# my life

The magazine from CardiomyopathyUK the heart muscle charity

Issue 06 | Summer 2016



## 'Helping with research made me more positive and gave me back some control'

David (right) talks about being involved in stem cell research for cardiomyopathy – Page 5

CardiomyopathyUK
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 and online training videos 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 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 Pages 3 and 19.

- 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 19

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.


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


# Contents



# Exciting research

Chair of trustees
Alison Fielding

It is an exciting time in research into cardiomyopathy and heart failure. The news of a genetic test that can search 174 genes for inherited heart diseases (see Page 11) brings hope of easier and more widespread testing for cardiomyopathy. Early research in mice has shown the possibility of genetically affected children being offered drugs to stop hypertrophic cardiomyopathy developing.

Cardiomyopathy UK is committed to helping research into cardiomyopathy and its effects. As well as promoting clinical trials, we are now looking at how we influence research, including the psychological effects of heart disease.

There is an opportunity for everyone to get involved at some level. It might be answering a survey, getting involved as a patient representative on research projects, sharing information about trials or even taking part in a trial yourself.

If you have views about research or feel able to represent patients' views, please contact me at chair@cardiomyopathy.org

# Making a difference

Chief executive
Joel Rose

Welcome to the latest issue of My Life.

Over the last year, with your help, we have provided support and information to more people than ever before.

We know that our support services make a real difference to the people who come to us for help.

Our challenge now though is to do more to make a real difference to everyone with cardiomyopathy. We can do this by supporting and shaping research, and in this issue of My life you can read how you can play your part in this.

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

# Find out more about cardiomyopathy and the treatments available

**Each year we hold information days around the country so affected families can find out more about the condition and meet others with it**

Our programme of cardiomyopathy information days for affected families continues this year with events in Belfast, Glasgow, Newcastle and London.

At our special days you can find out from top cardiomyopathy experts more about the condition, latest treatments and research. You can also meet other families affected by cardiomyopathy.

Speakers include Professor Perry Elliott and Dr Sam Mohiddin from the inherited heart disease team at Barts Heart Centre in London and Dr Gerry Carr-White from St Thomas' Hospital, also in London.

We are also planning a new national conference for affected families in London in November.

It will have presentations from doctors on cardiomyopathy and a variety of interactive lifestyle sessions to help people live well with the condition.

The events are ideal introductions to cardiomyopathy for newly diagnosed people but also help others, who have been living with the condition for a while, to get further knowledge.

The days also provide a chance for people to find out more about our work, and how to get involved in supporting others with cardiomyopathy and fundraising.

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

Medical staff are also welcome. For more details of these events see the panel on the right.

## Our medical conferences

We also hold conferences for the medical profession to raise awareness of cardiomyopathy and best practice in diagnosing and treating it.

Our national medical conference on Friday, 27 May in London will be on the diagnosis and management of rare cardiomyopathies.

Other medical events being planned, include some regional events for cardiologists, nurses and GPs.

Further details about these events will be available shortly.

If you can help to promote these events by taking posters to your local cardiomyopathy care team, please let us know.

We can provide posters and copies of the programme.

Email rona.eade@cardiomyopathy.org

## Dates and places for our information days for families

**Glasgow** – Saturday, 9 April, Hilton Glasgow Grosvenor, 1-9 Grosvenor Terrace, Glasgow G12 0TA. Main speaker Dr Gerry Carr-White, St Thomas' Hospital, London

Belfast – Saturday, 14 May, Maldron Hotel, Belfast International Airport, BT29 4ZY. Main speaker Professor Perry Elliott, Barts Heart Centre, London

Manchester – Saturday, 11 June. Holiday Inn Manchester, Central Park, 888 Oldham Road, Newton Heath, Manchester M40 2BS Main speaker Dr Gerry Carr-White, St Thomas' Hospital, London

Newcastle – Saturday, 25 June, Crowne Plaza Hotel, Hawthorn Square, Forth St, Newcastle NE1 3SA. Main speaker Dr Sam Mohiddin, Barts Heart Centre

London (national conference for affected families) – Saturday, 19 November. Venue to be confirmed

For more details, see **cardiomyopathy.org/information-days/home**, email **rona.eade@cardiomyopathy.org** or call us on 01494 791224

## Dates and places for our medical conferences

London – Friday, 27 May, Diagnosis and Management of Rare Cardiomyopathies, Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT. For those working in cardiology and other related specialities.

For more details about these events, call us on 01494 791224, email **rona.eade@cardiomyopathy.org** or see cardiomyopathy.org/medical-professionals/mp

# Why get involved in research?

**Rachel Walker** | cardiomyopathy support nurse, Cardiomyopathy UK

Rachel talks about why research is important in improving cardiomyopathy care, how to find out about it, and the pros and cons of taking part

'Without research going on, we're never going to find anything out. So taking part in research makes sense to me,' says Pauline Kings who has cardiomyopathy. See Page 6.

Research is an important part of developing practice and improving patient care.

In order to provide best practice, most inherited cardiac conditions (ICC) services will be involved in clinical trials for the various conditions they treat. It's the way we improve treatment and management of cardiomyopathy and other conditions.

Up to now, there has been very little research undertaken in the management of cardiomyopathies. Many of you will be aware of studies such as the stem cell trials and some of the heart failure trials which have included dilated cardiomyopathy as sub-studies to the main trial.

However, few trials have been directed purely at cardiomyopathy, and those that have were done on a small scale.

Clinical trials are subject to a lot of scrutiny. Before anything reaches the stage where it can be tested on patients the researchers are hoping to help, many years will have gone into studying the safety of any proposed treatment, and anything new is tested on healthy volunteers before it comes into contact with any patients. They are very closely monitored and every side effect is reported and documented.

Not everyone can take part in clinical trials. They have very strict eligibility criteria, which you need to meet. Things that may be included in the criteria are:

- age – there are usually upper and lower age limits
- the stage of the medical condition
- other medication being taken. If you are already on a certain medicine this may mean you are not eligible
- other health problems – if you have other underlying health problems or another condition (such as atrial fibrillation) associated with your cardiomyopathy you may not be able to take part.

Sometimes people hear about research and ask to be involved. In other cases your care team may ask you if you wish to take part. It is entirely up to you whether or not you get involved. If you don't wish to take part, this will not affect your treatment in any way. Similarly, if you do take part but for some reason do not wish to continue, you are able to withdraw from the trial and it will not affect your care.

If there are any concerns about the safety of the treatment during the trial, you will be informed and the regulators will stop the trial.

## The pros of taking part in a clinical trial

You may be one of the first people to benefit from a new treatment. You will be monitored much more closely for the duration of the trial to assess the effectiveness of the treatment. Each study will require certain investigations at certain times to measure any changes.

Once the trial is completed, you have the reassurance that the treatment recommended to you is the best available for you.

The information gained about your condition while you are on the trial will benefit you and others with your condition in the future.

## The cons of taking part in a clinical trial

Closer monitoring may mean you have to travel to the hospital more frequently than you would ordinarily.

The purpose of the research is to see if a course of treatment is effective. At the time of taking part, you won't know whether or not the treatment you are taking is effective. It may be that the new treatment is not as effective as the treatments currently offered.

If the trial involves the use of a placebo, you may not receive any treatment at all.

As with any treatment, you may experience side effects.

## What you need to know before volunteering to take part

Before agreeing to take part in a trial, you need to make sure you understand what it involves and why you are being asked to take part.

