

myLife

The magazine for people affected by cardiomyopathy and myocarditis



Marty's
story

Q&A with our
nurses

Our fundraising
superstars

Contact us

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Welcome to the winter edition of MyLife.

I wonder if like me you are pondering on how this year seems to have gone so quickly, as it's now time to wrap up warmly and enjoy the autumn and winter seasons and cherish all that they bring.



This time of the year is often time for families to get together, to reflect on the past year, celebrate, and make plans for the year ahead. One family who have much to celebrate is the Bishop family, who continue to come up with new fundraising ideas regularly to generously support the charity. This year they have much more to celebrate, you can read about the Bishop family and Marty's well deserved "Yorkshire Children of Courage" award on page 6-7. Well done Marty and family.

We have been heavily involved and busy the past few months with a particular emphasis on our international work. With the International Cardiomyopathy Network (ICoN) agreeing their programme of activity for 2024/25, and the Cardiomyopathy Council which consists of cardiomyopathy charities from around the world, agreeing to develop an international research project, drawing on patients experiences and inequalities in care and treatment, there promises to be exciting times ahead. Turn to page 4-5 for more detail.

If you are questioning your understanding of clinical trials, see the article on page 14-15 where all will become clear.

I wonder if like Julie Rees you wrote to your MP. Local elections may have been and gone, but it's never too late to do so. Julie shares her experience on page 16-17.

Thank you all for your continued support for Cardiomyopathy UK.

Season's greetings to you and your families. I sincerely hope the year ahead brings you good health and happiness.

Warm wishes,

Rita Sutton, Chair

Rita

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The international cardiomyopathy community

It is fair to say that the international community of cardiomyopathy charities continues to grow. Back in 2020, we led the way in finding and bringing together what was then a small handful of cardiomyopathy charities outside of the UK. We felt at the time that this was important as it created an opportunity to share information on global research efforts and drug development. It also enabled all cardiomyopathy charities to share ideas, resources and in particular, information on how people were coping with the COVID 19 pandemic.

As this network grew, we started to think about collaborating on international projects, whereby joining together, we could amplify our voice and reach more people. This led us to approach Global Heart Hub, an international network of heart disease charities, and ask them if they could host and support our cardiomyopathy network as one of their "councils."

Fast forward a few years, and thanks to the support of the Global Heart Hub team, the Cardiomyopathy Council now includes 26 charities from 15 different countries. All these charities either focus solely on cardiomyopathy or support people with cardiomyopathy as part of their work. As a council, we have delivered three international awareness campaigns, agreed protocols on research and shared resources worldwide.

At our most recent meeting this summer, we identified a number of areas of collaboration. We talked about how we can foster a culture of participating in clinical trials and make it easier for those who want to be involved to sign up where appropriate. This will involve improving our ability to share information about trial opportunities and working with healthcare professionals and other investigators to make trials more accessible to all communities.

We also talked about how we can make medications and health services for people with cardiomyopathy more focused on the actual needs of people with the condition. This means that, for example, when a drug trial looks at how affective a treatment is, it does not just measure clinical changes but also the improvements in day-to-day life that really matter.

Another big topic of discussion was the need to share evidence on the impact of cardiomyopathy and the experiences of people with cardiomyopathy in accessing care and treatment across the globe. This is something that we do very well at Cardiomyopathy UK. Our recent MyInsight survey had a tremendous response and will be used to provide evidence for our advocacy work as well as shaping our own services. Bringing together the insights from this survey with those from other countries will help us to provide stronger evidence and fill in some of the gaps in our own knowledge.

As ever, we also focused on how we can work together to raise public awareness of cardiomyopathy and the importance of knowing your own 'heart history'. While we have already done some great work in this area, we all agreed that there is still more to be done. Planning is now underway for

a fourth international awareness campaign focused on reaching people who may have been misdiagnosed or told that they have heart failure without being given the cause.

When we work together on international projects, we must recognise that different groups are working in very different environments. For example, access to genetic testing in the US is far below that of the UK and groups based in Eastern Europe are working where there are fewer cardiomyopathy experts. Differences in language, culture, geography and the political environment all make it more challenging to find common ground and projects that work for all.

