

# my life

The magazine from **Cardiomyopathy<sup>UK</sup>** the heart muscle charity

Issue 05 | Spring 2016

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**'I got so much help from a support volunteer  
that I later became one too'**

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## Our services

We provide information and support to anyone affected by cardiomyopathy.

- **helpline nurses**

Our specialist cardiomyopathy support nurses answer medical questions and queries about living with cardiomyopathy. You can reach them through our helpline 0800 0181 024 (free from a UK landline) or email them at [supportnurse@cardiomyopathy.org](mailto:supportnurse@cardiomyopathy.org)

- **information packs**

We have a wide range of information leaflets and booklets about cardiomyopathy that are full of information for people living with the condition. We also have booklets, CD-Roms and online training videos designed for doctors and nurses

- **support volunteers**

Our network of trained volunteers provide one-to-one support on the phone or by email. They are all affected in some way by cardiomyopathy

- **information days**

We hold seven information days around the UK each year. These days provide people affected by cardiomyopathy and their families with the chance to meet others who have the condition and hear leading experts talk about the disease, developments in care and latest research. Details of this year's information days are on Page 15

- **support groups**

Our support groups around the UK provide people with cardiomyopathy the opportunity to meet others and share problems and experiences with them. Meetings are always positive and encouraging, and often have experts speaking on cardiomyopathy and living with the condition. There are details of forthcoming support group meetings on Page 15

Our vision is for everyone affected by cardiomyopathy to lead long and fulfilling lives. Our goals are to:

- increase support
- improve diagnosis and care
- promote medical research.

If you would like more information on any of our services, please get in touch.



## Contact us

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Cardiomyopathy UK is now a charitable incorporated organisation (CIO) with a registered charity no 1164263

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## What's next for Cardiomyopathy UK?



**New chair of our trustees**  
**Alison Fielding**  
**talks about her vision for the future**

It is an honour, exciting and daunting to have taken over as chair of Cardiomyopathy UK at such an exciting time for the charity.

Our review last year showed that our services are highly valued but that there was also so much more that we could do to improve the lives of people affected by cardiomyopathy. We want to grow our services and professionalism but never lose the friendly feel which we know you value.

Building awareness of the disease and improving medical knowledge are both high priorities. So you can expect to see us continuing to work in these areas.

Our medical conferences are being expanded and delivered outside London to help patients get the best standard of care wherever they live in the UK. It has been encouraging that so many medical staff have registered for these events and we thank all of you who have helped us raise awareness of them in your areas.

A new innovation for this year is our clinical advisory group which will bring together over 20 of the country's leading experts on cardiomyopathy to share knowledge, debate best practice and co-ordinate research. It will also give doctors, nurses and patient representatives a unique opportunity to sit around a table and talk about what is really important to patients.

Our helpline, information and support groups have always been central to the support we provide and we look forward to these continuing to flourish and become even more accessible to people.

Many people have expressed a desire for us to do more in the way of advocacy for patients – both individually and as a group

– and this is an area which we will be asking you more about this year. We know that the medical aspect is just one area in which cardiomyopathy affects your life. So we will be improving our information on money matters and the emotional aspects.

The trustees have two main roles. One is setting the overall direction for the charity. The other is ensuring that we are a legal and viable organisation. Over the last few years we have spent more than our income and used our reserves to fund projects.

This year we are aiming to run all our services and expand in some areas. So we will be working hard on increasing our income. Your donations and fundraising efforts keep us running, and we recognise that we are too dependent on you. So in future, we will also be making more grant applications, signing up more corporate charity partners and supporting people in planning legacy gifts to the charity.

I look forward to meeting as many of you as I can. If you have any comments, contact me on [chair@cardiomyopathy.org](mailto:chair@cardiomyopathy.org)



**Message from Joel, our chief executive**

In this edition of My Life we are looking at the amazing work done by our support volunteers who give up their time to talk to people who are struggling with their cardiomyopathy.

They make a real and lasting difference by giving people with the condition the opportunity to chat to someone who truly knows what they are going through and who can point them in the right direction to get the help they need.

All of our volunteers play a massive part in the charity and without them we simply could not keep going.

So this year, if you have room for another New Year's resolution, please think about getting involved with the charity in some way.

Whether it's fundraising, setting up a support group or stuffing envelopes, we need your help.

As ever, if you have any questions about the charity and our work, call me on 01494 791224 or email me at [joel.rose@cardiomyopathy.org](mailto:joel.rose@cardiomyopathy.org)

## Cardiomyopathy information days planned for around the UK this year

### Each year we hold information days around the country for affected families

Dates for this year's cardiomyopathy information days are being finalised.

The first information day of the year is being held on Saturday, 27 February at the Bristol-Filton Holiday Inn in Filton Road, Bristol.

The main speaker will be Professor Perry Elliott from the inherited heart disease team at Barts Heart Centre in London.

There will also be an information day in Belfast on Saturday, 14 May. The venue is to be finalised, but the main speaker will again be Professor Elliott.

Other information days are planned for Glasgow in April, and Manchester and Newcastle in June, but dates and venues have yet to be confirmed.

These days are held so people affected by the condition, their families and friends can find out more about it, latest treatments and developments in research. They also get a chance to meet others who are affected.

All the events are on Saturdays and are free to attend. But those wishing to join us for lunch are asked for a contribution towards the cost of that.

For more details about our information days, see [cardiomyopathy.org/information-days](http://cardiomyopathy.org/information-days)



### Midlands conference for doctors and nurses

Our second regional cardiomyopathy conference for doctors and nurses is to be held in Birmingham.

The conference, at the Queen Elizabeth Hospital's education centre in Mindelsohn Way, Edgbaston, on Tuesday, 19 January, is designed to reach more cardiologists, specialist heart nurses and GPs in the regions where they work.

The conference, which is free, will focus on imaging, risk and future trends in treating cardiomyopathy.

Families can help us promote the day by taking details to their care teams. Email [rona.eade@cardiomyopathy.org](mailto:rona.eade@cardiomyopathy.org) for a copy of the programme.



