



Myasthenia Gravis Association of Queensland Inc.

# MessaGes

JULY 2022

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 JULY 2022

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. Please be aware that relatives of members can also nominate for the management committee and what they learn from that experience will be invaluable in supporting their family member.

The **Queensland Light Up Project** for International Myasthenia Gravis Month in June was a great success. Many thanks to everyone who got behind this project, particularly Donna from our management committee who spent many hours organising this very successful activity. It was also pleasing to see that this idea has spread to some other states.

Our **Art With Heart Project** is progressing well. Please see inside this newsletter for further details and information about how everyone can become involved. Also, please be aware that this definition of "art" is very broad. Submissions cut-off is 7 September, 2022 and the Auction goes from 11 September, 2022 to 8 October, 2022.

The management committee has noticed a decrease in the number of members renewing their membership. The category A membership is only \$20 and the perpetual membership which covers you permanently is \$250. This membership money covers printing and distributing newsletters, the 1800 number, information packs, Zoom meetings, stationery etc so that the committee can function each year. So, please think carefully about the importance of renewing your membership each year.

Remember that **PATIENT VOICES MATTER** so do not forget to complete the short survey on this link before 16 July: <https://redcap.alfredhealth.org.au/redcap/surveys/?s=WXWKWDM4CMPAJH4N>

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

Thanks, Carol

### Myasthenia Gravis Association of Queensland Inc

P.O. Box 16 MT. GRAVATT QLD 4122

National Freecall: 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)

#### COMMITTEE MEMBERS

**President** CAROL BUCHANAN

**Vice-President** SUSAN WHITE

**Secretary** YVONNE HORNBY-TURNER

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

**Treasurer** DENISE HANNAY

E: [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

Anita Jackson, Donna Formosa, Rosalyn Holland,  
Kirstine Shrubsole, Karen Downes, Craig Streatfeild

**Newsletter Editor:** GREG BREADEN

E: [MGAQ.editor@gmail.com](mailto:MGAQ.editor@gmail.com)

**PATRON:** DR CECILIE LANDER AM, Neurologist

Supported by



Queensland  
Government

Ausenco

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



## MYASTHENIA ALLIANCE AUSTRALIA

### NEWS UPDATE

The MAA are receiving some wonderful feedback from our MG Community. People are so thrilled to see the Awareness work that is currently happening. It is current, meaningful and brings instant results for efforts. Being able to have a conversation about our condition is important and this is a great way to do it.

The **Art With Heart Auction** is picking up pace, (see flyer page 3). Donations are now needed to add to the growing number of artworks and items already generously submitted. Remember, you don't need to be a professional artist. Simply create or donate something that makes you smile and let's see how much we can raise together!

For more information about how to donate, and to receive your artist's pack, message via Facebook or drop an email to - [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

Also, we really wanted to send out a huge thank you to Lyn Church, member of the Royal Queensland Art Society, and the RQAS Escape Artists, for her donation of her painting "Ocean views" to the auction. As you know Lyn must manage life with Myasthenia also and is a great inspiration to us all. See Lyn's donated work and check out the auction here. <https://airauctioneer.com/art-with-heart-auction-myasthenia-gravis>

A **"Pat on the Back"** is definitely in order for our whole membership! How awesome that the Myasthenia Gravis Community has once again rallied and achieved the goal set by researchers. With a target of 200 surveys to be completed for the *"Nation Wide Observational Study into The Impact of Covid-19 on Myasthenia Gravis Patients in the Australian Population"*, we have delivered. Drs. Buzzard and Siriratnam express their sincere appreciation and hopefully they will be able to provide some feedback before too long.

If you are Victorian, a great opportunity is unfolding. A fellow Victorian, Sue Floyed, has done the legwork and is providing a framework for all Victorians to have representation as an Incorporated State Association. She is asking people to come forward for a chat with her about how you may like to be involved. This involvement can take many forms and the ultimate structure will evolve. Please show her your support by reaching out to her and enquiring. Just registering with her may be all that you can manage but it will be welcomed. Her details are **0408 944 183** or [info@mygravis.org.au](mailto:info@mygravis.org.au)

Our deepest sympathies are extended to the family of Dr Ted Burns and to all our Myasthenia Friends in the USA. Such a sad loss. Please see more details below

Finally, but very importantly, I know that everyone joins me in saying thank you to the medical teams who are working so hard during this difficult winter season to ensure that we have continued access to our treatments and to our invaluable care. This commitment is greatly appreciated.

