



Messages

Myasthenia Gravis Association of Queensland

APRIL 2016



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Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

G'day all,

The MGAQ still does not have a Treasurer, and time is fast running out before the spectre of the Association 'folding' arrives.

The MGAQ functions as a result of the efforts of a host of people, both those who suffer from MG and those who don't, giving of their time, experience and knowledge totally in a volunteer capacity.

These people comprise the Management Committee, the Regional Coordinators and the newsletter Editor. Additionally, the families of these people offer various levels of assistance and support. For example, the grandchildren of a committee member often assist with the printing and distribution of the monthly newsletter, and a daughter of another committee member has kindly agreed to take on the day-to-day bookkeeping functions of the Treasurer's position.

It is this level of selflessness by so many people, all with the end-purpose of supporting sufferers of MG and their families, which makes me so exasperated that there is not one member (or a family member or friend) who is willing and able to step forward and accept the position of Treasurer of the Association now that the day-to-day tasks have been effectively 'outsourced' to a volunteer.

Anyone who is interested in putting their hand up for the Treasurer's position, please, pretty please, contact Acting Treasurer, Susan White, or myself. Once again I remind our members - No Treasurer means No MGAQ.

Finally I wish to remind those members who are prepared to have their contact details on the revised Chat List to please advise via email to info@mgaq.org.au, or telephone Freecall 1800 802 568 or by letter, of their Full Name (Surname will not be listed), contact phone number and location, i.e. Suburb or town name. It would be appreciated if this information could be forwarded by 30 April 2016. Only those members who respond to this request will be placed on the new Chat List.

New members since 1 July 2015 need not respond to this request unless their information has changed since they completed the Application for Membership form.

Cheers
Graeme

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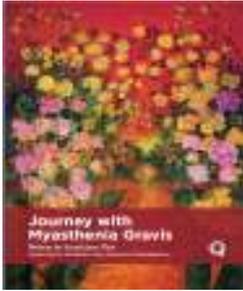
Ausenco

OBITUARY

It is with regret that we advise of the recent passing of Mr Bill Bennett, aged in his 90's. Bill and his late wife, Pearl, played a pivotal role in the formation of the MGAQ and were foundation members. Pearl was awarded Life Membership in appreciation of her efforts on behalf of sufferers of myasthenia gravis. Both before and after Pearl's passing, Bill maintained an active interest in the MGAQ and often offered contributions to the newsletter.

The President and members of the MGAQ wish to extend their condolences to the family of Bill on their loss.

"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER



Raising awareness of Myasthenia is as important as always and every opportunity to do so should be considered. The book is such a great tool for demonstrating the uniqueness of each journey with the condition and for bringing support to those affected as well as their families. Thank you to all those who read and share this book.

Contact the Association on 1800 802 568 or email at info@mgaq.org.au to arrange for your copy to be sent out.



Myasthenia
Alliance Australia

MYASTHENIA ALLIANCE AUSTRALIA

The next meeting of the Alliance Committee is scheduled for April 18th when the following items will be explored further.

A 2018 Conference is on the agenda. Conversation with internationally located Associations will commence with a view towards collaborative ideas being explored.

Dr. Stephen Reddel and Dr. Katherine Buzzard spoke at the 2015 Conference about a data base for Neuro-immunological Patients (eNID). This project is progressing well. Dr Reddel is to present information at an International Conference in Glasgow this year.

"MG Awareness Month" in June! Do think about how you can spread the word to raise awareness of this rare disease? This is a month to acknowledge yourself and the challenges you face. Perhaps just meeting up for coffee with friends and family would be a treat.

Follow the work of the Alliance by registering at the website

www.myastheniaallianceaustralia.com.au.

RAISING AWARENESS OF MYASTHENIA GRAVIS!

Work by the publicity agent who was engaged by the Association has continued with further excellent results occurring this month. Perhaps you have noticed the article in the Townsville Sun Newspaper on Sunday 22 March 2016 featuring Carol Buchanan, the Association's Secretary. We thank Carol for participating in this interview and for her passion to support others with this rare condition. Follow the links to read other recently published articles by our members.

