

MyeNews



#64 Summer 2023

Mashd N Kutcher 'It's Alright'

My Greatest
Walk

Mel's
Story

Welcome to our
new nurses

President's Report

Welcome to the Summer edition of MyeNews.

It has been a year of significant change and challenge.



It's been a year of significant change and challenge. Happily our amazing team of Myeloma Specialist Nurses across Australia were able to continue to provide their services to people at a very difficult time. The use of virtual support groups utilising technology is helpful and more recently we have been able to host some face-to-face support groups which has been welcomed by those attending. We do not underestimate the value that is created when people can come together to share their experience.

Mark and the team have also been very busy restructuring resources and working together to build a new and exciting culture fit for the future of Myeloma Australia.

One key area that we have been working on is to bring Myeloma Australia into the spotlight. Frankie J Holden, one of our dear and long-time supporters and his friends provided some high level energy at a great evening aimed at raising urgent funds to support our programs. In addition, we have secured a number of other high-profile Ambassadors for Myeloma Australia including Sandy Roberts and Denis Naphine.

Sandy of course is the face of our 'My Greatest Call' campaign and has been a wonderful spokesperson for myeloma and Myeloma Australia. The 'Greatest Call' Long Lunch which will be held in March next year has already sold out! Denis Naphine of course is a former Premier of Victoria and has happily put himself forward to support our work.

Our Adelaide workshops were very well attended with attendees hearing from a range of speakers across a variety of subjects. It is also where we launched our new flagship resource 'Myeloma a Comprehensive Guide' which has been very well received.

There was considerable work undertaken to pitch a proposal to Pfizer in relation to our Nurse Link program and I am very pleased to report that despite only five grants being available globally our team at Myeloma Australia were successful in securing a significant grant to support the Nurse Link program. This will mean that people in regional, rural and remote areas of Australia will be able to be supported through the program as it rolls out.

This is a huge development for our community and the team, led by Hayley Beer, are to be congratulated for securing the funding.

The development of our new strategic plan is underway, and we are also working on a new visual identity to be rolled out in 2024. It is indeed an exciting time for Myeloma Australia and I hope that you will help us spread the word so that everyone in Australia who is affected by myeloma will be able to feel the support that we can provide.

As the year draws to a close, our offices will be closed for the Christmas period from 22nd December to 8th January 2024. I wish everyone a very Happy Christmas, may you all spend it with those you love.

Karin

CEO's Report

2023 was my first year as the Chief Executive Officer and I feel very privileged to hold this title and work with such a wonderful group of people. I'm equally privileged to stand with and to stand up for the myeloma patient community. We are working hard to make sure that your voice is being heard.

I have learnt so much this year about myeloma that I likened the experience to "drinking from a fire hydrant". Wow, myeloma is so complex, and it impacts our patients and their families in so many ways. It still shocks me to think that most people at diagnosis have never heard of it.

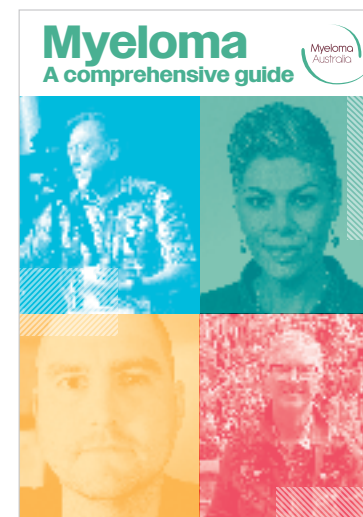
We have been focused on many parts of the organisation and the external messaging we are delivering out into the public. A big thank you to Sandy Roberts who declared his myeloma status to the public in May and that has created an avalanche of interest in myeloma. There has been a significant uplift in myeloma related content online and more and more people are understanding that when they hear myeloma they now know, "it's a blood cancer".



I want to thank my team and the board of Myeloma Australia for your continued support, positive energy, and your unwavering commitment to our myeloma community.

For 2024, we will continue to drive awareness. We firmly believe that through awareness there will be an increase in opportunities that will drive our ambition towards cure. As always, we will do all we can to support the 22,000 Australians and their family living with myeloma. You are the reason why we do what we do.

Mark Henderson
CEO Myeloma Australia



Updated Resource: Myeloma - A Comprehensive Guide

Make sure you take a look at our recently updated book, Myeloma a Comprehensive Guide. This resource will walk you through what myeloma is, how it affects the body, how it is treated and measures you can take to stay well.

Thank you to the members of our community who provided photos, quotes and reviews of the content and to Helen Chapman our editor with lived experience, MSAG member Dr Nick Weber who provided medical endorsement and Andrea from On the Ball Communications for bringing all the information together.

You will find it under the resources tab of our website www.myeloma.org.au and you can order a hard copy through the website shop or by calling 03 9428 7444.



Patient and Parliament Summit

In September we were pleased to be invited to attend the Patient and Parliament Summit at Parliament House in Canberra. This annual event convened by Bristol Myers Squibb provides an opportunity for members of support organisations to come together with healthcare experts and parliamentarians to discuss key health issues. CEO Mark Henderson, Lead - Stakeholder Engagement and Advocacy Hayley Beer and fierce advocate Geoff Nyssen represented Myeloma Australia at the event that discussed issues surrounding the theme, Medicines For All: Unlocking Universal Patient Access. We heard insightful keynote presentations from Health Reform Ambassador Dr Nick

Coatsworth, Chief Political Correspondent Phil Coorey, CEO Medicines Australia Liz De Somer and Deputy Chair of the Pharmaceutical Benefits Advisory Committee Jo Watson to name a few.

As part of the event, we were also fortunate to spend some time with Geoff's local Member of Parliament, Peta Murphy, to discuss the urgent need to reduce the time to access new therapies for myeloma in Australia. We are grateful for the opportunity to attend this event which allowed us to shine more light on the needs of the myeloma community and learn where we can join forces with other groups who are facing similar challenges.

Editors note: As we went to print we were saddened to hear that Peta Murphy has passed away from breast cancer. She was a great support to her electorate and we send our condolences to her family and friends.

Mashd N Kutcher Releasing 'It's Alright' with a cause greater than just being about the music



Mashd N Kutcher are a multi-platinum, unique, live electronic music act from Australia, created by Matt James in 2012 (who writes, records, performs, and produces the project's music). Combining elements of multiple genres & decades into their unique style of dance music, they perform live as a collective of DJs and multi-instrumentalists.

In August 2023, Matt James announced his diagnosis of multiple myeloma. In a parallel to the pandemic (and the release of their hit viral track 'Get on The Beers'), Mashd N Kutcher's Matt James has once again risen to a new challenge, albeit a personal one. Matt has turned to creating music in a way that channels positivity, in what would otherwise be a challenging situation. Matt has managed to write and produce 'It's Alright' whilst undergoing intense chemotherapy and specialist treatment. In conjunction with the release of 'It's Alright,' Mashd N Kutcher will donate 100% of the band's streaming royalties to Myeloma Australia, directly funding myeloma research, awareness & support.

