## Contents

### In this issue

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>From the President</td>
<td>3</td>
</tr>
<tr>
<td>National Myeloma Month Online Seminar Series</td>
<td>4</td>
</tr>
<tr>
<td>Queen’s Birthday Day Honours</td>
<td>5</td>
</tr>
<tr>
<td>Palette Idols</td>
<td>6</td>
</tr>
<tr>
<td>Tai Chi</td>
<td>7</td>
</tr>
<tr>
<td>Mater Hospital Queensland</td>
<td>8</td>
</tr>
<tr>
<td>My Myeloma Story</td>
<td>9</td>
</tr>
<tr>
<td>News from the Myeloma and Related Diseases Registry</td>
<td>11</td>
</tr>
<tr>
<td>Advocacy News</td>
<td>12</td>
</tr>
<tr>
<td>What’s happening – Community Engagement and Fundraising</td>
<td>12</td>
</tr>
<tr>
<td>What’s happening QLD</td>
<td>13</td>
</tr>
<tr>
<td>What’s happening SA</td>
<td>13</td>
</tr>
<tr>
<td>What’s happening TAS</td>
<td>14</td>
</tr>
<tr>
<td>What’s happening VIC</td>
<td>15</td>
</tr>
<tr>
<td>What’s happening WA</td>
<td>15</td>
</tr>
<tr>
<td>Medical Corner</td>
<td>16</td>
</tr>
<tr>
<td>Calendar of Events</td>
<td>18</td>
</tr>
</tbody>
</table>

---

**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.

---

**Office Hours:** 9am – 5pm Monday to Friday AEST  
**Head Office:** 333 Swan Street, Richmond, VIC 3121  
**Post:** PO Box 5017 Burnley, VIC, 3121  
**T:** 1300 632 100 (toll free)  
**T:** (03) 9428 7444

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

Myeloma Foundation of Australia Inc. ARBN 126 035 247  ABN 30 476 390 368
COVID-19 has changed the world as we knew it and there will be, once everything settles down, a new normal. This will be very different to what was normal at the beginning of this year.

Many of you, like my wife and I, have been self-isolating since the last week of March. Our adult children read the riot act to us and told us what to do in no uncertain manner. The roles had reversed. Other than a daily walk around the neighbourhood we have been staying at home catching up with friends and family via the phone or using Zoom. The interesting thing is that we used to speak to my son and his family about once a week, since this all started we speak to them daily and they drop in on Sundays and we stand in the driveway, social distancing, and talk with them all.

We have noticed, when out walking, it is always us who cross the road to avoid other walkers who normally do not move to allow space when passing. This reminds us of the period after Ros' transplant how we avoided people in the street, our version of social distancing which we are now doing again.

These last few months have seen many changes occurring at Myeloma Australia (MA) with staff working from home. We had been using Zoom technology as a way to reach to members of the myeloma community in rural Australia and the nurses are now using Zoom to continue the many Myeloma Information and Support Groups we have Australia wide. The Board has also been using Zoom technology for meetings.

I hope that many of you have had the opportunity to see at least one of the four Myeloma Month Online Seminars presented during May. These were excellent presentations and I would like to add my thanks to the doctors and allied health practitioners who presented and to our Myeloma Support Nurses who planned and presented them. I watched them all and as I have mentioned many times, I always learn something new each time I attend one of our seminars or webinars. All the presenters where excellent and I was impressed by the high standard of the questions asked by the audiences.

These webinars have been put on our website to be watched if you missed them, in addition, we have been adding short video presentations by members of the MSAG committee. Please log onto the site as there is new information now being added on a regular basis.

At the beginning of June the combination of Revlimid, Velcade and Dexamethasone (RVd) was approved by the PBAC and will be subsidised by the pharmaceutical benefits scheme for myeloma patients. This will be available for previously untreated myeloma. This is the first triple treatment subsidised for use in myeloma.

Thanks to all of you who placed a submission with the PBAC during early June in favour of the approval of daratumumab and the once daily use of carfilzomib. This is an important form of advocacy helping to get these new treatments approved for treating myeloma.

While we have been able to maintain our high standard of service to the community during the Covid-19 pandemic this has come at a cost to us. Many of our fundraising events have had to be cancelled or postponed. The funds raised by these events goes a long way in helping us to provide our support services and even with the help of the Government’s Jobkeeper fund we are eating into any reserves that we have. I know things are difficult for many of you but if you can find some way that you can support Myeloma Australia we would be very grateful.

I fondly remember the passion when we had differences of opinion when communicating late at night in those early days, by email or phone, and then we would meet the next day for coffee and resolve the issues that had us at loggerheads the evening before.

It was Bob’s drive and enthusiasm that set Myeloma Australia on the road to what we are now, and he was always excited to hear what we had achieved and what we were planning.

Bob was a real gentleman and he will be very sorely missed by all who knew him.

I fondly remember the passion when we had differences of opinion when communicating late at night in those early days, by email or phone, and then we would meet the next day for coffee and resolve the issues that had us at loggerheads the evening before.

It was Bob’s drive and enthusiasm that set Myeloma Australia on the road to what we are now, and he was always excited to hear what we had achieved and what we were planning.

Bob was a real gentleman and he will be very sorely missed by all who knew him.

Brian Rosengarten
Building Our Community

This year has seen changes in almost all aspects of our lives and National Myeloma Month was no exception. Not wanting to miss out on our usual month of seminars we decided to create a series of online seminars. Thankfully we were able to enlist the technical support of our landlords, CVP Productions. Darren, David, Mark and Jon worked hard behind the scenes to make sure we could have our speakers give their presentations from their homes or workplaces while maintaining contact with the audience via question submission.

We delivered four online seminars on Saturdays throughout May. The overarching theme of the month was Building Our Community with the focus being on all the people or services to engage when living with myeloma.

The beauty of this format was being able to bring to you a variety of speakers from all around the country straight to your living room. It was such a unique opportunity to be able to provide such quality information to anyone with a computer, smart phone or tablet and internet connection.

We took great delight in hearing from people from far reaching parts of Australia and even overseas. We are still trying to figure out how we had such a loyal group joining us from Chicago each week. If you’re reading this in Chicago, please get in touch. We’d love to hear from you! You can email nurses@myeloma.org.au.

