



# Messages

Myasthenia Gravis Association of Queensland  
**October 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.

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Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

*Welcome,*

The new committee has held its first meeting of the year. It was very successful with lots of ideas being passed around the table.

We had a very interesting visit from Fiona Jackson who writes up submissions for Grants monies. The submission preparation will be very time consuming and we may not get any results. We have asked Fiona for some more feedback in regards to the different grants and the associated fees and charges.

The committee has received good news from Queensland Health - we will continue to receive Grant money up to 30 December 2015. This has made it a bit easier for us to know what our finances are up until that date and allows the Association to continue operating. I would like to thank Carol for all her hard work in preparing the Transition plan that was submitted to Queensland Health.

The National Alliance has had its first meeting by teleconference. The Agreement has been signed by all parties so that is excellent work. The Alliance will develop a website and I will inform you when it is up and running. They are hoping to have a conference in Sydney on 20 June 2015 with the help of Dr Stephen Reddel and others. I will keep you informed of the progress.

The next function is the Christmas Party on 14 December 2014 at the Sandgate RSL Club. Please see further details later in the Newsletter. Looking forward to seeing you all attend this function.

Thanks Catherine for all your work in getting the Newsletter up and ready for everyone to read. Hope everything goes well for you in New South Wales.

*Take care,*

*Anita*

Supported by



Department of Health

## **PROJECT UPDATE**

### **SURVEY UPDATE**

How delightful it is to report that an author for the booklet of 'patient stories' has been found and the first interviews have been arranged. It is hoped to complete this project by mid next year allowing the Association to provide this resource as an additional item supporting the current information booklet. Ideally, the Association will be in a position to provide all financial members with a complimentary copy of the booklet.

### **SURVEY REMINDER**

Surveys continue to be distributed as contact is made with additional sufferers. However, the number of surveys returned is not keeping pace. Please be assured that whilst the first data review has been completed, it is still very important that surveys continue to be received and that the data base grows. If you have a survey and it has not been completed, please, can we ask that you complete it and return it to the Doctors. Your GP can complete the medical form if this makes it easier. Should you have reservation about aspects of the survey or need a new copy, do use the Freecall number on 1800 802 568 to discuss your queries or simply complete only those questions you are comfortable with. If you know someone who has not yet received a survey, ask them to make contact with the Association explaining the importance of this unique project. Thank you to everyone who has already responded.

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## **MYASTHENIA ALLIANCE AUSTRALIA**

The "Myasthenia Alliance Australia" has been formed and the first meeting has been held. This Alliance is seen as a significant step forward in enhancing the work of the State Associations and bringing greater support to those affected by a condition which brings unique and differing experiences to people affected by Myasthenic Syndromes.

Planned projects to date for this National Alliance include:

- the development of a specific website to provide news regarding events of National importance;
- to convene for the first time in Australian history a National Conference for Myasthenia sufferers, their families and supporters, for Health Professionals and for anyone interested in learning about these rare conditions. Tentatively, it is hoped that the conference will be held on Saturday June 20th 2015 at a venue in Sydney. More details will become available as they are confirmed.

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## **REMINDER- PHARMACEUTICAL DRUGS CAN AGGRAVATE MYASTHENIA GRAVIS**

As explained in your MGAQ information booklet (page 17), it is important that all sufferers are vigilant in checking with their doctor when being prescribed new medication. Drugs of concern are listed there. An initiative undertaken by the 'MG Friends and Support Group WA Inc.' involved publishing a pamphlet and listing on the website, an overview of drugs which can adversely affect MG. Kindly, we have been sent some copies of the brochure produced by the WA Group. They are available through the MGAQ library service if members would like to view this pamphlet.

**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 - BRISBANE**

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	32617564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414525241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
DENNIS	3855 9379	GAYTHORNE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
GEOFFREY	33556441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
TRACEY-LEE	3284 9949	REDCLIFFE
SYBIL	3219 9535	ROCHEDALE
CATHERINE	041851110	SPRINGFIELD LAKES
POPPY	3288 4484	SPRINGFIELD LAKES
JOHN	3633 0604	ZILLMERE

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**NOTE FROM THE EDITOR**

As you have no doubt noticed, due to unforeseen circumstances, this newsletter covers two months, October - November. The next letter will be the December edition.

