

myLife

The magazine for people affected by
cardiomyopathy and myocarditis

Issue 20/October 2019

PIP benefit form tips 7

Paul set for a runner's high 8

Our winter campaign 22

A photograph of a woman with voluminous, curly, light brown hair. She is smiling warmly at the camera. She is wearing a light blue ribbed top under a pink corduroy jacket. A thin necklace with a small pendant is visible. The background is slightly out of focus, showing a dark window frame on the left and some colorful items on the right.

CORRIE STAR ALI
SHARES HER STORY Page 22

Contact us

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

Call or write to us

Unit 10, Chiltern Court,
Asheridge Road,
Chesham, Bucks HP5 2PX

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
8.30am-4.30pm, Monday-Friday

Social media

/cardiomyopathyuk

@cardiomyopathy

@cardiomyopathyuk

Cardiomyopathy UK is a charitable incorporated organisation (CIO) with a registered charity no 1164263

Welcome



When I received the call asking me to write the intro for this My Life, which is focusing on the theme of community, I was far away from the community that supports me personally.

I was travelling through the Outer Hebrides with only occasional internet and mobile coverage.

As we travelled, I thought a lot about how it feels to be alone with cardiomyopathy – the worry about what may happen and no one easily available to help; the isolation of not knowing anyone else and even the possibility that communities with a small population could be restricted in partner choice if families carried genes for inherited diseases.

It made me doubly grateful that Cardiomyopathy UK are able to run our helpline, support groups and online Facebook groups.

We are also committed to opening more in-clinic services next year, so that people get support when they most need it and we reach people for whom travelling to support groups is not possible.

It has been lovely to see our community come together to celebrate our 30th anniversary and it's not too late to join in.

Thank you to everyone in our community who supports others through sharing their experiences; being a listener; volunteering with us; or fundraising to help this small charity make a big difference.

Alison Fielding, Chair

Alison

This magazine and its plastic wrapper is 100% recyclable



4. Become a regular giver

6. In-clinic volunteers

13. When Aaliyah met Pudsey

15. Community Voices

18 Tributes to Peter McBride

22: Our winter campaign



Sign up to change lives

Monthly giving is one of the easiest ways you can help others



› One of Carol's favourite photos of her mum Edie Harbour – 'She did enjoy a long chat on the phone!'

By the end of this our 30th anniversary year, we are looking for **30 new donors** to give monthly to save and change lives in the charity's fourth decade.

Join our community of regular givers by signing up between **November 1 and December 31** – by phoning 01494 791224 or donating via our website – and we'll send you a limited edition 30th anniversary mug.



The story behind every regular donor is precious to us and many tell us how it's their way of giving something back for the difference the charity has made to their lives.

They find that giving a small amount each month is affordable, but over a few years it adds up to make a huge difference to someone's else's family.

Carol Wood, 74, from Yorkshire, is one of our longest-serving regular givers who started giving in 2006. Her mother, Edie Harbour, was one of the founding members of our charity 30 years ago, after she was diagnosed with Hypertrophic Cardiomyopathy (HCM).

"The first sign of her problem was when she became very breathless while travelling on the Underground in London. There was some history of heart attacks in her family, but not cardiomyopathy," recalled Carol.

"She was signposted by Hammersmith Hospital to the newly-formed charity

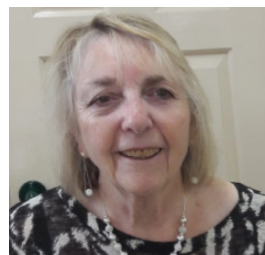
and became a founder member. She was always grateful for the help and support she received and never let HCM get in the way of her life – even pruning her fruit trees a week before she died," added Carol.

"As a family, we have supported Cardiomyopathy UK by 'doing' the London Marathon. My daughter, her partner and I have walked it several times, but my son has run it six times. We also take part in the charity's raffles and buy Christmas cards.

"But fundraising through marathons isn't compulsory – an easy way to support Cardiomyopathy UK is with a monthly donation and we're delighted our donations have helped the charity grow to be a force to be reckoned with."

Sheila Nardone, Head of Fundraising, says: "It's thanks to families like Carol's that the charity has been sustained over the past three decades. Her regular giving has helped us to gradually improve and extend our services.

"Setting up a monthly direct debit is one of the best ways you can help improve health outcomes for people with, or at risk of cardiomyopathy, right across the UK."



