



# Messages

Myasthenia Gravis Association of Queensland  
**October 2015**



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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**PATRON**  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

### President's Report October 2015

G'day Everyone,

This is my first report since being elected as President of the MGAQ at the recent 2015 AGM. It is a privilege to hold the position and I hope that I can contribute to the aims of the Association.

I would particularly like to thank Anita and Susan for their dedicated years of service to the members in their positions of President and Treasurer, respectively, and thank them for being willing to continue to serve on the Management Committee.

This year, 2015/2016, was looking to be very challenging for the MGAQ with the impending cessation of funding from Queensland Health from 31 December 2015.

However, since the AGM we have received advice from Queensland Health that our funding grant will now be continued from 1 January 2016 for a period of 3 ½ years. We are aware of some of the conditions that apply to the funding continuance, but we still await further details.

Although this news from Queensland Health is extremely welcome and will make the coming year somewhat less challenging, there are still challenges ahead for the MGAQ, particularly in progressing the Data Survey of MG sufferers (in association with the University of Queensland and the Royal Brisbane and Women's Hospital), and with further work under the Myasthenia Alliance Australia. We will also need to continue to try to raise funding from entities other than Queensland Health in order to provide more funding towards MG Research and to build up Reserve Funds in the event that, in the future, the Association may be required to continue to exist without Queensland Health funds. The impending full roll-out of the National Disability Insurance Scheme (NDIS) will possibly, indeed, probably, result in changes to the way in which Queensland Health distributes funding in the future. We will provide more information as it becomes available.

**I draw your attention to the item at the top of page 2 of this issue and ask that members give sincere consideration to its content.**

In the meantime, I look forward to working with all of those elected to the Management Committee, and with the MGAQ membership, to make the MGAQ a support organisation we can all be proud of.

Cheers  
*Graeme*

Supported by



**Queensland  
Government**

## **YOUR ASSOCIATION MUST HAVE A TREASURER - CAN YOU PLEASE HELP!**

At the recent Annual General Meeting held on 13 September, Tracey Porter was elected as Treasurer of the MGAQ for 2015/2016. Unfortunately Tracey has advised that she is now not in a position to take on the Treasurers role after all. Whilst we thank her for her willingness we must now again appeal to the membership to come forward and assist the Association.

It is possible for the Association to outsource the bookkeeping work which needs to be processed each month, but a Treasurer must sit on the Committee as an engaged member of the team. The Treasurer needs to take responsibility for the monies collected and cheques signed and should track the expenditure throughout the financial year. The months which are of most significance are June and July.

Very good systems are in place using an Excel Spreadsheet for recording and cross checking all the accounts. A meticulous record keeping system is in place and the books are balanced each month and then audited annually to ensure accuracy. The immediate-past Treasurer, Susan White, will be on hand for advice, support and guidance in this role should it be requested.

The MGAQ is a dynamic and progressive organisation and your commitment to the team will be well rewarded. Meetings are held once a month on the second Saturday morning of every month, except January. Outside of this, work is completed in advance of the meeting by email correspondence. If you are daunted by the Excel spreadsheet and the monthly data entry, we can arrange support in this area.

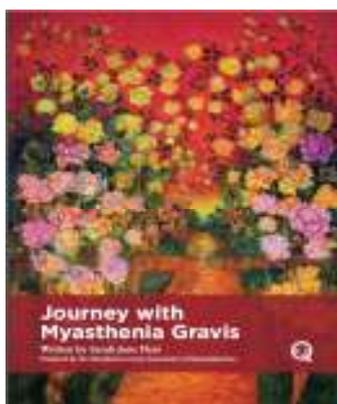
Please call the immediate-past treasurer, Susan White, the president, Graeme Peters, or our 1800 free call number if you have questions about the role of Treasurer of the MGAQ. You will be given full and truthful answers to enable a fully informed decision.

Please urgently consider, if not yourself, if there is a friend or family member, who would like to assist. The Treasurer must be a current financial member of the MGAQ or be prepared to join as a 'Supporter' Member.

Susan White cannot continue in the position for another year. She has MG too and has given seven years to the job along with many other tasks including Chairperson of the Myasthenia Alliance Australia Committee and Project Officer for the Book of Journeys and for the MG Data Survey. Now, however, the timing of the Treasurer's role will not always be compatible with the commitments she has with family. And she needs a rest!

