

myLife

The magazine for people affected
by cardiomyopathy and myocarditis

Darren's
Story

Our Fantastic
Fundraisers

Awards

Contact us

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

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Welcome



I am delighted to introduce this winter edition of MyLife, which I know from personal experience is such an important way for us all to stay in touch. This has been a really busy time for our staff team, led by our new CEO, Anna, and it has been so good to see how much progress is being made.

The Services team have excelled, as you can read in Becca’s update, gaining nominations for awards that recognise our Nursing Helpline and our emotional support programme, ACE. These are just a small part of all that the team are doing and developing. It is good to see that our ever-popular nurse Q&A feature is back too.

Our Research and External Affairs team, led by Katharine, have so much going on, and I am grateful for the ground-breaking research work underway and the careful examination of the new NHS England 10 Year Plan, and the implications for our community. We are also pleased to highlight our State of the Nation report on living with a cardiomyopathy – vital statistics and lessons we are already using in advocating for improved services. Thank you to the many of you who contributed to this work through our survey. There is more for us all to learn as well from the valuable article ‘New Medicines Update’ on pages 9-10.

The National Conference, on 28th March 2026, is in London again and looking really exciting. You can get a flavour of it in our conference article, and the key message, as ever, is to get onto Eventbrite and book early! I am personally very keen to see the photographic exhibition winners on display there; we still need more entries, so please do read about it in this issue.

And, I have to mention all that the fundraising team and our esteemed volunteer fundraisers are achieving - the stories in these pages speak for themselves. You are the life-blood of all that we do, and I want to thank everyone who has done so much - you are all stars!

Since this is the season of giving, a gentle reminder that a gift to the charity, especially one with Gift Aid added, allows us to achieve even more.

As this edition reaches you, I want to wish all of you – our staff team, trustees, vital volunteers and generous supporters, and those of you newly diagnosed as well as the “old hands” – a peaceful holiday season and a New Year filled with hope and blessings.

Stephen Kirkham, Chair of Trustees

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Darren's Journey to the UK

From Calgary to Sheffield: Darren's Coffee & Catch Up Journey

Lockdown beginnings

My name is Darren and I have been a regular member of Cardiomyopathy UK's Coffee and Catch Up (C&C) online social meet-ups for over five years now. What makes my story a little unusual is that I live all the way in Calgary, Canada, so each Friday I join C&C at 7am local time!

When the C&C meet-ups first started in 2020, my world (like everyone else's at that time) was dominated by lockdowns and "sheltering in place" messages. With all that going on, the opportunity to join online meetings with other cardiomyopathy-affected people like me was an intriguing one. At that time, the distance didn't seem like a big issue – whether you lived down the street or on the other side of the world, we were all spending more and more time in our homes.

Once I'd given C&C a try, I realised how great it was to have the opportunity to speak with people who shared common health challenges. We could instantly relate to one another and quickly built up strong rapports.

Forging friendships

As the weeks went on and I got to know my fellow C&C-ers a little better, the conversations turned more to our lives beyond cardiomyopathy. I had never been to the UK before, so hearing about life over there and the different towns and cities people on the call were from was fascinating to me.

Eventually, some of us started chatting over Facebook Messenger too, so the conversations continued between each C&C session. Soon we began to share photos of our lives with one another, and a friendship group started to take shape – one which is still going strong some five years after we first met!

Once things started opening up after the lockdowns and people were more comfortable meeting face-to-face, many members of the C&C group had opportunities to meet in person at events like the Cardiomyopathy UK Annual Conference. It was great to see photos of different members meeting up in person, and I was really pleased that they could do so.

Despite that, I was nevertheless a little disappointed that, because of the distance, I didn't have the same opportunity to meet people in person myself. I made it my mission to someday make the trip "across the pond" – not only to see the UK for the first time, but to see all my C&C friends too!



Heading across the pond

While I had initially thought that my UK trip might take a while to actually happen, I was delighted to have the opportunity to come to the UK this past September.

Although I was only able to stay for five days, I spent my time wisely and met up with so many friends that I had previously only seen on Zoom over the past five years. I spent a few days in London, and also took the train up north to see C&C friends in that part of the country as well. It was a wonderful opportunity to see as many people as I could, and it really felt like I was catching up with old friends, despite the fact that it was the first time we had seen each other in person.

As I reflect on my trip, I am left with feelings of incredible gratitude. I now have so many memories of little things that I don't think will ever leave my brain – like "Mind the Gap!" and "See it, Say it, Sorted".

The fact that I was finally able to visit the UK was, in itself, absolutely fantastic, but having so many friends to see while I was there made me feel like I wasn't just another tourist.

When I think back to how the world was in 2020 and 2021, I don't think any of us would want to go back to that time. But one positive that I will always take with me is that C&C was formed and I was able to join something that allowed me to establish friendships, despite the distance between us.

"I was able to join something that allowed me to establish friendships despite the distance between us."

Darren



Thank you to Cardiomyopathy UK for providing us with this opportunity, and to everyone in the C&C group for accepting me into their ranks. It has truly been an amazing journey and I look forward to the future – which will hopefully feature another trip to the UK!

