Finally, in Victoria COVID restrictions have eased and most of the community can return to a “COVID Normal” existence, catching up with the rest of Australia. We can now see our extended families and friends and do more than just supermarket shopping. Mask wearing is still mandatory indoors and where we cannot physically distance outdoors, as well as all the COVID safety precautions.

This is not so different from what we did for the first few years after my wife was diagnosed and then had the transplant and I would think many of those in the myeloma community would have done likewise.

November marks the 24th anniversary of my wife’s diagnosis and other than a scare in the last month with some unexplained pains she has been in remission. She had a PET scan to check out the pains and thankfully this did not show anything, so all good.

A very big thanks to the Myeloma Support Nurses who with the assistance of the Myeloma Australia staff have been able to continue and even increase the support groups which are being all held online as well as the number of seminars held online. The best part of this is that these are available to everyone no matter where you live if you have internet access. The numbers attending the support groups and webinars have proved to us how popular and successful they are.

The nurses are looking at ways to return Information and Support Groups to face-to-face meetings and are discussing what must be done with the local health departments and the local members of MSAG to ensure a safe environment for all. Going forward we will be continuing our Information and Support Groups both with video conferencing via Zoom as well as in person where safe to do so.

Thanks again to all of you who made submissions to the Pharmaceutical Benefits Advisory Commission (PBAC) over the past few months. The exciting news was that daratumumab was recommended to be subsidised with negotiations to be finalised before the Cabinet gives their approval. The results from the various trials using daratumumab have shown its value as one of the range of drugs that can be used in the treatment of myeloma.

The most important item that we have missed in the last seven months, is the inability of small fundraising events held by our community and their friends. Fundraising is essential to assist us to cover our expenses in providing the education and support, so if you can assist in any way please do.

Our Board has officially named our research fund the Bob Moran Research Fund to commemorate the work done by our Patron and co-founder the late Bob Moran. I am very proud of this decision and this is a very fitting way to remember his determination and passion that has made Myeloma Australia what it is today.

MYELOMA AUSTRALIA

Christmas Closure
Myeloma Australia will be closed for Christmas & New Year
From Thursday 24 December 2020 – 12 noon
and will re-open
Monday 11 January 2021 – 9:00 am.

Thank you all for your patience, understanding and support this year. We look forward to seeing you in 2021.
What is the Paraprotein?

Understanding the medical language surrounding myeloma can be difficult, it doesn’t help that the medical profession uses complex words and often has a number of words to describe the same thing. Many of you will have heard the words paraprotein, m protein, antibodies, immunoglobulins and light chains when speaking with the treating team or doing your own research.

This article aims to help you understand these complex concepts as it is important to understand how myeloma is categorised, how response to treatment is assessed and how myeloma is monitored over time.

Myeloma and the plasma cell

Plasma cells are made in the bone marrow and form part of the immune system. Their usual function is to make antibodies to fight infections against invading bacteria or viruses. These antibodies then attach to the bacteria or virus by finding a surface protein or ‘antigen’ to bind to. This then signals other immune cells to remove the invading bacteria or virus and overcome/eliminate the infection. Antibodies are also referred to as immunoglobulins.

Myeloma is a cancer of the plasma cells. When plasma cells become cancerous, they make abnormal antibodies in large quantities that serve no useful function. These abnormal antibodies can be found and measured in the blood and are referred to as paraprotein or m protein. Most people with myeloma will have a paraprotein in their blood, but some do not. Those without paraprotein will most likely have light chain myeloma or non-secretory myeloma.

Understanding immunoglobulins (antibodies)

There are many different proteins in the body and the blood, the most common being albumin and immunoglobulins. Immunoglobulins are molecules made up of 2 heavy chains and 2 light chains.

There are five types of heavy chains; IgG, IgA, IgM, IgD and IgE and two types of light chains; Kappa and Lambda. Each immunoglobulin is made up of 1 type of heavy chain and 1 type of light chain. Each diagnosis of myeloma is labelled according to the type of immunoglobulin that has become abnormal eg IgG Kappa. Sometimes only light chains become abnormal and break away from the heavy chain and reproduce on their own. We then label the myeloma according to the type of light chain eg. Lambda light chain myeloma.

Some people may over produce two different immunoglobulins eg. IgG Kappa and IgA Lambda. These are then measured as two different paraproteins and is referred to as bi-clonal myeloma.

<table>
<thead>
<tr>
<th>Immunoglobulin Type</th>
<th>Usual Function</th>
</tr>
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<tbody>
<tr>
<td>IgG</td>
<td>Most common immunoglobulin. Attaches itself to germs and mobilises the immune system to kill the germ.</td>
</tr>
<tr>
<td>IgA</td>
<td>Accumulates in mucous membranes and responds first to infection of these tissues</td>
</tr>
<tr>
<td>IgM</td>
<td>First response to sight of infection in the blood</td>
</tr>
<tr>
<td>IgD</td>
<td>Occurs in low levels in the blood. Thought to help IgM</td>
</tr>
<tr>
<td>IgE</td>
<td>Responsible for allergic reactions</td>
</tr>
</tbody>
</table>
Usual Function of Light Chains (Kappa and Lambda)

- Light chains help to make the antibody specific for a specific antigen or infection. Eg measles
- In myeloma the light chains can detach from the heavy chains and be more abundant than normal (light chain myeloma)
- Also called Bence Jones proteins because they were discovered in the urine by a doctor called Bence Jones in 1845
- Light chain proteins can pass through the kidneys but can also get stuck, causing kidney damage

Paraprotein measurements are done regularly at intervals (eg monthly or three monthly) to see how well the treatment is working and to check that the myeloma is remaining stable during periods between treatments.

In those that overproduce light chains, the same approach will be taken to monitor the myeloma’s activity. Unlike paraprotein, everyone will have some light chains in their blood. It is only when they increase above normal levels that monitoring is required.

The doctor will also be assessing other levels in the blood and any other symptoms that might be present as the paraprotein is only one feature of the disease.

Assessing response to treatment

The doctor will use the International Myeloma Working Group’s Response Criteria to assess the response to treatment, that is, how well is the treatment working against the myeloma. This is done by comparing the blood and/or urine level of paraprotein or light chains before treatment to certain timepoints during treatment, typically once each cycle of treatment has been completed.

