



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

APRIL 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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PRESIDENT'S REPORT



Welcome to another newsletter and Happy Easter to everyone. With the school holidays on us I am sure that many of you will be on Grandma and Grandad "duty" – an activity we all love to do and cherish every moment of it.

Not sure where Autumn has gone but it certainly seems to be hiding well. Like me, I am sure everyone is sick of the hot, humid days and warm nights. I hope that those who are still suffering from the drought have had some relief but there seems to be major areas that have missed out completely. Areas further south of the border will benefit with Lake Eyre filling up and the Murray-Darling system getting the run-off.

All financial members will receive information and the form for nominations for the 2019/20 Management Committee. This will be attached to this newsletter or emailed with the newsletter. Please give this due consideration as we need a full committee to keep doing all the work that we are currently managing. If you do not receive this information but feel you are financial, please phone **1800 802 568** or use info@mgaq.org.au

Registrations for the **MAA conference at the PA hospital in Brisbane on 3 August** are coming in steadily. Please take the time to read some of the feedback by participants from the last conference ([see Page 3](#)). At both conferences I have attended, the whole room has had such an air of positivity - people introducing themselves, sharing stories and making comparisons, availing themselves of the written information and representatives from each state to speak with and ask questions. Added to this is the wonderful quality of the speakers who will provide the latest information about all types of Myasthenia. So, make the effort and get organised as we cannot guarantee that another conference of this type will be available as we rely on the goodwill of nationally and internationally recognised neurologists and other medical professionals to give their time freely to us.

Our mid-year function will be held on Sunday, 9 June at the Southern Cross Sports Club. Our guest speaker will be Tracey Shaw from Carers QLD Australia. More information will be provided in the next newsletter.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



Preparations for the 2019 National Myasthenia Conference continue as registrations come in steadily. It is very exciting to see people coming from Victoria, New Zealand, NSW, ACT and of course, Queensland. It

is hoped that there will also be attendees from South Australia, Western Australia and Tasmania. Facilitating the 'meeting of others' from each region will be a focus for the organisers. Making contact with people who share similar experiences will also be important. This may include people with LEMS or MuSK or Ocular or Congenital Myasthenia disease. It is hoped that a group of younger sufferers will attend so that life long friendships can be established as happened at the previous conference.

On a more formal note, the key speakers are confirmed and indicative topics are now available (please see table below). There will be a question time with a panel of senior doctors. Research and latest treatments will be discussed. All Doctors have extensive experience in treating people with Myasthenia.

It is hoped that seeing this amazing line-up of highly skilled specialists who plan to share their extensive medical experience with our very small community will bring a rush of registrations as a

sign of appreciation to these dedicated and gracious Doctors who are donating their time.

The program for the day includes two opportunities to participate in 40 minute break-out sessions. These will be structured as smaller, more interactive groups and in less formal arrangements. With at least ten topics on offer, there is sure to be something of interest for everyone.

Cost, logistics, fatigue, transport are all issues being presented as obstructions to attending. Please call Susan on **1800 802 568** for tips on how some of these issues can be managed. This conference opportunity is extremely unique for a rare disease. Please do not assume there will be more opportunities into the future. Every event is a great bonus to the Myasthenia community. Please encourage others you know with MG to attend, consider sending a family member as a representative and share the details with your Health Professionals as they too will be welcomed. Treatments for Myasthenia are progressing quickly and are subject to change so be as informed and as prepared as possible. Pick up tips on how you can live the best life possible when managing myasthenia. Find out about the future research options.

The MAA and MGAQ Committees are working hard to bring you a special day and are keen to see you on August 3rd.

Susan White - President.

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

Preliminary Conference Program

2019 MAA Myasthenia Gravis Conference

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

- **Dr. Stefan Blum** - *Overview of Myasthenia Gravis and Therapies.*
- **Assoc. Prof. Stephen Reddel** - *eNID project Update.*
- **Prof. Pam McCombe** - *Guidelines for IVIg Therapy.*
- **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.**
- **Choose your Own Small Group Sessions!**
At least 10 topics - choose two.

Myasthenia Alliance Australia

Myasthenia Gravis Conference 2019

What's in it for me?

Are you undecided about whether to attend the MAA Myasthenia Gravis Conference in Brisbane on 3 August, 2019?

You're not sure what you will get out of the conference?

Interested in listening to Neurologists discuss different treatment options?

Or the on-going research into MG?

Read some attendees' comments from the MAA Myasthenia Gravis Conference - Sydney - 2017

Female, 69 years

Thank you to all Drs for your up-to-date information and very rewarding day.

