



Messages

Myasthenia Gravis Association of Queensland Inc

AUGUST 2009



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

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PRESIDENT'S REPORT

Thanks to the contributors to last month's Members' Forum. All articles were very interesting and, in their way, helped a variety of myasthenics. I had a lot of very positive feedback on our freecall line and for that I thank you again.

Please keep giving your experiences with MG to the Members' Forum – what you do not think is of interest can be a help to someone else.

The Annual General Meeting on Sunday 13 September is the next important meeting and it would be appreciated if as many members as possible could attend. We are working feverishly in an attempt to obtain a Guest Speaker, and hopefully will be successful in doing so. The details of the AGM are on page 8 of this newsletter, and the Agenda is on page 7. The AGM is always a great excuse for a get-together.

The Association has very recently received an extremely generous bequest from the estate of the late Des Zeimer (late of Bundaberg) and the money has been placed on Term Deposit until we work out the most judicious way in which to use it for the benefit of our members. We sincerely thank Des for providing the bequest in his will.

Thank you once again Gordon for answering the 1800 phone whilst Nev and I had a few days relaxation at beautiful Caloundra.

That's all for now,

Shirley

PS: Have you noticed that the people who are late are often so much jollier than those who have been waiting for them

Supported by



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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
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
DORA	03 5821 4191	SHEPPARTON VIC
BARBARA	03 9776 4985	SEAFORD VIC
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

WEB-Site Update

PLEASE NOTE: As our email address was compromised by an unscrupulous person who 'kidnapped' it to send 'spam' emails, we have had to change it to mgag@gil.com.au

Our website address is now www.mgag.org.au. Please change your bookmark to reflect this.

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*Always keep your words soft and sweet,
Just in case you have to eat them.*

Future Planned Activities

Sunday September 13 2009 Annual General Meeting, Carina Leagues Club
Creek Road Carina (refer map on page 8)

Sunday 6 December 2009 Christmas Function, Sunshine Coast

Venues and details of the above activities will be provided 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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Swine Flu

The following information is published on the website of the Myasthenia Gravis Foundation of America:

Patients concerned about infection with Swine Flu should contact their primary care doctor for advice regarding potential treatment. There are no reports of oseltamivir (Tamiflu) and zanamivir (Relenza) worsening myasthenia gravis, but that does not necessarily guarantee absolute safety. Presently, there is limited information regarding potential drug interactions with these medications.

Shirley's Recipe

BEEF AND BROCCOLI STIR FRY

(from quickfreerecipes.com)

Ingredients:

350g sirloin or rump steak (cut into short strips)
400g fresh broccoli
4 spring onions (finely sliced)
2 cloves of garlic (chopped finely)
1 red pepper (sliced)
2tbsp sunflower oil
3tbsp light soy sauce
3tbsp oyster sauce
Egg noodles or rice to serve

Method:

1. Boil water in a large pan, add broccoli and simmer for 3 minutes, then drain.
2. Heat oil in a large frying pan or wok. Add steak and stir fry on a high heat for approx 3 minutes. Push steak to the side of the pan/wok, add spring onions, garlic, broccoli and stir fry for 2 minutes.
3. Turn the heat down add the soy and oyster sauce and stir fry for 2 minutes, ensure the steak is well coated. Serve with either egg noodles or rice. Quick yet tasty.

(Serves 4)

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Two fish swim into a concrete wall. The one turns to the other and says, 'Dam!'

Two Eskimos sitting in a kayak were chilly, so they lit a fire in the craft. Unsurprisingly it sank, proving once again that you can't have your kayak and heat it too.

Two cows are standing next to each other in a field. Daisy says to Dolly, 'I was artificially inseminated this morning.' 'I don't believe you,' says Dolly. 'It's true; no bull!' exclaims Daisy.

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Progress in Treating Inherited Myasthenias Dr Dan Lashley, The Oxford Myasthenia Centre

In autumn 2007, Professor David Beeson told you about a new subgroup of these 'congenital myasthenias' caused by inherited faults in a 'new' gene called Dok-7. One reason for separating these subgroups is to match them to the most suitable treatments, as Dan now describes...

