



# MessaGes



Myasthenia Gravis Association of Queensland Inc

**DECEMBER 2008**

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**

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

E-mail: [mgqld@gil.com.au](mailto:mgqld@gil.com.au)

Internet: [www.mgaq.org.au](http://www.mgaq.org.au)

### **COMMITTEE MEMBERS**

#### *President*

Shirley JOHNSTON  
Ph. 1800 802 568

#### *Vice-president*

Anita JACKSON  
Ph. 3800 4913

#### *Secretary and Editor*

Graeme Peters  
Ph. 3288 4484  
email: [grapop@dodo.com.au](mailto:grapop@dodo.com.au)

#### *Treasurer*

Susan White  
Ph: 3358 1056

#### *Committee*

Kris KLITGAARD  
Ph. 3890 0115

John CHESTER  
Ph. 3899 9387

Judie BARBOUR  
Ph. 0439461288

#### **PATRON**

Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

Thanks to all the members who gave us such positive feedback after watching the DVD of Dr Rob Henderson's presentation to the AGM.

We have good news for our members in the Townsville Region – in response to our call in the previous issue of MessaGes, Carol Buchanan has offered to be the Coordinator for that region. We welcome her to the role and wish her all the best. As soon as the Christmas – New Year season is over, Carol will contact our members in the Townsville region and arrange a get-together.

The Management Committee made an approach to Dr Stephen Reddel to be guest speaker at our 2009 Annual General Meeting. Dr Reddel is a Staff Specialist Neurologist at Concord Repatriation & General Hospital, Sydney, with special clinics including Neuroimmunology / Myasthenia Gravis, Neuro-Ophthalmology and Neurogenetics. He was previously Fellow in Neurology at the Radcliffe Infirmary, Oxford, UK. Dr Reddel practices as a general neurologist and has particular interests including Neuroimmunology & Myasthenia Gravis, Neuro-ophthalmology, Neuro-genetics and Stroke. Unfortunately the date of the AGM was not compatible with Dr Reddel's very extensive national and international commitments. However we are attempting to organise a suitable date for Dr Reddel to come to Brisbane and give a presentation to our members on his work on MG. We are aiming for a June 2009 date. Again if we are successful in obtaining the services of Dr Reddel, we will make a DVD of his presentation and supply our members with a copy.

The Christmas Get-together was once again a very successful day and congratulations to John 'Lucky' Chester who won the raffle for the beautiful cot quilt made by member Judie Allison.

For those of you who may remember our grandson, Ben, from a tiny tot, he has now graduated from high school and Nev and I had the pleasure of being around when he was preparing for his formal; I must say that he looked very handsome in his black suit and tie.

Another successful year for the Association is coming to a close. Have a great Christmas and a happy, healthy New Year.

Until 2009,

**Shirley**

PS: As is customary, MessaGes will not be published in January and the next issue will be the February one.

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 – QUEENSLAND REGIONAL COORDINATORS**

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 1213	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
VACANT		DARLING DOWNS

**CHAT LIST – QUEENSLAND REGIONAL MEMBERS**

JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
HENRY	4982 6507	BLACKWATER
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
SHIRLEY	4128 3596	HERVEY BAY
SHARON	4151 7661	NORTH BUNDABERG
BARBARA	4124 2312	POINT VERNON
RAY / MARY	5443 8667	MAROOCHYDORE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
JOY	4165 4647	MUNDUBERRA
BILL / COLLEEN	4926 4847	ROCKHAMPTON
TOM / SCOTIA	4693 3730	PITTSWORTH
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
KELLY	4728 4913	AITKENVALE
VALMA	4068 0702	TULLY
PERLA / GEOFF	4939 2724	YEPPON
IAN	4623 5169	YULEBAR
CAROLYN	5472 0386	COOROY
ROBYN	5520 4242	BURLEIGH HEADS
MAUREEN	5572 7993	MERMAID BEACH
HELEN	5445 4853	SUNSHINE COAST
OWEN	4742 1190	CLONCURRY
PATRICIA	5535 0274	BURLEIGH WATERS
AILSA	4055 1303	CAIRNS
JUDIE	0439 461288	AIRLIE BEACH
BARRY	5483 1783	CURRA
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
DONALD	5563 7207	RUNAWAY BAY
RAJKO	5580 6404	OXENFORD
ELIZABETH	4936 2410	GLENLEE

MELISSA	4662 3337	DALBY
TERRY	5494 2470	MALENY
ROBERT	5492 9754	MOOLOOLAH VALLEY
MOYRA	5576 4979	BURLEIGH WATERS
GLORIA	5534 2669	CURRUMBIN
GEOFFREY	5437 3083	PELICAN WATERS
SARA	0422 109492	BLACK RIVER
DENISE	4788 0798	BUSHLAND BEACH
PAMELA	4151 5499	BUNDABERG

\*\*\*\*\*

**WEB-Site Update**

**PLEASE NOTE:** Our website address is now [www.mgaq.org.au](http://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.

