



Messages

Myasthenia Gravis Association of Queensland Inc

AUGUST 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

I'm back from my holiday and ready for action again.

As part of our drive to increase the public awareness of myasthenia gravis, our treasurer, Susan, contacted ABC Television in Brisbane and as a result, a representative of the ABC's 7:30 Report interviewed and filmed Shirley Johnston and Dr. Stefan Blum. Consequently, a segment of the interviews went to air on ABC 7pm News on Friday 10 August and was also aired on Channel ABC 24 News. As a follow up, ABC Radio 612 Brisbane conducted a live to air interview with Shirley and Dr. Blum on the afternoon of Monday 13 August. We are endeavouring to put links to the interviews on our website, so keep checking there if you missed the original segments.

It's only 3 weeks to the Annual General Meeting and we look forward to a good turnout to hear the presentations from our Guest Speakers regarding the progress of our two research projects. It is very important that we know how many are coming as we have to advise the venue for catering purposes. Therefore please make sure that if you are coming, you advise us on our 1800 802 568 freecall number. Full details of the day are on Page 8 of this issue.

As reported previously, the 2011/2012 Financial Audit of the Association is being conducted *pro bono* by the Business School at the University of Queensland. This is a one-off exercise only and the Committee is looking around to find an auditor for this financial year's accounts. To this end a motion will be put to the AGM asking to defer the appointment of an auditor for 2012/2013 until the committee have selected one.

This financial year is the final year of our current 3-year grant from Queensland Health and we are very hopeful that the grant will be renewed for the following 3 years.

Take care

Anita

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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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE 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
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	GILLEN NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

If at first you don't succeed, don't try sky-diving
 The two most common elements in the world are hydrogen and stupidity
 Why is it called "after dark" when it really is "after light"?
 If common sense is so common why are there so many people without it?
 Why is it called a "building" when it's already been built ?

PROJECTS UPDATE XXXXXXXXXXXX

Collecting data on sufferers of myasthenia gravis –

155 surveys have been selected for the initial data analysis which is currently underway. Preliminary information from the analysis will be the basis of Dr Stefan Blum’s presentation at the Annual General Meeting on September 9 next. More surveys are arriving each week and the information continues to be loaded.

With media publicity we are confident of making contact with additional sufferers of MG.

Progress remains steady.

‘Exercise Effect in MG’ Study –

All of the participants have completed the full exercise program and have had their final assessment. The data obtained from the study is now being analysed and preliminary results will be presented by Professor Jennifer Nitz at the Annual General Meeting on September 9 next.

Again, 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

APPLE PANCAKES WITH BLUEBERRIES AND RICOTTA

Ingredients:

- | | |
|----------------------------------|----------------------------|
| 2 large eggs | 1 cup buttermilk |
| 2 tsp honey | 1¼ cups self-raising flour |
| 1 small apple, peeled and grated | 125g reduced-fat ricotta |
| 1 tbsp icing sugar | Canola Oil spray |
| 125g punnet blueberries | maple syrup, to serve |

Method:

1. Whisk eggs with buttermilk and honey.
2. Sift flour into a large bowl, add buttermilk mixture and whisk to produce a smooth batter. Stir in grated apple.
3. Grease a heated non-stick frypan with cooking spray. Pour in ¼ cup of batter and spread to make a 12cm pancake.
4. Cook over medium heat until bubbles appear on the surface. Turn pancake and cook other side until golden. Remove from pan and keep warm. Repeat with remaining batter .
5. Mix ricotta and icing sugar until smooth. Serve pancakes with ricotta mix, blueberries and a little maple syrup.

* Apple pancakes can be cooked several hours ahead. Keep in an airtight container in a cool place. Warm the pancakes in the microwave just before serving

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MEMBERS’ FORUM

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There is no further information regarding this matter. We are still awaiting advice from Dr Pink.

Agenda for the Annual General Meeting of the Myasthenia Gravis Association of Qld Inc, to be held on Sunday 9 September 2012 at Club Pacific, Carindale.

- 1. OPENING
- 2. APOLOGIES
- 3. CONFIRMATION OF QUORUM
- 4. MINUTES OF THE PREVIOUS AGM HELD AT CLUB PACIFIC ON 11 SEPTEMBER 2011
- 5. BUSINESS ARISING FROM THE MINUTES
- 6. PRESIDENT'S ANNUAL REPORT
- 7. TREASURER'S REPORT
- 8. ELECTION OF MANAGEMENT COMMITTEE FOR 2012/2013

NOMINATIONS:

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

- 9. APPOINTMENT OF AUDITOR
Notice of Motion – That this meeting agrees to defer the appointment of Auditor for the year 2012/2013. And this meeting agrees to the Management Committee appointing the Auditor when a suitable one is selected.
- 10. BANK AUTHORITY
- 11. GENERAL BUSINESS
- 12. GUEST SPEAKERS – Dr Stefan Blum – progress on Data Survey Research Project
Professor Jennifer Nitz – report on the 'Exercise Effect in MG' Study
- 13. CLOSE

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The following article describes the potential of social media for patients et al:

Extract from an Article Entitled “At Twitter University, the courses are sent by e-mail”

Emma Commons & Rachel Leluhen (Aust. Fin. Review, Dec 4, 2011)

Meanwhile another profession known for its conservatism is confronting online developments that are changing the status quo. The rigid hierarchy of medicine where doctors held all the knowledge – and dispensed the same on a need-to-know basis is under siege.

