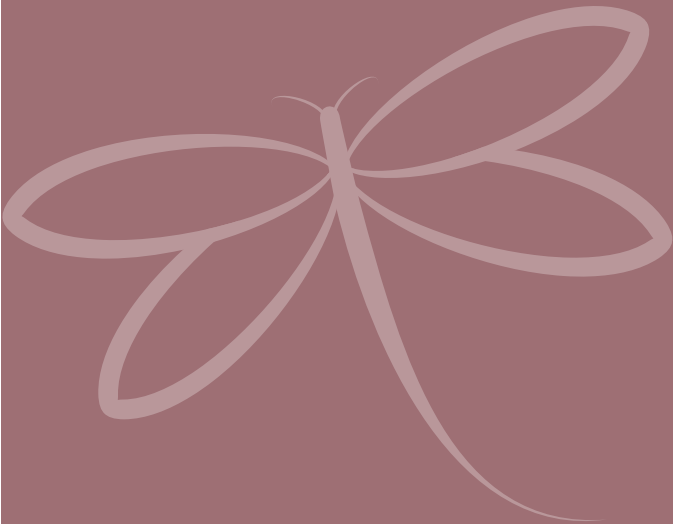




Annual Report
2020-21

Contents

Who We Are	1
Our Impact	2
President's Report	3
CEO's Report	4
Treasurer's Report	5
Nursing Services Report	7
Medical and Scientific Advisory Group Report	9
38mate Awareness Campaign	10
Fundraising Report	12
Our Team	14
Our Partners and Supporters	17



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Who we are

Myeloma Australia
is the only Australian
myeloma specific not-for-profit
organisation.

We support, educate, inform, empower
and bring hope to people who are living
with myeloma, and their loved ones. We
also facilitate myeloma research in Australia;
educate health professionals involved in
the care and treatment of those living with
myeloma; raise community awareness
and understanding of myeloma; and
advocate for improved patient
access to the latest treatments
at affordable prices.

Our purpose

- To enable those affected by myeloma to take control of their situation and work in partnership with their health professionals
- To support specialist clinicians and researchers and raise funds for myeloma research
- To raise awareness and understanding of the condition among health professionals and the wider community
- To create opportunities for fellowship within the myeloma community

Our values

- The needs of people with myeloma will always come first
- We are passionate about assisting and improving the quality of life of Australians living with myeloma
- We understand the myeloma experience and empathise with patients and family members
- We will operate in an inclusive and transparent manner
- We will present an organised and professional operation



Our history

Myeloma Australia was formed in 1998 by a small number of driven people who were each profoundly affected by myeloma. They discovered for themselves that the path to myeloma diagnosis was often slow and uncertain, and that reliable information and access to support was scarce.

Their response was to come together to form Myeloma Australia, to make the path easier for others in the future. One of our founders – Brian Rosengarten OAM – is still actively involved with Myeloma Australia as our President. Another of our founders – Bob Moran OAM – was also actively involved as our Patron up until he passed away in June 2020.

OUR IMPACT

During the 2020/2021 financial year, our services and programs had an impact for people living with myeloma, their loved ones, and the health professionals who offer medical care.



Service delivery

Our goal: to support, educate, inform, empower and bring hope to people who are living with myeloma, and their loved ones.

17 Myeloma Support Nurses provided services across all Australian states and territories

482 people called the Telephone Support Line

62 Information and Support Groups around the country

266 groups in total hosted around the country

* Due to Covid-19 restrictions, 125 of these groups were delivered via Zoom, 95 face-to-face and 46 a fusion of both

1,576 people attended Information and Support Groups



Advocacy

Our goal: to increase awareness and understanding about myeloma.

5,552 people received communications and publications from Myeloma Australia

1,119 people attended myeloma information seminars, with **15** seminars hosted

26 myeloma magazines, books and fact sheets available to the community



Education services for health professionals

Our goal: to support, inform and educate health professionals working in the myeloma field for the purpose of earlier diagnosis and improved patient outcomes.

992 health professionals attended education sessions

24 sessions hosted



Myeloma
Australia



Brian Rosengarten OAM
President

The end of October 2021 marks 25 years since my wife, Roslyn, was diagnosed with myeloma and our journey into the world of myeloma began, which thankfully continues. Our journey, like many others in the myeloma world, has its lows and some highs. The special times Roslyn was concerned about missing out on, was seeing our two children getting married and then having the pleasure of grandchildren. Thankfully, both children married special partners and we have six fabulous grandchildren.

This diagnosis also led me to meet up with Bob and Glenys Moran and together we started Myeloma Victoria, which then led to Myeloma Australia. This year, we have extended the number of Myeloma Support Nurses to 17 across Australia. Our original dream of providing education and support to the myeloma community is now being extended to all parts of Australia, especially through the extensive use of modern technology such as Zoom and webinars. I still miss my conversations with Bob as he never tired of hearing about our achievements.

This time last year I mentioned that the previous year had been difficult, but I think this past year has been even worse, especially in Victoria and New South Wales with the extended lockdowns. But like the previous year, our fabulous team of myeloma nurses have continued their support groups, workshops and webinars. I

President's Report

thank them all for their dedication and passion they bring to their responsibility in providing the latest information to all.

Unfortunately, we are feeling the effects of the extended Covid lockdown on our finances, as we have been unable to host many fundraising events. This is especially difficult, as we receive no government funding, and are totally dependent on the generosity of the myeloma community.

