

my life

Issue 15/July 2018

Cardiomyopathy^{UK}

The heart muscle charity magazine for people affected by cardiomyopathy



My ICD
story

PAGE 10

Contact us

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

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

2017 Impact Report

Since we became a charity nearly 30 years ago, we've helped thousands of families affected by the heart muscle disease cardiomyopathy - by delivering support services, raising awareness, improving treatments and influencing health policy and practice.

We are proud of the impact we've made in 2017 - a big year for the charity, as we launched our first national campaign.

Our success is down to our unique ability to bring together leading clinicians, people affected by the condition and charity professionals and we are grateful to all our fantastic staff, supporters and volunteers.

Below are some of the highlights from our Impact Report 2017.

Support services

- Launched a new peer to peer helpline
- Created a young persons' panel for people aged 14-25
- Opened 9 new support groups



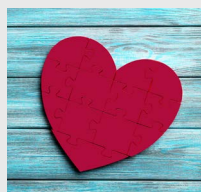
Treatment and diagnosis

- Worked as part of the heart failure research hub to help clinical researchers explore new research priorities
- Collaborated with the Alliance for Heart Failure during discussions about cardiomyopathy with politicians and key health policy makers
- Ran a national medical conference with the theme of 'Hidden in Heart Failure'



Raising awareness

- Ran our #MyHeart-Story national campaign
- Grew our social media presence to reach a wider and more diverse audience
- Secured local and national media coverage throughout the year



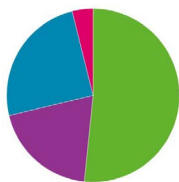
Information

- Created a new animated video explaining treatments for cardiomyopathy and 16 new factsheets
- Held six local information days aimed at people in under-represented communities
- Held our annual Cardiomyopathy UK national conference



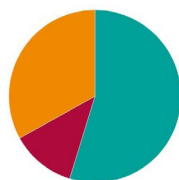
How we raise our funds

- Community fundraising
- Donations & legacies
- Trusts & corporates
- Merchandise & conferences



How we spend our funds

- Administration
- Fundraising
- Charitable activity



If you did not receive a copy of our Impact Report, or would like to know more about what we do, or ask us for help, then please get in touch (see details left).



Welcome

from Alison Fielding
Chair of Cardiomyopathy UK

Just like Brexit, religion and Marmite, the world seems to be on one side or the other when it comes to attitudes on whether you want an ICD or other device fitted.

I wanted one from the time I first knew they existed and during the post-diagnosis and pre-implant years, I had many nights of palpitations raging and wishing it was there.

On my travels, meeting people at our events and working as a peer support volunteer and Facebook moderator, I know that thousands of people have exactly the opposite response and worry about having an ICD implanted. That's why we have produced our new booklet on

ICDs and plan one on pacemakers soon.

It's much easier to decide when you know the pros and cons and understand more about them.

Being able to read what others have experienced helps too, so thank you to our own Andrew Kaponi, (See Page 10), who like many of you, has shared his story with an honest insight into the hopes, fears and reality of their devices.

I've been privileged to talk to people whose devices have saved their lives. Many also rely on their mobile phones for the reassurance they can offer. Technology is vital to so many whose lives depend on it.

INSIDE THIS ISSUE

National campaign - Page 4

Call to action - Page 6

Ask the experts - Page 9

My ICD diary - Page 10

My Life story - Page 13

My Life Interview - Page 15

#Teamcardio news - Page 17

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We will be celebrating our 30th anniversary in 2019 and are looking for organisations and companies that will support us throughout our birthday year.

If your employer can help, please contact
Sheila.nardone@cardiomyopathy.org

Meet The Communications Team

What's your favourite mobile phone app?



Priya Manek

PR & Communications Manager and My Life Editor

'Instagram - It's an amazing reprieve into a portal of escapism, full of inspiration and opportunity (as well as sharing your own stories) and sometimes stalking celebrities in their daily lives.'



Kerry Allan

My Life Editor

'WhatsApp - It helps me stay in touch with my sister, who lives in France, without clocking up a hefty phone bill.'

Debunking the myths and misconceptions

Thank you to those who filled in our survey. We are now moving full steam ahead to develop a campaign, which will be launched later this year, around tackling misconceptions for people with cardiomyopathy.

The campaign aims to confront the stereotypes about what a person with a 'heart condition' is like - what they look like and how they feel or behave - and it will stress the importance of seeking clinical advice if symptoms are experienced.

If you have suffered negative experiences at work, or in relationships, please tell me about them via email at: media@cardiomyopathy.org

By Priya Manek
PR & Communications Manager



Thank you for sharing your views

A massive 'thank-you' to the 500+ replies we had to our survey around your experiences of cardiomyopathy or myocarditis and how the condition affects your relationships and everyday lives.

Below are some of the highlights that overwhelmingly show how assumptions and misconceptions about your condition **do** affect you on a daily basis.

Cardiomyopathy UK is always here to help you and families manage the condition and our free helpline is always on hand to provide support.

Highlights

What condition were you diagnosed with?

- 36% had dilated cardiomyopathy
- 26% had hypertrophic cardiomyopathy
- 20% had Takotsubo cardiomyopathy

Does your condition negatively affect any of the following areas of your life?

- 77% - leisure activities and hobbies
- 59% - sports
- 50% - employment
- 38% - relationships

When you first told people about your condition, did you feel that they understood about it and

its impact and did they treat you any differently?

- 61% - they didn't understand
- 31% - they understood a bit

What do you think the general public's view is of someone with a heart condition?

- 84% - they would have an unhealthy lifestyle
- 73% - they would be overweight
- 70% - they would be a smoker
- 69% - they would be an old person
- 69% - they would look ill

In any of the following areas, has anyone made assumptions about what you can do?

- 69% - yes (leisure activities)
- 60% - yes (capabilities at sports/gym)
- 55% - yes (work)

In any of the following areas, has anyone made assumptions about what you cannot do?

- 63% - yes (leisure activities)
- 59% - yes (capabilities at sports/gym)
- 42% - yes (work)

Has anyone ever said anything hurtful (either accidentally or deliberately) about how your condition affects you?

- 45% - yes

Have pacemaker, will travel...

Mike Richardson, from Edinburgh, had always led a reasonably active outdoor life and as a biologist, was used to field work and hill walking.

But he knew something was wrong when in late 2007/early 2008, he began to get breathless very quickly, having to stop after 100 metres uphill.

Despite going to his GP several times, his dilated cardiomyopathy remained undiagnosed until in April 2008, he visited his son's doctor in a small village in France.

"I saw a French cardiologist the next day, who told me he was pretty sure I had heart failure and confirmed it at his main clinic later in the week," recalls Mike.

"It was a bit of a shock, but I was glad to finally have a diagnosis after six months.

