



MessaGes



Myasthenia Gravis Association of Queensland Inc

DECEMBER 2009

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
Founder Member, of Brisbane

PRESIDENT'S REPORT

******Please read the important Medication Alert on page 2******

The committee is making progress with investigating ways in which we can assist in MG research. We have been communicating with Dr Stephen Reddel with regards to his comments during his presentation and Bill Synnot has a meeting with him in Sydney in December. We are very excited about the prospects of the projects as they will help the medical profession and also our members with Myasthenia Gravis. Please refer to the article entitled 'What's Ahead in 2010??' on page 6 of this issue for more detail.

The committee is also planning a Management Committee meeting in Cairns in March 2010 so that we can meet our members in far North Queensland. We haven't made confirmation of exactly where we will be going but it will be around 13 March 2010 so keep a look out in upcoming newsletters for the exact details. We will be looking forward to meeting new members and also catch up on some whom we have not seen for a while.

Our Christmas party was a huge success at the Power Boat Club at Golden Beach and everyone enjoyed themselves. It was good to see some old members again, as well as new faces.

Our editor, Graeme, has advised that he will not be available to compile the Newsletter after the AGM next year. Consequently, we are looking for someone to take over that role (printing and distribution will still be done by Graeme). If you, or someone in your family, or someone you know, is interested in volunteering to compile and edit MessaGes from next year, please contact Graeme on 07 32884484 and he will explain what is entailed with this function.

I would like to take this opportunity to wish everyone a very Merry Christmas and the very best for 2010.

Take care

Anita

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IMPORTANT MEDICATION ALERT

Some of our members have advised that they are having trouble obtaining supplies of 60mg and 10mg Mestinon® from their pharmacist. Enquiries by the Association to Valeant Pharmaceuticals in Sydney (the Australian distributors) have ascertained that the Company has run out of stock of Mestinon® in Australia.

Consequently, if your pharmacist is unable to obtain Mestinon® from their normal supplier, advise them to contact Valeant Pharmaceuticals on Freecall 1800 630 056 and they will be advised on the procedure and necessary paperwork required to obtain 'emergency' supplies of the medication.

By now, your pharmacist should have received a fax from Valeant Pharmaceuticals outlining the situation. Valeant advise that it is expected supplies will be back to normal by February 2010.

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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.

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
GWEN	4954 5353	MACKAY
JOAN / HAROLD	4928 1438	ROCKHAMPTON
SHIRLEY	5443 1728	SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
SHARON	4151 7661	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
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
GEOFFREY	5491 5472	CALOUNDRA
OWEN	4742 1190	CLONCURRY
CAROLYN	5472 0386	COOROY
BARRY	5483 1783	CURRA

GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
ELIZABETH	4936 2410	GLENLEE
SHIRLEY	4128 3596	HERVEY BAY
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
TERRY	5494 2470	MALENY
RAY / MARY	5443 8667	MAROOCHYDORE
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH
BARBARA	4124 2312	POINT VERNON
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
VALMA	4068 0702	TULLY
KATHLEEN	416178458	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

Future Planned Activities

Saturday 13 March 2010	Committee Meeting – Cairns
Saturday 19 June 2010	Co-ordinators Conference – Brisbane
Sunday 20 June 2010	Guest Speaker Function – Brisbane
Sunday 12 September 2010	Annual General Meeting – Brisbane
Sunday 12 December 2010	Christmas Function – Gold Coast

More details will be published as each event becomes closer.

The Management Committee meets on the second Saturday of each month (except January) and all members are invited to attend. If you wish to attend any of these meetings, please contact Shirley on the 1800 number to find out the time and place of the relevant meeting.

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Is This the New Christmas Greetings?

I really wanted to send out some Christmas greeting but it is so difficult in today's world to know exactly what to say without offending someone. So I met with my solicitor yesterday, and on his advice I want to say to all of you: Please accept with no obligation, implied or implicit my best wishes for an environmentally conscious, socially responsible, low stress, non-addictive gender neutral, celebration of the summer solstice holiday, practised within the most enjoyable traditions of the religious persuasion of your choice, or secular practices of your choice, with respect for the religious/secular persuasions and/or traditions of others, or their choice not to practice religious or secular traditions at all. I also wish you a fiscally successful, personally fulfilling, and medically uncomplicated recognition of the onset of the generally accepted calendar year 2010, but not without due respect for the calendars of choice of other cultures whose contributions to society have helped make Australia great (not to imply that Australia is necessarily greater than any other country or is the only "AUSTRALIA" in the western hemisphere), and without regard to the race, creed, color, age, physical ability, religious faith, or sexual preference of the wishee. By accepting this greeting, you are accepting these terms: This greeting is subject to clarification or withdrawal. It is freely transferable with no alteration to the original greeting. It implies no promise by the wisher to actually implement any of the wishes for her/himself or others, and is void where prohibited by law, and is revocable at the sole discretion of the wisher. This wish is warranted to perform as expected within the usual application of good tidings for a period of one year, or until the issuance of a subsequent holiday greeting, whichever comes first, and warranty is limited to replacement of this wish or issuance of a new wish at the sole discretion of the wisher.