Thanks go to Professors Miles Prince AM and Joy Ho AM for leading the Medical and Scientific Advisory Group (MSAG) for the past years and helping to make this group of myeloma specialists, the leading experts in their field. They have now passed this role to Professors Simon Harrison and Hang Quach and I have absolute confidence in their ability in further strengthening this committee. One of the roles of MSAG is advocacy and through their work we have seen new treatments approved for the treatment of myeloma onto the Pharmaceutical Benefits Scheme (PBS). New treatments continue to be trialled in Australia as well as overseas and we are hopeful with the data collected by these trials, that further applications for these new drugs will assist in getting these products listed.

Steve and our two nurse managers, Hayley and Nella, have continued to meet with the international myeloma support organisations via Zoom and we continue to share information from these organisations from all corners of the world.

I would like to thank the Board for their total support over the past year. It seems a long time since we have been able to meet in person, but we are still having regular meetings via Zoom. One benefit to these remote meetings is the time saved by not having to travel to and

from the Myeloma Australia office.

A special thanks to our CEO Steve Roach and all the staff for keeping everything running so smoothly. Working from home has some benefits, but you do miss out on the regular conversations in the office around the water cooler. Even with the limited opportunity to work in the office together, the team have done a great job in keeping everything working so well. This year saw the launch of our first awareness campaign, known as 38mate. We are pleased to announce that the 38mate awareness initiative received an award for Most Outstanding Patients Campaign. Congratulations go to the staff for developing this initiative and spreading the word through social media and our website, and to the advocates who shared their stories during this campaign.

During the past couple of years, we have been working with the Rotary Clubs providing assistance in the coordination of our support groups, initially throughout the Victorian country areas. This further enables our Myeloma Support Nurses to run information and support groups remotely in regional areas.

Our nurses are also initiating a training program for nurses based in country towns around Australia. This will help them learn about myeloma and the latest treatments, so they can further support our community based in rural areas. We have just started this program on a trial basis and hope to further expand it in the next couple of years.

Finally, I would like to thank our myeloma community for your support in helping us achieve what we have in the past 23 years and to enable us to continue to provide our services to the Australian myeloma community wherever they live.



Steve Roach
CEO

The last year has seen Myeloma Australia continue to go about its good work despite the difficult circumstances. We continue to deliver quality programs, strengthen our support networks and develop quality literature. During this time, we have had to cope with the Covid-19 pandemic, but we do look forward with strength to the year ahead.

The fantastic people who work and volunteer at Myeloma Australia work hard on the day to day tasks of delivering our core programs, fundraising, promoting awareness and generally taking care of the day to day issues of running a business that is a charity. We are very lucky to have such dedicated staff and volunteers.

We particularly saw this with the Covid-19 pandemic as we moved our services online. In fact, online services have grown enormously and although we look forward to seeing everyone face to face again, we have managed to Zoom into the 2020's, keeping in touch with our community via virtual platforms.

Our nurses are an integral part of this work. Jacqui Keogh, NSW State Manager and Senior Myeloma Nurse has built a great team in NSW. Jacqui's team, Cath Bowley, Diana Yun, Juliet Hill and Rob O'Brien are a pillar of strength to the myeloma community there. Jo Gardiner has continued her great work in South Australia with Alicia Hopper. Alicia and Jo also look after the Northern Territory patient support services. Hayley

CEO's Report

Beer and Nella Combe manage the delivery of our programs and services nationally with the other nurses. Narelle Smith has done brilliantly developing and delivering services in the Western Australian community; and has been joined by Daniel Berk, who has quickly become part of the team. Megan McDowell and Natasha Clarke have grown services to patients significantly in Queensland and are really having an impact in that state. As Laura Jones went on maternity leave, EJ Furphy was joined by Emma Huybens who joined the team as a maternity leave appointment, as well as Rachel McCann who transferred from Newcastle, both fantastic additions to the team. Deborah Thompson in Tasmania has been brilliant at getting services up and going there.

Jaqueline Tate co-ordinates the activities and meetings of the professors, doctors and researchers in our Medical and Scientific Advisory Group (MSAG) to enable the members to concentrate on their work treating and researching myeloma.

Our office staff are as devoted as ever to the foundation. Alex Dawson looks after finance, payroll, HR and payments, webshop as well as general support in the office. Pina Civitarese looks after general support, website and support group updates, MyeNews, and database. Samantha Zeps has a science and research background and adds much in supporting nurses and patients and providing specific support for our nurses and publications and resources.

Matt Maudlin has made a big impression on the organisation since joining us in the role of Community Engagement and Fundraising Manager and in NSW Rob O'Brien joined us. Olivia Myeza joined the team as Major Gifts, Philanthropy and Corporate

Sponsorship Manager. We were also joined by Rita Hughes, looking after marketing and communications. Rita has made a huge contribution, including the 38mate campaign that won Myeloma Australia "Most Outstanding Patients Campaign" at the Australian Patient Association Awards.

Our fundraising events were few after Covid-19 struck and fundraising has proven difficult during extended Covid-19 lockdowns across the states. The onset of the virus and the shutdowns have had a major effect on us, but as usual our team adapted and we have worked through it with online events and community engagement.

We have continued providing advocacy for our community, providing feedback and information to the Pharmaceutical Benefits Advisory Committee (PBAC) for drug submissions. We have seen several successes with improved treatment regimens being approved for myeloma.

I would like to acknowledge the support of our sponsors from the pharmaceutical sector, and our philanthropic supporters, who provided funding towards our programs and services over the past year, helping to enable us to continue our good work.

My thanks go to our Board, for both the great work they do and for the support they have given me, and to all the staff and volunteers.

In particular, I would like to personally thank Brian Rosengarten for his support of myself and the staff and for his vision and dedication in continuing the work he started over two decades ago.

