

# MyeNews

Spring 2020 Issue no 55

Myeloma  
Australia



# Contents

## In this issue

From the President	3	What's happening	10
Profile – NSW Myeloma Support Nurse	4	Clinical Trials in Australia	12
Faye's Health Journey	4	MRDR	12
Exercising the Brain	6	Australasian Leukaemia & Lymphoma Group – Better Treatments, Better Lives	13
Meet "ROMP"	7	What is AMaRC?	14
Advocacy News	8	Medical Corner	15
What's happening – Community Engagement and Fundraising	9	Calendar of Events	18

MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

Contact Pina Civitarese:

(03) 9428 7444 (toll free) 1300 632 100

pina@myeloma.org.au

If you no longer wish to receive the MyeNews please let us know.

Design & layout: Greg Loveder Graphics

Printed by Eastern Press

Front cover photo: Faye Johnsen



Find us on Facebook and Twitter



## 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.

MyeNews is supported by an unrestricted educational grant from Celgene



**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

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

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

## From the President

A few weeks back we thought we were over the worst of the COVID-19 pandemic but unfortunately, in Melbourne, we are having a second wave and we are all now back in lock down. We are not allowed to travel outside a 5km radius from home unless for essential reasons and we have curfew from 8pm until 5am. Masks are mandatory when out in public. We are all hoping that by following these guidelines, this will stop the spread of the virus and allow the restrictions to be eased once again.

I congratulate all our nurses for maintaining our services such as the Information and Support Groups and Telephone Support Line plus arranging virtual seminars during this difficult time. Many of our nurses work part time in the major hospitals, the front line of the pandemic. I thank them all for the fantastic work they are doing.

Our Head Office has now been closed and all staff are working from home. Services are being continued as normal as possible.

It is very important to take care of ourselves both physically and mentally in these times. I know this is difficult especially for those living alone. Please, it is important to speak to others so that you do not feel alone. Join a virtual support group meeting, it does not have to be in your area. If you

have a myeloma question, feel free to ring the Telephone Support Line (1800 693 566 Mon to Fri 9am-5pm AEST).

About this time each year I am making plans to visit the American Society of Haematology's annual conference. This has always been an opportunity to meet with other myeloma groups from around the world and to listen to presentations of the latest trials looking for new treatments of myeloma. This year it will be a virtual conference with all presentations and meetings online. It will not be the same as catching up with all our friends, but it is the only safe way to do it for now. Hopefully, next year we will be able to catch up in person.

I love living in Melbourne but now I am extremely jealous of all of you who are outside Victoria. We miss the chance to visit our grandchildren go out for coffee or even go for a walk in the country. I know we will be able to do all these things eventually if we all keep safe and well. And that is what I am planning to do.

Brian Rosenzweig



## Coronavirus Update

At the time of publishing, Myeloma Australia's head office is currently closed due to Melbourne being under Stage 4 restrictions. We apologise for any inconvenience this may cause. Operations continue as much as possible with staff working from home. If you need to contact a member of the team you can do so directly or email the following departments:

<b>Myeloma Australia Nurses</b>	<b>E: <a href="mailto:nurses@myeloma.org.au">nurses@myeloma.org.au</a></b>
<b>Telephone Support Line</b>	<b>T: 1800 693 566 (Mon to Fri 9am to 5pm AEST)</b>
<b>Support Services</b>	<b>E: <a href="mailto:support@myeloma.org.au">support@myeloma.org.au</a></b>
<b>Fundraising</b>	<b>E: <a href="mailto:matt.maudlin@myeloma.org.au">matt.maudlin@myeloma.org.au</a></b>

All contact details of individual staff members can be found on our website ([www.myeloma.org.au](http://www.myeloma.org.au))  
<https://myeloma.org.au/who-we-are/team/>

For information on the coronavirus in relation to myeloma, please click the link on the front page of our website. If you do not have the internet, please call the Telephone Support Line on the number above and one of our Myeloma Support Nurses will send you some information.

We appreciate these times have been quite challenging for many of our members.

***Our Telephone Support Line service has not been affected by the restrictions and our specialist Myeloma Support Nurses are ready to chat to you 1800 693 566 (Mon to Fri 9am to 5pm AEST)***

## Profile



### Cath Bowley – NSW Myeloma Support Nurse

Hi, my name is Catherine Bowley and I'm so pleased to be joining Myeloma Australia as one of the NSW Support Nurses working in Sydney with NSW State Manager Jacqui Keogh.

I've been nursing for 17 years now and for most of that time have been working in Gosford Hospital on the beautiful Central Coast. The first half of my career was spent in

intensive care, but in 2013 I made the move to Cancer Services and found my new home! I began working in the outpatient chemotherapy day unit and after completing my post graduate certificate in cancer nursing. I was lucky enough to secure a clinical nurse specialist position caring for haematology patients. I have been fortunate to have been mentored by an amazing nurse practitioner Jacqui Jagger who has a special interest in myeloma, and I can thank her for sparking my passion in caring for patients with myeloma. I'm so excited about my new role with Myeloma Australia, I'm really looking forward to supporting patients and carers and helping educate health professionals and the wider community. I continue to work part time in the outpatient day unit too, I find it such a dynamic and exciting area to work in, and I'm still learning something new every day.

In my spare time I enjoy being outdoors, either on a long hike or relaxing by the beach. I also love camping and music and sport – I'm a big Sydney Roosters fan! At home I'm kept busy with my husband Mike, daughter Jazmyn and a couple of big dogs to look after!

I've started this role at an interesting time given the current pandemic, but I'm so impressed with how the organisation is adjusting and I'm beyond grateful for the opportunity to join the team. I really look forward to meeting members of our NSW myeloma community (and those throughout Australia thanks to Zoom) over the coming months.

## Faye's health journey

Thursday 18th June 2020 was a day I will remember for some time. I am a relapsed multiple myeloma patient, and that was the day my blood markers showed an amazing fall.

### My journey

I was diagnosed with multiple myeloma in August 2015, with my 4 cycles of dexamethasone and bortezomib (Velcade) starting immediately. This was quite a roller coaster ride I had 5 fractured ribs, eczema, and a painful bout of shingles. After 16 weeks, I chose to have my stem cells harvested and for my transplant to happen on my birthday. Happy to say this was a success.

My blood markers stayed low for 3.5 years and I felt so healthy and "normal". During this time, I continued pamidronate (Aredia) every 3 months to strengthen my bones. I was on no extra medication which I so appreciated. I am a fit person for my 70 years, so during this time, I did swimming (at the local pool), weight training (at the gym), riding a mountain bike and an electric scooter and walking after dinner. I love being out exploring nature and walking in our rainforests. I'll be the first to admit, it is not always easy or possible but as you may have guessed, I am a very positive and a strong-willed person...just ask my husband!



