



Myasthenia Gravis Association of Queensland Inc.

# Messages

**AUGUST  
2024**



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 AUGUST 2024

**Our Annual General Meeting is on**

**Sunday, 15 September, doors open at 10.00am for 10.30am start.**

**The venue is Aspley Hornets Football Club, Graham Road Carseldine.**

*This will be followed by Conversation, Connection and Companionship.*

We hope to see as many people as possible who can attend. We will not have a guest speaker but will rather be providing the opportunity for CONVERSATION CONNECTION and COMPANIONSHIP after the formalities of the AGM. We encourage those attending to stay for lunch and chat with friends both familiar and new.

Anyone who is attending the AGM should register prior to the event. Please either **PHONE 1800 802 568 OR EMAIL INFO@MGAQ.ORG.AU BEFORE 13 SEPTEMBER.** The club has managed social distancing well every time we have used that venue.

WE ARE STILL LOOKING FOR PEOPLE TO NOMINATE TO BE A MEMBER OF THE MANAGEMENT COMMITTEE SO THAT WE HAVE A FULL COMPLEMENT ON THE COMMITTEE. WE WILL ALSO ACCEPT NOMINATIONS FROM THE MEETING ON THE DAY IF ALL POSITIONS ARE NOT FILLED VIA WRITTEN NOMINATIONS. **TO MEET OUR LEGISLATIVE REQUIREMENTS WE DEFINITELY NEED A SECRETARY.**

The committee ensures that all people are comfortable with any projects in which they are involved and allows time for people to get to know the workings of the committee.

The agenda for the AGM is on page 10 of this newsletter.

**Thanks, Carol**

### Myasthenia Gravis Association of Queensland Inc

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#### COMMITTEE MEMBERS

**President:** CAROL BUCHANAN

**Vice-President:** SHARIN NISHA

**Secretary:** YVONNE HORNBY-TURNER

E: [info@mgaq.org.au](mailto:info@mgaq.org.au)

**Treasurer:** DENISE HANNAY

E: [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

KIRSTINE SHRUBSOLE

CRAIG STREATFEILD

SUSAN WHITE

LISA WRIGHT

**Newsletter Editor:** GREG BREADEN

E: [MGAQ.editor@gmail.com](mailto:MGAQ.editor@gmail.com)

**PATRON:** DR CECILIE LANDER AM Neurologist

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

## RESEARCH REPORT

The Myasthenia Alliance Australia (MAA) supports and promotes research that is specific to the experience of Myasthenia Gravis (MG) patients in Australia. But, we would not be able to do this without the essential and valuable contribution of Australians with MG.

One current project is VALUE-Ig, which aims to generate evidence to inform the optimal use of immunoglobulin (Ig) in four patient cohorts, including MG. This study is being conducted by a research team at Monash University Centre for Health Economics and is funded by the Australian Government's Medical Research Future Fund.

VALUE-Ig includes a Discrete Choice Experiment (DCE) to explore the treatment preferences of MG patients in Australia. The first round of focus groups to help design this DCE study has been completed and we sincerely thank the MG patients who gave their time and insights to this important research. Please read below for an update from the VALUE-Ig research team. To find out more, you can contact the team directly at [value.ig@monash.edu](mailto:value.ig@monash.edu) or reach out to the MAA by calling 1800 802 568 or emailing [info@mgaq.org.au](mailto:info@mgaq.org.au) or [info@myasthenia.org.au](mailto:info@myasthenia.org.au).

