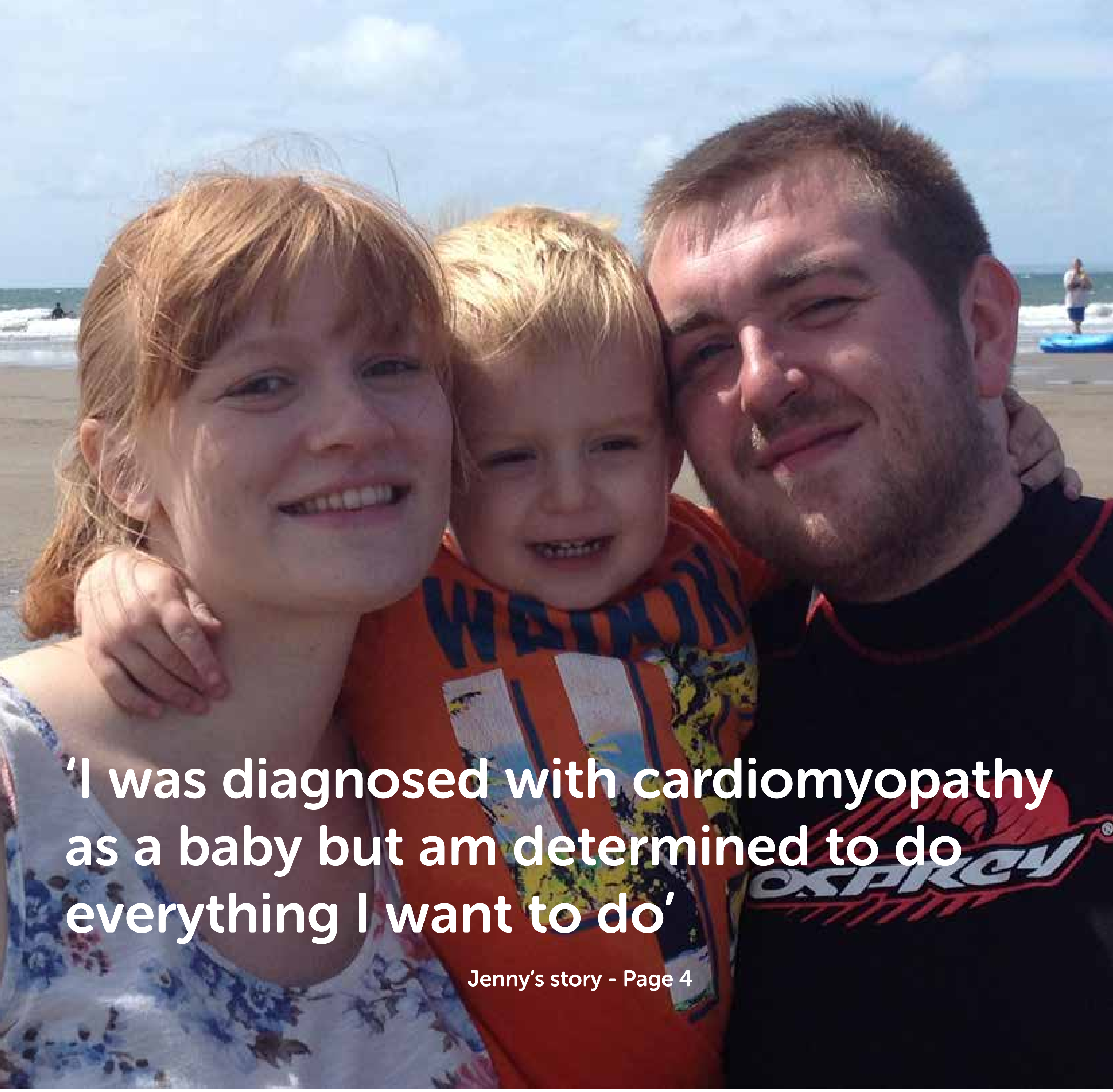
my life

The magazine from Cardiomyopathy UK the heart muscle charity

Issue 03 | September 2015



'I was diagnosed with cardiomyopathy as a baby but am determined to do everything I want to do'

Jenny's story - Page 4

Cardiomyopathy UK
the heart muscle charity

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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
- 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
Unit 10, Chiltern Court, Asheridge Road,
Chesham, Bucks HP5 2PX
Telephone **01494 791224**
Website **cardiomyopathy.org**
Helpline **0800 0181 024**
(free from a UK landline)
Email **info@cardiomyopathy.org**

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facebook.com/cardiomyopathyuk

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Join our Facebook group
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facebook.com/groups/cardiomyopathyuk

Cardiomyopathy UK is the operating name of the Cardiomyopathy Association, registered charity no 803262

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A message from Joel

Welcome to the latest edition of My Life.

When I started as chief executive of Cardiomyopathy UK almost three months ago, I felt that the charity was doing some great things.

I felt that people really benefited from information days, that the helpline made an impact and that there was a real need for our work.

It is not enough however to just feel that we are doing well; we need to show the evidence for it.

We can only fight for quality services if we can show the true state of things as they are.

I believe that charities must ask themselves the fundamental questions; "how good are we?" and "what do our people need?"

I have been asking these questions and am putting in place ways to monitor and evaluate our services as well as to capture what people think about the NHS treatment they receive.

At the end of July we launched a patient experience survey. In one week over 700 people responded. This has given us vital evidence to help develop and underpin our campaigning work.

From June we have been evaluating our nurse helpline service, trying to find out more about who is calling us and how they feel after the call. There is more about this on Page 8.

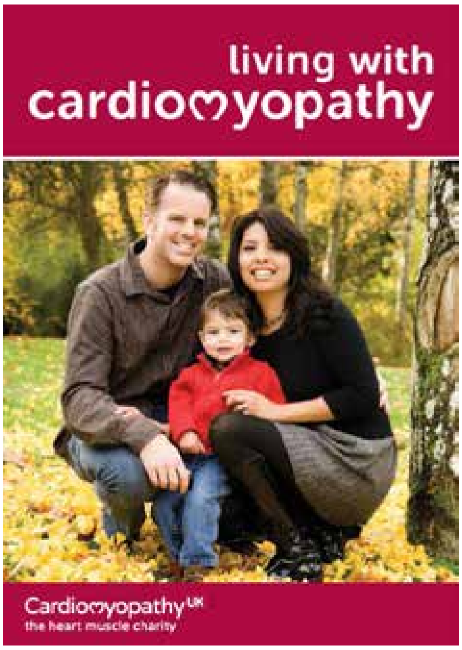
We will continue to gather the evidence we need to campaign. We will also share findings with you so that you know that your charity is not only asking itself the right questions but can also prove the value of its work.

