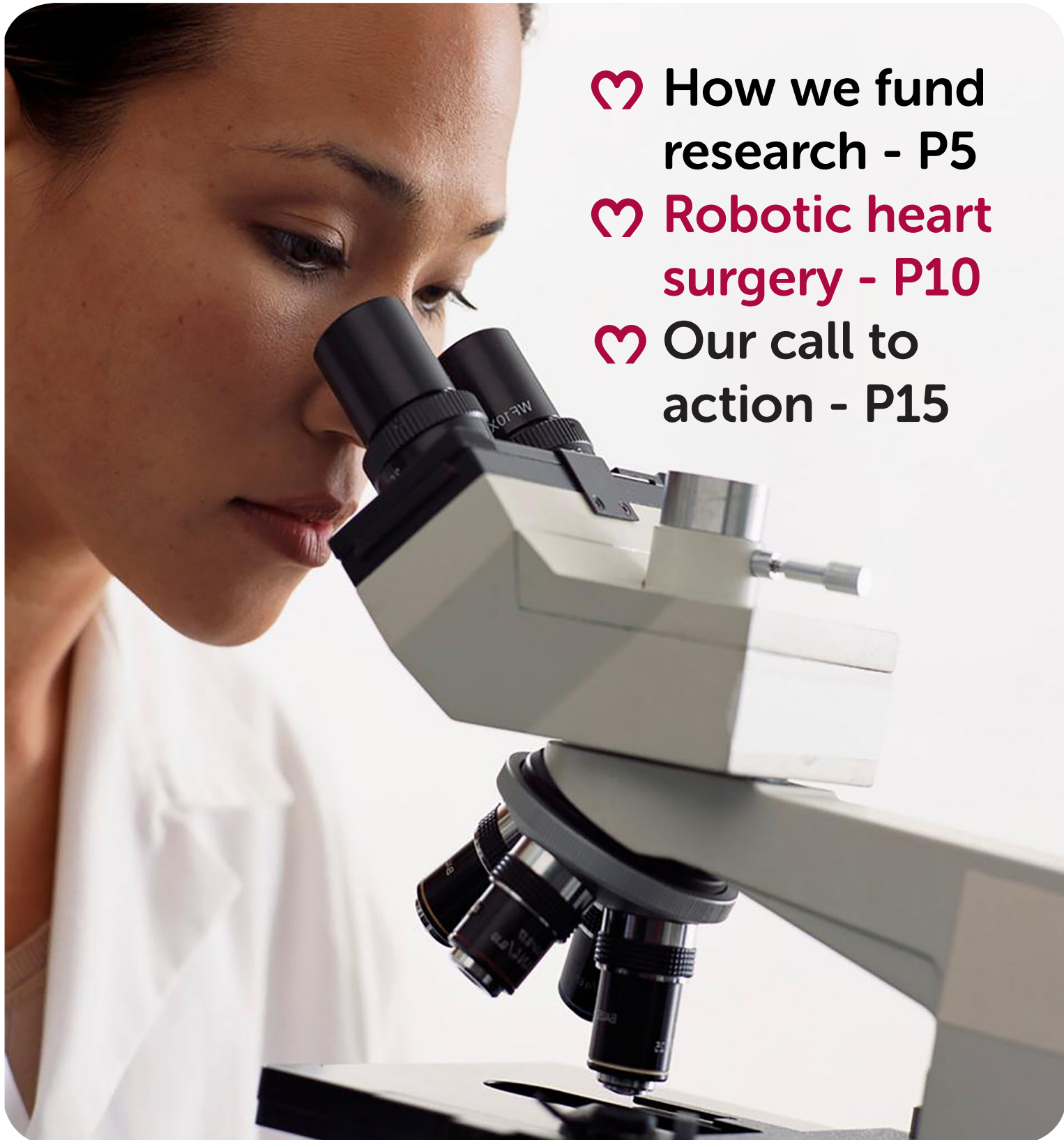


my life

Issue 19/July 2019

Cardiomyopathy^{UK}

The magazine for people affected by cardiomyopathy and myocarditis



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#teamcardio
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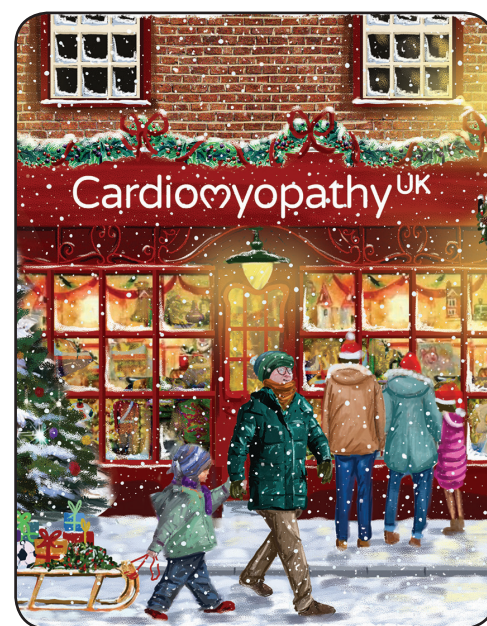


Research - Page 5



Robotic surgery
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GET AN EARLY START FOR CHRISTMAS!



CHRISTMAS CARD CATALOGUE
INSIDE THIS ISSUE OF MY LIFE

Who's new to the team



Becky Bryant
Challenge Events Fundraiser



Adam Thomas
AJF Fundraiser



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Head of Finance & Operations

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Live Chat

www.cardiomyopathy.org



Facebook

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[@cardiomyopathyuk](https://www.instagram.com/cardiomyopathyuk)





Welcome

**from Alison Fielding
Chair of Cardiomyopathy UK**

relevant and the results can be trusted.

Funders – both public and private – have poured millions into research to ensure we live better lives.

Please take a moment to read Joel Rose's account on **Page 5** of how Cardiomyopathy UK helps research too.

But the people most to thank are the generations of patients, who agree to be part of trials, whether or not they expect to see any personal benefit.

We hope our partnership with the Heart Hive will make it easier to connect patients with researchers and anyone who is interested can make a real difference to the next 30 years.

