

# MyeNews

Spring 2018 Issue no 47



## In this issue

From the President	3
Profile – Geo Sobrio	4
Profile – Sam Zeps & Jacqueline Tate	5
Information and Support Group Initiative	6
Exercise as Medicine	7
News from the Myeloma and Related Diseases Registry	9
My Myeloma Journey	10
Telephone Support Feedback Project	10
Fundraising	12
What's Happening – Fundraising	13
From the Nurse Manager	14
What's Happening – New South Wales	15
What's Happening – South Australia	16
What's Happening – Victoria	17
What's Happening – Western Australia	18
Medical Corner	19
Calendar of Events	21

MyeNews – Contact Information and Submissions

For feedback, comments, questions or stories for consideration

Contact Pina Civitarese:

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

[pina@myeloma.org.au](mailto:pina@myeloma.org.au)

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

Design & layout: Greg Loveder Graphics

Printed by Eastern Press

*Front cover photo: A profusion of flowers and blossoms heralding spring.*



Find us on Facebook and Twitter

MyeNews is supported by  
an unrestricted educational  
grant from Celgene



**Office Hours:** 9am – 5pm Monday to Friday AEST

**Head Office:** 333 Swan Street, Richmond, VIC 3121 **Post:** PO Box 5017 Burnley, VIC, 3121

**T:** 1300 632 100 (toll free) **T:** (03) 9428 7444

MyeNews is published quarterly by the Myeloma Foundation of Australia Inc. The information presented in MyeNews is not intended to take the place of medical care or the advice of a doctor. Your doctor should always be consulted regarding diagnosis and treatment. No part of this newsletter may be reproduced in any form without the prior written permission from The Myeloma Foundation of Australia Inc.

Myeloma Foundation of Australia Inc. ARBN 126 035 247 ABN 30 476 390 368

## From the President

**It is hard to believe that Myeloma Australia will celebrate its 20th birthday this year. It does not seem that long ago that I met with Robert and Glenys Moran, the Brown family, Pat Dobson of the Cancer Council Victoria, Professor Miles Prince and Associate Professor Paul Mitchell at the offices of the Cancer Council with the idea of starting a myeloma support organisation in August 1998.**

In May 1999 Myeloma Victoria was incorporated and the committee included Robert and Glenys, Pat Dobson, Leanne Lambert, a social worker and myself. Prof. Prince and A/Prof Mitchell were permanent advisors to our board.

We met every couple of months and our first big event was a patient seminar in April 1999 at the Crest Hotel in St Kilda. We had about 250 people attend the day listening to presentations on all aspects of myeloma given by Professors Doug Joshua, Miles Prince, Jeff Szer and Associate Professor Paul Mitchell. This event far exceeded our expectations and gave us the incentive to keep building our organisation as we saw the real need in the community for support and education.

In early 2000 we employed our first Myeloma Support Nurse and started the 1800 telephone support service which is still going strongly today.

In about 2002 Professor Doug Joshua chaired a meeting of a number of groups with an interest in myeloma from all over Australia to discuss the forming of an Australian organisation. After this meeting we joined with a group based in Liverpool, Sydney run by Shaun and Linda Raby and one from Adelaide run by Ian Driver, to start Myeloma Australia (Myeloma Foundation of Australia Inc.)

Our next step was to employ a Myeloma Support Nurse in both Adelaide and Sydney. Over the following years we formed a number of support groups and ran a number of patient seminars both in the capital cities as well as in the country centres.

At long last we are now a truly national organisation with Myeloma Support Nurses based in Perth, Adelaide, Melbourne, Sydney, Brisbane and shortly in Newcastle and Tasmania as planning progresses. The Northern Territory is covered from Adelaide and Canberra is covered from Sydney. Tasmania will soon have a Myeloma Australia nurse though presently this is covered from Melbourne. From the very beginning we decided that we would be a nurse based organisation with all of our services run by qualified myeloma nurses. We are the only organisation in the world providing an entirely myeloma nurse based support service to the myeloma community and all of our nurses are among the most knowledgeable myeloma nurses in Australia. One of the many services they provide is to visit hospitals and present myeloma education for the nurses.

Myeloma Australia has decided to celebrate our birthday by introducing awards to those volunteers who have helped make this all possible. This year we are making our first batch of volunteer recognitions and each year going forward we will recognise those people who have made a volunteer contribution to myeloma patients in Australia. We have three levels of awards with the first two groups being presented at events in their capital cities and the top awards will be presented at the 2nd National Myeloma Scientific Workshop in September. Award recipients will be notified soon and all the awardees will be in the next edition of MyeNews.



The National Myeloma Scientific Workshop that we are holding in September is held every second year and we invite researchers from Australia and New Zealand to present their work to their peers. Also, we have invited three international haematologists who will speak on their research.

With the growth of Myeloma Australia our need for funding increases and I thank the all our corporate supporters for their generous support. I would also like to thank those members of the myeloma community who have held fund raising events, run or walked in the many fun runs or those who have just donated, your money is necessary for us to maintain and grow the level of service we are supplying.

We are still a very small organisation with one full time staff member in Steve our CEO and six part time staff assisting with fundraising and administration. I would like to thank Steve as it has been under his guidance that we have really grown always along the directions set by the original Myeloma Victoria Board. Boy have we come a long way in twenty years!

I would like to add a personal comment as this year marks my wife Roslyn's 22nd year since diagnosis with myeloma and 21st year since a stem cell transplant and this year we celebrate our 50th wedding anniversary. This is something we never expected to reach and we make sure that we do not take anything for granted.

Keep hanging in there as there are new drugs being developed and hopefully we will see in our lifetime myeloma being classified as a chronic disease and hopefully a cure. ●

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

*Brian Rosengarten*  
President  
Myeloma Australia

### Geo Sobrio



My background in nursing started in 2006. After I finished my degree at my hometown in the Philippines, I was rotated to multiple areas in paediatrics, emergency, and surgery but ended up in complex medical unit and stayed there for 5 years. Not long after, I was enjoying my first Australian summer in 2012 in the quiet and beautiful town of Bendigo. There, I did a bridging program to get me used to the Australian health care system and learn the culture of course. Then few weeks later, I landed a job in Sydney and eventually, I called Liverpool my second home.

It was only when I became a haematology nurse in the inpatient ward of Liverpool Hospital that I learnt so much about blood cancers and myeloma. Looking after patients during intensive chemotherapy and bone marrow transplant requires specialty knowledge so I did post grad study in stem cell transplantation and it opened the door to more specialized haematology roles.

I became a clinical trials coordinator at Royal Prince Alfred Hospital where I was involved in the POLLUX study and the very promising CART Cell therapy. It was my first out-of-the-ward job setting and I really enjoyed the variety. A few months after that, I took a temporary role at the Australian Red Cross Blood Service. I was a Clinical Nurse Advisor in the management of IVIGs and coordinator for the HLA matched platelets. It was only there that I realized how much IVIGs are needed for the entire NSW community and the tremendous helpfulness of the organization. I was very impressed how I grew with them and became a clinical resource for complex cases. I then decided to study nursing leadership for my next career adventure.

It was at the beginning of winter when I joined the team at Myeloma Australia. I instantly enjoyed my new role because of its flexibility and the opportunities to learn deeper, and the gift of more time to listen to patients' stories as they go on their journey with myeloma. Ever since my first attendance at a support group meeting, I was inspired to reach out to patients and more importantly their carers. I have always been very passionate about empowering my patients and this has been the core of my nursing life.