The topics covered throughout the series include: An overview of myeloma, myeloma and the immune system, surviving steroids, supportive care, community pharmacy, exercise and fatigue. We were also able to call on the expertise of MSAG member, Associate Professor Hang Quach for dedicated Q&A sessions from the audience. One particular highlight of the events was in seminar two where we heard a beautiful recount of their experience building their team from Nick Allen who is living with myeloma and his wife Helen Nicolay. Both had really powerful messages to give.

We would like to extend a huge thanks to our speakers who volunteered their time and expertise. It can be quite a daunting experience but they managed the new way of presenting beautifully.

We also really value and appreciate the feedback received from the audience. Some of their comments are as follows:

“We are new to myeloma so it was useful in helping us to grasp what’s involved. Our last four weeks have been so hectic. This seminar proved to be a great occasion for us to cool a bit and feel clearer about our new world”

“Really enjoyed and learnt a lot from this today. I would not have attended a seminar if it was face to face as I live in a remote area. Looking forward to the next one!! Great Job!!”

“My carer also understood a lot more about myeloma and my treatment. I am very happy to know that there is ongoing research to find more treatment when needed.”

“I would just like to thank Myeloma Australia for organising this seminar – it was very informative and interesting. I was diagnosed eight years ago with Myeloma and Cardiac Amyloidosis and have always found the seminars to be quite informative and I am always learning new information. Thank you.”

The recording of all four events can be viewed on our website on the National Myeloma Month page. https://myeloma.org.au/national-myeloma-month/
Myeloma Australia are very proud to announce that two long-standing MSAG members have received Queen’s Birthday honours this year.

Professor Joy Ho has been awarded a Member of the Order of Australia (AM) for significant service to medical research, to haematology, and to professional bodies.

Professor Andrew Roberts received a Member of the Order of Australia (AM) For significant service to medical research, to haematology, and to cancer organisations.

On behalf of the myeloma community, we would like to thank Joy and Andrew for their hard work and dedication to improving the lives of people with myeloma.

Well done Joy and Andrew!

Thank you
Your support makes a big difference

Entertainment Book
**Get your Entertainment Membership NOW and help Myeloma Australia raise much needed funds!**

Help us raise funds for Myeloma Australia by buying an Entertainment Membership from us. Over $20,000 worth of offers the whole family will love!

You’ll receive hundreds of valuable offers for everything you love to do, and help our fundraising at the same time. Hurry, Entertainment Memberships sell out quickly.

For more information contact Matt Maudlin
Community Engagement & Fundraising Manager
E: matt.maudlin@myeloma.org.au • M: 0407 891 052
A creative group of individuals was looking forward to taking part in this year’s HBF Run For a Reason in Perth at the end of May. However, COVID-19 ensured the event was cancelled for 2020 – but this did not stop Darcy Connolly and her intrepid crew, Palettes Idols, from taking to the streets anyway!

I caught up with Darcy recently to ask her a few questions about her reasons for participating and the day of the event itself …

**Matt:** Hi Darcy, as we can see from the photos your Palettes group is a very colourful bunch of people! Please tell me a little about the group

**Darcy:** Hi Matt, Palettes is a dance group inspired by Japanese popular culture and cosplay, we all share a similar love for Japanese music and their idol culture. We have been a group for three years now, with two and a half years since the beginning of our actual activity. While not the founder of the group I am one of the original members and one of the main organisers for the group.

**Matt:** And what was your reason for taking part in the event to raise funds for Myeloma Australia?

**Darcy:** In January this year I lost my poppy to his battle with the side effects of myeloma. He had a severe infection in his infusion port as well as an infection in a fistula which had caused problems the year prior. He fought myeloma for 11 years and over that time the advancements made to treatment and care thanks to myeloma research made such a difference and it gave us more time. It allowed him the time to see all his grandchildren into adulthood and there is no way I can thank anyone enough for the extra time we got to spend with him.

**Matt:** Now as we know, all things coronavirus have got in the way of fundraising efforts of all charities nationwide – but coronavirus could not put a dampener on the Palettes group – although I understand that the weather tried to on the day?! Please tell us about your reasons for pushing on and about the day itself.

**Darcy:** We were extremely lucky with COVID restrictions lifting in our area in time for us to walk on the day that was originally planned for HBF run. We have always been a group who won’t take no for an answer so when HBF cancelled we made our minds up to walk anyway. Unfortunately for us curveballs also tend to come our way and this one came in the form of an ex cyclone hitting Perth and sending wild weather our way. We were determined to walk despite the weather and managed 8.5km of the 12 we had hoped for before we had to call it for our safety. We persisted as far as we could because for people who have myeloma or any other form of cancer, you don’t get to take a day off just because the weather is bad. It’s something you have to keep fighting. Giving up before we tried wasn’t an option.

**Matt:** That’s inspirational Darcy. Thank you for pushing through despite the elements and for reaching your fundraising goals. All of us at Myeloma Australia appreciate the efforts of your group. And what is next on the agenda for Palettes?

**Darcy:** The future of Palettes will be more performing together, many more memories made and hopefully a lot more money and awareness raised. We love getting to give back to our community so hopefully we can chase the finish line of the 12km next year!
Tai Chi

What is Tai Chi?

Tai chi can be different things to different people. It is often viewed as an ancient art form. Sometimes people associate it with martial arts. Today tai chi is practised by millions around the world as a gentle exercise form, often described as moving meditation.

Tai chi is practised with upright posture, slow, gentle and controlled movements. Practitioners’ attention is on coordinating upper and lower body movements, relaxing the joints as well as mindful of weight transfer. Practitioners also focus on synchronising the breath with movements which makes it a very relaxing mind body exercise.

Why Tai Chi?

Tai chi is safe and versatile. Its slowness and gentleness make it suitable for most people with stable chronic health conditions. It can be practised standing or sitting or even visualising the movements lying in bed.

Tai chi is also economical and portable. It does not require special clothing, or equipment. It can be practised alone or in company. It is not weather dependent, can be done indoors or outdoors.

Above all tai chi is easy to learn and very enjoyable.

What Are The Health Benefits?

Numerous studies have shown that practising tai chi improves muscular strength, flexibility, and overall fitness. With better muscular strength and flexibility, people are confident to move more. More movements lead to improved circulation and cardio vascular function. This in turn enhances the healing process and improves immune response.