I am looking forward to a great 2021-2022 financial year.



Peter O'Brien
Treasurer

Treasurer's Report 2019/20

Financial Results Summary

	2021 \$'000	2020 \$'000	2019 \$'000
Income	1,289	2,575	1,383
Expenses	(1,593)	(1,496)	(1,512)
Surplus / (Deficit)	(304)	1,079	(129)

Income

Along with many other organisations in Australia and around the world, the operations and results of Myeloma Australia (MA) for 2021 were again impacted by COVID-19. MA was unable to hold a number of large fundraising events as well as other community fundraising activities throughout the year, which resulted in significantly lower income. This lower level of fundraising income was partially offset by increased donations which MA was grateful to receive in such difficult times from our generous community.

The significantly higher income achieved in 2020 was mainly due to the one-off receipt of a major bequest of over \$1 million. This enabled MA to plan for the long term and for more services to be

offered directly to the myeloma community. As a result, we were able to expand the number of myeloma nurses, employ a major gifts manager and also employ a marketing co-ordinator.

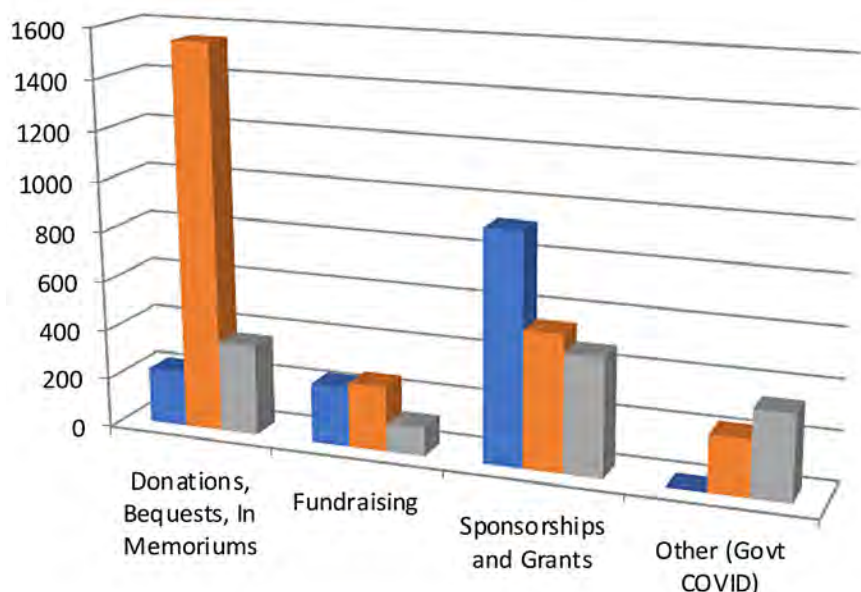
One of the major sources of funding from pharmaceutical companies was also lower during the year.

MA receives no funding from government for the provision of any myeloma services. Notwithstanding this, the overall reduction in MA revenue this year was improved with the government JobKeeper payments and cashflow assistance payments due to the pandemic. This enabled MA to retain all of its staff, the majority of which are specialist myeloma nurses.

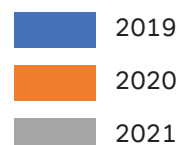
Expenses

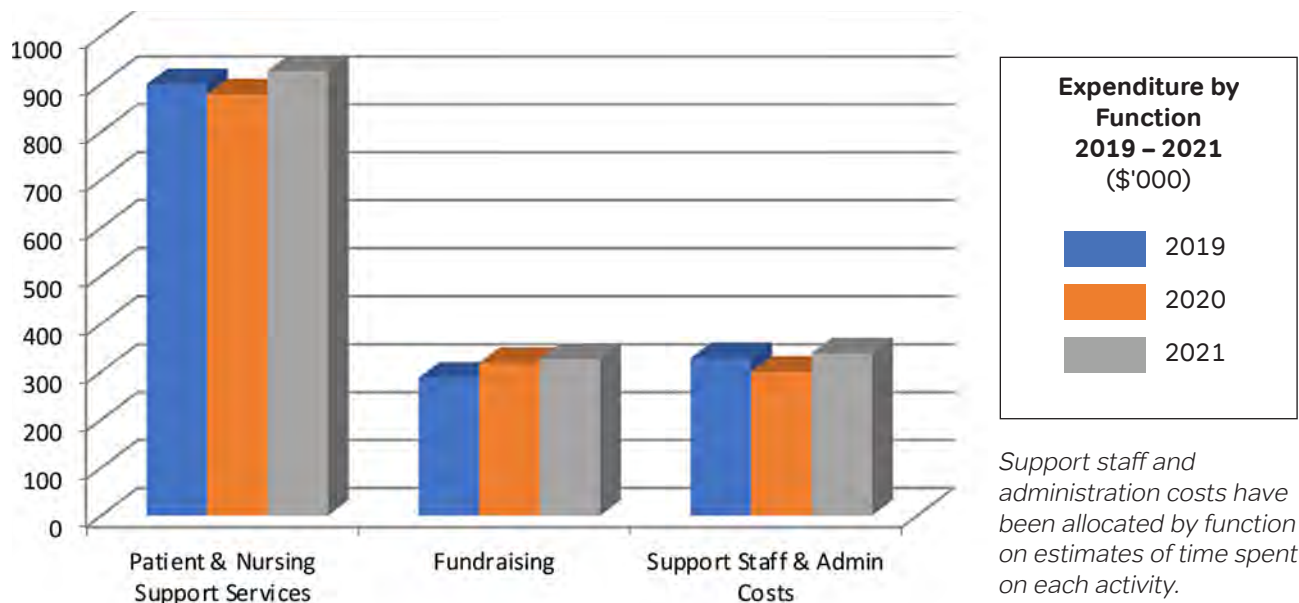
We have a national coverage of nurses and now employ 17 nurses in all states of Australia. We are now able to provide a broader range of services to a larger audience. The increased numbers of support groups, as well as the numbers attending webinars and other educational events are evidence of this. Our use of Zoom technology has enabled the various support groups, patient meetings and webinars – which the nurses are involved in – to continue on a virtual platform when face to face interactions were not possible.

