Myasthenia Gravis Association of Queensland Inc.

MessaGes

MARCH 2026

We take this opportunity to thank Queensland Health, who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

PRESIDENT'S REPORT MARCH 2026

The weather has certainly dominated conversations this summer! Potential cyclones, damaging storms, metres of rain and heat with high humidity that has not been pleasant for people with MG. The courage and mentality of Queenslanders is amazing in difficult situations. It is heartening to see how people have rallied to support their friends, neighbours and locals. Our best wishes go to all members and their families who have been directly impacted by these harrowing weather events and we hope that your life returns to normal as soon as possible.

Speaking of hot weather and humid conditions, I hope that all members have completed the **Heat Survey**. This research is groundbreaking and our liaison with Queensland University of Technology (QUT) will lead not only to research papers being produced but also very, very valuable information in relation to seeking resources for all of us. Please, if you have not competed this survey, make it a priority. If you are in remission, the project team encourages you to still do the survey as your information will be valuable and add to the 'story' of living with MG. Also, some people have partially completed their survey so I urge them to also take the time to complete it. More information about the survey is on page 4.

Rare Disease Day was held on 28 February. Susan White, representing the MAA, and Donna Formosa from the MGAQ management committee met with parliamentary personnel and representatives from Rare Voices in Canberra on that day. Being able to communicate and liaise with these people is a significant way of keeping our rare disease at the forefront of decision making.

On Rare Disease Day I hope that everyone took the opportunity to speak with family and friends about living with Myasthenia Gravis and also touched base with others who do have MG. I think that the R U OK banner is one we all should enact by connecting with others regularly.

Another significant event that is just a few months away is the **International Myasthenia Gravis Awareness Month**. The ***Lights-up Project*** continues to grow not only in Queensland but across other states as well. Do not forget to approach your local council about any local features that can be lit up in teal during the month of June.

The Myasthenia Alliance Australia (MAA) is busy organising the ***Art with Heart (AWH)*** activity. More information is with this newsletter.

The Management Committee wish you all a very Happy Easter with family and friends.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

Behind the scenes, there has been a lot happening for the MAA. All this activity has been well rewarded with Health Minister Butler's announcement at the recent RVA event in Canberra. (See page 5 for more details).

Health Minister Butler was very proud to share the news that the Myasthenia community are being given PBS access to a new innovative therapy after a very long wait for a new treatment. The access that has been provided is broad with Australia leading the way in this regard. It was a wonderful moment to be present as Chairperson of the MAA and to be representing the MG Community when this surprise announcement was made.

The new treatment, Ultomiris, is a complement inhibitor and is approved for people diagnosed with generalised MG having ACHR+ antibody status. If this is of interest to you please have a conversation with your Specialist.

The Rare Voices Australia (RVA) annual Rare Disease Day celebration was, yet again, a terrific event. RVA are very dynamic, very progressive and very supportive of all the rare disease communities they assist. The RVA highlight of this event was the announcement of a ***"Rare Disease Disability Toolkit"***. The toolkit is full of practical tips to assist everyone.

Please take a look by visiting **https://rarevoices.org.au/toolkit-page/** The MAA hopes to share more about this Toolkit in the coming months.

Additionally, Physiotherapist Rodney Wenceslao has shared his knowledge and expertise in working with myasthenia patients. He explained why maintaining activity is very important. He explained why our muscles work differently and advised on how to manage activity with this condition. He reassured us that activity is safe in myasthenia if used appropriately. This webinar will be posted to the MAA website as an ongoing resource for you and your physiotherapist. An announcement will be made when this has occurred. Thank you to UCB for assisting with this webinar.

Thanking each of our readers for supporting the Art With Heart project. A small and dedicated team of volunteers are working hard to make this June Awareness activity a success. **Your contributions are needed**. Please show everyone that this is an important conversation for the myasthenia community.

Also significantly, Australian patients have been given the opportunity to participate in a clinical trial. This is via the MyClad Study.

More information can be found here:
https://myastheniaalliance.org.au/myclad-study-myasthenia-gravis-clinical-trial-australia/ or by speaking with your specialist.

