

MyeNews

Summer 2019 Issue no 52



Contents

In this issue

From the President	3	What's happening NSW	11
Molecular testing at the Alfred Hospital	4	What's happening QLD	13
The Journey	5	What's happening SA	14
Wombats and Devils – and other beasts that appear whilst on steroids!	6	What's happening TAS	15
Myeloma and money	8	What's happening VIC	16
News from the Myeloma and Related Diseases Registry	9	What's happening WA	17
What's happening – Community Engagement and Fundraising	10	Medical Corner	18
		Calendar of Events	21



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From the President

The 1st of November is an important day to my family as it was when my wife Roslyn, was diagnosed with myeloma, now 23 years ago. Like everyone, at that time we had never heard about myeloma and naturally researched myeloma on Google. Twenty-three years ago, there was not a lot of reliable information around let alone much choice of treatments. So much has changed in the past years.

I remember a workshop when Professor Miles Prince spoke about thalidomide and that this was the first of the novel therapies that was having positive effects on treating myeloma, but they were not sure how it worked. Now the research has solved this problem and they understand how the myeloma cells communicate and accordingly this is leading to discovering compounds that interfere with this communication and can stimulate the breakdown and elimination of the myeloma cells.

I forgot to mention that Roslyn is well and very active enjoying our grandchildren and her hobbies as well as still working a couple of days a week. She has her bloods checked every three months and sees her haematologist every six months and so far, so good.

Again, this December Steve (our CEO), Nella (Myeloma Nurse Manager) and myself will be heading to Orlando for the American Society of Hematology's annual meeting (ASH19) as guests of the International Myeloma Foundation (IMF). We have been invited to several of their pre-meeting events as well as the opportunity to attend many of the presentations of myeloma research by scientists and doctors from around the world to learn about the latest research. Connected with this conference is a large trade show where we will be able to speak with representatives of the pharmaceutical companies who are developing these new treatments for myeloma.

This year the Pharmaceutical Benefits Advisory Committee approved the combination of three drugs for the treatment of myeloma. This is the first time they have approved a triplet combination for the treatment of myeloma. Lenalidomide in combination with bortezomib and dexamethasone (RVd) has been used in some overseas countries successfully for years. We are now waiting on Cabinet to approve the pricing structure before it will be placed on the subsidised list of medicines. At the time of writing, we are still waiting on the outcome of the approval of Daratumumab for the treatment of myeloma.

I am excited about how well our expanded team of Myeloma Support Nurses are going. They have expanded the number of myeloma support groups from 28 last year to 51 so far this year with over 1,630 people attending these groups during the year. We are working, with the help of Rotary, towards running support groups in country areas, by computer links with our nurses. This will save a lot of travel time and enable our nurses to "attend" meetings more often in more areas. We will keep you informed as this project advances.

Myeloma Australia is committed to providing our support services through our team of Myeloma Support Nurses. This is a very expensive way of providing support in comparison to that provided in other countries. To enable us to continue we need your support through fundraising. Every little bit helps, so even a small donation in place of a birthday present can make a difference.

Brian Rosenzweig



Christmas Dates

**Myeloma Australia will be closed from
12:00 midday on Tuesday 24 December 2019
Reopening at 9:00 am on Monday 6 January 2020.**

From everyone at Myeloma Australia – we thank you for your support in 2019 and wish you and your loved ones a Safe and Happy Festive Season.

Molecular Testing

Molecular testing at the Alfred Hospital

Cytogenetics is the study of chromosomes within a cell. Most commonly done at diagnosis, cytogenetic testing identifies the genetic mutations which characterise a person's myeloma. This information helps doctors understand more about a person's myeloma, how it may affect them over time, how it may respond to treatment and for some, cytogenetics can influence treatment decisions. Many people with myeloma want to know about their cytogenetics to help them understand more about their myeloma and what they can expect. There are a number of ways to look at a person's cytogenetics, we are very excited to share this story from the Alfred Hospital in Melbourne, the first hospital in Australia to introduce the MMprofiler™ technology for cytogenetic testing and we look forward to seeing more of this available around the country.

The Alfred Hospital via its Multiple Myeloma programme is the first specialist myeloma centre outside of Europe to introduce the innovative MMprofiler™ risk-profiling platform for newly diagnosed myeloma patients and is making the technology available to patients being treated at The Alfred. The MMprofiler™ assay measures the expression of all the genes in myeloma cells purified from the bone marrow prior to starting treatment, an algorithm called Skyline 92 then specifically calculates the expression of 92 genes and is able to define patients with 'high-risk' myeloma. Moreover, the use of the MMprofiler™, within only 48 hours, provides a more accurate way of defining the chromosome abnormalities usually detected with FISH testing, thus making FISH testing unnecessary. Patients with high-risk myeloma have more aggressive disease and are more likely to relapse early, so the information provided by the MMprofiler™ is critical to inform a more personalised approach to treatment for patients identified with high-risk disease. The team at The Alfred have been using the MMprofiler™ in a number of their investigator-initiated clinical trials of high-risk myeloma over the past 2 years and have optimised the assay in their hands including obtaining the appropriate accreditation for the

Molecular Testing
MMprofiler



use of the assay via Skyline Diagnostics in Rotterdam. The platform underwent several years of intensive validation and is now approved by the European regulatory agency the EMEA as a diagnostic tool. It was introduced for the first time in clinical practice at the Erasmus Medical Centre in Holland in July 2019 and is being made available to UK myeloma patients via Everything Genetic Ltd. Head of the Alfred Multiple Myeloma Programme Professor Andrew Spencer said 'the MMprofiler™ represents a highly robust and reproducible way of applying appropriately validated genetic risk analysis into the myeloma diagnostic process and now for the first time will enable us to personalise patient treatment by having real-time genetic characterisation of a patient's disease when it is first diagnosed'.

Professor Andrew Spencer

Photo supplied and used with permission

Team Myeloma T-shirts for Sale

\$25 each
Sizes S-2XL



Via head office: 1300 632 100
or the eBay shop:
<http://myeloma.org.au/volunteer-with-us/shop/>

The Journey

Kai Kasad decided to challenge himself to run an ultra 50km marathon in his 50th year, dedicating this to his friend and raising money and awareness for Myeloma Australia in the process. Below is an excerpt from his story which is featured as a blog on our website www.myeloma.org.au

“Last year, at a speed session at the Burwood Athletics track, I came across a thought while warming up/cooling down with a runner friend. I mentioned that night how it would be cool to run a 50KM race (an ultra-marathon) in our 50th year, given we both reached the milestone this year.

So on 23 September, I lined up to run the 50KM solo event at Surf Coast Century; an out and back route from Angelsea to Moggs Creek following an inland route, and a hillier course compared to the Surf Coast Trail Marathon which was a point-to-point race from Torquay to Fairhaven.

I generally adopt a charity close to my heart to raise funds in running and completing these endurance runs. So, when I learnt that my dear friend Kiri was diagnosed with stage 3 multiple myeloma, my choice of charity was clear – Myeloma Australia.



If you wish to donate to my cause, the fundraising page will remain open until January 2020:
<https://give.everydayhero.com/au/Running-kms-for-kiri-and-myeloma-aus>



Birgit with friend Jessica Clarke (L>R)



New York City Marathon

Our friend Birgit Bourne recently ran and successfully completed the New York City Marathon. Birgit dedicated her run to supporting Myeloma Australia following the loss of one of her friends to myeloma a little while ago. Birgit raised over \$2,000 through her efforts.

Thank you and congratulations Birgit!!

Matt Maudlin
Community Engagement
& Fundraising Manager

Wombats and Devils

Wombats and Devils – and other beasts that appear whilst on steroids!



"I feel like the Muddle Headed Wombat whilst on dexamethasone" Patient A
"They (dexamethasone) are the Devils Tic Tacs" Patient B

Corticosteroids (steroids) are important and highly effective drugs that have been used in the treatment of myeloma since the 1960's. Steroids form the backbone of treatment regimens and will continue to be part of the treatment paradigm for myeloma into the future. Whilst acknowledging their importance in the effective management of myeloma, we also recognise steroids can be hard to tolerate. This is due to a wide range of physical side effects, mood and behavioural changes that can occur and adversely impact the lives of patients and family members.

