In this issue

President’s Report 3
“My Hero” The Wishing Wall 4
15th International Myeloma Workshop 5
Vale – Associate Professor Laurence Preston Catley 6
Coping with loss and living with the ‘new normal’ 8
My myeloma experience 10
EMMA 11
MSAG Prize Winners 12
My half marathon 13
Nurse Report 15
NSW Division Report 17
SA Division Report 18
VIC Division Report 19
Medical Corner 20
Events for 2016 21
Calendar of Events 22-23
At this time of the year I remember back now 19 years to when my wife, Roslyn, received her myeloma diagnosis. She had just had her 50th birthday and we were making plans for the next few years. At that time, her options for treatments was very limited, a stem cell transplant or chemo. Her only wish then, was to see our two children get married and hopefully have grandchildren. Now, 18 years after her stem cell transplant she is in remission, our children are married and we have six beautiful grandchildren.

The options for treatment now are so different, with four drugs subsidised by the Pharmaceutical Benefits Scheme: Thalidomide, Velcade, Revlimid and Pomalyst. There are a number of new drugs which will hopefully be approved for use in Australia over the next couple of years with a further number being trialled both here and overseas. We need these multiple options for treatment and this is what is now happening.

I am writing this report as we get ready to head off to Orlando in the USA to attend the American Haematology Society’s annual meeting. I am travelling with our CEO Steve Roach and our Support Nurse Manager Hayley and this will be the third time we have attended this meeting. While there, we will be attending a number of events staged by the International Myeloma Foundation as well as meetings with pharmaceutical companies with the aim to improve the amount of support they give us. Hayley and I will also try and get to as many presentations as we can to hear the results about the new research being done all around the world.

I am excited to announce that we have now employed our fourth myeloma support nurse who will begin training in the middle of December. She will assist Hayley and enable us to increase our services to the Australian myeloma community.

By the time you are reading this edition of MyeNews our new website should be up and running. Unfortunately it crashed a few months ago and we have had to completely rebuild it which has taken much longer than we expected. It will be bigger and better than before as well as being easier to navigate. So please check it out at www.myeloma.org.au.

I would like to take this opportunity to thank all of our volunteers and supporters for all your help over the past year and I look forward to catching up with as many as I can over the next year. We only have a small staff to achieve what we do and I am extremely proud of what they have achieved over the past year. They have been assisted by you the volunteers who have also run our support groups and assisted the myeloma support nurses when ever possible.

Finally I would like to wish you and your families all the very best for the festive season and a happy and healthy New Year.

Brian Russoorten

Christmas Dates
Myeloma Australia head office will close for Christmas at 12 noon on Friday 24 December and re-open at 9.00 am on Monday 4 January 2016.
Become a “MyHero” by Going the Extra Mile for Myeloma.

Are you a MyHero?  
If so we would love to recognise you!

If you go the extra mile for the myeloma community by fundraising we want to recognise you. This may be through doing a fun run, a marathon, a triathlon, a walkathon, a community morning tea fundraiser, a film night, an open garden, a bike ride, shaking a tin, having a sausage sizzle, an art show, a garage sale, a luncheon, a workplace or school-based fundraiser, funny hat or tie day, fancy dress party, cocktail party, or anything else. These are all things people have done and do for us.

We are creating a MyHero wall at Myeloma HQ, where we will place a plaque on the wall with a description of what has been done, to recognise individuals and organisations that fundraise for us. These plaques will be the bricks of our MyHero Wall and will be recognised in MyeNews and on our social media platforms.

The Wishing Wall

Here at Myeloma Australia many individuals help us and we hope that we are helping many in return. We were looking for a way in which people could express their good will, their hope, their prayers and their thanks given the situation that people living with myeloma and their families find themselves in.

We have decided on a Wishing Wall!

A place where you can write your message and or photograph and sign it. A place where that message and photo and your autograph will stay.

We have dedicated a wall in our new offices for you to write your message, put up a photo of you and your family, or even just sign your name as part of the Myeloma Australia community. You may be a patient, a carer, a relative, a friend, a volunteer, just someone who cares! We want you to come into head office and put your message on the wall. If you are from interstate messages can be sent to us via email, post or phone for us to put up for you until you get a chance to come in yourself and sign it.

We will post photos of the wall regularly on our social media platforms, website and in MyeNews.

We love it when people drop in and this will give you a reason to do that! It would be great if everyone in the community could sign the wall and leave a message, or post a photo!

If you can’t get into the office, you can email your message to wishingwall@myeloma.org.au or telephone us on 03 9428744.

We look forward to seeing you and having you leave your mark at Myeloma Australia.

 Regards,  
Steve Roach
By Hayley Beer

This year I was fortunate to be given the opportunity to attend the 15th International Myeloma Workshop (IMW) which was held in Rome from September 23-26. This conference was very well attended by Australian’s particularly in the nursing stream and it was great to have Tracy King, Daniela Klarica, Carmel Woodrow and Michael Cooney there along with many of our medical and pharmaceutical colleagues.

Before the official conference began, I attended a workshop with the Global Myeloma Action Network, which is an International Myeloma Foundation initiative attended by representatives of consumer groups from around the world. It was fantastic to meet with members from like-minded organisations from many parts of the globe. However, I did come away with a sense that we are very lucky in Australia. While our PBS is not perfect, we certainly have a fair and equal system for all citizens. There are some parts of Eastern Europe who are struggling to even keep haematologists in their country as the pay is more attractive elsewhere.

The first day of the conference was a nursing symposium. Tracy King chaired the session and explained that the nursing stream of the IMW has grown from strength to strength in two years. It began as a half day and has grown into a full day program. It was great to hear about projects happening in other parts of the world. Some similar to Australia and others different. Daniela Klarica from the Alfred in Melbourne presented her extremely innovative Velcade at Home program where she is currently teaching suitable myeloma patients to reconstitute and self-inject their dose at home. The crowd were astonished to hear that some patients in Australia will travel 5 hours to receive treatment. For some Europeans, driving 5 hours would take them to a completely different country!

I was most impressed by two Italian nurses who not only gave their first ever presentation at a conference, they also presented in English which is obviously not their first language. They presented the Italian experience of toxicities associated with subcutaneous Velcade. It was also great to catch up with Beth Faiman, a nurse practitioner from The Cleveland Clinic in Ohio, USA who visited us in July this year. Beth is a vibrant wealth of knowledge and like all the presenters on the day inspires me to keep improving my own practices.

The rest of the conference consisted of medical lectures. It was great to hear reports on global and local clinical trials and pre-clinical research. It seems that Revlimid upfront is the way to go for the non-transplant eligible group. With a bit of luck the PBS will approve this indication in Australia very soon.

I also really enjoyed the supportive care session, particularly Associate Professor Maria-Victoria Mateos from Salamanca, Spain who spoke about peripheral neuropathy. Prevention of peripheral neuropathy is key to improved quality of life as most remedies are ineffective for most people. In the age of subcutaneous Velcade and Revlimid we should be seeing less people suffer with this horrible toxicity. One tip I picked up was to correct the vitamin B12 if deficient to help prevent peripheral neuropathy from occurring.

It was an action packed week with minimal time to see the sites, I did however consume my fair share of pizza and prosecco and manage to invest in some quality leather goods.

Thank you to Myeloma Australia who made the trip possible.
Associate Professor Laurence Preston Catley

The myeloma community was shocked and saddened by the untimely passing of Professor Laurence Catley, known to all as Laurie, in Venice in September this year. Laurie was Deputy Chair of MSAG and at their meeting on 17 November, colleagues paid tribute to his life and work.

