

Mark's Story

Nurses Q & A

New Cardiomyopathy Guidelines Announced

Cardiomyopathy^{UK} the heart muscle charity Issue 34 Winter 2023

Contact us

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

Call or write to us

75A Woodside Road Amersham Buckinghamshire HP6 6AA

01494 791 224

🔒 Helpline

0800 018 1024

(free from a UK landline) 8.30am-4.30pm, Monday-Friday

Find us online

www.cardiomyopathy.org

contact@cardiomyopathy.org

Live chat
 www.cardiomyopathy.org
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Social media

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Welcome to our winter edition of MyLife.

With the clocks going back and summer truly feeling like it's long gone, autumn and winter are upon us. This can only mean that it's time for our Cardiomyopathy UK Conference,



"Engaging Minds, Empowering Action". I hope you will be joining us for what will be a full and varied programme aimed at empowering people to live well with cardiomyopathy. Should you be reading MyLife after 18th November, I hope I had the pleasure of welcoming you on the day.

Looking back to August, we were pleased to welcome a new set of guidelines that patient representatives from the Cardiomyopathy Council contributed to. The guidelines for the clinical management of cardiomyopathy were published by the European Society of Cardiology. The guidelines will help to establish a shared understanding of how people with cardiomyopathy should be treated, leading to more standardised care. See page 12 for an overview of the guidelines.

September saw the start of a new school year which can be an anxious time for parents and children. For parents of a child with a medical condition such as cardiomyopathy, everyday life can be more challenging. How can we help? You can read about our new and exciting parent support programme "Thriving with your Child's Cardiomyopathy" on page 16.

The charity continues to develop and expand its policy and research work, with lots of new and potential opportunities. Work is currently underway on the planning of our biennial survey. An update on the Future Research Priorities Project can be found on page 18

Keen cyclists among us might want to turn first to page 10 for information about how you can support us by entering the iconic London to Brighton Bike Ride 2024. You will be joining thousands of other cyclists who will be taking part in the oldest charity bike ride in Europe. Go on, you know you want to.

In our next edition 2024, we will be launching the charity's new five-year-plan. Watch this space.

As we approach the end of 2023, I thank you for your continued support for Cardiomyopathy UK and wish you and your families good health and good wishes for the festive season, and the new year ahead.

Rita

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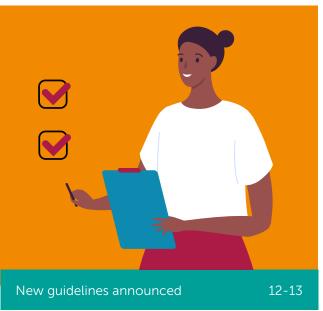
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Mark's story

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Mark's Story

E wan was diagnosed with hypertrophic cardiomyopathy (HCM) in 2008. Following his diagnosis, his family were referred for genetic testing which revealed that his mum, eldest brother Mark, his niece, and his youngest son all carried the gene.

His brother Mark sadly passed away at the end of 2022, and Ewan has shared their cardiomyopathy journey with us.

The impact of cardiomyopathy

I was diagnosed with hypertrophic cardiomyopathy back in 2008 and as a result, had to give up football and limit my exercise. Following my diagnosis, all my family were referred to a genetics clinic for testing. The genetic testing revealed that my mum, my eldest brother Mark, my niece, and my youngest son all carried the defective gene.



The impact of cardiomyopathy was no longer just with me, but with all the family members mentioned above. They will now have to have regular screening and monitoring for the rest of their lives to assess the progression of their condition which can vary from person to person.

Since my diagnosis, I was fitted with an ICD in 2017 and put on medication, unfortunately, my brother Mark lost his life to the condition on the 27th of December 2022.

Remembering Mark

Mark was the eldest brother of the 3 of us (Mark 46, Ewan 44 and Adam 39). He is also the father to three girls - Amy, Emma and Grace and husband to Danielle. He was a double-winning captain with his local amateur football team, Stonehaven Athletic, a former club secretary and at the time of his death he was a coach and a member of the management team. He was also a keen cyclist and covered thousands of miles each year, often raising money for various charities.

