

Annual report 2010

Supporting families with heart muscle disease



Registered charity no 803262



**People we
have helped**

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Bridget Connell: “ When my husband was newly diagnosed I remember the shock we were feeling, the fear of the unknown and confusion about diagnosis.

“The CMA gave us both so much help and support in those early days. Now Richard’s disease is under control and we understand it.”

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Who we are



The Cardiomyopathy Association (CMA) is a UK charity that provides information and support to families affected by the heart muscle disease cardiomyopathy.

The disease, which affects people of all ages including babies, is often perceived as rare and therefore receives less attention than many other conditions. But this perception is wrong. Some forms of the condition are estimated to affect one in 500 people.

The condition, which usually runs in families, is very variable. Some affected people will have no or minimal symptoms and not know they are affected. In others the first sign may be sudden death. Thankfully, the latter affects only a small percentage of those affected by the condition.

However, the risk remains and a great deal of medical attention focuses on identifying those at risk so preventative measures can be taken.

Being diagnosed with cardiomyopathy can be frightening. Those affected often feel anxious, isolated and confused as they try to come to terms with their diagnosis.

The CMA, set up in 1989, is here to help them. Our services, which include our freephone helpline, website, cardiomyopathy support nurses, booklets, information days, support groups and volunteers, help families understand cardiomyopathy and its treatment, lessening their fears and promoting independence.

Through our medical conferences we help to educate doctors and nurses about the condition and best practice in diagnosis and treatment.

Lorna Cooper: “When I was diagnosed my husband found the CMA website. He printed everything off and brought it to me to read in hospital.

“The charity enabled me to meet other sufferers and see how they were getting on with their lives.

“And CMA funding provided the video-link between the hospital where I was being treated and the Heart Hospital in London so my doctor could discuss my case with cardiomyopathy experts.”



By Peter McBride
Chairman of Trustees

We must do more

The world is in turmoil and this is having a terrible impact on the day-to-day lives of many people. It is likely that 2010 was the lull before the storm.

The CMA is aware that it cannot be complacent about the challenges ahead. The financial results for 2010 were a substantial improvement over 2009. However we do not receive funding from any government body or corporate sponsor and this position will not change in the near future.

Every donation, whether £1 from a child's pocket money or £20,000 from a major event, is important to us. However major events can make a significant difference. Major events are often as a result of the fundraising efforts of a family and friends following a tragic loss. This is a terrible irony. In 2010 several families raised substantial sums. This will not necessarily repeat itself in 2011. So we must remain focused.

With a grant from the John Ellerman Foundation, we appointed a part-time cardiomyopathy support nurse in January 2010. As a result of improvements in our finances we appointed a second part-time support nurse from the beginning of 2011. So we now provide full-time nurse cover. In a year's time the John Ellerman Foundation funding runs out and we shall need reserves for both positions.

The trustees believe we must continue to expand our services. All of this requires finance but the ability of people to give money is going to be under great pressure. We are all going to have to work even harder. I appeal to everyone associated with this charity to do whatever they can to raise money and awareness. Maybe there is a friend or a friend of a friend who can make a difference. Maybe an employer can help.

With apologies to Juvenal – don't just think what your association can do for you but what you can do for your association. You are the present but you are also facilitating the future. Together we will succeed.

People we have helped



Mhairi Morrison: "Through the CMA website and message board I realised I hadn't been given a death sentence and would live to see my 30th birthday.

"I now have some good friends on the CMA message board."



**By Robert Hall
Chief Executive**

Campaigning is vital

Firstly I want to thank all our supporters for the help they have given the CMA throughout 2010.

There has been a tremendous response to our work throughout the year, and this has enabled us to maintain and build our services.

The services we offer to those affected by cardiomyopathy improved significantly during the year.

The introduction of our cardiomyopathy support nurse, generously funded by the John Ellerman Foundation, was a significant step forward.

Her expertise was so much in demand that we soon decided to appoint a second nurse. So for the first time we have a nurse in our office every working day to respond to medical queries.

As we go into 2011, the long term consequences of the economic recession pose a real challenge to our work. We continue to work hard to raise funds and keep our costs low to achieve our aims.

The radical changes to the NHS and the squeeze on the public sector mean our campaigning role must become even stronger. It is vital that we make the Government aware of the issues facing our members, particularly as the new NHS reforms are implemented.

It is very important that we are made aware of what is happening to the quality of cardiomyopathy services in the UK. Only then can we use our voice to ensure the needs of cardiomyopathy patients are heard.

We will continue to fight to ensure families throughout the UK have access to the best cardiomyopathy services available.

