



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

MARCH 2020

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.

Myasthenia Gravis Association of Queensland Inc

P.O. Box 16

MT. GRAVATT QLD 4122

NATIONAL FREECALL:
1800 802 568

ABN 92 055 613 137

Email: info@mgaq.org.au

Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President

Carol BUCHANAN

Vice-President

Susan WHITE

Secretary

Ron STEPHEN

E: info@mgaq.org.au

Treasurer

Denise HANNAY

E: treasurer@mgaq.org.au

Committee

Anita JACKSON

Donna FORMOSA

Rosalyn HOLLAND

Ian HOLLINGWORTH

Kirstine SHRUBSOLE

Karen DOWNES

Newsletter Editor

Greg BREADEN

E: MGAQ.editor@gmail.com

PATRON

Dr Cecillie LANDER

Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Yet another month gone but the news has certainly been better for farmers and bush fire victims. It is wonderful to know that many dams are close to being full and that most of Queensland has benefited from the rain.

Exciting news that we received recently is that the eNID project technical build of the database to be attached to the MSBase has been completed. The next step is for testing to be done by the neurologists involved. I am sure that all members who contributed in any ways to this project will be very pleased with this achievement which will eventually benefit many, many people who live with Myasthenia.

I hope that everyone made the time to talk with someone about living with MG during Rare Disease Day. It certainly seems that Susan White's attendance in Canberra on behalf of the Myasthenia Alliance Australia and the MGAQ in conjunction with Rare Voices for the launch of "**The National Strategic Plan for Rare Diseases**" was very worthwhile.

Having the opportunity to speak directly to members of parliament about issues of national importance is a very powerful way of getting heard.

If you are a financial member please remember to apply for a new Medi-alert wallet card as the

old ones are now obsolete. The new card contains the latest "**List of Drugs to be Used with Caution**" and all your relevant medical contacts will be added before it is sent to you. The card is very compact and will fit easily into a wallet or purse. The application form is available on the website or can be posted to you by phoning **1800 802 568**.

The number of unfinancial members we have is of some concern. The membership fees are deliberately kept low but we still need to operate as an organisation and be able to maintain and grow the wide variety of resources and assistance for all.

Our treasurer, Denise, will soon send out reminders to those who are unfinancial. We ask that you please take note of this and act accordingly so that the quality services we provide can continue. All monies we receive are used to support the quality of life for people who live with myasthenia and their support personnel.

It is very important that we all try to remain as healthy as possible, particularly with the current pandemic. **I encourage everyone to carefully note the information on page 4 about the Novel Coronavirus - Covid-19.**

Thanks, Carol

Supported by



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MYASTHENIA ALLIANCE AUSTRALIA NEWS



News Update March 2020

This month the story is **ALL** about the exciting opportunity to represent the Myasthenia Gravis Community in Canberra, celebrating Rare Diseases Day along with the Rare Voices Australia team. Witnessing the launch, from Health Minister Greg Hunt, of the National Strategic Action Plan for Rare Disease was a privilege. Strong bi-partisan support and commitment to this Action Plan was made evident in the speeches from Shadow Minister Chris Bowen, Dr. Mike Freeland MP and Trent Zimmerman MP. Nicole Millis, CEO Rare Voices Australia, and Deputy Chair of the Board, Kane Blackman, undertook to keep the politicians accountable for the promises made.

Minister Hunt drew attention to the great uncertainty surrounding a rare disease diagnosis. He discussed the limited data, knowledge and awareness available for these conditions and promised a united and comprehensive policy. He

announced an initial 3.3 million dollars for data collection, patient support, research and clinical training.

Nicole explained that achieving this Action Plan had been 10 years in the making. She went on to explain the Action Plan deems that policy be

- **Person centered**
- **Give equity in accessibility**
- **Develop sustainable systems**

She stated that "Effective Policy" transforms people's lives and hoped that as change begins, momentum is created and action occurs.

There was palpable excitement in the room!

It was wonderful to participate at the launch and to be supported by the senior politicians and by my local member Trevor Evans who wrote to the Minister last March when the call for assistance went out. The photos included here will give some idea of the many people taking a serious interest in this event.



MAA News continued on Page 3

MAA News continued from Page 2

In regard to the MAA's quest to seek PBS approval for the medication Rituximab to be made available to people with Myasthenia, a response letter was sent to the Minister's Office in advance of attending the launch.