He had an infectious smile and was always there for anybody. He was someone you could rely on and was always there to help. He was a family man, a Stonehaven legend, and a great friend to many.

The diagnosis

To my knowledge, Mark never experienced many symptoms. His wife Danielle said he had an episode a couple of weeks before his death where he complained of a slightly elevated heart rate and feeling unwell. When he got home from work that day he had to go straight to bed. That is the only instance I can recall of him complaining of any symptoms.

Mark was diagnosed with HCM because of genetic testing and further screening at the cardiology department at ARI. He was also advised that his condition was very mild and that he fell into the 'low risk' category. He was advised, at the time, to carry on with his football and cycling and that he would continue to be monitored on a regular basis.

Living with cardiomyopathy

Mark's diagnosis didn't really impact him too much. As he was classed as 'low risk' and was allowed to continue with his football and cycling, nothing really changed much for him. He was understandably concerned that his middle daughter Emma also carried the gene but apart from that he was always quite relaxed about the condition (that was the feeling he gave out anyway). Even though Mark was classed as a 'low risk' patient he was routinely checked and attended all his appointments. The hard part about all of this is that Mark knew about his condition and was getting monitored for it. Mark's consultant at the hospital always classed him as 'low risk', but despite all this, he still passed away during a morning jog with his eldest daughter Amy. Losing Mark at such a young age has had a





profound effect on the whole family. Our Mum has lost a son, Danielle a husband, us a brother and his children a dad. The impact this has had will be with us all for the rest of our lives.

Raising awareness

My main message for anyone affected by this condition would be to communicate. Let your loved ones know if you are feeling unwell, pick up the phone and speak to your consultant or someone on the online support or helpline. Don't be scared to ask for help and discuss any queries or changes in your symptoms with the hospital as soon as you can. There are thousands of people with this condition and only by communicating with each other will we raise awareness and make further inroads into understanding the disease.

Hopefully one day they will find a cure for the condition or maybe there will be a breakthrough in the ability to modify the defective gene so that it doesn't develop into cardiomyopathy.

Read Mark's story on our website



cardiomyopathy.org/marks-story

Read how Mark's family have been raising funds in his memory on the next page. >

Fundraising Superstars

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

David completes twenty-two half marathons



My brother-in-law, Sean, was diagnosed with hypertrophic cardiomyopathy in 2001 after collapsing in the street and being rushed to hospital. My mother-in-law got in touch with Cardiomyopathy UK and I can simply say that they saved his life. After two major heart operations and great care, Sean was on his way to recovery.

To give back even just a fraction of what





David

Cardiomyopathy UK has done for my family, I decided to dust off my Adidas Bamba trainers (no expensive running shoes back then) and enter the Great North Run. Since then, I have taken part in (I can't use the word ran) the race for the last 22 years and have raised around £20,000! I've enjoyed every minute of it, with the highlight being my family's smiling faces as they welcomed me back with a coffee, banana & chocolate biscuit!

This year I knocked 19 minutes off last year's time, so if I carry on at this rate, I'll win the Great North Run in 2028!! Thank you for everything you do Cardiomyopathy UK.



Grace's family day for dad

Since his passing, Mark's family have been fundraising in his memory, including Mark's daughter, Grace, who held a fantastic family day raising over £4,500.

I wanted to do something in honour of my dad and make him proud. Cardiomyopathy is something that is near and dear to my heart. It's so important that we do our part so that other people don't have to go through the same thing my family have.

Jamie's charity ball

In September, Jamie held a charity ball at his school in memory of his father who passed away suddenly when Jamie was three years old. Guests enjoyed a champagne reception, dinner, raffle and disco with a live band.

Altogether raising an incredible £7,175!



CEPA with our nurses

Helpline

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

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



What is available to help me become an 'expert' in my cardiomyopathy?