The most commonly used steroids in myeloma are **dexamethasone** and **prednisolone**, or in true Aussie style of using abbreviations 'dexam' or 'pred'. Given in combination with other agents (e.g. chemotherapy, lenalidomide, pomalidomide, bortezomib, carfilzomib, daratumumab) patients often find themselves taking many courses of steroids for months or even years at a time.

How do steroids work in myeloma?

Steroids as treatment for myeloma:

- Actively destroy myeloma cells by blocking chemical messengers (cytokines) that promote myeloma cell growth.
- In combination with other drugs steroids act in synergy to increase the ability of combination treatments to destroy myeloma cells.

Steroids help manage side effects and symptoms:

- Decrease inflammation or swelling and therefore reduce pain and discomfort
- Prevent allergic reactions or hypersensitivity reactions
- Help reduce nausea and vomiting

Steroids are commonly taken as tablets, the dose and frequency varies between treatment protocol and individual person. The most common schedule would be to take steroids once per week. Your doctor, nurse or pharmacist would be best placed to provide you with details of your own individual steroid dose and schedule.

What are the more common side effects associated with taking steroids?

Whilst there is a wide range of possible side effects that can occur when taking steroids, I have included only the more common ones in the table below alongside suggested tips for management. For a more comprehensive summary, please see the 'Steroid Treatment Fact Sheet' from Myeloma Australia and the 'Understanding Dexamethasone and other Steroids' from the International Myeloma Foundation – listed in the following table.

SIDE EFFECT	SUGGESTED MANAGEMENT
Heartburn or indigestion	Take steroids with or immediately after food. May require over the counter medication to minimise gastric irritation (e.g. pantoprazole)
Increased blood sugar levels	Extra blood sugar monitoring will be required in those who are diabetic or have pre-existing raised blood sugar levels. Close liaison with GP or diabetes nurse is recommended. May require increase in diabetes medication/s
Disturbed Sleep	Take steroid in the morning. A small number of people find taking their steroid dose at night-time improves their sleep due to a delay in steroid effect. Some people require sleeping tablets on the days they take steroids. Discuss with your doctor and see 'Sleep Hygiene Tips' below.
Mood and behaviour changes • Anger & irritability • Agitation & nervousness	High and low moods, commonly around steroid days Family & friends may appreciate mood changes before patients Keeping active with simple tasks and exercises can help minimise the highs and lows. May require dose reductions or schedule changes (e.g. split dose over 2 or 3 days). Check with doctor or nurse before changing schedule
Energy changes	Increased energy on steroid days Loss of energy on days following Plan your day/week around predictable energy patterns
Increased risk of infection	May require taking preventative anti-biotics Recognise signs of infection (Temp > 38oC, productive cough, shivers and shakes) Seek same day medical attention if signs of active infection
Fluid retention (ankle, lower limbs or abdomen)	Exercise as tolerated Elevate lower limbs at rest May require diuretic medication – be directed by doctor
Blurred vision	Commonly improves when steroids cease Longer term effect – cataracts
Muscle cramps/ weakness	Exercise to improve muscle strength and reduce cramps

Steroids remain an important part of effective treatment for myeloma and your haematologist will be working to balance the efficacy of your treatment plan with known toxicities of each drug. Commonly we commence patients on standard treatment protocols, doses and schedules and then observe for any side effects that may occur. With monitoring and follow up, your team may make adjustments in doses or schedules to maintain good control of the underlying myeloma and allow you to better tolerate the course of treatment and maintain good quality of life.

As a myeloma nurse specialist with 30 years working with those affected by myeloma, I have developed a particular interest in understanding the impact of steroids for patients and family members. My PhD research studies involve developing and evaluating a tool to help us better understand and manage steroid effects in those with myeloma. The tool is called the Steroid Symptom Questionnaire Myeloma (SSQ-MM) and has been recently tested in 70 patients in 3 NSW hospitals. Findings showed the most commonly reported side effect associated with steroids for myeloma was insomnia and loss of energy, reported in over 94% of patients with intermittent agitation / nervousness reported in 75% of patients (King T in press 2019).

Findings from this pilot study have provided us with a greater understanding of the wide range of steroid effects and in time, we plan to be able to use this tool in our clinics to better manage patients' symptoms and side effects relating to steroids. Many thanks to those who participated and generously gave of your time.

How can patients better manage steroid associated effects?

Understanding how medications (including steroids) effect you as an individual, is key to managing the effects and learning to live better on myeloma treatment.

Keeping a symptom journal for the first few cycles of new treatment can be a useful way to understand the symptoms you experience, when they occur and possible associations. This can help you recall your experiences and more effectively report them to your medical team who in turn are able to manage your symptoms more effectively.

A note to family and friends

Steroids can change people's mood, energy and tolerance of others. Identifying the pattern and working life events around these often-predictable changes, is key to managing them. Be kind to each other – it can be tough learning to live with myeloma and its treatment. In our recent study, we found that those who had experience in managing steroids, managed ways around the symptoms and effects.



Top Tips to Optimise Sleep – Sleep Hygiene

Obtaining healthy sleep is important for both physical and mental health and improves overall quality of life.

- Limit daytime napping
- Avoid stimulants near bedtime e.g. caffeine

- Avoid heavy, rich, spicy food near bedtime
- Exercise to promote good sleep
- Establish regular relaxing bedtime routine
- Exposure to natural light during waking hours and darkness overnight
 - o Particularly useful to those who don't get outside much during the day
- Ensure sleep environment is pleasant and comfortable
 - o Avoid exposure to light from screens, TV, phones etc.
 - o Minimise noise
 - o Comfortable bed and cool temperature (16-19 degrees optimal)

<https://www.sleepfoundation.org/articles/sleep-hygiene>

Further reading

<https://www.myeloma.org/sites/default/files/resource/U-Dexamethasone.pdf>

<http://myeloma.org.au/wp-content/uploads/2018/09/Steroid-FS-Sep18.pdf>

*Tracy King RN MN, PhD candidate
Myeloma Clinical Nurse Consultant
Royal Prince Alfred Hospital Sydney.
Clinical Research Fellow, Cancer Nursing Research Unit,
Sydney University*

(Tracy won the Sydney Local Health District 'Outstanding Achievement Nursing & Midwifery Research Award 2019' for her work in better understanding the impact of steroids in those with multiple myeloma.)



L>R: Ms Ivanka Komusanac District Director of Nursing, Tracy King Myeloma CNC and Professor Elizabeth Denney-Wilson Professor of Nursing SLHD.

“We didn’t worry about money to start with...”

A diagnosis of myeloma can have a significant impact on your and your family’s financial circumstances. Co-payments for tests and procedures, medications, GP and allied health visits, as well as parking and travel costs, and accommodation costs if from a rural or regional area, combined with reduced income, can all cause financial difficulties.

Financial distress can be a consequence of living with myeloma. It may impact your wellbeing and that of your family as well as your ability to comply with all treatment recommendations. It is important that your treating team are able to identify whether you are at risk of financial distress and, if required, help you identify financial coping strategies and access financial assistance.

A questionnaire developed in the United States that measures financial distress in cancer patients allows patients to reflect and report on their financial circumstances and enables treating teams to easily see who among their patients is at risk of financial distress and provide the necessary support.

The Cancer Nursing Research Unit (CNRU) at the University of Sydney in partnership with the Centre for Health Economics Research and Evaluation (CHERE) at UTS, is currently working to determine the usefulness of this questionnaire in Australia. Because of the very different health systems in the two countries and the different population makeup it is necessary to test the questionnaire in the population in which it will be used.

As part of this process 20 cancer patients, 10 with myeloma were interviewed to explore their financial experience of living with cancer. While not all participants were under

financial stress, they recognised the potential for it to arise. Here is a small sample of what they said:

“Obviously I cut down on certain things as well, like entertainment, clothing, grocery shopping, and things like that. But whenever I ran too low, I put it on my credit card”.