› Carol Wood

Tribute fund to keep Josh's memory alive

Josh Deakin died in March 2018 from Left Ventricular Non-Compaction (LVNC) at the age of just 26 – but his memory lives on in the actions of his family, friends and loved ones, who have worked tirelessly to fundraise in his name.

Over the past 16 months, Josh's loved ones have shown incredible strength by raising a staggering £23,106 for Cardiomyopathy UK through a variety of fundraising events – from a charity football match and BBQ, to clay pigeon shoots and sponsored cycle rides, jumble sales, auctions, and much more.



› Josh with his parents and younger brother Elliott on Graduation Day

"Their collective passion and tenacity in overwhelmingly tragic circumstances has been astounding, and their contribution to the Cardiomyopathy UK cause will ensure we can be there for more families across the UK affected by heart muscle disease," said Cardiomyopathy UK's outgoing Community Fundraiser Christie Jones. (See Page 11)

Josh was a loving son to Sue and Steve, caring big brother to Elliott, loyal partner

to Abby, and treasured friend to many. He always put others first and had exceptional people skills, effortlessly striking up a conversation with anyone and immediately putting them at ease.

Since his death, the outpouring of messages from those whose lives Josh touched, has been nothing short of phenomenal and his selflessness and unwavering positivity will live on in the frontline services that his tribute funds will help to support.

'Their contribution to the Cardiomyopathy UK cause will ensure we can be there for more families across the UK affected by heart muscle disease'

"From everyone at Cardiomyopathy UK, we'd like to extend our sincere thanks to all who contributed to this incredible fundraising and awareness-raising effort – we are eternally grateful for everything they've done for our cause," added Christie.



› Josh & Elliott in their school uniforms



› In the car with partner Abby Lewis

Josh achieved much in his 26 years, including obtaining a BSc in Sports and Exercise Science, as well as setting a number of junior athletics records in 100m, 200m, and long jump.

He lived life to the fullest in whatever he did – a self-professed graphic novel and comic book 'geek', Josh enjoyed attending live rugby and wrestling events, and was a huge fan of rock acts like Alter Bridge, Tremonti, and Sevendust – bands that can now count mum Sue and dad Steve as enthusiastic converts!

How Ken is giving back

In-clinic peer support volunteer Ken Pugh is helping Cardiomyopathy UK develop our medical community by reassuring patients there is life after diagnosis.

Two years ago, we launched the country's first in-clinic peer support service at the rare disease department of the Queen Elizabeth (QE) Hospital in Birmingham.

Ken Pugh is our longest-serving volunteer at the clinic, who wanted to "give something back" for all the support he had received since being diagnosed with DCM in 2002.

"I met Dr Will Bradlow at the Cardiomyopathy UK West Midlands support group. Will asked if anyone would be willing to offer peer support to cardiomyopathy patients," Ken recalled.

"I felt that I could fulfil the role by making use of my own experience of the condition and having an ICD, as well as my skills as a marriage guidance counsellor for more than 10 years."

Ken can spend anything from a couple of minutes to an hour with patients, depending on how they react to what they've heard in their appointment with the consultant.

"Many patients forget what they've just been told amidst the trauma of the moment and only begin to ask questions once they return home," he said.



> Ken Pugh receiving his Cardiomyopathy UK Community Award at last year's National Conference from Dr Will Bradlow, who set up the in-clinic scheme

"Patients who may be hearing their diagnosis for the first time can experience a range of emotions and responses – from nonchalance and denial, to fear, anger, and even tears.

"I'm there to answer questions and point patients in the right direction. However, I'm cautious in giving advice as I'm always mindful that the process is for and about the patient.

"Hopefully, I reassure patients that for the majority, there's life after diagnosis and that a key to managing their cardiomyopathy is to listen to their own body, work with their medical team and learn about the condition from the range of information Cardiomyopathy UK provides.

"It's great that so many patients tell us what a good idea the in-clinic peer support concept is and how helpful it has been for them," Ken added. "But we'd like more patients to use the service and more people to help, as there are far more clinics held that can be staffed by appropriately-trained volunteers.

"Despite the challenges, I really enjoy being able to give something back and share a little of my experience and talents, such as they are!"

What you need to know about PIP

One of the most common questions I'm asked on our helpline is, "What should I put on my form when I'm applying for Personal Independence Payment (PIP)?"

I always start my response with, "What's a typical day like for you?" The biggest mistake people make when completing a PIP form is assuming the DWP appointed assessor will know and understand what cardiomyopathy is. This is seldom the case.

