

MyeNews

Spring 2017 Issue no 43

Myeloma
Australia



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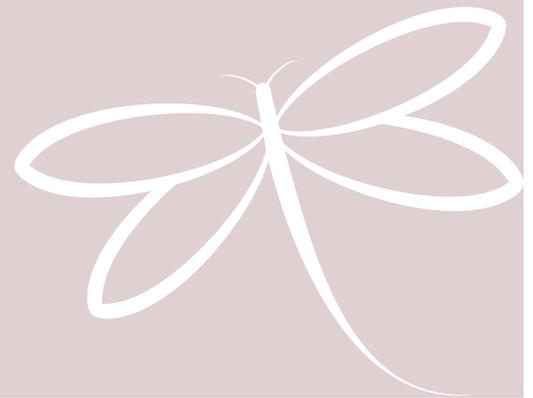
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Myeloma Support Line

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

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



MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

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

pina@myeloma.org.au

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

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President's Report

I have just read some articles on what seems like science fiction where scientists are now experimenting with modifying the DNA of a person. One process which is now being trialled in a couple of different cancers including myeloma is CAR-T cell therapy. This process involves taking some of the patient's cells and genetically modifying them and then returning them to the patient. These cells then harness and accelerate the body's natural immunity.

This is still very early days and currently a very costly process. Currently it is a wait and see while the Phase I trials look at the safety of this process. The other research is where the scientists are able to identify areas on the genes which have the mutations that cause genetically transmitted cancers and are attempting to remove these mutations from the gene in embryos and so prevent the spread of genetically transmitted diseases such as breast cancer. Maybe the identification of the mutations in patients with MGUS, the pre-cursor to myeloma, will enable the removal of the mutations in the gene and stop the transition to myeloma. The use of either of these processes are a long way off but it is fantastic to think these things could be possible in the future.

On looking back to when we started Myeloma Australia our priorities were on education through seminars and our myeloma support nurses. We soon found that our community wanted to be able meet together and so support groups were started with the first one in Melbourne being in Kew, Sydney at the Royal Prince Alfred hospital and another in Adelaide. We now have six myeloma specific support groups in Victoria, five in New South Wales and three in South Australia. We are looking at new ones in Perth, Darwin, Hobart plus extra ones in Victoria, New South Wales and South Australia. Please check the back of this newsletter for dates, venues and contact details. If you are interested in starting one please contact the Myeloma Support Nurses and they will assist in every way possible.

Our CEO Steve, has just returned from an international meeting where the discussions were about the movement towards nurse based patient support services. Steve then mentioned that we were already doing this in Australia and was asked to describe what our Foundation is doing. Those at this meeting were amazed at the services that we



provide through our Myeloma Support Nurses and they considered that we were world leaders in these services. We are looking at ways of extending these services through having myeloma nurses in the hospitals and even having our myeloma nurses visiting patients at home. This will all take time to develop plus a lot of money. As I mentioned in the last edition of MyeNews, we now have six myeloma support nurses and we are still looking for a second nurse for New South Wales and one in Perth.

Two international haematologists are attending a medical seminar in Melbourne on the 20th August and while here have agreed to attend a patient seminar. These are Dr Shaji Kumar from Mayo Clinic, Minnesota USA and Professor Phillipe Moreau from University Hospital Nantes, France and they will be joined by Professor Andrew Spencer from the Alfred Hospital in Melbourne. I apologise to all our readers from outside of Victoria but this was a unique opportunity which we could not pass up. This edition will be at the printers by the time of this seminar and if possible we will add a review of the seminar, if not we will put it in the next edition.

We are so fortunate that we have so many brilliant haematologists who are doing research into myeloma and the results of this work is producing many new treatments, eventually myeloma will become a chronic disease. ●

Brian Rusegarten

Anna Johnston

My name is Anna Johnston and I am the current Tasmanian representative on the Myeloma Scientific Advisory Group. I work as a clinical and laboratory haematologist at the Royal Hobart Hospital and I am the director of the Tasmanian Statewide Bone Marrow Transplant service.

I grew up in Tasmania but thought I needed to see the world (or at least mainland Australia) so I attended the University of Sydney and later trained in Haematology at the Royal North Shore Hospital, Sydney and The Canberra Hospital. I was also lucky enough to spend a year as a haematology fellow at a centre of excellence in Lyon, France. This was a hugely rewarding professional experience but also allowed me to indulge my love of France and the French language.

My interest in myeloma first developed as a medical student at Royal Prince Alfred Hospital in Sydney when I came to appreciate the major impact that myeloma may have not only on survival but quality of life. I have found the substantial increase in effective treatment options since that time particularly gratifying, whilst realising the very real need for further improvements for patients with relapsed and resistant disease. MSAG fulfils a very important role in facilitating research in myeloma in Australia but also advocating for patients and developing guidelines to assist clinicians to deliver excellent patient care.

I am very interested in improving the support patients receive as they traverse the often complex journey after diagnosis of myeloma. Since my appointment at the Royal Hobart Hospital together with colleagues I have worked to



establish a new position in our service, that of Haematology Cancer Care Coordinator. A proud Tasmanian I am also passionate about ensuring that patients in regional areas receive access to high quality care and clinical trials.

I am married to Mark and am the proud mother of 2 young children. I enjoy gardening, mountain biking and spending time with my family. I am currently in Manchester, England undertaking a sabbatical at the Christie Hospital, a valuable opportunity to see how the challenges of delivering excellent patient care are resolved in another health system. ●

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DO YOU HAVE AN EMAIL ADDRESS?

Myeloma Australia now circulate a monthly newsletter via email – The Myeloma Muster.

This is a great way for us to keep you updated on upcoming seminars, fundraising events, myeloma specific news items and what is happening at Myeloma Australia.

If you would like to receive The Myeloma Muster along with our seminar, support group and fundraising notifications please send an email to alex.dawson@myeloma.org.au so that she can add your email address to the circulation lists.

Rest assured that if you currently receive your *MyeNews* quarterly magazine via post you will continue to do so.



