

# MyeNews

Spring 2021 Issue no 59



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MyeNews – Contact Information and Submissions

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

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*Front cover: Top L>R: Professor Miles Prince AM, Professor Joy Ho AM.*

*Bottom L>R: Professor Hang Quach, Professor Simon Harrison.*



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## From the President

**No one would ever have foreseen what has happened over the past 18 months. COVID-19 has turned our world on its head, and we are hoping that over time that we will get our lives back to some sort of normalcy.**

Myeloma Australia was ready when we first went into lockdown as we had already started using the Zoom platform for communication. We have been able to keep our support groups going and we have noticed an increase in numbers attending. Our nurses are developing some special interest groups so watch out as these are promoted in the coming months.

I would like to express an enormous thanks to Professor Miles Prince as he steps down as chair of the MSAG subcommittee. He has done an enormous job in leading this group to becoming a major group for myeloma in Australia and as an advocate for the best available treatments for myeloma in Australia.

This October marks 25 years since my wife was diagnosed with myeloma and I would like to report that she is still very well and active. Her only problems are those we all have as we age. Like everyone in Melbourne we have spent over 200 days in lockdown so all we could do was go for long walks and watch lots of television, thanks to Netflix and Prime. Our only problem was like many others, we were not able to have our annual holiday in Queensland, again. We are concerned

by the spread of the delta variant of COVID-19 so we are taking all precautions. We have had our two doses of the vaccine and would like to recommend that if you have not had your COVID vaccine to speak to your doctor to discuss it.

Thanks to everyone who supported our last donation drive. Another side effect of the coronavirus is that we have not been able to hold any fundraising events for the past eighteen months and this is starting to have effects on our balance sheet. We usually have at least two or three events in Melbourne plus sponsored runners in the fun runs all around Australia. Also, there are many other events run by our community which helps to raise money. Our fundraising team is developing some alternate fundraising schemes, so watch out for them and if you can get involved, we will be very grateful. If anyone knows people in business who may consider sponsoring us in some small way, please refer them to us as every dollar helps us to continue to provide our services as we get no funding from State or Federal governments.

*Brian Rosenzweig*



### **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.



# Myeloma Australia's Medical and Scientific Advisory Group

## New Leadership for Myeloma Australia's Medical and Scientific Advisory Group

Myeloma Australia is fortunate to have our Medical and Scientific Advisory Group (MSAG) as a subcommittee of the organisation. MSAG is the peak expert body acting for the multiple myeloma community and is made up of leading clinicians and scientists working in myeloma in Australia and New Zealand.

MSAG was initially founded as the Myeloma Forum by Emeritus Professor Doug Joshua AM with Professor Luen Bik To and Professor Miles Prince AM to gather together those with a passion for myeloma. In 2006 the group became part of Myeloma Australia, gained the acronym MSAG and grew in number as those with a clinical, laboratory and research interests came aboard.

Professor Miles Prince AM took over as MSAG chair in 2008, and after more than 10 years will now step down from this role. "I think we have a lot to be proud of and I thank all the MSAG members for their support. It has been incredibly gratifying to observe during my time as Chairman, so many new drugs approved for myeloma – many of which have been approved more quickly because of the input by the MSAG. I am also so proud of our work developing consensus practice statements on the management of myeloma and related diseases and our major contribution to myeloma education in Australia. I look forward to continuing to be a significant contributor like Doug before me." – Professor Prince.

Myeloma Australia president Brian Rosengarten OAM was among the first to thank Professor Prince. "Miles is an important part of the myeloma community and has been with Myeloma Australia since its inception, we greatly appreciate all that he has done for us in this role." Myeloma Australia CEO Steve Roach thanked Miles and Professor Joy

Ho AM who is also stepping down as deputy chair. "This is a very significant moment. Miles has driven this group to its current standing as pre-eminent in this field across Australia and the world. This is a reflection on the work Miles and deputy chair Professor Joy Ho have done."

Both Professor Prince and Professor Ho will continue as MSAG members and Professor Prince will retain his position on the Board of Myeloma Australia.

Professor Simon Harrison has taken over the role of chair alongside Professor Hang Quach as deputy chair. Both are long standing MSAG members, haematologists, and leading clinician scientists of international renown. Professor Harrison is the Director of the Centre of Excellence in Cellular Immunotherapy and Director of Clinical Apheresis at the Peter MacCallum Cancer Centre, a clinician scientist in the Sir Peter MacCallum Department of Oncology at The University of Melbourne and has been the convenor of the Australian clinical and scientific workshop and the national education meeting since their introduction. Professor Quach is the Director of Clinical Haematology and Clinical Haematology Research at St. Vincent's Hospital Melbourne, a Professor of Haematology at The University of Melbourne and leads the effort to generate guidelines and scientific publications for MSAG. Professors Harrison and Quach are looking forward to building on the existing foundations and achieving the goals they have set themselves.

"I am very proud to lead the group in the next chapter in the story in the development of MSAG and Myeloma Australia." – Professor Harrison

MSAG has been and continues to be an important part of Myeloma Australia and the myeloma community. Myeloma Australia anticipates this continuing and growing in strength under new chair Professor Simon Harrison and deputy chair Professor Hang Quach.

*L>R: Professor Miles Prince AM, Professor Joy Ho AM, Professor Hang Quach, Professor Simon Harrison*



*Photos supplied and used with permission*

## Nourish through Myeloma

**We often can't control what treatment we need for myeloma, but, fortunately, we can control what we put in our mouths. This means a lot when it comes to myeloma treatment!**

At OnCore Nutrition, we believe it's imperative we look at how cancer patients and their carers can be best supported to optimise their health. Our team of Accredited Practising Dietitians are passionate about providing evidence-based, personalised care and support at each stage of your cancer experience. From diagnosis through treatment, we are here to help!



Whilst unfortunately there isn't a magic diet that prevents cancer altogether, nutrition certainly has a role to play in our health. From supporting your body during treatment to nourishing it through survivorship, we've got the know how! Let's break it down.

### Nutrition through myeloma diagnosis and treatment

Cancer treatments, including chemotherapy, immunotherapy, radiotherapy and stem cell transplants, increase stress on your body. Our bodies often need more nutrition to repair and recover. Side effects of treatment, including fatigue, nausea, changes in bowel habits and appetite, may mean that while your body needs you to be eating *more*, you actually feel like eating *less*.

It's far too common that people with cancer don't meet their nutritional needs, with 31-78% of Victorian cancer patients found to be malnourished in a recent study. This can happen regardless of body shape or size. We know that weight loss during treatment often impacts our muscle stores (rather than our fat stores) so it's important not to ignore even small amounts of weight loss or changes in eating patterns.

Seeking nutrition intervention and support from an oncology dietitian can help you improve your treatment tolerance and your long-term health and cancer outcomes.

### Managing side effects of treatment

Chemotherapy regimens for myeloma or conditioning therapies for transplant often target rapidly dividing cells in the body. This is key for targeting cancer cells, but unfortunately it also affects our good cells! Our gut can often bear the brunt of these treatments, resulting in side effects like mouth and throat ulcers, nausea, diarrhoea and loss of appetite. The big takeaway here is these treatments can really knock you around but there are nutrition strategies that can help.

#### If you're struggling with your appetite, try:

- Prioritising small, frequent meals built around high energy and protein foods. Think meat, chicken, fish, legumes, tofu, and dairy products.



*Elise Den and Lauren Atkins OnCore Nutrition.*

- Spice it up and try to make eating a pleasurable experience! Add variety and interest to meals by eating a rainbow of colours, herbs, spices, different textures and garnishes. It's true that we eat with our eyes!
- If you find yourself put off by the smell of food, try enjoying some cold meals to help reduce their scent. Seek help from loved ones with shopping and cooking.

#### If you're experiencing an inflamed mouth and throat, try:

- Nourishing fluids and softer textures to not aggravate your mouth and throat.
- High protein drinks; including smoothies, soups and good quality bone broths.
- Mouth care is also really important. Ask your treating team about topical pain relief options to keep you eating comfortably!

