



Messages



MYASTHENIA GRAVIS AWARENESS MONTH

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

JUNE 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

June is Myasthenia Awareness Month.

We all know that everyone with MG displays different symptoms and has a variety of treatments to ensure the best quality of life available. Because we are a minority group in terms of our condition, it is important that we continue to advocate and June is the month when we should really make an extra effort in this area.

One of our members, Henk, has been very busy contacting city councils and other organisations across Queensland with a view to highlighting Myasthenia Awareness Month to communities across Queensland. Ipswich City Council is lighting up Ipswich Civic Theatre and Studio 188, Toowoomba is lighting up the Victoria Street Bridge and Brisbane is lighting up the Story and Victoria Bridge. Please read more about these exciting initiatives in this newsletter.

Our June members' meeting was conducted using Zoom webinar. Many thanks to those who tuned in to listen to the presentation "My Metropolis Journey with MG" by Clinical Psychologist, Dr Angelo Contarino. This presentation will also be available to Category A financial members on DVD upon request or via computer link up.

As we approach the end of the financial year it is time for all mem-



bers to renew for 2020-2021. As a management committee we are trying to have as many people with Myasthenia and their families as financial members.

The benefits of being a financial member are considerable, particularly in relation to access to all of the support materials and information available. One example of this is our newly updated and very purposeful Medi Alert Wallet Card.

Fees for all types of membership remain the same this year and the membership renewal was in last month's as well as this month's newsletters. You can also renew via the website. Just a reminder that, if you do pay by direct deposit, please remember to send an email to treasurer@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction.

While it is great to hear that Queensland is slowly 'opening' again, please remain safe and follow the COVID-19 health procedures. The app on your phone is another safety measure.

Be assured that your management committee continues to work hard for all our members during these difficult times. Technology is certainly being used extensively to keep our projects moving forward.

Thanks, Carol

Supported by



**Queensland
Government**

Ausenco



MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

To be a MAA Board representative, you must first become a committee member of a State Association. The MGAQ are currently calling for nominations to their committee from September this year. Now is the time for Queenslanders to get involved if they have an interest in working with the Alliance. The same opportunity is available throughout the year in NSW and potentially in Victoria. For people outside these areas wanting to take an interest in the work of the MAA, this may be possible.

The MAA Board works exclusively via teleconference calling and possibly ZOOM meetings into the future, so access is easy. Our key interests are in promoting research, in liaising with Federal policy makers and in raising a National Voice for ALL Australians. We work with a Medical Advisory Board. It is exciting to be involved in discussions around new projects and to support the actioning of projects which have been developing since the inception of the MAA. We are so very fortunate to have these doctors interested in our rare condition so it is important that we are

able to support and encourage this interest. Minister Hunt and his counterparts do know about Myasthenia and are aware of the implications of living with a rare disease. There is so much to be achieved in bringing about best health policies for our people. In bringing ALL Australians together and in raising awareness and credibility the three National Conferences have played a key role.

The board is a very small group of 5 and it is very open to expansion. Three key people have driven the MAA since establishment. These three people are ageing and battling the ever-wearing effects of long term symptoms and significant treatments for Myasthenia. If further Conferences are to be considered, a fresh energy must be brought to the Board. If anything about the above information pulls at your heart strings, please speak to your State Associations or to me personally on 1800 802 568 for more information. Please come on board. It is not necessary to be an MG sufferer to become involved.

Susan White - MAA Chairperson.

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

Seeking people with Myasthenia Gravis for research



Who: Australian adults with a diagnosis of Myasthenia Gravis.

What: Complete an online survey (45-60 mins).

Why: To investigate knowledge and awareness of symptoms, and perspective on whether allied health services would assist in managing symptoms.

This research will help us develop educational and advocacy materials for people with Myasthenia Gravis to receive allied health services.

How: Use this link <https://tinyurl.com/MGAlliedHealth> or scan QR Code



For further information:

Ms Katrina Williams on 0407 550 930 or k.williams2@uq.edu.au



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA



This research is supported by the Myasthenia Gravis Association of Queensland Inc.



