



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**FEBRUARY 2017**

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

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Neurologist

Founder Member, of Brisbane

## PRESIDENT'S REPORT

Welcome to the New Year.

The members of the management committee hope that you had a wonderful Christmas with family and friends and that the new year has started well for you.

We also hope that those with MG are managing to cope with the very warm weather. Trying to stay cool at this time of year is bad enough without the high temperatures we have been experiencing this summer.

Our March Members' Get-Together will be held on Sunday 12 March at the same place as we held it last year. Everyone who attended was very impressed with the atmosphere and facilities at the Robell Domain at Springfield Lakes. We look forward to seeing as many people as possible there. Full details are at the end of this newsletter.

Our management committee urgently needs two new members, particularly from the Brisbane district. Remembering that all current

members of the management committee are Myasthenics, the individual current workload cannot be sustained. Anyone who offers to help does not necessarily have to want to be on the management committee but might be prepared to take on small projects. Prior experience is not an issue as all members of the management committee are there to help.

The MAA is very excited by the potential benefits of the eNID project and is very keen to see it established as quickly as possible. The Myasthenia Gravis Association of Queensland and the Australian Myasthenic Association of NSW are focused on helping to raise the \$40,000.00 required to fund this coding work. More details are contained in this newsletter.

Do not forget to encourage those children and students close to you to think about entering our MGAQ Scholarship competition.

Carol

Supported by



Queensland  
Government

Ausenco

**"The Myasthenia Gravis Association of Queensland and the Australian Myasthenic Association of NSW, are focused on helping to raise the \$40,000 required to fund the eNID Project"**

**\$40,000**



## MYASTHENIA ALLIANCE AUSTRALIA

Following on from the December newsletter, the Alliance Committee has chosen to repeat the report from Dr Reddel which gives a full explanation of the eNID

(electronic Neuro-Immunology Database) research project as it is a big topic to digest.

We encourage all our members to take the time to read it again and understand more about the work being undertaken.

It is hoped that people will be discussing it with family and with their treating Doctors.

The members' forum section of this newsletter could provide an excellent medium for comment and interesting discussion about this project so please write sharing your thoughts. Alternatively, conversation can be had on the Facebook page.

As discussed, the MAA is very excited by the potential benefits of this project and is very keen to see it established as quickly as possible. *The Myasthenia Gravis Association of Queensland and the Australian Myasthenic Association of NSW, are focused on helping to raise the \$40,000.00 required to fund this coding work.*

It is hoped it will be found as quickly as possible. The Associations will provide a platform for collecting funds which will be passed onto the MSBase Foundation's designated account (refer to letter from Dr Reddel).

Donations via both Associations are tax deductible. When contributing via an Association, please specify that the funds are to be forwarded to the eNID project and all donations will be forwarded on a regular basis.

The generous commitment by the MGAQ to donate \$10,000 towards this research has ensured that the fundraising campaign is off to a good start.

In addition, a donor has undertaken to match dollar-for-dollar all donations received via the MGAQ and prior to 30 April, 2017 to a maximum amount of \$5,000.

This is a great opportunity to have your dollar double its effectiveness in supporting a project of immense value to Myasthenics.

To date, the Association has received 8 donations towards our \$40,000 target.

**\$10,300**

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

**Read Dr Stephen Reddel's report on eNID-MG. The electronic neuroimmunology database for myasthenias**

**NEXT PAGE**

# eNID-MG

## The electronic neuroimmunology database for myasthenias

The nervous system is vulnerable to inflammatory damage caused by the immune system - collectively these are the neuroimmunological (NI) diseases. The best recognised of these conditions is multiple sclerosis (MS) which affects the central nervous system, this also causes the most disability and receives the most attention and research funding. The most common peripheral nervous system disease is myasthenia gravis (MG), with variants such as MG with MuSK antibodies and LEMS. There are many other NI diseases including neurosarcoidosis, autoimmune encephalitis and CIDP.

Neuroimmunological diseases are often chronic, requiring long-term treatment, and often associated with periods of significant disability. Other than MS these are a low priority for pharmaceutical-sponsored clinical trials. There is growing recognition that disease registries can be powerful and cost-effective instruments for expanding our knowledge of diseases and treatments, leading to improved patient outcomes. This is particularly in rare diseases where pooling 'real world' data enables a sufficient sample size (100s-1000s) for research, and to conclusively demonstrate treatment effectiveness without pharmaceutical trials.

