



# Messages



Myasthenia Gravis Association of Queensland Inc

**FEBRUARY 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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## PRESIDENT'S REPORT

Wow!! Christmas came and passed very quickly. Have you put your decorations away for next year? As we get older the years seem to pass more quickly. Hope you all had a happy festive season and are looking forward to 2009.

On behalf of the Association, I would like to pass on our heartfelt best wishes to those people in Victoria who were caught up in the horrific bushfires, in particular to any of our members who were directly affected by the tragedy, or who had family who were directly affected – our thoughts are with them.

Also, our thoughts are with the people of Northern Queensland who are fighting the floods. Again a special thought for any of our members directly affected by the flooding.

Thanks to Gordon for 'baby-sitting' the 1800 phone number while Nev and I fitted in a trip to Rockhampton for a 60<sup>th</sup> birthday party.

Please remember to jot down the dates of our planned get-togethers for this year on your calendar and please put pen to paper (or email) and send us your story for the members forum – I hear some very interesting variations of myasthenia gravis when talking on the freecall phone line, so come on, give it a go.

Our dear friend and member, Kath Ross (one of the driving forces behind the establishment of our association) is battling severe illness, but has still found time to pen the following New Year message as a plea for the association to continue:

*I wish all our members a happy New Year  
May all your dreams come loud and clear  
Especially our members on the committee  
All their work done to further MG  
On your behalf, always dedicated  
Their free time each one donated  
Now it comes to pass  
We need a lad or lass  
To carry on we must be bold  
Some of the committee are getting old.*

Hope to see you at the picnic on March 15

That's all for now,

Shirley

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**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

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**WEB-Site Update**

**PLEASE NOTE:** Our website address is now [www.mgag.org.au](http://www.mgag.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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*Conscience is what hurts when everything else feels good.*

\* \* \* \* \*

## Shirley's Recipe

### ROCKY ROAD PUDDING

(serves 8)

#### Ingredients:

- 16 chocolate biscuits
- 1 cup vanilla custard
- ¼ cup dessicated coconut
- 1 cup frozen raspberries, roughly crushed
- Chocolate Ice Magic, sprinkles and silver cachous (to decorate)
- 1 ¼ litres vanilla ice cream, softened
- 1 cup mini marshmallows
- ¼ cup granulated nuts
- vanilla custard (to serve)

#### Method:

1. Line an 8 cup capacity metal pudding steamer with plastic wrap, allowing a 2cm overhang.
2. Break 10 biscuits into 2cm pieces. Combine ice cream, biscuit pieces, custard, marshmallows, coconut, nuts and raspberries in a bowl. Smooth top. Top with remaining biscuits. Freeze overnight or until firm.
3. Stand pudding at room temperature for 5 minutes to soften. Turn out onto a plate. Carefully peel away wrap. Drizzle with Ice magic, top with sprinkles and cachous (optional). Serve with custard.

**NOTE:** I used cashew nuts as the granulated nuts, and frozen mixed berries, cut into quarters, instead of raspberries

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### Future Planned Activities

- Sunday 15 March 2009                      Outing, picnic at Macintosh Island, Gold Coast
- Sunday 14 June 2009                      Presentation by Dr Stephen Reddel
- 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.

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### *The Wedding Registry*

Jacob, aged 85, and Rebecca, aged 79, are all excited about their decision to get married. They go for a stroll to discuss the wedding and on the way go past a drugstore. Jacob suggests that they go in.

He addresses the man behind the counter: "Are you the owner?"  
 The pharmacist answers, "Yes."  
 Jacob: "Do you sell heart medication?" Pharmacist: "Of course we do."  
 Jacob: "How about medicine for circulation?" Pharmacist: "All kinds."  
 Jacob: "Medicine for rheumatism?" Pharmacist: "Definitely."  
 Jacob: "How about Viagra?" Pharmacist: "Of course."  
 Jacob: "Medicine for memory?" Pharmacist: "Yes, a large variety."  
 Jacob: "What about vitamins and sleeping pills?" Pharmacist: "Absolutely."  
 Jacob: "Perfect! We'd like to register here for our wedding gifts."

