



Messages

Myasthenia Gravis Association of Queensland

September 2014



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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.

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Association of
Queensland Inc
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PRESIDENT'S REPORT

Welcome

The AGM was held this month. Our Guest Speaker, Dr Rob Henderson, gave a very informative talk about Myasthenia Gravis, the Thymus gland and also our medication. It was great to see so many new members. I hope everyone gained valuable information about the disease and will return for the next function. It was also good to see our regular members who attend each function and support the Association as we have become like a family.

Welcome to our new committee members Donna Formosa, Rosalyn Holland and Iris Suen. We hope they enjoy our meetings and look forward to their ideas for running the Association.

I would like to thank Graeme Peters for all his help with the Secretarial support and advice. His assistance will be missed at the monthly committee meetings. I would also like to thank Catherine Ormsby for her help as the editor. This is the penultimate Newsletter that she is preparing as she and Andrew are moving to Sydney in December. Thanks for your help over the last 12 months. I hope that everything works out for you in Sydney.

The committee has been advised that the WA Association voted unanimously at their AGM to dissolve the group. Despite a number of attempts they were unable to get any volunteers to become committee members. It is sad but quite common to see this happen in many volunteer groups. We would like to thank the members of the WA Association for their support and hospitality to our members over the years. They will maintain their website and our 1800 phone is available for support.

We are hoping to have our Transition plan for future funding until December 2015 submitted to Queensland Health this week.

The next function is the Christmas Party on 14 December 2014 - venue to be advised. Looking forward to seeing you at the function.

Take care

Anita

Supported by



PROJECT UPDATE

SURVEY UPDATE

How delightful it is to report that an author for the booklet of 'patient stories' has been found and the first interviews have been arranged. It is hoped to complete this project by mid next year allowing the Association to provide this resource as an additional item supporting the current information booklet. Ideally, the Association will be in a position to provide all financial members with a complimentary copy of the booklet.

SURVEY REMINDER

Surveys continue to be distributed as contact is made with additional sufferers. However, the number of surveys returned is not keeping pace. Please be assured that whilst the first data review has been completed, it is still very important that surveys continue to be received and that the data base grows. If you have a survey and it has not been completed, please, can we ask that you complete it and return it to the Doctors. Your GP can complete the medical form if this makes it easier. Should you have reservation about aspects of the survey or need a new copy, do use the Freecall number on 1800 802 568 to discuss your queries or simply complete only those questions you are comfortable with. If you know someone who has not yet received a survey, ask them to make contact with the Association explaining the importance of this unique project. Thank you to everyone who has already responded.

PRESIDENTS ANNUAL REPORT and AUDITED FINANCIAL STATEMENTS

All current financial members who were not present at the AGM will shortly receive copies of the President's Annual Report and the full Audited Financial Statements for the year 2012/2013, which were presented to, and adopted by, the Annual General Meeting held on 14 September 2014.

If you have not received your copies by the end of October, please contact our 1800 802 568 Freecall number or email info@mgag.org.au

NEWS FROM THE 2014 AGM

The following were appointed to the Management Committee for 2014/2015:

- President - Anita Jackson
- Vice President - John Noble
- Secretary - Carol Buchanan
- Treasurer - Susan White
- Committee Members - Shirley Johnston, Donna Formosa, Iris Suen, Rosalyn Holland.

We welcome new members to the management committee.

Graeme Peters was conferred with Honorary Life Membership in recognition of his outstanding service and dedication to the ideals and aims of the Association;

BDO Audit Pty Ltd were appointed Auditors for 2014/2015. BDO offered to perform the audit pro bono as they did this year.

There will be no increase in Subscription Fees for the coming year.