The NHS choices website (**nhs.uk/conditions/clinical-trials/pages/introduction.aspx)** suggests that you should consider various questions including:

- what is the aim of the trial and how will it help people?
- who is funding the trial?
- how long is the trial expected to last, and how long will you have to take part?
- how long will it be before the results of the trial are known?
- is there an explicit commitment to report the results of the trial?
- what will happen if you stop the trial treatment or leave the trial before it ends?

You also need to know about the practicalities of taking part, such as how much of your time will be needed, will your travel costs be covered, what are the possibilities of side effects and who you contact if you have a problem?

If these questions are not covered in the information given to you, you should ask the research team.

## How can I get involved?

You can look for research trials yourself. Ask your doctor, look at the UK Clinical Trials Gateway website at **ukctg.nihr.ac.uk** or see the information on the Cardiomyopathy UK website **cardiomyopathy.org/research/get-involved-in-research**

# We've all been involved in research

David Ellis (left) took part in stem cell research for dilated cardiomyopathy

Pauline Kings (Page 6) is involved in hypertrophic cardiomyopathy research

The Rees family (Page 7) is taking part in a national genetics project

Julie Hepburn (Page 8) gets involved in the way research is carried out

## David Ellis' story

David, who has dilated cardiomyopathy, took part in research to see if injecting stem cells into hearts would improve their pumping power and lessen symptoms.

In 2007 I was manager of a large country estate in Scotland. Although I was 64, I was fit and active and not planning to retire.

My wife Clare and I were hill walkers and used to take regular five mile walks around the estate. After a short Christmas and New Year break we got back to our regular exercise, but I couldn't keep up with Clare and became breathless very quickly. This worried her. So she organised a visit for me to our local surgery.

My GP organised blood tests which showed I had an underactive thyroid. He prescribed medication and reassured me that this would cure the problem. It would take a week or two to readjust.

We went to Cyprus in May 2008 but while away I had some serious heart failure symptoms. I was so breathless in bed I had to sleep sitting on a dining chair with my head on the table.

Once home my GP arranged further tests including ECG and echocardiogram. The diagnosis was dilated cardiomyopathy (DCM). I was put on ACE inhibitors, beta-blockers, spironolactone and warfarin. My symptoms improved a little so I was able to sleep in bed but I remained incapable of walking and gardening. I reduced work to half days.

By November that year I was having serious heart failure symptoms not only after exercise, but sometimes while reading or watching TV. I was feeling fairly grim and low at this point.

One night I was so bad Clare took me to A&E and a few days on a cardiac ward followed. An ECG Holter monitor was fitted and it showed my heart rate was dropping to 20 beats per minute at irregular intervals. Within a week or two I was given a pacemaker which eliminated the sudden drops in heart rate making me feel better and a lot safer. While in hospital I met a cardiac nurse who introduced me to Cardiomyopathy UK.

The staff at the charity backed up by this magazine My Life and the excellent information days helped me and Clare understand a lot more about DCM and the implications for the future. It was in the magazine I read the article about stem cell trials taking place at the London Chest Hospital and that Professor Anthony Mathur and his team were looking for volunteers with DCM to join the trial.

The procedure involved taking stem cells from patients' bone marrow and injecting them back into their hearts in the hope that heart function would improve. I read up all I could about the treatment and discussed it with our son Charles who is a microbiologist doing medical research. He was very supportive.

I was still feeling far from normal and a bit fatalistic but the thought of helping to find new ways to improve the condition gave me back some feeling of control and a more positive attitude.

I applied, found I fitted the criteria and was accepted. I didn't know whether I would be getting stem cells or a placebo, but even if it were the latter the results could still lead to revolutionary treatments which might benefit me and other DCM patients.

I went into hospital in January 2011 to take part in the trial with some apprehension. However, the research team were extremely upbeat and with another volunteer in the trial, I had great banter and reassurance. I was there for a week and Clare stayed with me.

I was given daily injections to stimulate stem cell production in my bone marrow. At the end of the week some of my bone marrow was harvested from the hip bone. The stem cells were isolated and then they or a placebo were injected back (via my groin) into the arteries of my heart. After a day of checks I went home. Six months later I had a full review. I was later told I had received stem cells.

I started to improve but don't know if this was due to stem cells, the medication I continued to take or a combination of both. I found I could go out walking again and mow the lawn. I had recently given up my job and moved to Lincolnshire. There I was offered a cardiac rehabilitation course by the NHS. I was told to exercise moderately but was reassured that I wouldn't be doing myself any harm (walk and talk — good; walk and unable to talk — bad). Through the NHS I was able to join a gym with NHS qualified staff and there I was able to extend my exercising.

I continued to be more active and took up golf to celebrate my 70th birthday. At my last check-up my ejection fraction was 54 per cent (close to normal) and the dimensions of my heart were almost normal. I don't know if the stem cell treatment is responsible for any of this and I'm not sure if the research results for DCM patients will be published. But I told the research team that I would be happy to be involved in any follow up research they might want to do.

• David is pictured on the front cover with his wife Clare and grandson Christopher

# I'm in an international hypertrophic cardiomyopathy study

## Pauline Kings' story

**Pauline, who has hypertrophic cardiomyopathy, is taking part in research to identify which patients are at risk of complications and what treatments might help. She's also leaving her body to science.**

I was diagnosed with hypertrophic cardiomyopathy (HCM) eight years ago after my baby granddaughter Eva was found to have a heart murmur.

Tests showed Eva had the inherited condition and, when the rest of the family were tested, me, two of my daughters and members of the extended family were all found to have it.

I'd never thought I'd had any symptoms, but I've always been somewhat breathless when doing energetic activities – including sports as a schoolgirl. I often got picked last for teams.

At my first appointment at Stoke Mandeville Hospital a young doctor suggested I take part in some genetic research going on at Oxford University Hospitals.

I'm a dog breeder and in the world of pedigree dogs if you find a problem with a dog, you give the body to research (if the researchers agree it would be useful), fund the studies, get the information and help other dogs. So I thought it should be the same with people. All dogs can suffer with the same diseases as people. So often veterinary research runs along the same lines and what benefits dogs benefits people and vice versa.

I, my daughter and granddaughter were affected. So it was up to me to put my money where my mouth was, so to speak. Around the same time a friend, a retired nurse who had just lost her husband, gave out information about getting involved in medical research and told me her husband had donated his body to research.

So I went to Oxford and initially agreed to take part in a genetic research project. To be eligible I had to know the genetic mutation causing my disease and so I had genetic testing. More recently I am taking part in the HCM Registry, an international study looking at improving treatments for people with hypertrophic cardiomyopathy.

As part of this research project, I (and it is hoped another 2,749 others with HCM) will get a detailed assessment of their condition and be followed up for five years. The idea is that the data will help doctors predict which of us is likely to develop complications and help them give us more targeted treatment.

The tests I've had as part of the research include MRI, more genetic testing and testing biomarkers (natural substances in the blood which indicate heart muscle stress, damage and scarring).

I have spent a lot of time lying in an MRI scanner, and although I'm quite scared of needles, I have put up with various intravenous procedures. I just keep my eyes tightly shut.

Although I've never been interested in my family tree, I have drawn it up and put it on a genes website. I was very surprised to find what a big family I have and how many have had problems with their hearts at quite a young age. I discovered my paternal great grandfather dropped dead while out with a beagle pack running over a ploughed field at the age of 45.

