myLife

The magazine for people affected by cardiomyopathy and myocarditis

Karen's story

Our five year strategy

Top 10 research priorities

Cardiomyopathy UK
the heart muscle charity

Issue 35
Spring 2024

Contact us

If you would like more information on our services, please get in touch

Call or write to us

75A Woodside Road
Amersham
Buckinghamshire
HP6 6AA

01494 791 224

Helpline
0800 018 1024
(free from a UK landline)
8.30am-4.30pm, Monday-Friday

Find us online

www.cardiomyopathy.org

contact@cardiomyopathy.org

Live chat
www.cardiomyopathy.org
8.30am-4.30pm, Monday-Friday

Social media

/cardiomyopathyuk

@cardiomyopathy

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Welcome to our spring edition of MyLife.

As the evenings get lighter, the days longer and the weather warmer, we welcome the signs that spring is just around the corner and the much-anticipated summer months will soon be upon us. Maybe that might inspire you to get out there and take on a new challenge. With the London Marathon just a month away our team of runners are in training, pounding the streets and increasing their fitness levels in preparation. Our fundraising section might just inspire you too, see page 20.

The beginning of the year has been busy with lots of new developments, and we celebrated the launch of the charity's new five-year strategic plan. With the advances in research and new drugs coming on board, it is heartening to know that our understanding of cardiomyopathy is also increasing. With these things in mind, the time is right for us to take advantage of new opportunities and be more ambitious about what we can achieve together. See page 4 for an overview of the plan.

In January we held the final meeting of our partnership with The James Lind Priority Setting Partnership/Future Research Project in Birmingham. The meeting was well attended by people affected by cardiomyopathy, volunteers and healthcare professionals who have worked together over the past year to identify the top ten priorities for future cardiomyopathy research. Unsurprisingly the top priority was "What are the emotional and psychological impacts of living with cardiomyopathy? How are these treated and managed?" You can read the full list on page 8.

Talking of planning, I am off now to plan for my big birthday celebration this month!

My good wishes to you all.

Rita Sutton, Chair

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Our five year strategy

Our five year strategy sets out our work and objectives from January 2024 to December 2028 and shows how our work will bring about the changes we believe are needed.

Over the next five years, we want more people living with cardiomyopathy to receive the treatment and support they need to live a long and fulfilling life. We want health and social care professionals to be better able to detect and treat cardiomyopathy and we want to continue shaping research that will improve the long-term future of cardiomyopathy care.

Our vision:

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

Our 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:

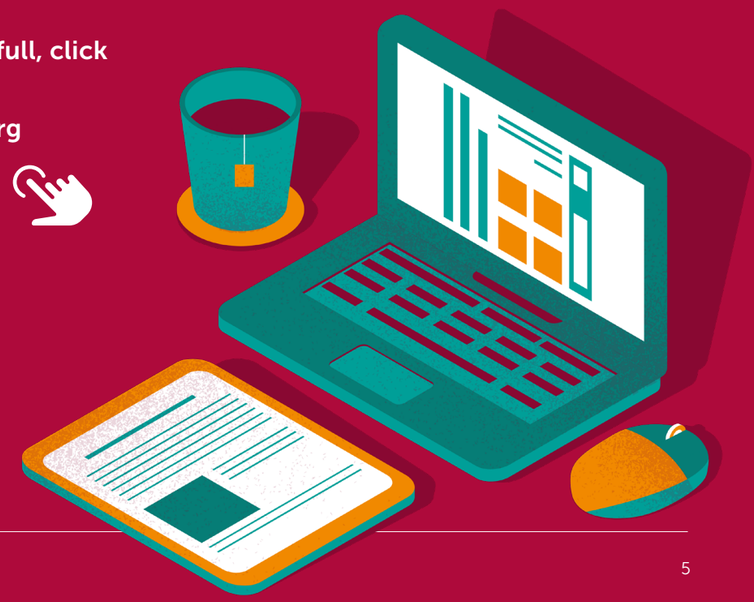
- **We want to improve the ability of people affected by cardiomyopathy to cope with the condition.**
- **We want health and social care professionals to be better able to detect and treat cardiomyopathy.**
- **We want there to be better treatment options and support services for people with cardiomyopathy.**
- **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.**

Our goals:

1. **Supporting people with cardiomyopathy and their loved ones:** 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.
2. **Working with health and social care professionals:** 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.
3. **Promoting and shaping the most impactful research:** We will be a leading driver of the highest quality clinical and experience-based cardiomyopathy research that delivers real benefits to our community.
4. **Shaping local and national policy throughout the UK:** 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.
5. **Raising awareness:** 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.

