and support groups has recently been focusing on bones and myeloma bone disease and Daniel shared a fantastic interactive presentation to groups online and face to face. Our next series of support groups will be focusing on managing fatigue so come along and learn some coping strategies.

Our final seminar for 2021 will be held on 29th November in Cottesloe and we have Consultant Radiologist Dr Vidisha Viadva presenting on imaging techniques in myeloma and Dr Brad Augustson will be back to answer any of your questions about tests, investigations and imaging at different stages of myeloma diagnosis and treatment.

*Narelle Smith and Daniel Berk – Myeloma Support Nurses*



Dr Carolyn McIntyre



# 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.

## ALLG Clinical Trials

### Current Myeloma Trials

#### MM22 – Leading doctor Professor Andrew Spencer

The FRail-M trial is evaluating the most appropriate treatments for patients with newly diagnosed, transplant-ineligible multiple myeloma, taking into consideration patient frailty/weakness and with the aim of reducing toxicity. This is an early phase randomised study that will recruit 300 patients across Australia and New Zealand. ALLG is thankful to the Australian Government's Medical Research Future Fund for funding to run this trial.

Recruiting Hospitals –

VIC – Alfred Hospital, Latrobe Regional Hospital, Sunshine Hospital;  
NSW – Calvary Mater Newcastle, Nepean Hospital, Concord Hospital, Tamworth Hospital;  
QLD – Princess Alexandra Hospital, Townsville Hospital, Sunshine Coast University Hospital, Toowoomba Hospital;  
SA – Royal Adelaide Hospital, The Queen Elizabeth Hospital;  
TAS – Royal Hobart Hospital;  
NT – Royal Darwin Hospital.



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

#### MM23 – Leading doctor Associate Professor Hang Quach

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 patients with newly diagnosed multiple myeloma.

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

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

#### MM24 – Leading doctor Dr Simon Gibbs

This is an international Amyloidosis trial, in collaboration with the French Myeloma Group IFM. It will evaluate a new treatment for relapsed/refractory amyloid patients at 4 sites across Australia – Box Hill Hospital VIC, Princess Alexandra Hospital QLD, Royal Adelaide Hospital SA and Fiona Stanley Hospital WA. ALLG is proud to bring this important international trial to Australian patients. We are working closely with our French colleagues and aiming to open MM24 in Australia in late 2021/early 2022.

## 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.



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

For more information contact Matt Maudlin  
Community Engagement & Fundraising Manager  
E: [matt.maudlin@myeloma.org.au](mailto:matt.maudlin@myeloma.org.au) • M: 0407 891 052



# News from Australasian Myeloma Research Consortium (AMaRC)

AMaRC has opened several new sites across our recruiting studies (see below), as well as opening a new study for recruitment, DVd PRO. Additionally, BelaCarD has now moved into Phase II and is actively recruiting across 3 states. We continue to look forward to the development of new projects, a few of which we anticipate opening in the new 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
- o NSW – Concord Hospital, Nepean Cancer Care Centre, Tamworth Hospital, Calvary Mater Hospital
- o QLD – Princess Alexandra Hospital, Sunshine Coast University Hospital, Townsville 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 (**new**), North Shore 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 (new)
- o SA – Flinders Medical Centre
- o TAS – Royal Hobart Hospital, Launceston General Hospital
- o WA – Fiona Stanley Hospital
- o QLD – Toowoomba 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 – 2 new site**

- o VIC – Alfred Hospital, St Vincent's Hospital, Geelong Hospital
- o NSW – St Vincent's Hospital
- o SA – Flinders Medical Center (new), Royal Adelaide 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 – 1 new site**

- o VIC – Alfred Hospital (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 next few months 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.amarconline.org](http://www.amarconline.org) **Email:** [amarc@alfred.org.au](mailto:amarc@alfred.org.au) **Twitter:** [@amarconline](https://twitter.com/amarconline)



**Coming soon to all your favourite  
podcast platforms or go to  
[www.myeloma.org.au](http://www.myeloma.org.au)**



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

The MRDR now has over 4900 patients registered and 55 approved sites. The latest site to receive approval to participate in the MRDR and M1000 Biobank is Ballarat Hospital. A big thank you to patients and staff at participating sites for your continued support.

Our annual Investigator Meeting was held on September 23<sup>rd</sup> providing an overview of the latest data, and registry progress. Current projects were presented, with Professor Joy Ho comparing patients diagnosed with the new 'biomarker' criteria for multiple myeloma (MM) to those diagnosed with the traditional organ damage criteria. Dr Khai Li Chai described the variation in use of immunoglobulin in patients with MM, and Dr Kate Vandyke presented progress on identifying a marker of high risk for progression from smouldering to active myeloma. To



Presenters at the MRDR Investigator meeting

close, Naomi Aoki gave an update on activities of the Asia-Pacific MRDR. The meeting highlighted the maturity of MRDR data and the relevant research that the registry enables.

