Myasthenia Gravis Association of Queensland Inc.
MessaGes
February 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 FEBRUARY 2025

Christmas and the holidays seem to have gone in a flash and we are back with the management committee starting on or continuing particular projects.

The end of any year brings with it necessary paperwork to be done as a charitable not-for-profit organisation. Reports to Queensland Health and the Australian Charities and Not-for-Profit Commission(ACNC) ensure that we are meeting our operational, financial and legislative requirements. Members also had the opportunity in January to write a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) in relation to possible future treatments for Myasthenia Gravis. With new and repurposed treatments becoming available it is important that we ensure that our *'Patient Voice'* is heard across all sectors of decision making. Sincere thanks to any of our members who made a personal submission to the PBAC.

If you received a phone call about expired membership, I hope that you have either updated your information and/or taken the step to renew. We only ask people to pay for the current year and do not ask for any payments in arrears from past years. As this money is used for things such as producing and sending out the newsletter, podcasts, website updates and functions for members it is important that we have funds available to continue these services.

If you are a current financial members and have not received the log-in for the Members' Only section of our website, please phone **1800 802 568** or email **treasurer@mgaq.org.au** . Much useful information is contained in this section of the website.

Rare Disease Day is observed every year on **28 February** (or 29 in leap years—the rarest day of the year). Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community. By sharing *'More Then You Can Imagine'* (photos, videos and experiences) online and with friends you are supporting Rare Voices' aim to change and improve the lives of the 300 million people worldwide who are living with a rare disease. Susan and Donna from our management committee attended a function in Canberra, representing both the MAA and MGAQ. Attendance at this function was vitally important as it was an opportunity to speak with politicians and decision makers in person and keep Myasthenia Gravis forefront in their minds.

Thanks Carol

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MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Welcome to 2025. This year we have hit the ground running with four PBAC Submissions for completion by January 29th. This opportunity allowed the MAA Board to connect with many people in the Australian MG Community. This was a true bonus to the fantastic opportunity of having four new and targeted medications put before the Pharmaceutical Benefits Advisory Committee for funding consideration. Whilst the MAA lodged four very comprehensive submissions on everyone's behalf, we were extremely keen to have these submissions supported by individual stories, preferences and concerns. It is our impression that people have done a great job in showing the PBAC that we indeed want more choices and we want the latest and most targeted treatments made available. I thank you all very much. Natalie Windle led the charge with this project and soon she will share more about the submissions and about the important role played by the general MG community on an on-going basis.

Our team has a very full schedule with specific areas of interest. Lisa Wright, MAA Board member, has significant experience in research and she is keen to utilise these skills for everyone's advantage. Currently she is working with a Sunshine Coast University student to explore *'Obstacles to Employment'* for people with Myasthenia. Thank you to everyone who has responded to the survey request.

Her next project is coming onboard and takes quite a different approach to telling the MG story. I do hope that you will consider participating. More information in the March newsletter.

You will continue to be introduced to our Board Members over the coming months but as a teaser, Craig has been working for many months on an updated MAA website. Keep watching out for this!

Donna Formosa and I represented Myasthenia patients in Canberra when Rare Diseases Day was celebrated. I hope you will share the social media posts and recognise the day in a meaningful way.

People may recall completing a survey way back in mid-2022 when researcher Dr Pakeeran Siriratnam was keen to understand more about our Covid experiences. He was delighted when 229 people successfully responded. After much time and effort Dr Sisriratnam's paper was published in a prominent journal just prior to Christmas. He has responded to the MAA request for feedback. Please see page 3 of this newsletter.

The MAA thanks everyone who generously assisted with this project.

Wishing everyone best possible health in 2025.

Warm regards
Susan White (MAA Chairperson)

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

DATE CLAIMER

Saturday, 14 June 2025

MG and friends celebration day for

Oh MG Art Exhibition

JUNE AWARENESS FUNCTION

MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

RESEARCH SUCCESS!

Doctor Siriratnam shares his appreciation.