\* \* \* \* \*

**As The Years Pass**

It seems to me that they are building staircases steeper than they used to. The risers are higher, or there are more of them or something. At any rate it is getting harder to take two steps at a time. Nowadays, it is all I can do to take one step at a time.

Another thing I've noticed is the small print they are using now. Newspapers are getting further and further away when I hold them, and I have to squint to make them out. The other day I had to back halfway out of a telephone booth in order to read the numbers in the phone book.

It is ridiculous to suggest that a person of my age needs glasses, but the only way I can find out what's going on in the world is to have someone read aloud to me and that's not very satisfactory because people speak in such a low voice these days that I can hardly hear them.

Everything seems farther away than it used to be. It's twice the distance from my house to the station now, and there's a fair sized hill that I've never noticed before. The trains leave sooner too. I've given up running for them because they start faster when I try to catch them.

They don't put the same material into clothes any more either – all my suits have a tendency to shrink, especially around the waist or in the seat of the pants, and the laces they put into shoes these days are much harder to reach.

Even the weather is changing. It's getting colder in winter and the summers are hotter than they used to be. I'd go away if it wasn't so far. Draughts are more severe too – it must be the way they build windows now.

I got to thinking about all this while shaving this morning. I stopped for a moment and looked at my reflection in the mirror. When did they start to use wrinkly glass in mirrors?

**Anon**

\* \* \* \* \*

**Members' Forum**

Disappointingly, there were no contributions to the Members' Forum this month.

Please let us and other members know about your experiences with MG.

## Shirley's Recipe

### BEEF SALAD WITH MACADAMIA DRESSING

#### Ingredients:

½ cos lettuce	1 cup (200g) chopped cooked beef
⅓ cup shredded fresh basil	1 ½ x 250g punnets cherry tomatoes, halved
½ cup macadamias, toasted, chopped	1 red Spanish onion, sliced.

#### Macadamia Dressing:

½ cup macadamias, toasted, chopped	2 cloves garlic, crushed
2 teaspoons brown vinegar	¼ cup lemon juice
⅓ cup water	2 tablespoons olive oil

#### Method:

1. Tear lettuce into bite-sized pieces.
2. Combine with beef, basil, cherry tomatoes, toasted macadamias and onion in a bowl.
3. Just before serving, pour macadamia dressing over top.

#### Macadamia Dressing:

Blend toasted macadamias, garlic, brown vinegar, lemon juice, water and olive oil until smooth.

Serves 4. Best made on day of serving

\*\*\*\*\*AAAAAAAAAAAAAAAAAAAAAAAA\*\*\*\*\*

### Future Planned Activities

Sunday 8 March 2009	Outing, probably picnic at Macintosh Island, Gold Coast
Sunday 14 June 2009	Outing/Function
Sunday September 13 2009	Annual General Meeting, Brisbane
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.

#####

*We thank the MGA UK for their kind permission in allowing us to publish the following article which was published in the Summer 2008 edition of MGNews.*

### Life with Gravis

The little finger of my right hand and the one next to it had been tingling for some time, in fact since the autumn of 2006.

Electro-myogram (EMG) tests were carried out to see what signals were getting to the nerve ends. "What you have is compression of your right median and ulnar nerves", the Neurologist who has the unenviable task of trying to manage my MG said. In layman's language that's trapped nerves in my right elbow. He said he would refer me to a plastic surgeon he knew who would decompress them for me. As I have mentioned before, we decided that the nerves had become impacted when, during a period of severe myasthenic weakness, I had propped my head in my hand, elbow resting on the desk. The weight and continuous pressure had been enough to compress the nerves.

I reported to the ward on a sunny Sunday afternoon, Mrs Gravis advising the staff not to take any nonsense. I suppose that I had the same level of apprehension that any patient facing surgery might experience. In

addition, although now very much on the path to good control of my MG, I am still advised against anything that would involve a general anaesthetic. I need not have worried, everyone was aware of my condition; My Neurologist had discussed me with the Surgeon.