While there are many differences between the groups in the Cardiomyopathy Council, there is much more that we have in common. We all want the same thing for our communities. We all want people who are affected by cardiomyopathy to be better able to cope with the condition, we all want more people to be aware of the signs and symptoms of cardiomyopathy, and we are all fighting for better access to quality treatment.

So while there is much work ahead, I have no doubt that by working with other cardiomyopathy charities from around the world to share ideas, insights and resources, we are better able to serve our own community and play our part in the global movement to improve the lives of people affected by the condition.



To learn more about Global Heart Hub's Cardiomyopathy Council, scan the QR code or visit:

 <https://tab.so/global-heart-hub>





Marty's story

During her pregnancy, Sarah and husband Darren were told that their unborn baby, Marty, had cardiomyopathy. 14 years later, the Bishop family have raised over £100,000 for Cardiomyopathy UK, and Marty has just been awarded a Yorkshire Children of Courage award. Marty's mum, Sarah, has shared their journey with us.

My son Marty Bishop was diagnosed with cardiomyopathy before he was even born. It was on my birthday when I was 22 weeks pregnant that we were given the devastating news that our baby had a very poor prognosis for survival and may not survive his birth. Our world came crashing down and how we felt was indescribable. Not knowing where to turn, we found support in a wonderful nurse called Gill who worked at what was then 'The Cardiomyopathy Association'. The weekly phone calls with her were our absolute lifeline.

Marty is now 14 years old and has been defying his diagnosis under the watchful eyes of the world-renowned specialists at Great Ormond Street Children's Hospital

ever since. Infact, since the discovery of the cardiomyopathy we have been on a diagnosis rollercoaster with Marty currently described as having mild features of cardiac muscle disease and mitral valve dysplasia. His heart functions well despite its far from normal appearance. Our future is still very much unknown, and he remains under regular review both in London and locally where we live in West Yorkshire.

Over the past 14 years Marty has found life very difficult at times. As well as coping with cardiomyopathy being a part of his life, he was diagnosed with autism, severe anxiety disorder and OCD. He has not been able to access a bricks and mortar school since 2019, but is now thriving taking his GCSE courses with an online School. Marty also spent time in

hospital last year being unwell with an MRSA virus and in true Marty style, handled this with bravery and a smile.

When Marty was one year old, his older sister Kimberley took on a skydive for Cardiomyopathy UK, and this was the start of our family fundraising. We launched the charity cause 'Marty's Penny bank' and it is now a huge success. We also raise funds and awareness for Great Ormond Street Children's Hospital Charity.

During the last 12 years we have organised many fundraising events including music nights, theatre shows, sky-diving days and bun sales, to name just a few. Many of our family and friends have taken on challenge events having been inspired by Marty's story, his resilience and bravery.

The fundraising total in Marty's fund at Cardiomyopathy UK is now over £100,000. We have raised over £10,000 for GOSH and we have hit Marty's target of 'ten million pennies' (although he has since moved the goalpost). We want to say a huge thank you to the generous attendee at the award show, who approached Marty after he accepted his award with an £8,000 donation.

We are so pleased and proud to have been able to give back to the charity and to help other families affected by a diagnosis of cardiomyopathy.

As well as raising vital funds, we have been able to raise awareness and bring people together who have needed support and inspiration. Marty is a truly inspiring young man and his story gives people hope and encouragement.

On Friday 18 October, Marty was awarded the winner in the teenage category of the 'Yorkshire Children of Courage Awards'. This was a simply stunning event held at the Royal Armouries in Leeds, where we as a family celebrated Marty's fundraising and his life story so far with hundreds of people at the



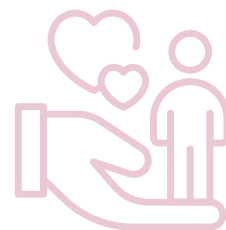
black-tie ball. When we listened to other people talking about Marty's achievements it was very surreal indeed.

Marty says, 'It is so good to have won the award and I hope we can keep helping other people'.

We hope that Marty being given the award makes him realise how special he is as he is always so humble about everything. We hope that we can now go on to hit his next fundraising target, and our next fundraising event in the diary is a spectacular evening of professional cabaret to be held at Yeadon Town Hall Theatre in Leeds on 23 February 2025. Tickets are available now and you can contact Cardiomyopathy UK for the details.

To say we are proud of Marty does not come close. We love him endlessly.





