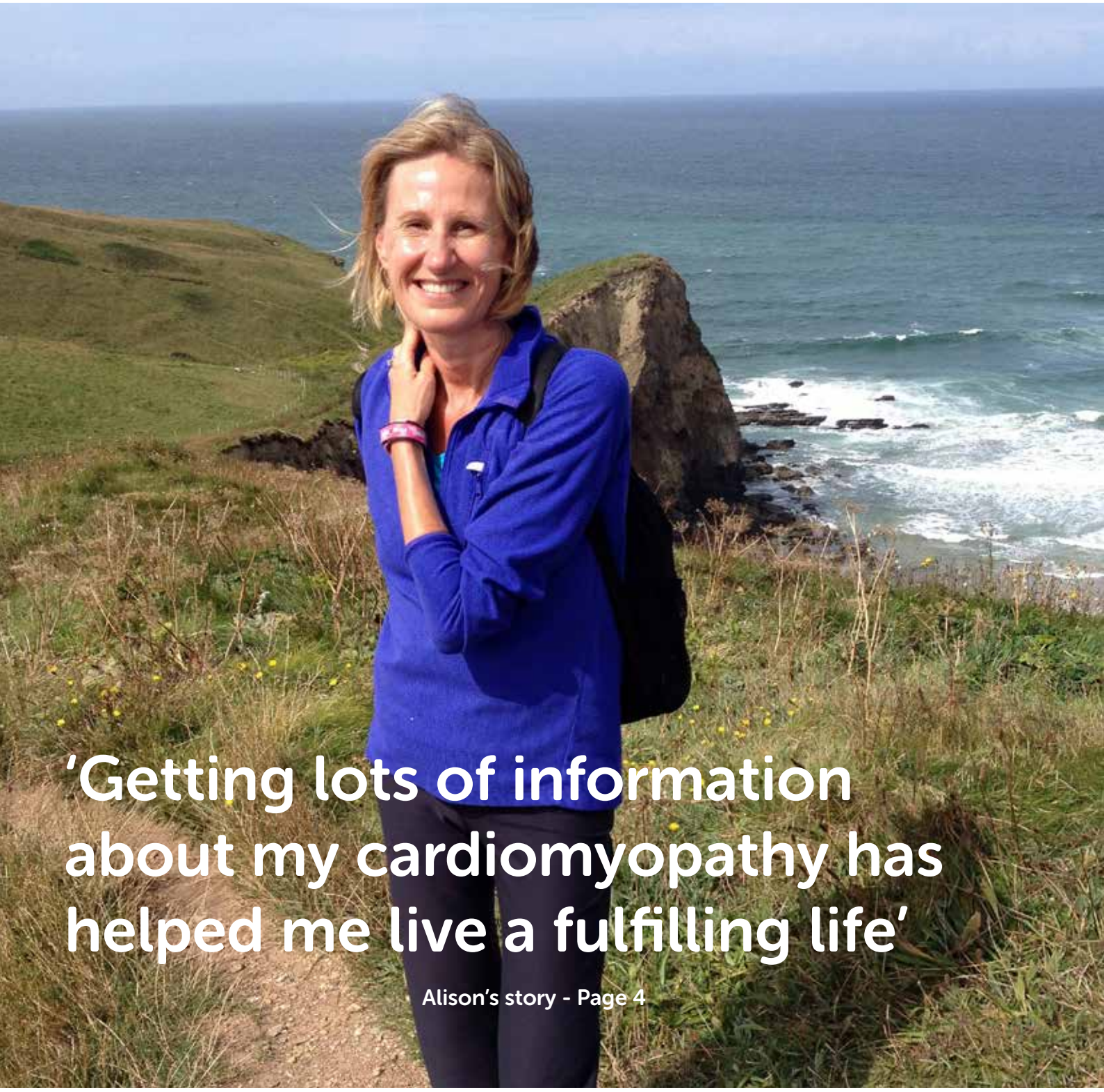
my life

The magazine from CardiomyopathyUK the heart muscle charity

Issue 02 | July 2015



'Getting lots of information about my cardiomyopathy has helped me live a fulfilling life'

Alison's story - Page 4

CardiomyopathyUK
the heart muscle charity

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the heart muscle charity

Our vision is for everyone affected by cardiomyopathy to lead long and fulfilling lives.

Our goals are to:

- increase support
- improve diagnosis and care
- promote medical research.

We provide information and support to anyone affected by cardiomyopathy. Our services include:

- **helpline nurses**
  Our specialist cardiomyopathy nurses can answer medical questions and queries about living with cardiomyopathy. You can call them on our helpline 0800 0181 024 (free from a UK landline) or email them at supportnurse@cardiomyopathy.org

- **information packs**
  We have a wide range of information leaflets and booklets about cardiomyopathy that are full of information for people living with the condition. We also have booklets, CD-Roms and online training videos designed for doctors and nurses

- **support volunteers**
  Our network of trained volunteers provide one-to-one support on the phone or by email. All volunteers are affected in some way by cardiomyopathy

- **information days**
  We hold seven information days around the UK each year. These days provide people affected by cardiomyopathy and their families with the chance to meet others who have the condition and hear leading experts talk about the disease, developments in care and latest research. Details of this year's information days are on page 15

- **support groups**
  Our support groups around the UK provide people with cardiomyopathy the opportunity to meet others and share problems and experiences with them. Meetings are always positive and encouraging, and often have experts speaking on cardiomyopathy and living well with the condition. There are details of forthcoming support group meetings on page 15.

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

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Chesham, Bucks HP5 2PX
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Website **cardiomyopathy.org**
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(free from a landline)
Email **info@cardiomyopathy.org**

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facebook.com/cardiomyopathyuk

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Cardiomyopathy UK is the operating name of the Cardiomyopathy Association, registered charity no 803262

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A message from Joel

It's a great pleasure to welcome you to the latest edition of My Life and to introduce myself as the charity's new chief executive.

I first got to really appreciate the importance of what we do at Cardiomyopathy UK when I went to an information day earlier this year.

As somebody new to the world of cardiomyopathy, it was a great opportunity to learn more about the condition and to speak to some of the people who came along to have their questions answered.

That day brought home to me the impact that cardiomyopathy has on people and their loved ones. It was also clear to see how awareness saves lives and how getting the right support and information means the difference between being on top of the condition and feeling vulnerable and isolated.

The charity will be working very hard this year to ensure more people than ever before know about cardiomyopathy and that people affected by the condition get the support and information they need.