The next morning I had a visitor, it was the anaesthetist who had come to look me over before the operation. She relieved my worries by telling me that the operation would be carried out under a 'local block'. This meant that she would use a local anaesthetic, avoiding the possible complications from a general. The surgeon further boosted my confidence when she did her round and explained what was going to happen. I still have one of my early school reports, in which one master says "he has a very enquiring mind". I am afraid that the passing years and experience have not dulled this lust for knowledge and so I found the whole procedure fascinating. In the anaesthetics room I was greeted by not one, but two anaesthetists. Between them they employed an ultrasound system to locate and systematically deaden each nerve in my arm and hand. They soon wished they had done the same for my tongue. They told me what they were doing and I could watch it all on TV. It took some time, but once they were happy that I could not feel anything and would not suddenly jump off the table in mid operation, I was wheeled into the operating theatre. I was somewhat taken aback by the fact that they were playing the 1812 overture on the theatre's sound system, but this was soon changed for something more relaxing. Once I had been arranged tastefully on the table and my right arm spread out and secured on a side table, they applied a tourniquet just below my shoulder to reduce the bleeding and to keep the anaesthetic in the arm. I have to admit that my enquiring mind did draw the line at watching the surgeon actually cut into my arm. I spent the time chatting to the anaesthetist, who from time to time asked if I could feel anything. When I said no, she said "you are sure you don't mean yes?" I assured her that where pain was concerned I would be very honest, a trait which Mrs Gravis knows well. Apparently the more macho patients are known to say no when in fact they are in agony. I know that I chattered on and am grateful to both surgeon and anaesthetist for putting up with it. I must confess that I did have a peep when the wound was being stitched up. Then the surgeon said, "I am done, the tourniquet can come off". "58 minutes" replied the anaesthetist and off it came. After a period in recovery, where several members of the theatre staff came to see me and place orders for the MGA's Volume 5 (I never miss a chance to spread The Word), I was returned to the ward. Here my arm which was cocooned in a foam sleeve was suspended from a stand beside my bed; this was to reduce the swelling. The next day, after both the surgeon and the anaesthetist had seen me, I was allowed to go home. Of course the arm still had to be kept suspended. I found that the bracket for the vanity mirror in the car was ideal, but what to do when I got home? The answer was my camera tripod. Extended to its fullest height it was just the job, both beside the bed and when sitting in an arm chair. For about 4 weeks, I was of course strictly left handed, and I am normally right handed. It is amazing what you can do lefthanded when you have to, I won't go into the more intimate moments, but I have become fairly ambidextrous. I am still using my pc mouse lefthanded.

The operation has been a success. Two months on, I have full feeling in my right hand and have regained a higher level of dexterity than I had before. The really good news is that although the operation left me a bit weak at the knees, as it would any healthy person, it did not lead to any problems with the MG. In fact I have generally continued to improve control of it. I am confident that given the excellent level of skill of which I had the benefit, Myasthenics have nothing to fear from local anaesthetics. As I am sure readers will appreciate, being in hospital and then one-armed, has rather slowed me down. This has meant that I have not been able to respond to the kind folk who have either written to or emailed me. Now that I am getting back to what passes as normal for me, I will do my best to catch up.

**May 2008**

**Editor's note:** *The Volume 5 referred to in the above article is the 'Information Pack for Medical Professionals' published by the Myasthenia Gravis Association of the UK. It may be viewed at their web site [www.mgauk.org](http://www.mgauk.org)*

\* \* \* \* \*

### **New Bumper Stickers for Seniors**

Adventure before Dementia

It's nice to be here – at my age it's nice to be anywhere

I'm so old I don't buy green bananas

## Some jokes to keep you going over the Festive Season

Texas Three-Kick Rule: A big-city California lawyer went duck hunting in rural Texas. He shot and dropped a bird, but it fell into a farmer's field on the other side of a fence.... As the lawyer climbed over the fence, an elderly farmer drove up on his tractor and asked him what he was doing. The litigator responded, "I shot a duck and it fell into this field, and now I'm going to retrieve it." The old farmer replied, "This is my property, and you are not coming over here." The indignant lawyer said, "I am one of the best trial attorneys in the U.S. and, if you don't let me get that duck, I'll sue you and take everything you own." The old farmer smiled and said, "Apparently, you don't know how we do things in Texas. We settle small disagreements like this with the Texas Three-Kick-Rule." The lawyer asked, "What is the Texas Three-Kick-Rule?." The farmer replied, "Well, first I kick you three times and then you kick me three times, and so on, back and forth, until someone gives up." The attorney quickly thought about the proposed contest and decided that he could easily take the old codger. He agreed to abide by the local custom. The old farmer slowly climbed down from the tractor and walked up to the city feller. His first kick planted the toe of his heavy work boot into the lawyer's groin and dropped him to his knees. His second kick nearly wiped the man's nose off his face. The barrister was flat on this belly when the farmer's third kick to a kidney nearly caused him to give up. The lawyer summoned every bit of his will and managed to get to his feet and said, "OK, you old coot! now, it's my turn." The old farmer smiled and said, "No I give up, you can have the duck."