Without research going on, we're never going to find anything out. So taking part in research makes sense to me. If by magic, genius or divine intervention something I have done through research benefits people all over the world that would be hugely rewarding – and a huge advantage to me and mine.

Since first going to the John Radcliffe Hospital in Oxford, I've had all my treatment there. I take an aspirin every day and am on the calcium channel blocker diltiazem hydrochloride which relaxes the heart muscle and helps reduce heart rhythm problems.

The hospital staff are very helpful and explain everything to me, including showing me videos of how my heart is working. I've told them that I'm keen to help with any research they are doing and that they can have any of my body parts they want when I die. You have to say in your Will that you are giving your body to research and this is what I have done.

But I'm not planning that yet. I'm 62 and still very active. I'm very busy with my dogs, including walking them uphill most days. I run a dog training club and grow fruit and veg (but don't like the digging bit). I read quite a bit and study, the latest course being one to look at dog cognition and compare it to humans. I write articles for the press and contact my MP a lot to tell him what I think of government policies especially ones concerning the NHS. Keeps him on his toes!

To find out more about the HCM Registry, see **hcmregistry.org**

### It's OK to ask

A campaign called OK to Ask is run by the National Institute of Health Research in England to encourage patients, carers and the public to ask their medical teams about available research, and to make everyone research aware.


# We're involved in genetic research

## The Rees family's story

Julie Rees, her husband Mark and daughter Jenny are taking part in the 100,000 Genomes Project which is mapping all the genes of thousands of people with inherited diseases and cancer. Julie says:

Our daughter Jenny was born with dilated cardiomyopathy and has responded well to medications, a bi-ventricular pacemaker and an internal defibrillator (ICD). She is now 23 years old and together we run the Cheshire and Merseyside Cardiomyopathy Support Group.

Jenny is seen at Liverpool Heart and Chest Hospital and staff there asked if we would like to take part in a research project that was mapping all the genes of thousands of families with inherited conditions and cancers.

The project, called the 100,000 Genomes Project, was launched in 2012 to find out more about genetic diseases and cancer to help promote the discovery of better treatments. We were asked to take part to find out if Jenny's heart condition was the result of a faulty gene passed on to her or a mutant gene that just appeared in Jenny.

We were already very interested in cardiomyopathy genetics (Dr Ian Ellis from Alder Hey Children's Hospital gave a talk on it at one of our support group meetings). Jenny was especially keen on the research project as any results would help her to make decisions about having children.

We were sent quite lengthy documents to read. These explained how the information would be kept securely and would never be removed by interested parties. But it could be included in research by other organisations to help find out more about cardiomyopathy and better treatments.

We were also offered the opportunity to have about ten other conditions looked for, including some cancers. We were concerned any results showing we were genetically pre-disposed to something could affect our life insurance. We were assured that, as it was a research project, we did not have to disclose that we had been tested. We were also told that, if we did have a genetic result for any of the conditions, we would get counselling, follow up care and early treatment.

We all signed up and have had our initial blood samples taken. The results are expected to take many months It takes a fraction of that time to carry out the DNA sequencing but a long time for the results to be analysed.

We will be contacted about four times a year for updates on our medical history and we have given the team access to our medical records from birth and forever. We all felt this was a perfect legacy – we'd leave our mark on the world and be part of something to help improve treatment of cardiomyopathy or perhaps even find a cure!

• Find out about other research Jenny is doing in the right hand column

# Other research opportunities

As well as taking part in the 100,000 Geonomes Project, psychology student Jenny Rees is carrying out her own research into psychological well-being and cardiomyopathy. More than 100 people aged 18 or over with cardiomyopathy are helping her with her online research.

Jenny, who has dilated cardiomyopathy and is on a psychology degree course at Chester University, has long been interested in the psychological effects of cardiomyopathy.

Jenny is a support volunteer for Cardiomyopathy UK and helps run the Cheshire and Merseyside Cardiomyopathy Support Group.

If you are taking part in the 100,000 Genomes Project you are being sought to join a participants' panel.

"The role of the panel is to ensure that the interests of participants are always at the centre of the project," said a spokesman for Genomics England. "The panel will make sure that the experiences of participants are improved, respond to feedback and oversee who should have access to the data." The panel is due to meet twice a year in London. Those who cannot attend in person will be able to take part on the telephone or via Skype. For more details see **genomicsengland.co.uk/participant-panel/**

## More information


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

**We have booklets about each of the main types of cardiomyopathy — dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy. Information about other types of cardiomyopathy is on our website.**

**We also have a booklet about living with cardiomyopathy. For copies of our booklets, email anne.foster@cardiomyopathy.org or call us on 01494 791224.**

## People with affected children 'need whole family care'

Doctors treating children with cardiomyopathy need to consider the effect on the whole family, says a new study.

Researchers, who questioned 300 parents with affected children, said the emotional effects on the parents and how the family functioned became increasingly problematic in families where children were severely affected.

Since families who felt worse were significantly more likely to have children who needed a heart transplant or who later died, this may mean that how the family reacts to the illness could be important.

The team, from the Children's Hospital of Michigan and Wayne State University of Medicine in America, said the findings raised important questions for families and children's doctors alike, and could play a role in expanding care for families.

The hospital's chief paediatrician Dr Steven Lipshultz said the study also showed the more problems the family had coping, the less likely the child was to do well. There was a clear association between poor health in a child and "impaired health-related quality of life and functional status". So measuring the effect long term illness had on the family might be helpful in improving how well the children did.

The results, reported in the Journal of Paediatrics, argued that finding ways to include the whole family in the treatment might be a more effective approach. This could include comprehensive medical management and a 'medical home' for the entire family that could include a cardiologist, a nurse practitioner, a social worker, a nutritionist and perhaps a psychologist.

Dr Lipshultz said that all too frequently children visited their cardiologists for only short periods of time. Their medications might be adjusted a little and then they were sent on their way.

The study seemed to suggest that this fragmented approach to caring for these young patients simply wasn't good enough, he added.

# I'm involved in how research is run

## Julie Hepburn's story

Julie, who has hypertrophic cardiomyopathy and works as a lay person in clinical research, talks about her work and how having a say in the way research is carried out gives her a great sense of satisfaction.

When I retired in 2013 I wanted to use my work and life experience in some community work but wasn't sure what was available. I had always been interested in medicine and health, having studied physiology and worked in the NHS for three years. For the last 25 years I had been in university careers work finishing as deputy director, which didn't, at first, seem particularly relevant to voluntary health work.

My first year of retirement went off the rails when I was diagnosed with bowel cancer and spent nine months getting over the surgery and treatment. Together with my diagnosis of hypertrophic cardiomyopathy ten years before, I had some relevant experience to act as a lay person in clinical research.

My first contact with health research was through signing up to do lay research protocol reviews through the National Institute for Health Research (NIHR). I completed one on statins and one on bowel cancer in my first six months. Through NIHR I found Involving People which offers opportunities in Wales to join research groups as lay members on trial management groups and steering committees.

Since then I have signed up for a wide range of opportunities and am currently on three bowel cancer research groups plus one looking at accident and emergency care. Although most of my work has come in the field of bowel cancer, I have also been involved in giving feedback on website design, helping to plan the HealthWise Wales campaign and becoming a lay member on the Health and Care Research Wales Public Delivery Board.

I have given feedback on documentation for research projects, for example patient information sheets and Plain English summaries of research projects, and attended multidisciplinary research team meetings to give a patient view on how the research is conducted. I have found that my previous work experience, although not health related, has given me useful skills which help me.

