



**The National Heart Patient Charity**  
**Empowering cardiovascular groups to improve awareness, education, prevention and treatment options**

## **HCP Newsletter November 2008**

### **PRESIDENT'S REPORT 2007 – 2008**

The last twelve months has been another exciting period of new initiatives and consolidation of established commitments.

The National Campaign for Cardiac Rehabilitation, of which we were founding partners, has entered its second year, and the latest Audit Report shows only a modest improvement in patients entering rehabilitation programmes. The best signs are the 73% of CABG patients who entered rehabilitation during 2006-2007 against a target of 85%, but the record of only 28% of PCI patients entering programmes is very worrying. For the British Heart Foundation this is the first lobbying campaign in which they have participated and they have committed themselves with enthusiasm. The other key players in the campaign are the NHS Heart Improvement Programme and the British Association for Cardiac Rehabilitation. It was excellent news when Professor Patrick Doherty, President of BACR, was appointed National Clinical Lead for Cardiac Rehabilitation and our own clinical lead, Dr Jane Flint, was appointed National Clinical Adviser, both of these posts are under the auspices of the new quality driving programme, NHS Improvement. There will be some ambitious activities in the coming months, and we are optimistic that the campaign will achieve success.

In promoting cardiac rehabilitation in a wider context we have encouraged Thrive, a charity which promotes gardening activities to support rehabilitation and recovery for people affected by heart disease and stroke. Similarly we have continued to support Sustrans, the increasingly influential active travel promoters of public health. We were delighted at Christmas when they won the £50 million lottery grant to develop still further over 80 walking and cycling schemes across the United Kingdom. At a Ceremony in Manchester in October, Sustrans presented our President with an Award for Services to Public Health in the spheres of Walking and Cycling.

We have continued to encourage the concept and practice of Women's Heart Health. Dr Jane Flint is the British Cardiovascular Society's clinical lead on this serious issue. At our instigation, Dr Flint presented her group's strategy to the Department of Health's Cardiovascular Programme Board, where it was also recognised as a significant pillar of evidence in the wider aspect of inconsistencies in provision for women generally. Thanks to Dr Flint's efforts WHH is also enshrined in the European Heart Health Charter. We should always remember that women make up more than half of the panel of heart patients and we are duty bound to continue to support this programme.

We have also continued to work with our Arrhythmia Awareness partners, particularly the Arrhythmia Alliance and SADS (UK), and we have been keen supporters of the campaign to promote the provision of AEDs in schools.

NICE have had a huge workload of cardiovascular activities over the last twelve months. We are recognised by them as a natural source of patient representation, which is really good and reflects well on us, and they always seek our support in finding suitable candidates. Regrettably we have not always been able to meet their needs and we must improve our networking to meet these requests. We really are very grateful to our members who have volunteered to serve on NICE committees or reference groups. These are important meetings that can sometimes be very demanding.

It is interesting that Ken Timmis and David Geldard were asked by the British Cardiovascular Society to attend an All Party Committee on Medical Technology in the House of Commons in December to provide expert patient comment on drug-eluting stents. It will be recalled that NICE had been obdurate on this issue. Both were surprised on the day to learn that there was only one other witness, an eminent cardiologist. They all must have created a positive impression because soon afterwards NICE issued fresh advice to enable these types of stents to be used.

Heart Care Partnership (UK) is also a founder member of the Cardio and Vascular Coalition (CVC), now comprising 36 groups, whose purpose is to develop a national Cardio and Vascular Strategy for 2010 –2020, which will be needed to replace the CHD NSF that is expected to conclude in 2009-2010. We are very grateful to the British Heart Foundation for taking the lead in this initiative. A Green Paper is to be launched in early November, and following wide-ranging consultations a White Paper is expected to follow in the spring of 2009. For the last twelve months Ken Timmis, our President Elect, has been our representative on this Coalition. Ken has devoted much time and energy to this enterprise that really is of significance for the future cardiac health of the Nation.

During the year the Society for Cardiothoracic Surgery in Great Britain and Ireland, SCTS, approached us to ask if we would be interested in providing patient representation to their organisation. David Geldard, a veteran of a six graft coronary bypass, has been appointed for a one year period in the first instance.

We are deeply involved with the British Cardiovascular Society, the Society for Cardiothoracic Surgery and the Royal College of Physicians' Joint Speciality Committee for Cardiology in providing patient representation for the deliberations concerning the re-certification and revalidation of consultant cardiologists and consultant cardiothoracic surgeons. These groups are formally required to involve patients in these proceedings.

