MyasthenIa GrAvIs ASSN. OF QLD INC.

MessaGes

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

FEBRUARY 2019

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 back to a new year and some very challenging weather. The bushfires before and after Christmas and those still causing stress in Tasmania, Cyclone Penny being very erratic, the floods in North and Western Queensland – the list just goes on. While Townsville and Western Queensland needed the rain it has certainly caused a lot of damage. As I sit typing this report I can hear the rain again beating on my roof and causing further damage on already saturated Townsville. I trust that everyone has managed to stay safe.

I am sure that Christmas is now a distant memory but I hope that people enjoyed the time with family and friends.

The work has not stopped and both the MGAQ and the National Alliance have been kept busy. Forward planning for the MGAQ has occurred and the National Alliance has been pushing forward with the conference and eNID. Please note the change of date for the conference. This was beyond our control because we had to work around the availability of very busy guest speakers. *Please read the information on page 2 of this newsletter so you have the most up to date information.* MsBase, the neurologists involved and the National Alliance have also been collaborating re eNID.

Our funding from Queensland Health is due to cease this year and, after that, we are not sure of what will occur. We ask that people pay their membership and that is one of the few sources of income that we get to keep the association running. Remember that, if your membership has lapsed, you do NOT have to backpay for those years. We only expect people to pay the 2018-2019 membership. **If in doubt please feel free to contact info@mgaq.org.au or 1800 802 568.**

We hope that members are putting a little away regularly so that they can attend the conference in Brisbane on 3 August. The committee will help as much as possible with accommodation, transport etc. This is the first conference we have managed to get in Brisbane and, as we always say, we cannot guarantee future conferences when we rely so much on the goodwill of others.

Thanks, Carol

Supported by

Queensland Government

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS

2019 Myasthenia Gravis Conference

CHANGE OF DATE

Saturday, 3 August, Brisbane

For more information: **Freecall 1800 802 568; email: info@mgaq.org.au**

MAA Myasthenia Gravis Conference 2019

It is with great excitement that a 2019 Myasthenia Gravis Conference is confirmed and registration is now available. Regrettably, the date required adjustment from **14 JULY TO 3 AUGUST** so as to ensure a wide range of speakers were indeed available for the day.

Our apologies are extended in regard to this change of date and if further conversation is required **please call Susan on 1800 802 568.**

The venue remains as previously advertised. The **TRI Conference Facility within the Princess Alexandra Hospital Woollooongabba, Brisbane**, is a modern and versatile space allowing for generous seating, disability access and generous private break out areas. The programme is still being developed but the aim is to make available a range of special interest sessions along with the latest in understanding and treating the many variations of Myasthenia Gravis, plus lots of opportunities to network with others.

The cost is **$90.00 per person** for a full day (8.30am - 5pm) and includes morning tea, lunch, afternoon tea and a program. Registration forms are now available (see page 6) and payments are being accepted. A more detailed information pack including an indicative programme, travel suggestions and access options will be sent to registered guests closer to the date.

Access is well supported by accommodation options, public transport and on-site parking. Susan is happy to answer questions by calling **1800 802 568**. If support is needed in assisting people to attend, there are likely to be ways in which the Brisbane community can help. Please ask. We hope that not only people affected by this condition will attend but also carers, family members, supporters and health professionals with a connection to this rare disease.

Please see registration form on Page 6 or email info@mgaq.org.au or call 1800 802 568 and a form will be sent to you.

Susan White, President

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

Rituximab and the PBS - a conversation needing support.

The MAA, supported by Dr Blum and others, has written in detail to Minister Hunt drawing to his attention the potential benefits of making Rituximab available via the PBS to people with Myasthenia Gravis and requesting that it be considered. Minister Hunt has written an initial response to this letter so he is aware of the communication.

To enable this action, standard policy cannot be used and therefore it becomes a more challenging process for him. (Please see Point number 4 below). The MAA Board continues to promote this question through a range of measures. We are also asking for your help!!

Our community needs to inform Minister Hunt

Rituximab and the PBS continues Page 3 >

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that this is an important community request and encourage him to consider it carefully. Therefore, please help us by making an appointment (in person or over the telephone) with your local Federal Member to discuss the following significant points. Your member should then respond by writing to the Minister's office asking for information on the progress of this question as it is important to their constituents.

The more requests, the greater the influence so please consider if you can help.

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.

• Susan White, pictured with Trevor Evans, local Federal Member for Brisbane.

Background information required for your visit to you local Federal Member.

