MessaGes

Myasthenia Gravis Association of Queensland Inc

OCTOBER 2008

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.

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Founder Member, of Brisbane

PRESIDENT'S REPORT

Congratulations to recently-joined member Melissa and her family – Samuel arrived by caesarean section on 17 September. Mother and baby are both well.

Vice-President Anita is celebrating a very special birthday this month – happy birthday Anita.

Since being founding members of our Association, and having served on the committee for countless years, Kath and Frank Ross have made many friends and I am sure most of you would like to know they have now moved from their home in Albany Creek to a retirement home at North Lakes. Enjoy your retirement Kath and Frank – take care, we all love you.

I had a phone call from a lady residing in Central Queensland who was diagnosed with MG last year and was in need of some information. On two occasions she was told by medical staff that she would end up in a wheelchair. I feel she was very misinformed as I was given that same information by a nursing sister thirty years ago, and I am certainly not in a wheelchair.

Nev and I had a great day with our daughter and grandson at the Amberley Air Show on 5 October. I am always amazed by the expertise and skill of the pilots flying so fast and so close to each other. The retiring F111 gave a great display as did all the others. Came home hot, tired and with sore feet, but well worth it.

We still need articles for the Members Forum, so please put pen to paper – I am sure there are lots of experiences among our members that are worthwhile telling. The article on page 3 entitled 'Hello and Goodbye MG' is a perfect example of the type of story that we are asking our members for.

Don't forget to keep Sunday 7 December free for the Christmas Function. Details are on page 8 of this issue.

Until next month,

Shirley

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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 –BRISBANE

JOHN	3269 5066	BRIGHTON
TERRY / JUDI	3824 4158	CAPALABA
JOHN	3899 9387	BRISBANE
JESSICA	3369 8315	BARDON
HELEN	3279 3060	JAMBOREE HEIGHTS
POPPY	3288 4484	SPRINGFIELD LAKES
EILEEN	3269 5660	BRIGHTON
PAM / RAY	3801 1335	CORNUBIA
PATRICIA / LES	5464 6719	PURGA IPSWICH
WILMA / NOEL	3807 2391	MT WARREN PARK
LORRAINE	3206 0789	CLEVELAND
GWENDA	3390 2643	CAPALABA
STEFAN	3807 0541	EAGLEBY
DANIELLE	3202 2509	IPSWICH
MIKE	3288 4037	SPRINGFIELD
ROGER	3379 8916	GRACEVILLE
HELEN	3203 0150	DECEPTION BAY
KEVIN	32819225	NEWTOWN
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
MARIE	3300 0053	THE GAP
BILL & JITLADA	0418196707	NORMAN PARK
MELISSA	0411039060	ACACIA RIDGE
CAROL	33901788	CAPALABA
SUSAN	33581056	NEW FARM

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WEB-Site Update

PLEASE NOTE: Our website address is now www.mgaq.org.au. Please change your bookmark to reflect this.

You can now download current and previous issues of MessaGes and we now have links to other MG sites. Also you can email us directly from the website. Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

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Since it's the early worm that gets eaten by the bird, sleep late.

The second mouse gets the cheese.

Drive carefully. It's not only cars that can be recalled by their maker.

When everything's coming your way, you're in the wrong lane.

Shirley's Recipe

LAYERED GARDEN SALAD

Place in layers:

1. ½ a small lettuce (roughly chopped)
2. 2 cups frozen peas (thawed)
3. 250 grams thinly sliced mushroom mixed with 2 finely sieved hard boiled eggs
4. 125 grams finely grated tasty cheese
5. 1 cup mayonnaise mixed with 1 tablespoon lemon juice and 2 tablespoons sour cream
6. Cover and leave overnight in fridge
7. When ready to use place fried bacon pieces, diced tomato and parsley on top.

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Future Planned Activities

Sunday 7 December 2008 Christmas Lunch - details on page 8 of this issue.

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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MEMBERS FORUM

There were no contributions to the Members Forum this month. However the following contribution to the MGANews, the official newsletter of the MGA UK, is reproduced here to give an indication of the type of experiences that our Association is looking for from our members. We thank the MGA UK for their kind permission in allowing us to reproduce the article.

Hello and Goodbye MG

(An account of the rapid onset of severe generalised myasthenia gravis and its complete disappearance two years later)

Like most people, I thought MG was just another sports car until Myasthenia Gravis came my way shortly before my 69th birthday. This is the story of my two years experience with MG and one year without it. Because it is an uplifting story, I hope it may give encouragement to others recently diagnosed with MG. I do appreciate that my experience will not necessarily be similar to that of anyone else, but knowing that such a good outcome can happen should still be encouraging.

