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The magazine for people affected by
cardiomyopathy and myocarditis



INSIDE THE SUPPORT GROUP

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Contact us

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

Call or write to us



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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

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Welcome



Welcome to the first My Life edition of 2020. It is a packed and varied read, reflecting the breadth of cardiomyopathy experiences and the services we provide to improve lives.

Most of you will be familiar with services such as the helpline,

support groups and website.

As well as helping individuals, we undertake policy work with the NHS and others to improve data and services, and we undertake awareness campaigns to try and save lives by making clinicians and the public aware of cardiomyopathy and myocarditis.

We are updating our three-year plan in 2020 and there will be lots of chances to have your say on what **you** think is important.

One area you will see more focus on this year is supporting people with advanced heart failure. Sadly, despite medication and devices, some people experience ongoing and sometimes worsening symptoms.

Our article on living with an LVAD shows the challenges of finding ways to remain active. Throughout this year, you'll see more information on symptom management, accessing the best care and one-to-one support on preparing for the future in both emotional and practical ways.

As always, we need to raise money to stay in business, so please check out the fundraising leaflet included with this issue, to see how you can help us continue supporting more people in 2020 than ever before.

Alison Fielding, Chair

Front page photo: Bristol Support Group



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Max and Keira's Law

The law around organ donation is changing



The act is known as **Max and Keira's Law** in honour of **Max Johnson, who received a heart transplant from Keira Ball, who died aged nine.**

From spring 2020, every adult in England will be considered an organ donor when they die, unless they choose to opt out, or are excluded.

The Organ Donation Act will help to reduce the number of people waiting for a life-saving transplant.

Those excluded from the new legislation are:

- Children under 18.
- People who lack the mental capacity to understand the changes for a significant period before their death.
- People who have not lived in England for at least 12 months before their death.

Families will still be involved before organ donation goes ahead and surgeons will take a full medical history from the family and consider medical notes to decide which organs can be safely donated and transplanted.

There has been tremendous progress in organ donation, but there is still a shortage of donors and more than 200 people have died in the past five years while waiting for heart transplants, according to NHS Blood and Transplant.

A spokesperson said: "Telling your family you want to donate and carrying an organ donor card are equally valid forms of consent, but sometimes cards are not available at such a critical time.

"We would always advocate that you register your decision on the NHS Organ Donor Register and share this decision with your family."

To speak to somebody about the new legislation, please call the NHS dedicated line on: 0300 303 2094 or visit the website <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/faq/what-is-the-opt-out-system/>

LVADs and e-bikes are a perfect match

In November 2017, Bob Gower was told he needed a new heart or he would die.

He was too ill for a transplant, so had a Left Ventricular Assistance Device (LVAD) fitted.

An LVAD is a powerful, battery-operated, artificial pump that's surgically implanted to help increase the output of the heart's left ventricle when it can't effectively work on its own.

Used to treat people with severe heart failure, it is sometimes called a "bridge to transplant" and can buy time for the patient, or eliminate the need for a heart transplant.

Bob, 66, from Lancashire, had been diagnosed with dilated cardiomyopathy (DCM) in 2001, aged 48.

After a short period in hospital, Bob returned home and with daily medication, was able to resume a reasonably normal

'I was back home with my family in time for the Christmas I hadn't been sure I'd see'



› Bob Gower

lifestyle, continuing full-time in his career and pursuing a wide range of physical activities – football, hill-walking, badminton, cycling and swimming.

However, over a period of time, his capacity for physical activity gradually reduced, until by late-2016, he was unable to walk more than very short distances, and any gradient posed a real challenge.

Continues on Page 6



Bob is a member of The Cranks Electric Cycling Club.

All the riders have LVADs and regularly cycle 20-30 miles together.

In the spring, they are planning to ride the Coast-to-Coast route.

By the end of that year, he had to stop exercising altogether.

The following year, Bob had an ICD fitted and told he was in the advanced stages of heart failure. By the time he had his LVAD fitted, he was probably only hours away from major organ failure.

"I was back home with my family in time for the Christmas I hadn't been sure I'd see," he says.

Following a period of cardiac physio, the keen cyclist regained a level of fitness to be able to think about getting back in the saddle.

