



# Messages

Myasthenia Gravis Association of Queensland Inc

**APRIL 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

Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

The picnic at MacIntosh Island, Gold Coast, on 15 March was a roaring success. Weather was fantastic and it was great to see some different faces. Our thanks to John and Marilyn for arranging the spot and for getting there at seven o'clock to ensure that we got a good location, both tables and shelter. Thanks also to John for 'boiling the billy' for a cuppa, although I wasn't going to mention that John ran out of gas for his portable stove, and his better half said, 'I told you it was nearly empty!', but I am sure that you can all relate to something like that happening at sometime. However, we all got our cuppa in the end (after John seconded more family members to assist). Sorry John!!!

As always, thanks to Judie A for the raffle prizes and to Mary for running around to sell the tickets.

Following on from the very successful and much appreciated presentation from Dr Rob Henderson last year, I am pleading with our members to make Dr Stephen Reddel's visit to Brisbane on 14 June next a resounding success.

Dr Reddel is generously donating time from his very busy schedule to come to Brisbane, so let's make him feel that his time has not been wasted. Dr Reddel has consented to answer questions after the presentation, so make sure you have your questions ready.

We need to know the numbers of attendees, so please put the date in your diary and give me a call on 1800 802 568 to let me know if you are coming, and how many in your party. Family and friends are most welcome – a presentation can help them better understand the nature of the beast, myasthenia gravis.

Details of the presentation are in this issue.

That's all for now,

*Shirley*

*PS: If you look like your passport photo, then in all probability you need the journey.*

Supported by



**Queensland Government**  
Queensland Health

**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	CAPALABA
JOHN	3899 9387	BRISBANE
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

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**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](mailto:mgag@gil.com.au)

Our website address is now [www.mgag.org.au](http://www.mgag.org.au). Please change your bookmark to reflect this.

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*Conscience is what hurts when everything else feels good.*

\* \* \* \* \*



## Shirley's Recipe

### **BEEF AND MUSHROOM CASSEROLE**

(serves 6)

#### **Ingredients:**

- |                    |                            |
|--------------------|----------------------------|
| 1.5 kg round steak | 60g butter                 |
| 1 tablespoon oil   | 2 medium onions            |
| 30g butter, extra  | 3 tablespoons flour        |
| 2 beef stock cubes | 1 cup dry red wine         |
| 2 cups water       | 2 tablespoons tomato paste |
| Salt, pepper       | 250g mushrooms             |
| Sour cream         |                            |

#### **Method:**

1. Remove fat and gristle from meat and cut into 2.5cm pieces.
2. Heat butter (60g) and oil in frying pan, add small quantity of meat to pan, brown well on all sides. Remove meat from pan and repeat process until all meat is well browned.
3. Add peeled and sliced onions and sliced mushrooms to pan, sauté gently for about 3 minutes, remove from pan.
4. Add extra butter and flour to pan, stir until flour is golden brown, remove pan from heat.
5. Add wine, water, crumbled stock cubes, tomato paste, salt and pepper, stir until combined. Return pan to heat, stir until sauce boils and thickens.
6. Return meat, onions and mushrooms to pan, bring to boil, reduce heat, simmer covered for 1 ½ hours or until meat is tender.
7. Serve sour cream separately; a spoonful can be stirred into each serving.

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### **DEAF WIFE??**

Frank feared his wife, Peg, wasn't hearing as well as she used to and he thought she might need a hearing aid. Not quite sure how to approach her, he called the family doctor to discuss the problem.

The doctor told him there is a simple informal test that Frank could perform to give doctor a better idea of her hearing loss.

'Here's what to do,' said the doctor. 'Stand about 40 feet away from her, and in a normal conversational speaking tone see if she hears you. If not, go to 30 feet, then 20 feet. And so on until you get a response.'

That evening the wife was in the kitchen cooking dinner and Frank was in the den. He says to himself, 'I'm about 40 feet away, let's see what happens.' Then in a normal tone he asks her, 'Honey, what's for dinner?'

No response.

So he moves closer to the kitchen, about 30 feet away this time, and repeats, 'Peg, what's for dinner?'

