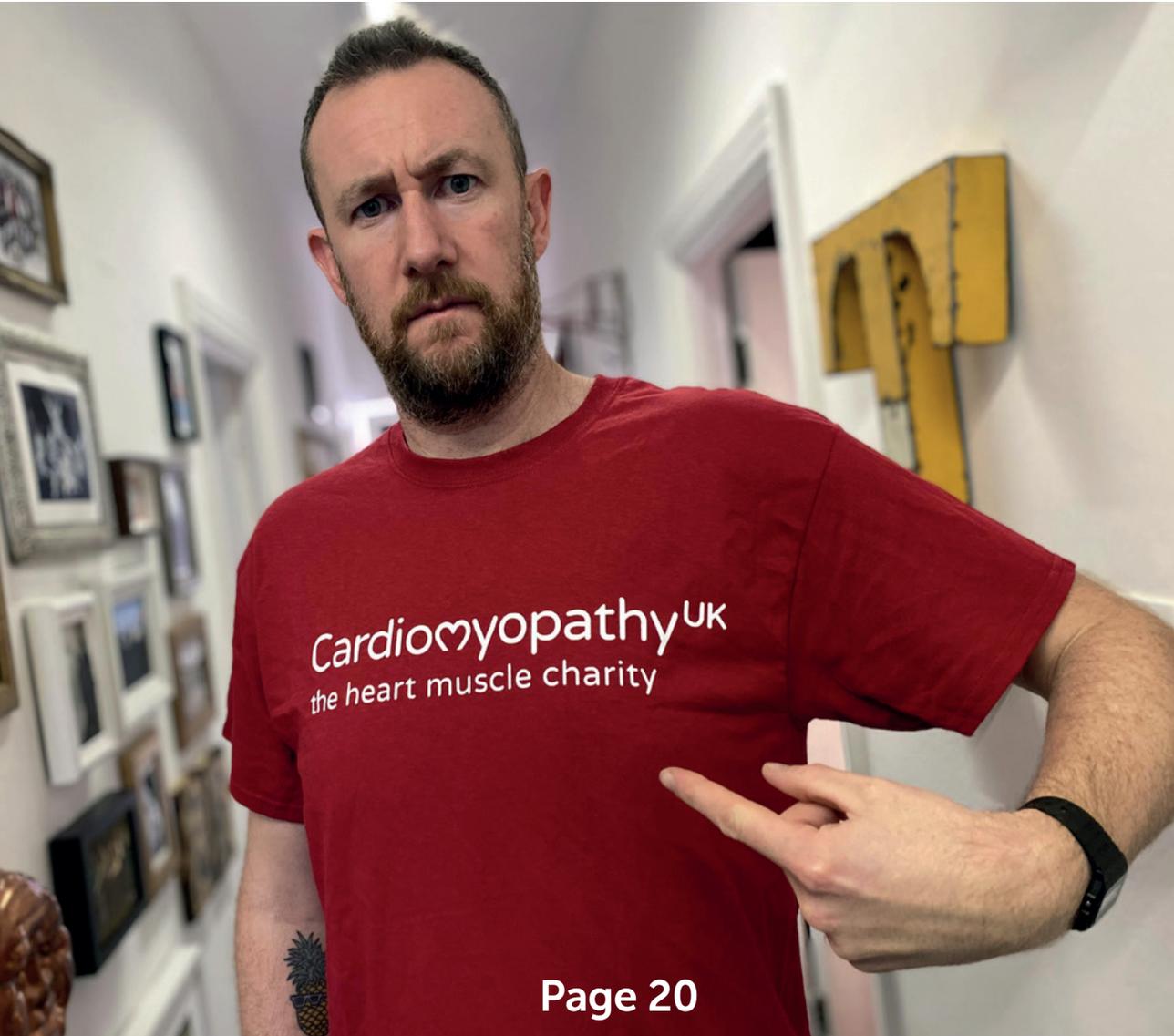


myLife

The magazine for people affected by
cardiomyopathy and myocarditis

Issue 25/Spring 2021

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Growing together online	21



Page 20

Cardiomyopathy^{UK}
the heart muscle charity

**Our Christmas
Campaign success!**

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 photo: Celebrity Alex Horne showing his support for Cardiomyopathy UK in the Taskmaster house.