To achieve this we need the insight and enthusiasm of all our friends and supporters. Whether it's advising us on new services or taking part in fundraising challenges, you can find out more about how to get involved in this magazine.

You can read more about our plans for the future on the charity's website. If you want to share any ideas you have about what more we can do, then do get in touch. You can reach me at joel.rose@cardiomyopathy.org or call 01494 791224.

Joel Rose, chief executive

Starting new groups are Willson, and Lorraine and Tracey

New groups for West London and Dorset

Cardiomyopathy support groups start in Ealing and Dorchester

Two new cardiomyopathy support groups have been started by our supporters.

The first, covering Dorset, is being run by Lorraine May, who has dilated cardiomyopathy, and heart failure nurse specialist Tracey Dare from Dorset County Hospital. The women held the first meeting in May and are holding the next one on Saturday, 19 September, 2pm at the Best Western Hotel Rembrandt, 12 - 18 Dorchester Road, Weymouth.

The main speaker will be chief cardiac physiologist Steve Howell from Dorset County Hospital.

The second new group, covering West London, is being run by Willson Hau, who has hypertrophic cardiomyopathy. This group has its first meeting on Tuesday, 14 July, 7pm at St Stephen's Church and Centre, St Stephen's Road, Ealing.

Willson said: "When I was diagnosed in 2011 I found Cardiomyopathy UK's resources and information days really helpful and I greatly appreciated the opportunity to meet others at my nearest support group. Now that is not running anymore, I thought I'd try to set up one where I live."

The main speaker will be research nurse Annashyl West, from the National Institute for Health Research's centre at the Royal Brompton and Harefield NHS Foundation Trust.

We have around 20 support groups around the UK but are always looking for volunteers to set up more.

If you' d like to set up a group, contact Sarah Dennis, 01494 791224 or email sarah.dennis@cardiomyopathy.org

Encourage your medical team to attend

Our medical conferences in November

To help improve care for people with cardiomyopathy, we hold regular conferences for medical staff.

These days help educate doctors and nurses about cardiomyopathy and best practice in diagnosing and treating the condition, and so contribute to better care for patients.

On Friday, 20 November we're holding a cardiomyopathy conference designed for nurses. It will be at the Cavendish Conference Centre in cental London.

On Monday, 30 November, we're holding our first regional cardiomyopathy medical conference in Bournemouth.

Over 150 cardiologists and specialist nurses attended our medical conference on hypertrophic cardiomyopathy in London in May

Do encourage members of your medical team to attend.

For hard copies of the flyers, email **robert.hall@cardiomyopathy.org**

The value of getting good information

Alison Fielding and Jim Lyness talk about how getting information has helped them take an active role in their care and get on with their lives

Alison Fielding's story

Alison Fielding, one of our trustees, explains how getting information and using new technology has helped her take an active part in looking after her health

From the day I came home from the cardiologist with the phrase 'cardiomyopathy' ringing in my ears, I have been using technology to make me a smarter patient.

Like many people, I sought information on the internet and fortunately found the Cardiomyopathy UK site early on. As well as informed patient communities like our own Facebook group and forum, I also registered on professional medical sites for cardiology, clinical trials and general medicine. Within weeks, I could have given many GPs and non-cardiologists a run for their money!

Each of us has a different view of how much we need to know about our condition and possible treatments. I'm at the 'want to know it all' end and, with effective filters to ensure you aren't spending your whole life looking at the internet instead of living, I think the empowered and informed patient is here to stay.

To keep track of my key medical data such as appointments, procedures, medications, test results and my internal defibrillator (ICD) information, I use Microsoft Health Vault, a free online place to record your medical details. You can enter some information manually and others can be automatically updated, such as exercise and weight information from fitness bands, scales or BP monitors. It's worth having a look as you can store profiles for family members, print out records to take to appointments or keep as a wallet card. As it's web based, you can access the information wherever you can access the internet or carry your smart phone.

On my smart phone, I downloaded an application called cardiio which works by using the phone camera to assess changes in skin tone as your heart beats to give you pulse data. I have found this to be an accurate and cheap tool in checking my heart rate on the go. But as my palpitations got worse, I upgraded to an AliveCor device which also clipped onto my iphone.

You hold two sensors while it takes a reading and displays the results on your screen. It's been trialled in several NHS areas and is particularly useful for detecting the abnormal heart rhythm atrial fibrillation. My iphone is always with me so I can use it to capture any strange feelings, make a note of what I was doing and how I felt and show it to my doctors. Having captured some unusual patterns, I showed my cardiologist who arranged for me to have an internal defibrillator (ICD) fitted.

I am now on a tele-health scheme organised by my local clinical commissioning group to support people with heart problems. By picking up any problems early and arranging appropriate care, the scheme aims to cut hospital admissions. I have been provided with a tablet computer linked wirelessly to scales, a blood pressure monitor and oxygen monitor.

Every morning I have to do a set of observations and answer some questions about how I feel that day. These cover fluid retention, dizziness, black outs, tiredness, palpitations, chest pain, breathlessness and so on. The results get sent off straight away to a monitoring centre and the nurses call me if there are any new symptoms or concerns. They can share the information with a local heart nurse or GP if I need follow up. I can take the tablet computer with me to hospital appointments to show them the last 30 days data. It's very easy to use and you don't need a home internet connection. If you have heart failure and think you may benefit, it's worth asking your GP or heart nurse if anything similar runs in your area. A morning weigh-in every day keeps me focussed on keeping my weight stable.

Once started on the technology trail and keen to avoid hospital visits, I have added:

- Home monitoring of my INR (as I take warfarin). I bought a monitor and send my readings by email. Check your anti-coagulant clinic is happy to train and support you. You will need to buy the device and it can be expensive. I bought direct from the manufacturer. GPs can prescribe the testing strips but make sure that they agree to this before you buy a machine
- Patient Access, an online access system to my GP so I can order medication and pick appointment times

• A remote monitoring unit for my ICD
• A fitness band to ensure I do my 10,000 steps a day and track my fitness
• Checking cardiomyopathy news via the Cardiomyopathy UK app
• If you have an i-phone, you can fill out the Medical ID app and access it via the white icon with the red heart and include your conditions, doctor, drugs and important contacts.

I still take a paper notebook to appointments. Sometimes, the old ways are still the best.

Jim Lyness's story

After attending a cardiomyopathy information day, Jim went back to his cardiologist and his medication was changed. Since then he hasn't had a day off work

My heart problem came to light in early 1996 after a visit to the pub, only a few beers mind you. In bed my heart started racing for about ten seconds but it seemed longer. I went to sleep thinking I'd go to the hospital the next day. Anyway, no further incidents meant I carried on as normal.

