



Myasthenia Gravis Association of Queensland Inc.

MessaGes

SEPTEMBER
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 SEPTEMBER 2026

Many thanks to those who attended our recent Annual General Meeting. It was pleasing to see some very familiar faces who support this association in all its endeavours. Also, a warm welcome to members who attended for the first time.

I want to express my personal thanks to the members who remain on the management committee and who work so hard for our members. I also welcome Jeff Reibel and Leilani Kami to our management committee. Every committee member has particular strengths and interests and can contribute in many ways to provide the very best for our members. The make-up of the management committee for 2026-2027 is on page 4 of this newsletter.

As well as the election of office bearers, other business included acceptance of the Annual Operational Plan, the appointment of our auditor and the decision to keep the annual membership fees the same for 2027. We urge people to renew their membership because these small membership fees add up and thus allow the MGAQ to remain functional.

Our Annual Operational Plan is a working document for the management committee and a way of ensuring that our four key foci of Member Welfare, Research, Awareness and Advocacy remain at the forefront of what we do. This plan also provides

the basis of our reporting to Queensland Health, both in person and by the regular reports we submit.

Four members of the management committee met with Qld Health officials on the Friday before the AGM and I am pleased to report that these officials were very impressed with what we had to say and show in relation to our four key foci. We acknowledge the wonderful funding and support we receive through the Community Funding Branch.

After the AGM we presented a slideshow of activities from Myasthenia Gravis Awareness Month as well as some important information currently available to members. We urge members who were not at the AGM to be aware of News Blasts which come via email as they keep everyone abreast of updates.

The research into **"The Effect of Heat on People living with Myasthenia Gravis"** is progressing well. The results have been collated, a research paper written and the team is progressing with further analysis of trends etc.

I hope that everyone is keeping well, particularly as we move into our summer which seems as if it will be a long, dry one with some excessive temperatures.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

P.O. Box 16 MT. GRAVATT QLD 4122

NATIONAL FREECALL: 1800 802 568

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: JULIE VON GRUM

Treasurer: DENISE HANNAY

E: treasurer@mgaq.org.au

ANITA JACKSON

SUSAN WHITE

CRAIG STREATFEILD

LEILANI KAMI

ROSALYN HOLLAND

LISA WRIGHT

DONNA FORMOSA

JEFF REIBEL

Newsletter Editor: GREG BREADEN

E: MGAQ.editor@gmail.com

PATRON: DR CECILIE LANDER AM Neurologist

Supported by

Ausenco

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



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

5th National Patient Conference October 31st in Brisbane!

Conference spaces are filling steadily with attendees coming from all over Australia. Now is the time for Queenslanders to come out and complete the registration process - patients, carers, supporters, HCPs. Please come if you possibly can. We do not want you to miss out on a day that is all about you! Register here - <https://meetings.medkom.com.au/QuickEventWebsitePortal/maa2026/registernow>

- ➔ Be a part of this special day (only second time ever in Queensland).
- ➔ Show your appreciation to the Speakers and the Volunteers who gift their time to make the day happen. Leading Australian Specialists are coming from Qld, NSW and Victoria to share their insights and to answer your questions.
- ➔ Ensure you are well informed about the treatment options - existing, new and still to come.
- ➔ Meet others and share stories.
- ➔ Help us create a group for younger patients (under 45 years of age)
- ➔ Show industry that we value their engagement with myasthenia gravis. Representatives will be attending, aiming to learn more about the challenges of living with MG. Talk with them!

Thank you to our Sponsors: Alexion, UCB, CSL, Merck and Argenx.

This industry support allows the MAA to offer more patient comfort,
more resources and a great day!

The Conference programme is included on page 3 of this newsletter or view it here meetings.medkom.com.au/QuickEventWebsitePortal/maa2026/registernow/ExtraContent/Content-Page?page=2

Check out the caliber of the presenters by viewing here - meetings.medkom.com.au/QuickEventWebsitePortal/maa2026/registernow/ExtraContent/Content-Page?page=1

Finally, the Patient Toolkit continues to draw many viewers to the MAA website and this month we are proud to have added the recording from the webinar with Fiona Lawton discussing Rare Voices Australia (RVA) Disability Toolkit. It is a very helpful conversation for everyone with a chronic condition. Lots of tips are given. Check it out <https://myastheniaalliance.org.au/patient-tool-kit/#educational-webinars>

See you in October!

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.



Myasthenia
Alliance Australia

MAA 5TH NATIONAL PATIENT CONFERENCE

Stronger Together. Brighter Futures.

PROGRAMME *for the Day*

TIME	SESSION
8.30 am	Registration Opens
9.00 am – 9.20 am	Welcome & Opening
9.20 am – 10.45 am	New Therapies • Introduction to MG and current MG treatments • What the new therapies offer and how traditional therapies relate to new therapies • Practical aspects of new therapies
10.45 am – 11.05 am	Morning Tea
11.05 am – 12.50 pm	Clinical Trials & Research • Clinical Trials & Emerging Therapies • Utility of diagnostic tests for MG • MGBase • MGBase thymectomy study • Interactive table discussion
12.50 pm – 1.50 pm	Lunch <i>After lunch, delegates will be invited to change tables and connect with new people.</i>
1.50 pm – 2.30 pm	Real World: PRO Research • MGAQ heat project • Barriers to workforce participation
2.30 pm – 3.00 pm	Q&A with Panellists <i>Your opportunity to ask questions and hear directly from our experts.</i>
3.00 pm – 3.15 pm	Afternoon Tea
3.15 pm – 4.10 pm	MAA: Education, Resources & Advocacy • MG-ADL: clinician and patient perspectives • MAA Website • MAA on the world stage and what we do
4.10 pm – 4.30 pm	Closing Address



Thank you for joining us at the MAA 5th National Patient Conference.

