



Myasthenia Gravis Association of Queensland Inc

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Founder Member, of Brisbane

Messages

Myasthenia Gravis Association Of Queensland Inc.

JULY NEWSLETTER

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.

PRESIDENT'S REPORT

I start my report this month on a serious note. It is amazing how this association has grown over the past years in relation to the amount of work and projects in which we are involved. This level of support and advocacy for our members can only continue if we have the personnel on our management committee and/or others who put their hand up to help with the multitude of 'jobs' to be done. Some of these require a level of skill but many just require people who are prepared to contribute their time and take on particular projects which occur during the year. It must be remembered that every member of the current MGAQ management committee also has Myasthenia and thus has good days and bad days but are still expected to meet commitments and timelines. So, please give this plea due consideration and remember that everyone has something to offer.

Our 30th anniversary celebration was very successful. Many thanks to those who took the opportunity to join the Zoom meeting. Our patron and guest speaker, Dr Cecilie Lander, gave a very moving and relevant address, the theme of which was "Family". It certainly fitted in

with the messages about the Myasthenia family that has evolved over 30 years. Congratulations must go to Cecilie and her husband, Mervyn, for both receiving an OAM in the Queen's Birthday Honours list. Someone commented on a website that Cecilie will never really retire! Also, remember that category A and E financial members can get a copy of Cecilie's presentation on DVD by phoning Susan on **1800 802 568** or emailing info@mgaq.org.au

All financial members should have received a copy of our 30th Anniversary Book. It really is a walk through time in terms of the people and the growth of the MGAQ. Many thanks to the people who put in so much time and effort in bringing this wonderful resource to fruition. There were times when we thought it would not be finished but a combined effort proved invaluable. If you did not receive a booklet, please phone Susan on **1800 802 568** so she can check on your membership status.

Finally, just another reminder that it is not too late to complete a nomination form for membership of the MGAQ management committee.

Thanks, Carol

Supported by



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Government

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Your Association is your **VOICE** with Government.

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

The MAA Board is working very hard and giving many hours but; There is no exciting announcement to make; There is no major change happening; And there is no ground breaking research story!

What IS happening you ask?

MGBase (formally known as eNID) is in place and slowly growing, a major Patient Reported Survey Research Project discussing side-effects experienced from treatments received is close to submission for ethics approval, Government departments including the TGA, MSAC, HTA all know who we are, Federal Ministers on both sides of politics are engaged with the issues presenting to the Myasthenia community and Industry partners are willing to work with our organisation. In addition, we are very happy to be steadily gathered more myasthenia patients into our folds.

So why do what we are doing?

This is an easy question to answer. The more the Board experiences, the more it becomes obvious that our work is extremely relevant and important. Treatments **ARE** limited, restricted and inequitable. As a rare disease, we face many issues common to the rare disease community. Federal politicians do have an appetite to understand but without our voice they just cannot know what needs to be done.

The MAA Board partners regularly with the team at Rare Voices Australia and draws on their experience and strength. The Action Plan for Rare Disease focusses on coordinated and centralised care centres. This goal is very important to the Myasthenia community. It is how we will all access knowledgeable, equitable and comprehensive treatment.

Please celebrate with us as we continue to be dogged in our pursuits. Please, do maintain your support and do be engaged when there is an opportunity.

Susan White, Chairperson

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au

MGAQ.org.au Member Log-in

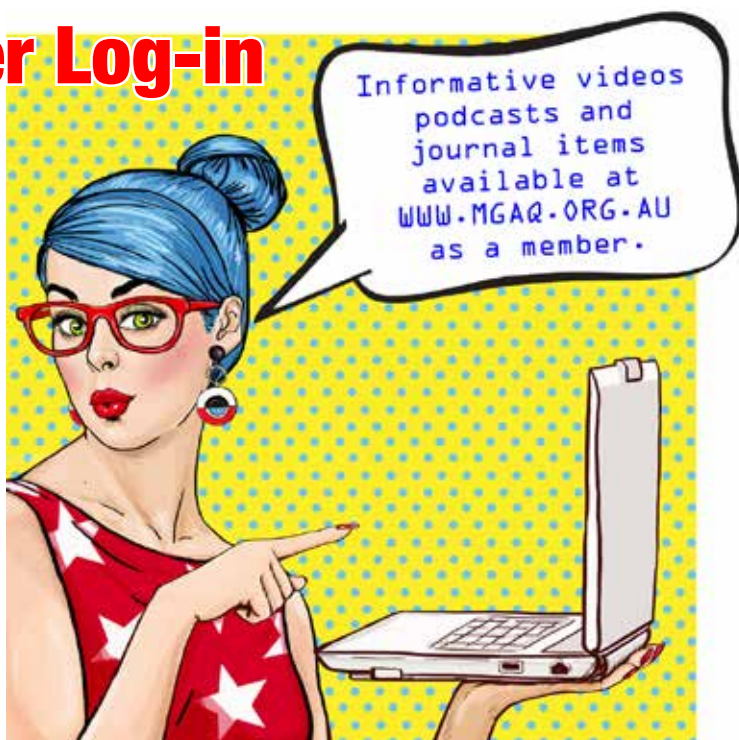
The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

