

MyeNews

Winter 2018 Issue no 46



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Myeloma Support Line

Monday – Friday 9am – 5pm (AEST)

1800 MYELOMA
(1800 693 566)

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



From the President

We have just completed Myeloma Awareness Month with seminars being held around Australia in conjunction with the Leukaemia Foundation. From all reports these have all been great events with good presenters. I went to the Melbourne seminar where 150 patients and carers heard excellent presentations from all the speakers. I have been attending these events now for eighteen years and I learn something new every time.

I have found that each presenter explains myeloma and the treatment in his or her unique way. Also, there are many new treatments being trialled both here and overseas. All the speakers stressed the need for patients to be open to these trials as it is a way to obtain some of the newer treatments before they are registered or subsidised. For more information on trials speak to your haematologist.

We are now a truly national organisation, with Myeloma Support Nurses in West Australia, South Australia, New South Wales and Victoria and we also now advertising for nurses in Queensland. Currently nurses are visiting Tasmania and the Northern Territory on a regular basis with plans for a nurse based in Hobart in the future. We are setting up an office in Sydney to house our two nurses and a Fundraiser. We have also employed an Project Manager/Liaison to support the Medical and Scientific Advisory Group.

We have come a long way in the nearly twenty years since we began. To celebrate this milestone we will be making awards to those who have made this all possible, but more about this later.

Here is a brief outline about how it all started.

Early in 1998 three couples approached the Cancer Council of Victoria looking for a myeloma support group only to be told there wasn't one. Pat Dobson as social worker responsible for support groups at the Cancer Council brought the three couples together for a meeting in August 1998. These three couples were Glenys and Bob Moran, Judith and Donald Brown and Roslyn and myself. The next meeting was in October and Professor Miles Prince and Dr Paul Mitchell agreed to act as advisors for the group. The group chose Myeloma Victoria as their name and started planning their first event, a seminar. This was held in April 1999 and attended by 240 patients, carers and their families. Myeloma Victoria supported the Australian trials on the use of thalidomide.



In November the first edition of the quarterly newsletter MyeVic was published. Subsequently twenty four editions of this were published with the last in November 2005. This was then renamed MyeNews and became a glossy publication which is now distributed both by post and electronically to over 5000 people.

In March 2000 we employed our first Myeloma Support Nurse, Jo Wilson and held workshops in both Kew and Shepparton during this year. In 2002 we held a second full day seminar at Leonda with 250 attendees and Kaye Hose took over as our Myeloma Support Nurse.

I will continue this in the next edition. In the early days the members of the committees did all the planning and ran the events now our Myeloma Support Nurses have taken over this role. From the very beginning our doctors have made themselves available for our seminars and workshops and have always vetted any professional handouts we have produced. We have always been focused on support and education and have been able to provide this through the use of our fabulous Myeloma Support Nurses. ●

Brian Rosengarten
President
Myeloma Australia

A handwritten signature in black ink that reads "Brian Rosengarten". The signature is written in a cursive, slightly slanted style.

NSW Fundraiser

It is with great pleasure that I introduce to you all Myeloma Australia's inaugural state-based Fundraiser, Santosh Ojha. Heading up fundraising in NSW Santosh commenced work with Myeloma Australia in late May.

As we continue to develop as an organisation, it's terrific to have Santosh on board. I know he is looking forward to meeting and hearing from members of the NSW myeloma community.

Matt Maudlin



As a 21 year-old in 2013, I initiated a program to help children in rural Nepal to get an education as a result of the personal hardships I experienced a child. A book by the 'Room to Read' Founder John Wood, (an organisation that believes World Change Starts with Educated Children), had a great influence on me to lead the education program. I led the scholarship program for five years, which managed to help over 2000 needy children across far flung villages of Nepal and it provided me with a sense of purpose in the work I chose. That's the longest time I spent working somewhere despite having promising prospects in previous work in media in Nepal.

I love reading books, keeping myself updated to the ever-changing trends and writing about politics helps me in understanding community development on a broader aspect. Working primarily in fundraising and volunteer mentoring, my experiences have helped me grow, encouraged me to be a better person and always believe in the power of humanity that can make wonders happen. Continuing my work that aims in strengthening and serving to the needs of community, I am thrilled to be a part of Myeloma Australia.

Santosh Ojha

Exclusive and Original Cards by Patricia Ball

10 cards x 5 Designs per pack
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per pack
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Available from Head Office
333 Swan St, Richmond, Vic
P: (03) 9428 7444 • Toll free: 1300 632 100
eBay store: <http://stores.ebay.com.au/myelomaaustralia>

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

Photo supplied and used with permission



my mount eliza 2018

WRAP UP

On Sunday 25th March, we saw over 800 people come together to participate in the MY Mount Eliza Run & Fun Festival. The purpose of the Festival was to bring families together to have fun, all whilst raising awareness of multiple myeloma, and funds for Myeloma Australia. In all aspects, the day was an amazing success. Despite the rain and wind, we had kids, parents and grandparents all come to tackle the 5km and 10km run and walk course. We felt very privileged to have many friends who have been directly affected by myeloma present on the day. Whether, they came to run, to fundraise have fun, to support and / or to remember, they came away with a smile, all in the knowledge that they had contributed to something bigger than themselves.

At the event, we had some fantastic attractions including the jumping castles, sumo wrestling area, a kids dash incorporating commando kids style activities, face painting and displays from the CFA and Victorian Police. We were

also thrilled to have great stage performances from Fox De Roache, Oskar Proy (who recently appeared on The Voice) and the folk band Lachlan Bryan & the Wildes. The fun run / walk, combined with the kids activities, stage performances, community exhibitors and the great food options, all made for a fun day in support of a great cause.

This day could not have been delivered without the great work done by Geoff Nyssen and the volunteer festival committee and staff from Head Office at Myeloma Australia. In addition, we extend our thanks to the festival community partner Ryman Healthcare, gold sponsors Peninsula Hot Springs and Ritchies Mount Eliza, and silver sponsors ANZ, Bartercard, Live Love Mount Eliza and PARC. We also thank all of the bronze sponsors that donated time, materials or items for the raffle, run prizes, silent action and fundraising prizes.

We look forward to seeing you there in March 2019 as we look to make the event even bigger and better.

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Will you be a part of **Team Myeloma** in Melbourne?



Team Myeloma are gathering for Run Melbourne on the morning of Sunday 29th July to raise awareness and funds for Myeloma Australia.

Join us as we walk and run the 5km, 10km and half marathon courses. A social gathering of the myeloma community will be held following the event.

To register please visit:

<http://events.solemotive.com/run-melbourne-2018-about/>

Any questions? Contact: matt.maudlin@myeloma.org.au



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

Through the keyhole: Clinical Trials

Clinical trials are an important way to improve treatment for people with myeloma. With a range of new treatments being developed for use in myeloma, an increasingly wide range of clinical trials are available to patients in Australia and New Zealand. For a drug to get registered with Therapeutic Goods Administration (TGA) it has to go through the trials process. Trials in the myeloma field give patients access to new treatments or different combinations of drug. Sometimes it is the only way to access medications that are otherwise unavailable in Australia.

If you are on a clinical trial chances are you have already gone through a few standard treatment options. Receiving your medication and checking in with your doctor is part of the routine. As a participant in a clinical trial you are suddenly thrust into the world of research, as well as treatment for your condition. The jargon is different; lots of colourful tubes are used when blood is taken. ECG's are involved and there could be different rules surrounding when and how to take medication. Timing can be crucial. You may need to keep a diary, fill out questionnaires each visit. Essentially there is a lot more questions and requirements when dealing with research.