We employed a major gifts manager for the first time in MA's history to try to broaden the sources of income to enable myeloma services to continue to



**Income by type
2019 - 2021
(\$'000)**





expand. This new role has had some success to date; however, we are confident that over time this will become an important area of funding income for Myeloma Australia.

MA has also employed a marketing co-ordinator who drives social media activities on Facebook, Twitter, Instagram and LinkedIn, and works with the fundraising and nursing teams to build awareness campaigns, fundraising campaigns and streamline communications including website and social media.

Our support staffing levels have remained consistent during this difficult period. Most of the MA staff have been working from home for long periods of the year under fairly trying circumstances.

Due to the various lockdowns, MA has been able to make some small savings with local and international travel being scaled back or unavailable. Support group costs were also lower due to the online nature of most of these events during the year.

Resourcing

Myeloma Australia has only one full time employee and 24 part time employees. This includes 17 nursing staff, four support services staff, three fundraising staff and one MSAG assistant.

Volunteers have a hugely positive impact on the operations of Myeloma Australia. Our volunteers assist with workshops and seminars, support groups, fundraising activities, administration support and include our Board members. However, the circumstances during the year did not allow MA to utilise this precious resource as much as we would have liked.

Outlook

MA is hopeful that at some time during the next financial year the world will return to a more normal setting. MA wants to continue to expand the services it provides and increase the utilisation of those services and their reach into the Myeloma community.





Hayley Beer
Nursing and Programs Manager



Nella Combe
Nursing and Patient Services Manager

Nursing Services Report

In February we said see you soon to Laura, who went off to have her second baby, while we welcomed Emma Huybens to cover Laura's maternity leave. In addition to Emma in head office, we also welcomed Rachel McCann to the Victorian team who relocated from Newcastle to Warrnambool. It's been great to have Rach local to an area that was largely underserved.

In March we were delighted to welcome Diana Yun into the Sydney office to help Jacqui and the NSW team support the state with the largest myeloma community.

We must also thank the Victorian team who stepped in to cover Tasmania while Deborah Thompson was on secondment at the Royal Hobart managing the specialist clinics there.

Telephone Support Line

Our Telephone Support Line (TSL) continues to be one of our most well-utilised and valuable services. This is demonstrated by the sheer number of people who turned to the TSL at each stage of the pandemic. In fact, since the pandemic began, we have seen a 200% increase in calls to the TSL. The myeloma community have had many concerns around their compromised immune systems and risks of exposure to COVID-19, fears around vaccine side-effects and uncertainty of vaccine effectiveness. These are all very valid concerns and our nurses have done an outstanding job staying across developments as they happen and helping to allay these fears.

Of course, in addition to calls about COVID-19, we have still received general calls about myeloma, treatments and living well. In this financial year, our average call time has remained at around 20 minutes per call.

Information and Support Groups

We are very proud that our team have been able to continue to foster opportunity for connection and empowerment with the myeloma community through our information and support groups. The majority of our groups have continued to run online as either 'Cuppa and Catch-ups' or discussions with invited guest speakers. Wherever possible, COVID-19 restrictions depending, we have also seen some groups get together face to face. We give huge thanks to our nursing team for being so flexible and adapting to the ever-changing rules to ensure our services continue. We currently have 62 groups around the country. Nine of those are new regional groups that have commenced in this financial year and we had a total of 266 groups hosting 1,576 people over the 12 months. This includes the National Telephone Support Group we co-facilitate with the Cancer Council, which continues to run strong with our NSW team at the helm.

While we all long for the day that we can get everyone together in the same room, we have seen the vast majority of our community embrace online technology, grateful for the opportunity to stay connected. One great benefit to using video conferencing is that it doesn't matter where you are, you can take part! We've had people log in from remote parts of Australia and even their hospital beds. It has also meant that we have been able to start some national groups. We've had state-based Younger Persons' groups for some time now and it's great to see this minority group get together and learn how to manage issues pertaining to living with myeloma when your career is in full flight, you have small children and an uncertain prognosis. During this

Reflecting over the last financial year, we are in awe of what our team and our community have achieved. Despite the challenges of a prolonged global pandemic, our team has grown in size and strength and continues to work hard to ensure people with myeloma, their loved ones and health professionals feel supported and empowered.

The nursing team are now 17 strong and have seen some movement over the past 12 months. In October 2020, we said farewell to Kerin Young who has taken an opportunity to implement a new role as haematology nurse practitioner in Albany, WA. Kerin continues to fly the flag for Myeloma Australia and we look forward to future collaborations with her and the WA team. After a very competitive recruitment process, we appointed Daniel Berk into the WA support nurse team with Narelle in January 2021.

financial year, we have offered a National Younger Persons' group which has been really well attended and has even welcomed some friends from New Zealand. It's great to see these members get to know each other and leave the group feeling that little bit more equipped to manage their health challenges.