I will be working every Thursday and Friday each week in our newly opened office in Parramatta. On my other days of the week, I run a private chemo clinic for solid tumours (medical oncology) and do one day on the weekend at my old haem ward or in ED at the public in Liverpool.

Even though I am very busy, I always find myself strolling and surfing along the beautiful sands in the south coast or at the edges of the cliffs of the blue mountains. Over the next few months, I will be in Adelaide, the Yarra Valley in Victoria and then Brisbane to attend conferences and to meet the myeloma nursing community. It's going to be great to get around the country to learn more about myeloma and meet members of the myeloma community. ●

Regards,

Geo Sobrio  
Myeloma Support Nurse, NSW

## The Myeloma Muster

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

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



### Sam Zeps



Photo © Pina Cvitarske

Just over a year ago now I moved with part of my family from Perth to Melbourne because of a job opportunity for my husband, Nik. When I say part of my family, that's because I have two step-children (Zen, 21 and Aisha 19), as well as two children of my own (Daniella 8 and Kira 6) and the eldest couldn't join us due to university commitments in other states. So, our move to the east has significantly affected our family in many ways. Not only have we been separated from one another, but I also had to leave my mother and lifelong friends, and of course the warmer climate of the sunny west. However, with this change has come many fantastic and positive life changing opportunities for us all.

Over the last year my focus was settling our daughters into their new school and extracurricular activities. Now, feeling very settled in our new home, I am very happy to be back in the work force and particularly with the opportunity to enter a new field of work. Over the last 12 years I worked as a laboratory based graduate research assistant working in cancer research; from prostate cancer in my honours year to leukaemia's in subsequent years at the Telethon Institute for Child Health Research and at the University of Western Australia. While I enjoyed the laboratory research, I knew that this was something I no longer wanted to do and that there were other components to cancer care I wanted to explore and be a part of. I am therefore very excited to have secured a position at Myeloma Australia as I'm now gaining experience and insight into another integral part of cancer care; the provision of personal support to those with cancer. While not dealing with patients directly I am delighted to be able to assist those that do, through the various tasks that are being assigned to me. My hope is that my experience in research will bring additional skills to the organisation and contribute to its growth and development. In the short time I have been at Myeloma Australia I have already acquired a greater appreciation of the needs and services required by people with myeloma, as well as their family and carers, and I'm honoured to have been given the opportunity to be a part of this important organisation.

Photo supplied and used with permission

Apart from my family and my work in cancer, my other great passion is triathlon, which has become an integral part of my life over the past four years. Working up from short distance to long distance events, it is the longer courses i.e. half ironman and ironman distances that are my favourite. I am currently training for the Busselton half ironman in December with the hopes to do my second full ironman in Port Macquarie next year if my knee holds up, having had surgery on it earlier this year. I remain forever hopeful that I can continue where I left off as I can't imagine this sport not being a part of my life. ●

*Sam Zeps*  
Support Services

### Jacqueline Tate



Hello! My name is Jacqueline. I love my role at Myeloma Australia as Project Manager and Liaison with the wildly talented group of clinicians and scientists we call the MSAG (Medical and Scientific Advisory Group). Before joining Myeloma Australia, I worked as a scientist investigating deafness, cell transplantation and the cochlear implant, also working abroad in cancer bioscience and clinical trials. Outside Myeloma Australia I am a passionate advocate for equal access to STEM (Science Technology Engineering and Maths), and a volunteer with organisations like Tech Girls are Superheroes. This year I was honoured to be a Future Makers Fellow through CSL Australia and named as a finalist for STEM ambassador to parliament. Right now, I am most excited about the upcoming National Myeloma Scientific Workshop. We run this event so that clinicians and scientists from around the world can share their knowledge. I also have a young family that loves adventure. On our most recent trip to Mt Buller the kids went from snowballs to independent skiing in two days flat! We are pictured here snorkeling in Northern Queensland. ●

*Jacqueline Tate*  
Project Manager and Liaison  
Medical and Scientific Advisory Group

*"This is a very special gift  
For a very special person.  
The reason, it's so special is,  
It's just for you from us.  
Whenever you are lonely,  
Or ever feeling Blue,  
You only have to hold this gift  
And know we think of you"*

*Members of the Beaumaris  
Myeloma Information and Support Group*

The Beaumaris Information and Support Group have been giving very special gifts to the myeloma community for years. Driven by member Jan Watt, these gifts are carefully considered, fundraised and shared to brighten someone's day.

A successful application to Melbourne's bayside city council around 7 years ago, awarded the Beaumaris group a grant to set up an office. This grant allowed the group to purchase office items and supported their proposed fund-raising endeavours. The generosity and kindness of the members and the local community, including local businesses, lead to a successful raffle. Prizes were both donated and handmade.

Following a generous donation to Myeloma Australia, the group had some money left over. A long discussion on what to do with the extra money led to an idea to create a 'Welcome Pack' for people living with myeloma. These packs were filled with small gifts to help patients on admission or at the time of a stem cell transplant. Receiving positive feedback, the raffle and welcome packs have become an annual project.

The latest version of the welcome packs contain a note book and pens to pass the time. Ear plugs for a decent sleep. Hand sanitizer, antiseptic cream, dove soap and hand cream to keep the bugs away. Tissues and jellybeans for the ups and downs. Lastly a Myeloma Australia support group meeting schedule and the above poem. To quote Jan 'it is not so much what is in the packs but the knowledge that they are not alone and someone cares.'

It is a team effort and once the packs are created, they are delivered and given out by the transplant coordinator at a Melbourne hospital to those in need of support. Ten very special 'Welcome Packs' are shared every four months or so with continued appreciation from the recipients.

The Beaumaris Support Group raffle will be drawn again at their October meeting, with special mention to the following fantastic top prizes; a handmade table by Ian Crothers created at Bayside Men's Shed using only recycled timber, a cot quilt handmade by Jan, bottles of wine from a member's winery and many gift cards."

Did something help you or someone close to you through a transplant? I'd love to hear about it. Send your tips through to [elli.foley@myeloma.org.au](mailto:elli.foley@myeloma.org.au) . ●

*Elli Foley  
Myeloma Support Nurse  
Victoria*



# Exercise as Medicine

**Exercise as Medicine! This seems like quite a bold statement and probably one that you have not heard often, especially as myeloma patients. However, the evidence is now overwhelming. Everyday there is more and more reporting of clinical and scientific research supporting this type of medicine and the importance of it being prescribed, together with traditional treatments, as normal standard practice in oncology care.**

The Clinical Oncology Society of Australia (COSA) recently released a position statement recommending that exercise be embedded as part of standard practice in cancer care with evidence supporting exercise as helping to counteract the adverse effects of cancer and its treatment.

Assoc. Professor Prue Cormie, one of the leading authors of the COSA position statement, stated on a recent episode of Insight (SBS) "If the benefits of exercise were encapsulated into a pill, this pill would be demanded by every patient, prescribed by every doctor and subsidised by the government." It is easy to imagine that this would be an extremely popular pill and one that people would readily accept into their medicine cabinet.

It's known that regular ongoing exercise through all stages of the treatment process has been shown to improve aerobic capacity, increase muscle mass and strength, slow or prevent bone mineral density loss, increase quality of life, reduce fatigue and aid recovery. However, only one in five people diagnosed with cancer are meeting national physical activity guidelines. The Australian Physical Activity guidelines

recommend that for good health we exercise at a moderate intensity for 150-300 minutes (ie: swimming, walking, light cycling) or 75-150 minutes at a vigorous intensity (fast paced jogging or fast cycling), plus two to three resistance training sessions per week. These numbers can be quite challenging to meet; therefore, it is important to remember any exercise is better than none and that it's ok to start off slowly, increasing the time spent exercising gradually each week.