My MG came on rapidly and severely. For about ten years before then, I had been regularly doing exercises with weights (dumbbells), just to keep reasonably fit. This proved invaluable as an early warning that something was wrong. Three times a week, I used to do two sets of eight push ups (lifting dumbbells from shoulder level to extending them vertically overhead). Firstly, I found I could not complete the second set, then I could not complete the first set. Shortly after that, I could not even do one of these 'push-ups' with the dumbbells and finally could not do one, even without the dumbbells. By this time I could not get my arm and hand up enough to comb my hair and could not chew or swallow solid food. All this happened in under a month. My GP quickly suspected MG and referred me to a neurologist, who arranged for me to have specific tests at Charing Cross Hospital. The 'tensilon test' and EMG both confirmed that I did have a classic case of generalised MG, and an acetylcholine receptor antibody test provided further confirmation when the result came through later. Medication started one week later, initially consisting of pyridostigmine (60mg every 3 or 4 hours) and prednisolone, 10mg every other day. In those early frightening and bleak days, finding out about and joining the MGA was a great comfort and support. It gave a massive boost to my shattered morale.

From the time of writing this, more than three years later, it is hard to remember how ill I was then. Fortunately I kept an MG diary, so I do know from that. The pyridostigmine seemed almost miraculous at first. It got me nowhere near back to normal but compared with how I was before medication, the improvement was dramatic. Unfortunately the benefit became less dramatic after the first week and side effects became an issue. These were mainly stomach cramps and diarrhoea. Some relief was obtained with

loperamide but much greater relief was obtained when I started taking propantheline tablets half an hour before each dose of pyridostigmine. During this time my prednisolone dose was increased, usually every two weeks, by an extra 5mg, on alternate days as before. After one month, azathioprine was added to the regimen. This made me feel very ill indeed. My appetite for food totally disappeared and I felt nauseous and unwell the whole time. One month later I had lost a stone in weight. I stopped the azathioprine and ceased feeling so unwell over a period of four or five days. Two weeks later, I tried azathioprine again at a lower dose, but quickly became very unwell again, so discontinued it altogether. Evidently I am one of a small minority who cannot tolerate this immunosuppressant. Two months after starting medication, my prednisolone dose had reached 50 mg on alternate days and I had started to experience days when I felt much better. I still had 'zero energy days' sometimes, but also good days. My prednisolone dose went up to 60 mg after another month, then came down to 55mg and 50mg over the next two months. My need for pyridostigmine also began to decrease and by five months into the treatment, I stopped pyridostigmine altogether because it was no longer necessary. My prednisolone dose was held at 50mg for the next five months, then started to be reduced by 5mg every two months so that by one year after starting medication for MG, I was on 40mg prednisolone every other day and no other MG related medication (apart from alendronic acid which I had been taking from the start to reduce the risk of osteoporosis).
So, after my first year with MG, I felt much better and my muscle strength had returned to about two thirds of what it had been before getting MG (judging by the dumbbell exercises). During the next six months my prednisolone doses continued to be reduced so that at eighteen months I was on 20mg every other day. By now my muscle strength was pretty much back to what it had been before MG, my general health was normal and I felt as if the MG was completely in remission (or completely suppressed by the steroids). By two years from the start of all this, my prednisolone dose was down to 5mg every other day, and my health was still completely back to normal. Finally, over the next two months, I reduced my prednisolone dose to zero and since then, have been on no other MG medication either.
This situation has remained so for more than a year now. This surely must mean either that my immune system has remained suppressed after medication has been discontinued, or that it has put itself right and stopped attacking my acetylcholine receptors. My feeling is that the latter is more likely. If all this leads you to think that my MG couldn't have been very severe, please reread my opening paragraphs.

John X, Slough.

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A Blonde Joke

A blonde goes into work one morning crying her eyes out. Her boss asked sympathetically, 'What's the matter ? '
The blonde replies, 'Early this morning I got a phone call saying that my mother had passed away.'
The boss, feeling sorry for her, says, 'Why don't you go home for the day? Take the day off to relax and rest.'
'Thanks, but I'd be better off here. I need to keep my mind off it and I have a better chance of doing that here.'
The boss agrees and allows the blonde to work usual. A couple of hours pass and the boss decides to check on the blonde. He looks out from his office and sees the blonde crying hysterically.
'What's so bad now? Are you gonna be okay?' he asks.
'No!' exclaims the blonde. 'I just received a horrible call from my sister. Her mother died, too.'

