

myLife

The magazine for people affected by
cardiomyopathy and myocarditis

Issue 23/Autumn 2020

Fundraising Appeal

9

Life after Lockdown

18

September Stroll

20



Page 14

MEET OUR INSPIRATIONAL FUNDRAISERS!

Cardiomyopathy^{UK}
the heart muscle charity

Contact us

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

Call or write to us



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Helpline

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(free from a UK landline)
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Find us online



www.cardiomyopathy.org



contact@cardiomyopathy.org



Live chat

www.cardiomyopathy.org

8.30am-4.30pm, Monday-Friday

Social media



/cardiomyopathyuk



@cardiomyopathy



@cardiomyopathyuk

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Welcome



Welcome to this edition of My Life.

Our theme is "togetherness."

I am sure that there have been moments during the last few months when many of you, or someone you know with cardiomyopathy or myocarditis have felt anything but 'together.'

We are living in unprecedented times. Life has transformed for most people, but more for those who have underlying health conditions. Confusion, fear, loneliness and frustration have been the common reasons why people have reached out to the charity. Head of Services Ali Thompson has written more on this on pages 18-19.

In response, we have tried to make current and relevant information available, and shifted our support online and via telephone. Turn to pages pages 4-5 for an update from CEO Joel Rose.

Lockdown has also seen the cancellation and postponement of our challenge events, including the London Marathon. In response to this and the increase to our services, we have launched a fundraising appeal (see our enclosed leaflet and page 9 for full details).

However, lockdown has not deterred some of our amazing fundraisers who have continued to show their support. Take a look at pages 14-15 to see what they have been up to.

Also included are our raffle tickets, and (because it's never too early), our Christmas Catalogue.

It has been great to see how well many of you embraced digital services for support, information and fun. Thank you to everyone who has been a part of our support and fundraising teams – we are in this together.

Keep well,

Alison Fielding, Chair

Front page photo: Peter Cooper after finishing his indoor marathon



Contents

4. Response to COVID-19

6. Stephanie's story

10. Latest News

12. Reader's Questions

16. Your Services Online

20. September Stroll



A positive response to challenging times



*By Joel Rose
Chief Executive of
Cardiomyopathy UK*

We all know that the COVID-19 pandemic has been incredibly challenging, especially for people with cardiomyopathy and their loved ones.

The impact of the pandemic will no doubt be felt for a long time and the changes that it brings to all aspects of society will be profound.

However, I feel that it is important not to lose sight of some of the positive things that change can bring and the huge opportunity that now exists for us to do even more for people with cardiomyopathy.

I have always been immensely proud of our services. The work that we do on the helpline, in hospitals, at conferences and in support groups has a real and lasting impact on people's lives.

We know that when people come to us for help, we make them feel less scared, less isolated and more able to cope with their condition.

It is fair to say that there are many more people out there who we can help not just directly through our services, but indirectly by working to ensure that they can all access the treatment and support they need through the NHS.

In the last issue of My Life (April 2020), I talked about our advocacy project and our plans to do more to shape the services that the NHS provides. With the pandemic ongoing, this work is needed now more than ever.

Many of you will have already seen how NHS services are changing because of the pandemic.

More appointments are being held online or in the local community; some have been delayed or cancelled as clinicians and local NHS providers are trying to adapt.

Our advocacy project is being launched at a time when the "new normal" is defined, and we are already talking to clinicians across the country to help input into their plans

"Good to chat and connect with others. A chance for some laughter too"

"Not alone. Believed."

so that as they re-design their services they do so with input from the people that their services will help.

It is not just NHS services that are changing, our services are also adapting to the pandemic.

We have been able to put more of our support groups online, launch informal "Coffee and Catch Up" sessions, and have run a number of Facebook Live sessions where leading clinicians answered your questions about the effect of COVID-19 on cardiomyopathy. Ali, our Head of Services, talks more about this later in this edition. (Pages 16-17)

It has been really positive to see that this online support is bringing in so many new people to the charity.