## **PROJECT UPDATE**

### **"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER**



Feedback is coming through from people who have now read the 'Journey' book. It is very exciting for the Committee to hear that the book is read and then re-read as the details in the stories are digested. Many report sharing it with family, friends and with their Doctors or ordering extra copies to give away. How wonderful that these books are out in the community working to raise awareness of MG and to foster greater understanding.

## News from the 2015 Annual General Meeting

The recent AGM held on Sunday 13 September 2015 was very successful with nearly 30 members, new and old, attending. Professor Pamela Mc Combe gave a very interesting and informative presentation on the history of MG and of current and future prospective condition management regimes. Her presentation was recorded and will be forwarded to current financial members when available, together with the DVD from the mid-year function held on 12 July 2015.

### Election of Office Bearers for 2015/2016

The following were elected to the Management Committee until the 2016 AGM:

President	Graeme Peters
Vice-President	John Noble
Secretary	Carol Buchanan
Treasurer	Tracey Porter (See Item on page 2 of this issue)
Committee Members	Anita Jackson, Susan White, Donna Formosa, Shirley Johnston, Rosalyn Holland

### Membership Fees

Members present at a General Meeting which followed the AGM passed a motion which increased Membership Fees for the year commencing 1 July 2016. The new fees are:

Category A (Myasthenia gravis sufferer)	\$20.00 per annum
Category D (Carer)	\$10.00 per annum
Category E (Supporter)	\$20.00 per annum
Category B (Paid up Life Member)	Application to Committee

**NOTE:** Now that we have received advice that funding to the MGAQ from Queensland Health will be continued until 30 June 2019, this matter will be reconsidered by the management Committee.

### Feedback from Members' Survey held early 2015

Feedback from this survey, of which there were 118 respondents, was given to members at the General Meeting held following the AGM. This feedback comprised the rankings of the importance members gave to particular services that the MGAQ provides, and to some possible initiatives for the future (some of which were included as 'initiatives to be considered' in the Transition Plan to retain Queensland Health funding up to 31 December 2015 that was submitted to, and approved by, Queensland Health).

### QUESTION 1 ASKED THE MEMBERS TO PRIORITISE THE THINGS THAT THIS ASSOCIATION DOES FOR THEM.

The rankings, in order of Most Important to Least Important, were:

1. Newsletter	2. Information Booklet
3. Research, e.g. MG Data Survey, etc	4. DVD 's of Guest Speakers
5. 1800 802 568 Support Phone Service	6. MGAQ Website
7. Guest Speakers at Brisbane Meetings	8. Regional 'Meet the Members' Meetings
9. Regional Get-togethers	10. MGAQ Lending Library

(The above rankings have to be 'read' according to the number of times these things happen or the number of times people have accessed something, e.g. a newly diagnosed member might use the 1800 number regularly but then their needs might drop off).

**QUESTION TWO RELATED TO THE FUNDING FROM QLD HEALTH CEASING AT THE END OF 2015. WITH THIS IN MIND, MEMBERS WERE ASKED TO TICK THE ACTIONS THEY AGREED COULD BE MODIFIED AND/OR CHANGED. IN ORDER OF ACCEPTANCE:**

1. Newsletter sent out every 2 months instead of every month - 66% agreed
2. Members who have access to a computer encouraged to receive their newsletter by email – 61% agreed
3. Raise annual membership fees e.g. Category A from \$15 to \$20 – 60% agreed. Also asked as part of this question was how they preferred to pay. In order of response - Direct Deposit (no. 1), Cheque (no. 2) and Paypal (no. 3).
4. Unfinancial members be contacted with a view to having them renew their membership. The committee did not expect payment for 2014/5 financial year or any arrears – 57% agreed. (The committee has already started this)
5. One DVD production per year instead of one after every guest speaker – 54% agreed.
6. Information books and resources only available to financial members – 52% agreed.

The Management Committee decision regarding actions to be taken from the Member Survey will be detailed in the November newsletter.

**MYASTHENIA ALLIANCE AUSTRALIA**



**Myasthenia**  
Alliance Australia

The Alliance Committee is currently following up on several projects and expects to issue updated alerts closer to Christmas. The Australian Blood Bank contracts for obtaining plasma are to expire at the end of the year. News regarding the new contracts is not yet available. This situation is being

monitored. A project for the new year is to make contact with existing overseas Associations. Options for collaborative work will be discussed. It is expected that this enquiry will be well received as the Alliance website [www.myastheniaallianceaustralia.com.au](http://www.myastheniaallianceaustralia.com.au) is proving popular with international browsers.

