



Myasthenia Gravis Association of Queensland Inc.

MessaGes

September
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 SEPTEMBER 2024

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. Also, a warm welcome to the 'new' members who attended.

I want to express my personal thanks to the committee members who remain on the committee and who 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. Thanks also to Kirstine Shrubsole and Yvonne Hornby-Turner who have been committee members for the past few years. Your work for the management committee has been appreciated. The make-up of the management committee for 2024-2025 is on page 3 of this newsletter. Our current Rules (originally the Constitution) has now been accepted and relevant paperwork submitted to the Office of Fair Trading. We thank McCullough Robertson lawyers and Aaron Dahl and Emma Hambleton in particular for their pro bono work on this, thus ensuring that we meet legislative requirements.

As well as the election of office bearers for 2024-

25 other business included acceptance of the Annual Operational Plan, the decision to keep the membership fees the same and the appointment of our auditor.

Our Annual Operation Plan is a working document for the management committee and a way of ensuring that Member Welfare, Research, Awareness and Advocacy remain at the forefront of what we do and what we achieve. This plan also provides the basis of our reporting to Queensland Health, both in person and by the regular reports we submit.

The next MGAQ activity to look forward to is our **Get-together on Sunday, 10 November at the Gold Coast**. We have this as our Christmas function as we have found that many people have commitments with family and friends in December. We look forward to catching up with as many members as possible in a relaxed, informal setting. More information on this get-together is on page 8 of this newsletter.

I hope that everyone is keeping well, particularly as we move into our summer and all the trials and tribulations associated with the hot weather. Please stay healthy and safe.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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COMMITTEE MEMBERS

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MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

The MAA Board continue to manage/follow a large and significant number of connections and projects. Recently the **Pharmaceutical Benefits Advisory Committee (PBAC) announced the outcome of their July Meeting**. The MG community were keenly waiting to hear the PBAC Outcomes as two new medications, Raviluzimab and Zilucoplan, had been reviewed. Regrettably both medications received a "Not Recommended" verdict. The PBAC did recognise the high clinical need for effective therapies for gMG. Whilst extremely disappointing it is not the end of the process. Both Pharmaceutical Companies assure the MAA that they will resubmit in 2025. Full minutes of the PBAC meeting will be published and these minutes will assist the Companies to gather additional information. Please see the statement provided by Alexion (page 7) A welcome new addition to the MGAQ website is a must see. Louise Healy, Education and Advocacy Manager for Rare Voices Australia (RVA) presented at the 2023 Conference. **Louise discusses how to advocate for oneself**. This may be at a personal level or a community level. She provides many good tips and details around how to proceed. Link here <https://mgaq.org.au/rare-diseases-and-advocacy> Craig Streatfield, MAA Board member and project officer, represented the MAA by attending the **Neurological Alliance Australia (NAA) Summit**. The MAA is an NAA Member. We thank Craig for travelling and making himself available.

Craig shares the following summary -

The National Summit was hosted by Neurological Alliance Australia (NAA) in Canberra on June 25, 2024. The summit was attended by approximately 100 people and included people with neurological diseases, policy makers, researchers and clinicians. The summit was a great success, and it was very pleasing to see the level of politicians attending.

The main points from key speakers included -

- **Rohan Greenland – Chair of NAA:**
 - o Importance of a collective voice that advocates for neurological conditions
 - o Strong focus on neurological focused research
 - o Access to new therapies and technologies
 - o Better integration between government sectors including aged care, health, disability etc.
 - o Importance of listening to patients lived experiences and importance of patient groups having a say in parliament
 - o Launched the Count Us in campaign
- **Hon. Ged Kearney – Assistant Minister for Health and Aged Care:**
 - o Committed to the mission of NAA and better integration of government sectors
- **Prof. Pam McCombe:**
 - o Importance of research and focusing on commonalities between different neurological conditions, not differences...better use of limited research money
 - o Importance of a national brain bank that ALL researchers have access to
- **Senator Jordan Steele-John – Greens spokesperson on Health and Disability:**
- **Georgina Carr – UK NA CEO:**
 - o Similarities between issues in Australia and the UK
 - o Strong focus on awareness, patients voice and lived experiences
 - o Issues with politicians simply not understanding the needs of people with neurological conditions
- **Hon. Bill Shorten – Minister for the NDIS:**
 - o Acknowledged issues with the NDIS including current cost, rorting, services not covered