We are planning to build on these changes and take the opportunity to reach more people who need us than ever before.

Amidst all the fear and doubt, our volunteers, supporters and staff have stood out.

It is their dedication that has enabled us to meet a massive increase in demand for our services.

It is because of them I am confident we can continue to adapt, meet the challenges of this pandemic and flourish.

> Service user comments taken from a survey we ran in response to COVID-19

"Just that it's so reassuring knowing that they're always there for us"

"I think they are very comprehensive and the charity responded rapidly and very effectively to the new situation that everyone has found themselves in."

Stephanie's Story



> Stephanie Cruickshank gives us extra support as a member of our Nurses team. Here she bravely shares her story about her diagnosis and living with cardiomyopathy.

Thirty years ago, my life changed forever.

I got up as normal, drove to the gym, dropped my son at the creche, and started a cardio workout.

After a couple of minutes, I apparently said to the gym instructor 'I don't feel very well', and with that I blacked out, stopped breathing and went into cardiac arrest.

I had multiple rounds of CPR, and after ten minutes an ambulance arrived and they defibrillated me.

They got me back, only to watch me go again, and again and again. I had multiple cardiac arrests that day, and prolonged resuscitation and defibrillation.

I was blue lighted to hospital and spent the next 48 hours on life support.

This was an extremely traumatic period in my life, I was shocked when I was told what happened; I did not believe it although my bruised ribs were proof that something dreadful had happened.

Ten days later I was discharged home. I cannot convey to you how scared I was.

When would it happen again?
Would I live?

I didn't really understand what was wrong with me. I am a nurse, married to a doctor, and we had never heard of cardiomyopathy.

I came across an article in a magazine about Cardiomyopathy UK's founder Carol Biro.

I got in touch, and we arranged to meet at her house which was also the office of the Cardiomyopathy Association (as it was known then).

Over the next six months we started working together on fundraising and raising awareness.

I took on volunteer roles, supporting newly diagnosed patients. I also helped to run information days and support networks.

As I became more involved, I became a trustee of the charity.

My hope was that with greater awareness of cardiomyopathy no one would feel like I felt when I was diagnosed.



> Stephanie pictured during her time with the Cardiomyopathy Association. (Top Dr Elijah Behr and Professor Bill Mckenna (Right)

I thought my life was over. I was never going to have a future, more children, or even see my son grow up.

Cardiomyopathy UK grew over the years, and was able to fund a nurse to work at St George's Hospital.

The role was to support families affected by cardiomyopathy and to help run the clinics. When they advertised for another nurse, I applied.

I spent the next ten years working for Cardiomyopathy UK as their support nurse. I was involved in answering queries, helping to run the various support meetings and promotion.

Thirty years on things have definitely changed in my world, and the world of cardiomyopathy.

I went on to have two more sons and a successful job as a Arrhythmia Nurse specialist in my local hospital.

Recently I have been able to help with the nurse support helpline, as Cardiomyopathy UK were overrun with COVID-19 worries.

I was happy to help, I know what it feels like to be scared, and talking it through with an expert is so reassuring.

I have been through an awful lot over the last thirty years; from my initial cardiac arrest, genetic testing for my children, ICD implantation to a pacemaker. You name it, I have had it!

I would not have got through any of this without the support and love from Cardiomyopathy UK.

Beta Blockers and Cardiomyopathy

Beta blockers, also called beta adrenergic blocking agents, have been shown to have a positive effect on hypertrophic cardiomyopathy.

One of their actions is to block the release of the stress hormones, adrenaline and noradrenaline in our body, resulting in the slowing of heart rate and reduction in the force at which blood is pumped around our body.

Blood pressure is lowered when angiotensin II (a hormone which increases water re-absorption in the kidney to increase blood pressure) production is blocked in our kidneys.

Studies have shown that cardiac patients who took beta blockers were less likely to die and had a better quality of life (JACC 2017).

