

Our impact

Changing and saving lives in 2018



Hello

We are proud to present this report outlining the impact that Cardiomyopathy UK staff, volunteers and donors achieved in 2018.

A charity's primary focus should always be to ensure that it delivers positive results for its beneficiaries and that it does so in a cost effective, ethical and legal way. These few highlights demonstrate the increasing breadth of ways that we aim to ensure that patients and their families are better diagnosed, treated and supported.

We are continually evolving the services to find better ways of doing things and better ways of reaching the people who need us most, for instance by opening up new in-clinic services. If you would like to know more, our Annual Report gives more detail of how we achieved the numbers in this report or you can get in touch directly. We are always happy to talk through our work.



Alison

Alison Fielding, Chair

2018 has been a fantastic year and one where the charity has continued to grow and develop, helping more people than ever before.

I am especially proud that the charity was able to reach out to more people who had previously not known about cardiomyopathy or the help and support that we can give. We achieved this through expanding our support group network, placing volunteers in more hospitals and running a successful national campaign.

It has also been pleasing to see the impact of our merger with The Alexander Jansons Foundation. Since the start of 2018 we have been able to provide support and information on myocarditis and to play an important part in supporting research efforts to improve diagnosis and treatment for people with myocarditis and cardiomyopathy.

As ever, all this has been achieved thanks to our generous supporters, volunteers, and staff who have continued to show their commitment to our work. Thanks to them, I am sure that the charity will continue to go from strength to strength.



Joel

Joel Rose, Chief Executive

"The support I have received has made such a difference to how I feel about my condition. It's nice to know that you are here and I have somewhere to turn to."

Helpline Caller

"The hospital volunteers have added an invaluable extra dimension to my service, patients get much needed information and encouragement from people who have been in their shoes. They come away feeling happy and reassured."

Dr William Bradlow, consultant cardiologist,
University Hospitals Birmingham Trust

"This line is literally a lifeline for me. I can speak to a nurse, find out about benefits and talk to a real person who has the disease and actually knows how it feels."

Helpline Caller

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Helpline

Introduction

Cardiomyopathy and myocarditis have a huge impact on a person's life and the lives of their family and loved ones.

The charity's helpline aims to help people to manage this impact. Our team of nurses can give all the time that a person needs to talk through the issues. They are there to offer clear and accurate information as well as practical and emotional support. In order to help as many people as possible, we make sure that our helpline team can be reached via email and our live-chat service as well as over the phone.



Outcomes

In 2018 our helpline was able to support 1,890 people over the phone, via email and online. This was a slight increase on the previous year. We have noticed that more people are coming to our helpline wanting emotional support or are looking for practical help with issues relating to welfare benefits.

We are really pleased to see that after speaking to one of our helpline nurses, the vast majority of people feel better informed about their conditions, better able to cope with their situation and know what steps they need to take. We are also pleased that our helpline team have been able to help more people with myocarditis, a heart muscle disease that can often lead to dilated cardiomyopathy.

Service usage



1024
Calls



409
Emails



457
Online

Support needed



71%
Medical



21%
Practical



8%
Emotional



of callers felt more informed, better able to cope or ready to take their next step

"Being able to talk to the nurses and then get advice has been so helpful. My cardiologist mentioned the charity and I'm so glad they did"

Helpline caller





Peer support

Introduction

Peer support is all about giving people the opportunity to share their thoughts and concerns with someone who really understands what they are going through.

Over the last few years we have been investing more in ensuring that people throughout the country have the opportunity to join one of our support groups, speak to someone over the phone or in hospital. Our trained support group leaders and peer support volunteers play a huge part in helping people to feel that they can cope with the impact of cardiomyopathy or myocarditis and live as full a life as possible.



Peer support outcomes

2018 was the second year of our support group expansion project funded by The Big Lottery Fund. Thanks to their support and the fantastic work of our support group volunteers we were able to open up 7 new groups and launch new online support groups for rarer cardiomyopathies and for people who would not be able to attend a group meeting. We are really pleased that in 2018 we held 89 meetings across the country with record numbers attending.

