



# Messages

Myasthenia Gravis Association of Queensland Inc

**DECEMBER 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

P.O. Box 16  
MT. GRAVATT QLD 4122  
NATIONAL FREE CALL:  
1800 802 568  
ABN 92 055 613 137

E-mail: [info@mgaq.org.au](mailto:info@mgaq.org.au)  
Internet: [www.mgaq.org.au](http://www.mgaq.org.au)  
MGAQ Facebook page:  
<https://www.facebook.com/mgqld/?fref=ts>  
MGAQ Discussion Forum:  
<https://www.facebook.com/groups/mgqld/>

### COMMITTEE MEMBERS

*President*  
Graeme PETERS  
Ph. 3288 4484

*Vice-president*  
John NOBLE  
Ph: 3269 5066

*Secretary*  
Carol BUCHANAN  
Ph. 4773 7122  
email: [info@mgaq.org.au](mailto:info@mgaq.org.au)

*Acting Treasurer*  
Susan WHITE  
Ph: 3358 1056

*Information Officer*  
Shirley JOHNSTON  
Ph. 1800 802 568

*Committee*  
Donna FORMOSA  
Ph: 4039 2148

Rosalyn HOLLAND  
Ph: 0407 697 206

Anita JACKSON  
Ph: 3800 4913

*Editor*  
Emily SEXTON  
Ph: 0425 821 670  
email: [emily.sexton@live.com.au](mailto:emily.sexton@live.com.au)

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

## PRESIDENT'S REPORT

G'day all,

Another year done and dusted – a year of achievement of which the MGAQ can justifiably be very proud. Among these achievements are the inaugural Australian Myasthenia Gravis Conference thanks to the efforts of the Myasthenia Gravis Alliance Australia with support from both myasthenia gravis support groups in Queensland and New South Wales; the continuing Data Collection Survey of MG sufferers and the MGAQ has three further tasks associated with this awaiting commencement; the book 'Journey with Myasthenia Gravis' was completed and published, has been very well received and orders are being received at a steady rate. And of course, the day-to-day support of our members has continued unabated.

The reinstatement of funding from Queensland Health for the next 3 ½ years has lifted a weight from the shoulders of the Management Committee, and for this we are truly grateful. But it does not mean that we can be complacent – funding can be removed at any time, so we must proceed as if the MGAQ will need to be self-sufficient into the future.

The only sour note is my disappointment that we still do not have a Treasurer for the MGAQ. Time is running out for Susan to continue as Acting Treasurer and we must have someone to take over within the next couple of months. A belated Christmas present to the association would be a volunteer to take on the job of Treasurer. Please contact our 1800 802 568 freecall number if you would like to help out and Shirley will connect you with either myself or Susan for more information about the position.

I want to thank my fellow committee members for their efforts and assistance in working very hard towards achieving the MGAQ's Mission of 'Improving the Quality of Life for People with Myasthenia Gravis and their families.'

Finally, I wish our members and their families a happy, healthy and safe Christmas and New Year and I look forward to a 2016 of continuing achievement by the MGAQ.

Cheers

*Graeme*

Supported by



**Queensland  
Government**

## PROJECTS - UPDATED

### SURVEY STATUS

The survey remains an important aspect of the work of the Association. It had been hoped that information pertaining to further work that will result from the data collected to date, could be shared with our members in time for Christmas but alas it is not yet time! We can tell you though, additional surveys are indeed going out each and every month and a new round of data entry is soon to take place. This painstaking work is again to be completed by a volunteer. Our sincere appreciation is extended to the young man who will so generously give of his time to complete this task.

### MYASTHENIA ALLIANCE AUSTRALIA



The Alliance Committee continues to meet regularly and has several projects on the working agenda. Confidence in our ability and willingness to host another Conference is growing but this event is not anticipated to take place in the near future.

The Alliance is aware of several sources currently providing information in relation to 'drugs to be used with caution in Myasthenia'. Comment on these resources will be sourced and summary information will then be made available to members. Always, it remains important that any new prescription be carefully assessed by both the prescribing doctor and the pharmacist for safe use in the case of each Myasthenic.