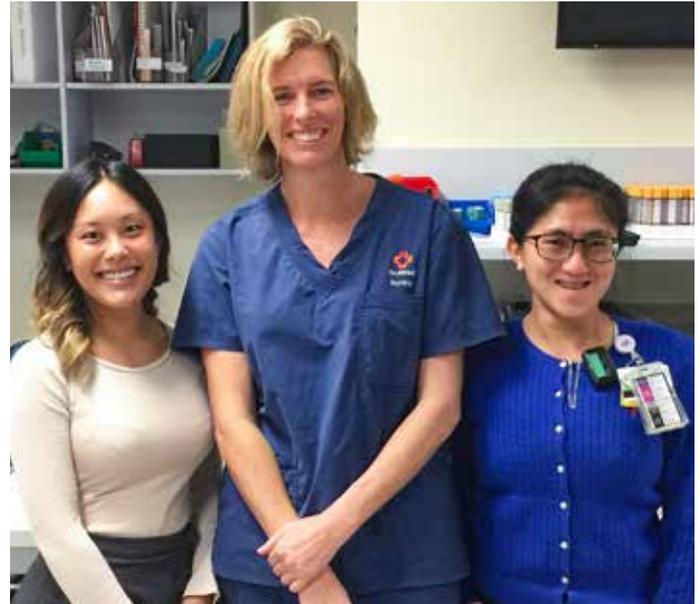
Being informed

Informed consent is always the first step. As a participant it is very important that you know all the facts about the trial, what you can expect and what is required. It is also important to know that you can withdraw at anytime.

Team approach

It has to be highlighted that clinical trials are a team effort. Before sitting in an outpatient chair to receive treatment a lot of work is completed. Trials have inclusions and exclusions criteria. Potential participants have to go through a lot of screening procedures such as skeletal surveys and heart scans. Past treatments are taken into account. A dedicated trial co-ordinator is working hard behind the scenes and continues to work with participants throughout. The doctors involved in your care also need to study the trial protocol and maintain optimum care during the trial. Sometimes certain medications are not allowed whilst on a trial, you might be advised not to eat certain food.

During visits you will hear terms like PK's and PD's. These abbreviations stand for pharmacokinetics and pharmacodynamics, blood collected from you on your visits help determine what the body is doing to the drug and what the drug is doing to the body. This is all part of the data collection component. Lab assistants deal with trial samples usually with strict guidelines and courier deadlines. Each setup is different but know that if you participate in a trial or know someone on one, there is a hive of activity going on behind the scenes at all times.



(L>R) Sharmaine Lagman RN, Sally Haines RN, Minh Pho Lab Assistant.

Nurses role in clinical trials

As a research nurse in clinical trials we are here to support you throughout your treatment. Explain procedures and make sure all trial specifications are met. Most importantly though is safely administering your treatment. Trials can run for months or years so it's nice to get to know patients and their families. Drugs like daratumumab and carfilzomib have been in different trials for years and are just two examples of MM drugs that are now becoming available. It's a long process but new treatments and medication combinations are being developed and trial participation is helping dictate future treatments.

*Sally Haines RN
Alfred Health*



Suggested reading

Australian Clinical Trials

<https://www.australianclinicaltrials.gov.au/what-clinical-trial/phases-clinical-trials>

Cancer Institute NSW 2017

<https://www.cancerinstitute.org.au/data-research/clinical-trials/how-do-clinical-trials-progress>

ClinTrial Refer

www.clintrial.org.au

Cancer Council: Clinical Trials

<https://www.cancer.org.au/about-cancer/treatment/clinical-trials.html>

My Myeloma Journey



Myeloma, life and beef farming

Things were starting to look pretty good in 2011. After a long career in medical science I was looking forward to retirement and a relaxed life on our certified organic beef farm in Gippsland. I was 58 years old and apart from Type 2 Diabetes was in good health. Sure I had a bit of back pain and I did get really tired every now and then, but that's just old age, right...?

During one of my regular diabetes check-ups it was noticed that my total protein level was increased. Further investigations revealed a paraprotein level of 24 g/l and free light chains of 565 mg/l and a bone marrow biopsy revealed 25% plasma cells. No doubt about it, I had multiple myeloma!

The next step in my journey was a referral to our local haematologist. My doctor, John was also a good friend with whom I had worked closely for many years. Induction therapy started with CTD (cyclophosphamide, thalidomide & dexamethasone) and I was referred to the Austin Hospital for an autologous stem cell transplant. In March 2012 five packs of stem cells were harvested with three packs used immediately and two put in storage for later use.

The transplant went well and I was back on the farm after 8 weeks on CTD maintenance therapy.

I was lucky that I tolerated the chemotherapy well, apart from the dexamethasone which deprived me of sleep and played havoc with my diabetes. Life on the farm continued much as before although now that I was immune-compromised I had to be very mindful of the risk of infection and any heavy lifting was done by the tractor.

I relapsed early 2018 and am back on CTD waiting for a second autologous stem cell transplant

Meanwhile my wife and I are actively involved in our local myeloma information and support group, and I have become a "blood buddy". I hope I can use my knowledge and experience to help other people dealing with myeloma.

Since diagnosis we have made a decision to get out and enjoy life. We have been overseas twice and love going up north to go fishing with our son and his family. We have just recently bought a caravan and are about to embark on a big slow lap of Australia.



Chris and wife Diane.

I believe that a positive attitude is paramount and to retain a sense of humour is vital.

This year I had a calf born with only one front leg (pictured). When I show photos of him to people I am careful to point out that I was not on thalidomide when he was conceived!!

Chris Bowlen

90 Years Young

Recently our mother Maureen celebrated her 90th birthday with family & friends, in lieu of gifts we requested donations to Myeloma Australia and raised an amazing \$455.00. Sadly 13 years ago, our sister Gail Gunn passed away from multiple myeloma. After Gail's diagnosis we attended the myeloma support groups and meetings and always gained knowledge of the disease and the work undertaken in managing it. Gail was an amazing person and her strength when fighting myeloma was inspirational, she is still greatly missed to this day by us all.

Gail's children Ellen & Kyle are pictured with their nanna Maureen.

Denise & Fiona

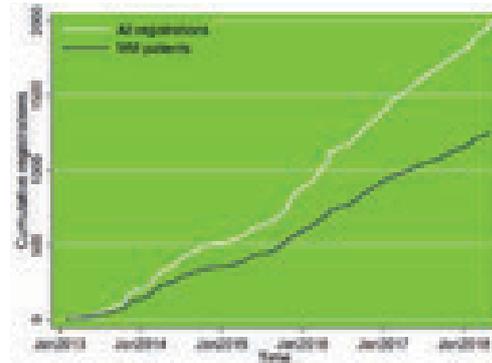
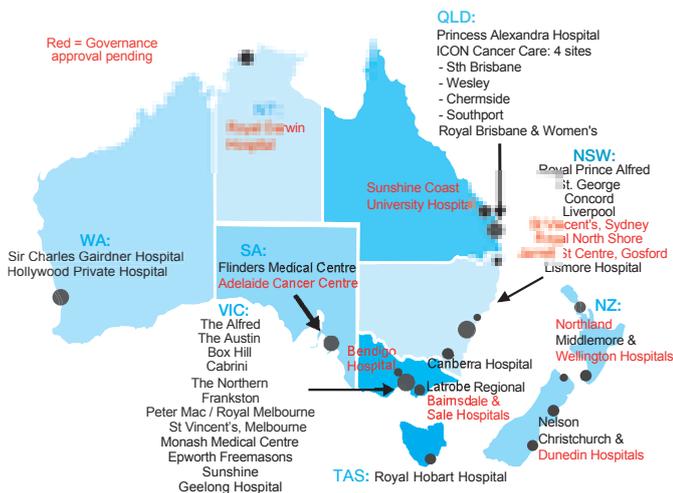


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NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

RECRUITMENT UPDATE: OVER 2000 PATIENTS REGISTERED!

