

# my life

The magazine from **Cardiomyopathy<sup>UK</sup>** the heart muscle charity

Issue 04 | November 2015

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Perry Elliott

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**'I couldn't walk to my front gate but now  
I've competed in the British Transplant Games'**

Jon (right) tells his cardiomyopathy story – Page 4

## Our services

We provide information and support to anyone affected by cardiomyopathy.

- **helpline nurses**

Our specialist cardiomyopathy support nurses answer medical questions and queries about living with cardiomyopathy. You can reach them through our helpline 0800 0181 024 (free from a UK landline) or email them at [supportnurse@cardiomyopathy.org](mailto: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. They are all 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 with the condition. There are details of forthcoming support group meetings on Page 15

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.

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



## Contact us

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

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## We've come such a long way but have much more to do



**Departing chairman Peter McBride talks about how far the charity has come in his 12 years at the helm**

I got involved with Cardiomyopathy UK because my brother-in-law had hypertrophic cardiomyopathy and died suddenly without any of the family knowing about the seriousness of the condition nor the need for family screening.

At the time the charity was doing a great job sending out information to families affected by the disease, but it was missing the presence and energy of its founder Carolyn Biro who had died.

It was 2002 when I became a trustee and there were few hospitals around the UK with expertise in diagnosing and treating the disease, and many patients were not getting the care they needed. It was common for patients not to know much about the disease nor that it could be inherited and so had implications for their families.

I became trustee chairman in 2003 and hoped my business and accountancy skills would help the charity run more efficiently and establish some financial stability, including through the worst economic downturn for decades.

One of the major initiatives the charity

started soon afterwards was to put funding into the London Heart Hospital's specialist cardiomyopathy service run by Professor William McKenna, one of the world's leading cardiomyopathy experts and president of the charity.

We funded a cardiologist and a specialist nurse to help the service grow so it could see more patients with cardiomyopathy and watch over their families. We put funding into hospitals in Belfast, the Glasgow area and Sheffield to help establish them as specialist centres too.

We wanted medical staff at these centres and other hospitals around the UK to understand more about cardiomyopathy and best practice in treating it.

So in 2004, with the help of Professor McKenna and his colleague Professor Perry Elliott, we started a programme of London cardiomyopathy medical conferences. Until that point there were no stand-alone medical conferences on cardiomyopathy. The disease, which can be difficult to diagnose and treat, only got a passing mention in general heart disease medical conferences.

To this day we still hold an annual medical conference for cardiologists and specialist nurses, and another every two years for nurses. The conferences have become highly respected and, over the years, more than 2,000 medical people have attended, including doctors from overseas, and gained knowledge to be used to help their patients.

Now we are starting a programme of regional conferences so more medical staff

have access to them. At first we charged for our conference but soon realised that trainee doctors could not get funding to attend. So we have been offering them free registration ever since.

We have also greatly increased what we do for affected families. We have cardiomyopathy support nurses available through our helpline, and have seven information days a year instead of three. We have updated patient information and published new booklets, including our latest on living with the disease.

Our network of support volunteers, who talk to others by telephone and email, has grown from fewer than 20 to over 80, thanks to regular training days.

We regularly communicate with 22,000 people, including almost 4,000 medical people (this is almost ten times the numbers in 2003), now using social media and email updates instead of only our regular magazine.

I am proud that our charity continues to be regarded with respect by patients and the medical profession. We remain reasoned in our approach to best care.

My vision is for us to be the first stop for everyone affected by cardiomyopathy and to offer all the support families need.

I would like to recognise the vast contribution of Robert Hall in helping establish a solid platform on which the charity can grow and flourish. I wish my successor Alison Fielding and our new chief executive Joel Rose every good wish in furthering the charity's tremendous work.



**Message from Joel, our chief executive**

Welcome to the latest edition of My Life. In this issue we see Peter, our long standing chair, sign off (above). As we look back over the amazing things that have been achieved we can see how the charity has grown and developed.

Now, one of the challenges is to continue to grow the charity in such a way that it can build on the work of the past. We want to go forward without losing any of the hard earned reputation for quality services that we have or the warm feeling that people have for us.

It was a pleasure to meet so many people at our recent AGM and information day and I felt that there was a real sense of excitement about the future. I left feeling convinced that by working together we can meet this challenge and build a charity that makes a real difference to people with cardiomyopathy and one that we are truly proud of.

As ever, if you have any questions about the charity then feel free to contact me at any time at [joel.rose@cardiomyopathy.org](mailto:joel.rose@cardiomyopathy.org) or call 01494 791224.

## Last information day of 2015

### Our 2016 events will be announced soon

Families affected by cardiomyopathy can find out more about the condition, latest treatments and research at our information day in Cardiff on Saturday, 28 November.

The main speaker is Dr Sam Mohiddin, consultant cardiologist at Barts Heart Centre in London, who will talk about the different types of cardiomyopathy and advances in care.

Professor Dhavendra Kumar, consultant in clinical genetics at Cardiff



University School of Medicine, will talk about developments in cardiomyopathy genetics, and arrhythmia nurse specialist Wendy Churchouse, from Swansea's Morriston Hospital, will talk about living with cardiomyopathy and what helps.

For full details or to book places, see [cardiomyopathy.org/info-day-Cardiff](http://cardiomyopathy.org/info-day-Cardiff) or call us on 01494 791224.



Jon Comb and Jane Barnett talk about how getting involved with a cardiomyopathy support group has helped them

# How support groups help our families

## Jon Comb's story

Jon, 50, talks about how he went from being unable to walk a few yards in 2013 because of his noncompaction cardiomyopathy to taking part in the British Transplant Games.

In 2009 at the height of the swine flu epidemic, I had all the symptoms of the condition. I went to the doctors and they put me on tamiflu pills. The symptoms went after a few days but my cough persisted.

After listening to my chest two weeks later, the GP sent me for x-rays. I was then given an ECG, echo and blood tests. I was told I had left ventricular noncompaction (LVNC) and was in heart failure. It was such a shock.

In LVNC the walls of the main pumping chamber of the heart become spongy. It's thought it develops that way while you're in the womb. The consultant told me he didn't know much about it and referred me to the Freeman Hospital in Newcastle.