To read our 5 year strategy in full, click the link below or visit:

www.cardiomyopathy.org/our-five-year-strategy



Karen's story

Karen was diagnosed with arrhythmogenic cardiomyopathy (ARVC) in January 1991 when she was 24 years old. Karen has shared her cardiomyopathy journey with us, from the initial diagnosis to now living with the condition for over 30 years.

The diagnosis

I was experiencing a few symptoms before my diagnosis. I started to notice my heart doing strange things. I was quite fit so my fast heart rate, popping out of my chest like Popeye, and feeling sweaty at minor exertion, seemed odd.

The process of getting a diagnosis was fairly quick. I was studying in Bath at the time of my diagnosis, and my GP, Dr Hubbard suspected ARVC almost immediately. I was put on a 24-hour Holter monitor which confirmed the diagnosis and recorded a heart rate of 360 beats per minute when I was climbing a flight of stairs.

Before being diagnosed with ARVC, I thought heart conditions were something older people had. A friend of mine had a pacemaker when she was only 20 which I thought was strange, little did I know that I would be fitted with an ICD (implantable cardioverter defibrillator). It was a Friday evening at the end of October 1993, and I was returning home on the bus. On that fateful evening, I decided to go to a yoga class. At approximately 6pm that evening I suffered a cardiac arrest. Fortunately, a member of the public performed CPR, an ambulance crew followed, and fifteen minutes later the paramedics brought me back to life with a defibrillator. I can't remember a great deal of this time. There was a film crew in the back of the ambulance making a programme about the South West Ambulance Service. They recorded everything of my cardiac arrest. Looking at myself is not an easy watch.

The emotional impact of cardiomyopathy

When I was first diagnosed, I admit to feeling a bit defeatist, and I struggled to settle into life and work. My sister remembers my cardiac team talking about me, saying I was unlikely to make it to 40. I chose to ignore that, and I'm glad I did, I'm nearly 57 now. I decided to see my diagnosis as a challenge. ARVC wasn't going to beat me. I was told early on that I wouldn't be able to have a family, which was devastating but at the same time, I was glad to be alive.

It hasn't been easy for my family or friends. My parents were living in Cyprus at the time of my cardiac arrest and had a horrific flight over to the UK, not knowing if I was dead or alive. I tended to avoid the pitying stares and distanced myself from many of my friends. While they were getting married, having their own families, and building their lives, I was dealing with a different reality.

Living with cardiomyopathy

I work part-time as a career adviser. Stress is my enemy, so I try to keep it to a minimum. I don't like it when my device shocks me. Feeling it building up to shock is almost more frightening than the shock itself, and then knowing that I'm going to lose my driving license is devastating. I gave up alcohol recently because I think that might have contributed to some of the shocks I was getting. I didn't drink a lot, but I still think it influenced my arrhythmias. For nearly twenty years I didn't experience many shocks, and in thirty years of living with ARVC, I haven't had much advice about alcohol and healthy eating. I've always been passionate about good food and I'm sure this has helped me.

> "I pinch myself every day for the second chance I've been given - I'm the luckiest woman alive."
>
> - Karen

My husband and I have two allotments. I've always loved cooking and eating, so getting an allotment seemed like a great pairing. We had the first one for eight years and decided to take on a second one this year to grow asparagus, which takes three years, and more soft fruits and fruit trees. I can dig right down to the ends of the earth for bindweed – that's probably the hardest job - I enjoy digging over the plots every winter, but of course, weeding in the summer is much easier.

I make sure I understand as much as I can about my condition, the advances in ARVC, and my drugs. Education is power, and it helps me to help myself. I feel I owe it to the great cardiologists who helped me to do my bit.

To read Karen's story in full, click the link below or visit:

www.cardiomyopathy.org/news-blogs/karens-story

Top 10 future research questions for cardiomyopathy

After several months of consultation and analysis, the list of the 10 research priorities for cardiomyopathy has now been published.