Professor Andrew Zannettino, a colleague and friend from Adelaide attended his funeral. He described the sad occasion and reflected on his friendship with Laurie:

Laurie was born on the 30th September 1964 in Kent and died on the 21st September 2015, Hotel Galleria, Grand Canal, Venice.

Laurie died peacefully in his sleep of a heart attack a few days short of his 51st birthday. He was with his loving wife Reggie at the time and was spending a few days in Venice before heading to Rome for the IMW meeting on Sept 23.

I, along with Noemi Horvath, Tim Hughes, Ken Davis, Marion Roberts and Heather Tapp attended his funeral in Adelaide on 16th October.

At the funeral, Bob, Pat and Reggie gave wonderful, heartfelt eulogies about their beloved Laurie. We all learnt from these wonderful reflections of his life that he attended Prospect Primary school and Adelaide High School. While he showed some sporting promise as a child, in particular in the sport of Aussie Rules, some issues with his knees saw him turn his attention to study.

He was a self-motivated student and won 4 prizes and was Dux of his year in 1981. Before entering Medical School at the University of Adelaide, Laurie spent his gap year mainly in the US.

I also had the opportunity to spend a quite a lot of time together as we lay captive at Athens airport on our way home from the IMW meeting in Kos in 2007. As you may recall, this was at the time when terrorists attempted to ram a jeep loaded with propane canisters into the glass doors of the Glasgow International Airport terminal. This meant that flights into and out of Europe were thrown into chaos. While the rest of us were frankly “freaking out” at what was happening, Laurie’s attitude, like always, was one of calm.

At that time, I learnt about Laurie’s love for music, and that in addition to being an excellent clinician/scientist, Laurie was an accomplished musician. He trained as a classical guitarist in Adelaide, and had performed in many hospital charity events. In fact, Laurie composed, recorded and remixed music on an 8-track recorder. Although knowing Laurie for more than half a dozen years, at this time, I also learnt that he had a son, Timothy.

Eulogies were offered by Laurie’s grieving wife Reggie, his father Bob, his mother Patricia and his older brother Phillip.

Laurie was a very private person and the funeral was an opportunity to learn more about a man that I got to know while I was completing my PhD studies in the mid-late 90’s at the IMVS and University of Adelaide. At the time, Laurie was a registrar at the IMVS, completing his haematology training.

While we would often bump into each other in the IMVS corridors, or share an exchange in the tea room, I got to know Laurie a bit more when we both participated in the Sail for Cancer event that was held each year at the Goolwa Yacht club and then on the Murray River. Laurie was a keen sailor and even had a wonderful sailors cap to prove it!
After medical school and his internship, Laurie did his tour of duty at the IMVS, after which he spent some time in New Zealand at Auckland hospital before taking up a position in the laboratory of Professor Ken Anderson in Boston. Laurie spent 5 years at the Dana Faber Cancer Institute before returning to Australia in 2006 to take up the position of Director of Haematology at the Mater Hospital in Brisbane and Associate Professor at the University of Queensland Medical School.

Bob reflected on Laurie’s innate intelligence and solitary nature. While remembered as a carefree and happy child, Bob indicated that as an adult, Laurie’s serious demeanor would often see him thought of as being rather “off-handed”. However, as many of us would recall, Laurie had a wicked sense of humor.

In addition to his love of music and yachting, we also learnt from Bob, Patricia and Reggie that Laurie also had a serious hoarding habit, a passion for wind surfing, roller blading, scuba diving, kite surfing and had learned French and Latin as a child.

Laurie’s brother Phillip recalled a wonderful story of Laurie’s childhood. As an 8 year old, Laurie had taught himself the piano…. while you may say that many before him had done this, what was surprising is that he did this by making a cardboard keyboard on which he coloured the keys in a standard piano format. With this, he would practice and practice. No surprise then, that when confronted with a real piano, he could actually play in an accomplished manner!

When in the US, he took up snow skiing and would tour the world skiing with his friends. Laurie would send his folks video footage of him skiing using a helmet-mounted camera, well before GoPro’s were invented or were fashionable.

In his mid-30’s, while in Boston, Laurie met the love of his life, Reggie. With Laurie moving to Brisbane and Reggie moving to New York, they conducted a long distance love affair over several continents. They would meet up regularly at various key spots throughout the globe. In 2014, Reggie moved to Brisbane and they were married in the Maritime Museum. They had 14 wonderful years together.

Bob and Patricia said that they were overwhelmed by the number of letters, gifts and cards from Laurie’s patients in Brisbane expressing their sadness at his death…. a true reflection of his bedside manner and the high regard in which his patients held him.

For me personally, and for those of us who shared time with Laurie, he will be very sadly missed.

Professor Peter Mollee, a colleague in Brisbane, caught up with several of Laurie’s Queensland friends to share their thoughts:

Peter also described Laurie as a private and quiet person. He summarised Laurie’s considerable scientific achievements both during his 5 years in Boston and in Australia. Laurie was proud of his research in myeloma at the Dana Faber Cancer Centre in Boston, working on the then “investigational” agents, bortezomib and lenalidomide. Ken Anderson, who headed the myeloma centre in which Laurie worked, always spoke fondly and highly of Laurie and his contributions.

Laurie returned to Australia from Boston to take up the position as Director of Haematology at the Mater Hospital in Brisbane and continued his research activities. Having spent 5 years in research, Peter noted the diligence with which Laurie set about updating his clinical skills. He was an active member of the Ethics Committee and chaired the hospital Grand Rounds every week.

Laurie’s serious demeanour belied a dry and very funny black sense of humour. He would see the funny side of everyday events and was happy to laugh at himself. Classically trained in guitar, Laurie formed a band while at Med School – Bedside FX (named after the Australian 80’s electro dance-rock band Def FX). It was another surprise to see this quiet man perform in the Mater talent and review shows.

Sport was another passion: Laurie was a keen supporter of the New England Patriots and followed the Super Bowl religiously, always attending games when travelling to the USA – he even took the day off work to watch the Patriots win this year. At home, he supported the Brisbane Lions, attending every home game, always listening to the umpire and radio commentary at the same time.

While on an overseas holiday a few years ago, Laurie decided to try kite surfing and loved it. He purchased his own board and sail and regularly kite surfed at Redcliffe. He would often check the BOM weather report during the day for a good wind to try and get a surf in after work.

Lastly, it was clear that Laurie loved to travel to new and interesting places and would head away a few times every year to see somewhere different. Although he loved Venice and was very excited to be spending some time there before the International Myeloma Workshop, his favourite city was New York.

The loss of this outstanding clinician scientist, myeloma expert, respected and loved colleague is devastating. The MSAG members extended their condolences to Laurie’s wife, his parents and family, and the patients for whom he cared. He is sadly missed by all. ♦

Laurence Preston Catley
1964 – 2015
R.I.P.
Hello multiple myeloma, goodbye life as you know it…sound familiar?

Living with myeloma often means learning to live with loss, sitting with uncertainty, and accepting change. Many of your best laid plans get thrown out the window, and life suddenly becomes a merry-go-round between doctor’s appointments, medical tests, waiting and watching, and hoping and praying.

A patient once told me that multiple myeloma is a marathon, not a sprint, with plenty of hurdles (losses) along the way. Loss of independence, loss of control, loss of identity (especially if your role within the family has changed, or you have had to suddenly retire early), financial losses, physical losses, the list can go on and on.

