

myLife

The magazine for people affected
by cardiomyopathy and myocarditis

A coffee &
catch-up

Cardiomyopathy
signs & symptoms


Take part in
research



Contact us

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

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Find us online

 www.cardiomyopathy.org

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 **Live chat**
www.cardiomyopathy.org
8.30am-4.30pm, Monday-Friday

Social media

 [/cardiomypathyuk](https://www.facebook.com/cardiomypathyuk)

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Welcome to our winter edition of MyLife.



In our last edition of MyLife, I referred to the additional holiday that many of us enjoyed celebrating the Queen's Platinum Jubilee. Since then, we have mourned the passing of the UK's longest serving monarch, Queen Elizabeth II, welcomed King Charles III and seen two new Prime Ministers appointed. What a period of change and uncertainty we are experiencing as we approach what is likely to be a potentially hard winter for many.

It was good to meet so many of you face to face at our National Conference "Together Again A Brighter Future" held in London, on 19th November. Don't worry if you missed it as you will find our conference roundup on pages 18-19. In addition, you will be able to access all presentations on our Cardiomyopathy UK YouTube channel.

Imagine if we could see an end to the genetic heart diseases that can lead to heart failure and sudden death. Our research update focusses on CureHeart – a cure for inherited heart muscle diseases that aims to do just that. We are proud to be part of the CureHeart team, in doing so, bringing hope to millions of people. Read more about this ground-breaking research on pages 12-13

Our Coffee and Catch-Up sessions continue to be well received, providing a welcome opportunity to make new friends over an informal coffee and chat, as you will hear from one of our volunteers, Julie on page 4.

Maybe like me you admire anyone who completes a marathon and raises money for good causes. Safe to say that Dougie and Pete have my thanks and full admiration for completing the ultramarathon the Marathon des Sables in memory of their beloved sister and wife. Check out their story on pages 6-8. Maybe you will be inspired to take up a challenge in the future.

Best wishes to you and your families for the festive season, and throughout the New Year

Rita Sutton, Chair

Contents

Rita's Welcome	2-3
Making Friends Over Coffee & Catch-Up	4-5
Dougie & Pete Take on The Marathon Des Sables	6-8
Brighton Marathon 2023	9
Raising Awareness of the Signs & Symptoms	10-11
The CureHeart Project	12-13
Take Part in Research	14
Winter Wellness	15
Improving Diagnosis & Treatment	16-17
Our 2022 National Conference	18-19
Looking Ahead to 2023	20-21
Christmas Cards	22



Coffee and Catch-Up

4-5



Dougie & Pete - Marathon Des Sables

6-8



Our 2022 National Conference

18-19



Making friends over a Coffee & Catch-Up

My name is Julie, I joined the first Coffee & Catch-Up session on Friday 27th March 2020 whilst I was shielding. It was set up by Cardiomyopathy UK as a way of staying connected with people all around the UK during lockdown - a fun, weekly chat during a difficult time for us all.

Everyone was encouraged to share their cardiomyopathy stories if they felt ready, but also to chat about general fun stuff - the main aim was to relax and meet up with others during a time when we couldn't see our families and friends. I also educated the group on a local Sheffield delicacy - Henderson's Relish. I'm proud to say it is now well-known around the UK, with many Coffee & Catch-Up members purchasing bottles!

In February 2021, the Cardiomyopathy UK team handed over the running of the group to myself and two other volunteers. We now had a core group of about 16 people who attended most weeks, and we set up a Facebook chat group so we could keep in touch throughout the week. As a result, the group became closer - we shared snippets of our lives, our families, and lots of photos.

If anyone was having a tough time, we listened and offered practical support and encouragement because we all knew what it was like to be going through a difficult period.

We have one member who regularly joins us all the way from Calgary in Canada, even though things kick off at 7am on his side of the pond! We have learnt so much of his life and he's shared lots of videos of the stunning scenery where he lives. We have also attempted to teach him British slang and



traditions - needless to say, this has caused much fun and laughter!