On the 2nd of February at the final workshop, people with lived experience of cardiomyopathy and healthcare professionals came together in groups to discuss which questions should make the final 10 priorities. Many people in the cardiomyopathy community have been involved in this project, which is an established process conducted in partnership with the James Lind Alliance.

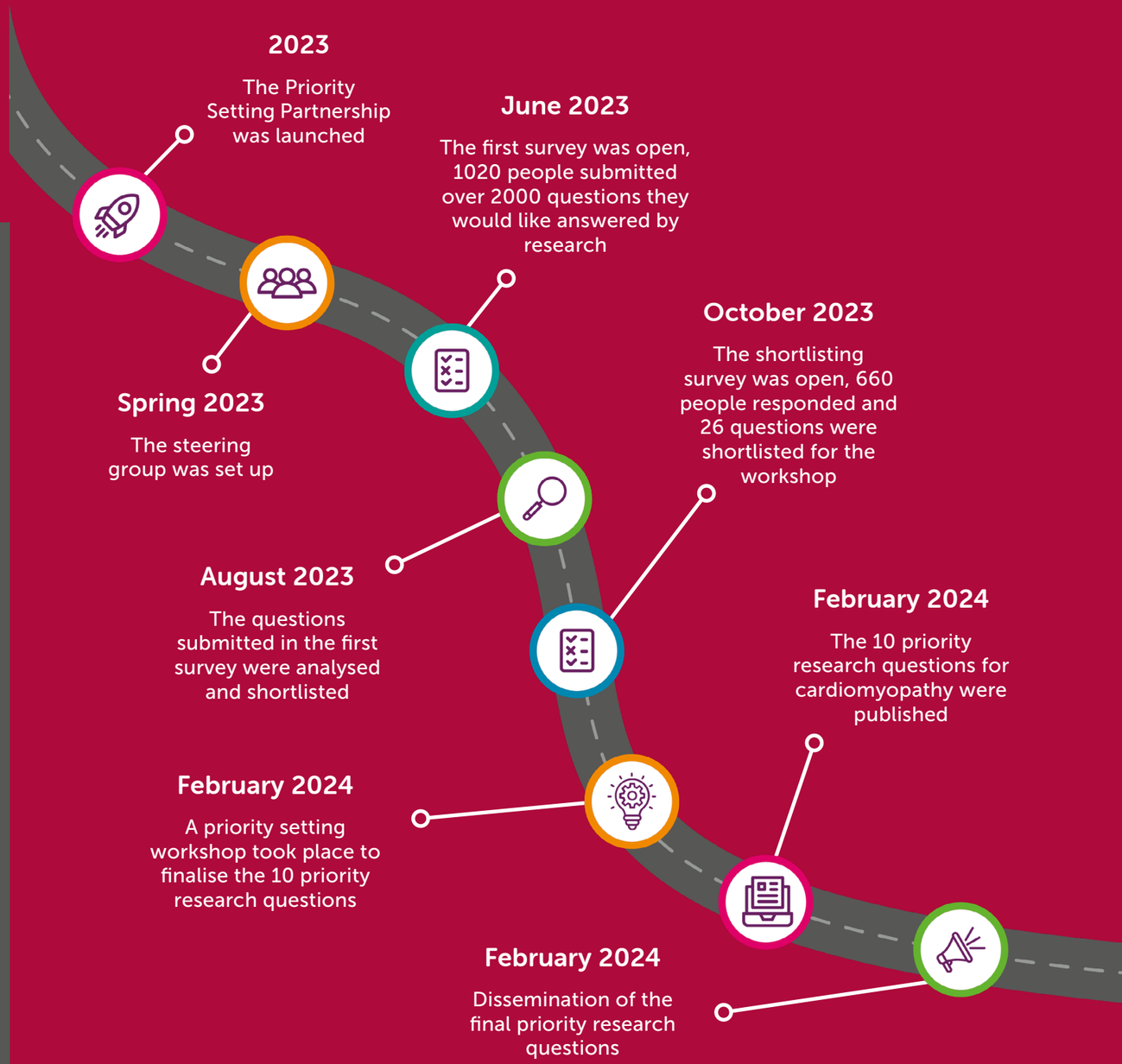
Here we are pleased to reveal the final 10 questions to you:

1. What are the emotional and psychological impacts of living with cardiomyopathy? How are these best treated and managed?
2. How often should family members at risk of developing cardiomyopathy be screened and which are the best tests to use? When is it safe to stop screening?
3. Should treatment for cardiomyopathy be tailored to the individual, e.g. based on their specific gene variant, age or gender?
4. What triggers the start of cardiomyopathy (e.g. age, stress, pregnancy, other health conditions)? How do these triggers work and can they be blocked?
5. Are there treatments which can prevent cardiomyopathy developing in people at risk? Are there treatments to stop it getting worse in people with symptoms?
6. What are the biological mechanisms that change heart muscle cells in cardiomyopathy? Could this understanding lead to new treatments?
7. Why are people with the same genetic variant affected differently? Why do some people with a genetic variant never develop cardiomyopathy? Could this understanding lead to new treatments?
8. Do people with cardiomyopathy experience better outcomes if they are treated at a specialist clinic rather than a general clinic?
9. What does ongoing monitoring and long-term care for people with cardiomyopathy need to include?
10. What are the best approaches to cardiac rehabilitation for people with cardiomyopathy?

It is important to say that the list of questions is not a top 10 – each question in the list is a priority, but it does help us all to focus on what research the community wants and what research we should prioritise.

Timescales

The timeline below shows the process. It involved consulting with the cardiomyopathy community through 2 surveys and a final discussion workshop. In the first survey, over 2000 questions were submitted. Through the process, these questions were narrowed down to 26 which went to the workshop. The final 10 questions were discussed and decided in the workshop.



How were the questions decided?

The process of determining the 10 priority research questions is a democratic process. The views of people with lived experience of cardiomyopathy are given equal value to those of healthcare professionals. It involved consulting with the cardiomyopathy community through 2 surveys and a final discussion workshop. In the first survey, over 2000 questions were submitted. These questions were narrowed down to 26 which went to a final priority setting workshop.

Priority setting workshop

The workshop was a fantastic day. It was very well attended by a cross sector of the cardiomyopathy community – people affected by cardiomyopathy, family members, doctors, nurses, psychologists, and genetic counsellors – which shows how committed and passionate the community is.

The 26 questions were discussed in group sessions and, through positive debates, the workshop participants came to the consensus on the final ten priority questions for future research.

What was impressive in the discussions was the high quality of the debate and watching participants change their own views once they heard the perspectives of others. It was especially important that people with lived experience had the same opportunities to decide on the 10 priorities as healthcare professionals. As one participant said, "As a patient, I felt so privileged to be there. What was impressive on the day was the robustness of the process, and we all felt safe and confident to speak our views."

Next steps

Now we have the research priorities for cardiomyopathy, we need to promote these, and seek opportunities to influence researchers to undertake the research and to secure funding streams. Some of the initial activities will include presenting the cardiomyopathy future research priorities project at cardiology related conferences and submitting articles to journals.

In the longer term, Cardiomyopathy UK will have conversations on which questions, when researched, could have a bigger impact on people affected by cardiomyopathy. We will also be approaching funders and looking for potential funding for the research.

In a way, the process of deciding on the priority questions was just the start and now we need to make sure that we can finally get answers to some of the questions that the community wants.

To learn more about the priority setting process, click the link below or visit:

www.cardiomyopathy.org/future-research

My Insight:
Our upcoming national survey

Every two years, Cardiomyopathy UK undertakes a 'state of the nation' survey of our community.

We ask questions about people's experiences of living with cardiomyopathy, to learn what's going well and where improvements are needed. We use these insights to underpin our influencing work.

The next survey will be called My Insight and will be going live later this year (expected: summer 2024). In order to make the survey bigger and better than ever before, we are working with a professional survey company: Picker Institute Europe. Picker delivers a wide range of health surveys, including NHS surveys, and has excellent credentials in data collection and analysis.

We're keen to make sure that a wide variety of people respond to the survey, including people with cardiomyopathy or myocarditis, and their families. This will give us the deepest possible insight into people's experiences. It will also provide strong underpinnings for our work to positively influence the structures and services that impact on people's experiences of treatment and care.

So, whoever you are, from whatever walk of life, and whether newly diagnosed or been living with cardiomyopathy for a lifetime, we will want to hear from you.

