



# Messages

Myasthenia Gravis Association of Queensland Inc



## APRIL 2008

Myasthenia Gravis Asscn 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

PO Box 16  
MT. GRAVATT QLD 4122  
NATIONAL FREE CALL  
1800 802 568  
ABN 92 055 613 137

E-mail [mgqld@gil.com.au](mailto:mgqld@gil.com.au)

Home page:

[www.mg-qld.qil.com.au](http://www.mg-qld.qil.com.au)

#### COMMITTEE MEMBERS

##### President

Dennis JENNINGS (Townsville)

Ph: 4774 0029

0402 285520

##### Vice-president

Anita JACKSON

Ph. 3800 4913

##### Secretary and Editor

Graeme Peters

Ph. 3288 4484

email: [grapop@dodo.com.au](mailto:grapop@dodo.com.au)

##### Treasurer

Kris KLITGAARD

Ph/Fax 3890 0115

##### Information Officer

Shirley JOHNSTON

Ph. 1800 802 568

##### Committee

John CHESTER

Ph. 3899 9387

Judie BARBOUR

Ph. 0439461288

##### PATRON

Dr Cecilie LANDER

Neurologist

Founder Member, of Brisbane

### PRESIDENT'S REPORT

Hi Everyone

I hope you are all well and have eaten all your Easter eggs.

I regret to tell you that I am resigning as your President, and as a member of the Management Committee from 12 April 2008.

As you know I have not been in the best of health so have decided to sell up in Townsville and move to Melbourne to be with my family, mainly my daughter and grand daughter. I have bought a unit in a Retirement Resort about 30 minutes away from my daughter's home. Things moved quicker than I thought they would - selling my home the first open day and having only 30 days to move.

I wish the Association all the best in the future and hope to still keep in touch and attend any functions that I can get to.

It is a sad moment writing this so will end now and hope to see a lot of you some time in the future.

See Ya

Cheers,

*Dennis*

PS: If ever in Melbourne take down my mobile number 0402285520, and call in for a coffee.

**Editor's note:** Dennis has been a member of the Association since 1997 and has served as Townsville Region Co-ordinator, Committee member and President. His contribution to the Association will be sorely missed. The Management Committee wishes Dennis all the best for the future, and we will certainly keep in touch.

**NB:** Is there anybody out there who is willing to take on the Townsville Co-ordinator role? If so, please ring Shirley on our Freecall number.

**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 - QUEENSLAND**

JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
HENRY	4982 6507	BLACKWATER
JOHN	3269 5066	BRIGHTON
TERRY / JUDI	3824 4158	CAPALABA
JOHN	3899 9387	BRISBANE
JESSICA	3369 8315	BARDON
HELEN	3279 3060	JAMBOREE HEIGHTS
POPPY	3288 4484	SPRINGFIELD LAKES
EILEEN	3269 5660	BRIGHTON
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
PAM / RAY	3801 1335	CORNUBIA
BEVAN / JEAN	4128 3262	HERVEY BAY
SHIRLEY	4128 3596	HERVEY BAY
SHARON	4151 7661	NORTH BUNDABERG
BARBARA	4124 2312	POINT VERNON
RAY / MARY	5443 8667	MAROOCHYDORE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
JOY	4165 4647	MUNDUBERRA
PATRICIA / LES	5464 6719	PURGA IPSWICH
BILL / COLLEEN	4926 4847	ROCKHAMPTON
TOM / SCOTIA	4693 3730	PITTSWORTH
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
KELLY	4728 4913	AITKENVALE
CAROL	4773 1213	HEATLEY
VALMA	4068 0702	TULLY
WILMA / NOEL	3807 2391	MT WARREN PARK
PERLA / GEOFF	4939 2724	YEPPON
IAN	4623 5169	YULEBAR
CAROLYN	5472 0386	COOROY
ROBYN	5520 4242	BURLEIGH HEADS
MAUREEN	5572 7993	MERMAID BEACH
HELEN	5445 4853	SUNSHINE COAST
LORRAINE	3206 0789	CLEVELAND
OWEN	4742 1190	CLONCURRENCY
GWENDA	3390 2643	CAPALABA
PATRICIA	5535 0274	BURLEIGH WATERS
AILSA	4055 1303	CAIRNS
STEFAN	3807 0541	EAGLEBY

