myLife

The magazine for people affected by cardiomyopathy and myocarditis

Our impact in 2021

An interview with Dr Juan Pablo Kaski

Mavacamten: NICE to review potential new treatment

Cardiomyopathy UK
the heart muscle charity

Issue 29
Spring 2022

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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Front page images: Supporters Jenny Taylor (top) and Change Maker Jess Maranzano (below) with their families.

How timely that the theme of our magazine is 'hope'.

To mark the launch of the final series of Ricky Gervais' Afterlife, 25 Mental Health 'Benches of Hope' have been donated by Netflix and the Campaign Against Living Miserably (CALM), to local councils. They have been installed in parks in the UK. Each bench carries the inscription "Hope Is Everything". They also have a QR code that can be scanned to reach support and guidance for anyone who needs to reach out.

Hope can mean something different to each of us, or at different times in our lives. On page 6, Stephen Kirkham shares what hope has meant to him throughout his cardiomyopathy journey.

This time of the year as the days get longer and the weather becomes warmer, we are reminded that spring is around the corner bringing new life; and the winter that can play havoc with health and well-being is almost behind us. As we emerge from the effects of the pandemic, we can now look forward with optimism for the future. Take a look at how we will be developing our services in the year ahead on page 17.

Advances in the clinical world always bring hope. You can read about exciting new developments in medication on page 13.

"Having hope may be the best protection against a more difficult tomorrow" *

It is at this time of the year that we begin to shape the charity's Annual Report, we are pleased to begin this issue with a review of the impact our services have made to patients and their families during 2021. On page 10, you can also read a round-up of our highly successful conference attended digitally by over 600 people on the day.

My hope as we move forward into this new year is that Cardiomyopathy UK continues to be the number one 'go to' for people living with cardiomyopathy and their families, and that with support those affected by cardiomyopathy live life as fully as they can.

Rita Sutton, Chair

*Human Flourishing Program, Harvard University's Institute for Quantitative Social Science

Contents

An interview with Dr Juan Pablo Kaski 8-9

Stephen's Story 6-7

Fundraising Superstars 18-19

In 2021...

167

support group meetings were held with a 46% increase in attendees

2,569

Information resources were sent out to our community.

600+

Over 600 respondents fed into the CureHeart research survey.

100%

of people said that they would recommend our peer support service to others.

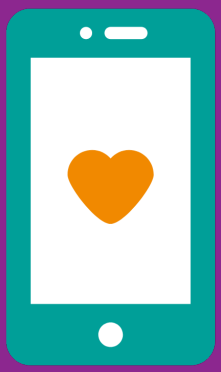
Our Impact in 2021

2021 was another difficult year for us all. With social restrictions still in place for much of the year, our support groups and annual conference remained online.

Although we couldn't meet in-person, our community continued to be there for each other, and we held more support groups than ever before. Our nurses continued to provide reliable, expert information through our helpline and website, whilst our volunteer Change Makers raised the voices of people with cardiomyopathy by advocating for better treatment and care. During 2021 we asked you how the pandemic had impacted you and listened to what this meant for you living with cardiomyopathy. Throughout the year we also continued to work with the research community to push for advancements in the future of cardiomyopathy treatment.

We've emerged from the past year hopeful and emboldened in our mission for 2022: to provide greater support, reach further in our awareness and campaigning work and continue engaging with the research community. Together, we can give hope to more people affected by cardiomyopathy than ever before.

> "We're incredibly proud that we were able to adapt and continue providing our services throughout 2021. It has been a tremendous joint effort by our community of supporters, trustees, staff and many more. We're immensely grateful for every contribution.
>
> **Joel Rose CEO**"



98%

of people who called our helpline felt they had gained a better understanding of their condition after speaking to one of our amazing support nurses.

Stephen's Story

Stephen was diagnosed with dilated cardiomyopathy (DCM) and heart failure in 2005. Here, Stephen recounts his experience and considers the idea of 'hope' from diagnosis, through treatment and a successful heart transplant.

