myLife

The magazine for people affected by cardiomyopathy and myocarditis

Our #InMyFamily Campaign

Our 2022 Conference

Nurses Q&A

Cardiomyopathy UK
the heart muscle charity

Issue 30
Summer 2022

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Front page images: Sabrina and Aaliyah, from our #InMyFamily Campaign.

Welcome to our summer edition of MyLife with our chosen theme "Family".

I hope that like me you were able to spend some much-needed quality time with your family recently, maybe over the additional holiday afforded to us to celebrate the Queen's Platinum Jubilee.

I begin my introduction by sharing some sad news in that one of our longest serving trustees Chris Horwood, sadly passed away in May. Chris's family meant the world to him. Our sincere condolences go to Chris's wife Esther and their three children. Sleep peacefully Chris; see page 10 for Chris's obituary.

Many of you have told us that you had never heard of cardiomyopathy until you, or a member of your family was diagnosed. You will find Tim's story of being diagnosed with dilated cardiomyopathy and then discovering that it was genetic on page 6.

We need more people to be aware of cardiomyopathy, not just those, like Tim, who become aware when they are diagnosed. That's why we launched our "In My Family" awareness campaign. Read more about it and how you can help to raise awareness of cardiomyopathy on page 4.

In this issue our nurses answer your questions on pages 14 -15, and our nurse, Jayne, gives an overview of genetics and cardiomyopathy on page 11.

As always, we bring you the latest updates in research and policy. You will find all you need to know on page 18.

Where will you be on Saturday 19th November 2022? Hopefully with me and the CMUK team at our Annual Cardiomyopathy UK Conference. We are looking forward to holding a face-to-face conference, after two years of not being able to meet in person. Hot off the press, we share with you details of the programme which promises to be something for everyone. I look forward to seeing many of you there. See pages 8-9.

Enjoy the rest of the summer and hopefully some family time too.

Stay safe and stay well.

Rita Sutton, Chair

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#InMyFamily

Many families share traditions, mannerisms, passions, and hobbies, but they don't always know that they may share health conditions, like cardiomyopathy, too.

In our latest awareness campaign, we highlighted the importance of knowing the symptoms of cardiomyopathy and speaking openly about the condition, especially where it may be an inherited condition that could run in the family.

Raising awareness is an important part of our mission. We know that sadly when cardiomyopathy goes undiagnosed, it can cost lives, but raising awareness can change that.

Through sharing information and real-life experiences, we can save lives.

Three families have shared their experiences living with the condition, how they've navigated the diagnosis, and why they would encourage people to talk about their heart health and the symptoms of cardiomyopathy.

Visit cardiomyopathy.org/inmyfamily or scan the QR code above to learn more about the campaign, watch the videos and find out how you can get involved.

Aaliyah and Sabrina - Know the Symptoms and Go to Your GP

Aaliyah was diagnosed with hypertrophic cardiomyopathy at the age of 12. Although there were a number of signs that suggested something wasn't right, including fatigue, breathlessness and chest pains, it took some time for Aaliyah to be diagnosed.

"No-one expects children to have heart conditions. When you go to your GP make sure someone checks your heart, not just your blood pressure and the simple things, but actually listens if you've got any doubts at all. That combination of symptoms can be other things, but getting that checked, it doesn't cost anything, it's a really simple solution to a bigger problem if it's not managed." - Sabrina, Aaliyah's mum

Matthew and Alex - Talk to Family and Friends

Matthew was diagnosed with left ventricular non-compaction cardiomyopathy (LVNC) at the age of 17. Since then, his family have undergone genetic testing and discovered that the condition is inherited. While Matthew's sisters all have the gene expression, this rare type of cardiomyopathy is most expressed in Matthew and his dad, Alex.

Alex says: "the theory is it came through on the male side of my family, we think my dad may have had it, but he was never diagnosed."

Since their diagnosis, they talk a lot about their heart health as a family, and with Matthew's openness around his friends, they are also aware of the condition and its symptoms.

