Myasthenia Gravis Association of Queensland Inc.

MessaGes

MARCH
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 MARCH 2025

What an unprecedented start to 2025! First it was massive floods in North Queensland and then Cyclone Alfred with its damaging winds, rain and more massive floods. The damage to many areas of Queensland have been overwhelming. But, we must remember that we Queenslanders are a tough bunch who rise to the challenge. It is always heartening to see how people rally to support their friends, neighbours and locals.

Our best wishes go to all members and their families who have been directly impacted by these harrowing weather events and we hope that your life returns to normal as soon as possible.

Rare Disease Day was held on 28 February. I hope that everyone took the opportunity to speak with family and friends about living with Myasthenia Gravis and also touched base with another person who has MG to just ask if they were okay. Susan White, representing the MAA, and Donna Formosa from the MGAQ management committee met with parliamentary personnel and representatives from Rare Voices in Canberra on that day. Being able to communicate and liaise with these people is a significant way of keeping our rare disease to the forefront of decision making.

Another significant event that is just a few months away is the **International Myasthenia Gravis Awareness Month.** The Lights-up Project continues to grow not only in Queensland but across other states as well. Do not forget to approach your local council about any local features that can be lit up in teal during the month.

While the MGAQ provides much free information, we certainly still need to have members who are financial so that the association can continue to operate. The $20 membership fee barely covers the cost of producing, printing and mailing out the newsletter 11 times a year. The association also has many ongoing activities and commitments such as running face-to-face and Zoom committee meetings, ensuring we provide the best two-way communication with members, continuing to produce and provide extra resources such as awareness information and brochures, being involved with research so that we have data and important information about the best treatments available, conducting meetings and get-togethers across the state – and the list goes on. So please, if you are not a current financial member, think about paying the $20 for category A Membership, $250 for category A Perpetual Membership and/or $20 for Carer/Supporters and help support YOUR association.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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

KNOW YOUR COMMITTEE

My name is **Anita Jackson** and I am a committee member and have had many roles in my time on the committee. I look after the Coffee and Chats in the Brisbane area and the organisation of other different functions which we have throughout the year. I was diagnosed with MG in the early 1960's as a teenager. I was lucky that I had a very good Neurologist who helped me with my medication and my general wellbeing as a person to continue a normal lifestyle. I had my thymus gland removed and it was a success and I was one of the first people to have it done in Brisbane. I have lived a normal life and have been off all medication for quite a few years now.

I enjoy the Coffee and Chats as I enjoy listening to other people's journeys and how they are coping with MG - spreading the awareness.

DATE CLAIMER

Saturday, 14 June 2025

MG and friends celebration day for

Oh MG Art Exhibition

JUNE AWARENESS FUNCTION

Scan to apply for Membership or to renew your existing Membership

Scan to make a donation to the Myasthenia Gravis Association of Qld Inc.

MYASTHENIA ALLIANCE AUSTRALIA

Framing the PBAC Submissions and why your participation has been impactful

PBAC SUBMISSIONS: YOUR PARTICIPATION IMPACT

Our vision is for each Myasthenia patient to have **equitable** and **timely access** to the **best available treatment** that most benefits **them**.

Thank you to everyone who joined us for the webinar about new treatments and Pharmaceutical Benefits Advisory Committee (PBAC) submissions, and to all of you who made a submission and shared your lived experience and treatment preferences as part of the PBAC process. The PBAC meeting takes place in March, and we will know the outcomes of this meeting about 6 weeks later.

We'd like to share with you a bit about what the MAA submissions looked like. The key message of all submissions was how the new treatments offer a real opportunity to come closer to our goals of reducing the burden of living with Myasthenia Gravis (MG). This includes not having well-controlled symptoms or living with the fluctuations of MG. Other goals include improving the quality of life for Myasthenia patients and increasing the opportunities for Myasthenia patients to participate in work, to enjoy more family and community activities, to travel more freely, and to spend less time at medical appointments and more time out of hospital. Our vision is for each Myasthenia patient to have equitable and timely access to the best available treatment that most benefits them.