> "The hopes and prayers of my family were answered, and I was gifted a donor heart by the wonderfully courageous and generous actions of my donor's family."

When thinking about hope, my lived experience, first as a soldier, then vicar, and then with an advanced cardiomyopathy leads me to shy away from the idea of "blind hope", preferring instead "realistic hope".

Here's the short version of my story. Diagnosed with DCM and severe heart failure in 2005; six months complete rest; then a return to part-time work for 18 months; early retirement in 2007. Gradual decline over the next seven years with arrythmias, two bouts of atrial fibrillation, a cardioversion, with amiodarone and warfarin added. There were periodic crises, ambulances, A&E admissions, followed by discharge home on increased medication; by 2013 I was on everything possible. Cardiac Resynchronisation Therapy (CRT) was prescribed in April 2014 (though would not be fitted until January 2015).

Then in August 2014 we moved to Scotland, but the effort involved precipitated a rapid decline. I was having to give up more, feeling ashamed that I could no longer get up hills. I was unaware (or unbelieving?) of the truth that I was moving into advanced heart failure. In the end the CRT was fitted in early 2015 by which time I was very frail. My idea of "a treat" was to be taken out to yet another garden centre and to be pushed to the coffee shop in a wheelchair - it was wretched. By March I'd had four blue light admissions to various Scottish A&E departments and then, after a chance encounter with my consultant whilst waiting on an Assessment Ward in Dundee, I was referred to the Glasgow Transplant Centre.

> "If ever you were to reach the stage where there is talk that you may need a transplant, I trust my story might provide you with reason for realistic hope."

In truth I had no idea how ill I was and it took a very frank, very forthright talk from the team looking after me to convince me I was dying and had only a short time to live. I was immediately put on the UK transplant list and given powerful IV drugs to help keep my heart beating, and then, just a day or so later I suffered a cardiac arrest in my sleep. I surfaced to find a nurse pumping on my chest, the "crash team" gathered around. They had saved me, but I needed mechanical support – an intra-aortic balloon pump – and was placed on the urgent transplant list. Just two weeks later, on the 9 May 2015, the hopes and prayers of my family were answered, and I was gifted a donor heart by the wonderfully courageous and generous actions of my donor's family.

Transplant wasn't an easy process and was further complicated because I'd been so weak before, but I was home just 22 days later. Inevitably, the first-year post-transplant brings issues for most people, and overall survival rates of 84% at the end of year one make it clear that there are no 100% guarantees. But I was fortunate; within 10 weeks of such major surgery, I'd cycled a 5kms circuit, and I conquered our local very big hill just 10 months post-transplant. My life had been saved and now, nearly seven years on, I continue to enjoy a really good quality of life and have the opportunity to give something back.

So, if ever you were to reach the stage where there is talk that you may need a transplant, I trust my story might provide you with reason for realistic hope.

An interview with:
Dr Juan Pablo Kaski

Dr Juan Pablo Kaski is a Consultant Paediatric Cardiologist at Great Ormond Street Hospital. We spoke to Dr Kaski about how he became interested in cardiology, his experience treating patients at Great Ormond Street Hospital and what he likes to do in his spare time.

What is the most rewarding aspect of your job?

There are lots of rewarding aspects, but one of the things I enjoy the most is getting to know children and their families, often from when they are babies, and seeing them grow, thrive and develop into young adults.

What would you say are the biggest challenges for a paediatric cardiologist?

One of the biggest challenges, but also something I really enjoy, is having to communicate in different ways with children of all different ages, and their parents – explaining often very complex medical issues in a way that young children, teenagers and young adults understand. A particular challenge can be discussing the implications of a new diagnosis of cardiomyopathy with a child or teenager and the potential impact this might have on their lifestyle and future aspirations – at the Great Ormond Street Hospital Centre for Inherited Cardiovascular Diseases, I am lucky to be able to work with an excellent team of nurse specialists, psychologists and counsellors, who make this a much easier process for the young person and their family.