DANIELLE	3202 2509	IPSWICH
MIKE	3288 4037	SPRINGFIELD
ROGER	3379 8916	GRACEVILLE
JUDIE	0439 461288	AIRLIE BEACH
BARRY	5483 1783	CURRA
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
DONALD	5563 7207	RUNAWAY BAY
RAJKO	5580 6404	OXENFORD
ELIZABETH	4936 2410	GLENLEE
MELISSA	4662 3337	DALBY
TERRY	5494 2470	MALENY
HELEN	3203 0150	DECEPTION BAY
ROBERT	5492 9754	MOOLOOLAH VALLEY
KEVIN	32819225	NEWTOWN
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
MARIE	3300 0053	THE GAP
MOYRA	5576 4979	BURLEIGH WATERS
GLORIA	5534 2669	CURRUMBIN
GEOFFREY	5437 3083	PELICAN WATERS
SARA	0422109492	BLACK RIVER

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**WEB-Site Update**

Our redesigned website is now up and running, and is available for viewing at [www.mg-qld.gil.com.au](http://www.mg-qld.gil.com.au)  
 You can now download current and previous issues of MessaGes and we now have links to other MG sites.  
 Also you can email us direct from the website.  
 Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

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**Shirley's Recipe**

**PEANUT BUTTER BISCUITS**

**Ingredients:**

- 375 g Crunchy Peanut Butter
- 1 cup brown sugar
- 1 beaten egg

**Method:**

1. Mix all ingredients together.
2. Roll into small balls and flatten.
3. Bake in a moderate oven for 15 – 20 minutes (be careful not to burn them).
4. Leave on tray for 5 – 10 minutes before transferring them onto cooling rack.

Note: Be sure to ask if your guests are allergic to peanuts before serving.

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**THE SENILITY PRAYER**

Grant me the senility to forget the people  
 I never liked anyway,  
 the good fortune to run into the ones I do, and  
 the eyesight to tell the difference.

\* \* \*



The following article was published in MGNEWS, the journal of the Myasthenia Gravis Association of the UK and is reprinted here with their kind permission:

## ‘ANTIBODY-NEGATIVE’ AND ‘MUSK’ MG NEW PROGRESS - PART I

You probably remember that patients with typical MG but without the typical antibodies have long been a challenge to the experts. Here is Nick Willcox's update.

### The problem that's puzzling us.....

As you know, the weakness in MG is caused by immune **antibodies** that damage the nerve muscle triggering system. Normally, when we decide to move, the chemical transmitter (acetylcholine; ACh) is released from the nerve endings; these 'ignition keys' latch into special 'locks' on the surface of the muscles – the ACh receptors (**AChRs**) – which then trigger them to contract. The AChRs are tightly packed on the muscle surface just opposite the nerve endings. That is mainly thanks to a special clustering system that is controlled by another protein called '**MuSK**'. In about 80% of typical MG patients, the antibodies directly attack the AChRs. That recruits the demolition system called '**complement**' that normally destroys germs, so AChR numbers fall and the muscles get weak. In the standard blood test, we measure binding of the patient's antibodies to tiny amounts of AChR that we dissolve from muscle cells and then label with a radioactive snake toxin. What about the 20% (or so) of 'negative' patients in whom we can't find these antibodies? They (you?) have provoked a lot of debate over the last 25 years. Their MG clearly improves when we wash away the antibodies by plasma exchange, so Prof Angela Vincent has long maintained that they must have **some** antibodies – but directed at other nearby targets. Indeed, in 1984, she showed that these antibodies weakened muscles without lowering AChR numbers. However, some of her critics argued instead that the standard blood test is just not sensitive enough and misses some 'false negatives'. Now, thanks to Prof David Beeson's genetic engineering, she can put more AChR into the test, and finds that about 5% of patients – who used to be borderline/negative – now become clearly positive (though weakly). So these critics got one piece of the jigsaw in the right place, **but...**