I encourage people to take 20 minutes with a pen and paper to jot down what a typical day is like for them: from the moment they wake up, to the time they close their eyes at the end of the day. This means considering the following:

- Are you symptomatic upon waking, are you fatigued?
- Can you put on slippers and walk down the stairs?
- Do you struggle to put on socks, tights, shoes?
- Can you prepare a healthy breakfast, or do you rely on breakfast snack bars, as preparing eggs on toast or similar is too physically taxing?
- Are you able to wash and style your hair, or do you need assistance as raising the arms above the head exacerbates symptoms? And so forth, throughout the day.

These reflections should form part of the applicant's response to Q15 'Additional

Information' on the form, which is your opportunity to articulate what your day is like. Some important points to consider including in a PIP application for cardiomyopathy are:

- If you experience fatigue, be clear that fatigue is not akin to tiredness and cannot be remedied by sleep or a rest.
- Explain why you are fatigued – your heart does not function as efficiently as a normal heart; the tasks that others take for granted can place extra strain upon the heart of a person with cardiomyopathy and can result in fatigue, breathlessness, etc.
- If you are no longer able to socialise as frequently because of fatigue or if on diuretics, include this. Social isolation and feelings of loneliness can lead to the presentation of emotional challenges, so include this and explain.
- If you identify as having anxiety or depression, but this has not been diagnosed, be clear that you experience feelings of anxiety or that your mood is depressed. If you state that you "have" anxiety or depression on the form, you may be asked to provide clinical evidence to support this.
- Be clear that any treatment such as medication or devices cannot cure cardiomyopathy, but rather help manage a condition that will deteriorate over time.
- If you have an ICD, explain what it is and why – to shock the heart into a normal rhythm should it fall into a dangerous, life-threatening rhythm.



By Ali Thompson
Head of Services

To find out more about PIP – if you are eligible to apply and how to appeal should your application be rejected, call Ali on our freephone helpline 0800 018 1024.

DWP
Department for
Work and Pensions

Our volunteer community is a huge part of what makes our services so effective.

Turn to Page 10 to read about our plans to run a new online training course

Paul's guaranteed to get a runner's high



In 2017, Paul helped put together a field of around 50 runners in the London Vitality 10k – making history for Cardiomyopathy UK with the charity's biggest team of running fundraisers to date.

Our community of fundraisers raise vital funds for our work through a variety of events, but Met Police sergeant Paul Hollis is taking running for Cardiomyopathy UK to new heights.

He has signed up for the Himalayan 100 Stage Race, which takes place over five days in November, with runners traversing isolated jungles, pine forests, villages and major rivers along a 100-mile course in the foothills of the Himalayas.

Paul is under no illusions how tough the race will be as right from Day 1, he'll face 24 miles of trail running with an altitude gain of more than 10,000ft.

"In all honesty, I'm somewhere between excited and terrified about it and realise how much I've taken on when I see people's reactions when I tell them!" he admitted.

Paul started running in 2010 after a knee injury prevented him doing contact sports and martial arts. That same year, he ran his first half-marathon for Cardiomyopathy UK after a friend's stepfather was diagnosed with the condition.

"That started my friendship with Cardiomyopathy UK," said Paul, who ran his first marathon for the charity three years later. "I have met some lovely people along the way and having realised what Cardiomyopathy UK does, I have kept you as my charity of choice."

Today, with a further 18 marathons under his belt, the 46-year-old is taking on his most ambitious challenge after his friend Sarah Russell told him about the Himalayan 100, which she completed in 2014.

"I help Sarah coach her running group in my home town of Tunbridge Wells and in return, she's been generous with advice and support," said Paul.

"Training for the Himalayas means I need to up my mileage and I've done nine marathons this year alone as 'training runs' and been to the altitude centre in London to see how I cope with the lack of air."

Today, the 46-year-old is taking on his most ambitious challenge, after his friend Sarah Russell told him about the Himalayan 100



Paul also supplements his average weekly running mileage of around 30 miles with 35-mile bike rides to Southwark Police Station before starting his night shifts.

"I'm getting used to running back-to-back days to give my legs an idea what I'm in for. However, my shift work makes it hard to have a strict training plan, so I can sometimes be found running on the treadmill in the middle of the night!"

The Himalayan 100 has been called the most scenic race in the world as runners take in panoramic views of Mount Everest, Lhotse, Makalu, and Kanchenjunga – four out of five of the world's highest peaks – and despite the rigours of his planning and preparation, Paul knows he'll enjoy a real runner's high when he catches sight of them.

› Runner on the trail that has been called the Most Scenic Race in the World.

