Myasthenia Gravis Association of Queensland Inc.

MessaGes

JULY
2025

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 JULY 2025

The end of the financial year is upon us and that means a wide range of very important activities and commitments need to be met. Reports to Queensland Health are required so their generous funding is continued. All the reports and paperwork need to be done for the **Annual General Meeting to be held on Sunday, 14 September at Aspley Hornets Football Club, Carseldine.** We hope that as many members as possible attend this important meeting and take the opportunity to chat with others over lunch.

The level of support and advocacy for our members can only continue if we have the personnel on our management committee and/or others who put their hand up to help with the multitude of 'jobs' to be done. Some of these require a level of skill but many just require people who are reliably prepared to contribute their time and take on particular projects which may occur during the year. We ask that members please consider nominating as a committee member on the management committee. The nomination form is on page 10 of this newsletter. **Nominations close on 1 August.**

International Myasthenia Gravis Awareness Month was celebrated in June with two projects being undertaken. The **Oh MG Art Exhibition** and the **Light Up for Myasthenia** activities were both highly successful and well supported by the MG community and the public in general. Many thanks to everyone who got behind these projects. At the Oh MG Celebration Day at the Logan Art Gallery on 14 June approximately 60 people attended a wonderful, enriching experience for people living with MG. Many, many thanks to the artist, Chloe Wigg whose hard work and dedication over several years came to fruition with this emotive art display. Also, special thanks to Donna Formosa from our management committee who, once again, spent many hours organising the Lights Up activity throughout Queensland and beyond. Both activities certainly spread the word about living with MG.

The management committee has noticed a decrease in the number of members renewing their membership each year. The category A membership is only $20 and the Perpetual Membership, which covers you permanently, is $250. This membership money covers the three Association insurances, management committee meetings, printing and distributing newsletters, the 1800 number, information packs, stationery etc so that the committee can function each year. Information about how to pay is on page 10 of this newsletter.

Thanks Carol

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Supported by
Queensland Government
Ausenco

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

THANK YOU!

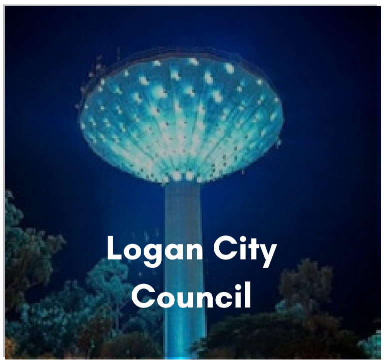
QUEENSLAND LIGHTS UP FOR MYASTHENIA

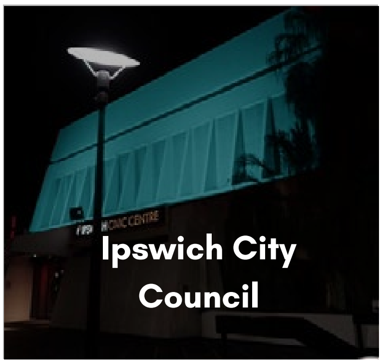

Rockhampton Regional Council


Toowoomba Regional Council

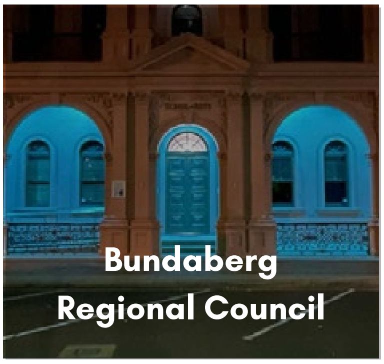

Brisbane City Council


Longreach Regional Council


Logan City Council



Ipswich City Council

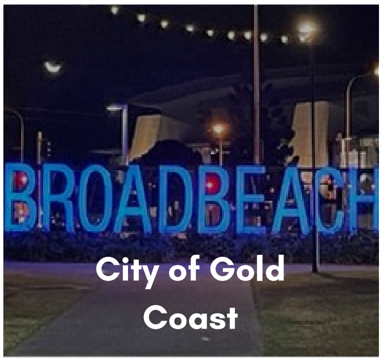

Bundaberg Regional Council

Mackay Regional Council

QLD Country Bank Stadium


Hinchinbrook Shire Council

Townsville City Council



City of Gold Coast

MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

June was a very exciting month for Australians and also for many countries around the world as we all celebrated Myasthenia Awareness Month!

