



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

MARCH 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

Many of you would have received some SMS messages from the association in the last month. We hope that everyone made it through the shortage of Mestinon. Secondly, and most importantly, we are asking people to register as soon as possible for the

**MAA Conference
to be held at the
Princess Alexandra
Hospital (PA) on
3 August this year.**

As well as hearing from the leading neurologist in the treatment of various forms of MG, talking with presenters and others associated with MG as carers, sufferers, family etc will be a significant part of the program.

The registration fee of \$90 also includes tea/coffee on arrival, morning tea, lunch and afternoon tea. The menu will cater for people with allergies including gluten and dairy and vegan and the food will be of a high quality for all.

It takes a great deal of organisation to have these conferences organised to work smoothly and

effectively so we ask for our MGAQ members to support the small band of MGAQ committee members by putting every effort into attending this conference.

Whilst in Brisbane, members of the management committee will be more than happy to provide assistance. Please read more on the venue and times on the registration form on [page 3](#) of this newsletter.

Feedback about the Regional get-togethers and the Coffee and Chats in the Brisbane environs is very positive, and anyone is welcome to attend these. Please see [page 8](#) for details.

The MAA (which also means the MGAQ representatives) are still communicating with MSBase re the eNID project and is now heavily involved in the communication occurring around this. We hope to have a more definite report for the next newsletter.

Please stay safe with all this inclement weather. I think it would be hard to find someone who has not been affected, either directly or indirectly, from the floods, fires and unbearably hot weather.

Carol

Supported by



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Government**

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MYASTHENIA ALLIANCE AUSTRALIA NEWS**MAA Myasthenia Gravis Conference 2019**

Registrations for the **3 August** Brisbane-based event, have been coming in steadily with conversation and interest for the next Conference growing.

Thank you to all those that have completed the paperwork and sent the money.

Many people actively responded to MGAQ and MG NSW requests to apply promptly. As the MAA runs on an extremely low budget and our plans for this event are big, this really helps manage commitments.

So what has been done? The Venue paperwork is almost completed, the Caterer's deposit is paid, advertising is under-way and the Programme is formulating in people's minds! This is excellent progress in the first month.

Susan has taken calls and emails from a range of people from a vast array of locations and

discussed accommodation and transport with several.

Usually there is discussion about seeing friends or family as well and definitely taking a break from the southern winter. Ultimately the conversation turns to the value of the day. Most are keen to understand current medical conversation and to speak with others who may share the issues that are so personal to their daily lives.

Some reflect on the additional support that may come from the day. Nobody, to date, has asked about the food or assistance available on the day but as in the past, the MAA community will be wanting you to feel very included and a bit special as well.

Your registration form is included on [page 3](#) of this newsletter and questions can be answered by calling **Susan on 1800 802 568** or emailing **info@mgaq.org.au**

Susan White

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

The Gold Coast MG group had their regular friendly coffee chat get together exchanging experiences in Southport Sharks Club on Saturday 23 February .

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



Welcome to our new member

Donna-Maree, Rockhampton Qld



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

Reach out to your local Federal Member

in support of a request for the drug
Rituximab to be made available via the
PBS for people with Myasthenia Gravis.

Should you wish to provide supporting material or understand the conversation better, Susan is available to help by calling 1800 802 568.

Remember to ask for a photo for the newsletter and permission to publish names.

- Denise Hannay (centre) and Vic Andressen (right), meet with their local Federal Member for Hinkler, Hon. Keith Pitt MP.



- Donna Formosa, Anne Hambleton, Maxine McPherson from MGAQ Cairns group with Hon. Warren Entsch, MP, Federal Member for Leichhardt.



RARE DISEASE DAY PARLIAMENTARY EVENT

20 FEBRUARY, 2019

Following on from the feature article in the February newsletter highlighting the Rare Diseases Parliamentary Event, the MAA is delighted to inform you that, thanks to sponsorship from Rare Voices and MGAQ Inc., Susan White was able to accept a personal invitation from Nicole Millis, CEO of Rare Voices, to attend this luncheon.

It was a fantastic opportunity to meet the full Rare Voices team, to see Nicole passionately advocating for people with a rare condition, to flag Myasthenia Gravis with interested Politicians and to experience the issues faced by others also managing a rare condition.

Full advantage was taken of the day. Susan had a private interview with MP Mike Freeland in the morning followed by an introduction to Health Minister Greg Hunt during lunch. A greater discussion was held with Minister Hunt's Senior Advisor. MPs Trevor Evans, John Alexander

and Mike Freeland also sought a conversation during lunch and educational materials were shared. The speeches given reflected the progress made in supporting people living with rare diseases and highlighted the great challenges still ahead.

Susan raised the issue of seeking to have Rituximab considered for inclusion on the PBS for people with Myasthenia Gravis. Keen interest was taken in the conversation but understanding of the deep issues surrounding such a question when it is applied to a rare condition seemed difficult. Pathways for further communication were established but the conversation needs to be continued. With an election looming, the Myasthenia community is strongly encouraged to continue raising this issue via questions put forward by as many Federal Members as possible.