"I have found strength in writing and producing music that I really care about. This song is about fun, positive vibes, no matter what the circumstances. It also means that 'It's Alright' to talk about things or carry a positive outlook when times are tough. In addition to people enjoying the record itself, I have decided to donate 100% of the project's Artist Streaming Royalties for this release forever to Myeloma Australia. It will directly contribute to awareness, research, support and funding for this blood cancer, in the hope to make a greater impact. People need to know more about myeloma and with enough funding, it helps get closer to a cure. Music lasts forever and with this in place, the song will always be generating money for cancer research, in turn helping others for many, many years to come."

Within days of its release, 'It's Alright' shot to the #1 dance song on the charts. You can stream 'It's Alright' and support Myeloma Australia and Mashd N Kutcher through Spotify, iTunes, Facebook, Instagram, TikTok, SoundCloud, and YouTube.



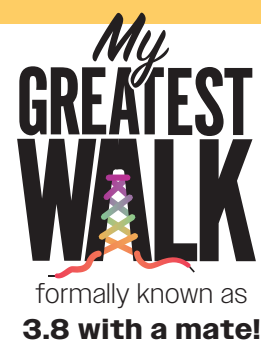
My Future My Life My Say CAR-T Cell Therapy Campaign

Thank you to everyone who made a submission to the Medical Services

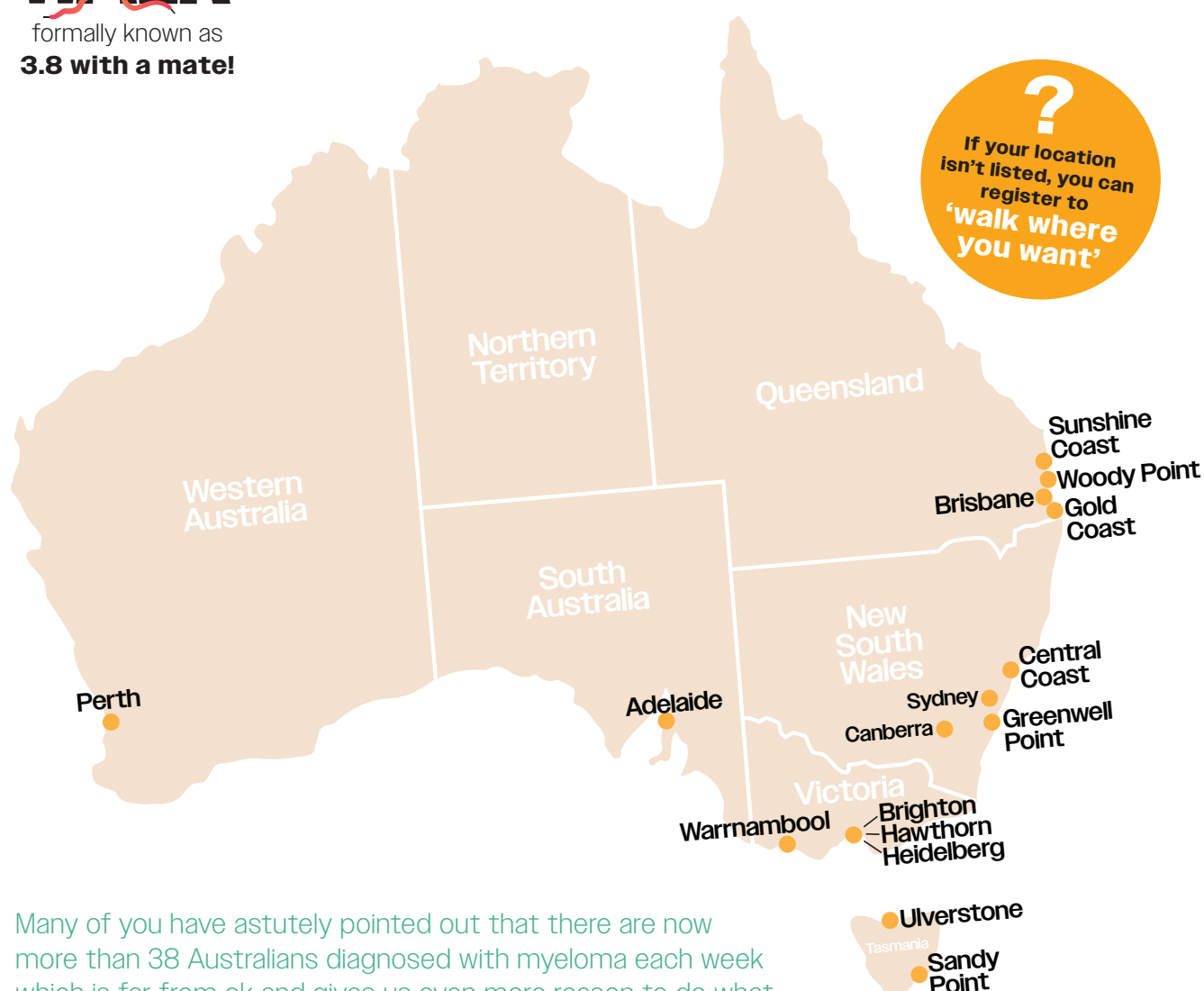
Advisory Committee to support the application for funding for CAR T cell therapy in Australia. We're told we have broken the record again for the greatest number of consumer comments received for an application and we now wait in hope that the committee will recommend that CAR T cell therapy be funded for myeloma. The committee discussed the application at their meeting in late November and we should know the outcome in the first quarter of 2024. We will share the outcomes with you all as soon as we hear.



If you'd like to become a volunteer Event Organiser, or set up a fundraising page to support your walk, contact Robert O'Brien
e: robert.obrien@myeloma.org.au ph: 03 9428 7444



My Greatest Walk Sun 3 March 2024



Many of you have astutely pointed out that there are now more than 38 Australians diagnosed with myeloma each week which is far from ok and gives us even more reason to do what we can to support each and every family affected.

With this in mind, we've decided to change the name of our annual walk to My Greatest Walk to complement Sandy Roberts' Greatest Call to find a cure for myeloma.

In gathering together for My Greatest Walk, we aim to raise community awareness and funds for Myeloma Australia. It can be a 3.8km walk – or a variation of this – it is a simple, achievable and community building event. We understand and appreciate that not everyone wants to, or is able to, run a 10km or half marathon – we are keen for the 3.8 to be as inclusive as possible.

We are very grateful to the volunteer Event Organisers around the country who have put their hand up to facilitate a walk in their area. We encourage you to gather your crew and join a walk near you. Locations are marked on the map below.

To register go to myeloma.org.au or call 03 9428 7444 for assistance.

Myeloma Australia's 4th Myeloma Education Workshops



Over 300 patients, carers and healthcare professionals gathered in Adelaide this August to learn about the latest in myeloma treatment and care.

The 4th Myeloma Education Workshops, brought together over 300 individuals for a series of presentations at The Adelaide Hilton on Saturday the 26th of August 2023. The event aimed to provide information, support, and a sense of community for those impacted by myeloma and their healthcare professionals.