Our patient experience is diverse and varies among us and this is why the MAA supports a broad range of treatment options being available and accessible. The MAA also considered where there are gaps and unmet needs with current treatments and how the new treatments offer new targeted treatment pathways and flexible or convenient delivery options, compared to current treatments.

The growing evidence base from our research and surveys over the last few years was crucial for the MAA submissions. We thank you for contributing to this research, because this informed the MAA submissions on behalf of patients. Your input to each of these surveys made a tangible difference.

Some interesting statistics that represent our experience in Australia include the following:

- The MAA surveyed 194 MG patients in January 2024: 47% of those surveyed did NOT feel that their MG condition/symptoms are currently well-controlled and 75% felt that their MG, including side effects from treatments, is a burden.
- Research conducted by Janet Sansoni and colleagues in 2023 surveyed 280 MG patients and found that 58.3% of MG participants reported moderate to severe limitations in daily tasks and activities and 28.4% reported some limitations. Compared to the survey conducted in 2011, this survey also showed that workforce participation has not increased over time in Australia.
- More recently in January 2025, 64% of our webinar participants who answered a live poll question said they feel their MG should be better managed in terms of reducing the burden of living with the condition and/or improving their quality of life.
- 96% of the webinar participants feel that it is important to be offered new treatments (79% felt it is extremely important and a further 37% thought it is somewhat important).
- Finally, at our 2023 national patient MAA conference, we asked the patient audience in a live digital poll to share one key word that comes to mind when they think of MG. The most common words were challenging and frustrating.

For more details on our past and current research projects, please visit **https://myastheniaalliance.org.au/research/**

Make sure you're registered for MAA news and updates at **https://myastheniaalliance.org.au/subscribe/**

You can also contact us directly by calling 1800 802 568 or reach out to one of our state associations: **MGNSW** or **MGAQ**.

It is a busy time for Myasthenia and we thank you again for your contribution to all research and advocacy activities.

Susan White (MAA Chairperson) & Natalie Windle (MAA Secretary)

Myasthenia
Alliance Australia

MYASTHENIA ALLIANCE AUSTRALIA

PROUDLY SUPPORTING MGBase

MGBase
Myasthenia Gravis Registry

The bold concept to have a physician captured, longitudinal data base reflecting real time evidence about treatment benefits for people with Myasthenia Gravis was first presented to the Myasthenia patient group in December 2016. The Myasthenia community committed to raising $40,000 to support this work. The project was known as eNID. At the 2017 Conference Dr Katherine Buzzard, who has been at the forefront of this work, explained the concept and by end of day the target had been met! Dr Buzzard and Dr Reddel continued to progress this project and by July 2020 additional funds had been raised inclusive of a total contribution of just over $100,000 from the Australian MG Community!

That feels like such a long time ago. Much patience was asked of our community but the outcome has been worth the wait. The eNID Project became **MGBase.** Please read on to understand more about how our Australian Specialists have taken the lead on this international opportunity!

The MGBase Registry is the first global observational registry to be launched for patients diagnosed with Myasthenia Gravis.

Take part by joining a collaboration dedicated to making a difference to the lives of patients with MG and other neuro-immunological diseases.

MAA proudly supporting MGBase!

The MGBase Registry is the first global, observational registry dedicated to evaluating outcomes data in myasthenia gravis. 'MGBase' was launched in December 2021, addressing a critical gap in the collection of 'real-world' patient data for this rare disease. Owned and operated by the MSBase Foundation, the MGBase Registry is built on the same robust governance and IT infrastructure that underpins the highly successful MSBase Registry for multiple sclerosis.

MGBase is developed for clinicians and provides them with access to a comprehensive data entry tool and an online research platform, paving the way for collaborative, international myasthenia research that aims to enhance the quality of care and improve patient outcomes. Membership is free and open to all practising neurologists treating patients with Myasthenia.

