

my life

Issue 18/May 2019

Cardiomyopathy^{UK}

The magazine for people affected by cardiomyopathy and myocarditis



1989-2019

30th Anniversary Special Edition

Welcome from Alison Fielding, Chair of Trustees

Everyone at Cardiomyopathy UK is excited to present this special issue of My Life for the charity's 30th anniversary.

So much has changed since those early days when Carolyn Biro sat at her conservatory table searching for support and information and finding little of either, decided to do something about it and founded a charity to help raise awareness and support patients.

Over 30 years, we have grown the breadth of our services to include regional support groups, online services, clinical education and funding for research.

Today, we are on the face of it very different, but have essentially the same ethos – that information helps patients manage their condition; that talking helps; that the public need to know more about the condition; that providing specialist medical education saves lives.

Our National Conference is my annual highlight and I can imagine how proud Carolyn would be to know that



every year, hundreds of you meet face to face and listen to the top speakers in the country.

Today's treatment and prognosis means many more people with cardiomyopathy and myocarditis are living long and fulfilling lives and we'll be looking at how much medical understanding has improved over 30 years in our next My Life.

As you read this issue, I hope you will be encouraged by how we have gone from an era of bedrest and death, through improved drugs, devices and tests, to a future of better understanding of genetics and newer therapies such as stem cell research.

We are honoured to have a clinical advisory board, who are at the international forefront of research, but still focused on helping us to achieve our goals.

However, the need to improve care for people physically, emotionally and financially is still there. Our job is not done. Roll on the next 30 years.

30th Anniversary Raffle



1st Prize **£500 Cash**
2nd Prize **£250 Cash**
3rd Prize **£100 Cash**

Plus 3 runner-up prizes of
30th Anniversary merchandise packages



Draw to take place on
2nd September 2019

Our annual raffle is back with some big cash prizes.

Our 2018 raffle raised an amazing £12,200 to help families across the UK affected by cardiomyopathy.

Thank you to each and every one of you who bought or sold tickets. Can you help us do even better during this landmark year?

For more information, please see the ticket book included with this My Life, or head to www.cardiomyopathy.org/raffle

We cannot thank the charity enough

Former CMA member Catherine Tooley writes:

My first husband died suddenly from HCM in 1992, aged 38 and with two young children.

His older sister had been diagnosed with the condition a while earlier as she had symptoms.

As a registered nurse, I had never heard of this condition. It was thanks to the Cardiomyopathy Association, as it was called then, that his sister (having stumbled upon it in a women's magazine) learned more about the condition, including the fact it was inherited and that her brothers should be screened.

Sadly, my husband died before this happened; one reason being he felt there was no need as he was fit and well with no symptoms - how wrong he was.

Following his death, the CMA was an enormous support to

us as a family – supporting and educating us, as well as arranging an appointment with Professor Bill McKenna at St George's Hospital for family members to be screened and also, to help with research (which we were more than happy to do).

So we feel indebted to the charity and cannot imagine how we would have coped without it.

Thankfully, much more is known about this condition now; the medical profession is also much more informed and there is greater awareness.

The family have had regular screening – those with the condition have been monitored and treated and my children have also been gene tested.

My sister-in-law had a successful heart transplant a year ago. I cannot thank the charity enough and send my very best wishes for your continued work.

How our
founder
Carolyn Biro's
vision and
determination
led to our
origin



Carolyn Biro and Sir Bill McKenna at the opening of the charity's first offices in 1995

'My mother... she always knew how to start something'

- Dr Brett Gray, Carolyn Biro's son



DO YOU LIKE SMALLER SIZE MY LIFE?

As part of our 30th Anniversary celebrations, we have created this special limited edition of My Life and want to take the opportunity to ask whether you'd like future editions of the magazine to be this size?

Let us know which version you prefer via a very short readership survey: <https://www.surveymonkey.co.uk/r/6XGFPTP> or email us at contact@cardiomyopathy.org. Thank you for your continued support and we look forward to continuing sharing our news during 2019.

Frustrated by the lack of information and support available to those affected by cardiomyopathy, Carolyn Biro launched Cardiomyopathy UK (first called the Hypertrophic Cardiomyopathy Association) three decades ago.

Her vision was to ensure that patients and their families received accurate information about their condition and had access to appropriate and effective care.

Many GPs were unaware of the signs and symptoms of cardiomyopathy, resulting in a lack of appropriate referrals, which could lead to misdiagnosis and devastating outcomes.

The genetic nature of cardiomyopathy was not widely recognised; thus, family screening was rarely initiated. Making matters worse, most local cardiologists lacked the education and experience to competently treat cardiomyopathy.

In an era when cardiologists

were treated more like demi-gods, Carolyn started breaking down the barriers.

"Cardiologists were not used to being challenged by their patients or being told what to do," recalls Professor William McKenna, who helped Carolyn set up the charity with a small group of others sat around the kitchen table at her Hertfordshire home.

"Carolyn knew a great deal about cardiomyopathy and the appropriate treatments. Her knowledge and commitment led her to confront physicians when she didn't think patients were receiving appropriate care. It was an uphill battle, but the charity continued because of her dedication and determination," he adds.

Carolyn was born in 1947 and grew up in Maryland, USA. While working as a medical assistant at Yale in 1977, she met her British medical researcher husband-to-be

Turn to Page 4

Carolyn's legacy continues

Continued from Page 3

Andrew. That summer, Carolyn, aged 30, had a blackout while driving and was later diagnosed with hypertrophic cardiomyopathy (HCM).

Doctors told her it was unlikely she would live more than five years.

Before her diagnosis, Carolyn had seen her doctor several times complaining of a fluttering sensation in her chest and feeling like she was going to faint.

But as she was going through a divorce from her first husband, the doctor felt it was her nerves and prescribed Valium, and a therapist was suggested to help her cope as a single parent.

"It was only after I was diagnosed that a name was put to it and we realised it was hereditary," said Carolyn, who later learnt her father, grandmother and aunt had all died from HCM.

Following her diagnosis, Carolyn's son Brett and daughter Amy were screened and she was told that Amy, then five, had the condition and Brett was clear.

Amy was seen by a cardiologist on a yearly basis, but did not need any medication as she was symptom-free and continued a normal lifestyle.

Carolyn was put on diuretics to control congestive heart failure and anti-arrhythmia drugs to stabilise her irregular heartbeat. She was hospitalised many times and made redundant because of her health.