Osian Evans and Nancy Williams talk about having cardiomyopathy and becoming support volunteers to help others

# How our support volunteers help others

## Osian Evans' story

Support volunteer Osian (above with his family) talks about the help he got from Cardiomyopathy UK and how he is supporting others by sharing his knowledge of the benefits system.

It was my first day at work in 2015 so having a heavy heart was somewhat expected. I hadn't been sleeping and woke up like a bear with a sore head. Walking was a struggle and I put my chest pain down to indigestion from Christmas celebrations. I stumbled to my car and went to work at a branch of Citizens Advice in North Wales.

I could not engage my brain, was breathless and in a cold sweat. A colleague demanded I see my GP. I got to my car in agony, feeling that I had a collapsed lung. The only thing I remember about the drive is hearing Peter Gabriel and Kate Bush singing 'don't give up' on the radio, which for some reason rang a bell. At the surgery my GP arranged an ECG. It showed the heart rhythm disorder atrial fibrillation (AF) and arrangements were made for me to be taken to hospital immediately.

I had not stayed a night in hospital and did not intend doing so. However I had to stay in on a drip and have a cardioversion (controlled electric shocks under sedation) to get my heart rhythm back to normal. While waiting for the procedure my cardiologist did an echo and told me I had dilated cardiomyopathy (DCM). This gave me a shock even before he grabbed the paddles.

The cardioversion did not work. So I was given intravenously the anti-arrhythmic drug amiodarone as well as a catalogue of other medications. My cardiologist and heart failure nurse said a virus may have triggered a dormant gene mutation for DCM.

I was off work for four months, mostly sleeping on the sofa and at constant appointments and return admissions to hospital. I don't think I would have survived without the love of my wife Sara, our children Gwydion (11) and Leah (7) and other family and friends.

I have paroxysmal AF, which means I have episodes of AF that come and go. I've been identifying triggers for these episodes, such as coffee, wine and shouting at my children!

The cardiologist is considering how best to treat this AF and

looking at an ablation (destroying the affected area of my heart that's causing the abnormal heart rhythm) or a pacemaker, but I appear to go back into normal rhythm myself.

I attended a cardiac rehabilitation gym and could manage baby steps as opposed to lifting heavy weights like I used to. That's what life is about now, slowing down and avoiding stress.

I took a mindfulness course to avoid getting worked up and going into AF and have started yoga. I now live every day as if it was my last as no one knows what's around the corner. I decided to buy the car I'd been promising myself and really enjoy the finer things in life (healthy ones, of course!)

I have been a senior caseworker at Citizens Advice for over nine years and am now a welfare rights officer for another organisation.

I found support from Cardiomyopathy UK and its helpline, website and information days invaluable as I came to terms with the condition. I was told by Julie Rees who runs my nearest support group in Cheshire that a warm welcome awaits me there, but I've been too tired after work to get there.

Nonetheless, I want to be involved and give something back. As my heart function has improved (my ejection fraction has increased from 20 per cent to 50 per cent), I decided to contact the charity to offer support to others.

I now share some of my knowledge on welfare benefits with people with cardiomyopathy. I usually do this by email or, in some cases, over the phone. I have helped with queries on benefits, housing and blue badges and hope my knowledge has been of help. I also plan to keep the charity appraised on welfare reform changes and how to navigate the ever changing system.

I have an in-depth knowledge of benefits including Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and concessions and am happy to put them in the context of people with cardiomyopathy.

I have also represented many clients over the years with appeal tribunals. I am happy to give some guidance on how to navigate the appeals system and put together an effective appeal. Of course, getting what you're entitled to is a challenge in the current climate and I cannot promise success.

Contact Cardiomyopathy UK and they will contact me if they think I can be of help.



# Nancy Williams' story

After being diagnosed with cardiomyopathy and helped by one of our support volunteers, Nancy decided to become one herself. She took on the role after attending a training day.

My diagnosis of ARVC (arrhythmogenic right ventricular cardiomyopathy) 12 years ago was triggered by near fainting spells and that my youngest sister had died suddenly at the age of 26. We had been told then that she had viral myocarditis, a common misdiagnosis of ARVC.

Like a lot of people with the genetic condition, I had enjoyed a lot of sporting competition – running, cycling and triathlons. So it was a big life changer to stop exercising and realise I was going to be on medication for the rest of my life. I had never heard of ARVC and felt totally alone. I contacted Cardiomyopathy UK and spoke to a support volunteer who helped me get things in perspective and pointed me in the right direction for information about the genetic implications for my children.

I can't stress enough how brilliant it was to talk to someone who not only knew about cardiomyopathy but also lived with it and fully understood what I was going through. She had children, a job and most of all a positive attitude to life. When I put the phone down I felt a huge weight had lifted from me. I knew then that I too could live a full life.

Back in 2003 genetic testing for cardiomyopathy was still quite new and we were lucky that a gene mutation was found to be the cause of my sister's death, and the heart problems my family had.

We had to decide about getting my three children Robert (18) Stacey (16) and Laurie (13) gene tested. Robert was the only one who got a positive result. It was hard for him having a clear memory of his aunt's death and knowing his siblings were clear.

But, two years later, we had become acclimatised to our new "normal" lives. So I attended a training day to be a support volunteer. I had had such a positive experience that I felt it was time for me to give back. I have enjoyed being available to listen and empathise.

I also helped for a few years to run with others a support group in East Anglia. But in 2009 my husband Stephen had a recurrence of cancer. He was given three to five years to live. So I decided to take a back seat with the support group and had a couple of years off from being a support volunteer. I am pleased to say Stephen is still alive and kicking. He has had numerous ground-breaking treatments, and is still running for our local running club.

Robert's heart is working fairly normally though he has had some rhythm problems. He still has annual heart checks. He exercises with a heart monitor and keeps his heart rate at a relaxed level. He and his long-term girlfriend know that if they decide to have children, they could have them free from the disease through pre-implantation genetic testing.

My ARVC has progressed. I am on my third internal defibrillator (ICD) and my symptoms now are mainly related to heart failure.

Two years ago I gave up work because I found it too tiring and I was taking a lot of time off going to hospital with Stephen.

Retirement has been a revelation. I took up golf, joining a nine hole club, and love it. I'm learning bridge and play with others at least three times a week. I take painting classes and make my own cards.