The MAA has always reached out to other organisations around the globe but found it hard to develop continuous relationships. With the MGFA arranging a Patient Advocacy Organisation Summit in advance of the Conference this has changed! We are very grateful that MAA Secretary, Natalie Windle, was funded to attend this meeting and the Conference that followed. Natalie clearly took great advantage of every opportunity given to her, meeting and collaborating with many people who share our passion and challenges to advocate for patients in their home countries. In just the few weeks since this Conference, we are sharing and engaging with many organisations in many countries. These include Japan, China, Italy, UK, USA, Belgium, France, Poland and more. We have seen examples of how each group have made great efforts to raise awareness with China organising a large Conference! These Global Patient meetings are exciting to attend despite the challenges of time zones. Australia is no longer alone!

With the MAA's agenda now bulging with diverse contacts, with research opportunities, with Government engagement and with community information we are asking everyone to please register at www.myastheniaalliance.org.au to keep up with the diverse and interesting newsfeed that we bring to you. There is too much content to share it all in the MGAQ newsletter.

To assist, the most recent titles are listed here. If you do not have access to the digital world perhaps ask a friend or family member to print out stories of interest or call 1800 802 568 and we will try to assist you.

- **MGBase** have published a "Launch" Research paper. Early statistics are shared here. Research projects utilising MGBase are already growing in number.
- **Value Mg, Value Ig.** Monash University, with the support of our patient group, "explored what matters to patients in choosing treatment options". Read what we shared via this paper.
- Fellow warrior and orthoptist, **Suzann Beaupark**, shared her research through a paper included as a poster at the MGFA Conference and the Orthoptist Conference held in Brisbane recently. The MAA congratulate her on this important work. The paper is shared with us.
- **Oh MG by Chloe Wigg.** The MGAQ supported Chloe's Art Exhibition at the Logan Art Gallery with a special event for Myasthenia patients, Health Care Professionals and families. You can hear her passionate speech describing her journey and her motivation to undertake this project.
- **MAA Update Poster** gives a summary of our work and of our objectives for 2025.

Art With Heart 2026! Awareness activities for 2026 will focus around engaging our community through arts and crafts. We are looking for one or more project officers to manage this programme. The work will need to be underway in November with a culmination of activities in June 2026. There will be lots of support available for the project officer but people will need to bring energy and commitment to make this our biggest success yet. Please call 1800 802 568 to find out how you might help!

PBAC recommendations update. Please read Natalie's words around progress to date.

Stayed tuned for more exciting news as 2025 unfolds.

Warm regards
Susan White (MAA Chairperson)

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

MYASTHENIA ALLIANCE AUSTRALIA

Conversations continue for access to new treatments

We appreciate that it has been a couple of months since the Pharmaceutical Benefits Advisory Committee (PBAC) recommended that 4 new treatments for AChR+ generalised MG patients be listed on the Pharmaceutical Benefits Scheme (PBS)… In this time, the MAA has continued conversations with clinicians, government, and industry stakeholders to make sure we understand the progress of these recommendations, and we continue to advocate for improved access to treatments.

The Public Summary Documents (PSDs) for the PBC March 2025 meeting were published online on 4th July 2025. HOWEVER, PSDs for the 4 treatments for gMG patients are still pending publication.

This means that more discussion is required and we appreciate the work being done by the department and pharmaceutical companies. While Australia has a rigorous process for approving medications and treatments on the PBS, the key point for us here is that a commitment remains from all stakeholders and things are still moving.

The MAA remains committed to ensuring that MG patients in Australia have equitable and timely access to the best available treatment that most benefits them. We remind stakeholders that timing is important to us and we do not wish to delay access unnecessarily.

