



Myasthenia Gravis Association of Queensland Inc.

# Messages

September  
2023



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 2023

Many thanks to the small group of people who made the effort to attend our Annual General Meeting. It was pleasing to see some very familiar faces who support this association in all its endeavours. While we did not fill all of the executive positions it was very pleasing to see that our current committee members have made a commitment for another year. We also welcome Lisa Wright to this group. It is always very beneficial to have a new member on the committee with fresh ideas and a commitment to making life easier for people with myasthenia. I also want to pass on my personal thanks to the committee members who continue to remain on the committee and work so hard for our members. Everyone has particular strengths and interests and we endeavour to link people to what they feel is important or of interest to them. Everyone can contribute in some way to enable us to offer the very best for our members.

Many thanks to Susan White for her tireless work as Vice President. It is also pleasing to know that Susan has chosen to remain on the committee and continue the fabulous work she does as Information Officer on the 1800 number.

Our current Rules (originally the constitution) clearly outline the expectations in relation to the makeup of the Executive. As we do not have a Vice President we do not meet the ongoing

requirements in relation to being able to operate into the future. If there is anyone who feels they can devote some time to the management committee please feel free to phone the 1800 number for further information. **THIS MATTER IS URGENT.**

As well as the election of office bearers for 2023-24 other business included acceptance of the Annual Operational Plan and the decision to keep the membership fees the same.

Three members of the management team met with Queensland Health on Friday 08 September to report on the activities of the MGAQ as well as discuss with them our particular needs in relation to the increased workload being undertaken by the committee. It was a very fruitful meeting with worthwhile discussion. The committee will continue to engage with Queensland Health on a regular basis.

As we approach the end of the calendar year I ask that people please give a great deal of thought to the need for our committee to have a Vice President so that the MGAQ can continue the fabulous work it is doing for our members. Please remember that family members can also nominate to be part of the Management Committee.

*Thanks, Carol*

### Myasthenia Gravis Association of Queensland Inc

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#### COMMITTEE MEMBERS

**President:** CAROL BUCHANAN

**Vice-President:**

**Secretary:** YVONNE HORNBY-TURNER

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**PATRON:** DR CECILIE LANDER AM Neurologist

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Queensland  
Government

Ausenco

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



# MYASTHENIA ALLIANCE AUSTRALIA

## NEWS UPDATE

There are many messages about the important work of the MAA and how the team is hard working but often we receive feedback indicating that people don't really understand what we are doing with our three hour meetings and jam-packed agendas.

The MAA workers are drawn from the Association Committees. This ensures that they fully understand the operations of the State Associations and more importantly, what is being done to support the individuals who take up membership and who have health concerns. All MAA board members do experience Myasthenia themselves but still choose to volunteer under two umbrellas.

With the first hand knowledge gained from spending time with the membership, the MAA team apply this to working with Federal Government policy makers plus industry partners and researchers to facilitate and enhance conversations relevant to our community. We are amazed at how many acronyms we need to learn and how many different government departments are involved in the regulatory process. We are delighted that researchers are finding the MAA as a contact point and how impressed they are that we can take a positive attitude confident of supporting the potential work. The MAA team also keep an eye on what is happening overseas. We are supported by a highly skilled medical advisory board to ensure that all engagement is suitable. Without a strong following from the Australian Myasthenia community we would not be able to take this lead. Researchers are impressed and empowered by the number of survey responses we can achieve. The MAA is a partnership of us all!

The MAA Board consists of the two State Association Presidents - Carol Buchanan and Natalie Windle. This is important as the work must align with the objectives of the State bodies. Natalie is currently the MAA Secretary and collating the large amount of correspondence is a big task. Supporting these ladies is Glenda Bidner from NSW plus Craig Streatfeild and Lisa Wright from Qld. Many will have spoken with Glenda or Susan as they answer the Freecall numbers. All team members are currently working with Industry partners on specific projects and lucky Craig handles the IT challenges which occur regularly. We are a strong team on a small budget and more help would always be welcomed.

