

# MyeNews



ISSUE #63 2023

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# President's Report

## Welcome to the Autumn edition of MyeNews.

In this, our first copy since the AGM I would like to acknowledge the significant work of our retiring Board members, Peter Allen, Peter O'Brien, Miles Prince and Jeffrey Hanlon. All have given freely of their time and experience over many years and Myeloma Australia is deeply appreciative of their time and energy in driving the Organisation through some challenging times. It would be remiss of me not to mention the remarkable work of Brian Rosengarten who is stepping down as President. Happily, for us he continues to serve on the Board. As one of the cofounders of Myeloma Australia Brian's contribution is second to none and the Organisation is where it is today because of his contribution. Thank you, Brian.

As we say goodbye to some directors, we of course have the opportunity to welcome new people onto our board, myself included. I would like to welcome our new directors, Alex Burke (located in Queensland), Tegan Addinsall, Vanessa O'Shaughnessy and Hamish George. Each brings a new and fresh perspective as well as extensive experience in their respective fields. As the new President, I look forward to working with the whole board to build a strong and resilient organisation that can continue to serve the needs of people living with myeloma, and their carers and families.

Another fresh face is our new CEO Mark Henderson. Many of you may have already met or spoken with Mark and in the short time that he has been with us he has shown himself to be an extremely energetic, committed and enthusiastic leader and Myeloma Australia is very lucky to have someone of his calibre on the team.

Over the past few months there have been some significant changes including the closing of our physical office space in Richmond. This space no longer served the Organisation and it was a huge drain on our resources without providing any benefits that couldn't be more efficiently gained elsewhere. For the moment our teams will work remotely and will meet physically at a shared space as required. Our telephone line of course remains the same and anyone needing to contact the Organisation or the nursing team can continue to do so via our email and telephone line.

We are currently looking to build a new strategic plan for the Organisation and as soon as this is complete it will be shared with our wider community. At some point in the future, we will look to establish a consumer advisory group in order to ensure that we are indeed meeting the needs of our community, more on this later. Our nursing team continues to provide their usual exceptional care and support to all who need it and I am acutely aware that they are the backbone of this organisation and a most valuable pool of knowledge, skill and experience.



Over the next 12 months we will be developing a variety of opportunities for the community to support Myeloma Australia. Some of you may have participated in our 3.8 With a Mate Walk - thank you! As we come to the end of our financial year you will shortly be receiving our tax appeal. While we acknowledge that not everyone can support everything, if you are able to support our tax appeal then you can be assured that your donation will go directly to ensuring our nurses can continue their important work.

I'd like to thank you for your support of Myeloma Australia and encourage you to contact either the CEO or myself if you have any feedback or questions about what we do

Until next time...

**Karin**

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we sell out!



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[www.myeloma.org.au/shop](http://www.myeloma.org.au/shop)



## 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.

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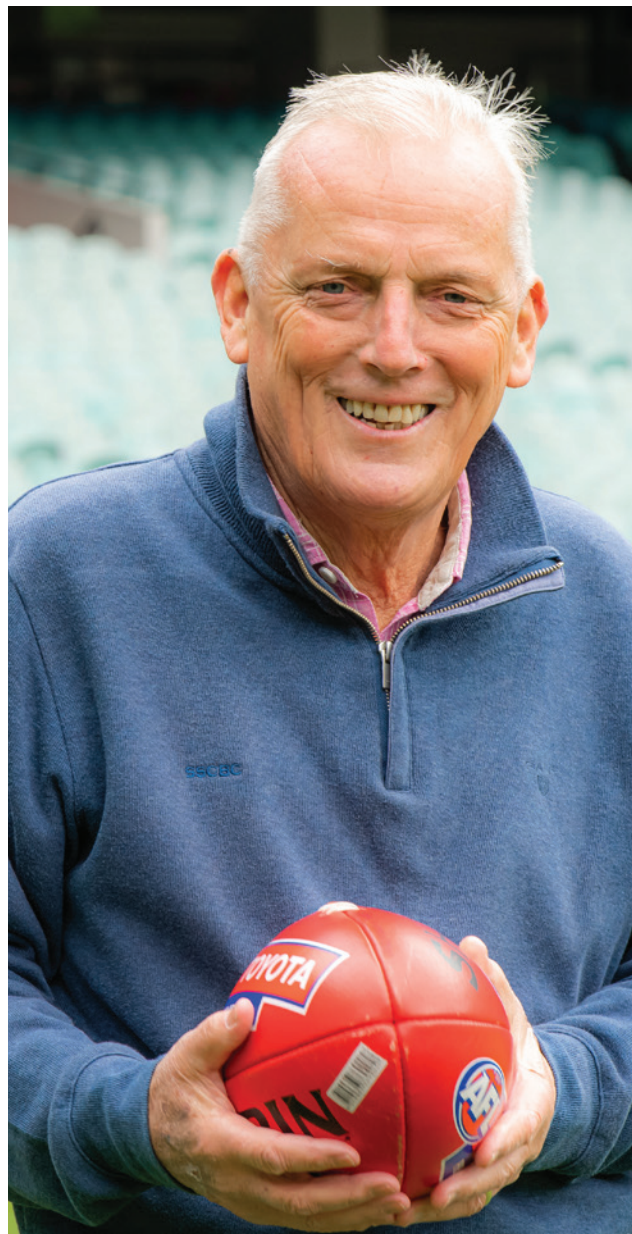
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# New Ambassador Sandy Roberts



In May 2022 I was diagnosed with myeloma. It came as a shock and to be honest, I had never heard of the disease. After coming to terms with this news, and after my wife Carolyn did some research, I was lucky enough to find myself connected to the team at Myeloma Australia. This was a game changer.

I am fortunate to have had a long media career and through this have built up a profile in the community. I approached Mark Henderson, Myeloma Australia CEO and asked whether there was anything I could do to help? We've had long chats over many months and I have accepted the invitation to join Myeloma Australia as an ambassador.

You may have seen my story across many media outlets as I made my first public announcement of my myeloma diagnosis. I'm doing it this to raise awareness, to educate and to raise important funds for Myeloma Australia. I have made many great calls in my career, but this is "My Greatest Call".

It's important to me that you know I'm on your side in this fight and as does the team at Myeloma Australia; I too believe there is a cure on the horizon.