Botanical – An Exhibition of Watercolours by Patricia Ball

By Pina Civitarese

To coincide with the beginning of Spring, Myeloma Australia proudly presents, "Botanical". An exhibition of exquisite watercolours by Patricia Ball, from Saturday 2nd September – Sunday 10th September.

There will be a collection of paintings for sale and a limited number are kindly on loan from the family collection for display. A3 and A4 posters of some of the paintings will also be for sale along with the greeting cards which have been very popular, so there will be something for everyone.

Patricia's involvement with the Foundation came in response to her daughter Alexandra's diagnosis in 2011. The Family have been heavily involved ever since and have been proud supporters of the Foundation over the years.

It has been such a privilege working on this project, Patricia's enthusiasm and passion is contagious and inspiring. If you would like to meet her, Patricia will be at the exhibition most days painting. So this will be a great opportunity to see her in action, have a chat and enjoy her work. Come along and bring your friends and family. We look forward to seeing you there.

The exhibition will be held right next door to us in our old office at 335 Swan Street, Richmond. If you would like any information please feel free to contact us on 9428 7444 or support@myeloma.org.au ●



Botanical

An Exhibition of Watercolours
by Patricia Ball

2nd – 10th September 2017
10 – 4 daily
335 Swan Street Richmond VIC

For more information **p:** 9428 7444

Money raised from the sale of the exhibition will assist in extending cancer patient services across Australia.

Proudly presented by
Myeloma Australia
www.myeloma.org.au



Photo © Pina Civitarese



Profile: Matt Maudlin

Myeloma Australia would like to welcome Matt Maudlin to the team as the new Marketing and Fundraising Executive. Previously employed for the past 20 years by Servants Community Housing Inc., Hawthorn, the last 15 of these as CEO. He concluded his employment there in January of this year to seek new adventures. Matt brings with him extensive knowledge of the not for profit sector, great experience as to the trials, triumphs and tribulations of marketing & fundraising and the ability to strategically bring about change in the tasks he undertakes. He considers community to be the bedrock of all he does and loves.

A part of the personal brief Matt gave himself as he considered different avenues for 2017 and beyond was 'to only become involved in projects and causes that can make a difference to the lives of vulnerable people.'

Matt is delighted to have joined Myeloma Australia and is looking forward to working alongside the team and continuing to raise the marketing and fundraising profile of the organisation.

In other areas of his life Matt is Head Coach of Badminton at Wesley College, is Strategic Development Manager for a charity working against human trafficking and is currently working on launching his own not for profit group that will offer an innovative, never seen before community approach to housing people at risk of homelessness.

Aside from his wife, 4 kids and 'dumb as a bucket' dog, Matt's passions are built around the Boston Red Sox, North Melbourne Football Club and English hard rock behemoths *Iron Maiden*.



Photo © Pina Civitarese

Matt would be delighted if you gave him a call to discuss any ideas you might have in regards to marketing and fundraising. ●

Trev's METS

By Kristine Taylor

As all our friends and family know our beautiful dad, Trevor Measday lost his courageous battle with multiple myeloma in early May.

We (Trevor's children) have decided to participate in this year's City to Bay in his honour.

Our dad was diagnosed early 2015, he was a member of many Myeloma Support Groups on Face Book not just in Australia but all over the world, he liked to share his journey and offer his story to fellow myeloma warriors through these avenues. We want to help raise awareness and hopefully someday find a cure for this disease.

While we are only aiming to walk the 12kms as we are no athletes and will have prams in toe, this cause is very close to our hearts.



We kindly appreciate any donations to help our cause and raise support and awareness for multiple myeloma through Myeloma Australia.

<https://citybay2017.everydayhero.com/au/trev-s-mets-multiple-myeloma-awareness>

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On Sunday 26 March 2017, Myeloma Australia hosted the Inaugural MY Mount Eliza Run and Fun Festival. The event was organised and delivered by Myeloma Australia volunteer Geoff Nyssen, along with his committee of dedicated friends and family, and support from the Myeloma Australia team.

As a myeloma fighter, it was Geoff's vision to organise an event where the myeloma community, friends and family could come together and where the focus would be on families having fun whilst participating in activities that support personal wellbeing. The event was also focussed towards raising awareness and much needed funds to enable

Myeloma Australia to continue their valuable work within the myeloma community.

The MY Mount Eliza Run & Fun Festival comprised a 5km and 10km run and walk through beautiful parkland in Mount Eliza, located on the Mornington Peninsula in Victoria. Blessed with beautiful weather on the day, the event had over 680 people participating, with ages ranging from five to 80 in attendance. There was everything from the highly competitive professional athletes, right through to families with prams attempt the course. It was obvious from later feedback that everyone had a great time. The run and walk was underpinned by an abundance of activities and festivities that continued throughout the day. Some of the activities and exhibitions included;

- Stage performances including a musical set from our own Steve Roach and the Storm Season.
- Reptile petting zoo, face painting, tattoos for kids (and the adults), jumping castle, and many health and fitness related activities.
- Yoga demonstrations, massage forums and podiatry support.
- Demonstrations and activities lead by the CFA and Victoria Police.
- A Gaelic sword fighting tournament.
- We even had a skate / scooter and BMX tournament!



Photos supplied and used with permission

All of this was supported by some amazing food stalls that kept everyone's bellies full and happy. Suffice to say, Geoff's vision was achieved as everyone who attended had a great time, and were very successful in raising awareness of myeloma to a new audience. The success of the event was also evident in the amount raised, an amazing \$30,050.

There are many people and organisations that contributed significantly to the success of the MY Mount Eliza Run & Fun Festival 2017. Myeloma Australia would like to thank Geoff and his committee for organising and delivering the event.



In addition, we extend our thanks to the 120 volunteers that helped in the lead up and on the day. We thank our Partners and Sponsors for the event including Community Partner Ryman Healthcare, Media Partner Mornington Peninsula Magazine, the Mornington Peninsula Shire Council, Gold

Sponsors Ritchies Mount Eliza and Peninsula Hot Springs, Silver Sponsors ANZ, PARC, Bartercard, RTEdgar, Peninsula Volkswagen, and all of our generous Bronze Sponsors.