This letter summarised the work that had been undertaken during the previous 12 months and it responded in detail to the suggested pathways that the MAA should explore. It was a very comprehensive letter, which fully explained that whilst all the parties with a responsibility for this decision were engaged with the well-supported question, it is stalled due to current legislation.

Nicole Millis joined me in meeting with the Ministers Chief Advisor where it was successfully communicated that Legislative change is needed. Such change is the responsibility of the Minister. The discussion was progressive and the

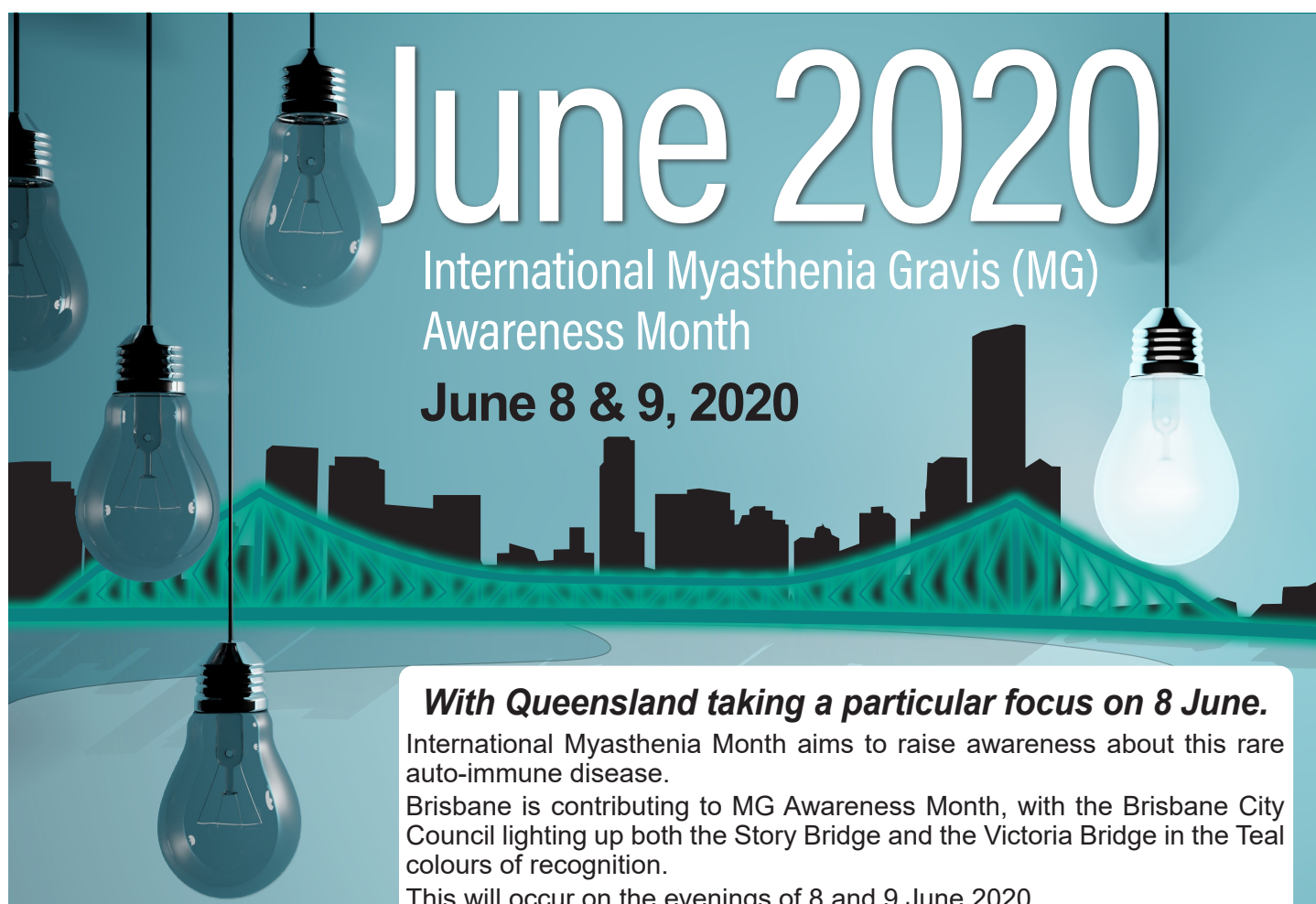
key issues have now been heard. A 'next step' response is expected in the coming weeks.

