

myLife

The magazine for people affected by
cardiomyopathy and myocarditis

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"There is hope after this diagnosis"



Cardiomyopathy^{UK}
the heart muscle charity

**Read Denise's inspiring
story on pages 12-13**

Contact us

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Welcome



Our theme in this issue is 'A bright future together'.

Earlier in the year this would have seemed an unthinkable idea, but COVID-19 has brought new opportunities along with its tragedy and challenges.

Virtual meet ups including our first digital conference and our online support groups have been empowering, informative and, in the case of the weekly Coffee and Catch Up sessions, fun.

Cardiac clinical services are transformed too and whilst there are some positives, we all need to pull together to ensure that care of Cardiomyopathy patients is protected and improved. Our increased focus on patient advocacy through the 'Cardiomyopathy Change Makers' (pages 20-21) will help to achieve this.

Our finances have been severely stretched, so we are particularly grateful that the National Lottery has provided a grant from The Office for Civil Society, part of the Department for Digital, Culture, Media and Sport (DCMS) towards our helpline costs.

To everyone in #teamcardio who took on 30 Day Home Challenges, organised personal events or birthday fundraisers; and to all those who donated to our appeal - thank you. See pages 10-11 to find out how you can get involved this Christmas.

My final thank you is to our staff team and volunteer leaders on the board or running support groups. They have all shown innovation and resilience in the face of changing knowledge and working demands and a desire to just get the job done.

Roll on 2021 - we are ready.

Alison Fielding, Chair

Front page photo: Denise Harris out cycling, her favourite hobby



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Our Plans for the future

Every three years the charity creates a Three Year Plan. The purpose of this plan is to set measurable objectives for each year with the confidence that everything that we do works towards achieving our vision.

Having a three year plan also helps us to know what resources we are going to need in the future, and how we are going to go about raising funds.

Our current Three Year Plan comes an end this December so we have been speaking to our volunteers, staff, service users and clinicians to make sure everyone's voice is heard.

We will be publishing our plans later in the year but we already know that we will be setting ourselves some big challenges.

We have seen the number of people who use our services increase every year but this is still

a small proportion of the total number of people who could benefit from our help.

We are also aware that in some areas of our work, the people who use our services do not reflect the diversity of the wider community. We want to change this.

Over the next three years we want to be able to support more people from outside the UK and play a part in creating and supporting a worldwide cardiomyopathy community.

We believe that being part of a worldwide community benefits everyone as we can share knowledge and information on a much wider scale.

We want to see more people coming to the charity for support and a better representation of all communities involved in our work.

We will achieve this through increasing our outreach work and making it easier to access



By Joel Rose
Chief Executive of
Cardiomyopathy UK

our services through our website and digital platforms.

Cardiomyopathy UK is unique; there is no other charity like it in the world.

This is why we see a large number of people from outside the UK use our online services.

We want to make sure that we can do this work without any negative impact on the support that we currently provide to our service users in the UK.

The global pandemic has had a considerable effect on the charity.

Income has been impacted due to the limitation imposed on community and challenge events while at the same time we are supporting more people than ever before.

We need to meet the challenge of increasing the income that we can raise. This includes new ways to donate towards the costs of our services.

With these big challenges come some exciting opportunities for the charity to grow and have a positive impact on more people than ever before.

Having seen how well we have worked through the current crisis and how far we have come as a charity, I am confident that with the support of the whole Cardiomyopathy UK family we can realise these opportunities and meet the challenges that we face.





Our Community Support

September 1st 2019 heralded the beginning of an ambitious 5-year Community Peer Support Project funded by the National Lottery Community Fund.

Between September 2019 and September 2020, over 1200 people attended a support group in England alone, against a target of 900 set by the funder.

Similarly, we also reached 270 people via our Telephone Peer Support Network against a target of 250. These impressive stats have been achieved in no small part thanks to our passionate, hard-working and ever-growing volunteer community

As of September 2020 our Telephone Peer Support roster totalled 69 individuals, against an NLCF target of 40.

