



Messages

Myasthenia Gravis Association of Queensland Inc

MARCH 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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Neurologist
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PRESIDENT'S REPORT

Welcome

Hope everyone is safe from all the flood waters raging at present throughout Australia. It certainly has been the silly season for the extreme differences in the weather and our Queensland weather is getting to be like Melbourne with the many changes in the one day.

I would like to take this opportunity to thank our members who are progressing through our Exercise Effect in MG project. I believe that you have found that with exercise you can do things better and even do things that you have not been able to do before. Hoping we can get the desired information out of this project that will help other members and also the medical profession.

Our next function for our members will be 17 June 2012 at the Carina Leagues Club so please mark it in your diaries as we have organised a very good speaker whose presentation will be very informative for you. Unfortunately I will not be present at this function as I am going to Europe for 2 months in June.

We are still posting our survey forms to our members so the project is still progressing and we will notify you of any developments that will happen from time to time.

We will also give you a report on our Meet the Members in Mackay in next month's newsletter.

Take care

Anita

CHANGE OF EMAIL ADDRESS

Please note that the Association's email address has changed.

The new address is: info@mgag.org.au

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.

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 – 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	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

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Future Planned Activities

Sunday 17 June 2012 Midyear function – Carina leagues Club - Guest Speakers arranged.

Sunday 9 September 2012 Annual General Meeting – Club Pacific, Carindale – Guest Speakers arranged.

Sunday 9 December 2012 Christmas function – Caloundra Power Boat Club

More details will be published as each event becomes closer.

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Shirley's Recipe

Note: The editor apologises for repeating the recipe for Rhubarb Tea Cake in the February issue.

ORANGE AND BLUEBERRY TEA CAKE

(serves 8)

Ingredients:

1 ½ cups self-raising flour	½ cup almond meal	½ cup caster sugar
1 egg	⅔ cup milk	60g butter, melted
1 orange	1 punnet blueberries	2 tablespoons caster sugar, extra

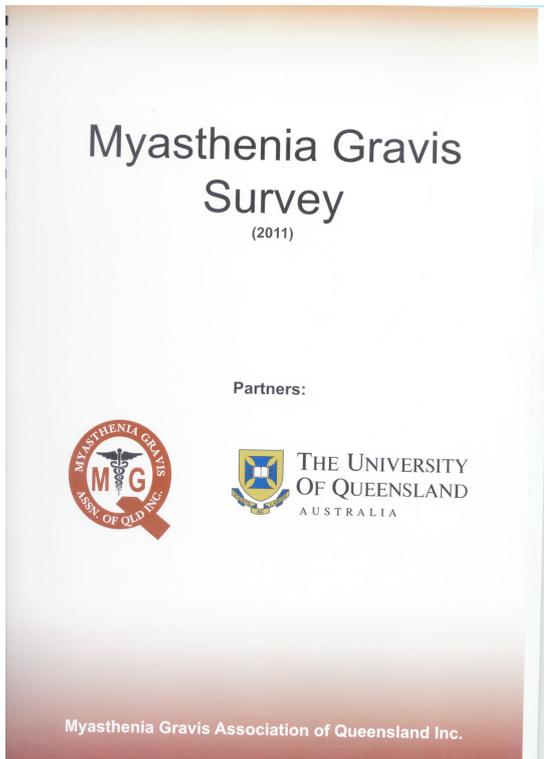
Method:

1. Preheat oven to 180°C. Grease a 22cm cake tin. Line base with baking paper. Combine flour, almond meal and caster sugar in a large bowl.
2. Whisk egg, milk and butter together until combined.
3. Finely grate rind from orange and put aside. Juice orange and add ¼ cup of the juice to the egg mixture. Pour liquid into flour mixture and stir with a wooden spoon until well combined. Pour into cake tin and scatter with blueberries.
4. Combine the grated orange rind and extra caster sugar, rubbing together with your fingertips. Sprinkle over the blueberries. Bake for 40 minutes or until a skewer inserted into the centre comes out clean. Leave in tin for 5 minutes then transfer to a wire rack to cool.

