

MyeNews

Autumn 2018 Issue no 45

Myeloma
Australia



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President's Report

The start of another year and I hope everyone had a good Christmas and New Year celebrations. For some it is a good time to catch up with family and friends and for others a chance to have a holiday or just enjoy Australia's beautiful summers.

As I have mentioned before, it is now nearly 20 years since we began as Myeloma Victoria. We have achieved so much more than we ever thought we would but now there is so much more we can do and we finalising our plans on further growth through our Myeloma Support Nurses to extend our services throughout Australia, but more about this later.

In early December Steve, Hayley, Nella and I travelled to Georgia, Atlanta to attend the American Society of Haematology's Annual Meeting with about 30,000 others from all around the world. We had a very busy time attending a number of meetings and medical presentations of the latest data on several potentially new treatments and comparing these with other drugs that have been around for a couple of years. Even with the large number of people attending this meeting we bumped into a number of Australian haematologists in the corridors of the conference centre. While in Georgia we were the guests of the International Myeloma Foundation and attended several of their events as well.

It is good to welcome Steve back after having some time off recovering from a hip replacement operation and so now he can move around more freely with no pain, though I know he was still doing some work from home.

Our web page has now been upgraded and is looking much better and it is now easier to navigate around it. Please check it out as we will be promoting events and seminars as well as reporting any news. Thanks to everyone who responded to the email sent out to write a submission into the Pharmaceutical Benefits Advisory Council (PBAC) in January trying to get Revlimid made available for maintenance therapy after a stem cell transplant. We have been told



that the PBAC read all the submissions and that we have been able to get more people to respond than any other organisation. As reported in the local press Carfilzomib was approved last year and became available on our National Health as the 1st January 2018.

Unfortunately the new drug Daratumumab was rejected by the PBAC at their last meeting last year but the manufacturers will be reapplying soon and hopefully they will be successful this time.

Watch our mail as we have a number of events being planned for this year both seminars, support groups and fund raisers, so if you can please support these.

I will be looking forward to catching up with many you during this year. ●

Brian Rosengarten
President
Myeloma Australia

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

Myeloma Australia Head Office will be closed for Easter on Good Friday 30th March and Easter Monday 2nd April.

We would like to wish all our members and supporters a safe and happy Easter.



Focus on

New South Wales & ACT



There are between 4000 and 5000 people in NSW living with myeloma. Over 600 people will be diagnosed in 2018.

1 in every 117 people who reach the age of 85 will be diagnosed with myeloma. Myeloma is the twentieth most prevalent cancer in NSW.



Hi All,

Welcome to our spot light on New South Wales (NSW) and Australian Capital Territory (ACT), what is going on in the myeloma community there and what the plans are at Myeloma Australia for our operation in the area. Our goal is to see more members of the myeloma community face to face, whether they be patients, carers, friends, family or medical professionals. Our national services like the Telephone Support Line are enhanced by these face to face meeting and programs.

There has been much activity over the last six months as we prepare to expand our operation in NSW. We have been advertising for a new myeloma nurse in Sydney to assist Jacqui and negotiating to put a nurse in Newcastle based at Calvary Mater Hospital. We are also looking to have a nurse in The ACT and NSW South Coast over the next year.

Our search for another Sydney based myeloma nurse to work with Jacqui continues. Jacqui has done a brilliant job and we desperately want to give her and the myeloma community in NSW more support. If there is a person with haematology/ oncology nursing experience who wants to work with, educate and support our myeloma community, get in touch with us at Head Office on 1800 693 566.

Our plans to have a myeloma nurse in Newcastle are well down the track and once we have done some fine tuning in our negotiations with Calvary Mater Hospital, that person will be in place.

Once we have the Sydney and Newcastle positions up and running our attention goes to the ACT and South Coast.

We also plan to open an office in Sydney in 2018. We think this is very important and having a local presence will assist

staff, patients and the broader myeloma community.

Our national fundraising manager Matt Maudlin, is looking at promoting and assisting in community events in NSW as well as any individual events our community wants to run.

Along with the office we will have a person based in NSW to work with the community to engage in myeloma activities outside the education and health based events.

If you are reading this and you are in another state and you wonder, "...what about us?" don't be concerned as you may have noticed we are expanding and plan to be in every state and territory. We are currently in the process of planning for our first Queensland nurses. However as NSW has between 4000 and 5000 myeloma patients (around 30% of the national number) we are working solidly to ensure those services are in place whilst also building our services nationally.

We are very excited about putting more people and services in place around the Country and particularly to be helping Jacqui and our NSW community. I hope we see you at a support group or event.

Steve Roach CEO

"I have been delighted to see the evolution of Myeloma Australia into a real force for good for patients with myeloma. Its importance as a clinical advocate cannot be underestimated to patients, their families and the nursing and medical community."

Prof Doug Joshua
(Royal Prince Alfred Hospital,
Sydney)



NSW and ACT Services

In the next twelve months Myeloma Australia will be increasing our services to people living with myeloma in NSW and ACT.

This includes more Information and Support Groups which are a great way to meet others with myeloma and their carers, share experiences and knowledge and hear from speakers about topics such as side effect management and support services

We will also be holding more seminars so our community can listen to haematologists talk about myeloma and latest treatment updates and can ask questions of experts on the day. In addition, our Myeloma Support Nurses will be visiting more treatment centres to provide education and resources to health professionals caring for patients in the hospitals and clinics.

If you would like to know more about our plans or be involved please don't hesitate to contact nurses@myeloma.org.au

Medical Scientific Advisory Group (MSAG)

MSAG is a sub-committee of Myeloma Australia and is the peak medical and scientific body convened to collaborate and facilitate scientific advances and medical care in myeloma. The group is made up of leading myeloma haematologists and researchers from across the country and New Zealand. The group meet twice a year, once in Melbourne and once in Sydney to collaborate on research projects, share information and guide best practice treatment of myeloma in our country.

The NSW and ACT members include Prof Doug Joshua, Prof Jo Ho, Dr Silvia Ling, A/Prof Chris Ward and A/Prof Dipti Talaulikar.

"Being part of the medical and scientific advisory group (MSAG) of Myeloma Australia has been an absolute privilege – it has provided opportunities to serve the myeloma community and make a real difference to patients and carers, and to those who manage myeloma. As members of the MSAG, we achieve this through education, clinical advocacy and collaborative research." A/Prof Dipti Talaulikar (Canberra Hospital)

"Myeloma care is becoming increasingly complicated as the treatment options improve and more care is delivered in the community and ambulatory settings. We're looking forward to working with Myeloma Australia to improve the support options for these patients in our region."

*Dr Wojt Janowski
(Calvary Mater, Newcastle)*

Newcastle

Myeloma Australia have a long standing Information and Support Group in Newcastle and are looking forward to working with the members and Calvary Mater clinicians to build on existing services and provide more support and education to the myeloma community this coming year.

Education

As part of the wider team at Myeloma Australia Jacqui is involved in national events such as National Myeloma Month (May 2018) in conjunction with the Leukaemia Foundation but also state wide patient and health professional seminars.

In 2017 Jacqui met with nurse educators and provided in service education in hospitals and wards at Liverpool, Westmead and Concord. Each unit's education program is slightly different and the best part of my role is that I can be adaptable and tailor topics to meet specific needs. So please do not hesitate to get in touch if you are a health professional and interested in any myeloma education.



Focus on New South Wales & ACT

In 2018, we will expand on this program of education and deliver more presentations and educational programs for health professionals across the state. By contributing to the professional development of clinical nurses and doctors they can better understand myeloma and the specific care needs of their patients.

Myeloma Support Groups

Support groups provide a safe place in which individuals can share experiences and information with other people who are in a similar situation. There are many platforms now where by which support can be accessed whether it be at a face to face group, online via group forums and social media or via online communities such as the Cancer Council.

Another option is the Telephone Support groups. When groups are held on the phone, individuals can be connected from anywhere in Australia. All that group members need is access to a telephone (landline or mobile) and a private, comfortable space for an hour.

The Myeloma Telephone Support group facilitated by Myeloma Australia and Cancer Council NSW meets once a fortnight (2nd and 4th Monday of the month). Each group has between 3-7 individuals and is facilitated by two trained

facilitators. Each session lasts 1 hour and participation is flexible. The facilitator ensures that a safe environment is maintained enabling individuals to speak freely on whatever topic that they want.

There is generally a wide range of topics discussed from managing medication and associated side effects to talking with loved ones about diagnosis and prognosis, nothing is 'off limits'. New members to the group have commented on how "wonderfully supportive the group is", "it's so good to be able to talk with someone else who has had the same treatment and come through it".

If you are interested in joining the group, please contact CCNSW on 1300 755 632 or myself (Jacqui Keogh) 0426 404 230

Jacqui Keogh,
NSW Support Nurse



Information and Support Groups NSW

The face-to-face Information and Support Groups are an integral part of the work of Myeloma Australia and assisted by voluntary group leaders and Myeloma Support Nurses we currently have 20 groups running nationally.

In NSW we currently have 5 Myeloma groups running, see below for details but please call if you require further information.

● Westmead Information and Support Group

Meets 3rd Thursday of every other month 10am-12pm

New location: Wentworthville League Club

Magpie Meeting Room 1,
50 Smith Street, Wentworthville

Facilitator: Jacqui Keogh

M: 0426 404 230 E: jacqui.keogh@myeloma.org.au

● Liverpool Information and Support Group

Meets 3rd Tuesday of every month 10am-12pm

Liverpool Hospital, The Wellness Centre,
(Entrance N off Campbell Street) Level 1,
Cnr Elizabeth & Goulburn Streets, Liverpool

Facilitator: Jacqui Keogh

M: 0426 404 230 E: jacqui.keogh@myeloma.org.au

● RPAH Information and Support Group

Meets every other month on a Tuesday 10am-12pm

Royal Prince Alfred Hospital, Education Centre level 5,
Chris O'Brien Lifehouse, 119-143 Missenden Road
Camperdown

Facilitator: Tracy King

P: (02) 9515 7310/9515 6111

E: tracy.king1@health.nsw.gov.au

● Central Coast Information and Support group

Meets every other month on a Thursday evening 6-8pm

Central Coast Leagues Club, Dane Drive, Gosford

Facilitator: Jacqui Jagger

P: (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au

● Newcastle Information and Support Group

Meets every other month on a Monday afternoon
3pm-5pm

Cancer Council Office, Level 1/215 Pacific Highway,
Charlestown

Facilitator: John Miller

P: (02) 4957 0711 E: miller32@optusnet.com.au

NSW/ACT Fundraising News



As the excitement of the expansion of Myeloma Australia continues at pace it is with considerable pleasure that I write to you about various fundraising opportunities and news! If you have a fundraising idea please, please, please share the idea with me! In my role of Fundraising & Marketing Executive nothing gives me more pleasure than hearing of your ideas and then assisting you in implementing them to help you both enjoy a great event and raise additional funds for the work of Myeloma Australia. The fundraising equation at Myeloma Australia is breathtakingly simple – the more funds we raise, the more nurses we are able to place into the community to work alongside folks living with myeloma.