Another part of the myeloma community that we are passionate about supporting are the carers. Pre-pandemic, we had been incorporating carer specific break out groups during our seminars to really focus on the enormous role the carer fills and to give them a space to be vulnerable and open about their fears and concerns. We did this during seminars as we had found that taking time for themselves to attend a group independent of their loved one was often not possible. Again, with people becoming more comfortable with using technology to meet, we have initiated online groups just for partners and carers. This has been a pilot program in Western Australia and South Australia and so far has been very successful. We will see this roll out across the country in the coming year.

Our future plan is to create more groups that are focused on common interests such as treatment type or diagnosis type, rather than geographic location. We hope that this will help people feel less alone and able to share experiences of similar situations in order to gain insights and hopefully cope better during that stage of their trajectory.

Seminars

Despite most of the country being in lockdown for the majority of this financial year, we did manage to host a healthy seminar program. National Myeloma Month not only saw three jam packed online seminars, we were also able to host a number of in-person, informal Q&A sessions with local MSAG

members around the country. Our nurses really enjoyed the chance to catch up with their communities after so long in the virtual space. It was also fantastic to be able to incorporate our first major awareness campaign, 38mate, into each of our events.

In total we were able to facilitate 15 seminars across the country this year.

Health Care Professional Education

Once again, the majority of our health professional education was held online this year. Despite treatment centres being extremely stretched coping with the pandemic, we were still able to deliver myeloma education to our peers. We facilitated 21 education sessions to 269 health professionals around the country via local nurses.

We also held our first nursing and allied health professionals' education evening with our nurses delivering presentations on four key topics and their nursing considerations. These presentations were recorded and are available on our website to be utilised by individuals or during local team education time.

Nationally, our team played a major role in each MSAG MAGIC event in conjunction with the LIMBIC bringing the nurse perspective to case study panel discussions.

Our team also provided support to MSAG in the facilitation of their biennial 3rd National Scientific Workshop.

Resources

Traditionally our resource content development has been managed completely in house with the support of skilled volunteers. As time goes on and more is discovered about myeloma and more treatments are developed, we are driven to make this information

more accessible to everyone. This means we need to provide information to suit all learning styles and reading levels. To this end, we have engaged the support of a medical writer who can help edit our information to make it more widely accessible. Stay tuned for a fresh approach to our information including an update to existing publications and exciting new formats such as animated videos and podcasts.

In addition to our well-loved MyeNews magazine and regular Muster e-newsletter, the nursing team have worked hard and fast to generate timely COVID-19 updates in conjunction with MSAG in the form of videos for social media and a dedicated webpage.

Advocacy

This year we finally saw the inclusion of the first monoclonal antibody therapy for myeloma listed on the Pharmaceutical Benefits Scheme. We are proud to have played a part in its approval through inviting members to provide consumer feedback and by making a submission on behalf of the organisation. Quite often medications have to go before the Pharmaceutical Benefits Advisory Committee multiple times before they are approved and we did see two other drugs rejected this year. We will continue to advocate for the approval of these medicines and invite the community again to have their say.

Globally, we've maintained our relationships with the Global Myeloma Action Network by attending their meetings. This has proved challenging at times due to them being held in European time, but we are grateful to be able to network with our international peers and share the great work being done around the world with a common goal to improve the lives of those living with myeloma.



Professor Simon Harrison
MSAG Chair

MSAG was founded in 2006 and is an integral part of Myeloma Australia. MSAG consists of approximately 30 clinicians and scientists who are experts in myeloma, as well as Myeloma Australia's president, CEO and two nurse managers. Jacqueline Tate is the MSAG Program Manager, responsible for the management of MSAG's activities.

Leadership Change

Professor Miles Prince AM has been MSAG chair since 2008 and has decided to step down from this role. Professor Joy Ho AM also stepped down as deputy chair. Both Miles and Joy will continue as MSAG members and Miles will remain on the Board of Myeloma Australia.

Professor Simon Harrison is the new chair with Professor Hang Quach as deputy chair. Both are long standing MSAG members, haematologists, and leading clinician scientists of international renown.

Education

MSAG provides education in world's best clinical practice in multiple myeloma. Members of MSAG regularly contribute to Myeloma Australia patient support events.

3rd National Myeloma Workshop: In 2020 Myeloma Australia and MSAG presented this full day event, welcoming over 400 delegates. The event featured a mix of local and international speakers, established experts and emerging

Medical and Scientific Advisory Group (MSAG)



L>R: Outgoing Chair Prof Miles Prince AM, Outgoing Deputy Chair Prof Joy Ho AM, Incoming MSAG Chair Prof Simon Harrison and MSAG Deputy Chair Prof Hang Quach.

voices with a scientific, clinical, and translational perspective. In 2020 the event was hosted online due to COVID-19 restrictions. *Myeloma Australia's Guided Interactive Cases (MAGIC Program):* MSAG members present clinical cases and discuss them as a panel to both live and virtual audiences. *Myeloma Interest Group:* MSAG regularly circulates the latest research and relevant myeloma events and opportunities for health professionals. Providing a valuable chance for patients to hear from leading experts.

Advocacy

MSAG advocates for equitable, timely access to important therapies and the highest standard of clinical care for Australian patients. MSAG advocated for various myeloma to the Pharmaceutical Benefits Advisory Committee (PBAC), and MSAG members were involved in preparing the '*COVID-19 Vaccination in Haematology Patients: An Australia and New Zealand Consensus Position Statement*'.

Practice Statements

The Practice Statements pillar of MSAG works to improve the standard of care for myeloma patients through scientifically validated, critically appraised

consensus guidelines for the myeloma community. All MSAG practice statements are available open access through the Myeloma Australia website.

