



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

OCTOBER 2018

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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PRESIDENT'S REPORT

I am pleased to report that, since our last newsletter when I expressed concern about the association not having a permanent secretary, we have received a nomination for the position. I would like to welcome Dee De-Almieda to our association. Once her nomination was received the management committee communicated via email to vote and make this a permanent position. It is great to have a full complement on the management committee as the list of what we hope to achieve this year just seems to get longer and longer.

I would also like to acknowledge the work of our long-standing members of the management committee, particularly that of John Noble who retired from the group at the AGM. However, John has kindly offered to continue to digitise our information so we will have well-organised, comprehensive records from past years and for years to come. Thank you John for your past contribution and we look forward to working with you in the future.

Current financial members should have received a copy, either by mail or email, of the President's Report, Treasurer's Report and audit report 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 Operation-

al Plan for the 2018-2019 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 the end of 2019.

Our Meet the Members get-togethers across the state appear to be going well. Feedback has been positive and people seem to appreciate meeting members of the management committee. Keep an eye on the newsletter for future dates.

Please take the time to read the information in this newsletter about the progress and communication that has taken place with the MS-Base personnel as well as with the leading Australian neurologists committed to keeping the momentum going with eNID.

Christmas will soon be upon us. The MGAQ Christmas lunch will be held on **9 December at Club Southside in Upper Mount Gravatt**. We hope to catch up with as many people as possible at this event.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS

As discussed in last month's newsletter, the Committee anticipated becoming more involved with the MSBase working group for the eNID project. This first joint meeting has occurred and it has proven to be very fruitful. Included in this edition is the Project Overview (as at October 1, 2018) compiled by MS-Base Foundation Director Helmut Butzkueven and MSBase Project Co-ordinator Charlotte Sartori. The interest shown by everyone involved to make this important project progress was clear.

In reading the Project Overview, more can be understood about the timing of the process required to bring this project to Australian Neurologists. In addition, details regarding the financial hurdles are highlighted. These hurdles must be overcome if this project is to progress. MSBase is supportive, the Doctors involved are actively engaged in seeking funding and the Myasthenic community has been asked to step up again to ensure that this project does not stall.

In good faith, two members of our community have already donated \$20,000 to this next stage. This money sits in a specially allocated account within the MGAQ, hopeful of being required in the coming

months. With such a good start, the MAA Committee is confident that another fundraising initiative can be successful. Whilst a fundraising drive will not be formally commenced until further eNID working group meetings indicate that the project can be funded, showing faith in the project by donating now can be managed and will represent a tremendous vote of confidence by our community to MSBase staff and to Drs Buzzard, Reddel and Blum.

For those feeling less confident, more details will follow in each monthly newsletter. Donating following the official launch of the campaign will be fantastic.

Tax deductible donations can be made through the MGAQ by visiting the website and using the **GIVE NOW** facility, by doing a direct debit deposit to **MGAQ BSB 124 032 A/C 10263772** or by post to **PO Box 16, Mt Gravatt 4122**. Please let us know of your gift and that it is directed to the eNID project by **emailing info@mgaq.org.au** or by **calling 1800 802 658**. Questions can also be answered using this Freecall number. The MGAQ accounts are audited annually by BDO and donations are tracked carefully.

Susan, MAA President.

Follow the work of the Alliance by registering at the website www.myastheniaallianceaustralia.com.au



MSBase
Neuro-Immunology Registry

eNID Project Update – October 1, 2018

Created for members of the eNID Steering Committee and Myasthenia Alliance Australia for distribution to potential donors

Project overview

Since 2016 when the MSBase Foundation Board and Scientific Leadership Group first agreed to scope the development of a registry to capture rare neuro-immunological diseases as defined by the electronic Neuro-immunology Database (eNID) group, a great deal of progress has been made.

The MSBase Board have offered their support to establish governance documentation for the project including the establishment of an independent eNID Scientific Leadership Group that would set the scientific direction and lead the project. A MoU between the eNID steering committee and MSBase was executed.

An MSBase Project Coordinator has also been appointed, to facilitate communication between the

eNID SLG and key stakeholders, as well as track project progress and milestones. Professor Stephen Reddel and Dr Katherine Buzzard have worked closely with the MSBase IT Project Manager and software development company, Kiandra, and have been instrumental in providing the data fields required for the eNID database for incorporation into the new MSBase Data Entry System (MDS) software.

The overall development of the MDS software and the rebuild of the MSBase Registry website has been the focus of MSBase IT resources throughout 2017 and 2018. These systems are critical for incorporating the first rare neuro-immunological disease into the MSBase Registry, which will be the Myasthenia Gra-

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vis Registry. MDS has recently been launched for new MSBase centres and will be available soon for existing centres. Once the system is functional for both new and existing centres, the next phase of eNID planning can commence. Further detail is provided below.