TIPS TO HELP MANAGE YOUR MYASTHENIA GRAVIS

The following tips for managing your myasthenia gravis are from the website:

http://myestin.com/Survival_Guide.htm

Energy Conservation:

These general suggestions for energy conservation may apply to the work place or home and to men, women and children.

General Suggestions

- Don't stand when you can sit;
- Schedule regular rest periods during each day;
- Reorganise daily tasks and reschedule some 3 to 4 times a week to allow for adequate rest each day;
- Delegate tasks to other family members;
- Plan all activities and eliminate extra steps, assemble all the necessary equipment before beginning;
- Move frequently used devices or objects to low, easily accessible shelves for your convenience;
- To ease difficulty getting up from a sitting position try leg extenders to elevate chairs;
- Use power tools, and electrical appliances when possible to conserve energy, e.g., electric mixer, electric screwdriver;
- Use walking aids if necessary for stabilisation and support. Install grab bars in your home, or use a cane, walker or wheelchair as needed;
- Try a shoulder pad or intercom phone to completely free your hands when talking on the telephone;
- Avoid hot and cold weather extremes - they exaggerate weakness;
- Avoid aerosol pesticides and cleaners, since they may trigger or aggravate symptoms (Many pesticides contain neuromuscular paralysing agents and may adversely affect the MG patient);
- Avoid excessive alcoholic drinks, tonic water (contains quinine) and smoking;
- Avoid any medications or activities that you know make you weaker;
- Avoid stressful situations.

Kitchen Tips

- When preparing foods chopping - dicing, etc., use a food processor;
- Look for various kitchen gadgets and aids in catalogues to help you;
- Transfer heavier bulk items, such as sugar and flour, into smaller containers easier to lift and handle.

Shopping Tips

- Shop at peak medication times; avoid shopping during peak store or traffic hours;
- Shop by yourself only when you need a few items, saving big shopping trips for other family members; or shop with a friend or family member who can assist carrying groceries;
- Shop by telephone or mail when possible;
- Obtain a disabled parking permit if necessary.

Personal Hygiene and Grooming Tips:

- Allow ample time to do grooming in "phases", with rest periods in between; use electric appliances to conserve energy, i.e. electric shaver;
- Place a stool in the bathroom to sit on while shaving or applying make-up. Prop your elbows on the counter top if necessary;
- Take short showers or baths using warm, not hot water;
- Install grab bars in the shower or next to the commode if needed.

Visual Disturbances (Blurred or Double Vision):

- If double vision is a problem, an eye patch may be helpful while reading or watching TV. Alternate the eye patch from one eye to the other to avoid eye strain;
- Have your eyes checked to make sure you do not also need glasses;
- Rest for 30 minutes with your eyes closed before going out. Also take along an eye patch if you develop double vision;
- Ptosis - eyelid crutches, tape eyelids open.

Eating Difficulties:

- Grind meats to make them easier to swallow;
- Between meals drink cold beverages; hot foods tend to increase muscle weakness and swallowing difficulties;
- Try semi-solid foods. They may be easier to handle than solids or liquids, (i.e. milk shakes, yoghurt, pudding, etc);
- Avoid foods that crumble and may be aspirated (i.e. toast, cake, and potato chips);
- Enlist the help of a registered dietitian if you need help in meal planning;
- If you take steroids, avoid salty foods and notify your physician of sudden weight gain (may indicate fluid retention) or gradual clouding or narrowing of vision (may be due to the development of cataracts or glaucoma).
- Keep nutritious snacks handy. Try milk shakes, diluted fruit juice or pudding for snacks.

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WEBSITE ENHANCEMENT

As part of ongoing activities of the Association, it was planned that the revamp of our website which occurred in 2008 was only the first stage of enhancing the site. The Committee now wishes to proceed to the next stage.

The following suggestions to expand the website’s facility have been put forward:

- Extract from DVD’s of Guest Speaker presentations to members;
- Additional links to other websites of interest to people with MG;
- All planned events;
- A list of the pamphlets available (with a brief description of each);

We would like to receive further suggestions from our members as to what additional features and functionality you would like to see on our website. Please forward your thoughts to mgaa@gil.com.au or via mail to PO Box 16 PO Mt Gravatt Qld 4022. Every idea will be considered.

Remember it is **YOUR** website.

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HELP - WE NEED YOUR IDEAS



The Committee would also like to hear from our membership on the following topics:

What would you like to see in the Newsletter?

What topics would you like to be considered for a Guest Speaker?

How can we better improve the services and support to our members?

