

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

Newsletter Number 91 — Spring 2017
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 Spring edition

You know that saying that the spirit is willing but the flesh is weak. Many of the long-term selfless volunteers for CMAA are in that position. Some have volunteered for well over 20 years and are patients themselves, either with a cardiomyopathy or some other trouble. Most are long retired and looking to cut down on the amount of volunteering they do for CMAA. Indeed, many volunteer for other charities or help with family.

Another saying comes to mind: if you want something doing, ask busy persons as they know how to organize their time. The editors look around groups that they are or have been involved with and notice two things in particular.

Firstly, the volunteers are happier and fitter – all that exercise and satisfaction, what was called warm fuzzies - from helping. You may recall, the Winter 2017 newsletter included an article supporting this view with research findings.

Secondly, at the same time, the volunteers are getting older but are still in roles because others are not stepping up to have a go.

Our Victorian contact is not well enough to continue after many years of service. Other volunteers have had to give up helping because of sickness.

Our association is not the only one to need people to take on roles. We regularly hear of other volunteer based associations whose members are wary of roles, afraid to commit because they might make mistakes. Well, we all learn from mistakes and there is always help around.

New people have ideas on how to do things better. New brooms often sweep better!!



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President's message

(presented at the AGM held on 10 September in Melbourne)

A warm welcome to those attending the 2017 Cardiomyopathy Australia Annual General Meeting. On behalf of my fellow directors I have much pleasure in presenting this report.

We are still in a sound financial position as evidenced by the audited statements provided. We continue to be served by an excellent, cohesive Executive Committee supported by a hardworking team of State and Territory and New Zealand Contact Persons also administration support. We enjoy a regular seasonal newsletter edited by Anne and David Abbott which is first class.

As with many support organisations looking for better ways to communicate with current and potential members we are increasingly reliant on our website and Facebook. To this end we are currently engaged in transferring those services to another supplier so we hope you will "like" the new look to be launched in coming months. We expect the membership database services to be more efficient in the new environment.

Many thanks to those who make donations and/or support fundraising activities such as fun run participation. While many of you recognise the need to meet costs incurred in running a support organisation others will appreciate the generation of funds to support research. This research will ultimately benefit people with cardiomyopathy. A specific purpose for raising funds with which our members can identify should be beneficial.

We have enjoyed a longstanding relationship with the Centenary Institute which maintains the National Genetic Heart Disease Registry. This included assistance with production of their information brochure. Familial heart muscle disease will be the immediate focus of special fundraising activities. Awareness, identification and treatment of inherited cardiomyopathies is our fundraising goal.

To this end we invited Professor Chris Semsarian AM, Head of Molecular Cardiology Program, Centenary Institute to be our guest speaker today. Chris is a long-time friend of the Association and one of our senior medical advisers. He is an internationally respected authority on inherited heart disease and it is with great pleasure we welcome him.

We ask him to receive what we hope will be the first of many cheques to assist in this research. Our Constitution provides as one of its objects **"To promote or assist in the promotion of research into the condition and its treatment and the publication of the results of that research."**

We have been considering for some time the appointment as ambassadors of persons who have made and continue to make significant contributions to the awareness of our Association and the support we provide. We are delighted that Professor Chris Semsarian and Doctor Mark Ryan have accepted this role.

In closing I wish better health for all of our members and their families.

Alistair Kerr, President

On behalf of the National Executive