### An update on MuSK MG

That still leaves a lot of 'negatives'. In 2000, Angela started collaborating with Dr Werner Hoch (then in Germany), and eventually identified a new target for the suspected antibodies – our new friend **MuSK** (Muscle-Specific Kinase). That led to a new blood test, which gives clear positive or negative results, just like the one against AChR. By giving more patients a hard-and-fast diagnosis, that now saves many doubts and delays. Working with Angela, Dr John McConville (now in Belfast— see page headed 'MG Study') found these new MuSK antibodies in only about 5% of home-grown British MG patients. Interestingly, they and our friends in Rome found about twice as many MuSK positives among patients with Italian, Greek or Balkan origins, whereas there seem to be almost none in Norway and very few in Portugal, China or Japan. We would love to know the reason(s) for these striking differences – do they involve genes, diet or infections? The one risk factor found so far (by our Dutch friends) is equally uncommon all over Europe (it is a tissue type called HLA-DR14).

### More questions than answers

Things aren't always what they seem. There are plenty of other antibodies that seem just to be markers of a particular patient subgroup (eg, the other anti-muscle antibodies in patients with thymomas). So there has been some bitching (mainly from the USA) about whether the MuSK antibodies really cause the myasthenia. As these critics point out, the antibodies belong to the one subgroup (IgG4) that doesn't normally trigger destruction by complement, and is even thought to protect against allergies. However, in some skin diseases like pemphigus, the antibodies against skin cells are nearly all IgG4 too, and the experts are quite convinced that they do cause that condition. To prove the same with MuSK is much easier said than done in humans, but Angela's team is busy.

### Watch this space

Even if the critics are right – which we doubt – the MuSK antibodies clearly do single-out a distinct MG subgroup. As Dr Maria Farrugia showed (before she moved to Glasgow), their MG affects the limbs less than in typical MG, and the face, mouth and throat more; even more seriously, nearly half of the patients have breathing crises at some stage (versus about 10 - 20% in typical MG). Surprisingly, some have actual wasting of their muscles in the long-term – which could be a combined effect of the years of steroid treatment plus the MuSK antibodies. Also, most MuSK patients find that Mestinon® doesn't really help them. Though a few have only mild MG, most end-up needing steroids and other immunosuppressants; we feel there is still plenty of scope for improving these treatments, and we look forward to further progress.

## The final gaps in the puzzle

We still have to account for a 'hard core' of 10% or so of antibody-negatives. One final clue comes from the thymus. As you know, it is the factory that produces and exports T cells; these 'control freaks' of the immune system decide which 'B cells' will start to make what antibodies. In typical young MG patients, it nearly always includes lymph gland-like invasions, apparently a sign that the T and B cell responses against the AChR are getting started there. By contrast, Dr Isabel Leite in our team finds that it is almost completely normal in patients with MuSK antibodies: how that response gets turned on is another puzzle. Intriguingly, in at least half of the 'hard core' of 'apparent negatives', Isabel finds invasions very similar to those in typical MG. What's more, she is, after all, beginning to find antibodies in that same half. But that's a story for next time...

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## MEMBERS FORUM

There were two contributions for the members Forum this month.

### **M-L of Brisbane writes:**

'I would really appreciate any effort or knowledge members may have regarding clinical trials for people with , malignant thymomas, thymic carcinoma. If anybody knows of any or are able to tell me how to go about finding information on them.'

### **Shirley L from the Sunshine Coast writes:**

'I am writing this letter to allow my fellow MG'ers with bowel problems a glimmer of light at the end of the tunnel.

As we shouldn't think all complaints are connected to MG, we also must consider some conditions could be due to our muscle strength.

Muscles play a large part in holding tissues in our bodies together and once weakened, we get all sorts of problems, men and women.

Most of us suffer throat problems, incontinence, eye problems, walking, etc, all due to the muscle weakness of MG.

However, our bowel also suffers as I found out after 18 months of problems that my yearly colonoscopy didn't pick up, which amazed me totally.

But diarrhoea, bowel leakage, unable to pass even soft motions (passing out while trying and needing a toilet roll factory), pressure and heaviness in groins, burning stomach, backache and needing to get off my feet often indicated something was wrong.

