my life

The magazine from CardiomyopathyUK the heart muscle charity

Issue 01 | April 2015

‘WE WON’T LET CARDIOMYOPATHY BEAT US’

Two families share their experiences

IMPROVING CARE AND SAVING LIVES
FEATURE PG 4-6

CardiomyopathyUK
the heart muscle charity

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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.

We provide information and support to anyone affected by cardiomyopathy. Our services include:

- helpline nurses
  Our specialist cardiomyopathy nurses can answer medical questions and queries about living with cardiomyopathy. You can call them on 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 medical professionals
- support volunteers
  Our network of trained volunteers provide one-to-one support on the phone or by email. All volunteers are affected in some way by cardiomyopathy
- information days
  We hold seven information days around the UK each year. The days provide an opportunity for people affected by cardiomyopathy to meet others who have the condition and hear leading experts speak about cardiomyopathy, 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 the opportunity for people with cardiomyopathy to share problems and experiences with others. Meetings are always positive and encouraging, and often have experts speaking on cardiomyopathy and living well with the condition. There are details on forthcoming support group meetings on page 15.

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 landline)
Email **info@cardiomyopathy.org**

Like us on Facebook
facebook.com/cardiomyopathyuk

Follow us on Twitter
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Join our Facebook group
(closed privacy settings)
facebook.com/groups/cardiomyopathyassociation

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

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A message from Robert

Welcome to the first edition of My Life, our redesigned magazine and one of the new initiatives resulting from our recent review of our services.

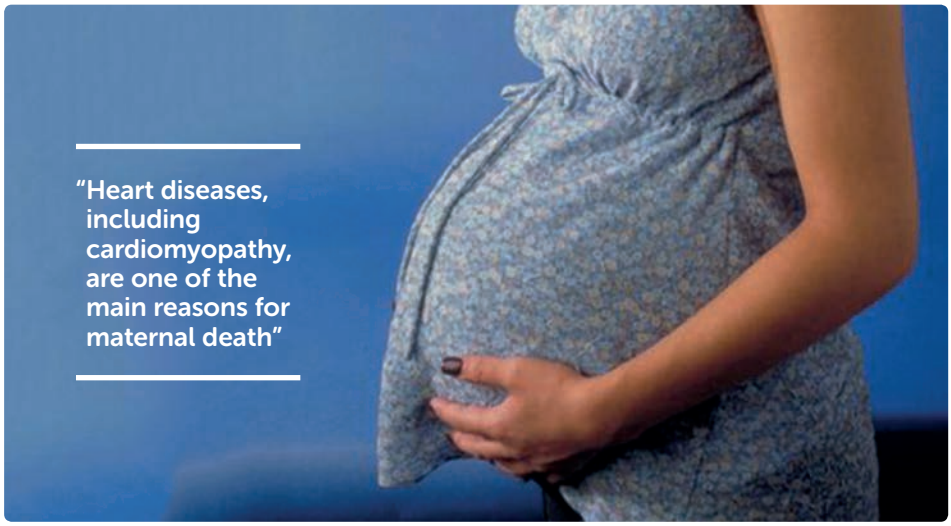
Our intention is to keep you even better informed on developments in cardiomyopathy care and the work of the charity. Therefore, you will receive My Life regularly, and each edition will focus on a particular theme. Our new website will be launched soon too, providing you with a wealth of easier-to-find information.

The importance of correct and timely care is highlighted in this issue of My Life. We have always placed great emphasis on the importance of providing educational opportunities for the doctors and nurses providing direct care to families. Our packed programme for 2015 includes five educational conferences, increasing links with clinical services and providing education and awareness resources for GPs.

To achieve this we have reviewed our structure and the charity has invested in the new role of medical director. I will be taking on this role in May and this will allow a much greater focus on the provision of our many services, from providing support to individuals, organising events and identifying new opportunities for collaborating with others.

This will therefore be my last message as chief executive. The steady growth of the charity in my tenure of almost 12 years has been tremendous, but there is still much to do. We will continue to represent people affected by cardiomyopathy and strive to improve the quality of services provided.

Robert Hall, chief executive



Cardiomyopathy in pregnancy conference

A medical conference for midwives is being held in London in June.

The conference, which is also for cardiac nurses and doctors, and all obstetric staff, will look at pregnancy in women with pre-existing cardiomyopathy and peripartum cardiomyopathy, which can develop in women in late pregnancy or in the months immediately after birth.

The all-day event, at the Cavendish Conference Centre, Duchess Mews, London W1G 9DT on Friday, 12 June, is being held by Cardiomyopathy UK with support from the maternal cardiology team at University College London (UCLH). Registration is free.