Designed by Hi Top Design

Welcome

Our 25th edition of My Life is "The Strength of our Families"



When life throws us a curve ball often it's our families we turn to. Families come in many forms; be it genetic or friendship and support groups. Over the past year many of you may have felt disconnected from your families.

As we continue to live with the challenges of COVID-19 we focus on the strength of our community and the difference we make to the lives of those living with cardiomyopathy or myocarditis and their families. Head of Services Ali Thompson updates us on how our support groups continue to provide vital information and support to families in their time of need on **pages 7-8**.

This issue features just some of the exciting developments that have begun for our charity this year. From a new office, a new website and growing our international family (**pages 13-14 and 21**) 2021 is already shaping to be another progressive year!

Thanks also to everyone who took part in our #12daysofchristmaschallenge and those who donated in support of our Christmas campaign. It was great to see individuals and families across our social media channels joining in and having fun. Well done to our worthy winner Lou who completed all 12 tasks and raised a fantastic £200 in sponsorship! Who knew we had such creativity and talent within? You can find out more on **page 20**.

On a personal note, I would like pass on my gratitude to our staff and trustees for their hard work in the success of our charity in 2020, despite the drop in income from cancelled events last year.

I finish by thanking Alison Fielding for her outstanding leadership and commitment to the charity over the past five years. We are pleased that she has agreed to continue working with us (**pages 4-5**).

Take care,

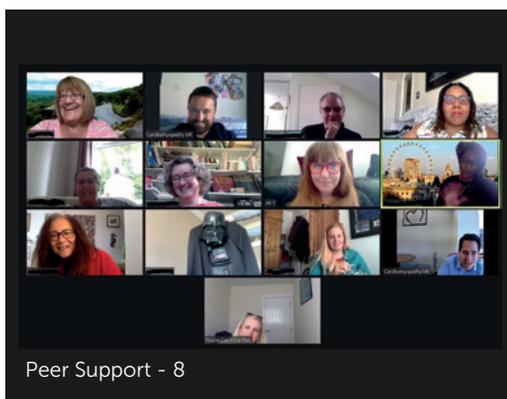
Rita Sutton, Chair

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Thomas Wheeler-Osman - 18



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We are moving!

In the midst of such exciting developments, we are also moving office. Our contact details remain the same.

Office - 01494 791224

Helpline - 0800 018 1024

Email - contact@cardiomyopathy.org

As of February 2021, our new office address will be:

Cardiomyopathy UK
75A Woodside Road
Amersham
Buckinghamshire
United Kingdom HP6 6AA



Goodbye from

Alison

We sat down with Alison as she reflects on her time as Chair for Cardiomyopathy UK. Here she shares her fantastic achievements and her plans for the future.

You have been a trustee for 7 years and Chair for 5 years, what made you get involved?

I have dilated cardiomyopathy and went along to an Information Day in London. I have been involved in the charitable sector since I was 18 including being a trustee so I offered any help that I could give. When the role of Chair came up, I had the time, experience and lots of ideas on how the Cardiomyopathy Association, as it was then, could build on its success. Over the years, we have had some great trustees and most have been directly affected either as a patient or family member. I think that has made a difference in ensuring that the charity keeps focussed on patient needs.



Alison at Buckingham Palace



Alison presenting prize at CGI fun run and cake sale

What does the Chair actually do?

The Board of Trustees are responsible for the strategy of the organisation and have legal responsibility for ensuring that the charity operates within the law, is financially stable and is focussed only on those areas that it was set up to do. Practically speaking, this involves working with the staff team and trustees to ensure that there is a work plan of what we want to do, policies on how we will operate and a constant oversight of the finances. I speak with the CEO every week about how things are going, look at reports on finance and services delivery, represent the charity externally and chair board meetings. I have also found it useful to be part of the Facebook community and a peer volunteer. It keeps me in touch with the range of experiences that impact people affected by cardiomyopathy.

What are you most proud of in the last 5 years?

The first thing that I was involved in as Chair was refreshing the branding, changing the name to Cardiomyopathy UK and launching a new website. This has helped us bring more people to the charity and for them to find the information that they need. We then set about expanding our services. Getting National Lottery funding was great not only for paying to expand things like the support groups, it was also a recognition of all the work that had gone in to getting the charity in shape in terms of governance and financial stability. I was also keen that we should move our services closer to patients so I hope that the in-clinic volunteer scheme can restart in the future, that video support groups continue and that awareness of the charity grows. Perhaps the stand out moments are those at our national conferences, when I hear the buzz in the room as hundreds of people talk to each other before the silence as each of our expert speakers take to the stage. I think the virtual events are here to stay but I hope face to face services can resume in future.

