

# MyeNews

Autumn 2019 Issue no 49

Myeloma  
Australia



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## From the President

### Now that the festive season is over we are looking forward to what 2019 brings.

The most exciting thing, at the moment, is that the Pharmaceutical Benefits Advisory Committee will be meeting soon to discuss the making the use of Daratumumab combined with Velcade a subsidised treatment of myeloma as well as easing the limitations on the use of Revlimid. Hopefully many of you have had the opportunity to log into the PBAC's web site to make a submission supporting these changes as we have been told the Committee read all submissions and they do count. All the evidence from the many trials shows these changes improve the treatment options available.

Thanks to everyone who has supported our donation drive at the end of last year and if you have any great ideas for fundraising please contact Matt in Melbourne or Santosh in Sydney as they will try and help you develop your ideas to raise valuable funding.

We are now a fully National organisation with Myeloma Support Nurses in all States of Australia with coverage of the two Territories. We understand that the nurses are in the major centres with limited cover beyond this, so we are looking at ways to increase our coverage. We are currently installing the equipment to enable us to reach out to everyone via the internet to where ever you are in Australia. We are hopeful that in the near future many of our seminars will be webcast so you can watch from your computer or tablet in your home. Our plans are to have Information and Support Groups in the rural areas of Australia. These will be led by a nurse on a computer from our office with the program we have chosen, to allow interaction between the nurse and the members of the group. The options are

unlimited. Currently MA only reaches a small percentage of the myeloma community and this has always been a problem for us, and we have been looking at ways so that we can reach more. We understand the problems of distance and wellbeing prevent many attending support groups and seminars so we are hoping to come to you wherever you are. This will be coming soon.



For now, check our calendar in this magazine as the nurses have been starting new groups all around the country as well as the regular seminars. If you wish to start an Information and Support Group in your area, please contact the Myeloma Support Nurses and they will give you all the help they can. Also, initially through a link with Rotary in Victoria, they may be able to help arrange meeting rooms in your area.

In December our CEO Steve and two of our nurses Nella and Jo, attended the American Society of Haematology's annual meeting in San Diego. Here we met the leaders of other support organisations from around the world and were able to share ideas and resources. We also attended many other meetings and heard the latest in the myeloma treatment options. It was great to see the contributions in the published research by our Australian doctors and scientists which reinforced the facts that our specialists are at the cutting edge in myeloma treatment.

*Brian Russekarten*

## Have you been getting our emails?

One of the primary methods Myeloma Australia communicates with our community is via email, which we hope you find valuable and of interest.

Recently there has been an issue with some Myeloma Australia emails going to junk (spam) folders instead of your inbox, this was due to an issue with our ISP. We would ask that you please check your junk/spam folder for any emails from us. Please mark these emails as safe/not junk/not spam, or alternatively mark our domain myeloma.org.au as safe to avoid this problem.

If you would like to subscribe or receive emails to only some of our communications including any of the following:

- Seminars/Information & Support Groups
- fundraising events
- special announcements (such as new drug listings)
- our monthly e-newsletter The Muster
- quarterly magazine MyeNews

*At the bottom of our email communications there is an option to unsubscribe, if you select this option you will not receive any email communications from Myeloma Australia regarding any subject.*

**please contact Alex at  
alex.dawson@myeloma.org.au  
or on (03) 9428 7444**



### Juliet Hill Newcastle Support Nurse

Hello, my name is Juliet Hill and I am one of the new Myeloma Support Nurses to be starting in Newcastle and the surrounding areas. I have been a haematology nurse at the Calvary Mater Newcastle since 2001 working in most areas of the Haematology unit including inpatient and outpatient wards, apheresis and the clinical trials unit. Like most haematology nurses, the patients we get to meet and care for everyday is what I love most about working in these areas. I am excited to be given the opportunity to work for Myeloma Australia and continue to meet and support myeloma patients in the community setting.

Away from my nursing role I get to share a crazy, hectic lifestyle with my husband Andrew and our three children Darcy, Leila and Flynn. We are currently transitioning to having a high schooler in the house and the realisation of how quickly time really does fly by. Living on six acres in a small country town a normal day for us involves ponies, flying cricket balls and a six year old on a quad bike constantly being told to "slow down"!

I am really looking forward to settling in to the new role of Myeloma Support Nurse in Newcastle, to continue increasing my knowledge of myeloma and getting out in the community meeting people living with myeloma. Please do not hesitate to get in touch with either my colleague Rachel or myself to say "Hi" and let us know what our patients need in Newcastle.



### Rachel McCann Newcastle Support Nurse

Hi, my name is Rachel McCann and I have just started working as a Myeloma Support Nurse with Myeloma Australia. I am based in Newcastle, NSW and working alongside Juliet. I began working in oncology nursing in 2013 at Epworth Healthcare in Melbourne; this is where I quickly developed my passion for this type of nursing and the constant learning it brings. At Epworth I had the privilege of looking after a variety of amazing patients with different types of cancer. I became really interested with the ever-changing treatments related to cancer and working alongside so many inspiring patients. This is where I had the opportunity to do my chemotherapy training and worked between the medical oncology ward and the day chemotherapy unit.

I then moved back to my home town of Warrnambool and worked in the day chemotherapy unit which was a nice change working with a much smaller community. I then moved to London and worked with the district nursing service in the UK where I was able to look after and understand patients in their own homes. Getting to know my patient's in their homes was such a pleasure and a different realm of care compared to in hospital. In London I met my now fiancé who is originally from Newcastle, so when moving back to Australia we decided Newcastle would be a nice warm, beachy place to settle with lots of opportunities. I am now working at Lake Macquarie Private in the medical oncology ward as well as with Myeloma Australia. I am so excited to have the opportunity to work in this Support Nurse role; to have this opportunity to provide support and education to people with myeloma is such a privilege. Outside of work I am now looking forward to my wedding in February 2020 and to continue to explore the beautiful Newcastle area.

## Profile



### Deborah Thompson TAS Support Nurse

Hi, my name is Deborah Thompson and I joined Myeloma Australia in January this year. I am very excited about being part of the team and providing information and support to those living with myeloma. Three days a week I am employed as the haematology cancer care coordinator at the Royal Hobart Hospital and have the privilege of working with an amazing team of doctors and nurses. Whenever I

attend conferences or workshops in other parts of Australia, I am reassured that here in Tasmania we are providing first rate care and are at the forefront of treatments and new developments in the management of haematology cancers. It is a privilege to be able to support patients along their cancer journey and I am constantly astounded by their strength, endurance and sincere gratitude for what we do for them.

My employment history reads a bit like a box of Liquorice Allsorts, having practised in many disciplines of nursing from when I qualified in England (a long time ago). I was first involved in cancer care when I moved to Australia in 1989 working with the Victorian Royal District Nursing Service, delivering chemotherapy to patients in their homes and caring for palliative clients. Since living in Tasmania my work roles have included rural and emergency nursing, as a nurse with the Australian Red Cross Blood Service and as a nurse teacher at TasTAFE. I started in haemo-oncology outpatients at the Royal in 2009 and have been in my current position as a cancer care coordinator since 2015. Other career paths have led to a period as part-time manager of a camp in East Gippsland where I was also a koala carer. I have three fantastic boys, all who are now finding their own places in the world, two are working in Australia and the third is in England on an (extended) gap year. I enjoy playing squash, cycling, walking and generally trying to keep fit. Otherwise I may be found in any of the abundant coffee shops in Hobart, catching up with friends.

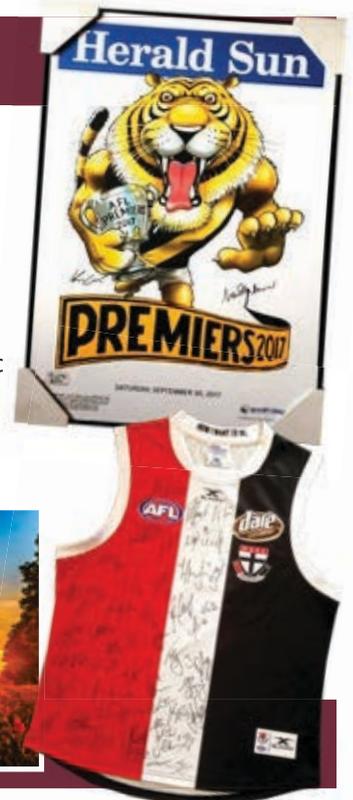
The first Hobart Myeloma Information & Support Group is planned for March and I am also looking forward to meeting health professionals in the north and north-west of Tasmania and helping to set up groups in those areas too.

Photo supplied and used with permission

## eBay - Online Shop

### Cards, Artwork, Sports Memorabilia and much more

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



The American Society of Hematology (ASH) held their annual conference in San Diego from the 30 November to 4 December 2018. As guests of the International Myeloma Foundation, Myeloma Australia staff CEO Steve Roach, Senior Myeloma Nurse Jo Gardiner, President Brian Rosengarten and myself had the opportunity to attend the conference.

The ASH medical and scientific program was overflowing with myeloma talks, posters and programs and it was impossible to get to every session. There were many oral abstracts and posters on new immune therapies, updates on novel therapies, and interesting new findings about the biology of myeloma which present the possibility for future targets and treatments. To find out more please read over the medical corner in this edition of MyeNews.

In the poster hall there were close to a thousand abstracts in the myeloma section and it was great to see so many posters from Australian and New Zealand researchers, MSAG members and groups such as Australasian Myeloma Research Consortium (AMaRC) and the Australasian Leukaemia and Lymphoma Group (ALLG).

At the ASH exhibition hall, we brought home educational resources for our Myeloma Support Nurses and got lots of ideas for Myeloma Australia projects back home. There were so many things to see and learn in the exhibition hall including a virtual reality experience of the bone microenvironment in myeloma and how new immune therapies engage with myeloma cells.