Reaching out across Australia to local Federal members is now as important as always. Queensland has been well represented by requests to the Minister but sadly, in 12 months of publicity around this project, no Federal Member outside this State has been asked to support this agenda. The MAA requests that people from the MG community right across Australia, actively foster conversation about this discriminatory situation and get behind this work by calling Susan on 1800 802 568 for more information should they be willing to make an appointment with their local Federal Parliamentarian.

To top off a wonderful trip I was fortunate enough to spend time with a few local MGers and I thank them very much for their enthusiastic support.

Susan White – President.

Follow the work of the Alliance by registering at the website
www.myastheniaallianceaustralia.com.au



June 2020

International Myasthenia Gravis (MG)
Awareness Month
June 8 & 9, 2020

With Queensland taking a particular focus on 8 June.
International Myasthenia Month aims to raise awareness about this rare auto-immune disease.
Brisbane is contributing to MG Awareness Month, with the Brisbane City Council lighting up both the Story Bridge and the Victoria Bridge in the Teal colours of recognition.
This will occur on the evenings of 8 and 9 June 2020.



COVID-19 Virus and Suggested Precautions

As people with a chronic illness, particularly inclusive of those who are immune suppressed, the Myasthenia Gravis community should be very familiar with the precautions needed to stay safe from infections. With the COVID-19 virus spreading it is important for patients and their families to be extra vigilant.

This includes:

- Keep your distance from other people and avoid all larger gatherings. Stay engaged with your community via the telephone.
- Washing and carefully drying hands and household surfaces frequently and thoroughly. Using a detergent solution in warm water is best and washing or discarding the drying cloth is ideal. Using hand sanitisers in between hand washing opportunities is also important.
- Be very aware of where your hands have been and do not let them come to your face.
- Stay at least 1.5 metres from anyone with a cough. Wearing a mask is not required unless you have a cough.
- If you become unwell, seek prompt medical support and identify the issue to the attending medical staff as early as possible. Calling ahead is the best protocol.
- **Government hotline numbers are National - 1800 020 080, Queensland - 1343 2584. Utilise your GP and the local hospitals. Call '000' if very unwell.**
- Think about how you will manage if you become sick and who will support you. This includes how to quarantine yourself in the home to protect anyone else living with you. Be sure to put the toilet bowl lid down before flushing and wash all bathroom surfaces regularly.
- Be prepared by having adequate stocks of your medications.

The MAA Medical Advisory Board recommends the following.

- Avoid all non-essential travel outside of Australia.
- Continue immunosuppression as usual.
- Patients experiencing flu like symptoms or URTI symptoms should call in advance to discuss postponement of any neurologist appointments and to get advice on how to manage their attendance at hospitals for infusions whilst they are unwell. For IVIG patients for whom the timing of their infusions is important, they should definitely speak to their treating neurologists if they are unwell.
- For all patients, good hand hygiene etc is advised.
- The situation is fluid and is likely to worsen before it gets better although there is **NO NEED TO PANIC**. The illness is mild in most patients.
- All patients should be up to date with influenza and pneumonia vaccination.

For monitoring of the global situation, Johns Hopkins live map monitoring is useful and also www.worldometers.info/coronavirus/

The Queensland health department have advice on the virus via the following website www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/diseases/coronavirus

