



Myasthenia Gravis Association of Queensland Inc.

# Messages

JULY  
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 JULY 2023

The end of the financial year is upon us and that means a wide range of very important activities and commitments need to be met. Reports to Queensland Health are needed to hopefully ensure their continued funding of our association. All the reports and paperwork needs to be done for the **Annual General Meeting to be held on Sunday, 10 September at Aspley Hornets Football Club, Carseldine**. The huge amount of organisation for the Myasthenia Alliance Australia Conference in October (see below) still has to be completed. These, plus the daily organisational activities of the MGAQ, certainly keep the management committee busy.

function each year. So, please think carefully about the importance of renewing your membership each year. Information about how to pay is in this newsletter.

Our management committee is in need of a Vice President. It is amazing how this association has grown over the past years in relation to the amount of work and projects in which we are involved. This level of support and advocacy for our members can only continue if we have the personnel on our management committee and/or others who put their hand up to help with the multitude of 'jobs' to be done. Some of these require a level of skill but many just require people who are prepared to contribute their time and take on particular projects which occur during the year. So, please consider nominating for this position as all Executive Positions must be filled for us to remain viable. We are also seeking more members of the management committee to help with ongoing activities and learn about what the MGAQ provides.

The Queensland Light Up Project for International Myasthenia Gravis Month in June was a great success. Many thanks to everyone who got behind this project, particularly Donna from our management committee who spent many hours organising this very successful activity. The photos in this newsletter show just a few of the Light Ups from all over Queensland. It was also pleasing to see that this idea has spread to some other states.

I trust that everyone will consider the information above and act accordingly.

**Thanks Carol**

### DO NOT MISS OUT ON THIS WONDERFUL OPPORTUNITY

**THE NATIONAL 2023 MYASTHENIA GRAVIS PATIENT CONFERENCE WILL BE HELD IN SYDNEY AT CONCORD HOSPITAL ON SATURDAY 21 OCTOBER**

Highly acclaimed speakers will provide the latest research and information in relation to living with Myasthenia Gravis

*This is a unique personalised opportunity that should not be missed.*

The management committee has noticed a decrease in the number of members renewing their membership each year. The category A membership is only \$20 and the perpetual membership which covers you permanently is \$250. This membership money covers printing and distributing newsletters, the 1800 number, information packs, stationery etc so that the committee can

## Myasthenia Gravis Association of Queensland Inc

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### COMMITTEE MEMBERS

**President:** CAROL BUCHANAN

**Vice-President:** SUSAN WHITE

**Secretary:** YVONNE HORNBY-TURNER

E: [info@mgaq.org.au](mailto:info@mgaq.org.au)

**Treasurer:** DENISE HANNAY

E: [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

CATHERINE BERGIN

ANITA JACKSON

DONNA FORMOSA

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CRAIG STREATFEILD

**Newsletter Editor:** GREG BREADEN

E: [MGAQ.editor@gmail.com](mailto:MGAQ.editor@gmail.com)

**PATRON:** DR CECILIE LANDER AM Neurologist

Supported by



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



## MYASTHENIA ALLIANCE AUSTRALIA

### NEWS UPDATE

# CONFERENCE 2023 - WE NEED YOU!

We, the Myasthenia Gravis Community of Australia, supported by the volunteers of the Myasthenia Alliance (MAA) need a **SOLD OUT** National Conference this October.

*The Conference will discuss -*

- new information about the condition,
- the additional treatments becoming available
- why a greater range and new variety of treatment options are needed for managing a life time with this condition,
- how the health system might give better support,
- why being well informed makes for effective advocacy for both the individual and also for the entire myasthenia community.

Rituximab has been utilised for myasthenia patients for more than ten years yet it only become available to all patients from September last year. This change was a direct result of the advocacy undertaken by the MAA and the willingness of Greg Hunt MP, Health Minister, to support a rare disease patient group. To succeed it required unique legislative change.

New medications for Myasthenia are promised for Australians and these will be discussed at the Conference. Indications are that some of these treatments will be very expensive. Unless a PBS listing is achieved, once again there is a good chance that they will be accessed by a limited number of patients and sometimes at great personal expense.

**WE** need to send a strong message to the Specialist Doctors, the Health Minister, Government Departments and the Pharmaceutical Companies that equality in care is of utmost importance.

