

Cardiomyopathy Association

Annual Report 2007/08



Fighting Cardiomyopathy

Cardiomyopathy Association

Annual Report 2007/08

Contents

- Introduction
- Chairman's Message
- Information & Support
- Raising Awareness
- Supporting Clinical Care
- Supporting the CMA
- Income & Expenditure
- Cardiomyopathy Association

Mission

The Cardiomyopathy Association's objectives are to:

- Provide information and support to people and their families affected by cardiomyopathy
- Raise awareness amongst, and provide information and education to, health professionals.

Introduction

The Cardiomyopathy Association is a national U.K. charity, formed in 1989, that works to provide information and support to individuals and their families affected by cardiomyopathy. 'Cardiomyopathy' is a medical term meaning 'disease of the heart muscle'. It is often thought of as a 'rare' condition. It therefore receives less attention than many other conditions. This perception is wrong. Some forms of cardiomyopathy are estimated to affect 1 in 500 of the population.

The condition can have a wide range of presentations. For example, there may be no or minimal symptoms and the individual may not even know they are affected. In others the first symptom may tragically 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 is focused on identifying those at risk so that preventative measures can be taken.

People diagnosed with cardiomyopathy may face a bewildering situation where they search for answers to the many questions that arise. These can range from fears about survival, lack of knowledge about the conditions, questions about treatments, and concerns about work and finances. The Cardiomyopathy Association meets this demand by providing a reliable and trusted service to help people and families to live with cardiomyopathy. The Cardiomyopathy Association's work aims to foster a return to independence within the boundaries imposed by the individual's cardiomyopathy.

The Cardiomyopathy Association is a respected and consistent supporter of medical education. The charity's annual conferences are now an established annual event in the United Kingdom medical educational conferences calendar.



The Cardiomyopathy Association has now been working to support people and families affected by cardiomyopathy and campaigning for improved services for 19 years.

The charity continues to aim to meet the founder, Carolyn Biro's, wishes to 'light a candle rather than curse the darkness'.

"The CMA has proved to be an invaluable source of advice and encouragement when I have 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"

Grace Evans

Chairman's Message

Throughout the past year the work of the Cardiomyopathy Association (CMA) has been focused on developing and continuing our current services whilst doing more of what we do well. The CMA has continued to provide its core services to assist and support people and families affected by cardiomyopathy. The past year has seen some additional developments which I shall discuss briefly.

The charity faced the challenge of moving the offices in the early part of the year. The culmination of this work was the relocation to our present office in Chesham, Buckinghamshire. Throughout this work we managed to maintain our services to cardiomyopathy patients.

We have continued our financial support to enhance cardiomyopathy services by funding specialist nurse's posts in London, Belfast and Glasgow. In January of this year we provided funding to the Northern General Hospital in Sheffield. This two-year funding commitment enabled the appointment of our fourth cardiomyopathy nurse specialist who will support the inherited cardiovascular disease clinic led by Professor Nigel Wheeldon.

This work links to, and is a practical example of support of, the National Service Framework for Coronary Heart Disease, Chapter 8, Arrhythmia and Sudden Death. The CMA has continued to serve on the Department of Health's Implementation Board aimed at improving services for people affected by conditions such as cardiomyopathy. The CMA is also serving on the UK Cardiac Genetics Forum whose remit is to provide a report and recommendations to Government on the need for increased provision of cardiac genetic services in the future.

The provision of effective pathology services is of crucial importance when a sudden death tragically occurs.



The CMA has worked with the UK Cardiac Pathology Network to improve education of trainee cardiac pathologists. In 2007 the charity organised its first cardiac pathology conference in London and provided free places to all cardiac pathology trainee delegates. In late 2008 we hope to see the launch of the first UK Cardiac Pathology Database. This will improve understanding of the prevalence and causes of sudden death in the UK.

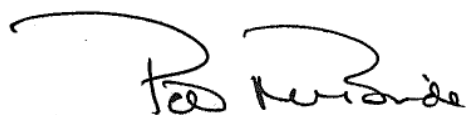
The CMA has always been a membership organisation and will continue to be so. The membership system provides a structure to ensure contacts are kept up to date with developments in cardiomyopathy care and the activities of the charity. Following an internal review it was felt the membership processes, whereby members were contacted to renew their annual membership, was not utilising the charities resources effectively. It was therefore agreed to change from an annual renewal system to a 'life membership' system. The annual subscription system has now been replaced by one where each member receives an annual letter from the CMA informing them of our work and achievements during the past year and inviting them to make a contribution to support the charity.