COSA recommends that all people with cancer avoid inactivity and return to normal daily activities as soon as possible following diagnosis. They suggest that all people with cancer should progress towards and, once achieved, maintain participation in at least 150 minutes of moderate intensity or 75 minutes of vigorous-intensity aerobic activity; and two to three resistance exercise (i.e. lifting weights) sessions each week targeting all major muscle groups.

So why are so few achieving these guidelines? Barriers to exercising have been reported as fatigue, pain, nausea, cost, lack of knowledge, time and confidence, no interest in, or friend to exercise with, as well as other health conditions. Myeloma patients also get to add bone pain, cancer related fatigue, muscle wasting and serious neurological complications such as cranial and spinal nerve compression as consequences of their extensive treatment protocols to this list.

Patients with bone lesions have traditionally been advised to avoid high intensity aerobic exercise, resistance training and impact training, however, recent research into various patient populations with bone metastases has established that a rest strategy only hastened decline and reduced survival rates. It has now been determined that resistance training and aerobic exercise programs that are specifically designed to avoid loading potentially fragile sites are both safe and effective.



WA Myeloma Association members Paul Sims and Chris Windsor working hard at the Curtin University Health & Wellness clinic, following the advice of their referring Haematologist Dr Brad Augustson to use exercise as medicine.

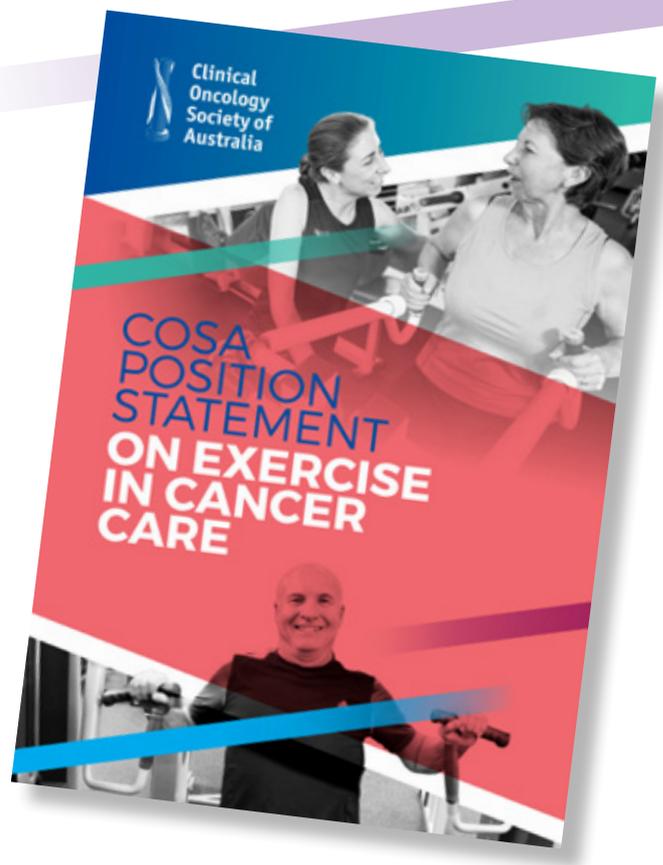


Photos supplied and used with permission

It's easy to understand why patients become confused as to when they should start exercising, what type of activity they should be undertaking, and at what intensity. Achieving the recommended guidelines can also seem somewhat overwhelming especially when you are undertaking strenuous treatment protocols and struggling to complete basic daily activities. It is important to remember that starting slowly and doing any exercise is better than none. Similarly, exercising in a supportive environment with appropriately trained supervision can help ensure that you avoid serious complications and/or injuries.

Included in the recent position statement by COSA was the recommendation that patients be referred to an accredited exercise physiologist (AEP) and/or a physiotherapist with experience in cancer care in order for them to receive the best care possible. An AEP is an allied health professional who specialises in the benefits of exercise to help patients with a chronic disease, such as cancer, achieve good health. These health professionals are trained to understand the need for exercise to be individualised to each person's abilities, experience and health status, and are able to adapt an exercise program to cater for the different stages of cancer diagnosis and treatment related side effects.

Patients are able to contact Exercise Sports Science Australia (ESSA) in order to help locate an Accredited Exercise Physiologist experienced in cancer care. ESSA can be contacted via:



- phone: 07 3171 3335,
- email: [info@essa.org.au](mailto:info@essa.org.au)  
or by logging onto the website and searching for an AEP in the required area using the below address
- <https://www.essa.org.au/find-aep/>
- <https://www.cosa.org.au> <http://exerciseright.com.au>



By Debbie Cooper  
Exercise physiologist ●

# NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

## MRDR RECRUITMENT

As of August 2018, close to 2300 patients have been registered on the MRDR. Thank you to all participants and participating hospitals for your support. The number of hospital / clinic sites continues to increase with 34 approved sites on board, and 29 sites actively participating. Sites to recently obtain approval to participate are: Dunedin, Wellington, and Whangarei

Hospitals in New Zealand; private practices at Adelaide Cancer Centre and Jarrett St Specialist Centre, Gosford; and Lismore Hospital in NSW. Our coverage in New Zealand has grown considerably and greater representation in Queensland will be possible when Royal Brisbane and Women's Hospital start recruitment. We also hope to have Royal Darwin

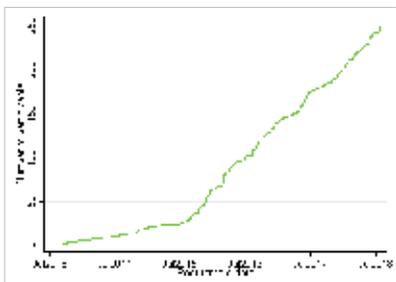
Hospital on board soon completing MRDR representation in all states and territories in Australia. We are certainly in the midst of a growth spurt! This is fantastic; thanks for all your efforts at contributing sites and for the growing interest in the registry. As the registry grows so has our team in the photo below.



L-R: Elizabeth Moore, Erica Wood, Laura Sellick, Cameron Wellard, Krystal Bergin, Neil Waters, Zoe McQuilten, Naomi Aoki, Samantha Francis-Pester, Andrew Spencer.

## MYELOMA 1000 PROJECT

Recruitment to the Myeloma 1000 project, a blood biobank substudy of the registry, has reached over 250 patients (see graph). Thanks to participating sites and patients for your collaboration. We have a couple of new sites with Princess Alexandra Hospital in Brisbane and Canberra Hospital joining recently; these are the first interstate sites, and it is pleasing that times to specimen reception in Melbourne have been within the required range.



Myeloma 1000 project participant accrual

The Myeloma 1000 project involves collection of one blood sample from 1000 newly diagnosed patients with multiple myeloma before treatment has commenced, and 1000 with MGUS. The project aims to establish a repository of blood specimens that will be available for analysis and future assessment of circulating biomarkers that may better predict treatment response, and individuals at risk of developing myeloma or accelerated disease progression.

## IMPROVE STUDY

The IMPROVE study (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. Blood cancers, including multiple myeloma are one of the most common indications for immunoglobulin (Ig) use in Australia; this practice is quite costly and Ig use is increasing with a lot of variation in practice and limited oversight. The IMPROVE study

will describe immunoglobulin use in multiple myeloma in Australia, including variation in practice, cost and patient outcomes. Results will inform policy and clinical practice related to immunoglobulin therapy in these patients.

