



# Messages

Myasthenia Gravis Association of Queensland Inc

**MARCH 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.

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## **PRESIDENT'S REPORT**

Well, now a cyclone – what else can we expect? I hope by the time you receive your newsletter, Hamish will have passed with no damage to anyone.

Good news from Dr Stephen Reddel. He is able to come to Brisbane for our June 14 function as a guest speaker. The venue has yet to be arranged, but we will keep you informed in future newsletters. If you have any queries about this function, please give me a ring on our Freecall 1800 802 568.

Thanks to Gwen for giving our Mackay members the opportunity to meet for lunch and have a chat.

Annette's account of her myasthenia gravis in the February newsletter was very interesting and I am sure that you are awaiting the final instalment. I could relate to a lot of her experiences, as I'm sure a lot of our members can.

One of our newer members, Melissa, will present her story in our April issue of Messages. So, come on all you other members whose story is of interest to our readers – send it in to the editor via email or 'snail' mail.

Some time in April, current financial members will receive nomination forms for the Management Committee for 2009/2010. I urge those of you who can, to please put your names forward for a position on the Committee.

And just remember, you can't change the past but you can ruin the present by worrying about the future.

That's all for now,

*Shirley*

**PS:** Don't forget to vote in the Queensland State elections on March 21

Supported by



**CHAT LIST:****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
KATHLEEN	0416178458	UPPER COOMERA

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**Future Planned Activities**

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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**LEMS Website**

Sue Wakefield, who suffers from LEMS (Lambert Eaton Myasthenic Syndrome) has started a website for fellow sufferers of the disease where they can share their experiences with others. The website is: [www.lems.synthasite.com](http://www.lems.synthasite.com)

**MG Cure Scam Website**

We have received advice that a website purporting to provide cures for MG and run by someone called 'Maria Menendez' is a scam and is to be avoided.



**Shirley's Recipe**

**EASY CHOCOLATE CAKE**

**Ingredients:**

- |                              |                                 |
|------------------------------|---------------------------------|
| 125g butter, roughly chopped | ½ cup Golden Syrup              |
| 2 cups plain flour           | ⅓ cup cocoa                     |
| 2 teaspoons baking powder    | 1½ teaspoons bicarbonate soda   |
| 1½ cups milk                 | ½ cup firmly packed brown sugar |
| 2 eggs                       | 1 teaspoon vanilla extract      |

**Icing:**

- |                          |                    |
|--------------------------|--------------------|
| 2 tablespoons milk       | 20g butter         |
| 1½ cups pure icing sugar | 1 tablespoon cocoa |

**Method:**

1. Preheat oven to 180°C.
2. Grease and line a 20cm square cake tin with baking paper. Melt butter in a saucepan. Remove from heat and stir through golden syrup until well combined.
3. Sift flour, cocoa, baking powder and bicarbonate soda over butter mixture..
4. Combine milk, brown sugar, eggs and vanilla in a large jug. Add to mixture and using a small whisk, gently whisk until all ingredients are well combined.
5. Pour mixture into prepared cake tin. Bake for 50 - 60 minutes or until the cake is cooked in the centre when tested with a skewer.
6. Cool in tin for 5 minutes before transferring to a wire rack to cool completely. When cold spread with icing.
7. Chocolate Icing: Put milk and butter into a small microwave-safe jug on high for 20 seconds or until melted. Sift icing sugar and cocoa over melted butter mixture and stir until a smooth icing forms, adding a little hot water, if required.

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**ANYONE FOR A LAWYER?**

ATTORNEY: This myasthenia gravis, does it affect your memory at all?

WITNESS: Yes.

ATTORNEY: And in what ways does it affect your memory?

WITNESS: I forget.

ATTORNEY: You forget? Can you give us an example of something you forgot?

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ATTORNEY: Now doctor, isn't it true that when a person dies in his sleep, he doesn't know about it until the next morning?

WITNESS: Did you actually pass the bar exam?

## Members' Forum

A Government helpline exists to answer general enquiries from the public about the prescription medications they may be taking. If you would like to call them the MEDICATIONS HELPLINE phone number is 1300 888 763.

Your committee has made contact with a staff member at the Helpline who is prepared to provide written answers to questions about the medications taken by myasthenia gravis patients. We have a selection of questions already and hope that our members will have further issues they would like clarified. By using the service in this way we hope to answer some questions or provide assurance about each individual's experiences with the disease.

The questions put forward to date are as follows:

1. How is the distinction between underdosage and overdosage of Mestinon® made? In what ways does the medication slowly begin to mirror the disease?
2. Patients can develop a 'tolerance' to pyridostigmine and require increasing medication. Can you please explain how this works?
3. Some members are fortunate enough to be in remission from MG symptoms. Should they be as careful when taking new medication as those experiencing symptoms?
4. Is long term use of methotrexate considered acceptable? What issues may arise?