My input has been valued by the research groups, and I get a great sense of satisfaction from having a say in the way research is carried out. All the group members have been very welcoming and encouraging and I would advise anyone interested in becoming involved to look at the Health and Care Research Wales website for further details if they live in Wales. In England a similar organisation exists called INVOLVE, though I think that opportunities are not spread evenly across the country. The National Institute for Health and Care Excellence (NICE) also offers opportunities for lay people to sit on their committees, though these all seem to meet in London or Manchester. The NIHR offers similar opportunities to review research protocols and sit on committees. For all this work travel expenses and an honorarium for attending meetings or completing a review are often paid.

# Q&A

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

Q: Does everyone who has dilated cardiomyopathy have heart failure?

A: The term heart failure often causes considerable distress when heard for the first time. In essence it simply describes a situation in which an individual has symptoms such as breathlessness or fatigue caused by abnormal function of the heart pump. In this sense, people with symptomatic dilated cardiomyopathy have heart failure. However, most people respond to medical therapy and can be stabilised to the point where they can have normal or near normal lives.

Q: Will knowing the gene mutation that has caused my cardiomyopathy affect my treatment in any way?

A: Current knowledge suggests that 20-40% of individuals with dilated cardiomyopathy have at least a predisposition to disease caused by one or more genetic abnormalities. At present knowledge of the gene does not alter therapy but may do so in the future as we gain more information. There are one or two exceptions to this – most notably mutations in a gene called Lamin A/C. People with abnormalities in this gene may require an implantable cardioverter defibrillator (ICD) in addition to their medical therapy.

Q: I have recently been diagnosed with hypertrophic cardiomyopathy and have become increasingly aware of my heartbeat. Is this common? Should I be worried about this?

A: This is a very common symptom and is nearly always benign in the sense that the heart rhythm is normal and that it has no prognostic significance. The symptom that most people describe is an awareness of a normal or forceful heart beat, often at night in bed, which is regular but neither slow nor fast. The term cardiac awareness if often used to describe this symptom but the cause is unknown. If the heart beat is very rapid, irregular or the symptom is associated with symptoms such as chest pain, breathlessness or faintness then you should report this to your specialist.

Q: My father, his late brother and my cousin have all been diagnosed with cardiomyopathy, but of different types. I am wondering how I go about being genetically tested to see whether I could have inherited the disease and passed it on to my young son. I have no symptoms of cardiomyopathy and a recent echo showed only mild to moderate tricuspid regurgitation.

A: The fact that other members of your family have a cardiomyopathy is strong circumstantial evidence for a genetic disorder in your relatives. When circumstances allow, it is usually best to first genetically test a family member who clearly has a cardiomyopathy. This is because we all carry variations in our genetic code that are difficult to interpret when there is no clear evidence of disease. If – as seems likely in your case – this is impossible, I would suggest regular screening with an ECG and echocardiogram as an alternative strategy.

Q: I am 50 years old and was recently diagnosed with apical hypertrophic cardiomyopathy (HCM). I still play 7-a-side-football which is a challenge. I feel I need help in keeping reasonably fit to carry on playing football. What would you advise?

A: Advice on exercise in HCM should be tailored to the severity of the condition. In general, strenuous competitive sports are discouraged, particularly when someone has features associated with a higher risk of dangerous heart rhythms or obstruction to the outflow of blood from the left ventricle. However, it is important to maintain reasonable fitness for your general health. If the football is becoming a struggle, it might be better to discuss with your cardiologist alternative ways of keeping fit.

Q: I have left bundle branch block and doctors think I have left ventricular non-compaction. Are these two linked?

A: Left bundle branch block can also be a non-specific finding in individuals with enlargement of the heart chambers (dilated cardiomyopathy) but left ventricular non-compaction can occur in association with a number of genetic diseases, some of which can cause abnormalities in the electrical system of the heart. It is certainly worth discussing the relevance of your bundle branch block with respect to genetic testing for the condition.

Q: Is there any sort of increased risk associated with a general anaesthetic and dilated cardiomyopathy. I am 68 years old and need a hysterectomy but the anaesthetist has not agreed yet. What are the risks and what would you suggest?

A: In general, the risks depend on the severity of the cardiomyopathy and your symptoms. If the condition is stable and symptoms are well controlled, the risks from anaesthesia are very small.

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**

# People with acute heart failure need specialist care, says NICE

NICE has set new standards for hospitals to ensure people with acute heart failure are seen by a specialist heart failure team within 24 hours of being admitted.

The new quality standard, for adults in England and Wales, is designed to save lives, reduce the length of hospital stays and readmission rates, and improve quality of life.

Acute heart failure is the sudden worsening of the signs and symptoms of heart failure, including difficulty breathing, leg or feet swelling, and fatigue. It is different to chronic heart failure which develops slowly over time and worsens gradually.

But acute heart failure can happen after a heart attack or because the body can no longer cope with chronic heart failure.

The main features of the standard are:

• People attending hospital with new suspected acute heart failure should have their BNP (natriuretic peptide) measured. BNP is a substance secreted by the heart when heart failure develops and worsens
• Those with raised BNP levels should have an echo within 48 hours of admission
• People admitted to hospital with acute heart failure should be seen by a dedicated specialist heart failure team within 24 hours of admission
• Those with acute heart failure due to reduced ejection fraction (a measure of how well the heart is pumping) are started on, or continue with, beta-blocker treatment during their hospital admission. They should also be offered an ACE inhibitor and an aldosterone antagonist
• Those with acute heart failure have a follow-up assessment with a specialist heart failure team within two weeks of hospital discharge.

The new quality standard aims to standardise the best care for acute heart failure across hospitals.

For more details, see **nice.org.uk/guidance/QS103/chapter/Introduction**

# Atrial fibrillation

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

**Our My Life series of articles on the heart rhythm problems that can occur in cardiomyopathy this time focusses on atrial fibrillation**


Atrial fibrillation, or AF, is a very common rhythm disturbance with nearly 1.4 million people in England alone estimated to be affected. So what is this arrhythmia and how does it affect the heart?

The heart is controlled by a system of electrical impulses which are conducted to the heart muscle causing them to contract and relax at the right time to ensure an efficient outflow of blood from the heart.

In atrial fibrillation this process is interrupted by abnormal impulses being produced in the walls of the heart's upper chambers, the atria. This causes the atria to contract randomly. Not all of these rhythms will be conducted to the lower chambers, the ventricles, though some will get through and this produces the characteristic irregular, often fast, heart rhythm.

The cause of atrial fibrillation is not entirely clear. It can affect people of any age and is certainly more common as people get older. Women appear to have a slightly higher chance of getting it. It can be associated with conditions which result in damage to the heart muscle, such as a heart attack. In cardiomyopathy it is thought it can be caused by the change in the heart's structure, particularly the change in dimensions of the heart in dilated cardiomyopathy.

Some people will be aware of a change in their heart rate and rhythm and it may provoke symptoms of breathlessness and dizziness. Others may not be aware, while some have intermittent bursts of the arrhythmia, known as paroxysmal atrial fibrillation.

Atrial fibrillation in itself is not a life-threatening rhythm but its effect on the heart does mean it requires treatment. As the normal system for controlling the heart's pumping has been over-ridden this can make the heart a much less efficient pump, so reducing the output of blood. In the presence of cardiomyopathy, atrial fibrillation can place additional load on the heart and worsen symptoms.