So much has changed in the 30 years since Cardiomyopathy UK was formed.

Research findings and changes in clinical practice mean that most people have far better outcomes than previously.

This is why one common piece of advice to our Facebook community is always: 'Don't Google – prognosis figures are out of date.'

There are many parties to

thank for these improvements, including the laboratory-based scientists looking at heart function and diseases. Our clinicians often combine seeing patients with research duties; taking research to the clinic and patients in order to help practice.

These clinical trials have whole teams of trial managers, statisticians, ethics advisers, peer reviewers and patient advocates ensuring that they are ethical,

Summer celebration lunch

**By Christie Jones
Community Fundraiser**



Summer is here and what better time to get together with family and friends to enjoy some great food for a great cause?

Once again, we've teamed up with gourmet chef Ian Human to create six

exclusive recipes to make this a summer to remember in our 30th anniversary year.

Ian has reinvented summer lunch with some mouth-watering recipes that work perfectly together and are full of delicious flavours and healthy ingredients.

The great thing about these recipes is that you can easily substitute any of the ingredients to suit your guests' individual tastes, allowing you to be as creative as you like with your menu.

Hosting a celebration lunch couldn't be easier – just head to **cardiomyopathy.org/30lunch** for sign-up information, ideas and more.

Your fundraising pack includes **six FREE recipe cards**, as well as a fundraising box to collect your guests' donations on the day.

If there's anything else you need, please let us know by emailing fundraising@cardiomyopathy.org or give Christie a call on 01494 791224. Bon appétit!



Pea, Broad Bean, & Edamame Salad with toasted seeds & feta

Carrot Salad with rose harissa, yoghurt, mint, & hazelnuts

Roasted Beetroot, Goat Cheese, Pecan Nut, & Spring Onion Salad

Pork & Rosemary Sausage Rolls with dried apricots

Spinach, Sun-Dried Tomato, & Olive Quiche

Pear, Carrot, & Apple Muffins for dessert

'We're overwhelmed by support for our work'

► New ways to connect patients and researchers are giving fresh hope of finding cures for cardiomyopathy and myocarditis

Researchers at Imperial College London are set to launch a ground-breaking project this summer, partnering scientists with the public.

Anyone with an internet connection can join the Heart Hive and directly contribute to the latest research into heart muscle diseases.

Heart Hive is spearheaded by Dr James Ware, consultant cardiologist and research group lead, and Angharad Roberts, consultant clinical geneticist and research fellow.

Dr Ware said: "The idea emerged from our conversations with patients.

"We want to put patients in the driving seat; connect them with research opportunities; show them what research is going on, and allow them to self-enrol in studies."

The Heart Hive platform gives patients access to the latest research projects while at the same time, giving researchers access to large data sets.

This enables research to be done faster and possible cures and treatments to be discovered sooner.

The Heart Hive team initially developed the platform with seed funding and have since run a successful crowd-funding campaign on Crowdfunder, which attracted more than 200 supporters and raised just over £40,000.

This was backed by Cardiomyopathy UK's Alexander Jansons Fund, which matched crowdfunder pledges up to £20,000.

Crowdfunding enables people to come together to fund the things that matter to them and thanks to this grass-roots support from the engaged community of people with



Dr James Ware
Research group lead &
Dr Angharad Roberts
Research fellow

cardiomyopathy and myocarditis, money has been raised to fully launch the platform and run a pilot research project to start recruiting participants.

Every penny will be used to empower those affected by heart muscle disease to drive research into their conditions.

Joel Rose, Chief Executive of Cardiomyopathy UK, said: "We are delighted to be supporting this project.

"It brings together researchers and people with heart muscle conditions and will prove a massive boost to research assets.

"And ultimately, it will help lead to better treatments for patients."

Dr Roberts added: "All our research is working to improve treatments and patient care.

"But we can't do it alone – the more people who take part, the more powerful the research is.

"During development, we sought the opinions of patients to ensure we build something they want and that they can use easily.

"We've been overwhelmed by the support we have received and the



Please consider signing up to join the Heart Hive community via the website at thehearthive.org and spread the word to give as many people as possible the opportunity to get involved.

Follow @thehearthive on **Twitter** and retweet the messages.

Like @thehearthive on **Facebook** and share their posts.

Follow @the_heart_hive on **Instagram** and like or share what the research team is doing.

feedback from the community in response to the platform and the crowdfund."

You're at the heart of our research

► Cardiomyopathy UK Chief Executive Joel Rose explains how we are expanding our research work to help more people with cardiomyopathy and myocarditis



I am sure most of you know about our fantastic services and our high-profile awareness-raising campaigns, but you may be surprised to know just how much research work we do.

Last month, we launched our third national survey with more

Joining the Association of Medical Research Charities

than 600 responses telling us about their diagnosis and treatment experience. [\(See Page 15\)](#)

When we looked at the responses, we were able to see that while GPs seem to have got better at identifying a potential heart problem, waiting times to see a cardiologist have become longer and fewer families are being screened, leaving more people at risk.

Fighting to improve patients' diagnosis and treatment

We have used this important piece of research to highlight gaps in the diagnosis and treatment process and will continue to use the findings to put pressure on local healthcare organisations to ensure that people with cardiomyopathy and

Your help shaping research strategy for the future

myocarditis in their area can access the treatment that they need.

As well as undertaking our own research, we work with researchers, who come to us for help with developing and shaping their projects, to ensure they meet the real needs of people with cardiomyopathy and myocarditis.

Sharing analysis to put pressure on local healthcare

We also help them to promote their work so they have enough participants for research studies and share their findings with others.

In some cases, we join research teams at the very beginning of the process and work with them as they bid for funding from large government agencies, such as the National Institute for Health Research or the European Union.

We are currently working with teams based at Oxford, Glasgow and the Barts Heart Centre, as well as a European team, who are looking at the connection

between heart failure and brain function.

Since joining up with the Alexander Jansons Foundation last year, we have also been able to provide some funding for research projects.

In the next few months, the charity aims to sign up as a member of the Association of Medical Research Charities (AMRC).