To find out more about C&C visit
www.cardiomyopathy.org/coffee



Heather's Fundraising

Golf Days, Race Nights and Marathons



Heather and her family share how they've raised nearly **£25,000** in memory of her husband Brian, supporting others living with cardiomyopathy.

In August 2025, we held the fourth annual Brian's Memorial Golf Day and Race Night, complete with raffles and plenty of emotion. This special event raised **£4,315** for Cardiomyopathy UK. Over the last three years, family and friends have also taken on marathons in Glasgow and Edinburgh, raising **over £6,000** – a tremendous achievement all round.

Fundraising was also organised to install a lifesaving defibrillator for the community, which now sits outside our local pub, The Kittoch, in Brian's memory.

Brian tragically died in 2022, aged just 49. He was diagnosed with hypertrophic obstructive cardiomyopathy and had an ICD fitted. Brian was waiting for a heart transplant when he was taken from us too soon.

His loved ones wanted to find a way to remember him and celebrate his life, while supporting his favourite charity.



Brian's family says:

We miss Brian so much and he is forever in our hearts – a loving dad, son, husband, brother and friend. Living with the condition was hard for him; he was often exhausted just trying to get through everyday tasks, yet he always put on a brave face. He always had a smile and jokes to share – even if some of them were bad ones!

Every year, we're fortunate to have so many people come together as a community. We are forever thankful for our fundraisers, family, friends, local companies and our staff at The Kittoch for all their brilliant support.

We are now very close to hitting our **£25,000 target** to celebrate an amazing man. We hope this will help other families affected by cardiomyopathy, improve people's lives and bring us closer to a cure for this life-limiting condition.

We will make Brian proud.
He's our hero! x



Running for a Cause Close to Home

The Great North Run



It was something truly special when one family lined up together at the Great North Run. They weren't just taking on 13.1 miles – they were running to support their youngest daughter and raise awareness. Paul and his family wanted to share what it meant to tackle the 13.1-mile challenge while raising awareness and funds for Team Cardio.

Why we fundraised for Cardiomyopathy UK

Their motivation began when their youngest daughter was diagnosed last year with severe arrhythmogenic dilated cardiomyopathy at just seventeen. The condition was discovered unexpectedly during routine screening for a separate hereditary heart issue – something the family remains deeply grateful for.

Because cardiomyopathy can be genetic, her diagnosis prompted wider family testing. Parents, a sibling and extended family members have since undergone assessments and monitoring. Throughout this time, Cardiomyopathy UK has provided trusted information, reassurance and guidance.

The experience also highlighted how little public awareness there is of cardiomyopathy, despite it being the leading cause of sudden cardiac death in under-35s. That realisation strengthened their determination to fundraise and help Cardiomyopathy UK continue supporting families like theirs.

The best part of fundraising

For the family, the biggest reward was the sense of purpose and the opportunity to raise awareness among friends, relatives and their wider community. The encouragement they received from loved ones – and from Cardiomyopathy UK – made the whole experience meaningful from start to finish.

Race day reflections

They approached the run without strict time goals, focusing instead on enjoying the day and representing a cause close to their hearts. The atmosphere was electric, and a highlight came right at the start line when Cardiomyopathy UK received a shout-out over the speakers.

Crossing the finish line brought a huge sense of pride, made even more special by having their wider family, including their youngest daughter, there to cheer them on.

Looking ahead

By sharing their story and taking part in the Great North Run, the family hopes to raise vital awareness and ensure more families receive the support they need. Cardiomyopathy UK has been there for them – and through fundraising, they hope to help the charity support many more people in the future.

Feeling inspired?

Join Team Cardio for the Great North Run 2026 – applications are now open, so secure your place and make every mile matter.

www.cardiomyopathy.org/great-north





Celebrating Our Incredible 2025 Team

As 2025 draws to a close, we want to extend our heartfelt thanks to every fundraiser who took on a challenge this year. From Tough Mudders and skydives to walks, treks, 10Ks, half and full marathons, you have inspired us with your courage, determination and generosity.

We've been truly overwhelmed by the support shown for Team Cardio in 2025. People have taken on challenges in memory of loved ones, in support of family or friends living with cardiomyopathy, and simply to make a difference. Every mile, jump and step has contributed to our mission and made a real impact.

While all our events have been popular, we'd like to shine a particular light on our walking portfolio. This year, walks have included events from the Ultra Challenge Series, such as the Jurassic Coast, treks up Mount Snowdon, the National Three Peaks, and even Everest Base Camp. Thanks to the dedication of our walkers, these events alone have **raised over £25,000**.

Some of our fundraisers wanted to share what these walks meant to them...

Feeling inspired?

Why not join Team Cardio next year? Whether you're ready for an Ultra Challenge Series walk, a marathon or half marathon, a cycling event or one of our UK treks, there's an adventure waiting for you. And if you're dreaming even bigger, we can help arrange unforgettable overseas challenges.



"Climbing one of Snowdon's toughest routes for such an incredible cause was a real privilege. Hitting my **£1,000** fundraising target felt amazing,

knowing it will help Cardiomyopathy UK continue their life-saving work and support people living with the condition. The climb pushed me, but I loved every minute of it!"

