

# MyeNews

Summer 2018 Issue no 48



1998 – 2018

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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

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**Office Hours:** 9am – 5pm Monday to Friday AEST

**Head Office:** 333 Swan Street, Richmond, VIC 3121 **Post:** PO Box 5017 Burnley, VIC, 3121

**T:** 1300 632 100 (toll free) **T:** (03) 9428 7444

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## From the President

**We have just celebrated twenty years since Myeloma Australia began but more importantly it is twenty two years since my wife was diagnosed with myeloma and twenty one years since her stem cell transplant. So much has happened since then, Roslyn was 50 and our two children were not yet married. Now they are both married and we have six fabulous grandchildren who give us so much pleasure. Still importantly, Roslyn is well and living a normal life.**



I met with our co-founder Robert Moran last month and we reminisced about the last twenty years, the first ten when he was president and what we have achieved since and we both never ever thought that what we started in 1998 would build to be what Myeloma Australia is today.

Our success goes initially to the fantastic Myeloma Support Nurses (MSN) that have been a part of MA since the beginning. They are the face of MA providing all of our services to the Australian myeloma community. We now have eleven MSN spread throughout Australia and soon we are to have another two to be based in Newcastle. Once the funding has been finalised we will place another MSN in Hobart, hopefully early 2019. Currently Hayley Beer, one of the nurse managers is on maternity leave and we hope to have her back later next year.

We recently held the second National Myeloma Workshop in the Yarra Valley with 150 physicians and researchers attending with four international speakers. Special thanks to Associate Professor Simon Harrison together with Steve Roach and the MA staff for running such a professional workshop which ran very smoothly.

At the dinner on the Saturday night we presented the "Outstanding Service" awards to those volunteers who have given over 15 years of service to MA. A full list is featured in this edition.

MA could not have reached the successes it has today without a lot of people contributing time and effort. We have

mentioned a number in the awards but there were many more who have contributed over the years in some way. Also, to the many doctors who have given of their time to speak at seminars and workshops, I thank you. You have helped to educate our community so that we can learn more and understand the treatment of myeloma.

On that note, we have a regular workshop in Victoria each November called "What is Myeloma". Professor Miles Prince has given this talk every year since 2003 along with a number of special guest speakers along the way. He has been a valuable member of our Board as well as being the current Chairman of MSAG. I would like to thank him for his enormous contribution to MA since we started.

I would like to also thank all the members of our community who have raised money for MA through events or going in fun runs. Your contributions enable us to grow and increase our reach throughout Australia so that we can aim to help every Australian with myeloma. ●

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

*Brian Rosengarten*  
President  
Myeloma Australia

## Christmas Dates

Myeloma Australia will be closed from

**Friday 21 December 3:00 pm**

**Re-opening on Monday 7 January 9:00 am**





## A Historical and Informal Review of the Myeloma Foundation of Australia

In late 1997 my wife Glenys and I were on holiday in the Kimberley region of Western Australia. She fell ill and shortly after, back in Melbourne, she was diagnosed with myeloma. After 35 years of a very happy marriage, myeloma was about to change our lives. For the very first time we were about to face serious adversity.

The emotional effects on all members of our family were traumatic. However, after a short period we made one of our best decisions ever. This was "to fight myeloma in every way we could".

Right from the start, our oncologist, Dr Paul Mitchell, was very helpful and he continued to be helpful for years to come. He put us in contact with Patricia Dobson, a Research and Development Officer with the Anti-Cancer Council of Victoria (as it used to be known). Pat proved to be a tower of strength. Later on she played a key role in the fortunes of the Myeloma Foundation of Australia. Pat also arranged a meeting at the Council's offices where we had the good fortune to meet two other couples who had much the same desire to fight this pernicious disease as we had; Brian and Roslyn Rosengarten and Donald and Judith Brown. In the case of Brian, he had owned a pharmacy and was and continues to be a successful businessman. His wife Roslyn had been diagnosed with myeloma and it is great to report she still lives with the condition today some 20 years or more after diagnosis. At this first meeting, some of the other attendees were Associate Professor Miles Prince and Dr Paul Mitchell. Even at that early stage Miles had established a reputation as a leading haematologist in the field of myeloma research. He had then and continues to have today a significant role within MFA.

So, there we had the embryo of an organisation which we believed was to make a major contribution to the Australian myeloma community. Such has been the case and to an extent this has occurred beyond our wildest dreams.



*Committee 1999*

*L>R: Brian Rosengarten, Glenys Moran, Robert Moran, Jo Wilson, Leanne Lambart & Pat Dobson.*



*Don & Judith Brown, MFA founding members c 2007*



*Glenys Moran, MFA founding member*



*Robert Moran OAM, founding member*

During May 1999 the Association was officially named Myeloma Victoria. It was not until November 2003 that the name was officially changed to Myeloma Foundation of Australia which for this article I refer to as "MFA".

From the beginning, Brian and I took on leadership roles at MFA. We met regularly over coffee and adopted a "what do we do now?" approach. I now endeavour to provide a story of how many individuals, corporations, institutions and groups have, during the last twenty years, made MFA what it is today. It is an organisation which supports and in many ways represents, the patients and carers of those affected by multiple myeloma in Australia.

It is 10 years since I voluntarily resigned from the Board. So, if I have inadvertently left out some important information or the occasional name please accept my apologies. This story generally covers the period to November 2008 but occasionally refers since then via my limited powers of observation.

### Boards and committees

Brian Rosengarten and I were the co-founders of the Myeloma Foundation and each has, in successive terms, held the position of President for an approximately equal period of time.

Other founding committee members included Adjunct Professor Peter Allen

Shortly after the start of activities Peter joined us. He was a well-known company director, a La Trobe University professor and a Rotarian. His contribution to the myeloma cause over 20 years has been invaluable.

Dr Elizabeth Johnson joined the Board in 2006. She is a medical research scientist and has been the face of the Medical Scientific and Advisory Group (MSAG) since its inception. MSAG is a division of MFA.



*First MFA Office in Kew c 2007*

Andrew Gibson

A chartered accountant and long time treasurer of MFA

Irene Beattie

Long time secretary of MFA and a volunteer "par excellence"

Shaun Raby

Chairman Myeloma NSW

Ian Driver

Chairman South Australia

Geoff Day

Chartered accountant and Rotarian

Kay Didenkowski

## Staff

The first general manager was Mike Bruce who had been a prior executive of the Smith Family and a director of the Epworth Medical Foundation. He was appointed in 2008 and worked for MFA until 2011. On Mike's retirement Stephen Roach became Chief Executive Officer. In every sense of the word Steve's contribution to MFA has been outstanding.

Alex (Clarke) Dawson joined in 2008. Initially she was an administration officer and later took on responsibilities for finance and HR.

Pina Civitarese also commenced in administration in 2009. Based on her past experiences she later took on roles in design/branding and running fundraising events such as "The Masters of Rock" & the "Botanical" exhibition.

All members of staff at MFA have been efficient, friendly and professional and it has always been a pleasure to be associated with them.

Volunteers who have left or are still leaving their mark

Peter Allen

Pat Dobson

Irene & Fred Beattie

Geoff Day

Mark Leatham

Alan Lyons

Andrew Gibson

Glenys Moran

Patrick Michaelson

At MFA volunteers are a critical component of daily work. They will always be welcome to become involved.

## Support Nurses

MFA quickly realised that patients needed help in learning about their newly diagnosed condition and what treatment options were available. It often takes a long time to make an appointment with a haematologist or other qualified medical experts. This is where there becomes a role for a qualified nurse. MFA embarked on a program of seeking out suitably qualified nurses and appointing them to serve by phone or by personal visits to meet this demand. The nurse has become a critical person in the everyday delivery of



L>R: Prof Doug Joshua, Robert Moran & Brian Rosengarten c 2008.

services to the myeloma community. Over many years such projects as "The Myeloma Support line" has been operated by specialised nurses and helped plug the gap caused by waiting times for the specialist they must necessarily meet.

Over many years MFA has employed several nurses and they have always been well received by patients, carers and doctors alike. While it is not the purpose to name them all I must give special credit to those who have especially given long and meritorious service to the myeloma cause.

Our first myeloma liaison nurse was Jo Wilson, she was appointed in June 2000. She set the scene for the policies and procedures to be adopted for the future delivery of those services which would best be needed for our special community.

Kaye Hose, our second such nurse played a leading role in Victoria and helped establish the first myeloma support group in Kew.

Tracy King originally worked for Myeloma UK where she specialised in myeloma related projects. She joined MFA and helped to establish a support group and strengthen MFA's presence in NSW. She was based at Royal Prince Alfred Hospital in Camperdown and from there helped expand the 1800 MYELOMA support line service. Tracy held the position of National Services Manager.

Hayley Beer (nee King) was appointed in May 2010. She ultimately became senior nurse at MFA and represented the organisation effectively in many ways. At the time of writing she remains a key person in the MFA nurse leadership team.

When I ceased my role as President in November 2008, I was honoured by being appointed the Patron of MFA. From then I became an observer of all that was happening. Insofar as the nursing team is concerned, I observed during the following 10 years until today, that the numbers of nurses employed now number in excess of 11 and are represented in most states of the Commonwealth. This is a very gratifying situation.

Without doubt the Support Nurses engaged by MFA over a twenty year period have contributed significantly to the improved health of the patients and carers in our special community.

## Medical Scientific and Advisory Group (MSAG)

Some details about this group are referred to in a separate article of this newsletter.

The MSAG group is the pathway for MFA's venture into myeloma research.

## Seminars

During my term as president, I was directly involved, along with Brian Rosengarten, in producing a number of full day patient and family myeloma seminars across three states. The first was held at the Carlton Crest Hotel in St Kilda. Brian and I had no idea how many to expect -- perhaps 40 persons may attend. In fact, 240 attended. They were rewarded by listening to inspirational presentations from leading haematologists and other myeloma related experts from across the country.

At least a further four major seminars were held at:

Leonda in Hawthorn

Brighton-Le-Sands in Sydney

South Parklands in Adelaide

Eden Bayside in Melbourne

Those speakers who freely gave their time and expertise to present at one or more of these seminars included:

Professor Douglas Joshua

Professor Bik To

Professor Miles Prince

Dr Noemi Horvath

Professor Jeff Szer

Professor Andrew Zannettino

Associate Professor Paul Mitchell

Professor Andrew Spencer

Associate Professor Ian Kerridge

Professor Stewart Dunn -- clinical physiologist

## Myeloma Support Groups

One of the key aims of MFA has been to foster the establishment of myeloma support groups in key areas around the country. Based upon the incidence of myeloma it has been policy to form these groups in cities having a population of at least 100,000. Over time this target is being effectively achieved. We were lucky to have on our committee someone highly experienced in the field of setting up cancer support groups. Pat Dobson was responsible for developing a network of over 170 cancer support groups for the Anti-Cancer Council of Victoria (now Cancer Council Victoria). Her work in this area for the Foundation has been invaluable. The support group initiative has been strengthened by constantly liaising with the Leukaemia Foundation. This has been a joint venture exercise in many ways and the beneficiaries have always been patients and carers.

## Haematologists and other doctors

Undoubtedly the most important and gratifying factor that has arisen during the entire life of MFA has been the way that haematologists have supported the myeloma community. To our knowledge not one of those attached to hospitals within Australia (public or private) has ever declined an invitation from MFA to support the organisation in any way possible. They have given their time freely to present at seminars and workshops, written technical and other information sheets in language readily understood, attended support groups and generally responded to technical requests from our staff and nurses at a moments notice. The list also includes a number of oncologists, general practitioners and other medical specialists. To all those experts directly involved with MFA and naturally with the patients and carers concerned, the words "THANK YOU" are offered in the most sincere way possible.

## The Pharmaceutical Industry

Without doubt MFA could not be in the strong position it is today without the ongoing support of the companies within this industry. These are the companies that manufacture and distribute the drugs that help keep our members alive. During the last twenty or so years, the drugs have been many and varied. So too have been the number of companies that manufacture and distribute these drugs. There are too many companies to list for this particular article. Suffice to say that their main assistance to us has been funding. But more than that they have been helpful in communicating with us and explaining all relevant factors about their drugs. We, in turn, can pass the information on to our members through MyeNews or via our workshops and seminars. This includes the technical details of exactly what is being consumed, its probable efficacy and its likely side effects, if any. This is invaluable help for all concerned.

## Funding

MFA relies on much of its funding from a variety of sources. The most important is from the pharmaceutical industry. However, MFA also relies for its survival on funding through its own efforts. There are presently three professional fund raisers on staff including CEO Steve Roach. In September 1999, the Rotary Club of Camberwell approved funding of \$40,000 over two years towards a research project led by Professor Miles Prince. Shortly after, the cheque itself was presented to me at one of the club's weekly meetings. It was six feet long.

Major events are a speciality and have included "Ride for Recovery" being a week-long cycling challenge throughout New South Wales, amongst other states. Fun-runs on the mainland, "Masters of Rock" concerts featuring the late Jim Keays of the "Masters Apprentices". Jim himself lived with myeloma for many years. There were numerous other activities as well. For example, Myeloma NSW ran various functions led by Shaun Raby including Trivial Pursuit events and similar activities.



During September 2017, a successful exhibition of watercolours was hosted in Melbourne by the well-known artist Patricia Ball. The exhibition was named “Botanical” because of the body of work produced. Patricia also donated thousands of greeting cards based on her botanical art to be made available for fund raising purposes.

The most significant of these functions was the Business of Winning Luncheon, the brainchild of board member Peter Allen. Peter is a long- term member of the Rotary Club of Camberwell. This is our biggest annual fundraiser at which sporting stars and celebrities come along to engage, enlighten and entertain and help us raise money and awareness for the myeloma cause. The Winners’ Lunch began in 1999 and was proudly led by the late, Ron Casey. So far it has been run at such venues as Crown Casino and the MCG for the past 19 years and has certainly proved to be a Winner.

## Expansion

During 2005, New South Wales was already running its own support organisation. Myeloma NSW was led by Shaun Raby who, with his committee agreed to a merger with MFA. On 15th Mar 2007 Myeloma South Australia officially merged with Myeloma Foundation of Australia. The Chairman of Myeloma South Australia was and continues to be Ian Driver.

## Government

During 2007 an approach was made to the Government for assistance. Through the Department of Health and Ageing the Commonwealth Government agreed to fund a business plan and provided a grant of \$50,000 for that purpose. The plan was prepared by Michael Bruce in conjunction with Chris Leptos of Ernst and Young and the plan helped MFA set a blueprint for the future.

## Newsletter / Magazine

Initially there were 24 quarterly editions of a Victorian publication named MyeVic. *MyeNews*, an all Australian newsletter, followed and was first distributed in the summer of 2006. It was a high quality 20 page publication. I recently



glanced through it and was so impressed with its content and quality. First there was a five page medical corner displaying detailed information on peripheral neuropathy, the latest developments on relevant drugs for myeloma as well as information on clinical trials. Brian Rosengarten, with his pharmaceutical knowledge and experience, oversaw the “Medical Corner” inclusions as they were all very important. I perused the “Calendar of Events” for the period Feb to June 2006. This listed 31 myeloma related events presented across five separate states. Two “Personal Experience” articles were included. One was from a well-known journalist, Pamela Bone, whose particular story was not only interesting but inspirational as well. Pamela was a senior journalist with *The Age*. The aim of the editors of *MyeNews* is to encourage its readers to participate in the activities of MFA. There are so many ways this can be done.

## Information sheets

These were regularly published. They dealt in detail on those subjects of most interest and relevance to MFA subscribers. Included were topics such as clinical trials, specific drugs, side effects, etc. They were generally written by medical experts and formed a valuable addition to all other information resources.