My husband and I like to say we "live" with our conditions. We can't say either of us really suffers. In both conditions there have been big steps in improving life expectancy and we hope that if we hang in there the sky's the limit. We always say how lucky we are.

I resumed my role as a support volunteer a few years ago and still enjoy giving something back. I always remember how I benefited from my call to a support volunteer and that still inspires me.

Recently a few of us who have cardiomyopathy and live in Bury St Edmunds in Suffolk have been meeting up at a pub for a drink to support each other. It's fairly informal but I feel we achieve a lot.

As I write this the sun is shining – another day to look forward to.

• Nancy is pictured on the front page with her husband Stephen

## Our support volunteers and how they help

Our 80 support volunteers around the country talk to others with cardiomyopathy and also help Cardiomyopathy UK in many other ways. Here are some examples:

**Ken Pugh** talks to others who have dilated cardiomyopathy. He also has an internal defibrillator (ICD) and helps run a support group for people with ICDs. He held one of our first Great Pancake Parties in 2014 and said: "It was a wonderful way to get everyone together and have a great time. It was really fun." For more details of this year's Great Pancake Party see Page 12.



**Tina Amiss** also has an ICD and it has fired several times. She is a trustee and supports us in many ways. At a day in Parliament looking at how medical technology helps patients, she told MPs and peers how her ICD had saved her life. She has also walked the London Marathon, and been dog sledding in Finland in sub-zero temperatures to raise funds for us.



**Lynn Hedgecoe**, who has dilated cardiomyopathy and a biventricular pacemaker, also talks to people at her local hospital who have been newly diagnosed with the disease. She supported us at a 'Don't Fail on Heart Failure' day at the House of Commons. She also inspired our Great Pancake Party.



**Stephan Weber**, who has hypertrophic cardiomyopathy and an ICD, enjoys exercise and has a healthy lifestyle. He has been raising money for our charity by taking part in the British 10K London Run, the Great South Run and a Tough Mudder. Stephan is pictured with his wife Fiona, who also runs for our charity.

- If you'd like to talk to a support volunteer, email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org)



## In the name of Rosie



Little Rosie Day is too young to understand, but one day soon she will need a new heart.

Three-year-old Rosie was diagnosed last year with restrictive cardiomyopathy, which makes the heart become stiff and restricts its ability to fill with blood properly.

Her mum Sara and dad Barry have been told that she will need a transplant sooner rather than later. Sara contacted Cardiomyopathy UK for help and advice after Rosie's diagnosis in July. She was so impressed with the support she received that she nominated us for her company's charity of the year.

The company, Mayer Brown LLP, a legal firm based in London, chooses a different charity to support every two years. Cardiomyopathy UK was chosen as the company's charity partner for 2016 and 2017.

Our chief executive Joel Rose said: "We are thrilled to have been chosen as Mayer Brown's charity partner. The partnership is a really big deal for us. Having a major organisation like Mayer Brown supporting our work will not only enable us to grow services but will also encourage other organisations to support us too".

Over the next two years staff at Mayer Brown will be getting together to help raise funds to support Rosie and other children with cardiomyopathy.

Taking on challenges like bike rides and abseiling as well as pancake parties and quizzes, the staff will be committed to raising funds for us.

To find out more about how your company could get involved in supporting Cardiomyopathy UK, visit [cardiomyopathy.org/fundraise-at-work](http://cardiomyopathy.org/fundraise-at-work)



## Bundle branch block



**Robert Hall** | cardiomyopathy support nurse,  
Cardiomyopathy UK

Our My Life series of articles on the heart rhythm problems that can occur in cardiomyopathy this time focusses on bundle branch block.

Normal heart



Left bundle branch block



The heart has its own system for producing electrical impulses to make it beat in a coordinated and efficient way. These impulses

are transmitted down to the ventricles via channels known as left and right 'bundles'. The term 'bundle branch block' is used when there is an obstruction or delay in the conduction of these electrical impulses down the bundles. This then alters the way in which the electrical impulses are distributed across the heart.

Bundle branch block is diagnosed with an ECG with distinctive patterns of the electrical impulse conduction being recorded. When the condition is intermittent it may be identified with a 24 hour ECG recording. It is a relatively common finding on ECG, particularly as people get older. In some people, particularly with a right bundle branch block pattern on their ECG, this may not be a problem requiring any treatment. The challenge doctors face is to confirm the significance of bundle branch block in each patient. Therefore, when the condition is identified it should be followed by further tests aimed at identifying the cause.

Blockage of the left bundle branch (known as left bundle branch block) can be associated with hypertrophic cardiomyopathy and dilated cardiomyopathy and can reduce the efficiency of the heart beat and reduce the output of blood. This is due to the ventricles only receiving an impulse down the right bundle and the impulse then having to travel further across the heart to make the left ventricle contract. This results in the heart's contraction being less coordinated and can contribute to increasing symptoms of heart failure.

Left bundle branch block in heart failure related conditions, such as dilated cardiomyopathy, requires expert assessment as it could indicate particular gene mutations and may also provide a crucial guide to future treatments, such as a biventricular pacemaker and/or an implantable defibrillator (ICD).

### More information

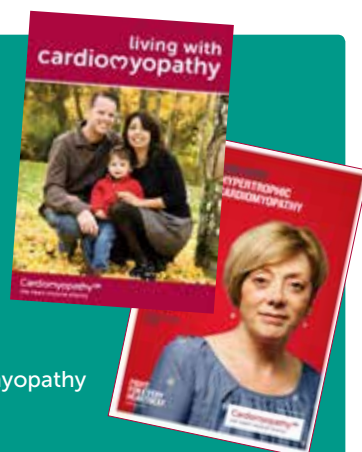
If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets, produced with support from the British Heart Foundation.

We have booklets about each of the main types of cardiomyopathy — dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy.

Information about other types of cardiomyopathy is on our website [cardiomyopathy.org](http://cardiomyopathy.org)

We also have a booklet about living with cardiomyopathy. For copies of our booklets, email [anne.foster@cardiomyopathy.org](mailto:anne.foster@cardiomyopathy.org) or call us on 01494 791224.

