

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

Newsletter Number 81 — Summer 2014
Includes selected articles from CMA UK Newsletter

Celebrating 20 Years of Progress — 1994 to 2014

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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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Editorial

It's been G20 time and we live under the flight path for Amberley RAAF base. The noise of aircraft has been at times deafening. When the plane carrying Obama's cars was coming in to land, it seemed that an alien spaceship was landing as in one of those sci-fi movies. We're glad we do not live near a busy airport.

Brisbanites generally left the city alone, despite being told to come into the city; cafés, restaurants, shops, hairdressers had to close. River bridges were locked off. Public transport took different routes and there were no-go areas.

We put up with the noise and inconvenience and even welcomed it as it meant world leaders met face to face. In these days of Facebook and Twitter, we can forget how important human contact is. People will write things that they would not say to a person standing in front of them. Some impersonal quality has entered and it's possible for people to lose sight of the humanity of the receiver of that nasty tweet. It is no different for politicians.

Meeting the person you are talking to is important as a relationship can be built up. In times of danger, it can make all the difference if two national leaders have met and forged a relationship. We ignore the value of personal contact at our peril.

Understanding another's point of view and appreciating what matters to that person is much easier when looking at a person's body language and hearing them speak. G20 may get some matters started but more meetings, smaller and more intimate, will still be necessary.

There is a lesson here for patients and carers. It's possible to find out a lot from this association's website and our newsletter. The British Association's website is good too. However, David and I know from experience, and from the reaction of people coming to meetings worried and leaving relieved and, not least, from doctors and nurses, that seeing fellow sufferers and carers helps enormously.

It's that face to face contact that helps. It's seeing people who have been through what others are still going through that helps. It's seeing proof that cardiomyopathy is not a certain sure death sentence when you see folk who have lived for 30 years after diagnosis and are more likely to be hit by a car than a heart attack. The old hands know what's what and share their knowledge and tips. Come to meetings whenever you can. If meetings are not near you, what about starting a group attached to your local hospital? There are more people living with cardiomyopathy than you think.

Anne and David

Newsletter editors

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President 's & National Executive Report

Dear Members and Readers

Thank you to everyone who assisted in making our 2014 Seminar a great success. The speakers addressed the theme “Cardiomyopathy – Keeping you on track” particularly well and post-seminar comments received were all positive. It was especially encouraging to have an increased number of health professionals attend who were enthusiastic regarding the presentations. A two DVD recording is now available for members who were unable to attend. A non-returnable copy can be obtained from our library and a small donation to cover postage and production will be appreciated.

(Please note—copies may not be made or redistributed without written permission from Cardiomyopathy Australia)

At our Annual General Meeting which preceded the seminar I reported that the Association was being managed well and is financially sound. I welcomed Kerry Shaddick, our South Australian State Contact as a director to the National Executive. No other nominations were received.

I expressed thanks to all those who had helped Cardiomyopathy Australia during the year, making special mention of the Secretary, the State Contacts, the website administrators, the membership secretary, the newsletter editors and all those ‘backroom’ people whose support was invaluable. I drew attention to CMAA’s successes during the year, noting the development of the website and databases, the younger members’ group and Facebook, administered respectively by Miranda Hill and Margot Maurice.

I noted the need for volunteers to be State Contacts, particularly in NSW. In conclusion referring to our 20 year anniversary, I commended all those who had developed the organisation from its establishment in 1994 and expressed pride in carrying on from Robyn Bell’s initiative as the founder.

We welcomed several new members during 2013-14 and trust that they are obtaining the support and information they seek.

It is with sincere regret that we mark the passing of Robert Flower on 2 October 2014. Robbie as he was known was a former Patron and life member of the Association and an Australian Football “legend”.

Best wishes to you all for the festive season and good health in 2015.

Alistair Kerr
President
on behalf of the National Executive