Myasthenia Gravis Association of Queensland Inc.
MessaGes
SEPTEMBER
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 SEPTEMBER 2025

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 the 'new' member who attended. I want to express my personal thanks to the committee members who remain on the committee and who work so hard for our members. I also welcome Julie von Grum 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 2025-2026 is on page 2 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 but work towards offering three, five and ten-year membership at a discounted rate from 2026.

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 they were very impressed with what we had to say and show in relation to our four key foci.

The next MGAQ activity to look forward to is our get-together on **Sunday 9 November at Club Southside, Mt Gravatt.** We have this as our Christmas function as we have found that many people have commitments with family and friends in December. More information on this get-together is on page 10 of this newsletter.

I hope that everyone is keeping well, particularly as we move into our summer with all the trials and tribulations associated with the hot weather. Please stay healthy and safe.

***Thanks Carol***

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***PATRON:*** DR CECILIE LANDER AM Neurologist

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# Conversation, Connection, Companionship

## *incorporating* the Annual General Meeting

### YOUR MANAGEMENT COMMITTEE FOR 2025-2026

We are pleased to announce your management committee for 2025-2026. They are:

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

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

- **Lucky Door Prize Winners:** Sharin presenting Roger and Chona with their MGAQ bags made by our Treasurer, Denise.

**Congenital Myasthenic Syndrome and use of Ruzurgi**

* 1. Does you or child have a confirmed diagnosis of Congenital Myasthenic Syndrome (CMS)?

○ Yes, I have confirmed diagnosis of CMS

○ Yes, my child has a confirmed diagnosis of CMS, and I am answering the survey on their behalf.

○ No

Next

Calling ALL
**CMS PATIENTS!**

MAA invites all Australians diagnosed with Congenital Myasthenic Syndrome (CMS) to complete our short survey and help strengthen the case for equal access to treatment.

**Scan the QR Code to Complete the Survey**

SCAN ME! »

The MAA would like to hear from ALL Australians diagnosed with CMS. We need to capture your numbers (parents/guardians can respond on behalf of children). We also want to learn about your experiences here in Australia regarding accessing Ruzurgi/Amifampridine/3,4-DAP as a treatment option.

The supplier of Ruzurgi is working towards achieving PBS funding for CMS patients. This will be done via a Repurposing Application. The MAA have previously been successful with such an application, and we are keen to assist on this occasion. The MAA firmly believe that "equal access to treatments for Australians" should mean that CMS patients have funded access to this treatment should they want it.

In order to approach the Health Department with an appeal we need to present data about the current situation and show why this is creating an unmet need.

If you are diagnosed with CMS, or can pass this information onto anyone who is diagnosed with the condition, we need you to complete this short survey.

**COMPLETE THE SURVEY HERE >> https://tinyurl.com/4rwecj5s**

There is an opportunity at the completion of the survey to leave your contact details should you be willing to provide additional information, but this is optional.

The MAA express our sincere appreciation to everyone who completes the survey. We are always keen to support our 'rare' community. Your assistance will be a great help in this endeavour, and we thank the company for taking this important step.

**Please call 1800 802 568 or email support@myastheniaalliance.org.au
if you require additional information.**

# MYASTHENIA ALLIANCE AUSTRALIA

## MAA UPDATE

Thank you to everyone who attended the lunch time presentation by Dr Antozzi on Myasthenia Gravis and symptom assessment tools to improve outcomes. It was wonderful to see the room filled and to hear the excellent presentation from Dr Antozzi. His compassion, empathy and deep understanding of Myasthenia was very much appreciated. The recording of this talk will soon be made available on the MAA website so keep a look out for a notification or visit the website www.myastheniaalliance.org.au. The MAA sincerely thank Argenx for making this event possible.

As promised, we are making on-line education a priority for this year. Soon to come will be two more webinar opportunities. Details will follow but please save the date for October 28th and November 18th, 4.30pm Qld time. Best regards from your small but mighty MAA team.

**Kind regards**
**Susan White MAA Chairperson**

- **MAA Team on the left and Argenx team on the right. Dr Antozzi closer to the banner.**

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

**We received a payment on 25th July with the description "Sub and Donation", if this was you, please email treasurer@mgaq.org.au**

If you are paying your membership via Direct Debit PLEASE add your name in the reference.

# MYASTHENIA ALLIANCE AUSTRALIA

## Why volunteer? Experiencing the MG Patient Advocacy Organisation (PAO) Summit is just one example!

In May this year, people who are both a patient and patient advocate or representative came together in Den Haag, in The Netherlands. We came from about 15 different countries. I had not met one of them before arriving there, and yet I felt immediately at home.

