



Myasthenia Gravis Association of Queensland Inc.

MessaGes

November
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 NOVEMBER 2024

It is hard to believe that we have less than two months left in 2024. They do say that, the older you get, the faster time goes by and I am sure this is true. Now, we all have to be thinking about Christmas.

The management committee had a long meeting this month. As well as conducting our usual business, we progressed the production of our handbook which outlines the accountabilities and responsibilities of committee members as well as unpacking the tasks undertaken throughout each year. This handbook will prove invaluable for both the current committee and others who join the committee into the future.

In order for our association to remain viable we must maintain and try to increase our financial membership. Unfortunately, each year this is becoming more of a problem. On our website in the Members' Only section there is a great deal of information, articles etc that can only be accessed by people who are financial.

Financial members should have received an email detailing the new log-in details to be used from 1 November. If you did not receive this email please contact Denise on treasurer@mgaq.org.au. All unfinancial members should have been contact-

ed by Anita in relation to renewing or cancelling your membership. If you know of anyone who has passed away or changed address please phone **1800 802 568** so we can act on this information.

At our Annual General Meeting in September two management committee members' positions remained vacant. Please phone **1800 802 568** if you want to know more about what membership of the management committee entails. Remember that, if you have a bit of spare time to give, it would be appreciated as every little bit of time helps.

Many thanks to those people who have been busy crocheting teal and white snowflakes for Chloe's art project. This is a huge undertaking and we thank Chloe plus her willing band of helpers for their continued efforts. If you wish to help please phone our 1800 number so this can be organised.

On page 4 you will find information inviting people to participate in an "MG and Work Survey". Please click on the link to find out more and then decide on possible participation.

Stay well, particularly as the summer heat is coming with a vengeance.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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Queensland
Government

Ausenco

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

HTA and PBAC? What/who are they and what does it mean for us?

You may be hearing more about HTA and PBAC from the MAA and among MG patient chats and meetings. You may have made your submission about new treatments for MG earlier this year, or you may generally follow updates about new treatments and how they come to be available to us in Australia. But what or who exactly is HTA and PBAC?

Let's take a step back and look at these important organisations and processes.

HTA stands for **Health Technology Assessment**. This is the multidisciplinary analysis and evaluation that studies the medical, economic, social and ethical implications of the development, diffusion and use of health service delivery and associated technologies, in a systematic, transparent, unbiased and robust manner.

PBAC is the **Pharmaceutical Benefits Advisory Committee**. They recommend new medicines for listing on the PBS (Pharmaceutical Benefits Scheme) based on medical conditions, clinical effectiveness, safety and cost-effectiveness.

It is also worth noting that the **TGA** is the **Therapeutic Goods Administration**, which is the regulatory agency that decides if a treatment is safe and fit for purpose. The TGA often approves a treatment or therapy before it moves to PBAC (but not always).

Now that we've covered the acronyms, let's take a look at why this matters for us as patients. Quite simply, it is because **the patient voice matters**. Our involvement in these assessment processes "ensures that the advice provided is informed by the needs of the people living with health conditions" ([Conversations for Change Report](#), 2023, p.1). When making a submission to PBAC, you can tell your story and talk about what it is like to live with MG, your unmet needs and your quality of life, the pros and cons of current treatments, the desired benefits of new treatments and how they might make a difference in our lives.

As an organisation representing MG patients across Australia, the MAA advocates for us to ensure that a range of beneficial treatments are **available, accessible, and affordable**. This aligns with Priority 2.4 of the [National Strategic Action Plan for Rare Diseases](#): Enable all Australians to have equitable access to the best available health technology.

The Patient Voice Initiative (PVI) provides some really useful tips for making submissions to PBAC:

1. **Do share what you know and tell your story** (don't cut and paste)
2. **Be specific** (don't give general information)
3. **Do explain the difficulties and impact of having a rare disease** (don't give number of cases/incidence)
4. **Do explain what the side effects are/were and what that meant for daily life** (don't say 'difficulty managing side effects')
5. **Do explain the reality of living with the condition** (don't explain the condition)
6. **Do explain the reality of having (or not having) treatment** (don't explain the treatment)
7. **Do submit what happens in the real world** (don't submit clinical data)
8. **Do consider collecting and contributing to studies that answer the questions you think are most important** (don't submit published literature and statistics)
9. Take a look at this clear diagram of how medicines/treatments are listed on the PBS: <https://www.patientvoiceinitiative.org/patient-experience-and-participation/pharmaceutical-benefits-scheme/#howpbsworks>

You can learn more about HTA and PBAC though PVI's Patient Voice Hub here:

<https://www.patientvoicehub.org/training/index.cfm?event=page.login>

You can subscribe to the government's HTA Engage communications here: <https://www.health.gov.au/using-our-websites/subscriptions/subscribe-to-hta-engage-communications>

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It is an exciting time for MG in terms of research and new treatments that offer us choices to better meet our preferences - for example, if you prefer taking tablets to an IV infusion in hospital, or if you prefer a lower cost treatment.

