



Messages

Myasthenia Gravis Association of Queensland

August 2014



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.

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Association of
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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

The month of August is upon us and the westerly winds are normally around the corner. This month also means Brisbane Exhibition which I attend every year. The Exhibition brings back lots of fond memories of my Grandfather and his trotting horses. I also remember my Father doing the stock take for the food stores and bars that he managed.

The committee has advised the WA Association that the NSW Association is willing to join us in forming a National Alliance. We will keep you posted of any new developments.

The committee is still working on a future funding Transition Plan for Queensland Health. We are hoping to have a plan drawn up shortly for BoardConnect to review and advise of any necessary changes before submission. It is very important that we get the Transition Plan right to secure funding up to December 2015.

An important item about the future of our Association is provided on page 2. Think very seriously about this matter as I would not like to see this Association fold. We have come such a long way since the early days and helped so many members. I would not like to think that any newly diagnosed person does not have the support of our Association.

The next function is the AGM on Sunday 14 September at Southern Cross Sports Club, Mt Gravatt. Dr Rob Henderson is our Guest Speaker so this will be another excellent presentation. Looking forward to seeing you at the function.

Take care

Anita

EDITORS NOTE: Starting with the September issue Emily Sexton is going to be the new editor of the newsletter. Could all future items for the newsletter please be sent to emily.sexton@live.com.au

Supported by



THE FUTURE OF THE MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

As members have been advised in previous editions of *MessaGes*, continued funding from Queensland Health is guaranteed only until 30 September 2014.

Funding from 1 October 2014 until 31 December 2015 is contingent upon the MGAQ providing Queensland Health with a Transition Plan which can prove to Queensland Health's satisfaction that MGAQ can, and will, be a financially viable organisation beyond 31 December 2015, after which date no funding whatsoever will be forthcoming from Queensland Health.

The Management Committee is currently working towards how the MGAQ will continue to function without Queensland Health funding. Some of the issues being considered have been advised in previous recent issues of *MessaGes*. The Management Committee is confident that the MGAQ will remain financially viable after 31 December 2015.

However, there is a greater threat to the continuing existence of the MGAQ. This threat is the lack of Members who are prepared to nominate for positions on the Management Committee.

For the upcoming Annual General Meeting to be held on Sunday 14 September 2014, there are only five (5) nominations for the seven (7) committee positions for the year 2014/2015. The current workload of the committee requires that at least 7 people are needed to handle it and anything less than a 7 member working committee would place an onerous workload on the committee. Additionally, changing the method of operation to continue as a self-funding Association places an extra load on the committee, especially during the initial period after no Queensland Health funding is forthcoming.

If the AGM results in a Management Committee of only 5 members, there is a very high likelihood that one or more of those 5 would decide to resign from their committee position and this would mean that the MGAQ would, most probably, be unable to continue to function.

The Myasthenia Gravis Association of Queensland Inc. **MUST NOT** be allowed to fold as it is a most valuable resource for sufferers of myasthenia gravis and their carers and families, in particular those who are newly diagnosed.

Therefore, I would implore Members to give serious consideration to nominating for a Management Committee position at the AGM. You do not have to be present at the AGM to nominate – just indicate your willingness to nominate and accept the position if successful, in writing (or via email to info@mgaq.org.au) and your nomination will be put to the AGM. There the vacant two (2) positions are 'non-executive' positions. You do not have to be an MG sufferer, however, you must be a current financial member.

If you would like more information on what being a member of the Management Committee entails, email the Secretary at info@mgaq.org.au or call Shirley on the Freecall number 1800 802 568.

Please DO NOT LET THE MGAQ PASS INTO OBLIVION.

