

my life

Issue 17/January 2019

Cardiomyopathy^{UK}

The heart muscle charity magazine for people affected by cardiomyopathy



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'Heart Bleeps'
Campaign

#EveryHeartUnique



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Who's new to the team?

People are at the centre of Cardiomyopathy UK. Meet three new faces who joined the charity at the end of 2018

Jill O'Connell joined our board of trustees in October 2018.

Jill was diagnosed with ARVC in 2003 and recently returned to the UK, having lived and worked in the Middle East for more than 18 years, working in aviation management and running her own training consultancy.

Jill's simple message to others is 'Don't judge the book by its cover' and is the reason she shared her story as part of Cardiomyopathy UK's Heart Bleeps campaign. **(Read about the campaign on Pages 10 & 11)**



Adrian Taylor joined Cardiomyopathy UK in November 2018 as the new Information and Educational Events Manager, following a career in training young people who were at risk of exclusion.

Having studied psychology, Adrian is particularly looking forward to meeting those affected by cardiomyopathy and learning more about their coping methods.

"I'm also very interested in innovation in the field – particularly CRISPR gene-editing technology," says Adrian. "In the short time I've had in post, I've had the chance to observe a small, but highly-motivated, enthusiastic and hard-working team at work."



Our new Digital and Social Media Officer is Rebecca Shirley, who joined us in October 2018, having worked in digital communications at another charity.

"Nowadays, social media can play such an integral role in how a charity is able to connect with its supporters and I hope I can build on this, particularly, to share more of the fantastic work that the charity does through filming events such as open days and fundraisers," says Rebecca. "Everyone has been so welcoming and I'm proud to work for such a dedicated charity as Cardiomyopathy UK."



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Monday - Friday

Live Chat

www.cardiomyopathy.org



Facebook

/cardiomyopathyuk



Join our Facebook group
(closed privacy settings)
facebook.com/groups/
cardiomyopathyuk

Twitter

@cardiomyopathy



Instagram

@cardiomyopathyuk



Cardiomyopathy UK is a charitable incorporated organisation (CIO) with a registered charity no 1164263



Welcome

from Alison Fielding
Chair of Cardiomyopathy UK

I hope that you all had a healthy Christmas and New Year holiday. With all that food and drink, it's hard to stay on the straight and narrow. All the hugs and kisses can add to the germ count too!

We ended 2018 with our Heart Bleeps campaign to show how

heart disease can affect anyone and you can't tell by looking at someone whether they are affected.

It was fantastic to see so many supporters actively engaging with the campaign through our social media.

Having a variety of different content such as videos, animations and infographics went down well across our social media platforms and we hope to make this year's campaign even more successful.

2019 is a big year for Cardiomyopathy UK as we celebrate being founded 30 years ago.

From a time when the only treatments were bed rest and Digoxin and the prognosis was poor, we have now reached

an exciting time — with much better treatments; a better understanding of the diseases and ongoing research into how we may be able to prevent or reverse cardiomyopathy and myocarditis in the future.

The charity has changed too. In the past few years, we have opened more support groups; launched our annual conference; developed our online materials and grown our closed Facebook group to nearly 5,500.

We also introduced nurse-led advice online; started to put volunteers directly into clinics; developed new services for young people based on their design; expanded the clinical training across the country and run two major PR campaigns that reached millions of people.

You can help us to make 2019 stand out

We would like everyone to join in by promoting awareness, fundraising, volunteering to help others and coming to our events. We have high ambitions and look forward to making it a great year for everyone.

Fitting tribute to our founder

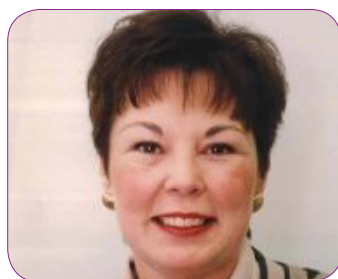
2019 is a landmark year for Cardiomyopathy UK as we celebrate our 30th anniversary



When Carolyn Biro, a mother of two young children, was diagnosed with hypertrophic cardiomyopathy in 1977, there was no patient information available on her disease.

Carolyn was shocked to find that many families were not being told of the need for regular heart checks and committed herself to making a difference.

In 1989, she founded the charity, initially called the Hypertrophic Cardiomyopathy Association; then the Cardiomyopathy Association and finally, Cardiomyopathy UK since 2015.



Carolyn Biro

The steady growth of the charity over the years has been tremendous and today, Cardiomyopathy UK is the leading charity for cardiomyopathies within the UK and recognised around the world for the quality of our information and support.

We will be celebrating our 30th anniversary in 2019 and would love to invite all our supporters and fundraisers to get involved.

The April edition of My Life will be dedicated to the anniversary, when we'll look back at how far clinical

intervention has come for people living with the condition over the past 30 years — including stories from the past three decades — and outlining where we'd like the charity to be in the next 30 years for future generations.

In the meantime, please look at our anniversary wish list on **Page 7** and our fundraising calendar on **Page 18** to see how you can get involved to help make a difference for everyone affected by cardiomyopathy and myocarditis.

"It will be a fitting tribute to our founder Carolyn Biro if we can make our 30th anniversary year one

where we continue to grow our charity and reach more people than ever before," says Cardiomyopathy UK Chief Executive Joel Rose.

"Carolyn's vision for everyone affected by cardiomyopathy to lead long and fulfilling lives, remains at the core of our work to improve the quality of services provided.

"With our supporters' help, we want to make 2019 a memorable year and continue to expand and improve our services so more people and families affected can get the information and support they need — when they need it most."

Do you have any memories and stories from the past 30 years to share?
Please contact My Life Editor Kerry Allan at kerry.allan@cardiomyopathy.org or give her a call on 01494 791224.

View from the clinic

William Bradlow has worked as a Cardiology Consultant at University Hospitals Birmingham NHS Foundation Trust for the past six years

How did it feel to win the Ronald Raven Award for Clinical Excellence at the 2018 Cardiomyopathy UK national conference?

I was absolutely delighted. It means a great deal to be recognised by patients, and Cardiomyopathy UK in particular, for our work.

What led you to choose to specialise in cardiomyopathy?

My training was primarily in cardiac imaging, but I'd also had experience of managing an inherited form of pulmonary hypertension (where the blood pressure in the lungs is higher than normal) during research.

My consultant job in Birmingham gave me the chance to combine imaging with running the cardiomyopathy service. The opportunity to positively impact a large group of patients was too good to miss.

What's the best thing about your job?

I enjoy being part of an extended team striving to improve the care of patients with cardiomyopathy. It involves working across the NHS, academia and industry, which makes for a really satisfying mixture of problem-solving and team-working.

What are you most proud of?

