

Cardiomyopathy<sup>UK</sup>  
the heart muscle charity

# Annual Report

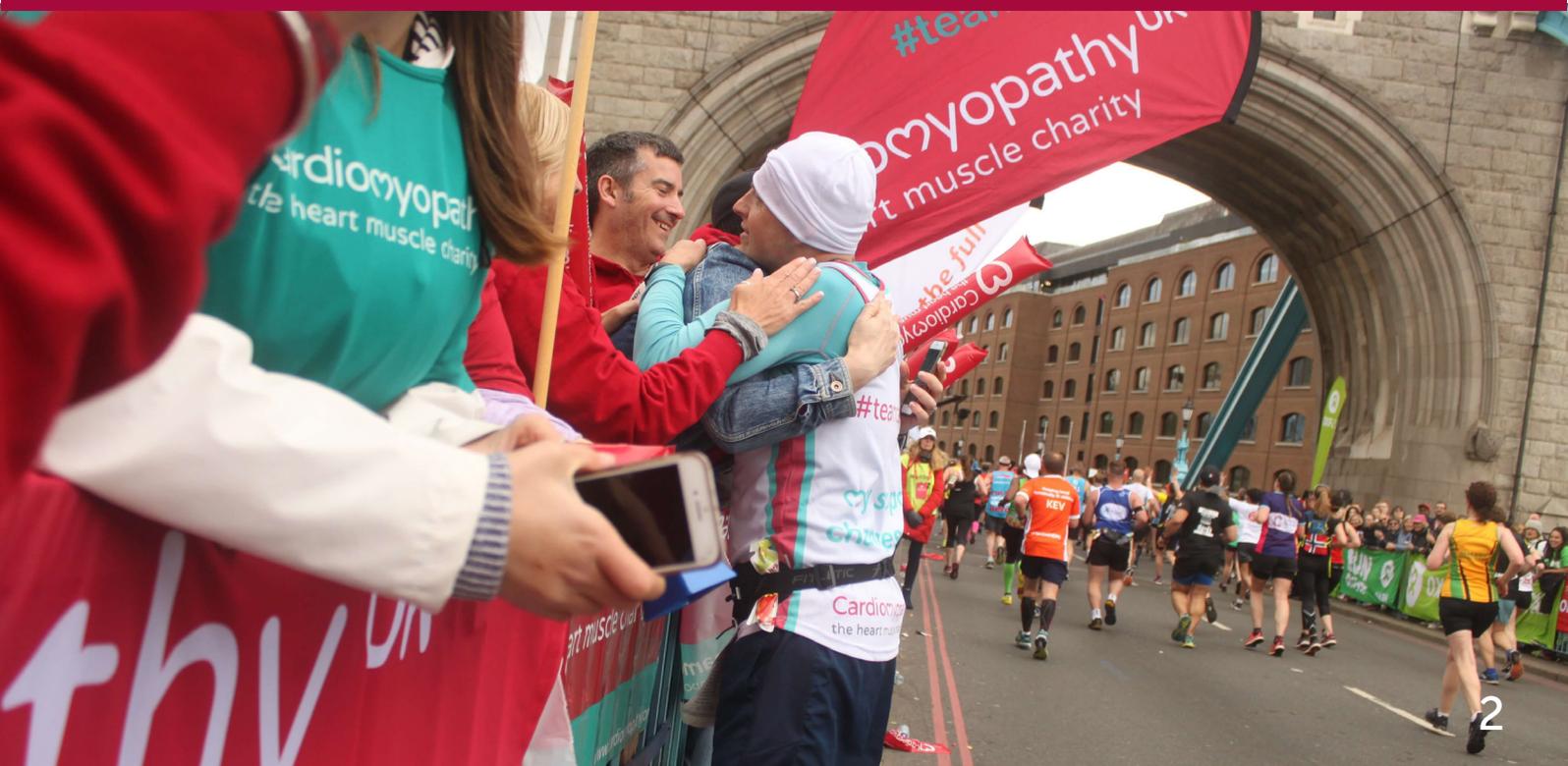
The difference we made in 2021



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# We're Cardiomyopathy UK.

We save and improve the lives of people affected by cardiomyopathy. Our vision is a world where everyone affected by cardiomyopathy should live a long and fulfilling life. In pursuit of this vision:



We raise awareness of the condition so that more people know the signs and symptoms and can be diagnosed early.



We campaign to improve access to quality treatment that meets the needs of people with cardiomyopathy.



We promote clinical research to advance the development of new treatments and provide hope for the future.



We support people affected by cardiomyopathy, every step of the way, so that nobody has to face cardiomyopathy alone.

**1 in 250** people have cardiomyopathy. That's approximately 266,000 people in the UK currently living with the condition.



# A Message From Our Chair

**A**s I look back over the last year, I'd like to first thank **Cardiomyopathy UK's team of dedicated staff, volunteers, and healthcare partners. Together we have ensured that individuals and families affected by cardiomyopathy receive the advice and support needed for them to cope and move forward in times of vulnerability, uncertainty, and concern; especially regarding COVID-19 and the potential impact on our clinically vulnerable people.**



With remote meetings replacing face-to-face consultations and clinics, the demand for our services greatly increased. With the magic of Zoom we were able to ensure all meetings not only continued but were increased.

The theme for our conference in October was "Resilience". We are right to be proud as we reflect on our achievements during the past year. The annual report demonstrates not only our ability to manage change and challenges but also highlights how we have moved forward in the face of adversity.

The expansion of our research and policy work, including the recruitment of our first Head of Research and Policy, is key to raising the profile of the charity and cardiomyopathy within medical and healthcare environments. By developing policies and conducting research, we can have an even greater impact on improving the care and quality-of-life relating to all aspects of cardiomyopathies and myocarditis.

Particularly pleasing is ending the year in good financial shape. Most of the charity's income comes from our community. We are blessed to

have the continued support of our committed fundraisers who participate in a variety of events and challenges throughout the year, usually in support of a loved one affected by cardiomyopathy or myocarditis. Our grateful thanks go out to every one of them for their support.

A special highlight during the year was our ex-chair and Vice President; Alison Fielding, being awarded a British Empire Medal in the Queen's Birthday Honours, for her services to cardiomyopathy. Alison is a true advocate for the charity. Through managing her own ill-health experiences, Alison ably represents the patient's voice.

As we move forward, we plan to build on this year's success and will continue to provide the tools, strategies, and support that will help those with cardiomyopathy or myocarditis and their families to understand and cope with their condition.

A handwritten signature in black ink that reads "Rita".

**Rita Sutton,  
Chair of the Board of Trustees**



“ When I heard there wasn't a support group in the Bristol area, but there were people looking to join, I put myself forwards to set up a group. This group has been a great source of support and knowledge for me, and I have been enriched by working with a group of such inspiring people.

Tony Hampson, Support Group Leader



# Achievements in 2021

Providing Support and Information



## Our Helpline

In 2021, as the pandemic continued to impact people's lives, our helpline provided support to those concerned about how COVID-19 could affect them and where people with cardiomyopathy fitted into the government's classifications of vulnerabilities.

As the year progressed, the number of COVID-19 related questions began to decrease, and these questions moved away from clinical concerns, focussing more on the emotional and practical impact of living with cardiomyopathy during the pandemic. We're proud that we were able to help our community through these concerns on the helpline, and that helpline satisfaction levels remained high with 98% of callers feeling they had gained a better understanding of their condition after speaking to one of our support nurses.

In 2021 we also saw an increase in the number of people coming to us for support after experiencing difficulties accessing Personal Independence Payment (PIP) benefits. During the year, we supported 188 people to successfully appeal their negative PIP assessment outcomes by helping assessors to understand the condition and its impact. We are now considering how this support could be extended to help more people.



calls were made to the helpline.



98%

of people who called our helpline felt they had gained a better understanding of their condition after speaking to one of our nurses.

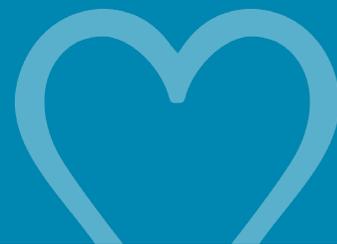
89%



of callers felt like they were ready to take the next step after speaking to a nurse.