Planning for the MY Mount Eliza Run & Fun Festival in March 2018 is now under way. It will be another mammoth effort to deliver this event, so if you are interested in helping out in some way, please let us know. Otherwise, we look forward to seeing you having fun with us in March 2018! ●



Global Myeloma voices come together to drive research and improve lives of patients

Recently I was in Madrid, Spain as a guest of the International Myeloma Foundation (IMF) to attend several meetings set around The European Haematology Association's annual meeting. This was a fantastic opportunity to be updated with everything going on in the world of myeloma. I met with patient groups from around the world as we discussed advocacy, drug access and patient issues and also doctors and researchers who are making great scientific and clinical advances in myeloma. It was pleasing to see that Australia is at the forefront of patient services and clinical advances.

Rather than repeat or paraphrase, I thought I would directly pass on the report of the Chairman of the International Myeloma Foundations Dr Brian Durie which does much more justice to the medicine and science than I can.

Steve Roach, CEO Myeloma Australia



(Re-published with permission by the IMF)

By Brian GM Durie MD

This past week was very busy and important for the global myeloma community, which is increasingly coming together with a single voice for myeloma research and patient care. In Madrid, Spain, on the eve of the 2017 Congress of the European Haematology Association, the IMF provided platforms for many of these global research voices at the 2017 International Myeloma Working Group® (IMWG) Summit, as well as during the regular research update meeting of the IMF Black Swan Research Initiative® investigators team.

In addition, the voices of myeloma patients were heard at a meeting of the Global Myeloma Action Network® (GMAN), a group of myeloma patient organizations from around the world whose aim is to support patients' needs. The GMAN Summit hosted 45 attendees from 25 countries representing 5 continents June 17-19. Experts on myeloma (Prof. Jean-Luc Harousseau and Dr. Rafat Abonour) and global advocacy (Dr. Durhane Wong-Rieger) shared research and strategic insights. Member organizations from Brazil, Canada, Colombia, France, and Korea described their challenges and accomplishments. And the 2016 Susie Novis Durie Grant recipients from Armenia, Croatia, and Paraguay reported on their progress. This year's grant recipients are from Argentina, Austria, and Romania.

Black Swan Research Initiative investigators meeting

The IMF's Black Swan Research Initiative team held its regular

research update meeting on June 19. Our signature research project has grown quite intense, with more than 30 projects ongoing or completed. Here are a few:

Myeloma interrupted: The iStopMM® project, launched in October 2016 in Iceland to prevent MGUS (monoclonal gammopathy of undetermined significance) from developing into full-blown disease. About 80,000 Icelanders have signed up to participate in this blood screening, and approximately 1,000 new cases of MGUS have been diagnosed.

The special clinic for bone marrow and other testing has opened. The Icelanders actually want to have a bone marrow test to contribute to the understanding of the disease. Congratulations to Dr. Sigurdur Kristinsson and his team for spectacular progress!

Next-generation myeloma testing: Dr. Alberto Orfao and Dr. Bruno Paiva updated the Black Swan investigators team on the progress made by Spain-based researchers. The newly developed and very sensitive NGF (next-generation flow) test to detect one in one million plasma cells in the bone marrow is now being used to test for myeloma cells in the blood with great results. All patients with active myeloma as well as SMM (smoldering multiple myeloma) have myeloma cells in the blood! This is really a whole new understanding of the disease. Myeloma becomes "multiple" because cells move to new spots in the bone marrow and elsewhere. Even MGUS patients can have some cells in the blood.

Studying these blood cells is the next phase of Black Swan research: Why are they there? How many are there? Are they

sensitive or resistant to treatment? What is happening with the immune system? Of course, for patients, a key question is: Can blood-testing replace bone marrow testing? And a preliminary answer is, maybe, yes! So, good news. Much more to come on this.

Latest in imaging: Dr. Jens Hillengass and Dr. Evangelos Terpos updated the Black Swan team on imaging research. WBLD (whole-body low-dose) CT is better than regular skeletal survey, detecting lesions in approximately 20 percent of patients when x-rays are negative. A new project will capture imaging results by computer analysis with an electronic report. Also, a special type of MRI (magnetic resonance imaging) is being compared to PET/CT (positron emission tomography/computed tomography).

Cure trials: Dr. María-Victoria Mateos updated the team on the CESAR trial, which is now fully accrued! This is a study of KRd (Kyprolis + Revlimid + dexamethasone) + ASCT (autologous stem cell transplant) in HR SMM (high-risk smoldering multiple myeloma), which has been well tolerated with a 100 percent response rate! Much more to come on that at the December 2017 annual meeting of the American Society of Hematology (ASH), I am sure. In addition, Dr. Shaji Kumar announced that the ASCENT trial in the US is about to begin (KRd + Daratumumab +/- ASCT in HR SMM). There is tremendous excitement about finally starting this important study to compare with the CESAR trial results.

Much more was reported at the Black Swan Research meeting, but this gives a flavor of the most exciting updates.

2017 International Myeloma Working Group Summit

The 8th Annual IMWG Summit in Madrid was a big success, with key myeloma opinion leaders (KOLs) participating, discussing, and reviewing the latest research. The format was enhanced to keep presentations short, with ample time for discussion. More than 100 members of the myeloma community were in the audience, including representatives of the pharmaceutical industry and myeloma patients. The immediate feedback was that the major topics and questions facing the myeloma community were covered in a fashion which engaged and stimulated new ideas and opened a very active discussion.

Frontline setting: Current and future options which considered both drug access and patient-risk status were reviewed. Dr. Philippe Moreau showed sobering global maps illustrating the very limited availability of new agents outside the US. The cost implications of new four- or even five-drug combinations drew concern.

Role of ASCT: The simple conclusion of this discussion was that ASCT (autologous stem cell transplant) clearly adds both PFS (progression-free survival) and survival benefit. The open question is how to optimally integrate the use in the frontline and/or early relapsed situations. It was agreed there is no need to keep reevaluating the value of ASCT as each new agent comes along.