Doctor writes -

Our experience working with MAA:

We are extremely grateful to Susan and MAA members for their generosity in completing our survey. We found our MG community extremely responsive and motivated to help each other and advance scientific knowledge.

Impact of our work.

As the pandemic experience in Australia was vastly different to other countries (with very low rates of COVID infections initially and strict lockdowns), the experiences and voices of our patients was very important to share. The major findings of our study published in an international journal was that of the 229 patients who responded, our population was highly vaccinated and had lower rates of hospitalisation for COVID-19 than in other countries. However, COVID-19 infection during the period of the survey did pose risks and many of our patients experienced negative psychosocial impacts. We hope our paper helps clinicians be aware of the range of impacts from the pandemic for our community.

Public access to the paper can be found at (https://rdcu.be/d410h). The abstract is as follows-

Abstract

Introduction/aims: Previous studies have demonstrated high morbidity and mortality in patients with myasthenia gravis (MG) who acquired COVID-19. We aimed to identify the impact of the pandemic on MG disease control, treatment and quality of life.

Methods: A prospective observational cohort study was conducted to identify the impact of the COVID-19 pandemic on Australian patients with MG. We conducted an online survey through Myasthenia Alliance Australia from May 2022 to July 2022.

Results: Among the 229 patients who responded to the survey, most patients had three (80; 34.9%) or four (116; 50.7%) doses of the COVID-19 vaccines, 65 (28.4%) had contracted COVID-19, with 6 patients (9.4%) requiring hospitalisation. A large proportion of patients responded that the pandemic had no impact on their MG disease control (123; 53.7%) or treatment (111; 48.5%). Most patients felt the pandemic had either a mild (111; 48.5%) or moderate (50; 21.8%) impact on their mood.

Conclusion: Our study provides a snapshot of the types of impacts experienced by myasthenic patients during the pandemic, in particular the psychosocial effects. As we continue to live with COVID-19, clinicians should consider its various impacts in the holistic management of their patients.

INTRODUCING OUR NEW MEMBERS

Gregory, Spreyton TAS

Jaymie and Belinda, Parkenham VIC

Daniel, Brisbane QLD

Anthony, Christmas Hills VIC

On Tuesday, 11th February 2025, I had the privilege of representing MGAQ alongside Susan White, Chair of Myasthenia Alliance Australia (MAA) at the Rare Voices Australia (RVA) Rare Disease Day Parliamentary Event in Canberra.

This was a valuable opportunity for us to engage with parliamentarians and together with other stakeholders advocate for the needs of individuals who have a rare disease including Myasthenia Gravis. It was an enriching experience to also meet Nicole Millis (CEO) and the RVA team and to witness the progressive work that has been undertaken by Rare Voices Australia for the rare disease community.

Donna Formosa

- **Dr Tarun Weeramanthri AM, Chair RVA**

- **Dr Mike Freelander MP, Co-Chair Parliamentary Friends of Rare Diseases**

Hon Mark Butler MP, Minister for Health and Aged Care

In summary the Hon. Mark Butler MP spoke on:

- Removing the obstacles to support Rare Disease Disability and to improve access for support.
- Establishing an Implementation Advisory Group which resulted from a recent Health Technologies Assessment (HTA) review. Nicole Millis (Chief Executive Officer RVA) has a seat on this group.
- Funding by the government to Rare Voices Australia (RVA) to create the RARE Portal Project (Rare Awareness Rare Education). It occurred because the government wants to improve the outcomes for people living with a rare disease. It will also include access to better information about rare diseases for patients and healthcare professionals..
- Looking to reform access to medicines and to increase PBS listings.

- **Hon. Warren Entsch MP with Donna and Susan**

- **Meeting with Annie and Fiona from Angelman Syndrome**

- **Dr Monique Ryan MP**

- Hayley, Neuromuscular WA

- Donna and Susan outside Parliament House

- Senator the Hon. Anne Ruston, Shadow Minister of Health and Aged Care

- Nicole Millis, RVA CEO and Senator Wendy Askew MP, Co-Chair Parliamentary Friends of Rare Diseases

- With the Rare Voices Australia team

- Susan and Dr Mike Freelander MP

RARE DISEASE DAY

FRIDAY 28 FEB. 2025

Rare Disease Day is the globally co-ordinated movement for Rare Disease Day working towards equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.