"I tend to be fatalistic and pragmatic and as a biologist, know that we all have to go sometime. I remember saying to the cardiologist: 'Will I see Christmas?' and he said: 'Yes, but maybe not in 10 years' time'."

Mike's next question was whether he'd be able to go to Greenland for his 70th birthday?

"I went and had a great time – my friend was post-hip replacement, so it was two old men going slowly!" he recalls.

Six years later, during a routine clinic appointment, it was suggested a pacemaker would help his left branch bundle block (which Mike knew nothing about).

"Apparently, impulses to the left ventricle were being delayed, so the two ventricles were out of sync and getting them firing together would help.

"I was told I'd need a pacemaker eventually, so I agreed to do it then while I was fit," he says.

A few weeks later, Mike had his procedure under a local anaesthetic.

"I felt no pain at all, but the most disturbing aspect was the actual physical pulling and tugging while the surgeon made space with fingers



80-year-old Mike Richardson's last check-up revealed he had nine years left on his pacemaker battery - but he fully intends to get a new one...

to take the device - he was quite energetic!

"I had a disturbed night as the device was making me twitch and wondered if I had made the right decision, but it was quickly sorted in the morning."

Having a pacemaker has been a positive experience for Mike, who admits he's hardly conscious of it.

"I've had no side-effects, apart from some itching at the site of the implantation for a while, but after four years, it's almost unnoticeable."

Mike attends a pacemaker clinic every six months – likely to be yearly now - and is full of praise for the pacemaker technicians, who last year, made adjustments to the rhythm of his pacemaker after he felt he was becoming tired more quickly.

"It's amazing what they can do without any intrusive treatment," he comments.

"At the clinic, you simply lie on the couch and have electrode pads stuck on arm and ankles. The technicians warn you that you might feel changes as they speed it up or slow it down, but I'm not conscious of my heart rate, as some people seem to be.

And they can tell you how long your battery has left."

Since having his pacemaker fitted, Mike tries to live life as before and until two years ago, was still going on research projects with his wife to Puerto Rico, doing field work and research in the rain forest.

A former glider pilot and photographer, he still enjoys travelling and thanks to a mobility scooter - which goes free on aircraft - he's enjoyed holidays as far afield as America and Gran Canaria in the past year.

He has no problems with going through airport security and often receives VIP treatment.

"Assistance at airports is excellent. I show my pacemaker card, but often they don't want to see it – just saying 'pacemaker' and patting it is enough - and I don't go through the scanning arch.

"I think I'm lucky when I read about other people's experiences. Although I'm limited in what I can do physically, it could be so much worse. Ten years on and I'm still around. My last check-up revealed I have nine years left on my battery - I hope to get a new one!"

SCRs - medical records in a digital world

Safe, effective care when you need it



By Joel Rose,
Chief Executive

Living with cardiomyopathy can involve dealing with a wide range of health care professionals and lots of paperwork.

It is not uncommon for some people to have a pretty thick pile of medical records, papers and letters.

Buried in this pile is some vital information that may one day be needed in an emergency.

This is why we encourage everyone with cardiomyopathy to ensure that their **Summary Care Record (SCR)** is up to date.

What is a SCR?

The SCR is an electronic summary of important information taken from your medical records.

It is designed to be a quick and easy way for medical staff and other authorised people in the health care system to access the information they need.

This makes the care you get safer, and reduces the risk of prescribing errors.

It also helps avoid delays to urgent care.

At a minimum, the SCR holds important information about:

- Your current medication
- Any allergies and details of previous bad reactions to medicines

- Your name, address, date of birth and NHS number.

How to include more information

You can add more information to your SCR by asking your doctor to add extra details from your medical notes, including:

- Your diagnosis of cardiomyopathy
- ICD type
- Details of your carer
- Your treatment preferences
- Communication needs (eg: if you have hearing difficulties or need an interpreter).

This will help medical staff care for you properly and respect your choices when you need care away from your GP surgery.

Ultimately, having more relevant information on your SCR means health professionals will have a better understanding of your needs and preferences.

How to protect your SCR information

Staff will ask your permission to look at your SCR - except in an emergency where you are unconscious, for example - and only staff with the

right levels of security clearance can access the system, so your information is secure. You can ask your GP to show you a record of who has looked at your SCR - this is called a Subject Access Request.

The NHS has been keen to encourage more clinicians to use SCRs and for more people to add to their own SCR where relevant.

The former NHS England director for long term conditions, Dr Martin McShane, says: "Continuity of information is a vital contributor to continuity of care and better outcomes.

"The ability to enrich Summary Care Records beyond medications, allergies and bad reactions, means more and more relevant information from the GP practice will be potentially available wherever a patient is receiving treatment in the NHS.

"This will improve safe, effective care and contribute to a positive experience for patients."

At Cardiomyopathy UK, we encourage everyone to speak to their doctor about their SCR and whether they should add additional information.

- For more information, contact us on 01494 791224.

Tina takes on Mongolia

Since having an ICD fitted, our intrepid Cardiomyopathy UK trustee Tina Amiss has walked the London Marathon and endured an Arctic dog sled challenge in Finland.

Her latest adventure is a five-day trek with her sister-in-law Liz across the Mongolian wilderness on horseback - navigating hills, valleys, forests and deserts and sleeping under the stars. Support Tina's journey to raise vital funds for our services to help others with cardiomyopathy at: <https://www.justgiving.com/fundraising/tina-amiss1>



No time like the present to leave a lasting impression

Leaving a gift in your will should be human nature, says Tim Aiton, (right)

We all lead such busy and hectic lives nowadays – work, family, friends, pets, DIY projects, social events – how do we manage to squeeze anything into the little spare time we have left?

The reason why I organise and structure my days is important to me.

I always make my bed before I leave the house, because if I never manage to accomplish anything else during the day, I have at least completed the first task!

Leaving a gift to charity in your will is a way of making others' lives easier and this desire to help others in need is all part of human nature.

It's also a way of 'leaving a lasting impression' on the world – a way of making sure that your memory lives on in the work of Cardiomyopathy UK.

Leaving money in your will helps fund vital support services and improve lives.

It also helps fund pioneering research into how cardiomyopathy impacts our daily lives so that we can educate those around us and make it a better world for people affected.



Without the money, this won't be able to continue and the work Cardiomyopathy UK does is so important. We all have heart issues of some sort and some of us wouldn't be here if it wasn't for the work the charity does.

I decided to leave a gift in my will to Cardiomyopathy UK because I wanted to demonstrate in a positive way how thankful I was for the support and aftercare I received from the charity – not only in the weeks and months before my diagnosis, but also up to and beyond the fitting of my ICD in

the cardiac wing at Worthing Hospital in West Sussex.