We encourage you to keep participating in research and submitting your feedback. This is how we can make the most of the opportunities to use our voice and share our lived experience. It is often said among stakeholders now that **patients are the experts in being patients and knowing how it feels to live with MG**. This is why we are part of these important decision-making processes.

If you have any questions or concerns, please reach out to the MAA by calling 1800 802 568 or emailing info@mgaq.org.au. You can also directly contact the state associations, same contact details for MGAQ and info@myasthenia.org.au for MGNSW.

Article by MAA Board Member – Natalie Windle

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

Conquer MG
Anywhere!

Coffee & CHAT Online!



Join us for a virtual coffee & chat support
meetup via Zoom to connect, share, and
support each other on our myasthenia journey.

www.mgaq.org.au 1800 802 568



**“Let’s talk Thymectomy - connecting individuals who have
undergone or are considering thymectomy as a treatment option”**

Wednesday, 20 November at 7pm via ZOOM

All MGAQ Financial Members are invited to register at info@mgaq.org.au

Coming Up

December: Conversation, Connection, Companionship: Online Coffee & Chat

January: Navigating a new chapter: Support for the newly diagnosed

MG is NOT just a car!

An Invitation to Participate in “MG and Work” Survey

**Participate in
“MG and Work”
survey**

The MAA has partnered with the University of the Sunshine Coast to conduct research on Myasthenia Gravis and people's ability to work.

myastheniaalliance.org.au

The **MAA** has partnered with the **University of the Sunshine Coast** to conduct research on Myasthenia Gravis and people's ability to work. The research team is led by Dr. Michele Verdonck.

MG can significantly affect people's ability to work. Little is understood about the factors that support or hinder people with Myasthenia wanting to work. We are seeking your valued input as a person living with MG. We are conducting research aimed at investigating the factors which impact someone who is living with MG and their ability to engage in and maintain paid work.

Participants are invited to complete an anonymous online survey, which will take approximately 30 minutes to complete. We are hoping to use the findings from this research to help improve the working lives of those diagnosed with MG through identifying the enablers and barriers commonly experienced.

For more detailed information and to access the survey, please use this link:

https://uniofsunshinecoast.syd1.qualtrics.com/jfe/form/SV_b8zGLyrsXJWYEwC

If you have any questions or concerns, please contact the Chief Investigator, Michele Verdonck, using michele.verdonck@usc.edu.au. If someone you know might also be interested in participating in this study, please feel free to share this email.

Ethics Approval: S242004

Use this link to download the Research Project Information Sheet:

<https://myastheniaalliance.org.au/wp-content/uploads/2024/11/MG-and-Employment-RPIS.pdf>

