



Messages

Myasthenia Gravis Association of Queensland Inc

JUNE 2010



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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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PATRON

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Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

It is hard to believe that we are half way through the year but we are all looking forward to the cooler months and managing our Myasthenia Gravis.

The committee is back at full strength with Bill Synnot returning from holidays in America and both Susan White and myself having returned last month.

We are looking forward to meeting with our Regional Co-ordinators and hearing their news and stories from the members in their districts. Hoping we can get some stories for the Members Forum in the Newsletter. Also it will be a very different presentation from Rick Carr from Multiple Dystrophy Queensland but a very interesting one just the same. It will be beneficial in the long term for all our members who have to see numerous members of the Medical profession as this should be a one stop for everyone especially beneficial if you have travelled far. Hoping to meet some new members of the Association at this meeting - it is amazing what we all get out of these meetings.

On behalf of the Committee and members of the Association I wish to convey our sincere condolences to our South Coast Coordinator, John Nielsen, and his wife, Marilyn and their family on the recent loss of John's mother. Our thoughts are with you at this time.

We have also organised our Guest Speaker for the AGM in September 2010 so hoping you have all marked the date in your diaries for 12 September 2010 at the Carindale Hotel.

Keep your Membership Renewals coming in as the strength of any organisation is in its members.

Take care

Anita

NOTE: The President's report was written prior to the weekend of 19-20 June

PS: Please note that the Secretary's new personal email address is graeme.peters2@bigpond.com

Supported by



Queensland Government
Queensland Health

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

Future Planned Activities

Sunday 12 September 2010 Annual General Meeting – Carindale Hotel
 Saturday 13 November 2010 Management Committee Meeting on Sunshine Coast
 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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GET WELL SOON

The Association expresses its best wishes for a speedy recover to our Cairns Regional Coordinator, Hanna Russell, following her recent motor vehicle accident. Unfortunately the accident has prevented Hanna from travelling to Brisbane to meet with the Management Committee at this time.

Shirley's Recipe

PINEAPPLE COCONUT SLICE

Ingredients:

- 185g butter, softened
- 3 eggs
- 1 3/4 cups self raising flour
- 44g can crushed pineapple, well drained
- 3/4 cup caster sugar
- 2/3 cup dessicated coconut
- 270ml can coconut cream
- 1/3 cup shredded coconut

Lime Glace Icing:

- 1 1/2 cups icing sugar
- 20g butter, melted
- 2 tblsp lime juice

Method:

1. Preheat oven to 180°C, fan forced. Grease 22cm x 32cm rectangular cake pan. Line base and sides with baking paper extending 5cm over edges.
2. Beat butter and sugar until light and fluffy. Beat in eggs one at a time. Stir in dessicated coconut, sifted flour, coconut cream and pineapple alternately in batches.
3. Spread mixture into pan. Bake for 45 minutes. Stand in pan for 10 minutes before turning out.
4. Icing: Sift icing sugar into a bowl, stir in butter and enough lime juice to make a paste. Spread icing over cake, sprinkle with shredded coconut. Cut into portions for serving.

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Update on WHAT'S AHEAD IN 2010??

A. Collecting data on sufferers of myasthenia gravis –

The first rough draft of the Survey Questionnaire is under consideration..

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 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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EXTENTION OF FUNDING

We are pleased to advise that Queensland Health have agreed to extend its funding to the Association for another three (3) years from 1 July 2010 to 30 June 2013.

We sincerely thank Queensland Health for its generous support.



- draining an infection.
- 1921** Euro Otto Loewi proved the importance of acetylcholine (Ach) in triggering muscles
- 1930** USA Surgeons developed a positive pressure ventilation enabling the removal of the Thymus gland.
- 1934** UK Mary Walker used Physostigmine to strengthen the muscles of a MG sufferer.
- 1939** USA Alfred Blalock removed a Thymoma from a patient.
- 1949** UK Geoffrey Keynes established that improvements following thymectomies were mainly confined to Myasthenics without Thymomas.
- 1954** UK Mary Walker developed Physostigmine to Pyridostigmine (Mestinon)
- 1960** UK-USA-Aust. Jacques Miller (in London and Aust) and Bob Good in USA demonstrate that the Thymus is the key immune organ generating T cells, the main source of antibodies to AChR
- 1973** UK Physiologists confirm that MG could be caused by antibodies, providing a measuring tool and a confirmation of MG.
- 1979** UK John Newson-Davis used *Plasma exchange* to wash antibodies out of the patient's blood stream.

Research is continuing world wide seeking causes, and more appropriate treatments and hopefully a cure.

USA.UK.Aust.

Effectiveness of Thymectomy with and without Thymoma

Aust. In **2003** Stephen Reddel defined the function of Muscle specific Kinase (MuSK) in stabilising the post synaptic structure of the muscle receptors. (AChR) Antibodies to MuSK have been identified

That Disguised Problem

Although MG was diagnosed in both males and females of all ages, generally the prevalence was mainly in women of child bearing age and men in their 60s to 80s. Over the last two decades, however, world wide research indicates an increase in the numbers of older women in their 70s and 80s being diagnosed. There is no known reason for this increase but it is considered that the symptoms have been masked and confused with the general signs of ageing.

Information gained from a survey of MG sufferers who are members of the MG Support Group in WA, illustrates how easily the MG symptoms are masked. Four examples are:

Eighty-two year old.