As at February 2025, the international registry contained over 1050 patients and is growing daily. Over half of the total patient cohort is being contributed by Australian MGBase centres in Victoria, Western Australia, NSW, QLD and Tasmania. 154 members (Specialists) are engaged across 12 countries and 24 clinics. The data is already contributing to research projects.

Patient registries such as MGBase are powerful instruments for expanding our knowledge of diseases. They are particularly useful in rare diseases, such as Myasthenia, where they can provide the opportunity to pool 'real world' data to reach a sufficient sample size for epidemiological and clinical research. If you're interested in having your clinical data contributed, please speak to your specialist about signing up to MGBase. A dedicated membership and IT team is available to support MGBase members. Visit the website for more information www.mgbase.org, or clinicians can contact info@mgbase.org directly for more information on how to join.

MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Lisa writes:-

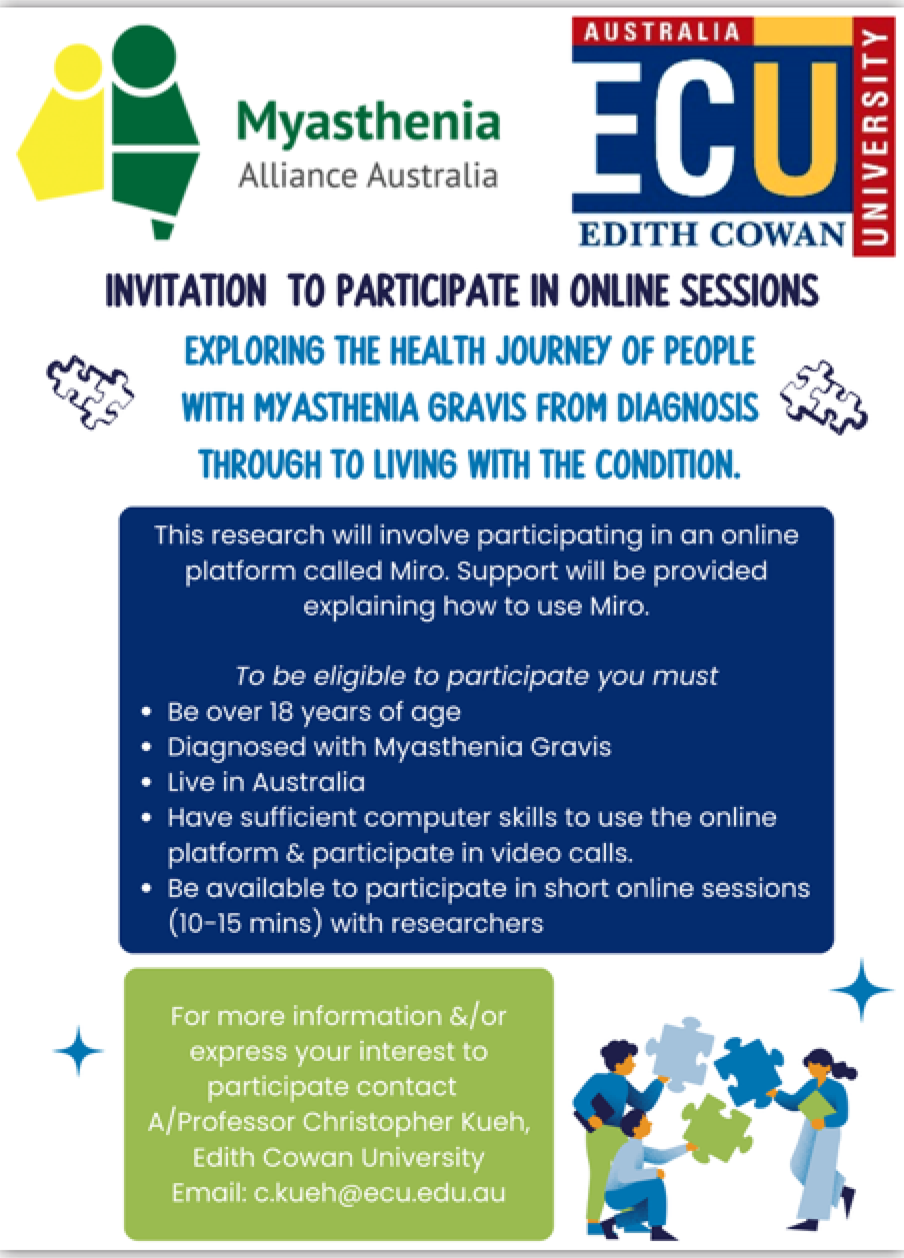
Invitation to participate in research exploring the Lived Experience of people with MG