However, because he quickly became breathless and in some pain from even quite low levels of exertion, Bob bought an electric bike.

"My e-bike enabled me to achieve a level of independence, as well as access to the open

countryside, which would otherwise be beyond my capacity to walk," he says.

Bob is now enjoying the benefits of his e-bike, together with a small group of like-minded LVAD patients (the self-styled 'Cranks'), who have attracted some attention both locally and nationally with their sense of adventure and refusal to be constrained by the limitations of their serious heart conditions.

As Bob says: "The sheer joy and freedom of cycling along in the open countryside on a beautiful day, feeling the air all around, is something most of us feared had been taken away for ever."

He is also convinced the benefits of cycling have helped him reach a level of health and positivity to be a good candidate for a heart transplant and is back on the waiting list.

Troponin: Why it matters

Cardiac troponin is a protein released into the bloodstream when the heart muscle has been damaged or when the heart is under some degree of stress.

Troponin levels will likely be measured using a blood test if you are experiencing chest pain or related symptoms, including: pain that radiates into your neck, back, arm or jaw; intense sweating; light-headedness; dizziness; nausea; shortness of breath and/or fatigue.

The two types of cardiac troponin that are commonly measured are Troponin I and Troponin T. Both of these are sensitive markers of heart muscle injury.

In people diagnosed with heart failure and cardiomyopathy, troponin levels are used to aid ongoing management during asymptomatic phases (without symptoms) or phases when someone has only very few symptoms.

Troponin levels can also be used to guide the clinician in referral to a heart failure or cardiac nurse service for patient monitoring and to plan the long-term management of their condition.

In people with suspected myocarditis, troponin levels can help to confirm a diagnosis as levels are elevated in some

people with symptoms associated with myocarditis.

However, a normal troponin level does not exclude a diagnosis of myocarditis.

Troponin levels are measured in nanograms per millilitre. Although a rise in troponin levels is often an indication of heart muscle damage, there are a number of other reasons why levels could elevate.

In addition to measuring your troponin levels, an electrocardiogram (ECG) may also be performed to look for any changes that may indicate a heart condition.

Other tests, including an echocardiogram (to look at the heart muscle, heart function and valves), a chest x-ray, or other blood tests may also be performed.

*By Jayne Partridge
Cardiomyopathy UK Support Nurse*



Troponin T will start to rise three to four hours after heart muscle injury has occurred and can stay elevated for up to two weeks.

In healthy people, troponin levels are low enough to be undetectable.

If a person experiences chest pain but troponin levels are still low 12 hours after the chest pain started, a heart muscle injury is unlikely.

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: I have HCM and work full time in a busy office as an administrator. I start at 8.30am and finish at 4.30pm. I am finding that I'm becoming more symptomatic and increasingly tired, but am too scared to speak to my boss in case she fires me. She knows about my condition, but I don't want her to think I'm incapable. What can I do?

Head of Services Ali Thompson says: "Book some time in with your boss for a chat and explain to her how your condition is making you feel. Maybe take a copy of our *What is Cardiomyopathy* and *Hypertrophic Cardiomyopathy* factsheets with you to share with your boss to help her understand the condition.

"Explain that you are committed to your role, but would like to discuss potential ways of working

that might help alleviate some of your symptoms where possible. These are called 'reasonable adjustments' and in accordance with the law, your employer must consider if certain changes to your role could be made to ensure you're not substantially disadvantaged when doing your job.

Such examples of 'reasonable adjustments' might include greater flexibility around your working hours and providing equipment.

Our helpful factsheet, *The Equality Act*, explains more about reasonable adjustments and certain protections under the law at work.

Before you meet with your boss, consider making some notes about the particular areas of your job causing you the most physical difficulty.

If your boss is not very helpful, call us on our helpline for more advice.

Q: Will my new smart meter affect my pacemaker?

Support nurse Jayne Partridge says: "A Smart meter transmits information in short bursts and with such a weak radio signal, it is extremely unlikely the signal can interfere with your device. So at present, they are safe to have in your home if you have an implanted device."

Q: How can I prepare my child for hospital?

