



MessaGes

Myasthenia Gravis Association of Queensland Inc

JUNE 2011



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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PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

It is hard to believe that we are half way through the year and it is nearly Tax time again and also the cooler months which help us greatly managing our Myasthenia Gravis.

The Committee is really looking forward to our Birthday Celebrations with Dr Lander as Guest Speaker. Hoping you are all coming to wish us well and hope that the Association continues for another 20 Years. Also we would like to see some new members as you would be amazed as to what information you receive by seeing us in person.

With respect to the 'Exercise Effect in MG' project, if you wish to participate, we are accepting late applications. Please call Shirley on the 1800 number and advise her that you will be applying to participating in the project. It will be very interesting to see how MG is affected with Exercise and how we can tailor our exercise according to the level of MG suffered.

The committee is organising our AGM for 11 September 2011 with Dr. Jean Foster from WA as our Guest Speaker. It will be very interesting to hear her story as we do not often get to meet a GP with MG.

Carol Buchanan has been working on preparing a consolidated Information Booklet for the Association and I would like to thank Carol as she has been doing a great job. We will advise when this booklet will be available for our members.

I just want to say a big Thank you to everyone in the Association for their condolences on the loss of my Mother. I took Mum along to many of the Association outings and the members all called her Mum and treated her like their own.

Take care

Anita

Editor's note: The President's Report was prepared prior to our 20th Anniversary function. A full report on the function will appear in the July issue of MessaGes.

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

The committee would like to express sincere thanks to all our members for the wonderful support shown for our survey. More than 50 surveys have been returned to date with 1-3 coming in each day. We are well on our way to reaching our goals. Having said this, more support is still needed and at each visit to your Specialist/Doctor we would like you to check that they are referring others to the survey via the website or the free-call number.

A special launch event is to be arranged by the University and we will welcome attendees at this function. More details will be provided as they come to hand.

Funding for research into 'Exercise and MG' –

Response to the invitation to participate in this project from members in the Brisbane area has resulted in insufficient numbers to proceed at this stage. The Committee wants the project to go ahead and consequently is considering the options available to enable this to happen.

Enhancements to our website –

The website is an evolving entity and we welcome suggestions on how we can improve it.

NOMINATIONS FOR 2011/2012 MANAGEMENT COMMITTEE

The following nominations for positions on the MGAQ Management Committee for the 2011/2012 year have been received and accepted:

- | | |
|-----------------------|------------------|
| President | Anita Jackson |
| Vice-President | |
| Treasurer | Susan White |
| Secretary | Graeme Peters |
| Committee Members (3) | Carol Buchanan |
| | Shirley Johnston |
| | Bill Synnot |

In accordance with the Association's Constitution and By-Laws, the above nominations will be appointed to the respective positions at the Annual General Meeting to be held on Sunday 11 September 2011, while nominations for the unfilled position will be called for from the floor of the meeting.

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It was all so different before everything changed.

It's hard to make a comeback when you haven't been anywhere.

It's not hard to meet expenses. They're everywhere.

If all is not lost, where is it?

What if there were no hypothetical questions?

Shirley's Recipe

PEA AND HAM SOUP

for slow cookers

Ingredients:

2 onions	2 carrots
2 celery stalks	1 swede
(all vegies finely chopped or grated)	
2 cups split peas, rinsed and drained	1 smoked ham hock (800g) or bacon bones
1 litre chicken stock	1 litre water
2 bay leaves	2 thyme sprigs

Method:

1. Put the onions, carrots, celery, swede, peas, ham hock, chicken stock, water, bay leaves and thyme sprigs in slow cooker.
2. Cook on low for 8 hours or until the peas are soft and the ham is falling off the bones.
3. Remove the ham bones and meat. When cool enough to handle, cut off any meat still attached to the bones, then cut the meat into small pieces.
4. Return the meat to the soup.
5. Season to taste with salt and freshly ground black pepper.

* * * * *

MEMBERS' FORUM

Bill from Brisbane has submitted an article which will be of assistance to our members. Because of the length of the article it will be published in three parts, the first of which follows. Parts 2 & 3 will cover the 17 lessons learnt:

Lessons (17) Learnt from Progressing Claims for Total and Permanent Disability re Myasthenia Gravis with 2 Insurance Organisations

Background

My wife was covered by 2 separate organisations' insurance policies for Total and Permanent Disability (TPD). One organisation was via her workplace (State Government Department); the other was via a private insurance firm. The latter was taken out when our 2 sons were young just in case my wife fell ill and I needed help raising our sons. I had kept the policies going, even though our younger son was in secondary school at the time of my wife's diagnosis with Myasthenia Gravis (MG) in 2006. After diagnosis, she found it harder and harder to work, and ceased working in early 2010.

