



# Messages

Myasthenia Gravis Association of Queensland Inc

**SEPTEMBER 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.

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## **PRESIDENT'S REPORT**

### *Welcome*

It is hard to believe that we have just held our 21<sup>st</sup> Annual General Meeting at Club Pacific. It was well attended by 35 of our regular members and some new faces. The two Guest Speakers gave very informative and interesting progress reports on the Data Collection Survey Project and the 'Exercise Effect in MG' Pilot Study (DVD's of the presentations will be forwarded to financial members when they are produced). Lunch was enjoyed by all with plenty of conversation at the tables. We thank Dr. Blum and Professor Nitz for giving freely of their time on a Sunday morning.

Our next regular function will be the Christmas Luncheon at the Power Boat Club in Caloundra - where has this year flown?

We have arranged for Dr. Joanne Pink, Red Cross Blood Service, to give a presentation on the current state of IVIg supply on Sunday 11 November 2012 and are in the process of locating a suitable venue on the northside of Brisbane for this. It is very short notice but Dr. Pink is having holidays in September through to October. We are hoping to have some feedback from our members who have had some reactions to a changed medication. If you cannot attend but have had some reactions can you please call Shirley on the 1800 802 568 freecall number and advise her of what they are so that they can be discussed with Dr. Pink. Please see Item 3 of the Members Forum in this issue.

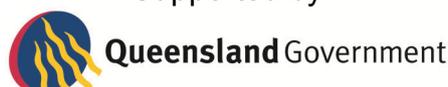
It is great news that the interview with Shirley Johnston and Dr. Stefan Blum went to air on the ABC TV and ABC Local radio. This will certainly help raise the public awareness of myasthenia gravis and the Association.

Take care

*Anita*

*Always laugh when you can. It is cheaper than medicine.- Lord Byron*

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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 – 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 (Alphabetical)**

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
SERAFINA	4751 6415	JENSEN
GEOFFREY	5341 8747	LITTLE MOUNTAIN
JUDIE	0439 461288	MACKAY
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
MAUREEN	0411331258	PACIFIC PINES
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
LARINA	4636 0046	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

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## **PROJECTS UPDATE**

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

Dr Blum presented preliminary results of the survey at the AGM. He spoke warmly of the experience of sharing our journey and commented on points of interest from both a physician's point of view and a sufferer's view of living with this condition. The research showed how difficult it is for a GP to diagnose the condition due to the wide variety of initial symptoms. It also showed the strong link to other auto-immune conditions. The current data entry will cut off at some point soon so that initial findings can be published. If you wish to be included it is time to be more proactive in completing your survey and seeing your doctor to gain the necessary validation via the blue form. We are very grateful to Dr Blum for the work that is taking place and for his time in attending the meeting. More details will follow for members via a DVD of the presentation.8

Dr Blum's presentation showed that it really was worthwhile for people to take the time and effort to complete the Surveys and for this we are very grateful.

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

Preliminary results were presented by Professor Jennifer Nitz at the Annual General Meeting on September 9. The DVD of her presentation will be available in the coming weeks.

Again, it is not too late to join the Study and if, after viewing the list of the exercises published in the March newsletter, you now feel inclined to join the study, and live in the Brisbane area, please contact the Secretary. (We now have one new participant who is about to commence the exercise program.)

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## MEMBERS' FORUM

1. Rosemary from Caboolture writes:

*"I've just read the latest MGAQ Newsletter and took particular interest in the ALICE REFLECTS item.*

*For 12 years I have thought I have had MG and the symptoms and some of the EMG tests certainly did back this up. But my muscles are wasting now and I am under the care of a wonderful Professor of Neurology at RBWH in Brisbane. In 2 weeks I go in for a muscle biopsy. After years of trying to find out why my muscles are becoming weaker and weaker I may now be close to an answer. One of the NCS tests they did on me at Brisbane Hospital was a repetitive NCS on my right shoulder. It showed that there was no gradual weakness going on the more they repeated the tests. This has proven I do not have MG.*

*I know with neurological disorders signs and symptoms can apply to so many different types of diseases. I have had blood tests which show I have a Mitochondrial Disorder, possibly Mitochondrial Myopathy. The other thing I am being tested for is Lower Motor Neurone Disease. What made me go and see another neurologist was that I lost 15kg very rapidly through muscle wastage and I know this does not happen with MG.*

*I think what I am trying to say here is that if a person has a neurological condition they should never give up on trying to find out why things are happening the way they are. It has taken me a long time to get to this stage even though I know the prognosis may not be good, but I will have an answer. Somehow I always had doubts about having MG, but then you trust what a doctor tells you.*

