



Messages

Myasthenia Gravis Association of Queensland Inc

JULY 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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Neurologist
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PRESIDENT'S REPORT

We have now had another great presentation – this time from Dr Stephen Reddel from Concord Hospital in Sydney. The response from members and their families was great, and each person I spoke to after the presentation was writing their questions down to take to their own neurologist. I would like to thank our team of hard workers for making the day go so smoothly.

Looking to the future, some of our current Management Committee members have accepted nomination for positions on the Committee for the 2009/2010 year, but have indicated that this will probably be the last year they will be available. Therefore I urge our members to give consideration to nominating for the Management Committee for the year 2010/2011 when nominations are called next year. If we have no Committee, we can not, of course, continue to function, and if that occurred, it would be a tragedy for all MG sufferers.

Another reminder to mark Sunday 13 September down in your diaries for the Annual General Meeting at Carina Leagues Club.

The Members' Forum this month contains some excellent contributions and we hope to continue to receive many more in the coming months.

Nev and I are looking forward to 25 July when our grand-daughter Kate arrives home from a sixteen months working holiday overseas in the UK and Europe.

That's all for now,

Shirley

PS The brightest smiles can best be seen in the toughest times.

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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 – BRISBANE

JOHN	3269 5066	BRIGHTON
TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JOHN	3899 9387	HAWTHORNE
JESSICA	3369 8315	BARDON
HELEN	3279 3060	JAMBOREE HEIGHTS
POPPY	3288 4484	SPRINGFIELD LAKES
EILEEN	3269 5660	BRIGHTON
PAM / RAY	3801 1335	CORNUBIA
PATRICIA / LES	5464 6719	PURGA IPSWICH
WILMA / NOEL	3807 2391	MT WARREN PARK
LORRAINE	3206 0789	CLEVELAND
GWENDA	3390 2643	CAPALABA
STEFAN	3807 0541	EAGLEBY
DANIELLE	3202 2509	IPSWICH
MIKE	3288 4037	SPRINGFIELD
ROGER	3379 8916	GRACEVILLE
HELEN	3203 0150	DECEPTION BAY
KEVIN	32819225	NEWTOWN
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
MARIE	3300 0053	THE GAP
BILL & JITLADA	0418196707	NORMAN PARK
MELISSA	0411039060	ACACIA RIDGE
CAROL	33901788	CAPALABA
SUSAN	33581056	NEW FARM
KIRSTIE	0408311110	EATONS HILL
GORDON	3398 7891	CARINA

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 mgaq@gil.com.au

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

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The Blonde and the Shepherd

Once upon a time, a blonde became so sick of hearing blonde jokes that she had her hair cut and dyed brown. A few days later, as she was driving around the countryside, she stopped her car to let a flock of sheep pass. Admiring the cute woolly creatures, she said to the shepherd, "If I can guess how many sheep you have, can I take one?" The shepherd, always the gentleman replied, "Of course." The blonde thought for a moment and for no discernible reason said, "352." This being the correct number, the shepherd was, understandably, totally amazed and exclaimed, "You're right! O.K., I'll keep to my end of the deal. Take your pick of my flock." The blonde carefully considered the entire flock and finally picked one that was by far cuter and more playful than any of the others. When she was done, the shepherd turned to her and said, "O.K., now I have a proposition for you. If I can guess your true hair color, can I have my dog back?"

Future Planned Activities

Sunday September 13 2009 Annual General Meeting, Carina Leagues Club
 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

JOY'S STRAWBERRY CHIFFON PIE

Ingredients:

8 inch short crust pastry case	1 tablespoon gelatine
¼ cup cold water	3 eggs
1 cup sugar	1 dessertspoon lemon juice
1 ½ - 2 cups roughly cut strawberries	whipped cream
Whole strawberries to decorate	

Method:

1. Soak gelatine 5 minutes in cold water.
2. Beat egg yolks and half of sugar until creamy. Add lemon juice and strawberries.
3. Stir over boiling water in basin until thickened to consistency of custard.
4. Cool slightly and fold in soaked gelatine. Stir until dissolved.
5. When cooled and beginning to thicken, fold in egg whites which have been beaten stiffly with balance of sugar.
6. Fill pastry case and chill until set. Decorate with whole strawberries and whipped cream.