“ *The researchers thank all the MG patients who participated in the first focus group sessions. Sharing their lived experiences helped us better understand MG and design our patient preferences survey, which will be launched in 2025. Overall, 19 patients joined the sessions, ranging in age from 35 to 82. Among them, 12 were female and 7 were male. The patients were from various regions: 9 from NSW, 5 from Vic, 4 from QLD, and 1 from WA.*

*They frequently highlighted the importance of improving healthcare workers' knowledge of MG and the availability of neurologists to ensure timely access to necessary treatments. There were also discussions about how location impacted the accessibility of health services. Especially those living in regional areas felt that they had less options for accessing treatments.*

*They helped us revise the descriptions of our hypothetical scenarios that will be presented to respondents of our future survey. During the sessions, MG patients discussed their priorities when receiving treatment for their MG in mild exacerbation, severe exacerbation, and maintenance treatment conditions. They listed the most commonly experienced treatment side effects and identified which side effects were most important to them when receiving treatment. Gastrointestinal side effects were the most consistently reported, while the side effects patients were most concerned about varied widely. Reported side effects of MG medications included fatigue, weight gain, depression, line infection risk, blood clotting risk, increased risk of skin cancer and diabetes, hair loss, bone loss and poor sleep. They acknowledged their ongoing need to balance the side effects of treatment and their MG symptoms.*

*Although it was not within the scope of our focus group sessions, it is important to note that the session evaluation survey results indicate that many MG patients are interested in learning more about new treatments available.* ”

Monash University  
Centre for Health Economics | Monash Business School  
Level 5, Building H, Caulfield Campus  
900 Dandenong Road, Caulfield East VICTORIA 3145, Australia

## MGAQ.org.au Member Log-in

The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

Don't forget you can find this on your PC and also your phone.

An access code with username and password is sent out to all current financial members via email.

Log on to: **www.mgaq.org.au**  
**Click on Log In**  
**Enter username and password**  
**Click on Member Only**



### Available Now

Associate Professor Jan Sansoni -

*"Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives"*

If you have problems signing in please contact 1800 802 568 or email [info@mgaq.org.au](mailto:info@mgaq.org.au)



## MGAQ Inc. PODCASTS

### CAN YOU SEE YOURSELF CREATING PODCASTS?

The MGAQ owns a suite of podcast and vodcast equipment. It is currently stored at the house of one of our management committee members. However with the downsizing of their residence there is no longer the space to store this equipment. Do you live in Brisbane and environs? Do you think this volunteer activity could be a new interest for you or a family member? The role comes with all the equipment provided plus tuition from our current Dr Podcast. What you see in the photo is what you will receive. Interested?

Please contact Dr Podcast at [podcast@mgaq.org.au](mailto:podcast@mgaq.org.au)



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



The MGAQ and its members give a special shout out to the people who are our carers.

Please know that you are valued and appreciated.

## NEW MEMBERS

Jessica, Haberfield, NSW

Natasha, Boyne Island, QLD

Daniel, Boyne Island, QLD

At your AGM we offer

## CONVERSATION, CONNECTION, COMPANIONSHIP

♥ *Meet your committee.*

♥ *Feature conversations.*

♥ *Time to ask questions.*

♥ *Put a face to a name.*

♥ *Plenty of time to just chat with someone who understands your condition.*

♥ *Lucky Door prize and giveaways.*



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



RAReST

Rare Disease Awareness,  
Education, Support, and Training

# For the rare disease sector, by the rare disease sector.

## Co-design and the person-centred approach

Including lived experience in the **co-design and continual improvement** of health care is vital to ensuring health care is **effective and appropriate** for the individual or community of its intended use. The National Safety and Quality Primary and Community Healthcare Standards (2021) mandate health services to **“work in partnership with patients, carers, families, and consumers to seek and incorporate their views and experiences into the planning, design, monitoring, and evaluation of services.”**<sup>1</sup>

“ We are people, there is the sector and the dollars, there’s diagnosis and there’s research. There’s all these things, but it really often forgets, I think, the human experience.”

Person living with a rare disease



“ Stories of someone’s diagnostic journey and experience managing their condition could be beneficial to clinicians and other health professionals to identify symptoms, make a prompt diagnosis and optimise treatment.”