**WE** need to be prepared!

**WE** need to begin these conversations now!

**WE** can do this by having a full house at the Conference.

Please register now or **send a family representative** to take advantage of this important day. <https://myastheniaalliance.org.au/mg-conference-2023-registrations-now-open/>

**Susan White (MAA Chairperson), Carol Buchanan (MGAQ President) and Natalie Windle (MGNSW President)**

If you are not already registered with the Alliance please go to [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)



# QUEENSLAND LIGHTS-UP

**“Queensland Lights Up for Myasthenia”** project, initiated by the MGAQ has continued to grow in 2023 through the support of the Councils and private companies who illuminated their assets in teal in recognition of **International Myasthenia Gravis Awareness Month**.

The **“Light Up”** project is to spread awareness of Myasthenia Gravis by starting a conversation, the impact it has on people and the message of **“Patient Voices Matter”**.

*MGAQ thanks the following Providers for their support with this extensive and important event.*

- Brisbane City Council
- Bundaberg Regional Council
- Cairns Regional Council
- Central Highlands Regional Council
- Sky Point, Gold Coast
- City of Gold Coast
- Ipswich City Council
- Logan City Council
- Longreach Regional Council
- Mackay Regional Council
- Toowoomba Regional Council
- Queensland Country Bank Stadium
- Townsville City Council





**WESTERN  
AUSTRALIA  
LIGHTS-UP**

June is International  
Myasthenia Gravis  
Awareness Month.



Perth became known as “the city of lights” when residents of Perth left their lights on as astronaut John Glenn passed over the city in his spacecraft as he orbited the earth. Now 61 years later, it is another big yes for Perth as it was lit up with colour teal to celebrate International Myasthenia Gravis Awareness Month. **Thank you to Main Roads WA, Rare Voices Australia (RVA), Yvonne, Annette, Donna and Hugh Jones MLA for the combined effort in this our first “Perth Lights Up”.**

### GrainCorp Silos in Newcastle, NSW



**Thank you to GrainCorp for helping me to bring Awareness of MG to more people and to MGAQ for what they do.** **Paul**

## JUNE FUNCTION SUMMARY

The MGAQ community met for our regular June gathering in celebration of International Myasthenia Awareness Month. It was a delightful day reminiscent of the pre-Covid gatherings. We warmed to again see long term friends and welcomed some new people to the gathering. Donna shared many photos of how Queensland sites were lit in honour of this condition and thanked member Henk for bringing this concept to the MGAQ. Anita had made a teal ribbon for us to wear throughout the month and Dr Reuben Beer graciously offered of his time to help us learn and understand the process we are all experiencing.

Dr Beer's talk is now available for all members to view and to use as a reference tool via the **"members only"** login area of the website [www.mgaq.org.au](http://www.mgaq.org.au)

It was an excellent presentation, **"How I Treat Myasthenia Gravis"**, outlining the steps and thought processes your Doctor is likely to consider when managing each individual's condition. He discussed the objectives of the treatments and the importance of having the correct diagnosis. He discussed how each treatment option works and the time parameters involved in each step. He outline some of the side effects he would be preparing for when choosing a treatment option and gave some options around choices when a set back occurs. Importantly, he discussed being proactive in our health choices to minimise additional issues. These included checking in on bone health, balance, strength and activity levels. He referenced the value of vaccinations in reducing health burdens and the benefits of seeking out community and information via patient support groups. Utilising Allied Health providers is clearly helpful. He reminded us to be aware and mindful that some medications can worsen Myasthenia Gravis. Informed patients are important self advocates.

It is a presentation that will be worthwhile viewing at regular intervals. We thanked him with a bottle of his favourite wine.

**Susan W.**



## NEW MEMBERS

Natalie,  
Ranges Bridge QLD

Rodrigo  
South Brisbane QLD

Julie, Wirragulla NSW

Norman,  
Edithvale VIC

Alanah,  
Helensvale QLD



## WELCOME MICHAEL SUNSHINE COAST CO-ORDINATOR

Hi just a few words to introduce myself as the new contact for Sunshine Coast Coffee & Chat for MGAQ. I would like to thank outgoing leader, Vicki who did a wonderful job in her role.

I hope I can fill her boots! I have lived on the coast for 28 years, being an ex Victorian with strong family ties still down there. I had my own business here and was first diagnosed at Sunshine Coast University Hospital (SCUH), April 2022. It has been a devastating realisation that I eventually had to close my business. I have been very fortunate to surround myself with an extremely competent health care team encompassing a wide variety of professionals. My partner has been such wonderful support for me as learning to live with MG is a Really challenging time that I have chosen to embrace and accept the cards I've been dealt. I am very much looking forward to bringing some positivity and enthusiasm to our Coffee & Chat Group. We are a great bunch and look forward to any newcomers with open arms and ears. So I look forward to seeing you at our next get-together, until then take care and embrace the challenge ahead.