### My new treatment begins

When I started my relapsed treatment in October 2019, my light chains were 374 compared to 1438 when I was first diagnosed. My current treatment consists of dexamethasone and carfilzomib (Kyprolis) twice a week. I believe this commitment to my fitness is helping me physically and mentally cope. I have always eaten healthily so when the dietitian made no changes to my diet, I was very happy. Where possible, I do a short 30 minute gym session in the small gym at the Oncology Rooms before my treatment, this helps "pump up my veins" and, therefore, makes it easy for the nurses to find a good vein for the cannula. I make it my mission to make someone laugh on my treatment days and



I have heard some amazing stories from other patients who have overcome so much.

### Now back to the future

After seven months of being on my new treatment, John (Oncologist) shared my recent blood results, I said, "Wow it's a miracle!" He replied, "Turbo", (his nickname for me) "it's the carfilzomib (Kyprolis) doing its job!" I shook my head...saying to myself, "I'm believing, it's much more than that!"

My masks are a talking point in the rooms and I always get a smile from the other patients with my drawings that I stick to the front of them.

My kidneys (which filter the drugs) and neutrophils/white cell count (immune system) are being closely monitored with blood tests every 2 months. Neutrophils are our "first responders" playing the role of the first line of defence against infectious organisms that enter our bodies. These cells are the first cells to arrive on the scene when we experience bacterial infections. Normal readings are over 2, my reading is 1.2, a reason for me to keep safe. I continue having quiet days after treatment until the side effects settle.

### Getting me through the COVID-19 challenge

My soul mate of 51 years and I continue to be careful and are aware of the ongoing dangers of COVID-19 for me. I avoid crowds, shopping centres, supermarkets and wear a mask for appointments. I so enjoy picnics with family or friends (allowing social distancing) in the many parks on the Sunny Coast Qld.

### Support

Two of my myeloma friends helped me celebrate my 70th birthday recently. We are such a strong support for each other. Cancer? What Cancer?

### The Power of my thoughts

Often I get asked, "How are you so strong and positive?" "My answer is, if you were in a similar situation you would also find an inner strength. My positive thoughts and my Christian Faith motivate me, guiding the way I live, feel, talk, and act. I also work at being thankful for the smallest thing. Before I go to sleep, I write in my "Thankful Journal" things I am grateful for in that day.

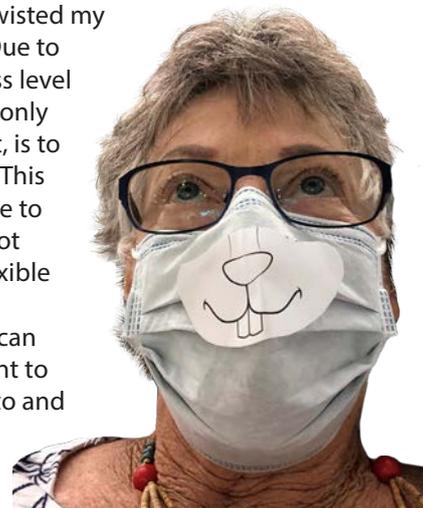


### What's next?

So many people ask me how long will I have to stay on this treatment? The answer is like Diabetics who must take insulin multiple myeloma cancer patients need to be on some type maintenance treatment which blocks the growth and spread of cancer cells while limiting damage to healthy cells. The drugs I am on may not be as effective down the track but I'm confident there will be other options to offer me.

### Faye's Future

In December 2019, I tripped on an electrical cord at the local swimming pool. I fell heavily on the cement, with hand and knee lacerations and twisted my neck and lower back. Due to ongoing pain my fitness level has been affected. The only way I know to handle it, is to take one day at a time. This way there is no pressure to reach goals that may not be achievable. I am flexible to how I'm feeling and spontaneous in what I can do that day. I have learnt to say, "No!" when I need to and I like to share my story with groups whenever I'm asked.



## Exercising the Brain



One of the most common effects of myeloma and associated treatments on the body is impaired cognition, otherwise known as chemo brain or brain fog. This can present as difficulty concentrating, short term memory loss, impaired ability to find words in conversation, difficulty learning new skills and mood swings.

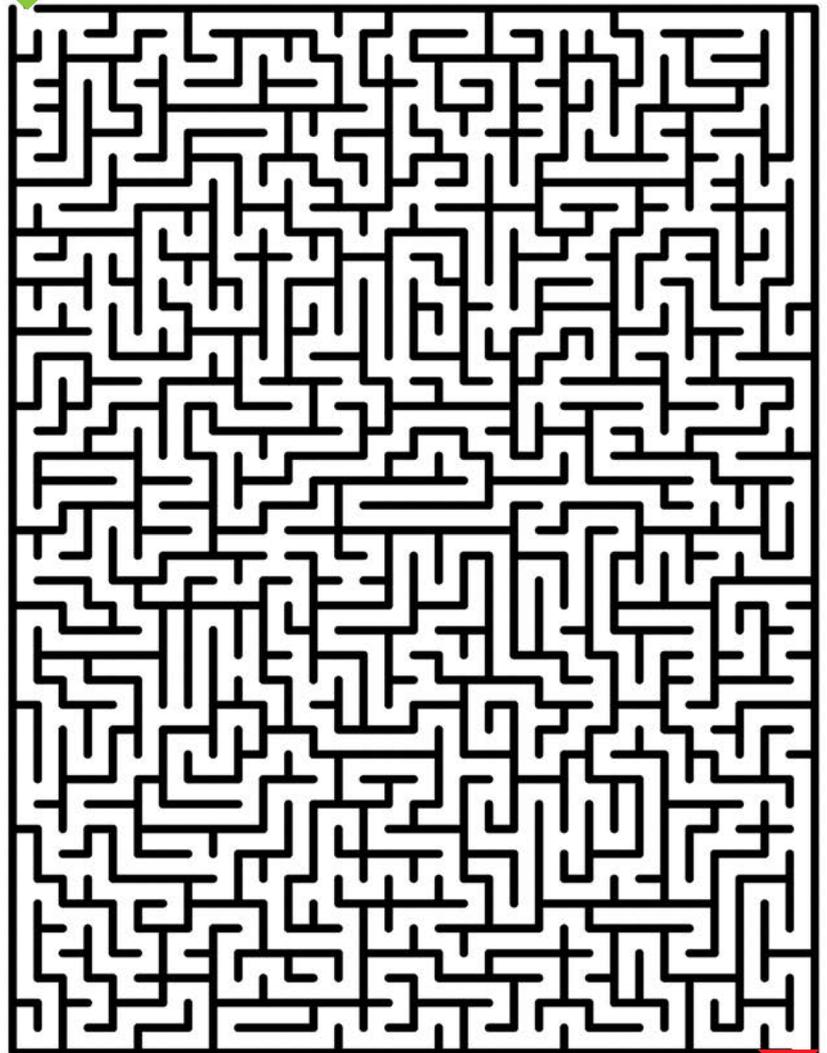
These symptoms can be even further compounded by the fatigue that is also caused by both myeloma and its treatment.

Some strategies to improve cognition include daily gentle exercise, adequate food and fluid intake and exercising the brain with puzzles, craft projects or learning a new hobby. If cognitive impairment is having a significant impact on the ability to function, a psychologist can help by way of cognitive rehabilitation.

