



Myasthenia Gravis Association of Queensland Inc.

MessaGes

APRIL
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 APRIL 2026

Well, March has come and gone and the year is slipping by very quickly. The management committee hopes that everyone had a healthy and safe Easter filled with love and laughter.

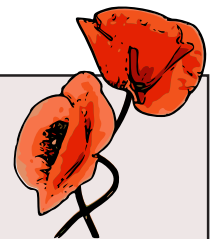
Our **Light Up Project for June International Myasthenia Gravis Awareness Month** is growing even bigger and more places around Queensland are participating under this year's theme **"Shine A Light on Myasthenia Gravis"**. More information will be included in the next two newsletters and we hope that, if you get the opportunity, please take a photo and then send it to info@mgaq.org.au for possible inclusion in our newsletter. Also, please remember that not all photos might appear in the newsletter but they will be saved digitally for future use.

Another important activity for June Awareness Month is the **Walk for Myasthenia Gravis Awareness** to be held on **Saturday, 13 June at New Farm Park in Brisbane**. Further details can be found on page 5 of this newsletter. We hope that all members, their families and friends support this wonderful awareness-raising activity.

In next month's newsletter you will see the membership renewal information. At our Annual General Meeting last year some new membership types were approved. Thus, our annual fee will remain at **\$20**, three years **\$55**, five years **\$90**, ten years **\$170** and perpetual **\$250**. These new fees will be outlined in the Application Renewal Form in next month's newsletter. I also must stress that one membership fee does not even cover the printing and posting of the newsletter so your management committee really does appreciate membership renewals which, unfortunately, seem to be becoming less and less in number each year. We need your support so that we can continue to support you.

We are always grateful to those people who make a donation at the same time as they renew their membership. Please make sure that, if you add a donation with your membership fee, that you tick the appropriate box. If you wish to share your donation please write the amount next to each box once you have ticked same.

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: CRAIG STREATFEILD

Treasurer: DENISE HANNAY

E: treasurer@mgaq.org.au

ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

SUSAN WHITE

LISA WRIGHT

JULIE VON GRUM

Newsletter Editor: GREG BREADEN

E: MGAQ.editor@gmail.com

PATRON: DR CECILIE LANDER AM Neurologist

Supported by



Queensland
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Ausenco

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



MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

As a special Easter gift, on April 1st the PBS Medicine Status Website showed that Zilbrysk (Zilucoplan) is now funded through the PBS system. Zilbrysk is a complement inhibitor available to generalised Myasthenia Gravis (gMG) patients who are AChR antibody positive. This is the second complement inhibitor available to Australians. We remain very thankful that the Government has seen the need to offer innovative therapies to the Australian Myasthenia community. Whilst the complement inhibitors are not offered to sero-negative patients we encourage this group to remain optimistic as more studies and trials are happening.

The next task for the MAA is to share some details about how these Complement Inhibitor medicines work and what the government requirements are for accessing these medications. Please ensure that you or a family member/carer is registered at www.myastheniaalliance.org.au so that you don't miss out on the range of information that will flow through in the coming months. There will also be conversation about the MG-ADL scores. Your Specialist may start to mention this during your appointment. I refer you to the introductory information previously shared via the MAA.

www.myastheniaalliance.org.au/expert-insights-myasthenia-gravis-and-symptom-assessment-tools-to-improve-outcomes

In addition to more webinar opportunities there are also surveys coming your way! Each survey has a different focus and each will benefit the MG community. The support for the Heat Project was wonderful making the analysis meaningful and impactful. Thank you to the MG community for responding strongly. Please keep offering your stories as more surveys are to follow this year. Just advertised is the Neurological Alliance Australia (NAA) survey. This organisation, of which MAA is an active member, aims to raise important questions and conversations with the federal government. MG needs are very specific but many overlap with other neurological conditions. The NAA aims to bring a unified and powerful voice to government allowing better support for people with neurological conditions. Participate via this link <https://myastheniaalliance.org.au/national-neurological-survey-australia/>

The MAA team, through its board members and also through its project officers, is dedicating many hours to developing the connections and conversations that raise awareness of our need for improved treatments, better care inclusive of nursing support and allied health access and for improved quality of life. To achieve a voice we require people from all avenues of life to be aware of Myasthenia. We hope that they will take notice of the condition and learn about the obvious and also the hidden burdens of life with MG. This is why the Art With Heart project is so important. It is a conversation starter with the general public.