May saw recruitment of over 2000 patients to the Myeloma and Related Diseases Registry (MRDR) which is an incredible achievement! Thanks to registry participants and all the staff at participating hospital sites who have made it possible to reach this exciting milestone. The most recent sites to join the registry are Lismore Hospital, University Hospital Geelong, and Royal Brisbane and Women's Hospital. We now have 30 participating sites and 11 more with approval pending (see map).



RESEARCH

IMPROVE (*Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology*) is a registry based study funded by the National Blood Authority through to 2020, which is commencing. MM is one of the areas of more intense immunoglobulin use in Australia, however there is limited information about where, when and how it is used. This study will describe its use in MM, including variation in practice. Results of this study will help to inform policy and clinical practice related to immunoglobulin therapy in these patients.

THANK YOU FOR HELPING US REACH 2000!

Thank you again for your generous support in reaching 2000 patients registered.

THE MYELOMA 1000 PROJECT

MRDR has reached over 1250 patients with multiple myeloma (MM) registered. The Myeloma 1000 Project that aims to recruit 1000 registry participants with MM and 1000 with monoclonal gammopathy of undetermined significance (MGUS) has close to 240 patients recruited. This is a biobank subproject of the MRDR, involving the collection of a once-only blood specimen from patients. Future investigation using specimens from this biobank could lead towards better prediction of patients' response to treatment, and identifying patients at greater risk of developing MM or disease progression.

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: mrdnet.au



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CRICOS Provider: Monash University 00008C. TRSU415464

“Mrs Ratty”

My husband Gary and I were living in the inner west of Sydney. We have two sons Nathan and Brad and two grandsons – Jordan and Joshua. I was preparing for Nathans wedding and though feeling very tired, I pushed through as I was working full time and generally burning the candle at both ends – my usual lifestyle. Little did I know what was about to unfold.

I began to experience rib pain in October 2010 but after discussing it with my sports doctor agreed to see if it was just a pulled muscle. It turned out to be a broken rib, largely unexplained, other than it may have happened at the gym. No gym until after Christmas. However, by March 2011 the rib had broken again and was showing a 7cm lesion, again unexplained.

After a battery of questions and tests it was determined that I had multiple myeloma, rather than a secondary bone cancer, which needed to be treated. I was referred to my Professor at RPAH, who said that although my protein level was relatively low I would need treatment as it was affecting my bones.

I was prepared for a stem cell transplant from May 2011 to November 2011, unfortunately I found out the hard way that I was allergic to Zometa – a bone strengthening infusion. It affected my eye badly and the eye specialist said it was a rare side effect but very serious as it could result in the patient going blind. I recovered with no lasting damage to my sight.

It came to the second last day of the window when the stem cells could be harvested – not enough stem cells!! A quick visit to the hospital at midnight and a small expensive injection remedied that. Just enough stem cells to harvest for the transplant!!

In December 2011 Gary and I moved into a new house with our son and his wife at Denistone. They welcomed a new baby boy – Cooper four days after the move. I wondered if I would get to see him start school.



(Son) Brad, Tracey & grandson Josh who live at the Gold Coast.



Gary, Lois, Nathan, Ricci & the grandkids.

The stem cell transplant was completed in late January 2012. Home from hospital after a couple of weeks, the long road to recover began. I returned to work part time in May. There was a set back in September 2012 when I contracted a bad case of shingles and was hospitalised for 12 days in isolation. I am very fortunate to only have very minor residual effects.

I retired from my position at the busy motor dealership in November 2012, deciding to help my son in the office of his plumbing company, where I still assist today.

We welcomed two more grandchildren – Maliyah who is turning 5 years in June 2018 and Hendrix who will be 2 years in October 2018.

Gary and I travelled to London and Europe as soon as I was well enough, whilst there I attended a course at Hampton Court Palace in embroidery and we went on a river cruise from Budapest to Amsterdam.

The stem cell transplant worked until December 2015, keeping my protein level under 2 without taking any drugs. In January 2015 I missed out on a drug trial as my numbers were one point under what was required to qualify.

By March 2015 it was agreed that I would commence treatment on Revlimid. I remain on that treatment until the present day. Managing the side effects of the steroids and other drugs that are taken with Revlimid is a challenge, however I have made it my business to be as well informed as possible about the management of the drugs I am taking, as they are extending my life.

I have participated in many meetings and studies about these drugs to try to reduce and manage the side effects as much as possible. I attend our group meetings at RPAH at the Lifehouse where we discuss whatever is important to us. It gives us a chance to network and see what others are doing and get as many tips and hints from each other as possible. The guest speakers cover many topics including exercise, diet, new drugs coming onto the market, travel and much more. Things like how to manage peripheral neuropathy which is caused by the life saving drugs we take.

Wear comfortable shoes and be kind to your feet in general. What works for one does not always work for everyone - but keep trying until you find what works for you. Even what time you take your medication can help with getting a better nights sleep. I have changed to taking my steroids late at night, which is never really recommended, but it works for me to get a better length of sleep. This was a tip I picked up from one of our meetings. Your time will be well spent if you find out where your local meeting is and attend so you too can get some hints and tips on the many and varied topics that arise when you are faced with having a life threatening disease. The taking of steroids gave rise to the name Mrs Ratty as that is how I described myself on the day I take them.

I also draw on the support of my close network of friends each providing me with a different strength to go forward

The next challenge is to have the cataracts removed from my eyes – brought on by the long-term use of steroids, as I am an avid embroiderer and need to be able to see to do my thing.

I am living well with multiple myeloma and its challenges and I am looking forward to seeing my youngest grandson start school in 2021.

Lois Wilson



Jordan, Cooper, Maliyah and baby Hendrix.



Find our new
Information Sheets
under the resources tab of our website
www.myeloma.org.au



We have just wrapped up another successful annual Myeloma Awareness Month with our nurses' hosting seminars across the country in Melbourne, Adelaide, Sydney, Perth and Gosford and Bomaderry in regional NSW in collaboration with the Leukaemia Foundation.

The events are a great way to learn more about myeloma as well as meeting other members of the community to share experiences and knowledge. The theme this year was 'Living with Myeloma – the what, how when and why' and we had a variety of speakers including patients, carers, haematologists, myeloma nurses, psychologists, exercise physiologists and pharmacists. They covered topics such as myeloma the disease, current treatments, new research and maximising wellness. Many of the events also incorporated a specific session for carers in the form of an interactive discussion. This space provided the opportunity for carers to share their experiences from being a carer, both the challenging and the rewarding. I was particularly inspired observing a group of carers at the Sydney event, share their wisdom to a gentleman whose partner had just been diagnosed with myeloma. It is times like these that I am reminded of how much knowledge the myeloma community have and when shared can make such a positive impact on another, easing feelings of anxiety and isolation and giving hope. We will continue to provide these sessions at our regular seminars and as always, carers are welcome to attend our Information and Support Groups.

