



# MessaGes

Myasthenia Gravis Association of Queensland Inc



## JUNE 2007

Myasthenia Gravis Assocn 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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### PRESIDENT'S REPORT

Hi everyone.

I hope everyone sent in their nominations for the committee for the year 2007/2008.

Don't forget the General Meeting on 17<sup>th</sup> June - the more the merrier. It will be a good time to catch up with new and old members and have a chat over lunch. It is important that we get as many financial members at the meeting so we can validate any resolutions passed. You have until Monday June 11 to let Shirley know if you are coming.

We have another very important meeting on Sunday 26th August - the Annual General Meeting, of which there is more detail in this issue of MessaGes. Please mark this day in your diary and come along to welcome in your new committee.

Don't forget to send items in to the Members Forum and also let us know of any interesting experiences you may have had, whether they may be associated with your MG or not.

Last, but by no means least, I am pleased to announce that Queensland Health have agreed to continue their annual grant to our association until June 2010. More on this in my Annual Report to be presented at the AGM.

That's all for this month.

Until next month keep smiling

Cheers,

*Dennis*

**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.

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 – QUEENSLAND REGIONAL COORDINATORS**

HANNA	4054 4538	FAR NORTH QLD
DENNIS	4774 0029	TOWNSVILLE
OWEN / GWEN	4954 5353	MACKAY
JOAN / HAROLD	4928 1438	ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE
		SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
SHARON	4151 7661	BUNDABERG/WIDE BAY
DARLING DOWNS	VACANT	

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**Future Planned Activities (Provisional)**

Sunday June 17	General Meeting
Sunday Aug 26	Annual General Meeting
Sunday Dec 9	Christmas function

Venues and details for the above functions will be advised closer to the dates.

The Management Committee meets on the second Saturday of each month (except January) and all members are invited to attend. If you wish to attend any of these meetings, please contact Shirley on the 1800 number to find out the time and place of the relevant meeting.

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**KITCHEN SIGNS**

So this isn't Home Sweet Home ... Adjust!

I clean house every other day. Today is the other day.



## **ANNUAL GENERAL MEETING**

Members are invited to attend the Annual General Meeting of the Association to be held on Sunday 26 August 2007 at a venue yet to be determined. The AGM proceedings will commence at 10:30am. After the various reports have been presented, the composition of the Management Committee for 2007/8 will be announced. This year our regional co-ordinators have been invited, so it will be a great opportunity to meet with them and find out more about our regional members.

Full details of the venue and other arrangements will be published in the July issue of MessaGes.

We look forward to a great roll up and know you will have a great day out.

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### **MGAQ Web Site Update**

The Management Committee is currently in the process in arranging for our current Internet web site to be re-designed to make it more appealing and interesting to visitors.

Our site ([www.mg-qld.gil.com.au](http://www.mg-qld.gil.com.au)) is a static page and contains only limited information. What we propose to do is:

- provide links to archived newsletters with a selection page;
- have links to other interesting MG sites;
- provide a general information page;
- have a contacts page from where you will be able to email directly to the association.

If you have any ideas on what else we should provide on our web site please let the Secretary know.

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### **Life with Gravis...**

*The following article was published in the Spring 2007 edition of the MGA News (UK) and is dated February 2007.*

At two o'clock in the morning there was a polite knock on my bedroom door and Mrs Gravis, accompanied by three firemen, entered. No, I was not on some exotic, illegal substance; the firemen from our local station had come to put me on oxygen pending the arrival of the ambulance. They now have a trained paramedic and turn out to urgent calls where the ambulance, because of the rural area in which we live, may take time getting to a call.

Over Christmas and the New Year I had contracted what turned out to be a nasty chest infection. I thought that I was getting over it, but as Mrs Gravis is ever ready to remind me, I am always too optimistic and the MG flared up to emphasise the fact. It rapidly started to affect my respiratory muscles and I became short of breath. Mrs Gravis phoned the Neuro Centre who care for me, but there was 'no room at the Inn'. Something to do with bed closures resulting from improvements in the NHS. Mrs Gravis was advised to use the GP Out-of-Hours Service which she did. I must confess to having had reservations about our GP Out-of-Hours Service, but I have to give them full marks for the way that they responded. Mrs Gravis explained that I had MG and was immediately asked all the right questions, right down to what my vital capacity was. This is the amount of air