If no paraprotein is detected after treatment or light chains return to normal levels, it is considered a complete response (CR). If the paraprotein has fallen and is still detectable and stable after treatment it is considered a partial response (PR). A stable low level of paraprotein maintained over time is often described as plateau phase. The term ‘plateau’ phase is used because a graph of the paraprotein results appears flat like a plateau.

For those with non-secretory myeloma it may be necessary to measure response to treatment with bone marrow biopsies or scans.

It is possible for myeloma to become active again without producing a paraprotein. This is why it’s so important to report any new symptom such as pain to the doctor for investigation.

For more information about myeloma and treatments, please see our book, Myeloma a Comprehensive Guide and our range of other resources. They can be found at www.myeloma.org.au or contact head office e: support@myeloma.org.au t: 03 9428 7444 (AEDT) for hard copies
Global Myeloma Action Network (GMAN) Summit 23 and 24th September 2020

Myeloma Australia’s Steve Roach, Brian Rosengarten, Hayley Beer and Nella Combe attended the online GMAN Summit on September 23rd and 24th. Fitting with the flavour of 2020, the theme was ‘More on Digital’ with over 70 participants from over 40 countries attending. We heard from some of the great advocacy work being done for the myeloma community in Iceland and Singapore and we also presented in the ‘Best Practice’ session about our unique Myeloma Support Nurse model and how we have moved to deliver ‘more on digital’ this year. We also attended breakout workshops on advocacy, awareness and access in the digital space. Our next GMAN meeting is early December and we will move into some actions on these three topics, collaborating with our international counterparts to improve the lives of those living with myeloma around the world.

Pharmaceutical Benefits Advisory Committee (PBAC)

Positive recommendations

We are pleased to inform our community that the PBAC made two positive recommendations at their last meeting in July.

The combination of daratumumab, bortezomib and dexamethasone for those who have had one prior line of therapy and weekly dosing of carfilzomib which is currently available for those with whose myeloma has come back.

We are thrilled with the outcomes, especially the new addition of daratumumab to our Medicare funded myeloma treatments. It has taken many years of submissions, advocacy and community feedback to achieve this, thank you to everyone who has been involved and provided feedback over this time. A real win for the Australian Myeloma Community!

Submissions for consideration at the upcoming December PBAC meeting

Ixazomib (proteasome inhibitor in tablet form) in combination with lenalidomide and dexamethasone for patients with relapsed or refractory myeloma.

Elotuzumab (monoclonal antibody targeting SLAM-F7) in combination with lenalidomide and dexamethasone for the treatment of patients with relapsed or refractory myeloma.

Thank you to all who have submitted comments, we eagerly await the recommendations made at the next meeting and will update you in the new year.

Buy a Membership to help us raise extra for our fundraising

For more information contact Matt Maudlin
Community Engagement & Fundraising Manager
E: matt.maudlin@myeloma.org.au • M: 0407 891 052
Fred has been living with myeloma since 2017. He recently chatted via Zoom with Olivia Myeza, our Manager of Philanthropy, Major Gifts and Philanthropy, to share his love of flying, his history of representing Australia as a sportsman, and his journey with myeloma.

Q: How and when were you diagnosed with myeloma?
A: I was diagnosed with myeloma in late 2017 after I went for an annual medical check-up as part of my pilot license renewal. My kidney function had been outside the normal range for a long time and was being monitored. As part of the monitoring process, they picked up an abnormal protein in my blood, which was the indicator that something was going on. It took about one week from the time the abnormal protein was picked up in my blood test, to the time I was diagnosed with myeloma – with a bone marrow biopsy the very next day after the blood results came back.

Q: How did you feel when you received the diagnosis?
A: Well, I had never heard of myeloma before, and neither had my family or friends. I was devastated, it was a real shock to the system. I was in no-man’s land having found out that I had this strange disease.

Q: How did you discover Myeloma Australia?
A: I did a google search for ‘myeloma’ and I stumbled across the Myeloma Australia website. I phoned the Telephone Support Line and spoke to one of your nurses, Jo. We chatted for over an hour that first call, and many times since. Jo is a very special person. She was very reassuring and at the end of the session we had built up a rapport. I was reassured that I wasn’t going to die tomorrow, that there were opportunities to live a reasonably productive life.

Q: Have you attended any Myeloma Australia Information and Support Groups?
A: Yes, I attended some in-person and some on Zoom once COVID-19 restrictions hit. They were helpful and it’s nice to meet others who are going through something similar.

Q: How is your health currently?
A: Well, I had a successful tandem bone marrow transplant in August and October 2018, and from there my myeloma was in remission until April 2020 when it relapsed. I started Revlimid in May 2020 and my most recent results showed a completely normal light chain ratio – in other words, I’m currently in remission again.

I was over the moon when they told me. It is hard because you’re always aware in the back of your mind that at this stage there isn’t a cure for myeloma, so it will come back to get you one day. I’ve had to adjust my mentality to say well that’s the reality of the situation and I’ll make the best of what I have left. I’ve been successful in doing that.

Q: How do you maintain your positive mindset?
A: Focusing on the positives is critical, and I recommend people take up a hobby and focus on that. For me, that hobby is flying. I obtained a private pilot’s license in my late
teens and pursued flying more actively about 15 years ago as I was approaching retirement and knew I’d need something to keep me busy and stimulate my mind. I’ve owned my own five-seater light aircraft for the past 10 years and I try to fly at least a couple of times per week. I’ve flown all over Australia and clocked up almost 2,000 hours of flying. One of my favourite places to fly is South East Queensland. In particular, an aero breakfast club where you fly into a location, cook, and eat breakfast, and fly home again.

Flying has been absolutely fantastic for me. When I’m flying, I feel amazing. I’m licensed to fly in the clouds and do approaches in bad weather – that’s really demanding, and I get a lot of satisfaction out of it. There was a period of a couple of years when I couldn’t fly due to my treatment, and that was really rough. To come back to flying, I’m a different person, it’s made a huge difference.

Q: In February 2020, you generously donated your time and your plane, and rallied two friends to do the same, to take Myeloma Australia’s Charity TV Ambassadors on a scenic flight along the Great Ocean Road in Victoria. This was part of the Myeloma Australia/Charity TV Adventure All Star TV show that will be screened on Channel 7 in 2021. Tell us about that experience.

A: I get a thrill out of helping other people. For me it was a two-way street, I was helping them, and they were helping me. The people that I took flying were so appreciative – it was a great day. I also got to meet nurse Jo face to face for the first time that day, which was very special after all the hours we’d spent talking on the Telephone Support Line.

