



Myasthenia Gravis Association of Queensland Inc.

Messages

FEBRUARY
2026



Myasthenia Gravis Association of Qld Inc **IN NO WAY** endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

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 FEBRUARY 2026

Christmas and the holidays seem to have gone in a flash and we are back into the swing of things with a busy year ahead for the management committee. I hope that everyone is managing the severe temperatures that have been difficult for all of us to tolerate this summer.

One very exciting project has been the collaboration between the MGAQ and the Queensland University of Technology (QUT) on **The Heat Sensitivity Research Project**. Everyone should have received information about this very exciting project which looks specifically at the effect of heat and humidity on people living with MG. It is the first time that such research has been conducted in Australia and the data gained will lead to research papers and potential critical information in relation to accessing vital resources for all of us living with MG. Please find information on **page 3** in relation to how you can contribute to this very important research by completing a survey.

The MGAQ is very appreciative of your support with this project. Many thanks to those people who have already taken the time to complete the survey and thus provided valuable information about the effect of heat and humidity on your daily lives.

Thank you to the members who continue to pay their membership fees on time. As this money is used for things such as producing and sending out the newsletter, member resources, website

updates and functions for members it is important that we have funds available to continue these services.

The end of any year brings with it necessary paperwork to be done as a charitable not-for-profit organisation. Reports to Queensland Health and the Australian Charities and Not-for-Profit Commission (ACNC) ensure that we are meeting our operational, financial and legislative requirements. Members also had the opportunity in January to write a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) in relation to possible future treatments for Myasthenia Gravis. With new and repurposed treatments becoming available it is important that we ensure that our 'Patient Voice' is heard across all sectors of decision making. Sincere thanks to any of our members who made a personal submission to the PBAC.

Rare Disease Day is observed every year on **28 February** (or **29** in leap years—the rarest day of the year). Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community. MGAQ Management Committee member, Donna will represent the association at Rare Voices Australia (RVA) Rare Disease Federal Parliamentary event in Canberra on 2 March 2026.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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Queensland
Government



Your Association is your **VOICE** with Government.



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

Welcome to 2026 and what will definitely be an exciting and positive year for all. The MAA have a full agenda ready for a rapid start to the year. Please make sure that you or a friend/family member are registered with www.myastheniaalliance.org.au so that you can stay fully informed and ready to participate in the activities that interest you. We wish that all the content and activities could be made available via this newsletter but this is so often not possible with the workings of a modern world. If we can help please call **1800 802 568**.

Some of what is coming up -

- Webinar Two from the “Your MG Journey Supported by Shared Care” series will be hosted by a physiotherapist. This conversation is aimed at helping muscle maintenance, improving balance, increasing activity levels etc all within a myasthenia patient’s capacities. This webinar will also be recorded and shared for you to reference again later and to share with your physiotherapist. Please consider attending so that your questions can be answered.
- A clinical trial will be offered.
- Research information will be shared.
- Updates will be issued on the status of the new medicines currently going through the PBAC processes. The MAA are very actively following all progress and remain positive.
- The Art With Heart project has been launched with an initial call out for everyone’s support. More details will now flow.
- Working for Congenital Myasthenic Syndrome patients. If you belong to this group Susan would value speaking with you. Please call on 1800 802 568.
- Congratulating MGVic on hosting their first meet ups and on forming a committee. These are very significant steps for all Victorians. More news from this Association will be shared as requested.

Supporting MGAQ in conducting, in partnership with QUT, the study into Heat Effects on MG has been a privilege. This is an innovative project designed to bridge a significant knowledge gap in understanding life with myasthenia and what may be required to better accommodate temperature and humidity challenges. As has been previously discussed, such studies become more impactful with the increasing number of responses. The MAA is confident that our Australian community will astound the researchers with our connection to this survey request. From there high quality results can flow and international recognition can follow. Thank you to everyone for partnering in this project.

Lastly, I share with you that you will be represented in Canberra again this year as **Rare Diseases Day is celebrated at an RVA (Rare Voices Australia) event to be hosted in Parliament house on Monday March 2nd**. Government representatives will hear our voices. It is a privilege and an honour to attend this invitation only event. **Please let your Federal Member of Parliament know that Myasthenia Gravis will be represented should they wish to attend.** Happy to grab a photo opportunity!

Please stay hopeful that 2026 can be a good year in so many ways.

Best regards to all.

Susan White, MAA Chairperson

Your Association is your **VOICE** with Government.

