



Myasthenia Gravis Association of Queensland Inc.

MessaGes

JULY
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 JULY 2026

International Myasthenia Gravis Awareness Month was celebrated in June. The number of cities and towns that participated was fabulous. Thanks to Tory who organised a wonderful **Walk for Myasthenia Gravis** in which over 100 people participated. Also, thanks to Danielle who participated (and finished) the **Brisbane Marathon** and raised much appreciated money for the MGAQ. Many thanks to Jaymie, who is nine years old, who has worked with her mother Belinda and Auntie Debbie, **making and selling teal beanies** to raise awareness and to support the MGAQ.

A special thank-you to Donna Formosa from our management committee who, once again, spent many hours organising the **Lights Up** activities and get-togethers throughout Queensland and beyond. A special representation of some of the events and activities will be presented to all members soon.

The end of the financial year is upon us and that means a wide range of very important activities and commitments that need to be completed. 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, 13 September, 10.30am 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. The nomination form is on page 9 of this newsletter. **Nominations must be received by close of business 3 August.**

Many thanks to everyone who has responded to the message about renewing their membership. The additional categories of membership have proven to be very popular. The membership money covers the three association insurances, management committee meetings, printing and distributing newsletters, the 1800 number, website upgrades, information packs, stationery etc so that the committee can function effectively. Information about how to **renew membership is on page 10 of this newsletter.**

Many thanks to those who completed the **"Effect of Heat and Humidity on People Living with Myasthenia Gravis"**. The data has been collated and some very worthwhile information has resulted. The MGAQ committee now has a research paper in draft form and is working hard to get it completed and published. Much of the data will be worthwhile in advocating for better support and treatment of MG.

I hope that the weather has been kind to all in helping manage your MG.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

P.O. Box 16 MT. GRAVATT QLD 4122

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ABN 92 055 613 137

Email: info@mgaq.org.au

Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President: CAROL BUCHANAN

Vice-President: SHARIN NISHA

Secretary: CRAIG STREATFEILD

Treasurer: DENISE HANNAY

E: treasurer@mgaq.org.au

ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

SUSAN WHITE

LISA WRIGHT

JULIE VON GRUM

Newsletter Editor: GREG BREADEN

E: MGAQ.editor@gmail.com

PATRON: DR CECILIE LANDER AM Neurologist

Supported by



Queensland
Government

Ausenco

Active Members, **Stronger** Advocacy, **Better** Outcomes



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

Thank you to absolutely everyone for raising an extraordinary amount of awareness in 2026. So many people have commented to me or asked some questions. This increased awareness is helpful to all patients and family members. Thank you in particular to the artists, bidders and many volunteers who contributed to the awesome Art With Heart campaign.

To conclude awareness month celebrations **Health Minister Butler and Prime Minister Albanese shared the word about Myasthenia Gravis when announcing that Rystiggo (Rozanolixizumab)** received a PBS listing. This means that MG patients in Australia have access to an FcRn Inhibitor through the PBS from July 1st. With this addition to the two Complement Inhibitors approved earlier in the year, the myasthenia community has access to new and innovative treatments. We are indeed very fortunate to receive this support. Come along to the October 31st conference to learn more about who can access these treatments and how they will be used.

Conference registration is very close. Look out for your email notification. The MAA and the MAA Medical Advisory Board are pleased to welcome everyone to the **5th National MAA Patient Conference** to be hosted at **The Rydges South Bank, South Brisbane on October 31st**. The conference is a full day event from 9am until 4.30pm inclusive of easy access, round table seating; morning tea, lunch and afternoon tea; good disability access and a very interesting programme. Join with your peers to **"Learn, Share and Engage"**. Ticket price is \$90 per person (GST inclusive).