Please forward your questions by email (to [mgqld@gil.com.au](mailto:mgqld@gil.com.au)), mail (to PO Box 16 Mt Gravatt 4122) or telephone (Freecall 1800 802 568) by 30 April next. Questions will be submitted following this date and the answers published in the Members' Forum as soon as they become available.

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And now to continue the great example of an MG experience of the type that we are asking our members to let other members know about. This article is from the Myasthenia Gravis Foundation of America.

**“August 2005:** With all my symptoms persisting, I went back to my family doctor's office. Since my physician was on vacation, my appointment was with yet another doctor in the practice. I told her about the swallowing issue, not sleeping well, as well as exhausted. I also informed her that I was under the care of a neuro-ophthalmologist for my eyes. She ordered a barium swallow and an ultrasound of the thyroid. The barium swallow was negative, but the ultrasound showed that my thyroid was very slightly enlarged and appeared multi-nodular.

This prompted her to order a TSH and T4 blood work and a radioactive iodine uptake test. The blood work for my thyroid came back within a normal range, but my uptake was high. During the uptake test, the doctor who reads the test told me that my scan was definitely looking like Graves Disease, which is a hyper active thyroid. I thought okay, maybe we are getting somewhere now. When I read up on the thyroid, every symptom you could think of could be caused by your thyroid acting improperly. But after all the results were in, we had no definitive answers, since the levels were not as high as they thought. They decided that my thyroid blood levels should be monitored every 4 months for the next year. So again, another dead-end to resolving my symptoms; this just threw us off course for a bit.

I reiterated to the physician my sleeping difficulties and how tired I was still feeling in addition to my visual problems. I explained to her that I had just seen the neuro-ophthalmologist and was waiting eight weeks to see the neurologist. I felt confident that the neuro-ophthalmologist would get to the root of the problem. I really felt like he was listening to me (he was) and running every test that he thought may be relevant. I informed her that he had just ordered an MRI of the orbits of my eyes to check the muscles around the eye. She wrote me a prescription for a sleeping pill, (which I never got filled) and chalked up difficulty sleeping to stress, since I had mentioned to her that our son had just gotten his driver's permit. This of course was not the

problem—the problem now was not the constant worry of not knowing what was going on, but knowing that there was surely something wrong, and it was beginning to get the better of me.

I also began noticing more motor skill issues. For example, I couldn't push the pump of a liquid soap bottle down with two fingers anymore; I had to use the palm of my hand to work the dispenser. Also, while eating I remember a time when I felt like I couldn't hold the fork between my fingers and I put it down for a few minutes and then resumed holding it as usual. And there was another incident, while peeling potatoes: after I had peeled a few, I remember feeling like I just couldn't grip another one; my fingers wouldn't stay around it. These are just a few examples. Something else was that, from time to time, my speech was just a bit slurred—only a word or two and not to the point that anyone would think anything of it, but I noticed. Remember, these symptoms were not constant, and I continued with my everyday activities, but when they occurred, I KNEW something was wrong.

**September 2005:** I expressed concern about these additional symptoms to the neuro-ophthalmologist; and so he ordered blood work to test for antibodies to things I'd never heard of, MG being one of them, as well as an echocardiogram to test for mitral valve prolapse, stroke and a hole in the heart. He also had my MRI's reread to double check for weakness in the eye muscles and again to rule out TIA or stroke.

**On September 30, 2005,** the neuro-ophthalmologist told me in a phone conversation that the rereading of the MRI's showed nothing, but the echo showed that I did have a hole in my heart. He expressed to me in that same telephone conversation that I also tested positive for myasthenia gravis. He continued on, saying that I had to have a CT scan of the chest to rule out a thymoma, or tumor (sometimes cancerous, he informed me) of the thymus gland. My head was spinning as the doctor transferred me to the secretary to set up these tests. I never thought I could be so frightened by information that I didn't even truly understand, but I was very, very frightened.

I had the CT done in the morning and went directly to see the cardiologist regarding the hole in my heart. He said not to be concerned, it had been there since birth and was extremely tiny. We would only revisit that issue if the neurologist felt that my symptoms were related to TIA or stroke, which the cardiologist felt was highly unlikely, due to my symptoms and testing positive for myasthenia gravis. He said we needed a positive diagnosis of MG from the neurologist. He told us that the CT could not confirm or rule out a tumor but the thymus gland was enlarged and the radiologist felt it was most likely residual thymus tissue. This cardiologist was so concerned with my symptoms and test results, he said I needed to see a neurologist ASAP (my previously scheduled appointment was still weeks away). He insisted on calling to speak with the neurologist directly, as we waited in the exam room. A new appointment with the neurologist was scheduled for the following Friday, Oct. 7. "Finally" I thought, "we might be getting somewhere."