It is your chance now to spread the word and increase the understanding. This could be with the general public, Health Care Professionals, your family and friends, local businesses etc!

Please get behind this event and make it a success. Show your volunteers that you appreciate their efforts. Also, the Art With Heart project facilitates operating/research funds for the MAA. As the MAA have no funding beyond the donations that we receive and small amounts earned when the Board members undertake a remunerated project, adding to the small reserves of the MAA directly benefits all members and allows us to be proactive and innovative. The AWH project is entering the critical final two months.

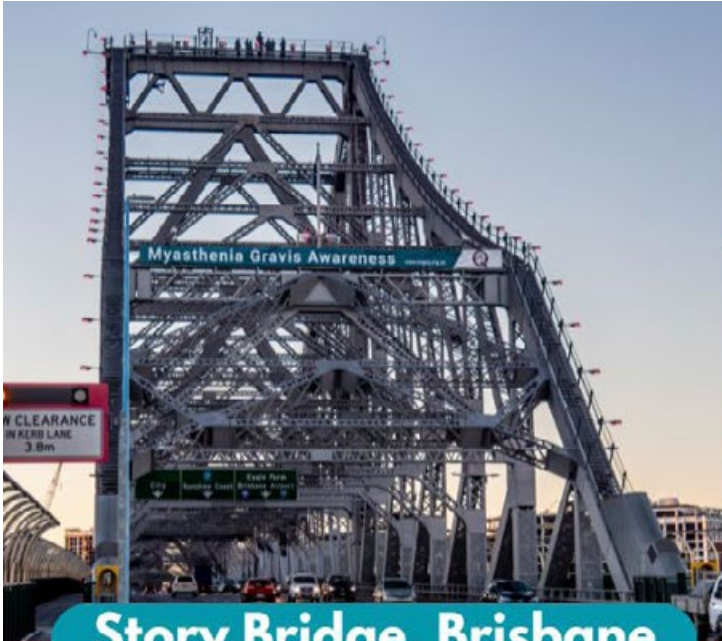
Please, in whatever way possible, help make this project a success. In doing this we recognise the generosity of renown artists who are instrumental in making this project viable.

Thanking you all for your continued support. Keeping the Associations functional and fun and engaging with all the activities offered ensures a strong voice for people with myasthenia gravis!

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.



Story Bridge, Brisbane

Shine A Light Qld

JUNE 2026

Myasthenia Gravis Awareness Month

Walk for Myasthenia Gravis Awareness 
Saturday 13 June | #WFMGA

LOOK OUT FOR OTHER INITIATIVES!



[myastheniaqueensland](https://www.instagram.com/myastheniaqueensland)



[facebook.com/mgqld](https://www.facebook.com/mgqld)



A CALL TO ALL MEMBERS WE NEED YOUR HELP!

ART WITH
HEART



We need each member to please find one donor!
Remember, it does not need to be artwork. It can be a service from a business in your community.

Supporting MG Awareness with "Art with Heart" 2026!

The Myasthenia Alliance Australia (MAA) is proud to continue its important work during International June MG Awareness Month 2026.

Challenge Your Friends and Family to Care

If you're wondering how you can contribute to and support the MG community, your involvement is essential. This event aims to strengthen our MG community by encouraging group interaction in a fun and positive atmosphere. It is also a vital opportunity to raise awareness of Myasthenia Gravis throughout the broader community.

Building Community Awareness

Help build awareness by reaching out to social groups and NGOs (Non-Government Organisations). Consider becoming a sponsor. If we hope for understanding and acknowledgment from others, including medical providers, it is important that they become familiar with our condition.

How You Can Help Make the Event Successful

- All contributions - big or small, service-based or tangible - are greatly appreciated.
- Please donate items or ask others if they would like to contribute.
- Share the news as widely as possible through focused conversation, emails, and social media platforms such as Facebook and Instagram.

MAKE A DIFFERENCE FOR PEOPLE WITH MYASTHENIA GRAVIS



www.myastheniaalliance.org.au



1800 802 568



Please email details of your donation to operations@mgaq.org.au



Myasthenia
Alliance Australia

RECIPE CORNER - MY MUM'S ANZAC BISCUITS

INGREDIENTS

- 1 cup rolled oats
- 1 cup plain flour
- $\frac{3}{4}$ cup sugar
- 1 cup coconut
- 125g butter
- 1 Tablespoon golden syrup
- 1 teaspoon bicarbonate of soda
- 2 tablespoons boiling water

METHOD

Combine oats, flour, sugar and coconut in a large bowl.