Work completed

Several stages of scoping and planning have taken place, including a two-day meeting involving Dr Katherine Buzzard, Prof Helmut Butzkueven, MSBase IT Project Manager Rob Milliken and the Kiandra Project Management team, which took place in December 2017. This workshop focused on the technical mapping of specific requirements for tracking Myasthenia Gravis (MG) and resulted in a very detailed scope for the registry implementation. The technological solution proposed was quoted for \$180,000.

Next steps and indicative timelines

As mentioned, MSBase has rebuilt the registry website, which contains both a database and Content Management System. In conjunction, MSBase has been building a new data collection tool; the MSBase Data Entry System (MDS), a locally installed software which aids both research data collection and clinical management, and from this system patients can also be enrolled into the registry function. These form two complex and sophisticated systems which work together to maximise research outputs and collaborative interactions and are required for the successful implementation of eNID fields.

MSBase has been focusing all technical resources on the complex development of the MDS system and launched the software to new MSBase centres in August. Kiandra have also been working on a complex data transfer piece which will enable transfer of existing MSBase centre databases to the new MDS. This will be complete by end of September. October – November will be an on-boarding phase which will see high value MSBase centres being transferred from their old database to the new MDS, in addition to addressing any bugs that may arise in the process.

December will then provide the next eNID project drive, with the opportunity to re-visit the technical build options and create an approach to be presented to the eNID Steering Committee and then the MSBase Board by February. The approach will be considered by both parties and with approval, the build will likely commence in 2019 and is scoped to take around 17 weeks, which would correspond to a June 2019 launch date. The major issue is funding, and lack of sufficient funds could result in a no-go decision by the MSBase board.

**Current donation summary:
Held in tied funding accounts**

The MSBase Foundation provided \$20,000 start-up

funds. The MSBase Foundation has gratefully received \$40,000 AUD from the QLD and NSW Myasthenia Associations of Australia as well as a generous \$20,000 donation from Prof. Stephen Reddel. Pharmaceutical donations have also been received from CSL Behring to the amount of \$10,000. All these funds are currently held in tied funding accounts within MSBase to be allocated once the project progresses. Half of the CSL grant has been used for Kiandra Project Management expenses, with \$5000 now remaining.

Future funding

Dr Katherine Buzzard has been very active in approaching pharmaceutical companies to raise additional funds. With a funding target of \$180,000 and positive indications for a further \$50,000 from commercial sources, this leaves a gap of \$45,000. The eNID group is aiming to attain a further \$40,000 from MG associations and individual donors, to reduce the co-funding amount required from MSBase as much as possible.

Donation summary:

Funds available	
Donor:	Amount:
QLD and NSW Myasthenia Association Australia	\$40,000
CSL Behring	\$5000 available (\$5000 used).
Stephen Reddel / Concord Hospital	\$20,000
MSBase Foundation Start-up funds	\$20,000
Total available:	\$85,000
Additional funds under review:	
Pharmaceutical Donation 1	\$25,000
Pharmaceutical Donation 2	\$25,000
Total under review:	\$50,000
Total available + under review:	\$135,000
Funding target:	\$180,000
Current gap:	\$45,000

Communications

A very fruitful teleconference was recently held with the eNID group and members from the Myasthenia Alliance Australia. Both parties received a project update and donation summary from Helmut Butzkueven and MSBase Project Coordinator, Charlotte Sartori. All members expressed their enthusiasm for this project to progress and agreed to meet on a monthly basis moving forward.

DVD ISSUES

Some members are still getting around to watching the DVD of the June Presentation given by Katrina Williams. As a few members have reported that the DVD is blank we request that everyone checks the DVD received.

Of the items returned, all have played. There may be an issue with certain pieces of equipment operating the supplied disc. Our supplier has suggested using a lens cleaning cloth to clean the head on the DVD player as dirt may be interfering with the read on these discs. We ask that you also try your DVD on another player.

If you have issues, please contact the Committee on 1800 802 568.

The DVD's recorded at the September AGM meeting have now been mailed. Our supplier has taken extra care with the recording process and has computer checked each disc. If you experience difficulties with this production we value your time in sharing your experiences with us.

The Committee apologises for any inconvenience caused.

There may be other ways of providing this information so please do make contact.



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.

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Henk wrote:

I have been a longtime receiver of the great benefits of Pilates exercises.

During that time I had the privilege of attending so called "Clinical Private Consultations" and always with a highly qualified and experienced instructor (a physiotherapist and almost always "one-on-one").

Since I was diagnosed some years ago with MG I continued attending very faithfully my weekly Pilates sessions, which have been and continue to be of truly great help and especially encouragement.