We are building an international database for patients with NI diseases. This database will be known as eNID (electronic NeuroImmunity Database). eNID will be built as an extension to MSBase, a highly successful international registry for patients with MS. MSBase currently has > 39,000 patients enrolled from 72 countries. The MSBase Foundation is assisting with IT development as well as providing administrative and operative support for eNID. eNID will be a pioneer in neuroimmunology research, providing the first opportunity for global big data, lead by Australian

investigators. eNID will comprise separate databases for each disease, such as MG, but also be able to compare diseases.

eNID will have data entry from clinicians but also include patient reported outcomes. A great advantage of MSBase is the pictorial display of the patient's course over time, combined with treatment. This encourages data entry and enrolment. To adapt MSBase to MG, we need to change many fields and the format of the graphical display. The cost of the eNID-MG IT will be approximately \$40,000. The fields include validated MG clinical and patient rating scales. The MG outcomes were agreed after a series of global teleconferences by MG experts.

Neurologists will require site specific ethics approval but in many cases neurologists will already be using MSBase. Patient consent will be required for enrolment. Only de-identified data is uploaded to the central registry. Data is freely available for research if ethical.

We believe eNID-MG will really advance practical care for patients. It will show which treatments work, how long they take, and what else to consider if initial approaches fail. A practical example is that MSBase has shown that rituximab is an effective treatment for MS; rituximab is also used off label for MG, but is neither approved nor established. eNID-MG will also provide good data on quality of life and disability aspects, and safety of treatments.

We are therefore writing to the Myasthenia Associations to encourage fund-raising for eNID-MG. Any donation can be sent to the bank account of the association marked for eNID-MG, which will then be transferred to the MS-Base foundation once logistics are completed.

*Stephen Reddel, for the Scientific Group - Katherine Buzzard, Stephen Reddel, Sean Riminton (Australia); and the MG Group - Ted Burns (USA), Carolina Barnett-Tapia (Canada), Stephen Reddel.*



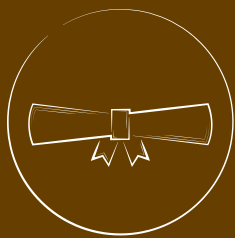
**MGAQ  
SMS  
ALERT**

### Dear Members

As part of our ongoing service to our members, your Committee requests that you register your mobile number so that we can text alerts to you.

Issues which cause concern could revolve around drug availability, or other urgent MG related information.

However it may be that the first alert you receive could well be a reminder that your dues are overdue. "Such is life!" **Many thanks, John**



# MGAQ STUDENT SCHOLARSHIP

**to win, just tell us about your experiences with MG**

The Myasthenia Gravis Association of Queensland is proud to announce two scholarships which are to be awarded in May 2017.

The **Kath Ross Memorial Scholarship** will provide a high school student with a prize of **\$300**.

Kath Ross was a driving force in establishing the Association.

The **Des Zeimer Memorial Scholarship** will award a primary school student with a prize of **\$200**.

Des Zeimer provided the initial donation to launch a collection of funds specifically allocated to research.

Students are asked to communicate  
**“HOW MYASTHENIA GRAVIS PLAYS A ROLE IN MY LIFE”**

**Things to consider could include:**

*What symptoms have you seen or experienced?*

*How does it impact you and/or the affected person's life?*

*What would you like people to know about Myasthenia Gravis? How do you manage or feel you help?*

Entrants must be either a Category A member of the Association or be a relative or close friend of a Category A member. All types of media can be used to convey the emotions involved in answering this question - journaling, drawing, a video and storytelling are some of the methods you might like to use.

Applications are now open. Entries will be judged with consideration given to the student's year level in 2017. The competition will close on April 3rd

2017, with winners announced in the May edition of *MessaGes*!

There will be an additional \$50 prize for two runners-up in each category.

It should be noted that this is a one-off award for the year of 2017 only.

Entries should be submitted on the understanding that they are made available to the MG community as seen appropriate by the MGAQ Committee and remain the property of the Association.

A panel of three will judge the entries and their decision is to be final.

