



**Heart Care Partnership
(UK)**

OCTOBER 2005

NEWSLETTER

HCP UK are grateful for input to the Newsletter, please contact
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Affiliated to the British Cardiac Society

FOREWORD

David H Geldard, Chairman Heart Care Partnership UK



Welcome to another edition of our newsletter, the second one edited by Anne Jolly. What a good job Anne has done in gathering together such an interesting range of articles, and thank you all for your contributions.

Our A.G.M. was a rewarding day. Kindly hosted by the Greater Manchester and Cheshire Cardiac Network, it was a full house and many notables including Dr Nicholas Brooks, the President of the British Cardiac Society, joined us.

In the morning the joint plenary session led by Dr Roger Boyle was a breath-taking tour through developments and progress since the launch of the NSF nearly six years ago. Dr Boyle had slanted his presentation to recognise the patient and carer interest of his audience and this was the first time that the patient partnership aspect had been addressed in so much detail in a public forum; probably not the last, but a timely first for HCP (UK). There were many questions covering a range of clinical and care issues. Dr Boyle's responses provided further evidence that he is the right man in the right job. During the rest of the day Dr Boyle participated in some of the formal sessions including our own AGM meeting. He also made himself available for discussions with special interest groups, which made the long journeys made by several of our colleagues very worthwhile indeed.

The AGM was relatively straightforward. Some hiccoughs need ironing out in our constitution. All our current Trustees remain. Because of the pending year long activities to celebrate the tenth anniversary of the foundation of Little Hearts Matter, Suzie Hutchinson felt it necessary to retire as secretary. This proposal was accepted with great regret as Suzie has worked very hard as our Secretary and she has been particularly good at setting out our management objectives and development strategy. Thanks ever so much, Suzie, for all that input, but we haven't lost you as you are still a Trustee which is really good news.

Anne Jolly was elected as Secretary; good move. When Suzie broached the news of her decision, Anne was Suzie's nominee. As well as being the founder and a driving force behind SADS UK, Anne is an IT whiz and edits with some style the SADS newsletter.

Two new trustees were elected; Trudie Lobban, founder of the Arrhythmia Alliance and Paul Willgoss from GUCH Patients association have been elected to our Trustee Board and are most warmly welcome.

In the afternoon we broadened out into wider issues. Dr Jane Flint on patient oriented evidence that matters (POETS), like the magician she is, produced some exciting prototypes of patient held records – more of this later.

Carol Reilly and Ken Timmis rolled out a strategy for developing formal contacts with networks and groups across the country. Peter Diamond, with a humorous touch appropriate to the end of a hard day, spoke of developments with patients within the BHF, which, like the rest of the clinical world, is suddenly starting to take the voice of the patient and carer much more seriously.

The meeting was a great day, a great start to the weekend and a great start to my Ruby Wedding expedition.

Through our attachment to the British Cardiac Society I have been formally confirmed in the position of Cardiac Patient and Carer Network member for the Royal College of Physicians, London. This follows the trend mentioned earlier where patient representation in all aspects of clinical pathway development is becoming regarded as a prerequisite. I will be assigned to the Joint Specialty Committee for Cardiology. I will do my best.

Sincere congratulations to Dr Jane Flint who has just been appointed to an important honorary position as a Trustee of the British Heart Foundation; another sure sign that the Metropolitan Old Guard is in retreat in the face of outstanding provincial quality.

The article enclosed about the D of H Health Care Products (not HCP!) Regulatory Agency is self-explanatory. I've been in touch and said we will assist. If this is one of your special interests please give me a ring. I'm hoping to arrange a meeting before Christmas.

North West Conference on Arrhythmia and Sudden Death (NSF)

In the New Year the three NW Cardiac Networks covering Cheshire, Lancashire, Cumbria, Greater Manchester and Merseyside are to co-host the above conference and HCP (UK) have been asked to assist in drawing together representatives from the various support groups and charitable organisations who might be interested in attending.

Stand by for action.

Cardiovascular Disease Specialist Library

During the summer I was asked to provide a guest editorial for the Library- see <http://libraries.nelh.nhs.uk/cardiovascular> (September 2005)

As a result I have been asked to attend a meeting with Adrian Reyes-Hughes, Clinical Director of NHS Direct Online and Shirley Large who has responsibility for patient and public involvement, together with Professor Tom Quinn, Professor of Cardiac Nursing at Coventry and Clinical Lead for the National Library of Health's Cardiovascular Disease Specialist Library. Please speak if you are passionate about this issue.