Look out for a follow-up interview with Paul in our next issue of My Life.



At the heart of our community

If you are interested in finding out more, or would like to be notified of the online training course when it is released, please contact our Head of Services Ali Thompson at Alison.thompson@cardiomyopathy.org

The charity is delighted to announce that we have been awarded a five-year grant from the National Lottery Community Fund that will see us support 19,500 people affected by cardiomyopathy through the development and continued growth of our peer support via in-clinic, phone and support group services.

Clearly we have a big job to do and will need lots of help and support to do it. This is why the charity is part-way through creating an online training course for all our volunteers who provide peer support – existing and new.

The interactive course will help our volunteers to understand the roles available; what is required and how the charity can support them.

Our core services rely on the empathy, personal understanding and experiences of our community members affected by cardiomyopathy and myocarditis and these make a very tangible, positive difference to

people's ability to cope and manage their condition well when they access Cardiomyopathy UK for peer support.

The charity is intending to further increase the number of support groups we offer (whilst maintaining the groups we have) and also looking to create a coordinator hub to steer the groups where people are reluctant to take on the sole responsibility of leader.

We will also be increasing the number of cardiac clinics we operate within, by presenting businesses cases to the respective NHS Trusts to demonstrate the benefits of having in-clinic peer support volunteers.

Our telephone peer support volunteers will also increase to ensure we have a more varied cache of supporters to better meet the increasingly diverse needs of the caller.



'Giving by taking' movement gathers pace

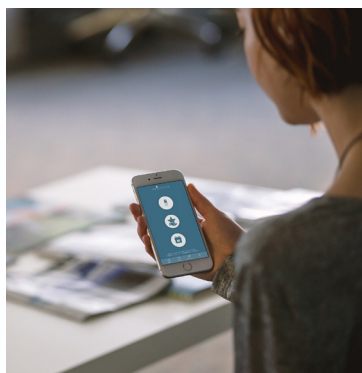
Since becoming one of the beneficiary charities for DrugStars, our community of cardiomyopathy app users have earned us more than 113,000 stars that will be converted into an annual donation of over £1,000.

You can earn stars by using the DrugStars app, which is really easy to use and free. You use it to remind yourself to take your medication – prescription

and/or over-the-counter – including painkillers, vitamins and minerals.

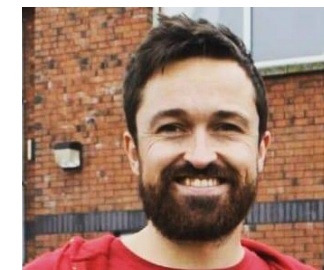
You can also earn stars by giving information to be used in research to help improve medication.

Join the 'Giving by taking' movement by downloading the DrugStar app on your phone or tablet via <https://www.drugstars.com>



Familiar face joins our services team

› Christie Jones talks about his role as our new Community Peer Support Manager



Tell us a little about your background?

I've been involved in the third sector from the age of 19 – volunteering in rural Madagascar teaching English and French; leading sports camps for kids in local villages; and helping out at a local radio station and at an inner-city zoo.

I became somewhat of an employment nomad after graduating and tried my hand at finance, IT, advertising tech, secondary school teaching and beard oil sales!

However, no matter where I worked, I often dedicated my spare time to charitable endeavours: mentoring pupils in inner-city London secondary schools; helping primary school children in Tower Hamlets to improve their reading skills; fixing elderly residents' IT issues in a Southwark care home; putting on my own arts festival, and much more!

Joining Cardiomyopathy UK in January 2018 as a Community Fundraiser was a dream come true – a chance to begin a full-time career in a charity that had been making a huge difference to the lives of families across the UK for almost 30 years.



What does your new job involve?

I'll be working with our volunteers to maintain and grow the charity's invaluable community peer support services – our in-clinic support services; our regional support groups; and of course, our telephone peer support network.

An essential part of my role will involve collaborating with our peer support volunteers and recruiting new volunteers to continuously adapt our frontline services to meet the diverse needs of our service users.

What do you hope to achieve?

First and foremost, to improve the well-being of those directly affected by cardiomyopathy and the well-being of their friends, family, and carers.

Thanks to funding from The National Lottery Community Fund for a five-year community peer support project, we've also been able to set a number of ambitious goals; increase our number of regional support groups from 35 to 50; build a 40-strong network of phone volunteers and establish a network of 15 in-clinic peer support services across England.

What are the challenges?