Aside from the conference itself, we attended several other meetings and events. We met with other myeloma support and advocacy organisations at the Global Myeloma Action Network (GMAN) meeting where there were representatives from twenty countries across North America, South America, Australasia, Europe and the Middle East. Serdar Erdoğan, the new director of GMAN and IMF Europe and Middle East gave a great presentation about patient support and advocacy initiatives in Turkey. It was a great opportunity to share ideas and learn from others and see what works in other countries. Carer support and programs was also a topic of conversation. Not all organisations have specific carer programs and it was great to hear from the people in Brazil about their carer programs which they run at various times through the year. They are solely for small groups of carers and run for six sessions over a few months. In this meeting we also planned our projects and collaborations for the next twelve months with all members of the GMAN group.

This year's IMF Satellite Symposium theme was 'New Strategies for Multiple Myeloma Care: Next Steps for the Future'. The audience comprised thousands of doctors and health professionals listening to myeloma experts Brian Durie (USA), Phillipe Moreau (France), Jesus San-Miguel (Spain), Shaji Kumar (USA) and S Vincent Rajkumar (USA) discuss topics such as risk stratification of plasma cell disorders, treating newly diagnosed patients, the role of transplantation, consolidation and maintenance after induction and therapeutic strategies for patients with relapsed/refractory myeloma. Each member of the faculty



*Christian Bryant.*

presented a case study and discussed clinical data that could guide the treatment relating to it. This was an interactive session with voting and discussion about treatment options and choices and a great way to learn more about myeloma and its treatment.

The International Myeloma Working Group (IMWG) breakfast meeting was held on the Friday morning before the official opening of the conference where we heard abstracts handpicked from the ASH program as well as current and future IMWG member projects including the role of whole body low dose CT, the role of surgery in myeloma bone disease of the spine and the natural history of smouldering myeloma to name a few.

On the Saturday evening, we attended the IMF's Brian D. Novis Research Grant reception where we listened to people share their story living with myeloma. Each story was different and moving, we celebrated together with their support network their achievements and their hope for the future. Several grants were awarded to researchers in the myeloma field from IMF fundraising events during the year. There were two grants awarded to Australian researchers this year. A senior research grant was given to MSAG member Prof Andrew Zannettino from The Myeloma Research Laboratory, Health and Medical Sciences at The University of Adelaide for his work entitled 'Single cell sequencing to discover tumor-associated changes in the bone microenvironment of myeloma patients: identification of prognostic markers and novel therapeutic targets' and Dr Christian Bryant from The Institute of Haematology – Multiple Myeloma Research Laboratory at Royal Prince Alfred Hospital, Sydney received a junior research grant for his work entitled 'Dissecting the structural and functional heterogeneity of terminal effector CD8+T cells from MGUS and newly diagnosed MM patients in order to identify therapeutic targets and unlock their anti-myeloma potential'.

Each of us who attended found the events to be very motivating and inspiring and extremely beneficial. We gained a lot from the educational opportunities and meeting with other myeloma organisations from around the world. Thank you to the IMF for hosting us and we look forward to sharing more of our learnings at upcoming Information and Support Groups and seminars across the country.

*Nella Combe  
Manager Nursing and Patient Services*

## Multiple Myeloma and Psychological Wellbeing

**The importance of paying attention to the emotional needs of myeloma patients has become recognised as a key component of best-practice care. The people who largely attend to the emotional and psychological needs of patients are clinical psychologists, who work alongside your doctors and nurses as part of the wider multidisciplinary team.**

Whilst it is very common for us to be involved with those affected by myeloma, people often don't appreciate what our role is. This short article aims to help describe the role of clinical psychologists, some of the work we do, and the potential benefits to those impacted by myeloma.

### What do clinical psychologists do?

Clinical psychologists use psychological skills to help you manage psychosocial difficulties, including anxiety, depression, adjustment to illness, and distress that comes up when navigating the treatment process. Therapy may involve providing education to help you better understand the problems that you are facing, exploring strategies to manage and cope with psychological distress, and helping you process the big emotions that often arise in the context of myeloma diagnosis.

Clinical psychologists do not prescribe medications; however, if it appears that you might benefit from medication, they can facilitate referrals to the appropriate health professionals (e.g., a psychiatrist).

In the context of a diagnosis of myeloma, a clinical psychologist's role often involves helping patients cope with:

- Adjustment to illness and undergoing associated treatment
- Low mood and/or anxiety (particularly living with uncertainty)
- Grief and loss associated with the significant changes that happen in one's life after diagnosis (e.g. loss of independence, loss of roles/identity, loss of imagined future)
- Specific fears (e.g., of needles) that might be barriers to receiving medical treatment
- Changes in body image and sexuality
- Communication with others about cancer (e.g., talking to children about cancer)
- Existential distress
- End of life support

### Why might I benefit from seeing one?

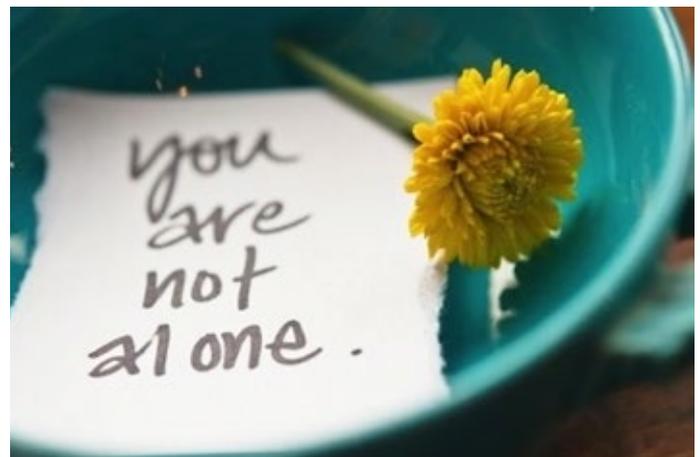
*"The problem is that myeloma returns and that it is not curable. So that is in the back of my mind always. . . It is always in the back of my mind that I know this thing is coming back and the*



*question is when. I think that's what's different maybe about this myeloma maybe than other cancers... certain cancers can be cured and myeloma can't. So I think that's a problem."*  
– myeloma patient.

Many people we see have never seen a psychologist before – they've never needed to. But receiving a diagnosis of myeloma can be devastating and living with the illness comes with various challenges which may be helped with the appropriate support. It is entirely normal to experience distress after finding out that you have myeloma but, for some people, this distress can be persistent and overwhelming, and may develop into symptoms of depression, anxiety, and hopelessness. These feelings can impact on people's ability to do things that are meaningful or important to them. Therefore, it can be helpful to see a clinical psychologist if you notice that you are experiencing elevated levels of distress. Some common signs of distress include the following:

- Feeling consistently low or flat
- Withdrawing from, or not enjoying, previously enjoyed activities
- Isolating yourself from others
- Feeling constantly worried and stressed
- Agitation or becoming easily frustrated with others
- Panic attack symptoms (e.g. racing heart, light headedness, nausea, breathing difficulties, sweating, and fear of losing control, going crazy, or dying).



People with a diagnosis of myeloma may benefit from psychological sessions that focus on strategies to help manage long term changes associated with a chronic illness. It is a two-way relationship between you and your psychologist; the goal is to come to terms with the diagnosis, help guide you through associated emotional storms, learn to adapt to and manage symptoms e.g. fatigue and pain, cope with living with uncertainty, and to ultimately live a meaningful life despite the illness.

Similarly, carers and loved ones can also experience increased levels of stress and have their own mental health challenges, often 'suffering in silence'. If your loved one is experiencing difficulty coping, please consider seeking psychological support.

## How do I get access to a clinical psychologist?

The pathway to accessing a clinical psychologist differs depending on where you live. The easiest approach is to contact your treating team at the hospital to ask for a referral, or your GP to access psychologists within the community. In some situations, you may be able to access free psychological

services (e.g., when you are an inpatient in hospital) and, in other situations, you may need to pay a fee to see a private psychologist.

Other resources that may be of help include:

- **Cancer Council NSW Helpline: 13 11 20. Available: 9am-5pm Mon-Fri. Provides help and support as well as recommend a range of other support services and programs that may also be of assistance.**
- **Mental Health Line: 1800 011 511. Available 24hrs. Anyone with a mental health issue can use the Mental Health Line to speak with a mental health professional and be directed to the right care for them.**
- **Cancer Council Booklet: Emotions and cancer. Can be found at <https://www.cancer.org.au/about-cancer/publications.html>**

We hope this brief introduction about the role of psychology in helping patients with myeloma has been helpful.

*John Chalmers, Pallavi Pillay, and Jade Chan  
Psycho-Oncology Team  
The Royal Prince Alfred Hospital, Sydney NSW*

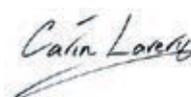
## The Carer

Are you up?  
Are you down?  
Are you mobile?  
Are you around?  
Do I have space to be?  
Or do I need to see  
What needs to done  
In this moment I'm free.  
  
I'm exhausted  
In body  
I'm confused  
In mind  
But I keep looking to find  
The strength  
To be, to see, to plan...  
  
To simply, breathe.  
  
Oh you wicked life  
You've dealt your card  
You've cut right through  
Our burgeoning hearts.  
You're cruel, you're mean  
We didn't see  
The space we had,  
When we could just be.  
  
Now its:  
Medical kit  
Appointments galore  
Restrictions  
Contradictions  
Redactions  
And action.  
Always, action.

I'm screaming for space  
A slower pace  
Grace  
I'm struggling with  
Energy  
Balance  
Conflict in needs  
Planting seeds  
Of hope, instead of fear.  
I'm here.  
I want to be here  
I'm clear.  
My love for you  
Will keep me always here and near.  
  
