Has Cardiomyopathy Touched Your Life?

Supporting people with cardiomyopathy and their families.

Newsletter Number 83 — Winter 2015
Includes selected articles from Cardiomyopathy UK Newsletter
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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The Cardiomyopathy Association in the UK has changed to become Cardiomyopathy UK. Their newsletter, parts of which appear in our newsletter, has changed too and is now named “My Life”. The content has changed a lot and it’s shorter but published every two months instead of quarterly.

Why the changes? I guess they realized that what had worked in the past was not working in the present. They changed which is the only way to deal with what is not effective.

Some things do not change. The deep human emotions do not change which is why the Ancient Greeks had long wars and we are commemorating a World War battle this year and witnessing battles in the Middle East. We are aggressive creatures. Some politicians, and there have been superb ones, tried something new so that nations now have a forum for nations to meet, talk and share tasks. We accept that nations will co-operate to bring about improvement. And improvement is change. If it does not work, it has to be changed. We evaluate things so that they can be improved.

Vaccination has conquered smallpox. (We hope the virus is very secure in American and Russian laboratories.) When first introduced, vaccination was spurned but the results confirmed the claims for it. Elimination of the disease in the world came about because some people accepted that, as smallpox was a foul disease, it had to be eradicated. Vaccination was a necessary change. Teams would have to educate people to accept vaccination and then rich nations would have to change some of their spending habits and fund teams to vaccinate throughout the lands where smallpox lurked. Change brought improvement.

We human beings do not easily accept changes. Some we have no control over. Really nasty ones like disasters bring change. Chronic illness brings change whether we like it or not. If we don’t deal with either of those changes, the resulting situation will be catastrophic.

Change will come to this newsletter because the content from the UK has changed and information can be found all over the net for us to bring to your attention, if it is from a reputable source. Your editors wonder if now is the time to ask if people want a place to state opinions, ask questions that are non-medical and generally have a say. It won’t exist without your contributions. Send us the material and we can get it ready for publication.

Anne and David Abbott
Newsletter editors
Email: abbottdm@gil.com.au
Phone: 07 3202 8138
Dear Members and Readers

I hope you are managing your cardiomyopathy well and remain positive with new treatments and procedures continuously being developed. If you are a carer or health professional you will be buoyed by the new information continually provided through our newsletter.

It is in that context I trust those who pay annually will renew their membership for 2015-16. We have kept the household fee at $30 despite increased operational costs but will always appreciate donations from all members including those where renewal does not apply.

We welcome our new Membership Secretary, Peter Smith to the team. He will be pleased to assist you keep up to date with personal details, payments and access to our website.

Please write to him by email to membershipsecretary@cmaa.org.au or letter to P.O.Box 273, Hurstbridge Vic 3099.

You will note in this newsletter and under Events on the website that our Annual General Meeting will be held in Adelaide on 29 August. Positions on the National Executive become vacant at that meeting. We welcome enquiries and nominations from members. Our meetings are held by teleconference so where you reside is not a problem.

If there are any matters you would like the National Executive to consider please contact our Secretary by email to info@cmaa.org.au or by letter to the above address.

Best wishes to you all.

Alistair Kerr
President
On behalf of the National Executive
Hello Victoria and all members

Our March meeting was well attended to hear our guest speaker Prof. Franklin Rosenfeldt give an excellent talk on the benefits of CoQ10 related to heart failure. The PowerPoint presentation is available to members from our library or on our website. Some GPs and cardiologists may not be in favour of “natural medicines” however the clinical trial produced positive results regarding CoQ10 and benefit to heart failure patients. As always you should confirm with GP/Cardiologist or pharmacist before starting a course of treatment.

Our next meeting at Epworth will be held on 19 July when our guest speaker Assoc. Prof. Chris Neil will speak on non-invasive angiograms and new procedures also stress related cardiomyopathy. I hope to see as many members as possible attend.

Access to travel insurance is still a problem for many members with different results obtained, sometimes with the same insurer. I will be pleased to hear about your experience. Several members have been successful though the Post Office (I believe at reasonable rates) where brochures should be available at counters.

Our next lunch at Matthew Flinders Hotel, Chadstone will be held at 12.30 pm on Saturday 23rd May – RSVP Thursday 21 May.

The following meeting will be held on 22 November. Please keep an eye on the website for further information.

I look forward to seeing you on 19 July.

With kind regards

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

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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.
**Tasmania News**

**Hi from Tasmania**

If "laughter is the best medicine" then the atmosphere created by the humour and positivity displayed within our luncheon group at Launceston on the 15th March, can be nothing but beneficial to all those who attended.

What an inspiration Linda, Jan and guest Ted are, all living with internal defibrillators. Linda about to have a replacement fitted, Jan very exhilarated about climbing over 200 steep steps on a Bruny Island walkway without any problems and Ted thankful that he has been given a second chance due to the quick action of his wife Alwyn, with some effective vigorous CPR. Along with these reports we also stand amazed that Dorothy, our most senior citizen, continues to travel to the UK to visit her family.

As most of us find that other commitments make March a very busy month, it is highly likely that next year our luncheon will be scheduled for April. I will contact you all well in advance.

As a regular feature I am submitting a "Getting to Know You" profile on one of our members. It is my intention to make this a regular article. I hope you find it interesting and can relate to some of the comments made.

