

myLife

The magazine for people affected by
cardiomyopathy and myocarditis

Issue 27/Autumn 2021

MRI My Device	6
Bayley Wells	10
Our Summer Appeal	14
New Website	17




Cardiomyopathy^{UK}
the heart muscle charity

Marty's Race to 50K
Pages 12-13

Contact us

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

Call or write to us

 75A Woodside Road
Amersham
Buckinghamshire
HP6 6AA

 01494 791 224

Helpline

0800 018 1024

(free from a UK landline)

8.30am-4.30pm, Monday-Friday

Find us online

 www.cardiomyopathy.org

 contact@cardiomyopathy.org

Live chat

www.cardiomyopathy.org

8.30am-4.30pm, Monday-Friday

Social media

 /cardiomyopathyuk

 @cardiomyopathy

 @cardiomyopathyuk

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

This magazine and its plastic wrapper is 100% recyclable

Front page image: Marty's race to 50k.

Designed by Hi Top Design

At last it is feeling like summer has arrived.

As Covid-19 restrictions lift, I hope like me, you are taking the opportunity to be outside as much as possible and enjoy catching up with friends and family. You may even feel enthused to join in with our Summer Appeal. See page 14.



It is with great pleasure that I congratulate our Vice President and former Chair, Alison Fielding on being awarded a British Empire Medal in the Queen's Birthday Honours. Alison has a long history of volunteering and continues to be a true ambassador for CMUK, raising awareness of cardiomyopathy and ensuring that the voice of our patients is heard. A truly worthy recipient. Well done Alison.

Patients with cardiac devices should have the same access to MRI scanning as everyone else. Unfortunately for many cardiac patients this is not the case. They are less likely to be referred for an MRI. Information on the MRI My Device Campaign can be found on pages 6-7.

Joel, our CEO, has been busy as we take the lead in bringing together colleagues from across the world to form an International Cardiomyopathy Network. Sharing knowledge and information and being part of a worldwide community is an exciting and beneficial partnership for the charity. Read more on page 4.

Thanks to the hard work of our Marketing team and developers, we now have a more user friendly website that will make it much easier to find what you are looking for. Read the latest update on page 17. Our Change Makers are off to a great start and are already making a difference. Read Libby's update on page 5.

Be inspired as we highlight Sarah Bishop's fundraising story (pages 12-13) and hear from Bayley Wells, member of our youth panel who shares his experience of making the transition from children to adult services (pages 10-11). On page 16 you can learn more about changing research.

It's back to the garden for me now. Enjoy the summer and stay safe.

Rita Sutton, Chair

Contents

Rita's welcome	2
Contents page	3
International Cardiomyopathy Network	4
Change Maker update and conference	5
MRI My Device	6-7
Nurses' Q&A	8-9
Bayley's story	10-11
Marty's race to 50k	12-13
Summer appeal	14
Alison Fielding MBE and news	15
Expanding our research	16
Our new website updates	17
Our fundraising family	18
Donation form	19-20



Our fundraising family - 18



Bayley Wells - My Story
10 - 11





By Joel Rose,
our Chief Executive

Cardiomyopathy UK and our international community

Since the last issue of My Life we have continued to work on developing an international network of cardiomyopathy charities and clinical experts.



The Cardiomyopathy Council includes international charities from Spain, America, Italy, the Netherlands, Germany and Australia. We are hoping that more will be joining us soon.

As a group we are working to prepare for the first ever international cardiomyopathy awareness week due to take place later this year. We will be highlighting the signs and symptoms of cardiomyopathy, along with the importance of knowing your heart history.

The Cardiomyopathy Council is part of a wider network of heart charities called the Global Heart Hub. The work we do will ensure that we are able to spread our message to an international audience.

We're also working with ICoN, an international network of cardiomyopathy experts. ICoN have already begun their educational work, running a series of short online presentations for clinicians, which has been very well received.

Later this year, the ICoN team are also planning an international cardiomyopathy meeting. This will bring together the world's leading cardiomyopathy experts and the international patient groups- for what promises to be a milestone event.