I was put on drug treatments (beta-blockers and sartans – ACE inhibitors didn't agree with me) and things started to stabilise. But in 2011 I had a mini-stroke, was medically retired from my job as a civil servant and doctors decided I needed an internal defibrillator (ICD) with biventricular pacing to help my heart beat in a more co-ordinated way. That was fitted in 2012. Again things improved but the following year I had lots of chest infections, one of which would not go away.

At my hospital appointment that spring, doctors told me they thought I should have a heart transplant assessment. It knocked me back, but I thought it was just an assessment. But by the time I went for it that July I was looking really blue and I was kept in hospital. Ten days later I was on the urgent list for a transplant and five days after that I got my new heart from a man in his 20s.

I woke up nine hours later in intensive care feeling on top of the world. The difference was absolutely immediate. I could feel that everything was working and my wife Win said I looked pink for the first time in years. My appetite was back and I could taste food. I ate like a horse – and still do. After five days I was back on a cardiac ward and three weeks later back home. For my first full

day at home I went for a half mile walk. Previously I could not walk from my front door to my front gate. Apart from a viral infection and a couple of chest infections since, I have been fine and never felt better.

The staff at the Freeman, from cleaners to consultants, are some of the most dedicated and amazing people I have ever met.

I've also become involved with the Freeman Heart and Lung Transplant Association and am their photographer. The group runs sports teams and raises money to buy equipment and help transplant families. I have hypermobility syndrome (my joints easily move beyond their normal range making me prone to injury). So I've never been sporty. But the group asked if I'd like to do some sports, especially as the British Transplant Games were coming to Gateshead this summer.

So I decided to take up archery. As the games are held over five days it was suggested that I should compete in a different event each day. So I took part in swimming, ten-pin bowling, throwing a cricket ball and the javelin. It was a wonderful experience. The atmosphere was absolutely fantastic and family and friends came from hundreds of miles to watch. Quite a few of us took part in the donor walk, including Win and my stepdaughter Heather.

I had joined the North East Cardiomyopathy Support Group when it started three years ago and it has really helped us. It is so welcoming and friendly, and we have a good laugh. It's a tonic in itself. It's so good to meet others with cardiomyopathy and we've made some really good friends. When I was in hospital Win gave an update on my progress to the group and I later made a presentation to them about my transplant. When I was at the games, group members came to cheer me on and manned a stand to promote Cardiomyopathy UK.

One friend from the group who gave me a lot of support is now facing a transplant himself and I'm trying to support him in return. My life is so blessed. And all because a family made a courageous and wonderful decision to donate their son's organs to save others. See [www.organdonation.nhs.uk/register-to-donate/](http://www.organdonation.nhs.uk/register-to-donate/)

• Jon is pictured top left at the British Transplant Games with stepdaughter Heather and her baby Connor. Front cover also includes Heather's husband David Thompson, all with their medals from the donor walk at the games.



# Jane Barnett's story

Jane (pictured left) talks about how she and her daughters were diagnosed with hypertrophic cardiomyopathy and how starting a support group has helped her family and others.

Like many others, we lived unknowingly with hypertrophic cardiomyopathy for some years before any diagnosis was made.

We were told by our GP that our daughters' (Judy and Lisa's) difficulties in certain areas, such as walking at a reasonable pace uphill or performing in team games at school, were a sign of asthma and they were promptly issued with inhalers.

It was not until Judy was 16 and midway through her GCSEs that a heart murmur was detected by a very astute young doctor who Judy went to see because she was suffering from a very bad cold.

We took her immediately to a local cardiologist who expressed concern and confusion over what he saw in the echo he carried out and asked if there were any siblings to be checked.

We were then told that Lisa, 14 at the time and who has since gone on to have a heart transplant, displayed similar signs on her echo. A similar diagnosis for me followed later.

It was some time before we found a cardiomyopathy specialist — Professor William McKenna, president of Cardiomyopathy UK and at the time he was based at the Heart Hospital in London.

It was still a while before we heard of Cardiomyopathy UK and the support the charity offered to families affected by the disease. Had we known about the charity and had some relevant counselling or been able to talk to people in similar situations at the time, this might have helped.

Most people we knew had not heard of cardiomyopathy. Sadly this still seems to be the case in the public at large. Heart disease is a difficult one for young people to cope with. It was easier for me at my age to explain to my friends and family. My husband David has had to go through the difficulties of having all his closest family affected and the complications that have resulted, and learn in his own way how to deal with it.

In 2009 both David and myself attended a training day to join the charity's network of support volunteers who talk to others by telephone and email. The network has around 80 people on it affected in some way by cardiomyopathy and we still belong.

I also decided to start a support group where we live in north London. It meets every few months on a Saturday afternoon at Finchley Memorial Hospital. We have expert speakers on cardiomyopathy and cardiomyopathy-related issues and sometimes we just have a social get-together.

My motivation in choosing to start a support group was that we know that people in many cases need to talk, if not to a trained counsellor, then to others in similar circumstances, while other people may just like to get on with it alone.

There was and still is little support for people with cardiomyopathy in the area apart from Cardiomyopathy UK and our support group.

I thought that starting the support group would help me as well as others in the area, by providing professional advice in all sorts of areas. Exercise, heart failure, holiday insurance, internal defibrillators (ICDs), and counselling are among some of the topics we've looked at.

At our last meeting in October, Cardiomyopathy UK's medical director came along, led a discussion about cardiomyopathy and answered people's medical questions.

But above all, the group enables its members to chat and exchange experiences with one another. Some of us have known each other for quite a number of years now

and so we can all empathise together.

• The Barnett family is pictured on the facing page, top right, left to right Lisa, Jane, David and Judy.

## How support groups help us

Our cardiomyopathy support groups around the country also help Cardiomyopathy UK in many different ways. Here are some examples:

The North East of England Cardiomyopathy Support Group had a Cardiomyopathy UK stand at the British Transplant Games in Gateshead this summer. The group also cheered on Jon Comb, a group member who was taking part in the games (see Page 4). Pictured are Susan Saunders (centre left) and Cathy Stark, who run the group, with Hazel (left) and Len.