I'm delighted to have this chance to give you a progress report. I have been working in David Beeson's lab in Oxford for nearly 3 years now, focussing specially on Congenital Myasthenias Syndromes. It has proven a very challenging and worthwhile experience. One of the most interesting developments here has been the re-emergence of our 'old friend' ephedrine as a useful treatment for some patients. Its use in autoimmune MG dates back as far as the 1930's in medical reports. In fact, it is probably one of the oldest medicines ever used by mankind, being the active ingredient in Ma Huang, a Chinese Medicine preparation used to treat conditions such as asthma and hay fever for over 5000 years. In many ways, ephedrine acts like adrenalin – one of our natural 'fright, flight, fight' hormones, that stimulates the heart and blood vessels. But it also has mild amphetamine-like effects on the brain.

Ephedrine was used in MG from 1929 to improve nerve muscle signaling, thanks to Dr Harriet Edgeworth. You may remember that, whilst taking it for monthly cramps, she noticed – by pure luck – that it also helped her MG. For a time, it became the 'best thing before sliced bread' for many MG patients. But it was soon overtaken by the '-stigmimes' developed by Dr Mary Walker in 1934, and, later on, by Mestinon®. From the 1960s, immunosuppressive drugs such as steroids and azathioprine came into use – but they are not suitable for any of the inherited myasthenias. However, specialists in congenital myasthenias have kept ephedrine up their sleeves as another option for cases when the '-stigmimes' fail – or even make things worse (as in the Slow Channel Syndrome). In about a quarter of his panel of congenital myasthenia patients, David Beeson and his team found (in 2007) inherited faults in Dok-7. This protein normally helps to cluster the ACh receptors tightly on the muscle surface just opposite the nerve endings that release ACh to trigger it. John Newsom-Davis, Jackie Palace and David re-assessed all of the newly identified patients in several marathon clinics, partly to tell them about the new discovery; also to form a more complete view of their particular condition. They noticed that their myasthenia particularly affects the muscles around the shoulders and hips, and usually starts at age 2-5 rather than at birth, i.e. after they have learnt to walk.

We soon realised too that many of these patients had not responded to pyrido-stigmine. What's more, several of them had instead been helped by ephedrine. So we next began cautiously offering it to other 'Dok-7 patients'. We made careful records of their strength and stamina before and after treatment – to be sure that any benefits they felt really were due to improvements in their muscle strength rather than just an 'adrenalin rush', for example.

Even hardened cynics in the team were surprised by the success we had in many of the patients. We soon got reports from parents who found themselves in possession of 'a new child'. One had started regular morning sit-ups sessions; another teenager had given up using elbow-crutches for walking and started going for a short jog in the evenings. One young woman was delighted that she could now wear high-heeled shoes for the first time. The facts and figures from the follow-up strength assessments were also very positive, and strongly supported the patients' reports. Interestingly, the benefits tend to build-up over several months, and are not all obvious at first. I'm afraid it's not all good news. A few people can't take ephedrine because it affects their blood pressure. Some notice annoying rather than harmful side-effects when starting it, such as anxiety or sleep troubles which are only to be expected of a 'fright, flight, fight' hormone. Fortunately, they can often be sorted-out with fine-tuning of doses and their timing.

How ephedrine works remains something of a mystery – one we are now trying to puzzle out. We suspect that it binds to receptors for adrenalin on the muscle surface and plugs in to a complex chain of chemical signalling that is involved in keeping the nerve muscle junction together in the right size and shape. We also wonder whether it may help in other similar congenital myasthenias, where there are a few encouraging hints. For the time being, we are using it only in patients with faults in their Dok-7 or cholinesterase ('Col-Q') and one or two other exceptional cases.

NB; we do **not** expect it to come back into use for MG.

The story of ephedrine has been one of the most exciting parts my work here in Oxford; listening to those success stories from the patients will rank amongst my best memories.

