



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

MAY 2019

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

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Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Dear Friends,

It is with much sadness that I inform you of the death of our dear friend, Mr Graeme Peters. Graeme died surrounded by family on 24 April. Please take the time to read the Vale to Graeme on page 4.

As stated in our constitution, all members of the management committee must retire at the Annual General Meeting, but are eligible for re-election, if they accept a nomination. People should have received their Nomination for Office Bearers form upon which any financial member of the association may nominate another financial member to serve as a member of the management committee. The nomination must be in writing, and must be signed by the candidate and the members who nominated and seconded him/her. Management committee members do not have to live in Brisbane. **Nominations MUST be received by the Secretary by the close of business on 7 JUNE 2019.**

Membership Subscriptions for the financial year 2019/2020 are now due. The envelope in which your newsletter is enclosed will advise you when

your membership expires. 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. If you are unfinancial, please take a minute to phone or email to advise whether or not you wish to retain your membership and thus receive all information from the association.

**We will be holding our
June meeting on
Sunday, 9 June at 10.00 am for
10.30 am at the Southern Cross
Sports Club, Cnr of Logan Rd
& Klumpp Rd, Mt Gravatt.**

Our guest speaker will be
Tracey Shaw
from Carers QLD Australia.
*Please see page 8 for further
information about this.*

June is MG Awareness Month. Please take the time to share information booklets and personal "stories" during this next month so that each of us is raising awareness about MG. Remember to talk with friends and family about what happens on good days as well as when things are not right medically.

Thanks, Carol

Supported by



**Queensland
Government**

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS



2019 Myasthenia Alliance Australia Myasthenia Gravis Conference

Preliminary Conference Program

- **Dr. Stefan Blum**
Overview of Myasthenia Gravis and Therapies.
- **Assoc. Prof. Stephen Reddel**
*Rationale and Progress on the eNID Project.
Risks of Immunosuppression.*
- **Prof. Pam McCombe**
IVIg for Myasthenia - new IVIg Guidelines.
- **Dr James Morton (Haematologist)**
Advanced Therapy Treatment including Plasma Exchange.
- **Dr Andrew Swayne**
Research in MG - where are we, where do we need to go?
- **Dr Fiona Chan**
Rituximab as a treatment for MG.
- **Discussion and Question Time** with
Drs Reddel, McCombe, Blum and Morton.
Session 1: MG and its Treatments.
Session 2: Research in MG.
- **Choose your Own Small Group Sessions!**
At least 10 topics - choose two.

Please note - this program is still being developed and additional content will be added.

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



Myasthenia Alliance Australia Myasthenia Gravis Conference 2019

Registration for the MAA 2019 National Conference to be held at the TRI Conference Facility, PA Hospital, Woolloongabba, Brisbane to be held on 3 August, is now open.

To attend, please complete the registration form below and send it along with your contribution of \$90 per person to either **info@mgaq.org.au** or **MGAQ, PO Box 1287, New Farm 4005**.

Any cheques should be made out to The Myasthenia Gravis Association of Qld Inc. Bank details for direct deposits are BOQ BSB 124032 and account number 10263772 and Reference to include wording 'conf' and your full name.

Please inform us by email at **info@mgaq.org.au** or call **1800 802 568** if you have paid your registration by direct deposit so this can be cross-checked.

Your successful conference registration, along with any additional information, will be confirmed by email, or, if you do not have email, by mail.

Morning tea, lunch and afternoon tea, plus the conference package are included in the cost of registration.

The selection of food to be served on the day will be forwarded in your information package to be issued prior to the date.

People with particular dietary needs can then decide if they want to bring along food to supplement what is offered.

As before, the day will be very informative and full of opportunity to meet with others. Do bring along a supporter and let your health professional know they are welcome also.

email info@mgaq.org.au with your registration and questions

MG Conference Registration Form

Name

Myasthenia affected / Carer / Supporter / Health Professional *(please circle one)*

Name

Myasthenia affected / Carer / Supporter / Health Professional *(please circle one)*

Name

Myasthenia affected / Carer / Supporter / Health Professional *(please circle one)*

Address

..... Postcode

Phone Number: Mobile Home.....

Email Address: *(Please complete if you have one so information can be forwarded using this medium)*

.....

Do you require wheelchair access?

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



VALE GRAEME PETERS

Graeme Maxwell Peters sadly passed away on 24 April surrounded by family members. He was a loving family man, a devoted husband, a colleague and friend to many.