LaRisha - You're Not Alone

Last year, after experiencing breathlessness, loss of appetite, dizziness and unusual swelling, LaRisha was diagnosed with dilated cardiomyopathy and later discovered that the condition ran in her family. As soon as LaRisha was diagnosed, she encouraged her family to get tested.

"At the end of the day, it doesn't matter what you accumulate, health is wealth, and nothing is more important than health and family. If you know it runs in your family, you can advocate for yourself more, especially when speaking to health practitioners.

Psychologically, it was a big hit, but I will say Cardiomyopathy UK saved my life. It's that support system of speaking to people that understand exactly what you're going through. Since the moment it turned up in my life, it's been an absolute blessing".

Tim's Story

Scan the QR code to read Tim's Story in full.

Tim was diagnosed with dilated cardiomyopathy (DCM) in August 2011. From his initial diagnosis, the events that followed, and now living with cardiomyopathy, Tim shares his extraordinary journey with us.

> "I've learnt to embrace generosity through all of this, making my friends an integral part of my life, making things happen and enjoying everything I can."

My symptoms first appeared back in 2011. I was working in a high-pressure IT job which involved an extensive amount of travelling, both domestically and internationally. I began finding myself increasingly breathless to the point I would almost collapse. After one episode, I gave in and went to my GP, who told me I was stressed and that I should go on holiday to relax, which is exactly what I did.

Within 2 days of arriving in Boston, I was so unwell with feelings of exhaustion that I was unable to walk. I went to the emergency room at the Massachusetts General ER and was diagnosed with a fever that was impacting my respiration and heart, so I was sent to get some medication. At the pharmacy, the pharmacist had received a note from the hospital for me to return as they had concerns over the diagnosis. Sure enough, as I walked through the ER door, I was laid on a stretcher and told "not to move or talk as I was experiencing some form of heart failure and was in a very critical state", it was terrifying. After days of investigations, angiograms, and bloodwork, I was diagnosed with dilated cardiomyopathy with a heart function of 11% and falling.

The diagnosis was very quick, two days or so from a standing start. However, that then evolved into a hugely complex process, with the dilemma of if and how I was to be treated, and if and how I could get home. As the days passed, the roller coaster of 'you need to prepare for the worst' to 'you seem to be stabilizing' continued. All the discussions were now around how would they get me home and if I set off, would I make it.

It was decided that I would return home to the John Radcliffe Heart Unit in Oxford to have a 'Cardiac Resynchronisation Therapy Defibrillator' (a CRT-D implant). My wife Maria and I would be flown home in a Medi-Vac jet with no toilet, three doctors, a nurse and two pilots on a 17-hour journey back to the UK. The kids had to fly home on their own ahead of us and hopefully, we'd all meet at the end in Oxford. We left for home, but it wasn't plain sailing. The plane broke down on the way to Goose Bay and we had to return to Montreal for a new plan and re-start... Finally, we arrive at the John Radcliffe Hospital, and I was alive.

At the time of my diagnosis, I had no idea if I had any family history of the condition, as I'm adopted and had no contact with my natural birth mother. In the months to come, I would, through a strange turn of fate, speak to my birth mother in Canada, only to find she too had been taken ill the same week in Toronto and diagnosed with dilated cardiomyopathy.

Before my diagnosis, I was never an ill person, I'd only been in hospital twice in my life. I was, and still am a fit and active person who loved

walking and cycling. I probably did things I shouldn't have but I never imagined I was ever going to get sick. In my mind, heart conditions were for heavy smokers, drinkers, and pie eaters, that simply wasn't me. How wrong I was.

After the diagnosis, I resigned from my high-pressure job, took a couple of weeks off and joined a small tech start-up business with some friends working four days a week. I started cycling again, bought myself a new mountain bike and was very quickly joined by my mates to form a group we call "Seth's 100 Milers". That year, and every year since we go on a 100-mile mountain bike weekend trip on one of the UK's long-distance paths. Yes, I can't cycle as fast as some of my mates (even with an eBike) – but who cares?

My experience has taught me how important it is to embrace my life, family, and friends. We have plans for the future, too many for them all to play out, but I am confident things will happen, and I know they will be good things.

Life is good, I'm here, we made it and that's what counts.

