

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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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*).

All reproductions must include an acknowledgment to the Cardiomyopathy Association of Australia Ltd. and, where applicable, the author.

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

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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.

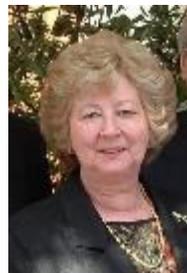
A happy day was had by the fourteen of us who attended our Christmas lunch, it was great to catch up with old and new faces.

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

Bushfire smoke: how does it affect our health?



The University of Sydney's Centre for Air pollution, energy and health Research (CAR) has released a fact sheet on bushfire smoke (www.car-cre.org.au). The section relevant to people with cardiomyopathy is summarised below.

Air pollution from bushfires is currently affecting the health and well-being of thousands of Australians. Some groups, however, including those with cardiovascular disease, are at a higher risk of being affected and therefore special precautions need to be taken.

Bushfire smoke contains hundreds of different components. The most important for health is suspended fine particulate matter (PM_{2.5}). These particles, 2.5 micrometres and below in size, can not only cause inflammation of the lungs, but are also able to enter the blood stream to affect different body systems. PM_{2.5} typically affects the respiratory, cardiovascular and immune systems and changes some metabolic functions. With heart disease, exposure to air pollution might lead to symptoms such as palpitations, chest pain or shortness of breath. If you suffer these or any other worrying symptoms you should call 000 for an ambulance.

How can we protect ourselves?

The most important protective step is to seek cleaner air. Where possible, stay indoors with doors and windows shut as this slows the movement of air indoors. When conditions clear, take the opportunity to open doors and windows and ventilate your home. If you have an air conditioner, set it to recirculate to avoid bringing in smoke from outdoors. Many public spaces such as shopping centres are air conditioned and can offer some improvement over the smoky outside conditions.

The only scientifically approved measure to improve indoor air quality is the use of indoor air cleaners. When choosing one of these, be sure it contains a high efficiency particle air (HEPA) filter. For an indoor air cleaner to work well, the room where it is used should be relatively well sealed and match whatever size is specified by the manufacturer. Note that humidifiers, negative ion generator and odour absorbers **do not** reduce air pollution.

Further ways to minimise our exposure to the smoke

Avoid outdoor physical activity when conditions are poor. Indoor physical activity is fine if the indoor air quality is good. It's also important to stay well informed about the air quality around you. Use real-time or hourly local air quality data if it's available in your area. Knowing the current air quality and if it's rising or falling helps with the best timing for when to seal or to ventilate your home. It also enables the planning of activities and travel to avoid places severely affected by smoke. Check out your state's website for reports on air quality.

Masks are an excellent idea, but please be aware that to work well they must have the correct filter and fitting. Surgical or patient care masks or dust masks will **not** protect you from particles (PM_{2.5}) associated with bushfire smoke. The materials in P2/N95 masks, on the other hand, **do** filter out PM_{2.5}. But a word of caution – the seal around the mouth and nose must be perfect for them to work well. This can be tricky, especially for those with facial hair or sideburns, or those with a small face. Another thing – when a good seal is achieved, the mask is often hot and can be uncomfortable if worn for a lengthy period. But these are individual responses and you may not encounter the same problems. Whatever you decide, remember that the most important thing is to remain safe!

Are Men Disadvantaged in the Health System?

What do YOU think?



Dr Janet George, CMAA Secretary

A recent article in The Australian Financial Review (Margo, 2019) discusses research that debates whether men are disadvantaged in the health system because of communication issues. On the one hand, it is claimed that men take a practical line in consultations, whereas women are more likely to disclose their feelings and thereby make diagnosis of health issues easier, especially of mental health matters such as depression. It is argued men are less health literate than women and general practitioners are more attuned to women patients because they attend the GP for more consultations, the excess accounted for by reproductive matters. That is, the highly respected men's health researcher, Professor Gary Wittner, of Adelaide University's Freemasons Foundation Centre for Men's Health, claims the health system is 'feminised', not considering the different ways men and women communicate with health providers.



This view is disputed by the head of the Royal Australian College of General Practitioners, Dr Harry Nespolon, and Dr Karen Price, deputy chair of RACGP Victoria. Their experience shows that men do talk about their mental health, as well as their physical symptoms. Dr Chris Hogan, Associate Professor in General Practice at the University of Melbourne, argues that GPs are 'trained observers and interrogators' (Hogan, 2018), with up to six topics going at the same time in a consultation. They need to consider the man's age, length of relationship with the doctor, cultural background and personality as well as the presenting problems.