# Achievements in 2021

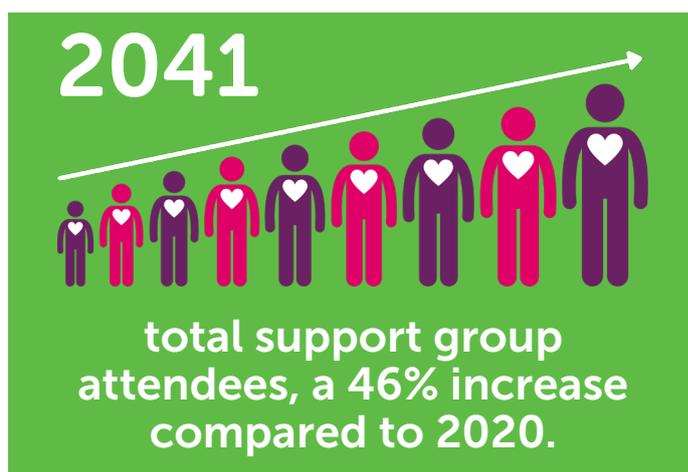
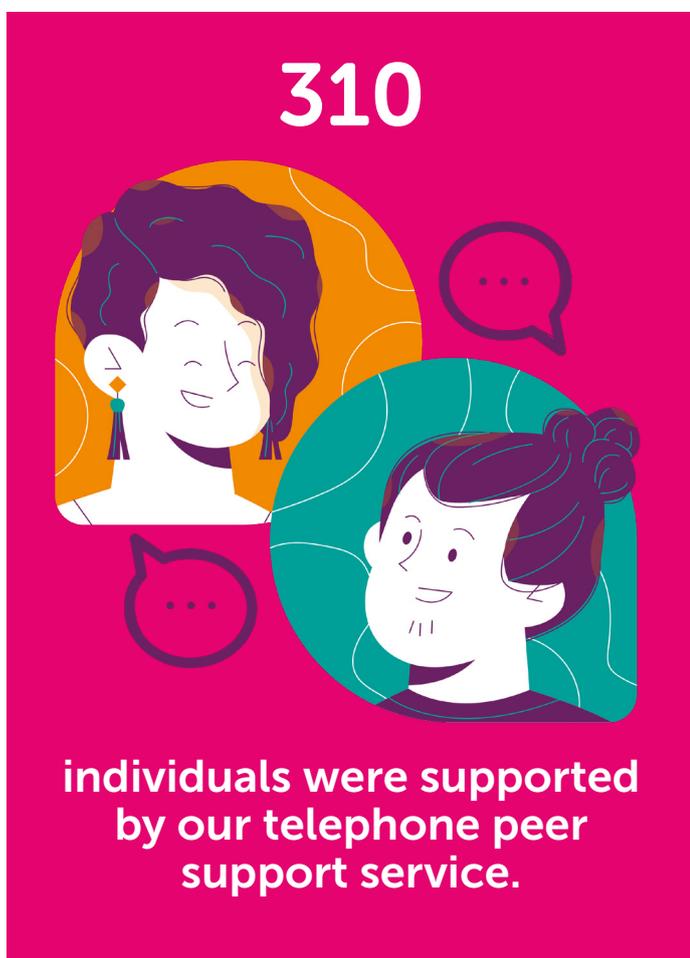
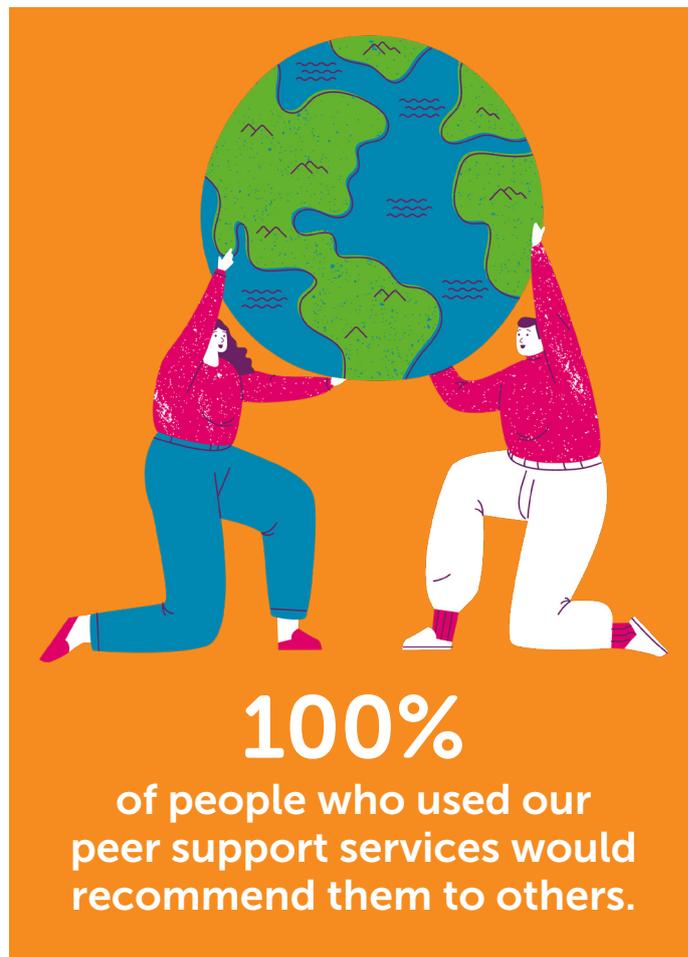
Providing Support and Information



## Peer Support

Our peer support work continued to flourish in 2021 with the support group network and peer support volunteers providing vital support online and over the phone. Overall, support group attendance continued to grow, and we achieved our targets for the peer support project funded by the National Lottery Community Fund.

Unfortunately, the ongoing pandemic meant that it was not possible to provide in-clinic peer support this year. We still aim to provide this important service as soon as it is possible in an NHS setting.



# Achievements in 2021

## Providing Support and Information



### Information

2021 also saw the launch of our new website, which has been designed to make it easier for visitors to access the information they need and discover the range of support services available to them. The importance of digital and accessible health information and support has been growing for some time, and never more so than in the past two years when face-to-face services have been cut. It was fitting therefore, that we launched our new website in 2021. Our hope is that the new site enables people affected by cardiomyopathy to easily access a range of reliable, clear and accurate information when they need it. We were delighted to receive positive feedback on the new website from our community, with users finding it easier to navigate and access information and services.

### Our Annual Conference

In October, we held our national conference online once again, ensuring the event was safe and accessible amidst pandemic restrictions. We provided a diverse and inspiring programme of talks aimed at helping our community to improve their understanding of cardiomyopathy and feel better able to cope with their condition day-to-day. Feedback from the conference was overwhelmingly positive and, as with the previous year, the online

format meant that many people who were previously unable to attend face-to-face events were able to join us online.



# Achievements in 2021

## Improving Diagnosis and Access to Treatment



### Change Makers

At the close of 2020 we launched our Change Maker project which brings together volunteers trained to advocate for better cardiomyopathy services in their local NHS organisations. During 2021, this project continued to grow with 20 active volunteers making real and impactful changes locally that will benefit the wider cardiomyopathy community. Our Change Makers have continued to raise the needs of people with cardiomyopathy in their area in accordance with our Change Agenda, a 16-point plan which outlines what people with cardiomyopathy want at all stages of their healthcare pathway.

### MedEd

We were delighted to launch our online medical education platform, MedEd. We created MedEd to increase the knowledge of cardiomyopathy and related disorders amongst healthcare professionals, consequently improving their ability to diagnose and treat the condition. The platform was launched with two live courses focused on the most common forms of cardiomyopathy: dilated cardiomyopathy and hypertrophic cardiomyopathy.

The courses have been created in collaboration with globally renowned experts in cardiomyopathy and offer 15 hours of CPD-certified learning.

Within the courses, healthcare professionals can access over 1,000 clinical images and diagrams, patient experience videos and expert videos to expand their clinical knowledge.

Following the launch, we have begun promoting MedEd to the clinical community at conferences and through our relationships with cardiology centres and networks across the UK. Since launching in October, we're delighted that 93 clinicians have registered with MedEd.

1000+  
clinical  
images,  
diagrams  
and videos.



93 clinicians  
have  
registered  
with MedEd.

15 hours of  
CPD-  
certified  
learning.



# Achievements in 2021

## Improving Diagnosis and Access to Treatment



### Research

Cardiomyopathy UK is uniquely placed to play an important role in supporting and shaping research projects for the benefit of our community by providing patient insight to researchers. In 2021, we participated as co-researchers in the CRUCIAL project looking at the connection between heart failure and cognitive function. We also provided insight to a number of clinical researchers to help them develop research projects that matter for the cardiomyopathy community. These projects included studies investigating the difference between male and female hearts, when medication can be stopped in dilated cardiomyopathy and genetic cures for cardiomyopathy. We also conducted our own research to understand how people with cardiomyopathy felt about remote appointments compared to face-to-face care. We shared the findings of this work with clinicians and NHS service managers so that they were better able to design their cardiomyopathy services during the pandemic.