The family moved to the UK in 1985 when Andrew took a job at London University.

Just before her 16th birthday, Amy developed dizzy spells and an irregular heartbeat that put her in hospital for tests.

Carolyn recalled: "Amy would need medication and while she was in hospital, I was asked if Brett would be willing to participate in the genetic research they were doing at the Hammersmith Hospital in a bid to identify the gene that caused HCM."

Part of the genetic study required Brett had an echo and ECG, which

showed that he now had the condition, aged 17.

Carolyn was devastated no one had ever suggested Brett should be rescreened at any time when she was receiving treatment, or while his sister was being monitored.

"It was at this point in my life that I realised something had to be done and this is why I started the charity," she said.

Carolyn started the Hypertrophic Cardiomyopathy Association in 1989 from her conservatory, determined that others with cardiomyopathy should not suffer through ignorance and lack of support.

She travelled worldwide to learn about the condition and was tireless in her work to help those at risk of cardiomyopathy get the right information and support, as well as access to the best medical care available.

She spoke to medical, media and public groups and formed a medical advisory group with leading cardiologists to raise awareness of the diagnosis and management of cardiomyopathy and to promote research.

The first patient information booklets were created in collaboration with Professor McKenna and his team. A concerted campaign was launched to educate GPs, ensuring symptoms were recognised, appropriate referrals were made and family screening was initiated. The association concentrated its efforts on raising money to expand its staff and succeeded in raising funds for a research nurse at St George's Hospital Medical School.

"Patients need to be as much in control of their condition as possible and have the proper information and advice at their fingertips," Carolyn always insisted.

By January 1995 – the charity, now renamed the Cardiomyopathy Association (CMA) – had outgrown its humble beginnings and moved into new offices in Watford.

"I can't drive or travel by public transport now, or walk as far without getting breathless, but I've made

running the association my mission in life," said Carolyn.

In the autumn of 1995, a fellow American, Lisa Salberg, contacted Carolyn after losing her sister to mismanagement of hypertrophic cardiomyopathy in the US.

Carolyn supported Lisa and the two formed a special bond. Carolyn had always foreseen the establishment of a similar organisation in her birth country and now she found the person to take charge.

Carolyn mentored Lisa in the establishment of the American Hypertrophic Cardiomyopathy Association (HCMA) and was a founding board member.

Today, the HCMA has provided services to over 10,000 families and has recognised over 30 centres of excellence in the US.

In 1995, the Watford offices were raided and computer equipment worth thousands was stolen and the CMA faced further problems caused by the failing UK economy.

The launch of the National Lottery saw the charity's income drop by 90 per cent and this set in motion applications to trusts for grants and efforts to come up with ideas to encourage donations from supporters.

1995 also had much happier events, in the birth of Carolyn's first grandchild, Andre. Being a grandmother was the only thing that Carolyn had more passion for than the charity and its endeavours.

However, when Andre was a few months' old, he too was diagnosed with hypertrophic cardiomyopathy. This fuelled Carolyn's drive to continue her work and improve the lives of those affected.

By the late 1990s, Carolyn's rapidly failing health meant she was considered for a heart transplant. She continued to come into the charity offices when her health would allow.

Other times, she would answer emails from around the world on her home computer and call the office for daily reports on individual members and new medical developments. She was also known for making calls from her hospital bed. In an interview

to mark the charity's 10th anniversary, Carolyn said: "I've certainly lived longer than the five years I was told I had and been dedicated to raising awareness of the illness and hopefully, helping to eradicate it."

Carolyn died on May 21, 2002 – a year after her heart transplant – having helped thousands of families overcome fear and learn how to live with their cardiomyopathy.

The charity she had begun was now involved in a wide range of activities, beyond what would be expected for its size. It provided free support and information to patients, educated health professionals and raised funds to promote excellence in clinical services for the benefit of those affected by cardiomyopathy across the world.

Following Carolyn's death, the charity initially struggled with its loss of strong leadership. After the appointment of some new trustees, a new chief executive and some restructuring, it was soon back on its feet and thriving.

Rebranded as Cardiomyopathy UK, the charity today continues to provide a reliable and trusted service to help people and families living with cardiomyopathy, with no government funding.

Carolyn's daughter, Amy Mann, who had a heart transplant in August 2018, adds: "The ripple effect of my mother's work is profound and vast. Personally, her efforts have ensured that I have been able to maintain a good quality of life despite my condition."

When her own health deteriorated two years ago, Amy, now a resident of the US, turned to the HCMA, which Carolyn had helped establish – her mother's legacy had come full circle.

"I'd like people to remember my mother's great passion and tenacity," she says.

"Despite her condition, day after day, she worked to improve lives of people affected by cardiomyopathy. She was a fierce advocate, who saw what needed to be done and did it."

Cardiomyopathy UK Chief Executive Joel Rose says: "Practical advice from her kitchen table was where we began, and today Carolyn's vision remains at the core of our work. Her drive and passion still helps to propel the charity forward and our challenge ahead is to ensure her legacy continues."

Bill McKenna

Professor William McKenna was President of the charity until 2017 and says Carolyn's drive and determination was a key factor in its success – especially in its aim to educate and support patients.

He says: "In the early days of the charity, patients from anywhere in the UK were at the mercy of



the system and referred to the Hammersmith Hospital in London. There are now dozens of centres of excellence across the country and today, patients know about the drugs they take and how to look after themselves.

"Doctors' attitudes have changed over the years and the patient is now at the centre thanks to the work of this charity, started by one determined, strong and amazing woman."

Stephanie Cruickshank

I first met Carolyn Biro around 1991.

I had suffered an out-of-hospital cardiac arrest and subsequently been diagnosed with hypertrophic cardiomyopathy. I was a nurse married to a doctor, but we had never heard of it.

I was terrified and felt that my life was over, before it had truly begun. I was newly married with a young son; this was devastating and I felt so alone. I started looking around to find out what I could and spoke to Carolyn on the phone. She was cheery and informative and she gave me hope. Soon after we met up, I became involved in the charity, planning events and fundraising and



then became involved in the support groups.

Later on, I joined the team and was involved in promoting awareness of cardiomyopathy. I also helped with the helpline and message board and I focused on

the educational meetings for nurses. Carolyn always had a smile on her face, but just below the surface was a steely determination to get things done.

She fought for what she believed in and worked with the ethos of nothing is too difficult; never give up and get the job done!

She was a truly inspirational woman who was a huge positive influence in my life.