In this context, tai chi is ideally suited for people undergoing medical treatment or on a rehabilitation journey. Tai chi practice can be as short as five minutes for those who get tired easily. Duration can be progressively increased and frequent short practices may increase your energy level and exercise endurance.

The slow, smooth and continuous movements induce a calming and meditative effect. It may help to reduce depression and contribute to better stress management and pain relief, enabling people to better manage activities of daily living.

Tai chi can be learnt easily and practiced at home in the current social distancing and stay-at-home period. There are some very good online subscriptions and self-paced learning DVDs for this purpose.

Tai chi is safe, enjoyable and effective in health improvement.

Would You Like To Have A Go?

1. Stand or sit with feet hip width apart, soft knees, upright body.
2. Bring your hands slowly up to prayer position as in photo 1.
3. Slowly breathe in and pull the arms apart to shoulder width as in photo 2.
4. Slowly breathe out and bring the arms together again as in photo 1.
5. Repeat three, six or nine times.

Remember to use the shoulder and upper arm muscles and you should feel the slight rise and fall of the chest.

To progress to a more complex level, at the in-breath, slowly pull arms apart, and gently allow the tummy to relax and swell a little. At the out-breath, bring arms closer, at the same time gently contract the lower tummy muscles and squeeze the pelvic floor muscles.

References

https://taichiforhealthinstitute.org/what-is-tai-chi/
https://taichiforhealthinstitute.org/why-tai-chi/

About the Author

Lorraine Norton is an Australian Exercise Professional, and a Senior Trainer with the Tai Chi for Health Institute. Lorraine teaches tai chi in the community and in residential aged care in Newcastle NSW.

Lorraine is happy to be contacted via email for information on online lessons and self-paced learning DVDs in the current pandemic environment.

Email: lorraine.norton88@bigpond.com
Facebook @taichiforhealthnewcastle
National Myeloma Month

Wards 8 East & 8 North in the Mater Private Hospital Brisbane deliver specialist inpatient care to individuals undergoing treatment for haematological and oncological malignancies as well as non-malignant haematological and immunological disorders. Patients admitted to 8E/N include those who have been diagnosed and require treatment for multiple myeloma which may involve chemotherapy, immunotherapy, radiotherapy, apheresis, blood product support and peripheral blood stem cell transplant.

Responsibility for monthly educational activities for the wards is allocated to a different team of nurses with the month of May focusing on multiple myeloma. Both wards were decorated with handmade banners designed to represent blood & platelet transfusion bags; information posters; quiz activities to test your knowledge of MM and a “Guess the Number of M&Ms fit inside the Bone” game with gold coin donations forwarded to Myeloma Australia.

Thanks to the creative efforts of Aleesha, Steven, Emma, Jess, Alphonsa, Daisy, Sonia and Esther, the staff and patients of Wards 8E/N now have a much better understanding of multiple myeloma and the implications this has for both the patient and those caring for them.

Your suggestions please

The team at Myeloma Australia are busy preparing our events calendar for the remainder of the year. We anticipate that social distancing will be necessary for quite some time but that doesn’t mean we can’t continue to provide high quality information via our online seminars.

We’d love to hold a seminar focusing on topics that are a little tricky to discuss or are seldom spoken about. Is there something that you find difficult to bring up with your health care team? Please let us know so we can include the topic in our event. For those with email addresses we will be sending out a survey very soon or you can submit topics anonymously via our Telephone Support Line or by posting a letter to 333 Swan St Richmond, VIC 3121.

Did you know that you can donate to us through your pay? It’s easy and quick, tax benefits are immediate and there’s no need to organise receipts at the end of June. It even has the possibility to double your donation to us!

We’re listed on the Good2Give workplace giving Platform. Scroll to the bottom of www.good2give.ngo and see if your employer is one of the 150 companies in the scroll bar. If your company isn’t yet on Good2Give, direct your corporate responsibility or payroll teams to www.good2give.ngo and suggest they request a demo.

Workplace giving streamlines our financial management of corporate donations and reduces our administration. Ninety nine per cent of all donations reach charities on the Platform, and 70 per cent of the companies match their employee donations!

You can even fundraise for us if your employer is listed on Good2Give, and channel your donations through workplace giving, again, potentially doubling your result!

Any questions? Please contact Matt at Myeloma Australia: matt.maudlin@myeloma.org.au
My name is Richard Thresher. My wife, Christelle, and I live in the beautiful Sunshine Coast. In 2015 when we were temporarily living in Melbourne I was diagnosed with multiple myeloma (MM). This diagnosis was a huge shock and came completely out of the blue. It really made us think about the future and to reassess our options in life. Travel plans were put on hold and treatment plans took priority.

My treatment was supervised by Prof. Miles Prince who proved to be a superb communicator. He first of all allayed our fears about the treatment and about the prognosis – I wasn’t about to depart this mortal coil in the very near future! The treatment plan consisted of a battery of tests and scans followed by four months of Velcade infusions prior to an autologous stem cell transplant (STC) at the old Peter Mac Hospital. During the Velcade treatment I was told to avoid infections but high temperatures saw me hospitalised on a few occasions. Eventually, early in 2016 it was time for the SCT which went very smoothly.

During my treatment we read lots of information about MM, with several publications being published by Myeloma Australia. From these and the website we learnt about the MA Information and Support Groups, and in time we joined the Beaumaris group which proved to be a mine of information to help us understand the condition as well as to avoid the inevitable pitfalls experienced by other members. Most of all it gave us a sense of belonging and a means to make friends with other people in similar situations to ours.

Within a month of leaving hospital after the Melbourne STC we packed up our belongings and implemented our plan to move to the Sunshine Coast. Soon after we settled into our new home, I went to see a specialist up here and was very pleasantly surprised to find the Clinic was very modern and had beautiful views out to Caloundra and the Coast (much better than the bare walls and rows of patients undergoing treatment at the hospital in Melbourne). We decided to have no maintenance therapy, preferring to be drug free, but I was put on monthly bisphosphonate treatment to help strengthen my bones, which had been weakened by the MM. My blood counts were also monitored and showed that the MM was pretty much quiescent. I was fortunate to get three years of drug free remission before my counts necessitated a return to treatment.