## Conclusion

In 2009 I was awarded an Order of Australia Medal for services relating to cancer and myeloma in particular. This was a great honour. From the foregoing it can be seen that this award should be shared with all those referred to in this article. Then when I think of my late wife Glenys, it should also be shared amongst the patients and carers who have been touched by myeloma and especially by the people of MFA. It has for me been a very great honour to serve in this cause. ●

*Robert Moran OAM  
Co-Founder, Past-President & Patron  
Myeloma Foundation of Australia*



Roslyn & Brian Rosengarten with grandson Benji.

# History of the Medical and Scientific Advisory Group

**In November 2005, a discussion took place in the Hilton Hotel at Melbourne Airport between two leading haematologists, Professor Douglas Joshua from the Royal Prince Alfred Hospital, NSW, and Professor Luen Bik To of the Royal Adelaide Hospital, SA, and Robert Moran, the then President of the Myeloma Foundation of Australia (now Myeloma Australia). The purpose of this meeting was to find a way for Myeloma Australia to forge closer medical links through clinical and research collaboration to improve outcomes for those living with myeloma, whilst ensuring that the best possible information available would be accessible to patients and carers.**

Dr Elizabeth Johnson, who was a new member of Myeloma Australia at that time, undertook to design and convene a "Medical and Scientific Advisory Group" (MSAG). MSAG formally came into being in 2006 as a subcommittee of Myeloma Australia. Its objects included facilitating research, furthering patient education and advocacy, liaising with industry regarding new treatments and clinical trials, and holding scientific meetings, including with international collaborators, to further myeloma research and treatment. MSAG was established with 14 foundation members, which comprised of many leading haematologists in the country. To ensure alignment of principles and activities. Board members from Myeloma Australia were also included. The group was initially Chaired by Prof Douglas Joshua, with Prof Miles Prince succeeding him.

Over 13 years, MSAG has grown to be a highly respected part of Myeloma Australia and one that differentiates our foundation from others internationally. Our members comprise of haematologists and scientists and has grown to include representatives from every State and Territory in Australia. Collegiate connections with haematologists across the Tasman Sea are long-standing, so the addition of New Zealand haematology representatives to the group in 2017 was welcome.

The group meets twice annually to consider a range of clinical developments (e.g. availability of new drugs, better use of current treatments, clinical trials), research and education opportunities in myeloma.

MSAG is now considered the peak myeloma body in Australia, being recognised by the clinical haematology community, Government and industry alike. It has proven itself to be a highly effective and collaborative organisation which contributes directly to improved management of Australian patients with myeloma. MSAG facilitates collegiate interaction and unified clinical opinion among haematologists nationally, whilst influencing key policy makers. Recognising that MSAG has an important specialist training role to play, in addition to one of supporting

collaborative research, it has more than lived up to its original aspirations. It was through Bob's leadership and initiative in connecting with the clinicians (not to mention his charm!) that enabled the conditions under which MSAG could come into being.

Key MSAG activities and achievements include:

- Establishment of clinical practice guidelines. This has been an important activity for the MSAG members as their publications now cover clinical management guidelines for myeloma and the related conditions of amyloidosis and Waldenstrom's macroglobulinemia, and for therapy with bisphosphonates. They are reviewed regularly and agreed updates made. Having these formally recognised guidelines has helped us to make the case to the authorities for improvements in treatment regimens.
- Dissemination of research and collaborative activities through regular forums. These now include the National Myeloma Conference, a biannual forum for researchers in myeloma that brings together clinician scientists and laboratory researchers with the goal of improving translation of research into improved clinical practice and new treatment approaches.
- Liaison with government agencies, particularly the Pharmaceutical Benefits Advisory Committee (PBAC). Since the establishment of MSAG there have been major changes in the therapeutic landscape for myeloma and others are on the horizon. The prospect of new treatments for myeloma is always good news and MSAG has played an important reference role in the access to new treatments for Australian patients.
- Clinical trials activity and linkage with the Australian Leukaemia & Lymphoma Group (ALLG) and with the Myeloma and Related Diseases Registry (MRDR). Clinical trials can allow early access to novel therapeutic agents ahead of their general availability, which can benefit myeloma patients. MSAG members are also active in seeking support for clinical trials that address real-world clinical issues in myeloma management.
- Training of advanced trainees, nursing and allied health practitioners. MSAG initiated specialised training in myeloma for junior haematology specialists and nurses specialising in myeloma, to ensure they are equipped with the best specialist and up-to-date knowledge of this complex cancer. National training workshops are held every two years.
- Supporting patient education in conjunction with Myeloma Australia patient-focussed activities, MSAG members regularly address patient and carer information events and contribute to preparing information materials. ●

*Robert Moran OAM  
Past President MFA  
&  
Dr Elizabeth Johnson  
Director / Convenor of MSAG*





## MSAG current members



*Prof Miles Prince AM*



*Dr Elizabeth Johnson*



*Prof Doug Joshua*



*Dr Noemi Horvath*



*Prof Andrew Zannettino*



*Prof John Gibson*



*Dr Peter Mollee*



*Prof Joy Ho*



*Dr Hang Quach*



*A/Prof Simon Harrison*



*Prof Jeff Szer*



*Dr Bradley Augustson*



*Prof Andrew Spencer*



*Dr Simon Gibbs*



*A/Prof Dipti Talaulikar*



*Dr Silvia Ling*



*Dr Wilfred Jaksic*



*A/Prof Chris Ward*



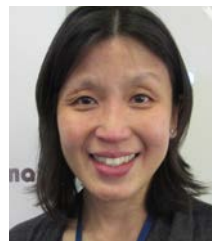
*Dr Akash Kalro*



*Dr Nicholas Murphy*



*Prof Andrew Roberts*



*Dr Cindy Lee*



*Dr Nicholas Weber*



*Dr David Simpson*



*Dr Ken Romeril*



*Dr Anna Kalff  
(alternate)*



*Dr Anna Johnston  
(alternate)*



*Dr Ian Prosser  
(alternate)*



*Dr Dejan Radeski  
(alternate)*



*A/Prof Ferenc Szabo  
(alternate)*

# The Business of Winning

## The Business of Winning Luncheon turns twenty



***"Winning isn't everything:  
It's the only thing."***

So the "Winners" luncheon is turning twenty? Who would have thought it way back then?

The year was 1999. It would be a long time before we would become Myeloma Australia. We were simply a tiny charitable outfit with some passionate volunteers and a keen commitment to support people living with myeloma. There was no shortage of ideas and plans but the same could not be said for the availability of funds to bring those ambitions to life. Simply, nothing much could be achieved without money and it would be needed increasingly and reliably if we were to be successful.

The idea of a corporate luncheon as part of the solution was born and The Business of Winning Luncheon was conceived. Enter our friends. The Rotary Club of Camberwell has been with us since "Day One" helping with funding, governance support and contacts. The club became our partner in the luncheon venture and has continued its support over two decades. Expo Hire Australia, a corporate friend, managed the event and the late great Ron Casey of "World of Sport" fame introduced us into – literally – his world of sport and opened an access avenue to guests for our luncheon.

With Ron Casey as our first Master of Ceremonies the success of our first luncheon seemed assured. In 1999 Ron stepped to the lectern at the Sheraton Southbank (as it was then) and announced, "This will be a luncheon called 'The Business



*Ron Barassi, John Kennedy Angela Pippas & Tommy Hafey.*

of Winning". Our on-stage guests that day in front of an audience of two hundred included AFL North Melbourne Premiership coach Dennis Pagan, and champion jockey Roy Higgins. We were on our way with a great function and a promising fund-raiser!



*BoWL panel – L>R John Kennedy, David Parkin, Dale Weightman & Michael Roach*

The formula has remained much the same – a professional MC leads a panel of mostly top sports-people as they together light-heartedly explore what it takes to win. There are auctions – both silent and live – that feature high value sporting memorabilia, travel and more. And there is music



*Ashley Naylor, Neil Balme & Greg Champion.*



*Peter Hudson, Bianca Chatfield & Mike Derum*





*Kevin Bartlett & David Cloke*



*Sharelle McMahon & James Tomkins*

and comedy too delivered by well-known professionals. It's a long lunch – a half holiday if you like – that for some extends to late in the afternoon and evening in what has become known as "the fifth quarter".

The list of panel members over the twenty-year journey reads like a "Who's Who" of Australian sport and especially AFL football. (CEO Steve Roach played AFL with the St Kilda, Richmond and Collingwood clubs and retains many friends from those days.)

There have been many stand-out panels but none as eminent than our "Coaches Emeritus" event in 2012 where the seemingly impossible was achieved. More than five hundred guests assembled at Crown Palladium to experience our panel of AFL coaching legends (or Coaches Emeriti more correctly for the scholars among us) – John Kennedy, David Parkin, Tommy Hafey and Ron Barassi. The panel was led by our long time MC from the Hawthorn Football Club, Michael Derum. As one guest observed, the luncheon "...had it all, and an embarrassment of riches".

The late Jim Keays, leader of Master's Apprentices band and a myeloma patient, was a great supporter. Following Jim's death a few years ago, his many friends from the music

industry have remained engaged with us and perform at the luncheon from time to time.

The funds generated by our Winners luncheons help us to maintain and develop our services to the myeloma community. There is a second great benefit from the foundation's public outings. Progressively, the profile of the myeloma disease is lifting. More and more people know about myeloma and less and less are we hearing, "Myeloma? What's that?". This collateral benefit helps us in our campaigns for support from government, sponsors, medicos and the wider community.

Fund-raising, like all activities of the Myeloma Foundation adds to the mix of components that support us on our journey towards fulfilment of our mission, "... a world without myeloma."

The 2019 Business of Winning will take place on Friday 15th Mar in the Members' Dining Room at the MCG. We'll be in touch again soon with more information. May we look forward to your support.

*Peter Allen,  
Director, Myeloma Australia*



*David Cloke, Pina Civitarese & Neil Balme.*



*Greg Champion.*



*Susan Alberti.*



## Profile

### Alex Dawson – Head Office

Many of you will have had contact with Alex in some way at some point over the last 10+ years. As the longest serving Myeloma Australia staff member, she can be considered a part of the furniture... but we would never refer to her as that (of course). At the Second National Myeloma Workshop in September this year, Alex was awarded a trophy marking her 10 years of service to Myeloma Australia. At the time of going to print Alex will be working up to nearly 11 years of service.

Since starting with Myeloma Australia or Myeloma Foundation of Australia Inc. as it was back in the "olden days", Alex has witnessed much change and growth. She has been a very valuable member of the organisation contributing to its success over the years. With a diploma in HR she is currently working on a policy & procedure manual which will be a valuable resource to all staff members as we continue to grow. At last count we have 18 of us dotted around the country with another three part-time nurses about to be employed. Alex looks after all things financial at Head Office along with HR, managing the data base, our volunteers and supporting the nursing staff across the country.

We would be lost without her, so on behalf of Myeloma Australia, volunteers and other members of the myeloma community, I would like to thank her for all her years of service.

*Pina Civitarese*  
Fundraising & Support Services



*Alex with her trophy.*



Alexandra (Alex) Clarke has spent much of her career in the medical field working for a paediatric surgeon and as practice manager for a plastic surgeon. She took eight years off to have her family and she and husband James are proud parents of Lachlan (8) and Laura (5), not to mention Allie the family dog. Alex returned to part-time employment in 2007, working for a building and architectural company but missed the medical side of things and is looking forward to working for the Myeloma Foundation.

Alex has an Advanced Diploma in Medical Secretarial Studies, is completing a Diploma of Accounting and – when she has the time – enjoys reading, cooking, exercising and spending lots of time with her family.

Both Mike and Alex will be working part-time initially and will be based at MFA's national office in Kew. We expect the office will be attended between the hours of 10:30am and 3:30pm, Monday through Friday. Contact details are: (03) 9853 8118 and (03) 9853 8110, email: (Mike) [info@myeloma.org.au](mailto:info@myeloma.org.au), (Alex) [admin@myeloma.org.au](mailto:admin@myeloma.org.au).

*MyeNews Summer 2008 #7*

*Photos © Pina Civitarese*

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*and much more...*

## Profiles

### Megan McDowell WA Support Nurse

My name is Megan McDowell and I am one of the newest support nurses for Myeloma Australia based in Brisbane, Queensland. I fell in love with haematology nursing at the Mater Private Hospital back in 2003. I was humbled and privileged to nurse some of the sickest patients in the hospital while learning from some of the best doctors and nurses in the country. I was then given an opportunity to learn more about stem cell transplant by seconding to the Mater Apheresis and Transplant unit. There I stayed for the following years where my love of blood and its complexity grew. After getting hitched to a good-looking pharmacist, travelling the world and having a few cute kids, I have continued working in both the haematology out-patient and in-patient settings. Over these past 15 years I have met some inspiring patients, as they walk through their multiple myeloma journey. I am very excited to be in this new role to provide support and continue learning from these amazing patients, who from the beginning of my career have always been my most valuable teachers.



Megan McDowell

### Natasha Clarke WA Support Nurse

Hi, my name is Natasha Clarke (although you'll quite often hear me call myself Tash). I started working for Myeloma Australia September 4th 2018, so I'm pretty new. However, I have been nursing in haematology/oncology for a little over 20 years and I love it. I have been privileged to work in this area during an era when there has been so much discovery about cancer and I am constantly learning. Some of these new discoveries have led to exciting new developments in treatments for cancer which means our patients are benefiting. Of course, the other reason I love this work is because my interactions with patients are so rewarding. I know, that as nurses, we give a lot to our patients and they value us highly, but I'm not sure if they realise just how much they give to us by sharing their experiences and knowledge. I have spent six years as a nursing educator and again I really enjoy the exchange that takes place of energy and ideas, in that setting. Now you know my passion at work, you can see why I am so excited to work for Myeloma Australia- it provides one of the best bits of nursing ie: talking to patients and other health professionals.

When I'm not at Myeloma Australia I work at Princess Alexandra Hospital as site manager for the Myeloma and Related Diseases Database and as a registered nurse in the haematology/oncology day hospital.

Originally from Adelaide, I moved to Brisbane in 1995 to be with my now husband, Mike. After the initial shock of hills and humidity I grew to love the easy, relaxed Queensland way of life. My favourite place to be is North Stradbroke Island, just off Brisbane. Mike and I have two daughters, Ella



Natasha Clarke

and Hannah. Ella is 17, finishing school and about to embark on her life as an adult so there is much excitement and a little nostalgia happening in our house. Hannah is 15 and in year nine. She plays netball, so I convene umpiring for her club. We all share a love of music, film and books, although our tastes differ a fair bit. We live in a leafy suburb that backs on to the Brisbane State Forest so going for walks is a great way to relax and exercise at the same time. At the end of a long hard day you can always find me relaxing with a great TV series/film or a good book.



## 2018 – The year that was!

### **Myeloma Australia has been growing our nursing and wider services to myeloma patients throughout Australia.**

We are seeking to enable and provide greater support for patients who live in all parts of Australia, especially to those with no close treatment centre available. Our desire is to empower and enable patients to access the best available treatment for their specific situation. This will take much stress away from the patient and their family and ensure that patients are able to avail themselves of the best available care.

We have been building our capacity with our nurses to have services on the ground in each state and to provide a platform to deliver future services from. To this end, we have built our nursing team significantly and have increased the number of patient publications we produce.

We now have two nurses in Western Australia, one nurse (to be two in 2019) in South Australia (this nurse has extended hours and also looks after the Northern Territory), two nurses in Victoria, four nurses in New South Wales including two newly appointed nurses in Newcastle for the central and northern NSW coast and Hunter region, two nurses in Queensland and one newly appointed in Tasmania. We have two nurse managers (one who is currently on maternity leave) who job share managing services, programs, publications and patient services. That is a total of 12 nurses



nationally. At the start of 2017 we employed four nurses and had 12 information and support groups nationally. We now have 28 information and support groups and that is growing by about one per month, around the country.

