



Impact Report 2020

Cardiomyopathy^{UK}
the heart muscle charity

Welcome



2020; a year that will go down in history as the year that we all stayed at home. While face to face meetings may not have happened and many fundraising events were put on hold, the demand for the charity's support increased. As we look forward to current restrictions being lifted and the return of face to face meetings and support groups, we should also look back and congratulate ourselves on what the charity has achieved; and acknowledge the difference we have made to the lives of people living with, or are affected by, cardiomyopathy or myocarditis during this extraordinary year.

Rita Sutton, Chair of Trustees



It is fair to say that 2020 has been an incredibly challenging year for the charity; the people we help and for society as a whole. I am very proud of how we have worked together to meet the challenges that we have faced. We have been resilient, creative and ambitious and with the help of our community, we have been able to continue our work and help more people than ever before at a time when they have needed us the most.

Joel Rose, Chief Executive

Our Helpline

The Charity's helpline aims to help people manage the huge impact that cardiomyopathy and related disorders have on a person's life and the lives of their family and loved ones. Our nurses can give all the time that a person needs to talk through their concerns and offer clear and accurate information as well as practical and emotional support.



At the start of the COVID-19 pandemic the helpline received a massive 300% increase in calls from people concerned about the impact of COVID-19 on cardiomyopathy. We are really proud that we were able to meet this increase in demand and provide support and advice at an incredibly challenging time for our service users.



Our Support Nurses

"This service is vital without a pandemic but during it's been, in my opinion, another emergency service."

Service User



300%

increase in calls at the start of the pandemic



40%

increase in all calls

Peer Support

It was clear from the outset of the pandemic that our service users were not only going to need more information and advice but that we also needed to meet their emotional support needs.

This was difficult as the Charity has traditionally provided this form of support in face-to-face settings via its support group network and in-clinic volunteers, this was no longer possible due to pandemic restrictions.

We were able to transform our support group network and work with volunteer support group leaders to provide online meetings and launch new groups to provide a much-valued opportunity to take a break from pandemic concerns.

Remarkably, overall support group attendances was up 25% on previous years and we were able to meet our targets for peer support work funded by the National Lottery Community Fund.

Although it was not possible to replicate in-clinic peer support during this time due to pandemic restrictions, we are confident that this form of support will return in 2021.

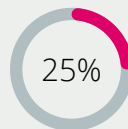
"Remembering that I am part of a valuable community is strengthening. Hearing from others is so valuable"

Service User



132 support group meetings

increase in support group attendance



Information

At the same time as managing the increase in demand on our helpline, we worked hard to make sure that we could meet the need to provide accurate and timely cardiomyopathy specific information about the pandemic.

We worked closely with our network of clinical experts to provide regular information on our website as well as a number of Facebook Live Q&A sessions with Professor Perry Elliott and other experts that received a total of over 17,000 views.



**17,000 views for our
Facebook Q&A
videos**

Pandemic restrictions meant that it was necessary to move our national conference to an online format, something that the charity had not done previously.

Feedback from the conference was overwhelmingly positive and the online format meant that many people who were previously unable to attend were able to join. Total attendance was up 160% and the charity welcomed attendees from 20 different countries.

"It's a trusted source of information for me and I feel comforted that I have Cardiomyopathy UK in my life"

Service User



**600 people
joined our
online
conference
from 20
countries**



**increase in online
information
accessed**

42%



Working with Clinicians

As the pandemic took hold, we worked with our network of cardiomyopathy experts across the country to help co-ordinate a national response to the crisis and ensure consistency of health advice among healthcare professionals. This helped to reduce the anxiety and confusion that many in our community experienced.

We were due to launch our new online medical education platform to increase the level of knowledge of cardiomyopathy and related disorders among healthcare professionals and improve their ability to diagnose and treat the condition.

Unfortunately, this project has been delayed as the pandemic made it impossible to record the necessary video materials and secure the time of health care professionals needed to ensure that information on the platform is fit for purpose.

Raising Awareness



Although the pandemic meant that we had to delay our national awareness campaign, there was a large increase in the number of people reached via social media.

Our overall reach increased by 10% as the Charity improved its social media presence and sought new ways to engage with supporters and the wider community.

Improving Care and Treatment

Despite the pandemic we were able to secure funding for our new advocacy project, "Change Makers" that aims to use patient power to improve cardiomyopathy services in the UK.

We recruited 18 volunteer "Change Makers" and gave them the training needed to act as advocates working to effect change in their local communities.

We also worked with our Change Makers and other stakeholders to create our Change Agenda that sets out how we want to ensure people with cardiomyopathy get the support and treatment they need.

Even with the widespread impact that the pandemic has had on the health service and the Charity, we were still able to play a role as part of the wider community.

We worked with other charities and medical organisations as part of The Alliance for Heart Failure and contributed to NICE appraisals for new medicines that could help people with cardiomyopathy.

