

# Five Year Strategic Plan

# Contents

## **1. Who we are**

- Welcome
- About us
- Our values

## **2. What needs to change**

- Cardiomyopathy and its impact
- The opportunities and challenges
- The change we want to make

## **3. Making change happen**

- Supporting people with cardiomyopathy and their loved ones
- Working with health and social care professionals
- Promoting and shaping the most impactful research
- Shaping local and national policy
- Raising awareness
- Welcoming everyone

## **4. Building our community**

- Communicating the difference we make
- Funding our work

## **5. Meeting our goals**

- Working in partnership
- Our role in the international community
- Developing volunteers and staff
- Monitoring our progress

## **6. Join Us**

# 1. Who We Are

## Welcome

If I think about when I first came to the charity, looking for support for my family, I can remember the worry, confusion, and chaos that cardiomyopathy caused. I can also remember how being part of the Cardiomyopathy UK community gave us the answers we needed and made us feel better able to cope in what was an incredibly difficult time. The charity's help made a real and lasting difference. That was eight years ago, and since then the charity has done a fantastic job of supporting so many families like mine.

The whole Cardiomyopathy UK team are proud of what has been achieved so far but we know that it is not enough. We have more to do. People with cardiomyopathy are still struggling to access the care and treatment they need. Families still face confusion, anxiety and, sadly, people at risk of sudden cardiac death remain unprotected. That is why we have set ourselves some very challenging goals in this five year strategic plan.

Although our goals are ambitious, they are achievable. This is thanks to the energy, passion and commitment of our volunteers, supporters, staff and many others. They enable us to deliver the work that we do and ensure that we have the resources we need to be there for anyone who is affected by cardiomyopathy. You can find out more about how you can support us [here](#). I look forward to welcoming you to the Cardiomyopathy UK community.

A handwritten signature in black ink that reads "Rita". The letter "R" is large and stylized, with a loop at the top. The letters "i" and "t" are smaller and connected to the "a".

Rita Sutton, Chair of Trustees

## About us

Cardiomyopathy UK is for anyone whose life is impacted by the heart muscle disease, cardiomyopathy. We work to save and improve the lives of people with the condition, and their loved ones, throughout the UK because we believe that everyone affected by cardiomyopathy should live a long and fulfilling life.

We work across the UK bringing together people with cardiomyopathy, their loved ones, medical experts, researchers, professional staff and other stakeholders to ensure we have the insight, lived experience, clinical knowledge and skills we need to make a real and lasting difference to people's lives.

Since our establishment over thirty years ago, we have worked to provide support and information so that nobody has to face cardiomyopathy alone. We have fought for better access to treatment so more people get the help they need, we have shaped research so that it truly addresses the needs of our community and we continue to raise awareness so more people seek help sooner and fewer people are at risk.

This document sets out our plans for the next five years and shows how our work will bring about the changes we believe are needed. It has been written for all the cardiomyopathy community and anyone who has an interest in our work. It is based on evidence from our national survey in 2022 as well as a further survey of our community in 2023. Trustees, who have overall responsibility for setting our strategy, also worked to collect the insights and views of our clinical advisory group, volunteers, staff team and a broad range of other key stakeholders.

## Our values

We believe that while it is important to be focused on achieving the changes we want to make, it is also important to ensure we act in accordance with our own set of values. We think that there is a right way to act, a view that we share with our supporters and stakeholders. Our core values are;

**Caring:** We are devoted to supporting anyone affected by cardiomyopathy and do our best to try and understand each individual's specific needs and unique perspective. We reach out to anyone affected by cardiomyopathy and ensure that everyone feels welcome.

**Dedicated:** We are committed to supporting people across the UK at all stages of their life and we are aware of the importance and urgency of our work.

- Responsive:** We reach out to anyone who needs us and ensure that we can adapt our ways of working to be as effective as possible.
- Collaborative:** We work with others whenever we can see how this would benefit those affected by cardiomyopathy
- Evidence based:** We provide up to date specialist knowledge about cardiomyopathy and ensure that our policies, comments and decisions are underpinned by robust evidence
- Realistic:** We are honest about the impact that cardiomyopathy can have and the course the condition can take
- Ambitious:** We are ambitious about the impact we want to make and are not afraid to set challenging goals, try new ideas and think big.