Medical guidelines and research activities are now frequently referencing patient **MG-ADL scores (Myasthenia Gravis - Activities of Daily Living)**. Becoming familiar with this score chart is now an important part of your care. To assist patients in using this score card the MAA are delighted to offer an App, **MG Connect**, for recording and tracking personal data. This data can be conveniently shared with treating Doctors. For patients who prefer hardcopy methods there is also a **pdf printable resource** for this purpose. Explanation of how this works is included with the resources in the Patient Toolkit section of the **MAA website** <https://myastheniaalliance.org.au/patient-tool-kit/#mg-connect-app>. We encourage ALL readers including Carers to become familiar with the MG-ADL system of data recording. This may take time and practice so do reference the information provided via the MAA website.

Professor Anneke van der Walt's excellent presentation is becoming available in the Patient Toolkit. She shared much insight into understanding your MG symptoms. She explained when to become concerned and at what level to seek extra support. She discussed what information to have handy when seeking support and how to manage daily variations. This is an essential resource for all patients and will be repeatedly useful. Again an excellent resource for our community. Please make yourself familiar with her guidance. <https://myastheniaalliance.org.au/patient-tool-kit/#educational-webinars>

More is on offer as **MAA hosts RVA (Rare Voices Australia) Disability Advocacy Manager, Fiona Lawton**. Fiona will guide patients and carers through avenues for accessing support when living with our chronic condition. This webinar is offered on July 28th at 12.30pm (AEST) and the recording will be made available through the MAA website. This initiative has been sponsored by a private donor with a targeted MAA donation. Such generosity is invaluable to continuing the broad ranging and independent activities of the MAA. Please register here <https://myastheniaalliance.org.au/rare-disease-disability-toolkit-webinar/>

The RVA has developed the **Rare Disease Disability Toolkit** as a nationally co-designed resource. It builds capacity in disability rights, provides self-advocacy tools, and helps people navigate complex systems like the NDIS.

RVA has invited the MAA to co-host the next round of **"Virtual Kitchen Table Peer Support Session"** zoom meet up on August 5th. These informal meetings will occur at 12 noon (AEST) for patients and 8pm (AEST) for carers. Look out for your email notification.

It is our goal that patients and families feel hopeful and more empowered by the work of the MAA.

Kind regards

Susan White, MAA Chairperson

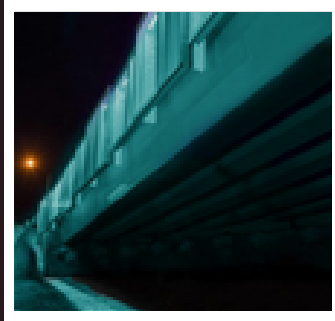
If you are not already registered with the Alliance please go to www.myastheniaalliance.org.au

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

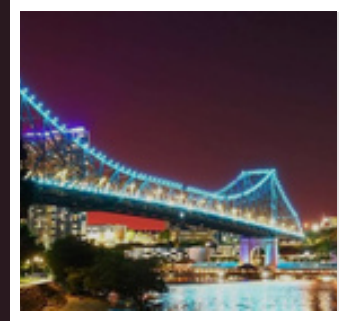
THANK YOU FOR SHINING A LIGHT DURING INTERNATIONAL MYASTHENIA GRAVIS AWARENESS MONTH



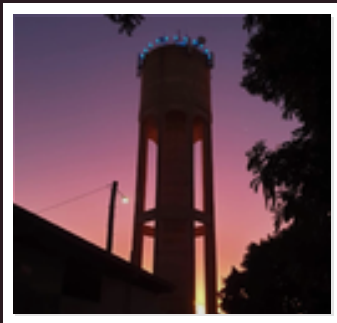
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Regional Council



