



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

AUGUST 2018

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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Dr Cecilie LANDER

Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Do not forget the
Annual General Meeting on
Sunday, 9 September,
10.00am for 10.15am sharp.

Please also note the venue is
Aspley Hornets Football Club,
50 Graham Road, Carseldine.

We are very lucky that, following the AGM, a presentation by Dr Dhushan Illesinghe MBBS, MD (Psych), FRCPsych, FRANZCP entitled "MG and the Big "D" will occur. Our patron, Dr Cecilie Lander, will also be in attendance. Further information is contained in this newsletter.

I would again remind members who receive the newsletter directly from the Association via hard-copy or email that, if you have not yet renewed your membership, please do so before 30 September if you wish to continue receiving your copy of the newsletter directly. If you are not sure of your membership status, please email to info@mgaq.org.au or contact our 1800 802 568 support line.

As I mentioned in the last newsletter, this association needs to make a concerted effort to attract all people who are eligible to be members to do so. We are finding that many people are accessing the website and using Facebook as a medium to access information provided by

the association but are not taking up membership to support not only our association but also our membership numbers – a very important aspect when seeking sponsorship, funding, etc. Further discussion about a strategy to endeavour to address this will be presented at the AGM.

Our Meet the Committee gatherings are being very well supported and the committee members who have attended these have been very positive about the interaction that occurred, the feedback to the management committee and the suggestions made by members. The next one will be held in **Toowoomba on Sunday, 11 November.**

The Myasthenia Alliance Australia has been speaking with some of the Australian neurologists who have expressed an interest in being involved with a national conference in Brisbane in 2019. This would be a coup if it happens as traditionally the neurology conferences that are held in the days prior to our conferences have been in Sydney. So, start saving your money so that you can attend this conference if and when we are able to confirm it. More details will be available in the coming months.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS

"Celebrating Four Years"

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 a myasthenic condition. Congratulations to those initial members involved in making this commitment.

The Associations are State registered entities and identify with State Regulations and Health Authorities. Prior to this day, there was no pathway for these Associations to have any influence, conversation or financial request on items under the jurisdiction of the Federal Government.

It was for this reason that a legal Alliance Agreement was drafted. Any State Incorporated Association in Australia is welcome to join this Alliance and support giving a voice to all Australians with Myasthenia.

When the Committee first met we could not foresee all the projects and possibilities for bringing benefits to Australians. In only four years, two very successful conferences have been hosted, effective communication is in place with our International counterparts, monies requested for a specified research project were raised, a regular Alert communication system has been established, a working relationship with Rare Voices has been created and much more!

There are several new projects currently on the go. (More about this next month!)

These projects do however include preparations for a conference in 2019 and investigating how we can bring influence in making the drug Rituximab/MabThera more equitably available to all Australians.

The returned questionnaires have been invaluable in the information gathering process. Thank you to everyone who has contributed. There is still time to respond. Actions are underway but it won't be a quick process - nor a certain one.

Susan - MAA President.

Last month I highlighted Dylan's desire to complete the Melbourne 5 km Fun Run raising money for donation to the Alliance. Well ... he did it! Despite not having run such a distance for 8 years, his Dad was waiting at the finish line so he was committed.

Dylan writes, "The run went well! I certainly didn't break any speed records but was happy to just get through it - I don't take it for granted that I'm able to do this when many with MG wouldn't be able to. I'm blown away by the many donations (and kind comments) from the MG community, and am glad that it's going to the MAA, whose work I really appreciate and admire."

Thank you Dylan.

The final tally reached \$1120. What a wonderful effort. This money will make a big difference to the Alliance. Thank you again Dylan. We hope you may make it an annual event!

Dylan proudly writes - "That's Marty, my Dad, on the right."

We wish you good health Marty and thank you for raising such a special son.



"KNOWING YOUR MG"

In the previous newsletter we discussed what you need to know about your MG sub-type. Understanding your MG will help direct your individualised care plan. MG is categorised as a chronic medical condition and your specific needs can be best met by understanding your MG sub-type.