Highlights

Attendees were warmly welcomed by Myeloma Australia Board Chair Karin Knoester, CEO Mark Henderson, and Ambassador Sandy Roberts, setting the tone for a day of informative presentations and lively discussion. The event featured parallel sessions for our patient and carer community and healthcare professionals, allowing us to tailor the topics to each audience.

Distinguished presenters, including members of Myeloma Australia's Medical and Scientific Advisory Group (MSAG) and South Australian myeloma specialists, along with international nursing expert Donna Catamero from Mount Sinai Hospital in New York, delivered insightful

presentations. Topics covered during the sessions included MGUS to myeloma, current treatment options, supportive care, and shared decision making.

The day concluded on a high note (pun intended!) with a special musical performance by Adelaide Vocal Union followed by a well-earned cuppa and a chat after a long day of learning.

If you missed it

If you were unable to attend we now have the recording available to view on our website: <https://bit.ly/3QFD8XO>. If you have any queries or technical issues please call 1800 693 566 or email nurses@myeloma.org.au.

Stay connected with Myeloma Australia for information about future education events and resources through Facebook, Instagram, and TikTok.

So you have myeloma.
I have myeloma too.

My Journey



Mel McMurray Living With Myeloma

Mel McMurray is a remarkable woman who has lived with myeloma for 9 years and it hasn't been easy. After ten lines of therapy, including an allogeneic transplant, a few episodes of radiation and a hip replacement she explains below how she copes. A full explanation of her therapy can be found on the website in the blog section.

Being diagnosed and living and surviving through the treatments and side effects has changed me over the years. In some warped sense, it is a blessing. Dealing with adversity opens many doors that might have been there but you didn't see.

I now live a much slower paced life but my quality of life is generally, very good. This is thanks to an awesome medical team who have given me the best chance of life, the nurses who look after me, and the many other people who I have come across over the years who have contributed to my wellbeing as well as, and no lesser, my family and friends. But also, my experiences, outlook and mindset, I believe, have been equally as important.

One experience that impacted me early on was during my first stem cell transplant. As for many, the experience wasn't pleasant. I couldn't eat and I had a lot of nausea and vomiting mainly because I was always too late asking for more anti-nausea medication (that is something I did learn from and during my next two transplants it was much more tolerable). But, for this first transplant I felt so unwell that I spent most of my time with my eyes closed, trying not to be sick and distracting myself by using my fingertips to feel the pattern on a quilt I had on my bed. I felt that all my other senses were in overdrive... smells, sounds, sight were just intolerable.

When I did go home, it was such a contrast sensory wise. The Jacarandas had come out whilst I was in hospital, it was quiet and peaceful at home (no beeping machines), I could feel the breeze and the warm sun. It was sensory bliss... This contrasting experience from hospital to home helped me become more acutely aware of my senses and to also appreciate the good feelings associated with them. So these days, I just soak up the sun, the rain, or the breeze or whatever my preferences are – and feel grateful for it – as it is so much better than that time I experienced in hospital!

Learning to take one day at a time and learning not to worry about the things that you cannot impact have been helpful strategies. With the constant feeling of the unknown and the possibility of one's myeloma no longer responding, is enough to increase anyone's anxiety levels. I have found focusing on things that I am able to do now, no matter how small, has helped shift one's mindset into a much better space.

Good nutrition and exercising, both within reason, have been important to me as I feel they help my body cope with the treatment. What might feel right for my body, may not necessarily be what another person needs so it's helpful to learn to tune in to your body requirements.

Finding hobbies and active interests that you enjoy is so helpful. Personally, I love walking outdoors and have always been into hiking, rock climbing and canyoning in my earlier years. These days my activities are modified but I do what I enjoy, walk, follow my latest passion of line dancing but also focus on keeping my body as in good condition as possible with specific strengthening muscle exercises. This helps me.

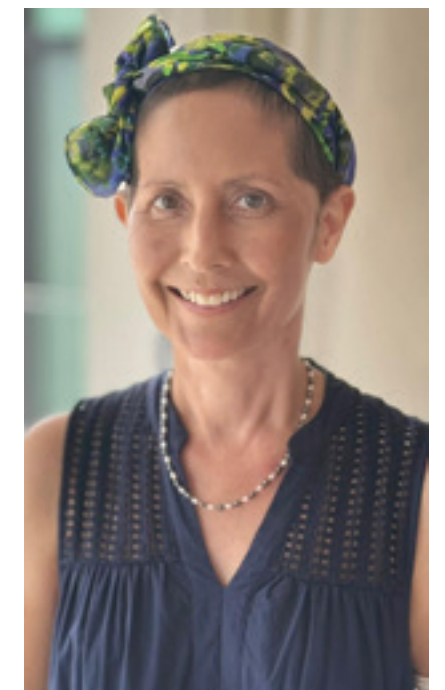
Having hope is so vitally important for me and to have a medical team around you that gives you hope but is also realistic is life changing.

Developing my own toolbox of coping strategies unique to me has been helpful. It's not something that happened overnight; rather, over the years, I have continued to fill my toolbox.

It was a matter of finding what worked for me considering my preferences, personality and what space I was in at the time. My toolbox might include different meditation techniques, mindfulness type strategies, breathing techniques etc. Find what works for you.

I have always been a goal-oriented person so it has been easy for me to set goals throughout recent years. More often than not, my goals have had to be tweaked or even changed thanks to the rollercoaster myeloma journey. Having flexibility, making them small and achievable, is the key.

Over these past 8 and a half years, I have been so fortunate to have access to a lot of new treatment options to manage my myeloma. It is only through research that better treatments become available. I encourage people to be involved in clinical trials if appropriate for them and to rally for more research funds either by fundraising or other means. We need research to progress towards a cure for myeloma because we need one.



We're pleased to introduce to you four fabulous new nurses at Myeloma Australia in Victoria and Western Australia. They have been busy getting to know our services and the myeloma community in their state. Thank you Cath, Danielle, Lucy and Sharni for joining the team and sharing a little bit about yourselves here.

Welcome to Our New Nurses



Cath Strickland (Vic)

I began my nursing career in 2006 at the Peter Mac Callum Cancer Centre in Melbourne as part of their graduate program. This is where my passion for haematology nursing was nurtured and I have continued on this journey throughout my nursing career. Patient, carer and nursing education are some areas I am truly passionate about and this has enabled me to work in various roles of professional and clinical practice development within haematology/ oncology. I've completed a graduate diploma in cancer and palliative care and look forward to completing my Masters at some stage in the not too distant future.

When I'm not working I'm busy with a family of four young children aged between 2 and 9 and have a wonderfully supportive husband. I enjoy keeping active with running and the occasional swim and of course love spending time with family and friends.

I'm very fortunate to be part of such a dynamic and experienced team at Myeloma Australia and look forward to the growth and development not only on a professional level but what I know this role will provide me with personally as well.



Sharni Dickenson (WA)

I have been a nurse for just over 10 years and have worked in various cancer services for most of that. Prior to starting work with Myeloma Australia, I was based on a bone marrow transplant ward. I now work as the bone marrow transplant clinical nurse in conjunction with my work at Myeloma Australia.

