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I attended the American Society of Hematology’s annual meeting (ASH) in Orlando in December along with our CEO Steve and the Myeloma Nurse manager, Nella. We were again the guests of the International Myeloma Foundation (IMF) who invited us to many of their sponsored events. These included the meeting of the International Myeloma Working Group (IMWG), their presentation night and their meeting of other support groups from around the world.

The IMWG is a group of about 250 physicians and scientists with a major interest in myeloma from around the world. They collaborate in research and trials and have published many papers in the medical journals. There are several Australian haematologists in this group who are working on research together with others from other countries. At this meeting short presentations were made about some of the latest research papers that were to be presented at the conference.

At the Global Myeloma Action Network (GMAN) meeting we heard about some of the services being offered by the other groups around the world as well as the challenges many are facing. We were able to share our experiences and hopefully help some of the smaller groups to solve their problems.

Each year the IMF holds a cocktail party where they present four patients who tell their personal stories about their diagnosis, treatment and hopes for the future. The IMF then present several awards to researchers for their work in myeloma. These awards are presented by members of the myeloma community who have raised the award money through their own fund-raising events such as fun runs or golf days.

We also had the opportunity to catch up with several organisations as well as attend some of the presentations on the research and development of new treatments being trialled for myeloma.

I have just caught up with our Patron and co-founder Robert Moran who has become very ill. We wish him all the very best and hope that his treatment will be successful.

Our first entrants in the Charity TV Global adventure have just completed their mystery trip and I hope that they all had a great time. Their entrance fee was to raise a certain amount of money for MA and I know that they all exceeded the minimum amount. I thank those of you who participated and your supporters for the twelve months of hard work. These funds are extremely important for the future of MA. We will let you all know when this show will be on TV.

Thanks to everyone who has made an online submission to the Pharmaceutical Benefits Advisory Committee about the new application going before them at the March meeting for another new myeloma treatment Plitidepsin (Aplidin®). They read all of them and they do take into consideration the messages received.

We are often offered new services that we can or should provide to help spread the support of MA. Our only problem is each extra service we add costs money and so to keep on increasing our reach and support we continuously need more funds. I understand that this is a bad time due to the horrible bushfires over the past few months and the desperate needs of those who have lost everything. Please remember us as well. We receive no government support and are totally dependent on your help.

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
Profile

Alicia Hopper
SA Support Nurse

Hi, my name is Alicia Hopper and I have just joined Jo Gardiner as Myeloma Support Nurse in beautiful Adelaide. I have been nursing for 18 years now, with 14 of those specialising in cancer nursing. I have a Bachelor’s degree in nursing as well as a Graduate Diploma of Nursing Science (cancer nursing). I have primarily worked in, as well as managed, outpatient oncology day units in public and private hospitals around Adelaide. I have also had some experience working in the inpatient haematology unit at the Royal Adelaide Hospital.

Most recently I have been working for a community organisation called Chemo@home who provide treatment for cancer and chronic-illness patients in their own homes. When I joined the SA branch of Chemo@home in 2017, we focused on treating people with myeloma. Seeing our patients week after week in the privacy of their own home meant I had a greater opportunity to appreciate and understand the complexity and impact that myeloma, its side effects and treatments has on individuals and families. It made me realise how important it is that people with myeloma have access to specific support and education to enable them to manage and live well with a treatable yet incurable disease.

Myeloma is a cancer that has touched my family personally as well. My mother-in-law Mary was diagnosed in 2000 in Melbourne and underwent a treatment journey that many others reading this would understand. She found the support groups and education services of Myeloma Australia to be of enormous benefit to her and enthusiastically supported the organisation.

In my personal time, I am passionate about exercise and am heavily involved in a community organisation called Parkrun. I hope to be able to combine my work with both organisations for the mutual benefit of both in the future! I am also a huge dog-lover and currently have one very spoiled golden retriever called Jemma, and would have more if only my husband would allow it!

I am so excited to be joining the Myeloma Australia team and look forward to meeting more of the community in South Australia in the coming months!

Alicia Hopper
Myeloma Support Nurse SA

Australia Day Honours

Brian Rosengarten OAM

When Brian Rosengarten’s wife Roslyn was diagnosed in 1996 with myeloma – a blood cancer that develops in bone marrow – and was told she probably only had three years to live, he looked for a support group for patients and their families, but there was none.

Two years later he co-founded the Myeloma Foundation of Australia, and has been its president since 2008, overseeing its expansion to having a branch today in every Australian state capital and Newcastle, helping thousands of Australians affected by the disease. For his service to community health, Rosengarten was recognised with a Medal of the Order of Australia (OAM) honour on Australia Day.

“Fortunately my wife survived and remains well, but I remember how it was a very difficult time back then because no support was available for myeloma, and there was a lot of false information about it around,” Rosengarten said. “We realised there was a need to provide education to our members, so that became a priority, and we also formed an advisory group of medical researchers and leading Australian haematologists.

“The Foundation started with one nurse with expertise in myeloma, and now it offers the services of 15 nurses around Australia who provide support and care for patients.” Rosengarten has also served on the board of Glen Eira-McKinnon Bowls Club for 14 years, including 10 as President, and is a recipient of a B’nai Brith Victoria Menorah Award, and a Paul Harris Fellow from Camberwell Rotary Club. Humbly accepting the OAM honour, he told The AJN, “I do voluntary work because there is a need for it… I’m very passionate about helping others.”

By Shane Desiatnik, Journalist

This article has been used with permission – originally published in the Australian Jewish News 30th January 2020
At Myeloma Australia, the Telephone Support Line (TSL) is one of our services we pride ourselves on, giving those with myeloma, family members and carers the opportunity to discuss concerns and ask questions in a confidential and personal manner with a specialist Myeloma Support Nurse.

Early last year, we conducted a survey over six months to see how we could further improve this service. Callers to the TSL were asked to complete a questionnaire after their call. The survey results gave us insight into the demographics of those who called, most common reasons for calling, along with how satisfied they were with the service provided, hence highlighting where improvements could be made.

109 surveys were sent out, of which we had 70 responses with 52 people fully completing the questionnaire. Majority of respondents were people with myeloma (79%), followed by carers / family members (19%) and health professionals (2%). Most (76%) were from metropolitan areas within Australia. Those with myeloma were mostly diagnosed between three and ten years ago, indicating a continued need for information long after the initial diagnosis.

Common reasons for calling were, for information about the disease and its effects, specific treatments and drug information, as well as assistance with accessing allied health and to request information on resources and support groups.

Our TSL was considered unique compared with other sources of information, primarily for the access to an experienced myeloma nurse and adequate time to talk and ask questions.

We were delighted to see that most callers (94%) said they had their needs met during the call and that they would use our service again if required. Those whose needs were not fully met, said not all their questions were adequately answered during the call. This highlights the importance of continuing to provide ongoing training, education and support for all TSL staff to ensure our nurses have or have access to up to date knowledge of myeloma and its treatment, in an environment which is changing rapidly in terms of access to new treatments and clinical trials. To this end, the nurse taking calls has a senior nurse available as a resource and, where needed, follow up the caller with more detailed information.