## MRDR: HOW CAN YOU BE INVOLVED?

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

## TO CONTACT THE MRDR:

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



MONASH  
MEDICINE,  
NURSING AND  
HEALTH SCIENCES



## My Myeloma Journey

**Michelle, a Myeloma Australia member in South Australia, wrote some prose in response to one of those feeling down days and posted it on a Facebook support page. She says “I really am OK. Sometimes I get a bit down in the mouth (and write something like this), but then I pick up pretty quickly afterwards.**

I sometimes feel guilty about having ‘down’ times, because compared to a lot of others, I’ve got it pretty cruisy at the moment. I guess it’s the unknown that gets to me, and I have to keep telling myself to live in the present and not worry about what’s coming up, because, really, no one ever knows that do they (smiley face)”.

As a Myeloma Support Nurse, we aim to give support to those affected by myeloma through our expert knowledge and learned experiences from people and their many different stories of myeloma. However, we can never really know what it is like to live each day with this disease. This poem beautifully opens a door to the everyday experience

of those who do. Insights like this are so valuable, for empathetic support for each other and to those of us who try to provide support.

Reading this will likely resonate with many people, the response on Facebook has been impressive. Therefore, we wanted to share her words more widely with the hope to normalise these feelings but also as an opportunity to remind everyone that there is help out there should these down days become more frequent.

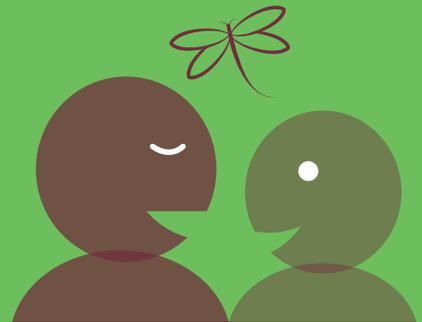
We wish to highlight the fact that it’s ok to have days like these, but not every day. If you think a friendly chat would help getting out of these down days, why not call the Support Line for a listening ear from one of our nurses? 1800 693 566 Monday – Friday, 9am – 5pm AEST.

We wish to thank Michelle for permission to share her thoughts with all our members. ●

*Jo Gardiner*  
Senior Specialist Myeloma Nurse  
SA/NT

Photo supplied and used with permission

## Telephone Support Line Feedback Project



At Myeloma Australia, we are continuously trying to improve how we support and assist people living with myeloma. One of our key services is our 1800 toll free Telephone Support Line.

Myeloma Australia is currently evaluating the service we provide with our Telephone Support Line and we will be inviting callers to participate by providing feedback on your recent call by completing a short survey. Your participation is voluntary, and all responses are anonymous.

We encourage you to participate to help Myeloma Australia continue to improve this service and ensure its effectiveness in meeting the needs of the myeloma community.

**If you wish further information about this, please call Jo Gardiner, Senior Myeloma Nurse Specialist and Project Leader on M: 0447 331 165 or email at [jo.gardiner@myeloma.org.au](mailto:jo.gardiner@myeloma.org.au)**



## 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.

## You Look So Well

"You look so well".

Hi. Haven't seen you for so long.  
Heard you've been sick.  
Cancer someone said. Is that true?  
It's been over a year. You must be better now.  
You look so well.

Keep active. Keep fit. Stay healthy.  
Take the dog for a walk.  
Why is this hill so hard. It never used to be.  
Pulse 180. Don't think that's good.  
Stars twinkling in front of my eyes.  
Still smile at the person walking past.  
You look so well.

Parents getting pretty old now.  
They need more and more help.  
I need to go to the doctors; the bank;  
I've run out of milk they say.  
So tired, I'll just rest my eyes at this traffic light.  
What? Why are you tooting?  
Oh the lights going yellow again now.  
Geeze. You look so well.

So tired, fall to sleep as soon as head hits the pillow.  
But then there's that dreaded hour.  
Without fail, you're wide awake.  
And then the mind games begin.  
If you're lucky you'll get back to sleep before  
the alarm goes for another day.  
Oh. You're looking so well.

Its 2am and there's a little whisper.  
Mum. I can't sleep. Can I have a cuddle?  
That's every night for 2 weeks this time.  
How much do they have to suffer?  
How can I ease their pain and reassure them?  
I can't because I won't lie to them.  
I don't know what's going to happen either.  
You look so well.

Hot flushes, night sweats, kilos piling on.  
Oh. Hello menopause. You decided to join the party too.  
Memory fails; Mind unable to focus on tasks;  
confidence waning.  
Hey chemo. Anything else you want to take?  
Wow. You didn't lose weight during your  
treatment did you?!

You look so well.

Who is that person in the mirror.  
That drawn face. Those black eyes.  
That curly flippin' hair.  
Haunted eyes look back at me.  
Where did all those lines come from?  
Makeup is now my best friend.  
But gee. You look so well.

Been sitting for a while now.  
Time to get up.  
Feet feel like I've walked for days, but its only 10am.  
Hips seized; Knees wont bend; Back hunched over.  
I shuffle like an old lady until I loosen up again.  
But its ok. Because you look so well.

Sore throat again.  
That's the 4th this winter. And we're only half way through.  
So tired of feeling like crap.  
But I don't want summer to get here.  
Because heat and I are no longer friends.  
You look so well.

So how much longer will I have.  
Am I one that will last 20 years? Or will I be gone in 5?  
Do we spend all our money making memories now?  
Or will that leave us with nothing if I survive a while?  
Certainly can't fall back on that insurance we thought we had.  
But, oh, you look so well.

What will the next treatment take from me.  
My mind?  
My ability to drive?  
My ability to walk?  
My ability to wipe my own backside?  
But that will all be ok. Because,  
You look so well.

I'm tired all the time. Every bone aches.  
But ask me and I'll say I'm fine  
Work to be done; family to look after; house to run.  
Things don't stop just 'cause you're sick.  
No one else to pick up the work  
You look so well.

Hi. Haven't seen you for so long.  
Heard you've been sick.  
Cancer someone said. Is that true?  
It's been over a year. You must be better now.  
You look so well.  
Well. I'm not.



# Fundraising

Congratulations and well done to all those who participated in Sydney's City to Surf on Sunday 12th August. It was the launch of 'Team Myeloma' in NSW with 25 runners. On top of the successful running events in Perth and Melbourne, the city2surf is now firmly on our fundraising calendar.

I ran 14km and felt ok by the end. I finished well but was feeling I could still run further... It has been suggested that a marathon may be next on the cards for Jacqui and I who felt awesome at the end of the run.

There are many more events coming up in NSW, feel free to contact me or one of the Myeloma Australia team for more information.

Santosh Ojha  
NSW Fundraiser



Santosh pictured centre with Team Myeloma



Santosh with Jacqui Keogh (bottom left) and Team Myeloma



Santosh (far right) with Team Myeloma



Jacqui Keogh with Team Myeloma

Photos supplied and used with permission

# What's Happening

## Fundraising

The news from the community engagement and fundraising realm of Myeloma Australia is short and sweet for this edition only! But this is not to say that there is a lack of activity on these fronts – quite the opposite in fact!

Santosh Ojha is settling nicely into his role as our NSW Fundraiser; having Sydney's City2Surf event proved to be the ideal opportunity for Santosh to really get into the swing of all things Myeloma Australia.

