



Messages

Myasthenia Gravis Association of Queensland Inc



NOVEMBER 2007

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
NATIONAL FREE CALL
1800 802 568
ABN 92 055 613 137

E-mail mgqld@gil.com.au

Home page:
www.mg-qld.qil.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

Committee
Shirley JOHNSTON
Ph. 1800 802 568

John CHESTER
Ph. 3899 9387

Judie BARBOUR
Ph. 0439461288

PATRON
Dr Cecillie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Hi Everyone

I hope you backed the winner of the Melbourne Cup – I didn't, I think I could run faster than the horse I backed!

Our new Management Committee has settled in and we look forward to a very successful year.

Please don't forget the Christmas function on Sunday 9 December at Sharks Club on the Gold Coast – if past Christmas functions are anything to go by, this year's will be a beauty. Full details are on page 8 of this issue.

Our secretary has returned to duty and is ready to get back into the swing of things.

That's all for this month

Till next time

Cheers,
Dennis

PS Don't forget to vote on November 24.

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	MORRISSET 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

Unfortunately there has been a breakdown in negotiations with the person who was commissioned to upgrade the Association's website, and we have been forced to cancel the arrangement.

Our Secretary is currently looking for another company to undertake the work and hopefully we will engage someone very soon.

Shirley's Recipe

BEST-EVER BANANA BREAD

From Sophie's kitchen

Ingredients:

- | | |
|--------------------------|----------------------------|
| 2 Bananas | 2 tablespoons Golden Syrup |
| ¾ cup sugar | 1 Egg |
| 1 cup self-raising flour | Pinch of salt |

Method:

1. Preheat oven to 180°C (160°C fan-forced).
2. Grease and line the base of a loaf pan.
3. In a medium bowl, mash bananas then add golden syrup. Add sugar and stir in.
4. Add egg, sifted flour and salt and lightly mix until combined.
5. Pour into loaf pan, cook for 30 mins or until a skewer inserted into the middle comes out clean.
6. Allow to cool in tin for 10 minutes, then turn onto wire rack to cool.
7. Enjoy it warm straight from the oven or lightly grill it and then enjoy with butter melting on top.

Tip: you can also make variations to this by throwing in a handful of chopped dates just before pouring into tin to bake or adding choc chips to make a choc banana bread.

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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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Future Planned Activities

Sunday Dec 9 2007 Christmas function

Sunday August 31 2008 Annual General Meeting

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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**It's frustrating when you know all the answers,
But nobody bothers to ask you the questions.**

MEMBERS FORUM

There were 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.

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.

Introducing a New Member of the Management Committee

John Chester was appointed to the Management Committee at the Annual General Meeting held on August 26 2007. John has penned the following profile of himself so that our members will know more about him:

I first contracted Myasthenia Gravis at the age of 30 years whilst living in Adelaide. Initially I experienced severe double vision – facial muscle paralysis – loss of energy. Little was known about Myasthenia in the 60's. I was first thought to be suffering from Bell's Palsy or Multiple Sclerosis. I used an eye patch for some time to combat the double vision and physio for facial paralysis. It was several years before the correct diagnosis was made.

We moved to the Gold Coast in 1981. During the years 1988 – 1993, I went into remission. However, after a triple bypass operation in 1993 when morphine was used for post-operative pain, my myasthenia returned.

Currently my main problem is lack of energy, it fluctuates considerably. My specialist does not prescribe drugs at this stage. I take several drugs for my artery problems – three visits by ambulance to St Andrews hospital in the last three years when stents were inserted into a problem artery.

I have been practising mantra meditation for about 16 years and assist in running two groups in the Brisbane area. It is a very simple type of meditation and I do it twice daily for 25 minutes. It helps me in handling stress of body and mind. It is well known that stress is not good for Myasthenia.

My wife, Marlyn, and I have two adult children and two grandsons, three years and one year old. We have lived in the Brisbane area now for six years.

All being well I hope to be able to assist the committee members in at least some small way.

John Chester

Note: A profile of our other new Management Committee member, Judie Barbour, will be published in the December issue of MessaGes.