1. Myasthenia Gravis is a rare disease with only about 2,500 Australians diagnosed. With this small number gathering a sufficient number of significantly impacted and similarly affected patients under one ethical approval process to enable a randomised clinical trial as required by the TGA to provide clearance for use of the drug in Myasthenia Gravis is proving unachievable. This is a standard situation for people affected by rare conditions and wanting access to particular therapies.
2. Whilst clinical trials are difficult to achieve due to the small numbers, other supporting papers regarding Myasthenia and Rituximab therapy are available. A retrospective case study conducted in Qld (Chan, Swayne et al. 2018) has shown that by using Rituximab a marked improvement in disease severity and a reduced use of other immunosuppressive therapies and Immunoglobulin use can be achieved. This has direct and indirect benefits by both assisting the Government health budgets and by improving patient outcomes.
3. For treatment therapies which can achieve proven outcomes and hence TGA clearance, then the drug company take the next step and apply to the PBAC for the drug to receive approval on the PBS. Rituximab is available via the PBS for other conditions including Rheumatoid Arthritis. Approximately 450,000 people suffer with Rheumatoid Arthritis. This is 180 times as many as those with Myasthenia. Studies have shown that Rituximab is effective in Myasthenia Gravis.
4. Without a TGA approval, the PBAC cannot process a drug therapy application unless specifically instructed to investigate it's suitability by the Health Minister.
5. The Liberal National Government has a policy to list all medications on the PBS following a recommendation to do so from the PBAC.
6. The Government is aware that not all medication is available via the PBS even though it can be helpful. To address this impasse, the Federal Government makes monies available through hospitals for selected pharmaceutical allocations. This is how some of our members are able to receive the treatment at no cost. As the drug is expensive, many smaller hospitals must choose not to support it's purchase. In bigger hospitals, qualifying criteria can be quite strict. For patients treated outside a major public hospital, the next option is to choose to self-fund and the cost can be up to $16,000 every 6 months. Private Health Funds are providing varied levels of support in such situations and most often well above policy requirements but it always leaves a significant gap. Therefore access to this treatment is inconsistent and limited.
7. Individuals cannot make application to the PBS for personal assistance.
8. If access was more equitably available broad based research could be considered.

Welcome to our new members

Elizabeth & Eric
Hope Island,
Qld

Alison,
Inglewood,
WA

Reginald,
Hope Island,
Qld,

Arthur,
Lancelin,
WA

MYASTHENIA ALLIANCE AUSTRALIA

President's Report

October 2018

On 4 July, 2014, the NSW Association for people with Myasthenia Gravis agreed to join with the Myasthenia Gravis Association of Queensland to form a National Alliance for Australians with Myasthenia. It is now four years later and the twelve months just passed have keenly highlighted the expanding scope of the work of the Alliance.

Jan Triggs' resignation from the committee was accepted and her contribution recognised. It was determined that each State should contribute three representatives to the Alliance board. We welcomed Dianne Herbert, Robert Dadge and Ian Hollingworth. This expanded capacity has been welcomed and valued. The on-going support, since inception, from Glenda Bidner and Carol Buchanan is significant and is recognised here. I express my sincere thanks to these ladies.

The Committee has met regularly throughout the past year. Initiatives undertaken during this period can be summarise in the following points.

1. Communication with the Alliance community has been regular and happens via the Website Alert System, the Association newsletters and Facebook posts. Communication recapped why the Alliance agreement was initiated and how there is a clear distinction between the work undertaken by the National Alliance Committee and the State based Associations. It was explained that the MAA allows for influence, conversation and financial requests on items under the jurisdiction of the Federal Government.

2. Contact was maintained with a group in Victoria. It is hoped that this Facebook group may progress to forming an Incorporated Association and therefore join the Alliance. No known other group in Australia is currently expressing an interest to participate at an official level.

3. The working relationship with Rare Voices has been maintained and advice sought on matters such as creating a Medical Advisory Board.

4. Preliminary planning for a 2019 Conference - Dr Blum is again the Chairperson for the Neuro-Immunology Association. This body will run a conference in 2019 and have offered to arrange a conference for the Myasthenia community at this time. Dr Blum will work towards creating a Brisbane Conference in mid-2019. Details to be discussed once a venue and date is sourced.

5. It was decided that a Medical Advisory Group for people with Myasthenia should be formed. The Committee drafted a relevant 'Terms of Reference' document and then approached key Doctors about their willingness to participate. The following positions have been accepted. Dr Blum as Chairperson, supported by Dr Stephen Reddel, Dr Katherine Buzzard and Dr Bill Harris. Our sincere appreciation is expressed to each Doctor for the time and interest given to being involved in this Medical Advisory Group. The Committee's next step is to work with the Doctors in identifying priority objectives for initial discussion.

