



Messages



Myasthenia Gravis Association of Queensland Inc

NOVEMBER 2008

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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

Another month has passed and soon it will be Christmas. Please let me know on the freecall 1800 802 568 phone number if you are coming to the Christmas get-together on Sunday 7 December. Details are on page 8 of this issue.

Those members who are eligible to receive their DVD of Dr Rob Henderson's presentation to the AGM on 31 August should by now have received their DVD's. If you think you are eligible (i.e. Category 'A' member, current year member, member at 30 June 2008, or Life Member) but have not received your DVD please ring me on the freecall number. Feedback on the DVD via our freecall number or email from our website, would be appreciated.

Nev and I had a brief stay in Rockhampton visiting relatives recently. I had the pleasure of meeting Lorraine, a new member, and had a pleasant chat with her. She is finding myasthenia gravis a little daunting so we now hope that she doesn't feel alone.

Ex-editor, Marie-Louise, is back from her trip to Paris and beyond. We look forward to hearing and reading of her journey.

IMPORTANT: We are looking for a Coordinator for the Townsville Region. If you reside in the Townsville area and you are interested in volunteering for this role, please give me a ring on 1800 802 568. The region has not had a Coordinator since our previous President and Coordinator, Dennis, moved to Victoria. The Coordinator's role is important in that it provides a mechanism for members to keep in touch with each other and thereby provide comfort and support to each other.

Nothing more to report this month.

Hope you are all coping with the heat.

Until next month,

Shirley

PS: Shirley's handy hint for cooking pasta for a pasta salad -
Put your pasta in a bowl, add a little salt, cover with boiling water then put a lid on the container and place in the fridge.

Supported by



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

You can now download current and previous issues of MessaGes and we now have links to other MG sites. Also you can email us directly from the website. Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

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Shirley's Recipe

MASH-TOPPED TOMATO BEEF PIE

Ingredients:

1 tablespoon oil	1 onion, chopped
1 clove garlic, crushed	500g minced beef
410g can crushed tomatoes	2 tablespoons tomato paste
½ cup frozen peas	1 tablespoon cornflour
2 teaspoons beef stock powder	½ cup water

Mash Topping:

1 ½ cups cooked mashed potatoes	1 ½ cups cooked mashed pumpkin
2 tablespoons thickened cream	

Method:

1. Heat oil in pan, add onion and garlic; cook, stirring, until onion is soft.
2. Add mince, cook, stirring, until mince is browned.
3. Stir in undrained crushed tomatoes, paste and peas; simmer, uncovered, for 10 minutes.
4. Stir in blended cornflour, stock powder and water; stir until mixture boils and thickens.
5. Spoon mixture into greased ovenproof dish (5 cup capacity), spread mash topping over top.
6. Bake in moderate oven about 40 minutes or until mash is lightly browned.

Mash Topping:

Sieve potato and pumpkin into bowl; stir in thickened cream.

Serves 4. Can be made a day ahead. Not suitable to freeze. Not suitable to microwave.

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Future Planned Activities

Sunday 7 December 2008

Christmas Lunch

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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MEMBERS FORUM

The following contribution from 'S of Brisbane' is a great example of a person who has myasthenia gravis not allowing the disease to rule her life:

Traveller's Tale

My fiftieth birthday was approaching and I felt quite cheated by the health events of my forties. I wanted to do something adventurous! We read about visiting China and Tibet on a tour that took a doctor with them. I thought this may be the adventure that would suit me and we signed up. It was eleven months before we actually departed and my confidence waned many times.

We flew to Hong Kong a few days before boarding a train to Guangzhou in mainland China. Here we joined our own private train for a journey of a lifetime. There were 64 guests and four tour staff plus four train tour staff and 70 general train staff. During the next two and a half weeks we covered 7,700km! Our early stops included cruising on the Li River, looking at the Reed Flute caves and driving amongst the strange karst rock formations.