**Sandy Roberts**  
Myeloma Australia Ambassador

## Myeloma Impact Fund

**A cure for myeloma is closer than ever before and our medical team, scientists and researchers say it's within our grasp. At Myeloma Australia we are inspired to make this a reality and we believe that a cure is possible.**

To fast track the path to cure, Myeloma Australia is creating the Myeloma Impact Fund. This is the first myeloma focused fund of its type in Australia; a multi-pronged funding vehicle focused on advancements in treatment, research, scientific innovation, education, and patient care (including the expansion of our nursing services).

The fund aims to raise \$10m and will be governed and actioned by the Myeloma Australia Board and representatives from our Medical Scientific Advisory Group (MSAG).



The funds will be invested across the sector in collaboration with industry partners and just like a financial fund, we expect it to generate positive and accountable returns. If you want to learn more about this initiative, you can go to the Myeloma Impact Fund page on our website.

This tax time we are asking the community for help to make cure a reality by donating to the Myeloma Impact Fund.

**Mark Henderson**  
CEO Myeloma Australia

## Selinexor (Xpovio®)

**Selinexor has been made available on the Pharmaceutical Benefits Scheme for people who have been treated with at least three prior lines of therapy.**

Selinexor is the first in a new family of medicines called selective inhibitor of nuclear export (SINE). Selinexor works by blocking the action of a protein called exportin 1 (XPO1) in the center of the myeloma cells. Myeloma cells have high levels of XPO1. Blocking this protein's action allows genes that control tumor growth to be retained in the nucleus of the myeloma cell and this leads to the controlled death of myeloma cells.

Myeloma Australia have developed a treatment fact sheet that gives further information on Selinexor, how to take it, how to know if it's working, what the possible side effects of Selinexor can be and lastly what to look out for while taking this therapy. To access a copy of this treatment fact sheet please go to our website [myeloma.org.au/resources/](https://myeloma.org.au/resources/) and click on the treatment fact sheet tab.

If you have been prescribed Selinexor and would like some extra support from the Myeloma Australia nurses, please call our telephone support line on 1800 693 233. The Myeloma Australia nurses are able to provide general support and side effect management whilst on this therapy.



Total of \$83,297 raised!

# Events

Save the date  
3.8 With a Mate  
Sunday 3 March  
2024



## 3.8 With a Mate 2023

On Sunday the 5th of March we saw the myeloma community join forces right around Australia for the second 3.8 With a Mate walk. This event is building in size and momentum.

As seen in the photos, it was a very successful day for community awareness and fundraising for Myeloma Australia. A significant benefit of the event is getting the myeloma community together with family and friends. We would like to thank everyone who registered, set up fundraising pages and made donations and congratulate you on raising a total of \$83,297.

The hard work of our event organisers ensured that we had numerous walks and that the day was a success. Myeloma Australia would like to thank our team of event organisers for 2023; Rob Walters (Yarralumla, ACT), Jo Little (Centennial Park, NSW), Cath Bowley (Central Coast, NSW), Mark Spring (North Shore, NSW), Christine Bates (Woody Point, QLD), Megan

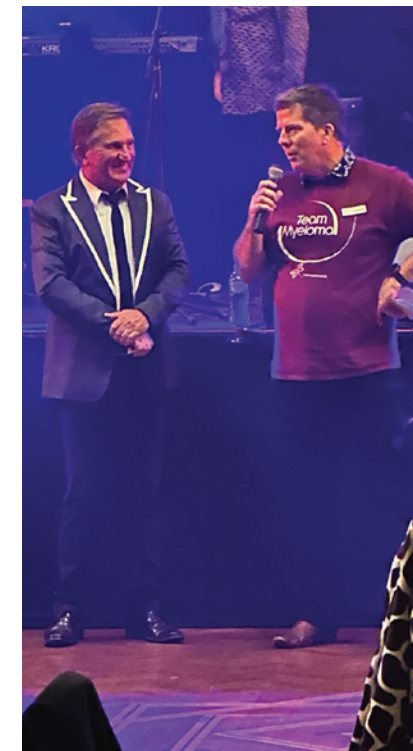
McDowell (Southbank Brisbane, QLD) Lorraine Taylor (Bendigo, VIC), Bob McMillan (Warrnambool, VIC), Natalie Caldwell (Brighton, VIC), Adrian Campbell (Camberwell, VIC), Paul Hoskin (Glenelg, SA) Kathy King, (Goolwa, SA), Pam Troup (Perth, WA) and Deb Stokes (Ulverstone, TAS).

It is great to see the enthusiasm of volunteers wanting to be event organisers particularly in areas not covered in the last two years. In 2024 we look forward to new locations on the Gold Coast and Sunshine Coast in QLD. If you would like to be considered as an event organizer for the 2024 walk, please contact our fundraising team e: [fundraising@myeloma.org.au](mailto:fundraising@myeloma.org.au)



## Legends of Rock

Thank you to the 220 people who gathered at the Thornbury Theatre in Melbourne for the Legends of Rock concert on Sunday 23 April 2023. The music and entertainment were brilliant, and the night was a huge success.



We must extend enormous thanks to Frankie J Holden OAM for bringing all the acts together and for MCing the event as well as performing all night. Thank you to Ray Pereira OAM and his family who opened the night with an African Drumming set followed by sharing with us his experience living with myeloma. We are also grateful to Wilbur Wilde & the Troublemakers, Mike Rudd, Freddie Strauks, and South African acappella group, Makepisi who blew the audience away with their music. We even had a cameo appearance from Frankie J's daughter Olivia, an ex Myeloma Australia employee who brought the house down with her rendition of Stand By Me which she dedicated to all the carers.

We must also thank oOh Media for gifting an advertising campaign, the Thornbury Theatre for hosting the event and CVP for providing the livestream so we could broadcast into the loungerooms of our community. Thanks also to Luxury Escapes, Echo Tone, artist Patricia Ball, Chemist Warehouse and JC Quality Foods for providing the raffle prizes.

Finally, thank you to those who supported the event by buying tickets either to join us at the Thornbury Theatre or via the livestream. If you missed out, you can still be part of the fun by watching the livestream recording. To find out how click the Legends of Rock tile on the front page of our website.