*Here are some examples of some puzzles that might help exercise the brain.*

	2	4	3	8				
					6			7
	5	8				4		
4				1				
			7		5			
				2				8
		1				6	7	
3			5					
				4	9	2	1	

Sudoku#1 – Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 – 9.



Answers on page 19

# Meet "ROMP"

## Rotary Clubs join the Myeloma Conversation

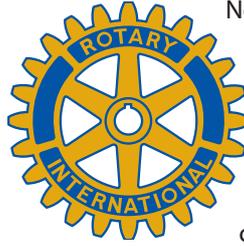
"No patient is to live more than one hour from a myeloma support group".

Rotary Clubs across regional Victoria are coming together to "Join the conversation" about myeloma. Much more than a conversation, the "ROMP" initiative is a formal collaboration between Myeloma Australia with the Rotary Club of Camberwell in support of the myeloma community.

(ROMP? Rotarians have a weakness for acronyms when they seek to describe their organised service efforts. So, the Rotary Outreach Myeloma Program has informally adopted the ROMP epithet.)

ROMP will build awareness of myeloma in country regions and promote and facilitate the services of Myeloma Australia – especially Information and Support Groups. The program is centred upon the conviction that "No patient is to live more than one hour from a myeloma support group". Engaged Rotary clubs in the Victorian regions look forward to supporting new myeloma Information and Support Groups to establish wherever they are needed.

The myeloma service landscape looks very different today with the arrival of the pandemic. Before the arrival of COVID-19, Rotarians in Victoria's Wimmera Region adopted the ROMP model and together established the first new support group. In normal times the new group will meet again at the magnificent Horsham Cancer Centre. (Congratulations are due to the Rotary Clubs of Horsham, Horsham East, Nhill and Warracknabeal now colloquially known as "Wimmera ROMP").



Now, social isolation adds to the challenges faced by all organisations and communities. Myeloma Australia and Rotary clubs have moved well to adopt and exploit the Zoom technology. Myeloma support groups by Zoom will be the model for at least months to come. When the pandemic is

behind us, face to face meetings will be back as the generally preferred meeting model. The ROMP aim is to ensure that regional myeloma communities have access to the best available meeting facilities whatever the model and will look forward to the return of face to face meetings.

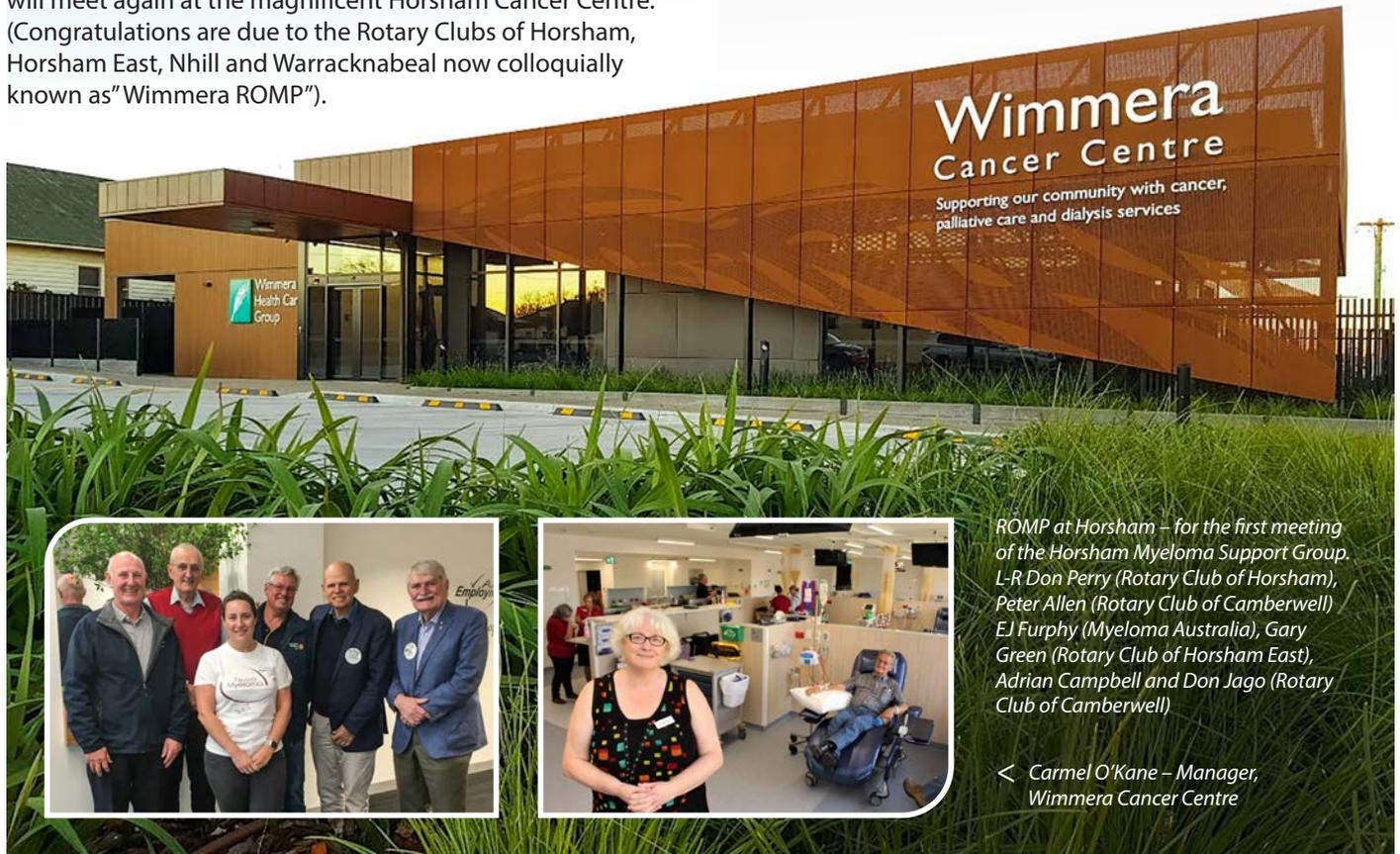
At the regional level (there are Rotary clubs everywhere) Rotarians are ready to arrange meeting rooms and technical facilities for new support groups when they are required. For existing groups Rotary clubs are ready to provide support as and when it is needed.