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**RECIPE****Rice Crusted Chicken and Vegetable Pie**

1 cup long grain rice	1 cup shredded cooked chicken
2 cups hot water	2 tbsp butter
3 eggs	2 tbsp flour
1tbsp chopped fresh parsley	1 cup milk
2 medium zucchinis, thinly sliced	salt and pepper to taste
1 red capsicum, seeded and chopped	¾ cup grated tasty cheese
1 cup broccoli	

1. Cook rice and set aside to cool for 5 minutes.
2. Lightly beat one of the eggs and add with rice and parsley. Mix well.
3. Spoon rice mixture into microwave-safe pie plate. Press the rice against the sides and base of the dish to form a shell.
4. Arrange zucchini, capsicum and broccoli in the rice case. Cover with plastic wrap. Microwave for five minutes or until vegetables are tender. Scatter chicken over vegetables.
5. Place butter in a small bowl. Microwave for 30 seconds to melt and stir in the flour. Blend in the milk, stirring constantly, until smooth. Whisk in the remaining eggs and seasonings.
6. Pour the sauce over the chicken and vegetables. Microwave on MEDIUM (50% power) for 3 minutes or until the filling is set. Sprinkle with the cheese. Place under a hot grill for 2 or 3 minutes or until the cheese has melted and is golden.

**Variation:** For a vegetarian version of this pie, replace the chicken with corn kernels.

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**NEVER SAY NEVER**

“Never get in a battle of wits without ammunition.” - Anonymous  
 “Never ask old people how they are if you have anything else to do that day.” – Joe Restivo  
 “Never kick a mule and turn your back.” – American adage  
 “Never let your schooling interfere with your education.” - Mark Twain  
 “Never buy a fur from a veterinarian.” – Joan Rivers

**FATHERHOOD**

Fatherhood is pretending the present you love most is soap-on-a-rope...Bill Cosby  
 I don't care how poor a man is; if he has family, he's rich...Colonel Potter  
 He didn't tell me how to live; he lived and let me watch him do it...Clarence Budington Kelland

## AUSTRALIAN TRIVIA

### SPORT

1. Which horse won the Melbourne Cup in 2002?
2. What was Sir Donald Bradman's batting average?
3. Who is Australia's only Formula One driver?
4. Who won the Brownlow Medal in 2003?
5. Who was the most recent Australian to win the men's singles title at Wimbledon?
6. Which Australian was named the most valuable player in the US's WNBA?
7. Which Australian has won the FIM World Motorcycle Championship 5 times?
8. How many gold medals did Australians win at the 2002 Winter Olympic Games?
9. Of our Australian male swimmers, who has won the most Olympic gold medals?
10. What Australian company is the largest surfwear manufacturer?

### *Answers*

1. *Media Puzzle*
2. *99.94*
3. *Daniel Ricciardo*
4. *Mark Ricciuto, Nathan Buckley, Adam Goodes*
5. *Lleyton Hewitt*
6. *Lauren Jackson*
7. *Michael Doohan*
8. *2 – Steven Bradbury and Alisa Camplin*
9. *Murray Rose*
10. *Quicksilver*

### General Knowledge

1. How many countries are larger than Australia?
2. In what state/territory was the highest recorded temperature, of 53°C, recorded?
3. Australia has the world's largest sand island. What is its name?
4. In what year was Advance Australia Fair proclaimed as the national anthem by the Governor-General?
5. Do all states/territories have the same blood alcohol limit for non-probationary drivers?
6. What animal is on the Western Australia flag?
7. In what city did the Commonwealth Parliament first sit?
8. What animal featured on the 2 cent coin?
9. Who is the only person to have been awarded both the Australian of the Year and Young Australian of the Year titles?
10. Who is on the front of the current issue \$100 note?

### *Answers*

1. *Five (Australia is the sixth largest country: Russia, Canada, China, USA, Brazil)*
2. *Queensland*
3. *Fraser Island*
4. *1984*
5. *Yes*
6. *Black swan*
7. *Melbourne*
8. *Frilled neck lizard*
9. *Cathy Freeman*
10. *Dame Nellie Melba*

## MEMBERS FORUM

Catherine writes....

