



Messages

Myasthenia Gravis Association of Queensland Inc

AUGUST 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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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

The Committee is working towards a very successful AGM with our Guest Speaker Dr Jean Foster from WA. It is not every day that we meet a Doctor who has MG so it will be a very informative presentation and very down to earth. Please make the effort to come and meet other members who have MG as you do not know what you will gain from meeting others with MG but you will be pleasantly surprised. I would ask you to read the details of the day on Page 8 of this issue, and to please let us know if you will be coming as it is essential that we provide the venue with approximate numbers so the necessary seating can be arranged.

The Vice President position is vacant for the next year and nominations will be called from the floor at the AGM for someone to fill this position. I would like to take this opportunity to personally thank Kris Klitgaard for all his support and knowledge that he has brought to the committee for many years and he will be missed.

On 13th November 2011 the committee is travelling to the Gold Coast for a 'Meet the Members' gathering and look forward to meeting our members who reside in the Coast region. The venue is Club Helensvale, so keep the date free. While this day is primarily for our members in the Gold Coast area, it does preclude members from elsewhere attending and we would welcome them. More details will be published in the next newsletter.

The Christmas function is on 11 December 2011 at Carina Leagues Club so please bookmark this date in your diaries. The year is just flying by and soon we will be saying how hot it is instead of the cold we are experiencing now.

Take care

Anita

Editor's Note: Shirley is now at home following her surgery and her rehabilitation is progressing very well.

Supported by



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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 8287	CANBERRA ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS 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
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

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Future Planned Activities

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

More details will be published as each event becomes closer.

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Shirley's Recipe

SWEET AND SPICY CORNED BEEF FOR SLOW COOKER

INGREDIENTS:

½ cup brown sugar	1 tblspn Cajun seasoning
2 teaspoons lemon pepper	1 tblspn Worcestershire Sauce
1.4 – 1.8kg trimmed corned beef	

METHOD:

1. Combine brown sugar, seasonings and sauce and spread on meat.
2. Place in sprayed oval slow cooker.
- 3 Cover with lid and cook on low for 6-8 hours or to your liking.

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MEMBERS' FORUM

Two contributions this month – Mike's story of his experience with MG and the final instalment of Bill's article about insurance claims for employment cessation because of myasthenia gravis:

Mike writes:

MY M.G. MOMENTS

Hi there. My name is Mike and I turned 70 this year and have been diagnosed with M.G. Since 2005. When I think back I have probably had symptoms for several more years but not been aware of the underlying ailment.

The diagnosis was made about 3 weeks after a major neck operation. It started with very bad double vision then progressed to slurred speech and I was unsteady on my feet. My better half suggested the unsteady bit was just old age on my part. My GP initially thought I may have had a stroke and I was sent to Hospital for tests. An MRI soon showed that a stroke had not occurred and the Neurologist then informed me that I had M.G. I explained that I used to drive an MG but that I had not come across the ailment before.

I was started on large doses of Prednisone and Mestinon 180. This medication caused me 2 weeks of chronic stomach cramps and diarrhea so it was discontinued and replaced with Azathioprine which is also called Imuran. After about a week, I woke up one morning shivering like I was in the antarctic in my underwear and freezing cold. On reporting to my GP I had a temperature over 40 degrees, blood pressure of 165/95 and a splitting headache. So back to hospital where it took a couple of days to get back to normal. This as it turned out was a febrile reaction to the Imuran. Apparently some people (myself included) can suffer a side affect like a gigantic dose of flue.

My treatment then became Mycophenolate or Cellcept as it is also known and Intragam transfusions along with short periods on good old Prednisone.

In early 2011 it appeared that I might be in remission which I was very happy about. Then a few weeks ago in May after an accident resulted in an operation on my right hand the double vision etc returned. I am now once again taking Cellcept and the Mestinon tablets but this time I take 2 Lomotil with the Mestinon which keeps the side effects previously mentioned under control.

As previously noted in our Messages magazine the use of anaesthetics can

result in the triggering of M.G. Symptoms. This occurred despite my warnings when admitted to hospital about my condition.