Your continued support will make this possible and help us to make a difference.

People we have helped



Paul Roome: "The CMA is the prime source of cardiomyopathy information and without it I would have felt lost."

"I went to a CMA information day and it helped immensely to hear the stories of other people and to feel that I'm not the only one with the condition."

"It gave me an opportunity to speak to specialist cardiomyopathy doctors and nurses, ask questions and get more information."

"This advice helped me to start running again very gently, keeping my heart rate nice and slow."

What we do

Providing information and support

The CMA was created in response to the lack of information available for people with cardiomyopathy.

Providing information and support to affected families remains a cornerstone of the charity's work. The new post of cardiomyopathy support nurse has been a significant step forward. The introduction of a second support nurse now provides families with a more comprehensive service.



**CMA's first
cardiomyopathy
support nurse
Gill Rogers**

Our information days provide a valuable opportunity for families to learn more about cardiomyopathy and meet others living with the condition. These meetings also enable people to learn to improve their ability to live with the condition. Over 370 people attended CMA information days in 2010.

The charity tries to ensure its services are accessible to everyone and are user friendly. The website (www.cardiomyopathy.org) remains one of the most active cardiomyopathy sites on the web. We continually update the site with latest developments in cardiomyopathy care and the charity's work.

The site attracted over 4.5 million page views during 2010 from people all over the world. The website's message board provides a means of contact for people worldwide living with cardiomyopathy. The CMA also has Facebook and Twitter sites.



Martina McConville, who has a young son with cardiomyopathy, said: "My quest for more knowledge led me to the CMA website and I became a member.

"Reassured that I was not alone I took comfort in the fact there were other people just like me with the same concerns and fears.

"The newsletters I receive are extremely informative and the personal stories are heart warming.

"It is good to see other people with the disease getting on with their lives and living a full life."

What we do

Our network of key contacts (volunteers who provide support to others by telephone and email) and our cardiomyopathy support groups continue to grow.



Learning more about pacemakers at a support group meeting

We help the support groups by mailing details about forthcoming group meetings to members in the area, helping to arrange speakers and providing direct funding where required. We try to ensure that every group has a visit from a CMA representative at least once a year.

The mainstay of our information and support resources continues to be our information booklets and our quarterly magazine CMA News. The booklets, redesigned in 2009, are published and widely circulated in partnership with the British Heart Foundation. CMA News provides medical articles, patients stories and up-to-date developments in cardiomyopathy care.

All our information materials are provided free of charge so people can receive them irrespective of their ability to pay.

Medical conferences

Throughout the charity's history our work has included educating healthcare professionals on the diagnosis and management of the different types of cardiomyopathy.

Because there was no annual academic medical conference dedicated to the clinical management of cardiomyopathy, in 2004 the CMA began organising one.



Karen Flavell: "The CMA has provided me with a wealth of information and it gave me the confidence to ask for a referral to see a cardiomyopathy specialist."

"This was the turning point in the management of my condition. I now felt I was being taken seriously by the medical profession for the first time and was put on medication."

"The CMA has been a constant support. Knowing there is always someone at the end of the phone has been enormously helpful."

People we
have helped

What we do



**CMA
medical conference**

Our medical conferences, held every year since 2004, have now become an established event in the UK cardiology calendar, attracting delegates from all over the UK, mainland Europe and beyond.

Each year the conference focuses on a different type of cardiomyopathy but in 2010 the meeting looked at the latest developments in the diagnosis and management of the three main types of cardiomyopathy.

The Carolyn Biro Lecture is included in the conference in tribute to the CMA's founder. The 2010 lecture was given by Mr Park Soon, Associate Professor of Surgery, The Mayo Clinic, Minnesota.

For the third year running we were able to provide places at the conference free of charge to trainee grade doctors and associated health professionals.

This strategy lessens any financial obstacles to doctors attending the meeting and is an investment in medical education that will be of benefit to people affected by cardiomyopathy. Over 100 delegates attended the 2010 conference.

The conference was followed by an academic seminar on Anderson Fabry disease and the heart. The seminar was supported by an educational grant from Shire Pharmaceuticals and provided an opportunity for 50 doctors to attend the meeting free of charge and learn more about this condition and its link to cardiomyopathy.