## 2. What Needs to Change

### Cardiomyopathy and its impact

Cardiomyopathy is a disease of the heart muscle. It is a group of conditions that affect the structure of the heart reducing its ability to pump blood around the body.

Cardiomyopathy can affect anyone, at any age. It affects around 1 in 250 people. For simplicity, when we use the term “cardiomyopathy” in this document we are referring to all forms of cardiomyopathy and related conditions of the heart muscle.

The function of the heart is to pump blood around the body, carrying oxygen and nutrients to ‘feed’ the cells and organs. When the heart function is impaired, the cells and organs do not receive enough oxygen and nutrients. This can lead to exhaustion, breathlessness, swelling in the abdomen and ankles, dizziness, fainting, palpitations and the risk of sudden cardiac death.

Some types of cardiomyopathy are caused by a genetic change in a person’s DNA which affects how their heart develops. Genetic conditions may be inherited so cardiomyopathy can run in families. If one person is diagnosed with cardiomyopathy, it is recommended that their close family members are tested for the condition.

There is currently no cure for cardiomyopathy, but symptoms can be managed through medication, implanted devices, surgery or in some cases a heart transplant. You can find out more about cardiomyopathy on our website ([www.cardiomyopathy.org](http://www.cardiomyopathy.org))

The physical symptoms of cardiomyopathy can have a significant impact on a person's life. In our recent survey one respondent summed up the experience that many people with the condition have;

*“I'm existing, not living, I've lost much of my mobility and have to rely on a walking stick, I can't walk more than about three feet without having to stop due to the pain and breathlessness and sheer exhaustion, I can't lay down at all so have to sleep sitting upright. I barely leave the house anymore except for appointments mainly. I want a life back”*

We believe that it is also crucial to recognise that cardiomyopathy has a significant impact not just physical health but also on the mental health of a person with the condition and their loved ones. In our recent national survey, most people with cardiomyopathy told us that they struggle to cope with the mental health impact of their condition. They told us that isolation and loneliness were especially hard to manage and they felt the loss of their previous active lifestyle. Typical comments were;

*“I have always been a very active person and used to take part in a lot of sports. Not being able to take part has massively impacted my confidence and social circles.”*

*“The feeling of loss, being unable to do activities that were once easy is depressing and also some of the symptoms create feelings of fear and anxiety.”*

This is also true when it comes to partners and loved ones because the condition can impact so heavily on family life and relationships. One partner of a person with cardiomyopathy described their experience;

*“Her life has got smaller as the symptoms have worsened, now she can become breathless just getting up in the mornings, needing rests between showering and dressing. She remains fairly independent, I pick up the tasks she can’t do, like making the bed and bending down, but her life is increasingly restricted by the condition”*

As well as having a significant impact on physical and mental health, cardiomyopathy also impacts the day-to-day practicalities of life such as employment, driving, pensions and insurance. A significant proportion of people that come to the charity for support, do so looking for help and advice with these issues. In our survey 88% of respondents told us that they had sought advice about accessing benefit to help manage the financial impact of the condition.

## **The opportunities & challenges**

The world of cardiomyopathy is rapidly changing. In the last few years there have been significant changes in the technological, research and healthcare environment as well as in broader society. These changes present some challenges but also, we believe, a great deal of opportunity to improve the lives of people affected by cardiomyopathy.

In 2023 the first ever treatment specifically for cardiomyopathy was approved for use in the NHS. This treatment is for people with the obstructive form of hypertrophic cardiomyopathy and whose condition has not been improved by other symptom management medication.

This is just the first of several new medicines coming through the drug development pipeline that could transform cardiomyopathy treatment. We will need to respond to this by ensuring that we provide the robust evidence of patient impact required in the drug approval process. We also need to be able to support healthcare professionals to put in place suitable processes to administer and monitor new medicines. Additionally, we need to ensure that the community has an accurate and realistic understanding of the potential risks and benefits of any new drug.

As well as the development of new treatments, there has also been a significant increase in cardiomyopathy focussed research. This growth in research interest will lead to further significant improvements to cardiomyopathy care and treatment.

