Myasthenia Gravis Association of Queensland Inc.

MessaGes

JUNE
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 JUNE 2025

This month is **International Myasthenia Gravis Awareness Month** and the activities planned are very significant for the MGAQ.

Oh MG is an art exhibition designed and produced by Chloe Wigg to give a voice to people with Myasthenia Gravis. Many people with MG and supporters of people with MG have reached out to work colleagues, craft groups, retirement villages, church communities, family and friends to crochet over 2500 snowflakes and collect many Mestinon bottles for this exhibition. MGAQ organised a special day for members, their family and friends. We were very fortunate to see this exhibition, discuss and share stories, both personal and throughout the exhibition, and catch up with friends, both familiar and new. The exhibition was shown at the Logan Art Gallery from 22 May to 14 June 2025 and is now travelling to **Warwick Regional Art Gallery to be viewed from July 10 July - to 16 August.**

The **Lights Up Queensland** project highlighted many teal coloured structures being lit up across Queensland as well as some in New South Wales, Victoria and Western Australia. I hope that you gathered together a group of family and friends to share the wonderful sites and have a discussion about your condition, highlighting both the positives and negatives. Also, if you did go to look at some lights, any photographs would be greatly appreciated by the management committee. Our co-ordinator for this project, Donna, can be contacted on info@mgaq.org.au

You will see in this newsletter the **nomination form for membership of the management committee of the MGAQ** on page 10. The offerings to our members, their families and friends continues to grow significantly. Please think seriously about getting involved with this team to manage and implement many significant projects and activities. Also, please remember that family members can nominate to be on this committee.

Membership fees will remain the same this year and it is important to maintain membership for yourself and for the association. Data from research is needed in order to have a voice with parliamentarians, industry representatives, researchers and groups such as Rare Voices Australia. The membership renewal form is on page 9 of this newsletter. If you pay using direct deposit please email our treasurer at treasurer@mgaq.org.au advising that you deposited your renewal and the date it occurred**.**

I hope that everyone is enjoying the cooler weather and that your MG is behaving itself.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

P.O. Box 16 MT. GRAVATT QLD 4122

NATIONAL FREECALL: 1800 802 568

ABN 92 055 613 137
Email: info@mgaq.org.au
Internet: www.mgaq.org.au
COMMITTEE MEMBERS
President: CAROL BUCHANAN
Vice-President: SHARIN NISHA
Secretary: CRAIG STREATFEILD
E: info@mgaq.org.au
Treasurer: DENISE HANNAY
E: treasurer@mgaq.org.au
ANITA JACKSON
ROSALYN HOLLAND
LISA WRIGHT
DONNA FORMOSA
SUSAN WHITE
Newsletter Editor: GREG BREADEN
E: MGAQ.editor@gmail.com
PATRON: DR CECILIE LANDER AM Neurologist

Supported by

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

OH MG ART EXHIBITION - Saturday 14th June

MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

The excitement continues for the MAA team and therein the State Associations also. So much to share with our readers today.

Firstly, the new website is now available to you with a much more reader friendly format, loads of information targeted towards patients but also it includes a specifically grouped tab allowing Doctors and HCP easy access. The website even has a search button - try it out with a question. Let's hope an answer can be provided from the wide range of information which has been gathered. The website is primarily focused on Australian content. It should be your first port of call when googling. Already we have received some very encouraging feedback. Please let us know what you enjoy about this new look. Thank you to Craig Streatfeild for his vision and work in creating this resource.

Secondly, Natalie Windle, MAA Secretary undertook the long journey to Europe to ensure that Australians were represented on the International platform. I am truly grateful to Natalie for making such a commitment on everyone's behalf. Please read her summary below. More details will unfold as the year progresses.

Thirdly, National Volunteer Week was celebrated in May. I celebrate the MAA team and thank each of them for putting up their hands to make a difference! Doing this work takes time, energy and passion - something each of our team members exhibits across many niche areas. This breadth of ideas allows us to grow our work and be as inclusive as possible. All done via zoom! Regrettably we did not receive any calls during May from people wanting to become involved. Not a problem however as calls are welcome at any time. Please consider your interest or that of a family member who may like to assist. Phone 1800 802 568 to learn more.

