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From the President

These are strange times we are living through. It is now 12 months since the COVID-19 pandemic arrived in Australia and a country we all considered as one suddenly had closed its state borders. Across Australia there have been sudden lockdowns in the attempt to limit the spread of the virus.

The situation changes so very quickly with long periods of no cases in the community to suddenly a case is found. Many of us have become very wary of crowds and do our best to avoid them. We are finding that many of our friends do not understand our not wanting to go to the movies or go inside a restaurant for a meal. We are anxiously waiting for the vaccine that will help us to return to a new “normal”.

Our Medical and Scientific Advisory Group have endorsed an Australian Consensus Statement on the COVID-19 vaccine recommending it to myeloma patients. You will find a summary of this document in this edition of MyeNews. Please discuss this important topic with your doctor.

The great news, just after Christmas, was that daratumumab was placed on the PBS as a subsidised medicine for myeloma. This is the first of a new group of drugs being developed. If you are starting treatment with daratumumab, please speak with our Myeloma Support Nurses. They are there to answer all your questions.

There are another two or three new drugs being presented to the Pharmaceutical Benefits Advisory Committee over the next year for review with the hope that they will become subsidised for the treatment of myeloma. There is still a lot of research being done looking for better and new treatment options.

We were planning to return some of our support groups to face-to-face meetings although we will be continuing the Zoom video conferencing meetings for those unable to attend a group for any reason. This is now being reviewed again due to the new cases of Covid19 in the community. Please check our website for further information. The Myeloma Support Nurses will also notify group members of any changes. For many of us these groups are very important as we can mix with others who understand what we are going through.

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.
COVID-19 Vaccine and Myeloma

With the news that Australia is soon to have access to COVID-19 vaccinations, experts from the Haematology Society of Australia and New Zealand have collaborated with infectious disease specialists to write a document titled: COVID-19 Vaccination in Haematology Patients: An Australian and New Zealand Consensus Position Statement.

Here we have summarised the information relating to those with myeloma. The full document is available to view on our website in the Health Professionals section under the Position Statements tab. We stress that this document is written for health professionals, includes all blood disorders and is very technical. If you have any questions about the paper or the COVID-19 vaccine in general, please contact our experienced Myeloma Support Nurses via the contact details below.

Myeloma is a blood cancer of the plasma cells meaning part of the immune system in those with myeloma is not functioning properly. When the immune system is not as strong, there is a higher risk for COVID-19 infection but also for a more serious outcome from the infection such as needing to be admitted to hospital or the intensive care unit.

Studies have suggested that treatment for myeloma may increase the risk for contracting COVID-19. However, other factors are also important risks such as being older (over 60 years old), having active or progressive myeloma and being less able to perform daily activities. It has also been found that those with blood disorders such as myeloma can experience long-standing immune system problems after a COVID-19 infection.

Vaccination against COVID-19 is an important tool to help protect people with myeloma. In general, vaccination against COVID-19 has been shown to reduce the risk of developing symptomatic infection and severe disease. It is not a live vaccine so it is safe for people with myeloma. However, specific information about COVID-19 vaccination in patients with myeloma is limited as the large clinical trials so far have not included people with myeloma.

Therefore, this group of specialists have put together some recommendations for the care of people with blood cancers to provide some guidance.

These include:

- Prioritising vaccination of people with blood disorders and their health care workers.
- Where possible the vaccine should be given at least two weeks before treatment starts.
- For those currently on treatment, it is not always recommended to interrupt treatment to have the vaccine. Your doctor will advise what is best for you.
- In some circumstances it may be necessary to wait three months after treatment to have the vaccine. Your doctor will be able to explain if this is the case for you.
- Vaccination of family members and close contacts is important to form a protective circle around the person living with myeloma.
- It is unknown how well the COVID-19 vaccine will provide protection in those with myeloma. Therefore, it is still extremely important to continue to adhere to infection prevention strategies such as regular handwashing, social distancing and mask wearing where necessary.
- It remains important to keep up with other regular vaccines such as influenza and pneumococcus.
- It is important to have the COVID-19 vaccine even if you have already been exposed to the virus.

For any other questions, feel free to contact our Myeloma Support Nurses through our Telephone Support Line – 1800 693 566 Monday – Friday, 9am – 5pm (AEDT) or email: nurses@myeloma.org.au
April 29, 2004 was a typical workday for me. I arrived via train at Flinders St (Melbourne) and began crossing the large Elizabeth St intersection with a horde of other commuters. I had taken about twenty steps when I was hit but an explosive pain in the middle of my back. It literally knocked me to my knees. I stayed there for a few seconds trying to move without triggering further pain as people just walked around me. Eventually I found a way to get up and stagger across the remainder of the intersection.

Despite the intense pain spot in my back, I went to work somehow figuring that I could manage the pain and that a few anti inflammatories would get me by. An hour later I was at Epworth casualty being gingerly assisted (after fainting with the pain at one point) and x-rayed. Another hour later I was advised that T11 had a tumour and was considerably damaged.

Next up was the need for a spinal fusion to replace T11 so that I could continue to function. After the operation I was told the good news that it had gone well and the bad news that something called multiple myeloma was detected in my body. A quick Google search revealed that the average survival time was five years. Yikes.

It was a nasty introduction to a disease I had never heard of. I had had back pain for the previous two years, but various experts had confidently told me it was a haemangioma. It clearly was not.

Now here’s the thing with multiple myeloma, it affects everyone differently. It hits some people aggressively, some people have it smoulder for years, some people stagger from one crisis to another. In my case the disease just periodically attacks me. I initially had four years of no activity (paraprotein stable) but then in 2009 an escalation occurred requiring 10 months of thalidomide (which arrested the disease’s progress but at the cost of giving me quite severe peripheral neuropathy). That bought me another three years without any treatment before it took off again and I ended up in ICU requiring a stem cell transplant after stabilisation. That kept the disease at bay (again with no treatment) for another three years at which point in late 2016 I was forced to start using Revlimid and then Pomalyst. And that’s where I am today. Sixteen years after diagnosis my paraprotein level is stable, I can cope with the drug and life goes on, more or less. Am I lucky? You bet.

