myLife

The magazine for people affected by cardiomyopathy and myocarditis

Travel, Holidays and Cardiomyopathy

Heart to Heart: Telephone Support

Cardiomyopathy UK Conference 2023

Cardiomyopathy UK
the heart muscle charity

Issue 33
Summer 2023

Contact us

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

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Hello and welcome to our summer edition of MyLife.

As I write this introduction, I am pleased to say the sun is shining and the air is warm, well very hot actually. I am not complaining, as it feels as though we have waited a long time for summer to arrive this year. It lifts my spirits; I hope it lifts yours too.

News that not only lifted our spirits but gave hope to our cardiomyopathy community, was the announcement that the Mavacamten drug has been approved for use in England. See page 6 for more about who might benefit from this new drug, and how the strong patient experience evidence that Laura gave to the NICE review helped to inform the panel's decision making.

Our research work is growing at a fast pace. On pages 14-15 we share our Future Research Priorities, and how working in partnership with the James Lind Alliance will take our work forward.

With a number of recent celebrations behind us, one being the Coronation of course, and equally important for us, an opportunity to thank our army of volunteers during National Volunteers Week. In this edition our Question & Answer article features Amy, one of our Heart to Heart support volunteers. In this interview, you can read about the important role our volunteers play on page 12.

Does cardiomyopathy run in families? With a focus on genetics, you will want to hear more about International Cardiomyopathy Awareness Week that ran from 26th June – 2nd July. Turn to page 7 for an overview.

Where will you be on Saturday 18th November 2023? Hopefully with me and the Cardiomyopathy UK team at our Annual Cardiomyopathy UK Conference. Building on the success of last year, we are looking forward to a programme which promises to be something for everyone. I look forward to seeing many of you there. Further details on pages 18-19.

I'm off now to enjoy the sunshine. Wishing you all an enjoyable summer.

Stay safe and stay well.

Rita Sutton, Chair of Trustees

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Laura's Story

Laura was diagnosed with obstructive HCM in 2019. Last year, Laura shared her story as part of the NICE approval process. In doing so, Laura has helped to get Mavacamten, the first ever drug developed for cardiomyopathy, approved by NICE for use in England, Wales and Northern Ireland.

Diagnosis

Before I started having symptoms, I lived a full and active life. I was very sociable, loved seeing friends and family and going on holidays. I especially liked taking part in sport and played badminton, volleyball and hockey. I also took part in fundraising walks and even did a skydive. I was fit, active and having fun.

Around winter 2019 I started to feel bad. I thought it was just asthma but could also feel my heart beating irregularly and was very tight chested. It got so bad one night that I had to go straight to A&E. I was admitted and after a week or so of tests and a cardioversion, I was diagnosed with hypertrophic cardiomyopathy. It helped that I could share with them my auntie's records as she has the same problem.

Living with cardiomyopathy

My cardiomyopathy impacts me in a number of ways. The biggest physical impact is being out of breath and exhausted. I struggle walking and am constantly getting out of breath. I even pretend to be texting on my phone as I feel like I look silly having to keep stopping all the time. On a good day, I can walk for a couple of minutes if I am going downhill or maybe about 25 meters if it is flat. Going up any sort of incline is impossible.

I also get chest pains and even holding a conversation can be completely exhausting. As I am not getting any exercise it feels like I am wasting away and loosing muscle tone.

> "Having a chance to share my story was really important to me. I wanted people to see the real-life impact of obstructive HCM."

As well as the physical impact, cardiomyopathy has had a massive impact on me mentally and on my relationships with my partner, friends and family. I hardly go out and get cabin fever being stuck indoors all the time. I miss seeing friends, I try to keep in contact but miss out on all the big occasions and being part of their lives. My family live in Northampton and getting there on a train from Brighton where I live is just too much to manage. All this also impacts on my partner and my stepson who is autistic and struggles to understand why I can't do anything with him, even simple things like going out for a coffee.

It has also had a big impact on work. I used to be very hard working and enjoyed work but now working is a real challenge. My employer is understanding but I can only work for about three weeks then I need three weeks to recover. I work with machinery

so it's not safe being at work when I am exhausted. The statutory sick pay is limited and can run out. I have also been turned down for benefits because some days I can cope with basic tasks. Because I am not earning, I am now getting into debt.

I am worried about needing to take three months off if I have an operation. I will have to time the operation in a way that I can take sick pay, otherwise I don't know how I can cover the costs and will be in more debt.

Waiting for treatment

I was given amiodarone but had to stop this after I had an ablation and went into AF. I have had four cardioversions in all and I also had an ICD fitted last September. The ICD has gone off twice since then. I now take 600 mg of disopyramide and 10mg of bisoprolol. I have not had any noticeable side effects. After the ablation, four cardioversions and pills I have some days that are better than others but ultimately, they have not helped much, and I am still in the same boat.