I'm proud of growing our service and creating a system where routine clinical information can be collected and used to improve delivery of care.

What's been the biggest challenge?

Collecting the data is a painstaking process as the information has to be taken from different sources. Managing this whilst developing the service is a challenge!

How many people a year do you see in your clinic with the condition?

The service manages more than 800 patients with hypertrophic cardiomyopathy (HCM) and almost 200 with dilated cardiomyopathy (DCM).

What does the future hold in terms of treatment for people living with cardiomyopathy?

We are entering an incredibly exciting period in medicine, which patients living with cardiomyopathy are well placed to benefit from. Thanks to the work of Cardiomyopathy UK and others, public awareness is growing. The huge national investment made in genomic testing through the 100,000

Genomes Project will shine a light on how changes in an individual's genome leads to

these conditions.

As well as powerful computers capable of dealing with this and other complex, clinical information, mobile phones will allow us to stay in touch with patients between appointments. These advances open the way for new treatments and will enable us to reach and support a wider group of patients. I am very optimistic that new discoveries are around the corner.

What does your work with Cardiomyopathy UK involve?

I have been working with the charity in several ways; for example, organising regional meetings for clinicians and speaking at patient information days. Most recently, I've helped to establish an in-clinic volunteering programme so patients have informed individuals, who know what they are going through, to talk to.

The charity has been a joy to work with.

If you had a £1million to help people with cardiomyopathy, how would you spend it?

I would invest it in systems that promote best practice care for patients.

What are your plans for 2019?

In February, we will be starting a project led by a cardiac rehab specialist on the hospital campus.

We recognise having cardiomyopathy puts people off exercise and can be an isolating experience.

We hope by offering patients the chance to take part in group activities, they will feel both physically and mentally better.

We will also be helping to organise a 2019 Midlands Cardiomyopathy UK event for doctors, including those in training, across the region, so they can be more familiar with cardiomyopathy.



Consultant cardiologist William Bradlow created the first Cardiomyopathy UK in-clinic patient support service at his Friday clinic

We are delighted to announce the winners of the 2018 Cardiomyopathy UK Awards that recognised people who have made a difference to the lives and well-being of people affected by cardiomyopathy and myocarditis.

The awards were made at our national conference **Knowing More, Living Better** held in Liverpool in October.



The Carolyn Biro Founder's Award
Winner: **Ann Harrison Power**



The Impact Award
Winner: **Colin McVittie**



The Fundraising Award
Winner:
The 'Jimmy Boy' Team
(Tribute Fund)



The Community Award
Winner: **Ken Pugh**



The Ronald Raven Award for Clinical Excellence
Winner:
Dr Will Bradlow

Read more about our 2018 national conference on Page 16

Straight to the heart of the matter



Dr Rameen Shakur, based at the Massachusetts Institute of Technology in the US, received a £95,000 fellowship award from the Alexander Jansons Fund for his research into the causes and treatment of myocarditis - an often forgotten, but devastating disorder of the heart muscle

What does the Alexander Jansons Fund fellowship award mean to you?

I am privileged and honoured to be the Alexander Jansons Fellow as this award reflects so much of my own ideas on how science and medical research should work.

I have always wanted to do research, which is difficult, but will also have a direct impact on the way patients are managed.

The Alexander Jansons Fund has been bold by investing in fundamental basic science research and how this can make a substantive contribution to our understanding of myocarditis treatment.

The award is enabling a really ambitious project like mine to become a reality and make inroads into developing a new treatment for myocarditis.

What discoveries have you made regarding myocarditis since you've been in America?

Myocarditis is an under-reported problem in the USA and there is a big demand for further research.

People also really want to see rapid progress on treatment and intervention



By Patricia Dean
AJF Fundraising Manager

points as well.

There is so much collaboration and diversity working under Professor Robert Langer in his lab at MIT, that I've been able to get quickly onto the main aspect of my research project,

which is to develop numerous novel nanoparticles (synthetic particles that are able to penetrate cells).

I'm trying to make these particles using innovative chemistry techniques in order to target only the heart.

This will be a first.

I am pleased to say that the first batch of particles I've produced are robust and on testing them on normal cells before we use the heart cells, show particular fast uptake.

The plan is to make 100 different formulations of these particles and screen them on different types of cells to reflect the many cellular subtypes within the body.

This is a very ambitious project and if successful, will have lasting benefits for this field of research.

What have you learnt from your

time working under Professor Robert Langer at the MIT?

It is unusual to have such an eminent scientist supporting a fellow like me in such a practical way. He's enabled me to ask difficult questions and think big.

A number of people under him have gone onto become scientific leaders in their own right.

What do you hope to achieve within the next two years?

We are on track to make some new discoveries on how the next generation of drugs specific to heart diseases such as myocarditis, can be treated.

Doing basic scientific research in the lab is often lonely, testing and doesn't help your vitamin D levels!

However, for the many hours I spend trying to get the experiments to work, I often reflect on how this pales into insignificance compared to the feeling of hope we have for finally finding an effective treatment for myocarditis.

What do you miss most about England? What food do you miss the most?

I really miss watching Match of the Day and being spoilt for choice in Cambridge and London for food with a bit of flavour. Peshwari naan with saag paneer any day!

Variety of AJF events on the horizon for 2019

The Alexander Jansons Fund (AJF) has lots of exciting events coming up throughout 2019 that you can be involved with to help support its work for myocarditis.

- 28th April — London Marathon
- May — Beetle drive
- June — Rowing at Windsor
- June — Tennis tournament
- 30th June — Skydive at Salisbury Plain

- July — 3 peaks challenge
- September — Charity clay pigeon shoot
- November — Rugby event
- December — Christmas wreath workshop

If you would like information about any of the upcoming events, please contact Patricia Dean on 01494 679971 or by email, at Patricia.Dean@cardiomyopathy.org



Our 30th anniversary wish list

All our supporters play a massive part in Cardiomyopathy UK and without them, the charity could not continue its work to improve the lives of people affected by the condition. So in this, our 30th anniversary year, we've come up with a wish list of how you can continue supporting us - either by raising awareness or funds - so we can make a real and lasting difference to people affected by cardiomyopathy and myocarditis. Find out more at www.cardiomyopathy.org/30years

1. Take the 30-Day Challenge! (see Christie's story below)
2. Buy our special anniversary hoodie and tote bag package (see bottom of page)
3. Become a regular giver – £5 a month can help two people access the helpline for a year
4. Like and share our social media posts to tell more people about Cardiomyopathy UK
5. Ask your local school to do a mufti day for us – we can send you a schools pack
6. Attend your first Cardiomyopathy UK open day
7. Tell your GP about our clinical events
8. Do a corporate challenge with work colleagues
9. Arrange a celebratory fundraising lunch with recipes from top chef Ian Human
10. Join us for a bespoke 30km challenge this summer
11. Organise a September Stroll to make this year the largest ever walk for cardiomyopathy
12. Celebrate with us at the Cardiomyopathy UK national conference in November
13. Sign up to easyfundraising.com
14. Leave a gift to Cardiomyopathy UK in your will

Join fundraiser Christie and take on a 30-Day Challenge

Why not join us in celebrating our 30th anniversary by taking on a 30-Day Challenge to help raise much-needed funds for people and their families across the UK affected by cardiomyopathy?