The MAA has partnered with the Edith Cowan University to conduct research on exploring the lived experience of people living with Myasthenia Gravis. The research team is led by Associate Professor Christopher Kueh.

Our project focuses on understanding the experiences of individuals living with Myasthenia Gravis (MG) in Australia. We want to know about the journey of getting diagnosed with MG, living with the condition, and what a typical day looks like for those affected. This information will help us create better support systems and improve overall health outcomes for people with MG.

Participants will be invited to attend short sessions on-line with researchers and then use an online whiteboard called Miro to record their experiences of living with MG. Participants will be given assistance along with instructions from researchers on how to use Miro. The use of Miro will allow researchers to understand the experiences of Australian people living with MG.

To express your interest, to participate or for more information on this research, **please email A/Professor Christopher** c.kueh@ecu.edu.au



INVITATION TO PARTICIPATE IN ONLINE SESSIONS

EXPLORING THE HEALTH JOURNEY OF PEOPLE WITH MYASTHENIA GRAVIS FROM DIAGNOSIS THROUGH TO LIVING WITH THE CONDITION.

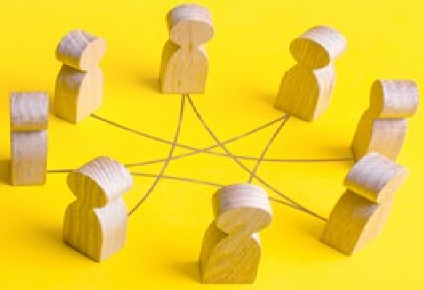
This research will involve participating in an online platform called Miro. Support will be provided explaining how to use Miro.

To be eligible to participate you must

- Be over 18 years of age
- Diagnosed with Myasthenia Gravis
- Live in Australia
- Have sufficient computer skills to use the online platform & participate in video calls.
- Be available to participate in short online sessions (10-15 mins) with researchers

For more information &/or express your interest to participate contact
A/Professor Christopher Kueh,
Edith Cowan University
Email: c.kueh@ecu.edu.au

MEMBERS' FORUM



Hi Everyone,
Melissa Giles shares her latest Blog.

Blog Post #12 "Pulling a rabbit out of a hat" is now available online:

https://story-telling.wixsite.com/seeing-things/post/12-pulling-a-rabbit-out-of-a-hat

Post #12 is about trying to adapt as a writer who has myasthenia gravis. This post introduces the new shorter style of blog post that I'll be writing from now on.

Regards, Melissa.

CONVERSATION CONNECTION COMPANIONSHIP

Craft on Fridays is a friendly group of like minded ladies who meet weekly to knit, crochet, chat, laugh and generally put the world to rights! Several of them very kindly helped make snowflakes for Chloe's installation.