Office Location

By the end of 2018 we will have a Myeloma Australia office open in Sydney. We are not necessarily keen on one particular location over another – it just has to be the right

location for us. Our NSW nurses and fundraiser will be based in this office. Are you able to help us with locating an office space? If so, please get in touch with me or our CEO, Steve Roach; we'd love to hear from you!

Fundraising Events

The two major fundraising events that are planned for the ACT and NSW respectively are The Australian Running Festival in Canberra on the weekend of 14th and 15th April and the City2Surf in Sydney on 12th August. At both of these events the newly formed 'Team Myeloma' will be walking and running the pavements and roads of Canberra and Sydney as we look to increase awareness in the community of the work of Myeloma Australia and look to raise funds to allow us to continue to place a still greater number of myeloma nurses to work alongside myeloma patients in the community. Will you consider signing up yourself, your friends, your family, colleagues and networks to be a part of Team Myeloma?

the more funds
we raise, the more
nurses we are able
to place into the
community to work
alongside folks living
with myeloma.

The first Team Myeloma events that will be held in Canberra and NSW respectively are: The Canberra Times Running Festival on Saturday 14th and Sunday 15th April: <http://runningfestival.com.au/> and the Sydney City2Surf on Sunday 12th August: <https://city2surf2018.everydayhero.com.au/team-myeloma>

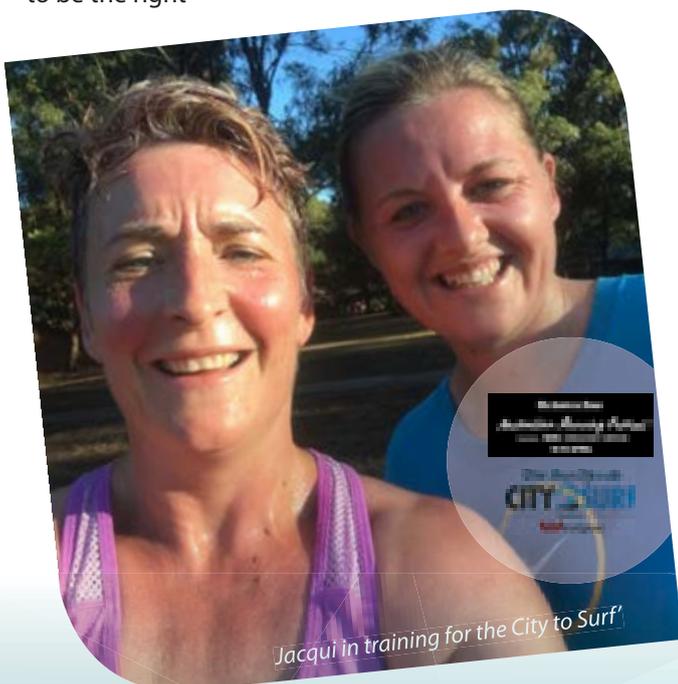
Fundraising NSW /ACT Manager

Once our new office in Sydney is up and running it will be occupied by our Sydney nurses, our Sydney Fundraising Manager and our NSW based volunteers. The Sydney Fundraiser position will be advertised in the coming weeks via www.myeloma.org.au, emails to the database, MyeNews, the Myeloma Muster, seek.com.au and our various social media channels. This paid position is likely to be for 16 hours per week. Alongside this, please feel most welcome to drop me a line if you are interested in finding out a little more about the role prior to it being advertised.

Volunteers

Our nurses and fundraisers in NSW will require various levels of volunteer support as their roles evolve. Such support might be in the area of helping to organise and host fundraising events or it might be in preparing documents in readiness for mailing. Again, please look out in the usual Myeloma Australia publications and social media channels for further details.

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



Carfilzomib (Kyprolis®) now available on the PBS

As of January 1, 2018 Carfilzomib (Kyprolis®) was included for reimbursement on the Pharmaceutical Benefits Scheme (PBS). Carfilzomib is now available in combination with dexamethasone for people who have already had at least one type of treatment.

Many people will have already accessed carfilzomib through a clinical trial or compassionate access scheme. It is fantastic to now be an option for all people living with myeloma.

Carfilzomib is in the same family of drugs as bortezomib (Velcade®), a widely used and effective treatment for myeloma. This family are known as proteasome inhibitors and Carfilzomib has been designed to target a different part of the proteasome which is thought to make it more effective and potentially cause fewer side effects than bortezomib.

Proteasomes are essentially the garbage disposals of all cells in the body. They remove, breakdown and recycle damaged proteins or those that are no longer needed by the cell. Proteasome inhibitors like bortezomib and carfilzomib work by binding to the proteasomes of the myeloma cells and stopping the garbage disposal process causing the myeloma cell to suffocate it its own waste.

Myeloma cells are more sensitive to proteasome inhibitors because they divide faster than healthy cells and produce unwanted proteins (paraprotein) at a greater and faster rate. They are therefore more reliant on this garbage disposal process.

Carfilzomib is given as a 30 minute intravenous infusion and dexamethasone is given in tablet form. Each drug is given on two consecutive days for three weeks followed by a week off. The usual pattern is to have treatment on days 1, 2, 8, 9, 15 and 16 of a 28 day cycle. The dose of carfilzomib is calculated on the individual's height and weight.

As with any medication, there are some potential side effects associated with carfilzomib.

The most common side effects associated with carfilzomib include: fatigue, anaemia, nausea, shortness of breath, diarrhoea and fever.

There have also been cases where carfilzomib has caused heart problems or exacerbated existing heart problems. Therefore, careful monitoring is required.

Like bortezomib, carfilzomib can also cause peripheral neuropathy which is a numbness, pain or tingling in the hands and feet. The risk of peripheral neuropathy is much less with carfilzomib than bortezomib.

If you would like to know more about carfilzomib, you can speak to your treating team or call our Support Line Monday to Friday 9am – 5pm AEST – 1800 693 566.

*Hayley Beer
Nursing and Programs Manager*

We'd like to acknowledge Myeloma UK whose fact sheet was used to write this article.

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*Proceeds from the sale of these cards will assist Myeloma Australia to continue their services to the myeloma community.
This project has been made possible by the generosity of Patricia & David Ball.*

My Myeloma Journey

I was diagnosed with myeloma in August 2012. I had been feeling slightly unwell for a couple of weeks, but having worked in the entertainment industry for over 20 years I just assumed I was a little run down. I then started waking up at night with cramps in my legs and finally my wife had enough and said I needed to get to the doctor to sort it all out.

I went in to see the GP who ordered some blood tests and told me to come back in a few days for the results. The next morning I got a call from the doctor who said I needed to get back to the hospital immediately.

It was shocking to find out that my tests showed I had cancer (multiple myeloma) and that my kidneys were failing – they were only operating on 5%.

Tests revealed my light chains were up around 3,000 and I was put onto immediate dialysis.

It was an extremely emotional time for both me and my family. It was really hard on us.

At one point they told me that I was going to die, they even called in the chaplain and I had to fill out the paperwork to give power of attorney to my wife. It really took a toll on her, I hated seeing her go through that.

I underwent stem cell treatment which helped fight the cancer for a couple of years. However, eventually I was told my numbers were rising again and my oncologist and I began looking for other options. I was put on a new trial for a medication, but unfortunately that also failed.

In mid-2016, I was put on the clinical trial for carfilzomib and I watched as my myeloma markers came all the way down to zero.

It has been so wonderful to experience family milestones over the last 18 months – like seeing my two grandsons start school and attend my daughter's wedding. I'm so thankful for these memories, because there was a stage when I didn't think I would get the chance to see them happen.

I'm able to go about my daily business again. As someone with kidney failure there weren't many treatment options I could try. So when this trial opened up I jumped at the chance.

My doctor is really pleased with how my myeloma marker has come right down, and we have hope for being able to maintain my health as is for quite some time.

It's been a difficult time with definite highs and lows, but I'm just taking it day to day and keeping a positive outlook. I think that's the most important thing

Mark Aitken, QLD



Nurse Manager Report

I'm delighted to see this edition of MyeNews once again bursting with all the great work happening around the Country. Our new team members in WA Kerin and Narelle have hit the ground running and Nella has been to Darwin to host our second information day there. We are slowly growing and expanding our reach. If we're not yet in your area, watch this space!



Hayley at the Blood Cancers Parliamentary Morning Tea, Canberra.

Rather than spending February 14 with my Valentine, I had the fantastic opportunity to go to Canberra to attend the Blood Cancers Parliamentary Morning Tea and the National Press Club. An opportunity that came from Steve our CEO being out of action recovering from a hip replacement. I was more than happy to jump at the chance.

Janssen, the drug company that make bortezomib (Velcade®) and daratumumab (Darzalex®), convened the Blood Cancers Parliamentary Morning Tea as an opportunity to meet with their Executive Vice President and Worldwide Chairman of their parent company Johnson and Johnson, Joaquin Duato and the Minister for Health, the Honourable Greg Hunt. We gathered at the House of Representatives Alcove with representatives from the Leukaemia Foundation, Lymphoma Australia, Janssen employees and some people living with blood cancers.

Mr Hunt was very generous with his time, meeting and greeting those with a blood cancer first before addressing the room. He spoke about the successes of the Pharmaceutical Benefits Scheme (PBS) and acknowledged that there is room for improvement. In relation to this we have been approached by the Pharmaceutical Benefits Advisory Committee to provide feedback on behalf of the myeloma community in anticipation of a workshop aimed at addressing some of the issues around access to treatments. Watch this space.

We then heard from Mr Duato who proudly spoke of Janssen's successes in developing treatments for myeloma and indolent lymphoma. He also spoke highly of Australia's contribution to the advancement of drug therapy and that we are seen as major players on the world stage. It was quite inspiring to be in the company of so many stakeholders and reaffirmed that progress is definitely a team effort.



Dr Emma Johnston, President of Science & Technology Australia.

Next stop was the National Press Club to listen to the Science Meets Parliament address. This presentation was delivered by Dr Emma Johnston, President of Science and Technology Australia. She delivered the most articulate and inspiring address focussing on the lack of funding invested into areas in Australia that will progress the country such as research and Science, Technology, Engineering, Mathematics and Medicine (STEMM) education.