6. It was brought to the Committee's attention that some people in Australia are accessing the drug Rituximab independent of the hospital pharmacy schemes and at considerable expense. To gain clarity on access to this treatment and cost associated with this access a survey was conducted in the form of a Questionnaire. Questions were kept simple and details will not be shared without additional permission. To better understand options, investigations were made with the Health funds, the PBS, Roche Drug Company and the TGA. The response to the questionnaire was good and identified that great discrepancies are occurring. An MGAQ member, indicated an interest in this issue and has worked with Susan to gather research papers etc. The committee took a resolution to take this matter to the Health Minister with a view to getting Rituximab considered for inclusion on the PBS. Dr Blum approached the MAA offering to work in collaboration with our alliance. This offer was accepted. Work has slowed as a relevant Journal item on use of the drug in Queensland until it is submitted for publication.

7. MG versus MGen - An unfortunate media release occurred in July this year. In discussing the Sexually Transmitted Infection, Mycoplasma genitalium (Mgen), a reference was made to this condition using the acronym MG. This is not the standard abbreviation used for this condition but unfortunately it was picked up by the journalists as a good headline. The article was shared with multiple media outlets and came to our attention via concerned members. Many letters have been sent from the Alliance highlighting the difficulties

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< MAA President's Report continued from Page 4

which may result from confusing the conditions. Whilst controlling the use of acronyms is not an achievable objective, discussing ways to strengthen the use of the acronym Mgen for Mycoplasma genitalium became our goal. Contact was made with clinical researchers, major Australian Universities, Australian Sexual Health and Public Health organisations, the International Journal of Epidemiology and with sister organisations around the world including the MGFA in USA and Myaware in the UK. Overall, the response has been very supportive particularly from fellow Australians. Mark White assisted in this project and his assistance is acknowledged.

8. The committee are very aware that a review of the 'Drugs to be Used With Caution' literature, which circulates in Australia, is in need of a review. Carol and Susan made contact with Doctors, a pharmacist and many International sites aiming for clarity. Progress has stalled due to the complexity surrounding generic and trade drug names, availability of drugs within Australia and differing options. It is hoped that the Medical Advisory Group will assist with this project.

9. eNID/MSBase Update - Having raised the requested $40,000.00 for the coding work for eNID, the Committee maintained contact with Dr Reddel and Dr Buzzard. Progress stalled and following a recommendation from Dr Reddel, we have now made a direct approach to MSBase for MAA inclusion with the eNID working party. An initial meeting has occurred and a request for the MAA to raise a further $45,000.00 was made. This undertaking has been agreed to in principle based on other key aspects of the project progressing. Robert is managing this communication.

10. An Information Card was produced and shared via the State Associations.

11. Website services remain an issue with upgrades not happening and alerts delayed. Ian to manage.

12. International contacts. This list has grown and was accessed during activities regarding MG versus MGen. Dianne to continue to develop this contact base.

The Financial situation of the MAA remains sound and has improved due to a fundraising initiative. Please find details in the Audit report provided to the MGAQ by BDO Audit partner, Anthony Whyte. All funds are held in trust by the MGAQ.

The MAA has a full program of works identified for the year commencing 1 October 2018 through to 30 September 2019.

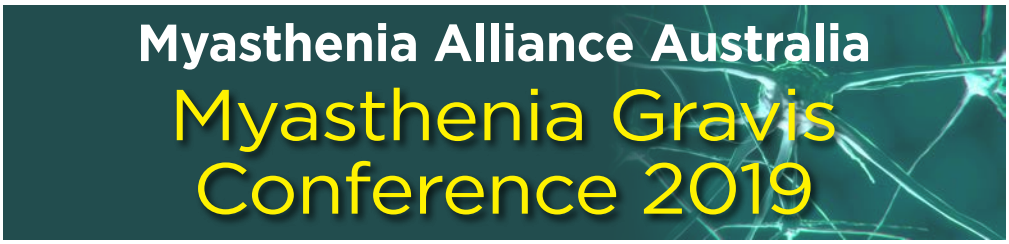
Susan White, MAA President

RARE DISEASE DAY PARLIAMENTARY EVENT

Now in its twelfth year, **Rare Disease Day falls on 28 February** and this year's global theme is: ***'Bridging health and social care.'*** To mark the occasion in Australia, RVA will be holding a Parliamentary BBQ lunch event in Canberra in the lead-up to Rare Disease Day on **Wednesday, 20 February from 12:15pm to 1:45pm.**

Along with Members and Senators and their advisers, RVA will promote the need for coordinated care and the importance of access to the NDIS as well as other services, and coordinated care for Australians living with rare disease. Mr Trent Zimmerman MP and Mr Steve Georganas MP, are pleased to co-host this event, with speakers including RVA's CEO, Nicole Millis. Rare disease patients, patient group leaders, clinicians, researchers and others will be in attendance.