Part of the challenge of living with myeloma is that unlike a short-term stressor where life eventually returns to normal, with myeloma you have to adapt to a whole new reality. And myeloma is not a one-size-fits-all illness, so making comparisons with what other patients go through won’t necessarily help give you a better idea of what to expect down the track. While well-meaning friends and family try and encourage you to ‘be positive,’ or remind you ‘it could be worse’ or ‘be grateful you are alive,’ most patients find no consolation in hearing these words. The truth is, feelings of fear, sadness, anger, frustration, confusion are perfectly normal and reasonable in this context, and are all part of the adjustment process.

With that being said, how do you work through it all and find a way to cope? Here are some tips and suggestions you may find helpful.

• **Be compassionate to yourself** — Give yourself permission to grieve the loss of what is familiar or what you have given up. It is normal to feel vulnerable or sad, especially if you are suddenly less capable of doing things for yourself. Facing uncertainty can be one of the hardest challenges for human beings. Don’t expect to be able to ‘be positive’ all the time, having a cry or moments of sadness does not make you a weak person, it just means you are human! Remember there are going to be specific time points when you will feel more emotional (such as waiting for a test result or before follow-ups), and even people with no history of anxiety will feel nervous and worried or find it hard to sleep leading up to them. Think of what you would say to a friend if they were in your shoes, and remember being critical of yourself is not going to help to motivate you.

• **Accept what is within your control:** Acceptance is not the same as giving up, or doing nothing. It is very common to get stuck on the ‘what ifs’. What if I relapse? What if treatment doesn’t work? What if my counts change, etc.? You can’t control or predict the future and getting caught up in these worries will often just paralyse you. Acceptance is recognising what is out of your personal control, and committing to action that improves and enriches your life, rather than takes away from it. So try and focus on more immediate day to day things that are within your control (e.g. going for a short, manageable walk as a way to try and prevent deconditioning, or practising brief relaxation regularly throughout the day to help you sleep better at night). Setting small, manageable daily routines and goals for each day can help you regain some sense of mastery and control over your life.

• **Focus on your values and what really matters to you:** Going through an experience like cancer can really shake people up. When faced with the prospect of death, the desire to lead a life with value, purpose and happiness, can suddenly seem so much more important. Use this as an opportunity to reflect on what you have been doing in your life, where
you are at, and what you would like to be doing differently. Have you been expending a lot of time and energy doing things to please others rather than yourself? You are more likely to live a satisfying and fulfilling life if you are doing things consistent with what is important to you – you will have less regrets and be better able to accept change. In the next 24 hours or the next week, what is one small step or behaviour you can change that will be more in line with that matters to you? For example if you value connecting with nature can you try and spend 5 minutes on the veranda every afternoon admiring the sunset, or simply listening to the sound of the wind? If you value expressing affection to your family, even on the days you feel tired can you send your children a text message to let them know you are thinking of them?

• Prioritise taking time out for yourself: Some people like to call this having a 'myeloma break'. Make sure to immerse yourself in something other than activities or tasks related to your physical treatment, or that remind you of having cancer. Being a cancer patient does not have to be your primary identity. Find activities that help to soothe you, or that you simply enjoy, as well as activities that help to nourish your body and give you a sense of achievement. Get a massage, practice meditation, listen to music, read, eat well, get regular exercise, play bridge with friends, take up a hobby; anything that helps you to take a step back, take a slow breath, and live in the moment. If you have pain or physical issues that make it hard to do the things you used to love, try to see if you can modify the way you do the activity. For example you could try doing it for a shorter period of time and then resting, rather than giving up on it completely. Or try listening to an audio book rather than reading a book if you are having trouble with vision. Or try a new activity that won't put too much pressure on your body. Myeloma sufferers often find their interests change because of their new perspective on life, so don’t dismiss an activity because it was something you didn’t think you would like in the past.

• Connect with others and communicate your needs: Many patients feel frustrated that people around them don’t always understand what it’s like to live with myeloma. They assume that because you ‘look well’ everything is okay. Other patients notice loved ones can become overprotective as their own way of coping with what is happening, and couples often find it hard to communicate and talk about their fears and worries as they don’t want to burden each other. Even strong relationships can become strained under the pressure of managing a complex illness. While it can be difficult to ask for help (especially when you are used to being the one that helps others!), reaching out to people and being specific about what you need is a useful strategy to help you adapt, and feel better supported. Remember people often feel privileged to be able to help, but they need guidance from you on what to do. If you are not sure what you need in that moment you can say something like: “Thank you that’s really kind, I’ll let you know what may be helpful when I’ve talked with my family”. Connecting with a myeloma support group can be useful, because it gives you a chance to debrief about your experience in a safe environment with people who understand. Having an opportunity to have your worries normalised can also be a great source of comfort.

Most of all, try to acknowledge the coping strategies and strengths you already have. Many of you may have dealt with stress and loss in your life before. What has helped you to cope? Rather than focusing on what you have lost or what has changed, try and remind yourself of all the things you are still managing to do despite being ill. Is there anything you have done now that you wouldn’t have done if you weren’t ill?

Remember adjusting takes time but if you feel that these issues are really weighing you down, or maybe you want some help to figure out what your values are, most treatment centres have a clinical psychologist or counsellor that can help teach you strategies to address this. Have a chat with your GP and they may be able to recommend a local service to you. ●

Myeloma Australia would like to thank the following Fundraisers for their efforts:

Steve Johnson
Daniel Cudmore
Jacqui Kouzoukas
Greg Nash
Trina Hide
Kate Smith
Tim Wheeler & Catherine Rich (wedding)

Your contribution makes the world of difference to a great many people.
My myeloma experience

By Neil Sill

I should start by mentioning that the treatment I received at the QEH by Dr. Cindy Lee and her team of doctors and nurses and paramedics and ancillary staff has been and is superb. I might add parenthetically that my wife too had another form of cancer and also received wonderful treatment from the oncology team. So it wasn’t just me, I am happy to relate.

But to the story. I was having severe back pain to the point I had to stand up at work and creep along very slowly. I received quite good support from colleagues, I might add. This also occurred when, prior to diagnosis I was bedridden for a time. My wife was in Scotland overseeing the birth of our second wee haggis and third grandchild. I wasn’t telling her anything. I had been to casualty on two occasions with my back pain and was basically given a couple of Panadol and told to man up. Not quite so callous, but the subtext was there. I know the doctors are run off their feet and people do go to casualty with a back twinge after digging the garden. However, I was in pain. The third time I went to hospital, I was about to be given the same treatment and I said that I am a lawyer, there is something wrong with me and unless you find out what it is, I am going to sue you.

For the first time I got a back X-ray. The report came back that I had lytic lesions in my spine. I was told nothing of what that meant, so I went to Dr Google and almost had a seizure. Lytic lesions can be indicators of cancer.

All this occurred on a Thursday evening/Friday morning if memory serves me correctly. On Monday I perchance had an appointment with an urologist as I had thought the pain in my back was kidney stones. My GP had organised this. The urologist looked at the X-rays and the letter. I told him I had googled lytic lesions and it had spooked me. He said it spooks everyone. He closed the doors and told me essentially I probably had cancer and he was referring me to the oncology unit.

From this point on, everything happened like greased lightning. I had blood tests and was interviewed by a senior oncologist who told me he was pretty certain I had myeloma. I had no idea what that was, of course, and he was referring me to haematology and Dr. Lee.

I went on my first course of oral chemo. I was fortunate. I didn’t get sick. I had Velcade injections and I was invited to take part in a trial. I agreed and firstly Amanda Jager followed by Andy Phuong became resources I was able to call at any time and ask questions, or if I had any problems, talk to them about them. This was between consults with Dr Lee.

