

MyeNews

Summer 2017 Issue no 44



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Myeloma Support Line

Monday – Friday 9am – 5pm (AEST)
1800 MYELOMA
(1800 693 566)

A confidential service providing those living with myeloma, their family and friends and health professionals access to specialist myeloma nurses. Open to anyone with a question about myeloma or just to have a chat.



MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

Contact Pina Civitarese:

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

pina@myeloma.org.au

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

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President's Report

As we approach the end of another year I can report on the rapid growth that has occurred this year at Myeloma Australia. I meet on a regular basis with our co-founder and the Patron of Myeloma Australia, Robert Moran and when I last wrote about what we have achieved this year he was totally amazed.

The level of support and education provided by Myeloma Australia matches or exceeds what most other myeloma organisations do maybe with the exception of the two major groups in the USA and Myeloma UK.

From the very beginning we stressed that we were a nurse based organisation with only one nurse working 16 hours per week, last December 2016 we had three nurses working 44 hours per week, we now have eight nurses working 124 hours per week. We are not stopping there. We have plans to employ another four nurses and increase by about 44 hours per week within the next year. This will then make us a truly national organisation with at least one Myeloma Support Nurse in every capital city.

2018 marks our twenty-year anniversary. Three couples in conjunction with two doctors and the support group co-ordinator at Cancer Council Victoria met and started Myeloma Victoria. When Robert Moran and I meet and review all that has happened in the past years and see what the organisation we started has achieved we find it hard to believe. The main growth has occurred in the last few years under the guidance of our CEO Steve Roach and the belief of the pharmaceutical Companies in that we can achieve what we promise and it is due to their generosity that we have been able to expand our services for the benefit of the myeloma community.

With our extra Myeloma Support Nurses we are able to offer more support groups and over the past year we have started a few and these will continue to be established across the country. You can find the calendar of events listed on the back pages of this edition. If you don't have a group in your area and you would like to start one please contact one of the Support Nurses via our National office and they will help you.

I always look forward to early December, when we go to the USA and to the American Society of Haematology's Annual meeting. This year our CEO Steve and our two Myeloma Support Nurse Managers and I will be attending this meeting in Atlanta. During this conference attended by over 27,000 people, we will have the opportunity to hear the latest research presentations from around the world as well as to



network with Myeloma Support Groups from all over. This has always been a very busy trip but extremely valuable in both what we learn as well as in the contacts we make.

We have many plans for 2018 from further increasing our services, celebrating our 20th birthday and another medical conference to be held in September. Our web site is being upgraded and along with the Myeloma Muster, (a regular emailed newsletter), this magazine and our social media pages we will be promoting all new events during the year so please watch out for notices.

As many of you know, there is another new treatment being submitted to the Pharmaceutical Benefits Advisory Committee for approval to become subsidised. The new treatment is daratumumab combined with Velcade or lenalidomide. This is a first in myeloma treatments in Australia where the application is for a drug combination. We can now hope that this is approved soon as the research shows this to be better than anything else currently available.

Finally I would like to thank you all for your support of Myeloma Australia and to wish you all a merry Christmas and a very happy and healthy New Year. ●

Brian Rosengarten
President
Myeloma Australia

A handwritten signature in black ink that reads "Brian Rosengarten".

New support nurse

Kerin Young

Western Australia
Myeloma Support Nurse

I am excited to be a part of the Myeloma Support Nurse team here in Western Australia.

Haematology nursing is a passion that I fell into. As a newly graduated nurse I applied for the Graduate nurse program at Royal Perth Hospital and following my induction into RPH I was offered a second year graduate program which allowed me to rotate through three speciality areas – one of those being BMU (Bone Marrow Transplant Unit) at RPH. This initially was a daunting experience not only having to learn a new language – (nursing and medicine love abbreviations) but also to nurse people who were often sick and vulnerable as well as facing a steep learning curve about complex diseases and chemotherapy. After finishing my graduate year I got the haematology bug and went back and worked in the haematology / oncology ward 10A at RPH.

Then it was time for me to grab my passport and backpack and head overseas where I was offered a job at the Royal Marsden in Sutton in the UK. Here I worked on an allogeneic bone marrow transplant unit called Bud Flanagan. This was busy and challenging experience for me and I made many friends who I often come across in haematology circles in Australia and we chat about the Marsden experience. From there I headed north to Edinburgh and worked at the Western General Hospital again in acute haematology and bone marrow transplant and ended up settling in the Kingdom of Fife.



After 8 years away from the sun-sea and surf I headed back to Australia with my family to take up the position of Cancer Nurse Coordinator – haematology in the WA Cancer and Palliative Care Network where I have been for the past 10 years. During that time I have also managed to squeeze in my Masters in Nursing (Nurse Practitioner) which I finally finished last year. When I am not working I am hanging out with my husband and two boys and our fur kid Milly.

I am really looking forward to working with Narelle in setting up Myeloma Australia here in WA. ●



5km & 10 km Trail Run/Walk

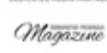
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Raising much needed funds and awareness to assist Myeloma Australia to extend their nursing services across Australia and further support the myeloma community.

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New support nurse

Narelle Smith

Western Australia
Myeloma Support Nurse

I am very excited to introduce myself as one of the Myeloma Support Nurses for Western Australia. In addition to this new role, I work clinically at Hollywood Private Hospital here in Perth in the oncology and haematology departments, predominantly providing chemotherapy services in the day treatment suite.

I spent my younger years growing up in Wagin, a small country town in WA's Great Southern, and then completed my nursing studies in Perth, where I currently live. I was lucky enough to discover a passion for cancer nursing whilst I was a graduate nurse and I have been so lucky to have worked in a variety of roles and locations since then, including working here in Perth with Curtin University on several research projects, and developing eLearning modules for nurses working in radiation oncology in collaboration with EviQed (Cancer Institute of New South Wales) and the Radiation Oncology Workforce. I was lucky enough to also live overseas in Ireland and Scotland for several years, working specifically in acute haematology, with a large focus on Myeloma patients.

I am passionate about improving support services for patients, particularly those living in rural and remote locations, of which there are many here in Western Australia. From a Myeloma perspective, this commitment has only been strengthened by the personal experience of my uncle's diagnosis ten years ago. He was also from a rural town in south-western WA and gave me a unique perspective into the challenges facing patients living a distance from metropolitan centres.



I see this role as a fantastic opportunity to work towards improving support and access for patients here in WA and to hopefully spread my enthusiasm. I am really excited to be sharing this position with Kerin Young, as I feel together we will be able to develop a fabulous support service in WA with Myeloma Australia.