My doctor has put me down for surgery. It is scary but it feels like it is the only way of getting my life back, I don't want to spend the rest of my time doing nothing and stuck in the flat. I had a pre-op assessment last September and was told the operation would be in November but I have not heard anything and don't have a new date. It is very hard not knowing when it will be as I have to plan taking three months off and sorting out care and not getting into more debt.

I have to say though that overall I feel I have been treated well by people and could not fault the NHS. My doctor in Brighton sent me to Guys and St Thomas' in London as they have the experts there and they know what they are doing. Where you live can make a difference. I now see my doctor in London (travelling from my home in Northampton) and my mum goes from Northampton to Oxford. Travelling can be really hard.

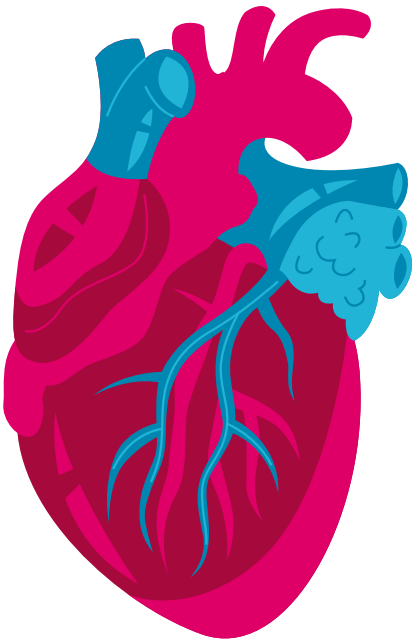
Cardiomyopathy in my family

My Aunty has the same condition but not as bad as me. My mum and brother also have it but they are coping better for now. When we knew it was in our family, my cousin did not want to know if he had it and did not want to go through the tests. He thought that there was nothing you could do anyway, and he would rather not know. Sadly, he died last year when he had a cardiac arrest in his sleep.

My brother is 34 and has the condition but is in the early stages. I think about his future and how he could have a new treatment that could save him going through all this pain and the impact it has on your life.

A new treatment

I used to live life to the full. I was fit, active and having fun. But obstructive HCM robbed me of my previous life. Having a chance to share my story was really important to me. I wanted people to see the real-life impact of obstructive HCM, what it has done to me and to my family. The decision to approve Mavacamten is just fantastic news, and I am delighted to have played a part in it.



NICE Recommends Mavacamten

The First Ever Drug Specifically for Cardiomyopathy

At the beginning of June, NICE (National Institute for Health and Clinical Excellence), the organisation that decides which treatments are available through the NHS, published their final draft guidance on Mavacamten of adults with obstructive Hypertrophic Cardiomyopathy (HCM).

This is the first ever drug developed specifically for cardiomyopathy. People who are struggling with their obstructive HCM despite trying the drugs that are currently available, or people for whom existing drugs are not appropriate, should now be able to access this new medicine.

What happens now?

As well as being recommended for use in the NHS by NICE, drugs also need to receive marketing authorisation, often called a licence, from the Medicines and Healthcare Products Regulatory Agency (MHRA). This is to ensure drug safety and quality. It is expected that Mavacamten will receive its licence by the end of July. It is likely that Mavacamten will go by the brand name, Camzyos which it uses in the US, where it is already available.

After that, hospitals will need to have their systems in place to be able to order sufficient supplies and closely monitor those people who are taking the drug. Having spoken to the drug company and our clinical network, we believe that people should be able to start receiving the drug by the end of the year.

What about Scotland?

NICE's recommendations only cover England, Wales and Northern Ireland. The pharmaceutical company that makes Mavacamten are hoping that the Scottish Medicines Consortium (SMC) will meet later this year to consider if the drug should be made available in Scotland. We will work with the SMC in the same way that we have worked with NICE to make sure that they have a fair and accurate understanding of the impact of obstructive HCM and why this medication is so important.

What about other drugs?

We are talking to pharmaceutical companies who are likely to be submitting new drugs for appraisal over the next few years. These drugs are not just looking at obstructive HCM but also non-obstructive HCM, DCM, arrhythmogenic cardiomyopathies and cardiac amyloidosis. There is no doubt that we are entering a new phase in drug development and, in time, better treatment options for people with cardiomyopathy.

Don't miss Professor Perry Elliott at our national conference in November, where he will be giving an update on new drug developments and sharing his thoughts on the future of cardiomyopathy treatment.

International Awareness Week 2023

The last week of June saw the second international cardiomyopathy awareness campaign co-ordinated by a network of cardiomyopathy charities from around the world.

