

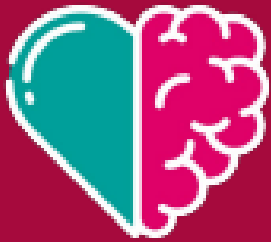
Chief Executive

Appointment Brief, December 2024



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.

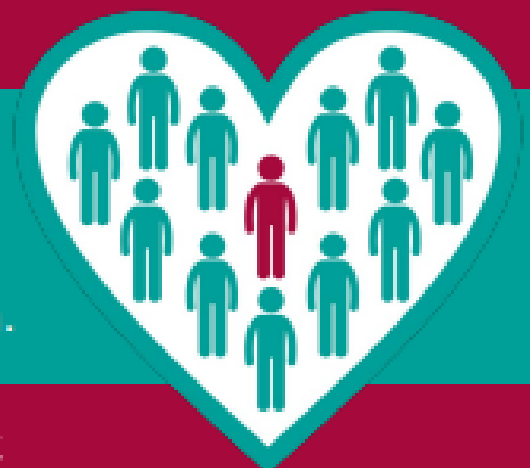


We promote clinical research to advance the development of new treatments and provide hope for the future.



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.



Dear Candidate,

Thank you for your interest in becoming Cardiomyopathy UK's next Chief Executive Officer (CEO). If successful, you will have the opportunity to lead a passionate community of volunteers, trustees and staff whose commitment to improving the lives of people affected by cardiomyopathy means that our charity has a huge impact.

You will be supported by a fantastic trustee team. Like most of our volunteers, we all have our own story to tell about how cardiomyopathy has affected our lives and the lives of our loved ones. We also all know how the right support and information, public awareness, education, advocacy and research can transform lives and help to achieve our ultimate vision that people with cardiomyopathy should live long and fulfilling lives. You will also have the backing of our excellent staff team who have the skills needed to transform strategy into action so that the charity can really deliver for our community.

It is a great time to be joining the charity. We have a strategy in place, a strong reputation, and financial stability. Our new CEO will have the time they need to find their feet and use their creativity and strategic thinking to work with staff, trustees and volunteers to develop plans, raise ambitions and identify new ways in which we can support people affected by cardiomyopathy.

Our next CEO will be a strong leader, confident spokesperson, and powerful ambassador, who is able to develop successful partnerships and influence stakeholders to ensure the future growth and development of the charity. They will need to be commercially astute with proven expertise in driving financial sustainability and effective fundraising, and the desire to foster a positive and caring culture.

Above all, our new CEO will share our values and our passion for improving the lives of those living with cardiomyopathy and their families by making a positive difference. If you feel you have the passion, ambition, enthusiasm, and leadership skills we are looking for, I look forward to hearing from you.

Yours sincerely,

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

What is cardiomyopathy?

Cardiomyopathy is a disease of the heart. It is not a single condition, but a group of conditions that affect the structure of the heart and reduce its ability to pump blood around the body. Cardiomyopathy can affect anyone, at any age. It is thought to affect around 1 in 250 people. That's approximately 266,000 people in the UK currently living with the condition.

The function of the heart is to pump blood around the body, carrying oxygen and nutrients to 'feed' the cells and organs. So when the heart doesn't work properly or as efficiently as it should the cells and organs don't get enough oxygen and nutrients. This can lead to tiredness, breathlessness, swelling in the abdomen and ankles, dizziness or fainting, palpitations and a risk of sudden cardiac death.

Some types of cardiomyopathy are caused by genetic change in the person's DNA which affects how their heart develops. Genetic conditions may be inherited so cardiomyopathy sometimes runs in families. Often if one person is diagnosed with cardiomyopathy, it is recommended that their close family members are tested for the condition too.

Cardiomyopathy is serious and frightening and as well as the physical impact, the condition can also have a significant impact on the emotional wellbeing of a person with cardiomyopathy and on their loved ones.

Cardiomyopathy can be managed through medication, implanted devices, surgery or in some cases a heart transplant. While there is no cure for the condition, it is possible to live a full life with cardiomyopathy.