In my precious free time, you will most likely find me hanging out with my husband Dan, 3 girls (aged 4 and 18th month twins) and our dog, Lionel; occasionally sneaking off to the beach or meeting up with friends.

I am really looking forward to connecting with patients, carers and health professionals in the Myeloma Community and I am so grateful for the warm welcome that I have already received from Myeloma Australia. ●

Meet and Greet Morning Tea

Myeloma Australia is delighted to invite you to an informal morning tea for people living with myeloma, their family and friends. This is a great opportunity to meet the new Myeloma Support Nurses for Western Australia, Kerin Young and Narelle Smith, while connecting with other members of the myeloma community.

Date: Monday, 11th December 2017
Time: 9:30am – 11.30am
Venue: Drabble House
2 Webster Street, Nedlands, WA 6009
Free parking

Enter through the carpark entrance between the library and Drabble house and park either in the unmarked bays of the car park or on the grassed area directly behind Drabble House.

RSVP: RSVP essential for catering purposes by 4th December 2017

Narelle Smith: narelle.smith@myeloma.org.au
Head office: 1300 632 100

Morning tea
provided

Myeloma
Australia

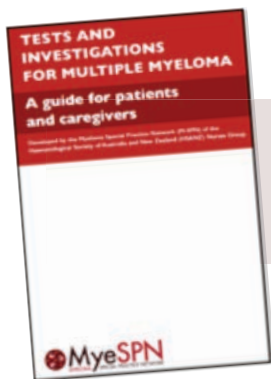
Myeloma Special Practice Network

Report from the Haematology Society of Australia & New Zealand Myeloma Nurses Group

Those nurses working in Australia and NZ who have a specialist interest in the nursing care of those affected by myeloma have the opportunity to participate in our special interest group. We have a focus on improving care of affected by myeloma through the development and promotion of information and education aimed at improving standards of care. We have been working on several programs and resources this year, some aimed at patients and family members, others at nurses.

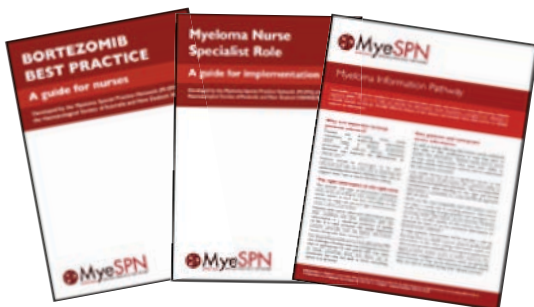
Understanding Tests & Investigations for Multiple Myeloma: A resource for patients

Providing good quality, up to date information for patients and their family members is an important role for nurses. Our group felt there was a gap in the information available explaining the wide range of tests and investigations those with myeloma may undergo. Two nurse members have written a new information booklet, with input from patients with myeloma and Dr Clare Weatherburn, a Haematologist. If you want to know more about all those blood tests, your myeloma bloods or scans, then this booklet may be of interest to you. The booklet is available as an e-copy direct from the MM nurses group or Myeloma Australia.



Email Myeloma Australia your e-copy of the 'Understanding Tests & Investigations' support@myeloma.org.au

Resources produced by our group this year specifically for nurses and clinicians include:



- Bortezomib Best Practice: A Guide for Nurses
- Myeloma Nurse Specialist Role: A Guide for Implementation
- Myeloma Information Pathway: A Guide for Nurses

Many thanks to the nurses group members who have lead and contributed to these resources. Daniela Klarica (VIC); Carmel Woodrow (QLD); Hayley Beer (VIC); Kerin Young (WA); Julija Sipavicius (NSW) and Tracy King (NSW).



This year the MM nurses group partnered with the Medical Scientific and Advisory Group (MSAG), Myeloma Australia, to host its annual workshop. Many of our group attended this excellent day and we were pleased to award travel grants to 2 successful grant winners, to help them attend the workshop. Congratulations to members Jacqui Jagger (NSW) and Petra Stolz Baskett (NZ). Please read Petra's report from the workshop in this newsletter.

HAA: Haematology Society Annual Scientific Meeting Sydney 2017

Each year the Haematology Society hosts an annual conference that brings together doctors, nurses, scientists, researchers and other clinicians working in the Haematology space. The nurses group invite an international haematology nursing speaker and this year we were lucky enough to have a myeloma Nurse Practitioner, Beth Faiman *PhD, MSN, APRN-BC, AOCN*, Cleveland Clinic Ohio, join us. Beth presented a workshop on nursing assessment and management of patients with blood clots; atypical presentations of plasma cell disorders and shared her experience of running a Myeloma Nurse Practitioner service. Beth also joined our myeloma nurses group for a lunchtime meeting and also visited some local Sydney hospitals and the Cancer Nursing Research Unit (CNRU), Sydney University. We plan to work with Beth on some future myeloma nursing projects with our group and CNRU.



Myeloma Nurses and Beth Faiman during HAA Conference Sydney 2017
L.Top: Tracy King, Beth Faiman, Julija Sipavicius, L. Bottom: Jacqui Jagger, Carmel Woodrow.

Elizabeth Moore (Research Fellow / Project Manager Myeloma and Related Disease Registry - MRDR), Tracy King and team, presented a poster of their research project on real time measurement of health-related quality of life in myeloma at the HAA conference.

If you have a nurse who you feel has an interest in myeloma or would like to join our group and benefit from extra information, education and mentorship from other nurses – please encourage them to contact the nurses at Myeloma Foundation who can tell them more. ●

1300 632 100.

Alternatively, interested nurses can contact me directly at **Tracy.king1@health.nsw.gov.au**

Tracy King RN MN

Chair HSAZ Myeloma Nurses Group



Tracy King (MM nurse RPA) and Elizabeth Moore (Myeloma Related Disease Registry Monash VIC).



Every year for the past 40 years there has been a Melbourne Marathon and the 2017 event maintained the event's status as Australia's largest marathon and in so doing, raised much needed funds for many selected charities.

Looking to make a small contribution to the Myeloma Australia coffers, I felt it time to call on friends and family to support the organisation and all it does to provide nursing care for myeloma sufferers around Australia. To give some focus to the exercise I decided to line up and trot around the 42.2 kilometre course on what turned out to be near perfect running conditions.

Over the last five or so kilometres when the temptation to walk was so strong, I reminded myself of the wonderful

people I have had the privilege to meet who have their myeloma battle to fight and do it with such strength and dignity. That was enough to persuade my brain cells that this event was about running, not walking, and so we got there; tired, sweaty, but happy and grateful to all those who have supported my run and Myeloma Australia.