Please consider if you can help!



- **Far Left**
The Hon Greg Hunt MP,
Minister for Health
- **Centre**
CEO, Rare Voices Australia, Nicole Millis.
- **Right**
(L-R) Mike Freeland MP,
Nicole Millis,
Susan White,
MAA President.

RARE DISEASE DAY - CAIRNS

On the last Sunday in February, the Cairns community commemorated International Rare Disease Day by holding a Walk, Ride and Run to support locals affected by rare diseases.

This year Denise Hannay, MGAQ Treasurer, joined MGAQ Cairns to represent Myasthenia Gravis for this event.



MEET THE COMMITTEE CAIRNS

FEBRUARY 26, 2019



- The February get-together was well attended and included a visit from the MGAQ Treasurer, Denise Hannay who was pleased with the opportunity to put faces to names.



MGAQ SMS ALERT

Dear Members

Recently there was a shortage of Mestinon and the MGAQ was pleased to be able to send alerts to members regarding this situation.

SMS alerts are a quick and efficient way to communicate with our members and this is one of the many benefits of being a financial member of the MGAQ.

Via social media, we received a lot of enquiries as to why some people received the alert and others didn't. Firstly you need to be financial, and secondly we need to have a mobile number for you otherwise we cannot send you an alert.

I would encourage members who didn't receive the alert to forward their mobile numbers, either via the **freecall number 1800 802 568** or email **treasurer@mgaq.org.au**

If you are unsure of your membership status, please contact us as well. 2019/2020 memberships become due again in June this year.

Membership numbers ensure that the association is able to move forward to continue helping the Myasthenia community.

Thank you

Puzzlers

Sudoku

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

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.

		8		1	8	33
12	4	3		10		33
		4	8	6	4	33
1	3			5	2	18
1		2			11	26
	0	11	12		0	27
23	27	32	36	25	27	14

Mad Cabs

They are a group of words, that at first glance and first saying don't make sense... but say them SLOWLY and LISTEN to what you hear to figure out what the phrase is. Example: Common Firm Their Rain = Come In From The Rain

1. Deaf Villain Disk Highs
2. Death Worm Dough Fur
3. Debt Snot Must Aisle
4. Deep Hits Perks Till Hears
5. Deeper League Hates

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

Bamboozable

ELAFINK ELAFINK	strength R	SHOP
SCHEME SCHEME SCHEME SCHEME SCHEME	BREAT	I c dog

Answers

14	27	25	36	32	27	23
27	0	1	12	11	0	3
26	11	2	3	2	7	1
18	2	5	3	4	3	1
33	4	6	8	4	6	5
33	2	10	2	3	4	12
33	8	1	8	8	7	1
40						

Bamboozable 27 Answers: 1. Fill in the Blanks; 2. Inner Strength; 3. Shop Online; 4. Pyramid Scheme; 5. Short of Breath; 6. Seeing Eye Dog

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

Mad Cabs 33 Answers: 1. Devil In Disguise; 2. Death Warmred Over; 3. That's Not My Style; 4. The Pittsburgh Steelers; 5. The Pearly Gates

NEWS FROM AROUND QUEENSLAND

Brisbane – Coffee & Chat

Ipswich – Queens Park Cafe, 10A Merle Finimore Avenue
Friday, 12 April at 10.00am

Burpengary – The Coffee Club, 164-166 Station Road at 2pm
Sunday, 14 April at 2.00pm,

Cleveland – Fiction Bar, 152 Shore Street West, Raby Bay
Friday, 10 May at 10.30am

Nundah – The Royal Hotel 1259 Sandgate Road
Saturday, 11 May at 3.00pm

The idea is to connect people that live in the same area. If you would like us to arrange a Coffee and Chat in your area in 2019, please email: info@mgaq.org.au or call Freecall 1800 802 568.

News From Cairns

The February get together was well attended and included a visit from the MGAQ Treasurer, Denise Hannay who was pleased with the opportunity to put faces to names. We will meet again on **Saturday, 22 June**.

Please diarise the future dates **Saturday, 21 September** and **Saturday, 7 December**.

All meetings are held at the Cairns RSL Club, Esplanade commencing at 11.00am.

Please call Donna on 0414397462 for more information.

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

We had our lunch at Suburban Bowls on 2 February and had a good attendance. All attending had an enjoyable lunch and enjoyable discussion on many subjects later. The next get together will be held on **Sunday, 5 May, 2019, at the Rice Buffet, Gregory St, 12 noon for lunch**.

Bill, Area Coordinator (07) 4954 1221, mobile 0429 729 685

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.

SC News From the Sunshine Coast

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

B

News From the Gold Coast

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

GC

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?

Let us know where you think it is!

FEBRUARY EDITION: On the Old Telegraph Track, Cape York

Send to: info@mgaq.org.au

or post to MGAQ, PO Box 16, Mt Gravatt, Qld, 4122

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