There were no Myeloma Australia Information and Support Groups in Queensland in 2016, but in 2017 my wife and I attended a morning tea and talk given by The Leukaemia Foundation at another local gem (the other gem is the clinic), Bloomhill Cancer Care Centre in Buderim. Being a not-for-profit organisation Bloomhill provides a range of therapies and support for cancer sufferers in a wonderfully peaceful rainforest setting. At the meeting we met several other MM patients and we talked over the chances of setting up a myeloma specific group on the SC. We mentioned the possibility to Bloomhill and they offered us a room for an hour and a half once a month. We named the group The Bloomhill Myeloma Peer Support Group and we held our first meeting in May 2018. Although Myeloma Australia did not have representation in Queensland at that point, they were informed about us and sent up lots of materials to help get us started. The group quickly grew and then in October 2018 MA appointed two Myeloma Nurses, Megan and Tash, in Brisbane, which was fantastic news. The group invited the nurses to attend one of our meetings and from there MA has taken over coordination of the group, although we still do a bit of organisation and liaison work ourselves.

I was offered the chance to have a second SCT using my own stem cells left over from the first. After discussions with my haematologist I decided to go ahead with it. My initial five months of treatment, which started in May 2019, was with Carfilzomib and Dexamethasone, as well as several other drugs designed to prevent infections and lessen the side-effects of the other drugs! This was done at my favourite clinic on the SC. The SCT could not be performed up here so we had to go to the Mater Hospital in Brisbane for that. The SCT took place in mid-October 2019 and went really well for a few days, but after that it proved to be a fair bit more difficult than the first SCT, possibly because I opted for the full 200mg melphalan treatment, because of my age and because of the lasting effects from the first. This time I had to spend six weeks in hospital with various ailments following the transplant and I was not the happiest of chappies. Nevertheless, the medical staff were great, and even the food must have been great, but I couldn’t enjoy it because of my total lack of taste and appetite, plus a mouthful of sores. I soon grew tired of the TV and luckily the guest wi-fi was really good so I managed to access some Foxtel programmes on my tablet and computer. The best thing was that I was able to Skype my son and his young family in the US every day. After six weeks, despite the great facilities and the even better nurses I was crawling up the walls to escape, and escape I did in early December.

At this point I should mention the assistance we received from the Leukaemia Foundation. They maintain several accommodation units in Brisbane with free transport to the hospitals for patients and carers from out-of-town. We were...
provided with a unit at the Clem Jones Sunland Village in Browns Plains. Christelle stayed there and took the courtesy bus on week days to see me at the Mater. This was a real boon as it boosted my morale during my treatment. She would not have been able to endure the 90Km each way trip to Brisbane on a daily basis, either by car or train.

After I left hospital, the follow up treatment consisted of weekly blood tests and visits to Brisbane to see my specialist and to have my Hickman Line flushed. The Hickman Line stayed in for six weeks after my discharge from the Mater just in case I needed more infusions. After the Hickman was removed the weekly specialist consults were conducted over Skype and when he was happy with my progress (Paraprotein Level 1, yeah) I was referred back to the clinic on the Sunshine Coast. Currently I am on carfilzomib and dexamethasone maintenance infusions one day a fortnight which, after an initial hiccup, I seem to be tolerating the therapy pretty well.

I think one of the factors that enabled me to have a second SCT was the fact that I tried to keep fairly fit, even when I was feeling a bit grotty whilst I was on treatment. During the SCT I used to do walking laps of the ward accompanied by my dancing partner, the infusions stand. I love bike riding which keeps my cardio vascular and respiratory system in good fettle but am hopeless at maintaining a home exercise regime. The Exercise Physiologist at Bloomhill prescribed a set of exercises which I started but I am very naughty and these have dropped off over time. I lost 10Kg during my second SCT, most of it seemingly muscle (why not fat!!) and I am hoping the exercises will help put on upper body muscle as well as improve my balance which suffered a bit. I really feel that the treatment goes much easier if you are reasonably fit.

Finally, and most importantly I have to acknowledge the contribution to my wellbeing through all the treatment and procedures by my wife, my carer. Her support and optimism have been the rock upon which I have leant during the good and bad times. She goads me to do more when I feel lazy, she reminds me to take my medication, she chides me for my chemo-induced forgetfulness and forces me to develop strategies to remember to do things, but most of all she encourages me to improve, to do better and to get through the bad times. What would I do without her?

By Richard Thresher

---

Do you have multiple myeloma?

We’d like to hear from you about your sexual well-being

Participate in 20-minute online survey

Go to https://is.gd/2020sexuality to participate

Complete surveys will be eligible for a draw for a $20 Visa gift card

(1 in 20 chance to win, email address is required for draw)

The Health Research Ethics Board of Alberta - Cancer Committee approved this study.
Study ID: REB: 19-0346
Principal Investigator: Dr. Lauren Walker

Questions?
Contact Megan Henkelman at Megan.Henkelman@ucalgary.ca or +1 (403) 614-2260
Dr. Lauren Walker at Lauren.walker@albertahealthservices.ca or +1 (403) 831-9581

The Health Research Ethics Board of Alberta - Cancer Committee approved this study.
Study ID: REB: 19-0346
Principal Investigator: Dr. Lauren Walker

Questions?
Contact Megan Henkelman at Megan.Henkelman@ucalgary.ca or +1 (403) 614-2260
Dr. Lauren Walker at Lauren.walker@albertahealthservices.ca or +1 (403) 831-9581
The MRDR team continues operations working from home since late March through June. We recognise the pandemic may affect research and appreciate any recruitment and data entry possible during this time. Our best wishes to all patients and site staff participating in the registry.

MRDR Recruitment update

June saw recruitment reach over 3700 patients to the registry. The most recent sites to join are Palmerston North Hospital in New Zealand, Royal Darwin Hospital and Orange Hospital in NSW. We now have 48 approved sites and 10 more with approval pending (see map). Regional sites are becoming better represented in the MRDR over time and we hope their participation continues to increase.

The Myeloma 1000 Project

The Myeloma 1000 biobank project now has samples for over 430 patients and is receiving research proposals for their use. Samples have been sent to the University of Adelaide to investigate a potential biomarker of progression from precursor disease to multiple myeloma. Further samples will be sent to a New Zealand laboratory once it is re-opened after closure due to COVID-19. Peter MacCallum Cancer Centre is the latest site to commence recruitment to the biobank and we look forward to more approved sites becoming active.

MRDR: how can your hospital be involved?