Your dad is a cardiologist, did you plan to become a cardiologist too, from a young age?

I knew I wanted to be a doctor from when I was a teenager, both my parents are doctors, and they have both been a huge influence in my career. When I was at medical school, I became interested first in genetics and then cardiology, but I have always enjoyed working with children.

I am very fortunate that I have been able to combine all three of these professional interests into my job as a paediatric inherited cardiologist.

What do you find to be the most interesting aspects of cardiomyopathy?

That's a really difficult question, as there are so many interesting aspects of cardiomyopathy! For me, one of the aspects I'm most interested in is trying to understand how the condition develops in children and why cardiomyopathies can express themselves in such different ways, even within the same family. This is one of the major focusses of the research programme I lead at UCL and GOSH.

What do you do for fun and to relax?

I enjoy playing tennis, reading, listening to music and playing the guitar. Most of all, though, I love spending time with my wife and three children and, particularly, supporting my children's football and hockey teams at the weekends!

How can Cardiomyopathy UK better help children and young people affected by cardiomyopathy?

The work that Cardiomyopathy UK does for children and young people affected by cardiomyopathy is incredible and I am honoured to be able to help in any way I can. The information resources available for children and young people from Cardiomyopathy UK are unique and extremely valuable to the children and teenagers we see in our clinic. The support group for young people (14 to 25 youth panel) is the only one of its kind in the world and an absolutely amazing and essential source of information, advice and support for teenagers and young people affected by cardiomyopathy (either because they themselves have it or someone in their family does). Thank you for all the help and expertise you provide to young people affected by cardiomyopathy in the UK and beyond!

How can parents who are worried about their child's condition access further advice and support?

Parents who are worried about their child's condition should always be able to seek advice and support from their child's cardiologist and their team. Many paediatric cardiomyopathy services have dedicated phone lines or email addresses that parents can use to get in touch directly with their medical team. Parents can also get in touch with the Cardiomyopathy UK helpline and the dedicated children's nurse support line. Of course, if they are worried that their child is acutely unwell or sick, parents should always seek urgent medical help from A&E or their GP.

A few of our resources for parents and young people...

Our Website

We have a wealth of information available on our website including fact sheets, videos and a full list of services. Simply head over to:

www.cardiomyopathy.org

Support Groups

We run a number of support groups for people affected by cardiomyopathy. To join a group, email:

christie.jones@cardiomyopathy.org

Our Paediatric Helpline

0800 018 1024

Our paediatric helpline takes place every other Wednesday between 6pm and 9pm.

The Cardiomyopathy UK Conference 2021: Round-up

In October 2021, we delivered our annual conference online for the second year running. We were delighted to be joined by over 600 people affected by cardiomyopathy who tuned in to hear from patients, clinicians and members of our staff team. Here is a round-up of the event, topics covered and interesting discussions that arose from the day.

For many years our annual conferences have been the place where we bring together our small staff team and our family of supporters and people affected by cardiomyopathy. Our goal has been to help people live well with cardiomyopathy, underpinned by the idea that knowing more helps us to live better.

Like our popular support groups, our conference events have always had a special appeal for our community. They act as proof that you can live well with cardiomyopathy, that you are not alone in your condition or experiences and that clinical research and developments continue to emerge in the world of cardiomyopathy. We know that for many people living with cardiomyopathy, the conference is an opportunity for them to share their experiences and support others who are more recently diagnosed.

Hosting our conference online for a second year was a difficult decision. We know that many of the special moments from our conferences happen during lunch break, whilst waiting for a session to begin, or in the celebration of achievements of clinicians and volunteers.

