

MyeNews

Winter 2019 Issue no 50

Myeloma
Australia



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

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From the President

This MyeNews is our 50th edition of the Myeloma Australia magazine. The first edition of what began as a quarterly newsletter was called MyeVic and was published in 2000. Comprising a number of photocopied pages stapled together posted or emailed out to our database. Over the years Pina, (whose background is in graphic design), has developed it into the more “glossy” printed magazine look it is today. The MyeNews has reflected the many changes of Myeloma Australia and the advancements we have made in the Foundation to date. It is now distributed by email, post and by hand to several thousand people. Thank you to all the editorial panel for the production of this quality magazine.

At the time of writing, we have not heard the results of the last Pharmaceutical Benefits Advisory Committee with respect to the four submissions relating to myeloma and its treatment. We eagerly await the news and hope for important advances in the treatment of myeloma in Australia.

Other exciting news is the Government’s funding to the VCCC in Melbourne to develop CAR-T cell treatments for various cancers including myeloma. This new treatment is showing very positive results in early trials overseas but there is a while to go before it will become freely available.

May was National Myeloma Month, we had programmed seminars in all states with the theme ‘Me and Myeloma – Empowerment and Living Well’. These seminars are always worth attending, I have been attending myeloma seminars for 20 years and I still learn something new every time. It is a great opportunity to hear about the research and trials of new drugs from around the world. It is also a great time to meet and talk with other members of the myeloma community who understand how you feel.

Our thanks go to the many volunteers and fund raisers around the country who are helping to raise much needed funds for Myeloma Australia. In Melbourne we had two major

events in March, the Business of Winning Luncheon held at the MCG Members Dining Room with over 200 people attending. We also had the My Mt Eliza Run & Fun Festival which again had a large crowd attending and everyone having a great day.

There are a number of fun runs organised around the country every year and if you are thinking of participating why not join Team Myeloma and use this opportunity to raise some money by getting your friends and work colleagues to sponsor you. If you want more information about fundraising events please contact Matt Maudlin at Head Office or Santosh Ojha in New South Wales.

We are currently working towards the ability to be able to broadcast our seminars via the internet so that those, who due to distance or health, cannot get to the seminars will have the opportunity to hear and see the speakers. As soon as we feel confident that we can do this successfully we will promote it to everyone. We are a truly national organisation now with Myeloma Support Nurses in all states. They have started many new Information and Support Groups and if you are interested in starting one in your area please give the nurses a call. They will assist you to get started. We are also looking at alternate ways to support our members in rural Australia and we are working with Rotary Clubs to find a way to do this. More about this as the process is developed.

I am amazed at what we have achieved in the past 20 years but there is still a lot more to be done. I am looking forward to the developments that will occur in the treatment of myeloma over the next few years. There is so much research being done in centres around Australia as well as overseas.



Brian Russekarten



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.

Taking it to the top

Myeloma to Mount Everest

Myeloma Australia was recently delighted to receive photos of our exclusive Team Myeloma t-shirts as they reached Base Camp at Mount Everest – and isn't the front cover of this edition of MyeNews just stunning?!

The back story to this occurring involves Melbourne-based myeloma patient Chris Francis and his cousin Rod. Here is their story.

In February 2019, my cousin Rod was planning a trip to Mt Everest Base Camp. I am living with multiple myeloma and thought if his team could wear Myeloma Australia t-shirts, this would go a long way in raising awareness for this relatively unknown disease.

From a personal point of view, I felt that I was there as well, that I was participating in this adventure. I had contemplated being part of the climbing crew before my diagnosis, now I was part of the crew in a different way.

Rod was more than happy to be involved in the t-shirt idea and suggested that the whole team would wear them if I could organise it.

I contacted Myeloma Australia, they loved the idea and were very supportive. We then collaborated on a design for Team Myeloma – Base Camp. Colours and concepts were discussed, and timing was of the essence. Myeloma Australia graciously covered the production costs and took care of all the details, making sure that I was able to present Rod with the t-shirts for the whole crew – the day before they left.

I am very grateful and would like to extend my thanks to everyone involved. I'm sure the efforts of Rod and his team have brought awareness to many more people that would otherwise not have known what myeloma is.

Chris Francis

Photos © Wayne Quayle



I had been planning a trip to Mt Everest Base Camp and after talking to my cousin Chris, who has myeloma, he came up with an idea for everyone to wear Team Myeloma t-shirts, to help raise awareness.

I had done this before, when walking the Kokoda Trail for a friend of mine to help raise awareness for MND (Motor Neurone Disease).

Everyone on the trip to Everest Base Camp said they would love to help out, so Chris organised the t-shirts and we got delivery just in time for our trip. Many photos were taken along the way and the t-shirts got the reaction we were hoping for, with many people, including our own team members asking what myeloma (cancer) was.

I'm sure that many more people know more about myeloma as a result of our trip to Base Camp and have hopefully donated to the cause. I hope we have made some sort of difference in bringing awareness to this terrible disease and hope that the myeloma research team can find a cure for my cousin.

Good luck Chris.

Rod Francis



Emma-Jane Furphy VIC Support Nurse

During my undergraduate placement at Royal Melbourne haematology inpatient unit, I knew this was the speciality for me. I was lucky enough to secure a position on the Graduate Nurse Program here as well. I then travelled to the UK and worked for Oxford Radcliffe Trust in the Haematology and Bone Marrow Transplant Unit as a nurse then junior sister and onto the practice development nurse. I was fortunate enough to be able to study in Oxford and complete my Masters Degree in a student design award. I named this Masters – Cancer Care and Clinical Practice Management. After nine years I decided it was time to come home to Australia and went into a research nurse position at the Alfred. Shortly after starting this I had my first son and moved to Peter MacCallum Cancer Centre. My son is now 10 years old and I have just celebrated 10 years of service at Peter Mac. I love working there as one of the myeloma nurse consultants with a great team of myeloma nurses. I am so lucky that I am now able to extend the breadth of my skills working with a team at Myeloma Australia.

In my spare time I like to relax by going open water swimming and spending time with my partner and boys. We all love to go bush walking, open water diving and supporting our footy team. Last year we travelled through Japan. The highlight of the trip was climbing Mt Fuji. We started the climb at 7 am and finished after 8 pm. This was such a memorable day that I will never forget. The mental and physical challenge was an experience I have never before had. Being on Mt Fuji was like what I imagine being in space is like. The terrain and the sounds of the rocks under my sneakers was surreal. There is very little plant life on the mountain. With this experience, I managed to conquer Mt. Fuji and my fear of heights!

I look forward to meeting more members of the myeloma community and I am hoping to start a new Information and Support Group in Shepparton later this year.

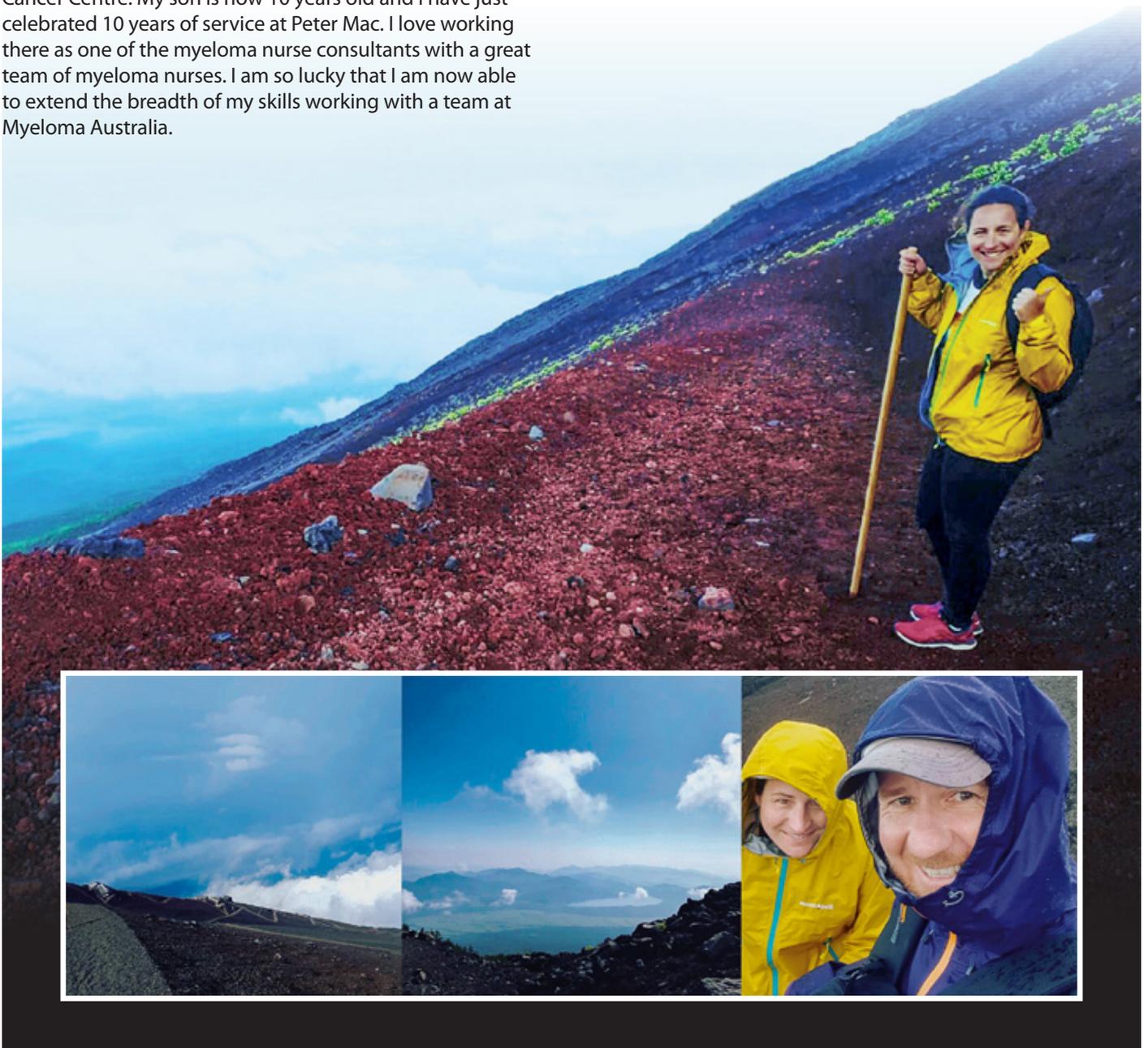


Photo provided and used with permission



Impact of cancer treatment on nerve function

Treatment-induced peripheral neuropathy is a major but poorly understood side effect of cancer treatment. Peripheral neuropathy produces damage to the nerves in the arms and legs and can develop with commonly used treatments for multiple myeloma, including bortezomib and thalidomide. Symptoms include sensations such as numbness, tingling, pins and needles and pain, with symptoms affecting the hands and feet. These symptoms can cause difficulties in the daily lives of those who experience them, including problems with doing up buttons, picking up small items, and tripping or stumbling when walking. However, at present there is little understanding of the impact of these symptoms on the lives of people who experience them.