The contents of library materials available to members is listed and a hint towards the range of research papers the Association can help members access is given. A detailed list of the papers will soon be posted.

Currently members need to reach out and request access to this area. The Committee are looking into making it easier for you.

Don't miss out - call 1800 802 568 or email info@mgaq.org.au to make your request.



SUPPORT your Association by taking **MEMBERSHIP.**

30 years anniversary
1991 ~ 2021

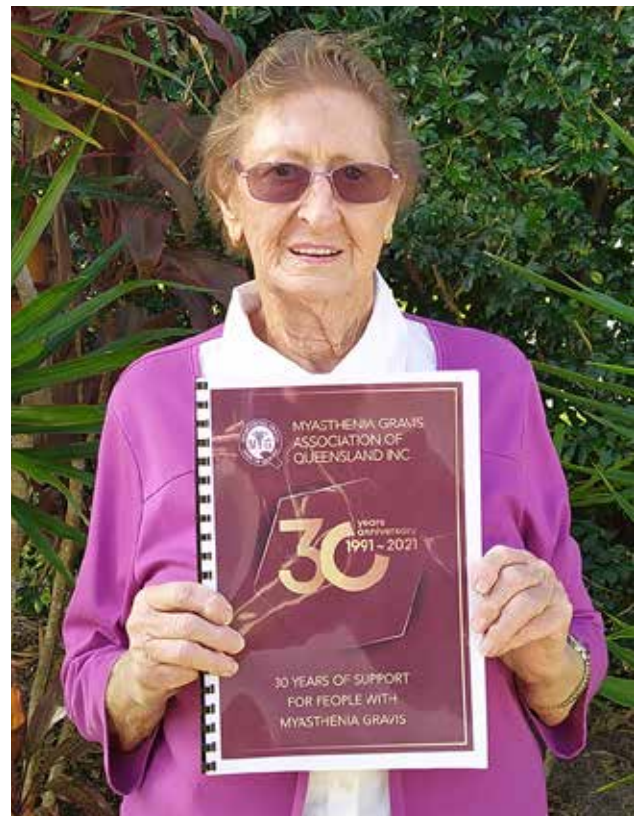
MGAQ Strong How far we have come!



• Shirley Johnston with her 30th Anniversary Book.



• A letter from Shirley Langshaw and pictured with her 30th Anniversary Book.



The **STRENGTH** of your Association is determined by the work undertaken.

MY MG JOURNEY

I AM MG STRONG - MY STORY WITH MYASTHENIA GRAVIS

Hello! My name is Bridget, I am 15 years old and I have Myasthenia Gravis. I first started feeling symptoms when I was in year 8 of high school (in 2019) before this I was completely normal, I went to school everyday and hung out with my friends like any other normal kid my age. The symptoms weren't that bad at first, it started off as just not being able to smile like normal, I couldn't run like normal and my legs would give out on me all the time so I pretty much always had some sort of scar on my knee.

Over the course of that year things only progressively got worse. I could no longer run at all or go up any stairs, my speech was slurred and anything I said was pretty much inaudible, I couldn't eat without cutting my food up like a baby, no one could understand what I was saying majority of the time and I stopped eating at school because I couldn't chew my food. Because at that point in time we didn't know what was wrong with me, I couldn't tell people what was going on to try and make them understand. People would laugh at me and call me names. As the symptoms got worse, so did people's behaviour towards me. I would get yelled at for faking and being an attention seeker (by this point I could only walk with crutches and/or support from other people). They would call me stupid, ugly, a brat, cripple, sticks, fat, the list goes on... I guess people found it funny that I would fall over easily, because on the rare occasion that I did go up stairs people would push me down and not help me get up, they would also walk up to me and just push me over just for fun I guess. Whenever I smiled people would laugh and say I looked like I was in pain, and honestly I kind of was. But not the kind of pain that you feel when you break a leg and wanna scream in excruciating pain, but more of a pain you feel when your trying

your hardest to tell your body to do something but it just doesn't do what your telling it to. For example, you can't breath and your trying your hardest to get even the tiniest bit of oxygen into your lungs... but you just can't. That's the kind of pain I was in, and it was unbelievably frustrating. I was finally diagnosed with MG in April of 2020. I was so relieved to finally know what was wrong



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LEARNING more about helping out is as easy as **PHONING 1800 802 568.**

Continued from page 4

with me and be able to let people know what was wrong, I thought "Hey, maybe things will finally get better and I can be happy and have friends again!" After about 3 weeks in hospital I was finally able to go home just in time for mine and my mums birthdays. Things were great, my medications were working, I was back at home, the weakness was gone and I was... happy.

