

HR-UK

Heart Rhythm UK



NEWS

Summer 2007

President's letter

The British Cardiovascular Society Annual Scientific Conference takes place next week (4-7 June 2007) at the Scottish Exhibition and Conference Centre, Glasgow. We look forward to seeing many of you at that meeting. As always, Heart Rhythm UK has a high profile. On Monday afternoon (the Specialist Registrars' training session) there will be a session on assessment of families at high risk of sudden cardiac death, with presentations highlighting the role of the pathologist, the general cardiologist, the electrophysiologist and the geneticist. On Tuesday morning we are co-hosting a session with the British Society for Heart Failure, on the topic of atrial fibrillation in heart failure. Areas to be addressed include the role for cardiac resynchronisation therapy in patients with atrial fibrillation and the role of radiofrequency ablation in patients with heart failure. On Tuesday afternoon we have a joint session with the Primary Care Cardiovascular Society on the topic of atrial fibrillation in primary care. This session will focus on the NICE guidelines for atrial fibrillation, including the indications for warfarin and/or antiplatelet therapy, and will involve discussion as to which patients with atrial fibrillation should be referred for specialist management. On Wednesday afternoon we have a session on challenges and complications in device therapy. This will be a case-based discussion session, and audience participation will be most welcome.

In addition to the above, there are abstract sessions on electrophysiology on Wednesday morning (8.30 – 10am) and Wednesday afternoon (2 – 3.30pm) and on device therapy on Thursday morning (8.30 – 10am). Other sessions of interest are lunchtime sessions on patient selection for CRT (Tuesday, 1.15 – 2.15pm) and management of cardiac arrest survivors (Wednesday, 1.15 – 2.15pm).

Heart Rhythm Congress Abstracts, 2006 and 2007

As I write this, I have just received the proofs of the 2006 Heart Rhythm Congress abstracts for publication in *Europace*. They should appear in print very soon. Thanks to the new editor of *Europace*, John Camm, and his predecessor, Richard Sutton, for working with us in ensuring that these abstracts get published.

The deadline for abstract submission for the 2007 Heart Rhythm Congress is 29th June, and we hope that researchers throughout the land will contribute to this and help us to achieve a high scientific standard at this congress. Further details can be found on the congress website, <http://www.ukheartrhythm.org.uk/html/abstracts.html>, and elsewhere in this newsletter.

Best wishes

Derek Connelly
President
HRUK

Heart Rhythm Congress 2007

The Business Committee for the forthcoming Heart Rhythm Congress (29th – 31st October) is pleased to invite you, on behalf of our colleagues, to attend the 2007 congress which, this year, is to be held at the Hilton Birmingham Metropole Hotel.

We have endeavoured to put together an exciting agenda which we hope you will thoroughly enjoy. Features include state of the art reviews of clinical practice and technologies, and interactive teaching sessions. The congress will host A-A sessions and HRUK courses in pacing, ICD and CRT, and an EP Master class, plus an advanced implantable devices course. Many presentations and discussions aimed at physiologists, doctors, nurses and patient groups will also take place during the course of the congress. [Read More](http://www.heartrhythm.org.uk/) and to register online, please go to <http://www.heartrhythm.org.uk/>

Trudie Lobban on behalf of the Business Committee

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Familial & Congenital Heart Rhythm Conditions

A renewed focus on patients, relatives and families with Familial & Congenital Heart Rhythm Conditions, (FCHRC) is needed and being considered by the DoH. These conditions have given rise to tragic deaths in young people, and such deaths led to the establishment of charities such as SADS UK, STARS, CRY and the CMA, and ultimately the Arrhythmia Alliance, an umbrella group charity which also brought medical professional groups into the fold. It was these charities, and their Alliance, which successfully lobbied Parliament and the Government, and led to a u-turn on including arrhythmias in the NSF for Heart Disease, and Chapter 8, Arrhythmias and Sudden Cardiac Death, in 2005.

However, progress with arrhythmias in England is painfully slow. There is plenty of evidence that patients with heart rhythm conditions are underserved. The current UK rates for pacemaker and ICD implantation are 50% of national (unbinding) targets, and there are still regular reports of tragic deaths in young people with conditions such as the congenital LongQT Syndrome, often misdiagnosed as epilepsy, (http://www.timesonline.co.uk/tol/life_and_style/health/child_health/article1469533.ece and http://www.dailymail.co.uk/pages/live/articles/health/womenfamily.html?in_article_id=450369&in_page_id=1774&ICO=HEALTH&ICL=TOPART)

FCHRC clinics are likely to be accredited centres which can offer electrophysiological expertise but they also need access to a network of expert pathologists so that phenotypes in SADS can be identified with much more certainty, and in a systematic way. This network of pathologist is vital because the FCHRC clinics are likely to only hear about a death long after the post-mortem has been completed and often after disposal of the body by the local pathological services. Therefore the expert pathologists will not only need to identify phenotypes (where possible) but also educate the pathological services in their region to ensure that SADS is appropriately investigated as soon as it occurs. In this way families who have suffered a bereavement can be managed effectively and sensitively, and undergo genetic testing, supported with counselling, to confirm a phenotype or carriage of an abnormal gene.

