



Messages

Myasthenia Gravis Association of Queensland

MAY 2016



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

P.O. Box 16
MT. GRAVATT QLD 4122
NATIONAL FREE CALL:
1800 802 568
ABN 92 055 613 137

E-mail: info@mgaq.org.au
Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President
Graeme PETERS
Ph. 3288 4484

Vice-president
John NOBLE
Ph. 3269 5066

Secretary
Carol BUCHANAN
Ph. 4773 7122
email: info@mgaq.org.au

Acting Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee
Anita JACKSON
Ph: 3800 4913

Donna FORMOSA
Ph: 40392148

Rosalyn HOLLAND
Ph: 0407697206

Editor
Emily SEXTON
Ph. 0425821670
email: emily.sexton@live.com.au

PATRON
Dr Cecillie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

G'day all,

Firstly, I would like to welcome Greg Breaden of Kings Meadows in Tasmania as the new Editor of the MGAQ newsletter. Greg comes with nearly 40 years of experience in the printing industry and will bring a new look newsletter to the membership. He will commence duties for the June issue, and the committee thank him for his offer to take on the job. Also, I extend the thanks of the committee and members of the MGAQ to Emily Sexton for her time as Editor of the newsletter and wish her well upon her move to Melbourne and hope that life treats her well in the future. This is Emily's last edition as Editor.

The Service Agreement between Queensland Health and the MGAQ provides certain conditions which the MGAQ must meet in order for funding from Queensland Health to continue. Subsequently, the Secretary and President met with Queensland Health officials in late April and outlined the work that MGAQ has been performing during the current financial year and what it proposes to do for the remainder of the year. The feedback from Queensland Health is that the MGAQ is performing in accordance with the Service Agreement.

The response to the call for members who are prepared to place their names on the re-vamped Chat List has been disappointing. I ask that members give this matter consideration and refer to page 3 of this issue for more information. Please note that the deadline for responses has been extended to 31 May 2016.

The search for a new Treasurer may have come to fruition as discussions are under way with a member who has expressed an interest in taking on the job.

I would remind members of our mid-year function on Sunday 12 June, the details of which are on page 8 of this issue. Unfortunately, because of privacy concerns of some of the material to be presented, we are not able to produce a DVD of Dr Pane's presentation. So if you wish to find out about 'MG and Eye Conditions' you will need to come along on June 12 – I'm sure it will be an enlightening address.

Finally, June is MG Awareness month for Australia. So why not get together with a few of your friends and make them more aware of what MG is and the affect it has on your everyday living.

Cheers
Graeme

Supported by



ORPHANET JOURNAL OF RARE DISEASES

The MGAQ was delighted to participate in a research paper entitled "The Involvement of Patient Organisations in Rare Disease Research: a mixed methods study in Australia". It was published by Deirdre Pinto, Dominique Martin and Richard Chenhall through the University of Melbourne. It is an interesting paper which highlights the value of organisations such as this in initiating and supporting research into rare diseases. It discusses how 'patient communities influence the directions, practices and cultures of biomedical science'. It supported the importance of data registries such as is occurring with the MG Survey run in conjunction with the RBWH and University of Queensland. It confirmed that the majority of organisations are indeed small volunteer run groups such as MGAQ and that these groups do have a significant influence although there are significant challenges for these organisations. The paper re-iterated the importance of policy support at a government level and the need for patient registries and bio-banks. Unification amongst the Support Organisations was suggested as an advantageous progression. For the full article please go to www.ojrd.com/content/11/1/2

It was interesting to note that Sussan Ley, Federal Health Minister, this month initiated conversation in regard to policy supportive of people with chronic conditions

REVIEW OF MGAQ CHAT LISTS

The Chat Lists which are published in the monthly newsletter have been in existence for a considerable number of years. As is the case with lists which are subject to consistent amendment over time, it is apparent that the Lists currently in use are not accurate for various reasons, such as members changing location or phone number and forgetting to notify of their new information, members passing away, or, indeed, oversight on the part of the MGAQ, etc.

Consequently, the Management Committee has decided to discontinue using the existing Chat Lists and construct a new Consolidated Chat List which will be published quarterly. This new list will continue to show Given Name, Contact Phone Number and Location and will be ordered alphabetically by Location within State.

To enable the List to be constructed would members who are willing to be on the Chat List please advise via email to info@mgaq.org.au, or telephone Freecall 1800 802 568 or by letter, of their Full Name (Surname will not be listed), contact phone number and location, i.e. Suburb or town name. It would be appreciated if this information could be forwarded by **31 May 2016**. Only those members who respond to this request will be placed on the new Chat List.

New members since **1 July 2015** need not respond to this request unless their information has changed since they completed the Application for Membership form.

Thank you for your assistance in this matter.

***** ***** ***** *****

Nominations for Management Committee for 2016/2017

By now, current financial members should have received the form for nominating persons to fill positions on the Management Committee for the year 1 July 2016 to 30 June 2017.

If you are currently financial but have not received the Nomination Form, please contact the Secretary on info@mgaq.org.au or by Freecall phone 1800 802 568.

Nominations close on 9 June 2016.

^^

I can totally keep secrets. It's the people I tell them to that can't.



Around Queensland

News from the Sunshine Coast: We had a good roll up at our last get together on the Sunshine Coast with some new faces present. Our next get together will be on Saturday 4th June at 12 noon at Buderim Tavern. All Welcome. Colleen McLean 0409491789 colleen4551@gmail.com

News from Mackay: Our lunch get together at the Boomerang Hotel/Motel on the 24/4/16 was attended by 14 people including one new member who was recently diagnosed with MG. Our guest, Barb, a Health, Wellness & Breath specialist delivered an interesting talk on her subjects. A gift was presented to Barb from us all to show our appreciation. It was decided our get togethers for the rest of the year will be held on the following dates:-
 Sunday 17th July, 1200 noon for lunch @ Harrup Park Country Club
 Sunday 18th September, 12 noon for lunch @ Mt Pleasant Tavern
 Sunday 13th November, Christmas Lunch 1200 noon will be held at Souths Milton Street.