This year we have delivered 15 major patient seminars, held over 120 information and support group meetings, conducted over 40 medical professional education events to approximately 700 medical professionals around the country and distributed literally thousands of books and pamphlets on myeloma. Our nurses have also taken over 600 calls on our 1800MYELOMA support line.

We have achieved all of this with huge support from the wider myeloma community and our plan is to continue to give back to this community. To date, we know we have only hit the tip of the iceberg. We are absolutely thrilled with patient responses everywhere we go; patients are reaching out for support and we will continue to do all we can to be there for them.



*Staff Photo (all staff as at September 2018)*

*Standing (L>R) Matt Maudlin, Santosh Ojha, Jo Gardiner, Narelle Smith, Sam Zeps, Elli Foley, Natasha Clarke, Steve Roach, Jacqueline Tate, Hayley Beer, Jacqui Keogh, Kerin Young, Geo Sobrio. Sitting (L>R) Nella Combe, Laura Jones, Alex Dawson, Megan McDowell & Pina Civitarese.*

Photo © Pina Civitarese



Behind the scenes of the nursing and patient services we have three part time support staff at head office who handle the administration, finance, communications and generally keep things running. We also have a part time assistant for our doctors and scientists on our MSAG to ensure the smooth running of medical and scientific affairs. In this last year we also appointed two fundraisers who work on community engagement and helping us raise the money to sustain all our patient services.

Along with myself as CEO we have a Committee of Management (the Board) who oversees the governance, direction and mission and financial security of Myeloma Australia.

I would like to thank all staff for their wonderful service to our community in 2018.

*Steve Roach*  
CEO

*Following is a list of all our people at the end of 2018:*

## **People**

### **Nursing team** (all nurses work part time)

Hayley Beer – Nursing and Programs Manager (Currently on maternity leave)  
Nella Combe – Myeloma Nursing and Patient Services Manager  
Jo Gardiner – Senior Myeloma Nurse Specialist, South Australia and Northern Territory  
Jacqui Keogh – NSW State Manager, Senior Myeloma Support Nurse New South Wales  
Geo Sobrio – Myeloma Support Nurse New South Wales and ACT  
Juliet Hill – Myeloma Support Nurse Newcastle and Hunter Region (starting January 2019)  
Rachel McCann – Myeloma Support Nurse Newcastle and Hunter Region (starting January 2019)  
Elli Foley – Myeloma Support Nurse Victoria  
Laura Jones – Myeloma Support Nurse Victoria  
Kerin Young – Myeloma Support Nurse Western Australia  
Narelle Smith – Myeloma Support Nurse Western Australia  
Megan McDowell – Myeloma Support Nurse Queensland  
Natasha Clarke – Myeloma Support Nurse Queensland  
Deborah Thompson – Myeloma Support Nurse Tasmania (Hobart starting January 2019)

### **Head office staff**

Steve Roach – CEO  
Alex Dawson – Finance / HR / Support Services  
Pina Civitarese – Fundraising / Communication / Support Services  
Samantha Zeps – Support Services / Nursing Support

### **Fundraising**

Matt Maudlin – Manager Community Engagement, Fundraising and Sponsorship  
Santosh Ojha – Community Engagement and Fundraising New South Wales

### **MSAG Support**

Jacqueline Tate – MSAG Project Manager and Liaison  
Committee of Management and Office Bearers (Board Members)  
President – Brian Rosengarten  
Treasurer – Peter O'Brien  
Secretary – Jeffrey Hanlon  
Director/Chair of MSAG – Professor Miles Prince AM  
Director/Convenor of MSAG – Dr Elizabeth Johnson  
Director/Executive Committee Member – Peter Allen  
Director – Ian Driver  
Director – Adam Schwab  
Director – John McLennan  
Director – Ajay Bhatia



# 2018 Inaugural Myeloma Australia Volunteer Awards

The seeds of Myeloma Australia were sown in 1998 by a small number of driven people, each profoundly affected by myeloma, who discovered for themselves that diagnosis of myeloma was often slow, uncertain and burdensome. Those people took it upon themselves to make a difference to others living with myeloma and their loved ones and friends.

Over the past twenty years many people have given their time, effort and passion to the myeloma community. In 2018 we decided to start recognising those people in our community who have given so much and applaud them for their service. This year we held four award presentation events around the country to recognise the first recipients of our volunteer awards.

Congratulations and thank you to all the recipients. We look forward to recognising many more of our volunteers in future years.

Following is a complete list of the 2018 volunteer award recipients.

## Outstanding Service Award

Robert Moran OAM  
Glenys Moran\*  
Brian Rosengarten  
Ian Driver  
Shaun Raby\*

Linda Raby  
Prof. Peter Allen  
Prof. Miles Prince  
Prof. Douglas Joshua

## Meritorious Service Award

Pat Dobson  
Irene Beattie  
Ilona Wright

Dr. Elizabeth Johnson  
Tracy King RN MN  
A/Prof. Paul Mitchell

## Recognition of Service Award

Jo Gardiner RN  
Ray Grummett  
June Grummett  
Sandra Driver  
John Miller  
Kay Didenkowski  
Wendy Pfeifer  
Mark Leathem  
Peter O'Brien

Geoff Day  
Peter Thornton  
Robyn Thornton  
Andrew Gibson  
Jacqui Jagger  
Patrick Michaelson  
Glenda Bailey  
\* indicates deceased



Award Recipients (L>R) Ian Driver, Robert Moran, Peter Allen, Brian Rosengarten & Prof Doug Joshua



Jo Gardiner



Linda Raby & Tracy King



Back Row (L>R) Steve Roach, Capt'n Patrick Michaelson, Prof Miles Prince, Peter Thornton. Front Row (L>R) Kay Didenkowski, Wendy Pfeifer, Robyn Thornton & Brian Rosengarten



## Introducing 'Big Al's Adventures

### A new myeloma travel blog to be featured on our website in 2019

#### Back Testing in South Australia

So here I am, having been happily roped into sharing in the MyeNews, an adventure I am about to undertake with my wife.

As they do, all my fantastic doctors and nurses have advised me to get on with life and enjoy. So, my wife Rowena (Ro) and I (my friends call me Big Al) have just procured a caravan so we can start planning our big trip around this fantastic island we call home.

I discovered I had multiple myeloma way back in October 2015 – an x-ray of my back confirmed I had multiple myeloma in my L1 vertebrae.

After having got over the initial shock and embarked on what has now been two years of treatment, I find myself in remission, which is great, although the myeloma has left my back, in what I feel is a very precarious position!

We both thought that it would be best to take the advice to enjoy life a bit more and take a short trip first to check all the Caravan smarts and more importantly to see if Ro and I were still talking at the end of it!

Oh, and most importantly test to see if my back can hold up!!

So, I informed Ro South Australia it is then, with a few stop-overs in Victoria on the way. Ro looked rather nonplussed, but when I advised that there were a few wineries to explore, well South Australia was just fine!

I will make a pact with you all, that it will not be my intent in my future news (noting that I am working on a MM blog) to "on sell" the manufactures of our new caravan or the vehicle (tug) we will be pulling it with. My intent is to share with you all what we encounter along the way with advice on where to go. Hopefully all this will be positive, but I won't hold back if it's not.



*Big Al & Ro*

So, to get to the trip, we have taken three weeks off, I think that will be long enough to see how we get on. We will leave our home in Patterson Lakes late November and head for our first stop in Echuca for two nights before pushing on down the Murray River via Swan Hill and Mildura then into South Australia and explore the wineries and a few more interesting places along the South Australian coast prior to setting course for home.

The plan will be to mix free camping with paid nights at some sights. Ro asked what "free" camping was all about. I thought it best left to keep her wondering (I mean free is good isn't it!) for the time being so I can plead ignorance if this is not what was expected. Only time and a potential warm conversation (!) will prove my case on this. Watch this space.

All the details of our initial adventure will be published in the next issue of MyeNews and the blog on the Myeloma Australia website. So, feel free to check it out.

In the meantime, stay positive!

*Big Al and Ro*



## Myeloma Support Line

**Monday – Friday 9am – 5pm (AEST)**

**1800 MYELOMA (1800 693 566)**

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



## Myeloma, travel and golf

In retrospect, pain playing golf, that would mysteriously appear in the ribcage and heal over a two week period, then the same pain bending over to pick something up off the ground, or starting the lawn mower was my then unknown introduction to myeloma in 2006. It remained undiagnosed for six months despite rigorous investigation. My urine and serum remained clear, nothing atypical, as did my kidney function. A huge variety of further tests including X-rays and bone density followed. The recommended top endocrinologist even sent me to three different pathology companies on the same afternoon for the same tests to compare! The results were found to be identical, he was stumped! In the interim, I had a whole of body scan which found seven vertebral crush fractures and a greater number of cracked ribs that were accompanied by intense pain necessitating super strong pain relief. It was a toss-up on the pain scale between my back and ribs or on the toilet! I could hardly walk. The endocrinologist finally suggested a marrow biopsy and I eventually found an orthopedic surgeon who would do it and my myeloma was identified via Sir Charles Gardiner Hospital Haematology Care Centre. I was found not to produce the M paraprotein, only a runaway kappa light chain component i.e. SLC.

My initial treatment was with thalidomide. Most people are aware of the history of thalidomide. Studies have shown it stops, among other things, limb formation in a foetus, but scientists also found it to impact on the proliferative capacity of myeloma cells. I was treated with thalidomide and selected chemotherapy drugs like cyclophosphamide over approximately a six month period, along with dexamethasone and a bisphosphonate called Zometa. Stem cells were collected and later after infusion I went home to recuperate. I went into remission for approximately three years and then my SLC kappa count started to elevate rapidly. Suddenly without any warning, my pulse dropped to 38. Following a hasty ECG, I was diagnosed with total heart block and admitted to a private hospital. No evidence of heart problems in my family existed, and overnight I was fitted with a pacemaker under local anaesthetic. During the first year on insertion the pacemaker was interrogated and found only to be required for 16% of the time. The pacemaker is in "standby mode."



The second treatment I had was tablet based. The immunotherapy approach lenalidomide (Revlimid) was very effective for me together with dexamethasone of course! I had almost zero side effects, maybe just a very little neuropathy and no tummy problems at all. Taking this drug I drove from Perth camping up the Canning Stock route to NW of WA then across the Tanami Desert into Alice Springs. During the Alice stopover I had bloods taken at the hospital and the results emailed back to my Perth haematologist to confirm all was OK, which it was. Then from Alice down the old Ghan railway to Finke, then east across the Great Sandy Desert to Birdsville for the races, and a few beers. We returned via Maree and Coober Pedy back to Perth. However, over time Revlimid's efficacy on me waned. My SLC began to rise unabated. My myeloma got smarter in avoiding detection and stopped the Revlimid from impacting on it. So, my period on Revlimid had to come to a close, a shame as it has been the most flexible lifestyle drug I have been on.

The third treatment has been by injection/infusion. Bortezomib (Velcade) is part of the proteasome inhibitor approach to myeloma treatment. When I started I found the Velcade fantastic, it gave my myeloma a thrashing, reducing SLC count from four figures to two figures in just in three



Photos supplied and used with permission

weeks. In the second cycle the side effects hit and were so severe with neuropathy in my hands, feet and legs up to the waist, and it caused permanent chemical damage to my nerve endings. I was immediately taken off Velcade and I now need Lyrica Pregabalin tablets to ease the pain. It affected my bladder, it is like standing on a BBQ, my hands and feet get so hot. As I release my bladder sphincter the pain is intense, then fades away to nothing. I have no sensitivities with the soles of my feet. In a boat I keep falling over! A MM colleague of mine on Velcade finds it like ice cream, loves it, no reactions at all! It is super effective with his myeloma. I can only assume the side effect reaction depends on your individual makeup, we are all uniquely different.

My next (fourth) treatment was with pomalidomide, a derivative along the thalidomide line, suggested to be a better acting drug than its predecessor, younger brother lenalidomide. I was disappointed with this drug, it certainly did not impact with a lot of kick. Maybe my long treatment on Revlimid had worked to my disfavour as the myeloma over time had mutated to find a way around the Revlimid attack, and the same actions were being repeated. There were no side effects experienced taking this drug, and its impact on my myeloma was zero! My light chain readings continued to climb. Like Revlimid though, it was a good traveller!

With pomalidomide doing zero, my doctor was able to access Ixazomib on compassionate grounds as treatment options were getting very few. This was my fifth treatment option. I commenced the Ixazomib full of hope but found it had as much impact as Vegemite. There were no side effects, together with pomalidomide, and no change! I repeat, probably for a different person Ixazomib would ring the bell! For me, the bell battery was flat!

Carfilzomib (Kyprolis) then was added to the PBS list! It is a proteasome drug, a sister of Velcade (one that I had very major neuropathy damage with) and was/is treatment six. I had to go to hospital for the initial infusion as an inpatient, a first in my myeloma treatment journey. In the three weeks of treatment my kappa light chains dropped from 1800 to 50! Fantastic! My health improved. My hair turned curly! Advantageously Carfilzomib did not "eat" my platelets and red cells as proteasome drugs have been known to during treatment. Expecting severe neuropathy from this drug, I received almost none. I settled in to a three week on with two infusions a week at SCGH both with Dexamethasone but a problem reared. An annual check on my pacemaker and subsequent heart scans confirmed carfilzomib had a deleterious impact on my heart pumping rate. My ejection fraction dropped from 55 to 37. Thus, I then found myself in the position of treatment of the heart with beta blockers and ACE inhibitors, problems with fluids and super fat ankles and shortness of breath. My pacemaker is now running 100%. Carfilz infusions were dropped from two per week for three weeks to one per week over the same period. Thus far, the diminished infusion has seen SLC continued to fall further! After six months on Carfilz I have developed diarrhoea, and now take Gastrostop as insurance to block me up when I need to attend



appointments away from home. I think now it is a touch of autonomic neuropathy impacting, following a colonoscopy which was 100% clear and negated that assumed diarrhoea cause.

So, the body is a bit battered after 12 years of treatment. My former 197cm height is now 189cm and my weight of 120kg now around 100kg. My ribs continue to migrate south; there is little difference between my bottom ribs and iliac crests, my stomach with nowhere to go but out in a small pot belly. Each month I have an infusion of the equivalent of 600ml (King Brown) of Intragam, an immunoglobulin back up to my non-performing immune system. I have set up a very strong team around me, my haematologist, my GP and my cardiologist. They send one another all reports and I arrange copies of my monthly bloods. Similarly, between my dermatologist, plastic surgeon and his anaesthetist. They talk too, about I think, the beach houses I am building for them! (Joking).

I have just returned from a 10-day trip (between Carfilz infusions) to Singapore and the Philippines, it took a bit of planning with the Gastrostop as I had not only planes to contend with but also a ferry. I don't mind sitting down the back by the toilets on a plane now! We have undertaken two boat cruises, one to PNG where I worked for 13 years, and one to Vietnam, where I worked for two years. I regularly go to Singapore to see my daughter. Travelling on tablet treatment is a snack, where your treatment is infusion based, it becomes a little trickier. Sure, there is risk as approaching 72 years of age not many insurance options are available but as they say "Carpe Diem" Seize the day! I still live at home, my partner (soon to retire) does most of the shopping and cooking, lawn mowing and gardening. I swim/wade three times/week to build up my proximal muscles as I found it difficult getting off the floor or the toilet without a wall to help me up. Sure, I go to sleep early at night, I blame it on my active lifestyle, but it could be the Shiraz I enjoy while cooking the evening meal!

Murray Day  
WA



## Second National Myeloma Workshop

The Second National Myeloma Workshop was held this past September to bring together myeloma researchers from around Australia and the world. We were delighted by the caliber of speakers and international guests attending this year. Associate Professor Simon Harrison (event chair and MSAG Education Lead) remarked in his opening address that it was a pleasure to read the papers submitted.