Research

MSAG members facilitate and collaborate on research projects which advance the care and treatment of myeloma patients. In 2020 Myeloma Australia created the **Bob Moran Memorial Research Fund** in memory of our co-founder Bob Moran OAM. Myeloma Australia is advised by MSAG on how scientific and clinical research funds are invested.

Retirements

During 2020 two of MSAG's most senior members and biggest contributors, Professor Jeff Szer AM and Professor Andrew Roberts AM decided to step down from their role at MSAG.

MSAG is pivotal in Australia's efforts to bring improved outcomes to our patient community and are committed to continuing this work.

For a full list of our MSAG members, please visit our website: <https://myeloma.org.au/who-we-are/medical-scientific-advisory-group-msag/>

38mate

MYELOMA AUSTRALIA

Meet Henry

Henry became a 38mate in 2015



“ I don't want others to go through what my family and I went through. Hearing about myeloma for the very first time when you're diagnosed. ”

www.myeloma.org.au/38mate



Meet Linda

Linda has been caring for a 38mate since 2004



“ In the beginning my carer's role was immediate, intense and prolonged for approximately 6 months. Then life went back to normal, albeit with the shadow of myeloma. ”

www.myeloma.org.au/38mate



Meet Peter

Peter became a 38mate in 2004



“ I've been relatively stable for five years now. I've been able to retire, live a pretty good life, travel, and continue playing in a professional rock band despite the side effects of treatment. ”

www.myeloma.org.au/38mate



Meet Natalie

Natalie became a 38mate in 2016



“ Being a mum of two young boys I was really overwhelmed and scared. I knew if this was going to be my life I needed to focus on all the good stuff I already had as a base. ”

www.myeloma.org.au/38mate



Meet Nimo

Nimo has been caring for a 38mate since 2006



“ After investigations, my wife was diagnosed with myeloma. We were in complete shock and were confused as to what this unheard of cancer was. This was followed by denial, fear, researching, anger, and lots of scary feelings, finally accepting. ”

www.myeloma.org.au/38mate



Meet Pana

Pana's dad became a 38mate in 2014



“ While Dad stayed positive and fought to the final hour through his 4 year journey with myeloma; his battle, pain and passing will be a scar that is felt forever by me, my family and all those who met him. ”

www.myeloma.org.au/38mate



Meet Ray

Ray became a 38mate in 2016



“ When I was first diagnosed with myeloma, I had no idea what this disease was and neither did any of my family or friends. In fact, most people thought that I had a melanoma. ”

www.myeloma.org.au/38mate



Meet Kiri

Kiri became a 38mate in 2019



“ I have learnt that through sheer strength, determination, amazing medicine and a very positive mindset you can surprise yourself with how strong you really are when faced with adversity! ”

www.myeloma.org.au/38mate



We would like to acknowledge and thank our myeloma advocates Henry, Linda, Peter, Natalie, Nimo, Pana, Ray and Kiri for taking the time to share their stories. We would also like to thank CVP Events, Film and Television and Mars Photography for helping us bring it all together.

Inaugural myeloma awareness campaign

We heard the community telling us that, in almost every case, they had not heard about myeloma until they or a loved one were diagnosed. We decided it was time to create an initiative that would respond to that and raise general community awareness about myeloma, whilst giving a voice to those impacted by myeloma. The initiative achieved these goals and more.

38 Australians are diagnosed with myeloma every week. Despite this, many people have never heard about myeloma until they or a loved one are diagnosed with it. This May, as part of National Myeloma Awareness Month, Myeloma Australia set out to change this by launching the inaugural 38mate awareness campaign. The campaign aimed to raise awareness about myeloma and show solidarity and support to the 20,000 Australians currently living with myeloma.

The 38mate campaign had two components – a series of short videos and a 38mate cap.

The video series shone a light on myeloma and told some of the stories behind the statistics of 38 new diagnoses each week. During May we shared the videos across social media, on our website, during myeloma information and support groups and seminars as well as in Rotary Club meetings.

The main 38mate video was released on 1st May in conjunction with the first day of National

Myeloma Awareness Month. So far, this video has been viewed over 26,000 times, a number we could have never imagined when we first considered this initiative. Throughout the month of May, we continued to release a series of eight short videos. Each of these videos tells the story of someone who is living with or who is affected by myeloma. These videos give a rare and personal insight into the lives of people affected by myeloma. Our 38mate advocates shared their stories openly in the hope of raising awareness, as in each case they had not heard about myeloma until they or a loved one were diagnosed.

In addition to the series of videos, a 38mate cap was – and still is – available to purchase from our webstore. The cap was designed to be a conversation starter about myeloma, both in the real world and on socials. Again, we could have never imagined just how supportive and excited our community would be. So far, we have sold 1,200 caps!

We are grateful to be a part of an initiative that not only builds awareness, but also gives a voice to those living with myeloma. Throughout May we have heard some beautiful stories and seen some wonderful photos of people proudly wearing their cap out in their community. Many ripple effects of impact have been created by this campaign, too many to count or mention here.

Myeloma Awareness Month wrapped up at the end of May,

but the 38mate initiative did not end there. Myeloma Australia continues to advocate for and share the stories of those affected by myeloma in the hopes that awareness grows in our community and that the first time a person learns about myeloma isn't when they or a loved one is diagnosed.

We will continue to sell 38mate caps so that you, our supporters and advocates, can start conversations about myeloma whilst out in your community.