Anita Jackson (President)

CHAT LIST:

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

The opinions expressed by the person you call are entirely those of that person. 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 there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

CHAT LIST – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435389883	TWEED HEADS SOUTH NSW
MAUREEN	02 4476 3734	NAROOMA NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
DIANNE	02 4574 3787	WINDSOR DOWNS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
EDMUND	03 95098920	CAULFIELD NORTH VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	ALICE SPRINGS NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

FUTURE PLANNED ACTIVITIES

14 Sept - AGM - Southern Cross Sports Club. Guest Speaker Dr. Rob Henderson (see page 8).

14 Dec – Christmas Function Brisbane venue TBA

CAIRNS GET TOGETHER

Meetings are held at the RSL Club Boardroom, Esplanade Cairns at 11.00am. Some people stay on for lunch in the restaurant afterwards (own expense)

Saturday 11th October at 11.00am

Saturday 6th December at 12.00 noon for our Christmas Lunch get together

Donna Formosa – Cairns Coordinator - Ph. 0414 397462 or email formosed@bigpond.net.au

NEWS FROM MACKAY

It was decided our next get together will be held at:

North Mackay Bowls Club Sunday 31/ 8/2014 for lunch at midday

Bill Area Coordinator – Phone 49541221

JOKES

Three blond men are stranded on an island. Suddenly a fairy appears and offers to grant each one of them a wish.

The first blonde wants to be intelligent. Instantly, he is turned into a brown-haired man and swims off the island.

The next one asks to be even more intelligent than the previous one, so he is turned into a black-haired man. The black haired man builds a boat and sails off the island.

The third blonde asks to become even more intelligent than the previous two. The fairy turns him into a woman, and she walks across the bridge.

My wife was hinting about what she wanted for our upcoming anniversary. She said, "I want something shiny that goes from 0 to 165 in about 2 seconds." I bought her a bathroom scale. And then the fight started.....

DVD's of PAST GUEST SPEAKERS

The Association has surplus copies of the following DVD's of past Guest Speakers. These are available to members on a 'first-in, first-served' basis. If you wish to obtain any of them, please contact our 1800 802 568 Freecall number.

Dr Cecilie Lander M.B., B.S., F.R.A.C.P., F.R.C.P.E.

Dr Lander talks about MG and gives an overview of autoimmune disease in the nervous system, with the perspective of being a neurologist for the last 35 years.

Dr Jean Foster M.B., B.S.

Making the most out of your GP

Dr Stefan Blum MD, FRACP and Dr Jennifer Nitz PhD, MphD, Bthpy, FACP

Dr Blum presents a preliminary report on findings from the Data Collection Survey on people with myasthenia gravis.

Dr Nitz presents preliminary findings from the 'Exercise Effect in MG' Pilot Study.

Dr Stefan Blum and Dr David Lee

Some Interesting findings from the MGAQ Survey

MEMBERS FORUM

No contribution to Members' Forum received 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 make 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.

HUMOUR

A couple robbing a store caught on camera could not be identified until the police reviewed the security tape. The woman filled out an entry form for a free trip prior to robbing the store.

Agenda for the Annual General Meeting of the Myasthenia Gravis Association of Qld Inc, to be held on Sunday 14 September 2014 at the Southern Cross Sports Club, Mt. Gravatt commencing at 10:15am.

- 1. OPENING
- 2. APOLOGIES
- 3. CONFIRMATION OF QUORUM
- 4. MINUTES OF THE PREVIOUS AGM HELD AT SOUTHERN CROSS SPORTS CLUB ON 15 SEPTEMBER 2013
- 5. BUSINESS ARISING FROM THE MINUTES
- 6. PRESIDENT’S ANNUAL REPORT
- 7. TREASURER’S REPORT
- 8. ELECTION OF MANAGEMENT COMMITTEE FOR 2014/2015

NOMINATIONS:

PRESIDENT Anita Jackson

VICE-PRESIDENT John Noble

SECRETARY Carol Buchanan

TREASURER Susan White

COMMITTEE MEMBERS (3) Shirley Johnston

9. APPOINTMENT OF AUDITOR

Notice of Motion – That this meeting agrees to the appointment of BDO Australia Ltd. as Auditors for the year 2014/15.

10. BANK AUTHORITY

11. GENERAL BUSINESS

12. GUEST SPEAKER – Dr. Rob Henderson

13. CLOSE

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NOTE: The AGM will be followed by a short General Meeting to set the membership fees.

