Cardiomyopathy Australia

Has Cardiomyopathy
Touched Your Life?

Supporting people with cardiomyopathy and their families.

Newsletter Number 84 — Spring 2015
Includes selected articles from Cardiomyopathy UK Newsletter

Cardiomyopathy Association of Australia Ltd is a not-for-profit registered charity
ABN 36 091 171 470

Cardiomyopathy Association of Australia Ltd

Contents

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.

Editorial

When we look at the television, listen to the radio or read the papers, we could be forgiven in thinking that everything is in a terrible mess. Re-read that sentence and let us think about it. Some things are bad; some people are in appalling circumstances; some men are disgustingly violent and some rulers are immoral, cruel fools. But we do not live in such circumstances nor are all things everywhere bad. We are part of a civilization that can be moved to unselfish action by a picture of a drowned child. Indeed, if you are reading this, you are indebted to the efforts of our association's founder and its current officers.

Our society has stable government (yes, indeed, despite changes of PM), the rule of law and networks of citizens who give freely of their time and effort to help others. All of those are the glue that holds our society and similar ones together.
Compare us with the horrific state of parts of Africa and the Middle East where good governance and unselfish behavior are in short supply.

Some refugees, who have really truly fled war, rape, famine, take care of a plastic bottle for carrying water, and that is all they have.

I can remember and so will many of you having far less money, far fewer items in the shops to save up to buy and being not one whit less happy. Pleasure often comes free. We gave a concert the other day to old folk who needed great care. Not all were confused but most were. We sang old songs, had sing-songs and when an old chap who had sat almost stupefied got up and pulled an attendant into a dance, we all had grins on our faces. We got such a buzz. Happiness which lasts is bound up with people not things.

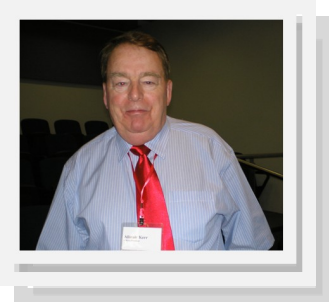
Some of us will not get our wants satisfied. Who hasn't remembered the days of being really fit? But we can do a lot to satisfy needs, our own and other people's.
Happiness and satisfaction can come from helping.

Anne and David Abbott

Newsletter editors

Email: abbottdm@gil.com.au
Phone: 07 3202 8138

Cardiomyopathy Association of Australia Ltd



President's & National Executive Report

(Delivered at the AGM in Adelaide on 29 August, 2015)

Dear Members and Readers

On behalf of my fellow directors I have much pleasure in presenting this report to the Cardiomyopathy Australia 2015 Annual General Meeting.

I am pleased to advise that Cardiomyopathy Australia is in safe hands with an harmonious, progressive National Executive and as you will observe from the Treasurer's report we enjoy a secure financial position. From that base we can not only pay our way but provide for future initiatives. You will note that despite higher outgoings due to the Seminar held in September 2014 the balance sheet is in good shape.

It is appropriate that this AGM is being held in South Australia where we are following the UK fund raising initiative through sponsored fun runs. The next run will be held on 20 September. A similar New South Wales event is scheduled to be held in Dubbo. Congratulations to all involved.

These excellent fund raising events can provide a platform to support new initiatives in the field of genetic research. This area is important not only for current CMAA members but more so for their children and grandchildren who will benefit from that research. The Executive believes that money should be raised not just for the sake of fund raising but we should have a purpose that we can all get behind and bring other members of the public with us. It can have the added benefit of raising the Cardiomyopathy profile to attract more members who currently may not be aware of the support we can provide.

Most of our new members first hear about us through the internet so we are investing a great deal of time in shaping our new website to reflect the way we wish to operate. We consider the membership area to be very important and our new membership secretary, Peter Smith, is working very hard to iron out wrinkles and improve services. You can assist by opening emails and accessing the newsletter. As this is our principle method of communication please help us to provide our support to you. Unfortunately the system tells us that there are currently too many unopened.

Your Executive again wishes to acknowledge the special efforts made by the State and New Zealand Contacts in providing front line support to our members. The Executive, the Contacts and support officers are all volunteers deserving of your support as they provide to you. We also thank all those who provide pro bono services.

Many thanks to those who have organised today's meeting also to hospitals and other agencies that provide facilities throughout the country for member meetings.

As always every best wish to members for good health in the coming year.

Alistair Kerr,
President

Victoria News

Cardiomyopathy Association of Australia Ltd

Hello Victoria and all members

At our July meeting we were pleased to welcome Assoc. Prof. Chris Neal who gave an excellent talk on Takotsubo Cardiomyopathy also non-invasive diagnostic procedures generating considerable discussion among members. A new member who has TC especially appreciated the talk and has kindly provided the following excerpt (condensed).

Takotsubo Cardiomyopathy – also known as Stress-induced Cardiomyopathy, Transient Apical Ballooning Syndrome, and Broken Heart Syndrome – differs from other forms of cardiomyopathy in that it is reversible. In spite of this, it is now a well-recognised cause of acute heart failure, ventrical arrhythmias and even ventricular rupture. Takotsubo is a non-ischemic cardiomyopathy, or form of congestive heart failure. Typically, it mimics a myocardial infarction (or heart attack) in that there are ECG changes, a rise in cardiac enzyme levels, and patients experience shortness of breath and chest pain.

However, angiograms reveal that there is no associated coronary artery disease which would normally explain these symptoms. Instead, the angiogram identifies the hallmark feature of Takotsubo, which is the shape of the heart. This unusual shape of the heart resembles an octopus pot, which explains the name “Tako tsubo” (meaning octopus pot in Japan, where this unusual condition was first diagnosed). The effect is a temporary weakening of the muscular portion of the heart, and abnormal heart motion, but the damage in most cases is relatively short-lived (normally within a few months) but can re-occur.

Common factors associated with Takotsubo cardiomyopathy are that it occurs suddenly and unpredictably, it is often triggered by physical or emotional stress, and it most commonly occurs in post-menopausal women. Dr Neil explained that the treatment of Takotsubo cardiomyopathy varies. Treatment includes drugs for heart failure, beta blockers and calcium channel blockers, and maintenance of physical health and stress-management are important.

I can provide the full article to any member who is interested.

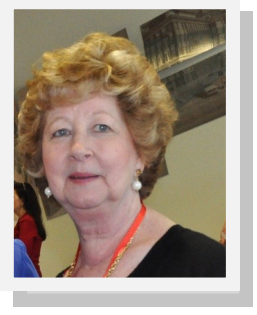
Our next meeting at Epworth will be held on 22 November when our guest speaker Dr Andris Ellims will speak on hypertrophic cardiomyopathy and the specialist HCM clinic at the Alfred. Of special interest to members will be information on genetic research at the Alfred Hospital and Baker Institute. The importance of this to our members was highlighted in the President’s report on behalf of our National Executive at the recent AGM.

Our next lunch at Matthew Flinders Hotel, Chadstone will be held at 12.30 pm on Saturday 10 October.

Please keep an eye on the website in case of updates.

I look forward to seeing you at both events.
With kind regards

Joan Kerr
Victorian Contact
phone: (03) 9848 7082
email: jakerr@iprimus.com.au



Tasmania News

*H*i from Tasmania

A solid dump of snow state-wide in August has been a real novelty and what a way to welcome relocated member Pam to Tasmania. No doubt a relief from the oppressive heat of Northern Australia !
Congratulations to my friend Vern, who is still going strong twenty years since he received his "new heart". During "DonateLife Week", Vern pleaded for people to register as organ donors. Has anyone in your family considered this option?
Should any of you know of any prospective members out there , please do not hesitate to provide me with contact details to enable me to follow it up.

Please contact me with any queries or matters I can help with at

vbaustin@bigpond.net.au or 6229 6181.