You simply choose something you'd like to do (or not do) for 30 days and have your friends, family, and colleagues donate in support of your efforts, (suggested donation of £5 per day).

Cardiomyopathy UK Community



Fundraiser, Christie Jones, (left), trialled the challenge in November by going vegetarian for 30 days and raised £195 while discovering a new-found love for Quorn!

Christie's colleagues at Cardiomyopathy UK are following his lead by taking on their own 30-day Challenges running throughout 2019.

We'll send you a free fundraising pack, including a handy chart that you can fill in day-by-day as you

Christie's veggie November for Cardiomyopathy UK
the heart muscle charity

Suggested donation £5 per day, all proceeds to the charity.

| | | | | | |
|-----------------|------------|-----------------|-----------------|----------------------------|-----------------|
| Omer £5 | Omer £5 | Omer £5 | Omer £5 | Nucci & Guy £10 | Nucci & Guy £10 |
| 1st | 2nd | 3rd | 4th | 5th | 6th |
| Tracey £5 | Andy C £10 | Andy C £10 | Andy C £10 | Andy C £10 | Andy C £10 |
| 7th | 8th | 9th | 10th | 11th | 12th |
| Mum £5 | Danni £5 | Danni £5 | Danni £5 | Mum £5 | |
| 13th | 14th | 15th | 16th | 17th | 18th |
| Rufaul £5 | Mum £5 | Yuwah & Olga £5 | Yuwah & Olga £5 | Dad £5 | Yuwah & Olga £5 |
| 19th | 20th | 21st | 22nd | 23rd | 24th |
| Yuwah & Olga £5 | Dad £5 | Dad £5 | Yuwah & Olga £5 | The Million Dollar Man £10 | |
| 25th | 26th | 27th | 28th | 29th | 30th |

collect your donations, (above).

For ideas on how to get involved, head to www.cardiomyopathy.org/30challenge, or contact Christie via christie.jones@cardiomyopathy.org or give him a call on 01494 791224.

New merchandise for 2019

Support us in our 30th year with this special zip hoodie and tote bag package at £30+pp to raise money for our services, which help people affected by cardiomyopathy.

Available via our online shop www.cardiomyopathy.org/shop



Why there's a buzz around Heart Hive research project

2019 is set to be an exciting year for cardiomyopathy and myocarditis patients keen to get involved in cutting-edge research

Feedback from people living with cardiomyopathy and myocarditis reveals many don't know how to go about using their experiences to take part in the latest research and help improve understanding and treatment of the conditions.

In response to this, researchers at Imperial College London, working with Cardiomyopathy UK, believe they have found a solution.

Dr James Ware, consultant cardiologist and research group lead at Imperial College London, and Angharad Roberts, clinical geneticist and research fellow at Imperial College, have been working on the launch of Heart Hive – a ground-breaking project that aims to make research easily accessible to all.

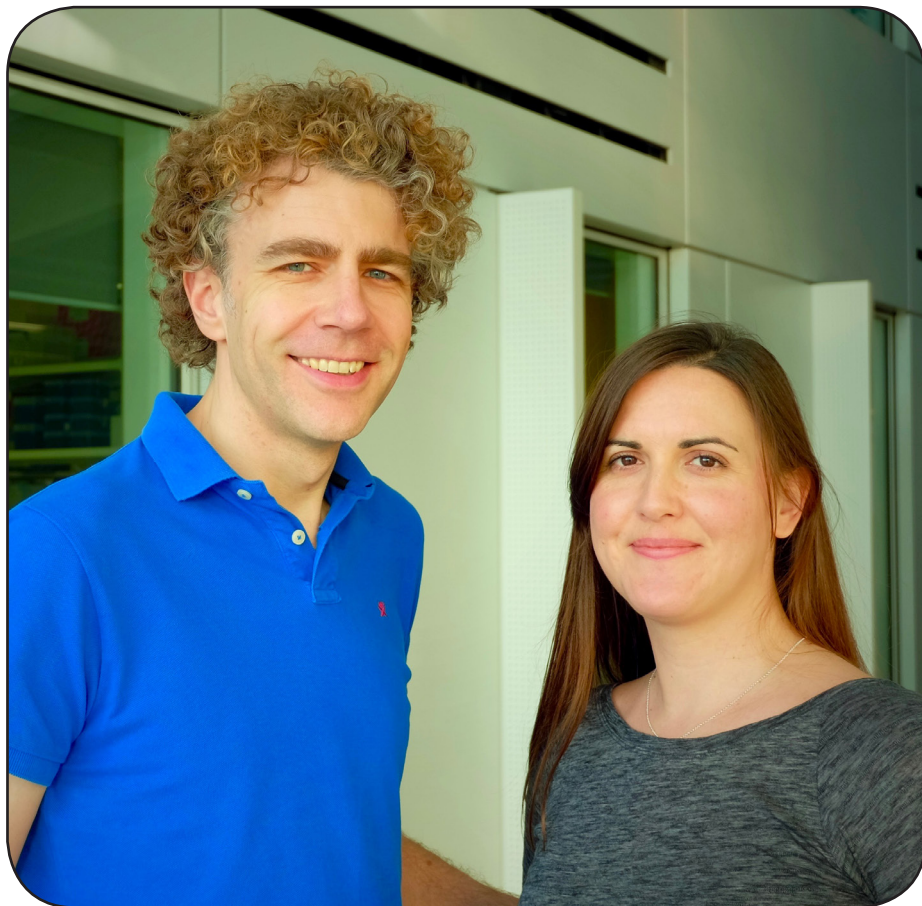
Heart Hive will use the latest technology to allow people to participate in research from their own home with genetic material collected from saliva, using kits sent in the post.

As Angharad explains: "More than 300,000 people in the UK are living with cardiomyopathy and myocarditis and research is the key to understanding these conditions and developing new treatments.

"Many want to help move science and healthcare forwards toward improved treatments and a better quality of life for themselves and the larger community, but it can be difficult to find a way to get involved," she adds.



thehearthive.org



Co-researchers James Ware and Angharad Roberts

"Heart Hive will make research accessible to everyone.