When the survey goes live, it will be sent out by email to those subscribed to our email lists. Those who only receive post from us will receive a paper copy of the survey through the mail. Picker will be sending out the surveys on our behalf, so please make sure to look out for the email/posted copy. We will provide further information about send out dates in future communications, including the next edition of MyLife.

Over the next few months before the survey goes live, Picker will be developing the survey. This will involve speaking directly with people affected by cardiomyopathy to make sure the survey asks the right questions, in the right way.

Thank you to those of you who completed our last national survey back in 2022. We received over 600 responses and since then we've used the evidence gathered to underpin important work including:

- **Advocating for improved mental health provision for people affected by cardiomyopathy and looking at our future service offer.**
- **Providing evidence to the NICE and the Scottish Medicines Consortium (the regulatory bodies responsible for approving new drugs) in support of mavacamten**

If you would like to stay up-to-date, you can join our mailing list. Click the link below or visit:

www.cardiomyopathy.org/stay-touch

Research in focus: CureHeart

The CureHeart research project aims to find the world's first cures for inherited cardiomyopathies. Here is everything you need to know about the project.

What is CureHeart?

CureHeart is a £30 million research programme funded by the British Heart Foundation. It supports a team of international world-leading scientists, aiming to develop cures for inherited cardiomyopathies using genetic therapies.

The aim is that these therapies will prevent cardiomyopathy from getting worse, and perhaps even reverse the disease. They may also prevent the disease from ever developing in family members who carry a faulty cardiomyopathy gene.

By the end of the project (late 2027), it is hoped that at least one therapy will be ready for clinical trials. If the trials are successful, this would represent a huge step forward.

What causes genetic cardiomyopathy?

DNA is present in every cell in our bodies. It provides the genetic instruction manual that tells our bodies how to build proteins, the body's building blocks. Our DNA is sorted into approximately 20,000 pairs of genes, each of which provide instructions for (code for) making a specific protein.

Inherited cardiomyopathies are caused by having a single faulty copy of one of a pair of genes which code for heart muscle proteins. It is like having a genetic 'spelling mistake'. This small but important mistake means the gene is issuing faulty instructions. Each genetic fault is rare and can be unique to a family.

In some cases, the faulty copy of the gene makes faulty proteins. Faulty proteins stop healthy proteins from working normally in the heart.

In other cases, the faulty copy of the gene does not produce any protein. Having one working gene means there are not enough healthy proteins made to keep the heart working properly.

How would genetic therapies work?

Inherited cardiomyopathies are complex to cure, as different approaches are needed depending on the type of genetic fault.

To prevent cardiomyopathy caused by a faulty gene making faulty protein, two approaches are being developed.

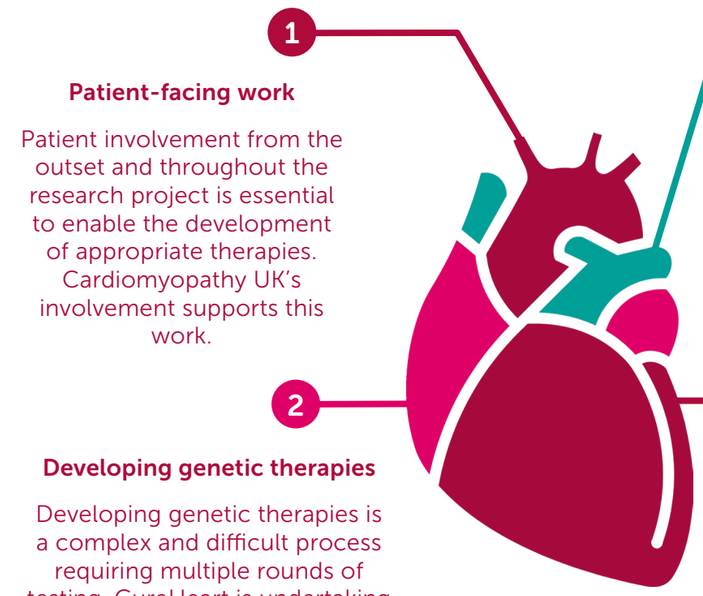
The first blocks the production of faulty proteins. This enables the healthy protein to function normally, allowing the heart to return to a healthier state. It is hoped that this approach will lead to a curative therapy involving periodic treatment by injection. Ongoing injections could prevent people who have inherited faulty genes such as these from ever developing cardiomyopathy.

