



MessaGes

Myasthenia Gravis Association of Queensland Inc



MARCH 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

PO Box 16
MT. GRAVATT QLD 4122
FREE CALL 1800 802 568
ABN 92 055 613 137

E-mail mgqld@gil.com.au

Home page:

www.mg-qld.gil.com.au

COMMITTEE MEMBERS

President

Dennis JENNINGS (Townsville)
Ph: 4774 0029
0402 285520

Vice-president

Anita JACKSON
Ph. 3800 4913

Secretary and Editor

Graeme Peters
Ph. 3288 4484
email: grapop@dodo.com.au

Treasurer

Kris KLITGAARD
Ph/Fax 3890 0115

Information Officer

Shirley JOHNSTON
Ph. 1800 802 568

Committee

John CHESTER
Ph. 3899 9387

Judie BARBOUR
Ph. 0439461288

PATRON

Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Hi Everyone

Our president, Dennis, is currently slowly en route to Victoria and has asked me to give a report on his behalf.

Firstly, I would like to say please join us at the picnic on Sunday 13 April at North Pine Dam (details on page 8 of this newsletter).

It will be good to catch up with our long time members and especially exciting to meet new members. The dam should have a lot more water in it following the recent rain.

Work is progressing on the redesign of our website and hopefully will be available in the next two or three weeks – keep your eye out for it. Part of the redesign will provide for MessaGes to be accessed online, including past issues.

More of your personal stories would be appreciated for the newsletter please, as our members enjoy reading of your experiences.

Also, in a few weeks we will be calling nominations for positions on the Management Committee for the year 2008/2009, so please give some thought to nominating yourself if you would like to contribute to the Association's aims in a more tangible way. In particular I would draw your attention to the urgent call on page 4.

That's all for this month

Till next time

Keep smiling

Bye for now,

Shirley

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
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	

Mackay Regional Coordinator

Following the recent bereavement of her husband and joint Mackay Regional Coordinator, Owen, Gwen Vines has advised of her wish to continue in the Coordinator's role and the Management Committee has agreed to this.

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HELPING TO EDUCATE THE NURSES

Following various experiences of attendance at a hospital, quite a few of our members have commented from time to time on how little some Queensland nurses (and interstate ones, for that matter) appear to know about myasthenia gravis.

As a result, the Association has made every tertiary institution in Queensland which provides Nursing Courses aware of the information packs on MG that we can provide to them, and have suggested that they may want to issue each nursing student with one. We are hopeful that we will be taken up on the offer.

Shirley's Recipe

PECAN MERINGUE

Ingredients:

22 Jatz biscuits, finely crushed	3 egg whites
120g (1 cup) pecan nuts, fairly finely chopped	
Pinch of salt	1 cup caster sugar
2 teaspoons vanilla	

Garnish:

Icing sugar, glazed pecans or walnuts OR
 1 cup whipped cream and 1 Flake chocolate, crumbled

Method:

1. Preheat oven to 170°C.
2. Line the base of a 20cm round cake tin with baking paper (a sponge sandwich tin is ideal), then butter and flour the tin. Tap out excess flour, set aside.
3. Prepare the biscuits and nuts, mix them together and set aside.
4. Put the eggwhites and salt in mixer bowl and whip until foamy, then slowly shake in sugar, a little at a time. Once it's all added, continue to beat until the mixture is stiff and glossy (as though you are making a meringue) – it will take about 5 minutes.
5. With a spatula, swirl in the vanilla, then very gently fold in the Jatz/nut mix only until just combined so the eggwhites do not deflate too much. Scoop into prepared tin and smooth down gently.
6. Bake for about 40 minutes until the top feels crunchy when lightly pressed and the middle seems set. Leave to cool in the tin for about 10 minutes, then carefully loosen around the edges with a spatula and turn out onto a rack. Remove paper and cool completely.
7. When cool, transfer to a serving plate and dust with icing sugar and top with glazed nuts OR top with whipped cream and crumbled Flake.

PS. – If you don't want to eat the cake immediately, put it on a plate, wrap with plastic wrap and store in the fridge for up to 5 days.

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Email copy of MessaGes

MessaGes is currently being delivered by email to those members who requested it.

If you have not yet supplied your email address and would like to receive your MessaGes via email, please advise the editor at grapop@dodo.com.au

For the technophiles among you, MessaGes is produced using MS Office Word 2003.

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Why do banks charge a fee on "insufficient funds" when they know there is not enough money in the account to pay the fee?

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### Future Planned Activities

- Sunday 13 April 2008 Picnic at North Pine Dam
- Sunday 15 June 2008 Get together (probably an indoor games day)
- 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.

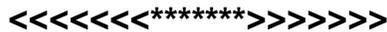
The Management Committee meets on the second Saturday of each month (except) January) and all members are invited to attend. If you wish to attend any of these meetings, please contact Shirley on the 1800 number to find out the time and place of the relevant meeting.



