



Messages

Myasthenia Gravis Association of Queensland Inc

JULY 2012



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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PRESIDENT'S REPORT

Welcome

Our June function was a great success with an attendance of 37. It was very pleasing to see quite a few new faces there, especially those who joined the Association on the day. I'm sure all who were present found both Guest Speakers interesting and informative.

We have now extended our integration into the digital age by having an MGAQ presence on the social medium Facebook. So, if you are on Facebook yourself, please go to www.facebook.com/mgqld and say you like us. Any suggestions for further sojourns into this modern-age phenomenon (social media) would be appreciated.

Committee members are busily working on the statutory returns in respect of the financial year which ended on 30 June 2102 for submission to the relevant government departments. The results of the year's operations will be presented to the Annual General Meeting to be held on Sunday 9 September at Club Pacific, Carindale (see page 8 of this issue for details). We are looking forward to our Guest Speakers presenting their progress reports on our two research projects, as I am sure our members are.

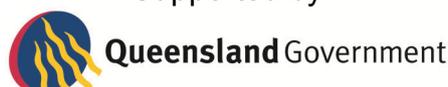
Take care

John Noble – Vice President

Life becomes harder for us when we live for others, but it also becomes richer and happier.

Albert Schweitzer

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Queensland Government

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 - 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
PETER	0414492606	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
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
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

The Serenity Prayer (a variation)

May God grant me the senility to forget the people I never liked anyway, the fortune to remember and run into the ones I do, and the eyesight to tell the difference.

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Work has now begun preparing a preliminary report on the data analysis undertaken to date. This preliminary report will be delivered to us in a presentation given by Dr Blum at the AGM in September. If you have not yet returned your survey and wish to be included in this round of data, it is not too late but do be quick. Surveys received after this initial report will, of course, still be as valuable as this is just a taster.

'Exercise Effect in MG' Study –

All of the participants have completed their supervised exercise program. Some have completed their final assessment, whilst others are currently undertaking the same exercises at home twice weekly for 4 weeks, after which time they will have their final assessment.

We look forward to Professor Nitz's report on the study at the Annual General Meeting on September 9 next.

Remember, it is not too late to join the Study and if, after viewing the list of the exercises published in the March newsletter, you now feel inclined to join the study, and live in the Brisbane area, please contact the Secretary.

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Shirley's Recipe

OVEN BAKED CHICKEN CRUNCHIES WITH LEMON MAYO

Ingredients:

2 ½ cups soft wholegrain breadcrumbs*	800g skinless chicken breast fillets, fat trimmed
¾ cup buttermilk*	1/3 cup grated parmesan cheese
2 tsp dried Italian herbs	black pepper, to season
Canola oil spray*	½ cup mayonnaise*
1 tbsp lemon juice	1 small garlic clove, crushed
1 tbsp fresh parsley, chopped	jacket potatoes, to serve
Garden salad, to serve	

Method:

1. For breadcrumbs, tear day-old wholegrain bread into pieces and process in a food processor.
2. Cut chicken into 1cm thick strips, then combine with buttermilk in a bowl, cover and refrigerate for 1 hour.
3. Preheat oven to 220°C (200°C if fan-forced). Mix breadcrumbs, parmesan and Italian herbs on a tray and season with pepper. Remove chicken from buttermilk and coat in breadcrumb mixture, pressing on gently with fingertips. Place strips in single layers on two baking paper lined oven trays and refrigerate for 15 minutes.
4. Remove trays from fridge, spray crumbed chicken with cooking spray and bake for 8-10 minutes until light golden.
5. Remove from oven, turn chicken strips, reapply cooking spray and return to oven for 8-10 more minutes until cooked through and light golden on other side. Mix mayonnaise with lemon juice, garlic and parsley.
6. Serve chicken with lemon mayo, jacket potatoes and garden salad.

* Chicken can be marinated in buttermilk several hours ahead. Keep refrigerated. Crumb chicken and bake as required

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You only live once, but if you work it right, once is enough

MEETING WITH FEDERAL MINISTER FOR DISABILITY REFORM

The Secretary, Graeme Peters, was fortunate enough to get a one-on-one meeting with the Federal Minister for Disability Reform, the Hon. Jenny Macklin, at the recent Federal Community Cabinet held at the Redbank Plains State High School in Ipswich. Graeme used this valuable opportunity to inform the Minister about myasthenia gravis and what our Association does as a volunteer support group.