### Collaborating With Partners

In 2021, we continued our work as an active member of The Alliance for Heart Failure and The Heart and Circulatory Disease Network. These coalitions of clinicians and heart disease charities work together to

raise awareness of the importance of the diagnosis of heart conditions in primary care and in particular advocate for improved access to and greater use of diagnostic testing. In December 2021, the Cardiomyopathy Council was officially launched. This group, chaired by our Chief Executive, Joel Rose, is part of the international Global Heart Hub, a charity that brings together the leaders of nine cardiomyopathy charities around the world.



respondents fed into to the CureHeart research survey.

71%



of people who took part in our survey felt they were missing out with face to face appointments.

# Achievements in 2021

## Improving Diagnosis and Access to Treatment

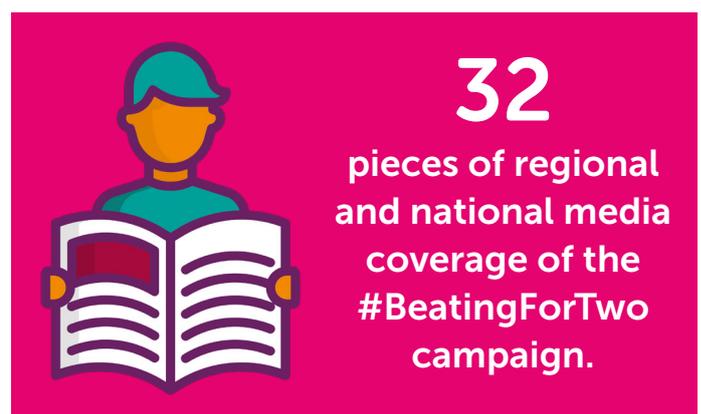
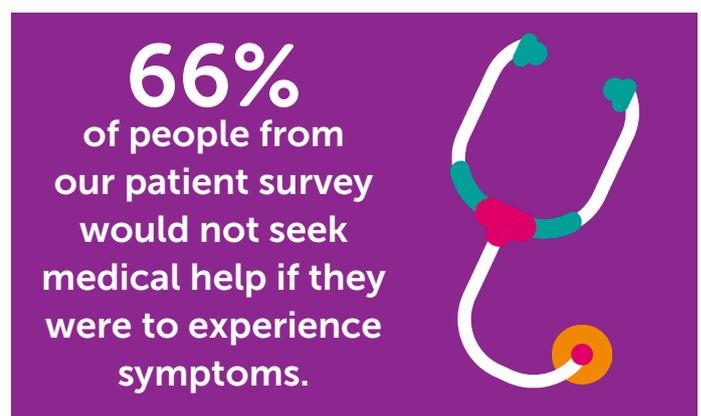
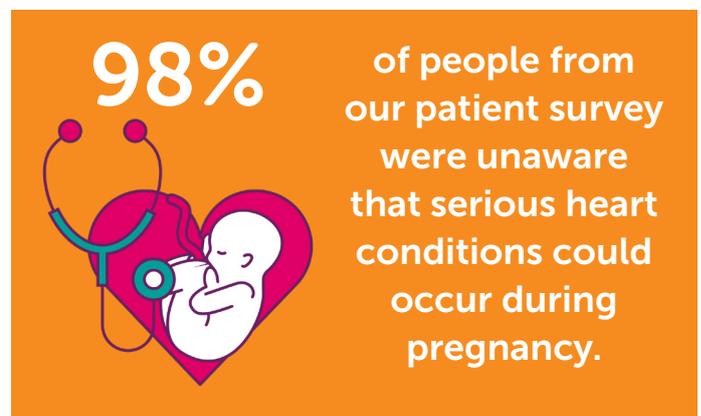


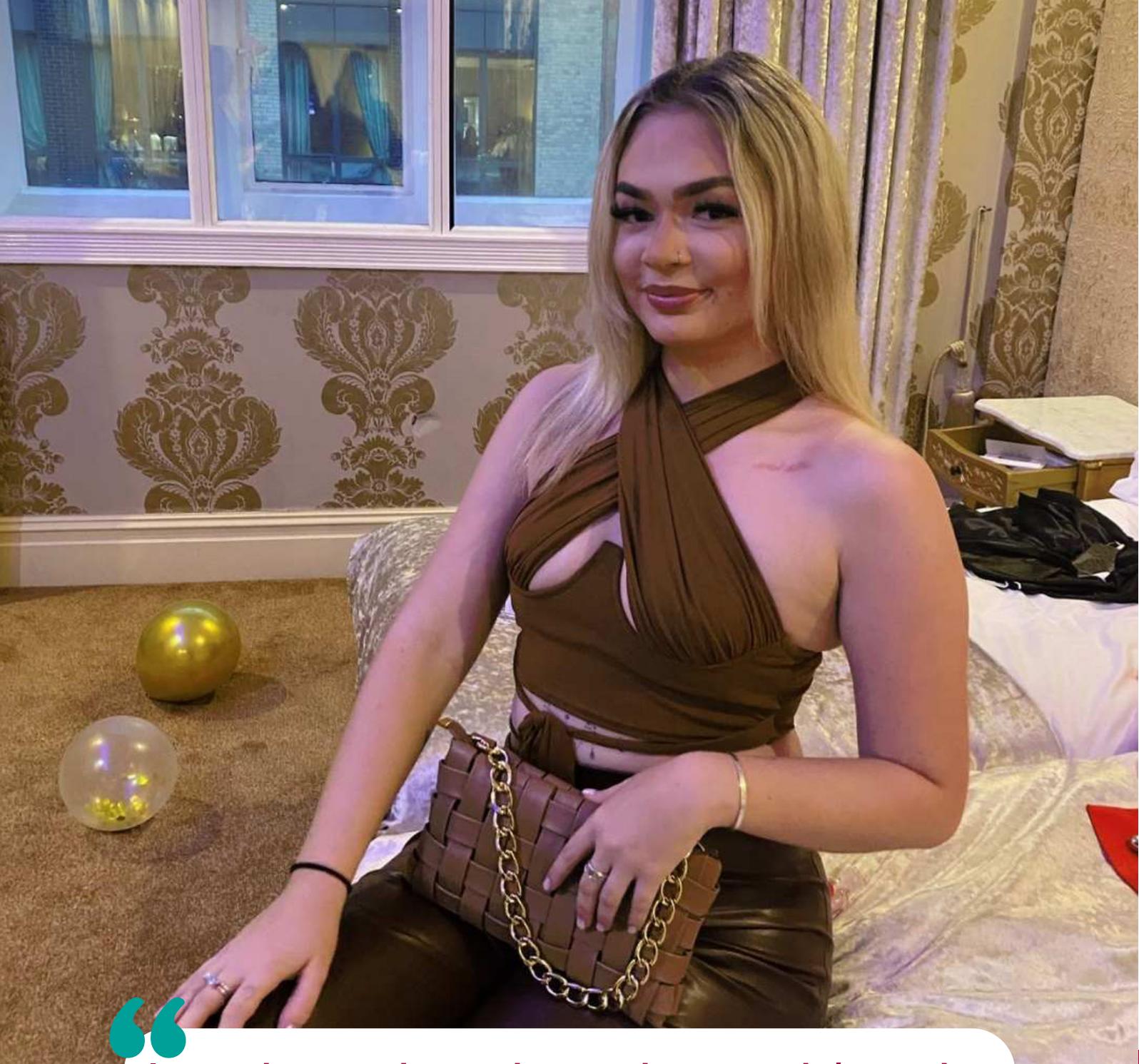
### Raising Awareness

When cardiomyopathy goes undiagnosed, it can cost lives. We know that raising awareness can change that. We'd like to thank everyone who shared their cardiomyopathy story in 2021, helping us to share real-life experiences, raise awareness of signs and symptoms and help people affected by cardiomyopathy to feel less isolated.

In February 2021 we launched a nationwide campaign called '#BeatingForTwo' to raise awareness of peripartum cardiomyopathy, a form of cardiomyopathy that can occur towards the end of pregnancy and the following months. Our research showed that the signs and symptoms of peripartum cardiomyopathy are very often dismissed as being normal during pregnancy or as a new mother. For this reason, our campaign focused on what was "normal" and "not normal" during pregnancy and the months afterwards.

The campaign was developed with support from women who kindly shared their experience of peripartum cardiomyopathy and a clinical team. The campaign was also supported by the Chief and Deputy Chief Midwife for England and Wales.





“It was interesting to hear other people’s stories as I thought I was one of the only few young people with the condition, but I saw there were a lot. Being able to hear other people’s stories has helped me a lot. In the hospital I was always in cardiac wards with elderly people which made me feel very out of place.”