Watch out for the steady stream of announcements from the MAA. Be sure to be registered at **www.myastheniaalliance.org.au**. We are providing research information and opportunities regularly and will be following progress with the remaining new treatments on offer which we hope will soon complete their PBS processes. News from the PBS flows after the first of each month through the Medicines Status Website.

With good wishes to all for a happy Easter.

Susan White, MAA Chairperson

If you are not already registered with the Alliance please go to **www.myastheniaalliance.org.au**

“EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE”

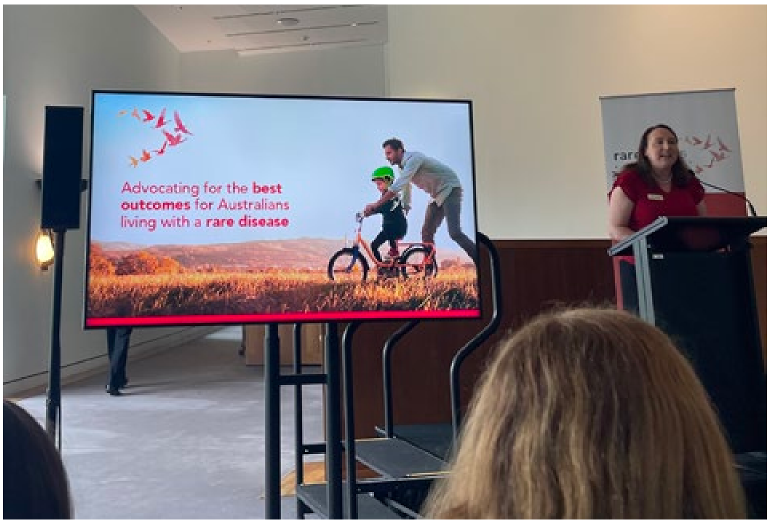
It was a privilege to represent MGAQ alongside Susan White, Chair of Myasthenia Alliance Australia (MAA) at the Rare Voices Australia 2026 Rare Disease Day Parliamentary Event held in Canberra on Monday 2 March. The event was hosted by the Parliamentary Friends of Australians Living with a Rare Disease.

A highlight of the event was the announcement by Hon. Mark Butler MP that the treatment, Ultomiris is now listed on the Pharmaceutical Benefits Scheme for the Myasthenia Gravis community. He also acknowledged Susan and the significant work that the Myasthenia Alliance Australia volunteers do for our community.

Rare Voices Australia (RVA) also launched the Rare Disease Disability Toolkit, which is available on their website at **https://rarevoices.org.au/toolkit-page/**

The opportunity to network allows the MGAQ to grow and develop what we offer.

Donna Formosa



- Top Left: **Nicole Millis, CEO RVA**
- Top Right: **Donna and Susan**
- Above: **With RVA team and RVA ambassadors**
- Left: **Susan speaking with Hon Mark Butler MP and Trent Zimmermann**
- Right: **Susan and Dr Mike Freelander MP**

STRENGTH IN COMMUNITY:

CELEBRATING CHLOE WIGG'S LATEST HONOURS

Image by Fotoforce Photography

The Myasthenia Gravis Association of Queensland community is proud to celebrate the ongoing achievements of member and advocate Chloe Wigg. Following an incredible year that included the powerful Oh MG art exhibition, 2026 has already begun strongly with Oh MG showcasing at the Lockyer Valley Art Gallery - closing on the 22nd of March.

Chloe was recently recognised at the Heart of Women Awards, where she received a Heart Award and was also named a finalist for Queensland Woman of the Year. She has also begun the 2026 Emerging Leaders Program with the Queensland Disability Network, where she is developing her skills to advocate more strongly for people living with disability and to learn how to effectively work with all levels of government to create meaningful change.

As a community, we are incredibly proud to see the wider world recognising the selfless actions of a woman who has given so freely of her creativity, skills and time to help others. Chloe's work continues to shine a light on the lived experience of people with myasthenia gravis and the strength of the community around them. We wish Chloe all the very best this weekend at the City of Logan People's Excellence Awards, where she is a finalist in the Artist category.