Two and a half years later, I cannot imagine life without C&C. It has become an essential part of all our lives. We look forward to meeting up and truly care about each other. We all agree that C&C has created enduring friendships and is so much more than just a weekly chat. We phone and text each other, and whilst on our travels around the UK, some of us have even met up in person. I have personally met 3 members face-to-face and it felt just like meeting up with an old friend! We are even planning a group get-together next year.

Here's to many more years of C&C!



Coffee and Catch Up has become in many ways, like an extended family. I love that I'm accepted for who I am, with all my quirks! With daily mental health struggles, I know and am incredibly grateful that I can come and go and always feel part of the group.

- Lou, Greater Manchester



C&C is an eclectic group from all over the UK and around the globe, who have one thing in common... cardiomyopathy. The support and friendships created in the group have been invaluable...long may it continue!

- Robbie, Lancashire



As the only regular attendee from outside the UK, C&C is such a blessing to me. While blurry eyed from just waking up each Friday morning, it doesn't take long to get the laughs and friendship going. It warms my heart, especially on those mid winter, -30 degree days.

Darren, Canada



To find out more, and to join a Coffee & Catch-Up, scan the QR code or go to:

www.cardiomyopathy.org/coffee



Dougie and Pete: Marathon Des Sables

Dougie and Pete sadly lost their wife and sister, Jane to cardiomyopathy unexpectedly 10 years ago. To mark the 10-year anniversary, earlier this year, Dougie and Pete took on one of the hardest challenges on the planet – the Marathon des Sables.

Remembering Jane

Pete: Jane was not only my sister but my twin. Jane and I had shared everything all our lives – from our mother’s womb to birthdays and everything in between. Her unexpected passing hit our family like a sledgehammer, and still feels very raw today. Jane was certainly one of a kind. Up for a laugh, she was extremely family oriented and in Doug, was very happily married. It is some comfort that whilst she had a short life, she was ultimately very happy.

It seemed appropriate for Jane’s ten year anniversary to find a challenge to celebrate her life that would push us not only physically but mentally. The Marathon Des Sables, sounded bonkers but the one to go for. I knew that very few people would agree to sign up but had an inkling that Doug would be keen! Doug, as expected, jumped at the suggestion and the event did not disappoint.

Dougie: Jane was one of those rare people who brought light to the world. She had time for everyone, no matter who they might be, and she gave endlessly to others no matter what their need might be. Her sudden death at age 32 was devastating for all of us. Personally, I have no recollection at all of about the next year of my life. I do however remember feeling very strongly that Jane would not want me throwing my life away and so I decided to channel as much of what I was feeling as I could into trying to help others not have to go through what we as a family had been through.

Preparing for the challenge

Pete: I was fortunate enough to have enough friends and family who thought I was so physically unfit that they felt obliged to join many training sessions and help me get to the start line. The covid pandemic prolonged the training program. We had some great fun getting out and about and I look back on some of the training that took place pre-event and have to say we had a great laugh. I have certainly caught the bug to do more of these, it’s a great way to improve your mental



and physical health, catch up with old friends and indeed meet new friends. I would highly recommend looking at some of the events that are put on around the country.

Dougie: We originally signed up to participate in the April 2020 version of the MdS but COVID had other plans for us. The race wasn't actually cancelled until March 2020 so we were pretty close to go-time. I was half way through a fundraising event at my local gym when I got the cancellation email. The organizers tried to run the race every six months thereafter and so our preparation was very stop-start until we finally got to the start line in April 2022.

For training, I combined a lot of miles each week running with a 20-lb weight vest with strength sessions at the gym. Our gym also has an infra-red sauna so I did a lot of sessions in there with the temperature up at about 120 degrees. That was actually pretty boring – sitting in a glass box in extreme temperatures isn't a great way to spend your evenings!

The event

Dougie: The MdS is a five-day race of 250km through the Sahara desert – effectively it's five marathons over five days – and it's often referred to as the toughest race on the planet. It's self-sufficient, meaning you carry all of your food and supplies needed to keep you alive with you as you race. The only thing you are given is water and a tent at the end of each day. The tent is shared with 7 other people. It's a significant challenge.