Thank you for recognising this very important research project on “HEAT SENSITIVITY”

If you haven't already participated in this survey, please open the attached file for all the information and click on the link to complete.

https://qsurvey.qut.edu.au/jfe/form/SV_6rOcwDvQWzhQOG2

A very timely survey with the crazy Australian weather at this time of the year.

The MGAQ is really appreciative of your support with this project.

Participate in Research:

Raise awareness about how heat affects YOU!

You can help raise awareness about how heat and hot weather affect people living with myasthenia gravis.

If you have been diagnosed with myasthenia gravis and are 18 years or older, we invite you to complete an online survey (20–30 minutes) about your experiences in the heat. Scan the QR code below to find out how you can participate.



https://qsurvey.qut.edu.au/jfe/form/SV_6rOcwDvQWzhQOG2

Your participation will help to shed light on the experience of heat sensitivity in people with myasthenia gravis and provide evidence to support advocacy and awareness campaigns.



Become **INVOLVED** - make a **DIFFERENCE** for yourself and others.



RARE DISEASE DAY

SATURDAY 28 FEB. 2026

Rare Disease Day is the globally co-ordinated movement for Rare Disease Day working towards equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.

Rare Disease Day Illuminations supported by MGAQ.

City of Logan

Jacaranda Tower; Telfer St Tower;
Wineglass Water Tower

28 February in Pink/Blue/Green

Caboolture Administration Building

28 February in Purple

Gold Coast

Isle of Capri Bridge;
Surfers Paradise iconic sign;
Garden lighting on the
Surfers Paradise foreshore

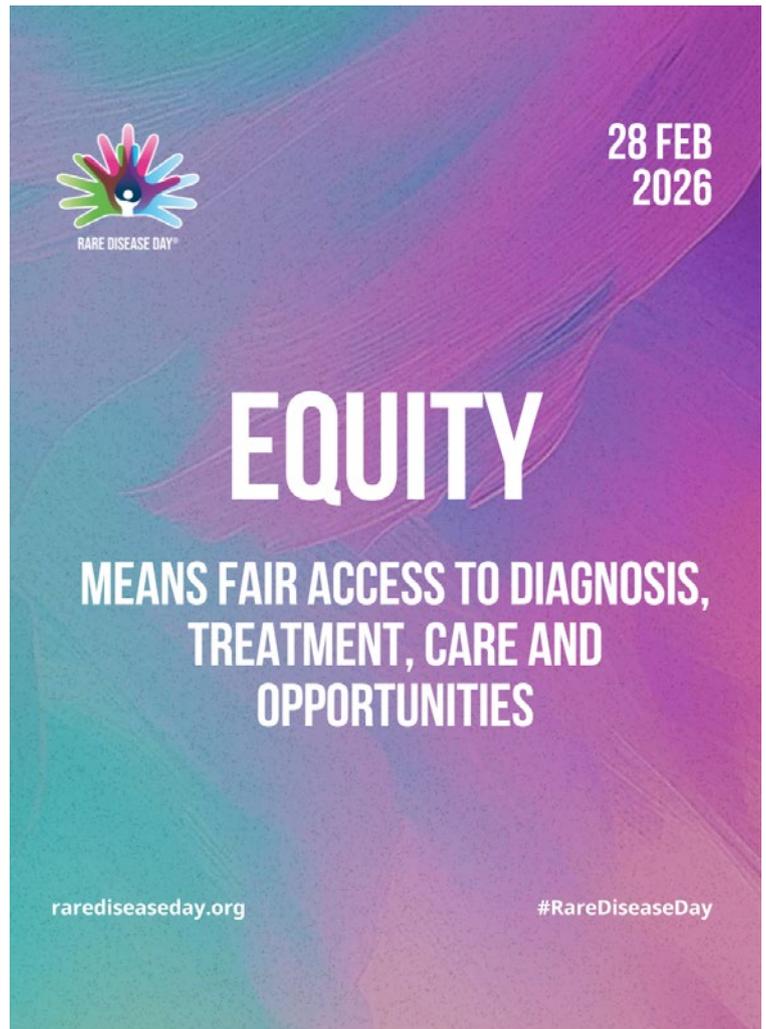
8 Feb-1st Mar in Pink

Longreach Water Tower

28 February in Green

Townsville

Townsville Sign; Victoria Bridge;
Wharton Reef Lighthouse;
Central Park Boardwalk;
Little Fletcher Bridge; George Roberts
Bridge – 28 Feb in Green



~ Date Claimer ~

SATURDAY 13TH JUNE

WALK FOR MYASTHENIA GRAVIS AWARENESS (WFMGA)

More details in March newsletter.