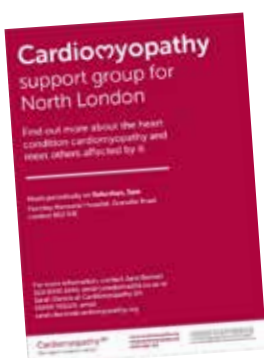
Members of the South Wales Cardiomyopathy Support group also raise funds for us. Last year they raised nearly £1,100 by staging their own September Stroll, our annual Cardiomyopathy UK walking event. Twenty people, including hospital nurses, secretaries and physiologists, joined a coastal walk.



As well as holding their own September Stroll this year, the Cheshire and Merseyside Cardiomyopathy Support Group greeted supporter John Kinnaird on his John O'Groats to Land's End cycle ride. John was diagnosed with dilated cardiomyopathy seven years ago. The group raised £155 from their stroll.



The Gordon Thomas family, who run the ARVC (arrhythmogenic right ventricular cardiomyopathy) Support Group, have been raising awareness of the disease and the charity at a heart day at daughter Marli's school in Erith, Kent. The children discussed what their hearts meant to them and watched a heart health video. Around £250 was raised. Marli is pictured right with her dad Lindsey and headteacher Phil Powell.





## Christmas cards

With the festive season almost upon us, have you seen our new Christmas collection? We have some stunning new cards and other Cardiomyopathy UK merchandise for sale.

Visit our online shop and place your orders today. All the proceeds go towards supporting families. See [cardiomyopathy.org/christmas](http://cardiomyopathy.org/christmas)

## New challenge events fundraiser

In October we welcomed a new member of the fundraising team — Sarah Moore. Sarah is our new challenge events fundraiser. Her background in event and triathlon organisation makes her ideal for supporting our fundraisers.



Sarah can be found on Facebook at [sarahcardiomyopathyfundraising](https://www.facebook.com/sarahcardiomyopathyfundraising). See [facebook.com/sarahcardiomyopathyfundraising](https://www.facebook.com/sarahcardiomyopathyfundraising). Her email address is [sarah.moore@cardiomyopathy.org](mailto:sarah.moore@cardiomyopathy.org)

## Charity of the year

We have been chosen by global law firm Mayer Brown, which has clients across the Americas, Asia and Europe, as its UK charity of the year for 2016. We are working with them to arrange a programme of events for their employees.

Does your company have any charity partnerships that we might be considered for? We can put together a programme of activities for them including an office olympics, a Great Pancake Party, a corporate skydiving day or even a team entry into the Spartan obstacle courses. For more information, visit [cardiomyopathy.org/fundraise-at-work](http://cardiomyopathy.org/fundraise-at-work)



## How the heart beats



**Robert Hall** | medical director,  
Cardiomyopathy UK

We are planning to include a series of articles in My Life on the various heart rhythm problems (arrhythmias) that can occur with cardiomyopathy.

As a starting point we thought a brief article describing how the heart beats would be helpful.

By any measure the heart is a remarkable organ.

Every day it will beat approximately 100,000 times at rest and pump around 7.5 litres (2,000 gallons) of blood. This is coordinated by the transmission of small electrical impulses which are generated in and transmitted through channels in the heart.

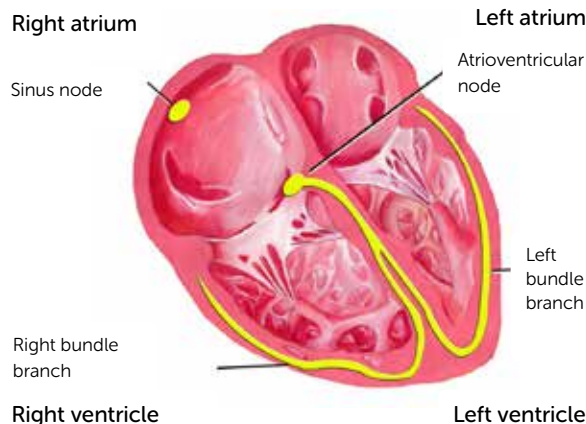
As you probably know, the heart is a four chambered pump with two atrial chambers at the top and two ventricular chambers at the bottom.

The heart's function is to pump blood around the body. It is fundamentally made up of two types of cells: muscle cells which provide the contraction of the heart necessary to pump the blood, and electrical cells which generate the electrical impulses required to cause the contraction at the right time.

An electrical impulse is produced in an area in the right atrium called the sinus node. This impulse spreads across the left and right atrium and collects at the atrioventricular node, a point at the junction between the atria and the ventricles.

The impulse is then transmitted down to the ventricle via channels known as bundles. There is a left and right bundle and some of you may have heard the term 'bundle branch block' which is used when, for some reason, an impulse is unable to travel down one of these bundles.

The electrical impulse spreads across the ventricles causing them to contract. The heart then prepares for the next impulse. This is a process which happens every time the heart beats. These electrical impulses can be recorded on a electrocardiogram (ECG) and provide a wealth of information on the heart's function.



## More information

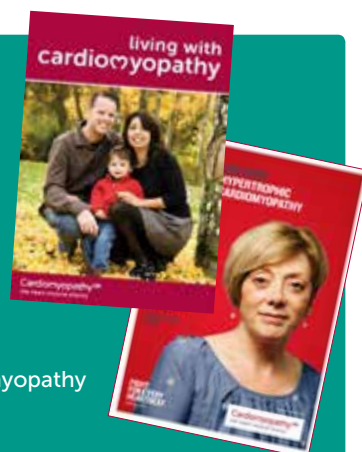
If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets, produced with support from the British Heart Foundation.

We have booklets about each of the main types of cardiomyopathy — dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy.

Information about other types of cardiomyopathy is on our website [cardiomyopathy.org](http://cardiomyopathy.org)

We also have a booklet about living with cardiomyopathy. For copies of our booklets, email [anne.foster@cardiomyopathy.org](mailto:anne.foster@cardiomyopathy.org) or call us on 01494 791224.