These figures are impressive given the huge impact that COVID-19 has had on our Peer Support Services. As of March 2020, our support group meetings moved from an in-person to an online format, which has radically transformed the way our service users meet and interact with other members of the cardiomyopathy community.



By Christie Jones,
Peer Community
Support Manager

Switching to an online format has given us the opportunity to develop all-new condition-specific Support Groups; including Emotional Well-Being, Genetics, and ICD Support Groups.

We have also established a weekly Coffee & Catch Up session which focuses on the emotional benefits of light-hearted, social interaction within the Cardiomyopathy UK community.

By chatting about anything from pork scratchings to interstellar travel, we've succeeded in providing respite during a turbulent and stress-inducing period of time.

We're so impressed by the success of our online support group meetings that we plan to continue them into 2021 and beyond.

Moving forward, our regional support groups will alternate between in-person and online meetings, allowing those unable to travel to in-person meetings to benefit from our Peer Support Services.

Online meetings also allow anonymity – for example, if you want to attend a meeting just to listen to others, you can turn off your camera and mute your sound.

2020 has given us the opportunity to radically change the way we meet the needs of our service users and I am confident that this will allow us to continue to meet and exceed the ambitious targets we have set for ourselves.

As such, we continue to strive towards establishing 50 active Support Groups, 100 Telephone Peer Support Volunteers, and 20 In-Clinic Services by September 2024.

With a new online training module set to launch before the end of the year, as well as new online support groups such as a Parents Support Group, we have already started to build upon the successes of year 1 of the Community Peer Support Project.

If you'd like to find out more about how Cardiomyopathy UK's Peer Support Services can help you, or to join our Peer Support Volunteer family, email christie.jones@cardiomyopathy.org.



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 been diagnosed with cardiomyopathy and I would really like to speak to someone else with the same heart condition as me, but I don't know anyone else. Could you help me find someone?

Nurse Jayne says: "We have various types of support which we can offer you these are online or via phone at present. We can arrange for you to speak to one of our peer support volunteers someone with the same type of cardiomyopathy of a similar age range.

We have numerous support groups who meet via zoom or you can chat to others at one of our weekly coffee & catch up meetings at 2pm every Friday. Maybe you would like to join in one of our online groups which are focused on living with cardiomyopathy. "

Q. I have cardiomyopathy, what benefits might be entitled to?

Head of Services Ali says: "Having cardiomyopathy does not automatically entitle you to benefits and all benefits have different application criteria.

Some benefits are means tested which means your eligibility is based upon how much money you have in the bank and any assets you might have.

There are benefits available for people who need extra financial support because they are unwell and unable to work such as ESA and non-means tested benefits for people who are unwell such as PIP.

Whether you can successfully claim any benefit is based not only on eligibility criteria but how your cardiomyopathy and affects you daily.

Find out what you might be entitled to using a benefit calculator such as the one at www.entitledto.co.uk or www.turn2us.org.uk"

Q. I am having my first virtual Telephone consultation from my cardiologist since COVID-19: What will it be like? Will it be the same as when I see him in Clinic?

Nurse Caryl says: "Due to the pandemic there will be a change to previous past consultations. There will be a reduction in face to face consultations.

Certain centers will have telephone consultation; others will have "Attend Anywhere" which is a secure NHS video call service for patients with pre-arranged appointment times.

Don't be afraid to voice your concerns if the sound or audio is poor quality as it is still important that you can hear and understand the conversation, ask them to repeat what was said if you did not hear properly.

You will have the opportunity to discuss everything with the consultant as you did in face to face appointments. To get the best out of your appointment make a list of all the things you'd like to ask or tell the doctor before the appointment.

If the consultant feels that after discussion and listening to your symptoms you require a face to face review or ECHO scan, this can be arranged at a later date."

Further information is available on our website (www.cardiomyopathy.org). You can contact our helpline nurses on 0800 018 1024.