The second approach uses gene editing. This would potentially offer a more permanent cure. The CureHeart team are developing cutting-edge gene editing tools that would permanently switch off the faulty copy of the gene by changing the DNA, so no faulty protein is produced. So, a single therapy could treat many different genetic faults within a single gene, preventing them from ever causing cardiomyopathy.

Some cardiomyopathies occur because a person has only one working copy of a gene, but both are needed to produce enough protein. To prevent cardiomyopathies caused in this way, a different gene editing approach is needed. This would involve boosting protein production from the healthy copy of the gene. This work is at an earlier stage in development.

From research to cure

For CureHeart therapies to become available to patients, the CureHeart team will need to work with commercial partners and pharmaceutical companies. Such companies test therapies to ensure they meet the high standards required to start treating patients. They also steer therapies through the regulatory processes required for a cure to become available on the NHS.



To learn more about the CureHeart project, click the link below or visit:

www.cureheart.org

Our youth project

We are excited to be championing the voices of young people at Cardiomyopathy UK, supporting them to share their experiences and to help others. 2024 is shaping up to be a productive year for our youth volunteers, and we're only just getting started! Here's an insight into the work we've been getting involved with already.

Volunteer Spotlight:

Toby, 14, is completing his Duke of Edinburgh Award with Cardiomyopathy UK. Those of you who were at our National Conference may have seen Toby hard at work on our welcome desk or busy organising rooms. Since then, he's been helping create new youth-focused content for our website, looking at what it's like to have a parent living with cardiomyopathy.

Q: What inspired you to volunteer with us?

A: "My mum was diagnosed with dilated cardiomyopathy soon after I was born and found great support through the charity and its members. Over the years, my family have also fundraised for the charity - my dad ran a sponsored 10k, and Cardiomyopathy UK was the chosen charity for my bar mitzvah as well as for several birthday fundraisers. When I found out about the volunteering part of my bronze DofE award, I wanted to volunteer for this charity because it is really important to me and my family."

Q: What will you take away from volunteering with Cardiomyopathy UK?

A: "Volunteering helps lots of people through tough times. It also helps the charity's community to grow and has inspired me to continue to be involved with the charity."

If Cardiomyopathy UK is important to you and your loved ones, please get in touch to discuss volunteering opportunities at:

youthhub@cardiomyopathy.org

Youth Panel

Our Youth Panel is made up of young people aged 16-24, all with lived experience of cardiomyopathy – either through having the condition themselves, or through supporting a loved one.

So far this year, the Youth Panel have been busy setting their 2024 agenda. Key targets include welcoming new members onto the panel, creating new content for our website, and looking at new ways in which the charity can support young people living with cardiomyopathy.

Panel member Emma said:

"I'm really looking forward to making a positive impact and helping to give back. Hopefully we can help other young people living with cardiomyopathy to feel part of a community and not to feel alone in their experiences.

If you are a young person affected by cardiomyopathy, I think you should join the Cardiomyopathy UK youth panel. We've all had similar experiences growing up with the condition that not many other people can relate to. We have a unique opportunity to share our thoughts and opinions and to use our experiences to shape the future and make a positive impact. It's also a great opportunity to meet other people in a relaxed environment and have some fun!"

Support for Young People

Our Helpline

Our Specialist Nurse Helpline is open to everyone, Monday to Friday, 8:30am - 4:30pm. Our nurses are available by phone, email, or via live chat on our website.

Heart to Heart Peer Support

Heart to Heart matches you up with a trained peer support volunteer who understands what you're going through. Our Heart to Heart volunteers are there to provide 1-to-1 support over the phone, email, or messaging services like WhatsApp.

To learn more about our nurse's helpline & Heart to Heart, click the link below or visit:

www.cardiomyopathy.org/support

The benefits of walking

As we stroll through winter towards spring, let's take a moment to talk about the benefits of walking. A wintery or spring walk is a really good way to get outdoors and to exercise, maybe enjoy the changing seasons by looking at the winter berries, frost on the grass or spring bulbs.

Walking can bring many pleasures and can be one of the best types of physical activity. It's a great way of boosting your mood and helping to reduce stress, even if it's just a short walk to your nearest shop or a walk around a park with friends.