How does one describe Graeme? He was a complex man with many traits which included being strong-minded, committed, knowledgeable, resourceful, dedicated, meticulous, giving, generous, considerate, quick-witted, liked detail, family-focused, energetic, loyal to his friends, a good judge of people ... and so the list goes on. Everybody who came in contact with Graeme would have a unique story to tell about that interaction. There was never a dull moment when he was around.

He approached new ideas with caution. Once he appreciated and/or saw the benefits of an idea, he would become its strongest supporter.

Despite having some serious health issues, he never let them get in the way of what needed to be done or what he wanted to achieve.

Graeme and Poppy were married for fifty-five years. As a family man, Graeme and Poppy raised four children in both Tasmania and Queensland and were blessed with six grandchildren, all of whom they adored and were very much a part of their lives.

In the 1990's, after Poppy was diagnosed with Myasthenia, they settled into the then new suburb of Springfield Lakes. Graeme became very involved with the MGAQ at the beginning of 2004, first as a committee member, then Secretary and finally President. Graeme was a valued member admired by the

management committee members throughout the long years. He was involved and was also respected and liked by many, many members. Even after his retirement from the committee he would often get phone calls asking for advice.

Graeme had a knack for words and often said something very garrulous when he could have said it in very simple language. The management committee members and, I am sure his family, would be aghast and wondering just what he said. His love of language was a source of entertainment for him in later years when he was often seen playing word games either at home or at the local club.

Graeme and Poppy loved travelling but Graeme had a soft spot for his beloved Las Vegas, travelling there on several occasions. He often spoke excitedly about planning his next trip to Vegas.

In his younger days, Graeme was a keen sportsman and, in his later years, watching sport took over from actually playing a variety of sports. Anyone who knew Graeme well also knew about his beloved Magpies – the Collingwood Football Club. He would often jokingly remind members that the management committee would have to finish by a certain time so he had time to get home and settled in his chair ready for the first bounce. Many quips crossed the table after the meeting about which was the best code of football, best club, etc.

Graeme will live on in our hearts and minds as he impacted our lives in many and varied ways.



**THE UNIVERSITY
OF QUEENSLAND**
AUSTRALIA
CREATE CHANGE

DO YOU KNOW HOW MANY STEPS YOU TAKE A DAY?

Researchers at the University of Queensland are seeking expressions of interest from people with myasthenia gravis to participate in an exciting new study about physical activity. The study is in the final stages of development and will begin recruitment shortly following final ethics approval.

If you are interested in participating, please contact Tahlia Alsop at t.alsop@uq.edu.au for further information.

🔍 www.mgaq.org.au/faqs



Myasthenia Gravis
Association of Queensland Inc.

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[RESOURCES](#)
[NEWS & EVENTS](#)
[MEMBERSHIP](#)
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📞 Freecall: 1800 802 568

The Myasthenia Gravis Association of Queensland has a comprehensive list of “Frequently Asked Questions”

Can I exercise with MG?

The short answer is this: Exercise within your limits is absolutely recommended. Don't exercise if you're weak. Short sessions with breaks are better tolerated than longer sessions.

Start slow with walking or using an elliptical machine and build gradually as you become stronger. Stop and rest as soon as you feel tired. Have another person with you or bring a mobile phone in case you run into trouble. It's important to stop short of muscle fatigue. This point will vary from person to person depending on age, overall fitness level, MG symptoms and other factors. Be careful not to drain reserves of energy as this will delay your recovery time.

Because your symptoms can vary so much from day to day, it's important to talk with your doctor about how and when to exercise. Together you can set up guidelines on how much exercise is healthy for you and under what circumstances you should attempt it. Working with a trained physiotherapist who can look into the efficiency of your movements and adjust activities according to daily energy levels should be considered. Focusing on muscle groups which bring stability, good posture and flexibility to the body can be just a useful as gaining additional strength.

The MGAQ have useful resources on exercise. These are available to members via the Lending Library.



“Coffee
and
Chat”

Myasthenia Gravis Association of Queensland Inc
1800 802 568 | info@mgaq.org.au | www.mgaq.org.au

Ipswich

Sunday 12 July @ 2pm;
Friday 25 October @ 10am
Queens Park Café, 10A Merle Finimore Avenue

Burpengary

Sunday 11 August @ 2pm;
Sunday 10 November @ 2pm
The Coffee Club, 164-166 Station Road

Cleveland

Sunday 22 September @ 2pm
Fiction Bar, 152 Shore Street West, Raby Bay

Nundah

Sunday 13 October @ 3pm
The Royal Hotel, 1259 Sandgate Road

MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2019/2020 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 6/19 which tells you (and us) that you are financial to 30 June 2019. Others may show 6/19 or even 6/20 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 _____