With ambitious targets come a number of potential challenges – one of which is to provide effective peer support to the more isolated areas of the country. Again, we will achieve this through building upon our existing network of volunteers and working closely with local key

stakeholders, such as clinicians and NHS Trusts. We will recruit and train new volunteers from diverse backgrounds to provide emotional support of the highest standard, wherever they are needed.

What do you do when you're not working?

I like to keep active – football, basketball, badminton and distance running are some of my favourites. I'm also a keen writer and have had some poetry and short fiction published. I also do a bit of acting when I can – either in small independent productions, or as an extra in big-budget blockbusters like *Fantastic Beasts* and *Bohemian Rhapsody*!

What piece of technology could you do without/never do without?

I'm trying to limit my phone usage at the moment as I like to be as mindful as I can during my downtime – although Saturday afternoons are still spent frantically keeping up to date with the football scores. But I'd be literally and figuratively lost without Google Maps!

The word on the street

Corrie Star Ali Mardell is among those helping to raise awareness of Cardiomyopathy UK

Our community of supporters who are willing to share their personal stories in the media – whether newspaper, magazine, radio or TV – plays a vital role in creating awareness about the work we do.

The internet and advent of social media also provides numerous opportunities to promote stories even further.

Coronation Street star Ali Mardell (top right) ran the Great Manchester 10k in memory of her father, who died from Dilated Cardiomyopathy (DCM) three years ago, and her story was featured in The Daily Mirror, The Sun, The Express, Hello! and Digital Spy.

"I was ready to raise awareness about DCM in the hope that it could prevent at least one family from suffering. Knowledge is power," Ali explained.

Sheffield support group leader and co-leader Julie Taylor and Sarah Glossop (right) appeared on BBC Radio Sheffield to discuss their experiences of living with cardiomyopathy and their diagnosis journey.

"Receiving support from Cardio-myopathy UK was like a weight lifted", Sarah told listeners, while Julie discussed how our support groups and helpline can provide support and accurate information.

Read more about joining our community of media volunteers on Page 22



Cardiomyopathy UK
22 August · G
Coronation Street's Alexandra Mardell found a hole in her heart after losing her father to cardiomyopathy in 2016.
When it was revealed that Ali's father died from undiagnosed cardiomyopathy, the coroner advised that her family get tested. Although the test came back clear, the results showed that she had a septal defect, a type of congenital heart disease.
Our recent survey found severe gaps in services, leaving people with cardiomyopathy and family members at risk. We must work together to ensure cardiomyopathy patients are receiving the right tests, treatment, specialist care and support, which could save lives.
Earlier this year, Ali took part in the 10k Great Manchester Run to raise awareness and funds for Cardiomyopathy UK. ❤️
Click here for the full story: <https://bit.ly/33OR1YB>
#ThursdayThoughts ITV



The Metro online – read by 1,248,000 across the UK – covered the shocking story of Katie Denial, whose symptoms of DCM were initially misdiagnosed, and our youth panel member Aaliyah Aries was featured in her local newspaper, The Milton Keynes Gazette, prior to her BBC Countryfile appearance (see facing page).

When Aaliyah met Pudsey



› Cardiomyopathy UK Support Nurse Jayne Partridge took these photos of the day

Our Youth Panel member Aaliyah Aries, 16, took part in this year's Countryfile Ramble for Children in Need and was filmed by a BBC television crew talking about her experience of being a teenager living with DCM.

Here is Aaliyah's diary of the day:

7.30am: Woke up, feeling a bit nervous but excited to raise awareness of cardiomyopathy and looking forward to taking part in the Children in Need ramble. I was glad to see the sun shining as rain was forecast.

9am: Arrived at Worcester race course and met up with my family. We met some of the production crew and had refreshments whilst we waited for everyone to arrive.

9.30am: I was introduced to the presenters and had a hot drink.

10am: Had a safety briefing and headed to the start line.

11am: We were joined by Pudsey Bear and some bangra dancers to get us all in a happy mood, then off we set. We all had matching hats so looked a bit crazy and some passers-by gave us funny looks, but it was fun.

Along the way we stopped at various points to film pieces for the TV show. I was interviewed (along with my mum) and was able to share my experiences of cardiomyopathy. Mum was able to add her perspective as a carer too. Towards the end, I was lucky enough to meet one of the wildlife photographers who gave me a short masterclass. I hope to put his tips into practice soon.

3pm: Arrived at the finish line. I was pleased I had completed it. I had managed well, but was very tired as it had been a long, but enjoyable day!

› Aaliyah was interviewed by presenter Ellie Harrison (top left) during the mass ramble through the city of Worcester, where they took in views of the River Severn and historic sights around the city.