I had a couple of stays in hospital over this time as I got the odd infection. I was put into a positive pressure room and because I had not prepared to go into hospital, was bored out of my mind. Lesson learned here – always have reading matter when going to hospital.

My stem cells were harvested over a period of three days. The nurses (the three Js) were terrific and once again I was really bored because I was quite uncomfortable and unable to properly concentrate on anything. However, it was finished and that was that.

Finally came transplant time and this is when everything goes quite hazy. The transplant didn’t take much time in the scheme of things. My daughter was there (along with my wife, of course, she had arrived back a couple of months beforehand) and took pictures, for goodness sake!

Then I became sick. This is a period I don’t remember well at all. I had all the usual ghastly things. All I could do for some days was lie in bed, curled up like a nautilus. Then something happened and I was able to sit up and give cheek to the nurses and actually have a conversation with my visitors – who usually sat around me and talked to each other.

Diarrhoea was a constant companion, and I was treated with dignity and respect by the nurses who had to attend to my needs. They were wonderful.

I was treated like a real human being with a brain – not a congenital idiot. I was informed of all my test results and was given a goal that my platelets had to reach before I was allowed out of my positive pressure dugout for a wee walk outside. When I got my first breath of fresh air, it was just wonderful. I was somehow reborn.

Currently, all my tests (blood test and BJP etc) are registering normal. Of course myeloma is still in my system, but I plan on living another 20 or so years, at least. This has been a time of steep learning for me.

I learned that when I was by myself at home often in bed, my cats (I have four) were just wonderful companions. I
talked to them all the time, and at least one stayed with me all the time. It’s like they took shifts. I really did learn the importance of companion animals.

I also learned that if you know you are ill, it is important to stick to your guns and find out what the problem was. For my backache I went to three practitioners (a chiropractor, a masseur and a physiotherapist – two who said I had a low pain threshold, and one who said he thought there was something seriously organically wrong. I did have the weapon of being a lawyer – but I think of those people who believe that what the doctor says is almost the voice of god. (This is in no way meant to be criticism of those often overworked doctors in Accident and Emergency).

Again I learned that the staff at the QEH in the oncology/haematology unit work like the dickens and really care about their charges. They may need to blow off steam, as it were, in their staff-room (I have no proof of this – it is pure conjecture on my part) but when they attend you, their kindness and gentleness shine through, along with a joke and indeed seriousness at the right time.

The treatment has made me fat, assisted in my eyesight becoming worse, and caused deafness. But I am alive and now after quite a long period soon getting back to work. This is something I look forward to. Everything finished 15th March this year – I so looked forward to that. I might even get a waistline back!

Myeloma is apparently incurable. However, with modern medical techniques such as the stem cell transplant and modern medication such as velcade, prednisolone and thalidomide etc., there is no reason why we myelomites can’t live an active, normal life.

Oh, I did forget the most important thing in therapy – the love and caring of friends and family and the wonderful attention and assistance of Drs Cindy Lee, Uve Hahn, Ing Soo and the rest of the therapeutic team, doctors and nurses, and ancillary staff – and especially the cleaners, who kept my room spotless and obviously were extremely important in keeping me well, when I was very vulnerable to infection.

What a terrific team!! Thank you…

Help uncover the causes of myeloma

More than 700 Australians who have been diagnosed with multiple myeloma, and their family members, are helping researchers at Cancer Council Victoria to investigate the causes of multiple myeloma and other related conditions.

The EMMA Study (EMMA is short for Epidemiology of Multiple Myeloma in Australia) is looking at the effects of genes, lifestyle and early life environment on the development of these conditions.

The researchers have designed the study so that taking part is relatively straightforward. It involves completing several questionnaires and providing a sample of saliva so that DNA can be analysed.

Family members are also invited to take part, as they provide the necessary comparison between those who are affected by the conditions and those who are not.

The EMMA Study needs to collect information and DNA from 1,300 people diagnosed with myeloma and 1,300 family members. We are well on the way to meeting this goal, but many more are needed to help improve our understanding of the causes of myeloma.

If you’ve had a diagnosis of multiple myeloma, or a related condition such as MGUS or plasmacytoma, and would like to take part in this research, please contact the EMMA Study Team on 1800 079 414 or email emma@cancervic.org.au
A/Prof Shortt’s myeloma research focuses heavily on how thalidomide and its closely related derivatives, lenalidomide (Revlimid) and pomalidomide (Pomalyst) work. Even though thalidomide was discovered in the 1940’s, and lenalidomide and pomalidomide in the 1990s, we still don’t know exactly how they work to both kill myeloma cells and stimulate the immune system. Our understanding of the side effects – sedation, constipation, birth defects etc. is even less clear. Although lenalidomide and pomalidomide are marketed as ‘stronger and newer’ than thalidomide, we now know that they bind with equal potency to a target protein in the cell. This causes changes to other proteins that overlap, but also differ between the three drugs. By understanding the differences in what happens to proteins in the cell following thalidomide, lenalidomide and pomalidomide treatment, we can start to separate the favorable (anti myeloma and immune stimulatory) effects from the toxicities. Ultimately this may lead to better versions of the existing drugs, and help us to understand how myeloma cells develop resistance.

In addition to identifying new targets for thalidomide analogues, A/Prof Shortt is an investigator on several myeloma trials in the clinic, including agents he has developed in the laboratory, and studies performed in collaboration with pharmaceutical companies.

“It is a great privilege to be able to study myeloma in the lab and help translate more effective treatments into the clinic at the same time”.

**Summary of HAA abstracts for Anna Kalff**

As part of her PhD studies in Myeloma with the MRG at The Alfred/Monash University, Anna has been investigating maintenance therapies following upfront ASCT.

The LEOPARD study investigated lenalidomide and prednisolone (RAP) maintenance – recruiting 60 patients from 5 hospitals in Melbourne and Geelong. This study now has a median follow-up of over 3 years, and demonstrated that RAP maintenance improved patients’ depth of response. Furthermore, this improved depth of response translated into improved patient survival. This study also involved the investigations of newer, more sensitive methods of disease detection – multiparameter flow cytometry and next generation sequencing.

A sub-study of the LEOPARD trial was also presented, looking at the biomarker potential of proteins of the Cereblon/Ikaros/Aiolos/MYC/IRF4 pathway, a pathway that has recently been implicated in the mechanism of action of the IMiDs, in particular, lenalidomide. Expression of these proteins was assessed through immunohistochemistry on bone marrow trephines. Higher expression of MYC and Ikaros both correlated with worse survival, suggesting that selected IHC markers may be able to predict response to IMiDs.

Finally, Anna also presented data from a study investigating single agent panobinostat (a pan-deacetylase inhibitor) as maintenance post ASCT (single centre study). She found that panobinostat maintenance post ASCT improved depth of response, and in some patients, induced a further reduction in tumour burden beyond 12 months post ASCT. This is the first study that definitively demonstrates efficacy of panobinostat as a single agent, in patients with MM as part of their upfront management.

Ikaros/Aiolos/MYC/IRF4 pathway, a pathway that has recently been implicated in the mechanism of action of the IMiDs, in particular, lenalidomide. Expression of these proteins was assessed through immunohistochemistry on bone marrow trephines. Higher expression of MYC and Ikaros both correlated with worse survival, suggesting that selected IHC markers may be able to predict response to IMiDs.

Finally, Anna also presented data from a study investigating single agent panobinostat (a pan-deacetylase inhibitor) as maintenance post ASCT (single centre study). She found that panobinostat maintenance post ASCT improved depth of response, and in some patients, induced a further reduction in tumour burden beyond 12 months post ASCT. This is the first study that definitively demonstrates efficacy of panobinostat as a single agent, in patients with MM as part of their upfront management.