To speak to a Cardiomyopathy UK support nurse, call 0800 0181 024 (free from a UK landline) or email [supportnurse@cardiomyopathy.org](mailto:supportnurse@cardiomyopathy.org)





# Q&A

Professor Perry Elliott, from the inherited heart disease team at Barts Heart Centre, London, answers your questions



**Q: Do men and women have the capability to transmit hypertrophic cardiomyopathy (HCM) equally?**

A: Our genetic code is held on structures called chromosomes. In most cells of the body, there are 44 chromosomes arranged in 22 pairs plus one pair of sex chromosomes (X and Y). When we reproduce each parent contributes one of the 22 chromosome pairs and one of the sex chromosomes to every child. In the majority of people with HCM, the condition is caused by a "spelling" mistake (or mutation) in the genetic code (or sequence) of one of the main sets of 22 chromosomes. For any parent, male or female, who carries such a spelling mistake, there is a 50% (or 1 in 2) chance of passing on the abnormal versus the normal gene. If the mutation occurs on one of the sex chromosomes, the risk of passing on the condition to a child varies according to the sex of the affected parent but this is a very rare situation in HCM.

**Q: I have recently been diagnosed with dilated cardiomyopathy (DCM) and am wondering if and when I can start exercising?**

A: In general, it is a good thing to be as physically active as your heart condition allows but it is important to discuss the type and intensity of exercise you can do with your specialist before starting exercise as there may be circumstances in which intense exercise could pose a risk.

**Q: Is there a link between dengue fever and takotsubo cardiomyopathy (TTC)?**

A: TTC, also known as takotsubo syndrome, broken heart syndrome and stress-induced cardiomyopathy, was first described in Japan in 1990. It is characterised by transient deterioration in heart function caused by ballooning of the main pumping

chamber of the heart (the left ventricle). The cause of TTC remains uncertain and it is likely that multiple factors are involved. TTC primarily occurs in postmenopausal women after a physical or emotional stress. It is also reported in patients with an adrenal tumour (on the adrenal glands attached to the top of each kidney). Alternative hypotheses include coronary artery spasm, drug use and inflammation. I am not aware of a connection with dengue fever per se.

**Q: Recent reports in the press suggest that digoxin dramatically increases the risk of death and should be used with great caution. As someone who has been taking 62.5mcg daily for the last five years, how concerned should I be? Is there a safer alternative?**

A: Digoxin is an old drug that is commonly used to control heart rate in patients with atrial fibrillation (AF), although there are few studies to support this long-standing practice. In a recent retrospective analysis of a trial evaluating a novel anticoagulant rivaroxaban (ROCKET AF trial) digoxin treatment was associated with a significant increase in all-cause mortality, vascular death, and sudden death in patients with AF. This association was independent of other measured prognostic factors, although other confounding factors could account for these results. Similar findings have been seen in trials of heart failure medication, but there is some evidence that the dose of digoxin is an important factor. For the moment, I suggest that you discuss your need for digoxin with your cardiologist, but do not stop the drug until you have done so.

**Q: I've been taking the drug spironolactone now for a number of years for dilated cardiomyopathy (DCM). I've also been advised recently that I have a kidney stone and above normal levels of uric acid. Are**

**you aware of any connection between this medication and the two symptoms?**

A: Some diuretics (or water tablets) can result in elevated uric acid levels. In the case of spironolactone, there is very little information but there have been some recent reports suggesting that it may also raise uric acid. With regard to your kidney stone, you should enquire as to what type of stones you are prone to make.

**Q: Is there a link between dilated cardiomyopathy (DCM) and chronic fatigue syndrome?**

A: DCM can certainly cause fatigue because it reduces the amount of blood that the heart can pump during exertion. Some of the drugs used to treat DCM (notably beta-blockers) can also cause fatigue.

**Q: Is there a link between pulmonary artery stenosis (narrowing in the large artery that sends oxygen-poor blood into the lungs) and hypertrophic cardiomyopathy (HCM)?**

A: In general, HCM is not associated with pulmonary artery stenosis, but there is a rare form that occurs in a condition called Noonan syndrome in which it can occur with abnormalities of the pulmonary valve and other congenital heart defects.

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](mailto:sarah.dennis@cardiomyopathy.org)

# Can you help us start more support groups?

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

Support groups are an opportunity for you and your family to find out more about cardiomyopathy and meet others with the condition.

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

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

Kirsty Gordon Thomas  
(pictured right)  
said:

"The support group we attended was an absolute godsend.

"It meant so much to talk to people who understood what we were dealing with.

"Now I run that support group."



## What is a support group?

Our support groups consist of people who share an interest in cardiomyopathy, and who meet regularly to discuss their experiences, share ideas, and provide emotional support for one another. Usually the group is run by one or more people affected by cardiomyopathy who understand the value of support groups and are keen to offer support to others affected by the disease.

## What do they do?

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

## Who can attend?

Anyone affected by the disease, but also family members and friends, can attend. Sometimes heart nurses and other medical staff attend, and heart nurses offer regular support to some of our groups.

## Benefits of a support group

One of the biggest advantages of support groups is helping people with cardiomyopathy realise that they are not alone and that others have similar problems. This is often a revelation and a huge relief to those who attend.

Being in a support group can also help you develop new skills to relate to others. Members of the group can also support each other and may suggest new ways of dealing with a particular problem.

When joining a support group, you may be uncomfortable at first. However, the fact that others are facing the same type of situation

may help you open up and discuss your feelings. In addition, everything that takes place in a support group is kept confidential.

## What to expect at a support group

Support groups vary, but are usually a small group of people (maybe no more than 10) who meet on a regular basis to discuss their experiences and provide mutual support. Meetings are usually led by the group organiser but often they have expert speakers on cardiomyopathy or topics related to living with the disease.

## Where are our support groups?

We have around 14 active support groups, including one based in Scotland (Glasgow) and four in London. We have a north London group, meeting in Finchley, a west London group in Ealing and a south London group that meets on the south bank. We also have a London-based support group particularly for people with arrhythmogenic right ventricular cardiomyopathy. This group is run by Kirsty Gordon Thomas (see photo above). Our other groups include ones based in the Thames Valley, south Hampshire, Kent, Cheshire and Merseyside, South Wales (Swansea), Cornwall, Dorset, Wiltshire and the North East (Newcastle).