Please make a note of the dates for next year's BCS Annual Scientific Conference, 24 -27 April 2006 in Glasgow. We are, after all HCP (**UK**). We will be communicating soon with more details.

Best wishes in all your endeavors.

Kindest regards. David H Geldard

NEW APPOINTMENTS

Arthur Kenneth Timmis MBE JP MACIE, Treasurer



I am sorry that Brian felt obliged to relinquish the post as I would have valued his expertise; however, his health must come first and I respect his decision.

As for me, I spent all my working life (35 years) in Barclays Bank before taking early retirement due to ill health, so I bring a little expertise to the job. I even did a stint in the Royal Army Pay Corps, when undergoing my two year's National Service for Queen and Country.

I have also been a Church Treasurer and Boys' Brigade Treasurer for many years and so have much experience of running charity accounts, which I am also qualified to independently examine. My first aim is to gain charitable status for the Heart Care Partnership UK, to validate the work of the charity.

Anne Jolly, Secretary



I am sorry that Suzie's workload means she can no longer continue as Secretary to Heart Care Partnership (UK); although I understand as the charity Little Hearts Matter reaches a landmark 10 years how busy Suzie, as Director of the charity, will be!

I am delighted to be appointed to the role and to work with Heart Care Partnership (UK). Their commitment to further educate, inform and empower patients and family to drive healthcare services has to be the way forward.

Trudie Lobban, Trustee



Trudie Lobban, Founder and Chief Executive of STARS (Syncope Trust and Reflex anoxic Seizures) founded the charity after her younger daughter, Francesca, was diagnosed with RAS. Since then she has personally answered tens of thousands of letters, emails and phone calls from sufferers, carers across the world affected by syncope (blackouts or transient loss of consciousness) and Reflex Anoxic Seizures. She was prompted to launch the charity at the request of her daughter's paediatric neurologist, Professor John B P Stephenson.

She has worked voluntarily together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures.

Trudie has initiated and organised many patient/carer conferences as well as organising the First International Medical Symposium for healthcare professionals in 2000, followed by subsequent meetings. In 2004 Trudie Lobban brought together a multi-discipline group of professionals from paediatricians to geriatricians, neurologists to cardiologists to form the STARS Medical Advisory Committee (STARS MAC). This is a unique international group.

Trudie has been invited to present and participate regionally, nationally and internationally at medical and patient/carer meetings including the American Autonomic Society, European Society of Cardiology Syncope Taskforce, Heart Rhythm UK/BPEG, CHD Collaborative, International Association of Patient Organisation's, the All Party Medical Group on Devices, the Labour Party Conference Health Forum, Patient Link Programme, and the European Federation Neurological Society – Transient Loss of Consciousness board.

In 2004, Trudie established a second charity, Arrhythmia Alliance (The Heart Rhythm Charity), after a successful political and awareness campaign to ask the Government to include arrhythmias into the National Service Framework for Coronary Heart Disease. The Arrhythmia Alliance brought together for the first time medical, patient and industry groups under an umbrella to work together to improve the quality of life for all those suffering with heart rhythm disorders. Prime Minister, Tony Blair, congratulated the founding of this organisation. Trudie was invited to sit on two expert groups with the Department of Health helping to write the new NSF chapter. Trudie is also a member of the New Programme Board established by the Dept of Health Heart Team to oversee the implementation of the new NSF chapter. She is a Trustee of Arrhythmia Alliance as well as Founder and CEO of STARS. In addition she has been called as a Patient Representative on a Government Health Select Committee, has been invited to sit on the council for Heart Rhythm UK (formerly British Pacing & Electrophysiology Group - BPEG) and is a Trustee for Heart Care Partnership. Trudie has been voted Charity Principal of the Year and STARS have won several awards for its efforts to help people across the world suffering from syncope and reflex anoxic seizures.

Paul Willgoss, Trustee



Born with Fallot's Tetralogy in 1971, Paul had his first open heart surgery on his 4th Birthday and due to the standards of hospital food in the 1970's has only just been able to start eating scrambled eggs again.