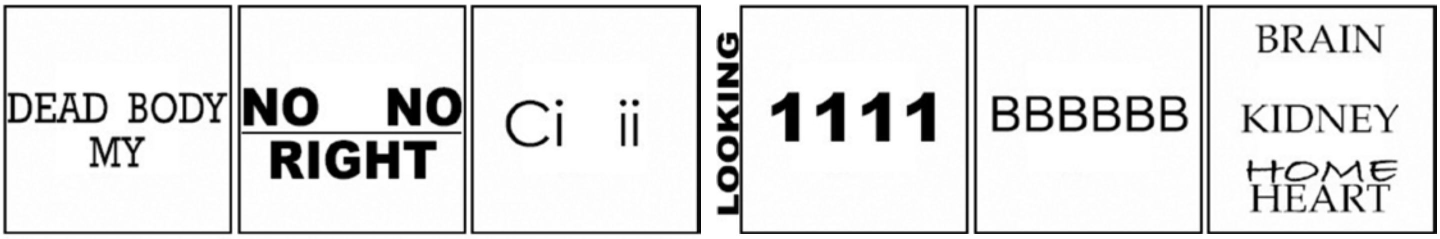
Please enjoy reading the article from Natalie about her trip.

Warm regards **Susan White (MAA Chairperson)**

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

Bamboozable 1

Bamboozable 2



Bamboozable 1 Answers: 1. Falling Temperature, 2. Two Under Par, 3. Fat Chance, 4. Broken Heart, 5. Hot Under the Collar, 6. Head in the Sand

Bamboozable 2 Answers: 1. Over my Dead Body, 2. Right Under the Nose, 3. See Eye to Eye, 4. Looking Out for Number One, 5. Beeline, 6. Home is Where the Heart Is

MYASTHENIA ALLIANCE AUSTRALIA

International Myasthenia Gravis Patient Advocacy Organisation Summit and Conference

I was very honoured to attend the recent inaugural MG Patient Advocacy Organisation (PAO) Summit and 15th international conference, on behalf of the Myasthenia Alliance Australia (MAA) and the Australian MG patient community. The event was held in Den Haag, The Netherlands and facilitated and organised by the Myasthenia Gravis Foundation of America (MGFA). It encompassed 5 days full of knowledge sharing, storytelling, and discussions about ways to move forward towards a world without MG.

The PAO Summit included discussions about our role as Patient Advocacy Organisations (PAOs), and we then identified the highest priorities for unmet needs within patient education and how we can merge synergies and best work together on these priorities. This included not only the patient perspective, but a clinician and researcher panel on these issues and how we can best work with the medical community.

I was able to listen to fellow patients who are also patient advocates and share some of our insights and learnings from Australia. It felt great to be in a room with people who understand living with MG and are facing some of the same challenges as PAOs. I am excited about building these connections and I have many ideas to explore further through the MAA.

The International Conference focused on scientific and clinical research. Over 240 papers were presented on posters, including work by Australian-based researchers, and nearly 700 people attended from all over the globe. To read more and see the sheer scale of the conference, take a look at the MGFA website: **https://myasthenia.org/events/2025-international-conference/**.

A highlight for me during the conference was the patient panel that discussed the social impact of MG. While some presentations were very scientific, we can rest assured that very talented and committed researchers and clinicians are working to better understand and treat Myasthenia Gravis, from autoimmunity and antibodies, to the special populations within MG, to the new treatments and non-medical interventions, to Artificial Intelligence (AI) and personalised care.

A huge thank you to MGFA and the sponsors, and to the fellow patient organisation representatives and many stakeholders that we will continue to collaborate with. I will share more with you all over the coming weeks and months and please follow the MAA and your State Associations to hear/read more.

Natalie Windle, MAA Secretary

MEMBERS' FORUM #1

Issues and Responses are published in the Members' Forum as-is without any recommendation as to their suitability or accuracy. The opinions expressed are entirely those of the contributor. Care should be taken if following advice or suggestions presented and it is strongly recommended that the advice of your GP or Specialist is taken in all cases.

Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.

This is a little about what I have learned through my several diagnoses.

This is a little about what I have learned through my several diagnoses.

- There are many hurdles, some too high to step over today. The biggest I discovered was myself.
- I learned that interacting with Specialists is all experiential.
- Being heard and to comprehend when receiving a diagnosis or a solution requires an in-depth summary or information about symptoms. You must be logical not emotional.
- Collate and supply to the various specialists all experienced sets of symptoms, reactions. Include references of what is consumed and activities. Be brutally honest.
- List all medications, supplements, perfumes, anything you put on your skin using correct names i.e. Pyridostigmine, the strength, dose and how many times a day you consume them i.e. 2 @ 10mg 4x daily 365.
- Information that is helpful to record. Times you eat, any symptoms during or after eating, exercising or relaxing, include other reactions add feelings and times experienced. There needs to be a complete picture of what is going on.
- Keep notebooks in the places you do your thinking. Include the car and your day bag.
- Gather and summarise that information over a 3 + month period, into Symptoms, Foods, Exercise, Medications and Supplements. (Do not throw away your original notes just yet.)