We also reiterate the impact of our submissions to PBAC earlier this year, which established the high unmet clinical needs of our patient community. The MAA maintains that this demonstrates a clear need for access to treatment options to improve the quality of life for all MG patients.

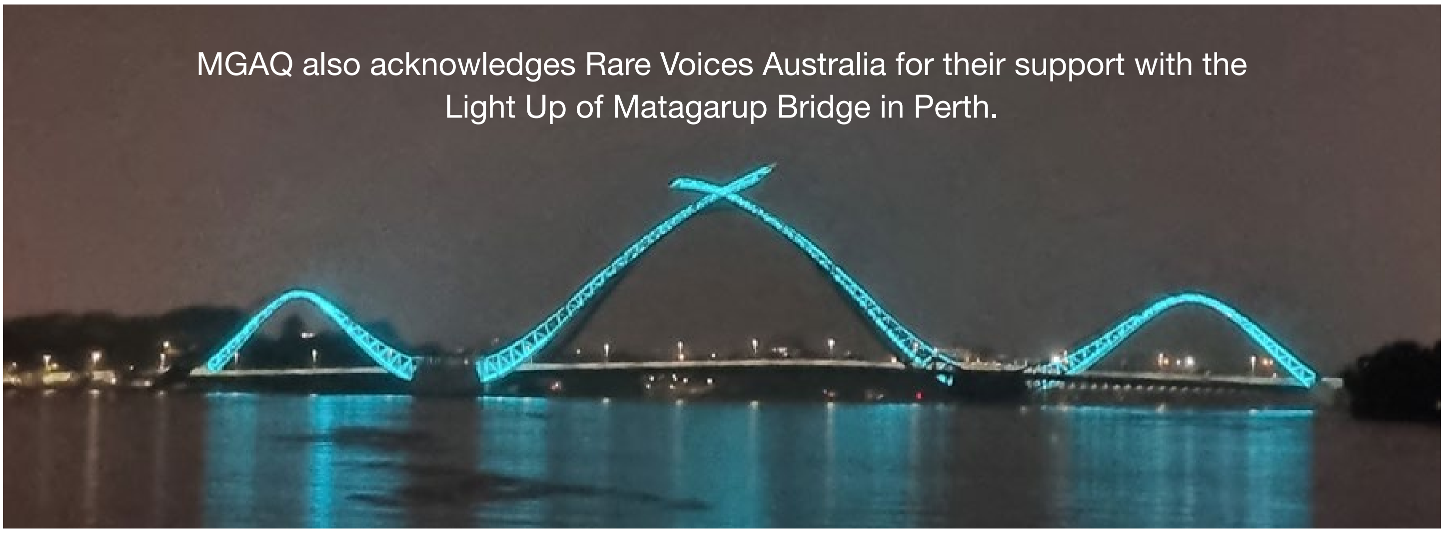
We understand that some patients are accessing these new treatments via Early Access Programs (EAPs). The MAA and State Associations would still be glad to receive feedback from people who are receiving these treatments via EAPs so please reach out by emailing info@mgaq.org.au or info@myasthenia.org.au, or calling 1800 802 568.

We will keep you updated on the progress of these new treatments being available on the PBS, including when the PSDs are published. Please check that you're subscribed to updates via the MAA website.

Natalie Windle MAA Secretary.

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

MGAQ also acknowledges Rare Voices Australia for their support with the Light Up of Matagarup Bridge in Perth.



SUPPORT your Association by **VOLUNTEERING**.

Oh MG “Giving people with Myasthenia Gravis a Voice”

Myasthenia Gravis Awareness month went to a new level this year with the Oh MG Art Exhibition held at the Logan Art Gallery in Brisbane. The artist, Chloe Wigg, who also has MG, worked for several years to stage this wonderful exhibition which highlights MG as a snowflake condition. The use of Mestinon bottles also sends a very clear message about the reliance of this medication by people with MG.