“It is a great privilege to be able to study myeloma in the lab and help translate more effective treatments into the clinic at the same time”.

**Summary of HAA abstracts for Anna Kalff**

As part of her PhD studies in Myeloma with the MRG at The Alfred/Monash University, Anna has been investigating maintenance therapies following upfront ASCT.

The LEOPARD study investigated lenalidomide and prednisolone (RAP) maintenance – recruiting 60 patients from 5 hospitals in Melbourne and Geelong. This study now has a median follow-up of over 3 years, and demonstrated that RAP maintenance improved patients’ depth of response. Furthermore, this improved depth of response translated into improved patient survival. This study also involved the investigations of newer, more sensitive methods of disease detection – multiparameter flow cytometry and next generation sequencing.

A sub-study of the LEOPARD trial was also presented, looking at the biomarker potential of proteins of the Cereblon/
My half marathon

After completing a challenging 11 day walk around Mont Blanc earlier this year, I was looking for my next challenge and thought the Medibank Melbourne Half Marathon in October would suit me down to the ground. It was only after I entered that I found out a dear friend of mine had been diagnosed with myeloma.

One Friday about a month before the race, I was out for an easy run and had a brainwave – what if I could ask for donations for a great cause that was close to my heart? After asking my friends if they would be happy for me to do this on their behalf (some things can be very private and are not to be shared), the time had come to spread the word to family, friends, colleagues and anyone else I could find to start the donations rolling in. By race day I had raised around $4,000.

Leading up to race day, I was training hard – I am not a natural runner – and every time I thought I wanted to stop or give up I only had to think of my friend and what he was going through – that would get me going again. My mantra is: Strength, Courage, Determination.....

Race day arrived and it was perfect weather and I was excited! I was running well and the spectators along the way were cheering and supporting which was fantastic. I had friends who gave out hugs and encouragement at the 14km mark and I was feeling strong and determined. From 14km to 18km I was able to stay with a couple of runners ahead of me and they got me through the hard part. I kept thinking of my friend and saying my mantra and it was working! At the 20km mark we hit a bridge! There were people everywhere groaning and I was thinking “why is there a bridge at the end?!” But after starting to slowly jog up there I suddenly thought that’s it – go for it and I sprinted up the bridge and over the top. Next stop was the MCG – one lap to the end. And I was done.

Two hours and 15 mins and it was my PB AND I had raised lots of money for Myeloma Australia. My friend is getting well looked after by specialists and those who love him – and I was honoured to be able to raise some money for this amazing cause. Thank you to all who supported me.

by Kate R Smith

Strength, Courage, Determination

Kate Smith after her half marathon.

Andy.
Recruitment update
October saw recruitment of 800 patients to the registry, and we now have a total of 850 patients registered. Cabrini Hospital has commenced recruitment and we welcome them aboard. Sixteen hospitals now contribute data from around Australia and New Zealand, and Flinders Medical Centre (Adelaide) and Concord Hospital (Sydney) are soon to commence.

MRDR attends the 15\textsuperscript{th} International Myeloma Workshop in Rome
Initial results from the registry were presented at the International Myeloma Workshop in Rome in September 2015 and the MRDR forged valuable links with sister registries from other countries. At this biannual Workshop attended by over 1500 delegates, members of the MRDR Steering Committee and Dr Elizabeth Moore met with representatives of the Austrian and Canadian Myeloma Registries, and the Korean Multiple Myeloma Working Group. All teams expressed interest in a proposed international research collaboration.

Season’s Greetings!
As 2015 comes to a close, we thank you for your contribution! We would not have come this far without your generous support. We wish you a very happy and safe holiday season.

The Myeloma 1000 project
The Alfred and St Vincent’s Hospitals in Melbourne are recruiting steadily to the Myeloma 1000 Project, which is a biobank sub-project of the MRDR. Congratulations to Box Hill hospital which has just commenced recruitment to the sub study and Frankston Hospital will soon start. The Myeloma 1000 project has initially rolled out to Victorian sites to test systems for specimen delivery and receipt, and will soon commence interstate.

MRDR at the HAA conference
The MRDR team recently attended the combined Scientific Meeting of the National Societies for Haematology, Blood Transfusion and Thrombosis (HAA). Dr Elizabeth Moore presented a poster detailing initial results from the MRDR, and along with Professor Andrew Spencer, and A/Prof Erica Wood, hosted an interest group meeting during the conference. The meeting was well attended, with over fifty people joining the breakfast to hear about the MRDR.

MRDR: How can you be involved?
Ask your treating specialist if your hospital contributes data to the MRDR and if you are eligible to participate. You will receive a patient information sheet about the registry, including how to opt off if you change your mind.

To contact the MRDR:
Phone: 1800 811 326
Email: sphpm.transfusion@monash.edu
Visit our website: https://mrdr.org.au

Prof. Andrew Spencer presenting at the MRDR breakfast at the HAA meeting.

MRDR poster at the HAA meeting.
By Hayley Beer

2015 has been another action packed year with the MFA and I would like to start by thanking Brian, Steve, Pina and Alex at head office and the Victorian committee for all their support throughout the year.

I would also like to thank Jo and Ian in South Australia and Monica in New South Wales for all their hard work, particularly Monica who has hit the ground running in New South Wales, picking up where Jane left off beautifully.

We had another great National Myeloma Awareness Month this year with lots of events in each state. I was fortunate enough to go to the Sydney, Perth and Adelaide events as well as host our event in Melbourne. Our theme this year was Treatment – The Now and the New with a real focus on new drugs in development which was really well received in each state. In Melbourne and Sydney we were fortunate to be able to host Associate Professor Maria-Victoria Mateos of the University Hospital of Salamanca in Spain and the Perth event heard from Dr Joseph Mikhail of the Mayo clinic in Arizona, USA. Jo had some great analogies including likening the different treatments for myeloma to different weapons of war.

Thank you to the Leukaemia Foundation for another successful collaboration. Each event hosted at least 100 people. The impact this has on the wellbeing of our members is invaluable.

In July we were given another fantastic opportunity to host some international speakers through Celgene’s symposium to launch the PBAC approval of pomalidomide (another great achievement for 2015). This was a three day event kicked off with our second MSAG coordinated Registrar and Senior Nurse Training Day. We reached capacity for this event with 40 registrars and nurses in attendance. The day was chaired by Dr Hang Quach with other members of MSAG facilitating the sessions. We also heard from Thierry Facon of Lille University Hospital, France, Nizar Bahlis of University of Calgary, Canada and Beth Faiman, Nurse Practitioner of the Cleveland Clinic, Ohio, USA. This day was a series of short, sharp lectures designed to mimic the chapters of a text book. The content, while intense, was absolutely brilliant and the feedback from the guests was very positive.

The following day Celgene held their pomalidomide symposium then on the third day, Sunday, we hosted an information day for the myeloma community. Dr Facon and Beth Faiman were very generous in giving us their time again and gave excellent presentations. Particularly Beth who spoke about side effect management. We also heard from Tracy King about steroids and Jo Gardiner sat in with Tracy and Beth for a Q&A panel.

In September I was lucky enough to attend the International Myeloma Workshop in Rome. This conference welcomed about 3000 people and was a solid 4 day program focussing on new developments in diagnosis, treatment and monitoring of myeloma. There was also a nursing symposium show casing nursing initiatives from around the world. We had a poster in this section of the conference about our computer literacy project.

