



Messages

Myasthenia Gravis Association of Queensland

MARCH 2014



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Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

Welcome,

Well we have certainly started the year off running as we have had extra projects on the go. Firstly we had representatives come to our meeting from the Funding and Contract Management Unit of Queensland Health to clarify the situation with respect to future funding grants from Queensland Health to the MGAQ. **Please see a more detailed report on page 8.**

Shirley Johnston and former committee member Bill Synnot met with Lecturers at University of Queensland at St Lucia to discuss a further meeting with approx. 20 students in May 2014 so the word is getting about.

Susan White and myself went to Rare Voices Australia seminar at the Wesley Hospital where there was much discussion as to how we can spread the word about rare diseases Australia wide. Rare Voices have been doing quite a lot of work in this field for a few years now and have given us ideas to follow through with their work. Afterwards they had a presentation of Specialists and people told of their journey with a rare disease or their children having a rare disease. Ms Teresa Gambaro Federal Member of Parliament also spoke. It was a very interesting day. Rare disease day was celebrated on 28th February 2014 Australia wide so we will be very interested in joining in with next year's celebration.

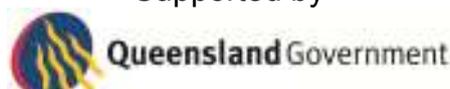
The committee welcomes Graeme Peters back on the committee to replace Katren Wallis as she has moved to NSW to be with her family. This is only temporary until the AGM when we can appoint someone to fill the position.

I will be in New Zealand when you are reading your Newsletter for 3 weeks holiday. Graeme Peters has just been to Tasmania and John and Mary Noble are off on a River Cruise through Europe in April

Take care,

Anita

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PROJECT UPDATE

SURVEY UPDATE

Collecting data on sufferers' of myasthenia gravis:

As previously reported, a paper discussing the **Economic impact of Myasthenia Gravis on the community and the individual** is now available via the MGAQ website (www.mgaq.org.au). We ask that you take a moment to visit the website and view the report. After logging in select "Resources", scroll down to "CIE Report" and click! Too easy! It is a few pages long with the last section being a summary of the responses to the survey questions. If all this is too much, just read the comprehensive report from page 1 - 3.

The report highlights the personal costs of suffering from this condition as well as giving some insight into the community costs associated with this chronic condition. The personal costs fan out to include the immediate family as well as the individual. It is an interesting and informative read and **we hope that this report will generate much conversation and understanding within the wider community.**

We encourage our members to read it, to discuss it with others and to promote it generally. It is surprising how a pebble dropped in a pond can ripple outwards. Let your comments be that pebble. Your feedback on the report is very welcome via the 'Contact Us page' on the website or the free call number 1800 802 568. **Please, we need your assistance to help generate maximum value from this endeavour.**

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EARS and EYES NEEDED!!!

The Committee has trialled a new initiative recently and would like your help in assessing the impact of this.

To advertise the recent MEET THE MEMBERS event held in Brisbane we engaged an internet based media outlet to send out a press release. The cost was reasonable and created a great deal of efficiency for us. Unfortunately, we did not feel that the cost for the above-mentioned media outlet to provide feedback on the effectiveness of the initiative was justified.

Consequently, to assist us in assessing the effectiveness of the initiative, we asked attendees at the meeting how they heard about the event. Additionally, we would like members who heard of the event on radio or television or read about it in a mainstream or local newspaper, even though they were unable to attend, to advise us of the fact by sending an email to info@mgaq.org.au or calling Shirley on the Free call number 1800 802 568 letting us know what you heard, saw or read.

Many thanks for this help.

RESIGNATION FROM MANAGEMENT COMMITTEE

At the Annual General Meeting held on 15 September 2013, Mr. Scott Mackay was elected to fill one of the vacant positions on the Management Committee for the year 2013/2014.

Scott has reassessed his personal situation, taking into account his experiences attending committee meetings and the pressures that committee duties (other than meetings) and the role of North Coast Coordinator have had on his life, and as a result he has reluctantly tendered his resignation from the Management Committee and as North Coast Coordinator.