From there we progressed to the Stone Forest, the Giant Pandas, Hot Pot Sichuan dinners, markets and ancient temples. Taking a break from the train we cruised the 'Three Gorges' for three spectacular days finishing by descending through five locks each with a 22 metre drop. Back on board the train it was off to

the ancient city of Xian and the Terracotta Warriors. Travelling west to more remote parts of China we saw the Maijishan Grottoes complex, a Mosque and visited a Buddhist temple before leaving our special train to join the high altitude train to Lhasa. (The trip was not at all strenuous to this point as it moved at the pace of the group and apart from a few occasions where it was necessary to climb some stairs the hardest part was getting on and off the trains and buses or the top bunk in the train cabin. I will say though, that it was tiring as the days often began early and involved dietary and cultural challenges.)

This new 'Roof of the World' trainline climbs to 5100 metres above sea level to cross the Tibetan Plateau. Oxygen is available onboard for anyone needing it. I was already feeling the altitude at 3,200 metres in Golmund where we boarded this special train so I was soon given the oxygen. Midway through the journey the stress triggered a flare up in my MG. I was already resting so continued to do so and I increased the frequency of the Mestimon®. In the last hour of the journey we descended into Lhasa at 3,600 metres and I improved. We had three amazing days here visiting with traditional Tibetan farmers, feasting with a nomadic tribe, viewing the summer palace built for the Dalai Lama just three years before he went to India, plus tasting yak and yak milk tea! Yes, despite the MG and the altitude I climbed 460 steps at the 17th century Potala Palace! I was not going to miss out on anything having come so far. I confess to being very relieved to touch down at Shanghai airport and to be at sea level again.

Being in Shanghai felt like being in a Jetson's set with so many roads and ring-roads set high in the sky. With 17 million people it is an enormous and vibrant city. By now we are all tired and I am reduced to taking the easy options each day plus the increased Mestimon®. From here we returned to Australia. Brisbane looked so lovely as we flew in. The sky was blue, the grass so green and the jacarandas made a flush of purple everywhere. People have space to move and cars drive in their own lanes.

I was agreeably surprised by what I learned about the Chinese of today; amazed by some of the scenery; privileged to have ridden on what I believe is the only private train operating in China and blessed to have experienced something of the traditional life of the Tibetan people before their culture is possibly lost. I thank the travel companies for their inventiveness in devising such a tour and for their unflinching service. Dr. Steve was wonderful in making this happen for so many.

Roll on 60!

Editor's note: *The author of this article undergoes plasma exchange monthly, so she is clearly not a 'minor' MG sufferer*

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The following is a report on the MGA UK's biennial Medical Conference held on 12 April 2008 and published in the Summer 2008 edition of MGA News and is reproduced here, in part, with their kind permission.

The biennial MGA Medical Conference 12th April 2008

The morning talks aimed to review the contributions of our late President, Prof John Newsom-Davis and his evolving team and to emphasise that the show goes on – as, indeed, it did in the afternoon workshops – as Nick Willcox describes here.

Prof Angela Vincent was the co-founder (in 1976) of John Newsom-Davis' team (of 25-35 researchers), which is still flourishing, so she was the ideal choice to summarise their work. Her review covered:- John's first evidence (1978) that plasma exchange is good short-term treatment for MG; our research on the thymus and thymomas in MG, and on inherited risk factors; the recent progress on finding antibodies in patients with typical MG who seem negative in the standard blood test (readers of MGA News may remember).

In 1981, John and Dr Bethan Lang had made another big step forward, when they showed that the LEMS is also caused by antibodies, but against the nerve endings instead of the muscle surface. That led on to an excellent blood test, and especially, to more suitable treatments with plasma exchange, steroids and other immunosuppressant drugs. Angela and John did something similar for – "neuro-myo-tonia". Here, other antibodies (against nerve fibres) cause unwanted muscle twitching/ rippling – some seem to affect the brain (if the normal barriers break down), even leading to fits and memory loss. Again, the key finding is that, if recognized in time, these patients may get quite a lot better with plasma exchange and immuno-suppressive treatments, whereas they might previously have been written off as hopeless cases.

An earlier advance had been showing the value of separating MG patients into subgroups, eg with pure eye muscle weakness or with thymomas. That can be even more important in the inherited ('congenital') myasthenias: a good treatment (like Pyridostigmine) for patients with a fault in one gene may even be bad for another. That was described by Dr Jackie Palace, who had been applying Prof David Beeson's discoveries of new targets in further subgroups of these patients. He and John set up a nation-wide diagnostic service to identify their particular genetic faults.