At my GPs in March with a bad cold he asked if I'd had any chest pain. I explained the episode, had an ECG and was referred to hospital. I was eventually diagnosed with Wolfe-Parkinson-White syndrome, where the heart beats abnormally fast. Over the next few years I had two catheter ablations (treatments to try to correct the abnormally fast heart rhythms).

During 2002 my health slowly deteriorated and arrhythmogenic right ventricular cardiomyopathy (ARVC) was suspected. My abnormal heart rhythms were lasting four to five hours and eventually became more frequent but shorter. I was advised to stop driving, went on sick leave from my job as a sales engineer and was advised to stop work completely. I went on incapacity benefit.

I could only walk short distances and not upstairs. I had to climb them in a sitting position. After wearing a 48 hour ECG monitor, ARVC was confirmed. I was delighted to be told what was wrong with me. I was kept in hospital for five days on a high dose of amiodarone (a drug to control heart rhythms) and later had an internal defibrillator (ICD) was fitted.

I began searching the internet and came across Cardiomyopathy UK. I'd been discharged by my consultant but still felt unwell. I attended the charity's annual information day and AGM in London.

During the ARVC session I compared my health with others there who had the same condition. My symptoms were not as well controlled as there's. Session leader Professor William McKenna, one of the world's experts in cardiomyopathy, advised me to go back my cardiologist and ask some more questions.

This I did and was told that the left side of my heart was affected. New medication really helped. In 2007 my health was sufficiently better so I attended a Cardiomyopathy UK training day to become a support volunteer. I wanted to give something back. The following January I went to the local Job Centre Plus and asked about returning to work. I attended a disability awareness course which helped me get a routine, prepare a CV and apply for work. I got a job at the Department for Work and Pensions. I haven't had a day off sick since, such is the importance of support and the right medication.

My fitness levels continued to improve and in 2010 I had my medication reduced. My sleeping improved and my energy levels increased. I now do a lot of walking and run up three flights of stairs two at a time. Recently my diagnosis was changed to dilated cardiomyopathy.

Alison and Jim both belong to our network of support volunteers who talk to others by telephone and email. There are over 80 volunteers on the network. If you'd like to contact someone on the network, call us or email **sarah.dennis@cardiomyopathy.org**

Have some summertime fun

The best fundraising is something that you enjoy; making it easy to organise and set-up, and fun to do. Now the sun is shining, we've put together some fun-filled fundraising ideas to get your summer started.

For more information and suggestions, as well as resources you can download, check out our website **cardiomyopathy.org/summer** and get in touch. We can send you all the materials you need.

Here are some suggestions to get you started:

Outdoor adventures
• Have a picnic party - get together with friends and have a picnic, anything from simple sarnies to sophisticated snacks. Ask for donations from friends or get everyone to bring cakes and savouries and sell them.
• Treasure hunt - ask for donations to take part and get prizes donated from local businesses
• Step it up - walk everywhere and donate what you would have paid for petrol or parking.

Home comforts
• Bake up - classic but ever popular, bake some of your favourite treats and sell them to family and friends, or workmates. Why not try some seasonal recipes?
• More tea vicar? If you love a good cuppa, have a teabreak in style with a selection of teas, and ask for donations per cup.
• Games evening - go retro with Kerplunk and Boggle. Have a tournament with donations to enter.

Helena Wheeler Osman (left), who has two young sons with cardiomyopathy, and her sisters Nicky Carter (centre) and Wendy Clarke raised almost £1,500 in a 20km Just Walk across the Sussex Downs in May

Christine Hilliard sacrificed her long locks for sponsorship, and raised £300 for us as well as donating her hair to make wigs for children having chemotherapy. She is pictured with her sons Fabian, aged 12, and Jayden, aged 10, who have cardiomyopathy

Support our summer raffle

Our annual charity raffle has gone on a bit of a holiday and has now moved to a summer raffle. This year's draw will take place on 31 August 2015, and will replace our draw in December. So this will be your only chance to buy tickets this year.

The raffle remains a great fundraiser for Cardiomyopathy UK, and allows us to continue to provide vital support for families, including services such as our helpline and free information, both online and in person.

Every single ticket bought makes a difference to families affected by cardiomyopathy, and there are some fantastic cash prizes to be won. So please do take part and buy (or sell) some tickets.

Buy online
You can also buy raffle tickets on our new website, by visiting **cardiomyopathy.org/shop**, where they are available as single tickets or books of 12. You can also give us a call on 01494 791224 to buy them.

Good information is key

Robert Hall | medical director, Cardiomyopathy UK

A diagnosis of cardiomyopathy can produce a range of emotions - disbelief, shock, fear and anger. There may even be a feeling of relief following a long period where there were problems confirming a diagnosis.

But in whatever form the diagnosis is given, the confirmation is life-changing. For many people the first reaction may be 'cardio..... what? It can seem that the longer and more difficult to pronounce a medical condition the more serious and rare it is.

Questions of survival may arise. Thoughts may then move to day-to-day living. Will I be able to return to work? How will my partner respond? What will my friends think? What will life be like? These questions may be mixed with feelings of isolation, and life being out of control.

The search for information takes many people to the internet. Typing 'cardiomyopathy' into Google will produce approximately 6,700,000 results. Unfortunately not all information there is accurate. For example, some sites state that people affected by dilated cardiomyopathy will die within 5 years. This is not true but it is devastating to read, particularly soon after diagnosis.

Patients in a stressful situation, such as initial diagnosis, will hear approximately 30% of what is said by their doctors. The remaining 70% might be misinterpreted. This has led to the publication of a vast amount of patient information. The aim, as stated by NHS England, is to:

- Remind patients what their doctor or nurse has told them if, due to stress or language difficulties, they are unable to remember
- Enable people to make informed decisions, giving them time to go away, read the information that is relevant to them, and think about the issues involved
- Involve patients in their condition and their treatment

Recent research suggests that people with health problems can do better if good, easy-to-read and understandable information is provided.

There are different types of cardiomyopathy and each affects people in different ways and with different symptoms and severity.

So try to understand your cardiomyopathy and how it affects you as an individual. This takes time and the information can be drawn from various sources, such as your doctors, nurse specialists, our information booklets, websites, others living with cardiomyopathy and through our cardiomyopathy support nurses available on our helpline.

Many questions will arise and it's important to get rid of your confusion and uncertainty. Do make full use our services and always remember, there is no such thing as a silly question.

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

More information

If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets, produced with support from the British Heart Foundation.