Despite their disagreement on whether the system is feminised and men are thereby disadvantaged, the researchers are agreed that men need to have an ongoing relationship with their GP so that a complex picture of their health can be made; and that their male traits of self-sufficiency, self-reliance, and action-orientation should be taken into account.

So what do you think? What's your experience? What advice would you give fellow patients? Please let us know at info@cmaa.org.au



Cardiomyopathy in Animals



Dr Tim Blowfield BVSc (Retired Veterinarian) shares some fascinating facts

Cardiomyopathy (CM) is a word referring to disease of the heart muscle. As such, if an animal has a heart then disease of that organ is probable though to date has not been documented in many species. Though an Octopus has three hearts, a main heart and two brachial hearts that circulate their blue blood through their gills, disease in one of the brachial hearts may not be important. Earthworms have 5 pairs of aortic arches that functionally act as hearts. No one has reported CM in an earthworm but it probably occurs.

In the animals most studied, dogs and cats, heart disease is common. In dogs, though cardiovascular blockages ('Heart Attacks') are uncommon (in 50 years of veterinary practice I saw just one case of myocardial infarction), cardiomyopathy is common with many causes. The Boxer breed has a genetic cardiomyopathy. So have Dobermans and Cavalier King Charles Spaniels. During the 1980s hypertrophic and dilated cardiomyopathy was increasingly diagnosed in cats. It has been suggested, though now is largely dismissed, that Phar Lap, whose heart was large (but not the largest), died from heart failure. But heart failure and CM have been diagnosed in other horses. Cattle, pigs and sheep may all be affected.



An understanding of heart muscle disease in animals can give clues to understanding Cardiomyopathy in persons. When cats were first being diagnosed with CM, hypertrophic and dilated forms were considered separate entities. Later it was found that in many cases the dilated form was often a progression of the other in an over-worked heart. The strain of pumping blood against an high systemic blood pressure caused the heart muscle to hypertrophy. The high BP itself was caused by chronic renal disease. There does appear to be a significant genetic component in CM of cats. With the advent of ACEIs and B-blockers in the 1990s lowering BP, regression of the heart disease became possible. Similarly, heart disease is common in King Charles Spaniels with ballooning of the heart, stretching of the valves, leaking of those valves. This, as in the Boxer CM, is largely genetic in its cause. Modern pharmacology has also increased longevity in this breed.

In farm animals, CM is largely a component of more widespread disease. In 2003 dilated cardiomyopathy was diagnosed in Friesian dairy cattle. It is considered genetic. Cardiomyotic fibrosis and degeneration with heart failure has been reported in cattle and goats. An altitude-induced right heart failure was reported in cattle in Montana in 1978. Cardiomyopathy in broiler chickens was reported as early as 1987. Reported causes included phosphorus deficiency, reovirus infections and high-altitude sickness but in most cases the causes were not determined.

In general, genetic diseased farm animals are actively culled, so are quite rare. Last year genome editing was used to produce Hypertrophic CM in piglets. Unfortunately, the piglets died within 24 hours of birth. Dilated and Hypertrophic CM does occur in pigs and is usually genetic though a recent report of CM in Brazil reported CM in pigs fed a poor quality soybean diet.



Dilated heart with cardiomyopathy and (A) pale areas of fibrosis - sheep

White muscle disease in cattle, sheep and goats is a CM caused by a deficiency of Selenium or Vitamin E. Marked pallor (whiteness) is characteristically seen in the heart muscles. In 2016 it was reported in 4 African lion cubs. In pigs Vit E deficiency causes Mulberry Heart Disease, an acute CM characterised by fibrosis and haemorrhage. Low methionine and cysteine levels and high fat in the diet appear to exacerbate the disease. Cobalt and Vitamin B12 deficiencies also affect the heart muscle. Enterotoxaemia is another cause of heart muscle failure in farm animals, caused by toxins produced by gut bacteria. Enteroviral infection have been implicated as causing CM in many species. Cardiomyotic symptoms are also seen in many other diseases such as heavy metal poisoning (cadmium, lead), deficiencies (copper, zinc), plant poisonings (belladonna, digitalis, heart leaf poison (contains 1080/sodium fluoroacetate)).