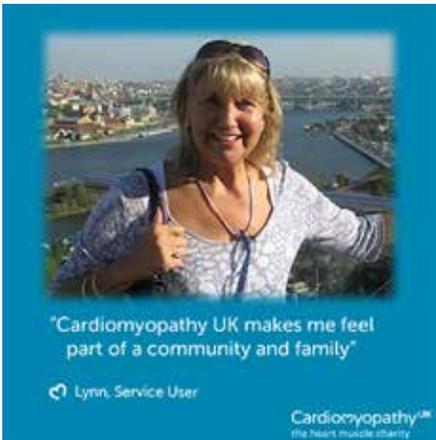
Thank you ... 

We are enormously grateful to you all for supporting our 'Change the world of cardiomyopathy' appeal. Your generous donations of over **£16,200** in single gifts and over **£6470** a year in new, regular gifts helps us to bridge the gap in income due to cancelled fundraising events.



Head of Fundraising Sheila gives an update on our Change the World of Cardiomyopathy Appeal, and the Big Give Christmas Challenge.

Your gift helps give people like Lynn to gain a more positive attitude to the future with their cardiomyopathy and helps improve early diagnosis and treatment.



We'd especially like to thank Professor Perry Elliott for launching the appeal in July in his excellent livestream presentation on 'COVID-19 and Cardiomyopathy' and to the service users who kindly shared their experiences of our services during the pandemic.

We have signed up to the Big Give Christmas Challenge between 1st to 8th December. The challenge is to raise the most we can during this week.

In the spirit of Christmas, why not give to someone else affected through the Big Give Christmas Challenge? Help us be there for everyone.

Every pound donated will be doubled by match funding of up to £7,000 pledged by three of our generous supporters and the Big Give Champion Funders.

The platform is live between 1-8 December and you can donate the Big Give's website

For example, a £20 donation will be doubled to £40 and, if gift aid is claimed, would then be worth £50.

We really appreciate all your fantastic support during this exceptional year.

<https://www.thebiggive.org.uk/s/christmas-challenge>



We have a range of fun and festive ways that you can support us this Christmas!

Spread some joy this December with our fantastically festive Christmas Collection.

With beautiful cards, fabulous wrapping paper and cute gifts, what better way to let your friends and family know you are thinking of them?



Our cosy hoodies will keep you toasty this festive season. At just £22, these red, zip-up hoodies are a great way to keep warm during the winter months whilst showing your support for our charity.

> Visit our online shop at <https://www.cardiomyopathy.org/shop/shop-intro> to see our full Christmas collection and merchandise range.

All proceeds from all sales go towards supporting people affected by cardiomyopathy.



Join in on our 12 Days of Christmas Challenge this festive season, where we will set 12 Christmassy challenges for you and your household to complete.

On December 1st, our first challenge will go live across social media. Each day we will share a new task. Informative, fun or downright silly? You'll have to wait and see!

Suggested entry of £12 donation per household.



Contact our Community Fundraiser, Jaye, on jaye.chassebi@cardiomyopathy.org for more information.

Denise Harris, a semi-retired nurse, was diagnosed in March 2020 with idiopathic dilated cardiomyopathy and heart failure.

"I am writing this to give hope and encouragement. Until March this year I was relatively fit- going cycling, camping and attending Glastonbury Festival (when I could get tickets!).

My symptoms gradually appeared over two months. I experienced shortness of breath, I had a cough and was exhausted. I was admitted to hospital unable to walk up stairs without stopping.

My ejection fraction was 20%, and unfortunately my three month ECHO check showed that my ejection fraction was still only 21%. I was treated with beta blockers, diuretics and initially ACE inhibitors but these have now been stopped and I have recently started Entresto.

It was the biggest shock ever, I was scared and overwhelmed. I was otherwise fit and only 56 with no family history of cardiomyopathy. I knew heart disease could affect all ages, but certainly not someone like me.

Being diagnosed at the beginning of a pandemic added huge stress. There were no cardiac rehab sessions and consultations were done by 'phone. I had to isolate and couldn't see my friends for months.



Denise's Story

There was a lot of uncertainty- my consultant told me to take all precautions as "I had no reserve".

