



Myasthenia Gravis Association of Queensland Inc.

Messagies

December
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 DECEMBER 2024

As we near the end of the calendar year I want to take the opportunity to let our MG community know of the wonderful work that all members of our management committee have undertaken this year. The ones that are directly available to all members are:

- The newsletter which contains a wealth of diverse information and activities;
- The 1800 802 568 number;
- The very informative website;
- The MGAQ Facebook and Instagram;
- The wide range of written information for members and the medical profession;
- The Coffee and Chats both face to face and via Zoom;
- The regional get-togethers organised by our Regional Co-ordinators;
- The south-east Queensland functions with guest speakers;
- The Annual General Meeting;
- Information about ongoing research and new medications;
- The emails containing urgent information to be distributed.

The ongoing responsibilities, both legislated activities and committee priorities, are very necessary but also time consuming for all management committee members who, like others, have good days and not-so-good days because of their MG.

THE LEVEL OF COMMITMENT BY ALL MEMBERS OF YOUR COMMITTEE IS EXCEPTIONAL AND I AM VERY PROUD TO BE THE PRESIDENT OF SUCH A GROUP OF PEOPLE WHO ALL HAVE MYASTHENIA GRAVIS BUT ALSO WORK TIRELESSLY FOR OTHERS WHO ALSO LIVE WITH MYASTHENIA GRAVIS.

I hope that everyone has a happy and safe Christmas with family and friends.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

As 2024 wraps up there is significant work happening for the MAA Board. We feel that there is currently, a very significant opportunity available to our community and we hope that our readers will participate by following and by making a contribution if at all possible. Should accessing technology make it difficult, please consider asking for help from family, friends or your local librarians.

It is time to act! The PBAC lists 4 new gMG treatments for consideration at the March 2025 meeting!

The Pharmaceutical Benefits Advisory Committee (PBAC) has published its agenda for March 2025 and there are 4 generalised Myasthenia Gravis (gMG) treatments for consideration. Two are resubmissions and the other two are new requests for PBS listings. You can see the full agenda <https://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/agenda/march-2025-pbac-meeting>

The closing date for consumer comments is Wednesday, 29th January 2025. The MAA will be making submissions on your behalf. The MAA is also here to help you make individual submissions by giving you relevant information and guidance, ensuring confident navigation of the process. We will be working hard throughout the Christmas-New Year break with a focus on telling a very strong story, hoping to secure new treatment options that are available as broadly as can be achieved.

We (the Australian Myasthenia community) are being offered a unique situation with 4 products being listed. No new products have been offered for Myasthenia for more than 20 years. Gaining access to clinically trialled and targeted products is something worth speaking up for.

Make sure you are subscribed <https://myastheniaalliance.org.au/subscribe/> to receive our MAA updates as soon as they are published.

To read more about PBAC and the Health Technology Assessment (HTA) process, see our recent article <https://myastheniaalliance.org.au/hta-and-pbac-what-who-are-they-and-what-does-it-mean-for-us/>

In closing, the MAA thanks patients, families and health care professionals for supporting our work throughout the year. We wish everyone joy and much hope during this festive season.

I thank the wonderful MAA team for the hours of dedicated work required to support research, to ensure our voice is heard and to advocate for improved health care and understanding for people with Myasthenia. New volunteers to our team would be warmly welcomed. For more information please call 1800 802 568.

Kindest regards, Susan White - MAA Chairperson.

LOUD

BAMBOOZABLE ANSWERS PAGE 8

<p>DANCE DANCE DANCE --->DANCE</p>	<p>CRYING CRYING CRYING CRYING</p>	<p>groPOOLund</p>	<p>ABCD EFGH a week IJKLM a week NOPQ a week RS_U a week -WXY Z</p>	<p>FREQUENCY</p>	<p>T T T I I I S S S</p>
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Be an MG **CHAMPION** – use your **VOICE**



Myasthenia
Alliance Australia



EXCITING RESEARCH RECRUITING



FEBRUARY 2025



UNDERSTANDING THE HEALTH JOURNEY OF PEOPLE WITH MYASTHENIA GRAVIS

The MAA and Edith Cowan University are collaborating to explore the health journey of people with MG from diagnosis through to living with the condition. Online workshops will be conducted to understand people's experiences of living with MG.



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

CONVERSATION CONNECTION COMPANIONSHIP

TOWNSVILLE



- Steven, Sara, Mary-lynn (our new member), Diana, Tim, Maree, Daphne, Serafina, Shirley and Carol (the photographer).