If you have any questions about this then please email me at joel.rose@cardiomyopathy.org or call 01494 791224

Joel Rose, chief executive

New living with cardiomyopathy booklet

A practical guide to help affected people get on with their lives



Our new booklet about living with cardiomyopathy is now available.

The 92-page, full colour A5 publication provides information about learning how to live with cardiomyopathy and getting on with your life.

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

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

Contributors to the new guide include Cardiomyopathy UK's cardiomyopathy support nurses, and inherited heart disease nurse specialists and clinical psychologists from University College London Hospitals NHS Foundation Trust. Thanks also goes to our supporters who donated towards the cost of publication.

The new booklet is designed to complement our booklets on the different types of cardiomyopathy (hypertrophic cardiomyopathy, dilated cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy) which we produce with the British Heart Foundation. These look at the diseases, management of them and treatments.

Cardiomyopathy UK medical director Robert Hall said: "We are very pleased to be able to offer the new living with cardiomyopathy booklet to people affected by cardiomyopathy and their families, and also to hospitals to give to patients.

"Our booklets about the different types of cardiomyopathy answer many of the medical questions people have when they are diagnosed with a cardiomyopathy.

"But we know people also have many questions about living with the condition, and we hope this booklet will help them with that.

"Of course our nurses are here too to help with any questions that affected families have."

You can download a copy from our website, order a copy at cardiomyopathy.org/order-booklet, email anne.foster@cardiomyopathy.org or call us on 01494 791224.

Places at London information day

We still have places at our September information day

Families affected by cardiomyopathy can find out more about the condition, latest treatments and research at our London information day on Saturday, 26 September.

The day, at the Holiday Inn Regent's Park in Carburton Street, W1W, also offers the chance to meet others who are affected.

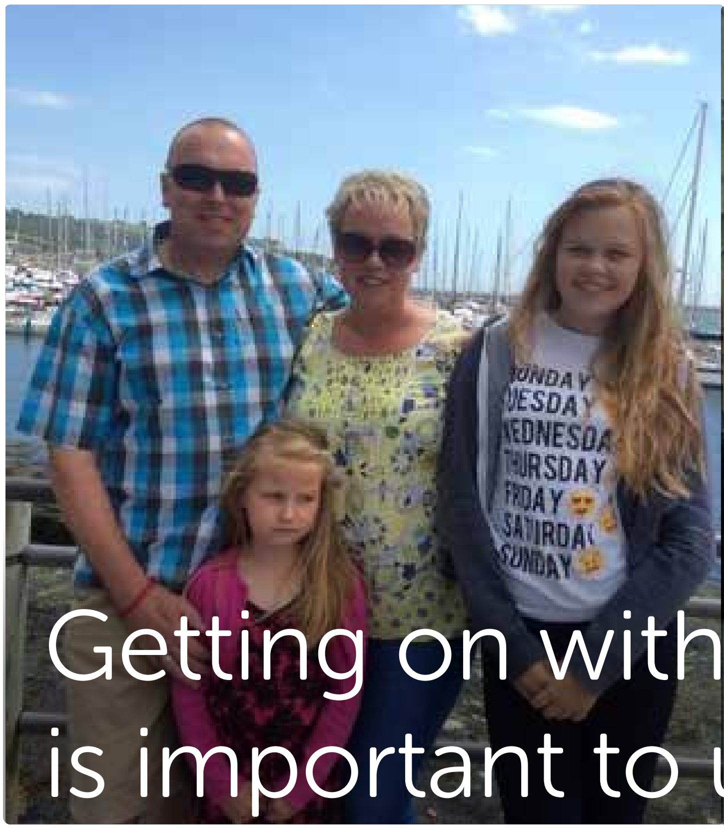
Experts in cardiomyopathy will lead separate, dedicated sessions on each of the main types of cardiomyopathy — dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy

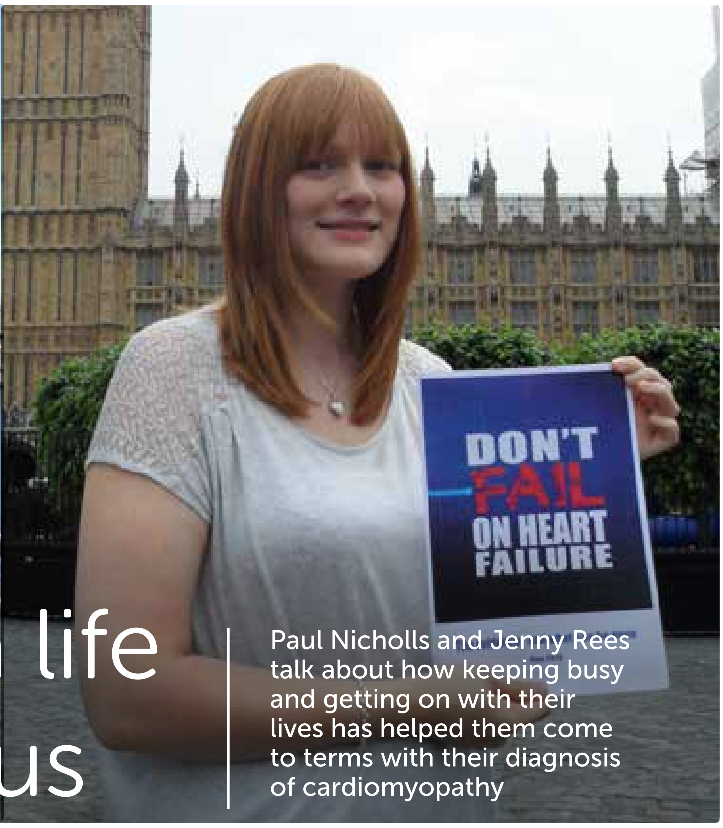
Professor Perry Elliott, from the inherited heart disease team at Barts Heart Centre, will talk about advances in care and lead the dilated cardiomyopathy session.