So. Today. Our lives are different.  
I need to find the good.  
I've now understood  
That life is precious  
It's raw  
It hurts  
It's beauty is flawed  
But it has a new law.  
Live. Love. Today.  
We may not get more.  
I love you with every claw  
Of my fingers  
Trying to close the door  
Against the tide and the roar  
Of my pain.  
It's insane.  
  
I love you  
I want the best for you.  
My heart bleeds  
With seeds of desperation

To find reason  
In this season of confusion  
That has become  
So precious. So precious.  
Today. We have today.  
Live that way.  
  
Give way.  
Play.  
Stay  
In the moment.  
It's my only way  
To make sense of  
Each precious, precious Day.  
  
I hope I can do this.  
I'm trying to do this.  
Please be patient while I try.  
I can't lie.  
This is hard.  
I'm relaxing my guard  
To be human.  
We're both human  
Struggling.  
I have no more delusion.  
  
In this new life  
Full of strife  
We have today.  
Only today.  
I'm trying to live that way.  
  
I love you.

By Carin Lavery



## A decade of movie fundraisers

Central Coast Myeloma Support Group (CCMSG) was founded in 2007 following multiple requests from patients and carers locally. The evening meetings are held bi-monthly at the local leagues club in Gosford. The objectives of the group are based on the principles of information giving, sharing knowledge and providing support in a very informal format. The group is facilitated by a senior haematology nurse (usually me!) and have guest speakers at many of the sessions.

An early key focus of CCMSG was to get involved with raising the profile of myeloma on the Central Coast and also raising funds that would assist those supporting people living with myeloma. After a brainstorming session at one of the support groups we looked into a collaboration with the Avoca Beach Picture Theatre to run fundraising movie nights. The rest as they say is history! We started our first 'Myeloma Movie Night' in 2009 with support from the lovely Shaun & Linda Raby (from the then MFA). The night was a resounding success with many support group members and people from the myeloma community pitching in to provide plates of nibbles, sell raffle tickets, sell movie tickets or do a bit of advertising. The night has gone from strength to strength and is usually almost sold out (250 people) each year. Funds raised are divided up with \$1,000 going to Myeloma Australia and the Leukaemia Foundation each year for their support with information resources, tea/coffee at the support groups, transport and funding of the annual Myeloma patient/carer seminar.

Remaining funds raised over the last two years have just gone to the hospital where we intend to buy electronic tablets that can be loaded with tailored supportive care information (for all cancer patients) and also collect patient reported outcome (PRO) data. Collecting PRO data will assist Cancer Services at CCLHD to identify how we can improve to facilitate truly patient centric care.



Movie night 2012.

The movie nights however, do so much more than raise funds. They help to raise morale, help to foster a community spirit and are just a great, happy evening – for staff as well as patients and carers. It is now 'that time of year again' as we make the most of daylight savings with our movie night booked for March 21st with a hilarious looking film *Swimming with Men!* Key committee members and volunteers help us to 'source' raffle prizes, sell tickets and plan the food. It will no doubt be another uplifting evening, we will give a nod to those that have lost their fight to the disease then move on to the business of 'Living with Myeloma'

The Central Coast Myeloma Support Group would like to take this opportunity to thank all those that have supported the group over the years with their, time, energy or expertise.

Jacqui Jagger  
Haematology Nurse Practitioner / Group facilitator



Avoca Beach picture theatre.

# NEWS FROM THE MYELOMA AND RELATED DISEASES REGISTRY

## RECRUITMENT UPDATE

We now have close to 2600 patients entered in the Myeloma and Related Diseases Registry, which is a 39% increase on December 2017. Congratulations to Christchurch Hospital for adding the 2500<sup>th</sup> patient! We have also reached 50 participating hospitals and clinics, with 37 approved sites and 13 more with approval pending. This is a huge achievement and could not have happened without the support of all participating patients and hospitals. The most recent site to join the MRDR is Royal North Shore Hospital.

## DATA REQUESTS AND ANALYSES

By the end of 2018, the MRDR had received a total of 12 requests for data and analyses. Eight of these were from investigators and four from industry. This is a great indication of the relevance of registry data and the importance of patients' contribution to the MRDR.



## INTERNATIONAL ACTIVITIES

Myeloma UK, a patient advocacy group, are exploring establishment of a UK Myeloma registry. They contacted the MRDR team to discuss our experience with the MRDR. Of the groups interviewed internationally, they found the MRDR to be one of the best examples of a model registry for myeloma and haematological diseases, and have invited us to participate in a follow-up stakeholder workshop. A great endorsement of the registry!

Dr Donna Reece, Director of the Myeloma Canada Research Network (MCRN) met with MRDR leads Prof Andrew Spencer and Prof Erica Wood in 2018. Subsequently, at ASH in San Diego, Erica and A/Prof Zoe McQuilten presented

## RESEARCH

### My-PROMPT

My-PROMPT is a multicentre pilot randomised trial to test the feasibility of real-time reporting of patient-reported outcomes to clinicians treating patients with multiple myeloma (MM). We completed recruitment in October 2018 with 32 patients, and follow-up will be complete in May 2019. We thank all patients and sites for their participation in this trial.

### IMPROVE

IMPROVE is a sub-study of the MRDR. Funded by the National Blood Authority, this study aims to investigate infections and immunoglobulin (Ig) use in patients with MM in Australia, and provide information to improve national Ig stewardship and patient outcomes.



### Myeloma 1000 Project

The Myeloma 1000 biobank project reached almost 300 participants recruited in 2018, with close to 100 patients enrolled in the last 12 months. There are now 11 approved sites and a further 5 with approval pending. We look forward to 2019 being another year of record recruitment towards our goal of having samples from 1000 MM and 1000 MGUS patients in the biobank.



the MRDR to the MCRN, and a number of interesting opportunities for further collaborations were identified.

A link with the Danish Myeloma Registry has been established following a meeting at University of Sydney in July 2018, with presentations on both registries, providing the opportunity for future collaboration.

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

## MRDR: HOW CAN YOUR HOSPITAL BE INVOLVED?

Ask your treating specialist if your hospital contributes data to the MRDR and if you



MONASH  
MEDICINE,  
NURSING AND  
HEALTH SCIENCES



AlfredHealth

CRICOS Provider: Monash University 00008C. FEB 2019



Trevor Hay

## Travel Insurance – My Story

I write this based on my experience (11 years ago) of being a travel consultant and my own experience in purchasing travel insurance since being diagnosed. I have written this in good faith, but I cannot guarantee its accuracy and it should NOT be taken to be expert advice. Always seek advice from a travel professional or the insurance company.

There is a saying in the travel business that if you can't afford the insurance, you can't afford the trip. This is especially true of people with pre-existing medical conditions, such as multiple myeloma (even though cover will cost more).

Because insurance companies are businesses who wish to make a profit and Existing Medical Condition (EMCs) constitute a higher risk they will ask for an extra premium to cover that perceived higher risk or, if they deem your EMC to be too high a risk, they won't cover it at all.

There are many companies offering travel insurance. Some of these claim to be cancer specialists, but in my experience this is a bit of marketing hype and 'regular' companies are just as likely to offer cover. The so-called 'specialists' might be your last resort however. Always read the Product Disclosure Statement (PDS) and ask questions if you don't understand something. MM sufferers have reported success with companies such as Covermore, Allianz, Australia Post, RACV, All Clear and Good2Go, among others. Be aware that many of these companies are retail 'brands' and the actual policy issuer is named in the 'fine print' - e.g.: both Covermore and Austpost are covered by Zurich insurance company.

It is very important to get at least three quotes. After declaring your EMC you will have to answer an extra set of questions or ring the company. These questions will be almost exactly the same for every company, but the result will almost definitely be different in every case. Questions include 'what stage are you', 'have you had a stem cell transplant', 'was it successful', 'is your condition terminal'? I was advised by one company that a reduced paraprotein

count would be considered a 'success'. To the best of my knowledge 'terminal condition' means you have been given a defined period (e.g. 'x' months) to live. To see all the questions I would suggest you do an online dummy quote with one of the companies. If you separate MM and bulging disc (back pain) for instance, you will get two sets of questions. It is important that you answer the questions truthfully. If you make a claim and the company finds out that you have not made a full and truthful disclosure the policy is void.

The total cost is the price shown on the first page of the quote plus the extra EMC premium. Different companies will give different premiums for the same set of answers, which is why it is important to get several quotes. If you cannot get a quote online give a couple of companies a call, but expect to answer the same questions. A human, however, will be able to give you guidance on the

grey areas.

One area of 'fine print' that should be of interest to all those taking out travel insurance, but particularly carers, is that EMCs for non-travelling close relatives need to be declared and assessed as well. The rationale is that if someone close to you has a condition that might require you to amend or cancel your travel, then that is a foreseeable risk that needs extra cover. If in doubt talk to your insurer about this.

Even if you cannot get cover for MM it is still advisable to take out a general travel insurance policy as this will cover you for non-related medical events (e.g. if you are involved in a crash), loss of luggage and the other bits and pieces in the policy. ALWAYS read the fine print and don't be seduced by big numbers in the "What you are covered for" section. I don't take \$20,000 worth of luggage with me when I travel!

You should take out travel insurance when the amount that you have at risk (e.g. non-refundable deposits and airfares) is greater than the cost of the policy. So if your deposits total \$1,000 and the policy costs \$500 take out the insurance immediately - don't wait until the week before you depart.

Be wary of 'free' credit card policies. Some of them, particularly with the 'high end' cards are very comprehensive and I was happy to use mine before I was diagnosed. As with the regular policies, however, you will need to check that you can get coverage for MM. Mine refused to cover me for MM so I have to take out another policy to ensure I am fully protected. On the other hand, the policy that is offered by some other card companies is, in my opinion, useless (even for non-EMCs) and I would not rely on it at all.