(article courtesy of the Summer 2009 edition of MGANews - UK)

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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)

Another Multiple Choice this month

1. What kind of tree is the Burke & Wills 'Dig' tree?
a) River Red Gum b) Iron Bark c) Coolabah
2. Who was the first woman in space?
a) Sally Ride b) Valentina Tereshkova c) Judith Resnick
3. Which of these Australian Prime Ministers did NOT die in office?
a) Joseph Lyons b) Andrew Fisher c) John Curtin
4. Who was the last Australian player to win the amateur Wimbledon singles title?
a) Roy Emerson b) Rod Laver c) John Newcombe
5. What book was banned in London in 1526, Paris in 1538 and in Spain in 1551?
a) The Decameron b) The Faerie Queen c) The Bible
6. Which Marx brother played the piano?
a) Harpo b) Chico c) Groucho
7. Who were the first people to blow their noses into paper tissues?
a) Chinese b) Japanese c) Indians
8. Which US state has the towns of Golf, Bunker and Tee?
a) California b) Florida c) New Hampshire
9. What royal house did Henry VIII belong to?
a) Plantagenet b) Tudor c) Hanover
10. How many people were executed for Abraham Lincoln's assassination?
a) None b) One c) Four
11. Who was the first white explorer to climb Mt Kosciusko?
a) Hamilton Hume b) Turno Gluszyna c) Paul Strzelecki
12. The aardvark is native to which continent?
a) Africa b) Asia c) South America
13. What is the chemical symbol for beryllium?
a) Be b) Bm c) B
14. Juan Peron was President of which South American country?
a) Brazil b) Venezuela c) Argentina
15. Columbia is the capital of which US state?
a) North Carolina b) South Carolina c) Oregon
16. What is the floral emblem of the ACT?
a) Royal Bluebell b) Common Heath c) Golden Wattle
17. Which great Austrian composer who died in poverty in Vienna at age 31 in 1797?
a) Schumann b) Schubert c) Strauss
18. Which US president introduced prohibition?
a) Woodrow Wilson b) William H Taft c) Grover Cleveland
19. Georges Simenon created which fictional detective?
a) Poirot b) Maigret c) Clouseau
20. Easter Island is in which Ocean?
a) Atlantic b) Indian c) Pacific

Answers: 1) C; 2) B; 3) B; 4) C; 5) C; 6) B; 7) B; 8) B; 9) C; 10) C; 11) C; 12) A; 13) A; 14) C; 15) B; 16) A; 17) B; 18) A; 19) B; 20) C.

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*Nobody cares if you can't dance well.
Just get up and dance.*

**Agenda for the Annual General Meeting of the Myasthenia Gravis Association
of Qld Inc Sunday 13 September 2009 at Carina Leagues Club Carina.**

1. OPENING
2. APOLOGIES
3. CONFIRMATION OF QUORUM
4. MINUTES OF THE PREVIOUS AGM HELD AT CARINDALE HOTEL ON 26 AUGUST 2008
5. BUSINESS ARISING FROM THE MINUTES
6. PRESIDENT'S ANNUAL REPORT
7. TREASURER'S REPORT
8. ELECTION OF MANAGEMENT COMMITTEE FOR 2009/2010

NOMINATIONS:

PRESIDENT	Shirley Johnston
VICE-PRESIDENT	Anita Jackson
SECRETARY	Graeme Peters
TREASURER	Susan White
COMMITTEE MEMBERS (3)	Kris Klitgaard John Chester

9. APPOINTMENT OF AUDITOR
10. BANK AUTHORITY and use of COMMON SEAL
11. GENERAL BUSINESS
12. GUEST SPEAKER (if available)
13. CLOSE