If you would like to throw your weight behind 38mate, you can still buy a cap and share the videos on your socials. You can view the 38mate videos and learn more about the initiative on our website <https://myeloma.org.au/38mate/>

- **38mate awareness campaign won Most Outstanding Patients Campaign at the Australian Patients Association Awards in 2021**
- **38mate introduction video has reached over 26,000 people via socials**
- **Series of short videos have reached over 20,000 people via socials**
- **1,200 caps sold so far!**

** At the time of printing*

38mate
MYELOMA AUSTRALIA

Fundraising Report



Matt Maudlin
*Community Engagement
& Fundraising Manager*

I reported last year that the 2019/20 could be split into two distinct periods of time – pre-Covid and Covid. Our community engagement & fundraising in 2020/21 was all lived in the shadow of the pandemic.

Due to the pandemic all four of our major Team Myeloma events were cancelled; we very much hope that 2021/22 and beyond will see us able to take our team to the major city community walking/running events again.

The absence of these major fundraising events has been significant to our finances; this made seeing our community rise up to host their own community fundraising events for us all the more special. We saw funds raised

Community Engagement

for us through, amongst other events, marathon runs, jam making, lawn bowls, trivia nights, haircuts and head shaves. Alongside these, we generated funds through the People's Choice Raffle, The Entertainment Book, items in our webshop and the wonderfully creative and environmentally sound Containers for Change venture.

We launched our 38mate awareness campaign in the month of May for Myeloma Month. It was extremely encouraging to witness though this campaign, the sale of 1,200 38mate caps. These caps, now an item always available in our webshop, were never intended to be a fundraising initiative – yet the sheer number of caps sold ensured that extra income was generated from the webshop avenue of our fundraising income.

In February 2021 we successfully sent a group of Myeloma Australia ambassadors away for the adventure of a lifetime with media group Charity TV Global. This was our first experience and not our last. We are excited to have another group of fundraising ambassadors this year. They have done a wonderful job in their fundraising but have yet to enjoy

their adventure because of the pandemic. This will now likely occur in early 2022.

In May of this year, we welcomed Rob O'Brien to the fundraising team as our NSW Community Engagement & Fundraising Executive. Rob brings with him to the role extensive experience in the financial and not for profit sectors. He has hit the ground running (even during a lockdown of several months in Sydney) and is already proving to be a great asset to Myeloma Australia.

We are never short of ideas for community engagement & fundraising. In fact, some of the thoughts we have for the future are going to be very exciting to bring to fruition alongside the myeloma community.

The many and varied paths that have led us to raising nearly \$95,000 through community fundraising this year have all been hugely appreciated. One thing is quite evident; the myeloma community is a generous one. We are thankful to each and every person who has helped us to raise the funds this year that we have.



Di McCaughey "Money for Jam" fundraising



Ross Hedrick – May 2021
– Great Ocean Rd Marathon



Biggenden Bowls Club QLD

Fundraising Report



Olivia Myeza
Manager Philanthropy, Major Gifts and Corporate Giving

Held the role from September 2020 – September 2021

The role of Manager Philanthropy, Major Gifts and Corporate Giving was a newly created role, designed to embrace local businesses, philanthropic foundations and major donors.

We have been delighted to welcome both new and returning major donors, trusts and foundations, local government grants and corporate/business supporters this year. Each gift helps us to support, inform, empower and bring hope to those living with myeloma, and their loved ones.

It's moving to see the deep connection to cause that exists for each donor or partner. Most of our major donors are either living with myeloma or have a loved one who is living with myeloma. The same goes for the small to medium sized businesses that partner with us – they tend to have a team member or a loved one impacted by myeloma. It is incredible that the very people who we exist to support, are in fact the people who are also supporting us.

When it comes to the trusts and foundations that have awarded first-time grants to Myeloma Australia this year, things are a

Corporate Giving & Major Gifts

little different. In most cases they had not heard about myeloma until we presented them with a funding proposal, and yet, they are prepared to provide grants to enable us to sustain and expand our services. We are so grateful.

Philanthropy

We were grateful to receive grants from the following trusts and foundations:

- **The John James Foundation:** donated \$25,000 to establish face-to-face myeloma information and support services in Canberra and surrounds.
- **Tour de Cure Local Community Grants:** donated \$10,000 towards the establishment of a new myeloma information and support group on the Fleurieu Peninsula in South Australia.
- **The Lin Huddleston Charitable Foundation:** donated \$10,000 towards myeloma research.
- **The Gwenyth Lennon Family Foundation:** donated \$4,700 towards general operations.
- **The Patrick Foundation:** donated \$3,000 towards general operations.
- **The Trailsend Foundation:** donated \$63,307(USD\$50K) towards general operations.

Local Government Community Grants

In this reporting period, we received a local government community grant.

- **The City of Unley local community grants:** donated \$2,860 towards the running of the Fullarton myeloma information and support group in South Australia.

Corporate Giving

This year we established ongoing partnerships with the following businesses:

- Hiline Home Modifications, Adelaide
- Victoria Sports and Rehabilitation Clinic, Melbourne
- Unified Music Group, Melbourne
- JC's Quality Foods, Melbourne
- Andrew Vanny Plumbing, Sydney

Each of these businesses are committed to providing an annual donation to Myeloma Australia and helping us to spread the word about myeloma amongst their networks.

We continued to receive regular donations from the Ringwood branch of Specsavers.

Major Gifts and Regular Donors

We received several generous major gifts from individuals and family groups, for which we are deeply grateful. We would also like to acknowledge and thank our regular donors who donate on a monthly or fortnightly basis throughout the year.

Gifts in Wills

We are grateful to the following people who left a legacy gift to Myeloma Australia in the past year:

- The Estate of Graeme William Vines
- The Estate of David Henry Knuckey



Our Team – Board of Directors

Our volunteer Board of Directors provide governance and strategic direction for the organisation.