Keep well,

Brian Austin (Tasmanian Contact)

Member Profile

Q	*A*
Name and location?	Linda, from West Launceston, Tasmania
What type of CM do you have?	Left Dominant Arrhythmogenic
When was it diagnosed and, What was your reaction?	2009. Very scared as I had only been diagnosed six months prior
What were your symptoms?	Multiple arrhythmias and shortness of breath
What treatment was suggested?	Electrophysiology studies, MRI then ICD fitted
How often do you see a cardiologist?	Annual checks
How does CM affect your life?	Always aware that life can change any minute
How does CM impact on the lives of other family members?	Has made them aware how precious life is
Do you keep abreast of research?	Yes, but there are very few with my type of CM. My son is researching my condition
Do others in your family carry the CM gene?	Yes, my elder brother
Are you happy to make contact with other CM sufferers?	Yes
Have you found CMAA to be beneficial?	Yes, talking has helped
Any other comments?	Yes, I would love to see a cure for CM

Cardiomyopathy Association of Australia Ltd

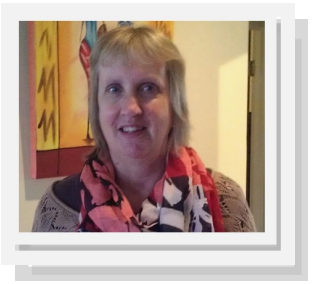
SA and NT News

Hello to all members in SA & NT

I hope everyone is happy and well as we've had what feels like a very long and very cold winter in SA, and I can imagine everyone can't wait for some much needed sunshine.
Our Annual General Meeting was held here in Adelaide on Saturday the 29th August 2015. Despite some hiccups with the venue, it all went well. We had quite a few members, and family and friends.

Lunch was served followed by our Guest Speaker Janice Clifford who spoke on ICDs and Pacemakers for people with Heart Failure. The AGM followed with Alistair, Janet and Hylton giving us the minutes of the last AGM. Bronwyn Batson was elected and I know she will be a great asset to the Exco Committee. A big Thank you to Bronwyn, Mary and Val for all their help over the last few weeks because without them it would not have been the success it was.

We have entered Cardiomyopathy Australia for the second year in a row in the City to Bay Fun Run. It will be held on Sunday the 20th September 2015. So far we have raised $6,190 and with a few weeks to go we hope to get near our target of $10,000. We are very grateful to 'Lifesyle SA' for sponsoring our 25 participants and because of their help we have certainly been able to achieve our goal of making a difference.



Take Care
Kerry Shaddick — SA and NT Contact:

Phone 08 8270 7747
Email kerry.shaddick@hotmail.com

Thank You

Our sincere thanks to our sponsor,
Direct Response Australia (DRA) whose Sydney manager, Wendy Cosgrave and her staff have undertaken the printing, collating and distribution of printed copies of our Newsletter.

Without this much appreciated assistance, our Newsletter simply would not exist in its printed form.

Cardiomyopathy Association of Australia Ltd

Queensland News

Hello from Queensland

Our thanks and appreciation to Glennys and Gus Govan who hosted our meeting on 6 June at which regular and other welcomed members attended along with some new members. It was pleasing to know the new members were surprised at how much information they learnt by listening to others' experience and the resultant hope they were given. Our meetings focus on helping others by talking about our condition with old and new members in an informal setting. It is felt to be a tremendous help, and we encourage as many as possible to attend.

Our last meeting was at on 5th September and again we had a small group of old and more recent members.

Our remaining meeting for the year will be on Saturday December 5, at 1.00pm in our usual venue at the Meeting Room of Toowong Library at the Toowong Village Shopping Centre. Free parking is available and public transport, train and bus, is very convenient. As always, all members, their families and friends are welcome. It's a great opportunity to meet and talk informally with others with CM and their carers.

As mentioned in the last newsletter, we are seeking members who can take on the task of arranging the quarterly meetings from 2016, either on an individual or shared basis. It's not an onerous duty. Anyone who is interested is welcome to contact us.

Queensland members, please remember that we have a stock of CMAA brochures. You can help spread the word about the Association by simply giving some of our brochures to cardiac clinics or hospitals every time you have an appointment. Please email or phone us and we can mail you some brochures. Although the information is on the website, many people like to read a hard copy.

Our best wishes to you all

David and Anne Abbott
Queensland State contacts
phone: 07 3202 8138
email: abbottdm@gil.com.au

Are you happy to continue to receive invitations to our regular meetings by mail or email?

*If you find you are **never** able to attend our meetings and events and would therefore rather **not** receive invitations, please let us know.*

*Just call your **State Contact** (see details on each State Contact's report) or drop a line to*

Membership Secretary
P.O. Box 273 Hurstbridge, Victoria 3099

Young Members Group (YMG)

Just before finalising this issue, we received the welcome news that Miranda has undergone a heart transplant and the last report is that she is doing well. Her own heart was failing rapidly. We are sure that everyone will join us in wishing her a successful recovery and look forward to an update from Miranda on her experiences in future issues.

(Newsletter editors)

Miranda Hill
miranda82@ymail.com
0411 962 946

CMAA Young Members' Group

This is an exciting and timely initiative for CMAA to pursue, harnessing the enthusiasm of Miranda and other young members to respond to their special needs and interests. We would welcome hearing first hand the issues facing younger people with CM. Please contact Miranda (details above) to express your interest in being part of the Young Members' Group and sharing your experiences.

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 enroll 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

News from New South Wales

Lunch Meetings

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 Second Floor Bistro, Mosman RSL Club, Military Road, Mosman, NSW. Please make a note in your diaries and organisers.

We meet at 12.00 noon for a 12.30 pm start. Please RSVP your intention to attend to info@cmaa.org.au.

Contact Person for NSW

We are still seeking a member to act as Contact Person for NSW.
As contact is mainly by phone, the role need not necessarily call for a Sydney based member. If you would like to find out more about the duties of a Contact Person, please do not hesitate to contact the Association's Secretary, Janet George, at info@cmaa.org.au or you may like to speak with any of the other State Contacts *(details on the website).*

News from New Zealand

Hi All,

Amazing how much better I feel with the change in season. It's been a long winter that has knocked a few of us around. Here is to a great summer and even better health.

The Cardiac Inherited Disease Group held an evening for everyone on the 18th September at the Langham Hotel. The title was "Saving Young Lives in New Zealand" and the event was free. They lined up some great speakers and had time to ask questions.

There'll be a report on it in the Summer newsletter.

Best regards

Andrea

andreafullerton@yahoo.com.au

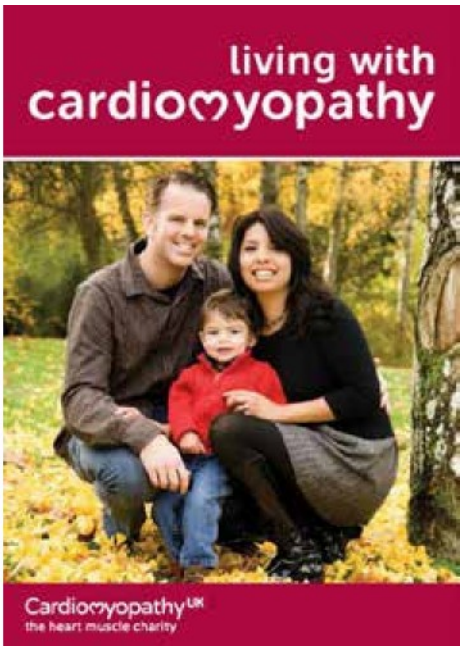
The second edition of Margot Maurice's book, "**Six Months to Live; *my cardiomyopathy story of Mind over Medicine,"*** *is available now as an* ***Ebook*** *from most well known online Ebook sellers around the world, as well as from the publisher,*

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 & Robertson at $6.50, a percentage of which will be donated to Cardiomyopathy Australia.

Cardiomyopathy UK has issued a new "Living with Cardiomyopathy" booklet



A new practical guide to help affected people get on with their lives is available from Cardiomyopathy UK.

The 92-page, full colour publication provides information about learning how to live with cardiomyopathy and getting on with your life.

The free booklet covers diagnosis and care, looking after yourself, coping emotionally, involving family members and partners, carrying on with life and getting support from others.

Issues looked at include coping with tiredness and the side effects of drugs, sleeping, exercise, handling your feelings, living with a heart device, sex, pregnancy, working, driving and finances.

While the booklet is primarily aimed at people with CM in the UK, there are many aspects covered that are relevant to coping with the condition in Australia and New Zealand.

You can download a copy from the Cardiomyopathy UK web-site, at:

http://www.cardiomyopathy.org/cardiomyopathy-information/living-well

---

Dear Doctor……..

This popular segment has been held over to our next issue. Please keep sending us your questions.

If there is something on your mind that you'd like an answer on, please either email your Dear Doctor questions to Newsletter on our website (www.cmaa.org.au) or post them to CMAA Ltd, PO Box 273, Hurstbridge, VIC 3099 for inclusion in future issues.

Cardiomyopathy Association of Australia Ltd

How can I be better informed about my condition? ...and what should I be asking my specialist?

Many people have been inquiring about questions to ask doctors and specialists. They also mention that they are embarrassed, in some trepidation about bothering a busy specialist, or just plain forgot to ask.