To learn more about the Rotary ROMP initiative for Myeloma Australia please visit the ROMP website [WWW.ROMP100.ORG](http://WWW.ROMP100.ORG)

Myeloma community members please call 1800MYELOMA(693 566) or E: [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

Rotarians and other community members please email Adrian Campbell E: [speedcampbell@hotmail.com](mailto:speedcampbell@hotmail.com)



**Wimmera Cancer Centre**  
Supporting our community with cancer, palliative care and dialysis services

ROMP at Horsham – for the first meeting of the Horsham Myeloma Support Group. L-R Don Pery (Rotary Club of Horsham), Peter Allen (Rotary Club of Camberwell) EJ Furphy (Myeloma Australia), Gary Green (Rotary Club of Horsham East), Adrian Campbell and Don Jago (Rotary Club of Camberwell)

< Carmel O’Kane – Manager, Wimmera Cancer Centre

## Advocacy News

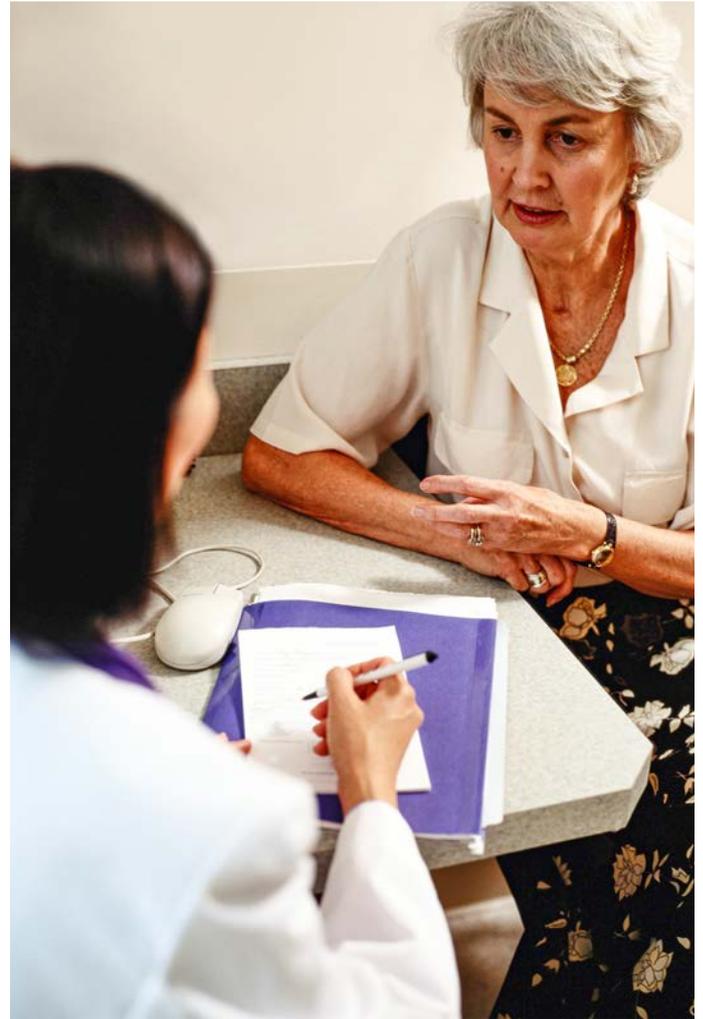
Together with Community and Patient Preferences Research Group (CaPPRe), Myeloma Australia worked on a study looking at treatment preferences in myeloma. Many members of our community were involved in the online surveys and face to face interviews which gathered information for this study, the first of its kind looking at the treatment preferences of those with myeloma, their carers, their doctors and nurses and how they compare. This type of research can impact on patient experience by facilitating shared decision making at an individual level when discussing a change to treatment, as well as at a higher level where it can be considered by decision makers and industry in the reimbursement of new myeloma treatments. It has also led to another collaboration with CaPPRe, a pilot study testing an App specifically designed for people with myeloma to foster shared decision making at the time of treatment decisions or changes.

In August, the Patient Voice Initiative held an online webinar 'Patient Based Evidence: Using patient based research for PBAC/MSAC' and alongside Jo Watson (PBAC deputy chair) and Dr. Simon Fifer (CaPPRe), Steve Roach and Nella Combe discussed Myeloma Australia's involvement in the study and insights gained.

Thank you to all who were involved in the study, if you would like to read the publication it can be found online

**Alignment of preferences in the treatment of multiple myeloma – a discrete choice experiment of patient, carer, physician, and nurse preferences.**

Fifer et al. BMC Cancer (2020) 20:546  
<https://doi.org/10.1186/s12885-020-07018-6>



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



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

FUNDRAISING WITH  
 *entertainment.*



## What's Happening

### Community Engagement & Fundraising

COVID-19 has undoubtedly had an enormous impact upon our community engagement & fundraising. As the months have rolled by I have watched the big city events that historically Team Myeloma gathers for in Perth, Adelaide, Melbourne and Sydney first be advertised and promoted, then delayed, followed by 'postponed until a later date' and finally cancelled. This has not been easy to watch as these events provide great community building and significant fundraising opportunities for us. Alongside the loss of the Team Myeloma events the number of fundraising events being held by members of the myeloma community has dropped significantly – as was to be expected.

But rather than dwell on 'what might have been' I prefer to think of what still might be and what will be in the future. In the last fortnight I believe I have begun to see the first green shoots of recovery on the fundraising front as a gentleman from Queensland contacted me to arrange a fundraising event in late August, a lady in Adelaide let me know that she is sending Myeloma Australia a piece of her amazing artwork for us to raffle and a Victorian Specsavers branch nominated us as their Community Benefit beneficiary. So, all is not lost!

The other news I would like to draw your attention to, and this is particularly but not exclusively for Sydneysiders, is the City2Surf Virtual which will be held on Sunday 18th October. Walkers and runners are being encouraged to partake in the 14km event regardless of where you might be in the world! Soooooo, if you are not in Sydney but would love to run this world-famous event – well, here is the perfect opportunity! All the details of the event, how to register and fundraise can be found here: <https://city2surf.com.au/entry-details> Please



consider not only taking part in this event but doing so with family, friends, others from the myeloma community and your broader networks. We have our splendid burgundy 'Team Myeloma' t-shirts for sale in our web shop for your sartorial consideration!

In the next few weeks details of our own awareness raising & fundraising event, "The Myeloma 500", will be released via our website and social media channels. If you are super keen to find out a little more about this in advance do please drop me a line and I will be happy to oblige!

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](mailto:matt.maudlin@myeloma.org.au)

good2give

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](http://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](http://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](mailto:matt.maudlin@myeloma.org.au)**

# WHAT'S HAPPENING

## New South Wales

As we continue to work from the isolation of our own homes, we have thoroughly enjoyed meeting with you in your own home. Over the past couple of months, NSW has hosted some wonderful Information and Support Groups via the zoom platform. We had a dietician speak at both our Tamworth and Orange Information and Support Groups who both gave us some great tips on eating well with myeloma. We also had an exercise physiologist from the Kaden Centre at our Newcastle Information and Support Group where we were able to tap into a local resource for exercising with myeloma. A pharmacist spoke at the last Tamworth Information and Support Group giving us information about why steroids affect us the way they do and managing this.

We hosted our second online webinar on Clinical Trials, with experts in the area Dr Wojt Janowski giving an overview of clinical trials, Dr Kate Burbury discussing Teletrials and Lisa Fisher offering an insight into the role of the clinical trial coordinator. If you didn't happen to catch it live it is now available on our website for viewing under the Patients and Carers tab on the Workshops and Seminars page.

Coming up we are hoping to grow Information and Support Groups in the Orange, Dubbo/Mudgee, Canberra and Lismore regions. We are looking forward to getting to know the myeloma community and health professionals in these areas.

And finally, we would just like to introduce Cath Bowley to the NSW team. Cath will be another Myeloma Support Nurse and you will no doubt see her on-line or talk with her on the support line. Welcome Cath, we are so excited to have you join the team.