Jodie



"In memory of my best friend Ro, who died suddenly from undiagnosed cardiomyopathy, I completed an ultra-marathon walking

challenge to raise funds for Cardiomyopathy UK, finding solace, connection and purpose along the way."

Nina



"We walked the Kiltwalk raising **£400** for Cardiomyopathy UK.

As a mum, wife and sister of someone with genetic DCM, I often feel helpless that I can't do anything to make it better. Taking on this challenge has made me feel like I've at least made a small difference, supporting those living with the condition and helping your charity continue to provide essential support every day."

Laura

Thank You to Our Fantastic Community Fundraisers



Through their Jurassic Coast Challenge, golf night and many other events throughout the year, the team has so far **raised over £40,000** for Cardiomyopathy UK.

In April, we had 17 incredible fundraisers take on a 30 Day Challenge. Their ideas included 30 days of walking, 30 days without chocolate and 30 days of push-ups. Each challenge was a fun and unique way to try something new, give something up or push themselves a little – all while raising valuable funds for Cardiomyopathy UK.

Thank you to all our community fundraisers, clubs, groups and corporate partners that have supported Cardiomyopathy UK in 2025. From bake sales and football tournaments to galas and race nights, we are grateful for every single fundraiser. Here are just a few highlights from an amazing year.

In May, we held our brand-new in-person walk, Walk With Your Heart. 32 dedicated walkers joined together in Amersham to walk 2km or 4km. It was very special to meet so many members of our community and to see individuals and families come together socially to support Cardiomyopathy UK.

We've also worked with some fantastic community groups who have gone above and beyond to raise donations and awareness. Millbrook Golf Club is one of these special clubs.



To everyone who has supported us this year. You are at the heart of everything we do.



New Medicines Update

The range of treatment options for cardiomyopathy looks likely to expand further. Three new potential medicines are now going through official checks (authorisation processes). Vutrisiran and acoramidis are both being assessed for the treatment of transthyretin-related amyloidosis cardiomyopathy (ATTR-CM), while aficamten is a new treatment for hypertrophic cardiomyopathy with obstruction (HOCM). These ongoing authorisation processes represent an important step towards bringing potentially life-changing drugs to our community. Here's a closer look at each one.

1. Vutrisiran

Vutrisiran (brand name Amvuttra) is a treatment for ATTR-CM, a rare, progressive condition in which amyloid protein deposits build up in the heart. This often causes symptoms including fatigue, breathlessness, swelling and mobility problems.

Vutrisiran is a long-acting treatment that targets the root cause of the condition. It reduces the amount of a protein called transthyretin (TTR) that the body makes, so there is less protein available to form amyloid deposits in the heart. It does this by blocking the genetic "message" (messenger RNA) that tells the liver to make TTR, using a process called RNA interference (RNAi). It is given as an injection every three months, providing an alternative way of taking treatment to tafamidis (Vyndaqel/Vyndamax), the existing disease-modifying treatment for ATTR-CM.

Vutrisiran is already available across the UK for the treatment of polyneuropathy (nerve disease/damage) associated with hereditary transthyretin-related amyloidosis.

However, it is now going through the medicine authorisation process again so it can also be approved for use in ATTR-CM. This is known as drug repurposing or "indication expansion" (using an existing medicine to treat another condition).

The Medicines and Healthcare products Regulatory Agency (MHRA), the UK medicines regulator, approved vutrisiran as being safe and effective for treating ATTR-CM in adults in mid-2025. In November, NICE (the National Institute for Health and Care Excellence – responsible for assessing whether the NHS should fund and use new medicines) issued its final draft guidance. This recommends vutrisiran for NHS treatment of ATTR-CM in England and Wales. People involved in the process can appeal or point out any factual errors before the guidance is officially published, expected in December.

What happens next?

If there are no appeals, vutrisiran will get the green light to be made available on the NHS to patients in England and Wales in December – and should then be made available to patients in the following three months. We expect that it will be evaluated by the Scottish Medicines Consortium (SMC) in 2026.



2. Acoramidis

Acoramidis (brand name Beyontra) is another ATTR-CM medicine currently going through authorisation, but it works in a different way from vutrisiran. It helps to keep a blood protein called transthyretin (TTR) in its normal shape so that it does not fall apart and form harmful deposits (amyloid) in the heart. These deposits can make the heart muscle stiff, so preventing them can help the heart pump better.

Acoramidis is a type of medicine known as a TTR stabiliser. Like tafamidis, an existing treatment, it binds to TTR and stabilises its usual four-part (tetramer) structure. This slows or stops the build-up of amyloid linked to ATTR-CM.

Acoramidis has been approved as safe and effective for UK use by the Medicines and Healthcare products Regulatory Agency (MHRA) and is now being reviewed by NICE to decide how well it works and whether it offers good value for the NHS (its clinical and cost-effectiveness) for routine use in England and Wales.

In December 2025, NICE issued its final draft guidance, recommending acoramidis for routine NHS use. Again, people involved in the process can appeal or flag factual errors before the guidance is officially published, expected in January.