The event began with a session lead by MSAG chairman and Myeloma Australia board-member Professor Miles Prince. He was joined by a panel of our international guests (Professor Leif Bergsagel – Mayo Clinic, USA, Assistant Professor Saar Gill – University of Pennsylvania, USA and Professor Kwee Yong – University College Hospital, London) for a lively discussion.

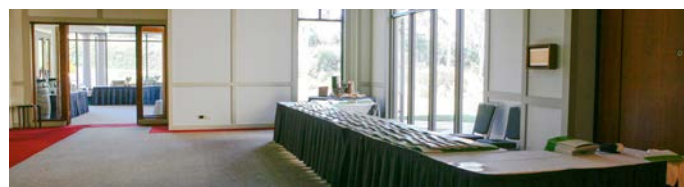
During the workshop we announced the four winners for best abstract: Dr Anna Kalff, Dr Ioanna Savvidou, Dr Kate Vandyke and PhD student Ms Khatora Opperman. In amongst the high standard of work submitted, theirs stood out and was selected by our panel of leading myeloma scientists and clinicians. Each winner presented their work with a talk preceding the Laurence Catley Memorial Lecture, given by Professor Leif Bergsagel.

While the focus was on the presentation of original scientific research, we also found time to celebrate Myeloma Australia's

20th Anniversary and honour some of our founding volunteers. As part of our ongoing celebrations CEO Steve Roach recounted Myeloma Australia's history and recognised some of the people who have made a volunteer contribution to myeloma patients across Australia. Our president Brian Rosengarten also gave a moving speech. Many scientists from the audience commented that this was a highlight of the event, giving them a new understanding of the work of Myeloma Australia.

Congratulations to Associate Professor Simon Harrison, Steve Roach, MSAG members and all the Myeloma Australia staff for making this event a resounding success. In fact feedback from the meeting was so positive that many were looking forward to the next event to be held in 2020!

*Jacqueline Tate*  
*Project Manager and Liaison, Medical and Scientific Advisory Group*



Back Row (L>R) Dr Kate Vandyke, Prof Andrew Zannettino.  
Front Row (L>R) Mrs Khatora Opperman, Dr Melissa Cantley,  
Dr Duncan Hewett



A/Prof Simon Harrison  
& A/Prof Saar Gill



Prof Miles Prince



Prof Leif Bergsagel



(L>R) A/Prof Saar Gill, Prof Leif Bergsagel & Professor Kwee Yong



MSAG meeting at Yarra Valley, Victoria



# Warrior Gold

Mark Ansiewicz was a valued member of the Newport Life Saving Club in NSW for 14 years. He joined initially as an associate member when his daughters joined Nippers. He later became an active member when he obtained his bronze medallion on 2 December 2007 following which he acquired 338 patrol hours. He was a well-known character on the Northern Beaches and loved by his fellow board paddling and surfing mates, but his biggest fan was his young daughter Tatum.

In 2014 Mark was diagnosed with myeloma, and in true Mark style, this diagnosis was not about to change his competitive nature or stop him achieving his goal of peak fitness.

When Mark passed away this year, the Club rallied together to raise funds to honour him and got together to recount the highlights of his many achievements. His daughter Tatum shares some thoughts about her feisty dad.

"I would love to speak about an absolute pinnacle of Dad's life... it all started many years ago, when I was still squad swimming... I'd say in about 2006-2007. I remember walking back to the car from the pool and dad said something along the lines of "Such and such said I'm no chance! No-chance-a wicz!" (dad had just started to compete for the Newport Masters Team). He then said, in true dad form, "How dare they!", I thank this person because from that day forward dad worked his butt off – training to be the best he could be. We celebrated many achievements over those years, from him getting into the finals at branch carnivals, then winning a medal at branch, then winning team medals at state and individual medals at state, winning the "Mad Masters" award and the one and only annual Wood Duck Award that brought him to tears on numerous occasions! (Presented by Rob Roland Smith aka The Sandhill Warrior who is a well-known, local fitness trainer). Dad went to "Aussies" (the Surf Life Saving Australian Championships) a few times... trying to win that elusive gold medal.

Somewhere on this quest and throughout all of these achievements he was struck down suddenly with the big C.



At the Masters Nick & Mark Board Rescue

It was absolutely heartbreaking. However, in typical dad form, the day he broke the news, he said to us "I'm going to show them that "Mark No chance a wicz" can get through this. And that he did.

I will never be prouder than the day dad called me from Perth to say he and his teammate Nick Carroll won gold at the Aussies in Apr this year (55-59 years Board Rescue).

Dad could rave on and almost celebrate how he survived his gruelling sessions at the "Warriors" where they did a hundred decline push ups, dips, incline push ups, sit ups, crocodile crawls, sprint sets, dune runes, wades and how he swam and paddled millions of kilometres in the one session! Or regale his audience with stories of his many races – second by second – but the way he spoke about winning the gold was absolutely priceless. I will never forget the way he described the race – so in the end it came full circle. I am so proud of my dad, of his achievements and the man he was.

Tatum Ansiewicz  
With intro by Jan Proudfoot



Find our Treatment Fact Sheets  
under the resources tab of our website  
[www.myeloma.org.au](http://www.myeloma.org.au)

## What a Bummer

It was around 8 am on a beautiful summers morning on Lake Macquarie just south of Newcastle, the water was flat, the sun was shining, family and friends were in the boat and I was just emerging from the water on my surfboard when I felt a slight twinge in my left hand side bum cheek.



Being the typical Aussie male, aged 51 years at that time, trying desperately to hold onto my youth... I simply shrugged off the "bum twinge" and gave myself the usual internal mental berating, you know... "you are getting old"... "you are unfit"... and... "you really are a bit of a fat bastard"... following which, I proceeded behind the boat...and my "bum twinge" was quickly forgotten.

Looking back now, that "bum twinge" event was really the conscious beginning of my multiple myeloma journey. In the year preceding I had had a urinary tract infection I could not get rid of, I had been feeling much more tired than normal and my beautiful wife who has been such an awesome support throughout this journey had been telling me I was smelling a bit like "cheese". This observation in itself is not unsurprising as I do love my cheese... maybe years of such an indulgence were catching up with me!

Let me paint the picture a bit more completely... My wife and I work together, we have had our own business for the last 25 years, our offices are across Australia and New Zealand... we spend a lot of time traveling... attending events and functions and meetings... the pace is hectic... but it's our baby and we both love it... so not being able to work because I had a "sore bum" just didn't compute with me.

Unsurprisingly it was on a business trip to New Orleans in Mar 2014, three months after my "bum twinge" that I found I could barely walk, I could not seem to concentrate and when I returned to Australia I was physically and mentally shattered from the trip – I was sore – I was living on Nurofen... something was badly wrong!

Our Sydney office is in Pitt Street. Ironically we have a medical centre in our building which I walk past every day, so after

the US trip instead of taking the lift to our floor, I detoured to the medical centre. For some unknown reason and having never had one before I insisted on an MRI.

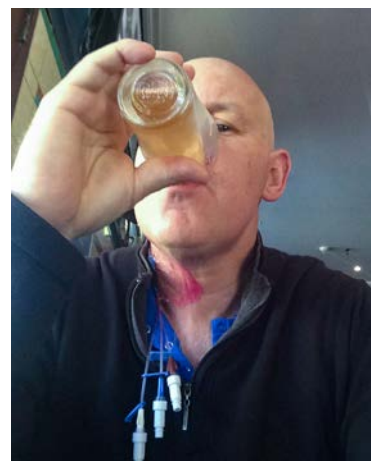
Well things happened pretty quickly from then. The MRI showed substantial lesions in the pelvis, spine, head and arms... subsequent x-rays showed two broken ribs. I began the round of seeing the specialists and within a week found myself with a clear diagnosis of MM, and requiring emergency surgery on my pelvis and hip.

Within a week I had a brand new hip, and a "renovated" pelvis having had a metal plate screwed to what remained of my left pelvis in order to support the hip replacement. In fact the orthopaedic surgeon told me that when he screwed the plate to my left pelvis it was like screwing into rotten timber. He then informed me that another month of waiting would have seen my left thigh bone protruding through my left pelvis. I was definitely paying for not listening to what my bum had been telling me.

The next few weeks were a blur of morphine, Endone and Targin, and I found myself undergoing radiation to my ribs and to harden the bone structure in my pelvis which the myeloma had in effect disintegrated. I also recall that at this stage my plasma cells were around 42% so after the hip stabilised it was time to get cracking on dealing with the myeloma.

Things were pretty standard after that. I did the three months Velcade, Cyclophosphamide, and I was introduced to my all-time favourite drug... Dexamethasone. I started on Zometa and as we all do, began dealing with the side effects, all in all that cycle worked really well to get the counts down, and we moved into the stem cell transplant...

The lead into the SCT was all pretty standard. I lost my hair, spent two weeks in hospital with infections leading into the transplant. The transplant itself took place in late September 2014 and in the final stages of my preparation I did manage to nip across the road from the hospital and get in a quick schooner before "lock down" commenced.



The SCT itself went really well, in fact the most harrowing part of the process was that whilst I was in "lock down" my football team, the Sydney Swans lost the Grand Final – badly – and looking back now I think I spent an extra week in hospital in a state of depression as a result... When the SCT was completed I went into "maintenance" with thalidomide. By that stage I was back at work and simply could not handle the thalidomide side effects... so the decision was made that I go "drug free"!





I managed to get 14 months clear sailing after the SCT but then the myeloma made its return – this time I listened to my body and I could feel the disease returning so it was no surprise when the counts confirmed that.

Since then (early 2016), I have been on the Dex, Revlimid, Ixazomib, Neulasta, etc...cycle is 21 days on seven days off... I take magnesium for the cramps, low dose aspirin to thin the blood, probiotics for the gut, Panadeine Forte for the back and bone pain... the Sydney Morning Herald for the diarrhoea... and I am still reading avidly almost three years later.

Life is certainly not normal, I am working but I am extremely foggy on some days which makes full time work impossible. I suffer a lot of back and bone pain. There is some symmetry however as I myself am often a pain to other people, particularly when on the Dex... and of course there are days when I just "feel like shit" (FLS)...

Am I grateful... absolutely... without the help of the team at RPA I would be dead... without the support of my family which includes my wife, my son and his fiancée, I would not

be able to indulge in the things that make life worth living. They put up with my Dex days and make allowances on my FLS days, they give me normality I otherwise would not have.

So what have I learned?

- First, and most importantly, there are some wonderful caring people in the world without whom cancer sufferers like myself would simply not live.
- Secondly, my MM journey is giving me a sense of purpose. I believe cancer will be cured and my small role in that quest is to help those who come after me by playing my part in the fight against this disease, maybe that means I participate in trials or just simply communicate like this.
- Thirdly, there is no support like "family support". Normality is quality of life... and finally
- I have now learned to listen to what my bum is telling me... it knows me well!

*Peter Davis*

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**good2give**

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

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

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

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



**Any questions? Please contact Matt at Myeloma Australia:**  
**[matt.maudlin@myeloma.org.au](mailto:matt.maudlin@myeloma.org.au)**

## Haematology Society of Australia and New Zealand (HSANZ) Myeloma Specialist Practice Network (M-SPN)

**Annual Seminar Report**  
**The Royal Adelaide Hospital. August 31st 2018**



Alicia

Now in its third year, the vision for the annual M-SPN's seminar was to bring together myeloma specialist nurses from around the country, to 'negotiate the maze of myeloma management.'

Writing this piece has certainly encouraged me to reflect on the meaning behind those words.

I work as the Practice Nurse for Prof H Miles Prince, Precision

Haematology Melbourne. The longer I am in my professional role, the more I appreciate the true meaning of complexity of cancer care. Myeloma provides us with perhaps one of the most diverse groups of patients to care for from a nursing perspective. From the variable ways myeloma can cause health issues (e.g. bone, kidney and immune issues), to the prevention, assessment and management of treatment-related side effects of an evolving list of therapies. Myeloma nursing has always been a dynamic role and attending educational seminars affords us the opportunity to gain clinical updates, develop our knowledge, and network with nursing colleagues from around Australia.

I always find it refreshing to listen to junior haematology doctors present their knowledge. Dr Kate Manos is one such haematology registrar from Flinders Medical Centre in South Australia, who set the scene with her presentation on an **Overview of Plasma Cell Dyscrasias: Myeloma**

**Focus.** Dr Manos demonstrated how far we have come in understanding myeloma through new developments in diagnostic technologies, through to understanding what has changed when treatments lose their effectiveness overtime.

The program continued with Dr Kate Van Dyke of SAHMRI, in her talk on the **Role of Bone Marrow Environment in Myeloma**. Dr Van Dyke highlighted what was happening in the research labs to better understand myeloma, and what questions research might help us answer in the near and distant future. It was a short but significant glimpse into how dedicated and talented professionals are working every day to assist the myeloma community move forward.

This helped set the scene for Dr Oi Lin Lee's (Myeloma Fellow, Royal Adelaide Hospital) presentation on **Disease Related Effects & Supportive Care**. A considered discussion of how life-changing myeloma can be both in the presence and absence of active disease, how one's ability to maintain quality in physical and psycho-social functioning may be compromised, and how we can address these considerations with evidenced-based supportive care measures.

We received the latest updates in both **Optimising Upfront Treatment** (Dr Cindy Lee, Haematologist, Royal Adelaide/ Queen Elizabeth Hospitals, South Australia), and **Optimising Relapsed and Refractory Disease Treatment** (Professor Andrew Spencer, Haematologist, The Alfred Hospital, Victoria). The latter show-cased the evolving treatment options that are becoming available in the relapsed setting, and emphasised the importance of clinical trial participation to help drive the development of these drugs and promote access to drugs that would otherwise not be available. This includes new classes of drugs that have not historically been used in the myeloma setting, such as the broad range of immune-therapies and small molecule targeted therapies. We were also excited to learn of the latest clinical trial activity, such as the administration of the antibody treatment *daratumumab* via an injection under the skin, for smouldering myeloma, an early form of myeloma for which the standard management approach is to simply monitor.



MSPN Seminar



MSPN Seminar Prof Spencer



These promising new treatments can cause different side effects and we as myeloma specialist nurses need to be familiar with them. Jacqui Jagger, (Haematology Nurse Practitioner from Gosford NSW) provided us with an overview in her presentation **Treatment Related Effects and Supportive Measures: Focus on precautions and effects of new treatments**. Jacqui discussed how her role as a nurse practitioner enables her to improve patient outcomes by proactively educating patients on, assessing for, and intervening early against, potential treatment side effects such as high blood pressure and other cardiac (heart) related issues, that can be associated with carfilzomib, the latest in class proteasome inhibitor.

The Myeloma and Related Disease (MRDR) data presented by Professor Andrew Spencer, portrayed the 'real world' Australian myeloma experience. The benefit of MRDR is that it captures local data, allowing us to benchmark how Australia performs in care, management and support of myeloma across different health care settings in our local region (Australia/NZ). It reminded us of the many factors that contribute to treatment approaches and disease management.

The point of difference for me was the **Improving Patient Outcomes: Panel Discussion**. A well-balanced collective of individuals with different perspectives on the myeloma patient experience, this session provided insight for the audience on aspects of myeloma that we do not always see or confidently understand. Dr Peter Hallett (psychologist) recounted his own experience and challenges in the psych-emotional health and well-being of individuals living with myeloma. Opportunities to better equip health care practitioners to initiate these discussions and respond therapeutically, are not as mainstream as they deserve to be.

Nella Combe from Myeloma Australia presented an update on the information and support that Myeloma Australia provide to myeloma patients and their families and described the invaluable work she and her nursing colleagues provide as advocates within the myeloma community.

Alicia Hopper, a chemotherapy nurse from Chemo@Home, spoke passionately about her role delivering cancer care in the home, and illustrated how this represents an opportunity for enhanced patient-nurse therapeutic relationships and improved patient experiences for those patients who encounter difficulties attending hospitals and day centres for treatment.