To speak to a Cardiomyopathy UK support nurse, call 0800 0181 024 (free from a UK landline) or email [supportnurse@cardiomyopathy.org](mailto:supportnurse@cardiomyopathy.org)





# Q&A

Professor Perry Elliott, from the inherited heart disease team at Barts Heart Centre, London, answers your questions



**Q: Is 3D printing of hearts with heart disease of any value in assessing the seriousness of the condition or choosing the best treatments? I wondered if the technique had been considered or if the cost outweighed its advantages.**

A: Three dimensional (3D) printing is a technology that uses a printer to build 3D models by laying down one thin layer of material, which bonds with another thin layer of material. The model is designed with a computer programme, sent to the printer. To create a model of the heart, 3D images need to be created using non-invasive imaging such as CT or magnetic resonance imaging (MRI). Current applications of 3D printing in medicine include the development of bespoke prosthetic implants and realistic anatomical models for educational purposes. In cardiac surgery, patient-specific 3D models of hearts with congenital defects, aortic disease and valve disease are reported. These models may help in pre-operative planning. The technique has yet to be applied to cardiomyopathies.

**Q: I have been diagnosed with late onset hypertrophic cardiomyopathy. I wondered what this meant for my children and grandchildren. Are they at any risk of dying suddenly when they are young, or are they just at risk of developing the disease when they are my age – in my late 50s?**

A: Hypertrophic cardiomyopathy is usually a genetic condition, but it rarely presents in childhood. It has been thought that most people will manifest signs of the condition in puberty or in their early 20s but there are some individuals that develop their disease in later decades – so called late onset disease. Importantly, there are some forms of genetic and non-genetic cardiomyopathy that present exclusively in older people. The question about risk for

your children and grandchildren depends on the underlying cause. If a genetic mutation has been identified, it will be easier to counsel your relatives. It is also just possible that you do not have a genetic disease and that there is no risk to your relatives.

**Q: My daughter who is 18 months old has recently been diagnosed with dilated cardiomyopathy (DCM). She is currently doing OK on her drugs. I understand doctors can't predict what will happen to her. But what are the statistical likelihoods of her a) making a full recovery, b) managing on drug treatments and c) needing a heart transplant at some stage.**

A: The term DCM refers to the situation in which the main pumping chamber of the heart – the left ventricle – is enlarged and functioning below normal. DCM is caused by many genetic and non-genetic conditions and to some extent the likelihood of recovery and the long-term prognosis will depend on the cause of her DCM. That said, most evidence suggests that people who respond to conventional therapy with beta-blockers, ACE inhibitors and aldosterone antagonists have a good prognosis at least in the short to medium term. Complete recovery, in the sense that the heart returns to normal and drug therapy is no longer required, is uncommon and usually suggests a transient illness such as myocarditis (inflammation in the heart muscle) caused by viral infection.

**Q: If and when the new drug Entresto is approved for treating heart failure, how would I go about seeing if I am suitable for it?**

A: Entresto is a new drug combination (formerly called LCZ696) containing valsartan and sacubitril which inhibits a hormone called neprilysin. A recent

randomised, clinical study found that Entresto significantly reduced the risks of death from heart failure and hospitalisation compared to therapy with the ACE inhibitor enalapril. I am aware that regulatory bodies and professional societies are drawing up guidelines for the use of the drug. I suspect that it will be initially recommended for people with heart failure who are not responding to conventional therapy and have similar characteristics to those people enrolled in the trial but we will know for certain in the next few weeks.

**Q: I have read that some antibiotics, including erythromycin, can cause the heart to beat very fast, leading to heart attacks, cardiac arrest and strokes. Are these drugs safe for people with cardiomyopathy?**

A: A number of drugs, including some antibiotics, can rarely trigger heart rhythm disturbances in people who have a genetic predisposition or when used in combination with other drugs that affect the electrical activity of the heart. In general, there is no evidence that people with cardiomyopathy are at greater risk of this phenomenon, but it is always important to check with your GP, pharmacist or specialist that any new medication does not interact with your regular therapy.

If you have a question you would like Prof Perry Elliott to answer in My Life, please send it to Sarah Dennis at [sarah.dennis@cardiomyopathy.org](mailto:sarah.dennis@cardiomyopathy.org)

# Our support volunteers have a lot to offer

We have around 80 volunteers affected by cardiomyopathy in some way who provide support to others by telephone and email.

They range in age from their early twenties to over 70, have different types of cardiomyopathy and have had different treatments.

Some are the parents of affected children.

But they are all keen to help support others affected by cardiomyopathy.



Some of our support volunteers at a training day.  
If you'd like to speak to a support volunteer, email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org)

## What are support volunteers

Our support volunteers are key people who are affected by cardiomyopathy in some way and who provide knowledge, experience, and emotional, social and practical help to others affected by cardiomyopathy. The volunteers, who have brief training from us, offer, as equals, a listening ear and support by virtue of their own shared cardiomyopathy experiences. They are volunteers who provide one-to-one support by telephone and email.

## Who are they?

We have around 80 support volunteers who range in age from their early 20s to over 70. Some are affected themselves but others have children affected or a partner affected. They have experiences of different types of cardiomyopathy, including dilated, hypertrophic, arrhythmogenic right ventricular and peripartum (pregnancy related) cardiomyopathy. Some are on drug treatments only while others have had invasive treatments such as a surgical myectomy or a septal alcohol ablation (these treatments are used to treat obstruction of blood flow from the heart in some hypertrophic cardiomyopathy). Some of our volunteers have experience of pacemakers, internal defibrillators (ICDs) and heart pumps. Others have had a heart transplant or have a child who has had a heart transplant.

## How support volunteers can help

People tell us that although doctors often provide them with a lot of information, they can't share with them what it is like to live with cardiomyopathy and deal with the anxiety it can sometimes cause. People affected by cardiomyopathy tell us that speaking to someone who understands what they are going through is enormously helpful to them. It lessens their feelings of isolation and helps them

realise they are not alone. Sometimes people affected by cardiomyopathy have different issues, such as difficulties with their job or getting benefits. So we also have volunteers with experience of particular issues, such as benefits and work issues.

## Getting in touch with a support volunteer

We know our support volunteers well so we can match callers with a support volunteer of a similar age, in a similar situation to themselves and who has been through similar treatments.