I'm also so grateful to the team there for looking after me during my initial stay and all the follow-up checks I've been to since.

It's so important to offer others help and support if they are diagnosed with similar conditions to you, because it shows them it's not the end to leading a full and normal life.

It's actually the beginning of a new chapter and they are not alone on this new journey.

So what you need to do right now is get organised and make a will for yourself and your family.

The old excuse we often hear is: 'I'm still only 25 and have years left to do this.'

Life is fast and ever-changing, so it needs to be done when all is well and not left to the last minute.

Please don't forget a lasting power of attorney for the same reason and put aside some money for Cardiomyopathy UK.

Every penny can, and does make a difference – what an amazing legacy to leave!

● To discuss leaving a gift in your will confidentially, please contact Sheila Nardone, Head of Fundraising and see our 'Gift in Will' section of the website.

Join us on the biggest ever walk for cardiomyopathy

Join Cardiomyopathy UK and take to your local woodlands, hills, or even mountains this autumn and organise your very own September Stroll.

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

Your September Stroll will help raise vital funds and awareness for Cardiomyopathy UK.

How to sign up

Contact our Community Fundraiser Christie Jones at christie.jones@cardiomyopathy.org or call 01494 791224, for your free September Stroll pack.



ICDs - 30 years of history

It's more than 30 years since the first patient received an ICD. Since then, technology continues to improve, offering more choices for patients and their doctors with the opportunity to monitor patients' health and pre-empt future problems

History

The ICD - short for Implantable Cardioverter Defibrillator - was developed by pioneering Polish cardiologist Dr Michel Mirowski and his team in the early 1960s.

Since then, millions of patients worldwide have received an ICD and uncounted lives have been saved.

Initially, ICD therapy was not widely accepted and many physicians actually considered this potentially life-saving device unethical.

Implantation was difficult and required electrodes to be placed directly on the surface of the heart. They were also so bulky that the device had to be placed in the wall of the upper abdomen as it was too large to be placed in the chest.

By the early 1990s, ICDs no longer required wiring directly on the heart, with leads that went through the vein to the inside surface of the heart. This made the implant procedure much easier, and recovery much quicker.

Over time, technology evolved rapidly and ICDs became smaller, allowing them to be placed in the upper chest - like a pacemaker - rather than in the abdomen.

Current devices are relatively small, can be implanted subcutaneously in the majority of cases and are channelled under the skin and laid alongside the breastbone (sternum).

Subcutaneous ICDs (S-ICD) are larger than traditional ICDs

as they need a larger battery, owing to the wire being outside of the heart. Some ICDs have a single lead where there is just one wire from the generator and others have a dual lead (one into the ventricle and one into the upper chamber - the atrium). Your cardiologist will make the decision on which ICD is best suited to your condition.

Key facts

An ICD is a small, battery-powered device with a generator, small computer, electrode (lead or wire) and a battery, which lasts five to 10 years.

An ICD is usually fitted under the skin, just below the left collarbone. Fitting can be done under a local or general anaesthetic, depending on the patient and usually takes about an hour.

Patients are given antibiotics because of a small risk of infection. Follow-up checks for your ICD are needed every three to 12 months.

■ Cardiomyopathy UK has produced a new guide about ICDs. For more information, call 01494 791224.

What ICDs do

ICDs are really implantable computers - programmed to keep track of a patient's heart rhythm and protecting an individual from dangerous heart rhythm changes that could result in cardiac arrest.

The heart normally beats in 'sinus rhythm', controlled by electrical signals from within the heart.

ICD are able to pace the heart if your heart rate is slow (bradycardia); deliver anti-tachycardia pacing (ATP) if your hearth rhythm is too fast and deliver a series of paced heart beats to restore a normal rhythm

If the device senses a dangerous rhythm, such as ventricular fibrillation and where ATP has not been successful, the ICD defibrillates (shocks) the heart to return the heart rhythm to normal.

This may feel as if you're being kicked in the chest and/or knock you off your feet. The pain typically lasts only a second and there should be no discomfort after the shock is over.

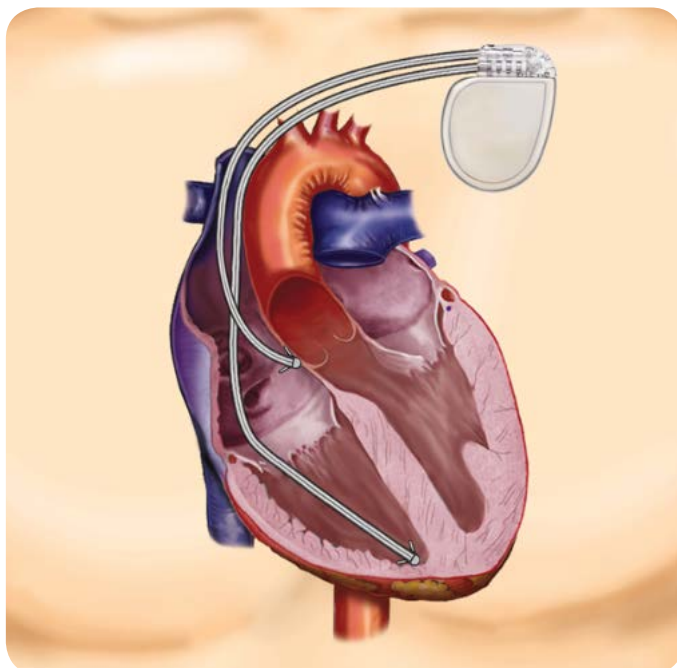
ICDs v pacemakers

Both ICDs and pacemakers are medical devices implanted inside the bodies of heart patients.

Pacemakers are designed to correct bradycardia or assist in the treatment of heart failure, by providing an electrical impulse to cause the heart to beat.

ICDs are safeguards against sudden life-threatening arrhythmias, (a general term for any abnormal heart rhythm, where the heart is not beating in sinus rhythm).

Cardiac resynchronisation therapy (CRT) - See Page 10





Head of Services Ali Thompson and Support Nurses Robert Hall, Jayne Partridge and Emma Greenslade answer your questions

Q: I love to cook and am concerned whether my induction hob in my kitchen could affect my ICD?

Support Nurse Jayne says:

Most household equipment, including microwave ovens, should not affect your ICD (or pacemaker).

However, if you use an induction hob for cooking, guidance from one of the manufacturers Medtronic is that you should maintain at least a 2ft (60cm) separation between the stove top and your ICD as the hob generates an electro-magnetic field that may interfere with your device settings.

This is because a magnetic field heats the metal pots directly only when they are placed on the stove top.

The stove top remains cool to the touch, while the metal in the bottom of the pan interacts with the magnetic field causing the heating of the metal.

But if you're planning to upgrade your kitchen in the future, it would be advisable to choose a conventional electric hob.