Mackay (Bill Harris): <http://www.ruralweekly.com.au/news/little-things-in-life-a-help/2926936/>

Mackay (Ron Aitcheson): <http://www.dailymercury.com.au/news/alarmed-by-odd--symptoms/2945751/>

Gladstone (Garth McClure): <http://www.gladstoneobserver.com.au/news/mcclure-finds-the-cure-for-support/2939929/>

ORPHANET JOURNAL OF RARE DISEASES

The MGAQ was delighted to participate in a research paper entitled "The Involvement of Patient Organisations in Rare Disease Research: a mixed methods study in Australia". It was published by Deirdre Pinto, Dominique Martin and Richard Chenhall through the University of Melbourne. It is an interesting paper which highlights the value of organisations such as this in initiating and supporting research into rare diseases. It discusses how 'patient communities influence the directions, practices and cultures of biomedical science'. It supported the importance of data registries such as is occurring with the MG Survey run in conjunction with the RBWH and University of Queensland. It confirmed that the majority of organisations are indeed small volunteer run groups such as MGAQ and that these groups do have a significant influence although there are significant challenges for these organisations. The paper re-iterated the importance of policy support at a government level and the need for patient registries and bio-banks. Unification amongst the Support Organisations was suggested as an advantageous progression. For the full article please go to www.ojrd.com/content/11/1/2

It was interesting to note that Sussan Ley, Federal Health Minister, this month initiated conversation in regard to policy supportive of people with chronic conditions

If you, or a family member, or a friend, would like to be involved in any aspect of the work undertaken by the Association do make contact on 1800 802 568 or info@mgaq.org.au as we would be delighted to discuss options with you.



Around Queensland

News from Mackay: The next lunch get together will be held at the Boomerang Hotel/motel on Sunday 24th April. For more information, Contact Bill Harris – PH: 49541221

News from Cairns: The next get together is on Saturday 18th June at the Cairns RSL Club, Esplanade commencing at 11.00am. For more information, contact Donna Formosa – PH: 0414397462. All Welcome.

News from Townsville: Our next lunch get together is at The Avenues Hotel, Kirwan, Townsville at 12 noon on Saturday 30th April. For more information, contact Daphne Clay – PH: 0400 778 637 or Email: daphclay@gmail.com

We welcome the following new members:-

David – Bongaree, Qld
Leslie & Valerie – Kilcoy, Qld
Jill – Maddington, WA

I started out with nothing, and I still have most of it.

Money talks ...but all mine ever says is good-bye.

I'm great at multitasking. I can waste time, be unproductive, and procrastinate all at once.

MEMBERS' FORUM

Trevor writes...

"DON'T FORGET ". A Recent Experience - A Warning Not Quite In Time

Although I did know to tell the doctor and dentists, that I have Myasthenia Gravis, I was recently booked in for a colonoscopy at our local Hospital where I normally have them done. When I went in for my pre-op chat, the doctor became very nervous which was a little disturbing.

Then he apologised and said I can't have it at the local hospital, because I had Myasthenia Gravis I need it to be done in a hospital with an Intensive Care Unit. Then I realised why he was nervous. He was the anaesthetist who did the anaesthetic last time, which was just after I had been diagnosed with MG. It seems he wasn't told or didn't read the paperwork. I remember having a long discussion with the pre-op doctor at that time and the assistant anaesthetist as I was being wheeled in for the procedure. " Oops "

This time I was done at a larger hospital and the outcome went well with no problems, although I was a little weaker than normal for a few days after the Op. Also, I had a few dizzy spells for a day or so. The procedure came back negative, all clear for another five years. This also explained why I was weaker than I had been after the previous procedure, four years ago.

My recent dental appointment though, was a different kettle of fish. The dentist (who was new to the surgery), actually knew all about Myasthenia Gravis.

P.S. Don't know about you Mob, but I'm glad the weather is cooling down.

Do you have MuSk MG? One of our members has recently been diagnosed with the same condition and is wanting to make contact with others. Please contact MGAQ Support Line on 1800802568

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.

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.

VICTORIAN SUPPORT GROUP

An Incorporated Association has now been formed in Victoria. This is very exciting news and we hope that Victorians will get behind the group and help it to be strong. It is early days and the spokesperson has indicated that it is 'low key' at present. Small gatherings have been organised and a website is available for contact. Please go to www.mygravis.org.au for more information.