If you have a particular issue you want to discuss with a support volunteer, we can try to find someone with knowledge of that particular issue. So if you have hypertrophic cardiomyopathy and are concerned about having an ICD fitted, we can put you in touch with someone with hypertrophic cardiomyopathy and an ICD. If you would like to speak to a support volunteer, call the office or email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org)

## Increasing our support volunteer network

We are always keen to increase the number of people on our support volunteer network so we can further improve matches between callers and volunteers. We are particularly looking for more young people to join the network and more parents of affected children.

## Training days for potential volunteers

We hold training days for people interested in becoming a support volunteer. These days help people understand the role of a support volunteer and enable those attending to decide if the role is for them. To find out more about the days email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org)



## European approval for new heart failure treatment

The new heart failure drug Entresto, the twice-a-day sacubitril and valsartan pill formerly known as LCZ696, has been approved in Europe.

The drug's maker Novartis says the European Commission has approved the drug for treating people with symptomatic chronic heart failure with reduced ejection fraction. This follows approval of the drug in America in July.

The medical community has been anticipating the introduction of Entresto since trial results last year, says the company. The trial was stopped early because of a significant reduction in mortality in the group taking the new drug compared to those on the ACE inhibitor enalapril. Final results of the trial showed that treatment with the drug improved survival and cut hospital admissions for

heart failure.

Researchers estimate it will give people with heart failure an extra one or two years on the ten or more years they are currently expected to live.

They estimated that for a 55-year-old survival would increase from 11.6 years to 12.9 years. The mean for avoiding death or a hospital admission was 2.1 years

For 65-year-olds life expectancy would increase from 10 years to 11.4 years. Extra survival for 75-year-olds was 1.1 years and for 80-year-olds an extra 0.2 years.

For more information about when the drug may be available on the NHS, see the Q and A on Page 7.



For more stories about developments in care and research, see [cardiomyopathy.org/news](http://cardiomyopathy.org/news)

## Young with hypertrophic cardiomyopathy do well

Young people with hypertrophic cardiomyopathy receiving up-to-date care have good outcomes, says a new study.

Historically, young patients with the disease have been considered at greater risk of complications.

But a new study from America of those aged between seven and 29 says that low mortality can be achieved with contemporary management strategies.

Trial authors, including Dr Barry Maron from the Minneapolis Heart Institute, said success was based on risk stratification and using consensus guidelines.

This included looking at major risk factors including family history of sudden death, unexplained recent fainting, thickness of

the left ventricle wall, the heart rhythm ventricular tachycardia and blood pressure response to exercise.

He said the use of internal defibrillators (ICDs) was life-saving but there was a problem with inappropriate shocks.

The researchers looked at 494 young people with hypertrophic cardiomyopathy for between two and 12 years.

During the course of the study 95 per cent of patients survived. Eighteen patients died, some from progressive heart failure and heart transplant complications.



For more details, see [cardiomyopathy.org/young-people-hcm](http://cardiomyopathy.org/young-people-hcm)

## Care better but survival varies, says audit

There is still a lot of variation in survival for people with heart failure, but improved prescribing of important treatments and more specialist care for patients has been identified in the latest National Heart Failure Audit.

The document, which covers April 2013 to March 2014, gives the findings for patients in England and Wales with an unscheduled admission to hospital for heart failure.

It says the findings show better keeping to medical guidelines, including those from NICE (the National Institute for Health and Care Excellence).

Differences in survival partly reflected the diversity of clinical care. Good clinical management by heart failure and cardiology specialists continued to result in patients doing better. The quality of care during the first hospital stay continued to produce noticeable survival

benefits for several years.

The patient representative on the National Heart Failure Audit Steering Committee Richard Mindham, who has dilated cardiomyopathy,

says: "Care is better as greater use of evidence-based treatments becomes commonplace and more people have their care delivered by a specialist multi-disciplinary team.

"I want to see care that compares with cancer treatment."



For more details, see [cardiomyopathy.org/hf-care](http://cardiomyopathy.org/hf-care)



## Are you taking part in genomic research?

Are you taking part in the 100,000 Genomes Project, a big Government project to find out more about genetic diseases to help improve treatments?



Then researchers at Oxford University would like to hear from you.

One of them, Melissa Stepney, said: "We would like to interview families who have been involved in the project about their experiences, feelings and thoughts about genomic research.

"What made you decide to take part in the project or why did you choose not to? What do you think are the benefits of genomic research and the risks of taking part in medical research?"

For further information, email [melissa.stepney@phc.ox.ac.uk](mailto:melissa.stepney@phc.ox.ac.uk)

## Delayed benefits from pacemakers?

Many heart failure patients who initially get no benefit from having a biventricular pacemaker can still go on to do better later, says a new study.

Biventricular pacing (also called cardiac resynchronisation therapy or CRT) can help the different chambers of the heart beat more in unison, easing symptoms. But some people see no early improvement after having the device.

But now a new study, led by Dr Kevin Burns from the United Heart and Vascular Clinic in St Paul, Minnesota, America, showed that many patients can do better later on. Survival and hospital admission rates among the late responders were also similar.

## New charity number

Cardiomyopathy UK has become a charitable incorporated organisation (CIO) with a new registered charity number 1164263.

Recent changes in charity law have enabled charities to establish a new type of legal entity called CIO which is much like that of companies but formed through and administered only by the Charity Commission.

The charity has been an unincorporated association, which trustees feel is not suitable for the size Cardiomyopathy UK has become.

# Good social support helps cardiac rehab



People with heart failure who have good social support tend to stick better to cardiac rehabilitation exercise programmes, says a new study.

Those with stable chronic heart failure did less exercise if they had poor social support and other barriers to exercise, although this did not always impact on how patients did, said the trial led by Dr Lauren Cooper of the Duke Clinical Research Institute in North Carolina, America.

People who exercised less had a higher risk of death or need for hospital admission compared with patients who exercised more.

And patients who were fully or partially committed to exercise programmes had a higher quality of life and lower levels of depression. They were also more likely to be married or living with a partner.

The findings added to results from an earlier trial which looked at exercise intensity as well as exercise time and showed that moderate exercise was associated with a reduced risk of problems from heart failure.