My very best wishes to all.

**Susan White- MAA Chairperson**

If you are not already registered with the Alliance please go to [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

## Australia Remembers Dr Ted Burns

In memoriam of Dr Ted Burns, who was an essential contributor to the initiation and design of MGBase.

Dr Stephen Reddel writes, Ted was a member of the MGBase committee that determined the field data sets, and he designed the Myasthenia Gravis Composite (MGC) that is the key outcome measure for MGBase, and was also instrumental in the MG Quality of Life scores (MG-QOL(-R)). Ted is sorely missed. He was a highly significant neurologist in MG and probably the most significant from the point of view of patient care and patient associations. A truly great bloke too.

Ted was a very committed human being with a particular passion for making MG research relevant to patients, and was a medical advisor to the Myasthenia Gravis Foundation of America.

Further information can be found at <https://myasthenia.org/About-Us/Blog/thank-you-dr-ted-burns-for-your-years-of-dedication-to-the-mg-community>

# ART WITH HEART AUCTION



## Calling all warriors and supporters of the Myasthenia Community

To join in the fun and help raise vital funds for **Myasthenia Alliance Australia**, you don't need to be a professional artist. You can simply create something or gift an item that makes you smile.

**Let's see how much we can raise together!**

### DONATIONS

Send a high quality image of your donation to [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au) or via message on [facebook.com/mgqld](https://www.facebook.com/mgqld)

### ARTIST KIT

Discover everything you need to know about joining in the auction [here](#).

### SUBMISSIONS

Submissions cut-off: 07/09/2022

### AUCTION

From 11/09/2022 to 08/10/2022

The hero piece for the **Art with Heart Auction** is the artwork donated by **Lyn Church**, a long term Myasthenia Gravis Warrior and a valued member of the **Myasthenia Gravis Association of Queensland Inc.**

Lyn is a modern impressionist artist who paints mainly in oils and on location. This becomes challenging as she needs to paint quickly before the natural scenery changes too much. It's pretty tricky when your vision is doubled, your arms are weak and you are wobbly when standing.

In her words:

***"Never give up! Even though we suffer from this rare condition, we are strong, and we can achieve!"***



**Myasthenia  
Alliance Australia**  
[myastheniaalliance.org.au](http://myastheniaalliance.org.au)



**Myasthenia Gravis Association  
of Queensland Inc.**  
PO BOX 16, Mt. Gravatt, QLD, 4122  
FREECALL 1800 802 568  
[mgaq.org.au](http://mgaq.org.au) • [info@mgaq.org.au](mailto:info@mgaq.org.au)







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



### *Ashleigh says*

To have support from the Brisbane City Council and to see some of Brisbane's key assets like the Story Bridge light up teal in the month of June will be truly heartwarming. Like many others, this disease isn't one of the common ones spoken about due to the rarity of it.

By lighting up the Story Bridge I am hoping that it will have people questioning 'what for' and start conversations about Myasthenia Gravis and other rare diseases.



### **Mango Hill Coffee & Chat 30 June**

### **WA Coffee & Chat - 19 June**



### *Lisa says..*

I am a parent of a child that was diagnosed in her teens. I had never heard of this disease and no one around me knew anything either. Having the support of the Queensland Myasthenia Gravis Association made all the difference to the education and support that my family needed in understanding MG for my warrior. It is a rare, invisible disease that most people haven't heard of including medical professionals. Putting trust in these people to treat my daughter is just as scary as the disease itself.

I am so touched that the Logan City Council have supported Myasthenia Gravis Awareness by turning the Water towers and Landmark Bridges, Teal. I will look at my local Hillcrest Water Tower when it is Teal and feel very proud for my daughter and all the other MG patients that battle this disease daily. I will definitely talk about this to the local community whom I come across. No words can describe how grateful I am to the Logan City Council and the Myasthenia Gravis Association of Queensland for turning Teal.





# QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.

**The MGAQ wish to thank the following for their support of International Myasthenia Gravis Awareness Month**

- Brisbane City Council
- Bundaberg Regional Council
- Cairns Regional Council
- Central Highlands Regional Council
- Skypoint Gold Coast
- Longreach Regional Council
- Mackay Regional Council
- Townsville City Council
- Stadiums Queensland
- Queensland Country Bank Stadium
- Logan City Council

**Brisbane**



Story Bridge - Kelly and Charlie Parker MC

**Brisbane**



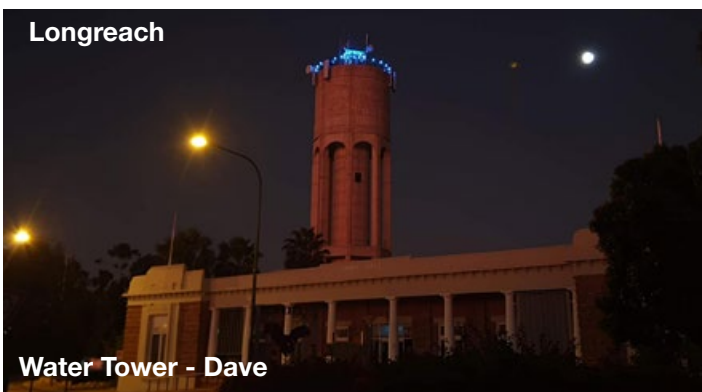
Story Bridge - Kelly

**Brisbane**



Queen Street Mall - Denise

**Longreach**



Water Tower - Dave

**MGAQ thanks Grain Corp, Newcastle for their support with "Lighting up for Myasthenia " and to Paul Carpenter for organising it.**

**Newcastle, NSW**



Grain Corp - Paul

**LISTEN** to audio Newsletter via **MEMBER ACCESS**



## MGAQ JUNE MEETING - 12 JUNE

### Sunnybank Community & Sports Club



Carol Buchanan, President MGAQ welcomes everyone.

### **Michael - Sunshine Coast**

My recent experience with my first MG zoom meeting was great. It all worked faultlessly. I was able to expand my understanding to grasp the bigger picture of rare diseases in Australia and the many hurdles in flying the flag! The difficulty in raising funds for ongoing research. It's an extremely complex issue. Looking very much forward to the next session and I thank all involved for the informative presentation.



- **Guest Speaker - Louise Healy from Rare Voices** discussing the topic *"Taking Action Together: collaborating to implement the National Strategic Action Plan for Rare Diseases"*



- **Snowflakes to decorate the tables** made by MGAQ member, Denise.

## MEMBERS' FORUM

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.**

### How the Devastation of the Brisbane Floods Gave Me Resilience

My MG has been a rollercoaster in my life. Symptoms were good one day and bad the next. I had to battle through a few scary exacerbations with hospitalisations and the wait for treatments to make a difference. I know many of you can empathise but as I write this life is better. I am not under any illusion things may go south at anytime but its not a focus anymore.

This came about from the most difficult of times for so many, the February Brisbane Floods.

You see, a deep seated fear of mine was that in such just a time my MG would raise an ugly head and I will be in real harm and I would not be able to cope.

That Sunday night the flood waters rose so quickly and cut us off from leaving. The water started to enter the house. My husband and son did their best to raise furniture and save as much as they could. I took baskets of small things and food up the stairs as much as I could till I was breathless. Then had to sit hoping and wishing I would be ok, Mestinon and Steroids beside me. My husband was secretly worrying too. Eventually we retreated upstairs and waited to see what was to come.