Be aware also that different travel agency chains have 'commercial arrangements' with certain insurance companies and that it is in the AGENCY's best interest, not necessarily yours, for you to deal with their preferred company. Caveat emptor (shop around).

Trevor Hay  
(Western Australia)

## My Myeloma Story



Stuart Goody

It's another August day in 2009 and I'm arriving at the depot to load my truck like I have done for the last 30 years operating my fruit juice distribution business. I go to get my trolley down from the truck where I experience the most excruciating pain I have ever had in the middle of my back, it would take another 12 months to find out that this was my T12 vertebrae "pancaking". Over these 12 months my GP sent me to so many "specialists" to have MRIs, CT scans, bone density scans, numerous blood tests only to be told I have osteoporosis which my GP didn't believe especially at 49 years of age, but didn't know what I had, during this time I was continuing with my blood and plasma donations at the blood bank.

In March 2010 my father had a hip replacement and at one of the post-operative meetings with the orthopaedic surgeon my mother picked his brains explaining my situation and if there was anyone he knew at St George Hospital that could help me with my "osteoporosis" situation. On August 2nd 2010 I saw an endocrinologist that specialized in metabolic bone disease, sending me to have a full body MRI and some specific blood tests. At 5.30pm armed with this information (MRI) along with my weight loss (23kg) and losing 13cm off my height (I use to be as tall as my father) he was sure I had a blood cancer called multiple myeloma, I said "that's the best news I've had in the last 12 months because now I've got a diagnosis". He informed me there was no cure but it could be managed and I was given the options of walking downstairs to the Accident & Emergency Department to start treatment or I could leave here and maybe last another six months. I took the treatment option.

During the three weeks in hospital I was finally diagnosed with non-secretory multiple myeloma, (a rare form of MM which cannot be detected by blood tests). The MRI on the 2 August 2010 showed that all my vertebrae from below my neck down to my tail bone had been compromised with fractures, compression, wedging or in the case of that T12 'pancaking'. I then returned to my parents place for the next 12 months of recuperation during the treatment process, which included four different types of chemo and a stem cell transplant. During this time, I literally had to learn to

walk again due to the loss of muscle tone and become independent enough to move back to my own home, at first just for overnight stays.

I am and will be, forever grateful to my beloved parents Elaine and John for their wonderful care, love, strength and unwavering support which was significant to my recovery. I am sure I caused them more worry, stress and concern than I ever did as a boy/teenager and that is saying something!!!

In March 2012 I was pronounced VGPR (very good partial remission) with my free light chains down to 86 from the original diagnosis 20 months previously of 7,300.

I would spend the next three and a half years with no treatment at all, only going to hospital for my usual check-ups and blood tests. It was during this time, being medically retired at such a young age, that I thought about what I could still do and not dwell on what I couldn't, and so volunteering filled this void by giving back to the community

I would eventually be driving two days a week for the Leukaemia Foundation in their patient transport scheme and one day a week for Angel Flight. Hearing the stories from other people and their journeys I gave thanks to the fact that I was very lucky as there were so many people out there that are far worse off than me.

In July 2015 I went back onto chemo (Revlimid) with the view of having a bone marrow transplant.

My FLC had reached 540 and needed to be brought down to the lowest point possible. Six months later and the transplant was off the table as the number of new drugs available made it a better option in my case to continue with just chemo. A transplant might be an option if needed further down the track.

In April 2016 a "tree change" decision was made to live out a long-life dream of living on acreage, with my eldest daughter living in Maroochydore Qld, so the Sunshine Coast was it. Getting out of Sydney in May 2017 and moving to the Sunshine Coast (Pomona) has been one of the better decisions I've made. The slower lifestyle, spending time in the garden (2.5 acres) have been great, growing vegetables and fruit, waking every morning with so much beauty around, it has a very calming effect on me

I consider myself truly blessed to live in a country where cancer medication and treatment is available and where I have been looked after exceptionally well by kind, caring specialists, hospital staff (a HUGE thank you to all the staff at Gympie Hospital and St George Hospital - you are the best) and brilliant haematologists and fantastic local GPs who have also been very supportive both here and back in Sydney

I finished chemo (finished 11 cycles of Velcade, as the Revlimid was no longer being effective) in August 2018 and so far so good, the numbers are remaining relatively stable FLC 152 up from the 92 when I finished chemo.

Cancer is a frightening word as sometimes, as with me, I look very healthy and well on the outside, but it's all happening on the inside!!! The "old life" I had is now long gone but I have

been given the opportunity through this illness to create a whole “new life” experiencing so many things that I would never of had the chance to if it wasn’t for this disease. I am grateful for every day, trying to pack in as much as I can. I have wonderful friends and family around me who have supported me through the thick, thin and dexamethasone days – NOT easy.

This is my journey and the things I’ve learnt about myself is to keep your faith as there will always be hope. Stay positive and optimistic; negative thoughts have no place in my lifestyle.

Concentrate on what you can still do without dwelling on what you can’t (those negative thoughts) Find your “happy

place”; for me it’s music, the places it takes me with the lyrics or the memories it creates.

Learn as much as you can about this disease and treatments. Join a support group it is very cathartic hearing other people’s journeys, problems and solutions to those issues that may arise, what is happening around the world and if you need to ask questions, ask, Knowledge is Power.

For all that you may be going through personally, and your support network around you, I wish you all the very best

PS: Dad I’m so glad you had that hip operation.

*Stuart Goody*

## Running from Melbourne to Athens

Earlier in 2018, my wonderful Dad lost his brave battle with multiple myeloma.

In 1978, at age 22, Dad ran his first Melbourne Marathon. In 2017, Dad stood at the starting line to compete in his 40th consecutive Melbourne Marathon despite his deteriorating health.

Dad always dreamed of running the Athens Marathon but his commitment to fronting up every October in Melbourne meant he was never able to make the journey over. While Dad wasn’t at the starting line in Athens, in November 2018 I stood in his place in Marathon in the hope of fulfilling a dream he tragically never got to achieve.

What a special memory I now have after completing the Athens Marathon myself. Mum and I felt his presence the whole way and know how much he would have absolutely loved it. The fact we raised money for this wonderful charity who put tireless work into supporting myeloma sufferers and their friends and families affected is a privilege.

Thanks

Pana



Photos supplied and used with permission

"In the following article regarding the upcoming Myeloma Australia/Charity TV project one of our selected Ambassadors, John Cortazzo, explains his journey with myeloma and his reasons for wanting to be a part of this adventure. John has crafted these words for the purpose of seeking donor support from his various networks. The article speaks for itself.

We are still on the lookout for the last three Ambassadors who will represent

Myeloma Australia when filming commences for five days in February 2020. Would you like to be considered as one of our Ambassadors or do you know someone who might? Our Ambassadors, at this stage include people living with myeloma, those whose lives have been impacted by myeloma in various ways, Myeloma Australia staff and one gentleman who has no direct relationship to myeloma whatsoever – he just wants 'to do something that is worthwhile.' If you would like further details about this project do please reach out to me."

*Matt Maudlin*



*John Cortazzo Charity TV.*

Advancements in myeloma research have allowed some people to have lengthy breaks from treatment, but unfortunately that isn't my experience or the experience of many others.

While there is an army of researchers, nurses, doctors and advocates who work tirelessly in exploring research around myeloma, not all myeloma patients have the same quality or length of life, there is much to do. There are also patients who unfortunately have limited access to the medical system because of financial or logistical reasons or who are fighting this battle alone.

As a myeloma carrier, I understand that the future is not certain and there is still a long way ahead for all of us living with myeloma. I want to advocate for equal access to new drugs as they become available because right now some people can pay for high cost drugs, but many others cannot. The more we tell people about our story, the quicker we can find solutions.

I am fortunate to have been given a fantastic opportunity to represent our story using one of the most powerful means – national TV, by partnering with Charity TV Productions and Myeloma Australia!

Charity TV will put together footage of me alongside others, some of whom are also living with myeloma, undertaking life-changing adventures. This project aims to inspire and show that life's journey is still enjoyable – and still can be!

The TV program combines adventures, travel, philanthropy and an opportunity to represent the Myeloma Community. Besides taking part in one of the most exciting adventures of my life, I have also committed to raising \$100,000!

By putting my hand up to be part of this TV program, my intention is not to just help create more awareness about the disease, but more importantly, to help contribute much-needed funding to advance research into this horrible disease through Myeloma Australia.

This organisation is doing amazing work within the community and I hope to raise the total amount with your support.

*continues over page*

## John's Story

I was in my mid 50's and living a pretty incredible life with my wife and kids, taking each day with positivity and enthusiasm.

It was early 2016 when I first experienced the symptoms of myeloma which kept me from enjoying everyday moments with my family. After a series of visits to the doctor, check-ups and lab tests, my perfect world was painfully shaken to the core when I received the diagnosis. Myeloma (or multiple myeloma) is an incurable blood cancer. Once the first line of treatment fails, there is no clear treatment path beyond. The next line of treatment depends on response and duration to the last treatment line to determine what can be tried next. When we lose control of myeloma, it destroys bones, kidneys and your immune system, wrecking your quality of life and cutting it short.

I was in denial for a while, but I was driven not to let this disease break me – or my family. The entire battle with medications and its side effects drained me and did not only challenge me physically, but also emotionally. With the unbelievable support and encouragement of my loved ones and the people around me, I focused on getting a new quality of life where I could once again thrive as a husband, father and businessman.

Fast forward to today, life is good and we embrace each day with a unique perspective on life which, as anyone who understands this disease knows, it's far from "normal". I have always had to be on treatment to keep the myeloma from damaging my body.

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Myeloma Australia is the only myeloma specific organisation in Australia supporting those living with myeloma. Myeloma Australia provides up to date information and caring support via their specialist myeloma nurses. All their services are free of charge and include: Myeloma Support Nurses, Myeloma Support Line, Information and Support Groups, various publications both hard copy and online, access to leading experts via seminars, workshops and video links.