Support Nurse Emma Greenslade says: "Having cardiomyopathy can mean lots of trips to hospital. It can be scary and overwhelming for children, so it is important to be honest when telling them why they need to go. If they are under six, tell them a couple of days beforehand. If they are older, tell them a week or two beforehand."

"This gives them time to prepare by asking questions and talking with you and others. Use simple words your child will understand, but be careful about making jokes as they may be confusing or frightening."

"Involve your child in preparations, e.g. help them with packing their bag and choosing special toys to take with them. Depending on their age, give them plenty of opportunities for 'hospital play'. You can get them to do things like bandaging a

teddy, or listening to a family member's heartbeat."

"Read books together about going to hospital and tell your child's school or nursery about the upcoming hospital visit as they will also be able to help prepare your child."

Q: I have been diagnosed with DCM and I feel like I'm having palpitations. What should I do?

Support nurse Caryl Evans says: "Palpitations is a sensation or feeling like your heart is skipping a beat or has added extra beats."

"It may feel like your heart is racing, pounding, or fluttering. Also, some individuals may feel a sensation in the neck, throat, or chest."

"A sustained episode lasting for more than a few minutes is often caused by supraventricular arrhythmia."

"If this sensation is prolonged, or gets more frequent, it is a good idea to get checked out."

"An ECG can see what the rhythm is showing and whether it is a regular or irregular rhythm. It would also be advisable to carry out a 48-hour ambulatory monitor. Unfortunately, in some cases this may not identify a cause for the palpitations. In this instance, the ESC guidelines indicate that an ILR loop recorder may be considered."



A perfect storm

Our 2019 awareness campaign reveals how the winter flu season is a crucial time for people to 'think heart' as 95% of people we surveyed were unaware that being unable to shake off flu symptoms could be a sign of heart disease

Last November, we launched **Our Every Heart Matters** campaign to encourage people to seek help if they have persistent flu or flu-like symptoms, breathlessness, chest pain, palpitations, swollen ankles or dizziness.

We decided to run our campaign during flu season because flu can lead to myocarditis, which if left untreated, can develop into cardiomyopathy. Flu can also mask

the symptoms of cardiomyopathy and myocarditis, making them harder to diagnose. We also learned that people are less likely to seek help or go back to the doctor, if they still feel unwell at that time of year.

As part of the campaign, we surveyed more than 2,000 people and found they are twice as likely to go to their GP with flu or cardiac symptoms in the summer rather than during flu season.

This is because if they feel unwell during flu season, they assume it's just a bug "going around" and their lingering symptoms will clear up on their own.

A big thank-you to our media volunteers (facing page) whose stories helped make Every Heart Matters such a success.

Their experiences helped secure 14 pieces of national newspaper and magazine coverage; 22 pieces of regional and a slot on Talk Radio with Matthew Wright.

Thank you to everyone who also got involved on social media to help us reach an even wider audience, and to our clinical experts who shared our campaign posts and tweets.

Read more about our Every Heart Matters campaign at www.cardiomyopathy.org/2019-campaign/every-heart-matters

Getting a better deal for people with cardiomyopathy and myocarditis

Cardiomyopathy UK is working with other charities and organisations to put pressure on government and the NHS to ensure people with cardiomyopathy and myocarditis are able to access the treatment they need.

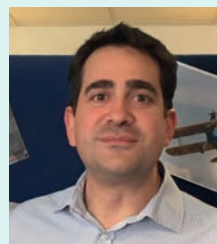
In 2020, we aim to expand our advocacy work through a new project that will bring together local service users, clinicians and other stakeholders, to develop regional 'action plans' that highlight areas in need of improvement and how to address them.

The nature of the NHS is increasingly regional with service provision commissioned and governed

by local organisations, which are required to have patient representation and expected to respond to patient input.

As such, a focused attempt to highlight deficiencies in regional provision by service users is likely to have a positive impact, especially where this can be supported by local healthcare professionals and the charity.

Our survey of people living with cardiomyopathy or myocarditis showed only 17 per cent of respondents experienced best practice in diagnosis and family testing, so we know there is much work to be done in this area. We'll keep you updated and let you know how you can get involved.