THE TEN COMMANDMENTS FOR REDUCING STRESS

1. Thou shalt not be perfect, or even try to be.
2. Thou shalt not try to be all things to all people, and spread thyself too thin.
3. Thou shalt leave things undone that ought to be done.
4. Thou shalt not criticise thyself for decisions that were made without the benefit of hindsight.
5. Thou shalt learn to say "No!"
6. Thou shalt schedule time for thyself and thy supportive network.
7. Thou shalt switch off, and do nothing regularly.
8. Thou shalt be boring, untidy, inelegant and unattractive at times.
9. Thou shalt NOT even feel guilty.
10. Especially, thou shalt not be thine own worst enemy, but be thy best friend.

Oooooooooo-o-o-o-o-oooooooooO

Millions of Stars

Sherlock Holmes and Dr Watson went on a camping trip. As they lay down for the night, Holmes said, "Watson, look up into the sky and tell me what you see".

Watson: "I see millions and millions of stars".

Holmes: "And what does that tell you?"

Watson: "Astronomically, it tells me that there are millions of galaxies and potentially billions of planets. Theologically, it tells me that God is great and that we are small and insignificant. Meteorologically, it tells me that we will have a beautiful day tomorrow. What does it tell you, Holmes?"

Holmes: "Somebody stole our tent!"

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Blonde's Revenge

WHAT'S BLACK AND BLUE AND BROWN AND LAYING IN A DITCH?
A brunette who has told too many blonde jokes.

WHY ARE SO MANY BLONDE JOKES ONE-LINERS ?
So brunettes can remember them.

Life with Gravis...

The following article was published in the Autumn 2007 edition of the MGA News (UK) and is dated August 2007.

Mrs Gravis the elder (my late mother) always warned me that my tongue would get me into trouble, this is a view regularly endorsed by Mrs Gravis, but neither of them quite had a medical condition in mind. Regular readers will be aware that over the past twelve months, I have not been one hundred percent, even for a myasthenic. During that time, as well as the dental problems, I have had a sore and blistered tongue; not a pretty sight I can assure you. Tongues normally have a rough surface and are nice and pink. Mine had completely lost its surface and where not blistered, was smooth with cracks and was very painful. When I awoke in the morning it was covered in white patches. My two periods in hospital in January and March of this year restored me to some kind of stability from the neck down, but my mouth, lips and tongue remained weak. Speech and manoeuvring food when chewing were at times impossible. I was silent and on a pureed diet again. Investigations including an attempt to culture a scraping from my tongue were inconclusive. Nothing seemed to have any effect.

Then I was seen by a member of our District Hospital's Oral team, he listened patiently to my tale of woe, took a careful look and told me that no matter that the culture had proved negative, he was sure it was a chronic fungal infection. He explained that this was not uncommon in patients who had been on a high steroid dose for a long time. I was prescribed a 14 day course of antifungal capsules, together with some antifungal lozenges. After about eight days my tongue, although still resembling something from a science fiction horror film, began to feel less uncomfortable. I have instructions to continue using the lozenges, although at a reduced dose, as the fungal infection comes under control.

After two months I am now in the happy position of having a tongue which is almost normal. As the tongue has recovered so the myasthenic weakness has receded and much to Mrs Gravis' delight, I am able to speak for reasonably long periods. I have even enjoyed a tender steak, albeit with plenty of gravy and mashed potato. I am convinced that the fungus was making my MG worse, a bit like tooth abscesses and other infections can do. So I was trapped in a vicious spiral; the worse the fungus, the weaker the muscles, the more steroids I needed, the more fertile the soil for the fungus, so more steroids and, well you get the picture.