Beta blockers are separated into two distinct classifications; "non-selective" and "selective" dependent on where in the body they mainly act. Non-selective beta blockers are active in blocking adrenaline and noradrenaline in other areas of the body, including the heart.

Selective beta blockers are used more commonly by cardiologists because their activity mostly affects the heart.

Beta blockers are an important treatment for people diagnosed with symptomatic hypertrophic cardiomyopathy and dilated cardiomyopathy.

They should be slowly introduced and gradually up-titrated (gradually increasing a dose monitoring your body's response, observing carefully for any undesirable side effects) ensuring they are well tolerated.

In hypertrophic cardiomyopathy beta blockers are used in the treatment of both obstructive and non-obstructive HCM and are effective in reducing chest pains and shortness of breath symptoms.

It is known to be generally well tolerated with only a few side effects- fatigue (due to a slower heart rate) and cold hands and feet being the most commonly reported.

*Written by Jayne Partridge,
Cardiomyopathy UK Support
Nurse*



Change the World of Cardiomyopathy

Urgent Fundraising Appeal

Your support is more vital today than ever before as we experience the biggest ever period of change in the charity's 31-year history.

We are really proud of how we redeveloped our services, rapidly innovating and adapting how we met the enormous increase in demand during these extraordinary times. We have also been working with clinicians to help them adapt through this period of change so that they are better able to help you.

We are now at the pivotal point where we can bring about a step change for thousands of people affected by cardiomyopathy in the future.

We have the unique opportunity to significantly change the world of cardiomyopathy, by influencing and shaping the NHS to improve early diagnosis, treatment and care for people developing cardiomyopathy today.

But we can't fully take advantage of this because the biggest challenge we are facing in the pandemic is the huge loss of funds due to cancelled fundraising events – usually the bedrock of our income – which will leave the charity short by **£180,000**; **20%** of our income by the end of 2020.

This is why **we urgently need your help** at this crucial time, so that we can **bridge the gap in income** and take the necessary steps to change the world of cardiomyopathy.

You can help make this change happen by **giving a regular gift of £10 or £25 per month, or a single gift of £40**. Your donations will strengthen our ability to bring about the change we need to make in the next phase of our evolution as a charity.



£10

Per Month

Will enable someone like you to get all the support and information they need to manage a new diagnosis

£25

Per Month

Will help fund our clinical education projects to improve early diagnosis, treatment and care

£40

One Off Donation

Will help someone with declining health to access vital medical advice via our nurse helpline in the times ahead

> To support us, please return the enclosed donation form in the freepost envelope, donate online via www.cardiomyopathy.org/donate or call us on 01494 791224.

Positive results for new HCM drug

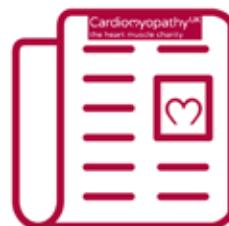
In May, US pharmaceutical company MyoKardia announced very promising results from their EXPLORER-HCM clinical trial of the drug Mavacamten, the first drug developed to target the specific molecular defect of obstructive Hypertrophic Cardiomyopathy.

The trial confirmed the drug's ability to relieve obstruction, control symptoms and improve quality of life for people with obstructive HCM.

It is hoped that the drug will be made available in the UK in the

near future once it has gone through some more testing and the licensing process.

Joel Rose says "these results are highly impressive. We could be looking at a major breakthrough in the treatment of obstructive HCM, with the real chance of more people with the condition avoiding heart failure and living fuller lives."



Heart Hive Update

Researchers from the Imperial College London are launching a new study to understand how the COVID-19 pandemic is affecting people with cardiomyopathy, on the Heart Hive - a platform to connect people with active research projects.

The Heart Hive COVID-19 study aims to learn how the pandemic has been affecting the health and wellbeing of those with cardiomyopathy. The pandemic has had a huge impact on healthcare services.

