



Myasthenia Gravis Association of Queensland Inc.

MessaGes

JUNE
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 JUNE 2024

This month is International Myasthenia Gravis Awareness Month. One of the activities planned is very significant for the MGAQ. The Lights up Queensland project continues to grow significantly with teal coloured structures being lit up in many places across Queensland plus some in New South Wales, Victoria and Western Australia. A compilation of the Light Ups can be found on page 7 of this newsletter and on our website. Please, if you do go to look at some lights, a photograph would be greatly appreciated by the management committee.

Our Co-ordinator for this project is Donna and she can be contacted on info@mgaq.org.au. To support this awareness campaign, why not gather 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.

You will see in this newsletter the nomination for membership of the management committee of the MGAQ. The offerings to our members, their families and friends continues to grow significantly. This was certainly a highlight acknowledged by the Community Funding Branch of Queensland Health when we met with them at the end of April. 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 also nominate to be on this committee.

I am pleased to announce that our funding from Community Funding Branch of Queensland Health

will continue for another five years starting from July this year. We are very grateful for the security this gives the MGAQ in terms of moving forwards.

Membership fees will remain the same this year and it is important to maintain membership for yourself and the association. Data from research is needed in order to have a voice with parliamentarians, industry representatives, researchers and groups such as and groups such as Rare Voices Australia. The membership renewal form is on page 10 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.

Another awareness activity is the Art for Heart auction. Please take the time to log in via our website or the MAA website and have a look at the wonderful pieces up for auction. More information is available on page 6 of this newsletter.

A Conversation, Connection and Companionship get-together for members and families was held in Brisbane on Sunday, 9 June with our guest speaker Associate Professor Jan Sansoni speaking about **"Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives"**. I am sure that everyone who attended gained some new and important information in relation to living with MG.

Kind Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Dear All,

This month is **MYASTHENIA GRAVIS AWARENESS MONTH** and it is very exciting for our community. There have been major buildings lit in teal, there have been meet-ups both casual and more formal, and there has been general public connection. Seeing the marathon runners under the sign on Brisbane's Story bridge was amazing!

The Art With Heart Auction campaign closes June 29th. Please get on board during the remaining days to make this activity a real success.

Myasthenia Gravis affects muscle strength. It is a very fatiguing condition which is prone to significant fluctuations. Unlike many other conditions that have fun runs, big walks or elaborate gala events to raise their profile we just don't have the energy. What we can do is craft! So we are celebrating our talents and bringing awareness through an Art Campaign.

It was Lyn Church who first raised the concept of an Art Auction as a mode for conversation. Lyn is a renowned Australian artist and is also an MG Warrior. This year, in support of Lyn, two other key Australian Artists have donated paintings supporting people with Myasthenia Gravis. The artists are Herman Pekel and Chris Searle. Other warriors have donated according to their skills or some due to their connection to people with MG.

You can explore what is available here:

airaucioneer.com/art-with-heart-auction-2024-myasthenia-gravis/resin-wall-artwork-set

Importantly you can help out by **sharing this information**. By encouraging others to visit the Myasthenia Alliance, the Myasthenia Gravis Association of Qld and the MGNWS websites they may better understand this condition and the work that is undertaken. This will achieve our key objective.

We want people to have heard of Myasthenia and to perhaps learn a little about the great challenges of living with this chronic neurological auto-immune condition. We know there are others with the condition who are not aware of the support offered through the Associations. Having a conversation can lead to great things.

Should you choose to participate in this auction by purchasing or donating (and we hope you will consider this opportunity carefully), the funds raised will empower the MAA to continue engaging in advocacy and awareness work. This year the MAA has already sent delegates to Canberra and Sydney for various formal activities. These included the RVA hosted Rare Disease Day Parliamentary Lunch, a round table meeting with Minister Butler focusing on HTA Reform and attending the Neurological Alliance Australia (NAA) National Summit on Neurological Conditions . We receive many invitations to attend highly relevant events but as the MAA is fully volunteer run and donation funded we must be very conscious of overheads. Monies raised will foster additional engagement with politicians, industry representatives and fellow rare disease advocates. With new treatments coming and a growing appetite to value 'the lived experience' it is important that we are represented.

Placing a bid also recognises the contributors and the journey that they undergo themselves or share with others. Please consider showing your support.

If you want more information I am available via the Freecall phone number - 1800 802 568 or visit

Art With Heart Auction: airaucioneer.com/art-with-heart-auction-2024-myasthenia-gravis/resin-wall-artwork-set

MAA - www.myastheniaalliance.org.au

Thank you for taking the time to read about the work that is so important to achieving best outcomes for the Myasthenia community.

Sincere regards, Susan White, MAA Chairperson.

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



IT'S TIME FOR ANOTHER MESTINON UPDATE

CREEPING CLOSE TO 800 BOTTLES NOW!

Keep them coming!