Cardiomyopathy UK
Conference 2022

We are delighted that the Cardiomyopathy UK National Conference will be returning in person on Saturday 19 November in London.

Whether you have cardiomyopathy or you support someone with the condition, everyone is welcome at our conference. The conference is also open to healthcare professionals at all levels of cardiomyopathy care and presents opportunities to hear patient insights, as well as the latest expertise in cardiomyopathy care and treatment. We feel passionately that there is great value in bringing patients and healthcare professionals together in one place.

This year's conference will feature speakers on different types of cardiomyopathy as well as topics including mental wellbeing, diet, supporting children and young people, genetic counselling and the latest in research.

We often hear that the most special thing about our conference is the opportunity for people to meet others affected by the condition and we ensure that there is plenty of opportunity in the day to chat and share.

So we hope that you will join us on 19 November. By coming together again, we can look towards a brighter future where everyone affected by cardiomyopathy can live a long and fulfilling life.

While we are really excited to be together again, we also recognise that some members of our community may still be unable to make it in person. We will be recording the conference sessions and making them available on-line as quickly as we can so nobody misses out.

Scan the QR code, visit: cardiomyopathy.org/conference-2022 or give us a call on 01494 791224 to book your tickets.

> "A really enjoyable day. It's always very nice to see familiar faces and friends."

Our Conference Programme

09:30	Registration
10:00	Welcome and Key Note Speaker
10:30 - 12:00	Dilated Cardiomyopathy: Overview, Update & Q&A Hypertrophic Cardiomyopathy: Overview, Update & Q&A Arrhythmogenic Cardiomyopathy & Myocarditis: Overview, Update & Q&A Left Ventricular Non-Compaction, Restrictive Cardiomyopathy & Takotsubo
12:00 - 12:30	Morning Break
12:30 - 13:30	Genetic Counselling in Cardiomyopathy Supporting Children & Young People Peripartum Cardiomyopathy Getting the Most From Your Clinical Nurse Specialist Team
13:30 - 14:30	Lunch Break
14:30 - 15:30	Surgery & Devices for Cardiomyopathy New Drug Treatments Women's Health & Cardiomyopathy Being Active With Cardiomyopathy
15:30 - 16:30	Get Involved: Research, Policy & Clinical Trials My Rights & Cardiomyopathy Mental Wellbeing & Cardiomyopathy Diet & Cardiomyopathy
16:30 - 17:00	Closing Remarks - Chair Rita Sutton
17:00 - 17:45	Stay for a while and meet with the charity team and friends.

Subject to change*

Remembering Chris Horwood

Those of us living with, or caring for someone with cardiomyopathy, know that there have been many advances in medications and treatments over recent years. This allows us to live with hope, but as discussed in the last edition of MyLife, this has to be a "realistic hope", acknowledging that our lives are a journey, one we want to be, as the charity's vision statement puts it, "as long and fulfilling a life" as possible.

A great friend of Cardiomyopathy UK died in May, and so it is with real sadness that we record the passing of Christopher Horwood, who at the time of his death on 16th May was the longest serving member of the Cardiomyopathy UK Board of Trustees. Chris was 62 years old.

He joined the Board in 2008 and was subsequently elected as our treasurer serving in that capacity until 2014.Thereafter, Chris continued as a trustee, helping to shape many of the Board's most important decisions. His in-depth knowledge of both financial and charity matters, combined with his wide experience, and his passionate desire to see things improve for cardiomyopathy patients and their families, means that we have lost a highly valued friend. Chris was such a warm and friendly man who was always keen to chat with members and supporters at our conference, and whose contributions in Board meetings were always thoughtful, well researched, considerate and balanced.

Chris was married to Esther, and with their three children, home was near Salisbury. Having been an international investment banker, the doctors advised Chris to retire in 2001 after his diagnosis with dilated cardiomyopathy two years previously. With an ICD implanted, Chris was considered for heart transplant in 2007 as his health deteriorated, but happily this stabilised, and remained so until last year. Complications arose after the New Year, he became very weak, was hospitalised, and by May 2022 was gravely ill. Towards the end, as Esther wrote, after 20 years of fighting the illness, he simply didn't have the strength to go on.