The causation of CM in animals is diverse, complicated and far from well understood, just as it is in human CM. But our understanding of Animal CM does suggest paths forward in the understanding and treatment of the latter.

Brian's story...

... or The Italian Connection

I count myself fortunate. Thanks to modern cardiology and related pharmacology I live a virtually normal life, luckily without the need for an ICD. I can undertake relatively strenuous activity without detriment, and long-haul air travel with minimal risk. Sometimes I feel a little tired, but don't we all. The only exercise I have foregone is endurance running, wishing not to tempt fate. I still fence with the foil and have competed in field athletics.

I had never heard of cardiomyopathy before diagnosis, and to hear it called heart failure was a bit daunting at first, but now that I understand the context, it's not such a hyperbole. My cardiomyopathy, whilst involving dilation, is unclassified, idiopathic but non-ischaeamic. Basically, the heart muscle is larger and stiffer than normal, to some extent. The cardiologist has me on a medication cocktail of Ramipril and Sotalol, with a dash of Apixaban – just in case. He has progressively fine-tuned the dosages since cardio-version, such that I now enjoy a 45-beat safe sinus rhythm and a BP of 110/80. (I've always had a low pulse rate.) Just before Christmas, I lapsed into AF (100 beats +/-), possibly as a result of the smokey atmosphere. But the rhythm reverted to sinus by itself. Oddly, I can hardly feel the effects of AF, except from feeling a little fidgety and a bit less fit.

Let's now turn the clock back to 2016 when I was diagnosed with cardiomyopathy at age 72. In March of that year I ran an off-road marathon in New Zealand, winning the oldest competitor trophy. Then in May, I did a pretty grueling 100km/24h event up and down some steep terrain in the Blue Mountains. The latter was really hard work, as beforehand I had started to experience symptoms of lethargy and fatigue.

In September, my wife and I were due to fly to Italy for a 3-week holiday, but in the two weeks beforehand I presented to my then-GP with sequential symptoms of abdominal pain, blood in the urine, an unrelenting hacking bronchial cough, an irregular elevated pulse, swollen feet/legs and abdomen, and feeling generally unwell. He diagnosed only AF and said it was OK to fly to Italy for three weeks, and arranged for me to see a cardiologist on return. In retrospect I contended, in my complaint to the HCCC/Medical Council NSW, that in the light of these symptoms – many of which indicated the probability of cardiomyopathy, the GP at best made an error of judgement, or at worst was negligent, in exposing me to the possibility of a stroke or cardiac arrest. As a result of my complaint the GP was required to review his related procedures. He is no longer my GP.

On arrival in Italy, where we stayed with friends in a villa at a lovely spot near Sorrento overlooking the island of Capri, the swollenness and lethargy/fatigue persisted, to the extent that my wife and our friends (one of whose dad had experienced certain similar symptoms relating to a heart condition) became quite concerned about my wellbeing. So, when my wife and that friend went to the fish market, they and the smelly fish took the opportunity to call-in on a local GP. He told them that *time eez not on eez side*, and that I should present to the emergency department of Sorrento general hospital *molto presto!* That caused them to sprint back, juggling the fish between them, to convey me to the ED.



My wife and some noisy friends visit me

... *continued*

Fortunately, there were two cardiology-trained doctors on duty when I arrived. Their eyeballs rolled back in the sockets when they learned I had been allowed to travel from Australia in such a condition, and after an ECG on a rickety old machine, sent me up to Terapia Intensiva in the Dipartimento di Cardiologia. It was a bit disconcerting to see my heart rate on the monitor going all over the place between 30 and 160 or thereabouts.

The medical and nursing staff were wonderful despite the clearly limited facilities and funds at their disposal compared to Sydney. They carried out ultrasound and CT-scan tests on aging equipment and were able to stabilise me with medication for release after nine days. Fortunately, a suspected clot in the heart turned-out to be a false alarm. They concluded that I had hypokinetic dilation with an ejection fraction down at 25%. After treatment in Australia it has risen to the lower end of normal.

I was regarded as a bit of a curiosity by the hospital staff and other patients as they were not used to Australian tourists turning up in ICU and being visited by their raucous mates. The ICU was a shared ward of 8 patients, and only one quiet visitor per patient allowed at a time, whereas I had five noisy ones.

As I said, the staff were fantastic —I was very grateful for their loving care. And despite having travel insurance, I walked out of the hospital without having to pay a single eurocent either for accommodation or treatment, as Australia and Italy have a reciprocal health-care agreement. Lucky me.