“You feel vulnerable, anyway, when you’re sick. And, I suppose, the last thing you need is financial stress and, yet, of course, you have it. You have it in the immediate sense that you can’t work and you’re a cost burden. So you’re not getting your income, but you’re actually incurring more costs”.

“I was starting to really drain my savings and it was getting to the point where I was running out of money to actually start paying my normal household things”.

“Basically just borrow extra money against your house, so we’ve got what you call a line of credit with the house, so we were financially well we had – we almost had our current house paid off and now we’ve got about a quarter of a million dollar debt on it”.

A successful outcome from this study would be to have the questionnaire used routinely by myeloma treating teams when assessing the side effects of cancer and its treatment. The use of the questionnaire would aid in the identification of patients and families suffering or likely to suffer financial distress. The treating team would then be able to assist this group in identifying coping strategies and accessing support.

By Louise Acret on behalf of the Research Team

Resources

For information on cancer and your finances the below resources may be helpful.

<https://www.leukaemia.org.au/what-is-the-financial-impact-of-cancer/>

<https://www.cancercouncil.com.au/cancer-information/legal-work-and-financial-issues/finances/>



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.

NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

RECRUITMENT UPDATE

2019 has been an excellent year so far for the registry, with great patient recruitment and expansion to multiple new sites.

We now have over 3200 patients participating, and are growing fast with 52 sites across Australia and New Zealand; 41 approved and 11 pending governance approval. The latest site to join the registry is Toowoomba Hospital. Welcome to new patients and sites and a big thank you to everyone involved in the registry for your continued support.



DR JESSIE ZHAO PRESENTING AT BLOOD 2019

MRDR AT BLOOD 2019



The annual MRDR Interest Group breakfast at Blood 2019 in Perth in October was a success with over 60 attendees representing patient groups, hospital sites, researchers, industry, and other collaborators.

Attendees enjoyed an update on registry data and progress by Dr Brad Augustson, the principal investigator for Sir Charles Gairdner Hospital in Perth. In addition, Dr Jessie Zhao won a Snowdome Travel Grant Award for her presentation titled,

Real-world treatment patterns in relapsed/refractory multiple myeloma in Australia: results from the Myeloma and Related Diseases Registry. A/Prof Hilary Blacklock gave a presentation on the characteristics of Polynesians in New Zealand with MM compared to other ethnicities using MRDR data, and Dr Elizabeth Moore presented results of the My-PROMPT trial. It is great to see patients' data being put to good use in such a wide variety of projects and analyses.

MRDR AT IMW 2019



The MRDR was well represented at the recent International Myeloma Workshop (IMW) in Boston, USA, in September, attended by over 3200 delegates. Prof Andrew Spencer, MRDR Coordinating Principal Investigator, gave an invited presentation on the role of myeloma registries in improving real-world outcomes, and Dr Elizabeth Moore presented results of My-PROMPT, a pilot randomised controlled trial to test the feasibility of real-time feedback of patient-reported outcomes to clinicians treating patients with MM.

MRDR posters included data on the impact of number of cycles of therapy on outcomes in patients treated with bortezomib induction (A/Prof Peter Mollee), and myeloma in Pacific Islanders in New Zealand (A/Prof Hilary Blacklock).

The inaugural APAC MRDR Investigators' Meeting was also held during the IMW in Boston. It was well attended with investigators from Australia, China, Hong Kong, Taiwan, and Singapore present. Presentations included results from the ANZ MRDR and an overview of progress of the APAC MRDR.

WEBSITE UPGRADE

The MRDR website has undergone an upgrade and has gone live! Feel free to check out our new look! The URL will remain the same (mrd.net.au).

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

P 1800 811 326
E sphpm-myeloma@monash.edu
mrd.net.au

THE MYELOMA 1000 PROJECT (M1000)

Recruitment to M1000 has reached over 360 patients and more interstate sites are coming on board. This is a blood biobank substudy of the MRDR aiming to collect samples from 1000 patients with multiple myeloma (MM) and 1000 with MGUS. The first samples have been sent to researchers from the University of Adelaide for a project investigating whether serum CTX-1 levels predict progression from pre-malignancy to active disease in MM. The participation of new Australian sites is welcome; see contact details below.



MONASH
MEDICINE,
NURSING AND
HEALTH SCIENCES



AlfredHealth

CRICOS Provider: Monash University 00008C. TRSU NOV 2019

What's happening

Community Engagement & Fundraising

And so here we are, at the end of another year of Community Engagement & Fundraising – and what a year it's been! I reflect upon 2019 as another year of positive and progressive growth in this area of Myeloma Australia.

Personally, I have had the privilege of meeting with members of the myeloma community in Victoria, NSW, Queensland and South Australia. It has been wonderful to see the many and varied ways that individuals and communities have adopted to raise awareness about myeloma and to raise vital funds for Myeloma Australia. One of my many highlights of 2019 was seeing the burgundy 'Team Myeloma' t-shirts being proudly worn by the group who went to Basecamp at Everest on the front cover of the Winter edition of MyeNews.

In addition to photos at Everest we have seen many people participating in Team Myeloma events at running events throughout Australia, we have had people running marathons in New York City, Melbourne and Athens, beautiful jewellery being made and sold to raise funds for us, businesses supporting our work through events they are hosting, a participant in a Tough Mudder event, a school raising awareness and fundraising for us, a lawn bowls event being held, an In Line Boots class was hosted, funds raised through Bunnings BBQs, morning and afternoon high-tea events, heads and beards being shaved (sometimes by very

young supporters!) and well, you get the idea! There are so many ways in which community engagement and fundraising is occurring right now – it's so encouraging! We are so appreciative of all the efforts that members of the myeloma community go to in order to raise awareness and funds; we thank you all.

And now we look ahead to 2020. The year really kicks into gear in the first week of February when we embark upon the Myeloma Australia/Charity TV Global adventure. The venue for this filming is Top Secret (!!) and details are being held by CEO Steve and myself! We will be sure to produce a bumper report regarding the adventure in one of the early editions of MyeNews next year.

There will be the established Team Myeloma community running events in 2020 – if you have ideas as to where we might introduce new events do please let me know. We will also be promoting the Dry July campaign and encouraging our community to consider becoming involved in our own Zero October campaign.

As always, please drop me a line with all your community engagement, awareness raising and fundraising ideas. I love hearing them all!

And finally, I wish you and yours a safe, peaceful and happy Christmas period and a positive and healthy start to 2020.

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

The logo for Good2Give, featuring the text "good2give" in a white, lowercase, sans-serif font with a stylized "2" and a registered trademark symbol, set against a dark orange background.

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**



As the end of the year rapidly approaches it is a good time to reflect on what we have achieved and what we would like to do next year. 2019 has proved to be an extremely busy but productive year for Myeloma Australia in NSW.