Ask your treating specialist if your hospital contributes data to the MRDR and if you are eligible to participate. If so, you will receive a patient information sheet about the registry including how to opt out if you change your mind.

TO CONTACT THE MRDR

P 1800 811 326  E sphpm-myeloma@monash.edu

mrdr.net.au

RESEARCH

Registry Projects

The MRDR is receiving an increasing number of proposals for analyses. More recent projects include an in-depth view of causes of death in patients with multiple myeloma; outcomes for bortezomib versus lenalidomide use in patients with newly diagnosed multiple myeloma who are ineligible for autologous stem cell transplantation; and outcomes for patients with early progression or sub-optimal response in multiple myeloma in Australia and New Zealand. We welcome further proposals and look forward to providing information on the outcomes of these projects.

My-PROMPT

The My-PROMPT trial was completed in 2019 and is now published. It confirmed the feasibility and acceptability of real-time feedback of Quality of Life questionnaires for patients with multiple myeloma to their treating clinicians before clinic visits https://onlinelibrary.wiley.com/doi/10.1002/ajh.25815.

Thanks to Gilead Sciences and Takeda Australia for their support of this project.

IMPROVE

The IMPROVE biobank is recruiting and seeks further participating sites in and close to Melbourne; a limited transport time restricts recruitment to this area. For sites interested in participating in IMPROVE (Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology) or the biobank please see the contacts. This registry-based study funded by the National Blood Authority will describe immunoglobulin use in Australia and inform policy and clinical practice in this area.
Myeloma Australia is involved in advocacy programs on both local and global levels. The aim of these programs is to improve the lives of people living with myeloma and work towards a cure. We do this by increasing awareness of myeloma, sharing the lived experience, building community and working to improve access to care, treatments and education both locally and globally. Advocacy work can take many forms and we are pleased to announce that we will updating you regularly through this new column.

**Changes to Pharmaceutical Benefits Scheme (PBS) listings**

RVd (Lenalidomide®/Velcade®/dexamethasone)

From June 1st the combination of RVd is available on the PBS for those with newly diagnosed myeloma. This triplet drug regimen is available regardless of the persons eligibility for a stem cell transplant.

Lenalidomide (Revlimid®) maintenance therapy

We are delighted to announce that as of April 1st the PBS have listed lenalidomide (Revlimid®) as maintenance therapy. This will now be available to those receiving or requiring maintenance treatment after an autologous stem cell transplant.

Upcoming submissions at the July PBAC (Pharmaceutical Benefits Advisory Committee) meeting

- Carfilzomib® weekly dosing
- Daratumumab®/Velcade®/dexamethasone for second line therapy

Thank you to all who have submitted comments, we eagerly await the recommendations made at the next meeting and will update you with the outcomes through our e-newsletter ‘The Muster’

In addition, our CEO Steve Roach, has been involved on an international working group addressing the inequitable access and price of myeloma treatments globally which we will report on in the next Advocacy column in the MyeNews.

If you would like to be involved in any of our advocacy programs, please contact

E: advocacy@myeloma.org.au

**Community Engagement & Fundraising**

The impact of Covid19 upon all aspects of our Community Engagement & Fundraising has been pronounced. It’s time like these when the old adage that ‘necessity is the mother of invention’ becomes quite true! But first, it would be remiss of me to NOT mention some of the community fundraising that has occurred across the past couple of months – you will see in this edition the story of Palettes Idols in Perth and their determination to keep walking/running for Myeloma Australia despite their event being cancelled and a tropical cyclone descending upon Perth as they headed out onto the streets for their event; this is an inspirational story! And I also make mention and thank all participants of the recently completed 2Beez Goldfieldz Tour which was organised by Brett and Bernard. June brings to an end our fundraising arrangement with our friend Marnie and her wonderful Marmalade Gardens jewellery – thank you Marnie for all your fundraising for Myeloma Australia!! We have noticed of late that an increasing number of people are fundraising for us through the Facebook Fundraising platform; whilst this is marvellous I would very much appreciate people hosting fundraising in this way to contact me – just to allow me to know who is fundraising for us. Thank you.

Back to the ‘necessity being the mother of invention’ truism – whilst the major community running events that Team Myeloma participates in annually in Perth and Adelaide have been cancelled for 2020 – and at the time of publishing the Run Melbourne and Sydney’s City2Surf must be considered extremely doubtful – we have been busy at Myeloma Australia HQ figuring out alternative community engagement/fundraising opportunities for later this year. I’m not giving too much away here and now – but you will hear of some upcoming opportunities in the very near future!

The coronavirus has delayed the employment of our new NSW Community Engagement & Fundraising Manager; we are now hoping to have this position filled very early in 2021.

And as always, do please contact me with your ideas around community engagement & fundraising – I love your ideas, great and small!

Kind regards,

Matt Maudlin
Community Engagement & Fundraising Manager
Myeloma Australia
M: 0407 891 052
E: matt.maudlin@myeloma.org.au
What’s happening QLD

We really enjoyed being part of the National Myeloma Month Webinar Series. For those of you who missed them you can still catch up on the recordings on our website. Megan and Tash joined forces with Deb in Tasmania (which meant we couldn’t complain about the cold) and covered topics such as new treatments, advocacy, building a community team and caring for the carer. One of the highlights from that particular webinar was listening to Nick Allan talking about his myeloma journey and his wife Helen talk about the challenges of being a carer. They presented a moving but practical picture of how it is to live well with myeloma. Thank you Nick and Helen.

Megan and I would like to give a big shout out to ward 8N at the Mater Private Hospital in South Brisbane who put on a fabulous display to raise awareness of myeloma for National Myeloma Month. It’s great to see hospitals getting in the spirit.

While it’s been really sad not catching up with people face-to-face we have been having some great virtual support groups, with the regulars getting a very competent hold on the technology. These groups will continue until we are able to meet face-to-face so look out for your invite and join in. Remember that you can always get technical support from Megan, Tash or head office. Now that Megan and I have embraced the technology we will start to expand on our skills and invite some speakers to talk on various topics while also providing more targeted talks to you all. Please have a look at the event calendar on our website for more information.