He also enquired of the eligibility aspects soon-to-commence National Disability Insurance Scheme (NDIS). The Minister advised that eligibility to claim under the scheme will be on a case-by-case individual basis according to the extent of a claimant's disability. An expert medical panel has been established to determine the criteria for eligibility. People who wish to find out more about the NDIS can do so via the NDIS website at www.ndis.gov.au

For those do not have access to the Internet, important information about the scheme will be published in MessaGes as necessary.

The Minister was given 2 copies of our new Information Booklet. Graeme said that the meeting was very beneficial to the Association in terms of public awareness of myasthenia gravis, and came away very happy with the outcome.

CHRONIC DISEASE MANAGEMENT PLAN

People with a chronic medical condition may be able to get Medicare benefits to cover allied health services that help manage their condition. Allied health services include physiotherapy, dietician, speech pathology, chiropractor and podiatry.

Under this program, your doctor may suggest a GP Management Plan. If you need treatment from two or more health professionals, your doctor may also put a Team Care Arrangements plan in place for you.

A GP Management Plan is a plan of action agreed between you and your GP. It identifies your health care needs, sets out the services to be provided by your GP and lists the actions that you need to take.

A Team Care Arrangements plan lets your doctor work with, and refer you to, at least two other health professionals who will provide treatment or services to you.

You may be eligible for Medicare benefits for specific allied health services if your doctor prepares both types of plans for you.

If you feel you may be eligible for this scheme, please discuss with your GP.

More information is available from the Medicare website:

www.humanservices.gov.au/customer/services/medicare/chronic-disease-management-plan

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Everyone is entitled to be stupid, but some abuse the privilege.

A successful man is one who makes more money than his wife can spend. A successful woman is one who can find such a man. Lana Turner

ALICE REFLECTS

(published in the Autumn 2011 Edition of the MGA News-U.K)

Things are not as simple as they may seem...

My knowledge about this illness back in 2005, was quite limited, but it initially seemed reasonably simple: I had a myasthenic crisis; I was fortunately treated on time by an excellent team of physicians; I was now gradually recovering back to my normal self. Most patients with myasthenia go back to lead a near normal life, I was told. Indeed, at first it seemed that I was making a very rapid recovery and could go back to work within a few weeks.

But, very soon after, it became obvious that my remission was very short lived. After a period in which it seemed that I was doing well, I would have gradually worsening breathing difficulties and severe weakness again. This could also happen (quite embarrassingly and unexpectedly) in the middle of hospital rounds, in my office, shopping, going out with family and friends or even at home. These disturbing symptoms would get better with a few days of rest, plasma exchange or IVIG only to abruptly return again.

I was not ready to accept that there was nothing I or my physicians could do to change this course of events. I really wanted to have my normal life back and was determined to do anything it would take. It was true that, as a physician, I knew that some patients do not respond to treatment in the way others do. On the other hand, I also knew patients who got completely better after such a very rocky course that recovery had seemed nearly impossible.

Apart from my clinical work, I was also involved in collaborative research aimed at finding novel treatment approaches for patients who no longer responded to anything available currently. I knew that diseases that are very resistant today may become much easier to treat tomorrow. Gaining a better understanding of the process involved in the disease, and so finding novel ways to tackle it, was the key.

Turning now to my own illness, I tried to pursue those avenues. I had many questions and very few answers. Could I actually be getting treated for the wrong disease? Was there anything I could do to avoid those more severe episodes? Was there any better drug treatment, even if experimental at this point, that could be a promising treatment and had not been tried yet? Could I adjust the dose of my medications better? But, my physicians had no answers. They were mostly frustrated, just like me, by the unusual ups and downs, the confusingly normal test results and my disappointing responses to various treatments. They were reluctant to consider experimental treatments (such as Rituximab) under those circumstances. At some point they also started doubting the diagnosis of my illness, even though they had no other reasonable alternative. They even suggested that I should just try to live with it as best I could, but they didn't say how. Should I continue to work full time, or part time? Should I try to improve my muscle strength by exercising or should I rest more? When should I seek their advice urgently and when should I just wait and see if things improved on their own?

Strokes of luck brought me to find some answers in an unexpected place.

Alice— Summer 2011...to be continued

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By three methods we may learn wisdom: First, by reflection, which is noblest; Second, by imitation, which is easiest; and third by experience, which is the bitterest.

Confucius

Help us to Help You

There has been much media attention given to the National Disability Insurance Scheme. For MG sufferers to take every advantage of what this scheme may offer it will be important that our politicians are familiar with the condition and understand our needs.

Over the coming months it would be good to share information with as many State and Federal members as possible and so we ask for support from our members. Firstly, if possible, call in to see your local representatives and make them aware of the condition. Take along an information Booklet, mention the website and share your story. It is probably best to make an appointment. Let us know of your success.