Q I'm trying improve my fitness and wondered if it was okay to wear a Fitbit as I have an ICD?

Support Nurse Robert says:

There's no reason why you shouldn't wear a Fitbit, or similar device. There's no reported evidence that these affect pacemakers or ICDs.

Q How do I make sure my child takes his medication?

Support Nurse Emma says:

It is important for both parent and child to fully understand their medication, along with the reasons why compliance is so important.

If you are having difficulties, it may be useful to change the formulation of the medication as they grow - ie: from tablets to liquid, or vice versa, and even the flavouring, depending on the age and size of your child.

Pill boxes are also very useful for children who are taking medications in pill formulation.

If your child is having difficulty swallowing a large tablet, it may be possible to replace that dose with two smaller tablets that will be easier to swallow.

A child or young adult may report having taken medications when in fact they haven't, or they may simply forget.

In these cases, they may benefit from the use of a mobile phone reminder, or some other electronic prompt.

Why not try having a note next to the bed or in the bathroom?

Make sure you approach medication compliance at every visit with your cardiologist and nurse specialist about how your child's medications are being taken and remember to always tell them if you are having difficulty.



If you have questions you would like the team to answer, email them to:
contact@cardiomyopathy.org

CRT gets your heart in sync

If your heart is not beating efficiently and you meet the criteria, you may be eligible for a cardiac resynchronisation therapy (CRT) heart device, which improves the heart's efficiency and in effect, "resynchronises" the heart so both sides beat in sync and thus helps the heart to pump more efficiently.

What is CRT and how can it help your heart?

CRT is used to help improve the heart's rhythm and symptoms associated with arrhythmia in heart failure patients.

The procedure involves implanting a pacemaker, (about the size of a pocket watch and weighing about 3oz) just below the collarbone.

The device has three leads, (one more than an ICD). The additional lead is attached to the left ventricle to monitor the heart rate to detect heart rate irregularities and emit tiny pulses of electricity to correct them.

Who is a candidate for CRT?

In general, CRT is for heart failure patients with moderate to severe symptoms and whose left and right heart ventricles are not beating in unison.

However, CRT is not effective for everyone and not advised for patients with mild heart failure symptoms, diastolic heart failure, or who do not have issues with the ventricles not beating together.

It is also only suitable for patients, once they have fully explored medication therapies and is often combined with other treatments to achieve the best results.

Benefits of CRT

Patients have reported alleviations of some heart failure symptoms - such as shortness of breath and studies also suggest CRT reduces the need for patients to be treated in hospital.

Why I Can Dream again



Being told he should have an ICD was a landmark that things were getting worse for Andrew Kaponi

"Deep down I, probably like others, thought I could beat my dilated cardiomyopathy and if not beat it, then at least control it.

"So when I was told I should have an ICD fitted, I felt numb," says Andrew Kaponi, 42, from London.

The father-of-two was at high risk of having a cardiac arrest and was told he would probably have an SCA in the next five years.

"When I was told I should have an ICD I felt numb. It meant so much for me. It meant this condition I was living with and having to adapt to, was not just an inconvenience and a life changer, but also a danger to my life."

Andrew swiftly set about finding out everything he could about ICDs - speaking to other patients, inspecting the devices and even speaking to people who worked at the manufacturers.

"When I went for my consultation, it was a bit like that advert where

the car salesman is trying to tell the customer all about the car's performance, while the customer is finishing his sentences because they know it all!" he recalls.

However, Andrew was pleasantly surprised to learn that home monitoring means wherever he is in the world (bar a few countries), there will be a team monitoring his ICD and knowing if something is wrong.

"That was an "oooh" moment for me," he admits, "so not only was this thing potentially going to save my life, but also, there are people somewhere out there, who have got my back.

"It's like a double safety net - cool I thought!"

Andrew admits he is prone to doom and gloom and in the run-up to his operation, went through a period of "mourning" his previous life and the fear he might not survive the procedure.

"I realise now how silly I was, but I took on board the chance of dying during the operation. Death didn't scare me and it was more a practical thing, so I did a few things like leaving secret, but findable messages and memories for my family once I was gone.



'I have learnt to

Mark Haberland, from London, has learnt to accept the side-effects of his LVAD (left ventricular assist device)

Having being diagnosed with dilated cardiomyopathy at the end of 1999, while living in Germany, Mark Haberland was successfully treated with medication.

After returning to the UK, he continued with his six-monthly check-ups and was soon classified "healed".

Left: Andrew Kaponi with wife Tina and children Christina, 11 and Steven, seven

"I also tried to sort out my affairs and say goodbye to people and visit things for the last time.

"I wanted to see everyone dear to me and I did pretty much. I also wanted to eat some of my favourite meals - which I did - and I went to church too."

Andrew also prepared for if he "survived", including buying loose-fitting shirts to wear post-op.

"On the day of the operation, it felt like I was preparing for an exam, so nerves set in and I woke up early and prepared myself," he recalls.

"I helped get the kids ready, fed our dog Alfie and walked the children to school, before I got on the bus to the station to get the train to St Bart's Hospital.

"I gave the kids and my wife a huge kiss and hugs - thinking that, after all, it may have been my last.

"Carrying my unduly heavy hospital bag, I set off on my green mile.

"On the train, I remember looking at people thinking, 'They're going to work, thinking about their lives oblivious to more serious things'.

"I thought they should be happy, but they looked so miserable.

"I had been one of them before, now I'm not - now my life is more complicated and in many ways, clearer.

"When I got to the hospital it all changed. It felt like I was having an appointment for a standard matter and everything ran smoothly.

"I was very comfortable from beginning to end and have had dental work that's been more painful than the ICD



being put in!"

Andrew now says he was wrong to think of his surgery as a major heart operation.

"Of course it's not a heart operation - it's an implant of a device that has leads going into the heart. Evasive and potentially life-threatening, but not that complicated with today's medical science," he reasons.

Andrew chose to have his ICD fitted under local anaesthetic sedation.

The one-hour operation went smoothly and says he "didn't feel a thing" when the ICD was tested.

Following a short wait - while X-rays were taken to see if the leads and everything were okay - he was discharged.

However, by the time he returned home, the drugs were no longer working and Andrew had to smile through gritted teeth and kiss and hug his children as best he could.

"That evening was a mixture of happiness, discomfort, pain and an upset tummy - not the easiest night, but the happiness got me through it," he says.

And in the days to follow, Andrew

was grateful for the advice from our Cardiomyopathy UK's support nurses that he was able to take stronger painkillers at regular times.

"The first few nights were tough pain-wise and I needed pillows to keep me propped up on my side, (other side to ICD), but it did get better after a week. There was also pain and dizziness the first few days and I had to remember not to use the arm the side of the implant," he reveals.