Joining AMRC will help to give us additional credibility and help us to take advantage of additional government funding.

We know that research plays an important part in improving the lives of people with cardiomyopathy and myocarditis and we hope to be doing more research work of all kinds in the coming years.

As a starting point, we are developing our research strategy to set out the kinds of research that we want to support and undertake ourselves.

While we are still developing this strategy, one thing that we can

Working with research projects from the start

say for certain, is that people with cardiomyopathy and myocarditis will be at the centre of this work – adding their unique expertise and insight and playing an equal part in fighting for better services and improving diagnosis and treatment.

Drugs: Trials and error

► **Drugs research is an ongoing process that for the past 30 years has helped people with heart failure live longer, healthier lives, says Cardiomyopathy UK's support nurse Robert Hall**

It's interesting to reflect on how treatments for cardiomyopathy have evolved in a relatively short space of time.

As recently as the early 1980s, the treatment for heart failure conditions, such as dilated cardiomyopathy, consisted of diuretic drugs (water tablets), perhaps digoxin and/or a nitrate drug and bedrest.

People would feel better – the congestion in their lungs having been relieved by the diuretics – but the therapy would have no positive effect on the long-term outcome.

A lack of standardisation in the treatment resulted in there being variations in the therapy being provided in different hospitals.

This all changed in 2010 with the publication by NICE (National Institute for Health and Clinical Excellence) of the first clinical guidelines for treating heart failure conditions.

For the first time, patients would receive a standard therapy, which was based on evidence.

Not only could the effects of the conditions be reduced, the therapy also improved the mortality rates.

The basis of this change was research, which is an ongoing process.

Perhaps one of the most significant developments was the use of the drugs known as ACE inhibitors in the treatment of heart failure.

ACE (angiotensin converting



**Robert Hall
Cardiomyopathy UK
Support Nurse**

enzyme) inhibitors were first introduced in the mid-1980s as a treatment for high blood pressure.

Dramatic benefits were first reported in the CONSENSUS study, published in 1987.

This showed a 40 per cent reduction in mortality in patients with severe heart failure who were using the ACE inhibitor enalapril.

Follow-up studies have since increased survival time to 50 per cent.

Various ACE inhibitors have now been marketed, with the most common one, ramipril, being widely used.

A further development, based on research, was the use of beta blockers in the treatment of heart failure.

Up to the late 1990s, beta blockers were strictly avoided in treating heart failure conditions as they were seen to further depress cardiac

contraction.

This changed with the increased understanding that heart failure was not purely a matter of the pumping function of the heart, but also a process that was heavily influenced by the neurohormonal systems that can have a further detrimental effect on the heart.

Various studies – the first being published in 2002 – showed the benefits of the use of beta blockers.

Research had resulted in a drug being initially considered to be one of the most dangerous in heart failure conditions, to being one of the most effective and a cornerstone of the therapy.

Bisoprolol and carvedilol are now the most commonly used examples.

More research has resulted in the use of other drugs, such as spironolactone.

New preparations such as ivabradine, and most recently, entresto have been introduced.

Research has not only been confined to drugs, with the use of devices such as ICDs (implantable defibrillators) and pacemakers being made available as treatment options.

The landmark MADIT trial, along with others published in the late 2000s, showed a significant reduction of over 50 per cent in mortality in people with severe heart failure and left bundle branch block,

compared to just an ICD.

This has led to the wider use of cardiac synchronisation therapy (CRT).

As research continues, what further developments can we expect?

Research into stem cell therapy continues to raise hopes, however, probably the most likely area of future development is in the area of gene therapy with the possibility of correcting gene mutations with the aim of curing forms of cardiomyopathy.



Derived from the purple foxglove plant, digoxin was first used to treat heart complaints 200 years ago



How satisfied have you been with your care?

It is estimated that one in three people with a long-term condition also have a mental health condition

► **Support group leader Jenny Taylor's research suggests patients who are unhappy with the level of care they receive when first diagnosed are prone to feeling stressed, anxious and depressed**

Cardiomyopathy UK volunteer Jenny Taylor, 26, from Cheshire, is carrying out research with both cardiologists and newly-diagnosed patients into the impact a diagnosis of cardiomyopathy has on patients, carers and family members.

Jenny was diagnosed with dilated cardiomyopathy (DCM) as a baby and had an ICD fitted as a teenager.

While researching for her psychology degree dissertation in 2016, the mother-of-one spoke to 200 cardiomyopathy patients about the psychological impact of having the condition and found a significantly high prevalence of clinically severe and extremely severe levels of stress, anxiety and depression for those with all types of the condition.

As she explains: "My degree helped me to fulfil a lifelong dream to become an 'expert' in the field of health psychology and I now want to continue using my research to discover new ways health services can be improved to help others."

Jenny, who also helps run the Cheshire and Merseyside Cardiomyopathy Support Group, is carrying out her latest research, while completing her PhD in health psychology at Liverpool John Moores University,

In a bid to better understand the cardiomyopathy diagnosis process, Jenny has looked at different UK



'I want to find new ways health services can be improved to help others'

- Jenny Taylor

hospitals; the diagnostic process; how patients are assessed and how their diagnosis is explained to them.

"My initial findings show that although the diagnosis of cardiomyopathy is often broadly correct, the explanation that has been given to the patient is very limited, sometimes non-existing, and occasionally incorrect," she reveals.

This miseducation – typically stemming from the initial assessment by GPs or at A&E by on-call registrars – is in turn, frustrating for clinicians faced with patients arriving with inaccurate information about their diagnosis, says Jenny.

"Patients report having a lot of questions at this initial diagnostic phase, but feel that there is a lack of sufficient information for them to be able to answer those questions before seeing a specialist."

She says many patients she spoke to reported feeling frustrated with the predominance of medical jargon in relation to their condition and the 'catch-all' nature of the term cardiomyopathy alone doesn't give patients the specific information they need about their condition.

Jenny's preliminary findings also discovered:

- Patients feel they have missed timely access to treatment as a result of initial misdiagnosis (often asthma) or delays in diagnosis.