Team Myeloma debuted in Melbourne at Run Melbourne in late July with over 70 participants representing the Team. Please keep an eye out for when Team Myeloma will be participating at an event in a city near you!!

There is one upcoming fundraising event that I would particularly like to draw your attention to – this being the Athens Marathon that will be undertaken by Pana Karageorgiou in honour of his late father, Manny. Pana's story can be found here:

<https://give.everydayhero.com/au/spartan-run>

As much as I would like to feature each and every fundraising activity that occurs in the community on behalf of Myeloma

Australia practicalities render this impossible. Please do understand that your awareness and community fundraising efforts are enormously appreciated and help us to continue to expand our nurse led services providing education, support and advocacy to the myeloma community alongside our commitment to myeloma research through our Medical and Scientific Advisory Group (MSAG).

The one awareness and fundraising idea I would like to leave you with is this .... Bunnings BBQ. A few supporters in Perth made mention of such an event, and I wondered if other people would like to explore with their networks the possibility of hosting a Bunnings BBQ (or similar) for Myeloma Australia. If this is something that interests you I would be happy to hear from you!

And as I sign off, please remember that I am here to help! I love hearing of your awareness raising and fundraising ideas – however great or small, madcap or sane, please let me hear about them and help you to bring them to fruition! ●

Kind regards,

*Matt Maudlin,*  
*Community Engagement & Fundraising Manager*  
*M: 0407 891 052*  
*E: [matt.maudlin@myeloma.org.au](mailto:matt.maudlin@myeloma.org.au)*



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](http://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](http://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](mailto:matt.maudlin@myeloma.org.au)**

# From the Nurse Manager

I'm pleased to once again have many exciting things to report in this edition from the Nurse Manager chair. Nella and I are so proud of the work our Myeloma Support Nurses are doing on the ground in their states and know many of you are seeing the benefits of a nurse in your area. The expansion project is far from complete so if we currently don't have a nurse in your state, there may well be very soon.

We have now appointed two nurses in Queensland, Tash Clarke and Megan McDowell. They both bring with them a wealth of experience working with people with myeloma across many different settings and will commence employment soon. They are very keen to start engaging the community and provide our services to those in QLD. We will introduce them in the next edition of MyeNews. We are very much looking forward to welcoming them to the team.

In Western Australia, Kerin and Narelle have moved into a new office space within the Solaris Cancer Centre in Cottesloe and are really enjoying the extra space and access to other like-minded organisations and wellness services within the building. Stay tuned for their grand plans for WA in 2019.

In NSW Geo Sobrio has joined Jacqui and Santosh in their new office space and has already hit the ground running... literally, with all three staff members participating in the City2Surf fun run in August. You can read more about Geo in his profile in this edition of MyeNews. I'm sure you'll all join me in extending a warm welcome to Geo.

Elli and Laura are now well and truly part of the furniture in Victoria and are managing to spread themselves far and wide. They too have grand plans to reach even further in 2019.

South Australia have also managed to increase their services without any extra staff members with the help of some motivated local health professionals and our ever-faithful SA volunteer committee led by Jo Gardiner.

Jo and Jacqui have been working on a survey to evaluate our toll-free 1800 MYELOMA (693 566) Support Line. We would really appreciate your honest feedback so that we can continue to improve this invaluable service. If you utilise the Support Line you will be asked if you're happy to receive the survey. Participation is completely voluntary and certainly not a requirement to use the Support Line.

As a group, the nurses have been working hard to bring to you both updated and new information.

We now have fact sheets about thalidomide, lenalidomide, pomalidomide, bortezomib, carfilzomib, ixazomib, daratumumab, venetoclax and steroids available for download on the website with associated quick reference cards printed.

We also have resources to help you know how to 'live well' with myeloma. Speak with our Myeloma Support Nurses on 1800 693 566 if you would like to discuss which resources are suitable for you.

If you would like any of our resources from the website but don't have a printer you are most welcome to request a print out from head office via [support@myeloma.org.au](mailto:support@myeloma.org.au).

Did you know that the flu season can continue past winter into spring? There is still time to get the flu vaccine if you haven't done so already. Not only is it important for people with myeloma to have the flu vaccine due to having a compromised immune system but it is also important for family and friends to also be protected against the flu to reduce the risk of passing the virus on.

We hope that you have managed to get through the winter unscathed and are now able to see a glimpse of spring on the way. ●

*Hayley Beer*  
Myeloma Support Nurse Manager



**Find our Treatment Fact Sheets  
under the resources tab of our website  
[www.myeloma.org.au](http://www.myeloma.org.au)**

# What's Happening

## New South Wales

It is hard to believe Winter is over and we welcome some lighter evenings and warmer weather (although the Sydney days have been beautiful).

In the last edition of MyeNews we announced the expansion of the NSW operation of Myeloma Australia. The last few months have been spent looking for our new house (office) and more recently we have been very busy moving into our new office in Parramatta and setting up our new working environment. Although I am very much part of the Myeloma Australia Team its lovely to be sharing an office with Geo (our new Myeloma Support Nurse) and Santosh (our Fundraiser) especially as I have spent the last 2 years working solo in NSW. This is an exciting time as we now have a greater capacity to deliver more services to the myeloma community in NSW.

Our Information and Support Groups at Westmead, Liverpool, RPA, Newcastle and Central Coast continue to meet bi monthly and are a combination of invited speakers and general discussion and support. In June, Liverpool heard from a financial group about the importance of getting advice and sorting out finances particularly when you have been diagnosed with cancer. There was an informal but very useful discussion especially around the frustrations of trying to access superannuation etc, a topic which is often discussed in group. At the Westmead group, the dietitian gave an interesting talk on diet and nutrition including the use of supplements and complementary therapies. For the next meeting dates please see the Calendar of Events in this MyeNews.

As I have mentioned before, if you are thinking of joining a face to face support group, then please give one of the Myeloma Support Nurses a call to discuss the group. Each group is open to patients, carers and family and has the common theme of providing information and support. However, they may be structured a little differently, for example a more informal group getting together over a coffee as opposed to invited speakers/topics at every session.



L > R Jacqui Keogh, Geo Sobrio & Santosh Ojha

As a regular facilitator of support groups, I can see the value of them and even if there is only a handful of people attending it can be extremely beneficial, sometimes more so as there is an opportunity of more in depth discussion.

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 rest of the year in NSW but if there are ways in which you think we could assist or if you have any ideas please get in touch.

[jacqui.keogh@myeloma.org.au](mailto:jacqui.keogh@myeloma.org.au); [geo.sobrio@myeloma.org.au](mailto:geo.sobrio@myeloma.org.au); [santosh.ojha@myeloma.org.au](mailto:santosh.ojha@myeloma.org.au)

And finally as I write this we are gearing up (or lacing up) for the City2Surf which is on this Sunday 12th August. This is the first fundraising event for "Team Myeloma" in NSW and we hope to raise a little money but more importantly raise community awareness of multiple myeloma. I look forward to reporting on our experiences in the next edition. ●

Jacqui Keogh  
NSW Manager  
& Myeloma Support Nurse

Photo supplied and used with permission

**Save  
the  
dates**

Dates have now been set for two of our major fundraising events in 2019. **The Business of Winning Luncheon** which will be held on **Friday the 15th of March** and the **Mount Eliza Run and Fun Festival** on **Sunday the 17th of March**. We will be releasing early bird tickets for the Business of Winning Luncheon late in September so keep an eye out for their release.