All donations made through my attempt to raise these funds, will be used by Myeloma Australia to expand their nurse led services to provide education, support and advocacy to the myeloma community. These funds will also support their on-going commitment to myeloma research through their Medical and Scientific Advisory Group (MSAG).

Myeloma Australia is a not for profit organisation, endorsed by the Australian Tax Office as a deductible gift recipient (DGR) and has charity tax concessions status.

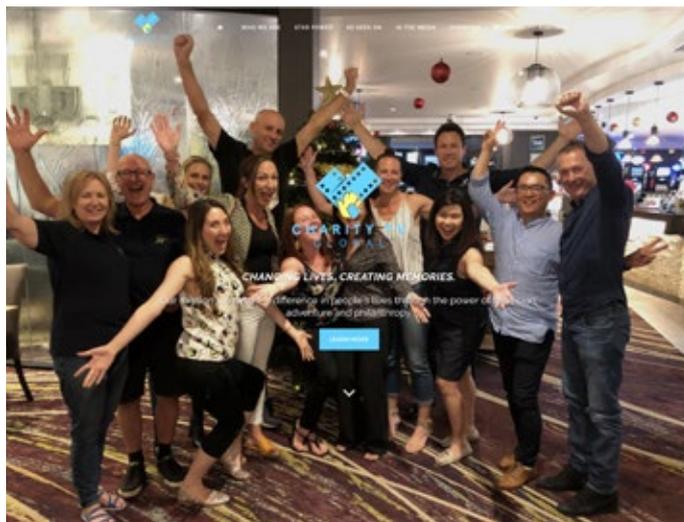
I have personally benefitted greatly from the care and support of Myeloma Australia's nurses and resources. Please help me to support their work.

## From the Nurse Manager

In January, we welcomed three new Myeloma Support Nurses to our team, Deborah Thompson in Tasmania and two nurses in the Newcastle and surrounding region, Juliet Hill and Rachel McCann. It is exciting to see our team grow and have nurses 'on the ground' in areas we haven't previously. All three nurses bring with them a wealth of knowledge and experience and as with our other nurses they work clinically in local hospitals caring for people with myeloma. They are already off to a flying start with events planned in the upcoming weeks to meet with the local myeloma community and commence their education and support services. We look forward to supporting and guiding them in their positions and planning services for the myeloma community.

As well as adding three new members to our team, we have also been busy informing our members about submitting their feedback to the Pharmaceutical Benefits Advisory Committee (PBAC) for their March meeting where three submissions relating to myeloma treatments will be considered. The PBAC decides which medicines will be reimbursed by the Pharmaceutical Benefits Scheme (PBS) in Australia and we are all hoping for outcomes which will make a positive difference for people living with myeloma.

Late last year, four of us from Myeloma Australia attended the American Society of Hematology (ASH) Conference in San Diego, USA as guests of the International Myeloma Foundation (IMF). Steve Roach, Brian Rosengarten, Jo Gardiner and I attended the conference and various satellite events. In this edition of MyeNews you can find out more about this event in the ASH report and Medical Corner.



To ALL of you who donate, thank you for fighting this battle with us!

*John Cortazzo*  
Charity TV Ambassador for Myeloma Australia

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In addition, Jo and I have been visiting local Information and Support Groups talking about the conference and sharing our learnings. These sessions are always enjoyed by participants and there are always lots of questions and healthy discussion generated. For this reason, we have decided to include a 'Best of ASH' theme to our first seminars for 2019 to further share some of the new and exciting research that was presented at the conference. We have events in Adelaide, Canberra, Melbourne and Sydney and we thank our speakers who have generously given up their time for these education days.

The Myeloma Support Nurse team are continuing to work on several projects including several publications in review and development and we look forward to sharing these with you as they're completed. Many of you have used our Telephone Support Line and our evaluation of this service continues to give us a lot of insight into the value of the service, why people call and areas for improvement. We will share the full results later in the year, however in the meantime we will be making some logistical changes to how we handle the calls in the coming months which we hope will reduce call back times, put you in touch with a nurse directly and connect you with your local nurse. Please keep providing your feedback and if you would like to speak with a Myeloma Support Nurse please don't hesitate to make contact on our toll free 1800 693 566 Telephone Support Line or email: [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au)

*Nella Combe*  
Manager Nursing and Patient Services

## What's happening

### Fundraising and Community Engagement

**There was such progress made nationwide last year in terms of community engagement & fundraising – yet I hazard a guess that when the time comes to reflect upon 2019 that we will see that 2018 was just the beginning of the adventure!**

One of the late highlights of last year was when we successfully applied for a significant grant from The Dry July Foundation that will enable us to fund the start-up of six new support groups across Australia in the early part of this year. One of the fundraising events I will be encouraging the myeloma community to become involved in this year will be Dry July. More details will follow in the near future via the usual channels so please consider if you, your friends, colleagues, families et al would be willing to participate in Dry July to help raise much needed funds for Myeloma Australia.

In this edition of MyeNews there are a couple of terrific news stories; Pana Karageorgiou tells the story of his Greek marathon adventure in memory of his late father, whilst John Cortazzo explains why he has decided to become involved as an Ambassador for Myeloma Australia as we head into a year of fundraising activities as a part of our Charity TV adventure. If you are still considering if you or someone close to you would like to be one of our Ambassadors please get in touch with me.

If I was to mention fMf to you the chances are high that you would not understand what this acronym represents – and rightly so! But as this year progresses you will be hearing a lot more about this adventure. fMf stands for 'fight Myeloma flight' and is being headed up by Fred Carter, a Queenslander living with myeloma and his Melbourne based mate, Mike. Both Fred and Mike are Cirrus pilots (I strongly recommend that you Google 'Cirrus aircraft' as they are impressive beasts to say the very least!!) To raise myeloma awareness and funds for Myeloma Australia Fred and Mike will be circumnavigating Australia in an anti-clockwise direction this September. It is a quite audacious project and one in which I am very hopeful that the myeloma community will support in many ways. The possibilities that arise from this project are mind-boggling! If you would like more information about this project than I can provide here do please drop me a line; there are certainly opportunities for individuals, Information and Support Groups and the like to become involved.

Up in Sydney, the community engagement & fundraising push into NSW is being successfully led by Santosh – if you are in NSW and have community engagement/fundraising ideas please reach out to Santosh – he'd love to hear from



*We are grateful to The Dry July Foundation for providing Myeloma Australia with significant financial support in their annual funding round which enables us to establish several new Support Groups around the country.*

you! With help from the myeloma community Santosh has hosted the first couple of Myeloma Australia BBQs at Bunnings – these have been great successes, not only in terms of raising significant money but also in raising awareness as to what myeloma is. If the thought of hosting a fundraising Bunnings BBQ is something that appeals to you please drop me a line and we can talk logistics.

Team Myeloma made its first appearance of 2019 at The Sun Run on the Northern beaches of Sydney in early February. Next stop for Team Myeloma – Mount Everest. True!! Hopefully there will be photographic evidence in the next edition of MyeNews to show that Team Myeloma is spreading its wings! Post Mount Everest the Team is starting to prepare for the HBF Run in Perth on Sunday 19th May. If you have running/walking events that you would like Team Myeloma to participate in please let me know – the more towns and cities we can raise awareness in, the better.

In the next edition of MyeNews I am hoping that we will be able to share a couple of truly heart-warming stories of fundraising events that will be occurring in March .... watch this space.

And to finish, please continue to reach out to me with your community engagement & fundraising dreams and ideas. If I can help you bring a concept to life, that's great! One of the great privileges of my job is in meeting people who are keen to raise awareness and raise funds; I love hearing from you all!

*Matt Maudlin  
Community Engagement & Fundraising Manager*

## What's happening

### Fundraising and Community Engagement NSW

**At the start of February we held a fundraising BBQ at Bunnings Northmead, raising over \$500. Thank you to all the volunteers who assisted on the day.**

OJim, a myeloma community member in NSW joined Santosh and Matt and walked in the Sun Cole Classic held on 2nd February from Dee Why to Mainly (see photos). It was a beautiful morning and a great day for walking and chatting to fellow participants as we continued to spread the word about Myeloma Australia.

There are many more activities planned in NSW as part of fundraising and community engagement.

1. Bunnings BBQ Sizzle in Northmead on Saturday 11th May. If you're interested in helping out at this event please get in touch with me.
2. City2Surf in August. Team Myeloma Australia in NSW is actively seeking partnership opportunities for City2Surf in Sydney with corporates and local businesses. And of course, we are looking for as many members of the myeloma network to join us as a part of Team Myeloma.
3. Dry Duly in July. As you will see elsewhere in this edition of MyeNews we are greatly appreciative of the funding we have recently received from The Dry July Foundation to enable us to establish more Myeloma Australia Support Groups nationwide. We will continue to work with Dry July and encourage the myeloma community to participate in Dry July later this year.
4. Myeloma Australia in Parramatta Westfield. We are looking for volunteers to run a Myeloma Australia stall in Westfield Parramatta. Our presence there will be aimed at providing



Santosh, Jim & Matt



Jacqui Keogh & Matt Maudlin



Northmead Sausage Sizzle



information about Myeloma Australia to new community members in the local area.