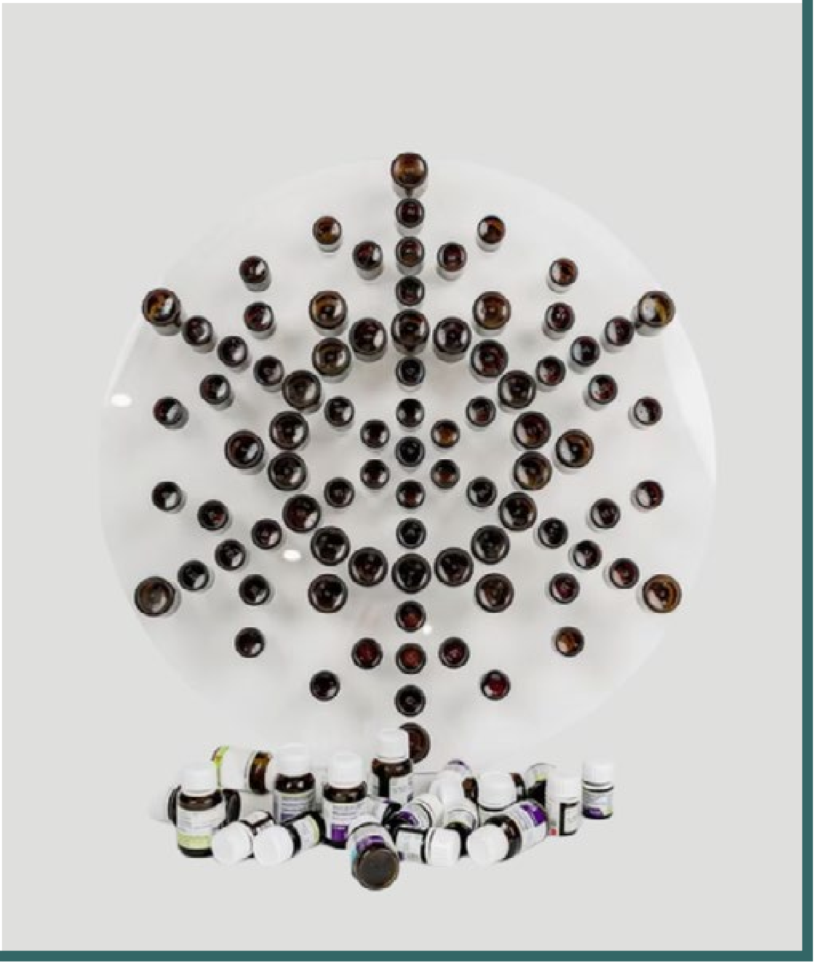
Listen to the artist, Chloe Wigg tell her story
https://vimeo.com/1098089255/347088b7ad?ts=0&share=copy

Oh MG

“Giving people with Myasthenia Gravis a voice”

CITY OF LOGAN
Queensland Government
MYASTHENIA GRAVIS ASSN. OF QLD INC.