SURVEY UPDATE

Collecting data on sufferers' of myasthenia gravis:

No news yet, but we are still hopeful of having not two, but three medical articles published soon. All articles will have resulted from the analysed survey results. Talks are evolving on processes for genetic studies. This will utilise the data base collected from the survey respondents who thoughtfully agreed to be contacted again if required. Hopefully there is to be some very interesting news unfolding during the latter part of the year. All this feedback is tantalising and requires patience as we wait.

WEBSITE

Your website has been enhanced. Please take a look at the new format by going to www.mgaq.org.au and having a browse. We would love to hear member responses in regard to the clearer, simpler model that is now running. A new addition is the ability for members and non-members to **sign up for automatic mail outs** (via email) of the monthly newsletter and any organisation events that may be of interest. Try it! You can safely unsubscribe if it is not for you. ***The Committee would like to thank Philipp Hartle of 'Interactive Focus' for his consistently thoughtful and continued support of the MGAQ and for his skills in producing and administering our website.***

REGIONAL COORDINATOR VACANCIES

Currently there are vacancies for the position of Regional Coordinator for North (Sunshine) Coast, Wide Bay/Burnett and Rockhampton regions.

With the impending cessation of funding to the MGAQ from Queensland Health, the role of Regional Coordinator will take on an increased importance as the conduit between our members in the regions and the Management Committee.

The role of Regional Coordinator includes: maintaining regular contact with the members in the respective region, usually by means of regular (say 3 to 4 monthly) get-togethers; dissemination of MGAQ Information Booklets and Pamphlets throughout the region; and bringing concerns or suggestions from local members to the attention of the management Committee.

The Management Committee would like to hear from members (or carers) who are interested in taking on the role of Regional Coordinator in any of the abovementioned regions via an email to info@mgaq.org.au or a phone call to our Freecall 1800 802 568 number.

WORDS OF WISDOM

- I have learned that in every face-to-face encounter, regardless of how brief, we leave something behind.
- I have learned that you can do something in an instant that will give you a heartache for life.
 - I have learned that a teenager's greatest fear is the fear of a broken heart.

2013/2014 ANNUAL GENERAL MEETING

- WHEN:** Sunday 14th September 2014 at 10:00am for 10:15am sharp
- WHERE:** Southern Cross Sports Club, Corner Klumpp and Logan Roads, Mount Gravatt (vehicle entry to club is via Klumpp Rd.)
Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.
- GUEST SPEAKERS:** Dr. Rob Henderson – Neurologist at Royal Brisbane Hospital
- 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 Map 201 Reference D7.
Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch.
RSVP: (important) Please let her know by **Friday 5th September 2014**

FUTURE NEWSLETTERS

This will be my last newsletter as editor. Shortly before Christmas my husband and I are relocating to Sydney for his work. I am happy to announce that Emily Sexton will be the new editor of MessaGes and I wish her all the best in her new position. I have enjoyed the past twelve months as editor and we will both be sorry to leave Brisbane. We have formed many good friendships within the association and hope to keep in contact.

The September issue of MessaGes will unfortunately not be available until early October this year. Graeme (our publisher), is taking an overseas holiday with his wife. We wish him and Poppy a safe, happy and well-earned break.

INDIVIDUAL BAKED CHEESECAKES (serves 4)

4 butternut cookies	1 tbsp. lemon juice
250g cream cheese, softened	1 tsp. vanilla essence
½ cup (125g) caster sugar	2 eggs, lightly beaten
1 tsp. grated lemon rind	mixed berries to serve

Pre heat oven to 180 c. Lightly grease four 1 cup muffin holes and line bases with rounds of baking paper. Place a butternut cookie in the base of each muffin hole. Using electric beaters, beat cream cheese until smooth. Add the sugar, lemon rind, lemon juice and vanilla and beat until smooth. Gradually add the eggs, beating well after each addition. Transfer to a jug for easy pouring, then pour into muffin holes, leaving 1cm rim. Bake 20 mins or until set. Leave for 5 mins, and then run a flat knife around each muffin hole and invert onto a plate. Remove the baking paper, turn upright and place each cheesecake on each serving plate. Serve with berries.