



Messages

Myasthenia Gravis Association of Queensland

MAY 2014



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
Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
John NOBLE
Ph. 3269 5066

Secretary
Carol BUCHANAN
Ph. 4773 7122
email: info@mgaq.org.au

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee
Graeme Peters
Ph: 32884484

Committee/Editor
Catherine ORMSBY
Ph: 0418451110
email: cocraftychick@hotmail.com

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

What a cool start we have had for the beginning of our cooler months. Just hope that it is not how it will be for the real winter months which are still to come.

We have been given the names of our Consultants from Queensland Health in regards to the development of our transition plan on how the Association will continue to function without our grant monies from Queensland Health. We are meeting them the beginning of July so we really need feedback from our members on how you think we can economise and continue to run the Association.

We have booked our guest speakers for the June meeting and the AGM. We look forward to what they will discuss as they are excellent speakers so they should make very interesting meetings.

The committee is still working on the National Alliance with our Lawyer but making sure that everything is correct so that we have the right direction in forming this Group.

With the impending cessation of funding from Queensland Health, it is more imperative than ever that the MGAQ has a full Management Committee to operate the Association. As Catherine and Graeme, who were appointed to fill Casual Vacancies on the Committee, are not seeking re-election, I would ask that members give serious consideration to nominating for the Management Committee for 2015/2016.

Also, we are still looking for willing people to be our coordinators for the Sunshine Coast and Gold Coast. It is a rewarding job; not that it is really a job as you would just have to organise a coffee morning or something similar every few months.

Looking forward to seeing our members either at the June meeting and the AGM in September.

Take care,

Anita.

Supported by



Take care,

SURVEY UPDATE

Collecting data on sufferers' of myasthenia gravis:

Dr Blum can confirm that surveys are still being received and contact with Australian sufferers continues to expand. During conversations with Rare Voices (see page 3) it became obvious that formulating registries of sufferers of Rare disease is a priority. Compiling such information is not easy and the survey work may be invaluable in this regard.

Dr Blum also confirmed that a first article for publication regarding malignant thymoma and MG was submitted a few weeks ago. As acceptance of papers usually takes a number of months there is no news as yet in this regard. The quality of life data article is also nearing final stages, and will probably be submitted to an Australian journal.

FUTURE OF QUEENSLAND HEALTH FUNDING - UPDATE

The management committee has been communicating with BoardConnect in relation to developing a transition plan which is now due at the end of September. A meeting between BoardConnect representatives and management committee members will be held on 04 July and, from this meeting, the committee should have a better understanding of what is expected and how to proceed with formulating the transition plan.

We urge members to peruse the list of possible revised strategies from the previous newsletter and provide feedback on how they think the association can be autonomous after 2015. We also encourage all members to ensure that their membership is current as this is one way of supporting the work of the association as we move forward.

REGIONAL COORDINATOR VACANCIES

Currently there are vacancies for the following positions of Regional Coordinator for the South (Gold) Coast, North (Sunshine) Coast, Wide Bay/Burnett and Rockhampton regions.

With the impending cessation of funding to the MGAQ from Queensland Health, the role of Regional Coordinator will take on an increased importance as the conduit between our members in the regions and the Management Committee.

The role of Regional Coordinator includes: maintaining regular contact with the members in the respective region, usually by means of regular (say 3 to 4 monthly) get-togethers; dissemination of MGAQ Information Booklets and Pamphlets throughout the region; and bringing concerns or suggestions from local members to the attention of the management Committee.

The Management Committee would like to hear from members (or carers) who are interested in taking on the role of Regional Coordinator in any of the abovementioned regions via an email to info@mgaq.org.au or a phone call to our Freecall 1800 802 568 number.

A bird in the hand will poop in your palm.

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
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
MAUREEN	02 4476 3734	NAROOMA 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
EDMUND	03 95098920	CAULFIELD NORTH 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	ALICE SPRINGS NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

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 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.

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.

Tangy Lemon Squares

125g butter	1 cup castor sugar
¼ cup icing sugar	2 tsps. Lemon rind
1 ¼ cups plain flour	½ cup lemon juice
3 eggs	

Method:

1. Heat oven 180c. Grease 23cm square slab pan, lined with paper – lined over the sides.
2. Beat butter and icing sugar in small bowl, stir in 1 cup of flour.
3. Press into base of tin.
4. Bake 15 minutes until lightly browned.
5. Whisk eggs, castor sugar, remaining flour, rind and juice.
6. Pour over base.
7. Bake a further 20 minutes or until firm.
8. Let cool in pan on rack.
9. Slice, dust with extra icing sugar.

It never hurts your eyesight to look on the bright side of things.

A pessimist is someone who believes that when her cup runneth over...she'll need a mop.

I'm not spoiled....I'M NOT. I'm not...I'm not...I'm not...

Myasthenia Gravis Association of Queensland is on Facebook!

MGAQ is on 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.