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)*

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### Member Profile

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<td><strong>Name and location?</strong></td>
<td>Brian, from Kingston, Tasmania</td>
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<td><strong>What type of CM do you have?</strong></td>
<td>Hypertrophic</td>
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| **When was it diagnosed and, What was your reaction?** | 1970
Unbelievable! |
| **What were your symptoms?** | Fatigue and a tightening sensation on the left lower chest area |
| **What treatment was suggested?** | Daily medication. Give up vigorous sport |
| **How often do you see a cardiologist?** | Annually |
| **How does CM affect your life?** | Tiredness restricts some activities. Sleep pattern can be irregular |
| **How does CM impact on the lives of other family members?** | My grandchildren are sometimes disappointed that I cannot fully participate in their activities. |
| **Do you keep abreast of research?** | Yes, I follow up any reports through all media |
| **Do others in your family carry the CM gene?** | Yes there are many on my family tree who have the rogue gene |
| **Are you happy to make contact with other CM sufferers?** | Yes I am very happy to discuss any aspect of the condition at any time |
| **Have you found CMAA to be beneficial?** | As a long time member I treasure my involvement with the CMAA Family. I believe that the contacts I have made have been not only helpful to me but also to my immediate family. It is vital that the members foster the support group wherever possible |
Hello to all members in SA & NT

Hoping that you are well. The year is flying by as usual. We have a few things going on here at the moment.

Our last meeting was on Thursday the 7th May 2015 at the Caledonian Hotel North Adelaide. Our Guest speaker was Murray Amos who spoke briefly on First Aid for people with cardiac conditions.

On Thursday the 14th May a Fashion Parade was organised at Blue Illusions at Westfield Marion. They kindly donated 15% of the Sales to Cardiomyopathy Australia. They have stores all across Australia and it is such an easy way to Fundraise. Hopefully some of the other states may follow with similar events.

As I said in the last Newsletter, this year it is South Australia’s turn to host the Association’s Annual General Meeting. This will be held on Saturday 29th August 2015 at the Warehouse, Marleston Avenue Ashford (opposite the Ashford Hospital Entrance) from 12pm to 4pm. Lunch will be served followed by the AGM. Then we will have a Guest Speaker, Janice Clifford, Heart Failure Nurse and Pacemaker Technician from Flinders Medical Centre presenting on Pacemakers and Defibrillators in patients with Heart Failure.

I appreciate everyone’s support for our activities.

Take Care

Kerry Shaddick — SA and NT Contact:
Phone 08 8270 7747
Email kerry.shaddick@hotmail.com

Annual General Meeting—29 August 2015
Call for Nominations for Executive Committee positions

This year’s AGM will be held in Adelaide and hosted by the SA members. Details of the timing, venue and guest speaker are provided above.

An important part of the AGM agenda is the election of members to vacant positions on the Executive Committee as a Director of the Cardiomyopathy Association of Australia Ltd. The Executive Committee is responsible for the management of the Association and is an ideal way in which members may contribute.

Members with email addresses will receive, separate from their emailed newsletter, an email with a “Call for Nominations” and a “Nomination Form”. Members without email addresses will have received these 2 documents with their printed copy of this newsletter.

Please give serious consideration to the opportunity to serve on the Committee. If you would like further information on the role of Committee Members, please do not hesitate to contact the President or Secretary in confidence.

Nominations need to be received by the Secretary by Friday 17 July, 2015.
Hello from Queensland

Our next meeting will be on Saturday June 6, which will be after we finalise this newsletter. In our absence, Glennys and Gus Govan have kindly taken on the task of hosting the meeting which will be at the usual time and venue at 1.00pm in the Meeting Room of Toowong Library. 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.

Our remaining meetings for this year will be on Saturday September 5 and Saturday December 5 at the same time and venue.

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: abottdm@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)

Unfortunately, at the time of preparing this issue of the Newsletter, Miranda was receiving hospital treatment and unable to provide an update. By the time this newsletter reaches you, we sincerely hope that Miranda is well on the way to a successful recovery and look forward to her future updates.

(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.inges@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 organizers.

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 Western Australia

Hi,
I do hope everyone has enjoyed the summer with the chill of winter coming. There has not been much on in Perth lately regarding cardiomyopathy that I know of. I was fortunate enough to attend the last Intra Cardio Device (ICD) meeting at the new Fiona Stanly Hospital (FSH). This was presented via video conference link from Royal Perth Hospital (RPH). The ICD meetings are always interesting & informative so please attend if you can. The video link works extremely well & extends to various country areas including Albany, Bunbury or wherever required.
I do apologise for the gaps of late in my newsletter articles. Often I’m not feeling that well. Despite this please remember I am always available & only a phone call away.

Cheers,
Rhonda Jobson, WA State Contact—phone (08) 9319 1034

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.
Dear Doctor

Question 1:

Our daughter has recently been diagnosed with CM at the age of 42. Her cardiologist is still doing tests to try and identify the cause. There is no family history of CM. She is a non smoker and non drinker but her weight is 102kg. Since diagnosis she has been put on medication as well as fluid tablets to assist her situation. She has also commenced a low salt, low sugar and fresh food only diet.

Despite it being early days in diagnosis, we have read many articles on CM. Most have stated that medication and diet will help to maintain a normal lifestyle but do not mention life expectancy. We are aware that it can differ depending on the condition and history of individual cases. One article mentions that, on average, 50% do not survive the first 2 years and 25% that do, do not survive beyond 5 years.

Are you able to provide any additional information on survival rates and life expectancy?

Answer:

The prognosis or outcome after a diagnosis of cardiomyopathy is very variable. The most important factor is what happens as far as the response to treatment. Your daughter would currently have damage to her heart muscle as shown by a test such as an echo and now that she is on all the correct treatment it depends whether that improves, stays stable or deteriorates. So the most important way of determining her prognosis will depend on repeat echos after 3 or 6 months of treatment.

The other issue is quoting what happens "on average". In cardiology we are very good at predicting what will happen to 100 people but for every individual it is impossible to say. Also the figures you quote probably do not take fully into account recent advances in treatment so it really is wait and see what the response to treatment is like.

Question 2:

A frequent issue raised at our support meetings is the effect of combining alternative therapies and supplements with prescribed drugs. Fish oil, Q10 and vitamin supplements are widely promoted as being beneficial for people with cardiovascular disease.