I was now able to go back to school everyday like normal, I was so excited to finally be normal again. Well, my whole idea of being normal and people being nice to me again went out the window real fast. Trying to explain my illness to people who don't want to listen isn't the easiest task. Even though I now had a real answer for what has been going on with me, people will believe what they want to believe. I was no longer the fat girl faking an injury for attention, I was now the same fat girl just this time I was faking an illness for attention. And even the people that did believe me said I was being 'dramatic' with the whole weakness thing. By this point my medication wasn't working how it used to and the weakness was back, my mum would have to help me get dressed, get on and off the toilet, help me walk and I couldn't sleep alone because my breathing was that bad. It was hard not having any people that truly tried to understand what I was going through, but hey, at least I had people to sit with and talk to at lunch. These people that I called 'friends' wouldn't invite me out with the group and when I asked why, they would just say "well your sick and we didn't think you would want to come." Well I did want to go... They would make fun of me and my illness and then say it was just 'a friendly joke'. I didn't find it very funny at all.

This brings us right up to this year. My IVIG only last about 2 weeks (I get the infusion every 4 weeks), I am on a cocktail of medications daily including steroids which add to my weight gain. My mental health runs hot and cold. I try my best to go to school but most of the time I'm too weak so I have to do my school work at home. When I

am at school no one other than those 6 'friends' will talk to me, so even though they pick on me I didn't want to be alone so I just sat there and acted like it didn't bother me. Quite recently, they told me they didn't want to hang out with me. I don't feel like I did anything wrong so I guess that's why I'm so hurt. I mean its not like they cared that much about me or did anything when I was in hospital. But it just hurts being alone. I still get laughed at and called names regularly.

I may not have any friends but I do have my family, I would say that my mum is my best friend and biggest supporter, I talk to her about everything and she teaches me how to be strong even when my body isn't. I have learnt that strength isn't just being able to hold heavy things with ease, but its more things that make u feel strong in your mind and heart. For me, strength is COLOUR!! I love drawing and art, I tried my best to represent my strength from colour and art in the drawing I made and submitted. Not everyone will find there strength in the same place, your strength might be from; a person, a song, a book, a movie, a place, or a feeling even. Once you find your strength to me, you have already beaten the weakness.

I am still currently suffering from symptoms pretty bad to this day, I feel sad that I can't go out and make new friends, hold and play with my baby brother and niece, go out with my family, go to school normally, run, dance, eat my food normally, or even hold my pencil to draw sometimes. But my mum has always told me to look for the good things so then the not so good stuff doesn't seem so bad. I like to make the most of my good days so that when I have bad ones it's not so upsetting. I hope that for my future I will have had my thymectomy, gone into full remission, return to school, make some new friends, go to an art and animation school and be as happy as possible with my family and loved ones. I am not afraid of my illness and am proud to say that I am MG strong!!!!

Love and strength, Bridget



Welcome to our new members

Anna C
Kewarra Beach,
Qld

Melissa G,
Toowong, Qld

Chloe W,
Rosedale South,
Qld

Swapna S,
Tugun, Qld

Lynette W,
Woodville
SA

Peter H
Elanora, Qld

Mary B,
Beaudesert
Qld

Ian A,
Wulgura, QLD

Become **INVOLVED** - make a **DIFFERENCE** to yourself and others.



We have reached 1000s of people during June MG Awareness Month



• Story Bridge MGAQ Awareness Banner.

"Crossed the Story Bridge today and saw the sign and thought of you." Sent from Yoli to her aunt Denise who has MG.



• Carol spreading awareness of the Light-up for MG with a story in The Townsville Bulletin.

Picture: Evan Morgan

Tory spreading awareness by sharing her father's story with Myasthenia.



View the Jeff Gill story
Toowoomba Rugby Football League Inc.