Mater Hospital

What’s happening SA

We had such plans…then COVID (new noun ruling our world). In late February the South-East meeting was held, which Alicia and Jo attended and combined with a road trip to the head office in Melbourne. The SE group were great as always. Jo presented a discussion on ‘MGUS to Myeloma’, which explained what MGUS is and what changes occur if it develops into active myeloma. Carol and Merridy shared their experiences of living and travelling with myeloma. As usual we were spoiled with the most beautiful cream puffs in the world, baked by Rhonda.

Back in Adelaide in early March and unbeknownst to us at the time, Alicia ran the last face-to-face SA Information and Support Group at the beautiful Living Kaurna Cultural Centre. Much of the discussion focused on COVID-19 and what risks it might present for everyone in the future. It was also announced at the meeting that Jenny Naylor was stepping down as coordinator of the group for personal reasons. We thank and acknowledge Jenny for her many years of hard work, energy and enthusiasm in helping make the Flinders group the vibrant and welcoming group that it has become.

In the following weeks our plans for the year ahead in SA were abruptly forced to change. With the very real fear of COVID-19 spreading through our community all support groups moved from in-person to online, in the form of Zoom meetings. Alicia and Jo really miss our face-to-face groups but our new program of Zoom Information and Support groups as well as the recent webinars has enabled us to achieve new and unexpected goals.

We started fortnightly Zoom meetings inviting all SA members to join in. Four SA meetings have been held to date with between 13 -21 people zooming (new COVID verb) in. Jo and Alicia have been gratified to see so many of our members give the technology a go! Our sessions so far have included discussions on how to use Zoom (which
we will continue to support you with), COVID-19, isolation and the changes it brought to hospital appointments and treatments. We held a Q&A session arising from the first two webinars held for National Myeloma Month in May and our most recent meeting focused on food and exercise with Libby Austin, physiotherapist, joining as a guest presenter. Zooming has allowed us to hold meetings more frequently and there will be more available for you to join when ever you feel like it.

We are excited to announce new support groups for specific parts of our community: these include a Younger Persons group, a Carer-specific group and a Northern Territory group as well. Please look out for announcements regarding upcoming dates on our website, Facebook and via email.

We remain committed to:

**Face to face groups** returning when we are advised by our Medical and Scientific Advisory Group (MSAG) that it is safe to do so. We have received commitments from our venues that we will be welcome to return when able.

**Tours** of Professor Andrew Zannettino’s Myeloma Research Laboratory based at SAHMRI and Dr Craig Wallington-Beddoe’s Multiple Myeloma Translational Research Laboratory and Clinical Trials Unit at Flinders Centre for Innovation in Cancer. New dates will be arranged once the facilities reopen to the public.

**Education for health professionals** caring for myeloma patients. We are planning an online seminar for health professionals in a similar format to the May webinars. Alicia and Jo are heading up this initiative.

Whilst the world has changed and our service delivery has changed with it, we remain dedicated to providing information and support to all our members in whatever way we can. However, we sure are looking forward to the day when we can again meet up in the same room (and indulge in Rhonda’s cream puffs)!

Feedback about our Zoom Information and Support Groups:

“It’s great to keep everyone connected and it gives me something to look forward to whilst I can’t get out of the house much.”

“It isn’t the same as a face to face group but it’s lovely to still be able to see each other and keep in touch.”

“I always come away with something new I’ve learned. It’s amazing just how talking with one another produces all sorts of unknown titbits I didn’t know before!”

“Groups online suit me…I don’t have to leave the house, dress up, drive the car and I can do stuff right up until the meeting starts!”

About the recent webinars:

“They were great, watched everyone…from the comfort of my own home.”

“Particularly loved the patient experience from Nick and Helen in week two, I was so impressed by their strength and courage.”

“It was fabulous to hear from doctors from around the country…the Myeloma Australia staff were great too. It all had a really good vibe.”

“There was so much variety in the presenters, and so much to take home. It was fabulous people could ask questions and have them answered in real time. The presenters talked TO us, made it very personable.”

What’s to come over the next few months…

- More online information events for you and health professionals.
- A Younger Person’s Support Group.
- Exciting speakers at our online groups.
Wow…. Where have the last couple of months gone in isolation? We have been busy beavering away flexing our services to fit with the current times.

Over the last couple of months, we have introduced a “Cuppa and Chat” each week. This has been a great opportunity to meet in a more informal way without speakers or prepared topics. We hope you have enjoyed the opportunity to speak with members from around the state as much as we have.

Once we return to face-to-face support groups, we will be starting new groups in Warrnambool, Bairnsdale and Mildura. We invite any new members to reach out to us and make contact if you are interested in joining these groups. We welcome you to attend our existing groups in similar regions in the meantime.

We know how popular the La Trobe Seminar is to our community, which is held annually in November. This will still go ahead, however may look a little different this year.

The year of 2020 so far has certainly been different with COVID19 providing some challenges for us in delivering our services and events to our community, but we have faced it head on and successfully rolled out an online program for Western Australia. So, while we have certainly missed meeting up with everyone face to face, we have embraced our national organisational approach of virtual online meetings as a mode to reach people who may not have had an opportunity in the past to attend our events. We look forward to the future whereby we can provide information and support groups both in face to face format as well as using this online technology to reach out to the wider myeloma community, improving access for all.

**Information & Support**

After the initial awkwardness and technical issues with the new online format, our regular support groups of North metro, South metro, Perth Hills, Younger Persons and South West have continued strongly with attendances of five to nine people at each online group and several new attendees at many of these groups. Meeting online has also provided us with a great opportunity to start a new regional WA group in addition to the pre-existing South West group that we co-facilitate with the Leukaemia Foundation. The Regional WA support group was held in April and had attendees from the far north to the far south of WA and it was great to hear the shared stories from those participating. We are looking forward to continuing this online support group as a regular fixture.

With May being National Myeloma Month, we in the west were able to showcase some local experts in one of the Myeloma Australia seminar series events, presented along with the support of our Queensland colleague Megan and an outstanding head office team. We were fortunate in securing Dr Hasib Sidiqi a haematologist from Fiona Stanley Hospital and fresh from his move back from the US, who gave some great insights into the immune system and its role in the treatment of myeloma.

We also had some of our allied health colleagues who provided practical advice about how to live well with myeloma. Amy Oliver a senior occupational therapist provided strategies in how to manage fatigue including the introduction the four P’s of Prioritise, Plan, Position, Pace as a practical framework to help with dealing with fatigue. This session complemented the session on Myeloma and exercise presented by Ben Kramer, an accredited exercise physiologist who highlighted the important role exercise plays in living with myeloma. He concluded his session with a workout session that can be done within your own home.