MGAQ SUPPORTS THE "LIGHT UPS" IN QUEENSLAND FOR RARE DISEASE DAY.

Brisbane City Council - 28 February

The Story Bridge, Victoria Bridge

City of Logan - 28 February

Wine Glass Water Tower, Hillcrest,
Jacaranda Tower, Underwood
Telfer Street Tower, Shailer Park

Ava, living with a rare metabolic disease, and her mum Tammie from Australia. Raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers. Visit rarediseaseday.org or scan the QR code to learn more.

Word Search

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

Word Search
Famous Female Singers

BLIGE
CAREY
CASS
CLOONEY
CROW
DION
ESTEFAN
FLACK
FRANKLIN
HILL
HOUSTON
JACKSON
LAUPER
LOPEZ
LOVE
MADONNA
MCENTIRE
NICKS
PARTON
REDDY
RONSTADT
ROSS
SIMON
STREISAND
SUMMER
TURNER
TWAIN
WARWICK
WINEHOUSE
WOMACK

CONVERSATION CONNECTION COMPANIONSHIP

Sunshine Coast kicks off the year

KNOW YOUR COMMITTEE

My name is **Rosalyn Holland** and I am the Medi Alert Officer. My role is to process Medi Alert applications after the Treasurer has taken their particulars. So, if you happen to get a call from me it is just to check that the information I have is correct.

I developed MG in 2013 in Mackay with symptoms not unlike a stroke. Fortunately, I received the right treatment promptly. I am one of the lucky ones on our committee as I am controlled by medication.

Myasthenia Gravis
Association of Queensland Inc.
P.O.Box 16, Mt. Gravatt, QLD 4122
Freecall 1800 802 568
www.mgaq.org.au

In case of Medical Emergency
I am not intoxicated. I am ill. I have
MYASTHENIA GRAVIS

My name is: ____
Address: ____
Phone: ____
Doctor: ____
Phone: ____
Specialist: ____
Phone: ____
Hospital: ____
Phone: ____

PLEASE CONTACT MY DOCTOR

Myasthenia Gravis Association of Queensland Inc.

Disclaimer

This is a short, incomplete list of medications that can worsen symptoms in patients suffering from myasthenia gravis (MG).
This list is designed as an aid to assist guiding therapeutic decisions for MG patients and their doctors.

Important

The effect of these drugs on MG symptoms is variable from patient to patient. ALL the drugs listed CAN be used in patients with MG with appropriate caution and in the appropriate clinical setting. If a drug appears on this list, this does NOT signify that it can never be used in MG patients. If a drug does NOT appear, this does not signify that it is safe to use in all MG patients

For further information:
www.mgaq.com.au/drugs_mg

MYASTHENIA GRAVIS

DRUG ALERT CARD

As a financial member of the MGAQ you can order your FREE Medi Alert at:
https://www.mgaq.org.au/request-for-medi-alert-card

OH MG ART EXHIBITION:

A Unique Opportunity to Share Your Myasthenia Gravis Story

The much-anticipated Oh MG Art Exhibition is set to open to the public at **Logan Art Gallery on May 22nd, with an exclusive opening night on May 30th. The exhibition will run until June 14th,** culminating in a special closing party for individuals affected by Myasthenia Gravis (MG), their families and friends, as well as healthcare professionals and other stakeholders.

Chloe, the curator of this powerful exhibition, is calling on the community to contribute in meaningful ways. She is seeking donations of crochet snowflakes and Mestinon bottles to be sent in by the end of March. Receipt of these donations by the due date is essential so that Chloe can remove the labels from the bottles and stitch together the snowflakes. This deadline will allow Chloe sufficient time to prepare these items for inclusion in the exhibition.