*By Joel Rose
Chief Executive of
Cardiomyopathy UK*



Our support groups
provide a sense of
community and
understanding
says Tony Hampson

Strength in numbers



› Tony Hampson, far right, who received Cardiomyopathy UK's Community Award at our 2019 national conference, top, with fellow Bristol Support Group members

Following his diagnosis of cardiomyopathy, Tony Hampson, from Somerset, felt he would benefit hugely from attending a support group.

Tony admits he was shocked to be diagnosed with hypertrophic cardiomyopathy (HCM) in 2017.

"As a keen trail runner, I thought some of my symptoms were normal for this activity and was shocked to learn that I had a life-changing condition," he says.

"I hadn't heard of HCM and didn't know anyone who had it. I felt isolated and wanted to talk to people who had the lived experience, but couldn't find a support group close to me.

"So I contacted Cardiomyopathy UK and talked to them about volunteering.

"I then decided to have a go at starting a support group myself and the charity gave me all the help I needed."

The Bristol Support group has 15-25 members from diverse backgrounds, who are united by their desire to make contact with others who are living with the condition.

"I felt welcomed and had a strong sense of belonging from the first meeting," Tony recalls.

"Everyone who attended also expressed their gratitude and said how they felt they now had somewhere to go where they

would be listened to and not judged," he adds.

"We agreed to meet four times a year and also have informal get-togethers that work very well.

"Between meetings, I plan the topic and speaker for each meeting.

"I always try to remember not to crowd the agenda and allow time for people to socialise and offer mutual support.

"I also stay in contact inbetween meetings with some of the most frequent attendees so we can discuss ideas and support issues and work together to help identify potential speakers.

"Nationally, support for groups has never been stronger, and offers practical training, enthusiasm and wisdom.

"I personally, and those around me, have benefited hugely from a support group and I now know I have people I can both trust and go to when needed."

If you need help finding a support group in your area, please contact our Community Peer Support Manager Christie Jones at christie.jones@cardiomyopathy.org or telephone 01494 791224.





Thank you Paul

Our amazing fundraiser Met Police Sergeant Paul Hollis has raised £1,218 for Cardiomyopathy UK after finishing third overall in the Himalayan 100 mile stage race. Read more about his Himalayan adventure on our website.



JUNE 2020

Save the date for our 1st Thames Bridges Trek.

We'd love you and your friends and family to join this exciting new event, so look out for more information coming soon.



Join #teamcardio

Call our fundraising team on 01494 791224

Will this be your year to take on a challenge and raise vital funds to help support our work in 2020?

We are involved with some of the best challenge events out there, so don't miss out on a chance to be part of #teamcardio this year.

Take a look at a few of our hottest events, or you will find many more on our website that may take your fancy.

Vitality London 10,000

The capital's most inspiring 10k returns to the iconic streets of London.

Set off along The Mall, before heading through the City of London and returning to finish in front of Buckingham Palace.

Whether you are new to running or a regular runner, this 10k offers a fantastic experience.

Prudential Ride London 100

In its 8th edition, this is the world's greatest festival of cycling.

The ride starts in the new Queen Elizabeth Olympic Park and follows a 100-mile route

through the capital and into Surrey's countryside. With leg-testing climbs, it's truly a spectacular event not to be missed.

Great North Run

The world's biggest half marathon (pictured right) with more than 57,000 runners is celebrating its 40th Birthday this year, making it extra special.

Skydive

Take on one of the ultimate adrenaline challenges and get the chance to jump for FREE when you fundraise for us.

We work with more than a dozen UK airfields, so simply let us know an airfield and we will organise the rest.

NEW: Royal Parks Half Marathon

A new one to our books this year and we are so excited to be able to offer places.

This scenic running route winds through four Royal Parks in all their autumnal splendour and gives runners the opportunity to take in magnificent views of London.



Last year, 37 supporters signed up to do our 30 day challenge, raising an amazing total of £6,622 for the charity.

Their challenges included everything from giving something up: such as chocolate, caffeine, or alcohol; or doing 30 days of an activity: such as a physical exercise (e.g. walking 10,000 steps per day); or a creative hobby, such as art, makeovers on friends and learning a new skill.