Please note that this is an invite only event - invitations will be sent to RVA Partner Organisations and other key stakeholders this week.



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

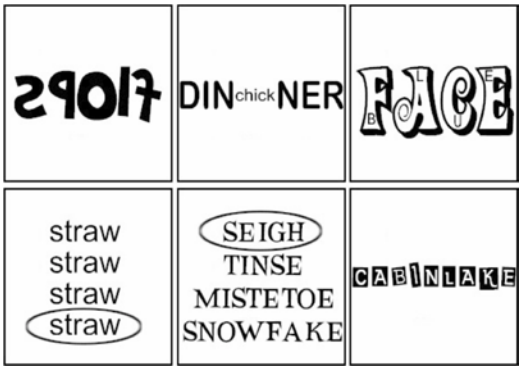
Puzzlers

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

Sudoku

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

Bamboozable



Math Challenge

Try to fill in the missing numbers.
Use the numbers 1 through 16 to complete the equations.
Each number is only used once.
Each row is a math equation. Each column is a math equation. Remember that multiplication and division are performed before addition and subtraction.

	×		/		12
+		+		-	
	+		+		15
-		-		+	
	×		+		16
1		13		7	

Answers

3	×	8	/	2	12
+		+		-	
5	+	6	+	4	15
-		-		+	
7	×	1	+	9	16
1		13		7	

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

Bamboozable 26 Answers: 1. Flip Flops; 2. Chicken Dinner; 3. Blue in the Face; 4. The Last Straw; 5. The First Noel; 6. Cabin by the Lake.

NEWS FROM AROUND QUEENSLAND

Brisbane – Coffee & Chat

Nundah – **The Royal Hotel, 1259 Sandgate Road at 3pm**
Sunday, 10 March; Saturday, 11 May; Sunday, 13 October

Burpengary –The Coffee Club, 164-166 Station Road at 2pm
Sunday, 14 April; Sunday, 11 August; Sunday, 10 November

Cleveland – **Fiction Bar, 152 Shore Street West, Raby Bay**
Friday, 15 March at 10.00am; Friday, 10 May at 10.00am; Sunday, 22 September at 2pm

Ipswich – **Queens Park Cafe, 10A Merle Finimore Avenue**
Friday, 12 April at 10am; Sunday, 12 July at 2pm; Friday, 25 October at 10am

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

We will welcome the MGAQ Treasurer, Denise Hannay at the next meeting on Saturday, 23 February as part of the 'Meet the Committee' campaign. This is a great opportunity to put a face to a name and have an insight into the working operations of your Association. Cairns will also be joining in on the **Rare Disease Day Fun Run & Walk on Sunday, 24 February on the Cairns Esplanade at 8.30am** (Registrations begin at 8am).

Please diarise the future dates **Saturday, 1 June; Saturday, 21 September and Saturday, 7 December. All meetings are held at the Cairns RSL Club, Esplanade commencing at 11.00am**. Contact Donna on 0414397462

News From Townsville

The next lunch for the Townsville group is on **Saturday, 23 February at The Avenues Hotel at 12.00 noon.** For details contact Daphne on 0400778637 or daphclay@gmail.com

News From Mackay

Our luncheons for 2019 until 30 June will be held on **Sunday, 24 February at 12.00 noon at Souths Suburban Bowls Club and Sunday 5 May at the Rice Buffet, Gregory Street at 12.00 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

Our first meeting for the new year will be on **Friday, 22 Feb. at the Kawana Bowls Club at 10.00am**. Hope to see you there. 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 next get together is on **Saturday, 23 Feb. at 10.00am at the Southport Sharks Club.** All are Welcome. Please call Nader on 0415 834 401 for more information.

WHERE IN QUEENSLAND? Let us know where you think it is:

DECEMBER EDITION: The large crocodile in Normanton
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	SATURDAY 8 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 Woollooongabba, Brisbane

MEET THE COMMITTEE DATES

WHEN IS IT?	WHERE IS IT?
SATURDAY, 23 FEBRUARY, 2019	CAIRNS RSL CLUB, ESPLANADE 11.00 am

The management committee feels it is important for members from across the state to meet and chat with some of our committee.
Therefore, over a period of time, two members from the management committee will travel to each of the areas. The regional co-ordinators will negotiate with the committee re the most suitable time of the year and these will be advertised in the newsletter.