



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**OCTOBER 2016**

Myasthenia Gravis Association of Qld Inc IN NO WAY endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

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

P.O. Box 16

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1800 802 568

ABN 92 055 613 137

Email: [info@mgaq.org.au](mailto:info@mgaq.org.au)

Internet: [www.mgaq.org.au](http://www.mgaq.org.au)

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#### PATRON

Dr Cecilie LANDER

Neurologist

Founder Member, of Brisbane

## PRESIDENT'S REPORT

It is a great honour to be the new President of such a dynamic, vital and effective organisation that is the MGAQ.

I would like to acknowledge all of the hard work done by the management committee and others who have volunteered their time freely. I particularly want to mention our retired President, Graeme Peters. Graeme has given many, many years of service to the association and has held a range of executive positions during that time. His knowledge, commitment and passion, as well as his reminders about the best AFL team Collingwood, will certainly be missed at our monthly management committee meetings. I wish both him and his wife, Poppy, all the best and hope that they have many hours of enjoyment together.

Your association is in need of a Secretary. One of our management committee members, Anita Jackson, kindly put up her hand to be Secretary so that we met all of the legislative requirements as an association. However, she will only carry out the requirements of that position until we find a permanent secretary. Remember that members of the management

committee do not have to have MG. Maybe you have a family member who might like to find out more details with a view to perhaps taking up the position. You can phone me on the number listed on the front page or email [info@mgaq.org.au](mailto:info@mgaq.org.au)

Current financial members will soon receive a copy, either by mail or email, of the President's Report, Treasurer's Report and audit from the AGM. I encourage members to take the time to read them and understand just how much the MGAQ achieves through the hard work of a small band of volunteers.

Our Key Priorities and Operational Plan for the 2016-2017 financial year have been forwarded to the Community Services Funding Branch of the Department of Health. This document lists the ongoing services we offer to members as well as outlining the key strategies that will be undertaken to help improve the knowledge about and understanding of MG and how it affects individuals, families and society. This document is an important part of our continued funding until 2019.

**Cheers  
Carol**

*Supported by*



Queensland  
Government

**Ausenco**

## RESEARCH UPDATE

Momentum is growing and the eNID project is progressing well.

Hopefully there will be news and details to share with our members in the very near future!

## MYASTHENIA ALLIANCE AUSTRALIA



**Myasthenia**  
Alliance Australia

The Alliance Committee continues to meet regularly utilising teleconferencing facilities.

The Committee members are located in Brisbane, Townsville, Wollongong and Canberra and hope to be able to represent a broad cross-section

of Australians affected by Myasthenia.

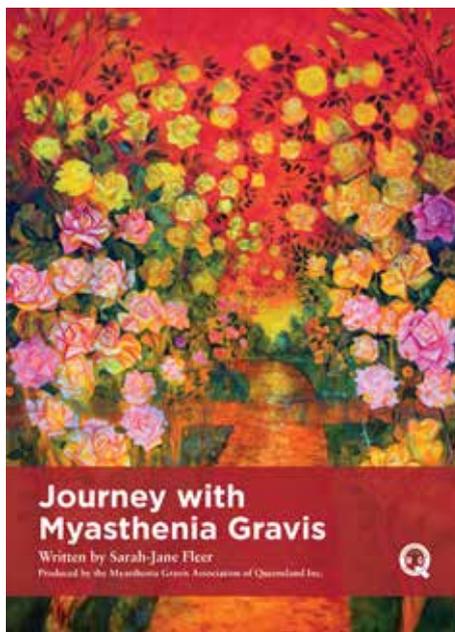
Discussions have commenced in regard to hosting the next conference. Many people have enquired about when another conference could be organised after the success of the inaugural event held in 2015.

Previous conversation suggested 2018 may be possible. The MAA is pleased to flag that it may be arranged for the second half of 2017.

Further information will be provided as it is known.

Follow the work of the Alliance by registering at the website  
[www.myastheniaallianceaustralia.com.au](http://www.myastheniaallianceaustralia.com.au)

## “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.

Contact the Association on 1800 802 568, email at [info@mgaq.org.au](mailto:info@mgaq.org.au) or go to our website [www.mgaq.org.au](http://www.mgaq.org.au) if you wish to purchase a copy.



“You only live once, but if you do it right, once is enough.”  
— Mae West



# What to expect from your DVD!

Nicole Millis left her family of three young children to travel to Brisbane on a Sunday. She must indeed have a passion for what she does to make such a journey.

She began her talk by explaining exactly why she does have this passion and in sharing her personal journey with rare disease she hoped everyone would know that she really does understand the issues faced by chronic and rare disease. She called it 'lucky' to get a quick diagnosis.