MGAQ Inc. podcast series

Latest & Upcoming MGAQ Podcasts

CURRENTLY AVAILABLE:

- **Episode 1 MGAQ Podcast Series Overview** - This provides an Overview of the planned MGAQ Podcast and Vodcast Series 1 through 5
- **Episode 2 Resilience** - This presents the MGAQ's first '**Ask the Expert**' podcast. It involves a discussion with Dr Angelo Contarino, a Clinical Psychologist and the current Chair of the College of Clinical Psychologists in Queensland, about Resilience. Dr Contarino will talk about Resilience, what defines Resilience, strategies for how we as individuals can build our Resilience and how to apply those strategies during the current outbreak of Covid-19.
- **Episode 3 Types of MG** - This presents the first podcast in the series entitled '**My Journey with Myasthenia**'. This podcast will discuss Myasthenia Gravis and the various types of MG.

COMING SOON:

- 1 July, 2020:** MGAQ Podcasts will present the second '**My Journey with Myasthenia**' podcast. This will include a conversation with three Sero-negative MG sufferers and the particular challenges they have faced together with the solutions or approaches they have adopted to help in dealing with their type of MG.
- 15 July 2020 :** MGAQ Podcasts will present the second '**Ask the Expert**' podcast. This involves a conversation with Tahlia Alsop, a trained Physiotherapist, on the benefits of Physical Activity and the impact of sedentary behaviour on MG Sufferers . Tahlia is on the UQ Academic staff where she is completing her PhD investigating physical activity and sedentary behaviour in people with MG. Tahlia was a guest speaker at the 2019 MAA National MG Conference held in Brisbane.

Podcasts are scheduled so that they become available from 5am on the dates given above. This will allow any of you who enjoys a crisp, early morning walk to listen to the latest MGAQ Podcast on those days.

Send us your questions. FreeCall **1800 802 568** Email: podcast@mgaq.org.au

COLOURING-IN COMPETITION WINNER

Thank you to everyone who entered our very first Colouring-In competition.

The Winner of the woven wall hanging is Helen from WA.





MGAQ UPDATED WEBSITE

The MGAQ Committee is very excited to bring to our members, a new looking and much enhanced Association website.

It is much easier to navigate and the key features are clearly displayed. Please go to www.mgaq.org.au and start exploring. The issue will be in deciding what to look at first. Good luck!

The **Home Page** displays our goals and values and clearly indicates that we are there to help all! You can see the latest, important Association activities by visiting the current **News and Events** or explore the history of our work. Reading for hours is supplied by the **archived Newsletter collection**.

Importantly, the updated **FAQ (Frequently Asked Questions)** answer so many important queries as people learn to live with this condition. Now include are comments from various Specialists and a Psychologist.

It is easy to **Make your Payments, Send a Donation, Take membership, Order the 'Journey' book or join a 'Closed Discussion' Facebook group** that suits you best. Signing up to stay in touch is very quick and easy.

Explore a little further by visiting the **Resources page**. Here the content deepens with our detailed **Information Booklet** available and **'mgexplained'** in simple graphics. This is a wonderful tool when trying to explain the condition to family and friends. It is here that you and your Doctors will find all the information needed when prescribing new medications. Everyone should be familiar with the **Drugs to be Used with Caution** list.

Dig a little deeper and you will see the **Library Resources** available to members plus a selection of research papers. This list will be enhanced as part of the next stage.

Contacting us has never been easier, just open the **Contact Us** page.

More Member Benefits will be added to website over the coming months including a wide selection of Podcasts and Vodcasts. Please stay in touch for easy access to these assets.

The screenshot displays the MGAQ website homepage. At the top, there's a navigation bar with links: HOME, RESOURCES, NEWS, MEMBERSHIP, FAQS, CONTACT US, and LOG IN. The main header features the MGAQ logo and the text 'MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.'. Below this, a large banner image shows a family walking in a park, with the text 'Supporting One Another' and a call to action 'MAKE A DONATION'. A sidebar on the right lists 'About MG', 'Treatment', 'Lifestyle', and 'Research'. The main content area is divided into sections: 'OUR MISSION' (improving quality of life), 'COMMON FAQS' (with links to 'About MG', 'Treatment', 'Lifestyle', 'Research'), 'Make a Donation' (with a 'MAKE A DONATION' button), 'Newsletter Archive' (with a 'NEWSLETTER ARCHIVE' button), and 'Membership Application' (with a 'CLICK HERE' button). Below these are sections for 'NEWS AND EVENTS' (listing recent news items), 'SURVEY UPDATE' (with a 'CLICK HERE' button), and 'SOCIAL INTERACTION' (with links to Facebook groups). At the bottom, there's a 'MESSAGES MAILING LIST' sign-up form and a footer with 'Queensland Government' logo, 'Site Links', and 'Get In Touch With Us' (with a 'FREE CALL 1800 802 568' button).