This network, called The Cardiomyopathy Council, is part of a larger network of heart disease charities; Global Heart Hub. The Council now consists of 19 charities across 13 different countries who worked together to develop this campaign.

The aim of this year's international campaign is to highlight the role of genetic testing in the diagnosis of cardiomyopathy and the importance of genetics in identifying family members who may be at risk of developing the condition. We want people with cardiomyopathy to ask their clinicians about genetic testing and we want people with a history of heart disease in their family to ensure that their doctor knows that they could be at risk.

Developing a campaign that works for all the charities in the council has been challenging and not just because all the materials need to be translated into local languages. The other significant issue is that council member charities face different challenges in improving access to testing. In the US for example, getting a genetic test can be very costly and only around 1% of people access this important tool. The average across Europe is variable but tends to be around 20%.

In our national survey last year, we asked people living with cardiomyopathy about their experiences of family screening and genetic testing. While genetic testing is still not at the level that we would wish to see, 56% of respondents saying that they have been tested, well above the US and Europe.

In the UK access to genetic testing is variable and where you live, or your type of cardiomyopathy makes a difference. There is also clear evidence that a lack of NHS funding is impacting the number of genetic counsellors available to support patients through the genetic testing process. This is one of the issues that our policy and advocacy work is attempting to address with the support of our volunteer Change Makers.

Working together with other cardiomyopathy charities from around the world means that we can get our important message out to more people than we could do by working alone. Council members are meeting up later in the year to start work on next year's campaign and we will keep you updated with its progress.

Travel, Holidays and Cardiomyopathy

Many people diagnosed with cardiomyopathy can travel and go on holiday and have a wonderful time. It's a good idea to check with your healthcare professional to make sure that you are fit to travel, especially if you're experiencing symptoms, waiting on test results, or have pending investigations.

Before you plan to travel, here are some things to consider:

Travel insurance

Travel insurance is important for anyone travelling abroad or away from home with a pre-existing medical condition. We recommend contacting companies directly to compare the cost and level of cover. It's important to check what's **included** in the cover, and what's **excluded**. Discuss your travel plans with your care team so you can plan and find the holiday that's right for you.

Contact the British Insurance Brokers' Association (BIBA) who have an impartial 'Find Insurance Services', both online and via telephone. When a customer contacts BIBA, one of their agents will take the details of the insurance needs. The agent will search for an insurance broker that can provide a quote based on those requirements and then transfer the customer to that broker. BIBA are currently working with several brokers that provide travel insurance quotes for someone affected by cardiomyopathy.

British Insurance Brokers' Association

biba.org.uk/find-insurance

0370 950 1790

Pre-existing medical holiday insurance could offer coverage for a variety of different things. Check the policy for the following:

Lost, Stolen or Damaged Personal Belongings

This could include any medication you take abroad with you, so it's an important benefit.

Emergency Medical Expenses and Repatriation

If you need emergency medical treatment abroad, the chances are you'll end up paying a hefty price for it. The cost of repatriation (emergency return back to the UK) is also high.

Cancellation and Curtailment

The insurance provider will cover you in the event of needing to cancel your holiday or cut it short for a certain reason (usually medical).

Travel Delay

This won't always be included, check with your provider.

Personal Liability

If you cause accidental damage to another person or someone's property, cover is provided.

More information:

cardiomyopathy.org
/practical-support
/travel-insurance

When booking your holiday

It is important to consider:

Accommodation

Is it close to amenities? Is there access to medical care such as a GP surgery or clinic? Make a note of these nearby facilities and whether they speak English.

Location and accessibility

You might require ramps or lifts to access rooms above the ground floor. Although these are likely standard in most hotels worldwide, it's always best to check before booking. You could even ask for ground floor accommodation to help avoid difficulty.

Climate

Speak to your cardiac team or GP if you're planning to travel to a very hot or cold climate as temperatures can affect some people.

Travel Assistance

If you need assistance at the airport or during the flight, let the airport and airline know in advance, including help with your luggage. If you have an implanted device, take your ID card with you and show it to airport security. You can ask for a hand search if you prefer.

Whilst on holiday

Take with you:

Medical Notes

A copy of your latest ECG, list of medications and clinical letter from your cardiologist (your GP receptionist or cardiac nurse can usually help with this). Consider translating these documents in the language of the country you're visiting so your needs and condition can be understood quickly. Google Translate is great for this.

Medication

Take plenty of medication (in case you're delayed) and a copy of your prescription. Pack them in your hand luggage so it's available.

Have a question? Speak to a nurse

0800 018 1024
Monday – Friday
08.30am-4.30pm

supportnurse@
cardiomyopathy.org

cardiomyopathy.org
(live chat)

Dilip's Cardiomyopathy Journey

Dilip had just returned from playing rugby in South Africa in summer 2022 when he first began to feel unwell. He persevered and was just completing his university application to study Medicine when things began to spiral.