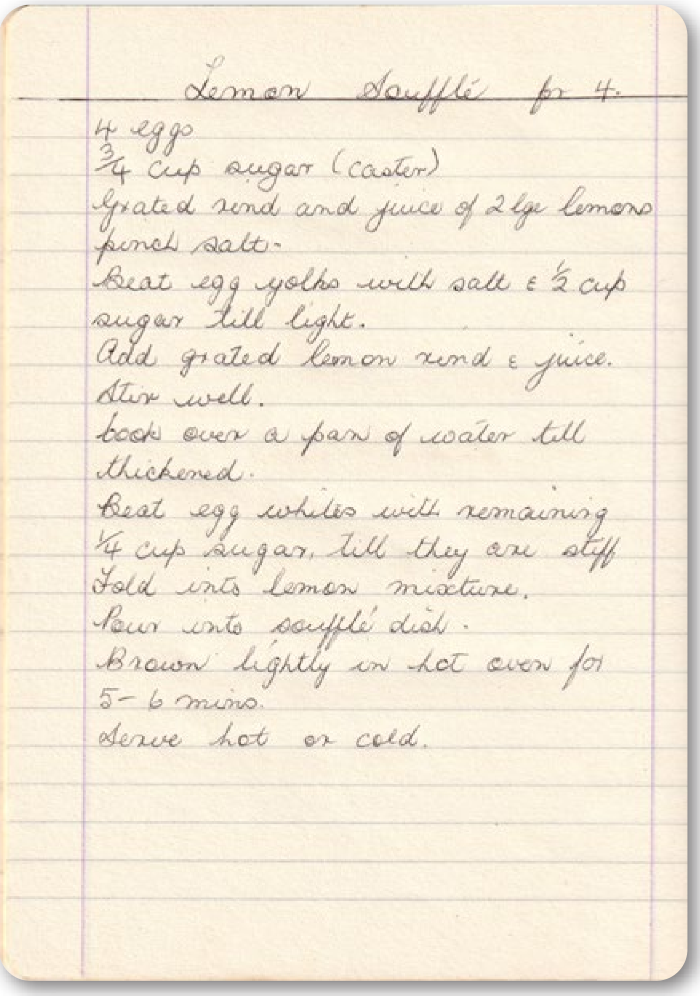
They are all looking forward to seeing her hard work and vision.

Sylvia

SUPPORT your Association by **VOLUNTEERING**.

CONVERSATION CONNECTION COMPANIONSHIP

The local Coffee and Chat is a safe space to share MG experiences with others. Here, Pat also shares her recipe.



Lemon Soufflé for 4.

4 eggs
¾ cup sugar (caster)
Grated rind and juice of 2 lge lemons
pinch salt.
Beat egg yolks with salt c̄ ½ cup
sugar till light.
Add grated lemon rind c̄ juice.
Stir well.
Cook over a pan of water till
thickened.
Beat egg whites with remaining
¼ cup sugar, till they are stiff
Fold into lemon mixture.
Pour into soufflé dish.
Brown lightly in hot oven for
5-6 mins.
Serve hot or cold.