She gave examples of how Australian scientific advancements are recognised and utilised worldwide. For example, the platform on which Google maps operated, seismic stations to identify looming tsunami threat to warn nations at risk, the world's first ever cancer vaccine and taking protein from milk to turn it into chewing gum that strengthens teeth saving an estimated \$12 billion in dental costs worldwide.

She strongly urged the Government to reconsider the reduced allocation of funds that forces our scientists to work under substandard conditions and spend far too much time writing grant applications to find funds to continue their research. She also advocated for increased investment in the STEMM subjects for both students to be interested in pursuing these careers, and for the educators to be better remunerated to encourage a higher standard of teaching.

Dr Johnston's presentation was well offset by the announcement that Janssen Pharmaceutical have recently commenced a partnership with Monash University. This multiyear research and commercialisation deal will focus on the early detection and prevention of rheumatoid arthritis, a debilitating autoimmune disease affecting 400,000 Australians.

This kind of collaboration is very encouraging to see and we hope that Monash and Janssen decide to focus on myeloma in a future project.

*Hayley Beer
Nursing and Programs Manager*

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march

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*Raising awareness and funds to assist Myeloma Australia
to further support the myeloma community.*



This year 'Team Myeloma' will be hitting the streets of a capital city near you! The concept is to have Myeloma Australia represented at various fun-run events around the country to raise awareness to myeloma and to raise funds to enable our work to progress in placing more myeloma trained nurses around the country.

We would love you to join Team Myeloma in a city near you and to spread the word of these fundraising events. Our aim is that following each event there will be an opportunity for the myeloma community to gather for a lunch or BBQ or social gathering of some description. The upcoming events we are currently concentrating on are the ones in Canberra in April and Perth in May – details below:

Canberra:

<http://runningfestival.com.au/>



Perth:

<https://hbfrun2018.everydayhero.com/au/team-myeloma>



Events in Sydney, Melbourne, Brisbane and Adelaide will be announced as the year progresses.

Please see the article in this edition about the people of the town of Yarrawonga and how they hosted the inaugural MyeTrim event in memory of one of their loved family members who passed away from myeloma. Working together they encouraged their entire town to get behind them as they raised over \$19,000 for the work of Myeloma Australia.

A major upcoming fundraising event on our calendar is on Sunday 25th March when the second iteration of the My Mount Eliza Festival is held (advert included in this magazine) Last year's event was a huge success and I encourage all members of the myeloma community in the Melbourne area to consider heading down to Mount Eliza for a day of fun activities and awareness raising.

A selection of the fundraising events that are currently being organised by members of the myeloma community include a MyeTrim event, a social bowls day, a Harley Davidson motorcycle ride and a flight around Australia! Fundraising events can be as simple or crazy as your heart's desire!

I am in the process of thinking through an idea of creating The Myeloma Morning Tea – or something similar – as an event that can be held in any kitchen or community venue throughout Australia. If you would like to join me in thinking this idea through this, please drop me a line. I love hearing of the fundraising ideas of the myeloma community and assisting you in bringing them to fruition, so please, don't be shy, I'm waiting to hear from you and, and if you are in Melbourne or surrounds I would welcome the opportunity to have a coffee with you and to hear your thoughts!

Matt Maudlin

Marketing & Fundraising Executive

E: matt.maudlin@myeloma.org.au M: 0407 891 052

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Money raised from the sale of these cards will assist Myeloma Australia to further their services to the myeloma community.

\$5 each

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E: support@myeloma.org.au

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Mye Trim

The MyeTrim Family Day held at the Royal Mail Hotel Mulwala recently raised a massive \$7,086 in total for Myeloma Australia in honour of well-known and respected Yarrawonga man Gav Dowling.

This amount included a \$600 donation from the host pub, the Royal Mail Hotel. The total tally for the entire campaign from October 15 to November 26 was a whopping \$19,000. Organiser of the event Jess Purtle said she and fellow organiser, cousin Xave Dowling were amazed by the response of the community and were massively grateful for all the money donated and support shown. "Xave and I have been completely blown away by the support that has been shown to our fundraiser and this is obviously a testament to the person that our uncle was," Jess said.

"We started with a modest goal and cannot believe that we made it to \$19,000. "We'd like to thank all the local traders, organisations and licensed premises that got behind us and donated their goods and services so generously as it's not an easy task to ask for charity and we truly appreciate and know that these goods and services make up part of their livelihood so we are very grateful."

Jess said that the generosity and compassion of the community was the most heart warming factor of the campaign and without their help the Mye Trim group could not have succeeded as much as they have.

"Mostly we are grateful to our beautiful community, friends and family," Jess said. "These are the important people that put their hands on their heart and in their pocket." "None of this would have been achieved without their compassion and generosity." Due to the large generosity of the community Jess and Xave decided to give something back as a thank you for the support. "Xave and I along with our MyeTrim Gang have decided that as our fundraiser far exceeded our expectations mainly through the community support we wanted to give something back to the community directly and will be donating \$3,000 from our total to Friends in Common. "We know that our uncle, farmer Gav would be looking down loving what we have done but hating all the fuss around what a wonderful man he was but we cannot be happier with what was achieved."

*Emma Prior
December 13, 2017*

Used with permission, originally published in the Yarrawonga Chronicle



Thank you to everyone who attended the Business of Winning Luncheon 2018

It was another successful day filled with laughs, amazing auctions, great food and wine as the sports panel entertained the audience in the MCG Members' Dining Room.



Angela Pippas



Nicholas Green & James Tomkins from the Oarsome Foursome



Peter, Hayley, Matt, Elli, Alex, Pina, Steve, Laura



Mike Rudd, Greg Champion, Brenden Mason & Michael O'Loughlin



Getting ready for the Business of Winning



Ken Cole, Nicholas Green, James Tomkins & Neil Balme



Do you travel a long way to see your specialist?

Seeing your specialist doctor by video – telehealth – is becoming more of an option across Australia. Generally, it is offered according to Medicare rules, which includes to people who live in regional or rural Australia, are in an Aged Care Facility or at an Aboriginal Medical Centre.

Haematologist A/Prof Simon Harrison is the Myeloma Disease Group Lead at Peter MacCallum Cancer Centre in Melbourne. Dr Harrison runs about one telehealth consultation a week, including for people with myeloma, and people seeking 2nd opinions. Dr Harrison explains “A telehealth consultation between appointments often provides reassurance for both of us that everything is ok”.

Who is telehealth for?

Telehealth can be suitable for anyone who finds travel difficult. This could be for any number of reasons including physical disability, long travel distances or the need to take time off work. Telehealth can also be really useful for planning ongoing care between your specialist and your local care team.

Telehealth has to be clinically appropriate too. It can be very useful for routine review appointments, as well as for urgent ‘in-between’ appointments. Sometimes, an in-person

consultation is unavoidable, for example if you need a test that can only be done at that centre. But many tests can now be done locally and results sent through to the specialist or accessed online.

Some conditions such as CLL (Chronic Lymphocytic Leukaemia) and myeloma can often be managed well with a mix of telehealth and in-person consultations.

What are the benefits?

The most obvious benefit of seeing your specialist by video is the convenience of saved travel. It can mean less time off work or away from home, less cost and possibly less impact on family members who also travel for appointments.

On the other hand, family members who can't usually travel to appointments can take part in important discussions if it is by video.

“The best thing was the knowledge that even though I am rural and not very mobile I have access to the doctor”

Telehealth including your GP

If the consultation includes your GP, or another healthcare professional such as a local oncologist, haematologist or nurse, they can be more involved in ongoing care.

Dr Harrison explains “If we need to change medications, the GP can manage this at the time. Having the consultation with both patient and GP keeps the loop tight – everyone knows what's going on and everyone can have input to planning and decision making. It also provides an opportunity for GP education relevant to their patient”.

Sometimes, when a physical examination is needed, this can be done by the GP with guidance from the haematologist.

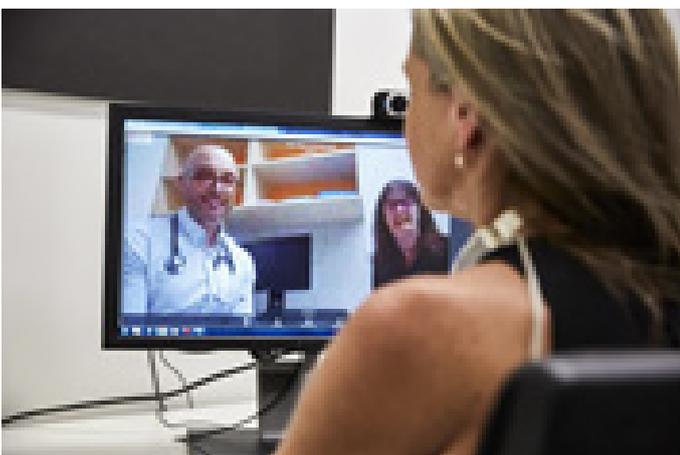
“2nd opinions” by telehealth often also work best when the referring doctor is part of the consultation. This often saves some time too, as the specialist can ask the local team questions and get details or results that can be harder to get at a distance.

Nora

Nora is a lady in her 60s with smouldering myeloma, which is stable but requires regular monitoring. Her main health issues are her arthritis and a mild heart condition. Because of the myeloma, her GP was nervous to manage these and other general health issues.

Nora now has regular 3-monthly telehealth consultations that include her haematologist and GP.

She has better management of her other health issues, as the GP is more confident in managing her day to day health. It also saves her money as she can see both doctors at the same time, and she only needs to visit the cancer centre in the city once a year instead of every 3 months.





Telehealth in your home

Many specialists also offer telehealth to patients at home. About half of the telehealth consultations at Peter Mac in Melbourne are to the home. These can be quicker and easier to organise and are good for many review appointments or getting routine results.

What do I need?

If you're going to have the telehealth consultation at home, you'll need a computer or a device such as an iPad or smart phone, with a webcam, and reliable internet of about 4G or better. If you can watch a YouTube video, you should be able to have a video call.

Some local services such as libraries, Men's Sheds, pharmacies, Community Health Services or GPs also have a computer available for telehealth if you don't have one at home.

"I live 5 hours away. I would normally have to spend three days away, at great expense, and have time off work to accomplish the same thing. The service worked exactly as advertised, sound and video were clear, and specialist was adept."

It's important to remember that telehealth can be useful for some, but not all appointments and you'll usually still need to see the specialist in person sometimes.

Ask about telehealth for your next appointment.

If you travel a long way or have difficulty getting to your appointments, ask your GP, haematologist or nurse coordinator about telehealth. They can tell you if telehealth could be an option, what you'll need and how to request telehealth.