In 2016 the Alliance hopes to make closer links with other supporting organisations located around the world. Preliminary research indicates that there are a significant number of registered organisations dispersed throughout the world.

Conversation with the National Blood Bank Authority has confirmed that the supply of some plasma products (eg. Kiovig and Octagam) is now from alternate providers. If concerned, a conversation with your practitioner in regard to any effects of such a change may be warranted. Details relating to this can be viewed on the following link provided via the Authority website. [http://www.blood.gov.au/plasma-and-recombinant-product-procurement#imported\\_supply](http://www.blood.gov.au/plasma-and-recombinant-product-procurement#imported_supply). A second article which is in pdf and doc.x format gives more information. Within this site be sure to open the following links.

- [Supply of Plasma Derived and Recombinant Blood Products Factsheet \(pdf\) \(101.65 KB\)](#)
- [Supply of Plasma Derived and Recombinant Blood Products Factsheet \(docx\) \(38.57 KB\)](#)

Follow the work of the Alliance by registering at the website [www.myastheniaallianceaustralia.com.au](http://www.myastheniaallianceaustralia.com.au)

## MAA Conference Feedback (No 6)

### **Dr Katherine Buzzard - "Advances in Treatment of the Myasthenias"**

Dr Buzzard is a consultant neurologist at Eastern Health and Royal Melbourne Hospital and holds an academic appointment at the Eastern Clinical School, Monash University. She has particular

research interests in inflammatory and autoimmune neurological diseases and is currently working on developing a global registry of patients with neuroimmunological diseases, including myasthenia gravis.

Dr Buzzard spoke about the important role B cells play in the immune system. They:

- Produce antibodies
- Help T cell function
- Release pro-inflammatory and anti-inflammatory mediators.

She also spoke about developing therapies:

- Monoclonal antibodies – designed to target very specific parts of the immune system
- Reinvention of some old treatments. Investigating the importance of exercise.
- Rituximab – Aimed at reducing B cells. Phase 2 trials occurring in USA but only with small numbers and restricted guidelines. \$7500 - \$10,000 per course.
- Belimumab – also gets rid of B cells. Being used on humans in USA. Cost US \$28 000 per year.
- Complement Activation Cascade – targets and gets rid of bacteria.
- Eculizumab – costs \$650 000 a year. Phase 2 study in USA, UK and Canada
- Cyclophosphamide – Previously used for MG in high doses without securing a long term result. New approach uses reduced dosages given at home in monthly cycles for 6 months followed by other oral immune-suppression afterwards. Positive benefits for majority of patients within three months.

Important work is being done in setting up a website called eNid – Electronic Neuroimmunology Database. Information on this available on the web. It sounds like a future valuable instrument.

---

**If you, or a family member, or a friend, would like to be involved in any aspect of the work undertaken by the Association do make contact on 1800 802 568 or [info@mgaq.org.au](mailto:info@mgaq.org.au) as we would be delighted to discuss options with you.**

---

### Shirley's Recipe

#### Slow Cooked Spicy Corned Beef

#### Ingredients:

- ½ cup brown sugar
- 1 tablespoon Cajun season (I use 1 Teaspoon)
- 2 teaspoons lemon pepper
- 1 tablespoon Worcestershire sauce
- 1.4 - 1.8kgs corned beef

#### Method:

1. Combine brown sugar, Cajun seasoning, lemon pepper and Worcestershire sauce in a pan or bowl and spread over corned beef.
2. Place in sprayed oval slow cooker.
3. Cover with lid and cook on low for 6 – 8 hours. Turning occasionally.