Delivering our conference online meant the event was accessible and safe for those who are clinically vulnerable. One attendee told us "I couldn't go to the Cardiomyopathy UK conference before covid! But now I can! And it's free!". It also meant that we could welcome participants from across the world.

Programme

We welcomed the superstars of the clinical world of cardiomyopathy to our conference, including Professors Gerry Carr-White and Perry Elliott. Our speakers focused on recent research findings, advice on lifestyle and the future of digital appointments.

These popular sessions ran in parallel to volunteer-hosted topics on living with long-term conditions and developing support networks. Feedback from these sessions strongly indicated that hearing from other people affected by cardiomyopathy was just as impactful as receiving advice from clinical specialists.

Resilience

We asked conference attendees 'How has COVID-19 affected your wellbeing?' when people registered for the conference. Our community told us a multi-faceted story of family dynamics, loneliness, and anxiety, but equally of new opportunities, spending time in nature and acceptance.

Clear themes arose around connection with others, the importance of good relationships with healthcare professionals and the support of the Cardiomyopathy UK community. Some told us how they were able to work from home and remain well throughout the pandemic. For many others it was an incredibly difficult time where they have had to remain extremely cautious, have medical appointments cancelled and found themselves increasingly isolated from the support of family and friends.

People told us that our helpline had been invaluable, and that the informal nature of our Coffee and Catch-up sessions had offered welcome respite to the stark reality of lockdown.

Conference 2022

The last two years of running the conference digitally have made us reflect on the purpose of these events. We want to ensure we can reach as many people affected by cardiomyopathy as possible and that these events continue to benefit people affected by cardiomyopathy. We've already begun thinking about our 2022 conference. We'll take your feedback and suggestions from the 2021 conference and continue to improve this important annual event.

Treating the Heart: Spironolactone

By Nurse Jayne

You may have heard of spironolactone, a common drug treatment used for patients in heart failure. Our cardiac support nurse, Jayne, explains when this particular drug is used, how it works and possible side affects.'

When someone is in heart failure there is often a need to remove the excess fluid that has built up in the body and the fast acting diuretic drug (water tablet) furosemide is used. This, in combination with the recommended standard treatment of an ACE inhibitor and low dose beta blocker, is often effective in controlling symptoms such as shortness of breath and ankle or abdominal swelling and can help the pumping of the heart.

Where people continue to have symptoms, spironolactone may be added to their medication to help remove excess fluid by inducing more urine.

Spironolactone is a mild diuretic medication, which helps prevent and treat build-up of fluid in the body, it is called an 'aldosterone antagonist' and/or 'Mineralocorticoid receptor antagonist' (MRA). Eplerenone is also an 'aldosterone antagonist'.

Aldosterone is a hormone, produced by the adrenal gland, which plays an important part in controlling the amount of sodium and water in the body.

Spironolactone acts to block the effect of aldosterone. This has the effect of decreasing the amount of sodium and water which is reabsorbed resulting in it being excreted in the urine. This then reduces the blood pressure and the workload of the heart.

The drug has the additional factor of limiting the amount of potassium which is excreted and the term 'potassium sparing diuretic' is often used.

The drug isn't used where the person has known kidney disease or where they have a high potassium level in the blood.

Research has indicated that spironolactone, along with the standard therapy of ACE inhibitors and beta blockers, can result in reduced levels of mortality and hospitalisations.

A common side effect of spironolactone can sometimes be breast soreness and breast enlargement in men.

Drinking alcohol can in some people increase the likelihood of some of the known side effects such as diarrhoea, feeling dizzy, changes in kidney function and passing less water than usual.

If you are prescribed spironolactone general advice would be to try to avoid a diet high in salt. Having salt in your diet can cause your body to retain water and can make this medication less effective.

In some people spironolactone can affect kidney function therefore you will likely be advised to have regular blood tests to monitor your kidney function whilst taking spironolactone.

