



Messages

Myasthenia Gravis Association of Queensland Inc

NOVEMBER 2013



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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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PRESIDENT'S REPORT

Welcome,

It is hard to believe that we are nearly at the end of the year. Christmas is fast approaching, the weather is warming up and we are all struggling with our MG in this warm weather.

We have received the report from CIE. The report will be presented at our December meeting and further discussions will be needed to see where we go from here. We are still corresponding with Queensland Health in regards to our Service Agreement up to the 31 December 2013 and also the new one which will take effect in 2014 for three years.

The 'meet the Members day' in Toowoomba on 10 November 2013 at the City Golf Club was a great success. I would like to thank Barry Sinclair for organising the room and also donating the cost of the hire of the room. It was very informal and I know that friendships have been formed amongst our members and a lot of information was also shared. I would also like to thank the members who travelled from Brisbane to attend.

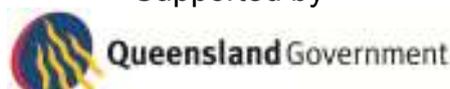
The committee is looking forward to travelling to the Gold Coast for our Christmas function on 15 December 2013 at the Dublin Docks Tavern at Harbour Town Drive on the Gold Coast. I am looking forward to seeing our members on that day. Please call Shirley to notify of the number coming so that we can confirm with the Tavern.

Our new editor of the Newsletter Catherine has asked if we could have some carer's stories as well as member's stories to be published. It is interesting to hear how the carer has coped with their partner having MG.

Anita

Editor's note: Please forward future contributions for the newsletter to Catherine Ormsby at cocraftychick@hotmail.com

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

In June this year, the MGAQ committee, in conjunction with Professor McCombe and Dr Blum of the RBWH and UQ, took the decision to seek out economic analysis of the data provided via the survey results. The CIE (The Center for International Economics) was engaged to provide this service. The firm is highly regarded for the work they perform and is based in both Canberra and Sydney. Collaborative work resulted and the final document has just now become available. The report will be tabled at the December committee meeting. Issues such as how to best make the report available to our members, to other appropriate bodies and to the public in general will be discussed. More information regarding this undertaking will follow in subsequent 'Survey Updates'.

Exercise Effect in MG' Pilot Study –

Doctor Jennifer Nitz, who conducted the Study at the University of Queensland's Neurological, Ageing and Balance Clinic, has kindly provided the Association with a booklet entitled '*Preventative Health – Exercise for your Bones, Strength and Balance.*'

The booklet details exercises which closely match those which were undertaken by participants in the abovementioned Study and are such that they can be undertaken by people in the comfort of their own home.

Each copy of the booklet comes with Cautionary Notes which should be read and understood before commencing any of the exercises.

Copies of the booklet are available, in either hard copy or electronic form (pdf), to current financial members. Those members wishing to obtain a copy should contact the Association on our Freecall number 1800 802 568 or via email at info@mgag.org.au and state whether you prefer hard copy or email copy.

Copyright of the booklet remains the property of Dr. Nitz and the University of Queensland and should not be reproduced in any form without their express permission.

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SHIRLEY'S RECIPE

WHITE CHOCOLATE & GINGERBREAD SLICE

100gm unsalted butter, chopped
 ¾ cup golden syrup
 ¾ cup brown sugar
 2 tspns ground ginger
 1tspn ground cinnamon

2 eggs, lightly beaten
 1/3 cup milk
 2 cups plain flour
 180g white chocolate, chopped
 Icing sugar for dusting

Pre-heat oven to 180 degrees. Grease and line 29cm x19cm slice pan with baking paper. Place butter, syrup, sugar, ginger and cinnamon in a saucepan. Stir on medium heat 2-3 minutes, until butter has melted and mixture is well combined and smooth. Remove from heat and cool slightly. Add eggs and milk and mix well.

Sift flour into a large bowl. Add chocolate. Fold through egg mixture and mix until combined. Fill prepared pan. Bake for 30-35 minutes, until firm. Cool completely in pan. Dust with icing sugar and cut into slices.

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The question isn't at what age I want to retire, it's at what income. George Foreman

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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435389883	TWEED HEADS SOUTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
DIANNE	02 4574 3787	WINDSOR DOWNS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	GILLEN NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

MEMBERS' FORUM

Tracy-Lee writes:

The Alien Within – My story

A young woman aged twenty-four, married, two children, a boy and a girl. Life was what she was told it should be, but that is another story.