NB: The funding target was a thousand dollars; (at the time of going to print) we are a few 'bob' short of that figure at the moment at \$764.16, so if any reader feels inclined to pitch in to get us over the line, please just go to:

<https://give.everydayhero.com/au/daniel-134> to do your bit; and thank you very much. ●

Clinical Education Workshop

Inaugural Myeloma Clinical Education Workshop

On 16th September 2017, I attended with around 130 other participants from around Australia and one New Zealand nursing colleague, the Myeloma Clinical Education Workshop. Still within my first year in the newly established role as Clinical Nurse Specialist Haematology/Oncology at Nelson Marlborough Health, I was fortunate enough to be supported by travel grants from the HSA NZ Nurses Group and Myeloma Australia, to connect with others caring for people and families affected by Myeloma and update and extend my knowledge around diagnostics, treatment and monitoring. I split the time of my 20 hours/week position usually between a) running nurse-led follow up clinics where I see people with various other blood cancer conditions and b) being the primary nurse/care coordinator of people with newly diagnosed blood cancers and complex needs requiring chemotherapy treatment. The latter includes all people with multiple myeloma of which we had around 14 newly diagnosed in the region over the past twelve months.

The inaugural education workshop was organized by Myeloma Australia, MSAG and HSA NZ NG, and kindly co-sponsored by five industry partners. The 9 am – 4pm program was hosted at the impressive facilities of the Victorian Comprehensive Cancer Centre and, chaired by Peter MacCallum's A/P Simon Harris, the morning was filled with seven presentations. Although hard to decide with the general high quality of presentations my four favorites were:

Dr. George Grigoriadis' eloquent outline of the discussion around appropriate criteria to describe response to treatment, drawing attention to new approaches to detect minimal residual disease (MRD), a marker promising new prognostic value and, hence, additional influence to treatment decision making in clinical practice.

Dr. Krystal Bergin's put spotlights on examinations of data from the Myeloma and Related Disease Registry (MRDR) pertinent to the question: "Do we do what we say we should do?". I have been involved in teaching and research, focusing on geriatric cancer care over the past decade in Switzerland before returning to New Zealand two years ago, and so, was not surprised to hear that chronological age appears to be the strongest factor predicting if a patient with myeloma will receive a stem cell transplant as part of their initial treatment. Thus, people over the age of 70 are almost never given that opportunity. In contrast, a general functional status measure

(ECOG) or level of kidney function did not appear to have significantly influenced the decision to support stem cell transplant. Aware that funding criteria of different countries might also play a role in decision making at that level, these MRDR findings still indicate to me, however, that there is a lack of best practice guidelines implementation around care for geriatric cancer patients that would mandate a comprehensive geriatric assessment for people over the age of (65 -) 70 years. Such an assessment would well support decision making as to who is fit for what type of treatment, rather than focusing on chronological age.



(L>R) Debbie Moore and Petra Stolz Baskett.

Dr. Simon Gibbs presentation about AL Amyloidosis has left me with valuable question to appraise practices in my own work setting on my journey of learning with regards to management of that particular disease presentation. Being located at NZ's "Top of the South", the organization I work for caters for around 160'000 of the one million or so main island inhabitants, i.e. opportunities to gain experience with some more rare conditions in the group of myeloma and related diseases are limited and educational sessions like this are a great way to get/stay up to date.

Last but not least, we were lead with great enthusiasm through Dr. Hang Quach's thought processes in relation to the need and make up of a national guideline for treatment algorithms for "non-intensive" myeloma treatment pathways. She emphasized the wise recommendation to decide by principles rather than rules in the quest for person-centered evidence based practice.

In the afternoon, Tracy King started off with chairing a panel session with three case presentations. This enabled contextualizing the wealth of knowledge gained in the morning with real world scenarios shared by three attendees. Complementing the previous program somewhat heavy on "treatment sciences", Prof. Madeleine King put the concept of health related quality of life into focus within research and clinical practice for people and family affected by myeloma. Although, quality of life is often mentioned in cancer research and clinical settings, we still have some way to go to, for example, with integrating an assessment of this patient reported outcome as standard care practice that would enable us to deliver patient-centered care more effectively. The presented MyPOS tool (www.pos-pal.org) would appear to be a valuable instrument within the area of Myeloma care in this regard. ●

Nga Mihi,

*Petra Stolz Baskett RN MA PhD(candidate)
CNS Haematology/Oncology
Nelson Marlborough Health – New Zealand*

Palliative Care

Palliative Care – An integral part of effective supportive care

Introducing Palliative Care Australia <http://palliativecare.org.au/>

The World Health Organisation defines palliative care as: "...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Palliative care is not restricted to care provided in the final stages of life, but will help you to live well with the diagnosis of myeloma, a currently incurable illness. Palliative care can be of benefit at initial diagnosis of this life-limiting condition, or be useful on and off through its various stages. Many people have long-term interactions with their palliative care team, seeing them through the course of their myeloma.

Palliative care offers services including expert pain and symptom management, psychological care and advice and support to carer/s. Palliative care aims to ensure you are kept comfortable and that you maintain good quality of life.

Palliative care is multidisciplinary team care – so care is shared between a range of providers, medical specialists, general practitioners, nurses and allied health professionals who all bring a range of skills to help you manage your myeloma symptoms. These professions include, but are not limited to:

- Palliative medicine physician, an expert in physical and psychological symptom support with skills and connections to assist keeping you at home or to assist with negotiating other accommodation options

- Haematologist for expert care with regard to myeloma assessment and its treatment
- Other specialist doctors as needed to manage diseases in other body systems
- Nurses giving expert symptomatic care
- Social workers for advice with finances, health costs and other social issues
- Physiotherapists to help maintain optimal mobility and fitness
- Occupational and speech therapists
- Psychologists
- Trained volunteers