Are there any potentially adverse effects of combining these supplements with medications that are usually prescribed for people with CM?

Answer:

Alternative therapies and supplements are very commonly used by people with cardiomyopathy. It is rare that they will interact with medical therapy but there is always a possibility. The best option is to ask the Pharmacist or your treating doctor about each specific drug and the supplement.

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.
Echocardiography is the use of ultrasound to study and take measurements of the heart. This is a vital tool used to not only diagnose cardiomyopathy but to also monitor the progression of the condition.

Cardiomyopathy (CM) is a broad term given to patients with disease of the heart muscle. There are three main types of cardiomyopathy (dilated CM, hypertrophic CM and restrictive CM) and echocardiography plays an important role in the management of each.

Dilated cardiomyopathy (DCM) is characterised by an enlarged ventricle (pumping chamber) with reduced function (contraction of the pump). In patients with this condition, the walls of the main pumping chamber do not contract normally.

Over time, to compensate for the reduction in contraction, the ventricle dilates so it doesn’t have to pump as hard to eject the same amount of blood out with each heart beat. We use echo to accurately measure the size of the ventricle and to determine which walls are affected and to what extent.

The percentage of blood ejected out the heart with each beat is called the ejection fraction (EF). This is an important measurement in patients with DCM. With echo, we are able to take multiple measurements to determine the EF accurately.

As the ventricle dilates this can cause other complications, such as dangerous arrhythmias and leaking valves as the leaflets get pulled apart. It is important to have periodic echocardiographic assessments to monitor the stability of the disease.

The results of the echo play an important part in the treatment of DCM which may involve changing medications, implanting defibrillators or pacemakers.

Hypertrophic CM is a condition in which the heart muscle becomes thickened, it may involve the entire ventricle (pumping chamber) or just one section (Figure 1).

Increased wall thickness in hypertrophic cardiomyopathy.

This form of CM is usually inherited and passed down through families, although it can be expressed differently in different family members.

The complications of HCM include abnormal heart rhythms, increased pressures within the ventricle and leaking heart valves.
The Doppler modes are also used to compare the degree of leakage across the mitral valve. This leakage can often be difficult to identify as the nature of the disruption of valve causes leakage that runs along the wall edges.

We can use many techniques to quantitate the degree of valve leakage. Colour Doppler displays the direction of blood flow and so we can use this to see the retrograde flow and quantitate it.

We can also use Doppler to map how far back into the atrium it is reaching. We also have methods to estimate the size of the opening or the volume of the blood leaking back.

Restrictive CM is a form of CM in which the walls are rigid and the heart is restricted from stretching and filling with blood properly. This causes dilated atria (collecting chambers of the heart), arrhythmias and leaking valves.

This CM can be caused by disorders in which certain proteins are deposited within the muscle that make up the wall of the heart.

Like any pump, the heart is not able to work efficiently if it does not fill with blood properly before trying to expel it around the body. In this condition, the rigid walls prevent the walls from sucking the blood in before pumping it out.

This, in turn, increases the pressure within the chambers of the heart, increasing the load on the heart. With echo, we can measure or estimate these pressures to determine the progression of the disease.

We can also measure chamber sizes using multiple techniques and views and assess the degree of any complicating issues such as leaking valves.

So, each time you are referred for an echocardiogram, keep in mind that the information gained from this test is giving the doctors an up-to-date assessment of the status of your heart which in turn, can be used to tailor your treatment appropriately.

Rebecca Riddle
My Story

My name is Ray Richards and I'm 72 years old, retired, have four children, divorced and live alone.

In May 2005 I considered myself to be fit for my age and in excellent health, lived an active life, walked most days and occasionally rode one of my motor bikes (I had a collection of 6 at the time). They have always been a passion. Sport was important in my life, playing squash at a high level as a teenager and till my 40's, also competitive touch football till 40 plus.

My career was at a peak, a senior executive with a State role in a large grocery company, at times long hours, hard committed work but still managing a reasonable work-life balance with quality time for the family. At the time my two youngest children were living at home. We were always able to plan at least one family holiday each year, either within Australia or overseas.

So back to May 2005 when my then wife and I departed for a European trip taking in Italy, The Czech Republic, Paris and London. All looking good at this stage.

The Italian leg was great, busy with some long days and walking. The last day on the Prague tour was a hot day and we spent many hours on our feet. I felt the heat badly and struggled to walk back to the hotel.

Looking back, I didn't realise at the time that this was to be the start of a significant change in my life. Paris and London didn't seem to be unusually demanding, and then home and back to work.

Day-to-day life became a struggle and I always seem to be tired and often short of breath, and this flowed to my employment. Looking back, it was lucky for me that my company employed a part time medical doctor whom I knew very well.

Sometime in July, I met the doctor in passing and he looked at me and said "You look terrible. Haven't you got over that jet lag yet!" He had previously sent me to a cardiologist because of consistent ectopic beats and to be fitted with a Holter Monitor for 24 hours.

Luckily he referred me to the cardiologist for a visit in August. After a number of tests including an echocardiogram, he called me in and informed me of bad news: I had cardiomyopathy.

The only thing I knew about cardiomyopathy was that Fiona Coote had it and was our youngest heart transplant recipient in Australia. Did this mean I would need a heart transplant?

The answer was 'No', as he informed me that in most cases it could be improved and controlled by medication. I had dilated cardiomyopathy, an ejection fraction (EF) of 25-35% and an enlarged heart. I headed home to inform the family and with prescriptions for Dilatrend and Atacand.

The next few months were not great, the DCM did not seem to be improving, a hot summer was approaching and my body not handling the medication all that well. I fell in a heap and had to push myself through every day. To make it worse my family didn't understand the illness and just believed I had become lazy.

One day I was researching dilated cardiomyopathy (DCM) on the internet and came across the Cardiomyopathy Association of Australia (CMAA) and there was a contact number to call. Up to this stage I had kept things close to my chest, hadn't even told my work colleagues or all of my friends and family, as I decided people may not understand.