There is some discrepancy between the medical interpretations of the diagnostic process, with some clinicians putting this down to the patient pathway.

- Some patients have been told 'It's a non-permanent condition' and 'You only have five years to live,' before receiving more accurate information from a clinician.

- There appears to be differing availability of specialist services (one factor is geography) but equally, there is a lack of knowledge about services where they do exist, i.e. GPs being unaware there are cardiac nurses covering the region in which they operate. This means that appropriate referrals are either being missed or delayed.

- Clinicians report feeling confused or frustrated at the interchangeable use of the terms 'heart failure' and 'cardiomyopathy'.

► **How our research reveals decline in standards of patient care - See Page 15**

'We give to help others'

Lisa Rochford says she and her family will never stop donating to Cardiomyopathy UK.

She finds comfort in knowing that her regular giving – in memory of a dearly loved sister – can help others.

Lisa's sister Tanya Jacobs died in August 2010, aged 40, at Harefield Hospital after years of treatment for hypertrophic cardiomyopathy (HCM).

Two years before she died, when her condition had sadly deteriorated and she desperately needed a new heart, Tanya gave an interview to the Southern Evening Echo in Southampton.

She talked about her efforts at fundraising for Cardiomyopathy UK, even though she was so unwell herself. An auction night in the village where she lived, raised more than £11,000.

"Giving to Cardiomyopathy UK is something that we've done since 1992 and something that we will always do," says Lisa.

"My mother frequently requests donations to the charity instead of



Lisa Rochford

presents for birthdays or Christmas

"This is both in Tanya's memory and because going forward, we fully believe there will be effective treatments developed for this surprisingly common condition.

"In some ways, we were fortunate that Tanya showed physical symptoms of the disease from an early age and therefore, her condition could be managed and monitored.

"This helped in identifying that her sons Toby and Luis also had the condition.

"Since Tanya's death, they've both

£5 a month will enable someone facing a new diagnosis to attend an event to get the vital information they need to understand and manage their condition.

£10 a month will pay for 5 people to access our helpline to get personalised medical advice and information when they need it most.

£15 a month will enable us to work with health care professionals to improve early diagnosis and access to treatment.

If you would like to become a regular giver, please email our Head of Fundraising Sheila Nardone sheila.nardone@cardiomyopathy.org

had to cope with heart-related issues, but she would be very proud if she could see them today."

Give by taking...

We are excited to be launching our new partnership with DrugStars, whose app is improving patients' daily lives by reminding them to take their medicine (prescription, over-the-counter and vitamins) and giving them the chance to support health charities for free.

How does it work?

The app allows you to track your medications and every time you take them, you are able to earn 'stars' that you can then donate to Cardiomyopathy UK.

It doesn't cost anything to take part and the charity will receive £1 for every 125 stars donated.

Not only will it help raise funds for our work, but by verifying your medications in the app, you'll be able to track your progress, receive advice and gain a better understanding of just how your medications work.

At the same time, you're providing DrugStars with valuable data that can affect the development of new and better medicines all around the world.

Go to <https://www.drugstars.com>

Q&A

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

Q: How can I find out more about taking part in a clinical research trial?

Support Nurse Jayne says:

When you express an interest, a doctor or nurse will talk to you and give you printed information about the trial.

A clinical trial compares the effects of one treatment with another and can involve healthy people, or patients or both.

Clinical trials help doctors understand how to treat a particular condition or disease and may benefit you, or others like you in the future.

You can find out about clinical trials that you might be eligible for from your GP or cardiologist.

You can search for trials and contact researchers via the UK clinical trials gateway at <https://www.ukctg.nihr.ac.uk/>



of these devices, with the error ranging from 2 per cent to 30 per cent.

Movement, skin pigmentation and tattoos can also affect their readings.

Unsurprisingly, the more expensive examples were shown to have greater accuracy.

It's important to note that these monitors are not designed to be medical devices. However, they are likely to play an increasing role in the future as the technology develops.

A study, published last year, showed them to be useful in estimating a normal fast heart rhythm, but underestimated the heart rate in underlying arrhythmias like atrial fibrillation.

If a person is recording a persistent fast heart rate whilst at rest, this could indicate some form of arrhythmia and would warrant medical guidance.

Q: How can I access genetic testing for my child?

Support Nurse Emma says:

Genetic testing on the NHS is available through your cardiologist, who orders the appropriate tests from an NHS-certified laboratory.

The clinician will request a test only if they know that the results will help them provide you with the most appropriate health-care.

Your cardiologist decides who is most likely to benefit from genetic tests.

The sample is usually taken by the cardiology team and is a quick blood test or saliva sample,

depending on your child. The laboratory will then analyse and interpret the results.

The cardiologist will then talk you through the results of the test.

Anyone having a genetic test on the NHS is also likely to see a genetic counsellor – both before and after testing.

After being referred, you will usually be sent a leaflet or letter explaining what will happen at your appointment.

This letter often asks you to bring your child with you to the appointment.

Before attending appointments, it is a good idea to write down any questions, you may want to ask when you are there.

You might also find it helpful to take along a notebook.

Genetic testing has various benefits, including the following:

- It can identify particular types of cardiomyopathy that require particular treatment or management.

For these types of cardiomyopathy, there may also be certain known risks that can be treated as soon as they are recognised.

Examples of this include Fabry disease (a rare genetic condition carried on X chromosomes) and Noonan syndrome (an autosomal dominant condition).

- It can be useful if you are considering starting a family, as it can look at whether you may pass on the gene to your children.

Genetic testing can also be important for your family.

Genetic testing can take a long time and you may have to wait several months for any result.

Q: I recently bought a smart watch as I thought it would be a good idea to monitor my heart rate. What should I look out for?

Support Nurse Robert says:

There are two types of sensors to measure the heart rate.

Firstly, electrical sensors that record electrical activity and are usually worn strapped to the chest.

The other is an optical sensor that measures blood flow through the skin.

The latter type is the most common sensor in smart watches.

There is a variation in the accuracy



Hospital pioneers robotic surgery milestone

A man from Wales has become one of the first people in the UK to undergo robotic heart surgery at Liverpool Heart and Chest Hospital.