I initially saw a Private Neurologist. 1st appointment = information gathering hearing what I had to say. Being Diagnosed. Walking in my front door and realising not much of what was said remained in the memory bank, I then hibernated for far too long. Follow up appointments were rubbish; Brain Fog had gripped me. Then I was discharged from that Neurologist as the practice closed. My lazy GP organised an appointment through the public system – same Neurologist! This time I took my friend Helen who is a nurse. That appointment went well. Helen and I had coffee in the hospital cafeteria. She told me, the Neurologist is my nephew! All other appointments went well. I currently see a private Neurologist who works closely with my Rheumatologist – same rooms & I feel heard. He works with me. I still do the chicken wing test!

I began a 4-ring binder with a list of all medical people I consult, including numbers, email and address at the front. I gathered plastic sleeves into groups of Specialists by colour. Each section has the newest information at the top. Sticky note on the uppermost sheet sleeve with Next Appointment details, I sync and diarise everything to my Google Calendar connected to my Google Home Nest which reminds me each morning at my preset time what I have on for the day.

Amanda

MEMBERS' FORUM #2

Hi Everyone,
Melissa Giles shares her latest Blog.

Post #17 "Being Moved" is now online:
https://story-telling.wixsite.com/seeing-things/post/17-being-moved

This post is about appreciating beauty and the power of the writing process.

I have completed 5 years of my 6-year PhD. In the next few months, I plan to finish my PhD blog, *Seeing Things Differently* (**https://story-telling.wixsite.com/seeing-things/blog**. Blog Posts 11 to 21 focus on how I use writing to make sense of my life with severe myasthenia. My research has been supported by an Australian Government Research Training Program Scholarship and participation assistants provided by the Queensland University of Technology.

Regards, Melissa.

KNOW YOUR COMMITTEE

Hi, my name is Denise and I am in my ninth year as Treasurer on the MGAQ Managwment Committee.

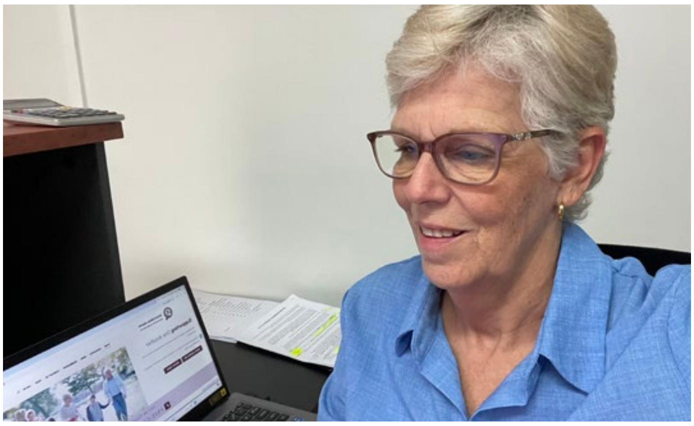
I was diagnosed with MG in January 2012, from my initial visit to my regional GP, who thought it was MG from this very first visit. That started my journey of specialists, tests and the usual for a confirmed, yes you have MG.

I joined the committee in 2016, when the MGAQ was calling for a treasurer. I hadn't met anyone with MG in the 4.5 years since learning of this condition, and when I first met the members of the then committee, it was like coming home. These are my people, so much relief.

As well as handling the finances and bookwork of the MGAQ and MAA, I look after the membership database, print/post and email the monthly newsletters and various other jobs that are needed. I was also involved with the AWH Auctions.

I have had the pleasure of attending Rare Voices Australia (RVA) National Summit as a representative of the MGAQ, attending RVA Rare Diease day functions at Parliament house on behalf of the Myasthenia community of Queensland.

It is a very rewarding experience and a pleasure to be a part of such an amazing committee and wonderful community.



Just a reminder that our yearly membership subscriptions are due for renewal in June. Without members there is no association so your continued support via membership is extremely important. The association is responsible for building/updating, maintaining and financing the MGAQ website along with all the produced resources that are supplied free to members. All because there is an active association.

CONVERSATION CONNECTION COMPANIONSHIP

The local Coffee and Chat is a safe space to share MG experiences with others.

CLEVELAND - MAY 17

EVANDALE (Tas) - JUNE 11

WELCOME TO OUR NEW MEMBERS

Shania, Brisbane QLD

Barbara, Wondecla QLD

Nikki, Runaway Bay QLD

SUNSHINE COAST

BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/c: 10263772

NEWS FROM AROUND QUEENSLAND

News from Cairns

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

News from Townsville

We are meeting again on **Saturday, 5 July at 12noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan.**

Looking forward to your company and thanks to everyone who came to our April lunch.