What happens next?

NICE is expected to publish its final guidance on acoramidis in January 2026.

3. Aficamten

Aficamten is a cardiac myosin inhibitor (CMI), a type of medicine designed to target the underlying cause of hypertrophic cardiomyopathy with obstruction (HOCM). It is a newer medicine that works in a similar way to mavacamten (brand name Camzyos). Aficamten helps the heart to relax and pump more normally, reducing symptoms and improving exercise capacity.

Aficamten has started the medicines authorisation process in England and Wales (Scotland is expected to follow in due course). It is currently under review by the MHRA. NICE published a draft scope for the aficamten appraisal (NICE's detailed review) in October 2025.

This defines the condition (HOCM) and outlines a series of questions the appraisal aims to answer. Cardiomyopathy UK shared feedback on the draft scope to reflect key considerations for our community.

What happens next?

Once scoping is complete, NICE can begin a full appraisal (detailed review) made up of several stages. This includes the manufacturer of aficamten (Cytokinetics) submitting evidence on how well the treatment works and whether it offers good value for the NHS (its clinical and cost-effectiveness). The NICE committee will also hear evidence from clinical experts, patient representatives and NHS commissioning experts.

Once draft guidance, with a set of early recommendations, has been produced by the committee, healthcare professionals and the public will be invited to comment on it.

Get involved

Evidence from patient organisations such as Cardiomyopathy UK is an important part of the medicines appraisal process (NICE and SMC reviews of new medicines). We submitted evidence to NICE's appraisal of acoramidis and vutrisiran and will do the same for the SMC appraisals. We also want to be able to share the views of our community for the appraisal of aficamten.

If you've participated in an aficamten clinical trial, we'd like to hear about your experience. Your insights will help shape our future NICE and SMC submissions. Contact us at policy@cardiomyopathy.org

Living with Cardiomyopathy: State of the Nation Report

In the last issue of MyLife, we shared findings from our 2024 MyInsight survey, the largest survey to date of people living with cardiomyopathy, or caring for someone with the condition, in the UK. We're pleased to say that the full report has now been published. It brings together people's views and experiences to give an up-to-date picture of cardiomyopathy care in the UK.

Drawing on insights from over **1,300** survey respondents, the key findings show significant gaps across the care pathway, including delays in diagnosis, care that feels fragmented, and limited access to personalised support and treatment. Based on feedback from those living with cardiomyopathy, their families and healthcare professionals, our new report sets out Cardiomyopathy UK's vision for improving outcomes for people living with cardiomyopathy and their loved ones.

Early diagnosis and timely access to genetic testing, where appropriate

Timely and accurate diagnosis is essential for people with cardiomyopathy, but many people are not diagnosed until they experience severe symptoms. Often, symptoms are missed or mistaken for other conditions, and access to genetic testing remains unequal. Our survey found that **a quarter of respondents** were diagnosed with cardiomyopathy following a check-up or medical attention for another condition, while a further **13%** were diagnosed after medical attention was sought on their behalf, for example in an emergency.

To address these critical gaps, we're calling on the government to support earlier diagnosis of cardiomyopathy by improving access to diagnostic services. We also want to see the UK National Screening Committee consider a stratified, targeted screening programme for people at higher risk of cardiomyopathy.

Holistic, person-centred care that reflects the range of individual needs

Although cardiomyopathy affects more than just the heart, we heard that too often people feel unsupported and are missing the holistic care that's essential to their wellbeing. In our survey, **34%** wanted access to cardiac rehabilitation but didn't receive it, while **32%** said they needed mood or emotional support. Care must cover the full range of support that's needed and wanted by people affected by cardiomyopathy. That's why Cardiomyopathy UK is calling for equal access to specialist cardiac care through integrated care plans and more routine access to mental health supports.

Enhanced access to treatment and continuity of care

Many of our survey respondents shared the difficulties they experienced navigating a complex healthcare system, including having to organise their own care because services do not link up well. Continuity of care is essential, yet **28%** of respondents said the healthcare professionals involved in their care do not work well together. Respondents also raised concerns about delays in accessing new treatments.

Urgent reforms are required to ensure the NHS is ready for new therapies, including investment in the workforce and technology. The implementation of the Single Patient Record – owned by the patient and shared across the system, so that every part of the NHS has a full picture of the person's care – should also be sped up to support seamless care coordination.

We're committed to ensuring that the findings and recommendations in this report lead to real change. Together with clinicians, policymakers, the NHS, researchers and other charities, we'll continue to drive this work forward. Read the full state of the nation report: www.cardiomyopathy.org/my-insight

The NHS 10 Year Health Plan for England

What it means for our community

In July, the government published its **10 Year Health Plan for England** – a blueprint built around three main shifts: moving care from hospital to community, transitioning from paper-based to digital services, and placing a greater focus on prevention.

The plan follows a national conversation called **'Change NHS'**, in which the public and health and care staff across England were invited to share their views, experiences and ideas to help shape its priorities. Cardiomyopathy UK contributed directly to the engagement process, highlighting the importance of early detection and diagnosis, as well as fair access to specialist treatment, care and services.