At a second level, the committee would like to write to each parliamentary member offering information and requesting support. If you can spare a little time to assist with this task, we would be extremely appreciative. Please call Shirley on 1800 802 568.

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ANNUAL SUBSCRIPTIONS

A friendly reminder to all who have not yet renewed their subscription for 2012/2013. Your subscriptions assist the Association in providing support to its members and their families.

Information on how to go about renewing your membership subscription is available in the May and June issues of MessaGes, or by contacting Shirley on the 1800 802 568 freecall number.

If you are currently unfinancial and do not intend to renew your membership, but are still receiving the monthly newsletter, we would appreciate your letting us know why you do not wish to continue your membership. This advice will assist us in our future planning.

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GROCERY SHOPPING FOR SENIORS

There was a bit of confusion at the supermarket this morning.

When I was ready to pay for my groceries, the cashier said, "Strip down facing me."

Making a mental note to complain to my local member about Security running amok, I did just as she had instructed.

When the hysterical shrieking and alarms finally subsided, I found out that she was referring to my credit card.

I have been asked to shop elsewhere in the future.

They really need to make their instructions to us seniors a little clearer!

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CONFUCIUS ALSO SAYS

Do not impose on others what you yourself do not desire.

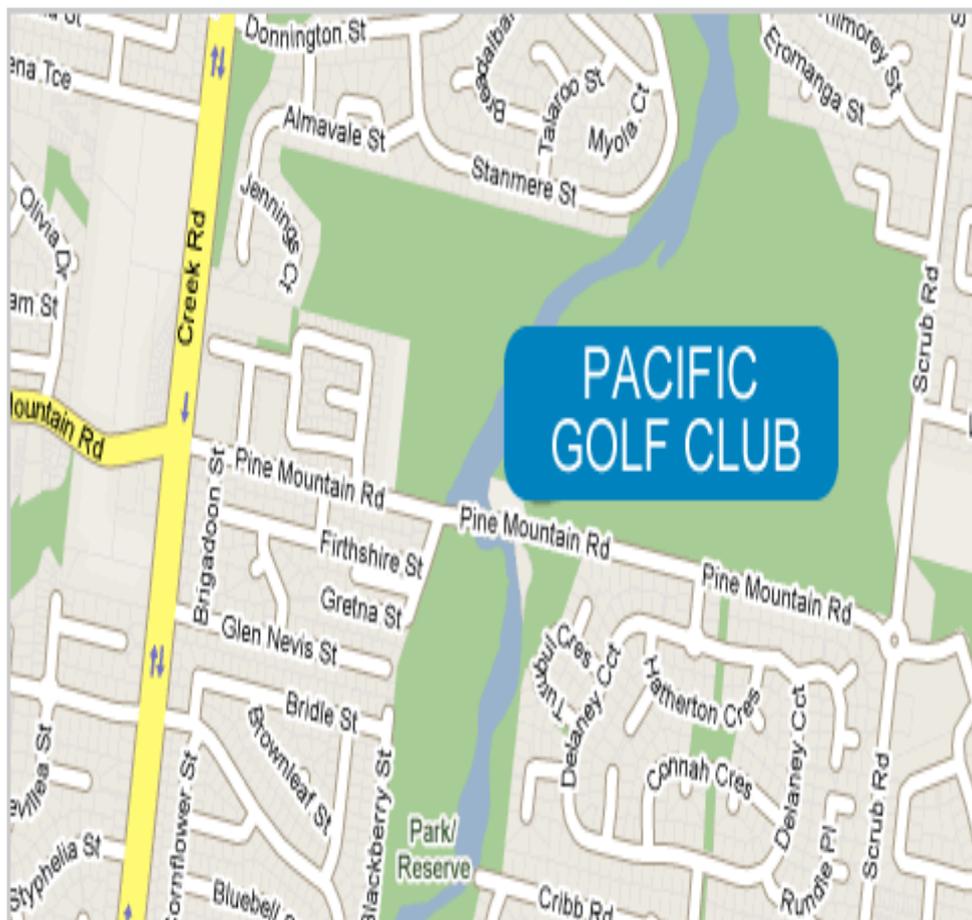
I hear and I forget. I see and I remember. I do and I understand.

Real knowledge is to know the extent of one's ignorance.

2011/2012 ANNUAL GENERAL MEETING

- WHEN:** Sunday 9 September 2012 at 10:00am for 10:15am 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 SPEAKERS:** **Dr Stefan Blum – Data Survey progress report.**
Professor Jenny Nitz – Exercise Study progress report
- 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 31 August 2012**

To Cleveland Rd



To Logan Rd