Thank you to all our speakers and community who volunteered their time to ensure our Myeloma Month events were a success and ran smoothly and a thank you to the Leukaemia Foundation on another successful collaboration.

Our nurses have been working hard on updating our resources and it was great to have them on display at the Myeloma Awareness Month events. As well as updating our existing fact sheets on fatigue, nutrition, pain, bone disease and exercise our new diaries and treatment quick reference cards were very popular. The patient diaries are a terrific way to keep all of your myeloma related information, contact details and appointments in one place and the

treatment quick reference cards outline a number of myeloma medications including thalidomide, lenalidomide, pomalidomide, bortezomib, carfilzomib, ixazomib. Full versions of the fact sheets can be downloaded on our website; we will be adding daratumumab, venetoclax and steroids soon. If you would like any of our resources posted to you, please contact head office at support@myeloma.org.au

In this edition we have the first of our new NSW team members to introduce, Santosh who will work in fundraising. In the coming weeks we will be welcoming a new Myeloma Support Nurse in NSW to work with Jacqui delivering education and support services and we look forward to a formal introduction next edition.

In Queensland, we are in the process of recruiting to our first Myeloma Support Nurse position based in Brisbane and in the last few months we are excited to have seen a new Information and Support Group start up on the Sunshine Coast in Buderim. This has been driven by some motivated members of our community that see the need for myeloma specific support groups and they have planned to meet the first Tuesday of each month at the Bloomhill Cancer Centre in Buderim from 2:00pm to 3:30pm. If you would like any further information about this group, please contact nella.combe@myeloma.org.au until we have our nurses up and running in Queensland.

Now that winter is officially here, it's a good time to remind our community that it is highly recommended that people with a compromised immune system, such as those with myeloma, receive the flu vaccine. It's also important that those in contact with people with myeloma such as family, friends and work colleagues also have the vaccine to protect against flu. 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 and safe travels to those who are lucky enough to escape the cold.

*Nella Combe
Myeloma Nurse Manager*

“Let the training commence”

February 2018:

Jacqui Keogh NSW Myeloma Support Nurse

“White rabbits” “pinch, punch first day of the month” also day one of my training for “Team Myeloma” City to Surf 2018! I have entered this event several times before so I know what I’m in for but it also coincides with the year that I hope to finally complete a half marathon. There I’ve said it out loud now so I’m committed.

Wednesday 1 Feb I met my friend for an early morning run before the day gets crazy and despite the 6am start it is a lovely way to begin the day. Fortunately, the humidity in Sydney has lessened and it was actually a cool, refreshing 16 degrees. I have managed to talk my friend into joining “Team Myeloma” so now there’s two of us!

I have posted a sweaty post run photo from Sundays run (the humidity returns!), not the best but at least you know we are out there trying. Please feel free to join our team and fundraise for Myeloma Australia. We can always coordinate some group training runs I’m sure or have a virtual team if you can’t be with us on the day.

I will keep you updated of our progress but would be interested to hear about other peoples adventures as well.

Keep moving!

Jacqui

Update May 2018:

Training has been going really well, up to running a comfortable 10kms however have just sustained a small injury which saw me miss the Mother’s Day Classic run at Paramatta park.

I didn’t want to miss out so I walked it with my girls, hopefully I’ll be back running in the next few weeks.

Team Myeloma is now registered so please join us if you want to be part of our first fundraising event in NSW.

Jacqui Keogh



Jacqui Keogh with her girls.

Team Myeloma Wants YOU in Sydney!!

Team Myeloma makes its Sydney debut at the City2Surf event on Sunday 12th August.

Will you gather some friends and run with us?
A social gathering of the myeloma community will be held following the event.

Details can be found here: <http://city2surf.com.au/>

Any questions? Contact: matt.maudlin@myeloma.org.au



New South Wales

Since the last MyeNews edition I am pleased to announce that the NSW contingent of Myeloma Australia has expanded to include another Myeloma Support Nurse and a fundraiser (see Santosh's article). This is an exciting time as we now can start to increase our services to the myeloma community. We are currently looking for office space so we will also have a physical base in Sydney.

Since my last update I have been busy assisting in the planning and organising of the seminars to coincide with National Myeloma Month. This year's theme is "The what, how, when and why". I hope many have managed to attend at least one of the various events that were held around the country. We were fortunate this year in NSW to have 3 events running at various locations. On Monday 7th May we held our first seminar at the Bomaderry Bowling Club. We were delighted to have a range of speakers including Dr Gurdeep Parmar who gave a concise overview of myeloma and where we are currently up to with new therapies. He also discussed the use of complimentary therapies and this prompted much discussion. Bill Jansens (Nurse Practitioner) from Shoalhaven Cancer Care Centre gave a presentation on peripheral neuropathy and its management, a topic unfortunately many myeloma patients are only too familiar with. The day ended with an acknowledgement of the important role of carers within the myeloma community and a reminder that it's also important to care for ourselves so that we can care for others.

May 14th saw our seminar on the Central Coast at Wyong Golf Club. We had an interesting mix of speakers who discussed topics such as diagnosis and monitoring of myeloma and upfront and relapsed treatment. In addition, Louise Cowdry who is a social worker at Gosford gave some practical advice on accessing support and financial services. Jacqui Jagger who is the Haematology Nurse Practitioner at Gosford and well known to many of the myeloma community, gave an overview of supportive care and reiterated the previous speaker's comments about looking after ourselves as much as possible with exercise and healthy diets and self-care.

Our final event was at the Chris O'Brien Life house and was attended by over 80 people. We had an excellent talk by

Dr Chris Bryant who discussed myeloma disease and new treatments. Tracy King who needs no introduction in the NSW myeloma community gave an entertaining presentation on treatment related side effects and shared some good practical tips and advice. The final session of the day was presented by Dr Judith Lacey who is the Head of Supportive Care and Integrative Oncology at Chris O'Brien Life house. She discussed interventions and measures to keep people living well with myeloma. In addition to this we ran a separate carers session which although was only a small group, it enabled some valuable space for discussion.

I would like to take this opportunity to thank everyone who attended these days for being involved and contributing to making them such a success. I also want to give a big THANKYOU to all the presenters who kindly gave up their time to also be involved.

As always, your feedback is welcome and important so that we can ensure these events are informative and valuable to you the myeloma community.

In addition to National Myeloma Month I have continued to work with the many support groups throughout NSW. With the expansion of the team here in Sydney it is hoped we can now look at exploring other areas where individuals may want to start a group, so if anyone is interested please get in touch. Both Liverpool and Westmead Information and Support Groups have had invited speakers covering updates on myeloma and an overview of clinical trials. Both of these sessions were very well received. We continue to look at ways to provide education and support to the myeloma community and hope to have a few more events through the year in NSW but if there are ways in which you think we could assist, please do not hesitate to contact us. I hope to meet many more of you at the various groups, seminars or even on the telephone over the coming months.

And finally, the City to Surf is rapidly approaching, I have my running shoes on and I am in training mode (apart from a slight calf muscle tear!). Please contact me or Myeloma Australia if you are interested in getting involved.