As my MG now becomes more controlled, under medical guidance I am slowly reducing my steroid level; the belief is that as this happens, the fungus will now slowly die out. At this point I must say that despite everything, I am still comfortable with using steroids. In treating a condition such as MG there are always trade-offs to be made. For me the benefits of the steroids far out weigh the potential problems. I am now on an extra immunosuppressant and as that cuts in and the fungal infection is cleared, I look forward to being back on a low maintenance dose. In the early part of this year, when my MG was at its worst, my neck muscles were badly affected, I did a 'Tom Dooley'. Older readers and fans of Country and Western may recall the ballad 'Hang down your head Tom Dooley', 1960s vintage I think. As a result I could not keep my head up to use the computer and it does help to be able to look at the screen rather than the keyboard. To overcome this I propped my head up with my right hand, the elbow firmly resting on the desk. Mrs Gravis has often commented on the size of my head and maybe she has a point. I began to find that I was losing manual dexterity and that my little finger tingled a lot of the time. I was always dropping things and my hand didn't always do what I thought it would. I casually mentioned it to the Neurologist, who knew straightaway what the problem was and although not the exact circumstances, said 'you have been resting on that elbow'. The weight of my head had put such pressure on the elbow that it had been distorted and the nerves passing through it had become trapped. I was hooked up to an electromyogram machine and sure enough the readings confirmed the diagnosis. Manipulation and exercises will not free it up and I currently face an operation to release the nerves. I now see why my mother always insisted 'elbows off the table!'

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Practice safe eating -- always use condiments.

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 was the author of the 'Noddy' books?
2. What is the third book of the Bible?
3. Who played the role of Samantha in the original TV series "Bewitched"?
4. What is the capital of the US state of Illinois?
5. What colour does beta carotene turn food?
6. What is the collective noun for a group of crows?
7. What is the hardest substance in the human body?
8. In which Australian state is Pannawonica?
9. Which popular singer died in 1977 after a game of golf?
10. Which country did the United States declare war on in 1898 over Cuba?
11. Who created the fictional detective Sherlock Holmes?
12. Myanmar was formerly known as what?
13. In which ocean is the island of Mauritius?
14. What is "Modulator and Demodulator" more commonly called?
15. The late Tim Gullikson coached which top tennis player?
16. 'Take my Breath Away' is a song featured in which film?
17. What city lies at the northernmost point of the Danube River?
18. Name one of the two moons, or satellites, orbiting Mars
19. What was the name of the ranch in the television show "Bonanza"?
20. Who entered Havana in triumph in January 1959?

Answers: 1) Enid Blyton; 2) Leviticus (1946); 3) Elizabeth Montgomery; 4) Springfield; 5) Orange; 6) A Murder; 7) Tooth enamel; 8) West Australia; 9) Bing Crosby; 10) Spain; 11) Sir Arthur Conan Doyle; 12) Burma; 13) Indian; 14) Modem; 15) Pete Sampras; 16) Top Gun; 17) Regensburg; 18) Phobos or Deimus; 19) The Ponderosa; 20) Fidel Castro

JINGLE BELLS JINGLE BELLS

Ho! Ho! Ho!, it's that time again - time for our annual **Christmas Get-Together**, so come along and have a great day with lots of fun and good company.

WHEN: Sunday 9 December 2007

TIME: 12 Noon

WHERE: Sharks AFC Club, Musgrave St., SOUTHPORT

WHAT WILL IT COST? Meals are priced from \$12.90 each and there is a varied menu.

WHAT DO I NEED TO BRING? Yourself and whomever else you wish to bring along.

HOW DO I GET THERE? From Brisbane, take Exit 62 (Helensvale South) off the M1. Follow that road (Gold Coast Highway or Brisbane Rd) for approx 7 km (or 10th set of traffic lights). Turn right into Olsen Ave (Labrador – Carrara Rd). After about 2km, turn left into Musgrave Ave. You can't miss Sharks. (UBD Gold Coast Map 28 ref L7)

RSVP Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 23 November 2007**

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Lights On

A blonde and a brunette are out driving, and the brunette tells the blonde to look out for cops - especially cops with their lights on. After they've been driving for a while, the brunette asks the blonde if she's seen any cops.

"Yes," says the blonde.

"Are their lights on?"

The blonde has to think for a moment, then says, "Yes. No. Yes. No. Yes. No."

Some Cat Jokes

Did you hear about the cat who swallowed a ball of wool?
She had mittens!

What is the difference between a cat and a comma?
One has the paws before the claws, and the other has the clause before the pause!