#### If you're experiencing diarrhoea, try:

- Switching up the fibre in your diet. Increasing foods rich in soluble fibre like oats, wholemeal or rye bread and bananas (these absorb liquid and become soft in your gut) over insoluble fibre rich foods like grainy bread, whole nuts or the skins of fruits and veggies (which may irritate your gut lining). Instead of whole chickpeas, choose hummus dip. Instead of whole nuts, go for a smooth nut butter.
- Making sure you're staying hydrated. Spruce up your regular water with fruit, herbs or even a cold infusion to help support regular sips!

### After cancer treatment

How we eat and nourish our bodies is key to supporting overall great health, especially following cancer. At OnCore our focus is not just on surviving, but on thriving!

Our top tips to support overall good health and reduce the risk of cancer recurrence include:

- Eat the rainbow! Enjoying plenty of colourful fruit and veggies is key as they provide lots of micronutrients and phytochemicals to keep our bodies thriving.



- Choose wholegrain breads and cereals, nuts and seeds to provide you with plenty of energy and fibre to keep the good bugs in your gut well fed.
- Enjoy lean proteins, especially those rich in omega-3s like salmon, sardines and tuna! Aim for less than 500g of red meat per week.
- Choose water as your beverage of choice over sugar sweetened drinks and alcohol (of course, enjoy a sip in moderation – if your Haematologist approves, so do we!).

Phew, that was a lot of information! If you're feeling like you would benefit from some one-on-one attention, we would love to help! With over 30 years combined, specialist experience in oncology nutrition, the team at OnCore can help clarify your questions and provide supportive care tailored to your unique situation. We're based in Victoria, working out of our clinics in Windsor, Brighton, Caulfield, South Melbourne and Torquay. We offer telehealth consultations so wherever you are, we can help!

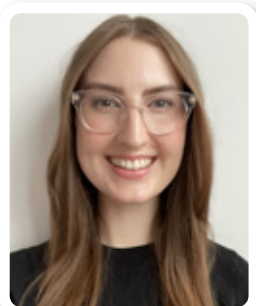
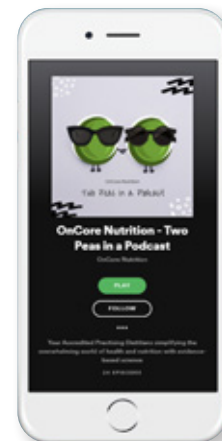
We happily offer **free 15 minute phone consultations** to help answer your niggling questions or explore how we can help you. This service is completely obligation free and

an opportunity for you to ask all of your burning questions about nutrition.

We would love to hear from you. Head to our website to book online or phone 0435 464 778 for more information or to chat to one of us.

**Looking for more?** Check out our website for a suite of nutrition guides and articles on topics of interest. We publish our weekly "Eat Our Words" newsletter where we nourish your inbox with the latest nutritional news to help you build your best you! We also have a podcast "OnCore Nutrition – Two Peas in a Podcast" where we explore the latest in the world of nutrition. Sign up and subscribe via our website!

If you have any questions and would like to get in touch, we would love to hear from you! Please find our details below and don't hesitate to drop us a line.



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<https://www.linkedin.com/company/oncore-nutrition/>



Lauren Atkins  
and Elise Den  
with OnCore  
Fruit and Veg.

# My Myeloma Journey

My story began on the Show Day holiday in Melbourne, September 1994.

I had volunteered to train as a Workplace First Aider and was a little put out that our final test was scheduled for a public holiday. I would miss spending half the day with my wife and our children; then aged nine and 15.

At the end of our simulated CPR, I needed help to get up from the floor. I didn't take it too seriously, as I thought it related to a motorcycle accident at age 17 where I suffered minor spinal damage which limited my movement. I had been experiencing increasing back pain for about a year.

After an uncharacteristically early 8pm retirement to bed, at about 2am I asked my wife Joy to get me a glass of water. Puzzled about why I couldn't get it myself, she nevertheless brought me the glass. I then asked if she could lift my head so I could drink it, as I couldn't raise my head.

At this point, she realised there was something seriously wrong. The next morning Joy declared that neither of us would attend work until we knew what the problem was.

Over the next few days, we visited three GPs, receiving diagnoses from suspected pulled muscles to malingering. At Joy's emphatic insistence, the last GP referred us to Werribee Mercy Hospital, coincidentally on the day an orthopaedic surgeon was scheduled to visit.

When he examined me, he exclaimed, "You poor man, you must be in agony!"

I was admitted on the spot and given enough morphine to kill a small horse. It barely eased the pain.

In 1994 multiple myeloma was commonly regarded as an 'old people's disease', encountered in the last stages of life where people had multiple health challenges and were bound to die of *something*. I was 46.

X-rays at Werribee showed serious damage to many of my bones. The orthopaedic surgeon's diagnosis: multiple myeloma.

Joy was told there was no cure for myeloma, and warned that with two vertebrae already collapsed, I may never walk again.

*(Since then, I have fractured both femurs and a humerus — now all titanium reinforced — and three more vertebrae have collapsed, but I'm still walking, and have passed my Medium Rigid Truck licence to drive our current eight tonne motorhome!)*

I was ferried to Geelong Hospital where more scans and tests revealed lesions in all major bones (*including my skull*), with my spine the worst affected. Detailed blood tests revealed 64% plasma cells in my bone marrow.

After the test results were in, Joy was offered a choice: treatment might see me last six to eight weeks, but I wouldn't see Christmas 1994; palliative care would 'keep me comfortable' for the anticipated two to four weeks before the cancer killed me.

To my eternal gratitude she chose treatment. I began immediate chemo and radiotherapy.



Joy and Ray Nolan.

In the interim, my employer had been advised of the diagnosis, as I required considerable leave for treatment. I was medically superannuated into early retirement.

Once my condition was stabilised — and I had survived beyond Christmas — my treatment was continued at Royal Melbourne Hospital (RMH) where I was admitted in April 1995 and finally discharged in September of that year.

At RMH I underwent further chemotherapy and an autologous bone marrow transplant. At the time, the autologous transplant was an experimental treatment for myeloma. I cannot praise the nurses and doctors at both Geelong and RMH highly enough. Their care and concern were top-notch.

Upon discharge I spent another year recovering, graduating from a walking frame to a walking stick and finally to unaided walking.

Our local community had gathered around and supported us during my hospitalisation. One friend even moved into our house temporarily as surrogate mother for our children while Joy stayed with me in hospital every day. *(The school where Joy taught was most understanding!)*

We decided that, with an anticipated five or so years left, we would see as much of Australia as possible while I was physically able to travel.

When advised of our desire to travel Australia, my oncologist set to work researching pill-based alternatives to the monthly infusions I was enduring. He finally gave us the green light, and we purchased an aged second-hand motorhome and began planning.

Our first four-month trip in 1998 was across the Nullarbor, up the west coast of WA, across to Darwin then down through the Red Centre to Adelaide and home to Melbourne.

We took our then 12-year-old daughter out of school to travel with us, Joy home-schooling her on the road. Our then 18-year-old son, in his first year at Melbourne University, was left at home, with responsibility for his studies and maintaining the house.

Over the next few years, treatment – and travel – continued, with a couple of myeloma outbreaks which were quickly brought under control with radiotherapy. I passed the



five-year mark, then ten and fifteen years, post-transplant. Over 22 years I continued regular treatment with a number of drugs and infusions, and radiotherapy when the cancer re-emerged. I have been on the testing panel for several treatments, including Thalidomide. *(A disaster, as I rapidly developed peripheral neuropathy. I still have minor nerve damage.)*

The trial of lenalidomide combined with dexamethasone proved to be my 'miracle drug'. In a few months it reduced my paraprotein level to 'undetectable to zero' in the pathologist's cautious language.