In the long run, patients save specialist time by asking questions and making sure they understand. It's worthwhile at the end of an appointment for the patient to go over what they understand the specialist to have said, checking with the specialist and writing it down. It's even better to take someone with you.

This advice is even more important for the first consultation and when getting the results of an examination.

It's not necessary to be like the UK patient *(see later article in the Best of British section)* who has embraced most sources of information and uses technology to keep track of her condition, but a patient aware and knowledgeable is likely to have better outcomes. Such patients are partners in their care. Check the spelling of medical procedures and drugs. Check the reason for those procedures. It's worth keeping a diary of your body's behaviour and reactions to all treatments. This will help the specialist. Put everything down, even if it seems unimportant.

So, here are some of the questions that patients may need to ask specialists. Treat them as prompts rather than a specific list and make sure that you concentrate on your "top of mind" issues that are of greatest concern:

Condition:

- What type of CM do I have?
- What does it do to my heart?
- Is it likely to get better, worse or stay the same?
- Might I need a device fitted? If so, what kind?
- Is it true most patients live a normal length of time?

Treatment:

- What tablets do I take and what do they do for my heart?
- Are there side effects I should know about?
- Might I need to have them changed?
- Should I have an annual flu jab?
- When should I see my GP?
- How bad should I feel before going to the doctor?

Recreation and Travel:

- Are there things I must not do?
- Can I drive?**
- If I have an ICD, are there activities I must avoid, such as theme park rides and saunas?
- What precautions should I take for long distance travel?

*(** remember that it is mandatory to advise your State or Territory driving licensing authority if you have CM and obtain an annual medical certificate for continuing validity of your driving licence and vehicle insurance)*

Work:

- I'm a _____ . Will my condition stop me doing that work?
- If not, what adjustments should be made at my workplace?
- I don't understand all this well myself. How do I explain this to my boss?

Future:

- How do I manage my condition in the long term?
- If I start to feel better, can I do more activities?
- Where can I go for further reliable information?

Family:

- My child has the condition. What can't my child do at school? Should I tell the school about the condition?
- My child resents being treated differently. Where can I go for help and advice?
- Should my family be tested? If so, how often?
- I've heard of young people falling dead on the playing field. Could this happen to my child?
- Can I marry? Will all my children have CM?
- What about mortgages and insurance?
- Where do genes come into it? And where can I get more information?

Then and now

"We were all happier then." How often have you heard those or similar words spoken by older people? The last time I read – and heard that statement was on the Isle of Lewis during this Northern summer. It's a bleak spot, pounded by the Atlantic Ocean, almost treeless, plagued by midges in the summer and biting cold in the winter. The 'then' referred to was fifty years ago.

The famous tweed is still woven on handlooms in crofts on Lewis and Harris which are actually one island; sheep and Highland cattle are the only animals daft enough to thrive there, except for people of course. The islands around Scotland are plagued by the same problem of country towns here: the young leave for jobs and better lives elsewhere. But many stay. Some even return. They have good housing, good schools, medical services, supermarkets and cheap whisky. Could a Scot want any more? The latest fashions, mobile phones and cars are bought, TV comes via satellite and the internet speed beats what's available here in Brisbane.

Yet, a comfortably off Lewis man, standing in his centrally heated fine modern home, talking of his grandchildren having so many toys and overseas holidays, said, "We were all happier then."

'Then' would have been dire to my eyes, even as a child in a post-war England with rationing. Many Lewis people lived in blackhouses, which were thick-walled single-storey stone dwellings, roofed by thick hay thatch kept from blowing off by ropes weighted by rocks. Heat came from two sources, the animals living at one end of the house and a central peat fire. There was no chimney and the peat smoke drifted through the house. It kept the midges out and perhaps helped to disguise the fragrance of animals. Light came from oil lamps during the long dark winter. Life was hard, work was hard, the ground was rocky and the surrounding sea was treacherous most of the time. Peat gathering was back-breaking. Fancy hewing your own coal? Cutting peat is much the same.

Yet, descriptions of life then emphasized the comradeship, the enjoyment of simple things, the appreciation of nature and the fun arising from storytelling around the peat fire or generated by singing and dancing in the local pub. It was all contrasted with today's bored kids who needed to have entertainment supplied and dissatisfied adults who wanted the latest gadgets.

I have just listened to David Brooks, a columnist from The New Yorker, who says that too many of us will have a eulogy like a CV. You know, 'Jim rose to become a first-class electrician. He was a good provider and worked hard to make sure his family had a fine house, holidays, labour-saving gadgets and drove around in a decent car. '

The columnist said that the human touch and character will be missing. Jim will not be remembered for fishing with his son, doing funny daft things with the family, helping around the neighbourhood and enjoying life. He says we are caught up in acquiring instead of doing, of looking good instead of being good.

I have greatly simplified his message but I feel it strikes home. Look at those magazines that celebrate the veneer of lives that are often rich with possessions but pretty unhappy. Many celebrities take drugs. Police say there is an ice epidemic. Some people spurn that lifestyle. A shock, an illness, an encounter, something has made them re-appraise their lives. They see clearly what really matters and stop living the life of a consumer and start to become more of a giver.

Over the years, I have listened to many brought face to face with their physical weakness who have turned life around and come to admit that the shock of illness was the best thing that ever happened to them. "I've got things in perspective now. Things are back in correct proportion now." They admit that the hard life in Lewis was rich in what matters most after all.

Anne Abbott

Small bits of news

While having a trawl through the latest news on heart research, I was struck anew how wary researchers are to claim any major breakthroughs. Contrariwise, the newspapers do not let much stand in the way of a good story.
Research is a long-term undertaking. As much as penicillin was needed, it took 12 years before the first successful experiments on mice demonstrated its effectiveness. Scientists now are often working on far more complex research.
Nevertheless, there are some signs of new drugs and successful research into basic biology.

Research undertaken by the Heart Institute in Sydney has found that an enzyme in the kinase group has great potential as a drug to stop blood clots while allowing normal action around a blood vessel injury. Note the word 'potential' which means here sounds good but not yet and only perhaps.

A very obvious piece of research. We should wash our hands thoroughly using ordinary soap and singing "Happy Birthday" through twice – yes really. That reduces bacteria on the skin by as much as more expensive antiseptic washes. We should brush our teeth thoroughly and keep our mouths clean. Inflammation arises in gums and can affect the heart. Thomas Van Dyke of Forsyth Institute has reviewed clinical evidence to prove that brushing teeth well is essential.

There has been concern in USA over another sudden death in a young athlete caused by an unsuspected cardiomyopathy. These deaths are rare; the incidence is about 1 in 200,000 but the grief for the family is real. An American cardiologist said that no matter what action is taken, some deaths will still occur but 'we could do better.' I have long advocated tests before playing team games, particularly in at risk families.
A form to fill in about family history might pick out some warning signs.

This has nothing to do with cardiomyopathy but is very interesting

We tend to think ourselves so capable and so clever while dismissing the olden days as hopeless except as times of exemplary behaviour. "We didn't behave like that in school in my day" and so on. But we are too dismissive. We forget that humans have really not got more intelligent over time. Fancy a debate with Socrates? Some scientists are looking again at old drugs that have fallen out of favour. I even imagine academics of differing subjects combining their knowledge.

Venice in 1347, faced with plague, may well have a method to deal with outbreaks of disease like Ebola. The authorities organized quarantine stations on near by islands , and started the usage of protective clothing for all, not just medical personnel. It's now called resilience management. It did well for Venice.

Some knowledge may be found after being lost. A 1000 year old textbook in the British Museum had recipes that contained known substances to combat infection but in combination. Medieval historians wondered how effective an Anglo-Saxon eye infection remedy made of bile from cow's stomachs, leek or onion, garlic and wine, left for 9 days in a bronze vessel would really be.

Colleagues in the University of Nottingham made up doses of it and tried it on petri dishes of s. aureus. The potion killed all but 1 in a 1000 of the bacteria.
"We thought that Bald's eye salve might show a small amount of antibiotic activity, because each of the ingredients has been shown by other researchers to have some effect on bacteria in the lab - copper and bile salts can kill bacteria, and the garlic family of plants makes chemicals that interfere with the bacteria's ability to damage infected tissues. But we were absolutely blown away by just how effective the combination of ingredients was." (Dr Freya Harrison, University of Nottingham)
Do **NOT** try this yourself. Your eye is not a petri dish!!!

