



Myasthenia Gravis Association of Queensland Inc.

Messages

November
2023



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 2023

For those people who attended the Myasthenia Alliance Australia Conference in Sydney on 21 October what a wonderful experience it was. The information provided by the guest speakers was first-rate and very relevant, the camaraderie among the participants was exciting and the whole day, even though it was long, was most worthwhile. Special thanks must go to the small group of volunteers who worked tirelessly for many months to pull it all together. All of the presenters deserve a massive acknowledgment for giving their time so freely. We are very lucky here in Australia to have such a committed group of medical specialists who support people with Myasthenia Gravis in so many ways. We also thank the pharmaceutical companies involved for their ongoing support. Please take the time to read the MAA report in this newsletter for information about the conference but also more exciting news about the outcomes that have resulted from the research that has occurred. Necessary data and information cannot be collected and used without the involvement of our members. Remember that **PATIENT VOICES MATTER.**

At our Annual General Meeting in September we were unable to secure anyone to fill the position of Vice President. I am very pleased to announce that Sharin Nisha has very kindly applied to fill this

position and her application for same was accepted at our meeting this month. It is vitally important that we meet all our executive committee requirements as a not-for-profit association.

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. A prime example of this is some of the presentations delivered by top medical specialists at the recent conference. If you want to have access to the most recent and relevant information about Myasthenia Gravis, the latest research and medications please make sure you pay or renew your membership so you have access to this. If you know of anyone who has passed away or changed address please phone our **1800 number** so we can act on this information. The **Art with Heart** was launched at the recent conference. We hope to make this an annual awareness campaign so please remember that this auction is for the benefit of all members so, not only make yourself aware, but share the information about the wonderful auction items and, of course, living with Myasthenia Gravis.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

The 4th National Patient Focused Myasthenia Conference is now completed.

The MAA wishes to express our thanks to everyone who attended this event for their awesome contribution towards achieving such a very positive day. The volunteers did a great job in making the day flow well and loved being there to engage with so many attendees. I thank these special people for all that they give to others. Many of the team have been working on this event since February. It was very much an MG Family Day inclusive of patients, family and carers, and Health Professionals.

The programme was very full with a great deal of information shared. Some of this information was a surprise, some was motivating and some was just too technical to remember! Overall, the day focused on the wide ranging areas of investigation which are occurring in our Myasthenia community.

- Dr Blum explained why research is difficult and acknowledged that we are complex and variable patients needing lots of care and requiring intricate treatment.
- The day revealed that thymectomy is having a positive outcome and that exercising is important and safe if carefully conducted.
- Dr Reddel outlined the range of treatments currently in use and what might be expected in the near future. The detail was complex but it was reassuring to understand that new treatment pathways are being found. He could not comment on when these medications may receive TGA approval nor if they will be PBS supported.
- There was regular reference to the use of steroids as an important treatment option and the need to follow instructions carefully when tapering. Dr Blum encouraged people to be vigilant should they get an infection though the initial risk is not higher. He reminded us to get our skin checks and blood tests regularly and to keep up with vaccination recommendations.
- Louise Healy from RVA inspired us all and gave invaluable tips for advocating in any situation whilst Kirstine Srubsole and Anna Neuwirth reported on how Allied Health services can be very helpful and that patients need to be proactive to gain best outcomes.
- Importantly, we learned about the rapidly increasing roll out of MGBase and how our data will be useful and important to achieving future goals. Hopefully everyone will soon be registered via their Specialist.



Sponsorship from Alexion, UCB, CSLBehring and Janssen Pharmaceuticals allowed for a high quality event. Feedback is being evaluated and suggestions for a future event have been noted.

MAA Update continues next page



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

“Clinical features, treatments, their impact, and Quality of Life for Myasthenia Gravis patients in Australia” Clinical Journal of Neurosciences Article is Published!

Everyone has waited so patiently for the results of the data collected via the Patient Reported Outcomes Survey Project and now it is available! It is exciting that 4 years work has resulted in the Australian Myasthenia journey being formally told through the article in the Journal of Neurosciences.

