



Messages

Myasthenia Gravis Association of Queensland Inc

NOVEMBER 2012



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: info@mgqa.org.au
Internet: www.mgqa.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

Secretary and Editor
Graeme PETERS
Ph. 3288 4484
email: graeme.peters2@bigpond.com

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee

Bill SYNNOT
Ph. 0418196707

Carol BUCHANAN
Ph. 4773 7122

PATRON
Dr Cecillie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

We had a very informative meeting with Dr. Joanne Pink from the Red Cross Blood Service where many questions were asked and the members concerns were answered. I would like to thank Dr. Pink for giving up her Sunday for our members.

It is hard to believe that Christmas is just around the corner and another year is almost over. The committee members are all looking forward to our Christmas function. It will be good to catch up with our members from in and around the Sunshine Coast especially the ones that cannot travel to Brisbane anymore. Don't forget to let us know if you will be coming to the Christmas Luncheon at the Power Boat Club in Caloundra on 9 December. Full details are on page 8 of this issue.

I think all the committee members are looking forward to having January off to give us some time to recoup and gather all the information that is required for another 12 months. I am looking forward to having some time off work as it has been very stressful and busy within the Government Departments and I will be able to catch up on a few jobs around the house as well as seeing my friends.

Our projects are still on the go and we are hoping to add to them in the coming year.

Take care

Anita

I do not feel obliged to believe that the same God who has endowed us with sense, reason, and intellect has intended us to forgo their use."

- Galileo Galilei (1564-1642)

Supported by



Queensland Government

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Even though the response has been over-whelming, we still want more sufferers (especially younger ones) to complete the questionnaires. So if you know anybody who is a sufferer and has not filled in the questionnaire, please let them know and/or ask them to contact us on 1800 802 568.

Also, when you next meet your medical professional ask "Do you have any patients who are MG sufferers and would be willing to be part of the survey?." If the answer is yes, see if you or the medical professional can make contact with them and/or get them to ring us (1800 802 568). The researchers are keen to expand the survey Australia-wide. Also, they are planning to write up the findings and publish in the appropriate scientific journal.

One person who needs to be thanked for his help as a volunteer during the survey is David McEniery - he did all the data input. The Association will be sending him a Certificate of Appreciation. Many thanks David.

In addition to the qualitative data there is much quantitative information (like personal stories). The latter could be written up as series of personal stories in a book form similar to what has been done for another auto-immune group. If this is to progress, we would need help with writing it up (any volunteers?). A suggested title is "The Silent Disease".

As most respondents agreed to be contacted about donating blood samples for future research, the researchers are in the planning stage of this.

Again, many thanks to those that completed the survey - give yourselves a big hug!!!!

'Exercise Effect in MG' Pilot Study –

EXERCISES AT HOME

Doctor Jennifer Nitz, who conducted the 'Exercise Effect in Myasthenia Gravis' Pilot Study at the University of Queensland's Neurological, Ageing and Balance Clinic, has kindly provided the Association with a booklet entitled '*Preventative Health – Exercise for your Bones, Strength and Balance.*'

The booklet details exercises which closely match those which were undertaken by participants in the abovementioned Study and are such that they can be undertaken by people in the comfort of their own home.

Each copy of the booklet comes with Cautionary Notes which should be read and understood before commencing any of the exercises.

Copies of the booklet are available, in either hard copy or electronic form (pdf), to current financial members. Those members wishing to obtain a copy should contact the Association on our Freecall number 1800 802 568 or via email at info@mgaq.org.au and state whether you prefer hard copy or email copy.

Copyright of the booklet remains the property of Dr. Nitz and the University of Queensland and should not be reproduced in any form without their express permission.

Also, if you have a try at these exercises and feel that you would like to undertake the complete set as part of the Exercise Study Project, and therefore contribute to the Study findings, please contact the Secretary on (07) 32884484 or via email at info@mgaq.org.au

* * * * *

No one can confidently say that he will still be living tomorrow.

Euripides

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.

The opinions expressed by the person you call are entirely those of that person. 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 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 3436	GOWRIE ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435389883	TWEED HEADS SOUTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	GILLEN NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

It's strange how you can be so content with how you look, until someone says something about it.

As we grow old, the beauty steals inward.

- Ralph Waldo Emerson

MEMBERS' FORUM

Please send in contributions to the Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is **YOUR** Forum and shared experiences with fellow MG sufferers makes understanding the condition just that little bit easier. 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 info@mgaq.org.au.

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.

+ + + + +

Obituary

It is with sadness that we advise of the passing of Bruce Knight of Condon. Bruce joined the association in July 1998 and was a paid-up Life Member. He has been a great supporter of the association and its objectives over the years.