Mr Domenic Scoleri, provided us with a personal account of the myeloma patient journey, and how this impact extends throughout the family circle. There is always something new to take away from every myeloma patient interaction you have been invited to share in and for that we are very grateful to Domenic.

These educational opportunities are a wonderful way to maintain professional development momentum and connectivity with our professional peers and renew enthusiasm for our role as myeloma nurses. I would like to acknowledge the hard work of Jo Gardiner, Jodie Wood, Tracy King, and numerous other special individuals who made this seminar possible. I would also like to thank the HSA NZ for their investment in supporting nursing education and professional development, through the provision of the travel grant I received to attend this event.

Alicia Snowden  
Specialist Haematology Nurse



Myeloma Australia – A Visual History





## Haematology Society of Australia & New Zealand Myeloma Nurses Group

### Background

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.

### Education

Maintaining updated to the current treatment and supportive care approaches in the dynamic and evolving field of myeloma is a priority of our group and each year we host a myeloma educational seminar for nurses. One of our members, Alicia Snowden (Practice Nurse for Prof H Miles Prince AM, Precision Haematology Melbourne VIC) reports from our recent educational seminar held in conjunction with Royal Adelaide Hospital. I would particularly like to thank the local nurse members Jo Gardiner, Erin Shooter, Jodie Wood and Liz Zwart for their hard work in helping to organise this meeting.

### International Networks



Building networks with myeloma nurses in other regions can help drive improvements in nursing care, support learning and provide nursing mentorship in clinical, academic and research areas. One such critical network has been with the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB). Established in 2006 the IMF NLB has the mission to enhance nursing care and self-care of patients with myeloma. Comprised of nurses from leading myeloma institutions in the US and abroad, NLB members collaborate year-round on patient education, nurse education, and nurse-led research projects. Since inception, the NLB has educated thousands of nurses and empowered hundreds of thousands of patients and their caregivers. Highlights from the NLB's tremendous body of work, include educational programs for both patients and for nurses with an estimated reach of 8000 each year, publications including six supplements and 2 textbooks, and research producing a number of journal articles. Diane Moran (Senior Vice



*Dr Joseph Mikhael (Chief Medical Officer International Myeloma Foundation), Tracy King (Myeloma CNC RPA Sydney); Dr Beth Faiman (Myeloma Nurse Practitioner Cleveland Clinic Ohio USA)*

President, Strategic Planning IMF) leads the NLB and through her strong leadership has been invaluable in helping the board to navigate their contributions across the country and throughout the world.

The NLB meet on an annual basis to review collective work over the past year and plan programs and meetings ahead. One of the most successful NLB programs is the 'IMF Satellite Symposium' run within Oncology Nursing Society (ONS) conference each year. NLB members Dr Joseph Tariman and Dr Beth Faiman co-chaired the 2018 meeting with Dr Kevin Brigle and Patricia Mangan as additional faculty. Over 740 nurses attended the NLB Myeloma Symposium this year with over 1500 on demand replays thus far.



*International Myeloma Foundation Nurse Leadership Board Members Annual Meeting Las Vegas Sept 2018*

Other work presented during the 2018 NLB meeting included research updates from Dr Joseph Mikhael, Chief Medical Officer of the IMF; updates on patient and caregiver teaching tools/resources by Teresa Miceli, A/Prof Mayo Clinic, Rochester and Dr Joseph Tariman, De Paul University Chicago who presented his work on shared decision making as a model to help improve patient/physician communication around treatment options and choices.

Tracy King (AUS) is an active member of the IMF NLB and is able to work in collaboration with her international myeloma nursing colleagues and the IMF to help develop and deliver



a range of educational programs to nurses, patients and caregivers. The aim of such collaborative work is to help improve the lives of myeloma patients and family members, wherever they may live. With exciting online educational programs in development, Tracy's participation ensures any news on clinical updates and innovative educational resources, are shared with Australian and New Zealand nurses, patients and family members in a timely manner.

NLB member Dr Beth Faiman has visited Australia to participate in Haematology/Myeloma meetings and mentors many Australian nurses through sharing of her expert knowledge and encouragement of collaborative work and research. The Australian myeloma nurses group gain much from collaborative networking with our IMF NLB colleagues and often take the time to catch up with each other at international conferences and meetings. We particularly thank Diane Moran who leads the IMF NLB for including an Australian nurse in this expert group. The IMFs continued support of Australian and New Zealand nurses through sharing of educational programs and resources for nurses and patients/family members alike, helps improve the lives of those living with myeloma in our region.

## Nurses recognised for their contribution to care of those affected by myeloma: Myeloma Australia Awards

Congratulations to M-SPN nurse members listed below for their recent awards recognising their significant contribution to the care and support of patients and family members impacted by myeloma.

**Jacqui Jagger:** Haematology Nurse Practitioner, Central Coast Local Health District, Gosford (NSW)

**Tracy King:** Myeloma Clinical Nurse Consultant, RPA Sydney (NSW)

**Jo Gardiner:** Myeloma Research Nurse, Royal Adelaide Hospital, Adelaide (SA)

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 Australia who can tell them more. 1300 632 100.

*Tracy King RN MN  
Chair HSANZ Myeloma Nurses Group*

**Alternatively, interested nurses can contact me directly at [Tracy.king1@health.nsw.gov.au](mailto:Tracy.king1@health.nsw.gov.au)**

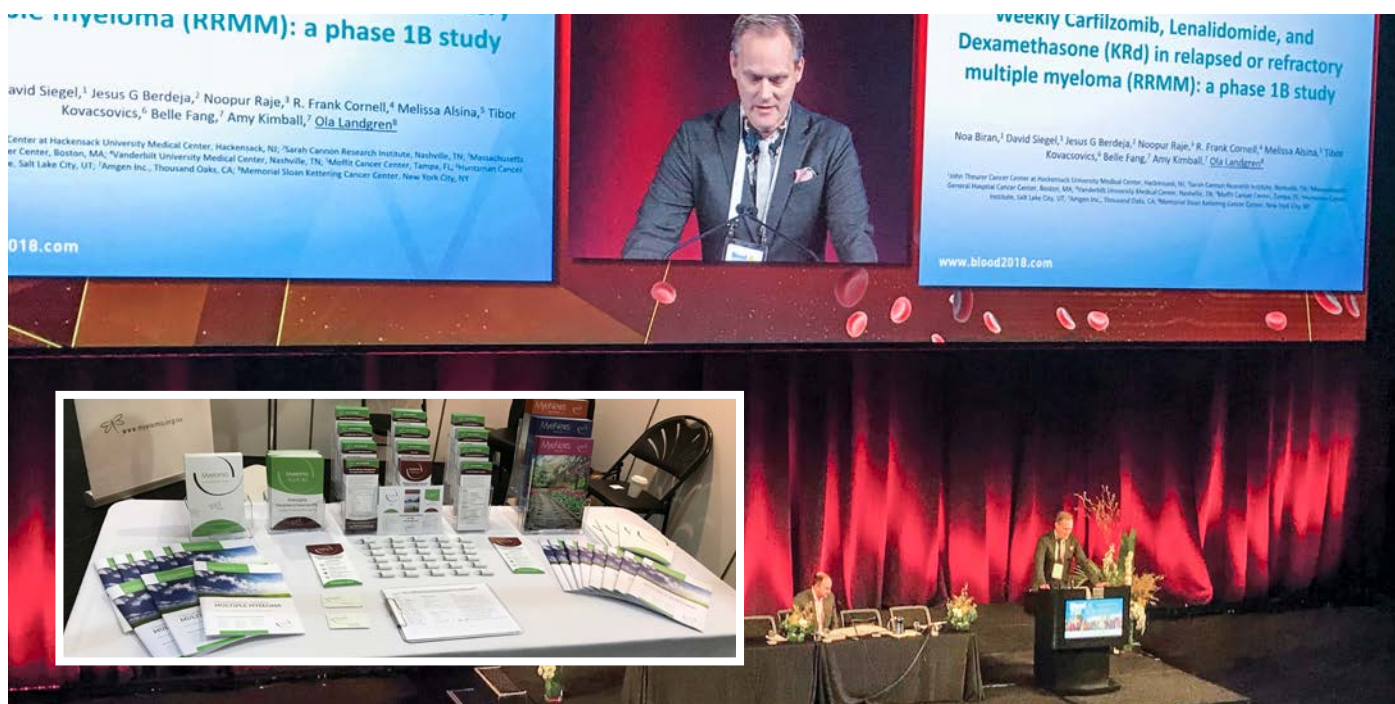
## Adelaide, SA

On Tuesday November 13th the Myeloma Research Laboratory at the South Australian Health and Medical Research (SAHMRI) Facility in Adelaide opened its doors to some members of the South Australian Support Groups. Drs Kate Vandyke and Duncan Hewitt introduced how the facility operates. Kate then described techniques used to grow and isolate myeloma cells and the cells in the bone marrow micro-environment that myeloma cells depend on to grow and multiply. This cell culture is the backbone to support their research efforts. The research scientists guided the group through the facility for a behind the scenes look at their current research. Microscopes were set up with myeloma cells for our members to look at

the source of myeloma, 'up close and personal'. After the laboratory tour, over refreshments, each of the scientific staff introduced themselves and briefly described their research projects. Afterwards, lively informal discussions between the staff and the Myeloma Australia group continued for quite a while before it was time to go. Our members felt comforted in the knowledge that such high-quality work is being undertaken in their own city, striving for new approaches to treat and overcome myeloma and that SAHMRI staff collaborate and go to work in similar facilities across the world. The SAHMRI staff were enthused for the opportunity to talk directly with those who benefit most from their work.

*Jo Gardiner  
Senior Specialist Myeloma Nurse SA / NT*





A team from Myeloma Australia had the opportunity to attend 'Blood2018' (formerly HAA) the largest haematology conference in Australia in Brisbane at the end of October.

With our team of ten Myeloma Support Nurses from across the country and CEO Steve Roach we descended upon Brisbane for three days of learning and networking with health professionals from Australia and New Zealand. In the many lectures attended we heard updates and results from large myeloma clinical trials from international speakers Prof Faith Davies and Prof Ola Landgren as well as local investigator led trials such as the ALLG MM18 from A/Prof Hang Quach. In addition, we listened to lectures about some of the exciting drugs in development and currently being explored in clinical trials in our country. It's always inspiring to hear that there is so much research going on and so much potential to help people living with myeloma.

The conference also has a substantial nursing stream and our Myeloma Support Nurses were able to attend a variety of presentations that relate to both their clinical roles in the hospitals as well as their roles in the community at Myeloma Australia. Expert nurses presented on how we best capture and measure patient reported outcomes and quality of life information, care for indigenous populations, and nurse led initiatives to improve care of people living with myeloma.

In addition to the conference meetings we heard the latest updates from the Myeloma and Related Disease registry (MRDR) and attended advocacy meetings with Lymphoma Australia, Leukaemia Foundation, Snowdome and the Australasian Leukaemia and Lymphoma Group (ALLG) to discuss ways to collaborate to improve drug access and clinical trial availability in Australia for people living with blood cancers.

We were also invited to an education event where Prof Ola Landgren and several Australian haematologists presented

and discussed the advances and applications of monitoring minimal residual disease (MRD) in myeloma and acute lymphoblastic leukaemia (ALL). Prof Landgren spoke about some current and upcoming trials designed to utilise MRD testing in myeloma to direct and augment treatment decisions or pathways. This was great food for thought and generated a good discussion about how MRD can be utilised in the clinical setting to improve patient outcomes.

Myeloma Australia had a small stand in the exhibition hall and seldom did we have a quiet time. Health care professionals and scientists picked up our literature, discussed the needs of their local myeloma communities and planned education and patient support programs with our Myeloma Support Nurses. We were especially thrilled to have our two new Queensland nurses Tash and Megan attend the conference in their home town. Having just started a month earlier, their network is now bigger with a number of events in the pipeline; a very exciting time for our Queensland myeloma community.

Overall the conference was a great success and our Myeloma Support Nurses have come back with information to share with their local communities through our information and support groups, telephone support line, seminars and health professional education programs. Having our team together was an added bonus, as with our nurses spread around the country, it's rare to have them all together and for three days they talked about their local programs. As a result the ideas were flowing on how we can continue to improve and expand our support and services for people living with myeloma... we can't wait to see what 2019 will bring.

Thank you to our pharma partners for supporting our team to attend this conference.

*Nella Combe  
Myeloma Nurse Manager*



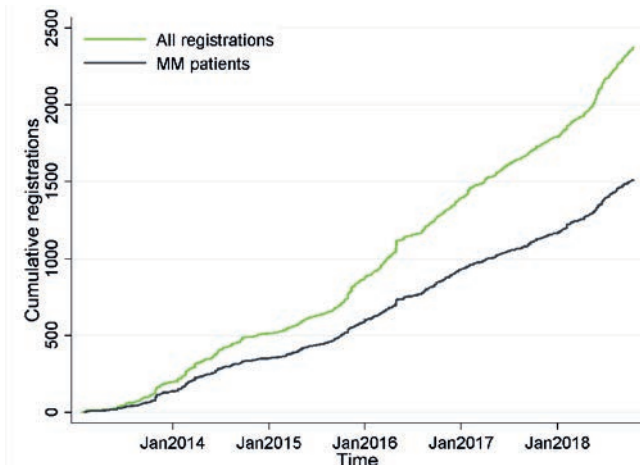
# NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

## RECRUITMENT UPDATE

December has seen close to 2500 patients registered to the Myeloma and Related Diseases Registry (MRDR - see graph). This is an incredible achievement and a big thankyou to all participants and participating hospitals for your support! The most recent sites to commence recruitment to the MRDR are Dunedin, Wellington and Whangarei Hospitals in New Zealand, and Royal Brisbane and Women's Hospital. Interest in participation is running high with 7 new sites recently initiating the process to join the registry. We now have 35 approved sites and 13 more with approval pending.

## RESEARCH

IMPROVE (*Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology*) is a registry based study funded by the National Blood Authority, which is now recruiting. Patients may be asked to participate in the IMPROVE biobank project, which involves the collection of blood samples at diagnosis, then every 4 months at 4 subsequent timepoints. Multiple myeloma is one of the areas of more intense immunoglobulin use in Australia, however there is limited information about where, when and how it is used. This study will describe its use in myeloma, including variation in practice. Results of this study will help to inform policy and clinical practice related to immunoglobulin therapy in these patients.



## MRDR AT BLOOD 2018

The annual MRDR Interest Group breakfast at Blood 2018 in Brisbane (ex HAA, the key ANZ haematology conference) was a success with over 60 attendees representing patient groups, hospital sites, researchers, industry, and other collaborators. Attendees enjoyed an overview of the Australasian Myeloma Research Consortium and the Myeloma 1000 Project by Professor Andrew Spencer, and an update on registry data and progress by Dr Zoe McQuilten (see photo). Zoe also presented an analysis of predictors of early mortality in multiple myeloma using registry data, and another two talks on behalf of Dr



Zoe McQuilten presenting at the MRDR breakfast



Liz Moore (Right) receives a poster award at Blood 2018

Krystal Bergin who was on maternity leave: *'The myeloma landscape in Australia and New Zealand'* and *'Upfront autologous stem cell transplantation in newly diagnosed multiple myeloma: a report from the MRDR'*. In addition, an MRDR poster submitted by Dr Liz Moore won the Best Myeloma Nursing Poster prize (see photo) – the poster was titled: *'Health-related quality of life at diagnosis in multiple myeloma: EQ-5D-5L results from the Myeloma and Related Diseases Registry and comparison with an Australian population norm'*. The registry was well-represented at Blood 2018, with additional presence at Monash University's Transfusion Research Unit booth in the exhibition area. It is great to see patient's data being put to good use in such a wide variety of projects and analyses.