Scott will remain an active member of the MGAQ and hopes to be in a position to reconsider a more active role further down the track.

The Committee wishes Scott the very best for the future.

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
VACANT		SUNSHINE COAST
VACANT		GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407697206	ANDERGROVE
DENISE	0431571399	AVOCA
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
DAPHNE	4773 3695	RASMUSSEN
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
SHIRLEY	4778 7117	YABULU
IAN	4623 5169	YULEBAR

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

TOWNSVILLE GET-TOGETHER

WHERE? The Avenues Tavern, Kern Brother's Drive, Kirwan.

WHEN? Saturday 29th March at 12 noon

Looking forward to catching up with both Myasthenics and partners/ family etc. for a get-together and lunch.

NEWS FROM CAIRNS

Thank you to all those people who braved the very wet weather to come along to our first meeting on Saturday 8th February at the RSL Club. The meetings are held at the RSL Club Boardroom, Esplanade Cairns, at 11.30am unless advised otherwise. Some people stay on for lunch in the restaurant afterwards (at own expense).

We have set the dates for the meetings in 2014.

- * Saturday 12th April
- * Saturday 21st June – Venue to be advised for “MG Awareness Month”
- * Saturday 16th August
- * Saturday 11th October
- * Saturday 6th December – Christmas function

Donna Formosa – Phone 0414 397 462 or email formosed@bigpond.net.au for more information.

NEW COORDINATORS NEEDED

We are calling for expressions of interest from members who reside in the Gold Coast (South Coast) region or the Sunshine Coast (North Coast) for the positions of Coordinator for their respective region, following the resignations of the current Coordinators. Members who may be interested in filling the positions can obtain more information from Shirley on our Freecall number 1800 802 568.

I have learned if you can smile when things go wrong, you have someone else in mind to blame.

I have learned that if you live each day as if it's your last. Someday you'll be right.

I have learned that life is like a scooter car; not much happens unless you do some pedalling.

I have learned that a police car behind me always makes me nervous.

CASUAL VACANCY ON MANAGEMENT COMMITTEE

The resignation of Scott MacKay from the Management Committee has resulted in a Casual Vacancy on the Committee.

We would like to hear from any currently financial member who is willing to fill this Casual Vacancy until the next Annual General Meeting. This would provide an opportunity for a member who has thought about nominating for the Committee to actually experience exactly what being a member of the MGAQ Management Committee entails.

Interested members can obtain more information by calling our Freecall number 1800 802 568.

THIS HAPPENING RIGHT HERE IN OUR OWN COUNTRY!

We Must Stop This Immediately! Have you noticed that stairs are getting steeper? Groceries are heavier. And, everything is farther away. Yesterday I walked to the corner and I was dumbfounded to discover how long our street had become!

And, you know, people are less considerate now, especially the young ones. They speak in whispers all the time! If you ask them to speak up they just keep repeating themselves, endlessly mouthing the same silent message until they're red in the face! What do they think I am a lip reader?

I also think they are much younger than I was at the same age. On the other hand, people my own age are so much older than I am. I ran into an old friend the other day and she has aged so much that she didn't even recognise me.

I got to thinking about the poor dear while I was combing my hair this morning, and in doing so, I glanced at my own reflection. Well, REALLY NOW - even mirrors are not made the way they used to be!

Another thing, everyone drives so fast these days! You're risking life and limb if you happen to pull onto the street in front of them. All I can say is, their brakes must wear out awfully fast, the way I see them screech and swerve in my rear view mirror.

Clothing manufacturers are less civilised these days. Why else would they suddenly start labelling a size 10 or 12 dress as 18 or 20? Do they think no one notices? The people who make bathroom scales are pulling the same prank. Do they think I actually 'believe' the number I see on that dial? HA! I would never let myself weigh that much! Just who do these people think they're fooling?

I'd like to call up someone in authority to report what's going on -- but the telephone company is in on the conspiracy too: they've printed the phone books in such small type that no one could ever find a number in there! All I can do is pass along this warning: WE ARE UNDER ATTACK! Unless something drastic happens, pretty soon everyone will have to suffer these awful indignities.