I remained on the lenalidomide/dexamethasone combination for the rest of my treatment, with the same paraprotein results every month: zero.



Upon Joy's retirement in December 2009, we took advantage of our new freedom to do *The Big Lap* over three years. On that long tour, we co-ordinated with RMH as we travelled. The hospital pharmacy packaged up pills every three months and mailed them to me, Post Restante, at a town where we planned to be two weeks later. The system worked well.

In 2013 we returned from *The Big Lap* and a few months later moved out of Melbourne to regional Victoria. I transferred treatment to Albury Base Hospital's Regional Cancer Centre.



In late 2015 my new oncologist began ordering a range of intensive tests and in January 2016 he declared me in remission... 22 years after diagnosis.

I am now off all prescription medications. Twenty-six years after I was told I had a few weeks to live, with us now both in our 70s, Joy and I enjoy an active life, have become involved in our new community, and are looking forward to many



more years together. As we continue to travel Australia, I have told my story to many people over campfires, at church services and at other social occasions. Some had friends or relatives with myeloma (or other cancers) and quite a few campers we met were living with various cancers.

I hope I have inspired in some of them a more positive attitude toward living with serious health challenges.

I would like to place on record my thanks to the many doctors who helped save my life.

And a special thank you to all the nurses in the hospitals I visited across Australia, for their unfailing kindness and professionalism throughout my hospitalisation and visits during our travels.

Ray Nolan





Myeloma Australia is involved in advocacy programs on both local and global levels. The aim of these programs is to improve the lives of people living with myeloma and work towards a cure by increasing awareness of myeloma and the lived experience, building community and together working to improve access to care, treatments and education both locally and globally.

Late in August, four members of the Myeloma Australia team will be attending the Annual Global Myeloma Action Network (GMAN) Summit which will be held virtually for another year running. The program looks fantastic with presentations from our international colleagues The International Myeloma Foundation and Myeloma UK, researchers from Iceland about the iSTOPMM Project and leading myeloma expert Dr Brian G.M. Durie. This meeting is being held on Central European time so our team will be staying up late to participate and connect with our international colleagues; we will report back on the meeting in the next edition of MyeNews.

### News from July 2021 Pharmaceutical Benefits Advisory Committee (PBAC) Meeting

Thank you to all of you who provided comments and feedback for the PBAC meeting in July, Myeloma Australia and our Medical and Scientific Advisory Group (MSAG) also submitted feedback on behalf of the Australian myeloma community. There were multiple submissions relating to myeloma and in August we were notified of the outcomes.

Pleasingly there were some recommendations that came from the PBAC and they are as follows:

- 1) A new drug combination of elotuzumab / lenalidomide / dexamethasone for people with myeloma that has come back or relapsed
- 2) Daratumumab will now be available as a subcutaneous injection (into the skin) as well as an intravenous infusion in combination with bortezomib and dexamethasone for when myeloma comes back or relapses the first time
- 3) Two generic brands of bortezomib (Velcade) will now be available

There will still be some time until these changes added to the Pharmaceutical Benefits Scheme. Your doctor will be able to let you know when these treatment options are available.

Unfortunately, both submissions relating to selinexor were not recommended at the meeting however it is not uncommon for submissions to not be recommended the first time they are considered.

There is one more PBAC meeting this year in November however there are not any myeloma related submissions on the agenda this time.

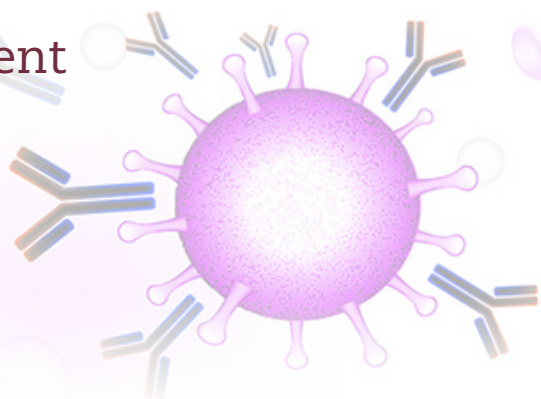
If you would like to read more about the outcomes please visit [www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/pbac-outcomes](http://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/pbac-outcomes) or contact our nurses on the Telephone Support Line 1800 693 566 (MYELOMA) or [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

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

## Daratumumab (Darzalex®) Treatment

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

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



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

## Staff Profile



### Robert O'Brien

#### Community Engagement and Fundraising Executive NSW

Robert O'Brien has joined the NSW team at Myeloma Australia as the Community Engagement and Fundraising Executive. Following a career in financial services, Robert's strengths are found in key account management, business development and relationship building.

Each week, in his spare time, Robert runs a dinner for the homeless and dispossessed in the City of Sydney via The Salvation Army. He has been involved in music from the age of eight and now manages two of the finest brass ensembles in Australia as well as playing in the Fize & Rescue NSW Band.

Robert is a strong believer in supporting community and brings with him strengths in business and community engagement.

## THE COMMUNITY AND RESEARCHER ENGAGEMENT (CARE) COMMITTEE

### BLOOD NOT BONE MARROW? THE POTENTIAL ROLE FOR BLOOD TESTING TO IMPROVE MULTIPLE MYELOMA DIAGNOSIS AND THERAPY

Understanding the genetic lesions in MM can transform diagnosis, prognosis and treatment. However, this has traditionally relied on single-site bone marrow biopsy that is inadequate for capturing the complexity of this cancer. Please join us as we discuss a new innovative alternative approach called liquid biopsy, which can transform therapeutic options for patients with MM.

**Please join us for a Q&A discussion with our speakers after the webinar.**



**MONASH**  
University

MONASH MEDICINE  
NURSING AND  
HEALTH SCIENCES

#### EVENT DETAILS

**DATE:** Thursday 7 October 2021

**TIME:** 5.30 – 7:00pm

Please register at:

[https://monash.zoom.us/webinar/register/WN\\_EttJxJVSUy0P4Zt-n9ylQ](https://monash.zoom.us/webinar/register/WN_EttJxJVSUy0P4Zt-n9ylQ)

#### CONTACT US

**EMAIL:** [acbd.care@monash.edu.au](mailto:acbd.care@monash.edu.au)

**TWITTER:** @CCS\_cares

**WEBSITE:** <https://www.monash.edu/medicine/ccs/blood-disease/community-engagement>



# Supporters in the Spotlight

## The Myeloma Business Collective

In this edition of Supporters in the Spotlight, we put the spotlight on several businesses who are part of the newly formed Myeloma Business Collective.

### About The Myeloma Business Collective

Launched in August 2021, The Myeloma Business Collective is a community of small to medium sized Australian businesses that stand with Myeloma Australia in our mission to support, inform, educate, empower and bring hope to those living with myeloma.

Myeloma Business Collective partners:

- ✓ Help us to spread the word about myeloma in their communities through their staff and customers, and
- ✓ Contribute an annual tax-deductible donation (of any size) to Myeloma Australia, that is put towards our most pressing needs in sustaining and increasing our services for people living with myeloma around Australia.