Peer support usage



1,212
support
group visits



968
Facebook
group users



113
helped by
peer support
volunteers



483
people
supported
in hospital

One to one support

We know that not everyone feels comfortable joining a support group or just don't feel ready or able to get out and meet others with the condition. Our team of telephone support volunteers are there to speak to people one-to-one so that they can still get the benefit or peer support. In 2018, thanks to our volunteers, we were able to help 113 people.



"The information has helped me to cope better and meeting other members have helped me to see the bigger picture"

Support group member

Hospital volunteers

Our hospital volunteers are there to offer peer support at cardiomyopathy clinics often speaking to people who have just been given their diagnosis and still in a state of shock. In 2018 we were able to expand this new area of work opening up a new site in Reading. In total our volunteers were able to support 483 people often at a time when they needed it most.

Information

Introduction

Being able to access clear and simple information can make a huge difference.

It can help you feel less scared about your condition and better able to cope with the day to day challenges that it causes. In 2018 we welcomed 379 people to our information events and provided information to over 245,000 people.



2018 info & conference days



felt more confident about managing and living with cardiomyopathy

"I thought I was the only one with this condition so coming here and seeing lots of people in my town with cardiomyopathy has been incredible and I don't feel the odd one out so much."

Information day attendee



Young people

Introduction

Ask anyone with cardiomyopathy and they will tell you that being diagnosed and living with the condition at a young age can be especially challenging.

That's why we have been working hard to do more to support young people. Our youth panel have met throughout 2018 to plan new resources and services that show young people how you can live a full life with cardiomyopathy or myocarditis.



"Joining the CYP&YA Panel has meant meeting some amazing people who live their lives with a condition many are unaware of."

Youth panel member

Young people plan for 2019

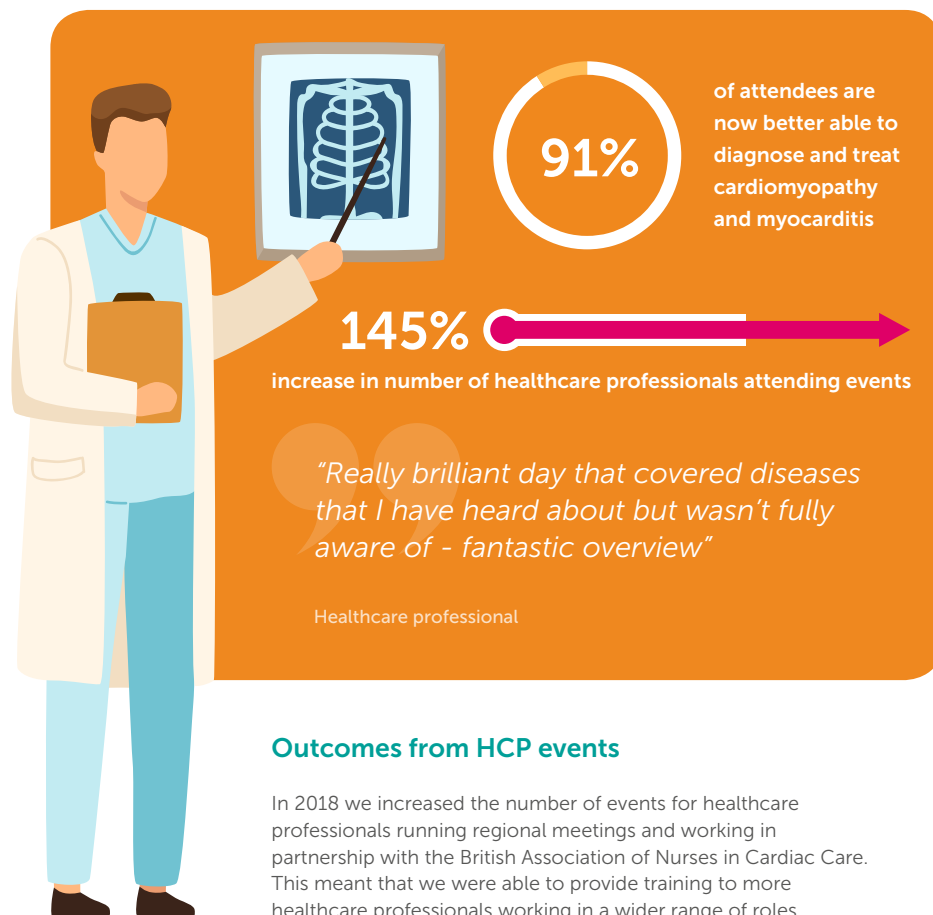
In 2018 the hard work of our youth panel has paid off and we were able to secure a grant from Children in Need to expand this work. This means that from 2019 we will be able to open up our helpline service for young people, run a youth conference and create the new materials that young people need.