After some trepidation I called the number, which was answered by Janet George, who went on to explain about CMAA and its benefits to sufferers like me. Hey someone understands! Janet passed on Sue Lord's number (the then state contact) and I later called Sue and I can't tell you how good it was to talk to someone who also had DCM and understood how I felt. She was so generous with her time, talking to me for over one and a half hours, I recall.
From that contact I joined the CMAA. In December 2005 I attended my first meeting at The Mosman Club which was the Annual Christmas Luncheon and was so pleased to meet others who shared similar stories to mine.

By June 2006 my results had improved considerably. My EF was greater than 50% and my enlarged heart was in the low end of normal, allowing medication to be reduced a little.

Some months later I noticed I was short of breath at times and tired. A subsequent visit to my cardiologist and an echocardiogram indicated my EF had dropped to 30-40% and he immediately increased my medication. It was decided to also fit a 24 hour Holter Monitor.

When I returned the following day the results from the Monitor displayed a sustained episode of Ventricular Tachycardia (VT), enough to have me conveyed to The Mater Hospital by ambulance to receive 24 hour monitoring. After an unsuccessful attempt at ‘ablation’ the cardiologist, in September 2006, decided to implant an internal defibrillator (ICD).

The good news is that in time, with medication and the implanted ICD, my EF has returned to 50% and heart size reduced to the low end of normal. After a settling period I have not experienced any further episodes of VT.

The whole chapter took its toll over a three-year period as my work was affected, forcing an earlier than planned retirement. It also affected my marriage, which broke down in late 2008.

I look back at the difficulty I had dealing with cardiomyopathy and having family understanding how it affected me at the time. It was frustrating and I struggled many days, but luckily this was picked up by my GP, who suggested that I undertake some counselling.

This I found highly beneficial and would recommend to others in a similar situation. It wasn't a time to look back, as that life had changed forever. So it was time to move on and plan the next chapter.

One of the common threads through all this, from 2006 till now, was the support, knowledge and friendship from the CMAA.

Following the first visit to the Mosman lunch in 2005, I have continued to attend on the last Friday of the month, and although a small group, I find it so important to be there.

Knowledge is everything and I'm fortunate to have a wonderful cardiologist looking after me, but adding to this has been the support and information from the CMAA which has been invaluable.

I knew nothing of cardiomyopathy when I was diagnosed. Now, through the informative newsletter, Mosman lunches, some earlier local group meetings and guest speakers at AGM's, I am so much more informed.

I have been fortunate to attend a number of local CMAA meetings with first class speakers such as Prof Anne Keogh from the Victor Chang Cardiac Research Institute, Anne Sullivan, in charge of a community-based cardiac rehabilitation service, a very informed pharmacist, who was so helpful with the medications we encounter, and many more I won't list.

In July 2013 my ICD was replaced and a suspect lead disconnected and a new one added in parallel with the hope that it could last up to 9 years. I'm so used to having an ICD, it's just part of my life now and I rarely even refer to it.

The good news is that although I have cardiomyopathy it is controlled sufficiently through medication and an ICD for me to live a 'normal' life.

I've continued to travel and in 2010 I travelled through Africa on safari spending 4 nights in Dubai on the way home. I have recently returned from a 16 day tour through Vietnam and 7 days in Hong Kong, this time travelling with a friend, Julie.

I met Julie in 2012 and soon realised we shared common interests in travel, dining out, movies, family events and each other's company. Fortunately, we meet most days and her company, friendship and support are very much a positive in my life.

I believe I'm fortunate to have progressed through some difficult times and now am able to live a happy and healthy life that in part I owe to the CMAA and my fellow members.

Ray Richards

Do you have a story to tell?

If you would like to share your story with your fellow members, please contact your newsletter editors (see page 3) or State Contact Person.
I can remember an outraged student fronting me because I failed his essay. I had done so because it was rubbish, badly written, full of syntactical errors and spelling mistakes. There were frequent references to characters that were not in the novel it was supposed to be about. And above all, I could tell he had not written it. His own writing was better than in the essay he handed in.

I had no proof he had not written it and so I marked it as if it were his work. It got the mark it deserved. He failed to convince me that it deserved a brilliant A. Spluttering in annoyance, he blurted out, "I paid $20 for that off the net." Poor kid. He had a trip to the Principal for punishment for plagiarism.

How did he come to get himself into such a hole? Well, the reasons are pretty plain and here they are:

- He pretended to do the work, cheated and thought he could deceive someone who knew better.
- He was lazy and wanted to save time.
- He paid good money for it, way beyond its value, and thought it was then bound to be good.
- He got it off the net which he considered the source of everything to believe in without question.
- He did not check it but took it at face value.
- He forgot that people like to make money and can misbehave to get it.
- He listened to one of his mates who told him about this good thing on the net: essays without work that got good results.

We can laugh at this student’s predicament but, in years of listening to people with cardiomyopathy, I can see similarities between that student and some patients. I can hear the complaint from here, “We’re not like that student.” But some patients, unaware, are behaving like him and reaping the consequences. These are the reasons some patients do not do as well as they expect:

- They do not take medication properly and think they can cheat their bodies but they cannot; their bodies cannot be deceived.
- Medication regimes and following instructions about changes in lifestyle take time and effort so they are ignored.
- They believe a product costing $$$$ will be more effective than a drug from the doctor.
- An advertisement on the TV, or on a pop-up on the net, or in an article by some chap who’s never felt better after taking this substance that doctors don’t want you to know about because it will halve their incomes, or the chap living down the street – whatever the source, is believed in preference to medical specialists.
- No attention is paid to the source or qualifications of the author of the information. All that matters is the information which says just what a person wants to read.
- Many items sold to people do no good, are spurious, or hideously over-priced. Often, the same result can be obtained by eating a decent diet. Sometimes, vitamin pills, some herbal remedies and shark cartilage are of doubtful value.
- Heed is paid to those who don’t have good information but are known to the patient and sound so comforting.