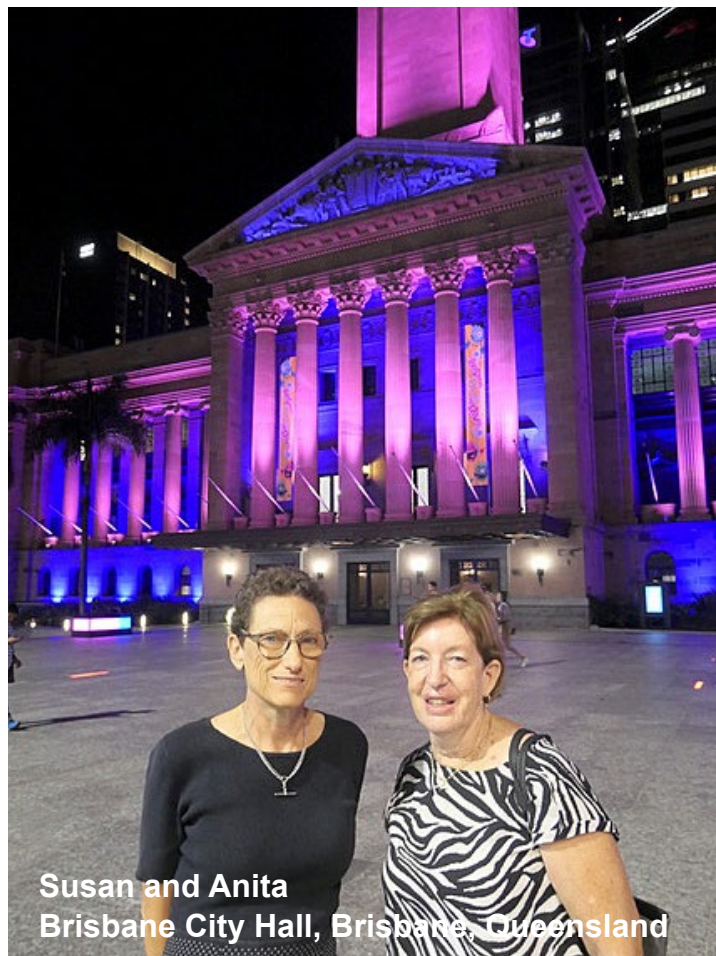
The Centre for disease Control and Prevention has a range of helpful tips.

Please visit <https://www.cdc.gov/coronavirus/2019-ncov/community/index.html>

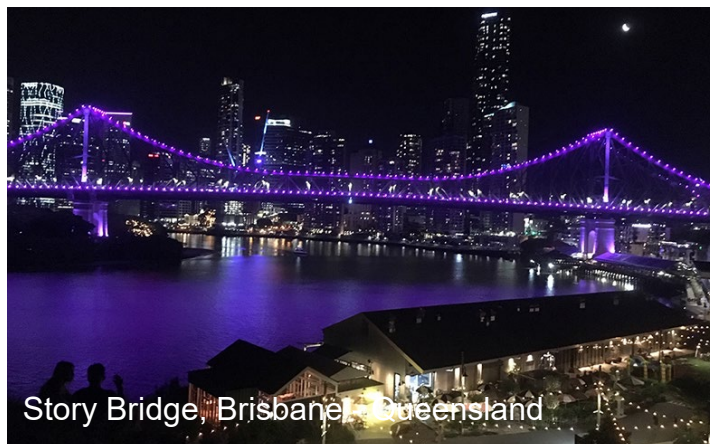
The gps-can.com.au website has some very good advice also.

AUSTRALIA LIGHTS UP FOR RARE DISEASE DAY

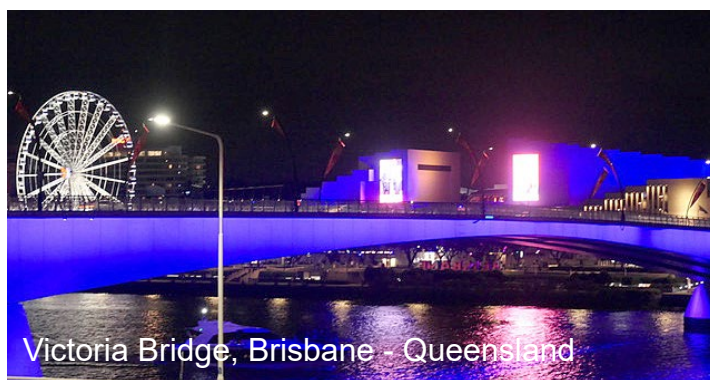
- FEBRUARY 29, 2020 -



Susan and Anita
Brisbane City Hall, Brisbane, Queensland



Story Bridge, Brisbane, Queensland



Victoria Bridge, Brisbane - Queensland



Brisbane City Hall, Brisbane, Queensland



Town Hall, Launceston - Tasmania



MURIEL'S DID YOU KNOWs?

- 1. 33% of Australians were born in another country
- 2. Over 300 different languages and dialects are spoken in Australia including 45 Indigenous languages
- 3. In fact 21% of Australians don't speak English at home!
- 4. WA is home to what is believed to be the oldest evidence of life on Earth - the Stromatolites
- 5. Vegemite was created by left over Yeast used to create Beer - so that's why it tastes so good!