Saying goodbye to the hospital interpreter

By contrast, the treatment I received from my travel insurer was appalling. The only time they showed any support or concern was when I wanted to board a plane to come back home, fearing no doubt that I might cost them some serious money if I became ill or carked-it during the flight. However I was able to convince them I felt fit and confident enough to travel home with my wife, without an accompanying doctor.

Hopefully, I will continue to enjoy my good luck. Mille grazie to my wife Elizabeth, our friend Frederique, the Ospedale Santa Maria della Misericordia Sorrento, and my cardiologist Dr Ru-Dee Ting.

Brian Adams

Share your own cardiomyopathy story with fellow members!

Email your story to florabloomfield@bigpond.com, or
Send to **CMAA Ltd, PO Box 43, Doncaster Heights, VIC 3109**

Patrick's story

My name is Patrick and I have been diagnosed with Dilated Cardiomyopathy.

Prior to my diagnosis I lived a life which focused on exercise and wellbeing. A normal week involved four or five runs and maybe a mountain bike ride in the Royal National Park trails in Sydney. I had been competing in athletics events since I was in my late teens mostly in running endurance events and regular fun runs and the odd Half Marathon. A normal Sunday morning would be a long run of up to 20k on trails. My most significant health concern up until my heart problem was Insomnia, which I was able to address between 2013 and 2014. It still remains a challenge now to get enough sleep. Through my 40s and 50s I participated in many trail and road running events, including a marathon in 2013. During 2014, I felt I was sleeping better than I had for years and was really enjoying life and exercise in general.



Sunday morning ride in Royal National Park, Sydney

Coming into 2015, however, I felt that despite my improved sleep pattern that I seemed more tired than I should have been. On that fateful Tuesday morning when I went to hospital, I woke in the middle of the night with a strange tightness in my chest. I got up and starting stretching my chest muscles etc. As the tightness subsided, I thought as I returned to bed that surely it could not be a heart problem. I went to work the next day, 22nd October 2015, at Sydney Trains Central Station. At about 9.30am I had a brief phone conversation about the night before with my partner (a nurse), and I was urged to get to hospital as soon as possible. I met a very worried Lauren at Emergency at St George Public Hospital where I was admitted.

I initially had a multitude of blood tests and an echocardiogram. It was found that my left ventricle was 'lazy' and I had an ejection fraction of 19%. Two days before I had run my typical trail run of about 20k with no ill effects and now here I was in hospital with an unknown heart problem. I then had a series of further tests to determine the cause of the left ventricle disfunction. It started with an angiogram; it was described as excellent result. It seems I had blood vessels you could fit a mini minor car in! The whole time I was in hospital I was attached to a heart rate monitor and leads attached to various positions on my chest and upper back. The heart monitor screens in my hospital room and throughout the floor were telling a worrying story. My heart rhythm had regular ectopic beats and my heartrate seemed to easily fall to 30-40bpm even during the day.

More blood tests followed, consultations with two cardiologists, and attempts to book me in for a cardiac MRI as soon as possible. After a couple of days in the Public Hospital I transferred over to St George Private. In both hospitals there was a lot of concern for my low heart rate, especially at night when it had a tendency to drop to less than 30 beats per minute when I fell asleep. Staff were so concerned about me that during the day I wasn't allowed to leave the floor unless I was accompanied by a nurse.

Ten days after admission, on my last day in hospital, I was transported to St Vincent's Hospital for the MRI. I was quite apprehensive about it from a claustrophobic point of view. However due to the caring staff I coped with the examination well. As a result, a diagnosis of Myocarditis was given, but there still was doubt about the cause. My ejection fraction had risen to 30 percent. I left hospital around 5pm that day, still uncertain about the cause.

A few weeks later I had a PET scan at the Prince of Wales Hospital in Sydney to check for Cardiac Sarcoidosis. This proved to be negative. By now I was starting to get my hopes up that it would not be too serious an illness. I was feeling good in general and had started exercising again. Within two to three months I was almost back to my previous level of fitness.

... continued

I was placed on a steroid treatment to try and reduce the inflammation in my heart when I left the hospital. Unfortunately, I sustained a pelvic stress fracture following a run. This was attributed to the steroid treatment which caused a reduction in bone density and a diagnosis of Osteopenia, a precursor to Osteoporosis. This led to a cessation of high impact exercise for 5 months.