When Renza Scibilia was diagnosed with type 1 diabetes 13 years ago she was 24 and the internet was still in its infancy. Google wasn't a popular search engine, let alone part of the language. It was difficult for people like Scibilia, who were determined to drive their own healthcare, to get their hands on good reputable information.

Much has changed. “There is not a really active diabetes online community. It's a new way of looking at healthcare,” she says. “There are lots of people who don't want to go and sit in a support group. They may be more comfortable with Twitter chats or responding to Facebook questions You do whatever you feel comfortable with. It makes you feel connected to a community where you can gather knowledge and compare what you know.”

Last week before speaking to the *Weekend Financial review*, Scibilia had participated in a Twitter chat where people all over the world offered suggestions as to what their pancreas would tweet if their pancreas could tweet. If you are not a diabetic, you probably can't imagine what your pancreas might want to tell the world. Diabetics, on the other hand, have no shortage of suggestions. That's the point; all those in the conversation knew they were talking to like-minded souls.

Each year diabetics spend an average of six hours with a health professional, Scibilia says.

“Most of the time we are doing it all on our own – it is a very self-managed condition – so to have people on the other side of the world, even if they are only allowed to use 140 characters, who are conveying exactly what you are feeling is very reassuring.”

Many doctors still tell their patients not to look up their disease online. If they are determined to be the font of all knowledge, it may pay off to shop around.

“You need to find a good doctor,” Scibilia says. “Mine is more than happy for us to have chats about what I've heard or read or seen tweeted.

“Mind you, I am not showing up saying ‘so I have heard I can solve my diabetes’. “There are a lot of miracle cures out there, so make sure what you look at and try comes from a reputable source,” she says.

In the US, the world famous Mayo clinic is doing its best to stay ahead of the curve. For the past five years it has used podcasts and Youtube videos to provide rich information to people about conditions their local doctor may have trouble diagnosing.

It was a blog post from a Mayo patient that proved to be the salvation for a 13 year old girl, Hayley Lairmore, who had a frightening condition no one was able to diagnose. Her mother, Christene, refused to accept the verdict of doctors who declared there was nothing physically wrong with Hayley – who was vomiting 10 or more times a day for six months – and palmed her off to counselling.

One night when Googling, Christine Lairmore came across a podcast from a girl who described her life living with postural orthostatic tachycardia syndrome and how Dr Philip Fischer from the Mayo Clinic had made it bearable. The symptoms described matched Hayley's. Lairmore then watched

a video Fischer had posted on YouTube about the condition and how it could be managed through lifestyle and diet. After treatment from Fischer, Hayley is also now successfully living with POTS. In some cases, the clinic is simply following the lead of patients such as Katherine Leon, who has helped turn the traditional paradigm of clinical tests upside down.

Women of child-bearing age aren't supposed to have heart attacks. Leon is one of the exceptions to the rule. She has the relatively rare condition of spontaneous coronary artery dissection and was 38 when she had a heart attack. After her diagnosis, she was shocked to discover no one had done any large-scale research on the condition so she was not able to get much of a prognosis. Leon took matters into her hands, explains the Mayo Clinic's social media manager Lee Aase. "She went to a woman's heart focused site, pulled together a group of 60 women who all had the same condition and then approached Mayo physician Dr Sharonne Hayes and said: 'do you want to study us?'"

An initial pilot study of 12 women from the US, UK and Canada has now expanded, with 100 women ready to be included.

"All of this came about because of one patient who says this isn't good enough," Aase says. "There's no doubt that social technologies will transform healthcare," he concludes.

LENDING LIBRARY

The committee has decided to establish a lending library of MG and related information resources. The collection is small to start off with but will be expanded over time. John Noble has been appointed Librarian.

Loans of material are available to financial members of the Association and loan period is 1 calendar month, postage out paid by MGAQ and return postage paid by the member,

To request a loan, please contact John on (07) 3269 5066 or email jam3740@optusnet.com.au

Initial offerings are:

- Myasthenia Gravis and Myasthenic Disorders (book)
- Living a Healthy Life with Chronic Conditions (book)
- Beyond Blue – volumes 1 & 2 (DVD)

We welcome donations of relevant material from our members.

2012/2013 ANNUAL FINANCIAL AUDIT

As previously reported, the Association has been fortunate enough to have our books audited by the University of Qld Business School this year. This service was provided free under their Social & Economic Engagement Program on a one-off basis.

As auditing has become a significant part of our annual costs, we are anxious to minimize these fees if possible and are now looking to find a firm who are willing to assist us for future audits. We are hoping that someone who understands a little about MG and the importance of the work that the committee is doing will be willing to assist us at a very reasonable rate, preferably *pro bono*. Being conscious of the time required for auditing, our aim is to present documentation as clearly and simply as possible. The University has assisted us to further simplify our record-keeping process and we are happy to show our processes to anyone considering working with the Association.

If any member of the Association has the skills to assist with auditing or knows of a contact who may be able to help, we would be extremely grateful and ask that you call Shirley on 1800 802 568 or email info@mgaq.org.au

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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**