I grew up in country Western Australia, originally on a farm. My parents did a sea-change and moved to a small cray fishing town on the mid-west coast of WA. I came to Perth for boarding school and then university where I met my (now) husband and have only been back home for visits since I have a young son – he is currently 3. His journey into the world was a bumpy one, so he is destined to be an only child. Our suburban block also houses a cat named Max, a big boofa dog named Spencer and 4 chickens named Chickoletta, Henrietta, Nori and Cluck Norris.

In my 'spare time' I love gardening. My favourite flowers are Frangipanis and I have over 17 different types. I also love baking and decorating cakes. I love cricket and it was this love that led me to play the sport. We have a camper trailer and enjoy getting out and exploring.

I'm looking forward to getting involved with Myeloma Australia!



Lucy Murphy (WA)

I joined the Western Australia team at Myeloma Australia, in June this year. I was raised in Geelong (Vic) where I enjoyed activities like swimming and running. These activities have been easy to transition into the WA lifestyle. I moved over from Melbourne in September last year. Previously working in a private haematology and oncology hospital in Melbourne then moving straight to rural WA has been an amazing opportunity for my growth and understanding of the holistic needs of people who live rurally when facing a chronic disease like myeloma.

I have 5 years of haematology experience and am constantly developing my myeloma knowledge whilst working at a tertiary hospital in Perth. I am still getting to know the geographic locations of WA but with your help I aim to bring this diverse experience to assist and reach as many WA people living with myeloma as possible. Along with Sharni and Narelle, we are looking forward to meeting you and building a community that best supports you.



Danielle Hovey (Vic)

I started with Myeloma Australia back in May this year. I have been a Haemtology/Oncology nurse for 17 years in a variety of roles. Currently I am also working within the transplant/ apheresis team at my local hospital. I am enjoying my new role with Myeloma Australia and looking forward to working with the myeloma community, whether that's through our local support groups or on the telephone support line. What interests me most about myeloma is the vast array of treatment options available and how unique each individual's journey with myeloma can be.

In my spare time away from my full time work, I am busy with my husband raising our three children 14, 13 and 10. They keep us both active and on our toes with all three heavily involved in a variety of sporting commitments. We love camping as a family and enjoying the limited downtime we get between sporting seasons. I enjoy going out early in the morning listening to a podcast and running with our Groodle Ziggy.



Farewell Nella Combe

The team and Board of Myeloma Australia would like to express our gratitude to Nella Combe for her 7 years of dedicated service to Myeloma Australia. Nella began working for Myeloma Australia as a Specialist Myeloma Nurse then transitioned to Manager of Nursing and Patient Services. Nella was heavily involved in the management of the nursing team and was heavily involved in the advocacy initiatives at Myeloma Australia. This work made a huge impact on our myeloma community in many different campaigns over the years. Nella was extremely passionate about her work at Myeloma Australia and caring for the myeloma community. We would like to wish Nella all the best in her future endeavors.

The combined Annual Scientific Meeting of the Haematology Society of Australia and New Zealand was held from November in Melbourne. Here we wish to showcase the posters submitted by Myeloma Australia staff and colleagues which were accepted to BLOOD 2023. This body of work demonstrates the varied areas of research our staff pursue to improve the lives of everyone living with myeloma.



Assessing the needs of people affected by myeloma in regional, rural and remote settings.

Natasha Clare, Jacqui Keogh, Narelle Smith Myeloma Australia

Myeloma Australia wanted to better understand the needs of people living with myeloma in regional, rural and remote areas to improve service delivery. We invited out community to participate in a 16-question survey to assess their information needs.

Key themes identified: Financial toxicity, from having to travel to a specialist centre; Feelings of isolation and a desire for connection to others affected by myeloma; A belief that local healthcare professionals would benefit from myeloma specific education; An overall desire to learn about myeloma, it's treatments and how best to live with it.

This survey has provided valuable insight into the experience of those individuals living with myeloma in regional, rural and remote areas of Australia. Tackling their needs over such vast distances is a challenge that Myeloma Australia hopes to overcome by expanding their Nurse Link program. This program provides specialised myeloma information and support to regional nurses in the expectation that they will educate and support local nurses about myeloma in their local health districts and be a contact point for Myeloma Australia. Myeloma Australia has increased its virtual presence and aims to increase their ability to provide the face-to-face support that people in regional, rural and remote areas require. We are also using the information gained in this survey to apply for grants, public funding and advocate for our myeloma community.

Developing a national information and support program for younger people living with myeloma in Australia

Narelle Smith, Laura Jones, Catherine Bowley, Nella Combe, Jacqui Keogh Myeloma Australia

There are unique challenges and information needs for people who are diagnosed with myeloma at a younger age. We invited people who identified as a younger person or their support person to complete an online survey. The survey consisted of 21 questions focused on current supports available and their suitability, the experience of being a younger person with myeloma, and unmet support and information needs.

105 surveys were completed with regional and metropolitan representation. Perspectives shared in the survey identified issues and needs, including parenting and relationship challenges, communication with children, navigating work, future planning, treatment late effects, employment, and accessing practical assistance. Current support programs were evaluated by participants. As a result of this work, we have continued our existing national younger person's support group, recorded two podcasts involving a young person with myeloma and held a national webinar (the recording of this is available on our website). A comprehensive, myeloma-specific younger person's written resource currently in development.

Co-designing a pilot patient support program (PSP) for RRMM therapy prior to listing on the pharmaceutical benefits scheme

Furphy EJ, Beer H, Jones L, Davidson G, Lorensuhewa N, Farrell J, Etto T, Robbins M – Myeloma Australia, Antengene and Atlantis Health

X-TEND is a comprehensive PSP that provides one-on-one support to patients on a complex drug regimen. It provides education on side-effect management, ensures the patient has a better understanding of their disease and offers unlimited emotional and psychosocial supportive care.

The PSP has filled gaps that the hospital system is not able to fill. Myeloma Australia has plans to replicate this model with other myeloma therapies.

Using digital health to empower multiple myeloma patients in shared decision-making: findings from the Choiceapp® pilot study

S Fifer, H Beer, N Combe; LJ Axford; JLM Godsell; M Joshi; D Monro; L Toh - Community and Patient Preference Research Pty Ltd (CAPPRE) and Myeloma Australia

Australia is embracing a patient-centred approach to healthcare, which includes the implementation of shared decision making. The ChoiceApp® pilot study investigated the effectiveness of a digital tool in empowering patients to identify and communicate their personal treatment preferences to their health care professionals, thus promoting shared decision making. This pilot study confirmed that digital tools like ChoiceApp® can be effective in assisting MM patients and their health care professionals to discuss individual treatment preferences and are particularly valuable at specific time points in the treatment pathway. Findings are limited by study size but early data from the full launch suggests that the risk of side effects is important to patients when choosing between treatment options, followed closely by the length of remission period. You can read more about ChoiceApp® at <https://choiceapp.com.au/>





Quality of life in patients with multiple myeloma treated with Selinexor who had dose reductions: a subgroup analysis of the boston study

H. Quach et al, poster Blood 2023 – St Vincent's Hospital Melbourne

The oral XPO1 inhibitor selinexor is FDA-approved for treatment of RRMM with dexamethasone (Xd) or bortezomib and dexamethasone (XVd) in adults who have received at least one prior therapy.