Between June and December 2015, I had further visits and another cardiac MRI. My illness was identified as Cardiomyopathy due to a viral infection. I was told I might have to have a defibrillator fitted if my ejection fraction did not improve sufficiently.

In March 2016 I was fitted with an ICD. It was placed under my chest muscle, as my body fat percentage was too low to allow skin only to keep it in place. It was only through the support of the Sharks, the Cardiac Rehabilitation team at Sutherland Hospital, that I had reached the point where I could accept this change of life. Following the insertion of the defibrillator, the team at Sutherland Hospital also helped me to regain my confidence in exercising.

It made a huge difference having an understanding partner, family and friends to support me through this very challenging time. Lauren, my partner, provided much needed emotional support. Her medical background helped me as well, during my time in hospital and through my rehabilitation and fitting of my defibrillator. As a Christian, my faith has helped me to make sense of everything and I felt I was ready to accept whatever the outcome would be. And at the same time, I felt positive about the future.

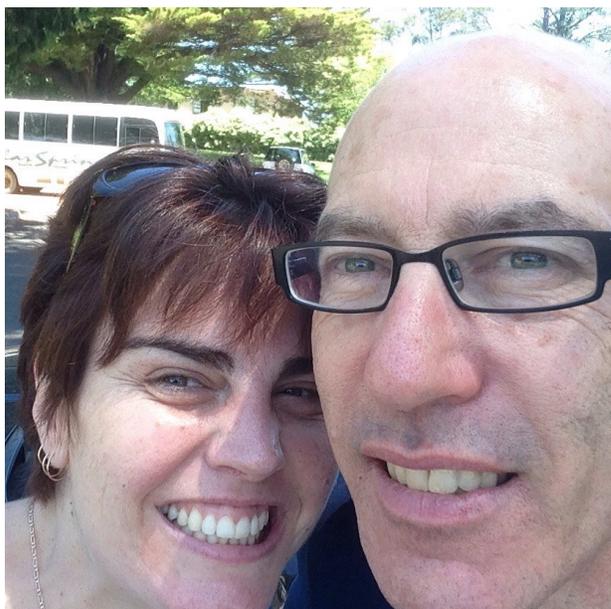
Despite a few hiccups I have recommenced the level of exercise that I had previously enjoyed, albeit with less focus on performance and more on enjoyment. From day to day I more or less live life the same as I did prior to my diagnosis, trying to be present in everything I do.

In 2018 I holidayed in the UK visiting some wonderful places and met up with some friends that I had not seen for quite some time. I felt quite challenged by the flights over there on my own but in the end had no reason to be concerned. I hope the future brings more opportunity for exciting travel destinations.

I currently take Aspirin, Crestor and more recently Entresto to aid my recovery. I have never had a shock from my defibrillator. The only episode I have experienced was in June 2019; however my heart was able to address the abnormal heart rhythm. I was totally unaware of this going on.

I remain my cardiologist's most successful patient (in terms of regaining normal activity — that is, normal for me!) I run three to four times a week and regularly ride my mountain bike. Now in my late 50s, I am still working full time but am looking forward to being able to spend more time with friends and loved ones, and travelling and running during my retirement.

Patrick Webb



Lauren and Patrick

Research into cardiac disease during and after pregnancy

Were you diagnosed with cardiomyopathy before, during or within the first year after pregnancy — *any* pregnancy? If so, your experience could play a vital role in a new research program concerning the needs of pregnant and postnatal women.

The research is being conducted by the University Technology Sydney (UTS) as part of a larger funded study by the NSW Heart Foundation.



Participation simply involves a phone conversation with a researcher about your experiences. The information is de-identified so your name and details are kept confidential and privacy is assured.

If you would like to take part in the study or would like further information, please contact:

Email: jane.frawley@uts.edu.au mobile: 0414 977 687

Email: Elizabeth.Sullivan@uts.edu.au

Are you still happy to receive this newsletter by post?

If you would prefer to receive the colour version of the newsletter by email in place of the black and white printed version, please let us know and we'll make the change.

You can advise us by email to info@cmaa.org.au or by mail to PO Box 43, Doncaster Heights, VIC, 3109 or you can get in touch with your nearest Contact Person.

CMAA urgently needs volunteers — remember, volunteering is good for your health!