### Future Planned Activities

Sunday 13 March 2016

Sunday 12 June 2016

Sunday 11 September 2016

Sunday 11 December 2016

Picnic Brisbane – Robell Domain, Springfield Central

Mid-year function – venue and Guest Speaker TBA

Annual General Meeting – venue and Guest Speaker TBA

Christmas function – Gold Coast – venue TBA

**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 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 SUPPORT LINE 1800 802 568****CHAT LIST – QUEENSLAND REGIONAL COORDINATORS**

DONNA	0414 397 462	CAIRNS
DEBBIE (Taroom)	4628 6103	DARLING DOWNS
NADER	0415 834 401	GOLD COAST
BILL	4954 1221	MACKAY
JEANNE	0437 048 361	ROCKHAMPTON
COLLEEN	5493 6391	SUNSHINE COAST
DAPHNE	4773 3695	TOWNSVILLE
GARTH (Gladstone)	4973 7983	WIDE BAY/BURNETT
JANET (Hervey Bay)	0429 622 438	WIDE BAY/BURNETT

**MGAQ SUPPORT LINE 1800 802 568****CHAT LIST – QUEENSLAND REGIONAL**

DAVID	5594 0489	ARUNDEL
KELLY	4728 4913	AITKENVALE
ROSALYN	0407 697 206	ANDERGROVE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
NOEL	5495 2938	BELLMERE
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
SYDNEY	4051 6896	BUNGALOW
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
JIM	0414 241 091	BURPENGARY EAST
DAVID	4053 2291	CAIRNS
HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
SCOTT	5446 3894	COOLUM BEACH

JOHN	0419 624 767	COOMBABAH
GAIL	0407 514 241	COOROIBAH
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
MARSHA	4987 6820	EMERALD
ELIZABETH	4936 2410	GLENLEE
LILLIAN	4933 4281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427 752 956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412 456 439	LABRADOR
KAREN	0408 153 285	LOWOOD
JUDIE	0439 461 288	MACKAY
TONY	4942 4676	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
RAYMOND	0407 752 956	MILLMERRAN
CAROLYN	5522 8987	MUNDUBERRA
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418 778 082	MONTEREY KEYS
CAROLYN	5522 8987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
BROOKE	0404 720 807	NAMBOUR
ALEX (BROOKE'S CARER)	0420 858 386	NAMBOUR
KEITH	5441 7236	COES CREEK, NAMBOUR
KARLIENE	0432 431 591	HERVEY BAY
MICHAEL	5545 2802	NORTH TAMBORINE
KARLIENE	0432 431 591	NANANGO
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411 331 258	PACIFIC PINES
JUNE	0409 63 6467	PALM BEACH
RICHARD	0418 249 640	PARADISE POINT
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
JEANNE	0437 048 361	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
DEBORAH	0457 148 486	SUNSHINE COAST
BERNIE	Joympaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
SUNSHINE	0487 365 363	TORQUAY
CAROL	4773 7122	TOWNSVILLE
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418 879 801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
SARA	0422 109 492	TOWNSVILLE
SHIRLEY	4778 7117	TOWNSVILLE
ANNE	0487305 153	TRINITY BEACH
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458 980 667	YANDINA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

Please note that \* indicates that this member is available via the VOIP Skype facility on a computer



## Around Queensland

### News from Cairns

Our last get-together for 2015 was well attended by members in Cairns. It was a great opportunity to catch up with everyone and share stories. We agreed to meet again at the RSL Club on the 19<sup>th</sup> of February 2016.

Donna Formosa  
0414397462 or 40392148

### News from the Sunshine Coast

Greetings from the Sunshine Coast Group. Our next gathering will be on Saturday 6<sup>th</sup> February and will be at Buderim Tavern at 12 noon. You may have lunch or just coffee and we will discuss further dates for the coming year. I suggest we meet on the first Saturday of the even months of the year but am open for suggestions. Hope to see you on 6<sup>th</sup> February

Colleen McLean  
0409 491 789  
[colleen4551@gmail.com](mailto:colleen4551@gmail.com)

### News from The Gold Coast

The Gold Coast MGAQ Group will meet again on Saturday 9<sup>th</sup> January 2016 at the Southport Surf Club, Main Beach at 10.00am. Please contact Nader if you are able to attend.