The findings of this study may help doctors to adapt healthcare services to better meet the needs of patients with cardiomyopathy in the future.

The study is also open to people without heart disease who can be part of our comparison group.

> Visit the Heart Hive website for full details: www.thehearthive.org/



New Organ Donation Law



The law around organ donation in England has now changed. From the 20th May, the introduction of Max and Kiera's Law means that all adults are now potential organ donors, unless they choose to opt out.

This will greatly increase the number of people on the donor register and makes a clear statement about the importance of organ donation.

Right now, there are around 295 people waiting for a new heart in the UK. The majority of these people have cardiomyopathy, which is the leading reason for heart transplants.

Although many people with cardiomyopathy have their condition and

symptoms controlled with medication, for some people in advanced heart failure, a heart transplant can be their best option of controlling their condition.

This is a positive first step that presents an opportunity to have much-needed conversations about individual wishes and helps create a culture where organ donation is the norm.

If you're fit and healthy, then donating your organs is likely to be the last thing on your mind – but it's a vital decision you can make now that could save lives in the future.

A donated heart can mean a whole new chance at life for someone living with advanced heart failure due to cardiomyopathy.

That's why we encourage everyone to consider staying on the register and telling their family about their wishes.

To find out more about the new law, and to read up on what the changes will mean for you, visit www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/ or call 0300 123 23 23

We have written two new factsheets on:

- Frailty
- Coping with Breathlessness

These fact sheets are now available for download on our website, or you can order via email at contact@cardiomyopathy.org

Download our new factsheet on frailty

Cardiomyopathy^{UK}
the heart muscle charity

cardiomyopathy.org/information



Q&A

with the Services Team

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



› Ali Thompson



› Jayne Partridge



› Emma Greenslade



› Caryl Evans

Q: How can I best support my child's mental health through the COVID-19 pandemic?

Pediatric nurse **Emma Greenslade** says: "Many families with children affected by cardiomyopathy are facing major changes in their lives because of COVID-19.

"Routines help our lives feel structured and safe, so help your child to create a new daily schedule.

"Check in with your child about how they're feeling and listen without interrupting. Hearing your child's concerns, validating their feelings and talking is important during this time.

"Early signs of anxiety can differ. For children it may be talking about their cardiomyopathy more and being afraid to go out.

"Common symptoms of anxiety include excessive worry, restlessness, fatigue, difficulty concentrating and trouble sleeping.

"Children can do things like taking deep breaths, counting backwards from 100 or going to a safe space in your home to relax. Work with your child to identify a place that makes them feel calm, like a bedroom or playroom.

"Instead of dwelling on issues that are out of our control, teach your child to focus on the things they can control."

Q: I really miss seeing my friends and family; what can I do?

Support nurse **Jayne Partridge** says: "Many people miss seeing their loved ones but there are things you can do to feel less isolated.

"Look after yourself, exercise if you can, get good quality sleep and try to eat a healthy diet. Try to avoid drinking too much alcohol or comfort eating.

"Stay connected to friends and family, make time to call your friends and family, send messages and use video calling so that you can talk about any worries, swap news and enjoy a joke.

"Try to establish a routine, use the extra time you might have to read more, use a mediation app or learn a language. Enjoy doing things you find meaningful.

"Meet new people - Cardiomyopathy UK have online Coffee and Catch Ups on Fridays 2pm-3pm, where you can talk about anything you like or just listen in.

Details can be found on our website here: www.cardiomyopathy.org/shared-experiences/coffee-catch-up

Q: Know Your Numbers Week is 7th-13th September. This is an awareness campaign encouraging adults across the UK to know their blood pressure numbers and take action to reach and maintain a healthy blood pressure. Why is this important?

Support nurse **Caryl Evans** says: "It is important to have an awareness of your blood pressure. Blood pressure is a measure of how strongly the blood presses against the walls of your arteries.

"The top number is the pressure of blood when the heart beats (and pumps blood out of the heart) The bottom number is the pressure of blood when the heart is resting between beats.