We believe that when experts and patients work together, we strengthen the voice of cardiomyopathy. We now have the opportunity to share best practice, resources and ideas to greatly benefit everyone.

Our online conference

The Cardiomyopathy UK Conference 2021 takes place on Saturday 23 October. Our annual conferences bring together globally renowned speakers to talk on and answer questions about cardiomyopathy, management and treatment.

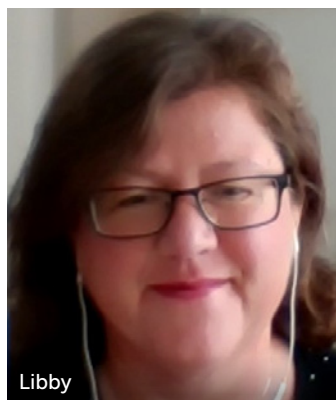
This year, the theme of our conference is 'resilience'. You'll find conference sessions on 'Resilience and living with long term conditions', and 'Lifestyle and self-care'. Leading clinicians will also delve deep into 'Understanding cardiomyopathy' and 'Genetics and your family'. Dedicated sessions will cover 'Latest thinking in cardiomyopathy' and a 'Research round-up', bringing together recent findings, therapies and updates about cardiomyopathy.

On the day you'll find information resources, meet others, and get to know members of the Cardiomyopathy UK team and our volunteers. You'll have the chance to have your questions answered by experts and learn more about cardiomyopathies. Whether you have attended our conferences in the past, or you are completely new to our work, we have designed our online event to be accessible and welcoming to all, free and from your own home.



You can get your tickets here:
www.cardiomyopathy.org/onlineconference2021

Our Change Maker update



Libby

"I have really enjoyed my first few months working as a Change Maker! Recently I've been able to forge links with both the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) and the Association of Chartered Physiotherapists in Cardiac Rehabilitation (ACPICR) to promote awareness of cardiomyopathy and the need for personalized exercise prescription

(Change Agenda point 12). I have written a piece about the project for both Associations' eBulletins, and we are working together to add cardiomyopathy specific training to the BACPR recognized national training courses. Look out for a new video and some exciting research news coming soon!"

MRI



My Pacemaker Project

by Alison Fielding, Vice President and
Ali Thompson, Head of Services

The MRI My Pacemaker Project was conceived by a group of UK-based cardiologists, radiologists, radiographers, cardiac physiologists and MRI physicists who are passionate about enabling patients with cardiac devices to have fair access to MRIs.

As well as educating the public and clinicians about this important issue, MRI My Pacemaker have set up referral centres specifically for those people wanting an MRI (magnetic resonance imaging) but who may have been refused by their clinical health provider. Given the wide and positive impact this project will have upon our community, Cardiomyopathy UK will be working closely with the Project

and its lead Dr Anish Bhuvu with Dr Bhuvu being invited to speak more on this exciting area of work at this year's national conference.

Dr Bhuvu says,

"More than half of us will need an MRI scan in our lifetime because it is now essential for diagnosis and treatment planning in a number of life-threatening medical conditions including cancer and stroke. Unfortunately, half a million people in the UK have cardiac pacemakers or defibrillators and have been told that they cannot have an MRI scan - advice that is now out-dated. Thanks to extensive research, we can scan almost all types of devices if needed, but patients still face huge barriers to receiving standard NHS care reliant on MRI. The MRI My Pacemaker campaign is working at multiple levels to accelerate change: connecting individual patients to services, supporting local services, and guiding national policy. The aim is simply to ensure that patients with cardiac devices have the same access to MRI as the rest of us."



“
 The MRI My Pacemaker campaign is working at multiple levels to accelerate change: connecting individual patients to services, supporting local services, and guiding national policy.”