On behalf of the members of the MGAQ we extend our sincere condolences to his widow, Irene, his family and friends.

* * * * *

Shirley's Recipe

COFFEE – ALMOND BISCUITS

Ingredients:

½ cup pure icing sugar	¾ cup caster sugar
1 cup almond meal	1 tsp instant coffee granules
1 tsp hot water	2 egg whites
½ cup flaked almonds	extra icing sugar, to dust

Method:

1. Line two oven trays with baking paper.
2. Place icing sugar, caster sugar and almond meal in a food processor. Process to combine. Add coffee dissolved in hot water. Process to combine. Add one of the egg whites and process until the mixture forms a soft dough.
3. Place remaining egg white in a shallow bowl. Beat lightly with a fork until frothy.
4. Place flaked almonds in a small bowl.
5. Remove dough from processor. Lightly dust a clean bench top with extra icing sugar. Shape 2 tsps of dough into a 5cm length. Dip into egg white and roll lightly in almonds. Repeat with remaining dough, egg white and almonds, placing biscuits 3 cm apart on prepared trays.
6. Cook in a slow oven (150°C) for about 20 minutes, or until golden.
7. Cool on trays. Biscuits will be soft once cooked but firm after standing.

NOTE: Biscuits can be made up to one week ahead and stored in an air-tight container. If you prefer, replace almond meal with ground hazelnuts and the flaked almonds with chopped hazelnuts.

(Makes 28 biscuits)

* * * * *

ALICE REFLECTS

(published in the Autumn 2012 issue of MGAnews – UK)

Friendships and Drama Lessons

My friend Claire was going to direct her first play. I was very happy for her, even though I was physically unable to attend due to some unexpected construction work next to the theatre. We have been friends for years, and even after long periods of being busy and not seeing each other it was always a pleasure for us to meet and share victories and defeats.

I was reminded of our phone conversation some years ago. Claire, a drama teacher, would always tease me about my lousy dramatic skills. Admittedly, I found it hard to even play the scarecrow in the 'Wizard of Oz.' A few years ago, after a very frustrating hospitalisation I picked up the phone and called her. 'Listen' I said 'you were completely wrong about me.' I caught her in the midst of preparing dinner and I could hear the clutter of the dishes on the other end of the line. I knew she had no clue of what I was talking about, and I went on. 'Remember, you always said that I have no artistic skills. Well you were totally wrong. You don't even know how good I am. How well I was able to 'fake' an illness. How amazingly convincing I was. I even managed to fool the head of anaesthesiology in my hospital, a very good and experienced clinician.

The only ones I couldn't fool were the neurology team. They knew better. But even they had to admit that my act was 'very good and convincing.' I then asked her if she could write me a good script before my next hospitalisation, because I am running out of ideas, and I really want to surprise them. How many times can you 'fake' someone who is having severe breathing difficulties and can hardly move in bed? It becomes extremely boring, and I really need her help in finding better 'stuff.' Talking with her made me feel much better. It gradually turned a very unpleasant experience into a comical/ridiculous situation and we laughed and joked about it like we used to when we were teenagers. It was a very frustrating situation. Due to the severity of my symptoms my neurologist at that time felt he had to treat me. Yet my perplexing clinical course, normal tests and unusual response to treatment led to recurrent belief from him and his staff. Talking with Claire about it helped me better endure this. This was one of many times in which my friends were there to encourage, advise and help. They not only came to visit, but were also sensitive enough to know not to stay too long. They were there to encourage me to trust myself and my clinical skills and not give up even during times of despair. They sent me beautiful flowers, they celebrated my victories and shared my failures, they encouraged me to go back to work and helped in doing so. They gave me legal, medical and other advice according to their training and skills. This illness also brought new friendships, myasthenics from all over the world, who despite the geographical distance and knowing very little about me, could understand without me having to explain.

'A friend is one who believes in you when you have ceased to believe in yourself.' 'A friend in need is a friend indeed.' Those clichés and many more became true, when I had to deal with numerous frustrating situations. Of course they did not and could not fully understand what I was going through. Occasionally they would make painful comment, or suggest various 'magic pills' and treatment approaches I should try. But this is inevitable when you have such an unusual illness that most people know very little about. I can't even imagine what my life would have been without them.

Alice – Autumn 2012

* * * * *

2011/2012 ANNUAL REPORTS

The President's and Treasurer's Report and the full Financial Audit Report for the year 1 July 2011 to 30 June 2012 are now available for viewing or downloading at our website

www.mgaq.org.au/association-reports

* * * * *

LENDING LIBRARY

The committee has decided to establish a lending library of MG and related information resources. The collection is small to start off with but will be expanded over time. John Noble has been appointed Librarian.

