



# Messages

Myasthenia Gravis Association of Queensland

July 2015



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

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PATRON  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## PRESIDENT'S REPORT

*Welcome,*

Our July function was a great success with the committee members giving feedback on some of the points spoken about by the Guest Speakers at the Myasthenia Alliance Australia National Conference in Sydney last month. The information passed on was well received and many questions were asked. I would like to welcome our new members who came to this function and hope that you found it interesting and look forward to seeing you again. It was good to see our regular members whom we have not seen for a while also.

It is important to acknowledge the partnership between the Myasthenia Gravis Association of Qld and the Australian Myasthenic Association in NSW in putting together this conference which is hopefully the first of many to come. Feedback from participants and the guest speakers was very positive and the contacts made should enable myasthenics and their supporters to establish loose networks in states that do not have an incorporated association.

Our book 'Journey with Myasthenia Gravis' which comprises a number of personal stories told by some of our MGAQ members is now available for purchase and an Order Form is on page 7 of this issue. This book has been well received from our members.

The next function is the AGM in September at Southern Cross Sports Club in Klumpp Road, Mt Gravatt. To date our Guest Speaker has not confirmed if they are available but we will keep you informed.

We are slowly getting a few stories trickling through for us to print so keep up the good work everyone as they tell a different story every time.

Take care,  
*Anita*

Supported by



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Government

## **SURVEY UPDATE**

At the recent inaugural National Alliance Conference Dr Stefan Blum again discussed some of the statistics of interest which resulted from the Myasthenia Gravis survey. For many it was the first time they have been made aware of this work and of the findings and several people came forward requesting to participate. This was a great result as there was strong support from each of the Doctors involved in research initiatives, for the Association to continue distributing the surveys. The information base is being utilized and the flow on potential in regard to a data base for the DNA research is important.

The recent media release brought forward more people willing to participate in the survey and potential research initiatives. This is an excellent outcome from the ABC News item aired on June 19th.

An opportunity for further analysis of content provided in the survey was discussed at the Conference and preliminary conversation has begun with a view to bringing this additional research project forward. It will again be an initiative between RBWH, UQ and the MGAQ. More information will be provided as it becomes available.

## **MAA Conference Feedback**

Myasthenics and their supporters travelled from many states across Australia to attend the recent Myasthenia Alliance Australia Inaugural Conference and the atmosphere of friendship, collegiality and support was both exciting and stimulating. Many people have exchanged contact details and we are confident that the communities of Myasthenics in those states without an incorporated association will continue to grow.

Our first speaker was Associate Professor Dr Stephen Reddel who is a consultant Neurologist with the Brain and Mind Research Institute at University of Sydney. He is also a staff specialist neurologist at Concord Repatriation and General Hospital and is well qualified to head the Neuroimmunology Clinic at Concord Hospital which focuses on safe treatment for neurological conditions of all kinds. Dr Reddel together with other Neurologists established a study in MuSK antibodies and homeostasis of the neuromuscular junction. He spoke about the use of Plasma Exchange to distinguish between immune MG or genetic MG and that the Tensilon Test can give a false negative. Treatment aims to recover as much muscle function as possible and sufferers need to understand that this condition is slow to recover so there is a need for patience with treatments. A neuroimmunology tool can be found at [www.immunosuppressionscreen.net.au](http://www.immunosuppressionscreen.net.au)

Participants were asked to complete an evaluation sheet and feedback was nothing short of fabulous. Everyone seems to have got something important from each of the guest speakers as every one of them was rated very high on a 0-10 scale. What is being done by a group of highly skilled medical professionals, the research being conducted, the 'thinking outside the box' in relation to the treatment of MG reinforced that some of the work being done in Australia is up there with anything happening on the international scene. Comments such as 'well planned', 'a great experience', 'dedicated, capable approachable speakers', 'great for networking within each state and across states', 'want to be kept informed about future treatments' showed the level of appreciation and satisfaction from those who attended.

## **FUND RAISING!**



The Association has registered with Give Now for online fund raising donations with the hope of people or businesses donating to our Appeal. Please take a look at this site and advise anyone who may be interested in donating or gifting through his or her Will to the Association.