"Ideally, your blood pressure should be under 140/90 mmHg (millimetres of mercury)

"Many people with high blood pressure feel fine and not symptomatic, for that reason it is important to get your blood pressure checked regularly. If your blood pressure is high (hypertension) it puts extra strain on your heart as it is required work harder to pump blood around the body.

Causes of High Blood Pressure:

- Drinking too much alcohol
- Smoking. New research shows that vaping e-cigarettes

with nicotine causes a stiffening of the arteries.

- Too much salt (sodium) in your diet
- Obesity
- Abstinence of any physical activity
- Stress

Possible Effects

- Stroke
- IHD (Ischaemic Heart Disease)
- Heart failure
- Trouble with memory or understanding
- Dementia

"Improving life style choice, including increasing physical activity, following a healthy diet and taking medication such as ACE inhibitors, Beta Blockers (see page 8 for more information), calcium channel blockers and diuretics can all help to maintain a good and well controlled blood pressure."

If you would like further information, please contact the support nurses on our Helpline 0800 018 1024 or via supportnurse@cardiomyopathy.org

Fundraising from Home

That's when we launched our #fundraisefromhome campaign. Here's how some of our amazing supporters responded:



Peter's Marathon Madness

Peter Cooper's plan was originally to run 6 marathons between November 2018 and March 2021 to raise funds for us in memory of his mother. Returning to Hong Kong in March, he had to stay quarantined in his apartment for two weeks. Still wishing to complete his fifth marathon, he decided to run the 26.2 miles in 5250 laps around his living room flat; raising an amazing £1600!

Challenge and community events have always been the bedrock of our fundraised income, thanks to our wonderful fundraisers. All that changed overnight when lockdown meant that all planned events had to be postponed or cancelled.



Barbara's Creative Crocheting

Nanny Chicken Knits, run by supporter Barbara Roberts, spent a month crocheting 112 colourful rainbows for her community to promote hope and happiness during lockdown, raising over £500 in donations for us!



The Frake's Fantastic Fundraising

Father and son duo Bob and Ryan Frake raised £150 by running up a 21 storey tower block. 11 year old Ryan completed the run in an impressive 3 minutes and 17 seconds, with Dad Bob achieving the climb in just 2 minutes and 26 seconds! As they live in a bungalow, Bob jokes that "*training was hard, but worth it to receive a donation of £150 for Cardiomyopathy UK.*"

Karen and Nigel's 30 Day Home Challenge

Karen and Nigel Felstead walked 2 to 3 miles every day for 30 days in May, raising a marvellous £277.50 (including Gift Aid). Living near the open countryside they could safely social distance on their walks, whilst enjoying breath taking views.



Lou's Fabulous Felting

Louise Ironmonger is a keen felt artist and has generously donated 10% from her online sales from her Felt From the Heart shop as well as donating two paintings; which raised a combined total (including Gift Aid) of £600!

2.6 Challenge!

Our 2.6 Challenge team of 33 'Home Heroes' took on a array of interesting challenges, from running and cycling, to dancing and head shaving! The total raised over £13,000 (plus Gift Aid), from 620 donations. Youth Panel's Elis Power and Jasmine Williams raised £2070 by livestreaming their 26 burpee challenge. Thank you to everyone who took part or donated!



A special thanks go to Trustees Jill O'Connell and Chris Horwood for their wonderful fundraising, and eight of our staff members who also took on a Home Challenge: Jaye Chassebi, Karen Gregory, Christie Jones, Jo Marychurch, Sheila Nardone, Jayne Partridge, Joel Rose and Ali Thompson!

Your Services Online

COVID-19 has had a huge impact on all our lives both at home and around the world.

How we deliver our services to people in the cardiomyopathy community has had to change, as support group meetings, in clinic services and social activities have been prohibited in line with the UK's Government's lockdown of the nation.

We understand how vital it is for our people to be able to connect with us and other people who either have cardiomyopathy or care about someone who does.