The conference will include talks on preconception advice for women with cardiomyopathy, the management of heart rhythm problems and hypertrophic cardiomyopathy in pregnancy, peripartum cardiomyopathy, dilated cardiomyopathy in pregnancy, clinical examination and imaging in normal pregnancy, and maternal death from heart disease.

Speakers include Dr Fiona Walker, head of the maternal cardiology programme at UCLH, and professor in inherited heart disease Perry Elliott, also from UCLH.

Cardiomyopathy UK chief executive Robert Hall said: "Heart diseases, including cardiomyopathy, are one of the main reasons for maternal death. The conference will highlight the importance of preconception advice, how women with pre-existing disease can have successful pregnancies, and how the disease can be identified in women who are pregnant. As in all types of cardiomyopathy, early diagnosis plays a key role in saving lives."

Get your care team on board

Promote our medical conferences to your doctor or nurse.

This year we are holding a conference on hypertrophic cardiomyopathy for cardiologists and another on cardiomyopathy and pregnancy for midwives, heart nurses and doctors.

The first is being held on Friday, 29 May, and the second on Friday, 12 June, both at the Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT.

Let your cardiologist, heart nurses and midwives at your local hospitals and health centres know. We can supply you with flyers about both events to take to them.

For hard copies of the flyers, email **robert.hall@cardiomyopathy.org**

Improving care and saving lives

We hear from two families about the help, support and medical care they received when diagnosed with cardiomyopathy, and how this inspired them to raise awareness and funds to support others

Kirsty Gordon Thomas' story

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

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

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

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

Kirsty and Lindsey are pictured with their daughter and son, Marli and Jaxon

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

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

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

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

The charity sent detailed accounts from other affected people as well as medical information. We felt an immediate sense of relief. We went to the next meeting of the ARVC Support Group and it was an absolute godsend. It meant so much to talk to people who understood what we were dealing with.

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

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

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

Lindsey is enjoying a good spell of health. He has got his driving licence back and regained some independence. We'll never be happy having cardiomyopathy in our life but we won't let it stand in the way of our happiness.

Sarah Jane's story

I've led a very active and full life. I joined the police, had six children, including twins, rode horses, swam and played in a band.

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

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

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

Cicely graduated from university but, unknown to me, did not attend her last heart appointment at Cardiff before moving. She went to work in the headquarters of a large company in Newcastle and while there had a cardiac arrest. There were three defibrillators in the building but no one there had been trained to use them. Cicely was saved by a colleague who had learned CPR with the scouts, the quick arrival of ambulance staff from the ambulance station next door and wonderful care from the Royal Newcastle Infirmary.

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

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

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

Sarah Jane, and her children (from left) Bryony, Cicely, Sebastian and Harriet

Superstar fundraiser Kirsty

Busy mum Kirsty is always finding new ways to help Cardiomyopathy UK to support families like hers who are affected by cardiomyopathy.

She was one of many supporters to hold a Great Pancake Party. Partygoers at her local children's centre tried their hand at arts and crafts activities, pancake races, singing and a raffle. Her son Jaxon and daughter Marli helped practise recipes beforehand.

Kirsty has also organised a Streetfit class, raising more than £800 to support our work. She also put together a cardiomyopathy awareness event at Marli's school.

Kirsty and the ARVC support group

Kirsty runs our special support group for people with arrhythmogenic right ventricular cardiomyopathy and their families. It meets in London about three times a year.

We have lots of other support groups around the country for people with all types of cardiomyopathy.

If you'd like more information about our support groups, email **sarah.dennis@cardiomyopathy.org**

Sarah raises awareness

Sarah and her family are keen to spread awareness of cardiomyopathy. They have given Cardiomyopathy UK booklets to GPs "so they are alerted to the importance of taking symptoms seriously", she said. Sarah was also interviewed on television and on the radio when she told her cardiomyopathy story to BBC Look East and BBC Radio Norfolk and appeared in the Eastern Daily Press newspaper to help promote our information day in Norwich.

Become a Cardiomyopathy UK champion!

Our champions:

- put posters in their local doctors surgeries, libraries and supermarkets
- give Cardiomyopathy UK booklets and leaflets to their doctors
- tell as many people as possible about the condition and how families can get help.

For more information about our champions see our website **cardiomyopathy.org**, email **info@cardiomyopathy.org** or call us on **01494 791224.**

Photo:facebook.com/yolofoto

Top marks for fundraising!

Do you want to get involved and support Cardiomyopathy UK at your school but are not sure how? We can help.