Negotiating Life With Chronic Illness

Cindy Gallois is our guest speaker for the Mid-year Function (see page 8)

Cindy Gallois is a professor of psychology and communication at The University of Queensland, and a Fellow of the Academy of the Social Sciences in Australia. Her research is focused on communication in health, including communication between health professionals and patients and communication across health professions, as well as the impact of communication on quality of patient care. She has a particular interest in communication, chronic illness, and disability.

GROWING OLDER

- As I've aged, I've become kinder to myself, and less critical of myself. I've become my own friend.
- Sure, over the years, my heart has been broken. How can your heart not break, when you lose a loved one, or when a child suffers, or even when somebody's beloved pet gets hit by a car? But, broken hearts are what give us strength, and understanding, and compassion. A heart never broken, is pristine, and sterile, and will never know the joy of being imperfect.
- I am so blessed to have lived long enough to have my hair turning grey, and to have my youthful laughs be forever etched into deep grooves on my face. So many have never laughed, and so many have died before their hair could turn silver.
- As you get older, it is easier to be positive. You care less about what other people think. I don't question myself anymore. I've even earned the right to be wrong.
- I like being old. It has set me free. I like the person I have become. I am not going to live forever, but while I am still here, I will not waste time lamenting what could have been, or worrying about what will be. And I shall eat dessert every single day (if I feel like it).
- I know I am sometimes forgetful. But there again, some of life is just as well forgotten. And, I eventually remember the important things.

AUSTRALIAN TRIVIA - Questions and Answers**Sport**

1. Which horse won the Melbourne Cup in 2002?
2. What was Sir Donald Bradman's batting average?
3. Who is Australia's only Formula One driver?
4. Who won the Brownlow Medal in 2003?
5. Who was the most recent Australian to win the men's singles title at Wimbledon?
6. Which Australian was named the most valuable player in the US's WNBA?
7. Which Australian has won the FIM World Motorcycle Championship 5 times?
8. How many gold medals did Australians win at the 2002 Winter Olympic Games?
9. Of our Australian male swimmers, who has won the most Olympic gold medals?
10. What Australian company is the largest surf wear manufacturer?

General Knowledge

1. How many countries are larger than Australia?
2. In what state/territory was the highest recorded temperature, of 53oC, recorded?
3. Australia has the world's largest sand island. What is its name?
4. In what year was Advance Australia Fair proclaimed as the national anthem by the Governor-General?
5. Do all states/territories have the same blood alcohol limit for non-probationary drivers?
6. What animal is on the Western Australia flag?
7. In what city did the Commonwealth Parliament first sit?
8. What animal featured on the 2 cent coin?
9. Who is the only person to have been awarded both the Australian of the Year and Young Australian of the Year titles?
10. Who is on the front of the current issue \$100 note?

Answers - Sport

1. *Media Puzzle*
2. *99.94*
3. *Mark Webber*
4. *Mark Ricciuto, Nathan Buckley, Adam Goodes*
5. *Lleyton Hewitt*
6. *Lauren Jackson*
7. *Michael Doohan*
8. *2 – Steven Bradbury and Alisa Camplin*
9. *Murray Rose*
10. *Quicksilver*

Answers – General Knowledge

1. *Five (Australia is the sixth largest country: Russia, Canada, China, USA, Brazil)*
2. *Queensland*
3. *Fraser Island*
4. *1984*
5. *Yes*
6. *Black swan*
7. *Melbourne*
8. *Frilled neck lizard*
9. *Cathy Freeman*
10. *Dame Nellie Melba*

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2014/2015 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 6/14 which tells you (and us) that you are financial to 30 June 2014. Others may show 6/15 or even 6/16 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 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 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.

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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.

MID-YEAR FUNCTION

- WHEN:** Sunday 15 June 2014 commencing at 10:00am for 10:30am
- WHERE:** Southern Cross Sports Club, corner Klumpp and Logan Roads., Mt.Gravatt (vehicular entrance is from Klumpp Rd). Lunch is available at the venue with a varied and reasonably priced menu.
- GUEST SPEAKERS:** Cindy Gallois - PhD FASSA – Living With Chronic Illness.
(See bio. on page 5)
- 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 6 June 2014.**

DATES TO REMEMBER

- 14 Sept** - AGM - Southern Cross Sports Club. Guest Speaker Dr. Rob Henderson.
- 14 Dec** – Christmas Function Brisbane venue TBA

FUTURE PLANNED ACTIVITIES FOR CAIRNS

Meetings are held at the RSL Club Boardroom, Esplanade Cairns, at 11.30am unless advised otherwise. Some people stay on for lunch in the restaurant afterwards (at own expense).

We have set the dates for the meetings in 2014.

Thank you to those who attended our meeting in May (postponed from April due to Cyclone Ita).

- * **Saturday 21st June** – Venue as above. Special “MG Awareness Month” Guest speaker is Gayle Rogers – Speech Pathologist.
- * **Saturday 16th August** - TBA
- * **Saturday 11th October** - TBA
- * **Saturday 6th December** – Christmas function

Donna Formosa – Phone 0414 397 462 or email formosed@bigpond.net.au for more information.