It was during a rugby match at school at the end of November 2022 that Dilip became very unwell and presented with vomiting, dizziness and shortness of breath. His GP initially suspected heartburn but then requested an ECG and X-ray, based on his mum's request. He was eventually admitted to hospital where he was initially diagnosed with heart failure and discharged with medication to manage this.

Dilip's condition declined once he was at home, and he was eventually referred to see a cardiologist on December 14th. The cardiologist performed a right heart catheter after noticing the signs and symptoms of a suspected cardiomyopathy. He was then diagnosed with dilated cardiomyopathy. Unfortunately, Dilip's heart deteriorated whilst in hospital and he was put on the urgent transplant list.

Thankfully after 14 days Dilip received the call that a heart was available. With a few bumps in the road Dilip has made a fantastic recovery. His transplant was a success, and he has been home and trying to adjust to life with a new heart.

Dilip has taken his cardiac rehab to the next level by riding on his Peloton exercise bike over 100 miles since his transplant whilst also helping with charity fundraising. He is completing his A levels next year and has an offer to study Medicine at St Andrews University. Dilip is the newest member of our Youth Panel and sat down for a chat with our Paediatric Cardiac Nurse Specialist and Youth Services Manager, Emma.

Nurse Emma

Emma: Hi Dilip! A belated happy birthday for turning 18 last month. How are you feeling after your heart transplant?

Dilip: I feel very lucky that I was diagnosed so quickly and received a heart. I feel physically very well and adjusting nicely.

Emma: What was the biggest challenge you faced in your recovery period ?

Dilip: Everything happened very quickly and so at first, adjusting to a new way of life was tough. I had biopsies every fortnight for the first four months, and these have only just been changed to conducted monthly. Taking immunosuppressant medication every day is also something that required a lot of thought especially because I had never taken any medicines before.

Emma: What do you think helped you get through your heart transplant?

Dilip: The team at Wythenshawe Transplant Unit are incredible. A good relationship with them all was vital to my recovery. The nurses, cardiologists and transplant surgeons were brilliant and explained everything that was going on throughout my journey. They helped me understand my condition as well as always being approachable when I had questions or any concerns. I also had access to a chaplain, a psychologist and cardiac rehab team and they have all been incredible.

Emma: We're delighted that you've joined our Youth Panel and will be contributing to the support we offer young people with cardiomyopathy. What motivated you to join the Youth Panel?

Dilip: My diagnosis and transplant happened so quickly that I felt the need to go and research about what cardiomyopathy is and why I became unwell. It was during this that I came across your website and saw the details about the Youth Panel. I joined because I feel that I am still learning about my condition, and I am on a long road to recovery. Meeting other people with cardiomyopathy will allow me to share our experiences and support each other.

Emma: What do you hope to achieve by joining the Youth Panel?

Dilip: Sharing our experiences, our concerns and also advice will be invaluable. As a youth panel, we could help raise awareness to other people and have a strong support network.

Emma: What do you believe to be the most important issues that the Youth Panel can help to improve for young people affected by cardiomyopathy?

Dilip: Fundamentally understanding the condition and how to live a normal and healthy life despite the diagnosis. Additionally, raising awareness will be very important because obtaining a diagnosis is not necessarily easy. As a group, we could share our experiences and offer support or answer questions about living with our condition. This would be much better than being tempted to research on Google!

Emma: What would you tell other young people who may want to get involved but are unsure about what it involves?

Dilip: It is a safe place to be yourself and talk about your condition. Shared experiences with like-minded people can help us but will also be helpful to our family and friends because they will feel reassured that we have support from others in a similar situation.

Emma: Thanks Dilip!

Interested in joining our Youth Panel?

We meet every couple months to discuss how we can provide the best support out there for young people affected by cardiomyopathy.

Did you know you can also follow our Youth Hub on Instagram?

@youth_cardiomyopathyuk

Meet Amy
Heart to Heart Volunteer

Our Heart to Heart service provides 1-to-1 support over the phone to people with a diagnosis of cardiomyopathy and their loved ones. Heart to Heart is an opportunity to speak to someone who understands what you're going through – someone like Amy, one of our wonderful Heart to Heart volunteers.

Please tell us a little bit about yourself?

I'm a self-employed osteopath living in Wiltshire with two boys, and I was diagnosed with obstructive hypertrophic cardiomyopathy (HOCM) about ten years ago. I had an ICD fitted four years ago.

Why did you decide to become a Heart to Heart volunteer?