We believe that cardiomyopathy research, is only truly impactful if it is designed to serve the needs of people with the condition. This means that we must have a full understanding of the needs of our community and be able to provide researchers with insight from people affected by cardiomyopathy. We also will need to play our part in promoting opportunities for people with cardiomyopathy to engage with research projects when appropriate and develop a culture of research participation.

In the last few years, the healthcare environment has changed a great deal and is likely to be in a state of continual change and development for several years. The challenges of dealing with the aftermath of the COVID-19 pandemic along with many pre-existing issues, has put significant pressure on the NHS. In many places we are seeing record waiting times to see a specialist, unacceptable delays throughout the treatment journey and significant variation in care and treatment. We are also seeing the NHS adopt new initiatives and ways of working, in part to manage delays and lack of resources. Where services are being redesigned without input from the people who will be using them, there is a real danger that they may not meet their needs or be in the best interests of our wider community.

We know that in a changing environment, opportunities arise to play a significant role in shaping the health and social care services that people with cardiomyopathy use. If we are to take advantage of this opportunity, we will need to be able to identify where we can make the most impact and have the volunteers and staff resources needed to ensure that we have a strong, authoritative and effective voice.

We recognise that we will also need to invest in our own services so that they can grow and develop to meet the increasing needs of our community especially as people with cardiomyopathy will be waiting longer between appointments and mental health support continues to be hard to access.

Cardiomyopathy does not exist in a vacuum, and our community is impacted by larger trends in society. We can see for example how the current rise in the cost of living has led to a significant increase in the number of people coming to us for help accessing statutory benefits. We have also seen how more of our community are looking to access our information and support remotely. While this presents the opportunity to reach more people across society, we must ensure that we do not lose the benefits that arise from people spending time together face-to-face.



We are confident that we can continue to track and analyse these recent developments, as well as emerging trends, over the course of this five year strategic plan. This is because we regularly gather information and insight from healthcare professionals, our volunteers, service users, the pharmaceutical and medical technology industry, the research community, other health and social care charities and cardiomyopathy charities from across the world.

We will be true to our value of being responsive, meaning that we will work quickly to address new challenges and capitalise on opportunities as they arise while still remaining focused on achieving the key goals set out here.

## **The change that we want to make**

Although new treatments are coming through for cardiomyopathy, there is still no cure. Getting quality care and treatment too often relies on good luck and exhausting, relentless determination. Families still face confusion and anxiety with too many people unaware that they are at risk of sudden cardiac death.

If we are to achieve our vision of a world where everyone affected by cardiomyopathy should live a long and fulfilling life, we must bring about significant changes. These are;

### **We want to improve the ability of people affected by cardiomyopathy to cope with the condition.**

This means that people with the condition, their family and loved ones feel better able to manage the emotional, practical and physical impact of cardiomyopathy. We want to make sure that the support we offer covers all parts of the cardiomyopathy journey including, for some, palliative and end of life care.

### **We want health and social care professionals to be better able to detect and treat cardiomyopathy.**

Our evidence shows that at present 53% of people with cardiomyopathy who go to the GP with symptoms, are initially investigated for non-heart related conditions and only 29% were asked about a family history of heart disease.

We want to improve the ability of health and social care professionals to diagnose, treat and provide ongoing support to people affected by cardiomyopathy. We want to make sure that all professionals involved in an individual's care are aware of best practice and have the right skills and training to provide the best level of care.

**We want there to be better treatment options and support services for people with cardiomyopathy**

We believe that we can play an important part in helping to develop new treatments for cardiomyopathy and better ways of providing support that are based on a real understanding on the needs of people affected by cardiomyopathy.

**We want it to be simpler and quicker to get appropriate support and treatment wherever you live**

We hear a great deal about the frustration people with cardiomyopathy feel in accessing treatment near to them. The delay in getting the right help leads to peoples' condition deteriorating and can increase the chances of cardiomyopathy impacting on emotional wellbeing. We want to make it easier for people with cardiomyopathy to access appropriate treatment in a timely fashion regardless of where they live.