Some credit for my longevity must go to my wife Linda who took it upon herself to learn about the disease when I was too fearful. She has guided, cajoled, directed and reprimanded me (in a most loving manner of course) to stay focussed and healthy. Myeloma Australia does a marvellous job in running seminars and talks about the disease and my knowledge has increased significantly. It definitely helps to understand what is going on. Likewise, the support groups that they run are excellent because other people’s experiences often shed light on your own.

Coincidently with the onset of the disease in 2004 I began playing in a professional rock band and have somehow kept playing (except when hospitalised) more or less ever since. Admittedly there have been times when I was having trouble standing up, but as they say the show must go on. And dexamethasone introduces some strange musical side effects, notably playing music at punk speed and with shaking hands. Through all the above I also managed to continue my IT career until I retired in 2016.

My relationship with Max Wolf, my haematologist, has been excellent, and I’m gratified that he sometimes errs on the side of ‘quality of life’ rather than reflexively adding treatment that may impair that ‘quality of life’. Early on in our relationship I asked him what the best prognosis was I might expect and I clearly remember his response “That you’ll die of something other than multiple myeloma”. That’s my goal.

Linda’s comments: As you can appreciate from reading Peter’s story it’s been something of a roller coaster ride and been quite intense at times because I worked until he had his stem cell transplant. We’ve enjoyed a number of extended overseas trips and had quality time with family, punctuated by intermittent hospital stays and drug induced tiredness. Most importantly, life must be lived with optimism and determination during both the good times and the health crises. Continuing advances in treatment also provide a positive outlook.

Peter Summers
Advocacy News

PBS reimbursement of new myeloma treatment combination

We welcomed the announcement from the Federal Government that from the 1st of January 2021, the combination of daratumumab/Velcade/dexamethasone is available on the Pharmaceutical Benefits Scheme (PBS) for those at the stage when myeloma has returned after treatment for the first time (first relapse).

Together with the myeloma community we have been advocating for access to this treatment for over three years and we are delighted to see it eventuate. Daratumumab is a monoclonal antibody (MoAb) that targets the CD38 receptor on myeloma cells. This is the first PBS listing of a treatment in the MoAb drug class which allows us to target and treat the myeloma in a new way when compared to the other treatments currently on the PBS.

November PBAC Meeting Outcomes

We were recently advised of the outcomes of the Pharmaceutical Benefits Advisory Committee (PBAC) meeting in November 2020 where there were two myeloma related submissions; ixazomib, lenalidomide and dexamethasone for relapsed myeloma and elotuzumab, lenalidomide and dexamethasone also for relapsed myeloma. Unfortunately, both submissions were not recommended by the PBAC. This is disappointing, particularly after the successful result of daratumumab from the previous meeting, but not unexpected. It often takes multiple submissions to get a drug approved.

We know there is a need for access to new and effective myeloma treatments, so there is always something more to do on an advocacy front. We will continue to work with our community, the PBAC and Department of Health to have wider access to daratumumab based combinations and access to treatments such as elotuzumab and ixazomib.

Thank you to everyone who gave feedback and comments to the PBAC. We will be sending out information on how to submit feedback and comments for upcoming PBAC meetings via our e-newsletter ‘The Muster’ so please make sure you subscribe to keep up to date with any opportunities and announcements.

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 to learn more.
Associated Factors and Exercise Program Preferences

People with multiple myeloma often experience symptoms of their disease and side effects of treatment that reduce their independence and enjoyment of life. Research in other cancers suggests that these may be alleviated through physical activity[1]. However, the majority of people with multiple myeloma do not achieve 150 minutes of physical activity per week which is recommended for maintenance of good health[2].

We explored the physical activity preferences and behaviours of people with multiple myeloma. We investigated whether their physical activity was influenced by their disease stage, myeloma symptoms, age, gender or advice from healthcare professionals[3]. Interest in, and preferences for exercise programs were also determined.

In total, 126 people with multiple myeloma from clinics across Southeast Queensland (77% response rate) responded to the survey. Over 85% of respondents experienced at least one myeloma-related symptom to a moderate intensity in the past month. The most commonly reported symptom was fatigue (56%), followed by back pain and other bone pain, tiredness due to lack of sleep and muscle weakness reported by almost half of the respondents.

Before they were diagnosed, one quarter reported that they were sufficiently active for health. After they were diagnosed and began treatment for multiple myeloma, this reduced to only 12% remaining active. This is much lower than the 45% of the general Australian population who report being active. Being physically active before diagnosis was the best indicator for remaining active after diagnosis. In our cohort, experiencing myeloma symptoms and receiving physical activity advice from healthcare professionals did not influence people remaining active.

Despite the low levels of physical activity and high frequency of myeloma symptoms, 55% of people with multiple myeloma were interested in participating in an exercise program. Respondents would like programs to be offered during both active treatment and remission (57%), and supervised by an exercise oncology specialist (48%). There was a strong preference for programs to be low-cost (77%), offered at flexible times (74%) and at locations close to home (69%).

We concluded that people with multiple myeloma, particularly those insufficiently active prior to diagnosis, should be offered convenient, low-cost exercise programs supervised by an exercise oncology specialist to increase physical activity participation.

We addressed this by creating a randomised controlled trial to investigate the impact of an individualised exercise intervention on the quality of life in people with multiple myeloma. This trial is supported by Brisbane Diamantina Health Partners, The University of Queensland and the Medical Research Future Fund.
Following the initial 12 weeks of individual exercise training sessions, participants are offered an additional 12 weeks of small group exercise sessions. Cardiorespiratory fitness, bone and muscle health, markers of inflammation and other measures of health and wellbeing are measured during and following the study.

Preliminary results have shown that participants find the exercise program very enjoyable with overwhelmingly positive responses and high adherence rates. The program has also been found to be safe.

