



# Messages

Myasthenia Gravis Association of Queensland Inc

**OCTOBER 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**

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**PATRON**  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

### *Welcome*

Arrangements have been finalized for interested members to be given an update on the current situation regarding IVIg supply. The meeting will be on Sunday 11 November 2012 at the Upper Kedron Hall. This will be especially helpful and informative and offers the opportunity to members to have their concerns answered. Please note the item on Page 6 regarding this meeting - it is imperative that we know the exact number of people who will be attending this meeting.

Shirley Johnston and myself had the pleasure of representing the MGAQ at a coffee morning at the Little Big Man Coffee Shop at Dickson Street, Woolloowin in commemoration of Paul, a gentleman who suffered from myasthenia gravis and passed away last year. Paul was not a member of the Association but his wife and friends wished to make some gesture towards helping others who suffer from MG and wanted to help people to gain an awareness of Myasthenia Gravis. We met some of Paul's family and friends and also doctors from the Royal Brisbane Hospital. If you live in that area, or go past it sometimes, please call in and make yourself known. There is a donation box on the counter and their customers donate to our Association in memory of Paul. Our treasurer, Susan White, met Paul's wife when he was first diagnosed with MG on one of her trips to the hospital and they have kept in contact.

Bill Synnot has just returned from Fiji where he combined work and holiday together so it will be good to catch up with him at the next meeting. Susan White is away in October enjoying the life on a cruise ship. Graeme is off to Tasmania next month so hope he has a safe and enjoyable trip.

Don't forget to let us know if you will be coming to the Christmas Luncheon at the Power Boat Club in Caloundra.

Take care

*Anita*

*When the power of love overcomes the love of power, the world will know peace.*

Supported by



**Queensland** Government

**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 - BRISBANE**

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	32617564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

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Practice makes perfect but then nobody is perfect so what's the point of practising?

Light travels faster than sound. This is why some people appear bright until they speak.

Does expecting the unexpected make the unexpected expected? *Dylan*

## MEMBERS' FORUM

Barry from Toowoomba has brought the following item of interest to our attention:

*"Working with mice, Johns Hopkins researchers say they have developed a gene-based therapy to stop the rodent equivalent of the autoimmune disease myasthenia gravis by specifically targeting the destructive immune response the disorder triggers in the body.*

*The technique, the result of more than 10 years of work, holds promise for a highly specific therapy for the progressively debilitating muscle-weakening human disorder, one that avoids the need for long-term, systemic immunosuppressant drugs that control the disease but may create unwanted side effects.*

*The research, if replicated in humans, could be a big leap in treating not only myasthenia gravis, but also other autoimmune disorders, the researchers say.*

*"To treat autoimmune diseases, we normally give drugs that suppress not only the specific antibodies and cells we want to inhibit, but that also broadly interfere with other functions of the immune system," says Daniel B. Drachman, M.D., a professor of neurology and neuroscience at the Johns Hopkins University School of Medicine and leader of the study published this month in the Journal of Neuroimmunology. "Our goal was to suppress only the abnormal response, without damaging the remainder of the immune system, and that's what we did in these mice."*

*A healthy immune system has the amazing ability to distinguish between the body's own cells, recognized as "self," and foreign proteins and other substances — including germs and tumors — to fight infections, cancer and other diseases. The body's immune defenses normally coexist peacefully with cells that carry distinctive "self" marker molecules. But when immune defenders encounter foreign molecules, they quickly launch an attack. Autoimmune disorders occur when the immune system makes a mistake, in which it confuses "self" with something foreign, and then launches an attack by immune cells and/or antibodies to seek out and damage the body's own cells.*

*Drachman, one of the world's leading authorities on myasthenia gravis and other neurologic autoimmune disorders, and his colleagues say they have found a way to create a "guided missile" approach as opposed to the "carpet bombing" of overall immunosuppression. Essentially, Drachman says, the method eliminates the cells of the immune system that are involved in the attack against self and leaves other cells alone.*

*The research team created the guided missiles by genetically engineering dendritic cells, which are the immune cells that specialize in presenting antigens to the immune system's T-cells. They extracted dendritic cells from mice with myasthenia gravis, purified them and inserted genes which direct these dendritic cells to target the auto-aggressive immune cells, and destroy them using a "warhead" known as Fas ligand. Then they injected back into the mice the genetically engineered cells, which homed in on the immune system's faulty T-cells. The newly introduced "guided missiles" then sought out and bound themselves to those T-cells, causing apoptosis, or cellular suicide, which halted the autoimmune attack before it could gain traction. "This way, the autoantibodies were specifically reduced, a key step in treating myasthenia gravis," Drachman says.*

*The therapy dramatically reduced the autoantibodies responsible for myasthenia gravis, without affecting other responses of the immune system. However, the study was not carried out long enough to determine whether the mice were permanently cured of their disease. Theoretically, a similar approach to treatment could be translated to patients with myasthenia gravis, but so far it*

has not yet been tested in humans, and it is not yet known whether repeated courses of the therapy might be needed.