Cardiomyopathy UK has grown into an amazing charity that is providing vital information and support to the thousands of people in the UK with cardiomyopathy.

Robert Hall

I first met Carolyn when she was admitted to my ward, where I was a charge nurse, at St George's Hospital. Subsequent to this meeting, I eventually became the first nurse to be appointed by the charity.

By any measure Carolyn was a remarkable person, combining drive and compassion in equal measure in her aim to improve the lives of people affected by cardiomyopathy.

She was someone I consider myself fortunate to have known. Sadly, Carolyn's ill-health eventually forced her to take a less active role in the charity. Losing such an inspirational



figure resulted in the charity having to take stock and decide on its future direction.

I was appointed to the post of chief executive as part of this process and was fortunate to be part of an

era that saw the charity grow its portfolio of activities aimed at ensuring its relevance to the people it served. Alongside the support of medical specialists, the successes of this period can largely be attributed to

the then chair of trustees, Peter McBride. Peter's leadership, support and overriding commitment to the charity saw the introduction of numerous initiatives aimed at improving medical understanding of cardiomyopathy and increasing the support of people affected by the conditions.

30 years of service and growth ma



- 1989 US-born Carolyn Biro has a vision to provide information and support to families in the UK living with HCM. She makes plans to start a charity and the Hypertrophic Cardiomyopathy Association is launched and run from the conservatory at her home in Hertfordshire.



- 1996 By the end of 1996, the charity is taking 20 calls a day, most of which are new enquiries following extensive coverage in the media. Under the direction of Chief Executive Gordon Rae (top left) the charity publishes leaflets, information guides and a members' black and white newsletter, which are all stored in Carolyn's garage.



1989 1990 1991 1992 1993 1994 1995 1996



- 1990 The charity is renamed the Cardiomyopathy Association (CMA) and granted charity status.



- 1992 The charity hits national headlines following the sudden death of sporty teenager Daniel Yorath, aged 15. Daniel's father, Welsh football boss Terry Yorath, becomes a patron of the charity, along with his TV presenter daughter Gabby Logan. The family's support will go on to help raise more than £250,000, as well as vital awareness of HCM, which many newspapers had wrongly labelled 'an old man's disease' at the time of Daniel's tragic death.



- 1995 Six years after its launch, the charity moves out of the conservatory (top) into new offices in Rickmansworth. At the opening, Carolyn is pictured (right) with world renowned cardiomyopathy specialist Professor Bill McKenna, who had helped set up the charity and held the post of President for many years. By this time, first-time enquiries to the charity for help and advice are growing by more than 60% each year.

de possible by hundreds of people

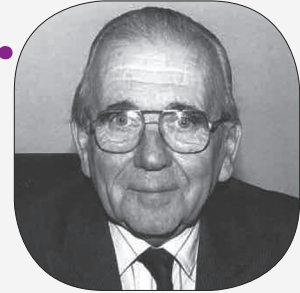


1999 The CMA celebrates its 10th anniversary and upgrades almost all of its services and begins to produce information CD-ROMs and videos, funded by the Yorath family. These are sent to every GP surgery in the country.

2000

The charity pays for a cardiomyopathy specialist nurse as a result of a substantial legacy donation.

2001 CMA's first President, Professor John Goodwin, of the Hammersmith Hospital, dies. He had been instrumental in taking the charity to a new level during his 12 years as President, including securing BHF funding to enable the charity to move into the Rickmansworth offices. In this year, Carolyn has a heart transplant after spending most of 2000 in hospital. Although seriously ill, she still keeps in daily contact with the charity.



2004

The CMA holds the first ever national medical conference in the country on cardiomyopathy, attracting prominent speakers from around the world. Attendees are updated on the disease and able to share their experience of dealing with the illness.

1997 1998 1999 2000 2001 2002 2003 2004



1998

Charity member Simon McKweon (above, far left) provides his services free of charge to help launch the charity's first website. Within two years, it has more than 200,000 visitors worldwide and 1,000 visits a day.

1997

The charity introduces a national helpline, where callers are offered a sympathetic and knowledgeable ear.



2003

Robert Hall becomes Chief Executive – a role he will hold for the next 12 years.

2002

Carolyn dies on May 21. Peter McBride (right) joins the trustees of the CMA and is made chairman the following year.





2005

Sarah Dennis (below) is appointed as the charity's first Information Officer. Part of her work involves starting more support groups, running key contacts training days and editing the CMA newsletter, which is now published quarterly. Regional information conferences and open days increase.



• • • • • **2008** Cardiomyopathy UK's current longest-serving trustee Tina Amiss (right) tells her story to The Guardian newspaper about living with an ICD. She is also selected to join a group giving advice on complex, invasive heart care to the new health service commissioners in order to help shape future health services for heart patients.



2014

The charity produces two online videos - written with the help of cardiomyopathy experts Professors Bill McKenna and Perry Elliott - to help GPs recognise cardiomyopathy and provide information on how to support patients with the disease. The GP videos were funded by the charity's first national fundraising campaign in aid of more medical education - the Great Pancake Party - from an idea suggested by supporter Lynn Hedgecoe. The charity appoints a community fundraising manager.



2005 2006 2007 2008 2009 2010 2011 2012



2007

The charity moves to new offices in Chesham, Bucks (left) and takes a significant step forward with the appointment of a new fundraising team as part of plans to increase activities for the benefit of patients and their families. The charity launches its Facebook group on May 14.

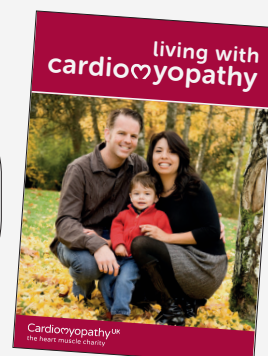
2010

The charity uses a substantial grant to appoint its first in-house support nurse, Gill Rogers (above), who is able to respond to telephone queries from affected individuals and their families. By 2012, the CMA has a trio of part-time nurses to help people contacting the charity.



2009

The charity celebrates its 20th anniversary with a variety of fundraising events, including a fire-walking event and eBay auction. Patient information booklets are redesigned and the CMA also sets out a goal to campaign for more gene tests for families.



2017

Cardiomyopathy UK introduces its first in-clinic peer support service at the Queen Elizabeth Hospital in Birmingham. We form a CYP&YA (Children, Young People and Younger Adults) Panel (right) to provide mutual support and guide the development of services. The Big Lottery support group project is launched



LOTTERY FUNDED

to increase our national support group network as a safe place for people to discuss their condition.