October was conference time again with the annual gathering of the HSANZ, ANZSBT and ASTH (HAA) which was held in Adelaide. On the Saturday before the conference started we added an extra seminar to Ian’s calendar and held an event at the new SAHMRI building which is truly a beautiful building with state of the art research facilities. Thank you to MSAG member Andrew Zannettino for enabling us to hold the event there and for taking us all on a tour of the research laboratory.

...continues on next page.
The conference was held at the Adelaide Convention Centre from Sunday to Wednesday and for the first time in many years we held a trade stand as part of the event. Thank you to Steve, Ian and Brian who manned the stand while Jo, Monica and I went off to the lectures to learn from our peers.

Publication wise Jo and I have enlisted the support of one of our enthusiastic Western Australian members to update the Peripheral Neuropathy book. That should hit the shelves early next year. We will also soon see a new-look website and be eager to learn the new database system as it gets implemented.

At this point as I write I can’t see the pace winding down just yet with two seminars, a nursing advisory board to convene, Christmas support groups and a trip to Orlando for the annual American Society of Haematology conference to come. Thank goodness we will soon have a new nurse in Victoria. I am looking forward to being able to focus more on national program development.

On reflection it is quite satisfying to see all the great work we are doing to support our community. We continue to improve our programs without much increase in resources. All we need now is a cure.

Wishing all our readers a safe and happy festive season.

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.
Firstly coming to Christmas I would like to thank all the NSW groups for the very warm welcome they have shown to me since commencing the position of NSW Myeloma Support nurse.

Christmas can often be many things to many people and it is often a time of year when we reflect on the past year, sometimes happy, sometimes sad and we wonder what the New Year will bring.

I wish you all a safe and event free Christmas and look forward to catching up again in 2016.

Now an update on events that have taken place in NSW since the last edition and if any of you out there have any special stories you would like to share in the MyeNews please contact me and let’s get them out to our members.

The Shoalhaven support group held their National Myeloma day on the 26th October at the Bomaderry Bowling Club.

Dr Lis Lane clinical psychologist opened the day with a session on loving kindness and how to support yourself psychologically whilst living with myeloma. This was a good starter for the day with questions from the audience with tips on how to manage their wellbeing.

“Taking the conversation to the kitchen table”.

Rhys Chamberlain client service executive for community engagement from Maurice Blackman Lawyers gave a very insightful update called taking the conversation to the kitchen table in the area of superannuation insurance benefits & wills. The focus was to share knowledge and expertise with those affected with myeloma and their families to reach those who could benefit most from this information.

A little Thai Chi after early lunch to rejuvenate for the afternoon topics.

First cab off the rank after lunch was Professor Peter Presgrave who covered “What is Multiple Myeloma? Current treatments clinical trials and upcoming areas of research and how this may impact in the future to those suffering from multiple myeloma.”

Professor Presgrave gave a very clear down to earth presentation which was very well received on a topic that is not often easily understood. Many questions were asked and answers given with practical and relevant application for the attendees.

Nurse practitioner Bill Jansen from the new Shoalhaven Cancer Care Centre and Jane Burgess our previous NSW myeloma nurse now haematology clinical nurse specialist at Wollongong hospital followed up with a robust nurse led panel question and answer session to wrap up the day.

The Shoalhaven Cancer Care Centre (SCCC) opened in 2013 and provides essential integrated multidisciplinary cancer care and essential cancer services with increased access to, allied health and support services for the growing South Coast population.

A big thank you for all the staff at the Bomaderry Bowling Club for their special service, great venue and wonderful food.

The annual Multiple Myeloma patient and family educational seminar held on Friday 20th November 2015 at the Kerry Packer education centre was a success despite the weather and Sydney’s traffic and the highlights will be presented in the next issue.

Reminder that The Newcastle Support Group has changed the time it meets from 3-5pm to 10am-12.00pm on the first Monday of every second month.
SA Division Report

By Ian Driver
Chairman

Well, we have come to the end of another year and most of us are still here, fighting and surviving this hideous disease. Hopefully our Division has helped our patients & carers this year with our guest speakers, support group meetings at Fullarton, Snowtown and Coonawarra, as well as the two main seminars in May and October. Our aim is to inform, support and bring myeloma patients & carers together and give them hope. We will of course be back next year continuing to help where possible.

Since the last MyeNews, at Fullarton we had David Cleghorn, a clinical dietitian at the RAH give an excellent presentation. Whether you are going through treatment or not, patients & carers are not sure what type of food is appropriate, either health wise or when side-effects impair the ability to swallow or enjoy food. David emphasized that it is crucial to maintain your body weight and that you don’t lose weight at a time when you need calories to maintain organ function while the drugs are attacking your body. It is better to eat small amounts more frequently than try to eat normal meals.

Once you are in stable health, follow the guidelines of a healthy diet, have a variety of foods, three regular meals a day, increase the plant foods, fibre, calcium & iron, while decreasing the saturated fats, sugar & salt. It is important for myeloma patients in particular to keep their calcium levels up. As long as you consume milk for breakfast, cups of tea/coffee with milk during the day, plus yogurt, ice cream or cheese at dinner, you will get a good amount of calcium. As calcium intake only lasts about 6 hours, and your body needs a constant supply while you are asleep, your body will look elsewhere for a ready source, which usually means from your bones.

To minimize the loss of bone calcium, he recommended that we take a calcium tablet before going to bed.

At our last meeting of the year on December 1st., we will have a patient, Dominic Scoleri give a patient story, followed by a Q&A session with a panel consisting of Dominic, Jo Gardiner (Support Nurse) and Ian Driver.

The Mid-North Support Group had their regional seminar on November 7th, with haematologist, Dr. Shriram Nath, his wife, Lakshmi Nath (Haem./Clinical Director of Clinpath) and Dr. Michael Metz (BioChemist at Clinpath) giving a joint presentation about myeloma overview, diagnosis and the tests that all patients go through and how they are analysed.

It was a small gathering, but many questions asked and everyone came away with a better understanding of the procedures.

The South-East Support Group met on November 10th and heard a confronting but interesting patient story from group member, Sharyn Flier and once again there was a good attendance and a great meeting.

Due to the HAA conference being held in Adelaide this year, we took the opportunity to hold a Patient Information Day on Saturday, 17th October at the SAHMRI building with guest speakers, Dr. Wilfed Jaksic, Krzysztof Mrozik and a Q&A Nurses Panel, consisting of Hayley King, Jo Gardiner and Monica Tucker. Thanks to Prof. Andrew Zannettino for arranging the venue, lunch and a guided tour of his Myeloma Laboratories upstairs.

On behalf of the SA Division Committee, I wish everyone a Merry Christmas, an enjoyable break, a Happy New Year and we hope that you all stay well.

Contact  T: 08 8552 6097
E: sandrian7@bigpond.com
Captain Patrick Michaelson
Victorian Chair

It is in the very nature of our organisation that each year we have to say farewell to some members and associates. That does not of course make it any easier. The year just past has been no different. That we have lost some familiar faces should continue to provide us with the inspiration and incentive to provide all support possible to Myeloma Australia.

Victorian Committee meetings have been held regularly throughout the year. Prior to the last meeting on 22nd October there have been some fairly thin attendances due largely to health matters. Support groups have met every second month at Mount Eliza, Beaumaris, Kew and Geelong and I find that attendance at their meetings affords both information and insights. Meetings have had both featured speakers and internal discussions.

Last year I mentioned a policy of seeking the help of volunteers to help in the Richmond office on a regular basis and that, despite a slow start, we had a list of people ready for training to provide that assistance. I understand that it is now not the intention to recruit volunteers but to take on persons (who, it is hoped will have the requisite skills) who are required to demonstrate to Centrelink that they are looking for work. Volunteer work will still be required for “one-off” events.

