



# Messages

Myasthenia Gravis Association of Queensland Inc

**AUGUST 2013**



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@mgagq.org.au](mailto:info@mgagq.org.au)  
Internet: [www.mgagq.org.au](http://www.mgagq.org.au)

### COMMITTEE MEMBERS

*President*  
Anita JACKSON  
Ph. 3800 4913

*Vice-president*  
JOHN NOBLE  
Ph. 3269 5066

*Secretary and Editor*  
Graeme PETERS  
Ph. 3288 4484  
email: [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com)

*Treasurer*  
Susan WHITE  
Ph: 3358 1056

*Information Officer*  
Shirley JOHNSTON  
Ph. 1800 802 568

#### Committee

Bill SYNNOT  
Ph. 0418196707

Carol BUCHANAN  
Ph. 4773 7122

PATRON  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## PRESIDENT'S REPORT

*Welcome,*

Queensland Health has offered the Association a new Service Agreement for the period 1 July 2013 to 31 December 2013. The new agreement contains new conditions and reporting requirements. The committee is currently analysing and investigating these conditions and requirements to ascertain the impacts and implications to the MGAQ should the offer be accepted. One result from the analysis is the committee may not accept the offer, in which case, funding from Queensland Health would cease and the MGAQ would need to continue operating using its own funds and resources. This would, of course, necessitate changes to the existing method of operation to reduce costs to the level of its received membership subscriptions, donations and other monies generated such as bank interest and raffles, etc. We will keep you informed.

The committee is working on our reporting requirements and financial statements for the 2012/2013 financial year so that they can be presented at the Annual General Meeting on 15 September 2013 at the Southern Cross Sports Club in Mt Gravatt.

We are also looking forward to a 'Meet the Members' in Toowoomba on 10 November 2013 and we will publish the details in future Newsletters. We hope to see our members from Toowoomba and the Darling Downs there as it is good to put names to faces and also to hear their journeys with MG.

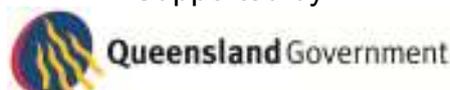
The committee is now all back in Brisbane again. I had a great holiday in Great Britain and Ireland and saw some amazing places and the scenery was a great shade of green everywhere. I did some family research and found my Great Uncle's house, which was built in 1885, still standing near Edinburgh. Bill is back from his holiday and work in Fiji. We both have missed out on winter weather that you have been having here.

Take care

*Anita*

**EDITOR'S NOTE:** The editor apologises for the late circulation of this issue, but a technological breakdown occurred which caused a severe delay.

Supported by



## **PROJECTS UPDATE**

### **Collecting data on sufferers of myasthenia gravis –**

The surveys continue to be received from all postcodes in Australia.

There are no further updates this month.

Raising awareness of MG (including the Survey opportunity) remains ongoing. For example, committee member Shirley is currently presenting her story and Information Booklets to nursing students at some tertiary institutions.

### **‘Exercise Effect in MG’ Pilot Study –**

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see. The paper is in the last stages of review and should be finally accepted for publication in the journal *Muscle & Nerve* in the near future. *Muscle & Nerve* is an international journal devoted to neuromuscular disorders & treatment options & is considered essential reading for neuromuscular, musculoskeletal, & EDX physicians.

It may seem like a long time since the Study was completed but apparently this is an average time for getting into print. Sometimes it can take years!

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

## **EXERCISES AT HOME**

Doctor Jennifer Nitz, who conducted the Study at the University of Queensland’s Neurological, Ageing and Balance Clinic, has kindly provided the Association with a booklet entitled *‘Preventative Health – Exercise for your Bones, Strength and Balance.’*

The booklet details exercises which closely match those which were undertaken by participants in the abovementioned Study and are such that they can be undertaken by people in the comfort of their own home.

Each copy of the booklet comes with Cautionary Notes which should be read and understood before commencing any of the exercises.

Copies of the booklet are available, in either hard copy or electronic form (pdf), to current financial members. Those members wishing to obtain a copy should contact the Association on our Freecall number 1800 802 568 or via email at [info@mgag.org.au](mailto:info@mgag.org.au) and state whether you prefer hard copy or email copy.

Copyright of the booklet remains the property of Dr. Nitz and the University of Queensland and should not be reproduced in any form without their express permission.

\* \* \* \* \*

Do not worry about being ignored. Worry about why you are thinking about it, for ignorance will always exist.

When people hurt you over and over, think of them as sandpaper. They scratch and hurt you. But later, you’ll be shining and polished, while they end up useless.



**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
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
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	GILLEN NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

\*\*\*\*\*

**TOWNSVILLE GET-TOGETHER**

The next Townsville get-together will be held on Saturday 23 November. Details in next issue of MessaGes.