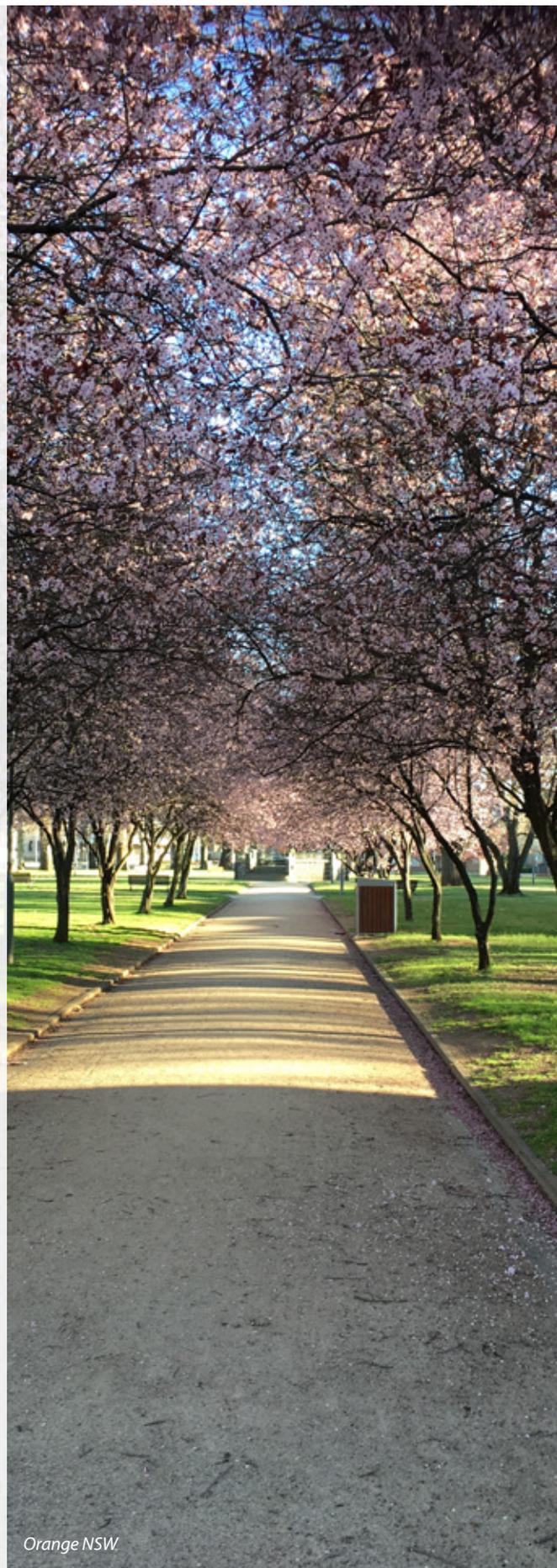
Our plan for this year was to grow our support groups and reach our regional communities. We know that a large portion of the myeloma community live in rural NSW and this creates many challenges. With our two myeloma nurses in Newcastle (Juliet and Rachel) we have been able to achieve so much more. Spring has seen even more growth in the Newcastle office with support groups in Newcastle, Forster/Taree and Rutherford. These regular catch ups are providing a wonderful relaxed environment for a cuppa and supportive conversation. Rachel and Juliet also visited Tamworth for a meet and greet in September. It was fabulous to meet people from the surrounding Tamworth areas living with myeloma who have the added challenge of living with the drought which is affecting so many. More visits to Tamworth are in the pipeline for 2020. For up to date information regarding our Support Groups and events please visit the website www.myeloma.org.au/event-calendar/

The Myeloma Telephone Support Group has continued again this year and along with the Cancer Council NSW I have facilitated this fortnightly group of between six to eight individuals living with myeloma throughout Australia. This is a fantastic alternative for those individuals who cannot for various reasons access a face to face group.

We have held many seminars this year starting with an ASH update in February. With the kind support of our local haematologists who attended the ASH conference we conducted two seminars, one in Parramatta (NSW) and one in Canberra (ACT) and both a medical and nursing perspective were presented. These ensured that the myeloma community had access to current and up to date information particularly in regard to clinical trials, new agents etc. They were well attended and received very positive feedback.

As usual we collaborated with the Leukaemia Foundation for National Myeloma Month in May with our main event being at the Royal Prince Alfred Hospital in Sydney. This was a very full day with interesting and engaging speakers and attended by over 160 people. For the first time this was also simultaneously broadcast live to Geelong, Canberra and Lismore. In addition to this we ran another three seminars across NSW in Newcastle, Gosford and Wollongong. Although these were obviously smaller events again, they were very well attended and extremely well received.

We recently held the 2nd Myeloma National Workshop in Sydney. This was a day for health professionals as well as a concurrent day for those living with myeloma. The event was a sell out with over 100 health professionals and 105 attendees from the myeloma community.



Orange NSW



Tamworth NSW

Another one of our goals for this year was to try and address some of the issues facing our culturally and linguistically diverse community (CALD) who live with myeloma. Western Sydney in particular, is represented by many nationalities and access to current information on myeloma and treatment

in other languages is a challenge. We will be running a myeloma seminar for the Arabic community to be held at Liverpool Hospital in late February 2020. We will have an Arabic translator who will translate the presentations on the day. Obviously, we will evaluate the feedback from this day but have plans to also run seminars in other languages throughout the year. Information about the Arabic seminar will be posted on the MA website and if you are interested in attending please get in contact with us. We are also looking at ways in which we can get some of our MA publications translated into different languages.

The NSW community have been busy attending BBQ's, running races- "The City to Surf" and "The Bay Run" to name a few and it is hoped that these events will continue to grow as we engage more with our myeloma community. October also saw Rachel hitting the pavement running 50km to raise awareness and funds for Myeloma Australia in the Zero October challenge raising \$688.

Our last event for the year is a community "Picnic in the Park" which is scheduled for December 7th in Parramatta Park. We hope that this will bring together many of our support groups and the wider community.

I think we are all looking forward to the Christmas break and will return in the new year with renewed energy and enthusiasm. We look forward to meeting many of you over the next year but in the meantime best wishes for a safe and happy festive season.

Jacqui Keogh
NSW State Manager/Senior Myeloma Nurse NSW

Profile

Congratulations to Pina on 10 Years

We must be doing something right at Myeloma Australia to have another staff member reach 10 years of service.

Pina Civitarese started with Myeloma Australia in September 2009. In the 10 years she has been with us, Pina has seen and been a part of much success, growth and change at the Foundation. She is an integral and valued member of the Myeloma Australia Team. Along with everyday administration and help with fundraising, her background in professional photography and a Bachelor in Graphic Design has kept her busy doing a major part of our design work. You may have seen Pina in action behind the camera at our fundraising events and seminars as well. Under Pina's guidance the MyeNews is now a lovely bright and informative magazine and the Myeloma Australia brand has been developed and incorporated into all things Myeloma Australia. We are fortunate that she has been able to bring these skills to her role here at the Foundation.

At the recent end of year Board drinks, Pina was acknowledged for her 10 years of service. On behalf of all of us at Myeloma Australia, our volunteers and community, I would like to thank Pina for her work, dedication and support over the last 10 years. The place would not be the same without you.

Alex Dawson
Finance and Support Services



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What's happening QLD

At this time of year it's great to reflect back on how far we have come in the last 12-14 months and there is no better example of this than the seminar we recently held at North Lakes Health Centre. On a blustery and rainy day we welcomed 40 participants to a very informative session by Dr Jason Butler – Haematologist from the Royal Brisbane and Women's Hospital and ICON Cancer Centre. Unfortunately, our other scheduled speaker, Professor Liz Isenring – nutritionist, could not attend due to illness but this gave Dr Butler time for extra questions and we are grateful for the generosity of his time. The rest of the time was spent catching up and discussing community engagement. We had some great volunteers and the day would not have gone so well without them. Megan and I would like to acknowledge Jane Jarrett, Andy Doughty, Ivy On Hing-McCleod, Ross and Billie McPherson (who threw together a raffle at the last minute), Jacqui Dawson and Chrissy Bates. Apologies to anyone we've left off.