Q: When you’re not flying, what keeps you busy?

A: During the period when I couldn’t fly due to the treatments I was having, I kept busy by purchasing a second home on the Sunshine Coast and took up lawn bowls.

I’m also a Rotarian and have been a member of the Toowoomba Garden City Rotary Club for the past five years.

I’ve been a very active person all my life. I played a lot of field hockey at an international level, most recently in 2014 when I went to Europe and played for Australia in an over 65’s side. I think one of the reasons I am coping so well with myeloma is because I’ve kept myself fit most of my life.”

Q: How has COVID-19 impacted you this year?

A: I love people and mixing with people and that got taken away as well as my flying, and I did struggle for a while there, but I’ve got on top of it now. I called the support line and chatted to a nurse whenever I needed to.

Q: What message would you like to share with others who are living with myeloma?

A: Talk. You need somebody in your life who you can talk openly to, whether it’s a family member, a friend or a myeloma nurse, you need someone to be able to tell them what’s going on in your head.

Q: What message would you like to share with the team at Myeloma Australia?

A: Keep doing what you’re doing, I think it’s a fantastic organisation. It is a need that has to be fulfilled and Myeloma Australia is doing a great job.

If you’d like to chat with us about sharing your story with myeloma in a future edition of the MyeNews magazine, either as someone who’s living with myeloma, or as a loved one/carer, please contact our Myeloma Support Nurses e: nurses@myeloma.org.au t: 1800 693 566

National Patient Advisory Group

Myeloma Australia (MA) is forming a National Patient Advisory Group made up of two members of the myeloma community from each state and will initially be chaired by the president of Myeloma Australia.

The National Patient Advisory Group exists to represent the myeloma community in Australia and takes a role in reviewing and improving the support services that we offer.

MA is committed to being community-centred across all aspects of the organisation and the National Patient Advisory Group will make a critical contribution to guiding what we do and how we engage with the myeloma community.

For more information, please contact our Myeloma Support Nurses e: nurses@myeloma.org.au or t: 1800 693 566 (Mon – Fri 9am-5pm AEDT) or our President, Brian Rosengarten e: brian.rosengarten@myeloma.org.au
Complementary and alternative medicines (CAM) are medicines or treatment that are outside conventional medicine and can range from biological therapies, such as herbs and vitamins, to mind and body practices, such as yoga, meditation and acupuncture [1]. Studies have shown that globally over the last 10 years over 50% of people with cancer have used some form of CAM [2]. Research is currently being conducted which aims to find the common CAMs currently being used by Australians with a diagnosis of cancer and develop educational materials regarding their safety in cancer care. This information collected will contribute to a knowledge about the use of CAM and allow their safe integration with the conventional medicines used in cancer care.

Assisting with this research would involve filling out an online survey. This survey is designed for people with a current or past diagnosis of cancer. It will ask about what CAMs you are taking and your beliefs regarding these therapies. It should take 10-15 minutes to complete. Please note that participation in the research is completely optional.

If you are interested in participating in the research please use the following link: https://www.surveymonkey.com/r/HJC9WB7

This will take you to the survey with and information page that will explain the survey in more detail.

References:
The Summer Sizzler

The Summer Sizzler at Tatura in central Victoria is a Western Performance show, and part of an annual event run by the Goulburn Valley Quarter Horse and Western Riding Club Inc., attracting an average of 5,000 enthusiasts with competitors from all over Australia. It’s the biggest futurity show in the country, a competition usually limited to younger horses, which offers significant prize money to winners. Andrea Gai O’Connell (better known as Gai), had a passion and love for horses from a very young age, learning to ride almost as soon as she could walk. Gai taught her four children how to ride the many horses that lived with them over the years. She was a highly skilled and accomplished competitor riding her prized and much-loved horse Denzel in the Summer Sizzler at Tatura.

There are many categories that make up the show, the Western Pleasure Walk / Jog section is a well contested event with competitors as young as five years of age vying for prizes. Once the contestants have mastered this section they generally move into the Western Pleasure Trail, a competitive class where horses and riders in western-style attire and horse tack navigate a series of obstacles.

To commemorate Gai’s participation in the Summer Sizzler, Tim O’Connell and his family have sponsored the Open Walk / Jog section with the monies raised by entry fees for this event generously gifted to Myeloma Australia in honour of Gai. When the event was held in February of this year, more than 30 participants competed for the first prize of the Buckle and Garland in this section.

The next Show is scheduled for February 24th-28th 2021. If you happen to be around the Tatura area and would like to attend a fun family event with plenty of colour and excitement, this won’t disappoint. The Andrea Gai O’Connell – Memorial Open walk / Jog; Western Horse-Riding Event is well worth a look. If you feel inclined to make a donation to Myeloma Australia helping them continue their valuable work supporting the thousands of people diagnosed each year and their families, please go to; www.myeloma.org.au or donate on the day at the event. There will be social media posts by Myeloma Australia closer to the time to keep you up to date.

*At the time of going to print the event was scheduled to run, however under the current circumstances, it is subject to change or cancellation due to COVID-19 restrictions.

Pina Civitarese

Please check their website for further updates. www.gvwesternhorse.org.au or Facebook – Goulburn Valley Quarter Horse and Western Riding Club
Staff Profile

Olivia Myeza
– Manager Philanthropy, Major Gifts & Corporate Giving

Olivia joined Myeloma Australia in September, in the newly formed role of Manager Philanthropy, Major Gifts & Corporate Giving. Olivia has over 15 years’ experience in executive leadership, fundraising and communications for not-for-profit organisations in both Australia and South Africa. She loves connecting donors from the philanthropic, corporate and community sectors with causes that matter to them, for mutually beneficial, high-impact partnerships.

Born and raised in Melbourne, her involvement as a volunteer with The Oaktree Foundation took her to South Africa in her early twenties, initially as a short-term volunteer. She went on to spend 10 years living in Durban and working at the coal face of the HIV/AIDS pandemic, returning to Melbourne three years ago with her family. In South Africa she worked in the healthcare sector, including in a fundraising and marketing role within a hospital and then as CEO of a not-for-profit community organisation that supports people who are living with and impacted by HIV/AIDS.

