



Messages

Myasthenia Gravis Association of Queensland Inc

JULY 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

What an outstanding success the 20th Birthday celebrations were. Dr. Cecile Lander spoke about MG and also the treatments and there were plenty of questions in question time. Our members really enjoyed this presentation and I would like to thank them all for taking the time to help us celebrate 20 years. The committee is now gearing up for Dr. Jean Foster from WA at our AGM in September

The Committee greatly appreciates the participation of our fellow MG sufferers from interstate as well as our Queensland members in the completion of the questionnaire and their involvement in the survey on MG. We look forward to this positive response continuing as all sufferers and their families, carers, medical professionals, researchers, government agencies etc will benefit from the survey's findings.

With respect to the Exercise Project, if you are running late with sending in your Application Form we will be taking late applications. Please call Shirley on the 1800 number and advise her that you wish to participate in the project.

Carol Buchanan is continuing with her work on constructing a consolidated Information Booklet for the Association and has forwarded it to our patron, Dr. Cecilie Lander, for her input and comments. It is hoped to have it finished and ready for printing in the not too distant future.

Take care

Anita

Editor's Note: Our 1800 Freecall number will be attended by Carol from July 24 for a period of approximately 3 weeks while Shirley undergoes a medical procedure and convalesces following it. We would ask that during this period you please do not ring the 1800 number enquiring after Shirley's health. We will keep you informed via the newsletter.

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 – BRISBANE

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
EILEEN	3269 5660	BRIGHTON
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
GORDON	3398 7891	CARINA
LORRAINE	3206 0789	CLEVELAND
PAM / RAY	3801 1335	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
MELISSA	0411039060	FOREST LAKE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
IAN	3266 2449	NUNDAH
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
MIKE	3288 4037	SPRINGFIELD
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

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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 the 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

QUICK AND EASY DATE SLICE

INGREDIENTS:

- | | |
|----------------------|----------------------------|
| 2 cups SR flour | 1 cup brown sugar |
| 125g softened butter | 1 cup finely chopped dates |
| 1 lightly beaten egg | ½ cup milk |

METHOD:

1. Blend flour, sugar and butter or rub in with fingers until mixture resembles fine breadcrumbs.
2. Press half of mixture into lamington tray lined with baking paper.
3. Add dates, beaten egg and milk to remaining mixture and mix well.
4. Spread and press on top of base.
5. Bake in moderate oven (180°C) about 25 minutes.

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News from Mackay

On 11 June the Mackay members of the MGAQ held a get-together at Porters to celebrate the 20th anniversary of the Association.

Seven people attended and had an enjoyable time. I would like to thank Porters Gardening Centre for the lovely flowering pot plant supplied for the raffle which was won by Hazel. We had another lady attend for the first time.

Our next get-together is for lunch at the Boomerang Hotel on 14 August at 12 noon.

Bill - coordinator Mackay area 0749541221

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MEMBERS' FORUM

Continuing with Bill's article about insurance claims for employment cessation because of myasthenia gravis:

Lessons (not necessarily in order of importance):

First lesson – *never agree to resign from your workplace for health reasons as this can result in you waiving your rights to an insurance claim.*

Much pressure will be put on the sufferer to "resign". This will include making you work when it is obvious that you are not coping with the work load.

You need to be "terminated" as you cannot perform your normal work duties owing to your health issues. As most forms only mention resigning, you need to write in "terminated", so that the precise circumstances of your ending employment are highlighted.

An adjunct to this is how to respond if you are asked to sign any form that you are not certain about. I suggest that you include one of the following types of statement: "By signing this form I am not waiving my right to any future claim that I might have against the organisation" or "I reserve my right to make future claims against this organisation".

Second lesson – *insurance coverage for those beginning family life is a good investment, irrespective of one's health status at the time of starting the cover.*

When we started my wife's policy, she did not have any known health issues. But we did imagine that this situation could change.

Third lesson – *the longer the policy is in place, the less chance of the insurance company rejecting the claim on the basis of a pre-existing condition being present when the policy started.*

I was informed that this is one of the main reasons insurance claims are rejected.

Fourth lesson – *you need to carefully read and understand the policy, especially the definitions of health issues that are included in, and excluded from, the policy's coverage.*

MG was not mentioned in either of the 2 insurers' TPD policies as an acceptable health issue for a claim.

Remember: you don't have to be in a wheel-chair to be disabled.

The TPD policies of the 2 organisations had similar definitions, i.e.

State government

"...A TPD benefit is payable if you have a disability and.....after considering relevant medical opinions, is satisfied you're unlikely ever to be able to work in any job for which you are reasonably qualified by education, training or experience..."