We also had an extremely touching patient's eye view of John. Michael Burrow, himself an Oxford patient for about 20 years had collated appreciations from many others. Some had already had several turns on the 'diagnostic merry-go-round', and were doubly grateful for John's kindly but honest reassurance that:- they did have a real physical illness, it would get better, but it would be "a marathon, not a sprint". Several stressed how carefully he would listen and try to tailor their treatment to suit their particular needs. He earned more thanks by encouraging several women to go ahead and have children, sometimes against previous advice. Very fittingly, Michael gave the last word to Patient JG, who said "I was dreading my next visit to the clinic (last autumn) with no Prof and no Eve and a new location, big changes to absorb. Then I saw Christina and David Hilton-Jones and all seemed as it should be."

That continuity was highlighted by David's own talk about the ongoing work of the Myasthenia Centre. Dr Camilla Buckley then updated us on the Thymectomy Trial, to which John had devoted so much effort after he 'retired'. The first patients have now had their operations and are progressing through their assessments over the following 3 years.

On the Question & Answer panel, we got double mileage both from these speakers and from our old friend Dr Marguerite Hill (now in Swansea) plus Dr Saiju Jacob, the MGA's current Neurology Training Fellow at Oxford. As usual, questions ranged widely and time was short. The more general themes included:-

1. The uneven levels of care for MG around the country.

The Specialist Centres (including Oxford) – and the MGA itself – are doing their best to help:- **(a)** by training young Neurologists – like Dr Jacob – who then go out and spread the gospel in other cities (the most recent disciples are in Glasgow, Belfast and Manchester). They are some of John's proudest products and one that the MGA is determined to perpetuate; **(b)** by 'pump-priming' new Specialist Nurse posts around the country to share the Neurologists' load, thanks to funding from Glaxo Wellcome. Many of you will already know Kate Fraser at the Walton Centre, Liverpool and Christina Goldsworthy (who succeeded Eve Goodger at Oxford at the end of 2006). We suspect it will take a marathon, not a sprint, to achieve full level care across the country.

2. Does MG run in families?

There are inherited risk factors, but, at worst, each one only increases your chances of getting autoimmune MG from about 1 in 10,000 to about 1 in 2,000. Some of these same genes are also involved in other autoimmune diseases like young-onset diabetes and thyroid disease, so these often 'flock together' in the same family, though not always in the same individual. In fact, it is very rare to find two myasthenics in the same family – unlike in the inherited myasthenias, which are completely different (obviously).

3. Why has my MG started getting worse?

NB; It is very typical for MG to start with the eye muscles and only to weaken other muscle groups months later, or even after a year or two. Also, many other autoimmune diseases get better or worse – out of the blue – over weeks or months. We don't know the exact reason(s), but the immune system has so many checks and balances that it is easy to imagine the scales getting tipped purely by chance.

4. Is stress a factor in MG?

There is no clear evidence that it actually causes MG, though it is very natural to blame it for any change in health. More likely, over-activity and fatigue can make people more aware of an underlying weakness that they might otherwise ignore.

5. Is it common for MG to get worse during an infection?

Yes, that **is** very common – and not only in autoimmune MG: in some small children with inherited myasthenias, these ‘dips’ can demand emergency visits to hospital and mechanical ventilation.

6. Is there any need for regular testing to monitor progress on treatment?

Some Neurologists may like to check EMGs, perhaps to make sure the treatment **is** working: others think that the key factor is how well patients feel / cope with their lives. The antibody test adds very little, even if done carefully side-by-side with previous samples. NB; patients can do DIY monitoring, by recording every 2 - 4 weeks some measure(s) of their own weakest muscle group(s), eg, timing how long they can hold an arm or leg out straight, how fast they can drink a tumbler of water, how long they can count while breathing out (once) after taking a couple of previous very deep breaths (healthy people should get above 60). **NB**; they would need to do that at a standard time of a standard day, eg, just before their Friday evening dose of Pyridostigmine. They could also compare with their personal best after their Pyridostigmine (etc) has worked to the full.