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PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –



WE NEED YOURS!

Sometimes people can be missed.

If this has happened to you please give us a call and allow us to send out a survey.

The freecall number is 1800 802 568

Dr Stefan Blum has kindly agreed to attend our Annual General Meeting in September and present an update on the Data Survey.

‘Exercise Effect in MG’ Study –

Participants in the study have, as at end of February, completed 7 exercise sessions at the University of Queensland and all are thoroughly enjoying it and commenting on how much fitter and better they feel so far. Professor Jennifer Nitz, who is overseeing the study has kindly agreed to attend our Annual General Meeting and present a report on the study to our members.

Page 8 of this issue has a list of the exercises that the participants are undertaking each session, and you can see from this list, that NONE of the exercises are IMPACT ones, but relate to things that people with MG do each and every day, such as walking, stretching, reaching, balancing, etc. Each exercise routine is repeated for approximately 5 minutes. Participants are free to select the sequence of the exercises and may rest at any stage during a session. They are under constant supervision and observation of staff from the UQ Neurological, Ageing and Balance Clinic.

If, after viewing this list, you now feel inclined to join the study, please contact the Secretary.

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Do not argue with an idiot. He will drag you down to his level and beat you with experience

My mother never saw the irony in calling me a son-of-a-bitch

He who smiles in a crisis has found someone to blame

MEMBERS' FORUM

Firstly, an apology to **Marion** from Tasmania, whom the editor incorrectly referred to as Miriam in last month's Members' Forum.

This month we have an important contribution from Gail of Woody Point concerning the supply of IVIg products.

Gail writes:

Hi Everyone

I have MG and I recently visited my doctor for my 6 monthly check-up. After discussing my progress and other related issues with my Neurologist he informed me that I would no longer be a recipient of the Intragam P product for my four weekly IVIg. This came as a surprise to me. To be perfectly honest I was also a little upset and confused.

I was told demand was outstripping supply and so it was advised all MG patients who are currently receiving Intragam P are now being given an alternate imported product namely Octagam or Kiovig.

I decided to investigate this a little further and subsequently found some interesting websites. One of these sites is the National Blood Authority, which is an Australian Government agency and is also one of the main bodies who set up the guidelines and criteria for all blood related medications and products. They work closely with the Red Cross Blood Service who supply the products.

First of all I called the Red Cross Blood Service as they are the main suppliers but did not initially come up with any definitive answers. It was suggested I call the pharmacy at the hospital where I receive my treatment. Eventually after many calls I did end up back at the Red Cross Blood Service and I left a message for someone to call me back and basically answer the following questions.

1. Who made the decision to discontinue the domestic product for all MG sufferers?
2. Why was this decision made?
3. How did they come to the conclusion of eliminating our particular condition/disease from receiving the domestic product?

Dr Joanne Pink, Chief Medical Officer with the Red Cross Blood Service called me back and the answers I received are as listed:

Answer 1.

Due to the increasing demand for Intragam P it was necessary to cut back the supply to specific recipients as demand is outstripping supply. Thus offering imported alternatives like Octagam and Kiovig.

Answer 2.

A committee of specialists and representatives from the Commonwealth and State and Territory Health Departments felt it was necessary to have a contingency plan in place whereby imported products like Octagam and Kiovig were available in ready supply if there was ever a need for a replacement for the domestic Intragam P due to some unexpected loss of supply or contamination.

The imported products have been used for a number of years and it was deemed it would be beneficial for Australia being a small nation to have a back up plan to ensure a continued supply.

Answer 3.

Basically it was described to me that all recipients of IVIg are broken down into 3 main groups.