A guide to benefits and welfare support

We understand how overwhelming it can be to navigate the complexities of the benefits system. We are here to support you in accessing personalised benefits and welfare advice for yourself or your caregiver. We have partnered with highly experienced external benefits and welfare advisors who work independently from the charity. They are committed to providing free and confidential advice to anyone affected by cardiomyopathy.

? Can I claim benefits?

When it comes to benefits, there are some rules about who can claim them. For instance, if you're dealing with a health issue that makes it hard to take care of yourself, you may be eligible for a benefit. Your income level also plays a part in determining if you qualify for certain benefits, which are known as income-related or means-tested benefits. On the other hand, there are benefits that you can only receive if you've made enough National Insurance contributions. We call these contribution-based benefits or contributory benefits.

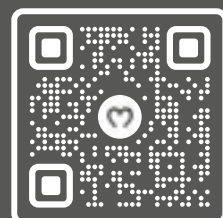
? If you are self-employed

The benefits you are entitled to may be different if you are self-employed. The benefits and welfare advisers can help you understand what support you may be eligible for.

We have partnered with Turn2Us, a national charity providing practical help to people accessing individual grants and benefits.

Turn2Us has a free and confidential Benefits Calculator to find out what benefits you are entitled to claim. Scan the QR code or visit:

 <https://benefits-calculator.turn2us.org.uk/>



Types of benefits

Personal Independence Payment (PIP)

If you're under State Pension age and need help with daily living or getting around, PIP might be for you. Our advisors will guide you through the application process and help you gather the necessary evidence.

Employment and Support Allowance (ESA)

ESA can provide financial support if your condition affects your ability to work. Our advisors will help you understand the different types of ESA and assist you in completing the Work Capability Assessment.

Universal Credit

This benefit is designed to support you if you're on a low income or out of work. Our advisors will help you navigate the online application and ensure you understand how to report your health condition.

Attendance Allowance

If you're over State Pension age and need help with personal care due to your condition, you might be eligible for Attendance Allowance. Our advisors can help you with the application and explain what evidence you'll need.






Carer's Allowance

If someone looks after you for at least 35 hours a week, they might be entitled to a Carer's Allowance. Our advisors can advise on how to apply and what information you'll need.

Blue Badge Scheme

If your mobility is affected, a Blue Badge can make parking easier. Our advisors will guide you through the application process and help you understand the eligibility criteria.

How we can help

-  One-on-one telephone support: our external benefit and welfare advisors offer personalised advice tailored to your situation. They will take the time to understand your needs and provide the best possible guidance.
-  Benefit checks: the advisors will thoroughly assess your personal circumstances and determine the benefits you are entitled to.
-  Help you understand how the symptoms of cardiomyopathy are relevant to the rules for welfare benefits and the questions used to assess them.
-  Form-filling assistance: our advisors help you complete any benefit-related forms accurately and comprehensively, even if they seem overwhelming.
-  Appeals and tribunals: don't lose hope if your application has been denied! Our advisors can assist you with the appeals process.

If you would like to speak to our free and confidential external benefits and welfare advisors, please get in touch with us:

 services@cardiomyopathy.org

 01494 791224

Q&A

with our nurses

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



Q. Who can I speak to about over the counter medications and vitamin supplements?



Nurse Jayne

Community pharmacists are available to provide advice and guidance about prescribed and 'over the counter' medications and supplements, they are for most people within a short distance or via phone. Pharmacists are experts in medication and are best placed to advise on questions on interactions and potential side effects of medications as they have access to specialised 'medicine management information.' They might also offer advice on NHS services such as smoking cessation, blood pressure checks, weight management and vaccinations.

Pharmacists are available to speak to confidentially about any health concerns. Speak to your pharmacist if you are finding medication expensive as they will be able to advise on prepayment schemes and prescription charge exemption.

Q. How do I find out if I am eligible for the new medication to treat HCM with obstruction?



Nurse Jayne

You would be advised to speak with your cardiologist or specialist nurse and ask if this would be suitable as part of your treatment, your cardiologist might need to refer you to a specialist clinic for initiation.

Mavacamten is available for prescribing in the UK by specialist cardiologists within strict guidance to people diagnosed with HCM with obstruction.