I have mentioned this anaesthetic problem when filling in our recent survey. Hope my observations in this little story can help others overcome the condition we suffer.
Mike

* * *

Now for the final instalment of Bill's article about insurance claims for employment cessation because of myasthenia gravis:

Final 8 Lessons (not necessarily in order of importance):

Tenth lesson – *get all verbal agreements in writing; take detailed notes of any verbal communications and keep copies of all your correspondence with all stakeholders involved in your case, such as insurance companies, workplace, tax accountant, etc.*

Ideally, you should promptly send a copy of your notes taken during a conversation to the other party so that they have a record of your understanding of what was discussed and agreed upon.

Sometimes the content and attitude in conversations are not reflected in the written communications. In our case, verbal conversations with insurance representatives tended to be more sympathetic and diplomatic, and less assertive and demanding than their written communications.

For example, in early discussions with a representative of the second insurer, she agreed to waive the 6 month waiting period but later had a change of mind. Unfortunately, I did not send her a copy of my notes of this phone conversation. If I had, the onus would have been on the insurer to dispute my file note.

It is important to keep a written record of everything that is spoken, etc. as you will need an auditable paper trail if the issue ends up in legal proceedings. Otherwise, it will be your word against theirs.

Remember: a verbal commitment is not worth the paper it is written on!!!!

Eleventh lesson – *make sure that the person conducting the independent medical assessment has copies of all relevant information (reports from doctors, specialists, medical professionals, insurance organisations, etc.) that supports your case.*

It is important that the independent medical professional understands the history of your health problem from all sides.

Twelfth lesson – *establish a positive relationship with your medical professional(s) who is/are corresponding with the insurance group(s) so that you are aware of the information required by the insurance group(s) and what is being provided by your medical professional(s) to the insurance organisation(s).*

The medical professional(s) will have to provide a lot of information, etc to the insurer. This can be tedious and time-consuming. They need to understand that they are providing information from the worst case scenario and are communicating to an audience which is less knowledgeable and has a poorer understanding of the health issues. For example, the insurance firm was using a generalist (a young, new-age GP) to quiz leading specialists (neurologists). As a result, some questions were rather basic and "insulting" to the specialist and did not elicit the most constructive answers.

Medical professionals need to realize that the insurance group is hoping to find ways not to pay-out. For example, one insurance firm was trying to delay any action on our claim until an operation was performed on my wife's thymoma, despite the medical evidence not supporting the benefits of this operation for her.

In addition to the medical/technical information, during the claim process document and pass on any observable changes in the sufferer's abilities. This might include their being less able to do basic household chores such as preparing meals; experiencing difficulty in hanging washing on the line; increased difficulty climbing stairs; less confidence in driving; etc.

Thirteenth lesson – *you need to check all your entitlements to leave and IP.*

There will be pressure applied from the insurance group to encourage you to use all your leave entitlements before going on IP; if a pay-out is agreed, they will try to stop your IP entitlements when they make the pay-out.

Fourteenth lesson – *be prepared for an exhausting journey; it can appear like a “war of attrition” or “paper warfare” as the insurance organisation will demand considerable information and documentation and delay decisions.*

The whole process is draining in terms of energy and emotions and exhausting – especially as the sufferer and/or carer are endeavouring to handle the new challenges of the health issues while battling the insurance organisations. At various times, we concluded that the insurance organisations were un-necessarily “dragging it out” to exhaust us in the hope that we would find it all too hard and go away.

You need to be very resilient.

Fifteenth lesson – *endeavour to make contact with the key decision-maker(s) in the insurance organisation.*

Usually your contact is with a gate-keeper/messenger and not the important decision-maker(s). For example, it was one of the gate-keepers who initially waived the 6 months waiting period and this was reversed later on by a more senior person.

Sixteenth lesson – *don't take anything that happens as personal, keep a “cool head” and be focused on the end game.*

This can be very hard to do as raw emotions are always near the surface and the insurance groups are using tactics to make it hard for you to be successful.

Seventeen lesson - *continue outside interests or hobbies so that you are able to “switch-off” from the pressure of handling the insurance claim.*

NB The above lessons are based on our experience with 2 different insurance groups. I reiterate that these opinions are mine (Bill's) alone.

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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Old people shouldn't eat health foods. They need all the preservatives they can get
Did you hear about the optometrist who fell into a lens grinder and made a spectacle
of himself?