Recent developments of interest close to home

Exercising with an ICD

We regularly hear of people fitted with ICDs who are uncertain about the nature, amount and degree of exercise that should be undertaken.

NSW Health through its North Shore Cardiovascular Education Centre supports a "Young ICD Network" with regular presentations on issues facing younger people with ICDs. These sessions are freely available on video and accessible via the Exercise on Demand website—www.exerciseondemand.com.au. Two sessions are currently available:

- *Exercising with Your ICD*
- *Feed your Heart and Mind*

When accessing the website, there is an option to "join here" but if you click on the actual picture it takes you straight in and you don't have to join.

The videos are available through the generosity of Martin Dunkerley (an ICD recipient and owner of Energize Health Club and Exercise on Demand) as Martin kindly funded the filming/editing of both sessions.

While it is a great resource for additional exercise options, please remember that **anyone with CM and/or an ICD needs to seek medical clearance before embarking on any exercise program**.

(Source: North Shore Cardiovascular Education Centre, NSW Health, September, 2015)

Sudden deaths on sporting grounds—World-first MRI trial

"A world-first medical trial is promising to identify those at risk of suddenly dropping dead on sporting fields." (Herald Sun, 26 June, 2015)

Melbourne based Baker Institute researchers are using MRI scans to examine the hearts of people with HCM and their relatives and identify those at risk.

Those of you who attended the CMAA 2012 Seminar in Brisbane will no doubt recall Dr James Hare's presentation on the potential uses of MRI scans for cardiac conditions such as CM.

Already, the research trial is reaping results. Dr Andris Ellims and his team have already identified 240 more people at risk by examining 60 patients. The use of state-of-the-art MRI scans can identify those at risk more effectively than traditional cardiac ultrasound.

Dr Ellims states that the use of MRI is particularly relevant to deaths at sporting events where symptoms can occur with no warning at all. People identified as being at risk can then avoid competitive sport and be provided with appropriate medication.

A further benefit is expected to be a better understanding of the condition. With an estimated 12,000 people in Victoria alone with HCM, the outcome of the trial will be eagerly awaited.

(Source: Herald Sun, 26 June, 2015)

Do you have a story to tell?

There's nothing like sharing actual experiences with people in similar situations who are having to address common issues. Members' stories always have great appeal with our readers. If you would like to share your story with your fellow members, please contact your newsletter editors (see page 3) or State Contact Person. Please remember that we are available to help with the writing of articles.

Anne and David Abbott—Newsletter editors

Cardiomyopathy Association of Australia Ltd

Recent Research Studies

Obese atrial fibrillation patients have a lower chance of arrhythmia recurrence if they have high levels of cardiorespiratory fitness, and risk continues to decline as exercise capacity increases as part of treatment, according to a study published in the *Journal of the American College of Cardiology*.

While weight loss is important for heart disease patients, especially those with arrhythmia, our study shows it's beneficial to have high cardiorespiratory fitness and continue to improve on that," said Prashanthan Sanders, M.B.B.S., Ph.D., senior author of the study and director of the Centre for Heart Rhythm Disorders at the University of Adelaide in Adelaide, Australia. "An ideal treatment plan would include a focus on both."

Cardiorespiratory fitness is a person's exercise capacity. It is a component of overall physical fitness involving the ability of the circulatory, respiratory and muscular systems to supply oxygen during sustained physical activity.

After four years of follow up, 17 percent of patients in the low cardiorespiratory fitness group were free from arrhythmia, compared to 76 percent in the adequate group and 84 percent in the high group.

Those who improved upon their cardiorespiratory fitness had even further risk reduction. Researchers found that for every increase in metabolic equivalent, or MET, a measure of the amount of oxygen consumed at rest, there was a 20 percent reduction in risk of arrhythmia recurrence, and this increase was still shown after adjusting for weight changes and baseline exercise performance. MET measures are used to determine exercise capacity in terms of energy a person uses to participate in physical activity.

Patients were also divided into four groups to determine freedom from arrhythmia based on weight loss and gains in exercise capacity, and researchers found that a gain in exercise capacity greater than 2 METs in addition to weight loss was associated with two times greater freedom from arrhythmia.

In an accompanying editorial comment, Paul D. Thompson, M.D., FACC, chief of cardiology at Hartford Hospital in Hartford, Connecticut, said, "What's most exciting about this new study is that it is the first to demonstrate that increasing exercise capacity reduces atrial fibrillation risk.

A study led by researchers at McMaster University has found that trans fats are associated with greater risk of death and coronary heart disease, but saturated fats are not associated with an increased risk of death, heart disease, stroke, or Type 2 diabetes.

The findings were published by the *British Medical Journal (BMJ)*. The lead author is Russell de Souza, an assistant professor in the Department of Clinical Epidemiology and Biostatistics with the Michael G. DeGroote School of Medicine.

"For years everyone has been advised to cut out fats. Trans fats have no health benefits and pose a significant risk for heart disease, but the case for saturated fat is less clear," said de Souza.

"That said, we aren't advocating an increase of the allowance for saturated fats in dietary guidelines, as we don't see evidence that higher limits would be specifically beneficial to health."

Guidelines currently recommend that saturated fats are limited to less than 10 per cent, and trans fats to less than one per cent of energy, to reduce risk of heart disease and stroke. Saturated fats come mainly from animal products, such as butter, cows' milk, meat, salmon and egg yolks, and some plant products such as chocolate and palm oils. Trans unsaturated fats (trans fats) are mainly produced industrially from plant oils (a process known as hydrogenation) for use in margarine, snack foods and packaged baked goods.

Contrary to prevailing dietary advice, a recent evidence review found no excess cardiovascular risk associated with intake of saturated fat. In contrast, research suggests that industrial trans fats may increase the risk of coronary heart disease.

Patients with mitral regurgitation face a dilemma of whether to undergo corrective surgery early, when they might have no or few symptoms, or wait until their condition worsens. Current guidelines allow for watchful waiting until certain symptoms appear that would then "trigger" the decision to proceed with surgery. The authors argue that these guidelines are based on relatively weak class C evidence from clinical experience that is now 20 to 30 years old, and surgical methods, including mitral valve repair instead of valve replacement, have now made surgeries safer with good long-term outcomes, especially when performed at high-quality, high-volume centers. The results of this study from Mayo Clinic indicate that delaying surgery until clinical triggers appear leads to increased mortality and congestive heart failure. In an accompanying Editorial, Dr. Donald D. Glower suggests that guidelines should be modified so that early surgery is made a class I indication for severe mitral regurgitation with a high likelihood of repair, and that patients should seek care from experienced surgeons at high-volume centers.

Dr. Glower agrees that the early surgery approach should be reserved for higher-volume institutions and patients with a high likelihood of repair. He urges "physicians to be honest enough to look at themselves, and not just at the patients" when making decisions about when, where, or by whom patients with MR should undergo surgery.

Source:

American Association for Thoracic Surgery

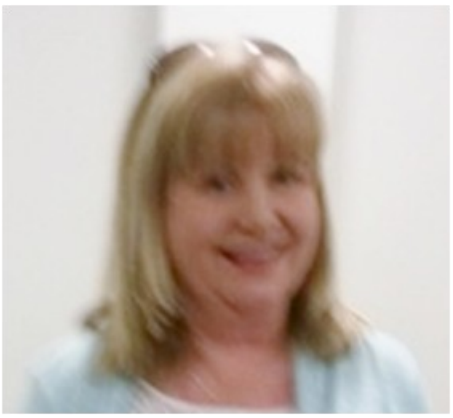
2015 Annual General Meeting

As reported earlier in this issue in the President's message and Kerry Shaddick's news item from SA and NT, the Association's AGM followed by a presentation by guest speaker, Janice Clifford, on ICDs and Pacemakers was held in Adelaide on 29 August. Our President's report demonstrated that the Association is in a sound position and in very good hands. The report is on page 4 of this issue.

Congratulations and thanks are extended to Kerry and her team of volunteers who organised and managed this successful event.

A special welcome is extended to Bronwyn Batson from Adelaide who was elected to the Executive Committee as a Director of the Association.

Bronwyn Batson—Director, CMAA



Janice Clifford—Guest Speaker

The members of the Executive Committee for 2015/16 are:

President:	Alistair Kerr
Vice President and Treasurer:	Hylton Mackley
Secretary:	Janet George
Directors:	David Abbott
	Bronwyn Batson
	Miranda Hill
	Margot Maurice
	Kerry Shaddick

2016 Annual General Meeting

(a note for your diaries)
This will be held on the Gold Coast, Queensland, in late August or early September, 2016. It's a great time of the year to visit. All members will be most welcome. Further details will be in our next issue.