Nurse Jayne

Being actively involved in your own treatment and plan of care and hearing about others' experiences, knowing that you're not alone and discussing experiences of symptoms can be valuable in learning how to live well with your condition, lifestyle adaptations, listening to your body and over time becoming more comfortable in getting more involved in your healthcare needs.

• Our online nurse-hosted support group meetings provide a safe place, to connect with other people living with cardiomyopathy to talk about anything from medications to driving with an ICD, are available at:



- We have an expert patient webinar on our You Tube channel where our nurses talk about how to become empowered in your own healthcare.
- Tracking your symptoms can also help you to become an expert in your own condition by giving you a daily record of how you're feeling, which you can discuss with your doctor. Our new symptoms diary can help you with this.

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

Q&A WITH OUR NURSES

Q.

I have read about "sick day rules" - what exactly are they? And are there any medications that I should stop taking?



Nurse Caryl

If you are experiencing symptoms of considerable vomiting, diarrhoea, and high temperature, and you are unable to tolerate fluids and diet, this in turn can lead to dehydration. Taking certain medications when dehydrated can result in a more serious illness, affecting the kidneys. The 'Medicine Sick Day Rules' is a list of medicines that should be temporarily stopped or paused during an illness.

For cardiac patients with cardiomyopathy and heart failure these medications include:

- ACE Inhibitors (e.g. Ramipril), ARBs (e.g. Candesartan) and ARNI: Sacubitril /Valsartan (Entresto)
- MRA e.g. Spironolactone, Eplerenone Diuretics
- "Water tablets" = Furosemide, Bumetanide, Torsemide, Bendroflumethiazide, Metolazone
- SGLT2 Inhibitors (medicine names ending in "gliflozin")

You should discuss and notify your own individual cardiology team or GP before temporarily stopping any medication for the sick day rule. When you are feeling better and eating and tolerating fluids and diet again, it is very important that you re-start these medications.

Q

Our 10 month old has dilated cardiomyopathy and is having gene testing.They said everyone in the family should. How does this help our baby?



Nurse Emma

Genetic testing allows us to study your DNA (the molecule that encodes genetic information) and look for alterations (known as genetic variants) which may be causing your cardiac condition. Testing involves looking at specific genes which have been associated with cardiac conditions.

Genetic testing is important for diagnosis confirmation as well as finding out whether family members are at risk of developing cardiomyopathy.

The results can help doctors to decide:

- if you should receive treatment
- if you should be monitored more closely
- if you can be discharged from follow up

You might be referred to a clinical geneticist, a genetic counsellor or specialist nurse to discuss the test as well as to discuss the results.

London to Brighton

16th June 2024

Take part in this iconic bike ride on Father's Day weekend whilst raising funds for Cardiomyopathy UK

Team Cardio places available now



cardiomyopathy.org/london-brighton

fundraising@cardiomyopathy.org

This event allows e-bikes.

Contact us if you have questions.



Support us this Christmas



cardiomyopathy.org

New cardiomyopathy guidelines announced

n August this year, The European Society of Cardiology (ESC) published new guidelines that set out best practice in the diagnosis and treatment of cardiomyopathy.

Although these guidelines are not mandatory, they are well respected by the healthcare professional community and so can play a significant part in helping to standardise and improve the treatment offered to people with cardiomyopathy.

The guidelines were prepared by a committee of cardiologists and healthcare professionals, with input from a person with cardiomyopathy. The committee was co-chaired by Juan Pablo Kaski, a member of our clinical advisory group.

The fact that these guidelines have been produced at all is a big step forward for the cardiomyopathy community.



These guidelines will help to establish greater consistency in the diagnosis, care and treatment of patients and families with cardiomyopathy. They reflect our most up to date understanding of this group of diseases and the treatment options that are available. We would like to see these implemented as widely as possible so that more people with cardiomyopathy can get the support and treatment they need.

They are the first comprehensive guidelines for all cardiomyopathies ever produced by the ESC and this demonstrates just how much interest in cardiomyopathy has increased over the last few years.



What are the key themes?

The guidelines are designed to be a detailed document covering specific aspects of diagnosis and treatment for all forms of cardiomyopathy.

