



Messages

Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2014



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,

I hope you all have had an enjoyable Christmas and New Year with family and friends and if you travelled that you had a safe trip. The weather has not been very kind to us as it is very hard to cope with our Myasthenia Gravis in these extreme heat wave conditions. I hope our southern members were not affected with the Bush fires doing so much devastation.

Our first function for this year is a Meet the Members at the Southern Cross Sports Club in Mt Gravatt on 9 March 2014 with a 10am for 10.30am start. Hoping to see some new members as well as the regulars as we do not always have the time to hear your full story of your journey with MG. This is the chance to hear your journey as well as others and it might just help with coping with MG.

The committee has had its first meeting of the year so it was good to start our projects for the year and follow through on the ones that are still in progress. We have received notification from Qld Health that we have their approval to receive our grant monies. There are a couple of things different but the committee is confident that it will be good.

We are still looking for information for our Newsletter so please think about putting pen to paper and telling your story. If you are a carer, you could do a 'living with and caring for someone with MG' story.

Take care,

Anita

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Editor's Note: I welcome and encourage all members to contribute to YOUR newsletter. To ensure that the newsletter meets the publishing deadline I would appreciate if all items could be e-mailed to me by the first Friday of each month.

Supported by



PROJECT UPDATE

Collecting data on sufferers of myasthenia gravis

A report discussing the economic impact of Myasthenia Gravis on the community and the individual is now available in full via the MGAQ website (www.mgaq.org.au). This report was commissioned by the Association in conjunction with the Dr Blum and Professor McCombe at the RBWH and was prepared by The CIE. "The Centre for International Economics, a Canberra and Sydney based firm is Australia's oldest independent economics consultancy, with experience across most areas of contemporary economics. With a dedicated health economics practice, the CIE has a deep understanding of the health sector and extensive expertise in health sector economic evaluation, economic modeling and providing policy advice to a government, industry or clinical audience. "

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 (not too lengthy) and we hope that it 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. The costings show how modern treatments can be beneficial economically as, despite the expense, they allow people to remain in the workforce. Research aimed at ultimately reducing the disease cost should be encouraged. Your feedback on the report is welcome. Please respond via the website.

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RECIPE

PUMPKIN, BROCCOLI AND CASHEW PASTA

350gm. large spiral pasta	375ml. evaporated milk
2 cups thinly sliced pumpkin wedges	1tbspn. cornflour
1 tbsp. oil	2 cups broccoli florets
1 onion, chopped	½ cup grated tasty cheese
2 cloves garlic, crushed	½ cup roasted cashews

1. Cook pasta according to directions on packet, drain and keep warm.
2. Place pumpkin in boiling water, simmer for 1 min and drain.
3. Heat oil in pan, add onion, garlic and pumpkin, cook stirring for 2 mins.
4. Add combined evaporated milk and cornflour, with broccoli, bring to boil stirring, simmer 1 min.
5. Remove from heat, stir in cheese.
6. Pour sauce over pasta, toss through, sprinkle cashews on top.

Serves 4

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- I have learned that most of the things I worry about never happen.
- I've learned that if someone says something unkind about me, I should live life so that no one will believe it.

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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435389883	TWEED HEADS SOUTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
DIANNE	02 4574 3787	WINDSOR DOWNS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	ALICE SPRINGS NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

Future planned activity**MEET THE MEMBERS – BRISBANE**

Continuing the program of bringing members together from the various regions around Queensland, the next 'Meet the Members' event will be held in Brisbane on Sunday 9 March 2014.

These get-togethers provide a valuable forum for MG sufferers and their carers to tell of their experience with MG while at the same time offering the opportunity to ask questions of other members regarding their experiences with MG. The meeting is open to all members whether they reside in the Brisbane region or not.

Members of the public, in particular medical practitioners, nurses and Allied Health professionals, as well as persons interested in learning about myasthenia gravis are also encouraged to attend and participate in the discussions.

- WHEN:** **Sunday 9 March 2014** commencing at 10:00am for 10:30am
- WHERE:** **Southern Cross Sports Club**, corner Klumpp and Logan Roads, Mount Gravatt (vehicular entrance is from Klumpp Rd). Following the Forum, lunch is available at the venue with a varied and reasonably priced menu. Tea and coffee are available from 10:00am.
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier.
- HOW DO I GET THERE?** **UBD Map 201 Reference D7.**
- RSVP:** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch. Please let her know by **Friday 28 February 2014**

NEWS FROM MACKAY

Hope everyone has had an enjoyable festive season. The Mackay area had our Christmas get together on the 8 / 12 / 2013 at the Boomerang Hotel/ Motel for lunch which was enjoyed by those attending.

The dates for our get togethers for the year 2014 is as follows:

- | | |
|----------------|--|
| 2 / 3 / 2014 | The Boomerang Hotel / Motel for lunch. |
| 18 / 5 / 2014 | Venue to be advised. |
| 31 / 8 / 2014 | Venue to be advised. |
| 30 / 11 / 2014 | Venue to be advised. |

Hope everyone has an enjoyable 2014.

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.

CHANGE TO MANAGEMENT COMMITTEE

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

Since then a change to Katren’s personal circumstances mean that she will be moving to New South Wales to live, and as a result she has tendered her resignation from the Management Committee.

Subsequently, the continuing members of the Management Committee have exercised their right under Clause 16 (1) of the Association’s Constitution and have appointed immediate Past Secretary, Graeme Peters, to fill the casual vacancy resulting from Katren’s resignation. The appointment is only for the period remaining until the 2014 Annual General Meeting.

