

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

Newsletter Number 92 — Summer/Autumn 2018
Includes selected articles from Cardiomyopathy UK Newsletter

Cardiomyopathy Association of Australia Ltd is a not-for-profit registered charity
ABN 36 091 171 470

www.cmaa.org.au

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Aims of the Association:

- ◆ To provide the opportunity for individuals and their families to share their experiences and to support one another.
- ◆ To provide accurate and up-to-date information about Cardiomyopathy, when it is available, to members, their families and those in the medical profession.
- ◆ To increase public awareness of Cardiomyopathy.
- ◆ To foster medical research in this area.

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Requests may be made to the editors (*contact details are on page 3*).

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From the editors

Welcome to our combined Summer & Autumn edition

Our congratulations go to the Association's President, Alistair Kerr, who was awarded a Medal of the Order of Australia in the 2018 Australia Day honours listing "for service to community health through a range of organisations." Read more about this on page 11.

Your editors have come to an acceptance of their situation: they are old. One has a cardiomyopathy and the other has arthritis. Moreover, both have had occurrences that have led to another incurable condition affecting one and worsening the condition of the other. Our brains remain fairly intact except for not remembering names, where we put spectacles and hanging the washing out.

Accordingly, we have decided that, although we have cast off other jobs for other organisations, and gained ourselves some time, we need to step down as editors of this newsletter.

Therefore, there is a great opportunity for some person or persons to take over the editing. The format could change to a shorter publication, perhaps fewer pages, but more frequently. The British Association has changed the format and content of their newsletter because they realised that the previous format was neither cost effective nor relevant.

Our members tend to either be a few who remain for years or the majority who find what they need in the way of information and help, and leave after two or three years. Many more concerned about cardiomyopathy use the website and the internet's information and never join the Association.

So, there are questions: Is a newsletter wanted? If wanted, in what format? And who will edit it? These important issues are being discussed by the Executive Management Committee, and the views of members will be appreciated (contact details are in this newsletter).

Further details on editing and producing the newsletter are provided on page 11 for those interested or who know of possible volunteers who may be interested.



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Contact us

Details of your nearest Contact Person are provided on the following pages.

They are also available on:

- our website at — **cmaa.org.au**
- our 24 hour message bank service — **1300 552 622**
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President's message

Another year is here bringing new challenges as well as opportunities. The tasks involved in maintaining a national support organisation in Australia and New Zealand totally run by volunteers are considerable. While we are fortunate to have such a dedicated team, health and aging issues are restricting the capacity of our longer term volunteers. We therefore welcome offers of help from any members, their families or friends who would like to join our team of volunteers.

Specific areas of immediate need are mentioned on page 11 of this newsletter, but there are also opportunities to help in other areas of the Association's operations. With the benefits of communications technology, it doesn't really matter where team members are located. Also, please remember, as was highlighted in one of last year's newsletters, research shows that volunteering is good for your health!

We are currently focusing on improving the use of technology in administering the Association. We already hold Executive Management Committee meetings by Skype rather than by phone and an upgrade of our member communication system is underway.

Looking forward to later in the year, I am delighted to announce that the Association's Annual General Meeting will be held on Saturday 8 September 2018 at the Centenary Institute, Royal Prince Alfred Hospital, Sydney. That day has been designated Cardiomyopathy Day and will be held in conjunction with the Centenary Institute's biennial Information Day. As well as the opportunity to meet other members, it will enable attendees to see first hand some of the research work into genetic cardiac conditions being undertaken by the Institute. Please refer to the website for further details—

<https://www.cmaa.org.au/events.html>

On behalf of the Association, I extend congratulations to two recipients of Member of Order of Australia awards (AM) in this year's Australia Day honours. Also, I wish to express great appreciation of those who nominated me and the way my OAM has been acknowledged by family, friends and members of CMAA..

My presidential predecessor and CMAA Honorary Life Member, Judge Chester Keon-Cohen received recognition for "his services to Law, the Judiciary and various health and community organisations."

Professor Morton Rawlin received his AM award for "significant service to the medical profession particularly through governance in the areas of general practice and medical education." Professor Rawlin's support of CMAA is much appreciated and those who attended the 2014 AGM in Melbourne will no doubt recall the excellent presentation that he gave on that occasion.

In closing, I wish everyone a safe, healthy and enjoyable 2018.

Alistair Kerr, President

On behalf of the National Executive