The special Countryfile episode featuring Aaliyah is due to be broadcast on Sunday, October 27.

Our new Christmas card range



Spend over £20 and receive a free gift!

Visit our online shop at www.cardiomypath.org/shop for a wider selection of cards to choose from

Spread festive cheer far and wide by sending a Cardiomypath UK Christmas card – the perfect way to show your friends and family that you support our work.

Our 2019 catalogue is included in this edition of My Life and features a range of cards for the festive season, along with our branded merchandise.

All proceeds from the sales of our merchandise go towards supporting everyone affected by cardiomyopathy, so whatever you buy, you'll be helping us raise vital funds.

Community voices

Our Information and Educational Events Manager Adrian Taylor spoke to Rosie and Elis – two members of our youth panel – at the first National Youth Gathering to ask them about their views on Cardiomypath UK and the future of our services



› Cardiomypath UK Information and Educational Events Manager Adrian Taylor

Why is it important for Cardiomypath UK to have a youth panel?

'To produce and aim resources specifically at younger people managing their condition. The stigma of heart condition usually relates to older people, and that's what you see when you look at most of the current resources out there.' [Elis]



How do you like to get information about your condition?

'I look online. I go to the Cardiomypath UK website and other online articles.' [Elis]

What help have you received from Cardiomypath UK?

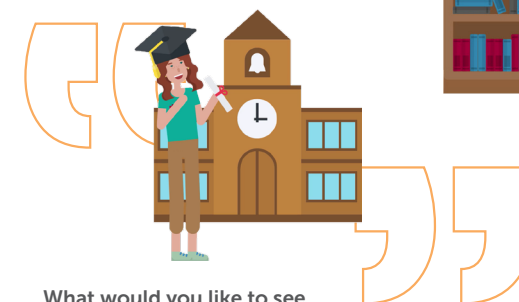
'I have received peer support from Cardiomypath UK, which I don't think I would have found anywhere else.' [Rosie]

'Cardiomypath UK has been invaluable to me – allowing me to see that there are plenty of people all over the UK and the world with

the same condition as me. It's made me feel a lot calmer about managing my condition. Putting on events such as National Conference is a great way to get people in the same place and talk to one another about their experiences.' [Elis]

What difference has knowing more helped with your condition?

'It always helps me to know as much as I can in any situation I find myself in. Finding out as much as I can about cardiomyopathy helps me to plan my life, explain it to others and be okay with it myself.' [Rosie]



What would you like to see more of in the future from Cardiomypath UK?

'I think more events around the country and partnering with universities and companies would be great to see.' [Rosie]

'More youth-specific events, maybe even a TV advert to spread the word in the same way larger charities have got national exposure.' [Elis]



#teamcardio highlights

from 2019

None of our vital services would be possible without our community of amazing fundraisers.

Whatever event you take part in, your support means more people affected by cardiomyopathy can get the information and help they need.



A huge thank-you to our fabulous fundraisers who have been raising money to support our work in this special 30th anniversary year.

The map right, shows how they have supported our work in 2019 so far, through a wide range of fundraising activity, including:

- 141 people signed up to take part in a physical challenge – from walks to runs, skydives to abseils and even the famous super challenges known as Ironman Triathlon and the Himalayan 100 Stage Race.
- 150 people organised a community fundraising event, 17 of which raised more than £1,000 and 30 people undertook our special 30-day challenge.
- 48 Virgin London Marathon runners raised a record-breaking £148,571 at the Virgin London Marathon; 20 runners in the Great North Run raised £9,300 and 15 skydivers raised £11,502.
- 8 organisations chose us as their charity of the year.
- 12 people organised an annual community fundraising event such as a sports tournament, dance or music event.
- In December, help finish 2019 on a high, by signing up for a Christmas fundraiser, or run Santa in the City over the Millennium Bridge? (Details on Page 20)



Tributes to former chairman



Peter touched many lives and had a transformational impact on the charity.

If you would like to share your memories of Peter we would love to hear them.

Please contact us at contact@cardiomyopathy.org

We are extremely sad to announce that former Chair of the charity, Peter McBride died this summer. We asked some of those he worked closely with to share their thoughts.

Current Chair of trustees Alison Fielding paid tribute to Peter's long-term commitment to being Chair: "Peter gave his time and accounting expertise over 11 years.

"He was passionate about spreading awareness of cardiomyopathy and each trustee meeting invariably started with him telling us about his latest discussions with people whom he met on his extensive travels."