Although it is unlikely that all countries, hospitals or even doctors will implement the guidance in the same way, these guidelines do reflect key trends and broader themes which will no doubt influence care and treatment across Europe. Among these are;



Cardiomyopathies need a unique approach and special treatment

The new guidelines make it clear that it is not acceptable to just treat cardiomyopathy as heart failure. Cardiologists should see cardiomyopathy as a separate and complicated condition that needs a specific and individualised approach.



You have to investigate the cause

Because cardiomyopathy is complicated it is important to investigate the underlying cause of the condition in each individual.

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Cardiomyopathies should be categorised by what you see (phenotype)

The best way to categorise the different types of cardiomyopathy is by what they look like. This leads to a more detailed examination, better use of imaging and encourages cardiologists to focus on really understanding what is going on in each individual's heart.

Genetic testing and counselling is vital

The guidelines state the importance of genetic testing in cardiomyopathy to help understand the risk to an individual and their family, and to help to decide the best treatment options.

A multi disciplinary دم ما دوم team is needed

The guidelines state that a multi disciplinary team approach is the best way to support someone with cardiomyopathy. This should include access to a genetic counsellor and psychological support. We are really pleased to see how closely these themes match our own Change Agenda and aim to address some of the inconsistencies in care and treatment that we saw in our recent State of Cardiomyopathy Care report.

Want to know more?

You can read the full guidelines on our website at:



cardiomyopathy.org/guidelines

The ESC are also working to produce a more readable version for a non-clinical audience

and this is expected to be available early next year. In the meantime, we are partnering with cardiomyopathy charities from across Europe to host a webinar with Juan Pablo Kaski who will talk through the guidelines and answer any questions from the community. We will share details when they have been finalised.

Sarah's Story

'm Sarah, I'm 23 years old and an identical twin and have two lovely cats. I was studying Press and Editorial photography at Falmouth University before my diagnosis of Cardiomyopathy and now I'm a member of the youth panel for Cardiomyopathy UK and my local BHF committee.



In September 2019 I started to experience intense chest pain and waking in the night gasping for air. I'd always experienced palpitations and issues with my heart in general but it was put down to being young or just having a 'funny heart' as health professionals would tell me. I had anxiety and stress through school, so I put my symptoms down to that, but they continued right through to the second year of university.

I loved sports and was very active and this was a big part of my identity, but I had always found it more tiring than most of my peers and always wondered why. In September 2019, my symptoms worsened, and I went to the GP a few times but was dismissed because I looked healthy and was only 19 years old. One day, I had a crushing chest pain that I had never experienced before. I spent the next night in agony before calling an ambulance. I knew that this was serious and the GP was wrong. After having various blood tests and a troponin test (an inflammatory marker for the heart), they discovered that I had a cardiac event and myocarditis. I spent the next month in hospital. It was a lonely and fearful month as I didn't understand what was happening and the Covid pandemic meant I couldn't have as much support from my family.

Because my chest pain continued and nothing seemed to improve, I eventually had a genetic test to look for any cardiomyopathies. This took a while but came back positive for ALVC (Arrhythmogenic Left Ventricular Cardiomyopathy). Learning all of this was scary but it took away some of the uncertainty of what was happening and validated my symptoms. It also meant that my family would need to be screened for the same condition. I am an identical twin, so it is certain my sister has ALVC too.

Letting go of sports, my studies and working has been a huge shift in my life, and I've been grieving for the person I once was.

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Part of me is glad that I brought this condition to light so that my family can have the right treatment. It helps me to cope with what I went through knowing I might have saved them from having a cardiac event in the future. I had to leave university and life has changed in many ways; a big part of my identity has been lost, especially with my love for sports and being active. I couldn't finish my degree, but I did attend my housemates' graduations which was lovely and spending time with my friends allowed me to forget about what I've been going through for a while. I wish I could've graduated too but I've worked on recovery and getting my chest pain under control - it's been a work in progress!

