



Messages



Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2010

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

P.O. Box 16
MT. GRAVATT QLD 4122
NATIONAL FREE CALL:
1800 802 568
ABN 92 055 613 137

E-mail: mgaq@gil.com.au
Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President

Anita JACKSON
Ph. 3800 4913

Vice-president

Kris KLITGAARD
Ph. 3890 0115

Secretary and Editor

Graeme PETERS
Ph. 3288 4484
email: grapop@dodo.com.au

Treasurer

Susan WHITE
Ph: 3358 1056

Committee

Shirley JOHNSTON
Ph. 1800 802 568

John CHESTER
Ph. 3899 9387

Bill SYNNOT
Ph. 0418196707

PATRON

Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome to 2010.

Hope everyone has had a good Christmas and New Year. It is certainly hard to believe that we are into February already.

What a few months we have had with extreme heat wave over most states and then bush fires and now cyclones or heavy rain depressions over the east coast. All of us who suffer with Myasthenia Gravis will be hanging out until the cooler weather comes as the heat certainly plays havoc with us all and makes us very tired and lethargic.

As previously reported the committee will be having a meeting in Cairns on 13th March 2010 at the Cairns RSL Club and we are hoping that we get to meet as many of our Cairns region members (I know that Hannah is busy beavering away to drum up attendees) and also that you will voice what you would like to see us do for the Association in regards to keeping you in touch even though you are miles away from Brisbane.

Bill Synnot paid a visit to Dr Stephen Reddel in Sydney on behalf of the Association just before Christmas to talk about possible MG research and the committee will be discussing the outcome of this at our next meeting. There are a couple of options open to us but just trying to work out which is the best value for money and also what will give our members, new and old, the best outcomes is not an easy task.

To-date we have received no response to our request for ideas for our website enhancement, nor any for improving our service to our members. The requests are repeated on page 5 of this issue. Please give them your attention as we want to do the best we can for our members.

Please send in contributions to our Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is YOUR Forum and sharing your MG experiences with fellow MG sufferers makes understanding the condition just that little bit easier.

Looking forward to seeing those who can make it in Cairns on 13 March.

Take care

Anita

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MESTINON® UPDATE

The following advice regarding the supply situation of Mestinon® as at 22 January 2010 has been received from Valeant Pharmaceuticals:

“Mestinon 10mg tablets - regular Australian supply has resumed;

Mestinon 60mg tablets - regular Australian supply has resumed;

Mestinon Timespan 180mg tablets - currently out of stock, however, we have an alternative (Mestinon-SR 180mg tablets) currently available via the Special Access Scheme. This requires a Category A or Category B form to be completed by the patients doctor. The imported tablets available on the Special Access Scheme contain the same quantity of active ingredient as the Australian tablets and are also sustained release, however, the inactive ingredients are slightly different. The imported tablets are available in a pack size of 30 tablets instead of 100 tablets as with the Australia stock. Regular Australian stock of Mestinon Timespan tablets will be available from April.”

If any of our members are having difficulties obtaining stock or if you have any questions or require any further information, please do not hesitate to contact the Association on our freecall 1800 802 568.

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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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 8287	CANBERRA ACT
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

Shirley's Recipe

KUMARA AND POTATO SALAD

(Kumara is an orange coloured sweet potato)

Ingredients:

- 1kg (about 4) kumara
- 1kg (about 6) potatoes
- 30g butter
- 2 onions, chopped
- 2 bacon rashers
- 2 cloves garlic, crushed
- 2 tablespoons chopped fresh basil
- ½ cup French dressing
- ½ cup sour cream
- 5 hard boiled eggs, chopped

Method:

1. Cut peeled kumara and potatoes into chips.
2. Place into pan, cover with water, bring to boil.
3. Reduce heat, simmer for 10 minutes or until just tender. Do not overcook, drain, cool.
4. Heat butter in pan, add onions and bacon, cook, stirring, for a few minutes or until onions are soft. Add garlic and basil, and pour into a bowl.
5. Stir in dressing and sour cream, then gently fold in kumara, potatoes and eggs.
6. Refrigerate, covered, until ready to serve.
7. Make salad day before if preferred.

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Future Planned Activities

- | | |
|--------------------------|-------------------------------------|
| Saturday 13 March 2010 | Committee Meeting – Cairns RSL Club |
| 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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TOUGH TEACHER

A school teacher injured his back and had to wear a plaster cast around the upper part of his body. It fitted under his shirt and was not noticeable at all.