People affected by cardiomyopathy, their family members and friends are welcome. Attendance is free, but those who wish to join us for lunch are asked to pay £10 each towards the cost.

Over 150 cardiologists and specialist nurses attended our medical conference on hypertrophic cardiomyopathy in London in May

For full details or to book places, see cardiomyopathy.org/information-days/london-information-day or call us on 01494 791224.





Getting on with life is important to us

Paul Nicholls and Jenny Rees talk about how keeping busy and getting on with their lives has helped them come to terms with their diagnosis of cardiomyopathy

Paul Nicholls' story

Paul found being diagnosed with dilated cardiomyopathy and heart failure daunting. But he says information he got from Cardiomyopathy UK and his local support group helped a lot

I was checked out after suffering some chest pains in late 2012 and after lots of tests including echo, CT scan and cardiac MRI I was diagnosed with dilated cardiomyopathy the following January. I was 46.

Before I knew it, I was on the drug treatments spironalactone, nebivolol (the only beta-blocker they'd try as I'm asthmatic) and losartan (I tried ramipril first but got the dreaded dry cough). While wearing a Holter monitor, irregular heart rhythms were recorded.

Then in 2013, because doctors felt I was at risk of developing a dangerous heart rhythm, I had an internal defibrillator (ICD) fitted. My cardiologist wanted me to have one with a combined biventricular pacemaker (officially called a CRT-D) but although I ticked all the other boxes to be eligible, my heart failure symptoms weren't severe enough – according to the NICE guidelines.

This didn't last for long though. My ejection fraction (EF – a measure of how well a heart is pumping) dropped to about half what it should be and my heart became more desynchronised.

So last year I had my ICD swapped for one with biventricular pacing. Almost immediately my breathlessness disappeared and nine months after implant my EF was up from 25% to 39% – still impaired but a significant improvement.

My main symptom is still fatigue. I worked as a construction site manager but this role was proving too demanding. I worked long hours under a lot of stress. So my employer, the large construction company Kier, found another, more flexible role in the business for me as a a skills co-ordinator and I still work full time.

I try to manage my condition and life, and try not to overdo things, though I fail quite often. I make sure I take my medicines at regular times, and plan my rest and relaxation. I would recommend to others with cardiomyopathy gaining a basic knowledge of your condition. Some of the information you read can be quite negative and out of date though, and you have to remember that medicines are improving all the time as is device therapy and even transplantation.

With some lifestyle changes, I can live a near normal life, even if I am high maintenance health wise.

My wife Becky and our two daughters, Jess, aged 13, and Joy, 7, keep me motivated and busy. I've recently been given the all clear to start cycling again which is very liberating – even if I do need a lot of rest to recover from it.

It was daunting being diagnosed with dilated cardiomyopathy and heart failure, especially as at the time I didn't really understand the medical terms and what they meant for me. I found things easier to accept and live with once I had a basic understanding of them.

Cardiomyopathy UK and the Cornwall Cardiomyopathy Support Group have helped me to understand things and accept my condition. The information day in Newquay, Cornwall was also very helpful and educational, not just for me, but also for my wife.

Pictured from left: Joy, Becky, Jess and Paul Nicholls

Jenny Rees' story

Jenny was diagnosed with dilated cardiomyopathy as a baby but has not let it stop her from getting on with life — going to university, working and helping others affected by cardiomyopathy

I was diagnosed at just six weeks old after getting fluid on my lungs. But I never really understood that I was different from anyone else. As far as I was concerned everyone took tablets every morning before school — I had no idea. I was a very sporty child. I did trampolining, dancing and played netball for the Wirral. But I can remember being so unbelievably tired but always determined.

At that time my parents didn't realise how serious dilated cardiomyopathy (DCM) was and so I just took my meds, saw my doctors each year but that was it. I wasn't given any sort of special treatment by staff at school, my friends or my family and that made me feel very normal. I did compare my sporting abilities to others but it made me more determined to do well.

When I spent at least two hours a day napping because I'd been out for the night with my friends, people thought I was a typical lazy teenager. Most of my friends at school had no idea I was ill at all until I needed a pacemaker fitted. I still needed to nap most days, but I enjoyed being busy and getting involved.

I'm not exactly the typical person with heart failure. I get funny looks when I park with my Blue Badge. But I have struggled to come to terms with some things, such as dizziness, fatigue and stress. But it's up to me how well I do in my exams, how good a friend I am and how I react to the difficult times. I sometimes have low moments thinking "why me?" but I wouldn't change it because I wouldn't be the same person without it. My dodgy ticker is part of me.

I have always had a job from potting plants in a greenhouse at 14, to waitressing to earn money through school and university. I'm currently an exams invigilator in a school. I work as and when I am able to, setting my own working hours and this has really helped me. I'm just finishing my psychology degree and am looking for a graduate job. I always wanted to get a Phd in educational psychology. It might take me twice as long to do it, but I'll never say never.

At 16 I became a support volunteer for Cardiomyopathy UK, talking to and emailing other young people with cardiomyopathy. I knew I couldn't be the only teenager with this disease so I decided to use my experiences to try and help others. I've set up a support group with my mum as there wasn't one for miles around. I had some free time, so why not?

I have also given a speech about how dilated cardiomyopathy affects me to MPs and Peers at the House of Commons as part of a Cardiomyopathy UK campaign to raise awareness of heart failure.

I'm very keen that people should get more psychological support when they have their pacemakers and internal defibrillators (ICDs) fitted. So I am supporting a Merseyside doctor who is trying to get that support provided for patients.

I look forward to having a long life and am determined to do everything I want to do. It's important to me that I show my stepson Nate, who is three, this but also prove to myself that no matter what, you just keep going until you find the good in every situation. My family, friends, partner Mark Taylor and Cardiomyopathy UK have all helped me to do that and for that I'm very grateful.