Opportunities for people affected by cardiomyopathy

While the plan is not specific to cardiomyopathy, there are several encouraging mentions of cardiovascular disease and broader commitments to patient care that could benefit our community.

This includes the development of modern service frameworks, with cardiovascular disease identified as a priority area. By creating clear, evidence-based standards for diagnosis and treatment and addressing inequalities, this framework has the potential to improve health outcomes, provided it delivers for all heart conditions, including rarer conditions such as cardiomyopathy.

A key theme in the plan is the integration of genomic medicine into healthcare. By studying the genes in our DNA, genomics can help predict a person's risk of developing certain conditions, enabling earlier detection and intervention. The plan commits to establishing a new genomics population health service and expanding testing for inherited causes of major diseases, such as a higher risk of cardiovascular disease.

Importantly, this could help ensure that people with inherited forms of cardiomyopathy receive the right care at the right time and are better able to manage their condition.

Digital transformation is another core focus of the plan. Patients will have a 'doctor in their pocket' through the **NHS App**, giving them more control over their healthcare and making the delivery of care more efficient. New tools will be added to the app to improve the way patients engage with the health service, including **'My NHS GP'**, which will provide a single source of instant advice for patients who need non-urgent care, and **'My Specialist'**, which will enable patients to self-refer to specialist care.

The plan also proposes the creation of Neighbourhood Health Centres, bringing care into local communities. This could improve health outcomes and patient experience by reducing long waits for tests and treatment and providing easier access to services. However, it will be crucial to ensure that people living with less common conditions, such as cardiomyopathy, have access to specialist care.

Next steps

Although the plan represents a major opportunity, meaningful change will depend on the detail of its proposals, how they are implemented and the resources allocated. Cardiomyopathy UK's policy team continues to actively engage with policymakers, advocating for the ideas in the plan to translate into genuine improvements in services for people with cardiomyopathy.



Get Involved in Cardiomyopathy Research



Cardiomyopathy research has reached an important turning point, with promising new treatments starting to emerge. We want to make sure people affected by cardiomyopathy are at the heart of this progress.

Our Research Network is for anyone who has cardiomyopathy or cares about someone with the condition and has an interest in research. When you join our Research Network, you'll receive monthly emails with opportunities to take part in and help shape research. You'll also be the first to hear the latest research news.

You can choose to do as little or as much as you like.

Shaping the research agenda

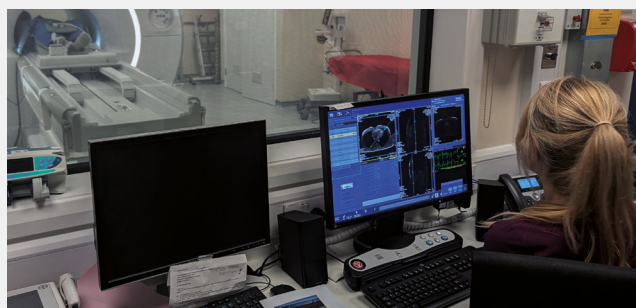
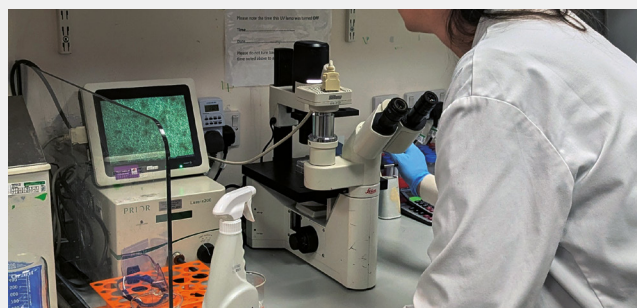
To ensure our research work reflects what matters to our community, we completed a Priority Setting Partnership (PSP) with the James Lind Alliance. People with lived experience of cardiomyopathy and healthcare professionals worked together to identify our top 10 research priorities. Find out more at: www.cardiomyopathy.org/future-research



Sandra Miller, who has hypertrophic cardiomyopathy (HCM), has been with us on our journey from the PSP to funding our own research.

"I first got involved with Cardiomyopathy UK about two years ago when I became a member of the PSP. It was interesting to be part of the team setting the **top 10** priorities for research and it introduced me to Cardiomyopathy UK's work. Following on from the PSP, I joined the Research Grants Committee this year and was involved in selecting two research projects that are in line with these priorities to receive funding from the charity. I found it really rewarding to follow the process through, narrowing down an extensive list of potential research areas in the PSP to two projects that were awarded funding."

We're excited to share more about our first ever Catalyst Grants early next year.



Groundbreaking research in action

We're part of the **£30 million** British Heart Foundation-funded CureHeart project, which aims to develop cures for inherited cardiomyopathies using advanced genetic therapies. Find out more on our website: www.cardiomyopathy.org/cureheart



Matthew Tosh, who has arrhythmogenic cardiomyopathy (ACM), joined our visit to the CureHeart labs in Oxford earlier this year.