I felt isolated and terrified of getting COVID. I missed work and I wanted to help, but now I had to look after myself and listen to what my body told me. I knew very little about cardiomyopathy and I soon became aware that googling it was not the answer!

I found the information Cardiomyopathy UK sent me extremely helpful, and the articles in "My Life".

< Denise pictured enjoying one of her favourite hobbies, cycling.

I then joined the Facebook group and was really comforted by people's stories from all ages, stages and their different treatments.

When I was told I would probably need an ICD I knew nothing about them but knowing there were other people going through the same as me was so helpful. As a nurse I had always encouraged patients to join in such self-help groups, but had not really appreciated how much you can learn and get from them. The helpline has been invaluable.

Cycling is my hobby and in one of my darkest hours lying in my hospital bed feeling very poorly, I imagined being back on my bike being able to ride 3 miles without being out of breath on Bournemouth seafront. I'm thrilled to say I've managed about 14 miles now!

I decided to help raise money for Cardiomyopathy UK, and I set myself the challenge of cycling 100 miles in August. During August I cycled 221 miles and to date I have raised over £800.



< Denise and her family. Her daughter lives in New Zealand, and following her surgery, she plans to go and visit.

My motto has always been "One life, live it" and this has never been truer. None of us knows what is around the corner, 2020 has showed all of us that.

I have a fantastic husband, family and circle of friends.

There's a long way to go and it has not been easy, but NEVER GIVE UP. Numbers on test results do not always correlate to how you feel and what you can achieve. Good luck to you all; there is hope after this diagnosis."



< Denise at Glastonbury Festival.

Your story matters.



Our media work is all about saving lives.

We are looking for individuals who are happy to share their own story as part of our ongoing media work, to feature on our website and across our social media channels.

Sharing your story helps to inspire other people who have been newly diagnosed, or are living with cardiomyopathy.

If you would like to share your story and your experiences to help others, please get in touch with our Digital Media and Communications Officer Jo Marychurch on media@cardiomyopathy.org



Beating for Two



Our upcoming new awareness campaign will highlight pregnancy related cardiomyopathy, known as Peripartum Cardiomyopathy.

We will be sharing peoples' experiences of how they were diagnosed and how they manage their condition. If you, or someone you know, would like to get involved, please email Jo on the address stated above.

Increasing our research



By Joel Rose,
our Chief
Executive.

In the next few years the charity wants to do more to help develop and support the cardiomyopathy research community. We will do this by providing insight, directing funds and undertaking our own research.

The charity already works to support clinical researchers by providing patient insight into their projects.

Researchers and research funders recognise the value of having people with direct experience of cardiomyopathy contribute to how their research is designed, conducted and disseminated.

In the next few years we hope to do more work in this area as it helps to make sure that research is focused on meeting the real needs of people with Cardiomyopathy.

By engaging with the research community we also make it easier for researchers interested in cardiomyopathy to secure the funding that they need for their work. The charity has also been able to work with other organisations to directly fund research projects.

We are currently working with the Arrhythmogenic Cardiomyopathy Trust to make a grant of £120,000 to ARVC researchers.

In the past we have worked with other organisations to help them better understand the research environment and use their funds in the most effective way.

We will continue to look for opportunities to work in this way in the future.

We have the unique ability to gather information about the real life experiences of people affected by cardiomyopathy and the state of NHS services.

In the last few years we have used this ability to undertake our own research and our findings have already contributed to government reports, shaped policy and driven national awareness campaigns.

Over the next year we want to do more of this type of research and work hard to make sure that our findings can have a real impact.

“There is no doubt that research plays a hugely important part in tackling cardiomyopathy.”

By working in this way to support and develop the cardiomyopathy research community we can have a major impact with our limited resources and play our part in helping people with the condition live a long and fulfilling life.

In Conversation with Professor Perry Elliott



What is currently in the pipeline in terms of medication and the way ahead?

Firstly, current therapies for managing diagnoses are very effective. Pharmaceutical companies are starting to focus on uncommon disorders including cardiomyopathies. There's the new combination drug (Entresto) and we're seeing a lot more patients now switched over from ACE inhibitors.