Our Vice President, Alison Fielding shares her own experience of having an MRI with a device implanted;

“I was already being treated for kidney cancer when my dilated cardiomyopathy and cancer treatment led to a decision that I would benefit from an ICD. As I knew that I would need to have MRI to monitor the cancer, particularly in my brain, I agreed to have an MRI-conditional device and waited until these were available at my hospital in 2015. An error meant that I was soon told that my device was not MRI-conditional after all, so I was left having the less accurate CT scan. When new brain metastases occurred, I was faced with the possibility of radiotherapy without detailed MRI available to plan the surgery accurately to avoid damaging healthy tissue. It took several years, more brain metastases and a possible brain bleed to bring the situation to a head in 2020.

The type of targeted radiotherapy that I needed is effective on small tumours, so it is important to act quickly. Despite that it took over 3 months to get agreement that I should have an MRI using a special protocol for non-conditional devices. After having

counselling on the risks, my device was checked and set to a ‘safer’ mode for the MRI. During this the physiologist noticed that the device inside me was not the one recorded on my records and my device was an MRI-conditional device after all. This made the procedure straightforward. I had a slight awareness of my device but no problems. My heart was monitored with an ECG. The device was then put back into normal mode and tested. The MRI showed 7 brain metastases when the CT had only showed 2 which shows why access to MRI can be important. It enabled me to have targeted radiotherapy. I now have MRI every 3 months and it is straightforward. The MRI My Pacemaker project should make other people’s journeys easier.”



For more information see the MRI My Pacemaker website:
www.mrimypacemaker.com

Q&A

with our nurses

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



Helpline

0800 018 1024

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



My son's cardiologist has been talking about him moving up into the adult service but he is only 13. Is this not too early?

In England the legal age you become an adult is 18 years, in other countries of the UK this varies. However, different NHS services apply different age criteria's which can be confusing. Wherever you live, by the age of 18 years you or your child should have a 'transition' plan in place. During this time your legal status as a decision-maker will change and you or your child will be encouraged to take a more active role in making decisions.

The transition process should start when your child is about 13/14 years old. You or your child may be invited to have a transition assessment with a specialist nurse. These meetings should take place every year, until you are settled into the new service.

Everyone's transition will be unique. Not only will it depend on your hopes and aspirations, it will also depend on what services and support organisations are in your area and available to you.

Unfortunately, there is evidence that the process of transitioning from child to adult health services is often associated with deterioration in the health of adolescents with chronic conditions such as cardiomyopathy. This is why transition services have been established to ensure no gaps or overlap are missed and the individual continues to receive quality care.



Nurse Emma



Why have I been advised that my heart failure nurse has to transition me onto Entresto?

NICE (National Institute for Health and Care Excellence) advises that the medication Entresto (Sacubitril/Valsartan) is started by a heart failure (HF) specialist nurse who can carefully increase and monitor the effects of the new medication.

Your HF nurse will need to advise you on stopping your ACE inhibitor or ARB for at least 36 hours before starting Entresto. Entresto comes in 3 doses, it is likely that you will be started on the lowest dose first with your dose being increased over a 2- 4 week period up to the maximum dose that you feel well with.

The usual maintenance dose is Sacubitril 97 mg-Valsartan 103 mg orally twice a day. Your HF nurse will likely check your kidney function before increasing your dose of Entresto. Further information about Entresto is available on our website here- www.cardiomyopathy.org/treatment



Nurse Jayne



What should I expect at my first appointment once I move to Adult Services?

When you move into Adult Services, your first appointment can feel overwhelming. As well as being in a new environment and seeing new people, you will be encouraged to take control of your own health and start to make decisions for yourself about your treatment and care.

You can go to the appointment alone or you can bring another adult along for support. You will be seen by a consultant (specialist doctor), and a specialist nurse may be available too. You will be asked about your medical history, any problems you may have and a physical examination. An ECHO scan may also be done.

The team looking after you at the new hospital will also go through and discuss lifestyle choices and issues that may be related to your heart condition such as:

- Healthy Eating & Weight Control
- Exercise and Sport
- Endocarditis (infection of the inner wall of the heart and/or the heart valves caused by bacteria that enter the bloodstream)
- Careers & Employment Options



Nurse Caryl

Bayley Wells

My story

We caught up with Youth Panel member Bayley Wells, who is in his final year at university studying Biomedical Science. Here he shares his experience with moving from children to adult healthcare services.