Agenda for the Annual General Meeting of the Myasthenia Gravis Association of Qld Inc, to be held on Sunday 11 September 2011 at Club Pacific, Carindale.

1. OPENING
2. APOLOGIES
3. CONFIRMATION OF QUORUM
4. MINUTES OF THE PREVIOUS AGM HELD AT CARINA LEAGUES CLUB ON 12 SEPTEMBER 2010
5. BUSINESS ARISING FROM THE MINUTES
6. PRESIDENT'S ANNUAL REPORT
7. TREASURER'S REPORT
8. ELECTION OF MANAGEMENT COMMITTEE FOR 2011/2012

NOMINATIONS:

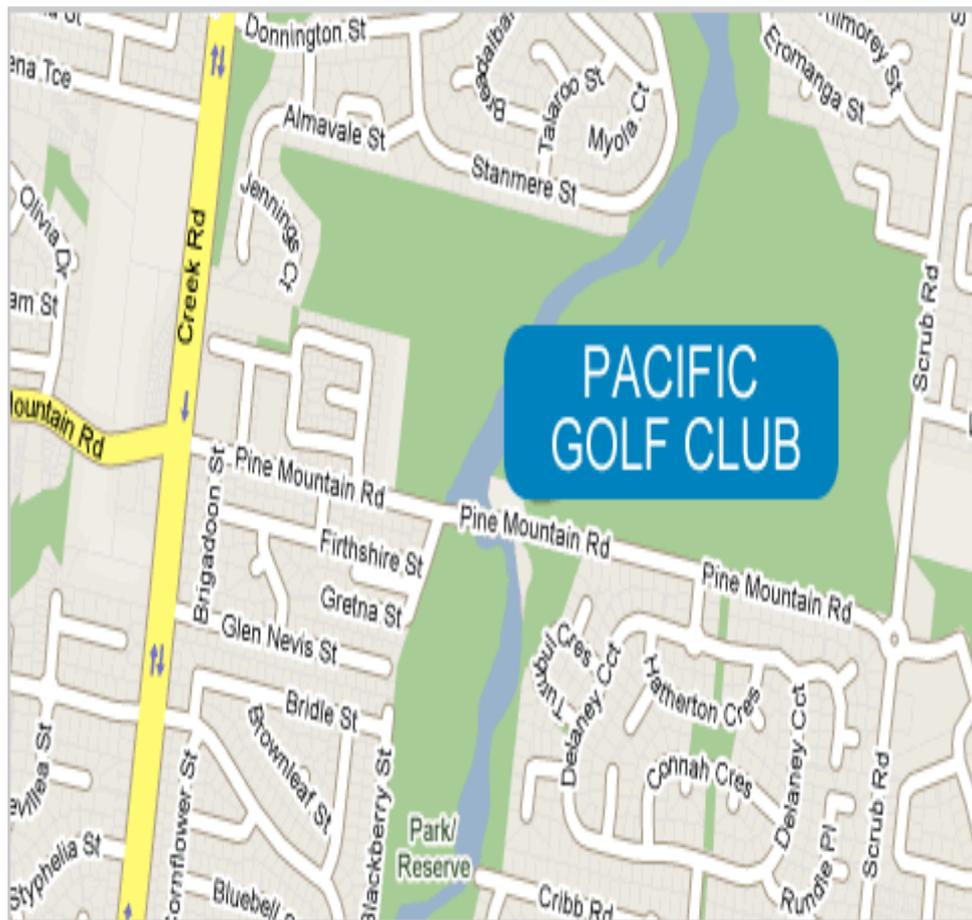
PRESIDENT	Anita Jackson
VICE-PRESIDENT	
SECRETARY	Graeme Peters
TREASURER	Susan White
COMMITTEE MEMBERS (3)	Shirley Johnston
	Bill Synnot
	Carol Buchanan

9. APPOINTMENT OF AUDITOR
10. BANK AUTHORITY
11. GENERAL BUSINESS
12. GUEST SPEAKER – Dr Jean Foster M.B., B.S., from WA
13. CLOSE

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 let us know if you are coming, how many, and if you are staying for lunch. It is important for us to know. Please let us know by **Friday 2 September 2011**

To Cleveland Rd



To Logan Rd