Paul has held a number of roles of which he is especially proud. He has served on the Management Committee of GUCH Patients Association (www.GUCH.org.uk) the national charity for adults who were born with their heart conditions. His roles have included being Vice Chair for the last 6 years, successfully representing GUCH at a number of

international conferences, participating as a mentor at Outward Bound courses for teenage GUCH's and has spoken on how to best to communicate with your cardiologist.

He was also the founding Chair of the Civil Service Disability Network and as such represented the views of the c40,000 disabled civil servants and in this role lectured at the National School for Government during the events supporting the European Year of the Disabled.

He also has post-graduate qualification in Occupational Health, a departure from his original background as an entomologist and takes it as an amusing sign of his flexibility that he may well be the only person to have both been a member of the Royal Entomological Society and the Chartered Institute of Personnel and Development.

Paul hopes this combination of personal experience; organisational knowledge and flexibility will be of use to HCP (UK) as it develops over the coming years.

THE HEART CARE PARTNERSHIP TRAINING RESOURCE – IN PATIENT EMPOWERMENT THROUGH EDUCATION AND INFORMATION

Dr Jane Flint MD FRCP is Lead Cardiologist in the Dudley Group of Hospitals and Clinical Director of The Black Country Cardiac Network. She led the Steering Group for Heart Care Partnership (UK) for the British Cardiac Society bringing together all groups supporting heart patients and their carers. Her background has involved championing the multidisciplinary subspecialties of cardiac rehabilitation and prevention, nuclear cardiology, and developing secondary care cardiology services.

As a Trustee of Heart Care Partnership (UK) Jane is committed to its development in partnership with the British Cardiac Society and all relevant bodies to see increasing patient empowerment. She has an educational background as Postgraduate Clinical Tutor for her Trust and a Consultant trainer in the West Midlands. Jane has just been re-elected to British Cardiac Society Council to further women in the cardiology workforce.

The HCP affiliated group website with the British Cardiac Society is being developed to explore education and information in the empowerment of cardiac patients and their carers. The aim of the project is to not only bring together the existing information sources of its member groups but to investigate issues of concern for all patients and carers who wish to become more involved in decisions regarding their own management and in promoting the development of services for all, allied to the public and patient involvement strategy. Several approaches have been taken through the interface between cardiac patients, carers and the multidisciplinary cardiac team to evolve a list of priority learning links for the resource. Particular needs identified are: a map of available literature, lay update of advances, ready access in range of formats/ languages, examples of hand held records/ individual action plans/ contracts, evaluation of current patient training resources (Hearty Voices, Expert Patient), learning from Discovery Interviews, Patient Choice, balance of local Trust, Network and national information, especial emphasis on lifestyle, travel insurance, palliative care, mental health and carer links, and benefits. Whilst the Cardiovascular Diseases Library must be included, there

needs to be explanation of acronyms and jargon. Communication issues have been explored in our previous British Cardiac Society sessions, proceedings to be available. A particular need for involved patients and carers, as for health professionals, is to develop confidence in questioning and presentation. Participation in the multidisciplinary team at continuing educational events and service development meetings is the best way forward for keen patient/carer representatives. These findings will inform the evolution of our Educational Resource. Please contact Heart Care Partnership (UK) if you have information you would like to share.

Dr Jane Flint

GREATER MANCHESTER AND CHESHIRE PATIENT AND PROFESSIONAL PARTNERSHIP GROUP & THE HEART CARE PARTNERSHIP UK ANNUAL GENERAL MEETING

The HCP UK Annual General Meeting was held alongside the Greater Manchester and Cheshire Patient and Professional Partnership Group (Triple PG) at The Waterside Hotel, Didsbury on the 30th September 2005. The Hotel was a tranquil environment, allowing the Patient and Public Involvement reps to meet and network at the beginning of the day before the official meeting.



HCP Chairman David Geldard was delighted to welcome people to the meeting and to introduce the keynote speaker Dr Roger Boyle, National Director of Heart Disease. David thanked him for the outstanding work that he had undertaken and achieved in the area of Heart Disease and improvements in cardiac care. His thanks extended to other key individuals who had contributed.



Dr Boyle gave a detailed account of the enormous amount of work that had been done in the area of heart disease and the Heart Team's commitment to further improve healthcare services for people living with heart conditions.