"Thanks to Cardiomyopathy UK, I had the rare chance to step inside the CureHeart research labs. The moment I'll never forget? Peering down a microscope at lab-grown human heart muscle cells – cardiomyocytes – twitching in unison. It was hypnotic. These tiny, living cells, beating away in their nutrient broth, are the very foundation of every single heartbeat. I've got a scientific background, but it still hit me right in the chest – a mix of awe, wonder, and sheer gratitude. The CureHeart team's passion and openness made the science feel personal, not just technical. I left feeling energised, hopeful, and proud to know that patients and researchers are walking this road together."



Take part in research

Research studies come in many forms, from questionnaires that can be done at home to testing new treatments. Taking part gives you the chance to make a real difference, helping researchers understand cardiomyopathy better, which could ultimately improve life for everyone with the condition. You may also have the chance to speak with researchers or healthcare professionals and learn more about your condition. You can choose the studies that feel relevant and comfortable for you – you don't have to take part if you don't want to.

Make a difference

Getting involved in research can be empowering, giving you a sense of control and helping you take an active role in shaping the future of treatment and care for yourself and others. By joining our Research Network you'll have the chance to take part in studies, share your experiences, and help guide the direction of cardiomyopathy research. We shared over 20 opportunities this year. Every contribution matters to ensure cardiomyopathy research involves, includes and represents all members of our community.

Sign up today to join our Research Network
www.cardiomyopathy.org/form/research-network-subscribe



Get in touch

If you have any questions about cardiomyopathy research or how to get involved, you can contact us at research@cardiomyopathy.org



Acceptance & Commitment Education Programme Helping You Feel More in Control

Life with cardiomyopathy can bring all sorts of challenges – worry, low moments and days when everything simply feels harder than it should. That’s exactly why we created our Acceptance and Commitment Education (ACE) Programme, an emotional support programme designed specifically for people affected by cardiomyopathy.

This programme gives you practical skills to help make everyday life feel more manageable. Think of it as learning tools to feel calmer, rebuild confidence and gently move towards the things that matter most to you.

Grounded in Acceptance and Commitment Therapy (ACT), the programme offers a warm, supportive space where people learn together. You’ll explore techniques such as mindfulness, ways to handle difficult thoughts, clarifying your values and taking small steps that support your wellbeing. We also talk through real day-to-day challenges like fatigue, sleep issues and worries about symptoms. Many people tell us they especially value connecting with others who “get it”.

In 2025, we delivered online programmes made up of six sessions spread over a few weeks. Each course supported up to 12 people and was led by fully trained and supervised ACT practitioners.

What people are saying

The feedback has been fantastic. Most participants tell us they feel less anxious and more able to handle their moods. Many say their worries about heart symptoms have eased too. Here’s what we’ve seen...



What’s coming in 2026

We’re expanding the ACE Programme to reach even more people. In 2026 you’ll be able to choose from:

- **Short e-learning modules** you can complete in your own time
- **Online workshops** and smaller workgroups
- **Group sessions** for up to 12 people

We’ve added these options to suit different learning styles and to create a truly accessible service that’s available when you need it. We’ll also continue our six-part programme with **Dr Louise Roper**, Principal Health Psychologist, and will be running four full courses during 2026.

Want to learn more?

To learn more about the programme and the different options available, please email emma.cottington@cardiomyopathy.org. Emma is our Wellbeing Manager and can talk you through what might suit you best.

Coming in 2026

Genetic Advice Helpline

Cardiomyopathy UK will be launching a new genetic advice helpline in 2026, offering expert guidance and reassurance for anyone who wants to understand more about cardiomyopathy and inherited risk.

The helpline builds on our long-standing specialist nurse-led service, which already helps hundreds of people each year with questions about diagnosis, treatment and living well with cardiomyopathy. The new service adds a dedicated strand of advice focused specifically on genetics, an area that is becoming increasingly important as more people are referred for testing.

Led by our cardiomyopathy nurse specialists, our genetic advice helpline will provide:

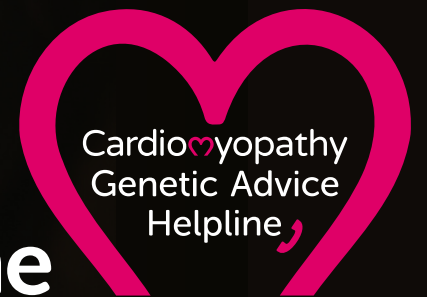
Information which is clear and reliable, about cardiomyopathy and inherited risk.

Help to understand screening and genetic testing.

Advice if a blood relative has been diagnosed with cardiomyopathy.

Time and space to talk if you’re worried about what genetic test results could mean for your children or wider family.

We’ll share more details on how to access the helpline in early 2026.



Helpline Partnership Award



Celebrating Our Helpline Partnership Award Win

We’re delighted to share that we’ve won a **Helpline Partnership Award for Wellbeing**. This recognition means a great deal to us and reflects both the dedication of our helpline team and the trust you place in our service.

As members of the Helpline Partnership, we’re part of a UK-wide network of organisations committed to providing high-quality information, advice and support. Together, members share best practice, learn from each other and work to improve the help available to people when they need it most.