The MGAQ thanks Tresorit for its support to sufferers of Myasthenia Gravis



Tresorit is an ultra-secure cloud-based data storage service with full GDPR (General Data Protection Regulation) and HIPAA (Health Insurance Portability & Accountability Act) compliance.

Tresorit provides End-to-End Encrypted File

Sync & Sharing service with features that make it a solution of choice for the Legal, Healthcare, Human Resources and Nonprofits sectors.

With the significant growth in its requirements for secure data storage functionality, the MGAQ approached Tresorit for support. In turn, Tresorit have gifted the Association ten units each of 1,000 Gigabyte cloud based data storage services. The regular cost of these services annually is \$3,500.



'Ask the Expert' podcast series

Send us your questions.

In our February Newsletter, we talked about a new Podcast service for 2020 targeted to further improve members knowledge and understanding of matters related to their Myasthenia Gravis (MG). One of the podcast series is entitled 'Ask the Expert'.

This Series allows members to ask general questions about MG, its impact and how to better cope, the various types of treatment options, etc. These questions will be incorporated into a recorded discussion with a relevant expert and from the recording, a podcast will be produced for distribution to members.

The first expert in this podcast series will be a speech pathologist. Speech pathologists provide assessment and treatment advice for swallowing difficulties and communication

problems arising from poor muscle control as a result of MG.

Please send through your questions, which are of a general nature, related to speech, swallowing or voice that you would like the Expert to answer.

Questions may be submitted via the
Freecall 1800 802 568
or emailed to info@mgaq.org.au.

Questions must be submitted by the
15th of April!

***Remember patient specific advice
cannot be given.***



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.

INTRODUCTION TO FORUM ITEM

Member Trevor has written regarding a recent hospital experience. It shows why it is important to be informed, to be vigilant and to question your medical staff. This story serves as a great reminder of the importance of carrying your medi-alert card or Drugs To Be Used With Caution brochure or to remind your prescribing doctor to visit www.mgaq.org.au and access the list easily found on the header bar.

Do note that the medications discussed belong in the opiate range and are known to potentially worsen MG symptoms. Please refer to Drugs To Be Used With Caution Booklet.

TREVOR WRITES

PAIN KILLERS.

I should have known better & tried something else. I finally received the long awaited Ankle Replacement and it proved much more painful than the previous experience with a Hip Replacement. The Medical Staff prescribed Endone / Targin. I am sure this medication was responsible for the down turn in my strength after the previous Hip Operation. So, this time, in less than 24 hrs on Endone / Targin my breathing became laboured. It felt a little like driving in 5th gear rather than 1st gear. It felt like driving up a big hill. My energy levels dropped.

So I asked for something else. PLEASE.

They did prescribed something else, but fortunately the pain levels dropped & I was able to cope with Panadol.

My breathing came back to normal quite quickly but my energy levels are still down. I'm sure the operation at 69 years of age, plays its part. So I'm now adding Endone / Targin to my Allergy List.

Don't know about 'You Mob' but glad of a slight drop in temperature thanks to the lovely rain. (Hope It's a Sign of An Early Winter) and maybe I will be back on the Motorbike soon thanks to the surgery.



Myasthenia Gravis Friends Western Australia

Come and join us for a Coffee & Chat

POSTPONED DUE TO COVID-19

SUNDAY 30 MARCH @ 10.30AM - ROSSMOYNE

Rossmoyne Waters (Pelican Room) 26 Freeman Drive

Please RSVP in Facebook group comments or call 1800 802 568 and Susan will give you the phone contact.

What I enjoy on a good day.



"Hitting the
slopes!"
Ian H

Send your message or photo to

Myasthenia Gravis Association of Qld Inc.

P.O. Box 16, Mt Gravatt, Qld 4122 • Freecall: 1800 802 568

Email: info@mgaq.org.au

GOLD COAST MG GROUP FEBRUARY - KURRAWA SURF CLUB



Myasthenia Gravis Australia Parents & Grandparents

Administered by the Myasthenia Gravis Association of Queensland Inc.

