



Messages

Myasthenia Gravis Association of Queensland

APRIL 2015



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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,

The weather looks like it going to start and get cooler so we are all hoping to see this change shortly as our Myasthenia Gravis can cope much better with these cooler months. I feel sorry for the members who live in North Queensland as you must struggle through the summer months.

The Alliance committee is busy planning for the National Conference to be held in Sydney on 20 June 2015. The registrations period has now been extended as a few places are still available. We have received a very good response to the conference.

The committee has started working on plans for a transition to operating post Queensland Health funding. I would like to take this opportunity to thank everyone who have sent in their Survey as the committee put a lot of effort to get this out to our members and it is nice to see that so many have responded back it makes us feel as though we are doing what you would like us to do for the Association.

The committee is only a small band of volunteers and we are making decisions on your behalf on how we think the Associations should be run so it is great that we are getting all this feedback with your views and comments.

We are still looking for information for our Newsletter so please think about putting pen to paper and telling your story or if you are a carer you could do living with and caring for someone with MG.

Take care,
Anita

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Department of Health

PROJECT UPDATE

MYASTHENIA ALLIANCE AUSTRALIA

Remember - To stay abreast of the work of the Alliance, visit the website www.myastheniaallianceaustralia.com.au and register for updates. Updates will only be posted when there is an issue of importance to all with Myasthenia. It is not planned to issue regular newsletters from this site. The web page will have current events listed.

ALLIANCE NATIONAL CONFERENCE

The Myasthenia Alliance Australia Committee is busy preparing for the first National Conference for Myasthenics, their supporters/carers and for health professionals interested in this rare condition. It will take place on June 20, 2015 at The Brain and Mind Research facility Camperdown, Sydney.

It is a full day programme with an interesting range of speakers and time to network with others travelling the same journey. Registration is now open and there are some spaces still available. Capacity is fixed. Please go to the website to request a registration form.

The Committee sincerely and gratefully acknowledge the generous support offered by Dr. Stephen Reddel in making this event possible. We thank all the Speakers who give so freely of their precious time. Details regarding some of the speakers can be found below.

Dr. Katherine Buzzard will speak about "Advances in Treatment of the Myasthenias.

Dr Stefan Blum will give an "MG Survey Update" plus discuss "Research Into the Future"

Mrs Megan Fookes will divulge 'Why the Rare Voices Organization is Important to You'

"Dr Katherine Buzzard, BSc (hons) PhD MBBS FRACP, is a consultant neurologist at Eastern Health and Royal Melbourne Hospital, and holds an academic appointment at the Eastern Clinical School, Monash University. She trained in neurology at Royal Melbourne Hospital and the Alfred Hospital, before being awarded the ANZAN overseas fellowship to complete her training at the National Hospital for Neurology and Neurosurgery, Queen Square London. She has completed fellowships in multiple sclerosis and neuroimmunology, the latter with Assoc. Professor Stephen Reddel at Concord Hospital in Sydney, during which time she published on the treatment of patients with medically refractory myasthenia gravis. She holds a PhD in cancer biology from the University of Melbourne. Dr Buzzard has particular research interests in inflammatory and autoimmune neurological diseases and is currently working on developing a global registry of patients with neuroimmunological diseases, including myasthenia gravis."

Dr Blum is a consultant neurologist in the Princess Alexandra Hospital and Mater Hospital, Brisbane. He has a research and clinical interest in neuroimmunology, including myasthenia gravis and multiple sclerosis. He did his medical training at the University of Heidelberg, Germany and neurology training in Germany, Princess Alexandra Hospital and Royal Brisbane and Women's Hospital, Brisbane. He recently completed a PhD in immunogenetics of Guillain-Barre Syndrome. He is involved in a neuroimmunology clinic at PAH where numerous MG patients attend, as well as an ongoing fruitful collaboration with MGAQ

Mrs Megan Fookes co-founded 'Rare Voices Australia' in 2012 and serves as Executive Director. In 2013 Megan published the 'Australian Experience of Living with a Rare Disease' – a collection of personal stories of people living with a rare disease launched at the 2013 Rare Disease Day

Parliamentary event and officially recognised as Australia's National Alliance for rare disease by the Federal Standing Health Committee.

SURVEY UPDATE

Dr. Stefan Blum has confirmed that the Myasthenia Survey Paper has now been accepted for publication in the Journal of Clinical Neurosciences. A review of the findings will be presented at the conference. The paper will only be available by subscription to this prestigious Journal.

The Data collection is ongoing and surveys are available by contacting MGAQ.

CHAT LIST:

You can FREECALL MGAQ from anywhere in Australia on **1800 802 568 FREE**. This phone is manned by Shirley and is a great resource for information or simply to have a person on the other end of the phone who understands. If the **1800 802 568 FREE** goes to message bank, please leave a message and Shirley will get back to you as soon as possible.

Remember your call is important to us, so please do not hang up without leaving a message.

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.