We also heard from many people within our community who were self-isolating and wanted the opportunity to talk about anything other than the pandemic.

We developed the Coffee and Catch Up sessions which take place at 2pm GMT every Friday via the online platform Zoom. These sessions are open to anyone and offer people respite through lighthearted chat as part of a supportive, friendly group.

The group details are published via our social media channels and on our main closed Facebook group (details can be found at the end of this article).

Once you register you are given the joining details to meet and share with us.

We have welcomed old friends and new to these sessions and they provide a safe space to talk about anything and everything with liked minded people.

Our traditional support groups which met regularly throughout the UK have been transferred online. Details of all online regional support groups can be found on our website under 'How We Can Help' section.

In addition to our regional support groups, we have also introduced topic specific groups hosted by one of our helpline nurse specialists. Topics include Genetics, HCM, DCM, ARVC and PPCM. If there is a topic you would like to see hosted online do let us know.



We have also offered a series of online groups which are targeted specifically at improving and managing emotional wellbeing and mental health, as we know that the psychological impact of cardiomyopathy during this pandemic can have.

Hearing from expert clinical speakers is very reassuring for people affected by a chronic condition, even more so during this time

That is why we have reached out to renowned specialist speakers to talk about the impact and answer your questions about the virus on people affected by cardiomyopathy both physically and mentally through our Facebook Live series.

Feedback we have received from the community has reinforced the need for this type of information and support.

The charity remains constant in its support and care for you. Our helpline and staff are at the end of the phone, email or online chat when you need us.

Our services and the way we reach out may have been different, but the family that is Cardiomyopathy UK remains reassuringly the same.

To book your place and join our Coffee and Catch Up sessions, visit our website: www.cardiomyopathy.org/shared-experiences/support-groups

Our Facebook group can be found at: www.facebook.com/groups/cardiomypathyassociation/

“.....they are like a one stop service for everything related to my condition - help, support, advice, support groups, meds management, assistance with benefit system, up to date information on science, medicine, treatments and just a forum for sharing and seeking help when needed on a variety of platforms and ways.”
Service User

Life After Lockdown



> Ali Thompson, Head of Services writes about coping with the pandemic, and what may become the new normal

None of us have lived through a pandemic which has seen the globe close its doors and watch from the window as a new type of living emerged.

On our TV's, phones and our newspapers; constant updates bombarding us with death rates, infection rates, new cases, new fears, new restrictions to our freedom.

As we begin to move towards some semblance of how things were before, with shops reopening and greater freedom of association, many of us are feeling understandably anxious and scared.

Some within our community have suggested that the move to lift certain restrictions is "too soon" and that the virus has not gone away

For some who have been self-isolating and shielding for longer, the anxiety about returning to work, moving around in public and using public transport is very real. This can have a detrimental effect on their sense of safety and well-being.

When we feel our security and physical health is at risk, feelings of anxiety, fear and depressed mood can become common.

In some instances we may even exhibit behaviours that could be symptomatic of phobia. One service user shared that they were "too frightened to walk to the end of the garden"; let alone return to a busy inner city office.

Depending on how severe and debilitating these fears and anxiety are (severe meaning that the majority of your time is taken over by this), there are some useful tips we can explore to build up our emotional well-being.

If we are afraid of venturing outside, we can set ourselves small, realistic goals which increase over time. For example, we can try walking to the end of our road or garden and remaining inside for three minutes before we allow ourselves to return indoors.

We can build this up by gradually by gently increasing the numbers we are outside and the distance from our home.

It helps, if we can, to have someone with us (at an appropriate distance) who we trust that can be with us during these exercises. If you are being told you must return to work, and are concerned that this is isn't suitable for your health,



call our helpline and we can advise on next steps.

Continue to take precautions where possible such as wearing a suitable protective mask, gloves and using hand sanitiser to clean your hands when washing is not an option.