**We want more people who may have cardiomyopathy or who are at risk of developing the condition to seek medical help.**

We want more people who may have cardiomyopathy or who are known to be at risk of developing cardiomyopathy to know the signs and symptoms of the condition and the importance of knowing your family's "heart history". We want these people to seek medical treatment in a more timely fashion. This is because a person with cardiomyopathy who has not been treated is at greater risk of experiencing a cardiac arrest.

## 3. Making Change Happen

In this section we set out the work that we will be undertaking over the next five years and describe how this work will help us to deliver the changes we want to make.

We have divided the work into six main areas of activity;

1. Supporting people with cardiomyopathy and their loved ones
2. Working with healthcare professionals
3. Promoting and shaping the most impactful research
4. Shaping local and national policy
5. Raising awareness
6. Welcoming everyone

For each area of activity we have set an overall goal. This goal articulates our overall ambition in that area. We have also set out a number of objectives which show what we want to achieve in that area of work over the next five years and the activities that we plan to undertake to meet these objectives.

### 1. Supporting people with cardiomyopathy and their loved ones

We believe the best way to help people affected by cardiomyopathy is to empower them with the information, skills and support they need to feel in control of their lives.

#### Our Goal:

We will be the most comprehensive and trusted provider of support and information for people living with cardiomyopathy. We will empower all our community so that everyone has the tools they need to live with the condition.

#### Our objectives:

- To empower people affected by cardiomyopathy by ensuring that they have the information they need to understand the condition and make informed decisions throughout their lives.
- To bring people with cardiomyopathy together in mutually supportive environments so that they feel understood, supported and better able to cope with the impact the condition can have on an individual's emotional wellbeing.
- To ensure people with cardiomyopathy have the support and tools they need to manage the impact cardiomyopathy can have on all aspects of daily life.

- To ensure that the charity is responsive, accessible, welcoming, and able to support anybody affected by cardiomyopathy at all stages of their life.

To achieve these objectives we will:

- ✓ Provide accurate, accessible and up to date information, resources and learning opportunities for all ages
- ✓ Provide safe and effective peer support opportunities both face to face and online
- ✓ Provide access to specialist mental health support for individuals when appropriate
- ✓ Provide specialist support on accessing benefits and managing issues relating to employment and housing
- ✓ Bring people together at an annual meeting to share information, provide additional support, celebrate individual achievements and energise the community
- ✓ Enhance the charity's ability to recruit, train and support volunteers from across the community
- ✓ Enhance the charity's ability to support young people and their siblings

## **2. Working with health and social care professionals**

Because we want health and social care professionals (HSCP's) to be better able to detect and treat cardiomyopathy, we need to be able to provide suitable learning opportunities and find ways to bring professionals together so that they can share best practice. We also need to ensure that HSCP's take an interest in cardiomyopathy and develop a passion and expertise in helping our community.

Our Goal:

We will be the most respected and accessible source of information for health and social care professionals regarding the diagnosis and treatment of cardiomyopathy. The charity will foster a knowledgeable and engaged health and social care community that is better able to serve people affected by cardiomyopathy.

Our Objectives:

- Support the education and professional development of health and social care professionals so that they are better able to diagnose cardiomyopathy and deliver excellent care and treatment.

- Bring HSCP's together so that they are better able to learn from each other and create networks and partnerships that will ultimately benefit people with cardiomyopathy.
- Create opportunities to support early career HSCPs so that they develop an interest and expertise in cardiomyopathy.
- Ensure all HSCPs are aware of the support that the charity can offer their patients and have the tools to refer patients to the charity's services.

To achieve these objectives we will:

- ✓ Provide online accredited learning opportunities for HSCPs
- ✓ Provide face to face training and networking opportunities for HSCPs on a regional basis
- ✓ Create mentoring opportunities for early career HSCPs to connect with established cardiomyopathy experts
- ✓ Provide face to face training and networking opportunities for HSCPs on a role basis such as specialist nurses, cardiac rehabilitation practitioners, pharmacists and GPs
- ✓ Attend all relevant conferences and meetings to seek opportunities to provide insights from people with cardiomyopathy, and raise the profile of our services
- ✓ Work with local volunteers to ensure that relevant HSCP's have information regarding the charity's support services

### **3. Promoting & shaping the most impactful research**

We know that without impactful research, based on the real-world insights and experiences of our community, we cannot hope to bring about better treatment options and support services for people with cardiomyopathy.