Car Dents

A blonde was driving home after a game and got caught in a really bad hailstorm. Her car was covered with dents, so the next day she took it to a repair shop.
The shop owner saw that she was a blonde, so he decided to have some fun.
He told her to go home and blow into the tail pipe really hard, and all the dents would pop out.
So, the blonde went home, got down on her hands and knees and started blowing into her tailpipe. Nothing happened. So she blew a little harder, and still nothing happened.
Her blonde roommate saw her and asked, 'What are you doing?' The first blonde told her how the repairman had instructed her to blow into the tail pipe in order to get all the dents to pop out.
The roommate rolled her eyes and said, 'Duh, like... HELLO! You need to roll up the windows first.'

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PLASMA EXCHANGE (PHARESIS)

The following article was published in the Summer 2008 edition of MGANews, the official newsletter of the Myasthenia Gravis Association of the UK and is reproduced here with the kind permission of MGA UK. Please bear in mind that the article relates to the UK experience, but the principles still apply in Australia:

MGA Fund Wessex Neurological Centre
Plasma Exchange Machine
(Dr G Burke, Dr A Eynon and Dr A Pinto)

The Wessex Neurological Centre would like to thank the Myasthenia Gravis Association for funding their new plasma exchange machine. It has already been used to successfully treat several patients with life-threatening myasthenic symptoms and will be a useful resource for the developing Wessex Myasthenia Centre.

"The new Plasma Exchange Service, which would not have been possible without the extremely kind and generous support of the MGA, represents a major breakthrough enabling the Wessex Neurological Centre to deliver comprehensive care for all MG patients. This new service is particularly important today given the current worldwide shortage of intravenous immunoglobulin which is likely to continue for the foreseeable future."(Dr A Pinto)

What is plasma exchange?

Plasma is the liquid part of blood comprised mainly of water, and contains dissolved minerals, proteins and antibodies. Plasma exchange (or plasmapheresis) is a procedure that removes plasma from the blood and replaces it with new plasma fluid.

Why is plasma exchange done?

Many immune-mediated or autoimmune diseases are due to circulating toxic substances, for example antibodies. In myasthenia gravis antibodies attack and damage the muscle acetylcholine receptor which results in muscle weakness. The antibodies circulate in plasma and so can be removed by plasma exchange. It is thought that plasma exchange probably does not simply act through removal of toxic substances, but, like intravenous immunoglobulin, also works through
modulation of the immune system but the mechanisms are poorly understood.

How long does it work for?

The benefit of plasma exchange generally only lasts a month or two as new antibodies are made. This is why most patients also need treatments that suppress antibody-production, such as corticosteroids.

How is plasma exchange used in myasthenia gravis?

Non-randomised studies suggest that plasma exchange is beneficial in myasthenia gravis in the short-term. Current practice is to use it for patients with an acute worsening of neuromuscular
weakness with swallowing or breathing difficulties, as benefit is usually observed faster than with corticosteroids alone. It is also used in preparing a patient for thymectomy and for deterioration
following surgical procedures. Intravenous immunoglobulin, a blood derived product, works just as well as plasma exchange, but supplies in the UK are currently so scarce that it may soon not be available.

Are there other neurological diseases that can be helped by plasma exchange?

Plasma exchange may be of benefit in other immune-mediated neurological diseases. Neurological conditions that have been treated with plasma exchange in addition to myasthenia gravis include
the Lambert-Eaton myasthenic syndrome (LEMS), Multiple Sclerosis, acute and chronic inflammatory demyelinating polyneuropathy and acute demyelinating encephalomyelitis.

How is the procedure carried out?

There are two ways to separate the plasma from blood. At the Wessex Neurological Centre we use a machine called a plasma filter; the other device is called a blood cell separator. Both methods require an intravenous catheter to access the blood.

In plasma filtration blood is pumped around a machine and through the plasma filter. The holes in the filter are so small that the blood cells cannot pass through them but plasma containing the antibodies can and so is collected. The blood cells are returned back to the body with replacement plasma fluid.

How long does it take?

A plasma exchange takes a few hours depending on how much plasma is removed. In myasthenia gravis we generally aim to remove 5% of the body weight in 5 exchanges over 5-10 days, although this is tailored to the individual.

Where will it happen?

At the Wessex Neurological Centre plasma exchange is currently carried out in the neurological high dependency unit as this is where staff with the necessary expertise are based. In other centres the procedure may be carried out on the general ward.

Are there any risks associated with plasma exchange?