Christopher had always received wonderful support from Esther, and his family participated in many fundraising events for Cardiomyopathy UK over the years, most recently when his three children competed as a team in a Tough Mudder. To Esther and the family, we extend our deepest sympathy, very much aware that you have lost your "brave, big-hearted and much beloved husband" and father. We at Cardiomyopathy UK have lost a caring, compassionate, dedicated, knowledgeable and wise friend who did indeed live a fulfilling life.

Genetic Testing For Cardiomyopathy

Genetic testing can be used to find out if you have a genetic change or a specific gene mutation which can lead to an inherited heart condition such as cardiomyopathy. This often involves referral to see a genetic consultant or genetic counsellor who will speak to you about your diagnosis and genetic testing. They will also take a blood or saliva sample.

Before you undergo genetic testing a specialist genetic consultant or counsellor will talk to you about your family history. They will ask you questions about family members who have been diagnosed with a heart condition or who have died. They will discuss the process of genetic testing, how long results will take and what the possible results might mean for you and your family. They will ask about close family members and advise on testing for them in the future.

Because cardiomyopathies can be inherited, it is important that if you have cardiomyopathy or a family history of cardiomyopathy that you tell family members so that you and your family can speak to a GP about screening.

Screening for cardiomyopathy involves an electrocardiogram (ECG- an electrical tracing of your heart) and an Echocardiogram (Echo- a scan of the heart which looks at the muscle and valves of the heart).

It is important that families who have an inherited heart condition are seen by a specialist cardiologist in an Inherited Cardiac Conditions service and receive accurate assessment, diagnosis, treatment, genetic testing and support from specialists.

Research is still ongoing into how certain genetic changes can impact the different types of cardiomyopathy. While some genes can cause a milder form of the condition, others may increase a person's risk of abnormal heart rhythms, called arrhythmias, which might mean more frequent follow-ups by a cardiologist or specialist cardiac nurse.

Genetic test results do not always identify a specific gene change which has caused the condition in the person being tested as the search for genes which cause cardiomyopathy are still ongoing.

Please note that this is general information and may not be applicable to you or your family.

0800 018 1024

Our nurses helpline is open Monday - Friday, from 8:30am - 4:30pm.

Scan the QR code to learn more about genetics and cardiomyopathy.

Nurse Caryl Goes the Extra Mile

Hi, my name is Caryl and I'm one of the support nurses on our helpline at Cardiomyopathy UK. I live in New Quay, West Wales and in my spare time love reading and I volunteer at the local library. I am a practicing cardiac nurse and also a member of the support nurse team at Cardiomyopathy UK.

When did you join Cardiomyopathy UK and what encouraged you to get involved?

I've been a cardiac nurse for many years in various roles and I first joined Cardiomyopathy UK in November 2019. My role at the charity is to provide support to patients, carers, and family members of those diagnosed or awaiting diagnosis of cardiomyopathy. I give professional advice and support via our helpline, live chat, email and closed Facebook group. I also contribute and write articles for our website or MyLife. Another part of my role is to oversee and facilitate support groups, which has obviously had to evolve and adapt during the pandemic.

What do you enjoy most about your role at Cardiomyopathy UK?

I enjoy all of the above. Nevertheless, I particularly enjoy being involved with the support groups. I am very passionate about heart failure and feel strongly about advocating for those with cardiomyopathy and heart failure. I run the Heart Failure Symptom Management Support Group.

Why did you decide to run the Cardiff Half for Cardiomyopathy UK?

I was fortunate enough to do the Cardiff Half in 2016 with a group of my friends which was an amazing event. The course was predominantly flat, making it ideal for first time runners (like myself!) and professionals alike. There was a mixture of all abilities, and it was an excellent, although exhausting, day. I always wanted to do it again but knew if I did it would be to raise money for a worthwhile charitable cause.

How do you hope your fundraising will help people affected by cardiomyopathy?