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ICE FISHING

A blonde wanted to go ice fishing. She'd seen many books on the subject, and finally, after getting all the necessary "tools" together, she made for the nearest frozen lake.

After positioning her comfy stool, she started to make a circular cut in the ice.

Suddenly, from the sky, a voice boomed, "THERE ARE NO FISH UNDER THE ICE." Startled the blonde moved further down the ice, poured a Thermos of cappuccino and began to cut another hole.

Again from the heavens, the voice bellowed, "THERE ARE NO FISH UNDER THE ICE." The blonde, now quite worried, moved down to the opposite end of the ice, set up her stool, and tried again to cut her hole.

The voice came once more, "THERE ARE NO FISH UNDER THE ICE."

She stopped, looked skyward and said, "Is that you Lord?"

The voice replied "No, this is the Ice Rink Manager!!!"

VVVVVVVVVVVVVVVVVVV

ANNUAL GENERAL MEETING - 2008/2009

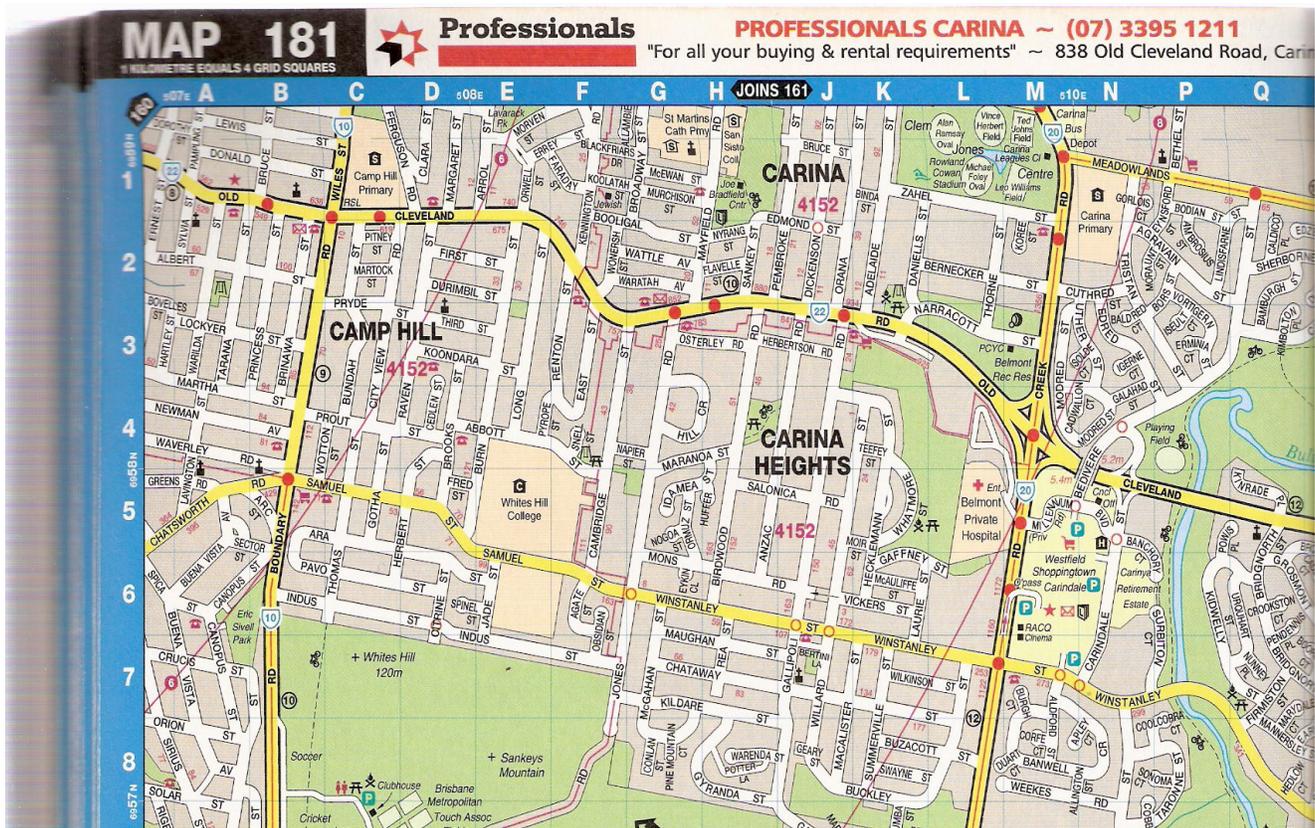
Members are invited to attend the Annual General Meeting of the Association to be held on **Sunday 13 September 2009** at the **Carina Leagues Club** located at **Creek Rd Carina Qld**. (It is part of the Clem Jones Centre). The club has excellent facilities and lunch may be purchased after the AGM from 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 2008/9 will be announced. We are attempting to obtain a Guest Speaker. The agenda for the AGM will be published in the August 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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Blonde's Revenge