Jenny talking to MPs, Peers and doctors at Westminster

Jenny supports us in so many ways

Jenny and her mum Julie (pictured) support people affected by cardiomyopathy and fundraise so we can provide more services to families. They:

- Run our Cheshire and Merseyside Support Group. The group meets regularly in Ellesmere Port and Liverpool and has expert speakers on cardiomyopathy and related issues. For meeting dates, see Page 15 or email Julie at julierees65@aol.uk

- Belong to our network of support volunteers (affected volunteers who talk to others on the phone and by email). For more details about speaking to a support volunteer, call us on 01494 791224 or email robert.hall@cardiomyopathy.org

- Have been campaigning for more care for people with heart failure (see story to the left). Jenny is also part of a local campaign for more psychological support for people having internal defibrillators (ICDs)

- Helping research. The Rees family is taking part in the 100,000 Genome Project, a Government programme designed to find out more about genetic diseases and help drug companies improve treatments

- Are taking part in our annual September stroll fundraiser by organising their own Lake District stroll on Saturday, 12 September.

  They're taking a 3k circular route around the beauty spot of Tarn Hows, but there is a 0.75k shorter walk for people who use a wheelchair or find it more difficult to walk.

  Julie said: "We like the idea of a stroll as it's a great way to socialise and get to know our members a little better as well as being an opportunity to raise money for Cardiomyopathy UK. We have invited all the members of our group as well as family and friends, and others are welcome to join us."

  If you'd like to take part, email Julie at julierees65@aol.uk

- Sell our Chistmas cards and merchandise, and handmade cards at events

- Hold coffee mornings to raise funds for us.

More than 70 people took part in the Humber Bridge Fun Run in June in support of nine-year-old George Coope (pictured with dad Steve and mum Serena) who has hypertrophic cardiomyopathy. They raised over £1,500. The runners included George's school friends, parents and teachers from Willerby Carr Lane Primary School

General population heart checks not recommended

The UK National Screening Committee has again decided that heart checks for all young people are not necessary.

The committee considered heart screening for people aged between 12 and 39 to prevent them dying suddenly from heart conditions such as cardiomyopathy.

The committee said it did not recommend systematic screening because:

- Currently there are uncertainties over the test, the conditions that can cause sudden cardiac death (SCD), and the overall benefit of identifying those at risk when weighed against potential harms
- There is very little research into the reliability of the tests for identifying those at risk of SCD
- There is no agreed treatment or care pathway for supporting those who have been identified as at risk of SCD. Someone who is identified as having a high risk of SCD may become anxious about their physical activity and stop regularly exercising which can be detrimental to their overall health.

Cardiomyopathy UK chief executive Robert Hall said: "We support the committee's stand. Rather than screening all young people, we believe many more lives can be saved in people of all ages by raising awareness of the condition with GPs, improving cardiology and emergency care, and more widespread availability of gene testing."

Left ventricular noncompaction

Robert Hall | medical director, Cardiomyopathy UK

Left ventricular noncompaction (LVNC) is a condition where areas of the heart muscle appear spongy or honeycombed.

Deep channels, known as trabeculations, are present in the heart muscle wall. These channels connect directly with the left ventricle (the main pumping chamber of the heart).

In the embryo the heart muscle is made up of interwoven fibres. As development progresses these fibres compress to form the muscular walls of the heart. It's probable that formation of the trabeculations is as a result of a defect in this process.

The condition can occur in isolation and be associated with other cardiomyopathies, particularly hypertrophic and dilated. There is evidence the condition runs in families and so screening of close family members is advised.

Controversy remains on the subject of whether LVNC can be categorised as a separate form of cardiomyopathy or is part of the spectrum of other types of cardiomyopathy. As such it remains an unclassified condition with no international guidelines on treatment. How common it is is not clear. It is considered rare though there has been an increase in the numbers being diagnosed in recent years because of improved imaging techniques. It is estimated that up to 24 people per 100,000 are affected, though this is probably an underestimation. It is diagnosed by echo, with subsequent magnetic resonance imaging (MRI) to confirm the diagnosis.

As LVNC cannot be cured, the treatment aims to alleviate symptoms, though some people have no symptoms. A comprehensive clinical history and diagnostic testing (such echo and MRI) are essential to determine the appropriate treatment for the individual. Therapy reflects the extent of and the position of the trabeculations. Treatment focusses on improving the heart's function and preventing complications. If LVNC occurs with another type of cardiomyopathy, this may need to be treated too.

In some people, there may be a risk of blood clots forming in the trabeculations, which could increase the risk of a stroke if they entered the blood stream. Blood thinning drugs, such as aspirin, or anticoagulants, such as warfarin, may be used to reduce this risk. This remains controversial but anticoagulants are now more commonly prescribed if patients also have reduced left ventricular function.

Arrhythmias, such as heart block (where electrical impulses are not being transmitted effectively to the lower chambers — the ventricles) resulting in a low heart rate, may occur and a pacemaker might be required. There may be cases where there is an increased risk of sudden death and an implantable cardiovertor defibrillator (ICD) would be used.

If the condition has resulted in a reduction of the heart's pumping action then national guidelines on treating heart failure would apply and diuretics, beta-blockers and ACE inhibitors or angiotensin II receptor blockers (ARBs) would be used. A biventricular pacemaker may also be needed.

Treatment plans must be devised to meet the needs of the individual.

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.

There is also information about other types of cardiomyopathy on our website **cardiomyopathy.org** To speak to a Cardiomyopathy UK support nurse, call our helpline **0800 0181 024** (free from a UK landline)

Q&A

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

Q: How common is it for people with cardiomyopathy and heart failure to have a deficiency in folic acid if they are on diuretics. Is there likely to be any long term effects and are iron supplements safe?

A: People on diuretics who eat a normal diet and have no other illnesses do not generally have folate deficiency and do not need supplements. Some people with severe heart failure can develop iron deficiency which can exacerbate heart failure symptoms. Iron supplements are generally safe in this situation but you should discuss therapy with your GP and/or cardiologist before taking them so that your iron stores can be measured on a blood test.

Q: Why do I suffer heart symptoms when I go out in the cold?

A: Some people with cardiomyopathy find that when they go out in the cold or into heat their symptoms worsen. This is because a change in temperature produces physiological changes in the body that can put extra pressure on the heart.

Q: Do you know if there is any evidence of eczema being linked to cardiomyopathy?