Cheat's Chicken Pie

Who ever thought making a delicious chicken pie for the family could be this simple?

Serves 4
Preparation time: 10 minutes
Cooking time: 25 minutes

Ingredients:

1 tbs olive oil*
460g skinless chicken breast, trimmed of fat, cut into 5-cm strips*
200g mushrooms, sliced
250g can chicken soup*
1/2 cup frozen peas*
1/2 tbs low fat Greek-style yoghurt
Cracked black pepper, to season
1 bunch broccolini, stalks trimmed
1 1/2 sheets reduced fat puff pastry, thawed*
1/2 egg yolk, beaten*
Steamed vegetables or green salad, to serve

* Products available with the Heart Foundation Tick. Remember all fresh fruit and vegetables automatically qualify for the Tick.

Instructions:

1. Preheat oven to 200°C (180°C fan-forced).
2. Heat 1/2 tablespoon of the olive oil in a large frypan and brown chicken strips for 1 to 2 minutes on each side. Remove chicken from pan and set aside.
3. Heat remaining oil and sauté mushrooms for 2 minutes.
4. Return chicken to pan with mushrooms; add soup, peas and Greek yoghurt. Season with cracked pepper. Bring to the boil, then turn off the heat.
5. Transfer mixture to a pie dish approximately 28 cm x 21 cm.
6. Arrange broccolini on top of chicken filling.
7. Cover pie dish with puff-pastry sheets, cut a hole in the centre using a sharp knife and press down edges with the prongs of a fork.
8. Brush pastry surface with beaten egg yolk and cook in oven for 25 minutes.

The Best of British

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

Reproduction of the excerpts is possible with the kind permission of Cardiomyopathy UK for which we express our appreciation.

Cardiomyopathy UK wishes to acknowledge the continuing support of the British Heart Foundation.

my life

The magazine from Cardiomyopathy UK the heart muscle charity

New heart failure treatment on its way

A new heart failure drug that has been shown to improve survival and reduce hospital admissions for heart failure has won its first approval.

The Food and Drug Administration in America has given the go-ahead for the Novartis drug Entresto (formerly called LCZ696) to be used in patients with a reduced ejection fraction (EF). EF is the percentage of blood pumped out of the heart with each beat and in people with heart failure, this figure can sometimes be severely reduced.

The drug, made up of two main ingredients (sacubitril and valsartan) is being reviewed by health bodies around the world, including in the EU.

"Millions of people diagnosed with reduced ejection fraction heart failure now have a much greater opportunity to live longer and stay out of hospital," said David Epstein, division head of Novartis Pharmaceuticals.

A recent study with 8,442-patients was stopped early when it was shown Entresto significantly reduced the risk of death when compared with the ACE-inhibitor enalapril.

At the end of the study, patients with reduced EF who were given Entresto were more likely to be alive and less likely to have been admitted to hospital for heart failure.

The twice-a-day tablet enhances the protective neurohormonal systems of the heart while simultaneously suppressing the harmful system.

For more details, see cardiomyopathy.org/heart-failure-drug

Harry gets world's first mini heart pump

A man from Northern Ireland has become the first man in the world to receive a new heart pump which is half the size of traditional heart pumps.

Retired father-of-three Harry Chivers, 63, has been fitted with the Miniaturised Ventricular Assist Device (MVAD) at the Freeman Hospital in Newcastle.

Harry was in advanced heart failure and waiting for a heart transplant when he was given the opportunity to join trials for the device. Reports say he has made good progress since the £80,000 device was fitted in July.

The MVAD, produced by HeartWare International, also has sophisticated controls and settings that allow it to adapt better to patients' lifestyles.

It weighs 78g and its reduced size may make it suitable for children with severe heart disease.

It is powered by a battery pack through a wire which passes out of the patient's stomach. The pack can be carried in a bag or around the waist.

The trials for the device are due to enrol 60 patients at 11 sites in the United Kingdom, Austria, Australia, France and Germany. In the UK, heart pumps are only allowed on the NHS for patients awaiting heart transplant.

For more details, see cardiomyopathy.org/miniaturised-heart-pump

New anticoagulants: new drug update

Paul Wright | lead cardiac pharmacist,
University College London Hospitals

New drugs are increasingly prescribed for those with cardiomyopathy thought to be at risk of having a stroke

Atrial fibrillation (AF) is a common rhythm disorder of the heart that causes the atria (the top chambers of the heart) to beat in a fast, uncoordinated way. This causes sluggish blood movement around the atria and increases the risk of clots forming and causing a stroke.

AF affects between 1.5-2% of the general population. It significantly increases with age and it commonly affects more than a quarter of people with cardiomyopathy. Patients need to be told their individual risk and the benefit of medication — anticoagulants — to reduce clots and the risk of stroke. Until recently the only readily available drug was warfarin. Now there are alternative medications.

Doctors may suggest prescribing anticoagulation in the absence of AF in patients with cardiomyopathy as there may be more reasons that blood may pool and clot in the chambers of the heart.

These reasons may include dilated atria, those with dilated cardiomyopathy with enlarged ventricles and in those where the ventricles are not pumping effectively. To date the new anticoagulants are not licensed to prevent clots for these conditions due to lack of clinical trials in these areas and as such warfarin may remain the preferred drug.

For those with AF, NICE has developed a risks and benefits guide. The risk tool calculates an individual's risk of stroke and calculates if you would benefit from anticoagulation. The higher the score, the higher an individual's risk of stroke and the more benefit there is of being on anticoagulation. The risks of treatment are predominantly related to excess bleeding.

It is now clear from evidence that although aspirin reduces the stickiness of blood, it is much less effective at reducing the risk of stroke in people with AF. Anticoagulants have shown a significant reduction in strokes reducing a baseline risk by about 65-70%. The novel oral anticoagulants (NOACs) are a rapidly expanding group of medicines also known as non-vitamin K oral anticoagulants. They are licensed for conditions including stroke prevention in AF, treatment and prevention of leg and lung clots, and short term use following hip and knee surgery. There are conditions where NOACs cannot be used (for instance those with mechanical heart valves).

As of July 2015 there are four NOACs available for the prevention of stroke in patients with AF: dabigatran (Pradaxa), rivaroxaban (Xarelto), apixaban (Eliquis) and edoxaban (Lixiana). Others in clinical trials may be available soon. This article focuses on the first three licensed products that NICE has appraised and suggested can be offered as an option for stroke prevention in AF.

Which NOAC is best?

NOACs have been compared against warfarin in a number of different clinical trials for stroke prevention in AF and all were slightly different, enrolling different patients. The drugs also have different characteristics meaning it is impossible to directly compare one against the other.

The new anticoagulants

Advantages
- Fixed doses
- Act immediately
- Routine blood monitoring not needed
- Minimal dietary interactions
- Fewer drug interactions

Disadvantages
- Less patient monitoring
- No antidote or reversal treatment for overdoses
- Dose reduction required for kidney problems
- More expensive than warfarin

In terms of efficacy, trials have been undertaken to show noninferiority to warfarin (the NOAC is not clinically worse than warfarin). In these trials, if noninferiority was shown, a further statistical analysis was undertaken to show superiority (NOAC is better than warfarin).

Dabigatran low dose and rivaroxaban have shown noninferiority to warfarin whereas high dose dabigatran and apixaban have shown superiority.

Caution needs to be taken as, although statistically significant, the absolute benefits over warfarin for high dose dabigatran is 0.58% per year, and for apixaban is 0.33% per year.

Warfarin, around for over 50 years and highly effective, does have drawbacks, including the need for frequent blood tests, variable dosing, lots of food and drug interactions, slow onset of action and delayed offset of action.

The use of NOACs in general practice has been relatively slow in part due to cost, lack of experience with the drugs, concern about bleeding and reversibility, and initial delays in guidance from NICE about their use.

With NICE indicating that all three can be considered, greater awareness of the NOACs and increasing numbers of AF patients receiving anticoagulation, this is changing. There are also ongoing trials with promising data for reversal agents specific to NOACs, and so giving doctors and patients increased confidence that major bleeds (should they occur) can be better managed acutely (these are undergoing trials and not currently available). The patient decision aid mentioned earlier may be a good tool to use when discussing anticoagulation options and may help decide the best choice for individual patients.