The fundamental reason for me to be running the Cardiff Half in October 2022 is to raise awareness of cardiomyopathy. I see first-hand the impact a diagnosis of cardiomyopathy can have on an individual, their family and their friends. I want to highlight the important work of Cardiomyopathy UK and the impact it has on the lives of thousands of people each year. Cardiomyopathy UK is the only charity in the UK supporting children, young people and adults with the life-limiting heart condition cardiomyopathy and without fundraising, their specialist services simply wouldn't be available for patients.

"I really believe in the work that Cardiomyopathy UK does and I want to support them by raising awareness around cardiomyopathy at the Cardiff Half Marathon 2022. - Caryl"

Q&A
with our nurses

If you have a question for our experts to answer, please email:
supportnurse@cardiomyopathy.org

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

Q. My husband has DCM and heart failure, and we'd like to go on holiday this year. Is there anything we need to consider before booking?

Nurse Caryl

Ensure you have the relevant travel insurance before you depart, information and companies can be located via our website. Take a copy of your latest clinic letter from the cardiology team with you. It's advisable to have a copy / photo on your phone of his baseline ECG, so if he becomes unwell the ECG will give an indication of what rate and rhythm is normal.

Make sure you have the relevant medication with extra in case of emergency. If flying, your husband should walk around when possible and keep hydrated. Try not to plan too many activities during the first few days to preserve energy levels and avoid activities in extreme temperatures or immediately after eating.

When you are away, especially if you are travelling to a warmer climate, again, keep yourself hydrated. Remember it's a holiday and take time to relax and enjoy!

Q. Why did the cardiac nurse ask me about my family history following my recent diagnosis of cardiomyopathy?

Nurse Jayne

The taking and recording of a family history of three generations is important in identifying family members who might be at risk of a familial condition. The genetic relationships of the affected people and their ages give vital information for clinical screening and/or genetic testing.

Information is recorded in a family tree which allows a pictorial representation of family relationships and those family members who have been diagnosed with cardiomyopathy including their age.

The family tree starts with the person diagnosed with cardiomyopathy, then 1st degree relatives (parents, siblings and children) are added. On the tree it is noted if any of the family members are known to have cardiomyopathy. The tree will be expanded to include aunts, uncles, nieces, nephews, grandparents and grandchildren.

Q. How can I help my fifteen-year-old child with cardiomyopathy look after themself?

Nurse Emma

Not everyone with a chronic condition like cardiomyopathy follows the advice of their clinician exactly and we know that one third of affected adolescents can demonstrate non-adherence. This means that sometimes they will take part in activities that their clinician has advised them against, or they may not take their medication as prescribed. This isn't always intentional.

As a parent you can talk openly with your child about why looking after their health is important and reassure them, they are not alone. Encourage your child to speak with other young people who have cardiomyopathy through our children and young people's services and to use the young person-friendly information resources available on our website to better help them understand their condition and how they can take good care of their health in ways they can understand.

Prescribing Our Services

We work closely with cardiac care teams, as it's vital that healthcare professionals know about our services so that they can signpost their patients to us for support. Through a new project, we hope to reach even more clinicians and patients.

Our cardiomyopathy community tell us how essential their clinical appointments are. Time with a clinician to talk about their health, address concerns, discuss test results and explore treatment options is incredibly valuable. Our community also tell us that they want advice and support about their mental health and emotional wellbeing, to be connected with other people similarly affected, support for their family members and advice on employment and benefits. Unfortunately, clinicians seldom have the time or resource to provide this type of detailed, often specialist support. An NHS already hugely overwhelmed means that more and more people affected by cardiomyopathy are unable to have all of their needs met, which in turn can lead to poorer mental health and increased stress.

Cardiomyopathy UK has embarked on a Social Prescription Project where clinical teams are invited to attend webinars delivered by Cardiomyopathy UK. In the webinars our Services Team explain the breadth of support services we offer to both patients and clinicians (our accredited medical education programme, MedEd, is aimed at cardiac clinicians looking to improve their understanding, diagnosis and treatment of cardiomyopathies). In the webinars we also tell clinicians how they can prescribe our services using an information resource we have created. Clinicians can tailor this information to the patient's cardiomyopathy type, medication and device details as required. This empowers newly diagnosed patients to know what cardiomyopathy they have and the details they need, should they request clinical advice between appointments.