Although we come from different countries with different languages, cultures and healthcare systems, we face similar challenges as MG patients with the multidimensional impacts and the overall burden of MG, and as PAOs, including aiming for equitable and timely access to treatments. Like us in Australia, many of the patient organisations in Europe are also run by patients for patients, and the work we do is making a positive difference for MG patients.

For nearly 2 days, we discussed and agreed on some of the most pressing unmet needs within MG patient education and how we can work together on actions. We shared ideas for educating and empowering patients including tools, resources and apps. We also considered how to ensure we (patients) are speaking the same language as clinicians, including how to best discuss our concerns and key questions to ask, and how we can better integrate allied healthcare to create a holistic landscape for our care.

Some of these areas are already included on the MAA website: https://myastheniaalliance.org.au and we are always working to consider how we can best support our patient community in Australia. The ideas are many, but we do need people to help make them a reality. So, I strongly encourage you to think about volunteering your time and skills with us, where and when you can. This could be helping out on one project or just one hour a week, it is up to you.

Why volunteer… volunteering is often about helping others, and on top of this, volunteering as a patient with lived experience is meaningful and can give you a real sense of purpose.

Personally, having been diagnosed at 8 years old, Myasthenia Gravis is with me for most of my life. I faced quite a few challenges with my MG as a child, a teenager and then young adult, but ultimately I had a positive experience in achieving a stable condition and living well with my MG. I first got involved as a volunteer with the hope that this can happen for all MG patients.

In the five and a half years I have been volunteering with MAA and MGNSW, I have had the opportunity to not only work with a dedicated team of fellow MG patients, but I have also had wonderful opportunities to learn, develop my own skills and knowledge, and engage in meaningful work, to ultimately improve what it is to live with MG.

Reflecting on being a MAA board member, I realise I have undertaken quite an amazing range of activities:

- Facilitated multiple research projects and studies, and I value this because building our evidence base, especially with patient reported outcomes, is so important for the patient voice.
- Attended many insightful webinars and collaborative meetings with stakeholders, including clinicians, and I have learnt a lot about the disease I live with.
- Drafted submissions for a range of national health and medicines policies and I feel that this is really an opportunity to play a part in the bigger picture.
- Contributed to organising and coordinating the national MG patient conference in 2023 and national awareness campaigns.
- Attended conferences and events in Sydney, Canberra, Brisbane and Adelaide, and this year, we took our work internationally to the MGFA PAO Summit and International Conference in The Hague, The Netherlands.

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And I have the absolute pleasure of meeting and speaking with fellow MG patients, listening to your stories and understanding what having MG means for you.

There are already more activities in the pipeline before the end of this year! So, if you'd like to have a chat about being involved, please reach out to us today at **info@mgaq.org.au**

Finally, I wish to acknowledge the financial support of the Myasthenia Gravis Foundation of America (MGFA) and their sponsors, which made it possible for me to participate in the amazing PAO summit and international MG conference on behalf of the Australian MG patient community.

*Natalie Windle*
*MAA Secretary/MGNSW President*

**The MAA is fully volunteer run and is solely donation funded. Please consider donating. It can be done via the website https://myastheniaalliance.org.au/**

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

# CONVERSATION CONNECTION COMPANIONSHIP

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

## PERTH - WA

## CURRUMBIN - GOLD COAST

## WURTULLA - SUNSHINE COAST

## DENMARK - WA

# DO YOU HAVE A FAVOURITE RECIPE?

We are seeking easy go-to recipes to feature in this newsletter.

**Please email info@mgaq.org.au**

# Puzzlers

Puzzles by
www.thinkablepuzzles.com
www.theteacherscorner.net

## Word Search

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

Antigua
Argentina
Bahamas
Barbados
Barbuda
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Brazil
Canada
Chile
Colombia
Costa Rica
Cuba
Dominica
Dominican
Republic
Ecuador
El Salvador
French Guiana
Greenland
Grenada
Guatemala
Haiti
Honduras
Jamaica
Mexico
Nevis
Nicaragua
Panama
Paraguay
Peru
Saint Kitts
Saint Lucia
Saint Vincent
Suriname
Tobago
Trinidad
United States
Uruguay
Venezuela

## Word Change

pouch

________

________

peace

## Answers

**Bamboozable 29**

**Answers:** 1. To Have and to Hold; 2. Overcoming the Obstacles; 3. Playing Hard to Get; 4. One Foot in Front of the Other; 5. Seasonings; 6. Trial Separation.