<https://fb.watch/6LdHA9hQkc/>

Valleys Diehards

<https://fb.watch/v/etqJ7ia0W/>

And also available on the MGAQ Website
as part of the

2021 - 30 Year Anniversary Video

<https://mgaq.org.au/members-only>



• Susan spreading awareness on Myasthenia via Win News, Channel 7 and the Toowoomba Chronicle.

SUPPORT your Association by **VOLUNTEERING.**



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 13 SEPTEMBER, 2021

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2021/2022

Eleven places are available for Committee nomination due to the MGAQ having an increasing range of projects in this new and exciting era of the Association. We always welcome anyone who wishes to nominate.

People can nominate themselves or anyone else they feel would be a suitable member of this very progressive and dynamic Committee.

Interested people need to be comfortable with using a range of technology and will need to maintain regular communication in order to stay abreast of issues throughout each month. Meetings are a full day held each second Saturday of the month excluding January and attendance via Zoom or in person is required for a majority of meetings.

To gain more information, discuss these roles and commitments you can phone **Freecall 1800 802 568**.

Members with Myasthenia and those with an interest in Myasthenia are welcome to apply. Carers and supporters also very welcome to nominate. To nominate, you must be a financial member 2021/2022.

Nominations **MUST** be received by the Secretary by the close of business on **FRIDAY, 8 AUGUST 2021**.

If more than one nomination is received for the same position, a ballot will be conducted to all financial members, with the votes to be returned by **Friday, 6 September 2021**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 12 September 2021.

Nominee (*Print name*):.....Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee (*Print name*):.....Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nominee (*Print name*):.....Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President** **Vice-President** **Secretary** **Treasurer** **Committee Member**

Nomination(s) (above) Seconded by (*Optional*)

Additional Nomination Forms available on request.

Members may be interested in offering support, but would prefer to nominate themselves for special project work rather than taking a Committee position. If this is preferred, provide your name, best contact details, and a little about the skills you can offer to the Association.

Name:.....Skills Offered:

.....Best Contact:.....

Your Association is your **VOICE** with Government.

RSVP ARE NOW REQUIRED FOR ALL FUNCTIONS DUE TO COVID-19 RESTRICTIONS

News from around Queensland

News from Cairns

Please note in your diary our next get together is on **Saturday, 21 August at 11.00am at the Cairns RSL Club Boardroom, Esplanade**. If you are visiting Cairns at this time, you are most welcome to join us. For more information, please contact **Donna** on **0414 397 462** or donnaformosa64@gmail.com

News from Townsville

Townsville MG lunch dates for 2021.

Saturday, 7 August, Saturday, 2 October, Saturday, 4 December.

For more details contact **Daphne** on **0400 778 637** or daphclay@gmail.com

News from Mackay

Thank you to Muriel for organising our social lunches prior to COVID-19.

Any MG members in Mackay district interested in joining our friendly group for lunch or coffee in near future please call. All suggested venues and days considered. Look forward to getting together. Stay safe and well.

For more information on Mackay, please call **Mary** on **4959 5251**.

News from Bundaberg

For more information, please contact **Denise** on **0431 571 399**

News from Hervey Bay – Wide Bay Burnett Region

For more information, please contact **Jan** on **0429 622 438** or janpowell3@bigpond.com

News from Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call **Garth** on **0408 155 954**.

News from the Sunshine Coast

Please join us on **Monday, 2 August at 10.30am** for a Coffee and Chat at **Kawana Club, Nicklin Way**. All Welcome. For more information please contact **Vicki** on **0411 146 898** or email avlplummer@gmail.com

News from the Gold Coast

Our next meeting will be at **Saturday, 17 July, 10am** on at **Southport Sharks Club**. I hope to see all there. For more information, contact **Nader Amiri**, Gold Coast Co-ordinator, **0415 834 401**.



Brisbane - Coffee & Chats

Banyo – Putia Pure Food Kitchen, 4/17 Royal Parade, Banyo – Thursday 29th July @ 10.30am
Ipswich – Queens Park Café, 10a Merle Finimore Ave, Ipswich – Saturday 7th August @ 10.30am
Calamvale – Coffee Club, 668 Compton Road, Calamvale – Wednesday 25th August @ 10.30am.
 Please contact **Anita** on **0414 588 312**.

what's coming up

What's On	When Is It	Where Is It?
AGM AND GUEST SPEAKER DR REUBEN BEER	SUNDAY, 12 SEPTEMBER 10.00 AM	ASPLEY HORNETS FOOTBALL CLUB 50 GRAHAM ROAD, CARSELDINE QLD 4034

Please note that due to COVID-19 Government Guidelines and Restrictions, the advertised event may change.

Best **CARE** for all Australians is our **GOAL!**