## MRDR: HOW CAN YOU BE INVOLVED?

Ask your treating specialist if your hospital/clinic 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](mailto:sphpm-myeloma@monash.edu)

Website: [mrdr.net.au](http://mrdr.net.au)



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# Community Engagement & Fundraising



(L>R) Santosh, Jacqui & Chanchal



L>R Dr. Silvia Ling, Peter Townend, Louise Ng and Tracy Townend

Photos - © Santosh Ojha

As we near the end of the calendar year there is much to reflect upon in the community engagement and fundraising sphere of Myeloma Australia. An ever-increasing number of individuals and businesses have both raised awareness and funds for us this year – with the momentum we have building this will only increase as we move into, and beyond, 2019. It has been wonderful to see Team Myeloma gather with such success in Perth, Melbourne, Sydney and Adelaide this year – we will repeat all of these events in 2019, hopefully with increasing levels of success ... as well as looking to establish a few more along the way!! If you would like Team Myeloma to participate in an event in a town or city near you please let me know.

One of my many highlights in 2018 was bringing Santosh onboard to start significant community engagement and fundraising in NSW. Santosh has made great progress to date and I know that he is greatly looking forward to continuing to build the NSW myeloma community in 2019.

Fundraising efforts this year have included the Team Myeloma events, other running events, haircuts, financial gifts to Myeloma Australia in lieu of birthday presents, lawn bowling, the development of our online shop, a Bunnings BBQ, morning teas, raffles ... and I am quite sure that this list is incomplete!

As we start to look forward to 2019 there are a few ideas I would like to leave with you, to consider perhaps becoming

involved in. We will be participating in Dry July in 2019 – is this something you, or those within your network, would consider participating in? Santosh recently hosted a Bunnings BBQ with the assistance of members of the Liverpool Support Group – the outcomes in terms of awareness raising and fundraising were both spectacular; would you, your networks and your local support group consider hosting a Bunnings BBQ in 2019?

2019 is looming as a BIG year in the community engagement and fundraising space of Myeloma Australia. I very much hope that you will join us with your ideas, creativity and support as together we move into the new year. Please continue to reach out to Santosh and me with your thoughts and ideas – we love helping you make these ideas a reality!

I wish you all a happy and peaceful Christmas and every good wish for a prosperous 2019.

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

*If you are thinking of some way to help Myeloma Australia – Would you, your networks and your local support group consider hosting a Bunnings BBQ in 2019?*



## Volunteering Opportunity for a Fundraising BBQ Sizzle

To register your interest please contact Matt Maudlin  
M: 0407 891 052 E: [matt.maudlin@myeloma.org.au](mailto:matt.maudlin@myeloma.org.au)



All money raised from these events will assist Myeloma Australia to continue their services to the myeloma community  
[www.myeloma.org.au](http://www.myeloma.org.au)





**Sign up & fundraise to win great prizes**

# my mount eliza run+fun festival

**Sunday  
17th  
march**

## **4km & 8km Trail Run/Walk**

- **Fun kids activities all day** • **Great local food vendors**
- **Community exhibitions** • **Live music on stage**
- ...and much more!**

**7.30am - 1pm - Mount Eliza Regional Park, Two Bays Rd, Mount Eliza**

**GOLD SPONSORS**



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**Register now: [www.mymounteliza.org.au](http://www.mymounteliza.org.au)**

*Raising much needed awareness of Myeloma and funds to assist Myeloma Australia to continue their work supporting Myeloma patients, their carers and families.*



## Fundraising

Myeloma  
Australia

### Team Myeloma 2019

Team Myeloma will be participating in the 2019 Sydney Morning Herald Sun Run on Saturday 2nd Feb. This event is a 10km run and a 7km walk/run. All the relevant details can be found here: <https://sunruncoleccionic.com.au/> When registering please look to join Team Myeloma. The password is myeloma. As of right now we are Team of one person, and when Santosh signs up there will be two of us!

Elsewhere in this edition of MyeNews you will find an advert promoting the 3rd iteration of the My Mount Eliza Run & Fun Festival. This event is aiming to raise \$80,000 in 2019 to help with employ more specialist myeloma trained nurses to work in the community. We will create a Team Myeloma to participate in this event. The date of the 2019 event is Sunday 17th Mar. If you are interested in joining team Myeloma for this 8km and 4km running/walking event, please drop me a line.



Saturday & Sunday, February 2-3, 2019

The Team Myeloma Calendar for 2019 is currently shaping up as follows:

- **Sydney**  
Saturday 2nd Feb. Sun Run. 10km and 7km run/walk
- **Mount Eliza**  
Sunday 17th Mar. My Mount Eliza Festival. 8km and 4km run/walk.
- **Perth**  
Sunday 26th May. Run for a Reason. 4km, 12km, 21km.
- **Melbourne**  
Sunday 28th July. Run Melbourne. 5km, 10km, 21km
- **Sydney**  
Sunday 11th August. City2Surf. 14km.
- **Adelaide**  
Sunday 15th September. City-Bay. 3km, 6km, 12km, 21km.

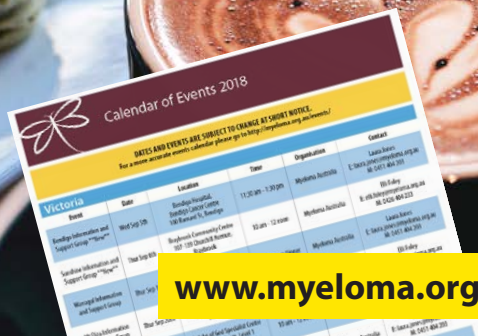
I very much look forward to adding to this calendar with events in Canberra, Brisbane, Darwin, Hobart, Geelong, Busselton, Newcastle, Townsville and so on and so on... but I'm going to need some help from some locals to bring this into being! I very much look forward to hearing from you!

*Matt Maudlin*  
Community Engagement & Fundraising Manager

## Come along

Myeloma Australia Support Groups, Events and Seminars. A great opportunity to learn more about myeloma while connecting with other members of the myeloma community. Check the website calendar for up to date groups, events and locations near you. All welcome.

**For more information feel free to contact us for a chat on toll free: 1300 632 100 or email: [support@myeloma.org.au](mailto:support@myeloma.org.au)**





## From the Nurse Manager

It is hard to believe that we are at the end of 2018. It has been a big year at Myeloma Australia and shows no signs of slowing down for 2019 with three new Myeloma Support Nurses starting in January... two in the Newcastle area and one in Tasmania, based in Hobart. We are thrilled to have Myeloma Support Nurses for the first time in these areas and cannot wait to see how the services to the myeloma community grow and develop.

Our Myeloma Support Nurse team have been busy working with their local communities to start new and support existing Information and Support Groups, seminars and health professional education days. In addition, you may have heard that we are evaluating our Telephone Support Line. We had an excellent response rate and some helpful feedback from the pilot which ran for four weeks. We have refined the survey based on the feedback and results and reopened the survey with the improved evaluation. We look forward to sharing the results with you all in the New Year. If you would like to provide feedback and haven't received a link to the survey, please contact project lead Jo Gardiner (jo.gardiner@myeloma.org.au for a link)

We have new publications near completion, our first Autologous Stem Cell Transplant Book which has been put together by our Myeloma Support Nurse Elli and reviewed by clinicians at leading hospitals around the country. We also have a new Living Well with Myeloma book which will collate and expand on the information already available in our fact sheets as well as new content covering topics such as emotional health, caring for carers, infection prevention, complementary therapies as well as practical aspects such as financial and legal information and travelling with myeloma. We have spent a lot of time collating this book and hope that you all find it helpful in the myeloma journey. Following

this, it will be time to update our Myeloma Comprehensive Guide too!

Heading towards the end of this year and into the first quarter of 2019 you will receive information from us regarding submissions to the Pharmaceutical Benefits Advisory Committee (PBAC). The PBAC is an independent expert body appointed by the Australian Government to recommend new medicines to be listed on the PBS, making them available to Australians through the public health system. Its membership is made up of doctors, health professionals, health economists and consumer representatives and they meet three times a year to discuss new listings. The Mar 2019 meeting will have a number of myeloma treatments being discussed; your comments and feedback are of great importance and valued highly by the PBAC. Myeloma Australia will keep you informed about the consumer comment period, how to submit feedback and details of the submissions. If you have any questions or would like to speak to a Myeloma Support Nurse about making a comment, please call 1800 693 566 or email [nurses@myeloma.iorg.au](mailto:nurses@myeloma.iorg.au) or myself [nella.combe@myeloma.org.au](mailto:nella.combe@myeloma.org.au)

From the Nurse Managers desk we have some exciting news. In October we wished Hayley Beer well for twelve months of maternity leave for the birth of her second child. Mum and bub are doing great and a few of us have been lucky enough to have some lovely cuddles with her baby son.

In signing off for the year, on behalf of the Myeloma Support Nurse team, we wish you and your loved ones a happy and safe festive season, may it be filled with love, laughter and good company. We look forward to catching up in 2019!

*Nella Combe*  
Myeloma Nurse Manager

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*This project has been made possible by the generosity of Patricia & David Ball.*

# What's Happening

## New South Wales

As the end of 2018 rapidly approaches, I have been reflecting on what has been a busy but exciting year for Myeloma Australia in NSW. Personally, in my new role as NSW State Manager, it is very satisfying to finally start to see some growth and be able to plan. Not only did we open our own office in Parramatta, Sydney but I now have a NSW team to work alongside with which includes Geo Sobrio (Myeloma Support Nurse) and Santosh Ojha (NSW Fundraiser). At the time of writing this MyeNews update we have just completed interviews for a Myeloma Support Nurse for the Newcastle area and I am pleased to announce that we will have two excellent nurses starting in the new year. More information will follow in the coming months.

Now we have more support nurses, the plan for 2019 is to facilitate the opening of more myeloma groups and we have already identified several key areas. We anticipate another five to six myeloma support groups to open in NSW next year. We are aware that there are a large proportion of myeloma patients living in regional and rural NSW and we are exploring ways in which we can provide support as well as being able to offer our seminars and events outside of the metro areas.

We have been able to continue our links with the major hospitals such as Westmead, Liverpool, Concord and Royal North Shore providing education and support to nursing teams. However, we now are planning to expand to other areas such as western NSW, Blue Mountains/Nepean as well as the ACT in 2019. We would like to be more present in our regional areas and establish connections with local treating centres as well as the communities.

Our face to face groups have continued throughout the year and the new venue for the Westmead group, Wentworthville



(L>R) Santosh, Geo & Jacqui

Leagues Club had proved very popular. The club has kindly supported us this year in providing free space for us to host our meetings. We have had regular invited speakers to our groups from haematologists giving updates from ASH to dietitians and clinical trials coordinators. I continue to work closely with the groups to assist in either facilitating or providing support.

Our final seminar for the year was held at Liverpool on Tuesday 6 November. Despite clashing with Melbourne Cup (noted for next year!) we had almost 50 people attend. I would like to personally thank Dr Silvia Ling and the other members of the haematology team at Liverpool for giving up their time and presenting on the day and Celgene for their support. We had an interesting range of talks from treatment options for myeloma patients either having a transplant or not, novel therapies under development as well as emotional wellbeing and symptom management. The team kindly made themselves available for a Q & A session which resulted in some valuable discussions. Dr Ling presented a session on clinical trials and sought some clarification from the attendees as to what research they would be interested in supporting. Topics such as investigating the cause of myeloma, new therapies and the role of exercise/

*Cancer Council – Saving Life Campaign*





wellbeing were most popular. The feedback from the day was overwhelmingly positive (despite a few technical problems with the PA system) and most importantly it provided a great forum for those individuals living with myeloma to meet others in a similar situation and share their experiences.

#### Fundraising and community engagement in NSW

We are constantly working to engage the Myeloma Australia community of NSW in meaningful activities. The myeloma community came together to run in our first event the City2Surf in August in Sydney. More recently volunteers from Liverpool organized a sausage sizzle fundraiser at Bunnings Warehouse at Hoxton Park on November 11th. This event was a success with the participation of 10 volunteers— Dr Silvia, Peter, Tracy, Chanchal, Arun, Suman including Myeloma Australia's NSW Fundraiser Santosh and nurse Jacqui. The Myeloma Australia community is organizing another BBQ sausage sizzle at Northmead Bunnings in Feb 2019 and possibly another later in the year. Calls for volunteering at the event is open. Interested community members can email Santosh at [Santosh.ojha@myeloma.org.au](mailto:Santosh.ojha@myeloma.org.au).

We've also started recruiting for community members for "Team Myeloma" in the Sun Run and Cole Classic Marathon in

Sydney on the 2nd and 3rd of Feb 2019. The start of 2019 is already busy!

The Myeloma Australia team from NSW were invited to attend the launch of the Saving Life 2019 campaign by Cancer Council NSW in Parramatta on November 9th. Local community members, politicians, Cancer Council officials and stakeholders came together to voice concern about public health issues and urged the local government members to take appropriate action and advocate for the NSW community.

The Myeloma Australia team in Sydney is looking for opportunities to collaborate with local businesses to partner for workplace giving, corporate engagement for volunteering or helping to keep Myeloma Australia donation boxes grow in NSW. Please get in touch if you can assist with anything.

As Christmas is rapidly approaching, I am really looking forward to 2019 and working with not only the NSW team but the whole organisation to really promote the work of Myeloma Australia and all that it has to offer the myeloma community. ●

*Jacqui Keogh*  
NSW Manager & Myeloma Support Nurse

## Kicking Goals for Myeloma

Bundoora United Football Club, Under 15 boys soccer team set out the season to finish first in their competition as most teams do. As we know, only one team can finish on top. With this in mind, a light-hearted group discussion was had and an idea was born. If the team achieved their goal of finishing first, they, along with their coach would shave their heads! A strange way to celebrate a win!!

It was barely thought or spoken of again until later in the season it began to become more apparent that this winning

the season was a real possibility. Not having lost a game to date, the talk become more prevalent around the club. When a family member of one of the players was diagnosed with myeloma, the desire to win and the focus to raise funds from the shaving became the team goal.

It was as the team had hoped, they won the season, shaved their heads and raised a whopping total of \$805 for Myeloma Australia. Well done everyone.

*Tom Popovski*  
Secretary (and parent) – Bundoora United Football Club



Photo supplied and used with permission

## South Australia

The South Australian report for this edition of MyeNews comes from our Senior Myeloma Nurse and South Australian Myeloma Support Nurse, Jo Gardiner. She has reviewed her activities over the last year and shared them here with the myeloma community:

'Throughout 2018 I have continued to work 2 days a week, which has supported our expanded activities introduced last year, to South Australia and the Northern Territory. I have continued responsibility for editing the Medical Corner in our quarterly MyeNews magazine and being a senior myeloma specialist for mentoring all staff. In 2018 I have contributed to the review and writing of our educational resources and articles for MyeNews. I continue to work on the support line service; I attend, arrange speakers for and present educational talks to our support groups and seminar days alongside continuing to provide education sessions for health professionals.

Under the Patient Support Program, our second metropolitan support group, servicing the Southern residents of Adelaide, is flourishing. We again sincerely thank our volunteer coordinator, Jenny Naylor, alongside Dr Craig Wallington-Beddoe and his haematology colleagues at Flinders Medical Centre for their support and promotion of the Flinders support group. Our Fullarton support group is held in the opposite month to Flinders with some people attending both groups. Our 2 regional groups continue to meet regularly with coordinators Carol Koch for the South-East group at Coonawarra and Bronwyn Gerschwitz for the Mid-North group at Snowtown. It has been a challenging year for both groups, with members passing and changing meeting days to avoid the regular hospital clinic days, enabling more members the opportunity to attend. I am grateful to all our volunteers who support us so generously with their time: Ian, Carol, Bronwyn, Jenny and the members of our SA committee. Your support and encouragement are greatly appreciated.