On the first day of the term, still with the cast under his shirt, he found himself assigned to the toughest students in school.

Walking confidently into the rowdy classroom, he opened the window as wide as possible and then started doing some desk work.

When a strong breeze made his tie flap around, he took the desk stapler and stapled the tie to his chest.

He had no discipline problems with any of his students that term.



MEDICAL ID

The following is an extract of an article by 'Glenda' published in the December 2009 issue of the The Australian Myasthenic Association in NSW and is reproduced here with their kind permission:

'I would like to stress the importance of wearing a medical bracelet and/or necklace and carrying a Medical ID Alert Card with you at all times.

Unfortunately on the 3rd September last I was involved in a motor vehicle accident (which caused me to miss our September meeting). I was able to get myself out of my car and inform the ambulance officers that I had myasthenia gravis and even tell them my doctor's name. I do not remember any of this but am relieved that I could relay this information. Had I not been able to convey this information they would not have known that I had any health problems. I do have a Medical Alert bracelet and carry an ID card with all my medical information. I also have a sticker on the windscreen of my car informing anyone of this.

When my family arrived at the accident they asked the paramedics did they know I had MG. Besides the fact that I had babbled a bit and informed them many, many times of this fact, they had actually seen the sticker on my car and found my bracelet so were aware that I had a medical condition. I am now very relieved that for 28 years I have worn my bracelet and carried my ID card and bothered to put the sticker on my car as it was noticed and made them aware of my situation. Had I been unconscious I would not have been able to inform anyone of my special needs and the outcome could have been very dangerous.

To continue this story, a few weeks later I became sick and found myself back at the emergency department of our local hospital. When I was attended to and relayed my problems, the nurse asked me, "What is myasthenia gravis?" – she had no idea. I was then asked if I wore medical ID and could I tell them what medications I was allergic to. I then produced the pamphlet that we all now have, 'Drugs that may aggravate Myasthenia Gravis'.

I was relieved that I had this information with me as the nurses (not the doctors) had no idea about myasthenia gravis or anything relevant to the condition.

I just wanted to share my experience as it can be a very scary situation to be in if you're not prepared and do not have this information with you.'

(The article concluded with information for the NSW members)

Editor's note: As our members are aware, the MGAQ provides, free of charge, Medi-Alert cards which provide pertinent information regarding the member's doctors and emergency contact numbers, plus on the reverse, a list of drugs to be used with caution.

The Association also supports the idea of members carrying some type of Medic-Alert jewellery, but given the range of options available, and in keeping with our policy, does not recommend any particular product – it is a matter of personal choice as to how much the individual wishes to expend. Members are urged to talk it over with their local pharmacist.

Additionally, Category A members (those who have been diagnosed as suffering from MG) were supplied with an Emergency Medical Information Book in a magnetic plastic cover for completing and placing in a very noticeable position (most likely on the fridge door) in their house. It is important that these booklets be kept up-to-date, especially with respect to medications taken. The Association will now issue each of our Category A members with another of these books so that they may be completed and carried with them at all times (it is desirable to carry them close to your wallet, as in an emergency, it is the most likely place for paramedical staff to look).

The Association will also look into the possibility of supplying stickers for our members to place on their car windscreens.

It is also timely to remind members of the need to insert the name ICE into your mobile phone contacts list with the number of the person whom you would like to be notified '*In Case of Emergency*'

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:

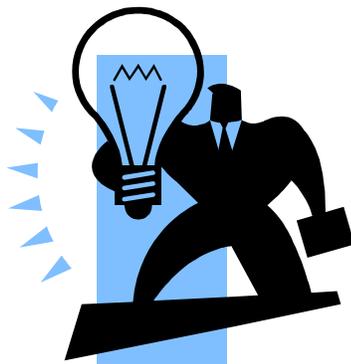
- Extract from DVD’s of Guest Speaker presentations to members;
- Additional links to other websites of interest to people with MG;
- All planned events;
- A list of the pamphlets available (with a brief description of each);

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 mgag@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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NEWSLETTER EDITOR

As mentioned previously in MessaGes, we are looking for someone to take over the role of editor of this publication. To date there has been no response. Surely there must be someone out there (it doesn’t have to be a member) who would be willing to take on this important task.

The current editor will continue to print and distribute the newsletter.

The newsletter is a vital part of our communication with our members, but if we have no editor, we have no newsletter. So please, the Management Committee is pleading with our membership to help us in this matter.

If you can help, please contact the Secretary on (07) 32884484 or email mgag@gil.com.au for more information.