2016

The charity introduces its annual Cardiomyopathy UK awards to recognise and celebrate individuals who make significant contributions to the charity.



Alexander Jansons Fund

part of **Cardiomyopathy UK**
the heart muscle charity

2018

The Alexander Jansons Fund joins forces with Cardiomyopathy UK to expand the knowledge, diagnosis and treatment of the heart muscle disease myocarditis.

2013 2014 2015 2016 2017 2018 **2019**

2015

A year of change sees the charity adopt a new name and logo. Robert Hall takes on a new role as Medical Director; Joel Rose (left) becomes Chief Executive and Alison Fielding (below) becomes the new Chair of Trustees.

The charity launches a bold new strategy – introducing new logos, leaflets and merchandise, as well as a packed programme of events, including the first national conference for families.

Cardiomyopathy UK joins the Alliance for Heart Failure and becomes a strong voice in Westminster by contributing to an All Party Parliamentary Group on Heart Failure enquiry and report.

The website is redesigned to become a vital source of information and support for people affected by cardiomyopathy and a new Live Chat service is started to enable people to connect via their computers to the charity's nurses.

My Life magazine is launched and copies are sent to doctors' surgeries, hospital waiting rooms and individuals.



Live Chat



Email our nurses

We're here for you



Call our helpline

Cardiomyopathy UK
the heart muscle charity

2019

Cardiomyopathy UK strives to continue Carolyn's legacy in a digital world and dedicates its efforts to helping people and families living with cardiomyopathy. Today, 90 calls are made each month to our helpline and more than 600,000 people visit our website.



Genes and diagnosis



By Dr Antonis Pantazis, Consultant Cardiologist at the Royal Brompton & Harefield NHS Foundation Trust and clinical lead for cardiomyopathy and Samantha Mason, Genetic Counsellor at the Royal Brompton and Harefield

Inherited heart muscle conditions (cardiomyopathies) are different in many aspects than acquired and degenerative heart conditions.

They are chronic conditions, often caused by a spelling mistake in the DNA, which nowadays can be identified in a good number of patients.

Inherited heart muscle conditions are not present in the heart from birth. They develop later in life because of the messages sent to the body from the DNA - the genetic library.

They can present early in life and may affect many relatives in the same family.

Inherited heart muscle conditions may be entirely asymptomatic, but can occasionally cause limiting symptoms and be associated with serious risks.

What is new in diagnosis?

A considerable volume of new information about these conditions has emerged in recent years.

Cardiac imaging has revealed details of the anatomy and function of the hearts that have led to better understanding of the condition and detection of early manifestations. Contemporary imaging can describe ultrastructural details of the heart cells, pick up inflammatory process and associate them with the clinical presentation.

Various types of cardiac monitoring have enabled us to keep a close eye on the patients with cardiomyopathy and detect rhythm abnormalities.

How has the use of genetic information changed?

In 2009, the CMA campaigned for genetic testing to be established as an important part of clinical practice and there has been major progress in this field.

Thirty years later, it is steadily becoming a standard of care to offer genetic testing to individuals who have a diagnosis of cardiomyopathy and is now broadly offered by the NHS. Although some clinical decisions may take into account the result of the genetic testing, genetic testing may have no clinical value to the individual already diagnosed with cardiomyopathy; however, it is important for the family members and it can help to identify individuals who are at risk of developing cardiomyopathy.

Inherited cardiac conditions usually have a 50% chance of being passed on and they do not skip generations.

It is also a useful test for family members who are thinking of planning a family and 'Preimplantation genetic diagnosis' (PGD) can be offered to patients diagnosed with cardiomyopathy - if a gene has been identified - in order to rule out the inheritance of the faulty gene.

What are the challenges?

Not all carriers of a genetic change linked to a cardiomyopathy will develop the cardiomyopathy.

Having a gene for cardiomyopathy means that the individual is at higher risk of developing this condition

compared to the normal population.

There is no way to predict who will and who won't get the condition, which is why it is important for the gene-carriers to attend regular screening.

However, the genetic testing is not perfect. In some families, a gene variation will be found in a person with an inherited heart muscle condition, but it may difficult to tell if this gene change is causing the cardiomyopathy or whether it is a normal genetic variant.

When no cardiac disease-causing genes are identified during genetic testing, this does not mean the condition is not genetic. It simply means that the current technology cannot find anything within the patient's DNA. Despite the progress, there are still great clinical challenges and research is trying to address them.

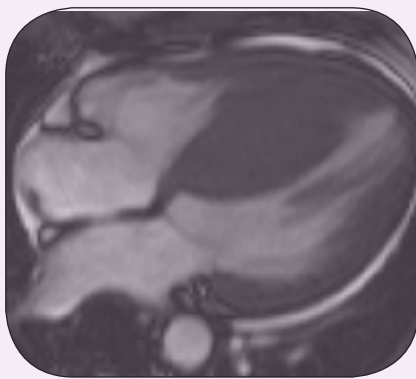
What will research be looking at in the next 30 years?

We are not sure what makes the DNA messages translate at some point in life into a clinical condition, nor do we know the exact effect of other genes on the main gene causing cardiomyopathy or how to prevent it.

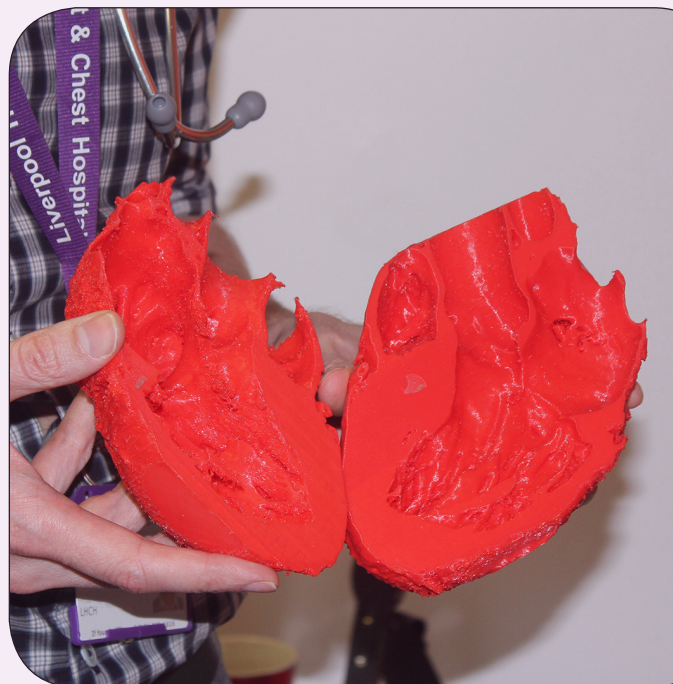
Questions remain, including what impact lifestyle and other factors, such as viruses, have on inherited heart muscles conditions.

