

Myasthenia Gravis Association of Queensland Inc.







Myasthenia Gravis Association of Qld Inc **IN NO WAY** endorses any products, 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 2025

It is hard to believe that we have less than two months left in 2025. 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.

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. 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 these. If you know of anyone who has passed away or changed address please phone Susan, our Information Officer, on 1800 802 568 so we can act on this information.

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**

The success of the Oh MG art exhibition continues with another showing to be held at the Lockyer Valley Art Gallery in Gatton early next year. The increased awareness of Myasthenia Gravis that has been a direct result of these exhibitions has been amazing. Stories from people with MG and carers and supporters sharing ideas are examples of the wonderful dialogue that has occurred. The MGAQ is very indebted to the artist, Chloe Wigg, and people far and wide who crocheted snowflakes and scrubbed Mestinon bottles.

I hope that everyone has fared well with the dreadful weather right down the eastern seaboard. The ferocious storms certainly have caused much damage and heartache. Then, the heatwave conditions over an extended period have had a huge impact on all of us living with MG. It will definitely be a long summer!

Stay well and focus on the positives each day.

Regards, Carol

Myasthenia Gravis Association of Queensland Inc

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Supported by











MYASTHENIA ALLIANCE AUSTRALIA

MAA UPDATE

Only weeks to go until the MAA team take a very welcome break over the festive season. It has been an incredible year for our community which has demanded an extraordinary commitment from the team at MAA. We thank our community for tirelessly following all that has been happening. We thank you for receiving so many posts as we worked hard to ensure that nobody missed out on knowing about an opportunity or being informed about the progress of new treatments. We also thank all MAA donors for ensuring that funds are available to issue the news items and to support our attendance at important events. The biggest expenditure this year involved an updated website which has allowed us to distribute a huge range of Australian MG content. We thank the MGAQ and MGNSW Associations for providing encouragement and for facilitating our priorities.

Latest news -

- **MGVic has launched!** This is very welcome news for everyone especially for our Victorian followers. **myastheniaalliance.org.au/were-excited-to-introduce-mg-vic**
- DrAntozzi'spresentation is nowloaded to the MAA website. The topic is crucial for usall to understand as communication with our Specialists is changing and everyone needs to understand the significance of the tools being used. Dr. Antozzi showed true compassion and understanding. Hopefully he gives everyone confidence in our future as patients. Thank you to Argenx for facilitating this opportunity. myastheniaalliance.org.au/expert-insights-myasthenia-gravis-and-symptom-assessment-tools-to-improve-outcomes
- One last webinar for 2025 will be offered on November 24th, at 2pm Qld time. This will feature a presentation from the Optimal Centre of Research Excellence team based at Monash University in Melbourne. To understand more about the depth of work involved in this very significant research project please do listen in. The MAA partner in this project and your feedback has already resulted in one Journal article. More research opportunities will follow. We hope that you will find it very interesting. Please note this webinar is not being recorded for your future participation. myastheniaalliance.org.au/register-now-multi-stakeholder-webinar-on-myasthenia-research-updates
- Art With Heart (AWH) is underway. See page 5 to learn more.

As Chairperson of the MAA I treasure the wonderful volunteers who support the vision for more awareness, more research and more advocacy for myasthenia patients in Australia. I ask that people reflect on the tremendous gift of time and passion offered by these volunteers. In doing so, we must ensure respect and support at all times. Without the volunteers - so much could not be offered.

Warm regards

Susan White MAA Chairperson

WELCOME TO OUR NEW MEMBERS

KYM EIMEO, QLD RAELENE, NORTHGATE, SA DEBRA, PEREGIAN BEACH, QLD

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





MGAQ CHRISTMAS FUNCTION

A very successful Christmas Function was held at Club Southside, Mt Gravatt on Sunday 9 November. In the main foyer we were greeted by a dazzling light display of snowflakes.

Once again it was a special opportunity for the MG community to come together to catch up with old friends and welcome new members.







SUPPORT your Association by **VOLUNTEERING**.



MGAQ CHRISTMAS FUNCTION



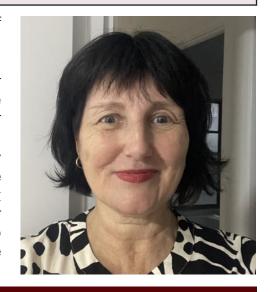


KNOW YOUR COMMITTEE

My name is Donna Formosa and I have proudly been part of the MGAQ Management Committee team for 11 years.

As a committee member, my main role is to support the Regional Coordinators throughout QLD. I am the Project Officer for the Qld Lights Up for Myasthenia campaign held during June Awareness month, and you will also see me on social media for MGAQ as an Admin.

I was diagnosed in Canberra in 1975 as an 11-year-old. My teenage years were tough having a rare disease that no one understood, but I was managed by a wonderful neurologist and a supportive family. Fast forward to five children and four grandchildren later and no medication, I feel very privileged to volunteer with such a wonderful team of people supporting the MG community.