## Queensland

As winter comes to a close, Queenslanders are currently taking a collective breath of air, in light of our very low numbers of COVID cases. For the myeloma community, those who had intensive treatments delayed, have now begun or are being scheduled to commence their recommended therapy.

In Queensland, Tash and I continue to run our Information and Support Groups online and we would love to hear from our new and veteran members. We have groups named under their "pre-covid" locations but if you are new to Myeloma Australia, or can't find a location close to you, please join any group that suits you. We would love to hear from our experienced myeloma patients, as your knowledge is so beneficial for our members who have recently been diagnosed.

A big thank you to our guest speaker Pam Gallagher, for attending our Younger Persons Zoom group in July. Pam was available to answer questions to help navigate the logistics of accessing superannuation and other financial queries. Pam has previously worked as a financial advisor and for the National Australia Bank. Pam vowed to help others with her knowledge after her own diagnosis with myeloma in 2019.

Keep up the great work Queensland! Stay vigilant with your COVID safety plan, stay connected to your community and especially your health care team. It is important to stay on top of your regular health checks, not just for myeloma.

We hope to see you through the screen soon!

## South Australia

In May we returned to our original schedule of planned Information and Support Groups, however still all via zoom. We have been lucky to have guest speakers for some of our meetings. Dr Angie Yong, a haematologist from Lyell McEwin spoke to the Flinders Information and Support Group about new treatments for myeloma, and Karen Linehan, a health psychologist gave an engaging talk about stress and resilience in these challenging times to the Fullarton Information and Support Group in August. Jo and Alicia have also been enjoying presenting to our colleagues in rural SA and Broken Hill through a series of online in-services as well as nationally through a Myeloma Australia healthcare professionals seminar in August. We look forward to seeing our members in the mid-North and South-East for online "Coffee & Catch-Ups" in the coming weeks.



## Tasmania



Hats off to Graeme Pearce, living with myeloma, who appeared on Tasmania's 7 Nightly News along with Dr Anna Johnston, for the launch of Revlimid on the PBS. Graeme (pictured) was filmed with his bike which was very apt, as both he and Anna are avid cyclists!

In September, Lauren Giles, a neurologist at Launceston General Hospital will be speaking at our Northern Information and Support Group and in October, Tracey Batt, a clinical haematologist at the Royal Hobart Hospital will be taking a Q & A session for the Southern Group.

A new member to our Southern Information and Support Group was delighted to pick up a valuable nugget of information. She was feeling very nauseous on Revlimid and another member who had suffered the same problem suggested taking it at night, as that had helped him.

Dr Nick Murphy, a haematologist at the Royal Hobart Hospital, went out of his way recently in response to a support line call, to assist a distressed family and their loved one overseas. Through contacting the doctor involved, Dr Murphy helped to allay the family's concerns for which they were extremely grateful. Thanks Dr Murphy!

## Victoria



Laura here, wishing everyone well, knowing things have been particularly challenging in Victoria these last few months. I have been personally inspired hearing your stories of positivity, creativity and the way you have found the light in each day in this 'new normal'.

Our community welcomed new members to three of our Information and Support Groups and discussed topics including telehealth, immunisations, as well as heard from expert guest speakers.

EJ and I spent time giving online in-services to nursing staff at many regional hospitals and were involved in an evening education event for nursing and allied health professionals across the country.

We continue to encourage members of the community who reside in Mildura, Bairnsdale, and Warrnambool to attend the current closest region online Information and Support Group – in the hope to begin a stand-alone group when face to face begins again.

Our ever-popular November La Trobe seminar will run again, this time in an online fashion. We hope those who would not normally be able to attend in person will also enjoy it this year.

I would love to hear about Information and Support Group topics you'd like to discuss in coming months ... whilst EJ and I have a good idea or two, the myeloma community is always a wealth of wonderful suggestions and experiences!

We are looking forward to the months ahead... and hope with the sunshine comes good news for Victoria.

Keep up the great work Queensland! Stay vigilant with your COVID safety plan, stay connected to your community and especially your health care team. It is important to stay on top of your regular health checks, not just for myeloma.

We hope to see you through the screen soon!

## Western Australia



Western Australia have launched some new Information and Support Groups in the past quarter, including a regional Western Australian group and a group for carers of people living with myeloma.

With reduced face to face meetings, the Western Australian nurses have embraced the Zoom technology with Information and Support Groups almost every week. Even though things have been very different this year, we have been kept busy receiving new referrals and meeting new people in the myeloma community over the phone and via online video technology. We have worked hard to maintain this connectedness and we will continue to offer these platforms even as restrictions ease here in Western Australia.

Behind the scenes, we have been working on many new projects that will improve our service provision and access for all in Western Australia. We are excited to share more about this soon!

Due to COVID-19 restrictions starting to lift in Western Australia, both Kerin and Narelle have been able to return to their office after working from home since March 2020. It is lovely to be working back together again.



# Clinical Trials in Australia

In this edition we are pleased to introduce to you two Australian-based organisations who facilitate myeloma research. They are the Australian Leukaemia and Lymphoma Group (ALLG) and Australasian Myeloma Research Consortium (AMaRC).



We will also continue to include updates from the Myeloma and Related Diseases Registry (MRDR).

There are also clinical trials conducted by other organisations such as pharmaceutical companies. Information about many of the clinical trials being run in Australia currently can be found via the ClinTrial refer app or the Australian Clinical Trials website at [www.australianclinicaltrials.gov.au](http://www.australianclinicaltrials.gov.au).

Each clinical trial will have its own inclusion and exclusion criteria and won't be suitable for everyone at every time point. Always discuss with the doctor whether a particular trial is suitable.

You can learn more about clinical trials and how they are conducted by watching our latest online seminar. The recording of this online seminar can be found on the Workshops and Seminars page under the Patients and Carers tab. We also have MSAG member Professor Joy Ho explaining drug development in Australia on the videos page under the Patients and Carers tab on our website [www.myeloma.org.au](http://www.myeloma.org.au)

## NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY (MRDR)

### PARTICIPATION

Recruitment to the MRDR is close to 3900 patients, which is very close to 4000 which is VERY exciting for a rare disease registry. This is thanks to patients and staff at all participating sites. We are steadily becoming more representative of regional areas and the latest rural/regional hospitals and clinics to join us are Border Medical Oncology, Calvary Mater Newcastle, Launceston, Orange Health Service, Palmerston North NZ, Sunshine Coast University Hospital, Toowoomba, and Townsville Hospitals. Welcome to all!



### MRDR AT THE NATIONAL MYELOMA WORKSHOP

Four recent proposals to use MRDR data were submitted for presentation at Myeloma Australia's National Myeloma Workshop. Professor Joy Ho compared characteristics, treatment and outcomes in patients diagnosed by SLiM criteria (myeloma defining events without organ damage) versus those diagnosed with existing organ damage. Another project looked at outcomes of patients with multiple cytogenetic abnormalities at diagnosis (Hasib Sadiqi/Brad Augustson); Rosalyn Cao conducted an in-depth analysis of causes of death in patients with multiple myeloma (MM); and another study compared patients with newly diagnosed transplant-ineligible MM who received bortezomib versus lenalidomide-based therapy (Natthida Khajornjiraphan).