So you have myeloma.  
I have myeloma too.

# My Journey



## Janis' Myeloma Travels

**I was devastated to hear the diagnosis. Life, as I knew it, changed drastically — I cancelled my long-anticipated Spanish Camino travel plans and was thrown onto a different path. After working in the field of medical imaging for 40 years, I was now the patient.**

I began my myeloma journey in 2016. Since then, I have undergone induction treatment, two stem cell transplants, and am now on Revlimid maintenance, with regular IVIG infusions.

I have always enjoyed travelling, and, of course, having MM does make this aspect of life more difficult. But I found family, friends and my wonderful health team to all be supportive and encouraging.

After the induction treatment, my husband of so many years, Peter, and I, decided we both were in need of a break. We could visit our friends in sunny Perth, which we had been meaning to do for years, and maybe even fit in a bit of a road trip to Albany via Margaret River. After all, there are hospitals in Western Australia and Medicare coverage.



And you know what? Despite a few teary moments along the way, it was wonderful for our mental health. It was there I concluded that I would be doing what I could, while I could.

Between the stem cell transplants (I had tandem ones) we also managed a trip to beautiful Far North Queensland. We drove to the Daintree Forest and the Atherton Tablelands, seeing the wild Southern Cassowary and the Tree Kangaroo. Exciting!

Still... I found I had retained that desire to see Spain. And so, five months post-second-transplant and feeling good, with the support of the haematology and post-transplant exercise teams, I finally went. Hurrah! Not walking the Camino, but nevertheless doing some beautiful hikes through the Sierra Nevada mountains.

After leaving Spain, we stayed with friends in the Netherlands, and visited Belgium. Both of which, reassuringly, have reciprocal medical agreements with Australia. Watching the Last Post being played under the Menin Gate, in Ypres, was hauntingly beautiful. My grandfather's name is on the Menin Gate.



I have learnt to never say no to an invite: Why not drive from Alice Springs to Darwin with a good friend? Why not head off with other friends on their trips to Hong Kong, Taiwan and New York? So, I did. And everyone was kind, and fabulous, and understanding.

I have had to work out appointments, blood tests, and monthly infusions around travel dates. Not all plans have gone smoothly — I cancelled a trip to Italy the day we were due to leave. I rearranged to leave a few weeks later, and was still not well enough to travel, thereby missing the wedding of my dear friend's son. These things can happen to anyone, but at least you are aware, when you have myeloma, that the likelihood is higher!

Then COVID19 happened, and stymied any overseas plans, and even interstate plans... But we could still go to Back O'Bourke and beyond — so we did! People in country towns are welcoming, and a lot of fun can be found in our own quirky backyard. Australia has such an extraordinary range of environments, and many are just a few hours drive from all of our front doors.

I may never have visited some of these places, because it is very easy, when living in the Kingdom of



the Well, to put things off to some future time. Whether it's to visit friends, or relatives, or that place you've always wanted to see. It does take some organising with treatment schedules, but the wonderful thing about getting away is that you can leave your troubles behind— for a few hours, days, or weeks.

Particularly after the COVID restrictions, we are all more aware about looking after our mental health. Not only that, it has become the norm to wear a mask, and no one thinks you're weird when sterilising your surroundings on the plane.

When first writing this, we were in yet another lockdown, and it was looking like we would be cancelling our adventure --driving a campervan from Sydney to Perth. But, hey, worse things can happen!

Since then, we made it across to Perth and even further, eventually circumnavigating the continent. We saw whale sharks in Exmouth, the caves and gorges of the Kimberley region, and ever so much more...

And yet my friend in Italy still waits. I hope to see her soon.

This is written with much gratitude for the care and expertise from the Haematology team at RPAH.



# MyeBlood team, at Lifeblood

- another way to donate  
to our Myeloma Community!

**Myeloma Australia and Australian Red Cross Lifeblood are asking our myeloma community to promote and where possible, join the MyeBlood team to boost the Australian donor blood supply. We ask anyone who is healthy to consider donating blood, an amazing way to show support for those living with this blood cancer.**

In Australia, donor blood products are given freely by healthy volunteers and demand is high. Therefore, Myeloma Australia wants to help encourage donations to replenish and increase the national supply to keep blood products available for everyone who needs them, when they need them.

To join the MyeBlood team via the website go to [my.donateblood.com.au /app/myteams\\_home](https://my.donateblood.com.au/app/myteams_home) and select MyeBlood.

**Blood products derived from donated blood that can be used to support people with myeloma:**

- Concentrated red cell transfusions: given for anaemia, improving oxygen-carrying capacity by increasing circulating red cells helping tiredness and fatigue.
- Platelet transfusions: given for a severely low platelet count to prevent or stop bleeding by forming a plug, held in place by clotting proteins.
- Immunoglobulin products (Ig) are solutions of human plasma proteins with a comprehensive antibody activity. Prepared from pooled plasma collected from several thousand blood donors, they give a temporary boost to blood immunoglobulin levels in those who have a low IgG level.
- Whole plasma: used during therapeutic plasma exchange where plasma containing levels of paraprotein is removed and replaced with donated whole plasma. Plasma may also be required during emergency bleeding events as it contains essential clotting factors.

Donors replenish their own blood quickly, 12 weeks for a red cell donor and 2 weeks for a platelet or plasma donor. Join our MyeBlood team today to give the precious gift of blood at a donor centre close to you. Every donation to the MyeBlood team is recorded. Myeloma Australia will publish the donation totals on our website and socials for our community to track. Please join and be part of this new initiative to show support for our Myeloma Warriors. #myelomaaustralia #lifeblood #MyeBlood.



## A note from Australian Red Cross Lifeblood

We are incredibly grateful Myeloma Australia has set up the MyeBlood team and thank those people who have joined already! Being a Lifeblood team member is a wonderful way to support Australians needing blood and blood products, including loved ones with myeloma.

More than one third of all donated blood collected in Australia is used to treat cancer and blood diseases, and more than 10,000 blood donations are needed every week to support cancer patients.

To book a donation, call 13 14 95 or alternatively book online at [www.lifeblood.com.au](https://www.lifeblood.com.au) or via the Lifeblood app.