We found that of those who’s call was answered by head office staff, 13% were not satisfied with the time it took the nurse to return the call. To address this, all calls are now answered directly by the TSL nurse. We have had a great response to this change and will continue this way of delivering the service. Some callers would value having access to the TSL on the weekend, however we are still currently unable to offer this service outside of Monday to Friday 9am-5pm AEST. We have expanded our service to cover some public holidays because we have nurses in each state who can take calls when not a holiday in their state. As our services and team continue to grow, we will continue to consider ways to increase the TSL availability.

This survey gave us good insight into the callers of the Telephone Support Line and revealed that respondents valued the service. We sincerely thank those who participated by completing the survey.

We will continue evaluation of our TSL service to ascertain how it meets the needs of the myeloma community in a changing myeloma landscape. We wish to explore in greater detail, the reasons people call, as many calls covered quite varied aspects of living with myeloma. We would like to work with our community to develop a survey and would be grateful for any volunteers to help design the next survey. However, until then if you do want to leave comment about the TSL or any of our other services, please do, your feedback is vitally important to us.

Nella Combe  
Manager Nursing & Patient Services  
& Samantha Zeps  
Support Services

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.
Many within the Myeloma Australia community will be aware of our partnership with Charity TV Global over the past 15 months as we worked towards filming an adventure holiday for the Myeloma Australia Ambassadors who raised money for us throughout 2019.

The reward for the Ambassadors was a trip down the Great Ocean Road in Victoria between 3rd and 7th February this year. The trip was filmed and will be screened on Channel 7 Two later this year.

Our very first Ambassadors signed up in late 2018 with others joining throughout 2019. Three Ambassadors were ultimately unable to make the trip due to their health and other people raised funds for Myeloma Australia throughout last year but chose not to come on the trip.

So, it was with equal measures of excitement and trepidation that our six Ambassadors, Sam, Racheal, Mark, John, Jo and Mario gathered together on the morning of Monday 3rd February to embark on an adventure that CEO Steve and I had been planning for 12 months! All the activities the Ambassadors embarked upon were kept Top Secret from the Ambassadors – to see their surprise, shock, horror, awe etc as we revealed each activity was one of our crew’s highlights of the week! The Ambassadors were joined by a support crew of four people from Myeloma Australia alongside the film crew of five.

So, what exactly did our Ambassadors get up to? Well, they sailed on the tall-ship Enterprize out of Docklands, Melbourne and would have got as far as Geelong if the weather had proved to be a little kinder! As it was, more than challenging conditions saw the ship turn around to dock at Williamstown. Quite a start to the adventure; all Ambassadors were clearly relieved to be back on terra firma! A tour of the fascinating Fort Queenscliff concluded Day one.

Day two commenced with Ambassadors being taken by motor-trikes down The Great Ocean Road – this scenic tour proved to be one of the favourite activities of the week. The Ambassadors were driven to Otway Fly in the Otway State Forest where they undertook an afternoon of zip-lining. It takes a considerable amount of courage to zip-line … and all Ambassadors embraced the challenge whole-heartedly. The night of Day two was spent in teepees in Apollo Bay thanks to our friends from Teepee Tours; this proved to be a truly unique experience!

The third day saw the Ambassadors taken on a surfing lesson at Lorne followed by a serious horse-ride through the bush and onto the beach at Aireys Inlet.

Day Four saw the Ambassadors donning flying goggles as three Cirrus aircraft took them up, up and away from Colac Airport and provided them with a bird’s eye view of The Great Ocean Road, including The Twelve Apostles, prior to landing at Lethbridge Airport (near Geelong).
I trust that some of the accompanying photos speak louder than words than the printed page can.

We are already working towards our next Adventure with Charity TV Global (to be filmed no earlier than 2021) and I am now inviting expressions of interest from interested parties for consideration for this Adventure. If the concept of raising awareness and funds for Myeloma Australia alongside embarking on the adventure of a lifetime appeals to you, or those within your networks, do please drop me a line!

Matt Maudlin  
Community Engagement & Fundraising Manager

The final night was spent at Big4 Beacon Resort in Queenscliff where Ambassadors enjoyed massages at Mud Day Spas.

The morning of Day five was back on and in the water as Ambassadors had a swim and frolicked with seals and dolphins just off the coast of Queenscliff. The adventure concluded with a sedate ferry crossing from Queenscliff to Sorrento prior to bags being unloaded back at Myeloma Australia HQ in Swan Street, Richmond.

It really was quite the week! The film crew are now busy sorting through their footage to create what I am told will be ‘the best 43 minutes of TV this year!’ The show, Adventure All Stars will be shown on TV later this year. I will ensure that the myeloma community is informed of when the show goes to air. Prior to it being shown on TV we will have the opportunity to show the finished film as community building/fundraising events in cinemas; and again, I will keep you all abreast of these developments.

The adventure was memorable in so many ways. I am aware that words alone do not do justice to the community that evolved during the time away.

Photos © Charity TV Global

Surfing Group

Photos...
1 Mario
2 Mark
3 Rey & Sam
4 Rey
5 Ship Group
6 Swimming with the Dolphins
7 Teepee
8 Trike Group
Caring for the whole person and not just the disease – the value of holistic supportive care

When it comes to supporting people living with multiple myeloma, it is vital that we look at how we can care for the whole person, at all stages of the disease and the impact the disease and its treatment has on that person.

Sounds simple and straight forward really, and common sense, yet this is sometimes an overlooked component of medical care. As we have made incredible inroads into keeping people living longer with a cancer diagnosis, we are increasingly in need of looking at how to keep those same people living well. And hopefully not just living, but also thriving.

This is where supportive care takes a role in care. The Multinational Association of Supportive Cancer Care, MASCC has defined supportive care as “the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to supportive care.”

It is a multidisciplinary approach to keeping people well.

Another growing approach to supportive cancer care incorporates evidence based complementary medicine and holistic medical assessment into cancer care. This is often now referred to as ‘Integrative Oncology’, ‘Integrative Medicine’ or ‘CIM’ and the most recognized definition, published in 2017 by the Society of Integrative Oncology (SIO) is:

“a patient-centered, evidence-informed field of cancer care that utilizes mind and body practices, natural products, and/or lifestyle modifications from different traditions alongside conventional cancer treatments. Integrative oncology aims to optimize health, quality of life, and clinical outcomes across the cancer care continuum and to empower people to prevent cancer and become active participants before, during, and beyond cancer treatment.”

So how do we turn these definitions and words into a practical and helpful approach to restoring wellbeing and empowering patients to make significant lifestyle changes to stay living well?

Well it often starts with the recognition that there is something that you can do to improve and maintain wellbeing. The most common complaints of patients I see with multiple myeloma are fatigue, poor sleep, bone pain, peripheral neuropathy, anxiety and depression sometimes related to fear of recurrence. Sometimes nausea and loss of appetite also feature here too.

It is this frequent cluster of symptoms, symptoms that occur together that we address as part of caring for the whole person, focusing on a person-centered approach. I look at how we can design a program of care and support to address one’s wellbeing, looking not just at medical interventions but also other interventions and safe use of herbs, supplements, nutrition and lifestyle modifications.