THIS MONTH'S TOPIC

OCULAR and GENERALISED Myasthenia Gravis

Myasthenia Gravis (MG) is differentiated into **two major clinical forms: ocular MG** (ocular meaning relating to the eye), in which the patient typically experiences weakness in only the eye muscles, and **generalised MG**, in which the patient develops generalised proximal weakness. Those with generalised myasthenia gravis have a more severe form of the disease and may experience weakness in other muscle groups.

The muscles of the eye are often affected first and patients may develop droopy eyelids (ptosis) and double vision (diplopia). Approximately 15% of patients with MG have strictly ocular symptoms. Patients who keep having strictly ocular symptoms for three or more years are unlikely to revert to the generalized aspect of the disease.

Generalised myasthenia gravis develops in about 50 to 80 percent of those who develop eye symptoms, with patients gradually experiencing

difficulty speaking (dysarthria), problems chewing and swallowing (dysphagia), and trouble performing everyday tasks, such as combing hair or climbing stairs, caused by weakness in the arm and leg muscles.

Patients may appear to be expressionless because the condition may cause facial muscle weakness. Nearly all patients who eventually develop generalised myasthenia gravis do so within two or three years of first displaying symptoms.

Sudden, severe weakening of the muscles involved in breathing results in a myasthenic crisis, a serious, life-threatening condition that is commonly provoked by an infection or surgery. Patients with myasthenic crisis often require emergency care.

People with ocular and generalised myasthenia gravis are treated with similar medications to control symptoms.

www.medscape.com; *Ophthalmologic Manifestations of Myasthenia Gravis*

Author: Edsel Ing, MD, MPH, FRCSC

<https://myastheniagravisnews.com/generalized-myasthenia-gravis/>

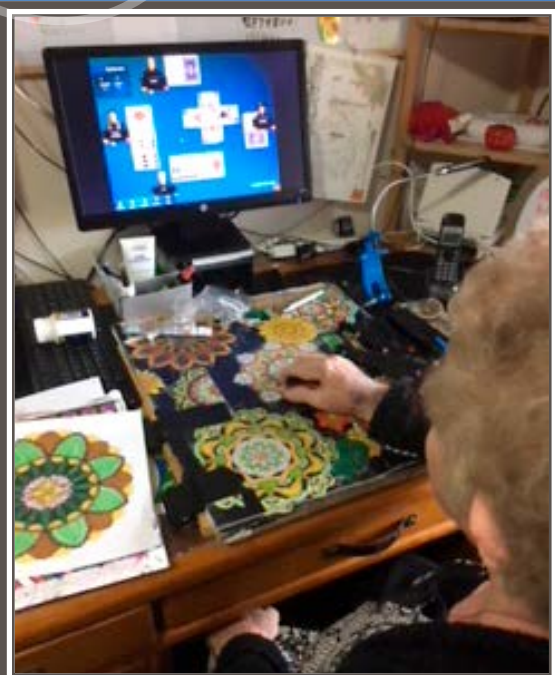
DISCLAIMER: Myasthenia Gravis Association Queensland Newsletter is strictly a news and information newsletter about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this newsletter.



MURIEL'S DID YOU KNOWs?

- Cows carry cow pox but chickens do not carry chicken pox.
- The London underground has made money from its famous map than it ever has from running trains.
- Jimmy Carter once sent a jacket to the dry cleaners with the nuclear detonation codes still in the pocket.
- If all the salt in the sea were spread evenly over the land, it would be 500 feet thick.
- Feeding canaries red peppers turns them orange.
- Dolphins shed the top layer of their skin every two hours.

What I enjoy on a good day.



Playing cards and scrabble on the computer. *Helen*



Colouring-in which gets covered in plastic and used for placemats and smaller one for bookmarks. *Helen*



Exploring while on holidays.