*I find it funny to look back on the last thirteen years of my life and remember being so unhappy with myself. I was unhappy with the way I felt and the way I looked. Prednisolone had taken its toll. My weight had crept up and mild depression had set in. I knew what I needed to do to feel better on the inside and outside. The doctors had been telling me for years. "You need to exercise." It was easy for them to say that, they didn't have Myasthenia Gravis. Even when I felt well, I kept telling myself that I couldn't. Negativity had reared its ugly head. Mild exercise left me feeling weak and breathless. I don't know what triggered that defining moment when I knew that I needed to change my attitude. Previously I had always been so active.*

*Like Dorothy in The Wizard of Oz, I had my magical shoes all along; I just needed to use them. They may not have glitter but they are magical to me. My magical shoes would help me, of this I was certain. The first day I slipped my old running shoes I felt power, I felt energy, I felt alive. At first I could only walk around the block, then half way around the lake, finally the entire lake and kept adding more streets as I became fitter and stronger. Eventually I was walking around five kilometres.*

*When I first started walking I made sure I walked with someone just in case I couldn't make it home. As I became fitter and more confident I went by myself, with a mobile phone and the medic alert card that the association had so thoughtfully provided. I always walked where there were plenty of other people. As a side bonus I got to meet some lovely people who enjoyed the exercise as well.*

*Every single day I walked. I was amazed that a lot of my breathlessness was because I was so unfit. I had not exercised for ten years. The first twelve months I don't think I missed one day. I told myself that I would let my body dictate how often I would walk. The more I walked the better I felt. It truly was addictive. As my body changed so did my attitude about myself. Not just because I was thinner but because I was doing something very important for myself and changing my destiny. A simple walk every day helped clear my head, strengthen my body and give me energy that I had not felt in such a very long time.*

*I could not have done it without my shoes. They became a symbol of power to me. If I did not put them on and go for a walk I was letting myself down. My clothes changed, my socks changed but my shoes remained with me every day.*

*I have since lose nearly ten kilo and feel great. The real triumph is the feeling of achievement. It's not vanity or pride, just peace. I am happy in my own skin. It's not perfect but its mine. I have the freedom to do whatever I want, I can choose. I feel strong, I feel powerful, I feel like me, the real me.*

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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 make 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](mailto: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.

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**CHRISTMAS FUNCTION**

**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 14 December 2014
- TIME:** 11.30am for 12 Noon
- WHERE:** Sandgate RSL, 50 Keogh Street Sandgate 4017;  
(Function room, kindly donated by RSL Sandgate)
- WHAT WILL IT COST?** \$19.90 per person; Ham and chicken or Pork and Turkey served alternately with roast vegetables, bread roll, and Plum pudding. Tea and coffee complimentary. Please RSVP Shirley with any dietary requirements.  
John will be collecting payment at door, as this is required in advance. Cash preferred, but EFTPOS available.
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along. Remember, as it is a 'user pays' function, friends and family are most welcome.
- HOW DO I GET THERE?** UBD page 110 Ref Q4.
- RSVP** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 5th December 2014**

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**FUTURE PLANED ACTIVITIES**

**NEWS FROM MACKAY**

Ten members attended our luncheon in addition to the guest speaker Catherine Bruce, Laboratory Scientist from Sullivan Nicolaides Pathology.

Every one enjoyed the presentation on Myasthenia Gravis given by Catherine and how blood is used to help diagnose medical conditions.

After answering questions from those attending, Catherine gave handouts showing how Myasthenia Gravis affects people.

It was decided our Christmas get together will be held on Sunday 30<sup>th</sup> November at midday at the Mt Pleasant Tavern. All welcome.

Bill Area Coordinator Mackay 07 49541221

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**CAIRNS GET TOGETHER**

Our members had a good discussion at the last meeting in October about the IVIG (Intravenous Immunoglobulin) treatment. A few of our members were able to share their personal experience of IVIG with a couple of our members who have just started this treatment.

Knowing that there are people who understand because they have been through similar experiences with MG is one of the main reasons why attending the meetings is important.

Our next get together will be on Saturday 13th December at 11.00am at the Cairns RSL Club Boardroom. The guest speaker is Kay Thoren (Kaizen Oriental Therapies) who will present a talk on the "Importance of Wellbeing". This meeting will also be our Christmas celebration. Please RSVP if you are able to stay for lunch (at own expense).

If you are visiting Cairns, you are most welcome to join us at any of our get-togethers

Donna Formosa – Cairns Co-Ordinator

M 0414 397462 H 07 40392148 E: formosed@bigpond.net.au

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**TOWNSVILLE GET TOGETHER**

The Townsville MG group had a well-attended get-together this month and shared good company and great conversation.

The next get-together will be on Saturday 31 January 2015, 12 noon at The Avenues Tavern.

Carol Buchanan – Townsville Coordinator Ph. 47737122

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