**Ray Golding: "The
Cardiomyopathy Association
has been a lifeline to me
and my wife."**

**"When Sharon was first
diagnosed, the charity
provided us with a wealth
of knowledge and support
during our darkest
moments."**

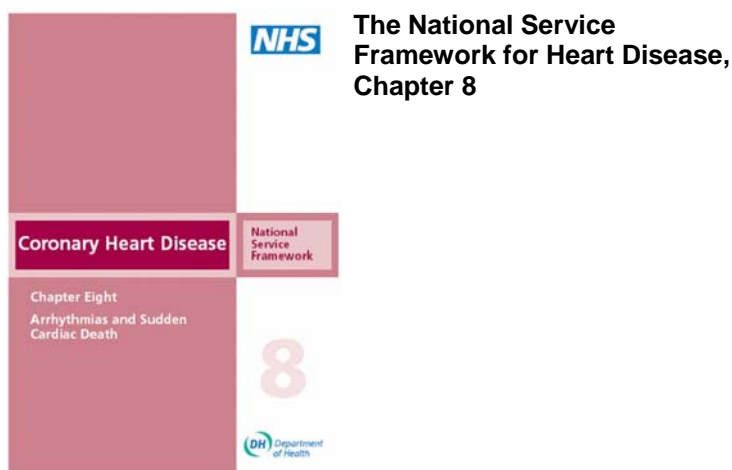
What we do

Working with Government

Since the charity was set up it has been working with Government to improve the services for cardiomyopathy patients.

In recent years the CMA accepted an invitation to contribute to the Government document on the future development of inherited cardiovascular disease clinics. A document entitled "Heart to Heart" was published in June 2009 and sets out clear recommendations on the services that should be available in clinics providing care for people affected by conditions such as cardiomyopathy.

Our work with Government on the National Service Framework for Heart Disease, Chapter 8 on Arrhythmia and Sudden Death concluded in 2010 with the completion of the programme and the election of a new Government.



The chapter brought about an increase in the provision of cardiomyopathy services and improved awareness of the conditions.

There remains, however, much to do and we must continue campaigning to improve services and widen the availability of genetic testing for affected families.



Nancy Smith: "In the early days after diagnosis and feeling lost, vulnerable and confused, I found the CMA.

"They advised me on getting referred to a specialist centre where the staff were marvellous.

"I can't stress enough how brilliant it was to talk to one of the CMA's volunteers, someone who not only knew about cardiomyopathy but also lived with it and understood what I was going through. She had children, a job and most of all a positive attitude to life.

"When I put down the phone I felt a huge weight had been lifted from me. I knew then I too could live a full life."

What we do

CMA support

The CMA receives no Government funding and relies predominantly on income from donations, supporter fundraising and gifts in Wills.

Our wide range of fundraising opportunities for supporters includes running events and an annual ebay auction.



**Our 2010 runners
in the
London Marathon**

Our running events produce significant income with the London Marathon being our highest single source, raising over £95,000 in 2010. In our ebay auction in 2010, heart doodles received from celebrities, such as Oscar winning actor Ben Kingsley, Olympic champion Kelly Holmes and comedian Ricky Gervais, were sold.



**Kelly Holmes and her
heart doodle**



Mark Hayden: “I’m really grateful for the support the CMA has given me — from providing me with lots of information about cardiomyopathy to giving me the chance to speak to others who know what I am going through.

“Having experienced first hand the help the charity provides, I want to support this work where I can.”

What we do

For the third year running the CMA was chosen as the main benefiting charity for the Tunbridge Wells Half Marathon. Our thanks go once again to the organisers for their continued support.

The Oxford University Air Squadron continued to support the CMA as their chosen charity with cadets organising and taking part in many fundraising events.



**Oxford University
Air Squadron
presenting a
cheque**

Because many people raise funds following the loss of a loved one, we have launched a tribute fund scheme. A tribute fund can be set up as a lasting tribute to someone special and in the name of that person. All donations in memory of that person can go into the fund.

The funds offer family, friends and colleagues the opportunity to help others by contributing to a living memory.

Space constrains us from mentioning all the tireless efforts that have been made to support our work. Our gratitude towards our supporters can never be overstated.

Whether they provide a small or large donation, they have valuably contributed to the development of the association.