PLEASE PASS THIS ON TO EVERYONE YOU KNOW AS SOON AS POSSIBLE SO WE CAN GET THIS CONSPIRACY STOPPED!

PS: I printed this in a larger font size, because something has happened to my computer's fonts - they are smaller than they used to be.

AUSTRIAN COFFEE CAKE

60 gms butter	$\frac{3}{4}$ cup sugar
2 cups S.R. flour	1 egg
Pinch salt	$\frac{1}{2}$ cup milk

Filling:

60 gms butter	$\frac{1}{2}$ brown sugar
$\frac{1}{3}$ cup plain flour	$\frac{1}{2}$ cup chopped walnuts
2 tspns cinnamon	

Method:

1. Rub butter into sifted flour and salt.
2. Add sugar.
3. Beat egg with milk, add to flour mixture.
4. Spread half into greased 8 inch tin.
5. Combine filling ingredients and sprinkle half over top of the batter.
6. Spread on the remainder of the batter and sprinkle with remainder of the filling.
7. Bake 180 degrees for 45-50 mins.

TRIVIA

Trivia is the Roman goddess of sorcery, hounds and crossroads.

A cough releases an explosive charge of air that moves at speeds of up to 60mph.

Britain's present royal family was originally named Saxe-Coburg-Gotha. The name was changed in 1917, during World War 1, because of its German connotations. The name Windsor was suggested by one of the staff. At the same time their cousins the Battenberg family, changed their name to Mountbatten.

From the 1500's to the 1700's, tobacco was prescribed by doctors to treat a variety of ailments including headaches, toothache, arthritis and bad breath.

Humans shed about 600,000 particles of skin every hour - about 1.5 pounds a year. By 70 years of age an average person will have lost 105 pounds of skin.

Damascus, Syria, was flourishing a couple of thousand years before Rome was founded in 753 BC, making it the oldest continuously inhabited city in existence.

The yo-yo was introduced in 1929 by Donald F. Duncan. The toy was based on a weapon used by 16th-century Filipino hunters.

A 'jiffy' is an actual unit of time for 1/100 of a second.

Absolutely pure gold is so soft that it can be moulded with the hands. A lump of pure gold the size of a matchbox can be flattened into a sheet the size of a tennis court. An ounce of gold can be stretched into a wire 50 miles long.

The Future of Funding from Queensland Health

The MGAQ management committee held a meeting with representatives from the Funding and Contract Management Unit of Queensland Health to clarify the situation with respect to future funding grants from Queensland Health to the MGAQ.

Funding Grants from Queensland Health to the MGAQ have been paid under Queensland Health's Community Self Care Funding Program. This program is to be transitioned to discontinuance from 31 December 2015.

Queensland Health have introduced a new program for funding Community Care bodies which involves the application for provision of these services being contested via an Open Tender process. The MGAQ submitted a response to the Request for Offer under the new funding program but has received advice that the application was unsuccessful.

In summary, therefore, the current situation with respect to QH funding is:

1. Funding will be provided for the 6 months to 30 June 2014;
2. Funding for the period 1 July 2014 to 31 December 2015 is contingent upon the MGAQ submitting a Transition Plan which provides evidence to Queensland Health's satisfaction, that the MGAQ will be a sustainable and viable organisation beyond 31 December 2015. In other words, if the MGAQ is unable to convince Queensland Health that it can continue to exist after 31 December 2015 without QH funding, then no QH funding will be provided beyond 30 June 2014. The Transition Plan is to be submitted by 30 June 2014 and QH will provide consultants to assist with the development of the Plan; and
3. Irrespective of the outcome of (2) above, no funding will be forthcoming from Queensland Health after 31 December 2015.

To assist the committee with the development of the Transition Plan, suggestions from our members which would assist in enabling the MGAQ to continue to exist without QH funding would be appreciated. Please forward all suggestions via email to info@mgaq.org.au or via Australia Post to MGAQ, PO Box 16, MT GRAVATT Q4122

If you require any further information on this matter, do not hesitate to contact any of the members of the Management Committee. Contact details are on Page 1 of the monthly newsletter.

MEMBERS FORUM

There are no contributions this month.

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