### Founding members of The Myeloma Business Collective...

#### Andrew Vanny Plumbing, Sydney

*"Myeloma Australia provided our family with information and support. Everyone involved with Myeloma Australia was fantastic to deal with. We hope that one day a cure will be found for myeloma, and in the meantime if even one person can be supported through their hard time, then our contribution will be more than worth it."*

Andrew Vanny, Founder and Director



**ANDREW VANNY PLUMBING**  
For fast, reliable and friendly service

#### Hiline Home Modifications, Adelaide

*"We are very grateful for the warm support Myeloma Australia provides to my dad and the founder of Hiline Home Modifications, Brian, who is living with myeloma and also to my mother who is caring for him. We hope our support will assist in extending these services to other people and families living with myeloma. And we hope that one day a cure will be found for myeloma."*

Paul Hoskin, Managing Director



#### Unified Music Group, Melbourne

*"My Mum has been living with myeloma for quite a few years and I've seen the impact it has had on her life. Myeloma Australia do a lot of amazing work to support people like my Mum, so the least we can do is support them."*

Jaddan Comerford, CEO and Founder



#### Victoria Sports and Rehabilitation Clinic, Melbourne

*"We are a proud supporter of Myeloma Australia. Our clinic has a personal connection as our director's mum has been living with myeloma for over 8 years. We appreciate all of the work that is done through this important organisation."*

The VSRC team



**VICTORIA SPORTS**  
AND REHABILITATION CLINIC

#### JC's Quality Foods, Melbourne

*"JC's is proud to support Myeloma Australia. We feel it's important to give support back to the community wherever possible and use our voice as a family business to get this important message out and raise awareness."*

Joe Cannatelli, Managing Director



#### Engineering Contracts Mediation

*"Being directly impacted by myeloma, our business is pleased to be able to sponsor the ongoing practical support, knowledge exchange and myeloma community wellbeing which is delivered so well by Myeloma Australia."*

Bruce Atkinson, Director



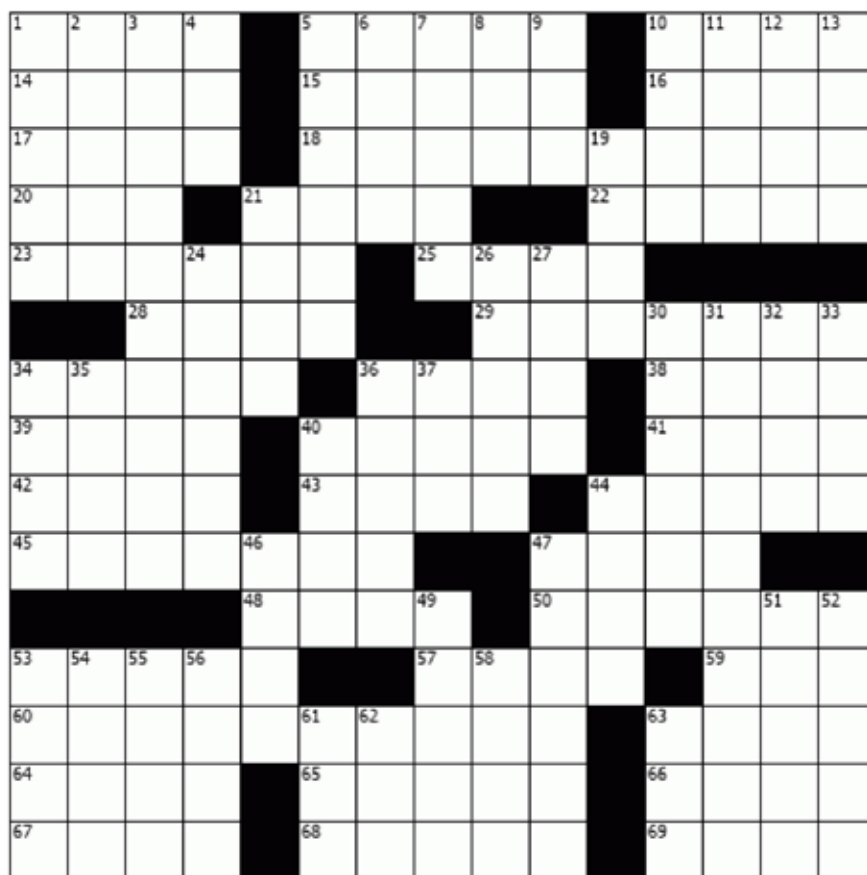
### Do you know a business that would like to join The Myeloma Business Collective?

We would love to welcome your business into The Myeloma Business Collective. To move forward with this, or to request further information or have a chat about your options, please contact our CEO Steve Roach on 0410 567 553 or via email at [majorgifts@myeloma.org.au](mailto:majorgifts@myeloma.org.au)

# Exercising the Brain



One of the most common effects of myeloma and associated treatments on the body is impaired cognition, otherwise known as chemo brain or brain fog. This can present as difficulty concentrating, short term memory loss, impaired ability to find words in conversation, difficulty learning new skills and mood swings. These symptoms can be even further compounded by the fatigue that is also caused by both myeloma and its treatment. Some strategies to improve cognition include daily gentle exercise, adequate food and fluid intake and exercising the brain with puzzles, craft projects or learning a new hobby. If cognitive impairment is having a significant impact on the ability to function, a psychologist can help by way of cognitive rehabilitation.



## ACROSS

- |                          |                       |
|--------------------------|-----------------------|
| 1. Curve                 | 41. Test answer       |
| 5. Tear to bits          | 42. Circle parts      |
| 10. Bloodhound's clue    | 43. Customer          |
| 14. Commandment start    | 44. Out of style      |
| 15. Pester               | 45. Dwell in          |
| 16. Presented            | 47. Evaluate          |
| 17. Grow weary           | 48. Significant times |
| 18. Available to anyone  | 50. Shoelace hole     |
| 20. Roadhouse            | 53. Elude             |
| 21. Flower container     | 57. Pub drinks        |
| 22. Changes direction    | 59. Grant's enemy     |
| 23. Fellow leading actor | 60. Useful            |
| 25. Stood up             | 63. Televises         |
| 28. Portable shelter     | 64. Snack             |
| 29. Limber up            | 65. Tango, e.g.       |
| 34. Pulls apart          | 66. Fit of temper     |
| 36. Step                 | 67. Sleigh            |
| 38. Food fish            | 68. Chose             |
| 39. Rabbit's kin         | 69. Slapstick items   |
| 40. Woman's title        |                       |

## DOWN

- |                             |                          |
|-----------------------------|--------------------------|
| 1. Garret                   | 32. Crossword hint       |
| 2. Horned animal, for short | 33. Listen to            |
| 3. Food thickener           | 34. Bangkok native       |
| 4. Shade                    | 35. Work for             |
| 5. Mouse Little             | 36. Italian staple       |
| 6. Egg layers               | 37. Lime drink           |
| 7. Less common              | 40. Naturalist John      |
| 8. Compass point (abbr.)    | 44. " of Our Lives"      |
| 9. Plaines                  | 46. Steak, e.g.          |
| 10. Bogeyman                | 47. Felt dizzy           |
| 11. Writer Barry            | 49. Canonized person     |
| 12. Concluded               | 51. Spooky               |
| 13. Nail polish shades      | 52. Experiments          |
| 19. At all times            | 53. Recedes              |
| 21. Moving trucks           | 54. Face covering        |
| 24. Calcutta's Mother       | 55. Opening wager        |
| 26. Movie award             | 56. Exploit              |
| 27. Flower support          | 58. Shoe fastener        |
| 30. Tycoon's property       | 61. Groom's vow (2 wds.) |
| 31. Meat-filled pasta       | 62. and gown             |
|                             | 63. Egyptian cobra       |

answers on page 23



## What's Happening

### Community Engagement & Fundraising

We are now well and truly into our second year of our community engagement & fundraising being impacted by the pandemic as various states are at differing times locked down.

Whilst it has been difficult to see the big city community runs postponed, events in which Team Myeloma would traditionally participate in to raise awareness and funds, it has been terrific to see individuals from within the myeloma community stepping up with their own personal fundraising projects. Amongst the fundraising campaigns we currently have operating, we have people raising funds as they prepare to participate in the Noosa Triathlon, Melbourne Marathon and the Sunset Coast Festival in Western Australia (this last one will be performed whilst dressed in a dragon costume!)

Of course, running vast distances might not be your thing and it has been tremendously encouraging to see funds for Myeloma Australia raised in many other ways – one of the more inventive and inspired fundraisers that has been a great success has been one of our more rural supporters selling bagged up horse poo and giving us the profit. Others are supporting us through haircuts, lunches and by going without alcohol. If you're keen to fundraise for us I am convinced that there will always be something you can turn your hand to!