These include:

- a) Patients requiring short-term treatment with IVIg (less than 6 months) – such as people with uncommon skin problems. These patients are the first group to receive imported IVIg and they are usually given imported product.
- b) Patients with chronic neurological conditions (MG being one of these.) In this group of patients the IVIg works by changing how the immune system works. These patients are the second group of patients to be given imported IVIg when there isn't sufficient Intragam P.
- c) Immune deficiency patients who often require life-long treatment. In these patients the IVIg replaces immunity and helps them fight infections. These patients are the last ones to be given imported product because it is important for them to have immunity against infections commonly found in Australia.

The committee made the above decisions.

A press release which is available for you to view is on the National Blood Authority website announcing these new guidelines. Address is as follows:

<http://www.nba.gov.au/supply/media-release-imported-ivig.pdf> or <http://www.nba.gov.au/supply/media-release-imported-ivig.pdf>

I have tried to keep this correspondence as simple as possible. I am sure once you have read my article you will have many more questions to ask, which remain unanswered.

Finally, if you have any concerns whatsoever please do contact your GP or Neurologist to discuss further as they are your best option at the present time.

Please note: Dr Joanne Pink has kindly checked out the above article for accuracy as I am not a medical doctor and I felt it best to let her read it before sending so I am not misleading anybody.

Thank you

Gail
Woody Point.

Editor's Notes:

.If anybody wishes to contact Gail and discuss this a little further please feel free to contact our 1800 802 568 freecall number or email info@mgag.org.au and we will provide Gail's contact details

.The management Committee have given Gail the authority to pursue this matter further on behalf of the Association and updates on her progress and findings will be published in future Members' Forums.

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 info@mgaq.org.au.

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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Did you know??

The Goldberg Brothers - The Inventors of the Automobile Air Conditioner

The four Goldberg brothers, **Lowell, Norman, Hiram, and Max**, invented and developed the first automobile air-conditioner.

On July 17, 1946, the temperature in Detroit was 97 degrees Fahrenheit.

The four brothers walked into old man Henry Ford's office and sweet-talked his secretary into telling him that four gentlemen were there with the most exciting innovation in the auto industry since the electric starter.

Henry was curious and invited them into his office. They refused and instead asked that he come out to the parking lot to their car. They persuaded him to get into the car, which was about 130 degrees, turned on the air conditioner, and cooled the car off immediately.

The old man got very excited and invited them back to the office, where he offered them \$3 million for the patent. The brothers refused, saying they would settle for \$2 million, but they wanted the recognition by having a label, 'The Goldberg Air-Conditioner,' on the dashboard of each car in which it was installed.

Now old man Ford was more than just a little anti-Semitic, and there was no way he was going to put the Goldberg's name on two million Fords. They haggled back and forth for about two hours and finally agreed on \$4 million and that just their first names would be shown.

And so to this day, all Ford air conditioners show --

Lo, Norm, Hi, and Max -- on the controls.

Control yourself !!!

EXERCISE EFFECT IN MG STUDY

Happy Participants undertaking their exercises



EXERCISE PROGRAM

Medicine Ball Throwing	Stand with your feet together. Maintain your balance with this foot position as you throw and catch the ball with a partner
Clock Exercise and Lunge	Shift weight and step to yellow tape Lunge down as weight shifts onto that leg Repeat with both legs, in all directions
Clock Exercise and Tap	Same as for above Clock Exercise, but instead of lunging, tap toe at each point. Repeat with both legs in all directions
Corridor Walking	Walk laps in hall way Take big steps and swing arms
Deep Squat	Start with feet about shoulder width apart Squat down by sticking your bottom out – as if you are sitting on a seat As you squat, try to keep your knees in line with your second toe
Reaching	Stand with your feet together Pick up cone from one extreme of your reach and place cone onto table at the other extreme of your reach
Sit - Stand	Sit on bed or chair – feet together, holding an item to balance Stand up – keeping item balanced
Balance Exercises	Feet apart, standing on black foam Turn head from side to side and maintain balance