Former Chief Executive Robert Hall, who worked with Peter from late 2003, said: "He became a valuable and supportive colleague, as well as a dear friend.

"Many people who attended the charity's events during this period will remember Peter as the person who introduced and closed meetings, often with jokes about his own driving.

"This was his public persona. His main contribution, however, was in the background where he showed a tremendous level of personal commitment to the charity's cause, travelling miles, often at his own expense, and displaying a deep compassion for people affected by cardiomyopathy.

"He was instrumental behind many of the initiatives introduced to assist people and increase the charity's relevance to those it sought to serve.

"That the charity has continued to thrive is a significant part of his legacy."

Joel Rose, Cardiomyopathy UK Chief Executive, worked with Peter towards the end of his time as Chair of the charity.

He said: "Peter was exceptional at seeing possibilities; deals that could be done, connections and networks that could be made to grow the charity and help more people.

"He had huge ambitions for the charity and an infectious enthusiasm that made him a pleasure to work with."

Protect yourself against the cold weather



> **Cardiomyopathy UK Support Nurse Jayne Partridge**

Experts are predicting this winter could bring the coldest weather for 30 years.

Cardiomyopathy UK has further advice on our website – 'Protecting yourself against the cold weather'.

With flu season just around the corner, our specialist nurse Jayne Partridge offers advice on how to protect your heart during cold weather.

Colder weather makes your heart works harder to keep your body warm, so as a result, your heart rate and blood pressure may increase.

These changes can sometimes make your heart-related symptoms worse and can sometimes affect how your heart copes with doing everyday things.

If you are concerned about any new or worsening symptoms and need advice, contact your doctor's surgery or GP out-of-hours service.

While cold remedies are used to relieve the symptoms of a cold, they often

contain a combination of drugs, which can include aspirin and ibuprofen.

It is a good idea to check with your pharmacist to ensure that there are no interactions with your usual medications before you take any over-the-counter medications.

The flu vaccination may be recommended for you by your GP or your cardiologist as it may be of benefit to people with a heart condition.

The vaccine encourages your body to develop an immune response to the flu virus. This won't stop you catching flu, but will help your body to fight the virus if you do catch it.

If you feel unwell with the flu and are concerned about any increase or change in your symptoms, see your GP or out-of-hours contact 111 or 999 for assistance.



Are you up for a challenge?

Sign up to an event and help us raise vital funds to support our work.

Call our Challenge Events Fundraiser Becky Bryant on 01494 791224.



Santa in the City
Want to get in the festive spirit early this December?

Then why not join our team and take part in Santa in the City? A joyful festive run across some of London's historic sites, a perfect occasion to get friends and family together to really get in the festive spirit this Christmas! And most importantly, you get to do all of this dressed as Santa whilst raising vital funds for Cardiomyopathy UK.



London Marathon
Applications for the 2020 Virgin London Marathon are still open.

Do you have what it takes? Don't miss out on this opportunity to take on the world famous 26.2 miles around the capital by filling out our application form for one of our charity spots.

Please put as much detail as possible in your application as we do receive a high number of applications.

Were you one of those lucky individuals to get a ballot place? If so, we would love to have you as part of #teamcardio taking on this huge challenge in a Cardiomyopathy UK vest and help families affected by cardiomyopathy.

Here's how we can support you:

- Cardiomyopathy UK performance running vest
- Full fundraising pack including London Marathon guide, sponsorship forms, banner and event posters
- Support from our dedicated fundraising team to help you smash your target
- Training day with our coach Sarah Russell
- Cheering points along the route with the loudest support
- Post-race reception on the day complete with showers, sports massage and food



Congratulations to our raffle winner Heather



› Ross Morgan, Heather Sim and her husband Nick Morgan

We're delighted to announce Heather Sim has bagged £500 as the winner of our summer raffle.

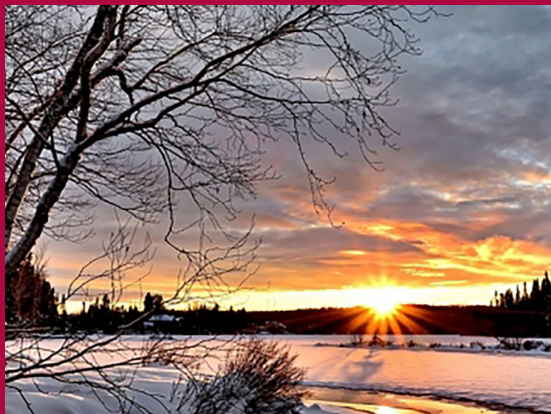
"It was such a surprise to get the phone call telling me I'd won the first prize and since then, I've had numerous thoughts about how to spend the money. However, there is one idea that I'm liking the most," said Heather.

