



Messages

Myasthenia Gravis Association of Queensland Inc

MAY 2011



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
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PRESIDENT'S REPORT

Welcome

The cooler weather is now upon us so we can all relax and enjoy this time of the year.

The projects are in full swing at present and Category 'A' members should have received their Survey documents by mail but if by any chance you did not receive your survey please call Shirley on 1800 802 568 so that we can send another one. I urge you all to fill this out as the information stored with UQ could be used to help future Doctors or even help the Government with the cost of us living with the disease.

I had a really good holiday in WA and would go back there to see more of it at the drop of the hat. I was made very welcome by the WA members and learnt a lot about them and what they are doing in the west. I am very pleased that we have Dr Jean Foster coming over to be Guest Speaker at the AGM in September so please mark it in your calendar as it will be a very interesting session.

Our next function is on 19th June when we will be celebrating our 20 years of being an Association so please come and help us celebrate our milestone. Our Patron, Dr Cecilie Lander, will be our Guest Speaker at the function. It will be good to see our members who have been with the Association since the beginning and also welcome any new members who have not been to any of our functions.

Take care

Anita

Editor's Note: Sadly, I have to advise that Anita's mother passed away on Saturday 14 May 2011. The committee and members of the Myasthenia Gravis Association of Queensland extend our sincere condolences to Anita and her family on this sad occasion.

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

More than 300 surveys have been packed and distributed to date with an excellent response from our members. Shirley has taken a number of calls on the 1800 number as people seek clarification on issues or refer us to other sufferers. Most significantly, a steady stream of completed surveys is now being received by the researchers. Dr Blum reports good support from the Neurologists and is in the process of organizing an official launch with the University. Thank you all very much for embracing this opportunity with such enthusiasm. It means a lot to those who have given so much time and effort to the project and we feel confident in the benefits it will afford us all.

Funding for research into 'Exercise and MG' –

By now all Category 'A' members who live in the Brisbane area should have received all the documentation from which they will be able to decide if they wish to participate in the Pilot Study to be conducted at the Phyiotherapy Department at the University of Queensland. If you are a Category 'A; member and live within the Brisbane area but have not received the documents, please let us know us on the 1800 802 568 number.

Enhancements to our website –

We have added a link to the Myasthenia Gravis Foundations of Illinois in the USA and we encourage our members to visit this site for some very interesting articles on MG.

The website is an evolving entity and we welcome suggestions on how we can improve it.

CAT NAV

Once there was a man who hated his wife's cat and decided to get rid of it.

The man picked up the cat, put it his car, drove 20 blocks across the city, and left the cat on the street there. But when he got home, he found the cat sitting on the door step waiting for him.

The next day, the man picked up the cat, put it his car, drove 40 blocks across the city, and left the cat on the street there. Again when he got home, he found the cat sitting on the door step waiting for him.

On the third day, the man picked up the cat, put it in his car, and drove to a part of a neighbouring city that he had never been to before, and left the cat there.

Hours later, the man phones his wife. "Is the cat there darling?" he says.

"Yes, why do you ask?" answers his wife.

"Can you put it on the phone. I'm lost and need some directions."

^

Shirley's Recipe CHEESY- VEGIE PASTA BAKE

Ingredients:

- | | |
|--|---------------------------------|
| 375g penne pasta | 300g broccoli, cut into florets |
| 500g cauliflower, cut into florets | 2 teaspoons vegetable oil |
| 1 large brown onion chopped finely | 1 teaspoon mustard powder |
| 1 teaspoon sweet paprika | ¼ cup (35g) plain flour |
| 1½ cups low-fat milk | 420g can tomato soup |
| 400g can diced tomatoes | |
| 1½ cups coarsely grated reduced fat cheddar cheese | |
| 2 tablespoons finely chopped fresh flat-leaf parsley | |

Method:

1. Cook pasta in large saucepan of boiling water, uncovered, until just tender; drain pasta through a colander in the sink. Cover to keep warm.
2. Meanwhile, cook broccoli and cauliflower in medium saucepan of boiling water, uncovered, until tender; drain through a colander. Cover to keep warm.
3. Preheat grill.
4. Heat oil in same large saucepan over medium heat; cook onion, stirring with a wooden spoon until softened. Add mustard, paprika and flour; cook, stirring, over low heat for 2 mins. Gradually stir in milk and soup; stir over heat until mixture boils and thickens. Add undrained tomatoes; cook, stirring, until mixture is hot.
5. Stir pasta, broccoli, cauliflower and 1 cup of the cheese into tomato mixture. Divide pasta mixture among 6 1-cup (250ml) ovenproof dishes, sprinkle with remaining cheese; grill until cheese melts and is browned lightly. Sprinkle pasta bake with parsley just before serving.