Our Goal:

We will be a leading driver of the highest quality research that delivers real benefits to our community.

### Our Objectives:

- To provide clinical researchers with a clear understanding of the needs and concerns of the cardiomyopathy community.
- To promote collaboration in clinical research, identify and develop new research projects.
- To create a culture of participation in research search by the cardiomyopathy community.
- To produce high quality, peer reviewed research that informs and underpins the charity's policy agenda.

### To achieve these objectives we will:

- ✓ Complete, publish and disseminate outcomes of a research priority setting partnership
- ✓ Recruit, train and retain a network of research volunteers to provide insight into clinical research projects
- ✓ Create a cardiomyopathy researchers network with an annual meeting to identify collaboration opportunities
- ✓ Provide a proof of concept funding scheme to support the development of new research ideas and leverage additional funding
- ✓ Continue to support and promote the Heart Hive platform and other projects that aim to facilitate research engagement
- ✓ Increase the visibility of research across the charity and use all media platforms to disseminate research findings and impact
- ✓ Improve the evidence base for the charity's influencing activity including the production of a biennial "State of the Nation" report with open access to data

### **4. Shaping local and national policy throughout the UK**

If we want to make it simpler and quicker to access appropriate support and treatment then we will need to work with the people who play a role in commissioning and managing the services that people with cardiomyopathy use and who set the policies that have an impact on their lives.

### The Goal:

We will be a vocal and effective advocate for the cardiomyopathy community, playing a fundamental part in shaping statutory services so that they meet their needs throughout their life.

### Our Objectives:

- To influence local NHS structures so they provide care in line with the charity's change agenda.
- To advocate for the needs of people affected by cardiomyopathy at a national level in all UK nations.
- To highlight variations of access to support and treatment across the cardiomyopathy community and offer solutions to address these.
- To identify and share best practice and facilitate the development of improved service provision in all nations.

### To achieve these objectives we will:

- ✓ Co-create a national policy strategy
- ✓ Recruit, train and retain advocacy volunteers able to work across all UK nations
- ✓ Update the charity's change agenda reflecting the changing needs of the community
- ✓ Create a policy infrastructure so that the charity can be represented by appropriate individuals in key policy discussions and forums in all UK nations
- ✓ Ensure that the charity has local policy expertise and is able to develop local networks in all UK regions
- ✓ Build strong networks and partnerships with relevant organisations working in genetics, transplantation, end of life care, heart failure, arrhythmia and other areas relevant to the community
- ✓ Engage with all relevant technology appraisals ensuring that the charity provides high quality input into the decision making process
- ✓ Use the charity's and others research data to highlight areas of inequality in access and provision across UK nations, disease types and populations.

- ✓ To create networking opportunity among Inherited Cardiac Conditions (ICC) centres and local health and social care providers, to better integrate ICC services with primary care

## 5. Raising awareness

Awareness is the key to ensuring that people who may have cardiomyopathy or who are at risk of developing the condition seek medical help. When people are aware of the signs and symptoms of cardiomyopathy and the history of heart disease in their family, they are more likely to seek help, get diagnosed and treated sooner, lowering the risk of a sudden cardiac event.

### The Goal:

We will take the lead in raising awareness of cardiomyopathy and be the first port of call for anyone who is concerned they may have or be at risk of cardiomyopathy and is looking for information or support.

### Our Objectives:

- To raise awareness of what cardiomyopathy is, the signs, symptoms and genetic risk factors, so that more people know about the disease and those more at risk seek medical advice when appropriate.
- To signpost individuals to the range of support and information services that the charity provides
- To promote a realistic understanding of cardiomyopathy and the impact of living with the condition.
- To be the leading voice on cardiomyopathy in the UK, particularly during key awareness raising activities such as International Cardiomyopathy Awareness Week and World Heart Day.

### To achieve these objectives we will:

- ✓ Create and run awareness campaigns on 'What is cardiomyopathy?' and symptom awareness.
- ✓ Collate a wide range of lived experience case studies reflecting all forms of cardiomyopathy and a wide range of voices for use across all media
- ✓ Create and run a targeted awareness campaign to promote the understanding of genetic risk and genetic testing in families affected by cardiomyopathy.