We have got lots of ideas and suggestions, and can send you everything you need to help you get started, with a full fundraising pack including balloons, sponsorship forms, posters and banners.

What about:

- **a dress down day where everyone donates £1 to wear their own clothes or dress in red for the day**
- **a mile of pennies, with the proceeds donated to Cardiomyopathy UK. This can also help with counting, and can be built into lessons**
- **learning about the heart in biology with a cake sale at lunchtime to raise funds**
- **mini Olympics, with everyone donating a small amount to take part.**

There's lots more ideas and suggestions on our newly updated website, whether you want to fundraise at school, work, or do something entirely different. We're here to help with whatever you need, so get involved and be part of **#teamcardio** today.
Contact us for more ideas:
email **fundraising@cardiomyopathy.org**
or visit our website
cardiomypathy.org/fundraising/school

Specialist clinic referral

Tina Bennett | Cardiomyopathy support nurse, Cardiomyopathy UK

Medical treatment in the NHS is divided into two different pathways, depending on how it is funded. The majority of conditions are treated at a local hospital and paid for by the local Clinical Commissioning Group. The treatment of cardiomyopathy is funded centrally by NHS England as it is classed as a specialist service. Specialist services are those that are provided in relatively few hospitals to geographically wide populations of patients. This is because it is accepted that a certain number of patients need to be seen in a treatment centre in order to achieve and maintain expertise and competence of the NHS staff. It also makes it easier to recruit and train experts as well as making best use of other resources, such as cardiac MRI scanners. There are a number of centres in the UK that specialise in the management of people with inherited cardiac conditions (ICCs), of which the cardiomyopathies are the largest group.

Many people will be under the care of a cardiologist at their local district general hospital. We are often asked by people if they should be referred to a cardiologist who specialises in the diagnosis and treatment of patients with ICCs. NHS England recommends that all people with an ICC or with a first degree relative with one of the conditions should have access to a specialist service. The role of the specialist service may be to diagnose or confirm diagnosis, risk assess and determine initial and ongoing management of the patient as well as assess the need for screening other members of the family. The specialist services will also have access to genetic counselling and testing facilities if appropriate. Once the patient has been evaluated in the specialist clinic they may then be referred back to their local cardiologist for ongoing care or may continue under the care of the specialist centre.

Specialist ICC centres are required to have:

- Consultant cardiologists with specific expertise in managing the range of ICCs
- Consultant clinical geneticists and genetic counsellors to help provide pre- and post-test genetic counselling, DNA testing and cascade testing of family members
- ICC nurse specialists trained in counselling and evaluation of adults and children with ICCs
- Cardiac physiologists with specific expertise in echocardiographic evaluation of ICCs.

Your GP can refer you to any specialist centre. In the past, the majority of patients were seen at The Heart Hospital in London. However, over the past five years there has been a move to spread the speciality throughout the UK and increasing numbers of patients are being referred to the regional centres.

There is a list of regional ICC centres on the Association for Inherited Cardiac Conditions website or contact Cardiomyopathy UK (see box). If you are unsure whether or not you require a specialist referral then we are happy to discuss this with you.

More information

If you want to learn more about any of the issues raised in this article, have a look at the links and information below:

Regional ICC centres: Association for Inherited Cardiac Conditions website, **aicc-uk.co.uk/specialists** or email **info@cardiomyopathy.org**

Article on 'The care you can expect': Cardiomyopathy UK website, **cardiomyopathy.org/care**

Cardiomyopathy UK support nurse helpline **0800 0181 024**

Q&A

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

Q: I'm 64, have arrhythmogenic right ventricular cardiomyopathy (ARVC) and an internal defibrillator. At my heart exercise class I get my heart rate up to 125 or 130bpms. I know research has suggested that vigorous exercise can cause ARVC to worsen. So when does exercise become sufficiently strenuous that it might progress my ARVC rather than help?

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

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

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

Q: My daughter has recently been diagnosed with hypertrophic cardiomyopathy but when I asked my GP to refer me for screening, he told me it wasn't necessary as I had no symptoms. Is this so?

A: No, this is incorrect. Many people who have the condition have few if any symptoms. You may be at low risk of serious complications, but this can only be determined by a careful assessment of you.

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

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

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

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

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

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

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

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

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

A: Genetic cardiomyopathies can appear at any age so it is prudent that the parents, siblings and children of affected people have an echo and ECG. The interval between checks is to some extent arbitrary, but we generally advise every three years or so.

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**

Protein key to how heart beats

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

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

For decades scientists have wondered how the heart generally stays so precisely and consistently in rhythm.