As Harry S Truman once said 'Give me a one-handed economist. All my economists say is 'On the one hand....on the other hand'

The following articles were published in the Summer 2015 edition of myaware news the newsletter of myaware, the UK support organisation for persons with MG:

MY FIRST HALF MARATHON

In 2006, at the age of 25, I began to feel that something wasn't quite right. I noticed that I sometimes couldn't take a sip from a cup and my smile was intermittently "wonky". It took neurologists six months to diagnose Myasthenia Gravis and two very long years later I had a thymectomy.

In 2008, after my operation, my MG was at its worst; it had progressed from affecting the muscles in my face to impeding my speech, blurring my vision and exhausting my arms and legs. It was indescribably frustrating. I could no longer work and struggled to control the never-ending symptoms. I set 2am and 6am alarm calls to take Mestinon so I would be strong enough to take my morning medication. In a moment of defiance I set a seemingly unrealistic goal "if I ever get better, I'll run a marathon."

At the end of 2008, I gradually turned the corner and began to slowly get my normal life back. I have since tested my condition with full time work, property renovation, relocation, marriage(!), two (healthy) pregnancies and full time motherhood. I now manage my MG, to the extent that, in May 2015, I went exactly half way to achieving my goal and ran my first half marathon – raising money for myaware, of course.

If you want to know more about my recovery or just need someone to talk to, you can email me at hope_sarah@hotmail.com

MYASTHENIA IS NOT THE SAME FOR EVERYONE

I first started to notice I was having double vision, but being someone not wanting to waste the doctor's time, I put it down to tired eyes. However as the double vision became more of a problem, and I was due an eye test, I visited my local opticians. Fortunately the optometrist that checked my eyes thought there was a more serious problem and referred me to the eye clinic at the local hospital.

My good fortune continued at the clinic as the consultant who checked my eyes decided after consulting with his senior colleague that it was not an eye problem but could be MG. They raised an internal request for me to see the neurologist.

It was at this point that I had to stop driving and inform the DVLA. This was one of the frustrating points as it was a lengthy period after my condition improved before the DVLA made the decision that I could have my licence back.

I received an appointment from the neurology department about three weeks later and at this consultation I was diagnosed with Ocular MG and prescribed with Pyridostigmine and other associated medication to counter the possible side effects.

I was on the medication for about three weeks when the MG moved to my neck. This is when I had the odd looks as I could not keep my neck upright. However, shortly after this the Pyridostigmine started to take effect and my symptoms disappeared.

Over the next year I reduced the dosage of Pyridostigmine and moved onto Azathioprine. I was eventually able to stop the Pyridostigmine completely and now take a daily dose of 150mg of Azathioprine. All signs of MG have disappeared and I am living a normal life except for a 3 monthly blood test.

I am sending this as I hope, it will give those newly diagnosed with MG the knowledge that it is not the same for everyone.

Derek McCalden

A Canadian psychologist is selling a video that teaches you how to test your dog's IQ. Here's how it works: If you spend \$12.99 for the video, your dog is smarter than you - Jay Leno

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are some questions for you to try. (Answers are at bottom of this page)

1. Mt Ossa is the highest mountain in which Australian state or territory?
2. What is the capital of the USA state of Maine?
3. Which artist had a 'Blue Period' and a 'Rose Period'?
4. What is the study of disease called?
5. Which Caribbean island is also the name of the pirate ship in 'Treasure Island'?
6. Nessiteras rhombopteryx is the scientific name for what?
7. Which well known ten letter word translated means 'mother city'?
8. In which port city was Christopher Columbus born?
9. What is the iron-containing protein called that gives blood its colour?
10. What is the scientific antonym for nocturnal? (seven letters)?
11. Which 15th century Italian artist's name means 'little barrel'?
12. Which country takes its name from a plant that was once the source for a valuable red dye?
13. The 17th century English pilot John Blackthorne is the central character in which best-selling novel?
14. Until 1911, Chinese males had to wear what as a symbol of submission?
15. What is Harry Potter's favourite kind of beer?
16. What is the vast lowland plains in Argentina called?
17. Capt. Quint meets a nasty end in which film?
18. Beluga, Ossetra, Sevruga and Sterlet are the four main types of what?
19. Which American physicist is known as 'the father of the atom bomb'?
20. Alphabetically-speaking, what is the last element?