In order to better understand the impact of side effects of neurotoxic treatments, the IN FOCUS research group from the University of New South Wales and University of Sydney recently conducted an anonymous online survey to look at the impact of these side effects on cancer survivors nationwide.

Over a thousand people from around Australia completed the survey. We received responses from people who have had a variety of cancer types, including 10.5% of respondents who have had multiple myeloma. Other cancer types represented include breast cancer, bowel cancer and ovarian cancer, and respondents finished their cancer treatment an average of 3.7 years ago. The majority of survey respondents (78%) reported experiencing nerve symptoms after completing cancer treatment, with 75% reporting that they currently experience nerve symptoms. In people who currently experienced nerve symptoms, 29% reported moderate or severe problems with walking, and 23% reported moderate or severe difficulties completing tasks with their hands, such as handling small items. Of those currently experiencing nerve symptoms, 29% reported that their symptoms had not improved since they finished their treatment.

Importantly, scores on questionnaires examining quality of life showed that respondents with current nerve symptoms experienced worse quality of life than those without current

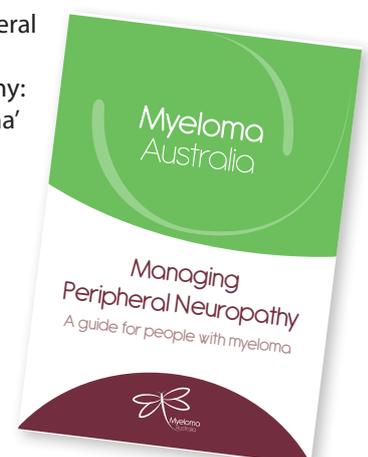
symptoms. Nerve symptoms also were commonly rated by respondents as having the greatest impact on their daily lives out of all treatment side effects, second only to fatigue.

Overall, the results of this survey suggest that peripheral neuropathy has a lasting impact on cancer survivors, with some experiencing symptoms for years without improvement. These symptoms also have an effect on their quality of life and ability to perform daily tasks. The impact of these symptoms supports the need for further work to improve assessment, prevention and treatment of the side effects of cancer treatments.

The IN FOCUS research group would like to thank everyone who took part in the survey. We would also like to thank those who helped to promote the survey, including a big thank you to Myeloma Australia for sharing information about the survey. Within our research group, we are continuing to run research studies involving nerve testing for people based in Sydney 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 research, visit <http://www.infocusstudy.org.au/>, or email in_focus@unsw.edu.au.

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.

*Eva Battaglini
Program Coordinator
IN FOCUS peripheral neuropathy
research program*



Australia Day OAM for Myeloma Director

“It’s all about Rotary. It’s what we do.”

We were delighted to learn that in the Australia Day honors list our director Peter Allen was awarded an Order of Australia Medal (OAM) for “services to a range of organisations”. On behalf of the Myeloma Australia team, we congratulate Peter and his wife Beverley for this well-deserved recognition and we thank him for his twenty years of service to Myeloma Australia – one of the “range of organisations” that have benefited from his service. I asked Peter to write a few words for MyeNews. Reluctantly at first, he agreed. His “open letter” is published here.

Steve Roach, Chief Executive Officer

Words are inadequate to describe the amalgam of surprise and gratitude tempered with some humility and more than a touch of “Why me...?”

It all began with an impressive letter-sized buff envelope in the letter box. The insignia of the Governor General of Australia suggested that this was to be no ordinary communication. A few short seconds later I was trying to absorb that I was invited to accept nomination for the award of an Order of Australia (OAM).

How could this be? Who made it happen? I now know that a friendly team of “conspirators” had met for months to create the application for the recognition. I have had the privilege to be a long term Rotary member and a director of Myeloma

Australia for two decades, so the members of the conspiracy were not hard to suspect – and mostly correctly.

I accepted the invitation and the honor that it provides and a few weeks later, with others I was pleased to receive the award from the Governor of Victoria – the Hon. Linda Dessau AC – and the right to attach the post-nominal OAM to my name.

Needless to say I am grateful to everyone who made it happen. Most of all I am grateful to Rotary International – I am a proud member and Past President of the Rotary Club of Camberwell – for giving me so many opportunities for community service and to my wife Bev for tolerating what can become obsessional at times.

Simply, service is what Rotarians “do” and it was Rotary that brought me to Myeloma Australia in the 1990’s. A fellow member of my Rotary Club, Robert Moran (also OAM) toiled with now President Brian Rosengarten and others to start MyeVic, the fledgling organisation that was destined to become the national Myeloma Australia that we are today.

The Rotary Club of Camberwell came on board at the start with funding and it has remained engaged throughout the journey. I joined the board soon after MyeVic’s beginnings and I have remained embedded in the Foundation ever since as a director. Needless to say I am proud of Myeloma Australia and I am proud of my Rotary Club that placed me here. In Rotary parlance “service is its own reward”, and the rewards have been many.

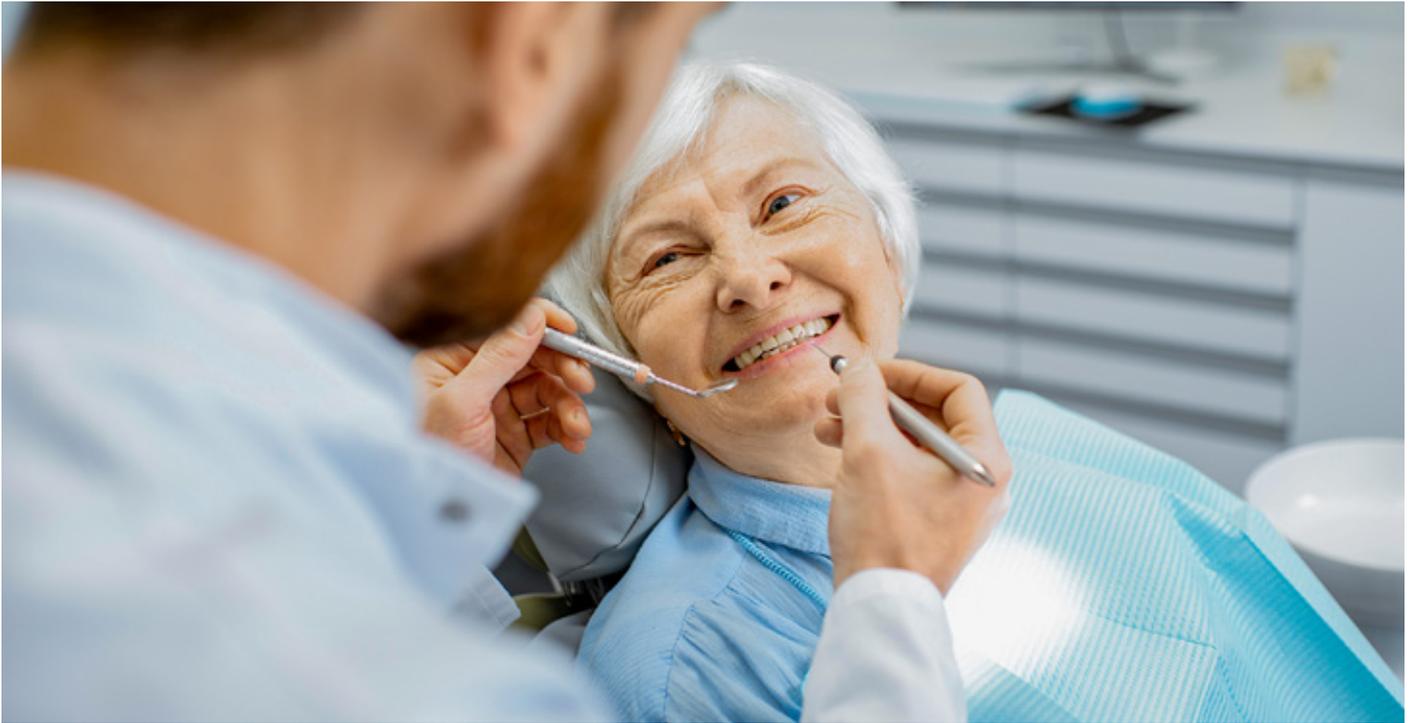
Our shared creation Myeloma Australia continues to contribute well to the myeloma community and our vision for “a world without myeloma” draws ever closer to realisation. May it be soon.

Peter Allen OAM

Peter Allen OAM congratulated by Victorian Governor the Hon Linda Dessau AC



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ONJ

At our Fullarton meeting in South Australia, Dr Tanya Lin from the Special Needs Unit at Adelaide Dental School discussed osteonecrosis of the jaw.

When bisphosphonate treatments have been used by myeloma patients, there is a higher risk of developing ONJ. Early diagnosis allows better outcomes, and whilst no cure, it can be managed with close monitoring and treatment when needed. Osteonecrosis occurs when part of the jaw bone becomes visible through the gum which fails to heal over it within eight weeks. It is more common amongst people on bisphosphonates, but can develop following trauma to the jaw bone, dental extractions, ill fitted dentures or occur spontaneously. If you or your regular dentist notice symptoms such as:- exposed necrotic bone, ulceration, signs of infection, redness, swelling, pus, intra or extra oral draining sinus tracts, loosening of teeth, numbness, pathological fractures of the lower jaw or any combinations of these, your Dentist should refer you to the Special Needs Unit at Adelaide Dental Hospital, for specialised care. There is no cost for concession card holders.

If ONJ is confirmed, your haematologist may stop the bisphosphonates for a while.

Complications as a result of ONJ include:-

- Impaired chewing, due to loss of teeth sustaining bone areas
- Aesthetic implications, e.g. tooth loss
- Impairment of facial contours due to extensive bone loss
- Deviation of lower jaw after partial resections
- Difficulty wearing dentures

Management of ONJ includes, regular checks for decay and gum disease, antimicrobial mouthwashes, removal of affected bone and soft tissue to relieve irritation, pain control, antibiotic therapy guided by microbial culture or swab analysis, stopping bisphosphate treatment and possible referral to an oral surgeon. If extraction is indicated, alternatives such as root canal are preferred. If extraction is necessary, atraumatic extraction technique is used with additional measures to manage risk of prolonged bleeding. Postoperative care includes mouthwashes and close monitoring. Prior to starting bisphosphonate therapy, a thorough dental check and x-ray of all teeth is required. Any dental work, especially extractions are done where possible, before bisphosphonates start. Inform your dentist you have multiple myeloma, as dentists have awareness of myeloma and its complications. To reduce the risk of ONJ, maintain good oral hygiene with gentle and thorough brushing and flossing, reduce sugar intake, use fluoride toothpaste, stop smoking, limit alcohol and have regular dental checks

Remember, if you have tooth or gum pain, see your dentist as soon as possible, in case it is more serious than just decay

If you would like to read more about osteonecrosis of the jaw and bone health in myeloma please see our new 'Living Well with Myeloma' book chapter on 'Bone Health' alternatively please call our Support Line on 1800 693 566 to speak with one of our nurses.