Our well established fundraising projects of The Entertainment Book and Containers for Change continue to raise funds for us too.

The success of the 38mate awareness campaign from May is still evident today. The manner in which the myeloma community embraced the campaign was tremendous. We are still posting 38mate caps out to people most days!



We have recently launched the 38mate Fundraising Appeal. This is in response to not being able to run over 20 fundraising events across the past 18 months due to the pandemic, which in turn means we have not been able to raise much needed funds. We are asking people to either donate directly to Myeloma Australia or to establish a

community fundraising event at this time. We hope to have at least 38 fundraisers in each State and Territory participating in this campaign. To establish the latter please visit: <https://www.justgiving.com/myelomaaustralia> and start by clicking 'Fundraise for us' in the top right hand corner of the page. If you have any questions please reach out to Rob or myself.

A further iteration of 38mate occurs on Sunday 27th February 2022. On this day we are encouraging the myeloma community nationwide to gather for The Myeloma Australia 3.8. We are well advanced in our planning for The 3.8 and details, once finalised, will be shared via our usual social media channels. In short, The 3.8 is an awareness and fundraising event in which we are encouraging members of the myeloma community to walk (although other activities are to be encouraged too!) 3.8km together as a local community to raise awareness of myeloma, build community with one another and raise funds for Myeloma Community. If you are keen to know more about The 3.8, please drop me a line.

Rob in Sydney, our NSW Community Engagement & Fundraising Executive, is going great guns – hampered only by the NSW lockdowns. Still, Rob would be super keen to hear from anyone in NSW with community building and fundraising ideas; please reach out to him: [robert.obrien@myeloma.org.au](mailto:robert.obrien@myeloma.org.au)

Our Charity TV Ambassadors have had their Adventure, originally planned for late July, now postponed twice because of lockdowns. As of right now there is no definite date as when their Adventure WILL occur. Rest assured, it will eventually happen, and we will bring you a full report of the excitement of their trip in a future edition of MyeNews. We are always on the lookout for people to become Ambassadors for Myeloma Australia on Charity TV – please reach out to me or Rob if you're keen to find out a little more.

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

Kind regards,



*Matt Maudlin*

*Community Engagement & Fundraising Manager  
M: 0407 891 052  
E: [matt.maudlin@myeloma.org.au](mailto:matt.maudlin@myeloma.org.au)*

An advertisement for the Containers for Change Scheme. It features a blue background with a green landscape and a body of water. On the left, there is a large, clear glass bottle and a 10-cent coin. The text 'DONATE YOUR CONTAINERS' is written in large, white, bold letters. Below it, 'WE RECEIVE 10 CENTS FOR EACH' is written in smaller white letters. At the bottom left, there is a circular logo with a green bar chart and the text 'CONTAINERS FOR CHANGE'.

### Containers for Change Scheme

Operating in Western Australia and Queensland we receive 10 cents for the deposit of every eligible bottle and can at Containers for Change recycling centres.



Further details about Containers for Change can be found at:

<https://www.containersforchange.com.au/>

The QR code you require is the numerical code is: **C10356476**

# What's Happening



## New South Wales

With the majority of NSW back into lockdown due to Covid 19 restrictions, all our support groups have returned to being held via Zoom, but not before we had the opportunity to meet some of our myeloma communities in regional areas. Our first meet and greet for winter was held in Nepean on the 2nd June with a huge turnout. It was wonderful to bring so many people together to be able to connect, support and provide information. On the 10th June, Juliet and Cath travelled to Port Macquarie for their first meet and greet in the area. It was a great opportunity to extend the Myeloma Australia support network further up the East Coast and meet some myeloma locals living in Port Macquarie and surrounding areas. From the Mid North Coast out to the

Central Tablelands, Cath and Diana travelled to Orange for a Meet and Greet on the 18th June. It was fantastic to connect with some old and new faces and a wonderful opportunity to meet with local haematologist Dr Doug Lenton and Clinical Nurse Specialist Katie Foy. We are looking forward to returning to face-to-face support groups when restrictions ease, but until then we will continue to offer groups via Zoom. We would like to highlight that our NSW cuppa and catch ups are being held via Zoom monthly and we encourage you to join us for a nice, relaxed chat with people living with myeloma from all around the state.

We are currently working on some content for online seminars to be presented in the latter part of the year and we will share the dates and times of those once they are finalised. Please reach out if you have suggestions or topics of interest.

*Myeloma Support Nurses – Jacqui Keogh, Juliet Hill, Catherine Bowley and Diana Yun.*



NSW Nepean



NSW Orange



## Queensland

Megan and Tash have been managing to run face-to-face support groups albeit with some juggling between lockdowns and restrictions. We would like to thank our community for their patience as we try to provide the opportunity to meet as safely as possible. It's been so nice seeing you all re-connect so long may it last. We've also been seeing many of you at our Zoom catch ups and it's great that, in this day and age, we have the technology to keep in touch this way.

As you would have read previously, we have the biannual MSAG Patient Workshop in November. All welcome.

Princess Alexandra Hospital combined with State of Origin to highlight a myeloma awareness day. Many thanks to all the staff at Princess Alexandra Hospital who bought and wore their Team Myeloma t-shirts and special thanks to Carmel Woodrow, Myeloma and Amyloidosis Clinical Nurse Consultant for her terrific engagement.

Meanwhile some of you have been escaping lockdowns and so forth by adventuring into the far north – Dan and Christine in the Northern Territory and Lenore in Far North Queensland.

*Myeloma Support Nurses – Megan McDowell and Tash Clarke*

*Above: Haematologists.*

*Left: Princess Alexandra Hospital Outpatients staff, Tash Clarke (MA Support Nurse) and Carmel Woodrow, Myeloma and Amyloidosis CNC – for promotion of myeloma whilst celebrating State Of Origin.*

*Right: Christine in QLD.*



Photos provided and used with permission





## South Australia

South Australia has continued to be lucky to be able to host hybrid face-to face/zoom support group meetings this year. Excitingly, SA has received a 2nd grant for the year - this time from the City of Unley Local Community Grants program. This grant enabled us to purchase a 'Meeting Owl Pro', a device that enables quality virtual participation in meetings thanks to its 360-degree camera and microphone. This gives our Fullarton support group members the choice of attending in person or virtually, while still participating fully in presentations or discussions. We are very grateful to the City of Unley for awarding us this grant!

We have had some great guests at our meetings such as Dr Tom Day, haematologist who has now spoken at both our Victor Harbor and Flinders Support group. His time and effort have certainly been appreciated by all those attending. We also heard from Sophie Wilson, RN and her new role at the Royal Adelaide Hospital as the first Myeloma Specialist Nurse in the state. It was encouraging to hear that myeloma patients at that hospital now have a nurse to provide more support and help navigate the challenging hospital system.

Our new support groups at Victor Harbor and Para Hills are continuing and we look forward to welcoming new members who live in those areas in the future. Please reach out to us for further information if you are interested in attending either group.

*Myeloma Support Nurses – Alicia Hopper & Jo Gardiner*

*Above: Alicia and Jo.  
Left: Jo presenting at Fullarton.  
Right: Alicia presenting.*



## Tasmania

Having been acting in another capacity, I am now back in my myeloma role good and proper!

We had a lovely turnout at Sandy Bay on Tuesday 3rd August and it was a pleasure to warmly welcome some new members. I did get reprimanded for not making scones, but Gail, one of the guests, made up for this by bringing along a yummy slice she had made.

At the meetings in the north on the 5th & 6th August, Michelle Towle, Health Promotion Officer, spoke enthusiastically to the Burnie group about the 'Get the Most Out of Life' program. In Launceston, Ryan West, from the Launceston Legal Community Centre, talked about legal issues and readily answered many questions from the guests. In Devonport, although a small group, meaningful discussion was had.

In July, Emma, a newly recruited Victorian Myeloma Support Nurse, travelled to Hobart to run the Southern Tasmania support group and gave a very well received talk on CAR T-cell therapy. Thank you, Emma!