"A few years ago, we moved to the Highlands of Scotland where we live in a house with views of the Cairngorm mountains.

We recently met a young artist whose parents were volunteer members of the Cairngorm Mountain Rescue Team and she was exhibiting her amazing paintings of the mountains to help raise funds for their work.

"Our son Ross, who has hypertrophic cardiomyopathy, has always enjoyed hill-walking and has recently taken up climbing, which he is loving. So I'm going to use the money to commission a painting from Elizabeth that is inspired by Ross, by his heart and by our family's enjoyment of the mountains and I will also be making a donation to Cardiomyopathy UK."

Every raffle ticket sold really does make a difference and will mean we can help more people that need us. Thank you to everyone who bought and sold tickets for us.



Winter 2019 Campaign

If you would like to be a part of our campaign and share your story with the media, please call Kerry Allan on 01494 791224

Our media work is all about saving lives. If we can get more individuals to recognise the signs and symptoms of cardiomyopathy then people with the condition will be diagnosed quicker.

This means that they do not have to run the risk of going without the care and treatment that they need.

Last year, our national media campaign 'Heart Bleeps' focused on some of the misconceptions around cardiomyopathy and how these misconceptions can lead to delays in diagnosis and make living with the condition even more difficult.

We were really pleased with the response that our campaign received and the coverage we achieved in national and local media.

This winter, we are running a new awareness campaign highlighting the symptoms of cardiomyopathy.

We will be telling people how it is especially important to be aware of these symptoms during the winter months, when cardiomyopathy and in particular, myocarditis can be mistaken for flu.

The charity is encouraging people and GPs to 'think heart' if they see lingering flu or flu-like symptoms, along with symptoms such as palpitations, dizziness, swollen ankles, or shortness of breath.

With cases of flu set to spike this year, we are concerned that a lack of public awareness of the condition, in particular myocarditis, will cause people to brush off signs of the condition as flu and not seek the help they need.

As part of the campaign, we will run a national survey of the general public to look at how people respond to flu-like symptoms; whether they put off going to the doctor and whether they go back to the doctor if symptoms don't go away.

We will also be using a number of case studies of individuals, who will be sharing their own story of how they were diagnosed with myocarditis and cardiomyopathy when they just thought that they had the flu.

We are still looking for individuals who are happy to share their own story as part of this campaign and our ongoing media work.



Our clinical community

Bringing healthcare professionals together to develop the next generation of cardiomyopathy experts

This issue of My Life features stories of how our community fundraisers help the charity grow; how our community services ensure that we can reach more people with the condition; and how our community of media volunteers help us to spread our life-saving awareness messages.

Another community of supporters who play a vital part in our work is our clinical advisory group.

The group, chaired by our President, Professor Perry Elliott, brings together some of the leading healthcare professionals with expertise in cardiomyopathy and myocarditis.

They represent a wide range of clinical centres from all across the UK and a wide range of disciplines, including senior clinicians, cardiac nurses, researchers and geneticists.

"The purpose of this group is to help the charity's work to campaign for better access to quality treatment and provide the best possible support and information for anyone affected by cardiomyopathy," said Cardiomyopathy

UK Chief Executive Joel Rose.

The group does this by providing clinical insight and ensuring our work is appropriate, helping us to keep up to date with developments in treatment and diagnosis and giving us a real understanding of changes on the ground."

In the past few years, the clinical advisory group has met to discuss a range of big issues, such as how we can provide more training to doctors; what a great cardiomyopathy service should look like and how we can do more to support research.

The group is also there to listen to the feedback that we give them from our national surveys, or from individuals who use their services, and discuss how they can improve the support that they can give.

One of the most exciting things about the clinical advisory group is the role it plays in developing the next generation of cardiomyopathy experts to ensure more clinicians choose to specialise in cardiomyopathy and myocarditis.

That way, we can be confident future generations get the expert help they need and we continue to make progress in detecting and treating the condition.



› Professor Perry Elliott



National Conference

ARVC | DCM | HCM | Restrictive

| Takotsubo | Myocarditis |

Research and
development

| Genetics |

Surgery
and devices

Heart muscle
disease and
young people

| Emotional
wellbeing



For more information and full programme:
www.cardiomyopathy.org / 01494 791 224



Tickets now available on **eventbrite**