## Supporting our support groups

We help our support groups in many ways. We print meeting posters for hospitals and health centres and send them to our medical contacts. We invite local people on our database and publish details of meetings in My Life, on our website and in our monthly email update. We can help find and supply speakers. If you are starting a new group we can help you get a story about it in the local media. If you would like to start a support group or help run one, do get in touch with us. Email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org)



## More families may soon benefit from IVF technique

More families affected by dilated cardiomyopathy (DCM) may soon be eligible for IVF treatment to ensure their babies are not affected.

The Human Fertilisation and Embryology Authority (HFEA) is looking at whether to license pre-implantation genetic diagnosis (PGD) for DCM families affected by mutations on the CMD1A gene.

PGD is a technique that enables people with a specific inherited condition in their family to avoid passing it on to their children. It involves checking the genes of embryos created through IVF. Then only those embryos without the gene mutation are implanted in the mother's womb.

The CMD1A mutations are particularly linked to electrical conduction abnormalities in the heart and muscular dystrophy.

The HFEA has already licensed PGD for DCM families affected by mutations on the Troponin T2 gene, those with hypertrophic cardiomyopathy caused by mutations on the MYBPC3 gene, and those with arrhythmogenic right ventricular cardiomyopathy.

PGD is designed to give families with a serious disease the chance to have IVF and PGD if they know the gene mutation causing the disease in their family.

Cardiomyopathy UK and the Genetic Alliance UK are making a joint submission to the HFEA in favour of the new licence. Members of the public can also have their say by emailing [pgd@hfea.gov.uk](mailto:pgd@hfea.gov.uk).



For more details, see [cardiomyopathy.org/ivf-help](http://cardiomyopathy.org/ivf-help)

## Genetic basis of dilated cardiomyopathy to be studied

Researchers have been given a large grant to study the genetic basis of dilated cardiomyopathy (DCM).

The \$12.4 million US project is designed to help doctors better understand the inherited condition and help prevent the disease developing in family members.

With the money, the researchers at Ohio State University's dilated cardiomyopathy consortium will look at the characteristics of the disease in 1,300 DCM patients and up to 5,200 family members.

The team will perform gene testing, looking at all the patients' genes, to try to find the disease causing mutation in each family so more family members at risk of developing the disease can be identified.

"We believe the new information will help doctors understand DCM as a genetic disease," said lead investigator Dr Ray Hershberger.

He said the new insight would also help prevent family members getting the associated health problems and the risk of early death from heart failure.

Collaborating in the consortium are researchers from many other hospitals, including children's hospitals.

The money comes from the country's medical research agency.



For more details, see [cardiomyopathy.org/DCM-study](http://cardiomyopathy.org/DCM-study)

## New heart failure drug available to some

The new heart failure medicine Entresto is now available for some people seriously affected by the condition.

The drugmaker Novartis has announced the drug, also called sacubitril-valsartan or LCZ696, is being made available to the NHS under the Early Access to Medicines Scheme (EAMS).

This scheme aims to give patients with life-threatening or seriously debilitating conditions access to medicines that do not yet have a marketing authorisation.

Novartis says the drug is the first non-cancer drug to gain the EAMS status under the Medicines and Healthcare Products Regulatory Agency's programme for innovative medicines.

The company can provide the drug to eligible patients before a final European licensing decision is made.

"This is great news for patients with heart failure," said Professor Iain Squire,

professor of cardiovascular medicine, University Hospitals of Leicester NHS Trust.

He added: "Based on what we've seen in clinical trials, access to this new medicine will help patients live longer and keep them out of hospital, compared to currently available treatment."

Entresto is a twice-a-day tablet which is designed to enhance the protective neurohormonal systems of the heart while simultaneously suppressing the harmful system.

Hugh O'Dowd, general manager at Novartis UK & Ireland, said: "We are working closely with the NHS to ensure eligible patients have rapid access under the scheme while we await the final European licensing decision."



For more details, see [cardiomyopathy.org/heart-failure-drug](http://cardiomyopathy.org/heart-failure-drug)

## Richard tells doctors about the impact of heart failure



Support volunteer Richard Mindham has been telling doctors, nurses, researchers and patients about the psychological impact of heart failure.

Richard, who has dilated cardiomyopathy, was addressing a heart failure event at the Royal Society of Medicine in London.

The conference was part of a programme to update doctors and give patients and carers a chance to tell the medical profession about the impact that diagnosis and treatment can have.

Organisers say healthcare professionals learn from and are inspired to improve care by hearing from patients.

The event was supported by the BHF and Cardiomyopathy UK sponsored a stand there.

Richard said that when he was diagnosed with cardiomyopathy the only psychological support he had was from Cardiomyopathy UK. It had taken him about five years to fully come to terms with the diagnosis and the changes he had to make to his life.

Richard has been a support volunteer for Cardiomyopathy UK for many years. In that role he talks to others affected by cardiomyopathy by telephone and email.

If you would like to talk to someone on our support volunteer network, email [robert.hall@cardiomyopathy.org](mailto:robert.hall@cardiomyopathy.org) or call him on 01494 791224.

## Record numbers at London information day and AGM

Around 170 people attended our cardiomyopathy information day and AGM in London in September.

The record numbers, at the Holiday Inn Regent's Park, listened to talks from cardiomyopathy experts and in a group session had their say on improvements in care they would like to see provided by the NHS and extra services they would like to see from Cardiomyopathy UK.

# New data on scale of cardiomyopathy



A registry set up to record the scale of cardiomyopathy in Europe and how well patients do has just published its first results.

The European cardiomyopathy registry, set up by the European Society of Cardiology (ESC), is collecting comprehensive data on the disease for the first time in a bid to improve care services and treatments.

The ESC says that individually the different disorders are relatively uncommon, but together around three per 1,000 people in Europe have it, putting a substantial burden on the healthcare services of all European nations.

The first observational study looked at 1,115 patients from 27 hospitals in 12 countries added to the register between 1 December 2012 and 30 November 2013.

