



Messages

Myasthenia Gravis Association of Queensland Inc

DECEMBER 2013



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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PRESIDENT'S REPORT

Welcome,

We have just held our Christmas Party at the Dublin Docks Tavern where 30 members and their friends enjoyed the day. It was perfect weather and the setting where we overlooked the water with the cool breeze blowing and the conversations flowed. It was good to see our regular members as well as some new ones and I hope you all enjoyed your day. Catherine had the duty of taking the photos that she has put in the Newsletter which is giving our Newsletter another avenue for our members who cannot get to these functions.

The CIE report was presented at our meeting and it will be put up on our Website after Christmas for you all to see and to compare some of the findings as it is very interesting. A hard copy has been presented to Professor Pamela McCombe and Dr Stefan Blum and also to Dr Stephen Reddel to express our appreciation of their support and input in compiling the report. The committee is still sending out the Survey to new members so this is an ongoing project.

We have received information in regards to our Grant monies by way of a phone conversation but we are waiting to see the paperwork so that we can digest this fully. We are hoping to receive this before Christmas so we can report on this in the next Newsletter which will be in February.

We are having a Meet the Members in Brisbane on 9th March 2014 with the venue still to be decided so please keep this date free as we are looking forward to seeing you all there.

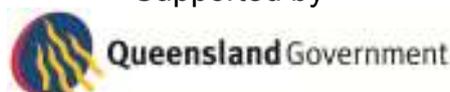
The committee does not meet in January as it gives us time for a breather and also a chance to charge up our batteries for the Year ahead.

I would personally like to wish everyone a very Merry Christmas and all the best for the New Year and if travelling safe travels.

Take care,

Anita

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

In summarising the economic costs of suffering from Myasthenia Gravis the report from "TheCIE" (a firm specialising in economic reporting - please refer to previous newsletter), highlighted that significant financial costs fall to both the individual and their family and also to the community through the use of assorted health services, need for social benefits and very importantly, lost participation or performance in the workplace.

Examples of interesting comment from the report include - 59% of working age patients in paid employment stopped working for a period due to the illness, the cost of providing IVIg for MG patients is estimated to be \$10,000,000.00 per annum and 92% of sufferers are managed by a specialist.

It is hoped that the full report will be made available to members via the website shortly. Further details on this will be provided as they come to hand. Members will be encouraged to help maximise benefits from the report by telling as many people as possible about it and the information provided. Helping the community to understand how, by effectively treating this condition, it is good for the patient and also for the community as a whole is invaluable.

“Exercise Effect in MG’ Pilot Study –

The results of the Study have now been fully documented and written-up formally.

The paper is now in the ‘Accepted article’ stage of publication in the journal Muscle & Nerve.

Muscle & Nerve is an international journal devoted to neuromuscular disorders & treatment options & is considered essential reading for neuromuscular, musculoskeletal, & EDX physicians.

This means the paper is available to the readership of the journal now but is not yet assigned to a particular volume.

When the paper has been published and is publicly available, we will advise our members and make it available to read to all interested members.

APRICOT SQUARES

1 cup sugar	1 cup plain flour
125g butter	$\frac{3}{4}$ cup coconut
2 eggs	1 cup chopped dried apricots
$\frac{1}{2}$ cup milk	1 tspn. vanilla

Cream butter and sugar, add eggs one at a time. Add flour and coconut, then apricots and lastly milk and vanilla. Place into greased slice tin and cook 180 or 160 fan forced oven for 30-35 mins. or until cooked. Leave to cool for 5 mins. Then cool on a wire rack. Nice with lemon icing. Enjoy.