I became a volunteer with Cardiomyopathy UK a few years ago after talking to a patient at work who was struggling to come to terms with having an ICD. Ten years into my diagnosis I feel I have come to terms with it and understand a great deal, but I remember the initial days feeling daunting and lonely. I've been incredibly lucky with my journey and wanted to offer support and a friendly ear to others.

What does being a Heart to Heart volunteer involve?

As a Heart to Heart volunteer, I speak to others who contact the charity needing support. I love listening to everyone's stories and offer guidance in any way I can. I've found the most popular question is discussing the ICD procedure: what happens before, during and after. I think it's important to be able to talk to others going through something similar to yourself.

What do you enjoy most about your role and what have you learned?

I feel honoured to work with cardiomyopathy patients both professionally and as a Heart to Heart volunteer for Cardiomyopathy UK. I have met some incredible and inspirational people through the volunteering process, and I hope I can advocate positive changes for people with cardiomyopathy.I remember reading a quote once:

"find your tribe"

Tribe: Noun.
'A distinctive or close-knit group'

It could range from family to close friends or teammates. However, more specifically to me a tribe is your support system. This sums up how I feel about the charity and the people I've met.

What would be your message to others considering volunteering for this role?

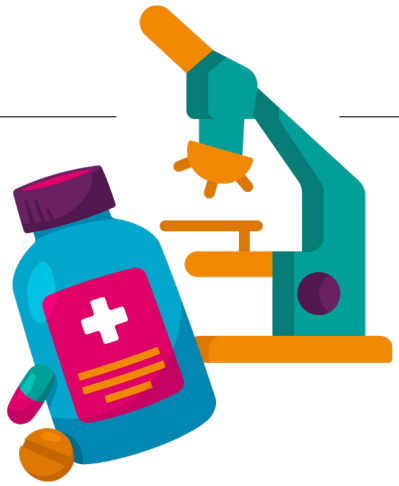
If you're debating about becoming a Heart to Heart volunteer, my quick advice would be to do it!

However, I also feel that you need to feel secure and positive about your own diagnosis before undertaking it. If anyone has recently been diagnosed and feels they'd like support, please contact the charity to be matched with one of our fabulous Heart to Heart volunteers.

Get in touch

If you'd like to speak to a Heart to Heart volunteer or become a volunteer yourself.

cardiomyopathy.org/heart-to-heart



Future Research Priorities

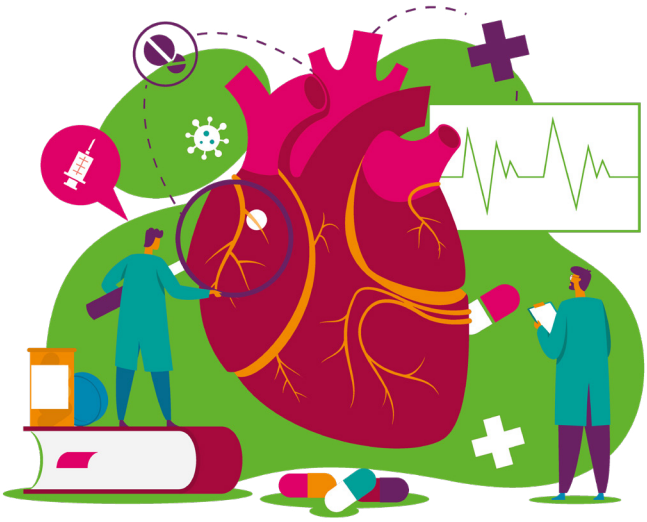
Research is key to improving the lives of people with cardiomyopathy. Research can lead to better understanding of the condition and its causes. It can enable people with cardiomyopathy to access better treatment and care, and wider services.

But despite ongoing research activity, in the UK and other countries, there are still many questions about cardiomyopathy that remain unanswered. Funding is highly competitive, and resources are limited. This means that researchers and grant makers need to know where best to focus their efforts to maximise impacts.

In order to maximise impacts, it is essential that research responds to the interests and needs of people affected by cardiomyopathy.

So, we have partnered with the James Lind Alliance (JLA) to take us through a 'priority setting process' (PSP) to identify the top 10 priorities for future research into cardiomyopathy. This is designed to raise awareness of research questions that are of direct relevance and potential benefit to patients, their carers and the healthcare professionals who work with them, with the aim of leading to changes in the way research funding is granted.

Establishing the top 10 research questions for cardiomyopathy will ensure that, going forward, researchers and funders can prioritise the most meaningful research questions. The optimum long-term outcome for any JLA PSP is that one or more of the top 10 priorities leads to a research study on that topic, and that this goes on to have a life-changing impact on the treatments or services available.