Pete: We had a great tent and the fact that all seven of us got round was incredible. It is not only the physical challenge, but the mental one too. Each day you would get a few emails sent from friends and family who were tracking your progress. I can remember getting quite emotional reading each of them and thinking about Jane. The challenge is so great, but you have much time to reflect on the most important aspects of life-Family, Friends, Health and Love. The hardest part for me was managing my feet which deteriorated rapidly towards the end. My daily hike to the medical tent to have infected blister managed was far from pleasant. An injection through my big toenail to suck up blister fluid on the final day along with injections in my thigh to reduce swelling being particularly horrid!

Dougie: For me, the most challenging part of the race was also my favourite. Day 4 was 'The Long Day', so called because it basically involves two marathons back-to-back. You start running at 8am on Day 4 and you basically keep going until you finish at some point the next day. At the end I don't think I've ever been as physically drained – running through the Sahara in total darkness is not something I'd like to repeat. It was the camaraderie and support of the group that got me through that without question, which is what made it my favourite part of the event. Additionally, we saw the sun rise over the desert from the top of a mountain ridge and that was pretty spectacular – definitely a Kodak moment, although unfortunately to save weight in my pack I didn't have a camera with me to record it!



Raising funds to support other families

Dougie: My hope for the future is that those with cardiomyopathy and their families become better informed about the condition and are able to adapt their lives accordingly. When Jane was diagnosed there really wasn't much information and we didn't know the full extent of what she was facing. We managed and adapted as best we could and although it wouldn't have changed anything, I always wish we had had more information. If our fundraising helps others where we didn't have the same resources, that will be a fantastic outcome. Having someone at the end of a phone or responding to email is really helpful and just knowing you have support when you need it is tremendously comforting.

Pete: You will be surprised how much enjoyment you get from physically and mentally challenging yourself, allowing you to spend time with old and meet new friends and connect with nature. The funds you raise will help others and that gesture, however big or small, is a great feeling. Don't overthink the quantum of the challenge, just find one that sounds great, a few friends crazy enough to sign up and go out and enjoy it.



Brighton Marathon

2nd April 2023



Join #TeamCardio

To apply for your place, scan the QR code or visit:

 www.cardiomyopathy.org/brighton-marathon



Raising awareness of Signs & Symptoms

In September, we marked World Heart Day by raising awareness online of the signs and symptoms of cardiomyopathy. When cardiomyopathy goes undiagnosed, it can cost lives. Raising awareness can change that. Thank you to everyone who has shared our symptoms information online.

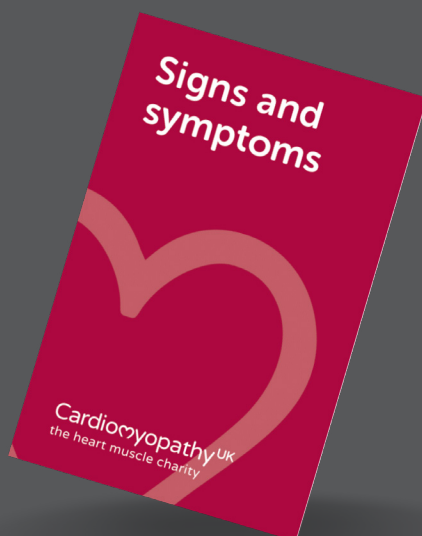


260
people
shared our
signs and
symptoms
posts



25,500
saw our signs and
symptoms posts

If you'd like to help us raise awareness, scan the QR code or visit:
www.cardiomyopathy.org/symptoms



Our new signs and symptoms booklet

Our updated signs and symptoms booklet is now available to order. Share them at fundraising events, at your local gym, school, sports club or GP practice.

To request copies of our new symptoms booklet, email contact@cardiomyopathy.org

What are the symptoms?



**Swollen ankles
and/or tummy**



Chest pain



**Dizziness and/or
fainting**



Breathlessness



Tiredness



Palpitations

If you are experiencing symptoms make an appointment to see your GP.

These six symptoms can also be symptoms of other types of heart conditions, so if you're experiencing them, it doesn't necessarily mean that you have cardiomyopathy. However, it is important to get checked by a doctor if you are concerned, particularly if you find that your symptoms change or get worse.



Cardiomyopathy Study Awarded £30 Million Grant



The CureHeart research project, which aims to find the world's first cures for inherited cardiomyopathies, has been announced as the winner of the Big Beat Challenge and will be awarded a £30 million research grant.