Rising treatment costs: Dr. Jean-Luc Harousseau had the unenviable task of discussing concerns about the progressive increases in the costs of myeloma care, including drug costs. The complexities here were very clear—the solutions much less so! Involvement of stakeholders is key. So, too, are recognition of regional differences, local situations, new expensive therapies versus drugs coming off patent. This year we hope to truly start to find solutions in this very complex time for healthcare delivery.

High-risk myeloma: Dr. Saad Usmani provided a comprehensive overview of high-risk myeloma, which was an excellent update for everyone. This is another area where much work remains to be done to provide better therapy for patients with high-risk disease.

Too many trials? Dr. Philippe Moreau, Dr. Vincent Rajkumar, and Dr. Wee Joo Chng gave a comprehensive update of global trials planned or ongoing in 2017. There are a staggering number of trials in process, both in the frontline and relapsed settings—a bit of a shock for both investigators and industry representatives. It made us aware that we need to look more closely to avoid duplication and to prioritize trials which are truly practice-changing.

The meeting wrapped up with a discussion of possible additional topics for next year plus considerable—and gratifying—feedback that #IMWG17 was a great success! Thanks to all who worked so hard to make this a meeting to be remembered. ●

From the Support Line



1300 693 566

A woman called the support line to discuss initial treatment for myeloma and the process of autologous stem cell transplant. Her father had just been diagnosed with myeloma and the caller has a holiday booked and wanted to ensure that she will be available to support and care for him leading up to and during the transplant.

The Myeloma Support Nurse was able to provide information about how long induction treatment and autologous transplant treatment will likely take, what to expect and potential complications or delays. This provided the caller with a good understanding of what to expect so she can take her holiday knowing that her father will be well supported during his treatment.

NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

RECRUITMENT UPDATE

We have now reached over 1700 patients registered on the MRDR thanks to the support of all participants and participating hospitals. We have 25 sites approved, with ICON Cancer Care the most recent addition. Monash Medical Centre is now active, ICON Cancer Care has 4 private clinics in Brisbane which will soon be registering patients, and Royal Darwin Hospital is currently obtaining approval to participate.

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

The Myeloma 1000 Project, a blood biobank substudy of the registry now has over 180 patients enrolled. This project is supported by Amgen Australia, Bristol Myers-Squibb & Janssen-Cilag.

MRDR RESEARCH

Three MRDR-related proposals for presentation were submitted for HAA, the major Australian haematology conference, held in Sydney this year, 29 October – 1 November. The submissions were:

- Renal impairment in myeloma – patient & disease characteristics, treatment, stem cell transplant & outcomes from the Australian and New Zealand Myeloma & Related Diseases Registry
- Polynesian Ethnicity and Outcomes for Multiple Myeloma in New Zealand: a single centre study from the Australia and New Zealand Myeloma and Related Diseases Registry.
- Patient reported outcome measures in multiple myeloma: real-time reporting to improve care (methodology of the My-PROMPT study).

These submissions give an indication of the research potential in the registry and the breadth and use of registry data. It is pleasing to see registry data maturing and questions being asked of the registry.

MRDR GROWTH

The registry is growing with a recent proposal to expand to 4 sites in the Asia-Pacific region approved for funding by Janssen. A MRDR proposal to improve national immunoglobulin stewardship and outcomes for myeloma patients has also recently been successful in receiving funding from the National Blood Authority. With this expansion the MRDR team including staff at the Transfusion Research Unit (TRU), Monash University, which administers the registry has also grown (see image).



R-L: Dr Zoe McQuilten (TRU Deputy Director), Mr Neil Waters (TRU Senior Projects Manager), A/Prof Erica Wood (TRU Head of Unit), Prof Andrew Spencer (MRDR Coordinating Principal Investigator & Steering Committee Chair), Dr Krystal Bergin (PhD student), Dr Elizabeth Moore (MRDR Project Manager & Research Fellow), Prof John McNeil (Steering Committee member), Dr Cameron Wellard (TRU Data Manager), Ms Gordana Kel (MRDR Research Assistant).

MRDR: HOW CAN YOU BE INVOLVED?

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

TO CONTACT THE MRDR:

Phone: 1800 811 326

Email: sphpm-myeloma@monash.edu

Website: mrdr.net.au

Nurse Manager's Report

In June we welcomed back Support Nurse Manager, Hayley Beer from maternity leave. It's great to have Hayley back and drawing on her expertise and experience in myeloma. Hayley and I are now job sharing the Support Nurse Manager role at Myeloma Australia in addition to our clinical roles at Peter Mac and will likely take turns at authoring this article each edition.

At the start of August, Steve and I travelled to Sydney to hear from the CaPPRe team the data results from the myeloma patient preferences study that many of you participated in, the previous 18 months. The study gathered information nationally from patients, carers, physicians and nurses. It compared a number of hypothetical myeloma treatments with variations in overall survival, remission duration, side effect severity and duration, hospital time, mode of administration and out of pocket costs.

This is the first study to align treatment preferences of patients with those of carers, physicians and nurses and there was discussion about what can be done with the information gathered. There are a number of possibilities, such as using it as a tool in clinic when speaking to the treating team, to influencing government when new treatments are put forward to the PBS. The data will be published in a journal and we will keep our members informed about when and how the information can be accessed.

We are in the process of appointing our first Myeloma Support Nurse for Western Australia. The part time role is based in Perth to provide 'on the ground' services to the Western Australian myeloma community through our key programs; face to face information and support groups, seminars for people living with myeloma, taking support line calls and providing myeloma specific education to health professionals. Thank you to all of our members who have reached out during this time to help us find our new team member. It has been great to see patients, carers, haematologists and nurses get on board and get excited about this new role and assisting us with finding our next myeloma support nurse. We look forward to introducing them formally in the next MyeNews.



Elsewhere in Australia, there are a number of new services planned in the next few months. On September 7th our Senior Myeloma Nurse Jo Gardiner is in Darwin to host a



Hayley & Nella.

myeloma discussion group for myeloma patients and carers. This is an opportunity for people to share information, learn more about living with myeloma and connect with others in the community. Jo is also booked to speak with local health professionals about myeloma and our services.