We have booklets about each of the main types of cardiomyopathy - dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy. There is also information about other types of cardiomyopathy on our website **cardiomyopathy.org**

To speak to a Cardiomyopathy UK support nurse, call our helpline **0800 0181 024** (free from a landline)

Q&A

Professor Perry Elliott from the inherited heart disease team at University College, London, answers your questions

Q: I am a 40 year old woman with dilated cardiomyopathy (DCM) and frequent ectopic beats. Following genetic testing, an abnormality in my DSP gene linked to arrhythmogenic right ventricular cardiomyopathy (ARVC) has been found. My sons (9 and 12) are regularly screened. Both appear non-symptomatic at present. My eldest is very sporty. Would screening for my children detect abnormalities linked to ARVC if they have been looking for DCM symptoms?

A: Mutations in the DSP gene (which codes for a protein called desmoplakin) can cause ARVC and DCM. It's unlikely that either of your sons would be manifesting abnormalities at their age, but screening with ECG and echo will pick up obvious signs of both diseases. It would be prudent to discuss the genetic results with your cardiology and genetics teams to see how certain they are that it is the cause of your DCM as this is not always obvious. When your boys are older, it may be appropriate to discuss genetic testing, taking into account all the positive and negative aspects of knowing whether they carry the same gene mutation.

Q: What are your thoughts on research into magnesium deficiency linked to cardiomyopathy? I have read lack of magnesium is also linked to facial tics, migraines, leg cramps, tiredness and low mood, all of which I have. I would like to try taking supplements but do not know if this is safe with my current medication. I take a very low dose of beta-blocker and ACE inhibitor and have an internal defibrillator (ICD).

A: Magnesium deficiency can occur in people taking large doses of diuretics, but is otherwise unlikely if you have a normal diet. Before taking any supplements have a routine blood test to check your kidney function and magnesium levels.

Q: Is there a connection between having an internal defibrillator (ICD) fitted and getting a frozen shoulder?

A: Yes, the two can be connected, usually due to people not moving their shoulder around after having the device fitted. They will have been told not to move their arms above their heads for a while, and sometimes people interpret this as not being able to move their arms or shoulders at all. At this time you should keep your joints moving – though not put your arm above your head.

Q: Can beta-blockers cause depression?

A: It is often said that beta-blockers are associated with substantial risks of depressive symptoms, but several large studies have failed to confirm this. One large analysis suggested that beta-blockers are associated with a reduction in the risk of depressive symptoms. In general, the risk of adverse effects should be weighed against the documented benefits of these drugs. For patients who experience new depressive symptoms, it is important to exclude other causes before beta-blockers are discontinued.

Q: I've been reading about the new heart drug LCZ696. Should I be on this instead of my usual ACE inhibitor?

A: LCZ696 is an investigational combination drug containing valsartan (used to treat hypertension and heart failure) and sacubitril (which inhibits the hormone neprilysin). A randomised, double-blinded study published in 2014 found that LCZ696 significantly reduced the risks of overall death, death from heart failure, and hospital stays for heart failure, compared to therapy with the ACE inhibitor enalapril. Despite these results, and before there is wholesale replacement of current heart failure therapy, further analysis of this trial and another currently underway called PARAGON-HF is necessary.

Q: I've seen reports that erectile dysfunction drugs can also help improve heart failure. So could this drug help in the treatment of dilated cardiomyopathy?

A: Phosphodiesterase type 5 (PDE5) inhibitors including sildenafil, vardenafil and tadalafi are the first line drugs for treating erectile dysfunction. They dilate blood vessels, a property that might theoretically be useful in patients with dilated cardiomyopathy. A number of clinical trials have explored their potential as a heart failure treatment. Results are mixed but seem to suggest they improve exercise performance with no increase in adverse events. Research continues.

Q: Does spironolactone cause nipple tenderness? I'm also going through the menopause. Could that be a factor?

A: This is a well recognised side effect of spironolactone. If very troublesome, the drug can be switched to a similar drug, eplerenone, which is less prone to this side-effect.

If you have a question you would like Prof Perry Elliott to answer in My Life, please send it to Sarah Dennis at **sarah.dennis@cardiomyopathy.org**

What people say about our information days

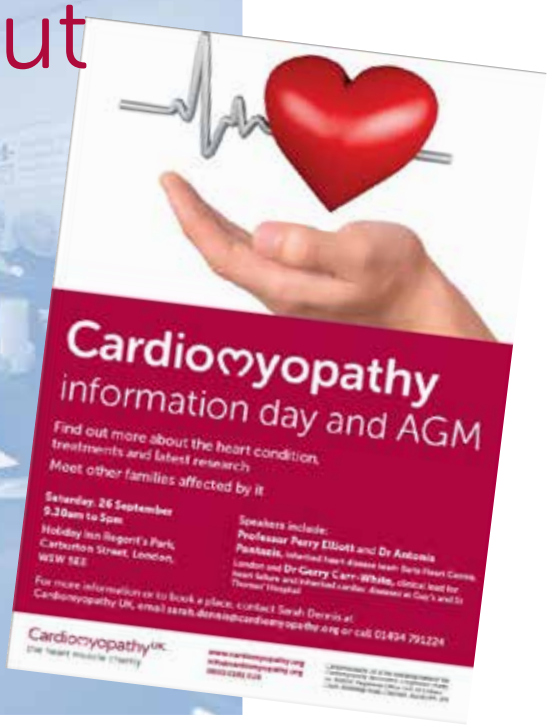
Every year we hold seven cardiomyopathy information days around the country for people affected by cardiomyopathy and their families and friends.

These days, always on Saturdays, give people the chance to find out more about the condition, latest treatments and research.

They also provide the opportunity to meet others who are affected.

Information days coming up include ones in London (26 September), Leeds (31 October) and Cardiff (21 November).

To book a place, see **cardiomyopathy.org/information-days/home**



Views on our Norwich cardiomyopathy information day

Vanessa Owen

son has recently been diagnosed with hypertrophic cardiomyopathy

Getting a diagnosis of cardiomyopathy in the family has been a harrowing time for all of us. We found the day very special indeed and it greatly increased our understanding of the disease. I am encouraged that our confidence will grow in dealing with the times ahead.

The day, including talks by national and local experts, covered many aspects of cardiomyopathy and addressed succinctly and sensitively the various concerns patients and their families raised.