**Please contact me at [Santosh.ojha@myeloma.org.au](mailto:Santosh.ojha@myeloma.org.au) for further details on any of the above items, or indeed all things community engagement and fundraising in NSW.**

*Santosh Ojha*  
Community Engagement and Fundraising NSW



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)**

# What's Happening

## New South Wales

As discussed in the last edition of MyeNews we have continued to grow our NSW team with the welcome addition of two Myeloma Support Nurses Rachel and Juliet. They are based at Lake Macquarie covering Newcastle and the surrounding region (you can read more about them in this edition). We are now in a position to offer more support to the myeloma community in that area and they are both looking forward to getting out and meeting as many people as they can in the local areas. Contact details are rachel.mccann@myeloma.org.au and juliet.hill@myeloma.org.au

Now that we have more Myeloma Support Nurses we will be looking to start more Information and Support Groups and we have already identified several key areas. Geo has spent that last few weeks out and about visiting units in Blacktown, Nepean and Bowral and we hope to provide more support to these areas. However, we are always happy to hear from members of the myeloma community particularly if you are in an area that you believe would benefit from a group.

Our 'Face to Face' groups are starting to meet again and we are currently investigating topics for discussion and inviting

speakers for the year. As always, we welcome any feedback or comments you may have. Ultimately our role within the support group is just as a facilitator, they are "your" groups and need to be responsive and reflect your needs, we can only do that with your input.

The Myeloma Telephone Support group also continues for 2019, this group is run in conjunction with the Cancer Council NSW. As the name suggests this is a telephone group available for any person living with myeloma wherever you may live. It is a free service and all you need is access to a phone and a quiet space. The groups meet on the 2nd and 4th Monday of the month. In 2018 we held 22 groups and had 27 people registered for the group. On average six people joined the group on a regular basis; please get in touch if this is something that interests you.

In addition to the Information and Support Groups we have been busy planning our two seminar events that will inform the myeloma community of the latest myeloma research and treatments updates from last Decembers ASH (American Society of Haematology) conference. These will be held in Canberra on the 23rd February and in Parramatta on 2nd March. We will also soon be planning events as part of our National Myeloma Month in May. More information on these events will follow.

Jacqui Keogh  
Manager & Myeloma Support Nurse NSW



Northmead Sausage Sizzle

Photos © Santosh Ojha

## Entertainment Book

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

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

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

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





## Queensland

Megan and I have been in the Myeloma Support Nurse role since September last year and are kicking off 2019 with Information and Support Groups north and south. After running two very successful 'Meet and Greet' sessions at the end of last year we have had many requests from people living with myeloma to start Information and Support groups around South East QLD. We would love to go further afield but alas, we are but two people only working three days a fortnight.

The Buderim Information and Support Group has been going strong since May last year. Led by the enthusiastic Richard and held in at the beautiful Bloomhill Cancer Care Centre, it attracts members from far and wide. In February, the group was joined by local GP, Dr Sally McKeon, to talk about the importance of your relationship with your GP when diagnosed with multiple myeloma. Dr McKeon gave a brief overview of multiple myeloma then answered some excellent questions from the group. Some of the takeaway messages included the importance of continuing your usual health surveillance with a chronic disease. Myeloma can sometimes distract the patient and health professionals from the simple but essential checks like, skin, prostate symptoms, breast and pap smear screening, heart disease, diabetes and other common conditions in the over 40 age group. Dr McKeon also answered questions about travelling overseas with myeloma and how useful it is to visit a specialist travel doctor before heading off. These doctors can give you specific advice on prophylactic antibiotics, what to do in emergencies and vaccinations.

We had our inaugural Brisbane based Information and Support Groups in Woolloongabba and Newmarket kick off

for 2019. Patients, families and carers had the opportunity to share their stories and ask a specialist myeloma nurse questions about myeloma, its treatments and any research coming out. We are looking forward to meeting our new group attendees at the Princess Alexandra Hospital, North Lakes, Labrador and Alderley over the next few months.

Megan and I have also been lucky enough to attend some haematology education sessions at the Mater and PA hospitals. It is great to see so many novice and experienced health professionals keeping up-to-date and informed about multiple myeloma and how best to assess, treat and support this complex disease.

We are also letting health professionals know that Myeloma Australia is now in Queensland and we are seeing that more and more people living with myeloma as well as doctors and nurses from the Sunshine State are getting in contact with our organisation and the community.

Natasha Clarke  
Myeloma Support Nurse QLD



### Big Al's Blog

*You may remember Alan (otherwise known as Big Al) from our last edition of the MyeNews where he announced his plans of "blogging" his 19 day caravan holiday with his wife Rowena. Alan and Rowena covered a distance of 6,500kms exploring a number of country towns across the states of Victoria, New South Wales and South Australia. Below is a small excerpt, it makes*

*for some fun, interesting and informative narrative about their journey. You can follow his travels on our Blog page on the Myeloma Australia website at: <https://myeloma.org.au/blog/>*

... "We left Cobdogla after consulting the maps to head for Crystal Brook. Ro had said she had seen some signs earlier, so she knew where to go. Totally ignoring Ro's advice, I (we) headed in a direction I thought best, only to find ourselves after a few km's off the black stuff and much to my surprise entering a private game reserve and a dirt road, Ro was not amused. Signs advised that we had to stay in the car whilst in the park as this was private property. Maybe we had to stay in the car as we might have been eaten by some big cat! – it was just a thought I had.

I was determined to press on after all this was a shorter route (well that's what I said) so onward through the Curlwaa Game Reserve (Road B 64 ? and to be honest a bit lost) we were

faced with what became a semi off road adventure with all the dreaded corrugations and numerous cattle ( big cat) grids, before we reached the start of the black stuff again 100 km's later at Morgan, a small village with an historical Port on the banks of the Murray. It was here that we got to understand just how long the River Murray is and how vital it is to the local region in terms of irrigation.

I was slightly disappointed as we did not see any big game i.e. any Lions or Giraffes or anything African in nature, only lots of Kangaroos and Emus oh and some strange creepy crawly things that looked like a green banana with legs. If nothing else, we gave the caravan a great shakedown trial literally!"

## South Australia

### Changes in South Australia:

At the Christmas lunch for the SA committee in December, the decision was made to dissolve the SA committee and structurally come into line with the other states. This means that Ian Driver will step down as SA Chair and stay on with Myeloma Australia as Fullarton Support Group Coordinator. Thankyou Ian for all your hard work over the last 20 years including; establishing and keeping myeloma support alive in SA and negotiating the transition for Myeloma SA to come under the umbrella of Myeloma Australia. I wish to acknowledge and thank all the committee members who have served Myeloma Australia over the past 20 years, especially Glenda Bailey, Ray & June Grummett, Sandra Driver, Ilona Wright, Geoff Rooke and Dominic Scoleri. Many of you have offered to continue in supportive roles, especially with hands on at our seminars.

### In future, SA will have the following structure:

Jo Gardiner, Myeloma Support Nurse for SA and NT;  
Ian Driver, Fullarton (Central Adelaide) Support Group Coordinator;  
Jenny Naylor, Flinders (Southern Adelaide) Support Group Coordinator;  
Carol Koch, South-East SA Support Group Coordinator;  
Bronwyn Gerschwitz, Mid-North SA Support Group Coordinator

### Congratulations

In the 2019 Australia Day awards, Glenda Bailey was awarded an OAM for her services to the community of South Australia, for service to community Arts and for membership of various community service groups including "Committee member of Myeloma South Australia since 2002". Congratulations Glenda for your richly deserved recognition.

### Seminar, Information & Support Group News:

To start our year, we have held meetings for all our groups. The Flinders group kicked off the year with a general discussion group and Jo running through some of the highlights from ASH2018 meeting. In our next meeting to be held on the 21st March, we are looking forward to a talk from the staff at the community centre we meet at about the historical significance of the site to the Kuarna people and the early white settlers of Adelaide. This will be followed by a moderated myeloma Q&A with Jo.

At the Fullarton meeting, Professor Nick Wickham reviewed the recent and exciting work presented on immunotherapy at ASH2018. He titled it "Immunotherapy – the holy grail?" and guided us through this complex area with unbridled enthusiasm for these future therapies. Our next meeting will have a presentation on bisphosphonates and ONJ from Dr Tanya Lin from Special Needs Unit at Adelaide Dental School.



Flinders Support Group

The annual South-East seminar was held on Friday 8th February with Dr Kate Vandyke from SAHMRI presenting the current research work trying to identify new targets for therapy within the bone marrow micro-environment. She also held a virtual tour of the laboratory to give our country members the opportunity to see the infrastructure and people behind this important work for those affected by myeloma. The next tour at the SAHMRI facility is on Wednesday 26th June so save the date!

The Mid-North group held their first meeting on 20th February at Snowtown. We had a good turn out with some returning and a couple of new members attending. Jo presented the ASH roadshow slides to the group which generated lots of questions and discussion.

Jo will be presenting to the first patient MA seminar in Canberra on 23rd February as part of our ASH2018 highlights program. We are then going to Darwin on Tuesday 16th April for a patient Information meeting in the afternoon also as part of the ASH2018 roadshow. Additionally, we will hold a staff education meeting at Royal Darwin Hospital on Wednesday 17th April in the morning. Plans are afoot for a return visit in August, more on that later.

### Fundraising:

Our local member John Cortazzo is busy fundraising for Myeloma Australia. He has been accepted as a contestant on Charity TV and has committed to raising \$100K to expand our nursing led services.

John is holding a charity event in Adelaide at the Cathedral Hotel on Friday 10th May. Please consider donating or if you are in Adelaide, attending. Details are at: <https://charitytv.everydayhero.com/au/john-cortazzo-myeloma-supportfund>

Jo Gardiner  
Senior Specialist Myeloma Nurse; MSN SA / NT

# What's Happening

## Victoria

Is it really 2019? And February to boot. I hope you all had a nice break and made some wild new year resolutions. Looking back at the final months of 2018 we marked the silly season with many festive get togethers as well as our annual myeloma seminar at La Trobe University with Prof Miles Prince.