In recent news, some drugs used to treat diabetes can improve symptoms of heart failure. We're moving towards standardised therapies regarding heart failure with four drugs, including Beta Blockers, Entresto, Spinelactone and possibly the new diabetes drug SGLT2 Inhibitors.

We are focussing more on the biology of these diseases and developing new drugs that target different aspects e.g. Mavacamten for those with HOCM.

Our key questions are: what is the right dose and is this the right therapy? We're also looking to bespoke therapies looking at rare genetic disorders such as laminopathies.

The ultimate goal is to prevent and find a cure.

What about ICD's?

ICD's have helped prevent sudden cardiac death in all cardiomyopathies. We know they have a psychological impact, and the question remains how best to support people when wires in the heart can cause further problems.

Companies are now trying to develop a defibrillator without leads inside the heart, and the biggest advance there is the S-ICD (subcutaneous). The wire runs underneath the skin, alongside the breast bone.

We caught up with our President and leading Cardiologist Professor Perry Elliott to find out about the latest developments in treating cardiomyopathy, and what the future might hold.



Pacemakers are getting smaller. There's a very simple device, the size of a bullet inserted with a catheter inside the heart. It's not possible to get a defibrillator which is that small, but there will be future developments towards miniature devices.

What are your thoughts on genetics/gene testing?

Genetic testing is, in theory, widely available in the UK but there are limited resources and expertise.

As all cardiomyopathies can be inherited, we advise family screening which can be a lifelong process.

If we're able to identify a genetic mutation in the patient, then we can screen other members of the family and rule them out. There are a small group of genes that seem to be associated with a much higher risk of arrhythmia and sudden death. This genetic information is used to make informed decisions for each patient.

How can Cardiomyopathy UK and the wider community help?

All of us need to work together from those who have the condition, the clinicians who care for them, the scientists and industries which create new trials and products.

We need to form a partnership, and Cardiomyopathy UK can act as the coordinator ensuring patients are heard.

What are your hopes for the future?

A cure would be great but, more realistically, prevention is the key.

If we can identify patients who carry the mutated gene and are at risk of developing the disease in the future, wouldn't it be great at that stage to prevent them ever getting sick?

20 years ago it was complete science fiction but now it's all there to potentially achieve that.

Improving Access to Psychological Therapies (IAPT)

While Cardiomyopathy is a physical condition, living with it can have a significant psychological impact on individuals and their families.

As a result, Cardiomyopathy UK ensures that its services are able to support people's emotional, as well as their physical wellbeing. <https://www.cardiomyopathy.org/emotional-health/emotional-health>

IAPT began in 2008 focusing on the large numbers of adults who experience anxiety and depression but who rarely could access psychological support, often referred to as "talking therapy".

All therapists undertake specialist training in the therapies they provide. IAPT matches the therapy to the person's need and can offer both individual and group therapies, as well as support via online programmes.

It is recognised that many people with physical Long Term Conditions, such as Cardiomyopathy, could benefit from accessing IAPT.

There are IAPT services for adults in every part of England, some provided directly by the NHS and some commissioned from other organisations. Last year these were accessed by almost 1 million people.

For details about services in different areas see <https://patient.info/treatment-medication/self-referral/refer-yourself-for-nhs-talking-therapy-counselling#nav-2>

IAPT services for children and young people have been developed by embedding psychological therapies within existing Child and Adolescent Mental Health services.

For information about them see <https://www.england.nhs.uk/wp-content/uploads/2014/12/delvr-with-delvrng-well.pdf>

Psychological therapy services are also available in Scotland, Wales and Northern Ireland but are organised in different ways to IAPT. Referrals would normally be from your GP. <https://portal.babcp.com/Portals/0/Files/About/CBT-Accross-Five-Nationspdf?ver=2020-06-30-143045-483>



Dr Ian McPherson, Clinical Psychologist and Cardiomyopathy UK trustee, shares the importance of getting mental health support when living with a long term condition.