NICE to Review Potential New Cardiomyopathy Drug

Earlier this year we were informed by the National Institute for Health and Care Excellence (NICE) that they will be starting the appraisal process for a new drug, mavacamten.

In trials, this drug has proven to be effective in reducing obstruction and improving exercise capability for people with obstructive hypertrophic cardiomyopathy, sometimes called HOCM. NICE is the organisation that decides whether a treatment can be used in the NHS in England so approval by NICE is needed before the treatment is available freely to the public.

The NICE assessment process brings together the key stakeholders including clinical experts, the manufacturers of the drug and people with personal experience of obstructive hypertrophic cardiomyopathy. These stakeholders present the evidence for the effectiveness of the drug and the impact that making it available would have on people's lives.

Cardiomyopathy UK has an important part to play in this process, giving NICE a real and honest account of the impact of obstructive hypertrophic cardiomyopathy on an individual and their loved ones. This includes insight into patients' experiences of having an ablation or a myectomy as these are the procedures that people with obstructive hypertrophic cardiomyopathy may need and could be replaced by mavacamten.

NICE National Institute for Health and Care Excellence

We will be gathering our evidence for NICE by holding focus groups and conducting a large-scale "state of the nation" cardiomyopathy survey, which will be announced in the spring. If you have obstructive hypertrophic cardiomyopathy and want to share your experience with us so that we can pass this onto NICE, please contact Wendy Edwards, our Head of Research and Policy by emailing, Wendy.Edwards@cardiomyopathy.org.

As well as looking at the impact that mavacamten can have on a persons' quality of life, NICE will also consider the cost effectiveness of the drug and ultimately whether the NHS can afford it and if so, for which people. This means that as well as explaining the real-life impact of obstructive hypertrophic cardiomyopathy to NICE, we need to work with the drug's manufacturer, Bristol Myers Squibb, to encourage them to make the treatment as affordable as possible. This way, there is a better chance of mavacamten being approved and made available.

We want to see effective treatments available in the community as soon as possible, making living well with cardiomyopathy a reality for more people than ever before. Mavacamten is the first drug of its kind and is likely to be followed by other treatments designed specifically for people with cardiomyopathy. NICE is due to review evidence for mavacamten this October. It's hard to predict how long the process will take and what the outcome will be, but there is no doubt that this is an exciting development in the world of cardiomyopathy.

Research Updates

By Joel Rose,
our Chief Executive

Introducing our new Head of Research and Policy

Over the last few years, we've been increasing the support we provide to clinical researchers to ensure that their projects meet the needs of people with cardiomyopathy. We've also been doing more of our own research and using our findings to direct our policy activity and prioritise our work.

We're now taking this work up another level with the recruitment of a new position on our Senior Management Team, our first Head of Research and Policy, Dr Wendy Edwards. We're delighted to welcome Wendy to the team.

Dr Wendy Edwards, Head of Research and Policy

Digital Health Partnership Award - Measuring Arrhythmia at Home

In November last year we were approached by a team of scientists based at Oxford University Hospital who wanted our help to develop a new research project. The team wanted to investigate how arrhythmia could be remotely monitored using newly developed artificial intelligence software and whether a patient's data could be analysed to identify if they were at risk of atrial fibrillation (AF) and alert their doctor. Cardiomyopathy UK became part of the research team and we have since helped to ensure that their project could work for people with cardiomyopathy.

At the end of last year, the project successfully secured funding from the NHS's Digital Health Partnership Award programme. This programme has been created to help NHS organisations accelerate the adoption of digital health technologies to support patients with long term conditions and investigate how digital products and services can support people to remotely monitor their health at home or in the community.

Our ongoing role as part of the research team will be to help ensure that the project meets the needs of people with cardiomyopathy, tell people how they can get involved and share the outcomes among the cardiomyopathy community. We are joined on the team by Arrhythmia Alliance and we look forward to working with them. The project is still in its early stages, but we hope to be able to share more information on its progress soon.