Even low levels of exercise have been shown to be beneficial compared with no exercise at all, said the researchers.

"When doctors refer their heart failure patients for a structured exercise programme such as cardiac rehabilitation, they must recognise the psychosocial factors that may limit a patient's ability to participate and benefit," said Dr Cooper.

She said the study could help doctors identify patients at high risk of not sticking to an exercise regime.

Tackling these issues might require different strategies for particular patients and include getting family members and friends involved in providing support and assistance, she added.

The study was reported online in *Circulation: Heart Failure*.

## What's cardiac rehab?

It's a supervised programme that helps improve the health and well-being of people with heart problems. It includes exercise training, healthy living information, and support to reduce stress and help people return to an active life.

## Study compares obstruction treatment

A new study has compared alternative treatments for treating obstruction in hypertrophic cardiomyopathy.

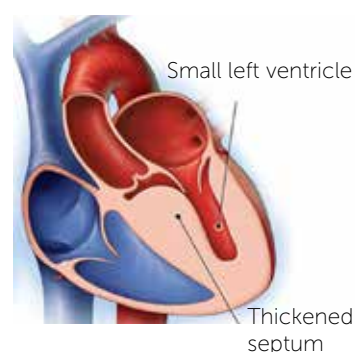
In some patients with the disease, thickening of the heart muscle can obstruct blood flow out of the heart. This can increase symptoms and may need treating.

Often drugs are sufficient, but sometimes more invasive procedures are needed. This is usually a septal alcohol ablation or myectomy. In a myectomy, a section of the thickened muscle causing the obstruction is removed during open heart surgery.

A septal ablation is less invasive. Medical alcohol is injected into the heart via a vein in the leg. This is designed to destroy heart cells in the problem area, causing them to die and reducing the obstruction. It is thought to be the best choice for older patients.

Now a small study in Holland of how patients do in the years after having the rival procedures has concluded that the long term risks of dying or surviving a cardiac arrest after either procedure are similarly low, but patients who have the septal ablation are twice as likely to need a permanent pacemaker and five times more likely to need additional septal reduction therapy compared to those who have a myectomy.

The study, led by Dr Max Liebrechts from St Antonius Hospital, Nieuwegein, included 16 patients who had had a myectomy and 11 who had had a septal alcohol ablation. They were followed up for a mean of 7.4 and 6.2 years respectively, with all having had the procedure at least three years before.



For more cardiomyopathy news stories, see on our website [cardiomyopathy.org/news](https://cardiomyopathy.org/news)

## Another new drug for heart failure?

Another new drug being investigated for treating chronic heart failure has shown some significant results in trials, the American Heart Association's scientific sessions were told.

Researchers say the drug, omecamtiv mecarbil, boosts the heart's function by prolonging the left ventricle's ejection time (when blood is pumped out of the heart).

The drug is a cardiac myosin activator that directly targets a force-generating cardiac enzyme, accelerating its activity to improve the heart's ability to contract.

In a presentation to the scientific sessions in November, Dr John Teerlink from the University of California said there were significant improvements in cardiac function in the study of more than 448 patients with long-lasting heart failure.

He said the patients had a left ventricular ejection fraction of less than 40 per cent (a mean of 29 per cent) and were on current optimal medical therapy – including beta-blockers and ACE inhibitors or ARBs. More than eight in ten were on diuretics. The patients were divided into three groups – one on 25mg of the drug twice a day, one on 25mg rising to 50mg a day and the third on a placebo.

He said that as well as significant benefits in the ejection time, there were also improvements in the amount of blood pumped out of the heart in each beat and a blood test measurement for assessing worsening heart failure.



For more cardiomyopathy news stories, go to [cardiomyopathy.org/news](https://cardiomyopathy.org/news)



# Beware herbal medicine and over-the-counter pills



**Steve McGlynn** | specialist principal pharmacist (cardiology), NHS Greater Glasgow and Clyde

Some over-the-counter treatments and herbal medicines can affect your heart. Here we look at the consequences taking them may have on people with heart problems such as cardiomyopathy

Over-the-counter medicines and herbal remedies are widely available and commonly used.

These treatments can affect the heart but often the general public doesn't realise the consequences taking them may have. The safety of many herbal remedies is unknown.

Sales of over-the-counter medicines totalled £2.45bn in 2013, up by £52.3m compared with the previous year, including £0.35bn on adult painkillers and £0.32bn on cough and cold remedies.

Medicines in the UK require marketing authorisation and there are three ways they can be supplied or sold:

- on prescription, referred to as prescription-only medicines (POMs)
- in a pharmacy without prescription under the supervision of a pharmacist (P)
- as a general sale list (GSL) medicine and sold in general retail outlets without the supervision of a pharmacist

Herbal medicine sales were around £0.5bn in 2012, three per cent up on the previous year. They can be licensed, requiring marketing authorisation or traditional herbal registration granted by the Medicines and Healthcare Products Regulatory Agency, or unlicensed, supplied after a one-to-one consultation with a practitioner.

In a small survey of heart patients by the journal BMC Public Health in 2012, 68 per cent took biological therapies designed to help the body's immune system fight infection and disease, 46 per cent used herbal remedies but usually the patients' doctors were unaware they were taking them.

In patients with heart failure, up to eight in ten patients were taking complimentary or alternative medicines.

Often these treatments are not considered medicines by patients, and 40 per cent of the public consider herbal medicines to be safe because they are "natural".

## Painkillers

The most understood medicines are the painkillers – aspirin and ibuprofen (GSLs), and naproxen (P). They can reduce pain, prevent or reduce fever and reduce inflammation. But they can also increase fluid retention, raise blood pressure, affect blood clotting, and can lead to more heart problems. The caffeine in some of these medicines, and on its own, can stimulate the central nervous system, raise blood pressure and cause a rapid heart rate.

The decongestants in cold and flu remedies can stimulate the heart, cause an abnormally rapid heart rate and interfere with the effects of beta-blockers.

We are mostly all aware of the dangers of too much salt in our food, but there is also salt in soluble paracetamol, for example,



and in some antacids taken for heartburn and cystitis remedies. Salt can increase fluid retention and raise blood pressure.