Jo Gardiner
Senior Specialist Myeloma Nurse; MSN SA/NT

Maddie's Story

We always love hearing stories from around the nation/world where community engagement, awareness raising, and fundraising are taking place. Each and every story is unique, is special and deserves to be shared with the broader myeloma community. We have so many events occurring at the present time that space in the magazine becomes an issue – truly, a good problem to have! That being said, I hope you enjoy the following article about one of our younger supporters.

Earlier this year 11-year-old Maddie created a fundraising page, writing the following:

"A year ago, on the 22 January 2018 I experienced a loss like I had never imagined. I lost my Lorraine (step Grandmother) who had battled for seven years with multiple myeloma. This loss has been an experience like I could never have imagined. It has affected me so deeply and it is my wish to do something to make a difference. My wish is to raise \$2,000 to donate to Myeloma Australia to help them support those fighting this terrible disease for which there is no cure. I intend to do that by shaving my hair off and using it to make wigs for children who are suffering in a similar way to my Lorraine. I would much rather kids with cancer have my hair and feel happy, confident and boost their self-esteem than me, because I know mine will grow back.

So my hope is, with your help, to not only give a child back their self-confidence but also raise money to donate to Myeloma Australia. Helping create happiness for one little person, making another person's journey through an incurable disease a little easier and maybe even find a cure to hopefully save another family from so much sadness.

Maddie's mum, Janyse, takes up the story following Maddie's head shave ...

"Emotions ran high in Maddie leading up to the big day as Lorraine was extremely important to Maddie, she wanted to make sure that she not only did Lorraine's memory justice but that she would be proud of her.

Nerves only hit Maddie when she was in the chair with her hair in plaits. She asked her best friend, Lilly, who was with us for emotional support, "Will you still love me", Lilly's response was "I'll love you more". Maddie's nerves calmed almost instantly. A beautiful moment that still brings tears to my eyes between two 11-year-old besties.

Maddie is enjoying her short hair, being able to get up in the morning running her fingers through it and it's done. As winter is setting in beanies are a must. 30/4 was her first trim since the big chop, she's still loving it.

She is talking about doing it again in a few years' time. I told her she needs to wait until she's 18 to give my nerves a rest.

I am an extremely proud Mum, who is in absolute awe of her only child.



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NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

RECRUITMENT UPDATE

The Myeloma and Related Diseases Registry (MRDR) now has close to 2800 patients. We have also reached 51 hospitals and clinics with 38 approved sites and 13 with approval pending. NSW is booming with all the latest additions to the registry: Nepean Cancer Centre, Royal North Shore Hospital and Calvary Mater Hospital in Newcastle. Welcome to new sites and a big thankyou to all participating patients and hospitals for your continued support.



INTERNATIONAL ACTIVITIES

Asia-Pacific MRDR (APAC MRDR)

APAC MRDR, a Janssen-funded parallel project to the MRDR, was established in 2018 to monitor the differences in access to and patterns of care and their outcomes in patients across multiple countries in the APAC region. The APAC registry has its own steering committee and country-specific databases and now has ten hospitals with ethics approval to participate. Korea and Singapore have active sites with 127 patients registered, and Taiwan and Hong Kong will follow.



Myeloma UK

The MRDR recently made an invited presentation for Myeloma UK, a patient advocacy group that is establishing a UK Myeloma registry. They held a workshop to assess stakeholders needs and asked MRDR to share how we generate data that help to inform decisions on treatment choice and the impact of patient reported outcomes in our research. Feedback was positive and the invitation supports the relevance of the registry.



MONASH
MEDICINE,
NURSING AND
HEALTH SCIENCES

RESEARCH

The Myeloma 1000 Project (M1000)

M1000 is a blood biobank substudy of the MRDR with the goal to collect samples from 1000 patients with multiple myeloma (MM) and 1000 with MGUS. Recruitment is close to 340 patients and interstate sites have now commenced with acceptable times to delivery. We have recently received the first requests from researchers and it will be gratifying to see biobank samples put to good use. The participation of new Australian sites is welcome; see contact details below.

IMPROVE

IMPROVE is a substudy of the MRDR funded by the National Blood Authority. This study aims to investigate infections and immunoglobulin (Ig) use in patients with MM in Australia, and provide information to improve national Ig stewardship and patient outcomes. The IMPROVE blood biobank is recruiting.



My-PROMPT

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. Recruitment was completed in late 2018, follow-up of patients is in progress and a manuscript is in preparation for publication. We thank all patients and sites for their participation in this trial. This study is funded by Gilead and Takeda.



MRDR: HOW CAN YOUR HOSPITAL BE INVOLVED?

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

TO CONTACT THE MRDR:

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



ACBD
Australian Centre for Blood Diseases

AlfredHealth

CRICOS Provider: Monash University 00008C. MAY 2019

At the National Myeloma Month RPA seminar, Mary Lou Spratt and Lois Wilson shared their experiences in living with myeloma, the impact on their families, treatment and side effects to date and top tips in how they have learnt to cope with myeloma. Mary Lou went above and beyond, presenting this short poem she had written for the occasion!

Me and My Myeloma and the RPA

Mary Lou Spratt

Nurse Jade from Infusion Centre, friends Esther Fran and Rose, said my poem is OK, so this is how it goes:

Myeloma is a blood cancer – it knocks on the plasma cell door.
When you find out you have it you want to know lots more.

It's sometimes trial and error and the procedures not too pleasant
but looking back on them today, they seem so very distant.

At the RPA we have co-coordinators – Tracy Eleanor and Sally they are
committed to assist us and they never dilly dally.

Appointments, tests, infusions need to be organised big time
– getting there is easier now with the Leukaemia Transport Line.

We still do what we did before though slower now, not fast
– except on good old dexta days – oh what a blast!

I still do the Herald crossword and get the odd letter in – meeting friends,
hobbies, walking, reading and music are worth continuing.

There's Me and my Myeloma as long as we separate the two and monitor
the Myeloma as well as we can do.

Last year I contracted pneumonia with complications it was pretty nearly
fatal – the Doctors and nurses at ICU kept me upright – I am so very
grateful. I saw an RPA counsellor she helped me through this time.
I found it very helpful and now am pretty fine.

Waiting for the blood tests is stressful every time – when they're in and
stable we know we must be fine.

Thanks to good old blood tests and the nurses at Haematology but
central to our progress is the department of Pathology.

The staff at Haematology deserve our thanks and praise – they organise
our schedules for days and days and days.

I want to say there's one fab guy that makes me a happy client
– he's a Haematologist at RPA and his name is Dr Christian Edward Bryant
– his expertise is well renowned by those outside the system but we
who see him all the time truly thank him for his wisdom.

With love and support from friends and family we try and make it through
each day and Me and My Myeloma enjoy the trip along the way.



National Myeloma Awareness Month

National Myeloma Awareness Month Seminar Sydney: Myeloma & Me

The Royal Prince Alfred (RPA) Hospital partnered with Myeloma Australia and the Leukemia Foundation for this year's patient and family seminar "Myeloma & Me: Empowerment and Living Well". Over 160 patients, family and friends attended in person at the Kerry Packer Education Centre RPA, with another 60 or more joining us via video conferencing from Barwon Health, Geelong, Canberra and Lismore Base Hospital.

Dr Anna Nelson (RPA) senior haematology registrar opened the day with a 'Myeloma 101' overview, describing how myeloma is diagnosed, monitored and how it may affect the body. Having set the scene, the medical management of myeloma was described by two leading haematologists Dr Nicole Wong Doo (Concord Hospital) and Professor Joy Ho (RPA). Dr Wong Doo and Prof Ho described the increasingly wide range of treatment combinations that are available to treat myeloma. Dr Wong Doo reminded us all of the importance of not only treating the myeloma effectively but also focusing on the patient's wellbeing through supportive measures, physical fitness and psychological support. The role of the patient organisations and a multidisciplinary health care team approach was further endorsed.



Professor Ho's presentation focused on the treatment of relapsed myeloma and described the important role of research and clinical trials in delivering best management of myeloma. With many new treatment combinations only available in the context of clinical trials in Australia, participation in a clinical trial provides patients a way to access novel treatment combinations. Clin Trial Refer (APP) lists available trials in our region and provides a way for clinicians to identify suitable trials for patients and refer suitable patients to other treatment centres to access studies.

Dr Susanne Park, provided an overview of peripheral neuropathy and the range of symptoms experienced including numbness, tingling, loss of sensation, commonly in hands and feet but also balance, walking and coordination problems. Dr Park was also able to describe her team's work on identifying the mechanisms of treatment induced peripheral neuropathy, a first step in finding ways to treat and manage this common, and often debilitating side effect.



Prof Joy Ho

A report on Dr Parks neuropathy study to date is included on page 7.

See 'Managing Peripheral Neuropathy: A guide for people with myeloma' available at <http://myeloma.org.au/wp-content/uploads/2017/10/Managing-Peripheral-Neuropathy-2017.pdf>

Continuing with the theme of supportive care and managing symptoms relating to myeloma, Professor Janette Vardy presented 'Cancer-related cognitive impairment: "Brain Fog"'. Often described as "Chemo-Brain", most patients with myeloma describe memory changes after their diagnosis. Prof Vardy described the range of changes in memory that impact people with any cancer and finds changes are likely related to a diagnosis (cancer-fog) and not just its treatment (chemo-brain). A helpful podcast is available on Cancer Council website for those who would like to explore more.

See "Brain-Fog and Cancer" available at

<https://www.cancercouncil.com.au/podcasts/episode-14-brain-fog-cancer/>

Patients Lois Wilson and Mary Lou Spratt presented the 'Myeloma is Me' session. Both ladies shared their experiences of living with myeloma, the impact on their families, treatment and side effects to date and top tips in how they have learnt to cope with myeloma. Mary Lou went above and beyond, presenting a short poem she had written for the occasion! Included for your reading pleasure in this edition on page 12.