**MAA Conference Feedback (No 4)**

Dr Stefan Blum is a consultant neurologist at the Princess Alexandra Hospital and Mater Hospital, Brisbane. He has a research and clinical interest in neuroimmunology, including Myasthenia Gravis and Multiple Sclerosis. He did his medical training at the University of Heidelberg, Germany and neurology training in Germany, the Princess Alexandra Hospital and Royal Brisbane and Women's Hospital, Brisbane. He recently completed a PhD in immunogenetics of Guillain-Barre Syndrome. He is involved in a neuroimmunology clinic at Princess Alexandra Hospital where numerous patients attend, as well as having an ongoing fruitful collaboration with the MGAQ.

The Myasthenia Gravis Association of Qld Inc. has been fortunate to have an ongoing professional relationship with Dr Stefan Blum. He worked very closely with this association in the preparation and collation of the Myasthenia Gravis Survey (2011) and is still involved with ongoing research from the data collected.

At the conference, Dr Blum presented a range of information from the surveys:

- 198 surveys have been returned, 165 of which were used in the first analysis.
- Mean age at onset was 49 and mean age at diagnosis was 51.

- Symptoms worsened as a result of infections (33%), vaccinations (6%), mental/physical stress (91%), seasonal changes (65%) and medications (24%).
- 54% of people have other autoimmune diseases and 40% had other family members with autoimmune diseases.
- Over 26% of people are on IVIg.
- Direct costs per head to the health system were \$5379 for medications, \$450 for specialists' visits, \$154 for travel and \$4060 for hospitalisation.
- Costs to individuals – only one-third of patients work; over 50% of those working took sick leave in the past year; 40% had to stop work altogether; 20% had to change their career; pre MG people worked an average of 3500 hours annually and post MG this dropped to an average of 1000 hours annually.
- The main inhibitors to the quality of life were the ability to think clearly, fatigue and lack of mobility.
- Areas for further study include triggers for the disease and genetic factors.

### Future Planned Activities

Sunday 13 December 2015

Christmas function – Caloundra Power Boat Club

### 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 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.

## **MGAQ SUPPORT LINE 1800 802 568**

### **CHAT LIST – QUEENSLAND REGIONAL COORDINATORS**

DONNA	0414 397 462	CAIRNS
DEBBIE (Taroom)	4628 6103	DARLING DOWNS
NADER	0415 834 401	GOLD COAST
BILL	4954 1221	MACKAY
JEANNE	0437 048 361	ROCKHAMPTON
COLLEEN	5493 6391	SUNSHINE COAST
DAPHNE	4773 3695	TOWNSVILLE
GARTH (Gladstone)	4973 7983	WIDE BAY/BURNETT
JANET (Hervey Bay)	0429 622 438	WIDE BAY/BURNETT

### **CHAT LIST – BRISBANE**

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON

JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	3261 7564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
EMILY	0425 821 670	BURPENGARY
KENNETH	0414 525 241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408 311 110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
DENNIS	3855 9379	GAYTHORNE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448 192 521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415 613 242	KANGAROO POINT
ROBYN	0434 532 853	KEDRON
GEOFFREY	3355 6441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	3886 7802	NARANGBA
SUSAN	33581056	NEW FARM
FARINAZ	0401 715 118	NEW FARM
KEVIN	3281 9225	NEWTOWN
BILL & JITLADA	3399 7041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
TRACEY-LEE	3284 9949	REDCLIFFE
SYBIL	3219 9535	ROCHEDALE
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JAMES	0433 662 913	WYNNUM
JOHN	3633 0604	ZILLMERE
ROSALYN	0407 697 206	ZILLMERE



## Around Queensland

### News from Cairns

We meet again on Saturday 17<sup>th</sup> October at the Cairns RSL Club in the Boardroom at 11:00am.

Donna Formosa

Ph: 4039 2148 or M: 0414 397 462

### News from The Gold Coast

My name is Nader Amiri and I have lived on the gold coast since 2000. Last month I volunteered to be the regional coordinator for the coast primarily because I thought being a people oriented person I could play a supportive role in this position.

In 2013 just as I was starting my retirement after a rewarding career in teaching I was diagnosed with 4<sup>th</sup> cranial nerve palsy but subsequently after few tests MG was confirmed.

Fortunately mine has been only ocular MG and under control so far. However as we know MG can be quite debilitating both physically and emotionally so it's a blessing to know we are not alone. I hope to be useful as a local contact person.