I am happy to receive anything connected to this project - any sized mestinon bottles, boxes, lids as well as crochet snowflakes in yarn colours of white or teal (and any colour that may be mistaken for them 🙏)

The Art Exhibition, Oh MG will exhibit at Logan Art Gallery, 21 May to the 14th June 2025, keep an eye out next year for opening night information.

I have also secured a second Art Gallery so the exhibition is officially a touring exhibition now! Yay! The second location is Warwick regional Art Gallery July 2025. Oh MG will be their main exhibition with their Jumpers and Jazz in July city wide event.

If you are interested in having your portrait included in the exhibition please send me a private message or email to info@mgaq.org.au with a clear photo of yourself from the shoulders up and a line or two about your self and your MG. I'm also looking for some good comparison photos - ptosis vs no ptosis, steroids vs no steroids, well vs sick that sort of thing.

Let me know if there is interest in online crochet snowflakes and chat sessions. I am going to film some tutorials but I think some connection would be nice too.

Thank you to everyone who has donated bottles and snowflakes so far. I love the postcards and letters as well they are really beautiful to read.

Please remember MGAQ are able to reimburse your postage costs if you reach out to them with your postage receipt.



Postal address is:

Chloe Wigg

**PO Box 628, Rochedale South
Queensland 4123**

MYASTHENIA AWARENESS



SUPPORT your Association by **VOLUNTEERING.**



JUNE AWARENESS FUNCTION

Our June Awareness Function was held on Sunday, 9 June with guest speaker Associate Professor Jan Sansoni speaking about **“Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives”**.

She spoke about:

- The absolute need for research to capture both quantitative (numerical and clinical) and qualitative (points of view and observations) data in order to make the best treatment decisions for patients.
- The value of the healthcare should be assessed in terms of how medical interventions improve or do not improve the patient’s quality of life.
- Do the treatments offered lead to improved treatment outcomes for patients when considered in relation to the economic impact.

In summary, she emphasized that both clinical measures and patient viewpoints must be considered when making decisions about treatment options.

Financial Members can view this presentation under the Members Section of www.mgaq.org.au



REMEMBER – PATIENT VOICES MATTER



PATIENT Voices Matter



NEW MEMBERS

Kevin, Highfields, QLD

Lorraine, Mount Lofty QLD

CONVERSATION CONNECTION COMPANIONSHIP

SPRINGWOOD COFFEE & CHAT - MAY



SUNSHINE COAST COFFEE & CHAT - JUNE



SUPPORT your Association by **VOLUNTEERING.**



Creativity *for* Positivity

ART WITH HEART AUCTION

LAST DAYS TO BID

Art with Heart is an online auction that raises awareness of Myasthenia Gravis.
Use your "Creativity for Positivity"
Please place your bids now at
airauctioneer.com/art-with-heart-auction-2024-myasthenia-gravis

Spread the Word and Turn Awareness into Action

How to place a bid on the AWH page

1. Open the following link
www.myastheniaalliance.org.au
2. Log in or create an account if you don't have one already
3. See what's available
4. Choose the item you want.
5. Place the bid.
6. Once the bid is successfully placed, you will receive an email confirmation of your bid

HELP! HELP! HELP

The MGAQ management committee needs urgent help with some secretarial work. The work would not be onerous but would help some members of the committee manage their ever-increasing workload. The help would only be for the next few months as we hope to have a successful nomination for the position of Secretary at the AGM.

For more information please contact Susan on 1800 802 568



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





QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.



Townsville

Matagarup Bridge, Perth



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



NEWS FROM AROUND QUEENSLAND

News from Cairns

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

News from Townsville

Townsville MG lunch is on **Saturday, 17 August 2024, 12 noon** at **Kirwan Sports Club, 159 Bamford Lane Kirwan**. For more information please contact Daphne on 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 Hervey Bay

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

News from the Sunshine Coast

The Sunshine Group will meet on the first Monday of each month 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! MG Gold Coast will next meet on **Saturday, 13 July** at **Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport** at **10.00am**. I look forward to seeing everyone there.

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



COFFEE & CHATS

RSVP Anita on 0414 588 312

Wellington Point – Saturday, 6 July 2024 at 10.30am,
Farmhouse Cafe, 623 Main Road Wellington Point
– All Welcome!

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
Conversation, Connection, Companionship MGAQ AGM	Sunday 15th September 2024	Hornets Football Club, Graham Road Carseldine
MGAQ Christmas Function	Sunday 10th November 2024	Southport Sharks Club, Gold Coast

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



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, SEPTEMBER 15, 2024

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2024/2025

Eleven places are available for Committee nomination due to the MGAQ having an increasing range of projects in this new and exciting era of the Association. 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 and attendance via Zoom or in person is required for a majority of meetings.

To gain more information, 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 2023/2024. Nominations **MUST** be received by the Secretary by the close of business on **Friday, 2 August 2024**.

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, 2 August 2024**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, September 15, 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:.....