A: I cannot think of a direct link between the two, but it might be possible that some drugs used to treat cardiomyopathy could exacerbate or trigger eczema.

Q: I have lost weight. So should my drug doses change?

A: If you have lost or gained a significant amount of weight since you were started on a particular drug, it may be advisable to speak to your doctor. The dosage of some drugs is calculated according to the patient's weight. If this has changed the dose may need adjusting.

Q: If I have an alcohol ablation, will I need a pacemaker?

A: An alcohol ablation is a procedure to relieve the obstruction to the outflow of blood from the heart that occurs in some people with hypertrophic cardiomyopathy. An ablation is done by carefully identifying the blood vessel that supplies the area of thickened muscle responsible for the obstruction and injecting pure alcohol into it. This causes scarring in the heart muscle. One of the complications of this procedure is that the conduction system (the electrical system of the heart), which is close to the area of thickened muscle, may also be damaged. This then requires treatment with a pacemaker. The risk of this is approximately ten to 15%.

Q: With hypertrophic cardiomyopathy will my heart continue to enlarge?

A: In about 95% of cases the thickening of the heart muscle stops when the patient is fully grown. The exception to this rule is the late onset variant of the condition where the changes in the heart occur later in life.

Q: What is a tilt test?

A: A tilt table test is sometimes used to identify the cause of fainting in some patients. The patient lies on a couch and is attached to a heart monitor and a blood pressure monitor. The table is then tilted to head up position at about 60 degrees for 30-60 minutes. In some people this provokes dizziness or fainting, or both. By monitoring the heart rate and blood pressure the correct treatment can be identified.

Q: I am taking regular medication for my cardiomyopathy and it's very expensive. Can I get any help with my prescription charges?

A: Some people are eligible for exemption from prescription charges. Details can be obtained at nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx If you are not entitled to free prescriptions, instead of paying £8.20 for each item, you can buy a prescription prepayment certificate which is £29.10 for three months and £104 for a year. You can apply online at nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx, call 0300 330 1341, or apply by post to NHS Help with Health Costs, PPC Issue Office, PO Box 854, Newcastle upon Tyne, NE99 2DE. For a postal application you will need a form which you can download from the website or pick up from your GP surgery or pharmacy. Some pharmacies may be able to sell you a prescription prepayment certificate.

Q: Can a parent carry a gene mutation for hypertrophic cardiomyopathy, not have any symptoms but then pass it on to their children?

A: Uncommonly a gene mutation can be inherited by an individual and not produce signs and symptoms of hypertrophic cardiomyopathy. This is known as non-penetrance. In situations such as this the gene mutation can still be passed on to the individual's children.

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**

How our support nurses help

What you say about the service

We have been looking in detail at the help our support nurses provide to people affected by cardiomyopathy.

We wanted to see not only who is talking to our nurses but also how our callers benefit.

Through our helpline (0800 0181 024) your can reach our experienced nurses who are there to provide free support and information. But you can also reach them on email at support nurse@cardiomyopathy.org or on the Cardiomyopathy UK forum and social networking sites.

> “Your help and advice were brilliant. Before I felt lost and that no one believed me. Now I feel in control,” said a recent caller to our helpline

How many people we help

In June and July our cardiomyopathy support nurses provided help and support to 288 people.

More people contacted them by email than telephone. So we are thinking about how we can make our helpline work even better for people who prefer to contact us in this way.

Outside of office hours, 8% of calls and 28% of emails were responded to during the evening.

While a 24 hours service is a long way off, we will be looking at how we can make sure that more people can get the support they need at a time when it is convenient for them.

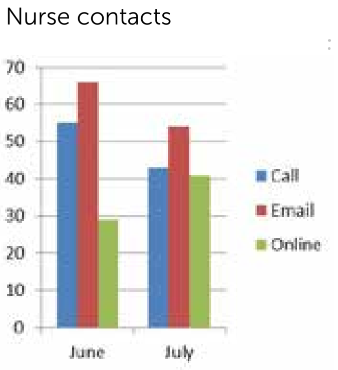
Who they are

Our cardiomyopathy support nurses provide support to people at different stages of their cardiomyopathy journey, from being concerned about a possible problem to feeling on top of their condition.

Many people get support from our nurses and move on. But around 70% are coming to us for the first time.

So perhaps we need to remain in contact better through regular calls and emails.

This is something that we may try to establish next year.



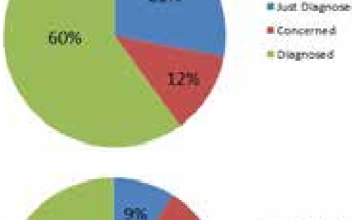
What you feel about our nurses’ help

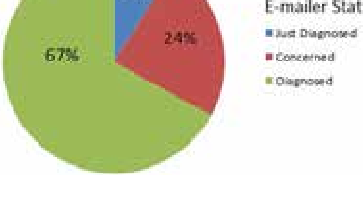
When we asked people who called our nurses how they felt after the call, 87% said it was “very helpful” while the remainder told us that they found the call “helpful”. This helps to show how well the service is regarded.

We want people who contact our nurses to feel more informed, better able to cope, less scared and more empowered to act. We are pleased to see that 75% felt better informed and that the vast majority felt able to take the recommended action.

A smaller proportion of people told us that they felt less scared and better able to cope with cardiomyopathy.

Over the next month we will be looking at the figures in more detail and asking ourselves whether we can do more to help people manage the fear that can come with a diagnosis of cardiomyopathy and give them more skills to cope with the condition. While there is more work to be done, we are very proud of this service and the impact that it has. One recent caller summed it up when she said: “I am so glad I found you.”





New heart failure treatment on its way

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

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

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

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

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

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

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

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

Harry gets world's first mini heart pump

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

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

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

The MVAD, produced by HeartWare International, also has sophisticated controls and settings that allow it to adapt better to patients' lifestyles. It weighs 78g and its reduced size may make it suitable for children with severe heart disease.

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

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

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

ICDs don't benefit children awaiting transplant — study

Children waiting for a heart transplant are seldom at risk of a cardiac arrest so do not benefit from having an internal defibrillator, says a study from America.

Implantable cardioverter defibrillators (ICDs) are known to reduce the risk of a cardiac arrest in adults with severe heart failure.