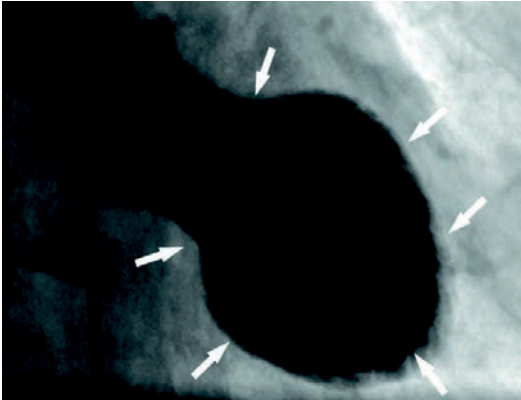
In 2020, we are looking for 30 new people to take on their own 30 day challenge. Simply decide on your challenge, sign up for a free 30 Day Challenge pack via our website and then ask your friends, family, and colleagues to sponsor you for each of the days on your handy challenge chart.

Go to <https://www.cardiomyopathy.org/30th-get-involved/30-day-challenge>

30 Day Challenge
#30challenge

Julie Taylor
No chocolate for 30 days
£130.00 raised

What is Takotsubo?



› The condition was first identified in Japan in the 1990s and was named Takotsubo – the Japanese for octopus pot because the heart's appearance resembles this shape

It is thought that at least 3,000 adults in the UK suffer from Takotsubo cardiomyopathy, but the true number may be even higher.

Takotsubo (often referred to somewhat unhelpfully in the press as “broken heart syndrome”) is a type of cardiomyopathy that gives the left ventricle a distinctive shape.

The name itself comes from the shape of the left ventricle and ballooning of the heart, which was thought to resemble that of a Japanese fisherman's octopus trap.

The symptoms can often present as that of a heart attack. The precise cause of

a Takotsubo event is not fully understood, but it is accepted that it can be brought on by either physically or emotionally stressful situations.

There exists a misconception that it is only negative events, such as the death of someone close that can cause Takotsubo.

However, positive events, such as a loved one's graduation or a party, can also trigger an event.

In some cases, an acute brain injury can lead to Takotsubo.

In 30 per cent of reported Takotsubo events, there has been no identifiable cause.

People who are experiencing a Takotsubo event seek clinical intervention as they assume they are having a heart attack, but clinical tests often demonstrate that this is not what has happened and a diagnosis of Takotsubo is confirmed.

Most common Takotsubo symptoms can include sudden and intense pain in the chest, shortness of breath and an abnormal heart rhythm.

To confirm a diagnosis of Takotsubo, an ECG is often conducted, as well as blood tests.

An echocardiogram and cardiac MRI can also detect the damaged heart muscle and rule out other potential causes.

Treatment of a Takotsubo event is often similar to the

treatment given for a heart attack, which would include assessing that the coronary arteries are not blocked or narrowed.

Breathlessness caused by fluid build-up on the lungs is treated by administering diuretics and if the heart muscle function has been reduced, ACE inhibitors and beta blockers will be prescribed.

Takotsubo often improves following prompt treatment, however researchers looking at the long-term effects of the condition have discovered that the condition can have a more prolonged effect on the heart and for some people, they may experience more than one Takotsubo event.

For more information on Takotsubo, see our website or call one of our specialist cardiac support nurses on 0800 018 1024.

Takotsubo can cause the heart to become enlarged and weakened, so it works less well than normal.

This can lead to symptoms such as chest pain that can feel like a heart attack.

Living well in heart and mind



*By Ali Thompson
Head of Services*

Around 320 BC, the Greek philosopher Aristotle wrote: “The seat of the soul and the control of voluntary movement – in fact, of nervous functions in general – are to be sought in the heart.”

Clearly, medicine and our understanding of human anatomy has evolved since the time of the ancient Greeks, however, the idea that we “feel” our emotions within our heart has persisted in literature, theatre, diverse religious orthodoxies and popular culture right up to the present day.

Good mental health or

emotional well-being is essential for everyone.

The connection between good mental health and good physical health is largely accepted, both clinically and theoretically.