Underrepresented Groups

Often, research misses people from certain backgrounds, who are less likely to get involved in research or to respond to surveys. We are particularly keen to hear from young people (aged 16-25), and Black and minority ethnic people. If you – or someone affected by cardiomyopathy who you know – is from one of these groups, please do complete the survey. Additionally, we are holding two online workshops in July to hear in more depth from people in these groups.
To get involved please email:

research@cardiomyopathy.org

About the Priority Setting Process (PSP)

The rigorous James Lind Alliance Priority Setting Partnership methodology is used to formulate the top 10 research questions for any given condition, in our case cardiomyopathy. All Priority Setting Partnerships follow the same method, which entails people with the condition, their carers, and the clinicians and healthcare professionals that care for people with the condition, equally in setting priorities for research.

The whole process usually takes around a year to 18 months to complete – though the final stage (dissemination of the top ten) can go on for much longer.

Key steps include

1. Establish an expert group to guide the project, decide what is in scope.

Our expert steering group of people with cardiomyopathy and healthcare professionals meets regularly to check progress, and make key decisions about various aspects of the project.

2. Consult the community via a survey on what they think researchers should study

We are currently undertaking this stage, gathering in people's views to come up with a long list of all the wider variety of topics the researchers could study. Please see below to get involved!

we are currently here

3. Reduce the research questions, grouping those on similar topics (short list)

We are working with an 'information specialist' (James Lind terminology) who will look through all the survey responses, check whether there is actually published evidence on them or not, and reduce the long list into a short list.

4. Hold a priority setting workshop

We plan to hold a workshop this winter 2023/2024 with representatives from across the cardiomyopathy community to narrow down the short list to produce the final top 10.

5. Communicate the top 10 to researchers and funders

We will use the top ten in our own work, to underpin decisions on which researchers/ research projects we work with/on. We are also working on our plans for disseminating the top ten in 2024 – watch this space! We hope that the 'cardiomyopathy top 10' will inform future priorities for generations of researchers in the UK and across the world.

Have your say

Please complete our survey about what researchers should be investigating. Whether you want more research into treatments, or about genetic causes of cardiomyopathy, or impacts on wellbeing or lifestyle – or something else altogether – we want to hear from you.

bit.ly/cardiomysurvey

Meet the Researcher

Brian Halliday

Brian is a senior lecturer and consultant cardiologist who is leading research into how medications can reduce the symptoms of dilated cardiomyopathy for patients long-term.

Please can you tell us about yourself?

I am a Clinical Senior Lecturer and Consultant Cardiologist at Imperial College London, Royal Brompton and Harefield Hospitals and Guy's and St Thomas'.
I look after patients with all forms of cardiomyopathies and I have a particular research interest in dilated cardiomyopathy. I am interested in finding ways of tailoring therapy to individual patients taking account of their specific type and stage of disease. I try to escape work and keep fit by running at the weekends and enjoy travelling and cooking.

Why did you choose a career in cardiology?

I was inspired to go into cardiology by mentors at medical school and during my early clinical training. I have found looking after patients with cardiomyopathy particularly rewarding as you get to know patients by looking after them throughout different periods of their life. It is a very exciting area of medicine to be involved in, with lots of new treatments emerging. I also work in a super team and together, we can make a real difference to the quality of patients' lives as well as their families.

What was the outcome of the first TRED HF study?

The first study showed that around 4 in 10 people with 'recovered' dilated cardiomyopathy will relapse in the short-term if we stop all heart failure medications.

What is the TRED2 study? What does it involve?

The second study is another trial funded by the British Heart Foundation, to whom we are immensely grateful. We will investigate whether some medications may be more important than others at maintaining remission after recovery from heart failure. The aim is to see if we can tailor therapies and maintain remission in the long-term.

Who works on the TRED2 study?

I am fortunate to be joined by Dr Saad Javed, a cardiology registrar working in Manchester. He will work with me as a clinical research fellow on the trial and study for a PhD at the same time.

What would a usual day for a researcher like yourself look like?

