



# Messages



Myasthenia Gravis Association of Queensland Inc

**DECEMBER 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  
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## **PRESIDENT'S REPORT**

### *Welcome*

It is hard to believe that this is the last Newsletter for the year as Christmas is just around the corner and another year has come to an end.

It has been a very exciting and successful year for the Association with our projects going forward and also our Guest Speakers for the year were fantastic. It will be our 21<sup>st</sup> year so that is another milestone we have made and we can all remember our own 21<sup>st</sup> Birthdays and how we had big celebrations on those occasions.

Our Meet the Members day on the South Coast was another huge success with new members in the area meeting others who have MG. The Committee is looking forward to our Meet the Members day in Mackay on 10 March 2012 to be able to put faces to names and also renew friendships. Our Mackay coordinator has been busy organising a suitable venue for the function.

Our Christmas party at Carina Leagues Club was a huge success. Although numbers were a bit down on previous occasions, those present enjoyed their meal and some Christmas cheer.

The Exercise Effect in MG study will go ahead even though we have limited numbers for the University of Queensland to pilot this project. We anticipate that we will get enough information out of this project to help everyone who has MG.

On behalf of the Committee I would like to take this opportunity to wish all our members far and wide a very Merry Christmas and all the very best for 2012

Take care

*Anita*

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 – QUEENSLAND REGIONAL COORDINATORS**

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

**CHAT LIST – QUEENSLAND REGIONAL MEMBERS**

JUDIE	0439 461288	AIRLIE BEACH
KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
LYNDA	4159 2890	BARGARA
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
DENISE	4788 0798	BUSHLAND BEACH
AILSA	4055 1303	CAIRNS
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
GEOFFREY	5341 8747	LITTLE MOUNTAIN
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
BROOKE	0404720807	NAMBOUR
ALEX (BROOKE'S CARER)	0420858386	NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE

DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
KARLIENE	0432431591	SUNSHINE ACRES
HELEN	5445 4853	SUNSHINE COAST
DIANNE	4638 8447	TOOWOOMBA
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	416178458	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

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### CHAT LIST CHECK

Our Chat Lists are very important in giving new members access to persons who also have MG and provide 'sounding boards' for them. The experience is that new members gain comfort and confidence from chatting with someone who understands their condition.

To ensure that the Chat Lists are up-to-date and accurate, would those members whose names appear on their relevant Chat List, please advise us if their information is correct or incorrect via our 1800 802 568 freecall number, or via email from the 'Contact Us' page on our website [www.mgaq.org.au](http://www.mgaq.org.au) or via email to [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com)

If the information is incorrect please advise of the correction required; if the information is correct, please advise us also.

If your name is not on the relevant Chat List, and you are agreeable to be included on it, please let us know also via any of the above means.

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### Future Planned Activities

Saturday 10 March 2012 'Meet the Members' at Mackay

More details will be published as each event becomes closer.

\* \* \* \* \*

### News from Mackay

We held our Christmas get together at the North Mackay Bowls Club on the 27/11/2011.

Seven members attended and had an enjoyable lunch. Each member received a Christmas gift.

The members decided our next get together will be at the Mackay 'Meet the Members' Meeting on the 10/3/2012 at the Boomerang Hotel/ Motel .

Muriel and I wish all a Merry Christmas and a Happy New Year for 2012.

Bill -  
Regional Coordinator Mackay

**INVITATION TO REGISTER SKILLS AND EXPERIENCE**

Members will be aware that from time to time, the Management Committee takes on special projects or tasks. For instance, current projects include the Data Survey project, the 'Exercise and MG Study' and a 'National Umbrella MG organisation' project. Past ones have been the re-design of our website, organising a 'Games day', etc.

Under the Association's Constitution, the Management Committee can appoint a sub-committee to undertake a project (or task), and that sub-committee can include persons who are not on the Management Committee. Concomitant with the appointment of a sub-committee is the fact that certain specialist skills may be required for the task at hand, e.g., accounting skills, legal experience and skills, computer skills, trade skills, etc.