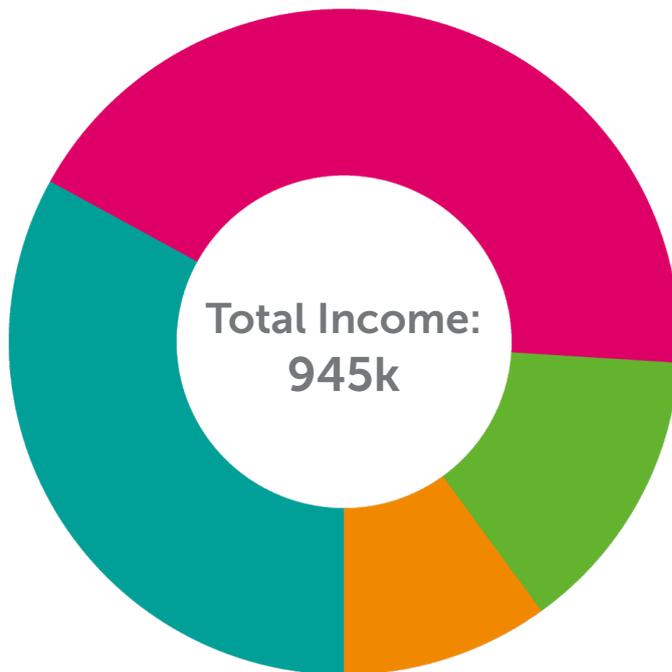
Lucy, Speaking From The Heart

# Funding Our Work

## Income and Expenditure



### Income:



Community and  
Challenge Events  
**33%**

Companies and Trusts  
**43%**

Donations  
**14%**

Legacies  
**10%**

### Expenditure:

Providing Support  
**35%**

Raising Funds  
**31%**

Research  
**10%**

Public and Professional  
Education  
**10%**

Governance and  
Administration  
**9%**

Campaigning  
**5%**



Total Expenditure:  
901k

# Funding Our Work



## Fundraising in 2021

Like many, we entered 2021 with hope that the social restrictions of the pandemic were largely behind us. We had hoped that large fundraising events would be possible by the spring, but unfortunately, events continued to be cancelled or postponed until the late summer and autumn.

Despite these challenges, we continued to be inspired by the creativity and determination of our community as they found imaginative ways to raise funds during pandemic restrictions. One supporter baked every day for a month as part of 30-Day Challenge event, another held a livestream DJ set and another did a mobile car wash in their local area. We saw larger community fundraising events gradually return from the late summer months with golf days and cricket events taking place.

The return of the London Marathon, our largest single fundraising event of the year, in October was a highlight. We were delighted to see our amazing #TeamCardio finally have their day on the iconic 26-mile course and were honoured to meet runners and their families at our post-race event. Having not been able to meet and thank any of our wonderful supporters in-person for the past 18 months, the day felt even more special. A huge thank you goes to our 46 runners who raised over £116,00 - a significant contribution to our successful end to the year of fundraising in 2021.

In addition, over 100 people fundraised for us on Facebook and Instagram, raising over £16,000 in celebration of birthdays, weddings and anniversaries. We also received just over £48,000 in donations made in memory of loved ones raised through funeral collections, tribute funds and memorial events.

Although the first half of 2021 continued to be a challenging fundraising environment, thanks to continued support from our funders and the return of community and challenge events in the latter half of the year, we were delighted to finish our financial year in December in a positive position with an income total of £945,478.



**£116,000+**  
was raised by  
the 46 runners  
who took part  
in the London  
Marathon.



**Over £6,000**  
was raised by the 10 very brave  
fundraisers that took on a skydive.



## Fundraising Responsibly

We are committed to raising funds in a responsible and sustainable way. Our fundraising is conducted either directly by our fundraising staff team or by volunteer fundraisers under their support and guidance. We do not use the services of third-party professional fundraisers or fundraising companies. We work to ensure that our fundraising activity meets the best practice standards laid out by the Charity Commission and the Fundraising Regulator and in 2021 we received no complaints regarding our fundraising activity. The charity also meets all GDPR regulations and has signed up to the Fundraising Preference Service. The Fundraising Preference Service's purpose is to guard against unreasonable intrusion on privacy, unreasonable persistent approaches for donations or placing undue pressure on a person to give money or other property.

## Thank you

We would like to take this opportunity to thank our community for their support during another challenging year. Together, we met these challenges head-on to ensure that we continued to deliver for our community. Thanks to the dedication and commitment of our volunteers, fundraisers, donors and funders we were able to remain a source of

support and information that our community could count on during these most uncertain times.

## In 2021 we were grateful for new and continued support from:

The National Lottery Community Fund, BBC Children In Need, The Garfield Weston Foundation, The Edward Gostling Foundation (formerly The ACT Foundation), Max's Foundation, The Edith Florence Spencer Memorial Trust, Browns Solicitors and the CAF Resilience Fund.





“ My world was flipped upside down when I was told I was in heart failure – my heart was failing me. Over time, I began getting back into walking and eventually got my steps up. I wanted to make something positive come out of my experience, so I decided to set myself a challenge to walk 10,000 steps a day. To some people, this is not a challenge, but when you come from not being able to walk up the stairs to be able to walk 5km in one go, it’s a big deal. It’s been amazing to give back to Cardiomyopathy UK.

Jodie, Fundraising Superstar



# Ambitions for 2022



## Providing Support and Information

In 2020 we saw an increase in the number of people using our services. Although this trend has continued in 2021, we recognise that the number of people that we help still represents a small proportion of the total number of people who could benefit from our services. We want to do more to increase the accessibility of our services so that a wider range of individuals feel that they can benefit from our support and feel welcome in our community. In 2022 we will be establishing an outreach committee tasked with taking a broad view of all the ways that we support people affected by cardiomyopathy and making practical suggestions for how we can improve accessibility.

There is no doubt that the pandemic has had a transformational impact on the NHS, our charity and the people we support. As the pandemic starts to abate, the time is right for the charity to look at its portfolio of support

and information services and assess if they are still meeting the needs of people affected by cardiomyopathy, what adaptations, if any, are needed, and whether there are new or unmet needs that we may be able to meet. In 2022 we will be reviewing our services and gathering feedback from stakeholders to ensure that we continue to meet needs in the new “post-pandemic” world. At the same time, we will continue to grow our youth activity and expand our peer support services.

Like many, we had expected and hoped that COVID restrictions would ease fairly early on in 2021, but sadly this was not the case. However, we are hopeful that we will see a return to in-person support groups and that peer support volunteers will be able to return to hospitals in 2022. We are also excited about the possibility of once again running an in-person national conference.

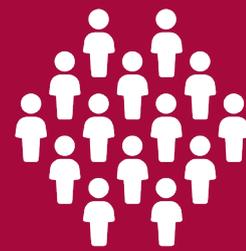
## In 2022 We Plan To...



**Do more outreach to increase accessibility to our services.**



**Review our services to ensure we meet the needs of our community.**



**See a return to in-person support groups and peer support services.**

# Ambitions for 2022



## Improving Diagnosis & Access to Quality Treatment

At the end of 2021, trustees decided that the time was right to invest in our research and policy activity through the recruitment of a new Head of Research and Policy. This new member of the Senior Management Team will be responsible for developing our research infrastructure so that we are better able to provide patient insight to clinical research projects and undertake our own social research to direct and underpin policy activity.

In 2022 we plan to further grow our Change Maker project by welcoming new volunteer Change Makers to the team and working to ensure that existing volunteers have the support, information and training that they need to successfully advocate for meaningful change in their local NHS organisations.

We are excited by the news that the first ever treatments designed for people with cardiomyopathy are likely to begin the drug approval process in 2022. One of these is the drug, mavacamten, which will begin its review in late 2022.

As an important stakeholder, we are ready to play our part in providing meaningful evidence and feedback from people with lived experience of cardiomyopathy to the National Institute of Health and Care Excellence (NICE), the body that determines the availability of treatments on the NHS.

In 2022, we will also aim to build on the initial success of MedEd, with three new modules covering genetics, arrhythmogenic cardiomyopathy (ARVC) and a "Hidden in Heart failure" unit to help clinicians understand the importance of providing a full diagnosis.

In 2022, we will continue to play our part in national initiatives such as the Alliance for Heart Failure, and the Heart and Circulatory Disease Network; working collaboratively with other relevant organisations to improve care and treatment for people with cardiomyopathy. In 2022, we will continue to lead the Cardiomyopathy Council and seek further opportunities to collaborate with members of the worldwide cardiomyopathy community.

### In 2022 We Plan To...



**Grow our Change Maker project.**

**Continue to provide patient feedback.**



**Add new modules to MedEd.**

# Ambitions for 2022



## Raising Awareness

A person with cardiomyopathy who has not been treated is at greater risk of experiencing a cardiac arrest. That's why one of our strategic goals is to get more people to seek medical help. To do this we need to raise public awareness of cardiomyopathy and its signs and symptoms. However, to truly have an impact, we need to raise awareness across the full spectrum of our population. To only reach a narrow segment of the population is simply not enough.