Please see the following article prepared by Natalie after she represented the MAA at a very significant conference in Adelaide. Her time there was important as she engaged broadly and brought home many learnings for the MAA team to utilise. Kind regards as always

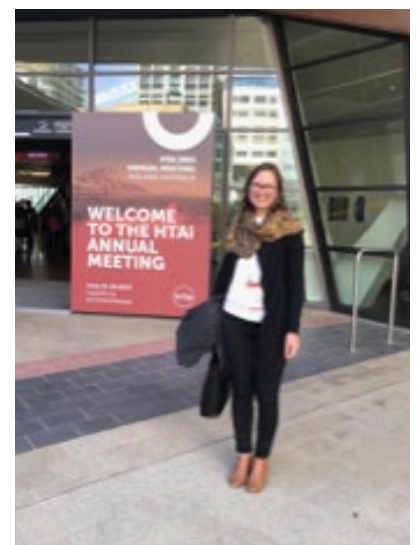
**Susan White (MAA Chairperson)**

### Health Technology Assessment International (HTAi) Global Conference in Adelaide

MGNSW President and MAA Board Member, Natalie attended the HTAi (Health Technology Assessment International) conference in Adelaide from 24th to 28th June 2023. This was thanks to a successful application for a grant from Patient Voice Initiative to attend this important conference on behalf of the MAA. Some of the key themes and messages included the importance and value of patient involvement and empowerment, timely and equitable access to medications/treatments, how to best collect and present data including qualitative data, real world evidence, and patient reported outcomes, and capacity building and training for patient organisations and representatives, noting the existing examples and resources.

HTA is a systematic and multidisciplinary evaluation that uses scientific evidence to assess the quality, safety, efficacy, effectiveness and cost-effectiveness of health technologies and interventions (ie. medications/treatments/medical devices). Australia is currently undertaking an extensive review of our HTA policy and processes and the MAA has made a submission on behalf of the MG patient community. More information is available here

[www.health.gov.au/our-work/health-technology-assessment-policy-and-methods-review](http://www.health.gov.au/our-work/health-technology-assessment-policy-and-methods-review)



Natalie Windle, MAA Secretary

If you are not already registered with the Alliance please go to [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

**PATIENT** Voices Matter



# Conversation, Connection, Companionship

## incorporating the Annual General Meeting

The first Conversation Connection and Companionship event incorporating the AGM was a great success. Craig presented a session on navigating the MGAQ website and what was behind the Member's Access tab. Members enjoyed listening to the activities

that had been achieved by the MGAQ over the past year. The happy conversation and camaraderie around the room made it a wonderful event. Some people even came away with lucky door prizes kindly donated by Denise.



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

## POSITION VACANT - VICE PRESIDENT

We urgently need a Vice President to comply with the Rules which govern the Association.

You or a family member can help.

Please call Susan on 1800 802 568 for more information.



*Dear MG Community*

This is an opportunity to make the voice of the MG community heard! MAA are supporting a pharmaceutical company to collect feedback from people with MG (or caregivers) on educational and support needs for MG medications. The survey will ask about your MG diagnosis, preferences for using internet and smart devices for managing MG and medications to treat MG.

The survey is completely anonymous, and your identity will not be shared with the company.

The results of the survey will be used to inform the development of a comprehensive program of resources to support the administration of medications to treat MG, and will aim to ensure the best experience for people with MG.

This is your opportunity to make your voice heard so please take the time to complete the 10 minute survey before it closes on 1 October 2023.

Click the link below to complete the survey.

<https://forms.office.com/e/MF2sSQittA>

**The Myasthenia Alliance Australia (MAA) Board**



## VICTORIAN REGIONAL MG LUNCHEON

to be held on

**Sunday, 24th September at 12 noon**

**Shepparton RSL Club, 88 Wyndham Street Shepparton**

**ALL WELCOME - RSVP by 22/9/2023.**

**For all bookings please call/text Pauline on 0419 332 260**

“*Nothing About  
Us Without Us!*”



## MEMBERS' FORUM

Please send in contributions to the Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is YOUR Forum and shared experiences with fellow MG sufferers makes understanding the condition just that little bit easier. If you have a response or an issue to raise, please forward it via mail to **PO Box 16 MT GRAVATT 4122** or via email to [info@mgaq.org.au](mailto:info@mgaq.org.au)

Issues and Responses are published in the Members' Forum 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.**

### ***The months are flying by this year***

The months are flying by this year. Is that a reference to getting older? Or can we look at the passing of years differently? I believe there are many benefits to accumulating years, and I am happy to be where I am.

In April this year my husband and I experienced deep personal change and renewal. For our families, Easter has always been a time to celebrate renewal, and Anzac Day a time to remember our family strength and resilience in times of war. This year was no exception and as it turns out, became very significant.

Before Easter I became unwell with shingles, and it was unpleasant (to say the least) but I focused on what I could do. I got the medical help I needed, and I ensured that I didn't have extraneous demands on my time and energy. I set work solutions in place, and I asked my business partner for help. I rested a lot and was in bed as much as my body needed. I meditated and got in touch with the inner part of me that knows how to return to balance. Healing takes time when combined with MG and a compromised immune system, but it is not impossible – nothing is. With these things in place, slowly I began to heal. It has renewed my sense of 'I can' and is now filed away as an additional component of my self-confidence.