Whilst we are still recruiting for the study so final results are yet to be determined, we recommend that people with multiple myeloma talk to their health professional about engaging in exercise that is safe and will provide the most benefit to the individual.

To ensure prolonged participation in physical activity for all people with multiple myeloma, we recommend:

• Consulting an accredited exercise physiologist or physiotherapist to ensure your exercise plan is tailored to your abilities, disease- and treatment-related adverse effects, anticipated disease trajectory and health status. Medicare (via a chronic disease management plan with your GP) and private health rebates are available to visit these exercise professionals.

• Choose activities you enjoy – this will help you stick with your exercise plan.

• Something is better than nothing so start low, even just a few minutes a day, and progress slowly.

• Even simple activities, such as taking the stairs or walking even a little further than usual, can help improve your overall health.

Mrs Jennifer Nicol, A/Prof Tina Skinner
School of Human Movement and Nutrition Sciences,
The University of Queensland

References

If you are interested in participating in the current exercise study for people with multiple myeloma, please contact by email: MyeEx@uq.edu.au.

Online Seminars 2021

Due to the success of our online seminar program in 2020 we have decided to continue to run some of our education events online this year too. We also plan to host face to face seminars where possible.

Our first online seminar was held on Saturday 13 March, it was a National Myeloma Update which included highlights from the American Society of Haematology (ASH) Conference. Our speakers were two expert haematologists from the Monash Medical Centre in Melbourne, Dr Michael Low and Dr George Grigoriadis. A recording of the seminar will be available for viewing on our website at www.myeloma.org.au/what-is-myeloma/workshops-seminars/

In May, during National Myeloma Month, we will again host a series of online education events. Stay tuned for details of the program.

For more information and to view any of our online seminars, including recordings of previous events, please go to www.myeloma.org.au/events
As a not-for-profit organisation that does not receive government funding, we rely on the generosity of our donors. In this new segment, we put the spotlight on our incredible supporters. Myeloma is a cause that's very close to our donors' hearts. Many of our donors are living with myeloma, caring for someone with myeloma, or have lost a loved one to myeloma.

Natalie and Glen are two of our regular donors. They are both living with myeloma. We spoke to them to find out why they give, what keeps them busy, and what message they would like to send to others who are also living with myeloma.

Natalie Caldwell, aged 38, living with myeloma since 2016.

Q: When and how did you first hear about Myeloma Australia?
A: I heard about Myeloma Australia shortly after my diagnosis of smouldering multiple myeloma at 38 years of age in 2016. I had never heard of myeloma beforehand.

Q: As a regular donor of Myeloma Australia, what keeps you passionate about the cause?
A: I am passionate about paying it forward. I love reading the great work of Myeloma Australia in the MyeNews magazine, and all the wonderful advancements in medications. I have always donated to charities and it feels good to contribute for the now and the future.

Q: What message would you send to people who are living with myeloma?
A: Whilst I myself have not required any medication or treatment at this stage, as I have smouldering multiple myeloma, it is hard to know what it feels like when you're going through that. What I do know is that there are still dark days when I feel overwhelmed by my diagnosis and worried that my situation may change. I try my best to live my life in moderation and always enjoy the moment and all the things that make it great.

Q: What message would you send to other people who are considering becoming regular donors of Myeloma Australia?
A: Myeloma is not a curable cancer but with donations there can be even more advances in medications, more support nurses and financial help for all the behind the scenes, working towards helping people navigate their illness in a supported community.

Glen Shepherd, aged 70, living with myeloma since 2014.

Q: When and how did you first hear about Myeloma Australia?
A: I gained information about Myeloma Australia from the internet, after I was diagnosed with smouldering multiple myeloma in 2014. I’d never heard of myeloma before then. I progressed to multiple myeloma in September 2015 and started chemo shortly afterwards.

Q: As a regular donor of Myeloma Australia, what makes you passionate about the cause?
A: I'm currently in remission, but I still appreciate the ability to read others’ stories in the MyeNews magazine, or speak to a myeloma nurse if needed. Funding makes all these wonderful services possible.

Q: What keeps you busy?
A: I am a retired science teacher. I've been married for 47 years to a very supportive spouse. We have travelled extensively, completing five bicycling and tenting trips over much of Europe. We both enjoy community volunteering, especially with the Ukulele Club - both playing and organising. I am fit and enjoy walking, swimming, cycling and playing jazz piano.

Q: What message would you send to people who are living with myeloma?
A: Support is available for all issues that you will encounter, especially problems that you may not broach with your oncologist because you may think them trivial.

Q: What message would you send to other people who are considering becoming regular donors of Myeloma Australia?
A: You can take comfort in the fact that the money is being used to help others – both patients and their family members.

Interested in becoming a regular donor?

Regular giving is just as it sounds – making small donations regularly (usually monthly or fortnightly). Regular donations enable us to plan ahead as an organisation, without the uncertainty of relying on ad-hoc gifts.

If you are interested in becoming a regular donor, you can do so via our website: https://myeloma.org.au/donate-2/.

To set up a regular donation over the phone using your credit or debit card, or to donate via cheque or bank transfer, please contact us on 03 9428 7444 or donations@myeloma.org.au.

Olivia Myeza
Manager Philanthropy, Major Gifts & Corporate Giving

To speak to Olivia regarding your giving options or potential partnerships, please reach out to her at E: olivia.myeza@myeloma.org.au or M: 0401 429 970
Hi everyone, my name is Daniel Berk, thank you for welcoming me to the Myeloma Australia team. I am really pleased to be joining Narelle Smith in providing support for people with myeloma in Western Australia.

Before switching to nursing, I studied film and television for a year and a half. That was some time ago. I have been a nurse for 19 years now, most of that time has been working within haematology and oncology at Sir Charles Gairdner and Royal Perth Hospitals in Perth. Moving between inpatient and outpatient care as well as domiciliary chemotherapy and staff development. More recently I worked as a clinical nurse specialist with the WA Youth Cancer Service, a role that I found equally challenging and rewarding. Then the opportunity arose for me to take some time to be more of a stay-at-home dad with our just over two-year-old son, a role that I relished and thoroughly enjoyed. During that time a colleague of mine let me know that Myeloma Australia were looking for a support nurse in WA and I was lucky enough and very grateful to be offered the role. It’s been amazing meeting everyone within the Myeloma Australia team, such a diverse, professional and cohesive group of amazing people.