When I was asked to put this on paper I discussed this request with some of my wonderful and great friends at the Pilates studio I go to. They were happy to assist and produced a wonderful article emphasizing the need for MG persons to exercise and how this can be done in a truly beneficial and secure environment.

Henk.

Using Exercise to Improve Strength, Mobility and Daily Function[©]

By Nadine Phillips, Doctor of Physiotherapy (DPT, B. Biomed Sci, Hons)

A vast majority of people with Myasthenia Gravis are not aware that exercise can help to physically and emotionally manage their condition and improve their quality of life. Many people with MG often worry about how their specific condition will respond to exercise. This is a common concern and if you worry about this, you are not alone! In fact, only **11%** of people with MG perform exercise as a part of their treatment plan.

However, research shows that for people with MG, exercise can improve strength, balance and flexibility, which makes it easier to perform daily tasks such as showering, walking and climbing stairs. Exercise can also decrease depression and make you feel more positive while enhancing your mood. It can also improve the effectiveness of medication and help the immune system to function at its best, decreasing the severity of your symptoms.

When looking to start an exercise program, many people worry that exercise may cause them to become more fatigued or that it may worsen their condition. Others may worry about their safety while exercising (especially if vision and balance are affected). Others may feel disheartened or overwhelmed by their diagnosis or may not know how to begin a safe exercise program.

Regardless of how long you have had MG or how severe your symptoms, a specialised exercise program can make a significant difference in your life. So how can you get started with exercise and who should you see to get a tailored exercise program? While there are so many options for exercise, it is recommended to see an allied health professional who has knowledge of this condition and experience in prescribing exercise for people with MG.

Physiotherapists

When thinking about seeing a physiotherapist, most people think about manual hands-on

treatment. However, physiotherapists also prescribe exercise and can create specialised exercise programs for you.

Seeing a physiotherapist is the safest option when embarking on a new exercise program as all physiotherapists have knowledge of MG as well as extensive knowledge of the body.

Regardless of the severity of your symptoms, a physio will be able to create a tailored program for you based on what you need to work on, focusing on:-

- ▶ Improving your strength and balance
- ▶ Improving functional abilities
- ▶ Breathing control
- ▶ Increasing stamina and reducing fatigue

In seeing a physiotherapist, you may be shown a range of exercises that you can perform at home. Or alternatively, you may be able to attend specific exercise classes at the physiotherapy clinic.

While any physiotherapist will be able to help you, not all physiotherapy clinics will have the facilities for you to exercise on site. As such, it is a good idea to look for private clinics, hospitals or universities which specialise in neurological conditions and rehabilitation and have access to gym equipment, Pilates machines or hydrotherapy to aid your exercise programs.

Exercise Physiologists

Similar to physiotherapists, most exercise physiologists will be able to create a specialised exercise program which is tailored to your specific needs. Exercise physiologists have an in depth knowledge of the body and their entire university degree is focused on creating exercise programs for specific conditions.

As a part of seeing an exercise physiologist, you would usually be taken through a tailored exercise program at the gym or clinic. Depending on your level of function, you may also be prescribed

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simple exercises that you can perform at home.

Most exercise physiologists have access to a wide range of exercise equipment to assist your exercise program.

When seeing a physiotherapist or exercise physiologist, you don't need a GP referral and most people with private health insurance are able to claim a rebate. If you do choose to obtain a GP referral, you may be able to also claim some sessions back through Medicare.

Whichever exercise specialist you choose, your

exercise program should focus on developing strength but not pushing you too hard (you should not feel overly fatigued after exercising). Ultimately, exercise should improve your condition, not worsen it, so it is best to go with someone who is experienced and is able to help manage your condition with exercise and improve your quality of life.

Stay tuned for Part II of this article, which will discuss the different types of exercise in more detail and how each type can benefit people with Myasthenia Gravis.

References

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Westerberg E, Molin CJ, Lindblad I, et al. Physical exercise in myasthenia gravis is safe and improves neuromuscular parameters and physical performance-based measures: A pilot study. *Muscle Nerve.* 2017 Aug;56(2):207-214. doi: 10.1002/mus.25493.

About the Author

Nadine holds a postgraduate Doctor of Physiotherapy and a Bachelor of Biomedical Science with Honours from Bond University. Nadine has worked in a number of private Physiotherapy clinics across Brisbane as well as working at Studio Pilates International for the last five years as a Physiotherapist and Clinical Pilates Instructor. Nadine treats a wide variety of patients from pre-post natal, post-surgical, athletic and elderly populations.



MURIEL'S DID YOU KNOWs?

- If you lived on an average sized street in Australia comprised of 100 households, on that street there would be a marriage every 9 months, a death every 7 months and a birth every 14 weeks.
- The year the queen came to the throne (1952), just 40 Australians turned 100. Last year, more than 2600 Australians turned 100.
- Currently there are almost 105 baby boys born for every 100 baby girls born in Australia
- On average, women in Australia outlive men by four years.