Our exploratory, post-hoc analysis indicates selinexor dose reduction was associated with improved quality of life (QoL) in patients with relapsed/refractory multiple myeloma (RRMM). Together with previous results that selinexor dose reduction was associated with improved tolerability and efficacy in the BOSTON phase 3 trial (NCT03110562), these findings highlight the importance of dose reduction in optimising treatment of RRMM.

HSANZ myeloma specialist practice network: consensus recommendations on supportive care for patients with multiple myeloma receiving Selinexor

King T, Jagger J, Woodrow C, Demajo J, Beer H, Karica D, Snowden A, White K, Catamero D, Quach H - HSANZ Myeloma Specialist Practice Network

Aim of these recommendations is to provide guidance for nurses to deliver best supportive care to those receiving Selinexor through development of living consensus recommendations.

All available published research on Selinexor use were examined. Three core areas form the focus of the consensus recommendations: 1. Patient and carer education to assist in symptom monitoring and medication adherence. 2. Prompt and proactive symptom management in the first few cycles can reduce the risk of treatment discontinuation due to toxicity. 3. Prompt dose reduction with a "go slow and low" approach helps patients to better adjust to therapy.

Home is best: patient experience of Carfilzomib at home program

Nella Combe, Trish Joyce, Emma-Jane Furphy, Hayley Beer, Simon Harrison, Amit Khot - Peter MacCallum Cancer Centre

Carfilzomib is a proteasome inhibitor or targeted therapy, for the treatment of relapse/refractory multiple myeloma. It is administered as a 30-minute infusion into a vein, along with oral dexamethasone. This study analysed the patient experience of the Carfilzomib at Home Program started in March 2020 through Peter MacCallum Cancer Centre.

Results show that the Carfilzomib at Home Program is feasible and acceptable and safe to deliver. Key findings were that home administration was more convenient with virtually no out of pocket costs. The patient experience was that home delivery was convenient, patients felt confident and supported by the hospital.

When you're undergoing treatment for myeloma, you need to focus on your physical health. This often leaves your mental health on the back burner. Yet your mind may hold the power to impact your journey more than you think. Psychology support can help.

We Can't Ignore the Mind-Body Connection

Myeloma puts a huge strain on the physical body. When under physical strain, it's normal for our bodies to shut down emotionally. This is our brain trying to help us survive. If we allowed ourselves to focus on our emotional experience as well as the physical stress, it may be far too overwhelming. It makes sense! But this disconnect can't be maintained; our emotions can't stay below the surface forever.

Think about trying to hold a ball under the water, have you ever done this? You struggle and focus so much on keeping the ball down and it keeps trying to come to the top. As soon as we stop focusing on it, the ball shoots up. The more we've struggled holding the ball down, the more forceful it may be when it rises to the surface. We can liken this to our emotions, they always come to the surface no matter how much we struggle to keep them down. The ball shooting up may look like panic, anger, anxiety, sadness, or even withdrawing from others.

Psychological stress will always exist during myeloma treatment because the body and mind are together. Illness is not just in your body. Psychologists can provide a safe space for you to acknowledge the emotions you are feeling and give you strategies to tolerate and understand them.

Feeling Powerless

You often can't control many aspects of myeloma treatment and its progression. You feel powerless. This is a challenging place to find yourself in and your brain recognises this as a problem! A problem it needs to solve to protect you. But what happens when your brain can't find a solution? It tries to control everything in an attempt to take some power back.

You start to try and control your diet, you gather all the knowledge you can so you can make informed choices about treatment, you implement routines and recommended activity. Some of this feels helpful. But this can also lead to trying to control things that aren't particularly helpful - things like the people around you and their reactions, the way that you feel, and the things that happen to you.

In situations where we feel powerless, there's some merit in taking power back but not trying to control things that we have no control over. Think about it, there's so many things we can't control - the weather, a pandemic, our feelings, an illness. Getting stuck trying to control things we actually can't control leaves us in high anxiety, high distress. The Circle of Control diagram is a good example. When you find your thoughts and energy are stuck outside of the circle, take some power back by stepping back into the circle.

The power lies in understanding how you can live with something you can't change while continuing to find purpose and meaning in your life. Understanding where the purpose and meaning comes from can lead to helpful things you can do. It may also be likely that the things you find purpose and meaning from after a diagnosis have changed from before diagnosis. And this is completely OK!

Change of Identity

Integrating an illness into your identity is a process, and one that takes time, self-care and patience. Pre-diagnosis, your identity may have been wrapped up in what you did for work, your hobbies, your role in the family or being a certain type of friend or personality. The way we view ourselves influences how we interact with others and in the world. Who you know yourself as may be completely thrown into turmoil after a diagnosis. How do you now make sense of who you are living with a chronic illness? And how do you now interact with the world around you as this new version of yourself? Your relationship dynamics change, your work might change, your capacity to engage in things you've previously done may change. You can feel very alone and lost.

Connecting with others with similar journeys, sharing your stories, and working closely with a professional to continue finding your purpose in the midst of constant change and uncertainty can allow you to feel grounded, connected, and help you make sense of it all.

How to Access Mental Health Support

Our team of clinicians are passionate about providing a space for you to acknowledge your emotional experience. A space to reflect on the change in your identity, effectively communicate with loved ones, and live a valued life while accepting something you can't change. Our clinics have face to face appointments available in Geelong, Ballarat, and Bacchus Marsh but also Telehealth sessions from anywhere within the country. To access a psychologist, visit your GP and ask for a Chronic Disease GP Management Plan which will give you access to Medicare subsidised psychology sessions.

Ambassador Program

Myeloma Australia is proud to be partnering with these prominent Australians who have all been affected by myeloma in some way. Through their profiles they all strive to build a deeper understanding of myeloma in our community and are driven to support the pathway to cure.

Sandy Roberts

Sandy started his broadcasting career in 1970 as a radio presenter at 3CS Colac in Victoria, before switching to BCV Bendigo television as a news broadcaster. In 1973 Sandy joined the Seven Network in Adelaide as a general announcer and presenter. In 1980 he was asked to be a commentator for the 1980 Moscow Olympics, after which he moved to Victoria to continue with Seven Network Melbourne.

While with the Seven Network Sandy called over 800 VFL/AFL football games, covered the Australian Open Tennis and Davis Cups for many years, the Spring Racing carnival, and many major golf tournaments including the Australian Masters and Open, and the US and British Open Championships. Sandy also hosted the Seven Network's Bathurst coverage four times, was host of Channel 7's famous World of Sport for many years and also hosted shows including It's Academic, Sporting Chance of a Lifetime, as well as AFL Grand Final week specials and proudly hosted many hours of the Good Friday Appeal.