The Committee is extremely thankful for the IT knowledge and for the hours of work provided by volunteers to produce this updated and very friendly website. All credit must be given to Interactive Focus for the well established history that began this project. Additionally the Committee are keen to acknowledge the engagement of interested health professionals including Dr Stefan Blum, Dr Fiona Chan and Dr Contarino.



JUNE AWARENESS MONTH ZOOM MEETING

With the support of Brett from Synergy Video, the Committee launched into a new initiative for our regular June meeting. Unable to come together locally, we widened our reach across Australia by inviting guest speaker Dr. Angelo Contarino to present via ZOOM. Offering lots of support, engagement and reminders (possibly too much at times) we really encouraged people to try attending using this new format. Many took up the offer of help and were rather chuffed to do so. With around 60 people joining in on a Sunday morning it was an excellent first attempt.

Early into Angelo's working career, life was interrupted by Myasthenia Gravis. Inspirationally Angelo went on to develop a very successful career as a Clinical Psychologist working in both the public and private sectors helping people of all ages with a huge variety of issues. Over a ten year period he completed his doctorate and is now Chair of the Australian Psychological Society, College of Clinical Psychologists in Qld. Angelo is passionate about family and thankful for having his wonderful family there to support him through his journey with MG.



Some people wondered why the title "My Metropolis Journey". All was revealed as we learnt that the Rollercoaster at Luna Park is named the Metropolis! Angelo likened life with MG to being on a rollercoaster. He also referenced that a metropolis is a large busy city with people going in

many different directions. A good analogy to the individual road map for each person with this condition. Big cities can feel very alone despite the noise - another good comparison.

Angelo shared what happened to him including being sero-negative for 20 years before one day receiving a positive antibody result! He shared what treatments he was given, what symptom ups and downs have occurred and how he experienced many emotions over the 21 years. He discussed the importance of self care, offering personal compassion and acknowledgement. He reminded us to hear our positive inner voice and to aim for positive action when adjusting life to the new situation. This very much means accepting help from family, friends and medical staff. Staying socially connected, particularly during this physical distancing period, is essential. Angelo threw in a quick cooking class and encouraged us all to laugh regularly.

Feedback from those who attended showed enormous appreciation for the depth of detail Angelo shared. This gave a strong human element to the meeting and everyone felt connected. This presentation will ultimately become available through the website and in the usual manner, is available by DVD. Category A members should contact the Association if they would like a DVD. Freecall 1800 802 568 or info@mgaq.org.au.

What a pleasure to spend the morning with Angelo. We even had an opportunity to ask a few questions. Thank you 'fellow traveller' for inspiring us, for encouraging us and for supporting our experiences with this rare condition.



Welcome to our new members

Jessica, Holland Park, Qld
Corinna, Grasstree Beach, Qld
Joanne, Southport, Qld
Karen, Horsham, VIC

Amanda, Boondall, QLD
Dennis, Lenah Valley, TAS
Katherine, Box Hill, Vic.



JUNE

International Myasthenia
Gravis Awareness Month

JUNE 8, 9 & 10 QUEENSLAND BRIDGES LIGHT UP FOR MG

- BRISBANE** - Story Bridge and Victoria Bridge
TOOWOOMBA - Victoria Street Bridge
IPSWICH - Ipswich Civic Centre and Studio 188

International Myasthenia Gravis Awareness Month was recognised in Queensland on the 8th, 9th and 10th June 2020 with the support of the Brisbane City Council, the Ipswich City Council and the Toowoomba Regional Council.