But now Dr Jonathan Lederer, professor of physiology at the university, and colleague David Warshaw, professor of molecular physiology at the University of Vermont, say they have found the particular protein that plays a central role in the heart's consistency.

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

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

Dr Lederer and his colleagues think that it may be possible to affect heart rhythm problems by modifying the activity of C protein through drugs. "I think this could be very big," says Dr Lederer. "This protein is definitely a drug target."

The research was funded by the National Institutes of Health and the results have appeared in the journal Science Advances.

"This is a really exciting finding. A lot of research can be done with this new knowledge"

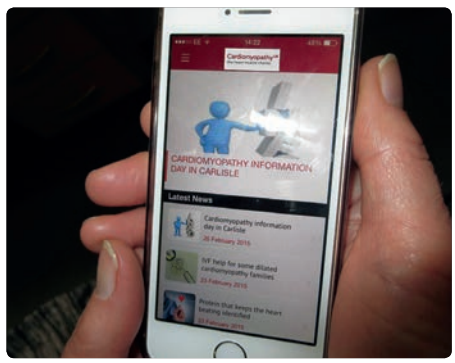
Introducing our phone app...

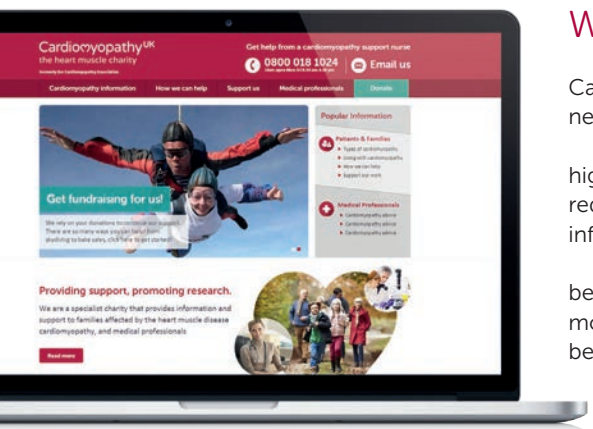
An app to help people affected by cardiomyopathy has been launched by Cardiomyopathy UK.

The app includes a medicine reminder, giving you a record of your treatments, and a journal to record how you are feeling and any symptoms you have. The information is helpful for doctors when they assess how you are doing and any changes in treatment you might need.

The software also has a link to the charity's website and a news feed to keep you up-to-date with developments in care, latest research and the work of the charity.

The app has been funded by the family of James Baker who had dilated cardiomyopathy and it is launched in his memory. James was a regular contributor to Cardiomyopathy UK's website message board, providing support to others. The app is free to download from the Apple App Store.





We've got a new website

Cardiomyopathy UK is launching a bright new website.

The website, which features our new highly-visible branding, is being rewritten, redesigned and reordered to make information easier to find and use.

With a more eye-catching design and a better navigation system, it is hoped that more people will use the site and be able to benefit from the wealth of information there.

There will be dedicated areas for each of the main types of cardiomyopathy including dilated, hypertrophic, arrhythmogenic right ventricular, restrictive, left ventricular non-compaction and takotsubo (sometimes called broken heart syndrome). There will be a new section on the pregnancy-related peripartum cardiomyopathy.

You will also be able to find lots of information about living with cardiomyopathy, looking at topics as diverse as exercise, coping with fatigue, benefits and coping with stress.

Visit us at **cardiomyopathy.org**

New protein uncovered that may affect ARVC

Scientists investigating cancer tumours say they have incidentally found a protein that may be involved in arrhythmogenic right ventricular cardiomyopathy (ARVC).

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

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

The researchers discovered that iASPP has a role in controlling desmosomes, which are responsible for heart muscle cell adhesion. Lack of iASPP appeared to weaken desmosome performance at the junctions of heart muscle cells, leaving mice more at risk of developing ARVC, said lead investigator Professor Xin Lu, director of the Ludwig Institute for Cancer Research at Oxford University.

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

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

See more at **www.ox.ac.uk/news/2015-02-17-protein-clue-sudden-cardiac-death**

DCM affected families may be eligible for IVF treatment

Some families affected by dilated cardiomyopathy are now eligible for IVF treatment to ensure their babies do not inherit the condition.

The Human Fertilisation and Embryology Authority (HFEA) has licensed pre-implantation genetic diagnosis (PGD) for families affected by mutations on the Troponin T2 gene.

PGD is a technique that enables people with a specific inherited condition in their family to avoid passing it on to their children.

It involves checking the genes of their embryos created through IVF (in vitro fertilisation) before they are implanted in the womb.