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Future Planned Activities

- | | |
|--------------------------|---|
| Sunday 19 June 2011 | 20 th Anniversary Function – Guest Speaker Dr C Lander |
| Sunday 11 September 2011 | Annual General Mtg – Guest Speaker Dr J Foster a GP from WA |
| Sunday 13 November 2011 | 'Meet the Members' at the Gold Coast |
| Sunday 11 December 2011 | Christmas function – Brisbane |
| Saturday 10 March 2012 | 'Meet the Members' at Mackay |

More details will be published as each event becomes closer.

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OBITUARY

It is with sadness that we advise of the recent passing of Mrs Gwen Vines, late of Mackay. Gwen was a long-standing member of the Association and although she herself was not a sufferer of MG (her late husband, Owen, was), she was the Mackay Region Coordinator until last year.

The Association extends its sincere sympathy to Gwen's family and friends.

MEMBERS' FORUM

Three items this month.

Firstly from Rosemary following her item in the March issue of MessaGes:

"Thank you for printing my article. I hope people get a lot from it even though I didn't go into great detail what MG does to me.

There is one thing you might like to put in your next issue. I recently had surgery and had to have a general anaesthetic. Apparently while under anaesthetic I went into "shallow breathing" and the anaesthetist had to force oxygen into me to get my respiratory muscles working again."

Just thought you might like to put a warning in the newsletter that Myasthenics MUST explain to anaesthetists about their condition. A lot of doctors still do not know what MG is."

secondly, Rosemary also comments following her article in the March issue of MessaGes and Gail's article last month, and writes:

"Well I'm glad I started something. It was good to see Gail's story. I can relate to her very much. Thanks for printing it because it does help and now I know I'm not an idiot. I used to think some of my symptoms were "in my head" and I was labelled as lazy. Reading Gail's story has made me feel so much better.

*Thank you
Rosemary"*

Thirdly, Bill writes of his and his wife's experiences at the Mayo Clinic in the USA:

"In 2010 my wife (Jitlada) and I travelled to the USA. Part of the trip involved appointments at a Mayo Clinic to obtain a second opinion on my wife's Myasthenia Gravis (MG) health issue.

The Mayo Clinic is recognized as a world leader in research and treatment of many health issues, including MG, and one of my wife's specialists had recommended visiting the clinic. The Mayo group has several clinics scattered around the USA, and Rochester is the original and largest of its clinics. It was founded by the Mayo brothers soon after the American Civil War. The Mayo family now has minimal involvement in the clinics that are currently run by a group of influential American citizens.

Rochester's population is around 100,000. About 70% of its residents work for the hospital/clinic; of these 70,000, around 8,000 are medical professionals. So Rochester is a very medical-orientated city.

When making an appointment from Australia, we had to lodge a deposit of \$US 5,000.00 with the Mayo Clinic. Luckily this is tax deductible! The total medical cost for the visit and treatment was around \$US 6,000; this excludes the travel and out-of-pocket expenses like accommodation, meals, etc and any shopping!!!

Apart from the travel agency confusing Rochester, New York with Rochester, Minnesota and the resultant mad panic at the New York airport to rescue bags going to the wrong Rochester and to change air bookings, we made it to Rochester, Minnesota safely and on time for our first appointment. Apparently, we were not the first to have this experience. In fact, others have travelled all the way to New York's Rochester by mistake!!!!

After settling into our hotel, we found that all the main hotels are connected by underground walkways (subways) to the clinic and hospital. This means that we could walk from our hotel to the clinic without being subjected to any inclement weather. Also, most hotels allow pets in recognition of their companionships being important therapy for some patients. Thus the entire accommodation scene is very patient friendly.

Our experience with the Mayo clinic was very professional. Even though we arrived with reports and records from Australia (including X-rays), they assumed nothing and took a very holistic approach. First, we saw a generalist who evaluated my wife's medical condition and then selected the most suitable medical professionals for her to visit and the necessary diagnostic tests, etc. They organized all the appointments. We ended up seeing all the necessary specialists/medical professionals during a 10 day stay (including a week-end). To see all these different types of medical professionals in Australia would have taken months,

and we would have had to arrange the appointments ourselves and travel across Brisbane to the different locations ourselves.

Having all the medical professionals in one location made it easier and more efficient for everyone involved. This compression of the time taken to make exhaustive investigations can be tiring but is a relief as there is no lengthy waiting period for results and/or subsequent visits to medical professionals. This could be potentially life-saving.

Based on our Mayo experience, I am now a supporter of large integrated, one-stop clinics rather than the scattered, autonomous practices that dominate the Australian medical landscape.