<https://www.givenow.com.au/myastheniagravisassociationofqld>

### 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.

## MGAQ HOTLINE 1800 802 568

### **CHAT LIST – QUEENSLAND REGIONAL COORDINATORS**

DONNA	0414 397 462	CAIRNS
DAPHNE	4773 3695	TOWNSVILLE
BILL	4954 1221	MACKAY
JAN (Hervey Bay)	0429 622 438	WIDE BAY/BURNETT
GARTH (Gladstone)	4973 7983	WIDE BAY/BURNETT
COLLEEN	5493 6391	SUNSHINE COAST

### **CHAT LIST – BRISBANE**

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	3261 7564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414 525 241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	3390 1788	CAPALABA
LORRAINE	3206 0789	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	0408 311 110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
DENNIS	3855 9379	GAYTHORNE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448 192 521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415 613 242	KANGAROO POINT
ROBYN	00434 532 853	KEDRON
GEOFFREY	3355 6441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	3886 7802	NARANGBA
SUSAN	3358 1056	NEW FARM
FARINAZ	0401 715 118	NEW FARM
KEVIN	3281 9225	NEWTOWN
BILL & JITLADA	3399 7041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
TRACEY-LEE	3284 9949	REDCLIFFE
SYBIL	3219 9535	ROCHEDALE
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JAMES	0433 662 913	WYNNUM
JOHN	3633 0604	ZILLMERE
ROSALYN	0407 697 206	ZILLMERE

### **FUTURE PLANNED ACTIVITIES**

**Sunday, 13<sup>th</sup> Sept** - AGM - Southern Cross Sports Club. Guest Speaker: TBA (see page 6 for more information).



### **Around Queensland**

#### **News from Gladstone**

My name is Garth McClure and I have recently accepted the position of Regional Co-Ordinator for the Gladstone area.

I am 55 years old and have lived in the Gladstone area all my life. My wife Colleen and I have four sons. I enjoy gardening and keeping busy.

I was diagnosed with ocular MG about 11 years ago. I work for Mini Excavations in Gladstone. I am very fortunate to have a very supportive workplace. In fact, when I was first diagnosed my boss 'googled' Myasthenia Gravis and printed out a whole lot of information for me. I was and still am very appreciative for his understanding of my condition, especially in the summer months when I fatigue easily.

Should you live in the Gladstone area, please feel free to contact me for a chat.

Garth McClure – PH: 4973 7983

**NEW MEMBERS**

We welcome the following new members:-

- Ronald, Magnetic Island QLD
- Peter and Liz, Kewarra Beach QLD
- Rhonda, Grange QLD
- Tanya, Mt Gravatt QLD
- Ronda, Mt Gravatt East QLD
- Melita, Melbourne VIC

**MEMBERS FORUM**

*Bill writes-*

*Myasthenia Gravis is not a death sentence if you accept what nature has done and follow your MEDICAL PRACTITIONER's advice.*

*It appears I had symptoms of MG for a considerable time and did not have any strength. I could not speak clearly. All my food had to be mashed up.*

*While all this was happening I had many tests. Was also sent to a shrink as I was supposed to be suffering from depression.*

*Had a blood test - a certain component was elevated which indicated I may have MG. My GP said I was the first patient in 25 years of practice to have MG.*

*The Christmas of 2004 MG was confirmed. There was only one neurologist working in QLD. My GP made an appointment to see a private neurologist in Townsville in January of 2005.*

*When the Townsville neurologist saw me he said he was sure I had MG but would conduct many tests which confirmed MG. The neurologist told my wife that if she thought I was sick now it would be a lot worse when treatment began and could be in hospital for up to 6 weeks. As luck would have it, I did not suffer major problems with the treatment and was out in the week. I had to see the neurologist every month for a while then every 2 months and then every 6 months.*

*When the neurologist retired in Townsville he suggested that I see a neurologist in Brisbane every 6 months.*

*I have a blood test every month and the results go to my GP and to the neurologist in Brisbane so if there are any changes they can be fixed up quickly. I do not want to go back to how it was at the end of 2004!*

*Before having MG, heat did not affect me. Now when it is very hot my dogs give the look to say it's time to go into the air-conditioning.*

*Before getting MG under control, I lost 27kg in weight and was told I looked like a P.O.W from 2<sup>nd</sup> world war.*