Chloe Wigg
ARTIST / DISABILITY ADVOCATE

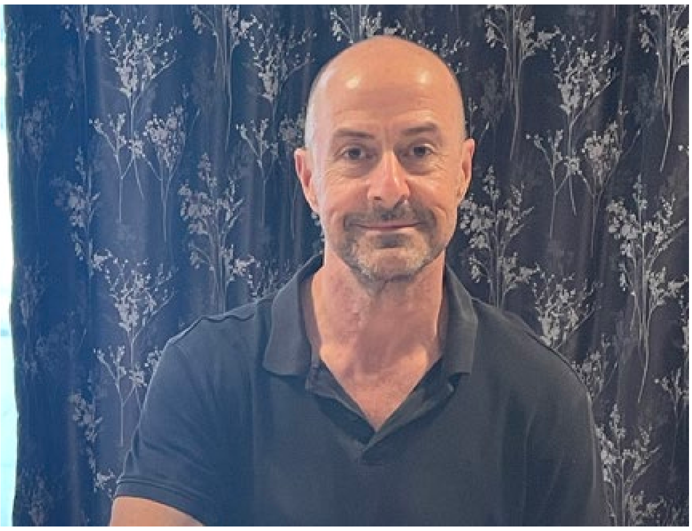


BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032   A/c: 10263772

KNOW YOUR COMMITTEE



I am Craig Streatfeild and my Myasthenia Gravis (MG) journey started ten years ago when I woke with an unusually bad headache and double vision. I was fortunate to receive a rapid diagnosis—my optometrist suspected MG on my second day of symptoms, which was confirmed by a neuro-ophthalmologist the following day and officially diagnosed by a Brisbane neurologist just days later.

I have been involved with the MGAQ since 2021, initially as a management committee member and now serving as secretary. I also assist with IT and website matters. I originally became involved to share my patient story and help others navigate their own MG journey. My research background has enabled me to self-educate on all aspects of MG, including current medications and the relationship between lifestyle, environmental factors, and autoimmune diseases.

I am also a board member of Myasthenia Alliance Australia (MAA) and have developed a particular interest in advocating for policies that improve quality of life for people with MG and related autoimmune diseases.

In this capacity, I serve as the MAA representative for the Neurological Alliance Australia, working to advance awareness and treatment options across the broader neurological community.

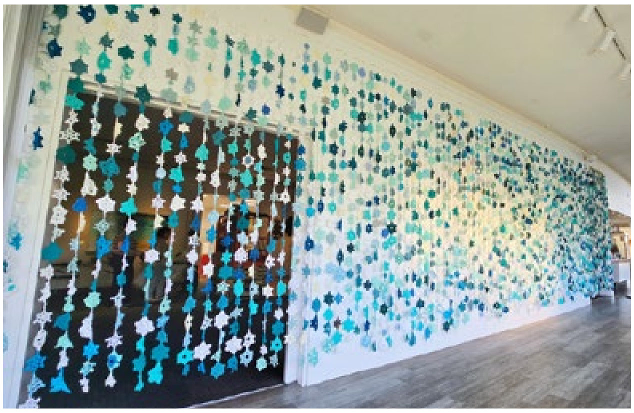
OH MG

By Chloe Wigg

“Giving People with
Myasthenia Gravis a Voice.”

FLOOR TALK 23 JULY | 6-7PM

Warwick Art Gallery
49 Albion Street, Warwick QLD.
10 JULY - 16 AUGUST



In 2021, after Chloe’s diagnosis with Myasthenia Gravis (MG), the MG community faced two prolonged shortages of a critical, life-saving medication. This exhibition sheds light on the fragility of access to essential treatments — especially those sourced globally.

Featuring powerful works of **portraiture**, **sculpture**, and **woven tapestry**, this collection is a tribute to resilience, solidarity, and creativity. With empty medication bottles donated by individuals living with MG across Australia, and delicate crochet snowflakes contributed by both the MG community and the broader public as a symbol of solidarity — this collection is a powerful expression of support and unity.

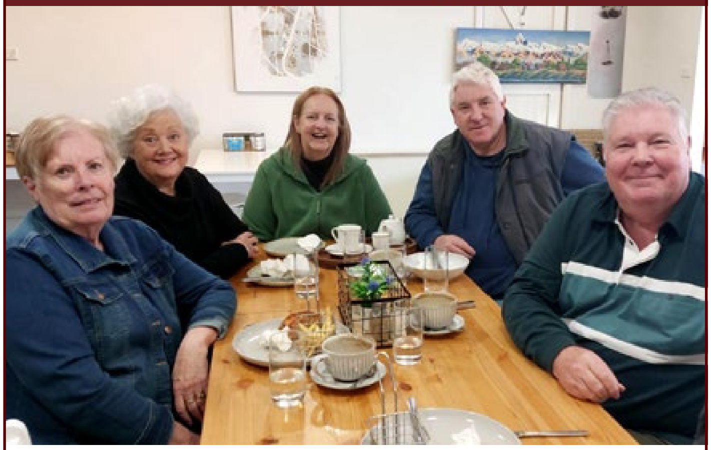
Find out more about Oh MG head to www.chloewigg.com/ohmg