Can new drugs be developed in order to treat symptoms and improve the life-expectancy of patients?

To answer these questions, research



Today, MRI devices are able to scan the inside of the body in intricate detail and 3D organ models help physicians make more informed decisions and precise plans prior to operations



Cardiac imaging

Developments in echocardiography, computed tomography (CT) and cardiac magnetic resonance imaging (MRI) have been excellent as they provide detailed information regarding the appearance of the heart to help make accurate diagnoses.

Once a diagnosis has been made, these various imaging modalities are used to help understand the severity of the condition, which can allow cardiologists to make more accurate assessments of the risk of sudden cardiac death (SCD), but also to understand the patterns of blood flow through the left ventricle – particularly important for people with hypertrophic obstructive cardiomyopathy (HOCM).



By Dr Rob Cooper,
Consultant Cardiologist
at the Liverpool Heart
and Chest Hospital

The anatomy of the exit point for blood flow out of the heart (often called the outflow tract) can vary significantly between patients with HOCM, and accurate treatment of the problem can only happen with a thorough understanding of these abnormalities.

This is where recent advances in imaging technology have really helped guide

treatments, such as alcohol septal ablation, surgical myectomy and even radiofrequency ablation.

The use of these imaging tests to choose an appropriate form of 'septal reduction' is critical and has led to better outcomes for patients with

this condition.

The use of 3D printing has also enhanced our ability to understand heart abnormalities.

Some patients also find it helps their understanding and can provide peace of mind going into treatment.

Being able to understand the 3D anatomy of the left ventricle allows cardiologists and surgeons to plan an operation in greater detail, offering the potential to improve outcomes and limit complications.

The development of imaging tests that take images of the heart is fundamental to our understanding of cardiomyopathies and allows us to personalise treatment options – particularly in treating obstruction to flow out of the left ventricle.

This technology will continue to evolve, providing exciting opportunities to improve care for patients.

can follow two main routes. One is the study of the genes and the cells of the heart in the lab and the other is the study of the clinical details of patients with cardiomyopathies.

The former is assisted by high level technology, which is becoming increasingly available in our era.

The latter requires large volumes of data in order to enable confident conclusions, given the variability and the complexity of these conditions.

The more people are included in

studies, the more we can learn about these conditions and their genetic aetiologies.

The requirement for data exceeds the capacity of individual institutions and occasionally, of individual countries.

Obviously, research of this scale often requires significant financial support.

Although a number of organisations have in their agenda the support of research in cardiomyopathy, the financial constraints create a competitive

environment.

The research ideas and projects that are more likely to be completed successfully and produce actionable results that will influence the patients' management are usually prioritised.

For these reasons, collaborative and carefully planned work; supported expert researchers, institutes and patients are well placed to answer the important and still open questions in inherited heart muscle conditions.



None of our vital services would be possible without our fabulous fundraisers, and much of what we have today is a consequence of their efforts over the past 30 years.

Head of Fundraising Sheila Nardone says: "The fundraising efforts of our supporters are the lifeblood of the charity and have played a crucial part in helping the charity to grow to where it is today.

"In this, our 30th anniversary year, we're hoping even more supporters will get behind us to ensure more families affected by cardiomyopathy and myocarditis have the information and support they need.

"As we get no statutory funding, we rely entirely on individual donations and the efforts of our fundraisers to fund our work.

"Every penny raised makes a real

Hearts and crafts

difference to the families affected. Whether you volunteer, take part in an event, or make a donation, you will be doing your bit to maintain and develop services."

Two families have raised a significant amount of money for Cardiomyopathy UK by using their creative skills in knitting and fine art. In 2018, the Baker family raised £1,777 for

Cardiomyopathy UK, bringing the JimmyBoy fund total to £55,396 since it started in 2010 following the death of Jackie's son James Baker, aged 27, in May 2009.

A spark of an idea and a real desire to do something positive in James' memory resulted in mum Jackie, aunt Sally and grandmother Mary reaching for their knitting needles to make story baskets, blankets and toys, which they sell at two annual craft fairs.

"It's really rewarding to be able to spread the Cardiomyopathy UK word and talk to the many people who have heart problems of their own," says Jackie. "My advice is to just find something you're good at and go for it! You'll be pleased you did and the charity will be pleased with whatever you can raise for them."



Our dedicated supporter Nayland Smith has been celebrating the life of his late wife Sue by selling packs of notelet cards featuring Sue's original artwork in aid of Cardiomyopathy UK.

Nayland sold the cards in packs of 10, each card featuring a different painting – from vibrant botanical designs, to soulful landscapes.

Sue's Much Loved tribute space has now raised close to £7,000 for the charity – an incredible amount and testament to the overwhelmingly positive impact Sue made on all whom she met. Sue was a great friend to

the charity and her creative talent and sunny disposition will live on in the support we are able to give families across the UK, with the help of the funds raised from her artwork.

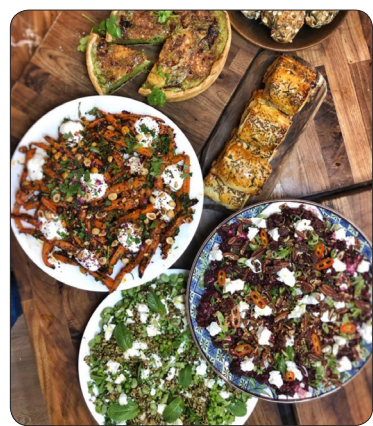


Table is set for an anniversary lunch

A mouth-watering new fundraiser is on its way this May.

Keep an eye on our website and social media accounts as we launch a fantastic foodie fundraiser to celebrate our 30 years as a charity.

Once again, we've teamed up with gourmet chef Ian Human to craft some incredible culinary creations that we think you'll absolutely love. So prepare yourself for the perfect excuse to get together with friends and family this spring or summer.