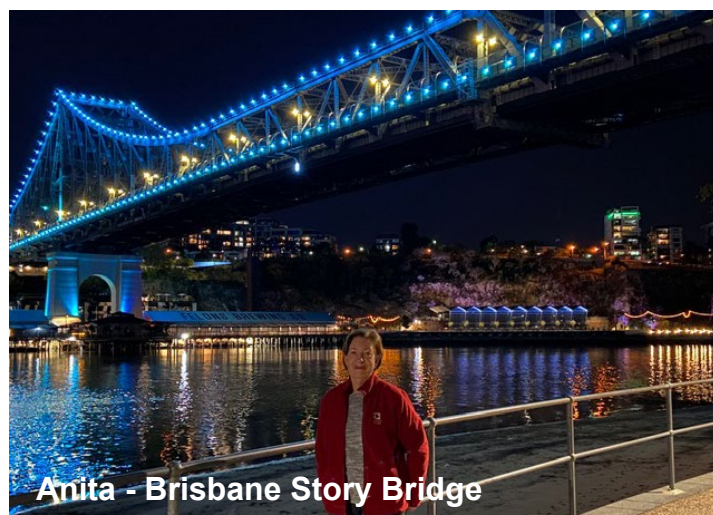
The "Light Up the Story" campaign was initiated by the MGAQ and with the support of the Councils listed above, Brisbane, Toowoomba and Ipswich all displayed in the teal colour of recognition for Myasthenia Gravis Awareness.

Our MGAQ community has welcomed this initiative which has brought solidarity and comfort to those affected by Myasthenia Gravis. This campaign was made possible when a member put up his hand to help and this is what makes our MGAQ so special.

The Myasthenia Gravis Association of Queensland Inc. would like to thank and acknowledge the Brisbane City Council, Ipswich City Council and Toowoomba Regional Council for their support with this campaign and a special thanks to Henk for supporting the committee.



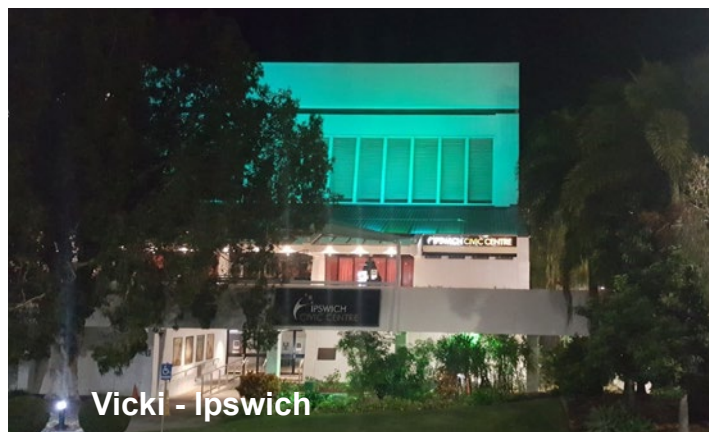
Carole - Brisbane Victoria Bridge



Anita - Brisbane Story Bridge



Betty - Toowoomba



Vicki - Ipswich

MEMBERS' COMMENTS

The Bridge looked spectacular in design and teal colour. I have no doubt it would have created much needed awareness for Myasthenia Gravis. Congratulations MGAQ and Brisbane City Council for arranging this fantastic lighting display... **Pauline**

A remarkable display showing support for Myasthenia Gravis & their carers. A great initiative organised by the MGAQ... **Chris**

When I saw the bridges lit up it made me feel proud. It allowed me to share the photos which has led to questions from friends and family and spread awareness of this rare disease... **Sara**

How marvellous to be able to support Myasthenia Gravis awareness this way... **Henk**



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.

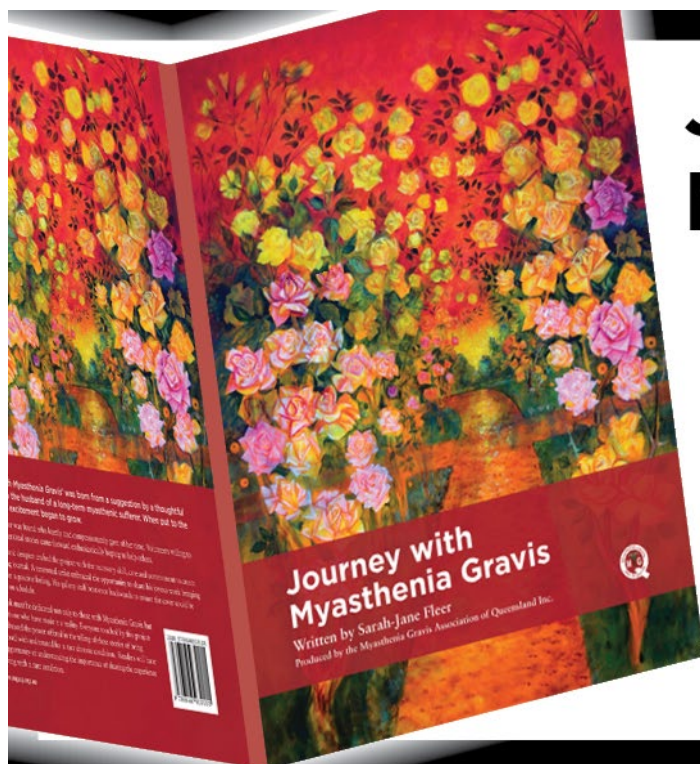
A Member writes:

One of our members, Susan, saw this bike in New Zealand and thought it was yet another interesting way people can try to keep mobile and moving. It allows for more stability when people are a bit wobbly on their feet.

We were in Blenheim in the north of the South Island of New Zealand. A lovely lady named Tash chatted to us about the bike.

We, in turn, told her about a shopping trolley that is much easier to use. Sharing ideas and tips is fun.

There is always something new to experience!



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



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 13 SEPTEMBER, 2020

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2020 / 2021

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 a full day held 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 2020/2021.

Nominations **MUST** be received by the Secretary by the close of business on **FRIDAY, 10 JULY 2020**.

If more than one nomination is received for the same position, a ballot will be conducted to all financial members, with the votes to be returned by **Friday, 7 August 2020**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 13 September 2020.

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.

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:.....



MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2020/2021 are due.

The envelope in which your newsletter is enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

If you receive the newsletter by email and are unsure whether or not you are currently financial, **please phone our 1800 802 568 freecall number or email treasurer@mgaq.org.au to enquire.**

The majority of members will have 6/20 which tells you (and us) that you are financial to 30 June 2020. Others may show 6/21 or even 6/22 to indicate they have saved time and postage by paying in advance.

If you are unfinancial, **please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive all resources.**

We are also giving you the option of paying your subscription directly into our bank account.

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE www.mgaq.org.au/membership-application-form and select Membership Renewal

Our bank details are:

BANK: Bank of Queensland

BSB: 124 032

ACCOUNT NUMBER: 10263772

ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.

REFERENCE: Your Name and Initials

If you use the direct deposit method, it would help if you could email us at treasurer@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.



If you wish to pay by Cheque or Money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc.

PO Box 16

MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____.

NAME _____ **Category A Myasthenic \$20**

(or) Category E – Supporter \$20

ADDRESS _____

And for _____ **Category D – Carer \$10**

ADDRESS _____

Mobile _____ Email _____



your regional co-ordinators

Cairns:

Donna on 0414 397 462

Townsville:

Daphne on 0400 778 637 or
daphclay@gmail.com

Mackay:

Muriel on (07) 4954 1221

Hervey Bay – Wide Bay Burnett Region:

Jan on 0429 622 438 or
janpowell3@bigpond.com

Gladstone – Wide Bay Region:

Garth on 0408 155 954 or (07) 4973 7983

Sunshine Coast:

Colleen on 0409 491 789 or
colleen4551@gmail.com

Gold Coast:

Nader on 0415 834 401

Brisbane:

Anita on 0414 588 312

If you
would like a chat,
pick up the phone
and call your local
regional
Coordinator.

your online discussion forums


MGAQ DISCUSSION FORUM

Administered by the MGAQ

Freecall 1800 802 568

Please follow the link and join

MGAQ Discussion Forum at

www.facebook.com/groups/mgqlid/


MYASTHENIA GRAVIS CARERS

Administered by the MGAQ

Freecall 1800 802 568

Please follow the link and join

Myasthenia Gravis Carers at

www.facebook.com/groups/284865318818756


**MYASTHENIA GRAVIS AUSTRALIA
PARENTS & GRANDPARENTS**

Administered by the MGAQ

Freecall 1800 802 568

Please follow the link and join

Myasthenia Gravis Australia Parents &
Grandparents at

www.facebook.com/groups/821532874970222


LAMBERT EATON LEMonS AUSTRALIA

Administered by the MGAQ

Freecall 1800 802 568

Please follow the link and join

Lambert Eaton LEMonS Australia at

www.facebook.com/groups/602254133711587/