Cardiomyopathy partners in groundbreaking CureHeart project

Earlier this year, the CureHeart research team won The British Heart Foundation's Big Beat Challenge and were awarded a £30 million research grant. Cardiomyopathy UK are delighted to be partners in the research co-led by Professor Hugh Watkins at the University of Oxford, and Dr Christine Seidman of Harvard Medical School, which aims to find the world's first cures for inherited cardiomyopathies. Our role is to provide patient insight and ensure that the views and experiences of people with cardiomyopathy shape the project as it develops.

Cardiomyopathy can be caused by a fault in a single gene, which can be passed to the children of someone with cardiomyopathy. Each specific gene fault is rare, and often unique to a family. CureHeart will use gene therapy to repair or replace the faulty gene in a person who has been diagnosed with inherited cardiomyopathy. They will do this by targeting the specific gene fault and correcting the action of the gene in a person's heart cells. The CureHeart researchers will start by developing and testing techniques for gene therapy, and then run clinical trials with patient volunteers. Only cardiomyopathies that have known genetic variants or faults can be researched as part of this project.

Why is a new treatment needed for cardiomyopathy?

Cardiomyopathies affect about 1 person in 250. For some people cardiomyopathy is mild and causes symptoms only in later life but in other people cardiomyopathies can cause serious problems even at a young age. There are currently no existing treatments which address the root cause of the condition or prevent it from getting worse.

How will the treatment work?

Genes are instructions to make proteins, which carry out important functions in the cells which make up the different organs in the body. The chemical component of genes is DNA. When a person has a variant or fault in a gene which makes a protein important in the heart, this can interfere with the way cells work and lead to cardiomyopathy.

Gene therapy will depend on the type of genetic variant or fault a person has, and the way it acts to change the protein function. Gene faults act in one of two main ways:

1. The fault results in loss of a protein. In this case, the treatment will either aim to replace the gene (gene replacement) or to make the healthy copy make more protein.
2. The fault changes the gene's instruction to make a protein, so the protein doesn't work as it should. In this case, gene therapy will aim to correct the faulty copy of the gene (gene editing or silencing).

If someone's cardiomyopathy is treated by gene therapy, could they still pass the condition to their children?

Yes. This is because the cells targeted (heart

cells) are not the cells responsible for making eggs and sperm. The cells treated by gene therapy will not be passed on to children.

How do you know that people with cardiomyopathy are interested in gene therapy?

Patients and family members are involved at every stage of the CureHeart study, and the team have partnered with Cardiomyopathy UK and the SHaRe Cardiomyopathy Registry in the US.

Cardiomyopathy UK surveyed people with cardiomyopathy and people caring for someone with the condition to understand their views and experiences. Of 634 people who responded to the survey, 93.6% answered yes to the question 'do you think that gene therapy should be developed for use in cardiomyopathy?'

When will clinical trials for CureHeart begin?

Clinical Trials will not start yet as there is a substantial amount of preliminary research that needs to be undertaken first which may take up to 2 - 5 years. Taking part in a trial is an important decision, which will be discussed fully with all patients who consider participation.

Do you expect the treatment to be available in the NHS in future?

All new medical treatments and their component parts need to be carefully regulated, to ensure that they perform to high standards. Different countries have different regulatory bodies which assess and approve treatments and decide which patients might benefit.

How can I find out more?

Scan the QR code to watch the video and sign up to receive updates:

www.cardiomyopathy.org/cureheart



Take Part in Research













We encourage participation in research that aims to make a real difference in the lives of people living with cardiomyopathy. This could mean participating in a clinical trial, completing a questionnaire, or taking part in a focus group.

These research studies are looking for participants:

GO-DCM Study

Researchers at Imperial College, University of London are leading a new study looking at improving diagnosis and treatment for people living with Dilated Cardiomyopathy (DCM). The team of experts will gather more information than ever before about the condition using advanced genome sequencing, high-tech heart imaging and detailed protein studies. They will search for new genes that cause DCM and will scan the heart to find out whether damage to the heart muscle, such as scarring, predicts how people with DCM will be affected. The new insights from this project will help to find better ways to diagnose DCM, understand which patients are most at risk from severe disease, unlock clues to new treatments and ultimately prevent the condition.

