



Messages

Myasthenia Gravis Association of Queensland Inc

JULY 2013



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,

Welcome from the Vice-President standing in for the President; sorry, the only vice I can offer is over-eating at lunch at the Annual General Meeting; See below.

Please don't forget the AGM on Sunday 15th September, at the Southern Cross Sports Club, Mt. Gravatt. Guest Speaker is Dr. Shaun Pandey, Geriatrician, Prince Charles Hospital, and his presentation is entitled 'Health in Ageing.' Full details are available on page 8 of this issue.

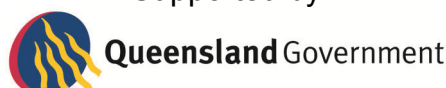
Your Committee is also finalising arrangements for our ongoing Meet the Members Regional programme. The next one is scheduled for Toowoomba, Darling Downs, on Sunday November 10.

A common comment from people when first diagnosed with MG is 'What is it?' While there are plenty of descriptions of the condition, one of the main things missing from those descriptions is that it is such an individual condition and there is no 'one size fits all' method of treatment. One way by which our members can be made aware of the variations to treatment regimes is via the Members' Forum. This affords members an opportunity to tell other members of their personal journey with MG and their experiences along the way. Unfortunately, of recent times, contributions to the Forum have been scarce. Your contribution to the Forum will help other members better understand MG and I ask that you give serious consideration to sending in your story. See page 4 to find out how to go about it.

Take care

John
for
Anita

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

On Sunday 16th June, Dr Stefan Blum and Dr David Lee generously gave of their time to present to the Association members the results of the past months' work in analysing the survey data. Dr Lee had devoted his holiday break to the task and Dr Blum did the presentation, afterwards fielding many questions. His presentation focused on several demographics and two key issues in particular. The details of this are best watched when all current financial Category 'A' members are forwarded the DVD of the presentation. Most humbling was the comment from Dr Blum, that the results highlighted to-date will affect his understanding of the condition and his recommendations for patient management. Medical Journal Articles will be prepared over the coming months and will hopefully be published by Christmas. Several projects for further research have been discussed. During the event, a few members said they had chosen not to complete their survey as they felt their story was not of significance or the diagnosis was too recent to be valuable. Dr Blum was quick to reassure them that this is not the case. All stories and contact with sufferers is wanted. Please call if you need a replacement copy of your survey. Thank you again to everyone for being so supportive. The story of the survey continues, with more information and benefit set to follow.

'Exercise Effect in MG' Pilot Study –

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see.

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

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SHIRLEY'S RECIPE

EASY EGG AND BACON PIE

(serves 4 – 6)

Ingredients:

5 or 6 eggs	4 middle bacon rashers
2 sheets puff pastry	black pepper
Parsley flakes	

Method:

1. Grease a medium sized pie dish and line with 1 sheet of pastry.
2. Break eggs, and place onto pie base evenly.
3. Cut bacon into approximately 4 cm pieces and cover eggs.
4. Sprinkle with black pepper and parsley flakes.
5. Add top sheet of pastry and baste with milk.
6. Bake in a moderate oven (180°C) for about 45 minutes until golden brown.

MORE OF BARRY'S LINKS OF INTEREST

The following links to item of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

Sara Kokley's story:

http://www.stltoday.com/lifestyles/health-med-fit/medical/study-hopes-to-ease-symptoms-for-those-with-myasthenia-gravis/article_422e11c9-bead-5cd2-b82d-7c7d7caad163.html

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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 – BRISBANE

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	32617564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414525241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	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
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
GEOFFREY	33556441	KEPERRA
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
CATHERINE	0418511110	SPRINGFIELD LAKES
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

Don't worry if you're a kleptomaniac, you can always take something for it

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

More questions for you to try on a cold night this winter. (Answers are at bottom of this page)

1. What was the name of explorer Ernest Shackleton's ship which was crushed by ice in Antarctica?
2. What is the dot over the lower case 'i' called?
3. The Nigerian port of Lagos is on which gulf?
4. How many tiles are there in a Standard game of Scrabble?
5. *Convallaria majalis* is the Latin name for which flower?
6. Xerophagy is the eating of what?
7. 'Albrecht Discount' supermarket is better known by which name?
8. The Ten Commandments first appears in which book of the Bible?
9. What is the name of the sidekick of cartoon hero *Super Mouse*?
10. An ascalor is what type of creature?
11. Talipes is the medical term for which condition?
12. Amsterdam, Kingston and Adelaide are all varieties of which vegetable?
13. Which Danish island was blown up by the British in 1847?
14. What was the name of US President Gerald Ford's golden retriever dog?
15. Who wrote the book '*Dubliners*' first published in 1917?
16. Ngultrum is the currency of which country?
17. Nanophilia is a strong attraction to which type of people?
18. Which US state is known as the Beef State?
19. In which Australian state or territory is Millicent ?
20. Garrotxa cheese is made from the milk of which animal?