*I wish everyone who reads the newsletter good luck in their journey with MG.*

*Kind regards  
Rosemary"*

2. Parents and carers of persons with a disability are becoming increasingly concerned about the future of their disabled dependant should the parents or carer depart this world suddenly, and are looking for assistance in planning for such a situation. Barry, from Toowoomba, has provided the following links to websites and articles which may be of assistance to members who may be interested in this issue:

<http://www.smh.com.au/money/planning/concern-for-daughter-20120716-225a7.html>

[http://www.fahcsia.gov.au/sites/default/files/documents/05\\_2012/planning\\_for\\_the\\_future\\_2011.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/planning_for_the_future_2011.pdf)

Barry also provided a link to a guide to Disability Trusts:

[http://www.colemangreig.com.au/Publication-36-Plain\\_English\\_Guide\\_to\\_Special\\_Disability\\_Trust.aspx](http://www.colemangreig.com.au/Publication-36-Plain_English_Guide_to_Special_Disability_Trust.aspx)

### **3. Myasthenia Gravis and IVIg:**

Dr, Joanne Pink has kindly consented to give an update, in person to a meeting of interested members, on the situation regarding the supply of IVIg (Intragam) in Australia, and is prepared to answer questions on this issue.

The meeting will be held on Sunday 11 November next and the committee is currently in the process of organising a suitable venue.

Full details of the meeting will be provided when the organising is completed.

In the meantime, if you have not already indicated your interested in this meeting, please do so by calling our Freecall 1800 802 568 number before 30 September next.

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Statistically 100 percent of all divorces start with marriage



## **ALICE REFLECTS**

(published in the Spring 2012 Edition of the MGA News-U.K)

### **Recording Movements**

Noa Eshkol, a dancer and choreographer, together with Abraham Wachman, a professor of architecture, developed a system for writing movement that is similar to the way notes are used in writing music. This system allows the documentation of the movement of every single muscle group in our body in three dimensions, as well as in time.

This system, which was initially developed for choreography in ballet, is so pure and analytical that it makes it easy to record movements in general. It has therefore been used to document anything from the movement of wild animals, to animations on computer screens. It was even used in the diagnosis or follow-up of various movement disorders. Probably because it is very cumbersome and requires a lot of patience and dedication, it is still not widely used.

Searching for someone who could help me find a way to live better with my (then) obscure illness, I reached by pure luck one of Noa Eshkol's students. For more than 10 years, she learned how to meticulously document every movement and each muscle group in the most accurate manner, until it became second nature for her to observe human movement in such a way. From our first lesson, she immediately recognised the weakness of my muscles, and even more so their very rapid fatigability, even on fairly minimal exertion. Although she did not understand the source of my problem, nor was she able to give it a name, she could clearly see it and document it, and also gradually reflect it to me.

At that time, 6 years ago, I was quite confused and overwhelmed by my fluctuating and constantly changing symptoms, not knowing what I could do and when. The same distance that I could readily walk in one direction became very long on the way back. An ordinary cup of tea turned into a heavy parcel I could no longer hold in my hand. It was as if I somehow accidentally fell into the rabbit hole and was now in the world of Alice, where nothing was predictable or made any sense.

I was desperately trying to cling to my normal life and function, and I wanted her help in doing so. I stated those goals very clearly – I want to be stronger, have better endurance and be able to do more. "Why" she asked me "do you want me to help you fight your body and make it do what it clearly can't?"

At first, I was reluctant to accept what she said, but I gradually realised that she was right. The fact that my neurologists could not (yet) understand my illness, give it a name or effectively treat it, did not make it unreal or disappear. The limitations I experienced in my daily activities were very clear and all-too-real, and fighting them was very counterproductive. She could not make me stronger or increase my endurance level - which was an impossible task. Yet, she gradually taught me to recognise early signs of weakness.

She also guided me to perform the same task using different muscle groups, thus allowing them to rest. I found out that you could even breathe much more efficiently like that. I would no longer walk a distance I could not walk back. I could estimate the "momentary" weight of every object, and so I knew when and how to pick it up. I learned how to preserve my smile, and how to talk in a way that would not exhaust my breathing capacity or make me appear "anxious". Just as important, she also helped me gradually accept my illness (with or without a name) and befriend my body again.

She also made me understand (what I have painfully learned) that in her words - "you are so energetic that you can easily fool people to think that you are much less ill than you really are. It is very hard for them to see you as someone who is weak".