"All people will need is an internet connection, a computer or smart phone and a postal address.

"Rather than relying solely on a handful of hospitals and doctors, patients will sign up through the web-portal, enter their own health information and decide which researchers can use it."

The Heart Hive will connect this group of willing research participants with active and collaborative researchers from around the world, so participants

will see what research is going on and be able to self-enrol in studies that interest them.

Visit thehearthive.org to learn more about the project and sign up to the mailing list to be notified when The Heart Hive platform goes live in March 2019



Email your questions to our team of experts at: contact@cardiomyopathy.org



Head of Services Ali Thompson and Support Nurses Robert Hall, Jayne Partridge and Emma Greenslade answer your questions

Q: I've heard there was a recent study that looked at the possibility of stopping drugs in people who have recovered from dilated cardiomyopathy. Will I be able to come off my drugs?

Support Nurse Robert says: The need for the continuation of therapy following improvement of heart function, following a diagnosis of dilated cardiomyopathy, is a question I'm often asked.

The recent TRED study, performed at the Brompton Hospital, researched the effects of stopping drugs.

The outcome was that 40% of people, during the period of the trial, had to restart their medications due to the function of their heart deteriorating.

The recommendation was that drugs should not be stopped and the outcome of the study will come as a disappointment to some.

However, the possibility of future work to identify the exact features in the sub-group of patients where withdrawal of treatment may be feasible, may still be possible.

We must also keep in mind the tremendous developments in the treatments available for DCM. The success of these therapies has made it possible for the question of withdrawal to be considered.

(Read more about TRED on Page 14)

Q: I have heard that the rules for getting a Blue Badge are changing. How will these changes affect me?

Head of Services Ali says: The DoT (Department for Transport) has amended the eligibility criteria for people applying for a Blue Badge.

From January 2019, people with 'hidden disabilities' will be able to apply.

The newly amended criteria for applying include the following:

- A person who cannot undertake

a journey without there being a risk of serious harm to their health or safety, or that of any other person (such as young children with autism).

- A person who cannot undertake a journey without it causing them very considerable psychological distress.

- A person who has very considerable difficulty walking (both the physical act and experience of walking).

If you meet one or more of the above - but did not meet the pre-January 2019 criteria - then you are eligible to make an application for a Blue Badge.

To find out more about the Blue Badge and how to apply, see: <https://www.gov.uk/apply-blue-badge>

Q: My teenage son had a holter monitor and it said he had non-sustained ventricular tachycardia. What is it?

Support Nurse Emma says:

Tachycardia is a term to describe an abnormally fast heartbeat caused by irregular electrical impulses to the chambers of the heart.

When it occurs in the lower chambers of the heart, (the ventricles), it is referred to as ventricular tachycardia.

Ventricular tachycardia that stops by itself within 30 seconds is called non-sustained ventricular tachycardia (or NSVT).

Because NSVT does not persist, it is substantially less dangerous than a sustained ventricular tachycardia (SVT) and may turn out to be completely benign.

However, NSVT can cause potentially worrisome symptoms and may indicate an increased cardiac risk, especially if you have cardiomyopathy.

The formal definition of NSVT is an episode of ventricular tachycardia with a heart rate of at least 120 beats per minute, lasting for at least three beats and persisting less than 30 seconds.

Most often, NSVT either does not cause any symptoms at all, or it may just cause palpitations.

Occasionally, NSVT can produce light-headedness, dizziness, or, more rarely, syncope (loss of consciousness).

NSVT is typically discovered on a routine cardiomyopathy investigation - perhaps while recording an ECG, exercise test, holter monitor, or during some other form of cardiac monitoring.

NSVT poses an increased risk of cardiac arrest and sudden death if it occurs in tandem with heart failure.

This is especially true in people with hypertrophic cardiomyopathy.

With that being said, the risk is related more to the reduced flow of the blood from the left ventricle (called the ejection fraction), than it is to the presence of NSVT.

To reduce the risk, an implantable defibrillator is strongly recommended.

Q: I have heard people talk about genetic testing and a project called 100,000 Genomes. Could you tell me more about it?

Support Nurse Jayne says: The NHS project aims to sequence 100,000 genomes from people and their families with a rare disease or cancer and is expected to reach its target early 2019.

Learning more about genomes can help to identify the cause of genetic conditions.

When the genome sequences of people with the same condition are compared, it is possible to see patterns, these can be put together and these may be linked to conditions such as cardiomyopathy.

This 'new' information will help to create a new genomic medicine service for the NHS.

This may help to identify the cause of, and provide a diagnosis of, rare conditions and in time, the potential of new and more effective treatments.

There's no such thing as a typical heart patient



By Priya Manek,
Kerry Allan &
Rebecca Shirley
- The Media &
Communications
Team

How our 2018 Heart Bleeps media campaign lifted the lid on the misconceptions and myths surrounding cardiomyopathy

Cardiomyopathy can affect anyone, at any age, and misconceptions around the condition can be a daily struggle.

Our 2018 'Heart Bleeps' Campaign centred around confronting stereotypes of what people with heart conditions look like, feel and behave and how these assumptions can lead to people living with cardiomyopathy facing challenges when it comes to employment, benefits and lifestyle.

Wrongly-held misconceptions can also prevent someone seeking medical help if they experience symptoms that could be attributed to cardiomyopathy, or even being misdiagnosed by medical professionals.

Nine of our supporters shared their stories, (see facing page),



INDEPENDENT



Spreading the word: National newspapers ran stories about our Heart Bleeps campaign

to publicise the misconceptions they face in their everyday lives — and how this affects them on a daily basis.

Four of our case studies — Becky Shorrocks, Chris Marshall, Jill O'Connell and Steffi Moore — also took part in a video to talk about their experiences, which was uploaded on to our website.

Professor Perry Elliott, President of Cardiomyopathy UK, explains: "We urgently need to debunk the many myths and misconceptions around the condition.

"At Barts Hospital, we see over 8,000 people each year with cardiomyopathy and I've lost count of those that thought they were too young and healthy to have a heart condition.

"The reality, as our research shows, is people are not aware of the important signs their bodies are telling them, which are putting them at risk.

"People of all shapes and sizes can be affected by cardiomyopathy and we need to challenge the stereotypes that exist in our society that older, overweight men are the typical heart patient."

New research reveals 'body blindness'

Around 500 people with cardiomyopathy and their partners took part in our internal survey as part of our 2018 Heart Bleeps campaign.

Most felt the public perception of what someone with a heart problem looked like was at odds with reality and even admitted to harbouring their own misconceptions about a 'typical heart patient' before being diagnosed with the condition themselves.