The guidelines require checking of bloods (for a specific enzyme) and an echocardiogram. Regular echocardiograms are required whilst on this treatment to assess heart function and assess symptoms.

Mavacamten is well tolerated and has been shown to improve symptoms and increase ability to exercise.

It's always a good idea to speak to your GP. They can assess your symptoms and alter medications. They will also be able to get direct advice from your cardiologist if necessary, and can ask for your appointment to be brought forward.

Most cardiology services have a nurse specialist team who can offer advice, as well as book tests for you and review you in their own clinic.

If your query is related to medication, please don't forget that your local pharmacist has a wealth of knowledge. Your hospital pharmacy may also offer a patient information service.

If your symptoms have increased dramatically or suddenly, then please do contact NHS 111, or attend accident and emergency.

Q. I have to wait a long time between appointments with my cardiologist, how do I get help in the meanwhile?



Nurse Emma

This is general advice only. If you have any concerns, speak to your GP, cardiac or heart failure nurse.



Join #TeamCardio

Our 2025 events calendar

From awareness days to fundraising campaigns and challenge events, here are all the ways you can join #TeamCardio in 2024 and help us save and improve the lives of those affected by cardiomyopathy.

📅 JAN 25-26	London Winter Walk with Ultra Challenge
📅 MAR 23	Hampton Court Palace Half Marathon
📅 APR 1-30	30-Day Challenge
📅 APR 6	Brighton Marathon
📅 APR 27	TCS London Marathon
📅 APR 27	Manchester Marathon
📅 MAY 1-31	Walk With Your Heart
📅 MAY 3	Yorkshire 3 Peaks Challenge
📅 MAY 16-18	3 Peaks Challenge
📅 MAY 17-18	Jurassic Coast Challenge
📅 MAY 18	Hackney Half Marathon
📅 MAY 24-25	Edinburgh Running Festival
📅 JUN 7	Blenheim Palace Triathlon
📅 JUN 15	London to Brighton Bike Ride
📅 JUN 28-29	Peak District Challenge
📅 JUL 13	London 10k

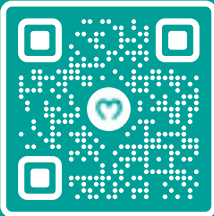
📅 AUG 23	Summer Walk London Ultra Challenge
📅 SEP 7	Great North Run
📅 SEP 5-7	3 Peaks Challenge
📅 SEP 10-14	London to Paris Bike Ride
📅 SEP 13-14	Thames Path Challenge
📅 SEP 13	Thames Bridges Walk
📅 SEP 12-14	24 Peaks Challenge
📅 OCT 5	Oxford Half Marathon
📅 OCT 12	Cardiff Half Marathon
📅 OCT 12	Royal Parks
📅 OCT 14-20	Bake a Difference
📅 OCT 18	Yorkshire 3 Peaks
📅 OCT 19	Amsterdam Marathon
📅 OCT 20	Great South Run
📅 OCT TBA	Manchester Half Marathon
📅 OCT 27	Chiltern 50 Ultra Challenge

Awareness Days

- APR 2 - National Walking Day
- SEP 29 - World Heart Day
- SEP 29 - World Coffee Day
- DEC 2 - Giving Tuesday

If you want to join #TeamCardio in 2025, scan the QR code or visit:

🌐 www.cardiomyopathy.org/fundraise



Understanding clinical trials

Research is paving the way for new treatments for cardiomyopathy. Once a potential treatment has been developed and tested in the lab, the next step is finding out if it is safe and effective through clinical trials in people.

Cardiomyopathy UK is part of the £30 million British Heart Foundation funded CureHeart project, which aims to develop the world's first cures for inherited cardiomyopathies. The international team of researchers hope that at least one new therapy will be ready for clinical trials towards the end of the project in 2027.

Clinical trials are carried out in a series of steps called phases (which often include a placebo or dummy treatment for comparison). Depending on the outcome, a potential new treatment may or may not progress to the next phase.

Phase 1

The new treatment is usually tested for the first time in a small number of people. The aim is to understand what happens to it in the body, learn about safety, identify side effects and find the best dose.

→ This is where therapies developed by the CureHeart team will start.

Phase 2

The new treatment is tested in a larger group of people to determine whether it works.

→ Various drug, genetic and stem cell therapies for cardiomyopathy are currently in phase 1 and 2 trials.