He spoke of attaining equity throughout the country & noted that with excellent treatments available more people were surviving and living with angina and heart disease.

The death rate from CHD has reduced and of special note were several campaigns which had contributed to cutting down coronary heart disease, including the ban on tobacco advertising and the advert about second hand smoke and how it affected children. The most recent advertisement with the fat coming out of the end of cigarettes had made a significant impact in stopping people smoking and Department of Health Cessation Clinics all played a part.

Dr Boyle spoke of how the input of national charities such as the British Heart Foundation, British Cardiac Society, Hearty Voices and Heart Care Partnership (UK) can help the NHS at all levels and how patient forums locally also help advise.

He also spoke of the Government consultation 'Your Health, Your Care Your Say', explaining this was biggest Government consultation to be held in the UK which asks the public, patients, service users, and staff for their views on how to improve the services in the community by the NHS and social care. The consultation can be seen at www.dh.gov.uk/Home/fs/en

He concluded that the NSF for Coronary Heart Disease had been a successful team effort, expensive but helpful; with challenges remaining. He said they must develop services with patients in mind and he liked the Chairman of the HCP UK David Geldard's saying when speaking about patients, '*Do nought about us without us*'
Anne Jolly

Heart Care Partnership UK Annual General Meeting

There was interest in the Heart Care Partnership UK Annual General Meeting held during the afternoon and Dr Roger Boyle came along to hear about the progress of the group.

After the formal proceedings Dr Jane Flint, Dudley Hospital, spoke of Patient Oriented Evidence that Matters (POEM). How important the patient perspective is and how patients should be empowered to give their views.

Jane spoke of the Patient Development portfolio she had put together, an A5 booklet which enabled people to keep a lifelong record of their care, further education about their condition, and subsequent involvement in local, network and even national patient activities. This would empower patients to take charge of their own personal and practical details, and would be easily accessible to those who may need the details.

Carol Reilly, Black Country Cardiac Network Service Improvement Lead and Ken Timmis of the Wolverhampton Aftercare Support Group spoke of the aims of Heart Care Partnership (UK) and how this could be translated into action by developing closer collaborative working with local and national patient and carer groups and organisations, cardiac networks, national cardiac initiatives and international initiatives. They spoke of how networks should look at their aims in line with those of the Heart Care Partnership UK and important it was for patients, carers and professionals to work in partnership to drive the cardiac agenda to their mutual benefit.

Peter Diamond gave an interesting and entertaining account about his involvement in the British Heart Foundation initiative, Hearty Voices. Speaking of how the Hearty Voices initiative has assisted in helping him and other patients understand organisational structures within the NHS, giving them confidence and understanding to empower them to make their voice heard in different forums.

'A LIFE IN THE WEEK'

The European Society of Cardiology from a distance



Jane Flint MD FRCP
Consultant Cardiologist and
Clinical Director Black Country
Cardiac Network
British Cardiac Society Council to
promote Women in Cardiology
Trustee Heart Care Partnership
UK

Thursday 1st September began with my lecture to patients on the Action Heart rehabilitation Seminar Programme (question on 'stress!') before meeting my new SpR trainee, a ward round, then 'email' lunch while sending my apologies for the inaugural 'Women's Breakfast' meeting in Stockholm on Monday and forwarding my UK Mentoring Network for young women in Cardiology to the American organiser.

Several circumstances prevent me attending the European Society of Cardiology (ESC) this year, not least of which include my twin boys returning to weekly boarding on Tuesday. A meeting with my Director for Foundation status in Trust and a rehabilitation clinic complete the 'day-job'. During the evening I email the mentoring network to Chairs of Higher Specialist Training Committees.

Friday 2nd saw a Cardiac Network meeting to finalise arrangements for our Network Patient and Carer Partnership meeting this year when I shall chair and provide a historical perspective to a session where three patients describe stories to demonstrate improving cardiac care in the Black Country. Carol Reilly, our Service Improvement Lead, and I discussed our PPI strategy and patients' mission statement for the Network; I told how promising our Acute Trust PPI strategy looked and my feedback (evening email!) imparting the learning from our 'Patient and Carer Open Day' in June of patient groups (not cardiac!) who still do not participate in their specialty Quality in Practice Development Teams. I had a pleasant surprise in afternoon clinic (usually finishing 6.30pm!) where my Associate Specialist had not managed to get a flight to Stockholm.