Since being in hospital, I have had therapy to help with PTSD and I am working with my local GP to manage my pain. Letting go of sports, my studies and working has been a huge shift in my life, and I've been grieving for the person I once was. However, I am rebuilding my sense of self and appreciating the good and bad emotions that come with it. I've found it important to focus on what I can do now and the things I could possibly do in the future. It's about understanding and having acceptance that living with ALVC is not a straight line; some days I am able to do more and some days I can't get out of bed.





In May 2023, I had an ICD fitted in St Thomas' in London to hopefully improve my symptoms and allow me to live a more normal life. The procedure was straightforward, and the surgeon explained what was happening all the way through. I remember my body trembling because I was afraid and the nurse in the operating theatre holding my hand and talking to me. It was a daunting experience especially being awake for the operation but having the ICD does give me a sense of reassurance.

I now live my life a day at a time and try not to worry too much about the future. This new path that I'm on has changed my perspective on life and I really appreciate the small things more. I have started counselling and have become a tutor for the Expert Patient Programme which supports others who are living with long term conditions. Helping others on their journey gives me a great sense of accomplishment and uses my experience with cardiomyopathy in a positive way.

Thriving with your child's cardiomyopathy

A new four week online programme for parents and carers of children living with cardiomyopathy.

Our new service will be co-hosted by:



Emma Greenslade



Willow Langdale-Smith

Cardiomyopathy UK Specialist Paediatric Nurse.

Emma has a considerable background in cardiac and paediatric intensive care and regularly supports parents of children living with cardiomyopathy on our helpline. A trained Counsellor with a Master's degree in Psychology and direct experience of caring for a child with cardiomyopathy.

Willow has previously run Carer Support Groups in the East Midlands, has chaired her local Parent Carer Forum, and frequently engages with health and social care professionals to champion the cause of families raising children with complex medical care needs.



This new programme takes into account the potentially intense journey of supporting a child with cardiomyopathy, a journey which can affect all aspects of your family's life.

Each one hour online session across the four week period will cover a different aspect of how your child's cardiomyopathy may impact your family life. The sessions will be run in small, supportive groups consisting of six families.

Emma and Willow will provide information and guidance to empower you and your family. There will be plenty of opportunities to interact with the other families taking part in the programme.



Programme schedule

- Monday 30th October at 11am
 Social impact / Emotional wellbeing
- Monday 6th October at 11am
 Financial impact
- Monday 13th November at 11am
 Educational barriers and options
- Monday 20th November at 11am
 Reflection and self-care

(Participants must be able to commit to attending all four sessions.)

More information and to request to take part

Please contact Emma at:



emma.greenslade@cardiomyopathy.org

We aim to provide this programme multiple times a year, so we will keep a waiting list of all families who have requested to take part. Those on the waiting list will also be invited to join a private online group (which will be moderated by Cardiomyopathy UK) to ensure that everyone waiting to join the programme will have the opportunity to support and be supported by other families in a similar position.

Future Research Priorities

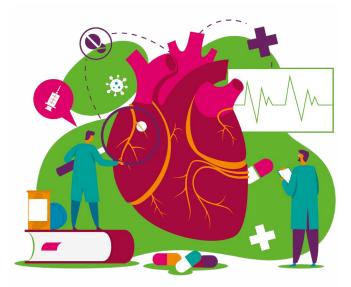
n the last issue of MyLife, we introduced our Future Research Priorities project – a process to determine the priorities for cardiomyopathy research in the future. Research is key to improving the lives of people with cardiomyopathy and it is important that all those affected have the chance to give their views on what should be researched in the future.

What have we done so far?

Cardiomyopathy UK has partnered with the James Lind Alliance in this 'priority setting partnership' to ensure that researchers and funders can focus research where it would have maximum impact.

The first survey was open in July. We asked you to give us questions that you would like answered by research. There were over 1000 responses and we received over 2000 questions.

Since then, members of the expert steering group have summarised the questions (where the same question has been asked in several



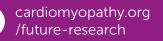
different ways, they have been summarised into a single question), and decided which of the submitted questions are in or out of scope.