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## Members' Forum

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

Please let us and other members know about your experiences with MG. Remember your contributions can be published anonymously, but we must have your name and address for authentication purposes.

However, the following is a great example of an MG experience that we are asking our members to let other members know about. This article is from the Myasthenia Gravis Foundation of America.

“Dear Myasthenia Gravis Foundation of America,

Please allow me to introduce myself, my name is Annette Kennedy-Bowman, I am a busy wife, mother and a corporate accounts sales manager for the Hilton hotel in my area. In addition, I am an interior designer, working hard to acquire clients for my design business. I also have myasthenia gravis.

I was diagnosed in the fall of 2005 after a long string of visits to doctor upon doctor and more medical testing than most people go through in a lifetime. I thought you may be interested in reading how I learned about MG.

**This story begins in the fall of 2004**, I had just turned 39. I began to feel a general sense of fatigue, but brushed it off, due the fact that I was a busy wife, mother and part-time art student, finishing my last year of design school.

**By February of 2005**, I began experiencing what I referred to as “ghosting,” kind of like double vision. I described it as seeing a shadow behind whatever I was looking at. It would be the same exact image of what I was actually seeing, but with a lighter, shadowy version just above or behind the real image. I first noticed this while watching television, *Law and Order* to be exact, with the white text on the black background that is displayed between scenes. Within the following weeks this “ghosting” was happening more frequently, along with the feeling that I was looking through a veil at times.

Because these symptoms were not constant, I would blame them on being tired. Unfortunately, they kept returning, and so I went to the eye doctor. The physician told me that I was just getting older, after all I was approaching 40 (like I needed to be reminded), and that my eyes were just having trouble focusing. A slight adjustment to my reading glasses prescription should do the trick. It didn't.

**In March**, a very strange thing happened. It was a very important night for me—my portfolio exhibit at art school. I was extremely excited and a bit nervous. As I walked across the parking lot carrying my portfolio bag by the handles, as I had done a million times before, my fingers let go of the handles. This really frightened me, but since I was able to regain the strength in my hand almost immediately, I continued across the parking lot, went up to the gallery, and set up my portfolio pieces. I don't think anyone noticed me flexing my fingers throughout the show. In the back of my mind I was thinking, “Did I just have a stroke or TIA?” I was thinking of my grandmother, who had suffered several TIAs prior to a major stroke that left her paralyzed and in a wheelchair over 10 years before. Now she was fighting for her life, congestive heart failure was getting the best of her, and my family had just met with Hospice earlier in the week.

Although this incident rattled me, I quickly returned to normal, and attributed it to being overly stressed. After all, it was a big night and I was only a few weeks from graduation.

**On April 2, 2005**, I graduated with honors from art school. My family threw a party and everyone was so proud of me, but mostly I was proud of myself for what I had accomplished. It wasn't easy to go back to school at my age, with the responsibilities of a family. Not to mention I was a “non-traditional” student, which basically meant I was not 18 anymore. Anyway, I was proud, but mostly felt very blessed to have the love and support of my family. They believed in my ability and encouraged me throughout the last 3 years,

and now that the schooling was over, I was an Interior Designer. The world was my oyster; I only wished I felt better.

My symptoms were persisting; I knew something was not right with my eyes. So I made another appointment, with my long time ophthalmologist, not the optometrist. Much to my surprise, the ophthalmologist told me the same thing; I was getting older and my eyes were too. The physician said that my eyes were healthy, and when I reiterated my eye symptoms, she made another joke about 40 being around the corner, smiled and sent me on my way. I left the office feeling very frustrated. In the doctor's defense, I never mentioned the muscle weakness or fatigue to her; it just never occurred to me that those symptoms may be connected to my vision issues.