Find out more

Peter MacCallum Cancer Centre telehealth
www.petermac.org/telehealth

Authors

Associate Professor Simon Harrison, Consultant Haematologist
and Susan Jury, Telehealth Program Manager
Peter MacCallum Cancer Centre

Myeloma Australia's
Trivia Night

Saturday April 21st, 2018
7pm - 10.30 pm
Glen Eira McKinnon
Bowls Club
Tyrone Street, Ormond
(corner at the end of Tyrone St driving through Joyce Park)

For further information contact
Alex Dawson
e: alex.dawson@myeloma.org.au
p: (03) 9428 7444

Bring your gold coins for lots of fun games
Lucky door prize
For more info contact alex.dawson@myeloma.org.au
Tables of 10 book a whole table or just turn up on the night and choose
Drinks at Bar Prices
Bring your picnic food
No BYO alcohol
BUMPER Raffle
Tickets \$25

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TryBooking proudly supports charities by donating back all booking fees

Research Update: Nerve Damage Following Chemotherapy Treatment

Identifying Neurological and Functional Outcomes in Cancer Survivors Study

Nerve damage following chemotherapy treatment, also known as chemotherapy induced peripheral neuropathy (CIPN), is a serious side effect of cancer treatment that may affect quality of life. CIPN develops with some of the most commonly used chemotherapies and other cancer drugs, including bortezomib (Velcade) and thalidomide, and results in sensations of numbness, tingling and pain. CIPN usually affects the nerves in the hands and feet, and may cause problems with everyday activities, such as walking and balance, and also handling objects. Patients may report that they have trouble typing, are unable to button clothes, are often stumbling and tripping, and experience other difficulties with everyday life. These symptoms may continue following completion of their treatment and affect balance and walking. However, there is a gap in our understanding



2 point Discrimination Task.



Grating Orientation Task.

of neuropathy, how best to identify and measure nerve changes, and no effective prevention or treatment is available at present.

The IN FOCUS research group from University of Sydney and UNSW is conducting an ongoing study to understand more about CIPN and its long-term effects. We are using a range different types of assessment tools to discover the best way the measure changes in nerve function, as well as developing models to identify risk factors and interventions to treat symptoms. So far, more than 500 people treated with chemotherapy and other cancer drugs have participated in these studies at research sites across Sydney including the Chris O'Brien Lifehouse, Royal Prince Alfred Hospital, Prince of Wales Hospital and sites in North Sydney. While the final results are still being collected, we completed an analysis of interim results to investigate long term characteristics of CIPN and compare patient-reported symptoms to objective nerve assessment.

Patients with varying cancer types (including multiple myeloma, breast cancer and bowel cancer) completed nerve assessments prior to starting their treatment, and then 3 months and 9 months after completing their final

treatment. At the 3-month follow-up, patients reported significantly more nerve symptoms in both the hands and feet than prior to treatment. Symptoms were described as "quite a bit" or "very much" numbness and tingling by 24% of patients in the hands and 39% in the feet. Furthermore, 26% of patients reported painful nerve symptoms. Objective measures of nerve function matched these patient reports, with reduced performance recorded in both the hands and feet on objective assessments of sensation compared to pre-chemotherapy levels. A task called the grating orientation task was used to measure sensation in the fingers and the 2-point discrimination task was used to measure sensation in the toes.

At the 9-month follow-up, patients reported improvements in neuropathy symptoms in both the hands and feet compared to the 3-month follow-up. However, 64% of patients still reported symptoms. Symptoms were now described as "quite a bit" or "very much" by 7% of patients in the hands and 21% in the feet. Interestingly, measures of sensation in both the hands and feet showed no significant improvements from the 3-month follow-up.

This suggests that while some patients report significant improvement in neuropathy symptoms by 9-months post chemotherapy, these improvements may be due to patient adaptation to symptoms rather than specific improvements in nerve function. This means that education and interventions to aid adaptation are vital to ensure patients with neuropathy are able to maintain function and quality of life. Development of improved assessment tools will enable better identification and

measurement of neuropathy and lead to improved outcomes following cancer treatment. This research will help to develop interventions to treat the symptoms of neuropathy, with the eventual aim to develop strategies to prevent neuropathy from developing following cancer treatment.

The IN FOCUS research group would like to thank all of the patients who have participated in the research to date as well as doctors and nurses for their continuing support. We are continuing to recruit participants who are either about to commence their treatment (bortezomib (Velcade) or thalidomide), or have completed in the last 5 years. If you are interested in participating in our study, visit <http://www.infocusstudy.org.au/>, call Hannah on (02) 9351 0701 or email at hannah.timmins@sydney.edu.au. For those not based in Sydney, there is an online survey about neuropathy, which is available at: <http://www.infocusstudy.org.au/survey>.

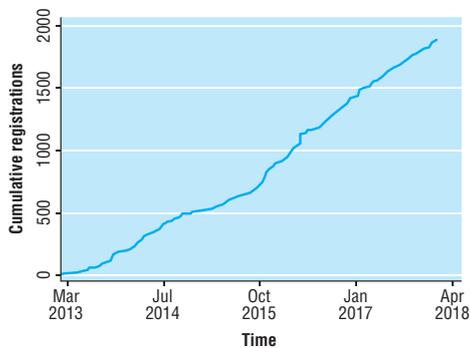
For more information on peripheral neuropathy, the patient guide 'Managing Peripheral Neuropathy: A guide for people with myeloma' is available from the Myeloma Australia website. ●

Tiffany Li

NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

2017 marked a year of significant growth for the registry and we expect a very positive and productive 2018. Below is a summary of our activities.

Participation: Recruitment has reached over 1900, with more than 1250 multiple myeloma (MM) and 520 monoclonal gammopathy of undetermined significance (MGUS) patients recruited from 27 hospital sites. Fourteen new sites have approval pending. The MRDR is also becoming more representative of regional hospitals and the private sector.



Data Linkage: Our first linkage with the Australian National Death Index (NDI) was performed in 2017. Mortality is a key outcome with potential for loss to follow-up, and linking with the NDI ensures its accuracy. Linkage with the Victorian Cancer Registry was also conducted and we are in the process of assessing MRDR case capture for MM in Victoria. These are key data quality measures supporting the MRDR.

Presentations at key state (1), national (6) and international (3) meetings were made in 2017 on diagnostics and treatment, renal impairment, stem cell transplant, outcomes for people of Pacific Islander ethnicity, and patient-reported outcomes. Manuscripts on renal impairment and stem cell transplantation in MM are in progress.

SUBSTUDIES

The Myeloma 1000 project has reached 214 patients enrolled (100 MM: 114 MGUS) and is the only prospective fully annotated 'liquid biopsy' biobank in the world. This study leverages the MRDR database to link biological data with clinical data to better predict treatment response and identify patients at risk of developing MM or disease progression.



Myeloma 1000 Project: blood is taken at sites, sent to the Alfred Hospital campus, processed, then freeze-stored

It involves recruitment of 1000 MM and 1000 MGUS patients pre-treatment. There is a once-only blood collection after consent and sites receive a \$150 per patient payment. We are expanding site participation – please let us know if your site would like to join us!

IMPROVE (Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology) is a registry-based study funded by the National Blood Authority through to 2020. It will describe immunoglobulin use in MM, including variation in practice. Results will inform policy and clinical practice related to immunoglobulin therapy in these patients.

My-PROMPT is a multicentre pilot randomised trial to test the feasibility of real-time reporting of patient-reported outcomes to clinicians treating patients with MM to improve care. It targets newly diagnosed patients within 7 days of starting first treatment. Recruitment is underway. Takeda and Gilead fund this study.

INTERNATIONAL COLLABORATIONS

Asia-Pacific expansion of the MRDR will receive funding from Janssen. Korea is the first pilot site in this process, then Singapore, Hong Kong and Taiwan. The MRDR team look forward to collaborating with regional colleagues and the opportunity to study patient characteristics, treatment and outcomes in each country.

Collaborations with sister registries in Austria (comparing diagnostics, access to care and first-line treatment) and Korea (comparing bortezomib- versus thalidomide-based first-line chemotherapy) are ongoing, led by PhD student, Dr Krystal Bergin.

International industry collaborations – The Takeda Global Insight Registry group (USA) and Celgene Connect® MM registry group (USA) have expressed interest in collaborating with the MRDR. The Amgen Centre for

Observational Research (USA) has requested a preliminary report of aggregate MRDR data to guide future potential collaboration.

THE AUSTRALASIAN MYELOMA RESEARCH CONSORTIUM (AMARC)



AMARC uses the MRDR as a platform for early-phase clinical trials, and recruitment to the first AMARC trials is underway. The MRDR's infrastructure including data collection system and established national network of sites make it an attractive platform from which to cost-effectively conduct clinical trials.

ENGAGING WITH COLLABORATORS

The 5th annual MRDR Interest Group breakfast meeting was held in Sydney, Oct 2017 at HAA, the key haematology meeting for Australia and New Zealand. The breakfast was well attended with strong representation from sites, patient groups, and industry partners. It provided a great opportunity to showcase the registry and engage with current and new collaborators.

We look forward to a dynamic and productive year in 2018. Thank you to participating patients and sites for your support and enthusiasm – the MRDR depends on you for its continued progress! We also thank our funding partners for 2017: Monash Partners Advanced Health Research Translation Centre, National Blood Authority, Amgen Inc., Celgene Pty Ltd, Gilead Sciences Pty Ltd, Janssen-Cilag Pty Ltd, and Takeda Pharmaceuticals Australia Pty Ltd. We appreciate your support.

TO CONTACT THE MRDR:

Phone: 1800 811 326
Email: sphpm-myeloma@monash.edu
Website: mrd.net.au

“Information is Power”

Royal Prince Alfred Hospital Myeloma Patients and Family Seminar

“Information is power”, so said Francis Bacon, 16th Century philosopher and father of scientific method. Sir Francis Bacon advocated that information was critically important in helping us understand and gain knowledge. We know this is of particular importance in modern day where the amount and pace of information available to us, fueled not least by the internet, can be useful in helping us make choices. In some cases, the internet (Dr Google!) can be a burden as we are able to access vast amounts of information and have to develop skills in interpreting that information. Is it accurate? Does it apply to me? Getting the right amount of up to date, relevant and accurate information, is more important than the volume of information.

In healthcare, we know that patients, family and friends are seeking more, increasingly detailed health-related information. We know also that being an active, informed participant in your own health care is beneficial in many



a large part of our jobs providing information and helping people understand myeloma, its treatment and a range of strategies that can help people live better. A highlight of the year for us, is our annual ‘Myeloma Patient & Family Seminar’, held at the Kerry Packer education center at RPA. Late last year Eleanor Romney (RPA myeloma CNC) and myself, with the help of many members of our ‘Living with Myeloma Group’, (not least Lois Wilson, raffle manager extraordinaire!) hosted an event for over 200 people affected by myeloma. We were able to video link direct to satellite sites in Geelong, Traralgon and Canberra and in such, ensured those not able to attend in person were able to join us for the day. The goals of the day included the provision of educational lectures covering a range of topics focusing on the management of myeloma; providing access to patient support groups (Myeloma Australia, Leukaemia Foundation & Cancer Council) and facilitating communication and informal support that comes from bringing a large group of people with shared experiences together.