**October 2005:** On Monday, Oct. 3, 2005, I received another call from my neuro-ophthalmologist telling me that I needed to see a pulmonologist, because the CT of the chest showed 3 very small nodules on my lungs. This phone call sent me into a panic; I had had about enough of this scary news as I could take. I don't know how I got through the next week, but I did. An appointment was scheduled with the pulmonologist, for Tuesday Oct. 11. At this point, I still have all my symptoms and the swallowing issue is getting worse. At times, when I try to eat I begin to cough and feel as if I may choke. This is extremely frightening and so I become afraid to eat much at all. Needless to say, I'd lost a considerable amount of weight, probably about 15 pounds at this point. I, like every other woman I know, don't mind losing a few pounds. This however, was not the way I wanted to lose them. Out of fear of aspirating, I ate very little.

**Friday Oct. 7** I met the neurologist. During my neurological exam, I was stunned at how weak I was. You must understand that twice a year, for about 18 years, I visited my former neurologist, for my migraine checkups. I always kind of laughed to myself at the exam, I NEVER had any difficulties keeping my balance, squeezing her fingers or pushing her away, but this time the exam was very different and it brought me to tears.

The neurologist confirmed the MG diagnoses and he was extremely concerned about my swallowing difficulties. He said that I must now see a neuromuscular specialist and he highly recommended physicians at two different hospitals. In his opinion, he told me that I must have my thymus gland removed. This would increase my chances of going into remission. Once the thymus tissue was removed, I wouldn't have to be concerned about it turning cancerous. He stressed that I should not have it removed by transcervical thymectomy, a small incision in the throat and removal of thymus, because all of the tissue must be removed so that it does not regenerate. He felt that a sternotomy, cracking the sternum and removing the thymus tissue underneath, was a much better option. Although I understood his point, that by opening up my chest cavity the surgeon would have a much better view of the thymus gland and be able to see and remove any remaining bits of thymus tissue, that was not what I wanted to hear. Needless to say, this was quickly becoming the worst day of my life. Upon checking out, my medical records were faxed to both hospitals. Thankfully, I had the support of my husband and my mom at that appointment. Although it was very difficult for them to see me so weak and to hear what the doctor had to say, I don't think I could have made it through that day without them.

The neurologist started me on medication, Mestinon. I noticed a change in my swallowing after just a few doses.

**On Tuesday Oct. 11**, the pulmonologist, reviewed the CT scan and told me that the nodules were old calcifications caused by exposure to some lung disease or infection, and we will never know exactly what caused them. He also remarked on the thymus gland, saying he felt that it should be removed too. He said that my lungs were in great shape and that unless I had breathing difficulties, I didn't need to see him again. Wow, finally some good news!

**Oct. 27:** I met with the neuromuscular specialist at the first hospital. I am very fortunate that he took me on as a patient because his case load was already very high. He adjusted my dose of Mestinon. He also agreed that at some point, I should have a thymectomy, done by full sternotomy. He was aware, and thought it was a good idea, that I was going for a second opinion. I felt that after all this time I owed it to myself to make sure I sought out the best medical treatment possible. So the "Three Musketeers," my husband, my mom and I, headed for the next medical center. I jokingly referred to this as the "Medical Tour." At least I saw some humor in these turn of events.

**November 7, 2005:** We met with the specialist at the second hospital. My appointment was Nov.7, (the day after my 40th birthday, let's just say it wasn't my best birthday and turning 40 had nothing to do with it.) He is one of the foremost authorities on MG in our country, perhaps the world, and I was very fortunate to be evaluated by him. After a thorough exam, he also expressed that a thymectomy by full sternotomy was the proper course of action to take sometime in the future.

Well, at least the two physicians were in agreement, and I trusted both of their opinions; now someone just had to convince me that cracking open my chest and removing a gland was the right thing to do. Anyway, I was responding well to the medication, so both physicians said to wait until after the New Year to revisit the thymectomy issue. I would decide which physician I was going to stick with after I decided on a surgeon.

So, that's what I did, the Three Musketeers took off again to interview Cardio Thoracic Surgeons at both hospitals. The first surgeon was very comfortable performing the full sternotomy. The second surgeon wanted to do the surgery using the da Vinci robot, but he could not guarantee that he would be able to remove all the thymus tissue. I decided to go on the advice of both neuromuscular specialists and so I had a thymectomy by full sternotomy.