Most ICD patients give themselves at least a month to recover and Andrew also recommends staying as mobile as possible within the home and stretching, whilst taking care of the implanted side and resting as needed.

"The procedure went like clockwork and the wound is healing well. I've now got a lifesaver in me - a guardian angel - and a team behind it, who are keeping an eye on me.

"I might be part-machine now, which is pretty cool in my book, but it might mean that I'm here a bit longer and I might achieve my dreams; seeing my kids grow up.

"I hope that everyone who has cardiomyopathy and needs an ICD gets one. It's a great thing to have. Yes, there are limitations - like you shouldn't go swimming by yourself; scanners and magnets are bad for you and you can't drive for a bit, but the upside is massive.

"But it's more than an upside - the ICD means I can dream again and look ahead. It's now time to get on with life - my new life."



Andrew Kaponi is a Financial Consultant for Cardiomyopathy UK

accept the LVAD for what it is'

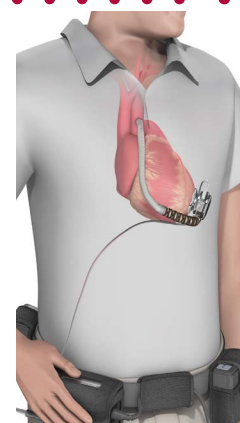
But in 2014, he was admitted to A&E by his GP, who was worried about Mark's recurring and worsening colds and extremely swollen feet and ankles. Mark suffered a blood clot-related stroke and LVAD surgery was regarded as urgent to keep his heart pumping.

Complications meant Mark was kept in hospital for nearly six months and is now likely to need a heart transplant. But thanks to his implanted

pump, his positive attitude and the support of family and friends, Mark copes with all the "annoying" side-effects, such as the LVAD constantly hanging over his shoulder.

"I have learnt to accept the LVAD for what it is - the reason I can again do or work towards doing most activities," he says.

■ **What is an LVAD? See Page 14**



An overview of PPCM

By Robert Hall
Support Nurse



Cardiomyopathy UK is dedicated to raising awareness of peripartum cardiomyopathy (PPCM) among obstetric and midwifery staff and has previously organised a national conference, as well as supporting a regional conference in Cumbria.

PPCM is rare and although it can affect women at any age, it seems to be more common in those over 30.

Similar to dilated cardiomyopathy, it can occur in the last month of pregnancy, or the ensuing five months following delivery.

The heart becomes enlarged and weakened and less able than normal to pump blood.

Whilst relatively rare, there are geographic variations in the incidence of the condition, generally stated between one in 1,000 to 4,500 live births.

The cause of the condition remains uncertain, with genetics and auto-immune response being implicated. For example, one theory is that the mother may have a genetic predisposition and the additional workload place on the heart due to pregnancy may cause the condition to develop.

Symptoms include breathlessness, fluid retention, fatigue and palpitations.

Awareness of the condition is essential, as it is important not to assume these are merely the effects of pregnancy and to make a cardiology referral if appropriate.

Treatment is the standard heart failure therapy. Although PPCM is serious, around 70% of women recover within a year, (based on their ejection fraction), rather than their symptoms and some will require ongoing therapy.

However, future pregnancies need to be discussed with a cardiologist so the individual level of risk can be assessed.

■ For more information on PPCM, go to www.cardiomyopathy.org or call 01484 791224

CLAIRE'S STORY

Did you have a normal pregnancy?

Yes, completely normal until the last few weeks of my pregnancy when my blood pressure was rising and dropping dramatically and I had slight fluid retention around my ankles

It wasn't until my waters broke that I noticed I must have been carrying a lot of extra water as they didn't stop coming for a very long time.

There were also signs during my labour, as I failed to dilate past 2cm in 38 hours since my waters broke.

In the end, my heart rate started dropping, so they had to rush me in for an emergency C section.

How did you first hear about PPCM?

It was my neighbour's daughter who lived in Dubai at the time, who after discussing my symptoms, told me that it could be PPCM.

On my eighth visit to my doctor's, I asked about PPCM and was told I'd be in a medical journal if I did have it.

The doctor seemed very amused when I suggested the condition and made me feel very silly.

Did your symptoms improve after diagnosis?

At diagnosis, on September 26, 2014, my heart function was at 20-25%.

I was in hospital a week where they worked on getting the water around my lungs out of my body. They also carried out the angiogram and got me on the right level of medication.

Then after three months, I had another echocardiogram that showed improvement to 40%.

Then by May 2015, my heart function was at 50%. My heart has not improved further since then and I continue at 50% heart function.

After seeing my cardiologist in February, they believe I still have a chance of reaching recovery 55-60%.

What medication do you take?

I'm currently on Ramipril 6.25mg, Bisoprolol 8.75mg, Spiractolone 25mg and Ivabradine 10mg. My Bisoprolol and Ramipril will be increased in August to 10mg, all being well.

Hopefully, I'll be able to cope with the highest medications for a year, then a follow-up echo will determine



if they can start lowering the dose. I'll be on medication for the rest of my life, but hopefully, this will be with a recovered heart and a reduced dose.

How do you feel today - four years after diagnosis?

Daily life is a challenge. The fatigue and dizziness are the worst after a busy day and on a Thursday morning, after working two 10-hour days, I do feel like a train has hit me.

But four years after diagnosis, I'm hopeful and positive for the future, filled with a recovered heart and life taking me down paths/experiences I never even thought could be possible.

I now know how to manage my condition; knowing when to rest; what different symptoms mean and what to do when I have them.

I may have PPCM, but I won't let it define who I am.

It's a condition I live with - not that controls my life.

Claire is part of online support groups, but there are not any heart failure support groups locally and she would love to connect with others in the Newport area, who have heart failure.

If you can help, please contact Cardiomyopathy UK (details on Page 2) and we'll put you in touch.

'My dream is to dance with Flynn at his wedding'

A diagnosis of PPCM means Claire Sheppard, from South Wales, may never have the large family she always dreamed of, but being a mum to Flynn is a gift she treasures

Like many families this summer, Claire and Steve Sheppard will be setting off on their annual holiday with their son Flynn, who turns four on August 7.

But unlike most families, the chance to relax and spend time together is particularly precious to Claire, who juggles being a busy mum with the daily challenges of living with peripartum cardiomyopathy (PPCM).

Claire, 34, who works part-time as a complaint manager for Lloyds Bank, noticed her symptoms starting three weeks after Flynn was born.

"In the end, the only way I could sleep was when utterly exhausted, sat up with my head on a pillow against the bedroom wall," she recalls.

"Then during the day, I'd feel exhausted all the time. I felt dizzy and lost my appetite completely."

Claire spent those first three weeks back and forth to her doctor's surgery with newborn Flynn in his car seat.