The benefits of walking:

- **Manage stress:** Many people can find life challenging at times, and stress is our body's response to pressures from challenging situations in life. Stress can often make you feel overwhelmed or under pressure, but getting outside can help. Research suggests that just a view of the outdoors can be beneficial, and 20 minutes of outdoor time each day can reduce levels of stress hormones.
- **Create time to be mindful:** Walking is a great form of exercise; it provides time to be mindful and think about anything which may be troubling you. This can be helpful if you are struggling with both stress and health concerns such as cardiomyopathy.
- **Spend time with others:** Shorter days and more time indoors can sometimes contribute to feeling low in mood, so staying active and keeping in touch with friends and family can help to give your mood a boost. Managing stress is important in keeping our immune system healthy, which is particularly important during the winter months.
- **Boost your mood:** Exercise can help some people feel more uplifted when they are feeling low in mood or anxious. A reduced amount of sunlight can mean that some people may not get enough Vitamin D which can also contribute to lower mood, check with your GP, practice nurse or community pharmacist for further advice.

If you have cardiomyopathy, it's important to exercise safely, enjoy your activity, listen to your body and know your limits. Wear layers which you can remove as your body warms up and remember to start slowly for the first few minutes and build up your speed gradually, remembering to reduce your pace again at the end of the walk to help your body cool down.

For more information about emotional wellbeing, click the link below or visit:

www.cardiomyopathy.org/emotional-wellbeing

30-Day Challenge

What will your challenge be?

Why not step into spring with a 30-Day Challenge and raise funds to improve the lives of people affected by cardiomyopathy? Whether you choose to try something active, learn a new skill or give something up, the money you raise will help to ensure that nobody has to face cardiomyopathy alone.

To sign up for your 30-Day Challenge, click the link below or visit:

www.cardiomyopathy.org/30day

Meet Andy:
Change maker

The Change Maker programme started in 2020. Change Makers engage with the NHS, clinicians, commissioners, and other organisations to campaign for improving healthcare for people affected by cardiomyopathy.

The volunteers shared their expertise and patient insight to influence the implementation of our Change Agenda. The Change Agenda sets out the policy and research goals that Cardiomyopathy UK is aiming for to improve health services for people affected.

We spoke to Andy about his experience of being a Change Maker over the last few years:

Q: How long have you been a Change Maker?

A: I've been involved since the programme was first set up in 2020. I read about Change Makers through the MyLife magazine and responded to the call for volunteers.

Q: Why did you volunteer to be a Change Maker?

A: I have been living with cardiomyopathy since 2012. Looking back, and hearing about the experiences of others, I realised I was very fortunate to have had a smooth route through the diagnostic and care pathway.
I volunteered so that I could speak up on behalf of those who don't have such a good journey. I want to improve care for people to reduce the fear they may feel when they're diagnosed and to help remove the restrictions we all face as a result of our diagnosis.

Q: What activities have you been involved with as a Change Maker?

A: As part of the first group of Change Makers I participated in the initial training programme. As well learning how the NHS worked, we were asked to indicate the amount of time we could commit and the sort of work we'd like to do. I opted to work at a national policy level.
For the past three years I have been a member of the patient panel for the British Society for Heart Failure alongside another Change Maker. I can raise awareness of cardiomyopathy and promote Cardiomyopathy UK's work as a member of various subcommittees. We have had the opportunity to sit on panels at the annual meeting and recently I attended the launch of a new British Society of Heart Failure policy initiative (25in25) as a patient representative.

Through the British Society for Heart Failure and Cardiomyopathy UK I have also been involved with the patient arm of the Global Heart Hub. Last September I had the privilege of attending a training course in Rome to help organisations develop a patient engagement strategy.

Q: What aspects of the role have you found most rewarding?

A: I've met some amazing people who are working to deliver better outcomes for people living with cardiomyopathy. It's great to be involved with an organisation that really values the patient voice. It's also been good to meet with other Change Makers and to see how policy work can improve the lives of people living with cardiomyopathy

Q: What are you looking forward to working on as a Change Maker?

A: I'm excited to see how the Change Makers can help to deliver Cardiomyopathy UK's new five year strategy. I would like to see people living with cardiomyopathy get more involved with making changes and getting measurable results to improve the health care system.

