



Messages



Myasthenia Gravis Association of Queensland Inc

SEPTEMBER 2010

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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

This month I met one of our newest and youngest members of the Association, Lani, for coffee. Lani is trying to set up coffee meets for the younger members of the Association and I can assure you it will be very interesting and informative. It was good to hear her story which was in the July Newsletter but it also helped her to hear our stories and we could compare notes. So come on all our younger members try and make time to come to one of these or if the time does not suit make suggestions for a better time or day as Lani is willing to devote her time to meeting other members. (Lani's contact details are phone 0448192521 or email her at happyhani87@gmail.com)

It is AGM time once again so this gives us time to reflect on what we have achieved during our last 12 months and what we need to do for the next 12 months to make our Association work for our members. Please send in any suggestions if you were unable to attend the AGM as we love to hear from our members.

Our next 'Meet the Members' is on the Sunshine Coast on 13th November and we are hoping that a large number of our members from the North Coast will make the effort to come so that they can find new friendships, hear stories about other members' journey with MG, and let the Management Committee know how we can improve the services for our members.

Expressions of interest for regional Coordinators are still needed for the Rockhampton, Wide Bay and Toowoomba (Darling Downs) regions. Coordinators are integral to the success of the Association throughout Regional Queensland, so I implore members from those regions to put their names forward for the positions. Details of what the positions involve are on page 4 of this issue.

Take care

Anita

PS: Learn to listen. Sometimes opportunity knocks very softly.

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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
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
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
CAROLYN	5472 0386	COOROY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
GEOFFREY	5341 8747	LITTLE MOUNTAIN
TERRY	5494 2470	MALENY
RAY / MARY	5443 8667	MAROOCHYDORE
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH

REGIONAL COORDINATOR MACKAY

THE Management Committee are pleased to advise that Mr Bill Harris has been appointed coordinator for the Mackay region. Bill succeeds Gwen Vines in the role and will be in touch with members in the region shortly. Bill's contact phone number is 07 49541221. We look forward to a long and fruitful relationship with Bill.

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Future Planned Activities

Sunday 12 September 2010	Annual General Meeting – Carindale Hotel
Saturday 13 November 2010	Management Committee Meeting on Sunshine Coast Followed by 'Meet the Members'
Sunday 12 December 2010	Christmas Function –Sharks Australian Football Club Southport
Saturday 12 March 2011	Management Committee Meeting at Townsville Followed by 'Meet the Members'
Sunday 19 June 2011	20 th Anniversary Function

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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'MEET THE MEMBERS' – SUNSHINE COAST

The next meeting in our 'Meet the Members' program will be held on the Sunshine Coast at the Pacific Paradise Bowls Club, 13 Menzies Drive, Pacific Paradise on Saturday 13 November 2010 commencing at 10am. While the meeting is primarily for Sunshine Coast members, ALL members are invited.

The meeting will be in the format of an open forum, where members will be encouraged to express their thoughts about the Association – how are we going, how can we improve, etc – and to tell their stories and experiences of living with MG. We welcome constructive criticism and look forward to seeing as many of our members as possible.

Following the meeting, the Committee would like have lunch with as many members as possible. Lunch is available at reasonable prices.

If you would like directions on how to get to the venue, please contact the Sunshine Coast Coordinator, Shirley Langshaw, on 07 54431728.

If you intend coming, please contact Shirley Langshaw on the above number or Shirley Johnston on our 1800 802 568 Freecall number.

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Some Blonde Jokes

Q: Why do blondes have "TGIF" on their shoes?
A: Toes go in first.

Q: What did the blonde ask her doctor when he told her she was pregnant?
A: "Is it mine?"

Did you hear about the blonde who returned a scarf to the store because it was too tight?

Q: Why shouldn't blondes have coffee breaks?
A: It takes too long to re-train them.

KEEP YOUR BRAIN ACTIVE

This week's questions compliments of www.quiz-winner.com. Answers are at the bottom.

1. What was Wilhelm Röntgen's most important discovery?
2. Who wrote '*Who's Afraid Of Virginia Woolf*'?
3. Who won the best director Oscar for '*Unforgiven*'?
4. Which language does the word *ombudsman* derive from?
5. Which French brothers invented the first films?
6. What are the international registration letters of a vehicle from Switzerland?
7. Which toy was the brain child of Ole Kirk Christiansen of Denmark?
8. Who flew in The Spirit Of St.Louis?
9. In which US state is Fort Knox?
10. Who is the Prime Minister of New Zealand?
11. What was the first movie made in Cinemascope?
12. Findel international airport is in which country?
13. Which drink was advertised with the song '*I'd Like To Teach The World To Sing*'?
14. Which American Indian tribe featured in '*Dances With Wolves*'?
15. Which famous sporting figure refused conscription to Vietnam in 1967?
16. In which Australian State or Territory is Liapoota?
17. Who wrote '*The Great Gatsby*'?
18. Ghana was previously known as what?
19. What is the University of Paris more commonly called?
20. What US state boasts a town called Captain Cook?