Our relationships with the Department of Health's Heart and Stroke Team remain robust. We are impressed by all they do and all they have done for their patients. In particular, Leonard Levy their Patient and Public Involvement Officer has been more than helpful since his appointment.

During the year it became apparent that some people were unaware of the range of activities, experience and involvement our Trustees had in their broad cardiovascular related duties representing patients and the public. We asked all our Trustees to provide a CV listing their various commitments. I think we were all amazed at the scale of these lists when they were submitted. Without exception this "Who's Who"

itemises in clear detail what a committed and experienced Trustee Board we do have.

I have received numerous comments of surprise and appreciation for the quality and experience of the Board following the publication of these lists. Our Who's Who is available on the web at [www.bcs.com/pages/about.asp?PageID=313](http://www.bcs.com/pages/about.asp?PageID=313)

During the year we have worked hard at developing our relationship with the other affiliated groups of the BCS. Ken Timmis represented us at the award evening for the British Association for Nurses in Cardiac Care, and had to make some presentations. Our Annual Meeting will be held in conjunction with the Arrhythmia Alliance's Conference. We have had more involvement with the British Congenital Cardiac Association, the British Society for Heart Failure, the Primary Care Vascular Society and the Society for Cardiological Science and Technology. Our relationships with the officers and staff of the BCS are cordial and productive, and we have been very well served by Lulu Ho our BCS Affiliates Coordinator who is hardworking, efficient and very pleasant indeed.

A business plan is being finalised, which will hopefully help to secure the necessary funding for HCP (UK) to obtain charitable status and expand its activities. A number of achievable objectives have been listed, with estimated costs. Future projects include a conference, information leaflets and training. The plan will be available for members to view on the website shortly.

This is my last report before I step down and hand on to Ken Timmis. Many, many people over the last five years have been extraordinarily kind and generous in thought and deed. Our Trustee Board members, each one without fail have been a pleasure to work with. Members of the BCS and now also the SCTS have taken an interest in our activities and welcomed us on board. The Heart Team at the D of H, the MINAP Board, the RCP/BCS Joint Speciality Committee for Cardiology, the Patient Involvement Unit at the Royal College of Physicians, the 32 Cardiac Networks across England and Wales and the newly emerging one in Northern Ireland have all made their mark. My own Greater Manchester and Cheshire Cardiac Network Board's Director Janet Ratcliffe and PPI Lead Sally Wells have been most encouraging and supportive. My wife, Ivy and my family have been very indulgent, though it was a mistake last week to wake Ivy at 4.55am and ask her if she wouldn't mind pressing my shirt!

There is still a lot to do, but I leave Heart Care Partnership (UK) in the very capable hands of Ken Timmis and his fellow Trustees, and I will still serve as and when required.

On my own behalf but more especially all those cardiac patients out there across the United Kingdom thank you all so very very much.

**David H Geldard,  
President 2004-2008  
Heart Care Partnership (UK)**

## INTRODUCING THE NEW PRESIDENT OF HCP (UK)

**Heart Care Partnership (UK)** was founded in 2003 to provide patient and carer input into the mechanism of the British Cardiovascular Society. The charity represents the needs of patients and carers and embraces under-represented groups, particularly ethnic minorities and women.

HCP (UK) is keen to hear from organisations and individuals who would like to join their membership to work together to improve the treatment of heart disease and, where possible, its prevention. The charity encompasses; national and international cardiac charities; cardiovascular and associated disease charities; regional and local cardiac support groups; cardiac and cardiovascular networks; umbrella groups; patient experts; patient representatives and patients.

In recent years Heart Care Partnership (UK) has been able to introduce patient and carer influence into The Society for Cardiothoracic Surgery in Great Britain and Ireland and in line with its parent organisation has been exploring links with Stroke groups.

**David H Geldard**, the retiring President, a former education officer in the Prison Service, is a Founding Trustee of the partnership and has served on a number of national committees during his five years in office as President as well as being a leading light and patient advocate in the Greater Manchester and Cheshire area. He is also a keen President of the Trans Pennine Cycling Club, and as part of his rehabilitation has cycled all over the world with scars to prove it. Over the years David and the cycling club have provided much needed support to the British Heart Foundation by way of sponsorship. He is also the Provincial Grand Charity Steward for the Masonic Province of East Lancashire.

David underwent a six way coronary artery bypass graft in 1995 and has a continuing desire to put something back into the system. Although he passes on the baton he remains a very active member of Heart Care Partnership (UK).