We now have a new venue for our support groups on the Eastern Shore, the Howrah Community Centre. Our previous location in Bellerive is being renovated. I received a warm welcome from Christie, the centre's coordinator, and happened to visit on a beautiful sunny day which made the venue very inviting. We look forward to having many productive meetings there.

To conclude, I have added a photo of our lovely snow-capped Mt. Wellington.

*Myeloma Support Nurse – Deborah Thompson*



# What's Happening



## Victoria

We continue to live in these ever changing and unknown circumstances. Victorians have shown such strength and resilience through these tough times, and we admire how you're all getting through it.

In June, Emma travelled to Ballarat and presented on CAR-T cell therapy while Rachel and EJ educated our online groups on deciphering blood results. Professor Hang Quach attended our online national young person's support group for a Q&A session hosted by EJ. This was a fantastic opportunity for younger members of our myeloma community to discuss topics affecting them including clinical trials, vitamin replacement and mindfulness. We thank Professor Quach for offering her time. Our younger person's support group is held online on a bi-monthly basis, if you would like to join this group, please reach out to one of our nurses for details.



Emma Huybens



Emma-Jane Furphy

In July we recommenced our face-to-face groups as restrictions eased. Warrnambool and Ringwood enjoyed a joint Q&A with haematologist Dr Sasanka Handunetti. Thank you to Dr Handunetti for offering your time. Our Mornington Peninsula group enjoyed a session on nutrition with dietician Brooke Norman from Peninsula Physical Health and Nutrition. Brooke spoke to us on the different food groups, the importance of maintaining nutrition during treatment and some strategies around managing nausea. Meanwhile, EJ jetted off to see our group in Mildura which continues to grow.

August began with face-to-face groups in Kew and Beaumaris. Guest speaker Cassie Browne, an advocate from Elder Rights Advocacy joined the Beaumaris support group. Cassie's presentation was filled with practical advice. If you have a particular topic that you would like to know more about, please do not hesitate to contact us.



Rachel McCann

Thank you for your understanding and attendance to our online groups on short notice as we continue in and out of lockdown.

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



## Western Australia

Your myeloma support nurses in WA, Narelle and Dan, have had an exciting and eventful couple of months. Support groups continue to grow across the Perth Metro and regional areas of Western Australia. In July, support groups were facilitated for Younger Persons with Myeloma, a regional WA Zoom-in, a road trip to the southwest town of Busselton for our southwest community, as well as a Perth Hills catchup.



At the beginning of August, Narelle and Dan had the opportunity to engage in some strategic planning, exploring creating additional support groups as well as forming plans to continue to work closely with health care professionals and the myeloma community in vast regional WA. Myeloma Australia was invited to provide a display and information stand at the West Australian Clinical Oncology Group haematology education day, which was well attended and was a fantastic opportunity to promote myeloma support available in WA. In professional development news, Narelle and Dan were invited to attend a WA seminar on Myeloma treatment pathways and clinical trial information. This multi-service collegiate evening brought together myeloma specialists from around the state for an informative and collaborative evening of sharing expertise and knowledge. We are looking forward to sharing what we have learnt with the myeloma community at our various support groups.

Planning for our next Seminar and morning tea is well underway, booked for Monday the 30th of August at our Cottesloe conference hall, we are delighted to have secured two expert presenters, Dr Collin Chin, Haematologist who will be speaking on "Breakthrough therapies for myeloma: the WA perspective" and Dr Carolyn McIntyre, Senior Lecturer, School of Medical and Health Sciences who will be presenting on the exciting and emerging field of "exercise as medicine for cancer." We are looking forward to putting on an informative and supportive event for the myeloma community in WA.

*Myeloma Support Nurses – Narelle Smith and Daniel Berk*



Photos: WACOG displays



The ALLG is the only not-for-profit collaborative clinical trial group in Australia and New Zealand, delivering research projects focused on blood cancers. We are a for-purpose organisation dedicated to delivering clinical trials to achieve better treatments and better lives for patients with blood cancer.

The ALLG membership includes more than 800 physicians and haematologists, nurses, scientists and professional support staff, from across Australia and New Zealand, with clinical trials taking place at 93 accredited hospital sites and cancer centres across the country. Our members include many of the world and Australia and New Zealand's pre-eminent experts in haematological malignancies and all of whom are looking for ways to better treat blood cancers through clinical research. Our Life Members include true pioneers in the field of haematology.

## ALLG Clinical Trials

### Current Myeloma Trials

#### MM22 – leading doctor Professor Andrew Spencer

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

Recruiting Hospitals – VIC – Alfred Hospital, Sunshine Hospital; NSW – Calvary Mater Newcastle, Nepean Hospital, Concord Hospital, Tamworth Hospital; QLD – Princess Alexandra Hospital, Townsville Hospital, Sunshine Coast University Hospital, Toowoomba Hospital; SA – Royal Adelaide Hospital; TAS – Royal Hobart Hospital; NT – Royal Darwin Hospital. In addition, Latrobe Regional Hospital is a Teletrial centre for MM22, linked to the Alfred Hospital.

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

The SeaLAND trial is a phase III randomised study evaluating a new treatment option called selinexor in maintenance therapy, versus the standard maintenance therapy for



Better treatments...  
Better lives.

post-autologous stem cell transplant patients. This is the only study globally assessing this new treatment option for patients with newly diagnosed multiple myeloma.

MM23 has opened 16 sites across Australia and New Zealand in 2021, and the investigating team is excited to embark on this journey with all of the investigators and ALLG clinical trial site teams at the participating sites, working together towards improvements in therapy for multiple myeloma.

Current Recruiting Hospitals – VIC – St Vincent's Melbourne, Austin Hospital, Alfred Hospital, Geelong Hospital, Monash Health, Peter MacCallum Cancer Centre, Sunshine Hospital; NSW – Concord Hospital, Orange Health Service, Border Medical Oncology, Lismore Hospital; SA – Royal Adelaide Hospital; QLD – Townsville Hospital, Princess Alexandra Hospital; WA – Fiona Stanley Hospital; TAS – Launceston Hospital. More hospitals to open in coming months.

### What's New

The ALLG has another new trial in development, due to open for recruitment in 2021.

#### MM24 – leading doctor Dr Simon Gibbs

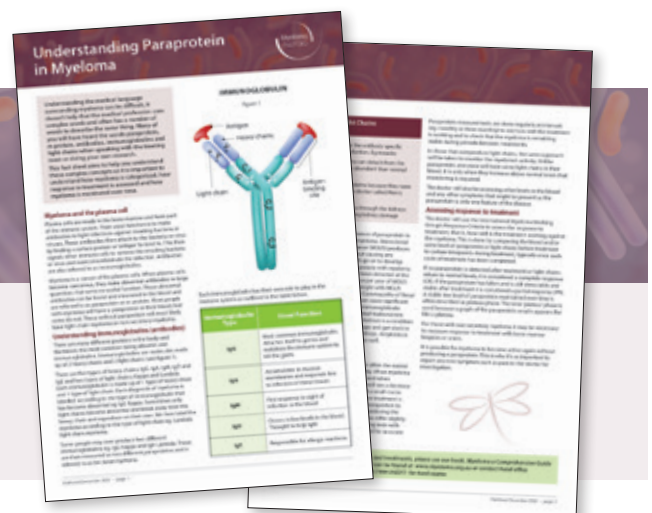
This is an international amyloidosis trial, in collaboration with the French Myeloma Group IFM. It will evaluate a new treatment for relapsed/refractory amyloid patients at 4 sites across Australia. ALLG is proud to bring this important international trial to Australia. We are working closely with our French colleagues and aiming to open this trial in Australia in late 2021.