Learn more about the NAA here - <https://neurologicalalliance.org.au/>

Kind regards Susan

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

Conversation, Connection, Companionship

incorporating the Annual General Meeting

YOUR MANAGEMENT COMMITTEE FOR 2024-2025

We are pleased to announce your management committee for 2024-2025. They are:

PRESIDENT	Carol Buchanan
VICE PRESIDENT	Sharin Nisha
SECRETARY	Craig Streatfeild
TREASURER	Denise Hannay
COMMITTEE MEMBERS	Anita Jackson, Rosalyn Holland, Susan White, Donna Formosa, Lisa Wright.

This group of volunteers will work tirelessly for people with myasthenia gravis and their families.

The AGM not only informed members of the wonderful work your association is doing for you but also allowed time to catch up with friends, both known and new.

While we filled all of our executive positions, we failed to have any nominations from the floor for the two vacant management committee positions. This makes it very difficult for members of the committee to provide the best service we can. Please contact 1800 802 568 if you can help in any way. Whilst the agenda was a full one, the decision

to not have a guest speaker meant that people could interact in a very informal way over lunch.

Our new Rules were accepted and now the required paperwork will be lodged with the Office of Fair Trading. Other items included appointing our Auditor for this financial year, accepting our Annual Operation Plan and keeping membership at the same cost.

Chloe Wigg spoke about the fantastic art project which she is leading and also facilitating.

CONTINUES NEXT PAGE



• **The MGAQ Inc. Committee (L-R)** Donna Formosa, Rosalyn Holland, Susan White, Denise Hannay (Treasurer), Carol Buchanan (President), Sharin Nisha (Vice President), Craig Streatfeild (Secretary) and Anita Jackson.

Her request for empty Mestinon bottles is ongoing as she has about half the amount she needs. She also asked if any members who can crochet or know of a craft group that does so, please get in touch with her if you can help.

Ella Bliss, Carer Gateway Wellways, spoke about the support available to Carers.

The information was very informative and she eluded to services about which people might now have known.



• Chloe Wigg speaking about 'Oh MG' art project.



• Ella Bliss, Carer Gateway Wellways.





Advocating for the **best outcomes** for Australians living with a **rare disease**

Rare Diseases and Advocacy - Louise Healy

Louise Healy is the Education and Advocacy Queensland Manager at Rare Voices Australia (RVA). Louise's connection with rare conditions began when her first child was born with a rare metabolic disorder. Louise has been involved in rare disease support and advocacy for over 10 years and has led successful advocacy campaigns for access to medicines and support programs for people with rare disorders of protein metabolism. Louise is a previous RVA Board member, current member of the Queensland Genomics Community Advisory Board and a founding board member of the Global Association for PKU.

Louise presented at the 2023 fourth National Patient Focused Myasthenia Gravis Conference in Sydney where she provided invaluable insights into effective advocacy for rare diseases.

Watch the presentation with Louise Healy HERE:

<https://player.vimeo.com/video/916610966?h=37966b0782>

“

SUPPORT *your Association by*
VOLUNTEERING.

”

MGAQ.org.au Member Log-in

The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

Don't forget you can find this on your PC and also your phone.

An access code with username and password is sent out to all current financial members via email.

Log on to: www.mgaq.org.au

Click on Log In

Enter username and password

Click on Member Only

Available Now



2023 MAA CONFERENCE VIDEO RECORDINGS

If you have problems signing in
please contact 1800 802 568 or
email info@mgaq.org.au



MGAQ Inc. PODCASTS

CAN YOU SEE YOURSELF CREATING PODCASTS?

The MGAQ owns a suite of podcast and vodcast equipment. It is currently stored at the house of one of our management committee members. However with the downsizing of their residence there is no longer the space to store this equipment. Do you live in Brisbane and environs? Do you think this volunteer activity could be a new interest for you or a family member? The role comes with all the equipment provided plus tuition from our current Dr Podcast. What you see in the photo is what you will receive. Interested?