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AT THE INQUEST

ATTORNEY: Doctor, before you performed the autopsy, did you check for a pulse? WITNESS: No.

ATTORNEY: Did you check for blood pressure? WITNESS: No.

ATTORNEY: Did you check for breathing? WITNESS: No.

ATTORNEY: So, then it is possible that the patient was alive when you began the autopsy? WITNESS: No.

ATTORNEY: How can you be so sure, Doctor? WITNESS: Because his brain was sitting on my desk in a jar.

ATTORNEY: I see, but could the patient have still been alive, nevertheless?

WITNESS: Yes, it is possible that he could have been alive and practicing law.

WHAT'S AHEAD IN 2010??

The Committee is currently investigating the feasibility of undertaking the following projects in 2010:

- Assisting in research to ascertain the cost to the nation of myasthenia gravis – this research was mentioned by Dr Stephen Reddel in his presentation to our members on June 14 2009;
- Assisting in research by collecting data on sufferers of myasthenia gravis so that, among other things, to see if there is any correlation between the incidence of MG and other diseases – this research was again referred to by Dr Stephen Reddel in his presentation to our members on June 14 2009;
- Establishing an Australia-wide MG 'umbrella' organisation which would address MG issues from a national perspective. This would possibly cover such things as such as research, government funding, etc.
- Enhancing our website to provide more information to our members, and others interested in MG.
- Providing funding to the University of Queensland to perform research into 'Exercise and MG' following on from Katrina Williams excellent presentation to our members at the AGM.

The Committee is also making enquiries as to what, if any, opportunities exist in Queensland to assist in MG research.

Not all or any of these projects may come to fruition, as time and cost considerations will require close scrutiny, but we will endeavour to obtain the best outcomes for our members.

In addition to the above, none of which will happen overnight, the Management Committee have decided to commence a cycle of 'taking the Committee to the regions'.

- To this end, the monthly Management Committee meeting will be held in Cairns on Saturday March 13 2010 at a venue yet to be advised. It is hoped that our members in the Far North Queensland region will take the opportunity to come along on the day and meet the Committee and raise any issues which are of concern to them, or perhaps offer some suggestions which would help us in improving our support to our members.
- In addition, all of our Regional Co-ordinators will be invited to Brisbane in June 2010 for a Co-ordinators Conference, which will give us an opportunity to 'pick their brains' and devise some strategies for improving our support to our regional members.

As you can see from the above, the Committee is desirous of providing continued support to our members and their families.

MEMBERS' FORUM

There were no contributions to the Members Forum this month.

Please send in contributions to our Members' Forum – it provides an ideal opportunity for members to share their experiences or questions.

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 grapop@dodo.com.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.

KEEP YOUR BRAIN ACTIVE WITH THE CHRISTMAS TRIVIA QUIZ

This month's questions are all related to Christmas. (Answers are at bottom of this page)

1. Which continent is the turkey from?
2. What year was the first commercial Christmas Card made in?
3. The Christmas classic The Nutcracker was written by whom??
4. In what year was the Queen of England's first Christmas holiday message broadcast?
5. Which of these was one of the three wise men? Gaspar, Gideon or Malcolm?
6. In Charles Dickens' "A Christmas Carol" what was the name of Scrooge's dead business partner?
7. When did the first Christmas cracker go on sale?
8. Who made the decision to celebrate Christmas on the 25th of December?
9. Who delivers gifts in Denmark?
10. Which Christmas Carol composed in 1818 was written for guitar?
11. What was the name of the horse in the song Jingle Bells?
12. Who wrote the classic Christmas song "White Christmas"?
13. What did my true love give to me on the ninth day of Christmas?
14. Traditional Christmas dinner in Ukraine has how many courses?
15. In the Christmas classic "A Christmas Carol" how many ghosts visit Scrooge?
16. In which ocean is Christmas Island?
17. What is the capital of Christmas Island?
18. Which company was the first to use Santa Claus in an advertisement?
19. Which reindeer is Rudolph's dad?
20. Which reindeer is left out of the "Night Before Christmas" song?

Answers: 1) North America; 2) 1843; 3) Tchaikovsky; 4) 1957; 5) Gaspar ; 6) Jacob Marley; 7) 1847 by English baker Tom Smith; 8) Pope Julius I; 9) Nisse; 10) Silent Night in 1818; 11) Bob (Bells on Bob's tail ring) – he pulled the sleigh; 12) Irving Berlin; 13) 9 drummers drumming; 14) 12 – one devoted to each Apostle; 15) 4 – Ghost of Christmas Past, Present, Future and his business partner Marley; 16) Indian Ocean; 17) The Settlement; 18) Coca Cola; 19) Donner; 20) Rudolph.

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*The President and
Management Committee
would like to wish
our members, supporters,
their families and friends
a joyous and safe Festive Season
and a
Happy and Healthy 2010*