The MRDR also held a webinar following the virtual National Myeloma Workshop sessions, providing an update on registry progress and projects including a presentation on the participation of rural sites in the MRDR and the introduction of an epidemiological modelling project to improve care delivery for patients with MM.



MONASH  
MEDICINE  
NURSING AND  
HEALTH SCIENCES



AlfredHealth

CRICOS Provider: Monash University 00008C. TRSU AUG2020

## Australasian Leukaemia & Lymphoma Group

### – Better Treatments, Better Lives

The ALLG is the only not-for-profit collaborative clinical trial group in Australia and New Zealand, delivering clinical trials and research projects focused on blood cancers.

The ALLG membership of over 450 clinicians includes haematologists from across ANZ, with clinical trials taking place at 92 accredited hospital sites and cancer centres across the country.

#### ALLG Clinical Trials

Our ALLG doctor members are dedicated to the delivery of world-class clinical trials and research outcomes for patients with myeloma and other blood cancers.

Clinical trials are the engine of cancer research. Virtually every treatment available to blood cancer patients today is the direct result of a clinical trial. Making an informed decision to participate in a clinical trial provides the gift of information that helps scientists and doctors develop new ways to treat and halt blood cancers.

ALLG's myeloma clinical trials provide access to new therapies and help to create better treatments and better lives for myeloma patients.

#### Current Myeloma Trials

##### MM19 – leading doctor Prof Andrew Spencer

Evaluating a new type of maintenance therapy/treatment for myeloma patients undergoing single autologous stem cell transplantation (ASCT) as part of front-line therapy. Open to 280 patients.

Recruiting Hospitals: VIC – Alfred, Barwon Health, Box Hill, Monash, St Vincent's Melbourne; NSW – Concord, Gosford, Orange Health, St Vincent's Sydney, Tweed, Westmead; QLD – Princess Alexandra, Townsville; SA – Royal Adelaide; TAS – Royal Hobart, Launceston.

##### MM20 – leading doctor Prof Andrew Spencer

Evaluating a new combination treatment against standard treatment for relapsed/refractory myeloma. Patients may be eligible if diagnosed with relapsed/refractory myeloma and had between 1-3 prior lines of therapy. Open to 300 patients.

Recruiting Hospitals: VIC – Alfred, Austin, Barwon Health; NSW – Calvary Mater Newcastle, Concord, Tamworth, Tweed; ACT – Canberra; QLD – Princess Alexandra, Townsville; SA – Royal Adelaide; WA – Royal Perth.

##### MM22 – leading doctor Prof Andrew Spencer

The FRAIL-M trial is evaluating the most appropriate treatments for patients with newly diagnosed, transplant-ineligible multiple myeloma, taking into consideration patient frailty (weakness). ALLG is thankful to the Australian Government's Medical Research Future Fund for funding to run this trial.

Recruiting Hospitals – VIC – Alfred, Sunshine; NSW – Calvary Mater Newcastle; QLD – Princess Alexandra; SA – Royal Adelaide; TAS – Royal Hobart; NT – Royal Darwin.

#### What's New

The ALLG has two new myeloma trials in development, due to open for recruitment late 2020/early 2021.

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

The SeaLAND trial will evaluate a new treatment option vs the standard maintenance therapy for post-autologous stem cell transplant patient. The trial is for patients with newly diagnosed multiple myeloma. ALLG will open this trial at 20 hospitals across ANZ.

##### MM24 – leading doctor Dr Simon Gibbs

The PISA trial is an international Amyloidosis trial, in collaboration with the French Myeloma Group IFM. It will evaluate a new treatment for relapsed/refractory amyloid patients at 4 sites across Australia. ALLG is proud to bring this important international trial to Australia.

#### For More Information

For more information about the ALLG and myeloma clinical trials, please visit <https://www.allg.org.au/clinical-trials-research/current-clinical-trials/>. You can also speak with your treating physician to find out more about ALLG trials.

<https://doi.org/10.1186/s12885-020-07018-6>



Better treatments...  
Better lives.

# What is AMaRC?

The Australasian Myeloma Research Consortium (AMaRC) is a not-for-profit myeloma clinical trial research group and is a collaboration of myeloma experts, scientists, other clinical specialists to develop and conduct doctor-led myeloma trials.

AMaRC aims to conduct early phase proof-of-concept studies, trialing new treatment regimens, biologics and drug products, so we can identify those that show the most promise and deserve further research in bigger trials. We also strive for a holistic approach in research by incorporating correlative science and health economic data collection, where possible.

Our members are part of a large haematology network, who work at the bedside providing high quality medical care, whilst providing their patients with information about the latest research and opportunities to participate in clinical trials. Our goal is to improve the quality of life and survival of patients living with multiple myeloma and ultimately, find a cure.

AMaRC also has established oversight committees to ensure research excellence and adherence to GCP practices:

- Steering committee – Responsible for the activities of the consortium and its future direction
- Research advisory group (RAG) – Composed of experienced researchers and a biostatistician, to provide expert guidance on the scientific quality of our trials and the integrity of our research programs
- Drug Safety Monitoring Committee (DSMC) – Composed of clinical specialists and pharmacovigilance experts that review study data on a regular basis to ensure trial patient safety

Using our extensive network of research specialists with support from the Alfred Hospital Haematology Clinical Research Unit, we facilitate all trial activities from conception to publication. Specifically, we provide support services on:

- Trial concept review
- Study protocol authoring
- Clinical trial feasibility activities
- Ethics and Research Governance submissions
- Contract negotiation
- Study drug supply procurement and distribution
- Ongoing trial management and site monitoring
- Safety reporting and monitoring
- Publication review

We also collaborate with Monash University's School of Public Health and Preventive Medicine and register all AMaRC trial patients into the Myeloma Related Diseases Registry (MRDR) to ensure real-world data on myeloma patients is centrally collected.



# AMaRC

AUSTRALASIAN MYELOMA  
RESEARCH CONSORTIUM

## Current activities

Below is a list of our current trials:

### Recruitment Open

- FRAIL-M – Frailty-stratified, randomised controlled Bayesian adaptive trial of bortezomib versus lenalidomide in transplant-ineligible myeloma – Prof. Andrew Spencer
- IRIL – Isatuximab, lenalidomide and dexamethasone for transplant ineligible multiple myeloma (Phase II) – A/Prof. Hang Quach

### Upcoming (Recruitment not yet opened)

- Belantamab mafodotin for relapsed refractory multiple myeloma (Phase I/II) – A/Prof. Hang Quach

### Recruitment Closed

- VCD-D – Daratumumab, bortezomib, cyclophosphamide and dexamethasone for transplant ineligible multiple myeloma (Phase II) – A/Prof. Peter Mollee
- Belantamab mafodotin for relapsed refractory multiple myeloma (Phase I/II) – A/Prof. Hang Quach
- V-VCD – Venetoclax, bortezomib, cyclophosphamide and dexamethasone for transplant eligible multiple myeloma (Phase II) – Prof. Andrew Spencer
- Kappamab for relapsed refractory multiple myeloma (Phase IIb) – Prof. Andrew Spencer and A/Prof. Jake Shortt
- Ixazomib, thalidomide and dexamethasone for relapsed refractory multiple myeloma (Phase II) – Prof. Andrew Spencer

*If you would like to know more about our trials or have an interest in supporting AMaRC, please contact us at E: [amarc@alfred.org.au](mailto:amarc@alfred.org.au)*

### AMaRC contact

Website: [www.amarconline.org](http://www.amarconline.org)

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

Twitter: [@amarconline](https://twitter.com/amarconline)

Please note the following information references some data, and medicines and/or the use of medicines that are not approved in Australia and/or New Zealand. For further information use the reference provided or call our Myeloma Support Nurses on the Telephone Support Line 1800 MYELOMA Mon-Fri 9am-5pm AEST.

