

Cardiomyopathy Australia



Has Cardiomyopathy
Touched Your Life?

Supporting people with
cardiomyopathy and their
families.

Newsletter Number 97 — Summer 2020
Includes selected articles from Cardiomyopathy UK Newsletter

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Contents

Contents and disclaimer.....	2
Editorial	3
President’s message.....	4
Your Contacts.....	5-6
Bushfire smoke — how to cope.....	7
Are Men disadvantaged in the Health System?	8
Cardiomyopathy in Animals	9
Brian’s story	10-11
Patrick’s story	12-13
Pregnancy and cardiac disease.....	14
Dear Doctor.....	15
Recipe.....	16
The Best of British.....	17-21
<i>(articles from Cardiomyopathy UK)</i>	
Library details.....	22

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 to all members and welcome to our summer edition.

We know that many of you must have had a difficult time so far this summer, with the bushfires devastating so many areas of the country and warnings that the fire season is far from over.

Even if we do not live in a bushfire area, most of us know of someone who does. Our own NSW Contact Person lives in one badly affected region. Thankfully his home survived, unlike many of the surrounding properties. You can read of his experiences on Page 6. And on page 7 you'll find some sound advice on how to cope with the effects of bushfire smoke. The smoke has been so widespread that we all need to take note of such precautions.

Whenever we receive personal stories for the newsletter, we are always interested to discover how very different each cardiomyopathy journey can be. In this issue we have two new stories — again quite different. We feel sure you'll enjoy reading them. And please — do consider writing your own story; you can rest assured it will be read with great interest by your fellow members.

Kindest regards to you all,

Flora



Flora Bloomfield
Newsletter editor

Email: florabloomfield@bigpond.com
Phone: 02 9969 5774

Contact us

Details of your nearest Contact Person are provided on pages 5 and 6.

They are also available on:

- our website at — **cmaa.org.au**
- our 24 hour message bank service — **1300 552 622**
- **HEARTLINE — 13 11 12**

Our postal address is:

PO Box 43, Doncaster Heights, VIC, 3109

Our email address is:

info@cmaa.org.au



President's message



Dear members and readers,

The National Executive continues to examine ways to keep your Association viable and to provide continued support for our members.

As part of our succession planning, I am particularly keen to find someone to take on the role of President (or Vice-President with a view to stepping up to that role in the future).

If you are interested in joining our Executive with this in mind, please email our Secretary on info@cmaa.org.au. I will be happy to discuss this with you if you wish.

As advised at the AGM, we are financially viable but need hands-on support in the key areas of membership, website management and Facebook. We are now back on line with a restored website and are in the process of updating information.

Best wishes to you all,

***Alistair Kerr
President
On behalf of the National Executive***

Your Contacts in Australia and New Zealand

Victoria

Hello Victoria and all Members

What a tragic start to the New Year, so many lives affected. My dear friend of over 70 years and her husband live in the high country surrounded by fires for an extended period but now safe for the time being. It makes one realise how fragile life is.

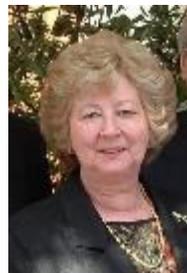
A happy day was had by the fourteen of us who attended our Christmas lunch, it was great to catch up with old and new faces.

A social support meeting in the form of a BBQ will be held at Reva and Tim Blowfield's building, 12 Queens Road, Melbourne on **Saturday 29 February from 11.30 am**. Meat, salads and sweets will be provided. A gold coin donation will be appreciated. **RSVP by Wednesday 26 February**. I hope to see you there as staying together will help ensure the Association's viability. Fresh ideas are essential so please give some thought as how you can help. If distance or ill health prevents your attendance, please feel free to send any thoughts by email or give me a call.

Kindest regards,

Joan

Joan Kerr
Temporary Victorian Contact
Tel: (03) 9894 8840
E: jakerr@iprimus.com.au



Queensland

Greetings to members in Queensland

We are now part of the way through a very hot and challenging summer season. No doubt we will look forward to some welcome autumn relief later in the year. Meanwhile, please ensure that you maintain adequate fluid intake throughout the day and avoid exposure to very high temperatures, particularly those above the normal blood temperature level of 37C.

We are still looking for any member to take on the role of Queensland Contact. The task is not onerous and with today's communication methods, the Contact Person could be located anywhere in Australia, but preferably here on Queensland. Please contact us if you are interested or have any questions about the role.

In the meantime, we continue to be the Contact Persons for Queensland. One on one conversations appear to help and ease most people, particularly those who have been recently diagnosed, so phone and email exchanges continue to be the preferred method of contact for most people. There are no plans to resume quarterly meetings in Brisbane or elsewhere in the State. We are always happy to speak to and email people who need information and reassurance.

Our very best wishes,

David and Anne

David and Anne Abbott
Queensland Contacts
Tel: (07) 3202 8138
E: abbottdm@gil.com.au



... continued



New South Wales & ACT

Hello Everyone,

What a start to summer! I hope you are all managing to stay safe and well. If you're in a bushfire zone, please take great care. I've had my own experience with the recent fires and it's not something I ever wish to repeat.

Please remember that I'm only a phone call (or email) away if you have any cardiomyopathy issues you'd like to discuss — or if you're a newcomer wanting information about the Association. And a reminder that all members (including any visiting Sydney) and their family and friends are welcome at the informal lunches held on the **last Friday** of every month at the **Ground Floor Bistro, Mosman RSL Club, Military Road, Mosman, NSW**. Please make a note in your diaries. We meet at **12.00 noon for a 12.30 pm start**. Please RSVP to info@cmaa.org.au.

Steve Ellwood MBBS.

NSW & ACT Contact

Tel: (02) 4471 6362 (please leave a message if calling during office hours)

E: stevan.ellwood@bigpond.com

Editor's note:

Steve Ellwood lives in the Moruya area and was evacuated from his home as fires raged in the area. Below is part of an email he sent to us describing his experience.

We're all ok here, though our area, like many, is devastated by fire. We were saved by a southerly change — 5 or 10 minutes more of north-wester and it would have well and truly taken out more than one house in Broulee. Rosedale and Malua Bay to the north and the rural properties took the brunt of it. There's a real randomness to which house survived and those that didn't. A number of local nurses and doctors lost their homes. One life was lost in our area — Sam McPaul (local from Moruya) who died near Albury when his fire truck was rolled onto him by extreme winds. He was his mum's only child — devastating for her and his expectant wife.

Our beautiful forest and animals have been absolutely smashed. A mate and I went up our usual single track where we ride our dirt bikes. I think I'll pack up the bike for the next twelve months — it's so hard to see all that flora and fauna lost. Luckily most of the bush will kick back, but the wet areas might not ever recover. Sad and strange days indeed .

All I'm suffering from is a smoke-induced cough and increased anxiety. Still haven't unpacked stuff as I'm not convinced it's all done till we get significant rain. Let's all pray for that.

Steve

South Australia, Western Australia, Tasmania, NT and NZ

We're still looking for State Contacts for these regions. In the meantime, I'll be standing in as Phone Contact, so if you have any issues you'd like to discuss, please call me on **(03) 9894 8840**.

Joan Kerr