**Word Change 29**

**Answers:** pouch, poach, peach, peace.

**Commonym 27**

**Answers:**

1. They have lobes
2. Crabs
3. Swimming strokes
4. They have trunks
5. They have claws
6. Lines
7. Detectors
8. Lights
9. Doors
10. Taxes

## Bamboozable

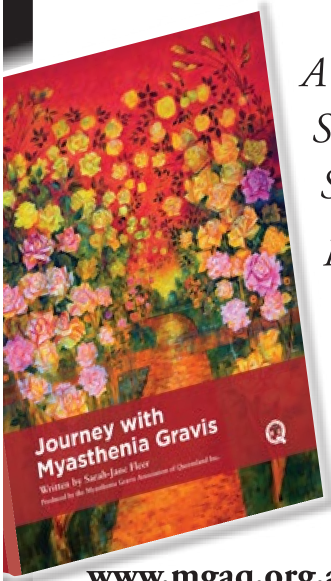
| | | |
|---|---|---|
| have have<br>**hold hold** | obstacles obstacles<br>COMING | HA play RD<br>get get |
| foot foot | INcccGS | TRI AL |

## Commonym

**What's a commonym you ask?** A commonyms 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. The Brain - The Lung - The Ear
2. Spider - Fiddler - Hermit
3. Back - Butterfly - Side
4. A Car - A Tree - An Elephant
5. A Bear - A Hammer - A Lobster
6. Finish - Fishing - Dotted
7. Metal - Radar - Lie
8. Stop - Spot - Strobe
9. Trap - French - Glass
10. State - Sales - Income

## Journey with Myasthenia Gravis



*A Book of Personal Stories, written by Sarah-Jane Fleer and produced by the Myasthenia Gravis Association of Queensland Inc.*

**www.mgaq.org.au/journey-with-mg**

**$28.50 incl. postage**

# ART WITH HEART AWARENESS PROJECT

## Join us and make a difference!

The Myasthenia Alliance Australia (MAA) continues its work with **International June MG Awareness Month in 2026.**

***Want to support the MG Community?***

Volunteer with Myasthenia Alliance Australia!
We're seeking enthusiastic individuals from all over Australia to help raise awareness and gather art donations and gifts for this project and Myasthenia Gravis.
This is an Australia-wide campaign.

**Your skills matter. All Skills are welcome!**

**Contact us at: operations@mgaq.org.au or Free call 1800 802568**

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

# COFFEE & CHAT ROUNDUP QUEENSLAND

## FREECALL 1800 802 568

| | | | |
|---|---|---|---|
| **Brisbane** | Anita 0414 588 312 | **Bundaberg** | Denise 0431 571 399 |
| **Gold Coast Southport** | Nader 0415 834 401 | **Mackay** | Mary (07) 4959 5251 |
| **Gold Coast Currumbin** | Julie 0423 766 321 | **Townsville** | Daphne 0400 778 637 |
| **Sunshine Coast** | Michael 0447 887 652 | **Cairns** | Donna 0414 397 462 |

## IN-PERSON COFFEE & CHAT

**Sunshine Coast – Wurtulla**

Monday, 6th October at 10.30am. Kawana Club, 476 Nicklin Way, Wurtulla

**Brisbane - Cleveland**

Thursday, 16th October at 10.30am Wellington Point Farmhouse, 2/623 Main Road, Wellington Point

**Gold Coast – Currumbin**

Saturday 25th October at 10.30am Currumbin RSL, 165 Duringan Street, Currumbin

**Gold Coast – Southport**

Saturday, 8th November at 10.00am Southport Sharks, Cnr Olsen and Musgrave Ave, Southport

**Townsville**

Saturday, 29th November at 12 noon Kirwan Sports Club, 159 Bamford Lane, Kirwan

*This is the Christmas Lunch*

## VIRTUAL COFFEE & CHAT

***"Starting the Journey: A Chat for the Newly Diagnosed"***

Friday 10th October at 5pm
Register at operations@MGAQ.org.au

# WHAT'S COMING UP

| What's On? | When Is It? | Where Is It? |
|---|---|---|
| **CHRISTMAS FUNCTION**<br>**Conversation, Connection, Companionship** | **SUNDAY 9th NOVEMBER 2025**<br>**11.30am** | **Club Southside, 76 Mt Gravatt Capalaba Road, Upper Mt Gravatt** |