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

BEHIND THE SCENES - Your MGAQ Committee are dedicated volunteers



MGAQ THANKS GOLD COAST GROUP FOR HOSTING THIS YEAR'S CHRISTMAS GATHERING



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

MGAQ CHRISTMAS GATHERING



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

CONVERSATION CONNECTION COMPANIONSHIP

DENMARK, WESTERN AUSTRALIA



Jenny and Dusty

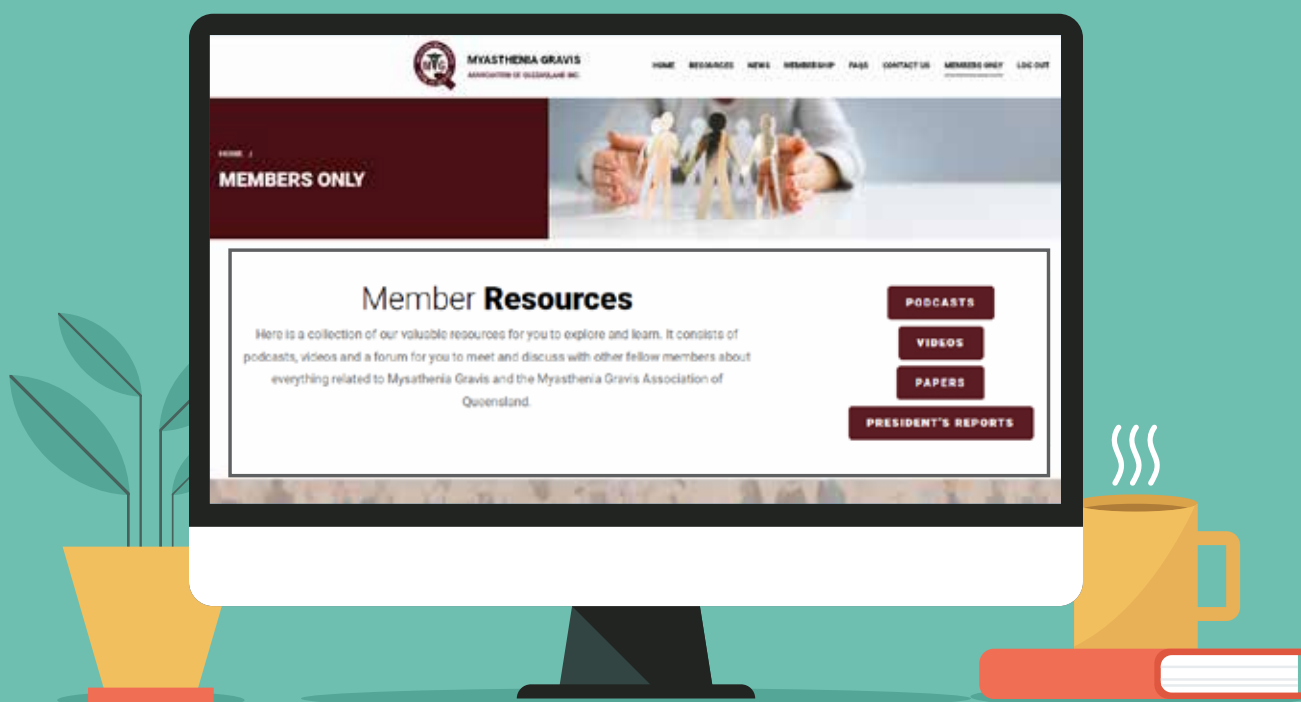
CAIRNS



It was a great turn out at the October Coffee & Chat. Unfortunately, we remembered the photo after some had left.

SUPPORT your Association by **VOLUNTEERING.**

MGAQ MEMBERS' ONLY LOG IN DETAILS UPDATE



All financial members of the MGAQ
can access the 'for members only' section of the website
which provides convenient access to a wide variety of useful
information in the form of:

- Videos of presentations made by experts in a variety of fields along with the 2023 MAA National Conference Videos

- Podcasts

- and Library Resources

Member Log in details are updated annually, with the new login details taking effect November 1, 2024.

You would have received an email from the Treasurer, Denise, at denisehannay21@gmail.com during the last week of **October**.

Please use the new supplied log in details from November 1, 2024 to access the '**for members only**' section of the MGAQ website.

If you haven't renewed your membership you will not be **sent an email with the new login in and thus you will not be able to access this important section of the MGAQ website.**

Puzzlers

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

Sudoku

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Bamboozable

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Word Change

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

Word Search - Books of the Old Testament

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| S | U | T | I | A | B | E | O | L | E | E | I |
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DEUTERONOMY
ECCLESIASTES
ESTHER
EXODUS
EZRA
GENESIS
JOB
JOSHUA
JUDGES
LEVITICUS
NEHEMIAH
NUMBERS
PROVERBS
PSALMS
RUTH

Answers

Answers: grate, grade, blade, blame
Word Change 28
Bamboozable 30 Answers: 1. Total Mess; 2. Paint by Numbers; 3. Four Part Harmony; 4. Poison Ivy; 5. Tilt a Whirl; 6. Internet Site.

NEW MEMBERS

Magali,
Flagstaff Hill SA
Mary Lynne,
Belgian Gardens QLD

Lee,
Victory Heights QLD
Carolyn,
Taunton QLD

Robin,
Taunton QLD

NEWS FROM AROUND QUEENSLAND

News from Cairns

For local support, 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

Join us in Mackay for an informal **Coffee and Chat** on **Tuesday, 19 November** at **9.30am**, **Harrup Park Cafe, Juliet Street Mackay**. All Welcome.

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 next meet on **Monday, 2 December** 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 will be on **Saturday, 18 January** at **10 am** 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
Mango Hill/Northlakes – SATURDAY 30th November at 10.30am,
Coffee Club, Mango Hill Market Place,
Cnr Anzac Ave & Halpine Drive
– All Welcome!



COFFEE & CHATS

RSVP Anita on 0414 588 312
Toowoomba – SUNDAY 15th December at 11.30am,
Picnic Point Café, Tourist Road, Toowoomba
– All Welcome!

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/C: 10263772

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