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 again on **Monday, 7 July at Kawana Club, 476 Nicklin Way Wurtulla at 10.30am**. Visitors are most welcome to join this very friendly group.

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

News from the Gold Coast

Hi everyone. MG Gold Coast had their get-together sharing experiences with other members in May. Our next meeting will be at **10am on Saturday, 12 July at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport.**

Hope to see you there.

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

COFFEE & CHATS

MANGO HILL - **Saturday, 28 June at 10.30am, Coffee Club, Mango Hill Market Place, Cnr Anzac Avenue & Halpine Dr Mango Hill**

IPSWICH - **Thursday, 17 July 10.30am, Queens Park Cafe, 10A Merle Finnimore Ave, Ipswich**

ALL WELCOME!

RSVP Anita on 0414 588 312

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MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again when Membership Subscriptions for the financial year 2025/2026 are due.

Category A	**Myasthenia $20.00**
Category E	**Associate $20.00**
Category D	**Carer $10.00**

(Cat D Carer membership must be attached to a Cat A membership)

If you are unsure whether or not you are currently financial **please phone our 1800 802 568 freecall number or email treasurer@mgaq.org.au to enquire.**

New payment option for members of "Perpetual membership"

Cat A (Myasthenia Member) & Cat E (Associate Member) $250 and **Cat D (Carer Member) $125.** This one-off payment would mean that you never have to worry about renewing your membership again. Please note that a Cat D membership must be attached to a Cat A Myasthenia Membership, it is not a stand-alone membership.

YOU HAVE THE FOLLOWING PAYMENT OPTIONS

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE

This method will take a credit card payment.

www.mgaq.org.au/membership-application-form and select **Membership Renewal**

Our bank details are:

BANK: Bank of Queensland **BSB:** 124 032 **ACCOUNT NUMBER:** 10263772

ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.

REFERENCE: Your Name and Initials

If you use the direct deposit method, it would help if you could email us at **treasurer@mgaq.org.au** to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.

Pay by Phone using your credit card on 1800 802 568

If sending a money order, cash or, cheque, please complete the form below.

The Myasthenia Gravis Association of Queensland Inc.
PO Box 16 MT GRAVATT Qld 4122 or email treasurer@mgaq.org.au

Herewith please find my money order, cash or cheque for the sum of **$**__________ being annual subscription **$**____________ and/or Donation **$**_____________MGAQ/MAA *(Please circle)*

NAME ____ **Category A Myasthenia $20**

(or) Category E – Supporter $20 **Perpetual Membership Category A or E $250**

ADDRESS ____

____

And for ____ **Category D – Carer $10**

Perpetual membership $125 (Cat D Carer membership must be attached to a Cat A Membership.)

ADDRESS ____

____

Mobile __________________________ Email ________________________________

ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS

SUNDAY, SEPTEMBER 14, 2025

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2025/2026

Eleven places are now available for Committee nomination as the MGAQ continues to have an increasing range of projects. We always welcome anyone who wishes to nominate.

People can nominate themselves or anyone else they feel would be a suitable member of this very progressive and dynamic Committee.

Interested people need to be comfortable with using a range of technology and will need to maintain regular communication in order to stay abreast of issues throughout each month. Meetings are a full day held each second Saturday of the month excluding January, April and October and attendance via Zoom or in person is required for a majority of meetings.

To gain more information or to discuss these roles and commitments you can phone **Freecall 1800 802 568.**

Members with Myasthenia and those with an interest in Myasthenia are welcome to apply. Carers and supporters also very welcome to nominate. To nominate, you must be a financial member 2025/2026.

Nominations **MUST** be received by **EMAIL info@mgaq.org.au or by POST to PO Box 16, Mt Gravatt QLD 4122**, by the close of business on **Friday, 1 August 2025.**

If more than one nomination is received for the same position, a ballot to all financial members will be conducted with the votes to be returned by **Friday, 29 August 2025.**

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, September 14, 2024.

Nominee *(Print name)*:.. Ph:..

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee *(Print name)*:.. Ph:..

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee *(Print name)*:.. Ph:..

Nomination Accepted *(Signature)*: ....

(Circle position of interest) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nomination(s) (above) Seconded by *(Optional)* ....

Additional Nomination Forms available on request.

Members may be interested in offering support, but would prefer to nominate themselves for special project work rather than taking a Committee position. If this is preferred, provide your name, best contact details, and a little about the skills you can offer to the Association.

Name:.. Skills Offered: ....

....

.... Best Contact:...