



# MessaGes

Myasthenia Gravis Association of Queensland Inc

**APRIL 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**

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### **COMMITTEE MEMBERS**

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#### **PATRON**

Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

A very special thank you to our members from the Cairns region who attended our meeting at the Cairns RSL Club on Saturday March 13.

Attendance on the day surpassed our wildest expectations and all who were there contributed to the discussions. There were some very interesting stories told on the day and we have encouraged those who told their story on the day to put pen to paper and forward it to our Members' Forum so that it may be shared with our full membership. A pleasing aspect of the day was the fact that a Speech Therapist and a couple of local Optometrists attended and gave a small presentation of their experiences of treating people with MG. All in all, it was 3 hours of full-on interaction and was a most successful and fulfilling day. We hope it is an indication of what we can expect when we continue with our program of our visits to the regions.

It would be remiss of me if I did not thank Cairns regional Co-ordinator, Hanna, for her efforts in organising the day and for rounding up the troops and also thanks to Robyn Pell for her efforts in publicising the day through the various radio and newspaper media outlets in Cairns.

You will note from our Schedule of Upcoming Events that we are inviting all of our co-ordinators to attend our monthly Management Committee Meeting in Brisbane on the weekend of June 19 and 20. Current indications are that most of our co-ordinators will be attending and we are looking forward to having meaningful and fruitful discussions over that weekend.

Work is progressing on our possible funding projects and an update is contained in this issue.

That's all for now

Take care

*Anita (in absentia)*

NB: We apologise for the late circulation of this issue of MessaGes, but our editor has been on holidays in Tasmania for three weeks.

Supported by



**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**

MELISSA	0411039060	ACACIA RIDGE
TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
EILEEN	3269 5660	BRIGHTON
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
GORDON	3398 7891	CARINA
LORRAINE	3206 0789	CLEVELAND
PAM / RAY	3801 1335	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
CARLY (14 years old)	3354 3014	MITCHELTON
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
MIKE	3288 4037	SPRINGFIELD
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

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**Future Planned Activities**

Saturday 19 June 2010	Co-ordinators to Committee Meeting – Brisbane
Sunday 20 June 2010	Guest Speaker Function – Brisbane
Sunday 12 September 2010	Annual General Meeting – Brisbane
Sunday 12 December 2010	Christmas Function –Sharks Australian Football Club Southport

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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## Shirley's Recipe

### MUESLI SLICE

#### Ingredients:

- |                              |                     |
|------------------------------|---------------------|
| 50g butter                   | ½ cup raw sugar     |
| ¼ cup honey                  | 100g pumpkin seeds  |
| 100g slivered almonds        | 1 Weetbix (crushed) |
| ½ cup cranberries (craisins) | ½ cup rolled oats   |
| ½ cup s-r flour              |                     |

#### Method:

1. Preheat oven to 170°C. Line 20cm square cake tin with baking paper.
2. Place butter, sugar and honey in a pan over medium to low heat. Cook, stirring, for 2 – 3 minutes.
3. Combine seeds, almonds, Weetbix, cranberries, oats and flour in a large bowl. Add butter mix, stir until combined.
4. Spoon into cake tin. Bake for 25 minutes. Cool in cake tin for 30 minutes.

Note: If mixture is too dry, add a little more honey.

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#### Update on **WHAT'S AHEAD IN 2010??**

The Committee is currently investigating the feasibility of undertaking the following projects in 2010:

##### **A. Collecting data on sufferers of myasthenia gravis –**

Further information is in the process of being obtained from Dr Stephen Reddel regarding the questions to be asked in the survey and the sub-committee is currently in discussion with business people to see if a computer platform can be provided for this project.

##### **B. Establishment of an Australia-wide MG 'umbrella' organisation –**

Dormant for the time being.

##### **C. Funding for research into 'Exercise and MG' –**

Awaiting response from Department of Physiotherapy at University of Queensland.

##### **D. Enhancements to our website –**

We really would like to hear from our members regarding this project. We have our own ideas, but they may not be what you, our members, want. **Please** let us know via email to [mgag@gil.com.au](mailto:mgag@gil.com.au) or via Australia Post to PO Box 16 MT GRAVATT 4122

##### **E. Opportunities in Queensland to assist in MG research –**

No further action at present.

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.

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#### **Misunderstanding!!**

Morris, an 82 year old man, went to his doctor to have a physical.