In light of the campaign, we commissioned new research to examine how aware British people are of what their bodies are telling them and whether they know their BMI, blood pressure, cholesterol, height, weight and other health indicators.

A poll of 2,000 adults discovered more than half of the population

WHAT MISCONCEPTIONS HAVE YOU FACED WITH CARDIOMYOPATHY?

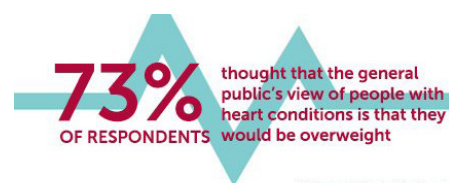


1 in 7 Brits admit to 'burying their head in the sand' when it comes to their health

#EveryHeartUnique

don't know their own blood type and a further 40 per cent could only guess at their weight.

The results revealed a shocking lack of awareness and education,



#EveryHeartUnique

which we believe is a contributing factor in why misconceptions exist towards those with cardiomyopathy.

"This survey highlighted how many people don't know their family health history, ignore symptoms and just bury their heads in the sand," says Joel Rose, Cardiomyopathy UK Chief Executive.

'Come on, you're fit and only in your 40s'



'At least you don't have cancer'

Like 50% of those who took part in our survey, actress Becky Shorrocks, (above), says her diagnosis was 'devastating' fearing it could have a detrimental effect on her career.



Sports fanatic Chris Marshall, (left), was forced to give up competitive

sport and exercise following his cardiomyopathy diagnosis in 2016. 84% of people who took part in our survey tell us they feel the general public assume it's only people with unhealthy lifestyles who have heart conditions.

'You look so well, you can't have a heart condition'



People are always shocked when Jill O'Connell, (left), reveals she has cardiomyopathy and backs up the 69% of respondents battling with the stereotype that heart patients will always look unwell.



Don't be such a lightweight and have a drink'

Elis Power, (right), wants to debunk the misconception that young people do not get cardiomyopathy and help people to understand why he takes his condition so seriously.

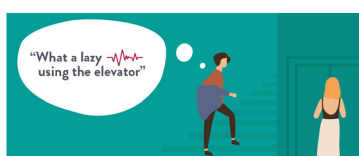


'Why is your wife carrying the shopping instead of you?'

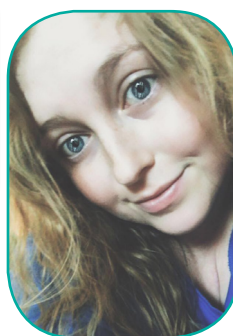
Peter Cope, (left), has endured many rude comments because he doesn't 'look disabled' and more than half of respondents say society often makes assumptions about what it thinks people with a heart condition can and cannot do.



'You should be using the stairs'



Heart transplant recipient Laura Malpass, (right), says she is often judged for being lazy when taking the lift because she doesn't fit the stereotype of older, overweight men as the 'typical heart patient'.



'Get a move on'

Teenager Aaliyah Aries, (below), says society 'expects' her to be healthy and people, constantly say negative things - either by accident or deliberately - which 45% of respondents also experience.



'Why would you need a transplant?'



Steffi Moore, (right), was 18 when she was diagnosed and feels embarrassed when airport staff look at her pacemaker card with scepticism. 69% of survey respondents agree there is a public myth that it's only older people who will have a serious heart condition.



'Why do you have a Blue Badge?'

Sadie Sanderson, (right), is often confronted by looks of disapproval when she parks in a disabled bay at her local supermarket, and like 45% of our survey respondents, reveals how she battles with the frustration of confronting such widespread ignorance on a daily basis.



Our merger paves way for ambitious plans

'Reaching more people than ever before'



2018 was a great year for the charity and I am incredibly proud of what we have been able to achieve, thanks to our dedicated team of volunteers and staff.

We are currently producing our annual report, which will be available shortly, but for now, below are a few things that I really want to highlight.



By Joel Rose
Chief Executive

2018

During 2018, we were able to extend our peer support services.

We know that good quality peer support can have a real impact on people, who are struggling to cope with their condition, so we opened up 14 new face-to-face and online support groups and extended our in-hospital service to two new hospitals.

We also know how important it is that medical



411
Peer
in-clinic
support



96
phone
& online
support

professionals have the skills they need to properly diagnose and manage cardiomyopathy and myocarditis.

That's why we expanded our clinical education programme, running local clinical education days and teaming up with the British Association of Nursing in Cardiac Care.

This way, we were able to reach more clinicians from across the spectrum of healthcare professionals — up by 145% — who are involved in the diagnosis, care and treatment of cardiomyopathy and myocarditis.

2018 saw the charity merge with the Alexander Jansons Fund and join forces to do more to provide support and information to people affected by myocarditis and fund research initiatives that will increase our understanding



145%
INCREASE
in healthcare
professionals
at events

of the condition.

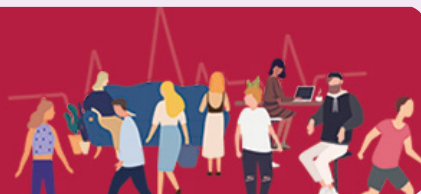
Our 2018 Heart Bleeps media campaign was a big hit, achieving wide coverage in traditional and social media.

We focused on cardiomyopathy myths and misconceptions and based our information on the feedback we got from all those who kindly completed our survey.

Of course, none of this would have been possible without the generous support of our donors and the hard work of our fundraising volunteers.

'Heart Bleeps'
Campaign

#EveryHeartUnique



2019

Thanks to them, the charity's income grew considerably last year and this means that we can build on the success of 2018 and be even more ambitious about what we want to achieve this year.

Plans for 2019 include a drive to continue increasing the availability of peer support.

We want to open up even more support groups where they are needed and put more volunteers in cardiomyopathy clinics across the UK.

We also want to increase the number of our clinical education days and start to offer online training for more healthcare professionals.

In 2019, we are also going to be talking more about myocarditis so more people will know the warning signs of this condition and more doctors will be able to spot it.

As people with myocarditis can go on to develop cardiomyopathy, we believe it is really important that we cover this issue.

We have already started to plan for a national awareness campaign later this year, but we know that given myocarditis can affect anyone, at any age, and can happen in people with no history of illness, it is going to be a big challenge to ensure that our message gets out to a wide audience.

We will be telling you more about this campaign and keeping you up to date with all our other projects in future issues of My Life, but if you do have any questions about our work, please email me at Joel.Rose@cardiomyopathy.org or call me on 01494 791224.

'They don't believe there's anything wrong with me'

Chris Marshall joins our Heart Bleeps campaign to help dispel the myths and misconceptions surrounding a 'typical heart patient'

Chris Marshall, 44, from West Sussex, was a self-confessed 'hardworking and happy' doctor when a devastating diagnosis changed his life forever.