The Inaugural National Myeloma Workshop on September 16th at the Victorian Comprehensive Cancer Centre (VCCC) in Melbourne is a collaborative event with MSAG and the HSAZ Nurses Group Myeloma Special Practice Network. It will become a regular biennial event and will host two concurrent education programs with myeloma expert presenters from across Australia. One program is for patients and carers whilst the other is for health professionals caring for myeloma patients such as general practitioners, pharmacists, nurses and medical staff. It will also showcase the research facilities at the VCCC. We will use this meeting to launch our new look website which we have been working on.

Heading further south, on Friday October 13th our first myeloma seminar in Hobart is scheduled. It will be hosted at the Royal Hobart Hospital Cancer Support Centre with haematologist Dr. Nick Murphy presenting the myeloma overview and new treatments as well as a Myeloma Australia support nurse presenting on supportive care.

We look forward to seeing a number of our readers at our upcoming events and please come up and say 'hi' to our nurses. If you would like any further information about these events or upcoming or new services in your state, please contact us at nurses@myeloma.org.au ●

Nella Combe
Support Nurse Manager

It is hard to believe winter is almost behind us and we look forward to lighter evenings and warmer weather (although the Sydney days have been beautiful).

At the time of writing the last report, we had not yet held our annual seminar that was run in conjunction with the Leukaemia Foundation. However, I am pleased to report that this was again a very successful day with over 80 attendees. The theme for this year was "Myeloma: Striving for a personalised approach to treatment", speakers included haematologist Dr Chris Ward from RNS and exercise physiologist Anna-Louise Moule.

Since the last edition we have held our first meeting of the Liverpool Myeloma Information and Support group and are soon to have a second meeting. We are very fortunate to be able to access the Wellness Centre at the hospital for our meetings. Dr Silvia Ling will be attending the August meeting to do a question and answer session. Please contact me if you are interested in joining this group, you would be very welcome.

Our other support groups at Westmead, RPA, Newcastle and Central Coast continue to meet bi monthly and are a combination of invited speakers and general discussion and support. As I have mentioned before if you are thinking of

joining a face to face support group then please give one of the myeloma nurses a call to discuss the group. Each group is open to patients and carers/family and has the common theme of providing information and support. However, they may be structured a little differently for example a more informal group getting together over a coffee as opposed to invited speakers/topics at every session. Also some groups are larger than others, this is not necessarily a reflection of the group but in my experience a reflection of the myeloma journey with appointments, sickness etc. often preventing people from attending. As a regular facilitator of support groups I know the value of them and even if there is only a handful of people attending it can be extremely beneficial, sometimes more so, as there is an opportunity of more in depth discussion.

As we move into the last quarter of the year Myeloma Australia has a busy time hosting many events so please keep a lookout in the newsletters and emails for information.

I look forward to meeting with many of you over the coming months and as always remember we have a telephone support line which is run by the nursing team so please call us with your questions or inquiries **1800 693 566**. ●

Jacqui Keogh
Myeloma Support Nurse

In May 2011, I was diagnosed with myeloma. "Cancer" is such a chilling word and I thought all my plans for my recently-retired future were automatically erased.

After being on chemo for 6 months, I had an SCT in December 2011, was in remission by August 2012 and have been ever since

In mid-2012, I was hopeful and then determined to continue my love of travelling. It took a while to locate insurance cover but after that, the "cabin fever" of early 2012 was cancelled by trips to Kyoto in their fall, Barcelona and northern Spain, Northern Ireland, many Aussie destinations, Devon and Cornwall, Dubrovnik and around the Adriatic and of course Venice!

This photo shows us relaxing with a sunset Spritz at a cafe on the edge of the Grand Canal. Life is so good – just one day at a time. ●

Heather Adie



An invitation to contribute

If you have a favourite travel or special event photo that you would like to share in the MyeNews or the E-Muster, please send it through. Be sure to include your name, how long you or your loved one has been diagnosed and where/why it was taken. The aim is to provide inspiration to our myeloma community.

SA Division Report



Prof Paul Rolan.

Prof. Paul Rolan was our June speaker at Fullarton and he outlined the process the drug companies go through to develop the drugs that save our lives or at least put us into remission. With his vast experience in the pharmaceutical and medical areas he explained why so many drugs fail to reach clinical trials and why they cost so much.

According to Prof Rolan there are negotiations going on all the time in Australia between pharmaceutical companies and the government through the PBAC and PBS agencies to have the drugs firstly accepted onto the PBS scheme and then at what cost. He gave some examples where the pharmaceutical companies did the right thing and also did the wrong thing by money gouging.

On Thursday, 20th July, we had another organised visit to the SAHMRI Myeloma Laboratories on North Tce., Adelaide thanks to Prof. Andrew Zannettino, who is always the perfect host. The group was small in numbers but everyone enjoyed the experience.

In August at Fullarton, we decided to do something completely different, instead of having a guest speaker we had our Support Nurse, Jo Gardiner conduct a Patient & Carer Quiz Day. We divided those attending into 4 per table and Jo asked a series of 20 multiple choice questions about myeloma. Even though there was an overall winning table, competition was not taken seriously and the 1½ hours was a fun and entertaining experience and a lot was learnt about myeloma. It was a pity that we didn't get a bigger attendance, but those who did attend had a great time.



Patient & Carer Quiz Day.

Our next meeting at Fullarton in October, will have Dr. Cindy Lee from the RAH as guest speaker, talking about clinical trials, new drugs coming onto the scene and their availability through the PBS Scheme.

The South-East Support Group had their meeting on August 29th, with their co-ordinator, Carol Koch telling the story of her journey through myeloma treatment and how she coped with having to travel from near Naracoorte to Adelaide. A long road trip for appointments and treatments. This also included staying at the Cancer Council's Flinders Lodge. Their following meeting in November will see Jo Gardiner going down to Coonawarra to do a presentation and general Q&A.



Jo Gardiner.

The Mid-North Support Group had their meeting on August 17th, with Jo going up to that meeting for a casual get together and Q&A session. Their following meeting on Saturday, November 4th will be the Regional Seminar, a speaker has yet to be confirmed.