The CMA's national medical conference continues to be an initiative which is valued highly by health professionals. Since the first meeting was held in 2004 the conference has become established in the annual conference calendar. Following the 2007 conference an audit was performed to identify the

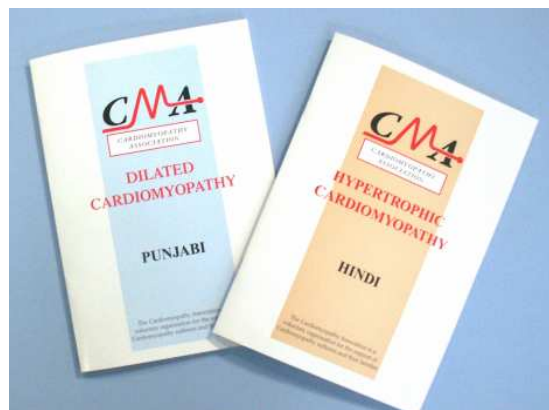
numbers of different medical staff grades who were attending. This revealed a decline in the numbers of trainee grades attending the conference. This was of concern as the education of junior grade medical staff on the care and management of the different forms of cardiomyopathy was viewed as crucial to the future improved understanding of the conditions. The reason for this downward trend was thought to be due to the financial situation in the NHS and the reduction of funding for training purposes. After consideration the CMA took the bold step of providing places at the 2008 medical conference free of charge to medical trainee grades. This was accompanied by a significant reduction in the registration fee for consultant grades. As a result of these changes over 150 delegates attended the conference.

The bearing of the significant financial burden of this initiative illustrated the charities determination that the conferences must meet the objective of improving medical education on the care of cardiomyopathy patients.

Lastly, the work of the CMA continues to rely solely on the many supporters who have donated and worked tirelessly to support us. I express our thanks to everyone who has, and continues to, provide their support.



Peter McBride
Chairman of Trustees
Cardiomyopathy Association



Translated versions of CMA information booklets



Supporters with CMA Chief Executive, Robert Hall, raising awareness at Derriford Hospital

"The trauma of this tragedy had devastated our family, not knowing what Richard died from was tearing us apart... we feel that we owe a lot for the help that the CMA has provided in the way of support and good rational information. The CMA has always given us genuine support."

Bob McConnachie

Information & Support

A diagnosis of cardiomyopathy can be frightening and confusing. There is also a great deal of misinformation and misunderstanding about the conditions. It helps to have someone who can explain what is happening, answer questions and provide support when it is needed. Our services are available to provide this help.

We provide up to date information booklets on the main types of cardiomyopathy, supplemented by information videos and CD Roms. Our philosophy is that information should be provided as a right and we make no charge to individuals or hospitals when we supply information resources. We completed a project, funded by a government grant, to translate our information booklets into Urdu, Hindi, Gujarati and Punjabi.

We provide a freephone Helpline where callers can speak to an experienced cardiac nurse. This is open every weekday on 0800 0181024. We provide a Help Desk' service on our website, (www.cardiomyopathy.org) where people can post questions and receive a response. We give information on medical issues; practical advice and emotional support where necessary. We receive many email enquiries not only from the UK but also from across the world.

We have continued to develop our website to ensure it is a vibrant, user friendly and useful source of information and support to users. In the past year the website has been redesigned with many additional pages of information added. It remains the most popular site for cardiomyopathy information on the internet and acts as an oasis of accurate and reliable information amongst many misinformed sites. The website also has a Message Board where people can register and make contact with other cardiomyopathy sufferers from across the world. The



board now has over 1,500 people registered.

We have a growing network of 'Key Contacts' and Cardiomyopathy Support Groups. This allows us to put people in touch with others affected by cardiomyopathy, both locally and nationally. We provide training for our Key Contacts to ensure they understand their role as envoys of the CMA and to reinforce the relationship with the CMA and the support they can call on.

We organise five regional information days annually in the UK. This allows people living with cardiomyopathy the opportunity to hear concise presentations on the development, care and treatment of cardiomyopathy from internationally renowned specialists. Delegates have the opportunity to ask questions and discuss their concerns. The meetings have the additional benefit of providing an often unique opportunity for people to meet other people and families affected by the condition.



CMA members attending the Key Contacts training day

"Thanks to the advice and help I received from the CMA, I am learning to live a perfectly normal life, without fear."