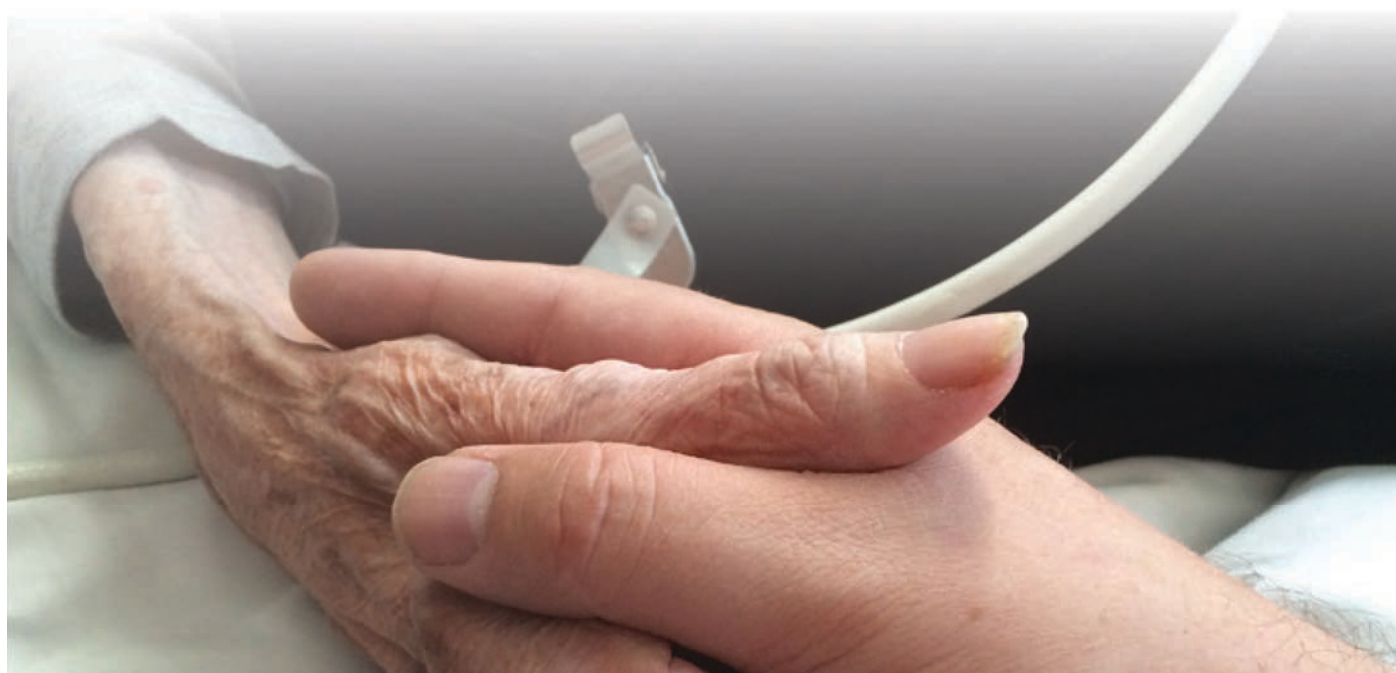
Palliative care can be accessed through referral from your General Practitioner, medical specialist or other health provider. To find a service in your local area go to the National Service Directory <http://palliativecare.org.au/directory-of-services/>

Most palliative care services are free, but there may be some costs associated with hospice and hospital care.

Palliative care also supports carers and family members. Caring for a person can be demanding. Carers try hard to keep things normal in an abnormal situation. Roles change. Relationships can come under strain as people adjust to their new lives. Yet, most families and carers talk about how rewarding it can be.

If any of the above relates to your situation, more information can be found on <http://palliativecare.org.au/> ●

*Adapted from Palliative Care Australia information,
by Jo Gardiner,
Senior Specialist Myeloma Nurse,
Myeloma Australia*



NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

MRDR RECRUITMENT

The Myeloma and Related Diseases Registry has close to 1800 pts registered, 25 approved hospital sites and 9 sites with approval pending. It has become more representative of myeloma in ANZ over time. We thank all MRDR participants and participating sites for your ongoing help.

Takeda, Janssen and Celgene Australia support the MRDR which enables this important research to continue.

MRDR AT HAA

MRDR Interest Group breakfast

The annual MRDR Interest Group breakfast at HAA in Sydney (the key ANZ haematology conference) was a success with over 70 attendees representing patient groups, hospital sites, researchers, industry, and other collaborators. Attendees enjoyed an update on registry data and progress by Professor Andrew Spencer (see photo), and an open forum discussion on ideas for MRDR projects and analyses lead by Dr Zoe McQuilten. The formation of Special Interest Groups to coordinate these activities was also explored. We would love to have more patient representation at next year's breakfast at the newly named 'Blood 2018' conference in Brisbane, 21-24 October 2018.



Andrew Spencer presenting at the MRDR breakfast, HAA 2017.

MRDR Presentations

Professor Joy Ho presented the results of an analysis on patients with multiple myeloma and renal impairment at HAA, looking at patient characteristics, treatment and outcomes. The findings generated plenty of interest and the analysis is being prepared for publication. Two MRDR posters were also presented:



Tracy King (L) and Elizabeth Moore (R) with the MRDR My-PROMPT poster at HAA.

- Polynesian Ethnicity and Outcomes for Multiple Myeloma (MM) in New Zealand (Hilary Blacklock)
- The My-PROMPT study: real-time reporting of patient-reported outcomes in MM to improve care (see photo).

Monash University Clinical Registries had a booth in the exhibition area at the conference where Elizabeth Moore of the MRDR was available for consultation.

MRDR AND THE AUSTRALASIAN MYELOMA RESEARCH CONSORTIUM

The Australasian Myeloma Research Consortium (AMARC) will use the MRDR as a platform for clinical trials. Its established network of sites, contacts and methods for data collection, make the MRDR an attractive platform from which to cost-effectively run clinical trials. Other points in favor are Monash's experience in running clinical trials, and the haematology-focused Transfusion Research Unit that administers the MRDR. Recruitment to AMARC trials is now underway.

MRDR: HOW CAN YOU BE INVOLVED?

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

TO CONTACT THE MRDR:

Phone: 1800 811 326

Email: sphpm-myeloma@monash.edu

Website: mrdr.net.au

Nurse Manager's Report

It's been a while since I've sat at the keyboard to write a report for MyeNews and boy have things changed! It was so lovely to return to work from maternity leave to find two new Victorian Support Nurses in Elli and Laura and a new fundraiser in Matt.

The office is now a buzz with activity and the pace just keeps ramping up. All this is fantastic for the myeloma community with our reach spreading wider all the time. I must say a huge thank you to Nella who stepped up into the Nurse Manager role and kept the momentum going beautifully.

At the beginning of October I had the pleasure of travelling to Perth to welcome our two new Western Australian Support Nurses, Kerin Young and Narelle Smith. Kerin and Narelle are both very experienced haematology nurses with a special interest in myeloma and are an absolute asset to Myeloma Australia. They have already started connecting with the myeloma community in WA, you can read more about them and their plans in this edition of MyeNews. A special thank you must go to our Medical and Scientific Advisory Group (MSAG) member Dr Brad Augustson who is providing some local support.

The nurse expansion program will continue into the New Year with new roles being created in other states. Stay tuned for more about those new nurses as plans come to fruition.