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

DONNA	0414397462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SCOTT	54481749	SUNSHINE COAST
KATREN	0418778082	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407697206	ANDERGROVE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
NOEL	5495 2938	BELLMERE
SARA	0422109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
SYDNEY	4051 6896	BUNGALOW
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
JIM	0414241091	BURPENGARY EAST
DAVID	4053 2291	CAIRNS
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
KARLIENE	0432431591	HERVEY BAY
SHIRLEY	4128 3596	HERVEY BAY

ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412456439	LABRADOR
KAREN	0408153285	LOWOOD
JUDIE	0439 461288	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418778082	MONTEREY KEYS
CAROLYN	55228987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
BROOKE	0404720807	NAMBOUR
ALEX (BROOKE'S CARER)	0420858386	NAMBOUR
KEITH	5441 7236	COES CREEK, NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411331258	PACIFIC PINES
JUNE	0409636467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
BERNIE	JoyPaul28 *	TEWANTIN
CAROL	4773 7122	THURINGOWA CENTRAL
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418879801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458980667	YANDINA
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 activity

Meet the Members in Brisbane – 9th March 2014. Venue to be announced closer to the date.
Please keep this date free.

Trivia

Two million hydrogen atoms might just cover the full stop at the end of this sentence.

OBITUARY Mr. Gordon Jiear

It is with great sadness that we advise of the passing of member Mr Gordon Jiear on Sunday 8 December 2013.

Gordon and his wife, Valmai, joined the Association in January 1998. From that time, Gordon was a Committee Member for 1 year, and then either President or Secretary until August 2005, when he retired from the Committee. During that period he also edited and distributed the Newsletter.

In recognition of Gordon's tireless efforts on behalf of sufferers of myasthenia gravis and the Association, Gordon was awarded Life Membership on 12 September 2010.

On behalf of the members of the Myasthenia Gravis Association of Queensland, the President and Committee extend their sincere sympathy to Valmai and her family on Gordon's passing.

MEMBERS' FORUM

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.

Editor's Note:

I would like to invite all the carers of sufferers of M.G. to tell their story. Speaking to many of you there are people who would benefit from hearing how others cope with the ups and downs of everyday life. Contributions to the newsletter can be sent to me at cocraftychick@hotmail.com

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CHRISTMAS QUOTES

The magi, as you know, were wise men - wonderfully wise men who brought gifts to the Babe in the manger. They invented the art of giving Christmas presents."
~ O. Henry

"Christmas, my child, is love in action. Every time we love, every time we give, it's Christmas."
~ Dale Evans Rogers

Bless us Lord, this Christmas, with quietness of mind; teach us to be patient and always to be kind."
-- Helen Steiner Rice

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PARAPROSDOKIA

Paraproisdokians (Winston Churchill loved them) are figures of speech in which the latter part of a sentence or phrase is surprising or unexpected; frequently humorous. Enjoy!

1. Where there's a will, I want to be in it.
2. The last thing I want to do is hurt you. But it's still on my list.
3. Since light travels faster than sound, some people appear bright until you hear them speak.
4. If I agreed with you, we'd both be wrong.
5. We never really grow up, we only learn how to act in public.
6. War does not determine who is right – only who is left.
7. Knowledge is knowing a tomato is a fruit. Wisdom is not putting it in a fruit salad.
8. To steal ideas from one person is plagiarism. To steal from many is research.
9. I didn't say it was your fault, I said I was blaming you.
10. In filling in an application, where it says, 'In case of emergency, Notify:' I put 'DOCTOR'.
11. Women will never be equal to men until they can walk down the street with a bald head and a beer gut, and still think they are sexy.
12. You do not need a parachute to skydive. You only need a parachute to skydive twice.
13. I used to be indecisive. Now I'm not so sure.
14. To be sure of hitting the target, shoot first and call whatever you hit the target.
15. Going to church doesn't make you a Christian any more than standing in a garage makes you a car.
16. You're never too old to learn something stupid.
17. I'm supposed to respect my elders, but it's getting harder and harder for me to find one now.

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MORE OF BARRY'S LINKS OF INTEREST

The following links to item of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

http://www.sciencecodex.com/new_cause_found_for_muscleweakening_disease_myasthenia_gravis-122755

<http://www.pinterest.com/cat92076/myasthenia-gravis-facts-and-humor/>

CHRISTMAS PARTY – DUBLIN DOCKS TAVERN

15 December 2013



MERRY CHRISTMAS



The President and Management Committee of the Myasthenia Gravis Association of QLD Inc. wish our members and their families the very best of wishes for the festive season and a safe and prosperous 2014.

They would also like to thank you for your support over the past year and look forward to a bigger and better 2014.

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