- ✓ Participate in key awareness events during the year, including International Awareness Week, World Heart Day, Heart Month and Organ Donation Week.

## 6. Welcoming everyone

We want to make sure that every single person that is affected by cardiomyopathy, benefits from the change that we will make. Cardiomyopathy affects people in all walks of life regardless of background, education, culture or wealth so if we want change to be meaningful and for us to be successful, we need to welcome everyone into our community.

### The Goal:

We will be there for everyone affected by cardiomyopathy. This means being visible, welcoming and accessible for everyone who needs us, where and when they need us. When someone leaves an appointment and searches online for information, we will be there. When someone speaks to their cardiologist or cardiac nurse, our information will be there. When someone goes onto our website, they will feel that this is a place where they are welcome, represented and understood.

### Our Objectives:

- To be visible to a greater number of people affected by cardiomyopathy so that more people have the choice to use our services.
- To make it as easy as possible for people affected by cardiomyopathy to access our information and support.
- To have diverse representation of all people affected by cardiomyopathy across our website, communications and resources and be a platform that elevates a wide range of voices and experiences.
- To be a place for everyone affected by cardiomyopathy, wherever they are along their cardiomyopathy journey.

### To achieve these objectives we will:

- ✓ Develop our brand and tone of voice to ensure it is reflective of the full spectrum of people affected by cardiomyopathy and their experiences
- ✓ Conduct audience insight research to inform our communications activity
- ✓ Monitor the diversity of people using our services and take action to reach groups that are underrepresented

- ✓ Work in partnership with health and social care professionals to reach underrepresented groups
- ✓ Share real-life experiences of people affected by cardiomyopathy
- ✓ Improve the accessibility and user-experience of our website
- ✓ Improve the search engine optimisation performance of our website so that it is easier for people to access our information and support

## 4. Building our Community

We know that we will not be able to affect the change we wish to make without the support and engagement of our community. For this reason, we have set ourselves clear goals and objectives in two additional areas of work;

7. Communicating the difference we make
8. Funding our work

### 7. Communicating the difference we make

We cannot hope to achieve the changes we want to make without the continued support, dedication and motivation of our community. That is why it is vital that we keep everyone up to date with our work and are able to share our successes and challenges with the community.

#### The Goal:

Our community will know the impact of our work and the important part their support has made in helping us achieve our mission.

#### Our Objectives

- To engage the cardiomyopathy community in our work and bring them along with us on the journey to achieving our vision.
- To be transparent and honest about the challenges we face as well as celebrating our achievements.
- To store and use data responsibly and ensure that all communication with our supporters is conducted in line with regulations.

#### To achieve these objectives we will:

- ✓ Provide updates on progress towards our strategic objectives through regular communications and annual impact reporting
- ✓ Continue to develop our relationship database and meet best practice in our data handling

### 8. Funding our work

If we are to bring about the change we want to make, we will need to increase our income over the next five years and do so in a way that is in keeping with our charity values.

### The Goal:

By 2028 our income will have doubled to £2million so that we can fund our ambitious plans.

### Our Objectives:

- To harness the passion of people affected by cardiomyopathy, those involved in their care and anyone who cares about the condition, turning this passion into action.
- To provide opportunities to get involved in supporting our work that engages all our community and inspires them to contribute and be part of achieving our vision.
- To be clear and realistic about what is required to fund our ambitious plans, the need for the action we take and the impact we aim to achieve from it.
- To conduct all fundraising activity responsibly, in line with charity regulation and in keeping with Cardiomyopathy UK's values, vision and mission. When making decisions about funding, we will carefully consider cost-effectiveness, sustainability (both for the charity and the wider environment) and the safety of our supporters.
- To be agile and entrepreneurial in our approach, proactively seeking and being responsive to new funding opportunities.