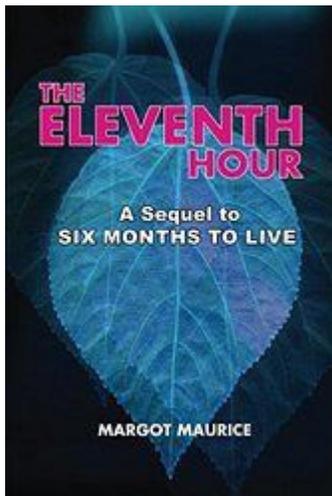
Cardiomyopathy Australia is a charitable support organisation and has been run entirely by volunteers over the past 25 years.

Our success depends on having access to a wide range of skills including communication, management, finance, administration, technology as well

having an interest in cardiomyopathy or related cardiac conditions. With today's technology, geographic location is not an issue.

If you would like to volunteer, please contact:

info@cmaa.org.au



The Eleventh Hour—by Margot Maurice

Margot Maurice's latest book is available on Amazon US or other online booksellers. Order your copy online. It is available in both paper book or eBook. You choose which format you would like.

The foreword to The Eleventh Hour is written by Doctor Greg Aroney, a senior cardiologist at Gold Coast University Hospital.

Go to Google and type in, "Amazon Author's page for Margot Maurice" and you will find all Margot's books.

Margot has kindly agreed to donate a portion of each sale to CMAA.

Dear Doctor.....



Q:

Are energy drinks and/or caffeine dangerous for people with cardiomyopathy?

A:

Energy drinks and caffeine which is often contained in them may cause trouble for someone with heart disease. The main issue is they can be a stimulus for arrhythmias or palpitations. The actual caffeine stimulates the heart and causes the irregularity. Caffeine per se is otherwise not dangerous for a normal heart.

Q:

My brother was recently diagnosed with DCM. Should I have genetic testing?

A:

Once someone in the family is diagnosed with a dilated cardiomyopathy there is a chance that it may be familial or inherited. Rather than genetic testing, members of the family should undergo screening with an ECG and echocardiogram. If these are both normal then genetic testing at that point wouldn't have anything to offer. The person with the dilated cardiomyopathy, as part of research, can undergo genetic testing and if a gene is identified which may be the cause of the cardiomyopathy family members can then be screened for the identified gene.

*Please send or email your questions to Flora soon for inclusion in our next issue.
Ph; 02 9969 5774 : email: florabloomfield@bigpond.com.au*

Have you enrolled in the National Genetic Heart Disease Registry?

If you or a family member have an inherited cardiomyopathy you may be eligible to take part in this registry.

We are aiming to enrol every family with an inherited heart disease in Australia, which will assist Australian research groups learn more about these conditions.

More information, including patient information sheets, can be found at our website

www.registry.centenary.org.au

To get an enrolment pack please contact:

Dr Jodie Ingles or Laura Yeates.

Molecular Cardiology Centenary Institute

Locked Bag No 6 Newtown NSW 2042

Phone 02 9565 6185 Wednesday—Friday

[Email: j.ingles@centenary.org.au](mailto:j.ingles@centenary.org.au)

Salmon & polenta pikelets

Cooking time: 5 minutes

Preparation time: 10 minutes

Serves 4



Ingredients:

- ¼ cup polenta
- ½ cup boiling water
- 1 egg, lightly beaten
- 2 tablespoons reduced fat milk
- ¼ cup wholemeal self-raising flour
- 2 tablespoons reduced fat cottage cheese
- 1 teaspoon lemon juice
- 2 tablespoons chives, finely chopped
- 2 x 95g can salmon in springwater, drained
- Spray olive oil

Method

1. Combine polenta and water in a medium-size bowl. Allow to sit for 5 minutes. Stir through egg and milk. Then fold in flour and mix until mixture is smooth.
2. Heat a non-stick frying pan over medium-low heat. Spray with olive oil. Pour 2-teaspoon portions of mixture around the pan, allowing room for spreading. Cook for 1 minute or until bubbles appear. Then turn and cook for a further 30 seconds or until golden brown. Repeat with remaining mixture.

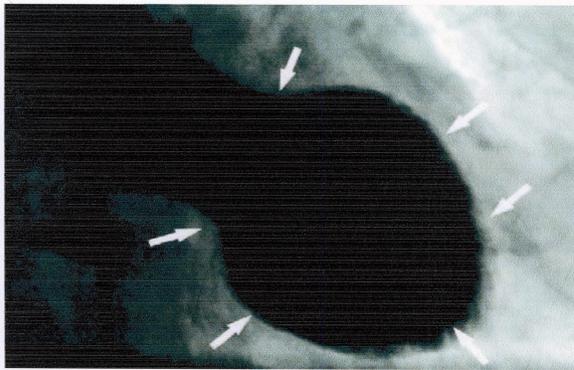
Combine cottage cheese, lemon juice and 1 tablespoon chives. Spread pikelets with cottage cheese mix and top with salmon and chives.

