



Messages

Myasthenia Gravis Association of Queensland Inc



MAY 2008

Myasthenia Gravis Asscn 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

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Neurologist
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PRESIDENT'S REPORT

Hi Everyone

This is my first attempt at the President's report for the Newsletter. The committee has accepted Dennis Jennings resignation with mixed emotions. We will miss him for his humour and also for the work that he did for the Association as a member and on the Committee. Hoping to see him at the AGM. I am acting as President until the AGM when we will have a new President.

Don't forget to send in your nomination form as we could do with some new blood on the Committee. It only is about 3 hours once a month at the Committee meetings and maybe some follow up work between the meetings.

The picnic at North Pine Dam was a very successful and enjoyable day with 26 people present and lots of good humour, food and company.

We met the Co-ordinator of the SA MG association last week so we are keeping the communication lines open to every one. If you ever go to a different area in Australia for holidays please see if there is a member of the Association in that area and try to catch up with them; you never know you may become life long friends.

I am off on holidays next week to Canada and Alaska and the USA and I am hoping to see lots of snow and glorious scenery. I will try and visit an Association some where over there also.

Hoping you are all well and will catch up with you at the AGM.

Regards

Anita

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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 8287	CANBERRA ACT
PATRICIA	02 4973 2532	MORRISET NSW
JEAN	02 4937 3110	KURRI KURRI NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
ERMELINDA	02 4392 7925	LAKE HAVEN NSW
FRANK	02 6767 1031	TAMWORTH NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
CANDY	02 6847 3732	WARREN NSW
PENNY	02 4868 2213	MOSS VALE NSW
NADINE	03 5766 2848	VICTORIA
MIKE	03 5743 1106	YARRAWONGA VIC
CORAL	03 5865 1378	KATAMATITE VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
ROLAND	03 9702 5107	BERWICK VIC
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
ALISON	03 6261 2258	MAGRA TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

WEB-Site Update

Our redesigned website is now up and running, and is available for viewing at www.mg-qld.gil.com.au. You can now download current and previous issues of MessaGes and we now have links to other MG sites. Also you can email us direct from the website.

Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

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Shirley's Recipe

CARROT CAKE

(This recipe was prompted by a yummy carrot cake a member brought for us all to share at the picnic on 13/04/2008)

Ingredients:

1 cup Self raising flour	1 teaspoon bicarbonate soda
½ teaspoon ground cinnamon	½ teaspoon ground cloves
1 cup firmly packed brown sugar	1 ½ cups finely grated carrot
½ cup sultanas	½ cup finely chopped glace ginger
½ cup finely chopped walnuts	⅔ cup vegetable oil
2 eggs lightly beaten	

Method:

1. Grease a 15cm x 25cm loaf pan, line base with paper, grease paper.
2. Sift flour bicarb soda and spices into bowl. Stir in sugar, carrot, sultanas, ginger and nuts.
3. Stir in combined oil and eggs. Beat with electric mixer on medium speed for 5 minutes.
4. Pour into prepared pan. Bake in a moderately slow oven for about 1 hour, or until cooked when tested. Stand 5 minutes and turn onto wire rack to cool.
5. Spread cold cake with frosting. Decorate with extra chopped walnuts, if desired.

Cream Cheese Frosting:

Ingredients:

60g packaged cream cheese	1 teaspoon grated lemon rind
30g soft butter	1 ½ cups icing sugar mixture

Method:

1. Beat softened cheese, rind and butter in small bowl with electric mixer until smooth.
2. Beat in sifted icing sugar.

Notes: Recipe can be made 2 days ahead. Suitable to freeze. Not suitable to microwave

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More on MuSK MG

The following email was received from Dr Stephen Reddel, Concord Hospital, Sydney, in response to the article on MuSK anti-bodies in last month's MessaGes:

Many thanks for the MessaGes newsletter that the Queensland association puts out – it's always heartening to see people working together to help themselves.

I am emailing about the section on MuSK antibodies and in particular the subsection on "more questions than answers". At the University of Sydney we have been working on the issue of how MuSK antibodies cause myasthenia gravis for the last three years, because as you correctly point out the mechanism has not previously been demonstrated, and despite the clear association between MuSK antibodies and myasthenia gravis some scientists had doubted they actually caused the disease. We now have in press the first paper to demonstrate that they do indeed cause disease and how they do it. For those who can cope with "scientific" rather than English, it can be accessed here: <http://www.ncbi.nlm.nih.gov/pubmed/18384168> with most libraries able to access a full copy for those interested in the details. I should add that a couple of Queenslanders have been kind enough to help the research with their plasma samples, and although I can't name them for obvious reasons, if they do read this, then thank you.