Puzzlers

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

Word Search

T L I Z A R B L K M B A G Q F A C E O S
 S N C I L B U P E R N A C I N I M O D E
 A Y E X A B S X A A B A R I T A T B J T
 I A P C D I I A I L I A T B N I A K U A
 N U C S N C B U I V A N R I A H A R V T
 T G E I O I G M I N E M R B A D E H C S
 L A Z V A H V L O G T U E M U P O O A D
 U R I E C M O T R L S K A T H D S S U E
 C A L N C B A A N Y O S I O A T A D G T
 I P E L I H C J G I T C N T A U J O A I
 A R B M E L S A L V A D O R T W G M R N
 F D N A L N E E R G U S I Q R S T I A U
 V E N E Z U E L A R E C U A D O R N C A
 A N T I G U A Q A D A D I N I R T I I B
 A D A N E R G S Y A U G U R U R R C N U
 C A N A D A T O B A G O R A M A N A P C

Antigua	Canada	Ecuador	Jamaica	Saint Lucia
Argentina	Chile	El Salvador	Mexico	Saint Vincent
Bahamas	Colombia	French Guiana	Nevis	Suriname
Barbados	Costa Rica	Greenland	Nicaragua	Tobago
Barbuda	Cuba	Grenada	Panama	Trinidad
Belize	Dominica	Guatemala	Paraguay	United States
Bolivia	Dominican	Haiti	Peru	Uruguay
Brazil	Republic	Honduras	Saint Kitts	Venezuela

Bamboozable

have have hold hold	obstacles obstacles COMING	HARD get get
foot foot	INCCGS	TRI AL

Word Change

pouch

peace

Answers

10. Taxes
9. Doors
8. Lights
7. Detectors
6. Lines
5. They have claws
4. They have trunks
3. Swimming strokes
2. Crabs
1. They have lobes

Answers:

Commonym 27

Answers: pouch, poach, peach, peace.

Word Change 29

Answers: 1. To Have and to Hold; 2. Overcoming the Obstacles; 3. Playing Hard to Get; 4. One Foot in Front of the Other; 5. Seasonings; 6. Trial Separation.

Commonym

What's a commonym you ask? A commonym is a 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 Brain - The Lung - The Ear
2. Spider - Fiddler - Hermit
3. Back - Butterfly - Side
4. A Car - A Tree - An Elephant
5. A Bear - A Hammer - A Lobster
6. Finish - Fishing - Dotted
7. Metal - Radar - Lie
8. Stop - Spot - Strobe
9. Trap - French - Glass
10. State - Sales - Income

NEWS FROM AROUND QUEENSLAND



News From Cairns

June is Myasthenia Gravis Awareness month.

We would love to see you on **Saturday, 22 June** at the Cairns RSL Club, Esplanade at **11.00am**. A guest speaker is being organised to attend.

For more information please call Donna on 0414397462

News From Townsville

The Townsville MG group's next lunch is on **Saturday, 15 June, 2019, 12 noon** at The Avenues Hotel. For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News From Mackay

It is with deep regret that we inform you that the Mackay Co-Ordinator, Mr Bill Harris, sadly passed away. His life will be remembered in the June Newsletter.

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 their regular friendly coffee & chat get together and an opportunity to exchange experiences at the Kurrawa Surf Club in Broadbeach on Saturday, 4 May.

Our next MG meeting will be on **Saturday, 29 June, at the Southport Sharks Club at 10am**. I look forward to seeing you all again. Cheers Nader, GC coordinator 0415 834 401.

WHERE IN QUEENSLAND?

Let us know where you think it is:

April Edition: Hervey Bay

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



Welcome to our new members

Cheryl C,
Tambourine Mt,
Qld

Sue C,
Sunnybank,
Qld

Diep H,
Aspley,
Qld

Wendy H,
Seven Hills,
NSW

Peter C,
Yeppoon,
Qld

MID-YEAR FUNCTION

"June is MG Awareness Month"

Sunday, 9 June, 2019 - 10am for 10.30am start

WHERE: Southern Cross Sports Club:

Corner Klumpp and Logan Rds, Mt.Gravatt (vehicular entrance is from Klumpp Rd).
Lunch is available at the venue with a varied and reasonably priced menu.

GUEST SPEAKER: Tracey Shaw from Carers QLD Australia.

Topic: Carers QLD services – Caring for Carers

WHAT DO I NEED TO BRING? Yourself and whomever else you wish to bring along – the more the merrier.

HOW DO I GET THERE? UBD Map 201 Reference D7.

RSVP: FREECALL 1800 802 568 and tell Susan if you are coming, how many, and if you are staying for lunch.

Please let Susan know by Monday, 3 June, 2019