**my**mount  
2019 **eliza**

**my wellness**  
**my empowerment**  
**my community**



## South Australia

A highlight of this edition of the MyeNews is the patient story which features a poem from Flinders Support Group member, Michelle McEvoy. Michelle posted some wonderful prose on Facebook as a bit of a rant. It received much positive feedback from people relating closely to what was said. With Michelle's permission, Myeloma Australia is privileged to share it with our wider readership.

Our Fullarton Information and Support Group meeting in June saw Dr Kate Vandyke, from SA Health & Medical Research Institute (SAHMRI), outlining the current research being conducted in the Myeloma Laboratory at SAHMRI on North Terrace, Adelaide. As well as bone disease research, a specific focus looks at how myeloma cells migrate, grow and are supported by the bone marrow micro-environment. Researchers are exploring ways to change the environment to make it hostile for the myeloma cells, hopefully inducing their death.

The following meeting on August 7th was special. We celebrated Myeloma Australia's 20th Anniversary with a cake and a visit from CEO Steve Roach, who presented Volunteer Service Awards to Committee Members who have dedicated much time and effort to help those affected by myeloma in South Australia for many years. As well as these presentations, lawyer, Amanda Stone explained differences between 'Power of Attorney'; 'Enduring Power of Attorney' & 'Advance Care Directive' and emphasised the importance of having a will. Not what we want to think about, but it is necessary for all to face, clear directions can help avoid unpleasant disputes.

For October 2nd meeting, the speaker is to be advised. December 4th will see Evelyn Tran from RAH Pharmacy talking about myeloma and supportive drugs and advice

on strategies to keep organised to take the right drug at the right time.

In July, the Flinders Information and Support Group meeting invited Joanne Wells, Nurse Consultant (Triage) from Southern Adelaide Palliative Services and Kirsty Wallis CN from Laurel House, to talk about Palliative Care Services based at FMC. It was evident they provide excellent and compassionate support for patients and their families.

The Mid-North Information and Support Group's met on August 16th. Our Myeloma Support Nurse, Jo Gardiner ran the meeting in Bronwyn's absence with a question & answer session on all things myeloma and an update on Myeloma Australia happenings. The Mid-North Regional Seminar is on Saturday, 3rd November, speaker to be advised.

The South-East Support Group's next meeting is on August 30th. Jo will attend the next meeting in November. Jo is planning another trip to Darwin on Thursday September 27th at 2pm for an Information and Support Group meeting, with Dr Akash Kalro coming along. A bigger venue has been booked in the meeting room at Casuarina Library.

Jo has recently given 2 presentations on myeloma at the RAH and 1 at the FCIC and FMC, with more than 25 staff attending over the 2 sites. Jo also gave a lecture to the Adelaide University Graduate Diploma Oncology students. Using online tools, working and regional students attended either live online or accessed the talk later.

In addition, Jo is also on the organising committee for the 3rd Annual HSAANZ Myeloma Nurse Special Practice Network 2018 National Seminar, on Friday August 31st at the RAH for health professionals. Invitations have been distributed with over 60 registering attendance from around Australia. ●

*Ian Driver, SA Chair*

*Jo Gardiner, SA Senior Specialist Myeloma Nurse*



Kate Vandyke



Amanda Stone

## Victoria

Although we thought long and hard about hibernating this winter, the Victorian myeloma community continued to learn, support and raise awareness. With great topics and guest speakers at our support groups and the fantastic efforts of Team Myeloma at Run Melbourne.

Our support groups continue to flourish and grow. Thank-you to the following guest speakers who gave us their time and expertise. Coburg welcomed Tracy Thompson, a dietician and nutritionist from Brunswick Integrative Care, who presented and initiated a discussion on managing nutrition with myeloma to glowing reviews. Berwick were lucky enough to hear from Dr Michael Low about upcoming clinical trials in the local area and welcomed new members. Geelong learnt about peripheral neuropathy from Robbie Thorogood from the Geelong Foot Clinic. Kew heard about Advanced Care Planning from the Austin Advanced Care Planning team and continue to get very high numbers. Beaumaris got moving with exercise physiologist Ben Southam from PACE Health Management Sandringham. Our Younger Persons Group met and managed a very passionate discussion about treatments,



transplants and trials. If you live in the west, we are coming for you, stay tuned for further information on our new Support Group...coming soon.

Absolute fantastic effort to Team Myeloma in Run Melbourne this July. Our team was 75ish people strong, a mix of runners and walkers but all raising funds and awareness for myeloma. Special mention to 'Team Toni' and the Bean Box Café whose contributions were significant and very much appreciated.

September brings our second Scientific Workshop to be held over an entire weekend in the Yarra Valley. Going on the success of the last meeting, we can expect the top clinical and scientific minds in the myeloma field to come together to present and share research and ideas. We look forward to hearing and sharing with you what's on the horizon.

So, what else is coming up? We are hitting the road, set to visit our regional myeloma community in the next few months. With Warrnambool, Bendigo and Albury first on our hitlist. Although Albury may not officially belong to Victoria we are going to claim them anyway. See you all soon! ●

*Elli Foley*  
*Myeloma Support Nurse*  
*Victoria*



# What's Happening

## Western Australia

Things have been steadily continuing in Western Australia in the last few months. In June, we relocated to our new office space in Cottesloe, with enough room to display all of our patient information resources and for us both to have our own desks. The office space is situated in the Cancer Wellness Centre in Cottesloe, shared with primarily Solaris Cancer Care, but also a number of other cancer support service not for profit organisations. Not only does the site have a comfortable and calming presence, we have been warmly welcomed by everyone and with so many other resources available under one roof, there will certainly be more events and opportunities for patients, carers, families and health professionals to access in the future.

Our Information and Support Groups have continued with a number of people attending the groups at Butler, Heathridge and Mandurah. We have also worked with Leukaemia Foundation to co-facilitate their myeloma support group in Innaloo. We are continuing to review our support groups to make sure that they are of benefit to those living with myeloma and value any feedback and any ideas about future groups.

Along with facilitating the Information and Support Groups we have also been super busy planning some new events for the Myeloma Australia calendar in WA. The first is the rollout of more Myeloma Information Seminars with first one planned for the morning of November 16th in the Conference Hall at the Cancer Wellness Centre in Cottesloe from 9.30-12.30am. We will have two speakers booked – Dr Dustin Hall, haematologist from Fiona Stanley Hospital