Change Agenda Key Priorities

- GP's to take, and have on record, a detailed family cardiac history.
- The referral process for diagnostic tests and entry into cardiology care to be streamlined.
- The cardiology team to deliver a specific cardiomyopathy diagnosis in a sensitive manner.
- The cardiology team to signpost newly diagnosed patients to Cardiomyopathy UK.
- Mutually agreed 'Care Plans' for patients.
- Support from specialist Heart Nurses.
- Access to an appropriate integrated package of care .
- All patients diagnosed with cardiomyopathy to be considered for genetic assessment .
- Genetic test results to be received by all patients and acted on.
- Patients with negative genetic test results to be considered for future testing.
- An established point of contact for concerns outside regular reviews.
- Advanced/advancing heart failure patients to be carefully monitored and supported.

Research

During the year we kept working with the research community to provide patient insight and ensure that clinical research meets the needs of people with cardiomyopathy and leads to real improvements in treatment.

**Imperial College
London**

We worked with the Heart Hive team at Imperial College to develop a platform to connect cardiomyopathy researchers with patients.

CRUCIAL

We worked with an international network of researchers on the CRUCIAL project to identify quicker ways of diagnosing heart failure at an early stage.

ACT
Funding cardiac research to save young lives

We worked with the Arrhythmogenic Cardiomyopathy Trust to fund the development of a new database to increase understanding of arrhythmogenic cardiomyopathy and kickstart new research.

Our own research

Our peripartum cardiomyopathy survey of the general public found that;

- 70% of people are unaware that serious heart conditions could occur in pregnancy
- 75% of people think that the symptoms of a serious heart condition are normal in pregnancy
- 55% of people would put off seeking help because of the COVID-19 pandemic

We will use this information as the basis of a nationwide media campaign in 2021.

Fundraising

2020 has been perhaps the most challenging year for fundraising.

A large part of our income usually comes from our fundraising volunteers running their own fundraising events and taking part in challenge events across the country. Pandemic restrictions meant that most of this fundraising activity could not take place.

But our community really stepped up and we were amazed by their ingenuity and adaptability - taking on a host of online fundraisers from gaming competitions to virtual marathons.



Peter Cooper planned to run 6 marathons between November 2018 and March 2021 to raise funds for us in memory of his mother.

Returning to Hong Kong in March, he had to quarantine for two weeks. Still wishing to complete his fifth marathon, he decided to run the 26.2 miles in 5250 laps around his living room.



Our 2.6 Challenge team of 'Home Heroes' took on an array of interesting challenges, from running and cycling, to dancing and head shaving! Youth Panel's Elis Power and Jasmine Williams raised £2,070 by livestreaming their 26 burpee challenge.

The total raised was over £13,000. Thanks to everyone who took part or donated!

Fundraising

Although the pandemic made things harder for our community fundraisers, we were able to increase the amount of support that we get from charitable trusts such as BBC Children in Need and The National Lottery Community Fund.

We increased the amount of income that we received from companies for work that we do to raise awareness of cardiomyopathy, advocate for better treatment and provide healthcare professional education programmes.



We also received some funding from the government to help us cope with the impact of COVID-19 and ensure that we could meet the increase in demand for our services.

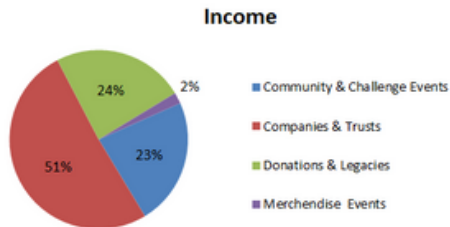


We rounded off 2020 with our brand new 12 Days of Christmas Challenge with the help of Taskmaster's Alex Horne; who set a fun and festive challenge everyday for the first 12 days of December.

The event was a great success raising awareness of cardiomyopathy to new audiences and helped us to raise over £20,000 with match funding from The Big Give.

Income & Expenditure

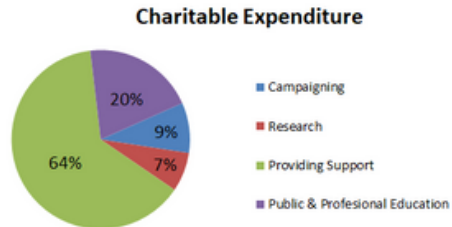
As you can expect, even with the fantastic efforts of our fundraisers and with more support from companies and charitable trusts, our income for the year was below that of 2019 when we raised £850K.



Total Income : £772K

Full detailed accounts are available on our website

Because of the reduction in our income due to the pandemic, we had to hold off spending money on some of our planned projects like our new website. It means that at the end of the year the charity is still in a good financial position.



Total Expenditure : £793K

Thank you

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The Cardiomyopathy UK team would like to thank all of our staff, volunteers and supporters.

In this exceptionally challenging year, their hard work and dedication has made it possible for us to continue to support people affected by cardiomyopathy at a time when they needed more help than ever before.

If you'd like to know more about how you can support our work in 2021 by volunteering, fundraising or campaigning, email us at contact@cardiomyopathy.org or call us on 01494 791224.

We would love to welcome you to our family.