WHAT DO BRUNETTES MISS MOST ABOUT A GREAT PARTY?

The invitation

WHAT DO YOU CALL A GOOD LOOKING MAN WITH A BRUNETTE?

A hostage

MEMBERS' FORUM

There are four contributions to the Forum this month.

Judie B from Mackay writes:

'I recently had my six monthly check-up with my Neurologist.

He was very happy with my progress, however he strictly warned against trying to reduce my medications at least for the next two years. I used to have a bad habit of slowly reducing my medications by myself!! That was until he told me the following.

He has found that many of his myasthenic patients are able to reduce their medications (under his guidance) to a very low dosage quite safely. But at a point – and as he says everyone is different – the patient becomes very unstable and often ends up back in hospital. I believe this happened to a person with MG in Townsville.

His experience is showing that the first myasthenic crisis a patient undergoes is quite easy to stabilise, but subsequent ones are VERY difficult to stabilise and in some cases, they never stabilise.

This was scary enough to put me back on the straight and narrow and I will NEVER interfere with my medications again. Luckily I learnt the easy way.'

Judie B also writes:

'Five years ago it was a trip to the dentist that resulted in me finding out that I had myasthenia gravis. Until that point, my symptoms were mild and had the doctors confused.

Just recently I have had to undergo some more dental treatment. I took great pains in explaining (to my new dentist) about MG, but she seemed to have a good understanding.

I had to have a large molar removed and to be on the safe side, she prescribed an antibiotic – no problems.

The following week I had to have some more work done, and another extraction. She once again suggested an antibiotic, but wanted a different one. Things got a bit hectic and I left the surgery without the prescription.

I later phoned the dentist and she said she would write the prescription and leave it for me to pick up – which I did.

It's lucky that I am such an untrusting soul (not really). I specifically asked the pharmacist to check the prescription and, sure enough, it is on the list of drugs to be used with caution on our Myasthenia Gravis Association Medi-Alert Card.

The moral of this story: It's your life and your health, so double check.'

Dora B from Shepparton in Victoria writes:

'I was diagnosed with myasthenia gravis in February this year, after my Eye Specialist referred me to a Neurologist at St Vincent's Hospital in Melbourne, when I was unable to open my eyes.

I had never heard of the disease although I believe I have had it for over 30 years. I suffer with rheumatoid arthritis, having 1 hip and 2 knees replaced, and blamed that for some of my problems. After treatment at St Vincent's I was excited to be able to walk, talk, swallow, get up from a chair, dress and turn my collar out much easier, and, of course, begin to open my eyes.

I was very well looked after at St Vincent's, and after I came home I felt very lonely. I didn't know a soul with MG and no one I know has ever heard of it. I felt anger and grief for the years my late husband and I lost.

My daughter brought me some information off the Internet and the freecall telephone number to your MG Association. I rang a friendly lady, we had a chat and within the week I had information and a medical guide – thank you Shirley. I would like to thank the Association and its financial supporters for their support, as we haven't any in Victoria. We need the Federal Government to fund a Myasthenia Gravis Awareness Week for all Australia.

Thanking you all,

Sincerely, Dora B'

Kevin of Ipswich replies to Perla's question in the May 2009 issue of MessaGes:

"Hi Perla,

I am sad to hear of the passing of your husband last January.

I too suffer from Myasthenia Gravis (15 years now). Thymectomy 10 years ago, monthly Intragam infusions, daily Mestinon® and Prednisolone, and weekly Methotrexate.

About five years ago I had a forced retirement due to my Myasthenia Gravis. I soon found myself taking medication for sleeping, stress, and anxiety (can't remember all the medication names now). All this medication, mixed with changing emotions and large quantities of alcohol soon found me in hospital for three weeks to 'have a rest'. I didn't know how to eat, or even the names of my two children. My brain had just shut down.