Most recently she has been working as a business development & partnerships manager within the Melbourne youth homelessness sector, mobilising partnerships across the local and state government, corporate, philanthropic and community sectors to build a new youth refuge in Melton. Olivia is excited to have the opportunity to now return to the healthcare sector in this role with Myeloma Australia. She loves working with nurses and being part of organisations that are making an impact on patients and their families.

Olivia said: “This is an exciting time for Myeloma Australia. I’m looking forward to connecting in with past, current and potential future partners and donors who care passionately about supporting people who are living with myeloma. It’s such a worthy cause, and there’s much to be done in terms of care and treatment, advocacy and research. Together, we’ll make things happen! Please reach out to me for a virtual cuppa if you’d like to share ideas or chat about your past, current or potential future support of Myeloma Australia.”

Outside of work, Olivia is kept busy by her big family of six. She is also a singer/songwriter and loves the power that music has to connect, uplift and break down barriers.

You can contact Olivia on E: olivia.myeza@myeloma.org.au or M: 0401 429 970

Photo supplied and used with permission

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

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

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

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

Any questions? Please contact Matt at Myeloma Australia: matt.maudlin@myeloma.org.au
Husband and grandfather-to-four, Graeme, 69, is an avid cyclist. Graeme grew concerned when he could no longer keep up his typical pace. After visiting his GP about his mounting exhaustion, he was sent to the emergency room, where tests revealed problems with Graeme’s kidney function.

Following a four-day stay in hospital and further testing, Graeme was diagnosed with multiple myeloma in April 2019. “The first time I heard of multiple myeloma was when I was diagnosed – I had to Google it to find out what the disease was” said Graeme.

After initial treatment Graeme was recommended by his haematologist to take part in a clinical trial. Within a few months of commencing the trial Graeme slowly began regaining his strength and was able to venture on longer walks with his wife and dog. “My family, in particular my wife, have been an incredible support throughout my journey with multiple myeloma.”

By October 2019, five months after being diagnosed with multiple myeloma, Graeme was happily back riding his bike. Throughout November 2019 Graeme underwent three gruelling stem cell collections before receiving an autologous stem cell transplant in February 2020 (using his own healthy cells). Today he continues to enjoy his life as a retiree, cycling, reading, and spending time with his family.

Quotes

• “People don’t often know how to react to my diagnosis because they don’t know what multiple myeloma is.”
• “Since my diagnosis and commencing treatment, my life hasn’t changed too drastically. I now have enough energy to ride my bike again and still enjoy reading. Although the worry of infection is constantly in the back of my mind it hasn’t stopped me living a relatively unchanged life.”
• “If you have been recently diagnosed with multiple myeloma, I highly recommend joining a support group, to hear from others living with myeloma, and to learn more about the disease.”
• “Raising awareness for multiple myeloma is so important as it improves the chances of new treatments being developed and brings us closer to a cure.”

If you would like more information about a support group near you, feel free to contact one of our specialist Myeloma Support Nurses on 1800 693 566 (Mon–Fri 9am – 5pm EST) or email: nurses@myeloma.org.au

Article reprinted with permission from Viva Communications

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.
Community Engagement & Fundraising

It goes without saying that 2020 has been a challenging year for us all! Our community fundraising has been greatly impacted this year – yet despite the difficulties caused by the pandemic the year has held very many positive moments for us. This commenced in February as our first group of intrepid Ambassadors set out on the ‘adventure of a lifetime’ along The Great Ocean Road in Victoria; the film of this will be shown on Channel 7 in 2021. Other fundraising events that have occurred this year have included a car rally, head shaves, walks, a major kayak paddle, craft sales, Bunnings BBQs, a raffle for a piece of art and a couple of students creating myeloma awareness and raising funds through high school projects.

The first green shoots of recovery in our fundraising space are now, thankfully, evident. We currently have a handful of community fundraising events that are live and raising both awareness and funds for us. I trust that 2021 will be a great year for our community engagement & fundraising.

We have many exciting plans afoot for 2021. Alongside several new Ambassadors raising awareness and funds for Myeloma Australia in our second adventure with Charity TV Global we will be hosting our own bespoke fundraising walk in the second half of the year. Team Myeloma will once again be participating in fun runs and walks around the nation and our web shop will be featuring a range of new items for purchase.

In early September it was a great joy to welcome Olivia Myeza to the Myeloma Australia team as our Manager of Philanthropy, Major Gifts & Corporate Giving. I am sure that Olivia will make a big impact upon the Myeloma Australia community.

In addition to Olivia joining us, we are looking forward to early next year when our new Community Engagement & Fundraising Executive NSW will be commencing their role in Sydney.

Our long-standing relationship with the online donations platform Everyday Hero has now come to an end as they ceased their operation at the end of November 2020. I am delighted to announce 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

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.

Finally, if you’re keen to support us by purchasing People’s Choice Lottery tickets, where 100% of every $2 ticket you purchase comes to Myeloma Australia, please visit this link: https://communitylottery.peopleschoice.com.au/collections/health-services/products/myeloma-australia

I wish you and yours a healthy, safe and happy Christmas and New Year period.

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

What’s Happening

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 host small end of year 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.

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/event-calendar/

For further information or help joining a group via Zoom, please contact your state Myeloma Support Nurse.
New South Wales

It is unbelievable to think that Christmas is upon us once again. What a year 2020 has been! While it proved challenging in many respects, there have been many positives experienced over the last 12 months. Our Zoom meetings have provided a valuable space for many to continue to stay connected to others in the myeloma community whilst others have preferred to wait for our face-to-face support groups to return. Our Tamworth and Orange/Dubbo/Mudgee support groups are a great example of us being able to extend our reach to our myeloma community throughout regional and rural NSW. This is possible through a wonderful collaboration with many rural nurses who work with us and spread the word about Myeloma Australia. We can’t thank them enough and look forward to working with them again next year. If you are a rural nurse keen to share the word about our services, please get in touch.

We also held our first combined States Younger Persons Support group (VIC & NSW) our own “State of Origin” which was a draw with equal participants from both states attending. We will look to continuing these groups via Zoom into next year.

We are still following advice from NSW Health regarding our face-to-face groups but hope to restart some of them early next year, so please watch this space. We are busy planning our information seminars for next year, at this stage we are uncertain whether they will be online or face to face but it is possible we will do a combination of both. As always, we are very interested to hear your thoughts and ideas, please email one of our NSW nurses with any suggestions you may like to share. From all of us here in NSW we wish you a wonderful safe Christmas and hopefully a more normal 2021.