"After being a passenger in a motor vehicle accident in June, 2005 when I had only minor injuries I started to have difficulties with chewing and swallowing often choking. I was provided with a puffer as asthma was suspected. I ended up in hospital with pneumonia and was treated by a respiratory specialist. I got droopy eyelids and saw an eye specialist and he gave me eye drops. I continued to have difficulty chewing, and swallowing and still choked and had droopy eyelids. I was sent for a CT scan when a stroke was suspected. The test was clear. My GP said it was not a medical problem and I might need new dentures. I had them made. No improvement, so I tried another dentist who made more new dentures but I still couldn't chew and choked a lot. The dental mechanic told me he had consulted with some of his colleagues and one of them said it might be Sjogrens syndrome and to go back to my GP. I was rushed to hospital again with pneumonia. This time the respiratory specialist called in a Neurologist who immediately suspected

MG. After positive diagnosis of MG in 2007 and being provided with medication I find that I can chew, swallow and not choke”.

Seventy-five year old

“I was diagnosed with MG Ocular in 2006. For a few years previously I had had double vision being treated with new spectacles and prisms until they just went haywire. Lucky for me the eye and ear hospital diagnosed MG. I gradually got a lot of weakness in my limbs and I walk really badly. I now realise I must have had a problem for some time. I suppose the stress of nursing and losing my husband just brought it all on in one bang”.

Eighty-three year old.

“I was diagnosed in 1999 at age 74. In 1994 I had started to have difficulty speaking and was unable to sing. This was thought to be ageing muscles I started to have difficulty swallowing and woke at night choking. The diagnosis was asthma and I was given a puffer. The problem continued and later droopy eyelids, and muscle weakness in arms and legs was thought to be depression and I was prescribed anti-depressants. I did not take this medication. Next came double vision and when a CT scan did not show signs of either stroke or tumour I was referred to a Neurologist. After a scan of the Thymus, Tensilon Test, and a Single Fibre Electromyography I was diagnosed with MG. My condition is controlled by medication and I am able to lead, although restricted, a fairly normal life”.

Seventy-two year old

“My first attack of dizziness in 1996 was diagnosed as either an inner ear problem or a stroke. This went on for about three years when an MRI scan showed it not to be a problem. My next major attack saw me put into a mental ward and placed on anti-depressants for one year. Next attack again into a mental ward where fortunately a young doctor diagnosed MG. With correct medication I am fine now for 99percent of the time. I hope this information will help other people. While in Fremantle Hospital I spoke to a large group of doctors to help them diagnose this disease”.

Most common symptoms of MG

Blurred or double vision
Slurred or nasal speech
Difficulty in holding the head up
Difficulty in chewing and swallowing
Choking
Unstable gait.

Drugs administered to Myasthenics in the treatment of other diseases and infections have been found in some cases to aggravate MG. Because of the long lists of such drugs, one of the tasks identified by the support group was to research and rank the degree of risk.

There is no known cure for MG but with improvements in treatments, the symptoms of the disease can be, to a large extent, controlled. Early diagnosis and treatment greatly improves the quality of life of this small group of older people.

Ron Okely
Hon. Secretary
Myasthenia Gravis Friends & Support Group WA Inc
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e-mail Contact@myastheniawa.info
website www.myastheniawa.info

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KEEP YOUR BRAIN ACTIVE*Answers are at the bottom.*

1. Which 4 USA states meet at Four Corners Monument, the only place in the USA where any 4 of its states meet?
2. Who is the Federal Minister for Finance?
3. What is the capital of Senegal?
4. Who is the new UK Prime minister?
5. What is the chemical symbol for Radium?
6. What colour is the flag of Libya?
7. In which Australian state or territory is Wycheproof?
8. How many miles in a league?
9. In what mountain range is the country of Bhutan ?
10. Which author wrote the 'Twilight' series?
11. What was the world's first National Park?
12. Which country did Iraq invade in 1990 to start the Gulf War?
13. 'Pinchbeck' is a cheap imitation of what?
14. What is the name of Israel's parliament?
15. Who composed the song 'My Way' made famous by Frank Sinatra?
16. What was the last Australian state to become self-governing?
17. Ships of which other nationality entered Botany Bay in 1788?
18. A millimetre is what fraction of a metre?
19. Is Queenstown on the East or West coast of Tasmania?
20. How many mens French Open Tennis singles championships has Raphael Nadal won?

Answers: 1. Arizona, Wyoming, Colorado, New Mexico; 2. Lindsay Tanner; 3. Dakar; 4. David Cameron; 5. Ra; 6. Green; 7. Victoria; 8. Three; 9. Himalayas; 10. Stephanie Meyer 11. Yellowstone; 12. Kuwait; 13. gold; 14. Knesset; 15. Paul Anka; 16. W.A. in 1890; 17. French; 18. One-thousandth; 19. West.; 20. Five.

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Try not to become a man of success but a man of value

Albert Einstein

If you would create something, you must be something.

Johann Wolfgang von Goethe

MEMBERSHIP SUBSCRIPTION RENEWALS

THIS YEAR 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

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.

SOME MEDICAL DEFINITIONS FROM CHILDREN

- Artery — Study of paintings
- Bacteria — Back door of cafeteria
- Barium — What doctors do when treatment fails
- Dilate — To live long
- Nitrate — Cheaper than day rate
- Rectum — It almost killed him
- Seizure — Roman emperor
- Terminal illness — Sickness at airport
- Tumor — An extra pair
- Node — Was aware of
- Cauterize — Made eye contact with her
- Caesarean section — District in Rome