In 2022, extending our reach beyond the most common groups and audiences will be one of our key areas of focus. Through a digital awareness campaign, we will reach out to communities to whom our services may have been or appeared previously inaccessible.

We have identified that people with cardiomyopathy from BAME communities and people with lower health literacy are underrepresented and under-supported in our work. Therefore, these are two groups which we will do more to support and engage in 2022.

## In 2022 We Plan To...



**Raise awareness of cardiomyopathy, the signs and symptoms.**



**Launch a digital awareness campaign to extend our reach.**



**Do more to support communities that are underrepresented.**



“ My brother, Alex, a.k.a. Scouse, had the greatest group of friends a man could ask for and they have done everything possible to honour his name and make sure that he didn't pass away in vain. When I heard that they were running for Cardiomyopathy UK I really wanted to get on board to raise money and to show Alex that I miss him dearly. ”

Gareth, Team Scouse  
Our London Marathon Super Team



## Structure, Management and Governance

The charity is controlled by its governing document and constitutes a charitable incorporated organisation. The charity is governed by its constitution adopted on 5 November 2015.

The charity continues to review and, where necessary, improve its trustee induction and training resources to ensure that new trustees are equipped to support the work of the charity to their maximum ability.

Appropriate policies and procedures have been put in place to ensure good governance including financial management, data protection and employment practice. Trustees maintain a risk register and work with the Chief Executive to ensure that strategies are in place to mitigate against identified risks.

In 2021, Trustees continued to work in accordance with the charity's three-year plan for the years 2021 to 2023. This plan was developed in 2020 with input from staff, clinicians and the wider cardiomyopathy community and is available on the Cardiomyopathy UK website.

Alison Fielding, the Chair for the previous 5 years stepped down at the start of the year and the Trustees were pleased to welcome Rita Sutton as

their chair. During the year the charity took occupation of its new premises in Amersham.

## Financial Review

Trustees are proud to report that despite the huge challenges faced by all in 2021, the charity was able to strengthen its financial position and rebound from the fall in income experienced in 2020 due to COVID-19 restrictions. This was achieved by the charity being able to increase unrestricted income from the community and challenge event fundraising, thanks in a large part to the London Marathon team, while at the same time continuing to build its restricted funding income.

Trustees note that the key financial challenge for 2022 will be for the charity to maintain levels of restricted income while at the same time returning unrestricted income to "pre-pandemic" levels. Trustees are hopeful that this can be achieved especially as the charity's network of supporters, fundraising volunteers and challenge eventers remain engaged with the charity and ready to continue their fundraising activities as soon as it is safe to do so.



## Related Parties

The charity works closely with expert clinicians from a number of NHS Trusts to help ensure that its work is clinically appropriate and that it is able to reach as many people with cardiomyopathy as possible.

During the year the charity continued to work with its President, Prof. Perry Elliott to develop the International Cardiomyopathy Network (ICoN), a registered UK Charity. The charity's Chief Executive provided strategic advice and patient insight to ICoN as part of a shared commitment to improving the level of cardiomyopathy knowledge among clinicians, developing best practice and fostering research that will make a real difference to the lives of people with the condition. The charity has a positive relationship with The British Heart Foundation, The Pumping Marvellous Foundation and a number of other charities that provide support and information relating to heart diseases. Where possible, the charity works in collaboration with these charities.

During 2021 the charity received funding from six pharmaceutical companies (Sanofi, Pfizer, Alnylam, Novartis, AstraZeneca and Bristol Myers Squibb) who have developed or who are developing treatments used by people with cardiomyopathy. The total income from these companies was £129,806; under 14% of the charity's total income. Income from

these sources covered the costs associated with the charity's medical education project, advocacy project, awareness raising and service delivery work. All funding was provided in accordance with the Association of British Pharmaceutical Industry code of practice and the charity's own policy on working with the pharmaceutical industry which is available at [www.cardiomyopathy.org/about-us/our-approach](http://www.cardiomyopathy.org/about-us/our-approach). This policy is designed to ensure the charity's independence.

## Reserve Policy

The charity aims to maintain unrestricted reserves at a level that equates to around six to nine months of normal unrestricted expenditure. Trustees believe this to be a prudent amount given that the charity operates in a competitive environment and, as the leading specialist provider of support services for people affected by cardiomyopathy, there is a duty to ensure that it can maintain core services for individuals in need.

## Public Benefit

Cardiomyopathy UK confirms that in setting its programme of support, it has had due regard to the Charity Commission's general guidance on public benefit. The programme of support also conforms to the charity's charitable objectives and aims. No persons are excluded from the work of the charity on grounds of gender, race or religion.

# Trustees Report

## Reference and Administrative Details



### Board of Trustees:

- A Fielding (Resigned Chair February 2021)
- T Amiss
- G Favier
- C Horwood
- S Kirkham
- I McPherson OBE
- E Jarman (Appointed February 2021)
- E Power
- A Smith
- R Sutton (Appointed Chair February 2021)
- T Bueser
- A Tickell (Resigned June 2021)
- P Thomas (Treasurer)

### Chief Executive Officer:

Mr J Rose

### Charity Number:

1164263

### Principal Address:

75A Woodside Road  
Amersham  
Buckinghamshire  
HP6 6AA

### Bankers:

CafCash Limited  
Kings Hill  
West Malling  
Kent  
ME19 4TA

### Auditors:

Seymour Taylor Limited Statutory  
Auditors  
57 London Road  
High Wycombe  
Buckinghamshire  
HP11 1BS

Lloyds  
82 High Street  
Rickmansworth  
Hertfordshire  
WD3 1AG

# Trustees Report

## Statement of Trustees' Responsibility



The trustees are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on:

and signed on its behalf by:

Rita Sutton, Chair of Trustees

# Independant Auditor's Report



## Opinion

We have audited the financial statements of Cardiomyopathy UK (the 'charity') for the year ended 31 December 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

## Basis For Opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit

of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions Related To Going Concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

## Other Information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

## Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for

such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

## Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- The information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

## Our responsibilities for the audit of financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Identifying and assessing potential risks related to irregularities

In identifying and assessing risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

- results of our enquiries of management about their own identification and assessment of the risks of irregularities;
- any matters we identified having obtained and reviewed the charity's documentation of their policies and

- procedures relating to: - identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of noncompliance; - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud; - the internal controls established to mitigate risks of fraud or non-compliance with laws and regulations;
- the matters discussed among the audit engagement team regarding how and where fraud might occur in the financial statements and any potential indicators of fraud.

As a result of these procedures, we considered the opportunities and incentives that may exist within the organisation for fraud. In common with all audits under ISAs (UK), we are also required to perform specific procedures to respond to the risk of management override.

We also obtained an understanding of the legal and regulatory frameworks that the charity operates in, focusing on provisions of those laws and regulations that had a direct effect on the determination of material amounts and disclosures in the financial statements. The key laws and regulations we considered in this context included the UK Charities Act and local tax legislation.

In addition, we considered provisions of other laws and regulations that do not have a direct effect on the financial statements but compliance with which may be fundamental to the charity's ability to operate.

## Audit Response to Risks Identified

As a result of performing the above, our procedures to respond to risks identified included the following:

- reviewing the financial statement disclosures and testing to supporting documentation to assess compliance with provisions of relevant laws and regulations described as having a direct effect on the financial statements;
- enquiring of management concerning actual and potential litigation and claims;
- performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud;
- reading minutes of meetings of those charged with governance; and
- in addressing the risk of fraud through management override of controls, testing the appropriateness of journal entries and other adjustments; assessing whether the judgements made in making accounting estimates are indicative of a potential bias; and evaluating the rationale of any significant transactions that are unusual or outside the normal course of business.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to any indications of fraud or noncompliance with laws

and regulations throughout the audit. A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our Report of the Independent Auditors.

## Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Seymour Taylor Limited,  
Statutory Auditor  
57 London Road  
High Wycombe  
Buckinghamshire  
HP11 1BS

Date: .....