Welcome to our new members

Leonie, Sinnamon Park, QLD

Dee, Leichardt, QLD

Judy, Leichardt, QLD

Peter, Bayview Heights, QLD

John, Upper Kedron, QLD

Puzzlers

Puzzles by
www.thinkablepuzzles.com
www.theteacherscorner.net

Sudoku

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

Bamboozable

BED BED	cycle cycle cycle	STAY NIGHT
$\frac{1}{1}$	i SLEPT	RACE

Word Change

cost
bowl

Word Search - African Countries

A C C M I T U O B I J D E I L G	ALGERIA
E L O A A A C E P A H N A E N E	ANGOLA
N T O M P D H M U X R N S I A R	BENIN
I A S G O E A F J J F O N N W I	BOTSWANA
U Y G A N R D G A J T E I V G T	BURKINA
G N S D O A O Y A H B K R H Y R	BURUNDI
V E R D E C B S O S R H A O C E	CAMEROON
B K G F N I O H A U C N A A W A	CAPE
A G O Y L F T Y B I A A M K W V	CHAD
A A J I P T S S Q X P E R A F N	COAST
I B M Y P T W Z O J R O F A S O	COMOROS
R O O Q B X A G B O Q T I B S O	DJIBOUTI
E N O F X N N N O D Z X T H M Z	EGYPT
G F B Z H V A N R A T X L B T V	ERITREA
L O H L D J B U R U N D I T P E	ETHIOPIA
A A I R E B I L Y R O V I I B Y	FASO
	GABON
	GHANA
	GUINEA
	IVORY
	KENYA
	LESOTHO
	LIBERIA
	LIBYA
	MADAGASCAR
	VERDE

Answers

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

Word Change 24 answers: cost, coat, coal, cowl, bowl.
 Bamboozable 23 Answers: 1. Bunk Beds; 2. Tricycle; 3. Stay overnight; 4. One on One; 5. I overslept; 6. A close race.

NEWS FROM AROUND QUEENSLAND

Brisbane – Coffee & Chat

Coffee Club, Village Square, 18 Commerce Drive, Browns Plains
at 10.30am on Saturday, 24 November.

News from Cairns

Visiting Cairns? You are most welcome to join us when we meet.
The next meeting for MGAQ Cairns will be on **Saturday, 27 October, at 11.00 am in the Boardroom at the Cairns RSL, Esplanade.**
For more information about the Cairns group, call Donna on 0414 397 462.

C News from Townsville

Thanks to members and family for attending our September lunch. Our chats were great.
The next meeting is on **Saturday, 24 November, at 12 noon at The Avenues Kirwan, Townsville,**
T At this meeting we will welcome some members from the MGAQ committee. We appreciate these members joining us for lunch.
As it is our Christmas meeting, we will have a secret Santa gift exchange. If you or family member would like to receive a gift, we invite you to bring a gift valued between \$15-\$20.
For details contact Daphne 0400 778 637 or daphclay@gmail.com

M News from Mackay

Everyone is welcome to attend our Christmas Lunch to be held at the **Mt Pleasant Tavern, North Mackay on 18 November, at 12 noon.** For more information about the Mackay group, call Bill on (07) 4954 1221.

G News from Gladstone-Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 4973 7983.

SC News from the Sunshine Coast

Our final morning tea for the year will be on **Friday, 23 November at 10am, at the Kawana Bowls Club.** Hope to see you there.
For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

B News from the Gold Coast

For more information about the Gold Coast group, call Nader on 0415 834 401.

WHERE IN QUEENSLAND?
Let us know where you think it is:

September Edition: Pumicestone Passage looking south
Send to: info@mgaq.org.au or post to MGAQ, PO Box 16, Mt Gravatt, Qld, 4122

what's coming up

What's On	When Is It	Where Is It?
Christmas Function	Sunday, 9 December, 11.30am for 12 noon	Club Southside 76 Mt Gravatt, Capalaba Rd, Upper Mt Gravatt

MEET THE COMMITTEE DATES

WHEN IS IT?	WHERE IS IT?
TOOWOOMBA - 11.30am SUNDAY, 11 November	Picnic Point Cafe, 164 Tourist Road
TOWNSVILLE - 12 noon SATURDAY, 24 November	The Avenues Hotel, 270 Kern Bros Drive, Kirwan

The management committee feels it is important for members from across the state to meet and chat with some of our committee.
Therefore, over a period of time, two members from the management committee will travel to each of the areas.
The regional co-ordinators will negotiate with the committee re the most suitable time of the year and these will be advertised in the newsletter.