Saturday 3rd was my 'day of rest' buying new socks, trousers, school shoes, rugby boots, geometry sets....and sitting in the late summer sun with the pretence of sewing names on socks! This bit was much better than being in Stockholm!

Sunday 4th found me on the net at 0700 www.escardio.org to discover the 'Women at Heart' track through the Congress. I could present tomorrow's Journal Club on line! I spent a compelling couple of hours looking at the sessions and some abstracts.



The ability to hear some up-to-date symposia on pioneering research, genetic discoveries, and every day issues in international perspective is not available until the session records are produced, but submitted original abstracts for presentation can be viewed. Hot-line reports started to appear on the web-site during the day, and were more comfortably viewed on my lap-top than when crushed into a desperately over-crowded lecture hall!

Monday 5th I checked the ESC site to look at the newscast before going into work. There was some impressive CT angiography which I decided to show at the beginning of Journal club, emphasising that the technique is unlikely to replace contrast coronary

angiography in the immediate future. I mentioned the Hot-line CIBIS III study which provides evidence that in moderate heart failure we should introduce beta-blockade as soon as ACE inhibition. A review of the abstract run 'Women at Heart' followed, I used the new presentations to highlight the evidence which has emerged from the Euro-Heart survey, showing women to often present late, have higher mortality, and less than their fair share of investigation and intervention for coronary heart disease. It was impressive to see all countries producing this data, and also that newer studies were showing the same phenomenon in other conditions.

I included a mention in my presentation of the September editorial in HEART explaining the reduction in full-blown heart attacks, the increasing number of newly presenting patients with earlier acute coronary syndromes, giving me an opportunity to remind colleagues of our new Chest Pain Assessment Unit pathway launched on 1st September. My nuclear cardiology reporting session in the afternoon goes with a swing.

Tuesday 6th and my weekly cardiac catheter session, followed by explanations to the patients and offer of Choice for revascularisation and valve repair where needed. Yesterday and today brought the best newscast from the ESC Congress, updating of the website was limited on Sunday. A new risk assessment program based on European rather than Framingham data is being derived. Implantable loop recorders are proving their worth in identifying the need for pacing; in my experience, they are not needed that often! Drug-eluted stents are not cost-effective if used in every case of angioplasty – no surprise there!

Wednesday 6th I am buried in clinic most of the day, the ESC winds down. A younger colleague rings in to check his appraisal time with me tomorrow after his enjoyable networking while away – and that of course is one of the most important functions of the meeting! Nothing much new seems the verdict of those who did and did not attend the ESC this year. I detected a further small advance in both science and clinical trials of therapies and devices. Clinical application of some basic science is still fraught with challenges, although we tend to know what we cannot exactly control – a similar message emerging from other fields this week.

As the week drew to a close I am embroiled in Network and West Midlands meetings but have enjoyed the few days of on-line escapism – able to continue the job but be stimulated and so stimulate others!

BRITISH CARDIAC SOCIETY COUNCIL MEETING

I attended my first and perhaps only BCS Council Meeting on Friday, October 7th, as a deputy for David Geldard, who was sunning himself in some foreign clime. I have to say at the outset that I was made very welcome and thoroughly impressed with the amount of ground covered and the attention paid to detail.

There were many reports from affiliated groups and specific reports from Ireland, Scotland and Wales.

Time was given to a document entitled "A Strategy For Change". Council members will have to forgive me if I have misinterpreted anything, because at times I got lost in detail. However, the BCS plans to change its name to British Cardiovascular Society in view of its wider remit. The "vision statement" is proposed as follows:

- The BCS is dedicated to promoting the best quality of cardiovascular health for patients
- The BCS sets standards of excellence; for individuals, organisations and the care of patients with cardiovascular disease
- The BCS is committed to training and education, and supports the practice of professionals working within cardiovascular health, science and disease management
- The BCS is the primary source of professional advice and advocacy about these to government, funding bodies and industry
- The BCS will deliver its strategy in collaboration with patients, the public and partner organisations.

A new organisational structure is being devised, which will strengthen its relationship with existing bodies and the Department of Health.

I have a copy of the document if anyone wishes to study it more fully.

There was also discussion on clinical training and accreditation.