*The new President, Ken Timmis, presents a Certificate of Appreciation to the retiring President, David Geldard, in the presence of Dr. Jane Flint, the founder of Heart Care Partnership UK.*

**Ken Timmis MBE JP LCIE**, the new President, is a retired Banker, a Church Treasurer, a Boys' Brigade District Treasurer and Honorary Battalion President and is Chairman of the Wolverhampton Coronary Aftercare Support Group, which has recently gained the Queen's Award for Voluntary Service 2008, the highest accolade available to a Group of its kind and equivalent to an MBE.

The Group, under Ken's leadership, was instrumental in the planning and building of the Heart and Lung Centre at Wolverhampton and is now its sole Charity and is very active in supporting its patients and carers. Ken is Patient Representative on the Wolverhampton Cardiovascular Disease Local Implementation Team and also on the Black Country

Cardiovascular Network Board. He is now finding his feet in the national arena and is keen to point out that he represents both patients and their carers.

Ken was a banker for 35 years until he suffered a heart attack in 1990 and, like David, was determined to repay the debt he owed to the Doctors and Nurses who saved his life. He received his MBE from the Queen in the year 2000 in recognition of his services to the Coronary Care Unit at New Cross Hospital, Wolverhampton, where he was a cardiac patient.



**Trustee Board** - Through its Board of Trustees, Heart Care Partnership (UK) has direct links with Arrhythmia Alliance (A-A), Grown Up Congenital Heart Patients Association (GUCH), Little Hearts Matter (LHM), Sudden Arrhythmic Death Syndrome (SADS UK), the MINAP Board, Cardiac Rehabilitation Campaign, Cardio and Vascular Coalition (CVC), Women's Heart Health Campaign, Sustrans Action on Active Travel, as well as a number of Cardiac and Cardiovascular Networks and some local Hospitals and Support Groups.

For more information on joining HCP (UK) membership please contact:-  
Lulu Ho [hcp@bcs.com](mailto:hcp@bcs.com) Tel: 020 7692 5414  
Individuals, as well as groups, are welcome to join.

## WEBSITE

- **Forum**

We are pleased to announce that a web forum solely for the use of HCP (UK) members has been set up on the BCS website. The forum is accessible to members with email addresses (which must be the same email address saved on their record on the HCP (UK) database. To use the forum:

1. Go to [www.bcs.com](http://www.bcs.com)
2. Register (if you have not already), using your email address and choose a memorable password
3. Once you are registered, log in and go to the 'Forum' tab at the top right hand of the page.
4. Select the HCP(UK) forum. To make a query or start a discussion, select 'new topic'.
5. Type in the text box and when you have finished click on the 'Post new topic' button.

- **Contact details for member groups**

The HCP(UK) webpages in the Affiliates section of the BCS website is also being developed with one of our aims being to facilitate communication between groups with similar interests.

If you wish to include your group's website or contact details, please forward these to [hcp@bcs.com](mailto:hcp@bcs.com).

## MAJOR EVENTS

### Queen's Award for Voluntary Service - Wolverhampton Coronary Aftercare Support Group

The Wolverhampton Coronary Aftercare Support Group received the ultimate accolade bestowed upon groups of its kind: the Queen's Award for Voluntary Service.

The award, originally established by Her Majesty the Queen in celebration of her Golden Jubilee to recognise groups of individuals who are giving their time freely for the benefit of others, is a prestigious national honour, which is equivalent to the MBE. It is the highest award in the UK that can be given to groups of this kind. It sets the national benchmark for excellence in volunteering, and the activities of those awarded it have been judged to be the best of the highest standard.



*Chairman Ken Timmis (left), Vice Chairman Ken Yates (right), receiving the award from the Lord Lieutenant of the West Midlands County (centre) on behalf of Her Majesty The Queen on 21 August 2008*

The chairman of the Group, Ken Timmis, also President Elect of HCP (UK), made the following statement:

"This achievement is a tribute to all who have served the Group since its formation in 1985. Each has played a significant part, whatever the sphere of service, and all should take a personal share in the accolade. Furthermore it goes without saying that each share the gratitude of the rest and also of every patient and carer who has made use of our services over that time.

We acknowledge with gratitude the partnership of surgeons, cardiologists, doctors, nurses, physiotherapists, management and administrators of New Cross Hospital, Wolverhampton and in particular of the Heart and Lung Centre at Wolverhampton which serves the Black Country and beyond.

Having been given this award, it now remains for those of us who serve today and those who will serve in the future to live up to the award and to be worthy of our heritage."