In the early stages of her problems with MG, she regularly missed work and was covered by an Income Protection (IP) policy at her workplace. IP is to cover temporary absences from work due to health issues. Soon it became apparent that her MG was "getting worse" and she was unable to perform her normal work activities. So discussions about transferring her to more a suitable position commenced. When this was found to be inappropriate, she was pressured by both work colleagues and various insurance company personnel to resign for health reasons. Statements such as "It would be better for you to find a more suitable job elsewhere", "You should look after your health", etc. were frequently directed at her. The pressure ranged from subtle to quite blatant.

Despite having already had 2 leading specialists classify her as TPD (one as early as 2008), in late 2009 her workplace insurer organised an independent medical opinion that confirmed that she satisfied their definition of TPD and agreed to pay her out in early 2010.

The second company, despite having the 2 specialists' and an independent doctor's report from the first organisation, decided to wait around 9 months (after the initial claim was lodged) before re-opening and reviewing the case. Despite their policy stipulating a maximum 6 month wait from when she stopped work, they initially wanted to wait 12 months; however, we negotiated a 9 month wait. During the review, they corresponded separately with us, our advisor and my wife's specialist. Their line of questioning become very repetitive, ie they asked similar questions on many occasions. It would appear that they were trying to catch us out on inconsistent responses. Then they organized their own independent medical review. Based on this report, they finally decided to pay-out my wife's claim. This was around 12 months after the initial claim had been lodged.

It is thought that these 2 pay-outs for TPD from MG are world firsts. Hopefully this has established a precedent that other MG sufferers can use to their advantage.

Based on our experience, I have listed 17 lessons I learnt in progressing the TPD claims through the 2 insurance groups. The views expressed in this article pertain to this personal experience.

Interestingly, in discussions with our independent advisor, he stated that what we went through was typical of the industry and based on his experience, he regarded the insurance groups' approaches in our case as reasonable.

In general, the process is not very transparent, which is exacerbated by feeling that the insurance company holds "all the aces". They seemed very reluctant to help us through the process and they provided only minimal information on an "as required" basis.

Please send in contributions to our 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 graeme.peters2@bigpond.com.

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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Future Planned Activities

Sunday 11 September 2011	Annual General Meeting – Club Pacific, Carindale – Guest Speaker Dr Jean Foster a GP from WA
Sunday 13 November 2011	'Meet the Members' at the Gold Coast
Sunday 11 December 2011	Christmas function – Carina Leagues Club, Brisbane
Saturday 10 March 2012	'Meet the Members' at Mackay

More details will be published as each event becomes closer.

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Isn't it a bit unnerving that doctors call what they do "practice"?

If you try to fail, and succeed, which have you done?

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.

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

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL MEMBERS (Alphabetical)

JUDIE	0439 461288	AIRLIE BEACH
KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
LYNDA	4159 2890	BARGARA
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
DENISE	4788 0798	BUSHLAND BEACH
AILSA	4055 1303	CAIRNS
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
CAROLYN	5472 0386	COOROY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
GEOFFREY	5341 8747	LITTLE MOUNTAIN
TERRY	5494 2470	MALENY
RAY / MARY	5443 8667	MAROOCHYDORE
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA

MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
KARLIENE	0432431591	SUNSHINE ACRES
HELEN	5445 4853	SUNSHINE COAST
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	416178458	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

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NEWS FROM MACKAY

On Sunday May 15th seven people attended lunch at the Mt. Pleasant Tavern .Our invited guest, Dr. Luke Notley, Paul Hopkins Medical Clinic, Mackay, answered questions & gave information on M.G. which was greatly appreciated .

There was a discussion held re 20th anniversary. It was decided to meet at Charlies @Porters at 10 a.m .Sat.11th June for coffee etc.

Our next get together will be held on the 14th August at midday at Boomerang Hotel for lunch, and we will try to arrange a guest speaker to attend .

Bill – Mackay Coordinator

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NEWS FROM TOWNSVILLE

On Saturday 21st May 2011 members from Townsville and environs met for lunch at Tom's Tavern. This get-together was an opportunity to follow up on the March 'Meet the Members' which people found most worthwhile.