Our President's view

Professor Perry Elliott is President of Cardiomyopathy UK and Professor of Cardiovascular Medicine at UCL and a specialist in Inherited Cardiovascular Disease at St Bartholomew's Hospital



Professor Perry Elliott has been involved with the charity since its early days and believes founder Carolyn Biro "would be proud" Cardiomyopathy UK has kept to the ethos of meeting the needs of patients by providing accurate information about the condition and raising awareness, which is "paramount".

He was among the group of young cardiologists who, at the start of their careers, responded to Carolyn's invitation to attend regular patient meetings in order to better understand the condition.

In the 1980s, there were no specialist clinics for patients with cardiomyopathy and the majority of patients were cared for by cardiologists in London.

"Understanding of the condition was poor, but this has improved significantly in the past 30 years - the medical community has changed its attitudes," he says.

"Today, there are lots of regional clinics around the UK, which means there is much more knowledge about cardiomyopathies than when the charity first started."

Looking back over the past 30 years, Perry points to the rise of the implanted defibrillator as one of the most important medical advancements.

"It's a fantastic innovation, as all

we had before this were drugs.

"Cardiomyopathy is all about personalised medicine, but defibrillators have allowed us to protect individuals."

Narrow thinking about cardiovascular medicine means that cardiomyopathy is often overlooked as a health issue and the reason Perry remains passionate about raising awareness of cardiomyopathy among the next generation of health care professionals.

"For example, in the National Heart Failure Audit, cardiomyopathy is barely mentioned, in spite of its impact on patients and families," he reveals.

"On the positive side, continuing education for health care professionals is improving and cardiomyopathy is now diagnosed far more often."

Discussions around current trials in cardiomyopathy and myocarditis and the rapid advancement in the development of drugs are also "very promising" for patients, according to Perry, and has created an "explosion of interest" among clinicians.

"We are training trainee cardiologists to build a legacy for the future and trials in HCM, DCM and myocarditis.

"Consensus is that real breakthroughs are only a few years away and drug companies are currently looking to reverse and prevent cardiomyopathies from developing," he adds.

The impact of genetics has also played an important role in understanding cardiomyopathy, according to Perry.

"DCM has been a 'Cinderella area' for many years and only now is getting the attention it has needed as the medical community realises this.

"We can accurately say that one in four people with DCM have it

Ultimately, we are here to cure a disease and there is much promise one day this will happen

because of a genetic mutation.

"Genetic testing in DCM is now receiving a lot more attention as clinicians understand its relevance to patients.

"In future, we need cardiologists to acquire a higher level of genetic literacy to stop cardiomyopathy falling off the radar."

And in a bid to reach global audiences, Perry is involved with setting up an International Cardiomyopathy Network (ICON) to bring together patients, industry, clinicians and scientists.

"Ultimately, we are here to cure a disease and there is much promise one day this will happen.

"Meanwhile, Carolyn's legacy continues, as supporting patients and families remains at the heart of what we at Cardiomyopathy UK do."



A photo of Perry in the early days of the charity

Our impact in 2018



In the 30 years since we became a charity, we have helped thousands of families affected by cardiomyopathy. We have taught hundreds of doctors and nurses about treatments and the latest research benefiting the patients they care for. We've also influenced health policy and practice. Cardiomyopathy UK Chief Executive Joel Rose reflects on some of the highlights from our activities in 2018



2018 was a fantastic year where we continued to grow and helped more people than ever before.

I am especially proud we were able to reach more people, who had previously not known about cardiomyopathy or about the help and support we can give.

We achieved this through expanding our support group network, placing volunteers in more hospitals and running a successful national campaign.

2018 was the second year of our support group expansion project funded by the **Big Lottery Fund**.

Thanks to their support and the fantastic work of our **support group volunteers**, we were able to open up 7 new groups and launch new online support groups for rarer cardiomyopathies and for people who would not be able to attend a group meeting. We are really pleased that in 2018, we held 89 meetings across the country with record numbers attending.

Our hospital volunteers are there to offer **peer support** at cardiomyopathy clinics, often speaking to people who have just been given their diagnosis and are still in a state of shock. In 2018 we were able to expand this new area of work, opening up a new site in Reading.

In total, our volunteers were able to support 483 people, often at a time when they needed it most.

We know that when more people know about cardiomyopathy then fewer people die. That's why our **national awareness** raising work is so important.

In 2018, we ran a campaign focusing on the misconceptions people have regarding cardiomyopathy and what a "typical heart disease" person looks like. The campaign received wide coverage in broadcast media and saw a 521% increase in engagement across the charity's social media platforms.

As well as working on these new projects, we were able to keep providing the vital

support and information services that we know so many people value.

In 2018 our **helpline** was able to support 1,890 people over the phone, via email and online - a slight increase on the previous year. We have noticed that more people are coming to our helpline wanting emotional support or needing practical help with issues relating to disability benefits.

We are really pleased to see that after speaking to one of our helpline nurses, the vast majority of people feel better informed about their conditions, better able to cope with their situation and know what steps they need to take.

We are also pleased that our helpline team have been able to help more people with myocarditis, a heart muscle disease that can often lead to cardiomyopathy.

We know not everyone feels comfortable joining a support group or just doesn't feel ready or able to get out and meet others with the condition. Our team of **tele-phone support** volunteers are there to speak to people one-to-one so everyone can still get the benefit of peer support. In 2018, thanks to our volunteers, we were able to help 113 people in this way.

Providing education and training to **health care professionals** has always been an important part of our work. In 2018, we were able to increase the number of events for health care professionals, running regional meetings and working in partnership with the British Association of Nurses in Cardiac Care, thus able to provide training to more healthcare professionals working in a wider range of roles. You can find out more on our website as well as some of our plans for this year.

As ever, all we have achieved is thanks to our generous supporters, volunteers, and staff, who have continued to show their commitment to our work. Thanks to them, I'm sure the charity will continue to go from strength to strength.



'Heart Bleeps' Campaign
#EveryHeartUnique

Helpline
0800 018 1024
Monday - Friday
8:30am - 4:30pm



'Now I want to help others'

Giving a regular gift to Cardiomyopathy UK enables families affected by cardiomyopathy and myocarditis get the vital support they need – when they need it most.

Andrew Lavender, 49, from Devon, set up a direct debit ten years ago.

"I contribute regularly to the charity because it has benefited me and I want people being diagnosed today and those in the future, to continue to have better information, support and services available to them," he explains.

Andrew was diagnosed with hypertrophic cardiomyopathy after collapsing at work.

"I'm on my second ICD and I manage my condition through a variety of medication," he says.