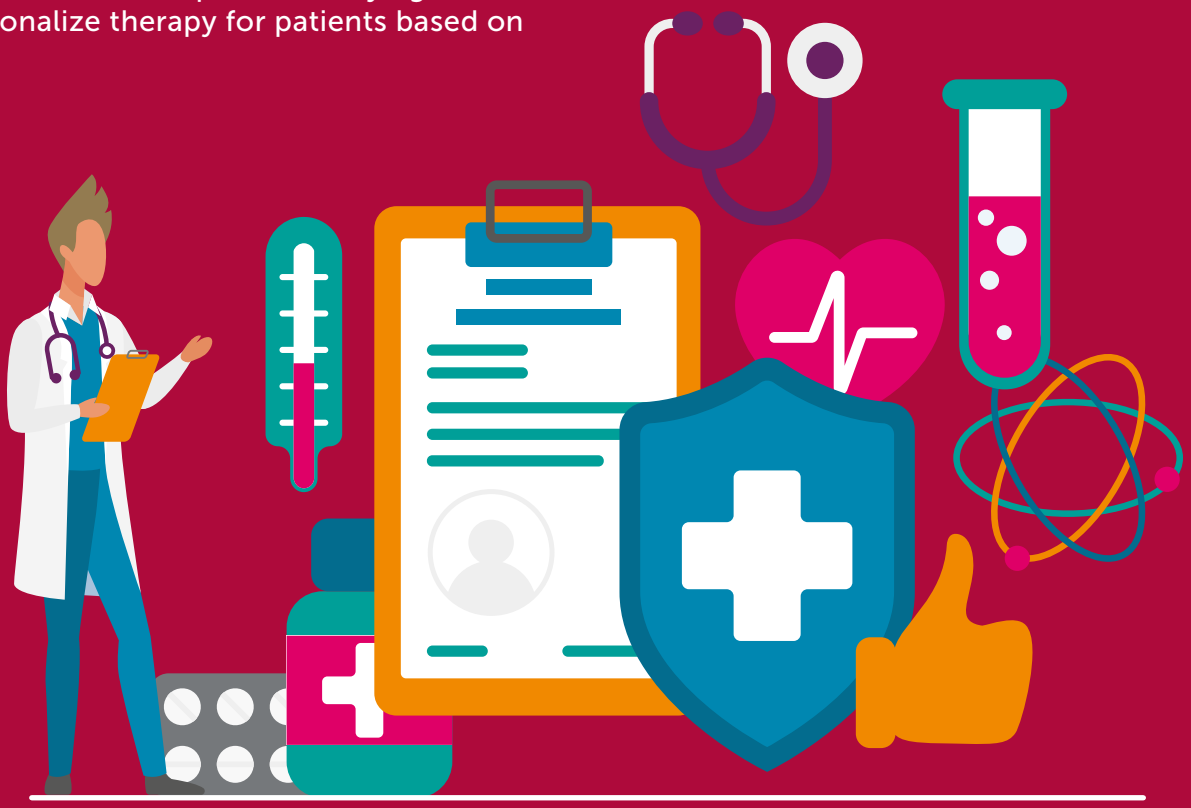
Every day is different! This is what makes being a clinical academic fun. Some days, I will supervise research scans or clinical trials. Other days, I write papers and grants or teach students or trainees. I also do clinics dedicated to looking after patients with cardiomyopathy and report cardiac MRI scans.

Why is the TRED2 study important? What could it mean for dilated cardiomyopathy patients?

This is another step towards trying to personalize therapy for patients based on the type of their cardiomyopathy and how it has responded to initial therapy. In the future, we hope to be able to find the right combination of drugs for the right patient to maintain and ideally, improve quality of life.

How can patients take part in the research? What are the requirements?

This study will focus on patients with a prior diagnosis of dilated cardiomyopathy who have responded well to initial therapy and are now well, without symptoms of heart failure and with normal heart function. If interested, I would suggest patients ask their usual doctors if it may be appropriate for them to take part in the study. We will put more information on the HeartHive when the study begins later this year and place an advert with Cardiomyopathy UK.



National Conference 2023

Saturday 18 November, London

The annual Cardiomyopathy UK conference brings together people affected by cardiomyopathy and healthcare professionals. Our conference provides you with information to help you on your cardiomyopathy journey, however far you have travelled so far.

On Saturday 18th November we'll be welcoming leading clinical speakers to discuss cardiomyopathies, as well as other healthcare professionals that will explore the wider impacts of cardiomyopathy and how to live well with the condition. Our focus this year is empowering people with the tools that they need to live well with cardiomyopathy.

We'll address the needs of those that are newly diagnosed and cover topics relevant to individuals that have been living with the condition for some time. We'll connect you with actively recruiting clinical trials and other people affected by cardiomyopathy. We'll explore self-monitoring, women's health, genetics, staying active and much more.

Following positive feedback in 2022, we'll be returning to our London venue, where we can offer a larger in-person capacity than ever before. We look forward to providing you with the information, support and networking opportunities that will help you to develop your knowledge, improve your confidence and empower you as a patient to live well with cardiomyopathy.