She then spoke about the establishment of Rare Voices after an inaugural conference in 2011 and how Australia is aiming to follow the model being adopted around the world in regard to management of the rarer conditions.

Rare Voices is working closely with Federal Government Health Ministers in order to establish

protocols for this group of people.

Making politicians aware of this need in the community is challenging and progress is slow. She stressed the value of making your local member aware of your condition and what is involved in your medical management including the difficulties of mis-diagnosis and delayed diagnosis.

There is much inefficiency and repeat handling involved with rare and chronic disease management and this comes at a large cost to the individual in so many ways and to the taxation system in general.

Rare Voices has a National Plan and this was discussed. She highlighted the difficulties associated with the various levels of Government being able to work together effectively.

## SURVEY UPDATE

Professor McCombe continues to receive completed surveys returned to the RBWH and has provided the support to have all the data from these surveys entered and available for analysis. It takes, on average, two hours for each survey to be fully entered. This is a very significant endorsement of the value of this survey work and indicates that it is important for people to take the time to complete and return their survey. She is waiting for more surveys to be returned! Her on-going commitment to this project is greatly appreciated.










As the numbers of surveys sent are tallied against the numbers returned, it is clear that not all surveys are returned. If you are still to participate, it would be wonderful if you could find the confidence to enter your story and to show the doctors that their interest in our condition is valued.

Certain issues may be making it harder for individuals and the Association is available to support you with this task. Do call 1800 802 568 or email: [info@mgaq.org.au](mailto:info@mgaq.org.au) if we can help.

These issues may include 'having the blue sheet signed off by your Specialist', 'messing up or misplacing the original copy', 'not knowing what to write for some sections or feeling uncomfortable answering other questions'.

Solutions can be found and include the following - 'your General Practitioner can sign the blue sheet and it will be accepted', 'a new copy can be sent if required', 'it is not compulsory to answer ALL the questions so move past anything that you do not understand or do not feel comfortable with'.

# UPDATED CHAT LISTS



Over the past few months we have asked members to let us know if they wish to remain on the chat list. Listed below are the people who responded and thus their name has remained on the list.

Should you think your name has inadvertently been left off the list or should you wish your name to be added, please contact [info@mgaq.org.au](mailto:info@mgaq.org.au) or the MGAQ Support Line 1800 802 568

## MGAQ SUPPORT LINE 1800 802 568

### Chat List – Queensland Regional Coordinators

Donna..... 0414 397 462.... Cairns  
 Daphne..... 4773 3695..... Townsville  
 Bill ..... 4954 1221..... Mackay  
 Jeanne..... 0437 048 361.... Rockhampton

Garth (Gladstone) 0408 155 954..Wide Bay/Burnett  
 Colleen ..... 5493 6391..... Sunshine Coast  
 Debbie (Taroom).. 4628 6103..... Darling Downs  
 Nader..... 0415 834 401.... Gold Coast

### Chat List – Queensland Regional

David .....5594 0489..... Arundel  
 Pam ..... 4151 5499..... Bundaberg  
 Elsie ..... 5520 0921..... Burleigh Waters  
 Scott ..... 5446 3894..... Coolum Beach  
 John ..... 0419 624 767.... Coombabah  
 Lillian .....4933 4281..... Gracemere  
 Angela ..... 0427 752 956.... Hope Island  
 Leslie .....0437 324 077.... Kilcoy  
 Marie ..... 0418 781 526.... Labrador  
 Tony.....4942 4676..... Mackay  
 Raymond .....0407 752 956.... Millmerran  
 Kerrie Lee.....5478 4262..... Mooloolaba  
 Gary .....0403 070 630.... Noosa Heads  
 Maureen .....0411 331 258.... Pacific Pines

Richard .....0418 249 640.... Paradise Point  
 Jeanne .....0437 048 361.... Rockhampton  
 Sunshine .....0487 365 363.... Torquay  
 Carol.....4773 7122..... Townsville  
 Daphne .....4773 3695..... Townsville  
 Kerri .....0408 777 494.... Townsville  
 Jo .....4723 8721..... Townsville  
 Maree .....4740 4399..... Townsville  
 Sonia .....0408 868 744.... Townsville  
 Ron .....0488 585 246.... Townsville  
 Ron.....0428 826 180.... Townsville  
 Kath .....5573 0439..... Upper Coomera  
 Andrea.....5486 7671..... Wolvi