Tracy King, Myeloma Clinical Nurse Specialist RPA described how the 'Muddle Headed Wombat' has come to describe





Dr Christian Bryant

how some of her patients feel whilst taking dexamethasone (steroids). Her talk described the role of steroids in myeloma and focused on the wide range of side-effects that may occur, both physical (e.g. high blood sugars and blood pressure) to mood and behavioral changes (e.g. jitters, insomnia, anxiety). Tracy's research studies are looking at developing a questionnaire to help patients better describe the range of side effects relating to steroids and in time, clinician's management of them.

See Steroids: Treatment Fact Sheet from Myeloma Australia available at <http://myeloma.org.au/wp-content/uploads/2018/09/Steroid-FS-Sep18.pdf>

One of the highlights of the day was Dr. Christian Bryant and his presentation "Immunotherapies and Future Directions".

Dr. Bryant is a haematologist at RPAH with a major interest in myeloma and transplantation, and has worked with Prof Ho on immunotherapy (CAR-T, see below) trials in RPA. Dr. Bryant had the unenviable task of presenting the highly complex human immune system and how science is exploring ways to harness parts of this (e.g. T cells) to target cancers (myeloma). The new treatment modalities of chimeric antigen receptor T cell (CAR-T) cell and bi-specific T cell engager (BiTE) therapy were explored. These new approaches are being explored in a range of cancers including myeloma. Studies are beginning to come to Australia and although we need to understand a lot more about these approaches and how they may be used in the management of myeloma ahead, they certainly represent exciting times for the future of myeloma treatment.

We would like to thank Tracy King and Eleanor Romney (Myeloma Nurses RPAH) for their tireless efforts in organizing this meeting and for including it in the National Myeloma Month events with Myeloma Australia and the Leukaemia Foundation by partnering with us on this year's seminar.

Thanks to satellite teams

Geelong: Jenny Hempton, Transplant & Apheresis Coordinator; Linda Saunders Leukaemia Foundation, Elli Foley Myeloma Australia & Deanne Linde Wellness Centre

Canberra: Deidre Mathis Haematology Nurse Care Coordinator

Lismore: Karin Plummer Leukaemia Foundation; Kylie Lindsay CNC Oncology & Haematology Lismore Base

www.myeloma.org.au • www.leukaemia.org.au
www.cancercouncil.org.au

Tracy King, Eleanor Romney, Prof Joy Ho

Thank you

The Myeloma Australia dragonfly has been beautifully brought to life by one of our Beaumaris Support Group members, Ian Crothers. Being a member of the Bayside Men's Shed in Beaumaris allows Ian the space and time to create many woodwork gems. In the past he has made tables (amongst other pieces) which he has kindly donated for raffles to raise funds for Myeloma Australia.

The carving inspiration for this piece came from the recycled timber of a cedar tree dating from the early 1900's.

We were told that the dragonfly has been much loved by members of the Beaumaris group and it was suggested to him that he should create one in wood. We are sure that he has dedicated many hours in the carving and finishing of the dragonfly, which he has generously gifted to the staff in Head Office. It proudly sits at the front desk for everyone to enjoy and comment on.

Pina Civitarese & Alex Dawson
 Myeloma Head Office



Photos supplied and used with permission

From the Nurse Manager

We just had our biggest National Myeloma Awareness Month, with events in more places than ever. Our Myeloma Support Nurses worked collaboratively with the Leukaemia Foundation to coordinate and host seminars in Melbourne, Adelaide, Sydney, Perth, Brisbane, Hobart, Canberra, Newcastle, Wollongong, Lismore and Geelong for people living with myeloma and their carers. It is wonderful to see how many more people we can reach with the latest expansion of Myeloma Support Nurses with first time awareness month events in Brisbane, Hobart, Canberra, Lismore and Newcastle. The theme this year was 'Me & Myeloma – Empowerment & Living Well'. Each event was arranged by the local representatives and showcased local expertise in the area of myeloma and its treatment and a variety of aspects of maximizing quality of life and wellness whilst living with myeloma, both for people with myeloma and their carers. Our speakers came from a variety of disciplines including medicine, nursing, psychology, exercise physiology, nutrition and we were lucky to have some people share their stories and experiences living with myeloma and how they manage to live the best life they can and be proactive in their health and wellbeing.



Being able to attend these events and hear first-hand how much it means to the community to have the opportunity to learn more about myeloma and connect with others is incredibly heartwarming and confirms the need to continue our vision to provide services to more people living with myeloma in Australia. Congratulations to all who contributed and attended and thank you to the Leukaemia Foundation on another successful collaboration.

We were also able to use Myeloma Awareness Month to launch our new resource 'Living Well with Myeloma'. This booklet combined our existing fact sheets and added additional chapters on various aspects of living with myeloma. Chapters include building a team, emotional health, infection prevention, bone health, fatigue, pain, food and fluids, exercise, complimentary therapies and practical help. This resource was produced as part of a donation from the estate of Dr Bob Cannon OAM and Dr Jean Cannon facilitated by their daughter Jill who has myeloma. Special thanks to members of our MSAG for their medical review and contributors, Dr Benjamin Teh (Infectious Diseases Physician & Clinical Research Fellow, Peter MacCallum Cancer Centre), Lori Hobbs (Social Worker, Haematology and Bone Marrow Transplant department, Royal Melbourne Hospital) and Peter Hallett (Psychology and Physiotherapy Manager, Calvary Rehabilitation Hospital) for their expert guidance on the content. Thank you to Helen Chapman our editor and long



L>R Tom Rendon, Gilberto Paz-Filho, Prof Saad Usmani, Nella Combe, A/Prof Simon Harrison & Steve Roach

time Myeloma Australia volunteer for assisting us with this publication. If you would like to access the resource, it can be downloaded from our website or if you would like to receive one in the mail please contact head office at support@myeloma.org.au

Since our last edition, our team wished our Victorian Support Nurse Laura Jones a very happy maternity leave for the arrival of her first child and welcomed Emma-Jane Furphy to the Victorian team. Emma-Jane has a wealth of knowledge and experience caring for people with myeloma and we are incredibly fortunate to have another passionate and talented nurse join our organization. No doubt many of you will meet her at upcoming Information and Support Groups and on the Telephone Support Line.

It has been a busy year on the advocacy front with both the March and July PBAC meetings having multiple submissions for myeloma. Thank you to everyone who submitted comments at the start of the year, we consistently hear from the PBAC that your comments are important and each comment is read and considered. Unfortunately, the submissions from the March meeting were unsuccessful and no changes have been made to myeloma drug access or reimbursement by the PBS. The submission regarding Lenalidomide (Revlimid®) maintenance following autologous stem cell transplant was deferred until the July meeting. The July meeting agenda has four items regarding myeloma, both treatments and supportive care medications. We eagerly await the outcomes of this meeting and hope that decisions will be made to improve access to myeloma treatments in Australia. Thank you again to all those who contributed comments and feedback to the PBAC, we will continue to advocate on your behalf and keep you informed about submissions and outcomes.

On a final note, winter is officially here and it's an opportune time to remind everyone that it is important that people with a compromised immune system, such as those with myeloma, receive the flu vaccine. It's also important that their friends, families and carers also have the vaccine. For more information speak with your treating team or GP or call our Support Line on 1800 693 566 to speak with a Myeloma Support Nurse.

I hope you all keep well and warm this winter and look forward to keeping you updated on all things in the next edition.

Nella Combe
Manager Nursing and Patient Services

Community Engagement & Fundraising

Activity in the Community Engagement & Fundraising space continues at great pace.

We were super excited to see our Team Myeloma reps arrive at the Base Camp of Everest – as per our very special cover photo! Truly, Team Myeloma is going global! If you would like to send me a photo or two of you wearing your Team Myeloma shirt in wild and wonderful places around the globe – please do so. I'd love to bring such photos to the broader myeloma community through these pages

You will find two very special articles in this edition, both of which are centred around awareness raising and fundraising – I hope you enjoy them

As we enter the winter months Team Myeloma is starting to prepare itself for the major walking/running events in Melbourne, Sydney and Adelaide. Details of how to participate in our Teams can be found elsewhere within this edition

One of the nationwide campaigns we will be participating in this year is Dry July in the month of, not surprisingly, July. I encourage you to consider giving up alcohol, or perhaps something equally significant to you, for the month of July whilst helping us to raise awareness and funds

I continue to encourage people to consider donating to Myeloma Australia via the Good2Give workplace giving platform; this provides an employer an opportunity to match donations made by an employee

I have been delighted to hear from a gentleman in Brisbane who is keen to create a version of our annual, signature Melbourne fundraising event, The Business of Winning Luncheon. I very much look forward to seeing how this develops. I would love to hear from people nationwide who would like to create a similar event to this in their own towns and cities; indeed, I always love hearing of your community awareness and fundraising ideas and welcome the opportunity to assist you in making them as successful as possible.

You will see in the NSW section that Santosh is keen to develop an event or two in the Sydney area in the coming months; if you are in NSW please reach out to Santosh directly.

Matt Maudlin
Community Engagement & Fundraising Manager
E: matt.maudlin@myeloma.org.au

eBay – Online Shop

Cards, Artwork, Sports Memorabilia and much more

Our online shop has a range of items that include greeting cards from renowned artist Patricia Ball and photographer Joe Rey, artwork by Patricia Ball that comes framed and ready to hang, first aid kits, sports memorabilia and promotional t-shirts from our iconic Masters of Rock event. Below is an example of our extensive range of items which can all be found at <http://myeloma.org.au/volunteer-with-us/shop/>



What's happening

New South Wales

How time flies, the colder weather is here again and we have now completed, National Myeloma month. The NSW team have been busy preparing for the various events throughout the State. This year was our busiest, collaborating in four education seminars and enabling another two satellite centres to be involved.



National Myeloma month kicked off first on the 10th May with a seminar at the Kerry Packer Education Centre in Sydney held in conjunction with the Royal Prince Alfred Hospital and the Leukaemia Foundation. This year's theme was Me and Myeloma – Empowerment & Living Well. As always this was a jam-packed day with lots of interesting speakers (see further report from Tracy King) and very well attended with over 160 members of the myeloma community present. Excitingly this was also simultaneously broadcast live to Geelong, Canberra and Lismore and it is hoped we can expand this in the future to reach many more people in regional and rural destinations.

We also held an event at the picturesque Gosford Golf Club attended by almost 40 people and listened to presentations from the team at Gosford Hospital. This was followed by the Newcastle event on May 17th and last but not least Wollongong on the 21st of May.