Male, 58 years

I enjoyed the day. I learn a lot today. It was done well. I am happy.

Female, 39 years

I have enjoyed the experience, very informative and much needed. Thank you. Look forward to next time.

Female, 51 years

Very informative. I enjoyed learning more of global research.

Male, 56 years

Hopefully there will be another conference to keep updated with ongoing treatments.

Male, 50 years

Thank you for all the information about meds and treatments.

Female, 61 years

Had a wonderful day, very worthwhile making the trip over from N.Z.

Female

Great day. Enjoyed connecting with MG people. Great topics. Very informative day of learning. Thank you.

Female, 58 years

The learning and knowledge gained went much further than just the presentations. Thanks to the organisers.

Male, 27 years

A very informative day, great getting into groups and meeting other MG sufferers and carers. Great work!

Male, 32 years

I am male and diagnosed 12 months ago. This is my first conference and I found it very helpful.

Female, 50 years

Really interesting day. We need to spread the word.

Not identified

Thank you so much to the organising committee in organising a truly wonderful, insightful, interesting and educational programme. Thank you also to the speakers for their commitment and dedication and gift of their time and knowledge. Thank you again to the committee for facilitating a warm, friendly atmosphere and for your commitment to MAA, helping to make peoples journeys easier and less challenging. Well done.

Female, 31 years

Thank you so much for this wonderful event. I feel so fortunate to have been a part of it. From all your MG Warriors we thank you for this educational day. Keep up the good work.

Carer 62 years

Thank you to the organisers and the speakers. Well done. Thoroughly enjoyed everything! Discussion groups were great too. Provided a good clinical/patient balance to the meeting.



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



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.

Townsville Floods



This picture shows the level of flooding in the Townsville area. The flood height (5 metres) in Ross River.
The lower markers are from previous floods.

MG Friends from around Australia Catch-up



Daphne, from Townsville (left) and Greg, from Launceston, Tas., have a catch-up and coffee during Daphne and Ray's travels around Tasmania.



Welcome to our new members

Donna-Maree D,
Frenchville,
Qld

Dianne S,
Wynnum West,
Qld

Stephen R,
Bargara,
Qld

Maureen B,
Waratah,
NSW



MURIEL'S DID YOU KNOWs?

- Squid travel faster when they jump through the air than they do under water.
- Lava can flow as fast as a sprinting greyhound.
- The U.S. Navy has more aircraft carriers than all the other navies of the world combined.
- Dogs can smell where electric current has been & human fingerprints that are a week old.
- Sea horses are the only fish with a neck and the only family of animals where the male gives birth.
- The cake for the Queen Mother's Wedding in 1923 weighed half a ton.

NEWS FROM THE TREASURER

DONATION ACKNOWLEDGEMENTS



Denise

The MGAQ is very fortunate in that we receive many donations, large and small. These donations, in addition to the generous baseline support of the Queensland Health Department, enable us to continue our wide-ranging work for the Myasthenia community.

The support of our Corporate Sponsor, Ausenco, and an anonymous private sponsor who both very generously make major contributions each and every year is very gratefully received. This solid support gives us confidence in tackling new initiatives.

You, our members, are also very generous. Donations are often included with membership renewals. Whilst never expected, as membership payment in itself is very much appreciated, all contributions are truly a bonus. The funds are empowering. The emails and notes of gratitude that we receive are equally embraced and are truly heart-warming. Thank you.

An example of how Community support comes in surprising packages can be highlighted by sharing a story about a wonderful donation from Reuben Packer-Hill. Reuben, a Brisbane Real Estate Agent, donates part of his fees from selling a property to the clients nominated charity. Harry and Veeta recently

sold a property through Reuben and graciously nominated the MGAQ. Thank you to this family.



Anita is pictured receiving the cheque from Reuben

Another large surprise donation recently came via the Paypal Giving Fund Australia Company Ltd. The Association was not aware that fundraising activities can be conducted through a PayPal account. 'Wendy' had a birthday function with donations to MGAQ in lieu of gifts. PayPal take no fees under this arrangement. Thank you to this unknown group of friends and to PayPal for providing the facility.

Whether it's a \$5 donation or \$500, everything that we are gifted is very welcome and helps to keep the Association operating for it's members.

As we are a registered charity, all donations are tax deductible.

More Members Reaching out for Rituximab



The Federal Member for Blair, Shayne Neumann MP, has pledged to give his support in getting Rituximab on the PBS for people with Myasthenia.

He has previous experience working with the TGA and understands the application process well. He supports equal access to healthcare and understands the benefits of reduced costs to hospitals and patients.