**Happy belated New Year to you all. I am writing to let you all know about an exciting new initiative called Nurse Link that we launched a year ago as a pilot program. The team at Myeloma Australia have been working hard to explore the information and support needs of our myeloma community particularly those in regional and rural/remote areas of our country where access to this is often more challenging than in metropolitan areas.**

The aim of this project was to help close this gap by offering mentorship and education opportunities to regional haematology nurses by establishing the Myeloma Australia (MA) Nurse Link (NL) Program. We were lucky to have seven nurses join the program, all who have a wealth of experience and a passion for myeloma. Currently they are in New South Wales- Orange, Tamworth, Tweed Heads, Victoria- Wangaratta, ACT and Tasmania-Launceston. With the assistance of grants from The Steadfast and Australian Communities Foundation we were able to meet monthly (online) with the group and provide education through a variety of speakers on topics of interest but more importantly bring the group together.

Being able to share experiences and challenges with others is invaluable. Each nurse received an MA resource manual, NL branded T shirt and badge, membership of a WhatsApp group and encouraged to share their knowledge with other members of the team & wider myeloma community. We were also able to offer some funding to each nurse to support their attendance at either the national haematology conference held in Sydney, or our scientific meeting held in Victoria. It was wonderful to meet a few of the nurse's face to face and the nurses reported that it was an invaluable learning experience.

We are also keen to work with the nurses to explore gaps in our service and reach to the community. As you are aware, although we enjoy traveling and catching up with our community, we are a small team and have limited resources. With the nurses in the program, we hope to be able to offer more local support to individuals and facilitate such things as enabling individuals with myeloma to meet with others in their area.

This year we are continuing our work on the program and are proud to announce we are expanding and taking on three more nurses in Queensland, Western Australia and South Australia. We are seeking more funding and hope to have at least a few nurses in each state. We are looking forward to the next phase of this project.

**Myeloma Australia engages in advocacy initiatives at both local and global levels with the goal of enhancing the lives of individuals living with myeloma and striving towards finding a cure. These programs focus on raising awareness about myeloma and collaborating to enhance access to care, treatments, and education.**

## Pharmaceutical Benefits Advisory Committee (PBAC) Update

We are pleased to share with you a recent update from the PBAC regarding the treatment of relapsed refractory myeloma. In the November meeting, the committee gave a positive recommendation for the use of selinexor in combination with bortezomib and dexamethasone. A step forward in helping our community access effective treatment options. In less positive news, the committee recently rejected an initial application for upfront treatment with daratumumab in combination with lenalidomide and dexamethasone for those unable to have a transplant. We have high hopes that this will get approved second time around.

We would like to thank everyone who submitted consumer comments for these submissions, your input and feedback played an important role in helping the PBAC make informed decisions about which treatments should be made available in Australia.

## Medicines Services Advisory Committee (MSAC)

In better news, in December 2022, the MSAC recommended the inclusion of the PET imaging modality for the initial diagnosis and staging of myeloma on Medicare. This recommendation is expected to improve the accuracy of diagnosis and staging and patient outcomes and is a result of the advocacy efforts of our Medical and Scientific Advisory Group (MSAG).

## Global Myeloma Action Network (GMAN) Meeting December 2022

This meeting with the International Myeloma Foundations' GMAN group was held online in December and both Hayley and Nella attended representing Myeloma Australia alongside 35 other members from around the globe. Dr Brian Durie presented his pick of the best abstracts and presentations from the annual ASH meeting held the week before. These included several on emerging therapies, results of trials in China using CAR-T in first line treatment, the Icelandic iStopMM project which had 10 abstracts and four oral presentations at the conference,

new approaches to MRD testing, and updates from the high risk smouldering myeloma trials (ASCENT and GEM-CESAR).

Announced at the meeting, GMAN are convening a focus group to work together to transform the GMAN into the future and plan activities. We are pleased that Myeloma Australia have been asked to be part of the focus group.

# Complementary medicine support

By Monica Francia, a Naturopath currently working at Goulds Natural Medicine Clinic in Hobart, consulting in person and via telehealth. She works regularly with oncology & haematology patients and advocates for a collaborative care model, incorporating both western medicine and complementary care.

**Complementary medicine is the use of herbal and nutritional interventions to complement conventional therapies such as chemotherapy and radiation. The aims of complementary therapies in cancer care are:**

- to support the patient's quality of life
- to manage or help prevent the side effects of conventional treatment
- to help treatments work more effectively or help patients stay on treatments for longer
- to support recovery from treatment and support remission for as long as possible

As naturopaths (trained in herbal medicine and nutrition) we work from an evidence-based perspective, meaning we like to use things that have been scientifically tested and shown to be safe. During active treatment the use of herbs can be limited by this, but simple dietary or nutritional changes can help make a big difference to a patient's quality of life. During remission or between active treatment there is a broader range of treatments we can use to support the body to heal.

It is best to talk to a trained naturopath for individual recommendations and to customise a plan that works for you, but below I have outlined some foundational health choices that can make a big difference on your cancer journey.



**In terms of nutrition I suggest:**

- Following a mostly pescatarian diet packed full of fruits and vegetables. Eating a diversity of plant foods from all the different colours of the rainbow supports inflammation levels and the immune system.
- Reducing processed foods (anything that comes in a packet) and as much as you can choose whole foods with as small an ingredient list as possible.
- Minimising high sugar foods such as lollies, pastries and cakes.
- Ensuring you are drinking 2-3L of water or other fluids each day to support your kidneys (unless otherwise directed by your treating team).

You can also include some foods we call 'Food as Medicine' that have big health benefits to the body. These include ground flaxseeds (2 tbsp daily), Brazil nuts (a great source of selenium, aim for 2-3 nuts daily), berries, mushrooms such as oyster and shiitake and fermented foods such as yoghurt, sauerkraut and kombucha to support your gut microbiome (good gut bacteria).

I also advocate for having your nutrition levels checked. This can be done through your GP or haematologist with a simple blood test. Ensuring you have good levels of iron, vitamin D and vitamin B12 can have a big impact on your treatment. Ask your GP if these have been checked recently.

**Other things you can do to support your body through and after treatment are:**

- regular exercise
- sauna
- yoga
- intermittent fasting or longer fasts

\*If you are using complementary medicine treatments such as herbs or nutritional supplements, you should always check with your haematologist and/or pharmacist for safety.