### NOT UNCLE SAM, BUT THE MGAQ NEEDS YOU

As mentioned on several previous occasions, the members of our Management Committee are not getting any younger, so we are continuously looking for new blood to serve on the Committee. Our current Honorary Treasurer for the last eight (8) years, Kris Klitgaard, has expressed a desire to step down at our next AGM. Consequently we are urgently looking for someone who is prepared to assist the Association and take over that function. The main requirement to perform the role is a basic working knowledge of Excel Spreadsheets and/or book-keeping. Kris is prepared to give the incoming Treasurer every assistance during the transition period.

If you are interested please contact us on our Freecall 1800 802 568 number.



### THE FINAL WORD ON NUTRITION

After an exhaustive review of the research literature, here's the final word on nutrition and health:

1. Japanese eat very little fat and suffer fewer heart attacks than us.
2. Mexicans eat a lot of fat and suffer fewer heart attacks than us.
3. Chinese drink very little red wine and suffer fewer heart attacks than us.
4. Italians drink excessive amounts of red wine and suffer fewer heart attacks than us.
5. Germans drink beer and eat lots of sausages and fats and suffer fewer heart attacks than us.

CONCLUSION: Eat and drink what you like. Speaking English is apparently what kills you.



Why is it that no plastic bag will open from the end on your first try ?

## LIFE WITH GRAVIS

*The following article was published in the Summer 2007 edition of MG News, the newsletter of the Myasthenia Gravis Association of the UK, and is reprinted here with their kind permission.*

Following my adventures at the beginning of this year, I soon had a follow-up appointment with the Neurologist. He had already mentioned that he felt that the Cell-Cept which I had been taking since 2004, was not giving me the control that I should have. I was still on far too high a dose of steroids. He suggested that I should change to Methotrexate, which he was sure would in my case be more effective. It is a powerful immuno-suppressant, and is used a lot for rheumatoid arthritis. To start with, Cell-Cept had seemed very promising and unlike Azathioprine, I tolerated it well, but I had to agree with the doctor and we decided that I would make the change. As with all changes of medication, there is a chance of the MG becoming worse whilst one drug fades out and the replacement takes over, so I was admitted to the Neuro ward in order that they could keep an eye on me whilst the change was made. Reporting to the ward I found myself amongst old friends, most of the staff who had cared for me on previous stays were still there. I always find this very comforting, but it does have its drawbacks. The senior sister in charge of the ward has actually known me for a long time. She was junior sister on the ward in the early 1990s when I was admitted for the first time. She knows me too well, so I have to behave. Mrs Gravis of course thinks that this is a good thing. The upside was that, knowing it would keep me quiet, I was allowed to take my laptop in with me. The Cell-Cept must have been doing something for me, because within five days of ceasing to take it, the MG worsened. The methotrexate had not had time to take over, so to help stabilize me it was decided that I should have a course of Ivlg (Intra-venous Intragam). I had a course of it two years ago, it helped, but was not dramatically effective. This time was different, the day after the first session, I began to feel the difference, after two days I began to feel as if I was Lazarus being called forth from the tomb, the difference was that dramatic. In the end I felt as strong as I have done for three or four years. I know that the effects of Ivlg are shortlived, six to eight weeks, but it is giving me time for the methotrexate to take effect. My tame Boffin tells me that different batches of Ivlg seem to have varying degrees of effectiveness, possibly due to the varying make-up of the plasma from different donors. Whatever the reason, I am grateful to them. I have been warned that there is an international shortage of Ivlg and that if I need a further boost, I may have to have a course of plasmapheresis. This involves being connected up to a machine which takes blood from the patient, washes out those hostile MG antibodies and returns the essential bits like the red and white cells. In my mind it is a similar process to kidney dialysis. I had a course of this in the very early days of my MG and it certainly got me back on my feet. The week following the Ivlg treatment, Mrs Gravis was allowed to come and fetch me home. I was still not perfect, a state which Mrs Gravis says is not possible in my case, but I have gradually been picking up. The MG seems to be retreating up through my body and is making a last stand in my mouth. This is frustrating, in that it affects my speech and eating. Mrs Gravis doesn't know whether to be pleased or not. It means that I can't rabbit on, but also means that she can't always understand what I am saying when she needs to communicate. Because of the eating problem, to start with I was on a pureed diet. When I tell people this, they recoil in horror. "How can you bear to eat it", they say. I have learned that they envisage the food all being put into the blender, producing a khaki gruel. It's not like that at all. Both the hospital kitchens and Mrs Gravis puree everything separately and the result, when the different parts are put on the plate, is not unlike nouvelle cuisine. It certainly tastes good. I find that even my pet hate, broccoli, is quite nice, now that's something Mrs Gravis never thought she would hear me say. In order to avoid any infection and there seems to be what the doctors describe as, "There's a lot of it about", going the rounds, I am confined to the great indoors. I do have regular visitors; being on methotrexate, I have a weekly visit from the phlebotomist. As well as taking the blood samples, she brings me up-to-date with what's going on in our community. Over all, the main thing that I have to do is pace myself, something I am not good at. That means stress and stress is bad for MG, oh dear what shall I do!