Phase 3

The new treatment is tested in a large number of people to confirm its effectiveness, monitor side effects and compare it with existing treatments.

→ The results from two phase 3 trials for cardiomyopathy have recently been published:

- Aficamten targets the dysfunction in the heart muscle in hypertrophic obstructive cardiomyopathy (HoCM).
- Vutrisiran reduces production of the transthyretin protein that builds up in the heart in cardiac amyloidosis.

Following positive results in a phase 3 trial, all new treatments must be approved by the UK medical regulators before they can be made available.

This rigorous process takes time – an average of 10 years in the UK. Mavacamten is the first drug of its type to target the underlying cause of HoCM (aficamten is the second). The first phase 1 trial of mavacamten started in 2015. Phase 3 results were published in 2020 and it was approved for use in the UK in 2023.


Future CureHeart trials


Cardiomyopathy is often caused by a fault in a single gene which can be passed down through families. The CureHeart team are developing genetic therapies for these inherited forms of the condition. They are working on two approaches depending on how the genetic fault causes cardiomyopathy.


One works by preventing the faulty gene from producing a faulty protein. The other involves editing the DNA sequence to 'switch off' the faulty gene or boost production from the healthy gene. Depending on the therapy, it may involve regular injections in the arm or a one-off injection directly into the blood vessels that supply the heart.


The decision to take part in a clinical trial requires careful consideration of the potential risks and benefits. Our role is to ensure that the views and experiences of people affected by cardiomyopathy are taken into account at every stage.

CureHeart definitions

 DNA – the code or instruction manual for our body contained within our cells.

 Gene – a section of DNA that tells our body how to build a specific protein. We have two copies of every gene, one inherited from each parent.

 Protein – the building blocks of the body.

 Genetic therapy – a medical treatment that works by modifying genes or their function

Take part in a trial

Taking part in a clinical trial can make a vital contribution to improving treatment for people with cardiomyopathy. It can mean you spend time with experienced healthcare professionals and may give you early access to a new treatment. There are usually several studies looking for participants at any one time.

Every trial has specific eligibility criteria. Future trials of genetic therapies will likely require people to have a particular type of genetic fault. Always discuss taking part in a trial with your clinical team.

Find cardiomyopathy trials

- Ask your clinical team about current trials you may be eligible for.
- Join thehearhive.org which matches people living with or at risk of developing cardiomyopathy with researchers.
- Search for studies on: beartofresearch.nih.ac.uk
- Find out about opportunities to take part in research by subscribing to our research network newsletter: www.cardiomyopathy.org/form/research-network-subscribe
- Contact us at research@cardiomyopathy.org if you have any questions about cardiomyopathy research.

To learn more about CureHeart, scan the QR code or visit:

 www.cardiomyopathy.org/cureheart





Policy and advocacy update

We listen to our community to understand the issues that you are facing in accessing cardiomyopathy services, support and treatments. We liaise with the relevant decision-makers to influence them and to effect change. Here are some examples of the work we have done.

Some people with HCM have faced recurrent issues with shortages of disopyramide. Recently, we liaised with the Department of Health and Social Care regarding this. We told them that disopyramide is the only suitable medication for many people with HCM and used stories from our community to show the difference it makes to a person's quality of life. There was a brief period of improvement, but we're aware that there are shortages once again. We understand from our engagement with the Royal College of Pharmacists that there are systemic issues around medicines access leading to these recurrent shortages.

We are also working on welfare reforms, especially changes to Personal Independence Payments (PIP). We held focus groups with our community to understand the barriers in accessing and using PIP. We submitted this evidence to the Department for Work and Pensions in response to proposals from the previous Government.

If you want to get involved in our policy and advocacy work, you might like to become a Change Maker. For more information, scan the QR code or visit:



www.cardiomyopathy.org/change-makers



The UK held a general election early in July 2024. We wanted to take this opportunity to tell as many of the UK's new MPs as possible about cardiomyopathy in the first 100 days since the election. We can also start building relationships with MPs by involving them in our work.

We spoke to Julie Rees, who shared her experience of contacting her MP as part of our 'First 100 Days' Campaign:

Q&A with Julie Rees:

Why did you write to your MP about cardiomyopathy?