Patient portals can help deliver better care

Will Bradlow | consultant cardiologist,
University Hospitals Birmingham
NHS Foundation Trust

Our patient portal, a secure website that gives patients 24-hour access to personal health information, helps to deliver high quality care to patients

A growing number of my patients are benefiting from an online portal that gives them access to their own health records. The system, called myhealth@QEHB, is currently available to nearly 9,000 outpatients across 22 specialities. More than 500 seen by the heart muscle disease service are currently signed up. myhealth@QEHB was developed by the in-house technical development and informatics team at University Hospitals Birmingham NHS Foundation Trust. The close involvement of doctors and patients ensures the portal has a positive impact on care.

myhealth@QEHB allows patients to remotely access and upload information into their own healthcare record. The portal gives users a view of their laboratory results, letters, medication, plus past and future outpatient appointment details. Patients can also interact with each other and create their own support networks, talk to each other, keep journals and publish information to their support network.

Many of the patients seen at the trust live further afield than the usual hospital catchment area and, for these patients in particular, myhealth@QEHB allows them to play a greater role in managing their care remotely, including the ability to check results online. Finding out more about our individual patients' conditions allows us to personalise their treatments and better respond to their symptoms.

The system supports this approach by allowing personalised support and giving patients access to their own bespoke care plans. Ultimately, with more knowledge and understanding of how to manage their condition, patients should have better outcomes.

In the near future there are plans to extend the service to offer care planning, e-learning and virtual clinics. The care planning tool enables patients to view data pertinent to their treatment and condition as well as add to the record. Involvement of patients improve both patient satisfaction and compliance.

Seeking out information using the internet has recently been shown to be associated with lower levels of anxiety amongst a cohort of individuals with or at risk of cardiomyopathy (See story below).

The e-learning package will build on this approach to improve patient understanding of their condition by providing high quality and accessible interactive patient information leaflets and patient training materials to complement knowledge and understanding.

Virtual clinics are a new feature in myhealth@QEHB, allowing patients and their clinician to engage in online video, voice and text chat. Patients using myhealth@QEHB will be given the option of booking a virtual appointment instead of attending a physical appointment at the hospital.

The sign-up process is simple. Patients who have received a leaflet from their clinic can hand it to their consultant asking to be registered to use the system. The consultant will then use the unique reference number on the leaflet to register the patient.

myhealth@QEHB uses security systems like those used in internet banking. So personal information is safe, as long as patients keep their log-in details secure.

A recent survey of patients using the portal showed more than 77% of respondents agreed or strongly agreed that by using myhealth@QEHB they were more prepared for hospital visits while 73% agreed or strongly agreed that they felt more in control of their medical care.

Online cardiomyopathy information can reduce patient anxiety, says study

People with cardiomyopathy or at risk of developing the disease suffered less from anxiety after seeking online information about the disease, says a new study published in the American Heart Journal.

The study, led by Clara Minto from the department of cardiac, thoracic and vascular sciences at the University of Padova in Italy, looked at those searching for online health information and anxiety levels among 104 patients – 48 with cardiomyopathy and 56 at risk of developing it.

The patients completed three different questionnaires – one on using the internet, one on quality of life and one measuring anxiety levels. For both groups of patients those seeking online health information had substantially lower anxiety levels.

The researchers concluded that internet technology could be helpful to people due to its informational power and its potentially therapeutic value".

Q&A

Professor Perry Elliott from the inherited heart disease team at University College, London, answers your questions

Q: I am a 40 year old woman with dilated cardiomyopathy (DCM) and frequent ectopic beats. Following genetic testing, an abnormality in my DSP gene linked to arrhythmogenic right ventricular cardiomyopathy (ARVC) has been found. My sons (9 and 12) are regularly screened. Both appear non-symptomatic at present. My eldest is very sporty. Would screening for my children detect abnormalities linked to ARVC if they have been looking for DCM symptoms?

A: Mutations in the DSP gene (which codes for a protein called desmoplakin) can cause ARVC and DCM. It's unlikely that either of your sons would be manifesting abnormalities at their age, but screening with ECG and echo will pick up obvious signs of both diseases. It would be prudent to discuss the genetic results with your cardiology and genetics teams to see how certain they are that it is the cause of your DCM as this is not always obvious. When your boys are older, it may be appropriate to discuss genetic testing, taking into account all the positive and negative aspects of knowing whether they carry the same gene mutation.

Q: What are your thoughts on research into magnesium deficiency linked to card iomyopathy? I have read lack of magnesium is also linked to facial tics, migraines, leg cramps, tiredness and low mood, all of which I have. I would like to try taking supplements but do not know if this is safe with my current medication. I take a very low dose of beta-blocker and ACE inhibitor and have an internal defibrillator (ICD).

A: Magnesium deficiency can occur in people taking large doses of diuretics, but is otherwise unlikely if you have a normal diet. Before taking any supplements have a routine blood test to check your kidney function and magnesium levels.

Q: Is there a connection between having an internal defibrillator (ICD) fitted and getting a frozen shoulder?

A: Yes, the two can be connected, usually due to people not moving their shoulder around after having the device fitted. They will have been told not to move their arms above their heads for a while, and sometimes people interpret this as not being able to move their arms or shoulders at all. At this time you should keep your joints moving – though not put your arm above your head.

Q: Can beta-blockers cause depression?

A: It is often said that beta-blockers are associated with substantial risks of depressive symptoms, but several large studies have failed to confirm this. One large analysis suggested that beta-blockers are associated with a reduction in the risk of depressive symptoms. In general, the risk of adverse effects should be weighed against the documented benefits of these drugs. For patients who experience new depressive symptoms, it is important to exclude other causes before beta-blockers are discontinued.

Q: I've been reading about the new heart drug LCZ696. Should I be on this instead of my usual ACE inhibitor?

A: LCZ696 is an investigational combination drug containing valsartan (used to treat hypertension and heart failure) and sacubitril (which inhibits the hormone neprilysin). A randomised, double-blinded study published in 2014 found that LCZ696 significantly reduced the risks of overall death, death from heart failure, and hospital stays for heart failure, compared to therapy with the ACE inhibitor enalapril. Despite these results, and before there is wholesale replacement of current heart failure therapy, further analysis of this trial and another currently underway called PARAGON-HF is necessary.

Q: I've seen reports that erectile dysfunction drugs can also help improve heart failure. So could this drug help in the treatment of dilated cardiomyopathy?

A: Phosphodiesterase type 5 (PDE5) inhibitors including sildenafil, vardenafil and tadalafi are the first line drugs for treating erectile dysfunction. They dilate blood vessels, a property that might theoretically be useful in patients with dilated cardiomyopathy. A number of clinical trials have explored their potential as a heart failure treatment. Results are mixed but seem to suggest they improve exercise performance with no increase in adverse events. Research continues.

Q: Does spironolactone cause nipple tenderness? I'm also going through the menopause. Could that be a factor?

A: This is a well recognised side effect of spironolactone. If very troublesome, the drug can be switched to a similar drug, eplerenone, which is less prone to this side-effect.

Gene treatment for hypertrophic cardiomyopathy?

A company in America has begun trialling a gene treatment for hypertrophic cardiomyopathy (HCM).

The company, MyoKardia, says it is the first ever therapy designed to target the underlying cause of hypertrophic cardiomyopathy in patients with a particular genetic make-up.

People with HCM have gene mutations that cause the heart muscle to thicken and stiffen, which can cause the heart to contract too much.

The company says it has begun a study designed to correct one of the most common molecular mechanisms causing HCM (identified from genetic testing) and reduce heart muscle contractility.

A spokesman said it is an important milestone in the development of treatment for HCM.

Dr Tassos Gianakakos, company chief executive, said that by targeting a molecular defect causing HCM, it was hoped the treatment (MYK-461) could restore normal heart muscle contraction and relaxation, and reduce or prevent disease progression.

The first phase of the trial will assess the safety, tolerability and effects of oral doses of MYK-461 in healthy volunteers.

In parallel, there will also be a trial of the treatment in patients with mutations in the MYBPC3 gene, which provides instructions for making the protein cardiac myosin binding C, involved in heart muscle contraction.

For more details, see www.cardiomyopathy.org/genetherapytrials

Young affected children at low risk of dying suddenly

Researchers have been looking into the risks of young children dying suddenly from cardiomyopathy.

Though the disease can be serious in young children and difficult to treat, during a median follow-up of 12 years they found only around one in 20 had died suddenly, the researchers reported in the Journal of the American College of Cardiology.

A total of 289 children aged under ten were enrolled in the National Australian Childhood Cardiomyopathy Study. The study is assessing all children diagnosed in the country with cardiomyopathy from 1987 to 1996.