At Chris O’Brien Lifehouse, in collaboration with researchers from the University of Sydney, we run the bone marrow transplant pre-habilitation and rehabilitation program, with a focus on exercise. This has really been highly successful and empowering. Our exercise physiologists work to improve wellbeing. Guest speakers talk about other therapies and aspects of wellbeing and there is access to evidence based complementary therapies like acupuncture, oncology massage, yoga, mindfulness meditation and more. The program has really been successful and as with all of our programs in our supportive care and integrative oncology service we look to empowering patients to build and maintain a strong and healthy mind and body.

As a doctor and director of the service, I have become very passionate about how we can work to improve the wellbeing of every person living with and after cancer. I strongly believe that there is always something we can do to try to improve the lives of the person with multiple myeloma: to enhance one’s approach to living well with and after treatment. I know I share these views with my close-knit multidisciplinary care team and we look forward to continuing to be available to provide this holistic supportive care to haematology patients through the services we provide in the ‘livingroom’ at Chris O’Brien Lifehouse.

For those of you not living close to our Centre, it is important to seek out support programs in your area and discuss programs available with your local treating team.

A/Prof Judith Lacey
Head of Supportive Care
Chris O’Brien Lifehouse
Mix in a little music and maybe a comedian. Find a perfect room and fill it with business and professional people, their friends and families. And there, you have it!

So, who will be our on-stage guests at the 2020 Winners’ Lunch? We are delighted to report that this year’s panel is right up there with the very best of the luncheon’s two-decade history – every one of them a star and needing no introduction – Leigh Matthews, Peggy O’Neal, Peter Hudson, Chelsea Roffey and Gareth Andrews with your MC for the afternoon, Graham ‘Smokey’ Dawson.

It’s a tribute to the great reputation of our luncheon and its mission to support Myeloma Australia. It will be – again – “the best ever…”. It is humbling to know that the sporting personalities that make up each year’s on stage panel generously provide their time and service free of charge.

Won’t you join us on 3rd April? Or if the lunch is not for you, please spread the word to your networks. You will be supporting the mission of Australia’s unique myeloma support organisation, Myeloma Australia.

Peter Allen OAM, Director, Myeloma Australia

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**The Business of Winning Luncheon turns 21!**

**April 3rd in the MCG Members’ Dining Room**

When we’re told (and it happens every year) that the “Winners’ Lunch” – a joint venture of Myeloma Australia and the Rotary Club of Camberwell – is the best corporate lunch in town we know that we are doing something right.

History shows that we’ve be doing it right since 1999 when Melbourne’s great TV personality Ron Casey stepped onto the stage at what was then the Sheraton Hotel at Melbourne’s Southbank and announced “This is a lunch called the Business of Winning”. He then introduced an awesome line-up of sporting stars – AFL coach Dennis Pagan, champion jockey Roy Higgins, boxer Michael O’Malley and test cricketer Max Walker. A great day was in store.

It was – and still is – a simple formula. Provide a first-class lunch with fine wines and a small panel of sports personalities from the Who’s Who of Australian sport.

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**THE BUSINESS OF WINNING LUNCHEON**

**Friday 3rd April 2020, 12 noon**

in the MCG Members’ Dining Room

**with Leigh Matthews AM • Peggy O’Neal AO • Peter Hudson AM • Chelsea Roffey • Gareth Andrews**

*Book online at TryBooking: https://www.trybooking.com/BIKGD*

**Single ticket price is $160. Tables of ten $1600**

*(GST does not apply to this fund-raiser)*
RECRUITMENT UPDATE

Myeloma and Related Diseases Registry (MRDR)

Enrolment to the MRDR has come along in leaps and bounds, with a record 853 patients recruited in 2019 and the addition of multiple new sites. We now have over 3400 patients participating, with 54 sites across Australia and New Zealand; 43 approved and 11 pending governance approval. The latest sites to join the registry are Townsville Hospital, Launceston General Hospital, and Lyell McEwin Hospital in Adelaide. It’s great to see the registry becoming more representative of myeloma and related diseases in Australia and New Zealand; a big thank you to everyone contributing to the registry for all your work and support.

The Myeloma 1000 Project (M1000)

Recruitment to M1000 has reached over 400 patients, with 113 patients recruited in 2019. This is a blood biobank substudy of the MRDR aiming to collect samples from 1000 patients with multiple myeloma (MM) and 1000 with MGUS.

RESEARCH

Registry Projects

The MRDR had a year of increasing research growth in 2019. Several new investigator-initiated analyses using MRDR data or infrastructure are at different stages of development in areas including: timing of treatment and outcomes of patients with biochemical relapse in MM; use of bortezomib-based therapy in non-transplant eligible patients; comparison of characteristics and outcomes of patients diagnosed with MM by traditional criteria versus ‘newer’ biomarkers of malignancy; treatment patterns and sequencing; and regional outcomes in MM. Please visit the MRDR website for a list of projects. We welcome proposals for projects using registry data.

MRDR AT ASH

Professor Andrew Spencer represented the MRDR at ASH in Orlando, USA in December. This is a key global meeting of the American Society for Haematology. Prof Spencer presented on outcomes for MRDR patients with MM and early progression or sub-optimal response to treatment. This analysis is being worked up for publication.

IMPROVE

IMPROVE is a substudy of the MRDR funded by the National Blood Authority. This study aims to investigate infections and immunoglobulin (Ig) use in patients with MM in Australia, and provide information to improve national Ig stewardship and patient outcomes. The IMPROVE blood biobank is recruiting and welcomes more participating sites in Victoria; a limited transport time restricts recruitment to within this state.
Community Engagement & Fundraising

I start this first update of 2020 by informing you that our NSW Community Fundraiser, Santosh Ojha, has now left us as he has moved on to seek new adventures. Anyone who has come into contact with Santosh will know what a diligent, hard-working and kind individual he is. He will be missed. All of us here at Myeloma Australia wish Santosh every success in his future endeavours. We are currently in the process of finding someone to replace Santosh as NSW Community Fundraiser.

The year has started with a bang with several members of the Myeloma Australia community contacting me to talk through fundraising concepts. 2020 is shaping to be yet one more year when we take significant steps forward in the community engagement and fundraising areas of our operation.

CEO Steve and I have recently returned from a week of filming our Ambassadors as they undertook an adventure that was filmed by Charity TV Global and will be shown on commercial TV later in 2020 – there is an article about this elsewhere in this edition of MyeNews.

Details of the first major Team Myeloma fundraising walk/run of the year, the HBF Run for a Reason in Perth on Sunday 24th May will be up soon on our Facebook page.

Do please consider supporting Myeloma Australia through purchasing The Entertainment Book – this book offers great value for money and is one more way in which funds come into our organisation.

Much of my attention now turns to our signature, annual fundraising event, The Business of Winning Luncheon at the MCG on Friday 3rd April. Though I say so myself the panel of guests this year is really extraordinarily good! I hope that I will see many of you at the Luncheon this year.

As always, if you have community engagement and fundraising ideas that you would like some help exploring do please drop me a line – I love hearing from you all and seeing your ideas come to life!