We are looking forward to continuing to provide our support groups and information seminars in an online format for the remainder of 2020 and we are also excited about some new programs in development using the online format including a focus on carers. We will be hosting another information seminar in August. This will be an online format and we will have further information available about this in the coming weeks.
COVID-19 mortality in patients with cancer on chemotherapy or other anticancer treatments: a prospective cohort study; Lennard Y W Lee, DPhil; UK Coronavirus Cancer Monitoring Team et al; Published: May 28, 2020; DOI: https://doi.org/10.1016/S0140-6736(20)31173-9

Data suggest chemotherapy and anticancer treatments not significant contributors to worse outcomes in cancer patients with COVID-19

An analysis published in The Lancet of the largest cohort presented so far of cancer patients with coronavirus disease 2019 (COVID-19) has concluded that recent chemotherapy use is not a significant contributor to more severe disease or a predictor of death from COVID-19. Moreover, there were similar observations for immunotherapy, hormonal therapy, targeted therapy and radiotherapy.

“Our data are strongly indicative that COVID-19 mortality in patients with cancer is principally driven by advancing age and the presence of other non-cancer comorbidities,” wrote Lennard Y.W. Lee, University of Birmingham, UK, and colleagues. They warned that “withstanding effective cancer treatments from many cancer patients during the pandemic runs the very real risk of increasing cancer morbidity and mortality, perhaps much more so than COVID-19 itself.”

Once versus twice weekly carfilzomib in relapsed and refractory multiple myeloma by select patient characteristics: phase 3 A.R.R.O.W. study subgroup analysis


The phase 3 A.R.R.O.W. study demonstrated that treatment with once-weekly carfilzomib (70 mg/m2) and dexamethasone (once-weekly Kd70 mg/m2) improved progression-free survival compared with twice-weekly carfilzomib (27 mg/m2) and dexamethasone (twice-weekly Kd27 mg/m2) in patients with relapsed and refractory multiple myeloma (RRMM; median, 11.2 versus 7.6 months).

Once-weekly dosing also improved response rates and depth of response. We performed a subgroup analysis from A.R.R.O.W. according to age (<65, 65–74, or ≥75 years), renal function (creatinine clearance <50, ≥50–<80, or ≥80 mL/min), number of prior therapies (2 or 3), and bortezomib-refractory status (yes or no). Compared with twice-weekly Kd 27 mg/m2, once-weekly Kd 70 mg/m2 reduced the risk of progression or death and increased overall response rates in nearly all the examined subgroups, consistent with reports in the overall A.R.R.O.W. population. The safety profiles of once-weekly Kd70 mg/m2 across subgroups were also generally consistent with those in the overall population. Findings from this subgroup analysis generally demonstrate a favourable benefit-risk profile of once-weekly Kd70 mg/m2, further supporting once-weekly carfilzomib dosing as an appropriate treatment option for patients with RRMM, regardless of baseline patient and disease characteristics. However, it should be noted enrolment for this study closed prior to the current approved dosing of twice-weekly Kd56 mg/m2 limiting comparison with current treatment guidelines.

Subcutaneous daratumumab in patients with multiple myeloma who have been previously treated with intravenous daratumumab: A multicenter, randomized, phase II study (LYNX).

Nizar J. Bahlis, et al; Journal of Clinical Oncology, Volume 38, Issue 15 suppl

Background: The intravenous (IV) formulation of daratumumab (DARA), a human CD38-targeted monoclonal antibody, is approved in many countries for use as monotherapy in relapsed/refractory multiple myeloma (RRMM) and in combination with standard-of-care regimens in RRMM or newly diagnosed MM. A subcutaneous (SC) formulation of DARA is under investigation in several ongoing studies. In the phase 3 COLUMBA study, DARA SC was shown to be non-inferior to DARA IV, demonstrating similar efficacy and pharmacokinetics, with a significantly decreased rate of infusion-related reactions and reduced administration time.

The phase 2 LYNX (MMY2065) study will evaluate the efficacy and safety of retreatment with DARA SC in combination with Carfilzomib and dexamethasone (Kd) compared with Kd alone.

© 2020 American Society of Clinical Oncology; Clinical trial information: NCT03871829; Research Sponsor: Janssen Research & Development, LLC

Prolonged lenalidomide maintenance therapy improves the depth of response in multiple myeloma

Clinical Trials & Observations

Rafael Alonso, María-Teresa Cedena, Sandy Wong, Nina Shah, Rafael Rios-Tamayo, José M. Moraleda, Javier López-Jiménez, Cristina García, Natasha Bahri, Antonio Valeri, Ricardo Sánchez, Luis Collado-Yurrita, Thomas Martin, Jeffrey Wolf, Juan-José Lahuerta, Joaquin Martinez-López

Maintenance therapy has been considered a key component in the treatment of multiple myeloma (MM) for at least a decade. The underlying concept of maintenance is to control the disease by both direct activity against malignant plasma cells and enhancement of the immune response. Despite its proven benefits, it has only very recently been approved by all regulatory agencies. The ideal maintenance should be convenient and well tolerated and, for these reasons, most treatments for MM have been unsuitable for prolonged maintenance.

We retrospectively analysed 139 patients who received lenalidomide maintenance in real-world clinical practice and...
whose minimal residual disease (MRD) levels were observed during the treatment period. Lenalidomide maintenance correlated with an increased depth of the disease response, with 38.1% of patients achieving maximal response during maintenance. Moreover, 34.3% of patients who were MRD positive after induction treatment achieved MRD-negative status during maintenance and ultimately had improved PFS. Sequential MRD assessments identified patients with progressively decreasing MRD levels who also had better PFS outcomes, compared with patients not showing a decreasing pattern of MRD. These results support the role of maintenance therapy, not only to sustain, but also to increase the depth of disease response with a PFS benefit. In addition, MRD monitoring during maintenance can provide information that may help in their clinical management.