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

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BAMBOOZABLE ANSWERS PAGE 8

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

SUPPORT your Association by **VOLUNTEERING.**

CONVERSATION CONNECTION COMPANIONSHIP

SUNSHINE COAST



- Michael, Michelle, Les, Sonia and Scott

NEW MEMBERS

Lorraine, Elanora QLD
Carmel, Kingscliff NSW
Anthony,
Kangaroo Point QLD
Lesley,
Kangaroo Point QLD
Patricia, Cooroy QLD
Kevin, Nundah QLD
Mark,
Grasstree Beach QLD
Alexandra,
West End QLD
Beryl,
Waterford West QLD
Donald,
Waterford West QLD

SOUTH AUSTRALIA



- Amanda, Kate, Lyn, Jo, Tony, Jean and Lori.

*The Myasthenia Gravis Association of Queensland Inc.
Committee would like to wish everyone a*



*Merry
Christmas and a safe
and happy
New Year!*

MessaGes will take a break over January and looks forward to resuming
in February 2025 Thank you to all contributors during 2024.

MEMBERS' FORUM

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.

Welcome to “Seeing Things Differently”!

This blog documents my process of reading stories by writers, editors and journalists who experienced vision changes that affected their work. The causes of their vision changes are wide and varied - everything from migraine to multiple sclerosis and macular degeneration. This blog also documents how I tried to make sense of changes to my own vision and other effects of myasthenia gravis.

My name is Melissa Giles. I have produced this blog and compiled the list of featured stories as part of my PhD by Creative Works at the Queensland University of Technology in Brisbane, Australia. My research is supported through an Australian Government Research Training Program Scholarship.

Links to the audio versions of posts read by Melissa Dobbie will be added to each post page as they are produced.

Hi everyone!

Blog Post #11 “Losing the Rhythm” is now available online:

<https://story-telling.wixsite.com/seeing-things/post/11-losing-the-rhythm>

This post is the start of Series 2 of my blog.

In Series 2, I'll acknowledge what I've learned from some of the stories I wrote about in Series 1 (Post #1 to #10). However, I'll also share more of my own stories about life with myasthenia gravis.

Regards, Melissa.

Complete the grids.