Combine butter and golden syrup in pan, stir

over low heat until butter is melted.

Dissolve bicarb with water in a cup until dissolved then add to butter mixture.

Stir into dry ingredients while butter mixture is warm.

Place a heaped tablespoon of mixture together about 4cm apart on lined baking tray.

Press down lightly and bake in slow oven for about 15-20 minutes or until golden brown.

Loosen biscuits while warm and allow to cool.

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

Walk for Myasthenia Gravis Awareness

#WalkForMG



As part of Myasthenia Gravis Awareness Month, MGAQ is excited to announce our very first

Walk for Myasthenia Gravis Awareness

WHEN: **Saturday 13th June 2026**

WHERE: **Rotunda, New Farm Park, Brisbane**

TIME: **9.30am to 2.00 pm**

Participants to arrive at 9:30 am for departure at 10:00am

This is a fun day out for everyone. A range of distances are offered, and it is wheelchair friendly. If preferred, settle in at the historical New Farm Park Rotunda and be the cheer squad. Fun for everyone!

Register Now! <https://forms.office.com/r/5GbiYR0v2z?origin=lprLink>



HEAT SENSITIVITY AND COOLING INTERVENTIONS IN MYASTHENIA GRAVIS

Raising Awareness About How Heat Affects You

Many thanks to those who took the time to complete the Heat Survey. The response was fabulous! These surveys will be collated and analysed as soon as possible and the important information and trends identified. These results will provide important data and information that can be used to agitate for heightened awareness and resources for people living with MG.

The Literature Review has been submitted for approval to publish in an accredited medical/scientific journal.

The MGAQ thanks QUT and the research committee for their continued professional and personal support for this groundbreaking initiative.



MYASTHENIA GRAVIS
ASSOCIATION OF QUEENSLAND INC.
(MGAQ)

QUT Queensland
University
of Technology
QUT ethics approval 10508



CONVERSATION CONNECTION COMPANIONSHIP

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

Cairns



Gold Coast - Currumbin



Moreton Bay - Mango Hill



Mackay



Sunshine Coast – Wurtulla



Gold Coast – Southport



SUPPORT your Association by **VOLUNTEERING.**



PUZZLES

Sudoku

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

Bamboozable

U can 1,2,3,... IT	DO ¹² OR	CAN'T DO CAN'T DO CAN'T DO CAN'T DO
GOODNESS GOODNESS NEST	WEIGH PRICED	living SHOESTRING

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.

									35
8	6		1		4	1	3		34
	8	2	5	1		0	2		29
4	11		1	11	11	2	0		46
9	4			9	9	5	1		53
8		12	1		5	8	4		50
8	7	8	9	7	3	8	12		62
3	1	6	4	11		8	7		44
2	3	7	4	2	9	0	1		28
51	44	54	32	56	47	32	30		49

Mad Cabs

They are a group of words, that at first glance and first saying don't make sense... but say them SLOWLY and LISTEN to what you hear to figure out what the phrase is. Example: Common Firm Their Rain = Come In From The Rain

1. Abe An An Appeal
2. Abe Autumn Lisp Hit
3. Abe Ax tree Tally
4. Abe Hair Heat Rash You're
5. Abe Hum Pen Thin Height

Answers

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

49	30	32	47	56	32	54	44	51
28	1	0	9	2	4	7	3	2
44	7	8	4	11	4	6	1	3
62	12	8	3	7	9	8	7	8
50	4	8	5	8	1	12	4	8
53	1	9	9	7	9	4	9	9
46	0	2	11	11	1	6	11	4
29	2	0	2	5	1	2	8	9
34	3	4	1	7	4	4	6	8
35								

Living on a shoestring;
bamboozable 17 Answers: 1. You can count on it; 2. Foot in the door; 3. No can do; 4. Honest to goodness; 5. Way overpriced; 6.

Mad Cabs 1 Answers: 1. A Banana Peel; 2. A Bottomless Pit; 3. A Back Street Alley; 4. A Buried Treasure; 5. A Bump in the Night

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



VICTORIA KEEPS CONNECTING NEW PEOPLE.



In late March, Victoria hosted another highly successful Morning Tea at the Mercure Doncaster. The event reached full capacity, including one delightful lady who travelled three hours from Traralgon just to attend. It was a wonderful morning filled with discussion, connection, laughter and comparison of our worlds. A great morning tea, finishing at 2 pm.