Loans of material are available to financial members of the Association and loan period is 1 calendar month, postage out paid by MGAQ and return postage paid by the member,

To request a loan, please contact John on (07) 3269 5066 or email jam3740@optusnet.com.au

Initial offerings are:

Myasthenia Gravis and Myasthenic Disorders (book)

Living a Healthy Life with Chronic Conditions (book)

Living Well With Autoimmune Disease (What your Doctor Doesn't Tell You – That You Need To Know) (book)

Beyond Blue – volumes 1 & 2 (DVD)

We welcome donations of relevant material from our members.



DVD's FROM ANNUAL GENERAL MEETING

By now current financial Category 'A' members should have received their copy of the DVD produced from the presentations by Dr Stefan Blum (Preliminary findings from the MG Data Survey) and Dr Jennifer Nitz (Preliminary findings from the 'Exercise Effect in Myasthenia Gravis' Pilot Study).

If you are a Category 'A' member and were financial at 30 June 2012 but have not received the DVD, please contact our 1800 802 568 Freecall number or email info@mgaq.org.au



A WALK THROUGH THE CEMETERY

Two men were walking home after a Halloween party and decided to take a shortcut through the cemetery just for laughs. Right in the middle of the cemetery they were startled by a tap-tap-tapping noise coming from the misty shadows.

Trembling with fear, they found an old man with a hammer and chisel, chipping away at one of the headstones.

"Holy cow, Mister," one of them said after catching his breath, "You scared us half to death. We thought you were a ghost! What are you doing working here so late at night?"

"Those fools!" the old man grumbled. "They misspelt my name!"



Future Planned Activities

Sunday 9 December 2012

Christmas function – Caloundra Power Boat Club

Sunday 10 March 2013

Picnic in the Park – North Pine Dam - Petrie

More details will be published as each event becomes closer.



UPDATE ON MG AND IVIG

Dr Joanne Pink, Red Cross Blood Service, gave an update on the supply situation regarding Ivlg on Sunday 11 November 2012. A detailed report on this meeting will be published in the December issue of MessaGes.

KEEP YOUR BRAIN ACTIVE – TRIVIA QUIZ TIME

Answers are at the bottom.

1. In which city is the Soumaya Museum?
2. Who is the Federal Assistant Treasurer?
3. Which English racehorse recently retired unbeaten?
4. In badminton, how many feathers are there in an official championship shuttlecock?
5. Alphabetically which is the last of Shakespeare's plays?
6. How long is a tennis court?
7. What kind of animal is a Russian Blue?
8. MQL is the Airport Code for which Australian city?
9. Who wrote the George Smiley series of spy novels?
10. Who won the 2012 NRL Premiership?
11. Chorophobia is the fear of what?
12. How many players in a men's lacrosse team?
13. Which horse finished second in the 2011 Melbourne Cup?
14. On which free-to-air TV channel is *Embarrassing Bodies*?
15. The headquarters of the United Nations is in which city?
16. The daily newspaper of Hobart is called what?
17. In which town is the Australia's oldest continuously used bridge?
18. Who was the first actress to win 4 Oscars?
19. Which English-speaking Caribbean island has a name which is Spanish for 'bearded'?
20. Which USA state is bordered by eight other states?

Answers: 1. Mexico City; 2. David Bradbury; 3. Frankel; 4. Sixteen; 5. Winter's Tale; 6. 23.774 metres (78 feet) ; 7. Cat; 8. Mildura; 9. John le Carre; 10. Melbourne Storm; 11. Dancing; 12. Ten; 13. Red Cadeaux; 14. Channel Nine; 15. New York; 16. The Mercury; 17. Richmond, Tasmania; 18. Katherine Hepburn; 19. Barbados; 20. Tennessee (Kentucky, Missouri, Arkansas, Mississippi, Alabama, Georgia, North Carolina and Virginia).