Denise

Send your message or photo to
Myasthenia Gravis Association of Qld Inc.
P.O. Box 16, Mt Gravatt, Qld 4122 • Freecall: 1800 802 568
Email: info@mgaq.org.au

NEWS FROM THE TREASURER



Denise

The MGAQ is very lucky to have the continued support of our 2 major donors. This will be the fourth year in which Ausenco and a private donor, have contributed generously. More Corporate donors would bring greater security to the organisation and recognition is available. We are also extremely grateful to our members who have very willingly donated \$3888.36 during the last year. The additional funds have been key to some of the projects undertaken this year. The heartfelt thank you messages that members have forwarded with their donations and memberships are very uplifting for the committee. Staying in touch is what we are all about.

Our membership is growing, and fees for the coming year are now due. I would encourage anyone that hasn't yet renewed their membership to look into doing so, remember without you, our members, we have no association. The MGAQ needs the membership numbers to be able to continue working for Myasthenics, to be able to assess Qld Health funding, to have a platform and a voice with Governments, to push to have research in MG. Membership fees received for the last financial year totalled \$4800.00. Membership fees and donations aren't enough to cover our operating costs and the funding we receive from Qld Health is invaluable to the MGAQ. We thank Qld Health for this continued support for Queensland people with a myasthenic condition.

As well as donations through the normal channels, we are registered with GIVE NOW and anyone can go online and donate by typing in 'Myasthenia Gravis'. Crowd Raising platforms are a great tool for fundraising events and Give Now offers this easy use facility at very competitive rates. You may have read about Dylan, whose dad has MG, and he wanted to do something. He set up a Crowd Raiser on the MG page and raised over \$1000 in just a few weeks. He designated that these funds should go towards the work of the Myasthenia Australia Alliance and this has been attended to.

Every year there is a handful of enquiries from people about paying fees via the phone using their credit card. The MGAQ has investigated the viability of setting up this facility. The costs involved are significant for our level of trade. It is not warranted.

Payments can always be made via direct bank deposits: Please always put your name against your transaction, and if you are able to send an email to treasurer@mgaq.org.au to let us know you have made a payment, that would be lovely. You can also go onto the website and renew your membership and pay via pay pal using your credit card. We still take cheques and of course cash.

I have very much enjoyed becoming involved as the Association's Treasurer. It has brought many new people into my life as well as expanded knowledge and new challenges. I encourage others to think about bringing value to their experiences with myasthenia by helping others.



Welcome to our new member

Peter D-R, Beaudesert, QLD

NEWS FROM AROUND QUEENSLAND - Freecall 1800 802 568

News from Brisbane

Coffee and Chat – Nundah

Friday, 28 September, 10.30am at the Royal Hotel, 1259 Sandgate Rd, Nundah

News from Cairns

Visiting Cairns? You are most welcome to join us when we meet.

The next meeting for MGAQ Cairns will be on **Saturday, 27 October, at 11.00 am in the Boardroom at the Cairns RSL, Esplanade.**

For more information about the Cairns group, call Donna on 0414 397 462.

News from Townsville

C The next Townsville Lunch is at **The Avenues Hotel on Saturday, 22 September, at 12 noon.**

For details or more information about the Townsville group, call Daphne on 0400 778 637 or email daphclay@gmail.com

News from Mackay

T Nine members attended our lunch on August 8 and had an enjoyable lunch and discussion on many subjects.

All attending the luncheon signed a sympathy card which was given to Hazel in memory of her sister Dorothy.

Everyone is welcome to attend our Christmas Lunch to be held at the **Mt Pleasant Tavern, North Mackay on 18 November, at 12 noon.**

For more information about the Mackay group, call Bill on (07) 4954 1221.

News from Gladstone-Wide Bay Region

M For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 4973 7983.

News from the Sunshine Coast

G We will be meeting again on **Friday, 2 November, at Kawana Bowls Club.** All Welcome.

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

News from Darling Downs and Beyond

I am just a phone call away if you would like any assistance.

Call Debbie on 0457 148 486 or (07) 4657 5974.

News from the Gold Coast

DD Our next MG meeting will be on **Saturday, 25 August, in Southport Sharks Club at 10.00 am.**

I look forward to seeing you all again. For more information about the Gold Coast group, call Nader on 0415 834 401.

WHERE IN QUEENSLAND?

Let us know where you think it is.