The HFEA's licensing committee has given approval after hearing from experts, the family that applied for the licence and a joint submission from Cardiomyopathy UK and the Genetic Alliance UK. The charities highlighted the impact dilated cardiomyopathy can have on affected people and their families.

The committee had previously approved PGD in arrhythmogenic right ventricular cardiomyopathy and for MYBPC3 gene mutations in hypertrophic cardiomyopathy.

For a family's experience of PGD, see **cardiomyopathy.org/PGD-help**

Study to find those at risk of complications

People with hypertrophic cardiomyopathy (HCM) are invited to take part in an international study looking at who is most at risk of getting complications.

The study, called the HCM Registry, is giving volunteers a detailed assessment and then following them up for five years.

The study's co-chief investigator Professor Stefan Neubauer said: "The study is designed to improve the ability of doctors to predict which patients are likely to develop complications, and based on that, to improve treatment."

Assessment of patients will use sophisticated tests, including MRI, genetic testing and testing biomarkers (natural substances in the blood which indicate heart muscle stress, damage and scarring).

The research, funded by the National Institutes of Health, is being organised by the University of Oxford and the University of Virginia in America. There will be 40 research centres in the US, Canada and Europe and 2,750 people with HCM will be enrolled over two years.

Currently 29 centres, including six in the UK, have been recruiting patients, and 241 volunteers have been enrolled so far. Another 11 centres will be involved soon.

The ones in the UK, other than Oxford, are the University of Glasgow, University Hospitals Birmingham, Royal Infirmary of Edinburgh, University of Leeds, Glenfield Hospital (Leicester), and four hospitals in London – the Chest Hospital, Kings College St Thomas', Royal Brompton Hospital and St George's.

For further information, visit **hcmregistry.org** or email research fellow Dr Masliza Mahmod **masliza.mahmod@cardiov.ox.ac.uk**

We want to know what you think

This is the first issue of our new magazine and we value your thoughts.

Do you like what you've read? Have we included the sort of information that you find interesting? What are the topics you would like to know more about? Have we got the right mix of news and research, features and fundraising?

We would like to know what you think and have compiled a short survey to gather your views. In it, we seek your feedback on whether My Life has too much, too little, or the right amount of:

- news
- research and medical articles
- personal stories
- fundraising news and opportunities
- information on our services.

We also want to know which is your favourite part of the magazine – and your least favourite.

The survey takes no more than a couple of minutes to complete and is available on our website at **cardiomyopathy.org/mylife/survey** Alternatively, you can ring us on **01494 791224** and ask to speak to information manager Jennie Saunders.

Not just genetics

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

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

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

Genome centres

Eleven genomics medicine centres are being set up in England to map all the genes of thousands of people with rare diseases, heart conditions and cancer.

The new centres will be taking the DNA of patients and family members as part of the first wave of the government's 100,000 Genomes Project announced in 2012.

The aim is to sequence all the genes (genome) of 100,000 people within three years to help develop new treatments.

Doctors will offer suitable patients the opportunity to take part in the scheme.

The centres, which opened across England in February, are at:

- Cambridge University Hospitals NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust, London
- Liverpool Women's NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital NHS Foundation Trust, London
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Oxford University Hospitals NHS Trust
- Royal Devon and Exeter NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- Imperial College Healthcare NHS Trust, London
- University Hospitals Birmingham NHS Foundation Trust.

NHS England says the centres are just the first wave of the project that will eventually cover the whole of England.

Pilot projects have already been run and 3,000 genomes were due to have been sequenced by the beginning of this year.

All the data will be stripped of anything that could identify the patients and then be made available to drugs companies and researchers to help them create precision drugs for future generations.

A partnership between the health service, industry and academics will deliver a new era of genetics-based medicine.

NHS England medical director Prof Bruce Keogh said the impact of genomic medicine will be on the same scale as other British successes including the smallpox vaccine and IVF.

He said: "Our NHS is better equipped for the emerging science that will determine the future practice of medicine than any other Western healthcare system.

"It puts us in a position to unlock a series of secrets about devastating diseases, that have remained hidden for centuries, for the whole of human kind."

Takotsubo cardiomyopathy

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

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

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

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

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

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

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

The full story is on our website
cardiomyopathy.org/Takotsubo-recovery

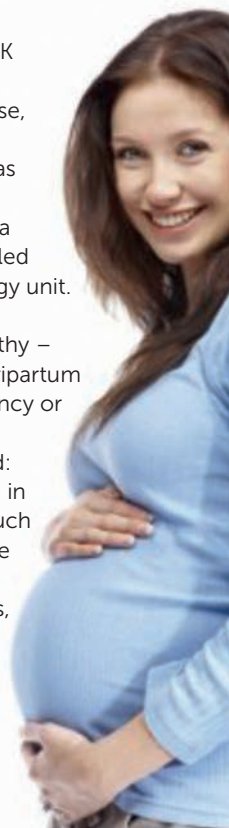
Maternity care

The incidence of childbirth-related deaths among UK women has dropped but levels remain high among women with medical conditions such as heart disease, warns the Royal College of Midwives (RCM).