Our Myeloma base continues to grow in the Sunshine State with over 300 professionals, patients and loved ones on our Myeloma Australia contact list for Queensland constituents. In 2019, Tash and I facilitated 45 support groups in South East Queensland. We have connected with many myeloma

champions in hospitals around the state and provided myeloma education to nurses in treating areas in Brisbane. We collaborated with the Leukaemia Foundation to facilitate the very popular Myeloma Day seminar in Dutton Park as well as hosting another successful patient seminar in North Lakes last month. Tash and I have immensely enjoyed getting to know and learning from so many Myeloma Warriors in Queensland. We have heard so many different experiences from patients and carers on this myeloma journey and we have benefited from their experience and insight to better support to others in similar situations. In 2020, we will continue to run our regular support groups with more planned in Hervey bay and Bundaberg. We will also be providing more seminars on the Gold Coast, Sunshine Coast and hopefully further abroad. If you are interested in having a support group or seminar close to you please contact us directly at megan.mcdowell@myeloma.org.au, Natasha.clarke@myeloma.org.au or the Myeloma Australia Support Line on 1800 632 100

*Tash Clarke & Megan McDowell
Myeloma Support Nurses – QLD*



Megan & Tash



What's happening SA

As we come to the end of another year, we are holding our last support group for the year at Fullarton Park Community Centre on 4th December. Our other groups have held their end of year meetings and with this I particularly want to thank our Support Group Coordinators, Ian Driver, Jenny Naylor, Carol Koch and Bronwyn Gerschwitz for their work over this year, keeping the groups vibrant and meaningful. We also wish to acknowledge the support we have received from Katnook Winery in the Coonawarra, who host our South-East group in their beautiful function area for no charge and Snowtown Hospital who donate their meeting room for our Mid-North group. There was some uncertainty about the venue for our Southern Adelaide group (Flinders) but I'm pleased to say that the Kaurna Living Cultural Centre at Marion has been secured for next year.

I particularly wish to acknowledge and thank our Myeloma Australia member John Cortazzo for his truly amazing fundraising efforts this year, he has raised \$70,000! Much work with support from his family and friends, has achieved this wonderful total, all the while John has been receiving active treatment for his myeloma. Well done John, your effort is greatly appreciated.

Along with our nursing team, I attended Blood 2019, the annual Australian and New Zealand Haematology Conference. This year it was held in Perth. We were able to present our review of the services provided on our Telephone Support Line, which was accepted as a poster. Having the team together was terrific, allowing us to plan together our services nationally for 2020.

Our exciting news for this edition is the appointment of Alicia Hopper our second Myeloma Support Nurse for South Australia who will start in January. Alicia will introduce herself to you in our next MyeNews and will be attending our support groups over the coming year for the opportunity to personally meet you all. Alicia will work 3 days a fortnight which will allow Jo to return to working one day a week for Myeloma Australia and retain her 2 days a week as Myeloma Research Nurse at Royal Adelaide Hospital. Alicia's appointment will allow us to increase our support services for SA and NT next year.

Jo Gardiner
Myeloma Support Nurse SA/NT



SAVE THE DATE

Business of Winning Lunch

Members Dining Room - MCG
Friday 3rd April from 12 noon

Details including our panel of experts will be announced in the new year.

Keep an eye on our website or alternatively contact us to make receive email notifications of everything Business of Winning.



Marmalade Gardens

If you are looking for something unique and beautiful for that special person in your life, Marmalade Garden handcrafted jewellery is the perfect Christmas gift. In support of her mother who was diagnosed with myeloma in 2007, Marnie will donate \$1 from every online sale to Myeloma Australia until the end of 2020.

<https://www.marmaladegardens.com/>



What's happening TAS

Our Southern Tasmania group is continuing to flourish. We've had three very enjoyable monthly meetings at the Glenorchy Health Centre, the Sandy Bay Cancer Council site in October and at the Clarence Integrated Care Centre. At Sandy Bay we enjoyed a short presentation from Marg McKenzie, a Cancer Council (CC) Support Coordinator, on what was happening with CC Tasmania in our area. In November, at Clarence, Associate Professor Rosie Harrup gave a comprehensive talk regarding clinical trials. It is a joy to see everyone get on so well, make new friendships and show concern for one another e.g. when a regular member has not turned up to a meeting. The only concern I have is what to take/bake for morning tea!

Things are growing steadily in the north and it is great to know people are embracing Myeloma Australia there too. In November I travelled to Launceston for the second support group in the area. I have had a positive response from patients who I have contacted so far and am sure will see the groups increase in numbers. Staff at Launceston General, Mersey Community and North West Regional hospitals are being very supportive and I met with Dr Mohamed, a clinical haematologist, when I was in Launceston.

I was given the opportunity by both Myeloma Australia (MA) and the Royal Hobart Hospital to attend the BLOOD Annual Scientific Meeting in Perth recently and it was wonderful to put bodies to voices of many of the other Myeloma Support Nurses whom I had not met before. It was a great and full-on conference and terrific to talk to and gain knowledge and support from other MA staff.

From an educational perspective I have given two presentations to nursing personnel at the Royal since my last report and have a further session booked at the end of November for staff in our Ambulatory Care setting. I have also been invited to give talks to district nurses at three of the community centres in Hobart.

I look forward to meeting and supporting more people living with myeloma as I increasingly travel around the state, spreading awareness of what Myeloma Australia offers.

Deborah Thompson
Myeloma Support Nurse TAS



What's happening VIC

Thank you to everyone in the myeloma community, those living with myeloma, their supporters and health professionals alike. We all play a role and we all share the same goal. So, keep supporting each other, keep raising the profile of myeloma, united we are strong. Another year has given us more treatment options, better supportive care and very promising research moving into 2020.

Highlights over the last couple of months include our new Myeloma Information and Support Group in Shepparton. A very successful educational seminar featuring A/Prof Phillip Campbell and many other impressive presenters in Geelong. Our annual seminar held at La Trobe University in Bundoora with Prof Miles Prince. Connecting with the regional myeloma community at the first Warrnambool Cancer Expo. There have been numerous creative fund-raising efforts including a fun filled night at the Little Creatures Brewery

teaming up with Comedy for a Cause and the Beaumaris Information and Support group's annual raffle. Our team continues to provide local health professional education including presentations at Epworth Richmond, Peter MacCallum, Goulburn Valley Health and Ballarat Regional Integrated Cancer Centre to name a few

So, what's next? We are looking forward to our final Information and Support Groups for the year to be held at various cafes and restaurants, this is always a special way to finish up the year. Early next year we will again be teaming up with the haematology team at Monash Health to bring you our first educational seminar for the year. See you all then

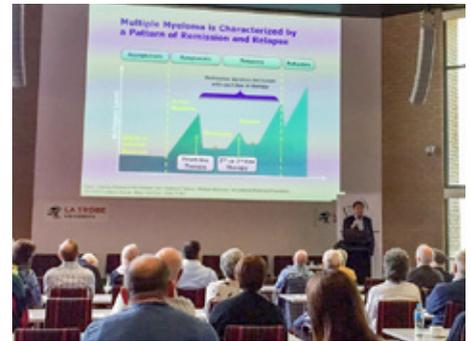
Elli Foley
Myeloma Support Nurse – VIC



Professor Miles Prince at La Trobe Seminar



Myeloma Australia resource display



Professor Miles Prince at La Trobe Seminar



As we write this we are packing up from our most recent patient and carer information seminar which was held in 39 degree heat in the Conference Hall at the Cancer Wellness Centre in Cottesloe. This seminar had a transplant in myeloma focus and had more than 30 attendees to the event. We were lucky enough to have two fantastic speakers and the morning tea was popular as always. Our first speaker was Dr Hasib Sidiqi, a haematologist who has recently returned from the Mayo Clinic in Minnesota take up a consultant post at Fiona Stanley Hospital. Dr Sidiqi held a very busy question and answer session about transplant in myeloma and this was followed by Tina Crosbie, Nurse Practitioner Haematology and Autologous Stem Cell Transplant from Sir Charles Gairdner Hospital who spoke about supportive care and what to expect in transplant, also really well received by the audience. We were really pleased with the topics discussed and warmth of the community in attendance.

When we signed off on our last report, we were about to hold our August seminar which was also well attended by the myeloma community here in Perth. Consultant Haematologist Dr Andrew McQuillan spoke about treatment decisions in myeloma and Louise Angus, Nurse Practitioner in Palliative Care ran an interactive session about pain management in myeloma. With almost 40 attendees to the event, the speakers provided quality information and were able to answer some tricky questions from the audience. We will hopefully have both speakers back in the future to present again.

We began a new evening support group in early September for the young and young at heart held in Cottesloe and are hoping to get some more interest at our next meeting planned for the 25th November. It is hoped that people in the myeloma community who are unable to attend a support group in the morning or afternoon will find this group an easier option and we encourage anyone interested to come along for some supper and a supportive chat.