– Edited by Jo Gardiner, Senior Specialist Myeloma Nurse

### International harmonization in performing and reporting minimal residual disease assessment in multiple myeloma trials

Luciano J. Costa, Benjamin A. Derman, Bruno Paiva;  
Leukemia (2020) Published: 11 August 2020

Minimal residual disease (MRD) assessment is incorporated in an increasing number of multiple myeloma (MM) clinical trials for analysis, an endpoint or determining subsequent therapy. There is substantial variation across clinical trials in how MRD is assessed and reported, creating challenges for data interpretation and for the design of subsequent studies. We convened an international panel of MM investigators to harmonize how MRD should be assessed and reported in MM clinical trials. The panel provides consensus on which MM trials should include MRD, the recommended time points for MRD assessment, and expected analytical validation for MRD assays. We subsequently outlined parameters for reporting MRD results implementing the intention-to-treat principle. The panel provides guidance regarding the incorporation of newer peripheral blood-based and imaging-based approaches to detection of residual disease. Recommendations are summarized in 13 consensus statements that should be followed by sponsors, investigators, editors, and reviewers engaged in designing, performing, and interpreting MM trials.

### Cytogenetic abnormalities in multiple myeloma: association with disease characteristics and treatment response

Nadine Abdallah, S. Vincent Rajkumar, Patricia Greipp, Prashant Kapoor, Morie A. Gertz, Angela Dispenzieri, Linda B. Baughn, Martha Q. Lacy, Suzanne R. Hayman, Francis K. Buadi, David Dingli, Ronald S. Go, Yi L. Hwa, Amie Fonder, Miriam Hobbs, Yi Lin, Nelson Leung, Taxiarchis Kourelis, Rahma Warsame, Mustaqeem Siddiqui, John Lust, Robert A. Kyle, Leif Bergsagel, Rhett Ketterling & Shaji K. Kumar

Blood Cancer Journal volume 10, Article number: 82 (2020)

Cytogenetic abnormalities are found in most multiple myeloma (MM) patients. Although their prognostic value has been well studied, there are limited data on the association of primary cytogenetic abnormalities with disease characteristics and treatment response. This study was designed to evaluate these associations and included 2027 Mayo Clinic patients diagnosed with MM between February 2004 and February 2018 with cytogenetic testing by FISH at diagnosis. Translocations t(4;14), t(14;16), t(6;14), and t(14;20) were associated with anaemia, beta2microglobulin >5.5 µg/ml and ≥50% bone marrow plasma cells; t(4;14) was associated with higher serum monoclonal protein and plasma cell proliferation. Overall response rate to proteasome inhibitor (PI)-based treatment was higher for IgH translocations compared to trisomies but was higher for trisomies with immunomodulatory drug (IMiD)-based treatment. Time to next treatment was longer with trisomies than IgH translocation with IMiD-based and PI + IMiD-based treatments. Outcomes were superior with PI + IMiD combinations in all groups.

Our results show that t(4;14), t(14;16), t(6;14), and t(14;20) are associated with high-risk disease characteristics, and IgH translocations and trisomies may be associated with better responses to PIs and IMiDs, respectively.

### Daratumumab subcutaneous formulation for the treatment of multiple myeloma

Barry Paul, Issam Hamadeh, Shebli Atrash, Manisha Bhutani, Peter Voorhees & Saad Z. Usmani; Expert Opinion on Biological Therapy; Published online: 16 Aug 2020

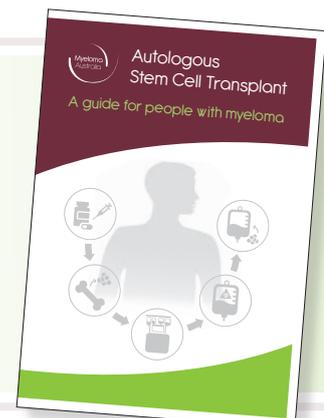
Intravenous daratumumab has shown unprecedented anti-myeloma activity when used as a single agent or in combination with other myeloma therapies. Recently, a subcutaneous formulation of daratumumab was approved for use in both the United States and European Union based on data which showed shorter infusion times and decreased rate of infusion reactions while maintaining non-inferior efficacy.

### 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](http://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](mailto:support@myeloma.org.au)



## Long-term Outcomes After Definitive Radiation Therapy (RT) for Solitary Plasmacytoma

Curry, Jayden BS; O'steen, Lillie MD; Morris, Christopher G. MS; Kirwan, Jessica M. MA; Mendenhall, William M. MD

We retrospectively reviewed the medical records of adults with solitary plasmacytoma treated with definitive RT between 1963 and 2015 at a single institution, and assessed disease control, survival, and toxicity. Forty-two patients with solitary plasmacytoma of the bone (SPB, n=27) or extramedullary plasmacytoma (EMP, n=15) were treated with definitive RT with (n=11) or without (n=31) surgical resection. The median age at diagnosis was 59 years (range: 28 to 76y). Twenty-two patients had tumors  $\geq 5$  cm and 20 had tumors  $< 5$  cm. Immunoglobulins were elevated in 23 patients and M-protein in 14. The median RT dose was 45 Gy (range: 15 to 54 Gy) over a median 25 fractions (range: 1 to 38 fractions) with 3 patients receiving twice-daily fractionation and 6 received elective nodal irradiation. No patients received adjuvant chemotherapy. The median follow-up was 10.3 years. The 10-year local control rate after RT was 88%. Five patients who developed a local recurrence had SPB  $\geq 5$  cm. The 10-year multiple myeloma-free survival rates were: overall, 47%; SPB, 24%; and EMP, 87% (P=0.0012). The 10-year cause-specific survival rate was 75%: 64% for SPB versus 93% for EMP (P=0.0116). The 10-year overall survival rate was 60%. Three patients experienced late grade 2+ toxicity.

### Conclusions:

Definitive RT with moderate doses results in excellent local control. We observed a higher rate of progression to multiple myeloma and lower survival in patients with SPB compared with EMP.