Christopher Honey

Raising Awareness

We work to ensure all our efforts, whether fundraising or organising regional meetings, involves increasing understanding of the cardiomyopathies and the problems faced by people and families affected by the conditions. This is done by working with our supporters to produce press releases which are of interest to the local media.

We actively monitor media reports on cardiomyopathy and challenge misinformation which may perpetuate misunderstanding about the conditions.

Our quarterly newsletter, 'CMA News', is distributed to all our 3,000 members and to many NHS cardiology clinics across the UK. Whilst providing news of the charities work it also includes stories from people affected by cardiomyopathy, emphasising the positive aspects of the persons ability to live with their condition, and informative articles from cardiology specialists.

To ensure the profile of cardiomyopathy and the Cardiomyopathy Association is kept as high as possible in the cardiology community we exhibit at the annual British Cardiovascular Society Congress. This brings us into direct contact with cardiologists of all grades.

We also ensure the CMA is represented at public orientated events including larger events such as the London Marathon exhibition and numerous smaller meetings.

'Raising awareness' can be an overused phrase. In the context of educating health professionals about cardiomyopathy our annual educational conference programme aims to not only raise awareness of cardiomyopathy but to provide education on relevant research and the development, diagnosis, and treatments for cardiomyopathy. This improves the longer-term experience

Heart muscle disease pair set up local support group



CMA members Sue Chapple & Emma Kemp raise awareness of the new Cardiomyopathy Support Group in Cornwall

of patients diagnosed with cardiomyopathy.

The 2008 national medical conference focused on Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) and once again included a live echocardiogram session to guide doctors in the diagnosis of this challenging condition. We were honoured to have Professor Jeffrey Saffitz from Boston University to deliver the second annual Carolyn Biro Lecture on the genetics of ARVC.



Professor William J. McKenna presents Professor Jeff Saffitz with a commemorative certificate for delivering the '2008 Carolyn Biro Lecture'

"Their (CMA) literature is brilliant! It's easy to read and understand. I really look forward to the newsletters – the stories have sometimes made me cry, but the advice is always good and I know I can phone up if I'm worried."

Ethel Mason

Supporting Clinical Care

The aforementioned National Service Framework Chapter on Arrhythmia and Sudden Death recognises the need for specialist services for some people diagnosed with cardiomyopathy. Whilst working as part of the development group and subsequently on the implementation process, the CMA had already initiated its own Regional Clinics Project in 2005. Many patients were seen in cardiology clinics which were structured for people suffering from coronary artery disease. This structure did not lend itself well to the needs of cardiomyopathy patients with the range of investigations and assessment of family history required.

The CMA's Regional Clinics Project provided two year funding for a specialist nurse post in Glasgow and later Belfast. These nurses' posts provided the additional time and resources to meet the needs of these patients and enhance the services in these hospitals.

In addition, the CMA has provided a telemedicine service where there is a need for a more specialised opinion on a patient's case. This allows the regional centre ready access to the specialist services at The Heart Hospital in London and reduces the need for patients to make long, expensive and often difficult journeys to London. The service also promotes learning through the regional centres direct contact with medical staff specialising in the treatment of cardiomyopathy.

To ensure there were adequate specialist resources in the London centre to provide this service the CMA provided the first two years funding for a consultant cardiology post. This funding commitment was completed in July 2008 and has provided an additional two consultant cardiologists.



Dr Perry Elliott speaking at the 2008 CMA National Medical Conference



CMA funded Cardiomyopathy Specialist Nurses, Rachel Walker (Sheffield), Joanne McCosker (Belfast), Joan Anusas (Glasgow), and Simon Waller (London)

"Our family GP knew nothing about it. Oh, I don't blame him, I've since learned that this condition is not widely known – well, I'd never heard of it before my son was diagnosed, but I do think there should be more awareness, especially amongst GPs and at the hospitals."

Diane Jackson

Supporting the CMA

We rely on your support to fund the vital services that help so many people affected by cardiomyopathy. This year so many people have helped in so many ways. We would like to thank every one for their efforts. Here are just a few of the highlights.

Once again, our supporters have been very active in the running events programme throughout the UK as well as many overseas marathon events. Our biggest annual fundraising event continues to be the London Marathon. Once again we had 40 intrepid runners taking on the 26 mile course to raise funds to help us to continue our crucial services.

We were also able to enter significant numbers in events such as the Great West Run, the London 10k Run, the London Triathlon and the Great North and Great South Runs.

We have received continued support from Zurich Cares which provided us with a £1,500 grant to allow us to purchase camera equipment to support our website and publications.

