



Myasthenia Gravis Association of Queensland Inc.

MessaGes

APRIL
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 APRIL 2023

The MGAQ, in association with Myasthenia Alliance Australia (MAA), is still busy working with Rare Voices Australia and politicians in Canberra to ensure that our voice is represented in any decision-making which will benefit people with rare diseases. This constant work by the MAA has certainly been successful with some issues but the work is ongoing. We must all remember that "*Patient Voices Matter*" and take every opportunity we can to have our voices heard.

Our Light Up Project for June is growing even bigger and more places around the state are becoming involved. More information will be in the next couple of newsletters and we hope that, if you get the opportunity, please take a photo and then send it to info@mgaq.org.au for possible inclusion in our newsletter. Also, please remember that not all photos might appear in the newsletter but they will be saved digitally for future use. More information can be found in this newsletter.

We are also keeping information and photos etc from each year so that our 30 Years' Book can be expanded for each year. Please send anything you have that could be worthwhile to info@mgaq.org.au

The requests have been heard and the Myasthenia Alliance Australia (MAA) is busy preparing for a

Conference in Sydney on **Saturday, 21 October**. We must acknowledge the neurologists who are so generous with their support for this event. More information will become available in the near future.

In next month's newsletter you will see the membership renewal information. We are always grateful to those people who make a donation at the same time as they renew their membership. Because the MAA does not have any direct line to donate to this very busy and worthwhile group, you will find boxes which ask you to which group you want your donation to go – to the MGAQ or to the MAA. Please make sure that, if you add a donation with your membership fee, that you tick the appropriate box. If you wish to share the donation please write the amount next to each box once you have ticked same. I also must stress that one membership fee does not even cover the printing and posting of the newsletter so your management committee really does appreciate membership renewals which seem to be becoming less and less each year. We need your support so we can support you.

Happy Easter to all. Everyone please stay safe and well and enjoy the time you now have with friends, children, grandchildren and even great-grandchildren.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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

MYASTHENIA AWARENESS

QUEENSLAND LIGHTS UP for MYASTHENIA



The Myasthenia Gravis Association of Queensland Inc has currently secured 13 local councils and/or private companies around Queensland to illuminate their assets in teal in recognition of International Myasthenia Gravis Month in June.

The locations and dates will be available in May Newsletter.

OCTOBER

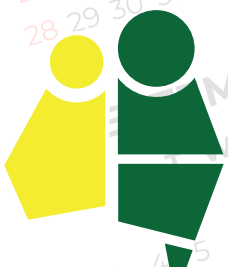
21
2023

“SAVE THE DATE”

Saturday October 21 2023
Myasthenia Conference Sydney
Concorde Hospital - Education Centre
9.00am to 4.30pm

(Parking available)

“Attendance by Application”



Myasthenia

Alliance Australia

myastheniaalliance.org.au

MYASTHENIA AWARENESS

Have you seen the **MGAQ Billboard?**



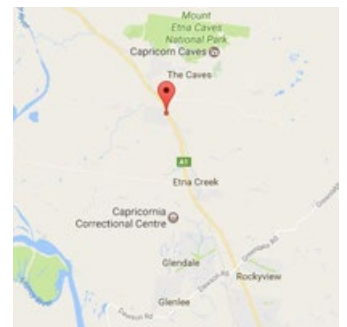
Site No: LS145A

Outbound Rockhampton

Located 15km north of the Rockhampton (Yeppoon turn-off) on the Bruce Hwy. It's on the left hand side as you travel north out off Rockhampton. (Approx. 1km south of the Caves)

6.00m x 3.000m

[-23.189922, 150.467633](https://www.google.com/maps/place/-23.189922,150.467633)



RECIPE CORNER

My Mum's Anzac Biscuits

Ingredients

- 1 cup rolled oats
- 1 cup plain flour, sifted
- 1 cup sugar
- ¾ cup coconut
- 125g butter
- 1 Tablespoon golden syrup
- 1 teaspoon bicarbonate of soda
- 2 tablespoons boiling water

Method

Combine oats, sifted flour, sugar and coconut in a large bowl.
Combine butter and golden syrup in pan, stir

over low heat until butter is melted.

Dissolve bicarb with water in a cup. Add to butter mixture, then stir into dry ingredients while mixture is warm.