But whether they should be used in children waiting for heart transplants had not been established, said the researchers.

So the study, led by Dr Iqbal El-Assaad, from the pediatrics department at Cleveland Children's Clinic in Ohio, and Dr Sadeer Al-Kindi, from the advanced heart failure centre at Harrington Heart and Vascular Institute, also in Cleveland, investigated the role of ICDs in preventing death in children listed for heart transplant.

They used information from the United Network for Organ Sharing database for all patients aged 18 or under listed for heart transplants between 2005 and 2014.

The list of 5,072 children with a mean age of just over six included ones with myocarditis (inflammation of the heart muscle), restrictive cardiomyopathy and dilated cardiomyopathy. A total of 426 (8.3%) of the children had an ICD at the time of listing.

At six months 65% had had their transplants. Around 15% had died (4% had died suddenly) and 20% were living. But having an ICD did not improve survival.

The researchers said the risk of sudden death remained low in these children and did not differ between those with or without an ICD at listing.

For more on cardiomyopathy and children, see **cardiomyopathy.org/cardiomyopathy-in-children/cic**

Supporters join world heart failure project

From left, Tina, Alison and Richard

Three Cardiomyopathy UK supporters have been helping a project to improve the lives of people with heart failure around the world.

Trustee Alison Fielding and support volunteers Richard Mindham and Tina Kinsella, who all have dilated cardiomyopathy, are working with the International Consortium for Health Outcomes Measurement (ICHOM).

It wants care to be measured by how well patients do after treatment, rather than the traditional way that uses process measures, such as tests patients have and which drugs they are on.

In heart failure the new measurement might look at reductions in hospital readmissions, how many patients still have fluid retention problems, psychosocial outcomes and whether patients can return to normal life and work.

Tina, who helps run our South London Cardiomyopathy Support Group, Alison and Richard have been among patients identifying the best outcomes in heart failure. ICHOM will now check the measurements agreed by the patients are suitable for all heart failure patients. Then it will prepare a standard for publication next year.

For details see **cardiomyopathy.org/project-to-improve-lives**

Printing charity help

A charity, originally set up to look after printers and their widows, wants to help more people.

The Printing Charity helps those who have worked in organisations that produce a printed output and dependant family members.

It provides means-tested grants. For people on relatively low incomes, regular financial assistance is paid twice a year and can be used for any reasonable purpose.

For details, see **cardiomyopathy.org/printing-charity-help**

Bigger dose of stem cells may help hearts

A new way of getting more stem cells into damaged heart muscle has shown early promise in treating severe heart failure, say researchers.

They treated 48 heart failure patients and, after a year, the patients on average showed a modest improvement in the heart's pumping ability, said the team led by Dr Amit Patel, director of cardiovascular regenerative medicine at the University of Utah in America.

He said it was not yet clear whether the improvements were meaningful but larger trials were now underway to see whether the approach could be a treatment option.

Researchers have been using stem cells as a potential heart failure treatment, including for those with dilated cardiomyopathy, for many years with limited success so far.

What is new in this research, also involving specialists in Germany, is how the stem cells are delivered to the body, said the team.

As in some previous trials the researchers took stem cells from patients' bone marrow but this time they put them into the heart through a large vein called the coronary sinus.

Dr Patel said: "Most other techniques have infused stem cells through the arteries."

One obstacle of that was that people with heart failure often had hardened, narrowed coronary arteries, and the infused stem cells did not always go where the researchers wanted them to, he said.

Researchers have also tried to inject stem cells directly into the heart during surgery or through a catheter.

But Dr Patel said that only a limited number of cells could be safely injected that way.

The new approach, he said, allows a bigger stem cell dose to reach the heart.

For more details about stem cell research, see the news section at **cardiomyopathy.org**

What are stem cells?

Stem cells are mother cells that have the potential to become any type of cell in the body. They have the ability to renew themselves or multiply while maintaining the capacity to develop into other types of cells.

Quarter of ICD patients' hearts improve

A quarter of people having an internal defibrillator for declining heart function experience improvements making them no longer fit the criteria for having one of the devices, says a study.

The patients had a markedly lower risk of dying and were far less likely to suffer device shocks, suggesting their hearts were less prone to developing a dangerous heart rhythm, said the study from the Johns Hopkins University School of Medicine in America.

Researchers looked at 1,200 people who were fitted with the devices, termed an implantable cardioverter defibrillator or ICD, because doctors thought they were at risk of a cardiac arrest. None had had a cardiac arrest.

A report on the study, published in the Journal of the American College of Cardiology, said researchers attributed the improvement mostly to heart drugs that help the heart's ability to pump and, in a small portion of patients, the use of devices that include a biventricular pacemaker for synchronising the contraction of the heart's chambers. The researchers said the real surprise was not that patients got better, but rather how many did.

The researchers said arrhythmia risk was not completely eliminated and patients may continue to get some protection from defibrillators even as their hearts become less susceptible to dangerous rhythms.

But because defibrillators can also cause serious complications, the risk-benefit ratio does shift in people whose heart function improves dramatically, the researchers said.

There was an urgent need to continually reassess the benefit in people and not just at the time of device implantation, said senior investigator Dr Alan Cheng.

The full story is on our website
cardiomyopathy.org/icds-boost-heart-function

New standard for treating AF

A new quality standard to improve the care of people with the heart rhythm disorder atrial fibrillation has been announced by NICE.

The National Institute for Health and Care Excellence has announced the standard for NHS treatment and management of the rhythm problem which can affect people with cardiomyopathy and make them more at risk of having a stroke.

Atrial fibrillation (AF) is an irregular and often abnormally fast heart rhythm which can cause poor blood flow round the body, and increase the risk of blood clots and stroke.

The new standard covers identification, treatment and management of atrial fibrillation in the over 18s. It is made up of six statements that describe high quality care for the condition.

The standard covers adults with both valvular and nonvalvular atrial fibrillation.

Nonvalvular AF refers to cases in which the rhythm disturbance occurs in the absence of valve problems caused by rheumatic fever or an artificial heart valve.