Outside of work, my wife and I are really enjoying being first-time parents to our son and our first “baby”, Jensen, a fun-loving Beagle. We enjoy getting to one of Perth’s fabulous beaches or parks whenever possible, spending time with our families and friends, as well as being regulars at our local café/bakery, with the aim of keeping life simple in our spare time. Outside of nursing, one of my major passions is photography, particularly street and music photography. One of my all-time favourite jobs was working as a concert photographer for an online music review site, despite the high pressure and late nights, being up close and having unique access to some of my favourite artists was amazing and scary and a lot of fun. Music is a big part of my life every day. I still pick up the guitar as often as I can, however my son doesn’t seem to be all that fond of my playing nor my voice!

I’m very excited to have joined the Myeloma Australia team, and I’m very eager to contribute to and learn from this very supportive community.

Rita has recently joined Myeloma Australia, in the newly formed role of Marketing & Fundraising Co-ordinator. She will support the Community Engagement, Fundraising and Major Gifts team as well as focusing on raising the profile of Myeloma Australia in the community.

Rita is a marketing all-rounder with over 15 years’ experience across multiple industries, including community radio, manufacturing, IT and software services. Initially starting her career in sales and customer relationship management, she saw the need to tailor communications and services for the individual and took the opportunity to develop programmes and services that focussed on communications and local brand development. Rita found her passion working for boutique, independent organisations that needed support developing their voice, their brand and presence. During this time, she has worked closely with community groups, local councils and service providers to build community engagement and long-term relationships.

Originally an art and design student, Rita loves that she gets to combine her need to plan and organise with a bit of creative flare. She is looking forward to working with the team at Myeloma Australia, raising awareness in the community and supporting fundraising efforts that will contribute to much needed care and assistance in the Myeloma community.

On a personal note, Rita is blessed to live on three acres in the Dandenong Ranges. She loves roaming the hills, talking to all of the native animals that visit her property, from the local echidna to the beautiful bright birds that wait by her window to be fed. When she’s not talking to the animals, she is supporting the local BMX club. While her daughter rides you will often see her volunteering at events, writing grant applications or cooking in the canteen.
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. Snoozes
5. Extinct birds
10. Companions
14. Loads (2 wds.)
15. ___ & Roeper
16. Prayer ending
17. Acapulco coin
18. Owned apartment
19. Flaring star
20. Role player
22. Startling revelation (2 wds.)
24. Begged
26. Birthday count
27. Hair goo
28. Paid athlete
30. Unnecessary
34. Native of England’s capital
36. Trials
40. Done
41. Breaks suddenly
44. Gent
45. Piano part
47. Winnipeg’s province
49. Uncivilized
52. CT time zone
53. Compass reading (abbr.)
56. Golf gadget
57. Pod dwellers
59. Bland
63. Tailor again
66. Different
67. Aquatic animal
69. Aspect
70. Cruising
71. Texas landmark
72. Wallet stuffers
73. Sunday service
74. Ledger entry
75. Animal enclosures

DOWN
1. ___ Valley (vineyard site)
2. Guinness of “Star Wars”
3. Put off
4. Counter seat
5. Winter mo.
6. Bassoon’s relative
7. Refute
8. Trial
9. Curly or Moe
10. Window glass
11. Amid
12. River embankment
13. Growl
21. Casino city
23. Annoying person
25. Family rooms
28. Falling sound
29. Ramble
30. Poet’s “still”
32. Stage offering
31. Religious subgroup
33. Unexciting
37. Loafer polish
38. Bar bills
39. Argument
42. Golf norm
43. Barbershop sound
46. Behind schedule
48. Cake decorator
50. Fill again
51. Ladybug, e.g.
53. Iron setting
54. Hot sauce
55. Some curves
58. Fable author
60. Afternoon affairs
61. Pierce
62. 18-wheeler
64. Paradise
65. Military cafeteria
68. Deteriorate

answers on page 23
Community Engagement & Fundraising

I am pleased to report that our fundraising team continues to grow. Alongside Olivia joining us last September as our Manager of Philanthropy, Major Gifts & Corporate Giving we have been joined this month by Rita Hughes as our Marketing & Fundraising Co-ordinator.

The first signs of fundraising recovery after the difficult year we all endured in 2020, were evident as last year drew to a close; I am thrilled to report that this recovery has continued into the early stages of 2021. There are currently several community fundraising events that are being held – from a ‘no junk January’ campaign, to a lawn bowls fundraiser to head-shaves and marathons. In addition to these our People’s Choice Lottery campaign has been an overwhelming success with us, at time of writing, closing in on our goal of $10,000.

We are hopeful that this year we will be able to bring Team Myeloma to the streets of our major cities once again for fun-run events. Sadly, the first victim of 2021 has already occurred with Perth’s ‘HBF Run For a Reason’ event, planned for May, already cancelled. If there are any folks in Perth who would still like to get together for a fundraising event of some description in May do please let me know.

Our second Charity TV Global/Myeloma Australia ‘Adventure All-Stars’ TV Adventure will be held and filmed in late July. Our Ambassadors are currently doing a great job raising funds for Myeloma Australia ahead of the Adventure. If you are keen to explore possibilities of becoming involved in future Adventures, it is never too early to give me a call to discuss possibilities.

In May, as a part of National Myeloma Month we will be launching our bespoke awareness-raising campaign entitled ‘38, mate.’ As it’s never too early to promote a fundraising event (!!) we will also be hosting our very own ‘38, mate’ fundraising event for Myeloma Australia in early September. As excited as we are about both the awareness-raising and fundraising components of ‘38, mate’ we will not be releasing tooooo many details just yet …. but do stay tuned, details WILL be forthcoming!