Dr Simon Gibbs at VCCC

In September, Jo Gardiner our Senior Support Nurse in South Australia visited Darwin to engage the myeloma community there. She was warmly welcomed by attendees at a support group and also delivered some education to the staff at the Darwin Hospital. Jo is planning to return to Darwin in Feb to continue offering our services to the Northern Territory.

Also in September we held our inaugural National Myeloma Workshop at the Victorian Comprehensive Cancer Centre in Melbourne. This workshop was a collaboration between Myeloma Australia, our MSAG and the Haematology Society of Australia and New Zealand Nurses Group's Myeloma Special Practice Network. This event saw our first ever delivery of concurrent health professional and patient/carer education. Using the facilities of the brand new hospital we were able to maximise on the knowledge and expertise tailoring two programs to suit the audience in each room. In the patient/carer room we heard about new treatments, the supportive care measures required to stay well with myeloma, how myeloma is investigated and how new drugs are developed. We also had a break out session just for carers. These presentations were recorded and will be available on our website very soon. ●



Seminar at VCCC (Peter MacCallum)



President's Report

In the health professionals room they had presentations from expert clinicians about the diagnosis, treatment and management of a myeloma patient. The feedback from both rooms was really positive and the plan is to host this event every second year in a different state each time.

In October we had our first patient and carer seminar in Tasmania at the Royal Hobart Hospital, Myeloma Australia CEO Steve Roach welcomed attendees and gave an overview of Myeloma Australia whilst Dr Nick Murphy presented an informative and entertaining presentation on 'Myeloma and new treatments'. This was followed by a presentation from our Support Nurse Nella Combe about 'Living well with myeloma'. It was a great day and we look forward to hosting more education and support services for Tasmanian patients next year.

At the end of October a team of ten Myeloma Australia staff attended HAA, the national haematology conference which was held in Sydney this year. This was a fantastic learning opportunity with medical and nursing streams at the conference. This year's nursing international speaker was Beth Faimen who is a great friend of Myeloma Australia. It was great to catch up with Beth again and hear about her advanced practice role at the Cleveland Clinic in Ohio. Her patients in America have many of the same struggles with treatments and hospital systems as we do despite our very different health care systems.

Once again we had a trade stand in the exhibition hall and saw many new and familiar faces drop by to hear about our programs and pick up some copies of our resources. It was also a great place to network with our industry partners who support many of our programs.

Thank you to all our members who made public submissions to the Pharmaceutical Benefits Advisory Committee to strengthen the application to include daratumumab on the Pharmaceutical Benefits Scheme (PBS). We have everything



Myeloma Foundation Nurses at HAA.

crossed for a positive recommendation when they meet in November. Daratumumab is what's classed as a monoclonal antibody. This type of drug works by signalling the body's own immune system to fight the myeloma cell. This type of drug has been used to treat other cancers but not myeloma before. The clinical trials using daratumumab have been very promising so far so it will be great to have another weapon in the armamentarium to fight myeloma if it gets approved.

If you have a question about drug development or access or in fact any question about myeloma please be in touch with our Myeloma Support Nurses on the Support Line 1800 693 655, Monday – Friday 9am – 5pm AEST or via email nurses@myeloma.org.au. We will be happy to answer your questions in confidence.

On behalf of Nella and I, I'd like to wish you all a safe and happy Christmas and we look forward to working with you all in 2018. ●

A Point of History...

With the transfer to the new Royal Adelaide Hospital in October this year, much archival material was sorted through. At a farewell to the old RAH Haematology Unit, this poster was displayed from the mid 1990's. The medical & nursing staff from RAH and haematologists and scientists from the affiliated Hanson Centre for Cancer Research based on campus, were pioneers in purification and quantification of a correct dose of stem cells, for re-infusion after high dose chemotherapy for a range of blood (including myeloma) and solid cancers. This is now known as autologous stem cell transplant (ASCT).

Jo Gardiner, our Myeloma Support Nurse from SA established the role of Transplant Coordinator at the RAH and was involved with caring for the early autologous stem cell transplant patients, from 1990-1996. Some of those patients are still alive today.



NSW Division Report

It has been a busy few months for Myeloma Australia with many events taking place including the very successful seminar for patients and health professionals which was held in September at the VCCC in Melbourne.

For those of you in NSW there is a Multiple Myeloma Patient and Family Educational Seminar at the RPA on the 1st December details will be provided on the website or either contact me or Tracy King at RPA.

The Myeloma Support groups have continued to meet over the last few months with a few invited speakers attending. At Liverpool we had an interesting and informative presentation on Nutrition and eating well during treatment and in Newcastle Exercise and Myeloma was the topic of the month. As always if there is a topic of particular interest to you please let the facilitator of your group know.

As I have mentioned in previous reports I also co facilitate the Myeloma Telephone support group and we have had quite a few new members over the past few months which has been great. If you are interested in any of the face to face groups or the telephone group, please do not hesitate to contact me.

As well as facilitating support groups part of my role at Myeloma Australia is to meet and support health

professionals who are involved in the care of people with Myeloma. So I have been busy over the last few months meeting with teams at Liverpool, Westmead and Concord Hospitals to mention a few.

In September I was invited to present at the ACI (NSW Agency for Clinical Innovation) Blood and Marrow Transplants Network Symposium in Sydney. This was an ideal opportunity to discuss the work that Myeloma Australia do and inform the health professionals in the room what services are available for Myeloma patients.

I was also very fortunate to be asked to present a letter of appreciation to Derek Mullally and Martin Longwill and the team at QuickwaY in Chester Hill Sydney who raised over \$16,000 for Myeloma Australia at this year's City to Surf. We are extremely grateful to them for choosing Myeloma Australia as their charity this year.

As we move towards 2018 planning is beginning for the various myeloma related education workshops and seminars. Please look out for future dates for NSW activities in 2018. I look forward to meeting many more of you at the various events next year. ●

Jacqui Keogh
Senior Myeloma Nurse

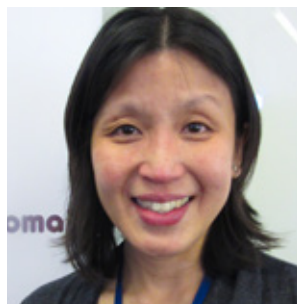


Jacqui Keogh with Derek Mullally from QuickwaY



SA Division Report

Dr. Cindy Lee from the RAH was our guest speaker at our October meeting at Fullarton, talking about clinical trials, new drugs coming onto the scene and their availability through the PBS Scheme. She talked us through the process and listed the clinical trials that are currently being undertaken at the RAH and QEHL as well as talking about the new novel agents coming onto the myeloma spectrum.