The Myasthenia Community of Australia is ex-

tremely appreciative of the opportunity to partner with TerumoBCT and the researchers to make this happen. More information is available via the link. Do have a read to see how life with myasthenia presents in the Australian situation. Please visit it before December to gain free access.

Your article link: -[https://authors.elsevier.com/sd/article/S0967-5868\(23\)00285-0](https://authors.elsevier.com/sd/article/S0967-5868(23)00285-0)

Achieving a voice! Helping with treatment planning! Successful collaboration!

Recently, a call went out for information. Again, this was facilitated via a survey process. A pharmaceutical company wanted some feedback on how patients might manage certain protocols when taking treatments. That company was UCB Pharmaceuticals.

They were so delighted with the response received from the Australian community that the survey was closed ahead of schedule allowing

for some results to be shared with Conference attendees. Please see page 4 of the newsletter for the Infograph which was made available at the Conference.

UCB representatives who attended the Conference where certainly keen to express their appreciation. Our community contribution was very valued and having a voice mattered to us so well done everyone.

Time for the MAA to get some well earned rest perhaps - or maybe not as there is more to be done!

Kind regards

Susan White (MAA Chairperson)

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

“SUPPORT *your Association* by VOLUNTEERING.”

PATIENT Voices Matter



The use of internet and devices, and interest in digital and home services: A survey of Australian caregivers and people with generalised myasthenia gravis¹

A recent survey of people with generalised myasthenia gravis (gMG) and their carers, conducted between 13 and 25 September 2023, highlighted that there is an opportunity to increase access to educational resources and awareness for medication support for gMG via digital channels.

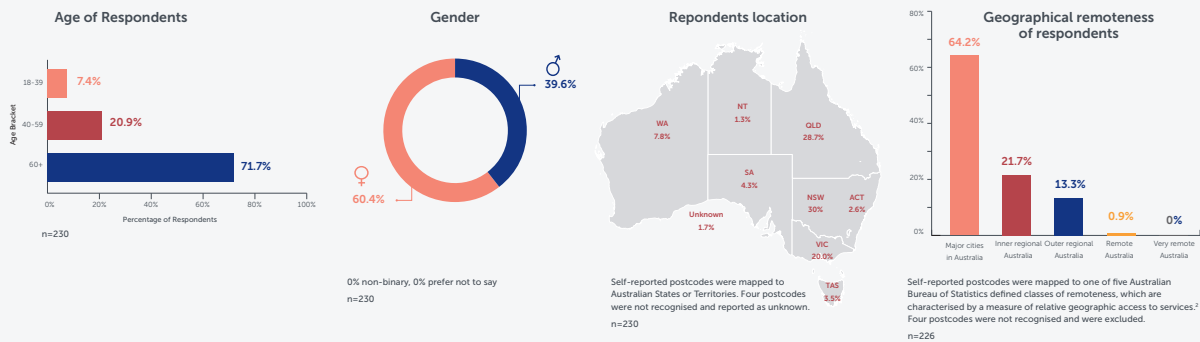
Conducted in collaboration with Myasthenia Alliance Australia and UCB Australia, a pharmaceutical company, the survey recruited respondents through Facebook posts and email distributed from Australian gMG patient organisations. Respondents were asked to answer a short series of questions describing how frequently they use the internet and self assess their proficiency in accessing information in this way. Key results of the research are outlined here and will help to inform future educational initiatives and provide tailored support related to medications used to treat MG.



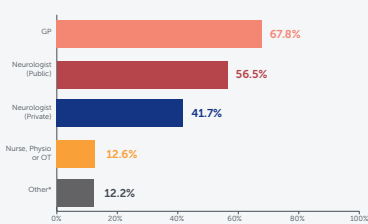
Excluded Responses:

- 3 did not provide informed consent
- 14 responses were not from a person with, or caregiver of a person with MG
- 45 were ocular MG only
- 1 was <18 years of age

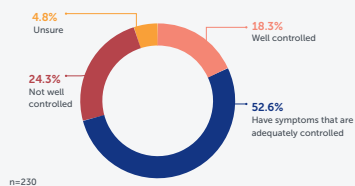
Respondent demographics



MG care providers



Self-reported gMG symptom control



Internet and device use

Over 80% of patients surveyed use the internet every day.

n=194/230

Over 75% of people gave their skills at using the internet a 4-star rating or higher.