Now the similarities between my cheating student and some patients are clear.

Patients given a nasty diagnosis don’t take in much beyond that. Many people are frightened of doctors, particularly busy specialists who can be abrupt. Dealing with a disease, particularly a chronic one, involves co-operation between doctor and patient.
Beware and be wary (continued)

Doctors need to listen to the patient, ask questions and be sure the information is understood. Some of the questions need to be leading questions to help a patient formulate replies. Doctors should bear in mind that medical jargon is a huge turn-off. All of this will save time in the long run. It may well save a hospital admission. Perhaps they should suggest a friend or relative accompany a patient to the follow-up visit.

Patients, for their part, should accept that doctors want to help and will use their expertise, gained over time and with considerable effort, to do the patient good. Patients must follow a drug regime, report any thing that worries them, make a clean breast of all those extra tablets that they take which could do damage when taken with medication and make sure they understand what they are told.

Patients need to be patient too. Confirming which drug is best and what dosage or even combination of drugs is most effective can take time. Patients do have the right to explanations and should ask to have them. Doctors, meanwhile, have the right to be given the full picture.

And patients should check the qualifications of people on and off the net. My student learned his lesson but his actions did not affect his health. A sick patient, who does not follow a doctor’s advice, instead believing someone on the net, can be a danger to himself.

Yes, I know that some few doctors may be unhelpful. Patients, in the vast majority of cases, can change doctors, or ask for another opinion. Less seriously, they may have misunderstood or caught a weary GP at a bad moment. Again, this is a two-way situation. Patients can be unpleasant. We are all people.

I remember a phone call from a near hysterical woman whose father apparently had been told that half of all cardiomyopathy patients died within six months and the rest could not live a full life. I suggested speaking to the specialist again as I thought he’d been misunderstood.

A relieved lady phoned me back. The specialist actually said that the patient should not worry about dying, although about 50% of patients might take six months to settle to a drug regime and that most lived a full life.

Patients might like to take notes to make sure what they think they hear is what was said. Far better, to have someone with them who can say, “So what this means is ……” and then listen as the specialist makes it clear. Shocked people make mistakes.

Doctors and patients alike must act to make co-operation possible and fully functioning. Best outcomes for all lie that way.

Anne Abbott

A nutty bit of information

According to the Dept of Nutritional Sciences at The Pennsylvania State University, peanuts in an otherwise fatty meal can maintain normal vascular function as measured by flow-mediated dilation. So peanuts are not only a tasty nibble (unsalted, of course) but they might even do a bit of good if you over-indulge in a cholesterol laden meal. And walnuts seem to be good too – at least in rats, but we’ll await results in humans. Meanwhile, eat carefully and accept that nuts are good for us in moderation.
Pesto pasta with vegetable ribbons

This tasty dish will have everyone coming back for seconds!

Serves 4
Time: 20 minutes

Ingredients:
200g wide fettuccine*
3 pieces rindless shortcut bacon, trimmed of all visible fat
1 large carrot
2 large zucchini
1 teaspoon olive oil*
2 garlic cloves, crushed
2 tablespoons basil pesto
Cracked black pepper, to taste
120g reduced fat ricotta*
2 cups baby rocket leaves, to serve
Fresh basil leaves, to garnish

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

Instructions:
1. Bring a large saucepan of unsalted water to the boil and cook fettuccine according to the packet directions. Drain, reserving 1/3 cup of cooking liquid.
2. Chop bacon. Cut carrot and zucchini into ribbons with a vegetable peeler.
3. Heat a non-stick frying pan over medium-high heat. Add olive oil, bacon and garlic, cook for 5 min.
4. Add prepared carrot and zucchini and cook, stirring often, for a further 2-3 min.
5. Add the fettuccine, basil pesto and the reserved cooking liquid. Toss until well combined.
6. Season with cracked black pepper and top with ricotta. Serve with rocket leaves and garnish with fresh basil leaves.

Nutritional Information:

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The Best of British

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Protein key to how heart beats

Researchers in America believe they have identified a protein that plays a large part in heart disease, and lack of it can lead to heart rhythm problems.

The team from the University of Maryland School of Medicine says the myosin-binding protein C ("C protein") allows muscle fibres in the heart to work in perfect synchrony. They hope the discovery will eventually help scientists develop new drug treatments for heart problems, including cardiomyopathy.

For decades scientists have wondered how the heart generally stays so precisely and consistently in rhythm. But now Dr Jonathan Lederer, professor of physiology at the university, and colleague David Warshaw, professor of molecular physiology at the University of Vermont, say they have found the particular protein that plays a central role in the heart’s consistency.

Dr Lederer said: “This is a really exciting finding. A lot of research can be done with this new knowledge. We will continue to investigate this in all kinds of ways.”

The C protein was known to exist in all heart muscle cells but its function was unknown until now. Using an animal model, the researchers studied the physiology of sarcomeres (the fibrous proteins that make up heart muscle cells) and they found a C protein enables the sarcomeres to contract synchronously.

Dr Lederer and his colleagues think that it may be possible to affect heart rhythm problems by modifying the activity of C protein through drugs. “I think this could be very big,” says Dr Lederer. “This protein is definitely a drug target.” The research was funded by the National Institutes of Health and the results have appeared in the journal Science Advances.
I’ve led a very active and full life. I joined the police, had six children, including twins, rode horses, swam and played in a band.

My second child died at four days old and at the time doctors said I was the one in 100 whose baby had a heart problem. When I was expecting twins (Bryony and Cicely) and my sons Sebastian and Marland, scans showed their hearts were fine.

When I was 45 I started feeling tight chested when swimming. I had a scan but was told nothing was wrong. Three years later and often very tired, I had the same problem on a walking holiday. But I was still advised there was nothing wrong.