Within the FCHRC clinics, support from specialist nursing and counselling will help families coping with such a diagnosis. However, these clinics cannot possibly see every patient with a blackout in order to exclude a life-threatening substrate for an arrhythmia.

Even after creation of the FCHRC clinics there remain some difficult issues that need resolution:

Use of Implantable defibrillators in FCHRCs.

NICE ICD Guidelines are very succinct, (<http://guidance.nice.org.uk/page.aspx?o=appraisals.icds>).

Whilst guidelines for implantation outside the UK may be lengthy and exhaustive, offering several levels of strength of indication for implantation, NICE ICD Guidelines are only prescriptive about the use of the ICD in patients with coronary heart disease and SCD risk. They are vague about use in patients with

FCHRC and congenital heart disease, indicating only that a patient's needs to be perceived to be "at high risk", but not defining this for individual conditions, such as Long QT Syndrome and the Brugada Syndrome. This potentially creates a wide variation in the type of patients with FCHRC offered an ICD in England. In some areas ICD prescription could be very liberal, raising concerns about low risk patients being exposed to the risks and life-restrictions of ICD therapy, and in other areas higher-risk patients might be denied. Some more detailed analysis and guidance of the type of patient who is suitable or mandated an ICD in a variety of FCHRCs would be welcome, to ensure that a further "post-code lottery" for ICD therapy in FCHRC is not created, and also to ensure that commissioners are obliged to fund an ICD for a patient with a FCHRC deemed to be at high-risk of SCD, even if they are currently asymptomatic, e.g. patients with Type 3 Brugada Syndrome and deaths in the close family.

Data-Collection.

In England, all cardiothoracic procedural data should be uploaded to CCAD. This is preferable to collection and management of data by any single centre, because CCAD is seen as a shared-resource and a natural repository of communal data-collection and national audit. CCAD also have experience of plotting service provision against need, being involved in the National Pacemaker Survey, which has identified the wide variability of provision of heart rhythm device therapy across and within Cardiac Networks. We would argue that the current DoH working group on FCHRC should support CCAD in developing a FCHRC Module for data-collection and audit.

Feeding into FCHRC Clinics.

About 30% of patients suffering SCD/SADS have premonitory symptoms, and in many cases these will include symptoms during exercise, and/or an unexplained blackout. Whilst these cases rightly receive a high profile, the vast majority of patients with blackouts have Reflex Syncope, and their medical prognosis is largely benign. Identifying which patients have a benign prognosis, and the small but very important numbers who might have a FCHRC is vital, and this cannot be achieved in primary care. The NSF for Arrhythmias and Sudden Cardiac Death require Rapid Access Blackouts Clinics, (RABC) to be established for a number of reasons. These include:

- The high cost to acute medical services of "security" admissions of patients with blackouts in whom there is no apparent cause, and in whom emergency staff feel uncomfortable about discharge home. In Central Manchester in 2004, there were 304 such patients staying in hospital for an average of 9 days and discharged with no clear diagnosis. Many of these could go home without admission if a RABC appointment was available shortly after.
- Many patients with a blackout are assumed to have epilepsy, but most will have had convulsive syncope because syncope affects 30-50%, and epilepsy less than 1% of the population. "Convulsive" features tend to direct patients to neurology, often with long waiting times. In most cases convulsive syncope is caused by Reflex Syncope, and RABCs need to be equipped to exclude a FCHRC.
- In neurology clinics generally, less than 1:20 patients will have an ECG, but in first-seizure clinics data show that about 70% of patients are thought to have syncope. Most GPs are not experienced in the detailed analysis of the ECG. RABCs need to be hospital-based, or community-based with cardiology, falls and neurology input/governance from a hospital.
- Guidelines for epilepsy, (NICE), arrhythmias, (NSF for Arrhythmias), and Falls, (NSF for the Elderly), may establish three different settings for blackout patients to be managed in any Acute Trust, but by different specialists working in isolation. A multidisciplinary specialist-nurse lead RABC brings such patients together in one setting.
- Patients need to know what to expect, and what to seek, in terms of medical advice. One of the Founder Charities of the Arrhythmia Alliance, STARS, (www.stars.org.uk) has produced a "Blackouts Checklist", for the Alliance and its member groups, to help patients navigate the system and ensure they get good advice. There has been discussion about an "SCD Checklist", for patients and families, but this might not be appropriate for a setting of bereavement. Patients need advice if they have been found to have a FCHRC, or have, or have lost a family member with such a condition. At the right time, they need help to locate their nearest FCHRC clinic, explain what they should expect at that clinic in terms of pathological, clinical and genetic evaluation, ensure that they receive appropriate counselling, and discuss likely treatments, e.g. ICD therapy, and where information and support for this can be found. The best way of supporting such families in getting to a FCHRC clinic and getting advice needs to be determined.