We got through that night, the clean up, moving ourselves to a rental while our home of 40 years is repaired. To my amazement I got through it. I did have a couple of not nice days but I got through them myself. I realised my fear had disappeared and I am very proud of myself. I no longer live with waiting for the next bad time. I live for my enjoyment of my grandchildren and life in general. MG no longer rules me **I AM RESILIENT.**

*Karen*







## MGAQ Inc. podcast series

# UPDATE

### Greetings All

During July, three new Podcasts have or will be produced. They include:

- A discussion with MAA Chairperson Susan White about the activities and focus of the Myasthenia Alliance of Australia and how it is working to improve MG patients lives through greater access to services. This podcast will be distributed on Thursday, 21 July.
- An audio podcast with Rare Voices executive Louise Healey on the roll of Rare Voices together with patient Associations such as the MAA and the MGAQ to ensure Patient Voices Matter at a Federal Government level. This podcast is scheduled for distribution on Thursday 4th August; and
- An audio podcast of the July 2022 MessaGes Newsletter which will be distributed as soon as the Newsletter is available and can be recorded.

We look forward to your company and should you have any suggestions for potential content, feel free to contact Dr Podcast at [podcast@mgaq.org.au](mailto:podcast@mgaq.org.au)

## POSITIONS VACANT

### VICE PRESIDENT

### ADDITIONAL COMMITTEE MEMBERS

All new committee members will be fully supported. You do not need to live in Brisbane.

For more information please email [info@mgaq.org.au](mailto:info@mgaq.org.au) or call 1800 802568

## WELCOME TO OUR NEW MEMBERS

**Reuben,  
Brisbane Qld**

**Lisa,  
Rosedale South Qld**

**Sairin,  
Regents Park Qld**

### MURIEL'S DID-YOU- KNOWS

- Melbourne was the capital city of Australia for 26 years between 1901 and 1927 before the capital shifted to Canberra
- There are three times as many sheep than people living in Australia
- The Australian Emu – a large, flightless bird – can run as fast as 45km/h (28mph)
- Platypus are highly poisonous, and have enough poison to kill a dog or make a human seriously ill

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



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**Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.**

### Tips for Accessing Rizurgi

*Sharon, MGAQ Facebook Admin - Lambert Eaton LEMonS Australia suggests the following for easy access.*

A reminder to Australians living with LEMS that Ruzurgi will be accessible on the Australian PBS from 1 July.

You will not be able to use your previous hospital scripts after 1 July. You will need a brand new script from your neurologist with the PBS number on it. The PBS covers 200 tablets per repeat and it will cost \$6.90 for concession card holders and \$42.50 for everyone else.

If you need more than 200 tablets per month, your neurologist needs to call the TGA when they write each new script and get an authority number for the extra amount and write it on the script.

Each script will be for 6 months supply. The script can be faxed directly to your pharmacy of choice (or the pharmacy in Gosford NSW mentioned in the information sheet) both of who will send it directly to your door if you so wish.

Some hospitals are agreeing to order and supply under the PBS, so the new script is still needed, but you may have to check if your usual hospital will do this. Keep in mind, that means you still have to travel to that location to collect. They will not despatch it to you.

After the first prescription is written by your neurologist, a GP can write subsequent scripts (under the supervision of a neurologist). Your GP will need to obtain the same TGA authority each time they write a new script for patients who take more than 200 tablets per month - and write it on the script.

# what's coming up

What's On?	When Is It?	Where Is It?
<b>AGM and Guest Speaker:</b> <b>Dr Geraldine Moses AM</b> DCLinPharm-Adj. Pharmacist Assoc. Professor	<b>SUNDAY,</b> <b>11 September</b> <b>10.15am for</b> <b>10.30am</b>	<b>Sunnybank Community &amp; Sports Club,</b> <b>470 McCullough St.</b> <b>Sunnybank</b>

## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us on **Saturday, 3 September (NOTE DATE CHANGE)** in the **Boardroom at Cairns RSL Club, Esplanade at 11am - 12.30pm**. If you are visiting Cairns region at this time, you are most welcome to come along.

For more information, please contact **Donna** on **0414397462** or email [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com)

### News from Townsville

Thanks for attending our June Dinner. I look forward to your company at our next lunch on **Saturday, 27 August at 12.00 noon, Sports Club, 159 Bamford Lane, Kirwan**. Family members are welcome.