The consultant anaesthetist admits he would play sport 'at any opportunity' and cycled more than 20 miles a day, to and from his job at Worthing Hospital.

"I was very fit, driven, hard-working and happy. Sport was a huge part of my identity," he recalls.

"I used sport to de-stress after a tough day at work and if things were going badly, I'd just go for a run."

However, in May 2016, a blockage to Chris's heart was discovered by chance. While taking out the recycling, one rainy morning, the father-of-two slipped and fell down the side of some concrete steps.

He landed heavily on his side, breaking five ribs in the process and rupturing a disc. When he lost all feeling in his left foot, he was booked in for emergency back surgery and given an ECG while waiting for the operation.

"I remember saying to the doctors, 'I don't understand why you're doing an ECG on me, I'm fit and healthy'," he recalls.

However, the ECG found a problem with Chris's heart in the left ventricle and he was later diagnosed with dilated cardiomyopathy, which had caused left bundle branch block (LBBB).

A year later, he had a pacemaker fitted.

"On reflection, I'd had some fairly significant symptoms over the past few years, including 'heart rate dangerously high' whenever I measured it on the running machine and cramp in my neck muscles whenever I sprinted," he admits.

"I'd get extreme shortness of breath and found cycling harder and harder; falling asleep straight away as soon I got home from the hospital.

"I put it down to working too hard or needing to get fitter, so I went to the gym, even though I'd get out of breath and drenched in sweat in no time. I didn't believe the signs and

symptoms and being a doctor, I naturally ignored them!

"Even though my diagnosis made a lot of sense and was probably the result of a virus I'd had a few years before, I was devastated not to be able to play sport any more and have had to stop pushing myself and settle into a much more

sedate and less competitive level of self-care, as opposed to exercise.

"I've significantly reduced my hours and stopped being on-call in an attempt to reduce the uncertainty and stress, as much as possible.

"But I've felt guilty about not pulling my weight at work and letting my colleagues down, as well as not being able to earn and provide for my family as I had been doing before."

Like others living with cardiomyopathy, Chris says the physical implications of his condition have affected every facet of his life.

"My diagnosis was a huge and devastating piece of news and I felt bitter and cheated.

"Acceptance has been slow and without the incredible

support of my wife and family, I wouldn't have been able to cope."

However, Chris is finding ways of coming to terms with his condition and an uncertain future.

"I take an antidepressant and focus on mindfulness. I've also bought an electric bicycle and use this to commute the short distance to work."

Chris has also joined Cardiomyopathy UK's Heart Bleeps campaign to show how heart conditions are not always the result of an unhealthy lifestyle.

"There have been thoughtless comments by people who don't believe there is anything seriously wrong with me, as I look so well – with little comprehension of the emotional and physical impact this has had on me and my family," he reveals.

"So many people don't understand what this diagnosis means. Many say things like, 'Well you're in your 40s now; Everyone's tired aren't they? or, 'But you'll get better won't you?'

"I hope my story helps to show how cardiomyopathy affects people of all shapes and sizes and not just older, unhealthy people."



Study exposes danger of withdrawing DCM medication

A ground-breaking new study looks at whether systems of dilated cardiomyopathy could return after medication is gradually withdrawn

Cardiomyopathy UK and the Alexander Jansons Fun, which joined forces with Cardiomyopathy UK in 2018, supported what is believed to be the first randomised trial to explore the effects of treatment withdrawal in patients with 'recovered DCM'.

The two-year pilot study was conducted by a group of clinicians, who form part of the cardiology and research team at The Royal Brompton Hospital.

The research, known as TRED-HF,

(withdrawal of drug treatment for heart failure in patients with recovered dilated cardiomyopathy) focused on those patients with DCM, whose heart function and symptoms appeared to have returned to normal.

The purpose of the research, says The Lancet, was to ascertain if the symptoms of DCM would return after the gradual withdrawal of medication.

Patients had to meet a strict entry criteria, measuring the function of their heart, the presence of symptoms and other complications, in order to be included in the trial. Of the 50% of patients in the study who had their treatment withdrawn, 40% experienced a gradual decline in heart function and re-emergence of symptoms.

This resulted in treatment being restarted. Clinicians were unable to predict which patients would relapse post treatment withdrawal and who would not.

Consequently, further research will be required to identify how clinicians can accurately predict who will fare well after stopping medication and who will see their health decline.

As a result, the TRED-HF research concluded medication prescribed for patients diagnosed with DCM should continue indefinitely.

"We will continue to work with the research team on any future developments," says Joel Rose, Cardiomyopathy UK Chief Executive.

Patients had to meet strict criteria

Researchers find biomarkers link to atrial fibrillation

Researchers have identified two biomarkers that could help in the diagnosis of a heart condition that raises the risk of stroke.

Atrial fibrillation is the most common heart rhythm disturbance, affecting around 1.6 million people in the UK. Common symptoms include heart palpitations and when the heart is fluttering or beating irregularly.

Sometimes atrial fibrillation does not cause any symptoms and a person is unaware their heart rate is irregular.

This study, by researchers at the University of Birmingham, found three clinical risk factors and two biomarkers had a strong connection with atrial fibrillation.

Those most at risk of the condition were older males with a high BMI. The researchers looked at 638 hospital patients, who were recruited between 2014 and 2016 for acute illnesses and given an echocardiogram.

Researchers found two biomarkers stood out as a link to atrial fibrillation.

One is a hormone secreted by the heart called brain natriuretic peptide (BNP) and the other is a protein responsible for phosphate

regulation called fibroblast growth factor-23 (FGF-23).

The researchers say people at risk could be screened for the condition by testing their blood to see if they have elevated levels of the two biomarkers.

Lead author Yanish Purmah said: "The biomarkers we have identified have the potential to be used in a blood test in community settings such as in GP practices to simplify patient selection for ECG screening."

The research was published on 13th November 2018 in the European Heart Journal.

Dr Winnie Chua, joint first author of the research said: "Atrial fibrillation is often only diagnosed after a patient has suffered a stroke, so it is important patients at risk are screened so that they can begin taking anticoagulants to prevent potentially life-threatening complications."

Jayne Partridge, Cardiomyopathy UK support nurse, comments: "This research could help diagnose atrial fibrillation within community screening programmes and thus provide correct treatment to those individuals sooner."

Be the perfect patient in 2019

Why not make a late New Year's resolution to keep a symptom diary to take with you to appointments throughout 2019?

Our 28-page diary enables you to record symptoms (such as breathlessness and palpitations); your readings (such as weight and heart rate); exercise, sleep and mood levels; drug treatments (including side-effects) and also information about your care team and details of appointments.