Please contact Dr Podcast at podcast@mgaq.org.au



Be an MG **CHAMPION** – use your **VOICE**

PBAC JULY MEETING OUTCOME - RAVULIZUMAB

Alexion has shared the news that unfortunately their medicine, Ravulizumab, was not recommended by the PBAC at the July 2024 meeting.

They assured us that although they are deeply disappointed, they are committed to working with the PBAC alongside the MG clinical and patient community to bring access at the earliest opportunity to their treatment, and are focused on preparing another PBAC submission.

Their Patient Advocacy Director, Libby Noble told us: “We had hoped for a different outcome and we understand it’s both upsetting and frustrating to many who struggle with this condition and especially to those who took the time to share their views to the PBAC. We want to extend our sincere gratitude to MAA and the MG community for their invaluable input and support throughout this process. On a positive note, we are pleased that the PBAC recognised the high clinical need for effective therapies for MG, particularly in patients who are not responding to or are unable to use existing therapies, and for those with refractory disease. That recognition is testament to the lived experience shared by patients and caregivers that helped to shape that understanding, and sets a strong foundation for our continued efforts to bring access to much needed new treatment options.”

Alexion are working on their next steps and will share an update on timings with us as soon as possible. They would also like to invite the community to join a webinar on Friday 11 October to share the PBAC outcomes in greater detail, address community concerns, and update on their continued efforts to advocate for timely and equitable access in MG.



“ We had hoped for a different outcome and we understand it’s both upsetting and frustrating to many who struggle with this condition and especially to those who took the time to share their views to the PBAC.

”

SUNSHINE COAST September 24



PATIENT Voices Matter

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us in Cairns on **Saturday, 26 October**, at **Vines Cafe (Limberlost Nursery) 113 Old Smithfield Road, Freshwater at 10.30am** for informal Coffee & Chat. Visitors to Cairns are most welcome. For more information, please contact **Donna on 0414 397 462**.

News from Townsville

Townsville MG lunch will be our **Christmas Lunch** and is on **Saturday, 16 November 2024**, at **12 noon at Kirwan Sports Club, 159 Bamford Lane, Kirwan**.

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

News from the Sunshine Coast

The Sunshine Group will meet on **Monday, 7 October at 10.30am** at **Kawana Club, 476 Nicklin Way Wurtulla**. All visitors to the area are also welcome.

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

News from the Gold Coast

Hi Everyone, Our next meeting will be **for lunch at 11.30am on Sunday 10th November at Southport Sharks Club, Corner Olsen and Musgrave Ave. Southport**. I hope to see you all there. Visitors are welcome.

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



COFFEE & CHATS

RSVP Anita on 0414 588 312

GREENSLOPES – Saturday 12 October at 10.30am,

The Jam Pantry, 2/575 Logan Road Greenslopes

– All Welcome!

NEW MEMBERS

Amy, South Brisbane QLD

Roger, Churchill VIC

Bruce, Toowoomba QLD

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
MGAQ Christmas Function	Sunday 10th November 2024 at 11.30am	Southport Sharks Club, Gold Coast

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

Coffee & Chat
Support



Conquer MG Anywhere!

www.mgaq.org.au

1800 802 568



***Have a virtual
cuppa with us!***

Coffee & Chat Support Via Zoom.

If you can't attend a coffee and chat session in person, Do Not Despair.

MGAQ is happy to introduce a virtual coffee and chat via zoom in the comfort of your home.

Craft and Chat with Chloe

"Come join Chloe for an online craft & chat session.

**Session will be held
26 September at 10:30am.**

Bring along something you have been working on or just bring a cuppa, meet others with MG and have a good chat. "Get in quick as numbers are limited."

This is a Member Only benefit.