Dr Roger Boyle, National Director for Heart Disease, reported on another 4% reduction in mortality rates. Networks, he said, are developing at a good rate, though progress varies from region to region. The MINAP team is moving premises. The financial state of the NHS is now critical and the "Agenda for Change" is affecting morale. Payment by results is not working at the moment because of not working it through properly. The White Paper should be written up by Christmas.

The programme for the Annual Scientific Conference in Glasgow, April 2006, is well advanced and contains innovations. I will not bore you with the administration and financial reports save to say that they were very thorough.

I returned home very tired from a busy day. I even slept on the train!

Ken Timmis

ALL PARTY GROUP ON MEDICAL TECHNOLOGY

Heart Care Partnership (UK) was invited by Des Turner MP to the inaugural meeting of the All Party Group on Medical Technology. SADS UK had also been invited and I was pleased to attend the meeting at the House of Commons on 10th March on behalf of both charities.

The aim of the meeting was to raise awareness of the benefits of medical technologies and to highlight the problems of patient access to these. The new All Party Group will act as a forum for Parliamentarians to discuss these important issues.

It was considered that by promoting awareness and creating a greater understanding of how people can better manage their conditions they would continue to lead longer and relatively healthy lives. An increase in the provision of medical technology has been shown to be cost effective over the medium to long term. Non-invasive surgical procedures lead to higher re-admissions.

The introduction was made by Dr Des Turner, MP, in which he expressed that he was happy to be associated with this All Party Group. There were 17 founding MP's and 12 Peers. He went on to say that he would work closely with the Group and N.I.C.E. to ensure that patients (regardless of their post code in the UK) would be able to receive the same access to Medical Technology to improve their quality of life. The UK still has a shortfall in numbers of ICD's being fitted in relation to our European neighbours and the All Party Group will also address these issues in the Commons.

Trudie Lobban, the Chief Executive of STARS, (Syncope Trust And Reflex anoxic Seizures) and Trustee of the Arrhythmia Alliance endorsed these findings with the presentation she made also discussing the human story behind the technology.

Professor Andy Adam, Professor of Interventional Radiology, St Thomas' Hospital spoke of the work that he carries out and his support for the All Party Group.

Finally, the election of Officers took place of the All Party Group.

It was good to see so many people there in support of the aims of the group. I met with cardiologists, representatives from charities and industry.

Further projects suggested for the All Party Group in 2005 include:

- Learning from the patient experience of Medical Technology
- The impact of NICE on patient access to Medical Technology
- The implementation of Payment by Results and patient access to Medical Technology
- Conditions and illnesses most commonly brought to the attention of MP's by their constituents.

Anne Jolly

THE HEALTHCARE INDUSTRY TASK FORCE (HITF)

The Healthcare Industry Task Force (HITF) was set up as an initiative between government and the healthcare products industry to explore issues of common interest and identify opportunities for co-operation that would bring benefit for patients, clinicians, health and social care services and industry.

One of the recommendations made by this Task Force was to *"increase the general understanding and appreciation of the role medical devices and technology play in public health, by more effective communication to health professionals, patients and the public of the risk benefit profile and the regulatory system for devices"*. In order to progress this recommendation, a joint working party has been set up between members of the Medicines and Healthcare products Regulatory Agency and representatives from industry.

It is the strong feeling of HITF that, if they are to make any significant impact in addressing this recommendation, it is important that they seek the input of both clinical and patient organisations.

HITF have requested the assistance of Heart Care Partnership (UK) in identifying the information required and the format of that information, both in terms of supporting clinicians in a better understanding of relevant aspects of medical devices, including aspects of the regulatory system, the adverse incident reporting system and in terms of risk benefit analysis; and in communicating a wider understanding and appreciation of medical devices to patients.

They feel it is essential to hear, from a patient perspective point of view, what they would actually like to see and find help for and Heart Care Partnership (UK) are keen to input into this initiative.

David Geldard

SADS UK PATIENT SUPPORT SEMINAR

The seminar was an informative and interesting day, with crucial patient input, showing how passionate patients drive their needs forward to GP's who are in the front line when it comes to diagnosing and deciding on treatment options for patients. We were pleased that supporters and members are bringing the new NSF chapter 8 guidelines for arrhythmias and sudden cardiac death to the attention of their doctors.