*Jacqui Keogh
Senior Myeloma Support Nurse
NSW and ACT*



Central Coast Seminar.



*Jacqui Jagger, Glenda from
Leukaemia Foundation
& Jacqui Keogh.*



Sydney Seminar.



Bomaderry Seminar.

South Australia

At the last support group meeting held at Fullarton, Peter Hallett, a Psychologist from Calvary Rehabilitation Hospital and Adelaide Oncology & Haematology spoke of many emotions that patients and carers experience with serious disease.

When diagnosed, "it is all a blur until it sinks in". Reactions of family and friends are varied. He spoke about anxiety, frustration, fatigue, loss of energy, difficulty in concentration and memory, agitation, upset stomach and feelings of worthlessness or guilt, explaining however that some overlap with side effects of chemotherapy or other treatment drugs.

Peter emphasised the difference between sadness and depression. Sadness being a normal and necessary emotion but if out of control, it becomes depression and psychological help is needed. Keeping positive emotions is important as they are an essential part of our wellbeing.

His talk was well received. The carers appreciated him discussing the emotions and stresses that carers can go through worrying about their loved ones, he emphasised how carers need to also look after themselves.

The next meeting at Fullarton will be on June 5th, Dr. Kate Vandyke, researcher at SAHMRI will talk about current projects conducted at the Myeloma Research Laboratory.

The Flinders Support Group have had 2 meetings since our last report. Both were facilitated discussions by Jo Gardiner. The group decided to approach the Palliative Care Unit at Flinders Medical Centre to provide a speaker for the next meeting, to speak about their many support services, including massages for patients and carers.

The Mid-North Support Group had their last meeting on May 17th at Snowtown. It is a small discussion group who meet to share experiences and friendship. The next meeting is 16th August, where Jo will attend to facilitate discussion and answer questions

The South-East Support Group have their next meeting on August 30th and Jo will facilitate discussion with questions and answer session. To help increase community awareness,



Hayley Beer & Jo Gardiner with Leukaemia Foundation staff.



South Australia Seminar.

Jo gave a radio interview in April and upcoming meetings will be advertised in the community section of the local paper.

Another day for information and support is planned for patients in Darwin on Thursday 27th September at the Casuarina Library. Please check our website for more details.



Jo Gardiner & Michael Low.



Peter Hallett.

The South Australian National Myeloma Day Seminar was held in collaboration with the Leukaemia Foundation, on Saturday, May 12th. Feedback indicated it was a very successful event. The venue at Fullarton Park Community Centre was brilliant, the food was enjoyable and the speakers were excellent. Our patron, Dr. Noemi Horvath opened the program with "Overview of Myeloma", followed by Domenic Scoleri, a local myeloma patient, who gave an entertaining talk of his experiences and treatment, including

being on a clinical trial. This was followed by Dr. Michael Low from Monash Health in Melbourne, who gave two excellent presentations covering Clinical Trials, Novel Therapies and PBS applications. Using Venetoclax, (Bcl-2), developed for CLL in Melbourne as the example, he used a timeline to outline the 38 year development which preceded the current clinical trials. Venetoclax may be a useful drug for myeloma. This example illustrated why new drugs take so long to develop and cost so much.

The last speakers were Jo Gardiner who covered Supportive Care for Myeloma Treatments, while Hayley Beer (Myeloma Australia Nurse Manager) conducted a Carer's Group session in the adjacent room. It was an informative day for the 100 people who attended.

In addition to attending the above support groups, Jo has been providing in-service education to staff at the new Royal Adelaide Hospital with a program of 3 presentations, the first held in May. Planning is underway to provide the staff at Flinders Medical Centre with the same program. Jo is also on the planning committee for the Haematology Society of Australia and New Zealand Myeloma Special Practice Network annual seminar to be held in Adelaide in August.

Ian Driver – SA Chair

Jo Gardiner – Senior Myeloma Nurse Specialist

What's Happening

Victoria

May was Myeloma Awareness Month and we were lucky enough to kick start this year's first awareness event here in Melbourne together with 150 guests from the local myeloma community. Our educational seminar was held at the RACV City Club which offered a breathtaking view of the city and a rare opportunity to hear from international guest speaker Professor Joseph Mikhael from the Mayo Clinic, USA.



Melbourne Seminar.

Not to be out shone, our local experts delivered insightful presentations, starting with Dr Jay Hocking who effortlessly walked us through an overview of myeloma.



Laura Jones & Dr Jay Hocking.

Prof Mikhael offered a fresh take on new and emerging treatments internationally as Dr Hang Quach brought it home discussing treatment opportunities in the Australian context. We were then treated to a lively 'Question and Answer' panel with Dr Mikhael and Dr Quach which was equally as informative as it was entertaining. Thank you to our guests for their incredibly thoughtful questions.

Switching gears after lunch clinical psychologist Nina Edwards delivered a presentation on emotional wellbeing, an aspect of self-care often underestimated. This included practical strategies for stress relief, building resilience and



Myeloma Australia information display.

sleeping well. We were also treated to a short mindfulness session by Nina hopefully sending everyone home feeling relaxed and mentally lighter. Thank you to our cohosts from the Leukemia Foundation and to our fantastic guest speakers for donating their time.

I am delighted to introduce our newest Information and Support Group who meet in Berwick on the last Friday of alternate months at St John of God Specialist Centre. We had a great first meeting, with nine energetic attendees and special guest Bob Moran OAM, Myeloma Australia's co-founder. Bob delivered a short yet inspiring account of Myeloma Australia's beginnings and his experiences with support groups really highlighting how important they can be.



(L>R) Hayley, Laura & Nella.

With the addition of Berwick we now have 9 Information and Support Groups meeting regularly in Victoria. Each group has developed a unique style and culture, representative of the local communities where they are held. We are working to facilitate further Information and Support Groups to cover more of the state and would love to hear from anyone interested in being involved.



Prof Mikhael & Dr Hang Quach.

So what have our other groups been up to? Our Beaumaris group welcomed two quest speakers from Austin Health's Advance Care Planning volunteers team. Topical due to recent changes in legislation, the discussion was very informative and everyone went home with an Advance Care Planning pack. We also have a couple of very creative members in Beaumaris who have designed and made slippers by hand with removable heat packs to combat peripheral neuropathy

Geelong invited back social worker David who lead the group through some relaxation exercises and initiated an insightful discussion. Mt Eliza welcomed Tony a local exercise physiologist involved in the PACE 'Living with Cancer Program' who managed to get everyone on their feet. Our Younger Persons' group met at head office and continues to attract new members, with so many things to discuss two hours almost isn't enough time. Laura continues to support our other Information and Support Groups in Kew, Coburg, Traralagon and Warragul.

Elli Foley
Myeloma Australia Support Nurse

What's Happening

Western Australia

The momentum has continued here in the West with a number of projects keeping us busy over the past few months. We now have 3 support groups up and running with two in the north at Butler and Heathridge and one in the south in Mandurah. We have been delighted with the turn-out at these groups and we are looking forward to growing these groups and expanding to another group at a more central location in the upcoming months, so watch this space.



BeBe Scher (Middle) with WA Team Myeloma.

In March, we headed down to Bunbury to a venue called Dot's Place to host our first regional Meet and Greet and it was lovely to meet those that attended that event. We are hoping to host an educational event in the South West later in the year as well as hopefully travelling to the Great Southern and to spread the word about Myeloma Australia.