Being a woman, first stop was an examination by a gynaecologist; then being put onto a magnetic chair that automatically worked the pelvic floor muscles – total disaster. First time I couldn't get off the chair or walk, was in pain, and to sleep for 1 hour at surgery before I could drive home. Here I was in another situation where my explanations fell on deaf ears. Second time I collapsed half way through – panic – lady doctor got cranky and so sent me to another doctor. This one was a man – bless him – he examined me and immediately phoned a bowel specialist who saw me two days later. He examined me and sent me along the passage for a special Barium Check and followed then and there by a special bowel X-ray. Booked me straight away into hospital same week for a FRYKMANN GOLDBERG RESECTION RECROPEXY - bowel replacement operation.

They found my bowel completely collapsed due to muscles stretching and then collapsing allowing my bowel to fall down. So 4 days in Intensive Care and another 5 days in hospital. Not easy to get my bowel going again – 2 atom bomb drinks later and home I could go.

Still up and down for some months and as I had lost 1 metre of bowel also, one now goes 5 – 6 times during the day and sometimes at night.

I accept now that this is the norm for me – so life goes on in my crazy MG way. My sunnyside is up again, so you can keep smiling with me.'

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 [grapop@dodo.com.au](mailto:grapop@dodo.com.au).

Your questions and responses may be anonymous for publication, but we will require your full name and address to be submitted to ensure genuineness. When forwarding a response, please refer to the issue or question raised so that we may correctly associate it to the issue or question.

**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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## **A PLEA FOR NOMINATIONS FOR POSITIONS ON THE MANAGEMENT COMMITTEE**

Very shortly, current financial members will receive forms calling for nominations for positions on the Management Committee of the Association for the Financial year 2008/2009.

As indicated in the previous edition of *MessaGes*, our Treasurer wishes to step down at the Annual General Meeting, and as you will have noted in this edition, our President has resigned. This means we will have 2 vacancies to fill at the AGM. In addition, some of our present Committee Members are now well into their senior years, and it would be disastrous for people with MG if the Association had to fold because of lack of interest.

A place on the Committee involves approximately ½ to ¾ of a day per month for meetings and some other small portion of your time (Treasurer, Secretary or the Information Officer obviously involves more time).

Please give consideration to putting your name forward for a place on the Committee, so we can look forward with confidence to the future of the Association.

If you would like to discuss this with members of the current Committee, please feel free to give them a call – their telephone numbers are on the front of the newsletter.

## **SERENITY**

Just before the funeral service, the undertaker came up to the very elderly widow and asked,

'How old was your husband?'

'98,' she replied, 'Two years older than me'

'So you're 96,' the undertaker commented.

She responded, 'Hardly worth going home, is it?'

**XXXXXXXXXXXXXXXXXXXX**

The nice thing about being senile is you can hide your own Easter eggs.

These days about half the stuff in my shopping cart says, 'For fast relief.'

Q. What is the common term for someone who enjoys work and refuses to retire?

A. NUTS!

**KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ**

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. What is the capital of Paraguay?
2. In 1399, Richard II was the first English king to do what?
3. The English Derby is run on which racecourse?
4. The Air Canada Silver Broom is awarded in which sport?
5. Who wrote *'The Adventures of Huckleberry Finn'*?
6. Which wedding anniversary does copper or pottery celebrate?
7. A numismatist studies which two things?
8. A group of turtles is called a what? A) Bale B) Turn or C) Shell
9. Where is the Sea of Tranquility?
10. Greenland is an External Territory of which country?
11. A mixture of chalk powder and boiled linseed oil is better known as what?
12. Abyssinia is the former name of which country?
13. Florence Nightingale was a nurse during which war?
14. Which city is home to the American football team the *Redskins*?
15. Who wrote the novel *'Rebecca'*?
16. What language is spoken in Catalonia, Spain?
17. Which bird can swim the fastest?
18. Sergei Bubka excelled in which athletic event?
19. Which aviator was the creation of Captain W E Johns?
20. Alphabetically what is the first US state?

**Answers:** 1) Asuncion; 2) Abdicate; 3) Epsom; 4) Curling; 5) Mark Twain; 6) Ninth; 7) Coins & medals; 8) Bale; 9) On the moon; 10) Denmark; 11) Putty; 12) Ethiopia; 13) Crimean; 14) Washington; 15) Daphne du Maurier; 16) Catalan; 17) Penguin; 18) Pole Vault; 19) Biggles; 20) Alabama.