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 397462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
COLLEEN	5493 6391	SUNSHINE COAST
VACANT		DARLING DOWNS
DENISE	5545 0645	GOLD COAST
JANET	0429 622438	BUNDABERG / WIDE BAY

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407697206	ANDERGROVE
DENISE	0431571399	AVOCA
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	0422109492	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	0414241091	BURPENGARY EAST
DAVID	4053 2291	CAIRNS
HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE

KARLIENE	0432431591	HERVEY BAY
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412456439	LABRADOR
KAREN	0408153285	LOWOOD
JUDIE	0439 461288	MACKAY
PAULINE	49575686	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418778082	MONTEREY KEYS
CAROLYN	55228987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
KEITH	5441 7236	COES CREEK, NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411331258	PACIFIC PINES
JUNE	0409636467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
DAPHNE	4773 3695	RASMUSSEN
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
BERNIE	JoyPaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
CAROL	47737122	TOWNSVILLE
HEATHER	4728 7550	TOWNSVILLE
HEATHER	0438743234	TOWNSVILLE
LUCY	0418879801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458980667	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

JOKE

My wife was hinting about what she wanted for our upcoming anniversary.
She said, "I want something shiny that goes from 0 to 165 in about 2 seconds."
I bought her a bathroom scale.
And then the fight started.....

OBITUARY - HANNA RUSSELL

Don and Hanna Russell arrived in Cairns in 1954, with Don starting work as an optometrist with Bill Marley in Abbott St. They lived in the housing commission estate at Earlville in Cairns. Eventually Don bought out Bill Marley and owned the business outright. Hanna always helped out in the office-reception, book work, ordering stock etc.

Hanna was quite smart and every so often she would do some study. She did a uni course while her son Jon was at uni but didn't finish it. They worked until Don was 65 and then retired with plans to travel and spend leisure time together. They took up golf with a passion and also did a few good trips overseas and in Australia.

But Don was starting to have MG symptoms and they didn't know what it was. When he was finally diagnosed they both took it upon themselves to understand all aspects of MG. His failing health limited their activity. Don died of a heart attack in 1993 and Hanna was devastated. She took a long time to recover.

Her son Jon coaxed her to join the Leukemia Foundation as he was then the treasurer. It was good for her to get involved and she of course took over as treasurer within the next year. Hanna saw how support organisations could work and how good they could be.

She decided that she should try to set up something similar for MG in 1994. That was an affliction she was passionate about.

Hannah co-ordinated the get-togethers in Cairns for over 20 years. She was passionate about spreading the awareness of Myasthenia Gravis in the Cairns region. She stayed in touch keeping a keen interest up until a year or so ago. She enjoyed listening to her son, Jon read the MessaGes Newsletter.

Hanna Russell passed away on Monday 15th September 2014. She will be sadly missed by all who knew her.

HASTY BAKED PUDDING

1 cup S.R. Flour
 ½ cup sultanas
 1tblspn sugar

¾ cup milk
 pinch salt

Mix these to a batter and put into a greased oven proof dish, only half full. Then take ½ cup golden syrup and 1 tablespoon butter. Place in a heat proof jug and add 1 cup of boiling water. Stir and pour over mixture in the dish. Bake in a moderate oven for ½ to ¾ hour. Serve with hot custard.

(This is an old recipe that Grandma used to make and is loved by all generations.)

My wife sat down next to me as I was flipping channels.
 She asked, "What's on TV?"
 I said, "Dust."
 And then the fight started...

MEMBERS FORUM

The following article was written by the husband of one of our members. It shows that we should not let Myasthenia Gravis rule our lives. Life is what we make it.

Andrew writes,

Life is full of unexpected twists and turns that can lead you on paths that you never imagined. Such is my story as a carer for someone who developed Myasthenia Gravis over a decade ago. Now some would say that such an occurrence could be considered an unfortunate event. In some respects I guess it was. However, it is not in the good times that one forges character. Character finds its foundation in the challenges and turbulence that constitute our experience of living in the world.

When my wife first displayed symptoms of Myasthenia Gravis it was unsettling. My vibrant, and to that point healthy, wife had her life turned upside down. As a family we had to make adjustments to our lifestyle, moving from a dual income to a single wage. Further, we had to learn to recognise when and how quickly we needed to respond to the occasional myasthenic crisis. Thankfully as a Registered Nurse I am not prone to panic, even when extremely concerned. Ultimately, despite multiple emergency admissions, we averted ventilation.

Adjustment to lifestyle, however, did mean giving up on the things that we love. With the judicious use of a wheelchair we managed to tour Europe a couple of times. Cobble stone streets with significant gradients became the norm. A silver lining, however, can be found in all experiences. Travel through Europe is much more economical for a carer and we lost count of the number of tourist lines we dodged as we were ushered into separate entrances.