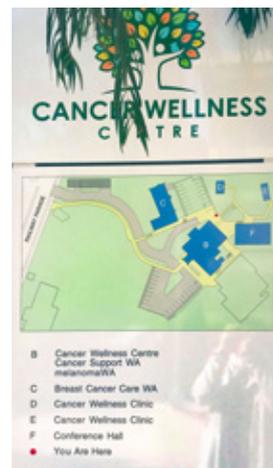
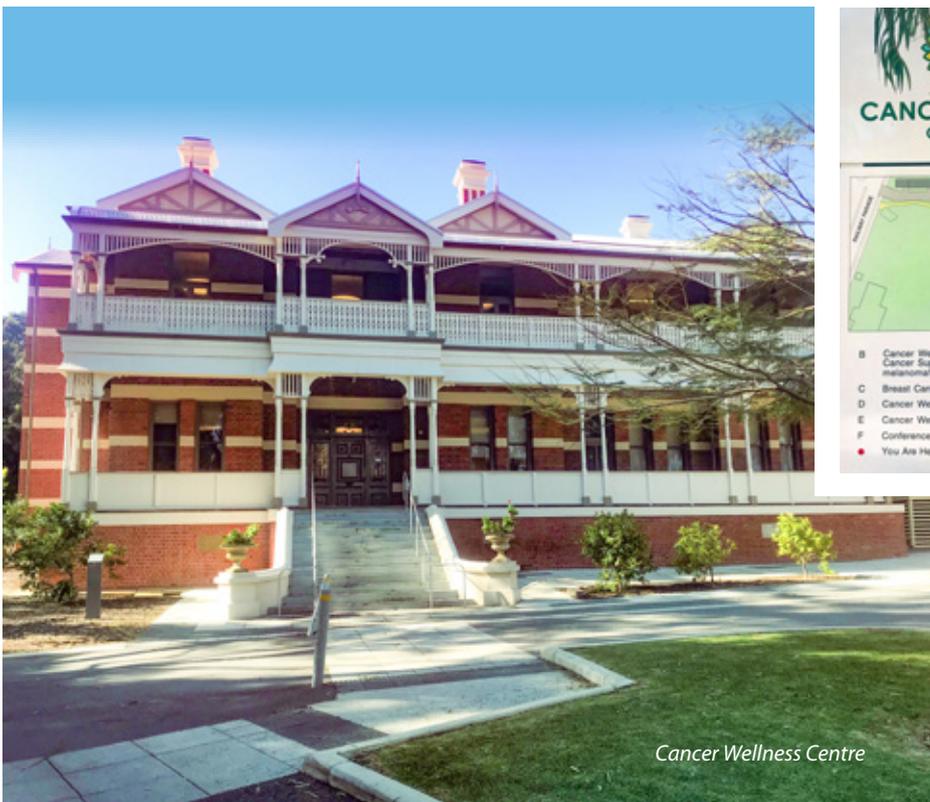
and Wayne Epton, a senior dietitian from Royal Perth Hospital. This looks to be an informative session which along with great speakers includes morning tea. Details on the website and on a flyer will be circulated soon with more information about the event or you can contact either Kerin or Narelle about the event.

The other new addition to the calendar is our first Coffee & Chat morning in December. This is an informal “drop in” to meet with the Narelle and Kerin and is an opportunity for people to ask any questions of the Myeloma Support Nurses they may have related to side effects of treatments or their disease, to discuss support services or to simply have a chat as well as meet others living with myeloma. This will be held on the 10th of December and will provide us an opportunity to wind up and look forward to planning for 2019.

We have continued to provide health professional education to sites in the Perth metropolitan area in the last few months. Most recently, Kerin presented to almost 90 nursing and allied health professionals about myeloma, the disease and its treatments and the services offered by Myeloma Australia. In the next few months, we will be holding another evening educational event for nurses about myeloma, which we anticipate will be well attended, and we will be providing education to nurses via telehealth to the new haematology service in Kalgoorlie.

We are certainly looking forward to the warmer weather rolling in and celebrating our first year in operation here in WA with a slice of cake and future planning of events. ●

*Kerin Young & Narelle Smith  
WA Myeloma Support Nurses*



Photos supplied and used with permission

## **Treatment: Autologous Stem Cell Transplant (USA):**

**Autologous hematopoietic cell transplantation for multiple myeloma patients with renal insufficiency: A Center for International Blood and Marrow Transplant Research Analysis**

**Anuj Mahindra, et al; Bone Marrow Transplant. 2017 December**

Autologous hematopoietic cell transplantation (AHCT) in multiple myeloma (MM) patients with renal insufficiency (RI) is controversial.

1492 patients who underwent AHCT for MM between 2008-2013 were identified and grouped as normal/mild RI (1240 patients), moderate RI (185 patients) and severe RI (67 patients). Of the 67 patients with severe RI, 35 were on dialysis prior to AHCT.

Patients received melphalan 200 mg/m<sup>2</sup> (Mel200) in 92% of normal/mild RI, 75% of moderate RI and 33% severe RI patients; the remainder received 140 mg/m<sup>2</sup> (Mel140).

Thirty four of 35 patients with severe RI achieved post-AHCT dialysis independence. The 5-year Progression Free Survival (PFS) for normal, moderate and severe RI was 35%, 40% and 27% respectively; 5-year Overall Survival (OS) for normal, mod and severe RI was 68%, 68% and 60% respectively. With moderate RI, 5-year PFS for HDM 140 mg/m<sup>2</sup> was 18% and for Mel200 was 46%. With severe RI, 5-year PFS Mel140 was 25% and for Mel200 was 32%.

**We conclude** that AHCT is safe and effective in patients with MM with RI.

## **Observation & Commentary:**

**Multiple Myeloma and Its Precursor Disease Among Firefighters Exposed to the World Trade Center Disaster (USA)**

**Ola Landgren, MD, PhD<sup>1</sup>; Rachel Zeig-Owens, DrPH<sup>2,3,4</sup>; Orsolya Giricz, PhD<sup>5</sup>; et al; JAMA Oncol. Published online April 26, 2018**

**Question:** Are environmental exposures from the World Trade Center disaster site associated with multiple myeloma and its precursor disease, monoclonal gammopathy of undetermined significance (MGUS), in New York City firefighters?

**Findings:** In this case series, 16 participants were diagnosed with multiple myeloma after September 11, 2001, with a median age of disease onset of 57 years, and in subsets with relevant data, a high proportion of the cases had light-chain myeloma, and plasma cells were CD20 positive. In the screening study, World Trade Center exposure was found to be statistically significantly associated with light-chain MGUS and overall MGUS.

## **Editorial regarding above article: Some Thoughts on Exposure to the World Trade Center Wreckage and Cancer (USA)**

**Otis W. Brawley, MD, MACP; JAMA Oncol. Published online April 26, 2018**

The 16 cases of multiple myeloma out of 12 942 WTC-exposed firefighters represent a small proportion. It is difficult to make a firm correlation with WTC service. There may be a latency period, and, over time, this group may have a larger number of patients with myeloma, and a link to WTC exposure may become more apparent. In noting the differences, one must appreciate that the firefighting profession is documented to be associated with a higher risk of MGUS and multiple myeloma compared with that of the general population. One study comparing firefighters with people from a general population tends to show a higher than true relative risk. It would be preferable to compare the WTC-exposed firefighters with an intensively screened age-matched cohort of firefighters from another big city.

Landgren and colleagues note that they cannot find an exposure gradient. They report that WTC-exposure may be a risk factor for the development of multiple myeloma and its precursor disease, MGUS. This is appropriately worded. The operative word is "may." These trials, because of the size of cohort, cannot identify a small increase in cancer risk due to WTC exposure, and correlation does not mean causation. Perhaps this issue is beyond the limits of science.

## **Observation & Commentary:**

**Global Burden of Multiple Myeloma: A Systematic Analysis for the Global Burden of Disease Study 2016.**

**Cowen et. al. JAMA Oncol. Published online May 16, 2018 (Worldwide)**

**Question:** What is the burden of multiple myeloma globally and by country, how has it changed over time, and how widely available re treatments for this disease?

**Findings:** Myeloma incident cases and deaths increased from 1990 to 2016, with middle-income countries contributing the most to this increase. Treatment availability is very limited in countries with low socioeconomic development. The 3 world regions with the highest age standardised incidence rate of MM were Australasia, North America, and Western Europe.

**Meaning:** Marked variation in myeloma incidence and mortality across countries highlights the need to improve access to diagnosis and effective therapy and to expand research on etiological determinants of myeloma.