**CARDIOMYOPATHY UK**

**STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 DECEMBER 2021**

	Notes	Unrestricted funds £	Restricted funds £	31.12.21 Total funds £	31.12.20 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	553,435	262,237	815,672	749,555
<b>Charitable activities</b>					
Providing support	4	-	21,100	21,100	21,100
Public and medical education		-	48,800	48,800	-
Research		-	59,906	59,906	-
Investment income	3	-	-	-	1,174
<b>Total</b>		<u>553,435</u>	<u>392,043</u>	<u>945,478</u>	<u>771,829</u>
<b>EXPENDITURE ON</b>					
Raising funds	5	276,593	-	276,593	271,179
<b>Charitable activities</b>					
Providing support	6	75,351	243,449	318,800	319,348
Public and medical education		46,439	46,787	93,226	72,674
Campaigning		21,887	19,947	41,834	48,049
Research		12,236	81,882	94,118	17,184
Other		60,110	16,569	76,679	64,927
<b>Total</b>		<u>492,616</u>	<u>408,634</u>	<u>901,250</u>	<u>793,361</u>
<b>NET INCOME/(EXPENDITURE)</b>		<u>60,819</u>	<u>(16,591)</u>	<u>44,228</u>	<u>(21,532)</u>
<b>Transfers between funds</b>	16	<u>1,891</u>	<u>(1,891)</u>	<u>-</u>	<u>-</u>
<b>Net movement in funds</b>		<u>62,710</u>	<u>(18,482)</u>	<u>44,228</u>	<u>(21,532)</u>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<u>331,200</u>	<u>191,534</u>	<u>522,734</u>	<u>544,266</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>393,910</u></u>	<u><u>173,052</u></u>	<u><u>566,962</u></u>	<u><u>522,734</u></u>

The notes form part of these financial statements

**CARDIOMYOPATHY UK****BALANCE SHEET 31  
DECEMBER 2021**

	Notes	Unrestricted fund £	Restricted funds £	31.12.21 Total funds £	31.12.20 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	12	8,871	-	8,871	8,857
<b>CURRENT ASSETS</b>					
Debtors: amounts falling due within one year	13	244,659	-	244,659	161,908
Debtors: amounts falling due after more than one year	13	29,006	-	29,006	4,006
Cash at bank and in hand		<u>183,379</u>	<u>173,052</u>	<u>356,431</u>	<u>440,685</u>
		457,044	173,052	630,096	606,599
<b>CREDITORS</b>					
Amounts falling due within one year	14	(72,005)	-	(72,005)	(92,722)
<b>NET CURRENT ASSETS</b>					
		<u>385,039</u>	<u>173,052</u>	<u>558,091</u>	<u>513,877</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>					
		<u>393,910</u>	<u>173,052</u>	<u>566,962</u>	<u>522,734</u>
<b>NET ASSETS</b>					
		<u>393,910</u>	<u>173,052</u>	<u>566,962</u>	<u>522,734</u>
<b>FUNDS</b>					
Unrestricted funds	16			393,910	331,200
Restricted funds				<u>173,052</u>	<u>191,534</u>
<b>TOTAL FUNDS</b>					
				<u>566,962</u>	<u>522,734</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 23rd June 2022 and were signed on its behalf by:



Rita Sutton, Chair of Trustees

The notes form part of these financial statements

**CARDIOMYOPATHY UK****CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 DECEMBER 2021**

	Notes	31.12.21 £	31.12.20 £
<b>Cash flows from operating activities</b>			
Cash generated from operations	1	(79,637)	6,224
Net cash (used in)/provided by operating activities		(79,637)	6,224
<b>Cash flows from investing activities</b>			
Purchase of tangible fixed assets		(4,617)	(5,063)
Interest received		-	1,174
Net cash used in investing activities		(4,617)	(3,889)
<b>Change in cash and cash equivalents in the reporting period</b>			
		(84,254)	2,335
<b>Cash and cash equivalents at the beginning of the reporting period</b>		440,685	438,350
<b>Cash and cash equivalents at the end of the reporting period</b>		356,431	440,685

The notes form part of these financial statements

CARDIOMYOPATHY UK

NOTES TO THE CASH FLOW STATEMENT  
FOR THE YEAR ENDED 31 DECEMBER 2021

1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES			
	31.12.21		31.12.20
	£		£
<b>Net income/(expenditure) for the reporting period (as per the Statement of Financial Activities)</b>	44,228		(21,532)
<b>Adjustments for:</b>			
Depreciation charges	4,603		2,751
Interest received	-		(1,174)
Increase in debtors	(107,751)		(19,266)
(Decrease)/increase in creditors	(20,717)		45,445
<b>Net cash (used in)/provided by operations</b>	<u>(79,637)</u>		<u>6,224</u>
2. ANALYSIS OF CHANGES IN NET FUNDS			
	At 1.1.21	Cash flow	At 31.12.21
	£	£	£
<b>Net cash</b>			
Cash at bank and in hand	440,685	(84,254)	356,431
	<u>440,685</u>	<u>(84,254)</u>	<u>356,431</u>
<b>Total</b>	<u>440,685</u>	<u>(84,254)</u>	<u>356,431</u>

The notes form part of these financial statements

# Notes To The Financial Statements For The Year Ended 31st December 2021



## 1. Accounting Policies

### Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Cardiomyopathy UK is a charity limited by guarantee and incorporated in England and Wales. The charity's principal address is 75A Woodside Road, Amersham, Buckinghamshire, HP6 6AA. The registered charity number is 1164263.

The presentation currency of these financial statements is Sterling (£), being the currency of the primary economic market in which the entity operates. All amounts in these financial statements have been rounded to the nearest pound unless stated otherwise.

The significant accounting policies applied

in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

In light of the rapid global spread of the Coronavirus "COVID-19" since early 2020, the trustees have reviewed and stress tested projections and budgets for the next twelve months. Following this review, the trustees consider there to be little impact on the Charity's ability to act as a going concern.

The trustees have reviewed the fundraising possibilities and the capital resources available and consider that the charity has adequate resources in place to continue operations for the next twelve months.

# 1. Accounting Policies (continued)

## Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

## Government Grants

The charity receives government grants in respect of Coronavirus Job Retention Scheme. Income from government grants are recognised at fair value when the charity has entitlement after any performance conditions have been met, it is probable that the income will be received and the amount can be measured reliably. If entitlement is not met then these amounts are deferred.

## Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

## Allocation and apportionment of costs

Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with use of the resources.

Salaries have been apportioned in accordance with the duties to which they relate.

Premises costs have been apportioned on the basis of percentage of floor space used.

## Tangible Fixed Assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - at variable rates on reducing balance

## Taxation

The charity is exempt from tax on its charitable activities.

# 1. Accounting Policies (continued)

## Fund Accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

## Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

## Financial Instruments

The charity has applied the provisions of Section 11 "Basic Financial Instruments" and Section 12 "Other Financial Instrument Issues" of FRS 102 to its financial statements.

Financial instruments are classified and accounted for, according to the substance of the contractual arrangement, as either financial assets, financial liabilities or equity instruments. An equity instrument is any contract that evidences a residual interest in the assets of the company after deducting all of its liabilities.

## Debtors and creditors due within one year

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in the Statement of Financial Activities in administrative expenses.

## Cash and cash equivalents

Cash and cash equivalents in the Statement of Financial Position comprise cash at bank and in hand and short term deposits with an original maturity date of three months or less. Bank overdrafts are disclosed within creditors on the Statement of Financial Position.

**CARDIOMYOPATHY UK**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 DECEMBER 2021**

**2. DONATIONS AND LEGACIES**

	31.12.21 £	31.12.20 £
Donations	192,761	178,166
Grants and legacies	361,996	246,868
Fundraising	260,915	324,521
	<u>815,672</u>	<u>749,555</u>

Grants received included above are as follows:

	Unrestricted £	Restricted £	2021 Total £	2020 Total £
Browns Solicitors	-	64,800	64,800	60,800
Alexander Jansons Fund	-	(290)	(290)	-
BBC Children in Need	-	23,925	23,925	10,825
Big Lottery Fund - CommunityPeerSupport	-	58,821	58,821	108,868
Heart Hive	-	(1,891)	(1,891)	-
The Edward Gostling Foundation	-	-	-	15,000
Max's Foundation	-	-	-	14,776
Cunningham Family Trust	-	-	-	10,000
Myokardia/Vistra IE UK	-	-	-	10,000
The Moss Family Charitable Trust	-	-	-	1,000
European Consultancy	-	-	-	6,356
Burdett Trust Due	-	2,203	2,203	-
Arrhythmogenic ACT	-	57,628	57,628	-
CAF Resilience Fund	-	10,000	10,000	-
CAF Main Grant	-	44,850	44,850	-
The Girdler's Company CharitableTrust	1,450	-	1,450	-
Edith Florence Spencer MemorialTrust	11,000	-	11,000	-
Total Grants	<u>12,450</u>	<u>260,046</u>	<u>272,496</u>	<u>237,625</u>
Total Legacies			89,500	4,000
Coronavirus Job Retention Scheme			-	5,243
			<u>361,996</u>	<u>246,868</u>

**CARDIOMYOPATHY UK**

**NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 DECEMBER 2021**

**3. INVESTMENT INCOME**

	31.12.21 £	31.12.20 £
Deposit account interest	-	1,174
	<u>          </u>	<u>          </u>