Planning is well and truly underway for the 2020 information and support group and information seminar calendar in Western Australia. We are hoping to spend more time reaching out to rural areas and have some other exciting community events in the planning for the Perth metro

area so watch this space. At this stage the information and support groups in Wanneroo, Baldy, Kalamunda and at Cottesloe will continue in 2020, with at least one rural event planned so far for early in the year.

The Coffee and Chat program has proven extremely successful, with 25-30 attendees to each morning tea in 2019 and this event will also continue in 2020. Our final Coffee and Chat event for 2019 will be held in the Conference Hall at the Cancer Wellness Centre in Cottesloe on Friday 13th December 2019 with a festive theme, we hope that we will see as many members of the local myeloma community as we can to this event. Flyers will be sent out soon.

Health Professional Update

In October, Kerin and Narelle represented WA at the national Blood Conference held at the Convention Centre in Perth. We welcomed myeloma support nurses from around Australia and together we promoted Myeloma Australia and the amazing services we offer. We were very proud to share our services in our home town of Perth and enjoyed the opportunity to continue fostering important professional relationships in the myeloma space.

At the beginning of November, we rolled out the new referral form to consultant haematologists, allied health and healthcare providers, haematology clinics and treatment centres so that they can easily assist people affected by myeloma to access the services offered by Myeloma Australia and the two myeloma support nurses in WA. If you are a healthcare professional working in WA and have not received the electronic referral form but would like to, please contact Kerin or Narelle, or Myeloma Australia Head Office.

Early planning for an advanced myeloma health care professional education evening has commenced for the first half of 2020 and we hope to share some more information about this in our next report.

Signing off until our next report, we are always grateful for the support we receive from the myeloma community here in WA.

*Kerin Young and Narelle Smith
Myeloma Support Nurses – WA*



Andrew McQuillan – WA Seminar August 2019



Louise Angus



WA Seminar August 2019

Please note the following information references published data, and medicines and/or the use of medicines that are not approved in Australia and/or New Zealand. For further information, use the reference provided or ring our Myeloma Nurses on 1800 MYELOMA.

Edited by Jo Gardiner, Senior Specialist Myeloma Nurse

New Therapies:

Managing the toxicities of CAR T-cell therapy

Sattva S. Neelapu; Haematological Oncology;
First published: 12 June 2019 <https://doi.org/10.1002/hon.2595>

CAR T-cell therapy is highly effective in relapsed or refractory aggressive B-cell lymphomas and CAR T products targeting novel antigens in Hodgkin lymphoma and T-cell lymphomas, multiple myeloma, B-cell leukemias and lymphomas are in development. Because of the unique toxicities of CRS and ICANS observed with these therapies and because of the potential to create a paradigm shift in the management of these malignancies, hematologists and oncologists need to become familiar with the grading and management of these toxicities. Current management strategies are focused on careful monitoring, early recognition of toxicities, and prompt intervention with supportive care for low-grade toxicities and tocilizumab and/or corticosteroids for severe toxicities. It is possible that in the future, prophylactic strategies may mitigate the toxicities without compromising efficacy. Innovative design of CARs including “tunable” CARs that allow control of the rate of expansion and activity of CAR T-cells when given to the patient may further improve the safety of these therapeutic products.

Experts Propose New Consensus Scale for CAR T-cell Therapy Toxicities

February 12, 2019 Jose Marques Lopes, PhD, PHD In News.

The American Society for Blood and Marrow Transplantation (ASBMT) proposed a new consensus scale for toxicities associated with CAR T-cell therapies to better categorize their severity in both the hospital setting and clinical trials. The study, “ASBMT Consensus Grading for Cytokine Release Syndrome and Neurological Toxicity Associated with Immune Effector Cells,” appeared in the journal *Biology of Blood and Marrow Transplantation*. Chimeric antigen receptor (CAR) T-cell therapy consists of collecting a patient’s own immune T-cells and modifying them for improved recognition and killing of cancer cells.

CAR T-cell therapy may have side effects, including cytokine release syndrome (CRS), a form of systemic inflammatory response causing flu-like symptoms; and neurological toxicity — now referred to as immune effector cell associated neurotoxicity syndrome (ICANS) — that presents with difficulty concentrating, agitation, tremor, and seizures, among other symptoms.

The assessment and grading of these side effects have varied significantly, representing a challenge to compare safety and toxicity of different treatments and limiting the ability to develop optimal strategies to manage these toxicities.

“We believe that our proposed grading system is objective, easy to use, and more accurately categorizes the severity of these toxicities,” the scientists stated.

What Is the Best Approach for Patients with Smoldering Myeloma?

<https://brianduriemd.myeloma.org/blog-posts>;
Submitted By Blackswan On Thu, 10/31/2019 – 12:30

The recent publication of the ECOG trial evaluating lenalidomide (Revlimid) treatment versus observation for patients with Smoldering Myeloma has prompted considerable discussion about the current recommendations for treatment. That discussion has largely been triggered by the study’s closing summary, which indicates that the data “support early therapy [with lenalidomide] as a standard of care in high-risk SMM (HR-SMM).”

Daratumumab, Bortezomib, and Dexamethasone Versus Bortezomib and Dexamethasone in Patients With Previously Treated Multiple Myeloma: Three-year follow-up of CASTOR

Maria-Victoria Mateos et al; Clinical Lymphoma Myeloma and Leukemia; Available online 9 October 2019

Background: In the phase 3 CASTOR study in relapsed or refractory multiple myeloma (RRMM), daratumumab, bortezomib, and dexamethasone (D-Vd) demonstrated significant clinical benefit versus Vd alone. Outcomes after 40.0 months of median follow-up are discussed.

Methods: Eligible patients had received ≥ 1 line of treatment and were administered bortezomib (1.3 mg/m²) and dexamethasone (20 mg) for 8 cycles with or without daratumumab (16 mg/kg) until disease progression.

Results: Of 498 patients in the intent-to-treat (ITT) population (D-Vd, n = 251; Vd, n = 247), 47% had 1 prior line of treatment. Median progression-free survival (PFS) was significantly prolonged with D-Vd versus Vd in the ITT population (16.7 vs 7.1 months) and the 1PL subgroup (27.0 vs 7.9 months). In lenalidomide-refractory patients median PFS was 7.8 versus 4.9 months. Minimal residual disease (MRD)-negativity rates (10-5) were greater with D-Vd versus Vd (ITT: 14% vs 2%; 1PL: 20% vs 3). PFS2 was significantly prolonged with D-Vd versus Vd. No new safety concerns were observed.

Conclusion: After 3 years, D-Vd maintained significant benefits in RRMM with a consistent safety profile. D-Vd provided the greatest benefit at first relapse and increased MRD-negativity rates.

Supportive Care:

Supervised and home-based physical exercise in patients newly diagnosed with multiple myeloma—a randomized controlled feasibility study

Rikke Faebo et al; Department of Physiotherapy and Occupational Therapy, Zealand University Hospital, Roskilde, Denmark; Open Access Research; First Online: 12 November 2019

Background: The study evaluated the feasibility and safety of the exercise intervention and physical test procedures of our ongoing randomized controlled trial, examining the effect of physical exercise in newly diagnosed patients with multiple myeloma.

Methods: Patients are randomized 1:1 to a control group (usual care) or an intervention group (usual care and exercise). The exercise intervention consists of eight supervised exercise sessions combined with home-based exercise over a 10-week period. Bone disease is systematically evaluated to determine limitations regarding physical testing and/or exercise. Feasibility outcome measures were study eligibility, acceptance, and attrition, and furthermore attendance, adherence, tolerability, and safety to the exercise intervention. Additionally, test completion, pain, and adverse events during the physical test procedures were evaluated. Outcome assessors were unaware to which group the patient was allocated.