Kind regards,

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

CENTRAL COAST MYELOMA SUPPORT GROUP
ANNUAL MOVIE FUNDRAISER
March 19th 2020

Tickets still only $25 includes a glass wine/soft drink and nibbles.
A huge array of raffle prizes to be won on the night.
6pm nibbles for 7.30pm movie
Tickets available from Wendy Ball: 0419280760 or Cancer Day Unit
Tickets also available at: https://www.avocabeachpicturetheatre.com.au/
Happy New Year from the NSW team. As you may have read in the recent Myeloma Muster we are slightly depleted in the Parramatta office after the departures of Geo and Santosh. I would personally like to thank both of them for all their hard work and commitment to Myeloma Australia and wish them well with their new endeavours.

We are currently recruiting for the Myeloma Support Nurse position so hopefully by the next edition of MyeNews I will be introducing our newest team member. In the meantime, I will do my best to hold the fort and please don’t hesitate to get in touch if I can be of any assistance.

Our face to face Information and Support Groups are starting to meet again and we are currently investigating topics for discussion and inviting speakers for the year. The Liverpool group met last week and Dr Silvia Ling gave an excellent update on ‘Immune Therapies and Myeloma’. At Westmead next week we have Dr Chun Kei Kim Ma a haematologist from Westmead Hospital who will be giving a brief update from the ASH 2019 conference and our new Younger Persons group is due to meet at the end of February as well. There are obviously many other groups meeting so please check the website for details or get in touch. As always, we welcome any feedback or comments you may have.

The Myeloma Telephone Support Group also continues for 2020. This group is run in conjunction with the Cancer Council NSW. As the name suggests this is a telephone group available for any person living with myeloma wherever you may live. It is a free service and all you need is access to a phone and a quiet space. The groups meet on the 2nd and 4th Monday of the month. In 2019 we held 18 groups and currently have 14 people registered for the group. On average six people joined the group on a regular basis. Please get in touch if this is something that interests you.

We are busy planning events and seminars for 2020 including those during National Myeloma month (May) so please check the website and your emails and letterboxes for flyers about upcoming events. Our Sydney event in collaboration with Leukaemia Foundation and The Royal Prince Alfred will be on Friday 15th May so keep that date free if you are interested in attending. More details will be available nearer the time.

News from Newcastle:

It is hard to believe that we are almost halfway through February already!! The end of 2019 saw many members of our support groups affected by the bushfires and the continuing drought. It is wonderful news to see some areas in much need of rain to receive some over the past few weeks, ensuring most of these fires are out, filling dams and water tanks. 2020 is shaping up to be another positive year for Newcastle and surrounding areas. We are looking forward to our Forster Taree Information and Support Group on the 27th February in Forster with exercise physiologist Deanna Parvin presenting on staying active during treatment. Our Newcastle group have changed our meetings to Friday this year. Our next catch up is at Club Charlestown on the 6th March 10.30am-12.30pm. We are busily preparing our Myeloma Awareness Month seminar for May and are hoping to live stream the RPA seminar to some regional areas which is very exciting. Speaking of exciting news – our Newcastle nurse Rachel and her fiancée Matt were married on the 8th February in her hometown of Warrnambool, Victoria. From all of us here at Myeloma Australia we wish Rachel and Matt a wonderful future together.

Jacqui Keogh
NSW Manager & Myeloma Support Nurse

Entertainment Book

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

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

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

Hurry, Entertainment Memberships sell out quickly.

For more information contact Matt Maudlin
Community Engagement & Fundraising Manager
E: matt.maudlin@myeloma.org.au • M: 0407 891 052
Wow! Hard to believe it’s getting to Autumn (at the time of writing). In Queensland we have been consolidating our work from last year with our Information and Support Groups. We now have core groups of people at all sessions and it’s lovely to see you all whenever we meet. We are trying to get our heads around the vastly populated state we live in and how we can support you all. Megan has held a couple of Meet and Greets up at Hervey Bay and will continue to do so throughout the year—watch out for announcements in The Myeloma Muster. Tash will continue to find a way to support Toowoomba and foster relationships up there. We have embraced technology to support our fabulous Buderim group and we have connected remotely for a couple of meetings, with great success. Unfortunately, this is only possible at venues that support the technology and is something Myeloma Australia is investigating at an organisational level. Just before Christmas, Megan visited Lismore and had a very productive catch up with health professionals and patients. Megan will continue to work with our NSW team to support this area of Australia. To those of you who live in regional areas, we are aware of your unique set of circumstances and would love to hear of any problems you would like addressed or any ways in which we can support you.

In February, we held a seminar at The Gold Coast University Hospital. We had a great turnout and people came from far and wide. Thank you so much to Mary-Lou and Ingrid who volunteered their time and helped with registrations and packing up. Dr Michelle Bryson from Gold Coast University Hospital gave a fantastic overview of myeloma and its challenges. She was followed by Dr Kwong Chan from Griffith University who discussed the challenges of coping with a myeloma diagnosis. Dr Chan was very entertaining but also has an interesting vision of life and death. He spoke a lot about the difficulties and uncertainties with a myeloma diagnosis and how life can feel like a roller coaster, particularly from one appointment to the next. We are very honored to have such busy and capable people volunteering their time to speak to us and share their specialist knowledge.

We are now turning our attention to more seminars in the year and particularly National Myeloma Day, which as always, will be done in collaboration with the Leukaemia Foundation. We look forward to seeing you all as the year goes on and continue to work together to support those affected with myeloma.

Tash Clarke and Megan McDowell
Myeloma Support Nurses QLD

Team Myeloma T-shirts for Sale

$25 each
Sizes S - 2XL

Via head office: 1300 632 100
or the eBay shop:
With the start of the new year SA has also welcomed a new Myeloma Support Nurse, Alicia Hopper, to provide and expand our services to our myeloma community in South Australia. Alicia started work on 15th January and hit the ground running, meeting everyone at the South Metro Support Group the following day. We had a great talk from exercise physiologist, Sarah Harfield, from the local Marion physiotherapy centre. She described the benefits of increased mobility and exercise, especially on fatigue, walking and balance in the Next Steps Cancer Rehabilitation program. The 8-week course is free and available nationally through the Pinc & Steel website: https://au.pincandsteel.com/

In early February, Alicia attended the open day of the new Cancer Wellness Centre (located in the Flinders Cancer Innovation Centre at Flinders Medical Centre). The centre hopes to become the focal point of a new cancer wellness program, as well as help ease the burden of cancer and address many of the unmet needs of patients and their families during and after cancer treatment. Alicia was able to provide information about myeloma and our services that can now be accessed through the centre.

In February, Jo was part of the support team to our myeloma Ambassadors filming the Adventure Allstars Charity TV program along the Great Ocean Road. A personal highlight for Jo was meeting one of our interstate myeloma community members, Fred Carter. Fred, along with his mate Stewart, flew his Cirrus light plane from Toowoomba to take our ambassadors on a scenic flight over the coast. Such a generous gesture and a beautiful recognition of the importance of the nursing-led services that Myeloma Australia provide. Thank you so much Fred! This was one of many great moments during the week. Our ambassadors and the film crew were all such lovely people, who formed wonderful bonds and friendships during their week together.