I am also proud of how we reacted to COVID 19 – in terms of how we survived the year without needing to cut services, switched to virtual working and what we did, and are still doing, to meet the needs of people affected by cardiomyopathy and myocarditis. We have learnt lessons but we did the best that we could with the information we had at the time.



Alison during her time as Chair with Trustees



Alison giving evidence to the All Party Parliamentary Group on Heart Failure



Alison showing support at the London Marathon

What is still left to do?

Lots, we have mapped out our goals in a new 3 Year Plan! More work will be done to focus on how we make the charity more accessible and relevant to a diverse community – both as service users and as patient leaders. We also want to use our experience to influence how NHS services are delivered. Our team of Change Makers are trained and ready to find ways to make inherited cardiac services across the UK into the services that we need. The impact of lost funds will continue in 2021. We will need support with fundraising if we are to deliver all the plans that we have had to put on hold.

What are your plans now?

I won't be putting my feet up! I am part of the Change Maker team and working on an international project to support the development of organisations supporting cardiomyopathy patients across the world.

Thank you to everyone, staff and volunteers, for being part of #teamcardio and for the many personal notes when I announced that I would be standing down. I wish Rita Sutton, the incoming Chair, every success.

Introducing

Rita Sutton



Prior to 2015 I had never heard of Cardiomyopathy.

I became aware of the term in July 2015 when my daughter rang to say our youngest grandchild two year old Rosie had just been diagnosed with Restrictive Cardiomyopathy (RCM) a rare heart muscle disease that affects one in a million and that she would at some point need a heart transplant.

Rosie was a happy healthy child up to the age of two when she became unwell. She subsequently underwent six months of doctors and hospital visits being tested for everything but heart disease. Rosie's diagnosis was the beginning of a search for information to learn more about RCM which wasn't easy. Finding Cardiomyopathy UK (CMUK) was a lifeline as we were finally able to access information, support and advice which proved to be invaluable.

Shortly after Rosie's diagnosis we attended a CMUK conference in London looking to build on our new found knowledge and understanding. I had recently taken retirement from my post as Operational Director for an educational charity working with children and families. Having worked for more than thirty years in the voluntary sector my intention was to find a charity where I could become a volunteer and give something back.

I joined the CMUK Board of Trustees in January 2016 and was amazed to find that my fellow trustees uniquely all had a personal link to Cardiomyopathy.

Our chosen theme for this edition of My Life "The Strength of Family" couldn't be more fitting for me as I begin a new role within the CMUK family as your Chair.

"A family doesn't have to be perfect; it just needs to be united"
Author unknown

PS - Rosie received the most precious gift of a heart transplant in 2016.



Rita and her family

Research news



By Joel Rose, our Chief Executive

In the last issue of My Life (October 2020), I mentioned that the charity has been working with the Arrhythmogenic Cardiomyopathy Trust to make a grant of £120,000 to a research project that focuses on arrhythmogenic cardiomyopathy.

We were able to bring together a team of independent peer reviewers to identify three fantastic research proposals, and in October 2020, Arrhythmogenic Cardiomyopathy Trust decided to award the grant to a team at University College London (UCL) overseen by Professor Elliott.

The UCL team believe that advances in cardiac imaging and the introduction of genetics into everyday clinical practice have revealed that there are in fact many different types of arrhythmogenic cardiomyopathy. These are themselves caused by a variety of different genetic mechanisms. This complexity makes it very challenging to diagnose and treat people with arrhythmogenic cardiomyopathy especially given that there are few therapies that target the underlying cause.

The UCL team's project will work to define and understand the different types of arrhythmogenic cardiomyopathy and build up a unique bio resource that will in turn drive forward not only their own research but that of other researchers for years to come.

Our role is to provide the patient insight that will shape the project and ensure that it meets the needs of people affected by cardiomyopathy.