Health professional education has also been a big focus for us with a number of education sessions being hosted at Hollywood Private Hospital, St John of God Hospitals in Midland and Subiaco. In April, Kerin presented at the annual state conference of the Haematology Society of Australia and New Zealand Nursing Group in Mandurah where she spoke about current treatments in myeloma to nurses. Further hospital based education sessions are planned at several sites in the coming months including Fiona Stanley Hospital.

The big focus for the past few months has been the National Myeloma Month Seminar which we hosted in collaboration with Leukaemia Foundation at Technology Park in Bentley. It was a great event with a number of knowledgeable speakers presenting on various aspects of myeloma disease, its management, supportive care and clinical trials and was well attended by just over 100 patients and carers.

Dr Brad Augustson opened the seminar with a great presentation on the background to myeloma as a disease, its diagnosis and symptoms and the various treatment options available. He also discussed the importance of clinical trials in myeloma. The second speaker was Matt Schmidt, a pharmacist from Sir Charles Gairdner Hospital who followed on with a more in-depth discussion of clinical trials in myeloma. Debbie Cooper, a clinical exercise physiologist for the Health and Wellness Centre at Curtin University provided a great insight into the benefits of exercise and practical advice on what exercises are best for those living with myeloma. She energised the room with her



WA Seminar.

presentation and got everyone up and moving with some easy exercises aimed at building strength. After lunch, Dr Matthew Wright provided an opportunity to ask questions about the treatment of myeloma armed with a white board and markers.

To end the day, the seminar was split to provide the carer attendees with a designated session. This session proved popular with 21 participants in attendance and provided an opportunity for those providing support to a person living with myeloma to discuss the challenges faced in being a carer. One of the hot topics raised involved the challenges of travel and holidaying whilst living with myeloma. Concurrent to the carers session, other attendees were treated to an inspiring presentation from Dr Caesia Burger who shared her wealth of experience as a person living with myeloma and the impact it has had on her life. She not only shared her personal experiences but also offered some words of wisdom to others in the room. It was a privilege to have Caesia share her very personal experiences with the attendees.

To finish up the National Myeloma Day weekend festivities, Myeloma Australia had a team in the HBF Run for a Reason with 30 participants representing Team Myeloma. All distances offered at the event were covered by the participants, by either running the half marathon, and running or walking the 12km or 4km. Whilst the day was overcast with a forecast of showers, we were fortunate that we only had a light shower to whilst we were participating. Team Myeloma was strongly bolstered by a Victorian Myeloma Australia contingent with Matt, Nella and Hayley from head office donning the trainers and joining in the fun. Afterwards there was a gathering at Victoria Park hotel to recover and have an opportunity to meet with other members of the myeloma community.

Our latest news involves our planned relocation to a new office space at the Cancer Wellness Centre in Cottesloe in June. This move will allow for our planned expansion and to access a number of facilities and services on site. We are really looking forward to using this venue to also host some events later in the year.

What an eventful quarter we have had, we cannot wait to see what the next few months bring for the WA Team.

*Kerin Young
Narelle Smith
Myeloma Australia Support Nurses*

Commentary:

Shaji Kumar, MD – *ClinicalThought*™ 1/29/2018

How New Data May Change Myeloma Care in 2018 and Beyond

Treatment paradigms in myeloma are undergoing a dramatic shift due to newly available information, including better disease definitions, acceptance of potential benefit from early intervention, development of new classes of agents leading to highly effective combinations, and the advent of various immunotherapeutic approaches. In this commentary, I discuss a few interesting new studies presented at the 2017 ASH annual meeting.

New Data in Newly Diagnosed Myeloma

The arrival of new monoclonal antibodies, such as daratumumab and elotuzumab, have ushered in a new era for treatment of newly diagnosed and relapsed myeloma. The lack of overlapping toxicities allows daratumumab to be added to various standard-of-care treatment regimens in the relapsed/refractory setting. For patients with newly diagnosed myeloma, the phase III ALCYONE trial enrolled patients ineligible for autologous stem cell transplantation to assess the efficacy and safety of the addition of daratumumab to standard treatment with bortezomib/melphalan/prednisone (VMP). Results of this trial demonstrated an increased response rate (91% vs 74%), depth of response (MRD negativity: 22% vs 6%), and improved PFS (median: not reached vs 18.1 months) with the addition of daratumumab to VMP vs VMP alone.

These findings open up the possibility of other quadruple combinations, and several of them are being tested in clinical trials including combinations of carfilzomib/lenalidomide/dexamethasone and bortezomib/lenalidomide/dexamethasone (VRd) with daratumumab and VRd with elotuzumab. The demonstration of high response rates with these 4-drug regimens may offer several opportunities to move the field forward, including the potential to eliminate the need for steroids and to limit the duration of therapy, especially in patients who achieve MRD-negative disease.

New data in relapsed/refractory myeloma

Finally, multiple immune-therapeutic approaches have shown dramatic responses in patients with relapsed or refractory myeloma. CART-cell therapy, in particular, has been of immense interest in hematologic malignancies, including myeloma, and results of several trials have been presented so far.

Although CAR T-cells targeting CD19 have been developed and approved for relapsed or refractory large B-cell lymphoma and are in development for many other hematologic malignancies, this is not an optimal target for myeloma. However, CAR T-cells specific to BCMA—a TNF receptor superfamily expressed on myeloma tumour cells, nonmalignant plasma cells, and some mature B-cells—has demonstrated activity in myeloma. Multiple trials with

BCMA-targeted CAR T-cells were presented at ASH 2017. One such trial was the phase I trial of bb2121 anti-BCMA CAR T-cell therapy in patients with relapsed or refractory myeloma after ≥ 3 previous lines of therapy or those with double-refractory disease. In this report of updated results, bb2121 demonstrated significant activity for these patients who failed all available therapies. At a median follow-up of 40 weeks, 56% of patients achieved CR and 9 of 10 evaluable patients achieved MRD negativity at the higher doses tested. These responses appear to be durable, with some patients remaining in response beyond 1 year.

The results with the other anti-BCMA CAR T-cell approaches, including different BCMA targeting constructs, treatment with or without a chemotherapy conditioning regimen, and in combination with CAR T-cells targeting different antigens, also appear to be of significant clinical benefit.

These early-phase trials are very promising, but clearly, more work needs to be done to better identify the patients with myeloma who are most likely to benefit from CAR T-cell therapy and to delineate the potential for intervention earlier in the disease course, particularly for patients with high-risk disease. In addition, logistical concerns remain. Significant effort is required for the apheresis and ex-vivo manipulation of each patient's T-cells. Furthermore, the time delay between T-cell collection and infusion of the CAR T-cell product can be difficult for a patient with aggressive disease. To ameliorate some of these concerns, off-the-shelf immune approaches such as a BCMA-targeted bispecific T-cell engager, or BiTE, may offer some advantages and are also being tested in clinical trials.

Supportive Care:

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

Noopur Raje, Evangelos Terpos, Wolfgang Willenbacher, Kazuyuki Shimizu, Ramón García-Sanz, Brian Durie, Wojciech Legieć, Marta Krejčí, Kamel Laribi, Li Zhu, Paul Cheng, Douglas Warner, G David Roodma; *Lancet Oncol* 2018; 19: 370–81

Findings From 2012, to 2016, we enrolled 1718 patients and randomly assigned 859 to receive either s/c denosumab and monthly IV placebo or, IV zoledronic acid (Zometa) and monthly s/c placebo. The study met the primary endpoint; denosumab was non-inferior to zoledronic acid for time to first skeletal related event. Incidence of the most common adverse events for denosumab and zoledronic acid were similar in both groups: neutropenia, thrombocytopenia, anaemia, febrile neutropenia pneumonia (most common serious A/E at 8%), and osteo-necrosis of the jaw (3-4%).