The Institute of Haematology RPA has a particular focus on managing myeloma and we are blest with a range of expert researchers and clinicians we could draw upon to participate in the day. Dr Ashley Campbell set the scene with an introduction to the blood system and myeloma. She described the features of myeloma and how it may



Dr Claire Weatherburn



Eleanor Romney Myeloma CNC

ways. It helps promote healthy behaviors, informs treatment discussions and decisions in partnership with your health care team and overall improves the effectiveness of clinical care. It is widely established then, that helping patients and their families stay up to date and informed about their health conditions (including myeloma) is an important role for all of us. Myeloma Australia’s work focuses, in many ways on ensuring patients and families are kept up to date with all aspects relating to myeloma. This MyeNEWS is a great example of that important work.

As Clinical Nurse Consultants (CNC) in myeloma, we spend

impact the body, describing complications of the bone, blood and kidneys. Dr Clarie Weatherbrun followed on with a talk on how myeloma is treated using treatments we can readily access on the PBS. She was able to make what can be a complicated range of options, seem clearer to those attending. Dr Jane Estelle from Concord hospital, followed on with a talk on how we treat myeloma when it comes back. She discussed best practice in treating myeloma from relapse and also described the important role clinical trials have in accessing new drugs and testing drugs/combinations. The information learnt from clinical trials (studies) allow

researchers and clinicians to understand how to improve the treatment of myeloma and improve outcomes for those affected by myeloma. Prof Joy Ho also discussed clinical trials and focused on novel drugs that target myeloma in new and improved ways. She was able to share her vast experience in myeloma research and data from studies ongoing within Australia but also in other countries. Monoclonal antibodies such as Daratumumab, Elotuzumab and Isatuximab were presented with results looking particularly promising. Emeritus Prof Doug Joshua presented a look into the future of myeloma treatment, discussing research that explores how the body's own immune system may be manipulated to respond to kill its own cancers and how this is fueling new immune approaches such as CAR-T cell therapies.

Balancing all the important drug and immune research we also had a range of speakers talking about supportive care. Dr John Chalmers, Clinical Psychologist RPA spoke about coping and managing uncertainty that comes with a diagnosis of myeloma. Sharing some strategies that can help patients and families cope better with the psychological impact of a myeloma diagnosis. John was able to normalize the importance of looking after your psychological self, with many participants sharing positive experiences of seeking counselling support. Eleanor Romney (MM CNC) presented a session 'Learning to live well with myeloma', exploring some of the important strategies such as being informed, maintaining physical and emotional fitness and utilizing a 'team' approach to managing your health. The patient groups were also then able to update participants to the wide range of excellent support programs and resources they have available to help people affected by myeloma. Dr Haryana Dhillon, senior researcher at Sydney University presented their research on fatigue in those with cancer, including myeloma. Exploring what we understand about fatigue, why it is so common and more importantly, some of the strategies to help manage fatigue.

Evaluations from those who attended were overwhelmingly positive. Much was learnt and shared on the day, funds were raised for local research and prizes galore were won in the process. Particular thanks go to all the speakers for giving of their time so generously. To the patient groups who attended and shared their good work and the patients and family

members who helped us with planning, administration, raffle and clearing up at the end. To the nurses and patient groups who facilitated in Geelong (Jenny Hempton, Elli Foley), Traralgon (Laura Jones) and Canberra (Deidre Mathis, Lexi Walker). We also thank Celgene, Janssen and Takeda for their support of catering and technology on the day.

In summary, I encourage each and every one of the MyeNews readers to continue in your pursuit of being an informed health consumer. We should all take the time and responsibility to seek out reliable information to help us manage living well with myeloma.

A range of useful myeloma related websites is available at the back of the Myeloma Comprehensive Guide – available on Myeloma Australia website.

Some commonly used sites are also listed below.

www.myeloma.org.au

www.myeloma.org

www.myeloma.org.uk

www.themmrf.org

www.leukaemia.org.au

www.cancer.org.au (www.iheard.com.au)

www.carersaustralia.com.au

www.humanservices.gov.au

(Centrelink and Medicare services)

Clinical Trials

www.anzctr.org.au

www.australianclinicaltrials.gov.au

www.clintrial.org.au

www.eviq.org.au

(Cancer Institute NSW cancer treatment protocols)

Tracy King

Myeloma Clinical Nurse Consultant Royal Prince Alfred Hospital, Sydney. Clinical Research Fellow, Cancer Nursing Research Unit, Sydney University

The Myeloma Muster

The Myeloma Muster is your monthly round up of news from Myeloma Australia.

Filled with the latest information on what's what in the myeloma community, from fundraisers across the country, latest medical information, updates on Support Groups and much more. If you would like to be added to the list for this email only newsletter, please contact us at support@myeloma.org.au or on P: (03) 9428 7444.



A team from Myeloma Australia visited Atlanta USA in December 2017 as invited guests of the International Myeloma Foundation (IMF). This gave us the opportunity to attend the world's biggest haematology event, and many other meetings and events that were attached to it, as well as meet with myeloma support organisations from all over the world.

The American Society of Hematology held their annual conference in Atlanta from the 9th to the 12th December 2017. Myeloma Australia staff Steve Roach, Hayley Beer, Nella Combe and president Brian Rosengarten attended as guests of the IMF.



Nella, Steve, Hayley & Brian.

The medical and scientific program were jammed packed with myeloma talks and abstracts and we attended many sessions covering a wide variety of myeloma disease and treatment information presented by world renowned clinicians and researchers. Maria V Mateos, Peter Sonneveld and Shaji Kumar presented an interesting session entitled 'Novel Therapeutics in Myeloma' covering the role of transplant in an era of more treatments becoming available, tailoring treatments according to the persons level of fitness or frailty, the types of immune therapies currently in trials and the different ways that they work. Another great session was 'Controversies in myeloma' presented by Ola Landgren, Faith Davies and Heinz Ludwig discussing topics such as should we treat people with smouldering myeloma, should minimal residual disease (MRD) negativity be the goal of treatment and if so how should it be used in the clinic as well as weather treatment should be fixed or continuous in



duration. We also attended abstract presentations on myeloma biology, CART cells, MRD, immune therapies and antibiotic prophylaxis to name a few. At the exhibition hall we filled our bags with educational resources for our support nurses and got loads of ideas about how we can improve our resources back home. We watched 3D videos of how the immune therapies work and not

surprisingly the best coffee there was made by an Aussie!

Aside from the conference itself, we attended a number of other meetings and events. We met with other myeloma support and advocacy organisations at the 'Global Myeloma Action Network (GMAN)' meeting. With representatives from USA, Canada and Europe we discussed global issues such as drug access and costs, awareness and access to reliable information. We began planning our projects and collaborations for the next twelve months with all members of the GMAN group.

On our way to the next meeting, the 'IMF Satellite Symposium' snow began to fall in Atlanta, a rare occurrence, especially for December. The theme of the symposium was 'Getting Clear Answers to Complex Treatment Challenges in Multiple Myeloma' and the panel consisted of 'myeloma royalty' Brian Durie, Phillippe Moreau, Jesus San Miguel, Bruno Paiva and S Vincent Rajkumar. They presented case studies and information on a topic each with interactive live voting and discussion about choices and preferences.

We woke early the next morning for the International Myeloma Working Group (IMWG) breakfast meeting and Atlanta had been transformed into a winter wonderland. So much snow!

We got to hear abstracts handpicked from the ASH program presented and discussed before the meeting had officially opened as well as the upcoming IMWG projects which include imaging guidelines, renal failure guidelines and bone prophylaxis. We couldn't resist a walk in the snow to our next meeting which was an inspiring and thought-provoking talk at the Celgene Patient Partners event. The theme was 'Achieving the extraordinary through imagination and ambition' and the keynote speaker Brian Reich addressed a room of 100 people from advocacy and



Atlanta.



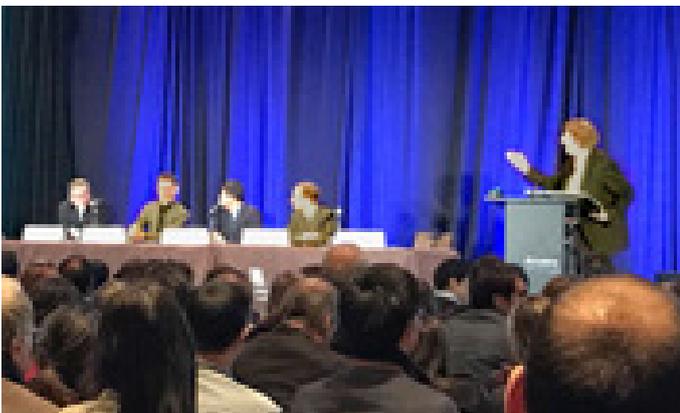
So much snow!



ASH conference.



IMWG breakfast.



IMF Satellite Symposium.

support organisations from around the globe. Unfortunately, he was unable to attend in person as his flight had been cancelled due to the snow so he presented via video link the importance of imagination in the work that we do and fostering a work environment that encourages imagination and creativity and focuses on the 'can' instead of the 'cannot'.

In the evening we attended the IMF's Brian Novis Research Grant reception where we listened to four people share their story living with myeloma. Each story was different and moving, we celebrated together with their support network their achievements and their hope for the future.

Several grants were awarded to researchers in the myeloma field from fundraising events during the year. A researcher from Brisbane, Dr Jacqui McGovern was a recipient for her work developing a humanised animal model to be used in the future to develop new therapeutic strategies in myeloma.

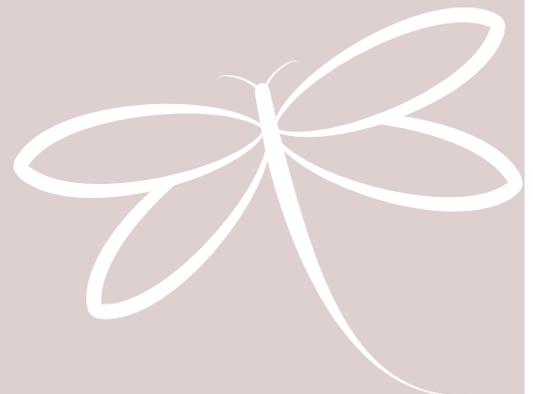
Each of us who attended found the trip to be very beneficial and gained a lot from the educational opportunities and meeting with other myeloma organisations from around the world. Thank you to the IMF for hosting us and we look forward to sharing information and resources that we brought back at our support groups and seminars throughout the year.