By getting a better understanding of your condition and treatments, you can become an 'expert patient', working better with your medical team and more able to make informed decisions about your care and treatment. Knowledge is power.

■ To get your copy, call us on 01494 791224, or email services@cardiomyopathy.org



I want better - so much better, for people today



Stephen Kirkham has been involved in the Scottish Heart Failure Hub and the Scottish Organ Donation and Transplant Group since 2015. He is also Co-ordinator for Cardiomyopathy UK's Scottish Support Group.

Q1: What were the highlights of your 26-year career as an infantry officer in the British Army and why did you then decide to train as a vicar?

As corny as it sounds, my life in the Army was always about service. It was physically active, intellectually challenging, always demanding, and occasionally dangerous. I loved (almost) every minute!

Then, whilst not everyone will understand this, in 1995, I sensed I should obey a call to Christian ministry, so in 1996, I headed to Cambridge for two years of preparatory study.

As strange as it may seem, a lot of the people skills I'd developed in the Army were transferable and it was a great privilege to be able to go on and serve a local community as their vicar.

Q2: What were the consequences of being diagnosed with DCM in 2005?

I was told by a General Registrar that I had severe heart failure and dilated cardiomyopathy on a ward-round. She simply added: 'Don't worry, they're good at transplants these days.'

As she turned to go, the Sister recognising shock, went off to organise hot sweet tea. Later in outpatients, I finally saw a cardiologist, who told me I had to stop everything for six months and then should consider taking early retirement. Having rested, I tried going back part-time, but in 2007, had to accept it wasn't working for me.

At 56, it was devastating and I felt I'd let people down, as well as losing everything myself – my physical strength, but also my identity and purpose in life. That took a long while to come to terms with.

Q3: Why did you decide to move to Scotland.

After nine years of DCM, arrhythmias and AF, we recognised we had only limited time if we were to move closer to family.

We have two sons, whose work could take them anywhere, but our daughter's family – with our two

grandsons – are anchored in place by their business. So in 2014, it was a simple choice to move to Kinross, where we're actually just a mile-and-a-half away from them across the fields.

Q4. Was that a straightforward move?

Not in terms of my health. There is no protocol in place for patients moving between NHS England and NHS Scotland, so my nine years of hospital and GP notes were reduced to a summary of a side-and-a-half of A4 paper.

I couldn't be transferred from consultant to consultant. Everything had to start from scratch again with my new GP referring me to a consultant in Perth, whom I got to see 14 weeks later.

Sadly, the anxieties and stresses arising from that long wait contributed to my heart deteriorating rapidly, to the point that I needed a life-saving transplant in May 2015.

Q5: What role does Cardiomyopathy UK play in helping patients get the best treatment?

As a Trustee, I've been privileged to see the huge amount that has been and is being achieved, but of course, there's always more to do. I've no doubt it needs a broad approach to get the best treatment for patients.

On the one hand, medical professionals need to be educated and encouraged; commissioning bodies need to be persuaded to implement guidelines and researchers need to be motivated to go after the things that matter to patients.

Equally, patients need to be informed, resourced and encouraged to play a full part in their own care. Carers need support, and those who have experience of cardiomyopathy given the opportunity to offer peer to peer encouragement.

And this needs to encompass the whole cardiomyopathy journey, for all ages and all outcomes. My judgement is that our office team and our volunteers know what is needed and are on the case!

Q6: What lessons have you learnt from your cardiomyopathy journey?

I didn't always receive the best of care, but then, that must be balanced by knowing that a lot has changed for the better in the last few years. (Indeed, the care I received whilst waiting for and post-transplant was superb).

So my own journey has really motivated me to want better – so much better, for people being diagnosed and treated today.

I feel passionate about this. It's why I'm a Trustee of Cardiomyopathy UK and it's why I'm continually looking for ways to spread the message.

79%
Would attend
another event

161
Attendees

13
Presentations

'I enjoyed seeing
my husband talk
to others and
understand he is
not on his own'
[Pauline]



Lookback on a good day in Liverpool

By Ali Thompson
Head of Services

Our national conference Knowing More, Living Better, was held in Liverpool in October 2018.

The charity welcomed renowned experts to the stage, such as Professor John Somauroo, who is the consultant cardiologist to Liverpool FC and Dr Antonis Pantazis, the Royal Brompton & Harefield NHS Foundation Trust's clinical lead for cardiomyopathy.

Prof Somauroo spoke about exercise — a common theme on our helpline — and Dr Pantazis gave an insight into the lesser known types of cardiomyopathy and myocarditis and spoke about research and treatment developments.

The day's programme covered devices, treatment, genetic testing and surgery and along with clinical discussions, sessions were available



on the non-clinical aspects of living with cardiomyopathy, such as emotional well-being, employment and benefits.

The conference saw us welcome old friends and new and gave delegates the opportunity to ask leading experts questions about the issues important to them.

The most common type of cardiomyopathy experienced by those delegates with the condition was hypertrophic, closely followed by dilated.

Attendee feedback reported the primary reason for attending was to

know more about cardiomyopathy in general, with wanting to meet other people similarly affected and meet the charity as other key reasons for attending.

Every person diagnosed with cardiomyopathy, who attended the conference, told us they knew more about their condition and how to effectively manage it having attended the conference and 97% of carers/supporters who attended, stated the same.

"Our annual national conferences are the best way for people affected by cardiomyopathy and myocarditis to learn more about every aspect of their condition, as well as meeting others who have walked in their shoes," says Joel Rose, Cardiomyopathy UK Chief Executive.

- Read an article by Dr Antonis Pantazis, based on his conference presentation in the next issue of My Life.

2019 plans for end of life care and children's helpline

As the leading provider of support to people affected by cardiomyopathy in the UK, the charity is keenly aware that we need to create services aimed directly at people facing the end of their life.

In 2019, we are committed to providing services sensitive and appropriate to the needs of people with advanced cardiomyopathy and ensuring those living with terminal illness receive timely support.

This service will focus on the emotional needs of the person and not on palliative care treatment.

Also in 2019, we commence our three-year Children In Need project improving and expanding our reach to

children and young people.

Our paediatric nurse will be offering an evening helpline service twice a month to children, young people and their caregivers.

We will be creating a new suite of information resources aimed at children and young people.

A new storybook directed at children, aged four to nine, will be published soon which seeks to explain the different cardiomyopathies in a way children can better understand.

We will also be building on our existing network of support groups alongside the development of our in-clinic peer support service.