Still no response.

Next he moves into the dining room where he is about 20 feet from his wife and asks, 'Honey, what's for dinner?'

Again he gets no response.

So he walks up to the kitchen doorway, about 10 feet away from Peg. 'Honey, what's for dinner' Again there is no response.

So he walks right up behind her. 'Peg, what's for dinner?'

'Frank, for the FIFTH time, CHICKEN!!'

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## Members' Forum

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](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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### MELISSA'S STORY

Hi! My name is Melissa and I was diagnosed with MG the first week of 2004 and have been riding that roller coaster ever since. First signs of the disease for me were whilst trying to type I couldn't get my little fingers to behave. Then while renovating I had difficulty holding up a light fitting for my husband and my arms began to shake – I became weak and could not hold it up. My husband and I joked about me being so weak, but inside I knew something was wrong. My voice became nasally while reading to the kids and one night I almost dropped my son, Hamish, who was almost three, carrying him to bed. I was getting pretty worried and had started to think maybe I had had a stroke at the age of 26. Things progressed quickly within a six week period and I decided to go and see a doctor. The day I went I was having a very bad day and he diagnosed me on the spot and rang a specialist who fitted me in within the week. The day I arrived to see my specialist I was having a good day and I went away thinking she (the specialist) was going to think I was crazy or just pretending. Once I finally had blood taken at the pathology lab, it was only a week or so later my specialist's secretary rang asking me to come in the next day. I knew then that something WAS wrong. The blood test had confirmed I had MG and we did a nerve test and one other test to be sure. By this time, I was 5 or 6 weeks pregnant with my second son. I began to cry – what was this thing and how was it going to affect me and my baby. I remember my doctor holding my hand and telling me, "look at it this way, at least we will be long friends."

No one in my family had heard of it, and both myself and my family were quite scared. I quit work the day of the diagnosis and kept very quiet on the doctor's orders. While attempting to have my Mestinon® script filled while on holidays on the Sunshine Coast, I was expecting to just walk into any chemist to have it filled. Six chemists later still no success so we decided to try the Nambour Hospital. I rang and yes, they had it. After doing the 40 minute drive and arriving to pick it up, they had failed to realise that it was out-of-date! Was this stuff so rare and so unused? We had it ordered in and it arrived the next day. I was 18 weeks pregnant and everyone was happy by this stage – baby's organs had developed enough. I increased the doses as I increased in size. I remember crying after taking my first tablet, not sure of what I was doing to my baby or myself. The delivery date fast approached with no problems. The obstetricians, neurologist and paediatricians conversed with each other to ensure they were happy, which kept me happy. Everybody did their research on what to expect – the worst for me was that the baby could develop MG after birth for anywhere up to 3 months until my antibodies were out of his system. I kept my fingers crossed.

Three days before the C-section, I started my first IVIg. I had it 5 days in total, which included the morning of the delivery and the day after. There were drugs on hand for little Maxwell and myself if either of us needed it during the surgery. We both did not need anything. It was just wonderful – all this preparation had paid off.

I have continued on with Mestinon® and IVIg. The highest dosage of Mestinon® was 5 tablets a day and IVIg fortnightly until the time had come to have my thymus gland removed. I had managed to defer this surgery as long as I could due to the fear, but also the possibility of remission and leading a normal life was too tempting to pass up, despite such surgery.

November 2007 and surgery was done and completed as planned. My parents moved in to help with Max, who was 15 months old, while I was in hospital and at home recovering for the next 7 weeks. Hamish, who was almost 5, went on a holiday to my brother’s in Bathurst for 3 weeks the day after the surgery.

Two weeks after the surgery I was off all medication, I felt on top of the world, it appeared to have worked. It had been worth it. I started lessons with a personal trainer and was working on that pre-baby body at week 8 after the surgery. Then about 11 weeks out my symptoms crept back on me. Training became harder, my muscles would give out on me and I started back on medication. I was devastated.