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 bring 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. We work to provide support and information so that nobody has to face cardiomyopathy alone. We fight for better access to treatment so more people get the help they need. We shape research so that it truly addresses the needs of our community and we raise awareness so more people seek help sooner and fewer people are at risk of sudden cardiac death.

Our Values



Caring

We're devoted to supporting people affected by cardiomyopathy.



Dedicated

We're committed to providing information, advice and support across the UK.



Responsive

We reach out to anyone who needs us.



Collaborative

We work with others to benefit those affected by cardiomyopathy.



Realistic

We're honest about cardiomyopathy and the impact it can have.



Ambitious

We are ambitious about the impact that we want to make and are not afraid to set challenging goals, try new ideas and think big.



Evidence based

We provide up-to-date specialist knowledge about cardiomyopathy and ensure that our policies, comments and decisions are underpinned by robust evidence.



Vision

Our vision is that everyone affected by cardiomyopathy should live a long and fulfilling life.



Mission

In pursuit of our vision, we raise awareness, provide support, improve care and treatment and shape research to provide hope for the future.

The change we want to make:



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



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



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



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



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

What success will look like

While our new CEO will have the autonomy to bring their own ideas and insight to the role, success for them and Cardiomyopathy UK is likely to look like this:

One year from appointment:

- The new CEO has hit the ground running, building strong relationships internally and externally, and the charity has not lost its momentum in the transition period.
- The new CEO has reviewed the current strategy, and has identified gaps and opportunities, including launching some new projects.
- The new CEO has developed their own network, leading to:
 1. The charity's research and policy work, including advocacy and international influence, has been further developed.
 2. The charity has maintained and built strong relationships with the pharmaceutical industry.
- The charity has reviewed and built its social media presence, and uses it as an effective communications tool.

Five years from appointment:

- The profile of Cardiomyopathy UK and of the condition have been raised significantly, with greater public awareness of the condition. When a person is diagnosed, it will not be the first time they have heard of cardiomyopathy.
- Cardiomyopathy UK and our CEO have an international reputation in relevant clinical circles.
- The charity plays a key role in the network of similar charities around the world, with our CEO being a prominent figure.
- Cardiomyopathy UK is firmly established as the go-to organisation for patient access and insight for cardiomyopathy research.
- The charity reaches everyone in the UK affected by cardiomyopathy, including people in "hard to reach" communities.
- The charity is still fully centred on people affected by cardiomyopathy, and has kept its community feel.

Job Description

Post title:	Chief Executive
Accountable to:	Board of Trustees (via the Chair of Trustees)
Contract type:	Full time permanent. 35 Hours. 26 Days Holiday p/a
Salary:	£70,000
Location:	Cardiomyopathy UK office, Amersham, Bucks/ Remote working

Job summary

The Chief Executive of Cardiomyopathy UK is responsible for leading the development and management of the charity in line with its objectives and the on-going needs of people affected by cardiomyopathy.

The post holds ultimate responsibility for ensuring that the management of staff and resources delivers an optimum result for users of the service, a legally compliant organisation and a supportive working environment for employees and volunteers.

Main areas of activity

Strategic and operational planning

The postholder will be responsible for developing the charity's strategic plan and operational plans in accordance with the strategic direction determined by Trustees. Activities include:

- Working with the Trustee team to agree medium and long term strategic objectives.
- Consult with staff, volunteers, service users and other relevant external stakeholders to review strategic objectives and subsequent annual operational plans
- Keeping up to date with relevant changes in the health and regulatory environment to ensure that plans and objectives remain relevant and meet the needs of the cardiomyopathy community.
- Regularly review and assess the need of people affected by cardiomyopathy to ensure that the charity's services are appropriate and impactful.

Governance

The postholder will work with the Chair of Trustees to ensure the Charity meets all governance requirements and meets best practice in charity governance. Activities include:

- Providing support to the Chair of Trustees in conducting regular trustee meetings.
- Ensuring trustees have the information required to facilitate decision making and measure progress against objectives.
- Ensure relevant policies are in place, regularly reviewed and complied with.