At this year’s annual Helpline Partnership conference, we heard inspiring examples of how helplines are evolving. Sessions explored how tools like artificial intelligence can help us better demonstrate the impact of our calls, making it easier to show funders and stakeholders the difference these conversations make.

There were also discussions on supporting volunteers, reaching underserved communities and making helplines more accessible.



The focus on measuring emotional wellbeing outcomes and supporting people through digital channels – while keeping that vital human connection – was especially valuable. It was encouraging to meet other teams facing similar challenges and to share what we’ve learned.

Winning the Wellbeing Award recognises our commitment to supporting not only the physical aspects of living with cardiomyopathy, but the emotional and psychological ones too. Above all, it honours what our helpline team does every day: listening, understanding and helping people feel less alone.

Thank you for trusting us with your stories, questions and concerns. This award belongs to our whole community.



Recognised at the 'Third Sector Awards'



This year, we were proud to be finalists at the **Third Sector Awards**, where we were shortlisted in two categories.

The first was **Volunteer Team of the Year**, recognising the hard work and dedication of our amazing volunteers. They give their time, energy and kindness to support our community and help people connect with others living with cardiomyopathy.

Their support changes lives every day. We may not have taken home the top spot, but our volunteers are always winners in our eyes.

We were also finalists for **Best Service Innovation** for our Acceptance and Commitment Education Programme – a unique emotional support offer created specifically for people affected by cardiomyopathy. It is the only programme of its kind in the UK, and we are incredibly proud to be leading the way in this field.

Being recognised alongside so many impressive projects and charities was a real honour. Even though we didn't win first place, seeing our programme celebrated at such an important charity sector event was a moment of pride and a reminder of the impact this work is having.

Cardiomyopathy UK Gains PIF TICK Certification



Cardiomyopathy UK has been awarded the **PIF TICK** – the UK's only assessed quality mark for print and online health and care information.

To become a "trusted information creator", we underwent a detailed assessment to show we meet 10 key criteria. This means you can be confident that what you're reading, watching or listening to from us is evidence-based, up-to-date and easy to understand.

The PIF TICK, launched in 2020, is run by the Patient Information Forum (PIF) charity.

We're always keen to involve our community in shaping our information. If you'd like to help us ensure our resources are clear and easy to use, we're creating a database of volunteers to review our materials. To find out more about what this involves, please email services@cardiomyopathy.org



Photography Competition 2025

'Living with cardiomyopathy'

Cardiomyopathy often feels invisible, but there are many situations which highlight the reality of living with the condition.

We are now excited to invite our people - patients and carers, family and friends - to participate in a photography competition, to help us create a library of images which will be used to raise the profile of cardiomyopathy.

We are looking for images which illustrate what it means to live with a diagnosis of a cardiomyopathy. Photographs may be of individuals, of groups, or may speak in some other way of what it means to have the disease. **Be as creative as you like!**

How to enter

You can submit your entry through our online form at www.cardiomyopathy.org/photograph or you can download the entry form on the same webpage, and email it to photo@cardiomyopathy.org by **20th January 2026**.

High resolution images of the winning pictures will be displayed at our National Conference in London on 28th March 2026.

Prizes

Overall Winner: **£100 voucher + feature article in MyLife magazine**

Runners-up: **£20 voucher each**

More details can be found on our website at www.cardiomyopathy.org/photography



Staying Well this Winter



Cold weather makes your heart work harder to keep your body warm. As a result, your heart rate and blood pressure may increase. These changes can sometimes make heart-related symptoms worse and affect how well your heart copes.

Try not to become overheated when outside. If you sweat due to physical activity, your blood vessels can dilate, which may lower your blood pressure and lead to dizziness or feeling faint.

You may be entitled to financial help with making your home more energy-efficient or with energy bills. To check what support is available, visit www.turn2us.org.uk and search for **"How do I claim a Winter Fuel Payment?"**

If you feel you may be developing a cough or cold, seek advice early. Reliable information is available from the NHS at www.nhs.uk — for example, by searching **"Common cold"**.

During the winter months, GP surgeries can be busier than usual. Our nurse team recommends considering the following sources of advice and support:

Community pharmacist

Pharmacists can give advice about many minor illnesses and over-the-counter medications. They can also advise whether you need to see a GP or seek urgent care. For more information, visit www.nhs.uk and search **"How pharmacies can help"**.

GP online services

Many GP surgeries offer online forms to request an appointment, ask a question or request repeat medication. You can find out more by visiting www.nhs.uk and searching **"NHS online services"**.

NHS website

If you are unsure about a condition or injury, the NHS "Conditions A to Z" pages provide clear, evidence-based advice. Visit www.nhs.uk and search **"Conditions A to Z"**.

Urgent Treatment Centres and walk-in centres

Walk-in centres can help with minor illnesses and injuries such as sprains, strains and cuts/grazes. Many are open seven days a week. To find your nearest centre, visit www.nhs.uk and search **"When to visit an urgent treatment centre (UTC)"**.

GP practice nurses and nurse practitioners

Many GP practices have nurses who can see people for minor illnesses. Some can also prescribe medications, such as antibiotics.