Plasma exchange is generally considered a safe procedure but it is not entirely innocuous. As with any treatment there is a small risk of an allergic reaction to the replacement plasma fluid and medication may be given to prevent this. A donated blood product, human albumin, is often used to replace the plasma. There is a small risk that diseases can be passed on this way but every product is screened according to recommendations from the transfusion service. The exchange of large volumes of plasma can lead to changes in blood pressure, cold hands or feet, or breathlessness. The specialist carrying out the procedure will look out for these effects and can adjust the procedure accordingly.

What happens to the removed plasma?

In most centres the removed plasma is discarded. However, in centres actively participating in research, the plasma is a useful source of antibodies and other proteins for experiments. In such cases you will be asked if your removed plasma can be used to research purposes.

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Presentation by Dr Rob Henderson to the AGM

The presentation on *myasthenia gravis* given by Dr Rob Henderson to the Annual General Meeting on 31 August 2008 was lauded by all present as an excellent and informative presentation. The presentation was video taped by a committee member and been made into a DVD. The sound quality of the video is not the best and a small part of the presentation is missing due to a camera malfunction. However, the committee is of the opinion that the DVD is of sufficient quality, and the information contained in the presentation is of such importance to our members, that it be distributed to our members.

Therefore, a free copy of the DVD will be mailed to each member who was eligible to vote at the AGM on 31 August – that is, each member who is currently financial for the year 2008-2009, members who were current at 30 June 2008 and all Life and Honorary Members. Where 2 or more members have the same mailing address, only 1 DVD will be sent to that address.

Those who do not fall into the eligibility criteria above, but wish to acquire a copy please contact our Freecall telephone number 1800 802 568.

Delivery will commence towards the end of October and will continue until December. If you do not have your copy by the end of December, please let Shirley know on our Freecall 1800 802 568 number.

Please remember that this an amateur production, so do not expect professional quality.

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Never put both feet in your mouth at the same time,
Because then you won't have a leg to stand on.

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. Who is Tenzin Gyatso better known as?
2. Which is the only planet to rotate clockwise?
3. Who is the Federal Minister for Finance?
4. What is a 'gross' multiplied by a 'baker's dozen'?
5. Can giraffes swim?
6. USA chemist John Pemberton is famous for inventing what?
7. What is the only word in the English language that begins and ends with 'und'?
8. Which flag has three legs joined together on it?
9. What was the main family's name in the TV show 'Upstairs and Downstairs'?
10. In which Australian state or territory is Tocumwal?
11. Is a 'bongo' an animal, bird, fish or insect?
12. Which is the only continent without active volcanoes?
13. What European capital city used to be called Lutetia?
14. Who was the first actress to appear on a postage stamp?
15. Who was the first monarch to live in Buckingham Palace?
16. What country put the Yeti on its 1958 protected species list?
17. Who won the AFL's fairest & best award (the Brownlow Medal) in 2008?
18. What sea did the Romans call 'mare nostrum'?
19. What film did Jane Fonda call 'a present to my father'?
20. What abbreviation appears on a luggage tag going to Los Angeles International Airport?

Answers: 1) The Dalai Lama; 2) Venus; 3) Lindsay Tanner; 4) 1872; 5) No; 6) Coca Cola; 7) Underground; 8) Isle of Man; 9) Bellamy; 10) NSW; 11) Animal; 12) Australia; 13) Paris; 14) Grace Kelly; 15) Queen Victoria; 16) Nepal; 17) Adam Cooney; 18) Mediterranean; 19) On Golden Pond; 20) LAX.

JINGLE BELLS JINGLE BELLS

Ho! Ho! Ho!, it's that time again - time for our annual **Christmas Get-Together**, so come along and have a great day with lots of fun and good company.

WHEN: Sunday 7 December 2008

TIME: 11am for 12 Noon

WHERE: Carindale Hotel located at Carindale Rd Carindale Qld. (It is part of the Carindale Shopping Centre complex). Car parking is available in the Shopping Centre

WHAT WILL IT COST? Meals are priced from approx $12.00 each and there is a varied menu. Raffles will be on sale, including a beautiful hand made cot-sized quilt made by Judi Allison.

WHAT DO I NEED TO BRING? Yourself and whomever else you wish to bring along.

HOW DO I GET THERE? See mud map below. (UBD Map 181 Reference N5)

RSVP Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 28 November 2008**

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We could learn a lot from crayons..... Some are sharp, some are pretty and some are dull. Some have weird names, and all are different colours, but they all have to live in the same box.