Sandy re-joined the Seven news team in 2005 and presented sporting events for a further nine years. In 2014 Sandy moved to Fox Footy to call AFL and Croc Media to host and commentate on radio for many AFL matches. In 2019 Sandy retired and is now a proud ambassador for Myeloma Australia.

"I am very proud to be a Myeloma Australia Ambassador – I agreed to this role to increase the awareness for the 22,000 fellow Australians suffering from this insidious disease and to hopefully raise desperately needed funds to find a cure."

The Honorable Dr Denis Napthine AO

The Hon Dr Denis Napthine AO served as the 47th Premier of Victoria. He served in the Victorian Parliament for 27 years representing South West Victoria and was a Minister in three Governments. In 2020, Dr Napthine was made an Officer of the Order of Australia (AO), for distinguished service to the people and Parliament of Victoria, particularly as Premier, to veterinary science and to the community.

Dr Napthine grew up on a family farm in Winchelsea, Victoria and was one of ten children. He and his wife have three adult children. He is passionate about regional and rural development, services for people with disabilities, regional educational opportunities and health services.

Dr Napthine is currently a non-executive Director of GMHBA Ltd and the NDIA (NDIS). His educational qualifications include a Bachelor of Veterinary Science (BVSc), Master of Veterinary Studies – Epidemiology and Preventative Medicine (MVS) as well as a Master of Business Administration (MBA).

Dr Napthine has been impacted personally by myeloma when his sister was diagnosed two years ago. *"I feel proud to join Myeloma Australia and to put my strength and energy in supporting the team as they seek out a cure."*

Frankie J. Holden OAM

Frankie J Holden was born in 1952, the same year as the FJ Holden was first manufactured, and during the course of his diverse career he has become as much of an icon as his automotive namesake.

Frankie J. Holden began his show business career with the legendary rock group, OL' 55, and has gone on to be recognised as one of our most versatile and popular performers. He is a multi award-winning actor and received a Silver Logie in 2019. Along the way he has created some of Australian television's most memorable characters through leading roles in long-running serials: Police Rescue, Round the Twist, Something in the Air, Underbelly and A Place to Call Home.

Frankie J Holden is also a very experienced and successful television presenter. From 1993 to 1996, he was part of the team roaming the globe for the Channel Seven show The Great Outdoors. For three years from 1996, he hosted the live variety programme In Melbourne Tonight for the Nine Network.

Frankie J Holden is a Paul Harris Fellow, the highest award bestowed by the Rotary International movement and was awarded a Medal of the Order of Australia in 2016 for services to the community and the arts.

"I've lost some dear friends to myeloma, including the late, great Jim Keays. I'm proud to be doing what I can to help Myeloma Australia in their efforts to support all Australians living with myeloma."



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.

When you go to donate, ask when you check in to have your name added to the MyeBlood team. You can also do it through your LifeBlood app: Lifeblood app: Account->Teams->and select 'MyeBlood'

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. Myeloma Australia is aware of the stress financial burdens can add when diagnosed with myeloma, 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.

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. In turn, as a partner of Myeloma Australia, ACA will make a regular financial contribution to support our Telephone Support Line.

To make contact, call 1300 013 328, or email aca@afrm.com.au for a free eligibility check

Australasian Leukaemia and Lymphoma Group (ALLG) Clinical Trials in Myeloma

– Key updates November/December 2023



For fifty years, the ALLG cooperative group has been bringing together blood cancer experts from across Australia and New Zealand 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 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.

Learn more at <https://www.allg.org.au/clinical-trials-in-myeloma-for-better-treatments/>

Professor Hang Quach is leading ALLG clinical trial **MM23 SeaLAND** that is evaluating a new medicine for patients called selinexor in the maintenance treatment stage, after a stem cell transplant. This is the only trial globally assessing this new treatment option for adult patients who are newly diagnosed with multiple myeloma and eligible for an autologous stem cell transplant. MM23 has opened 18 hospital sites across Australia and New Zealand.

Professor Quach is also leading two new ALLG clinical trials, the **ALLG MM25 VIBER-M** clinical trial and **ALLG's MM26 NORM** trial.

The **MM25 VIBER-M** trial is now open to recruitment at 2 Australian hospital sites, with a further 5 sites planned. This study is assessing a new oral (by mouth) treatment combination for patients with first or second relapse of Multiple Myeloma t(11;14).

The **ALLG MM26 NORM** clinical trial is for patients with relapsed and refractory multiple myeloma who have progressive disease after 1 prior line of therapy. The NORM trial aims to give more patients with myeloma greater access to new treatments via a platform study design. It has opened at 2 hospitals sites, with a further 3 planned.

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 <https://www.allg.org.au/clinical-trials-research/current-clinical-trials/> and read Frequently Asked Questions on clinical trials: <https://www.allg.org.au/clinical-trials-research/current-clinical-trials/faqs/>

The ALLG turned 50 this year. With over 1,000 members today – haematologists, nurses, scientists and professional support staff – the ALLG has contributed to what are now standard treatments for some blood cancers and continue to drive change for greater access to new and more effective therapies for patients. Learn more about ALLG's five decades of impact: <https://www.allg.org.au/about-us/5-decades-of-impact/>

Keep informed. Visit <https://www.allg.org.au/news/>, follow ALLG on Twitter, LinkedIn, and Facebook and subscribe to ALLG News. Learn more.

Updates from the Australasian Myeloma Research Consortium



The Australasian Myeloma Research Consortium (AMaRC) is a not-for-profit myeloma research group partnering myeloma experts and researchers to conduct myeloma trials in ANZ.

It has been a busy 2023 for the AMaRC team with a number of myeloma trials simultaneously recruiting (see below). Our BelaCarD and I-RIL studies with Prof. Hang Quach have also finished recruiting and we are excited to announce that both these studies will be presented as posters at the upcoming 65th American Society of Hematology (ASH) Annual Meeting. We also have a few proposals in development and hope to share these with you in 2024.

Currently Recruiting Trials

1. RIDDLE-M-X

Prof. Andrew Spencer & Dr. Sueh-li Lim

RIDDLE-M-X is a risk-stratified, response-adapted study using selinexor with bortezomib, lenalidomide, and dexamethasone for TE NDMM patients who are considered high risk (using the SKY92 MM Profiler) and/or do not achieve MRD negativity post ASCT.

VIC, NSW, and QLD.

www.amarconline.org/clinical-trials/riddle-m-x

2. 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).