The research is currently being conducted at the following hospitals in England. If you would like to find out more information about the study, please contact the hospital most convenient to you.

-  **Leeds General Infirmary**
-  leedsth-tr.icresearch@nhs.net
-  **Glenfield Hospital, Leicester**
-  cvresearch@uhl.tr.nhs.uk
-  **Liverpool Heart & Chest Hospital**
-  research.lhch@lhch.nhs.uk
-  **John Radcliffe Hospital, Oxford**
-  claudia.nunes@nhs.net
-  **Southampton General Hospital**
-  strokeresearchteam@uhs.nhs.uk
-  **Royal Brompton & Harefield Hospitals**
-  go-dcm@rbht.nhs.uk

This research will help inform health care provision for pregnant mothers across the UK. To find out more please contact the researchers at:

mumpredict@contacts.bham.ac.uk or visit www.mumpredict.org

MuM-PreDICT Study

Researchers at the University of Birmingham are looking for pregnant women (28 weeks or more) and mothers of under 2's with cardiomyopathy and another health condition to take part in a survey. This includes physical conditions (e.g., cardiomyopathy, diabetes, asthma, kidney disease, epilepsy, eczema, psoriasis etc.) or mental health conditions (e.g. depression, anxiety etc).



Winter Wellness for people with cardiomyopathy

As we stroll through the autumn into winter, let's take a moment to think about our heart and how we can protect it during the cooler months of the year.

Colder weather can mean that your heart works harder to keep your body warm. As a result, your heart rate and blood pressure may increase. These changes can sometimes affect how our heart copes with doing everyday things. If you're concerned about any new or worsening symptoms and need advice, contact your GP or for out of hours enquiries dial 111.

Cold and flu

Cold remedies taken to relieve the symptoms of a cold may contain a combination of drugs such as non-steroidal anti-inflammatory medication and decongestants which might not be suitable for some people with heart conditions. It's advisable to check with your community pharmacist to ensure that there are no interactions with your usual medications before you take any over the counter medications.

The Covid 19 and flu vaccinations may be recommended for you to encourage your body to develop an immune response to the Covid 19 and flu viruses. These won't stop you catching Covid 19 or flu but will help your body to fight the viruses if you do catch them.

Exercise and diet

Some people may find that they crave 'comfort food' during the winter months. Balance is key when it comes to healthy eating, and it's important to fuel your body with the foods it needs to stay healthy. Fruit and veg are packed full of essential vitamins and minerals which boost your immune system, meaning that you're better equipped to fight off a cold or flu infection.

Walking can bring many pleasures and is one of the best types of physical activity. It's a great way of boosting your mood and reducing stress by enjoying a woodland walk or admiring the sunrise or sunset on one of the shorter winter days. Walking is a great year-round activity, even if it's just a short walk to your nearest shop or a walk around a park with friends. Wear layers which you can remove as your body warms up and remember to start off slowly for the first few minutes and build up your speed gradually, remembering to reduce your pace again at the end of the walk to help your body cool down.

Mental wellbeing

Shorter days and more time indoors can make you feel low in mood, so staying active and keeping in touch with friends and family can help to boost your mood. Managing stress is important in keeping our immune system healthy, which is particularly important during the winter months. More information about emotional wellbeing is available on our website at: cardiomyopathy.org/emotional-wellbeing

Our Helpline
0800 018 1024

Our nurses helpline
is open Monday to
Friday, from 8:30am
to 4:30pm.



Improving Diagnosis & Treatment

Earlier this year we launched a National Survey asking our community to tell us about their cardiomyopathy, their care and wellbeing, and invited people to sign up to take part in research. We had over 550 responses from people living with cardiomyopathy, and over 60 responses from their families and friends.

Our initial findings show that people affected by cardiomyopathy would like:



More wellbeing support



Better access to genetic testing



to take part in research to advance the understanding of the condition

We have begun to address these initial findings by:



Launching a Cardiomyopathy Voices Network at our National Conference in November. This network will provide opportunities to take part in cardiomyopathy research and have your voices heard.