**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.**

## Understanding Paraprotein in Myeloma

The latest fact sheet "Understanding Paraprotein in Myeloma" is now available for download on our website [myeloma.org.au/resources/](https://myeloma.org.au/resources/)





# News from Australasian Myeloma Research Consortium (AMaRC)

AMaRC has opened several new sites across our recruiting studies (see below). Of note, FRAIL-M is now also opened in New Zealand. We have five (5) upcoming projects that are progressing well and we should see a few of these open in the next quarter.



## Currently recruiting trials

### 1. **FRAIL-M (MM22) study – Prof. Andrew Spencer**

This study aims to look at use of lenalidomide and/or bortezomib based on a patient frailty (weakness) score to identify optimal treatment for myeloma patients.

The FRAIL-M study is a collaboration with the Australasian Leukaemia & Lymphoma Group (ALLG) and funded by the Australian Government's Medical Research Future Fund (MRFF).

#### **Recruiting hospital sites – 3 new sites**

##### **Australia**

- o VIC – Alfred Hospital, Sunshine Hospital, **Latrobe Hospital (new)**
- o NSW – Concord Hospital, Nepean Cancer Care Centre, Tamworth Hospital, **Calvary Mater Hospital (new)**
- o QLD – Princess Alexandra Hospital, Sunshine Coast University Hospital, Townsville Hospital
- o SA – Royal Adelaide Hospital, Queen Elizabeth Hospital
- o TAS – Royal Hobart Hospital
- o NT – Royal Darwin Hospital

##### **New Zealand – Middlemore Hospital (new)**

2. **I-RIL study – Prof. Hang Quach – This study** explores the addition of isatuximab in specific cases to improve treatment for patients already receiving lenalidomide and dexamethasone to treat newly-diagnosed myeloma

#### **Recruiting hospital sites – 4 new sites**

- o VIC – Alfred Hospital, St Vincent's Hospital, Epworth Freemasons, **Goulburn Valley Hospital (new)**
- o NSW – Calvary Mater Newcastle, Border Cancer Hospital, Concord Hospital, Nepean Cancer Care Centre, **Lismore Base Hospital (new)**
- o SA – Flinders Medical Centre
- o TAS – Royal Hobart Hospital, **Launceston General Hospital (new)**
- o WA – Fiona Stanley Hospital
- o QLD – **Toowoomba Hospital (New)**

### 3. **BelaCarD study – Prof Hang Quach –**

The BelaCarD study explores a combination of belantamab, carfilzomib and dexamethasone to treat patients with relapsed/refractory myeloma.

#### **Recruiting hospital sites – 1 new site**

VIC – Alfred Hospital, St Vincent's Hospital, **Geelong Hospital (new)**



If you would like to know more about our trials or have an interest in working with AMaRC as an investigator or patient representative, please contact us at [amarc@alfred.org.au](mailto:amarc@alfred.org.au).

**AMaRC contact:** **Website:** [www.amarconline.org](http://www.amarconline.org) **Email:** [amarc@alfred.org.au](mailto:amarc@alfred.org.au) **Twitter:** [@amarconline](https://twitter.com/amarconline)

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)**

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

2021 has been a big year so far for the MRDR, with patient recruitment and expansion to new sites. The registry now has over 4700 patients registered – thanks to all patients and sites for your support and participation. Welcome to North Shore Hospital in New Zealand and Ballarat Health Service in Victoria, the latest sites to join the registry – great to see NZ expansion and another regional centre!

The Blood 2021 virtual conference is fast approaching and the MRDR has provided data for four presentations. Three poster presentations and one oral presentation by Professor Joy Ho are listed below. Presenters range from a student to a senior haematologist and professor, with a broad range of topics.

The MRDR data has certainly been put to work and in addition, we are pleased to report a number of publications this year:

*The Myeloma Landscape in Australia and New Zealand (ANZ): The First Eight Years of the Myeloma and Related Diseases Registry (MRDR).* Krystal Bergin et al. [link: doi: 10.1016/j.clml.2021.01.016 ]

*Receiving four or fewer cycles of therapy predicts poor survival in newly diagnosed transplant-ineligible patients with myeloma who are treated with bortezomib-based induction.* Stephen Boyle et al. [ insert link: doi: 10.1111/ejh.13677 ]

*Real-world utilisation of ASCT in multiple myeloma (MM): a report from the Australian and New Zealand myeloma and related diseases registry (MRDR).* Krystal Bergin et al. [Insert link: doi: 10.1038/s41409-021-01308-8 ]

Many thanks to participating patients and sites – without you all this valuable information would not be available.

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

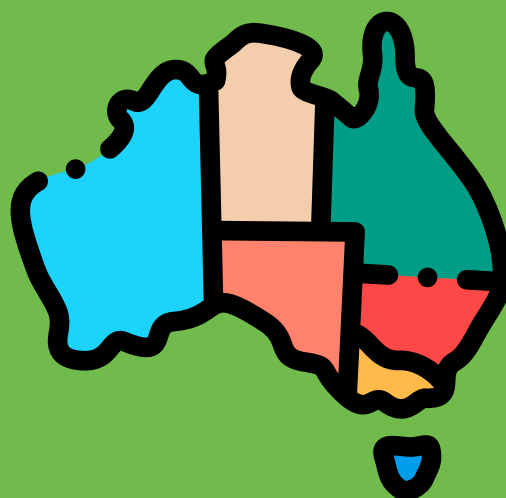
### To contact the MRDR:

E: [sphpm-myeloma@monash.edu](mailto:sphpm-myeloma@monash.edu) | P: 1800 811 326 | W: [mrdr.net.au](http://mrdr.net.au)



## People across Australia, we need you!

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



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



Please note the following information references some data, and medicines and/or the use of medicines that are not approved in Australia and/or New Zealand. For further information use the reference provided or ring our Myeloma Nurses on 1800 MYELOMA.

### Requirements for operational cure in multiple myeloma

**Mohamad Mohty, Hervé Avet-Loiseau, Jean-Luc Harousseau; DISCUSSION| JULY 29, 2021; blood.2021012854; <https://doi.org/10.1182/blood.2021012854>**

Multiple myeloma is usually considered as an incurable disease. However, with the therapeutic improvement observed in the last few years, achievement of an "operational" cure is increasingly becoming a realistic goal. The advent of novel agents, with or without high-dose chemotherapy and autologous transplantation, uncovered a correlation between the depth of response to treatment and the outcome. Of note, minimal residual disease (MRD) negativity is increasingly shown to be associated with improved progression-free survival (PFS), and MRD status is becoming a well-established and strong prognostic factor.

**Feasibility and benefits of a structured prehabilitation programme prior to Autologous Stem Cell Transplantation (ASCT) in patients with Myeloma; A prospective feasibility study Susan Mawson and Carol Keen et al; Physiotherapy Available online 5 August 2021; <https://doi.org/10.1016/j.physio.2021.08.001>**

Evidence supports the benefits of exercise-based rehabilitation in promoting recovery in myeloma patients following autologous stem-cell transplantation (ASCT). However, 'prehabilitation' has never been evaluated prior to ASCT, despite evidence of effectiveness in other cancers. The authors investigated the feasibility of a mixed strength and cardiovascular exercise intervention pre-ASCT. Quantitative data were collected to determine feasibility targets; rates of recruitment, adherence and adverse events, including 6 minute walking distance (6MWD) test and patient reported outcome measures (PROMs). 23 patients were recruited who attended a mean percentage of 75% scheduled exercise sessions. However, retention rates were limited, with only 14/23 (62%) completing the programme. In these patients, the 6MWD (distance) increased by a mean of 105 meters, with no serious adverse events. Whilst participants found the exercise programme acceptable and reported improvement in their physical fitness and overall mental health and wellbeing prior to ASCT, the study identified challenges in hospital attendance for the prehabilitation schedule whilst receiving induction or re-induction chemotherapy. Evaluation of digitally-enhanced directed but remote prehabilitation models for this patient group is warranted.

