



Myasthenia Gravis Association of Queensland Inc.

# MessaGes

MAY  
2025



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 MAY 2025

June is a special month in the Myasthenia Gravis 'world' and it continues to be especially significant for Queensland. This year we have two major foci – **"Light Up"** and **"OH MG"**.

The **"Lights Up for Myasthenia"** continues to gain momentum. Please take the time to see page 5 of this newsletter for the various towns, buildings and landmarks that will be lit up on various dates. If you can manage it I am sure a drive to look at these in your local area will prove well worthwhile. If you are able to take a photograph of these structures the committee would appreciate an emailed copy of same. Remember to try to wear a teal-coloured ribbon next month so that people might ask you the meaning behind it.

The **"OH MG"** art exhibition is a candid demonstration of living with Myasthenia Gravis. Chloe Wigg, who also has MG, has produced a fabulous exhibition that shares the stories of those living with MG. All financial members should have received a personal invitation to this event to be held at the **Logan Art Gallery on 14 June**. The exhibition is open to all people with MG, their families and supporters as well as the medical

community. Please see further details on page 4 of this newsletter. This art exhibition will be in place of the usual guest speaker presentation.

Also, in this newsletter on page 10 you will see the membership renewal form. I cannot stress too strongly the importance of being a financial member of the MGAQ. Your association really relies on membership fees to fund the many and varied booklets, pamphlets, flyers etc that are readily available to all. Also, being a financial member gives you access to the Members Only section of the website. You will find a wide collection of valuable resources such as podcasts, videos and research papers.

Some wonderful news from the recent Pharmaceutical Benefits Advisory Committee (PBAC) in that the four new medications presented have been recommended for further consideration. While this is only the first step it is certainly encouraging in relation to possibly having additional drugs to help manage MG symptoms.

Please enjoy the cooler weather over the next few months.

**Thanks Carol**

### Myasthenia Gravis Association of Queensland Inc

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Supported by



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Government

**Ausenco**

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



# MYASTHENIA ALLIANCE AUSTRALIA

## MAA UPDATE

Such wonderful news that the PBAC has recommended all four new treatments for PBAC support. Thank you to everyone who contributed via a direct submission. Please see the letter on page 3 of this newsletter which was distributed by the MAA to explain the implications of these recommendations. We remain hopeful but there is still much involved to complete the process.

Given the above good news it may be time to listen to the webinar recording which gives a summary of current treatments and also the potential new treatments. It is available on [myastheniaalliance.org.au](https://myastheniaalliance.org.au/news-trail) news trail. The MAA thank all the speakers for consenting to this content being shared. There is much to take in so a repeat listen may be useful. For those without technology, please ask family or friends to assist with access <https://myastheniaalliance.org.au/understanding-expanding-treatment-options-january-2025/>

More interesting information came through in the form of a summary from several presentations given last November at the International Congress of Neuromuscular Disease hosted in Perth. This has been prepared by UCB and the MAA express sincere appreciation.

- Dr Blum discussed fatigue in myasthenia
- Dr Barnett-Tapia gave insight on how doctors assess symptoms accurately
- A/P Leite talked about pregnancy and MG
- Prof. Punga shared views on lifestyle interventions aimed at reducing fatigue in MG.

All very interesting. <https://myastheniaalliance.org.au/18th-icnmd-patient-summary/>

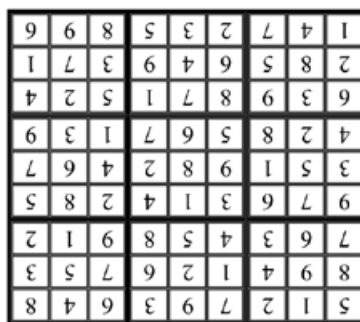
**The new website will be live in the coming week. We hope that you will find it interesting.**

Both the existing website and the new website have an easy facility to make a donation directly to the MAA. As the MAA is primarily dependent on donations and the work that we are doing does incur costs, donations are appreciated and essential if we are to continue at such a fast pace. Donations are tax deductible and a receipt is issued promptly. Myasthenia is a current focus for Government, Industry and researchers - we must foster this opportunity. Please show us your support.