## REPORTS FROM THE MEMBERSHIP

- **Arrhythmia Alliance (A-A)**

2008 has brought another year of commitment and dedication to Arrhythmia Alliance (A-A) and the shared goal of promoting diagnosis, effective treatment and quality of life for sufferers. Notably, the past year has seen rapid growth for A-A, with the launch of Atrial Fibrillation Association (AFA), which joins its sister charities of A-A and STARS (Syncope Trust and Reflex Anoxic Seizures), in championing quality care for cardiac arrhythmia sufferers. Furthermore, the number of affiliates and world organisation supporters has continued to rise, with over forty affiliated patient groups and the launch of A-A in Portugal.

In June, we hosted our fifth Awareness Week event, which was a great success. Local participants organised fundraising events and awareness displays across the UK. A-A held its official launch for the week at Portcullis House and celebrated World Heart Rhythm Day with supporting organisations from around the world. The Awareness Week for 2009 promises to be even more ambitious, with plans already underway.

This month we are celebrating the third Heart Rhythm Congress which is being held in Birmingham. Medical professionals, patients, patient groups and industry members will convene a four-day conference to exchange ideas and discuss the key issues affecting cardiac arrhythmia patients. Looking forward, we hope this meeting of minds will continue to grow and seek developments for those affected by affecting cardiac arrhythmias.

Despite our successes over the past twelve months, there is still much to be done. A-A will continue to set itself new challenges, seek and uncover new projects and campaigns, and pursue new avenues of research and success.

- **Black Country Cardiovascular Network**

Patients and Carers across stroke and heart disease continue partnership working to push forward with service improvement work within the Black Country Cardiovascular Network

### **Promoting Health through Football (Patient and Carer led initiative)**

Further work has been undertaken to make links with local football clubs to raise the profile of stroke. A photo shoot took place with Wolverhampton Wanderers Football Club Captain Karl Henry, through Rachel Heyhoe Flint on 30<sup>th</sup> April 2008.

### **Dudley**

Dudley Football Club – Halesowen Town (professional league team) and Two Gates Football Club (amateur league team) 5<sup>th</sup> August 2008. The occasion was a family evening event held in Homer Hill Park, Cradley to celebrate the 120th Anniversary of Two Gates Football Club. Health checks and children's competitions were part of the evening.

The medical team comprised of Wychbury Medical Practice, Dudley stroke teams, Action Heart, Lloyds Pharmacy and the Black Country Cardiovascular Network which were assisted by various volunteer patient groups Wychbury Patients' Forum, Dudley Stroke Association to carry out Health Screening: cholesterol, glucose and BMI testing with history delivering lifestyle advice and in addition offering smoking cessation, diet & nutrition and Expert Patients Programme.

### **FAST Message on Amateur Football Strip (Patient and Carer led initiative)**

FAST and 999 message to be put on amateur football strip, 3 adult and 3 youth teams to maximise publicity Black Country-wide. Chosen teams will receive a full strip for 17 players made up of 15 out-player and 2 goal keeper strips.

We have been approached by Castle High School & Visual Arts College, St James's Road, Dudley who have just started a 14 to 16 year girls football team for this season and, as it's their first year, they have no kit and are having to borrow old stuff from the boys. The school has introduced girls football as part of the new Extended Schools Programme but have no funding.

As the girls are really desperate for kit to wear we have agreed to bring the project forward and to help them immediately if we can. We intend to enlist the help of Castle High School in order to gain maximum publicity for the rest of the project.

Agreement has been given by Stroke Association to use the logo and FAST message in this way

### **Network Events**

Network Conference Cardiac today...Cardiovascular tomorrow... 4<sup>th</sup> March 2008 presentations of best practice were given from across the network for stroke and heart disease.

### **National Stroke Conference**

The conference aimed to explore the diverse care pathways and services for stroke patients and carers. The focus was to discuss and gain a greater understanding of the development needs against the ten point action plan in the national stroke strategy. The event was being organised with the University of Wolverhampton in partnership with the Black Country Cardiovascular Network for 19<sup>th</sup> and 20<sup>th</sup> June 2008, City Campus, Wolverhampton. Speakers from across our Network participated.

Network patient and carer leads attend meetings and are involved in the planning and development of services.

### **Patient, Public and User Involvement Training 2008**

The training programme has been updated with some information on stroke. Three training sessions have been delivered this year making a total of six to date. A full evaluation of the training through 2008 will be presented to the December board meeting. Meetings and presentations have taken place with the Public Affairs and Marketing Departments at the Stroke Association who are interested in looking into the training further to establish if it could be utilised as the national PPI training programme for stroke.