NHS 111

If you have an urgent medical issue and are unsure what to do, call 111 or visit 111.nhs.uk. This service is available 24 hours a day, seven days a week.

Cardiomyopathy UK specialist nurses

You can speak to one of our specialist nurses through our **"Speak to a nurse"** service. Visit www.cardiomyopathy.org and select 'Speak to a nurse' from the website menu.

Q&A with our Nurses

If you have a question for our experts to answer, please email: supportnurse@cardiomyopathy.org



Helpline
0800 018 1024
(free from a UK landline)
8.30am-4.30pm
Monday-Friday

Q. I've heard about trouble getting hold of some medications from the pharmacy. What should I do if this happens to me?

Sometimes there can be supply chain issues that affect the availability of certain medications. If this happens to you, we advise:

- **Talk directly with your pharmacist** – they may be able to explain what's happening and suggest alternatives.
- **Check other local pharmacies**, as they may have stock. Your GP can send your prescription to a different pharmacy if needed.

- **Ask whether another dose or form of the medicine** (for example, a liquid) is available and could be prescribed instead.
- **Speak to your cardiology team** about whether an alternative medication can be prescribed.
- **Let us know**, so we can look into whether this is likely to be a longer-term issue and share information with our community.

Q. Could my diagnosis of heart failure due to dilated cardiomyopathy be affecting my sleep?

Yes, heart failure can affect your sleep in several ways:

- Chest discomfort or breathlessness can make it harder to relax, fall asleep or stay asleep.
- Lying flat can sometimes bring on breathlessness.
- You may need to get up in the night to pass urine. Fluid can settle in your legs or feet during the day and then move towards your lungs when you lie down. **Diuretics** (water tablets) help to reduce fluid build-up.

- A sleep specialist can assess whether there is an underlying medical cause for your sleep problems and recommend treatment.

Sleep is important for both our overall health and our heart health. You can find tips to improve your sleep on our website: **"12 Tips for a Good Night's Sleep"**

For some people, sleep problems are linked to anxiety. If you're worried about your mental health, speak to your GP or visit Mind's **"Sleeping with Anxiety"**



Welcome to our new nurse Janice

Cardiomyopathy UK is pleased to welcome Janice to our specialist bank nurse team. Janice is a registered nurse with extensive experience as an Arrhythmia Specialist Nurse in inherited cardiac conditions, and as a Genetic Counsellor in the West of England. She holds a Master's degree in Inherited Cardiac Care/Arrhythmia Nursing, and has recently completed Master's-level modules in Genomics. Janice is also a registered Genetic Counsellor. We're delighted to have her expertise supporting our community.

Journeying Together Cardiomyopathy UK 2026 Patient Conference

Tickets
Now
Available



We're delighted to announce that tickets are now on sale for the **Cardiomyopathy UK Patient Conference 2026**, taking place on **Saturday 28 March 2026 at 155 Bishopsgate, London**. This year's conference brings together people affected by cardiomyopathy – whether newly diagnosed, living with the condition long-term, or supporting a loved one – to learn, connect and look ahead with confidence.

The day opens at 09:00 with a warm welcome from our Chair of Trustees and CEO, followed by a keynote from **Professor Hugh Watkins**, who will share the latest breakthroughs from the CureHeart programme and the emerging promise of genetic therapies.

Throughout the programme, delegates can choose from a wide range of expert-led sessions reflecting the real questions and challenges faced by our community. Women affected by cardiomyopathy can join **Dr Paz Tayal** and **Dr Tracey Ketepe-Arachi** for an in-depth discussion on the unique diagnostic and treatment journey for female patients. Those newly diagnosed may benefit from a session with **Professor Gerry Carr-White** and Specialist Nurse **Jayne Partridge**, who will introduce genotypes, phenotypes, treatment pathways and the support available through Cardiomyopathy UK.

A strong theme for 2026 is innovation. **Professor Perry Elliott** will host a panel on emerging therapies, while industry experts – including medical technology manufacturers – join **Professor Lis Neubeck** to explore the future of wearables and remote health monitoring. You'll also hear from **Dr William Bradlow** and **Dr Jason Dungu** about their vision for the future of healthcare service delivery, following the release of the **"Fit for the Future: the NHS 10-Year Health Plan"**.

For those wanting practical skills, **Dr Louise Roper** will share strategies for managing fatigue, sleep and medication using approaches such as Spoon Theory. Clinical Exercise Physiologist **Shane Purcell** and **Dr Joyee Basu** will offer tools to help patients advocate for themselves during clinical appointments. Additional sessions will cover cardiac devices, surgery, interpreting heart data and the power of community-led peer support.

We are pleased to welcome Cardiomyopathy UK President **Professor Perry Elliott** for our closing keynote, before CEO **Anna Tomlinson** shares charity updates to round off the day. The event will close at 16:00.

Join us as we journey together towards better understanding, better support and better care for everyone affected by cardiomyopathy. To find out more visit www.cardiomyopathy.org/conference

Book your place at
hov.to/0466aad9
or by scanning the
QR code:



Cardiomyopathy UK Donation form

Please complete the form below and return in the enclosed free-post envelope to:
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

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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