For many years now, every November Prof Miles Prince has presented to the Victorian myeloma community at La Trobe University Bundoora. Although the venue hasn't changed, each year the audience finds out something new about myeloma and this year was no exception with many more treatment options being trialled in Australia and around the world. It is a popular event on the Myeloma Australia calendar with the number of both attendees and insightful questions growing each year. We also welcomed three friends of Myeloma Australia all living with myeloma to discuss their personal experiences with steroids on a panel. We asked about their personal physical, emotional and social experiences of which they willingly shared with exceptional honesty and humour. Lessons learned and self-management strategies were also shared with untold value to the community present on the day. A special thank-you to Wendy, Peter and Henry. During the break, in between the jam and scones of course, myself, Laura and Nella hosted an 'ask the nurse' station. We thought of this as a live 'info and support line,' it was well utilised and appeared to be well

received. We had so many conversations, that by the time I got to the scones all the cream had gone.

Many of our Information and Support Groups got together to celebrate their last meet up for the year at local cafes/ restaurants with a bon bon or two. The Beaumaris group enjoyed a festive lunch at St Vincent's café and we were lucky enough to have an old member drop in who now lives and facilitates a myeloma Information and Support Group on the Sunshine Coast. Geelong were in the festive spirit at the Telegraph Hotel with record numbers including a couple of new faces. Our other groups also caught up at different locations around Victoria and it is such a pleasure to be involved and see our community connect socially.

Saturday March 2nd was our first seminar for the year. We teamed up with the haematology team at Monash Health for a loaded information day. Dr Michael Low, Dr Pasquale Fedele and Dr George Grigoriadis presented on treatments, trials and transplants and our special guest speaker Cathy shared with us her experience as a carer for someone living with myeloma. Very interesting topics were presented which generated lots of discussion and questions, even the hot weather didn't deter a great turnout.

Hope to see or hear from you all soon.

*Elli Foley*

*Myeloma Support Nurse – VIC*



Beaumaris Support Group



Geelong Support Group

## 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.



## Western Australia

With the festive season behind us we are really looking forward to another exciting and busy year supporting people affected by myeloma and promoting Myeloma Australia here on the West coast.

### Information and Support Groups

Commencing in 2019 we have added to our existing groups with the first Perth Hills group due to commence on Monday 25th February which we look forward to reporting about in the winter edition of MyeNews. The first WA Information and Support Group meeting for 2019 was the South Metro group which was held in the new venue of Mary Davis Library and Community Centre in Baldivis. It was great to see some old faces return and we also welcomed some new attendees. We look forward to growing this group throughout the year. The North Metro group has also held its first meeting in the new venue for 2019 in the group study room at the Wanneroo Library and this group was really well attended with many people making the move from both the Heathridge and Butler groups of 2018. This group will happily take new members and will consider an additional northern suburbs group should numbers continue to rise in 2019.

### Information mornings

In December, we held our first Coffee&Chat session at our Cottesloe offices, which was a great informal way to meet over coffee and a sausage roll and Christmas cupcake. It provided a great opportunity to share experiences with myeloma as well as ask questions of Narelle and Kerin in an informal setting. Chandrika Gibson, Director of Wellness Education and Research at Solaris Cancer Care dropped in and shared information about the services on offer from Solaris Cancer Care (also based in Cottesloe). A hot topic of conversation was that of support resources including the independent Facebook page – The Multiple Myeloma Australia Support Group. Our next event – an information morning is going to be hosted on 22nd February 2019 at Cottesloe discussing the topics

*Christmas cupcakes*

of getting the most out of specialist appointments and a detailed discussion about common tests and investigations for myeloma.

### Health professional education

Kerin and Narelle have been busy planning a nursing and allied health education evening, which will be held in April 2019. It is hoped that nurses caring for myeloma patients will come along to learn more and get up to date about current therapies, toxicity and side effect management. It is hoped that this will be the first of many of this type of event.

Signing off for this edition, we are looking forward to sharing our news about all the events we have coming up in WA for Myeloma Australia.

*Kerin Young & Narelle Smith  
Myeloma Support Nurses WA*



*Photo supplied and used with permission*



## Highlights from Multiple Myeloma Sessions ASH 2018; Dec 1-4, San Diego, California

### Including comments from Australian & New Zealand – Myeloma Ambassador Program (ANZMAP) members.

Please note the following information references unpublished data, and medicines and/or the use of medicines that are not approved in Australia and/or New Zealand. ANZMAP Comments are the individual interpretation of the ANZMAP Ambassador, reflecting their opinion rather than those of the research group or scientific journal.

#### Newly Diagnosed Myeloma:

##### Double vs single autologous stem cell transplantation (ASCT) for newly diagnosed multiple myeloma: long-term follow-up (10-years) analysis of randomized phase 3 studies; Abstract 124, Michele Cavo et al

**Conclusions:** Results of this pooled analysis of phase 3 studies incorporating bortezomib-based triplets into ASCT confirmed the superiority of ASCT-2 over ASCT-1 in terms of extended PFS and OS. The subgroup of pts at high-risk mostly benefited from ASCT-2, in particular those who had advanced ISS stage, adverse cytogenetics and failed to achieve CR.

**ANZMAP Comments:** Highlights the role of tandem ASCT in high-risk patients especially with lack of access to novel combination therapies. Data were from studies using bortezomib-based induction therapy and help confirm the phase III EMN randomised clinical trial data. These data now provide enough information to incorporate tandem transplant as being offered as standard of care for NDMM patients with high-risk cytogenetics. The risk score developed for consideration of double ASCT could be useful.

##### Bortezomib-thalidomide-dexamethasone (VTD) versus thalidomide-dexamethasone (TD) before and after double autologous stem cell transplantation for newly diagnosed multiple myeloma: final analysis of phase 3 GIMEMA-MMY-3006 study and prognostic score for survival outcomes.

**Abstract: 125, Paola Tacchetti, et al**

**Conclusions:** With a follow up of 10 yrs, the final analysis of the GYMEMA MMY-3006 trial comparing VTD versus TD showed a persistent PFS benefit translating into extended OS for the VTD arm. A prognostic model based on cytogenetic, ISS stage and achievement of CR, identified three risk groups

with statistically different long-term survival probabilities, Standard Risk (SR), Intermediate Risk (IR) and High Risk (HR). Both IR and HR groups significantly benefited from VTD. A PFS time of 78 months predicted for long term survival outcomes in the SR and IR groups.

**ANZMAP Comments:** Relevant to Australian practice with the future potential expansion in thalidomide use. A possible overall survival benefit with VTD demonstrated, although all patients received tandem autologous stem cell transplant

##### LYRA: a phase 2 study of daratumumab (dara) plus cyclophosphamide, bortezomib, and dexamethasone (CyBorD) in newly diagnosed and relapsed patients (pts) with multiple myeloma (MM)

**Abstract: 152, Habte A. Yimer et al**

**Conclusion:** Dara-CyBorD was active and well tolerated in pts with newly diagnosed and relapsed/refractory myeloma, including pts with high-risk cytogenetics. ORR, VGPR+, and CR rates improved with cycles 5-8 of induction, indicating that longer therapy with dara results in deeper response. Preliminary PFS and OS data in ND pts in the first year are comparable to dara-VMP. The safety profile was consistent with that previously reported for dara, with no new safety signals observed. Split first daratumumab dosing was feasible, reduced Day 1 infusion time, and resulted in a similar infusion reaction rate as previously described for single-dose administration. These findings indicate that dara-CyBorD, using a split-dose first infusion, can be safely administered in the community setting and may be an effective treatment option for pts with MM.

**ANZMAP Comments:** Treatment in a community setting is of interest, although the nature of the setting was not explained. Plan for transfusions if required was one query

##### One-year update of a phase 3 randomized study of daratumumab (dara) plus bortezomib, melphalan, and prednisone (D-VMP) versus bortezomib, melphalan, and prednisone (VMP) in patients (pts) with transplant-ineligible newly diagnosed multiple myeloma (NDMM): ALCYONE

**Abstract: 156, Meletios A Dimopoulos et al.**

**Conclusions:** With 1 year of additional follow-up, the combination of DARA and VMP in transplant ineligible NDMM pts continues to demonstrate a significant PFS benefit, including in pts  $\geq 75$  years of age, and allows for maintenance of PFS benefit during the subsequent line of therapy. Improvements in duration and depth of response continue to be observed with D-VMP with longer follow-up. No new safety signals emerged following the addition of DARA to VMP, and grade 3/4 infections continue to be manageable with no notable increase in rates. These results continue to support the use of D-VMP in the first line of treatment in transplant ineligible NDMM.

**ANZMAP Comments:** These are encouraging results. The CR rates achieved with D-VMP were comparable to CR rates following ASCT in younger patients. The response rate is similar to MAIA (abst. LBA-2) suggesting the benefit of dara induction and maintenance regardless of chemotherapy

...Continues over page

backbone used for transplant ineligible patients.

### **Efficacy and feasibility of dose/schedule-adjusted Rd-R Vs. continuous Rd in elderly and intermediate-fit newly diagnosed multiple myeloma (NDMM) patients: RV-MM-PI-0752 phase III randomized study**

**Abstract: 305, Alessandra Larocca et al.**

**Rd-R:** Lenalidomide (Revlimid) 25mg Day 1-21 for 9 cycles followed by Lenalidomide 10mg Day 1-21 until progressive disease or intolerance

**Rd:** Lenalidomide 25mg Day 1-21 /dexamethasone 20mg weekly until progressive disease or intolerance

**Conclusion:** This is the first prospective randomized phase III trial specifically designed for real-life intermediate-fit NDMM patients. A dose/schedule-adjusted Rd-R treatment was more feasible compared to full dose continuous Rd treatment in elderly intermediate-fit NDMM patients, with no negative impact but rather a comparable outcome. These results confirm the need for an appropriate definition of patient frailty and pave the way to a frailty-adjusted treatment approach to better balance efficacy and safety in elderly NDMM patients.