Owen Veldhuizen, from Llan-dudno, underwent the pioneering procedure to repair his mitral valve – between the left atrium and left ventricle – and returned home within 48 hours.

The 51 year old admitted: "I was a little bit nervous when they told me that I would be one of the very first patients in the country to undergo this type of robotic heart surgery, but as soon as they explained the benefits of the procedure and told me how quickly I would recover and be back at home, I felt reassured and was confident I was in the very best and safest hands possible."

With its team of newly-trained robotic surgeons, the trust expects to carry out 250 to 300 heart and lung cases in the first year.

Mr Mike Shackcloth, one of the trust's robotically trained consultant thoracic surgeons, added: "Our robotics programme will not only allow us to provide even better care for our patients, but it will also enable us to develop a training and research programme that will ensure we can attract top trainees and consultants in the future."

Mr Paul Modi, consultant cardiac surgeon at the hospital, said the

new robotics programme would enable more patients requiring specialist cardiothoracic treatment to benefit from cutting-edge surgery.

"The benefits for our patients will be enormous. With this new

► Traditional open chest surgeries involve dividing the sternum (breastbone) and spreading the ribs to view the heart and obtain access to operate on the mitral valve. This takes about 8 to 12 weeks to recover from, with no lifting of anything heavier than a bag of sugar for the first 6 weeks

robotic surgery programme, we will be able to significantly increase the number of patients who can undergo minimally invasive surgery.

"Equally importantly, we will also be able to reduce their post-operative pain, lower their risk of infection, and ensure that their stay in hospital is considerably reduced, getting them back to their family and loved ones quicker, which is

where they want to be."

He added: "The programme will also enable us to operate on those who are currently considered inoperable because of their health, as there is far less trauma to the body operating through small incisions only a few millimetres in length, rather than the more traditional open surgery.

"This is especially important as we live in an ageing society and more people are living with a number of health problems.

"Robotic surgery can make a huge difference to their lives."

The four-armed da Vinci robot is named after the Renaissance artist and inventor who foresaw the coming of robots.

Operated by a consultant surgeon, the robot behaves the same way as a surgeon would when carrying out open surgery, but through tiny holes – a technique known as minimally invasive surgery.

Surgeons are able to get a high-definition view of the operating site in 3D via a screen inside the control console, ensuring even greater surgical precision.



Owen Veldhuizen, with consultant cardiac surgeon Paul Modi and robotics surgeon Doug Murphy

'The best thing is meeting patients'

► **Research nurse Sara Salmi, 25, talks about her role working in the Cardiovascular Research Centre at the Royal Brompton Hospital.**

I have always had an interest in cardiology and wanted to work as a research nurse because it gives me the chance to learn more about different cardiac conditions and be a part of research that could help patients.

I've been involved with the clinical research studies looking at myocarditis and DCM (dilated cardiomyopathy) for over a year now.

My role includes talking to patients about ongoing research studies and involving suitable patients who want to take part in research.

I also see patients together with the study team, when they come for hospital visits, for example, if they are having research blood tests or a cardiovascular magnetic resonance scan.

The best thing about my job is meeting patients and knowing that the research we do could help them.

I hope that in the future, there will be more knowledge about how best to treat and follow up patients who have myocarditis, thanks to the work we and other centres are doing.



Small is beautiful

► Clinical research studies at the Royal Brompton Hospital and the work of AJF fellow Dr Rameen Shakur in the US are using the latest technological advances to drive forward our understanding of acute myocarditis with the aim of finding a cure

Over the past three years, Cardiomyopathy UK's Alexander Jansons Fund (AJF) has funded an ambitious study of patients with myocarditis.

Led by Dr Sanjay Prasad, consultant cardiologist at the Royal Brompton Hospital, more than 230 patients took part in the study, which involved specialised blood tests for new biomarkers and genetic analysis, detailed questionnaires and a state-of-the-art cardiac MRI scan.

The research analysis is almost complete, with new findings set to shed light on underlying genetic predispositions and also serial changes in hi-res images of the heart, relevant to early diagnosis and disease monitoring.

The AJF is also funding a second research project led by Dr Rameen Shakur, who has focused his research on develop-



Dr Sanjay Prasad

application of nano-particles to deliver novel drug therapy straight to the heart.

Dr Shakur says: "In your urine there are cells that scrape off from your urinary tract and they are seen in the microscope. I have developed a system that allows us to grow these cells and then

convert them to stem cells, which we can then make into heart cells.

"From these induced pluripotent heart cells, I've tested some novel drugs that seemed from our experiments to have unique anti-inflammatory effects not previously reported before, which is very exciting.

"This has meant that for the first time we can test our potential drugs safely, robustly and repeatedly.

"We have been excited by the initial data on the cells and so would like to ramp up using these novel particles. Fingers crossed, so far so good!

"We desperately need to push the basic science and clinical field so that for the first time we have an all-encompassing method of potentially treating this debilitating fatal disease regardless of its cause.

"The support of Cardiomyopathy UK and the great clinical work with Dr Sanjay Prasad will continue to help us as we work to find answers."