What happened from there was a long hard battle with depression, anxiety and panic attacks. I can't imagine the grief you must be experiencing, but I can feel for some of the other 'tricks your mind is playing on you'.

I had many sessions with psychologists, and eventually found the right medication through using a psychiatrist. I now use Avanza® daily, and Epilim® twice daily (which is a medication for Epilepsy that assists me with mood swings).

It did take a while to get the medications right, and to gain confidence and trust in my specialists, but every day I find it easier to cope.

The psychologists provide the tools, while the psychiatrists provide the medication. They each have a role to play in your recovery, and that is why they are experts in their field. There is no need to battle on alone, and people are always there to help. The best thing you could have ever done, Perla, is to ask for help. Well done!

I hope this helps.

Please feel free to ring me if you wish to discuss further, or just need an ear.

Regards,
Kevin"

NOTE: Members wishing to contact Kevin can obtain contact information from the Secretary on (07) 32884484, or via email at grapop@dodo.com.au

* * *

Please send in contributions to our Members' Forum – it provides an ideal opportunity for members to share their experiences or questions.

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 grapop@dodo.com.au.

Your questions and responses may be anonymous for publication, but we will require your full name and address to be submitted to ensure genuineness. When forwarding a response, please refer to the issue or question raised so that we may correctly associate it to the issue or question.

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.

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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)

Multiple Choice this month

1. What were Calotypes early examples of?
a) Prints b) Posters c) Photographs
2. On which date did man first walk on the moon?
a) 19 July 1969 b) 20 July 1969 c) 21 July 1969
3. What Shakespearean character has a mother called Gertrude?
a) Hamlet b) Othello c) Titus Andronicus
4. Which musical tells of a race to find the fastest engine on the American railroad?
a) Casey Jones b) Starlight Express c) Midnight Express
5. Which musical's story is loosely based on Puccini's Madam Butterfly?
a) The Mikado b) Evita c) Miss Saigon
6. Which island group stretches from the coast of Florida almost to Haiti?
a) The Bahamas b) Leeward Islands c) Windward Islands
7. Which is America's Gem State?
a) Washington b) North Carolina c) Idaho
8. In which country is Condor, the world's highest railway station?
a) Bolivia b) Peru c) Ecuador
9. What is the floral emblem of Tasmania?
a) Flowering Red Gum b) Flowering Blue Gum c) Flowering White Gum
10. The Stanley Cup is played for in which sport?
a) Basketball b) Baseball c) Ice Hockey
11. How long is a cricket pitch?
a) 20 yards b) 22 yards c) 24 yards
12. Where was the Solidarity movement created?
a) Poland b) Romania c) Czechoslovakia
13. What is the chemical symbol for chlorine?
a) Ce b) Ch c) Cl
14. How long is Queensland's coastline?
a) 8800km b) 9800km c) 10800km
15. What percentage of the area of Australia does the ACT comprise?
a) 0.3% b) 0.4% c) 0.5%
16. What country received all the Nobel Prizes awarded for 1976?
a) USSR b) USA c) France
17. What is the airport code for Coolangatta?
a) COO b) OOL c) CGA
18. In what year was John Lennon murdered?
a) 1980 b) 1981 c) 1982
19. What is the capital of the US state of California?
a) Los Angeles b) San Francisco c) Sacramento
20. What is the first letter of the Russian alphabet?
a) A b) G c) K

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

REMINDER - IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2008/2010 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 6/09 which tells you (and us) that you are financial to 30 June 2009. Others may show 6/10 or even 6/11 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/08, 6/07, etc and we continue to send our newsletter to these non-financial members because we do not know what they want. If you are non-financial, 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 - she 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.

Senior Personal Ads
(from Florida and Arizona newspapers)

SERENITY NOW: I am into solitude, long walks, sunrises, the ocean, yoga and meditation. If you are the silent type, let's get together, take our hearing aids out and enjoy quiet times.

WINNING SMILE: Active grandmother with original teeth seeking a dedicated flossier to share rare steaks, corn on the cob and caramel candy.

MEMORIES: I can usually remember Monday through Thursday. If you can remember Friday, Saturday and Sunday, let's put our two heads together

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