> "Sometimes my Mom feels like I don't understand what she's going through, coming to this conference has allowed her to feel heard."
>
> 2022 attendee

Get your ticket now

cardiomyopathy.org
/cardiomyopathy-conference

Cardiomyopathy Conference 2023

Engaging minds, empowering action				
09:30 - 09:55	Registration and breakfast			
10:00 - 10:25	Welcome and Key note 1			
What is cardiomyopathy?				
10:30 - 11:25	Hypertrophic cardiomyopathy	Dilated cardiomyopathy	Arrhythmogenic CM & myocarditis	LVNC, RCM & Takotsubo
11:30 - 11:55	Morning break			
Living well with cardiomyopathy				
12:00 - 12:55	Newly diagnosed with cardiomopathy	Living as a young person with cardiomyopathy	Living to your full potential throughout life	Advancing illness; Living well?
13:00 - 13:55	Lunch break			
Managing cardiomyopathy alongside your clinician				
14:00 - 14:55	Personalised medicine - Are we there yet?	Managing your activity & lifestyle	Shared decision making	Managing devices - The psychological & the practical
15:00 - 15:25	Afternoon break			
The empowered patient				
15:30 - 16:25	Genetics - Advocating for yourself & your family	Women's health & cardiomyopathy	Rhythm & digital - Self monitoring	Get involved in research
16:30 - 17:15	Key note 2 - New horizons in cardiomyopathies - What does the future hold?			
17:15 - 17:30	Closing remarks			

Draft programme - Subject to revision

Engaging Minds, Empowering Action

Cardiomyopathy UK
National Conference 2023

Fundraising Superstars

A big thank you to everyone donating and raising funds to support our work!

Jason's Cycling Challenge

"I chose to support Cardiomyopathy UK as my uncle has hypertrophic cardiomyopathy and both my cousins have also unfortunately inherited it. My uncle's condition has sadly progressed, and he is now on the heart transplant waiting list.

I wanted to challenge myself by taking part in RideLondon-Essex and thought it would be great if I could also raise money towards Cardiomyopathy UK. The research and support you offer is so important to all those affected by cardiomyopathy, and any funds raised will hopefully help to find better treatments, which would also benefit my cousins in the future.

Seeing the donations come in gave me so much more motivation to complete this challenge, not just for me personally, but also for all those that were supporting me by donating."

Catriona's Mighty Kiltwalk

Catriona and a mighty team of 20 friends and family completed the 18-mile Aberdeen Kiltwalk in June, raising a fantastic £2,400 in loving memory of two friends, Mark and Steve, whom they sadly lost to cardiomyopathy.

Kelly's Golf Day for Dad

"After suddenly losing my dad in February 2022 to cardiomyopathy, his mates knew that a golf day was needed to celebrate his life and memory. It was then quickly decided to turn it into a fundraising day. This has now turned into an annual event with hopes to get bigger each year.

We've just successfully held the second golf day and it's just an amazing day, seeing all his friends and family get together and share stories of my dad. It's also a great support day for us all. It means a lot for me raising the funds for Cardiomyopathy UK to honour my dad, but to also help raise awareness and help such a great charity moving forward."

Bake a Difference

You are invited to

Bake a Difference

Hold a bake sale or coffee morning with friends, family or colleagues and raise funds to save and improve the lives of people affected by cardiomyopathy.

Get your Bake a Difference pack today!

Bunting, posters, invitations and a free Cardiomyopathy UK t-shirt.

cardiomyopathy.org/bake-a-difference

Cardiomyopathy UK
Donation form

If you'd like to donate, please complete the form below and return in the enclosed free-post envelope to:
Cardiomyopathy UK, 75A Woodside Rd, Amersham, Buckinghamshire HP6 6AA.

Or donate online at:
www.cardiomyopathy.org/donate

Your donation

I would like to make a single gift of:

☐ £10 ☐ £25 ☐ £50 £ Other

Your Details

Title

First Name

Surname

Address

Post code

Telephone

Email

☐ I would like to receive updates by email from Cardiomyopathy UK about how they're providing support and information, campaigning for change, shaping future research and ways to get involved.

I would like to donate by:

☐ cheque enclosed (made payable to 'Cardiomyopathy UK')

☐ credit/debit card (card must be registered to the address overleaf)

Your card details

Name on card

Card number:

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Start Date: ☐☐/☐☐

Expiry Date: ☐☐/☐☐

Security Code: ☐☐☐☐

Is your donation in memory of a loved one? ☐ **Yes** ☐ **No**

Gift aid declaration – increase your donation by 25p for every £1 you donate

In order to Gift Aid your donation you must tick the box below.

☐ Yes, I want to Gift Aid my donation and any donations I make in the future or have made in the past 4 years to Cardiomyopathy UK. I confirm that I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Date ☐☐/☐☐/☐☐☐☐

You can also donate online at **www.cardiomyopathy.org/donate** or by calling us on **01494 791224**. For any queries, please contact **fundraising@cardiomyopathy.org**

Thank you

Cardiomyopathy UK is a registered charity in England, No. 1164263
Cardiomyopathy UK, 75A Woodside Road, Amersham, HP6 6AA