Dr Cindy Lee.

The next and last meeting for the year will be on December 5th, when our favourite Dietitian, David Cleghorn will do a presentation on dietary issues. He is always entertaining and so it should be a good day. We also have our Christmas Raffle on the day and finish with some finger food and drinks.

The South-East Support Group will have their next meeting on Friday, 17th November, when our Support Nurse, Jo Gardiner will travel down there to do a Patient Quiz and general Q&A. This will be their last meeting for the year followed by their Regional Seminar on Friday, 9th Feb 2018.

The Mid-North Support Group's last meeting was the Regional Seminar on Saturday, 4th November when Stuart McDonald was the Guest Speaker. Stuart is always entertaining and a wealth of information about coping and exercise. It may be a small group but they appreciate us bringing up good speakers to keep them informed about

what is happening in the myeloma scene. We thank Stuart for making the effort to come over to S.A.

Our efforts to start a new support group at Flinders Medical Centre for myeloma patients being treated there and who may live in the surrounding areas was a great success with 18 people turning up at the first meeting and the Myeloma Haematologists promoting the group strongly.

It was agreed that the group have a casual tea, coffee and biscuit set up and we have the resources to bring in any health professionals from Flinders Medical Centre at any time to explain any issues that the group may have. Their next meeting is on Thursday, 16th November and we are expecting an increase in numbers attending.

We will have a decrease in Committee numbers next year with the recent and sudden passing of Robert Atkinson and also having two other members leaving the Committee. However, we have already started organising guest speakers for next year and before we know it, it will be National Myeloma Day and the 20th Anniversary of Myeloma Australia, so there is a lot to keep us busy. ●

Ian Driver

Chairman

T: 08 8556 6041

E: sandrian7@bigpond.com



Flinders Support Group.

Photos supplied and used with permission



Haematology Study Day.

As the flowers start to blossom here in Victoria, so too does our new Support Group in Traralgon. This day time group was set up to complement an ever growing wonderful Warragul evening group, with the two aiming to support the needs of a varied community. We look forward to hosting special guest speakers in 2018, which will be held every second month (opposite Warragul) at the Gippsland Rotary Centenary House. We look forward to meeting some more of the myeloma community at an information morning, being held at the Latrobe Regional Hospital in Traralgon, on 1st December, video linked live from the Royal Prince Alfred Hospital in Sydney.

We have been busy planning our annual Myeloma Update at La Trobe University in Bundoora set for the 25th of November, this year we will also be video linking this popular event live to the Bendigo campus and hope to start up a Bendigo support group in the New Year. Guest speakers include Professor Miles Prince and senior Occupational Therapist Andrew Smith. We are sure their take on exciting treatment options on the horizon, as well as practical strategies for physical health and energy, will be interesting for all.

Current support groups have been continuing across Victoria. Our Kew group enjoyed a lively discussion on some common support line calls, as well as refining their financial knowledge with financial information services officer Bill Burn providing some wonderful guidance. At our Beaumaris support group, Kelly Vibert an exercise physiologist from



Elli Foley & Laura Jones.

Moving Behind Cancer and Cancer Rehab Melbourne joined us for a discussion on exercise and myeloma. Her energy, knowledge and practical demonstrations were a hit amongst the group. It was also time for the annual raffle, many great prizes were donated from the community and I'm sure there was some very happy winners. Geelong welcomed Lauren Nevin a dietitian from Barwon Health who brought her expertise to the discussion on eating well with myeloma. There were so great many questions that we ran out of time and the group hopes to invite Luran back again sometime next year.

Given our commitment to reaching regional areas, Laura recently provided some updates of services and new resources to the myeloma nurses in the Goulburn Valley and Ballarat areas. We are working with the current myeloma support services in the area to come up with a plan for the upcoming year, to best support the community moving forward. If you are interested in speaking about myeloma support group opportunities, we would love to hear from you.

We continue to strive to reach and inform health professionals, with recent education and updates at Shepparton, Traralgon, Ballarat, Epworth, St Vincent's, Peter MacCallum, Frankston Hospital and Peninsula Private. ●

By Elli Foley and Laura Jones
Myeloma Support Nurses



Warragul Support Group.



Support Group display.

Diagnostic and disease monitoring:

Whole-body computed tomography versus conventional skeletal survey in patients with multiple myeloma: a study of the International Myeloma Working Group

Hillengass et al; *Blood Cancer Journal*, August 2017

Skeletal survey (SS) is a series of plain xrays of skull, vertebrae, ribs, pelvis and long bones. Myeloma lytic lesions show as characteristic "punched-out" lesions. When compared to whole body computed tomography (WBCT), 20% of patients with no detectable bone disease on SS, had detectable disease on WBCT, indicating myeloma treatment was needed. IMWG concludes that "WBCT identifies significantly more sites of bone destruction than SS. On the basis of this and other studies, WBCT should be the current standard for the detection of osteolytic lesions in MM".

Treatment:

The Danish biotechnology company, Genmab, have announced that the Phase III trial, ALCYONE (started Dec 2014), has achieved its primary endpoint of improving progression-free survival in newly diagnosed myeloma patients.

This study compared daratumumab (Darzalex®) in combination with bortezomib (Velcade®), melphalan and prednisone (VMP) to VMP alone. Treatment including daratumumab was demonstrated to reduce the risk of disease progression and death by 50% when compared to treatment with VMP alone. The median PFS for patients treated with daratumumab in combination with VMP has not been reached, compared to an estimated median PFS of 18.1 months (1.5yrs) for patients who received VMP alone.

Daratumumab is currently being assessed for use on the PBS by Australian drug appraisal bodies (November 2017 meeting) for relapsed and refractory myeloma patients, in combination with lenalidomide (Revlimid®) or bortezomib (Velcade®).

Treatment:

McCarthy PL, Holstein SA, Petrucci MT, et al: Lenalidomide maintenance after autologous stem-cell transplantation in newly diagnosed multiple myeloma: A meta-analysis.

J Clin Oncol 35:3279-3289, 2017

Three large randomized trials are the subject of meta-analysis to look at overall survival evaluating the benefit of maintenance with lenalidomide vs placebo after stem cell transplant for patients with myeloma. Collectively, these three trials, representing >1,200 patients, showed that progression free survival (PFS) was 52.8 months (4.4 yrs) with lenalidomide maintenance compared with 23.5 months (1.95 yrs) with placebo. OS was not reached with lenalidomide, whereas it was 86 months (7.2 yrs) with placebo in nearly all subgroups, but importantly, it was not the case in patients with stage III disease or those with high-risk cytogenetics, such as deletion of 17p, t(4;14), and t(14;16). Time to second progression was also prolonged by Lenalidomide maintenance versus placebo (73.3months (6.1 yrs) v 56.7 months (4.7 yrs), respectively).