Management and leadership

The post holder will be responsible for managing the senior leadership team (SLT) and providing leadership to the wider staff and volunteer team. Activities include:

- Ensuring all staff have clear objectives in-line with operational plans and that progress is measured appropriately.
- Working with the SLT to ensure HR policies and practices are in place and meet the needs of the charity and the wider staff team.
- Ensuring that staff team feel supported, motivated and have opportunities for development within the organisation.
- Ensuring all volunteers have the skills and resources needed to meet the objectives of their roles and that they feel safe, supported and motivated.
- Setting a positive organisational culture and leading by example.

Financial oversight and risk management

The post holder will work with the Chair of trustees, Treasurer and Head of Finance and Operations to ensure the financial stability of the charity and that potential risks are identified and managed. Activities include:

- Working with the Head of Finance and Operations to share financial management information with trustees on a regular basis and effectively communicating relevant financial information.
- Ensuring that the charity makes best use of its resources in pursuit of its objectives, minimising waste and increasing efficiency.
- Reviewing organisation risks and putting in place relevant processes to mitigate risks including financial and data security measures and emergency procedures.
- Work with Head of Finance & Operations, Treasurer and other members of SMT to prepare the organisations annual budget.

Growth and development

The post holder will work with the Head of Fundraising and wider staff team to identify opportunities to grow the charity's income and diversify income streams. Activities include:

- Supporting the Head of Fundraising in all fundraising activity and represent the charity to key organisational and individual funders.
- Managing the charity's relationships with the pharmaceutical industry in-line with the charity's policy of accepting income from this source.
- Ensuring the health and wellbeing of fundraising volunteers including those taking part in challenge event activities.

Representation and advocacy

The post holder will seek opportunities to advocate for the need of people affected by cardiomyopathy. Activities include:

- Working with the Head of Research and Policy to define and seek opportunities to advance the charity's policy objectives.
- Representing the charity and people affected by cardiomyopathy in relevant NHS, Department of Health, Clinical and charity forums.
- Acting as a spokesperson for the charity in traditional and social media forums, conferences and relevant events.
- Work with the Head of Research and Policy to provide evidence for NICE appraisals and to underpin policy objectives.

Stakeholder development and networking

The post holder will represent the charity at all levels to develop strong relationships with all relevant stakeholders. Activities include:

- Working with the Charity's president and vice presidents to build strong and mutually beneficial relationships within the clinical, NHS and policy communities.
- Building strong relationships with other relevant patient organisations both in the UK and internationally that will provide benefit to the charity's community.

Person Specification

Experience

- Relevant, recent and substantial experience of working at a strategic leadership level in the not-for-profit/charity sector, ideally in the clinical / health field
- Experience of developing and implementing wide-reaching strategic plans for organisations, and leading teams through the resulting organisational change.
- Business development experience, with a track record of growing organisational income, with an ability to identify emerging trends and deliver on opportunities.
- Experience of successfully overseeing use of resources to deliver on organisational goals, including budget management at a comparable scale.
- Experience of holding an ambassadorial role, including a successful track record of stakeholder management, influencing external organisations and raising an organisation's profile.

Skills and abilities

- Leadership skills to undertake a complex management role in a national organisation with international reach.
- Ability to “horizon scan” – seeing wider operating environment for the organisation and anticipating risks and opportunities.
- Ability to advocate for a community to a range of audiences, including the general public, senior clinicians and policy makers.
- Strong communication skills and the ability to engage a wide variety of internal and external stakeholders.

Knowledge

- Demonstrable understanding of the clinical and charity sectors, and a willingness to develop further knowledge in both areas as needed.
- An understanding of research and policy, and how the two areas interact.

Education and training

- No one specific qualification is required, but evidence of recent continuing professional development in a professional area relevant to the post is required. For example: Governance of Charities; leadership; lobbying and strategic policy formulation.

Application Process

Applications Closes:	09.30 Monday 13 th January
Stage One interviews	Week of 20 th January
Final Stage interviews	Week of 27 th January

To apply for this role, please send a C.V and cover letter (no more than 2 pages) outlining your suitability for the post and why you are interested in joining the Cardiomyopathy UK team.

Please send application to joel.rose@cardiomyopathy.org

For an informal conversation about the role please contact Joel Rose, Chief Executive
joel.rose@cardiomyopathy.org

More information about us and our work

[Strategic Plan](#)

[Annual Report 2023](#)