Q: What would you change in the NHS to improve services for people with cardiomyopathy?
A: I would push hard for GPs to have more training and gain a better understanding of cardiomyopathy. I would also like to see more mental health support. Living with the condition has an impact on the mental health and wellbeing of both the patient and their family.

Q: What would you say to anyone thinking of being a Change Maker?

A: I'd say if you're thinking about it, you've probably already recognised the need for a patient voice. You may be wondering if you can have an impact. From my experience of being a Change Maker you will have a voice and it will be heard.

To find out more about getting involved as a Change Maker volunteer contact:

laura.cook@cardiomyopathy.org

Our fundraising superstars

A big thank you to everyone donating and raising funds to support our work.

Calcot Park Golf Club chooses Cardiomyopathy UK as charity of the year

Under the presidency of Ray, Calcot Park Golf Club selected Cardiomyopathy UK to be their charity of the year. Through their annual president day, a ball sweep, their punishment jar, and other fun events through the year, Calcot Park Golf Club raised an incredible £3572!

Ray

My wife, Sylvia, was first diagnosed with hypertrophic obstructive cardiomyopathy in 2017. During that year her condition was being assessed by the cardio team consultants at The Royal Berks hospital, Reading. We were introduced to a member of the Cardiomyopathy UK team at the hospital and we become involved in the charity. When I became president of Calcot Park Golf Club I decided to make Cardiomyopathy UK my nominated charity. Due to the tremendous generosity of our club members we managed to collect £3,572 in donations during my time as president.

John takes on a park run challenge

Before his diagnosis with HOCM, John loved exercise and worked in fitness. John got in touch with Cardiomyopathy UK in 2023 after learning of his new condition. After using our services and attending our national conference, John wanted to give back. With the support of his doctors, John has been able to start slowly exercising again and so set himself a park run challenge of running or walking a different park run every Saturday.

"I chose to support Cardiomyopathy UK because they provided invaluable support and guidance after my diagnosis of HOCM and the fitting of an ICD last year. Their nurses and all the team have been a constant source of assistance and encouragement. This charity holds personal significance to me, as they've not only helped me come to terms with living with HOCM, but also helped me with my mental health focussing on raising some funds through participating in park runs in and around Essex and London and raising awareness for others." - John

Neil's run for research

Across January and February, Neil took on the challenge of a double header of runs, starting with a 5-mile race and then a 10km race. After losing someone close, Neil wanted to contribute to Cardiomyopathy UK's research work and help raise awareness of the condition.

"Last year, our family lost an amazing young man to this disease. He was an inspiration to all he met, so I wanted to do my little bit of fundraising to ensure Cardiomyopathy UK can be there to support many others." - Neil

Great North Run

8th September 2024

Join #TeamCardio

To apply for your place, click the link below or visit:

www.cardiomyopathy.org/great-north

Cardiomyopathy UK

Donation form

Please complete the form below and return in the enclosed free-post envelope to:
75A Woodside Rd, Amersham, Buckinghamshire HP6 6AA.

Or donate online at:
www.cardiomyopathy.org/donate

Your donation

I would like to make a single gift of:

☐ £10 ☐ £25 ☐ £50 £ Other

Your details

Title

First Name

Surname

Address

Post code

Telephone

Email

☐ I would like to receive updates by email from Cardiomyopathy UK about how they're providing support and information, campaigning for change, shaping future research and ways to get involved.

I would like to donate by:

☐ Cheque enclosed (made payable to 'Cardiomyopathy UK')

☐ Credit/debit card (card must be registered to the address overleaf)

Your card details

Name on card:

Card number:

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Start date: ☐☐/☐☐ Expiry date: ☐☐/☐☐ Security code: ☐☐☐☐

Is your donation in memory of a loved one? ☐ **Yes** ☐ **No**

Gift aid declaration – increase your donation by 25p for every £1 you donate

In order to Gift Aid your donation you must tick the box below.

☐ Yes, I want to Gift Aid my donation and any donations I make in the future or have made in the past 4 years to Cardiomyopathy UK. I confirm that I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Date / /

You can also donate online at **www.cardiomyopathy.org/donate** or by calling us on **01494 791224**. For any queries, please contact **fundraising@cardiomyopathy.org**

Thank you

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Cardiomyopathy UK, 75A Woodside Road, Amersham, HP6 6AA