We have had a busy events programme with successful events such as a sponsored tall ships mast climb in partnership with the Jubilee Sailing Trust, a Valentine's black-tie ball in Belfast, a Lands End to John O'Groats tractor run and the 'Row 4 a Reason' event in Heybridge Basin, Essex.

The annual golf day organised in memory of Alun Jenkins once again provided significant support to our work.

The Robertson trust provided support to our Regional Clinics Project in Glasgow.

We have been honoured to continue to be the Oxford University Air Squadron's chosen charity. The squadron has held numerous events to raise funds for us.



Victoria Brown was one of 40 CMA runners who took part in the 2008 London Marathon



Staff from Sullivan Upper School in Holywood, Northern Ireland, organised a craft and coffee morning



The Hannis family organised a John O'Groats to Lands End tractor drive

"I lead more or less a normal life, occasionally however I feel alone, it's good to know the CMA is there to help me through those days."

Karen Flavell

Income & Expenditure

The Statement of Financial Activities shows a deficit of £24,748 for the year compared to a deficit of £ 55,756 for 2006. So that although there was an increase in the funds expended on the charitable activities in the year there was an improvement in the net result because of an increase in the funds generated by members.

The aim of the Trustees is to maintain the current level of specialist support and when circumstances allow increase the level of resources available to patients by the provision of a support nurse and more specialist nurses in the cardiac clinics.

The Association receives no support from any Government Department and the support from Corporations is focussed on the Medical Conferences. So that the ability of the Association to meet its current commitments and increase those is totally reliant on voluntary income raised by the membership and their supporters.

Statement of the Trustees

The Statement of Financial Activities and Balance Sheet are a summary of the information that appears in the full accounts, which have been audited. Copies can be obtained from the registered office: Unit 10, Chiltern Court, Asheridge Road, Chesham, HP5 2PX.

The full accounts were approved by the Board of Trustees on 19th September, 2008 and have been submitted to the Charity Commission.

Peter McBride FCA ATII
Chairman
Signed on behalf of the trustees
19th September 2008



The Oxford University Air Squadron welcome CMA staff and supporters to an open day at RAF Benson. The squadron have chosen the CMA as their charity for the past three years.



The Salmon brothers ran the British London 10k Run in memory of their brother Mick.

Income and Expenditure Account	2007	2006
	£	£
Incoming Resources		
Voluntary Income	436,659	377,240
Activities for Generating Funds	26,862	31,216
Investment Income	17,703	15,668
Total Incoming Resources	481,224	424,124
Resources Expended		
Cost of Generating Voluntary Income	121,152	126,385
Fundraising Costs	60,442	49,507
Charitable Activities	308,142	290,531
Governance Costs	16,236	13,457
Total Resources Expended	505,972	479,880
Net Incoming/(Outgoing) Resources	(24478)	(55756)
Balances at 1 January, 2007	338,121	393,877
Balances at 31 December,2007	313,373	338,121

Balance Sheet at 31 December 2007	2007	2006
	£	£
Fixed Assets		
Tangible Assets	12,398	14,412
Current Assets		
Debtors	54,613	32,664
Cash at Bank	287,749	370,606
	<u>342,362</u>	<u>403,270</u>
Creditors: amounts falling due within one year	<u>41,387</u>	<u>79,561</u>
Net Current Assets	300,975	323,709
Total Assets less Liabilities	<u>313,373</u>	<u>338,121</u>
Unrestricted Funds	308,217	338,121
Restricted Funds	5,156	-
	<u>313,373</u>	<u>338,121</u>

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.

The Cardiomyopathy Association

Registered Charity No. 803262

President: Professor William J. McKenna MD FRCP

Vice-President: Dr Perry Elliott MBBS MRCP

Trustees

Chair: Mr Peter McBride

Secretary: Mrs Amy Williams

Treasurer: Mr Vijay Herath

Board members:

Mr Robert McConnachie

Mr Peter Davies

Mrs Gillian McFarlane

Mrs Tina Amiss

Patrons

Professor Sir Magdi Yacoub FRCS

Mr Terry Yorath

Mrs Gabby Logan

Mrs Stephanie Cruickshank

Mr Mike Parry

Chief Executive

Mr Robert Hall

The Cardiomyopathy Association

Unit 10 Chiltern Court

Asheridge Road

Chesham

Bucks.

HP5 2PX

Tel: 01494 791224

Email: info@cardiomyopathy.org

Web: www.cardiomyopathy.org