The salt substitute potassium is also in cystitis remedies and since some heart medicines can cause the body to retain potassium, this can cause very high levels of it (hyperkalaemia) and can lead to cardiac arrest.

## Other treatments

The migraine drug sumatriptan, now available over the counter, can cause spasms in the coronary arteries and should not be used in people with coronary artery disease.

Mebeverine, used to treat irritable bowel syndrome, and the travel sickness drug hyoscine can also cause a faster heart rate.

## Physiological effects of herbal medicines

Herbal medicines can affect fluid in the body, blood pressure, your heart rate and rhythm, and blood clotting. They can also interact with other drugs.

Liquorice, used to help in stomach ulcers, bronchitis, sore throats and in hepatitis, can increase fluid retention, raise blood pressure and increase potassium deficiency.

Hawthorn, used as a herbal treatment in heart failure, widens blood vessels and can cause low blood pressure which is not helpful if you are taking it for angina or digestive problems.

Motherwort, taken to ease anxiety, a weak heart, sleeping problems and in women whose periods have stopped, also relaxes blood vessels, causing low blood pressure. It may cause heart rhythm problems. Motherwort can also cause stomach irritation and increase the risk of bleeding, especially if you are taking antiplatelet or anticoagulant medicines.

St John's wort is used to treat depression, anxiety and insomnia but has interactions with many heart drugs including warfarin (and some other anticoagulants), digoxin, statins, beta-blockers, calcium-channel blockers, and anti-arrhythmic drugs.

Ginkgo, taken to help boost thinking, knowing and remembering and in dementia, also increases the risk of internal bleeding and interacts with many other medicines.

Garlic, used to help lower cholesterol and high blood pressure, can also increase the risk of internal bleeding if taken with blood thinning medication.

## Conclusion

Patients with heart conditions, or taking certain medicines, should ask for advice before buying over-the-counter medicines and should avoid complimentary medicines, especially herbal remedies, without checking first with their doctor or pharmacist.





# Great Pancake Party 2016



## Cardiomyopathy UK's Great Pancake Party is back!

Since its launch two years ago the Great Pancake Party has raised an incredible £35,000 to educate and train GPs and nurses, and to support families affected by cardiomyopathy.

We still hear far too many stories of misdiagnosis and misinformation, of fear and frustration, of unnecessary anguish and of lives lost. But we know that with all the right ingredients – **clear information, expert knowledge and real understanding** – we can save lives and help stop the misery caused by cardiomyopathy.

This year the Great Pancake Party is raising funds for our frontline services. Our specialist nurse helpline and website help ensure that more people than ever before are aware of the signs and symptoms of cardiomyopathy and have the information, support and treatment they need to get on top of the condition.

That's why we're asking you to show your support and have a party this February. While you enjoy yourselves with friends and family, you'll be raising money so we can be there for everyone affected by cardiomyopathy. With your help we can ensure families can spot the signs, ask the right questions and get the treatment they need.

We can't do it without you. So please sign up today – [cardiomyopathy.org/pancake](http://cardiomyopathy.org/pancake)



**Pancake parties are simple, fun and easy to do.** It doesn't matter if yours is a grand party for 100, a cookery badge being earned for a brownie pack, or a perfect excuse for a catch up with friends. Every party, every person, every pound makes a real difference to the work we can do.

We've got a dedicated section on our website with ideas and inspiration, delicious recipes to try, and all the information you need. We'll even send you a free party pack filled with goodies to make your party perfect.



## Without Cardiomyopathy UK, children like Marty might not be here

When she was pregnant, Marty's mum Sarah Bishop found out he had hypertrophic cardiomyopathy and was advised he would be unlikely to survive until birth.

Sarah contacted us and we were able to give her the right information and support, and help her to get a second medical opinion.

Thankfully Marty defied the doctors' predictions and is now a happy and lively five year old.

Sarah said: "We spoke to a support nurse at Cardiomyopathy UK who gave us hope."

With your support we can be there for more families like Marty's, and make sure that everyone gets the best advice and care.





# #teamcardio highlights

We would like to say a huge thank you to all our intrepid #teamcardio fundraisers for braving the elements, organising events and even knitting like mad to support our work. Thank you all!



Interested in being part of #teamcardio?  
Get in touch with our fundraising team at [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org) or visit our website [cardiomyopathy.org/support-us](http://cardiomyopathy.org/support-us)

## Beach battle



Ian Walton from Hereford took on the 'maddest and baddest' motorbike beach race for us - the gruelling three hour endurance Weston Beach Race. Ian raised over £500 in support of a family member with cardiomyopathy

## Scottish success



Runner Cheryl Freeburn is celebrating with her daughter Jessica after successfully completing the Great Scottish Run for us in October. Cheryl, from Glasgow, raised a wonderful £578

## Everyone's a winner



Young fundraiser Marty Bishop was the star of the show when corporate supporter Gecko, a communications and marketing company, held a race night in his honour. Gecko has been fundraising all year, raising over £3,000

## Off on the right foot



Dance teacher Jan Gregory and her pupils performed a Dance-A-Cise show called 'A little bit of this a little bit of that'. The talented dancers and teachers raised over £1,000 in memory of Jan's husband John

## Braving the elements



Jacqui Alland and Vanessa Simpkins survived the mud and rain and took on Gaelforce West for us. Their incredible 67km mountain run, cycle and kayak challenge raised over £1,700

## All the right notes



Musically inclined Matt Erlanger, pictured on sax, organised a fundraising gig to support us with his band Cactus Jam. The gig in October went down a storm and raised £250



Your support changes lives





## Silverstone Half — March



### Silverstone Half Marathon 13 March

*Always dreamed of racing your way around Silverstone? This is your chance!*

The Silverstone Half Marathon boasts a flat, fast course to suit both beginners and experienced runners trying to improve their personal best.

So put your winter training to the test, get that vest on and run for Cardiomyopathy UK at this famous venue.