**The next few weeks** were a whirlwind. My grandmother passed away, and so I put everything else aside and dealt with her death. I read at the funeral, through my tears; everything went double on me for just a moment. I regained my composure and finished the reading. Later that day everyone gathered at our home. As I sat around with family members, telling stories and reliving our time spent with our grandmother, I looked around the room at my extended family thinking how lucky we were to have each other. I also remember wishing that I had the energy that I saw in my cousins and thinking to myself, "What is happening to me?"

**And so it goes...on April 28** while driving my son to the dentist, I began having visual disturbances. At first, I thought I was getting a migraine, since I have suffered from classic migraine since I was eight years old. Visual disturbances at the onset of a migraine attack were nothing new to me. This, however, was different from anything I had ever experienced, instead of "blind spots" and "shattered images," objects seemed to be coming toward me in 3-D double vision. The episode lasted only a few minutes and then my vision cleared, only to repeat itself 30 minutes later.

My husband came to the dentist immediately. He called our family physician's office from the car. We were told to come right in, and so we did. My physician was unavailable, so I met with someone else in the practice. Of course I had never met her before, and so she didn't know me from Adam...I was very upset and frightened. She immediately ordered a STAT MRI. The MRI was negative (great, no signs of stroke) and so the conclusion was drawn that this episode was some sort of "strange migraine," although I never got a headache, nausea, numbness or confusion, as I normally do with a migraine attack. Keep in mind, at this point, I was telling whomever I saw about ALL of my symptoms, but no one was tying them together. I wanted to believe this migraine conclusion, even though it just didn't seem to fit. I guess in my heart I knew better, but I just hoped and prayed that it would never happen again...wishful thinking.

**By the time May rolled around,** I was still experiencing fatigue that would come and go, along with the vision "ghosting" and periodic episodes of double vision. I also began to experience a different visual; I would see two images of an object, but not clearly separate images, more like an overlapping. Since the MRI was negative and my ophthalmologist said my eyes were fine, I really didn't know what to do. I also noticed some muscle weakness. For example, there were times I couldn't turn the key in the ignition of my car the first time I tried. Or when I went to turn up a tube of lipstick with a quick twist, I needed two hands to turn the tube. I felt fatigued more often and so I thought I should see a neurologist. I was scared to drive at night, due to the visual disturbances. Daytime driving was at times challenging enough, but at night with the glare of the lights, it was becoming frightening. Definitely time to see the neurologist.

Herein lies the irony, since I was a teenager I had a neurologist that I saw twice a year for my migraine management. Fortunately, my migraines have remained the same and I usually only get 3-5 a year. My neurologist had retired six years earlier, and since my migraines were under control at that time, I opted to just see my family doctor for treatment. Anyway, the point is that now, when I needed a neurologist, I couldn't just call and make an appointment myself. I had to see my family physician first, and get a referral from him. The neurologist's office would not schedule an office visit unless it was requested by my family doctor. This is because I was a "new patient," even though it was the same group I had seen for 20 years! So...

I saw my family physician in early June and told him about every symptom I had been experiencing. He recommended that I see a neuro-ophthalmologist and a neurologist just to be thorough. With my family physician's referral, I could now schedule the appointments. The neuro-ophthalmologist couldn't see me for 4 weeks and the neurologist for 8 weeks. In retrospect, I should have asked my family doctor to speak to the physicians and try to get me in sooner, but I didn't. Live and learn.

July, finally it was time to see the neuro-ophthalmologist. When I met him, I felt hopeful that my vision problems would be diagnosed and corrected. He first focused on my corneas, due to the fact that my brother has Degenerative Corneal Disease and has had a transplant. Fortunately, my corneas were fine, so he continued testing. Sometime in July, I began to have an additional symptom, the feeling that something was stuck in my throat. I could swallow, but I had to swallow hard sometimes, and even then, I had the sensation that food or even a baby aspirin was just "hanging" in my throat. Some days I would be extremely aware of this feeling and other days I wouldn't even notice it. This sensation could occur even if I had not eaten anything. By this time, I was not sleeping well. I would fall asleep, but awake around 3:30 a.m. every morning. Things were taking a toll on me.