Bringing up two children, one with a severe physical disability was a big enough challenge. She did not have time for herself as it was and rarely gave it to herself. So when she started to feel unwell, life became more difficult to juggle and she was forced by something that was unknown at the time to make herself No 1.

At first she tried to dismiss that there was anything wrong, she was just tired she would tell herself. But as the symptoms grew worse, she had to concede that something was wrong and she would need help.

There is a saying, "the eyes tell it all", but unfortunately the eyes of this young woman were not telling anyone anything except to say that there is something wrong.

No one could understand why this woman was having the symptoms she was, why she was constantly seeing double of everything, twenty-four hours a day, seven days a week.

Life's daily grind was getting harder to handle for her, but being the woman she is, she learnt to adapt. Silently to herself she was filled with so many emotions and she was feeling very alone.

The doctors continued to send her off for all sorts of tests, some very painful and leaving her feeling worse than before.

Through all this she kept her focus on her main priorities, her beloved children. Her son needed her continued support with his disability and her beautiful daughter was her world. She felt guilty for all the time she was unable to spend with her during the birth of her brother, and has vowed to make up for that. But as hard as she tried to stop it, she could feel a force growing inside her that was trying to stop her doing this. She described it as being like an "alien within her" slowly taking over her life and body.

It was becoming apparent to this young woman that she might never find out what was wrong with her. Test after test and still not a bit closer to the reason why. Test after test, always by herself, no support from the man she called her husband.

After one horrifying test, that afterwards left her almost totally blind, she was left to fend for herself and find her own way home with only the help of a kindly old taxi driver. She was so angry that she was put into this vulnerable situation. She would cry herself to sleep at night just wanting someone to hold her and tell her it will be ok. Someone to tell her she is not going mad and what she is going through is real. But she knew that for this voyage in her life, she would have to travel alone, alone with only her courage and the love of her children to help her through.

No one understood her fears. "You are just tired" one would say. "It's all in your head" another would say. Maybe this was true, maybe it was all in her head and she was going crazy. The loneliness continued.

These are the thoughts and feelings of someone who will be diagnosed with Myasthenia Gravis (MG), eventually, and from a young age learning to adjust her life so that MG can be a large part of it.

I was eventually diagnosed after waking one morning with a drooped eye; doctors were convinced straight away what was wrong with me. I had just had endured double vision for two years and they could not find out anything, but a droopy eye and 'it's positive'. A quick trip to hospital, injection into the arm, bingo, positively confirmed, Myasthenia Gravis.

Sadly though, the time taken to diagnose MG still takes time and you endure endless months knowing that there is something wrong but no one can pin point it. At least there is now more research going into finding more about this disease and hopefully, the time it took to get my diagnosis will not be as long in the future.

I have now reached my 24th anniversary of my 'up and down' relationship with MG and the trials and tribulations that go along with the diagnosis. I hope that my story can provide some strength to any young women and men that have been recently diagnosed.

Keep positive

Tracey-Lee

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 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 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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Future Planned Activities

Sunday 15 December 2013 Christmas Function – Gold Coast – venue Dublin Docks Tavern, Biggera Waters

Refer to page 8 of this issue.

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The Grinch Who Stole Christmas

It came without ribbons. It came without tags. It came without packages, boxes or bags. The Grinch thought of something he hadn't thought of before. Maybe Christmas doesn't come from a store. Maybe Christmas.....means a little bit more.

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Need Medical Help? Not sure about what to do or where to go?

Queensland Health operates a 24 hour, 7 day-a-week State wide telephone service providing access to health information, triage and referral.

If you are not sure about the seriousness of your symptoms or where you should go for help, there are qualified nurses manning the phones to listen and assist. They will direct you to the most appropriate service.

The Phone number is: **13 43 25 84 (13HEALTH)**

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I.C.E. (IN CASE OF EMERGENCY)

In case of emergency (ICE) is a program that enables first responders, such as [paramedics](#), [firefighters](#), [police officers](#) and hospital personnel, to contact the [next of kin](#) of the owner of a [mobile phone](#) to obtain important medical or support information (the phone must be unlocked and working). The phone entry (or entries) should supplement or complement written (such as wallet, bracelet, or necklace) information or indicators. The program was conceived in the mid-2000s and promoted by [British](#) paramedic Bob Brotchie in May 2005. It encourages people to enter emergency contacts in their mobile phone [address book](#) under the name "ICE". Alternatively, a person can list multiple emergency contacts as "ICE1", "ICE2", etc. The popularity of the program has spread across [Europe](#) and [Australia](#), and it has started to grow into [North America](#).