1. Private firm

"...is "unable to work":

he or she is unable to follow his or her occupation for a continuous period of six months because of an injury or sickness and in our opinion, based on medical or other evidence, because of an injury or sickness, he or she is unlikely to ever be able to follow any occupation for which he or she can be reasonably suited to by education, training or experience..."

Both these definitions stress that TPD is applicable when you are unable to return to your "normal" job based on your level of education, experience, etc.

Fifth Lesson – *if you have more than one policy to claim against, prepare one claim at a time and start with the more/most straight-forward.*

We decided to start with the claim against the State Government-based organisation as we felt that we would have more chance of success. They had a reputation for being easier to handle and the value of the potential pay-out was considerable less. Additionally, we anticipated that having a precedent would increase your chance of success with the second. This choice proved prudent, as the process of dealing with one at a time was very taxing and draining (see below). To deal with both claims simultaneously might have been too much.

Remember: the insurance companies are trying to discover ways, or loop holes, to avoid making a pay-out.

Sixth lesson – *obtain the services of a trusted, independent, industry-knowledgeable advisor who thinks differently from you, is willing to challenge your views and is solely focused on achieving the best results for you. At the same time, remember that you are the decision-maker, not the advisor.*

The advisor's role is guide you through the process and to help you understand the pitfalls, obstacles, etc and develop the best strategies, tactics, etc so that you maximize your chances of success.

The advisor is also there to help you handle the emotions that can cloud your judgment, decision-making, etc from time to time. Preparing the detailed documentation required by the insurance group is very exhausting emotionally as you are "re-living" the demise of your health and it is re-enforcing your disability status.

Also, there is an art to completing the documents so that you improve your chance of success and the advisor can be very helpful on this matter.

You need to be careful in your choice of advisor as the insurance group prefers to deal directly with the advisor and use him/her to communicate with you. Thus the need for complete trust in the advisor so that he/she is focused solely on looking after your interest and does not become more concerned about his/her relationship/credibility, etc with the insurance group than with your requirements.

Seventh lesson – *as policy pay-outs have different tax implications, you need to check to see that any pay-out from your policy has minimal tax liabilities.*

Linked with this is seeking professional advice about where best to place your potential pay-out to maximize investment opportunity and reduce any tax liability (current and future).

Eighth lesson – *make sure that all the information sent to the insurance companies is correct and accurate; don't send any mis-information.*

There is a large amount of information and documentation required and it can take considerable time and effort to collect it - from your workplace, from your tax accountant, from medical professionals, etc.

We accidentally wrote an incorrect date of birth on one form. When we wanted to correct this, we had to find the original birth certificate, etc and much time and effort was wasted.

Ninth lesson – *use of photos to show your symptoms, conditions, workplace, job, etc can help*

Remember: a photo can be worth a thousand words.

The final 8 lessons will be published in the August issue of MessaGes.

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.

BETTER LATE THAN NEVER

While cleaning the garage, Joan and Harry found an old stub for some shoes they had left at the repair shop 10 years ago. They thought it would be funny to go to the shop and see if the shoes were still there. So on the following Monday they did. They handed the stub to the repair man who took it and went and looked out the back of the shop. He came back and said, "They'll be ready on Wednesday."

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Dr Blum has lost count! With 100-plus surveys now stacked up in his locked room he is struggling to maintain the tally. Surveys continue to arrive on a daily basis and he is absolutely delighted with the response. He reported that the data base has been prepared and the data entry has commenced.

As reinforced by Dr Lander at the 20th Anniversary Celebration, this survey is of huge importance. Having the opportunity to participate in such a programme and having it here in our own state is awesome. Our members clearly agree. We can also report that surveys are beginning to arrive from interstate and we would particularly like to thank Dr Steven Reddel (Concord Hospital, NSW) and Mrs. Glenda Bidner (MG support Group in NSW) for their support.

Thank you again for helping and do remember to spread the word as widely as possible. No date has yet been set for the launch.

‘Exercise Effect in MG’ Study –

The Committee is still considering the options available to enable this Study to proceed.

Enhancements to our website –

Please let us know of any suggestions you may have to improve our website.

20th Anniversary Celebration

The 20th Anniversary Function held at the Carina Leagues Club on Sunday 19 June 2011 was a resounding success.

42 people attended including members and visitors from as far afield as Lismore in NSW, Shepparton in Victoria, Townsville, Sunshine Coast and the Gold Coast. Quite a few members were attending an MGAQ function for the first time.