**James
Lind
Alliance**

Priority Setting Partnerships

Supporting a James Lind Alliance (JLA) priority setting partnership. We will engage a range of stakeholders including patients, carers, health professionals and researchers, and work together to identify what questions we want answered to improve care for people living with cardiomyopathy. We plan to engage our Cardiomyopathy Voices in this project. Find out more about JLA: www.jla.nihr.ac.uk



Working with research teams to identify where the gaps are in accessing genetic testing for inherited cardiac conditions. We want to find out how many people struggle to access genetic testing and why.

Informing treatment development

Our survey data has also been used to support the work we do with NICE (National Institute for Health and Care Excellence). Every new medicine or technology has to be approved by NICE in order to be prescribed in the NHS. Cardiomyopathy UK recently submitted data to support the consultation on Mavacamten, a new drug and one of the first treatments to successfully pass through clinical trials for cardiomyopathy.

Mavacamten is specifically marketed for the treatment of obstructive hypertrophic cardiomyopathy (HoCM). There is never a guarantee that approval will be given by NICE as there are so many factors which influence

NICE

National Institute for
Health and Care Excellence

their decisions, such as whether other treatment options give a better quality of life, the cost of the new treatment and how easy it is to roll out in the NHS.

We hope that NICE are supportive of this new ground-breaking medicine Mavacamten. We should find out the outcome of the NICE consultation on Mavacamten in March 2023.

Change Makers raise awareness for World Heart Day

Two of our Cardiomyopathy UK Change Makers, Robbie and Lynn, have been working with the Liverpool Centre for Cardiovascular Science (LCCS), to help support people in Liverpool to live healthier lives. This region, which includes Blackpool, has some of the worst heart health in the country and so on World Heart Day in September, Robbie and Lynn led various cardiomyopathy awareness activities, including lighting up the Blackpool Tower in red!

Robbie has been working with various groups and local businesses in Blackpool where one of their aims is to make their coastline the leader for heart safety in England. As part of this mission, they have had 14 defibrillators installed at venues along the Promenade in Blackpool and delivered CPR training to staff and residents. Meanwhile, over in Liverpool, Lynn convinced over twenty iconic buildings in the area to turn red to shine a light on heart health for World Heart Day. The region's police force also joined in by completing comprehensive training at each of the force's mobile units in the region.

A massive congratulations and thank you to Robbie and Lynn for all their hard work in their local area.

If you'd like to find out how you can get involved with improving cardiac health services locally contact:

charlotte.gallagher@cardiomyopathy.org





Cardiomyopathy UK 2022 National Conference

On Saturday 19th November, 280 members of the Cardiomyopathy UK community registered to come together again and discuss a brighter future for people affected by cardiomyopathy.

Chair of Trustees Rita Sutton welcomed a full room of attendees to our first in-person conference in three years.

Our keynote speaker, LaRisha Porter, provided the first talk of the day; discussing her experience of being diagnosed with dilated cardiomyopathy and the support she has received from Cardiomyopathy UK.

Experts from across the country travelled to London to be at the event, meeting individuals and families affected by cardiomyopathy and dedicating their time to providing information and answering questions. As well as our President, Professor Perry Elliott, and Vice-President, Professor Gerry Carr-White, we welcomed a number of new speakers to the event.

Dr Dawn Adamson spoke on peripartum cardiomyopathy and women's health, including addressing menopause and the unique experiences of women affected by

cardiomyopathy. Dr Tom Butler explored his research on diet and cardiomyopathy and how what we eat could make a difference to disease progression. Dr Anne-Marie Doyle talked about the psychological impact of cardiomyopathy; a topic selected directly as a result of our recent National Survey in which you told us that this area needed to be more fully investigated. Former Cardiomyopathy UK Head of Services Alison Thompson dedicated her session to establishing what the Equality Act means for the rights of people impacted by cardiomyopathy.

We recorded all of the presentations delivered on the day and we are preparing to publish them on our YouTube channel. This is to ensure that those who weren't able to join us on the day, and the global audience that we know already accesses the information we provide, will be able to receive the same high-quality information, advice and guidance as those in attendance in London.