I'm not offended by all the dumb blonde jokes because I know I'm not dumb... and I also know that I'm not blonde. [Dolly Parton](#)

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 9 December 2012

TIME: 11am for 12 Noon

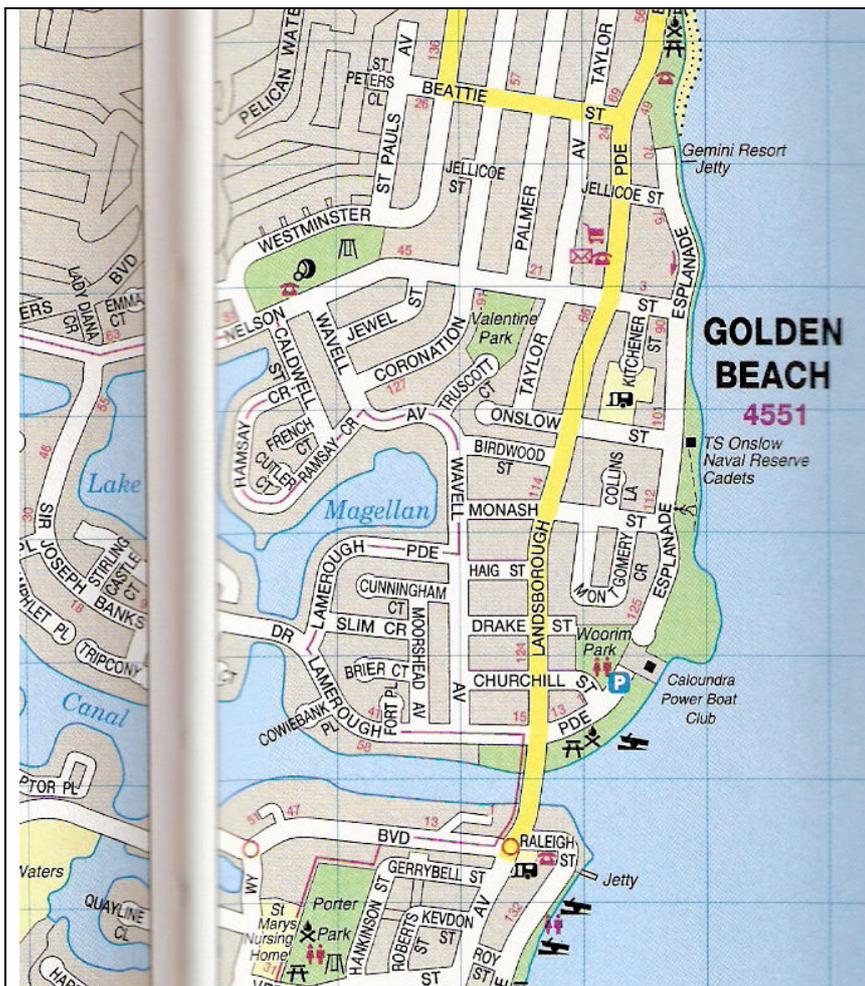
WHERE: Quarterdeck Restaurant, Caloundra Powerboat Club, Woorim Park, The Esplanade, Golden Beach. Car parking is available.

WHAT WILL IT COST? Meals are priced from approx \$15.00 each and there is a wide and varied menu. Raffles will be on sale

WHAT DO I NEED TO BRING? Yourself and whomever else you wish to bring along. Remember, as it is a 'user pays' function, friends and family are most welcome.

HOW DO I GET THERE? See map below. (UBD Sunshine Coast Map 110 Reference D7)

RSVP Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 30 November 2012**



To get there from Brisbane:

Exit from Bruce Highway onto **Caloundra Rd**. Proceed for about 9.5 km. **Caloundra Rd** becomes **Bowman Rd**. Continue on **Bowman Rd** for about 0.4km.

Turn **right** at **Park Place**. Proceed along **Park PI** for approx 0.2km, when it becomes **Landsborough Pde**.

Continue on **Landsborough Pde** for approx 0.4 km when it becomes **Esplanade**.

Continue on **Esplanade** for approx 1.1 km.

At the roundabout, take the **1st** exit onto **Landsborough Pde**. After approx 0.2km there will be another roundabout. At this roundabout, take the **1st** exit onto **Jellicoe St** for approx 100 metres.

Turn **right** at **Esplanade**.

Club is on the left after approx 1km.

From Noosa, etc:

Travel along **Nicklin Way** to **Caloundra Road**.

Turn **left** into **Caloundra Rd** at roundabout.

Caloundra Rd becomes **Bowman Rd**. Continue on **Bowman Rd** for about 0.4km. Turn **right** at **Park Place**. Proceed along **Park PI** for approx 0.2km, when it becomes **Landsborough Pde**.

Continue on **Landsborough Pde** for approx 0.4 km when it becomes **Esplanade**.

Continue on **Esplanade** for approx 1.1 km.

At the roundabout, take the **1st** exit onto **Landsborough Pde**. After approx 0.2km there will be another roundabout. At this roundabout, take the **1st** exit onto **Jellicoe St** for approx 100 metres.

Turn **right** at **Esplanade**.

Club is on the left after approx 1km.