## **SBS News reported on the above article:**

<https://www.sbs.com.au/news/australia-nz-has-highest-rates-of-myeloma>

...continues over page

### Australia and New Zealand has the highest rates of myeloma

"Australia and New Zealand have the world's highest rates of multiple myeloma, a rare form of blood cancer that attacks the body's bone marrow, a study has found. The research, published in the journal JAMA Oncology, confirms evidence the cancer is on the rise in Australia due to an ageing population. Researchers at the University of Washington analysed data from the Global Burden of Disease Study in 2016 to examine the burden of multiple myeloma. The analysis showed Australasia topped the list of 21 world regions for the highest rate of multiple myeloma at 5.8 cases per 100,000 people, followed by North America and western Europe. There were 138,509 cases of multiple myeloma worldwide in 2016, with the disease affecting 2.1 per 100,000 people. Western Europe was the region with the most cases of myeloma for both sexes. The analysis also showed the incidence of MM had risen significantly during the past two decades. From 1990 to 2016, the global incidence of the disease increased by 126 per cent. Population growth contributed to 40.4 per cent of the increase and ageing population contributed 52.9 per cent."

### Observation & Commentary:

#### Patient-centered practice in elderly myeloma patients: an overview and consensus from the European Myeloma Network (EMN) (Europe)

**Larocca A 1, Dold SM 2, Zweegman S 3, Terpos E, Wäsch R 2, D'Agostino M 5, Scheubeck S 2, Goldschmidt H 6, Gay F 5, Cavo M 7, Ludwig H 8, Straka C 9, Brinthen S 5, Auner HW 10, Caers J 11, Gramatzki M 12, Offidani M 13, Dimopoulos MA 4, Einsele H 14, Boccadoro M 5, Sonneveld P 15, Engelhardt M 2 ; Leukemia [25 Apr 2018]**

Multiple myeloma is a disease typical of the elderly, and, because of the increase in life expectancy of the general population, its incidence is expected to grow in the future. Elderly patients represent a challenge due to their diverse medical histories and fitness. Besides the availability of novel agents, a careful evaluation of elderly patients showed to be a key factor for the success of therapy. A geriatric assessment is a valid strategy to better stratify patients. The choice of treatment-transplantation, triplets, doublets, or reduced-dose therapies including novel agents-should depend on the patient's fitness status (fit, intermediate-fit or frail). Second-generation novel agents have also been evaluated as salvage therapy in the elderly, and these new agents represent a further step forward in the treatment options for elderly patients with multiple myeloma. ●

## Exclusive and Original Cards by Patricia Ball

10 cards x 5 Designs per pack  
Left blank inside for your personal message

\$10  
per pack  
+ p&h

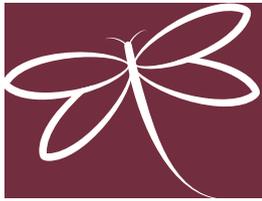


#### Available from Head Office

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.



# 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
Bendigo Information and Support Group <b>**New**</b>	Wed Sep 5th	Bendigo Hospital, Bendigo Cancer Centre 100 Barnard St, Bendigo	11:30 am - 1:30 pm	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Sunshine Information and Support Group <b>**New**</b>	Thur Sep 6th	Braybrook Community Centre 107-139 Churchill Avenue, Braybrook	10 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
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: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> 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 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Berwick Information and Support Group	Fri Sep 21st	St John of God Specialist Centre Wellness Room, Level 1 55 Kangan Drive, Berwick	10 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Coburg Information and Support Group	Wed Oct 3rd	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10 am - 12 noon	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Beaumaris Information and Support Group	Thur Oct 4th	Beaumaris Theatre 82 Wells Road, Beaumaris	10 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Kew Information and Support Group	Thur Oct 11th	Kew Library Corner Charles St & Cotham Rd, Kew	10 am - 12 noon	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Geelong Information and Support Group	Fri Oct 12th	SCC Meeting Room (Andrew Love Centre) 70 Swanston Street, Geelong	10 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Traralgon Information and Support Group	Wed Oct 17th	Gippsland Rotary Centenary House 39 Valley Drive Traralgon	10 am - 12 noon	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Younger Persons Information and Support Group	Thur Oct 18th	Myeloma Australia Head Office 333 Swan Street, Richmond	6 pm - 8 pm (light dinner)	Myeloma Australia	Elli Foley & Laura Jones E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a>
Sunshine Information and Support Group	Thur Nov 1st	Braybrook Community Centre 107-139 Churchill Avenue, Braybrook	10 am - 12 noon	Myeloma Australia	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Warragul Information and Support Group	Thur Nov 8th	Rotating at local venues, details published closer to date	6 pm - 8pm Dinner	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203

## South Australia

Event	Date	Location	Time	Organisation	Contact
Flinders Information and Support Group	Thur Sep 20th	Living Kurna Cultural Centre Function Room Warriparinga Way, Bedford Park	10 am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Oct 2nd	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	Sat Nov 3rd	Snowtown Hospital 70 Railway Tce E, Snowtown	12 pm - 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 Nov 8th	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 Nov 15th	Living Kurna 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
North Metro Information and Support Group	Mon Sep 3rd	Heathridge Community Centre Activity Room 2, 1/16 Sail Tce, Heathridge	1 pm - 3pm	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 Oct 8th	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 Oct 29th	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 Nov 5th	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)
Myeloma Information Seminar	Fri Nov 16th	Cancer Wellness Centre, Conference Hall 80 Railway Street, Cottesloe	9:30am - 12:30pm	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)

## Queensland

Event	Date	Location	Time	Organisation	Contact
Buderim Information and Support Group	Tues 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)
Buderim Information and Support Group	Tues Oct 2nd	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	Tues Nov 6th	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	Tues Oct 9th	Royal Prince Alfred Hospital Chris O'Brien Lifehouse Education Centre Level 5 119-143 Missenden Rd, Camperdown	10 am - 12 noon	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	Tues Oct 16th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10 am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Westmead Information and Support Group <i>*Change of Venue</i>	Thur Oct 18th	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Oct 25th	Central Coast Leagues Club Dane Drive, Gosford	6 - 8pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger E: jacqueline.jagger@health.nsw.gov.au P: (02) 4320 9641 1800 MYELOMA (693 566)
Newcastle Information and Support Group	Mon Nov 5th	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)
Liverpool Information and Support Group	Tues Dec 11th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10 am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
RPAH Information and Support Group	Tues Dec 11th	Royal Prince Alfred Hospital Chris O'Brien Lifehouse Education Centre Level 5 119-143 Missenden Rd, Camperdown	10 am - 12 noon	RPAH & Myeloma Australia	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 / 9515 6111 pager 87524 1800 MYELOMA (693 566)
Westmead Information and Support Group <i>*Change of Venue</i>	Thur Dec 13th	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10 am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Dec 13th	TBA	12 noon - 2 pm	Gosford Hospital & Myeloma Australia	Jacqui Jagger E: jacqueline.jagger@health.nsw.gov.au P: (02) 4320 9641 1800 MYELOMA (693 566)

## Northern Territory

Event	Date	Location	Time	Organisation	Contact
Darwin Information Afternoon	Thur Sep 27th	Casuarina Library 17 Bradshaw terrace, Casuarina	2pm - 4:30pm	Myeloma Australia	Jo Gardiner E: jo.gardiner@myeloma.org.au M: 0447 331 165 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: tsg@nswcc.org.au

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

# Myeloma Australia is the only myeloma specific support organisation in Australia



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



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



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



Visit **[www.myeloma.org.au](http://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](mailto:nurses@myeloma.org.au) W: [www.myeloma.org.au](http://www.myeloma.org.au)**