3 letter words

BOW ○

MAN ○

TON ○

VAN ○

5 letter words

DANCE ○

FINAL ○

FINCH ○

MOTOR ○

MOVIE ○

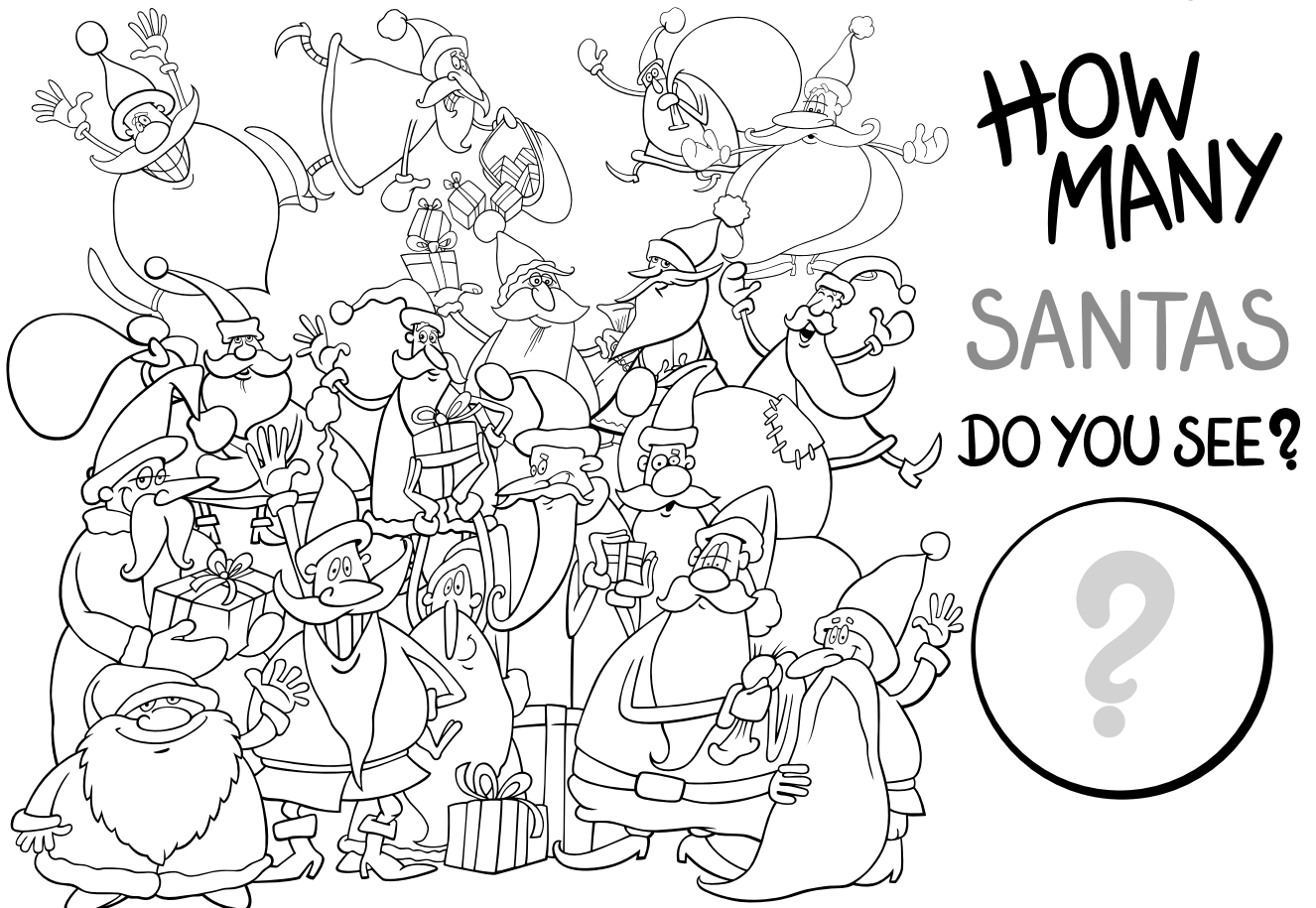
ROBIN ○

ROMAN ○

ROWAN ○

Spot the missing fragment.

ANSWERS PAGE 8



NEWS FROM AROUND QUEENSLAND

News from Cairns

For local support, please contact **Donna** on **0414 397 462**.

News from Townsville

Dear members. Thanks to everyone for the beautiful gifts at our Christmas lunch. Welcome to our new member Mary-lynn.

The **Townsville MG Lunch** will be held on **on Saturday, 15 February 2025, at 12 noon at Kirwan Sports Club, 159 Bamford Lane, Kirwan**. Looking forward to your company. Family members are welcome.

To RSVP or for more information please contact **Daphne** on **0400 778 637** or email **daphclay@gmail.com**

News from Mackay

For more information, please contact **Mary** on **07 4959 5251**.

News from Bundaberg

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

News from the Sunshine Coast

The Sunshine Coast group will meet again on **Monday, 3 February 2025, Kawana Club, 476 Nicklin Way, Wurtulla at 10.30am**. Wishing you all a Merry Christmas. For more information please contact **Michael** on **0447 887 652**.

News from the Gold Coast

Hi everyone. MG Gold Coast group had their Christmas lunch get together with some members from Brisbane sharing experiences with other members in November. Our next Coffee and Chat will be at **10am on Saturday, 18 January at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport**. I hope to see you all there.

I take this opportunity to wish everyone a Merry Christmas and a happy New Year. **For more information, please contact Nader** on **0415 834 401**.



COFFEE & CHATS

RSVP Anita on 0414 588 312

CARSELDINE – 10.30 am Saturday, 15 February 2025,

Hornets Aspley Football Club, 50 Graham Rd, Carseldine

– All Welcome!

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032

A/C: 10263772

PAGE 3 BAMBOOZABLE: 1. Last Dance; 2. For Crying Out Loud; 3. Inground Pool; 4. No TV for a Week; 5. High Frequency; 6. Sit Ups

PAGE 4 BAMBOOZABLE: 1. Drawn to scale; 2. Round of Applause; 3. Splitting Hairs; 4. They're all the same; 5. There's no end to it; 6.

Different strokes for different folks

PAGE 7 ANSWERS: Word Grid Answers: First Crossword: ROMAN. VAN. FINCH. Down: MOVIE. MAN. DANCE.

Second Crossword Across: MOTOR. BOW. FINAL. Down: ROBIN. TON. ROWAN.

Missing Fragment: 5. How Many Santas: 17

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