When she suggested PPCM, one GP dismissed her concerns - branding her an over-anxious new mum.

But one night, as her symptoms started to get a lot worse, Steve took Claire to A&E and an echocardiogram confirmed her suspicions had been correct.

"When the echocardiographer said during the scan that I had the condition, I could have cried with joy as someone took me seriously and knew what was making me so ill," she adds.

Despite "counting her lucky stars" she did not need to have a heart transplant or pacemaker, the hardest part of being diagnosed with PPCM for Claire is not the lifelong medication of beta blockers and ACE inhibitors, but being told "no" to having more children.

"I always dreamed of having a large



family and adore children," admits Claire.

"I've had a second opinion with a pregnancy cardiologist and been told that even if I reach recovery, I still run a 25% chance of death in my next pregnancy.

"Also, they don't think my heart can function without a certain level of medication.

"To be honest, I cried myself to sleep almost every night for a few months afterwards.

"I think I needed time to mourn the children I will not be able to have and the brothers/sisters I won't be able to give Flynn," she adds.

But during that time, Claire managed to see her life would take another path and has since thrown herself into an "amazing" community of friends with children, who ensure Flynn is never lonely or without someone to play with.

"My friends are fantastic and understand my limitations - although I've been told I do more than most 'normal' mums!

"Meanwhile, Flynn has pictures of

him and his friends on his bedroom wall to remind him and me of how many 'brothers/sisters' he has," says Claire.

"He's never once asked me for a brother or sister, as I hope he feels completely loved and content.

"We like to take Flynn to a new country each year and take him on as many adventures as possible. Life's an adventure and why not start them experiencing that adventure young?" she explains.

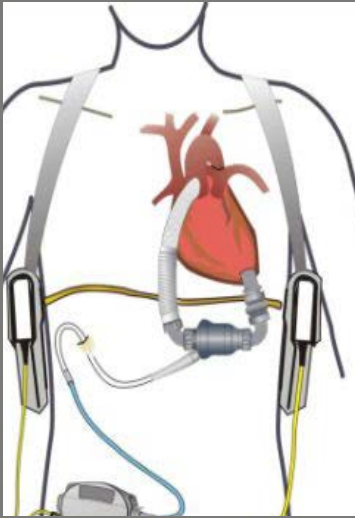
"Of course, adoption if always an option in the future and that might be a path we'll go down when Flynn is a bit older. I need to focus at the moment on reaching recovery.

"Although my heart may be 'broken' it is filled with a lot of love to give another little one.

"Having PPCM has changed my outlook on life completely. Flynn is a gift and so is my life - gifts I plan on enjoying to the full and will never take for granted.

"My dream is to dance with Flynn at his wedding and I truly hope I will be there."

Pump up the volume



What is a left ventricular assist device (LVAD)?

A left ventricular assist device (LVAD) is the most common device applied to a defective heart. An LVAD is a powerful, battery-operated, artificial pump that's surgically implanted to help increase the output of the heart's left ventricle when it can't effectively work on its own.

When is an LVAD used?

An LVAD is sometimes called a "bridge to transplant," but at present, is only permitted on the NHS for people, who have very severe heart function problems, while awaiting a transplant. An LVAD can "buy time" for the patient or eliminate the need for a heart transplant. Most recently, LVADs are being used longer-term as 'destination therapy' in end-stage heart failure patients when transplantation is not an option.



Small is beautiful



By Jayne
Partridge
Support
Nurse

What is an implantable loop recorder?

An implantable loop recorder (ILR) is a device, similar in size to a memory stick, which monitors and records the electrical activity of the heart.

Why do I need an ILR?

You may be experiencing symptoms that have not been detected by previous ECGs or a Holter monitor, such as palpitations, dizziness or blackout/fainting episodes.

The ILR monitors and records any abnormal rhythms.

If you experience any symptoms you hold an activator (the size of a computer mouse) over the ILR and press a button on the activator to record your heart rhythm.

It is important to carry the activator with you at all times. A recording will then be stored for analysis later by your device team.

How is the ILR implanted?

The ILR insertion is usually performed as a day case. It is inserted beneath the skin in the upper chest under local anaesthetic (to numb the area of the skin).

The procedure takes around 15-20 minutes and the wound is stitched using dissolvable sutures.

A small dressing will be applied to cover the area.

What happens after it is implanted?

A cardiac physiologist programmes the ILR to required settings just after implantation, which only takes a few minutes and using your activator will also be explained to you at this time.

What happens when I get home?

After the procedure you should be able to go home and rest. You may eat and drink as normal and sleep in your usual position at night.

The morning after, you can have a wash or a bath, but you must keep the wound completely dry for seven days after the procedure. The wound dressing should remain in place for seven days after the procedure.

To help the wound heal, you should avoid raising your arm above shoulder level on the side of the ILR for 48 hours after the procedure. However, it is important to keep gently moving your shoulder, but avoid lifting, pushing or pulling anything heavy until the wound has healed.

You will be given an identification card and activator - both of which you should keep with you at all times. The card has the details of your ILR and its settings.

How and when will my ILR be removed?

Removal will be when your heart's activity has been monitored sufficiently, or it has been three years after implantation. It is similar to the implantation procedure and will usually be performed as a day case.

Always follow specific advice from your cardiologist, device team or cardiac nurse.

'Out of the mouths of babes'



Dr Juan Pablo Kaski is a Consultant Paediatric Cardiologist at Great Ormond Street Hospital & Honorary Senior Lecturer at UCL Institute of Cardiovascular Science

How did you become a paediatric cardiologist and what made you choose this career?

Ever since I was a medical student, I have been interested in the workings of the heart and circulation. I have always liked the idea that you can work out what's going on in an organ that's hidden from view, by listening to the patient and using clues from different tests, like the ECG.

Both my parents are doctors (my dad is an adult cardiologist) and they have been an enormous inspiration to me. I have also always liked talking to children and listening to what they have to say and really enjoyed my paediatric rotations as a student, so I thought I could combine these two passions by training in paediatric cardiology.

What field do you mainly work in and how long have you been working at GOSH?

I specialise in inherited heart diseases in children and have been working at GOSH in this field since 2004 - initially as a research fellow and junior doctor and since 2011, as a consultant.

I have been very lucky to have been supported by my colleagues at GOSH and UCL to set up the GOSH Centre for Inherited Cardiovascular Diseases, which is now the largest centre in Europe dedicated to caring for children with inherited heart diseases.

How do you divide your time between inherited cardiovascular/paediatric work/lecturing?

I am really fortunate to be able to dedicate all my clinical time to paediatric inherited cardiovascular diseases. We run several specialist clinics within our Centre at GOSH for children with different genetic heart conditions, including specialist hypertrophic cardiomyopathy clinics twice a week for children with HCM, or who have a family history of HCM, as well as clinics for other types of cardiomyopathy.