*I still do most things I did before MG. I work my own cane farm; work dozer and scraper; make and repair equipment; help with cattle at my son's block; cart cane for harvesting contractor.*

*In my opinion, animals are a wonderful help when you have MG. When I was first diagnosed I had a calf that I had to feed with the bottle. I got it to lie as if dead, shake hands etc. I still have her, but much too big to play with now.*

*I am thankful to the medical practitioners, my wife (Muriel), my children (Janet and Ian) that I can still enjoy life today. My advice is to make sure you get the medication your medical professionals prescribe not the generic brands that some chemists will try to make you accept.*

*I would suggest anyone with MG to join the Association so you realise that you are not alone. If the local area is having a get together, it is important to attend as talking to others about anything helps.*

Contact Myasthenia Gravis Association of Qld (MGAQ) on free call 1800 802568 or email [info@mgag.org.au](mailto:info@mgag.org.au) to find out who the Regional Co-Ordinators are in your area. The MGAQ is represented in Cairns; Townsville; Mackay; Wide Bay (Gladstone; Hervey Bay); and the Sunshine Coast.

Thank you for allowing me to tell how Myasthenia Gravis has affected me.

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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## 2014/2015 ANNUAL GENERAL MEETING

- WHEN:** Sunday 13th September 2015 at 10:00am for 10:15am sharp
- WHERE:** Southern Cross Sports Club, Corner Klumpp and Logan Roads, Mount Gravatt (vehicle entry to club is via Klumpp Rd.)  
Lunch is available at the venue with a varied and reasonably priced menu.  
Tea and coffee will be available prior to the meeting.
- GUEST SPEAKERS:** To be advised
- 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 **Friday 4th September 2015**



facebook

Have you “liked” us on Facebook yet?  
“post” a comment, start a discussion and help spread awareness.

<https://www.facebook.com/mgqld?fref=ts>



## “Journey with MyastheniaGravis”

*A Book of Personal Stories, written by Sarah-Jane Fleer and produced*

*by the Myasthenia Gravis Association of Queensland Inc.*

*Made possible with the support of the Queensland Department of Health.*

*“Journey with Myasthenia Gravis” was born from a suggestion by a thoughtful specialist to a husband of a long-term myasthenic sufferer. First an author was found who keenly and compassionately gave of her time. The editor and designer crafted the project with the necessary skill, care and commitment to create an engaging journal. A renowned artist embraced the opportunity to share his joyous work, bringing to the cover a positive feeling. This book must be dedicated to not only those with Myasthenia Gravis but also to those who have made it a reality. Everyone touched by this project has embraced the power offered in the telling of the stories of being diagnosed with and treated for a rare chronic condition. Readers will have the opportunity of understanding the importance of sharing the experience of living with a rare condition.*

After being launched at the inaugural Myasthenia Alliance Australia conference, this wonderful book is now available to our members, to the general public and to medical professionals interested in understanding more about life with Myasthenia.

Books can be purchased from the Association using the attached order form or via the website ([info@mgaq.org.au](mailto:info@mgaq.org.au)). Books cost \$22.00 incl GST plus \$5.00 postage and handling for one copy or \$10.00 postage and handling for two or more copies.

*We are also giving you the option of paying direct 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 debit method, it would help if you could email us at [info@mgaq.org.au](mailto:info@mgaq.org.au) to advise us 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. **Also, ensure that you include your name and address so we know to where we need to post the book/s.**

.....  
**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

Please find my cheque / money order / cash for the sum of \$\_\_\_\_\_ being payment for  
\_\_\_\_\_ copies of the book "Journey with Myasthenia Gravis" plus \$\_\_\_\_\_ for postage – a total of  
\$\_\_\_\_\_

NAME \_\_\_\_\_ PHONE NO \_\_\_\_\_

ADDRESS \_\_\_\_\_

ADDRESS \_\_\_\_\_

Your receipt will be forwarded to you with the book/s you have purchased.

# IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2015/2016 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 phone our 1800 802 568 freecall number to enquire.

The majority of members will have 6/15 which tells you (and us) that you are financial to 30 June 2015. Others may show 6/16 or even 6/17 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/13, 6/12, 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 phone 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**

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**ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.**

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**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**  
**(or) 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.