1-star = poor and 5-stars = excellent

n=176/230

Over 60% of people gave their skills at using a smartphone a 4-star rating or higher.

1-star = poor and 5-stars = excellent

n=144/230

Support programs

Over half of respondents rated an online support program (e.g. nurse support and educational resources) as 4 thumbs up or higher for usefulness.

1 thumbs up (Not useful at all) to 5 thumbs up (very useful)

n=130/230

Symptom tracking & research

More than 80% of respondents were willing to complete a regular survey to measure their MG symptoms.

n=193/230

Over 85% of people were willing to share information about MG treatment and symptoms to further research.

n=202/230

If you have any questions or you would like to request a copy of this infographic, please email ucbcares.au@ucb.com

Abbreviations: ENT = Ear, Nose and Throat; GP = General Practitioner; gMG = generalised myasthenia gravis; MG = myasthenia gravis; OT = Occupational Therapist.

Acknowledgments: This survey was conducted by UCB Pharma and Myasthenia Alliance Australia (MAA). UCB acknowledges MAA for their support reviewing the questions and distributing the survey to their members via email and Facebook. UCB would like to thank the patients and their caregivers for their valuable contribution.

References: 1. Data on File. AMP2635. 2. Australian Bureau of Statistics. Australian Statistical Geography Standard (ASGS): Volume 5 - Remoteness Structure, July 2016. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/1270.0.55.005/July%202016?OpenDocument>. Accessed October 2023.



UCB Australia Pty Ltd. (ABN 48 005 799 208) Level 1, 1155 Malvern Road, Malvern VIC 3144. Telephone: +61 (3) 9828 1800. Facsimile: +61(3) 9828 1860. AU-DA-2300018. October 2023.



The Australian MG story is now told!

The MAA are proud to announce that the Patient Reported Outcomes Study, which was strongly supported by the Australian Myasthenia community, is now referenced via an article in the Journal of Clinical Neurosciences - *Clinical features, treatments, their impact, and Quality of Life for Myasthenia Gravis patients in Australia*.

We congratulate the researchers Janet Sansoni, Nidhi Menon, Lachlan Viali, Susan White and Steve Vucic for their contribution of significant time and much diligence which has resulted in this comprehensive and impactful document.

The paper has been made available with free access until December 2023 and following this via the Journal.

It can be found here - [https://authors.elsevier.com/sd/article/S0967-5868\(23\)00285-0](https://authors.elsevier.com/sd/article/S0967-5868(23)00285-0)

The MAA gratefully acknowledge TerumoBCT's significant contribution to this project and for the opportunity to work in partnership.

There are significant and indisputable, evidence based findings highlighted in the document. These findings will support conversations with Government and Specialists, and will help others to understand the challenges of living with this condition. The MAA hope that further research projects result.

Journal of Clinical Neuroscience 118 (2023) 16–22



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Journal of Clinical Neuroscience

journal homepage: www.journals.elsevier.com/journal-of-clinical-neuroscience



Original Research

Clinical features, treatments, their impact on quality of life for Myasthenia Gravis patients in Australia



NEW MEMBERS

Elizabeth M, Bribie Island QLD

Ben M, Bribie Island QLD

Nigel C, Bell Post Hill VIC

Genevieve D, Richmond VIC

Laurie M, Woolloongabba QLD

Dorothy R, Mordialloc VIC



VICTORIAN REGIONAL MG LUNCHEONS

to be held on

Sunday, 3 December at 12 noon

Mulwala Water Ski Club, Mulwala

RSVP is essential. Please call Pauline 0419 332 260 - All Welcome

SUPPORT your Association by **VOLUNTEERING**.