A few days later the doctor spotted Morris walking down the street with a gorgeous young blonde on his arm. The doctor spoke to Morris and said, "You're doing very well". "Just doing what you said doc – get a hot mamma and be cheerful" replied Morris.

"I didn't say that," said the doctor, I said "you've got as heart murmur and to be careful."

\* \* \* \* \*



## National Disability Insurance Scheme

As we are in a Federal election year, it may be a good time for the Myasthenia Gravis members (carers and sufferers) to ask candidates in their local Federal seats the following question:

### **What is their position/view on the concept of a national disability insurance scheme?**

According to the Harmer Pension Review (2009) as quoted by the Australian Financial Review (Monday February 15, 2010)

*"...the development of new approaches to funding services and support for people with disability is important to the long term sustainability of the system.....in particular, the idea of a national disability insurance scheme is worthy of consideration..."*

Momentum for this issue is certainly building, with the yet-to-be-released Henry Review possibly recommending a 0.4% disability levy as a way of funding services to the disabled. All this is linked with the whole Intergenerational Report Framework of an aging population, productivity agenda and health in general.

This means that disability has moved from being considered a charity and compassion issue to being debated as an economic one. Furthermore, it is now being seen as a question of income support, rather than of service provision.

Remember: a nation should be judged more on its approach to disadvantaged groups in society rather than the "materialistic consumption" and narrow economic and financial criteria, such as GNP, GDP, etc. It has been suggested that people living on the full age pension are living below the poverty line; people on disability support pensions are even worse off!!!!

It is estimated that around 2 million Australians are sufferers or carers who have been described as "poor and powerless". In the past, specific disabled groups tended to focus entirely on their own individual agenda, rather than banding together in a common cause. Furthermore, there are in large equities in the system where benefits to a few can be multimillion dollar payouts, while others receive very little.

The idea of a national disability insurance scheme received some attention in the 2020 summit. It was suggested that this scheme could be funded by a special supplement to the Medicare levy, third party car insurance and/or workplace insurance.

Specific groups and individuals who are investigating the concept include the Productivity Commission, PricewaterhouseCoopers (John Walsh), Disability Investment Group (Allan Fels, Ian Silk, Bruce Bonyhady, Helen Sykes & Bill Moss) plus the Parliamentary Secretary for Disability and Children Services (Bill Shorten).

*The above item was compiled by Committee Member, Bill Synnot, and is based on articles published in the Financial Review on Monday 15 February 2010*

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Far North Queensland  
**Progressive Neurological Movement Disorders**  
 Symposium

Sunday 2nd May 2010

The Hilton Hotel Cairns  
 Conference Centre

- 1.30 pm Guest speaker presentation
- 2.30 pm Afternoon Tea and Trade Displays
- 3.15 pm Panel Discussion
- 4.15 pm Conclusion and Trade Displays

*The aim of this educational and promotional symposium is for clients, carers, GP's, specialists and health professionals in Far North Queensland to increase their knowledge regarding progressive neurological movement disorders.*

### Guest Speaker



Professor Peter Rathjen is the Deputy Vice-Chancellor (Research) at the University of Melbourne. Prior to this he held positions as the Dean of the Faculty of Sciences at the Universities of Melbourne and Adelaide. He was appointed to the Chair of Biochemistry at the University of Adelaide in 1995.

Professor Rathjen has a longstanding involvement in Embryonic Stem Cell research dating from postdoctoral research at the University of Oxford in the late 1980s, to the commercialized of his work on understanding the processes by which stem cells differentiate into functional cell types during embryo development. He was a founding member of the Australian Research Council (ARC) Special Research Centre for the Molecular Genetics of Development, and the Australian Stem Cell Centre (ASSC).

There is considerable excitement about the potential therapeutic use of human Emryonic Stem (hES) cells as they retain the ability to give rise to many of the cells found in the human body. In practice, therefore, hES can be transformed into an unlimited number of any type of cell that is normally present in the embryo or adult. This opens up new avenues for precise treatment, by cell transplantation, of diseases caused by cell loss, dysfunction and damage, including Parkinson's Disease, Multiple Sclerosis, Motor Neurone Disease, Stroke, Heart Failure and viral infection. Professor Rathjen will explain the science behind stem cell technology and research developments in a way that we can all understand!

**Please RSVP your attendance to : [dcronin@fnqrdgp.org.au](mailto:dcronin@fnqrdgp.org.au)**

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**Blonde's Revenge**

WHY ARE BRUNETTES SO PROUD OF THEIR HAIR?  
 It matches their moustache