Warm regards

**Susan White (MAA Chairperson)**

If you are not already registered with the Alliance please go to [www.myastheniaalliance.org.au](https://www.myastheniaalliance.org.au)



Word Change: rough, cough, couch, pouch, poach

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



## MYASTHENIA ALLIANCE AUSTRALIA

### Success: Four new treatment options recommended for MG patients in Australia!

The Pharmaceutical Benefits Advisory Committee (PBAC) has published the outcomes from their March 2025 meeting. **PBAC has recommended that all 4 new treatments for MG patients be listed on the Pharmaceutical Benefits Scheme (PBS).**

This is wonderful news for our patient community in Australia and it shows that our submissions and engagement with the assessment process were impactful and credible. Thank you again to all of you who made a personal submission and described your lived experience.

The outcome also demonstrates that together, and with our clinicians, we established the unmet needs of our patient community. This is not commonly stated in PBAC outcomes, so it is important that this has been recognised. Here is their wording -

The outcome also demonstrates that together, and with our clinicians, we established the unmet needs of our patient community. This is not commonly stated in PBAC outcomes, so it is important that this has been recognised. Here is their wording -

*"The PBAC appreciated the input provided by patients, carers and clinicians and 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. The comments outlined the significant impact that gMG can have on quality of life, including the impact on patient's families. The comments also described the limitations of currently available treatment options including adverse events and lengthy administration times."*

Please note the PBAC recommendation for these treatments is for generalised MG (gMG) and AChR antibody-positive adult patients. **The MAA will continue to raise awareness and advocate for those of us who do not fit into this group of MG patients.**

Once a recommendation by the Committee has been achieved, next steps can be undertaken by the supporting Government departments. This means that it will still be a few months before these treatments can be available on the PBS. Guidelines will also be established. **The MAA is working closely with key stakeholders to fully understand the next steps and to ensure we receive answers to the questions that matter to patients.**

Some patients will be fortunate enough to receive the treatments early through the Pharmaceutical Company Early Access Programmes. This is an establishment process and is limited. The MAA and State Associations would be glad to receive feedback from people on these programmes.

We will keep you informed so make sure you receive our updates by **subscribing at**

<https://myastheniaalliance.org.au/subscribe/>

More information on the PBAC outcomes is available here: <https://tinyurl.com/ycxt5z7z> and the detailed summaries will be published in the coming months.



### Four New MG Treatments Receive PBAC Recommendation

## MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND



Invites you to

# OH MG *Art Exhibition*

Join us for an exclusive MG and friends celebration day experiencing Oh MG by Chloe Wigg. An art exhibition sharing the stories of those with MG.

**SAT 14 JUNE**

**AT 10:30AM - 1:30 PM**

Light refreshments provided

Logan Art Gallery  
Cnr Wembley Rd & Jacaranda Avenue,  
Logan Central QLD 4114  
Inquires: 1800 802 568

**RSVP Now!** Click the link to secure  
your FREE ticket:  
<https://bit.ly/3RWAA71>

You are invited to experience Oh MG, an art exhibition created by Chloe Wigg, celebrating the strength, creativity, and resilience of the Myasthenia Gravis (MG) community. This exhibition is dedicated to those with MG, their families, friends, as well as health professionals and others who are passionate about supporting those with MG.

A special closed event for the MG community, hosted by MGAQ, to come together, celebrate, and share in the power of art as a form of advocacy. We invite you to be part of this inspiring and meaningful experience.

### Exhibition Dates:

22nd May – 14th June

Shared opening night 30th May



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





# Light Up For Myasthenia

## BRISBANE 8 JUNE

Story Bridge  
Victoria Bridge  
Reddacliff Place Sculptures  
Tropical Dome  
Wickham Terrace Car Park Architectural wall  
Breakfast Creek Bridge

## BUNDABERG 9 - 15 JUNE

School of Arts Building

## CITY OF GOLD COAST 26 - 30 JUNE

Isle of Capri Bridge  
The Surfers Paradise sign  
The Broadbeach sign

## CITY OF LOGAN 4 JUNE

Jacaranda Tower  
Wine Glass Water Tower  
Telfer St Tower

## IPSWICH 7 - 14 JUNE (Excl. 11 JUNE)

Ipswich Civic Centre  
1 Nicholas St Façade (1NS)