We are in the process of starting a new support group near Flinders Medical Centre (called Flinders Support

Group), mainly for patients at FMC or those living in the surrounding areas. The first meeting will be on Thursday, September 14th, 2017 from 10.00am to 12.00noon at the Living Kurna Cultural Centre Function Room at Bedford Park (Warriparinga Way, Bedford Park), details in the calendar of events in the back pages of this issue. ●

Ian Driver

Chairman

T: 08 8556 6041

E: sandrian7@bigpond.com



VIC Division Report

Although it's been cold outside these last few months we've been running hot here in Victoria at Myeloma Australia. Our Victorian nurses team has now doubled, allowing us to deliver more services to the myeloma community and provide expert education to health professionals across the state.

Given our growing team, a slight restructure of roles and responsibilities has been necessary to utilise each of our individual skill sets and experiences. Elli and Laura have eagerly taken on the title of Victorian Support Nurse. With support being our focus we will be managing the information and support groups in Victoria, be available via the support line and support other health professionals by providing myeloma specific education. Nella and Hayley have moved into a more managerial role with a national focus including overseeing national service delivery, recruitment and program development.

We continue to get strong numbers at our information and support groups in Victoria complimented by some fantastic guest speakers. Andrew Smith, an occupational therapist from Melbourne Cancer Rehab, was invited along to our younger person's support group at the end of July. He spoke about 'Improving physical health and well-being' particularly focusing on influencing factors such as regular exercise, sufficient sleep and ability to adapt to change. His expertise in haematology and practical strategies to manage cancer related fatigue lead to a very interesting and well received discussion. Andrew may have even found himself a few new clients.

At our Mt Eliza group Marie Butler, a local podiatrist from the Mornington Foot Clinic, gave us a presentation on peripheral neuropathy in myeloma from a podiatrist's perspective. Marie was able to suggest some very practical safety tips and advice for preventing falls and skin injuries similar to the tips suggested in our 'Managing Peripheral Neuropathy' guide. This opened up a great conversation about people's own experiences with neuropathy and their personal tips for managing.

One of our newest Victorian support groups fondly known as Coburg Support Group, but technically located in Brunswick West, met and welcomed some new members. The group looks to be gently developing their own unique feel and culture. Together with our holistic care consultant Stuart McDonald we had a discussion on the ups and downs of myeloma. The topic facilitated an informal yet important conversation really reinforcing the positive impact peer support can have.

Driven by locals a new social support group has been meeting in Warragul for dinner. Laura and Nella were able to attend the most recent meeting with both first time and



Stuart McDonald with support group.

familiar members attending. The group is hoping to connect with others living with myeloma in the area and share experiences. Please let us know if you would like any further information about the meetings in Warragul or any of our support groups.

We have been busy planning an information day to be held at the Victorian Comprehensive Cancer Centre (VCCC) on the 16th of September with two programs running concurrently. The first program is being held for people living with myeloma, their families and friends. The second program has been designed for health professionals with a particular interest in myeloma in collaboration with the HSNZ myeloma special practice network. All event invitations have now been sent out. Don't forget to register and we hope to see you all there.

We have also been busy providing myeloma specific information and education for health professionals by travelling to different hospitals and presenting in their allocated education times. Laura has recently presented at the Peter Mac Haematology Study Day to a very welcoming audience and will present again at their second study day in September. Upcoming nursing education sessions include Epworth, Eastern Health, Ballarat, The Alfred, St Vincent's, Monash, Goulburn Valley and Northern Health. We are also creating an information and referral resource to make joining our community easier. Please don't hesitate to contact us if you are interested in myeloma specific education at your workplace anywhere in Victoria.

We would like to thank everyone for welcoming us into the myeloma community and look forward to the challenge of extending our support and education services further across Victoria. ●

*By Elli Foley and Laura Jones
Myeloma Australia Support Nurses*

Elotuzumab Plus Lenalidomide/Dexamethasone for Relapsed or Refractory Multiple Myeloma

British Journal of Haematology – July 2017

Extended 3 year follow up data from the phase III ELOQUENT-2 study (elotuzumab plus lenalidomide/dexamethasone (ELd) versus lenalidomide/dexamethasone (Ld) showed continued benefit for the group treated with elotuzumab (ELd) over those who did not receive elotuzumab (Ld) with a 27% reduction in risk of disease progression or death. Additionally, interim survival data suggested a trend in favour of the elotuzumab arm. The safety profile was comparable between both arms.

Overall, elotuzumab, lenalidomide, and dexamethasone appears to provide a durable and clinically meaningful response in patients with relapsed/refractory multiple myeloma.

Pomalidomide, Bortezomib, and Dexamethasone for Relapsed, Lenalidomide-Refractory Multiple Myeloma

Blood – July 2017

This multicentre, nonrandomized, investigator-initiated phase I/II trial was designed to evaluate the safety and activity of pomalidomide, bortezomib, and dexamethasone (PVD) for 50 patients with relapsed, lenalidomide-refractory multiple myeloma. Patients had been exposed to a median of two prior regimens. After a median follow-up of 42 months, the objective response rate was 86%, with a stringent complete response rate of 12% and complete response rate of 10%. Response rates were similar between high/intermediate-risk and standard-risk groups. The regimen was well-tolerated, with myelosuppression noted as the primary adverse effect.

These data support the use of PVD as a second-line option, particularly in patients with lenalidomide-refractory disease.

Prospective Value of MRI vs PET-CT at Diagnosis and Before Maintenance Therapy in Patients With Multiple Myeloma

Journal of Clinical Oncology – July 2017

A prospective trial in 134 patients with MM compared detection rates of bone lesions at diagnosis and potential prognostic values of MRI vs PET-CT. At diagnosis, there was no difference between MRI and PET-CT for detecting bone lesions. Normalization of MRI after three cycles of induction was not predictive of progression-free or overall survival. However, normalization of PET-CT after three cycles of treatment, was associated with a trend to improved 30-month PFS and PET-CT normalization before maintenance showed these patients having improved 2-year progression-free survival and overall survival.