The number of deaths in or around childbirth has dropped by 10 per cent from 11 in every 100,000 in 2006-2008 to 10 in every 100,000 in 2010-12, says a report called Saving Lives, Improving Mothers' Care led by Oxford University's national perinatal epidemiology unit.

One of the main reasons for maternal deaths is undiagnosed heart conditions such as cardiomyopathy – including pregnancy related cardiomyopathy (or peripartum cardiomyopathy) – that can come on late in pregnancy or in the early weeks after birth.

RCM director for midwifery Louise Silverton said: "We welcome this long-awaited report and the drop in maternal deaths due to pregnancy complications, such as eclampsia, blood loss or blood clots. However, we remain concerned about the high level of deaths among women with pre-existing medical conditions, such as cardiac and neurological conditions."



The full story is on our website
cardiomyopathy.org/Midwives-call

Heart failure treatment: new drug update

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

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

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

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

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

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

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

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

In a recent trial, called PARADIGM-HF, the new LCZ696 was compared with the ACE inhibitor enalapril. Treatment with LCZ696 led to significantly lower rates of death and hospital admission in patients with heart failure and a low left ventricular ejection fraction (a measure of the volume of blood pumped out of the heart with each beat).

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

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

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

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

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

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

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

Drug granted accelerated assessment by European review body

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

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

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

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

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

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

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

New merchandise

It's all change here at Cardiomyopathy UK. We have a new name and a new-look magazine and website – and all our charity branded merchandise is having a smart new makeover too.

Now available in our lovely new Cardiomyopathy UK red, we have t-shirts, running vests, cycling jerseys, wristbands and pinbadges, all of which can be found at our new online shop at **cardiomyopathy.org/shop**

All proceeds from our merchandise go towards vital support services for families affected by cardiomyopathy, so please do have a look and be part of **#teamcardio**

Cardiomyopathy UK's Dan Prescott and Leanne Langdon model our new-look t-shirt. Also pictured are designs for our running vests and cycling jerseys

Pictured, from left: site manager Inge Haugland, Margaret Cullen, OGN safety adviser John Cullen, project director Kevin Bougeois and OGN construction manager Graham Brooks

Thanks John

Long-term supporter John Cullen nominated us for a Safety at Work Incentive Scheme where safe working practices at his company, the OGN Group in Tyne and Wear, are rewarded with donations to good causes.

The company and its staff generously donated £1,537.50 to support our work.

Anne (right) and supporter Tracy Bush are pictured at Poppies Tea Rooms, in Burgate, Pickering, where many of the hand crafted mice were sold

Soper stars

Anne Soper and her family and friends went mad about mice for us last year in what they called their 'Year of the Mouse'.

Making and selling hand-knitted mice was just one of the many ways that Anne and her supporters raised £6,145 for us in memory of Anne's son Mike, who died in 2004. They also held fundraising events and took part in half marathons.

Starting on the right note

Sarah Lofthouse-Bishop's months of work organising Heartbeats2 has raised more than £2,000 for Marty's Penny Bank. Sarah brought together five different musical acts for the sell-out night of music and fun, plus a jam packed prize raffle.

Sarah's son Marty Bishop was diagnosed with cardiomyopathy before he was born. Marty's Penny Bank raises funds and awareness for causes that Sarah says "are very close to our hearts".

Marty's Penny Bank raises funds for us and for Great Ormond Street Hospital where Marty is an outpatient

Also getting musical were Rob Mitchell and his bandmates, who decided to welcome in the New Year in style with a fundraising rock gig on 3 January in Worcester.

Rob's band, The Lost Dogs, performed with other local acts on the night, raising a whopping £730 to support our work.

"We decided to support Cardiomyopathy UK as one of the band members has a close relative with the condition," said Rob. "The gig went fantastically well, everyone had a great evening."

Vocalist Rob is pictured, second left. Completing The Lost Dogs line-up, from left, are Paul Overfield on guitar, Adam Fincher on drums, Jason Carter on guitar and Ross Hopkins on bass

THE GREAT
PANCAKE
PARTY

BEATING HEART MUSCLE DISEASE

A big thank you to everyone who helped make our Great Pancake Party such a wonderful event.