How you can take part

We now have a list of potential research questions, and we need your help to decide which of these should be an area of focus for research in the next few years. Complete this short survey and select the

research questions you believe researchers

should focus on.





What's next?

Once we have the survey results, we will draw up the shortlist of questions, which we will take to a workshop in February 2024. Through discussions in small groups, the aim is to create our top 10 priority research questions at the end of the day. The workshop will take place in Birmingham, and we are inviting you to submit an expression of interest if you'd like to take part. If you want more information on the workshop, please email:



research@cardiomyopathy.org



Key steps include

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

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

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

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

3. Reduce the research questions to form a short list.

There is now a second survey open, and we ask you to respond. You will read through the list of questions and choose which 10 you would like to prioritise to research. This will create a short list of potential research questions.

Other priority setting partnerships

The Cardiomyopathy UK priority setting partnership (PSP) is not the only one running at the moment. There are others which the cardiomyopathy community may like to have their say.

The role of digital technology in heart health complete the survey at:



digitalheartpsp.napier.ac.uk

Future palliative and end of life care research for more information, go to:



palliativecarepsp.wordpress.com

4. Hold a priority setting workshop.

We will hold a workshop in February 2024 with representatives from across the cardiomyopathy community to narrow down the short list to produce the final top 10.

5. Communicate the top 10 to researchers and funders.

we are

here

currently

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





Improving mental healthcare for people with cardiomyopathy

As part of World Mental Health Day 2023, we collaborated with Centre for Mental Health to host a discussion on improving mental healthcare for people with cardiomyopathy.

The discussion was hosted by Katharine McIntosh, our Head of Research and Policy and Andy Bell, CEO of Centre for Mental Health.

At Cardiomyopathy UK, we know that the mental health needs of people living with cardiomyopathy and their loved ones are not being met. That's why we're collaborating with organisations like Centre for Mental Health to highlight the needs and experiences of people affected by cardiomyopathy and promote discussion on how services can be improved.

One of the things that decision makers need to hear is that there isn't just need, there's demand.

Andy Bell, CEO, Centre for Mental Health

Watch the discussion

If you missed the live webinar, you can still watch Katharine & Andy's discussion on demand by scanning the QR code or going to:



cardiomyopathy.org /getting-better -treatment



Topics will include:

- What is mental health?
- The links between mental health and physical health
- What progress is being made in mental healthcare?
- What changes do we need to see?



The need for more mental health support

In our State of Cardiomyopathy Care Report:

50% felt that they struggled to cope emotionally over the last 6 months.

46% feel access to counselling & therapy would help their emotional wellbeing.

9% with cardiomyopathy had been offered mental health support as part of their care.

Get involved

To hear about upcoming opportunities to get involved in our influencing work, including a workshop on mental health, contact:



research@cardiomyopathy.org

Support available for you

To find out more about peer support, support groups or telephone support available from Cardiomyopathy UK, visit:



cardiomyopathy.org/support

I live alone and I get very scared about my condition and how to cope with it. Also, I feel anxious a lot of the time as I never know what will happen next in my body.

Cardiomyopathy UK survey 2022

Always in our hearts

Visit our online memory wall and leave a message dedicated to someone who will always be in your heart.

Share a memory, message or photo in honour of lives touched by cardiomyopathy.

cardiomyopathy.memorypage.org/alwaysinourhearts





Cardiomyopathy UK Donation form

If you'd like to donate, please complete the form below and return in the enclosed free-post envelope to:

Cardiomyopathy UK, 75A Woodside Rd, Amersham, Buckinghamshire HP6 6AA.

Or donate online at:

www.cardiomyopathy.org/donate

Your donation

I would like to make a single gift of:

£10	£25	£50	£	Other
Your Details				
Title	First Name			
Surname				
Address				
		Post cod	e	
Telephone				
Email				
providing		by email from Cardiomy ion, campaigning for ch		

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:
ls your donation in memory of a	a loved one?	Yes No

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

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

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

Date

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

Thank you

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