Answers: 1) Endurance; 2) Tittle; 3) Gulf of Guinea; 4) 100; 5) lily of the Valley; 6) Dry food; 7) Aldi; 8) Exodus; 9) Ernest Penfold; 10) Fish; 11) Club foot; 12) Carrot; 13) Heligoland; 14) Liberty; 15) James Joyce; 16) Bhutan; 17) Short or small people; 18) Nebraska; 19) South Australia; 20) Goat.

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You know you're getting old when it takes so much effort to procrastinate

LIFE WITH GRAVIS

(published in the Spring 2013 edition of MGA News – UK)

When I wrote the last 'Life with Gravis' in August 2010 I said, "At the minute I am quite stable and intend to be around for a long while yet". Well, I am still here, so what has happened in the years since then? Mrs Gravis has continued to keep me in order. "Gravis, I don't think you should be doing that", or "eating that", "that" usually being something that I thoroughly enjoy. The wonderful medical team that manage my MG have brought me to a point where they tell me I am in a drug-controlled remission. I won't say what medication I am taking, because, as you will know, not every Myasthenic is the same, but it is a standard MG medication. It was just a matter of finding the right one.

I have had one or two adventures since I last wrote. Being an obedient soul (something which Mrs G might dispute) I responded to the invitation to send in a sample to see if I might have the early signs of bowel cancer. As a result I was invited to go for a look inside (a colonoscopy) to see that all was well. The procedure is usually done as a day patient, but the preparation requires two days of fasting. Knowing the stress that this might cause and not wishing to aggravate my MG, I contacted my MG Team. They arranged for me to be admitted through the Neuro Ward the night before and to be discharged from there the day after. The procedure was very interesting. I was conscious and able to watch it all on TV. I have seen a side of myself that I never thought to see, my inside. There were three small polyps which they removed, it did not hurt and I now have a clean bill of health. I always make sure that the MG team know what other specialists are doing.

I continue to enjoy my membership of our local MGA branch. The value of branch membership has been brought home to me by the help given to one of our members. Please forgive me if you recognise yourself, but telling your tale will help others. George (not his real name) came to one of our meetings and afterwards joined us for a pub lunch. He had great difficulty with a bowl of soup; in fact it took him nearly an hour to eat it, coughing and choking all the time. He had what the medics call Dysphagia, severe swallowing problems to you and me. We recognised the problem and George was guided to the right place to get help. The next branch event was a fish and chip lunch and I am pleased to say that he was tucking in with the rest of us.

A year ago I was invited to talk to some County Ambulance Service crews about Myasthenia Gravis from a patient's point of view. It was amazing how little some of them knew of the condition. I know from experience that, when in a myasthenic crisis where your respiratory muscles are weak, the last thing you want is to be laid out flat, which is the standard procedure for ambulance crews. Sitting up you have the benefit of gravity assisting your diaphragm to move up and down. I believe that raising awareness like that is one of our most important tasks. If you get the chance to talk about the condition, grab it. If you are unsure about talking, consult your Regional Organiser. I am periodically asked to chat to medical students, which I am always pleased to do. If they never meet a myasthenic, how will they ever learn about us?

My thanks to readers who have enquired after me and Mrs Gravis. Who knows – I might be tempted to write again one day.

Spring 2013

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Never deprive someone of hope — it may be all they have

It's easy to stop making mistakes - just stop having ideas

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

A final reminder that Membership Subscriptions for the financial year 2013/2014 are due. Membership Fees are the same as last year. Remember that financial membership entitles you to more Association benefits, such as free DVD's of Guest Speakers and access to Lending Library material.

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. If you receive the newsletter by email and are unsure whether or not you are currently financial, please ring our 1800 802 568 freecall number to enquire.

The majority of members will have 6/13 which tells you (and us) that you are financial to 30 June 2013. Others may show 6/14 or even 6/15 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/12, 6/11, 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 at info@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.

2012/2013 ANNUAL GENERAL MEETING

- WHEN:** Sunday 15 September 2013 at 10:00am for 10:15am sharp
- WHERE:** Southern Cross Sports Club, Corner Klumpp and Logan Roads, Mount Gravatt (vehicle entry to club is via Klumpp Rd.)
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. Shaun Pandy – 'Health in Retirement'
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier.
- HOW DO I GET THERE?** UBD Map 201 Reference D7.
- 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 8 September 2013**

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Polishing Apples

A young man asked an old rich man how he made his money.

The old guy fingered his expensive wool vest and said, "Well, son, it was 1932 - The depth of the Great Depression. I was down to my last nickel."

"I invested that nickel in an apple. I spent the entire day polishing the apple and, at the end of the day, I sold the apple for ten cents."

"The next morning, I invested those ten cents in two apples. I spent the entire day polishing them and sold them at 5:00 pm for 20 cents. I continued this system for a month, by the end of which I'd accumulated a fortune of \$9.80."

"Then my wife's father died and left us two million dollars."

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Label Instructions

Here are some actual label instructions on consumer goods:

On a hairdryer: "Do not use while sleeping"

On a bag of Chips: "You could be a winner! No purchase necessary. Details inside"

On Marks & Spencer Bread Pudding: "Product will be hot after heating."

On Nytol Sleep Aid: "Warning: May cause drowsiness."

On Nanna's Tiramisu dessert (printed on bottom): "Do not turn upside down."