Future Planned Activities

Friday 6 June 2008	Close of nominations for Management Committee
Sunday 15 June 2008	Get together – Games Day (see details this issue)
Sunday 31 August 2008	Annual General Meeting – Guest Speaker Neurologist Rob Henderson
Sunday 7 December 2008	Christmas Lunch

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.

MEMBERS FORUM

There were no contributions for the members Forum this month.

The following obituary was first published in the *Los Angeles Times* and then in *The Age* newspaper on April 12 2008. Thanks to Ruth from Melbourne for telling us about it.

DEMYSTIFIED RARE MEDICAL COMPLAINT

DAVID GROB
NEUROMUSCULAR EXPERT
23-2-1919 - 23-3-2008

By DELTHIA RICKS

Dr David Grob, a pioneer in the study and treatment of neuromuscular disorders and the physician-scientist who helped develop an effective therapy for the rare condition known as myasthenia gravis, has died from infection caused by contaminated medical equipment at a Long Island hospital, New York. He was 89.

In the late 1940's, myasthenia gravis was a mystifying condition, typified by progressive and insidious muscle weakness. Affected patients cannot easily control their eyelids and have trouble chewing, talking, swallowing and breathing.

While on staff at the John Hopkins medical institutes in Baltimore, Grob probed the condition and discovered that it is caused by faulty communication between nerves and muscles.

In 1948, he and his colleagues developed a treatment – the use of cholinesterase, a vital biochemical that allows nerves and muscles to “talk” to each other. Now, largely because of Grob's work, doctors recognize the disorder as both a neuromuscular condition and an autoimmune disease, a condition in which the body's own turncoat constituents launch the attack.

From 1958 to 1989, Grob chaired the department of medicine at Maimonides, and from 1989 to 2006 he was medical director of the Maimonides research Foundation in Brooklyn.

Grob was born in New York City and was so precocious that he finished high school at the age of 14, and graduated from the City College of New York at 18. He received his medical degree from

John Hopkins University in 1942, then volunteered as a battalion surgeon in World War II and was awarded a Bronze Star.

His wife, Elizabeth, died in 1998. He is survived by a son, two daughters and four grandchildren.

FAMILY FUN DAY OUT - GAMES DAY

- When:** Sunday 15 June 2008 at 10am for 10:30 start
- Where:** Carindale Hotel
- What do I need to bring:** Yourself, family, friends, whomever you wish to bring. Lunch is available for purchase from a varied menu with prices starting at \$12. Tea and coffee will be provided.
- What's on:** Bingo, Trivia, Board Games or any other you can think of. Please let Shirley know on 1800 802 568 if you have any ideas for games. Prizes will be given.
- How much:** A gold coin donation to offset prizes, plus the cost of your lunch.
- RSVP:** Monday June 9 2008 on 1800 802 568.
- How do I get there:** Below is a 'mud' map of where the hotel is:
(UBD Map 181 Reference N5)



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. David Ben Gurion became Prime Minister of which country in 1948?
2. How many stars appear on the New Zealand flag?
3. 'Lutz' is a term used in which sport?
4. What is the last letter in the Greek alphabet?
5. In which Australian state or territory is Lunawannah?
6. Which wedding anniversary does china celebrate?
7. What is the chemical symbol for Iron?
8. The musical 'West Side Story' is based on which Shakespeare play?
9. Who was the first woman to fly solo from England to Australia?
10. Who was the second president of the USA?
11. How many pieces are there in a chess game?
12. Jupiter and Uranus are on either side of which planet?
13. How many sides does a nonagon have?
14. Which Argentine cruiser was sunk by a British submarine during the Falklands War?
15. What is the capital of Finland?
16. Which newspaper did 'Superman' work for?
17. What is the currency of Kiribati?
18. What was the name of Popeye's dog?
19. Which mountain overlooks the city of Cape Town?
20. What is the capital of the USA state of South Dakota?

Answers: 1) Israel; 2) 4; 3) Skating; 4) Omega; 5) Tasmania; 6) Twentieth; 7) Fe; 8) Romeo & Juliet; 9) Amy Johnson; 10) John Adams; 11) 32; 12) Saturn; 13) 9; 14) The General Belgrado; 15) Helsinki; 16) Daily Planet; 17) Australian Dollar; 18) Jeep; 19) Table Mountain; 20) Pierre.

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2008/2009 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 6/08 which tells you (and us) that you are financial to 30 June 2008. Others may show 6/09 or even 6/10 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/07, 6/06, 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.

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.

*If you lend someone \$20 and never see that person again,
It was probably worth it.*

*Birthdays are good for you.
The more you have, the longer you live.*