I also really enjoy lecturing - I have learnt a great deal from the children and families I look after and I am privileged to be able to share this knowledge with other professionals.

What does a typical day look like?

One of the great things about working in this field is

that no two days are the same! I usually do the school drop-off in the mornings, and then I'm either in clinic all day, or in the office doing paperwork and attending meetings.

I also try to dedicate at least one and a half days a week exclusively to research.

What do you most enjoy about your work?

The most rewarding and enjoyable bit of my job is seeing my patients thrive and develop as they grow up - sometimes overcoming significant challenges related to their cardiomyopathy.

It is a privilege to be able to look after children, often from the moment they're born, through childhood and adolescence, and to see them become young adults.

It's very sad when the moment comes to transition their care to our adult colleagues, but I'm now beginning to look after their own children, which is amazing.

What are the challenges?

One of the biggest challenges of my job is to get the balance right between protecting children from the potential risks associated with their heart condition and allowing them (and indeed encouraging them) to live normal lives, so that the social and psychological impact is as small as possible.

We are very lucky to have a team of excellent specialist nurses and psychologists within our centre to help us achieve this.

One particular example of this is the use of ICDs in children. We know these are potentially life-saving devices, but they can also be associated with significant complications and psychological issues and so we always work very closely with the child and family beforehand to make sure we can anticipate and address any issues that might arise.

What are your research interests and are you currently working on anything in particular?

My research interests are focused on two aspects:

1: Detecting very early signs of cardiomyopathy in children by measuring new markers in blood and urine tests and advanced imaging techniques, such as MRI, to see if we can eventually prevent the condition developing; and 2: Identifying markers of increased risk of ventricular arrhythmias (dangerous abnormal heart rhythms) in children with HCM.

I am currently leading an international project aimed at developing a new model to predict risk in children with HCM, which will hopefully allow us to better identify which children would benefit from an ICD. This work is being coordinated by Dr Gaby Norrish, one of my PhD students.

Do you have any hobbies?

I enjoy spending time outside work with my wife and three children and this keeps me very busy.

I have also recently started playing tennis again after many years, having joined my local 'Rusty Rackets' club - although I hadn't realised quite how rusty my racket was!

Up, closed and personal

Online groups offer support anytime and anywhere

Traditional arenas for clinical and emotional support might include the GP's surgery, the therapist's office and the family living room.

However, today's society has seen a shift from these more recognised avenues of seeking support, to online communities - where people are sharing experiences, seeking advice and participating in reciprocal peer support.

Cardiomyopathy UK has long recognised the benefits of providing our service users with a safe and supportive platform, which enables them to share their stories about cardiomyopathy, whether they have been diagnosed, or are supporting someone with the condition.

The charity currently operates three closed Facebook groups:-

- A general group for people diagnosed with the condition and their carers,
- A group specifically for supporters and carers of someone with cardiomyopathy and,
- A group for 14-25 year olds affected by the condition.

The nurses and some staff are members of these groups and can be contacted for clinical advice (nurses only), information on benefits and welfare rights, accessing charity events such as information days and local face to face support groups and the charity's services.

A team of nine administrators are responsible for the daily monitoring of the groups and ensuring that the rules of the group are being adhered to by members.

As with any large community (the generic closed group has in excess



topics such as types of treatment or common drugs. They also respond to direct messages members send when they want to speak privately about their health to a nurse.

Popular topics include medication, clinical appointments, devices and applying for Personal Independence Payment (PIP).

The charity historically offered a forum that was moderated by the

nurses, but given the popularity and accessibility of Facebook, the forum was closed and the Facebook closed groups took off.

In order to keep our service users safe, we have a number of core rules that all members are expected to agree to and uphold, eg: only the nurses are permitted to provide clinical advice; no one should be discriminated against and no one should post anything of a potentially defamatory or inflammatory nature.

One of the main advantages of the Facebook groups is accessibility - members can access the group via their PC or phone, and anywhere they have Facebook installed.

Services users can post to the group and contact the charity/nurses wherever they are and the nurses are available Monday to Friday, from 8:30am until 4:30pm, so people who are working can make contact discretely during office hours.

Our Facebook closed groups do make a real difference to people's lives and as one service user posted: "This group has been my life line. Without it I don't know what I would have done."



**By Ali Thompson
Head of Services**

of 4,500 members) there can be differences of opinion and opposite views.

Healthy and respectful discussion is encouraged and if a member feels that they or someone else are being treated without respect, they can alert an administrator who will step in.

The groups afford members the opportunity to read and learn more about cardiomyopathy and how other people manage the condition in their daily lives.

The charity's specialist cardiac nurses respond to clinical questions posed within the groups and post about

Left: Chris Johnson raised an incredible £8,279.12 for his nephew who was diagnosed with hypertrophic cardiomyopathy at 16 months' old. Below: Helen Macken ran for her sister Liz and her mum who both have cardiomyopathy and has raised £4,086



Above: Dylan Hughes ran in memory of his schoolfriend who had cardiomyopathy and raised £2327.50



Left: Leon Lima, who almost lost his son Luka when he was eight months' old from DCM, has raised £2,748.30 and was our first runner to cross the finishing line

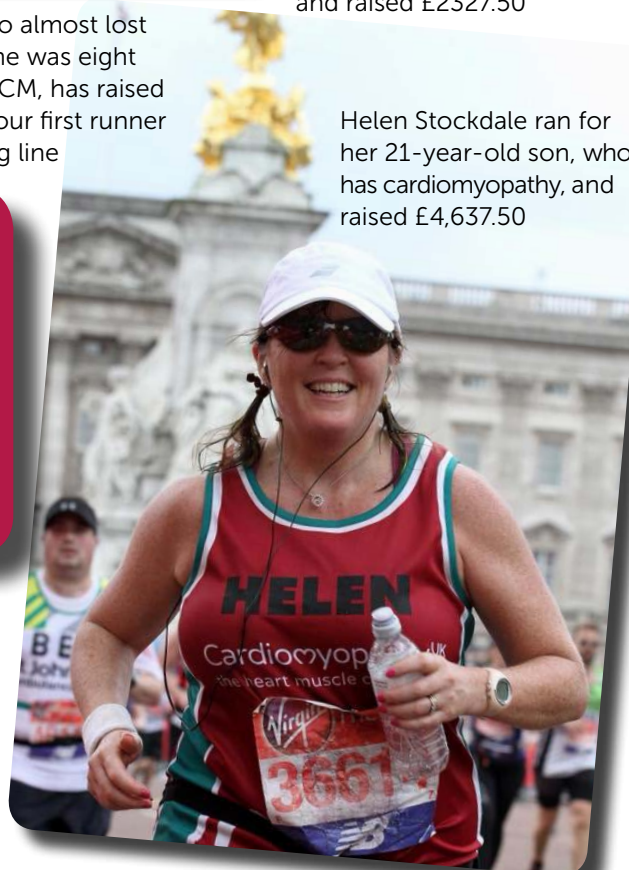
Take a look at our incredible #teamcardio runners, who took to the streets of London in April for the iconic Virgin London Marathon 2018 and continued smiling despite running in the hottest marathon to date.