Very clear, good accessible language, empathetic approach. We need more doctors like Dr Carr-White and more resources to give doctors the time to be like this - thank you.

An excellent variety of presentations.
Many thanks for the day.

Cardiomyopathy Conference 2020

80%
Sessions
Rated 5/5

402
Questions
Asked

25
Countries
- Peru,
Iceland,
Russia...

485
Attendees
Live
Streaming

588
First Time
Conference
Attendees

223
Attendee
Networking
Messages



22 Session Recordings Now Free to Watch on YouTube

There was a good choice of options and I found the content relevant and useful. My main motive was to learn more.

Comprehensive presentation with useful tips and advice about how to ensure patient-centred care is at the forefront. Very informative.

Shaping the Future

Cardiomyopathy Change Makers

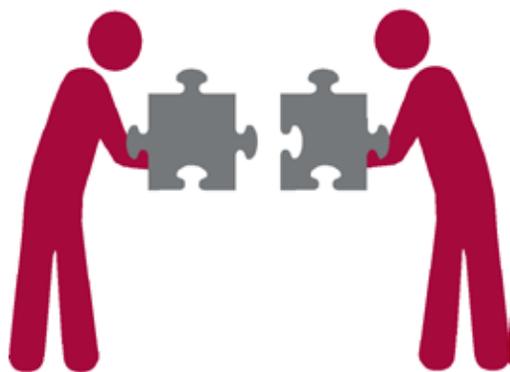


Natalia Bartolome Diez, Policy and Advocacy Manager

Meet Natalia, our new Policy and Advocacy Manager. Here she shares exciting new developments for the charity and our future, and why you we need you to join our community of Change Makers.

“Over the last few years, we have been working with people affected by cardiomyopathy to gather more information about their own diagnosis, treatment and access to genetic testing and care.

Our work highlighted that only 9% of people with cardiomyopathy are receiving ideal care and treatment, and that many patients are not being informed about the potential genetic nature of cardiomyopathy - or being offered genetic testing.



9%

of people with cardiomyopathy are receiving ideal care and treatment.

Earlier this summer we launched our new Policy and Advocacy Project, which aims to identify and address problems in the current care and treatment pathway.

We are recruiting for Cardiomyopathy Change Makers from across the United Kingdom.

This is a brand new volunteering role for the charity, and we hope that by bringing together clinicians and people affected by cardiomyopathy, this will give us a stronger voice to influence key decision makers in healthcare.

We want to make changes to the NHS services that meet your needs. This is a fantastic opportunity to shape the future of cardiomyopathy treatment.

Working with our Change Makers, we will create a Best Practice Policy with our Clinical Advisory Board and our Board of Trustees, which will then be shared with everyone who needs our support.

This is our opportunity to put together a business case that highlights the differences in how cardiomyopathy services are currently delivered across the United Kingdom.

We want to raise awareness and implement necessary change so that whoever needs these services will have access to better care and support.

Have your say or get in touch:
For more information, contact Natalia on natalia.bartolome-diez@cardiomyopathy.org

Could you be a Change Maker?

Share your experiences with us and have your say on how best to shape the future of cardiomyopathy services. Help us to investigate what cardiomyopathy services look like in your local and regional area.

Acting as a representative of the charity, work with us to put together local action plans with realistic and specific goals, so we can improve care and treatment where you are.

Champion the needs of cardiomyopathy patients by giving a different perspective. Get involved and work with expert clinicians to identify opportunities for us to influence change. Help us understand what is working, and what needs to change so that we can learn together.

Cardiomyopathy Change Makers

"New patient voices are always needed so we get a good picture of how services are changing and ideas for the future"

Alison, Head of Trustees

Apply now!

CardiomyopathyUK
the heart muscle charity

Let's work together to increase the 9% to 100%.

#teamcardio

A huge thanks to everyone who undertook a personal challenge for us this year, including The Cronin family for scaling Snowdon and Rhianna for cycling 180km.

To all our #teamcardio runners and cyclists for taking part in the

Prudential MyRide London, the Great North Run Reimagined and the London Marathon 40th race virtual challenge.