This year, the charity has also been working as part of the Cure Heart research team lead by Professor Hugh Watkins at Oxford University. This project aims to develop a treatment to target and "switch off" the faulty genes associated with cardiomyopathy. The team is one of four shortlisted for a multi-million pound grant from the British Heart Foundation. Our role is to provide the patient insight that will shape the project and ensure that it meets the needs of people affected by cardiomyopathy. Towards the end of next year we will find out if the project has been successful in securing the grant. Thank you to those volunteers who have already given time to help shape this project.

Peer Support

The Heart of the Cardiomyopathy UK Family



By Ali Thompson, Head of Services

2020 has been a year unlike any other experienced by many families around the world, and for our cardiomyopathy family the COVID-19 pandemic has had a significant impact.



Our support groups were unable to meet in person, our helpline was inundated with people seeking advice and reassurance and those of our community who were required to self-isolate told us they felt more alone than ever.

With the help of our incredible peer support volunteers we moved our geographical support groups online, we provided issue and condition specific online groups, plus delivered psychological well-being support and information groups throughout the UK.

We introduced the hugely popular weekly Coffee and Catch Up group which gave us an

opportunity to come together as a family and talk about anything and everything that we wanted to. The balance between the traditional therapeutic model of support as experienced at our groups and the informal, light-hearted nature of the Coffee and Catch Up sessions gave a familial feel to our support services.

Like any family, we had tears, anxiety and worry but we also had solidarity and hope. We recruited and trained even more peer support volunteers as the demand for this service increased in response to the pandemic.

We have welcomed new friends from across the seas to our peer support family and introduced more clinicians to the support services we offer.

Cardiomyopathy^{UK}
the heart muscle charity

2020

1500+ Support Group Attendees


19 New Telephone Peer Support Volunteers


15 New Support Groups


Here's to a supportive 2021!

Weekends and evenings, by online, telephone and email, we were there to support our people when they needed us the most. For me personally, meeting new members of our cardiomyopathy community and sharing more time with those already known to us, has been the genuine proverbial silver lining of the pandemic cloud.

In times of hardship it is hoped that families pull together and support each other, and this has been so true of our peer support family. Our support group leaders, telephone peer support volunteers, our Young People's Panel and our staff have ensured that no one within our community is left struggling or alone.

By providing clinical information, advice and support through our nurse team, helping people to receive the welfare benefits they need and to

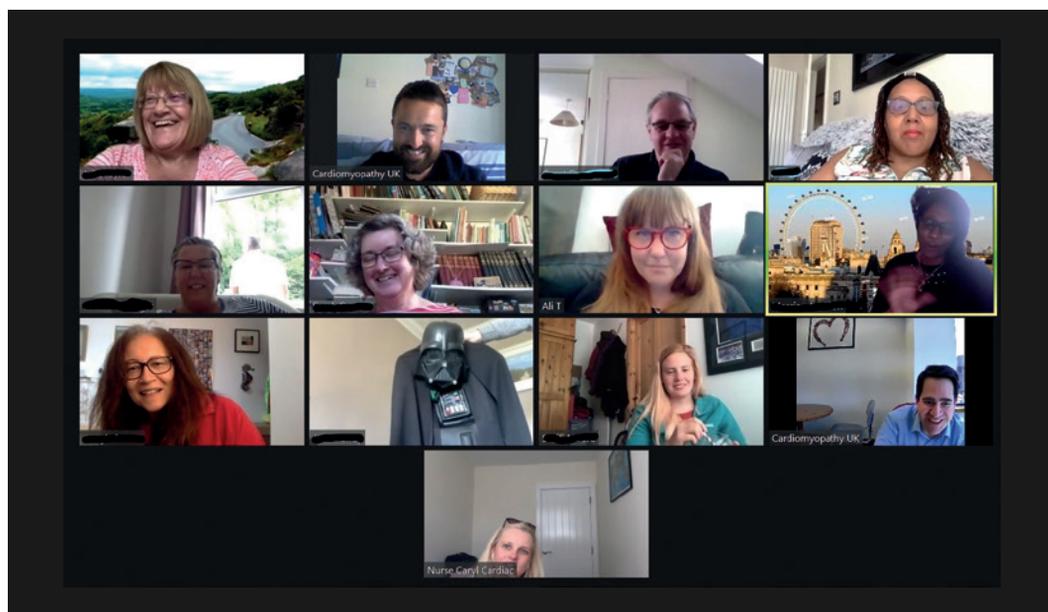
navigate difficulties within their workplace and by sharing coping strategies, a listening ear and empathy, our family has proven itself in these difficult and unknown times.