Queensland

In Queensland headquarters, Tash and Megan have been building up their myeloma networks around this large state. Thanks to the ever-widening advantages of virtual connections, we have been able to provide valuable training to health professionals in hospitals thousands of kilometres away in places we have yet to visit in person. Our online patient and health professional seminars remain increasingly popular and allow our members to hear from expert speakers from around the country.

Tash and Megan also had the pleasure of attending the inaugural Queensland Myeloma Interest Group for health professionals. The goal was to learn, share and network together in myeloma. Presenters included MSAG members Dr Nick Weber, Royal Brisbane Hospital and A/Prof. Peter Mollee, Princess Alexandra Hospital and Dr Ian Irving, Icon Cancer Care. Colleagues from around the state were able to share difficult cases and discuss current and future treatment strategies. We look forward to meeting again with this group in 2021.

Despite all the positive outcomes we have benefited from during the “Zoom Revolution”, we have been missing seeing you all in person. We will remain adaptable and will follow state health guidelines as well as advice from our MSAG representatives as we plan for next year’s catch ups.

We know that attending an Information and Support Group in person may not be possible for many of our members for various reasons, which is why we will continue to offer our online Zoom meetings to all Queenslanders. To keep up-to-date with all Queensland myeloma events please check the calendar of events on the website and your email inbox.

South Australia

We have continued our online Information and Support Groups throughout SA and NT including holding the second meeting for our partners and carers in September. It was wonderful hearing attendees talk about the challenges and rewards involved in supporting someone with myeloma. Our last Flinders group Zoom meeting in October was well attended with a lot of interest on the topic of how the PBAC/PBS works and potential new drugs available in Australia in the coming months. We hope to continue providing our support groups in both formats in 2021.
Our first face-to-face group since March will be held at the Cancer Council in Sandy Bay on December 8th at 11am. There will be a big screen available so our friends from the north can join in via Zoom. Don’t forget your Christmas hat!

Planning a new look for the north in 2021 - hoping to make it an overnight trip from Hobart and host support groups in Launceston and the North West over the two days every two months: February, April, June, August, October & December.

Tracey Batt, a clinical haematologist at the Royal Hobart Hospital, discussed the medication Selinexor at our state-wide November Information and Support Group and answered several questions put to her by guests. A big thank you Tracey!

After a successful fundraiser at the Royal Hobart Hospital selling the velvet glasses cases in September, we have been working hard on another batch to sell in December. A big thank you to an ex co-worker, Nina Brown, who helped make a number of the covers.

Laura here, smiling a collective sigh of relief with the rest of our Victorian community. You should be so proud of the strength, support, and positivity you showed during such challenging times.

We again warmly welcomed new members to some of our support groups and enjoyed our regular cuppa and catch-ups. EJ and I focused this quarters groups on ‘Understanding Tests and Investigations’ and ‘Understanding Myeloma Trials’. If you missed these and would like further information on these topics, we invite you to reach out to either of us.

Moving into the new year, we continue to encourage members of the community who reside in Mildura, Bairnsdale, and Warrnambool to attend the current closest region Information and Support Group. The aim is to begin a stand-alone group in these regions very soon.

We hope you all enjoyed the 18th La Trobe Myeloma Update as much as I did – presented in November nationally for the first time. Professor Miles Prince gave a wonderful overview of myeloma and its treatments, and the audience submitted some interesting and thought-provoking questions. You can view the recording of this online seminar on our website www.myeloma.org.au/seminars

As the state moves towards a new normal, we are excited to be making tentative plans to meet in person again. Although our online format has many benefits, I know many are looking forward to the return of face-to-face events. Please keep an eye out for information on December Christmas celebrations throughout the state. Hopefully by the time you read this, it won’t be long till these plans’ become reality.

EJ and I wish you and your families a wonderful Christmas and look forward to watching the myeloma community spirit continue to flourish in the new year.

There is a lot of exciting change occurring in the West. Regular virtual support groups are continuing with strong attendance and are really exhibiting a true sense of community.

Excitingly, planning is well and truly underway for recommencing some face-to-face events.

The first face-to-face event will be a Christmas Cuppa and Catch Up and is planned for the 14th December 2020. This will be held in the Conference Hall at the Cancer Wellness Centre in Cottesloe. Mark your calendars and watch your inboxes for the invite.

Sadly, we said goodbye to our amazing Myeloma Support Nurse for WA, Kerin at the beginning of November. Kerin has moved into a nurse practitioner position in regional Western Australia. We were very sad to farewell Kerin, but we will stay in touch as myeloma remains close to her heart. The search is on for another amazing nurse to join Narelle in the coming weeks, so watch this space.

In the meantime, Narelle is really excited to have the opportunity to present at the upcoming HSANZ WA Nurses Group meeting in December as well as being invited to attend some other health care professional groups to share her experiences of being a Myeloma Support Nurse within Myeloma Australia.
What is ‘chemo brain’?

Current research depicts the evolution of the concept ‘chemo brain’ to chemotherapy related cognitive impairment then to cancer related cognitive dysfunction or crisis brain. This highlights the level at which cognitive changes can occur due to cancer treatments.

It is well documented throughout current literature that treatment related side effects can impact one’s quality of life, specifically cognitive changes. As such, it is an important area that should be considered when creating a care plan. For the purpose of this article, we will use the term ‘chemo brain.’

Some individuals describe ‘chemo brain’ as:
- A sense of ‘fogginess,’ feeling disorganised and that things take a lot longer to do than previously
- Changes in attention or concentration, such as difficulty focusing on the task at hand and a shortened attention span
- Trouble multi-tasking, previously if you were able to do multiple things at once now losing track if you are doing too many things
- Difficulties with memory, such as remembering details and common words
- Trouble learning new things

For some people ‘chemo brain’ happens quickly and only lasts a short time, for others it can be long term. It can be a result of your treatment, for example chemotherapy, radiotherapy or transplant but for others it might be something that was pre-existing. It has also been linked to other complications, such as low blood counts, medications, infection, mood or other illnesses. There has been evidence to support ‘chemo brain’ as passing in nature, one specific study demonstrated treatment related improvements one-year post bone marrow transplantation.