that you can draw into your lungs, the lower the reading the more compromised the patient's breathing has become. It is measured using a gizmo called a spirometer. The Gravis household does not have one, so that question had to go unanswered. Mrs Gravis was told that an ambulance was on its way and to please unlock the door and put on the outside light. As she was doing this, much to her surprise, the Fire Engine arrived with the paramedic and the oxygen. Ten minutes later the ambulance arrived. Helped by the firemen, the ambulance crew soon had me on the trolley, down our long garden path and into the ambulance. Twenty minutes later, I was being assessed in the A and E department of our local hospital. All my vital signs were checked and I was transferred to the medical admissions ward where I was monitored until the next morning. I was dozing quietly when I heard my name called. I looked up to find that among the consultants doing a ward round was a familiar face, the respiratory consultant who manages my sleep apnoea and had arranged for me to have a CPAP; he is also well versed in MG. Before I knew what had happened he had taken charge of me and I was on his ward being sorted out. The chest infection stood no chance now that he was on the job; the MG was going to take longer. Being on a medical ward was a new experience for me; all my other hospital stays have been on neurology wards. They don't see many myasthenics and everyone wanted to know more, so I asked Mrs Gravis to get some Volume 5's from MGA HQ and put them on my bedside locker. When anyone showed interest I gave them a copy. The registrar put a copy with my notes as a reference. She was another friendly face, familiar with my history; she had been an SHO in the Neuro Centre which sorted me out in 2004. Mrs Gravis never ceases to marvel at the way that however often I fall in the manure, I seem to come out smelling of roses. Regular readers of my adventures will know that I always make a point of having copies of Volume 5 with me when being assessed or looked after by health professionals. The important thing is not to push it; leave them where they can be seen and let them ask for a copy. When I was discharged, I left the remaining copies with the Ward Sister, who seemed very pleased with them. When I went back for a follow-up clinic, I paid a visit to the ward and left some copies of the Winter MGA News. I am home again, breathing well and slowly getting on top of the MG. Before anyone complains that I am writing a horror story, let me repeat what a consultant told me. The majority of myasthenics are well controlled and will never experience the kind of relapses that I seem to experience. As Mrs Gravis will have it, I seem to attract these kind of adventures; if it is going to happen, it will happen to me. Perhaps she is right, but it has given me a wonderful knowledge of MG and the various ways of managing it.

**NOTE:** The Volume 5 referred to in the above article is the Information Pack for Medical Professionals published by the Myasthenia Gravis Association of the UK. It may be viewed at their web site [www.mgauk.org](http://www.mgauk.org)

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### Last Will & Testament

Jack has died. His lawyer is standing before the family and reads out Jack's Last Will and Testament.

"To my dear wife Esther, I leave the house, 50 acres of land, and 1 million dollars.

To my son Barry, I leave my Big Lexus and the Jaguar.

To my daughter Suzy, I leave my yacht and \$250,000.

And to my brother-in-law Jeff, who always insisted that health is better than wealth, I leave my sun lamp."

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## KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

New format this month – a multiple choice quiz (at least you have a 1 in 3 chance of getting them right). Please let the editor know if you prefer this format or one of the previous styles.

1. What nationality was Felix Mendelssohn?  
(a) Swiss (b) Austrian (c) German
2. Which movie was the 1986 sequel to The Hustler?  
(a) The Colour of Money (b) The Colour Purple (c) Three Colours Blue
3. Which is the USA's Peninsula State?  
(a) California (b) Louisiana (c) Florida
4. What US general was known as "Old Blood and Guts"?  
(a) Patton (b) Eisenhower (c) MacArthur
5. What artificial organ was first developed by Gordon Murray?  
(a) Heart (b) Kidney (c) Spleen
6. In which sport are squat and benchpress?  
(a) Weightlifting (b) Athletics (c) Gymnastics
7. Which religious leader was born in approx 563BC?  
(a) Buddha (b) Confucius (c) Lao-tse
8. What material forms a Sumo Wrestling ring?  
(a) Clay (b) Sand (c) Salt
9. What nationality was tennis star Maria Bueno?  
(a) Mexican (b) Argentinian (c) Brazilian
10. What animals call an apiary home?  
(a) Ants (b) Aphids (c) Bees
11. Which US president repealed Prohibition?  
(a) Roosevelt (b) Truman (c) Eisenhower
12. What would a Tibetan monk have in his hand if he was playing with his dung?  
(a) A trumpet (b) A prayer wheel (c) A Buddhist rosary
13. What was Rodgers and Hammerstein's first co-written musical?  
(a) Carousel (b) Allegro (c) Oklahoma
14. What musical is set in Catfish Row?  
(a) West Side Story (b) Porgy and Bess (c) Cats
15. Which film's funeral scene involved 300,000 extras?  
(a) Cleopatra (b) Gandhi (c) Amadeus
16. The Nullabor Plain is so named because it has?  
(a) no plants (b) no water (c) no trees
17. Who was the German counterpart of Tokyo Rose?  
(a) Berlin Betty (b) Axis Sally (c) Nazi Nancy
18. What do you call the offspring of a male tiger and a female lion?  
(a) Tiglon (b) Tigron (c) Tiglion
19. How many times did Jackie Stewart win the World Motor Racing Championship?  
(a) Three (b) One (c) Five
20. Which of the four Presidents carved into Mt Rushmore is wearing glasses?  
(a) Lincoln (b) Washington (c) Roosevelt

**Answers:** 1) c; 2) a; 3) c; 4) a; 5) b; 6) a; 7) a; 8) a; 9) c; 10) c; 11) a; 12) a; 13) c; 14) b; 15) b; 16) c; 17) b; 18) a; 19) a; 20) c.



**REMINDER - IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME**

It's that time of the year again when Membership Subscriptions are due.

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.

The majority of members will have 6/07 which tells you (and us) that you are financial to 30 June 2007. Others may show 6/08 or even 6/09 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/05, 6/04, 6/03, or 6/02 and we continue to send our newsletter and other matter 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.

Please help to make our Treasurer happy - he loves writing receipts.

.....  
Tear off along this line

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.

For those of you who have already renewed your membership, we thank you, especially those who forwarded a donation with their subscription.

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