**ANZMAP Comments:** This is a realistic study in patients who typically are excluded from clinical trials. Lenalidomide dose adjustment and omitting dexamethasone occurs in practice. The comparable PFS and OS data for

lenalidomide-dexamethasone therapy followed by lenalidomide maintenance versus continuous lenalidomide-dexamethasone are reassuring. These results support the need for frailty studies in MM – using frailty as a criterion to adjusted treatment.

### **Relapsed/Refractory MM (RRMM)**

#### **Results of the pivotal STORM study (part 2) in penta-refractory multiple myeloma (MM): deep and durable responses with oral selinexor plus low dose dexamethasone in patients with penta-refractory MM**

**Conclusions:** Results of the pivotal STORM Part 2 in penta (PI, IMiD, dara)-refractory MM (relapsed after >5 lines of therapy) demonstrated that oral selinexor plus low-dose dexamethasone (Sd) was highly active with an ORR of 26.2%. Importantly, responses were rapid and deep with 2 patients achieving sCRs (both MRD negative) in these heavily pre-treated penta-refractory MM pts (median 7 prior regimens, 53% high risk). Adverse events (AEs) are a function of dose/schedule/disease severity and can be managed with dose modifications and supportive care. No major organ toxicity was observed, and AEs were typically transient and reversible. Sd is an all-oral, first in class mechanism with novel mechanism of action and represents a potential therapeutic option to the growing number of pts with penta-refractory MM who have exhausted approved therapies.

## Common abbreviations used in Medical Corner

**ASCT:** autologous stem cell transplantation

**BM:** bone marrow

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

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

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

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

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

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

**NDMM:** newly diagnosed multiple myeloma

**ORR:** overall response rate

**OS:** overall survival

**PFS:** progression free survival

**PI:** proteasome inhibitor (ie Bortezomib, Carfilzomib)

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

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

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

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

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

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

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

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

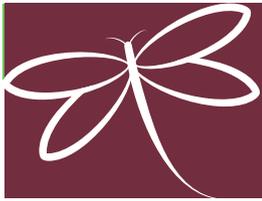
**RR/MM:** relapsed or refractory to therapy multiple myeloma

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

**Tandem transplant:** 2 ASCT performed to intensify treatment

**Triplet:** 3 drugs used in combination

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



# Calendar of Events 2019

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

## Victoria

Event	Date	Location	Time	Organisation	Contact
Sunshine Information and Support Group	Thur Mar 28th	Braybrook Community Centre 107 - 139 Churchill Ave, Braybrook	10am - 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 Apr 3rd	Coburg North Meeting Room Shop 19/180 Gaffney St (Coles site)	10am - 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 Apr 4th	Beaumaris Theatre 82 Wells Road, Beaumaris	10am - 12 noon	10am - 12 noon	Elli Foley E: <a href="mailto:elli.foley@myeloma.org.au">elli.foley@myeloma.org.au</a> M: 0426 404 233
Wangaratta Information and Support Group	Thur Apr 4th	Wangaratta Library, Seminar Room 21 Docker St, Wangaratta	11am - 1pm	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Albury Information and Support Group	Fri Apr 5th	Albury Wodonga Regional Cancer Centre, Wellness Room, 201 Borella Rd, East Albury	10am - 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
Bendigo Information and Support Group	Wed Apr 10th	Bendigo Cancer Centre, Bendigo Hospital 100 Barnard St, Bendigo	11am - 1pm	Myeloma Australia	Laura Jones E: <a href="mailto:laura.jones@myeloma.org.au">laura.jones@myeloma.org.au</a> M: 0451 404 203
Kew Information and Support Group	Thur Apr 11th	Kew Library Corner Charles St & Cotham Rd, Kew	10am - 12pm	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 Apr 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 Apr 17th	Gippsland Rotary Centenary House 39 Valley Dve Traralgon	10am - 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
Berwick Information and Support Group	Fri Apr 26th	St John of God Hospital Level 1, 55 Kangan Dv, Berwick	10am - 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 May 9th	Rotating at local venues, details published closer to date	6pm - 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

## Tasmania

Event	Date	Location	Time	Organisation	Contact
Hobart Information and Support Group	Tues Mar 12th	Cancer Council Tasmania 15 Princes St, Sandy Bay	10am - 12 noon	Myeloma Australia	Deborah Thompson E: <a href="mailto:deborah.thompson@myeloma.org.au">deborah.thompson@myeloma.org.au</a> M: 0433 511 689 1800 MYELOMA (693 566)

## New South Wales

Event	Date	Location	Time	Organisation	Contact
Liverpool Information and Support Group	Tues Apr 9th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
RPAH Information and Support Group	Tues Apr 9th	Royal Prince Alfred Hospital Kerry Packer Education Centre, Seminar Room 4.5 John Hopkins Dve, Camperdown	10am - 12 noon	Myeloma Australia / RPAH	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 pager: 87524
Westmead Information and Support Group	Thur Apr 18th	Wentworthville Leagues Club Magpie Meeting Room 1 50 Smith St, Wentworthville	10am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230
Central Coast Information and Support Group	Thur Apr 18th <i>*1 week earlier due to ANZAC day</i>	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 May 6th	Cancer Council Office Level 1/215 Pacific Highway, Charlestown	3pm - 5pm	Myeloma Australia	John Miller E: miller32@optusnet.com.au P: (02) 4957 0711 1800 MYELOMA (693 566)
Patient Information Seminar	Fri May 10th	TBC	TBC	Myeloma Australia / RPAH ?	Tracy King E: tracy.king1@health.nsw.gov.au P: (02) 9515 7310 pager: 87524
Liverpool Information and Support Group	Tues Jun 11th	Liverpool Hospital The Wellness Centre (Entrance N off Campbell St) Level 1, Cnr Elizabeth & Goulburn Sts, Liverpool	10am - 12 noon	Myeloma Australia	Jacqui Keogh E: jacqui.keogh@myeloma.org.au M: 0426 404 230

## South Australia

Event	Date	Location	Time	Organisation	Contact
Fullarton Information and Support Group	Tues Apr 2nd	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10am - 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)
South East Information and Support Group	Thur May 9th	Katnook Estate Riddoch Highway, Coonawarra	11.30am - 2.30pm	Myeloma Australia	Carol Koch E: clk@live.com.au M: 0427 659 014 1800 MYELOMA (693 566)
Mid North Information and Support Group	Wed May 15th	Snowtown Hospital 70 Railway Terrace E, Snowtown	12 noon - 2pm	Myeloma Australia	Bronwyn Gerschwitz E: graemebrownwng@bigpond.com P: (08) 8664 0682 1800 MYELOMA (693 566)
Flinders Information and Support Group	Thur May 16th	Living Kurna Cultural Centre Function Room Warriparinga Way, Bedford Park	10am - 12 noon	Myeloma Australia	Jenny Naylor E: Jenny.Naylor1@gmail.com M: 0405 391 616 1800 MYELOMA (693 566)
Fullarton Information and Support Group	Tues Jun 4th	Fullarton Park Centre 411 Fullarton Rd, Fullarton	10am - 12 noon	Myeloma Australia	Ian Driver E: sandrian7@bigpond.com M: 0417 874 252 1800 MYELOMA (693 566)

## National Telephone Support Group (Cancer Council NSW)

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

## Queensland

Event	Date	Location	Time	Organisation	Contact
Alderley Information and Support Group	Fri Mar 22nd	Alderley Arms 2 Samford Road, Alderley	10am - 12 noon	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Woolloongabba Information and Support Group	Tues Mar 26th	Woolloongabba Senior Citizens Centre 22 Qualtrough St, Woolloongabba	10am - 12 noon	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tues Apr 2nd	Bloomhill Cancer Centre 58 Ballinger Road, Buderim	2pm - 4pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
PAH Information and Support Group	Wed Apr 10th	Princess Alexandra Hospital 199 Ipswich Rd, Annerley	11am - 1pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)
North Lakes Information and Support Group	Fri Apr 26th	North Lakes Health Conference Centre, Oncology 7 Endeavour Bvd, North Lakes	10am - 12 noon	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Alderley Information and Support Group	Fri May 3rd	Alderley Arms 2 Samford Road, Alderley	10am - 12 noon	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Buderim Information and Support Group	Tues May 7th	Bloomhill Cancer Centre 58 Ballinger Road, Buderim	2pm - 4pm	Myeloma Australia	Tash Clarke E: natasha.clarke@myeloma.org.au M: 0416 019 585 1800 MYELOMA (693 566)
Labrador Information and Support Group	Wed May 8th	Labrador Community Centre 57 Billington Street, Labrador	10:30am - 12:30pm	Myeloma Australia	Megan McDowell E: megan.mcdowell@myeloma.org.au M: 0416 019 022 1800 MYELOMA (693 566)

## Western Australia

Event	Date	Location	Time	Organisation	Contact
South Metro Information and Support Group	Mon Mar 25th	Mary Davis Library & Community Centre 17 Settlers Av, Baldivis	10am - 12 noon	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Apr 8th	Wanneroo Library Group Study Room, Level 1 3 Rocca Way, Wanneroo	1pm - 3pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)
Perth Hills Information and Support Group	Mon Apr 29th	Zig Zag Cultural Centre 50 Railway Rd, Kalamunda	10am - 12 noon	Myeloma Australia	Kerin Young E: kerin.young@myeloma.org.au M: 0426 404 310 1800 MYELOMA (693 566)
North Metro Information and Support Group	Mon Jun 10th	Wanneroo Library Group Study Room, Level 1 3 Rocca Way, Wanneroo	1pm - 3pm	Myeloma Australia	Narelle Smith E: narelle.smith@myeloma.org.au M: 0426 404 280 1800 MYELOMA (693 566)

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



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



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



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



Visit **[www.myeloma.org.au](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)**

**Mon – Fri 9am – 5pm AEST**

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