



Messages

Myasthenia Gravis Association of Queensland

JUNE 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**
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1800 802 568
ABN 92 055 613 137

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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

It looks like we will be having winter after all. That will be good as we don't have to worry about our MG and the heat.

The committee is looking forward to meeting our Queensland Health Consultants in July. The meeting will discuss the development of our transition plan on how the Association will continue to function without our grant monies from Queensland Health.

Our Guest Speaker Dr Rob Henderson has been booked for the AGM. We are really looking forward to hearing what he will discuss as his last talk was excellent. Hoping to see as many members as possible at the meeting. The committee puts a lot of effort into organising the venue and getting the session videotaped so that our country members can also see the presentation.

At the AGM we would like to find replacements for the two committee members that we are losing as we cannot survive without them. Please think about coming on to the Committee. We value any input on how the Association will move forward without the grant monies. It will be very disappointing if the Association has to fold, as so many people have put a lot of work into keeping the Association going over the years.

We are still looking for a person to be our coordinator for the Sunshine Coast as 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.

I would like to extend a warm welcome to Denise Botke as our coordinator for the Gold Coast.

We welcome Susan back from her overseas holiday and hope that she has fresh ideas to work for another year on the committee.

Take care,

Anita

Supported by



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 is continuing to speak with and provide information to BoardConnect, the consultants appointed by Queensland Health to guide the development of our Transition Plan. Our first face-to-face meeting with BoardConnect will take place on 04 July and, after that meeting, we are hoping to have a better understanding of what is required for this transition plan and how best to proceed with completing it. Our Transition Plan is due to be completed and with Queensland Health by the end of September and, if the plan is accepted, funding for our association will continue until the end of 2015. Whether or not the plan is accepted, this association will have to decide on how best to remain a vital and viable group that has members' welfare and support central to what we do into the future.

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.

- I've learned that you can get by on charm for about fifteen minutes. After that, you'd better know something.

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 – QUEENSLAND REGIONAL COORDINATORS

DONNA	0414397462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
VACANT		SUNSHINE COAST
DENISE	5545 0645	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407697206	ANDERGROVE
DENISE	0431571399	AVOCA
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
SARA	0422109492	BLACK RIVER
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	0414241091	BURPENGARY EAST
DAVID	4053 2291	CAIRNS
ALAINE	40544330	CAIRNS
HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
GAIL	0407514241	COOROIBAH
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
KARLIENE	0432431591	NANANGO

ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412456439	LABRADOR
KAREN	0408153285	LOWOOD
JUDIE	0439 461288	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418778082	MONTEREY KEYS
CAROLYN	55228987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
KEITH	5441 7236	COES CREEK, NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411331258	PACIFIC PINES
JUNE	0409636467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
DAPHNE	4773 3695	RASMUSSEN
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
CAROL	47737122	TOWNSVILLE
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418879801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458980667	YANDINA
PERLA	4939 2724	YEPPOON
SHIRLEY	4778 7117	YABULU
IAN	4623 5169	YULEBAR

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

FUTURE PLANNED ACTIVITIES

14 Sept - AGM - Southern Cross Sports Club. Guest Speaker Dr. Rob Henderson.

14 Dec – Christmas Function Brisbane venue TBA

DATES TO REMEMBER 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.

- **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.

NEWS FROM MACKAY

Our lunch, get together was held at the Harrup Park Country Club. Those attending enjoyed themselves. The intended guest speaker was unable to attend as a member of her family had health problems but advised she will attend our next get together. Muriel Harris stepped in and gave a talk on handy hints that will assist in daily life.

Our attendance was down, as one family suffered the loss of a family member in a traffic accident the previous week. Those attending signed a sympathy card.

It was decided our next get together will be held at:

North Mackay Bowls Club Sunday 31/ 8/2014 for lunch at midday

Bill Area Coordinator – Phone 49541221

TOWNSVILLE GROUP

A get-together for the Townsville group is planned for **Saturday 26 July, 12 noon** at The Avenues Tavern, Kern Brothers Drive. Rosie Miacle, the nurse in charge of the Ambulatory Care Unit at the Townsville General Hospital, will be in attendance. Many locals will know Rosie and her wonderful team who administer the infusions to MG sufferers. Rosie will be available to discuss and answer general questions. She cannot, however, discuss or answer questions about specific individuals' medical concerns.

We will also discuss the list of matters outlined on page 2 of the April newsletter, which could be considered as part of our Transition Plan.

Please phone, SMS or email Carol (0418748849, c.buchanan@bigpond.com) to let me know if you can attend. Looking forward to seeing as many people as possible because, as well as being lucky to have Rosie attend, the conversation and 'stories' shared by people who attend are most worthwhile.

NOMINATIONS FOR MANAGEMENT COMMITTEE FOR 2014/2015

The following nominations have been received and accepted by the nominees, for positions on the MGAQ Management Committee:

President	Anita Jackson
Vice-President	John Noble
Treasurer	Carol Buchanan
Secretary	Susan White
Committee Members	Shirley Johnston

There were no nominations received for the remaining Committee Member positions and in accordance with the MGAQ Constitution, nominations for this position will be called for from the floor at the Annual General Meeting.

MEMBERS FORUM

There are no contributions for the June newsletter.

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.

ARTICHOKE DIP

2 tins artichoke hearts (drained)

1 cup grated parmesan cheese

1 clove garlic (crushed)

4 – 5 tablespoons whole egg mayonnaise

1 teaspoon paprika

Chop artichoke hearts and mix in all ingredients. Spread into ovenproof dish. Bake in moderate oven until brown and bubbling hot (approximately 30 minutes).

Serve warm with corn chips.

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.

SUBSCRIPTION RENEWAL RECEIPTS

Receipts for members who have renewed their membership in the first 2 weeks of June will be forwarded with the July newsletter.

INCREASING AWARENESS OF MYASTHENIA GRAVIS

One of the aims of Myasthenia Gravis (MG) Association of Queensland Inc. is to increase the community's awareness of MG, including medical professionals.

On Monday May 19th 2014, Shirley Johnston (an MG sufferer, now in remission) and Bill Synnot (a carer) were invited to present their respective stories to a group of around 25 clinical psychology students at the School of Psychology, University of Queensland (St. Lucia Campus). This was organised by senior lecturers, Vanessa Cobham and Ada Kritikos.

After each presentation, a Q & A session followed; then the students discussed a case study developed by Bill based on his family's experience of visiting a psychologist.

There was an interesting and robust discussion with the students on the presentations and case study. Each student was given an MG information pack and extra packs were requested for other students. As a result of this session Vanessa has invited Shirley and Bill back to present to the next group of students. As a suggestion, the next session should be recorded on video.



Shirley and Bill at the Uni