## TOOWOOMBA 20 - 27 JUNE

Victoria St Bridge  
Annex

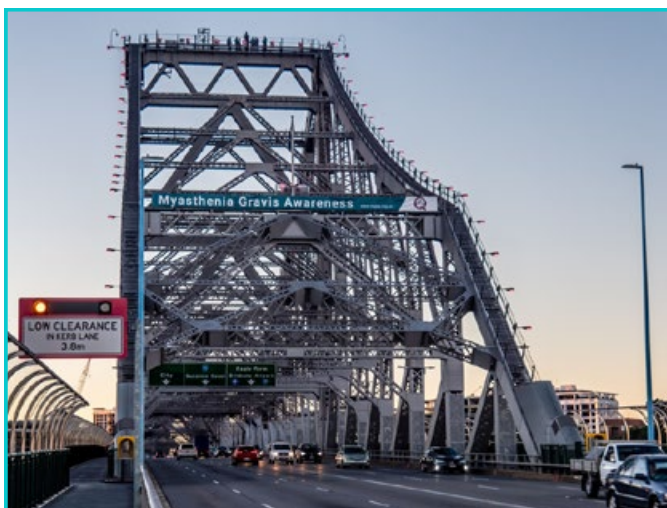
## TOWNSVILLE 9 - 16 JUNE

Townsville Sign  
Victoria Bridge  
Wharton Reef Lighthouse  
George Roberts Bridge  
Old Magistrates Court House  
Central Park Boardwalk  
Little Fletcher Bridge

## QLD COUNTRY BANK STADIUM 1 JUNE

QLD Country Bank Stadium

\*Please note that the venues reserve the right to change the advertised dates. Other venues still to be confirmed.



## Story Bridge, Brisbane

The Myasthenia Gravis Association of QLD banner will be displayed on the Story Bridge in Brisbane (inbound) from 2 June - 15 June 2025.

**SUPPORT** your Association by **VOLUNTEERING.**

## CONVERSATION CONNECTION COMPANIONSHIP

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

### SUNSHINE COAST - MAY



### GOLD COAST - MAY



## BECOME INVOLVED - MAKE A DIFFERENCE

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

**BSB: 124032**

**A/c: 10263772**

## WELCOME TO OUR NEW MEMBERS

Alicia,  
Campbelltown  
SA

Catherine,  
Caloundra West  
QLD

Leah,  
Morayfield  
QLD

Lawrence,  
Lowood  
QLD

Alan,  
Bilinga  
QLD

MESS +MESS +MESS	paint276 paint514 paint693	ha rm on y
IpoiseV	WHIRL	teNrr net sight

grate
blame

**Bamboozable Answers:**  
1. Total Mess; 2. Paint by Numbers; 3. Four Part Harmony; 4. Poison Ivy; 5. Tilt a Whirl; 6. Internet Site.  
**Word Change:** grate, grade, glade, blade, blame

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

MYASTHENIA GRAVIS  
ASSOCIATION OF QUEENSLAND

# Volunteers Needed

We need your help to continue providing  
the service our community relies on!

**Multiple roles are available and they can be adapted to suit  
your skills and interests!**

**URGENT ASSISTANCE NEEDED**

ADMINISTRATION | PODCAST DEVELOPMENT

What skills can you contribute to share the load and help us make  
an impact? Get in touch for more details.



1800 802 568 | [info@mgaq.org.au](mailto:info@mgaq.org.au) | [www.mgaq.org.au](http://www.mgaq.org.au)





**Conquer MG  
Anywhere!**

# Coffee & CHAT Support!



Join us for a virtual coffee & chat support meetup via Zoom to connect, share, and support each other on our myasthenia journey.

[www.mgaq.org.au](http://www.mgaq.org.au)  
1800 802 568



## Starting the Journey: A Chat for the Newly Diagnosed

**Sunday, 25<sup>th</sup> May at 3pm**

Recently diagnosed with myasthenia gravis? You're not alone.  
Join us for our next Zoom chat!

**LIMITED SPACES** - Register via email: [info@mgaq.org.au](mailto:info@mgaq.org.au)  
All MGAQ Financial Members are invited to register.

**LOUD**

<b>DANCE</b> <b>DANCE</b> <b>DANCE</b> ---> <b>DANCE</b>	<b>CRYING</b> <b>CRYING</b> <b>CRYING</b> <b>CRYING</b>	groPOOLund	ABCD EFGH a week IJKLM a week NOPQ a week RS_U a week -WXY Z	<b>FREQUENCY</b>	<b>T T T</b> <b>I I I</b> <b>S S S</b>
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**Bamboozable 8 Answers:** 1. Last Dance; 2. For Crying Out Loud; 3. Inground Pool; 4. No TV for a Week; 5. High Frequency; 6. Sit Ups

**SUPPORT** your Association by **VOLUNTEERING.**



## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us on **Saturday, 24 May** from 10am to 12 noon at **Blackbird Warehouse, 205 Newell Street Bungalow** for informal coffee and chat.