\*\*\*\*\*

**MEMBERS' FORUM**

New member, Maureen, tells her story this month:

*'Well, here I am, both surprised and pleased to have myasthenia gravis.*

*This may seem strange, but after being misdiagnosed for over 6 months, steadily losing weight (down to 49kg) and having endured a battery of tests of many of the organ systems of my body, I was referred to a consultant neurologist in Canberra, ACT. It took only a very short time for him to come to a provisional diagnosis of myasthenia gravis and to order a same-day scan of the thymus gland and blood tests, which confirmed the diagnosis.*

*After two weeks there was a pronounced improvement in my condition. It is now six months since that first consultation and it's like Harry Potter magic...clarity of speech and vision and I am able and willing to swallow solid foods. My weight is now 69kg.*

*My long term goal is to return to the golf course once full strength returns to my upper body which, strangely, has been affected more than the lower regions.*

*I am extremely grateful to the Myasthenia Gravis Association of Queensland for the information and support given to me. My contact with the Association came indirectly via a relative who was visiting the Mind and Brain Clinic at Royal Prince Alfred Hospital, Sydney*

*And noticed contact details on the Clinic's Notice Board. Life can be truly stranger than fiction.*

*Maureen'*

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.

\*\*\*\*\*  
**MORE OF BARRY'S LINKS OF INTEREST**

The following links to item of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

Getting diagnosed:

<http://fightmg.blogspot.no/p/getting-diagnosed.html>

\* \* \* \* \*

**AMENDMENT TO MACKAY GET-TOGETHER DATE**

The lunch for Mackay members at the Boomerang Hotel/Motel originally scheduled for Sunday 15 September has been transferred to **Sunday 22 September** at the same venue.

If you have any enquiries regarding this, please contact the Mackay Regional Coordinator, Bill Harris, on 07 49541221.

\* \* \* \* \*

When you are courting a nice girl an hour seems like a second. When you sit on a red-hot cinder a second seems like an hour. That's relativity. *Albert Einstein*

**Agenda for the Annual General Meeting of the Myasthenia Gravis Association of Qld. Inc. to be held on Sunday 15 September 2013 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 CLUB PACIFIC ON 9 SEPTEMBER 2012
5. BUSINESS ARISING FROM THE MINUTES
6. PRESIDENT'S ANNUAL REPORT
7. TREASURER'S REPORT
8. ELECTION OF MANAGEMENT COMMITTEE FOR 2013/2014

**NOMINATIONS:**

<b>PRESIDENT</b>	Anita Jackson
<b>VICE-PRESIDENT</b>	John Noble
<b>SECRETARY</b>	Carol Buchanan
<b>TREASURER</b>	Susan White
<b>COMMITTEE MEMBERS</b>	Shirley Johnston Bill Synnot

9. APPOINTMENT OF AUDITOR  
**Notice of Motion** – That this meeting agrees to the appointment of BDO Australia Ltd. as auditors for the year 2013/2014.
10. BANK AUTHORITY
11. GENERAL BUSINESS
12. GUEST SPEAKER – Dr. Shaun Pandy – Health in Retirement
13. CLOSE

\* \* \* \* \*

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

**IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME**

It's that time of the year again when Membership Subscriptions for the financial year 2013/2014 are due. Membership Fees are the same as last year.

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 ring our 1800 802 568 freecall number to enquire.

The majority of members will have 6/13 which tells you (and us) that you are financial to 30 June 2013. Others may show 6/14 or even 6/15 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/12, 6/11, etc. and we continue to send our newsletter to these unfinancial members because we do not know what they want. **If you are unfinancial, please take a minute to ring 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](mailto: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.

.....  
Tear off along this line

**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 \$15**  
**Category E – Supporter \$15**

ADDRESS: \_\_\_\_\_

AND FOR: \_\_\_\_\_ **Category D – Carer \$5**

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.

**2012/2013 ANNUAL GENERAL MEETING**

- WHEN:** Sunday 15 September 2013 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. Shaun Pandy – Health in Retirement
- 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:** Please let her know by **Friday 6 September 2013**

**NOTE:** Dr Shaun Pandy is a Geriatrician and staff Physician at The Prince Charles Hospital, since 2007. He is the Queensland state-wide coordinator of Advanced Training in Geriatric Medicine.

\*\*      \*\*      \*\*      \*\*      \*\*

**FEEDBACK**

Members are encouraged to provide feedback to the committee on anything to do with support for sufferers of myasthenia gravis, such as the content of the newsletter, further information and services that you think we should provide for members, research projects you feel may benefit MG sufferers, etc.

Your comments can be forwarded via email to [info@mgag.org.au](mailto:info@mgag.org.au) or via mail to P.O. Box 16 Mt. Gravatt Qld 4122

\* \* \* \* \*

Recession is when a neighbour loses his job. Depression is when you lose yours.  
*Ronald Reagan*

All generalizations are false, including this one. Mark Twain

There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. There are things we don't know we don't know. *Donald Rumsfeld*

My definition of an intellectual is someone who can listen to the William Tell Overture without thinking of the Lone Ranger. *Billy Connolly*

Older people shouldn't eat health food - they need all the preservatives they can get. *Robert Orben*