Place a heaped tablespoon of mixture together about 4cm apart on lined baking tray. Press down lightly.

Bake in slow oven for about 15-20 minutes or until golden brown. Loosen biscuits while warm and allow to cool.

The Australian War Memorial, Canberra ACT, suggests that these biscuits were not named Anzac Biscuits until after World War 1, when they were made and sold as fundraisers for returned soldiers.

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

MEMBERS' FORUM

Please send in contributions to the Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is YOUR Forum and shared experiences with fellow MG sufferers makes understanding the condition just that little bit easier. If you have a response or an issue to raise, please forward it via mail to

PO Box 16 MT GRAVATT 4122 or via email to info@mgaq.org.au

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.

Myasthenia Journey And Thymectomy

"I was diagnosed with MG three days after Christmas in 2021. I remember my symptoms starting in August. I couldn't chew my food properly, I would speak for 30 seconds to a minute and my voice would sound nasally, it was difficult to speak. I was also struggling to walk. Going up stairs I could feel my legs were going to give way. One day at work I was walking up the stairs at work and my left leg gave way, I fell down the stairs, smacked my head and I was concussed. I took a trip to hospital and I remember chatting to the doctor about my symptoms. I knew I needed to go and see my doctor; something wasn't right. After my diagnosis things moved quickly, I was on mestinon and 50mg of steroids daily. The side effects of the steroids were horrible. I was then referred to a surgeon to chat about having my thymus gland removed. I was told there was a 50/50 chance of it working. If it worked, it would reduce the amount of medication I needed to be on. Straight away I knew this was something I wanted to have done, I didn't like the thought of having to be on multiple medications.



•Pictured: Ashleigh after having a Thymectomy in September 2022.

The day of the surgery came and I was excited. I remember waking up after it in a fair amount of pain. I looked down and there was a tube coming out of my chest. I asked the nurse what happened as I was told there would only be three incisions around my right breast. She said that during the surgery they nicked a vein and needed to drain the blood out of my lungs. For the next three days I had to cough to ensure the blood would drain out. After the first 24 hours I had cannula taken out and I had to take pain medication orally which was no fun. Overall, my recovery wasn't too long. I took two weeks off work and spent most of my time in bed. It is just over 6 months since I had my surgery and I was told if it worked, I would start to see results in 6-12 months. I am hopeful that it will work"

Kind regards, Ashleigh

MYASTHENIA AWARENESS

The MGAQ Banner will be displayed on the **Story Bridge** in **Brisbane** (*inbound*) from 29 May to 11 June.



GOLD COAST 1 APRIL



SUPPORT your Association by **VOLUNTEERING.**

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Being and not always doing

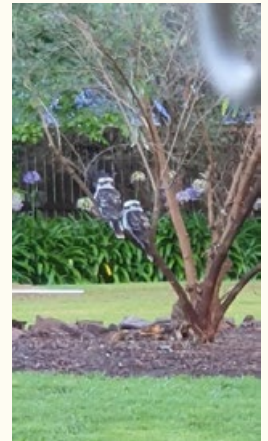
I have now found a balance between activity and taking time for myself, but it wasn't always this way. Before Myasthenia Gravis (MG) I was always occupied with work, and back then I did not fully understand how important it was to find the balance between being active and resting. I do now!

There is a definite skill to 'being and not always doing'. I begin my day doing what makes my heart sing. I have a cuppa, meditate, and then put on some music and relax (or jig) into the morning. As the day progresses I take care of jobs around the house, in our business or both; always with the view of achieving balance and feeling great. It is a skill that requires constant monitoring and adjustment because so many things can intervene.

For example, recently we hired some help to tame our overgrown garden. Somehow, I found myself moving more and not resting adequately. My energy became totally depleted. Even though my MG is medically controlled if I overdo activity, like on this occasion, the MG soon tells me. Once I recognised what was happening, I was able to put into practice what I have learnt and reestablish my balance.

These are some of things that help me rebalance: -

- I choose to sit in the garden for lengthy periods and take in the beauty. Sometimes I take a book to read but other times I do absolutely nothing.
- I appreciate fleeting snippets of joy like watching a bird hop around the garden, listening to our resident kookaburras laughing, or taking in the aroma of the bush settling after recent rain.
- I give myself time to write down how it feels. Reflecting on my journey has multiple benefits (some of which you see when they are published in the newsletter).
- I unplug and don't look at my phone or computer. I prefer to take a long hiatus from these for the most benefit.
- And I share my joy with the happy people around me.