We believe that FCHRC clinics will be a valuable development, drawing together arrhythmia, genetic and pathology skills, and encouraging learning and development of services. However our priorities have to be preventing FCHRC and this will only be achieved by ensuring that rapid and appropriate investigation of patients happens at a local level. Therefore a primary role of FCHRC clinics has to be reaching out and educating the regions they serve and ensuring that they do not become isolated centres of excellence. Better guidelines are needed on the application of ICD therapy in these conditions in the UK. We need centralised data-collection through CCAD for audit, and understanding of well-served and under-served areas, on a national basis, to facilitate resource allocation. Improved services are needed to feed symptomatic patients who may be at risk to FCHRC clinics, and more RABCs and better information and support for patients and families are needed urgently.

Adam Fitzpatrick
Richard Schilling

Physiologists

Guidelines for running Cardiac Rhythm Management Clinics

These are now published on the HRUK website. Thanks to Geraldine McParland from Belfast for working hard on these much needed updated guidelines. We hope that these will provide the backing for physiologists to establish appropriate staffing levels and standards in device clinics. Your feedback on these would be invaluable.

HRC and HRUK accreditation

The second Heart Rhythm Congress in October in Birmingham this year will be the venue for the updated and revised “Cambridge” foundation and advanced course for ICD’s and Pacemaker management. This course will provide the underpinning knowledge for those taking the HRUK accreditation exam later in the year. We have particularly included a section on CRT programming and troubleshooting. The exam has also been revised and last year was the first of the current format. For more details of the course content, syllabus and exam format check out the HRUK website.

What are your concerns??

We now have 4 Cardiac Physiologists on Council and are having a discussion session at the Heart Rhythm Congress on the future of Physiologists and the extension of our role in CRM. We need your input and hope that you will attend this session. We would welcome new members to HRUK and want to see more involvement from our members around the country. Come and tell us what you think and give us your input. Email us and we will get back to you. HRUK is here to represent you. Get involved.

Sue Jones on behalf of the Physiologists

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HRUK Nurses

I would like to welcome all the new nurse members to HRUK, there are now approximately 70 nurses specialising in arrhythmia management in the UK and this number continues to rise. Many of the nurses who are new in post are currently setting up new services such as arrhythmia clinics, requiring the development of protocols and guidelines. Could I take this opportunity to remind you that we have an excellent clinical network for sharing such information within the HRUK nurse group. Please contact me if you need any further information with regards to this.

Education

Congratulations to Clair Malone and Angela Hall, Specialist Arrhythmia Nurses from James Cook University Hospital, Middlesbrough who were the first two nurses to pass the HRUK exam. Clair and Angela successfully completed the core and specialist electrophysiology sections of the exam. Well done to both of you.

We are hoping that more nurses will sit the exam in the future and that it will become a national standard for all arrhythmia nurses to work towards. The role of the specialist arrhythmia nurse does vary from centre to centre dependent on local service needs and we are keen to ensure that the content of the exam reflects this. Therefore we are planning to add another optional section to the exam this year based around general arrhythmia management. This will provide a means of accreditation for those of you who are not specialising in just one aspect of arrhythmia management such as electrophysiology or device management.

A number of HRUK nurse members have been involved with the development of a masters level arrhythmia management module supported by the British Heart Foundation (BHF) and endorsed by HRUK and The Arrhythmia Alliance. Teesside University, Middlesbrough and South Bank University, London have been working with BHF and a number of health care professionals specialising in arrhythmia management to develop this module. Teesside University is currently running the first cohort of the module and South Bank University plan to start theirs in July of this year.

