



Myasthenia Gravis Association of Queensland Inc.

Messages

October
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 OCTOBER 2023

Many thanks to the people who attended the Annual General Meeting last month. Our theme of Conversation, Connection and Companionship was certainly well received and members, both new and familiar, had time to talk and share information and stories from the past year. As we did not have a guest speaker and limited time, everyone was relaxed and welcomed the opportunity to just catch up with others and welcome new members.

The position of Vice President was not filled at the AGM but, since then, we have received a nomination. The confirmation of Sharin Nisha as Vice President for the 2023-2024 year will be confirmed at our next meeting which is in November. Susan White has chosen to remain on the committee as a member and we thank her for her continued commitment to the association.

The work of the new management committee has already started with everyone trying to manage the workload from so many projects. Remember that, if you have a bit of spare time to give, it would be appreciated as every little bit of time helps. We are also looking for project managers for some smaller activities which will have a start and end date attached so people know the level of commitment required.

A big thank-you must go to the representatives from Queensland Health who made the time to meet with three of our management committee members on the Friday prior to our AGM. They were amazed at the work of the association and the outreach we have achieved across the state and beyond. As well as the management committee the Regional Co-ordinators and Coffee and Chat co-ordinator work hard to ensure that both new members and the ones who have been with the association for many years are provided with opportunities to meet and chat with people and share 'stories'.

A group of management committee members has been working very hard as part of a small group who are organising the Myasthenia Alliance Australia National Conference to be held in Sydney on 21 October. Many thanks to these people and particular thanks to Catherine Bergin who took a lead role in this process. We are very lucky to have very knowledgeable and influential medical practitioners who give freely of their time to present valuable information at these conferences. We thank you again and again for your ongoing support for people living with Myasthenia Gravis.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

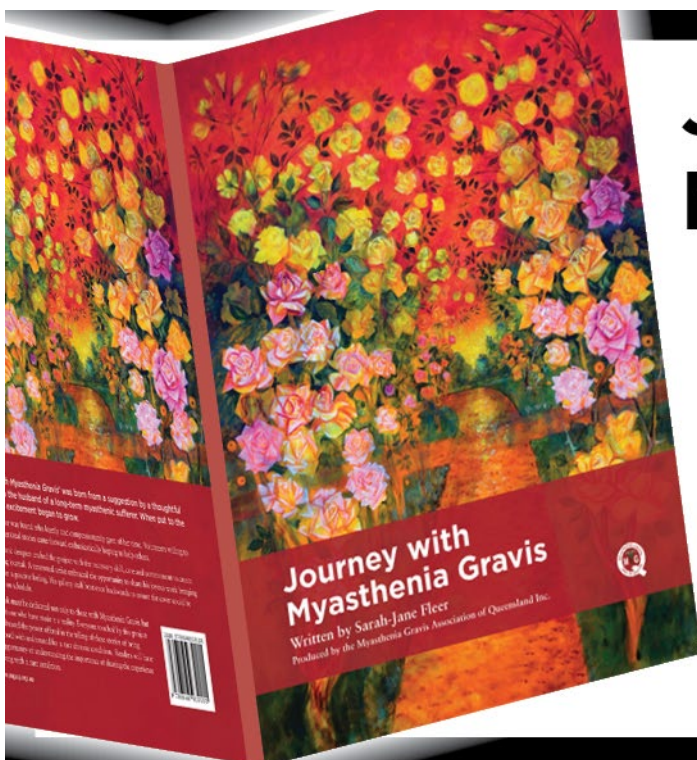
As imagined, the MAA team have been heavily focused on Conference preparations and maximising the event for the benefit of all. Other commitments are still being met as the need arises and you will be aware that we supported a Pharmaceutical Company looking to enhance their patient understanding with a view to presenting a new medication for TGA and PBS approval. This was done via a survey which was distributed throughout the membership in all the usual channels. Thanks to our amazing MG community here in Australia, the company closed off the survey earlier than expected due to the overwhelming response. The company was delighted with the information gathered and we are delighted to show that new treatment options are important to us. An info-graph summarising the results is expected shortly and it will be shared.

All the best to each and everyone. Kind regards

Susan White (MAA Chairperson)

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

“SUPPORT *your Association* by VOLUNTEERING.”



Journey with Myasthenia Gravis

A book by Sarah-Jane Fleer

Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition.