CHAT LIST –BRISBANE

QUEENSLAND REGIONAL CO-ORDINATORS

DONNA	0414 397 462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
COLLEEN	5493 6391	SUNSHINE COAST
JAN	0429 622 438	BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS
VACANT		ROCKHAMPTON
VACANT		GOLD COAST
TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	3261 7564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414 525 241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408 311 110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
DENNIS	3855 9379	GAYTHORNE

ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448 192 521	INDOOROOPIILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415 613 242	KANGAROO POINT
GEOFFREY	3355 6441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	3886 7802	NARANGBA
SUSAN	3358 1056	NEW FARM
FARINAZ	0401 715 118	NEW FARM
KEVIN	3281 9225	NEWTOWN
BILL & JITLADA	3399 7041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
TRACEY-LEE	3284 9949	REDCLIFFE
SYBIL	3219 9535	ROCHEDALE
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JAMES	0433 662 913	WYNNUM
JOHN	3633 0604	ZILLMERE
ROSALYN	0407 697 206	ZILLMERE

Please note that any member wanting to fill the Vacant Regional Co-ordinator's positions should contact Shirley on the 1800 number for more information.

MEMBERS FORUM



News from Townsville

Daphne writes,

"I have taken on the role as the coordinator of the Townsville MG group. I am retired and was diagnosed with ocular MG in 2013. I would like to thank Carol Buchanan for telling me about the group and to thank her for the work that she has put into the group. I enjoy the lunches and I look forward to being part of the MG group."

The next Townsville get-together will be on Saturday 02 May at The Avenues commencing at 12 noon. Please phone Daphne on 47733695 if you are able to attend.

News from Cairns

The Cairns group meet in the new upstairs Boardroom of the RSL Club. The next get together is on Saturday 27th June at 11.00am.

Donna Formosa – 0414 397462 or 40392148

FUTURE EVENTS.

Please note that the usual members meeting in June will be on 12 July 2015 at Southern Cross Sports Club at Mt Gravatt. The change of date is so that we can inform our members of feedback and the information that was discussed at our Conference in Sydney. Hoping you can all attend so please mark it on your calendars.

For Those Who Take Life Too Seriously
Submitted by Member

1. Save the whales. Collect the whole set.
 2. A day without sunshine is like...night.
 3. On the other hand, you have different fingers.
 4. 42.7 percent of all statistics are made up on the spot.
 5. 99 percent of lawyers give the rest a bad name.
 6. Remember, half the people you know are below average.
 7. He who laughs last thinks slowest.
 8. Depression is merely anger without enthusiasm.
 9. The early bird may get the worm, but the second mouse gets the cheese in the trap.
 10. Support bacteria. They're the only culture some people have.
 11. A clear conscience is usually the sign of a bad memory.
 12. Change is inevitable, except from vending machines.
 13. If you think nobody cares, try missing a couple of payments.
 14. How many of you believe in psycho-kinesis? Raise my hand.
 15. OK, so what's the speed of dark?
 16. When everything is coming your way, you're in the wrong lane.
 17. Hard work pays off in the future. Laziness pays off now.
 18. Everyone has a photographic memory. Some just don't have film.
 19. How much deeper would the ocean be without sponges?
 20. Eagles may soar, but weasels don't get sucked into jet engines.
 21. What happens if you get scared half to death twice?
 22. If you can't repair your brakes, make your horn louder.
 23. Why do psychics have to ask you for your name?
 24. Inside every older person is a younger person wondering what happened.
 25. Just remember - if the world didn't suck, we would all fall off.
 26. Light travels faster than sound. That is why some people appear Bright until you hear them speak.
 27. Life isn't like a box of chocolates... it's more like a jar of jalapenos. What you do today, might burn your butt tomorrow.
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“JOURNEY WITH MYASTHENIA GRAVIS” – A Book of Stories.

The Association is excited to report that the project of producing a book which recounts a range of sufferers stories, is well under way. The stories have been collected and compiled thanks to the diligence of our author . An editor has been engaged and soon the work will go to a designer in preparation for the printing process. It is planned to launch the published work at the Conference on June 20th. More details in regard to this work and it's availability to you will flow as they become available. The Association is confident that this work will bring comfort and support to sufferers and their families and friends. We also hope that Medical staff will read it with keen interest and gain some insight into a journey which begins with a diagnosis of a chronic condition known as Myasthenia Gravis.

GIVE NOW DONATIONS

The Association has registered with Give Now for online fund raising donations with the hope of people or businesses donating to our Appeal. The committee was informed of this website after some discussions with Board Connect who Queensland Health has put us in touch with so that we can actively continue to be a support group for all people with Myasthenia Gravis. Please take a look at this site and advise anyone who may be interested in donating to the Association.

<https://www.givenow.com.au/myastheniagravisassociationofqld>

MGAQ Facebook Page

If you haven't visited the MGAQ Facebook site in a while, please take the time to go back and check it out. We have updated the page to make it more interactive with our members. It's not perfect yet and therefore we would like your input. Please "post" a comment and start a discussion. "Like" the page and spread awareness of Myasthenia Gravis.



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.