**4. INCOME FROM CHARITABLE ACTIVITIES**

Grants received included above are as follows:

	Unrestricted £	Restricted £	2021 Total £	2020 Total £
Pfizer Ltd	-	21,100	21,100	21,100
Online Medical Education(AstraZen)	-	10,000	10,000	-
Medical education grant (SanofiGenzyme)	-	5,000	5,000	-
PSG Grant (Novartis)	-	23,800	23,800	-
e-learning courses (Alnylam UK Limited)	-	10,000	10,000	-
Growth & Development Project (Bristol-Myers Squibb Pharmaceuticals Limited)	-	59,906	59,906	-
	<u>          </u>	<u>          </u>	<u>          </u>	<u>          </u>
Total Grants	-	129,806	129,806	21,100
	<u>          </u>	<u>          </u>	<u>          </u>	<u>          </u>

**5. RAISING FUNDS**

**Raising donations and legacies**

	31.12.21 £	31.12.20 £
Staff costs	153,704	175,069
Rates and water	1,013	605
Insurance	422	926
Postage and stationery	2,157	4,839
Sundries	5,187	146
Event costs	64,351	31,950
Marketing	15,953	23,122
Travel and subsistence	32	56
Computer	6,223	3,456
Recruitment	550	7,692
Staff training	26	-
Rent	11,301	9,486
Professional fees	917	2,777
Donation charges	9,860	6,512
Bank charges	347	3,481
Subscriptions	3,674	238
Depreciation	876	824
	<u>          </u>	<u>          </u>
	<u>276,593</u>	<u>271,179</u>

## 6. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Grant funding of activities (see note 7) £	Totals £
Providing support	318,800	-	318,800
Public and medical education	93,226	-	93,226
Campaigning	41,834	-	41,834
Research	12,236	81,882	94,118
	<u>466,096</u>	<u>81,882</u>	<u>547,978</u>

## 7. GRANTS PAYABLE

	31.12.21 £	31.12.20 £
Research	<u>81,882</u>	<u>1,646</u>

The following Grants were paid to Institutions during the year;

	2021 £	2020 £
Alexander Janson's Myocarditis	1,269	1,646
Global Heart Hub	22,985	-
University College London	57,628	-
Total	<u>81,882</u>	<u>1,646</u>

## 8. SUPPORT COSTS

	Management £	Governance costs £	Totals £
Other resources expended	<u>70,179</u>	<u>6,500</u>	<u>76,679</u>

## Analysis of support and governance costs

The charity initially identifies the costs of its support function. It then identifies those costs which relate to the governance function. Having identified its governance costs and support costs these are apportioned between the key charitable activities undertaken in the year. Please refer to the table below for the basis of apportionment and the key analysis of support.

	General Support £	Governance function £	Basis of apportionment
Wages	24,736	-	The duties to which they relate
Property related expenses	10,950	-	Floor space
General office and administration	33,408	-	Specific support costs
Legal and professional fees	-	-	Specific support costs
Bank charges	219	-	General charges
Depreciation	866	-	Floor space
Audit fees	-	6,500	Governance
Total	<u>70,179</u>	<u>6,500</u>	

## 9. Auditor's Remuneration

The auditor's remuneration amounts to an audit fee of £6,500 (2020 - £5,050) and payroll services paid to the auditor of £864 (2020 - £1,716) are included in legal and professional fees.

## 10. Trustee's Remuneration and Benefits

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2020.

## Trustee's Expenses

During the year ended 31 December 2021, trustees received reimbursed expenses of £nil (2020: £547) for travel and other charitable related costs. At the year end date £nil (2020: £nil) was due to trustees in relation to expenses.

## 11. Staff Costs

	2021	2020
	£	£
Wages and salaries	464,818	482,236
Social security costs	39,087	39,020
Other pension costs	12,353	13,463
	<u>516,258</u>	<u>534,719</u>

Total redundancy / termination payments during the year amounted to £nil (2020 - £17,881)

### Transactions with key management personnel

	2021	2020
	£	£
Total compensation of key management personnel	<u>64,297</u>	<u>64,297</u>

The average monthly number of employees during the year was as follows:

	2021	2020
	<u>18</u>	<u>18</u>

The number of employees whose employee benefits (excluding employer pension costs) exceeded £60,000 was:

	2021	2020
£60,001 - £70,000	<u>1</u>	<u>1</u>

## 12. Tangible Fixed Assets

	Computer equipment £
<b>COST</b>	
At 1 January 2021	28,966
Additions	4,617
	<u>33,583</u>
At 31 December 2021	33,583
<b>DEPRECIATION</b>	
At 1 January 2021	20,109
Charge for year	4,603
	<u>24,712</u>
At 31 December 2021	24,712
<b>NET BOOK VALUE</b>	
At 31 December 2021	8,871
	<u>8,871</u>
At 31 December 2020	<u>8,857</u>

## 13. Debtors: Amounts Falling Due Within One Year

	31.12.21 £	31.12.20 £
Trade debtors	69,906	15,982
Prepayments and accrued income	174,753	145,926
	<u>244,659</u>	<u>161,908</u>

## 14. Creditors: Amounts Falling Due Within One Year

	31.12.21 £	31.12.20 £
Trade creditors	11,009	8,503
Social security and other taxes	11,353	12,312
Other creditors	2,528	4,018
Accruals and deferred income	47,115	67,889
	<u>72,005</u>	<u>92,722</u>

## 15. Leasing Agreements

Minimum lease payments under non-cancellable operating leases fall due as follows:

	31.12.21 £	31.12.20 £
Within one year	26,400	33,393
Between one and five years	105,600	105,600
In more than five years	103,400	129,800
	<u>235,400</u>	<u>268,793</u>

## 16. Movement in Funds

	At 1.1.21 £	Net movement in funds £	Transfers between funds £	At 31.12.21 £
<b>Unrestricted funds</b>				
General fund	331,200	60,819	1,891	393,910
<b>Restricted funds</b>				
Medical education	10,018	-	-	10,018
Providing support helpline	-	1,180	-	1,180
Youth services	3,974	(3,974)	-	-
West Midlands support fund	924	-	(924)	-
Alexander Janson's Foundation	1,260	(1,260)	-	-
BBC Children in Need	4,314	(2,345)	-	1,969
Heart Hive	1,891	-	(1,891)	-
Max's Foundation	13,929	(13,278)	-	651
Community Peer Support (National Lottery Community Fund)	-	(139)	924	785
Building Capabilities (National Lottery Community Fund)	17,844	(17,844)	-	-
Online Medical Education	19,574	(16,242)	-	3,332
Advocacy	27,803	11,672	-	39,475
PPCM Campaign	4,941	(4,941)	-	-
BLF Helpline	20,572	(20,572)	-	-
Building the Community	64,490	(53,412)	-	11,078
Awareness Campaign	-	8,794	-	8,794
CAF Resilience Fund	-	9,201	-	9,201
CAF Support Fund	-	26,938	-	26,938
BMS Grant	-	59,631	-	59,631
	<u>191,534</u>	<u>(16,591)</u>	<u>(1,891)</u>	<u>173,052</u>
<b>TOTAL FUNDS</b>	<u>522,734</u>	<u>44,228</u>	<u>-</u>	<u>566,962</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	553,435	(492,616)	60,819
<b>Restricted funds</b>			
Providing support helpline	30,000	(28,820)	1,180
Youth services	-	(3,974)	(3,974)
Alexander Janson's Foundation	10	(1,270)	(1,260)
BBC Children in Need	23,925	(26,270)	(2,345)
Max's Foundation	-	(13,278)	(13,278)
Community Peer Support (National Lottery Community Fund)	58,821	(58,960)	(139)
Building Capabilities (National Lottery Community Fund)	-	(17,844)	(17,844)
Online Medical Education	25,000	(41,242)	(16,242)
Advocacy	55,900	(44,228)	11,672
PPCM Campaign	-	(4,941)	(4,941)
BLF Helpline	-	(20,572)	(20,572)
Building the Community	-	(53,412)	(53,412)
Awareness Campaign	23,800	(15,006)	8,794
ACT/UCL	57,628	(57,628)	-
CAF Resilience Fund	10,000	(799)	9,201
Burdett Trust	2,203	(2,203)	-
CAF Support Fund	44,850	(17,912)	26,938
BMS Grant	59,906	(275)	59,631
	<u>392,043</u>	<u>(408,634)</u>	<u>(16,591)</u>
<b>TOTAL FUNDS</b>	<u>945,478</u>	<u>(901,250)</u>	<u>44,228</u>