For me, resting and not always participating in activity is a skill that journeying with MG has really brought to the fore. I now actively practice 'being and not always doing'. Allowing myself time to re-establish my energy equilibrium is very empowering. I find when I treat myself with compassion and kindness there is a lightness to my spirit, and my life works better.

Helen T

About the Author: I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.

Puzzlers

Sudoku

9			6			7		
5	6		7	3	9	2		
7						9	6	
1		4		9				
					5		9	2
	5	9		6	3	8	1	
4				1	7			9
	9		2		8			4
3		7					2	5

Commonym

What's a commonym you ask? A commonym is group of words that have a common trait in the three words/items listed. For example: the words; A car - A tree - An elephant.. they all have trunks. These will make you think!

1. The Navy - A Deli - An Absent Teacher
2. A Person - A Watch - A Mountain
3. A Bowling Alley - A Roof - A Street
4. High - Uneven - Parallel
5. Goose - Theresa - Hubbard
6. Mare - Mustang - Bronco
7. Killer Whales - Referees - Old T.V's
8. Music - Mail - Safe Deposit
9. Rail - Chain - Picket
10. Palm - Easter - Hot Fudge

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

Bamboozable

drawn scale scale		rab bit rab bit rab bit
THERE THERE THERE	Ittttttt...	folks folks folks folks

Word Change

Can you morph one word into another by just changing one letter at a time?

stale
plate

Answers

3	8	7	9	4	6	1	2	5
6	9	1	2	5	8	3	7	4
4	2	5	3	1	7	6	8	9
2	5	9	4	6	3	8	1	7
8	3	6	1	7	5	4	9	2
1	7	4	8	9	2	5	3	6
7	4	3	5	2	1	9	6	8
5	6	8	7	3	9	2	4	1
9	1	2	6	8	4	7	5	3

Word Change 26 Answers: stale, state, plate, plate

Sundays/Sundaes

Commonym 26 Answers: 1. They all have subs; 2. They have faces; 3. They have gutters; 4. Bars in gymnastics; 5. Mothers; 6. Horses; 7. They're black & white; 8. Boxes; 9. Fences; 10. All

Bamboozable 18 Answers: 1. Drawn to scale; 2. Round of Appause; 3. Spitting Hairs; 4. They're all the same; 5. There's no end to it; 6. Different strokes for different folks

NEWS FROM AROUND QUEENSLAND

News from Cairns

Cairns - Get togethers are held regularly and visitors to Cairns are most welcome to attend. For more information, please contact **Donna on 0414 397 462**.

News from Townsville

We are looking forward to our next lunch on **Saturday, 22 April at 12 noon - Sports Club, 159 Bamford Lane Kirwan**. Family members are very welcome. Look forward to seeing you there. For more information, please contact Daphne on **0400 778 637**.

News from Mackay

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

News from Bundaberg

For local support in Bundaberg, 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

Join us at our next get together which will be held on **Monday, 8 May at 10.30am - Kawana Club, 476 Nicklin Way**. For more information, please contact **Vicki on 0411 146 898** or email avplummer@gmail.com

News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get together sharing experiences with other members on Saturday 1st of April at Broadbeach Kurrawa surf Club. Our next meeting will be at on Saturday, 27 May 10am at **Southport Sharks Club**.

I hope to see all there

Kind regards Nader Amiri, Gold Coast Coordinator **0415 834 401**.



COFFEE & CHATS

RSVP Anita on 0414 588 312

IPSWICH – Saturday 29th April at 10.30am
Queens Park Café, 10A Merle Finimore Avenue Ipswich – *All Welcome!*

WELLINGTON POINT – Thursday 18th May at 10.30am
Wellington Point Farmhouse Restaurant,
625 Main Road, Wellington Point – *All Welcome!*

myasthenia gravis

**south
australia** friends

mgsouthaustralia@gmail.com

SA Coffee & Chat - Adelaide

Saturday 6 May - 10.30am

Hope Inn (Apple Room)

348 Port Road, Hindmarsh

Ample Parking (wheelchair entrance off South Road)

RSVP to mgsouthaustralia@gmail.com

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