It has been exciting over the last few weeks to watch fundraising dollars appear as a result of the ‘Containers for Change’ recycling/fundraising scheme that we have signed up for in Western Australia and Queensland (see below for further details) This is the ultimate win/win scenario – doing good for the planet whilst raising important funds for Myeloma Australia; there is nothing to not like about this!

I encourage our Western Australian and Queensland based MyeNews readers to support us through this scheme.

I mentioned in the last MyeNews that our long-standing relationship with the online donations platform Everyday Hero has now come to an end and that we have moved across to the donations platform Just Giving. To create a fundraising page for Myeloma Australia please now visit: www.justgiving.com/myelomaaustralia Thank you to all of those who have already registered fundraising events on the Just Giving page.

We are slowly adding new items to our web-shop all the time and I would particularly encourage you to look at the furry-glasses cases, as made by our very own nurse Deborah in Tasmania and the beautiful, limited edition photography prints from Julia Belova.

I appreciate that I say the following words in every edition of MyeNews, but these words remain absolutely, categorically, 100% accurate… do please remember that I am here to help and that I love hearing about your community engagement & fundraising ideas and seeing where I just might be able to add extra value to your concepts. Big or small, simple or complex, reasonable or completely insane, please bring your ideas to me and let’s work on them together to see what we might be able to create!

Matt Maudlin
Community Engagement & Fundraising Manager
M: 0407 891 052
E: matt.maudlin@myeloma.org.au

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
Happy New Year from the NSW team. The start of 2021 is still proving to be challenging as we all navigate our way through this new COVID way of living. However, it’s an exciting time for NSW with our team expanding! We will have another myeloma support nurse starting soon.

We are so pleased to have been able to resume some face-to-face support groups this month and we are working hard on plans to reach some of our regional areas with face-to-face groups in April but hope to have most groups meeting in person by then.

Friday the 5th of February saw the return of our first face-to-face support group for almost 12 months in Newcastle. This was also our first support group where both face-to-face and Zoom worked cohesively. It was a wonderful feeling to be sharing the same room with our fellow myeloma community once again. We welcomed new and returning members to the group catching up on their myeloma diagnoses, treatment as well as their lives outside of myeloma. There was a buzz in the air at being reunited whether it be at Club Charlestown or virtually via the Zoom link. While we are still taking each day as it comes with the ever-changing COVID-19 situation, we are cautiously looking forward to more face-to-face groups with the option to link in via Zoom.

Tamworth kicked off their first meeting for 2021 on Zoom with Cathie Milton from the Calvary Mater as a guest speaker discussing all things stem cell transplants in myeloma. Cathie was a wealth of information making this an enlightening session as well as a nice social catch up. Molly Hirst, a physiotherapist at the Orange Health Service spoke at our first Orange support group for the year. Molly’s practical tips and enthusiasm has started the year off on the right foot for the Orange group. It was great to see members of these groups connect and support each other.

Jacqui co-facilitated our first national younger person’s group via Zoom with the team from Victoria. It was great to have so many people from around the country connecting with representation from NZ, QLD, and NSW. This group is aimed more specifically to those individuals who are still working, possibly have younger children and are grappling with balancing this with treatment/living with myeloma. If you would like to find out about this group, please contact anyone of the Myeloma Support Nurses.

We are currently working on our myeloma seminar and events program for this year and as soon as we have dates and details, we will let you know. In the meantime, if you have any suggestions or ideas please get in touch.

– Jacqui Keogh, Cath Bowley & Juliet Hill

Queensland

Tash and I are so grateful to be seeing many of our new and regular members in person with our Information and Support Groups back in place for 2021. Like previous years, we will have regular groups running in the Sunshine Coast, North Lakes, Inner North and South Brisbane and the Gold Coast. NSW and QLD are working together to support our northern NSW population with online Zoom video conferencing groups as well as a meet and greet later in the year.

Tash and I will also continue our regular online Zoom meetings every other month on Tuesdays or Fridays. For more information on dates and times you can check out the events calendar on the Myeloma Australia website or email us directly. Please keep an eye on your email or Facebook for unexpected changes due to this pesky pandemic.

If you live outside of these areas and would like to meet in person with other myeloma members, please get in touch, as we are happy to facilitate more groups where there is enough interest.

Tash and I would also like to take the opportunity to thank those members who share their experiences and stories with us. We learn so much from you, which allows us to better support other myeloma members in the clinics and on the support line. We hope you gain as much knowledge and empowerment from our meetings as we do as specialist nurses. Whether you have smouldering myeloma, have just been diagnosed with active myeloma or are many years down the myeloma journey, you have experience and what you have learnt or wish you knew, may just be the thing another person needed to hear. So, once again we thank you and if you have never attended a group before then this may be something worth giving a go in 2021. We would love to meet you and learn from you too!

– Megan McDowell & Tash Clarke
South Australia

In South Australia, we are excited to have restarted our face-to-face group activities afresh for 2021. Our support groups are now planned to be a combination of face-to-face and Zoom throughout the year. This will mean that those unable to join us at our venues can still dial in and engage with the groups. We trialed this combination with positive feedback, at our Flinders and Fullarton meetings in January – one participant was even able to join the support group while sitting in the chemotherapy unit receiving treatment!

We are pleased to announce that the Mid-North support group is now based in Kapunda, as suggested by the group. At the first meeting of the year, it was encouraging to see a mix of new and old faces joining Jo and myself to plan the future of the group discussing venues, casual catchups and topics of interest. As always, we are grateful to Bronwyn Gerschwitz for her enthusiasm and passion in coordinating this group.

Our other regional group in the South-East, coordinated by the wonderful Carol Koch, held their annual seminar on Friday 26th February. Our speakers were Dr Ben Teh, Infectious Diseases Consultant at Peter Mac, and an advisor to Myeloma Australia’s Medical & Scientific Advisory Group, with a Q&A about COVID vaccines and Alicia discussing daratumumab, the drug recently listed by the PBS for treatment of myeloma.