Practical tips for living with ‘chemo brain’:

An occupational therapist can recommend an intervention or strategy according to the symptom you are experiencing. Below are more generalised strategies and tips for managing ‘chemo brain,’ however if you are experiencing what you think is ‘chemo brain’ or any other form of cognitive changes please talk with your treating team.

Tips for managing difficulties with attention and concentration:
- Learn how to manage your fatigue, as this is going to enable you to focus and concentrate on what you are doing
- Try not to multitask; focus on one thing at a time, keep it simple, set specific time aside for certain tasks
- Focus your attention by minimising background noise, for example turn the radio or TV off in the background

Tips for managing changes with your memory:
- Use a detailed daily planner or your smart phone, as keeping everything in one place makes it easier to find the reminders that you might need
- Try to keep to a routine as best you can as this will help things to become habit, such as pick a certain place for commonly used objects (like keys)
- Write things down so that you can look back over them
- Don’t be afraid to ask people to repeat what they have said or to slow down
- Have a family member or friend come with you to appointments so that they also can hear the information and assist you in recalling the events of plans to come
- Track your memory problems in a diary, as this may help you to identify a pattern, for example certain periods within your treatment or certain times of day
- Do the most demanding tasks at the time of the day when you feel your energy levels are the highest, for example not leaving important conversations or bill paying till the end of the day if this is when you feel your foggiest

Other important things to note:
- Exercise your brain, for example take a class, do word puzzles, learn a new language or get family or friends to ask you about a book you have been reading or something you just read in the paper to test your recall.
- Get enough rest and sleep
- Eat a balanced diet
- Move your body, regular physical activity is not only good for your body, but also improves your mood, makes you feel more alert and decreases tiredness (fatigue).

Who should I talk to about it?

If you are at all concerned or feel that you are experiencing some of these ‘chemo brain’ symptoms, please talk with your treating team or your general practitioner. From here you may also be on referred to an occupational therapist for more specific assessment and tailored strategies to your individual needs.

Amy Oliver and Skye Hewitt
Senior Occupational Therapists
Fiona Stanley Hospital, Western Australia.

Try our Exercising the Brain crossword on the next page…
Crossword

Across
1. Pack tightly
5. Picks
9. Shine
14. Existence
15. Cats' feet
16. Soup dipper
17. Keen
18. Cleveland's waterfront
19. Infuriate
20. Agra attire
21. Pester
22. Athens' country
23. Made happy
25. Tavern orders
26. Ironed fold
28. Hooting bird
31. Scoffs
35. Intimate apparel
38. ___ dot
39. Train depot (abbr.)
40. Clumsy
41. Performance group
43. Girls
44. Pint-sized
45. Male pilot
47. Liability
49. A Great Lake
54. Restaurant
57. Army insect
58. Comic ___ Carvey
59. Amphitheater
60. Land unit
61. Drama divisions
62. Leases
63. Designer Christian ___
64. Actor Richard ___
65. Old hat
66. First garden
67. Love god

Down
1. Necklace part
2. Competitor
3. In flames
4. Radio and newspapers, e.g.
5. Can ___ (kitchen devices)
6. Formal procession
7. Tiny branch
8. Compass dir.
9. Blinding light
10. Highway divisions
11. Brim
12. Actor ___ Baldwin
13. Slight
22. Secluded valley
24. Beat it!
25. India's continent
27. Modify
28. Mineral deposits
29. Rub dry
30. Rents out
31. Gush forth
32. Naught
33. Otherwise
34. Supplement
36. Huge
37. Certain dashes
39. Cut
41. Portable lamp
46. Actress Marilyn ___
47. Fender nicks
48. Rub out
50. Old saying
51. Marathon runner
52. Preface
53. Desert stops
54. Wyatt ___
55. Length times width
56. Perfect scores
57. Tart
60. Citrus drink

answers on page 26
The MRDR has been collecting and interpreting healthcare information about the diagnosis, treatment and outcomes of myeloma, monoclonal gammopathy of undetermined significance (MGUS), plasma cell leukaemia and plasmacytoma in Australia and New Zealand since 2012.

**MRDR:** We now have 62 sites across Australia and New Zealand; with 50 approved and 12 pending governance approval. The latest sites to receive local hospital approval to participate are Sunshine and Royal Darwin Hospitals. It’s great to see the registry becoming more representative of all jurisdictions.

**The Myeloma 1000 project (M1000):** Recruitment to M1000 has reached over 480 patients with 14 approved and 11 active sites. This is a blood biobank substudy of the MRDR aiming to collect samples from 1,000 patients with multiple myeloma (MM) and 1,000 with MGUS.

**IMPROVE:** has reached its target of 300 patients registered! This is a substudy of the MRDR funded by the National Blood Authority to investigate immunoglobulin (Ig) use and infections in patients with MM in Australia, in order to improve national Ig stewardship. The IMPROVE blood biobank is still recruiting and welcomes more participating sites in Melbourne; a limited transport time restricts the zone of recruitment.

The Asia-Pacific MRDR now has 554 patients registered with 14 active sites in Korea, Singapore and Malaysia, and with further expansion to Taiwan, Hong Kong and China underway. This will allow benchmarking of Australian practice and outcomes against regional neighbors. This expansion project is funded by Janssen.

We are excited to announce that the MRDR has now accrued 4,000 patients! Thanks, and congratulations to participating patients and sites, this is a huge milestone and could not have happened without your support. Well done Wellington Hospital, where the 4,000th patient was registered on September 30!

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**Online Seminar Recordings**

One benefit of social distancing has been hosting all our seminars online. This has meant we’ve been able to create programs with experts from all over the country and broadcast them to anyone in Australia and overseas with a computer or smart phone and internet connection.

All events were recorded and you can now watch them on our website. Just go to [www.myeloma.org.au/seminars](http://www.myeloma.org.au/seminars)

If you have any questions about the information in these recordings, please get in touch with our Myeloma Support Nurses:

e: nurses@myeloma.org.au

t: 1800 693 566 (Mon – Fri 9am – 5pm AEDT)
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 preeminent experts in various conditions, 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.