Answers: 1) Queensland; 2) Augusta; 3) Picasso; 4) Pathology; 5) Hispaniola; 6) Nessie, the Loch Ness monster; 7) Metropolis; 8) Genoa; 9) Haemoglobin 10) Diurnal; 11) Sando Botticelli; 12) Brazil (brazilwood tree); 13) Shogun; 14) Pigtails; 15) Butterbeer; 16) The Pampas; 17) Jaws; 18) Caviar; 19) Robert Oppenheimer; 20) Zirconium.

Where there's a will, there's a relative – *Ricky Gervais*

Education is what remains after one has forgotten everything he learned in school – *Albert Einstein*



“Closed Facebook Group” vs “Open Facebook Page”

Many people ask what the difference is between the two MGAQ Facebook Pages.

MGAQ Discussion Forum is a “Closed Facebook Group” which allows like-minded people to communicate between each other in a safe forum. New members need to JOIN and then be approved by Admin before they can join the conversation. Only members who also belong to the group can see the posts or chats within it. This is a wonderful forum to share your MG Journey and chat to others on their MG Journey. To join:-
<https://www.facebook.com/groups/mgqld/>

The MGAQ Facebook Page is an “Open Facebook Page.” The difference is that this page is Public and can generally be seen by anyone on Facebook. The Facebook page allows the MGAQ to communicate broadly with people who “Like” the page. When the MGAQ publish a post or an announcement it appears in the newsfeed of people who “like” the page. To spread the awareness of MG we need as many people as possible to “Like” the page. Help us to achieve this by visiting the MGAQ Facebook Page and click “Like” at
<https://www.facebook.com/mgqld/>

SHIRLEY’S RECIPE

Crustless Spinach & Ricotta/Cottage Cheese Slice

Ingredients:

4 eggs lightly beaten
 ½ cup self raising flour
 ½ cup bread crumbs
 2 x 250g packets frozen spinach (thawed and well drained)
 500g tub Ricotta or Cottage Cheese
 1 onion finely chopped
 1 tbsp minced garlic
 1 tsp dried herbs
 1 cup grated tasty cheese
 6 cherry tomatoes (halved)

Directions:

1. Whisk the eggs with flour in a large bowl until smooth.
2. Add remaining ingredients, except tomatoes.
3. Season with salt and pepper and mix well.
4. Pour mixture into a lightly greased 20cm x 30cm rectangular dish (oven proof)
5. Top with halved tomatoes.
6. Bake in 180C pre-heated oven for 40-50 mins or until set and lightly browned,
7. Stand 5-10 mins before cutting.
8. Serve with salad
9. Serves 6— 8 people

I'd like to live like a poor man - only with lots of money – Pablo Picasso
 How come you never see a headline which says ‘Psychic wins Lottery?’ – Jay Leno

MID-YEAR FUNCTION

- WHEN:** Sunday 12 June 2016 commencing at 10:00am for 10:30am
- WHERE:** Southern Cross Sports Club, corner Klumpp and Logan Roads, Mt.Gravatt (vehicular entrance is from Klumpp Rd). Lunch is available at the venue with a varied and reasonably priced menu.
- GUEST SPEAKER:** Neuro ophthalmologist, Dr. Anthony Pane
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier
- HOW DO I GET THERE?** UBD Map 201 Reference D7.
- RSVP:** 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 6 June 2016.

THE ASSOCIATION'S REGIONAL CO-ORDINATORS WILL BE ATTENDING THIS FUNCTION. WE HOPE YOU WILL TAKE THIS OPPORTUNITY TO MEET THEM AND HAVE A CHAT

PLEASE NOTE:

THE MYASTHENIA AUSTRALIA ALLIANCE HAS ASSIGNED JUNE AS AUSTRALIA MYASTHENIA GRAVIS AWARENESS MONTH

EXPRESSION OF INTEREST – Due to our wonderful Editor moving to another State, MGAQ Management Committee is keen to hear from members who may be interested to volunteer as the Newsletter (*MessaGes*) Editor. Please email info@mgaq.org.au

HINTS AND TIPS

Keep a small pill container with extra tablets in your handbag, office desk or glove box in the car

Before google, there were librarians. Here are some queries posed to the poor, suffering staff of public libraries:

- A woman wanted “inspirational material on grass and lawns.”
 - “Who built the English Channel?”
 - “Is there a full moon every night in Acapulco?”
- “Music suitable for a doll wedding to take place between a Shirley Temple doll and a teddy bear.”
- “Can the New York Public Library recommend a good forger?”