It aims to support those affected as well as their families and friends.

If you would like to purchase a copy,

Contact the Association

Freecall: 1800 802 568

Email: info@mgaq.org.au

Website: www.mgaq.org.au



Myasthenia Gravis Friends Western Australia Coffee & Chat -

Date: **Sunday, 5 November - 11.30 am**

Venue: **Flames Restaurant, 55 Central Avenue, Rossmoyne**

For more information, please contact Annette on 0413 855 077.



VICTORIAN REGIONAL MG LUNCHEONS

to be held on

Sunday, 3 December at 12 noon

Mulwala Water Ski Club, Mulwala

RSVP is essential. Please call Pauline 0419 332 260 - All Welcome

MURIEL'S DID-YOU- KNOWS

- The Daintree Rainforest, found in tropical north Queensland, is the country's largest and covers around 1,200 square kilometres
- The Aussie state of Tasmania has the world's cleanest air
- While mining is one of Australia's biggest industries, more land is covered by pubs than mines
- Uluru (Ayers Rock) is known as the largest monolith in the world and is over 8km wide at its widest point

MGAQ Website Member Only Access

Only current financial members have access to the Members Only feature of our website and member login details are changed annually.

All current members will receive their new login details via email in early November.

If you haven't received yours by then, please email treasurer@mgaq.org.au



GOLD COAST - SEPTEMBER



SUNSHINE COAST

CAIRNS - OCTOBER



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

Sero- Negative

How does this Make Things More Difficult?

*Summary of a Break out session with Dr. Stefan Blum
Myasthenia Alliance Australia – Conference 2019.*

10% of the diagnosed Myasthenia Gravis population are termed Sero-Negative.

The quandary for Doctors is how do they make this diagnosis before treatment begins. Therefore, the Doctor may be appearing to be hesitant.

Testing for Sero-Negative Myasthenia Gravis is not clear cut. The blood tests to detect the MG antibodies have quantitative cutoff levels to be termed a positive result. This may not be at a suitable level for the individual being tested and is designated negative. Also, the way the blood test is conducted through the protein binding may change results.

Other pathways are then investigated to rule out any other causes for the symptoms.

After the main blood tests (Anti-MUSK, AChR) were done a few people in the group commented they also did not get conclusive diagnosis from Nerve conduction tests also. The new blood test LRP4 is available but has to be sent overseas for testing and at a cost. There was an inconclusive discussion whether it was warranted to be retested at a later date.

The next diagnostic intervention is a positive response to Mestinon in the reduction of symptoms. Dr Blum said for him that is a strong indication for the diagnosis of Sero-negative MG as Mestinon does not work for other diseases. The Tensilon test is not really used anymore as it can have major side effects, has to be done in a hospital with emergency equipment and it needs to be a 3-syringe blind test.

There was interactive discussion on the frustration people felt when going through the diagnosis process and this was very impacting to them. Due to this uncertainty, prolonged process of diagnosis and the beginning of treatment and sometimes the feeling of not being believed posed the question of did it lead onto psychological problems for these patients? Discussion termed it is a hard path for people and one has to deal with it in some way.

The last discussion was that lifestyle factors are very important to be considered in conjunction with treatment. It is important to be as healthy in your lifestyle as you can be physically and mentally that is appropriate to the individual.

Puzzlers

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

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1	5	7	6	4	2	8	3	9
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1

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

BAMBOOZABLE 60

Grid of 6 bamboozaible 60 puzzles. 1. Think IT Think. 2. WALK over H2O. 3. VAD ERS. 4. Mind ur Mind ur Mind ur Mind. 5. KEEP smiling. 6. IT + IT ?

BAMBOOZABLE 59

Grid of 6 bamboozaible 59 puzzles. 1. STAND over icu. 2. YOU DID IT MIND. 3. AALLLL. 4. house PRAIRIE. 5. sentenc_. 6. 1. DRACULA 2. DRACULA 3. DRACULA.

BAMBOOZABLE 58

Grid of 6 bamboozaible 58 puzzles. 1. HE'S life. 2. did i no. 3. 1. your blessing 2. your blessing 3. your blessing. 4. TROUIMBLE. 5. DONT BET IT. 6. HAND IT NOW.