**Location** - Silverstone Racing Circuit

**When** - 13 March

**Distance** - Half marathon (13.1 miles)

To register or get more information visit [cardiomyopathy.org/silverstone](http://cardiomyopathy.org/silverstone)

## Paris Marathon — April



### Paris Marathon 3 April

*This prestigious marathon offers an ideal course that both runners and spectators will enjoy.*

As one of over 40,000 runners, you'll be lining up at the start on the famous Champs-Élysées, passing historic sites including Notre Dame Cathedral, the Bastille and the Eiffel Tower before finishing on the Avenue Foch, in sight of the Arc de Triomphe.

**Location** - Paris

**When** - 3 April

**Distance** - Marathon (26.2 miles)

To register or for more information visit [cardiomyopathy.org/parismarathon](http://cardiomyopathy.org/parismarathon)

## Great Run series



### Calling all runners...

Become part of a GREAT team! We have places in this year's Great Run series, including in the Great North, Birmingham and Manchester runs. So if you have your eye on a running challenge look no further.

### ...and swimmers

New! This year for the first time we also have places in the Great Newham London Swim. Held in London's Royal Victoria Dock, your family and friends can cheer you on from the dockside.

To register or get more information visit [cardiomyopathy.org/greatruns](http://cardiomyopathy.org/greatruns)

## GET INVOLVED

To take part in any of these events, email [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org) or call 01494 791224. We provide a free fundraising pack with a t-shirt or running vest – and can help you smash your target!



## London to Paris The next Chris Froome?



If you enjoy being in the saddle there is no greater or more popular bike challenge than London to Paris, a true must for any cycling fan and all in aid of Cardiomyopathy UK... three days, two countries, one bike!

You will be cycling 234 miles from west London and crossing the finish line three days later at the Eiffel Tower.

*'It's the best thing I've ever done',  
Steve Coope  
LTP 2014*

To register or for more information see [cardiomyopathy.org/londontoparis](http://cardiomyopathy.org/londontoparis)

## Great Wall discovery



If you're on the hunt for a unique challenge, then this is the one for you.

We are looking for adventurous fundraisers to trek the length of the Great Wall of China, imperial China's former frontline defence.

In this nine day trek you will not only get to see the world famous wall but also Beijing's Forbidden City and Tiananmen Square.

To register or get more information visit [cardiomyopathy.org/greatwall](http://cardiomyopathy.org/greatwall)



# Dates for your diary

## January

*Tuesday 12 January, 7pm*

### West London Support Group

St Stephen's Church and Centre, St Stephen's Road, Ealing, London W13 8HB  
Main speakers Bethan Cowley, inherited cardiac conditions specialist nurse, Royal Brompton Hospital, London, and Bill Bartholomew on life insurance  
For more details, call Willson Hau on 07777 633398 or email him at willsonhau@gmail.com

*Thursday 14 January, 7pm*

### South London Support Group

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY  
Speaker is Cardiomyopathy UK's Robert Hall on progress with technology: medication and devices  
For more details see enquiries panel

*Tuesday, 19 January*

### Regional Medical Conference

Education Centre, Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston, Birmingham B15 2GW  
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

*Monday 25 January 7-9pm*

### Cheshire and Merseyside Support Group

Outpatients Dept, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool, L14 3PE  
Dr Chris Hale from Have a Heart charity and consultant Dr Thomas Giles on living with cardiomyopathy  
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

## February

*Saturday 13 February, 2pm*

### North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle  
Speaker is Cardiomyopathy UK's Robert Hall  
For details contact Cathy Stark, 0191 276 6399 or suze.saunders@btinternet.com

*Tuesday 23 February, 2pm*

### Cornwall Support Group

Inn for All Seasons, Treleigh, Redruth TR16 4AP  
Medtronic cardiac device specialist Helen Simpson on cardiac devices  
For more details contact Eric on 01736 351439

*Saturday, 27 February, 9.30am- 5pm*

### Information day, Bristol

Bristol-Filton Holiday Inn, Filton Road, Bristol BS16 1QX  
Main speaker Professor Perry Elliott, from Barts Heart Centre, London  
For more details see enquiries panel below

## March

*Thursday 17 March 7-9pm*

### Cheshire and Merseyside Support Group

Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL.  
Speakers Liz Kevan and Jane Chesby from Chester Heart Support Group and Dr Chris Hale from Have a Heart charity  
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

## April

*Saturday 9 April, 2pm*

### North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle  
Speaker to be confirmed  
For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

*Thursday 14 April, 7pm*

### South London Support Group

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY  
Speaker to be confirmed  
For more details see enquiries panel

*Saturday 16 April, 11am-2.30pm*

### South Wales Support Group

Education centre, top floor, new main entrance, Morriston Hospital, Swansea SA6 6NL  
For details contact hannah.goss@wales.nhs.uk

*Saturday 23 April, 2-4pm*

### Cheshire and Merseyside Support Group

Outpatient Department at Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE  
Dr Ewan J McKay, heart failure and pacemaker cardiologist at Manchester Heart Centre, Manchester Royal Infirmary on coping with ICDs  
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

*Tuesday 26 April, 2pm*

### Cornwall Support Group

Inn for All Seasons, Treleigh, Redruth TR16 4AP  
Nigel Parry talks about his cardiomyopathy story, including his heart transplant  
For more details contact Eric on 01736 351439

## Enquiries



If you have questions about

- our information days and support groups
- how to register for one of our events
- how we help people affected by cardiomyopathy

please phone us on **01494 791224**, email [info@cardiomyopathy.org](mailto:info@cardiomyopathy.org) or visit our website at [cardiomyopathy.org](http://cardiomyopathy.org)

## Tell us

# your story

My Life is your magazine and we welcome contributions on any cardiomyopathy-related topic.

If you would like to share your story with other people who are affected by cardiomyopathy, contact My Life editor Sarah Dennis at [sarah.dennis@cardiomyopathy.org](mailto:sarah.dennis@cardiomyopathy.org) or telephone **01494 791224**.



# THE GREAT PANCAKE PARTY

All the right ingredients  
to save lives

Join the party and help us

beat cardiomyopathy

Pancake  
Week 2016  
February  
6-13

**Cardiomyopathy<sup>UK</sup>**  
the heart muscle charity  
Reg charity no 1164263

**Sign up and get your pack**

It's quick and easy just visit our website:

**[www.cardiomyopathy.org/pancake](http://www.cardiomyopathy.org/pancake)**