Myeloma made a rare appearance in the local press in August in an item in the Herald Sun concerning very promising results resulting from trials of a drug named Daratumumab. The drawback would appear to be in the suggested price before the PBS gets involved – $20,000 per month. As I wrote in MyeNews recently, “Available often equates with affordable…”.

There has been an effective programme of seminars during the year. A very successful and well attended Myeloma Day seminar, in conjunction with the LFA, was held at the Moonee Valley Racecourse on 2nd May. Featured speakers included Prof. Andrew Spencer, (consultant haematologist at the Alfred) and Assoc. Prof. Maria-Victoria Mateos (consultant haematologist University Hospital of Salamanca, Spain). They spoke about new treatments for myeloma – Andrew from an Australian viewpoint, Maria-Victoria from an international perspective. Apart from insights gained on these occasions the follow-up Q&A sessions are of great value.

“Living with Myeloma – Side Effect Management” (also in conjunction with the LFA) was held at Convention Place, South Wharf, on 19th July. Again there was an international flavour with speakers from France and the USA as well as our own Jo Gardiner and Tracy King. This subject was of particular interest as in my contacts with support groups the subject of side effects and their management is one of, if not the most discussed subjects between members. It is also worth noting that Myeloma Australia’s book on peripheral neuropathy has been asked about when I have made publication deliveries to Metropolitan and Latrobe Valley Hospitals.

On 21st November Prof. Miles Prince will have delivered his annual “Update” at Latrobe University. There will also be a presentation on “Personal Experience” by recently recruited Committee member Geoff Nyssen.

Fundraising activities have been pursued at different levels. The annual “Business of Winning Luncheon” took place at the MCG on 13th March. It was clear from the composition of the panel membership that the degree of inspiration gained depended largely on which AFL team one followed. “Masters of Rock’ was held at Crown Casino on 17th May. Enthusiasm was displayed (with an incredible array of flashing lights) by performers and audience alike; in the words of the Classics a good time was had by all (including, one hopes, the coffers of Myeloma Australia).

There was fundraising at a more local level on 31st January with a successful sausage sizzle at Bunnings Hawthorn. This event will be Peter and Robyn Thornton’s last as they contend with health problems. They have also been very involved in the Kew and Geelong support groups and we owe them a great debt of gratitude.

A very successful film night was held at the Lido Complex, Hawthorn on October 29th. Attendance at “The Dressmaker” appeared to be a sell-out and special thanks are due to Helen Chapman and Jill Stansfield. There have also been fundraisers at support group level.

As always our thanks go to support nurse Hayley Beer, particularly for her central role in the organising of seminars and support groups, and the unstinting help always available from Pina Civitarese and Alex Dawson in the Office.
November 2015

Ixazomid approved by FDA in United States of America

The US FDA has granted approval to Ninlaro (Ixazomib) made by Takeda, which is the first and only oral proteasome inhibitor used in combination with lenalidomide and dexamethasone.

Ninlaro is designed to block enzymes that spur the growth and survival of multiple myeloma cells, the FDA said in the news release. Ninlaro is approved in combination with another multiple myeloma drug, Revlimid (lenalidomide), and the corticosteroid drug dexamethasone.

September 2015

Farydak® receives European approval as a treatment for myeloma

Novartis has recently announced that the European Commission has approved Farydak (panobinostat) as a treatment for relapsed and/or refractory myeloma patients who have received at least two previous lines of treatment, including Velcade® (bortezomib) and an immunomodulatory drug. This is the first histone deacetylase (HDAC) inhibitor with epigenetic activity to be made available in the European Union, providing a new treatment option with a novel mechanism of action for patients in this setting. Sept 4 2015

Published in Oncology: September 25, 2015

Bortezomib, Cyclophosphamide, and Dexamethasone in Relapsed Multiple Myeloma

This open-label, single-arm, nonrandomized multicenter study investigated efficacy and safety of six cycles of induction low-dose cyclophosphamide, bortezomib, and dexamethasone followed by 1 year of maintenance therapy with bortezomib and cyclophosphamide in 59 patients with relapsed pretreated multiple myeloma. Overall response rate was 71%. Median progression-free and overall survival were 18.4 and 28.1 months, respectively. These findings show that this regimen is feasible and effective in relapsed multiple myeloma.

Daratumumab approved by FDA in United States of America

The US FDA has granted approval to Darzalex (daratumumab) to be used as a monotherapy in myeloma patients who have received at least three prior treatments.

Daratumumab belongs to a group of drugs known as monoclonal antibodies which are a type of “immunotherapy”. Monoclonal antibodies are designed to recognise and attach to specific proteins on the surface of cancer cells, enabling the immune system to target and destroy them. Daratumumab specifically targets a protein known as CD38.

Carfizomib approved by the European Commission

Following a Phase III clinical trial, the European Commission has approved the use of Kyprolis (Carfizomib), in combination with Revlimid® (lenalidomide) and dexamethasone (decadron), for myeloma patients who have received at least one prior treatment.

Kyprolis belongs to a group of drugs known as proteasome inhibitors and has been developed to specifically target a different area of the proteasome to Velcade. This is thought to make Kyprolis possibly more effective and potentially cause fewer side-effects than Velcade.
**Events**

**Sisters of Song**
*Friday February 26th*

**Coming up in 2016**

**Masters of Rock**
*(date TBC)*

**Business of Winning Luncheon**
*March (date TBC)*

---

**How you can help Myeloma Australia**

**Donations:**
Myeloma Australia is the only myeloma specific foundation in Australia dedicated to supporting people touched by myeloma. Donations help us to grow and develop the services we deliver to the myeloma community. Your contribution can be made directly over the phone or online at www.myeloma.org.au

**Volunteering:**
There are many ways to help the Foundation. Head office is situated in Melbourne and we welcome your call or email to discuss how you can become involved (toll free) 1300 632 100 or (03) 9428 7444 or email us on admin@myeloma.org.au

**Bequests:**
A wonderful way to make a gift to Myeloma Australia is through a bequest in your will. After making allowance for your loved ones, a bequest of a specific amount or a proportion of the residue of your estate, and is a way of leaving a real and lasting legacy to the future.

> Your bequest to Myeloma Australia would be used to support our mission to care for patients, carers and families and help us achieve our vision to find a cure for myeloma.

You may choose to make a bequest that allows Myeloma Australia to decide how your bequest is best used, or you may prefer to make that decision yourself e.g. direct your bequest to patient support or research. Your legal adviser can provide further information on the different types of bequests, and on the appropriate wording for a bequest.

As a guide, the following wording may be useful:

> I give and bequeath free of all duties (here state amount/percentage or share/residue or assets to be gifted to the Myeloma Foundation of Australia Inc. 335 Swan Street, Richmond, Vic, 3121.

- For the general charitable purpose of the said Foundation (this is the Myeloma Australia’s preferred option); or
- For the purpose of patient and family support; or
- For the purpose of research into the cause, cure or treatment of myeloma

> Please contact head office for further information on how you can be involved.