This aim of the module is to enable health care professionals to achieve advanced knowledge and skills to care holistically and competently for patients with arrhythmias and those at risk of developing arrhythmias. It incorporates all aspects of arrhythmia patient assessment, investigation and treatment. It is delivered over 8 days held in two blocks one 5 day block followed by one 3 day block five months later which allows time for consolidation of knowledge and application to practice. Assessment for this award is in two summative parts. Part one is a multi station OSCE, the student is expected to undertake the OSCE at the end of the second 3 day block of study. Part two is an unseen timed exam which will also be undertaken at the end of the 3 day block study.

The first 5 day block of the Teesside module held during the first week in May has evaluated fantastically well. Twenty two nurses and physiologists accessed the module with many more showing interest in joining the next group. Interest has also been expressed from general practitioners, and general practitioners with specialist interests.

The Module has been very well supported by a number of health care professionals and members of industry and I would like to thank everyone who has contributed.

National Awards

The Cardiac Nursing Awards organised by The British Journal of Cardiac Nursing in association with The British Association for Nursing in Cardiac Care were held on April 20th 2007 at the Café Royal in London. It was fantastic to see that a category for 'Excellence or innovation in arrhythmia care' was included within the 11 categories. Eileen Firman from the Heart Hospital, London and myself were delighted to be chosen as the two finalists for this category. The profile of arrhythmia management was raised even further by Win Bell, Specialist Arrhythmia Nurse from Manchester Heart Hospital, who was

presented with a 'Lifetime Achievement' award in recognition of her valuable contribution to the development of arrhythmia services.

Heart Rhythm Congress 2007

The 2nd Heart Rhythm Congress meeting is due to be held on the 29th – 31st October at the Hilton Birmingham Metropole Hotel. The nurses sessions are planned for the morning of Tuesday 30th October. As a reflection of the move towards generic working we have worked with the physiologists to form an allied professionals section which will be held in the afternoon of the same day. We have put an exciting agenda together with some excellent speakers and I look forward to seeing you all there. The HRUK nurses annual meeting will be held during the congress meeting, I will confirm the meeting room and time with you as soon as possible.

Jayne Mudd
Nurse Representative HRUK Council

Dates for your Diary

Monday 4th – Thursday 7th June 2007

British Cardiovascular Society Annual Scientific Conference & Exhibition.
Scottish Exhibition & Conference Centre (SECC), Glasgow. Further details from
http://www.bcs.com/pages/scientific_conference.asp

Monday 11th – Sunday 17th June 2007

Arrhythmia Alliance Awareness week.
For further information and to register if you wish to receive promotional material for an event or exhibition stand you may be hosting during the week, please go to <http://www.aaaw.org.uk/>

Wednesday 13th June 2007

World Heart Rhythm Day.
For further information, please go to <http://www.aaaw.org.uk/WHRAD/index.html>

Thursday 12th July 2007

Arrhythmia Nurses' Study Day, Oxford Hotel, Wolvercote Roundabout, Oxford, 9.30 am – 4.30 pm.
A meeting for new BHF Nurses and existing Arrhythmia Nurses. Speakers to include: Dr Yaver Bashir, Dr Dave Tomlinson, Edward Blair, Trudie Lobban, Nicola Meldrum, Jayne Mudd

Topics to include: Management of atrial fibrillation, Anti-arrhythmic drugs, Genetic screening for sudden cardiac death, Role and developments of the Arrhythmia Alliance, An introduction to catheter ablation for AF, Cardiac resynchronization therapy, Case presentations of arrhythmia patients, Follow-up of ICD patients

Please contact Laura Newton to register your interest.
Email: aa@stars.org.uk Telephone: 01789 451831

Monday 24th – September 2007

The Royal College of Physicians is organising a one-day conference entitled 'Management of breathlessness in advanced disease' at the college.
For more information contact: **Conference coordinator**, Tel: 020 7935 1174 ext. 252,
email: conferences@rcplondon.ac.uk
<http://www.rcplondon.ac.uk/event/details.aspx?e=676>

Monday 29th – Wednesday 31st October 2007

Heart Rhythm Congress 2007, Hilton Birmingham Metropole.
For further information and to register, please go to <http://www.heartrhythm.org.uk/>

Welcome to New Members

We are delighted to welcome the following new and returning Members, who have joined HRUK/BPEG in recent months.

Moira Allison
Nadine Alix Balicki
Emma Coleman
Karen Collins
Michelle Colton
Bridget Humphreys
Nicky Margerison
David Moorhead

Dr Calum Redpath
Margaret Rodaway
Catherine Shannon
Shelley Steed
Ross Ward
Jamie Waterall
Sarah Williamson

HRUK Contact details

If you wish to contact HRUK/BPEG on any matter please write, email or telephone:

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