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

standard of care for patients with multiple myeloma with bone disease

Editors note: The manufacturers of denosumab have applied to the Pharmaceutical Benefits Advisory Committee for access to denosumab for myeloma patients in Australia via the Pharmaceutical Benefits Scheme. Myeloma Australia will advise if the application is successful in due course.

Treatment: Autologous Stem Cell Transplant (USA)

Impact of duration of induction therapy on survival in newly diagnosed multiple myeloma patients undergoing upfront autologous stem cell transplantation

Rajshekhhar Chakraborty et al, British Journal of Haematology, <https://doi.org/10.1111/bjh.15244>; Version of Record online: 29 April 2018

The optimal duration of induction therapy (IT) in transplant-eligible multiple myeloma (MM) patients is not well defined, resulting in a wide variation in clinical practice. The objective of our study was to determine whether the duration of IT in patients undergoing upfront autologous stem cell transplantation (ASCT) has an impact on progression-free survival (PFS) in the era of proteasome inhibitors and immunomodulatory drugs. A total of 596 patients who underwent ASCT at Mayo Clinic between 2007 and 2014 were included. The patients were divided into two cohorts based on the duration of IT: IT ≤ 4 and IT > 4 months. There was no significant difference in overall survival (OS) in the two groups (P = 0.904). The lack of impact of IT duration on PFS and OS was consistent in subgroups with high-risk features at diagnosis (International Staging System III or high-risk cytogenetics) and different depths of pre-transplant response [≥very good partial response (VGPR) and <VGPR]. In conclusion, prolonging the duration of IT beyond 4 months does not impact survival in patients with newly diagnosed MM who complete a single line of IT followed by consolidation with ASCT.

Treatment For Relapsed Myeloma (Daratumumab) (East Asia)

Daratumumab, lenalidomide, and dexamethasone in East Asian patients with relapsed or refractory multiple myeloma: subgroup analyses of the phase 3 POLLUX study

Kenshi Suzuki, Meletios A. Dimopoulos, Naoki Takezako, Shinichiro Okamoto, Atsushi Shinagawa, Morio Matsumoto, Hiroshi Kosugi, Sung-Soo Yoon, Shang-Yi Huang, Xiang Qin, Ming Qi, Shinsuke Iida; Blood Cancer J. 2018 Apr; 8(4): 41

In the phase 3 POLLUX study, daratumumab plus lenalidomide and dexamethasone (DRd) significantly reduced the risk of progression/death and induced deeper responses vs. lenalidomide and dexamethasone alone (Rd) in patients with relapsed/refractory multiple myeloma (RRMM). We report a subgroup analysis of East Asian (Japanese, Korean, and Taiwanese) patients from POLLUX based on a

longer follow-up of 24.7 months. Median progression-free survival was not reached (NR) for DRd vs. 13.8 months for Rd, and overall response rates were higher for DRd vs. Rd (90.2 vs. 72.1%). DRd extended the median duration of response vs. Rd (NR vs. 20.2 months), and minimal residual disease-negative rates at the 10⁻⁵ sensitivity threshold were 21.2 vs. 9.1% for DRd vs. Rd. No new safety signals were observed. Similar efficacy and safety were observed in the smaller subgroup of Japanese patients treated with DRd vs. Rd. These results demonstrate favourable efficacy and safety of DRd vs. Rd in East Asian patients and also in the Japanese-only patient subgroup that are consistent with findings in the overall patient population of POLLUX.

Measuring Response To Treatment (Pet/Ct):

Treatment to suppression of focal lesions on positron emission tomography-computed tomography is a therapeutic goal in newly diagnosed multiple myeloma.

AUTHORS: Faith E Davies et al; Haematologica 2018 [Epub ahead of print]

PET-CT in myeloma can detect and number focal lesions by their metabolic activity. The aim of this study was to determine the prognostic significance of the suppression of metabolic activity seen by PET-CT at several time points after therapy started including day 7 of treatment, after first treatment course completed (post induction), post-transplant and at maintenance therapy. 596 patients underwent baseline PET-CT and were re-tested during their disease. We demonstrate that the presence of more than 3 focal lesions at diagnosis identifies a group of patients with an adverse progression free survival and overall survival. At day 7 of therapy patients with complete focal lesion signal suppression revert to the same prognosis as those with no lesions at diagnosis. At later time points, the continued suppression of signal remains prognostically important. We conclude that for newly diagnosed patients with focal lesions treatment until they are suppressed is an important therapeutic goal, as the prognosis of these patients is the same as those without lesions at diagnosis.

Real World Experience Using Registry Data (Europe):

Melphalan 140 mg/m² or 200 mg/m² for autologous transplantation in myeloma: results from the Collaboration to Collect Autologous Transplant Outcomes in Lymphoma and Myeloma (CALM) study

Authors: Auner H et al. Haematologica 2018;103(3):514-21

Summary: This report by the European Society for Blood and Marrow Transplantation Chronic Malignancies (EBMT) Working Party gives results from the retrospective, observational Collaboration to Collect Autologous Transplant Outcomes in Lymphoma and Myeloma study.

The researchers analysed 1,964 single first single autologous transplantation episodes to determine the optimum pre-autologous transplant conditioning dose of melphalan

– 200mg/m² or 140 mg/m² for different groups of MM patients. There was no difference between the melphalan dose groups.

(140 mg/m², n=245; 200mg/m²) in overall survival, progression free survival, incidence of relapse or second primary malignancy rates. The only tested variable that influenced transplant outcomes including OS and PFS was disease status at transplantation. Patients transplanted in less than partial response showed a better response to melphalan 200mg/m² whereas patients in very good partial or complete response had a higher OS with melphalan 140mg/m² dose.

Comment: Studies confirming the superiority of high dose melphalan and ASCT over conventional chemotherapy in MM have established Mel 200 as the conditioning regimen of choice. However, some studies demonstrate excess morbidity and mortality associated with Mel 200 dosing in older patients, particularly in those patients with renal impairment. This retrospective analysis of nearly 2000 patients from the EBMT set out to evaluate ‘real world’ outcomes in European MM patients transplanted between 2008 and 2012. Only 12% of the cohort received Mel140 and these patients tended to be older, less fit and had more significant renal impairment. Although there was no significant difference in OS or PFS between the 2 conditioning regimens, subgroup analysis suggested Mel140 transplants could be a safer alternative to Mel200 in those patients achieving excellent responses to induction therapy. As more patients currently achieve deeper responses to induction therapy, this paper suggests further investigation of the optimum melphalan dose prior to ASCT is warranted.

Real World Experience Using Registry Data (France):

Real life management of patients hospitalized with multiple myeloma in France

Charles Dumontet, Sandrine Couray-Targe, Marion Teisseire, Lionel Karlin, Delphine Maucourt-Boulch
Published: May 1, 2018,
<https://doi.org/10.1371/journal.pone.0196596>

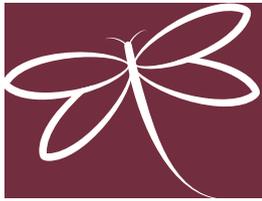
Patients with multiple myeloma included in prospective clinical trials are highly selected and therefore are unlikely to represent the entire patient population. Additionally recommendations based on literature data and randomised trials are not systematically implemented in all patients. We sought to determine how patients hospitalised with a diagnosis of multiple myeloma are currently treated in France.