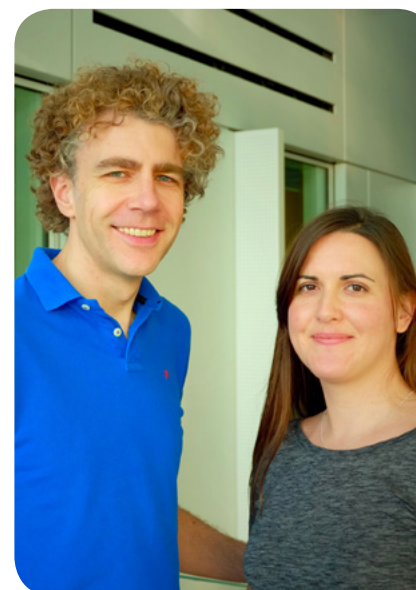
Clinical education

Introduction

We know that far too many people with cardiomyopathy and myocarditis experience delays and difficulties getting the right diagnosis and treatment. Sometimes they are given a broad diagnosis such as heart failure without being given the cause or being told the implications on their family. One of the best ways to improve this is to ensure that healthcare professionals have the skills that they need through providing education and training opportunities.



Research & collaboration



The more that we get to understand cardiomyopathy and myocarditis then the better we will be at detecting and treating these conditions.

That is why the charity works with clinicians and researchers to design their research studies and encourages people with cardiomyopathy and myocarditis to sign up for research trials where appropriate.

From 2019 we will be directly funding new research initiatives that focus on cardiomyopathy and myocarditis and that bring together researchers and patients to encourage greater participation in clinical trials.

AJF merger

At the beginning of 2018 the charity merged with the Alexander Jansons Foundation, a charity that was set up following the tragic death of Alexander Janson from myocarditis. The Foundation had been raising funds to support research into myocarditis, which is often a precursor to cardiomyopathy. As part of this merger we set up a separate fund to continue this work supporting researchers in their efforts to know more about myocarditis and cardiomyopathy.



"Support from Cardiomyopathy UK's Alexander Jansons Fund will make a huge difference to our work and help us learn even more about cardiomyopathy and myocarditis so we can get better at detecting and treating these diseases."

Dr Angharad Roberts
– Consultant Geneticist

Campaigns

2018 Heart Bleeps

When more people know about cardiomyopathy then fewer people die. That's why our national awareness raising work is so important.

In 2018 we ran a campaign focusing on the misconceptions that people have regarding cardiomyopathy and what a "typical heart disease" person looks like. These misconceptions drive misdiagnosis and can result in individuals not seeking medical help for their symptoms. The campaign was able to receive 27 pieces of coverage in broadcast media and saw a 521% increase in engagement across the charity's social media platforms.

 **521%**
increase in engagement across the charity's social media platforms from campaign

 **17%**
increase in social media throughout the year

 **10%**
increase in website visitors



Fundraising

None of our vital work would be possible without our superstar fundraisers.

Their support means that people with cardiomyopathy and myocarditis can get the help that they need. In 2018 we saw 132 community fundraisers and 98 challenge eventers sign up to be part of #teamcardio and take part in a wide range of fundraising activity. They were joined by our corporate partners and their staff who chose to support our work. We are always so impressed by our fundraisers' passion and dedication as well as some of the incredibly creative ideas that they come up with.