To be continued in March 2009 issue of MessaGes

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### Bran Muffins

The couple were 85 years old and had been married for sixty years. Though they were far from rich they managed to get by because they watched their pennies. Though not young they were both in very good health largely due to the wife's insistence on healthy foods and exercise for the last decade.

One day, their good health didn't help when they went on a rare vacation and their plane crashed, sending them off to Heaven. They reached the pearly gates and St. Peter escorted them inside. He took them to a beautiful mansion furnished in gold and fine silks, with a fully stocked kitchen and waterfall in the master bath. A maid could be seen hanging their favourite clothes in the closet.

They gasped in astonishment when he said "Welcome to Heaven. This will be your home now." The old man asked Peter how much all this was going to cost. "Why, nothing, remember, this is your reward in Heaven". The old man looked out the window and right there he saw a championship golf course, finer and more beautiful than any ever built on Earth. "What are the green fees?" grumbled the old man. "This is heaven, St. Peter replied. You can play for free every day." Next they went to the Club House and saw the lavish buffet lunch laid out before them, from seafood to steak to exotic desserts, and free flowing beverages. "Don't even ask," said St. Peter to the man. This all free for you to enjoy."

The old man looked around and glanced nervously at his wife. "Well, where are the low fat, low cholesterol foods and decaffeinated tea?" he asked. "That's the best part" St. Peter replied. "You can eat as much as you like of whatever you like and you will never get fat or sick. This is Heaven!" The old man pushed "No gym to work out at?" "Not unless you want to" was the answer. "No testing my sugar or blood pressure or..." "Never again. All you do here is enjoy yourself".

The old man glared at his wife and said, "You and your Bran Muffins. We could have been here ten years ago."

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"OLD" IS WHEN.... You don't care where your spouse goes, just as long as you don't have to go along.

**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 world's most northerly national capital city?
2. What is the world's most southerly capital city?
3. Which was the first American state to ratify the US Constitution?
4. What is the Fossil Emblem of West Australia?
5. What is the chemical symbol for Magnesium?
6. Who wrote 'The Saint' series of novels?
7. What is the capital of Greenland?
8. Who is the federal Minister for Defence?
9. What movie won the recent Golden Globe Award for best picture?
10. In which Australian state or territory is Lenah Valley?
11. Barry Alan Pincus is better known as whom?
12. Who won the 2009 tennis Australian Womens' Singles Championship?
13. What is the collective noun for a group of buzzards?
14. Gamophobia is the fear of what ?
15. "Have you ever heard of multiple personality?" is the opening line in which Joanne Woodward movie?
16. What are the colours of the Hungarian flag?
17. Which Australian city unsuccessfully bid to stage the 1996 Olympic Games?
18. Which African country has a name meaning 'free'?
19. Who was the oldest of the Marx brothers?
20. "God, bless us everyone" are the last 4 words in which Charles Dickens novel?

**Answers:** 1) Reykjavik (Iceland); 2) Wellington (New Zealand); 3) Delaware; 4) Gogo fish; 5) Mg; 6) Leslie Charteris; 7) Thule; 8) Joel Fitzgibbon; 9) Slumdog Millionaire; 10) Tasmania; 11) Barry Manilow; 12) Serena Williams; 13) A wake; 14) Marriage; 15) The Three faces of Eve; 16) Red, white & green; 17) Melbourne; 18) Zimbabwe; 19) Chico; 20) A Christmas Carol

This year we will hold our first function of the year, a Picnic in the Park, on Sunday March 15.