*Kind Regards Michael*

## RECIPE CORNER

### Lamb Rogan Josh

**Serves:** 6; **Prep time:** 15 minutes;  
**Cook time:** 35 minutes

 2½ serves per portion

#### INGREDIENTS:

500g lamb, diced into 2cm cubes  
3 tablespoons rogan josh curry paste  
2 tablespoons natural yoghurt  
2 tablespoons olive oil  
1 large onion, diced  
2 cloves garlic, finely chopped  
3cm piece fresh ginger, grated  
400g can diced tomatoes

2 potatoes, diced  
250mL water  
½ tablespoon cornflour  
2 cups green beans,  
trimmed and halved

**To serve:** Brown rice, Roti,  
Plain yoghurt



Everyday Food

#### METHOD:

MARINATE lamb with 2 tablespoons of the rogan josh curry paste and yoghurt for two hours in the fridge.

HEAT saucepan on medium heat until hot then add oil and onion. Cook until onion has softened, about 5 minutes. Add the garlic, ginger and remaining curry paste and cook for a further 1-2 minutes fragrant. ADD lamb to pan and sear until outside is brown.

ADD tomatoes, potatoes and water. Bring to the boil then reduce heat and simmer for 20 minutes.

MIX cornflour with equal parts water and stir until combined. Add the cornflour paste and green beans to the curry. Simmer for a further 10-15 minutes until green beans are tender.

SERVE with rice or roti bread and a dollop of natural yoghurt.

Recipe courtesy of [qcwacountrykitchens.com.au](http://qcwacountrykitchens.com.au)

## WELLINGTON POINT COFFEE & CHAT - MAY 18



**SUPPORT** your Association by **VOLUNTEERING.**

## NEWS FROM AROUND QUEENSLAND

### News from Cairns

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

### News from Townsville

We look forward to seeing you at the next Townsville lunch on **Saturday 22 July, 12 noon at Sports Club, 159 Bamford Lane, Kirwan.** Please RSVP to Daphne on **0400 778 637** or email **daphclay@gmail.com** Don't forget to bring your empty Mestinson bottles for Chloe's art project.

### News from Mackay

For local support, please contact **Mary on 07 4959 5251**

### News from Bundaberg

Carol and Gary, Susan and Mark along with Denise had a lovely catch up at The Spotted Dog in Bundaberg on Saturday, 1 July. It was great to have Susan White, MAA Chairperson and MGAQ Communication Officer in attendance. 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

We would love to see you at our next Coffee & Chat on **Monday, 7 August at 10.30am, at Kawana Club, 476 Nicklin Way Kawana.** All are welcome! Don't forget to bring your empty Mestinson bottles for Chloe's art project. For more information please contact **Michael on 0447 887 652.**

### News from the Gold Coast

Hi Everyone! Our next meeting will be at **10am on Saturday, 29 July at Broadbeach Kurrawa Surf Club.** I hope to see all there. Don't forget to bring your empty Mestinson bottles for Chloe's art project. For more information, please contact **Nader on 0415 834 401.**



## COFFEE & CHATS

**SPRINGWOOD – Saturday 29th July at 10.30 am**

**Café 63, 99 Cinderella Drive Springwood.**

All welcome. Table booked under MGAQ

## WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
<b>MGAQ AGM Conversation Connection Companionship</b>	<b>10.15 for 10.30 am Sunday 10 September</b>	<b>Hornet's Football Club, Graham Road Carseldine</b>
<b>MAA Patient Conference</b>	<b>Saturday 21 October 9am- 4.30pm</b>	<b>Concord Hospital – Education Centre, Sydney</b>

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



# MELBOURNE JUNE LUNCHEON



Melbourne June Luncheon to celebrate Myasthenia Gravis Awareness Month. Old friends reunited, new friends made. Sadly, some of our younger members were unwell on the day - we look forward to seeing/ meeting them next time. Socialising and relevant discussion relating to topics of relevance to all of us. Enthusiasm for the MAA conference in October, in 2023. We look forward to meeting at our next Lunch, with more new faces. **Please contact Catherine on 0418 563 557 if you would like to be included on the VIC list for catch ups.**

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## Bamboozable

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Bamboozable 30 Answers:  
1. Total Mess; 2. Paint by Numbers; 3. Four Part Harmony; 4. Poison Ivy; 5. Tilt a Whirl; 6. Internet Site.

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# ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 10 SEPTEMBER, 2023

## CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2023/2024

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 held from 8.30am-12.30pm 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, 5 August 2023**.

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, 8 September 2023**.

**Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 10 September 2023.**

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.**

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*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:.....