The investigators concluded: "There is no difference in the detection of bone lesions at diagnosis when comparing PET-CT and MRI. PET-CT is a powerful tool to evaluate the prognosis of de novo (newly diagnosed) myeloma."

Effects of single-agent bortezomib as post-transplant consolidation therapy on multiple myeloma-related bone disease

British Journal of Haematology – July 2017

This Phase II study suggests that post high-dose chemotherapy and auto stem cell transplant (ASCT), with bortezomib as consolidation therapy had no obvious effect on bone mineral density in patients with myeloma related bone disease compared with observation (ie no consolidation therapy) alone. However, there was a benefit demonstrated in increased progression free survival and the bortezomib therapy was well tolerated.

This Phase II study suggests that post high-dose chemotherapy and auto stem cell transplant (ASCT), bortezomib consolidation therapy had no obvious effect on bone mineral density in patients with myeloma related bone disease compared with observation alone. However, there was a benefit demonstrated in increased progression free survival and the bortezomib therapy was well tolerated.

Safety of Modulating Panobinostat Plus Bortezomib and Dexamethasone for the Treatment of Multiple Myeloma

British Journal of Haematology – July 2017

This sub analysis of the PANORAMA 1 trial was designed to evaluate the impact of dose intensity on safety in 768 patients with relapsed or relapsed/refractory multiple myeloma randomized to panobinostat, bortezomib, and dexamethasone or placebo, bortezomib, and dexamethasone. The trial was designed to deliver treatment in two phases, both with consistent dosing of panobinostat, but reduced dose of bortezomib/dexamethasone in the second treatment phase. Serious adverse effects were meaningfully reduced following dose adjustment, including thrombocytopenia (47.1% vs 5.9%), diarrhoea (25.5% vs 8.8%), and fatigue (14.7% vs 2.0%).

The results of this study provide a potential strategy for optimising dosing of this regimen as it could improve tolerability potentially leading to improved outcomes for patients.

Second Phase 3 Study Shows Kyprolis® (Carfilzomib) Regimen Significantly Improves Overall Survival In Patients With Relapsed Multiple Myeloma

PR Newswire – July 13, 2017

Amgen announced results from the final analysis of the Phase 3 ASPIRE trial. The study met the key secondary endpoint of overall survival (OS), demonstrating that KYPROLIS®(carfilzomib), lenalidomide and dexamethasone (KRd) reduced the risk of death by 21 percent over lenalidomide and dexamethasone alone (Rd) (median OS 48.3 months for KRd versus 40.4 months for Rd). Per protocol, patients received 18 cycles of KYPROLIS® with Rd before continuing treatment with Rd alone to progression.

Daratumumab Plus Pomalidomide and Dexamethasone in Relapsed/Refractory Multiple Myeloma

Blood – June 2017

This open-label, nonrandomized, multicentre phase Ib study was designed to evaluate the safety and tolerability of daratumumab in combination with various treatment regimens for relapsed and/or refractory multiple myeloma. In 103 patients receiving daratumumab combined with pomalidomide and dexamethasone, the safety profile was similar to that of pomalidomide and dexamethasone alone, except for daratumumab-related infusion reactions and a higher incidence of neutropenia (with comparable rates of febrile neutropenia and infection).

Responses to treatment with daratumumab in combination with pomalidomide and dexamethasone appeared to be rapid, deep, and durable in this population of heavily pre-treated patients with multiple myeloma.

Improved Responses and Survival With Carfilzomib Regimens in Multiple Myeloma Patients Relapsing After ASCT

Leukemia – June 2017

This subgroup analysis evaluated outcomes of participants in the ASPIRE trial and in the ENDEAVOR trial to study outcomes based on prior Autologous Stem Cell Transplant (ASCT) status. In total, 446 ASPIRE participants and 538 ENDEAVOR participants had undergone prior ASCT. Median progression-free survival was longer for patients with one prior line of therapy that included ASCT, those who had not undergone ASCT, and those with prior ASCT who received carfilzomib-based regimens compared with non-carfilzomib based regimens. Patients receiving carfilzomib-based regimens also exhibited improved overall response rates.

These findings indicate that carfilzomib-based therapy may result in improved progression-free survival and response

rates independent of prior transplant status, warranting further studies

Lenalidomide maintenance treatment demonstrates significant overall survival benefit following HDT-ASCT

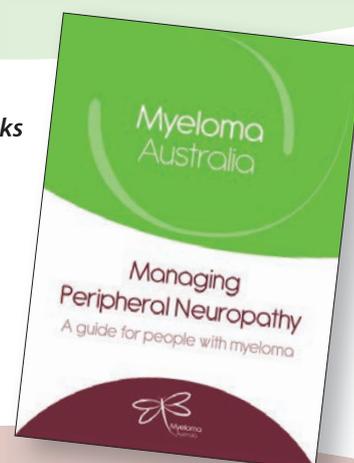
Myeloma UK – July 2017

Meta-analysis of results from three randomised control trials has demonstrated that maintenance treatment with lenalidomide (Revlimid®) following high-dose therapy and autologous stem cell transplantation (HDT-ASCT) in newly diagnosed myeloma patients has a significant overall survival (OS) benefit.

Published in the *Journal of Clinical Oncology*, the results of this meta-analysis, which used data pooled from the CALGB 100104, IFM 2005-02 and GIMEMA RVMM-PI-209 trials, showed that lenalidomide maintenance treatment reduced the risk of death by 25% when compared to the control group. The median progression free survival (PFS) for patients receiving lenalidomide maintenance treatment was 52.8 months compared to 23.5 months for patients receiving the placebo. Furthermore, seven year survival was reached in 62% of patients receiving lenalidomide maintenance treatment versus 50% of patients in the control group.