In other news, Ian Driver has stepped down as volunteer coordinator of the Fullarton group. Ian was the driving force behind the establishment of a myeloma support network in South Australia and continues to sit on the Myeloma Australia board. Jo and I would like to acknowledge and thank Ian for his many years of hard work and enthusiasm for Myeloma Australia in SA. Myeloma Australia South Australia would not be the same without him and we hope he enjoys being able to relax at future meetings!

If anyone is keen to take over from Ian as Fullarton Coordinator, please reach out to Jo or Alicia to discuss.

– Alicia Hopper & Jo Gardiner

Tasmania

In the first week of February we held our first face-to-face support groups for the year. The first was in Sandy Bay, Hobart and it was lovely to welcome new members to the group. We also celebrated Jim’s birthday with a yummy cake Linda brought in to share.

Later that week I travelled north to hold groups in Burnie, Devonport & Launceston. It was great to see familiar faces and catch up with everyone’s news. The Burnie support group was held at a new venue – the Burnie Community Health Centre, which worked out very well.

The attached photo was taken in 1934 and is of Alan’s family home. Alan, who has myeloma, lived there for a time as a child and the photo was taken by his father when he was about two years old.

The house is no longer there, but on that site is the Sandy Bay Cancer Council building where we hold our support groups. Alan kindly gave the staff a copy of the photo who were thrilled to receive such a piece of history, and it is now displayed in the Centre. Cheers Alan!

– Deborah Thompson
I hope that you all had a wonderful summer and were able to enjoy all the activities you had been dreaming about during lock down. I made the most of the ocean and did lots of ocean water swimming. But again, we are here in a state of the unknown, but we will push on and come out the other end at some point. Thank you for your understanding in this ever-changing environment and being so malleable and continuing to support one another in our support groups.

Despite Victoria having so many restrictions, Myeloma Australia in Victoria is reaching more and more people and we have already started our new groups in Ringwood, Mornington Peninsula, Warrnambool, Mildura and Bairnsdale. Through collaborating with Rotary, the Rotarians at Alfreton, Horsham, Nhull and Eaglehawk have been working hard with us to promote the groups and spread the “M” word! Thank you for all your hard work and collaborating with your communities to raise awareness to support our patients, their carers and families.

In March we will be running our first National Myeloma Update with highlights from ASH via our online platform. We invite people living with myeloma, their family, friends and care givers to learn more about myeloma, common treatments and new treatments in development. We have two experienced consultant haematologists from Monash Medical Centre in Melbourne providing an overview of myeloma and an update from the American Society of Hematology conference. This is the largest and most prestigious haematology conference in the world and was held virtually last December. Formal invitations will be sent closer to the time but keep Saturday 13th of March free.

Sadly, I say “Happy Maternity Leave” to Laura and send her our best wishes for bub number 2. Despite only working one year together (and probably only five times in the office together face to face due to lock down!), we became a cohesive and close team. We wish you all the best for the next chapter Laura, Sam and Manny. We cannot wait to hear the news of the new baby.

In other news we were so thrilled to hear that Rachel McCann was moving back to Victoria from Newcastle. I am sure many of you will have seen Rachel at our online seminars and will get to meet her in the not-so-distant future in our support groups. Rachel comes to us with a wealth of myeloma experience and deep knowledge of our organisation.

– Emma-Jane Furphy, Laura Jones & Rachel McCann

The biggest news for Team Western Australia is that we have welcomed Daniel Berk as our new Myeloma Support Nurse. Daniel has a wealth of experience as a haematology nurse and has worked at several hospital sites throughout his career. He has a real passion for supporting people affected by myeloma and helping them to live well. Daniel will be working on Mondays and alternating Fridays and we are so fortunate to have him on board.

In December 2020, we were able to hold our first face to face event as a Christmas Cuppa and Catch Up at the Cancer Wellness Centre in Cottesloe. It was a relaxed morning where attendees were able to catch up in a safe, socially distanced setting and enjoy a delicious morning tea. It was certainly a time for us to feel grateful that we were able to meet face to face.

We have planned to recommence our support groups for 2021 in a face-to-face capacity, however we will have Zoom links set up for these meetings for people to attend virtually as well. Most support groups will be held in venues we have previously used, with the exception of the South Metro Information and Support Group, which will now be held at the Gary Holland Community Centre in Rockingham.

We will only be running the WA Partners and Carers Support Group in a virtual setting for 2021.

More information regarding upcoming support groups will be sent out via email the week before each group. Contact the WA Myeloma Support Nurses, Narelle and Daniel, if you have any queries about these and other local events.

– Narelle Smith & Daniel Berk
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’s 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). ALLG is thankful to the Australian Government’s Medical Research Future Fund for funding to run this trial.


**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. This trial has opened in January 2021 at two sites, with 18 more hospital sites to open this year.

Current Recruiting Hospitals – VIC – St Vincent’s Melbourne; NSW – Concord Hospital. More hospitals to open in coming months.

**What’s New**

The ALLG has one new myeloma 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 trial in Australia next year.

**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.
Over the last few months, AMaRC have made great progress with our studies. We’ve been able to open new sites for FRAIL-M and can confirm that FRAIL-M will be expanding into New Zealand. The BelaCarD study is now also opened. We continue to work and develop three (3) new studies with the aim to open these mid-2021.