Additionally, the extra facilities in the clinic were first class with all types of restaurants available; free access to computers and Internet; children's play areas. We experienced very little waiting for appointments; information officers were everywhere to direct us to the appropriate places; all buildings were wheel-chair friendly, etc.

We remain impressed by the supportiveness of the environment for visiting patients and their carers, who are obviously all under significant emotional pressures/stress. However, we did notice that in the Mayo clinic there are very few Hispanic, Native Indians and African Americans present as patients. I suspect this is due to the expensive nature of the American health system and therefore less accessible.

On reflection, it seems that the Mayo Clinic specialists would have approached my wife's MG via a different treatment path from the Australian specialist's approach. They would have focused on and selected the most suitable treatment, irrespective of cost. While in contrast, our experience of diagnostic and treatment paths in Australia is that we are encouraged to start with the "cheapest" and work our way to the more expensive treatments - if the cheapest have not worked. The difference is perhaps that the Australian treatment is publically funded and the medical authorities are more cost-conscious than in the USA; the latter relies very heavily on private medical funding. Despite this difference in approach, the Mayo Clinic professionals were satisfied with the apparent stability of my wife's MG symptoms, which is due to treatments in Australia."

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 graeme.peters2@bigpond.com.

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.

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DEAD TED

Two elderly women meet at the launderette after not seeing one another for some time. After inquiring about each other's health, one asked how the other's husband was doing.

"Oh! Ted died last week. He went out to the garden to dig up a cabbage for dinner, had a heart attack, and dropped down dead right there in the middle of the vegetable patch!"

"Oh dear! I'm so very sorry," replied her friend, "What did you do?"

"I opened a can of peas instead."

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 MARILYN	02 6285 2661 02 6291 8287	CANBERRA ACT CANBERRA ACT
BARBARA ROBERT JEAN MAX PENNY FRANK CANDY ELLEN	02 9524 9224 02 6652 6745 02 4937 3110 02 6621 6386 02 4868 2213 02 6767 1031 02 6847 3732 07 5599 9511	CARRINGBAH SOUTH NSW COFFS HARBOUR NSW KURRI KURRI NSW LISMORE NSW MOSS VALE NSW TAMWORTH NSW WARREN NSW WEST TWEED HEADS NSW
ROLAND TAMARA CORAL DENNIS BARBARA DORA	03 9796 6592 0409 186 809 03 5865 1378 0402 285 520 03 9776 4985 03 5821 4191	NARRE WARREN VIC HOPPERS CROSSING VIC KATAMATITE VIC PATERSONS LAKES VIC SEAFORD VIC SHEPPARTON VIC
DIANE RONA	0421387904 08 9459 7168	CARINE WA MADDINGTON WA
DIANE DAPHNE	03 6327 2563 03 6428 6733	RIVERSIDE TAS SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

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LOOKING GOOD

My face in the mirror isn't wrinkled or drawn.

My house isn't dirty. The cobwebs are gone.

My garden looks lovely and so does my lawn.

I think I might never put my glasses back on.

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2011/2012 are due. Membership Fees are the same as last year.

The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

The majority of members will have 6/11 which tells you (and us) that you are financial to 30 June 2011. Others may show 6/12 or even 6/13 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/10, 6/09, etc and we continue to send our newsletter to these unfinancial members because we do not know what they want. **If you are unfinancial, please take a minute to ring on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes".**

LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions.

We are also giving you the option of paying your subscription directly into our bank account. Our bank details are:

BANK: Bank of Queensland
BSB: 124 032 **ACCOUNT NUMBER:** 10263772
ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc
REFERENCE: Your Name & Initials

If you use the direct deposit method, it would help if you could email us from the 'Contact us' page on our website www.mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

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Tear off along this line

If you wish to pay by cheque or money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc
PO Box 16
MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$ _____ being annual subscription \$ _____ and/or Donation \$ _____:

NAME: _____ **Category A – Myasthenic \$15**
Category E – Supporter \$15

ADDRESS: _____

AND FOR: _____ **Category D – Carer \$5**

ADDRESS: _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

20TH ANNIVERSARY FUNCTION

- WHEN:** Sunday 19 June 2011 commencing at 10:00am for 10:30am
- WHERE:** Carina Leagues Club, Creek Rd Carina Qld. (It is part of the Clem Jones Centre and is immediately opposite Meadowlands Rd)
Lunch is available at the venue with a varied and reasonably priced menu.
- GUEST SPEAKER:** Dr Cecilie Lander M.B., B.S., F.R.A.C.P., F.R.C.P.E.
Dr Lander will talk about MG and give an overview of autoimmune disease in the nervous system, with the perspective of being a neurologist for the last 35 years.
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier
- HOW DO I GET THERE?** See map below. (UBD Map 181 Reference M1.)
- 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 10 June 2011**