The MAA thank him for his support.

Please help us gather support for this campaign by visiting your local federal member with a copy of your February newsletter.

- **Dee and Judy with Hon. Shayne Neumann MP, Federal Member for Blair**

Puzzlers

Sudoku

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

Number Block

Try to fill in the missing numbers.

The missing numbers are integers between 0 and 12. The numbers in each row add up to totals to the right. The numbers in each column add up to the totals along the bottom. The diagonal lines also add up the totals to the right.

	0	1		6		25
7		8		0	6	20
5	4		2		2	34
	5	5	6	7	10	28
5		10		8		41
			2	8	8	36
34	24	40	25	37	35	41

Word Change

house
gorge

Word Change
30 Answers:
house
rouse
rouge
gouge
gorge

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

Bamboozable

1,3,5... WHELMING	AIR vanished AIR	Y R web
25 25 25 25	MY SKIN He's getting	TI ME JOB

Answers

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

41	35	37	25	40	24	34
36	8	8	2	9	3	6
36	0	8	10	10	3	5
41	10	7	6	5	5	8
28	2	8	2	7	4	5
34	6	0	4	8	9	7
20	9	6	1	1	0	3
25						

Bamboozable 28 Answers: 1. The Odds are Overwhelming; 2. Vanished into Thin Air; 3. Wireless Internet; 4. Close Quarters; 5. He's Getting Under my Skin; 6. Part-time Job

NEWS FROM AROUND QUEENSLAND

News From Cairns

We will next meet on **Saturday, 1 June at the Cairns RSL Club, Esplanade at 11.00am**. June is Myasthenia Gravis Awareness Month and a guest speaker is being organised to attend.

For more information please call Donna on 0414397462

News From Townsville

Next Townsville MG lunch will be held on **Saturday, 27 April, 12 noon at The Avenues Hotel, Kern Bros Drive, Kirwan, Townsville**.

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

News From Mackay

Our next luncheon will be held on **Sunday, 5 May at the Rice Buffet, Gregory Street at 12 noon**.

For more information about the Mackay group, call Bill on (07) 49541221

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

The Gold Coast MG group meet regularly for a friendly coffee chat get together exchanging experiences.

Our next MG meeting will be on **Saturday, 4 May in Kurrawa Surf Club in Broadbeach at 10am**.

I look forward to seeing you all again. Nader GC coordinator 0415 834 401.

WHERE IN QUEENSLAND? MARCH EDITION: Cape Melville

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



"Coffee and Chat"

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

Cleveland	Fiction Bar, 152 Shore Street West, Raby Bay Friday 10th May at 10.30am
Nundah	The Royal Hotel, 1259 Sandgate Road Saturday 11th May at 3.00pm
Ipswich	Queens Park Cafe, 10A Merle Finimore Avenue Sunday 12th July at 2pm
Burpengary	The Coffee Club, 164-166 Station Road Sunday 11th August at 2pm

what's coming up

What's On	When Is It	Where Is It?
JUNE AWARENESS MEETING	SUNDAY 9 JUNE, 2019	Southern Cross Sport Club, Cnr of Logan & Klumpp Rds, 51 Klumpp Road, Upper Mt Gravatt
MAA MYASTHENIA GRAVIS CONFERENCE 2019	SATURDAY 3 AUGUST, 2019	TRI Conference Facility within the Princess Alexandra Hospital Woolloongabba, Brisbane
MGAQ INC ANNUAL GENERAL MEETING	SUNDAY 15 SEPTEMBER, 2019	Aspley Hornets Football Club, 50 Graham Road, Carseldine



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 15 SEPTEMBER, 2019

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2019 / 2020

11 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. Your interest in being involved is urgently requested. 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 regular email communication and will need to print materials staying abreast of issues throughout the month. Meetings are a full day held each second Saturday of the month excluding January, and attendance via teleconference or in person is required for a majority of meetings.

To gain more information, discuss these roles and commitments by phoning **Freecall 1800 802 568**. Members with Myasthenia and those with an interest in Myasthenia are welcome to apply. Carers and supporters very welcome to nominate.

Nominations **MUST** be received by the Secretary at the close of business on **FRIDAY, 7 JUNE 2019**.

If more than one nomination is received for the same position, a ballot will be conducted (by mail-out) to all financial members, with the votes to be returned by **31 July 2019**.

Should there be no nomination for a particular position, nominations will be called for from the floor at the AGM to be held on Sunday, 15 September 2019.

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) **Seconded by** (*Optional*)

Regards, Carol Buchanan on behalf of 2018/2019 Management Committee, May 2019

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:.....