### To achieve these objectives we will:

- ✓ Inspire and support people to hold and take part in fundraising events
- ✓ Invest in digital fundraising tools that provide easy and accessible ways for people to engage, donate and support the charity
- ✓ Regularly evaluate the funding portfolio and take prompt action to mitigate any risks to income sustainability
- ✓ Produce annual reports in line with charity commission requirements
- ✓ Develop our data and monitoring practices to continually evaluate the cost-effectiveness of our fundraising activities
- ✓ Develop existing and new relationships with funders to generate additional income through trusts and foundations, commercial partnerships and research activity

## **5. Meeting our Goals**

### **Working in partnership**

One of our core values is to be collaborative. This is because we know that we can only achieve our ambitious goals through working in partnership with other stakeholders. We have worked hard to develop good relationships with other health and social care charities and professional organisations such as the Alliance for Heart Failure, the British Heart Foundation, the Association for Inherited Cardiac Conditions and a host of other charities and professional organisations. We will continue to work in this way and find opportunities, where our objectives align, to work with others to meet our goals and deliver for our community.

### **Our role in the international community**

We are a UK charity and as such our focus will always be to support people affected by cardiomyopathy in all UK nations. Our support services, information and policy work are designed to meet the needs of our community and the unique challenges they face.

It is also important to recognise that cardiomyopathy is a global issue and we do not have all the answers. That is why there is real benefit to our community from working in partnership with cardiomyopathy charities, healthcare professionals, researchers, medical associations, and policy makers across the globe.

Our work as part of Global Heart Hub's Cardiomyopathy Council enables us to learn from other similar charities, amplify our voice and put the charity on a global stage. As part of this network, we will continue to play a leading role in international cardiomyopathy projects such as awareness campaigns and work that energises global research initiatives.

We will also continue to work with the International Cardiomyopathy Network (ICoN) the network of cardiomyopathy healthcare professionals and scientists. In addition we will continue to work with groups such as the European Society of Cardiology to ensure that their best practice and policy setting work reflects the needs of our community.

### **Developing Volunteers and Staff**

We rely on a fantastic team of volunteers to deliver our work and over the next five years we will need to grow this team and make sure that each one of them has the appropriate training and support to do their work. We want our volunteers to feel appreciated and enthusiastic about the contribution they make and to stay with us for a long time. We also want to make sure that we are supporting our staff and that they have opportunities to grow and develop while they work for the charity. We will invest resources each year to fund staff

and volunteer training and ensure that the right staff and volunteer recruitment, management and support processes and policies are in place.

## **Monitoring our progress**

This document is designed to guide our activity over the next five years. As the environment continues to change, and new opportunities and challenges emerge, our plans will need to be reviewed regularly to make sure that they are still the best means of achieving the goals we have set out.

Our Trustees are ultimately responsible for ensuring that the charity remains on track and work with the staff team to monitor progress. Trustees also work with the staff team to translate this five year strategic plan into annual operational plans and budgets that give specific targets and timeframes for each activity.

Over the next five years we will keep all our stakeholders up to date with the progress we are making via our MyLife magazine, annual reviews, events and regular communications.

## 6. Join Us

We believe that the challenges cardiomyopathy creates are best addressed by bringing together people affected by the condition, healthcare professionals and charity professionals. By working in this way we have the insight, clinical knowledge and skills we need to deliver our work and meet our objectives.

Our team of trustees bring with them a wide range of skills and have all been touched by cardiomyopathy in some way either as people with the condition, carers or as someone who has sadly lost a loved one. They are always working to meet best practice in charity governance, and take the lead in monitoring our progress against plans to ensure that we deliver great work on time and on budget.

Our clinical advisory group is made up of leading healthcare professionals and researchers in cardiomyopathy. They come from across the UK and represent a range of specialisms. The clinical advisory group helps the charity to ensure that its work is clinically relevant, they advise on changes in clinical practice and NHS services and enable us to extend our network of healthcare professionals.

Our volunteers play a significant role in helping us to deliver our services and to spread the word about cardiomyopathy. We have volunteers who are willing to share their story with the media, to run support groups and help others to deal with the emotional impact of cardiomyopathy. We have volunteers who give up their time to help at events and in our office as well as volunteers who take on truly inspiring fundraising challenges to raise the funds we need for our work.

Our staff team bring with them a considerable amount of professional and clinical experience. They share a commitment to our cause and their skill means that we can deliver on our objectives and make a significant impact.

You can find out more about our work and how you can be part of our team at [www.cardiomyopathy.org](http://www.cardiomyopathy.org)