ZILBRYSQ (ZILUCOPLAN) NOW AVAILABLE VIA THE PBS!

Zilbrysq (zilucoplan) has been listed on the Pharmaceutical Benefits Scheme (PBS)
for generalised Myasthenia Gravis (gMG)

<https://myastheniaalliance.org.au/zilbrysq-pbs-myasthenia-gravis-australia/>

Integrating Physiotherapy into Your Care Team

webinar is now loaded onto Myasthenia Alliance Australia website

<https://myastheniaalliance.org.au/integrating-physiotherapy-into-your-care-team-webinar>



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



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

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.

Beanie's for a Cause: Jaymie's Journey with Congenital Myasthenic Syndrome (CMS)

Jaymie was born in 2016. As her parents, already caring for two older children, we noticed early on that she wasn't meeting her developmental milestones. She also suffered from chronic eczema. Despite these challenges, Jaymie has always been a fun-loving child who will give absolutely anything a go. As she grew, we became increasingly concerned about her speech. Even with ongoing speech therapy, her progress was slow. More worrying was her difficulty swallowing food safely; choking became a real risk. These issues led us back to her paediatrician, and eventually to specialists at the Royal Children's Hospital. After years of uncertainty, Jaymie was finally diagnosed at age seven with a typical presentation of myasthenia gravis, a rare neuromuscular condition. There is no cure, but having a diagnosis meant we finally knew what we were fighting. The doctors involved have been extraordinary – not only in diagnosing her, but also in helping us advocate for Jaymie when she was removed from the NDIS after her diagnosis and when school failed to educate her safely. Their support helped us fight to get her NDIS reinstated.



Jaymie began her first medication, but instead of improving, she deteriorated. She was then given the chance to trial a second medication. While it hasn't solved everything, it has given her a little more energy each day. Last year she managed to attend school only 30% of the time. This year, she has already reached 80% (of the four days medically allowed) which feels like a huge victory.

Jaymie's aunty Debbie has made about 100 teal beanies for Jaymie to sell to raise awareness of myasthenia gravis. The number of times that Jaymie has presented to unfamiliar doctors, only to be met with confusion or unnecessary emergency responses, shows how little awareness there is of this condition.

The beanies are sold for \$10 each with all proceeds going to Myasthenia Gravis. Even when people don't buy a beanie, we tell them about the condition and ask them to take a selfie wearing one. We're collecting all these photos to create a large portrait made up of every person who has learned about myasthenia gravis through Jaymie in the past 12 months. This is our way of spreading awareness, building community and showing Jaymie that she is supported by an army of people who have an insight into what MG is.

Belinda

If you would like to support Jaymie's cause and buy a beanie, please email info@mgaq.org.au and we will put you in touch with Belinda.



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
ToowoombaJohn 0412 576 888	

COFFEE & CHAT ROUND-UP



- **Bundaberg**
Saturday, 18th April at 10.30am, Urban Dragonfly Cafe, 1B/1-9 Enterprise St
(Next to Bob Jane T-Marts tyres, Svensson Heights)
- **Sunshine Coast – Peregrine Beach**
Saturday 2nd May at 11.00am, Peregrine Beach Hotel,
221-229 David Low Way, Peregrine Beach
- **Gold Coast – Currumbin**
Saturday, 2nd May at 10.30am, Currumbin RSL, 165 Durling Street, Currumbin
- **Sunshine Coast – Wurtulla**
Monday, 5th May at 10.30am, Club Kawana, 476 Nicklin Way, Wurtulla
- **Gold Coast - Southport**
Saturday, 9th May at 10.00am Southport Sharks Club, Corner Olsen &
Musgrave Avenue Southport
- **Townsville**
Saturday, 16th May at 12 noon, Sports Club, 159 Bamford Lane, Kirwan
- **Moreton Bay – Mango Hill**
Friday, 22nd May at 10.30am, The Coffee Club, Mango Hill Market Place,
Corner Halpine Drive & Anzac Avenue, Mango Hill
- **Brisbane – Mount Gravatt**
Saturday 30th May at 10.30am, Club Southside, 76 Mount Gravatt Capalaba Rd,
Upper Mount Gravatt
- **Mackay**
Saturday 20th June at 10.30am Coffee Club Riverside, Canelands Central,
Matsuura Avenue, Mackay

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/c: 10263772

Ref: YOUR NAME