**February 15, 2006**, was the date of my surgery. Everything went well, other than the fact that I learned I'm allergic to painkillers. I had never had major surgery before, so this was new information to me. I went home with Tylenol and Advil for the pain. The first week was the roughest. Breathing and moving hurt and coughing was almost unbearable, but then things starting looking up quickly. It took about 10 weeks until I

was able to resume all of my normal activities. It really is amazing how fast you begin to recover. I was very fortunate to have family and friends to support me through this time. I know that I am a very lucky girl.

**Three years after my diagnosis**, I am happy to report that I am doing extremely well in regard to my MG. I have not needed any additional treatment or surgeries. I continue to take Mestinon three times a day, and it does a great job of controlling my symptoms. I sometimes still experience double vision if I wake up after falling asleep in front of the television late at night. I rarely have difficulty swallowing, and I do very well at my neurological exams. I do have to pace myself and keep in mind that I am living with a chronic illness. I feel extremely lucky that my body has responded so well to the medication and the surgery, and I live my life to the fullest. It takes years to know if the thymectomy plays any part in reducing the symptoms. Over the past two years, I have had my share of medical issues that are completely unrelated to my MG. I'm told by my physicians that the fact that these conditions have not affected the myasthenia gravis is a very good sign that I may one day go into remission.

So, that's just a glimpse (yes, really I left so much out, I could write a book) of my life over the past few years. What prompted me to write this letter is that we need to get the word out to the masses, especially to young women, who may think that their symptoms are just part of their overworked, overstressed everyday lives.

I know there are other people walking around saying to themselves, "What is wrong with me and why can't anyone find the answers?" I would like to help them find the answers, and so I personally will be writing to politicians, magazines, news programs and talk shows. Knowledge is power; we must provide this information to everyone, so that they can have a stronger hand in their own health care.

There is help, but first you have to know what's wrong. Every one of the physicians I visited was doing their best to make a proper diagnosis. Unfortunately because myasthenia gravis is such a rare condition, most people have never heard of it and it is not one of the first things that doctors think to test for. This fact makes it all the more frightening when you or someone you love is diagnosed with MG.

I found the Myasthenia Gravis Foundation of America on the Internet. I know that the Foundation works tirelessly to spread awareness and education about MG. I look forward to helping you with this effort, and as the website says, "Strive for a world without MG."

Sincerely,

Annette Kennedy-Bowman

\*this letter was originally sent to MGFA in Oct. 2007 and was updated by Annette Nov. 2008

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## TELEPHONE SCAM ALERT

The following is a copy of an email from a Detective Senior Constable in the Victorian Police Service that was sent to the Editor:-

"I got a call last night from an individual identifying himself as a Telstra Service technician who was conducting a test on our Telephone lines.

He stated that to complete the test I should touch nine(9), zero ( 0), hash (#) and then hang up. Luckily, I was suspicious and refused. Upon contacting the telephone company, I was informed that by pushing 90#, you give the requesting individual full access to your telephone line, which allows them to place long distance telephone calls billed to your home phone number.

I was further informed that this scam has been originating from many of the local gaols/prisons.

**DO NOT press 90# for ANYONE. PLEASE pass this on to your friends.**

If you have mailing lists and/or newsletters from organizations you are connected with, I encourage you to also pass this on to them."

**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 musical is set in 'Catfish Row'?
2. Who was the subject of the film 'What's Love Got To Do With It'?
3. Which mountain range runs through Liechtenstein?
4. Which ocean covers an area of 64 million square miles?
5. What is the chemical symbol for gold?
6. How many tiles are there in a standard dominoes set?
7. What is the common name for the body part known as the patella?
8. What is the capital city of California?
9. What do camels store in their hump?
10. How many bicuspid teeth are there in a normal set of human teeth?
11. Who was the last president of the Soviet Union?
12. What was 11th-century Spanish military leader Rodrigo Diaz de Vivar better known as?
13. What is the University of Paris more commonly called?
14. What U.S. state boasts a town called Captain Cook?
15. What is the Greek name for hell?
16. What do the Chinese call kwai-tsze, or "quick little fellows"?
17. What city boasts the largest Greek population in the world outside of Greece?
18. What does a bromidrosiphobic shoe salesman fear?
19. What word appears exactly 773,692 times in the King James Bible?
20. Can horses vomit?

**Answers:** 1) Porgy and Bess; 2) Tina Turner; 3) Alps; 4) Atlantic; 5) Au; 6) 28; 7) Knee-cap; 8) Sacramento; 9) Fat; 10) 8; 11) Mikhail Gorbachev; 12) El Cid; 13) The Sorbonne; 14) Hawaii; 15) Hades; 16) Chopsticks; 17) Melbourne; 18) Smelly feet; 19) Amen; 20) No.