Almost 100 pancake parties were held in support of Cardiomyopathy UK during Pancake Week in February. There were pancake tossing competitions, parties at work, parties at school with pancake shapes and painting, pancake brunches, and parties at cafés and shops.

This was our second Great Pancake Party – our first last year raised a whopping £20,000 towards our online training videos for GPs. This year's is helping to fund our vital support services, including our nurse helpline and information days. The finale of the week was at our information day in High Wycombe, attended by 70 people affected by cardiomyopathy, where we even had a mini pancake party during the lunch break.

Our information days are just one example of how your support is so vital. Every party and every pancake is helping to support families affected by cardiomyopathy. We rely wholly on the generosity of our supporters, so thank you so much to everyone that got involved, whether it was party planning, mixing the batter or just eating the pancakes. We couldn't do it without you.

For a full roundup of the party and to see exactly where all the funds raised will go, visit our website **greatpancakeparty.co.uk**

Watch this space for news of some exciting ideas for next year's Great Pancake Party

Jennifer Hall's pancake party

Jennifer Hall and her friends and colleagues at the school of dental hygiene at University of Bristol Dental Hospital have made Cardiomyopathy UK their charity of the year for 2015 in memory of their colleague Linzay Clark, who died in November.

They have set up a tribute fund in Linzay's memory, and have so far raised more than £700.

Throughout this year Linzay's colleagues are taking part in various events in her honour; they had a pancake party, are entering a team in the Bristol 10k, as well as taking part in half marathons and even a students versus teachers beer pong tournament. They have set themselves a fundraising target of £2,000 for the year – and look set to smash it.

NightRider London 2015 6-7 June

NightRider London is a charity cycling event with a difference – it's a 100k moonlit cycle past London's iconic landmarks.

You could be among 4,000 cyclists raising more than £2 million for hundreds of good causes.

You should be confident in cycling alongside London traffic as the streets are busy, even at night. The route is mainly on quieter roads but takes in some of London's busy spots such as Trafalgar Square and Leicester Square.

Participants follow a 100k circular route past more than 50 of London's most famous landmarks. You will have stops every 20k for high energy snacks and water. At the end you will be greeted with a well-earned breakfast roll.

- **Registration: £39**
- **Pledge: £175**

To sign up, visit the NightRider website at **www.nightrider.org.uk**. Enter your coupon **CARDIOMYOPATHY** to register for just £39

September Stroll

Help us raise vital funds 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.

Perhaps you would like to organise a September Stroll near you. Simply think of somewhere you like walking, pick a date and route and start encouraging others to join you.

Please get in touch if you want to organise a stroll or take part in one near you. We can provide Cardiomyopathy UK t-shirts, banners, buckets, balloons and give you advice on fundraising to help make your event a success.

Trek Sahara

Imagine the feel of the desert, dramatic sand dunes as far as the eye can see and mesmerising scenery beyond your wildest expectations. Trekking the Sahara Desert will provide you with an unbelievable experience you will never forget.

- **24-31 October 2015**
- **Eight days**
- **£199 registration fee and £2,050 min sponsorship**
- **Self-funding and mixed funding options available**

GET INVOLVED

To take part in any of these events, just email **leanne.langdon@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!

Other events

Virgin London Marathon, 26 April
Watch out for the 49 runners in in our new Cardiomyopathy UK vests taking part in the world's biggest fundraising event. We will have supporters cheering our runners on along the route and always welcome more.

Great Manchester Run, 10 May
Europe's biggest 10k running event has seen more than a quarter of a million enthusiastic runners take to the streets of Manchester since it was established in 2003. We have five plucky participants taking part for Cardiomyopathy UK this year.

Super Hero Run, 17 May Regent's Park, London
Discover the hero in you and join **#teamcardio**
Get a free super hero costume and join thousands of other heroes in this brilliant 5k/10k event.
Target £100

Bupa 10k, 25 May
British 10k, London Run, 12 July
Take part in one of these fantastic 10k runs, passing some of London's iconic landmarks.
Target £150

Three Peaks Challenge, Friday-Sunday 29-31 May
Participants attempt to climb the highest peaks in Scotland, England and Wales in 24 hours. If you fancy the challenge or know anyone who would like to take part, please get in contact.

Grand Union Challenge, 27-28 June
25k, 50k or 100k
Most supporters walk, but some may choose to jog or even run. A unique endurance event from the heart of London and into the Chilterns. See more at **grandunionchallenge.com**.

Sky Dive, 22 August
Brackley or Maidstone airfields. Take the plunge and raise £400/£450 as part of a **#teamcardio** sky diving day
We are looking for as many Cardiomyopathy UK supporters to jump as possible.