We held the Central Metro SG on the 12th February where we heard from Amanda Catherwood, Red Cross Blood Service BloodSafe nurse about how blood products are used to support some myeloma patients. This week Alicia and I are driving to Mt Gambier for the South East seminar, then on to head office in Melbourne for planning and orientation for Alicia.

This year we will be holding tours of both myeloma research facilities in Adelaide. We are arranging for tours of Professor Andrew Zannettino’s Myeloma Research Laboratory based at SAHMRI in June and Dr Craig Wallington-Beddoe’s Multiple Myeloma Translational Research Laboratory and Clinical Trials Unit at Flinders Centre for Innovation in Cancer in September. Numbers will be limited, so we will be asking for expressions of interest a bit later in the year.

In addition to our regular Information and Support Groups we are planning an educational seminar on myeloma for nurses and allied health professionals in conjunction with the SA Cancer Nurses Society of Australia to be held in May, as well as the Myeloma Month Awareness Annual Seminar which will also be held in May.

Jo Gardiner
Senior Specialist Myeloma Nurse/Myeloma Support Nurse SA/NT

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
What’s happening TAS

What will 2020 bring for those of us in Tassie? Hopefully a greater friendship base for those with myeloma and their loved ones as they meet and share experiences.

A few people, including myself, were lucky enough to get away over Christmas and it was good to share stories about the holiday period at our first two Information and Support Groups of the year, in Bellerive and Burnie. There were new guests at both venues. We welcome you warmly and hope you keep coming! It’s great to share knowledge and there is always something new to learn. We discussed how we stage myeloma and that brought up further discussion and an idea for future groups - examining blood and lab tests. It is very heartening to see how well the groups are coming together, to see animated conversation and to hear laughter resonate around.

For the rest of the year, plans are afoot in conjunction with the Leukaemia Foundation, for our National Myeloma Day in May, and this year we are proposing it is held on the Eastern Shore. We are hoping to run two further seminars later in the year in Launceston and the north-west. Otherwise our groups will continue to roll out each month, on the first Tuesday in the south and either in Launceston or the north-west on the second Tuesday.

I am looking forward to meeting familiar and new faces throughout the year.

Until then…

Deborah Thompson
Myeloma Support Nurse TAS
Happy new year to all. I hope you enjoyed your Christmas and New Year with your families and friends. It's been a busy start to 2020. Sadly, we said goodbye to Elli Foley and thank her for all her hard work over the last couple of years. She will be greatly missed by our team but we wish her all the best with her full time role as a myeloma nurse consultant at the Alfred Hospital. We are welcoming back Laura Jones from maternity leave during the month of February. I know a lot of you are excited to see her again after welcoming her baby boy into the world.

I have been busy planning and organising lots of great speakers for the year ahead to come along to our information and support groups. We will also be forming a brand-new group in Horsham. With the support of the local Rotary group this will also be run using Zoom technology. This is very exciting as we will now be able to reach more of our community and we look forward to working with Rotary to capture more groups in the future.

In February we held our annual Monash Myeloma Seminar at the Monash Hospital. At the event we discussed Myeloma, Supportive Care in Myeloma and Updates from ASH in Myeloma and the seminar was a great success with many people attending to hear from the excellent speakers from the hospital and from individual experiences of living with myeloma.

Have a great year ahead and best wishes.

Emma-Jane Furphy
Myeloma Support Nurse VIC

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**What’s happening VIC**

Rotary group this will also be run using Zoom technology. This is very exciting as we will now be able to reach more of our community and we look forward to working with Rotary to capture more groups in the future.

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Have a great year ahead and best wishes.

Emma-Jane Furphy
Myeloma Support Nurse VIC

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**Marmalade Gardens**

If you are looking for something unique and beautiful for that special person in your life, Marmalade Garden handcrafted jewellery is the perfect gift.

*In support of her mother who was diagnosed with myeloma in 2007, Marnie will donate $1 from every online sale to Myeloma Australia until the end of 2020.*

[https://www.marmaladegardens.com/](https://www.marmaladegardens.com/)
Happy new year to everyone in the WA myeloma community and beyond. I am solo reporting this quarter as Kerin has snuck away for a well-deserved holiday and I have been flying the flag for Myeloma Australia here in the West. As is often the case, the end of a year allows time for reflection and I certainly feel as though we are providing support to increasing numbers of people affected by myeloma in the community, but we are always keen to do more.

Towards the end of the year, we rolled out a referral form for healthcare professionals to use within clinical settings and in clinics to give access to Myeloma Australia and its support services. Initial feedback has been positive and we are hoping that more clinicians will become aware of the form over the coming months as we continue to promote and distribute it.

Our Information and Support Group program for 2020 began with our first Younger Persons Information and Support Group for the year in January and we will continue to hold these evening meetings at the Cancer Wellness Centre in Cottesloe every two months. This group is suitable for anyone who finds it easier with work and appointment constraints to attend an evening support group and we welcome new members to come along.

Our Northern Suburbs Information and Support Group has moved to a larger room within the Wanneroo Library and Cultural Centre this year to accommodate the increasing numbers attending and we were all very happy to see the coffee and tea facilities within the room. For future groups, we will have a speaker or presentation from a Myeloma Support Nurse at the beginning of each meeting to address the common issues raised by the group.

Our Perth Hills group was held on Monday 17th February 2020, it was great to see many faces returning from last year. The Zig Zag Cultural Centre in Kalamunda is a lovely venue and we are looking forward to our first meeting there for 2020. The first meeting for the South Metro was held in February in the Honeyeater Room at the Mary Davis Library.

Finally, we have re-established our collaboration with the Leukaemia Foundation to host the South West support group in Busselton which will be held at the Busselton Community Resource Centre. New members are always very welcome to attend and similar to the North Metro group, we plan to have invited speakers along to present at each of the meetings in 2020.

Our first Information Seminar was held on Monday 24th February with two fantastic speakers coming along to present to our WA community. Consultant haematologist, Dr Dejan Radeski outlined myeloma and discussed some of the rarer forms of myeloma as well as answering questions from the audience. Dr Alissa Jacobs, a consultant dentist and research fellow at the University of Western Australia shared her knowledge about oral care in myeloma. We are so lucky to have such experienced clinical specialists offer their time.

Our first Coffee and Chat for the year will be held on the 20th March 2020. This is a free, informal drop-in event with both Kerin and I in attendance to chat or answer any questions you may have. As nurses, we have found these events to be especially enjoyable as they foster the supportive myeloma community that exists here in Perth. If you are unsure whether to attend a Myeloma Australia event here in Perth, please consider coming along to this Coffee and Chat session and you will be warmly welcomed.

Upcoming events in the planning phase include the National Myeloma Month Information Seminar in collaboration with Leukaemia Foundation, a wellness workshop, and an advanced Myeloma Information Seminar for health care professionals following on from the success of our introductory seminar in April 2019. Watch your email and post boxes for flyers with further information about each of these events in the coming weeks and months.

On behalf of Kerin and myself, thank you to the WA myeloma community for your ongoing support. We look forward to seeing you at one of our events soon.