The full story is on our website
cardiomyopathy.org/atrial-fibrillation-new-standard

New anticoagulants: new drug update

Paul Wright | lead cardiac pharmacist,
University College London Hospitals

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

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

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

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

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

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

It is now clear from evidence that although aspirin reduces the stickiness of blood, it is much less effective at reducing the risk of stroke in people with AF. Anticoagulants have shown a significant reduction in strokes reducing a baseline risk by about 65-70%.

The novel oral anticoagulants (NOACs) are a rapidly expanding group of medicines also known as non-vitaminK oral anticoagulants. They are licensed for conditions including stroke prevention in AF, treatment and prevention of leg and lung clots, and short term use following hip and knee surgery. There are conditions where NOACs cannot be used (for instance those with mechanical heart valves).

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

Which NOAC is best?

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

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

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

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

The new anticoagulants

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

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

This means you would need to treat 172 patients with high dose dabigatran or 303 patients with apixaban instead of warfarin to prevent a clot or stroke. Choosing which is the best NOAC is further complicated by balancing side effects (most notably bleeding) with all NOACs having a lower risk of bleeding in the brain but similar overall bleeds to warfarin. NICE has suggested that all three NOACs and warfarin should be discussed as an option in preventing AF related strokes allowing patients and doctors to discuss the pros and cons and choose the best option for the patient.

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

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

With NICE indicating that all three can be considered, greater awareness of the NOACs and increasing numbers of AF patients receiving anticoagulation, this is changing. There are also ongoing trials with promising data for reversal agents specific to NOACs, and so giving doctors and patients increased confidence that major bleeds (should they occur) can be better managed acutely (these are undergoing trials and not currently available).

The patient decision aid mentioned earlier may be a good tool to use when discussing anticoagulation options and may help decide the best choice for individual patients.

See http://guidance.nice.org.uk/CG180/PatientDecisionAid/pdf/English

It's beginning to look a lot like………

We know it's quite early, but the new range of Cardiomyopathy UK Christmas cards and gifts is here.

Our new, smart, seasonal range is available from our Christmas catalogue and our online shop at **cardiomyopathy.org/christmas**

Every card purchased helps us support families affected by cardiomyopathy — so why not have a look today?

Pictured (below) is our selection of Christmas cards and (right) our money wallet.

Be part of our September Stroll

Help us to raise vital funds and awareness to support families affected by cardiomyopathy by being part of our September Stroll

Whether you are walking in memory of a loved one, supporting someone living with cardiomyopathy or simply walking to raise awareness, we are here to support you every step of the way.

There are beautiful places to explore and enjoy all around us, and the stroll can be anything from half a mile to a 10 mile hike.

Think of somewhere you like walking, pick a date and route, and start encouraging others to join you.

Some people invite just family and close friends while others promote their walk in their local community.

Would you like to organise your own September Stroll?

For details visit **cardiomyopathy/ september-stroll** and we'll give you what you need to get started

British London 10k

Eight of our runners took part in the British London 10k in July raising many hundreds of pounds.

They included (from the top right clockwise) Richard Prior, Paul Hollis, Chris Keegan, Ellen Pierce and Ben Cole.

The run takes in many historic London landmarks, including Nelson's Column, The Embankment and Big Ben.

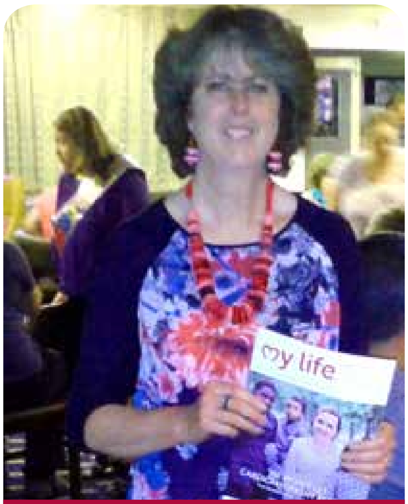
If you'd like to take part next year, see our website or call us on 01494 791224. We ask you to raise a minimum of £150.

Teamcardio highlights

Al-packing is a lot of fun

Monica Gleadall and Oscar the alpaca were among those who supported Cardiomyopathy UK at an open farm day

Jill Fearon and her family showed support for Cardiomyopathy UK at an open farm day in Wakefield. Jill, her daughter Antonia and mum Monica had an information stand and sold fruit to the event's 1,700 visitors. Even alpacas Oscar and Hennessey got in on the act and helped to raise over £600.



Michele Bamberg held a quiz night for family and friends

Michele gets quizzical

Supporter Michele Bamberg, from Bushey in Hertfordshire, organised a quiz night for family and friends in June, raising over £350 to support our work.

Michele lost her husband Laurence to cardiomyopathy three years ago.

If you're interested in having a quiz to support our work please see **cardiomyopathy.org**

Thank you teamcardio

Over the summer our #teamcardio fundraisers have been taking part in events from skydives to farm days, fashion shows to marathons — thank you all. If you would like to be part of the fun, visit **cardiomyopathy.org/support us**

Your support changes lives

Pud for good

Eileen Vickery organised a night of treats in aid of Cardiomyopathy UK, hosting a pudding night for family and friends in Norfolk and raising £300. The menu included lemon and gooseberry meringue pies, treacle tart and bread and butter pudding....sounds delicious.

Fruit pie was on the menu at Eileen Vickery's pudding night

Batting for the cricketers

Young supporters Abby Walker and Izzy Simpson held a bun sale at their local cricket club and raised £100, thanks to some very hungry cricketers

Walking for Rebecca

Present and former staff at a school in Northern Ireland walked in memory of a pupil who died from cardiomyopathy

More than 50 past and present staff from Sullivan Upper School in Holywood, County Down, took part in a nine mile walk in memory of student Rebecca Graham. The walk was led by Catherine Steenson and raised over £1,500.

Virgin London Marathon 2016

Calling all ballot runners

If you're lucky enough to get a place in the London Marathon ballot, why not run for us and be part of #teamcardio?

We'll give you all the help and support we can, and even offer a training day to help you on your way.

For more information, visit **cardiomyopathy.org/london-marathon**

Still looking for a place?

If you missed out on a ballot place, please contact us as we still have a few places available.

Pledge: £1,500

To apply visit **cardiomyopathy.org**

Skydiving day 2016

Join us for our special Cardiomyopathy UK skydiving day on Saturday, 12 March.