Community events



Challenge events



Corporate fundraising

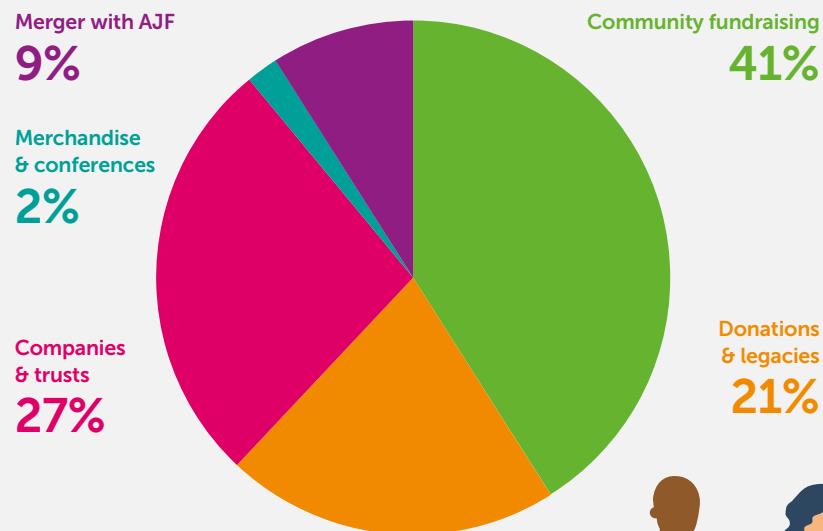


Income & expenditure

When we tell people about what we are able to achieve as a relatively small charity they are often amazed. We are proud to "punch above our weight" and make such a considerable difference to so many people despite having no government or NHS funding and relying entirely on the generosity and dedication of our supporters.

Income

2018 saw the charity raise record funds and finishing the year with total income over £1million for the first time. This large increase in income was partly due to our merger with the Alexander Jansons Foundation. We were also fortunate to receive two large legacies from people who the charity had helped in the past.



Total income
£1.1million

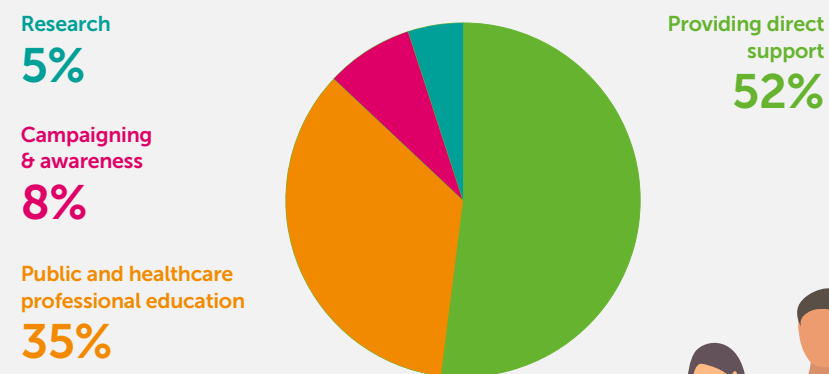


Expenditure

We spent less money than we raised in 2018. This was mainly because we received some funds later on in the year that we were not expecting. We also wanted to take some time to decide how best to spend money on research so that we could make the most impact on people's lives.

We were able to keep our administration costs down to around 12% of our total expenditure and we were pleased that the investment we made in our fundraising work really paid off. It meant that we had more than ever to spend on our charitable activity.

Spending on charitable activity



Total expenditure
£816k



Thank you

Volunteers

The Cardiomyopathy UK team would like to thank all of our volunteers who have worked so hard to help make 2018 such a success. We want to continue to build on this success in 2019, a special year for us as we mark our 30th anniversary. If you would like to know more about how you can volunteer and support our work please visit www.cardiomyopathy.org or just give us a call, we would love to welcome you to our family.

Governance

Cardiomyopathy UK is a unique charity. We bring together leading clinicians, people affected by the condition and charity professionals so that we fully understand the challenges of cardiomyopathy and myocarditis and have the skills, knowledge and resources that we need to meet these challenges.

Our Trustees have overall responsibility for the work of the charity. They have the range of skills that we need to be a successful charity and a deep personal understanding of the impact of cardiomyopathy and myocarditis.

- Alison Fielding, Chair
- Sheila Philips, Treasurer
- Tina Amiss
- Guillaume Favier
- Andy Janson
- Stephen Kirkahm
- Chris Horwood
- Ian McPherson
- Jill O'Connell
- Rita Sutton
- Adam Tickell
- Pete Thomas





Cardiomyopathy^{UK}

the heart muscle charity

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Get realtime support live chat via our website

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Office address: **Unit 10, Chiltern Court
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For details about supporting us, visit our website

www.cardiomyopathy.org

Cardiomyopathy UK, registered charity no 1164263