In 2020 alone through our direct services (not including Facebook groups or our National Conference) we supported nearly 10,000 individuals and welcomed many new people to our family.

Even as we grow and our charity evolves, Cardiomyopathy UK will always retain that closeness and family feel with our community - and it is this that sets us apart from many other providers.

As we move into another year, we hope that you will join us and make our family even bigger and more enriched.

// In times of hardship it is hoped that families pull together and support each other, and this has been so true of our peer support family. //



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



I have been turned for PIP and have applied for a Mandatory Reconsideration. If this gets turned down, I can then appeal to a tribunal. What is the difference between these two please?

A Mandatory Reconsideration is the first tier of appeal which means the DWP must review your initial application and the reasons given for not awarding PIP. Tribunal hearing is the second tier of appeal where your claim is looked at by a judge and medical experts. You attend court (during the pandemic all hearings take place via telephone) and are asked questions by the medical experts and judge who, after the hearing, decide whether to award the benefit or uphold the DWP's initial rejection. It is worth going to Tribunal as experience shows you have a greater platform to tell the judge / medical experts what life is really like with your condition.



Ali Thompson
Head of services



I am really struggling with fluid retention. How can I manage this?

Excess fluid in your body can take a variety of forms from tummy bloating and swollen ankles to nausea, persistent coughing and fatigue. You may be tempted to dismiss these problems as having little to do with your heart. Fluid build-up can quickly escalate worsened heart function, which can then lead to heart failure. The good news is: is that you can tell if you're beginning to retain fluid by getting on the scales. Weight change is the earliest sign of fluid imbalance. People can retain 4-10kg of excess fluid before they see leg and tummy swelling. However, symptoms such as coughing and shortness of breath, loose stools, and feeling full without eating much may develop at 2-5kg. Keep a diary of weights for reference. It is advised you act as soon as you notice weight increasing. Don't wait until you feel unwell, speak to your GP.



Nurse Emma



I was diagnosed with dilated cardiomyopathy at 26. Ten years down the line I now have a diagnosis of heart failure. My family are supportive but sometimes I feel that they don't fully understand my heart failure symptoms. How can I help them understand?

Heart Failure is long term with often debilitating symptoms and can have a profound impact on daily life. It can also have a significant psychological impact. It is important to be open and honest about how you are feeling with your family and addressing barriers by planning a daily routine to accommodate your needs. If you find this difficult you can get support from your heart failure nurse or our helpline. Informing family members either by discussion, support groups or written materials regarding managing your symptoms is helpful. Look at our factsheet on heart failure for more information and advice on how to live well with heart failure: <https://www.cardiomyopathy.org/about-cardiomyopathy/heart-failure> This may help you family understand more about your condition and needs.



Nurse Caryl



My cardiologist has told me that my cardiomyopathy is inherited, what does that mean for my family?

Cardiomyopathy can be caused by changes in genetic material. Genes can sometimes change in their genetic code and these changes are sometimes called mutations. This altered function can cause cardiomyopathy. Genetic testing involves looking at genetic material for these changes and mapping a person's family tree. Genetic testing can be used to confirm whether your cardiomyopathy has a genetic cause and sometimes used to test family members. Genetic conditions may be passed on from parent to child so cardiomyopathy sometimes runs in families. Often if one person is diagnosed with cardiomyopathy it is recommended that their close family members such as parents, siblings, and children (first degree relatives) are screened for the condition. This involves your relative asking their GP to refer them for an electrocardiogram (ECG) and Echocardiogram (ECHO), then to see a cardiologist.



Nurse Jayne

We have some really fun Community and Challenge Events for families to get involved in this year!

There are lots of challenges to take on that can be done whenever suits you- from walking the distance to Everest to working out in your back garden at home.

Visit our website

www.cardiomyopathy.org/events

for our full list of events.

Colour and Bubble runs

Navigate an obstacle course of inflatables, or an inflatable course with space hoppers whilst being sprayed with colour and bubbles. There are courses all across the country, or you can do an event of your own.



Fun runs and running festivals usually have a race for children. If you are feeling adventurous you could even climb a mountain, like the Cronin Family!

Mum Laura was diagnosed with Dilated Cardiomyopathy in 2016. After turning to our charity for support, the family decided to give something back by raising funds and awareness of the disease. The Cronin family climbed Mount Snowdon last August- and despite bad weather on the day, they managed to raise over £1000 for us!