ANNUAL GENERAL MEETING - 2008/2009

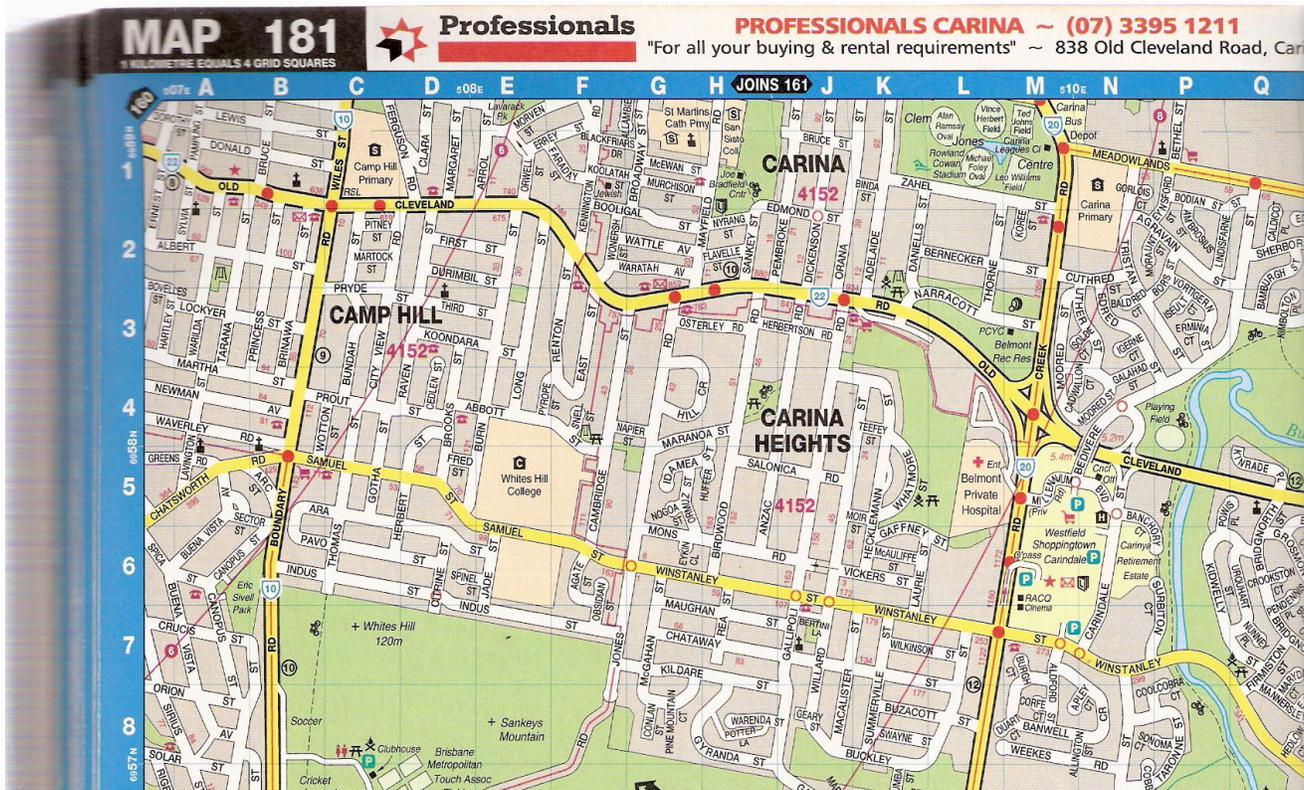
Members are invited to attend the Annual General Meeting of the Association to be held on **Sunday 13 September 2009** at the **Carina Leagues Club** located at **Creek Rd Carina Qld**. (It is part of the Clem Jones Centre and is immediately opposite Meadowlands Rd). The club has excellent facilities and lunch may be purchased after the AGM from a menu which is reasonably priced and comes highly recommended. Car parking is available. We will have access to the venue from 10am, with the AGM proceedings to commence at 10:30 sharp. After the various reports have been presented, the composition of the Management Committee for 2009/10 will be announced. We are attempting to obtain a Guest Speaker. The agenda for the AGM is published in this issue of *MessaGes*.

Following the AGM there will be a short General Meeting for the purpose of setting Subscription Fees for the next year.

To help us and the caterers, please advise of your intention to attend by calling our FREECALL 1800 802 568 as soon as possible, but not later than Monday 7 September 2009. If the phone is unattended, please leave a message advising your name and how many will be attending the AGM.

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

How do I get there: Below is a map of where the venue is:
(UBD Map 181 Reference M1)



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The Plot Thickens

I went to the cemetery yesterday to tidy up some memorials.

I saw 4 politicians walking around carrying a coffin.

Three hours later they were still walking around with the coffin.

Typical, I thought. They've lost the plot!