

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

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Includes selected articles from CMA UK Newsletter

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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
AGM - Call for Nominations.....	10
Those old wives and their tales.....	11
“Why on Earth?”.....	12
Dear Doctor.....	13
CM and Driving Licences.....	14
Heart Foundation Recipe.....	15
Know your medicines and your fruits.....	16
The Best of British (articles from CMA UK).....	17-26
Library details & Newsletter Order form.....	27
Back Page Contact Details.....	28



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.



The views and opinions expressed in this newsletter are those of the authors. They do not necessarily represent the views or policies of the Cardiomyopathy Association of Australia Ltd. While every effort is made to check the accuracy of information reproduced in this newsletter, readers are advised to check with the original source before acting on it. Medical details are specific to each case, and although conditions may appear similar, readers who require more specific information should consult their Cardiologist.

Any reprints of personal stories in this newsletter need permission from the President or author. Any other articles may be reprinted with an acknowledgment to the Cardiomyopathy Association of Australia Ltd.

Margot and John, who have edited the newsletter for more years than they care to remember, have passed the job on. Despite Margot's poor health and John's duties as carer and person who says, "Don't do so much!", they continued to edit for a while. The Association owes them a debt, as it does to all those who have cardiomyopathy themselves but volunteer their time. We can hear the cheers around the country for Margot and John for a good job well done for such a long time.

We, David and Anne Abbott of Queensland, have taken on the task and will welcome any suggestions that you, the readers and members, care to make.

This newsletter does go all over the country and not only to the sick and their carers. It is read by cardiac care nurses and exercise specialists; it's read by other organisations; it's read by specialists. We hope it is useful and appreciated.

The Cardiomyopathy Association exists to help. We aim to be the very approachable face of officialdom. In fact, we try to be as unofficial and unstuffy as possible. The Association is a forum for help in making sense of a frightening diagnosis, for sharing experiences and seeing others who have coped and are coping. To be told that something is wrong with your heart shocks the living daylights out of you. To hear that diagnosis when it is about a partner, a child, any member of the family is frightening.

It is difficult to remember how alone we felt when David was diagnosed years ago. The specialist told us that he could not send us anywhere for information as there was nowhere. Then Robyn Bell, bless her, decided to do something. The Association was founded in Queensland and has been a help to us ever since. Knowledge about the condition continues to grow fast. The condition is no longer considered rare. Many rogue genes have been identified. Drugs have been developed. Surgical procedures have been refined. Technology has helped many sufferers to lead a near normal life. The condition positively is no longer a terrifying prospect in the vast majority of cases .

So at a time of change for this newsletter, let us remember with gratitude all the people who have changed this condition, from a problem little-known, to a condition that can be so improved.

Anne and David

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Cardiomyopathy
Association of
Australia Ltd

President's & National Executive Report

The World Cardiac Congress was held in Melbourne from Sunday 3 – Wednesday 7 May where over 6000 visitors attended from all parts of the globe. We are extremely grateful to the Heart Foundation for allowing us to share their booth in the Exhibition Hall. Our new banner was prominently displayed attracting interest from many overseas and Australian health professionals including cardiologists from Russia, Central Africa, Turkey and Malaysia. Most overseas cardiologists informed us that there were no similar organisations to ours in their countries. Special thanks to our volunteer members, Reva, Tim and Clive who attended the stand on other days assisting Joan and myself to increase awareness of Cardiomyopathy Australia. Arrangements are continuing for our own seminar to be held following our Annual General Meeting on 13 September in Melbourne. We have adopted the theme “Cardiomyopathy – Keeping you on track” and will update you on the program through the website and in our next newsletter.

With this newsletter you will receive a request for nominations to the National Executive for 2014-16 also a membership renewal form for 2014-15 for those who are not life or extended period members. We welcome and thank Kerry Shaddick who has agreed to fill one Executive position in a casual appointment until the AGM elections. Kerry will continue to be our South Australian State Contact a role which she has performed splendidly, building on that established by Val Stevens and Janet Weissmann. We sincerely regret that Rosie Johnson has resigned as a director however we are delighted that she will continue as our librarian.

We have kept membership fees at their current level and hope you will continue to help support your Association with timely renewal. All members should take this time as an opportunity to notify any change of personal details either on the renewal form, letter or through our website.

I often comment to health professionals and others including visitors to the Cardiac Congress that we take pride in the fact that our members are well informed of their condition. This assists us to provide a high level of support. Our newsletter is a shining example providing updates of developments in diagnosis and treatment. You will note that this edition contains special features from our sister organisation in the United Kingdom such as “Cardiomyopathy and Pregnancy” that younger members may wish to retain for reference. I extend best wishes to Anne and David Abbott for their first edition as editors. They know they have a hard act to follow in Margot and John who have set the bar at the highest level. On your behalf and the Executive, I extend special thanks for a job well done.

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 & Robert son @ \$6.50 a percentage of which will be donated to Cardiomyopathy Australia.