Dr Sunil Nair

consultant cardiologist at Norfolk & Norwich Hospital

These days offer patients the opportunity to learn more about their condition, meet fellow patients, share their experiences, and hear from local and international experts about cardiomyopathy and treatment options. They also spread knowledge among the greater population and healthcare workers, which in turn helps to highlight important symptoms that patients should report to their GPs for referral to cardiologists for further expert assessment.

Susan Tooke

Dr Sunil Nair's secretary at the Norfolk & Norwich Hospital

The day was extremely informative – especially the visuals - and did not go over my head. It made me aware of the different types of cardiomyopathy for the first time and how they differ from other heart diseases. It also made clear the need to stress to doubtful patients the importance of follow-up and clinic attendance. I would encourage admin staff to attend too because it can help us do our job to a fuller degree and makes it interesting . Carry on the good work.

Janet Shreeve

cardiac nurse specialist team leader, James Paget Hospital

The day was very informative from a patient/carer's aspect as well as a heart failure nurse's perspective. I was surprised to see so many people there and all interested in learning more about these conditions. The topics covered enabled everyone to learn something new and ask the experts questions.

I found it so beneficial to help understand the everyday challenges patients face and the impact that it has on their lives.

Any health professional would have benefitted from attending.

Anthea Brown

heart failure nurse, Norfolk & Norwich Hospital

Patients and relatives seemed to really appreciate all the information given. The talks were informative, understanding, and friendly.

I came away with a greater respect for patients living with this condition, and a better understanding of the Cardiomyopathy UK charity, which I will inform patients about. For me, the pitch was just right but I did hear one lady say she had difficulty understanding some of the information.

Gene treatment for hypertrophic cardiomyopathy?

A company in America has begun trialling a gene treatment for hypertrophic cardiomyopathy (HCM).

The company, MyoKardia, says it is the first ever therapy designed to target the underlying cause of hypertrophic cardiomyopathy in patients with a particular genetic make-up.

People with HCM have gene mutations that cause the heart muscle to thicken and stiffen, which can cause the heart to contract too much.

The company says it has begun a study designed to correct one of the most common molecular mechanisms causing HCM (identified from genetic testing) and reduce heart muscle contractility.

A spokesman said it is an important milestone in the development of treatment for HCM.

Dr Tassos Gianakakos, company chief executive, said that by targeting a molecular defect causing HCM, it was hoped the treatment (MYK-461) could restore normal heart muscle contraction and relaxation, and reduce or prevent disease progression.

The first phase of the trial will assess the safety, tolerability and effects of oral doses of MYK-461 in healthy volunteers.

In parallel, there will also be a trial of the treatment in patients with mutations in the MYBPC3 gene, which provides instructions for making the protein cardiac myosin binding C, involved in heart muscle contraction.

For more details, see **cardiomyopathy.org/gene-therapy-trials**

Young affected children at low risk of dying suddenly

Researchers have been looking into the risks of young children dying suddenly from cardiomyopathy.

Though the disease can be serious in young children and difficult to treat, during a median follow-up of 12 years they found only around one in 20 had died suddenly, the researchers reported in the Journal of the American College of Cardiology.

A total of 289 children aged under ten were enrolled in the National Australian Childhood Cardiomyopathy Study. The study is assessing all children diagnosed in the country with cardiomyopathy from 1987 to 1996.

The risk varied depending on the type of cardiomyopathy. At 15 years, those with non-compaction were twice as likely to die suddenly as those with restrictive cardiomyopathy, almost four times as likely as those with hypertrophic cardiomyopathy and almost five times as those with dilated cardiomyopathy.

The researchers said risk factors also included older age at diagnosis, a family history of cardiomyopathy and severity of left ventricle dysfunction. A higher posterior heart wall thickness was the sole risk factor identified for children with hypertrophic cardiomyopathy.

For more details, see **cardiomyopathy.org/news/low-risk-in-children**

More understanding of inheritance helps families

Patients need to better understand the genetics of hypertrophic cardiomyopathy to help share the risk of the disease with other family members.

That is the conclusion of a study looking into family communications in those at risk of hypertrophic cardiomyopathy (HCM).

Each child of a parent with the disease has a 50:50 chance of inheriting it. So immediate family members should be checked. But when someone is diagnosed it is them, rather than medical people, responsible for telling family members they might also be at risk. Encouraging family discussion forms part of genetic counselling.

The study, led by a team in the department of human genetics at the University of Michigan in America, looked at identifying factors that affected communication in families.

Nearly 400 people completed an online survey assessing the family (gender, genetic test results, HCM family history and severity of the disease), how the illness appeared, family cohesiveness, coping styles, comprehension of how the disease is passed on to family members and sharing the HCM information to relatives at risk.

Data from 183 people was analysed. The researchers found that women and those with more understanding of how the disease was passed on increased the level of discussion with siblings and children.

They concluded that promoting patient comprehension was important and may help family communication.

For more information, about the genetics of HCM, **see www.cardiomyopathy.org/genetics**

What do you think?

What do you think about our new magazine My Life? Let us know by filling in and returning a survey card (included in some magazines) or by completing our online survey at **cardiomyopathy.org/mylife/survey** Alternatively, call us on **01494 791224** or email sarah.dennis@cardiomyopathy.org

Non-beating hearts

More people with advanced cardiomyopathy may get transplants following advances at Papworth Hospital in Cambridge.

The hospital has become the first in Europe to transplant a non-beating heart into a patient. The 60-year-old London man was out of critical care after four days and soon recovering at home. Previously it was thought unsafe to transplant non-beating hearts.

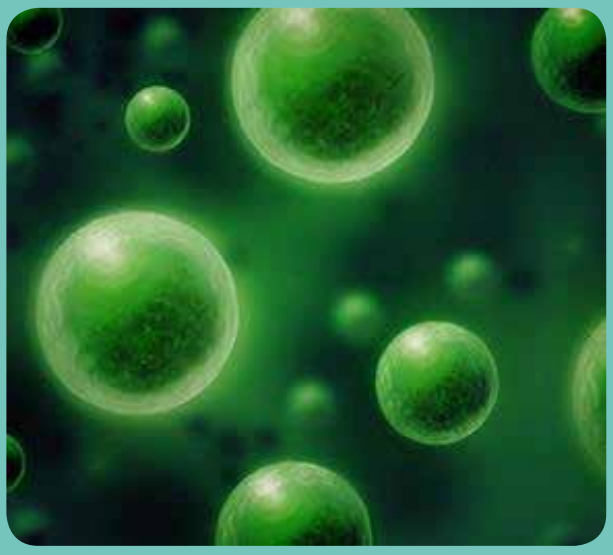
Dilated cardiomyopathy is one of the main reasons for a heart transplant. Though most people with the disease never need a transplant, some die because of organ shortages. Last year around 170 people were given new hearts in the UK. Experts estimate that the new procedure could lead to another 40 to 50 transplants a year.