Dates for your diary

April

Thursday 23 April, 7.30pm
Hampshire Support Group
Cosham Marriott Hotel, Portsmouth
For more information contact Brian Luff at **brian.luff@hantscma.org.uk** or **023 8011 1335**, or Paul Griffin at **paul.griffin@hantscma.org.uk** or **07786 735163**

Friday 24 April, 2pm
Cornwall Support Group
The Inn For All Seasons, Treleigh, Redruth TR16 4AP
Head of clinical pharmacy services John Glinn will speak on what's new in drug therapy

Saturday 25 April, 9.30am-5pm
Information day, Carlisle
Hallmark Hotel, Court Square, Carlisle, Cumbria CA1 1QY
For more details, see enquiries information

Thursday 30 April, 7pm
Cheshire and Merseyside Support Group
Outpatients Department, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE

May

Saturday 9 May, 2pm-4pm
North East Support Group
Function Room 137, Education Centre, Freeman Hospital, Newcastle NE7 7DN
Moira Hill will be speaking on healthy eating

Saturday 16 May, 2pm-4pm
Launch of Dorset Support Group
Dorford Centre, Dorchester Baptist Church, Bridport Road, Dorchester, Dorset DT1 1RR
Main speaker will be Cardiomyopathy UK's Robert Hall. Dorchester hospital heart failure nurse Tracy Dare will also give a short presentation. For more information contact Gilbert Wheeler at **wheelers11@live.com** or **07775 330416**

Friday 29 May
New ESC guidelines on hypertrophic cardiomyopathy
Cardiomyopathy UK conference for medical professionals
Cavendish Conference Centre, Duchess Mews, London W1G 9DT
For more information contact Cardiomyopathy UK's Robert Hall at **robert.hall@cardiomyopathy.org** or **01494 791224**

June

Sunday 7 June, 12 noon
West Scotland Support Group
Glasgow Royal Infirmary
Main speaker will be cardiomyopathy nurse Joan Anusas from the Western Infirmary, Glasgow

Friday 12 June
Cardiomyopathy and pregnancy
One-day seminar for midwives and medical staff, organised by Cardiomyopathy UK
Cavendish Conference Centre, Duchess Mews, London W1G 9DT
For more information contact Cardiomyopathy UK's Robert Hall at **robert.hall@cardiomyopathy.org** or **01494 791224**

Saturday 13 June, 9.30am-5pm
Information day, Newquay
Best Western Hotel, Narrowcliff, Newquay, Cornwall TR7 2PQ
The speakers include Dr Gerry Carr-White, consultant cardiologist and clinical lead for cardiology, heart failure and inherited cardiac diseases at Guy's and St Thomas' NHS Foundation Trust, London. For more details, see enquiries information

September

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 The Heart Hospital in London. For more details, see enquiries information

October

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 the inherited heart disease team at The Heart Hospital in London. For more details, see enquiries info below

November

Saturday 21 November
Information day, Cardiff
Venue to be confirmed.
For more details, see enquiries information

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**

In the July issue...

Information
and how it helps you

We look at the importance of having the correct information and how it can:

- improve people's understanding of cardiomyopathy
- reduce anxiety
- enhance the care that you receive.

Coming soon...

September
Our 'Stop Sudden Death' campaign

November
Children's services

January
Pregnancy and cardiomyopathy

Tell us your story

My Life is your magazine and we welcome contributions connected with our forthcoming magazine themes or on any other cardiomyopathy-related topic. If you would like to share your story with other people who are affected by cardiomyopathy, please contact information managers Sarah Dennis or Jennie Saunders at **sarah.dennis@cardiomyopathy.org** or **jennie.saunders@cardiomyopathy.org**, or telephone **01494 791224**.

Set up a Cardiomyopathy UK Family & Friends Fund

Get together and grow your support for families affected by cardiomyopathy. We put all the funds raised by your family and friends together in the pot so you can watch the total soar.

Choose to name your fund after your family, or after an inspirational person living with cardiomyopathy.

Whatever you decide, tell us who is in your fundraising team and we'll record all your activities so you can watch your fund climb to new heights!

A fund of £500

means 1,000 people can get the information they need for their family through our website

A fund of £2,000

can provide 500 children and their parents with a special pack to help them understand cardiomyopathy

A fund of £5,000

can pay for 500 families to have a 15 minute call with our specialist cardiomyopathy nurse

Email fund@cardiomyopathy.org to set up your fund, or call us on 01494 791224

www.cardiomyopathy.org/familyandfriends