The commonest cardiomyopathy was hypertrophic (681 patients), followed by dilated (346), arrhythmogenic right ventricular (59), and restrictive (29); 423 patients (46.4%) had familial disease.

There were more men for all the types except restrictive.

Most patients (813) were in New York Heart Association heart function class I (no limitation of physical activity and ordinary physical activity did not cause undue fatigue, palpitation or shortness of breath) when put on the register.

But 139 (12.5%) reported loss of consciousness, most frequently in ARVC. Nearly half (45.5%) of patients had had a cardiac MRI (magnetic resonance imaging), 117 (10.6%) a heart biopsy, and 462 (41.4%) genetic testing with a disease-causing mutation reported in 236 people (51.1%). Just over 1,000 patients (92.0%) were on drug treatments; 316 (28.3%) had an internal defibrillator (termed an implantable cardioverter defibrillator or ICD). The highest proportion of those with an ICD had ARVC.

The researchers included Professor Perry Elliott, from the Barts Heart Centre in London, and other doctors from France, Spain, Italy and Poland.

For more details, see [cardiomyopathy.org/registry-data](http://cardiomyopathy.org/registry-data)

## What is the registry?

The European Cardiomyopathy and Myocarditis Registry is collecting previously unobtainable data on the patterns, causes and effects of the diseases from hospitals around Europe to improve services and treatments.

## Suppressing gene may help heart pump

A gene that plays an important role in heart development has been found to also play a role in dilated cardiomyopathy (DCM).

If the gene COUP-TFII overexpresses (has a bigger effect than it should) it can cause heart function problems, say researchers at Baylor College of Medicine in Houston, America.

They have found that by suppressing the gene in mice with heart failure it can prolong their lives. The findings have been published in Nature Communications.

Dr Sophia Tsai, professor of molecular and cellular biology at Baylor and co-corresponding author on the study, said that mice who had overexpression of the gene had a rapid decline in health.

The mice had a similar level of gene overexpression as was seen in patients with DCM. So they decided to look into why this happened.

Dr Tsai and her colleagues also found the gene plays a role in cells that are responsible for energy production. When levels of the COUP-TFII were overexpressed it created an overload of reactive oxygen which damaged the cell causing heart failure.

When the system functions properly, COUP-TFII expression is very low. But when its expression is induced in heart disease patients, function is disrupted and the heart is damaged, said researchers.

They believe this finding may eventually lead to a treatment inhibiting COUP-TFII for patients with DCM.

Researchers said: "It was thought that the gene expression was a consequence of dilated cardiomyopathy, but we have found that it is part of the cause. This gives us a target for further research needed before clinical application."



The full story is on our website  
[cardiomyopathy.org/suppressing-gene](http://cardiomyopathy.org/suppressing-gene)

## Gene testing urged in post mortems

All young people who die suddenly from a suspected heart problem should have their DNA analysed, new European guidelines suggest.

The European Society of Cardiology (ESC) has recommended that detailed genetic testing should be a fundamental part of the post mortem examination.

Identification of a genetic cause, such as cardiomyopathy, could help ensure that relatives were quickly diagnosed and protected, the society said.

The guidelines, which focus on preventing people with dangerous heart rhythms dying suddenly, have been published in the European Heart Journal and on the ESC website.

"For the first time these guidelines have incorporated the concept proposed by several documents that DNA analysis should be a fundamental component of post mortem assessment in young victims," said Professor Silvia Priori, chairman of the guidelines task force.

"The molecular analysis helps to identify genetic diseases that can occur in a structurally normal heart and therefore cannot be identified during autopsy."

Identification of a genetic cause helped early diagnosis and treatment of family members, she concluded.



For more cardiomyopathy-related news stories go to  
[cardiomyopathy.org](http://cardiomyopathy.org)



# Stroke risk in hypertrophic cardiomyopathy



**Drs Oliver Guttman and Costas O'Mahony |**  
Inherited Cardiovascular Diseases Unit,  
Barts Heart Centre, London

Doctors are using a new improved way of assessing which patients with hypertrophic cardiomyopathy are at risk of having a stroke. Here we look at the problem and the new method for estimating the risk.

Hypertrophic cardiomyopathy (HCM) is a common, inherited disease of the heart muscle and causes abnormal thickening of the main pumping chamber of the heart, the left ventricle. Patients with HCM have a higher risk of stroke than the general population and this article reviews stroke and its prevention.

## Stroke in HCM

Most patients with HCM have a good life expectancy but unfortunately some are affected by stroke (cerebrovascular accident), a serious neurological disorder caused by the sudden interruption of the blood supply to the brain. Brain tissue is starved of blood and the ensuing damage can cause sudden limb weakness, visual loss or difficulty speaking.

In HCM, stroke can be caused by blood clots from the heart that dislodge, travel to the brain and obstruct blood vessels. Stroke refers to permanent neurological damage; if the neurological deficit lasts less than 24 hours, the term mini-stroke (transient ischaemic attack) is used.

Occasionally, clots from the heart can block off the blood vessels to the legs, arms, eye or kidneys which result in local tissue damage. This process is called peripheral embolisation and is essentially a variant of stroke. In some patients, strokes are caused by narrowing of the blood vessels, most commonly in the neck or brain or less commonly by bleeding in the brain.

Approximately 4% of patients with HCM are affected by stroke over the course of ten years. If diagnosed early, stroke can be treated with a clot-busting drug that restores the blood flow and limits brain damage. After stroke, rehabilitation is essential to restore lost function. Despite advances in drug treatment and rehabilitation, stroke remains a devastating illness and a significant number of patients are disabled or die as a direct consequence. It is therefore of utmost importance to prevent strokes rather than to deal with the consequences.

## Stroke prevention

Most strokes in HCM are thought to be caused by blood clots, most likely formed as a consequence of stagnant blood in the heart. Sluggish blood flow is encountered in atrial fibrillation (AF), an abnormal heart rhythm characterised by an irregular heartbeat. Approximately a fifth of HCM patients develop AF over a ten year period and AF is a major risk factor for stroke.