Cardiomyopathy UK had developed the Cardiomyopathy Manifesto 2024, setting out their policy goals for the diagnosis and treatment of people with cardiomyopathy. On the run up to the general election in July 2024, the charity asked members to share the manifesto with their candidates.

What did you include in your email to your MP?

I wrote to Justin Madders, the sitting MP, just before the General Election and introduced ourselves as constituents. I shared our story of having a daughter, Jenny, diagnosed at six weeks old with dilated cardiomyopathy and our early struggle, those many years ago, to find accurate information and other parents to talk to who understood our anxieties. Cardiomyopathy UK was life changing for us. I invited Justin to attend a local support group meeting and attached a copy of the manifesto.

When Justin was re-elected as an MP, I telephoned his office and requested a face-to-face meeting.

What did you talk about in the meeting?

I attended the meeting with my husband, Mark, and our daughter, Jenny. I took along a file of local newspaper and Cardiomyopathy UK's 'MyLife' magazine articles featuring our story, our support group and Jenny's work raising awareness of the charity and the condition.

Jenny talked about her PHD research into the diagnosis of cardiomyopathy and how she currently works as an Assistant Clinical Psychologist at Liverpool Heart and Chest Hospital. She explained the lack of continuous funding for cardiac rehabilitation and the importance of psychological support for patients and their families following diagnosis. We presented Justin with a paper copy of the manifesto, and he promised to write to the Cheshire and Merseyside Integrated Care Board (ICB) on our behalf.

What happened following the meeting?

Justin Madders wrote to the Chief Executive of Cheshire and Merseyside ICB, asking "What policies and strategies does the ICB currently have in place in relation to cardiomyopathy?" Justin promised to contact us again when a response was received from the ICB.

Why is it important to engage with your MP?

We wanted to make our MP aware of the condition and the work of the charity, so he could provide an informed input into relevant policy discussions. Positive relationships with MPs can help drive long term positive outcomes for the benefit of all. There is the potential for your MPs to be powerful ambassadors and allies.



Julie, her husband Mark and their daughter Jenny

What advice would you give to the cardiomyopathy community about contacting their MP?

I would urge everyone to share the Cardiomyopathy UK Manifesto with their local MP to raise awareness of the condition and to share their personal stories and experiences. It is only by sharing our 'lived experience' we can affect any real change in services and support. Personal stories can be related to more easily and can change perspectives of policy makers.

To get involved and contact your local MP about cardiomyopathy, scan the QR code or visit:



www.cardiomyopathy.org/working-with-government





Become a support group leader

Our support groups are run by fantastic volunteers who give their time to provide a support network to people affected by cardiomyopathy.

We are recruiting for Support Group Leaders in:

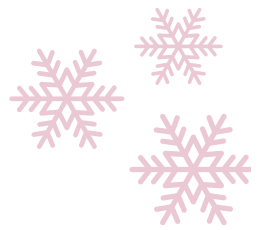
-  Lancashire
-  Surrey
-  Staffordshire
-  Lincolnshire

-  Areas with active support groups
-  Areas we would like to start support groups in



If you are interested in becoming a Support Group Leader and you want to learn more about the role, scan the QR code or visit:

 www.cardiomyopathy.org/groupleader



How to manage in cold weather

During winter, cold weather can affect our body and people with heart conditions can notice that the colder weather affects how they are feeling. Cardiomyopathy UK Specialist Nurse Jayne has shared her advice and top tips for managing in cold weather.

When the weather is cold, this makes your heart work harder to keep your body warm, so as a result your heart rate and blood pressure may increase. These changes can sometimes make your heart-related symptoms worse and can sometimes affect how heart copes with everyday things.

10 tips for managing in cold weather:

1. Keep your home warm and stay indoors, when possible, try and keep the temperature indoors as near to 18°C as possible.
2. Stay active whilst you are indoors, try to move around at least once per hour and avoid sitting in one place for long periods.
3. Having regular hot meals and drinks will provide your body with the energy it needs to keep you warm however large meals should be avoided if possible.
4. Wrap up in layers of clothing, layers help to trap air between them, forming a protective insulation. Heat is easily lost from your head so try to wear a hat and scarf when going outside.
5. Be cautious if you need to exert yourself outside during cold weather, do so with caution as even walking in cold weather causes our hearts to work harder. Avoid shovelling snow if you have a heart condition as this activity can lead to overexertion for some people.
6. Try not to become overheated when outside. If you notice that you are sweating due to physical activity, your blood vessels may dilate causing blood pressure to drop, which can lead to

dizziness or feeling faint. General advice would be to go indoors and remove your outer clothing to allow your body to cool down as soon as you can.