**May 2007**

**Note:** Many MG patients on Cell-Cept are doing very well. As with all things myasthenic, each person's experience is different.

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## MEMBERS FORUM

There are no contributions for the members Forum this month.

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](mailto: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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## SHARING

An elderly couple walked into McDonalds. The old man placed an order for one hamburger, small French fries and a drink.

He unwrapped the plain hamburger and carefully cut it in half, placing one half in front of his wife.

He then carefully counted out the French fries, dividing them into two piles and neatly placed one pile in front of his wife.

He took a sip of the drink, his wife took a sip and then set the cup down between them. As he began to eat his few bites of hamburger, the people around them were looking over and whispering.

Obviously they were thinking, 'That poor old couple - all they can afford is one meal for the two of them.'

As the man began to eat his fries a young man came to the table and politely offered to buy another meal for the old couple. The old man said, they were just fine - they were used to sharing everything.

People closer to the table noticed the little old lady hadn't eaten a bite. She sat there watching her husband eat and occasionally taking turns sipping the drink.

Again, the young man came over and begged them to let him buy another meal for them. This time the old woman said 'No, thank you, we are used to sharing everything.'

Finally, as the old man finished and was wiping his face neatly with the napkin, the young man again came over to the little old lady who had yet to eat a single bite of food and asked 'What is it you are waiting for?'

She answered:

'THE TEETH.'

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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)

1. Who is Australia's Foreign Minister?
2. What is controlled by a rheostat?
3. When were the Oscars first held? A) 1928 B) 1932 or C) 1936
4. Which was the last state to be admitted to the USA?
5. Which US film actress had a life jacket named after her?
6. Who was Agnes Gonxha Bojaxhiu better known as?
7. Who created the cartoon characters 'Charlie Brown' and 'Snoopy'?
8. In which Australian state is Moe?
9. In which city was Christopher Columbus born?
10. What is the capital of Madagascar?
11. How long is a full size snooker table?
12. What did American Express introduce in 1891?
13. The Maldives are in which ocean?
14. What is a female donkey called?
15. What is a pollywog?
16. Which important gas did Joseph Priestley discover in 1774?
17. From which film & stage show did the song 'If I were a rich man' come?
18. Which movie star was the 'Girl with the Million Dollar Legs'?
19. Which two countries border Panama?
20. Aleksei Leonov was the first person to do what?

**Answers:** 1) Steven Smith; 2) Electric current; 3) A - 1928; 4) Hawaii in August 1959; 5) Mae West; 6) Mother Theresa; 7) Charles Schulz; 8) Victoria; 9) Genoa; 10) Antananarivo; 11) 12 feet; 12) Travellers' cheques; 13) Indian; 14) A jenny; 15) A tadpole; 16) Oxygen; 17) Fiddler on the Roof; 18) Betty Grable; 19) Costa Rica & Colombia; 20) Walk in space.

## PICNIC TIME

Because of the early Easter, this year we will hold our first function of the year, a Picnic in the Park on Sunday April 13.

**WHEN:** Sunday 13 April 2008

**TIME:** 10:30am onwards

**WHERE:** North Pine Dam, Dayboro Rd Petrie

**WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along, and whatever you wish to eat and drink. (and a good mood, of course) The picnic grounds have BBQ's

**HOW DO I GET THERE?**

If coming from the Sunshine Coast:

Take the Anzac Ave off ramp and turn right at the top of the ramp. Proceed along Anzac Ave through Kallangur and until the roundabout at Petrie, then follow **ALL** below.

If coming from Brisbane:

*Off the Bruce Highway*, take the Dohles Rocks Rd exit and swing left at the top of the off ramp. Proceed along Dohles Rocks Rd until the roundabout at Kallangur and take the Anzac Ave exit to the left towards Petrie. Proceed along Anzac Ave until the roundabout at Petrie. Then follow **ALL** below.

*Off Gympie Rd*, take the turn off to Strathpine and follow Gympie Rd through Strathpine until the roundabout at Petrie. Then follow **ALL** below.

**ALL:**

At the Petrie roundabout, take the Dayboro Rd exit. Follow Dayboro Rd past the North Pine Historic Village and Park. Approx 1.4 kilometres past the Historic Village, turn left into Vores Road (small sign on post indicating North Pine Dam) and continue to picnic ground at the dam wall on left, and look for the MG Association sign.

**(UBD Map 87 Ref L19)**

**RSVP**

Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 4 April 2008**

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### MORE OF WHAT I'VE LEARNED

I've learned.... That even when I have pains, I don't have to be one.

I've learned.... That the best classroom in the world is at the feet of an elderly person.

I've learned.... That we should be glad we don't get everything we ask for.

I've learned.... That you can tell a lot about a person by the way he/she handles four things: a rainy day, the elderly, lost luggage, and tangled Christmas tree lights.

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