"When I was first diagnosed, I had no information about my



£5 a month will enable someone facing a new diagnosis to attend an event to get the vital information they need to understand and manage their condition.

£10 a month will pay for 5 people to access our helpline to get personalised medical advice and information when they need it most.

£15 a month will enable us to work with health care professionals to improve early diagnosis and access to treatment.

condition and the first internet searches were scary. It was only when I found Cardiomyopathy UK that things changed.

"The information on the website, the forums with others who have the same condition and the helpline, where I could speak to someone, were all hugely important to me.

"My life changed when I got diagnosed and I still feel that impact

every day. Throughout the past ten years, I've regularly sought information, advice and support from Cardiomyopathy UK and its members and want to help ensure services continue improving the lives of more people affected each year."

Head of Fundraising Sheila



Nardone says: "Thanks to our regular donors giving the charity steady income, we can improve and expand our services to save and improve

the lives of more people affected each year. There's still more to do to sustain the growth and reach our charity goals and that's why we value this form of giving.

"Whatever you can give will make such a difference to others."

Please sign up via our website, or contact Sheila on 01494 791224, or email her at Sheila.nardone@cardiomyopathy.org

Mandeep is champion of champions

Since the launch of the 30 Day Challenge back in February, 27 of our superstar supporters have already signed up to be part of our Challenge Champions team.



We are absolutely delighted with this response and have really enjoyed following the progress of each member of the team as they've tackled their respective challenges.

Here are the most popular challenges taken on by our supporters so far:

8 supporters gave up chocolate for 30 days.

7 supporters took on a running/walking challenge for 30 days – from 8,000 steps per day to a complete tour of the Isle of Wight.

5 of our supporters gave up tea/coffee/caffeine for 30 days.

Many congratulations to all our Challenge Champions and we cannot wait to see what new challenges you'll come up with next.

An extra special 'well done' goes to Mandeep Chumber, who is our current 'Champion of Champions', having raised a whopping £556 from giving up caffeine in February.

If you would like to take on a 30 Day Challenge to celebrate Cardiomyopathy UK's landmark year, go to www.cardiomyopathy.org/30challenge or contact our Community Fundraiser Christie Jones, via christie.jones@cardiomyopathy.org or call him on 01494 791224 to get involved.



Mandeep Chumber
Caffeine-free for 30 days
£556.00 raised

'There was no internet when I was diagnosed'

In the 1980s Hugh Brazier had never heard the word cardiomyopathy

It was while waiting as a patient to see Professor Bill McKenna at St George's Hospital, London, in 1994, that Hugh Brazier noticed something pinned to a noticeboard – a leaflet advertising the Cardiomyopathy Association.

"For the first time I had a sense of not being alone, and I joined," Hugh recalls.

Before then, Hugh had hardly heard the term dilated cardiomyopathy (DCM).

"Looking back, I'm astonished at how uninformed I was in those early years," he admits.

In June 1986, his brother Andrew had died suddenly while taking part in a fell-running race.

"Andrew was 32, and because I was his identical twin I found myself in hospital undergoing tests, including an angiogram and a MUGA scan," says Hugh.

"My coronary arteries were clear, but I had an enlarged heart and a reduced left ventricular ejection fraction.

"The cardiologist explained almost nothing to me, and it wasn't until I saw my GP a few weeks later that I had any feedback at all."

Hugh was referred to a different cardiologist for an annual echocardiogram. The new doctor was more supportive and communicative, but the word cardiomyopathy was barely mentioned. Still feeling rather lost, Hugh drew on his experience as a medical librarian to find out more.

"There was no internet then of course, so I looked in textbooks and journals – although I didn't really know what I was looking for. I had no symptoms, and as far as I know my brother had never had any either.

"I found some scary stuff, but had no easy way to work out how it related to me," he admits.

Hugh soon resumed his normal,



active life and "got out of the habit" of seeing his cardiologist as often as he should.

"When I did go back after an interval of a couple of years (prompted by some chest pains), the consultant was suddenly very concerned," he recalls.

"He told me my heart was now severely enlarged and my ejection fraction had dropped dramatically.

"I was started on a range of drugs (warfarin, amiodarone, an ACE inhibitor) – which in those days meant careful monitoring over several days in hospital while the drugs were titrated."

Shortly after moving from Dublin to York in 2002, Hugh had an ICD fitted to treat his abnormal heart rhythm, which allowed him to be taken off amiodarone – and in 2012 this was upgraded to a CRT-D device.

"I've had a few shocks along the way (including once when I was sailing a dinghy single-handed!) but in general, it's been a positive

experience," he maintains.

Over the years, drug treatment improved and became more sophisticated and Hugh's drug regimen changed as cardiologists got better at understanding how to tweak the physiology of the heart.

But his ejection fraction has declined steadily over the years.

"I'm sure the drugs slow the decline, but I have never seen an improvement in signs or symptoms, not even when I started on the new 'wonder-drug' Entresto.

"I am also a non-responder to the resynchronisation side of the CRT-D. They keep fiddling with the settings – to no avail – but I carry on carrying on," he declares.

And despite the fact Hugh is now listed for a catheter ablation to deal with ever-increasing atrial fibrillation and is on a six-monthly transplant review, the 65-year-old freelance editor still walks up mountains (although not as fast, or as far, as he used to), still sails a dinghy (although only in very light winds) and enjoys birdwatching and DIY.

He is also delighted that people diagnosed with cardiomyopathy today are able to understand every aspect of their condition, thanks to the work of Cardiomyopathy UK.

"Cardiomyopathy UK is an amazing organisation," he declares.

"From modest beginnings and that rather scruffy notice I saw in the hospital corridor 25 years ago, it has grown dramatically in size and stature and is now the go-to source for information on everything to do with cardiomyopathy and myocarditis.

"I'm sure that anyone newly diagnosed today will feel much more supported and much better informed than I did when I was first diagnosed all those years ago."

Why our website was a lifesaver for Tracey

Prior to the onset of her takotsubo cardiomyopathy (TTS) Tracey Robson, 46, was fit and healthy – working out between three and five times a week doing high-intensity training and running.

But in July 2018, while at work in her job as a key worker for children with social, emotional and mental health difficulties, she began to have palpitations.

"It had been a stressful day at work so I put it down to that," recalls the mother-of-two from Stoke.

"I'd had to deal with a number of aggressive incidents with pupils and realised I felt quite weak. I then had a sharp pain in the centre of my chest which only lasted a short time, but I was immediately called to support in another heightened situation.

