MessaGes

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

JUNE 2019

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

June is Myasthenia Gravis Awareness month. We all know that everyone with MG presents differently in relation to their symptoms and treatment so it is important that we are all our own advocates in relation to this. In the past, many guest speakers have reminded us of the importance of this and each and everyone's management plan should be as comprehensive as you can make it. Our guest speaker, Tracey Shaw from Carers Queensland, spoke about one of the group upon which many of us rely and that is our carers. I am sure that both sufferers and the people who care for them gained a lot of information from this talk.

As we approach the end of the financial year it is time for members to renew for 2019-2020. As a management committee we are trying to reach as many people with Myasthenia and their families as possible. However, we are finding that a considerable number of people are accessing website information but not taking up financial membership. The benefits of being a financial member are considerable and we ask that everyone think about becoming or remaining financial so that our association can continue to do all of the good work that is happening. Fees for all the different types of membership remain the same as they were last year.

Do not forget the wonderful MAA conference that is being held in Brisbane on 3 August. As we have previously mentioned, the MAA cannot guarantee that there will be conferences into the future as we rely heavily on the goodwill of some very highly respected neurologists from across Australia. By having the conference in Brisbane we hope that many Queenslanders will take advantage of this opportunity. A list of guest speakers is in this newsletter. There will also be two workshop groups which will cover a range of discussion topics. We ask that all members and supporters take the time to consider this amazing opportunity.

Register online at
www.myastheniaallianceaustralia.com.au/myasthenia-gravis-conference/

For the past year the management committee have been working on updating our Constitution and By Laws. We have been very lucky to have the services of a lawyer who specialises in this area plus a very knowledgeable committee member leading us through the process. Hopefully, we will be able to present and have the new constitution accepted at our AGM in September.

It is with regret that I inform you of the death of Bill Harris who was our Mackay regional co-ordinator for many, many years. Our heartfelt condolences go to his wife, Muriel, and the family.

Thanks, Carol

Supported by

Queensland Government

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS

Exciting News!

The MAA website has been upgraded and it is fantastic.

Do check it out by visiting
www.myastheniaallianceaustralia.com.au

This wonderful work has been gifted to the Alliance by Anna Wilen Clarke. A graphic designer by trade and a generous supporter of the Alliance she saw the great need and responded to the challenge. Work progressed quickly and the new site is full of great features. Our most sincere appreciation is extended to Anna. Her skill and generosity is very much appreciated. Her practical offer of support for others is keenly felt.

Most exciting is that Conference Registration and Payment can be made on-line.

It is now also very easy to register for the News and to follow the work of the Alliance. If you have not yet done so, please consider staying informed and allowing the MAA to help you as you help us.

Preparations for the Conference are progressing well. Please see the included and updated Preliminary Program. Nicole Millis from Rare Voices will speak and an interesting selection of presenters is gathering to provide a range of choices for the break out sessions. Do note, that for organisational purposes, **a CLOSING DATE for Conference Registrations has been set for Friday, 12 July.** With ALL the organisers being volunteers and spread across much of Australia, this time will be needed so please, do not miss out.

Susan White

Follow the work of the Alliance by registering at the website www.myastheniaallianceaustralia.com.au

Preliminary Conference Program

2019 MAA Myasthenia Gravis Conference

Please note - this program is still being developed and additional content will be added.

- **Dr. Stefan Blum**
  Overview of Myasthenia Gravis and Therapies.
- **Assoc. Prof. Stephen Reddel**
  Rationale and Progress on the eNID Project.
  Risks of Immunosuppression.
- **Prof. Pam McCombe**
  IVIg for Myasthenia - new IVIg Guidelines.
- **Dr James Morton** (Haematologist)
  Advanced Therapy Treatment including Plasma Exchange.
- **Dr Andrew Swayne**
  Research in MG - where are we, where do we need to go?
- **Dr Fiona Chan**
  Rituximab as a treatment for MG.
- **Nicole Millis (CEO Rare Voices)**
  Advocacy and Rare Disease.
- **Discussion and Question Time** with
  Drs Reddel, McCombe, Blum and Morton.
  Session 1: MG and its Treatments.
  Session 2: Research in MG.
- **Choose your Own Small Group Sessions!**
  At least 10 topics - choose two.