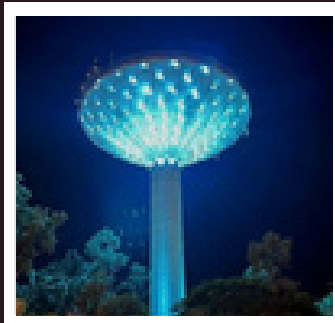
Toowoomba
Regional Council



Brisbane City
Council



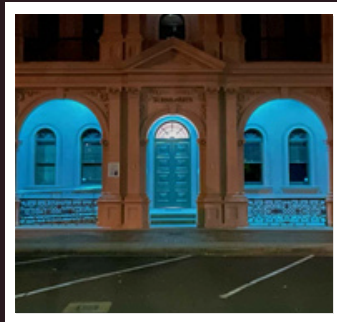
Longreach
Regional Council



Logan City
Council



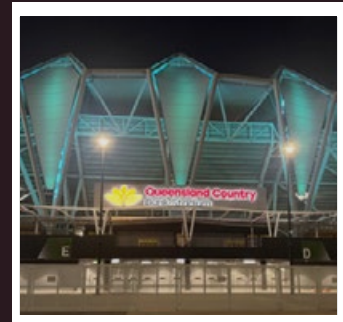
Ipswich City
Council



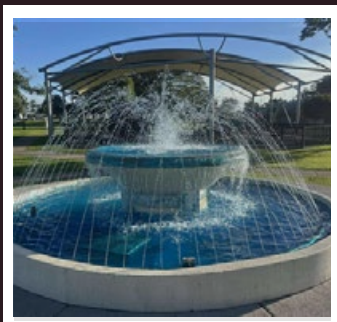
Bundaberg
Regional Council



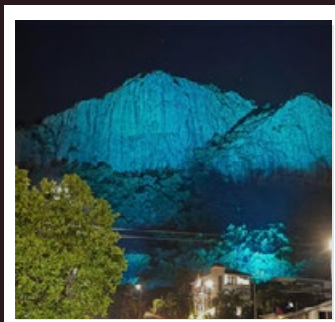
Mackay Regional
Council



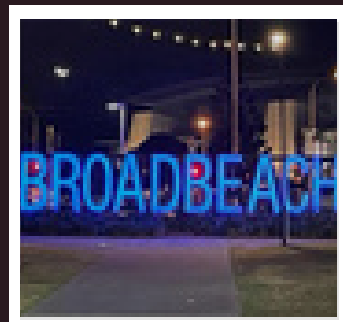
Stadiums
Queensland



Hinchinbrook Shire
Council



Townsville City
Council



City of Gold Coast

CONVERSATION CONNECTION COMPANIONSHIP

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

Mackay



Gold Coast - Currumbin



Townsville



Bamboozable

LOUD

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

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

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

Your Annual General Meeting offers
**CONVERSATION, CONNECTION,
COMPANIONSHIP**

Meet your Committee | Ask questions | Connect with people who understand



Sunday 13 September 2026

10am for 10:30am Start
Hornets Football Club, Graham Rd, Carseldine



RSVP to this in-person event:
MGAQ Information Officer
1800 802 568

KNOW YOUR MG

What type of Myasthenia do I have???

ASK YOUR SPECIALIST IF UNSURE

✓ *Tick all that apply*

☐ AChR positive

☐ Seronegative

☐ LRP4 positive

☐ LEMS

☐ MuSK

☐ Congenital Myasthenia

☐ Ocular only

☐ Generalised MG

CONNECT WITH MGAQ



Freecall

1800 802 568



Email

info@mgaq.org.au



Website

www.mgaq.org.au



Instagram

myastheniaqueensland



Facebook

Myasthenia Gravis Association of Queensland Inc.



LinkedIn

Myasthenia Gravis Association of Queensland Inc.



MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND

SUDOKU

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

WORD CHANGE

rough
poach

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

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

Active Members, **Stronger** Advocacy, **Better** Outcomes

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
Toowoomba John 0412 576 888	

COFFEE & CHAT ROUND-UP



- **Toowoomba**
Wednesday 29th July at 11.00am, Picnic Point Cafe,
164 Tourist Rd, Toowoomba
- **Sunshine Coast – Wurtulla**
Monday 3rd August at 10.30am, Club Kawana,
476 Nicklin Way Wurtulla
- **Sunshine Coast – Peregrin Springs**
Saturday 15th August at 10.30am, Peregrin Springs Golf Club,
95 Peregrin Springs Drive, Peregrin Springs
- **Townsville**
Saturday 22nd August at 12 noon, Cowboys Leagues Club,
313-335 Flinders St Townsville
- **Gold Coast - Currumbin**
Saturday 29th August at 10.30am,
Currumbin RSL Club, 165 Durling St. Currumbin