A major risk factor of atrial fibrillation is that of developing a stroke. Due to the irregularity of the heart rate, blood can move more slowly through the heart. This in turn can cause clots to form which can then block the blood supply to parts of the brain and cause a stroke. It is extremely important for patients diagnosed with atrial fibrillation to be given anti-coagulant therapy, such as warfarin.

Treatment and management of atrial fibrillation is guided by NICE guidelines, updated in 2014. The treatment focusses on restoring normal heart rhythm, if possible, and controlling the heart rate. For some people the first treatment may be to give a small electric shock to the heart, under general anaesthetic. This is known as a cardioversion. This helps to restore normal rhythm. Drugs, such as digoxin, amiodarone, beta-blockers and calcium channel blockers, are commonly used to control heart rate and rhythm.

When patients have difficulty tolerating drugs, or where they are not effective in controlling the rhythm, there are invasive procedures that can be used in some patients. One such procedure is the AV node ablation. This removes the conducting link between the upper and lower chambers of the heart .The pumping of the ventricles is then controlled by an implanted pacemaker. It is important to remember that despite the symptoms of atrial fibrillation being alleviated, the risk of stroke remains and anti-coagulant therapy should be continued.

## Genetic test looks for mutations on 174 genes

A more comprehensive genetic test for inherited heart diseases is being made available across the UK.

Cardiomyopathy is caused by a variety of gene mutations on many genes. Until recently genetic testing only looked at a handful of genes to try to find the mutation causing the disease in a particular family.

But now a test has been launched that looks at mutations on 174 genes thought to be implicated in causing inherited heart diseases.

The test, already being used at the Royal Brompton Hospital in London, is being made available to testing laboratories across the UK and overseas. It is quicker and more reliable than previous tests, reducing costs and allowing patients to be diagnosed quickly and more reliably.

It has been developed from research funded by the Department of Health, the Wellcome Trust and the British Heart Foundation. The research was an international collaboration between researchers in Singapore and Imperial College London.

Dr James Ware, one of the lead researchers and a cardiologist at the Brompton, said: "Genetic tests can help to make the initial diagnosis, and to choose the best treatment for the affected person."

It then becomes simple to test other family members. Those who do not carry the mutation can be reassured and spared countless hospital visits.

Cardiomyopathy UK chief executive Joel Rose said: "This as an important step towards making targeted genetic testing for cardiomyopathy more accessible. But we don't yet know how effective it will be."

For more details see **cardiomyopathy.org/gene-testing**

## Drug helps prevent cardiomyopathy in mice

Researchers say they may have pinpointed a treatment that might prevent hypertrophic cardiomyopathy (HCM).

Using research from 15 years ago that showed the condition can be caused by problems in the myosin protein, the team has been testing a small molecule inhibitor on mice with myosin gene mutations.

Myosin is responsible for making the heart muscle contract and relax as it pumps blood. A mutation in myosin can damage the heart's "power-generating capacity" and cause it to enlarge.

In their study, reported in Science, the researchers found the inhibitor altered the myosin motor's power generation to a more normal level. They gave the drug containing the molecule to mice as early as eight weeks old, and found it prevented the HCM from surfacing, said the team.

Because HCM runs in families, a young child who tests positive for the genetic mutation could receive the treatment to help stave off the disease. However, development of a human drug would require much more extensive testing.

The researchers are from Harvard Medical School, Stanford University School of Medicine, University of Colorado, and drugs company MyoKardia.

For more details, see **cardiomyopathy.org/inhibitor**

## Should more people with heart failure be on digoxin?

More research is needed to see if a drop in use of the drug digoxin in treating people with heart failure is appropriate or whether it is depriving them of an important medication, say researchers.

In America in 2005, a third of patients with heart failure and reduced ejection fraction (the amount of blood being pumped out of the heart at each beat) were on digoxin but by 2014 it was just one in ten. In those with heart failure and a preserved ejection fraction, 16 per cent were on the drug in 2005 and just over one in 20 in 2014.

Digoxin is derived from digitalis, a potentially poisonous compound found in foxgloves, and can help make the heart beat stronger and with a more regular rhythm. It was widely used in treating heart failure before beta-blockers. and the older drug has been questioned in some more recent studies.

The researchers, led by Dr Nish Patel from the University of Miami Miller School of Medicine in Florida, said that trials were needed to see if there was a benefit to adding digoxin to contemporary guideline-based treatments. Such studies might also show if the drop in use "is appropriate and enhancing patient safety or whether it may be depriving patients of an important medication to reduce hospital admissions."

For more details, see **cardiomyopathy.org/digoxin**

## Do women do better in single-sex cardiac rehab?

Women with heart disease who take part in cardiac rehabilitation appear to suffer less anxiety and depression if they join women-only programmes, new research suggests.

Results from a study in Canada show that women in single sex groups had significantly lower anxiety and depressive symptoms than those in mixed-sex sessions. Those in women only groups did better with their diets, but both groups had increased quality of life.

The associations did not hold after full adjustments but the researchers said that given the high degree of anxiety seen, the findings deserved more investigation.

Researcher Liz Midence, from York University in Toronto, said: "Strategies to ensure more women use cardiac rehabilitation should be implemented."

## Hot and cold can increase heart symptoms

Warm and cold temperatures can increase symptoms in people with hypertrophic cardiomyopathy (HCM), say researchers.

The research team, from the heart diseases' division of the Mayo Clinic in America, looked at 173 patients with HCM, including 143 (83 per cent) who had symptoms of the disease. Temperature changes worsened symptoms for half of them (72).

Of these, nearly eight in ten found their symptoms worsened only in hotter conditions, while two in ten found their symptoms worsened only in the cold or with both heat and cold.

Patients affected by any temperature change were more commonly women who had had a myectomy (surgery to remove heart thickening), a heart device, a family history of the condition and a lower quality of life, said the researchers, including Dr John Bois.

For more news stories about cardiomyopathy treatments and latest research, see **cardiomyopathy.org/news**

# The difference we make

**We've been doing more than ever to support people affected by cardiomyopathy and help ensure doctors and nurses can spot the condition and provide up-to-date treatment and support**

In 2015 we were able to do more than ever to support people affected by cardiomyopathy and help ensure the medical profession is able to diagnose cardiomyopathy promptly and provide appropriate support and treatment.

We also changed our name, our look and launched a new website, all with the aim of helping more people affected by cardiomyopathy.

## Providing information

Good quality information is vital. Finding out that you have cardiomyopathy can be a frightening experience and leave you feeling confused and uncertain about the future.

Our materials give people clear and simple information to help them fully understand their cardiomyopathy and the treatments available. This can help them regain some control over their lives.

"Everything I know about the condition I found out from you and your website. It's amazing, I got home from the doctor's and didn't know anything, and found you online." Nicola, Cardiomyopathy UK website user

In 2015 we were able to meet our objective of ensuring that people affected by cardiomyopathy feel more informed, know what their next steps are and feel better able to cope.

## My Life magazine

Our My Life magazine, which you are reading, was launched last April. We send out nearly 12,000 copies of each issue to individuals, doctors' surgeries and hospital waiting rooms. The magazine is also read by the medical profession.

## Booklets

As well as our three cardiomyopathy booklets (on hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy) and our children's booklets, we also last year produced a brand new booklet called Living with Cardiomyopathy.