Narelle Smith
Myeloma Support Nurse WA
T(11;14) and high BCL2 expression are predictive biomarkers of response to venetoclax in combination with bortezomib and dexamethasone in patients with relapsed/refractory multiple myeloma: biomarker analyses from the phase 3 BELLINI study
Authors: Harrison S et al.; 61st ASH 2019 Annual Meeting and Exposition Conference Review - Focus on multiple myeloma; Abstract #142; www.researchreview.com.au

2 subgroups with the greatest PFS improvement were t(11;14) chromosomal abnormality and high BCL2. Among patients with t(11;14) or high BCL2, median PFS was not reached with venetoclax versus 9.9 months with placebo. Venetoclax also had higher rates of overall response (88% vs 70%), very good partial response or better (73% vs 33%), and complete response or better (42% vs 3%). Overall survival (OS) in the t(11;14) negative and low BCL2 subgroup favoured placebo (HR 3.13; 95% CI 1.2-8.13; p = 0.019). Comment (A/P Hang Quach): In March 2019, the FDA placed a hold on all venetoclax studies in MM based on results from this BELLINI study which showed increased treatment-emergent deaths (TED) with venetoclax plus bortezomib and dexamethasone compared to bortezomib and dexamethasone (21% vs 11%). Here, a subset analysis showed remarkable efficacy of venetoclax plus bortezomib and dexamethasone in patients with t(11;14) or high BCL2, with a 91% and 74% relative risk reduction in progression or death in favour of venetoclax plus bortezomib and dexamethasone, in each group, respectively. In contrast, in the non-t(11;14)/low BCL2 group, while PFS was similar between the venetoclax plus bortezomib and dexamethasone and the bortezomib and dexamethasone group, there was a trend for inferior OS in the venetoclax plus bortezomib and dexamethasone arm (HR 1.52), presumably due to increased TED in this cohort. Of note, the story of TED with venetoclax plus bortezomib and dexamethasone is not quite straightforward. While the imbalance in TED was attributed to increased infections in the venetoclax arm, many deaths occurred late and at the time of progressive disease. In addition, the reason why infection-related (not progression-related) deaths should occur with venetoclax more so in the non t(11;14)/low BCL2 subgroup as opposed to across the board remains unclear, and indicates that there may be some interplay between venetoclax and t(11;14)/BCL2 from an immunological perspective, over and above the pro-apoptotic effect on MM cells. There is no doubt that venetoclax will be a game changer for patients with t(11;14)/

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

Edited by Jo Gardiner, Senior Specialist Myeloma Nurse

Clinical efficacy of daratumumab, pomalidomide, and dexamethasone in patients with relapsed or refractory myeloma: utility of re-treatment with daratumumab among refractory patients
Authors: Nooka AK et al. Reference: Cancer 2019;125:2991–3000; reviewed in issue 32 of Multiple Myeloma Research Review.
Summary: The utility of retreatment with daratumumab among refractory patients, as well as in naïve patients, was retrospectively analysed in 34 patients with MM treated with combination daratumumab, pomalidomide and dexamethasone. All the patients had received prior therapy with immunomodulatory drugs and proteasome inhibitors, and they were divided into cohorts based on their prior exposure to daratumumab and pomalidomide. Cohort 1 (n=12) comprised patients naïve to both daratumumab and pomalidomide. Cohort 2 (n=22) included patients who were refractory to daratumumab and/or pomalidomide when treatments were received individually and included a subgroup (cohort 3) of 12 patients who were refractory to both agents. Patients naïve to daratumumab and pomalidomide treatment had an ORR of 91.7% and included four stringent complete responses. At a median 41 months of follow-up, this group had not reached median PFS duration. Cohort 2 had an ORR of 40.9% and a median PFS duration of 3.2 months. Cohort 3 had an ORR of 33.3% to the combination therapy, with a PFS duration of 2.5 months. Comment (Ken Romeril): This is a small study that has been around for a while and was first presented at ASH 2016 in San Diego. The extremely good PFS benefit certainly shows the benefit of adding a monoclonal antibody to any regimen, and this even worked in people who had exhibited prior refractoriness to both daratumumab and pomalidomide. It is an attractive triplet that may mean that a quadruplet regimen may not be required.

Response to first cycle is the major predictor of long-term response to lenalidomide and dexamethasone therapy in relapsed and refractory multiple myeloma: can we spare patients the toxicity and costs of additional agents?
Summary: Patients with relapsed or refractory MM who had a good response (PFS >24 months) to lenalidomide plus dexamethasone salvage therapy were identified and characterised in this research; 227 patients with evaluable data from three tertiary-care hospitals were identified. A

Response to first cycle is the major predictor of long-term response to lenalidomide and dexamethasone therapy in relapsed and refractory multiple myeloma: can we spare patients the toxicity and costs of additional agents?
Summary: Patients with relapsed or refractory MM who had a good response (PFS >24 months) to lenalidomide plus dexamethasone salvage therapy were identified and characterised in this research; 227 patients with evaluable data from three tertiary-care hospitals were identified. A
multivariate analysis revealed that the main independent predictor of PFS > 24 months was achieving a partial response after the first therapy cycle, which, along with standard-risk cytogenetics, also predicted a higher complete response rate. The only baseline characteristic associated with long-lasting response was prior plasma-cell dyscrasia. Significant prognostic factors for poorer OS were high-risk cytogenetics and no history of monoclonal gammopathy of undetermined significance, whereas there was a trend for improved OS in patients who had received only one prior therapy.

Comment (KR): This is a nice ‘real world’ study that is relevant to our current NZ practice. It clearly shows that the quality of response to the first cycle is a major predictor of a good long-term response. The fact that a high-risk genetic signature is a negative prognostic factor should guide clinicians to looking at some supplementary more active therapy, such as bortezomib. The recent lifting of restrictions on the use of bortezomib may allow clinicians to augment treatment in such high-risk cases as the t(4;14), which we know is more susceptible to bortezomib.

**Upfront bortezomib, lenalidomide, and dexamethasone compared to bortezomib, cyclophosphamide, and dexamethasone in multiple myeloma**

Authors: Uttervall K et al. reviewed in issue 32 of Multiple Myeloma Research Review.

**Summary:** This was a retrospective analysis of patients treated with first line VCD or VRD, with or without subsequent high-dose treatment and autologous SCT; 351 patients received VRD with and 213 without high dose treatment, and 71 received VRD with and 46 without high-dose treatment. Compared with VCD, use of VRD was associated with: i) a higher ORR (98% vs. 88% [p<0.001]), including among those who did not receive high-dose treatment (98% vs. 79% [p<0.001]); ii) a higher 18-month PFS rate overall (88% vs. 63%), in the subgroup who did not receive high-dose treatment (82% vs. 32%) and the subgroup who did (91% vs. 73%); and iii) a higher 18-month OS rate (95% vs. 89% [p=0.048]).

Comment (Ken Romeril): This is an important comparison because the study compares our standard induction regimen of CyBorD (VCD) with VRD, which is very popular in the US but which we cannot offer to our patients. I understand that VRD has been approved by the PBAC in Australia recently. This quite large study yielded a very impressive ORR of 98%. The 18-month analysis showed that the VRD-treated group had superior survival also. We need to be able to offer this sort of induction regimen to our patients, and it is yet another unmet clinical need.