For more information, please contact **Daphne** on **0400 778 637** or email [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **Mary** on **4959 5251**

### News from Bundaberg

We would love to see you on **Saturday, 30 July at 10.30am** at **The Spotted Dog, Railway Hotel**. The table is booked under MGAQ. Look forward to seeing you there.

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

### News from the Sunshine Coast

The Sunshine Coast Coffee and chat group enjoyed a morning catch up at the Kawana Club on Monday, 13 June. It was well attended and we welcomed Michael into our group. We were too busy chatting to get a photo. OOPS!

The next coffee and chat has been organised for **Monday, 1 August at 1030am** at the **Kawana Club, 476 Nicklin Way, Kawana**. All welcome to attend. Contact **Vicki** on **0411 146 898** or email [avplummer@gmail.com](mailto:avplummer@gmail.com)

### News from the Gold Coast

Hi Everyone, MG Gold Coast group had their get-together sharing experiences with others on Saturday 18th June at Broadbeach. Our next get together is at **10am, Saturday, 13 August at Southport Sharks Club, Cnr Olsen & Musgrave Ave**. I hope to see you all there.

Your local contact for the Gold Coast group is Nader, contact number is **0415 834 401**.



## COFFEE & CHATS

RSVP Anita on 0414 588 312

### WELLINGTON POINT

**Thursday, 21 July at 10.30am - Farmhouse Restaurant and Coffee Shop  
625 Main Road, Wellington Point  
Hope to see you there!**

### IPSWICH

**Saturday, 30 July at 10.30am - Queens Park Cafe  
10A Merle Finimore Avenue**

### SPRINGWOOD

**Thursday, 4 August at 10.30am - Cafe 63  
99 Cindarella Drive, Springwood**

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





## ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 11 SEPTEMBER, 2022

### CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2022/2023

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, 5 August 2022**.

If more than one nomination is received for the same position, a ballot to all financial members will be conducted with the votes to be returned by **Friday, 5 August 2022**.

**Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 11 September 2022.**

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.**

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*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:.....

# MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2022/2023 are due.

The envelope in which your newsletter is enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

If you receive the newsletter by email and are unsure whether or not you are currently financial, **please phone our 1800 802 568 freecall number or email [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au) to enquire.**

The majority of members will have 6/22 which tells you (and us) that you are financial to 30 June 2022. Others may show 6/23 or even 6/24 to indicate they have saved time and postage by paying in advance.

If you are unfinancial, **please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive all resources.**

We are also giving you the option of paying your subscription directly into our bank account.

## **New payment option for members of "Perpetual membership"**

**Cat A (Myasthenia Member) & Cat E (Associate Member) \$250 and Cat D (Carer Member) \$125.**

This one-off payment would mean that you never have to worry about renewing your membership again. Please note that a Cat D membership must be attached to a Cat A Myasthenia Membership, it is not a stand-alone membership.

## **MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE**

**[www.mgaq.org.au/membership-application-form](http://www.mgaq.org.au/membership-application-form) and select Membership Renewal**

Our bank details are:

**BANK: Bank of Queensland      BSB: 124 032      ACCOUNT NUMBER: 10263772**

**ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.**

**REFERENCE: Your Name and Initials**

If you use the direct deposit method, it would help if you could email us at [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au) to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.



If you wish to pay by Cheque or Money Order, please use the following form and forward to:

**The Myasthenia Gravis Association of Queensland Inc.**

**PO Box 16 MT GRAVATT Qld 4122**

Herewith please find my cheque / money order / cash for the sum of \$\_\_\_\_\_ being annual subscription \$\_\_\_\_\_ and/or Donation \$\_\_\_\_\_.

NAME \_\_\_\_\_ **Category A Myasthenia \$20**  
**(or) Category E – Supporter \$20      Perpetual Membership Category A or E \$250**

ADDRESS \_\_\_\_\_

And for \_\_\_\_\_ **Category D – Carer \$10**  
**Perpetual membership \$125 (Cat D Carer membership must be attached to a Cat A Membership.)**

ADDRESS \_\_\_\_\_

Mobile \_\_\_\_\_ Email \_\_\_\_\_