An editorial by Joseph R. Mikhael, JCO, October 2017 notes that these results do not suggest a more aggressive clone is being created by maintenance therapy and Mikhael concludes that lenalidomide should be considered a standard of care in this setting.

Questions however remain regarding maintenance therapy, such as, should other medications be given with maintenance for patients with high-risk disease and, how long maintenance should be given for. Issues of affordability, toxicity, and second primary malignancies make these questions highly relevant. Perhaps measuring minimal residual disease, could allow for a more tailored approach, one that would better indicate the duration of maintenance for an individual.

Treatment:

Efficacy of daratumumab-based therapies in patients with relapsed, refractory multiple myeloma treated outside of clinical trials.

Lakshman A et al. *Am J Hematol*. 2017 Aug 11. doi: 10.1002/ajh.24883. [Epub ahead of print].

Outside of clinical trials, experience with daratumumab-based combination therapies is limited. 126 patients were reviewed who had received >1 daratumumab-based combination therapy. Overall response rate was 47%. Median follow-up was short at 5.5 months. Median progression-free survival was 5.5 months; median overall survival was not reached with any regimen. Median progression free survival was worst for those refractory to 5 or more myeloma therapies. Non-hematologic toxicities included infections (38%), fatigue (32%), and infusion reactions (18%). Grade 3 or higher haematological toxicities were seen in 41% of patients. The authors concluded that daratumumab-based combination therapies are effective in relapsed, refractory multiple myeloma and that overall response rates and progression free survival in heavily pre-treated patients were lower than those reported in clinical trials.

Treatment:

Carfilzomib or bortezomib in relapsed or refractory multiple myeloma (ENDEAVOR): an interim overall survival analysis of an open-label, randomised, phase 3 trial

Dimopoulos MA et al *Lancet Oncol*. 2017 Oct; 18(10):1327-1337. doi: 10.1016/S1470-2045(17)30578-8. Epub 2017 Aug 23.

The phase 3 ENDEAVOR trial was a head-to-head comparison of two proteasome inhibitors in patients with relapsed or refractory multiple myeloma. Patients were randomly assigned (1:1) to receive carfilzomib & dexamethasone or bortezomib & dexamethasone. Between June 20, 2012, and June 30, 2014, 929 patients were randomly assigned (464 to receive carfilzomib and 465 to receive bortezomib). The cut-off date for this pre-specified interim analysis was Jan 3, 2017. The authors found that "Carfilzomib provided a significant and clinically meaningful reduction in the risk of death compared with bortezomib. To our knowledge, carfilzomib is the first and only multiple myeloma treatment that extends overall survival in the relapsed setting over the current standard of care. This study is informative for deciding which proteasome inhibitor to use for treating this disease".

Treatment:

Phase II study of bortezomib, cyclophosphamide and dexamethasone as induction therapy in multiple myeloma: DSMM XI trial.

Einsele H et al; *Br J Haematol*. 2017 Sep 29. doi: 10.1111/bjh.14920. [Epub ahead of print]

This paper assessed the safety and efficacy of bortezomib, cyclophosphamide and dexamethasone (VCD) induction therapy in previously untreated multiple myeloma patients. A total of 414 patients received three 21-day cycles of VCD prior to autologous stem-cell transplantation (ASCT). Most common grade ≥ 3 adverse events were leucopenia (31.4%) and thrombocytopenia (6.8%). The overall response rate (ORR) was 85.4%. No clinically relevant differences in ORR post-induction were seen between patients with or without high-risk cytogenetic abnormalities (86.2% vs. 84.3%). 113 patients receiving ASCT were also included in a prospective consolidation trial (median follow-up, 55.5 months); median progression-free survival (PFS) was 35.3 months and median overall survival (OS) was not reached. In patients with high-risk cytogenetics median PFS was 19.9 vs. 43.6 months ($P < 0.0001$) in patients with standard-risk cytogenetics, and median OS was 54.7 months versus not reached ($P = 0.0022$). The authors concluded VCD is an effective and tolerable induction regimen; results suggest that VCD induces high response rates independently of cytogenetic risk status, but after long-term follow-up, cytogenetic high risk is associated with markedly reduced PFS and OS post-ASCT.

Supportive care:

Bisphosphonate guidelines for treatment and prevention of myeloma bone disease. Lee OL, Horvath N, Lee C, Joshua D, Ho J, Szer J, Quach H, Spencer A, Harrison S, Mollee P, Roberts AW, Talaulikar D, Brown R, Augustson B, Ling S, Jaksic W, Gibson J, Kalff A, Johnston A, Kalro A, Ward C, Prince HM, Zannettino A; *Intern Med J*. 2017 Aug;47(8):938-951. doi: 10.1111/imj.13502.

Dr Oi Lin Lee is Myeloma Fellow at Royal Adelaide Hospital and worked with Myeloma Australia's Medical and Scientific Advisory Group (MSAG) to publish these guidelines.

80% of patients with MM show evidence of myeloma bone disease (MBD) which significantly increases the risk of pathologic fracture, spinal cord compression and hypercalcaemia. Bisphosphonates (BP), are the only pharmacological agents currently recommended for the treatment and prevention of MBD and remain the standard of care. Pamidronate and zoledronic acid are most commonly used. Although generally safe, BP are associated with adverse events such as renal toxicity and osteonecrosis of the jaw and optimal duration and dosing of BP therapy is required in order to minimise BP-associated adverse events. These guidelines provide currently available evidence for the adoption of a tailored approach for clinicians when using BP for the management of MBD.

Myeloma research pathways:

Evolutionary biology of high-risk multiple myeloma

Charlotte Pawlyn & Gareth J. Morgan
NATURE REVIEWS CANCER | REVIEW

Outcomes for the majority of patients with myeloma have improved over recent decades, driven by treatment advances. However, there is a subset of patients considered to have high-risk disease who have not benefited. Understanding how high-risk disease evolves from earlier stages which respond better to treatment is crucial if we are to improve outcomes. This can be done by identifying the genetic mechanisms and mutations driving the change of a normal plasma cell to one with features of the following disease stages (clones): monoclonal gammopathy of undetermined significance, smouldering myeloma, myeloma and plasma cell leukaemia.