Brian Rosengarten OAM
President



Ian Driver
Board Member



Peter O'Brien
Treasurer



Adam Schwab
Board Member



Jeffrey Hanlon
Secretary



Ajay Bhatia
Board Member



Peter Allen OAM
Board Member



Annree Wogan
Board member
(elected to the board
in November 2020)



Professor H. Miles Prince AM
MBBS (HONS) MD FRACP FRCPA
AFRCMA AFRACD FAHMS –
Board Member

Outgoing Members

We acknowledge the service and contribution of Dr Elizabeth Johnson and John McLennan, who both resigned from the board in November 2020. We thank them for their time and expertise while serving on the board.

Medical & Scientific Advisory Group (MSAG)

Myeloma Australia's Medical and Scientific Advisory Group (MSAG) is the peak medical and scientific body convened to collaborate and facilitate scientific advances and medical care for multiple myeloma.

For a full list of MSAG members please visit
www.myeloma.org.au/who-we-are/medical-scientific-advisory-group-msag/

Our Team

The past 12 months has seen a huge shift in the way our team works, with all of our staff working from home and adapting to a more isolated working environment. The ingenuity of our staff meant we were still able to deliver key services to our community, while each state had different restrictions due to COVID, they adapted quickly and efficiently. Introducing Zoom meetings, virtual seminars and even hybrid of both where it was practical.

Even in a time where fundraising proved difficult and service delivery was altered, Myeloma Australia still had the ability and opportunity to grow as a team.

Our nursing services saw the addition of a nurse to support delivery of support groups and educational materials. In our promise to continue to grow our services, two newly created roles in the Fundraising team were also developed.

As we welcomed new team members, we also said goodbye to Kerin Young. We thank Kerin for her contribution and wish her well. We also can't forget Laura Jones, who hasn't said goodbye, but who is currently on maternity leave after welcoming a beautiful baby girl named Clover to her family. Congratulations Laura!

HEAD OFFICE – VICTORIA



Steve Roach
CEO



Hayley Beer
Nursing and Programs Manager



Nella Combe
Nursing and Patient Services Manager



Matt Maudlin
Community Engagement & Fundraising Manager



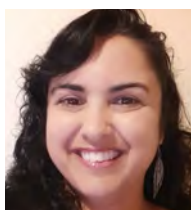
Pina Civitarese
MyeNews Co-ordinator and Support Services



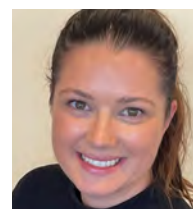
Alex Dawson
Finance and Support Services Co-ordinator



Emma-Jane Furphy
Senior Myeloma Nurse, Special Projects



Rita Hughes
Marketing and Fundraising Co-ordinator



Emma Huybens
Myeloma Support Nurse



Laura Jones
Myeloma Support Nurse (Maternity Leave)



Rachel McCann
Myeloma Support Nurse



Jacqueline Tate
MSAG Programs Manager and Liaison

...continues over page



Samantha Zeps
Nursing Support Services



Olivia Myeza
Manager Philanthropy,
Major Gifts & Corporate Giving
(held role from Sept 2020
– Sept 2021)

NEW SOUTH WALES



Jacqui Keogh
Senior Myeloma Nurse
and State Manager



Catherine Bowley
Myeloma Support Nurse



Juliet Hill
Myeloma Support Nurse



Robert O'Brien
Community Engagement
& Fundraising Executive



Diana Yun
Myeloma Support Nurse

QUEENSLAND



Natasha Clarke
Myeloma Support Nurse



Megan McDowell
Myeloma Support Nurse

SOUTH AUSTRALIA



Jo Gardiner
Senior Specialist Myeloma Nurse



Alicia Hopper
Myeloma Support Nurse

TASMANIA



Deborah Thompson
Myeloma Support Nurse

WESTERN AUSTRALIA



Narelle Smith
Senior Myeloma Support Nurse



Daniel Berk
Myeloma Support Nurse



Kerin Young
Myeloma Support Nurse
*Held the role from
October 2017
– November 2020*

Our Partners and Supporters

Our impact on the myeloma community of Australia was made possible thanks to the generous support of our partners and supporters.

From the individuals who made personal donations, to those who asked their friends to make donations in celebration of their birthday or other special occasion. From our incredible Charity TV Ambassadors who each raised over \$10,000 for Myeloma Australia, to those who left a

legacy by contributing a gift in their will. From those who made donations in memory of a loved one, to those who contributed regularly via workplace giving programs. We are deeply grateful for each and every generous contribution and partnership.

Corporate partners:











Community partners:






Support us

Myeloma Australia is Australia's only dedicated Myeloma charity. We are not government funded, relying on the generosity of our donors and partners to provide our services – all of which are delivered free of charge to ensure equitable access.

By donating to or partnering with Myeloma Australia, you can help us to support, inform and empower those living with myeloma; give hope to them and their loved ones; and work with myeloma health professionals to improve patient outcomes and quality of life.

We are a not-for-profit organisation, endorsed by the Australian Taxation Office as a deductible gift recipient with charity tax concession status.

There are many ways to support our work. You could:

- Subscribe to receive Myeloma Australia newsletters and communications: www.myeloma.org.au/subscribe/
- Make a once-off or regular donation of any size via our website: www.myeloma.org.au/donate
- Leave a bequest or gift in Will to Myeloma Australia
- Become a corporate partner
- Attend or host a fundraising event
- Shop at our online store: www.myeloma.org.au/shop/

On behalf of the 20,000 Australians currently living with myeloma, and their loved ones, thank you for being here with us.

Myeloma Australia
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Australia

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support@myeloma.org.au

www.myeloma.org.au