**Grace Evans: “The CMA has
been an invaluable source of
advice, support and
encouragement when I
needed it most.**

**“When I am feeling anxious
about my condition it is
good to know that the CMA
is only a phone call away.”**

Key 2010 achievements

- ♥ With the help of supporters, created two additional cardiomyopathy support groups in the UK
- ♥ Recruited nine more people (60 in total) to our key contact network that offers one-to-one support by telephone or email
- ♥ Appointed our new cardiomyopathy support nurse Gill Rogers to the CMA team in Chesham
- ♥ 370 people attended our five information days
- ♥ Our updated booklets on dilated cardiomyopathy, hypertrophic cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy were all reprinted in partnership with the British Heart Foundation
- ♥ Continued to provide free information and support to individuals and their families affected by cardiomyopathy through our literature and website (we had over 4.5 million page views)
- ♥ Continued to provide free information to clinics and hospitals
- ♥ 100 doctors attended our annual medical conference on frontiers in cardiomyopathy diagnosis and treatment
- ♥ 50 doctors attended our second European medical seminar on Anderson Fabry disease, which has a close association with hypertrophic cardiomyopathy
- ♥ Provided 120 free places to medical trainee grades at the medical conferences to assist in their understanding of best practice in managing and treating cardiomyopathy
- ♥ Helped draft the new National Institute for Health and Clinical Excellence (NICE) guidelines on diagnosing and treating heart failure
- ♥ Continued to work with Government in our campaign for better services for cardiomyopathy patients



Daniel Jackson: “When I was first diagnosed at 13, it felt like my world had crashed down.

“I was confused and scared. I needed help and the CMA provided that help.

“They gave me lots of advice and they encouraged me to regain my independence and live my life.”

Income and expenditure

The CMA is facing challenges caused by the world economic downturn by seeking new sources of income and maintaining strict control over costs.

Even greater efforts will be required by the CMA and its supporters to continue the achievements of 2010. That year income was increased and expenditure reduced, turning a loss of over £22,000 in 2009 to a surplus of over £100,000. This has enabled an expansion in the association's services and support, including recruiting a part-time support nurse in 2010 and a second part-time support nurse at the start of 2011. However, efforts will be required to maintain these new levels of commitment.

As reported last year the association renegotiated its premises' lease with effect from March 2010. The revised terms have facilitated the adoption of a new reserves policy, which has reduced financial constraints on the trustees.

The trustees believe that thanks to the tireless support of members, supporters, friends and volunteers, 2011 will be another successful year enabling the association to at least maintain but hopefully to expand the support it provides to sufferers and their families.

Statement of the trustees

The statement of financial activities and balance sheet are a summary of the information that appears in the full accounts that have been audited. Copies can be obtained from the charity's registered office: Unit 10, Chiltern Court, Asheridge Road, Chesham, HP5 2PX. The full accounts were approved by the board of trustees on 5th March, 2011 and have been submitted to the Charity Commission.



Peter McBride FCA ATII, Chairman
Signed on behalf of the trustees



Lynn Hedgecoe: "After being given my diagnosis, I was in a severe state of shock.

"I was given a website address by a medical student. This was my introduction to the wonderful support machine called the CMA."

Income and Expenditure Account	2010	2009
	£	£
Incoming Resources		
Voluntary Income	640,262	461,294
Activities for Generating Funds	34,580	14,184
Investment Income	928	1,246
Total Incoming Resources	675,770	476,724
Resources Expended		
Cost of Generating Voluntary Income	149,135	121,075
Charitable Activities	344,164	339,055
Governance Costs	16,215	16,781
Total Resources Expended	509,514	476,911
Net Incoming/(Outgoing) Resources	166,256	(187)
Balances at 1 January, 2010	208,959	209,146
Balances at 31 December, 2010	375,215	208,959
Balance Sheet at 31 December 2010		
	2010	2009
	£	£
Fixed Assets		
Tangible Assets	7,036	9,382
Current Assets		
Debtors	71,370	59,949
Cash at Bank	359,466	206,303
	430,836	266,252
Creditors: amounts falling due within one year	62,657	66,675
Net Current Assets	368,179	199,577
Total Assets less Liabilities	375,215	208,959
Unrestricted Funds	272,740	162,882
Restricted Funds	102,475	46,077
	375,215	208,959

These summarised accounts may not contain sufficient information to allow for a full understanding of the financial affairs of the charity.

For further information the full accounts, including the auditor's report, should be consulted and can be obtained from our offices.

People we
have helped

Our details

The Cardiomyopathy Association

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Registered charity no. 803262
President: Professor William J McKenna MD FRCP
Vice-President: Dr Perry Elliott MBBS MRCP

Trustees

Chair: Mr Peter McBride
Treasurer: Mr Christopher Horwood

Board members:

Ms Amy Williams
Mr Robert McConnachie
Mr Peter Davies
Mrs Gillian McFarlane
Mrs Tina Amiss
Mr Mark Hayden
Ms Louise Baker

Patrons

Professor Sir Magdi Yacoub FRCS
Mr Terry Yorath
Mrs Gabby Logan
Mrs Stephanie Cruickshank

Chief Executive

Mr Robert Hall

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Anne-Marie Cole: “The CMA has been very supportive to both me and my family.

“It has also helped me as well as other young people talk about heart muscle disease issues more openly.”



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