Registrations for the Conference close 12 July - Places filling steadily.

Myasthenia Gravis Association of Queensland

Mid-Year Function, June 9, 2019

JUNE AWARENESS FUNCTION

To celebrate Awareness Month the Committee again hosted a Sunday event allowing people with Myasthenia to gather together and to share. Well attended by regulars and by first timers, we gave hugs, wore teal ribbons, won lucky door prizes, shared a meal and conver-sation and came away much better informed.

Tracey Shaw from Carers Qld, spoke with kindness as she discussed the importance of supporting the people who support those with Myasthenia. It is estimated that 2.7 mil-lion Australians are unpaid carers. This care can be given at many levels but it may bring emotions of grief and loss, it may cause stress and burn out, or foster a sense of isolation and possibly even involve issues around fam-ily conflict. Carers are important advocates for sufferers. Carers need support too and this is the role of this organisation. **In Qld call 1800 052 222 to learn more.**

- **Tracey Shaw** (below).

Tracey focused on the importance of prepar-ing for the future and explained how the NDISis there to support people to live well once permanent disability (physical or mental) is established. Support is life long provided the application process is commenced prior to 65. Applications are evaluated very much on an individual basis. It is not condition based. Using a trained provider in making an application is recommended. After 65, care is provided through "My Age Care" and relies on QCAT assessments facilitated through a GP. Other supporting legal documentation was also dis-cussed. The talk was recorded, members are encouraged to view the DVD or listen to the talk on a CD player.

Tahlia, whose Physio-therapy Research proj-ect is highlighted on **Page 4** of this newslet-ter came along to ex-plain more about this important project and how it can be easy for us to help!

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

Physical activity, quality of life, fatigue and function in myasthenia gravis

Researchers at the School of Health and Rehabilitation Sciences (SHRS) at the University of Queensland are seeking individuals with myasthenia gravis to participate in a study investigating levels of physical activity and sitting time and their relationship with fatigue, quality of life and functional mobility. There is a substantial amount of evidence indicating that physical activity and sitting time have a significant impact on a broad range of health and wellbeing outcomes, however there is currently limited research in this area in people with MG. This study will contribute to our understanding of activity in individuals with MG and what factors might contribute to and impact on physical activity participation.

Aim: To investigate levels of physical activity and sitting time in individuals with myasthenia gravis and explore its relationship with fatigue, quality of life and functional mobility.

Type of volunteers needed:

- Individuals with myasthenia gravis aged 18 – 70 years
- Individuals able to mobilise independently with or without a walking aid (excluding wheelchairs)
- Stable symptoms for the last four weeks prior to commencing the study (can be currently receiving treatment)

What is involved?

- Completion of an online questionnaire
- 1 hour assessment of walking and mobility (at the UQ campus in St Lucia, or at a suitable clinical location convenient to you)
- Wearing two small activity monitors for 7 days during normal everyday life
- An interview exploring your views on your own physical activity and any potential barriers and facilitators to participation

How active are you?

We are seeking people with myasthenia gravis (MG) to help us better understand the impact of MG on levels of physical activity and sitting time.

Participation involves completing an online survey and wearing two small, lightweight activity monitors for seven consecutive days as you go about your normal day to day life, and then answering some questions about your activity levels.

For more information and to access the survey, scan the QR code with your device or go to:

www.surveymonkey.com/r/MG2019SURVEY

For more information on this study, please contact:

Tahlia Alsop (Honours student) t.alsop@uq.edu.au
Dr Sjaan Gomersall (Principal advisor) s.gomersall1@uq.edu.au or 3365 4528

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.