The risk varied depending on the type of cardiomyopathy. At 15 years, those with non-compaction were twice as likely to die suddenly as those with restrictive cardiomyopathy, almost four times as likely as those with hypertrophic cardiomyopathy and almost five times as those with dilated cardiomyopathy.

The researchers said risk factors also included older age at diagnosis, a family history of cardiomyopathy and severity of left ventricle dysfunction. A higher posterior heart wall thickness was the sole risk factor identified for children with hypertrophic cardiomyopathy.

For more details, see www.cardiomyopathy.org/news/lowrisk-in-children

More understanding of inheritance helps families

Patients need to better understand the genetics of hypertrophic cardiomyopathy to help share the risk of the disease with other family members.

That is the conclusion of a study looking into family communications in those at risk of hypertrophic cardiomyopathy (HCM).

Each child of a parent with the disease has a 50:50 chance of inheriting it. So immediate family members should be checked. But when someone is diagnosed it is them, rather than medical people, responsible for telling family members they might also be at risk. Encouraging family discussion forms part of genetic counselling.

The study, led by a team in the department of human genetics at the University of Michigan in America, looked at identifying factors that affected communication in families.

Nearly 400 people completed an online survey assessing the family (gender, genetic test results, HCM family history and severity of the disease), how the illness appeared, family cohesiveness, coping styles, comprehension of how the disease is passed on to family members and sharing the HCM information to relatives at risk.

Data from 183 people was analysed. The researchers found that women and those with more understanding of how the disease was passed on increased the level of discussion with siblings and children. They concluded that promoting patient comprehension was important and may help family communication.

For more information, about the genetics of HCM, see www.cardiomyopathy.org/genetics

Non-beating hearts

More people with advanced cardiomyopathy may get transplants following advances at Papworth Hospital in Cambridge.

The hospital has become the first in Europe to transplant a non-beating heart into a patient. The 60-year-old London man was out of critical care after four days and soon recovering at home. Previously it was thought unsafe to transplant non-beating hearts.

Dilated cardiomyopathy is one of the main reasons for a heart transplant. Though most people with the disease never need a transplant, some die because of organ shortages. Last year around 170 people were given new hearts in the UK. Experts estimate that the new procedure could lead to another 40 to 50 transplants a year. Non-beating hearts could increase UK heart transplantation by up to a quarter, said consultant surgeon Stephen Large.

Good life expectancy

Today's treatments for hypertrophic cardiomyopathy (HCM) have improved so much that death rates in adults is close to that of the general population, says a new study from America. Dr Barry Maron, director of the Hypertrophic Cardiomyopathy Centre at the Minneapolis Heart Institute Foundation (MHIF), said research and technology advances, including internal defibrillators (ICDs), had dramatically changed treatments for HCM patients over the last 15 years.

The value of getting good information

Alison Fielding and Jim Lyness talk about how getting information has helped them take an active role in their care and get on with their lives

Alison Fielding's story

Alison Fielding, one of our trustees, explains how getting information and using new technology has helped her take an active part in looking after her health

From the day I came home from the cardiologist with the phrase 'cardiomyopathy' ringing in my ears, I have been using technology to make me a smarter patient.

Like many people, I sought information on the internet and fortunately found the Cardiomyopathy UK site early on. As well as informed patient communities like our own Facebook group and forum, I also registered on professional medical sites for cardiology, clinical trials and general medicine. Within weeks, I could have given many GPs and non-cardiologists a run for their money!

Each of us has a different view of how much we need to know about our condition and possible treatments. I'm at the 'want to know it all' end and, with effective filters to ensure you aren't spending your whole life looking at the internet instead of living, I think the empowered and informed patient is here to stay.

To keep track of my key medical data such as appointments, procedures, medications, test results and my internal defibrillator (ICD) information, I use Microsoft Health Vault, a free online place to record your medical details. You can enter some information manually and others can be automatically updated, such as exercise and weight information from fitness bands, scales or BP monitors. It's worth having a look as you can store profiles for family members, print out records to take to appointments or keep as a wallet card. As it's web based, you can access the information wherever you can access the internet or carry your smart phone.

On my smart phone, I downloaded an application called cardiio which works by using the phone camera to assess changes in skin tone as your heart beats to give you pulse data. I have found this to be an accurate and cheap tool in checking my heart rate on the go. But as my palpitations got worse, I upgraded to an AliveCor device which also clipped onto my iphone.

You hold two sensors while it takes a reading and displays the results on your screen. It's been trialled in several NHS areas and is particularly useful for detecting the abnormal heart rhythm atrial fibrillation. My iphone is always with me so I can use it to capture any strange feelings, make a note of what I was doing and how I felt and show it to my doctors. Having captured some unusual patterns, I showed my cardiologist who arranged for me to have an internal defibrillator (ICD) fitted.

I am now on a tele-health scheme organised by my local clinical commissioning group to support people with heart problems. By picking up any problems early and arranging appropriate care, the scheme aims to cut hospital admissions. I have been provided with a tablet computer linked wirelessly to scales, a blood pressure monitor and oxygen monitor.

Every morning I have to do a set of observations and answer some questions about how I feel that day. These cover fluid retention, dizziness, black outs, tiredness, palpitations, chest pain, breathlessness and so on. The results get sent off straight away to a monitoring centre and the nurses call me if there are any new symptoms or concerns. They can share the information with a local heart nurse or GP if I need follow up. I can take the tablet computer with me to hospital appointments to show them the last 30 days data. It's very easy to use and you don't need a home internet connection. If you have heart failure and think you may benefit, it's worth asking your GP or heart nurse if anything similar runs in your area. A morning weigh-in every day keeps me focussed on keeping my weight stable.

Once started on the technology trail and keen to avoid hospital visits, I have added:

- Home monitoring of my INR (as I take warfarin). I bought a monitor and send my readings by email. Check your anti-coagulant clinic is happy to train and support you. You will need to buy the device and it can be expensive. I bought direct from the manufacturer. GPs can prescribe the testing strips but make sure that they agree to this before you buy a machine
- Patient Access, an online access system to my GP so I can order medication and pick appointment times

- A remote monitoring unit for my ICD
- A fitness band to ensure I do my 10,000 steps a day and track my fitness
- Checking cardiomyopathy news via the Cardiomyopathy UK app
- If you have an i-phone, you can fill out the Medical ID app and access it via the white icon with the red heart and include your conditions, doctor, drugs and important contacts.

I still take a paper notebook to appointments. Sometimes, the old ways are still the best.

Jim Lyness's story

After attending a cardiomyopathy information day, Jim went back to his cardiologist and his medication was changed. Since then he hasn't had a day off work

My heart problem came to light in early 1996 after a visit to the pub, only a few beers mind you. In bed my heart started racing for about ten seconds but it seemed longer. I went to sleep thinking I'd go to the hospital the next day. Anyway, no further incidents meant I carried on as normal.

At my GPs in March with a bad cold he asked if I'd had any chest pain. I explained the episode, had an ECG and was referred to hospital. I was eventually diagnosed with Wolfe-Parkinson-White syndrome, where the heart beats abnormally fast. Over the next few years I had two catheter ablations (treatments to try to correct the abnormally fast heart rhythms).

During 2002 my health slowly deteriorated and arrhythmogenic right ventricular cardiomyopathy (ARVC) was suspected. My abnormal heart rhythms were lasting four to five hours and eventually became more frequent but shorter. I was advised to stop driving, went on sick leave from my job as a sales engineer and was advised to stop work completely. I went on incapacity benefit.

I could only walk short distances and not upstairs. I had to climb them in a sitting position. After wearing a 48 hour ECG monitor, ARVC was confirmed. I was delighted to be told what was wrong with me. I was kept in hospital for five days on a high dose of amiodarone (a drug to control heart rhythms) and later an internal defibrillator (ICD) was fitted.

I began searching the internet and came across Cardiomyopathy UK. I'd been discharged by my consultant but still felt unwell. I attended the charity's annual information day and AGM in London.

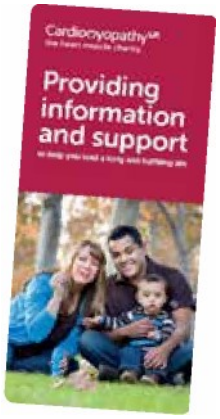
During the ARVC session I compared my health with others there who had the same condition. My symptoms were not as well controlled as theirs. Session leader Professor William McKenna, one of the world's experts in cardiomyopathy, advised me to go back my cardiologist and ask some more questions.