Recipe and image reproduced with permission. © 2018 National Heart Foundation of Australia. For other healthier recipe ideas, visit www.heartfoundation.org.au/recipes or phone 1300 36 27 87.

The articles in this section of the Newsletter are excerpts from the *Cardiomyopathy UK* magazine.

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What is Takotsubo?



› The condition was first identified in Japan in the 1990s and was named *Takotsubo* – the Japanese for octopus pot because the heart's appearance resembles this shape

It is thought that at least 3,000 adults in the UK suffer from Takotsubo cardiomyopathy, but the true number may be even higher.

Takotsubo (often referred to somewhat unhelpfully in the press as “broken heart syndrome”) is a type of cardiomyopathy that gives the left ventricle a distinctive shape.

The name itself comes from the shape of the left ventricle and ballooning of the heart, which was thought to resemble that of a Japanese fisherman's octopus trap.

The symptoms can often present as that of a heart attack. The precise cause of

a Takotsubo event is not fully understood, but it is accepted that it can be brought on by either physically or emotionally stressful situations.

There exists a misconception that it is only negative events, such as the death of someone close that can cause Takotsubo.

However, positive events, such as a loved one's graduation or a party, can also trigger an event.

In some cases, an acute brain injury can lead to Takotsubo.

Continued...

...Continued

In 30 per cent of reported Takotsubo events, there has been no identifiable cause.

People who are experiencing a Takotsubo event seek clinical intervention as they assume they are having a heart attack, but clinical tests often demonstrate that this is not what has happened and a diagnosis of Takotsubo is confirmed.

Most common Takotsubo symptoms can include sudden and intense pain in the chest, shortness of breath and an abnormal heart rhythm.

To confirm a diagnosis of Takotsubo, an ECG is often conducted, as well as blood tests.

An echocardiogram and cardiac MRI can also detect the damaged heart muscle and rule out other potential causes.

Treatment of a Takotsubo event is often similar to the

treatment given for a heart attack, which would include assessing that the coronary arteries are not blocked or narrowed.

Breathlessness caused by fluid build-up on the lungs is treated by administering diuretics and if the heart muscle function has been reduced, ACE inhibitors and beta blockers will be prescribed.

Takotsubo often improves following prompt treatment, however researchers looking at the long-term effects of the condition have discovered that the condition can have a more prolonged effect on the heart and for some people, they may experience more than one Takotsubo event.

For more information on Takotsubo, see our website or call one of our specialist cardiac support nurses on 0800 018 1024.

Takotsubo can cause the heart to become enlarged and weakened, so it works less well than normal.

This can lead to symptoms such as chest pain that can feel like a heart attack.

Troponin: Why it matters

Cardiac troponin is a protein released into the bloodstream when the heart muscle has been damaged or when the heart is under some degree of stress.

Troponin levels will likely be measured using a blood test if you are experiencing chest pain or related symptoms, including: pain that radiates into your neck, back, arm or jaw; intense sweating; light-headedness; dizziness; nausea; shortness of breath and/or fatigue.

The two types of cardiac troponin that are commonly measured are Troponin I and Troponin T. Both of these are sensitive markers of heart muscle injury.

In people diagnosed with heart failure and cardiomyopathy, troponin levels are used to aid ongoing management during asymptomatic phases (without symptoms) or phases when someone has only very few symptoms.

Troponin levels can also be used to guide the clinician in referral to a heart failure or cardiac nurse service for patient monitoring and to plan the long-term management of their condition.

In people with suspected myocarditis, troponin levels can help to confirm a diagnosis as levels are elevated in some

people with symptoms associated with myocarditis.

However, a normal troponin level does not exclude a diagnosis of myocarditis.

Troponin levels are measured in nanograms per millilitre. Although a rise in troponin levels is often an indication of heart muscle damage, there are a number of other reasons why levels could elevate.

In addition to measuring your troponin levels, an electrocardiogram (ECG) may also be performed to look for any changes that may indicate a heart condition.