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I WANT TO SEE SOMETHING REALLY CHEAP

After being away on business for a week before Christmas, Tom thought it would be nice to bring his wife a little gift.

"How about some perfume?" he asked the cosmetics clerk. She showed him a bottle costing \$50.

"That's a bit much," said Tom, so she returned with a smaller bottle for \$30.

"That's still quite a bit," Tom grouched.

Growing disgusted, the clerk brought out a tiny \$15 bottle.

Tom grew agitated, "What I mean," he said, "is I'd like to see something real cheap."

So the clerk handed him a mirror.

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We had grandma for Christmas dinner...Really? We had turkey.



KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Multiple choice quiz again (at least you have a 1 in 3 chance of getting them right).

1. Who is the Federal Education Minister?
(a) Peter Dutton (b) Christopher Pyne (c) Ian Mc Farlane
2. Where did Australian bike rider Cadel Evans finish in the 2007 Tour de France?
(a) First (b) Second (c) Third
3. Poatina is in which Australian State or Territory?
(a) Victoria (b) Northern Territory (c) Tasmania
4. In which year did the Thredbo disaster occur?
(a) 1997 (b) 1998 (c) 1999
5. Who was Australia's second Prime Minister?
(a) Alfred Deakin (b) John Watson (c) George Reid
6. What was the scarecrow in the Wizard of Oz lacking?
(a) A heart (b) A brain (c) Courage
7. What is the most common name in nursery rhymes?
(a) Mary (b) Tom (c) Jack
8. How many sides does a dodecagon have?
(a) 8 (b) 12 (c) 16
9. What nationality is tennis player David Nalbandian?
(a) Mexican (b) Argentinian (c) Brazilian
10. The koala is the faunal emblem of which Australian State or Territory?
(a) Queensland (b) New South Wales (c) Victoria
11. What is Queensland official bird emblem?
(a) Rainbow lorikeet (b) Sulphur Crested cockatoo (c) Brolga
12. How long is Western Australia's coastline?
(a) 10500km (b) 11500km (c) 12500km
13. What is the approximate area of New South Wales?
(a) 701600 sq km (b) 801600 sq km (c) 901600 sq km
14. Which card game did Harold Vanderbilt invent in 1925?
(a) Contact bridge (b) Whist (c) Blackjack
15. Which element is missing in inorganic chemistry?
(a) Hydrogen (b) Uranium (c) Carbon
16. In the movie 'The Full Monty' how many of the strippers were black?
(a) Zero (b) One (c) Two
17. Who was the first Premier of Queensland?
(a) R G W Herbert (b) A Macalister (c) R R Mackenzie
18. What is the floral emblem of Tasmania?
(a) Flowering Red gum (b) Flowering Blue Gum (c) Flowering Yellow Gum
19. Whose compositions include 'The Four Seasons'?
(a) Bach (b) Schubert (c) Vivaldi
20. Which book of the Bible begins with 'In the beginning was the Word'?
(a) The Gospel of Matthew (b) The Gospel of John (c) The Gospel of Luke

Answers: 1) b; 2) b; 3) c; 4) a; 5) a; 6) b; 7) c; 8) b; 9) b; 10) a; 11) c; 12) c; 13) b; 14) a; 15) c; 16) b; 17) a; 18) b; 19) c; 20) b.

Christmas Drink

A woman walks into a bar and asks for a double entendre.....
So the barman gives her one.



TOOWOOMBA GATHERING

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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 15 December 2013
- TIME:** 11.30am for 12 Noon
- WHERE:** Dublin Docks Tavern, Harbour Town Shopping, Harbour Town Drive, Biggera Waters. Car parking is available.
- WHAT WILL IT COST?** There is a wide and varied menu.
- 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?** From Brisbane Road turn into Oxley Drive (Hope Island Road), then from there left into Harbour Town Drive. Venue is on the right. UBD reference, Gold Coast map18, N 15
- RSVP** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 6 December 2013**

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How would you fire Santa?
Give him the sack...

If Santa rode a motorcycle, what kind would it be?
A Holly Davidson.