Participate in a unique MGAQ research project:

THE SURVEY “HEAT SENSITIVITY IN PEOPLE WITH MYASTHENIA GRAVIS” IS NOW AVAILABLE FOR COMPLETION.

TAKE THIS OPPORTUNITY TO TELL US HOW HEAT AFFECTS YOUR DAILY LIFE

CLICK THE BUTTON BELOW TO ACCESS

“Closing Soon – Don't Miss Out!”

Follow the link:
https://myastheniaalliance.org.au/heat-myasthenia-gravis-survey-reminder/

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC. (MGAQ)

QUT Queensland University of Technology (QUT)
QUT ethics approval 10508

NEW TARGETED THERAPY FOR MYASTHENIA PATIENTS LISTED ON THE PBS!

Natalie Windle and Susan White from Myasthenia Alliance Australia (MAA) reported this significant March 2nd announcement.

Generalised Myasthenia Gravis (gMG) patients can now have access to a new targeted therapy Ultomiris, via the Pharmaceutical Benefits Scheme (PBS), broadening our treatment options.*

The MAA shared the important moment when Health Minister Butler announced that this new treatment has been listed, at the annual Rare Disease Day parliamentary event.

Access to new targeted therapies can help increase the opportunities for Myasthenia patients to participate in work, to enjoy more family and community activities, to travel more freely, and to spend more time out of hospital.

The outcome from the Pharmaceutical Benefits Advisory Committee (PBAC) meeting in March 2025 noted that together patients, carers, and clinicians established the unmet needs of our patient community. PBAC "found the comments very informative for understanding the high and unmet clinical need for new effective treatments and the potential use of the new therapies in practice."

After more than 2 years of advocacy, the MAA is pleased that a new treatment is offered widely to patients to address our unmet needs. Using evidence from research and patient surveys, we told the patient story, especially for refractory patients who are not responding to current treatment(s) sufficiently and still experience MG symptoms every day.

The MAA also advocated for early and upfront treatment to minimise the poorer outcomes that result from last resort practices, and we highlighted the diversity of our patient experience and our different preferences.

Susan White, Chairperson of MAA said: "It is such an important day for myasthenia gravis patients as they will now have PBS access to a new treatment for this condition. It's been a long journey to see a new medicine reach the PBS and we thank the government for making an innovative medicine accessible for Australians."

The advocacy does not stop now. The MAA will continue to work with pharmaceutical companies and clinicians to ensure we monitor and capture adequate and useful data on the use of this therapy.

We will also work to ensure people living in regional/remote areas are not left behind and that other sub-groups of MG patients, including non-AChR+, ocular MG patients and children, can access the best possible treatment for their individual condition.

The MAA aims for MG patients in Australia to have equitable and timely access to the best available treatment that most benefits them.

The MAA thanks the sponsoring company for their work through the PBAC process to offer this therapy for gMG patients via the PBS and for working with us to better understand the new treatments.

Please talk to your healthcare professional to discuss your treatment options and plan, including any possible side effects or risks.

If you have any questions or feedback to share with the MAA, please contact us by emailing info@mgaq.org.au or info@myasthenia.org.au, or calling 1800 802 568.

*The MAA and state associations do NOT provide medical advice regarding medications or treatments for individuals. Decisions about whether new treatments will be suitable for you as a patient must be discussed with your doctor or health professional.

CONVERSATION CONNECTION COMPANIONSHIP

The local Coffee and Chat is a safe space to share MG experiences with others.

Oh MG & GATTON

SOUTHPORT

WALK FOR MYASTHENIA GRAVIS AWARENESS

COMING THIS JUNE!

As part of Myasthenia Gravis Awareness Month, we are excited to announce our very first Walk for Myasthenia Gravis Awareness (WFMGA).

The walk will take place in Brisbane at New Farm Park on 13 June from 9.30am for a 10.00am start. Bringing this community together to raise awareness and support for people living with Myasthenia Gravis.

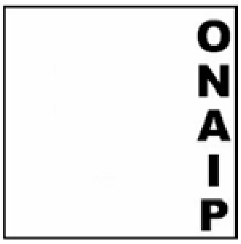
This is a fun day out for everybody. A range of distances is offered and it is wheelchair friendly. If preferred, settle in at the historical New Farm Park Rotunda and be the cheer squad. Fun for everyone!