RSVP NOW at www.warwickartgallery.com.au/chloe-wigg-exhibition-talk

CONVERSATION CONNECTION COMPANIONSHIP

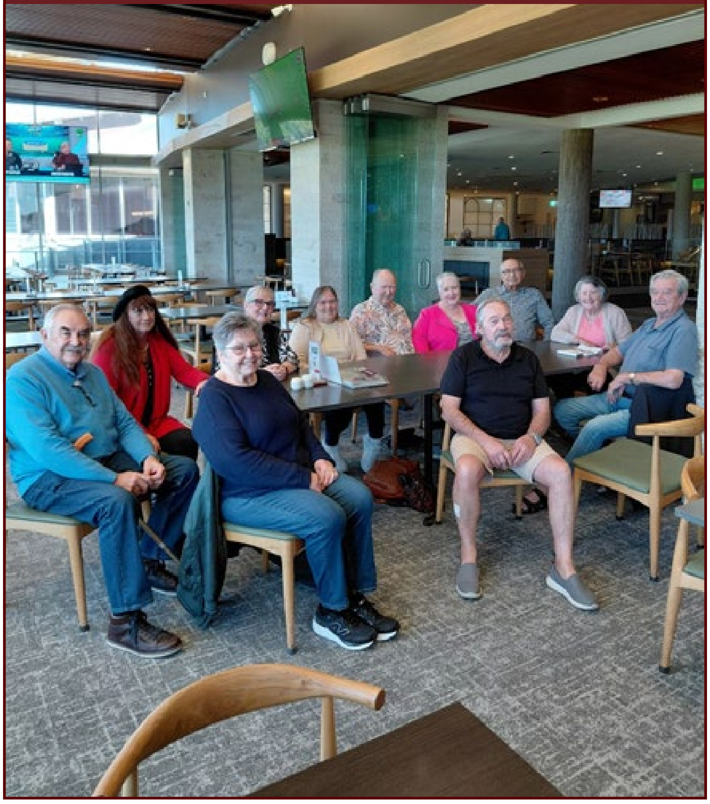
The local Coffee and Chat is a safe space to share MG experiences with others.

TASMANIA - EVANDALE

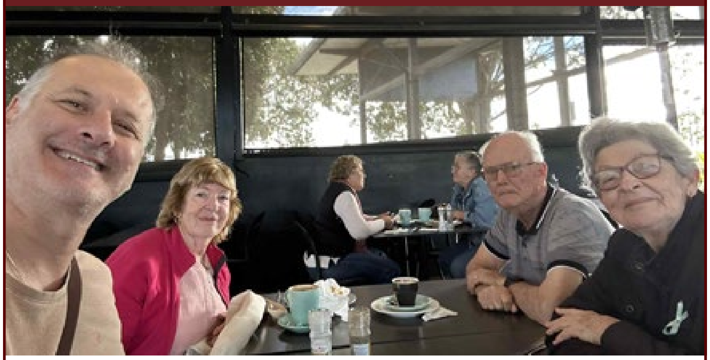


The next Coffee & Chat will be Thursday, 14 August, 11.00am at Evandale Cafe, 14 Russell Street.
For more information, call Vicki 0411 146 898.