The Myeloma 1000 biobank is growing, and now has samples for over 540 patients. This is a substudy of the MRDR aiming to collect blood samples from 1000 patients with MM and 1000 with MGUS. Another M1000 biomarker proposal was recently approved - it's pleasing to see the biobank data in use.

AL amyloidosis has recently been added as a diagnosis on the MRDR, and we now collect whether participants have a family history of plasma cell dyscrasias. These updates help the registry to better reflect myeloma and related diseases in Australia and New Zealand.

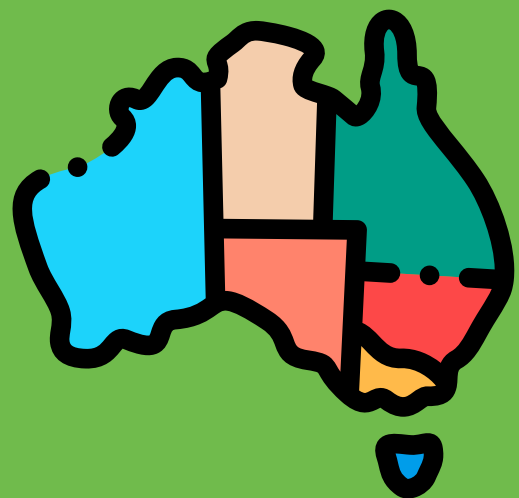
*If you are interested in participating in the registry, ask your treating specialist if your hospital contributes data to the MRDR and if you are eligible to participate. If so, you will receive information about the registry including how to opt out if you change your mind.*

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)



## People across Australia, we need you!

Today we are asking you to show your support by donating to, or fundraising for, the 38mate Fundraising Appeal.



Donate today or learn how you can start your own fundraising event  
[www.myeloma.org.au/38mate](http://www.myeloma.org.au/38mate) | [www.myeloma.org.au/donate](http://www.myeloma.org.au/donate)



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.

**Clinical features and diagnosis of multiple myeloma: a population-based cohort study in primary care; Anouchka Seesaghur et al; BMJ Open, Vol 11, Issue 10 <http://orcid.org/0000-0003-2997-5867>**

Patients with multiple myeloma (MM) experience significant delays in diagnosis due to non-specific symptomatology. The aim of this study was to characterise the frequency and timing of clinical features in the primary care setting prior to MM diagnosis using electronic health records data of approximately 17 million patients (2006–2016) within the UK Clinical Practice Research Datalink.

**Results:** Nearly half of patients with newly diagnosed MM presented with a bone pain symptom in primary care (eg local doctor, physiotherapy), approximately 7 months prior to MM diagnosis. Diagnostic tests to explore evidence of the CRAB criteria were underused. Investigations for hypercalcaemia and advanced imaging were not frequent in patients presenting with bone pain. **Conclusion:** Increased awareness of clinical features of MM, including its early presentation as bone pain, may lead to early recognition and testing of MM in primary care, thereby potentially accelerating disease diagnosis and timely medical care.

**Association between diabetes and acute lymphocytic leukemia, acute myeloid leukemia, non-Hodgkin's lymphoma, and multiple myeloma; Ji Zhong Zhao et al; International Journal of Diabetes in Developing Countries; Published: 13 October 2021; <https://doi.org/10.1007/s13410-021-01021-8>**

Diabetes is known to increase the risk for solid cancers, but it is not clear whether it is associated with hematologic malignancies. This study investigated the association between diabetes and acute lymphocytic leukemia (ALL), acute myeloid leukemia (AML), non-Hodgkin's lymphoma (NHL), and multiple myeloma (MM). We found that the prevalence of diabetes was 19.7%, 21.3%, 12.5%, and 12.0% in ALL, AML, NHL, and MM, respectively, which was higher than that (9.1%) in the local people. In MM patients, the increase in diabetes prevalence (18.6%) occurred only in females. Approximately 70% of the diabetic patients were undiagnosed before the diagnosis of the blood cancer. Approximately half of the pre-existing diabetic patients had anti-diabetic treatment, with over 70% of them still had poor glycemic control.