*Myasthenia gravis, a condition found in an estimated one to seven per 10,000 people worldwide, occurs in individuals who appear to be genetically predisposed, though it is unclear exactly what triggers the disease. Overall, however, an estimated 80 to 100 known autoimmune disorders affect more than 23 million Americans.*

*Patients who take immunosuppressant drugs are more susceptible to infections and even some forms of cancer.*

Source: [Johns Hopkins Medicine](#)

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](mailto: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.

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## **PROJECTS UPDATE**

### **Collecting data on sufferers of myasthenia gravis –**

Dr Blum presented preliminary results of the survey at the AGM. He spoke warmly of the experience of sharing our journey and commented on points of interest from both a physician's point of view and a sufferer's view of living with this condition. The research showed how difficult it is for a GP to diagnose the condition due to the wide variety of initial symptoms. It also showed the strong link to other auto-immune conditions. The current data entry will cut off at some point soon so that initial findings can be published. If you wish to be included it is time to be more proactive in completing your survey and seeing your doctor to gain the necessary validation via the blue form. We are very grateful to Dr Blum for the work that is taking place and for his time in attending the meeting. More details will follow for members via a DVD of the presentation.

Dr Blum's presentation showed that it really was worthwhile for people to take the time and effort to complete the Surveys and for this we are very grateful.

### **'Exercise Effect in MG' Pilot Study –**

Preliminary results were presented by Professor Jennifer Nitz at the Annual General Meeting on September 9. The DVD of her presentation will be available in the coming weeks.

Again, it is not too late to join the Study and if, after viewing the list of the exercises published in the March newsletter, you now feel inclined to join the study, and live in the Brisbane area, please contact the Secretary. (We have two new participants who have commenced the exercise program.)

\* \* \* \*

If you can't explain it to a six year old, you don't understand it yourself – Albert Einstein



**UPDATE ON MG AND IVIG**

Dr Joanne Pink, Red Cross Blood Service has agreed to give an update on the supply situation regarding Ivlg on Sunday 11 November 2012. As a courtesy to Dr Pink, we have chosen a venue close to where Dr Pink resides. The venue is the Upper Kedron Hall, 78 Cedar Creek Rd., Upper Kedron.

As numbers will be restricted because of venue limitations, only those who have expressed an interest in attending this meeting will be advised of the full details. If you wish to attend but have not yet advised of your interest, please do so by contacting the 1800 802 568 Freecall number by Friday 20 October next.

**Please note:** this a ‘meeting only’ event and no lunch is available at the venue. Tea or coffee will be available to attendees.

**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](mailto:jam3740@optusnet.com.au)

Initial offerings are:

**BOOKS**

Myasthenia Gravis and Myasthenic Disorders

Living a Healthy Life with Chronic Conditions

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

**DVD's**

Beyond Blue – volumes 1 & 2 (DVD)

We welcome donations of relevant material from our members.



**MORE CLEVER ANAGRAMS**

**ANIMOSITY becomes IS NO AMITY**

**ELECTION RESULTS becomes LIES – LET'S RECOUNT**

**SNOOZE ALARMS becomes ALAS! NO MORE Z'S**

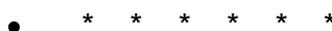
**A DECIMAL POINT becomes I'm A DOT IN PLACE**

**THE EARTHQUAKES becomes THAT QUEER SHAKE**

**ELEVEN PLUS TWO becomes TWELVE PLUS ONE**

**and for the Grand Finale**

**MOTHER IN LAW becomes WOMAN HITLER**



**KEEP YOUR BRAIN ACTIVE – THE QUIZ IS BACK!**

Answers are at the bottom.

