



Messages

Myasthenia Gravis Association of Queensland

MARCH 2015



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Myasthenia Gravis Association of Queensland Inc

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Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

The weather has not been very kind to us as it is very hard to cope with our Myasthenia Gravis in these extreme heat wave conditions roll on the cooler weather. I hope that our members and their families who live in the Rockhampton region were not affected by the Cyclone.

Our first function of the year was at the Gold Coast, it was a success and the weather was kind to us. It was good to see some of our regular members especially the ones who drove from N.S.W and the ones from the coast region as we were able to swap many stories.

The Alliance committee is busy planning for the National Alliance Conference to be held in Sydney on 20 June 2015 with it progressing really well. Thank you to our members who have registered to attend it will be good to see you all again.

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 has returned their Survey and others still have to opportunity to send it in if by chance you have forgotten it. We will be taking notice of all your suggestions and putting them into place so that we can move forward after December 2015. A big thank you to the members who have given the Association a donation with their renewal membership.

I had the opportunity of attending a Conference put on by Board Connect in regards to finding either a company or companies to sponsor us or fund raising awareness. It was interesting as we had other organisations like ourselves there going through the same things that we are only they have paid staff and get a lot more money from Queensland Health.

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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Queensland Government

PROJECT UPDATE

SURVEY 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. More than 40 Australians have now done so and the number grows daily. 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 will close promptly by 31st March. If you are still pondering about attending, do act soon as more than half the spaces are now filled. Capacity is fixed. A Registration Form has again been included with this newsletter. Please follow the instructions listed on the 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. Dr. Katherine Buzzard will speak about "Advances in Treatment of the Myasthenias.

"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.

SURVEY UPDATE

Dr. Stefan Blum has confirmed that the Myasthenia Survey Paper has now been accepted for publication in the Journal of Clinical Neurosciences. Dr. Blum described it as an involved process with the result that the papers have been combined into a longer summary paper giving "a cross-section of the highlights of the survey". Comment will be presented at the conference.

Discussion continues in regard to bringing the paper to our members. At this point, copyright permission from the Journal Publisher allowing for the paper to be put onto the MGAQ website has not been provided.

The Data collection is ongoing. Dr. Blum remains involved with the project even though he has made some changes in regard to his working arrangements and we are informed that Professor McCombe also is committed to progressing research based around the Survey Data.

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 – QUEENSLAND REGIONAL COORDINATORS

DONNA	0414 397 462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
COLLEEN	5493 6391	SUNSHINE COAST
VACANT		GOLD COAST
JAN	0429 622 438	BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407 697 206	ZILLMERE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
NOEL	5495 2938	BELLMERE
SARA	0422 109 492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
SYDNEY	4051 6896	BUNGALOW
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
JIM	0414 241 091	BURPENGARY EAST
DAVID	4053 2291	CAIRNS
HELEN	4051 3286	CAIRNS

OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
GAIL	0407 514 241	COOROIBAH
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
MARSHA	4987 6820	EMERALD
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	4933 4281	GRACEMERE
KARLIENE	0432 431 591	NANANGO
ANGELA	0427 752 956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
CHRISTOPHER	0412 456 439	LABRADOR
KAREN	0408 153 285	LOWOOD
TERRY	5494 2470	MALENY
CAROLYN	5522 8987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
KEITH	5441 7236	COES CREEK, NAMBOUR
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411 331 258	PACIFIC PINES
JUNE	0409 636 467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
CAROL	4773 7122	TOWNSVILLE
DAPHNE	4773 3695	TOWNSVILLE
HEATHER	0538 743 234	TOWNSVILLE
LUCY	0418 879 801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
SERAFINA	4751 6415	JENSEN
ANNE	0487 305 153	TRINITY BEACH
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458 980 667	YANDINA
PERLA	4939 2724	YEPPOON
SHIRLEY	4778 7117	YABULU
IAN	4623 5169	YULEBAR

Please note that * indicates that this member is available via the VOIP Skype facility on a computer

MEMBERS FORUM

News from Townsville

A get-together of the Townsville group was held on 21 March. While some regulars could not attend because of other commitments, those who were there enjoyed the opportunity to chat with people they might not have had a chance catch up with in the past.

Carol Buchanan – Townsville Region Co-Ordinator
Ph: 4773 7122

News from Mackay

Mackay area had its first get-together for 2015 at Magpies Sporting Club on Sunday 8/2/15. All those attending had an enjoyable lunch and discussion on many subjects.

It was decided to hold our next Get together is on **Sunday 10 May 2015 at North Mackay Bowls Club, Malcomson Street, Mackay**. At this lunch, we will decide the dates and venues for get togethers from July to December 2015. All MG sufferers and Carers are invited to attend our functions. Wishing everyone a happy and safe Easter.

Bill Harris – Mackay Regional Co-Ordinator

Ph: 07 4954 1221

News from Cairns

We held our first get together for 2015 with special guest, Mr John Bal from Carer's Qld. Carer's Qld is a not for profit organisation set up to support family carers of people with disabilities, chronic illness or frail aged. They have offices throughout regional Queensland and provide services such as Carer support groups; support for the children of people with chronic illness or disabilities or free short term counselling regarding carer related issues. Our members found his presentation very interesting and didn't realise what support was available for Carers.

