

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

Newsletter Number 80 — Spring 2014
Includes selected articles from CMA UK Newsletter

Celebrating 20 Years of Progress — 1994 to 2014

Contents

Contents and Disclaimer.....	2
Editorial.....	3
President's Message.....	4
News from Victoria.....	5
News from Tasmania.....	6
News from South Australia and NT.....	7
News from Queensland.....	8
Young Members' Group.....	9
News from New Zealand.....	10
Cardiomyopathy Week & AGM reminders.....	10
City to Bay Fun Run Fundraiser.....	11
Facts about your hardworking heart.....	12
“That same old thing”.....	13
Dear Doctor.....	14
CMAA 2014 Biennial Seminar.....	15
Heart Foundation Recipe.....	16
Genetics Conference on Heart Disease.....	17
Recent Topics in the News.....	18
The Best of British (articles from CMA UK).....	19-28
Library details & Newsletter Order form.....	29
Back Page Contact Details.....	30



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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Any other articles may be reprinted with an acknowledgment to the
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Editorial

It's hard to believe that CMAA is 20 years old. A small meeting, called by Robyn Bell in Queensland started it all. Her daughter was sick with HCM and she found that there was no -where to go to for a chat. What was more, there was no-one who would be there to listen and to talk to about this, apparently, quite rare condition. The specialist was busy and could not possibly be there when she and all the other patients needed support. Robyn started something that day.

Now the association meets throughout Australia and New Zealand. Volunteers answer calls from people who need someone to listen, explain, and comfort. Each of those volunteers can say, "I know what it's like". Just hearing that said helps patients. Robyn knew the value of meeting a fellow patient. Many of you will agree that seeing another person who has coped with an unpleasant diagnosis like yours and come out the other end is so worthwhile.

Yes, we can be pleased with what has been achieved. However at 20, we have passed our troublesome teenage years and should now be deciding what to do in our more mature years. Certainly, we could do with more volunteers. The officers, many of whom have a cardiomyopathy themselves, are ageing and will not be able to be so energetic in the future. The past editor of this newsletter edited from her sickbed. The current editors have a joint age of nearly 150. The association must look to the future and it isn't with us oldies.

So much needs to be done. How do we raise awareness of the increasing number of cardiomyopathies being diagnosed? Should we work towards funding a research scholarship? There are immense possibilities for a national organisation to raise cash that are limited only by our imaginations and preparedness to do something.

We believe the vast increase in medical knowledge can be applied eventually to dealing with genetic conditions, but research scientists need salaries, laboratories and then money to fund research. Governments cannot do it all. So much has been discovered and points the way to further research but much is up to us.

Anne and David

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Stop Press:

As we were about to publish this edition, we received word about the development of a potentially beneficial new drug for heart failure patients by the Swiss pharmaceutical company, Novartis. Hopefully, we will have more information for the next newsletter, but meanwhile, you may be interested in the following link to the article in the Sydney Morning Herald:

<http://www.smh.com.au/national/health/new-drug-gives-hope-to-heart-failure-sufferers-20140831-10am9c.html>



President's & National Executive Report

Dear Members and Readers

I look forward to meeting as many as possible of you again at the Annual General Meeting and Seminar on 13 September. It promises to be a worthy culmination to Cardiomyopathy Week 2014 and the celebration of our twentieth anniversary.

The response to our invitation to attend has been most encouraging despite the late finalisation of arrangements. Thank you to everyone helping with the organisation of our events. I never lose sight of the fact that we are all volunteers.

I am advised that several members have not taken renewal time as an opportunity to update their personal details either on the renewal form, by letter or through our website. In particular this is the case with email addresses. We also note that some emails remain unopened. Please assist us to communicate with you better. An email to membership@cmaa.org.au can resolve any queries you may have.

I am also advised that some of our communications have been sneaking into junk folders so please be on the alert for this.

Thank you to members who have renewed their membership and special thanks to those who were in a position to include a donation. I trust those who have not yet renewed will do so with their reminder.

Best wishes to you all on behalf of the National Executive.

Alistair Kerr
President

The second edition of Margot Maurice's book, "**Six Months to Live; my cardiomyopathy story of Mind over Medicine,**" is available now as an **Ebook** from most well known online Ebook sellers around the world, as well as from the publisher,
www.Ebookit.com

With the continuing popularity around the world of Ebooks, Margot felt it was the way to go with her second edition.

You can purchase your copy online from your favourite online book retailer such as Amazon, Barnes & Noble or Australian sellers such as Bookworld & Angus & Robertson at \$6.50, a percentage of which will be donated to Cardiomyopathy Australia.