I got involved with the charity because my Dad has hypertrophic cardiomyopathy. He was diagnosed around the age of 30. He found he was getting breathless walking up and down the stairs. He went on to have an ICD fitted, but my grandfather also had the condition which got worse over the years.

I ran a half marathon in memory of a friend and Alison Thompson contacted me asking if I wanted to be a part of the panel for cardiomyopathy. Ever since then I have educated myself more about the condition.



When did you find out you'd be moving to adult services? Did you feel ready to move?

Ever since I can remember I've been having tests at Great Ormond's Street Hospital (GOSH). They normally take place once a year and the tests are done to make sure my heart is healthy. Until I was about 13/14, I didn't really know why I was doing it or what was going on. It was just one of those things I had to do once every year.

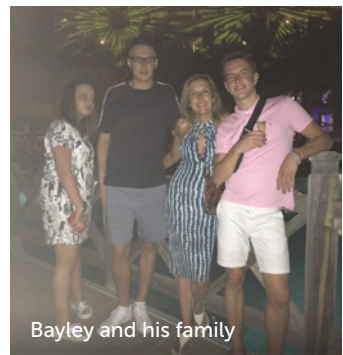
It was only when I was about 17 or 18 that they said to me that 'this will be one of your last appointments here'. They didn't really discuss any of the transition process. It wasn't until I had to leave that they started to bring it up and said I was moving onto St. Bartholomew's Hospital (Barts).

What was your first appointment like?

I went to Barts for the first time by myself. The biggest thing for me was the independence.

It was strange because at the time I got used to my mum dealing with appointments and information wasn't given to you directly, but to my mum who was with me. It was only when I went to my first appointment at Bart's that there was an expectation that I would understand what was going on and what I have to do.

I remember the one time, I had to have a 24 hour monitor put on and I had all the scans. The consultant said it was fine, you won't need the monitor and that's it. I went on my way after that.





Young Bayley ice skating with his dad

Was there anything that could have helped to make the transition easier?

It very much depends on the individual, but I'm quite laid back, like my Dad has been about it. I wouldn't have needed anything specifically but just having someone there for a general chat would have been really helpful. Speaking to someone your own age who has experienced what you're going through would have eased my anxiety because of the seriousness of it.

How has COVID affected your appointments?

I was meant to have my yearly appointment in May last year but that got cancelled completely. They re-arranged that, but I've only had my latest a month ago. There has been a gap of two years between appointments because of COVID.

It makes me feel more anxious because I could develop the condition at any time, and it was such a big gap. When I did have my appointment, I was in and out within about 15 minutes, which makes a change! I had my tests straight away and then a follow up phone call.

How do you feel about genetic testing?

I remember at GOSH they pushed for genetic testing. I didn't fully understand at the time, and when you're being told it's going to affect all your later life, including the job I wanted to do, I was put off for years.

It's only recently I've properly thought about getting it done, and will do so at the next available opportunity. Having that confirmation to say you don't have the gene would relieve so much anxiety. Right now it's all up in the air. It almost makes it worse - I definitely think it's for the best. Knowing either way puts you more in control, for me anyway.



Dedicated in loving memory to Keith Wells, my granddad.

Our Youth Panel members have been taking over Instagram!

You can watch videos and short clips about their experiences on our social media.



@cardiomyopathyuk



Marty's race to

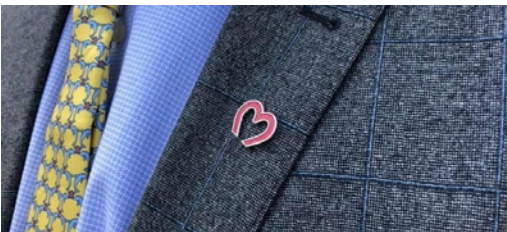
£50k

During her pregnancy, Sarah and husband Darren were told that their unborn baby, Marty, had cardiomyopathy.