Person living with a rare disease



## The importance of storytelling

Storytelling can foster a **better understanding of the experiences** of people living with a rare disease (PLWRD), including families and carers, and is integral to the inclusion of people living with a rare disease in **decisions that impact them**.

**Health professionals** can also offer their professional experiences of caring for PLWRD. This can **highlight the needs, systemic barriers, gaps and solutions** needed to enable better care and support for people living with a rare disease.

Each person’s **medical journey** is often very **personal** and sometimes **traumatic**. Stories may contain sensitive information, and therefore, must be handled **carefully and respectfully**.<sup>2</sup>

Storytelling can also offer **insights into cultural practices**, beliefs and nuances that can help inform culturally safe and appropriate ways to co-design and collaborate.

1. Australian Commission On Safety And Quality In Health Care. National Safety and Quality Primary and Community Healthcare Standards. Accessed <https://www.safetyandquality.gov.au/standards/primary-and-community-healthcare> on 11 October 2023.

2. Medics 4 Rare Disease. Rare Disease 101 - Australia: Respectful and Effective Communication. Accessed <https://learn.m4rd.org/> on 11 October 2023.

The information in this factsheet includes authentic quotes from people within the rare disease community.



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Myasthenia Gravis  
Association of Qld Inc.



# Puzzlers

Puzzles by  
[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)  
[www.theteacherscorner.net](http://www.theteacherscorner.net)

## Sudoku

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

## Word Change

grate
blame

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

## Commonym (1)

What's a commonym you ask? A commonym is group of words that have a common trait in the three words/items listed. For example: the words; A car - A tree - An elephant.. they all have trunks. These will make you think!

1. A Ball - A Fish - A Cold
2. A Ball - A Salad - A Coin
3. A Cork - A Question - A Balloon
4. A Bottle - A Baseball Player - A Mushroom
5. A Bell - Mouth - A Shoe
6. A Tug of War - The Nightly News - A Boat
7. Seventeen - Time - People
8. A Basketball Court - A Highway - A Bowling Alley
9. Fog - A Jack - A Body Builder

## Bamboozable

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

## Answers

blame  
Word Change 28 Answers: grate, grade, glade, blade,  
7. they are magazines, 8. they have lanes, 9. they lift  
4. they have caps, 5. they have tongues, 6. they have anchors,  
1. they are caught, 2. they are tossed, 3. they are popped,  
Commonym Answers:  
Internet Site.  
bers; 3. Four Part Harmony; 4. Poison Ivy; 5. Tilt a Whirl; 6.  
Bamboozable 30 Answers: 1. Total Mess; 2. Paint by Num-



## RECIPE CORNER

# Succulent Lamb Stew

- ½ bunch fresh rosemary (15g)
- 800g lamb shoulder (bone out)
- 150g mixed colour olives (stone in)
- 1 x 280g jar of small pickled onions
- 2 x 400g tins of plum tomatoes

### Method

Preheat the oven to 170°. Place a 30cm shallow casserole pan on a high heat, strip in the rosemary leaves, add 1 Tablespoon of olive oil. Crisp up for 1 minute while you dice the lamb into 3cm chunks. Scoop out the rosemary and put aside, adding the lamb to the pan for 2 minutes to get colour. Meanwhile squash the olives and remove the stones.

Drain the pickled onions and stir into the pan with the olives. Toss well and pour in the tinned tomatoes, breaking them up with a wooden spoon and add 2 tins worth of water.

Cover and cook in the oven for 2 hours or until tender, stirring halfway.

Taste, season with salt and black pepper. Sprinkle over the crispy rosemary leaves and serve.



**Recipe by Jamie Oliver**

**5 Ingredients – Quick and Easy Food**

[https://youtu.be/cvn8B1hm\\_Oo](https://youtu.be/cvn8B1hm_Oo)

“

SUPPORT *your Association by*  
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”

## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us in Cairns on **Saturday, 12 October**, at **Vines Cafe (Limberlost Nursery) 113 Old Smithfield Road, Freshwater at 10.30am** for informal Coffee & Chat. Visitors to Cairns are most welcome. For more information, please contact **Donna on 0414 397 462**.