Phone (toll free) 1300 632 100 or (03) 9428 7444
## Calendar of Events

### Victoria

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
<th>Time</th>
<th>Organisation</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Eliza Information and Support Group</td>
<td>Thurs Jan 21st</td>
<td>Mount Eliza Community Hall</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Beaumaris Information and Support Group</td>
<td>Thurs Feb 4th</td>
<td>Beaumaris Theatre</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Geelong Information and Support Group</td>
<td>Fri Feb 5th</td>
<td>Northside Geelong Community</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Kew Information and Support Group</td>
<td>Thurs Feb 11th</td>
<td>Kew Library</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Mt Eliza Information and Support Group</td>
<td>Thurs March 17th</td>
<td>Mount Eliza Community Hall</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Geelong Information and Support Group</td>
<td>Fri April 1st</td>
<td>Northside Geelong Community</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Beaumaris Information and Support Group</td>
<td>Thurs April 7th</td>
<td>Beaumaris Theatre</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Kew Information and Support Group</td>
<td>Thurs April 14th</td>
<td>Kew Library</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
<tr>
<td>Mt Eliza Information and Support Group</td>
<td>Thurs May 19th</td>
<td>Mount Eliza Community Hall</td>
<td>10am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Myeloma National Office 1300 632 100 (03) 9428 7444</td>
</tr>
</tbody>
</table>

### South Australia

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
<th>Time</th>
<th>Organisation</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fullarton Coast Information and Support Group</td>
<td>Tues Feb 2nd</td>
<td>Fullarton Park Centre 411 Fullarton Road, Fullarton</td>
<td>10 am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Ian Driver - <a href="mailto:sandrian7@bigpond.com">sandrian7@bigpond.com</a> (08) 8552 6097 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>South East Regional Seminar</td>
<td>Fri Feb 12th</td>
<td>Katnook Estate – Coonawarra (6km north of Penola)</td>
<td>11.30 am – 2.30 pm</td>
<td>Myeloma Australia</td>
<td>Carol Koch (08) 8765 9014 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>Mid North Information and Support Group</td>
<td>Thurs Feb 18th</td>
<td>Snowtown Hospital Snowtown</td>
<td>12 noon – 2 pm</td>
<td>Myeloma Australia</td>
<td>Bronwyn Gerschwitz (08) 8664 0682 <a href="mailto:graemebronwyn@bigpond.com">graemebronwyn@bigpond.com</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>Fullarton Coast Information and Support Group</td>
<td>Tues April 5th</td>
<td>Fullarton Park Centre 411 Fullarton Road, Fullarton</td>
<td>10 am – 12 noon</td>
<td>Myeloma Australia</td>
<td>Ian Driver - <a href="mailto:sandrian7@bigpond.com">sandrian7@bigpond.com</a> (08) 8552 6097 1800 MYELOMA (693 566)</td>
</tr>
</tbody>
</table>

### National Telephone Support Group (Cancer Council NSW)

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Time</th>
<th>Organisation</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone Support</td>
<td>2nd &amp; 4th Wednesday every month</td>
<td>1.30pm -2.30pm</td>
<td>Cancer Council NSW with MFA NSW</td>
<td>Cancer Council NSW 1300 755 632 E: <a href="mailto:tsg@nswcc.org.au">tsg@nswcc.org.au</a></td>
</tr>
</tbody>
</table>
## Calendar of Events

### New South Wales

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
<th>Time</th>
<th>Organisation</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoalhaven Information</td>
<td>Mon Jan 11th</td>
<td>Bomaderry Bowling Club Blue Gum Room (1st floor) 154 Meroo Rd, Bomaderry</td>
<td>10am – 12pm</td>
<td>Myeloma Australia</td>
<td>Brian Law (02) 4423 4205 / 0411 773 579 <a href="mailto:brialey0@bigpond.com">brialey0@bigpond.com</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newcastle Information</td>
<td>Mon Feb 1st</td>
<td>Cancer Council Office Level 1/215 Pacific Highway, Charlestown</td>
<td>10am – 12pm</td>
<td>Myeloma Australia</td>
<td>John Miller (02) 4957 0711 <a href="mailto:miller32@optusnet.com.au">miller32@optusnet.com.au</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoalhaven Information</td>
<td>Mon Feb 8th</td>
<td>Bomaderry Bowling Club Blue Gum Room (1st floor) 154 Meroo Rd, Bomaderry</td>
<td>10 am – 12 pm</td>
<td>Myeloma Australia</td>
<td>Brian Law (02) 4423 4205 / 0411 773 579 <a href="mailto:brialey0@bigpond.com">brialey0@bigpond.com</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Royal Prince Alfred Hospital Information and Support Group</td>
<td>Tues Feb 9th</td>
<td>Chris O’Brien Lifehouse Living Room Group Room (Gr Floor) 119-143 Missenden Rd, Camperdown</td>
<td>10 am – 12pm</td>
<td>RPAH &amp; Myeloma Australia</td>
<td>Tracy King (02) 8627 1570 <a href="mailto:tracy.king@sswahs.nsw.gov.au">tracy.king@sswahs.nsw.gov.au</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Westmead Hospital Information</td>
<td>Thurs Feb 18th</td>
<td>Crown Prince Mary Cancer Care Centre Conference Room 2 Westmead Public Hospital Hawkesbury Rd, Westmead</td>
<td>10 am – 12pm</td>
<td>Myeloma Australia</td>
<td>Monica Tucker M: 0447 334 435 <a href="mailto:monica.tucker@myeloma.org.au">monica.tucker@myeloma.org.au</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central Coast Information</td>
<td>Thurs Feb 25th</td>
<td>Central Coast Leagues Club Dane Drive, Gosford</td>
<td>6 – 8pm</td>
<td>Gosford Hospital &amp; Myeloma Australia</td>
<td>Jacqui Jagger (02) 4320 9641 <a href="mailto:jacqueline.jagger@health.nsw.gov.au">jacqueline.jagger@health.nsw.gov.au</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoalhaven Information</td>
<td>Mon March 14th</td>
<td>Bomaderry Bowling Club Blue Gum Room (1st floor) 154 Meroo Rd, Bomaderry</td>
<td>10am – 12pm</td>
<td>Myeloma Australia</td>
<td>Brian Law (02) 4423 4205 / 0411 773 579 <a href="mailto:brialey0@bigpond.com">brialey0@bigpond.com</a> 1800 MYELOMA (693 566)</td>
</tr>
<tr>
<td>and Support Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Brisbane - Informal Group

Contact Helen Parsons  
e: Hpa83339@netspace.net.au  
m: 0415 106 092

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

## Myeloma Support Groups Facilitated by Leukaemia Foundation

<table>
<thead>
<tr>
<th>State</th>
<th>Location</th>
<th>Group</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>VIC</td>
<td>Preston</td>
<td>Haematology Group</td>
<td>1st Thursday alternate months of Kew Group</td>
</tr>
<tr>
<td>VIC</td>
<td>Bendigo Group</td>
<td>Haematology Group</td>
<td>2nd Monday each month</td>
</tr>
<tr>
<td>NSW</td>
<td>Artarmon</td>
<td>Haematology Group</td>
<td>1st Friday monthly (from February)</td>
</tr>
<tr>
<td>NSW</td>
<td>Wollongong</td>
<td>Haematology Group</td>
<td>3rd Wednesday alternate months (from February)</td>
</tr>
<tr>
<td>ACT</td>
<td>Canberra</td>
<td>Haematology Group</td>
<td>2nd Tuesday monthly (from February)</td>
</tr>
<tr>
<td>WA</td>
<td>Perth</td>
<td>Haematology Group</td>
<td>Monthly meetings (from February)</td>
</tr>
</tbody>
</table>
MyeNews is published quarterly by the Myeloma Foundation of Australia Inc. The information presented in MyeNews is not intended to take the place of medical care or the advice of a doctor. Your doctor should always be consulted regarding diagnosis and treatment. No part of this newsletter may be reproduced in any form without the prior written permission from The Myeloma Foundation of Australia Inc.