* * *

WHO HAS MYASTHENIA? *It is always a tricky thing to pick. The following story has come our way via contact with the Information Officer through the MGAQ website and the storyteller is an amazing Queenslander! Gresham writes to give you inspiration, hope and encouragement. His journey with Myasthenia does still continue but read on to learn what he has been able to achieve after a rocky beginning. Also, he has a request for information.*

If you can help, please respond via info@mgaq.org.au or by calling 1800 802 568.

Gresham writes,

I am these days an old fart – 65, and have lived in Cairns for the last thirty years. The MG developed whilst I was working in New Zealand; global symptoms with the usual range of problems.

Significant Dysarthria, Respiratory weakness, Dysphagia, Diplopia, marked fatigue and general muscle weakness. I would often choke on both liquids and solids, and needed a stool in the shower to take the needed frequent rests, - nothing unusual.

Symptoms controlled up to a point on biggish doses of mestinon. A myasthenic crisis in the UK led to hospitalisation and thymectomy in 1983.

This basically resulted in a reasonable remission, although I still experience a range of symptoms when fatigued or stressed.

I was a little reluctant to accept the advice at the time advocating limited work and activity . With some challenges along the way, there is no doubt that I function much better when reasonably fit and active, and tend to be more symptomatic when I let the activity slide for a bit.

I have tended to follow my own exercise regimes, although interestingly my wife is a Pilates instructor.

About five years ago, I retired from an 80 hour a week job that commenced before the MG ,

Currently I ‘work' as a volunteer guide taking groups along the Kokoda Track, so no option to select times of day / distance walked or rest breaks, as the basic requirements to complete each day require a moderately controlled timeline, and back this up with a range of other activities that are based around three or so hours per day of moderately vigorous outdoor activity.

When at home, my spare time is taken up with my garden, and helping some friends with theirs, to a total of about eight acres, which in the tropics takes a bit of time.

I am interested to know if any others with Myasthenia have walked the Kokoda track or have found a regular exercise regime to be helpful for them.

Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.

Hi my name is Fergus, I was diagnosed with ocular Myasthenia Gravis (MG) almost 4 years ago. I have muscle fatigue most days and constant double vision. Life has changed a lot since my diagnosis but, I've learned to adapt to my new life and to accept and embrace the things I can't change. While I may have MG I won't let it define me.

Last year, I set myself the challenge of competing in the Brisbane 10km which I completed. It was an accomplishment to say the least.

But, this year I thought I'd go one step further and see if I could complete the Brisbane half marathon. I trained in the lead up to it but I wasn't sure I could pull it off. On the 2nd June 2019 I completed my first half marathon with my fiancée by my side. We ran it together and I believe we encouraged each other to cross the finish line. Also, all the supporters along the way really helped to motivate us and keep us going.

The sense of achievement I feel is immense. But, it's safe to say I won't be aiming for the full marathon next year haha.