I do not pretend that the going has always been smooth due to the ups and downs of my wife's health. Myasthenia Gravis, however, does not define our lives or our relationship. The enduring feeling is that we share this journey and dictate our own path. As Viktor Frankl (1962, loc 909) once remarked: 'everything can be taken from a man but one thing: the last of human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own circumstances'.

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.

- I've learned that my children's birthdays make me feel older than my own birthday does.
- I've learned that if I eat donuts today I will wear them tomorrow.
- I've learned that when your husband cooks, you should complement everything he makes.
- I've learned that you shouldn't look back, except to learn.

AUSTRALIAN TRIVIA**Entertainment**

1. What were the first names of the winning couple from *The Block*?
2. What is the highest grossing Australian movie?
3. Who is the longest serving presenter of *Playschool*?
4. What three movies are parts of Baz Luhrmann's "Red Curtain Trilogy"?
5. Who are the actors who play *Kath and Kim*?
6. Cate Blanchett has received an Academy Award nomination for what movie?
7. What Australian movie includes the phrase "Tell him he's dreaming"?
8. What song played during Scott and Charlene's wedding on *Neighbours*?
9. Which actor has had leading roles in *Phar Lap*, *The Man from Snowy River* and *Eureka Stockade*?
10. Who won consecutive Gold Logies from 1997 to 2000?

Answers

1. *Fiona and Adam*
2. *Crocodile Dundee*
3. *Benita*
4. *Strictly Ballroom, Romeo and Juliet, and Moulin Rouge*
5. *Jane Turner and Gina Riley*
6. *Elizabeth*
7. *The Castle*
8. *Suddenly*
9. *Tom Burlinson*
10. *Lisa McCune*

Geography

1. Name Australia's western-most point?
2. How much of Australia is classified as desert A) 8% B) 16% C) 25% D) 35%
3. Which is the second largest city in NSW?
4. In what state/territory is the Brisbane Ranges National Park?
5. The Tamar River flows to which Tasmanian town/city?
6. What is the tallest waterfall in Australia?
7. What is the longest river in the Northern Territory?
8. The landmark *Katu Tjuta* is also known as what?
9. What is Australia's largest non-salt lake?
10. What is South Australia's largest island?

Answers:

1. *Steep Point (Shark Bay)*
2. *D - 35%*
3. *Newcastle*
4. *Victoria*
5. *Launceston*
6. *Wallaman Falls, QLD*
7. *Victoria*
8. *The Olgas*
9. *Lake Mackay, WA*
10. *Kangaroo Island*

FUTURE PLANNED ACTIVITIES

14 Dec – Christmas Function Brisbane venue TBA

NEWS FROM MACKAY

It was decided our next get together will be held at:

North Mackay Bowls Club Sunday 31/ 8/2014 for lunch at midday

Bill Area Coordinator – Phone 49541221

CAIRNS GET TOGETHER

It was wonderful to catch up with our members in Cairns on Saturday 16th August at the RSL Club. The sun was shining and it was a beautiful day to spend some time chatting about life with MG.

We meet at the RSL Club Boardroom, Esplanade Cairns at 11.00am. Some people stay on for lunch in the restaurant afterwards (own expense). Add the following dates to your diary.

Saturday 11th October at 11.00am

Saturday 13th December at 11.00am (note change of date) – Guest Speaker – Kay Thoren (Kaizen Oriental Therapies) who will present a talk on The Importance of Wellbeing.

Donna Formosa – Cairns Coordinator Ph. M 0414 397 462 H 07 40392148 or email: formosed@bigpond.net.au

TOWNSVILLE GET TOGETHER

The Townsville group recently had a get-together with sixteen people in attendance. Rosie Maicle, the nurse in charge of administering IVIG at the Townsville Hospital, also attended and answered general questions for some members. It is always great to listen to people sharing stories, chatting with new members and meeting in a very social atmosphere.

Our next get-together will be at

Saturday 18th October at 12 noon at The Avenues Tavern, Kern Brothers Drive.

I look forward to seeing as many members at possible there.

Carol Buchanan – Townsville Coordinator Ph. 47737122