These results provide substantial evidence of the benefits of lenalidomide maintenance treatment. ●

Peripheral Neuropathy books are available from head office. If you would like a copy please contact us via support@myeloma.org.au with your full name and postal address or call (03) 9428 7444



Calendar of Events

Victoria

Event	Date	Location	Time	Organisation	Contact
<i>Botanical</i> – A Collection of Watercolours by PE Ball	Sat 2nd Sept – Sun 10th Sept	335 Swan Street Richmond, Vic	10am – 4 pm daily	Myeloma Australia	Pina Civitarese pina@myeloma.org.au 0412 244 734
Coburg Information and Support Group	Thur Sep 7th	Campbell Turnbull Library, Library Meeting Room Corner Melville Rd and Irvine Cres, West Brunswick	10am – 12 noon	Myeloma Australia	Laura Jones laura.jones@myeloma.org.au 0451 404 203
Warragul Information and Support Group (NEW)	Thur Sept 14th	TBC	6pm – 8pm	Myeloma Australia	Laura Jones laura.jones@myeloma.org.au 0451 404 203
National Myeloma Workshop	Sat Sept 16th	The Victorian Comprehensive Cancer Centre Peter MacCullum Cancer Centre 7th Floor Auditorium 305 Grattan Street, Melbourne,	9.30am – 3pm	Myeloma Australia Head Office	support@myeloma.org.au Ph: 1300 632 100
Mt Eliza Information and Support Group	Thur Sept 21st	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10am – 12 noon	Myeloma Australia	Elli Foley elli.foley@myeloma.org.au 0426 404 233
Beaumaris Information and Support Group	Thur Oct 5th	Beaumaris Theatre 82 Wells Road, Beaumaris	10am – 12 noon	Myeloma Australia	Elli Foley elli.foley@myeloma.org.au 0426 404 233
Kew Information and Support Group	Thur Oct 12th	Kew Library Corner Charles St & Cotham Rd, Kew	10am – 12 noon	Myeloma Australia	Laura Jones laura.jones@myeloma.org.au 0451 404 203
Geelong Information and Support Group	Fri Oct 13th	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10am – 12 noon	Myeloma Australia	Elli Foley elli.foley@myeloma.org.au 0426 404 233
Coburg Information and Support Group	Thur Nov 2nd	Campbell Turnbull Library, Library Meeting Room Corner Melville Rd and Irvine Cres, West Brunswick	10am – 12 noon	Myeloma Australia	Laura Jones laura.jones@myeloma.org.au 0451 404 203
Mt Eliza Information and Support Group	Thur Nov 16th	a Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10am – 12 noon	Myeloma Australia	Elli Foley elli.foley@myeloma.org.au 0426 404 233

South Australia

Event	Date	Location	Time	Organisation	Contact
Flinders Information and Support Group	Thur Sept 14th	Living Kuarna Cultural Centre Warriparinga Way, Bedford Park	10 am – 12 noon	Myeloma Australia	Jo Gardiner jo.gardiner@myeloma.org.au 0447 331 165 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Oct 3rd	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am – 12 noon	Myeloma Australia	Ian Driver - sandrian7@bigpond.com (08) 8556 6041 1800 MYELOMA (693 566)
Mid North Regional Seminar	Sat Nov 4th	Snowtown Hospital Snowtown	11 – 2.30 pm	Myeloma Australia	Bronwyn Gerschwitz (08) 8664 0682 graemebronwyng@bigpond.com 1800 MYELOMA (693 566)
South East Information and Support Group	Tues Nov 14th	Katnook Estate – Coonawarra (6km north of Penola)	11.30 am – 2.30 pm	Myeloma Australia	Carol Koch M: 0427 659 014 E: clk@live.com.au 1800 MYELOMA (693 566)
Flinders Information and Support Group	Thur Nov 16th	Living Kuarna Cultural Centre Warriparinga Way, Bedford Park	10 am – 12 noon	Myeloma Australia	Jo Gardiner jo.gardiner@myeloma.org.au 0447 331 165 1800 MYELOMA (693 566)

Calendar of Events

New South Wales

Event	Date	Location	Time	Organisation	Contact
Newcastle Information and Support Group	Mon Oct 9th	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm – 5pm	Myeloma Australia	John Miller (02) 4957 0711 miller32@optusnet.com.au 1800 MYELOMA (693 566)
RPAH Information and Support Group	Tues Oct 10th	Royal Prince Alfred Hospital Education Centre Level 5 Chris O'Brien Lifehouse 119-143 Missenden Rd, Camperdown	10am – 12pm	RPAH & Myeloma Australia	Tracy King (02) 9515 7310 / 9515 6111 pager 87524 tracy.king@sswhs.nsw.gov.au 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Oct 17th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am – 12pm	Myeloma Australia	Jacqui Keogh jacqui.keogh@myeloma.org.au 0426 404 230
Westmead Hospital Information and Support Group	Thur Oct 19th	Crown Prince Mary Cancer Care Centre Conference Room 2 Westmead Public Hospital Hawkesbury Rd, Westmead	10am – 12pm	Myeloma Australia	Jacqui Keogh jacqui.keogh@myeloma.org.au 0426 404 230
Central Coast Information and Support Group	Thur Oct 26th	Central Coast Leagues Club Dane Drive, Gosford	6 – 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger (02) 4320 9641 jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)

Tasmania

Event	Date	Location	Time	Organisation	Contact
Hobart Information and Support Group	Fri 13th Oct	Royal Hobart Hospital Cancer Support Centre	1 pm – 3:30pm	Myeloma Australia	Nella Combe nella.combe@myeloma.org.au 0447 334 435

Northern Territory

Event	Date	Location	Time	Organisation	Contact
Darwin Information and Support Group	Thur Sept 7th	Shop 9, Nicole Manisons Office Hibiscus Shopping Centre <i>RSVP essential</i>	5pm – 6pm	Myeloma Australia	Jo Gardiner jo.gardiner@myeloma.org.au 0447 331 165

Myeloma Support Groups Facilitated by Leukaemia Foundation

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

National Telephone Support Group (Cancer Council NSW)

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

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

Myeloma Australia is the only myeloma specific support organisation in Australia



Call our **Myeloma Support Line** for advice, and emotional support **1800 693 566**



Learn about myeloma from experts and meet others at our **patient and family seminar workshops**



Find your nearest **myeloma support group** to meet other people



Visit **www.myeloma.org.au** to download the latest information, find support and seminar events etc

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

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