Please send your items to:

**PO Box 16  
 Mt Gravatt QLD 4122  
 or to [info@mgaq.org.au](mailto:info@mgaq.org.au)**

**Release form on Page 5**





**Thank you for contributing to the MGAQ Inc. STUDENT SCHOLARSHIP event 2017.**

In completing this release form you and your Parent/Guardian agree to the terms outlined in the flier.

These include the need to be either a Category A member of the Association or be a relative or close friend of a Category A member. Entrants must be either a Primary or Secondary School student in 2017. The entry must reflect in some way, "How MG Plays a Role in My life". Work, which may utilize any medium, becomes the property of the MGAQ Inc. and may be shared as deemed suitable.

The Judges' decisions are final.

This form asks you to give your copyright to the Myasthenia Gravis Association of Qld Inc.

The Association also reserves the right to edit material as necessary for publication and to avoid publishing defamatory material. It does not stop you from using the entry for your own use.

Your interest is greatly appreciated. Good luck with your entry.



I, (Parent/guardian name): .....

Join with (Student Name): .....

Age: ..... Grade: ..... School .....

Category A Member known to me (Name not for publication): .....

Assign to the MGAQ Inc. any copyright owned by me in relation to the material contributed as attached.

Student Signature: .....

Printed Name: .....

Parent/Guardian Signature: .....

Address: .....

Contact Details:- (email/phone): ..... Date: .....

**Association Representative (Office use only)**

Signature: .....

Printed Name and Position: .....



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.**

**Debbie (Darling Downs and Beyond Regional Co-ordinator) writes:**

*Surprise to All!*

*I am back on the newsletter again.*

As most of you may know, my hubby and I have bought another property and moved to Blackall.

Been very busy times, packing up and relocating to Blackall.

Thoroughly enjoying the change and having a break from my Nursing career.

If you are travelling through give us a call on (07) 4657 5974 or mobile 0457 148 486.

**My goal for 2017 is..**

Spreading the word on MG within this area and hopefully inspire new members.

The MG society need our utmost support, not only for our personal assistance but to continue lobbying the Government for well needed funding. Research is a vital component of improving outcomes for a broad spectrum of people affected by MG.

Let's all get behind it and promote the society in everyway.

My congratulations to new committee, and good luck to Shirley after her years of dedication to MG Society  
*Debbie Hawkins*

**BAMBOOZABLES**

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

Answers below

crycrycrycryBANK	stake stake	BAD BAD	EAHiiYM	skirt	AALLLL
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**SUDOKU**

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

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

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

- Bamboozable 7 Answers:**
1. Cry all the way to the bank.
  2. The stakes are high.
  3. That's too bad.
  4. Eyes in the back of my head.
  5. Miniskit.
  6. All in All



**MURIEL'S DID YOU KNOWs?**

- One third of all the salt produced in the U.S. is used to melt ice on roads .
- Just like humans ,British cows moo in accents specific to their region .
- The water in the Blue Whales mouth weighs as much as its entire body .
- A language dies every 14 days .
- Thomas Edison proposed to his second wife in Morse Code .



**13th International Conference on Myasthenia Gravis and Related Disorders**  
**WHEN: MAY 15 - 17, 2017**  
**WHERE: THE NEWYORK ACADEMY OF SCIENCES**

For additional information on our list of over 40 speakers and the agenda, visit our event website:  
[www.nyas.org/Events/Detail.aspx?cid=0758b61f-ec5c-4051-8903-e6a8732fc0df](http://www.nyas.org/Events/Detail.aspx?cid=0758b61f-ec5c-4051-8903-e6a8732fc0df)

## NEWS FROM AROUND QUEENSLAND

We would like to advise that Jeanne Harp has resigned as Regional Co-Ordinator for the Rockhampton region due to her health. The MGAQ thanks Jeanne for her contribution to the Association and wishes her well.

### News from Cairns

Cairns will hold its first get together for 2017 on Saturday, 25 February at 11.00am at the Cairns RSL Club, Esplanade.

Our get togethers are informal and a perfect opportunity for people to chat with others on the same journey.

Members visiting Cairns are also very welcome to come along.

Please contact Cairns Co-Ordinator, Donna Formosa on 0414 397 462

### News from Darling Downs and Beyond

I am back on the newsletter again. As most of you may know, I have moved to Blackall.

If you are travelling through, give us a call. Please note, my new landline contact number is (07) 4657 5974 or mobile 0457 148 486.