John Snowden, Chair of the Autoimmune Disease Working Party, comments on the publication entitled “Vitamin D deficiency predicts for poor overall survival in white but not African American patients with multiple myeloma;” (Yellapragada SV et al; Blood Adv. 2020 Apr 28;4(8):1643-1646..) “published in EBMT newsletter 30 April 2020

Vitamin D has association with a range of ‘non-classical’ roles in a wide range of disease processes including immunity, inflammation, auto-reactivity, cancer, and now even in recovery from stem cell transplantation. Myeloma combines all these disease processes and SCT. Yellapragada showed that vitamin D deficiency is associated with significantly reduced survival outcomes in patients with symptomatic myeloma. They identified 1889 patients with myeloma who had vitamin D measurements within 62 months of diagnosis. Vitamin D deficiency was a significant independent predictor of overall survival in white patients but not in African American patients, despite lower Vitamin D levels and higher rate of deficiency. There was no association between serum vitamin D levels and sex, stage, initial therapy, or SCT, but in white myeloma patients with vitamin D deficiency there was a stark difference in survival (median, 2.71 years vs 3.87 years).

Vitamin D deficiency may affect mortality in myeloma because of skeletal-related events, bone marrow microenvironment, myeloma cell growth and survival, areas where vitamin D may play a unique role in myeloma compared with other cancers. It may be that, like in asthma, vitamin D potentiates the effect of high dose corticosteroids routinely used in myeloma, perhaps enhancing disease control. More studies of vitamin D and its deficiency in myeloma are required to explain these associations.

Screening for vitamin D deficiency has been recommended in the long-term follow up of patients with myeloma. Replacement and maintenance is simple, inexpensive, and probably harmless in most patients. Active monitoring of vitamin D is therefore recommended, and higher doses of supplementation may be indicated.

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

**BM:** bone marrow

**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

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

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

**Phase III trial:** accrue large numbers (thousands) of patients to confirm efficacy and monitor long term effects of the study drug/s

**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

**Randomized study:** one cohort gets the active drug and the other does not

**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 remission (as for CR plus normal blood light chain ratio and absence of clonal cells in bone marrow)

**Tandem transplant:** 2 ASCT performed to intensify treatment

**Triplet:** 3 drugs used in combination

**VGPR:** very good partial remission (>90% reduction in myeloma markers)
During this time of required social distancing, our Information and Support Groups will be conducted through Zoom video conferencing technology. This will allow us to continue delivering ongoing support and education to the myeloma community. Zoom can be accessed through a computer, iPad or smartphone with an internet connection.

If dialling in using an iPad, iPhone or smart phone you will first need to download the Zoom Cloud Meetings app via the App store or Google Play store. If you don’t have access to a computer, iPad or smart phone you can still access this meeting by using your telephone.

Listed below are the current Information and Support Groups being held across the country. To find out specific log in details for each group please go to our website https://myeloma.org.au/event-calendar/
For further information please contact your State Myeloma Support Nurse

---

**Information and Support Groups ACT**
- Canberra

*For enquiries please contact*
**Jacqui Keogh**
E: jacqui.keogh@myeloma.org.au
M: 0426 404 230

---

**Information and Support Groups NSW**
- Central Coast
- Forster / Taree
- Liverpool
- Lismore
- Mid North Coast ‘Cuppa & Chat’
- Newcastle
- Orange
- Regional NSW ‘Cuppa & Chat’
- RPAH
- Tamworth
- Westmead
- Younger Persons

*For enquiries please contact*
**Jacqui Keogh**
E: jacqui.keogh@myeloma.org.au
M: 0426 404 230

**Juliet Hill**
E: juliet.hill@myeloma.org.au
M: 0433 511 554

**Rachel McCann**
E: rachel.mccann@myeloma.org.au
M: 0433 511 606

---

**Information and Support Groups QLD**
- Alderley
- Buderim
- Fraser Coast/Wide Bay
- Gold Coast
- North Lakes
- Princess Alexandra Hospital
- Younger Persons

*For enquiries please contact*
**Tash Clarke**
E: natasha.clarke@myeloma.org.au
M: 0416 019 585

**Megan McDowell**
E: megan.mcdowell@myeloma.org.au
M: 0416 019 022

---

**Information and Support Groups SA**
- Carers
- Flinders & Southern Adelaide
- Fullarton & Central Adelaide
- Mid-North
- South-East
- South Australia
- Younger Persons

*For enquiries please contact*
**Jo Gardiner**
E: jo.gardiner@myeloma.org.au
M: 0447 331 165

**Alicia Hopper**
E: alicia.hopper@myeloma.org.au
M: 0426 716 165

---

Calendar of Events 2020
*Groups / events are subject to change at short notice.*
*Please check the website for a more up to date schedule.*
https://myeloma.org.au/event-calendar/
**Information and Support Groups TAS**

- Launceston
- North West
- Southern TAS
- Cuppa & Catch-up – South
- Cuppa & Catch-up – North

*For enquiries please contact*

Deborah Thompson  
E: deborah.thompson@myeloma.org.au  
M: 0433 511 689

---

**Information and Support Groups VIC**

- Albury / Wodonga
- Ballarat
- Beaumaris
- Bendigo
- Berwick
- Cuppa & Catch-up
- Coburg
- Geelong
- Horsham
- Kew
- Shepparton
- Sunshine
- Traralgon
- Wangaratta
- Warragul
- Younger Persons

*For enquiries please contact*

Laura Jones  
E: laura.jones@myeloma.org.au  
M: 0451 404 203

Emma-Jane Furphy  
E: EJ.Furphy@myeloma.org.au  
M: 0426 404 233

---

**Information and Support Groups WA**

- Coffee & Chat
- North Metro
- Perth Hills
- South Metro
- South West
- Younger Persons

*For enquiries please contact*

Kerin Young  
E: kerin.young@myeloma.org.au  
M: 0426 404 310

Narelle Smith  
E: narelle.smith@myeloma.org.au  
M: 0426 404 280

---

**Our latest resource is now available**

Autologous Stem Cell Transplant – A guide for people with myeloma is a comprehensive explanation of what to expect when the doctor recommends an autologous stem cell transplant in the treatment plan.

The book can be found on our website www.myeloma.org.au under the Patients and Carers tab > Resources page.

Please contact head office if you’d like a hard copy  
P: (03) 9428 7444 or E: support@myeloma.org.au
Myeloma Australia is the only myeloma specific support organisation in Australia

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

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

Find your nearest myeloma support group to meet other people

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

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

Mon – Fri 9am – 5pm AEST

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