Initially given a poor prognosis for survival, Marty has just celebrated his 11th birthday. After receiving support from our helpline, the family set up Marty's Penny Bank and since 2011 have raised over £44,000 to help other families affected by the condition. Ten years on, they are determined to reach their £50,000 target. This is their journey.

"When we first received Marty's diagnosis we were thrown into a world of fear and unknown. Our lives were changed in an instant. It was a frightening and confusing period of time that I will never forget."

Sarah nervously rang the Cardiomyopathy UK helpline and spoke in depth with one of our support nurses, who quickly became their family's lifeline. She listened, cared and gave the family information, understanding and support that was vital in those early days.



At that time, every call was a lifeline. I was immensely grateful to Cardiomyopathy UK. Marty's Penny Bank is our way of giving back.



Marty performing

Over the past 10 years, Marty's Penny Bank have held music nights, theatre shows, bake sales, tombolas, you name it!

"It's been a real community effort. Every person and every penny makes a difference. We are so grateful to everyone that has been involved with Marty's Penny Bank fundraising in the last 10 years".

Speaking with Sarah, one moment she said she will always remember was at a local street party, where she held a tombola with items donated by Tracey Porter, the community champion at their local Tesco store.

"A gentleman came over to speak to us. He was quite emotional and told us that two members of his family had been diagnosed with cardiomyopathy and he'd never spoken to another family about it. That day we raised £70, but the most memorable moment was helping that gentleman and his family.

We feel proud to have raised a fantastic amount for a wonderful charity and their services, but it's also about raising awareness of cardiomyopathy along the way, being able to support other families and seeing people smiling and enjoying our events. You never really get over having a child with a heart condition, it's part of who we are, and Marty's Penny Bank is part of who we are as a family. Reaching £50,000 would mean so much to us."

The Bishops have come a very long way from their initial heart-breaking diagnosis and Marty is now described as having a mild uncategorised cardiomyopathy with features of non-compaction and valve dysplasia. The previous significant hypertrophy and a hole in his heart have subsided as he's grown.



On 22nd August, ten courageous fundraisers will be completing a skydive to help Marty's Penny Bank reach their £50,000 target. If you'd like to help Sarah and Marty reach this special milestone, you can donate here: <https://www.justgiving.com/fundraising/sarah-bishop57>

Help us be there for our community

Summer
Appeal

//

Remembering that I am part of a valuable community is strengthening. Hearing from others is so valuable.

//



This past year we've seen the incredible difference we can make together, and we want to ensure we can still be there for those who need us.

The road to recovery will be challenging but we're hopeful that, with the world starting to open back up, we can build back stronger than ever for our community. Each donation we receive helps ensure that everyone affected by cardiomyopathy lives a long, fulfilling life.

Donate online at www.cardiomyopathy.org/donate, by returning the form on the back of this issue or by calling us on 01494 791224.

With your support we can:

- Provide more support services for children and young adults like Bayley (pages 18-19) helping them to better understand what they're going through.
- Answer more helpline calls from people like Sarah (pages 12-13) in times of need.
- Educate clinicians to spot the signs of cardiomyopathy and know how to treat it. (Page 5)
- Campaign for improved healthcare services with quicker diagnosis and better-quality care. (Pages 6-7)
- Use our expertise to shape research and provide future hope for people with cardiomyopathy. (Page 16)

News updates

Queen's Birthday Honours list for Alison Fielding

We are delighted to share that our former Chair and current Vice President, Alison Fielding, has been awarded an honour in the Queen's Birthday Honours for services to people with cardiomyopathy.

As well as playing a pivotal part in developing our charity, Alison is a highly respected and passionate advocate for the need to hear the voice of patients both in cardiomyopathy and in cancer.

We are thrilled that her fantastic work has been recognised. Congratulations, Alison!

"The real honour is that people let all of us into their lives at difficult times and share their journeys on the rollercoaster of cardiomyopathy and heart failure. Let's continue to make it better."



Watch this space

As COVID-19 restrictions gradually lift, we have been busy making plans for later in the year.