News from the Gold Coast:

Gold Coast third MG meeting was held on 16th of April in Kurrawa Surf Club in Broadbeach. Our next get together will be on 26th of June. The venue will be mailed to all Gold Coast members by one of our members Angela who will kindly be taking care while I'm overseas. Her contact number is 0427752956
 I look forward to seeing you all again when I return in August. Cheers Nader

News from Cairns: Our Cairns group meet again on Saturday 18th June in the Boardroom, Cairns RSL Club, Esplanade at 11.00am. Visitors are welcome.

News from Townsville:

Thanks to the 18 people who attended our lunch in April. It was great to chat with other members. Our next lunch is on Saturday 23rd July 2016.
 For details contact Daphne - 0400778637

We welcome the following new members:

Natalie - Wellington Point, Qld
 Sonia - Clayfield, Qld
 Gary - Noosa Heads, Qld
 Mary - Balberra, Qld

Shirley's Recipe Hayley's Healthy Date Loaf

Ingredients:

½ cup chopped dates	½ cup chopped walnuts or pecans
½ cup chopped apricots	½ cup shredded coconut
1 cup SR flour	½ cup sugar
1 cup low fat milk	

Method:

Mix all ingredients together.
 Place into sprayed loaf tin and bake in a moderate oven for 30 to 40 minutes.

Try to learn something about everything and everything about something.- Thomas Henry Huxley

MEMBERS' FORUM

There were no contributions this month.

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.

***** ***** *****



“Closed Facebook Group” vs “Open Facebook Page”

Many people ask what the difference is between the two MGAQ Facebook Pages.

MGAQ Discussion Forum is a “Closed Facebook Group” which allows like-minded people to communicate between each other in a safe forum. New members need to JOIN and then be approved by Admin before they can join the conversation. Only members who also belong to the group can see the posts or chats within it. This is a wonderful forum to share your MG Journey and chat to others on their MG Journey. To join:- <https://www.facebook.com/groups/mgqld/>

The MGAQ Facebook Page is an “Open Facebook Page.” The difference is that this page is Public and can generally be seen by anyone on Facebook. The Facebook page allows the MGAQ to communicate broadly with people who “Like” the page. When the MGAQ publish a post or an announcement it appears in the newsfeed of people who “like” the page. To spread the awareness of MG we need as many people as possible to “Like” the page. Help us to achieve this by visiting the MGAQ Facebook Page and click “Like” at <https://www.facebook.com/mgqld/>

Actual Instruction Labels...

- ON A KOREAN KITCHEN KNIFE: Warning keep out of children.
- ON A HAIR DRYER: Do not use while sleeping.
- ON A BAG OF FRITOS: You could be a winner! No purchase necessary. Details inside.
- ON A BAR OF DIAL SOAP: Directions: Use like regular soap.
- ON A FROZEN DINNER: Serving suggestion: Defrost.
- ON A HOTEL-PROVIDED SHOWER CAP: Fits one head.

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. Who is the Queensland Minister for Health?
2. In 1867 the USA purchased what from Russia for \$7.2 million?
3. What is the chemical symbol for Xenon?
4. Who designed the Sydney Opera House?
5. Wake Island is an External Territory of which country?
6. In which year was Melbourne settled?
7. Edmund Barton, Australia's first PM, was a member of which political party?
8. What is the main religion of Sweden?
9. The Australian Broadcasting Commission (ABC) was established in which year?
10. Which city hosted the Olympic Games in 1904?
11. Which UK TV series is set in the fictional place called Walford?
12. Who did Ronald Reagan defeat to win his first US presidency?
13. In which Australian state is Gilgandra?
14. Pure gold is how many carats?
15. What kind of artist does the word 'limner' describe – sculptor, poet or painter?
16. Who was Clint Eastwood's orangutan buddy?
17. Which Portuguese place was 'visited' by the Virgin Mary in 1917?
18. What Caribbean island was the last Spanish dependency in the western hemisphere?
19. What did the ancient Greeks believe to be a cross between a tiger and a horse?
20. Which world boxing champion had 23 brothers and sisters – Ali, Tyson or Liston?

Answers: 1) Cameron Dick; 2) Alaska; 3) Xe; 4) Jan Utzon; 5) USA; 6) 1835; 7) Protectionist; 8) Evangelical Lutheran; 9) 1932; 10) St Louis (USA); 11) Eastenders; 12) Jimmy Carter; 13) NSW; 14) 24; 15) Painter; 16) Clyde; 17) Fatima; 18) Cuba; 19) Zebra; 20) Sonny Liston.



I have not failed. I've just found 10,000 ways that won't work - Thomas Alva Edison

Forgive your enemies, but never forget their names - John F. Kennedy

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2016/2017 are due.

As voted at the 2015 Annual General Meeting, membership fees have increased this year by \$5 for each type of membership. The envelope in which this notice was 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 to enquire.

The majority of members will have 6/16 which tells you (and us) that you are financial to 30 June 2016. Others may show 6/17 or even 6/18 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 "MessaGes".** LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions. We are also giving you the option of paying your subscription directly into our bank account. 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 & Initials

If you use the direct deposit method, it would help if you could email us at info@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.

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE
<http://www.mgaq.org.au/membership-application-form>

.....
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 _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

*** **

Some cause happiness wherever they go; others, whenever they go - Oscar Wilde