To prepare for those occasions where specialist skills and experience may be required for a project (or task), the Committee is desirous of maintaining a register of skills and experience that members (or a family member or friend) may have, and are prepared to volunteer to use those skills and experience to assist if, and when, required. Should there be a need to call upon the skills or experience from the register, the time commitment required of the person will be kept to an absolute minimum so as to have minimal impact upon the person's family and working situation.

The information that will be recorded in the register is: Member Name - Contact Phone Number and email address - Name of Person with the skills and experience (if not the member) - Contact Phone Number and email address of the person with the skills (if not the member) - Details of the skills and experience areas. If the details refer to a family member or friend, the member will be the primary contact. The register will be strictly confidential and information WILL NOT be disclosed to any person or organisation other than the Management Committee of the MGAQ.

If you (or a family member or friend) are prepared to have your skills and experience registered, please contact the Secretary by any of the following:

Email [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com) ; or  
via the email facility on the 'Contact Us' page at our website [www.mgaq.org.au](http://www.mgaq.org.au); or  
via the following form to PO Box 16, MT GRAVATT Qld 4122

Member Name: \_\_\_\_\_ Phone No.: \_\_\_\_\_

Email Address: \_\_\_\_\_

Person with Skills/Experience: \_\_\_\_\_ Phone No.: \_\_\_\_\_

Email Address: \_\_\_\_\_

Skills/Experience Areas:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If you have any enquiries regarding this matter, please contact the Secretary on (07) 32884484.

## MEMBERS' FORUM

Two contributions this month, both from Rosemary.

Rosemary writes:

*"All my life I have suffered with some form of muscular weakness then a doctor in Sydney diagnosed me with MG after a series of tests. I came to QLD and saw a neurologist at Redcliffe Hospital and he said I had been mis-diagnosed and I had LEMS rather than MG. MY GP then referred me to another neurologist as I didn't like the one at Redcliffe and the first thing he wanted to do was get all of my medical records from Westmead Hospital and the doctor who diagnosed me with MG.*

*He got the hospital records but unfortunately not from the private neurologist as he shreds his records after 7 years. The first thing my new doctor did was examine the hospital tests and other stuff he was able to get and had to admit my condition was beyond his capabilities. So now I am off to Royal Brisbane Hospital.*

*My muscles are wasting and I am getting weaker, which I know does not happen in MG, but I would be interested if anyone knows of something like this."*

And Rosemary followed up with the following:

*'I wonder how many people are misdiagnosed with MG because of muscle weakness.*

*After all these years and with my muscles wasting and getting weaker, I have been given a diagnosis of Motor Neurone Disease. I have, over the last 3 months, lost nearly 20 kg, most of this being muscle mass. I have no muscle tone and very little strength. I am still walking at this stage but will no doubt end up wheelchair bound.*

*The reason I am writing this to you is that I always questioned in the first place as to whether I had MG and of course the problem is that a lot of neuromuscular diseases have very similar symptoms. So I just want to impress upon people that if you are not satisfied with your first doctor's diagnosis, don't stop there. Keep seeking until you get a correct diagnosis.*

*I asked this last neurologist I went to see how come initially Mestinon worked for me, which of course it does not now. She said that because it gave me that "extra burst" for the message from the nerves to get to the muscles. She even said I could keep taking it now if I thought it would help but I have ceased taking it.*

*So unfortunately I do not have a good prognosis but feel relieved that I am not some sort of nut case in continuing to seek out the answers to my questions, because the more I read about MG, the less it did not fit with what was going on with me.*

*I am 58 and in the right age bracket when a diagnosis for MND is usually made, even though I was probably born with it, or a virus may have started it.*

*I don't want to scare the readers but if you notice anything extraordinary outside of what MG should be like, please get it followed up. MND is not curable but there are drugs that can slow the process.'*

Please send in contributions to the 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](mailto: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.