At the very core of the ALLG is the delivery of world-class clinical trials and the dedication of our doctor members in producing research outcomes for patients with myeloma and other blood cancers. In October we conducted our second Scientific Meeting for 2020. The virtual event was a fantastic opportunity for all members to come together to discuss latest research findings. Our doctor members presented progress reports on current trials and discussed new areas to focus on for future research in Myeloma. The ALLG Scientific Meeting ran from Monday 12 October to Friday 16 October with a record number of 533 attendees, bringing ALLG Members, HSANZ Members, Staff, Sponsors and Foundation Supporters together as a blood cancer community. It was a fully packed five-day event for the Haematology community, with local key medical and scientific leaders as well as a broad range of guest and expert international presenters from all over the world. We welcomed to the Australia & New Zealand haematology community – Dr Katie Allen MP, Ajai Chari, Peter Borchmann, Gordon Cook, David Kurtz, and Konstanz Dohner.

We were thrilled to have Federal Liberal member Dr Katie Allen MP address the members live, in the opening session,
regarding current health affairs. She offered a tremendous amount of her time to answer questions from the members and it was certainly a well-attended session.

In addition, two sessions were conducted dedicated specifically to advance myeloma research in Australia. As highlighted by Myeloma Working Party member Dr Georgia McCaughan “We were fortunate to have Professor Gordon Cook from Leeds Cancer Centre, UK, kick off the Myeloma Working Group Plenary at the ALLG Scientific Meeting. He spoke about the rationale for the establishment of the United Kingdom Myeloma Research Alliance and discussed strategies to create a collaborative and inclusive research network, to engage and encourage new researchers and to build a successful translational research program”

The ALLG extended an invitation to the Myeloma Australia nurses from around the country to attend the myeloma plenary session to get up to date and latest news in myeloma treatments and clinical trials. This was a fantastic opportunity to hear from our leading doctors in this area, Hang Quach, Andrew Spencer and Peter Mollee. We look forward to continuing our collaboration with Myeloma Australia into the future.

ALLG Clinical Trials

Current Myeloma Trials

MM22 – leading doctor Prof Andrew Spencer

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


What’s New

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

MM23 – leading doctor Associate Professor Hang Quach

The SeaLAND trial will evaluate a new treatment option vs the standard maintenance therapy for post-autologous stem cell transplant patient. The trial is for patients with newly diagnosed multiple myeloma. This trial will be opening imminently with the aim to begin recruitment before the end of the year at 20 hospitals across ANZ.

MM24 – leading doctor Dr Simon Gibbs

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. 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.
As the ongoing COVID-19 continues to present challenges in all facets of society, clinical trials certainly have not been immune to this. Despite that, the AMaRC team have been able to continue to adapt to the evolving situation. We have been busy ensuring that our trials continue to recruit and operate as normal. In addition to operating our existing studies, we are currently in the process of developing three new myeloma trials and we will share details when it is appropriate to do so. Below is an updated list of our currently recruiting and upcoming trials:

**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 in order to identify optimal treatment for myeloma patients.

   **Recruiting hospital sites**
   - VIC – Alfred Hospital, Sunshine Hospital
   - NSW – Nepean Cancer Care Centre
   - QLD – Princess Alexandra Hospital, 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

**Upcoming Studies**

1. **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 new combination of belantamab, carfilzomib and dexamethasone to treat patients with relapsed/refractory myeloma. This study is expected to open in the next few months. The Alfred Hospital and St Vincent’s Hospital Melbourne will be the first two participating sites with more to open over the coming months.

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
Future direction for stem cell transplants?  
Daratumumab in transplant regimens for myeloma?  
Jean Luc Harousseau, Mohamad Mohty

https://ashpublications.org/blood/article/136/8/917/463240

When autologous transplantation is chosen for newly diagnosed myeloma patients, the standard pretransplant induction and posttransplant consolidation therapy is the triplet combination of lenalidomide, bortezomib, and dexamethasone (RVd). In this issue of Blood, however, Voorhees et al show that the addition of daratumumab to this regimen increased rates of stringent complete response (CR) and minimal residual disease (MRD) negativity at the end of consolidation. Because the safety profile of this new combination was acceptable, the authors state that this combination may be a potential new standard for transplant-eligible myeloma patients.

Post-transplant care:  
Recommendations for vaccination in multiple myeloma: a consensus of the European Myeloma Network

Heinz Ludwig, Mario Boccadoro, Pieter Sonneveld, Leukemia (2020)

https://www.nature.com/articles/s41375-020-01016-0

Vaccination is one of the most successful medical interventions that has saved the lives of millions of people. Vaccination is particularly important in patients with multiple myeloma, who have an increased risk of infections due to the disease causing immune suppression, and because of the immune suppressive effects of therapy. Hence, all appropriate measures should protect against common pathogens like influenza, pneumococci, varicella zoster virus, and to those bacteria and viruses (haemophilus influenzae, meningococci, and hepatitis) that frequently may pose a significant risk to patients with multiple myeloma. Patients after autologous, and specifically after allogeneic transplantation have severely reduced immune function, and therefore require a broader spectrum of vaccinations. Response to vaccination in myeloma often is less vigorous than in the general population, mandating either measurement of the postvaccination antibody levels and/or repeating the vaccination. This work aims to provide the necessary medical background and recommendations for an optimal vaccination strategy in myeloma patients likely to benefit from this important preventive measure.

Improvement in drug administration:  
Greater treatment satisfaction in patients receiving daratumumab subcutaneous vs. intravenous for relapsed or refractory multiple myeloma: COLUMBA clinical trial results


This trial evaluated the experience of those who received daratumumab as a short injection into the skin (subcutaneous) vs a long infusion into a vein (intravenous).

The results suggest patients in the daratumumab subcutaneous group were more satisfied with their cancer therapy than those in the daratumumab intravenous group.

Is the risk of second primary malignancy increased in multiple myeloma in the novel therapy era?  
A population-based, retrospective cohort study in Taiwan

Yanfang Liu, et al; Scientific Reports volume 10, Article number: 14393 (2020)

https://www.nature.com/articles/s41598-020-71243-z

Longer survival in patients with multiple myeloma (MM) after treatment with novel agents such as thalidomide, bortezomib, and lenalidomide may be associated with increased risks of developing second primary malignancies (SPM). There is little data describing the risk of SPM in patients with MM in Asia. The International Myeloma Working Group into SPM in myeloma found the overall risk of SPM in myeloma to be low. They feel the potential of SPM should not alter the treatment decision making process and previous estimates of SPM risk in myeloma are unlikely to be relevant in the modern treatment environment.