This booklet gives advice and information on many aspects of life with cardiomyopathy, including working and finance. We sent out over 5,000 copies of the new booklet.

## Information days

We held seven cardiomyopathy information days last year across the UK, with over 450 people attending.

## Website

Our website **cardiomyopathy.org** has always been an important source of information and support for people affected by cardiomyopathy. Last April we updated the website to make the information and the services we provide easier to find. As a result we had over 200,000 unique visitors to the site.

## Working with doctors and nurses

"I now have a better understanding of hypertrophic cardiomyopathy and will be more confident in my care of patients with the disease," a doctor after attending our medical conference

It can take far too long for people to be diagnosed with cardiomyopathy and when they are, often they face a struggle to receive the treatment that they need. We know how important it is that doctors develop their own understanding of cardiomyopathy and the latest developments in treatment, which is why we are in regular contact with over 2,200 medical professionals. We want doctors to be better able to diagnose cardiomyopathy and to support their patients in the most appropriate way. During 2015 we made great progress towards this vital goal.

## Medical conferences

In 2015 we had over 321 healthcare professionals attend our 4 medical conferences and the vast majority told us that they felt better able to support a person with cardiomyopathy after attending.

## Growing networks

Last year saw the launch of our clinical advisory group. We brought together leading cardiomyopathy doctors and academics across the country to help ensure our work is appropriately focussed, that we can reach even more clinicians, and we can develop our research and campaigning plans in the best ways to benefit our families.

# to cardiomyopathy care

Cardiomyopathy UK has given me a wealth of information, and gave me the confidence to ask for a referral to see a cardiomyopathy specialist. This was the turning point in my condition. I was taken seriously by the medical profession for the first time. And knowing there is always someone at the charity to speak to has been enormously helpful," supporter Karen Flavell

## Giving support

Living with cardiomyopathy can have a huge impact on all aspects of life. We know that getting the right support can make the difference between feeling overwhelmed and feeling you can cope.

"As a family, we have lost a lot because of cardiomyopathy, but we will never give in. Talking to others who have gone through the same things makes me feel better." John, support group member

## Helpline

Our nurse helpline (0800 0181 024) offers the chance for people affected by cardiomyopathy to get one-to-one support and advice from a trained nurse. In 2015 our nurses helped over 1,500 people.

## Support groups

Sharing personal experiences can make a person with cardiomyopathy feel less isolated. In 2015 we had 17 cardiomyopathy support groups which held over 40 meetings.

## Online community

We grew our already active online community, giving people the chance to chat with and support others affected by cardiomyopathy all over the world. Our private Facebook group was particularly active with around 1,000 new members. We also launched our new forum which had over 500 members by the end of December.

## Improving access to quality treatment

One of the best ways to make a real difference to the lives of people affected by cardiomyopathy is to work with other charities and organisations to raise the standard of care by developing best practice guidance and lobbying for better access to services.

In 2015, as a member of the Alliance for Heart Failure, we were able to push for a parliamentary inquiry to assess inequality in treatment and make recommendations for change. We also worked with the National Institute for Health and Care Excellence (NICE) on reviewing its guidance on heart failure to ensure it meets the needs of patients.

## Thanks to you

We couldn't have achieved any of our success in 2015 without the help of our wonderful supporters, including:

- 340 fundraisers who took part in runs, baked cakes, climbed mountains and flipped pancakes and went the extra mile for us this year, raising over £400,000
- supporters who bought over £12,000 of Christmas cards and Cardiomyopathy UK merchandise
- Over 1,860 people who made a donation to our work.

## The difference we will make this year

We know the impact we made last year, but we also know that we need to do much more. We have ambitious plans for the year ahead focussing on:

### Supporting you all the way

We'll be working with young people to develop services for them and recruiting a children's cardiomyopathy specialist to offer support to parents. We'll be giving more support to our support group leaders in the running of their groups and helping to establish new groups. We are planning a 'live chat' service with our support nurses.

### Improving diagnosis

We aim to increase the number of medical education events we provide and work with clinicians to develop and promote simple guidelines for GPs. We'll also be working with government, the NHS and others to make it easier for relatives of people with cardiomyopathy to get genetic testing.

### Getting specialist help

We'll be doing more to highlight inequality in getting treatment and we'll be calling on local health organisations and the government to make it easier for people to get specialist care. We want to develop an advocacy service to help people secure referral for the treatment they need. We also want to ensure that psychological support is made available.

### Supporting research

We'll be getting more involved in research boards to help ensure research meets the needs of people with cardiomyopathy. We will do more to encourage people to take part in research trials and to spread information about the results of new research.

# More families now eligible for IVF help

*Picture courtesy of Guy's Hospital embryologists*

More families affected by dilated cardiomyopathy can now get IVF treatment so their babies escape inheriting the disease.

The Human Fertilisation and Embryology Authority (HFEA) has granted a licence allowing families affected by mutations in the Lamin A/C gene (dilated cardiomyopathy type 1A) to have pre-implantation genetic diagnosis (PGD).

PGD helps families with an inherited condition avoid passing it on to their children. The lamin mutations are particularly linked to electrical conduction problems in the heart, and muscular dystrophy.

The HFEA had already licensed PGD for dilated cardiomyopathy families affected by mutations on the Troponin T2 gene. It has also licensed PGD for families with hypertrophic cardiomyopathy caused by mutations on the MYBPC3 gene, and for families affected by arrhythmogenic right ventricular cardiomyopathy.

Cardiomyopathy UK and the Genetic Alliance UK, a charity representing over 150 patient organisations for those with genetic conditions, made a joint submission to the HFEA in favour of the new licence.

**What is PGD?**

PGD enables people with a specific inherited condition in their family to avoid passing it on to their children. It involves checking the genes of embryos created through IVF. Then only those embryos without the gene mutation are implanted in the mother's womb.

PGD is designed to give families affected by a serious disease the chance to go through IVF and PGD if they know the gene mutation in their family causing the disease.

Before granting a licence, the HFEA has to be satisfied that the mutations lead to a significant risk of a serious illness or disability.

Individual families make the application for a licence, supported by their PGD clinic. But once a licence is granted for a particular gene, other families with mutations on the same gene can proceed using the existing licence.

For more about cardiomyopathy genetics and PGD see **cardiomyopathy.org/genetics-of-cardiomyopathy/intro**

## Few baby issues for women with ARVC

Most women with arrhythmogenic right ventricular cardiomyopathy (ARVC) tolerate pregnancy well, says a new study.

Researchers in America and the Netherlands looked at women with the condition treated at Johns Hopkins Hospital in Baltimore and on a Dutch ARVC registry. They wanted to see how the pregnancies went and how well women did afterwards.

They found 26 women with the disease who had had 39 pregnancies of more than 13 weeks. They looked at their symptoms and treatments, the success of the pregnancy and for heart failure signs and episodes of dangerous heart rhythms.

Incidences of dangerous heart rhythms (sustained ventricular arrhythmias) and heart failure were compared with rates in the women before they were pregnant. Their long-term disease was compared with 117 childbearing-age women with ARVC who had not been pregnant.

For the 39 pregnancies, 16 were getting beta-blockers, six on antiarrhythmic drugs, three on diuretics and in 28 cases the woman had an internal defibrillator (ICD). Five pregnancies (13%) had one episode of a dangerous heart rhythm, including two ICD firings.

Heart failure problems not needing hospital admission developed in two pregnancies (5%). All babies were born alive and without major obstetric complications.