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## **Shirley's Recipe**

### **RHUBARB TEA CAKE**

(serves 10)

#### **Ingredients:**

125g butter, softened	1 cup brown sugar
1 egg	1 teaspoon vanilla extract
2 cups plain flour	1 cup bicarbonate of soda
1 teaspoon cinnamon	1 cup sour cream
3 stalks rhubarb, finely sliced	

#### **Topping:**

¼ cup caster sugar	¼ cup slivered almonds
¼ cup desiccated coconut	½ teaspoon cinnamon

#### **Method:**

1. Preheat oven to 180°C. Grease a 20cm spring-form tin. Line base with baking paper.
2. Beat butter and brown sugar together until pale and creamy. Add egg and vanilla and beat well. Sift flour, bicarb soda and cinnamon together. Add to butter mixture with sour cream and fold through until well combined.
3. Reserve ½ cup of the rhubarb, add remainder to cake batter and stir well. Transfer to cake tin and smooth top.
4. To prepare topping: combine topping ingredients in a small bowl with reserved rhubarb. Scatter over cake batter, pressing rhubarb slices into surface. Bake for 1 hour until cooked when tested. Cool for 10 minutes before removing from tin, then cool on a wire rack.

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### **News from Townsville**

The Townsville MG group met for lunch on Saturday 26 November at The Avenues Hotel. Twelve members attended and apologies were received from others who were already booked for Christmas functions.

Good food, great company, interesting conversation and sharing of ideas made for a very pleasant gathering.

Carol – Coordinator Townsville Region

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When you stop believing in Santa Claus is when you start getting clothes for Christmas.

## **PROJECTS UPDATE**

### **Collecting data on sufferers of myasthenia gravis –**

We are heading for 150 completed surveys (around 2/3 from Queensland). We greatly appreciate the active support to our sister organisations in NSW and WA. The wider the net, the better the findings will be.

Our questionnaire is based upon a survey developed for a Norwegian study. They had a 77% response rate. Let's see if we can get a better result !!!!!

Many thanks to those who have already participated. The data inputting continues to progress well.

If you are a sufferer, or you know of a sufferer, and need a copy of a questionnaire, please contact us on the toll free phone number (1800 802 568)

### **'Exercise Effect in MG' Study –**

The Committee have approved this study on a scaled-down basis. Initial assessments of those participating will be held in January 2012. Professor Jenny Nitz, who is supervising the Study, advises that there is no other study of this kind anywhere else in the world that she has been able to discover, so we have an opportunity to be responsible for a 'world-first' which is something the Association can be very proud of.

### **Enhancements to our website –**

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

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## **MEET THE MEMBERS - MACKAY**

- WHEN:** Saturday 10 March 2012 at 10:00am.
- WHERE:** Boomerang Hotel/Motel, 307 Nebo Rd, MACKAY
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier. Remember you do NOT have to reside in the Mackay region to attend.
- CATERING:** Tea and coffee are available from 10 am.  
Lunch is available from the hotel Bistro from a varied menu and at reasonable prices.
- ENQUIRIES:** Further information is available by ringing our Freecall number 1800 802 568 or by contacting the Mackay coordinator, Bill Harris, on (07) 4954 1221
- RSVP:** Ring our FREECALL 1800 802 568 and let us know if you are coming, how many, and if you are staying for lunch. It is important for us to know. Please let us know by **Friday 2 March 2012.**

# MERRY CHRISTMAS



*The President and  
Management Committee*

*of the Myasthenia Gravis  
Association of Queensland Inc*

*wish our members and their  
families*

*the very best of wishes for the  
Festive Season*

*and a safe and prosperous 2012.*

*They would also like to thank you*

*for your support over the past  
year*

*and look forward to a bigger and  
better 2012.*