## Impact of autologous stem cell transplantation on long term renal function and associated progression-free and overall survival in multiple myeloma

Ala Abudayyeh ORCID Icon, Heather Lin, Omar Mamlouk, Maen Abdelrahim, Rima Saliba, Gabriela Rondon; Published online: 29 Jul 2020

The long-term impact of Autologous Hematopoietic Stem Cell Transplantation (ASCT) on renal function, and the impact of renal function on progression-free survival (PFS) and overall survival (OS) in patients with multiple myeloma are not known. We reviewed the records of 885 patients at our institution. We studied the change in estimated glomerular filtration rate (eGFR) and assessed associations between the eGFR, PFS and OS. Analyses were conducted at days 0, 100, 180, and 365 post-ASCT. eGFR post-ASCT was significantly lower than at day 0 but stabilized at approximately 80 mL/min/1.73 m<sup>2</sup>. There was no association between eGFR and PFS or OS.; However, relapsed disease and ISS stage were associated with shorter PFS and OS. This data suggests that although there is a modest decline in eGFR post-ASCT, it is not associated with an adverse impact on PFS or OS.

### Key points:

Advanced MM stage at diagnosis was associated with reduced eGFR at all stages of chronic kidney disease.

eGFR was not associated with PFS or OS in any of the analyses, but disease-related factors prior to ASCT were all associated with reduced eGFR, PFS and OS.

ASCT did not adversely impact kidney function and mitigated the risk of CKD on outcomes in MM.

## Myeloma Patient Value Mapping: A Discrete Choice Experiment on Myeloma Treatment Preferences in the UK

Simon Fifer; Jayne Galinsky; Sarah Richard; Patient Preference and Adherence 2020;14 1283–1293; Dovepress open access to scientific and medical research;

Background: While myeloma patients are living longer, they are living with symptoms and treatment side effects.

Objective: To evaluate myeloma patients' preferences for treatment. This study set out to define the relative importance of key treatment attributes, characterize the risk-benefit trade-offs in patients' decision-making, and to analyse the predictive power of basic demographic factors.

Methods: Four hundred seventy-five myeloma patients in the UK were invited to participate by Myeloma UK. Data were collected through an online survey.

Results: Not surprisingly, average survival was most important to all patients but there were significant contrasts between the class preferences.

Patients in Class 1 placed greater importance on average survival and mild-to-moderate side effects, whereas patients in Class 2 focused on the mode of administration and the average out-of-pocket costs. Patients living with others and those diagnosed in the last 5 years were more likely to be in Class 1.

Conclusion: Different treatment features were not valued equally among all myeloma patients. This has important implications for healthcare policy decisions and could be used to guide decisions around the value of new myeloma medicines.

## Recurring Donations

Have you thought about making an automatic recurring donation to Myeloma Australia?

We are now able to set up and process recurring donations when paid via a credit or debit card. There are a variety of recurring options available such as fortnightly, monthly, and quarterly and you can choose to cancel your recurring donation at any time.

**For more information on recurring donations or to set one up please contact Alex on P: (03) 9428 7444 or email alex.dawson@myeloma.org.au**

## Common abbreviations used in Medical Corner

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

**ASCT:** autologous stem cell transplantation

**BM:** bone marrow

**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

**ISS stage:** International Staging System defines stage of myeloma at diagnosis (Stage 1, 2, or 3)

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

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

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

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

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

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

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

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

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

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

**Randomised study:** comparing the study drug with standard of care treatment. Participants are grouped at random.

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

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

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

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

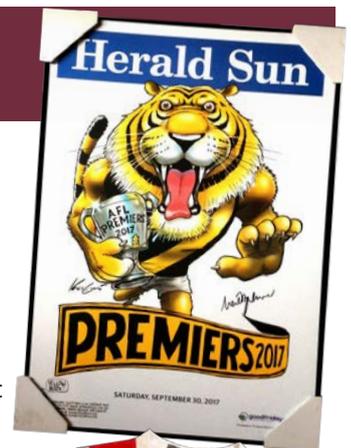
**Triplet:** 3 drugs used in combination

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

## eBay – Online Shop

### Cards, Artwork, Sports Memorabilia and much more

Our online shop has a range of items that include greeting cards from renowned artist Patricia Ball and photographer Joe Rey, artwork by Patricia Ball that comes framed and ready to hang, first aid kits, sports memorabilia and promotional t-shirts from our iconic Masters of Rock event. Below is an example of our extensive range of items which can all be found at <http://myeloma.org.au/volunteer-with-us/shop/>





# 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/>

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 and Catch-Up
- Newcastle
- Orange
- Regional NSW Cuppa and Catch-Up
- 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
- 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

- Partners and 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

## 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](mailto:deborah.thompson@myeloma.org.au)

**M:** 0433 511 689

## Information and Support Groups VIC

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

**For enquiries please contact**

**Laura Jones**

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

**M:** 0451 404 203

**Emma-Jane Furphy**

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

**M:** 0426 404 233

## Information and Support Groups WA

- Partners and Carers
- Cuppa and Catch-Up
- North Metro
- Perth Hills
- South Metro
- South West
- Younger Persons

**For enquiries please contact**

**Kerin Young**

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

**M:** 0426 404 310

**Narelle Smith**

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

**M:** 0426 404 280



**NATIONAL TELEPHONE  
SUPPORT GROUP  
(CANCER COUNCIL NSW)**

**Telephone Support**

**2nd & 4th Monday every month  
Available to those with myeloma  
1.30 pm – 2.30 pm (AEST)**

**Cancer Council NSW  
with MA NSW**

**Cancer Council NSW  
1300 755 632**

**E:** [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au)



You can also follow us on Facebook  
[www.facebook.com/MyelomaAustralia](http://www.facebook.com/MyelomaAustralia)



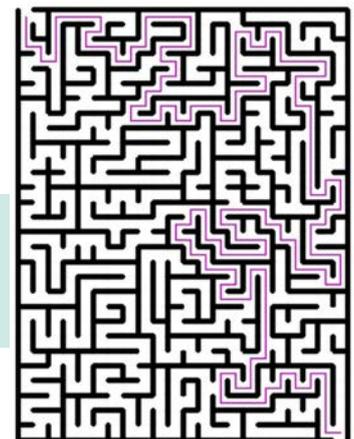
Twitter [twitter.com/MyelomaAust\\_MFA](https://twitter.com/MyelomaAust_MFA)  
for all updates and events.



*Answers to Sudoku #1  
and Maze Puzzle  
from page 6*

Sudoku #1

6	2	4	3	8	7	5	9	1
1	3	9	4	5	6	8	2	7
7	5	8	1	9	2	4	3	6
4	9	6	8	1	3	7	5	2
2	8	3	7	6	5	1	4	9
5	1	7	9	2	4	3	6	8
9	4	1	2	3	8	6	7	5
3	6	2	5	7	1	9	8	4
8	7	5	6	4	9	2	1	3



# Myeloma Australia is the only myeloma specific support organisation in Australia



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



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



Find your nearest **myeloma support group** to meet other people



Visit **[www.myeloma.org.au](http://www.myeloma.org.au)** to download the latest information, find support and seminar events etc

**Myeloma Support Nurses are on call at**

**Freecall: 1800 693 566 (1800MYELOMA)**

**Mon – Fri 9am – 5pm AEST**

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