# Insurance claims

## Has Myeloma Impacted Your Ability to Work? New partnership with AFRM Claims Advocacy

Has a diagnosis of myeloma impacted your ability to work? If so, you may be entitled to payments from your personal insurance- which includes the default personal insurance cover within your superannuation fund. Myeloma Australia is aware of the stress financial burdens can add when diagnosed with myeloma. Finding time and head space to investigate financial entitlements can seem impossible so we are pleased to announce a new partnership with AFRM Claims Advocacy (ACA) in an effort to help reduce some of this stress. ACA can check if you are owed payments from your personal insurance by reviewing your policies. If there is a claim to be made, they will approach the insurance company on your behalf and can also liaise with your doctor or treating hospital to get the paperwork filled in correctly. A claim can be made even if you were diagnosed some time ago and are no longer working.

By mentioning Myeloma Australia when you first call, the eligibility checking fee will be waived (valued at \$880). For a free eligibility check and to learn more about ACA call 1300 013 328, or email [aca@afrm.com.au](mailto:aca@afrm.com.au). In-turn, as a partner of Myeloma Australia, ACA will make a regular financial contribution to support our Telephone Support Line.

For further information go to [afrmclaimsadvocacy.com.au/myeloma](https://www.afrmclaimsadvocacy.com.au/myeloma)

To make contact, call **1300 013 328**, or email **[aca@afrm.com.au](mailto:aca@afrm.com.au)** for a free eligibility check



Hi Myeloma Australia,

I was diagnosed with multiple myeloma last year at the very unfortunate age of 36 with 3 young kids aged 4, 3 and 8 months at the time.

I am a nurse by trade, and due to the impacts of myeloma and its treatments on my body I couldn't return to that role just yet due to its demands both physically and mentally. I applied for income protection through my super last year and really wasn't getting anywhere with them, time was dragging on and I wasn't being paid or even hearing if my application was successful. In March I was told about the service that Bruno provides from one of the nurses with Myeloma Australia and the hosp at which I am treated. From the very beginning Bruno has been approachable and helpful, he advised me of the first steps to take to get clarification from the Super fund and when there was no further action from them, he was there to help me with the next step, advocating for me at a time when... dealing with insurance claims aren't exactly high up on my list of enjoyable activities!

With Bruno advocating for me we were able to get my application escalated and assessed by the right person and I received confirmation that it had been approved shortly after, which I know would not have happened if it weren't for his advocacy skills. There are still questions that need to be answered and ensuring that they follow through appropriately and Bruno is still there ensuring that I know I can contact him for support.

I would highly recommend Bruno to anyone within the myeloma community, he is professional, reliable and kind which is exactly what anyone needs at one of the hardest times of one's life

Louise



## Australasian Myeloma Research Consortium

### 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)

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).

The Australasian Myeloma Research Consortium (AMaRC) is a not-for-profit myeloma research group and is a consortium of myeloma experts, scientists, other clinical specialists to develop and conduct multiple myeloma investigator-initiated trials (IITs) in Australia and New Zealand.

We collaborate with the Myeloma and Related Diseases Registry to ensure our trials address areas of need to improve the diagnosis, treatment and outcomes of myeloma patients across Australia and New Zealand. We work closely with the Myeloma Research Group (Monash University) to incorporate translational research in our studies, to explore novel diagnostic and therapeutic approaches for multiple myeloma (MM).

### Currently Recruiting Trials

#### IBIS study

Prof. Andrew Spencer & Dr. Sueh-li Lim

The IBIS study explores a combination of iberdomide, isatuximab, and dexamethasone to treat patients with functional high-risk multiple myeloma (patient who relapse within 12 months after stopping their first myeloma treatment). We have 1 site opened in VIC and more sites to be opened in VIC, NSW, SA and TAS.

Link for more info: [www.amarconline.org/clinical-trials/ibis](http://www.amarconline.org/clinical-trials/ibis)

#### 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. We will also investigate patients' preferences for combination treatments in transplant-ineligible multiple myeloma. 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). We have 21 sites across:

Aus: VIC, NSW, QLD, SA, TAS, NT

NZ: Middlemore, Dunedin, North Shore, Christchurch

Link for more info: [www.amarconline.org/clinical-trials/frailm](http://www.amarconline.org/clinical-trials/frailm)



### BelaCarD study

Prof. Hang Quach & Dr. Masa Lasica

The BelaCarD study explores a combination of Belantamab, Carfilzomib and Dexamethasone to treat patients with relapsed/refractory myeloma. We have 11 sites across VIC, NSW, QLD, SA

Link for more info:

[www.amarconline.org/clinical-trials/belacard](http://www.amarconline.org/clinical-trials/belacard)

### PRO-DVD

Prof. Andrew Spencer & Dr. Sueh-li Lim

The PRO-DVD study explores patient reported outcomes in patients receiving Daratumumab, Bortezomib, and Dexamethasone for relapsed multiple myeloma. We have 7 sites across VIC and NSW

Link for more info:

[www.amarconline.org/clinical-trials/pro-dvdt](http://www.amarconline.org/clinical-trials/pro-dvdt)

### Recently Approved Studies

#### RIDDLE-M-X

Prof. Andrew Spencer & Dr. Sueh-li Lim

The RIDDLE-M-X study looks at the incorporation of selinexor with bortezomib, lenalidomide, and dexamethasone for transplant eligible NDMM patients deemed to be high risk using the SKY92 MM Profiler (risk stratification), as well as for standard risk patients who do not achieve MRD negativity via EuroFlow (response adaptation) post ASCT. This study has recently received HREC approval with sites to open in VIC, NSW, SA, QLD and TAS.

### Upcoming Studies

#### ZEPFHR-MM

Prof. Andrew Spencer and Dr. Sueh-li Lim

A platform study for functional high-risk myeloma. Individual phase II protocols with different novel treatment combinations will be added as individual domains, while working under a central Ethics approval. The platform will enable a tailored approach so that participating sites can choose domains most appropriate for their institution.

## Australasian Leukaemia and Lymphoma Group

For five decades now, our cooperative group has been bringing together blood cancer experts from across Australia and New Zealand (ANZ) to volunteer their time and run clinical trials to change the way the disease is treated.