Non-beating hearts could increase UK heart transplantation by up to a quarter, said consultant surgeon Stephen Large.

Good life expectancy

Today's treatments from hypertrophic cardiomyopathy (HCM) have improved so much that death rates in adults is close to that of the general population, says a new study from America. Dr Barry Maron, director of the Hypertrophic Cardiomyopathy Centre at the Minneapolis Heart Institute Foundation (MHIF), said research and technology advances, including internal defibrillators (ICDs), had dramatically changed treatments for HCM patients over the last 15 years.

Stem cells that help repair mice hearts



Scientists in the UK have used stem cell therapy to help mice recover from heart attacks and stop them developing heart failure.

The research, being carried out at Imperial College London, has been published in Nature Communications.

"We have found stem cells in the heart that have a specific protein – called PDGFR alpha – which on their surface have the greatest potential to repair damaged hearts," said Prof Michael Schneider, one of the authors of the study.

The researchers will now try to establish if the human heart has similar heart-repairing stem cells to those found by this method in mice.

Stem cells are young cells that are able to transform into specialised cells in the body. Heart tissue is damaged when it is deprived of blood during a heart attack and can lead to heart failure, when the heart is unable to pump sufficient blood to meet the body's needs.

Prof Schneider added: "When we injected stem cells with this protein into damaged hearts, we saw a significant level of heart repair.

What are stem cells?

Stem cells are mother cells that have the potential to become any type of cell in the body. They have the ability to renew themselves or multiply while maintaining the capacity to develop into other types of cells.

Now that we know which stem cells to use, we want to find their equivalent in human hearts for more efficient heart repair and regeneration after heart attacks.

"The potential of PDGFR alpha to heal the heart had been identified in several scientific papers in the past decade but it is still a long way from human trials.

"Future treatments could be injections of stem cells, as in our current experiments, or use of the healing proteins that these cells make,"

Prof Schneider said at present there were more than 20 stem cell human trials going on, including looking at treatment for dilated cardiomyopathy.

But none had been approved by the US regulator the FDA or the European Medicines Agency for general use.

3D simulated heart allows virtual tests

A French software company has designed a simulated human heart that researchers and doctors can use to perform virtual tests.

The 3D design company says the 3D simulator of a four-chamber human heart will allow researchers, heart device manufacturers and doctors to perform virtual tests and visualise the heart's response in ways that are not possible with traditional physical testing.

The model, made as part of Dassault Systemes commercial Living Heart Project, is designed to represent a healthy heart which can be modified to represent the shape and tissue properties of a heart with heart disease and other problems.

The model includes anatomic details of the heart and has realistic electrical, structural, and blood flow physics, says the company. Medical devices can be inserted into the simulator to study their influence on heart function, check how well they work, and predict reliability under a range of conditions.

Dr Robert Schwengel, professor of medicine at Alpert Medical School at Brown University in America, said: "A product like this could be very powerful in helping to educate patients, students of medicine, and current medical professionals, as well as lead to improved diagnostic capabilities and the personalisation of medical therapeutics."

The Living Heart Project has members from regulatory organisations such as the Food and Drug Administration (FDA) and the Medical Device Innovation Consortium (MDIC), as well as cardiologists and leading hospitals. They have identified the best uses for the simulator and associated technologies which will help shape future versions of the living heart.

The full story is on our website
cardiomyopathy.org/new-simulated-heart

All ICDs may be MRI safe in ten years

An internal defibrillator which allows people with it to have an MRI scan has performed well in safety trials, say doctors.

It's long been considered unsafe for people with most implantable cardioverter defibrillators (ICDs) to have MRI scans because they generate a strong magnetic field that could affect the device and cause the wires to overheat.

ICDs are given to people thought to be at risk of having a dangerous heart rhythm as they can shock the heart back into a normal rhythm.

Now a device designed to be safe for a full-body MRI has met all safety and efficacy endpoints, Dr Michael Gold from the Medical University of South Carolina told a meeting of the Heart Rhythm Society. He predicted that about ten years down the road all ICDs will be MRI compatible. "There's no downside to it per se. So it's hard to imagine this won't become standard care at some point," he said.

The study included 263 patients (median age 60.4 years) from 42 centres in 13 countries who had the MRI-compatible device.

The full story is on our website
cardiomyopathy.org/ icds-ten-years

Patient portals can help deliver better care

Will Bradlow | consultant cardiologist,
University Hospitals Birmingham
NHS Foundation Trust

Our patient portal, a secure website that gives patients 24-hour access to personal health information, helps to deliver high quality care to patients

A growing number of my patients are benefiting from an online portal that gives them access to their own health records.

The system, called myhealth@QEHB, is currently available to nearly 9,000 outpatients across 22 specialities. More than 500 seen by the heart muscle disease service are currently signed up.

myhealth@QEHB was developed by the in-house technical development and informatics team at University Hospitals Birmingham NHS Foundation Trust. The close involvement of doctors and patients ensures the portal has a positive impact on care.

myhealth@QEHB allows patients to remotely access and upload information into their own healthcare record. The portal gives users a view of their laboratory results, letters, medication, plus past and future outpatient appointment details. Patients can also interact with each other and create their own support networks, talk to each other, keep journals and publish information to their support network.

Many of the patients seen at the trust live further afield than the usual hospital catchment area and, for these patients in particular, myhealth@QEHB allows them to play a greater role in managing their care remotely, including the ability to check results online. Finding out more about our individual patients' conditions allows us to personalise their treatments and better respond to their symptoms.

The system supports this approach by allowing personalised support and giving patients access to their own bespoke care plans. Ultimately, with more knowledge and understanding of how to manage their condition, patients should have better outcomes.

In the near future there are plans to extend the service to offer care planning, e-learning and virtual clinics. The care planning tool enables patients to view data pertinent to their treatment and condition as well as add to the record. Involvement of patients with chronic disease in their own care has been demonstrated to improve both patient satisfaction and compliance.

Seeking out information using the internet has recently been shown to be associated with lower levels of anxiety amongst a cohort of individuals with or at risk of cardiomyopathy (See story below).

The e-learning package will build on this approach to improve patient understanding of their condition by providing high quality and accessible interactive patient information leaflets and patient training materials to complement knowledge and understanding.