Dr Rameen Shakur

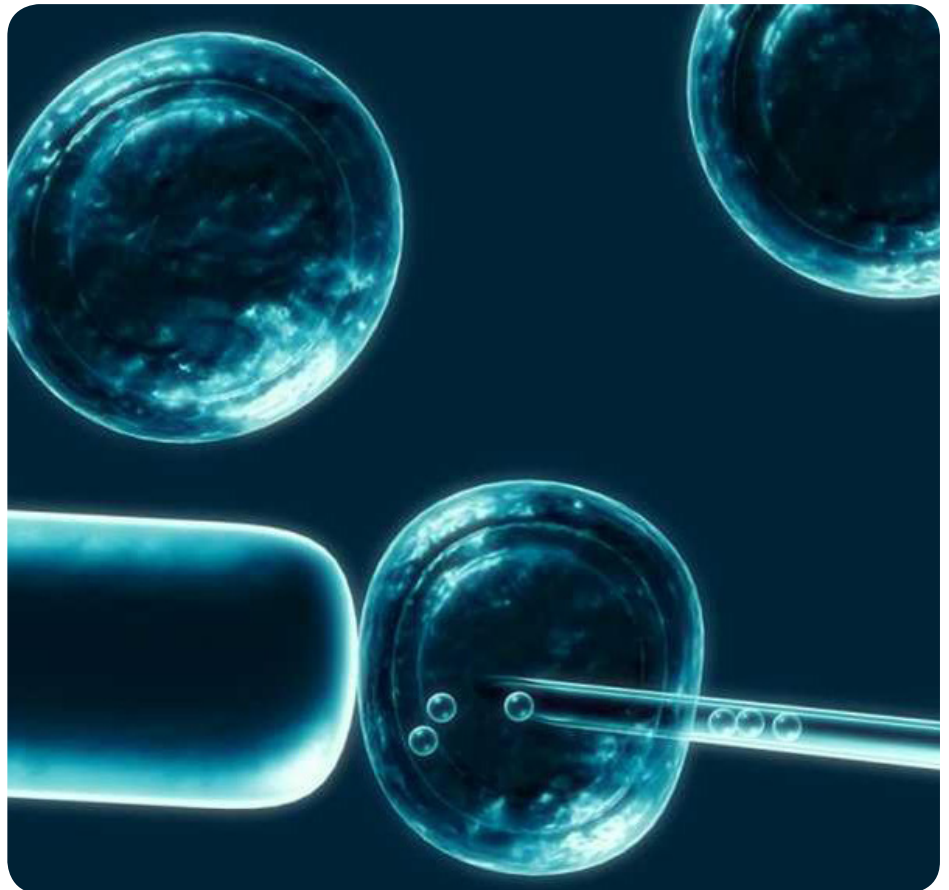
ing the next generation of treatments for myocarditis.

Based at the Massachusetts Institute of Technology (MIT) in the US, Dr Shakur's work involves the

Can a person's own cells mend a broken heart?



Professor Anthony Mathur



► **In the past, the idea that a heart could replace itself – through so-called regenerative medicine – seemed like science fiction, but today, researchers believe the day is coming when they will use stem cells to make healthy new heart cells**

A field of medicine based on peer reviewed medical research is now emerging with the potential to offer new treatment options for patients suffering with heart disease.

There has been a tremendous amount of effort in conducting clinical trials in regenerative medicine for cardiovascular diseases with research conducted in two main groups:

- **Those involving a patient's own cells – autologous cells –**

taken from bone marrow and the adult version of stem cells, with minimal processing and,

- **Those involving cells taken from either the patient or a donor – 'engineered cells' – having undergone extensive manipulation.**

(There is considerable controversy over the use of the more complex 'engineered cells').

Over the past 15 years, a team of researchers based at St Bartholomew's Hospital has

conducted four stem cell trials to understand for themselves what role autologous cell therapy has in treating heart disease.

The St Bartholomew's Hospital clinical trials suggest that autologous cells appear to produce beneficial effects with minimal safety concerns.

"Regenerative medicine offers the promise of treating heart conditions, which until now had no definitive cure," says Professor Anthony Mathur, director of cardiology at St

Stem cells : Where are we now?

In utero and early infancy, stem cells have a unique ability to transform into any type of cell within the human body, making them an exciting and revolutionary treatment option.

Initial research began in **1981** using embryonic cells taken from mice.

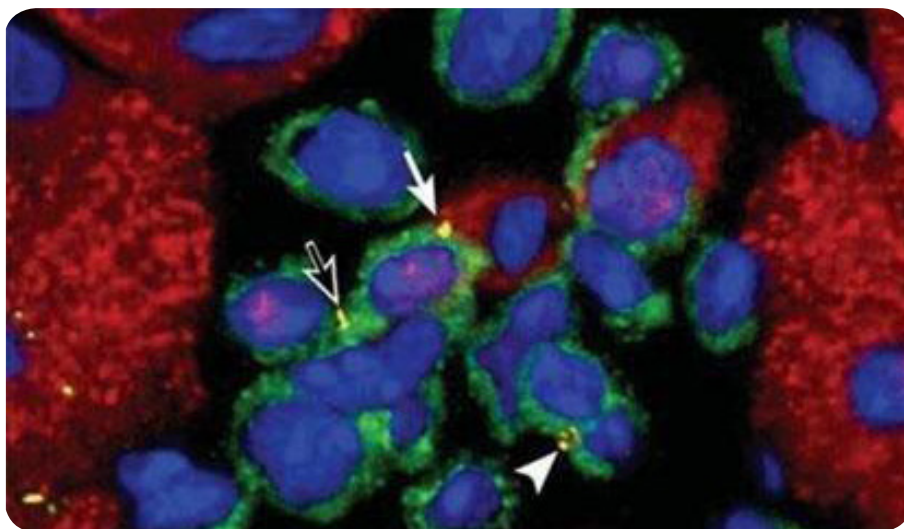
This led to further research in **1989** when the first human embryonic stem cells were first grown.

In **2001**, stem cells were used to create beating heart cells outside of the body.

By **2002**, this research allowed scientists to use human embryonic stem cells to form human heart muscle cells, with the possibility of stem cells fixing our heart.

Researchers discovered in **2004**, that fat cells from beneath our skin could be instructed to form new heart muscle.

This was an easier way of



Heart stem cells

making new heart muscle cells and led to human skin cells (**2007**) being used to make induced pluripotent stem (iPS) cells which have similar properties to stem cells. IPS cells could now be used to make new heart cells.

Research with bacteria polymers are being developed to

grow patches that encourage the growth of cells.

It is thought that these special polymer patches could be attached onto areas of damaged heart muscle by cardiac surgeons. Current research is on rabbits, however human clinical trials could commence within the next two years.

Barts Health NHS Trust.

"We previously presented the early stages of our trials to Cardiomyopathy UK and can now report that we have completed and published all of our results.

"In particular, these show that patients with DCM benefit from infusion of their own cells into the heart (improved heart function, quality of life and symptoms).

"We are now raising funds to conduct larger trials to confirm these findings and give us a clear answer for our patients regarding this potentially revolutionary treatment.