Two information and support days (Feb & September) have been held in Darwin this year. In September the venue was changed to Casuarina Library meeting room, a bigger venue with AV equipment, which is closer to Royal Darwin Hospital (RDH) which allows staff to pop down to attend the meeting. In Feb an educational dinner was held with the support of Celgene at which Dr Hang Qach from St Vincent's Hospital in Melbourne spoke. In September nursing staff from RDH and Alice Springs hospital (video-link) attended an in-service presentation in which I provided an overview of myeloma and the recommended treatment pathways as per the Australian Treatment Guidelines.

We have been unable to proceed with plans for starting further support groups based around the Queen Elizabeth

Hospital in the western suburbs and the Lyell McEwen Hospital and Central Districts Private Hospital in the northern suburbs of Adelaide. Until there are further nursing hours in South Australia we are unable to service new groups; however, this issue should be resolved in 2019.

In May our annual Myeloma Awareness Day seminar was held with Dr Michael Low from Monash Health in Melbourne as our key speaker; other speakers that day included Dr Noemi Horvath, Mr Domenic Scoleri and yours truly! The day was very well attended, and the Fullarton venue proved the ideal setting for the day.

The Education for Health Professionals program also saw me give three in-service presentations to staff at Royal Adelaide Hospital and one to Flinders Medical Centre. In July I gave a lecture to the post graduate nursing students enrolled in Graduate Diploma Oncology at Adelaide University. During the year I was on the organising committee for the HSAANZ Nurses Myeloma-Special Practice Network annual seminar, held at the Royal Adelaide Hospital in August. Over 60 nurses from around the country attended, with speakers including Professor Andrew Spencer from Monash Health, Drs Kate Manos and Cindy Lee from RAH, Dr Kate VanDyke from SAHMRI Myeloma Research Laboratory and specialist psychologist Dr Peter Hallett from Calvary Hospital in Adelaide.

Personally, I have been able to attend the MSAG Scientific Meeting held in Yarra Valley in September as well as HAA 'Blood' Annual Conference in Brisbane in October. Locally in Adelaide I have attended the South Australian Myeloma Interest Group meetings chaired by Dr Noemi Horvath. In December I will have the opportunity to attend American Society of Haematology (ASH) meeting in San Diego, the world's largest haematology conference.

This year, we have welcomed 3 specialist nurses, Megan McDowell and Natasha Clarke in Brisbane, and Geo Sobrio in Sydney, as well as Jacqueline Tate and Samantha Zeps in research and administration based in Melbourne to our team. It was great for us to be all together at the Yarra Valley meeting. I want to formally welcome them all. How exciting it is to be part of such a dynamic organisation and feeling that our effectiveness to provide support to a wider range of people affected by myeloma is increasing! I wish to acknowledge and thank our tireless CEO for driving our growth and success, thanks Steve. I also want to wish our Support Nurse Manager Hayley Beer best wishes for her accouchement leave, I wonder what the ever-expanding world of Myeloma Australia will look like when Hayley returns?!

*Jo Gardiner*  
*Senior Specialist Myeloma Nurse*



# What's Happening

## Victoria

The increasing amount of sunshine in Victoria has pleasantly coincided with more time out of the office and on the road, as we begin to expand services and focus our efforts more regionally.

September was a busy one, with the Yarra Valley National Myeloma Workshop and four new support groups, really engaging our myeloma community spirit. It was wonderful to hear from international guest speakers, on the latest scientific research happening both locally and abroad. We enjoyed networking and spreading the word among the medical myeloma community on our varied support services for those living with myeloma.

I had the pleasure of visiting Bendigo, Wangaratta, and Albury, receiving a grateful, positive and excited response. I know these communities will do wonderfully making new connections and supporting one another. At each information and support group, I spent time formally presenting on myeloma and its treatments, as well as facilitating the sharing of stories between guests. Each group looks forward to meeting again in November, as do I. Elli facilitated our first Western Metro Information and Support Group in Sunshine. This group met again recently and continues to grow and support each other.

Kew continues to meet bi-monthly, with a large group enjoying each other's company. At one of our meetings we trialled a breakout session where carers, and those who receive care, spoke separately about their experiences. The session received very positive feedback, especially from carers, and I will likely offer the format at other support groups in the future.

Coburg continues to support each other and enjoys also meeting bi-monthly. Our meetings recently included

discussing living well as a family, as well as general open conversation time.

Traralgon has welcomed some new and old members to its meetings recently, meeting regularly at the Gippsland Rotary Centenary House. Whilst still growing in numbers, the members have wonderful respect and time to listen to each other. Recent topics of discussion include stem cell transplants and travelling with myeloma.

Warragul continues to meet for informal support dinners at rotating venues. Whilst not a regular information support group style, the meetings allow connection, sharing and mateship between the local myeloma families.

Elli continues to support the groups in Geelong, Mt Eliza, Berwick, Beaumaris, and facilitated the second half of the years younger persons group. She looks forward to visiting Warrnambool at the end of November.

Elli and myself have also enjoyed time targeting our nursing colleagues, increasing their knowledge of myeloma, its treatments, and supportive care strategies. Whilst continuing to do small in-services in the hospital setting, I also ran education dinners for nurses in Wangaratta and presented alongside my colleague Elli in Traralgon, as well as a large myeloma education evening for 55 attendees in the CBD. The collaborative event between Myeloma Australia and St Vincent's Hospital, Melbourne included presentations from MSAG member Hang Quach, as well as chemotherapy staff, and myself.

As the year comes to an end, I warmly wish the people whose lives we are privileged to be a part of all the best for them and their families this Christmas holidays. Many I will see at upcoming Christmas lunches, for those I don't, know I am thinking of you at this special yet often challenging time.

*Laura Jones*  
Myeloma Support Nurse



Laura Jones – La Trobe Seminar



Wangaratta Nurse dinner



Prof Miles Prince at La Trobe Seminar



La Trobe Seminar



Wangaratta Information and Support Group



Elli Foley with Robert Moran OAM

## Western Australia

The warmth of summer is nearly upon us and the WA Myeloma Support Nurses have been spending their time planning the next year ahead with a number of events scheduled.

WA support groups have continued along at a steady pace across the board. The northern suburbs groups are solidly attended by six to ten people each meeting whilst the southern suburbs group has six regular attendees to each meeting in Mandurah. As the year is drawing to a close, a review of our support groups and their geographical location has resulted in some relocations of the current groups and will see the commencement of two new groups in the Perth metropolitan area. From Feb 2019, both northern suburbs groups will amalgamate into one group and move to a more central venue of the Wanneroo Library. The southern suburbs group will also undergo a venue change moving to the Mary Davis Library in Rockingham for 2019.

A new support group will begin in Feb 2019 in the Perth Hills, something that both of us are really excited to be offering, and we hope it will be well attended. The first meeting will be on the 25th Feb from 10am-12pm at the ZigZag Cultural Centre in Kalamunda, so feel free to contact Kerin (kerin.young@myeloma.org.au) if you would like more information.

Another new event upcoming for WA will be a Coffee & Chat "Drop In" Morning Tea where you can call by and visit us in our Cottesloe offices and have a chat with us over a cuppa. This will be an ideal opportunity to informally ask any questions of the WA Myeloma Support Nurses, be it related to side effects of treatments or to even discuss support services or simply have a chat. The first one of these Coffee & Chats will be held on the 10th December from 9:30am -11:30am in the Conference Hall at Solaris Cancer Care in Cottesloe, this will coincidentally be the last event on the WA Myeloma Support Nurse Calendar for 2018. If you would like more information please contact Narelle (narelle.smith@myeloma.org.au).

We held our first Information morning in Cottesloe on the 16th November which was well attended with 26 patients and carers coming along. Presenters included Dr

Dustin Hall, a haematologist from Fiona Stanley Hospital who provided a great overview on myeloma followed by a question and answer session where members of the audience were able to ask everything and anything about myeloma and its treatment. The feedback from this session was overwhelmingly positive with many of the participants saying they felt that they now had a better understanding of the disease. This was followed up by dietitian Wayne Epton who is the head of department for the Royal Perth and Bentley Hospitals who presented on the role of dietitians and nutrition in myeloma care. This session was also well received generating a discussion around learned food aversions and hospital food. Preliminary feedback from the event was extremely positive, and we are looking forward to holding our next Information morning on the 22nd Feb 2019. More details about this event will be available soon.

Aside from patient and carer support groups and information seminars, both of us have been busy representing WA and Myeloma Australia at Blood 2018 – the national haematology conference, this year held in Queensland at the Brisbane Convention Centre. This event was a fantastic opportunity from both a networking and professional development view point whilst also allowing some important team building and planning with all the other Myeloma Support Nurses across Australia and well worth the five hour flight both ways.

The WA health professional education program has continued with in-services held at SJOG Subiaco and Kalgoorlie Health Campus. The Kalgoorlie session proved an exciting regional opportunity for rural WA and was successfully attended and held via video link. We are in the process of organising a free education event for health professionals to be held in early 2019, involving the discussion of current topics of interest in the management of myeloma.

As we sign off for 2018, we would like to wish the entire myeloma community a safe Christmas and we are really looking forward to expanding our services here in WA for 2019

*Kerin Young  
Narelle Smith  
Myeloma Support Nurses WA*



*Dustin Hall presenting*



*Morning tea on verandah*



*Wayne Epton presenting*



### New Drugs

**“Promising activity of nelfinavir-bortezomib-dexamethasone (NeVd) in proteasome inhibitor-refractory multiple myeloma,” in *Blood*, September 20, 2018**

**Driessen, C. et al as reported by Myeloma Beacon 2/10/2018; <https://myelomabeacon.org/news/2018/10/01/nelfinavir-velcade-combination-very-active-in-advanced-multiple-myeloma/>**

Nelfinavir (Viracept) is an oral protease inhibitor. Nelfinavir was approved by the U.S. Food and Drug Administration in 1997 for the treatment of human immunodeficiency virus (HIV), the virus that causes acquired immune deficiency syndrome (AIDS). Preclinical research showed that nelfinavir may overcome resistance to proteasome inhibitors, such as Velcade (bortezomib), Kyprolis (carfilzomib), and Ninlaro (ixazomib), in myeloma cells. These findings prompted Swiss researchers to assess the efficacy and safety of nelfinavir in combination with Velcade and dexamethasone in myeloma patients who were refractory to a proteasome inhibitor-containing treatment regimen. A Phase 1 clinical trial investigating the nelfinavir combination showed that five out of six patients responded to the treatment.

In a follow up phase 2 study, 34 heavily pre-treated and proteasome inhibitor refractory patients were treated with the combination of nelfinavir, Velcade, and dexamethasone. 65% achieved at least a partial response and 20% of the patients had either a minimal response, or a period of stable disease, in response to the three-drug treatment regimen.

Based on their findings, the Swiss researchers recommend further investigation of nelfinavir in combination with Velcade or other proteasome inhibitors, such as Velcade or Ninlaro (ixazomib), in a wide range of myeloma patients, not just those who are heavily pretreated.

### Treatment Outcomes:

**Survival gains in multiple myeloma from 2003 to 2014.**

**Rafael Fonseca, Anupam B. Jena, Desi Peneva, Zoe Clancy; *Journal of Clinical Oncology* 36, no. 30\_suppl (October 20, 2018) 98-98.**

**Background:** Survival probabilities for patients with multiple myeloma have increased considerably over the past several decades, and a conservative estimate of 5-year survival today is approximately 50%, perhaps higher with optimal treatment. Treatment options for multiple myeloma have grown significantly beginning in 2003 with the approval of bortezomib, followed by approvals for lenalidomide and thalidomide in 2006. The second wave of novel agent approvals began in 2012 with carfilzomib, followed by pomalidomide in 2013. The aim of this study was to estimate the survival gains associated with multiple myeloma therapies after the introduction of novel therapies beginning in 2003 in the United States.



**Conclusions:** Patients diagnosed with multiple myeloma during 2010–2014 had significant improvement in survival relative to patients diagnosed in 1998–2002. This study found continued improvement in survival in multiple myeloma patients in the most recent 5-years of survival data available, demonstrating the considerable progress made since the wave of multiple myeloma innovation began in 2003.

### Clinical Trials Vs Real World Experience for Myeloma Patients:

The majority of newly diagnosed myeloma patients do not fulfill the inclusion criteria in clinical phase 3 trials

Tobias W. Klausen; Henrik Gregersen; Niels Abildgaard; Niels Frost Andersen; Ulf Christian Frølund; Peter Gimsing; Carsten Helleberg; Annette J. Vangsted; *Leukaemia*, Published: 28 September 2018

Real-world data are important as randomized clinical trials have strict inclusion and exclusion criteria that do not allow evaluation of the effect and toxicity of new drugs or treatment modalities in patients that do not meet these criteria. Renal failure, affected performance status (frailty) and severe co-morbidity were the most frequent exclusion criteria along with “cancer within 5 years”.

A large population-based study data from the Danish Multiple Myeloma Registry shows that only 36.6% of elderly and 45.2% of younger patients met the inclusion and exclusion criteria for eight-chosen phase 3 randomized clinical trials and these patients from the registry, who met these criteria, had a better change to overall survival than those who did not.

Drug registration phase 3 randomized clinical trials are often the quickest and easiest design to show superiority of new treatment but are not reflective of clinical standard of care in the community, where we adjust the dose of the individual drugs according to the co-morbidity, frailty, and disease complications.

We plan to use the real world data from our Danish Multiple Myeloma Registry and the Danish National Patient Registry to analyze outcome and major side effects of new drugs in patients in clinical practice, with a focus on patients that do not meet the inclusion criteria in randomized clinical trials. We suggest that inclusion criteria in randomized clinical trials for performance status, renal disease and other cancers are adjusted, and that the design of studies is reconsidered to better reflect daily practice. Furthermore, we recommend world-wide investigator-initiated studies on patient's who do not meet inclusion criteria.

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### Radiotherapy:

#### The Safety Profile of Concurrent Therapy for Multiple Myeloma in the Modern Era.

**Lucas Resende Salgado MD, MPA; Shutao Wang PhD; Ava Adler; Sanders Chang; Meng Ru MS; Erin Moshier MS; Kavita Dharmarajan MD; Jay Hearn Cho MD PhD; Richard Bakst MD; Advances in Radiation Oncology; Available online 27 September 2018**

The management of multiple myeloma (MM) has evolved in the modern era partially owing to the increasing number of biological therapeutics. Nonetheless radiation continues to be an important treatment in the management of painful lytic lesions from MM. The goal of this study is to evaluate the side effect profile of radiation therapy while patients are concurrently being treated with biological agents.

**Conclusions:** Our study did not detect any significant toxicity rates from palliative radiation while patients were concurrently receiving biological agents.

### Economy of Treatment Outcomes:

#### Real-world economic outcomes of early progression in newly diagnosed multiple myeloma (NDMM) patients (Pts).

**Zoe Clancy, Shivani Pandya, Sulena Shrestha, Li Wang, Onur Baser, Quanhong Ni**

**Background:** Despite improved survival with advanced multiple myeloma (MM) treatments (Tx), 15–20% of pts experience early relapse. We assessed the economic impact of early progression among non-stem-cell transplant NDMM pts.

**Results:** 2 cohorts were examined, 'early progression' and 'delayed progression'. Patients in the early progression cohort were younger and incurred higher all-cause inpatient (\$17,332 vs \$10,455), outpatient hospital (\$18,183 vs \$15,097), emergency department (\$462 vs \$395), office (\$37,728 vs \$29,174), and total costs (\$130,948 vs \$108,003) compared with the delayed progression cohort. Similarly, the early progression cohort had higher MM-related total costs (\$87,284 vs \$72,150) including inpatient and outpatient costs.

**Conclusions:** Early progression after first line of therapy is associated with substantially higher economic burden indicating the need for future studies of therapies that delay progression and potentially result in cost savings.