We have set the dates for the meetings in 2015. We have an informal get-together in the Boardroom at the Cairns RSL Club, Esplanade Cairns at 11.00am. Some people will stay on for lunch in the restaurant afterwards (at own expense).

- Saturday 18th April
- Saturday 27th June "MG Awareness Month"
- Saturday 15th August
- Saturday 17th October
- Saturday 19th December

Donna Formosa – Cairns Regional Co-Ordinator

Ph: 4039 2148 M: 0414 397 462

News from the Wide Bay Area

Wide Bay now has a co-ordinator. I would like to introduce myself. My name is Jan Powell and I am happy to accept this position. I am 69 and have had a quite mild form of MG for the last 40 years. I was diagnosed 2 years after my second child was born. For many years I struggled with the symptoms and some experimental medication (by a couple of Doctors) until I was settled on Mestimon. Over the following years the level of medication has increased, but I have always been fortunate to be able to function quite well by controlling my activities in accordance with my strength or lack of it.

What has been difficult (and I am sure everyone of you have been in this position) is the lack of

tolerance from family and friends when I get tired or suffer badly in summer especially in the hot humid times. Why am I relating this to you? Because a couple of years ago, after I had been told I had a mini stroke because I do the MG walk, and occasionally end up bumping into doors etc., you all know what I am talking about, my GP gave me a drug to prevent further strokes that negated my Mestinon and almost sent me into a myasthenia crises. My husband got onto the Myasthenia Gravis web site in desperation to find what was happening and to find a solution and what a blessing that was. To know we were not imagining my symptoms or hatred of summer heat, but that I was only having normal symptoms for my illness!

I am so grateful for the help I found and have subsequently had through the Myasthenia Gravis Association, that I am happy to be in a position to now help other fellow sufferers in my region. My phone number is 0429622438 and while my husband and I do a bit of travelling in our caravan I can usually be contacted on that number.

If anyone ever needs an ear to listen to them please do not hesitate to ring me, I am a pretty good listener.

My aim, in the future is to have a couple of get togethers a year in a town that is as central in Wide Bay as possible and to keep in contact with all you members in Wide Bay by phone or email. If I can be a help to anyone, as the Association has been a help and comfort to me then I will consider that a blessing.

Jan Powell – Wide Bay Regional Co-Ordinator
Mobile: 0429 622 438

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.



MGAQ needs your HELP

My name is Mark White and I need your help with one of MGAQ's major challenges, a challenge of assuring on-going funding for the MGAQ. The challenge I referred to is sourcing this funding.

The MGAQ needs to raise a minimum of \$24,000 on an annual basis to maintain its present level of effort in relation to Member Welfare, Advocacy and Awareness. As advised in earlier newsletters, the Queensland Health Department is highly unlikely to provide funds beyond 2015. For MGAQ to secure this \$24,000, we are in search of nominally ten philanthropic sponsors each contributing \$2,000 per year.

How can you help?

The greatest help would be if you are able to identify a company and a contact person within that company for the Association to approach. The firm is likely to be one that:

1. You or a member of your family knows well,
2. A senior person within the company who is familiar with the struggle that Myasthenia Gravis brings to a sufferer, most likely through yourself,
3. The company has the potential to donate \$2,000 per year. Note: A company with greater than 5 to 10 employees is likely to have the capacity to donate \$2k per annum. Naturally whether they can make such a donation, will depend on what other commitments they might have; and
4. A business which would value that none of its donated funds are lost in wages, cars, buildings, etc but is spent entirely on supporting the sufferers of Myasthenia Gravis.

Identifying sufficient potentially supporting donors is the first and likely greatest challenge we will face with this effort. Once you have identified a potential candidate, please either send the details through to info@mgaq.org.au or telephone through the details to 1800 802 568.

Incidentally I am, by the way, not an MG sufferer but my wife is and because I see the great value brought by MGAQ, *I believe this is a challenge we should all work to overcome to maintain a healthy, viable MGAQ.*

Please help MGAQ continue to support you!

Together we are **STRONG**



Myasthenia Alliance Australia - Conference 2015

Thank you for showing interest in attending the Myasthenia Australia Alliance’s Conference to be held at the Brain and Mind Research Institute, Sydney on Saturday, 20 June.

Please complete the registration form and send it along with your registration fee of \$70 per person to either info@mgaq.org.au or MGAQ, PO Box 1287, New Farm 4005. Any cheques should be made out to The Myasthenia Gravis Association of Qld Inc. Bank details for direct deposits are BSB 124032 and account number 10263772 and Reference to include wording ‘conf’ and your full name. Please inform us by email at info@mgaq.org.au if you have paid your registration by direct deposit so this can be cross-checked. Your successful conference registration, along with any additional information, will be confirmed by mail.

Morning tea, lunch and afternoon tea plus the conference package are included in the cost of registration.

Participant/s Name/s

Please indicate if each participant is:

Name

Myasthenic/ Carer/Supporter/Health Professional (please circle one)

Name

Myasthenic / Carer / Supporter/Health Professional (please circle one)

Address

.....Postcode

Phone Number (home)(mobile)

Email Any

Particular Dietary Requirements Any

Particular Access Requirements Any

.....

THE CLOSING DATE FOR REGISTRATIONS IS 31 MARCH