Heart Hive Findings Released

The team at Imperial College London have published their findings on the impact of the COVID-19 pandemic on people with cardiomyopathy.

Their research was based on the experiences of volunteers who had signed up to the Heart Hive platform as well as patients in the Royal Brompton Cardiovascular Research Centre Biobank.

The research found that people with cardiomyopathy were equally likely to test positive for COVID-19 than the UK population. However, those that did test positive were more likely to require hospital treatment during the early stages of the pandemic. They also saw that significantly more participants with cardiomyopathy felt that their physical health had deteriorated due to the pandemic compared to participants without heart disease, despite very few reporting COVID-19 symptoms.

As well as this, 40% of patients with cardiomyopathy did not feel that their health needs were being met by the health services and information being delivered from a distance, for example through digital channels or over the phone.

Their research points to the indirect impact of COVID-19 in delayed appointments and missed opportunities to diagnose. It is some of these issues that our policy work and Change Maker volunteers are working to address.

Scan the QR code or visit www.cardiomyopathy.org/heart-hive to read the full research paper.

Improving Care and Treatment: Latest Updates

Our Change Maker meet up

Our Change Maker Volunteers continue to promote our Change Agenda for better standards of care and treatment in their local areas. In December, we brought our Change Makers together to share their success stories, ideas and challenges that they've faced. It was heartening to see the progress that is being made. This project is really starting to make headway with important networks and contacts being formed within the healthcare community. I have no doubt that this is going to be vital as the NHS starts to gradually recover from the pandemic.

International collaboration

Over the winter, we were also able to play our part in some important national policy initiatives. We have been working as part of the Alliance for Heart Failure and the Network for Heart and Circulatory Diseases to ensure that politicians, health services commissioners and other stakeholders are aware of the impact of the pandemic on diagnosis and treatment.

We have continued to work with the two organisations who are responsible for evaluating heart disease services: the National Institute for Cardiovascular Outcomes Research (NICOR) in England and the Scottish Cardiac Audit Programme (SCAP) in Scotland. We want to ensure that these organisations can provide clear data relating to people with cardiomyopathy and that the data they provide can be shared easily among researchers and other stakeholders to help them identify areas of best practice as well as areas where improvement is needed.

Internationally, we participated in the Global Heart Hub "Unite" conference where we officially launched the Cardiomyopathy Council; our network of 10 cardiomyopathy charities from around the world. The Council will be launching its first major awareness campaign this year.

2022 is shaping up to be an important year for people with cardiomyopathy. There is a great deal to do to ensure that services can return to normal (or indeed better than) pre-pandemic levels and at the same time, there are exciting new opportunities to shape and direct important research projects.

Remaining at The Heart of Our Community

By Ali Thompson,
our Head of Services

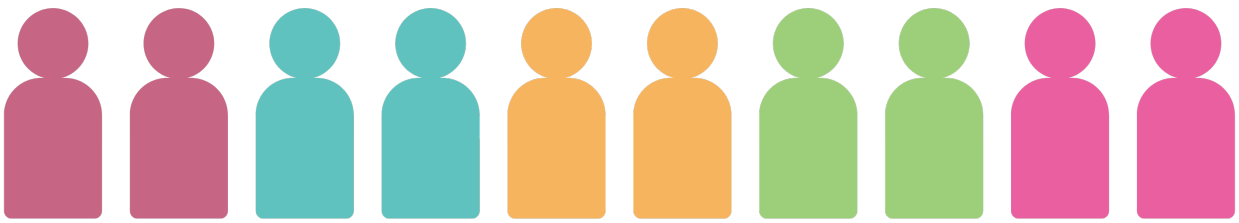
Our Head of Services, Ali Thompson, shares an insight into how we are listening, reviewing and adapting in order to continue providing the best possible support for people affected by cardiomyopathy.