Then my daughter Cicely, 17 at the time, collapsed at the gym. She was diagnosed with hypertrophic cardiomyopathy (HCM) and put on beta-blockers. This led to me getting my own diagnosis of HCM at 49. I was fitted with a biventricular pacemaker, which changed my life. I now swim, dance, walk my dog, walk up hills, all without getting tight chested. The pacemaker makes me feel safe.

Cicely now has had an internal defibrillator (ICD) fitted and is waiting for a myectomy, an operation to improve blood flow from her heart. Bryony and Sebastian have also been diagnosed and Sebastian has an ICD while Bryony is soon to have hers. Bryony, despite her diagnosis, has just had a lovely baby girl while under the care of Leeds General Infirmary.

The gene mutation causing the disease in our family has been found and relatives are being checked to see who is also at risk of developing the disease. My father Richard, who is 80 and a former fighter pilot, and my brother Nick, an enthusiastic skier, also have it.

The disease does define our lives but it has also inspired us to really live and appreciate the gift of life. Much of our emotional journey has been about accepting the condition, and this is especially difficult for young people. But appropriate medical intervention has helped reduce fear, and information from Cardiomyopathy UK has helped dispel some of the horrors of the internet.
Kirsty Gordon Thomas’ story

My husband Lindsey had gone to hospital as he was feeling dehydrated with a tummy bug. The phone rang and I expected to hear him say he was on his way home. But instead it was an A&E nurse: “Your husband has taken a turn for the worse, you need to come immediately.”

Three years before I had received a similar call to be at my mum’s bedside and didn’t get there in time. So I was filled with desperation. Mum had had cancer but Lindsey was only 30, and appeared fit and healthy.

I found Lindsey alive but being worked on. So after swift “I love yous”, I was ushered away and told he was very poorly.

He had had a cardiac arrest. He had been resuscitated but his major organs were failing and his lungs were full of fluid. He looked a shadow of the man I’d seen three hours earlier.

He was moved to a cardiac unit where he had tests while waiting for a transfer to a specialist centre. Every day I sat with him. Every night I spent hours researching treatments they were doing, medications they were trying and diseases they were testing for.

Once at St Thomas’ Hospital in London, Lindsey was told he had arrhythmogenic right ventricular cardiomyopathy (ARVC) and given an internal defibrillator (ICD). He was given drugs to take morning and night for life, an armful of books on heart failure, assigned a heart failure nurse and sent on his way.

It was a lot to take in but we felt we could move on. Then six weeks later Lindsey’s ICD fired while he was climbing stairs on his way to work. He was petrified.

I searched the internet for groups where he could meet other guys like him and open up a bit. This is what led us to Cardiomyopathy UK.

The charity sent detailed accounts from other affected people as well as medical information. We felt an immediate sense of relief.

We went to the next meeting of the ARVC Support Group and it was an absolute godsend. It meant so much to talk to people who understood what we were dealing with.

Cardiomyopathy UK quickly found a special place in my heart. I feel like they know and care about every story and every sufferer and every family they support. The London cardiomyopathy information day last September was another fantastic source of information for us.

Inspired to help, I became a Cardiomyopathy UK champion, helping spread awareness of the disease and the charity in my area.

I took over the running of the ARVC Support Group. I am working with the fundraising team to organise events and I’m waiting for training to join the network of affected volunteers who provide support to others by telephone and email.

Lindsey is enjoying a good spell of health. He has got his driving licence back and regained some independence. We’ll never be happy having cardiomyopathy in our life but we won’t let it stand in the way of our happiness.
Q: I’m 64, have arrhythmogenic right ventricular cardiomyopathy (ARVC) and an internal defibrillator. At my heart exercise class I get my heart rate up to 125 or 130 bps. I know research has suggested that vigorous exercise can cause ARVC to worsen. So when does exercise become sufficiently strenuous that it might progress my ARVC rather than help?

A: Advice on exercise is one of the most vexing questions we deal with. In general, we advise people with cardiomyopathy to avoid competitive exercise or activities that provoke symptoms. Giving precise guidelines can be difficult and will vary between individuals. I generally advise that your maximum heart rate should be no more than 80 per cent of 220 minus your age. (If you are 64, it will be 80 per cent of 156, which is close to 124 bps).

Q: I have hypertrophic cardiomyopathy. My cardiologist says I do not need an internal defibrillator (ICD). Should I buy an external defibrillator and should my workplace buy one?

A: If you have been assessed properly, there should be no need to buy an external defibrillator or to insist your workplace buys in one.

Q: My husband has been diagnosed with dilated cardiomyopathy (DCM) aged 45. His father died suddenly with heart problems when my husband was seven. We have a seven-year-old. When should he start being screened?

A: The timing of screening in children is difficult. Our experience with hundreds of families is that it is extremely rare for the offspring of DCM patients to develop symptoms when they are children. However, your son could be screened now with an ECG and echo. If everything is normal, then he would need repeat screening in approximately three years’ time.

Q: I have hypertrophic cardiomyopathy and the cardiologist recommends that I have an exercise stress test. Why is this important?

A: An exercise test provides information on the severity of your condition, how much exercise you can do and helps assess your risk of developing serious heart rhythms.

Q: My wife has been diagnosed with hypertrophic cardiomyopathy and is awaiting gene testing. I’ve asked our GP about heart checks for our teenage children but he says we should wait for the genetic test results. Is this the correct way to proceed?

A: If the genetic test is being done and your children have no worrisome symptoms, then you could wait for the results of the genetic test. But if the test is unlikely to be done in the near future, your children should be screened with an ECG and echo. These checks do not exclude disease development so they will need repeat assessment. If a definite gene mutation is found in your wife and gene tests on your children show they do not have it, then they will not need follow-up.