7. How to get referred to suitable experts:-

We heard that, on average, any random GP might see only one MG patient in a whole career, any group practice might have only one on their books, and any Neurologist only about 10. It's a good general rule in medicine to consult people who see your disease **often**. They are the ones who best know the ins and outs of diagnosis, of patient subgroups and of treatments. Our dream is for each region to have an established Neurologist post (or Centre) specialising in nerve/muscle disease, plus a Specialist Nurse. In real life, in far corners of the country, coverage is so thin that patients still need to use far-away Referral Centres, which may involve a lot of travelling and expense, alas. **NB**; if you are not content with your current care, you are entitled to ask for a second opinion; that will be easier if you get your GP on your side.

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JOKE TIME

"OLD" IS WHEN... Your sweetie says, "Let's go upstairs and make love," and you answer, "Pick one, I can't do both!"

"OLD" IS WHEN.... A sexy babe catches your eye and your pacemaker opens the garage door.

"OLD" IS WHEN..... "Getting a little action" means I don't need to take any fibre today.

DON'T MESS WITH OLD PEOPLE

Harold was an old man. He was sick and in hospital. There was one young nurse who just drove him crazy. Every time she came in, she would talk to him like he was a little child. She would say in a patronizing tone of voice, "And how are we doing this morning, or are we ready for a bath, or are we hungry?"

Old Harold had had enough of this particular nurse. One day, Old Harold had breakfast, pulled the juice off the tray, and put it on his bed side stand. He had been given a urine bottle to fill for testing. The juice was apple juice. So .. you know where the juice went!

The nurse came in a little later, picked up the urine bottle and looked at it. "My, but it seems we are a little cloudy today .." At this, Old Harold snatched the bottle out of her hand, popped off the top, and drank it down, saying, "Well, I'll run it through again. Maybe I can filter it better this time."

The nurse fainted ...! Old Harold just smiled!

Moral of the story – **DON'T MESS WITH OLD PEOPLE!!!!**

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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. Which of the 4 kings in a pack of playing cards holds an axe instead of a sword?
2. How many times has Australia hosted the Commonwealth Games (or its predecessor)?
3. Who is the Queensland Treasurer?
4. What is the capital of Liechtenstein?
5. What is the currency of Portugal?
6. Which horse won the Melbourne Cup in 1930?
7. What was the name of Johnny O'Keefe's backing group?
8. What is the chemical symbol for Antimony?
9. Who starred as the bigot Alf Garnett in the TV show 'Till Death do us Part'?
10. In which Australian state or territory is Renison?
11. Who invented the incandescent light bulb?
12. To which country does Heard Island belong?
13. From which language is the word 'coleslaw' derived?
14. What is the capital of the USA state New Mexico ?
15. Who was Prime Minister of Australia in 1980?
16. What colour is yak's milk?
17. Which team won the 2008 NRL premiership?
18. What is the third letter of the Greek alphabet?
19. Which film won Best Film Oscar in 1950?
20. What is the fear of sharks called?

Answers: 1) King of Diamonds; 2) Four – 1938, 1962, 1982, 2006; 3) Andrew Fraser; 4) Vaduz; 5) Euro; 6) Phar Lap; 7) The DJ's; 8) Sb; 9) Warren Mitchell; 10) Tasmania; 11) Thomas Edison; 12) Australia; 13) Dutch; 14) Santa Fe; 15) Malcolm Fraser; 16) Pink; 17) Manly Sea Eagles; 18) Gamma; 19) All About Eve; 20) Selachophobia

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 7 December 2008

TIME: 11am for 12 Noon

WHERE: Carindale Hotel located at Carindale Rd Carindale Qld. (It is part of the Carindale Shopping Centre complex). Car parking is available in the Shopping Centre

WHAT WILL IT COST? Meals are priced from approx \$12.00 each and there is a varied menu. Raffles will be on sale, including a beautiful hand made cot-sized quilt made by Judi Allison.

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

HOW DO I GET THERE? See mud map below. (UBD Map 181 Reference N5)

RSVP Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 28 November 2008**



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Q. Why are retirees so slow to clean out the attic or garage?

A. They know that as soon as they do, one of their adult kids will want to store stuff there.