"Our aim at Barts Heart

Centre is to continue our 15-year programme, which has used a patient's own cells with minimal manipulation, to affect important improvement in their heart condition and overall quality of life."

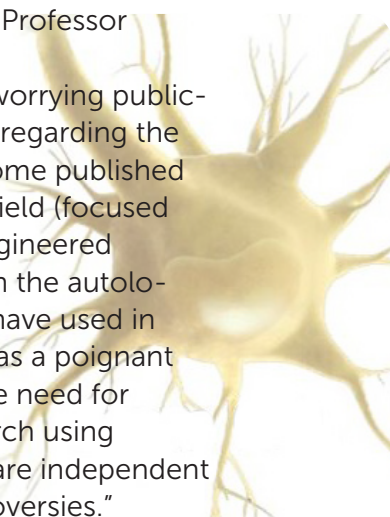
If successful, the next set of trials will provide evidence for the NHS to consider adopting autologous cell therapy as standard care.

Based on the request of patients, the team at St Bartholomew's Hospital has also used its clinical trials experience to establish the first compassionate cell therapy unit in the UK.

"We set up the unit with

charity Heart Cells Foundation to continue giving us more experience of autologous cell therapy in the treatment of heart failure patients, as well as fulfilling the wishes of patients," adds Professor Mathur.

"The recent worrying publicity in the press regarding the credibility of some published studies in this field (focused around the 'engineered cell' rather than the autologous cells we have used in our trials) acts as a poignant reminder of the need for ongoing research using therapies that are independent of these controversies."





You will have the opportunity to meet and talk to Cardiomyopathy UK President Professor Perry Elliott and Chair of Trustees Alison Fielding at this year's national conference on November 9



Save the date

By Head of Services Ali Thompson

As you probably know if you've seen our website or follow us on social media, we're planning for this year's national conference!

As 2019 is the charity's 30th anniversary, we wanted to make this important event bigger and further-reaching than ever.

This year's conference will see a record number of expert speakers talking on a wider range of subjects, including physical health; emotional well-being; welfare and lifestyle, as well as supporting someone with cardiomyopathy or myocarditis, and caring for an affected child.

We are returning to the Royal National Hotel in London and we are looking forward to welcoming as many of our friends and community as possible.

The national conference is always special as it brings people together from all over the UK – the newly-diagnosed; those who have lived with the condition from birth; young people



and families and of course, our amazing volunteers.

National conference brings together the charity and our community; offering people the opportunity to meet our trustees, community and fundraising volunteers, our staff and the clinicians we work with.

Something we hear at every national conference is from newcomers to the charity, who are often amazed that there are many other people living with or have direct experience of cardiomyopathy or myocarditis.

Feeling that you are not alone and that there are people who are similarly affected and are living well with the condition is a feature of the national conference that cannot be underestimated.

Many people have told us that they turned up at the event feeling lost and alone and left feeling hopeful and that they had somewhere to turn for the betterment of their physical and mental health.

People living with cardiomyopathy often tell us that being able to speak freely to one of the clinicians speaking at our national conference is also hugely advantageous.

Having only ten minutes with a nurse or cardiologist at set appointments is often not long enough for people to ask the questions they really need to ask, so being able to talk to globally-renowned cardiologists and nurses at the conference has proved invaluable.

Tickets are available to book your place online. Just go to our website and follow this link <https://www.cardiomyopathy.org/nationalconference2019-nationalconference2019-/nationalconference2019> or search for "national conference" in the search box.

Our call to action

Cardiomyopathy UK research reveals patients are being left at risk owing to inefficient care pathways

During our 30th anniversary year, we are calling for a change in the way cardiomyopathy is diagnosed and treated in the UK, following our largest ever patient survey.

Cardiomyopathy UK questioned more than 600 people living with the condition and found declining standards throughout the entire 'care pathway'.

We found family members are also at risk, as patients are not being told that the condition can be genetic and screening for individuals, siblings and children is being overlooked.

Cardiomyopathy UK Chief Executive Joel Rose, says: "Over the past 30 years, improvements in genetic screening and medicines have completely transformed the potential to diagnose and treat cardiomyopathy.

"We've also seen that detection amongst GPs has improved, with numbers being immediately referred to cardiologists going up by more than 10%.

"But these improvements and breakthroughs in detection, genetics and medicine are pointless unless healthcare professionals are able to screen and treat cardiomyopathy patients and their families efficiently.

"As such, it's deeply concerning to see from our research that standards in the care pathway for cardiomyopathy are declining," he adds.

"It's clear that we need to work together to ensure patients are receiving the right tests, treatment, specialist care and support, which could save lives."

In response to our research, we plan to work with local healthcare providers and commissioners to share best practice, identify improvements and help to find local solutions that will improve the diagnosis and treatment pathway across the UK.

We are also calling on the Government to ensure funding is available to improve access to the specialist services that people with cardiomyopathy need.

Key findings of our survey



Care pathway: Only a small number of individuals (13%) are experiencing the ideal care pathway – from first reporting symptoms to treating the disease.

This has become more inefficient since 2017, with 16% experiencing the ideal care pathway two years ago.

A third (32%) of patients were not satisfied with their experience.



Family screening: Half of patients are not being told that the condition could be genetic, leaving thousands of family members at risk.



Cardiologist referral times: Waiting times to see cardiologists are lengthening – 54% of patients are being left unprotected for more than a month before seeing a cardiologist, with 13% waiting for four months to a year.

We have also worked with our Clinical Advisory Group to identify solutions to fill the gaps our research has identified in the care and treatment of patients to produce the "ideal" care pathway.

And at the time of My Life going to press, we are sharing our findings through a publicity campaign aimed at the healthcare media, using case studies of patients who are happy to share their stories and experiences to help our call to action.

"Left unmanaged, cardiomyopathy can lead to cardiac arrest, which makes efficient diagnosis and treatment of the disease absolutely critical," insists Joel.

"This is why an efficient care pathway is critical in order to save lives.