Creativity *for* Positivity

ART WITH HEART AUCTION

FEBRUARY 2024 - JUNE 2024

SPREAD THE WORD

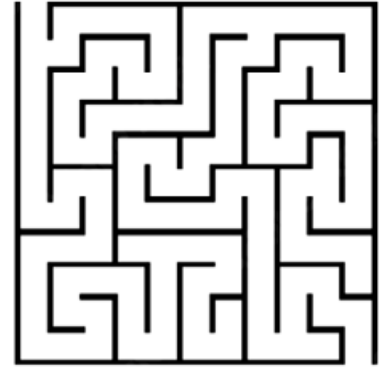
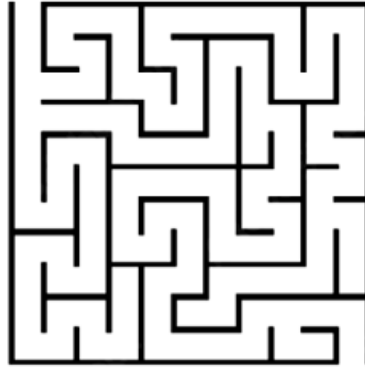
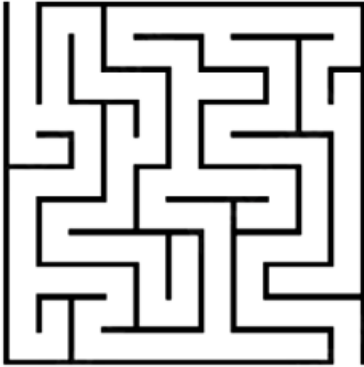


www.myastheniaalliance.org.au



Puzzlers

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

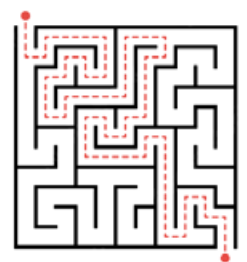
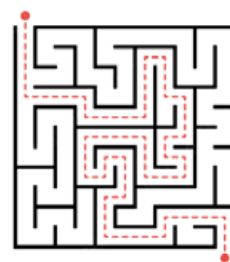
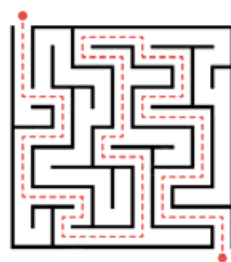


ANSWER BELOW

Find 10 differences.



If you find all the differences, let us know by emailing your answers to info@mgaq.org.au and we'll put them in next month's newsletter and we will send you a Conference pen.



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

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us for a **Coffee & Chat on Saturday, 25 November at The Nest at 10.30am**. The Nest is located at **180 McManus St, Whitfield**. Hope to see you there.

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

News from Townsville

The December Lunch is at **Sports Club, 159 Bamford Lane, Kirwan, on Saturday, 2 December at 12 noon**. As this is our Christmas lunch, you are invited to bring a gift (\$15-\$20) and we will exchange gifts. Looking forward to your company. Family members are also welcome.

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

News from Hervey Bay

For local support, please contact **Jan on 0429 622 438**.

News from the Sunshine Coast

I look forward to our next catch up which will be **Monday, 4 December at 10.30am, Club Kawana, 476 Nicklin Way Wurtulla**. Don't forget to bring your empty Mestionon bottles for Chloe's art project.

If you are in the area, please join us. For more information please contact **Michael on 0447 887 652**.

News from the Gold Coast

Our next meeting will be at **10.00am on Saturday, 18 November at Broadbeach Kurrawa Surf Club, Old Burleigh Rd, Broadbeach**. I hope to see you all there and don't forget to bring your empty Mestionon bottles for Chloe's art project.

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



COFFEE & CHATS

**SPRINGWOOD - Saturday 2nd December at 10.30am Cafe 63
99 Cinderella Drive, Springwood.**

ALL WELCOME!

RSVP Anita on 0414 588 312

WHAT'S COMING UP

What's On?

When Is It?

Where Is It?

Christmas Function Cancelled

Unfortunately, due to other commitments by the MGAQ Management Committee, the Christmas function previously advertised has been cancelled. However, we encourage local groups to get together within their regions to celebrate the year.

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