Hamish started Prep in 2008 and whilst waiting I would talk to other parents coming and going. I met Shirley Johnston, President of MGQA, who was dropping off her grandson. I felt very comfortable with her and we would often have a quick natter in passing. One day she noticed my red and very noticeable scar and asked if I had had heart surgery. I told her I had had my thymus gland removed. She replied, “Not for myasthenia gravis?” I was amazed someone else knew about it. She went on to tell me that she was in remission from MG and that she, too, had had the surgery almost 30 years ago. The world works in mysterious ways – what is the chance of such a thing happening?

Since the beginning of 2008 I have managed another pregnancy, surprise, but nonetheless with the same perfect results – little Samuel born September 2008. I am back to 4 Mestinon® a day and IVIg fortnightly, which is not too bad considering my very busy existence with 3 small boys. I really enjoy the 2 hour sit down while having the IVIg, and it’s been great comparing notes with others with the same condition and plus it almost feels like my timeout. I have also found a group on “Facebook” on the Internet with people from all over the world with MG. We chat amongst ourselves supporting each other, which is nice. I try not to think too much about the future and take every day as it comes. I have come to realise since meeting some others via treatment (IVIg) and the Internet, that I really am very lucky to be able to manage 3 young and very active boys. Things could be worse.

I still have my fingers and toes crossed for remission, despite feeling very blessed!!

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**COMMENTS MADE IN THE YEAR 1955**  
(that’s only 54 years ago)

If cigarettes keep going up in price, I’m going to quit – 25 cents a packet is ridiculous.

It won’t be long before young couples are going to have to hire someone to watch their kids so they can both work.

I read the other day where some scientist thinks it’s possible to put a man on the moon by the end of the century. They even have some fellows they call astronauts preparing for it down in Texas.

I’m afraid the Volkswagen car is going to open the door to a whole lot of foreign business.

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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 the new Queensland Minister for Education?
2. In 1867 the USA purchased what from Russia for \$7.2 million?
3. What is the chemical symbol for Xenon?
4. Who designed the Sydney Opera House?
5. Wake Island is an External Territory of which country?
6. In which year was Melbourne settled?
7. Edmund Barton, Australia's first PM, was a member of which political party?
8. What is the main religion of Sweden?
9. The Australian Broadcasting Commission (ABC) was established in which year?
10. Which city hosted the Olympic Games in 1904?
11. Which UK TV series is set in the fictional place called Walford?
12. Who did Ronald Reagan defeat to win his first US presidency?
13. In which Australian state is Gilgandra?
14. Pure gold is how many carats?
15. What kind of artist does the word 'limner' describe – sculptor, poet or painter?
16. Who was Clint Eastwood's orang-utan buddy?
17. Which Portuguese place was 'visited' by the Virgin Mary in 1917?
18. What Caribbean island was the last Spanish dependency in the western hemisphere?
19. What did the ancient Greeks believe to be a cross between a tiger and a horse?
20. Which world boxing champion had 23 brothers and sisters – Ali, Tyson or Liston?

**Answers:** 1) Geoff Wilson; 2) Alaska; 3) Xe; 4) Jan Utzon; 5) USA; 6) 1835; 7) Protectionist; 8) Evangelical Lutheran; 9) 1932; 10) St Louis (USA); 11) Eastenders; 12) Jimmy Carter; 13) NSW; 14) 24; 15) Painter; 16) Clyde; 17) Fatima; 18) Cuba; 19) Zebra; 20) Sonny Liston.

## PRESENTATION BY DR STEPHEN REDDEL

- WHEN:** Sunday 14 June 2009
- TIME:** 10:15am for 10:30am sharp
- WHERE:** Victoria Park Golf Complex, behind the Proshop (near Car Park C), Herston Avenue, Herston. Car parking is available but is at various distances from the Proshop. However, if someone has difficulty walking, they can be dropped off at the Proshop.
- WHAT WILL IT COST?** Meals are reasonably priced and there is a varied menu.
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more, the merrier.
- HOW DO I GET THERE?** See map below. (UBD Map 18 Reference H5)
- RSVP** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 5 June 2009**
- Please note:** It is important that we commence at 10:30 sharp as we only have access to the venue until 12:30.