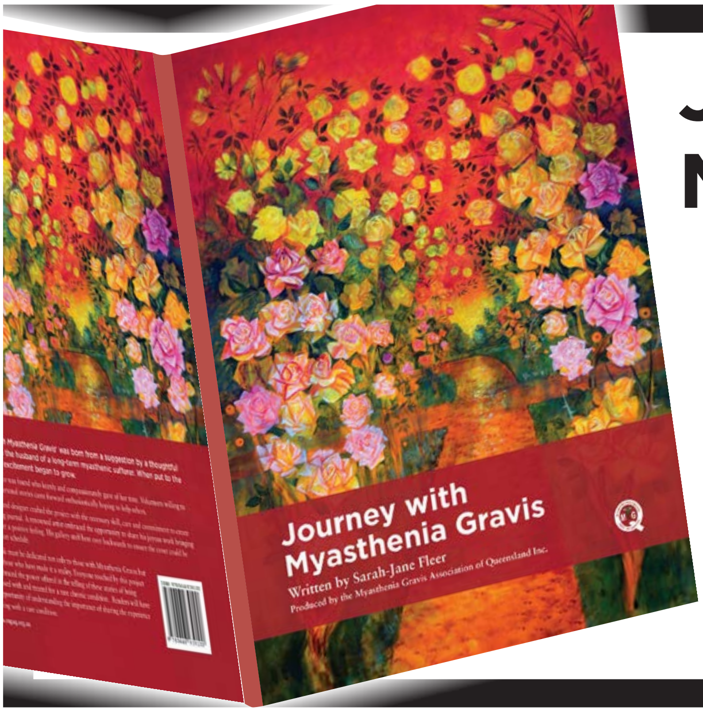
Fergus

MGAQ Inc. ANNUAL GENERAL MEETING

SUNDAY, 15 SEPTEMBER, 2019

Aspley Hornets Football Club, 50 Graham Road, Carseldine

More details in July's edition of MessaGes



Journey with Myasthenia Gravis

A book by Sarah-Jane Fleer

Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition.

It aims to support those affected as well as their families and friends.

If you would like to purchase a copy,

Contact the Association
Freecall: 1800 802 568
Email: info@mgaq.org.au
Website: www.mgaq.org.au

MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2019/2020 are due.

The envelope in which your newsletter is enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

If you receive the newsletter by email and are unsure whether or not you are currently financial, **please phone our 1800 802 568 freecall number or email treasurer@mgaq.org.au to enquire.**

The majority of members will have 6/19 which tells you (and us) that you are financial to 30 June 2019. Others may show 6/20 or even 6/21 to indicate they have saved time and postage by paying in advance.

If you are unfinancial, **please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive all resources.**

We are also giving you the option of paying your subscription directly into our bank account.

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE
www.mgaq.org.au/membership-application-form and select **Membership Renewal**

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 and Initials

If you use the direct deposit method, it would help if you could email us at **treasurer@mgaq.org.au** to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.

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 $20**

(or) Category E – Supporter $20

ADDRESS ____

____

And for ____ **Category D – Carer $10**

ADDRESS ____

____

Mobile _________________________ Email _______________________________________

NEWS FROM AROUND QUEENSLAND

News from Cairns

Our next gathering will be on **Saturday, 22 June at the Cairns RSL Club, Esplanade at 11.00am**.

Guest Speaker: FNQ Allied Health Services.

Any visitors to Cairns are welcome to join us. For more information, please call Donna on 0414 397 462,

News from Townsville

The Townsville MG group's next lunch is on **Saturday, 15 June, 2019, 12 noon at The Avenues Hotel.** For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

News from Gladstone-Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 973 7983.

News from the Sunshine Coast

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

News from the Gold Coast

The next MG meeting will be on **Saturday, 29 June in Southport Sharks Club at 10.00am**. I look forward to seeing everyone there.

For more information please call Nader, Gold Coast Co-ordinator on 0415 834 401.

News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.

Ipswich	**Sunday, 12 July at 2pm; Friday, 25 October at 10am** ***Queens Park Café, 10A Merle Finimore Avenue***
Burpengary	**Sunday, 11 August at 2pm; Sunday, 10 November at 2pm** ***The Coffee Club, 164-166 Station Road***
Cleveland	**Sunday, 22 September at 2pm** ***Fiction Bar, 152 Shore Street West, Raby Bay***
Nundah	**Sunday, 13 October at 3pm** ***The Royal Hotel, 1259 Sandgate Road***

For more information, Contact Anita on 0414 588 312

WHERE IN QUEENSLAND?
Let us know where you think it is:

May Edition: Cape York
Send to: info@mgaq.org.au or post to MGAQ, PO Box 16, Mt Gravatt, Qld, 4122

Welcome to our new members

Dennis S,
Edmonton
QLD

David U,
Melbourne
VIC

Fergus R,
Bracken Ridge
QLD

what's comingup

What's On	When Is It	Where Is It?
MAA MYASTHENIA GRAVIS CONFERENCE 2019	**SATURDAY 3 AUGUST, 2019**	**TRI Conference Facility within the Princess Alexandra Hospital Woolloongabba, Brisbane**
MGAQ INC ANNUAL GENERAL MEETING	**SUNDAY 15 SEPTEMBER, 2019**	**Aspley Hornets Football Club, 50 Graham Road, Carseldine**