Answers: 1. X-Rays; 2. Edward Albee; 3. Clint Eastwood; 4. Swedish; 5. Lumiere Brothers; 6. CH; 7. Lego; 8. Charles Lindbergh; 9. Kentucky; 10. John Key; 11. The Robe; 12. Luxembourg; 13. Coca Cola; 14. Sioux; 15. Muhammed Ali; 16. Tasmania; 17. F Scott Fitzgerald; 18. Gold Coast; 19. The Sorbonne; 20. Hawaii.

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Our lives begin to end the day we become silent about things that matter.
(Martin Luther King)

Why is it that we rejoice at a birth and grieve at a funeral? It is because we are not the person involved.
(Mark Twain)

LIFE WITH GRAVIS

From time to time readers write to, or email me, asking what medication I am on and what the doses are. Many times in this column, I have emphasised that every myasthenic is different and what suits one will not be good, or may even be dangerous for another. The only person who can safely advise you is your GP or Consultant. For this reason neither the MGA nor myself can give this kind of information. Mrs Gravis finds it particularly disturbing when at MGA meetings she overhears members swapping advice on drugs and doses, some of it potentially lethal.

During the past six months I have had a lesson in being overconfident. Regular readers will recall my stories of ever increasing improvement and the expansion of my level of activity. In November this came to a shuddering halt, following a dose of the Swine Flu vaccine. I had had the ordinary Flu vaccine, without any problem, but the Swine Flu jab really hit me and I have been recovering ever since. I have asked around and found that most Myasthenics had no more problems than healthy patients, but a significant number experienced very much the same effects as I have. I do not wish to put people off having protective vaccinations, but urge that you discuss it with your doctor before going ahead. As ever, as soon as I realised that there was a problem I went straight to my GP's triage clinic and was immediately sorted out. I did not see my regular GP on this occasion, but the doctor who saw me is up to date on MG as are her partners. I keep the surgery supplied with the latest MGA publications and of course the MGA News.

The Neurologist who has the task of keeping me on the rails, has kept a close eye on me since and directed the change in medication necessary to managing and reversing the down turn in my condition. This task has been greatly assisted by the care of the MG Nurse attached to the hospital, one of six sponsored by the MGA. She has telephoned me every fortnight and kept the Consultant up to date. This has been a real help and I am sure, saved the Consultant no end of time. I hardly dare write this, but I am steadily getting back to where I was last autumn. Indeed I was strong enough to brave the journey to Oxford for this year's Medical Conference. I found the sessions on the Children's Branch particularly of value. It was also good to meet old friends and to make new ones. If you can get to MGA's Regional meetings or Conferences do go along, but beware, you may bump into me.

Just after Easter I began to have problems with my eyes and nose. I could not for the life of me make out why. There was obviously a myasthenic element, described by the MG Nurse as Ocular Bulbar, that's Neuro speak for weakness in the eye, face, mouth and throat muscles. Then a friend commented on how she was suffering from Hay Fever and described it as being like having pepper thrown into her eyes. The symptoms matched mine exactly and so I went to see my local pharmacist. She knows me and my problems well and knows what I can and cannot take. She advised that I try some eye drops, these worked like magic. My eyes opened and even the MG receded into the background. In all my many years on this earth I have never before suffered from hay fever. So it has been a relief to find a simple remedy. No, I am not going to tell you what the eye drops were, but do use a pharmacist who knows you, they will advise. I have of course kept both my GP and Consultant aware of what I am using.

One curious thing that I have noticed is the reaction to my being in, or not being in, my wheelchair. When I can manage a few steps, I do; Mrs Gravis is sure that the exercise does me good and I am sure she is right. When I can't walk far, or I'm on an outing, I use the faithful powered chair. When I am seen walking, people in the village hail it as a miraculous recovery: when in the chair I am seen to have had a severe relapse. Of course, neither is true, it is just a reflection of the variability of MG and as Mrs Gravis will tell you, a reflection of when I have overdone things.

Well the summer is upon us and I am hoping for a good one, but with a low pollen count. If I have learned anything from the last six months, it's that things can go down as well as up, but there is always up. I have also been aware that when things do start to take a dip, it is essential to seek medical help immediately.

May 2010

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