\* \* \*

Murphy drops some buttered toast on the kitchen floor. It lands butter-side-up. He looks at what he has done in astonishment, for he knows it's a law of nature that buttered toast always falls butter-down. He rushes round to the presbytery to fetch the priest. He tells the priest that he thinks a miracle has happened round at his flat. He won't say what it is but wants Fr Flannagan to see it with his own eyes. He brings Fr Flannagan into the kitchen and asks him what he sees on the floor.

"Well," says the priest, "it's pretty obvious what we have here. Someone dropped some buttered toast, and then for some reason flipped it over so that the butter was on top."

"No, Father, I dropped it and it landed like that."

"Well," Fr Flannagan says, "it's certainly a natural law of the universe that dropped toast never falls butter side up. But it's not for me to say it's a miracle. I'll report the matter to the bishop, and have him send people round, to interview you, take photos, etc."

An investigation of some rigour is conducted, not only by priests of the archdiocese, but by scientists sent from the Curia in Rome. The final ruling is a negative, however. It reads:

"It was certainly an extraordinary event that occurred in Murphy's room, quite outside the normal run of the phenomena. Yet we have to be very cautious before ruling any happening miraculous, ruling out all possible natural explanations. In this case we declared no miracle. For it was possibly the result of Murphy buttering the toast on the wrong side."

\* \* \*

Tightwad Ted was an old man who had worked hard all his life, had saved all his money, but was a real miser when it came to his money. Just before he died, he said to his wife..."When I die, I want you to take all my money and put it in the casket with me. I want to take my money to the afterlife with me." And so he got his wife to promise him, with all of her heart, that when he died, she would put all of the money into the casket with him. Well, he eventually died. He was stretched out in the casket, his wife was sitting there - dressed in black, and her friend was sitting next to her. When they finished the ceremony, and just before the undertakers got ready to close the casket, the wife said, "Wait just a moment!" She had a small metal box with her; she came over with the box and put it in the casket. Then the undertakers locked the casket down and they rolled it away. So her friend said, "Girl, I know you were not fool enough to put all that money in there with your husband." The loyal wife replied, "Listen, I'm a Christian; I cannot go back on my word. I promised him that I was going to put that money into the casket with him." You mean to tell me you put that money in the casket with him!?!?!? I surely did," said the wife. "I got it all together, put it into my account, and wrote him a check.... If he can cash it, he can spend it."

\* \* \*

There are three signs of old age – the first is loss of memory. I forget the other two.

We got married for better or worse – He couldn't do better; I couldn't do any worse.

I'm so old that whenever I eat out they ask for payment in advance.

**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. What is the capital of Burkina Faso?
2. Which three colours appear on the flag of Thailand?
3. Hyenas are native only to Africa – true or false?
4. Who was the first horse to win two Melbourne Cups?
5. What is the chemical name for Quicksilver?
6. Who played Perry Mason in the TV series of the same name?
7. How many times did Sean Connery play James Bond in movies?
8. In Greek mythology who was Ulysses wife?
9. Who is the Federal Shadow Treasurer?
10. In which Australian state or territory is Narbethong?
11. Which country's head of state sits on the 'Chrysanthemum Throne'?
12. Which 17 year old won the Wimbledon Mens Singles Title in 1985?
13. Which country issued the first holographic stamp?
14. Which company pioneered the CD ?
15. What was the name of the first US space shuttle?
16. Which Australian cricketer tried to use an aluminium bat?
17. What is the most common colour of lapis lazuli?
18. What direction was usually at the top of a map when cartographers thought the world was flat?
19. Which Italian city would you visit to stroll on the Via Veneto?
20. What was Kojak's first name?

**Answers:** 1) Ouagadougou; 2) Red, White, Blue; 3) False – also Asia; 4) Archer – 1860 & 1861; 5) Mercury; 6) Raymond Burr; 7) Seven; 8) Penelope; 9) Julie Bishop; 10) Victoria; 11) Japan; 12) Boris Becker; 13) Austria in 1989; 14) Philips; 15) Columbia; 16) Dennis Lillee; 17) Blue; 18) East; 19) Rome; 20) Theo



*The President and  
Management Committee  
would like to wish  
our Members, supporters,  
their families and friends  
a joyous and safe Festive Season  
and a  
Happy and Healthy 2009*