VIC, NSW, and SA.

www.amarconline.org/clinical-trials/ibis

3. FRAIL-M (MM22) study

Prof. Andrew Spencer

Using a patient frailty (weakness) score, FRAIL-M aims to optimise treatment with lenalidomide and bortezomib for patients with TI NDMM while also investigating patients' preferences for combination treatments. The FRAIL-M study is a collaboration with the ALLG and funded by the Medical Research Future Fund (MRFF). We have 23 sites across:

Aus: VIC, NSW, QLD, SA, TAS, NT
NZ: Middlemore, Dunedin, North Shore, Christchurch, Palmerston North, Tauranga
www.amarconline.org/clinical-trials/frailm

4. MY-PROMPT-2

Prof. Andrew Spencer & Dr. Sueh-li Lim

A collaboration with the Transfusion Research Unit (TRU) at Monash University, MY-PROMPT-2 tests whether real-time symptom feedback using patient-reported outcome measures improves duration on treatment, leading to better patient outcomes and more efficient use of these high-cost medicines. We have 4 sites across VIC, NSW and QLD.

www.amarconline.org/clinical-trials/my-prompt-2

5. 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.

VIC and NSW.

www.amarconline.org/clinical-trials/pro-dvd

Upcoming Studies

1. ZEPFHR-MM

Prof. Andrew Spencer and Dr. Sueh-li Lim

A platform study for functional high-risk myeloma with individual phase II protocols having different novel combinations as separate domains, working under a central Ethics approval, allowing a tailored approach for participating sites to choose treatments most appropriate for their institution.

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.

Website: www.amarconline.org

Email: amarc@alfred.org.au

Twitter: @amarconline

News from the Myeloma and Related Diseases Registry (MRDR)



The Australian and New Zealand MRDR has over 6,600 patients registered with 57 approved sites. All Australian States and Territories are represented in the registry, along with strong representation in New Zealand. Thank you to all participating patients and staff at MRDR sites for your ongoing support.

Projects

MY-PROMPT-2

This trial aims to improve treatment experience and in turn, duration on therapy for patients with relapsed myeloma receiving commonly used treatments. Patients will complete questionnaires assessing symptoms and quality-of-life before clinic visits, and this is fed back to clinicians before the visit. This timely information on patients' response to treatment could help clinicians detect and treat emerging symptoms in a timely fashion, and lead to better health outcomes.

Myeloma 1000 (M1000) Biobank

This is a sub-project of the MRDR. The biobank aims to establish a repository of blood samples for assessment of biomarkers that better predict treatment response and patients at risk of developing myeloma or accelerated disease progression. Over 650 patient samples have been received to date and are being used in approved projects.

Publications

We are pleased to report a recent registry-based publication thanks to the valuable data provided. This publication aims to explore the outcomes of patients with translocation of chromosomes 11 and 14 referred to as t(11;14), in a cohort of Australian multiple myeloma patients. To read this publication and many others using MRDR data, head to our website: <https://www.mrdr.net.au/publications/>

Conferences

The MRDR hosted the Annual Breakfast Meeting at Blood 2023, the key ANZ haematology meeting. The meeting was a huge success with numerous collaborators across Australia and New Zealand coming together for an update on the registry's progress. The following MRDR projects were presented as posters at Blood: the MY-PROMPT-2 trial, EpiMAP; a disease modelling project, the prognostic impact of t(11;14), and a longitudinal study looking at factors associated with quality-of-life.

The MRDR was also active at the International Myeloma Society Annual Meeting in September, presenting 2 posters, and we have one oral presentation using M1000 data, and two posters using joint data from the ANZ and Asia Pacific MRDR registries for presentation at the American Society of Haematology Annual meeting 2023. We are certainly making good use of the data that patients and MRDR sites provide.

MRDR team and MRDR site representatives after the breakfast at Blood 2023

If you are interested in participating in the MRDR, ask your treating specialist if your hospital contributes data and if you are eligible to participate.



South Australia / Northern Territory

The second half of 2023 has been a busy one. It is great to see the Whyalla support group for the Upper Spencer Gulf up and running and Jo was delighted to be there in September. Our support groups are well attended but we are working to attract new members. We are planning how we proceed with the groups next year and will shortly send you a survey for your ideas as we really value your input.

We have received such positive feedback for the 4th Myeloma Education Workshop held at the end of August, it was fantastic to see the full house and that Sandy and Carolyn Roberts attended was a real highlight. The recording of the event is now available on the seminars and workshops page of our website.

The response for the tour of the myeloma research laboratory at SAHMRI in August was overwhelming and we have another planned for Monday 19th February 2024.

It was wonderful to be able to get back to Darwin where we held some health professional education and a support group meeting. If you're in the Northern Territory and not receiving our emails, please reach out. We'd love to hear from you.

The SA Facebook group are very active with another enjoyable lunch held in October. In November their first Adelaide MM road trip went to meet the South-East group, it's fantastic to see the social connections arising from something no-one chooses.

Please save the date – on Sunday March 3rd 2024, we will hold our 3rd annual 3.8 with a Mate walk (now My Greatest Walk) at the Patawalonga Reserve at Glenelg. A fun day is planned to bring our community together to raise awareness for myeloma.

Wishing all our SA and NT members and families a safe and happy festive season.

Jo and Alicia
Specialist Myeloma Nurses, SA/NT



Queensland

Over the past few months Megan and Tash have been enjoying seeing you at our regular information and support groups. It's fabulous to hear the sharing and support that you provide to one another- because no one quite understands the experience of myeloma as much as those who are living with it.

Our Inner Brisbane Walk and Talk group is still going strong, with our volunteer Jenny Nicol- thank you very much Jenny. We have two new groups forming- one on the Gold Coast at Paradise Point with volunteer Sue Perkins and one on the Sunshine Coast at Mountain Creek with Emma Chettle. John from the Sunshine coast said *"Thanks for the opportunity... I met a delightful group who were very supportive and informative not only to me, but to my family... It was nice to be active while talking"*. Look out for invitations to your local groups or on our events calendar or contact Tash via email, natasha.clarke@myeloma.org.au.

Denyse Hopkinson organised a painting workshop which also raised valuable funds for Myeloma Australia. Tash, who attended, found that art is a lovely way to unwind and practice mindfulness.

In September Megan and Tash were privileged to have Dr Phil Wong and Clinical Nurse Consultant Ron Middleton present to a seminar in Toowoomba. It was also lovely to meet all of you and we plan to get there a bit more next year.

We would love to be able to provide support groups to everyone in Queensland but unfortunately, we are quite limited with our resources. We hope that Myeloma Australia's efforts at fundraising will mean that we can expand to areas out of Southeast Queensland. In the meantime, we have our virtual Statewide Catch Ups that run monthly – just check the Events Calendar and keep an eye out for the invitation.

Megan and Natasha
Specialist Myeloma Nurses, QLD

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 <https://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.





New South Wales / ACT

Wow 2023 seems to have flown by hasn't it?! Here we are wrapping up another busy year!!

It's been wonderful to resume some of our face-to-face support groups this year and we are so pleased that other regular social groups are forming around the state and territory. We constantly hear how worthwhile it is to make these connections, both for people newly diagnosed and those who have been living with myeloma for many years, as well as the carers who are able to relate with others in similar situations. We also love facilitating our monthly NSW/ACT online catch up for the same reasons – it's always very well attended, and we thank you for sharing your stories with us and each other!

In 2024 we do hope to improve our reach to areas where we may not have a presence or where we need to re-establish connections, particularly in our regional areas. Please reach out to us if you have any suggestions or are interested in forming a local group in your area.