Q: I was diagnosed with peripartum cardiomyopathy after having my last baby. My doctors are saying my children don’t need heart checks. Is this so?

A: Strictly, peripartum cardiomyopathy is a condition triggered by pregnancy alone but some affected mothers may have had an undiagnosed cardiomyopathy that only manifested itself during pregnancy. I would advise screening if there is a history suggestive of cardiomyopathy in other family members. In the absence of such a history or any worrying symptoms, I would wait until your children are old enough to understand the pros and cons of screening (such as the potential impact on insurance and employment) and are able to decide for themselves.

Q: My father died suddenly 15 years ago with dilated cardiomyopathy. We were told that it was probably caused by a virus but the family were all screened at the time. Now my brother has been diagnosed in his 30s. To what age should family members be re-screened? My father’s siblings are now in their 70s and 80s.

A: Genetic cardiomyopathies can appear at any age so it is prudent that the parents, siblings and children of affected people have an echo and ECG. The interval between checks is to some extent arbitrary, but we generally advise every three years or so.
Scientists investigating cancer tumours say they have incidentally found a protein that may be involved in arrhythmogenic right ventricular cardiomyopathy (ARVC).

The team, led by Oxford University researchers, was looking at how the protein iASPP might be involved in the growth of tumours.

They found that mice lacking iASPP could die suddenly and prematurely. Closer investigations showed these mice had ARVC, a condition that causes heart muscle cells to come apart under stress and be replaced by fatty and scar tissue.

The researchers discovered that iASPP has a role in controlling desmosomes, which are responsible for heart muscle cell adhesion.

Lack of iASPP appeared to weaken desmosome performance at the junctions of heart muscle cells, leaving mice more at risk of developing ARVC, said lead investigator Professor Xin Lu, director of the Ludwig Institute for Cancer Research at Oxford University.

Further studies of heart tissue from humans who had died from ARVC showed that some of them had similar desmosome problems as the mice, suggesting that the faulty gene controlling iASPP could also be responsible for ARVC deaths in humans.

The team said that further research is needed to look into families with a history of ARVC to see if the gene controlling iASPP could be used to diagnose those at risk of developing the condition.

A new study has suggested that other health issues as well as genetic factors may play a role in the development of hypertrophic cardiomyopathy (HCM).

Researchers from the Loyola University in Chicago concluded that carriers of HCM gene mutations may be at greater risk of developing the disease if they have extra stresses on the heart, such as high blood pressure, diabetes and alcohol use.

The team, led by Dr Sakthivel Sadayappa, associate professor in cell and molecular physiology at the university’s health sciences division, looked at why some people with gene mutations for HCM never get symptoms.
Non-beating heart used for transplant

More people with serious heart problems, such as advanced cardiomyopathy, could get transplants following pioneering work at Papworth Hospital in Cambridge.

The hospital has become the first in Europe to transplant a non-beating heart into a patient. The recipient, a 60-year-old London man, was out of critical care after four days and is now recovering at home.

Previously it has been 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. Experts estimate that the new procedure could lead to another 40 to 50 heart transplants a year.

Specialists at Papworth Hospital, who spent more than a decade working on the procedure, said that Huseyin Ulucan, who had been ill after a heart attack in 2008, had made a remarkable recovery.

"The use of this group of donor hearts could increase heart transplantation by up to 25 per cent in the UK alone," said consultant surgeon Stephen Large.

Traditionally hearts used in transplants have come from donors who are declared dead, but still have blood pumping around their bodies. But in the Papworth transplant, the donor's heart had stopped beating.

Doctors assessed the restarted heart for 50 minutes before approving it for transplantation. They then removed it from the donor and placed it in a machine, which kept it beating for three hours until the operation went ahead.

Takotsubo cardiomyopathy

Researchers studying stress-related takotsubo cardiomyopathy say that affected people do not always recover as quickly as previously thought.

Academics and doctors, led by consultant cardiologist Dr Dana Dawson from Aberdeen Royal Infirmary, say that although the heart may look normal on echo, problems were still apparent months later.

Dr Dawson, also a senior lecturer in cardiovascular medicine at the University of Aberdeen, said: "Acute stress-induced cardiomyopathy is a serious condition, but after the acute episode it appears that overall the heart pumping function recovers spontaneously.

"However, when talking to the patients they report that they are still not feeling themselves, cannot take part in strenuous activity and many have been unable to return to work."

"Four months on we found that the parts of the heart most affected by the condition were still swollen and the heart energetics had partly improved but were not at normal levels."

The researchers spent four years looking at the condition, also called broken heart syndrome. It appears to be triggered by an episode of major stress such as bereavement, being involved in an accident, divorce or other emotional trigger. It was first described in Japan in the 1990s and gets its name from the similarity of the abnormal shape of the heart to a Japanese octopus fishing pot (tako=octopus, tsubo=pot).

Dr Dawson said that if patients do not recover fully "it opens up new questions" as to whether their problems were caused by acute stress-induced cardiomyopathy or whether there was something underlying beforehand that made them susceptible to this kind of episode.

The full story is on our website cardiomyopathy.org/Takotsubo-recovery
Heart failure treatment: new drug update

John McMurray | Professor of cardiology,
Institute of Cardiovascular and
Medical Sciences, University of Glasgow

Since the publication of two key studies in 1987 and 1991, ACE inhibitors drugs (enalapril, lisinopril, ramipril and the other “prils”) have been a standard drug treatment for patients with heart failure caused by dilated cardiomyopathy.

The drugs (their correct name is angiotensin-converting enzyme inhibitors) prevent the body from creating a hormone known as angiotensin II, which is overactive in heart failure. It has harmful long-term effects on the heart, blood vessels and kidneys.

The two other main treatments for heart failure – MRAs (mineralocorticoid receptor antagonists) such as eplerenone and spironolactone, and beta-blockers such as bisoprolol and carvedilol – act in a similar way to block other inappropriate actions of the body’s hormonal and nervous systems.