My husband spoke at our local Anzac Ceremony this year. This is something he would not have contemplated when he was younger but with age comes a confidence that enables us to accomplish things far greater than we previously thought ourselves capable. Many people approached him after he spoke, thanking him for his heartfelt message of strength and hope. His achievement is now also another important element of his life's successes.

These events led to a change in our self-perception and a renewed depth of self-awareness. Part of our wider journey, these experiences are examples of how age brings with it the strength to embrace and be who we truly are. For us, the passing of years is the biggest gift in this journey of life.

***Helen T July 2023***

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*About the Author:* I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.

# Puzzlers

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

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

<b>1,3,5... WHELMING</b>	A v i s h e d A i r v a n i s h e d A i r	Y R - web
25 25 25 25	<b>MY SKIN</b> He's getting	TI ME JOB

## Answers

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

### Number Block

Try to fill in the missing numbers.

The missing numbers are integers between 0 and 12. The numbers in each row add up to totals to the right. The numbers in each column add up to the totals along the bottom. The diagonal lines also add up the totals to the right.

	0	1		6		25
7		8		0	6	20
5	4		2		2	34
	5	5	6	7	10	28
5		10		8		41
			2	8	8	36
34	24	40	25	37	35	41

### Word Change

house
gorge

Word Change  
30 Answers:  
:house  
rouse  
rouge  
gouge  
gorge

41	35	37	25	40	24	34	41
36	8	8	2	9	3	6	36
36	0	8	10	10	3	5	41
41	10	7	6	5	5	8	28
28	2	8	2	7	4	5	34
34	6	0	4	8	9	7	20
20	9	6	1	1	0	3	25

Bamboozable 28 Answers: 1. The Odds are Over-  
whelming; 2. Vanished into Thin Air; 3. Wireless Internet;  
4. Close Quarters; 5. He's Getting Under my Skin; 6. Part-  
time Job

## IPSWICH COFFEE & CHAT - AUGUST



*Thank you so much for letting me know about this. I went to my first support group (Coffee & Chat) on Saturday, it was absolutely wonderful. Wish I had done it earlier, I think I was just nervous about going”*

Irfana



## WA COFFEE & CHAT



For more information on get togethers in Perth, please contact Annette on 0413 855 077

### NEW MEMBERS

Lynette, Pyramid Hill, VIC

Michelle, Watson, ACT

## Member Survey

The Member Survey will be available soon. The Committee is keen to gain your feedback on how we can serve you better. We need your assistance to hear your preferences. The Survey will be available in 2 formats, Hard Copy - mailed with Newsletter and on-line via Survey Monkey.

Upon completion, we will analyse responses and in time provide insights.

We thank you for upcoming participation, any issues - **please call the Helpline on 1800 802 568.**

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



## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us on **Saturday, 14 October 11am** at **Il Chiosco, 47 Vasey Esplanade Trinity Beach**. For more information, please contact **Donna** on **0414 397 462**.

### News from Townsville

**DECEMBER LUNCH** Dear Members, **Lunch Sports Club 07 4773 1223, 159 Bamford Lane, Kirwan, Townsville, Saturday, 2 December 2023 at 12 noon**. If you can come please **RSVP Daphne Clay 0400 778 637**, email **daphclay@gmail.com**

Looking forward to your company. Family members are welcome. Thanks for attending our July lunch. As this is our Christmas lunch you are invited to bring a gift (\$15.00-\$20.00) and we will exchange gifts. 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 more information, 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

Our next catch-up will be **Monday 25 September at 10.30am, at Kawana Club, 476 Nicklin Way Kawana** and looking forward to a surprise visit from Donna who will be in our area visiting. Until then, cheers and stay positive. For more information please contact **Michael** on **0447 887 652**.

### News from the Gold Coast

Our next meeting will be at **10am, Saturday 23 September at Southport Sharks Club**. Please bring your empty Mestixon bottles for Chloe's art project. I hope to see you all there. For more information, please contact **Nader** on **0415 834 401**.



### COFFEE & CHATS

**WELLINGTON POINT FARM HOUSE RESTAURANT – Saturday, 16 Sept at 10.30am**  
**2/623 Main Road, Wellington Point**

*We would love to see you there!*

**RSVP Anita on 0414 588 312**

## WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
<b>MAA Patient Conference</b>	<b>Saturday 21 October 9am-4.30pm</b>	<b>Concord Hospital – Education Centre, Sydney</b>

### Christmas Function Cancelled

Unfortunately, due to other commitments by the MGAQ Management Committee, the Christmas function previously advertised has been cancelled. However, we encourage local groups to get together within their regions to celebrate the year.

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