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REAL LIFE ADS (believe it or not)

Man wanted to work in dynamite factory. Must be willing to travel.

Wanted, man to take care of cows that does not smoke or drink.

Three-year old teacher needed for pre-school. Experience preferred.

Free puppies: ½ cocker spaniel, ½ sneaky neighbour’s dog.

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 the Cairns RSL Club. 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.

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MEMBERS' FORUM

Again, 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. 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 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.

LIFE WITH GRAVIS

The following episode of 'Life with Gravis' was published in the Winter 2009 edition of MGANews, the official newsletter of the Myasthenia Gravis Association of the UK, and is reproduced here with their kind permission:

Excitement had been gathering for days, ever since the Gardening Club Secretary had phoned to say that she had received a very special invitation. The Club had written asking to be put on the list for a visit to the gardens at Highgrove, HRH The Prince of Wales' home in Gloucestershire. We could take 25 members and we would travel by coach. Mrs Gravis, who is this year's Madam Chairman, decided that I was now strong enough to attempt this kind of outing. Needless to say I would not be able to manage a day on my feet and my faithful powered wheel chair, the Bockie, would have to go as well.

The day came and we awoke to a perfect warm, sunny autumn morning. I trundled down to the village shop where we were to meet the coach, setting Mrs Gravis a good pace. The coach turned up on time and a very helpful driver put the Bockie in the baggage hold. After a spell on the motorway and a run along country roads, we came to the entrance of the Highgrove estate. Here a couple of Police Officers came on board and checked that we were all honest gardeners.

We had been warned that we should have a form of photographic identity with us. This could be a passport or the new type of driving licence. I have neither, being quite happy with the old style driving licence and have no passport, being unable to travel abroad. I am advised not to fly and the old passenger liners of my younger days have long since been taken out of service and broken up. My OAP bus pass and the old style driving licence proved sufficient. The coach deposited us outside the very attractive Orchard Room, which accommodates the many meetings of the Prince's

various charities and organisations, where we met our guide. By the time I got off the coach our driver had retrieved Bockie from the baggage hold and I followed the group into the Orchard Room for a short DVD, in which HRH told us all about his garden and how he had developed it. We then set off on the tour of the garden, our heads full of things to look out for. As with all proper gardens Highgrove is a living thing, ever evolving, with new ideas being tried and successful ones being built upon. The garden is full of gifts from friends and admirers, ranging from statuary to plants. The Prince has an interest in an organisation which enables young people to take up apprenticeships in stone masonry. In a wooded area he has created a wall into which apprentice pieces, which have been given to him as a thank you, have been incorporated.

Thankfully the garden is wheelchair friendly, although one or two of the cobbled paths did test the suspension. The day continued warm and bright and we really noticed the warmth when we entered the walled kitchen garden. It was quite comforting to see that even a Prince can be troubled by ground elder. A team of gardeners were carefully digging out every last root that they could see and we were told that they will have to repeat the exercise in the spring, to clear the bits they missed. Highgrove is totally organic and so of course no chemicals can be used as a short cut.

Having walked round the garden we were taken back to the Orchard Room and given a cup of tea; a very kind thought and a welcome courtesy to guests who visit the garden. Before getting back on the coach we had the chance to visit the shop, which sells all sorts of special Highgrove wares. All the profits raised from sales to visitors, plus their donations, are given to the Prince's Charities Foundation. Eggs for the House are provided by hens kept in a run in the garden; these hens feature on the very attractive crockery sold in the Shop. Despite Mrs Gravis' protests that we had enough mugs to give drinks to everyone in our Village, I had to have a couple. These are now brought out when we have a visit from our chicken fancier friends from across the valley.

So what has all this to do with Myasthenia Gravis? Well, in 2004 I was on a ventilator having gone into a myasthenic crisis. Regular readers may remember that I actually wrote one Life with Gravis from the intensive care unit. Now, with the right treatment and management, I am recovered sufficiently to enjoy a day out like this. I hope that my experience will give those of you who may just be starting the journey with MG, the assurance that life is good despite and – strangely – because of MG. The last bit may sound strange but, because of MG, I have come to know a whole host of wonderful people that I would never otherwise have met.

The one problem that I have with regaining some strength is that people now feel able to call on me and ask me to do things. I no sooner get down to relaxing and watching an uplifting programme like Star Trek, than the door bell goes or the phone rings. Under Mrs Gravis' strict guidance I am having to learn the art of a polite and diplomatic NO. I have had three interruptions while writing this. Don't get me wrong, I am pleased