We often find that newly diagnosed patients can't always recall what they have been told or the medication they have been prescribed, which can lead to some feeling confused and anxious. A number of hospitals and clinics have invited our team to present this exciting new project to their wider cardiac clinical teams at MDTs (multidisciplinary team meeting), as they recognise how beneficial our services will be for current and new cardiomyopathy patients.

The Social Prescription Project is part of the charity's long established Community Peer Support service, funded by the National Lottery Community Fund. The project aims to assist cardiac departments by meeting the full range of needs of cardiomyopathy patients, alleviating pressure on clinicians and saving the NHS money. Throughout our services, we're seeing more diverse needs from patients, and we believe that we are the best possible provider of support, information and guidance for people living with cardiomyopathy who are affected physically, emotionally and through their daily living.

If you are a clinician or someone living with cardiomyopathy, and think this might be of benefit to your clinical team and want to know more, please call us on 01494 791224 or email Christie.Jones@cardiomyopathy.org, our Community Peer Support Manager, for more information.

How to Manage in Hot Weather

Anyone can find the hot weather difficult to cope with, but if you have a heart condition you might find the heat can affect you more.

When the weather is warm, your heart needs to work harder to pump blood to the surface of your skin to assist with sweating to cool your body. When you sweat to cool down you lose more fluid than usual from your body, which can lower your blood pressure and make your heart beat faster.

It is important to always check with your GP or cardiologist for advice if you are on a fluid restriction and you're concerned about your fluid intake during a period of hot weather. Otherwise, try to take frequent sips of fluids like water, and try to reduce caffeine-based drinks, as they can make you more dehydrated.

You might also find that you need to rest more during warmer weather because your heart is working harder to keep you cool. Try to find a cool room and wear light comfortable clothing.

Sometimes medications for heart conditions can reduce the body's ability to cool when it is warm. It is advisable to try to reduce the time you are outside in the sun, try to keep indoors and as cool as possible. You may need to speak to your GP or heart nurse if you are taking diuretics and you are concerned about safe levels of fluid intake during a period of hot weather.

The main risks during a heatwave (when the daytime temperature reaches 30 degrees) and hot weather are, dehydration, overheating, heat exhaustion and heat stroke.

10 Tips for managing in warmer weather

1. Try and stay out of the sun and don't go out between 11am and 3pm if you are vulnerable to the effects of warmer weather.
2. Shut your windows and keep curtains, blinds or shutters closed when it is hot outside. You can open the windows for ventilation during the cooler parts of the day.
3. Try having slightly cooler water in your shower or bath. Sometimes splashing yourself with cool water can help to cool your skin.
4. Drink cooler drinks regularly, such as water or diluted fruit juice. Try to avoid drinking alcohol and drinks high in caffiene or sugar.
5. Plan ahead to make sure you have enough supplies of drinks, food and any medications you need.
6. Identify the coolest room in the house so you can go there to keep cool.
7. Wear loose clothing, a hat and sunglasses if you go outdoors. Sit outside during cooler hours and try to remain in the shade.
8. Limit physical activity during the hottest parts of the day and do light exercise during the cooler hours.
9. Eat light meals; avoid hot heavy meals and reduce the use of your oven to keep your rooms cooler.
10. Some medications can increase your risk for heat stress, ask your pharmacist if any of your medications could increase your risk.

Our Latest Updates In Research

Here at Cardiomyopathy UK, we work with researchers to provide information and patient insight to help improve the lives of people with cardiomyopathy. Our Head of Research and Policy, Wendy Edwards, has shared the latest updates in research and clinical trials.

The I-CARE Study

Innovative Cardiac Analytics Platform for Remote Monitoring

This innovative research project is looking at new technology called 'Cardiolyse' that could revolutionise the care of patients with atrial fibrillation (AF) by helping patients to manage their condition from home using an app. Over 1.3 million people in the UK are living with diagnosed atrial fibrillation, with an estimated 500,000 potentially undiagnosed.