VALUE-MG Study Update

The VALUE-MG Study has reached its recruitment target. We sincerely thank all people with Myasthenia Gravis who participated in the study.

We recruited 216 Myasthenia Gravis patients

From 5 hospital sites



Brain and Mind Centre



VALUE- MG study will show how MG affects people's health, daily activities, and work over time, and link this information with real-world treatment and healthcare use.

If you would like to take part
in future MG studies, please
contact us at
value.ig@monash.edu



Art With Heart WE NEED YOUR HELP!



Supporting MG Awareness with "Art with Heart" 2026!

The Myasthenia Alliance Australia (MAA) is proud to continue its important work during International June MG Awareness Month 2026.

Challenge Your Friends and Family to Care

If you're wondering how you can contribute to and support the MG community, your involvement is essential. The first step in our awareness campaign is for our strong and committed Myasthenia community to reach out to family, friends, neighbours, colleagues, health professionals, government representatives, and everyone else to ask for contributions to the auction.

This event aims to strengthen our MG community by encouraging group interaction in a fun and positive atmosphere. It is also a vital opportunity to raise awareness of Myasthenia Gravis throughout the broader community.

Building Community Awareness

Help build awareness by reaching out to social groups and NGOs (Non-Government Organisations). Consider becoming a sponsor. If we hope for understanding and acknowledgment from others, including medical providers, it is important that they become familiar with our condition.

How You Can Help Make the Event Successful

- All contributions - big or small, service-based or tangible - are greatly appreciated.
- Please donate items or ask others if they would like to contribute.
- Share the news as widely as possible through focused conversation, emails, and social media platforms such as Facebook and Instagram.
- **Please email details of your donation to operations@mgaq.org.au**

MAKE A DIFFERENCE FOR PEOPLE WITH MYASTHENIA GRAVIS



operations@mgaq.com.au



1800 802 568



www.myastheniaalliance.org.au



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3	5	9	2	8	4	1	6	7	3

1. Somewhere Over the Rainbow
2. X Marks the Spot
3. Put two and two Together
4. Just Right
5. I Before E Except After C
6. High Seas

Become **INVOLVED** - make a **DIFFERENCE** for yourself and others.

CONVERSATION CONNECTION COMPANIONSHIP

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

CURRUMBIN



SOUTHPORT



Emily writes...

MG Vic hosted our first morning tea and it was such a lovely day! After such a long time being the only person in my circle with myasthenia gravis, it was so exciting to be in a room filled with people that know exactly what you're going through. Being able to compare symptoms and whatnot was a highlight for me as were the cakes and scones provided by the cafe and a generous donation that made it all happen. I'm so excited for the future of MG Vic and where it will go from here.

MG Vic Facebook group <https://www.facebook.com/groups/1166104618247778>

Contact: Catherine on 0418 563 557



SUPPORT your Association by **VOLUNTEERING.**

FREECALL 1800 802 568

Brisbane Anita 0414 588 312	BundabergDenise 0431 571 399
Gold Coast SouthportNader 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
ToowoombaJohn 0412 576 888	

IN-PERSON COFFEE & CHAT



Sunshine Coast – Wurtulla

Monday 2 March at 10.30am, Kawana Club, 476 Nicklin Way, Wurtulla

Gold Coast – Southport:

Saturday 14 March at 10.00am, Southport Sharks Club,
Corner Olsen & Musgrave Avenue Southport

Gold Coast - Currumbin:

Saturday 21 March at 10.30am, Currumbin RSL, 165 Duringan Street, Currumbin

Ipswich:

Saturday 21 March at 10.30am – Queens Park Café, 10A Merle Finimore Avenue, Ipswich

Townsville:

Saturday 21 March at 12noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan

Cairns:

Saturday 28 March at 1.30pm, Cairns RSL Club (Bistro area)
119 Esplanade, Cairns

WELCOME TO OUR NEW MEMBERS

Peter,
Nollamara WA

Jeffery,
Townsville QLD

Lisa,
Karalee QLD

Anna,
Sadliers Crossing QLD

Sandra,
Ningi QLD

Kerry,
Hoya QLD

Katren,
Kearneys Springs QLD

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032

A/c: 10263772