### Chat List – Brisbane

Carol ..... 3390 1788..... Capalaba  
 James ..... 3390 3039..... Capalaba  
 Sonia .....0400 457 025... Clayfield  
 Mark ..... 0433 911 210... Eatons Hill  
 Dennis ..... 3855 9379..... Gaythorne  
 Zoe & Lisa .....0417 706 630... Hillcrest  
 Robyn ..... 0434 532 853... Kedron  
 Susan ..... 3358 1056..... New Farm  
 Craig ..... 0408 729 679... Mackenzie

Colin ..... 3409 435..... Macleay Island  
 Bill & Jitlada..... 3399 7041..... Norman Park  
 Lynne ..... 3398 4407..... Norman Park  
 Tracey .....0421 193 301... Northgate  
 Tracey-Lee ..... 3284 9949..... Redcliffe  
 Sybil.....3219 9535..... Springwood  
 Poppy .....3288 4484..... Springfield Lakes  
 Stephen & Annette 0419 611 565..Tewantin

Brisbane Chat List continued on Page 5

# UPDATED CHAT LISTS

Brisbane Chat List continued from Page 4

**MGAQ SUPPORT LINE 1800 802 568**

## Chat List – Brisbane

Diane ..... 3300 4519 ..... The Gap  
 Craig St ..... 0432 949 073... Warner

Kris & Barbara ..3822 1832..... Wellington Point  
 Natalie .....0488 665 815... Wellington Point

## Chat List – Interstate Members

### NSW

Julius ..... 02 9365 5828..... Bellevue Hill  
 Trevor ..... 02 66795507 ..... Uki  
 Dianne ..... 0400293582 ..... Windsor

### VIC

Anthony ..... 03 94806317 ..... Preston  
 Edmund ..... 03 9509 8920..... Caulfield North

Melita .....0412 124 017 ..... Eltham

### WA

Helen .....08 92973528..... Ellenbrook  
 Robert .....08 9578 3113 ..... Gidgegannup  
 Jill .....08 94529414..... Maddington

### N.T.

Terri .....0419 681 044..... Berrimah

## Has this happened to you?

You have a disabled parking permit and you take a trip to the shopping centre, park in the disabled bay and then asked:

- Do you realise you are parking in a disabled spot?
- Why are you parking in a disabled spot? Doesn't look like there's anything wrong with you!
- Get disapproving looks when you park in the disabled spot?
- No-one offering you a seat and you're out on your feet?

It happens all over the world!  
 Spotted these on a UK Facebook Group.



## COMMITTEE NOTICE BOARD

**YOUR ASSOCIATION URGENTLY NEEDS A SECRETARY!**

Can you help in any way?  
 Contact Carol or  
[info@mgaq.org.au](mailto:info@mgaq.org.au)  
 for further details



This month, we welcome the following members:  
**HELEN - Proserpine**  
**ROSEMAY - Tully**



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](mailto: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 Annual General Meeting Trip

My wife and I had been thinking for a few months about visiting friends in sunny Queensland, and noticed the AGM was being held in September, so it worked in nicely to visit friends, have a look around, do some whale-watching and attend the meeting.

Having chatted to Graeme regularly on the phone about the newsletter and things AFL related, emailing back and forth with other committee members, it was the ideal time to the committee members and other MGers.

As soon as we walked into the room, Shirley made us feel right at home. After a few more introductions, it was great to put faces to names.

It was interesting to listen to Nicole's presentation about her work with Rare Voices Australia.

During lunch, it was fantastic to sit with members and chat about everyone's experience with MG, how medications differ from person to person and how we all deal with MG and listening to newly-diagnosed members going through the same learning experience.

It's great to chat on the phone, via social media, but nothing beats chatting face-to-face. And it would be great to make another meeting in the future.

**Cheers, Greg Breaden.**

## From the MGAQ Kitchen

### Whole Orange Cake

#### INGREDIENTS:

- 1 orange, roughly chopped and seeds removed
- 170g butter, roughly chopped
- 1 cup sugar
- 3 eggs
- 1½ cups self-raising flour

#### METHOD:

- Pre-heat the oven to 180°C. Lightly grease a loaf or cake tin and line with baking paper.
- Process all the ingredients in a food processor or thermal blender until smooth.
- Pour into tin and bake for 40-50 minutes, until a skewer comes out clean when inserted into the centre.
- Set aside for 10 minutes, then turn out onto a wire rack. Ice or dust with icing sugar.