For more information, please contact **Donna** on 0414 397 462.

### News from Townsville

We are meeting again on **Saturday, 5 July**, at 12noon, **Kirwan Sports Club, 159 Bamford Lane, Kirwan**.

Looking forward to your company and thanks to everyone who came to our April lunch.

For more information, please contact **Daphne** on 0400 778 637 or email [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **Mary** on 07 4959 5251

### News from Bundaberg

For more information, please contact **Denise** on 0431 571 399.

### News from the Sunshine Coast

The Sunshine Coast group will meet again on **Monday, 2 June, Kawana Club, 476 Nicklin Way Wurtulla at 10.30am**. Visitors are most welcome to join this very friendly group.

For more information please contact **Michael** on 0447 887 652.

### News from the Gold Coast

Hi everyone MG Gold Coast had their get-together sharing experiences with other members in May. Our next meeting will be at **10am on Saturday, 12 July at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport**.

Hope to see you there.

For more information please contact **Nader** on 0415 834 401.



## COFFEE & CHATS

**MANGO HILL** - Saturday, 28 June at 10.30am, Coffee Club,  
Mango Hill Market Place,  
Cnr Anzac Avenue & Halpine Dr Mango Hill

**IPSWICH** - Thursday, 17 July 10.30am, Queens Park Cafe,  
10A Merle Finnimore Ave, Ipswich

ALL WELCOME!

RSVP Anita on 0414 588 312

## WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
<b>JUNE AWARENESS FUNCTION</b> <b>MG and Friends celebration day for</b> <b>OH MG ART EXHIBITION</b>	<b>Saturday,</b> <b>14 June 2025</b> <b>10.30am-1.30pm</b>	<b>Logan Art Gallery,</b> <b>Wembley Road &amp;</b> <b>Jacaranda Avenue</b>

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

# MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2025/2026 are due.

Category A ..... Myasthenia \$20.00

Category E ..... Associate \$20.00

Category D ..... Carer \$10.00

(Cat D Carer membership must be attached to a Cat A membership)

If you are unsure whether or not you are currently financial,  
**please phone our  
1800 802 568 freecall number  
or email  
treasurer@mgaq.org.au to enquire.**

## New payment option for members of "Perpetual membership"

**Cat A (Myasthenia Member) & Cat E (Associate Member) \$250 and Cat D (Carer Member) \$125.**  
This one-off payment would mean that you never have to worry about renewing your membership again.  
Please note that a Cat D membership must be attached to a Cat A Myasthenia Membership, it is not a stand-alone membership.

## YOU HAVE THE FOLLOWING PAYMENT OPTIONS

**MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE**

This method will take a credit card payment.

[www.mgaq.org.au/membership-application-form](http://www.mgaq.org.au/membership-application-form) and select **Membership Renewal**

Our bank details are:

**BANK: Bank of Queensland      BSB: 124 032      ACCOUNT NUMBER: 10263772**

**ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.**

**REFERENCE: Your Name and Initials**

If you use the direct deposit method, it would help if you could email us at [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au) to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.

## Pay by Phone using your credit card on 1800 802 568

If sending a money order, cash or, cheque, please complete the form below.

**The Myasthenia Gravis Association of Queensland Inc.**

**PO Box 16 MT GRAVATT Qld 4122 or email [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)**

Herewith please find my money order, cash or cheque for the sum of \$\_\_\_\_\_ being annual subscription \$\_\_\_\_\_ and/or Donation \$\_\_\_\_\_ MGAQ/MAA (Please circle)

NAME \_\_\_\_\_ **Category A Myasthenia \$20**

**(or) Category E – Supporter \$20      Perpetual Membership Category A or E \$250**

ADDRESS \_\_\_\_\_

And for \_\_\_\_\_ **Category D – Carer \$10**

**Perpetual membership \$125 (Cat D Carer membership must be attached to a Cat A Membership.)**

ADDRESS \_\_\_\_\_

Mobile \_\_\_\_\_ Email \_\_\_\_\_