Rachel and Juliet in Newcastle have tackled the task of organising their first seminar for National Myeloma month. They had the opportunity to meet so many new people and their families who are living with myeloma and are hoping to reach out to many more. They are currently exploring other areas in which they can establish support groups so would be keen to hear from interested individuals.

Recently Rachel, Juliet and Geo attended Support Group Leader



L>R: Jacqui, Santosh & Geo.

training at Cancer Council NSW in Sydney. They had a wonderful time together with other support group leaders from around the country, sharing knowledge, experience and updating their skills. This will help with planning for their upcoming support groups in the Newcastle area, the Southern Highlands and Western Sydney.

We were also pleased to provide updates on ASH (American Society of Haematology) at our patient information days. This was well received and generated plenty of audience participation. We had 22 attendees in Canberra and 30 in Parramatta. The ASH update was also discussed at the support group meetings in Westmead and Liverpool for those who were not able to attend.

We are also looking forward to meeting the myeloma community at Nepean and Blacktown in June. Dates will be confirmed and we will send information flyers to the infusion/outpatient centres in the area.

In the coming weeks, we will be sending a short survey to the attendees of current support groups in NSW. We hope to learn a little more about why you attend or choose not to attend the support groups and how we can possibly improve this aspect of our service. I would be very happy to receive additional thoughts or comments you may have, please email me jacqui.keogh@myeloma.org.au

We hope to meet many of you over the rest of the year, please come along and say hello or contact us via email or the support line if we can be of any assistance.

*Jacqui Keogh
NSW State Manager /
Senior Myeloma Nurse NSW*



What's Happening

Queensland

It was a beautiful day in Brisbane if you were in the sun but a bit chilly in the shade. Luckily, we were inside to bask in the wisdom of our fabulous presenters for National Myeloma Day. After some fun days of planning and organising with our friends from the Leukaemia Foundation's Queensland office there was a nervous wait for the RSVP's to come in. We needn't have been nervous – we ended up with a full room

The day kicked off with Dr Nick Weber providing a great overview of what myeloma is, how it's treated and managed and what exciting new treatments are coming. With much generosity he answered many questions and stayed back over lunch to talk to patients and their families. We thank him so much for giving up his precious time

In the spirit of Empowerment and Living Well, Tamara Jones, an exercise physiologist, delivered a session to patients explaining how tailored and supervised exercise plans can better support patients with myeloma. There are many myths associated with myeloma and exercise because of the risks of fractures and spinal damage. Tamara explained that a tailored and supervised program ensures that those risks are negated and delivers, among many things, pain relief, relaxation, improved general health and improved bone health. In the true spirit of empowerment, researcher Jenni Nicholl introduced her PhD study which is hoping to show that exercise can reduce tumours – wouldn't that be great

While the patients were learning how to empower their lives through exercise, carers were taken aside to share and learn how to look after themselves while also looking after their loved ones. Maryanne Skaparis talked about the three P's of self care. The first P is Permission. Carers quite often don't give themselves permission to take the time to recharge and re-energise but this is incredibly important. Having a Passion that engages your mind so intently for a



period of time so that it takes your mind away from the stresses of the day provides the space for this recharge. Many of the carers shared their passions such as gardening, music, cooking, as a way for their minds to escape for a while and re-energise. There was a range of people from many stages of the myeloma journey – some had only just heard about their loved one's diagnosis while others had been a carer off and on for over 11 years. Some had just come out of the transplant process and some had just relapsed. It was beautiful to hear the care and advice from those with many years caring experience given to those still in the initial stages of shock of the myeloma diagnosis. And the best gift they gave is Perspective.

They had the ability to tell the story of how the journey begins and where it leads, talking about the downs and ups, bad times and good times, remembering that it won't be awful all the time. I think we all came away Empowered to Live Well following the three P's

We finished the day embracing relaxation and mindfulness strategies to improve our health and well-being. Yoga and relaxation specialist Craig Smith discussed further the concepts of mindfulness that Maryanne had touched on in the carers session. He described the importance of narrowing our minds to focus on one thing at a time. This prevents ourselves becoming overwhelmed by all of the information and tasks in our heads. To demonstrate, he had us do a simple breathing exercise which was a lovely way to round off the day.

This was our first seminar and we are so pleased with how it went. Many thanks go to our CEO Steve Roach for coming up to the Sunshine State and providing us with moral support. The whole experience was an absolute joy

*Natasha Clarke & Megan McDowell
Myeloma Support Nurse QLD*



South Australia

Mcultural liaison from Warriparinga Community Centre (windy place by the river) where we meet, describing the historical significance of the site to the Kuarna people and the early white settlers of Adelaide. Andrea explained how the grounds were a central meeting place for many indigenous groups before white settlement. She showed us 'the front door' to the grounds comprising river red gums (Tjirbruki Gateway) still emblazoned with shields, and other areas in the grounds whose use relates to how our own houses work as meeting places for our families. Afterwards white settlers made it their home, growing produce and grapes for wine along the fertile grounds of Sturt River wetlands

The following meeting in May saw Jo hold a discussion about tests and investigations and how to interpret them. This was in lieu of an apology from the invited speaker who will attend the next meeting in July to discuss home care available through a federal government program My Aged Care

At our Fullarton meeting, Dr Tanya Lin from the Special Needs Unit at Adelaide Dental School discussed osteonecrosis of the jaw. The summary in our local newsletter drew lots of positive feedback, so it has been included in this MyeNews as a separate article.

The next Fullarton meeting on 4th June saw Mr John Cortazzo, give an entertaining talk sharing his myeloma story along with his efforts to fundraise for Myeloma Australia by participating in My Charity TV. John has committed to raise \$100,000 by February 2020, (despite only \$10,000 being the required amount!) and it is with gratitude I say, so far, he has raised an amazing \$66,440 for Myeloma Australia. If you wish to help John achieve his goal, please follow this link to his fundraising page: <https://charitytv.everydayhero.com/au/john-cortazzo-myeloma-supportfund>

The South-East Information & Support Group was held on Friday 9th May with Liz Southall, Regional Manager from Resthaven for the South East. She spoke about entitlements available to myeloma patients under the My Aged Care Federal Government program. This was well received and will be addressed again at the next Flinders information group.



Chris Ridley



Kerri Ireland & Karen Linehan

The Mid-North group was unfortunately cancelled and therefore we are planning an informal catch-up morning in Clare at a café, provisionally on Wednesday July 3rd.

The Australian Amyloidosis Network Workshop was held on Sunday 5th May with international speaker Dr Angela Dispenzieri from the Mayo Clinic as well as interstate and local speakers addressing the range of amyloid types and damage to different organ systems.

Following this the National Myeloma Day seminar was held on Saturday 11 May 2019 at Fullarton Park Community Centre and was convened by Myeloma Australia (MA) & the Leukaemia Foundation of Australia (LF) with 67 people in attendance. "Myeloma & Me: Empowerment and Living Well" was the theme of the day, which started with Dr Wilfred Jaksic, consultant haematologist at The Queen Elizabeth Hospital (TQEH), Adelaide Haematology & Oncology and MSAG member, giving an 'Overview of myeloma disease and standard therapies available on PBS', which aimed to give a refresher of information for those diagnosed for a while and to help those newly diagnosed.

Following on, Nella Combe and Jo Gardiner, senior MA Myeloma Support Nurses, discussed strategies for 'A lifelong partnership – Effective communication with your treating team; building a team for medical & supportive care'. A lively session with discussions and questions ensuing.

The third session was taken by Kerri Ireland, Exercise Physiologist in Day Rehabilitation Service at TQEH, entitled 'Tailored & supervised exercise programs support better living with myeloma, on & off treatment'. Kerri showed a



John Cortazzo at Fullarton Support Group



Dr Wilfred Jaksic

powerful video on how you feel when exercising vs being sedentary, which can be found at this link: <https://www.youtube.com/watch?v=IA5hKombXVI>

She then explained how studies show that survival and quality of life are increased in many cancer types with regular movement and exercise. Kerri engaged our audience to join in with some simple exercises which were impressive in rejuvenating concentration levels and gave practical examples of how to build movement and exercise into your daily routine.

Next up was our invited Clinical Health Psychologist, Karen Linehan, who currently works at Chronic Heart Failure Service at TQEH and the Paediatric Chronic Pain Service at the Women's and Children's Hospital. Karen prepared a thoughtful presentation on 'Resilience in the Face of Myeloma'. She showed a video giving an example of just what resilience is, which can be found at this link: <https://www.youtube.com/watch?v=cM5A1K6TxxM> She explained how stress is a natural response which can be helpful, but if uncontrolled can have negative impacts. Karen then gave us a 'tasting plate' of 13 tips for increased resilience, designed for you to pick and choose from, according to your taste (or feeling at the time). These are summarized in a brochure that Karen prepared for the seminar and is available by contacting Jo Gardiner.

Our last invited speaker was myeloma patient Mr Chris Ridley, who is on extended sick leave as a social worker and bereavement counsellor with the Central Adelaide Palliative Care Service based at TQEH. Chris has a unique perspective from 'both sides of the fence' and is inspired by the many people he has had the privilege to work with over the years facing all manner of health challenges. Learning what helped others has been of tremendous help in navigating the ups and downs of his own journey with multiple myeloma after his diagnosis in late December 2017.



Nella, Jo, Steve & Matt

In a concurrent session, Karen and the LFA staff moderated a discussion group with the carers, exploring 'learning how to cope, planning your own life and taking care of your own well-being'.

The day concluded with Jo Gardiner returning to give a brief overview of the guiding questions discussed in the myeloma field at the American Society of Haematology (ASH) conference that she and Nella attended in San Diego last December. Jo then reviewed the growing list of available myeloma therapies over the decades, concluding with some early success with phase 1 clinical trials using CAR-T cell therapy presented at ASH.

Please contact Jo by email, jo.gardiner@myeloma.org.au if you wish a copy of the slides presented for the amyloid workshop and/or the myeloma seminar.

Lastly, we are thrilled that the SAHMRI Myeloma Research Laboratory tour to be held on Wednesday 26th June is fully booked, we will keep you informed about future tours.

Jo Gardiner
Senior Specialist Myeloma Nurse, MSN SA/NT

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good2give

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

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

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

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



**Any questions? Please contact Matt at Myeloma Australia:
matt.maudlin@myeloma.org.au**

What's Happening

Tasmania

Here in Tasmania we have held our first two Information and Support Groups. The first one was run at the delightful new Cancer Council Centre in Sandy Bay, just south of town. Gill Sheldon-Collins, my desk buddy and the bone marrow transplant coordinator here at the Royal Hobart Hospital, came along for moral support as I was a bit nervous as to how the first session would go. I needn't have worried, everyone seemed to enjoy it and it was great to hear people's stories and see them interact. We all agreed afterwards, that to try and accommodate people from around Hobart and southern Tasmania, we would alternate the group between three venues each month.