**International Myeloma Working Group risk stratification model for smouldering multiple myeloma (SMM) Mateos et al. Blood Cancer Journal (2020) 10:102**

Smouldering multiple myeloma (SMM) is an asymptomatic precursor state of multiple myeloma (MM). Recently, MM was redefined to include biomarkers predicting a high risk of

progression from SMM, thus necessitating a redefinition of SMM and its risk stratification. We analysed a large cohort of 1996 SMM patients, and identified three independent factors predicting progression risk at 2 years: serum M-protein >2g/dL (20 g/L), involved to uninvolved free light-chain ratio >20, and marrow plasma cell infiltration >20%. This translates into 3 categories with increasing 2-year progression risk: 6% for low risk (no risk factors); 18% for intermediate risk (1 factor), and 44% for high risk (2–3 factors). Addition of cytogenetic abnormalities (t(4;14), t(14;16), +1q, and/or del13q) allowed separation into 4 groups (low risk with 0 factors, low intermediate risk with 1, intermediate risk with 2, and high risk with ≥3 risk factors) with 6, 23, 46, and 63% risk of progression in 2 years, respectively. The 2/20/20 risk stratification model can be easily implemented to identify high-risk SMM for clinical research and routine practice and will be widely applicable.

### Smoldering multiple myeloma – Past, present, and future

**Hashim Mann; et al; Division of Hematology/Oncology, Tufts Medical Center, Boston, MA, USA; The John Conant Davis Myeloma and Amyloid Program, Tufts Medical Center, Boston, MA, USA; Blood Reviews; Available online 22 July 2021; <https://doi.org/10.1016/j.blre.2021.100869>**

Smoldering multiple myeloma (SMM) routinely precedes the development of multiple myeloma. While some patients experience aggressive disease, others have more indolent courses akin to those with monoclonal gammopathy of undetermined significance (MGUS). Much effort has been made to understand the pathobiological basis of this variability. Over time, the emergence of various clinical and genomic markers of relevance have led to development of disease definitions. More recently, research into manipulation of biological pathways has intensified in a bid to stall or halt disease progression. Studies with lenalidomide have highlighted the promise of early intervention and numerous therapeutic approaches remain the subject of ongoing clinical investigation. This review summarizes the historic progress made in defining SMM as a distinct disease entity and pathological process, it provides a critical appraisal of the evidence guiding risk assessment, and suggests a pragmatic approach to its modern-day management. Finally, an overview of developments on the horizon is also provided.

### Safety of outpatient stem cell mobilization with low- or intermediate-dose cyclophosphamide in newly diagnosed multiple myeloma patients

**Alessandra Pompa, Hematology Unit, Milan, Italy; European Journal of Haematology, First published: 23 July 2021 <https://doi.org/10.1111/ejh.13693>**

Autologous stem cell transplantation remains the gold standard for eligible newly diagnosed multiple myeloma patients. We aimed to assess safety and



efficacy of mobilisation therapy with low-dose (2 g/m<sup>2</sup>) and intermediate-dose (3-4 g/m<sup>2</sup>) cyclophosphamide administered as outpatient. A total of 176 consecutive newly diagnosed transplant-eligible myeloma patients receiving outpatient mobilisation were retrospectively evaluated. Chemotherapy was very well tolerated, Target for 2 autologous stem cell transplantation (at least 6 CD34+ × 10<sup>6</sup>/kg) was reached by 76.3% of patients. Administration of plerixafor (to enhance stem cell yield) on demand was necessary in 12.1% of patients.

### High prevalence of peripheral neuropathy in multiple myeloma patients and the impact of vitamin D levels, a cross-sectional study

**B. E. Oortgiesen et al, Department of Clinical Pharmacy and Pharmacology, Medical Centre Leeuwarden, Leeuwarden, The Netherlands; Supportive Care in Cancer (2021); Open Access Published: 17 July 2021**

Peripheral neuropathy (PN) is common in patients with multiple myeloma (MM). We hypothesised that the relationship between hypovitaminosis D (low blood vitamin D levels) and PN described in diabetes mellitus patients may also be present in MM patients.

This multi-centre cohort study showed that PN and hypovitaminosis D are common in MM patients, and addressing low vitamin D levels in the treatment of MM patients might be beneficial in reducing the risk of PN. More attention for PN is warranted, as PN is underreported by clinicians. Further research is needed to fully understand the implications of vitamin D in the development of PN in patients with MM.

### Optimal Supportive Care with Selinexor Improves Outcomes in Patients with Relapsed/Refractory Multiple Myeloma

**AjaiChari, Icahn School of Medicine at Mount Sinai, New York; Clinical Lymphoma Myeloma and Leukemia; Available online 18 July 2021; <https://doi.org/10.1016/j.clml.2021.07.014>**

Supportive care improves outcomes in many cancers. In the pivotal STORM study selinexor, and low-dose dexamethasone proved to be an effective treatment for patients with triple-class refractory myeloma. We looked at a sub-cohort of the STORM study, to test the hypothesis, that increased use of supportive care measures prolonged treatment duration with, and improved efficacy of, selinexor. The STORM protocol included specific recommendations for dose modifications and supportive care to mitigate selinexor's most common adverse events (AEs) including nausea, fatigue, and thrombocytopenia. The sub cohort receiving prompt and more aggressive supportive care for nausea and platelet support, including more frequent dose reductions, may have contributed to the low discontinuation rate, longer duration therapy, and greater efficacy rates observed in this cohort.

## 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

**R-ISS stage:** Revised International Staging System to stage myeloma at diagnosis (Stage 1, 2, or 3)

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

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

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

**PI:** proteasome inhibitor (ie Bortezomib, Carfilzomib)

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

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

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

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

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

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

**Randomised study:** Grouping patients at random to compare two or more different interventions

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

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

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

**Tandem transplant:** 2 ASCT performed one after the other to intensify treatment

**Triplet:** 3 drugs used in combination

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



# Calendar of Events 2021

Groups / events are subject to change at short notice.

Please check the website for a more up to date schedule. <https://myeloma.org.au/event-calendar/>

Where possible, our Myeloma Support Nurses are working hard to put COVID-safe plans in place to allow face-to-face get-togethers with our Information and Support Groups. We thank everyone for their patience and for embracing the online groups via Zoom. We plan to move forward making the most of both face-to-face and online gatherings to allow as many people as possible to connect with each other and our team. Listed below are the current locations of our Information and Support Groups being held across the country. To find out specific Zoom login details for each group or if they are being held face-to-face, please go to our website.

<https://myeloma.org.au/events>

For further information or help joining a group via Zoom, please contact your state's Myeloma Support Nurses

## Information and Support Groups ACT

- Canberra

For enquiries please contact

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## Information and Support Groups National

- Younger Persons' Information and Support Group

For enquiries, please contact:

**Myeloma Support Nurses**

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M: 1800 693 566

## Information and Support Groups NSW

- Central Coast
- Forster / Taree
- Liverpool
- Lismore
- Mid North Coast Cuppa & Chat
- Newcastle
- Port Macquarie
- Orange / Mudgee / Dubbo
- Regional NSW Cuppa & Chat
- RPAH
- Tamworth
- Westmead
- Younger Persons'

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## Information and Support Groups QLD

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

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## NATIONAL TELEPHONE SUPPORT GROUP (CANCER COUNCIL NSW)



**Telephone Support**

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

**Cancer Council NSW with MA NSW**  
**Cancer Council NSW**  
**1300 755 632**

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

## Information and Support Groups SA

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

**For enquiries, please contact**

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**Alicia Hopper**

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## Information and Support Groups TAS

- Burnie
- Devonport
- Launceston
- Southern TAS

**For enquiries, please contact**

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## Information and Support Groups VIC

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

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[Myeloma Australia](https://www.linkedin.com/company/myeloma-australia)

- Sunshine
- Traralgon
- VIC State Cuppa & Chat
- Wangaratta
- Warragul
- Warrnambool

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## Information and Support Groups WA

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

**For enquiries, please contact**

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**Answers to the crossword on page 12**

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



# 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)**