**Conclusions:** Our results suggest that diabetes is associated with ALL, AML, NHL, and MM, at least in adult patients.

**Pomalidomide, bortezomib, and dexamethasone for multiple myeloma previously treated with lenalidomide (OPTIMISMM): outcomes by prior treatment at first relapse**

**Meletios Dimopoulos et al; Reference: Leukemia 2021;35(6):1722-31**

This post hoc analysis of the original study focuses on RRMM patients at first relapse, and demonstrates impressive activity and safety of the pomalidomide, bortezomib, and dexamethasone (PVD) combination over bortezomib and dexamethasone (Vd). This analysis evaluated outcomes in patients at first relapse by lenalidomide-refractory status, prior bortezomib exposure, and prior stem cell transplant (SCT). Significant improvement in overall response rate and progression free survival were achieved with median extensions in PFS of between 5.8 to 11.2 months with pomalidomide, bortezomib, and dexamethasone (PVD) compared to bortezomib and dexamethasone (Vd) in all subgroups.

*The recent approval by the PBS for Daratumumab in second line treatment has seen a large uptake of use in Australian treatment centres. Here we focus on some recent publications.*

**The real-world outcomes of multiple myeloma patients treated with daratumumab; Agoston Gyula Szabo et al; Published: October 13, 2021; Plos One; <https://doi.org/10.1371/journal.pone.0258487>**

Most patients cannot be included in randomised clinical trials. We report real-world outcomes of all Danish patients with multiple myeloma (MM) treated with daratumumab-based regimens until 1 January 2019.

We find that the real-world outcomes of multiple myeloma patients treated with daratumumab are worse than the results of clinical trials. Outcomes achieved with daratumumab were best when daratumumab was used in combination with IMiDs and in early lines of therapy. Patients with high-risk cytogenetic abnormalities (CA) had worse outcomes, but patients with *amp1q* had similar outcomes to standard-risk patients. The poorer clinical performance of daratumumab-based therapies in our cohort compared with the results of phase 2 and 3 studies may be explained by later timing of daratumumab, higher percentage of patients with high-risk CA and shorter follow-up in the real-world setting.

**Treatment patterns and effectiveness of patients with multiple myeloma initiating Daratumumab across different lines of therapy: a real-world chart review study**

**Shebli ATRASH, et al; BMC Cancer volume 21, Article number: 1207 (2021)**

Real-world insights on treatment patterns and outcomes among patients with MM initiated on daratumumab, including among patients treated and re-treated with daratumumab, are limited. A retrospective study design using data from electronic medical records (EMR) and medical charts was employed. De-identified data were retrieved from two clinical sites, Levine Cancer Institute (Atrium Health) and Weill Cornell Medicine



In this study, patients initiating daratumumab across different lines of therapy had high rates of response and long PFS. Patients treated with front line daratumumab showed the greatest clinical benefit, with response rates comparable to those observed in recent clinical trials of newly diagnosed patients. Patients initiating daratumumab in later lines

and patients re-treated with daratumumab also had high response rates. These findings suggest that daratumumab-based regimens are an effective treatment option across all lines of therapy in real-world practice, with the greatest benefit observed in first line.

## 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 2021

**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

**For enquiries please contact**

**Catherine Bowley**

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**M:** 0426 404 766

## Information and Support Groups National

- All States

**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
- Forster / Taree
- Liverpool
- Lismore
- Mid North Coast Cuppa & Catch Up
- Nepean & Blue Mountains
- Newcastle
- Port Macquarie
- Orange / Mudgee / Dubbo
- Regional NSW Cuppa & Catch Up
- RPAH
- Tamworth
- Westmead
- Younger Persons'

**For enquiries, please contact**

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...continues next column

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### Diana Yun

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**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

- Friday Zoom Cuppa & Catch Up
- Gold Coast
- Inner North Brisbane
- Inner South Brisbane
- North Lakes
- Sunshine Coast
- Tuesday Zoom Cuppa & Catch Up

**For enquiries, please contact**

**Tash Clarke**

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**M:** 0416 019 585

### Megan McDowell

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## 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 and Carers
- Fleurieu Peninsula
- Marion (Southern Adelaide)
- Fullarton (Central Adelaide)
- Mid-North
- Parra Hills (Northern Adelaide)
- South-East

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## Information and Support Groups TAS

- Burnie
- Devonport
- Launceston
- Southern TAS

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## Information and Support Groups VIC

- Albury / Wodonga
- Bairnsdale
- Ballarat
- Beaumaris
- Bendigo
- Berwick
- Coburg
- Geelong
- Horsham
- Kew
- Mildura
- Mornington Peninsula
- Ringwood
- Shepparton

...continues next column

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- Wangaratta
- Warragul
- Warrnambool

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## Information and Support Groups WA

- Cottesloe
- North Metro
- Partners & Carers
- Perth Hills
- Regional WA
- South Metro
- South West
- Younger Persons'

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**Answers to the crossword on page 9**

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

# 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)**