Patients who have had AF-related ablation surgery are at a higher risk of early recurrences of atrial arrhythmias. There are 9000 atrial fibrillation ablation procedures in England every year. Patients require a significant amount care for 12 weeks post-ablation with regular visits to the hospital and GP surgery, often at short notice. Patients spend many hours waiting or traveling for ECGs and other tests.

To reduce the burden on the patient and the healthcare system, Oxford University Foundation Hospitals Trust (OUH) are testing an exciting new app called Cardiolyse. Patients install the Cardiolyse app on their smartphone and wear a device that links to the app. The easy-to-wear device takes ECGs and analyses the results instantly. It then sends the information directly to the cardiac team. Patients then receive a user-friendly report on their heart risk level, and their doctors receive a comprehensive report from the app. A traffic light system on the app will identify any critical risks as a red alert and the patient can immediately be admitted to hospital without lengthy delays.

It is hoped that findings from this research will improve patient outcomes and lead to the use of the Cardiolyse app more widely across the NHS.

Note: This research study is recruiting patients who are under the care of the OUH and meet the inclusion criteria for the project only. If your care is based at OUH and you would like to find out if you are eligible to take part please ask your cardiac specialist.

The Crucial Study

Vascular Dementia and Heart Failure

Cardiomyopathy UK are delighted to be part of a group that is researching how comorbidities (having more than one medical condition at once), such as hypertension, diabetes and high cholesterol, affects both the brain and heart. The research group brings together 12 partners from multiple fields including clinicians, scientists, and patients representing seven countries including the UK, Netherlands, Spain and Greece. It's hoped that by undertaking this research at an international level, there will be more sharing of ideas and technologies which will lead to better outcomes for patients.

These comorbidities are linked to the development of diastolic heart failure, (where some of the chambers in the heart don't pump properly), but also to vascular dementia (a type of dementia caused by restricted blood flow to the brain). There is a common theory that both these conditions arise because of a reduction in microvascular density (fewer blood vessels in the brain) causing reduced blood supply. As part of this study the consortium will enhance and develop a range of clinical tools, including imaging techniques and blood tests, which will enable them to measure and investigate the role of reduced blood flow in cognitive impairment and heart failure. The hope is that they will be able to diagnose people earlier before permanent damage occurs.

Get Involved

We aim to support research that will make a real difference in the lives of people living with cardiomyopathy. If you are a patient and interested in participating in a clinical trial, reviewing patient information leaflets, completing a questionnaire, or being on a focus group, scan the QR code or visit our website.

If you are a researcher from a university, NHS Trust, or other accredited research institution and would like to find out more, get in touch by emailing research@cardiomyopathy.org.uk

Policy Updates

Introducing our new Policy and Advocacy Manager

We're pleased to welcome Charlotte Gallagher to the team as Policy and Advocacy Manager. Charlotte will be working with our volunteer Change Makers to improve access to quality care and treatment for people affected by cardiomyopathy.

"I'm delighted to be joining Cardiomyopathy UK to manage the Change Maker Project in co-production with volunteers around the U.K. to raise awareness and influence positive outcomes to support people affected by cardiomyopathy.

I've spent most of my career within charity and community organisations managing projects and services, recently undertaking quality improvement and primary care intervention roles within a local Clinical Commissioning Group (CCGs are groups of GPs which come together in each local area to commission the best services for patients in their area) and the UK Health Security Agency. I will shortly graduate from Queen Mary University of London with a Masters in Global Public Health. I have a particular interest in Health Equality, and I'm looking forward to working with patients, clinicians and volunteers to evaluate the inclusivity of health services for those affected by cardiomyopathy.

I love art and in my spare time I like to visit any art exhibition that I can, and I continue my struggle to play musical instruments to a reasonable standard!"

If you're interested in finding out more about the Change Maker project, you can contact Charlotte at charlotte.gallagher@cardiomyopathy.org.

Our 2022 National Survey

In June we launched our 2022 National Survey, with a focus on diagnosis, treatment and care. The survey aims to give us an up-to-date picture of the cardiomyopathy experience since COVID 19 and the change that the pandemic has had on diagnosis, treatment, well-being, and daily life.