1. Who is the Republican nomination for Vice-President in the USA presidential elections?
2. Which team won the AFL 2012 Premiership?
3. In which Australian state or territory is Gazette?
4. Who followed Queen Elizabeth 1 as monarch of England?
5. How many Oscars for Best Actress has Meryl Streep won?
6. Who was the oldest person to be appointed Australia's Prime Minister?
7. What does the French word 'legume' mean in English?
8. How many sides does a rhombus have?
9. Who co-wrote 'Fame' with David Bowie?
10. Marco Polo Airport is the airport for which city?
11. If you were suffering from *pyrexia*, how would you feel?
12. The fear of becoming bald is called what?
13. Michael Bond created which famous bear?
14. What was the first US entertainment TV program to be shown in China?
15. Which organisation appoints the 15 judges of the World Court?
16. Which city hosted the Winter Olympics in 1964 and 1976?
17. The song 'I Talk to the Trees' was featured in which musical?
18. What element gives amethyst its violet colour?
19. What century saw the invention of the shoelace?
20. A stoat's fur is called what?

Answers: 1. Paul Ryan; 2. Sydney Swans; 3. Victoria; 4. King James 1; 5. Three, Kramer vs Kramer, Sophie's Choice and The Iron Lady; 6. John 'Black Jack' McEwen – aged 67 years and 8 months ; 7. Vegetable; 8. Four; 9. John Lennon; 10. Venice; 11. Feverish; 12. Phalacrophobia; 13. Paddington Bear; 14. The Man from Atlantis; 15. United Nations; 16. Innsbruck; 17. Paint Your Wagon; 18. Manganese; 19. Eighteenth.; 20. Ermine.

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Be who you are and say what you feel, because those who mind don't matter and those who matter don't mind.

- Dr. Seuss

## 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

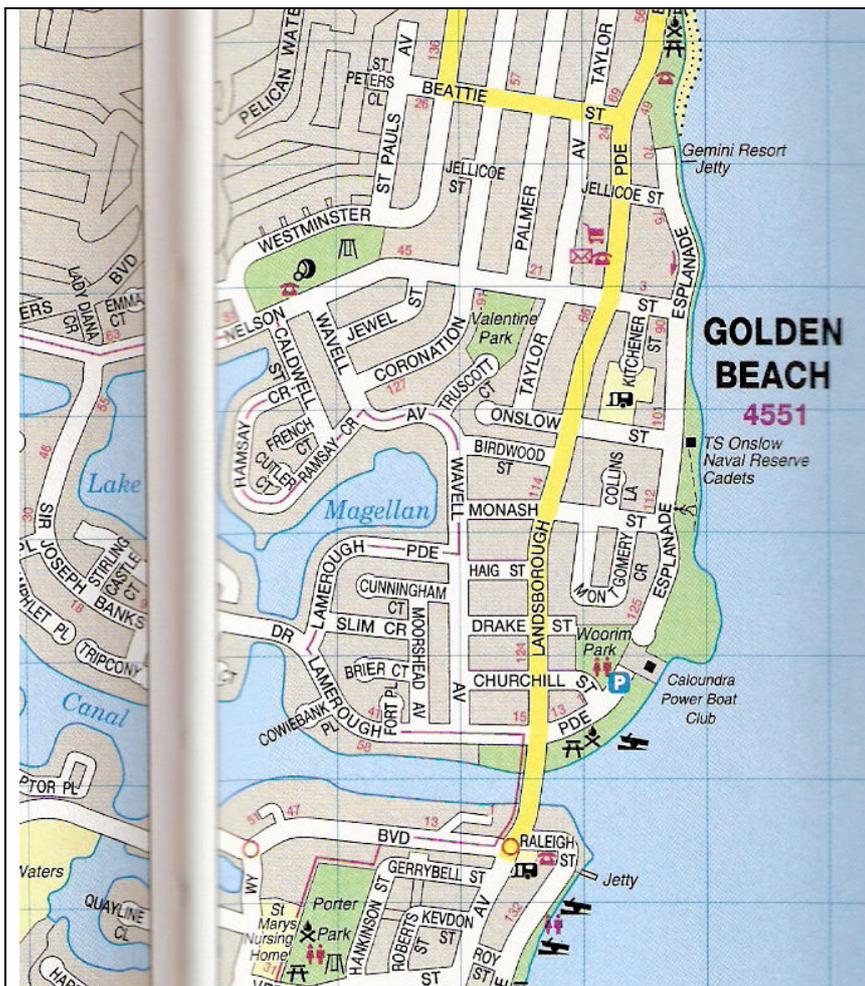
**WHERE:** Quarterdeck Restaurant, Caloundra Powerboat Club, Woorim Park, The Esplanade, Golden Beach. Car parking is available.

**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.

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