You might have called our helpline, attended one of our support groups, maybe you have been to one of our conferences and maybe your clinical team are enrolled on our medical education programme. These are just some of the services that Cardiomyopathy UK provides for people involved in the cardiomyopathy world whether as a patient, a loved one or a medical professional.

To ensure that we provide the best information, support and care for our community, we're currently reviewing the services we offer to ensure that we can fully meet the diverse needs of the people who reach out to us. We understand that the Covid-19 pandemic has had a significant and, in some instances, sustained impact on our cardiomyopathy community. That is why this year we will be looking more closely at our services to understand better what people now need from us and to make positive changes to remain the trusted, vital provider of support that Cardiomyopathy UK is known for. Each service that we provide will be critically assessed and any gaps in provision will be reviewed so that we can establish how best to bridge these for the benefit of people affected by cardiomyopathy.

As part of our review, we will continue to work with our Outreach Committee to explore and develop how we engage with communities who are currently less likely to access our services. These may be minority groups or people less able to access the information and support they need. We want to reach out and engage with these groups to understand what we could do more of, or what we could do differently to support them and help more people with cardiomyopathy to live a long and full life. We want to be here for everyone affected by cardiomyopathy and this means being there for people across the full spectrum of our population. Extending our reach will be a key area of focus for us in 2022 as we consider how we can best meet the needs of people affected by cardiomyopathy.

The voices of our community and stakeholders are essential to this process and we value your views, insights and ideas. Therefore, targeted surveys will be made available to the community and also to those people who don't know of the charity or have not yet used our services so that we can bring your views into future services and help shape the support we provide. I hope that you will take part in these surveys which will be made available through our usual channels.



Our Fundraising Superstars

Christmas fundraising at Glenmoore and Winton Academy

Students at Glenmoore and Winton Academy in Bournemouth are supporting Cardiomyopathy UK in memory of their teacher and colleague, Mr Ferris-Oates who sadly passed away. Their latest event, a Christmas fayre, raised a wonderful £918.

Teacher, Mr May, says "We have been fundraising for Cardiomyopathy UK for a number of years now and we put some new charities up for a vote, but Cardiomyopathy UK was the most voted charity, so our fantastic efforts will continue. Hopefully we can raise a huge amount again for this amazing charity which does such great things for people affected by this disease."

Band rock out in support of band member

Ramin and his band, The Groan Room, organised a concert in aid of Cardiomyopathy UK raising a fantastic £280. Ramin says: "The effects of cardiomyopathy have been felt first-hand by our bandmate who, in 2020, experienced a very sudden family bereavement. We arranged the concert in The Castle Hotel in Manchester to raise awareness of the condition and were thrilled to be able to contribute some funds to Cardiomyopathy UK's tremendously important cause".

Raising funds and raising spirits

Jane selected Cardiomyopathy UK to be charity of the term at her local choir group, which has been an uplifting support throughout her cardiomyopathy journey. At their weekly sessions, the group have been taking it in turns to bring cakes to enjoy during the break in return for donations. Thank you Jane, and everyone at GleeClubUK!

Ruby's swim for her dad

Ruby, age nine, used her passion for swimming to raise funds for Cardiomyopathy UK by completing a sponsored swim throughout March. After reaching her target of 100 lengths in just two weeks, Ruby doubled her target to 200 lengths, a whopping 4000 metres.

Ruby's dad was diagnosed with cardiomyopathy in 2012 at the age of 30, after he suffered a cardiac arrest whilst playing football. As a result, Ruby and her sister, Thea, will undergo regular checks on their hearts to monitor whether they inherit the condition.

Congratulations and a huge thank you to Ruby!

We would like to say a huge thank you to all our amazing fundraisers! If you have any questions, stories or queries about fundraising then don't hesitate to email us at fundraising@cardiomyopathy.org

GREAT NORTH RUN

11 SEPTEMBER 2022

www.cardiomyopathy.org/great-north

Cardiomyopathy UK
the heart muscle charity