WELCOME TO OUR NEW MEMBERS

Kay, Upper Coomera QLD	Haylee, Sunnybank Hills QLD	Franca, Haberfield NSW	Simon, Dalby QLD
David, Upper Coomera QLD	Ken, Sunnybank Hills QLD	Darryl, Aitkenvale QLD	Pam, Birtinya QLD

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
Conversation, Connection, Companionship MGAQ AGM	Sunday, 13th September 2026 Doors open at 10.00am for 10.30am Start	Aspley Hornets Football Club 50 Graham Road, Carseldine

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



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS

10.30 am SUNDAY, SEPTEMBER 13, 2026

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2026/2027

Eleven places are available for Committee nomination as MGAQ expands its range of projects. We warmly welcome dedicated volunteers to nominate.

We encourage nominations from all over Queensland. Financial members living with Myasthenia Gravis, their family members, carers, or supporters can nominate themselves.

What is the Commitment?

Meetings: Nine meetings per year on the second Saturday of the month (excluding January, April and October). This includes five virtual meetings via Zoom and four in-person meetings in Brisbane. The meetings are from 8.30am to 12.00 noon approximately.

Technology: Nominees must be comfortable using technology for regular communication to stay informed on key issues. Technological equipment and ongoing technical support will be provided by the association.

To discuss the roles, responsibilities, or time commitments in greater detail, please contact Susan on **Free-call 1800 802 568**.

Completed nomination forms must be received by email at info@mgaq.org.au by the close of business on **Monday, 3 August, 2026**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, September 13, 2026.

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

Nomination Accepted (*Signature*):

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

Nomination (above) Seconded by (1).....

(2).....

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:.....

SUPPORT your Association by **VOLUNTEERING**.



MYASTHENIA GRAVIS
ASSOCIATION OF QUEENSLAND INC.

MEMBERSHIP RENEWAL

Membership subscriptions for 2026/2027 financial year are now due.

CAT A. MYASTHENIA MEMBER

A person diagnosed with Myasthenia Gravis.

Please select one option:

- ☐ 1 Year Membership (\$20)
- ☐ 3 Year Membership (\$55)
- ☐ 5 Year Membership (\$90)
- ☐ 10 Year Membership (\$170)
- ☐ Perpetual Membership (\$250 one off)

Payment Options:

- **Direct Deposit**
BSB: 124 032 Account No: 10263772
Reference: Your surname and initials
Email confirmation to:
treasurer@mgaq.org.au
- **Online:** www.mgaq.org.au
- **Credit Card (phone):** 1800 802 568

CAT D. CARER MEMBER

A person who cares for a Myasthenia Member (this category must accompany CAT A. Membership).

Please select one option:

- ☐ Annual Carer Membership (\$10)
- ☐ Perpetual Carer Membership (\$125 one off)

CAT E. ASSOCIATE MEMBER

A person who supports the Association.

Please select one option:

- ☐ Annual Associate Membership (\$20)
- ☐ Perpetual Associate Membership (\$250 one off)

Note that the Financial Year for Membership is from 1 July to 30 June

Member Details

Family Name: _____ Given Name: _____

Postal Address: _____

_____ Post Code: _____

Email Address: _____

Mobile or Phone Number: _____

MEMBERSHIP RENEWAL INCLUDED: Total \$ _____

DONATION TO MGAQ: All donations received with appreciation \$ _____

If sending cash, please return this entire form to:
The Myasthenia Gravis Association of Queensland Inc.
PO Box 16 Mt Gravatt QLD 4122 or email treasurer@mgaq.org.au

To check your membership status, freecall 1800 802 568 or email
treasurer@mgaq.org.au to enquire

CHEQUES
ARE **NO**
LONGER
ACCEPTED
BY THE
MGAQ BANK