This survey is vitally important, giving us a clear picture of the current status of cardiomyopathy care in the UK, and helping to identify areas for improvement. We will share these findings later on in the year.

Scan the QR code or visit our website to fill in our survey and help us change the lives of those living with cardiomyopathy.

International Cardiomyopathy Awareness Week

The 20th to the 26th of June was the first ever International Cardiomyopathy Awareness Week. The campaign, which encouraged people to #GetToTheHeartOfIt, was led by the Cardiomyopathy Patient Council of the Global Heart Hub.

This is a group of 10 cardiomyopathy charities, including Cardiomyopathy UK, from around the world who have come together to raise awareness of cardiomyopathy worldwide and advocate for the needs of the global cardiomyopathy community. We worked closely with the other international member charities to develop and promote the campaign.

The aim of the awareness week was to increase understanding of what cardiomyopathy is, the signs and symptoms and the importance of knowing your family history. We're delighted that the campaign received a fantastic response, and we look forward to continuing to work with our international partners.

Get to the heart of it

Scan the QR code or visit our website to learn more about the campaign.

Our Fundraising Superstars

We'd like to say a heartfelt thank you to everyone raising funds to support our work. All of the wonderful and unique ways that you fundraise, means that we're able to provide information and support, every step of the way, so that nobody has to face cardiomyopathy alone.

Michelle's 30 Day Challenge

Throughout May, Michelle completed a 30 Day Challenge, walking 10,000 steps a day for the month. Michelle said:

"I chose Cardiomyopathy UK as I have supported them since I was diagnosed with dilated cardiomyopathy in 1999. I chose this challenge because I had a heart attack in August 2021 and again in March 2022. And so I decided this would be a great start back to fitness and what better way to celebrate this than by fundraising for Cardiomyopathy UK.

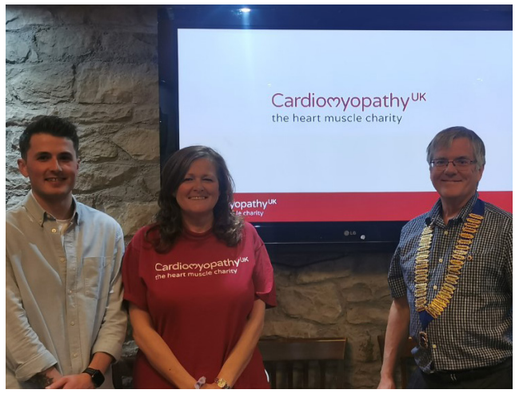
Walking For Maddy

Five years after her daughter, Maddy, passed away, Barbara is walking a total of 130 miles between May and August in her memory.

"There isn't a day goes by when we don't remember her unbelievable courage in the face of everything she had to go through. The paper heart has become a symbol for Maddy – we gave them out at her funeral to promote organ donation. I'll also be leaving painted pebbles in her memory along the route."

Raising Awareness in the Community

Our Bridgend Support Group Leader, Ann, and her son, Ellis, recently gave a presentation to their local Lions Club about Cardiomyopathy UK. After losing their husband and father, Raymond, 25 years ago, the pair have continued to volunteer, raise awareness and raise funds for Cardiomyopathy UK to help support other families affected by the condition. As well as raising awareness to the community, they also received a £100 donation from the club.



Toby's Bar Mitzvah

As part of his Bar Mitzvah celebrations, Toby ran 1.5km a day for 30 days, raising £800. Toby said:

"My synagogue encourages those celebrating their Bar Mitzvah to give back to the community, through either fundraising or volunteering. I decided to fundraise for Cardiomyopathy UK as it supports people suffering from cardiomyopathy, including my mum, who has dilated cardiomyopathy".

If you'd like to do some fundraising of your own, our friendly team are here to help. You can call us on 01494 791224 or email fundraising@cardiomyopathy.org. We'd love to hear from you.

Cardiomyopathy UK
the heart muscle charity

Together Again
A Brighter Future

2022 National Conference

Saturday 19th November

Scan the QR code or visit our website at
www.cardiomyopathy.org/conference-2022
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