Nella Combe
Manager Nursing & Patient Services

Myeloma Support Line

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

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



South Australian Report



David Cleghorn.

Our last meeting for the year was Fullarton's December and Christmas meeting on December 5th. Our favourite dietitian, David Cleghorn was informative and entertaining again and gave an excellent presentation on all dietary issues for patients and carers.

All cancer patients, but myeloma patients in particular, have many dietary issues while going through treatment. He emphasised that it is crucial that you don't lose weight at a time when you need calories to maintain organ function and energy while the drugs are attacking the body. If the body doesn't get the nutrients it needs from food, it can rob regions of the body for the nutrients, thus putting the organs and bones at risk. For that period, it is acceptable to eat some undesirable fatty foods, like "junk food" as well as the good food, as long as you EAT!

Once you are in stable health, follow the guidelines of a healthy diet and have a variety of foods, regular 3 meals a day, increase the plant foods, fibre, calcium & iron, while decreasing the saturated fats, sugar and salt. 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, but as calcium intake only lasts about 6 hours in your digestive tract and your body needs a constant supply, while you sleep, your body will look elsewhere for a ready source, which usually means from your bones.

The day finished on a high note with the Christmas Raffle raising \$760 which was much appreciated.



Alison Lorenzen.

The topic for the February meeting was Exercise, so we had Alison Lorenzen from Calvary Rehab. talk to us mainly about how it is important for myeloma patients to stay active and exercise regularly because exercise has been proven to help treatment and minimize some of the side effects of the chemotherapy drugs, such as fatigue, tiredness and muscle issues. She also

demonstrated a few exercises that anyone could do at home and explained the many exercise facilities you can attend now to get expert help to improve your fitness.

The Flinders Support Group had their second meeting in November, which was just as successful as the first. Jenny Naylor has agreed to be the Group's Coordinator and their next meeting will be on Thursday, March 15th, 2018, as it was agreed not to have a meeting in January.

After the success of the Mid-North's Regional Seminar in November, their next meeting will be a quieter event on Thursday, February 15th 2018.

It will be a general get together.



South East Regional.

The South-East Support Group had a very successful Regional Seminar in February with David Cleghorn doing the same dietary presentation he gave at Fullarton in December. The second speaker was Peter Westley, a lawyer from Naracoorte, who was very informative on the subject of Enduring Power of Attorney and Medical Power of Attorney, or as it is now called, 'Advance Care Directive'. He emphasized how important it is to have your affairs in order, especially if you have a disease like myeloma. You never know what is going to happen and you need to find one or two (preferably) people you trust to carry out your wishes if you are either away or medically unable to do them yourself.

Myeloma Australia is going to be very busy this year and South Australia is no exception with plans to expand our services here in South Australia.

Ian Driver

SA Chairman

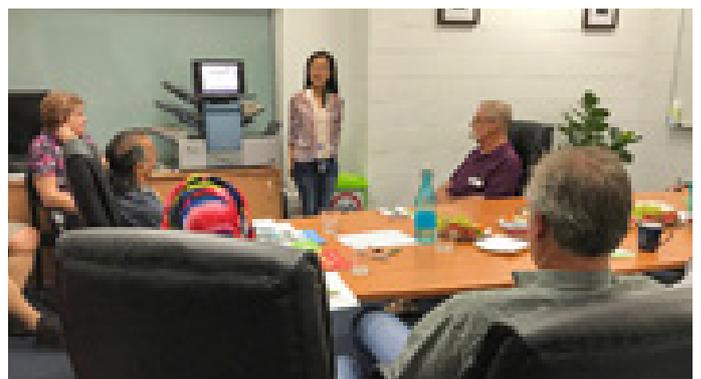
T: 08 8556 6041 M: 0417 874 252

E: sandrian7@bigpond.com

Nurse Report

Whilst Ian will report on our local support group and seminar activities, I'd like to let you know about the nursing activities in SA and NT.

In October last year SA health moved the old RAH down North Terrace to the new site at the western end of Adelaide. Things are slowly settling down but the upheaval has interrupted our education service within the local hospitals



Dr Hang Quach in Darwin.



Dr Hang Quach in Darwin.

as all our SA hospitals have shared an increased workload to accommodate the move. In-service education has therefore been on hold for a few months. However, planning is well underway for the HSNZ Myeloma Nurse Special Practice Network 2018 Annual National Seminar to be held on Friday Aug 24th. More about this event in our next edition.

Our commitment to provide on the ground services to Darwin is increasing and on 15th February Nella Combe kindly went to Darwin on my behalf as I was on leave.

Dr Hang Quach and Nella held an informal information session using a question and answer format for approximately 15 attendees. In the evening, Nella spoke at a dinner attended by doctors, nurses and allied staff looking after myeloma patients living in NT, about the support and advocacy services Myeloma Australia offer.

Our 2 new support nurses in Perth are settling in well and as part of our staff training and mentorship program, I went to Perth at the end of January. MA recognises how important the support is for our staff Australia wide which in turn helps them provide quality support for our members.

All our nurses are participating in our current review and update of the information we provide via our fact sheets. This is advancing well and should be available on our website very soon.

I am away in February on holidays in New Zealand, walking and kayaking. I'm looking forward to this holiday and will be back on deck in early March.

Jo Gardiner
Senior Myeloma Nurse Specialist

photo supplied and used with permission

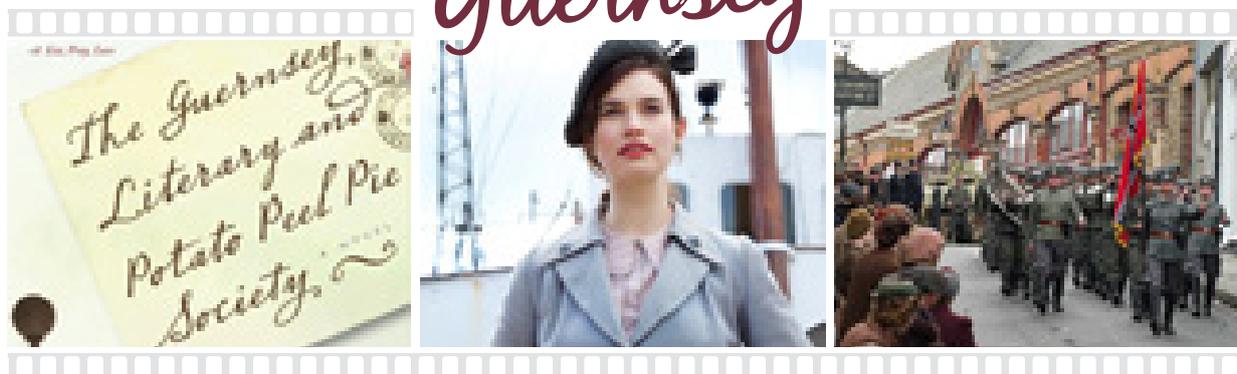


CENTRAL COAST MYELOMA SUPPORT GROUP
9th Movie Night Fundraiser
THURSDAY 19TH APRIL 2018
 6.30pm wine and light supper • Movie starts 7.30pm

Tickets only \$25!

Great Raffle Prizes!

Guernsey



Tickets available from the theatre booking office on P: (02) 4382 1677 or call Wendy on M: 0419 280 760



Victorian Report

With a busy end to the year here in Victoria, a warm break over Christmas was just what the doctor ordered before we swing back into a bright and busy 2018.

Information seminars were a-plenty towards the tail end of 2017. In November, our Latrobe day ran as well as ever. Almost 100 guests enjoyed greeting old, and meeting new faces, before hearing from Professor Miles Prince and Occupational Therapist Andrew Smith. The presentation was video-linked regionally to Bendigo, where Elli met with a group to watch the presentations, and discuss the content together. In December, Elli worked alongside the Leukaemia Foundation at the Andrew Love Centre in Geelong. Together they enjoyed supporting over 25 guests viewing the video-stream event from RPA in Sydney. Unfortunately record rainfall put a dampener on our Traralgon video-stream, we look forward to meeting people again at our next support group there in February.



Monash Seminar.

We welcomed in the year with an exciting information day at Monash Health, the first of hopefully many in collaboration with Monash medical and research teams. Over 70 guests enjoyed hearing from Dr George Grigoriadis, Dr

Michael Low, and Associate Professor Jake Shortt, and were treated to a tour of Monash myeloma research facilities after lunch. Information and support groups continue to grow, with a hopeful south-eastern support group blossoming over the upcoming months.

Kew members enjoyed themselves at a social Christmas lunch at the Skinny Dog Hotel in December, before meeting again in February. Mary Di Iorio, a musculoskeletal physiotherapist and Director of Restore Physiotherapy, was delighted by the applause following her fantastic presentation on clinical pilates and safe exercise for those with myeloma bone disease. We had a laugh as we used Thera-bands and tried



(L-R) Helen Chapman, Laura Jones and Jill Stansfield, Kew Support Group Xmas Lunch.



(L-R) Laura Jones, Dr George Grigoriadis, Dr Michael Low, A/Prof Jake Shortt & Elli Foley.



Elli Foley with gift hamper from Beaumaris Support Group & Xmas Lunch.

practicing some of her techniques, before enjoying morning tea together.

Coburg started the year with a new meeting room, and a few new members. We used the new year to reiterate some of the key values the group holds, as we built a group agreement. The topic of the month was trials, and we explored what might be involved when on a clinical trial, as well as trial resources and availability.



A/Prof Jake Shortt (Monash Seminar).

Warragul met for dinner in January at Middels in Drouin, with a few new faces. Supportive group leader Bernard lead discussion, making for a great night out.

Traralgon looks forward to meeting on the 21st February at their new home, the Gippsland Rotary Centenary House. All are welcome to join in conversations on "dealing with Dexamethasone" and some morning tea, as this group continues to grow.

Myself and Elli continue to meet with the Younger Persons group, who enjoyed dinner in November at our head office in Richmond. The large group discussed the challenges of traveling with myeloma. We shared information on reciprocal healthcare, travel insurance, medications, and tips to make holidays run smoothly. We look forward to meeting again in February with Support Nurse Manager Hayley leading a discussion on recent changes within the PBS.

Elli continues to support our Beaumaris, Geelong, and Mt Eliza information and support groups. They enjoyed Christmas lunches in December, and have met again welcoming new members in 2018. Special thanks to Beaumaris, who's annual raffle raised over \$500 for Myeloma Australia.