This I did and was told that the left side of my heart was affected. New medication really helped. In 2007 my health was sufficiently better so I attended a Cardiomyopathy UK training day to become a support volunteer. I wanted to give something back. The following January I went to the local Job Centre Plus and asked about returning to work. I attended a disability awareness course which helped me get a routine, prepare a CV and apply for work. I got a job at the Department for Work and Pensions. I haven't had a day off sick since, such is the importance of support and the right medication.

My fitness levels continued to improve and in 2010 I had my medication reduced. My sleeping improved and my energy levels increased. I now do a lot of walking and run up three flights of stairs two at a time. Recently my diagnosis was changed to dilated cardiomyopathy.

Good information is key

Robert Hall | medical director, Cardiomyopathy UK



A diagnosis of cardiomyopathy can produce a range of emotions - disbelief, shock, fear and anger. There may even be a feeling of relief following a long period where there were problems confirming a diagnosis.

But in whatever form the diagnosis is given, the confirmation is life-changing. For many people the first reaction may be 'cardio …… what?' It can seem that the longer and more difficult to pronounce a medical condition the more serious and rare it is.

Questions of survival may arise.

Thoughts may then move to day-to-day living. Will I be able to return to work? How will my partner respond? What will my friends think? What will life be like? These questions may be mixed with feelings of isolation, and life being out of control.

The search for information takes many people to the internet. Typing 'cardiomyopathy' into Google will produce approximately 6,700,000 results. Unfortunately not all information there is accurate. For example, some sites state that people affected by dilated cardiomyopathy will die within 5 years. This is not true but it is devastating to read, particularly soon after diagnosis. Patients in a stressful situation, such as initial diagnosis, will hear approximately 30% of what is said by their doctors. The remaining 70% might be misinterpreted. This has led to the publication of a vast amount of patient information. The aim, as stated by NHS England, is to:

- Remind patients what their doctor or nurse has told them if, due to stress or language difficulties, they are unable to remember
- Enable people to make informed decisions, giving them time to go away, read the information that is relevant to them, and think about the issues involved
- Involve patients in their condition and their treatment

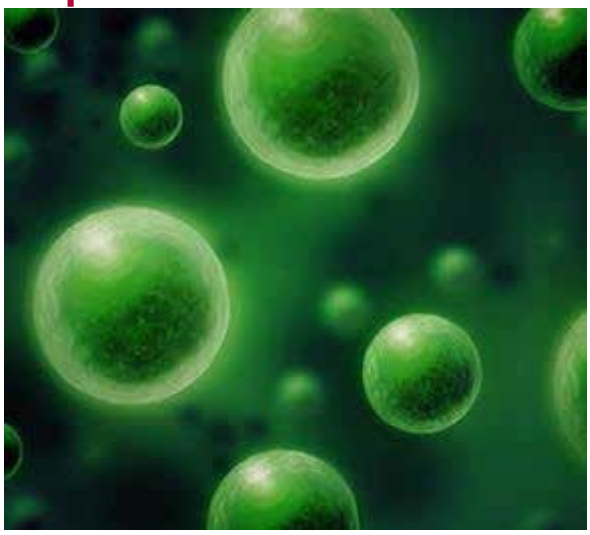
Recent research suggests that people with health problems can do better if good, easy-to-read and understandable information is provided. There are different types of cardiomyopathy and each affects people in different ways and with different symptoms and severity.

So try to understand your cardiomyopathy and how it affects you as an individual. This takes time and the information can be drawn from various sources, such as your doctors, nurse specialists, our information booklets, websites, others living with cardiomyopathy and through our cardiomyopathy support nurses available on our helpline.

Many questions will arise and it's important to get rid of your confusion and uncertainty. Do make full use of our services and always remember, there is no such thing as a silly question.

By getting a better understanding of your condition and best treatments, you can become an 'expert patient', working better with your medical team and better able to make informed decisions about your care and treatment. Knowledge is power!

Stem cells that help repair mice hearts



Scientists in the UK have used stem cell therapy to help mice recover from heart attacks and stop them developing heart failure.

The research, being carried out at Imperial College London, has been published in Nature Communications. "We have found stem cells in the heart that have a specific protein – called PDGFR alpha – which on their surface have the greatest potential to repair damaged hearts," said Prof Michael Schneider, one of the authors of the study. The researchers will now try to establish if the human heart has similar heart-repairing stem cells to those found by this method in mice.

Stem cells are young cells that are able to transform into specialised cells in the body. Heart tissue is damaged when it is deprived of blood during a heart attack and can lead to heart failure, when the heart is unable to pump sufficient blood to meet the body's needs.

Prof Schneider added: "When we injected stem cells with this protein into damaged hearts, we saw a significant level of heart repair.

What are stem cells?

Stem cells are mother cells that have the potential to become any type of cell in the body.

They have the ability to renew themselves or multiply while maintaining the capacity to develop into other types of cells.

Now that we know which stem cells to use, we want to find their equivalent in human hearts for more efficient heart repair and regeneration after heart attacks.

"The potential of PDGFR alpha to heal the heart had been identified in several scientific papers in the past decade but it is still a long way from human trials.

"Future treatments could be injections of stem cells, as in our current experiments, or use of the healing proteins that these cells make,"

Prof Schneider said at present there were more than 20 stem cell human trials going on, including looking at treatment for dilated cardiomyopathy.

3D simulated heart allows virtual tests

A French software company has designed a simulated human heart that researchers and doctors can use to perform virtual tests. The 3D design company says the 3D simulator of a four-chamber human heart will allow researchers, heart device manufacturers and doctors to perform virtual tests and visualise the heart's response in ways that are not possible with traditional physical testing.

The model, made as part of Dassault Systemes commercial Living Heart Project, is designed to represent a healthy heart which can be modified to represent the shape and tissue properties of a heart with heart disease and other problems.

The model includes anatomic details of the heart and has realistic electrical, structural, and blood flow physics, says the company. Medical devices can be inserted into the simulator to study their influence on heart function, check how well they work, and predict reliability under a range of conditions.

Dr Robert Schwengel, professor of medicine at Alpert Medical School at Brown University in America, said: "A product like this could be very powerful in helping to educate patients, students of medicine, and current medical professionals, as well as lead to improved diagnostic capabilities and the personalisation of medical therapeutics."

The Living Heart Project has members from regulatory organisations such as the Food and Drug Administration (FDA) and the Medical Device Innovation Consortium (MDIC), as well as cardiologists and leading hospitals. They have identified the best uses for the simulator and associated technologies which will help shape future versions of the living heart.

The full story is on our website
cardiomyopathy.org/new-simulated-heart

All ICDs may be MRI safe in ten years

An internal defibrillator which allows people with it to have an MRI scan has performed well in safety trials, say doctors.

It's long been considered unsafe for people with most implantable cardioverter defibrillators (ICDs) to have MRI scans because they generate a strong magnetic field that could affect the device and cause the wires to overheat.

ICDs are given to people thought to be at risk of having a dangerous heart rhythm as they can shock the heart back into a normal rhythm.

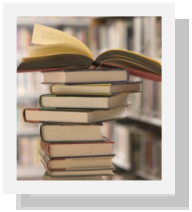
Now a device designed to be safe for a full-body MRI has met all safety and efficacy endpoints, Dr Michael Gold from the Medical University of South Carolina told a meeting of the Heart Rhythm Society. He predicted that about ten years down the road all ICDs will be MRI compatible. "There's no downside to it per se. So it's hard to imagine this won't become standard care at some point," he said.

The study included 263 patients (median age 60.4 years) from 42 centres in 13 countries who had the MRI-compatible device.

The full story is on our website
cardiomyopathy.org/icds-ten-years

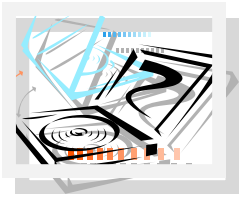
CMAA Library

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*

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

Cardiomyopathy Australia

If you are reading someone else's copy of our newsletter and would like information about the Association, why not contact us?

Please email us at info@cmaa.org.au or return this slip to the Membership Secretary, CMAA Ltd, PO Box 273, Hurstbridge VIC 3099

Name: _____ _____

Address: _____ _____

_____ _____

_____ **P/Code** _____ _____

Phone: _____ **Email:** _____ _____

Type of CM: _____ _____

For details of your nearest Contact Person please phone:

1300 552 622
(24 hour message bank service)

or

HEARTLINE

1300 362 787

Or visit our website at:

www.cmaa.org.au

Cardiomyopathy Association of Australia Ltd