**WHEN:** Sunday 15 March 2009

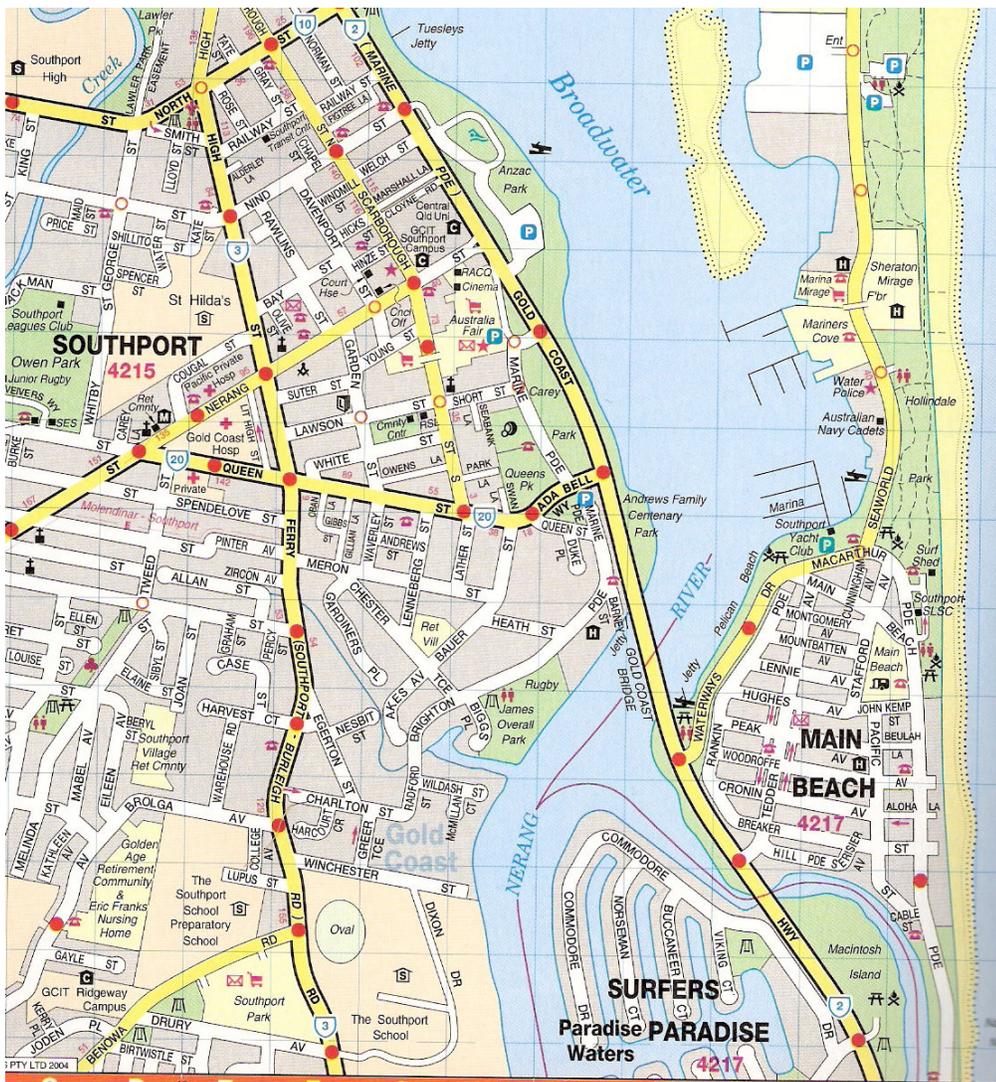
**TIME:** 10:30am onwards

**WHERE:** MacIntosh Island, Gold Coast Highway (see Map below)

**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 and hot water is available.

**HOW DO I GET THERE?** Take the Gold Coast Highway through Southport and MacIntosh Island is on the left just past Tedder Ave, which in turn is just past the big bridge. UBD Gold Coast map 29, L19

**RSVP** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Wednesday March 11 2009**.



← Here is MacIntosh Island