Discussions about the survey and newsletter were positive. Members were well on the way to completing the survey and were excited about the potential positive outcome which could eventuate. Members also gave good feedback on the usefulness of the newsletter.

At the next meeting we hope to have a guest speaker. The date will be based on the availability of the speaker.

Carol – Townsville Coordinator

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Is there another word for synonym?

What do you do when you see an endangered animal eating an endangered plant?

If a turtle doesn't have a shell, is he homeless or naked?

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2011/2012 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.

The majority of members will have 6/11 which tells you (and us) that you are financial to 30 June 2011. Others may show 6/12 or even 6/13 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/10, 6/09, 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 from the 'Contact us' page on our website www.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: _____

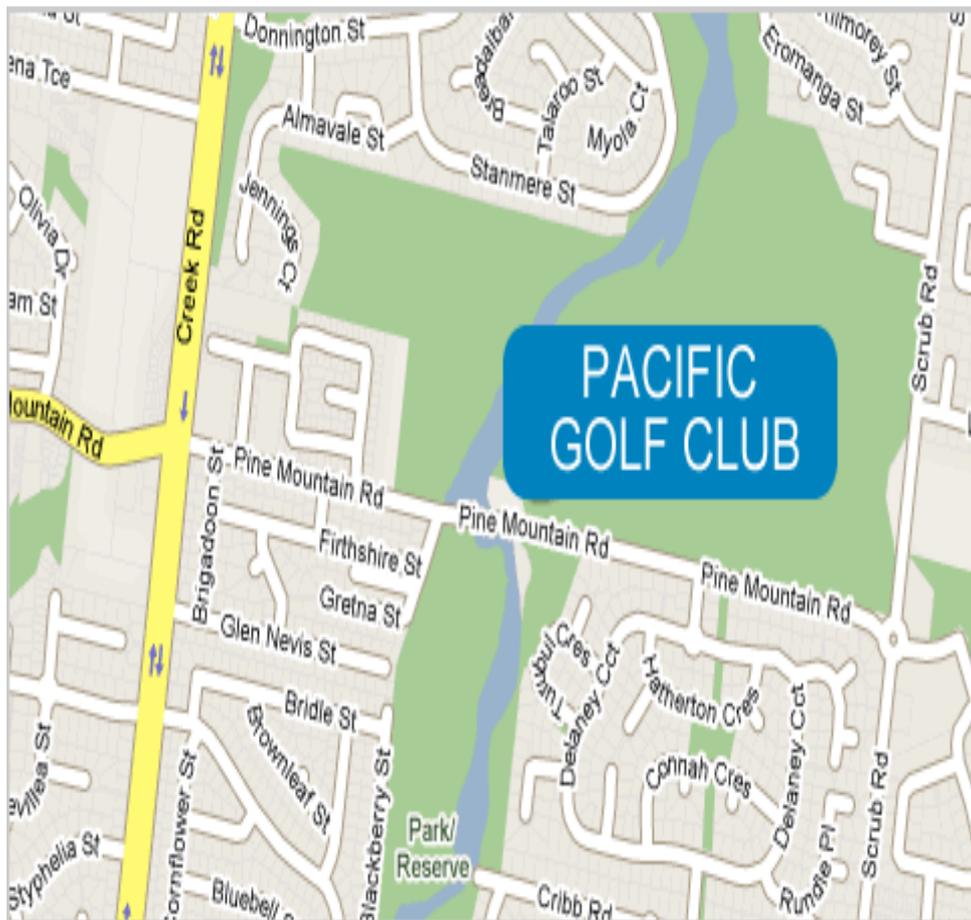
Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

2010/2011 ANNUAL GENERAL MEETING

- WHEN:** Sunday 11 September 2011 at 10:00am for 10:30am sharp
- WHERE:** **Club Pacific, 430 Pine Mountain Rd Carindale.** (Previously known as the **Pacific Golf Club**)
Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.
- GUEST SPEAKER:** **Dr Jean Foster M.B., B.S., a GP from Bedford in WA who has MG. Dr Foster will talk about 'Making the most out of your GP' and her experience of living with a chronic health condition.**
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier.
- HOW DO I GET THERE?** See map below. (**UBD Map 181 Reference P12.**)
- 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 2 September 2011**

To Cleveland Rd



To Logan Rd