With the support of our wonderful volunteers Linda and Catherine, we continue to supply resources to hospitals who treat myeloma. The two visited Western locations in December, dropping off comprehensive guides, peripheral neuropathy management tools, support group magnets, and our new referral form. If you, or somewhere you know needs resources, we'd love to hear from you.

Laura Jones
Myeloma Support Nurse

Western Australian Report

What an amazing few months it has been in Western Australia. Since coming on board in October 2017, we have hit the ground running. It was fabulous to meet over 20 patients and their families at our first meet and greet morning tea which was held in a beautiful old house in Nedlands in December with a number of attendees travelling a long distance to the event. We really enjoyed the opportunity to chat one on one with everyone and to gather ideas and suggestions for future patient events here in the West.



Narelle and Kerin at the Meet and Greet.

We have also been meeting with health care professionals, and haematologists to promote the Myeloma Support Nurse role and patient support services here in WA. Over the next few months, we

hope to provide comprehensive myeloma information and resources into each of the cancer treatment centres in the Perth metropolitan area and regional centres.

In the early weeks of 2018, we have spent much time planning events for the year and working towards setting up some patient support groups in the greater Perth metropolitan area.

In the northern suburbs, the first support group will be held on Monday, 5th March from 1.00-3.00pm in the meeting room at Butler Community Centre, 55 Knightsbridge Boulevard, Butler. These support groups will be held on the first Monday of each month, alternating between an afternoon and evening timeslot to allow for those wishing to attend who are also working. Contact Narelle for queries and RSVP: narelle.smith@myeloma.org.au.

In the southern suburbs, the first support group is planned for Monday 26th February from 1.00 – 3.00pm at the Mandurah Seniors and Community Centre, 41 Ormsby Terrace, Mandurah. Contact Kerin for queries and RSVP: Kerin.young@myeloma.org.au.

We will be collaborating with the existing Leukaemia Foundation Myeloma Specific Support Group conducted on the first Friday of the month at the Osborne Park Community Centre. Contact the Leukaemia Foundation for further details.

Excitingly, we have also planned our first regional Meet and Greet morning, planned to take place on



Drabble House.

19 March, 10.30am-12.30pm at Dots Place, Forrest Avenue in Bunbury. We would love to welcome patients and their families to attend and meet with us both. All queries and RSVP to Kerin email: kerin.young@myeloma.org.au.

With May being National Myeloma month, we have been working in the initial planning stage of creating an exciting, informative patient seminar. Watch this space for further details as they come to hand.

Finally, we are excited to share that Myeloma Australia will have a "Team Myeloma" for the HBF Run for a Reason, being held on May 27th 2018. Everyone is encouraged to sign up and join Narelle, Kerin and other members of the Myeloma Australia team to either walk or run 4km, 12km or 21km. Follow the link (<https://hbfrun2018.everydayhero.com/au/team-myeloma>) to support this worthwhile fundraiser, the first of its kind for Myeloma Australia in WA for 2018.

*Kerin Young and Narelle Smith
Myeloma Support Nurses*



Treatment:

Flavopiridol enhances ABT-199 sensitivity in unfavourable-risk multiple myeloma cells *in vitro* and *in vivo*

Zhou L et al; *British Journal of Cancer*, Published online: 14 December 2017

Venetoclax (ABT 199) has been reported to be principally active against favourable-risk multiple myeloma (MM) cells, prompting efforts to extend its activity to include more resistant, higher-risk MM subsets. The findings argue that CDK9 inhibitors, for example, Flavopiridol may increase the anti-myeloma activity of Venetoclax (ABT-199), including in unfavourable-risk MM minimally responsive to Venetoclax (ABT-199) alone.

Treatment:

Daratumumab plus Bortezomib, Melphalan, and Prednisone for Untreated Myeloma: In this article, we report a pre-specified interim analysis of this randomized, phase 3 trial (ALCYONE) of bortezomib, melphalan, and prednisone with or without daratumumab in patients with newly diagnosed multiple myeloma who were ineligible for autologous stem-cell transplantation.

Mateos M et al. *New England Journal of Medicine*, December 12, 2017 DOI: 10.1056/NEJMoa1714678

In this phase 3 trial, daratumumab added to bortezomib, melphalan, and prednisone resulted in significantly longer progression-free survival than bortezomib, melphalan, and prednisone alone and saw a 50% lower risk of disease progression or death among patients with newly diagnosed multiple myeloma who were ineligible for stem-cell transplantation.

This planned interim analysis supported the primary analysis, showing significant differences in the depth of response. Rates of complete response and of stringent complete response was nearly twice as high in the daratumumab group as in the control group. However infusion-related reactions were seen in the daratumumab group which also had more infections, including a higher rate of pneumonia (which did not result in higher rates of discontinuation or death). The usual chemotherapy-related toxic effects were not increased by the addition of daratumumab. Rates of MRD negativity in this study were three times higher in daratumumab arm.

Treatment:

Single center experience in treating patients with t(4;14) multiple myeloma with and without planned frontline autologous stem cell transplantation

Chan H et al. To appear in: *Clinical Lymphoma, Myeloma and Leukemia*; Accepted Date: 29 December 2017

This study is one of the few published report specifically focused on patients with t(4;14) MM in the era of novel agents with a reasonable sample size for this patient subgroup. Even in the era of novel agents, t(4;14) remains a negative prognostic marker for patients with MM, and the

prognosis is further worsened with the addition of del(17p). ASCT remains an essential tool in the treatment of patients with t(4;14) MM, and frontline ASCT following bortezomib-based induction provide a better PFS and OS than chemotherapy alone. Although it may be possible to defer ASCT to second line treatment without adversely affecting the OS, not all patients will still be transplant eligible at the time of relapse. Further prospective studies are needed to address this issue of frontline versus deferred ASCT.

Treatment:

Daratumumab: A Review in Relapsed and/or Refractory Multiple Myeloma

Blair H A *Drugs*. 2017 Dec;77(18):2013-2024. doi: 10.1007/s40265-017-0837-7

Intravenous daratumumab (DARZALEX®) is a monoclonal antibody against CD38 available for use in patients with relapsed and/or refractory multiple myeloma (RRMM). In phase I/II and II trials and a pooled analysis of these studies, daratumumab monotherapy achieved an overall response (partial response or better) in approximately one-third of patients; responses were rapid, deep and durable. An overall survival (OS) benefit was seen with daratumumab monotherapy, including in patients with a minimal response or stable disease. In phase III trials, daratumumab in combination with either bortezomib plus dexamethasone or lenalidomide plus dexamethasone significantly prolonged progression-free survival and induced deep and durable responses compared with bortezomib plus dexamethasone or lenalidomide plus dexamethasone. An OS benefit with daratumumab triple combination therapy is yet to be demonstrated (as the OS data were not mature at the time of the last analysis). Daratumumab was generally well tolerated when used as monotherapy and had a generally manageable tolerability profile when used in combination therapy. Infusion-related reactions (IRRs) were the most common adverse events; these were predominantly grade 1 or 2 and mostly occurred during the first infusion. The most common grade 3–4 adverse events associated with daratumumab triple combination therapy were thrombocytopenia, neutropenia and anaemia. Although final OS data are awaited, current evidence indicates that daratumumab is a valuable addition to the treatment options currently available for patients with relapsed or refractory multiple myeloma.

Supportive Care:

Denosumab versus zoledronic acid in bone disease treatment of newly diagnosed multiple myeloma: an international, double-blind, double-dummy, randomised, controlled, phase 3 study

Raje N et al. Published: 08 February 2018; *The Lancet Oncology*

Denosumab, a monoclonal antibody targeting RANKL, reduces skeletal-related events associated with bone lesions or metastases in patients with advanced solid tumours. This study aimed to assess the efficacy and safety of denosumab

compared with zoledronic acid for the prevention of skeletal-related events in patients with newly diagnosed multiple myeloma.

In patients with newly diagnosed multiple myeloma, denosumab was non-inferior to zoledronic acid for time to skeletal-related events. The results from this study suggest denosumab could be an additional option for the standard of care for patients with multiple myeloma with bone disease.

2017 Top Stories in Oncology: Multiple Myeloma

Written by Rafael D. Fonseca MD Published in Oncology, Expert Opinion / Commentary · December 15, 2017

What a year it has been for multiple myeloma! It is hard to believe how fast the pace of research has been. Just 1 year ago, we were all delighted to know that daratumumab in combination with various other drugs (eg, lenalidomide) would result in very profound disease control in recurrent disease. Daratumumab was the “belle of the ball.” A year later and we have very active new tools. Most notable are the CAR-T cells as myeloma therapeutics. While other targets are attractive for potential CAR-T-cell development, most of the early success has focused on the cell surface molecule BCMA. BCMA is ubiquitously expressed in myeloma, albeit at various densities. Other targets such as SLAMF7 and CD19 are also being explored. One clinical trial presented at the American Society of Clinical Oncology Annual Meeting demonstrated that the response rates obtained in patients with relapsed or refractory myeloma were truly unprecedented (100% ORR).¹ This trial, carried out by a Chinese biotech company Nanjing Legend, demonstrated responses in a small series of patients with advanced myeloma, many of whom achieved a complete response. Some of these patients had extensive extramedullary disease and had progressed on all known therapeutics for the disease. A similar study, conducted by Bluebird (Celgene) and presented at the annual meeting of the American Society of Hematology, demonstrated an impressive overall response of 94%, with 56% complete response rate.² Progression-free survival had not been reached at a median follow-up of 40 weeks, and an MRD-negative status was obtained in 9 out of 10 patients tested. Responses have been ongoing for as late as 15 months. And this is just the beginning.

Many questions remain regarding the optimal time to use these new therapies, and whether some of them could eventually replace standard treatments such as autologous stem cell transplantation. However, the competitive field is quite crowded. Several companies are working in this arena developing other CAR-T-cell constructs, and others are actively pursuing development of bispecific antibodies. Hang on to your seats as the ride will be fast!

Case Report:

Deep sustained response to daratumumab monotherapy associated with T-cell expansion in triple refractory myeloma

Usmani SA et al. *Experimental Hematology & Oncology* 2018

A male patient, 70 years of age at diagnosis of multiple myeloma in 2011, relapsed after five lines of therapy, including autologous stem cell transplantation. The patient’s disease, was considered high risk with a deletion of chromosome 17p and advanced quickly and was triple refractory 2 years after diagnosis leaving few treatment options. He was treated with daratumumab monotherapy in the SIRIUS clinical trial resulting in a stringent complete response and clearance of minimal residual disease. The duration of the patient’s clinical response is now over 3.5 years without relapse, compared with a median of 7.6 months for similarly treated patients. The patient’s immunophenotype revealed CD8+ T-cell expansion, clonal expansion of the T-cell receptor repertoire, and decreases in regulatory T cells during daratumumab therapy, suggesting a robust adaptive immune response. This immune response was still present 32 months into daratumumab therapy.