### What's New

Professor Hang Quach is a member of the ALLG's Scientific Advisory Committee that sets the research strategy for the ALLG. She also chairs ALLG's Myeloma Scientific Working Party and is a member of the Myeloma Scientific Advisory Group (MSAG) for Myeloma Australia.

Prof Quach is leading ALLG clinical trial MM23 SeaLAND that is evaluating a new medicine for patients called selinexor in the maintenance treatment stage, after having had a stem cell transplant. This is the only study globally assessing this new treatment option for adult patients who have been newly diagnosed with multiple myeloma and who are eligible for an autologous stem cell transplant - a procedure in which a patient's healthy stem cells (blood-forming cells) are collected from the blood or bone marrow before treatment, stored, and then given back to the patient after treatment. MM23 has opened 18 hospital sites across Australia and New Zealand. Learn more [www.allg.org.au/clinical-trials-in-myeloma-for-better-treatments/](http://www.allg.org.au/clinical-trials-in-myeloma-for-better-treatments/)

The ALLG MM22 FRAIL-M clinical trial, led by Professor Andrew Spencer, aims to optimise first line therapy in older patients with multiple myeloma by maximising efficacy while minimising side-effects. The study aims to prospectively define appropriate doses for the trial's treatment regimens according to patient fitness. This is an extremely important goal for this group of patients who are at high-risk of side-effects. MM22 has opened at 19 sites across Australia.

If you are interested in participating in a clinical trial, speak with your doctor and visit our website to learn more [allg.org.au/clinical-trials-research/current-clinical-trials/](http://allg.org.au/clinical-trials-research/current-clinical-trials/) and read Frequently Asked Questions on clinical trials: [allg.org.au/clinical-trials-research/current-clinical-trials/faqs/](http://allg.org.au/clinical-trials-research/current-clinical-trials/faqs/)



## Myeloma and Related Diseases Registry (MRDR)

The MRDR now has close to 5900 patients registered with 57 approved sites, and the Myeloma 1000 biobank has recently recruited its 600th patient with the Austin Hospital soon to join. In 2022, registry sites recruited a total of 803 patients - we send a big thankyou to patients and staff at all participating sites for your ongoing support.

### Research: MY-PROMPT-2 trial

The MRDR has a new registry-based trial that is open for recruitment at approved, activated sites. This trial is MY-PROMPT-2: More efficient delivery of high-cost standard-of-care therapies in relapsed multiple myeloma using real-time feedback of patient-reported outcome measures (PROMs). Treatment of multiple myeloma can be quite complex, and some patients may stop therapy early due to side-effects. If treating clinicians are made aware of emerging patient symptoms, they can be addressed in a timely manner. MY-PROMPT-2 will test whether routine real-time symptom feedback to clinicians at clinic visits using PROMs improves duration on treatment for patients with relapsed multiple myeloma. We hope that this could lead to better outcomes for patients.

### Publications

We are pleased to report another publication using registry data. This paper on disease staging evaluates the second revision of the International Staging System 2 (R2ISS) in an Australian and New Zealand Population. The paper was published in the British Journal of Haematology in November and can be accessed with the following link: [doi.org/10.1111/bjh.18536](https://doi.org/10.1111/bjh.18536). This is one of 3 registry papers published in 2022.

### Conferences

Blood 2022, in Sydney in September was a great meeting for the MRDR with seven presentations of MRDR and M1000 biobank data. The presentations covered diverse areas in myeloma research including, impact of therapies for relapsed myeloma, biomarkers for high risk of progression in smouldering myeloma, the impact of variation in use of immunoglobulin, and modelling the impact of treatments.

If you are interested in participating in the MRDR, 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.





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

Frail Multiple Myeloma Patients Deserve More Than Just A Score

Hannah Louise Miller and Faye Amelia Sharpley

Hematology Reports. 2023, 15(1), 151-156; <https://doi.org/10.3390/hematolrep15010015>; Accepted: 16 February 2023 / Published: 21 February 2023

Frail myeloma patients can struggle with treatment, resulting in dose reductions and ceasing treatment, potentially shortening progression-free and overall survival. Efforts have focused on the validity of existing frailty scores and on the development of new indices to identify frail patients more accurately. This review article explores the challenges of the existing frailty scores, including the International Myeloma Working Group (IMWG) frailty score, the revised Myeloma Co-morbidity Index (R-MCI), and the Myeloma Risk Profile (MRP). We conclude that frailty scoring must translate into a tool useful in real-world clinical practice. The future of frailty scores lies in their ability to be woven into clinical trials, to create a robust clinical evidence base for treatment selection and dose modification, and to identify a cohort of patients who merit additional support from the wider myeloma multidisciplinary team.

Chemotherapy-Driven Gut Dysbiosis In Patients With Multiple Myeloma

M Kozyk , K Strubchevska, S Palli , B Secor; Georgian Med News; 2022 Dec;(333):35-37.

Bortezomib, lenalidomide, dexamethasone (RVD regimen) is still considered a gold-standard therapy for myeloma but can lead to a wide range of side effects, one of which is gut toxicity (enterotoxicity). Effective gut protective interventions have not yet been developed. This literature review assesses the development of chemotherapy-driven dysbiosis through Toll-like receptors (TLRs) and explores the hypothesis that the gut microbiome could provide significant enteroprotection. In conclusion, we found further studies of gut microbiome variety and function are necessary and could be used in development of treatment and prevention strategy of chemotherapy enterotoxicity.

Improving Outcome-Driven Care In Multiple Myeloma Using Patient-Reported Outcomes: A Qualitative Evaluation Study

Christine Bennink, et al; The Patient - Patient-Centered Outcomes Research (2023) Abstract Published: 15 February 2023

Multiple myeloma brings a considerable illness and treatment burden, which negatively impacts patients' quality of life. This study aimed to evaluate multiple myeloma care in five Dutch hospitals, related to three objectives of outcome-driven care, providing information for shared decision making in individual patient care, supporting the learning capacity of healthcare professionals and healthcare institutions through benchmarking and developing outcome-driven and patient-centred contracting by health insurers. Semi-structured interviews about experiences with patient-reported outcomes were conducted with patients, healthcare professionals and other stakeholders at 2 years after implementation. The data was thematically analysed, and emerging topics were clustered around the three objectives of outcome-driven care. Results showed patients with multiple myeloma were willing to complete patient-reported outcomes, although integration of patient-reported outcomes in shared decision making fell short in clinical practice. Aggregated patient-reported outcomes were considered important for improving quality of care; however, data collection and data exchange are hindered by privacy legislation, limitations of IT systems and a lack of data standards. Patient-reported outcomes were expected to contribute to cost-effective multiple myeloma treatment, yet outcome-driven reimbursement is still lacking.

