



# Messages

Myasthenia Gravis Association of Queensland Inc

**MAY 2013**



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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1800 802 568  
ABN 92 055 613 137

E-mail: [info@mgqa.org.au](mailto:info@mgqa.org.au)  
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Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## PRESIDENT'S REPORT

*Welcome,*

The weather has certainly cooled down so we all can relax as we now do not have to worry about our MG and the heat.

The committee is at present working on ideas about the new Federal Government Disability Scheme. We are thinking of getting a Socio-economic findings analysis from data taken from our surveys and hopefully being able to put this to the politicians in regards to the cost to the community of each person with MG.

June is MG awareness month and it is widely advertised in the USA - I just wish we could do something like that in Australia.

Our mid-year function on Sunday 16 June at the Southern Cross Sports Club with Dr. Stefan Blum may incorporate something about awareness month also. Please notify Shirley on the 1800 number if you are coming to this event.

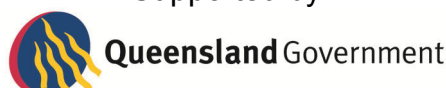
The committee is in holiday mode at present as Graeme Peters has just come back from holidays in the USA. I am off to the UK for seven weeks holiday in June. Bill Synnot is off to Fiji for work and holidays for two months.

Take care

*Anita*

**Editor's Note:** The editor apologises for the late distribution of this newsletter, but he did not return from overseas until 25 May and then fell ill for 5 days. Hopefully things will be back to normal for the June issue.

Supported by



**Queensland** Government

## **PROJECTS UPDATE**

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

Currently, it is anticipated that the survey results will be written up during the month of April, thus allowing time for a full 200 survey results to be entered into the data base.

What an effort from everyone involved! Thank you!

As explained previously, the survey recording will not stop with this write up. There is a target to find 500 Australian sufferers for the data base.

### **‘Exercise Effect in MG’ Pilot Study –**

#### **EXERCISES AT HOME**

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see.

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

Doctor Jennifer Nitz, who conducted the 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 above mentioned 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@mgag.org.au](mailto:info@mgag.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@mgag.org.au](mailto:info@mgag.org.au)

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### **“SURVEY SNIPPET”**

#### **KEEN SUPPORT**

As regularly reported, we are delighted with and grateful for the positive response that we have had for this survey. To further indicate that this research is important to people, 76% of Physicians were willing to provide further information if required and 85% of patients said they are happy to be contacted again regarding further research.

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A man can't keep people from having a bad opinion of him, but he can keep them from being right about it - Anon

**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
DIANNE	02 4574 3787	WINDSOR DOWNS 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

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We make a living by what we get; we make a life by what we give – *Winston Churchill*

Life is something that everyone should try at least once – *Henry J Tillman*

**Myasthenia Gravis Association of Queensland is on Facebook!**

MGAQ has recently joined Facebook and we now have a Facebook page. You can find us at <http://www.facebook.com/mgqld?ref=hl> or search for us when you log into Facebook.

The Management Committee has made the decision to join this online community so there is a place to share your stories, experiences, and recommendations with each other. We have already shared links to other people’s experiences of living with MG and we would love to hear from you.

For those of you who are not on Facebook yet but are interested in joining us in this online community you might want to click on one of the following links: <http://www.facebook.com> or [Explaining Facebook](#). In order to join Facebook you will need to have an email address and be older than 13.

Kate Lloyd – MGAQ Social Media Administrator

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**MORE OF BARRY’S LINKS OF INTEREST**

The following links to items of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

Researchers try A New Approach to Manage MG

<http://www.slu.edu/rel-hayat-1116>

Cello Advocacy and the University of Catastrophe

<http://www.diabetesmine.com/2013/01/cello-advocacy-and-the-university-of-catastrophe.html>

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**Obituary**

It is with great sadness that we advise of the passing of our Gold Coast Coordinator, John Nielsen.

John was a passionate supporter of the Association and was totally committed to its aims and objectives. He was the quintessential Australian ‘good bloke’ – always smiling, generous to a fault and always willing and available to help someone in need. He was a regular contributor to the humour which appears in the newsletters. As a mark of respect to John, the editor has included the last joke which was submitted by John just days before he contracted the illness which led to his passing.