If you have a recipe you would love to share with other members, send your recipe to: Email: [mgaq.editor@gmail.com](mailto:mgaq.editor@gmail.com) or post to:

**The Myasthenia Gravis Association of Qld Inc., PO Box 16, Mt Gravatt, Qld 4122**

**BAMBOOZABLES**

[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)

Answers below

<b>PLAY</b> WORDS	SHGETAPE	MONKEY RUOY	DR. DO	FOO G NIN	BUkickT
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**SUDOKU**

[www.theteacherscorner.net](http://www.theteacherscorner.net) Printable Sudoku

	8					5	2	
9			7	8			1	4
	1	6	5	9				
					4			8
5	9			6	7		3	1
7		8	2			4		
	7			3		1	9	
2	6	9	1	7	5	8		
							6	

**Math Challenge**

[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)

Try to fill in the missing numbers. Use the numbers 1 through 9 to complete the equations. Each number is only used once. Each row is a math equation. Each column is a math equation. Remember that multiplication and division are performed before addition and subtraction. *Answers below*

	+		-		1
-	■	+	■	+	
	x		-		29
-	■	x	■	-	
	x		-		-1
-10		9		1	

-10		9		1	
8	x	1	-	9	-1
-	■	x	■	-	
2	x	1	-	9	29
-	■	+	■	+	
3	+	5	-	4	1

5	6	7	8	2	9	3	4	1
3	4	8	5	7	1	6	9	2
2	9	1	6	3	4	5	7	8
6	5	4	9	1	2	8	3	7
1	3	2	7	6	8	4	9	5
8	7	9	4	5	3	1	2	6
7	8	3	2	9	5	6	1	4
4	1	6	3	8	7	2	5	9
9	5	2	7	8	3	6	1	4
3	8	7	6	4	1	5	2	9

**Bamboozable 4 Answers:** 1. Play on Words; 2. Get in Shape; 3. Monkey on Your Back; 4. Dr. Doltle; 5. Fooling Around; 6. A Kick in the Butt

## NEWS FROM AROUND QUEENSLAND

### News from Cairns

The local MGAQ group in Cairns meet every couple of months at the Cairns RSL Club Boardroom. This is a wonderful opportunity to meet others with M.G., and carers, to chat.

The final get-together for 2016 will be on Saturday, 19th November.

For more information, please contact Donna on 0414 397 462.

### News from Mackay.

The Mackay Area held its lunch at the Mt Pleasant Tavern, on September 18. A warm welcome was extended to Donna Formosa (Qld Coordinator) and her children, who attended on their way south for school holidays.

This was appreciated by all in attendance. Fourteen people attended, with six apologies from others unable to attend.

Everyone had an enjoyable lunch and socialised afterwards.

Our guest speaker was held over and will attend our Christmas lunch get-together.

The date for next get-together is: Sunday, 13th November, 2016, for our Christmas Party at Souths Milton Street, at 12 noon.

All M.G. Association members, carers and interested people are welcome to attend.

For more information on any of these events, contact Bill, Area Co-ordinator, Mackay 07 4954 1221, Mobile 0429 729 685

### News from Townsville.

The September lunch meeting was well attended and members discussed their M.G. concerns.

Our next lunch is on Saturday, 3rd December, 12 noon at The Avenues Hotel.

RSVP to Daphne-0400778637 or  
[daphclay@gmail.com](mailto:daphclay@gmail.com)

As this is our Christmas lunch, you are invited to

bring a gift (cost \$15-\$20) and we will exchange gifts.

Congratulations and thanks to the new committee members from our Townsville group. We appreciate and the value of your dedication and hard work for the M.G. organisation. For any more information, please contact Daphne on Mobile: 0400 778 637 or Email: [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Rockhampton

For more information, contact Jeanne Harp. [jharp08@hotmail.com](mailto:jharp08@hotmail.com) or 0437 048 361.

### News from Wide Bay (Gladstone)

If you would like to find out if there are any upcoming functions, get-togethers, contact Garth, the local support Co-Ordinator for Gladstone-Wide Bay on mobile 0408 155 954 or (07) 4973 7983

### News from the Sunshine Coast Group

We will meet again on Saturday, 12th November, at 12noon for lunch at the Buderim Tavern. This will be our final gathering for 2016 so hope to see many of you there.  
Colleen McLean

[colleen4551@gmail.com](mailto:colleen4551@gmail.com) Phone 0409 491 789

### News from the Gold Coast

Any queries from the Gold Coast, contact Nader on 0415 834 401.

### News from Darling Downs

Love to hear from anyone whom I can be of assistance to in any way.

Debbie Hawkins, Email [debsy570@yahoo.com](mailto:debsy570@yahoo.com) or phone (07) 4628 6103 or mobile 0457 148 486.

Please leave a message and I will return calls or reply via email.



# SAVE THE DATE

Just a reminder to everyone that our Christmas get-together will be held on

**Sunday, 11th December.**  
**Southport Sharks**  
 Cnr Musgrave and Olsen Ave, Southport  
 11.30 am for 12 noon

Further details will be in next month's newsletter.