Our long-standing Patron, Dr Cecilie Lander, gave a very interesting presentation in which she gave an encapsulated history of both myasthenia gravis and the Myasthenia Gravis Association of Queensland, and spoke of her experience as a practising neurologist for 35 years. A quite lengthy and varied Question and Answer session followed. In her presentation Dr Lander also extolled the benefits of both of the research Projects which we are undertaking, the Data Collection Survey and the ‘Exercise Effect in MG’ Study, and encouraged our members to actively participate in them. Following her presentation, Dr Lander was presented with a Certificate of Appreciation and a floral tribute. She was then invited by President Anita Jackson to perform the ceremonial cutting of the 20th anniversary cake. Lunch followed and members intermingled and chatted with each other for quite a while.

A DVD of Dr Lander’s presentation and the Question & Answer Session will be forwarded to all current financial Category ‘A’ members shortly.

We look forward to meeting more of our members at our next event, the Annual General Meeting to be held at Club Pacific, Carindale, on Sunday 11 September 2011, on which occasion Dr Jean Foster, a practising GP from Perth, WA, who herself has MG, will be the Guest Speaker. Full details of this function appear on our website under ‘News and Events’ and in the July and August issues of our newsletter, MessaGes.’

SNAPS FROM THE 20TH ANNIVERSARY FUNCTION

The 20th Birthday Cake



The cutting of the cake



Happy Attendees



President Anita Jackson with
Foundation member Shirley Johnston



For people who like peace and quiet – get a phoneless cord!

There are two rules for success: 1. Don't tell all you know.

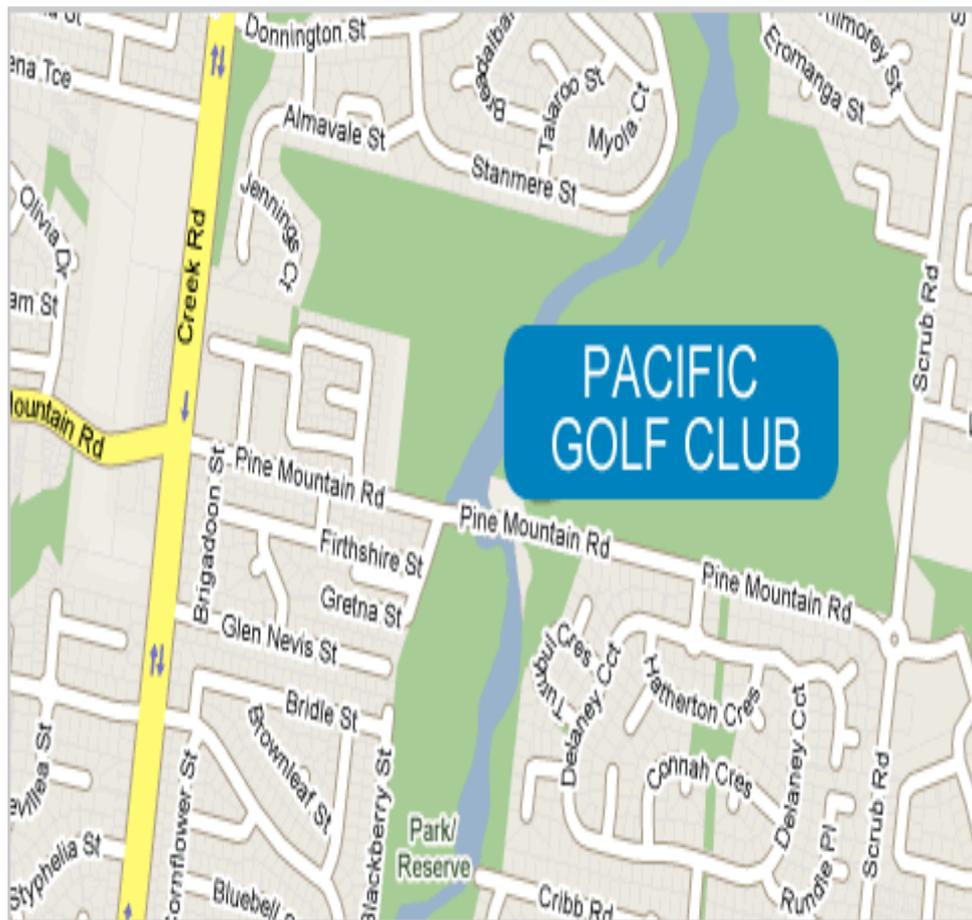
I finally got my head together, now my body is falling apart.

Lead me not into temptation – I can find the way myself.

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