

Cardiomyopathy Australia



*Supporting people
with cardiomyopathy
and their families.*



Newsletter Number

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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 editor

Hello everyone, and welcome to our 100th newsletter!

To commemorate this milestone, we've asked our contributors to submit pieces on the theme 'Looking Back'. This they have willingly done, and we have a wonderful selection of fascinating articles, many covering the significant advances in research over the decades, others recalling personal memories.

Our newsletter has undergone quite a few changes since it first appeared in 1994. This historic first edition is reproduced on page 6 and is followed by some very early recollections of our association from Leigh Bell, the daughter of Robyn Bell, our founder. Leigh was on hand to witness the very beginnings of the association, and recalls Robyn's outstanding determination and her many achievements.

Now it's my turn to look back! My initial role with CMAA (from 1997–2004) was as Membership Secretary. I remember, though, that roles inevitably overlapped in those earlier days, and we all helped out where necessary. So before I became editor, I found myself helping with the printing of the newsletter (all hard copies in those days) and its preparation for distribution. The North Shore Heart Research Foundation (now Heart Research Australia) had very kindly offered us the use of their copying facilities, so when newsletter time came around, the current editor (Kate Moncaster) and I spent many hours printing, collating and stapling several hundred copies and labelling each envelope. Somehow, when we came to assemble the last copy, we *always* found we'd ended up with the wrong number of pages. With a sigh, we'd go back through every stapled page of every copy until at last we came across those that were missing. It was quite a big day!

In 2002, Julie Temple and I took over from Kate, and when Julie retired I became sole editor. This involved a dramatic learning curve for me as my computer skills were still fairly primitive. I continued until Margot Maurice and John Gallagher took over, and Margot and John were followed by Anne and David Abbott until they took on other roles three years ago. Then I was back at the invitation of our President, Alistair Kerr.

I was determined to stay until this, the 100th edition! And now I've decided it's time to retire. Much as I've enjoyed the role, I'm hoping to devote more time to other aspects of my life, although I'll still be involved with the CMAA in many ways. My thanks go to everyone who has supported me in the role. Janet George in particular has been a wonderful back-up, and Bev Motteram has offered invaluable support from the very beginning.

I'm handing over the reins to not just one, but *three*, very capable volunteers! Carly Bannan (our Membership Secretary and Facebook Manager) and her two sisters, Dannalee and Elise, are all set to combine their creative skills as joint editors! I feel sure they will enjoy the experience and I send them my very best wishes.

Kindest regards to you all,

Flora



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President's report



Dear members and readers,

It is certainly worthy of many congratulations that this edition of our newsletter is its one hundredth. Since its founding in 1994 the newsletter has been the Association's window displaying to our readers a mixture of informative articles and anecdotes. During this time there has only been a handful of editors trusted with providing the latest news to provide support and hope for members and their families who look forward to each edition.

Our founder, Robyn Bell was the first editor and it is great that a copy of the first edition is available to include in this edition. Kate Moncaster, Flora Bloomfield and Julie Temple were editors in the formative years of the Association and were instrumental in setting high standards carried forward to today.

Special mention must be made of Margot Maurice who, assisted by her partner John Gallagher, was editor from 2006 to 2013. Margot was diagnosed with dilated cardiomyopathy in 1984 and given "six months to live" – the subject of her first book. She passed away in August last year in private as she wished – I understand **not** from cardiomyopathy. I referred to her as a bionic woman who despite many serious health setbacks continued to serve as a director to the end – Vale Margot, a dear friend and colleague.

David Abbott, President of the Association when first incorporated and his wife Anne a former National Secretary took over the editorial reins in late 2013 and continued until 2018. Anne continues to provide enjoyable copy.

Flora Bloomfield, the current editor, has maintained the tradition of providing members and other readers with information concerning cardiomyopathy, those that have it and those that treat it. However as you will read in her editorial, Flora is soon to retire from the position. This has been her second term as editor since joining CMAA in November 1995. A current director, Flora also served previously as membership secretary.

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Everyone connected with the newsletter production should be applauded. Many people do not realise or have not thought about the effort involved – researching, verifying, formatting and finding the right amount of copy for each edition also ensuring that copyright laws are not infringed.

In the UK section of this edition you may be interested to read of the international forum initiated by Joel Rose, Chief Executive, Cardiomyopathy UK. Our National Secretary, Janet George and I have been pleased to participate in Zoom discussions leading to the formation of an international network to be known as “The Cardiomyopathy Council”. The formal engagement is through the Global Heart Hub which is the first global non-profit organisation established to provide a voice for those affected by heart disease. Our hope is that a regular dialogue will benefit our members and encourage research funded through donations to the consortium. No Cardiomyopathy Australia funding is requested or required. I expect to inform our readers further as the initiative develops.

Best wishes to you all,

Alistair Kerr
President
On behalf of the National Executive

Contact us:

Details of your nearest Contact Person are provided on pages 24 and 25.

They are also available on:

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