Have you set yourself a 2021 goal?

Take on a 30 Day Challenge with your family and friends. Why not set each family member their own challenge to complete, or have a joint challenge for the whole household? Whether you would like get fitter, eat healthier, or even learn a new hobby, our 30 Day Home Challenge can be suited to you.

30 Day Home Challenge



Cardiomyopathy^{UK}
the heart muscle charity

Donate your date night!

Make Cardiomyopathy UK your valentine this February. Send a heart inspired card to someone you care about, or donate the cost of your date night on the 14th.

www.cardiomyopathy.org/shop

Get your hands on one of our exclusive stay-at-home Valentines kits, packed with recipes and fun activities. We also have a family pack available in case there are more of you joining this year!



Tony and his dog, Oskar

Think you have the best pet in show? Well we have the purr-fect event for you! Coming in March, a virtual pet show for all the family to join in with. We have some great categories, so whether your pet is cute, crazy, feathered or furry, there is something for everyone.

Coming soon to a screen near you...

Join us for Cardiomyopathy UK's first charity gaming live stream event! Contact Community Fundraiser Jaye at jaye.chassebi@cardiomyopathy.org for more information.



Celebrate birthdays and anniversaries with a Facebook fundraising page. Celebrate in style with your loved ones by asking for a donation to us.

Thinking of getting involved this year? Contact our fundraising team via email fundraising@cardiomyopathy.org or call us on **01494 791224**

Our

International Family



By Joel Rose, our Chief Executive

In the last edition of My Life, I talked about how one of the charity's objectives for the next three years is to play more of a role in developing and supporting an international cardiomyopathy community. We want to do this because we believe that being part of a worldwide cardiomyopathy community benefits everyone as we can share knowledge and information on a much wider scale.



I am pleased to say that we have already been able to push ahead with this work. Over the last few months I have been speaking to cardiomyopathy focused groups, charities and associations from Germany, Italy, the Netherlands, Spain, Australia and the US group. Some of these groups we already knew but some had never connected with any other cardiomyopathy charity before.

It was really heartening to know that all the groups I spoke to share our view that by working together we can achieve a great deal for all of our communities and we decided to form an international network which will be known as "The Cardiomyopathy Council".

The Cardiomyopathy Council has four main objectives. Firstly, it will be a forum for all groups to share ideas, information and resources to support each other's work. Secondly, the council will work to support and encourage new cardiomyopathy groups in regions where none currently exist. Thirdly the council will collaborate on international projects such as awareness campaigns or best practice setting. Finally, the council will work together to help to shape international research and promote engagement with research projects from around the world.

Two of the charities in the council, the Hypertrophic Cardiomyopathy Association in the US and the Cardiomyopathy Association of Australia were formed around the same time as Cardiomyopathy UK and inspired by our charity's founder, Carolyn Biro. In fact, Carolyn had the vision of an international network or "family of cardiomyopathy charities" years ago. Now however, the time is right to make this vision a reality.

We know that clinicians and researchers are working more collaboratively across the globe. In fact the charity has also played a part in making this happen by supporting the development of an international network of clinicians led by Professor Elliott. It is vital that as charities we can support and work with this clinical network to help ensure the best outcomes for people affected by cardiomyopathy.

// —————
 We decided to form an international network which will be known as "The Cardiomyopathy Council".
 //

We also all know how much COVID-19 has impacted on our lives. A global pandemic requires a global response and all of the charities in the network share the same concern about how we can ensure that people with cardiomyopathy are safe now and that their needs are met in the future as healthcare systems are redesigned and rebuilt.

In this edition of My Life, we have talked a lot about the role that families can play and how important it is to have people around you for support when you living with cardiomyopathy. Families don't have to be just the people you are related to, they can also be the communities that you feel a part of, that provide support and understand what you are going through. I hope you already feel that Cardiomyopathy UK is part of your family.

Now with this new international network, the family has just got much bigger.

Our Pioneering Family of Change Makers



By Natalia Bartolome-Diez, Policy and Advocacy Manager

In summer 2020 we launched our Policy and Advocacy Project, 'Change Makers', which aims to identify, address and act on problems in the current care and treatment pathway for people affected by cardiomyopathy.