Virtual clinics are a new feature in myhealth@QEHB, allowing patients and their clinician to engage in online video, voice and text chat. Patients using myhealth@QEHB will be given the option of booking a virtual appointment instead of attending a physical appointment at the hospital.

The sign-up process is simple. Patients who have received a leaflet from their clinic can hand it to their consultant asking to be registered to use the system. The consultant will then use the unique reference number on the leaflet to register the patient.

myhealth@QEHB uses security systems like those used in internet banking. So personal information is safe, as long as patients keep their log-in details secure.

A recent survey of patients using the portal showed more than 77% of respondents agreed or strongly agreed that by using myhealth@QEHB they were more prepared for hospital visits while 73% agreed or strongly agreed that they felt more in control of their medical care.

Online cardiomyopathy information can reduce patient anxiety, says study

People with cardiomyopathy or at risk of developing the disease suffered less from anxiety after seeking online information about the disease, says a new study published in the American Heart Journal.

The study, led by Clara Minto from the department of cardiac, thoracic and vascular sciences at the University of Padova in Italy, looked at those searching for online health information and anxiety levels among 104 patients – 48 with cardiomyopathy and 56 at risk of developing it.

The patients completed three different questionnaires – one on using the internet, one on quality of life and one measuring anxiety levels. For both groups of patients those seeking online health information had substantially lower anxiety levels.

The researchers concluded that internet technology could be helpful to people due to its "informational power and its potentially therapeutic value".

Teamcardio highlights

Workplace fundraising

Posing for the camera is Marty Bishop, who has cardiomyopathy, and a member of the racing school staff

Leeds-based marketing agency Gecko, and staff and students at Bristol School of Dental Hygiene have chosen Cardiomyopathy UK as their charity of the year.

Gecko has organised its very own Go Kart Grand Prix for us. So far the staff have raised over £2,500 to support our work.

The school is supporting us after one of its students, Linzay Clark, died from cardiomyopathy. Having set up a tribute fund in her name, the students and staff have raised over £2,000 in her memory.

If you'd like to know more about getting your organisation to adopt us as its charity of the year, see cardiomyopathy.org/workplace

Football tournament for Mitchell

Players from the Ben Cole X1 (from left) Gary Griffin, Luke Addy, Ehren West and Mitchell's brother Ben Cole

Keith Bell organised the third football tournanament in memory of former professional footballer and Cardiomyopathy UK ambassador Mitchell Cole. Mitchell, a former West Ham and Stevenage player, died from cardiomyopathy in 2012. Six teams played in the memorial event at Arlesey Town FC in Bedfordshire in May.

The winners were the team captained by Mitchell's brother Ben, who scored a last minute goal in the highly-competitive 1-0 final.

Cardiomyopathy UK's community fundraising manager Bex Noble said: "Our thanks go again to Keith for organising the tournament, all the players, and their families for cheering." Over £1,600 was raised on the day.

In memory of Mike

The Carpe Diem Gentlemen's Club raised £4,245 at a gala dinner in memory of friend Mike Polden, who died aged 20, 15 years ago. Over the years the club has held many activities in Mike's memory to support our work. Michael Woodrow, Tom Williams and Fred Rylah head the club, and Mike's family continue to support our work.

Mike Polden's Tribute Fund has now topped £75,000

Annual match in memory of Lisa

Old Pond Football Club from Hove Edge raised £545 from its annual football match in memory of Lisa Freeman

Kerrie's abseil support

Family and friends cheered on Kerrie Shelley (centre) as she descended a 170 metre tower in Portsmouth

Kerrie Shelley abseiled down Spinnaker Tower, a visitor attraction overlooking Portsmouth Harbour and the Solent, in April as a thank you for the support she received from our charity following her cardiomyopathy diagnosis. She raised £1,000.

A marathon effort from our runners

A massive thank you to our 46 runners who took part in the London Marathon for us this year. They have already raised over £110,000 and the total keeps growing.

Not only did they train for months, they have also put time and effort into fundraising which has most certainly paid off.

Many of them will have first-hand experience of what the funds raised will enable us to provide for affected famiies.

"It will make a massive difference to us", said Cardiomyopathy UK events fundraiser Leanne Langdon.

"We had four cheering points on the course with staff and volunteers trying to spot everyone in #teamcardio to take photos and give them a cheer. "

"As well as this we met our team at the post race venue where they got a shower, massage and food."

If this year's marathon has inspired you and you would like to take part in the 2016 London Marathon, please apply for one of our charity places. Contact fundraising on 01494 791224 or email fundraising@cardiomyopathy.org

If you would like to join one of our cheering points next year, then please get in touch with our events team.

Kevin's proposal to Jools after she finished her marathon

London Marathon runner Jools Plummer sports her engagement ring at the post race party. She was running in support of her boyfriend Kevin Roome, who has cardiomyopathy. He proposed to her after the run and she said yes.

Great South Run

We are looking for 15 runners to join teamcardio in the Great South Run in October.

The run is Europe's premier 10 mile event taking runners through the historic Portsmouth docks, past Nelson's flagship HMS Victory, and the Mary Rose. It finishes on the seafront at Southsea.

As well as crowds of people encouraging you on, you will also have a teamcardio cheering team on the day to help you get around.

This popular event, on Sunday 25 October, is part of a weekend of sport at the island city and is growing year by year.

- **Registration: free**
- **Pledge: £300**

For more details see **cardiomyopathy.org/events**

Half marathons

We are also looking for runners for two events:

Royal Parks on 11 October starting and finishing in London's Hyde Park.

Pledge £400

For more details see **cardiomyopathy.org/events**

Great Birmingham Run on 18 October taking in sights including the Bullring, Cadbury World in Bourneville and Edgbaston Cricket Ground.

Pledge £250

For details see **cardiomyopathy.org/events**

Spartan races

Spartan races are obstacle races designed to test charity runners' grit and determination. With a host of gruelling obstacles and challenges these are fun but demanding fundraising events. There are different levels of difficulty – called sprint, super and beast – to cater for beginners and more experienced athletes.

We are looking for competitors for:

- Cambridgeshire Spartan Sprint, 5 September at Elton Hall near Peterborough (5+km run and 15 obstacle race) is ideal for all abilities, including anyone new to Spartan
- South Spartan Sprint, 19 September at Ashburnham Place near Battle (5+km run and 20 obstacles). A muddy sprint for all
- South Spartan Super, 20 September, Ashburnham Place, is more difficult and over rugged terrain (13km and 25+ obstacles)
- South Spartan Beast, 27 September, Ashburnham Place (16+km and 30+ obstacles) is a really gruelling race to take you out of your comfort zone.