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The Cardiomyopathy UK team provided some wonderful examples of supportive literature including the social prescription booklet.

-Amy

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I enjoyed the good mixture of Drs & patients at the same conference; it helped me as a doctor to be in the patient shoes and know how to address their concerns in the future.

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Sometimes my Mom feels like I don't understand what she's going through - coming to this conference has allowed her to feel 'heard'

- Blossom

//

Looking Ahead to 2023

This year has been incredible. The charity has continued to grow and develop, taking on more areas of work and supporting more people across the country. As ever though, there is still a great deal more that we want to do and we have some exciting plans for the coming year.



Providing support and information:

Perhaps one of the most striking things about 2022 has been how we have continued to see the impact of COVID-19 on people with cardiomyopathy and on the NHS. People are waiting longer for regular assessments and finding it harder to access services. On top of this we're seeing more and more people coming to us for support with benefits, partly as a result of the current cost of living crisis.

As ever, we need to respond to this and in 2023 we want to:

- **Reach more people** across the UK by working with local hospitals to ensure that all cardiomyopathy patients are made aware of the help that Cardiomyopathy UK can provide
- **Review the services we provide** for people who are struggling to access benefits because the financial impact of their condition is not being properly understood
- **Continue to grow our support group and peer support networks** so that more people have the opportunity to speak to someone who understands what they're going through
- **Provide more online webinars and information events** as well as running our annual national conference
- **Further develop the support we give to children and young people** with cardiomyopathy and their parents



Raising awareness:

In 2022, we were part of the first ever International Cardiomyopathy Awareness Week. We also ran our own campaigns highlighting the signs and symptoms of cardiomyopathy and the importance of knowing your family's heart history. In 2023, we will be continuing to raise awareness of cardiomyopathy and aim to:

- **Take part in the second International Cardiomyopathy Awareness Week**, building on the success of the first campaign and focussing on the importance of heart history and how genetic testing can save lives
- **Continue to provide a platform for the voices of people affected by cardiomyopathy** to show real-life experiences and break down myths and assumptions



Improving diagnosis and access to treatment:

Over the last year we've been growing our research and advocacy work. In 2023 we're planning to continue doing more to promote and shape clinical research, gather robust evidence on the needs of people affected by cardiomyopathy and advocate for improved access to quality treatment and support. In particular, we are planning to:

- **Continue to grow our Change Maker volunteer network** and do more to help them push for improvements in their local health services
- **Keep working alongside other national and international charities** and networks to have a bigger collective voice and ensure that the needs of people with cardiomyopathy are heard by policymakers.
- **Provide evidence to NICE**, the organisation that decides which medicines are available on the NHS, to show the positive outcomes that new cardiomyopathy drugs will have.
- **Undertake a research priority setting partnership** bringing together clinicians, scientists and people affected by cardiomyopathy to agree the top research priorities.
- **Publish our own research** into the availability of genetic testing and the impact of cardiomyopathy on mental health.
- **Provide real world patient insight** to researchers as partners in ground-breaking research projects like CureHeart and the TRED-2 study.



Educating healthcare professionals:

This year we have added more units to our online medical education platform that provides detailed and accredited education for clinicians so that they are better able to diagnose and treat cardiomyopathy. In 2023 we will:

- **Add two new units** to our online medical education platform covering genetics and arrhythmogenic cardiomyopathy.
- **Work with a newly formed nurse-led team** to help them provide education and training on inherited cardiac conditions for all nurses across the southeast.

There is a huge amount to be achieved in the year ahead, but we know that with the support of our dedicated community of volunteers, donors, fundraisers, clinicians and research partners we can make important progress towards saving and improving the lives of more people affected by cardiomyopathy.

Our work simply wouldn't be possible without the kindness and generosity of our supporters and, especially during this difficult time, we are truly grateful. It is their support that drives us forward and helps us to achieve amazing things. Together, we can make it possible that one day, everyone affected by cardiomyopathy can live a long and fulfilling life.

Christmas Cards



Christmas cards are now available to buy on our online shop. Get yours now and spread some Christmas cheer this holiday season, whilst also supporting those affected by cardiomyopathy.

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

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

Card number:

Start Date:

Expiry Date:

Security Code:



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.

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