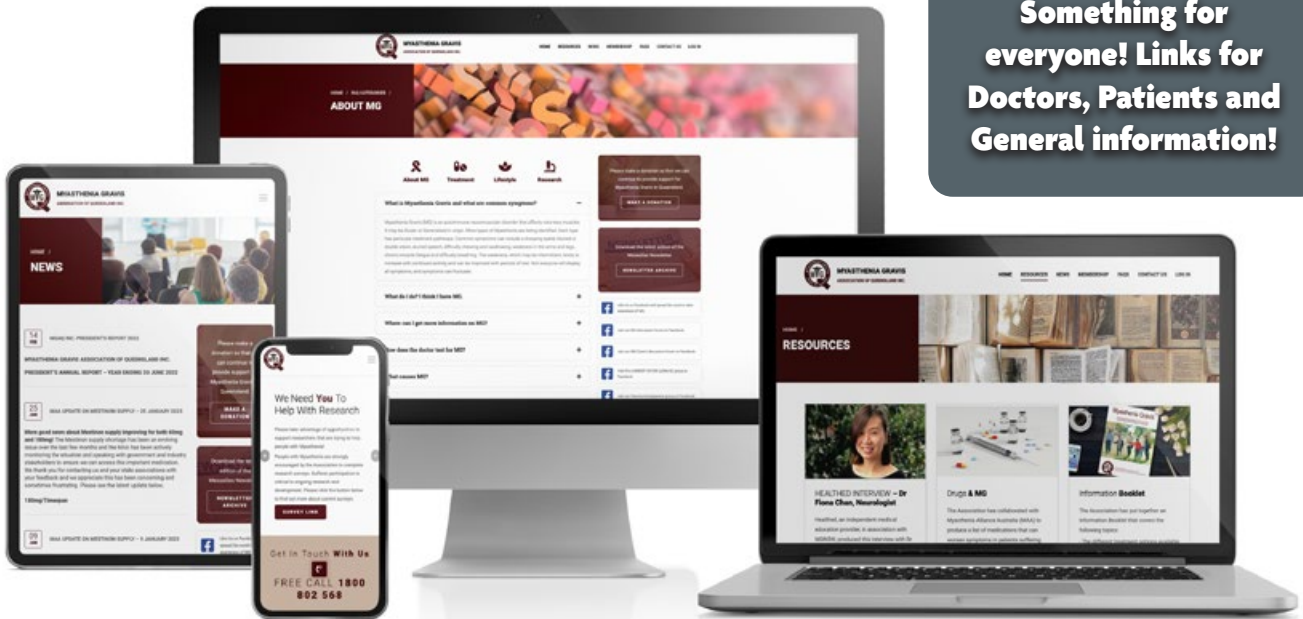
**To register please email:
info@mgaq.org.au**



There's more to the MGAQ.org.au website!



Scan to access



Something for everyone! Links for Doctors, Patients and General information!

FREQUENTLY ASKED QUESTIONS



Useful information organised under four categories. Visit mgaq.org.au/faqs or scan the QR code to access.



About MG



Treatment



Lifestyle



Research

INFORMATION BOOKLET

The Association has put together an Information Booklet that covers the following topics:

- the different treatment options available
- information about the condition
- medication
- facts for the patient and their family

The Information Booklet is available by download at mgaq.org.au

A paperback version of this booklet is available by contacting the Association via the contact page, or calling the Freecall number 1800 802 568.

LATEST NEWS & EVENTS

Keep up to date with the latest information, medications and events about MG in Australia and access all work that the MGAQ has done throughout the years visiting mgaq.org.au/news or scan the QR code to access directly.



DRUGS & MG, MEDI-ALERT WALLET CARD

The Association has collaborated with Myasthenia Alliance Australia (MAA) to produce a list of medications that can worsen symptoms in patients suffering from myasthenia gravis (MG).

This list is designed as an aid to assist in guiding therapeutic decisions for MG patients and their doctors.

Members can avail themselves of a credit card sized, laminated "Wallet Card" designed to provide "Medi-Alert Support".

The card quickly identifies the condition and includes basic personal details with emergency contact information.

It also includes the "Drugs to be Used With Caution" information.

There is no extra charge for this service.

An application form can be obtained via the website or via contact on 1800 802 568.

RESEARCH OPPORTUNITIES

LIBRARY RESOURCES

FACEBOOK CLOSED DISCUSSION GROUPS

CONTACT ACCESS

MEMBERSHIP ACCESS

DIRECT MEMBER BENEFITS ACCESS