Your amazing physical achievements and fundraising have supported the charity through a very difficult time, thank you.



Alyson McShane and Karen Aloe and taking on the huge challenge of virtually scaling Everest!



We are delighted that we managed to walk across the UK for our first ever Collective September Stroll this year, all thanks to our 20 amazing teams that took part from Scotland, Wales and England.

20 teams, including 8 support groups, were able to collectively walk the distance across the UK, raising funds for people with cardiomyopathy and raising awareness for our cause.



We would also like to give a special thanks to Kirsty Gordon-Thomas who organised the staff where she works at Keltie LLP, an intellectual property company, to join in and collectively walk the distance between their four offices (over 800 miles!).

Are you up for a challenge?

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

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Email fundraising@cardiomyopathy.org with enquiries about our events

NEW CHALLENGE ALERT!

Take on the Welsh Three Peaks. It takes in the three peaks of Wales: Snowdon (North), Cadair Idris (mid-wales), and Pen y Fan (South). Not as well known as the National or Yorkshire Three Peaks, but a higher ascent than Yorkshire's peaks, and over less distance. A mountain guide, transport, food and drink is provided.

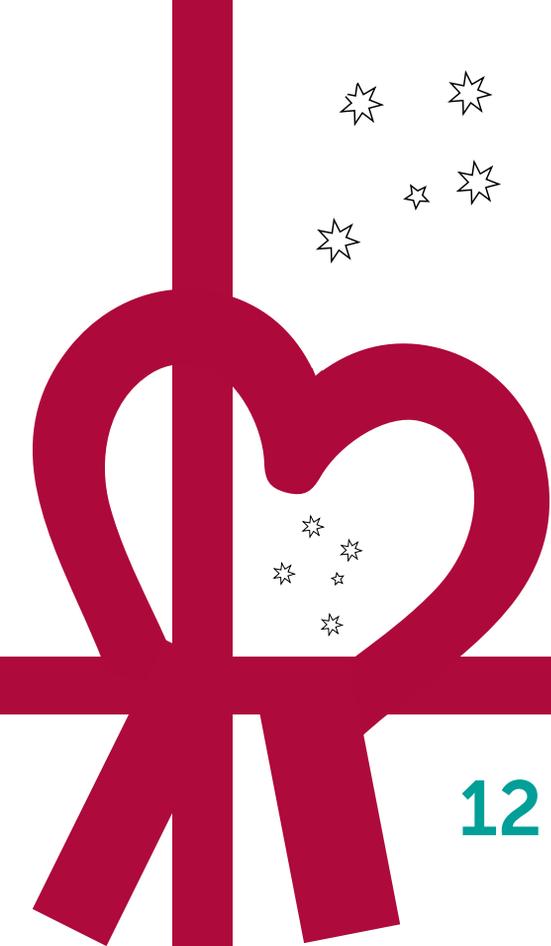
Santa Dash - December 2020

Want to get in the festive spirit early this December?

Do a run of either of 3, 5 or 10km from your home, wearing a Santa hat, or full costume! Join in the fun and bring festive cheer to our charity service users by fundraising £100. Ho, Ho, Ho!

2021 Challenge Events Schedule

- February ● Brighton Half-Marathon & 10k
- March ● London Vitality Big Half Marathon
- April ● Tough Mudder, Paris Marathon, London to Paris Bike Ride, Skydive
- May ● Tough Mudder, Skydive, Welsh Three Peaks, Edinburgh Marathon
- June ● Tough Mudder, Three Peaks Challenges
- July ● Tough Mudder, Welsh Three Peaks
- August ● Prudential Ride London, National Three Peaks
- September ● Great North Run, September Stroll, National Three Peaks
- October ● London Marathon, Cardiff and Bournemouth Half Marathons, 5K/10K



**The 12 Days
of Christmas
Challenge!**

12 challenges



£12 donation per household

Can you complete them all?



**See Page
11 for full
details!**

Cardiomyopathy^{UK}
the heart muscle charity