## 16. Movement in Funds (continued)

### Comparatives for movement in funds

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
<b>Unrestricted funds</b>			
General fund	457,553	(126,353)	331,200
<b>Restricted funds</b>			
Medical education	22,600	(12,582)	10,018
Providing support helpline	164	(164)	-
Youth services	6,664	(2,690)	3,974
West Midlands support fund	924	-	924
Alexander Janson's Foundation	116	1,144	1,260
BBC Children in Need	2,937	1,377	4,314
Heart Hive	1,891	-	1,891
Max's Foundation	11,755	2,174	13,929
Community Peer Support (National Lottery Community Fund)	4,662	(4,662)	-
Building Capabilities (National Lottery Community Fund)	25,000	(7,156)	17,844
Online Medical Education	10,000	9,574	19,574
Advocacy	-	27,803	27,803
PPCM Campaign	-	4,941	4,941
BLF Helpline	-	20,572	20,572
Building the Community	-	64,490	64,490
	<u>86,713</u>	<u>104,821</u>	<u>191,534</u>
<b>TOTAL FUNDS</b>	<u>544,266</u>	<u>(21,532)</u>	<u>522,734</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	420,657	(547,010)	(126,353)
<b>Restricted funds</b>			
Medical education	179	(12,761)	(12,582)
Providing support helpline	30,000	(30,164)	(164)
Youth services	15,000	(17,690)	(2,690)
Alexander Janson's Foundation	2,924	(1,780)	1,144
BBC Children in Need	10,825	(9,448)	1,377
Max's Foundation	14,776	(12,602)	2,174
Community Peer Support (National Lottery Community Fund)	63,218	(67,880)	(4,662)
Building Capabilities (National Lottery Community Fund)	-	(7,156)	(7,156)
Online Medical Education	30,000	(20,426)	9,574
Advocacy	51,900	(24,097)	27,803
PPCM Campaign	18,700	(13,759)	4,941
BLF Helpline	45,650	(25,078)	20,572
Building the Community	68,000	(3,510)	64,490
	<u>351,172</u>	<u>(246,351)</u>	<u>104,821</u>
<b>TOTAL FUNDS</b>	<u>771,829</u>	<u>(793,361)</u>	<u>(21,532)</u>

## 16. Movement in Funds (continued)

### Total Funds

Medical education - Towards the costs of providing educational events and opportunities for healthcare professionals. This includes the Olsen-Gourley Lecture fund and the M Hicks Educational fund transferred from Cardiomyopathy Association.

Youth services - Towards the costs of developing and providing support services for children, youth and young adults. This includes the Wates Foundation fund, the Childrens Book Restricted Fund, Chairman's Appeal 2013 fund and the Children and Young People Office fund transferred from Cardiomyopathy Association.

Providing support helpline - Towards the costs of providing a nurse lead clinical helpline for people affected by cardiomyopathy. This includes the Chairman's Appeal 2013 fund, Support Nurse Helpline fund, Raft Race Appeal fund and the Cardio Connect fund transferred from Cardiomyopathy Association.

BLF Heart to Heart Project - To fund the support and provision of a network of support groups throughout England. This includes the Sussex Support Group fund, Hampshire Support Group fund and the Winchester Support Group fund transferred from Cardiomyopathy Association.

West Midland support group - to provide support for those with cardiomyopathy in

the West Midlands.

Alexander Janson's Foundation - to fund research into the causes, prevention and cures for Myocarditis.

BBC Children in Need - To improve the emotional, physical and psychosocial (empowerment) well-being of young people under 18. Information resources (web and hard copy), paediatric helpline (out of hours), and national event, plus Panel meetings.

Tesco's Community Groundwork Fund - Towards the holding of a musical event raising the awareness of Cardiomyopathy in Leeds.

Heart Hive - Online platform that aims to match researchers at Imperial College with individuals interested in taking part in research trials. The objective is to seek ways of improving treatment for cardiomyopathy and myocarditis.

Max's Foundation - Three year grant to fund the position of Youth Support Manager.

Community Peer Support (National Lottery Community Fund) - A five year project partly funded by the National Lottery Community Fund to develop an innovative face to face and phone peer support service for people with life limiting heart muscle disease throughout England.

Building Capabilities (National Lottery

Community Fund) - National audit pan England of those NHS trusts and service providers providing clinical care and treatment to people affected by cardiomyopathy and myocarditis.

Online Medical Education - Towards the development of an online learning program which will improve diagnoses of cardiomyopathy and access to treatment by upskilling clinical knowledge of patient facing clinicians.

Advocacy - Developing the patient voice to affect purposeful change within the relevant statutory agencies.

PPCM Campaign - To raise public awareness of peripartum Cardiomyopathy in particular statutory health providers.

BLF Helpline - To provide a dedicated frontline service to anyone affected by Cardiomyopathy or related conditions.

Building the Community - To raise awareness of Cardiomyopathy to English speaking countries internationally.

Awareness campaign - To fund a national awareness campaign aimed at raising awareness of the signs and symptoms of cardiomyopathy among hard to reach communities. This funding has been received from Novartis Pharmaceuticals UK.

CAF Resilience Fund - Funding to help the charity improve its ability to raise income, deliver services and develop its policy positions with the support of

external consultants. This funding has been received from the Charities Aid Foundation's coronavirus emergency fund.

CAF Support Fund - Funding to ensure that the charity can continue to deliver its core services and improve its ability to reach more communities and individuals affected by cardiomyopathy. This funding has been received from the Charities Aid Foundation's coronavirus emergency fund.

BMS Grant - Funding from the pharmaceutical company, Bristol Myers Squibb to cover the costs of the charity's national conference, website, outreach and awareness work.

ACT/UCL Grant - Funding from the Arrhythmogenic Cardiomyopathy Trust (Charity No.1176790) to fund a research project based at University College London focused on risk stratification in Arrhythmogenic Cardiomyopathy.

## **17. Related Party Disclosures**

There were no related party transactions for the year ended 31 December 2021.

**CARDIOMYOPATHY UK****DETAILED STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 DECEMBER 2021**

	31.12.21 £	31.12.20 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	192,761	178,166
Grants and legacies	361,996	246,868
Fundraising	260,915	324,521
	<u>815,672</u>	<u>749,555</u>
<b>Investment income</b>		
Deposit account interest	-	1,174
<b>Charitable activities</b>		
Grants	129,806	21,100
	<u>945,478</u>	<u>771,829</u>
<b>Total incoming resources</b>		
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Wages	138,826	156,741
Social security	11,662	13,030
Pensions	3,216	5,298
Rates and water	1,013	605
Insurance	422	926
Postage and stationery	2,157	4,839
Sundries	5,187	146
Event costs	64,351	31,950
Marketing	15,953	23,122
Travel and subsistence	32	56
Computer	6,223	3,456
Recruitment	550	7,692
Staff training	26	-
Rent	11,301	9,486
Professional fees	917	2,777
Donation charges	9,860	6,512
Bank charges	347	3,481
Subscriptions	3,674	238
Depreciation of tangible fixed assets	876	824
	<u>276,593</u>	<u>271,179</u>
<b>Charitable activities</b>		
Wages	303,533	302,165
Social security	25,698	24,146
Pensions	8,587	7,534
Insurance	5,200	3,970
Carried forward	343,018	337,815

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**CARDIOMYOPATHY UK****DETAILED STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 DECEMBER 2021**

	31.12.21 £	31.12.20 £
<b>Charitable activities</b>		
Brought forward	343,018	337,815
Light and heat	1,623	662
Telephone	5,000	3,254
Postage and stationery	4,021	5,494
Advertising	58,767	49,375
Sundries	178	320
Medical conferences and events	10,065	2,253
Public conferences and events	11,580	14,036
Computer	7,364	9,167
Travel and subsistence	1,949	1,402
Recruitment	275	11,075
Staff training	911	1,491
Support costs	1,015	1,519
Consultancy	1,254	210
Rent	16,215	15,975
Depreciation of tangible fixed assets	2,861	1,561
Grants to institutions	81,882	1,646
	<u>547,978</u>	<u>457,255</u>
<b>Support costs</b>		
<b>Management</b>		
Wages	22,459	23,330
Social security	1,727	1,844
Pensions	550	631
Rates and water	421	708
Insurance	-	307
Light and heat	573	44
Telephone	1,500	2,218
Postage and stationery	4,981	3,819
Sundries	1,505	3,768
Computer	21,858	8,232
Rent	6,518	3,225
Repairs and maintenance	3,438	5,581
Travel and subsistence	-	493
Subscriptions	868	1,061
Legal and professional fees	2,696	4,148
Bank charges	219	102
Depreciation of tangible and heritageassets	866	366
	<u>70,179</u>	<u>59,877</u>
<b>Governance costs</b>		
Auditors' remuneration	6,500	5,050
Total resources expended	<u>901,250</u>	<u>793,361</u>
<b>Net income/(expenditure)</b>	<u>44,228</u>	<u>(21,532)</u>

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