Together, we can strengthen our community and create brighter futures for all Australians living with myasthenia gravis.

Supporting you **TODAY** - Advocating for your **TOMORROW**

Conversation, Connection, Companionship incorporating the Annual General Meeting

YOUR MANAGEMENT COMMITTEE FOR 2026-2027

We are pleased to announce your management committee for 2026-2027. They are:

PRESIDENT	Carol Buchanan
VICE PRESIDENT	Sharin Nisha
SECRETARY	Julie Von Grum
TREASURER	Denise Hannay
COMMITTEE MEMBERS	Anita Jackson, Rosalyn Holland, Susan White, Lisa Wright, Craig Streatfeild, Donna Formosa, Leilani Kami, Jeff Reibel

This group of volunteers will work tirelessly for people with myasthenia gravis and their families.



SUPPORT your Association by **VOLUNTEERING.**

CONVERSATION CONNECTION COMPANIONSHIP

CURRUMBIN



SANDSTONE POINT



GOLD COAST - SOUTHPORT



BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/c: 10263772

Ref: YOUR NAME

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

PUZZLES

Word Search - African Countries (2)

E N O E L A R R E I S A A M E Q
R V A N F T I B H E B I I A U H
A D N A W R U N O P K B R L Q U
T G S Z B Z T N A I Q M E A I Q
A I O I D V Y Z I T V A G W B V
M A U R I T I U S S I Z I I M K
T P E Z R M F S E A I R N M A S
O Z A E B Y W L W T I A U E Z M
G P G A Z W L P A A Q B G A O M
O I B J S E W L J N Z L I B M L
N W F K H T X A J Z D I E M A E
E O C C O R O M D A H C L G A I
W A Y R M J N Q H N J G E A R N
X E S O M A L I A I A N T S N W
S S H M J Z L K Q A E G U L H D
O S U D A N U I P S R Z U W M U

MALAWI
MALI
MAURITANIA
MAURITIUS
MOROCCO
MOZAMBIQUE
NAMIBIA
NIGER
NIGERIA
RWANDA
SENEGAL
SEYCHELLES
SIERRALEONE
SOMALIA
SUDAN
SWAZILAND
TANZANIA
TOGO
TUNISIA
UGANDA
ZAMBIA
ZIMBABWE

Answers

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

bamboozable 33
Answers:
1. Spread a Little
Happiness, 2. Pay
Earth, 3. Peace on
Old Too Learn,
Room for One More,
Upright Piano
Word Change 25
Answers
last
moon
loot
loon
moon

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

Word Change

last
moon

Bamboozable

h a p p i n e s s	PAY	PPPPPP EARTH
Never Old Learn Old Learn	MORE MORE MORE MORE MORE	O N A I P

WHAT WORKS FOR YOU?

Share your best Tips & Tricks and a photo for making life with MG easier.
Email info@mgqaq.org.au to feature your ideas in this section

TIPS & TRICKS *to better handle* MYASTHENIA GRAVIS



Practical tips
Better days
Stronger you

Carry a portable whiteboard:

When my speech is affected by MG or I am in a situation (like a loud gathering) where trying to talk would fatigue me. I pull out my little whiteboard. I picked it up from Officeworks and it is small enough to fit in my handbag with two small whiteboard markers that have little erasers on the end.

Anna



Issues and Responses are published in the What Works for You as-is without any recommendation as to their suitability or accuracy. The opinions expressed are entirely those of the contributor. Care should be taken if following advice or suggestions presented and it is strongly recommended that the advice of your GP or Specialist is taken in all cases.

Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.



TIPS & TRICKS *to better handle* MYASTHENIA GRAVIS



Practical tips
Better days
Stronger you

“Keep Your Mestinon Fresh”.

Fact - This medication in all forms needs to be kept in airtight containers and away from heat. This is particularly true of the Timespan version.

Tip - To take your medications out and about seek out sealed containers and refresh contents regularly. Toiletry travel bottles can be ideal as they are designed to seal well. Such items can be found at travel suppliers, chemist or supermarkets.

Susan



Manage symptoms



Save energy



Stay strong

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



- **Townsville**
Saturday 3rd October, 12 noon Kirwan Sports Club,
159 Bamford Lane, Kirwan
- **Cairns**
Wednesday 7th October, 10.30am Cairns RSL Club, Esplanade
- **Toowoomba**
Saturday 17th October, 11.00am Picnic Point Café, 164 Tourist Road
- **Sunshine Coast – Peregrin Springs**
Saturday 24th October, 10.30am Peregrin Springs Golf Club,
95 Peregrin Springs Drive
- **Bribie Island**
Saturday 7th November, 10.30am, Bribie Island RSL Club, 99 Toorbul Street Bongaree
- **Gold Coast – Currumbin**
Saturday 7th November, 10.30am Currumbin RSL Club, 165 Durling Street

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
MAA Patient Conference	Saturday, 31st October 8:30 am	Rydges South Bank, South Brisbane
MGAQ Christmas Function Sunshine Coast	Sunday, 15th November 11:30 am	Brightwater Hotel, 15 Freshwater Street, Mountain Creek

WELCOME TO OUR NEW MEMBERS

Rosemary, Ethelton SA Heather, Toowoomba QLD Robert, Bellara QLD Cassandra, Mt Cotton QLD
Carl, Park Avenue QLD

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