We speak to many people through our helpline, who tell us that upon diagnosis and at different times in their life living with cardiomyopathy, they sometimes feel low in mood, helpless, frightened and anxious.

Some people within our community also share that they feel the depression of mood and sadness.

In 2016, the charity surveyed people affected by cardiomyopathy and those supporting them, to discern what impact cardiomyopathy had upon their emotional well-being.

Out of the 455 people surveyed, 22 per cent (people living with cardiomyopathy) and 28.6 per cent (supporters) stated that the condition negatively impacted them emotionally, all or most of the time.

The results showed 32.5 per cent (people with) and 77.1 per cent (supporters) stated that the condition negatively impacted their emotional well-being some of the time.

Less than nine per cent of people with the condition and less than three per cent supporting someone, stated that cardiomyopathy doesn't affect their mental health.

We saw there was a need for the charity to focus more on what support we could provide to enable people to improve their emotional well-being and to work with clinicians to raise the issue of impacted

emotional well-being on patients and the supporters.

The majority of both those directly affected by cardiomyopathy and their supporters reported that, "...having a chat with someone with similar experiences" and being able to "share experiences in a group such as a support group..." would help improve their mental well-being.

Since the survey and ensuing round table discussion with senior clinicians working in cardiology and psychology, the charity has doubled its efforts to support the cardiomyopathy community to achieve good emotional well-being.

During 2020, we will be increasing the number of peer support volunteers to engage with people who are not in a good place emotionally through telephone support, support groups and in clinic.

We will also be offering a series of online emotional well-being groups, hosted directly by the charity, for affected people with more details to follow via our website and social media.

The charity has doubled its efforts to support the cardiomyopathy community to achieve good emotional well-being

Meet our new helpline nurse

We are pleased to introduce Caryl Evans, who joins our nurse team, alongside Jayne Partridge and Emma Greenslade.

Caryl started working two days a week (Thursdays and Fridays) on our helpline in November last year.

Caryl also works as a clinical nurse specialist as part of the Adult Congenital Heart team at the Bristol Heart Institute.

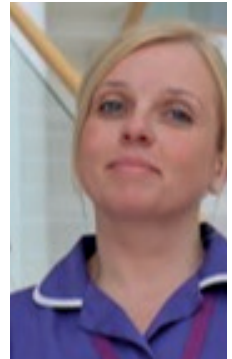
Caryl has theoretical and practical knowledge of end-of-life care and working with patients in

palliative care settings, as well as clinical research and diverse cardiac conditions.

Caryl says, "I'm passionate about providing high standards of care for patients affected by heart conditions such as cardiomyopathy."

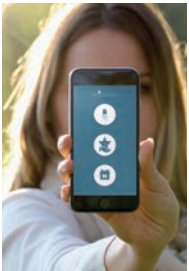
"I will be working to meet the needs of an increasing patient population in an ever-changing health services and it's a privilege to support these patients."

Contact Caryl via our helpline on 0800 018 1024, or at supportnurse@cardiomyopathy.org



› Caryl Evans

DrugStars: Giving by taking



DRUGSTARS®

2020 is off to a great start for the charity as we have just received our first donation of £935 from the DrugStars App since we became one of its charity partners in April 2019.

Stars are earned each time you take your medication – whether prescribed or over-the-counter medicine or vitamins – which you then donate to Cardiomyopathy UK and we receive £1 for every 125 stars donated.

So why not join the 440 of our supporters using this simple way to support us, whilst being reminded to take their pills?



› Head of Fundraising
Sheila Nardone with
DrugStars founder
Claus Moldrup

You'll be in good company

Corporate fundraising makes a huge difference to our work

Louise Matthews is a long-standing supporter of Cardiomyopathy UK, ever since her cousin Ryon Barr died unexpectedly while playing football in 2005.

Years later, Louise, her mum and aunt were also diagnosed with ARVC and in May 2019, Louise had a defibrillator fitted.

Louise is UK and Ireland marketing director for the multinational software company VMware, which helps businesses with their digital transformation.