The second group meeting was held across the Tasman Bridge on the eastern shore, at the Clarence Integrated Care Centre in Bellerive. We had a lovely big room which turned out to be a good thing as 18 guests turned up. Dr Nick Murphy, a clinical haematologist at the Royal, did a Q & A session. Several people made a point of letting us know how valuable the gathering was. (TIP: If you are thinking of making scones for an event, don't believe everything you read – that you can make them a day before, keep them in the fridge and then bake them the following day. Some were okay but others were more like rock cakes!)



Our next Information and Support Group meeting will be held at the Cancer Council Tasmania – Support Centre in Sandy Bay.

On Friday 17th May we ran the National Myeloma Day seminar with the Leukaemia Foundation, in the Cancer Support Centre at the Royal Hobart Hospital. Nella Combe, Nurse Manager for Myeloma Australia, flew over from Melbourne for the day, and Amber Laidler from the Leukaemia Foundation came down from Launceston. It was a pleasure to have two guests travel from Launceston for the day too. The speakers were great. Dr. Nick Murphy spoke about the future of treatments. He interspersed his PowerPoint presentation with lovely pictures of his girls and as always – a sense of humour. Dr Kym Nutting, a psychologist, spoke warmly about coping skills. Bruce, who has myeloma, gave a very interesting talk about his own experiences since diagnosis. Katie Taylor gave a comprehensive presentation around diet and supplementary medicine and Charlotte Blake and Trena Youngblutt, physiotherapists, added some fun demonstrations to their talk about exercise and myeloma. Amber wrapped up the day very nicely with a talk on navigating the health system whilst adding her own really useful tidbits.

So things are well and truly underway in the south of Tasmania. I did travel to the north in March and had a warm welcome from staff at the North West Regional Hospital and the Launceston General. I also met with Cancer Council staff from Launceston, Devonport and Burnie and I look forward to working closely with the myeloma community in the future to plan more events for people living with myeloma.

*Deborah Thompson
Myeloma Support Nurse TAS*



Dr Nicholas Murphy



Bruce Taylor



Bruce



Kym Nutting

Victoria

Since my last MyeNews article we have farewelled fellow Victorian Support Nurse Laura, who is on maternity leave until next year. Her son Manny was born 11th May and Laura is 'exhausted but smitten'. In her place we have welcomed the fabulous Emma-Jane, known fondly as EJ, a very exciting addition to the Myeloma Australia team, if you haven't already please check out her intriguing profile in this edition

In May we had two fantastic seminars to mark Myeloma Awareness Month. The first event was held at the InterContinental Hotel featuring Prof Saad Usami, a renowned and passionate haematologist from the United States of America. Prof Usami presented on the evolution of myeloma treatment internationally, giving us a rare and unique insight into how myeloma is managed outside of Australia and what's coming our way. A/Prof Simon Harrison presented on immunotherapy, CarT cells and upcoming treatments available on clinical trial, a hot topic which was very well received. The second event was co-hosted with



Prof Saad Usami

our friends at Leukemia Foundation at the Royal Melbourne Hospital. The event's focus was on living well and we had 3 interesting and valuable presentations. Dr Mary Ann Anderson was very engaging and interactive with the audience and presented on myeloma the disease as well as current treatments. Gail Rowen, senior pharmacist, delivered a fascinating talk on complimentary medications and Daniel Jones, financial planner, discussed managing



A/Prof Simon Harrison

finances with myeloma. Thank-you to everyone who attended and to our speakers for sharing their time and expertise.

I am very pleased to welcome a new Myeloma Information and Support Group in Ballarat. Having met twice now at the impressive Ballarat Regional Integrated Cancer Centre. It has been a pleasure to meet some of the local myeloma community and learn about the services available. The next meeting will be held on Friday 26th July. We have had too many interesting Information and Support Group topics and guest speakers to mention in this article, but I will be sure to fill you in next time

Please save the date for our next Victorian seminar in Geelong on Thursday 29th of August at the Waurn Ponds Hotel, further and exciting details to come soon. We are also collaborating on an event with St Vincent's Hospital and Leukemia Foundation on the Monday 16th August in Melbourne.

Elli Foley

Myeloma Support Nurse – VIC

Entertainment Book

Get your Entertainment Membership NOW and help Myeloma Australia raise much needed funds!

Help us raise funds for Myeloma Australia by buying an Entertainment Membership from us. Over \$20,000 worth of offers the whole family will love!

You'll receive hundreds of valuable offers for everything you love to do, and help our fundraising at the same time. Hurry, Entertainment Memberships sell out quickly.

**For more information contact Matt Maudlin
Community Engagement & Fundraising Manager
E: matt.maudlin@myeloma.org.au • M: 0407 891 052**



What's Happening

Western Australia

It's hard to believe how quickly 2019 is going, as we look back on the WA happenings since our last report, we have continued to develop strong support and educational opportunities for people in the myeloma community, as well as health professionals. We are both really feeling the strength of community here in the west

Information and Support

Our program for 2019 has seen groups held in Baldivis in the south, Wanneroo in the north, and Kalamunda in the hills, as well as a cofacilitated group with the Leukaemia Foundation in the South West. All of the groups have grown in attendance numbers and the sense of community is very strong. Recent topics discussed at these meeting have included immunisations post-transplant, treatment side effect management and tips to help prepare for doctor's appointments and the supported sharing of personal stories in relation to these topics added a warmth and understanding within the groups. New attendees are always welcome at any of the Information and Support Groups running in WA, so please get in touch if you are interested in coming along

The other informal meeting run in Cottesloe each quarter is the Coffee&Chat. This event was held on the 18th March in the Wanslea room and was very well attended. This event is an opportunity for people to drop in and meet up with other people in the myeloma community. A delicious morning tea was provided for attendees and the warm drinks flowed, leading to conversations surrounding sharing the experience of treatment with myeloma. These groups are often attended not only by people who have myeloma, but also their carers and it is a great chance for people to meet and make connections with others in a similar situation. The next Coffee&Chat event will be held on Friday 26th July 2019, all welcome.



Narelle, Dr Brad Augustson, Jo & Kerin

Information Mornings

On the 22nd February, the first information seminar for 2019 was held in the Conference Hall at the Cancer Wellness Centre in Cottesloe. We had approximately 30 attendees who were treated to the WA Myeloma Support Nurses, Kerin Young and Narelle Smith presenting. Firstly, Kerin spoke about "Preparing for your next medical appointment". Kerin and Narelle often hear from people feeling as though they wanted more information or even more time at their medical appointments, and Kerin explained some simple ways to approach each appointment so that the time and quality is maximised. Following on from Kerin's discussion, Narelle spoke about understanding tests and investigations in myeloma. This session proved quite interactive and touched on diagnostic tests, as well as ongoing investigations that may happen throughout treatment or at different times in myeloma. Both presentations were well received, and morning tea was delicious

On 24th May, the annual event in collaboration with the Leukaemia Foundation in support of National Myeloma Awareness Month was held at Technology Park in Bentley. With the theme of Me and Myeloma – Empowerment and Living Well, this event had four amazing speakers each providing the audience with quality information about



Amy Oliver



Xuan Ni Ta



Margaret Sealy



important and timely topics. Firstly, Dr Matt Wright (Clinical Haematologist Fiona Stanley Hospital) opened the event with a myeloma overview and an interactive question and answer session. Following on from Dr Wright, Dr Margaret Sealey (Lecturer in Counselling, Murdoch University) shared some useful insights in the importance of caring for our emotional wellbeing with a focus on carers. The tips provided by Margaret were certainly applicable to all of those living with myeloma. After a delicious morning tea from the onsite caterers at La Mint, Amy Oliver (Senior Occupational Therapist, Fiona Stanley Hospital) shared some excellent practical solutions for managing fatigue and there were several questions from the audience about this topic. The seminar was rounded off with another hot topic with Dr Xian Ni Tan (Clinical trials fellow, Dir Charles Gairdner Hospital / Linear Clinical Research) who shared a comprehensive update on current clinical trials on myeloma and upcoming treatments. The event was a great success, with over 85 attendees and

a fantastic venue and informative speakers. It was also great to have Steve and Nella back in WA spending time with us and the wider myeloma community. The seminar also gave us a great opportunity to work with the local Leukaemia Foundation team to put on this fantastic event

The next information seminar for people living with myeloma will be held at the Cancer Wellness Centre in Cottesloe on the 23rd August 2019. Keep an eye out for more information about this in the coming weeks as it is shaping up to be another interesting and informative event

Health Professional Education

On the 8th April 2019, we held a nursing and allied health professional event with the generous support of Amgen. This dinner event was held at Acqua Viva on Swan and was focused on the basics of myeloma as a disease and supportive care and almost 70 people in attendance. The first speaker of the evening was Dr Brad Augustson (Clinical Haematologist at Sir Charles Gairdner Hospital and Hollywood Private Hospital in Perth and MSAG member) who shared a compelling explanation of myeloma as a disease and detailed the common treatments currently in use. This was followed by a practical yet humorous presentation by Myeloma Australia's own Senior Myeloma Nurse from South Australia, Jo Gardiner. With the popularity of this event, we are hoping to hold another event later in the year with a more advanced focus

We are always so grateful for the ongoing support from the myeloma community here in WA enabling us to do what we are passionate about.

*Narelle Smith and Kerin Young
Myeloma Support Nurses WA*

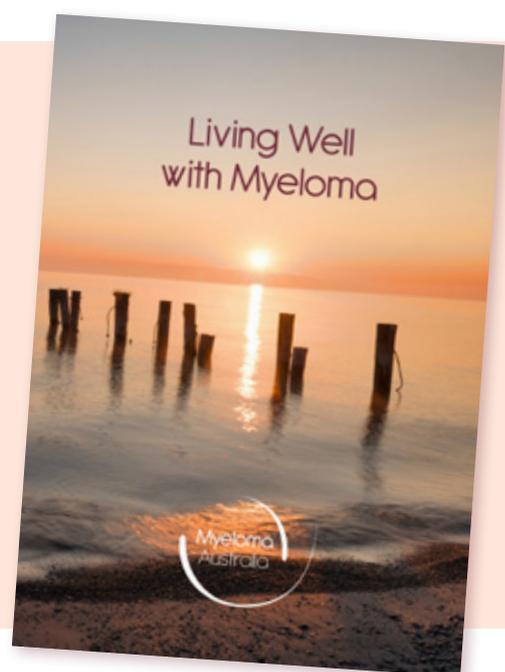
Photo supplied and used with permission

The "Living Well with Myeloma" book is now available from head office and your local Myeloma Support Nurse

This resource is written for people who are living with myeloma, it will also be helpful for their families, friends and health professionals. It provides information about various aspects of living with myeloma including building a team, managing side effects, maximising wellness and practical help. Information about other useful resources and organisations are also included throughout the book.