Look out for news on this year's Christmas cards and gifts in the next issue of My Life. We're also working on an exciting new raffle which we hope to bring to you soon.

If you would like to buy or sell raffle tickets, or if you're holding a summer event and would like to hold a raffle, contact our fundraising team on 01494 791224 or email fundraising@cardiomyopathy.org



Expanding our Research



By Joel Rose, our Chief Executive

Over the last few months, we have been working to help clinicians, researchers and service providers to develop a better understanding of cardiomyopathy and the impact that it has on peoples' lives.

We want to increase the amount of research we do and use our unique insight and experiences of our community. This will answer specific questions highlighted by our clinical advisory group and inform and underpin our policy work.

We also want to do more to highlight opportunities for people to be involved in steering and shaping research projects as well as participating in trials where appropriate.

At the start of the Summer, we ran a survey asking for feedback on face-to-face and online appointments for those with cardiomyopathy. From this we are now using the results to help service providers further develop their services, plus manage the backlog of appointments caused by the pandemic.

We also recently brought together a small group of people with personal experience of dilated cardiomyopathy (DCM) to help a researcher develop their new project looking at the differences between DCM in men and women.

Their insight has helped to keep this project focused on meeting individual needs, and will mean that people with the condition are able to fully participate in the study. We have also continued to support the CRUCIAL research project, which is looking into the links between heart failure and cognitive function.

We are currently working as part of the international CureHeart team that is one of four projects shortlisted for a £30million research grant. This project is looking to develop genetic treatments for cardiomyopathy which could reverse the damage to the heart muscle. We hope that it can even prevent the condition developing in people who carry the genes for cardiomyopathy.

“ We are currently working as part of the international CureHeart team that is one of four projects shortlisted for a £30million research grant.

There is a real sense that the amount and quality of research is expanding. Our Charity is playing an important part in this, and I believe that this will make a meaningful difference to the lives of people with cardiomyopathy and their loved ones.

”

Highlights from our fundraising family

Alan's 200th Walk

Congratulations to Alan, who completed his 200th walk from Hailey Park to Castel Coch in May. Alan decided to take on this challenge after receiving his cardiomyopathy diagnosis.



"It's taken five years on mostly weekends to do a seven mile round trip from my house to Cardiff's Castel Coch and back. I am delighted to have received a final flurry of donations, with 91% of my target achieved. Thank you for your support and I am utterly delighted to have chosen Cardiomyopathy as my chosen charity".

Thankyou Councillor



We'd like to say a big thank you to Councillor Olivia Sanders, who has been elected as the new Mayor of Brentwood and has chosen Cardiomyopathy UK as one her selected charities.

"Cardiomyopathy directly affected a Brentwood family whose son Michael passed away at age 21 very suddenly from this disease. Since Michael's passing his family have been actively raising money for Cardiomyopathy UK and so I chose this charity to help raise awareness. I will be arranging charity events throughout the year and hope that this can make some difference to help support the charity. Working on the frontline of the NHS myself, I know how significant raising awareness and donations can be."

We'd like to wish Cllr Sanders all the best for her Mayoral year.

Hugs for marathon heroes

Join Team Cardio for the London Marathon in 2022.

"Crossing Tower Bridge, a memory that will stay with me forever, the wall of noise, the people and a tear in your eye." - John

Sunday 24 April - Fundraising target: £2,000

Sign up now
fundraising@cardiomyopathy.org.uk
01494 791224



Cardiomyopathy UK Donation form

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

Your donation

I would like to make a regular gift of:

£10
 £25
 £50
 Other (please fill out below)
 per month.

£
 Every
 month/s

I would like to make a single gift of:

£10
 £25
 £50
 £
 Other

I would like to donate by:

cheque enclosed (made payable to 'Cardiomyopathy UK')
 credit/debit card (card must be registered to the address overleaf)

Name on card

Card number:

Start Date:

/

Expiry Date:

/

Security Code:



Your Details

Title	First Name
Surname	
Address	
Post code	
Telephone	
Email	

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

Is your donation in memory of a loved one?

Yes

No

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

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

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

Date

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

Thank you