We searched the Programme de Médicalisation des Systèmes d’Information (PMSI) database which includes anonymous data for all patients hospitalised in France. We identified newly diagnosed cases in 2012 and analysed the number and duration of hospital stays, coexisting conditions and treatment given with data available until the end of 2015. Intensive therapies with stem cell transplants were performed in 1033 patients (16% of total), the majority of which were aged less than 65 (881 patients, 85.3%). Stem cell transplants were performed more frequently in males while the distance between the site of residence and the transplant center had no impact on likelihood of receiving a transplant. Only 60% of patients less than 65 years old who were treated for their disease underwent intensification with stem cell transplant within the 4-year follow-up period.

Conclusions: a large majority of patients hospitalised with a diagnosis of multiple myeloma are elderly, in particular females, and not eligible for transplants. Among the patients aged less than 65 and receiving therapy for their disease, 40% do not undergo transplants. These data emphasize the need for alternative therapies.



Find our new
Treatment Fact Sheets
under the resources tab of our website
www.myeloma.org.au



Calendar of Events 2018

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
Kew Information and Support Group	Thur Jun 14th	Kew Library Corner Charles St & Cotham Rd, Kew	10 am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Traralgon Information and Support Group	Wed Jun 20th	Gippsland Rotary Centenary House 39 Valley Drive Traralgon Vic	10 am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Jul 12th	Rotating at local venue, details published closer to date	6 pm - 8 pm Dinner	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur Jul 19th	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30 am - 12.30 pm <i>(note time change)</i>	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Younger Persons Information and Support Group	Thur Jul 19th	Myeloma Australia Head Office 333 Swan Street, Richmond	6 pm - 8 pm (Dinner)	Myeloma Australia	Elli Foley & Laura Jones E: elli.foley@myeloma.org.au E: laura.jones@myeloma.org.au
Berwick Information and Support Group **New**	Fri Jul 27th	St John of God Specialist Centre Wellness Room, Level 1 55 Kangan Drive, Berwick	10 am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Coburg Information and Support Group	Wed Aug 1st	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10 am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Beaumaris Information and Support Group	Thur Aug 2nd	Beaumaris Theatre 82 Wells Road, Beaumaris	10 am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Kew Information and Support Group	Thur Aug 9th	Kew Library Corner Charles St & Cotham Rd, Kew	10.am - 12.pm	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Geelong Information and Support Group	Fri Aug 10th	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10 am - 12 noon	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233
Traralgon Information and Support Group	Wed Aug 15th	Gippsland Rotary Centenary House 39 Valley Drive Traralgon Vic	10 am - 12 noon	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Warragul Information and Support Group	Thur Sep 13th	Rotating at local venue, details published closer to date	6 pm - 8 pm (Dinner)	Myeloma Australia	Laura Jones E: laura.jones@myeloma.org.au M: 0451 404 203
Mt Eliza Information and Support Group	Thur Sep 20th	Mount Eliza Community Hall 90-100 Canadian Bay Road, Mount Eliza	10.30 am - 12.30 pm <i>(note time change)</i>	Myeloma Australia	Elli Foley E: elli.foley@myeloma.org.au M: 0426 404 233

South Australia

Event	Date	Location	Time	Organisation	Contact
Flinders Information and Support Group	Thur Jul 19th	Living Kuarna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tue Aug 7th	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10 am - 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)
Mid North Information and Support Group	Thur Aug 16th	Snowtown Hospital 70 Railway Terrace E, Snowtown	12 noon - 2 pm	Myeloma Australia	Bronwyn Gerschwitz E: graemebronwyng@bigpond.com P: (08) 8664 0682 1800 MYELOMA (693 566)
South East Information and Support Group	Thur Aug 30th	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 20th	Living Kuarna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)

Western Australia

Event	Date	Location	Time	Organisation	Contact
South Metro Information and Support Group	Mon Jun 25th	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3pm	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 Jul 2nd	Heathridge Community Centre Activity Room 2, 1/16 Sail Tce, Heathridge	1 pm - 3 pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Aug 6th	Butler Community Centre Activity Room 2, Meeting Room, 55 Kingsbridge Bvd, Butler	1 pm - 3 pm	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 Aug 27th	Mandurah Seniors & Community Centre 41 Ormsby Terrace, Mandurah	1 pm - 3 pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Sep 3rd	Heathridge Community Centre Activity Room 2, 1/16 Sail Tce, Heathridge	1 pm - 3 pm	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
Buderim Information and Support Group	Tue Jul 3rd	Bloomhill Cancer Centre 58 Ballinger Rd, Buderim	2 pm - 3:30 pm	Myeloma Australia	Nella Combe E: nella.combe@myeloma.org.au Toll free: 1300 632 100 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tue Aug 7th	Bloomhill Cancer Centre 58 Ballinger Rd, Buderim	2 pm - 3:30 pm	Myeloma Australia	Nella Combe E: nella.combe@myeloma.org.au Toll free: 1300 632 100 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tue Sep 4th	Bloomhill Cancer Centre 58 Ballinger Rd, Buderim	2 pm - 3:30 pm	Myeloma Australia	Nella Combe E: nella.combe@myeloma.org.au Toll free: 1300 632 100 1800 MYELOMA (693 566)

New South Wales

Event	Date	Location	Time	Organisation	Contact
RPAH Information and Support Group	Tue Jun 12th	Royal Prince Alfred Hospital Chris O'Brien Lifehouse Education Centre Level 5 119-143 Missenden Rd, Camperdown	10 am - 12 pm	RPAH & Myeloma Australia	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 / 9515 6111 pager 87524 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tue Jun 19th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230 1800 MYELOMA (693 566)
Westmead Information and Support Group <i>Change of Venue</i>	Thur Jun 21st	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Jun 28th	Central Coast Leagues Club Dane Drive, Gosford	6 - 8 pm	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 Jul 2nd	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3 pm - 5 pm	Myeloma Australia	John Miller E: miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)
RPAH Information and Support Group	Tue Aug 14th	Royal Prince Alfred Hospital Chris O'Brien Lifehouse Education Centre Level 5 119-143 Missenden Rd, Camperdown	10 am - 12 pm	RPAH & Myeloma Australia	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 / 9515 6111 pager 87524 1800 MYELOMA (693 566)
Liverpool Information and Support Group	Tue Aug 21st	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts Liverpool	10 am - 12 pm	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230 1800 MYELOMA (693 566)
Westmead Information and Support Group <i>Change of Venue</i>	Thur Aug 23rd	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12pm	Myeloma Australia	Jacqui Jagger (02) 4320 9641 E: jacqueline.jagger@health.nsw.gov.au 1800 MYELOMA (693 566)
Central Coast Information and Support Group	Thur Aug 30th	Central Coast Leagues Club Dane Drive, Gosford	6 - 8 pm	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 Sep 3rd	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3 pm - 5 pm	Myeloma Australia	John Miller E: miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)

National Telephone Support Group (Cancer Council NSW)

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

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

Myeloma Australia is the only myeloma specific support organisation in Australia



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



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



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



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

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

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