Results: Of 49 patients screened, 30 were included. The median age was 69 years, range 38–90, 77% were males, and 67% had bone disease. Study eligibility was 82%, acceptance 75%, and attrition 20%. Attendance at supervised exercise sessions was 92%, and adherence to supervised exercise sessions and home-based exercise sessions was 99% and 89%, respectively. No serious adverse events attributed to exercise or physical tests were reported. All patients completed the physical tests, except for two patients, where physical test procedures were modified due to bone disease.

Discussion: The exercise intervention and physical test procedures were feasible and safe in patients with multiple myeloma, even in older patients with multiple myeloma and in patients with myeloma bone disease.

Living With Multiple Myeloma: Self-Management Strategies

Matthew R LeBlanc, et al; *Innovation in Aging*. 2019 Nov; 3(Suppl 1): S928; Published online 2019 Nov 8. doi: 10.1093/geroni/igz038.3379

Dramatic improvements in survival over the past fifteen years have transformed myeloma into a chronic disease for many. The disease and its toxic, ongoing treatment lead to significant challenges for patients. In this study we explore the self-management strategies patients use to address the challenges of living with myeloma through semi-structured one-on-one interviews with myeloma patients and clinicians. Fifteen myeloma patients and ten myeloma clinicians were interviewed between September 2017 and September

2018. Self-management strategies emerged in five major categories; managing uncertainty, finding emotional strength, seeking support, medication management, and activity management. The care of MM patients has made great strides as new and more effective treatments have extended survival for many patients. Effective self-management strategies are critical in addressing the challenges of this increasingly chronic disease. Our study explores the ways myeloma patients address the many challenges they face due to their disease and its' treatment. Findings from this study could inform the development of interventions to optimize and support patients living with myeloma self-management.

Common abbreviations used in Medical Corner

Adverse events: any untoward medical occurrence in a patient receiving treatment. It may or may not have a causal relationship with the treatment

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

ISS stage: international staging system to stage myeloma at diagnosis (Stage 1, 2, or 3)

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

Phase 2 trial: accrue larger numbers (hundreds) of patients to determine if the study drug/s work as intended (efficacy)

Phase 3 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)

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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)



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- Talking time – 18 Hours
- Playing time – 10 Hours (with ANC on)
- Charging time – 3 Hours
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Recurring Donations

Have you thought about making an automatic recurring donation to Myeloma Australia?

We are now able to set up and process recurring donations when paid via a credit or debit card. There are a variety of recurring options available such as fortnightly, monthly, and quarterly and you can choose to cancel your recurring donation at any time.

For more information on recurring donations or to set one up please contact Alex on P: (03) 9428 7444 or email alex.dawson@myeloma.org.au



Calendar of Events 2020

Groups / events are subject to change at short notice.

Please check the website for a more up to date schedule. <https://myeloma.org.au/event-calendar/>

Support Groups NSW

BLACKTOWN

4th Friday of every 2nd month starting Jan 24th
Time: 11:00am – 1:00pm
Blacktown Bowling Club
15 Lismore St
BLACKTOWN NSW 2148
Contact: Geo Sobrio
E: geo.sobrio@myeloma.org.au
M: 0426 404 766

BOWRAL

4th Thursday of every 2nd month starting Feb 27th
Time: 10:00am – 12:00pm
Forster Palms Motel
Wingecarribee Community Health Care Centre
Louisa Atkinson Room
20 Bendooley St
BOWRAL NSW 2576
Contact: Geo Sobrio
E: geo.sobrio@myeloma.org.au
M: 0426 404 766

CENTRAL COAST

Last Thursday of every 2nd month
starting February 27th
Time: 6:00 – 8:00pm
Central Coast Leagues Club
1 Dane Dve
GOSFORD NSW 2250
Contact: Jacqueline Jagger
E: jacqueline.jagger@health.nsw.gov.au
P: (02) 4320 9641

FORSTER / TAREE

Last Thursday of every 2nd month starting Feb 27th
Time: 10:30am – 12:30pm
Alternating – Venues TBC
Contact: Rachel McCann
E: rachel.mccann@myeloma.org.au
M: 0433 511 606

LIVERPOOL

2nd Tuesday of every 2nd month starting Feb 11th
Time: 10:00am – 12:00pm
Liverpool Hospital
The Wellness Centre
(Entrance N off Campbell St) Level 1
Cnr Elizabeth & Goulburn sts
LIVERPOOL NSW 2170
Contact: Jacqui Keogh
E: jacqui.keogh@myeloma.org.au
M: 0426 404 230

NEPEAN

4th Thursday of every 2nd month starting Jan 23rd
Time: 10:00am – 12:00pm
Penrith City Library
Joanne Pearson / Margaret Prask Room
601 High St
PENRITH NSW 2750
Contact: Geo Sobrio E: geo.sobrio@myeloma.org.au
M: 0426 404 766

NEWCASTLE

1st Friday of every 2nd month starting March 6th
Time: 10:30am – 12:30 pm
Club Charlestown,
5 Lincoln St
CHARLESTOWN NSW 2290
Contact: Rachel McCann
E: rachel.mccann@myeloma.org.au
M: 0433 511 606

ORANGE

1st Thursday of every 2nd month
starting February 6th
Time: 4:00pm – 6:00pm
Giyalang Ganya Community Services Centre
286 Lords Place
ORANGE NSW 2800
Contact: Geo Sobrio
E: geo.sobrio@myeloma.org.au
M: 0426 404 766

RPAH

2nd Tuesday of every 2nd month starting Feb 11th
Time: 10:00am – 12:00pm
Royal Prince Alfred Hospital
Seminar Room 4.5
Kerry Packer Education Dve
CAMPERDOWN NSW 2050
Contact: Tracy King
E: tracy.king1@health.nsw.gov.au
P: (02) 9515 7310 pager 87524

RUTHERFORD

Thursdays every 3rd month starting April 2nd
Time: 10:30 am – 12:30 pm
Rutherford Community Ctr
13 Arthur St
RUTHERFORD NSW 2320
Contact: Juliet Hill
E: Juliet.hill@myeloma.org.au
M: 0433 511 554

WESTMEAD

3rd Thursday of every 2nd from Feb 20th
Time: 10:00am – 12:00pm
Wentworthville Leagues Club
Magpie Meeting Room 1
50 Smith St
WENTWORTHVILLE NSW 2145
Contact: Geo Sobrio
E: geo.sobrio@myeloma.org.au
M: 0426 404 766

YOUNGER PERSONS

Wednesdays / every 2nd month
Time: 6:00pm – 8:00pm
Wentworthville Leagues Club
Magpie Meeting Room 2
50 Smith St
WENTWORTHVILLE NSW 2145
Contact: Jacqui Keogh
E: jacqui.keogh@myeloma.org.au
M: 0426 404 230

Support Groups QLD

ALDERLEY

Friday / every 2nd month
Time: 10:30am – 12:30pm
Alderley Arms Hotel
2 Samford Road
ALDERLEY QLD 4051
Contact: Tash Clarke
E: natasha.clarke@myeloma.org.au
M: 0416 019 585

BUDERIM

1st Tuesday of every month (excluding January)
Time: 2:00pm – 4:00pm
Bloomhill Cancer Centre
58 Ballinger Rd
BUDERIM QLD 4556
Contact: Tash Clarke
E: natasha.clarke@myeloma.org.au
M: 0416 019 585

LABRADOR

Wednesday / every 2nd month
Time: 10:30pm – 12:30pm
Labrador Community Centre
57 Billington St
LABRADOR QLD 4215
Contact: Megan McDowell
E: megan.mcdowell@myeloma.org.au
M: 0416 019 022

... QLD list continues next page

NORTH LAKES

Friday / every 2nd month
Time: 10:00am – 12:00pm
North Lakes Health Conference Centre
9 Endeavour Bvd
NORTH LAKES QLD 4509
Contact: Tash Clarke
E: natasha.clarke@myeloma.org.au
M: 0416 019 585

PRINCESS ALEXANDRA HOSPITAL

Wednesdays / every 2nd month
Time: 11:00am – 1:00pm
Cancer Conference Centre
Ground Floor Oncology
Princess Alexandra Hospital
199 Ispwich Rd
WOOLONGABBA QLD 4102
Contact: Megan McDowell
E: megan.mcdowell@myeloma.org.au
M: 0416 019 022