- I’m a child of the Sixties. I still wear jeans and yes, my butt looks big in them but then my butt looked big in 1965.....Julia Richardson

SOUTH COAST COORDINATOR

We are calling for expressions of interest from members who reside in the Gold Coast (South Coast) region for the position of Coordinator for that region, following the resignation of the current Coordinator.

Members who may be interested in filling the position can obtain more information from Shirley on our Freecall number 1800 802 568.

MEMBERS' FORUM

Catherine writes:

Until 11 years ago I hadn't thought much about the "what if's" of life. Sometimes, however, life has something in mind for you that you certainly don't expect. In February 2003 I was diagnosed with myasthenia gravis. While MG doesn't normally shorten one's life span, it can dramatically alter a life style. For some years I had been working permanent night shift as a nurse and enjoyed a full and active life. Talk about a wakeup call.

In October 2002 my tongue became tired one night while I was licking an ice cream and my speech slurred momentarily. I thought it odd at the time but thought no more of it until my speech started slurring while out at dinner and I had trouble chewing my meal. I began to have doubts about my health. The progression over the next few weeks was rapid. Not only did my speech slur but I had trouble chewing, dysphagia (difficulty in swallowing), ptosis (drooping of the upper eyelid) when I got tired, weakness of facial muscles with characteristic 'snarl' on trying to smile and occasional diplopia (double vision). I saw my family doctor who quickly gave me a brain scan, thinking I may be having TIA (transient cerebral ischemic attacks). The scan was clear and he was quick to point out that he had no idea what could be causing these symptoms. He promptly referred me to a neurologist. In most cases you don't get to see a specialist overnight. My case was no different. It was going to take 6 weeks for me to see a specialist. It was at this time that I thought it best to give up nursing, not only for my own health but for the safety of my patients. In particular I was afraid that I would not be able to call the emergency over the phone if a patient had an arrest. I sounded drunk when my speech slurred.

I deteriorated quickly. In the next two weeks I began to having muscular weakness in my hands, arms and legs in addition to my original symptoms. Generalised lethargy became part of my everyday life. I lived on yoghurt and even had trouble swallowing that. Every night I had to sleep propped up on pillows to breathe properly. Most nights I would be woken because I was unable to swallow my own saliva. I didn't have the strength to rollover in bed, let alone go to the bathroom during the night without help.

Because of my rapid deterioration I was able to get my neurology appointment brought forward to the next week. During this time my husband, who is also a nurse, made the initial diagnosis of Myasthenia Gravis. Two days later my neurologist confirmed my husband's diagnosis. Mestinon was prescribed.

The next day I had a positive tensilon test and a CT of the chest revealed a rather large thymoma (tumour of the thymus). Two days later my airway became compromised and I was subsequently admitted to hospital. On discharge I was referred to another neurologist because the previous specialist had never had a patient with MG and he felt it was in my best interest to hand me over to a professor at another hospital.

I had to have a Thymectomy (removal of thymus gland) but first I had to be made well enough to withstand the anaesthetic. I was placed on a very high dose of steroids as well as another drug to improve my breathing. During all this my husband had to look after our little girl, run the house and continue to work full time. Thinking back now I don't know how single parents cope at a time like this. The tumour was benign but my long road through MG was only beginning. My symptoms after the operation became less severe.

I have been able to reduce my steroids from time to time but every time I became unwell for any reason the dose was again increased. I have had several episodes of difficulty breathing that required hospital admission. I have been on IVIG for the last 6 months in an endeavour to reduce my steroid dependency. I am feeling quite well at the moment, considering. Only time will tell if I can reduce more of my medications and stay well.

When I look around me I see people who have gone through a lot more than me. I thank God for getting me through the worst of it. It has been a struggle at times but I think I have come through it a better and more patient person.

*Stay well,
Catherine.*

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

Humour

- I said to my husband, my boobs have gone, my stomach's gone, say something nice about my legs. He said "Blue goes with everything."Joan Rivers
- Musicians don't retire; they stop when there's no music in them.....Louis Armstrong
- I used to hate weddings - all those old dears poking me in the stomach and saying, "You're next." But they stopped saying that when I started doing the same to them at funerals....Gail Flynn
- It's never too late to become what you might have been....George Eliot

LESSONS FROM THE GEESE

1. As each bird flaps its wings, it creates an “uplift” for the birds following. By flying in a V formation, the whole flock adds 71% to the flying range than if each bird flew alone.

Lesson

People who share a common direction and sense of community can get where they are going quickly and more easily because they are travelling with the combined thrust of one another.

- 2 Whenever a goose falls out of formation, it suddenly feels the drag and resistance of trying to fly alone and quickly gets back into formation to take advantage of the “lifting up power” of the bird immediately in front.

Lesson

If we have as much sense as the goose, we will stay in formation with those who are headed where we want to go.

- 3 When the lead goose gets tired, it rotates back into formation and another goose flies at the point position.

Lesson

It pays to take turns doing the hard tasks and sharing leadership with people, as with geese, interdependent with each other.

- 4 The geese in formation honk from behind to encourage those up front to keep up their speed.

Lesson

We need to make sure our honking from behind is encouraging and not something less helpful.

- 5 When a goose gets sick or wounded or shot down, two geese drop out of formation and follow them down to help and protect them. They stay with them until they are able to fly again or die. Then they launch out on their own to join another formation or join their own flock.

Lesson

If we have as much sense as geese, we’ll stand by each other like that.

QUESTION

If we’re the “intelligent” animals, why do we have to learn what the geese already know?

*Source: CANCER NURSING NEWS, DIVISION OF NURSING ONCOLOGY, October 1992
Strong Memorial Hospital, Rochester N.Y.*

Trivia

The word ‘news came from the first letters of the words North, East, West, and South. This was because information was being gathered from all different directions.