About ART WITH HEART



Art with Heart: Creativity, Community, and Philanthropy

Art with Heart is an inspiring online event that brings together artists, community leaders, and supporters for a unique celebration of creativity, connection, and philanthropy. The event is designed to foster a sense of unity while encouraging artistic expression and charitable giving.

Supporting Myasthenia Gravis Research and Awareness

All proceeds from Art with Heart are directed towards advancing Myasthenia Gravis (MG) research, strengthening patient support programs, and funding public education campaigns aimed at raising awareness of this challenging disease. By participating in and supporting the event, attendees contribute directly to making a meaningful difference in the lives of people affected by MG.

JOIN US & MAKE A DIFFERENCE





operations@mgaq.com.au



www.myastheniaalliance.org.au



Why This Event Matters

The event is dedicated to increasing both awareness and essential funding for the Myasthenia Alliance Australia (MAA)—the national peak body committed to supporting and advocating for individuals living with Myasthenia Gravis. MG is a rare, chronic, and often misunderstood neuromuscular disease. The funds raised empower the MAA's volunteer team to continue providing vital educational resources and events for patients, facilitating research initiatives related to MG, and acting as a unified voice in national advocacy efforts.

Making an Impact for the MG Community

Through Art with Heart, the MAA is able to maintain regular communication with the patient community across Australia, ensuring ongoing support and engagement. The event plays a crucial role in helping the MAA raise public awareness and deliver resources that make a tangible difference for those living with Myasthenia Gravis.

MEMBER CONTRIBUTION

CHILLI CON CARNE - SYLVIA STYLE

INGREDIENTS

- 500gr Lean minced beef
- 1 large onion
- Large tin crushed tomatoes
- 2 beef cubes
- Tin red kidney beans (drained)
- Large can BBQ Baked beans.
- Mexican spice mix or chilli powder to taste.
 Garlic if you like.

INSTRUCTIONS

- Brown mince and finely chopped onion
- Add tomatoes, beans and beef cubes crumbled.
- Garlic and chilli to taste.
- Simmer for about an hour, adding more water if you need to.

NOTES

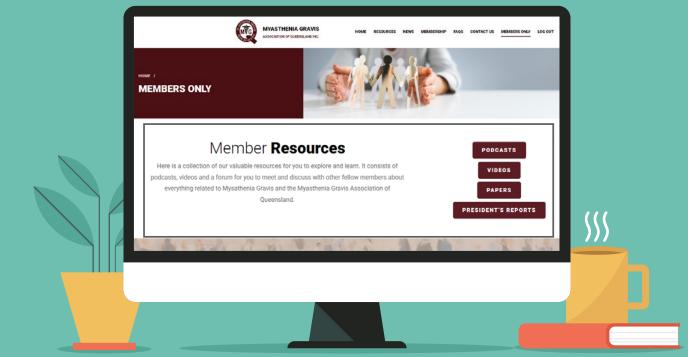
- I always serve with mashed potatoes, but you can serve with crackers, American style.
- This quantity serves about 6.
- Freezes well too!
- A great use for any left overs is to bake a large potato (I use my air fryer for this recipe) and when fully cooked, split and squeeze apart.
 Put large spoonsful of chilli mix on top, sprinkle with grated cheese.

Bake for about 5 minutes until heated fully. Serve with Guacamole and sour cream.





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



and Library Resources

Member Log in details are updated annually.
You would have received an email from treasurer@mgaq.org.au
on 1 November advising the new login details.

If you did not receive the email with updated login details, please contact treasurer@mgaq.org.au

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.





CONVERSATION CONNECTION COMPANIONSHIP

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

CURRUMBIN



COOROY







COFFEE & CHAT ROUNDUP QUEENSLAND

FREECALL 1800 802 568

Brisbane Anita 0414 588 312 Gold Coast Southport Nader 0415 834 401 **Mackay** Kym 0410 616 165 Gold Coast Currumbin Julie 0423 766 321 **Townsville**......Daphne 0400 778 637 Sunshine Coast......Michael 0447 887 652

IN-PERSON COFFEE & CHAT

Moreton Bay - MANGO HILL

Thursday 20th November at 10.30am, Coffee Club, Mango Hill Market Place, Corner Anzac Ave & Halpine Drive, Mango Hill



Mackay

Friday 21st November at 11.00am, Coffee Club - Riverfront, Carpark 4, Matsuura Drive, Mackay

Toowoomba

Saturday 22nd November at 11.30am, Picnic Point Café, 164 Tourist Road, Toowoomba

Townsville

Saturday 29th November at 12 noon, Kirwan Sports Club, 159 Bamford Lane, Kirwan This is the Christmas Lunch

Sunshine Coast - WURTULLA

Monday 1st December at 10.30am, Club Kawana, 476 Nicklin Way, Wurtulla

BAMBOOZABLES www.thinkablepuzzles.com

 PAR







MUMBO JUMBO

www.thinkablepuzzles.com

Unscramble each of the clue words. Take the letters that appear in boxes and unscramble them for the final message.

FRI PIEN PUSCER

ERD KAO

Final Message: FOREST Spruce, Red Oak, Answers: Fir, Pine, oquinc oquinw

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

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