Planning is already underway and we are looking forward to sharing more details with you over the coming weeks and months.

Keep an eye on our social media pages and the next newsletter for the registration form and further event updates. We hope you can join us for this special day of community, connection, and awareness.

Bamboozable

Answer Page 7



MYASTHENIA GRAVIS ASSN QLD INC HAS BEEN ADDED TO
BRISBANE MARATHON FESTIVAL 2026!

In the wise words of Peter R Hulme (aka dad) -
"keep moving your arms, and your legs will follow".

Hi everyone,

This June, my running is going to be serving a more personal purpose.

A few years back my dad was diagnosed with Myasthenia Gravis (MG).

June is Myasthenia Gravis Awareness Month which also coincides with the Brisbane Marathon. I will be running 42.195 kilometres to raise $1,000 in support of Myasthenia Gravis Assn Qld Inc. Their mission is to raise awareness and educate the public about MG and provide support to patients and their families.

Please help me by making a donation through my page.

It only takes a minute and any money you can give (no matter how large or small) will go a long way to helping me support this important organisation.

Thank you, I appreciate you. Danielle.

https://bmf26.grassrootz.com/myasthenia-gravis-assn-qld-inc

PUZZLES

Sudoku

3	2		6	9			8	
8				4		5		
6					2		9	3
	7	6	9			3		4
		4	7			8		
2		3	1		4	9	7	
	1		2	7		6	3	
		8		1				
	6				9		4	7

Answers

bamboozable 33
Answers:
1. Spread a Little Happiness, 2. Pay Raise, 3. Peace on Earth, 4. Never Too Old Too Learn, . Room for One More, . Upright Piano

Word Change 25
Answers
last
lost
loot
loon
moon

Word Change

last
moon

3	2	5	6	9	7	4	8	1
8	9	7	3	4	1	5	6	2
6	4	1	5	8	2	7	9	3
1	7	6	9	5	8	3	2	4
9	5	4	7	2	3	8	1	6
2	8	3	1	6	4	9	7	5
4	1	9	2	7	5	6	3	8
7	3	8	4	1	6	2	5	9
5	6	2	8	3	9	1	4	7

FREECALL 1800 802 568

Brisbane	Anita 0414 588 312	**Bundaberg**	Denise 0431 571 399
Gold Coast Southport	Nader 0415 834 401	**Mackay**	Kym 0410 616 165
Gold Coast Currumbin	Julie 0423 766 321	**Townsville**	Daphne 0400 778 637
Sunshine Coast	Michael 0447 887 652	**Cairns**	Donna 0414 397 462
Toowoomba	John 0412 576 888		

COFFEE & CHAT ROUND-UP

- **Moreton Bay – Mango Hill**
  Friday 20th March at 10.30am, The Coffee Club, Mango Hill Market Place, Cnr Halpine Ave & Anzac Ave, Mango Hill.
- **Gold Coast – Currumbin**
  Saturday 21st March at 10.30am, Currumbin RSL, 165 Duringan St, Currumbin
- **Ipswich**
  Saturday 21st March at 10.30am, Queens Park Café, 10A Merle Finimore Ave, Ipswich
- **Mackay**
  Saturday 21 March at 10.30am, The Coffee Club at Riverside, Canelands Central, Matsuura Drive.
- **Townsville**
  Saturday 21st March at 12 noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan
- **Cairns**
  Friday 27th March at 11.30am, Cairns RSL Club Bistro area, Esplanade Cairns *(Please note date change)*
- **Sunshine Coast – Wurtulla**
  Monday 6th April at 10.30am, Kawana Club, 476 Nicklin Way, Wurtulla
- **Bundaberg**
  Saturday 18th April at 10.30am, Across the Waves Sports Club, 1 Miller St Bundaberg

WELCOME TO OUR NEW MEMBERS

Meryl, Avenell Heights, QLD

BECOME INVOLVED - MAKE A DIFFERENCE

For membership payments and donations, the MGAQ account details are:

BSB: 124032 A/c: 10263772

Ref: YOUR NAME