**Once-weekly versus twice-weekly carfilzomib in patients with newly diagnosed multiple myeloma**

Authors: Bringhen S et al. Reference: Haematologica 2019;104:1640–7; reviewed in issue 32 of Multiple Myeloma Research Review.

**Summary:** These researchers analysed pooled phase 1–2 trial data to compare efficacy and safety of once weekly versus twice-weekly dosing of carfilzomib in patients with newly diagnosed MM. The trials comprised 121 transplant-ineligible participants who received nine induction cycles of carfilzomib, cyclophosphamide and dexamethasone followed by carfilzomib maintenance. Sixty-three participants received a once-weekly schedule of carfilzomib 70 mg/m2 and 58 received a twice-weekly dose of 36 mg/m2. No significant difference was seen between the once-weekly and twice-weekly dosing groups for median PFS (35.7 vs. 35.5 months [p=0.26]), 3-year OS (70% vs. 72% [p=0.50]) or grade 3–5 haematological adverse events (24% vs. 30% [p=0.82]).

Comment (Ken Romeril): This is the ARROW study that has been extensively referenced by speakers at recent meetings. The results clearly show that the more convenient once-weekly approach using a single high dose of carfilzomib prolonged the median PFS of relapsed MM patients. Many clinicians in the US have been using the once-weekly approach for some time now, and the ARROW phase 3 trial results confirm that it is a reasonable approach to deliver a more convenient schedule.

**Pain Management in Patients with Multiple Myeloma: An Update**

Flaminia Coluzzi 1 et al; Cancers 2019, 11, 2037; doi:10.3390/cancers11122037 www.mdpi.com/journal/cancers; Published: 17 December 2019

**Abstract:** Most patients with multiple myeloma (MM) suffer from chronic pain at every stage of the natural disease process. This review focuses on the most common causes of chronic pain in MM patients: (1) pain from myeloma bone disease (MBD); (2) chemotherapy-induced peripheral neuropathy as a possible consequence of proteasome inhibitor therapy (i.e., bortezomib-induced); (3) post-herpetic neuralgia as a possible complication of varicella zoster virus reactivation because of post-transplantation immunodepression; and (4) pain in cancer survivors, with increasing numbers due to the success of antiblastic treatments, which have significantly improved overall survival and quality of life. In this review, non-pain specialists will find an overview including a detailed description of physio-pathological mechanisms underlying central sensitization and pain chronification in bone pain, the rationale for the correct use of analgesics and invasive techniques in different pain syndromes, and the most recent recommendations published on these topics. The ultimate target of this review was to underlie that different types of pain can be observed in MM patients, and highlight that only after an accurate pain assessment, clinical examination, and pain classification, can pain be safely and effectively addressed by selecting the right analgesic option for the right patient.

**Developments in continuous therapy and maintenance treatment approaches for patients with newly diagnosed multiple myeloma**

Meletios A. Dimopoulos, Andrzej J. Jakubowiak, Philip L. McCarthy, Robert Z. Orlofski, Michel Attal, continues over page
Joan Bladé, Hartmut Goldschmidt, Katja C. Weisel, Karthik Ramasamy, Sonja Zweegman, Andrew Spencer, Jeffrey S. Y. Huang, Jin Lu, Kazutaka Sunami, Shinsuke Iida, Wee-Joo Chng, Sarah A. Holstein, Alberto Rocci, Tomas Skacel, Richard Labotka, Antonio Palumbo & Kenneth C. Anderson
Blood Cancer Journal volume 10, Article number: 17 (2020)

Abstract: The evolving paradigm of continuous therapy and maintenance treatment approaches in multiple myeloma (MM) offers prolonged disease control and improved outcomes compared to traditional fixed-duration approaches. Potential benefits of long-term strategies include sustained control of disease symptoms, as well as continued cytoreduction and clonal control, leading to unmeasurable residual disease and the possibility of transforming MM into a chronic or functionally curable condition. “Continuous therapy” commonly refers to administering a doublet or triplet regimen until disease progression, whereas maintenance approaches typically involve single-agent or doublet treatment following more intensive prior therapy with autologous stem cell transplant (ASCT) or doublet, triplet, or even quadruplet induction therapy. However, the requirements for agents and regimens within these contexts are similar: treatments must be tolerable for a prolonged period of time, should not be associated with cumulative or chronic toxicity, should not adversely affect patients’ quality of life, should ideally be convenient with a minimal treatment burden for patients, and should not impact the feasibility or efficacy of subsequent treatment at relapse. Multiple agents have been and are being investigated as long-term options in the treatment of newly diagnosed MM (NDMM), including the immunomodulatory drugs lenalidomide and thalidomide, the proteasome inhibitors bortezomib, carfilzomib, and ixazomib, and the monoclonal antibodies daratumumab, elotuzumab, and isatuximab. Here we review the latest results with long-term therapy approaches in three different settings in NDMM: (1) maintenance treatment post ASCT; (2) continuous frontline therapy in nontransplant patients; (3) maintenance treatment post-frontline therapy in the nontransplant setting. We also discuss evidence from key phase 3 trials. Our review demonstrates how the paradigm of long-term treatment is increasingly well-established across NDMM treatment settings, potentially resulting in further improvements in patient outcomes, and highlights key clinical issues that will need to be addressed in order to provide optimal benefit.

Medical Corner...continued

Common abbreviations used in Medical Corner

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

**BM:** bone marrow

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

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

**IMiD:** Immunomodulatory drug (ie Lenalidomide, Thalidomide, Pomalidomide)

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

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

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

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

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

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

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

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

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

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

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

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

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

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

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

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

**Triplet:** 3 drugs used in combination

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

**BLACKTOWN**
- **Time:** 11:00 am – 1:00 pm
- **Location:** Blacktown Bowling Club, 15 Lismore St, BLACKTOWN NSW 2148
- **Contact:** Jacqui Keogh
- **Email:** jacqui.keogh@myeloma.org.au
- **Phone:** 0426 404 230

**NEWCASTLE**
- **Time:** 10:30 am – 12:30 pm
- **Location:** Club Charlestown, 5 Lincoln St, CHARLESTOWN NSW 2290
- **Contact:** Rachel McCann
- **Email:** rachel.mccann@myeloma.org.au
- **Phone:** 0433 511 606

**NEPEAN**
- **Time:** 10:00 am – 12:00 pm
- **Location:** Penrith City Library, Joanne Pearson / Margaret Prask Room, 601 High St, PENRITH NSW 2750
- **Contact:** Jacqui Keogh
- **Email:** jacqui.keogh@myeloma.org.au
- **Phone:** 0426 404 230

**ORANGE**
- **Time:** 4:00 pm – 6:00 pm
- **Location:** Gyalang Ganya Community Services Centre, 286 Lords Place, ORANGE NSW 2800
- **Contact:** Jacqui Keogh
- **Email:** jacqui.keogh@myeloma.org.au
- **Phone:** 0426 404 230

**RUTHERFORD**
- **Time:** 10:30 am – 12:30 pm
- **Location:** Rutherford Community Ctr, 13 Arthur St, RUTHERFORD NSW 2320
- **Contact:** Juliet Hill
- **Email:** juliet.hill@myeloma.org.au
- **Phone:** 0433 511 554