### Supportive Care:

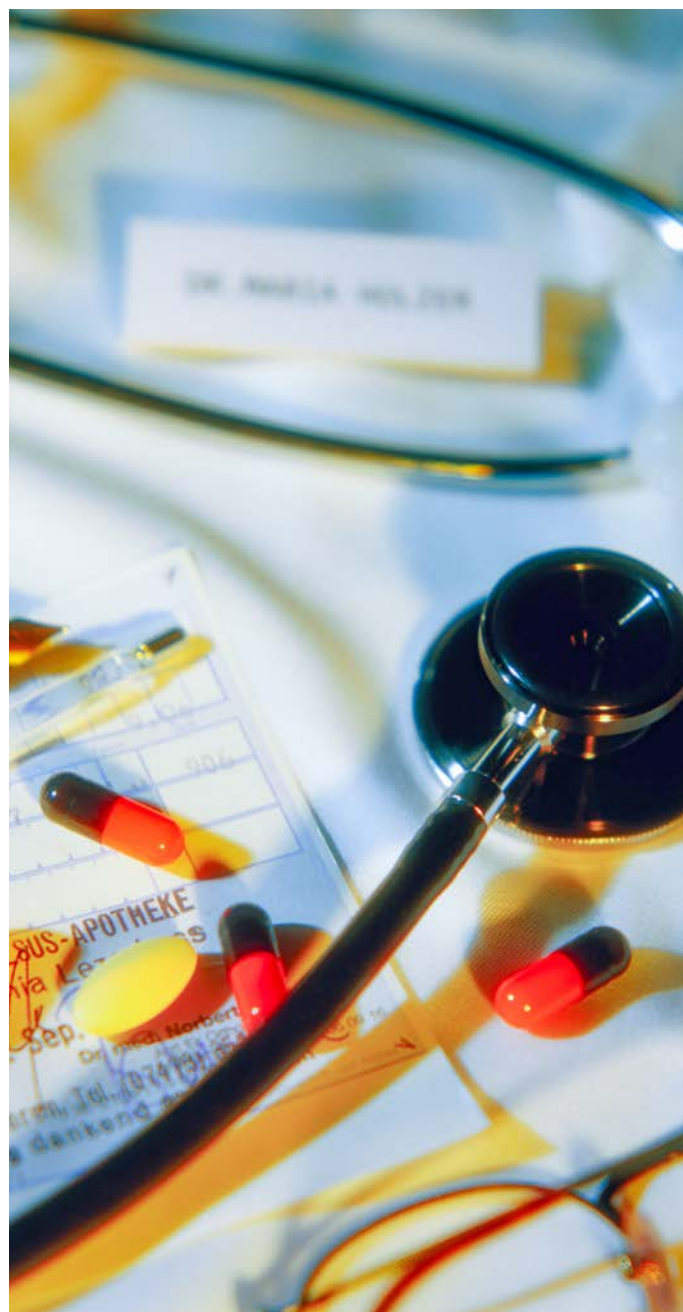
#### Management of multiple myeloma bone disease: impact of treatment on renal function

**Nikolaos Kanellias, Maria Gavriatopoulou ORCID Icon, Evangelos Terpos & Meletios Athanasios Dimopoulos**

**Journal: Expert Review of Hematology; Accepted author version posted online: 04 Oct 2018**

**Expert Commentary:** Bisphosphonates (BPs) remain the cornerstone in the management of myeloma-related bone disease. Zoledronic acid and Pamidronate are currently the gold standard, however cannot be used in patients with severe renal dysfunction. Renal impairment is another hallmark of myeloma with approximately 60% of the patients presenting with or developing renal dysfunction during the disease course. Although BPs rarely cause renal impairment, they should be administered with caution in patients with impaired renal function. The exact mechanism by which BPs cause renal impairment is yet to be elucidated. Another promising agent is Denosumab, a RANKL inhibitor, which can be administered regardless of renal function and does not need the relevant dose-adjustments.

MA editor comment: PBAC recently approved Denosumab







# Calendar of Events 2018

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

## Victoria

| Event                                    | Date          | Location                                                                                | Time                | Organisation      | Contact                                                                                                         |
|------------------------------------------|---------------|-----------------------------------------------------------------------------------------|---------------------|-------------------|-----------------------------------------------------------------------------------------------------------------|
| Coburg Information and Support Group     | Wed Dec 5th   | Vasili's Garden & Café<br>(Festive Lunch)<br>21-25 Munro St, Coburg                     | 12 noon onwards     | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Beaumaris Information and Support Group  | Thur Dec 6th  | Vincent Café Restaurant<br>(Xmas Lunch)<br>468 Beach Rd, Beaumaris                      | 12 noon onwards     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |
| Kew Information and Support Group        | Thur Dec 13th | Skinny Dog Hotel<br>(Festive Lunch)<br>155 High St, Kew                                 | 12 noon onwards     | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Geelong Information and Support Group    | Fri Dec 14th  | Telegraph Hotel<br>(Xmas Lunch)<br>2 Pakington St, Geelong West                         | 12 noon onwards     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |
| Traralgon Information and Support Group  | Wed Dec 19th  | Festive Lunch<br>TBA                                                                    | 12 noon onwards     | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Warragul Information and Support Group   | Thur Jan 10th | Rotating at local venues,<br>details published<br>closer to date                        | 6pm - 8pm<br>Dinner | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Sunshine Information and Support Group   | Thur Jan 31st | Braybrook Community Centre<br>107 - 139 Churchill Ave,<br>Braybrook                     | 10 am - 12 noon     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |
| Berwick Information and Support Group    | Fri Feb 1st   | St John of God Hospital<br>55 Kangan Dv, Level 1, Berwick                               | 10 am - 12 noon     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |
| Coburg Information and Support Group     | Wed Feb 6th   | Coburg North Meeting Room<br>Shop 19/180 Gaffney St<br>(Coles site)                     | 10 am - 12 noon     | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Wangaratta Information and Support Group | Thur Feb 7th  | Wangaratta Library,<br>Seminar Room<br>21 Docker St, Wangaratta                         | TBA                 | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Beaumaris Information and Support Group  | Thur Feb 7th  | Beaumaris Theatre<br>82 Wells Road, Beaumaris                                           | 10 am - 12 noon     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |
| Albury Information and Support Group     | Fri Feb 8th   | Albury Wodonga Regional<br>Cancer Centre, Wellness Room,<br>201 Borella Rd, East Albury | 10 am - 12 noon     | Myeloma Australia | Laura Jones<br>E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a><br>M: 0451 404 203 |
| Geelong Information and Support Group    | Fri Feb 8th   | SCC Meeting Room<br>(Andrew Love Centre)<br>70 Swanston Street, Geelong                 | 10 am - 12 noon     | Myeloma Australia | Elli Foley<br>E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a><br>M: 0426 404 233    |

## South Australia

| Event                                   | Date          | Location                                                                        | Time               | Organisation      | Contact                                                                                            |
|-----------------------------------------|---------------|---------------------------------------------------------------------------------|--------------------|-------------------|----------------------------------------------------------------------------------------------------|
| Flinders Information and Support Group  | Thur Jan 17th | Living Kurna Cultural Centre<br>Function Room<br>Warriparinga Way, Bedford Park | 10 am - 12 noon    | Myeloma Australia | Jenny Naylor<br>E: Jenny.Naylor1@gmail.com<br>M: 0405 391 616<br>1800 MYELOMA (693 566)            |
| Fullarton Information and Support Group | Tues Feb 5th  | Fullarton Park Centre<br>411 Fullarton Rd, Fullarton                            | 10 am - 12 noon    | Myeloma Australia | Ian Driver<br>E: sandrian7@bigpond.com<br>M: 0417 874 252<br>1800 MYELOMA (693 566)                |
| South East Regional Seminar             | Fri Feb 8th   | Katnook Estate - Coonawarra<br>(6km north of Penola)                            | 11.30 am - 2.30 pm | Myeloma Australia | Carol Koch<br>E: clk@live.com.au<br>M: 0427 659 014<br>1800 MYELOMA (693 566)                      |
| Mid North Information and Support Group | Wed Feb 20th  | Snowtown Hospital<br>70 Railway Terrace E, Snowtown                             | 12 noon - 2 pm     | Myeloma Australia | Bronwyn Gerschwitz<br>E: graemebronwyng@bigpond.com<br>P: (08) 8664 0682<br>1800 MYELOMA (693 566) |
| Flinders Information and Support Group  | Thur Mar 21st | Living Kurna Cultural Centre<br>Function Room<br>Warriparinga Way, Bedford Park | 10 am - 12 noon    | Myeloma Australia | Jenny Naylor<br>E: Jenny.Naylor1@gmail.com<br>M: 0405 391 616<br>1800 MYELOMA (693 566)            |

## Western Australia

| Event                                     | Date         | Location                                                               | Time               | Organisation      | Contact                                                                                       |
|-------------------------------------------|--------------|------------------------------------------------------------------------|--------------------|-------------------|-----------------------------------------------------------------------------------------------|
| Coffee&Chat Patient                       | Mon Jan 11th | Solaris Cancer Centre<br>Wanslea Room<br>80 Railway Road, Cottesloe    | 9:30 am - 11:30 am | Myeloma Australia | Narelle Smith<br>E: narelle.smith@myeloma.org.au<br>M: 0426 404 280<br>1800 MYELOMA (693 566) |
| Southern Information and Support Group    | Mon Jan 21st | Mary Davis Library<br>& Community Centre<br>17 Settlers Av, Baldivis   | 10 am - 12 noon    | Myeloma Australia | Kerin Young<br>E: kerin.young@myeloma.org.au<br>M: 0426 404 310<br>1800 MYELOMA (693 566)     |
| Northern Information and Support Group    | Mon Feb 11th | Wanneroo Library Group<br>Study Room, Level 1<br>3 Rocca Way, Wanneroo | 1pm - 3pm          | Myeloma Australia | Narelle Smith<br>E: narelle.smith@myeloma.org.au<br>M: 0426 404 280<br>1800 MYELOMA (693 566) |
| Patient Information Morning               | Fri Feb 22nd | Solaris Cancer Centre<br>Conference Hall<br>80 Railway Road, Cottesloe | 9:30 am - 12 noon  | Myeloma Australia | Kerin Young<br>E: kerin.young@myeloma.org.au<br>M: 0426 404 310<br>1800 MYELOMA (693 566)     |
| Perth Hills Information and Support Group | Mon Feb 25th | Zig Zag Cultural Centre<br>50 Railway Rd, Kalamunda                    | 10 am - 12 noon    | Myeloma Australia | Kerin Young<br>E: kerin.young@myeloma.org.au<br>M: 0426 404 310<br>1800 MYELOMA (693 566)     |
| Coffee&Chat Carer                         | Mon Mar 18th | Solaris Cancer Centre<br>Wanslea Room<br>80 Railway Road, Cottesloe    | 9:30 am - 11:30 am | Myeloma Australia | Narelle Smith<br>E: narelle.smith@myeloma.org.au<br>M: 0426 404 280<br>1800 MYELOMA (693 566) |
| Southern Information and Support Group    | Mon Mar 25th | Mary Davis Library<br>& Community Centre<br>17 Settlers Av, Baldivis   | 10 am - 12 noon    | Myeloma Australia | Kerin Young<br>E: kerin.young@myeloma.org.au<br>M: 0426 404 310<br>1800 MYELOMA (693 566)     |

## Queensland

Queensland Information and Support Groups coming soon, please check "Events" at  
[www.myeloma.org.au](http://www.myeloma.org.au) for updates early 2019



## New South Wales

| Event                                                              | Date                                                          | Location                                                                                                                      | Time            | Organisation                         | Contact                                                                                                |
|--------------------------------------------------------------------|---------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-----------------|--------------------------------------|--------------------------------------------------------------------------------------------------------|
| Liverpool Information and Support Group                            | Tues Feb 12th                                                 | Liverpool Hospital<br>The Wellness Centre<br>(Entrance N off Campbell St) Level 1,<br>Cnr Elizabeth & Goulburn Sts, Liverpool | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Westmead Information and Support Group                             | Thur 21st Feb                                                 | Wentworthville Leagues Club<br>Magpie Meeting Room 1<br>50 Smith St, Wentworthville                                           | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Central Coast Information and Support Group                        | Thur 28th Feb                                                 | Central Coast Leagues Club<br>Dane Drive, Gosford                                                                             | 6 - 8 pm        | Gosford Hospital & Myeloma Australia | Jacqui Jagger<br>E: jacqueline.jagger@health.nsw.gov.au<br>P: (02) 4320 9641<br>1800 MYELOMA (693 566) |
| Newcastle Information and Support Group                            | Mon Mar 4th                                                   | Cancer Council Office<br>Level 1/215 Pacific Highway,<br>Charlestown                                                          | 3 pm - 5 pm     | Myeloma Australia                    | John Miller<br>E: miller32@optusnet.com.au<br>P: (02) 4957 0711<br>1800 MYELOMA (693 566)              |
| Liverpool Information and Support Group                            | Tues Apr 9th                                                  | Liverpool Hospital<br>The Wellness Centre<br>(Entrance N off Campbell St) Level 1,<br>Cnr Elizabeth & Goulburn Sts, Liverpool | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Westmead Information and Support Group                             | Thur Apr 18th                                                 | Wentworthville Leagues Club<br>Magpie Meeting Room 1<br>50 Smith St, Wentworthville                                           | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Central Coast Information and Support Group                        | Thur Apr 18th<br><i>* 1 week earlier<br/>due to ANZAC day</i> | Central Coast Leagues Club<br>Dane Drive, Gosford                                                                             | 6 - 8 pm        | Gosford Hospital & Myeloma Australia | Jacqui Jagger<br>E: jacqueline.jagger@health.nsw.gov.au<br>P: (02) 4320 9641<br>1800 MYELOMA (693 566) |
| Newcastle Information and Support Group                            | Mon May 6th                                                   | Cancer Council Office<br>Level 1/215 Pacific Highway,<br>Charlestown                                                          | 3 pm - 5 pm     | Myeloma Australia                    | John Miller<br>E: miller32@optusnet.com.au<br>P: (02) 4957 0711<br>1800 MYELOMA (693 566)              |
| Liverpool Information and Support Group                            | Tues June 11th                                                | Liverpool Hospital<br>The Wellness Centre<br>(Entrance N off Campbell St) Level 1,<br>Cnr Elizabeth & Goulburn Sts, Liverpool | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Westmead Information and Support Group<br><i>* Change of Venue</i> | Thur June 20th                                                | Wentworthville Leagues Club<br>Magpie Meeting Room 1<br>50 Smith St, Wentworthville                                           | 10 am - 12 noon | Myeloma Australia                    | Jacqui Keogh<br>E: jacqui.keogh@myeloma.org.au<br>M: 0426 404 230                                      |
| Central Coast Information and Support Group                        | Thur June 27th                                                | Central Coast Leagues Club<br>Dane Drive, Gosford                                                                             | 6 - 8 pm        | Gosford Hospital & Myeloma Australia | Jacqui Jagger<br>E: jacqueline.jagger@health.nsw.gov.au<br>P: (02) 4320 9641<br>1800 MYELOMA (693 566) |

## National Telephone Support Group (Cancer Council NSW)

| Event             | Date                            | Location                        | Time                        | Organisation                      | Contact                                                   |
|-------------------|---------------------------------|---------------------------------|-----------------------------|-----------------------------------|-----------------------------------------------------------|
| Telephone Support | 2nd & 4th Monday<br>every month | Available to those with myeloma | 1.30 pm - 2.30 pm<br>(AEST) | Cancer Council NSW<br>with MA NSW | Cancer Council NSW<br>1300 755 632<br>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](http://www.myeloma.org.au)** to download the latest information, find support and seminar events etc

**Myeloma Support Nurses are on call at**

**Freecall: 1800 693 566 (1800MYELOMA)**

**Mon – Fri 9am – 5pm AEST**

**E: [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au) W: [www.myeloma.org.au](http://www.myeloma.org.au)**