What is often forgotten, though, is that potentially beneficial hormonal systems are also working in heart failure, although they may not be as active as they should be.

The heart also secretes the hormones A- and B-type natriuretic peptide, which circulate in the blood and are thought to have beneficial effects on the blood vessels and kidneys in heart failure. Other substances with similarly favourable actions are produced in the blood vessels and elsewhere.

For many years there have been attempts to develop treatments that boost the levels and actions of these helpful hormones. One approach has been to block the enzyme nephrilysin, which breaks down several of these helpful substances.

By coupling a nephrilysin inhibitor (sacubitril) with the ARB (angiotensin II receptor) valsartan, Novartis produced a drug (sacubitril-valsartan or LCZ696), which both blocks the harmful angiotensin system and boosts the helpful hormone levels (and possibly levels of other beneficial substances).

In a recent trial, called PARADIGM-HF, the new LCZ696 was compared with the ACE inhibitor enalapril.

Treatment with LCZ696 led to significantly lower rates of death and hospital admission in patients with heart failure and a low left ventricular ejection fraction (a measure of the volume of blood pumped out of the heart with each beat).

Patients treated with LCZ696 were also less likely to report worsening of their heart failure symptoms, require other treatments for heart failure or need to attend a hospital’s A&E department.

The positive effects of LCZ696 over enalapril were seen irrespective of the cause of heart failure, including in patients with dilated cardiomyopathy.

The trade-off for these benefits was an increased risk of hypotension (low blood pressure), which can cause symptoms such as dizziness, and a small increase in the risk of swelling to the body’s tissues as you see in an allergic reaction or inflammation.

This usually appears as swelling of the face, lips or tongue and can rarely cause breathing difficulties (although this more severe type did not occur in any patient in the trial).

While the results of the PARADIGM-HF trial were statistically convincing and clinically important, patients studied were selected and LCZ696 may not be suitable for everybody.

Those taking part had an ejection fraction of 40 per cent or less, existing treatment with at least a moderate dose of an ACE inhibitor or an ARB, and a systolic blood pressure figure (the first number) of greater than 95.

This new evidence has to be reviewed by regulatory agencies in Europe and the USA before any decision about approval of LCZ696 for general use can be made. This review process is likely to take until this summer.

Accelerated assessment by European review body

A new drug found to cut heart failure deaths significantly may be available for use in the UK sooner than expected.

The drug, LCZ696, which research suggests can cut deaths by 20 per cent, has been granted accelerated assessment by a European review body.

Drug company Novartis say this means the Committee for Medicinal Products for Human Use’s opinion will be given at day 150 from its initial meeting, two months earlier than normally happens.

The company says it is expecting to submit for marketing authorisation with the EU regulators early this year and if approved, the drug could be authorised for use in the UK towards the end of this year.

NICE will then need to determine its use on the NHS, which could happen as soon as early 2016.

The drug helps improve blood flow in heart failure patients and researchers found it helped prevent the number of hospital admissions for heart failure.

The study was carried out by researchers from the University of Glasgow, the University of Texas Southwestern Medical Centre and Novartis, in collaboration with an international team of researchers from other universities and research institutes around the world.
Antidepressant may help in treating heart failure

Researchers have found that an antidepressant drug appears to improve heart failure in mice. In the study, published in Science Translational Medicine, researchers at the Centre for Translational Medicine at Temple University’s School of Medicine in Philadelphia concluded the antidepressant paroxetine improved cardiac function in the rodent and, in some instances, even reversed some signs of heart failure.

Paroxetine (trade name Paxil among others) is a selective serotonin reuptake inhibitor (SSRI) used to treat major depression, obsessive-compulsive disorder, panic disorder, social anxiety, posttraumatic stress disorder, anxiety disorder and for menopausal hot flashes and night sweats.

Study co-author pharmacology professor Walter Koch, from Temple, said it was surprising that paroxetine had worked so well in mice with heart failure.

They believed it was due to the drug affecting the protein GRK2 which is unregulated in the failing human heart.

Paroxetine has been shown to inhibit GRK2, and the study showed that, by treating mice for four weeks with the antidepressant, it was possible to see the heart’s left ventricle improve in structure and function.

Mice that had had a heart attack were used in the study. Paroxetine improved the left ventricle’s ability to pump blood and protected the heart from scarring and fibrosis, said the team.

Professor Koch said: “Our study proves that small molecule pharmacological inhibitors of GRK2 would be truly innovative and may offer new hope for heart failure therapy.”

But he warned that the dose of paroxetine needed to inhibit GRK humans might be too high.

However, he felt new compounds derived from paroxetine that were more targeted to GRK2 without affecting serotonin (the operating drug agent in depression) could be developed to treat heart failure.

“We are certainly trying to come up with these compounds because heart failure is a disease where new drugs are needed,” Professor Koch said.

Researchers are currently looking at available clinical data where heart failure patients were treated with paroxetine to see if they can uncover existing data where paroxetine did improve cardiac pump function.

Trials begin on gene therapy for hypertrophic cardiomyopathy

A company in America has begun trialling a gene therapy treatment for hypertrophic cardiomyopathy. 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 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 phase one of a clinical 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 for patients and the doctors who care for them.

Dr Tassos Gianakakos, chief executive officer of MyoKardia, said that by targeting an underlying 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.

MYK-461 is an oral, selective, small molecule allosteric modulator of cardiac myosin. The MYBPC3 gene provides instructions for making the cardiac myosin binding protein C (cardiac MyBP-C).

The phase 1 clinical trial will assess the safety, tolerability and effects of oral doses of MYK-461 in healthy volunteers. In parallel, there will also be a phase 1 study of MYK-461 in patients with HCM.
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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

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Sydney ‘Cardiomyopathy What’s Working’ 2010
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Cardiomyopathy Australia

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