Remember that you are not alone; thousands of people share similar fears about returning to life after lockdown.

Cardiomyopathy UK can help you face these fears, and work with you to improve how you are feeling.

"Life won't be the same for any of us after lockdown as this pandemic has changed us all in some way- how we work, how we live and where we travel."

Gratitude for our friends and family, and the revisiting of relationships which we now hold more dear are positives we can all share in.

If you are having difficulty with prolonged and continued feelings of anxiety or low mood, contact your GP who will be able to help you.

> If you would like further advice or information, please contact the support nurses on our Helpline 0800 018 1024 or via supportnurse@cardiomyopathy.org

September Stroll

Throughout September we are hoping that 150 of our supporters in the UK and Ireland will come together for a collective stroll across the UK - that's 500 miles!

Walk 3 miles each around your local area, or whatever you can manage, and help to raise money for Cardiomyopathy UK.

To take part, simply plan a walk or a number of walks of any length during the month of September on your own or in a small group, then tell us how far you went and send us your donation.

Record your walk, encourage your friends and family to do the same, and then donate to our Just Giving campaign.

Watch the miles and donations rise as we reach our fundraising goal of £4000!



> Scan this unique QR code with your smartphone camera to be taken straight to our September Stroll campaign page on Just Giving. Suggested donation amount is £20 per walker.

New to the team



> Jo Marychurch

Despite joining at the beginning and during lockdown, we welcomed two new members of staff to our team.

Digital Media and Communications Officer Jo Marychurch, who now runs our social media, website and produces My Life.

Youth Support Manager Sade McCarthy, who will be developing our resources for 0-25 year olds, and working with the Youth Panel to expand our youth services.

We'd love to hear from you, so do get in touch on 01494 791224!



> Sade McCarthy

Extended Summer Raffle Deadline!

Our annual Summer Raffle has been extended! With prizes worth £500, £250 and £100, why not try your luck and enter?

Use the raffle ticket booklet inside this My Life to buy tickets for yourself and sell to your family and friends, then simply send the ticket stubs to us. (Please recycle any unused tickets).

The closing date is now October 28, and only tickets purchased online and received in the post by the end of the

> You can also visit our online shop to buy tickets in booklets of 6 or 12 at www.cardiomyopathy.org/shop or scan the QR code on the right hand side of this page.

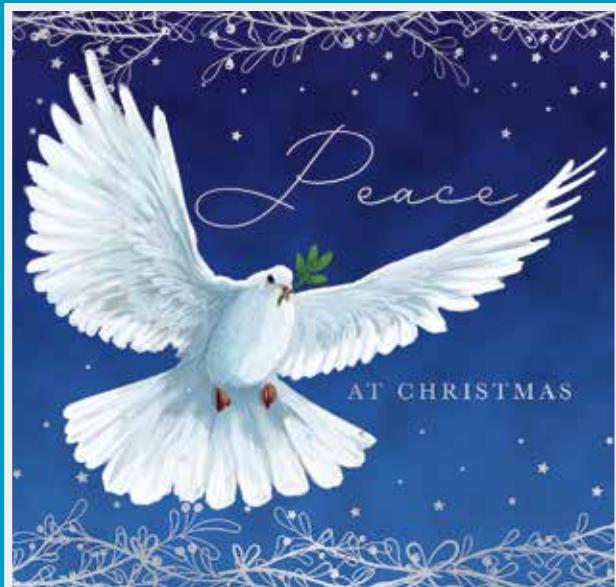
day on October 28, will be counted. The draw will take place on 31 October

Each £1 ticket helps support our vital work and enables us to be there for families who need us.

To find out more information, contact our Community Fundraiser Jaye on jassebi@cardiomyopathy.org



New Christmas Cards!

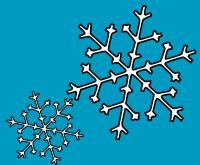


Spread some cheer and warm wishes this Christmas, with our new range of Christmas cards, now available on our online shop.