CAR-T cell therapy: Patient Perceptions Regarding Ciltacabtagene Autoleucel Treatment: Qualitative Evidence From Interviews With Patients With Relapsed/Refractory Multiple Myeloma In The Cartitude-I Study

Cohen A et al; Clin Lymphoma Myeloma Leuk 2023 Jan;23(1):68-77

Ciltacabtagene autoleucel (cilta-cel), a novel chimeric antigen receptor T (CAR-T) cell therapy, has demonstrated early, deep, and durable clinical responses in heavily pretreated patients with relapsed/refractory multiple myeloma (RRMM), and improvements in health-related quality of life.

Qualitative interviews were conducted in a subset of CARTITUDE-1 patients (n = 36) at screening, Day 100, and Day 184 post cilta-cel on living with MM, therapy expectations, and treatment experiences during the study. Most patients reported that their expectations of cilta-cel treatment had been met (70.8%) or exceeded (20.8%) at Day 184, and 70.8% of patients considered cilta-cel therapy better than their previous treatments. Overall HRQoL improvements and qualitative interviews showed cilta-cel met patient expectations of treatment and suggest the long treatment-free period also contributed to positive sentiments.

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)





## South Australia

Alicia and Jo have enjoyed the brighter outlook of 2023 and reconnecting with our myeloma community. Our support groups are back face to face and have been real. Special thanks to our local tech geeks with laptops to enable Alicia and I to zoom in for those groups we can't attend in person.

With kind help and support from Bruce and clinic staff in Whyalla, a new support group for Upper Spencer Gulf region is planned, aiming for first group in July.

Alicia and I gave myeloma education to staff at Royal Adelaide Hospital, Chemo@Home and country SA (via Teams) with attendances from Pt Lincoln to Mt Gambier. We also contributed to the national on-line seminars held in March which are available to view on our website.

The joy of reconnecting has flourished with the SA Facebook group enjoying lunch together in February and the 3.8 with a Mate walks, held at Goolwa and Glenelg. We succeeded in raising awareness for myeloma and celebrated our community of myeloma warriors and supporters. Thanks again to our event organisers. The next SA lunch is planned for Saturday, 22nd July 2023. Please contact Jo or Alicia for details for the lunch or SA Facebook group.

We wish to pass onto Sandy and Carolyn Roberts the thanks we have received from our SA community for your Greatest Call campaign and the much needed awareness you are generating, your efforts are appreciated.

Save the date for a tour of the Myeloma Research lab at SAHMRI for Wednesday 23rd August, contact Jo or Alicia if you wish to come.

**Jo and Alicia**  
**Specialist Myeloma Nurses, SA**



## Queensland

Please join Tash and Megan online for our regular statewide catchups. You can find our next group on the events page of our website. This year we plan on focusing on a topic each meeting to help encourage our new members to join us and learn something helpful about living with myeloma. We have recommenced Face-To-Face catch-ups so look out for your invitations- it's so lovely to see your smiling faces in person now. These groups are open to patients, carers and loved ones.

Our monthly "Walk and Talk" group meets one Saturday a month at the SouthBank Piazza. This group is facilitated by our specialist volunteer, Jenny Nicol who has dedicated her research to proving the benefits of exercise for those living with myeloma. Join her to meet other members and to learn about the MyeEx clinical trial she is heavily involved in. The walk is suitable for all fitness levels with plenty of places to rest along the way if needed. We would love to see more groups happening around Queensland so if you are interested in leading a group please email Tash - natasha.clarke@myeloma.org.au- for information on how to start one up. (photo taken by Ken- participants- Mel McMurray, Dan and Christine Carter, Jenny Nicol- group leader, Tash Clarke- Queensland myeloma Support nurse) Ross McPherson, Meg and Neil Taylor)

Megan and I have been providing education to nurses and educating ourselves by attending myeloma education sessions. There is so much exciting information to share with you all and we look forward to actually seeing more of you during the year.

**Megan and Natasha**  
**Specialist Myeloma Nurses, QLD**



## New South Wales

At the end of 2022 we had some Christmas gatherings for the Canberra, Central Coast and Westmead support groups and it was a terrific way for people in the myeloma community to be re-connected. Sadly, we also said goodbye to our two myeloma nurses from the NSW team Tina & Juliet who both will be sorely missed not only by the myeloma community but also by the Myeloma Australia team. We wish them well in their new roles moving forward.

In 2023, NSW will continue support groups via the zoom online platform on a quarter monthly status with some meetings scheduled in April to be face to face. We are excited to announce we have introduced a new online support group at the end of 2022 for partners and carers, and this is continuing bi-monthly.

Our monthly online statewide support groups will continue the last week of every month. These groups are well attended by people all over the state and territory and all are welcome! It is a wonderful way to connect if there is not currently a local group close to you. We are keen to introduce a few more support groups later in the year after securing some funding.

We hope this year we can connect with the wider myeloma community in rural and regional areas around NSW.

Our myeloma community in NSW and ACT were well represented in our "3.8 with a mate" walks early in March. It was wonderful to see the support and to raise awareness within some of our local areas in Sydney, Canberra and the Central Coast.

**Cath, Jacqui & Diana**  
**Specialist Myeloma Nurses, NSW**

# State Reports



## Tasmania

Over the last year or so we have had to hold many support groups online, and it is great that we can now officially hold them face-to-face again. That said, I will next be travelling northward on the 23rd of May to hold groups at the Penguin Football Club and at the Northern Cancer Support Centre in Launceston where, in February, a very successful 'members only' face-to-face group was held. Many new people attended, a few even travelling down from the north-west to be there. In the south, our next group will be at the Howrah Community Centre on Tuesday June 6th. Members thought it would be great to keep in contact via a Tasmanian Facebook page, which one of our participants kindly agreed to organise. Topics discussed in the groups have included steroids & fatigue in myeloma, managing pain (thank you to Bernadette Smith), treatment with daratumumab and Car-T cell therapy, whilst education sessions have been given to the nursing staff at Calvary Hospital, and also to newly registered student nurses at the Royal Hobart Hospital.