Other tests, including an echocardiogram (to look at the heart muscle, heart function and valves), a chest x-ray, or other blood tests may also be performed.

*By Jayne Partridge
Cardiomyopathy UK Support Nurse*



Troponin T will start to rise three to four hours after heart muscle injury has occurred and can stay elevated for up to two weeks.

In healthy people, troponin levels are low enough to be undetectable.

If a person experiences chest pain but troponin levels are still low 12 hours after the chest pain started, a heart muscle injury is unlikely.

LVADs and e-bikes are a perfect match

In November 2017, Bob Gower was told he needed a new heart or he would die.

He was too ill for a transplant, so had a Left Ventricular Assistance Device (LVAD) fitted.

An LVAD is a powerful, battery-operated, artificial pump that's surgically implanted to help increase the output of the heart's left ventricle when it can't effectively work on its own.

Used to treat people with severe heart failure, it is sometimes called a "bridge to transplant" and can buy time for the patient, or eliminate the need for a heart transplant.

Bob, 66, from Lancashire, had been diagnosed with dilated cardiomyopathy (DCM) in 2001, aged 48.

After a short period in hospital, Bob returned home and with daily medication, was able to resume a reasonably normal

'I was back home with my family in time for the Christmas I hadn't been sure I'd see'



› Bob Gower

lifestyle, continuing full-time in his career and pursuing a wide range of physical activities – football, hill-walking, badminton, cycling and swimming.

However, over a period of time, his capacity for physical activity gradually reduced, until by late-2016, he was unable to walk more than very short distances, and any gradient posed a real challenge.



Bob is a member of The Cranks Electric Cycling Club. All the riders have LVADs and regularly cycle 20-30 miles together.

In the spring, they are planning to ride the Coast-to-Coast route.

By the end of that year, he had to stop exercising altogether.

The following year, Bob had an ICD fitted and told he was in the advanced stages of heart failure. By the time he had his LVAD fitted, he was probably only hours away from major organ failure.

"I was back home with my family in time for the Christmas I hadn't been sure I'd see," he says.

Following a period of cardiac physio, the keen cyclist regained a level of fitness to be able to think about getting back in the saddle.

However, because he quickly became breathless and in some pain from even quite low levels of exertion, Bob bought an electric bike.

"My e-bike enabled me to achieve a level of independence, as well as access to the open

countryside, which would otherwise be beyond my capacity to walk," he says.

Bob is now enjoying the benefits of his e-bike, together with a small group of like-minded LVAD patients (the self-styled 'Cranks'), who have attracted some attention both locally and nationally with their sense of adventure and refusal to be constrained by the limitations of their serious heart conditions.

As Bob says: "The sheer joy and freedom of cycling along in the open countryside on a beautiful day, feeling the air all around, is something most of us feared had been taken away for ever."

He is also convinced the benefits of cycling have helped him reach a level of health and positivity to be a good candidate for a heart transplant and is back on the waiting list.

CMAA Library

Books and DVDs are available from our Library for members' information.

Books:

Living a Healthy Life with Chronic conditions by Long, Sobel, Laurent
Inherited Heart Conditions Ventricular Cardiomyopathy
Inherited Heart Conditions HCM & Inherited Heart Conditions DCM

DVDs:

DCM... The Facts HCM.... The Facts
One life a Second Chance *HAS*
Cardiomyopathy Heart Failure 'Speaking from experience.' CMAA
Preventing Sudden Cardiac Arrest.. (*Medtronic*)
Living with CM CMAA *Dr Lindsey Napier 2005*
A Multi Disciplinarian Approach to CM *Professor Sindone 2006*
Chronic Heart Failure CMAA *Dr C de Pasquale 2004*
HCM CMAA *Dr Mark Ryan*
Maintaining Heart Health *Dr E Barin 2004*
Cardiomyopathy—The Journey, *Dr Greg Aroney 2016*



CMAA Conference DVDs:

Brisbane 2005.. Sydney 2006. Melbourne (4 discs) 2008 Melbourne 2008
Sydney 'Cardiomyopathy What's Working' 2010
Brisbane 'Cardiomyopathy a Moving Picture' 2012
Melbourne 'Cardiomyopathy Keeping you on track' 2014

Books are returnable but DVDs are Non returnable.

A small Donation would be appreciated towards running the Library

For all borrowings & enquiries please contact

*The Librarian at CMAA Ltd P.O Box 43 Doncaster Heights Vic 3109
or email info@cmaa.org.au*

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