Please contact Head Office for your hard copy **T: (03) 9428 7444** or **E: support@myeloma.org.au**

The guide is also available for download on our website **<https://myeloma.org.au/resources/>**



Patient Experience:

Treatment preferences of patients with relapsed and refractory multiple myeloma: a qualitative study

Janet A. Parsons, Nicole R. Greenspan, Natalie A. Baker, Chris McKillop, Lisa K. Hicks and Olivia Chan; *BMC Cancer* 2019;19:264

This study sought to understand patients' lived experiences of RRMM and its treatment, and to identify which features of treatment were most important to them.

Interviews identified side effects that had significant impacts on patients' lives, including physical, cognitive, and psychological/emotional side effects and identified specific treatment features important to them. These were compiled and used in the focus groups to understand patients' priorities. Higher prioritized attributes were: life expectancy, physical and cognitive side effects, and financial impact. Mode of administration, treatment intervals, psychological side effects, and sleep/mood effects were identified as lower priorities.

Conclusions

RRMM and its treatments impact patients' quality-of-life across a range of domains. Patients prioritized treatment features that could enhance life expectancy, minimize side effects and offset financial burdens.

Implications for cancer survivors

Articulation of patient priorities can contribute to treatment designed with patients' concerns in mind, promoting a more patient-centered approach to care.

How people with myeloma perceive patient-reported outcome measures

Jayne Galinsky Health services research manager, Myeloma UK, Edinburgh, Scotland

Sarah Richard Researcher, Myeloma UK, Edinburgh, Scotland; *Cancer Nursing Practice*. doi: 10.7748/cnp.2019.e1574

There is a lack of literature on what patients with myeloma think about patient-reported outcome measures (PROMs). This study aimed to examine the views of patients and their family members about commonly used PROMs in myeloma to help guide future development and use.

Two patient groups reviewed selected validated PROMs used in myeloma: EQ5D-5L, HADS, FACT-G and the MyPOS, according to their perceived relevance to patient's lives, ease of completion, language and comprehensiveness.

Participants believed that PROMs had a validating effect on their concerns. MyPOS and FACT-G PROMs were preferred over the EQ5D-5L and HADS for language and content and greater relevance to their illness experience. Patients believed PROMs are important but underused in clinical practice.

Upfront Treatment:

Ixazomib maintenance therapy in newly diagnosed multiple myeloma: An integrated analysis of four phase I/II studies

Meletios A. Dimopoulos Jacob P. Laubach Maria Asunción Echeveste Gutierrez Norbert Grzasko Craig C. Hofmeister Jesus F. San-Miguel Shaji Kumar Richard Labotka et al; *European Journal of Haematology*; First published: 3 April 2019 <https://doi.org/10.1111/ejh.13231>

121 patients were enrolled to evaluate the safety and efficacy of maintenance therapy with the oral proteasome inhibitor ixazomib in patients with newly diagnosed multiple myeloma (NDMM) not undergoing transplantation. They had achieved stable disease or better after ixazomib-based induction and received ≥ 1 dose of ixazomib maintenance. Grade ≥ 3 drug-related adverse events occurred in 24% of patients during maintenance; each event was reported in $\leq 2\%$ of patients. Rates of complete response were 22% after induction and 35% after maintenance. A total of 28 patients (23%) improved their response during maintenance. **Conclusions:** Ixazomib maintenance following ixazomib-based induction is associated with deepening of responses and a positive safety profile with no cumulative toxicity in patients with NDMM not undergoing transplantation, suggesting that ixazomib is feasible for long-term administration. Phase III investigation of ixazomib maintenance is ongoing.

Supportive Care:

Gastrointestinal (GI) Microbiome and Mycobiome changes during Autologous Transplantation for Multiple Myeloma: Results of a Prospective Pilot Study

Najla ElJurdi MD et al; *Biology of Blood and Marrow Transplantation*; Available online 5 April 2019; <https://doi.org/10.1016/j.bbmt.2019.04.007>

GI microbial imbalance has been associated with adverse ASCT outcomes. The researchers hypothesized that high-dose melphalan and antimicrobials (antibiotics, anti-fungals), in patients undergoing ASCT for MM results in oral and gastrointestinal microbial imbalance (dysbiosis) that is associated with regimen-related toxicities. Their prospective study described the longitudinal changes in oral and gastrointestinal bacteriome (bacteria) and mycobiome (fungi) in this patient population. They showed that microbiome composition present at baseline is associated with the incidence and severity of post-transplant nausea, vomiting, culture-negative neutropenic fevers and rates of neutrophil engraftment. They demonstrated an association between the microbial communities at cell count nadir and the development of regimen-related GI toxicities commonly observed after exposure to high-dose melphalan. While bacteriome diversity largely recovers a month after transplantation, there is a continuous decrease in oral and GI mycobiome (fungal) diversity suggesting that the mycobiome requires longer to recover compared to the bacteriome after transplantation.

Cost of peripheral neuropathy in patients receiving treatment for multiple myeloma: a US administrative claims analysis

Xue Song, Kathleen L. Wilson, Jerry Kagan and Sumeet Panjabi; *Therapeutic Advances in Hematology*; 2019, Vol. 10: 1–28;

These researchers evaluated the economic burden attributable to PN among MM patients in real world practice settings in the US. 1387 patients with PN and 2594 controls were identified. Baseline characteristics were well balanced between cohorts; mean follow up was 23–26 months. Total costs were significantly higher by \$1509 for patients with PN than controls, driven by higher hospitalization (PN 77.4%, controls 67.2%; $p < 0.001$) and emergency department rates (PN 67.8%, controls 58.4%; $p < 0.001$) and more outpatient hospital-based visits per patient per month (PN 13.5 ± 14.7 , controls 11.5 ± 18.0 ; $p < 0.001$).

Conclusions

PN is a prevalent MM treatment complication associated with a significant economic burden adding to the complexity and cost of MM treatment. Highly effective novel treatments such as carfilzomib may reduce the overall disease burden.

Multiple myeloma and kidney transplantation: the beginning of a new era

Ines Van den bosch Ben Sprangers Morie Gertz; *Clinical Kidney Journal*, Volume 12, Issue 2, April 2019, Pages 213–215; Published: 1 March 2019

The introduction of several novel therapeutic agents has improved the outcome in multiple myeloma (MM) patients including those with chronic kidney disease, and it is predicted that MM will become a curable disease in a substantial subset of MM patients. While in the past—because of inferior post transplant outcomes—renal transplantation was not offered to MM patients, recent data suggests that renal transplantation is a viable treatment option in patients treated with modern anti-myeloma induction therapy followed by autologous stem cell transplantation achieving durable complete responses. The article of Shah, Ibrahim, Delaney et al. [Risk of relapse of multiple myeloma following kidney transplantation: a case series report. *Clin Kidney J* 2018 (in this issue)] in the current issue of *Clinical Kidney Journal* adds to this evidence and highlights the limitations and outstanding questions concerning renal transplantation in MM patients. **It concludes:** “Forty percent of our cohort experienced a relapse in MM within 2 years of kidney transplantation. Death-censored graft survival and patient survival were 80% at 4 years. Our study adds to the growing literature supporting kidney transplantation following successful ASCT for MM and is useful when counselling patients regarding renal and haematological outcomes.”

Common abbreviations used in Medical Corner

ASCT: autologous stem cell transplantation

BM: bone marrow

Consolidation: short duration of treatment given after ASCT to intensify response

CR: complete response (no abnormal blood or urine myeloma markers, disappearance of any soft tissue plasmacytomas and < 5% plasma cells in BM)

IMiD: Immunomodulatory drug (ie Lenalidomide, Thalidomide, Pomalidomide)

Induction: first line treatment after diagnosis for fast disease control with minimal toxicity

Maintenance: long term treatment given after induction +/- ASCT to maintain response from induction

MoAB: monoclonal antibody (ie: daratumumab, elotuzumab, isatuximab)

NDMM: newly diagnosed multiple myeloma

ORR: overall response rate

OS: overall survival

PFS: progression free survival

PI: proteasome inhibitor (ie Bortezomib, Carfilzomib)

Phase I trial: accrue small numbers (tens) of patients to evaluate safety (a safe dose range and identify side effects)

Phase II trial: accrue larger numbers (hundreds) of patients to determine if the study drug/s work as intended (efficacy)

Phase III trial: accrue large numbers (thousands) of patients to confirm efficacy and monitor long term effects of the study drug/s

PR: partial response to treatment (>50% reduction in myeloma markers)

PD: progressive disease (increase of > 25% from lowest response value of myeloma markers)

Prospective study: real time study accruing patients as they are diagnosed or relapse

Randomized study: one cohort gets the active drug and the other does not

Retrospective study: one that looks back at cohorts of patients with similar characteristics

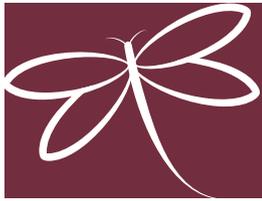
RR/MM: relapsed or refractory to therapy multiple myeloma

sCR: stringent complete remission (as for CR plus normal blood light chain ratio and absence of clonal cells in bone marrow)

Tandem transplant: 2 ASCT performed to intensify treatment

Triplet: 3 drugs used in combination

VGPR: very good partial remission (>90% reduction in myeloma markers)



Calendar of Events 2019

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

Victoria

Event	Date	Location	Time	Organisation	Contact
Sunshine Information and Support Group	Thur Jul 25th	Braybrook Community Centre 107 – 139 Churchill Ave, Braybrook	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Beaumaris Information and Support Group	Thur Aug 1st	Beaumaris Theatre 82 Wells Road, Beaumaris	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Coburg Information and Support Group	Wed Aug 7th	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site) Coburg	10am – 12 noon	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Bendigo Information and Support Group	Wed Aug 7th	Bendigo Cancer Centre, Bendigo Hospital 100 Barnard St, Bendigo	11am – 1pm	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Kew Information and Support Group	Thur Aug 8th	Kew Library Corner Charles St & Cotham Rd, Kew	10am – 12 noon	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Aug 8th	Rotating at local venues, details published closer to date	6pm – 8pm Dinner	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Geelong Information and Support Group	Fri Aug 9th	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10am – 12pm	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Younger Persons Information and Support Group	Thur Aug 22nd	Myeloma Australia Head Office 333 Swan St, Richmond	6pm – 8pm	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Berwick Information and Support Group	Fri Aug 30th	St John of God Hospital Level 1, 55 Kangan Dv, Berwick	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Wangaratta Information and Support Group	Thur Sep 5th	Wangaratta Library Seminar Room 21 Docker St, Wangaratta	11am – 1pm	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Albury Information and Support Group	Fri Sep 6th	Albury Wodonga Regional Cancer Centre Wellness Room, 201 Borella Rd, East Albury	10am – 12 noon	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Traralgon Information and Support Group	Wed Sep 18th	Gippsland Rotary Centenary House 39 Valley Dve, Traralgon	10am – 12pm	Myeloma Australia	Emma Jane Furphy E: EJ.Furphy@myeloma.org.au M: 0451 404 203
Sunshine Information and Support Group	Thur Sep 19th	Braybrook Community Centre 107 – 139 Churchill Ave, Braybrook	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233