Each one of our 47 runners did an amazing job and worked so hard raising a phenomenal £118,000, including Gift Aid, for Cardiomyopathy UK.

We cannot thank you enough and look forward to doing it all over again in next year's event.

If you want to join #teamcardio for the **2019 Virgin London Marathon**, then please take a look at our website <https://www.cardiomyopathy.org/vlm2019>

'Thank you for giving me the opportunity to run the marathon for Cardiomyopathy UK. What a brilliant and emotional experience, which I shall never ever forget' -
Gill #teamcardio 2018



Helen Stockdale ran for her 21-year-old son, who has cardiomyopathy, and raised £4,637.50

Messing about on the river

A corporate rowing event took place in June at Dorney Lake - the home of the Olympics - in aid of the Alexander Jansons Fund that offers help and support to people with myocarditis. Each boat consisted of six rowers and one cox rowing a distance of 350m in three timed heats and then a very tense final, which was won by "And Then There Were None" team (pictured right). For more information about AJF fundraising events, please contact fundraising manager Patricia Dean at:

alexanderjansonsfund@cardiomyopathy.org



We can find the right challenge for you

Sign up to an event and help us raise vital funds to support our work

★ Ultra Challenge Series

Whether you're a walker and new to endurance events, or a corporate team looking to up the company challenge, this could be just the event for you.

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Resolve will be tested and spirit will be required - with new friends made enroute and an overwhelming sense of achievement as you finish.

Join us today, via our website:

<https://www.cardiomyopathy.org/walks-and-treks-home>



Bournemouth Marathon Festival

Be part of this stunning seaside festival of running for the 2018 Bournemouth Marathon Festival.

With races from 5km right up to a full marathon, there is a distance to suit everyone.

Bournemouth Marathon Festival is one of only five races in the UK to have also been awarded a bronze status by the International Association of Athletics Federations. There are even junior races on offer, so why not bring the whole family and make a day of it?

Location – Bournemouth

When – 6 - 7 October

Distance – 5km, 10km, half and full marathon

To register or for more information, please visit:

[cardiomyopathy.org/bournemouthmarathon](https://www.cardiomyopathy.org/bournemouthmarathon)



★ When the going gets tough, the tough get going

Are you considering a corporate team-building event? Then we have just the thing for you.

Join #teamcardio for the 2018 Tough Mudder series and sign up to an awesome experience you and your work buddies will never forget.

With an event for every fitness level - starting at 5K of pure obstacle fun and ending with 10 miles of mud and ice - there's

no excuse not to get out from behind your desks.

Don't think you can convince your colleagues to spend their weekend in a field? Tough Mudder 5K is in the heart of four major cities across the UK and even offers the chance to hang out after hours on a Friday night with Tough Mudder 5K - Up Late.

<https://www.cardiomyopathy.org/tough-mudder>



July

28th July, 12-2 pm

Chelmsford Support Group

Summer Social in the beer garden at The Tulip, Church Lane, Springfield, Chelmsford, CM1 7SF

Tel 01494 791224

Email jo.franks@cardiomyopathy.org

August

18th August, 2:30-4:30 pm

West London Support Group

Theme tbc

Friends' Meeting House, 17 Woodville Road, Ealing, London, W5 2SE

Tel 01494 791224

Email ealingcardiogroup@yahoo.com

September

5th September, 2:30-4pm

ARVC Online Support Group

with Jayne Partridge, Support Nurse

Email www.cardiomyopathy.org/shared-experiences/online-support-group-arvc

8th September 3 to 5pm

Sussex Support Group

Alison Warren, Consultant Pharmacist, Cardiology The Friendship Centre, Mayfield Avenue, Peacehaven, East Sussex, BN10 8PB

Email cardiomyopathysussex@gmail.com

Tel 01494 791224

8th September, 2-4 pm

Bridgend Support Group

CPR & automated defibrillator session

Pencoed Welfare Hall, Heol-Y-Groes,

Pencoed, Bridgend CF35 5PE

Email anniej@btinternet.com

Tel 07970 669239

13th September, 7-9 pm

Cheshire and Merseyside Support Group

Martin Richards from Involve North West will be talking about claiming PIP and other benefits

Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port, CH65 2AL

Tel 07949 241026

Email julierees65@aol.co.uk

CARDIOMYOPATHY UK NATIONAL CONFERENCE

Bookings are now open via our website, so you can book yourself a place online. Support Group leaders are entitled to a free place and Support Groups booking 5 or more places get a discounted rate of £10

(See details overleaf)



15th September, 2-4pm

Bristol Support Group

Theme tbc

Brookway Activity Centre, Brook Way, Bradley Stoke, Bristol, BS32 9DA

Tel 01494 791224

Email jo.franks@cardiomyopathy.org

15th September, 2-4pm

Cumbria Support Group

Treatment options, Robert Hall, Support Nurse

Penrith Methodist Church, Wordsworth Street, Penrith, CA11 7QY

Tel 01494 791224

Email jo.franks@cardiomyopathy.org

15th September, 1:30-3:30pm

Chelmsford Support Group

Relaxation, breathing and mediation Springfield Parish Centre, St. Augustine's Way, Springfield,

Chelmsford, CM1 6GX

Tel 01494 791224

Email jo.franks@cardiomyopathy.org

October

7th October, 12-3pm

West Scotland Support Group

Theme tbc

Glasgow Royal Infirmary, Castle Street, Glasgow, G4 0SF

Email sg.kirkham@btinternet.com

Tel 01494 791224

8th October, from 7:15pm

South London Support Group

Theme tbc

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY

Tel 01494 791224

Email jo.franks@cardiomyopathy.org

CONTACT US

Phone us on 01491 791 224, email contact@cardiomyopathy.org or visit www.cardiomyopathy.org

for information on:-

- Support groups
- Registering for an event
- How we help people affected by cardiomyopathy

National conference 2018

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living better**

Saturday 27 October 2018

Holiday Inn Liverpool, Lime Street, Liverpool, L1 1NQ

- Hear from expert speakers
- Share your experiences about emotional wellbeing and lifestyle
- Meet others with cardiomyopathy, and family, friends and carers



**Prof Perry
Elliott**



**Prof John
Somauroo**



**Dr Graeme
Gillespie**



**Dr Antonis
Pantazis**

**To book your place visit
www.cardiomyopathy.org/natconf2018**