The project is now underway and is developing at a great pace. Twenty Change Makers, representing all the cardiomyopathies and ranging from 24-73 years of age, have been recruited from across the United Kingdom. Together, they have been sharing their experiences and insights in order to help us develop our Change Agenda.



Our Change Agenda highlights the changes that need to happen at the point of diagnosis, specialist treatment, genetics and family testing, and long-term care and support within the healthcare service to improve patient experience, care and treatment.

Our drafted version of the Change Agenda is currently being reviewed by clinicians to ensure that we can bring in the changes that have now been identified



// _____

Working alongside the charity and other Change Makers to bring the patient and family perspectives to the Change Agenda really is a privilege and I can't wait to see what we can achieve together!



_____ //

Libby, Change maker

Here are some of the things which need to be prioritised:

- The need for clearer and improved communication between clinicians and patients, at all stages of the healthcare process
- Improved communication and access to mental health and lifestyle support, for managing a long term health condition.
- The development of thorough care plans for everyone involved in a patient's treatment to be aware of their management
- Better access to cardiology care, specialism and genetics; with care and treatment given in a timely manner.
- Providing information, resources and support from trusted sources like Cardiomyopathy UK so that those affected can be confident in understanding more about their condition.

The Change Makers are now preparing to influence and action our Change Agenda in their local and regional areas. They will work with clinicians, hospitals and cardiology teams to establish the next steps.

Once our Change Agenda has been finalised, we shall share all the priorities with you, so keep an eye out on our website www.cardiomyopathy.org where we post our updates!

If you are interested in becoming a Change Maker, please get in contact with Natalia, Policy and Advocacy Manager (natalia.bartolome-diez@cardiomyopathy.org)



Thomas Wheeler-Osman

Thomas, a car salesman and FA qualified youth football coach shares his personal experiences with his family's inherited cardiomyopathy.

My story



Thomas and his fiancée Megan

We have a family history of inherited cardiomyopathy, passed down from my Father's side. I was diagnosed with dilated hypertrophic cardiomyopathy in 2002, and I first experienced symptoms when I was about 27. Although my diagnosis did not come as a shock, the effect on my family and the impact on others has been difficult. My brother was also diagnosed with the disease, which I found particularly hard. He had a very successful heart transplant about 6 years ago, after a diagnosis of heart failure.

I often read the Cardiomyopathy UK magazine and have found it really helpful to know that other families are experiencing similar things to us.



Heart disease can affect anyone, and often those that you least expect might be having the hardest time.





< Thomas, his brother and his father.

For the first 5 or 6 years I found it very hard to process what my diagnosis meant for me, as I was always playing sport and led a very active lifestyle. I did not appear to have any symptoms; and whilst I understood my diagnosis, it didn't really fit with how I felt. I've since found that having a balance between your health and pursuing goals can be a challenge. I used to enjoy football, but I now play lower impact sports such as Golf, Target Shooting and Pool.

I recently had a period where my symptoms were quite severe, but by making changes to my medication, I'm pleased to say that they have improved greatly. It's really important to work with your consultants and be honest with them.

I try to focus on the pleasures of what is happening today, rather than becoming too worried about what the future may hold, or worrying about any past decisions I have made. My fiancée Megan has also really helped to shape me as a person into

someone who is reliant, and who aims to get the most out of life. You can either laugh or cry, and I have certainly found it easier to laugh when possible!



Remember that you are rarely alone even when it feels like you are, there is a whole community out there to support us and that is perhaps the most inspiring thing when things are tough.



Megan and I are planning to start a family, we have recently bought our first house and I feel certain that whatever comes up in the future; we will be strong enough to deal with it together.

I dedicate this article to Nigel Kenneth Wheeler-Osman 1956 – 2020, My father and inspiration.

#12daysofxmaschallenge

Thank you to everyone who supported us through our Christmas campaign last year. Whether you took part in our 12 Days of Christmas Challenge, ran a Santa Dash, did your own thing or donated via the Big Give; we're delighted to share that we've raised a staggering

£21,258

including Gift Aid!



Alex Horne

During the first 12 days of December, our first ever digital online campaign **#12daysofxmaschallenge** lit up our social media channels.

Inspired by Channel 4 TV show Taskmaster, we created our own 12 Days of fun challenges to help raise awareness and funds for cardiomyopathy and myocarditis. We reached out to Chesham based local celebrity and creator of Taskmaster, Alex Horne, who sent us some exclusive videos from the Taskmaster set introducing some of our challenges.