Nader Amiri  
0415834401

### News from Townsville

Townsville MGAQ group Lunch – Saturday 6<sup>th</sup> February 2016

Daphne – 0400 778 637  
Email: [daphclay@gmail.com](mailto:daphclay@gmail.com)

### NEW MEMBERS

We welcome the following new members:-

Greg – Kings Meadows TAS  
Craig – Mackenzie QLD

### MEMBERS' FORUM

There were two contributions this month

Helen writes,

*I read in the last newsletter about putting a black patch over one eye at a time if you have double vision. I did this for 6 months until I was sent to an Ophthalmologist who put a prism on my left side of day glasses and right side of reading glasses and I can see perfectly with either pair on.*

*I was wondering if anyone else has a feeling as if insects are crawling under the skin as I do on my arms and legs.*

*My telephone number is 08929735280 if anyone wants to contact me.*

Jan writes,

*I read with great interest the article by Trevor regarding his adventures with GP's and Specialists in his search for a medication regime that is suitable for him and his lifestyle.*

*Trevor, I feel great empathy with you as I have always had similar experiences in my 40 years living with a quite mild form of MG.*

*I have had a GP tell me "you can't have MG as you walked in here well and can sit up in that chair," I have been told "you must be in remission, keep taking your medication!" just to name a couple of my experiences.*

*My experience, and this is just a personal opinion, is that we who have a mild form of MG that is controllable with Mestinon, either confound Doctors or are not that interesting as we can usually manage our symptoms reasonably well.*

*Having said that, I find it is really challenging to be, at times ignored, or the daily struggles we deal with, to find a dosage that allows us to lead as normal life as possible, then once we achieve that, to be told we are in remission or just continue what you are doing.*

*After one experience when a GP who told me he knew all about MG gave me a drug that almost sent me into a Myasthenia Crisis, decided it was because I was not on a high enough dosage of Mestinon and sent me to a specialist.*

*He decided I was fine and the dosage was ok and I didn't need to change my medication! Back home I developed bad leg cramps so I decided, with my GP's approval to increase my Mestinon, not the level but took my 60mg every 3 hours, not every 4 hours. This worked well, but a new Specialist told me I was having too much Mestinon and that was giving me the leg cramps! I did explain the cramps had stopped with the different routine, but he would not have that!*

*I have continued with my 60mg every 3 hours and at night a Timespan of 180mg that maintains my Mestinon level overnight.*

*I am now managing very well on this routine, in fact so well that another Specialist told me I was showing no symptoms so I must be in remission, but to keep taking my medication!*

*It is confusing but fortunately I now have a GP that is happy to work with me and together we work out a routine that suits me, and mostly leaves me to suggest any changes, and we either go ahead with these changes or not. For example I am struggling with my energy levels at the moment, so together we decided to try adding a 10mg to my 60mg at times during the day when I am most active. This seems to be working.*

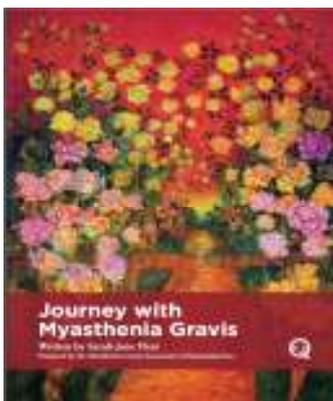
*We certainly have a challenge living with MG in its many forms don't we?*

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 make 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.

## **"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER**



What an unexpected and enriching Christmas gift this book makes! It is not too late to arrange for copies to be delivered to you. Free Christmas wrapping is on offer upon request so gifts can be posted direct to the recipients! Raising awareness of Myasthenia is as important as always and every opportunity to do so should be snatched. The book is such a great tool for demonstrating the uniqueness of each journey with the condition. Contact Susan on 0419 912 652, or email at [info@mgaq.org.au](mailto:info@mgaq.org.au)

# Merry Christmas!!



+++++

*The President and Management Committee of the Myasthenia Gravis Association of QLD Inc. wish our members and their families the very best of wishes for the festive season and a safe and prosperous 2016.*



*They would also like to thank you for your support over the past year and look forward to a bigger and better 2016.*



+++++

## And have a happy New Year!