I enjoyed participating in the seminars for National Myeloma Month and hope you got a lot from listening to them. The '3.8 with a mate' events around the country were a great success and I would especially like to thank Deb and Adrian for organising such an excellent walk in Ulverstone, in northern Tasmania.

**Deborah Thompson,**  
**Specialist Myeloma Nurse, TAS**



# State Reports



## Victoria

The team in Victoria have enjoyed watching the community reconnecting through our information and support groups. Thank you for your dynamic and flexible commitment to connecting with each other. We are grateful and impressed with the ability of new community facilitators, in welcoming new members, and working alongside us to create safe places for face-to-face connection. We encourage you to RSVP to groups, so we can forward plan and ensure our efforts are most impactful.

If you are interested in being involved, please see our events tab on our website, contact the support line on 1800 693 566 or email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

Emma and Laura enjoyed last year's November Online seminar, where Professor Miles Prince provided a comprehensive but easy to understand overview of myeloma disease and treatments in Australia. Our team was also heavily involved in the events for National Myeloma Month.

You can find all these presentations recorded for viewing in your own time on our website.

It is with mixed emotions that we farewelled Emma in the new year and wish her all the best with her new role. Laura is now on extended leave while she focuses on her studies for the next few months. We have recruited into the position and look forward to introducing you to the new team member.

**EJ Furphy**  
Specialist Myeloma Nurse  
and Special Projects, VIC



## Western Australia

I would like to extend a warm hello to everyone in the WA myeloma community, as we have welcomed the start of 2023 with some cafe catchups and groups for the myeloma community. We had a great turnouts for all of our meetings to date with each providing a great opportunity for everyone to be face to face and catch up. New members are always welcome at any of our events and groups. Keep an eye out for the invitations arriving in your email inbox.

Thank you to the community members that attended the 3.8 with a Mate walk at Lake Monger. Event organiser, Pamela Troup did a wonderful job organising this day and I am very grateful that the day was a huge success. I have enjoyed looking at all the wonderful pictures that have been submitted.

If you are looking to connect with other members of the myeloma community here in WA, or looking for support and information about myeloma, please get in touch with me so we can chat about some of the upcoming events and meetings that might be of interest to you or to discuss how we can support you.

**Narelle Smith**  
Specialist Myeloma Nurse, WA

## Clinical Trial Database – ClinTrial Refer

ClinTrial Refer is an online search tool that displays all the clinical trials, and other available trials within the myeloma space. ClinTrial Refer provides extensive information about each study, including key eligibility criteria and trial site contact information. You have the option of using the ClinTrial Refer mobile app or the ClinTrial Refer website to search [www.clintrialrefer.org.au/](http://www.clintrialrefer.org.au/)

### Using the ClinTrial Refer Mobile App or Tablet

Download ClinTrial Refer App for mobile and tablet devices and start searching today. ClinTrial Refer is free to download from the Apple App Store or Google Play on your smartphone or tablet.

**You can also scan the QR code for fast download access.**



## Lenalidomide (Revlimid) can now be taken with or without Food

### DID YOU KNOW?

Lenalidomide (also known as Revlimid®) can now be taken with or without food

Contact our Myeloma Support Nurses to learn more  
1800 693 566

Lenalidomide is an immunomodulatory medication that is very commonly used in the treatment of myeloma. Through feedback from our community, our team at Myeloma Australia discovered that the administration guidelines in Australia differed from those overseas whereby, in Australia it was recommended to take one hour before or one hour after food.

We are pleased to announce that through our advocacy program, we have been able to influence change to the protocols published by EVIQ, a Cancer Institute of NSW organisation who provide evidence-based, consensus driven treatment protocols to Australian health professionals, to follow international guidance that lenalidomide can be taken with or without food.

If you or your loved one is taking lenalidomide (Revlimid), speak to your treating team about this change in administration guidance.

**For more information on myeloma medications, you can visit our website or contact our Myeloma Australia nurses on 1800 693 566.**



# Information and Support Group Contact Details

There are many Information and Support Groups around Australia. These are held both online and face-to-face. For information about individual groups dates and times, please see our calendar of events.

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

**For further information or help joining a group via Zoom, please contact your state's Specialist Myeloma Nurse via the contact details to the right**

## Information and Support Groups National

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

For enquiries, please contact:

### Myeloma Support Nurses

**E:** [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)  
**M:** 1800 693 566

## Information and Support Groups South Australia

For enquiries, please contact:

### Jo Gardiner

**E:** [jo.gardiner@myeloma.org.au](mailto:jo.gardiner@myeloma.org.au)  
**M:** 0447 331 165

### Alicia Hopper

**E:** [alicia.hopper@myeloma.org.au](mailto:alicia.hopper@myeloma.org.au)  
**M:** 0426 716 165

## Information and Support Groups ACT

For enquiries, please contact:

### Cath Bowley

**E:** [cath.bowley@myeloma.org.au](mailto:cath.bowley@myeloma.org.au)  
**M:** 0426 404 766

## Information and Support Groups Tasmania

For enquiries, please contact:

### Deborah Thompson

**E:** [deborah.thompson@myeloma.org.au](mailto:deborah.thompson@myeloma.org.au)  
**M:** 0433 511 689

## Information and Support Groups New South Wales

For enquiries, please contact

### Catherine Bowley

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**M:** 0426 404 766

### Diana Yun

**E:** [diana.yun@myeloma.org.au](mailto:diana.yun@myeloma.org.au)  
**M:** 0452 027 765

## Information and Support Groups Victoria

For enquiries, please contact

### Emma-Jane Furphy

**Laura Jones** (On leave)

**E:** [ej.furphy@myeloma.org.au](mailto:ej.furphy@myeloma.org.au)  
**E:** [laura.jones@myeloma.org.au](mailto:laura.jones@myeloma.org.au)

**M:** 0426 404 233

**M:** 0416 129 267

## Information and Support Groups Queensland

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

## Information and Support Groups Western Australia

For enquiries, please contact:

### Narelle Smith

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**M:** 0426 404 280