Although myeloma initiating events are clonal (the daughter cells inherit the same mutation), subsequent driver lesions often occur in a subclone of cells (further mutations enhancing cell survival and giving a separate myeloma clone), which facilitate progression by Darwinian selection processes. Understanding the co-evolution of the clones within their microenvironment will be crucial for developing therapies to interrupt the process. The end stage of disease progression is a state of treatment resistance, increased proliferation (cell growth), evasion of apoptosis (signals for cells to commit suicide, a normal cellular function) and an ability to grow independently of the bone marrow micro-environment. This Review, discusses these end-stage high-risk disease states and how new information is improving our understanding of their evolutionary trajectories, how they may be diagnosed and the biological behaviour that must be addressed if they are to be treated effectively.

Recent Visits of Myeloma Experts to Australia:

Professor Philippe Moreau, Head of the Haematology Department at the University Hospital of Nantes, France (August) "Immunotherapies in multiple myeloma - treatment principles"; "Sequencing of therapies and implications for relapsed/refractory patients with novel agent combinations"; discussion panels

Dr Shaji Kumar, Mayo Clinic, Rochester, Minnesota (August); "MRD and deep response in myeloma"; discussion panels

Prof Keith Stewart, Mayo Clinic, Phoenix, Arizona | Rochester, Minnesota (September); "First line treatment algorithm for non-transplant eligible newly diagnosed multiple myeloma and Research update";

Dr Donna Reece (October); Director of the Program for Multiple Myeloma and Related Diseases in the Department of Medical Oncology and Haematology at Princess Margaret Cancer Centre/University of Toronto; "A Canadian perspective on the management of multiple myeloma" ●



Calendar of Events 2017- 2018

Victoria

Event	Date	Location	Time	Organisation	Contact
Kew Information and Support Group	Thur Dec 14th	Kew Library Corner Charles St & Cotham Rd, Kew	10am – 12 noon	Myeloma Australia Head Office	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Jan 11th	Rotating at local pubs, details published closer to date	6pm – 8pm Dinner	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur Jan 18th	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Beaumaris Information and Support Group	Thur Feb 1st	Beaumaris Theatre 82 Wells Road, Beaumaris	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Coburg Information and Support Group	Wed Feb 7th	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10am – 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Kew Information and Support Group	Thur Feb 8th	Kew Library Corner Charles St & Cotham Rd, Kew	10am – 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Geelong Information and Support Group	Fri Feb 9th	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Younger Persons Information and Support Group	Thur Feb 15th	Myeloma Australia Head Office 333 Swan Street, Richmond	6pm – 8pm (Dinner)	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Traralgon Information and Support Group	Wed Feb 21st	Gippsland Rotary Centenary House 39 Valley Drive Traralgon Vic	10am – 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Mar 8th	Rotating at local pubs, details published closer to date	6pm – 8pm Dinner	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur Mar 15th	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30am – 12.30pm (note time change)	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233

South Australia

Event	Date	Location	Time	Organisation	Contact
Fullarton Information and Support Group	Tues Feb 6th	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am – 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: (08) 8556 6041 1800 MYELOMA (693 566)
South East Information and Support Group	Fri Feb 9th	Katnook Estate – Coonawarra (6km north of Penola)	11.30 am – 2.30 pm	Myeloma Australia	Carol Koch M: 0427 659 014 clk@live.com.au 1800 MYELOMA (693 566)
Mid-North Information and Support Group	Thur Feb 15th	Snowtown Hospital, Snowtown	12 noon – 2.00pm	Myeloma Australia	Bronwyn Gerschwitz P: (08) 8664 0682 E: graemebronwyng@bigpond.com 1800 MYELOMA (693 566)
Flinders Information and Support Group	Thur Mar 15th	Living Kuarna Cultural Centre Warriparinga Way, Bedford Park	10 am – 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Apr 3rd	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am – 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com P: (08) 8556 6041 1800 MYELOMA (693 566)

Calendar of Events 2017- 2018

New South Wales

Event	Date	Location	Time	Organisation	Contact
RPAH Information and Support Group	Tues Dec 12th	Royal Prince Alfred Hospital Education Centre Level 5 Chris O'Brien Lifehouse 119-143 Missenden Rd, Camperdown	10am – 12pm	RPAH & Myeloma Australia	Tracy King (02) 9515 7310 / 9515 6111 pager 87524 E: Tracy.king1@health.nsw.gov.au 1800 MYELOMA (693 566)
Central Coast Information and Support Group	Thur Dec 14th	Central Coast Leagues Club Dane Drive, Gosford	6 – 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Dec 19th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am – 12pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Newcastle Information and Support Group	Mon Feb 5th	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm – 5pm	Myeloma Australia	John Miller miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)
RPAH Information and Support Group	Tues Feb 13th	Royal Prince Alfred Hospital Education Centre Level 5 Chris O'Brien Lifehouse 119-143 Missenden Rd, Camperdown	10am – 12pm	RPAH & Myeloma Australia	Tracy King (02) 9515 7310 / 9515 6111 pager 87524 E: Tracy.king1@health.nsw.gov.au 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Feb 20th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am – 12pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Westmead Hospital Information and Support Group	Thur Feb 22nd	Crown Prince Mary Cancer Care Centre Conference Room 2 Westmead Public Hospital Hawkesbury Rd, Westmead	10 am – 12pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Feb 22nd	Central Coast Leagues Club Dane Drive, Gosford	6 – 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)
Newcastle Information and Support Group	Mon Apr 9th	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm – 5pm	Myeloma Australia	John Miller E: miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)

Myeloma Support Groups Facilitated by Leukaemia Foundation

State	Location	Group	Time
VIC	Preston	Haematology Group	1st Thursday alternate months of Kew Group
VIC	Bendigo Group	Haematology Group	2nd Monday each month
NSW	Artarmon	Haematology Group	1st Friday monthly (from Feb)
NSW	Wollongong	Haematology Group	3rd Wednesday alternate months (from Feb)
ACT	Canberra	Haematology Group	2nd Tuesday monthly (from Feb)
WA	Perth	Haematology Group	Monthly meetings (from Feb)

National Telephone Support Group (Cancer Council NSW)

Event	Date	Location	Time	Organisation	Contact
Telephone Support	2nd & 4th Monday every month	Available to those with myeloma	1.30pm -2.30pm (AEST)	Cancer Council NSW with MFA NSW	Cancer Council NSW 1300 755 632 E: tsq@nswcc.org.au

DATES AND EVENTS ARE SUBJECT TO CHANGE AT SHORT NOTICE.
For a more accurate events calendar please go to <http://myeloma.org.au/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)

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