Triathlon triumph

Adam, Helen, Kat and Katie smashed their target for the Woburn Abbey Triathlon last year, raising a fantastic £3,902.50 for #teamcardio

Walking wonders

2018 fundraising highlights



The Evans and Gibson families raised £920 from their sunny August amble

Row, row, row your boat

A rowing event at Eton Dorney raised £6,885 for the Alexander Jansons Fund



Reach for the skies

The 2018 Alexander Jansons Fund skydive raised an incredible £8,600



Catch the pigeon

Sharon and Roy Clark, above, raised £3,017 through a Clay Pigeon Shooting day in September



#teamcardio

#teamcardio raised more than £14,000 from our group skydiving day and individual jumps across the UK throughout the year



On your marks

Staff at Almary Green Investments, above, raised £1,650 from various running events throughout 2018

Neopost Ltd

Neopost Ltd was our corporate fundraiser of 2018, raising £14,707



Colourful capers

The Gelston Manor Day Nursery raised £791 through a colour obstacle course in August



Be part of #teamcardio in 2019 - a special year for Cardiomyopathy UK as we celebrate our 30th anniversary. Take a look at the events on our calendar, or if you have your own idea, please get in touch and we can provide you with posters, balloons, banners and collecting tins to make your event extra special. We rely entirely on donations to fund our work, so every penny raised makes a real difference.

January

Join in with our anniversary celebrations by taking on a 30-Day Challenge. Walk, knit, eat, paint — the possibilities are endless. Just choose something to do, or not do, for 30 days in a row, then ask friends, family, and colleagues to sponsor you for each day.



February

We are setting a new challenge to walk, cycle, swim or run 30km or 30 miles for #team-cardio. This exciting new challenge can be done at any time anywhere across the UK, so join us in celebrating 30 years by going above and beyond in 2019.



March

Join 20,000 other runners and don your own Cardiomyopathy UK vest for The Vitality Big Half — a new one-day festival in London centred around the half marathon distance.



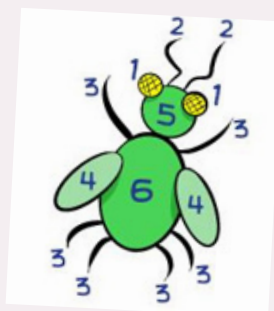
April

If you're lucky enough to get a ballot place in this year's Virgin London Marathon in April, we would love to have you as part of #teamcardio (or come along to cheer them on) for one of the world's biggest marathons.



May

The AJF is staging a Beetle drive in Bucks - an old family favourite for all ages that requires very little to organise.



June

if you fundraise for us, you can take part in a charity skydive for FREE. Choose your date and location and we'll do the rest.

July

Trek the highest mountains in Scotland, England and Wales in one continuous attempt and make new friends with the 3 Peaks Challenge, this year.



August

Our annual summer raffle raised more than £11,300 in 2018 to help families across the UK affected by cardiomyopathy. Can you help us do better in 2019?



September

Organise your very own September Stroll around your local countryside to help raise vital funds and awareness for Cardiomyopathy UK.



October

Take part in the Bournemouth Marathon Festival - from 5k to a full marathon, there is a race distance for everyone.



November

The AJF is inviting a famous rugby icon to take part in a Q&A session, so if you're a fan of the game, why not put the date in your diary?



December

Watch this space for details of our Christmas campaign, which will be running throughout the month to finish off 2019 with a bang.



Email fundraising@cardiomyopathy.org or call 01494 791224 for details

'Two hours goes so quickly'

Spotlight on Support Group Leader Cathy Thurlow

Cathy Thurlow was diagnosed nearly 20 years ago after her brother Scott died, aged 27, from a Sudden Cardiac Arrest (SCA).

Initially, Cathy was told she had DCM and then in 2016, she finally received the gene result that confirmed she had Arrhythmogenic Dilated Cardiomyopathy.

"Many of my family are affected, (my dad also died from an SCA in 2015)," says Cathy, "so I'm keen to help raise awareness of the disease, especially in young, fit people who may be at risk of cardiac arrest."

The mother-of-three offered to become a support group leader because she feels it is important people with cardiomyopathy stay informed about the condition and share the "ups and downs with people who understand".

She manages to run the **London ARVC Group** despite sometimes having to deal with the tiredness of living with the condition.

"I try to listen to my body and rest when I need to — not always successfully, as I can overdo it," she admits.

Cathy works from home offering digital marketing and admin support services to small companies and has been running the support group for just over a year, with about 10 members.

"We get on so well it's just wonderful," she says.

"Although we are small, it's a really positive group and I love seeing how happy our members are to spend time together and hope they go away feeling more informed and supported."

Members, who come from all



over, including Hertfordshire and Surrey, meet three to four times a year in a hall in Northolt and stay in touch via WhatsApp.

"We also try to have a social lunch and a walk in London inbetween meetings," explains Cathy. "At a normal meeting, we have tea and biscuits (one of our lovely members always brings something delicious), while we catch up and then listen to our speaker, if we have one, followed by questions."

"Two hours goes so quickly and we often wish it could be longer."

Arranging relevant speakers is one of Cathy's biggest challenges.

"But I have a lovely lady called Debbie, who helps me with the running of the group and being proactive and thinking ahead helps," she says.

"Looking back on 2018, our best speaker was the genetic counsellor from Barts, who provided very useful information that members were particularly interested in."

"Looking ahead, I want to help the group discover as much as possible about the progression of ARVC and what factors influence it, as well as hearing about medical advances that could benefit our children."

WHAT DO THEY DO?

They are self-help groups, which are not usually led by a medical professional, but help people understand more about cardiomyopathy and help them cope better with their diagnosis and get on with their lives.

Support groups enjoy regular meetings, often with expert speakers and social activities.

HOW DO WE HELP?

We help our support groups in many ways. We print meeting posters for hospitals and health centres and send them to our medical contacts.

We can help find and supply speakers and invite local people on our database.

We have support groups around the country, but we are keen to find people to help us start more.

If you cannot find a convenient group in your area, we can help you set up one.

If you would like to start a support group or help run one, do get in touch with us. Contact Jo Franks on 01494 791224 or email jo.franks@cardiomyopathy.org

Upcoming meetings:

January 31 - South London

February 2 - North East England

February 2 - West London

February 9, - Dorset



Raise vital funds for families
affected by cardiomyopathy
with our...

Day Challenge

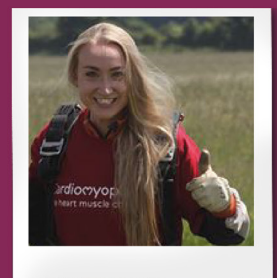


**'I'm going sugar free in January
2019 for the 30 Day Challenge!'**

-Ali Thompson, Head of Services

'I'm running 5km a day in March.'

-Danni Devine, Challenge Events Fundraiser



www.cardiomyopathy.org/30challenge

Alternatively, see inside on page 7 for more details.