GOLD COAST

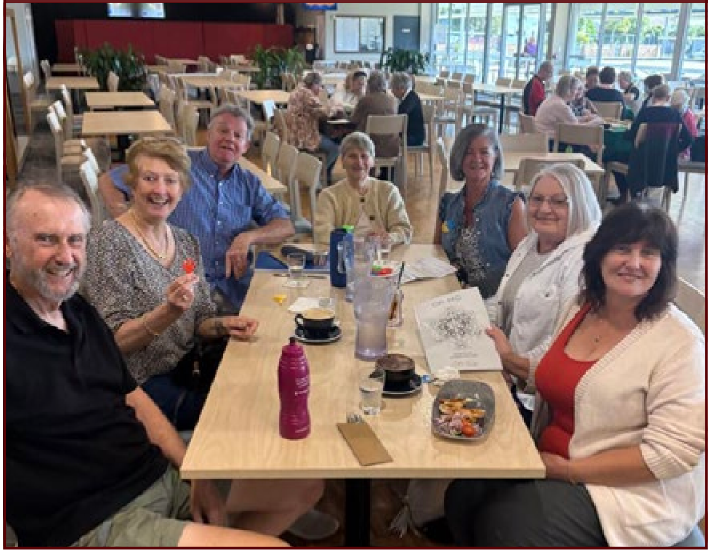


MANGO HILL



Angelo writes…
Wonderful morning attending a coffee & chat catch-up with members of the MGAQ. Not so wonderful being somewhat younger than those attending today but winning the prize for the greatest number of medications taken, for my various conditions.
Had been a while since I have been able to attend one of these catch-ups and a small number were in attendance, but it was lovely to reconnect with people who experience the same condition. We all present so differently – just like snowflakes. Just another act of self-care! Thanks to all were there.

SUNSHINE COAST



NEWS FROM AROUND QUEENSLAND

News from Cairns

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

News from Townsville

We are meeting again on **Saturday 6 September at 12 noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan.**

For more information, please contact **Daphne on 0400 778 637 or email** 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, 4 August at Kawana Club, 476 Nicklin Way Wurtulla at 10.30am.** Visitors are very welcome.

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

News from the Gold Coast

Hi everyone. The next get together at **Southport Sharks Club, Corner of Olsen and Musgrave Avenue Southport is on Saturday, 13 September at 10am**.

I look forward to seeing you all. For more information please contact **Nader on 0415 834 401.**

COFFEE & CHATS

SPRINGWOOD - Thursday 14th August at 10.30am,
More Cafe, 1/34 Fitzgerald Avenue

WELCOME TO OUR NEW MEMBER

Julie, Currumbin QLD

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
Conversation, Connection, Companionship **MGAQ AGM**	**Sunday 14th September 2025** **Doors open @ 10am for 10.30am start**	**Hornets Football Club, Graham Road Carseldine**

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 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** 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

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 ____

ANNUAL GENERAL MEETING
ELECTION OF OFFICE BEARERS
SUNDAY, SEPTEMBER 14, 2025

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2025/2026

Eleven places are now available for Committee nomination as the MGAQ continues to have an increasing range of projects. We always welcome anyone who wishes to nominate.

People can nominate themselves or anyone else they feel would be a suitable member of this very progressive and dynamic Committee.

Interested people need to be comfortable with using a range of technology and will need to maintain regular communication in order to stay abreast of issues throughout each month. Meetings are a full day held each second Saturday of the month excluding January, April and October and attendance via Zoom or in person is required for a majority of meetings.

To gain more information or to discuss these roles and commitments you can phone **Freecall 1800 802 568.**

Members with Myasthenia and those with an interest in Myasthenia are welcome to apply. Carers and supporters also very welcome to nominate. To nominate, you must be a financial member 2025/2026.

Nominations **MUST** be received by **EMAIL info@mgaq.org.au or by POST to PO Box 16, Mt Gravatt QLD 4122**, by the close of business on **Friday, 1 August 2025.**

If more than one nomination is received for the same position, a ballot to all financial members will be conducted with the votes to be returned by **Friday, 29 August 2025.**

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, September 14, 2024.

Nominee *(Print name)*:..Ph:...

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee *(Print name)*:..Ph:...

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee *(Print name)*:..Ph:...

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nomination(s) (above) Seconded by *(Optional)* ....

Additional Nomination Forms available on request.

Members may be interested in offering support, but would prefer to nominate themselves for special project work rather than taking a Committee position. If this is preferred, provide your name, best contact details, and a little about the skills you can offer to the Association.

Name:..Skills Offered: ....

....

....Best Contact:...