**Actively Recruiting**

1. **FRAIL-M (MM22) study – Prof. Andrew Spencer** –
   Frailty-stratified, randomised controlled Bayesian adaptive trial of bortezomib versus lenalidomide in transplant-ineligible myeloma

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

   **Recruiting hospital sites – 3 new sites**
   - VIC – Alfred Hospital, Sunshine Hospital
   - NSW – Concord Hospital (new), Nepean Cancer Care Centre, Tamworth Hospital (new)
   - QLD – Princess Alexandra Hospital, Sunshine Coast University Hospital (new), Townsville Hospital
   - SA – Royal Adelaide Hospital
   - TAS – Royal Hobart Hospital
   - NT – Royal Darwin Hospital

2. **I-RIL study – Prof. Hang Quach** –
   A prospective Phase II study of Isatuximab Rescue for Inadequate response to Lenalidomide and Dexamethasone in transplant ineligible patients with newly diagnosed multiple myeloma (IRIL)

   This study explores the addition of isatuximab in specific cases to improve treatment for patients already receiving lenalidomide and dexamethasone for their newly-diagnosed myeloma

   **Recruiting hospital sites**
   - VIC – Alfred Hospital, St Vincent’s Hospital, Epworth Freemasons
   - NSW – St George Hospital, Calvary Mater Newcastle, Border Cancer Hospital, Concord Hospital, Nepean Cancer Care Centre
   - SA – Flinders Medical Centre
   - TAS – Royal Hobart Hospital
   - WA – Fiona Stanley Hospital

3. **BelaCarD study – Prof Hang Quach** –
   A phase I/II single arm study of combination Belantamab Mafodotin, Carfilzomib, Dexamethasone in patients with early relapsed multiple myeloma.

   The BelaCarD study explores a combination of belantamab, carfilzomib and dexamethasone to treat patients with relapsed/refractory myeloma. More sites will open in Q1 2021.

   **Recruiting hospital sites**
   - VIC – Alfred Hospital, St Vincent’s Hospital

If you would like to know more about our trials or have an interest to work with AMaRC as an investigator or patient representative, please contact us at amarc@alfred.org.au.

**AMaRC contact**
Website: www.amarconline.org
Email: amarc@alfred.org.au
Twitter: @amarconline

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**Understanding Paraprotein in Myeloma**

The latest fact sheet “Understanding Paraprotein in Myeloma” is now available for download on our website myeloma.org.au/resources/
The MRDR now has over 4,300 patients registered, with Royal Adelaide Hospital the most recent site to obtain approval to participate. And we have some exciting news from the Myeloma 1000 biobank, that has reached the milestone of more than 500 patients with samples collected! – that’s a huge achievement and many thanks to all participating patients and sites for making this happen.

Now, an update on our sister registry in the Asia-Pacific region (APAC MRDR) that is kicking goals:

The APAC MRDR has received $5.3 million from international pharmaceutical company Janssen-Cilag Pty Ltd. The funding will support the continuation of the APAC MRDR as well as the expansion into additional hospitals and also the fifth country, China. Currently there are 638 patients registered with 16 active sites in Korea, Singapore and Malaysia, with Taiwan soon to follow.

Professor Andrew Spencer, principal investigator of the APAC MRDR and Australian/New Zealand MRDR said, “The range of treatment options available to patients with myeloma has increased dramatically over the last 30 years, resulting in improved survival. The APAC MRDR, in addition to enabling clinicians to benchmark against national and international standards, will also serve as a platform for a wide range of studies such as health economics analyses, and a basis from which to explore the viability of more targeted interventional studies.”

We look forward to the ongoing growth of the APAC MRDR and the potential for future collaborations with the MRDR.

Thank you $9,774 raised!
Real world experience of treating myeloma:
Clinical trials generally include people with no organ dysfunction (eg kidney or heart) or serious other medical issues. Real world practice treats all patients with many other challenging medical issues. This issue cites 3 articles with discussion of real world experience of treating myeloma.

The Myeloma Landscape in Australia and New Zealand (ANZ): The First Eight Years of the Myeloma and Related Diseases Registry (MRDR)
Krystal Bergin; Cameron Wellard; Elizabeth Moore; Zoe McQuilten; Hilary Blacklock; Simon J. Harrison; Joy Ho; Tracy King; Hang Quach; Peter Mollee; Patricia Walker; Erica Wood; Andrew Spencer
Clinical Lymphoma Myeloma and Leukemia; Available online 30 January 2021
Real-world multiple myeloma (MM) data are scarce as most data originates from clinical trials. The MRDR is a prospective, clinical quality registry of newly diagnosed cases of plasma cell disorders, established in 2012 operating at 44 sites in Australia & NZ as of April 2020.

We reviewed all patients enrolled onto the MRDR between June 2012 and April 2020. Baseline characteristics, treatment, and outcome data were reviewed for MM patients and analysed to estimate progression free survival and overall survival.

Results: As of April, 2020, 2405 MM patients were enrolled (median age 67y, 40% >70y).
High-risk features were present in 13-31% of patients: FISH [≥1 of t(4;14), t(14;16) or del17p] 18%, ISS-3 31% or R-ISS-3 13%. Cytogenetics/FISH were performed in 50% and 68% of patients, respectively, with an abnormal karyotype in 34%.
Bortezomib-containing therapy was the most common first-line therapy. Patients not receiving bortezomib were older (median age 76y versus 65y) with worse performance status. Median PFS and OS were 30.8 and 65.8months, respectively. Younger patients had better OS (76.3m <70y vs 46.7m ≥70y).
Staging (R-ISS) was available in 50.7% of patients and higher R-ISS showed worse OS (R-ISS-1 68.1m, R-ISS-2 33.2m, R-ISS-3 not reached).

Conclusion: Clinical registries provide a more complete picture of myeloma diagnosis and treatment and highlight the challenges of adhering to ‘best practice’ in a real-world context.

Real World Treatment of Patients with Relapsed/Refractory Myeloma
Ioannis Ntanasis-Stathopoulos; Maria Gavriatopoulou; Evangelos Terpos; Meletios A. Dimopoulos; Department of Clinical Therapeutics, School of Medicine, National and Kapodistrian University of Athens, Athens, Greece
Clinical Lymphoma Myeloma and Leukemia; Available online 30 January 2021
Continuous advances in treatment of multiple myeloma (MM) have led to the approval of several novel agents and their combinations that significantly improved patient outcomes. Despite their undoubted effectiveness in clinical trials, their impact on real-world (RW) clinical practice remains debatable. RW data on the role of novel agents and their combinations in patients with relapsed/refractory MM have confirmed the efficacy of proteasome inhibitors, immunomodulatory drugs, and monoclonal antibodies. However, the degree of benefit and safety profiles may differ among RW studies and between RW and clinical trials. Variables that may affect these observations include patient selection, ethnicity, age, comorbidities, disease stage at diagnosis and at relapse, number of prior lines of therapy, disease subtype, presence of renal impairment, extramedullary disease, and cytogenetic abnormalities, expertise of each medical center and the treatment setting in terms of availability and drug access are particularly important, as well. These variations may contribute to the differing treatment outcomes in RW patients. RW observations may serve as a proof-of-concept basis for designing new clinical trials.