Providing education about myeloma for both patients/ carers and health professionals is an integral part of our role as Specialist Myeloma Nurses. We were fortunate to be involved in patient seminars on the Central Coast and in Concord Hospital recently. We have also enjoyed visiting hospitals and treatment centres around the state and territory to educate nursing staff. We look forward to more of these opportunities in 2024.

We wish all of our members and their loved ones a safe and happy festive season as we look forward to 2024.

Cath Bowley and Diana Yun
Specialist Myeloma Nurses, NSW



Tasmania

It is lovely to feel some warmth come our way this side of the strait and see flowers and plants flourishing in everyone's gardens. Likewise, it has been great to see our support groups flourish. Over the last few months we have enjoyed presenters Dr Helen Cooley, rheumatologist, talking on fragility in myeloma in the south of the state, and podiatrist Virginia Bower who discussed peripheral neuropathy at one of our Launceston groups.

At our October meeting in the south, it was a real pleasure to have Will Plumb, whose mother has myeloma, talk to us about his plans to raise funds for Myeloma Australia by running the Western Arthurs Traverse in south-west Tasmania in December. The traverse is considered one of Tasmania's most challenging walks. It covers approximately 60km with almost 4000m of elevation and is usually hiked over several days. Will, his brother and a small team, are planning to run it in under 24 hours. You can support Will through 'JustGiving' online. At the time of writing, Will has raised almost \$12,000. Talking of fundraising, plans are underway for two walks for '3.8 with a mate' (now My Greatest Walk) on Sunday 3rd March next year. One will be held in Ulverstone and the other in Lower Sandy Bay.

I had the opportunity to attend and participate in the MAGIC conference in Adelaide in August, organised by Myeloma Australia, which turned out to be a terrific success both for patients and health professionals alike.

I would like to thank our supporters in Tasmania, namely Cancer Council Tasmania, the Howrah Community Centre and the Penguin Football Club whose staff have been so kind in providing their facilities for us to hold our face-to-face meetings, and I am looking forward to our 'End of year catch-ups' in a few weeks' time across the state.

Deborah Thompson,
Specialist Myeloma Nurse, TAS



Victoria

We are busy planning for what will be an exciting 2024 and are looking forward to making some changes to benefit the myeloma community. In our recent statewide cuppa and chat sessions we have been fortunate enough to host various guest speakers. This has been well received and we will look to continue to incorporate this further in the new year.

We are pleased to welcome Rachel back to the Victorian team with open arms. Rachel will assist us in facilitating information and support groups and seminars in the South West region.

Much collaboration has begun with health care providers across the state with a large focus on healthcare professional education. We were lucky enough to host an educational evening with Donna Catamero, a nurse practitioner in the multiple myeloma program at Mount Sinai Hospital in New York City. This was a great opportunity to share experiences, knowledge and professional education about the provision of nursing care for patients, families, carers and friends in the myeloma community.

The annual National Myeloma update was once again a great success. We'd like to thank Professor Miles Prince for providing such relevant information on myeloma and new and emerging therapies. This seminar will be available to view via our website for those who were unable to attend.

We are looking forward to co-facilitating a Clinical Trials Patient Information Seminar in collaboration with St.Vincent's Hospital, the Leukaemia Foundation and Lymphoma Australia. This event will be held in February 2024.

We'd like to thank everyone for such a warm welcome and wish you all a very safe and happy holiday period and we look forward to welcoming in the new year with you.

Danielle, Catherine and Rachel
Specialist Myeloma Nurses, Vic



Western Australia

There has been a lot of growth behind the scenes at Myeloma Australia within the WA team with the addition of two new nurses to the team. Lucy joined the team in June and Sharni shortly after in August. Both nurses bring fresh ideas and enthusiasm with planning well and truly underway for events both in the Perth metro area as well as regionally in 2024.

In addition to getting established in their new roles and getting to know members of the myeloma community at some of our support groups, Lucy and Sharni are very keen to spend some time building relationships and providing health professional education within the different health sites across the state and further details will follow about this.

Narelle has taken a period of leave whilst she undertakes another work opportunity with the Cancer Network WA. Narelle was able to come along to the HSA NZ WA nurse group dinner to share a presentation about some of the most common symptoms and side effects experienced by people living with myeloma and some nursing insights into management strategies. Narelle will be returning to work with Lucy and Sharni in the New Year 2024.

The WA nurses are planning a local cuppa and catch up with a haematologist to be held in early 2024, so please keep an eye out for an invite to this event. In the meantime, Lucy and Sharni are both very keen to meet more of the WA myeloma community so please reach out to them using the contact details on our website.

Merry Christmas and we look forward to connecting with you all more in 2024.

Narelle, Lucy and Sharni
Specialist Myeloma Nurses, WA

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

We have now switched from Zoom to Teams for all online Information and Support Groups. For further information or help joining a group via Teams, please contact your state's Specialist Myeloma Nurse via the contact details below

Please take note of the updated phone numbers for our nurses. If you'd like to send a text message you can do so on 0483 955 501 stating the person's name or state you would like to contact and it will be forwarded on.

Information and Support Groups National

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

For enquiries, please contact:

Myeloma Support Nurses

E: nurses@myeloma.org.au

M: 1800 693 566

Information and Support Groups NSW/ACT

For enquiries, please contact:

Cath Bowley

E: cath.bowley@myeloma.org.au

Ph: 03 9967 4278

Diana Yun

E: diana.yun@myeloma.org.au

Ph: 03 9968 5477

Information and Support Groups Queensland

For enquiries, please contact:

Tash Clarke

E: natasha.clarke@myeloma.org.au

Ph: 03 9968 5474

Megan McDowell

E: megan.mcdowell@myeloma.org.au

Ph: 03 9968 5472

Information and Support Groups SA/NT

For enquiries, please contact:

Jo Gardiner

E: jo.gardiner@myeloma.org.au

Ph: 03 9968 5473

Alicia Hopper

E: alicia.hopper@myeloma.org.au

Ph: 03 9968 5475

Information and Support Groups Tasmania

For enquiries, please contact:

Deborah Thompson

E: deborah.thompson@myeloma.org.au

Ph: 03 9967 4267

Information and Support Groups Victoria

For enquiries, please contact:

Danielle Hovey

E: danielle.hovey@myeloma.org.au

Ph: 03 9968 5479

Catherine Strickland

E: catherine.strickland@myeloma.org.au

Ph: 03 9967 4248

Laura Jones

E: laura.jones@myeloma.org.au

Ph: 03 9967 4295

Rachel Lochrin

E: rachel.lochrin@myeloma.org.au

Ph: 03 9967 4279

Information and Support Groups Western Australia

For enquiries, please contact:

Narelle Smith

E: narelle.smith@myeloma.org.au

Ph: 03 9967 4265

Sharni Dickenson

E: sharni.dickenson@myeloma.org.au

Ph: 03 9967 4297

Lucy Murphy

E: lucy.murphy@myeloma.org.au

Ph: 03 9968 5478