"A diagnosis of cardiomyopathy can be life-changing, but with the right treatment and support, most cardiomyopathy patients can live full and active lives."

30th anniversary September Stroll



Help us celebrate our landmark year by making our 2019 September Stroll the biggest ever for cardiomyopathy.

All you need to do is use our guide, pick a location where you would like your walk to take place – your local woodlands, hills, or even mountains – then set a date in September and get as many friends, family and members of your community as possible to join you.

Whether you're walking in memory of a loved one, supporting someone living with cardiomyopathy, or

simply strolling to raise awareness, we're here to help you every step of the way.

We've got everything you need to make your 30th anniversary stroll a success; including sponsorship forms, banners, and a helpful risk assessment grid.

We can also add your stroll to our 2019 map.

Head to cardiomyopathy.org/september-stroll for sign-up information, fundraising ideas and more. Or just contact our Community Fundraiser Christie



Jones at fundraising@cardiomyopathy.org or call him on 01494 791224.

Running events



October offers a chance for runners of all abilities to don their #teamcardio vests.

The Bournemouth Marathon Festival has distances from 5k to a full marathon to choose from; or you can head to the Midlands for the region's leading half marathon event – the Great Birmingham Run.

www.cardiomyopathy.org/running

The Cardiff Half Marathon on October 8 is recognised as one of the fastest half marathon events. The predominately flat and fast course makes it ideal for beginners and elites.

cardiomyopathy.org/half-marathons/cardiff-half-marathon



Yorkshire Three Peaks

24 miles, 12 hours, 5,200ft, 3 mountains – The Yorkshire Three Peaks on September 15 is a fun adventure.

Join our team at: cardiomyopathy.org/walks-and-treks/yorkshire-three-peaks

Are you up for the challenge?

We can help you smash your target and provide a free fundraising pack, t-shirt or running vest when you register for a #teamcardio event. Get in touch via email at fundraising@cardiomyopathy.org or call us on 01494 791224



Congratulations to our 53 incredible 2019 London Marathon runners and everyone who helped support #teamcardio on the day.

Each runner worked so hard over the previous six months, taking time to train and raise money. The support has been overwhelming and together our runners pooled a record £141,598 for the charity's work.

A special thank-you to Browns Solicitors who sponsored Jamie Gray £20,000.

"I was a complete wreck at the end of the race and was trying to get to the charity base, when up stepped two Cardiomyopathy UK volunteers.

"I could not have asked for any better support for the hobble back to base.

"To then sit and listen to stories from family members and volunteers afterwards was an even bigger inspiration.



"I want to flip the stereotype about the focus being on the runners and put the spotlight and thanks on the team of support – family, friends and the charity's fundraising staff and volunteers.

"It was a real honour to put on the #teamcardio vest and represent Cardiomyopathy UK."

Dave Needham



Julie Rees & Jenny Taylor group leaders for Cheshire & Merseyside support group celebrating the group's 5th anniversary with our Support Nurse, Robert Hall



'They are often the faces of our charity'

Could you become a peer support volunteer?

A significant portion of our support services to those affected by cardiomyopathy and myocarditis are delivered by our highly-skilled community peer support volunteers.

The term "community peer support volunteer" refers to those volunteers who lead and help out our support groups.

They offer peer support through the helpline (previously known as "key contacts") and regularly attend their local hospital or cardiac clinic to provide support to patients.

Being a community peer support volunteer can be highly rewarding and is an essential component of Cardiomyopathy UK's representation within the community and such volunteers are often the faces of the charity.

At Cardiomyopathy UK, we are always looking for people to join us as community peer support volunteers.

We are looking for individuals



**By Ali Thompson
Head of Services**

who are empathetic; able to be alongside a potentially emotional client and someone who can understand the diverse needs of our community and can accurately reflect the values of the charity.

Cardiomyopathy UK is currently creating an online course that all community peer

support volunteers – both potential and existing – will need to complete.

The online course will better equip our volunteers with a number of core skills, including active listening; how to model a person-centred approach to support and how to look after their own well-being whilst volunteering.

The course will also explain how to actively safeguard vulnerable groups; what constitutes a safeguarding concern and the procedure for reporting, as well as understanding the difference between secrecy and confidentiality.

If you are interested in finding out more about community peer support volunteering; what's involved or how to become a volunteer, you can email me at Alison.thompson@cardiomyopathy.org or give me a call on 01494 791 224 – we'd love to hear from you.



Event for young at heart

On Saturday August 10, **Cardiomyopathy UK** is holding its first national event specifically for young people.

Anyone aged between 14-25, who is affected by cardiomyopathy or myocarditis, is invited to attend this free event at the Amba Hotel in London.

We recognise that children, young people and younger adults affected by heart muscle disease often have diverse and sometimes complicated needs that affect their emotional and psychosocial well-being, as well as their physical health.

Attendees will be able to choose from a programme of events, including sessions on information about the different cardiomyopathies and myocarditis, and sessions centred around employment, education, intimate relationships, fertility and mental health.

As well as a DJ Master class, there will also be a creativity workshop for young people to attend and opportunities to meet and share experiences with others.

Clinical speakers will be led by the highly respected paediatric consultant cardiologist Dr



Our CYP&YA (Children, Young People and Younger Adults) Panel, above, is working with Cardiomyopathy UK's services team to ensure the programme for the day and optional activities are appropriate for our delegates

Juan Pablo Kaski, of Great Ormond Street Hospital, and members of our CYP&YA Panel; Cardiomyopathy UK's cardiac nurse specialist Jayne Partridge and charity staff will also be there on the day.

The youth gathering has been funded by the Edward Gostling Foundation and BBC Children in Need to help us bring young people together whilst giving them a safe space to share and learn how to manage their well-being holistically.

You can book your place/s via our website. Just look for the Young People tab on the homepage and click! <https://www.cardiomyopathy.org/young-people/national-youth-gathering-2019>

Independence

Relationships

**Condition-
Management**

Education

Work

Cardiomyopathy^{UK}
the heart muscle charity

Cardiomyopathy National Youth Gathering

**Hypertrophic
Dilated
Restrictive
Myocarditis
& more**



10.08.19
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