Thank you Alex Horne for all your support and helping to make this such a success!

Challenges included throwing a sprout from the furthest distance, sending a heart felt message and completing household tasks dressed as a Christmas tree! Here are just some of the entries we received.

Our Winner was: @LoungeLou, who took part on Twitter.

Not only did Lou complete all 12 challenges over the course of our fundraising event, she also raised £200 for us! Here's all 12 of Lou's entries. Congratulations, Lou!



Growing together online!

2021 is already shaping up to be a very exciting year for Cardiomyopathy UK.

As our charity continues to grow internationally (you can read more on this on pages 14–15) with visitors from all over the world visiting our website, and technology enabling us to be more connected than ever before, we decided to make some changes and update our website.

Later this spring, we will launch our brand new website; which is currently being rewritten and redesigned to make navigation simpler. We are introducing colour coded sections that will make it easier to find information on each of

the types of cardiomyopathies, how to join a support group and information on getting practical help; including benefits and emotional wellbeing. There will also be a whole new section packed full of exciting ways to fundraise and support us, with a dedicated secure area for giving donations hassle free.

We hope that the new website will be less crowded, but still with access to crucial information and keeping our friendly community feel. Please note the website name www.cardiomyopathy.org will stay the same.

This is our 25th edition of MyLife!



We are also planning to feature a digitalized version of the MyLife magazine on our website that is interactive, alongside the printed copies that are sent out. We always welcome feedback and suggestions, so if there's a topic that you would like to see covered, email Jo Marychurch on jo.marychurch@cardiomyopathy.org

In summer we hope to introduce a new monthly e-newsletter you can sign up to which includes regular (monthly) communications on latest the charity news, and dates for your diary too.

We're looking for volunteers who can spend 5 to 10 minutes testing our new website. If you are interested and want to be involved, please email Jo Marychurch, Digital Media and Communications Officer – jo.marychurch@cardiomyopathy.org

2021 Events Calendar

January

1st to 31st - Run 26 miles over January for our Virtual New Year Run

February

14th - Donate your date night! (see page 13)

14th - Valentines Virtual Run – 10k

March

14th - Mother Day

April

1st to 4th - Virtual Easter Run – 5K

11th - Run for Colour, East Anglia

May

30th - Edinburgh 5K, 10k, Half-Marathon, Marathon

June

25th - The Wales Swim

27th - Choose from 5k 10k, Half-Marathon or Marathon, South Wales.

20th - Father's Day

July

3rd - The Inflatable 5k Obstacle Course, Bath Somerset

3rd & 4th - Tough Mudder 5k, Scotland

August

Date tbc - Prudential Ride London Surrey 100

Date tbc - Summer Picnic

September

5th - Milton Keynes Festival Half Marathon

12th - Great North Run, Newcastle

Date tbc - September Stroll

October

3rd - London Marathon

3rd - Cardiff Half Marathon

9th - 10th - Bournemouth Half-Marathon Festival

December

Date tbc - Santa in the City Run

Whole month - Christmas campaign

All year round

Big Fun Run

Dog Jog

Inflatable Obstacle courses

Colour Run Obstacle courses

London to Paris Cycle

Three Peaks Treks –National, Yorkshire and Wales.

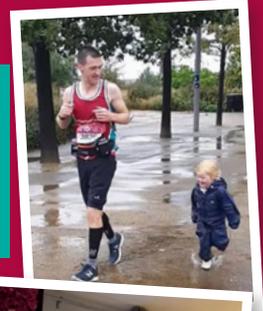
Tough Mudder

Bungee jumping UK

UK Parachuting

Spartan Trifecta

A special mention goes to our London Marathon Team who ran the virtual London Marathon 40th Race on 4th October! To those in the UK who ran through the wind and rain, or ran in extreme heat, your dedication to run 26.2 miles without the crowds cheering you on is truly inspiring.



#teamcardio highlights

To all our amazing fundraisers who supported us in 2020 by taking part in live and virtual events, we couldn't have got through last year without you.

Whether you held a celebratory Facebook fundraiser, took part in our September Stroll or joined in with our biggest Christmas campaign ever – Thank you!

Here's to 2021- together let's make it our biggest fundraising year yet!



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