Our Christmas 2020 catalogue is included in this edition of My Life.

All profits from our online sales go towards supporting everyone affected by cardiomyopathy.

> Visit www.cardiomyopathy.org/shop for more



Charlotte's Story



> Charlotte Carney is a member of our CYP&YA Panel, who under went a heart transplant due to her diagnosis of Restrictive Cardiomyopathy. Here she writes about how the current pandemic has effected her.

On 15th March I told my employer I wouldn't be coming into work on Monday as I did not feel safe given the current COVID-19 pandemic. People thought I was being dramatic.

I don't think at the time people understood how serious it was, and they didn't understand how I was at higher risk as a transplantee. I had a heart transplant in February 2018 and I am immunosuppressed to prevent my body rejecting my heart.

This means I'm more prone to infections and also normal infections can cause more of an issue to me than normal people. However, I stood my ground as my health and my heart's safety is so important to me.

Thankfully, a couple of weeks later it was announced that I needed to 'shield'. The store I work in was also closed and I was furloughed.

Luckily I have been paid throughout this time because my main worry was not being able to pay my bills and having no option but to work.

"It's been quite difficult being shielded, I haven't left my house since 16th March; other than for the odd night time walk."

I haven't been able to see family which is especially difficult now that they are meeting up with each other and I am stuck at home. We've had food and medicine delivered, and my mum has been dropping off supplies when needed.

It has been challenging. I'm a very outgoing person, and not socialising every day and being out and about has been tough.

It's also been mentally difficult as I was housebound for a few months before my transplant and it's taken me right back to that place of feeling helpless and vulnerable.

It's weird as a transplant patient because I don't see myself as vulnerable. I'm healthy, my new heart is good and I had my life back so it's not been fun going back to feeling like a poorly person again.

Thankfully I've remained healthy by following the guidelines and we're busy making plans for when we can travel again and get back to our lives. It's always nice to have something to look forward to."

Join #teamcardio

Make the most of Summer and Autumn 2020 after lockdown, challenge yourself and help to raise virtual funds for us. Take a look at our events below.

Virtual Challenges

Date: Your choice

Challenge yourself and support us during lockdown!

Complete 10,000 steps or a Home Combo of 4 exercises over the course of a month.

Run 5K, 10K or tackle a half marathon named after the UK's London iconic parks.

Looking for an ultra challenge? You could scale Everest, walk the Inca trail OR cycle/run extreme distances up to 120 miles. All participants will be awarded a beautiful and unique medal.

Simply decide and sign up via our website, then ask your friends, family and colleagues to sponsor you.



To take part in any of the events listed above, visit our website: www.cardiomyopathy.org/virtual-events/virtual-events

Email fundraising@cardiomyopathy.org or ring us on 01494 791224.

Treks

Date: 12th September 2020

Take on the Yorkshire Three Peaks challenge and feel on top of the world.

To find out more, visit our website www.cardiomyopathy.org/walks-and-treks/yorkshire-three-peaks



Skydive for us

Have the experience of a lifetime by skydiving over the beautiful countryside of Salisbury in September, or at a choice of airfields across the UK.

A skydive is one of the most unforgettable ways to raise money for us AND help support thousands of people affected by cardiomyopathy.

PS: If you raise £450 you jump for FREE!

Change the World of Cardiomyopathy

Now is the time to act to shape the future for others

**Urgent
Fundraising
Appeal**



"The clinical community has always admired the vital work that Cardiomyopathy UK does, especially during the Covid-19 pandemic when many more people needed help. To remain an essential resource, the charity must have the funds to support the people who need it, to educate clinicians, guide research, shape NHS services and fight for better access to treatment. But at a time when the charity is needed most, it is dealing with the huge financial impact from the suspension of its fundraising events. That's why this fundraising appeal is so important"

Professor Perry Elliott, President of
Cardiomyopathy UK

See page 9 for further details

Cardiomyopathy^{UK}
the heart muscle charity