VMware encourages its employees to volunteer for charity and in 2019, a group of VMware interns came together to create VMgiving to help support Cardiomyopathy UK as two employees in their Staines office have cardiomyopathy and wanted to increase awareness about the disease.

Throughout 2020, VMgiving plans to run a series of events to raise



› Louise Matthews and below, the VMgiving intern team



money, awareness and bring people together in support of Cardiomyopathy UK.

All funds raised by staff will be match-funded by the firm.

To find out how your employer can support us in 2020, go to <https://www.cardiomyopathy.org/corporate-partnerships-2/corporate-partnerships>



› Steffi Moore, who was 18 when she was diagnosed with hypertrophic cardiomyopathy (HCM) with mum Elayne and brother Chris

It's a family affair

Getting a diagnosis of cardiomyopathy when you're a teenager is a frightening experience and something that impacts the whole family.

Giving a regular gift enables us to support families like Steffi Moore's, from Surrey, to better understand their condition and access the medical advice and emotional support that the whole family needs at such a scary time.

"Cardiomyopathy is one of those things that you have to get through as a family," says Steffi, 23.

"We went along to the local Cardiomyopathy UK support group and I got in contact with other young people with the condition. It was horrible at the time, but five years on, look where we are now? We're all happy and healthy and that's all that matters."

Mum Elayne agrees: "We were lucky to find Cardiomyopathy UK as we found the correct

information about the condition and became much more aware."

Chris, Steffi's brother, recalls: "We were waiting in the family room at the hospital when my sister was being diagnosed. I knew straight away something wasn't quite right. I told myself to be brave and be the man of the family."

"Today, we're getting on with the condition and Steffi's heart condition doesn't stop her having a laugh with me. She's sometimes got more energy than me, which is annoying, but she's still my sister and I love her!"



If you would like to become a regular giver (£10 a month will pay for five people to access our helpline and get vital medical advice) and make a real difference to affected families, please go to <https://www.cardiomyopathy.org/support-us-donate/regular-donations>

'Give PIP a go'

Debbie Miller, 54, from Hampshire, says she's not someone who easily gives up, but admits she felt disheartened when her first application for Personal Independence Payment (PIP) was rejected.

"Before my diagnosis of dilated cardiomyopathy (DCM) four years ago, I could easily do my housework in three hours," she says.

"But in the end, it was taking me two days and I was wiped out by permanently working and doing housework."

Debbie first applied for PIP in 2017 – a year after her diagnosis.

"I'd never applied for benefits, so I was rather naive and assumed because I was able to work, I wouldn't be eligible. But PIP is not means-tested and it doesn't matter if you have a job or not. Everyone's circumstances are different.

"But when my application was refused straight away, I just thought, 'Well that's it' and gave up."

Debbie soon switched to working part-time and had to cope with a dramatic drop in the family's finances.

But when her friends at the Surrey Support Group urged

her to appeal, she found she had left it too late and couldn't face going through the whole process again.

"It is very-time consuming, but between my support group and Cardiomyopathy UK's Head of Services Ali Thompson, they persuaded me to give it another go.

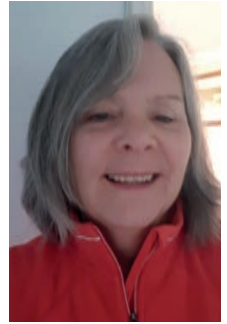
"The PIP form is very big, but I filled it out and emailed it to Ali, who went through it and helped make sure it was worded properly as the PIP assessors don't seem to know anything about cardiomyopathy and assume it's just a heart condition."

Debbie also took Ali's advice to keep a diary, so she could explain exactly how her DCM affects her daily life.

"Because I look normal, people assume I'm okay. They have no idea that I have an CRT-D, or that I need to keep sitting down just getting washed and dressed in the morning."

A delighted Debbie found out just before Christmas that her PIP application had been successful and was able to use the money to help pay for a cleaner.

"My message to others is not to be put off applying, as Cardiomyopathy UK will help you every step of the way."



› Debbie Miller

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.

**Out-of-Hours
Helpline**

0800 018 1024

**For young
people and
parents**

**Alternate
Wednesdays
6 - 9 pm**

**Give our
Paediatric Nurse
Emma a call!**



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