### Support Groups QLD

**ALDERLEY / NEWMARKET**
- **Time:** 10:30 am – 12:30 pm
- **Location:** Alderley Arms Hotel, 2 Samford Rd, ALDERLEY QLD 4051
- **Contact:** Tash Clarke
- **Email:** natasha.clarke@myeloma.org.au
- **Phone:** 0416 019 585

**BUDERIM**
- **Time:** 2:00 pm – 4:00 pm
- **Location:** Bloomhill Cancer Centre, 58 Ballinger Rd, BUDERIM QLD 4556
- **Contact:** Tash Clarke
- **Email:** natasha.clarke@myeloma.org.au
- **Phone:** 0416 019 585

**LABRADOR**
- **Time:** 10:30 am – 12:30 pm
- **Location:** Labrador Community Centre, 57 Billington St, LABRADOR QLD 4215
- **Contact:** Megan McDowell
- **Email:** megan.mcdowell@myeloma.org.au
- **Phone:** 0416 019 022

### Calendar of Events 2020

**Groups / events are subject to change at short notice. Please check the website for a more up to date schedule.**

https://myeloma.org.au/event-calendar/

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**YOUNGER PERSONS**
- **Time:** Various Wednesdays of every 2nd month
- **Location:** Wentworthville Leagues Club, Magpie Meeting Room 3, 50 Smith St, WENTWORTHVILLE NSW 2145
- **Contact:** Jacqui Keogh
- **Email:** jacqui.keogh@myeloma.org.au
- **Phone:** 0426 404 230

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**Other Notes:**

- Groups / events are subject to change at short notice.
- Please check the website for a more up to date schedule.
- Calendar of Events 2020
- Contact details for each group are provided.
- Website: https://myeloma.org.au/event-calendar/
NORTH LAKES
Various Fridays of every 2nd month
Time: 10:00 am – 12:00 pm
North Lakes Health Conference Centre
9 Endeavour Blvd
NORTH LAKES QLD 4509
Contact: Tash Clarke
E: natasha.clarke@myeloma.org.au
M: 0416 019 585

PRINCESS ALEXANDRA HOSPITAL
Various Wednesdays of every 2nd month
Time: 11:00 am – 1:00 pm
Cancer Conference Centre
Ground Floor Oncology
Princess Alexandra Hospital
199 Ipswich Rd
WOOLOONGABBA QLD 4102
Contact: Megan McDowell
E: megan.mcdowell@myeloma.org.au
M: 0416 019 022

Support Groups SA

FLINDERS
3rd Thursday of every 2nd month
Time: 10:00 am – 12:00 pm
Living Kaurna Cultural Centre
CC Meeting Room
Warriparringa Way
BEDFORD PARK SA 5520
Contact: Jenny Naylor
E: Jenny.Naylor1@gmail.com
M: 0405 391 616

FULLARTON
1st Wednesday of every 2nd month
Time: 10:00 am – 12:00 pm
Fullarton Park Centre
411 Fullarton Rd
FULLARTON SA 5063
Contact: Ian Driver
E: sandrian7@bigpond.com
M: 0417 874 252

SOUTHERN TASMANIA
1st Tuesday of every month starting February 4th
Time: 10:00am – 12:00pm
Venue will alternate between:
Cancer Council Tasmania
15 Princes St
SANDY BAY TAS 7005
and
Glenorchy Health Centre
404 – 408 Main Rd
GLENORCHY TAS 7010
Contact: Deborah Thompson
E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

Support Groups VIC

ALBURY / WODONGA
1st Thursday of every 2nd month
Time: 10:00 am – 11:30 am
Albury Wodonga Regional Centre
Wellness Room
201 Borella Road
EAST ALBURY NSW 2640
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

BALLARAT
3rd Thursday of every 2nd month
Time: 10:00 am – 11:30 am
Ballarat Community Health Centre
Sebastopol Multipurpose Room
260 Vickers Street
SEBASTOPOL VIC 3356
Contact: Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

BEAUMARIS
1st Thursday of every 2nd month
Time: 10:00 am – 12:00 pm
Beaumaris Theatre
82 Wells Road
BEAUMARIS VIC 3193
Contact: Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

BENDIGO
2nd Wednesday of every 2nd month
Time: 9:30 am – 11:00 am
Bendigo Hospital Cancer Centre
100 Barnard St
BENDIGO VIC 3550
Contact: Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

BERWICK
3rd Friday of every 2nd month
Time: 1:30 pm – 3:00 pm
St John of God Hospital
55 Kangan Dve
Level 1
BERWICK 3806 VIC 3193
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

COBURG
2nd Wednesday of every 2nd month
Time: 1:30 pm – 3:00 pm
Coburg North Meeting Room
Shop 19/180 Gaffney St
COBURG VIC 3058
Contact: Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

GEELONG
2nd Friday of every 2nd month
Time: 10:00 am – 11:30 am
Barwon Health – SCC Meeting Room
Andrew Love Cancer Centre
Wellness Lounge
70 Swanston St
GEELONG VIC 3220
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

Support Groups TAS

LAUNCESTON
2nd Tuesday of every 2nd month
Time: 10:00 am – 12:00 pm
Cancer Council Tasmania
69 Howick St
SOUTH LAUNCESTON TAS 7249
Contact: Deborah Thompson
E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

NORTH WEST
2nd Tuesday of every 2nd month
Time: 12:30 pm – 2:30 pm
Venues will alternate between:
NW Regional Hospital
The Wellness Centre
BURNIE TAS 7320
and
Cancer Council Tasmania
2/45 Best St
DEVONPORT TAS 7310
Contact: Deborah Thompson
E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

…VIC list continues next page
HORSHAM
4th Friday of every 2nd month
Time: 11:00 am – 12:30 pm
Cancer Centre Horsham
7-9 Robinson St
HORSHAM VIC 3400
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

WARRAGUL
3rd Thursday of every 2nd month
Time: 6:00 pm – 8:00 pm
Venues will rotate each session
Contact: Laura Jones
E: laura.jones@myeloma.org.au
M: 0451 404 203

YOUNGER PERSONS GROUP
2nd Thursday of every 2nd month
Time: 6:00 pm – 8:00 pm
Myeloma Australia Head Office
333 Swan St
RICHMOND VIC 3121
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

Support Groups WA

COFFEE AND CHAT
Various Fridays of every 3rd month
Time: 10:00 am – 12:00 pm
Wanslea Room
Cancer Wellness Centre
80 Railway Road
COTTESLOE WA 6011
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

NORTH METRO
1st or 2nd Monday of every 2nd month
Time: 1:00 pm – 3:00 pm
Wanneroo Library and Cultural Centre
Meeting Room 1, Ground Floor
3 Rocca Way,
WANNEROO WA 6065
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

TRARALGON
3rd Friday of every 2nd month
Time: 10:00 am – 11:30 am
Gippsland Rotary Centenary House
39 Valley Dve
TRARALGON VIC 3844
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

WANGARATTA
1st Thursday of every 2nd month
Time: 1:30 pm – 3:00 pm
Wangaratta Library
Seminar Room
21 Docker St
WANGARATTA VIC 3678
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

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

**Groups / events are subject to change at short notice. Please check the website for a more up to date schedule. https://myeloma.org.au/event-calendar/
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