### News from Townsville

Townsville MG lunch is on **Saturday, 17 August 2024**, at **12 noon** at **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 local support, please contact **Mary on 07 4959 5251**

### News from Bundaberg

For local support, please contact **Denise on 0431 571 399**.

### News from Hervey Bay

For local support, please contact **Jan on 0429 622 438**.

### News from the Sunshine Coast

The Sunshine Group will meet on **Monday, 2 September at 10.30am** at **Kawana Club, 476 Nicklin Way Wurtulla**. All visitors to the area are also welcome.

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

### News from the Gold Coast

Hi Everyone, MG Gold Coast group had their get together sharing experiences with other members on **Saturday, 13 July** at **Southport Sharks Club**. **Our next meeting will be at 10am on Saturday, 7 September at the same venue**. I hope to see you all there. Visitors are welcome.

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



## COFFEE & CHATS

GREENSLOPES – **Saturday 12 October at 10.30am**,

The Jam Pantry, 2/575 Logan Road Greenslopes

– All Welcome!

RSVP Anita on 0414 588 312

## WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
<b>Conversation, Connection, Companionship MGAQ AGM</b>	<b>Sunday 15th September 2024 Doors open @ 10am for 10.30am start</b>	<b>Hornets Football Club, Graham Road Carseldine</b>
<b>MGAQ Christmas Function</b>	<b>Sunday 10th November 2024</b>	<b>Southport Sharks Club, Gold Coast</b>

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





# AGENDA FOR THE ANNUAL GENERAL MEETING

of the

## MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

**SUNDAY, 15 SEPTEMBER, 2024**

at the

**Aspley Hornets Football Club, Graham Road, Carseldine**

**Doors open at 10.00 am for 10.30 am Start**

Lunch is available at the venue with a varied and reasonably priced menu.  
Tea and coffee will be available prior to the meeting.

The meeting will be followed by **Conversation Connection Companionship**

Everyone Welcome – **RSVP is required. Ring our FREECALL 1800 802 568 by Thursday 12 September 2024**

1. **OPENING**
2. **APOLOGIES**
3. **CONFIRMATION OF QUORUM**
4. **MINUTES OF THE PREVIOUS AGM – Held at Aspley Hornets Football Club,  
Graham Road Carseldine on 10 September 2023.**
5. **BUSINESS ARISING FROM MINUTES**
6. **PRESIDENT'S ANNUAL REPORT**
7. **TREASURER'S REPORT**
8. **ELECTION OF MANAGEMENT COMMITTEE 2023/2024**  
**NOMINATIONS:**

PRESIDENT	(Resolution 1)	Carol Buchanan
VICE PRESIDENT	(Resolution 1)	Sharin Nisha
SECRETARY	(Resolution 2)	VACANT
TREASURER	(Resolution 1)	Denise Hannay
COMMITTEE MEMBERS		Anita Jackson, Rosalyn Holland, Susan White, Donna Formosa, Craig Streatfeild, Lisa Wright.
9. **APPOINTMENT OF AUDITOR** **Notice of Motion - Auditor:** That this meeting agrees to the appointment of Keeley Business Advisors and Accountants, Darren Hart CPA for the year 2024/25
10. **GENERAL BUSINESS:**

(Resolution 3) **Amendment of Rules of the MGAQ Inc.**  
**Notice of Motion- Bank Authority:** That the signatories for the Bank of Queensland accounts will be the President, Vice President, Treasurer and Secretary.  
**Notice of Motion – Annual Operational Plan:** That the membership accepts the Annual Operational Plan (AOP) as presented.
11. **CLOSE - NOTE** – The AGM will be followed by a short general meeting to confirm membership fees.

**RSVP is required. Ring our FREECALL 1800 802 568 by Thursday, 13 September 2024**