L-R Pat, Sonia, Donna, Michelle, Scott

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/c: 10263772

WELCOME TO OUR NEW MEMBER

Annette S, Newport VIC

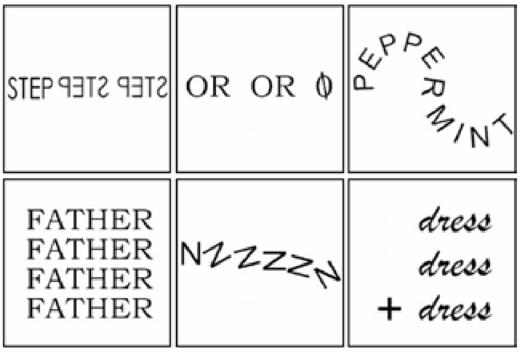
Puzzlers

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

Sudoku

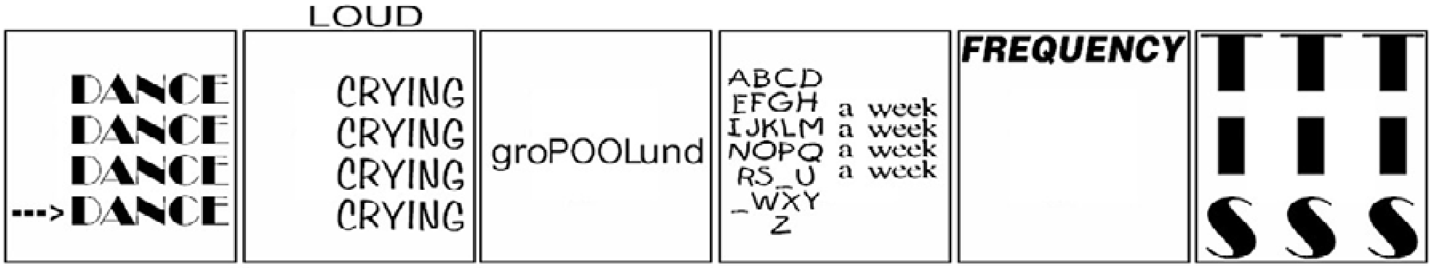
				1				
7		1	4	8		6	3	
5	6		2			8	4	
9		4	1	3				
	8		6		2	9	1	7
6				5	9			4
		7	9		4	1		3
	4	6			3	5		9
2				6				

Bamboozable



Bamboozable 16: 1. One step forward, two steps back; 2. Double or nothing; 3. Peppermint twist; 4. Forefathers; 5. Enroll; 6. Addresses.

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



WHAT WORD?

Can you guess what ONE word we are describing? It is just ONE word and this can get a little tricky but fun.

Example:

Clue: Display the animal hair

"Literal" Answer: Show Fur

End Answer: Chauffeur

1. Halt, tells the time
2. Off opposite, bird home
3. Tell the dog/cat to get away, car noisemaker
4. Animal wagger, used in plumbing
5. Noah's boat, aluminum container, cuts wood
6. Automobile, fix the piano sounds
7. Police officer, 5th letter, dog opposite
8. Clean the floor, cut of beef
9. 2+2, dads
10. 4th letter, dog wagger

ANSWERS

Bamboozable 8 Answers: 1. Last Dance; 2. For Crying Out Loud; 3. Inground Pool; 4. No TV for a Week; 5. High Frequency; 6. Sit Ups

What Word 2 Answers: 1. Stopwatch; 2. Honest; 3. Shoehorn; 4. Tailpipe; 5. Arkansas; 6. Cartoon; 7. Copycat; 8 Sweepstake; 9. Forefathers; 10. Detail

Look out for our
OTHER INITIATIVES

Queensland Lights Up

Story Bridge, Brisbane

Myasthenia Gravis Awareness Month

June 2025

Oh MG Art Exhibition

Logan Art Gallery (May 22 - June 14)

Exhibiting stories of those living with Myasthenia Gravis - **stories of resilience, strength, and hope**.

MG & Friends Celebration Day
SATURDAY, 14 JUNE 2025

www.mgaq.org.au

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us in Cairns on **Saturday, 22 March, at The Bluewater, 7 Harbour Drive Trinity Park at 12 noon** for informal Coffee and Chat. Visitors to Cairns are most welcome.

For more information, please contact **Donna on 0414 397 462.**

News from Townsville

We are meeting again on **Saturday, 26 April at 12 noon, Kirwan Sports Club, 159 Bamford Lane Kirwan**. Looking forward to your company.

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 more information, **please contact Denise on 0431 571 399.**

News from the Sunshine Coast

The Sunshine Coast group will meet on **Monday, 7 April at Kawana Club at 10.30am, 476 Nicklin Way, Wurtulla** for informal Coffee & Chat. All are welcome to attend.

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

News from the Gold Coast

For more information **Nader Amiri, Gold Coast Coordinator 0415 834 401.**

COFFEE & CHATS

Cleveland - Saturday 17th May at 10.30am
Farmhouse Café, 625 Main Road Wellington Point

ALL WELCOME! **RSVP Anita on 0414 588 312**

**Please send empty Mestinon bottles and crocheted snowflake donations to Chloe by 31st March 2025.
We are now stringing the snowflakes together and need Brisbane based volunteers to help.**

Oh MG Working Bee

**Saturday 5th April 10am to 1pm
Kingston Butter Factory,
270 Jacaranda Avenue, Kingston**