7. Besides cold temperatures, wind and rain can also steal body heat. Wind removes the layer of warmer air from around your body, which can cause the body to lose heat very rapidly. Similarly, dampness can also cause your body to lose heat faster than at the same temperatures in drier conditions.
8. If you feel like you may be developing a cough or cold seek advice early you can get advice from your pharmacist or GP.
9. Check to see if you are entitled to any financial assistance with making your home more energy efficient. If you would like to speak to our free and confidential external benefits and welfare advisors, go to page 8 for more information.
10. As well as protecting your own health try and check on elderly or vulnerable neighbours during cold weather to make sure they are keeping well.

To read the blog in full, scan the QR code or visit:

 www.cardiomyopathy.org/cold-weather





Our fundraising superstars

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

Jenny's annual garden party for Cardiomyopathy UK

In August, Jenny held her annual Bake a Difference in the form of a garden party. Her friends and family raised an incredible £650, which has been match-funded by Jenny's work.

"After very surprisingly being diagnosed with hypertrophic cardiomyopathy in December 2019, my family are now all being tested. I will continue to hold my annual coffee morning and raise money for Cardiomyopathy UK in the hope that more people will get help and the support that is needed when having this scary condition, that not many people have ever even heard of. I am very grateful to have Cardiomyopathy UK there when I need them." - Jenny



Ann's birthday fundraiser

Ann and Elis have been supporters of Cardiomyopathy UK for over 20 years, after losing husband and father, Ray, in 1997. Recently, Ann celebrated a special birthday and asked her friends and family to donate to Cardiomyopathy UK, raising an amazing £1511 through her special day!



"My reason for choosing Cardiomyopathy UK is because the charity has supported us a lot since Ray's death in 1997. Having donations instead of birthday gifts was an ideal way to raise money and give something back to the charity. I'm blessed in life to have everything I need, including amazing friends and family, and so donations to Cardiomyopathy UK seemed the best option as I celebrated my 60th birthday." - Ann

Phil and team take on the London to Brighton bike ride

In spring, Phil, Jason, Gavin and Tom took on the mighty London to Brighton bike ride, in memory of Phil's friend, Matt. Through their 55-mile challenge, the four were able to raise an incredible £1500, which has been doubled by their company, Volkswagen.

"When four work colleagues from Volkswagen UK agreed to take part in the London to Brighton bike ride, we knew we were taking on a big challenge. Cycling was an enjoyable pastime for all of us but pedalling for 55 miles was going to be another level for the team, especially those that needed to borrow a bike that could go that far! We had lots to think about; what did we need to take with us and how we were going to get to London and back from Brighton. Jason slept in his Volkswagen Caravelle the night before on someone's drive in Clapham!

Deciding on the charity was the easy bit for me and I immediately suggested Cardiomyopathy UK when the topic was raised on the WhatsApp group. I told the team that I had lost a good friend over 30 years ago, and how there was absolutely no warning for a seemingly fit and healthy man in his early 20's. I knew that people who knew Matt, or knew his story, would be pleased that we were remembering him and would be willing to sponsor us. Our sponsors exceeded our expectations by raising £1500 which our company brought up to £3,000 through matched funding.

It turned out to be a great day! We even did a photo stop at a Volkswagen retailer in Haywards Heath, although the team did initially complain about the extra two miles! Towards the end of the bike ride, we met another group who were also raising money for Cardiomyopathy UK. Their story certainly inspired us to tackle the notorious Ditchling Beacon! We were elated as we crossed the finishing line in a little over four hours in Brighton where we were met by some family members. Being welcomed by some of our children was a fitting end to a great Father's Day." - Phil



Our 2024 Christmas cards

Spread some Christmas cheer this year whilst supporting people affected by cardiomyopathy with our Cardiomyopathy UK Christmas cards!



To grab your Cardiomyopathy UK Christmas cards, scan the QR code or visit:

 www.cardiomyopathy.org/online-shop



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

☐

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