Stroke prevention currently relies on blood thinning medication (warfarin and newer agents such as rivaroxaban and dabigatran) which prevent blood clots from forming. As these drugs increase the bleeding risk, they are only used if the potential stroke prevention benefits outweigh the bleeding risk. As in other cardiac diseases, other measures include lifestyle modification such as exercise and healthy diet.

Current HCM guidelines recommend that doctors commence blood thinning once AF is detected and this approach is effective in preventing a significant number of strokes. However, a

substantial number of strokes occur in patients without AF and this is a major limitation. Identifying HCM patients without AF who are at risk of stroke and would benefit from blood thinning is very important.

## A new risk prediction model for stroke: HCM Risk-CVA

To improve the prevention of stroke in HCM, a collaboration of European investigators developed a new method of assessing risk called "HCM Risk-CVA". This model provides a numerical estimate of risk of stroke in patients with and without AF. This is achieved using a mathematical formula based on data from a large group of HCM patients.

HCM Risk-CVA works similar to health insurance policies where companies use data from previous customers to calculate the risk associated with a particular applicant. In the same way that a middle aged applicant with a long list of medical problems pays a higher premium than a young applicant without a medical history, an older HCM patient with palpitations and additional risk factors has a higher risk of stroke than a younger patient without any risk factors.

## Assessing the risk of CVA using HCM Risk-CVA

The aim of HCM Risk-CVA is to identify patients at high risk of stroke who would benefit from more frequent follow up and early blood thinning. The risk assessment should include a clinical review, an ultrasound scan of the heart (echocardiogram) and a heart rhythm monitor (Holter).

In addition to AF, the following factors have been found to be associated with a high risk of future stroke:

- Age of the patient: the older the patient the higher the risk of stroke
- History of a previous stroke
- A New York Heart Association class (NYHA class): a classification for shortness of breath
- Enlarged left atrium
- History of vascular disease
- Severity of thickening of the left ventricle

Patients with these risk factors should be followed up more closely, with frequent heart rhythm monitoring and institution of blood thinning treatment at the earliest sign of atrial fibrillation or in some cases prior to the development of atrial fibrillation.

## Conclusions and future directions

Predicting the risk of a stroke, irrespective of method or heart condition, is challenging. HCM Risk-CVA represents an improvement in the management of HCM patients, but it is not perfect and currently it is not possible to predict all cases of stroke. This new tool allows clinicians to target high risk patients for closer monitoring and early treatment with blood thinning medication.



## Are you interested in becoming a trustee?

Cardiomyopathy UK is a registered charity with a board of trustees supporting the staff team in setting the direction of the work and in ensuring that the charity is governed effectively.

After the retirement of three trustees who have given us over 30 years of combined service, we are conducting a national search for three new trustees to join the board. The role involves ensuring that we are operated in a legal and ethical manner and that the services meet the needs of people affected by the disease.

Trustees do not have to have cardiomyopathy themselves or even have any family or friends affected. What is important is that they are committed to our aims and bring personal and business skills to the role. This time, we are specifically seeking trustees with experience in:

- human resources practice
- marketing or fundraising
- working with volunteers or running support groups
- working in a charity at a senior level

All trustees need to be able to contribute to the debate on strategy and be able to understand charity finance (with training).

There are meetings in London four times a year plus an annual planning meeting. There are opportunities to join sub-committees which usually hold meetings by conference call.

The positions are unpaid but reasonable travel expenses can be paid.

If you are interested, send a CV to [chair@cardiomyopathy.org](mailto:chair@cardiomyopathy.org) along with a covering letter explaining why you think you can help. We will then be in touch to arrange an informal discussion.

## The Great North Run



In September, 26 of our intrepid runners completed the Great North Run, one of the UK's most difficult and popular half marathons, raising over £10,000.

They walked, ran and some even managed a sprint finish. Well done to all of our #teamcardio runners!



## Great Pancake Party 2016

We know that with the right ingredients – clear information, expert knowledge and in-depth understanding – we can and will save lives and help stop the worry and anxiety that can be caused by cardiomyopathy.

That's why in the new year our Great Pancake Party is raising money for our frontline services.

Our website and helpline work together to ensure that more people than ever before are aware of the signs and symptoms of cardiomyopathy and have the information, support and treatment they need to live with the condition.



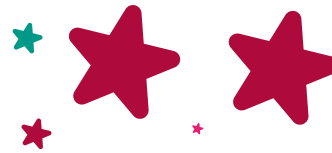
Have a party with friends and family and help us save lives

Download your pack today at  
[cardiomyopathy.org/pancake](http://cardiomyopathy.org/pancake)





# #teamcardio highlights



Angela Herdman (pictured with her son Luke Bailey) at her masquerade ball

## Masquerade ball

Supporter Angela Herdman from Barrow in Furness in Cumbria held a masquerade ball in memory of her daughter Carly who died from peripartum cardiomyopathy in 2012.

The evening was a huge success and raised £4,000 to support our work.

## Thank you #teamcardio

None of the work we do would be possible if it weren't for our #teamcardio fundraisers.

You've climbed mountains, baked cakes, run marathons, had clubberthons and even jumped out of planes. All of you have gone the extra mile to support families affected by cardiomyopathy – thank you all. If you're interested in fundraising for us and being part of the team, have a look at [cardiomyopathy.org/support-us](https://cardiomyopathy.org/support-us) for ideas and inspiration.

Your support changes lives



Naomi Wright put the funk into fundraising when she organised a special fitness class in August. The popular class raised £800 for our work.



Keen cyclist Thomas Porton (with dad Mat) cycled 109 miles to challenge himself and raise funds as he has lost family members to cardiomyopathy



Ten-year-old Philip Price (pictured with his uncle John Hayes) raised £250 for us when he completed the Swansea Bay 3k in September



Leslie Craig and friends completed the Mizen to Malin cycle ride (over 400 miles from Ireland's most southerly to most northerly points) raising £2,500



Jonathan Miller completed the London to Brighton cycle for us in September in memory of his friend Mike Polden who had cardiomyopathy





## Skydiving day — March

### Skydiving day 12 March

Join us for the ultimate adrenaline challenge and take on a skydive to help us raise vital funds.