Please don't hesitate to contact me at any time. I live in Southport.

Nader Amiri  
0415 834 401

### **News from Mackay**

Mackay Area of the MGAQ held our lunch get-together at the Western Suburbs Football Club on Sunday, 30/8/2015.

All our regular members attended and we also welcomed two members John and Pauline.

Our guest speaker Marg gave an interesting talk on Acupuncture that was appreciated and she also answered questions on the subject and then spoke on the subject of how to get the best out of your Doctor.

An enjoyable lunch was had by all.

Our Christmas lunch will be held at the Boomerang Hotel Motel on Sunday 29<sup>th</sup> of November 2015 at noon.

I have given a copy of Journey with Myasthenia Gravis to my Doctor and Marg our guest speaker and other copy is with our members.

I would like to wish everyone a Merry Christmas and a Happy New Year.

All are welcome to attend our functions please phone 0749541221 or mobile 0429729685

### **News from Townsville**

Townsville MG Lunch – Saturday 17<sup>th</sup> October at the Avenues Hotel, 270 Kern Brothers Drive, Kirwan, Townsville at 12noon.

RSVP to Daphne – 07 4773 3695 or 0400 778 637

Email: [daphclay@gmail.com](mailto:daphclay@gmail.com)

### **NEW MEMBERS**

We welcome the following new members:-

Tracey – Northgate

Charles – Mackay

Elisa – Mackay

Kirstie – Eastern Heights

James - Capalaba

Helen – Ellenbrook, WA

### **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 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](mailto: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.

## JINGLE BELLS JINGLE BELLS

Ho! Ho! Ho!, it's that time again - time for our annual Christmas Get-Together, so come along and have a great day with lots of fun and good company.

- WHEN:** Sunday 13 December 2015
- TIME:** 11am for 12 Noon
- WHERE:** Quarterdeck Restaurant, Caloundra Powerboat Club, Woorim Park, The Esplanade, Golden Beach. Car parking is available.
- WHAT WILL IT COST?** Meals are at reasonable prices and there is a wide and varied menu. Raffles will be on sale.
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along. Remember, as it is a 'user pays' function, friends and family are most welcome.

### HOW DO I GET THERE?

#### To Get There From Brisbane:

Exit from Bruce Highway onto Caloundra Rd. Proceed for about 9.5 km. Caloundra Rd becomes Bowman Rd. Continue on Bowman Rd for about 0.4km. Turn right at Park Place. Proceed along Park Pl for approx 0.2km, when it becomes Landsborough Pde. Continue on Landsborough Pde for approx 0.4 km when it becomes Esplanade. Continue on Esplanade for approx 1.1 km. At the roundabout, take the 1st exit onto Landsborough Pde. After approx 0.2km there will be another roundabout. At this roundabout, take the 1st exit onto Jellicoe St for approx 100 metres. Turn right at Esplanade. Club is on the left after approx 1km.

#### To Get There From Noosa, etc:

Travel along Nicklin Way to Caloundra Road. Turn left into Caloundra Rd at roundabout. Caloundra Rd becomes Bowman Rd. Continue on Bowman Rd for about 0.4km. Turn right at Park Place. Proceed along Park Pl for approx 0.2km, when it becomes Landsborough Pde. Continue on Landsborough Pde for approx 0.4 km when it becomes Esplanade. Continue on Esplanade for approx 1.1 km. At the roundabout, take the 1st exit onto Landsborough Pde. After approx 0.2km there will be another roundabout. At this roundabout, take the 1st exit onto Jellicoe St for approx 100 metres. Turn right at Esplanade. Club is on the left after approx 1km.

### RSVP

Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by Friday 27 November 2015.

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### BOILED FRUIT CAKE

- Step 1.** Stir and bring to boil slowly 500 grams mixed fruit, 125 grams butter, 1 small cup sugar, 1 level teaspoon bicarbonate soda, 1 level teaspoon mixed spice and 1 heaped teaspoon ginger (spices according to taste) 1 cup milk.
- Step 2.** Allow to cool and meanwhile line a 20 cm round or square deep cake tin with baking paper.
- Step 3.** Stir into cooled mixture 2 well beaten eggs and 1/2 teaspoon vanilla or 1/4 to 1/2 cup of rum. Add and mix in 1 cup S.R. flour and 1 cup of plain flour.
- Step 4.** Pour batter into prepared tin. Bake in moderate oven for 1 to 1 1/2 hours. Time varies so always test with skewer.