Support Groups SA

FLINDERS

Thursdays / every 2nd month starting January 16th
Time: 10:00am – 12:00pm
Living Kaurna Cultural Centre
CC Meeting Room
Warriparringa Way
BEDFORD PARK SA 5520
Contact: Jenny Naylor
E: Jenny.Naylor1@gmail.com
M: 0405 391 616

FULLARTON

Wednesdays / every 2nd month starting Feb 12th
Time: 10:00am – 12:00pm
Fullarton Park Centre
411 Fullarton Rd
FULLARTON SA 5063
Contact: Ian Driver
E: sandrian7@bigpond.com
M: 0417 874 252

MID-NORTH

Wednesdays / every 2nd month
Time: 12:00pm – 2:00pm
Snowtown Hospital
70 Railway Tce E
SNOWTOWN SA 5063
Contact: Bronwyn Gerschwitz
E: graemebronwyn@bigpond.com
P: (08) 8664 0682

SOUTH EAST

Thursdays / every 2nd month
Time: 11:30 pm – 2:30 pm
Katnook Estate
Riddoch Highway
COONAWARRA SA 5263
Contact: Carol Koch E: clk@live.com.au
M: 0427 659 014

Support Groups TAS

LAUNCESTON

2nd Tuesday / every 2nd month starting March 10th
Time: 10:00am – 12:00pm
Cancer Council Tasmania
69 Howick St
SOUTH LAUNCESTON TAS 7249
Contact: Deborah Thompson
E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

NORTH WEST

2nd Tuesday of every 2nd month starting February 11th (3rd Tuesday in April)
Time: 12:30pm – 2:30 pm
Venues will alternate between:
NW Regional Hospital
The Wellness Centre
BURNIE TAS 7320

and

CANCER COUNCIL TASMANIA

2/45 Best St
DEVONPORT TAS 7310
Contact: Deborah Thompson E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

SOUTHERN TASMANIA

1st Tuesday of every month starting February 4th
Time: 10:00am – 12:00pm
Venue will alternate between:

CANCER COUNCIL TASMANIA

15 Princes St
SANDY BAY TAS 7005
Clarence Integrated Care Centre
Bayfield St
BELLERIVE TAS 7018

and

GLENORCHY HEALTH CENTRE

404 – 408 Main Rd
GLENORCHY TAS 7010
Contact: Deborah Thompson
E: Deborah.thompson@myeloma.org.au
M: 0433 511 689

Support Groups VIC

ALBURY / WODONGA

Thursdays every 2nd month starting February 6th
Time: 10:00am – 11:30am
Albury Wodonga Regional Centre
Wellness Room
201 Borella Road
EAST ALBURY NSW 2640
Contact: Emma-Jane Furphy
E: E.J.Furphy@myeloma.org.au
M: 0451 404 203

BALLARAT

Thursdays every 2nd month starting February 27th
Time: TBC
Venue: TBC
Contact: Elli Foley
E: elli.foley@myeloma.org.au
M: 0426 404 233

BEAUMARIS

Thursdays every 2nd month starting February 6th
Time: 10:00am – 12:00pm
Beaumaris Theatre
82 Wells Road
BEAUMARIS VIC 3193
Contact: Elli Foley
E: elli.foley@myeloma.org.au
M: 0426 404 233

BENDIGO

Wednesdays every 2nd month starting February 12th
Time: 9:30am – 11:00am
Bendigo Cancer Centre
100 Barnard St
BENDIGO VIC 3550
Contact: Emma-Jane Furphy
E: E.J.Furphy@myeloma.org.au
M: 0451 404 203

BERWICK

Fridays every 2nd month starting February 21st
Time: 10:00am – 12:00pm
St John of God Hospital
55 Kangan Dve
Level 1
BERWICK 3806 VIC 3193
Contact: Elli Foley
E: elli.foley@myeloma.org.au
M: 0426 404 233

COBURG

Wednesdays every 2nd month starting February 12th
Time: 1:30pm – 3:00pm
Coburg North Village
Contact: Emma-Jane Furphy
E: E.J.Furphy@myeloma.org.au
M: 0451 404 203

...VIC list continues next page

GEELONG

Fridays every 2nd month starting February 15th
Time: 10:00am – 12:00pm
Andrew Love Cancer Centre
Wellness Lounge
70 Swanston St
GEELONG VIC 3220
Contact: Elli Foley
E: elli.foley@myeloma.org.au
M: 0426 404 233

KEW

Thursdays every 2nd month starting February 13th
Time: 10:00am – 12:00pm
Kew Library
Cnr Charles St & Cotham Rd
KEW VIC 3101
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0451 404 203

SHEPPARTON

Thursdays every 2nd month starting February 20th
Time: 10:00am – 11:30am
Shepparton Library
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0451 404 203

SUNSHINE

Thursday every 2nd month starting February 27th
Time: 10:00am – 12:00pm
Braybrook Community Centre
107 – 139 Churchill Ave
BRAYBROOK VIC 3220
Contact: Elli Foley
E: elli.foley@myeloma.org.au
M: 0426 404 233

TRARALGON

Fridays every 2nd month starting February 21st
Time: 10:00am – 12:00pm
Gippsland Rotary Centenary House
39 Valley Dve
TRARALGON VIC 3844
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0451 404 203

WANGARATTA

Fridays every 2nd month starting February 21st
Time: 1:30 pm – 3:00pm
Wangaratta Library
Seminar Room
21 Docker St
WANGARATTA VIC 3678
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0451 404 203

YOUNGER PERSONS GROUP

Thursdays every 2nd month starting February 13th
Time: 6:00pm – 8:00pm
Myeloma Australia Head Office
333 Swan St
RICHMOND VIC 3121
Contact: Emma-Jane Furphy
E: EJ.Furphy@myeloma.org.au
M: 0451 404 203

Support Groups WA

COFFEE AND CHAT

Fridays of every 3rd month starting March 20th
Time: 9:30 am – 11:30am
Wanslea Room
Cancer Wellness Centre
80 Railway Road
COTTESLOE WA 6011
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

NORTH METRO

1st or 2nd Monday of every 2nd month starting February
Time: 1:00pm – 3:00pm
Meeting Room 1, Ground Floor
Wanneroo Library and Cultural Centre
3 Rocca Way,
WANNEROO WA 6065
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

PERTH HILLS

Monday every 2nd month starting February 17th
Time: 10:00am – 12:00pm
Meeting Room, Zig Zag Cultural Centre
50 Railway Road
KALAMUNDA WA 6067
Contact: Kerin Young
E: kerin.young@myeloma.org.au
M: 0426 404 310

SOUTH METRO

2nd Monthly commencing February 21st
Time: 10:00am – 12:00pm
Wattlebird Room
Mary Davis Library and Community Centre
17 Settlers Avenue
BALDIVIS WA 6171
Contact: Kerin Young
E: kerin.young@myeloma.org.au
M: 0426 404 310

SOUTH WEST

2nd Monthly commencing March 6th
Time: 10:00am – 12:00pm
Busselton Community Resource Centre
Meeting Room 3
21 Camilleri St
BUSSELTON WA 6280
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

YOUNGER PERSONS

Mondays of every 2nd month starting January 13th
Time: 6:00pm – 8:00pm
Wanslea Room
Cancer Wellness Centre
80 Railway Road
COTTESLOE WA 6011
Contact: Narelle Smith
E: narelle.smith@myeloma.org.au
M: 0426 404 280

**Groups / events are subject to change at short notice.
Please check the website for a more up to date schedule.
<https://myeloma.org.au/event-calendar/>



You can also follow us on Facebook
www.facebook.com/MyelomaAustralia



Twitter twitter.com/MyelomaAust_MFA
for all updates and events.

Myeloma Australia is the only myeloma specific support organisation in Australia



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



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



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



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

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

Mon – Fri 9am – 5pm AEST

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