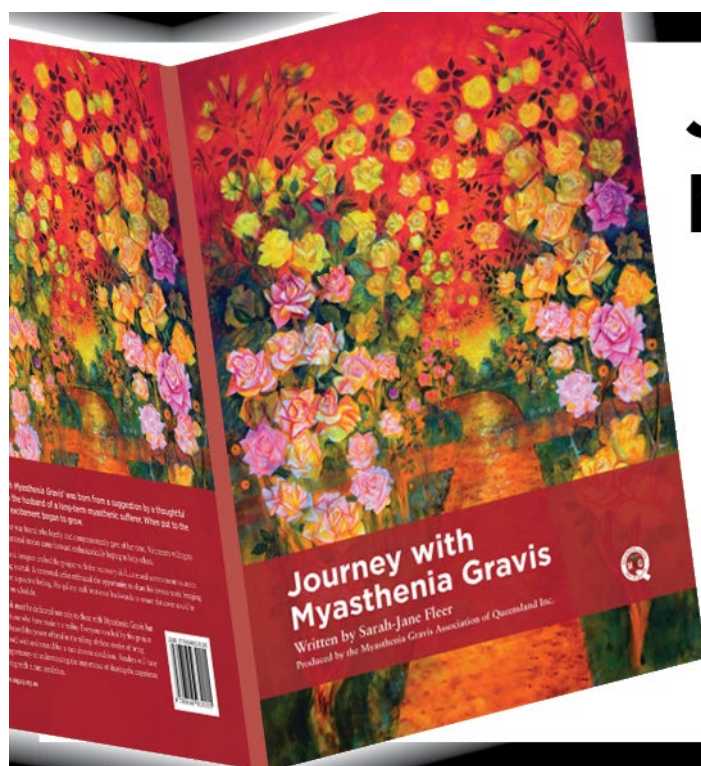
The Myasthenia Gravis Australia Parents & Grandparents Facebook page has been established for Parents and Grandparents of children (under 25 years old) diagnosed with Myasthenia Gravis.

It is a place that offers a positive and supportive environment for the sharing of information, experiences and questions with both Admins having a child with MG.

The Facebook page is closed for privacy and only accepts Parents and Grandparents of children under 25 years old who have MG and reside in Australia or New Zealand as treatment and services can be different from those in other countries.

We look forward to building a stronger community with this resource.

Please follow the link and join Myasthenia Gravis Australia Parents & Grandparents at
www.facebook.com/groups/821532874970222



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

NEWS FROM AROUND QUEENSLAND

News from Cairns

The first meeting for 2020 will be held at the Cairns ESQ on **POSTPONED DUE TO COVID-19** at 11am on Saturday, 21 February. The meeting room next to Biscuits.

Future dates for your diary are Saturday, 20 June; Saturday, 19 September and Saturday, 21 November.

For more information, please contact Donna on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

Our next lunch will be on **POSTPONED DUE TO COVID-19** at the Hotel, Kirwan. All welcome.

For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

The attendance at our February get-together was lower than normal after receiving 526mm of rain. **POSTPONED DUE TO COVID-19** seeing everyone at the next meeting on Saturday, 20 April at 12 noon at The Shamrock Hotel, 165 Nebo Road. For more information, please contact Muriel on (07) 4954 1221.

Hervey Bay – Wide Bay Burnett Region

Please join us for a catch-up **POSTPONED DUE TO COVID-19** at Bunnings Café, Boat Harbour, Hervey Bay on Saturday, 11 April at 10.30am.

For more information, please contact Jan on 0429 622 438 or janpowell3@bigpond.com

News from Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 4973 7983.

News from the Sunshine Coast

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

News from the Gold Coast

Hi Everyone. The Gold Coast MG group had the usual get together sharing their experiences on Saturday, 15 February at the Kurrawa Surf Club.

Our next meeting will be at the Southport Surf Club on Saturday, 18 April at 10am.

I look forward to seeing you all. **POSTPONED DUE TO COVID-19** For more information on the Gold Coast group, please contact Nader on 0415 834 401.

News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area.



Cleveland Wednesday 25th April 10.30am

POSTPONED DUE TO COVID-19

Mango Hill Friday 17th April. The Coffee Club

POSTPONED DUE TO COVID-19

Unit Anzac Ave & Halpine Drive, Mango Hill

For more information, Contact Anita on 0414 588 312



WHERE IN QUEENSLAND?

FEB: Hill Inlet,
Whitehaven Beach

Pauline L from Mackay was correct.

Let us know where you think it is:

Send to: info@mgaq.org.au
or post to MGAQ, PO Box 16,
Mt Gravatt, Qld, 4122

**Contact
your local
coordinator
for more
information.**



Welcome to our new members

Carl B,
Latham, ACT

Yvonne H-T
Mango Hill, Qld