Strapped to an instructor, you'll be flown to 10,000ft before diving out and freefalling at 120mph. Training takes place on the day. This is a once in a lifetime experience.

If you raise a minimum of £425 you jump for free!

Our skydiving day is on Saturday 12 March at the Hinton Skydiving Centre, Brackley, Northants.

### Pledge £425

For more information, visit [cardiomyopathy.org/skydive](http://cardiomyopathy.org/skydive)



## Silverstone Half — March

### Silverstone Half Marathon 13 March

Taking place at the world famous Formula 1 circuit near Towcester, Northamptonshire, the Adidas Silverstone Half Marathon is a great event on its own, but also a perfect training opportunity for the London Marathon.

Brought to you by the same team that organises the capital event, this race at the home of the British Grand Prix is fast and flat making it great for beginners and experienced runners alike.

### Pledge £300

To register, visit [cardiomyopathy.org/silverstone](http://cardiomyopathy.org/silverstone)



## #teamcardio runs

### Calling all runners

If you've missed out on a place in next year's London Marathon, there are still lots of other runs you can enter as part of #teamcardio. We have places in a variety of alternative events including:

Paris Marathon, Sunday 3 April  
London BUPA 10k, Monday 30 May  
British 10k London, Monday 10 July

Get in touch with the fundraising team to find out more. Email [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org) or call us on 01494 791224.

## GET INVOLVED

To take part in any of these events, just email [fundraising@cardiomyopathy.org](mailto: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!



## Kilimanjaro Trek 2016



Trek to the summit of the world's tallest free-standing mountain in this challenge of a lifetime. Encounter African jungle, spectacular wildlife, breathtaking glaciers and something others will only ever dream of.

Date: 2 - 11 June

### Registration

£390

### Minimum

Pledge

£3,900

For more information, visit

[cardiomyopathy.org/kili](http://cardiomyopathy.org/kili)

'The most exciting thing I've ever done',  
Dylan Kelly,  
Trek 2013

## Ride London 100



Take part in the cycling version of the London Marathon for #teamcardio next year. We have a limited number of places available in this prestigious event, so don't delay.

Starting at Queen Elizabeth Olympic Park, the 100 mile ride on 30 and 31 July then follows closed roads through the capital and into Surrey's country roads and hills.

### Pledge £500

To sign up, see [cardiomyopathy.org/ridelondon](http://cardiomyopathy.org/ridelondon)



# Dates for your diary

## November

*Sunday 15 November, noon*

### **West Scotland Support Group**

Boardroom, Glasgow Royal Infirmary, Castle Street, G4 0SF

Main speaker physiotherapist Marina DiMarco on exercise for people with cardiomyopathy

For more details contact Bob McConnachie, mess@talk21.com or 07710 789581

*Friday, 20 November*

### **Nurses' Conference**

Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT  
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

*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

*Saturday 28 November, 9.30am-5pm*

### **Information day, Cardiff**

Holiday Inn M4 Jct 32, Merthyr Road, Tongwynlais, CF15 7LH

Main speakers consultant cardiologist Dr Sam Mohiddin, Barts Heart Centre, London, Professor Dhavendra Kumar, consultant in clinical genetics, Cardiff University School of Medicine and arrhythmia nurse specialist Wendy Churchouse, Morriston Hospital, Swansea  
For more details see enquiries panel below

*Monday, 30 November*

### **Regional Medical Conference**

Post-Graduate Education Centre, Bournemouth Hospital, Castle Lane East, Bournemouth BH7 7DW  
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

## December

*Saturday 5 December, 5pm*

### **North East England Support Group**

Newton Park pub, Benton Rd, Newcastle NE7 7EB

Christmas meal. Places must be booked.

For details contact

Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

*Friday 18 December, noon*

### **Cornwall Support Group**

Inn for All Seasons, Treleigh, Redruth TR16 4AP

Christmas lunch. Places must be booked.

For more details contact Eric on 01736 351439

## January

*Tuesday 12 January 7pm*

### **West London Support Group**

St Stephen's Church and Centre, St Stephen's Road, Ealing, London W13 8HB

Main speakers Bethan Cowley, inherited cardiac conditions specialist nurse, Royal Brompton Hospital, London, and Bill Bartholomew on life insurance

For more details, call Willson Hau on 07777 633398 or email him at willsonhau@gmail.com

*Thursday 14 January 7pm*

### **South London Support Group**

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY  
For more details see enquiries panel

*Monday, 19 January*

### **Regional Medical Conference**

Post-Graduate Education Centre, Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston, Birmingham B15 2GW  
Contact Robert Hall, 01494 791224, email robert.hall@cardiomyopathy.org

*Monday 25 January 7-9pm*

### **Cheshire and Merseyside Support Group**

Outpatients Dept, Liverpool Heart & Chest Hospital, Thomas Drive, Liverpool, L14 3PE.

Dr Chris Hale from Have a Heart charity and consultant Dr Thomas Giles on living with cardiomyopathy

For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

## February

*Saturday 13th February 2pm*

### **North East of England Support Group**

Function Room 137, Education Centre, Freeman Hospital, Newcastle. Speaker to be confirmed.

For details contact Cathy Stark, 0191 276 6399 or suze.saunders@btinternet.com

## March

*Thursday 17 March 7-9pm*

### **Cheshire and Merseyside Support Group**

Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL. Speakers Liz Kevan and Jane Chesby from Chester Heart Support Group and Dr Chris Hale from Have a Heart charity

For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

## 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](mailto:info@cardiomyopathy.org) or visit our website at [cardiomyopathy.org](http://cardiomyopathy.org)

## Tell us

# your story

My Life is your magazine and we welcome contributions on any cardiomyopathy-related topic.

If you would like to share your story with other people who are affected by cardiomyopathy, contact My Life editor Sarah Dennis at [sarah.dennis@cardiomyopathy.org](mailto:sarah.dennis@cardiomyopathy.org) or telephone **01494 791224**.

*'A thrilling,  
once-in-  
a-lifetime  
experience!'*

**Skydive with**  
**Cardiomyopathy<sup>UK</sup>**

*Full details on page 14*