Quality of life in caregivers of patients with multiple myeloma

M. Graça Pereira et al; Journal Aging & Mental Health; Volume 24, 2020 – Issue 9,

https://www.tandfonline.com/doi/abs/10.1080/13607863.2019.1617240

This study aimed to assess the relationship between sociodemographic, clinical, and psychological variables with quality of life (Qol) and the moderating role of caregivers’ age and caregiving duration in caregivers of patients with multiple myeloma. 118 caregivers completed questionnaires that assessed psychological morbidity, satisfaction with social support, coping, burden, unmet
needs, and QoL. High psychological morbidity, burden and information, financial and emotional unmet needs were associated with lower QoL, while higher satisfaction with social support and more effective use of coping strategies were associated with better QoL. The relationship between caregivers’ psychological morbidity/social support and QoL was mediated by emotional needs and double mediated by coping and burden. The caregivers’ age moderated the relationship between psychological morbidity/social support and emotional needs.

This study found interventions supporting caregiver’s emotional needs to promote their QoL are needed. These should be particularly tailored to older caregivers who report greater psychological morbidity and younger caregivers less satisfied with their social support, as these issues have a negative indirect impact on carer’s QoL.

Editor comment: our Myeloma Support Nurses are available for carers to call on the Telephone Support Line 1800 MYELOMA Mon-Fri 9am-5pm AEST

Don’t Compromise Myeloma Care Due to COVID-19 Pandemic!

Nikhil C. Munshi1,2 and Kenneth C. Anderson1 , Blood Cancer Discov 2020;1:1–3
https://bloodcancerdiscov.aacrjournals.org/content/bloodcandisc/early/2020/10/16/2643-3230.BCD-20-0151.full.pdf

Patients with active myeloma, especially with earlier stages of the disease, are susceptible to COVID-19 infection and can have adverse outcomes, even in those on first-line treatment. Clinical features and outcomes of 100 patients with multiple myeloma and COVID-19 infection at five academic centres in New York City, which was the epicentre of the first wave of infection in the United States, were evaluated. Importantly, the emerging data suggest that myeloma therapy can be safely administered in patients with COVID-19 infection, and that optimal control of myeloma is associated with improved outcome of COVID-19 infection.

Physical Activity in People with Multiple Myeloma: Associated Factors and Exercise Program Preferences

Jennifer L. Nicol, Carmel Woodrow, Nicola W. Burton, Peter Mollee, Andrew J. Nicol, Michelle M. Hill and Tina L. Skinner

People with multiple myeloma (MM) often experience disease symptoms and treatment toxicities that can be alleviated through physical activity (PA). However, most people with MM are insufficiently active. This study looked at PA in people with MM, including differences by treatment stage, symptoms and demographics, and programming preferences. 126 people with MM (77% response rate) completed the survey. Pre-diagnosis, 25.4% were sufficiently active, with 12.0% remaining active after treatment. Respondents who were physically active pre-diagnosis were 46.7 times more likely to meet PA guidelines after their MM diagnosis compared to people not meeting guidelines pre-diagnosis. Experiencing MM symptoms and receiving PA advice from healthcare professionals were not associated with meeting PA guidelines. People with MM were interested in exercise programs (55%) that are low-cost (77%), offered at flexible times (74%), and at locations close to home (69%), both during active treatment and remission (57%), and supervised by an exercise oncology specialist (48%). People with MM, particularly those insufficiently active prior to diagnosis, should be offered convenient, low-cost exercise programs supervised by an exercise oncology specialist to increase their physical activity.

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

Support Line 1800 693 566 | MyeNews 23
**Common abbreviations used in Medical Corner**

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

**ASCT:** autologous stem cell transplantation

**BM:** bone marrow

**Consolidation:** short duration of treatment given after ASCT to intensify response

**CR:** complete response (no abnormal blood or urine myeloma markers, disappearance of any soft tissue plasmacytomas and < 5% plasma cells in BM)

**IMiD:** Immunomodulatory drug (ie lenalidomide, thalidomide, pomalidomide)

**Induction:** first line treatment after diagnosis for fast disease control with minimal toxicity

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

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

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

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

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

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

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

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

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

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

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

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

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

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

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

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

**Triplet:** 3 drugs used in combination

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

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**eBay – Online Shop**

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

Our online shop has a range of items that include greeting cards from renowned artist Patricia Ball and photographer Joe Rey, artwork by Patricia Ball that comes framed and ready to hang, first aid kits, sports memorabilia and promotional t-shirts from our iconic Masters of Rock event. Below is an example of our extensive range of items which can all be found at [http://myeloma.org.au/volunteer-with-us/shop/](http://myeloma.org.au/volunteer-with-us/shop/)
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 host small end of year get together 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/event-calendar/
For further information or help joining a group via Zoom, please contact your state Myeloma Support Nurse

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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

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**Information and Support Groups NSW**

- Central Coast
- Forster / Taree
- Liverpool
- Lismore
- Mid North Coast Cuppa and Catch-Up
- Newcastle
- Orange
- Regional NSW Cuppa and Catch-Up
- RPAH
- Tamworth
- Westmead
- Younger Persons

*For enquiries please contact*

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**Juliet Hill**
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M: 0433 511 554

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

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**Information and Support Groups QLD**

- Alderley
- Buderim
- Fraser Coast/Wide Bay
- Gold Coast
- North Lakes
- Princess Alexandra Hospital
- Younger Person
- Fraser Coast

*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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**Information and Support Groups SA**

- Carers
- Flinders & Southern Adelaide
- Fullarton & Central Adelaide
- Mid-North
- South-East
- South Australia
- Younger Persons

*For enquiries please contact*

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

**Alicia Hopper**
E: alicia.hopper@myeloma.org.au
M: 0426 716 165
Information and Support Groups TAS

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

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

Information and Support Groups VIC

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

For enquiries please contact
Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

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

Information and Support Groups WA

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

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

NATIONAL TELEPHONE SUPPORT GROUP
(CANCER COUNCIL NSW)

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

Cancer Council NSW
with MA NSW
Cancer Council NSW
1300 755 632
E: tsg@nswcc.org.au

You can also follow us on Facebook
www.facebook.com/MyelomaAustralia
Twitter twitter.com/MyelomaAust_MFA
for all updates and events.

Answers to the crossword on page 17
Myeloma Australia Staff 2020

Thank you to all the amazing staff at Myeloma Australia for their enthusiasm and care in this challenging year.
We could not have achieved all we have without them. Sadly we farewelled some of the team and wish them well on their new ventures. We look forward to a positive and healthy 2021.
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