The results from this case report showed that a patient with advanced multiple myeloma, who had exhausted all treatment options with existing regimens, mounted an ongoing, deep, and durable response to daratumumab monotherapy. Further investigation of the immunologic profile provided additional patient-level evidence of an immunomodulatory mechanism of action of daratumumab.

Australian Pharmaceutical Benefits Advisory Committee (PBAC) Update:

The PBAC met in November 2017 to review the most recent applications for new drugs or amendments to the prescribing rules for existing drugs; four myeloma drugs were reviewed.

CARFILZOMIB (Kyprolis®)

You may recall in August in edition 7 of the Myeloma Muster we announced that the PBAC had made a positive recommendation that carfilzomib (Kyprolis®), a proteasome inhibitor in the same family as bortezomib (Velcade®) be used in combination with dexamethasone for patients who have failed at least one prior line of therapy.

We are now pleased to announce that as of 1 January 2018, carfilzomib (Kyprolis®) is available for reimbursement on the Pharmaceutical Benefits Scheme (PBS) for relapsed myeloma.

DARATUMUMAB (Darzalex®)

The PBAC reviewed an application for a new monoclonal antibody therapy, daratumumab (Darzalex®) to be included on the PBS in combination with bortezomib (Velcade®) or lenalidomide (Revlimid®).

Myeloma Australia invited you to provide consumer comments to add strength to the application. The PBAC welcomed these comments and took them into consideration when making their decision however decided not to recommend daratumumab (Darzalex®) for reimbursement at this stage.

It is quite common for drugs to go before the PBAC more than once before gaining approval. The manufacturer will consider the feedback from the PBAC and resubmit the application in due course.

Thank you to everyone who provided their consumer comments. They really do add strength to an application. We will continue to invite you to make submissions to the PBAC when the application is resubmitted for daratumumab (Darzalex®).

LENALIDOMIDE (Revlimid®)

Lenalidomide (Revlimid®) is currently available on the PBS for patients who are newly diagnosed and not eligible for a stem cell transplant or who have progressive disease and have had at least one prior line of therapy that includes thalidomide. The necessity to have thalidomide before gaining access to lenalidomide (Revlimid®) has been counter-intuitive for some patients so the manufacturer (Celgene), with the support of our Medical and Scientific Advisory Group (MSAG), lobbied the PBAC to remove this requirement.

The PBAC have modified the rules for prescribing lenalidomide (Revlimid®) to remove the necessity to have thalidomide before being eligible for lenalidomide (Revlimid®).

Also, previously lenalidomide (Revlimid®) was only available for treatment once. With the new listing it is possible to gain access to treatment with lenalidomide (Revlimid®) a second time if the first treatment was successful.

These positive recommendations are fantastic news for patients needing treatment with lenalidomide (Revlimid®).

The next PBAC meeting is set for March 2018. On the agenda for this meeting is to review an application to

make lenalidomide (Revlimid®) available to patients as maintenance post autologous stem cell transplant. Currently doctors can only prescribe thalidomide (Thalomid®) in this setting which, for some patients, cannot be tolerated long-term. Lenalidomide as maintenance post autologous stem cell transplant will be a huge step forward for improved quality of life and overall survival for people living with myeloma.

Thank you to everyone who made submissions to the PBAC, we will keep you updated of the result once available.

POMALIDOMIDE (Pomalyst®)

Pomalidomide (Pomalyst®) is currently available on the PBS for patients who have progressive disease and have previously failed treatment with lenalidomide (Revlimid®) and bortezomib (Velcade®). This is barrier to patients who would benefit from treatment with pomalidomide (Pomalyst®) but are unable to have lenalidomide (Revlimid®) or bortezomib (Velcade®).

The PBAC have ruled that pomalidomide (Pomalyst®) also be made available to patients with relapsed or refractory myeloma in special circumstances where it is not in their best interests to be prescribed lenalidomide (Revlimid®) or bortezomib (Velcade®) or they have tried either drug and side effects or intolerances mean they cannot continue with that therapy.

These changes will mean a much smoother transition between lines of therapy and again, we will provide an update when they are made available on the PBS.

Information & Support Group Changes

(all changes and additions in the Calendar of Events 2018)

New venue for WESTMEAD

**Wentworthville Leagues Club
Magpie Meeting Room 1
50 Smith Street,
Wentworthville, NSW**



New dates for NEWCASTLE

**Meeting the first Monday
of alternate months**

March 5th
May 7th
July 2nd
September 3rd
November 5th
December (TBC)

New Groups for WESTERN AUSTRALIA

**Northern Information
and Support Group**

Butler Community Centre
Activity Room 2 (meeting room)
55 Kingsbridge Blvd, Butler, WA

**Southern Information
and Support Group**

Mandurah Seniors and
Community Centre
41m Ormsby Terrace, Mandurah, WA

Calendar of Events 2018

Victoria

Event	Date	Location	Time	Organisation	Contact
Mt Eliza Information and Support Group	Thur Mar 15	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30am - 12.30pm <i>(note time change)</i>	Myeloma Australia Head Office	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Berwick Information and Support Group <i>New Group</i>	Fri Mar 23	St John of God Specialist Centre Wellness Room, Level 1 55 Kangan Drive, Berwick	10.am - 12.pm	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Coburg Information and Support Group	Wed Apr 4	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Beaumaris Information and Support Group	Thur Apr 5	Beaumaris Theatre 82 Wells Road, Beaumaris	10am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Kew Information and Support Group	Thur Apr 12	Kew Library Corner Charles St & Cotham Rd, Kew	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Geelong Information and Support Group	Fri Apr 13	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Traralgon Information and Support Group	Wed Apr 18	Gippsland Rotary Centenary House 39 Valley Drive Traralgon Vic	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Younger Persons Information and Support Group	Thur Apr 19	Myeloma Australia Head Office 333 Swan Street, Richmond	6pm - 8pm (Dinner)	Myeloma Australia	Elli Foley & Laura Jones E: elli.foley@myeloma.org.au E: laura.jones@myeloma.org.au
Warragul Information and Support Group	Thur May 10	Rotating at local venue, details published closer to date	6pm - 8pm (Dinner)	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur May 17	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30am – 12.30pm <i>(note time change)</i>	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Coburg Information and Support Group	Wed Jun 6	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Beaumaris Information and Support Group	Thur Jun 7	Beaumaris Theatre 82 Wells Road, Beaumaris	10.am - 12.pm	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Geelong Information and Support Group	Fri Jun 8	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Kew Information and Support Group	Thur Jun 14	Kew Library Corner Charles St & Cotham Rd, Kew	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Traralgon Information and Support Group	Wed Jun 20	Gippsland Rotary Centenary House 39 Valley Drive Traralgon Vic	10am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Jul 12	Rotating at local venue, details published closer to date	6pm - 8pm (Dinner)	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur Jul 19	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30am - 12.30pm <i>(note time change)</i>	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Younger Persons Information and Support Group	Thur Jul 19	Myeloma Australia Head Office 333 Swan Street, Richmond	6pm - 8pm (Dinner)	Myeloma Australia	Elli Foley & Laura Jones E: elli.foley@myeloma.org.au E: laura.jones@myeloma.org.au

South Australia

Event	Date	Location	Time	Organisation	Contact
Flinders Information and Support Group	Thur Mar 15	Living Kuarna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Apr 3	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am - 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)
South East Information and Support Group	Tues May 3	Katnook Estate - Coonawarra (6km north of Penola)	11.30 am - 2.30 pm	Myeloma Australia	Carol Koch E: clk@live.com.au M: 0427 659 014 1800 MYELOMA (693 566)
Flinders Information and Support Group	Thur May 17	Living Kuarna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Mid North Information and Support Group	Thur May 17	Snowtown Hospital 70 Railway Terrace E, Snowtown	12 noon - 2 pm	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Jun 5	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am - 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)
Flinders Information and Support Group	Thur Jul 19	Living Kuarna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)

Western Australia

Event	Date	Location	Time	Organisation	Contact
South West Meet & Greet	Mon Mar 19	Dot's Place South West Cancer Support Centre 62 Forrest Ave, Bunbury	10:30 am - 12:30 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
Southern Information and Support Group	Mon Mar 26	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
Northern Information and Support Group	Mon Apr 2	Butler Community Centre Activity Room 2 (meeting room) 55 Kingsbridge Blvd, Butler	1 pm - 3 pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
Southern Information and Support Group	Mon Apr 30	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
Northern Information and Support Group	Mon May 7	Butler Community Centre Activity Room 2 (meeting room) 55 Kingsbridge Blvd, Butler	1 pm - 3 pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
Southern Information and Support Group	Mon May 28	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
Northern Information and Support Group	Mon Jun 4	Butler Community Centre Activity Room 2 (meeting room) 55 Kingsbridge Blvd, Butler	1 pm - 3 pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
Southern Information and Support Group	Mon Jun 25	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)

New South Wales

Event	Date	Location	Time	Organisation	Contact
RPAH Information and Support Group	Tues Apr 10	Royal Prince Alfred Hospital Education Centre Level 5 Chris O'Brien Lifehouse 119-143 Missenden Rd, Camperdown	10 am - 12 pm	RPAH & Myeloma Australia	Tracy King (02) 9515 7310 / 9515 6111 pager 87524 E: Tracy.king1@health.nsw.gov.au 1800 MYELOMA (693 566)
Westmead Hospital Information and Support Group <i>Change of Venue</i>	Thur Apr 12	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Liverpool Information and Support Group	Tues Apr 17	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Apr 26	Central Coast Leagues Club Dane Drive, Gosford	6 - 8 pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)
Newcastle Information and Support Group <i>Change of Date</i>	Mon May 7	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3 pm - 5 pm	Myeloma Australia	John Miller E: miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)
RPAH Information and Support Group	Tues Jun 12	Royal Prince Alfred Hospital Education Centre Level 5 Chris O'Brien Lifehouse 119-143 Missenden Rd, Camperdown	10 am - 12 pm	RPAH & Myeloma Australia	Tracy King (02) 9515 7310 / 9515 6111 pager 87524 E: Tracy.king1@health.nsw.gov.au 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Jun 19	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Westmead Hospital Information and Support Group <i>Change of Venue</i>	Thur Jun 21	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Jun 28	Central Coast Leagues Club Dane Drive, Gosford	6 - 8 pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)

Myeloma Support Groups Facilitated by Leukaemia Foundation

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

National Telephone Support Group (Cancer Council NSW)

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