Attendees were pleased to hear of the important Quality Markers in chapter 8 advocating the provision of effective support, information and treatment of people with arrhythmias, people presenting with arrhythmias and families bereaved by a sudden cardiac death, including identifying those at risk. They endorsed the guidelines supporting the appointment of an Arrhythmia Care Co-ordinator as a single point of contact for people diagnosed with a long term condition as an excellent initiative.

Attendees were pleased to hear the presentation from Anna Lane, Development Officer for Patient and Public Involvement on behalf of the NHS National Genetics Education and Development Centre, and the West Midlands Regional Clinical Genetics Unit who outlined the work of the new Centre and described how they wanted the involvement of patients to inform the development of education and training in genetics for NHS staff. In developing their learning support materials they aim to use first hand accounts of patients to demonstrate the clinical utility of genetics and to tailor them to the needs of the different health care groups.

The current experience of patients, and their views on the knowledge, skills and attitudes that health care professionals need for a positive patient experience will help focus genetics education appropriately. Therefore it is important that we to gain an understanding of what patients want their health professionals to know about genetics.

Activities where patients with genetic disorders, their families and carers, may wish to help include;

- Advising on what you expect health professionals to know about genetics,
- Recounting the usefulness (or otherwise!) of genetic information,
- Sharing experiences,
- Reviewing learning resources,
- Reviewing our website.

If you would like further information on how your views, opinions and experiences will help the Centre to develop genetics education in the NHS please contact, Anna Lane, on 0121 623 6905 or email anna.lane@bwhct.nhs.uk

Anne Jolly

FORTHCOMING EVENTS

- Walsall Patient & Carer Partnership, Friday 9th December, Barons Court Hotel, Walsall Wood, Walsall, 10am till 3.30pm

Contact: Carol Reilly, Black Country Cardiac Network Service Improvement Lead
carol.reilly@rwh-tr.nhs.uk, 07966 400143, 01902 694414

- British Cardiac Society Annual Scientific Conference, April 24-27th 2006, Glasgow – www.bcs.com
- SADS UK Support Group Meeting, April 29th 2006 Nowgen Centre, Manchester
- SADS UK Annual Conference, September 21st 2006, National Motorcycle Museum, Birmingham

Contact: Anne Jolly, SADS UK, Tel: 01277 230642, info@sadsuk.org

Formal Membership of the Heart Care Partnership UK

Dear Colleague

I am writing to you on behalf of the Heart Care Partnership's Board of Trustees inviting you to formally become a member of the Heart Care Partnership.

The Partnership was set up in 2003 in response to a request from the British Cardiac Society, to draw together users that could represent patients and carers within the process for cardiac service improvement.

The Partnership is currently developing a strategy to take the user's voice forward.

To ensure that we have up to date details of the user groups who would like to be involved in the work of the Heart Care Partnership, we have designed an application form overleaf. We would be grateful if you could complete the form and return it to Susannah Gray at the address given.

As soon as we have received your application, we will be able to start sending you details of forthcoming events like the British Cardiac Society's scientific conference in Glasgow in April 2006.

Affiliated group members are able to attend British Cardiac Society meetings at a reduced rate.

Please feel free to contact me if you have any questions about membership of the group.

Yours sincerely
Anne Jolly
Secretary

Tel: 020 7692 5413 E-mail: hcp@bcs.com

**APPLICATION TO BECOME A MEMBER OF
THE HEART CARE PARTNERSHIP
AFFILIATED TO THE BRITISH CARDIAC SOCIETY.**

**Please return to: Susannah Gray, HCP (UK), 9 Fitzroy
Square, London, W1T 5HW
Email: hcp@bcs.com**

REPRESENTATIVE NAME:

ADDRESS:

TELEPHONE NO:

EMAIL ADDRESS (*essential information*):

A BRIEF OVERVIEW OF YOUR ORGANISATION'S WORK:

MEMBERS OF THE HEART CARE PARTNERSHIP WILL RECEIVE INFORMATION ON MEETINGS, TRAINING COURSES AND EDUCATION AND INFORMATION SERVICES

Please tick this box if you are happy for your information to be given to the British Cardiac Society for use when sending information on cardiac related Issues

**MEMBERSHIP OF THE HEART CARE PARTNERSHIP IS
FREE TO USERS**