"At this point I felt a heavy sensation in my chest (like a bolder had been placed on it) and my left arm and hand went numb.

"I couldn't do anything other than inform a colleague and talk the pupils down. I then became extremely fatigued and as it was the end of my working day, I went home and to bed. I felt agitated and felt something wasn't right, but convinced myself it couldn't be anything serious as I was so fit and active. In the early hours of the morning, I rang for medical advice. An ambulance was sent and although my ECG was not overly concerning, my blood

pressure was high and the paramedic felt that I needed my troponin levels checked as he felt something might be wrong."

Tracey was admitted to hospital and spent four days on the cardiac ward.

"The consultant's diagnosis was a suspected heart attack and stress cardiomyopathy. He briefly explained this was an acute form of heart failure linked to stress," she recalls.

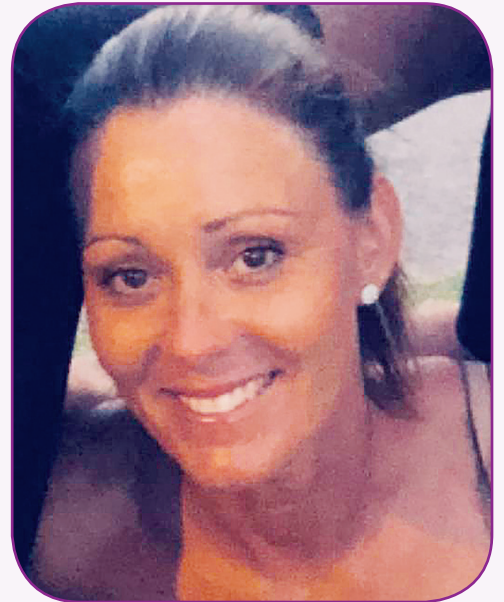
"After I was discharged, I couldn't believe how weak I was. I struggled to walk from one room to another without getting out of breath and needed to sleep several times a day.

"Although my MRI and echo have ruled out a heart attack and confirmed that my heart has returned to normal, I am still symptomatic. I get out of breath walking up the stairs, struggle to lift things above my waist, struggle at times to wash and dry my hair etc and I get very tired.

"I have to take the good days and listen to my body on the bad. I have daily skipped heart beats and palpitations, which have been very scary. I've also been unable to return to work or exercise, so feel I've lost the two things that I love."

Tracey found the Cardiomyopathy UK website when she decided to go online to learn more about TTS.

"I'd come out of hospital confused as to what was happening. I felt alone having



to deal with my symptoms and trying to process it all.

"Without Cardiomyopathy UK, and the support and help from my rehab team I don't know where I would be.

"I've spoken to a Cardiomyopathy UK nurse a number of times for reassurance and advice and they have helped me to understand the condition better.

"I'm also grateful to all the lovely people in the support groups.

"Takotsubo is still being researched and I feel this is invaluable. I am eight months post the onset of TTS, but am still in recovery and awaiting more test results.

"I know with the continued support I receive from Cardiomyopathy UK and my rehab team (for as long as I am with them), my family and close friends, I am able to try and remain positive for my future."



A day in the life of...

our Head of Services Ali Thompson

MY career has been spent exclusively within the voluntary sector and I've always chosen roles where I'm able to work with service users, whose cause I can strongly identify with.

In each of my roles, I've developed new services and worked face to face with the charities' beneficiaries.

As the Head of Services for Cardiomyopathy UK, my job is incredibly varied and it is this variety of work and the people I get to meet that makes my role so enjoyable.

I manage the services team, which includes our clinical cardiac specialist nurses and I am responsible for the

strategic oversight and daily delivery of our helpline services; peer support work within the community; information resources; clinical and public events, as well as services directed at children, young people and younger adults.

I also provide the benefits and welfare advice aspect of our helpline and I'm an administrator for the Facebook closed groups we offer.

My days are varied and fulfilling, but a typical week for me is overseeing the support group network, which the charity has grown considerably over the past three years; working with our young people's panel to improve our services for young people; arranging and delivering open days and study days for clinicians; providing advice on benefits and employment and presenting the charity's services and wider remit to other private and public sector individuals.

The part of my role I truly love is talking to our community – our amazing volunteers, clinicians, service users and of course, our staff.

I hold our volunteers in very high regard. They lead our support groups; moderate our Facebook groups; provide essential support in clinics; advise on our information outputs and provide a listening ear over the phone to service users who are sometimes very scared, or in a state of shock post diagnosis.

The team I manage and the wider staff team are committed to providing the highest calibre of support to the charity and our beneficiaries, and working alongside them and our volunteers is a privilege.

Over the past 30 years, the charity has honed its knowledge and capability to provide a truly holistic service that fully reflects the needs of people affected by cardiomyopathy and myocarditis.

For individuals, families, young people and carers, Cardiomyopathy UK offers clinical advice, emotional support and practical information about welfare.

The charity is reaching and working with more health care professionals



**30th
anniversary
hoodie and
bag package**

Support us in our 30th year with our special notelets (above) by artist Melissa Gloode (£5 for pack of 10) or our special zip hoodie and tote bag package (right) at £30+pp to raise money for our services to help people affected by cardiomyopathy and myocarditis. Available via our online shop

www.cardiomyopathy.org/shop





Teamwork: Clinical support nurses Jayne Partridge (on left) and Emma Greenslade, with Information Education Events Manager Adrian Taylor (right)

'The part of my role I truly love is talking to our community'

than ever to work towards early detection, prompt diagnosis and fair access to treatment.

Our national conference has become a staple in the charity's diary and this year, we are going to host a national event solely for 13-18 year-olds.

As we move towards the next 30 years, we hope to provide anticipatory grief support to give more practical and emotional assistance to those with advanced heart failure, extend our coverage of Wales and Scotland and increase our community peer support volunteer services.

Cardiomyopathy UK is and always has been a family – our volunteers, our beneficiaries, our clinical advisory group, our staff – we're all in this together.

By Ali Thompson

**Follow me on Twitter
@HeadofServices**

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

Helpline

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

Live Chat

www.cardiomyopathy.org



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24 miles, 12 hours, 5200ft, 3 peaks

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the heart muscle charity

Pen-y-ghent, Whernside and Ingleborough

What's included?

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15th September 2019

Help us celebrate our 30th anniversary year and sign up today!



Call Danielle on 01494 791 224 or email: danielle.devine@cardiomyopathy.org