Take part in the ultimate adrenaline challenge and help us raise vital funds.

You'll be tandem jumping from 13,000ft attached to a professional instructor.

If you raise a minimum of £425 you jump for free.

Our skydiving day is being held at Hinton Skydiving Centre, Brackley, Northants.

Pledge £425

For details see **cardiomyopathy.org/skydive**

Paris Marathon 2016

Are you looking for an overseas marathon? Then why not try the Paris Marathon on Sunday, 3 April.

The fast and flat course is suitable for experienced runners and newcomers alike, and is a great way to experience this beautiful city.

More than 40,000 runners start on the Champs Elysees and finish at the Avenue Foch.

Pledge £500

For details see, **cardiomyopathy.org/marathons/paris-marathon**

GET INVOLVED

To take part in any of these events, just email **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!

Adidas Silverstone Half Marathon March 2016

Taking place on the world famous F1 circuit in Northamptonshire on Sunday 13 March, this event is a perfect training opportunity for the London Marathon.

Brought to you by the same team that organises the London Marathon, this race is fast and flat making it great for beginners and more experienced runners.

Pledge £300

To register see **cardiomyopathy.org/silverstone**

London to Paris Cycle April 2016

Cycling 300 miles through beautiful English villages and into stunning rural France, you'll pass historical landmarks and famous battlefields from World War I on your way to Paris. This event is from 20 to 24 April.

Deposit £99

Pledge £1,500

For more details see **cardiomyopathy.org/pariscycle**

Dates for your diary

September

Thursday 17 September, 7pm-9pm
Cheshire and Merseyside Support Group
Holiday Inn, Lower Mersey Street,
Ellesmere Port CH65 2AL
Prof John Somauroo, consultant cardiologist, Countess of Chester Hospital, on drug treatments
For more details contact Julie Rees, julierees65@aol.co.uk or 07949 241026

Saturday 19 September, 2pm
Dorset Support Group
Best Western Hotel Rembrandt, 12 - 18 Dorchester Road, Weymouth, Dorset, DT4 7JU
Chief cardiac physiologist Steve Howell from Dorset County Hospital
For more information contact Lorraine May, 07833 258190, email lorrainemay@rocketmail.com

Friday 25 September, 2pm
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Heart nurse team lead Jo Davies on developments in managing cardiomyopathy
For more details contact Eric on 01736 351439

Saturday 26 September, 9.30am-5pm
Information day and AGM, London
Holiday Inn, Regents Park, Carburton Street, London W1W 5EE
Speakers include top cardiomyopathy specialists from Barts Heart Centre in London. For more details see enquiries panel

Saturday 26 September, 5pm
ARVC Support Group
Hotel Bar, Holiday Inn, Regent's Park, Carburton Street, London W1W 5EE
For details email Kirsty Gordon-Thomas at kirstyarvc@gmail.com

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** or visit our website at **cardiomyopathy.org**

October

Saturday 3 October, 2pm
North East England Support Group
Function Room 137, Education Centre, Freeman Hospital, Newcastle NE7 7DN.
Speaker from Healthwatch Newcastle
Contact Cathy Stark on 0191 276 6399 or Susan Saunders at suze.saunders@btinternet.com

Monday 5 October, 7pm
West London Support Group
St Stephen's Church and Centre, St Stephen's Road, Ealing, London W13 8HB
Cardiomyopathy UK medical director Robert Hall
For details contact Willson Hau, 07777 6333398, email willsonhau@gmail.com

Wednesday 14 October, 2pm
Cheshire and Merseyside Support Group
Outpatients Department, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE
Clinical genetics registrar Victoria McKay, Liverpool Women's Hospital, on the genetics of cardiomyopathy
For more details contact Julie Rees, julierees65@aol.co.uk or 07949 241026

Saturday 17 October, 9.30am for 10am
Kent Support Group
Mercure Maidstone Great Danes Hotel, Hollingbourne, Maidstone ME17 1RE.
For details contact Colin McVittie, 07973 412775, email cardiomyopathykent@gmail.com

Saturday 17 October, 11.30am
South Wales Support Group
Education centre, top floor, new main entrance, Morriston Hospital, Swansea SA6 6NL
For details contact hannah.goss@wales.nhs.uk

Thursday 22 October, 7pm
South London Support Group
Crypt Meeting Room, St John's Church, Waterloo Road, London SE1 8TY
For information see enquiries panel

Friday 30 October, 2pm
Cornwall Support Group
Chacewater Garden Centre, Threemilestone Road, Chacewater TR4 8QG. Social get-together

Saturday 31 October, 9.30am-5pm
Information day, Leeds
Holiday Inn Leeds, Wakefield Road, Garforth, Leeds, LS25 1LH
The main speaker will be Professor Perry Elliott from Barts Heart Centre in London
For more details see enquiries panel

November

Sunday 15 November, noon
West Scotland Support Group
Boardroom, Glasgow Royal Infirmary, Castle Street, G4 0SF
Open forum
For more details contact Bob McConnachie, mess@talk21.com or 07710 789581

Friday, 20 November
Nurses' Conference
Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

Friday 27 November, 2pm
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Heart nurse team lead Jo Davies on developments in managing cardiomyopathy
For more details contact Eric on 01736 351439

Saturday 28 November, 9.30am-5pm
Information day, Cardiff
Holiday Inn M4 Jct 32, Merthyr Road, Tongwynlais, CF15 7LH
Main speaker consultant cardiologist Dr Sam Mohiddin, Barts Heart Centre, London
For more details see enquiries panel

Monday, 30 November
Regional Medical Conference
Post-Graduate Medical Centre, Bournemouth Hospital, Castle Lane East, Bournemouth BH7 7DW
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

December

Saturday 5 December, 5pm
North East England Support Group
Newton Park pub, Benton Rd, Newcastle NE7 7EB
Christmas meal. For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

Friday 18 December, noon
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Christmas lunch. Places must be booked.
For more details contact Eric on 01736 351439

Our Great Pancake Party is back in 2016

6 - 14
February
2016

6 - 14
February
2016

All the right ingredients to save lives...

Cardiomyopathy UK
the heart muscle charity