Most pregnancies were tolerated well, but 13% were complicated by dangerous heart rhythms and 5% by heart failure, said the researchers.

For more details, go to **cardiomyopathy.org/ arvc-pregnancy**

## Low risk but not zero risk with ICDs

Though internal defibrillators (ICDs) can be lifesaving in some people with cardiomyopathy, there is a very small risk associated with having the device, a new study confirms.

And young patients particularly face cumulative exposure to complications. So "careful consideration of the risks and benefits of having an ICD were needed before it was fitted".

Researchers led by Dr Joris Groot, from the Academic Medical Centre in Amsterdam, said: "The low but not zero risk of ICD-related mortality should be taken into account."

He said having an ICD carried a significant risk in young patients of inappropriate shocks and complications developing in hospital and after discharge.

The study looked at the data from almost 5,000 patients. Twenty two per cent had ICD complications, including one in five having inappropriate shocks in four years of follow up. One in 200 died from problems related to the device.

Annually, 4.7% had inappropriate shocks, 4.4% other ICD-related complications, and 0.08% died from ICD-related issues.

But Dr Groot said the devices were life-saving and complications were almost always manageable.

While the ICD mortality and complication figures have remained steady over the years, the number of inappropriate shocks people get began to drop in 2008, the report said.

For more details, go to **cardiomyopathy.org/ ICD-risk**

# Challenges in treating children with cardiomyopathy

**Matthew Fenton** | consultant paediatric cardiologist, Great Ormond Street Hospital for Children

With up-to-date treatments, many children with cardiomyopathy do well. But doctors find there are still challenges in treating the sickest children

Cardiomyopathy is a rare condition in children. The diagnosis of cardiomyopathy includes a broad range of heart problems.

In general, cardiomyopathy is described by the heart's appearance and function, either as dilated, hypertrophic or restrictive types.

Over the last few years we have become more scientific in our approach by looking for specific genetic mutations in order to be more accurate in our diagnosis.

This process has been useful, especially when screening affected families, but has also shown us that we have a lot more to understand about what causes cardiomyopathy.

Many of the specific genetic mutations that cause dilated cardiomyopathy for one family might cause restrictive cardiomyopathy in another, suggesting that, as always, nature is more complicated than we would like it to be.

Many children will be seen in the clinic for screening because other members of the family are affected by cardiomyopathy. If other members of the family have cardiomyopathy we can use genetic information from affected relatives to determine whether others might be at risk.

The benefit of this is that if we can identify a genetic problem that might be responsible for their cardiomyopathy, it is possible to exclude them from screening, reducing anxiety for the families involved.

At the moment genetic testing remains reasonably expensive but we are hoping that routine testing will become part of mainstream care in the very near future, particularly as techniques for finding genetic mutations are becoming increasingly more sophisticated and cheaper.

Sadly some children come to us already unwell as a result of their heart problems. The children who come to the outpatient clinic are treated with medicines which usually make them feel better and even improve how their hearts work.

One of the challenges of treating children with cardiomyopathy is that we do not have enough affected children to be able to divide them into groups and see which medicines or combination of medicines are the most effective.

Most of the information we have comes from adult patients and we all know that children are not just small adults! Despite this we do have good medicines and are successful at treating children, with excellent results throughout childhood.

We have learned that it is important to see the children we look after regularly in order to optimise the medication and check the response to our treatments.

This gives us the chance to change things if the treatments are not working.

Many children, even those with severe cardiomyopathy, can get better, many of them slowly improving over many months from the start of treatment. The large majority of children will remain well and will never need treatment such as a heart transplant. Children with severe heart problems need to be admitted to intensive care and some will need mechanical hearts while they wait for a heart transplant.

Technology has marched on rapidly with better equipment, but we still do not have the ideal solution especially for smaller children.

At the moment we use a Berlin Heart to help support young children waiting for a heart transplant. This is an extremely effective method but comes with a number of difficulties. Children are restricted in their daily lives and are unable to leave hospital without significant nursing support.

They are unable to return home while they wait for organ donation and often spend many months waiting in hospital. We do our best to enrich their development and schooling but there is no doubt that it is a strain for all the family.

Older children are able to benefit from adult-sized mechanical hearts, which are much more portable and enable them to take part in normal life, including returning to school and even horse-riding for one of our teenagers.

Extensive research and development is required to improve these pumps. Because the number of young children with cardiomyopathy is small, the drive for expensive research has so far not focused on mechanical hearts that are suitable to use in children.

However, there is hope on the horizon. With increasing miniaturisation we hope that in the very near future we will have smaller pumps that will mean that even small children will be able to return home while they await a heart transplant.

The biggest challenge that we face for the sickest of our young patients is a lack of suitable organ donors.

Of course this problem is not just for children with heart disease but it is an important problem for many children who have serious health problems.

The solution to this problem lies not only with the government and organisations that set transplant policy but also with the general public embracing more organ donation.

Heart transplantation in children is increasingly successful and offers hope and quality to the life of the sickest children that need our help.

- For details about the NHS Organ Donor Register, see **organdonation.nhs.uk or call** 0300 123 23 23

## Summertime raffle

Our summer raffle is back. Could you be one of our lucky winners? With fantastic cash prizes of £500, £250 and £100 to be won, you've got to be in it to win it.

Each year our raffle raises over £8,000 for our work, helping us to be there for even more people affected by cardiomyopathy. We know living with cardiomyopathy can be tough, whether you're newly diagnosed or have had the condition for some time.

With every raffle book sold we can be there to support another family that needs us. Please help us by selling tickets to your family and friends. And you never know, you could be one of the lucky winners.


## On cloud nine...

On Saturday 12 March, seven intrepid supporters took on the ultimate adrenaline challenge and completed a tandem skydive for us — including our own challenge events fundraiser Sarah!

Despite a foggy start, all of our #teamcardio skydivers took to the skies at Brackley airfield in Northamptonshire, cheered on by family and friends. Everyone had a fantastic time and the event raised over £9,000.

If you want to be part of the fun, our next skydiving day is on 21 August in Nottinghamshire. If you raise a minimum of £450, you can jump for free.

For more information, visit **cardiomyopathy.org/skydive**





## London Marathon

By the time this magazine goes to print, Cardiomyopathy UK's London Marathon runners will be almost ready for the big day. This year we have 50 runners taking part for #teamcardio and all of them have trained for months and spent long hours fundraising to support our work.

Thank you to the whole team for all your support. Every single one of our fabulous fundraisers gives the event their all; whether they're training for the marathon or having a marathon cake baking session.