July Edition: Hamilton Island, taken from Dent Island.

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?
Christmas Function	Sunday, 9 December, 11.30am for 12noon	Club Southside 76 Mt Gravatt Capalaba Rd, Upper Mount Gravatt

MEET THE COMMITTEE DATES

WHEN IS IT?	WHERE IS IT?
TOOWOOMBA - 11.30am SUNDAY, 11 NOV	Picnic Point Cafe, 164 Tourist Rd
TOWNSVILLE - 12 noon SATURDAY, 24 NOV	The Avenues Hotel, 270 Kern Bros Drive, Kirwan

AGENDA FOR THE ANNUAL GENERAL MEETING

of the



MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

SUNDAY, 9 SEPTEMBER, 2018

at the

Aspley Hornets Football Club, 50 Graham Road, Carseldine
10.00 am for 10.15 am sharp

Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.

Bring yourself and whomever else you wish to bring along – the more the merrier

1. **OPENING**
2. **APOLOGIES**
3. **CONFIRMATION OF QUORUM**
4. **MINUTES OF THE PREVIOUS AGM HELD AT SOUTHERN CROSS SPORTS CLUB ON 17 SEPTEMBER, 2017**
5. **BUSINESS ARISING FROM MINUTES**
6. **PRESIDENT'S ANNUAL REPORT**
7. **TREASURER'S REPORT**
8. **ELECTION OF MANAGEMENT COMMITTEE 2018/19**
NOMINATIONS:
PRESIDENT Carol Buchanan
VICE PRESIDENT Susan White
SECRETARY Anita Jackson
TREASURER Denise Hannay
COMMITTEE MEMBERS (5) Donna Formosa, Rosalyn Holland, Veeta Bassi, Ian Hollingworth

As no accepted nomination for a fifth committee member was received, nominations will be called from the floor at the AGM.
9. **APPOINTMENT OF AUDITOR** *Notice of Motion* - That this meeting agrees to the appointment of BDO Australia Ltd as Auditors for the year 2018/19
10. **BANK AUTHORITY**
11. **GENERAL BUSINESS**
12. **GUEST SPEAKER:** Dr Dhushan Illesinghe MBBS, MD (Psych), FRCPsych, FRANZCP
13. **CLOSE**

NOTE – the AGM will be followed by a short general meeting to present the association's Annual Operational Plan 2018-2019

RSVP - Ring our 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 September, 2018



Myasthenia Gravis Association of Queensland Inc.

2017/2018 ANNUAL GENERAL MEETING

when **Sunday, 9 September**
10.00am for 10.15am sharp

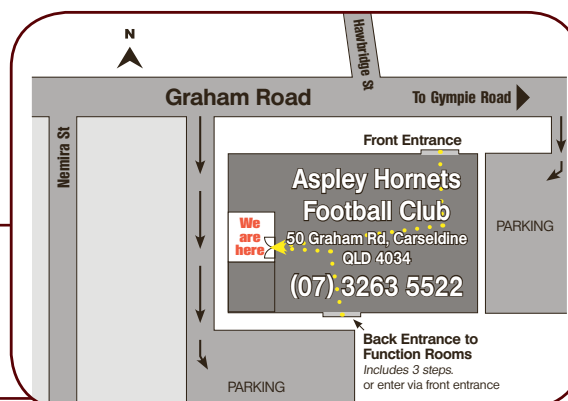
where **Aspley Hornets Football Club,**
50 Graham Road, Carseldine
Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.

guest speaker **Dr Dhushan Illesinghe** **TOPIC** **MG and the Big "D"**
MBBS, MD (Psych), FRCPsych, FRANZCP
As a psychiatrist, Dhushan has had a passion for teaching, training and providing support for patients and families.
He considers families and carers to be a vital ingredient in assisting patient's recovery.

special guest *Our Patron, Dr Cecilie Lander will also be attending.*

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 reference:
Map 119 J1



RSVP Ring our **FREECALL 1800 802 568** and let Susan know numbers attending and if you are staying for lunch.
Please RSVP by Monday 3 September 2018.
Also call if you require help with transport.