



MessaGes

Myasthenia Gravis Association of Queensland Inc

JUNE 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

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

E-mail: info@mgqaq.org.au
Internet: www.mgqaq.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

Secretary and Editor
Graeme PETERS
Ph. 3288 4484
email: graeme.peters2@bigpond.com

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee

Bill SYNNOT
Ph. 0418196707

Carol BUCHANAN
Ph. 4773 7122

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

Well June has arrived so we have half way through another year and all wondering where has it gone. One thing is for sure that the weather is now cooler and a lot better for all of our members with MG.

The committee has been busy organising different things this year as we are trying to keep up to date with technology and also improving our image and spreading the word about MG.

For those members who have access to the Internet, Google have a facility called 'Google Alert' whereby you can receive advice of any new articles which are posted on the Internet on a subject you have specified. Committee member, Bill Synnot, has set up a Google Alert for anything to do with to MG and he forwards them to the committee. We are amazed at what gets posted to the internet about MG as there are some very interesting articles - we found out that June is MG month. You may like to set up a Google Alert for yourself. If you require any assistance in setting up one for yourself, please send an email to info@mgqaq.org.au .

With regards to our letter showing support for one of Dr. Stephen Reddel's research partners we have received confirmation that the scientist, Bill Phillips, has retained his position at Sydney University, so that is good news.

I will be in Barcelona on the 17 June so my thoughts will be with you all at the meeting.

Take care

Anita

NOTE: Report on the June 17 function will be published in the July issue of MessaGes

Supported by



MEMBERS' FORUM

IVIg and Intragam

We are still waiting to hear of the availability of Dr Joanne Pink, Australian Red Cross, regarding giving an update on the IVIg supply situation in Australia, so at this stage we are unable to advise whether or not the presentation will go ahead.

Additionally, response from members regarding their interest in attending such a presentation has been minimal and, as such, disappointing.

To enable the Committee to make a decision on whether or not we proceed with the invitation for Dr Pink to a meeting of members, would those members interested in finding out more about IVIg or asking questions on the current state of affairs regarding Intragam in Australia, and have not yet let us know of their interest, please ring our 1800 802 568 freecall number and advise if you are prepared to attend a presentation, in Brisbane, in July. We are aiming for Sunday morning July 22. If we proceed with the meeting, full details will be notified directly to those who have expressed an interest.

Your responses are required urgently, please.

Alex of Nambour writes:

'Our 15 year old granddaughter, Brooke, was diagnosed with MG 6 years ago, and we are finding that her Intragam treatment is now only lasting for about 3 weeks at a time.

The doctors at the Royal Childrens' Hospital are now recommending that she switches to Rituximab for treatment. From what we have been able to find out this is a treatment which is largely experimental at this stage, and has some potentially serious side effects.

We would like to find out more about Rituximab as a treatment for MG. Does anyone have personal experience of this treatment?'

If you are able to help Alex in this matter, please contact our 1800 802 568 freecall number and you will be provided with contact information for Alex.

Shirley's Recipe

COUNTRY CORN BAKE

Ingredients:

1 finely chopped onion	½ cup grated carrot
½ cup grated zucchini	½ seeded and chopped capsicum
½ cup diced celery	½ cup chopped shallots
4 rashers finely diced bacon	400g can drained whole corn
½ cup grated tasty cheese	½ cup sifted self-raising flour
30g melted butter	4 eggs
Salt and pepper to taste	

Method:

1. Combine all ingredients in a bowl and season to taste.
2. Mix well and spoon mixture into an 8in (20cm) round cake tin (greased and lightly dusted with dry breadcrumbs). A larger and flatter tin may be used.
3. Bake in a moderate oven for 35-40 minutes until set.

* * * * *

Successful people are simply people who learn to solve their problems... they are not people without problems.

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
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
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

Please note that * indicates that this member is available via the VOIP Skype facility on a computer

Future Planned Activities

Sunday 9 September 2012	Annual General Meeting – Club Pacific, Carindale – Guest Speakers arranged.
Sunday 9 December 2012	Christmas function – Caloundra Power Boat Club
Sunday 10 March 2013	Picnic in the Park – venue to be advised

More details will be published as each event becomes closer.