BAMBOOZABLE 57

Grid of 6 bamboozaible 57 puzzles. 1. ROAD. 2. CU CU CU CU CU CU CU CU CU CU CU CU. 3. SPLOSTACE. 4. 123safety456. 5. HOLD 00:01:00. 6. CONFUSION CONFUSION CONFUSION...

Vertical letter lists for word search: I B Y W E A T H E R V T C F H D, E H A T Q Z V M A K H C O I U A, C R G R I E E L U U O D N E R M, W L U P O D P E N L N T D R R I, R E I T R M I D R I L O E E I S, O O H M A E E M W B T R N H C U, P P A N A R C T U N E N S P A L, A Z T S S T E I E H T A A S N U, V C C T R J E P P R E D T O E M, I F O G X B H S M I X O I P S U, F R D P I O O S C E T B O O I C, M P Q P L M P I C C T A N R I R, T N O I T A R O P A V E T T N A, H N C A C R I N S O L A T I O N, R K J A U G N I N T H G I L O E, Z G I S R A B O S I R F R B U N

ATMOSPHERE, BAROMETER, BREEZE, CIRRUS, CLIMATE, CONDENSATION, CUMULUS, EVAPORATION, FOG, HUMIDITY, HURRICANE

INSOLATION, ISOBAR, LIGHTNING, PRECIPITATION, TEMPERATURE, THUNDERSTORM, TORNADO, TROPOSPHERE, VAPOR, WEATHER

- Bamboozable 60 Answers: 1. Think Twice About It; 2. Walk on Water; 3. Space Invaders; 4. You Are Always on my Mind; 5. Keep on Smiling; 6. It Doesn't Add Up. Bamboozable 58 Answers: 1. He's Larger Than Life; 2. Little did I Know; 3. Count Your Blessings; 4. I'm in Trouble; 5. Don't Bet on It 6. Hand it Over Now. Bamboozable 59 Answers: 1. I See You Understand; 2. Did it Cross Your Mind?; 3. All in All; 4. Little House on the Prairie; 5. Incomplete Sentence; 6. Count Dracula. Bamboozable 57 Answers: 1. Middle of the Road; 2. See You Around; 3. Lost in Space; 4. Safety in Numbers; 5. Hold on a Minute; 6. Mass Confusion

NEWS FROM AROUND QUEENSLAND

News from Cairns

Thank you to all those who came along to our Coffee & Chat at Trinity Beach. It was a lovely afternoon catching up after so long. Our next Coffee & Chat will be in Edge Hill in late November and advertised in the November newsletter. For more information, please contact **Donna on 0414 397 462**.

News from Townsville

DECEMBER LUNCH Dear Members, **Lunch Sports Club 07 4773 1223, 159 Bamford Lane, Kirwan, Townsville, Saturday, 2 December 2023 at 12 noon**. If you can come please **RSVP Daphne Clay 0400 778 637**, email **daphclay@gmail.com**

Looking forward to your company. Family members are welcome. Thanks for attending our July lunch. As this is our Christmas lunch you are invited to bring a gift (\$15.00-\$20.00) and we will exchange gifts. For more information, please contact Daphne 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 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

I look forward to our next catch up which will be **Monday, 4 December at 10.30am, Club Kawana, 476 Nicklin Way Wurtulla**. Don't forget to bring your empty Mestion bottles for Chloe's art project.

If you are in the area, please join us. For more information please contact **Michael on 0447 887 652**.

News from the Gold Coast

Hi Everyone. MG Gold Coast Group had their get-together sharing experiences with other members on Saturday, 23 September at Southport Sharks Club. Our next meeting will be at **10am on Saturday, 18 November at Broadbeach Kurrawa Surf Club**. I hope to see all there. Kind regards Nader Amiri, Gold Coast Co-ordinator. For more information, please contact **Nader on 0415 834 401**.



COFFEE & CHATS

MANGO HILL - Saturday 25th November at 10.30am, the Coffee Club, Mango Hill Market Place, Cnr Anzac Parade Halpine Drive, Mango Hill

ALL WELCOME!

RSVP Anita on 0414 588 312

WHAT'S COMING UP

What's On?

When Is It?

Where Is It?

Christmas Function Cancelled

Unfortunately, due to other commitments by the MGAQ Management Committee, the Christmas function previously advertised has been cancelled. However, we encourage local groups to get together within their regions to celebrate the year.

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