Even though my area is huge, please contact me for any assistance. Debbie Hawkins

### News from Gladstone

Please contact Garth, your local support Co-Ordinator in the Gladstone-Wide Bay region on 0408155954

### News from the Gold Coast

Hi everyone. Our Gold Coast MG group met for a friendly coffee, chat, exchanging experiences on 14 January.

Our next meeting will be at Southport Sharks Club (cnr Musgrave and Olsen Ave Southport), Saturday, 18 March 2017 at 10am. I look forward to seeing you all again For

more details please contact Nader 0415 834 401 (G.C. Co-ordinator)

### News from Mackay

Our next get-together will be held on Sunday, 26 February at noon for lunch at the Boomerang Hotel/Motel.

Later in the year, another lunch will be held on Sunday, 7 May, at the North Mackay Bowls Club, at noon for lunch.

Contact Bill, Area Co-ordinator, Mackay  
07 4954 1221, Mobile 0429 729 685

### News from Rockhampton

For support in the Rockhampton region, please contact Bill at Mackay; Garth in Gladstone or Debbie on the Darling Downs.

### News from the Sunshine Coast

Happy New Year to all. Our next lunch will be on Saturday 11 February at 12noon at the Buderim Tavern. We should all have recovered from Christmas by then so hope to see many of you there to kick off the new year.

Colleen McLean 0409 491 789,  
colleen4551@gmail.com

### News from Townsville

Dear Members - Welcome to 2017!

Lunch- The Avenues Hotel, 270 Kern Brothers Drive, Kirwan, Townsville. Saturday, 25 February, 2017 at 12 noon. Looking forward to your company. Family members are welcome. Thanks for attending our December lunch.

If you can come please RSVP Daphne Clay (07) 4773 3695, Mobile 0400 778 637 or email: daphclay@gmail.com

## BRISBANE GET-TOGETHER



A "Coffee and Chat" afternoon was attended by 12 people at Nundah on the North side of Brisbane this month. It was a wonderful opportunity to meet others who are also on the MG journey.

Those who attended had a very enjoyable afternoon and look forward to the next one in April.

For more information contact [info@mgaq.org.au](mailto:info@mgaq.org.au)



EVERYONE  
WELCOME

# PICNIC IN THE PARK

## WHEN:

Sunday, 12 March 2017 from 10:00am

## WHERE:

Robell Domain Springfield Lakes off Sinnathamby Blvd)  
UBD Map 256 Reference P5

### WHAT DO I NEED TO BRING?

Yourself and whomever else you wish to bring along – the more the merrier. Don't forget your picnic lunch. Children very welcome.

**RSVP:** Ring our **FREECALL 1800 802 568** and tell Susan if you are coming, but please let her know by **Friday, 4 March 2017**

### HOW DO I GET THERE?

**From Brisbane, Sunshine Coast and Gold Coast:** Proceed on the Centenary Highway towards Warwick (Yamanto).

Take the Springfield Central (Greenbank Arterial Road) exit.

At the roundabout at the foot of the exit ramp, turn left onto Greenbank Arterial Road.

At the traffic lights, turn right into Sinnathamby Blvd.

At the second set of lights turn right into Education City Drive. Proceed straight at the round-

about and turn left at 'The Circle'. This will lead to a parking area. From the car park walk towards the Robell Domain Café and follow the MGAQ signs. If you get lost call Anita 0414 588 312.

### From west of Springfield

Same as above except for: Connect with Sinnathamby Blvd from either Augusta Parkway or Centenary Highway.

From Sinnathamby Blvd, turn left into Education City Drive.

**Public Transport:** If you would like to come to the picnic but are unable to drive to the venue, there is a regular train service to Springfield Central station.

If you will be coming via train, please let us know and we can arrange to pick you up from the station.



**NOTE:** Facilities at the Robell Domain include play areas for children, a cafe which sells snacks, ice creams and hot and cold drinks, and lots of paved walking paths if you wish to wander around and take in the full extent of the Domain. It is also a short walk across to the Orion Shopping Centre which has heaps of places for eat-in or take-away. If the weather is warmish, it is only a short walk to the free entry swimming 'Lagoons' so you may wish to bring your bathers. (The Lagoons are attended by life guards).

**Ring our FREECALL 1800 802 568 for more details**