... Victoria list continues over page

Victoria – continued

Event	Date	Location	Time	Organisation	Contact
Coburg Information and Support Group	Wed Oct 2nd	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site) Coburg	10am – 12 noon	Myeloma Australia	Emma Jane Furphy E: E.J.Furphy@myeloma.org.au M: 0451 404 203
Beaumaris Information and Support Group	Thur Oct 3rd	Beaumaris Theatre 82 Wells Road, Beaumaris	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Bendigo Information and Support Group	Wed Oct 9th	Bendigo Cancer Centre, Bendigo Hospital 100 Barnard St, Bendigo	11am – 1pm	Myeloma Australia	Emma Jane Furphy E: E.J.Furphy@myeloma.org.au M: 0451 404 203
Kew Information and Support Group	Thur Oct 10th	Kew Library Corner Charles St & Cotham Rd, Kew	10am – 12pm	Myeloma Australia	Emma Jane Furphy E: E.J.Furphy@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur 10th Oct	Rotating at local venues, details published closer to date	6pm – 8pm Dinner	Myeloma Australia	Emma Jane Furphy E: E.J.Furphy@myeloma.org.au M: 0451 404 203
Geelong Information and Support Group	Fri Oct 11th	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
Berwick Information and Support Group	Fri Oct 25th	St John of God Hospital Level 1, 55 Kangan Dv, Berwick	10am – 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Wangaratta Information and Support Group	Thur Nov 7th	Wangaratta Library Seminar Room 21 Docker St, Wangaratta	11am – 1pm	Myeloma Australia	Emma Jane Furphy E: E.J.Furphy@myeloma.org.au M: 0451 404 203

New South Wales

Event	Date	Location	Time	Organisation	Contact
Rutherford Meet & Greet	Wed Jul 10th	Rutherford Community Centre Elphick Room 13 Arthur St, Rutherford	10am – 12 noon	Myeloma Australia	Juliet Hill E: juliet.hill@myeloma.org.au M: 0433 511 554 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Aug 13th	Liverpool Hospital; The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10am – 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
RPAH Information and Support Group	Tues Aug 13th	Royal Prince Alfred Hospital Kerry Packer Education Centre, Seminar Room 4.5 John Hopkins Dve, Camperdown	10am – 12 noon	Myeloma Australia / RPAH	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 pager: 87524
Westmead Information and Support Group	Thur Aug 15th	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10am – 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Aug 29th	Central Coast Leagues Club Dane Drive, Gosford	6 – 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger E: jacqueline.jagger@health.nsw.gov.au P: (02) 4320 9641 1800 MYELOMA (693 566)

... New South Wales list continues next page

New South Wales – continued

Event	Date	Location	Time	Organisation	Contact
Newcastle Information and Support Group	Mon Sep 2nd	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm – 5pm	Myeloma Australia	Juliet Hill E: juliet.hill@myeloma.org.au M: 0433 511 554 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tues Oct 8th	Liverpool Hospital; The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10am – 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
RPAH Information and Support Group	Tues Oct 8th	Royal Prince Alfred Hospital Kerry Packer Education Centre, Seminar Room 4.5 John Hopkins Dve, Camperdown	10am – 12 noon	Myeloma Australia / RPAH	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 pager: 87524
Westmead Information and Support Group	Thur Oct 17th	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10am – 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Oct 31st	Central Coast Leagues Club Dane Drive, Gosford	6 – 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger E: jacqueline.jagger@health.nsw.gov.au P: (02) 4320 9641 1800 MYELOMA (693 566)
Newcastle Information and Support Group	Mon Nov 4th	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm – 5pm	Myeloma Australia	Juliet Hill E: juliet.hill@myeloma.org.au M: 0433 511 554 1800 MYELOMA (693 566)
Newcastle Information and Support Group	Sun Dec 1st (Xmas Lunch)	TBA	12pm – 4pm	Myeloma Australia	Juliet Hill E: juliet.hill@myeloma.org.au M: 0433 511 554 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tue Dec 10th	Liverpool Hospital; The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10am – 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230

Tasmania

Event	Date	Location	Time	Organisation	Contact
Southern Tasmania Information and Support Group	Tues Aug 6th	Clarence Integrated Health Centre (CICC) Meeting Room 2 16-22 Bayfield St Bellerive	10am – 12 noon	Myeloma Australia	Deborah Thompson E: deborah.thompson@myeloma.org.au M: 0433 511 689 1800 MYELOMA (693 566)
Southern Tasmania Information and Support Group	Tues Sep 3rd	Glenorchy Community Health Centre Art Room Level 3 404 - 408 Main Rd Glenorchy	10am – 12pm	Myeloma Australia	Deborah Thompson E: deborah.thompson@myeloma.org.au M: 0433 511 689 1800 MYELOMA (693 566)
Southern Tasmania Information and Support Group	Tues Oct 1st	Cancer Council Tasmania 15 Princes St, Sandy Bay	10am – 12 noon	Myeloma Australia	Deborah Thompson E: deborah.thompson@myeloma.org.au M: 0433 511 689 1800 MYELOMA (693 566)
Southern Tasmania Information and Support Group	Tues Nov 5th	Clarence Integrated Health Centre (CICC) Meeting Room 2 16-22 Bayfield St Bellerive	10am – 12 noon	Myeloma Australia	Deborah Thompson E: deborah.thompson@myeloma.org.au M: 0433 511 689 1800 MYELOMA (693 566)
Southern Tasmania Information and Support Group	Tues Dec 3rd	Glenorchy Community Health Centre Art Room Level 3 404 - 408 Main Rd Glenorchy	10am – 12 noon	Myeloma Australia	Deborah Thompson E: deborah.thompson@myeloma.org.au M: 0433 511 689 1800 MYELOMA (693 566)

South Australia

Event	Date	Location	Time	Organisation	Contact
Flinders Information and Support Group	Thur Jul 18th	Living Kurna Cultural Centre Function Room Warriparinga Way, Bedford Park	10am – 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Wed Aug 14th <i>*Date Change</i>	Fullarton Park Centre 411 Fullartoan Rd, Fullarton	10am – 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)
Mid North Information and Support Group	Wed Aug 21st	Snowtown Hospital 70 Railway Terrace E, Snowtown	12 noon – 2pm	Myeloma Australia	Bronwyn Gerschwitz E: graemebronwyng@bigpond.com P: (08) 8664 0682 1800 MYELOMA (693 566)
South East Information and Support Group	Thur Aug 29th	Katnook Estate Riddoch Highway, Coonawarra	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 Sep 19th	Living Kurna Cultural Centre Function Room Warriparinga Way, Bedford Park	10am – 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Wed Oct 9th <i>*Date Change</i>	Fullarton Park Centre 411 Fullartoan Rd, Fullarton	10am – 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)

Western Australia

Event	Date	Location	Time	Organisation	Contact
Coffee & Chat	Fri Jul 26th	Solaris Cancer Centre, Wanslea Room 80 Railway Road, Cottesloe	9:30am – 11:30am	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
South Metro Information and Support Group	Mon Jul 29th	Mary Davis Library & Community Centre 17 Settlers Av, Baldivis	10am – 12 noon	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Aug 12th	Wanneroo Library Group Study Room, Level 1 3 Rocca Way, Wanneroo	1pm – 3pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
Perth Hills Information and Support Group	Mon Aug 26th	Zig Zag Cultural Centre 50 Railway Rd, Kalamunda	10am – 12 noon	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
Coffee & Chat	Fri Sep 20th	Solaris Cancer Centre, Wanslea Room 80 Railway Road, Cottesloe	9:30am – 11:30am	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
South Metro Information and Support Group	Mon Sep 23rd	Mary Davis Library & Community Centre 17 Settlers Av, Baldivis	10am – 12 noon	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Oct 14th	Wanneroo Library Group Study Room, Level 1 3 Rocca Way, Wanneroo	1pm – 3pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)

Queensland

Event	Date	Location	Time	Organisation	Contact
PAH Information and Support Group	Wed Jul 3rd	Princess Alexandra Hospital 199 Ipswich Rd, Annerley	11am – 1pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Labrador Information and Support Group	Wed Jul 17th	Labrador Information and Support Group	11am – 1pm <i>*Note new time for this session only</i>	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Woolloongabba Information and Support Group	Tues Jul 30th	Woolloongabba Senior Citizens Centre 22 Qualtrough St, Woolloongabba	10am – 12 noon	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tues Aug 6th	Bloomhill Cancer Centre 58 Ballinger Road, Buderim	2pm – 4pm	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Alderley Information and Support Group	Fri Aug 9th	Alderley Arms 2 Samford Road, Alderley	10am – 12 noon	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
North Lakes Information and Support Group	Fri Aug 23rd	North Lakes Health Conference Centre, Oncology 7 Endeavour Bvd, North Lakes	1pm – 3pm <i>*Note new time for this session only</i>	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
PAH Information and Support Group	Wed Aug 28th	Princess Alexandra Hospital 199 Ipswich Rd, Annerley	11am – 1pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tues Sep 3rd	Bloomhill Cancer Centre 58 Ballinger Road, Buderim	2pm – 4pm	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Labrador Information and Support Group	Wed Sep 11th	Labrador Information and Support Group	10:30am – 12:30pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Woolloongabba Information and Support Group	Tues Sep 24th	Woolloongabba Senior Citizens Centre 22 Qualtrough St, Woolloongabba	10am – 12 noon	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tues Oct 1st	Bloomhill Cancer Centre 58 Ballinger Road, Buderim	2pm – 4pm	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)

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	1.30 pm – 2.30 pm (AEST)	Cancer Council NSW with MA NSW	Cancer Council NSW 1300 755 632 E: tsg@nswcc.org.au

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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)

Mon – Fri 9am – 5pm AEST

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