In conclusion, clinical trial and RW data are complementary and they should be considered as important feedback to improve both clinical trial designs and clinical practice.

Comorbidities in multiple myeloma and implications on survival: a population-based study
Ingigerður S Sverrisdóttir, Ola Landgren et al
Abstract
High proportions of patients with multiple myeloma suffer from comorbidities which may alter clinical management, so our aims were to evaluate the prevalence of comorbidities and their impact on survival. We included patients diagnosed with multiple myeloma from 1990 - 2013 in Sweden and all the comorbidity diagnoses from each patient from 1985.
A total of 13,656 patients with multiple myeloma were included in the study, and 54% had comorbidity at diagnosis. The risk of death was increased for those with one comorbidity at diagnosis compared to those with none. The risk was higher for those with two and three or more comorbidities respectively. Furthermore, the risk of death was increased in patients with prior history of cancer, arrhythmia, heart failure, diabetes mellitus, cerebrovascular disease, chronic lung disease, psychological disease, peptic ulcer, neurological disease, peripheral vascular disease, chronic kidney disease, dementia, and inflammatory bowel disease. This large study shows that over 50% of multiple myeloma patients have a comorbidity at diagnosis and survival decreased with increasing numbers of comorbidities.

In conclusion, this emphasises the importance of comorbidities when evaluating patients and deciding on treatment strategies for individuals with multiple myeloma.

**MINIMAL RESIDUAL DISEASE EVALUATION**

Evaluation of Sustained Minimal Residual Disease Negativity with Daratumumab-Combination Regimens in Relapsed and/or Refractory Multiple Myeloma: Analysis of POLLUX and CASTOR

Hervé Avet-Loiseau MD; Jesus San-Miguel, MD; Tineke Casneuf, PhD; Shinsuke Iida, MD; Sagar Lonial, MD; Saad Z. Usmani MD et al

Journal of Clinical Oncology; Published online January 29, 2021

PURPOSE

The POLLUX and CASTOR clinical trials for relapsed and/or refractory multiple myeloma (RRMM), evaluated daratumumab efficacy and found that daratumumab significantly reduced the risk of progression or death. Minimal residual disease (MRD) is a sensitive measure of disease control. Using the POLLUX and CASTOR studies this largest set of MRD data collected from patients with RRMM was analysed. Patients who achieved MRD-negative status had improved progression-free survival (PFS) compared with MRD-positive patients. Sustained MRD negativity was associated with improved PFS compared with patients who obtained MRD-negative status but did not maintain MRD durability. The benefit of MRD negativity and durability occurred regardless of therapy, but daratumumab-based regimens enabled many patients with RRMM to attain deep and sustained MRD-negative responses, resulting in longer periods without disease progression.

In conclusion, achieving durable MRD negativity may predict long-term outcomes, as durable MRD negativity improves PFS and increases the time between treatment relapses for RRMM.

SAVE THE DATE

FOR THE

Australian Amyloidosis Network’s

**AMYLOIDOSIS WORKSHOP 2021**

*For Patients and Carers*

On National Amyloidosis Day

**Saturday May 8th**

In-Person Meetings in 6 States

- Adelaide
- Brisbane
- Hobart
- Perth
- Melbourne
- Sydney

with presentations by

International Experts, Professor Claudio Rapezzi & Professor Morie Gertz

The Melbourne patient and carers meeting will be live-streamed for those who cannot attend the in-person meeting

For registration, location and program details for your State’s meeting go to

https://amyloidosis.net.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**: accure small numbers (tens) of patients to evaluate safety (a safe dose range and identify side effects)

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

**Phase 3 trial**: accure 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 response (>90% reduction in myeloma markers)

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**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
All at Myeloma Australia are so relieved to see restrictions easing around the country and communities being able to get together in our new ‘COVID-normal’ environment. 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 log in 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

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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 National
- Younger Persons’ All States

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 & Catch Up
- Newcastle
- Orange / Mudgee / Dubbo
- Regional NSW Cuppa & Catch Up
- RPAH
- Tamworth
- Westmead
- Younger Persons’

For enquiries, please contact
Jacqui Keogh
E: jacqui.keogh@myeloma.org.au
M: 0426 404 230
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Information and Support Groups QLD
- Friday Zoom Catch up
- Gold Coast
- Inner North Brisbane
- Inner South Brisbane
- North Lakes
- Sunshine Coast
- Tuesday Zoom Catch Up

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

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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
Information and Support Groups SA

- Partners and Carers
- Flinders & Southern Adelaide
- Fullarton & Central Adelaide
- Mid-North
- South-East
- 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

- Burnie
- Devonport
- Launceston
- Southern TAS

For enquiries, please contact
Deborah Thompson
E: deborah.thompson@myeloma.org.au
M: 0433 511 689

Information and Support Groups VIC

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

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For enquiries, please contact
Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

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

Information and Support Groups WA

- Cottesloe
- Cuppa & Catch Up
- North Metro
- Partners & Carers
- Perth Hills
- Regional WA
- South Metro
- South West
- Younger Persons’

For enquiries, please contact
Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

Daniel Berk
E: daniel.berk@myeloma.org.au
M: 0426 404 310

Answers to the crossword on page 11

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

You can also follow us on Facebook
www.facebook.com/MyelomaAustralia

Twitter twitter.com/MyelomaAust_MFA
for all updates and events.
Myeloma Australia is the only myeloma specific support organisation in Australia

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

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

Find your nearest myeloma support group to meet other people

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

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

Mon – Fri 9am – 5pm AEST

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