Carol Reilly (Network Manager) is having discussions with PCT staff to see how training can be offered to Patient Forums. Excellent feedback was given from members of a Dudley Patient Forum who attended the June and September training.

Walsall PPI department have attended the training and are looking on it favourably for staff and patients and carers. Training dates were in March, June and September around the region.

- **Patient & Carer Support Group of Action Heart, Dudley**

During the year Action Heart enjoyed the support of some 87 active volunteers (mainly ex-patients and carers), as well as that of hundreds of well-wishers and fundraisers. A 3<sup>rd</sup> calendar publication and used book sales supplemented income.

The Education Programme delivered by Action Heart began to follow a 4 weekly cycle, which new heart patients can join at any time. This change and improved administration has led to an 11% increase in attendances. The Patient and Family Support Service (PFSS) give high priority to attending these seminars to share experiences with new patients and carers.

Staff and volunteers worked together to develop a 'Buddy' system of volunteers assisting patients exercising in the rehabilitation clinic. Buddies now have an identified role, training

package and regular 6 weekly updates. The service has been expanded from an initial 3 mornings per week to include all day sessions as more buddies have been trained.

The 'Take Heart' booklet of patients' experiences was completed on schedule and introduced to the coronary care wards across the Black Country from November 2007. The PFSS has now been given funding by the Workforce Deanery to produce a similar booklet for stroke. The Stroke booklet name is being voted on and confirmed at the Network Stroke Stakeholder event on 19<sup>th</sup> November 2008.

Volunteers took part in the 2008 review of the West Midlands Cardiac Rehabilitation Standards and with staff completed development of 'patient to patient interviewing' to gain local feedback on Action Heart. They also supported through the BCCN the recent emergence of the Cardiovascular Network.

- **SADS UK (Sudden Arrhythmic Death Syndrome)**

SADS UK continues with the charity's commitment to help save lives and employs different methods to meet its aims.

The charity and members are pro-active in raising awareness of the signs and symptoms that could indicate a person is suffering from a cardiac condition and requires medical assessment and treatment. Information booklets entitled 'Heart Disease does not just affect those in the later years of life' providing information about conditions that may cause SADS (Sudden Arrhythmic Death) and the need for treatment were sent to every GP throughout the country again this year. Medical training schools, together with frontline ambulance staff and other health professionals have also been provided with these booklets, which are widely available. Feedback has shown how useful these booklets are in helping people understand the conditions of the conduction system of the heart.

The AED Campaign and EDM 395 'Cardiac Arrest in Schools' has moved forward apace, with 68 MPs to date signing in support of the Early Day Motion to bring forward a strategy to make AEDs (Automated External Defibrillators) available in all schools. SADS UK's online Downing Street petition has 596 signatures in support of this action being taken. In the meantime, the charity continues to donate AEDs to schools and organises lifesaving skills and training in use of the defibrillator. The national SADS UK Conference this year included a teacher speaking about the school's experience of working with SADS UK to put training and an AED in place on the premises. She remarked on how thorough the process was and how pleased they were to now have this equipment in place and the ability to use the AED should an emergency occur.

Doctor's surgeries and hospitals continue to benefit from event recorders and 24 hour heart monitors being donated to them. Feedback has shown the equipment enables them to quickly refer people with more serious arrhythmias and reassure people who may be experiencing symptoms but whose arrhythmia is not a cause for undue concern.

SADS UK has grown substantially over the last few years and continues to grow, enabling the charity to progress further with their aims to save lives.

## **THRIVE**

The HCP was requested by Leonard Levy, Department of Health, to help in actively promoting the above charity. It is a national charity that promotes the advantages of gardening for everyone with a disability. Its objective is to encourage more people to try gardening as part of their rehabilitation after suffering from either a stroke or cardiac disease.

Thrive published in May its pocket book "Just 30!" Gardening for hearts and minds. It is an excellent step-by-step guide of gardening activities. Since that time over 400 copies have been distributed to the following:

British Heart Foundation exhibition stand @ BCS Annual Conference.  
Cheshire & Merseyside Heart & Stroke Collaborative Patients Day.  
BHF Heart Health Editorial Meeting, London  
Countess of Chester Hospital Cardiac Rehab. Dept.  
Chester Heart Support Group Meeting.  
Community Specialist Stroke Nurses West Cheshire PCT  
Director Aeron Care Homes  
Lord Mayor Chester BHF Fundraising Dinner.

If you would like more information regarding any of the groups above, please contact us at [hcp@bcs.com](mailto:hcp@bcs.com) and we will put you in touch with the requested organisation.