In addition, Chloe is inviting people to submit their portraits for inclusion in the exhibition. This is a unique chance to share your personal MG journey. Chloe emphasizes that this exhibition is not about showcasing the “sickest” or most challenging story—each person’s experience with MG is valid, and she wants to highlight the diverse and individual stories within the community.

If you would like to send in your portrait, ask questions, or learn more about the exhibition, please don’t hesitate to reach out to Chloe via email at **chloe.wigg@gmail.com** or visit her website **www.chloewigg.com/ohmg**

This exhibition is about telling the stories of those living with Myasthenia Gravis—stories of resilience, strength, and hope. Don’t miss the chance to be part of this important and heartfelt project.

Donations can be sent to:

PO BOX 628

Rochedale South QLD 4123

Volunteers Wanted For Important Task

Let's Make a Difference to support Chloe with her preparations for the Oh MG Art Exhibition.

MGAQ are seeking volunteers to remove labels from the donated Mestinon bottles.

For more information contact Donna on 0414 397 462

Homemade Mango Ice Cream Recipe

Author: Nagi | RecipeTin Eats **Prep:** 15 mins **Cook:** 10 mins **Total:** 25 mins
Dessert

INGREDIENTS

- 2 large mangoes, ripe and juicy - to make 2 cups puree
- 395 g / 14 oz sweetened condensed milk (1 can)
- 2 cups thickened cream / heavy cream / whipping cream , cold

INSTRUCTIONS

1. Dice the flesh of the mango. Puree using a blender, food processor or stick blender then measure out 2 cups of mango puree (about 2 1/4 cups of diced mango).
2. Pour puree into a non stick skillet over medium low heat. Cook, stirring constantly, for 8 - 10 minutes or until it reduces by half. The test is when you can drag a wooden spoon across the skillet and the path remains there for a second. Or measure out the puree to ensure it's reduced to at least 1 cup - less is even better!
3. Cool puree.

ICE CREAM

1. Combine cooled mango and condensed milk in a bowl. Whisk until combined.
2. Beat cream with a hand held beater or stand mixer until stiff peaks form.
3. Take a scoop of cream and put it in the mango mixture. Fold through until mostly combined - lumps is fine (this is just to lighten it up a bit).
4. Then pour the mango mixture into the cream. Fold through rather than mixing vigorously like you would cake batter, until lump free. This will take a few minutes.
5. Pour into a container (preferably with a lid). I recommend glass, if you can, or other non reactive container.
6. Place a piece of baking / parchment paper on the surface. Then place lid on or using cling wrap.
7. Freeze for 12+ hours.
8. Remove parchment paper. Stand for 5 minutes to soften slightly, then scoop and serve!
9. If frozen for 24 hours or longer, it will need a couple of extra minutes to soften to a scoop able consistency.

NEWS FROM AROUND QUEENSLAND

News from Cairns

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

News from Townsville

The Townsville MG Lunch was held on Saturday 15 February at Kirwan Sports Club. Everyone enjoyed coming together for the start of 2025. Our next lunch will be on **Saturday 26 April** 2025**, at 12 noon at Kirwan Sports Club, 159 Bamford Lane, Kirwan**. Looking forward to your company. Family members are welcome.

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 March 2025, Kawana Club, 476 Nicklin Way, Wurtulla at 10.30am.** For more information please contact **Michael on 0447 887 652.**

News from the Gold Coast

Hi everyone. Our next Coffee and Chat will be at **10am on Saturday 15 March at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport.** I hope to see you all there.

For more information, please contact **Nader on 0415 834 401.**

COFFEE & CHATS

RSVP Anita on 0414 588 312

SPRINGWOOD – 10.30 am Saturday 20 March 2025,
More Cafe, 1/34 Fitzgerald Ave Springwood
– All Welcome!

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/C: 10263772

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
JUNE AWARENESS FUNCTION **MG and friends celebration day for OH MG ART EXHIBITION**	**Saturday, 14 June 2025**	**Logan Art Gallery, Wembley Road & Jacaranda Avenue**