**We simply couldn't do it without you — thank you**

# #teamcardio highlights

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

Interested in being part of #teamcardio? Get in touch with our fundraising team at **fundraising@cardiomyopathy.org** or visit our website **cardiomyopathy.org/support-us**

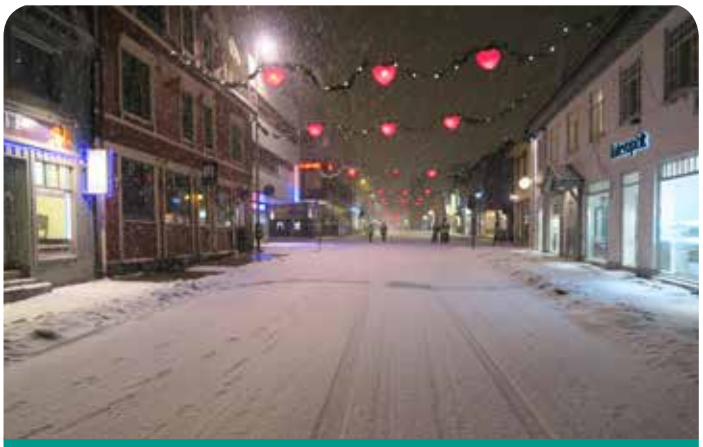
## Hair today, gone tomorrow

Supporter Debbie Bingham from the West Midlands braved the ultimate chop for us in January and shaved off her blonde locks for sponsorship, raising £1,650 for our work

## Society success

Newcastle University Raising And Giving (RAG) society nominated Cardiomyopathy UK as its chosen charity for its ball in February and raised £5,000 for us. Thanks to all involved

## Poles apart



Brothers Tom and Rowan Staszkiewicz took on the Polar Night Half Marathon in Tromso, Norway in January, running, slipping and crawling across 13.1 miles of Arctic terrain in the middle of the two month polar night. In total the brothers raised over £600 for us

## Fundraising in full swing


The annual Oz Cup Charity Golf Day took place in July 2015, in memory of Marc Osborne who died in 2008. The day raised over £2,500 for us. Over the years Marc's family and friends have raised over £15,000 for our work. Thank you to the organising committee and all the players

## Pancake perfection

Our Great Pancake Party kicked off in February with supporters up and down the UK tossing pancakes and having a great time while raising vital funds. Thank you to everyone who had a party, made donations, supported our work and ate pancakes.
We are so grateful for all of our #teamcardio supporters. We hope you had a flipping marvellous time


### Great Manchester Run

*The 300,000th runner will cross the 2016 finish line, could it be you?*

Be part of #teamcardio for the biggest 10K event in Europe. The Great Manchester Run is suitable for all types of runner from the complete novice to the elite. If you're looking to set a personal best over this distance or simply to enjoy a great atmosphere for your first 10K run — this offers you that chance.

Location - Manchester
When - 22 May
Distance - 10K

To register or get more information please visit
cardiomyopathy.org/great-man


### Ride London

*A world class festival of cycling to celebrate the London 2012 Olympic Games' legacy*

This 100 mile cycle is from Queen Elizabeth Olympic Park through closed roads to the capital and into the Surrey countryside before returning to the finish line in The Mall. Experience some leg burning climbs and thrilling descents.

Location - Queen Elizabeth Olympic Park
When - 30-31 July
Distance - 100 miles

To register or get more information visit
cardiomyopathy.org/ride-lon


### BUPA 10K

*Come and be part of #teamcardio and take on this iconic 10K run*

What better way to spend your Spring Bank Holiday than running along part of the 2012 Olympic marathon route through central London. Starting and finishing at Buckingham Palace the course takes you past some of the city's most famous landmarks including Nelson's Column and the London Eye.

Location - London
When - 30 May
Distance - 10K

To register or get more information visit
cardiomyopathy.org/bupa-10k

## GET INVOLVED

To take part in any of these events, 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!

## Great London Swim
16 July

If you're looking for a new sporting challenge with a difference, then the Great Newham London Swim could be for you. London's skyline creates the backdrop for this one mile open water swimming event and your family can support you from the dockside along the course.

'Such an amazing experience', *Helen Carter GNS 2015*

To register or get more information visit
cardiomyopathy.org/swim

## London to Paris

For any cycling fan the journey on two wheels from London to the Eiffel Tower is a must. You'll be completing the 234 mile journey over three days and testing yourself to the limit. So saddle up and take on this once in a lifetime cycling challenge for Cardiomyopathy UK.

To register or get more information visit
cardiomyopathy.org/lon-to-par

# Dates for your diary

## April

*Saturday 9 April, 9.30pm-4.30pm*
**Information day, Glasgow**
Botanic Suite, Hilton Glasgow Grosvenor
1-9 Grosvenor Terrace
Glasgow G12 0TA. Main speaker is Dr Gerry Carr-White, St Thomas' Hospital London
See panel below for further details

*Saturday 9 April, 2pm*
**North East England Support Group**
Function Room 137, Education Centre, Freeman Hospital, Newcastle
Speaker is Julie Goodfellow, cardiac genetics nurse, North of England Cardiac Family History Service.
For details contact
Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

*Saturday 9 April, 3pm*
**North London Support Group**
Finchley Memorial Hospital, Granville Rd, London N12 0JE
Social get-together. Lisa Barnett will talk about her heart transplant in 2013.
For details, contact Jane Barnett on 0208 343 1940 or email jane@email58.co.uk

*Thursday 14 April, 7pm*
**South London Support Group**
Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY
Speaker is Cardiomyopathy UK's support nurse Robert Hall on the emotional impact of living with cardiomyopathy.
For more details see enquiries panel

*Saturday 16 April, 11am-2.30pm*
**South Wales Support Group**
Education centre, top floor, new main entrance, Morriston Hospital, Swansea SA6 6NL
Speaker is Cardiomyopathy UK's support nurse Robert Hall
For details contact hannah.goss@wales.nhs.uk

*Saturday 23 April, 2-4pm*
**Cheshire and Merseyside Support Group**
Outpatient Department at Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE
Dr Ewan J McKay, heart failure and pacemaker cardiologist at Manchester Heart Centre, Manchester Royal Infirmary on coping with ICDs
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

*Tuesday 26 April, 2pm*
**Cornwall Support Group**
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Nigel Parry talks about his cardiomopathy story, including his heart transplant
For more details contact Eric on 01736 351439

## May

*Saturday 14 May 9.30pm-4.30pm*
**Information day, Belfast**
Maldron Hotel, Belfast International Airport, BT29 4ZY.
Main speaker is Professor Perry Elliott, Barts Heart Centre, London.
See the panel below for more details

## June

*Saturday 4 June, 2pm*
**North East England Support Group**
Function Room 137, Education Centre, Freeman Hospital, Newcastle
Speaker to be confirmed
For details contact
Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

*Saturday 11 June 9.30pm-4.30pm*
**Information day, Manchester**
Venue to be finalised
Main speaker is Dr Gerry-Carr White, St Thomas' Hospital, London
See the panel below for more details

*Sunday 12 June, 12-3pm*
**West Scotland Support Group-**
Boardroom, Glasgow Royal Infirmary from 12-3pm
Speaker to be confirmed. For more details contact Bob McConnachie on 07710 789581 or email mess@talk21.co m

*Thursday 16 June, 7-9pm*
**Cheshire and Merseyside Support Group**
Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL.
Speaker Janet Davies, joint clinical lead, Liverpool Anticoagulation Service.
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

*Tuesday 21 June, 2pm*
**Cornwall Support Group**
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Specialist cardiac nurse Sam Dimmock and specialist cardiac physiotherapist Dawn Foss talk about community cardiac services in Cornwall.
For more details contact Eric on 01736 351439

*Saturday 25 June 9.30pm-4.30pm*
**Information day, Newcastle**
Crowne Plaza Hotel, Hawthorn Square, Forth Street, Newcastle NE1 3SA
Main speaker is Dr Sam Mohiddin, Barts Heart Centre, London.
See the panel below for more details

## July

*Saturday 30 July, 2-4pm*
**Cheshire and Merseyside Support Group**
Outpatient Department at Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE
Cardiomyopathy support nurse Robert Hall on Cardiomyopathy UK's helpline and an update on treatments.
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

## 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**

## Tell us

# your story

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

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

# Cardiomyopathy UK

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