Information Booklet

Our new Information Booklet has been completed and printed and is now available for distribution. The booklet replaces the previous numerous brochures, and presents information about myasthenia gravis in a structured and consolidated format.

Current financial members will be mailed a copy of the booklet shortly. Regional Coordinators will be contacted individually regarding their requirements.

The committee, on behalf of the members, extends its sincere thanks to committee member Carol Buchanan for her untiring efforts over a considerable period of time in bringing this project to fruition.

2012/2013 Management Committee Nominations

All current Management Committee members have been nominated, and accepted nomination, for their respective positions for the 2012/2013 year.

As no other nominations were received, those nominated will be appointed at the Annual General Meeting on 9 September.

ALICE REFLECTS

(published in the Spring 2011 Edition of the MGA News-U.K)

As a physician I have been in the ICU/recovery unit many times. So, when the neurologist I talked to asked me to go there to be seen by the head of anaesthesiology, (who I knew very well), I felt very comfortable about it. It made perfect sense, I was having gradually worsening shortness of breath over the last few days, to the extent that I could now hardly talk to him. He was concerned and wanted me to be seen by someone who has a good understanding of respiratory diseases.

I slowly walked there from the near-by car park, leaning on my husband. By the time we got there I could no longer stand or even sit properly. The excellent nurse who saw me got me a bed right away, and had me propped up as he saw my significant difficulty breathing when lying down. "Danny will be here shortly", he said, calling the head of anaesthesiology by his name. I slowly nodded my head and tried to smile, as I could hardly talk any more.

Danny, a cheerful talkative and chubby man with smiling and reassuring blue eyes that always gave comfort to patients under his care, was now by my side. "Don't try to talk" he said, seeing how difficult it was for me to breathe. "I will do the talking. The neurologist told me that they think you may have Myasthenia Gravis, but aren't done with their tests yet. For all I care, you are having significant and obvious respiratory distress and I want to get to the bottom of it. I will do some tests and then we can decide how to proceed".

He then had me blow as hard as I could into a device he held in his hand. After looking at the numbers he said "I don't think we need to do any more tests. You have significant weakness of your respiratory muscles. You are on the verge of requiring intubation, and we need to treat you fast, before there is any further deterioration in your condition". He then looked at my eyes, and did a very brief examination not to tire me too much. "You have ptosis, pre-intubation respiratory muscle weakness. You improve with Mestinon and they think you have myasthenia gravis. So, one does not have to be a genius to understand that you have a myasthenic crisis, and need to be treated accordingly".

I felt relieved and overwhelmed at the same time. I did not realise that I was so ill, and yet if he is going to treat me, I will be well again. I didn't realise that "treatment" meant inserting a central line into my neck and doing a plasma exchange. As a haematologist, I have supervised this procedure many times, but the thought of having this done to me was quite scary. "I will have to lower your bed down" he said "and you have to lie very still and not move until I am done". But, this was quite impossible for me, as the moment he put my bed down I could hardly breathe. I felt I was suffocating. He noticed my agony and put the bed back up again.

He now talked to the nurse. I could hear him say "I don't want to intubate her for that, but we may have no choice". And then he said- "let's try one more thing". He then injected something into the line I had in my arm. Within minutes I felt as if this was all just a bad dream. I could sit straight in bed and talk; I could easily move my arms and legs. "Thanks", I said, "I feel great, I am sure that if you do those tests again, they will be fine". All is well, I was saved. I didn't really need all this, I could go home, I thought to myself. Danny asked me to blow into the device again just like I did before. He said, looking at the numbers. "Everything went back to normal". I felt relieved. "This means that I could go home?" I asked. "No, this means that we have a short window in which we can insert the central line and start the plasma exchange", he replied. "Didn't you understand what I said before? You have a myasthenic crisis and need an emergency plasma exchange, before your condition deteriorates any further. Your dramatic response to the neostigmine (Tensilon®) which I gave you, is just another proof of what I think. Sometimes it works in patients with a partial response to Mestinon." (This was the first time I experienced the effect of neostigmine or heard about it. Only later did I learn that this drug was not developed by anaesthesiologists, but actually

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2012/2013 are due. Membership Fees are the same as last year.

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.

The majority of members will have 6/12 which tells you (and us) that you are financial to 30 June 2012. Others may show 6/13 or even 6/14 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/10, 6/09, 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@mgag.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.

.....
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.