- **Registration: £35**
- **Pledge: £300**

For more details, see **cardiomyopathy.org/spartan**

GET INVOLVED

To take part in any of these events, just email **fundraising@cardiomyopathy.org** or call **01494 791224**. We provide a free fundraising pack with a t-shirt or running vest – and can help you smash your target!

Towering support

Niall Stewart raised over £2,400 in the London to Paris Cycle in support of his wife Judith who has hypertrophic cardiomyopathy.

Also in the French city this year were our seven Paris Marathon runners who raised a total of more than £6,000.

To take part in the:

London to Paris Cycle

Pledge £1,500

For details see **cardiomyopathy.org/cycling**

Paris Marathon

Pledge £500

For details see **cardiomyopathy.org/events**

Tough call

Pat Hogan has been taking on some difficult challenges - a Tough Mudder obstacle race and a skydive in memory of her nephew Michael Bowe. She was joined in the first event by her daughter, Natalie Hogan, plus her daughter's friend and boyfriend - Kay Brockwell and Tom Wilks. They raised over £1,500.

Dates for your diary

July

Saturday 11 July, 2pm-4pm
Cheshire and Merseyside Support Group
Outpatients Department, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE
Financial advisor Bill Bartholomew on getting life insurance
For more details contact Julie Rees, juliereES65@aol.co.uk or 07949 241026

Saturday 11 July, 3pm
North London Support Group
Finchley Memorial Hospital, Granville Road, London N12 0JE
Social get-together. For details contact Jane Barnett 020 8343 1940 or email jane@email58.co.uk,

Monday 13 July, 7pm
South London Support Group
Park Plaza County Hall, 1 Addington Street, London, SE1 7RY
Senior heart pharmacist Clare Thomson, St Thomas's Hospital, on drug treatments
For more details see enquiries panel

Tuesday 14 July, 7pm
West London Support Group
New group at St Stephen's Church and Centre, St Stephen's Road, Ealing, London W13 8HB
For more details see Page 3

Thursday, 16 July, 8pm
Thames Valley Support Group
Grange United Reformed Church Hall, Circuit Lane, Reading RG30 3HD
Rob Williams, directorate manager for acute medicine, Royal Berkshire Hospital NHS Trust and Christine Baker, matron for acute medicine Royal Berkshire Hospital, Reading.

Saturday 18 July, 2pm
North East of England Support Group
Function Room 137, Education Centre, Freeman Hospiital, Newcastle NE7 7DN
Paul Robson on HeartStart - Emergency Life Support Training

Enquiries

If you have questions about
- **our information days and support groups**
- **how to register for one of our events**
- **how we help people affected by cardiomyopathy**

please phone us on **01494 791224**, email **info@cardiomyopathy.org** or visit our website at **cardiomyopathy.org**

Friday 31 July, 2pm
Cornwall Support Group
Afternoon tea at the home of Jenny and Howard Richards, The Cottage, Canonstown, Hayle TR27 6NB
For more details contact Eric on 01736 351439

September

Sunday 6 September, mppm
West Scotland Support Group
Boardroom, Glasgow Royal Infirmary, Castle Street, G4 0SF
Anne Harrison from the Headstart Course
For more details contact Bob McConnachie, mess@talk21.com or 07710 789581

Thursday 17 September, 7pm-9pm
Cheshire and Merseyside Support Group
Holiday Inn, Lower Mersey Street, Ellesmere Port CH65 2AL
Prof John Somauroo, consultant cardiologist, Countess of Chester Hospital, on drug treatments
For more details contact Julie Rees, juliereES65@aol.co.uk or 07949 241026

Saturday 19 September, 2pm
Dorset Support Group
Best Western Hotel Rembrandt, 12 - 18 Dorchester Road, Weymouth, Dorset, DT4 7JU
Chief cardiac physiologist Steve Howell from Dorset County Hospital.
For more information, contact Lorraine May, 07833 258190, email lorrainemay@rocketmail.com

Friday 25 September, 2pm
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Heart nurse team lead Jo Davies on developments in managing cardiomyopathy
For more details contact Eric on 01736 351439

Saturday 26 September, 9.30am-5pm
Information day and AGM, London
Holiday Inn, Regents Park, Carburton Street, London W1W 5EE
Speakers include top cardiomyopathy specialists from Barts Heart Centre in London. For more details, see enquiries panel

October

Wednesday 14 October, 2pm
Cheshire and Merseyside Support Group
Outpatients Department, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool L14 3PE
Clinical genetics registrar Victoria McKay, Liverpool Women's Hospital, on the genetics of cardiomyopathy

Friday 30 October, 2pm
Cornwall Support Group
Chacewater Garden Centre, Threemilestone Road, Chacewater TR4 8QG
Social get-together

Saturday 31 October, 9.30am-5pm
Information day, Leeds
Holiday Inn Leeds, Wakefield Road, Garforth, Leeds, LS25 1LH
The main speaker will be Professor Perry Elliott from Barts Heart Centre in London.
For more details see enquiries panel

November

Sunday 15 November, noon
West Scotland Support Group
Boardroom, Glasgow Royal Infirmary, Castle Street, G4 0SF. Open forum
For more details contact Bob McConnachie, mess@talk21.com or 07710 789581

Saturday 21 November
Information day, Cardiff
Provisional date
Venue to be confirmed.
For more details see enquiries panel

Friday 27 November, 2pm
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP
Heart nurse team lead Jo Davies on developments in managing cardiomyopathy
For more details contact Eric on 01736 351439

Friday, 20 November
Nurses' Conference
Post-Graduate Medical Centre, Bournemouth Hospital, Castle Lane East, Bournemouth BH7 7DW BH7 7DW
For more details see enquiries panel

December

Friday 18 December, noon
Cornwall Support Group
Inn for All Seasons, Treleigh, Redruth TR16 4AP. Christmas lunch.
Places need to be booked
For more details contact Eric on 01736 351439

Join us for a...

Cardiomyopathy UK
the heart muscle charity

September Stroll

Each year we ask our supporters to organise a stroll in their area to raise vital funds for Cardiomyopathy UK.

This year WE NEED YOU to organise a September Stroll where you live or join a walk to raise funds. It can be anything from a half mile walk to a 10 mile hike - the choice is yours.

Simply think of somewhere you like walking, pick a date and a route, and start encouraging others to join you.

There are beautiful places to explore all around us.

Contact us

Let us know the details of your date and route, and we can provide all the materials you need to promote it.

Get in touch with us at fundraising@cardiomyopathy.org