On behalf of all members of the MGAQ we express our sympathy and support to John’s wife, Marilyn, and her family.

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**Late Obituary**

It is with deep sadness that we advise of the passing of Isadora (Dora) Cook in her 91<sup>st</sup> year. Dora and her husband, Alfred, were members of the Association for 16 years.

On behalf of the members of the MGAQ we express our sympathy and support to Alfred and his family.

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**IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME**

It's that time of the year again when Membership Subscriptions for the financial year 2013/2014 are due. Membership Fees are the same as last year.

The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address. If you receive the newsletter by email and are unsure whether or not you are currently financial, please ring our 1800 802 568 freecall number to enquire.

The majority of members will have 6/13 which tells you (and us) that you are financial to 30 June 2013. Others may show 6/14 or even 6/15 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/12, 6/11, etc. and we continue to send our newsletter to these unfinancial members because we do not know what they want. **If you are unfinancial, please take a minute to ring on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes".**

LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions.

***We are also giving you the option of paying your subscription directly into our bank account. Our bank details are:***

**BANK:** Bank of Queensland  
**BSB:** 124 032      **ACCOUNT NUMBER:** 10263772  
**ACCOUNT NAME:** Myasthenia Gravis Association of Qld Inc.  
**REFERENCE:** Your Name & Initials

If you use the direct deposit method, it would help if you could email us at [info@mgaq.org.au](mailto:info@mgaq.org.au) to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

.....  
Tear off along this line

**If you wish to pay by cheque or Money Order, please use the following form and forward to:**

The Myasthenia Gravis Association of Queensland Inc.  
PO Box 16  
MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$ \_\_\_\_\_ being annual subscription \$ \_\_\_\_\_ and/or Donation \$ \_\_\_\_\_:

NAME: \_\_\_\_\_ **Category A – Myasthenic \$15**  
**Category E – Supporter \$15**

ADDRESS: \_\_\_\_\_

AND FOR: \_\_\_\_\_ **Category D – Carer \$5**

ADDRESS: \_\_\_\_\_

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

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## MID-YEAR FUNCTION

- WHEN:** Sunday 16 June 2013 commencing at 10:00am for 10:30am
- WHERE:** Southern Cross Sports Club, corner Klumpp and Logan Roads., MountGravatt (vehicular entrance is from Klumpp Rd) Lunch is available at the venue with a varied and reasonably priced menu.
- GUEST SPEAKERS:** Dr Stefan Blum – Neurologist – More information from the Data Survey, followed by a general question and answer session on MG
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier
- HOW DO I GET THERE?** UBD Map 201 Reference D7.
- RSVP:** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch. Please let her know by **Monday 10 June 2013.**

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### A RETIRED PERSON'S HEALTH MESSAGE

As I was lying around, pondering the problems of the world,  
 I realized that at my age I don't really give a rat's arse anymore.  
 ....If walking is good for your health, the postman would be immortal.  
 ....A whale swims all day, only eats fish, drinks water, but is still fat.  
 ....A rabbit runs and hops and only lives 15 years, while  
 ....A tortoise doesn't run and does mostly nothing, yet it lives for 150 years.  
 And you tell me to exercise? I don't think so.

Just grant me the senility to forget the people I never liked,  
 the good fortune to remember the ones I do, and the  
 eyesight to tell the difference.

+++++

### Bus for Alaska

Fay was a busy housewife with a demanding husband, six children and a large house. The only relief she got from her chores was the twice-a-week bridge game she shared with a dozen other women. The only flaw in the bridge club relationship was that Fay loved to tell off-colour stories and the girls didn't want to hear them.

To teach Fay a lesson, the other women decided that the next time she told an off-colour story, they'd just get up, walk out, and meet at another home but without Fay.

Sure enough, at the next meeting, Fay started, "You know, girls, there's a rumour going around that a busload of prostitutes will be leaving in the morning for that big gold find up in Alaska, and they say...." Just then, the women all stood up and started for the door. Fay was disconcerted but only for a moment, then she understood what was going on and said, "Hey! Girls! Hold on, hold on! There's plenty of time 'cause the bus doesn't leave till morning!"