Arrhythmia Alliance
The Heart Rhythm Charity

Highlighting the Work of Arrhythmia Alliance 2008-09

Arrhythmia Alliance provides information, education and support to patients and medical professionals. •

• International, National & Regional Conferences • Awareness & Advocacy Campaigns

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An Introduction from Professor A. John Camm President Executive Committee

Arrhythmia Alliance (A-A) successfully manifested itself when in 2004, the charity helped to push through one of the most fundamental policy issues to affect cardiology and cardiology patients. This was the extension of the National Service Framework (NSF) for Coronary Heart Disease, to include a chapter on Arrhythmias and Sudden Cardiac Death.

Years later A-A continues to strive for access to early diagnosis, appropriate treatment, on going patient support and improved quality of life for those affected by cardiac arrhythmias. The unique coalition of charities, organisations, patients, carers, patient groups, medical and health care groups and allied professionals provides an integral support and information network for those affected by arrhythmias and it is a springboard for medical discussion and health service improvement. The coalition represents thousands of individual members including patients, doctors, nurses, physiologists, cardiologists and patient carers.

Building on the success of previous events and initiatives, Arrhythmia Alliance has added to its milestone achievements over the past year. A-A's sister charity, Atrial Fibrillation Association (AFA) has launched a new database for its medical members and issued a new AF Toolkit alongside a range of new publications for individual medical professionals and centres.

In October 2008, Arrhythmia Alliance and HRUK held the third annual Heart Rhythm Congress (HRC), with over 2600 delegates. A unique forum of patients, medical professionals and industry representatives, the congress enabled groups and individuals to meet and exchange information and ideas. At HRC 2009, there are plans for a Pan-European roundtable meeting of representatives of existing and prospective member countries to discuss best practice and future collaboration.

The past year has seen the growing international organisation of Arrhythmia Alliance with the launch of A-A Japan and A-A Sweden due to take place during World Heart Rhythm Week 8th – 14th June. A-A has responded to the increasing international demand and growing awareness of cardiac arrhythmias, by establishing World Heart Rhythm Week (WHRW).

In 2008, Arrhythmia Awareness Week (AAAW) reviewed the successful implementation of the NSF chapter on Arrhythmias and Sudden Cardiac Death. A-A received the support of over 200 MPs, illustrating the continued and strengthening support from government. Over 750 events were held across the UK with hundreds more throughout the world.

In the coming year, I shall look forward to the continued national and international growth and success of the charity in raising awareness of cardiac arrhythmias.

Professor A. John Camm
President Arrhythmia Alliance Executive Committee

30% of adults and 39% of children in the UK are misdiagnosed with epilepsy when in fact they have a heart rhythm disorder.

Cardiac arrhythmias are one of the leading causes of death in the world.

1 in 4 stroke patients are admitted to hospital in Atrial Fibrillation (AF) in the UK.

In the UK, almost 700,000 people suffer from Atrial Fibrillation (AF) – the incidence of which is rising by 5% annually.

120,000 people experience unexplained loss of consciousness each year in the UK.

There are 100,000 sudden cardiac deaths each year in the UK. This is the equivalent of a jumbo jet crashing every day.

Sudden cardiac arrest leads to more deaths worldwide than breast cancer, lung cancer and AIDS combined.

There are more than 2 million people (diagnosed and undiagnosed) with an arrhythmia in the UK.

Executive Committee

President

Trustees

Patrons

What is an arrhythmia?

A cardiac arrhythmia is the medical term for an irregular heart beat or abnormal heart rhythm. There are essentially two main things that can go wrong with the heart: the plumbing and the electrics. Many of us are keenly aware of the heart's plumbing problems, yet we remain largely unaware of the electrical faults which cause an arrhythmia. Arrhythmias can occur in the upper chambers of the heart, (atria), or in the lower chambers of the heart, (ventricles). Arrhythmias may occur at any age. Some are barely perceptible, whereas others can be more dramatic and can even lead to sudden cardiac death.

Two basic types of arrhythmia, with variations of each:

Bradycardia -	a heart rate that is too slow, usually less than 60 beats per minute.
Tachycardia -	a heart rate that is too fast, usually more than 100 beats per minute.

CAUSES:

- The heart's natural pacemaker (the SA node) develops an abnormal rhythm.
- The normal conduction pathway is interrupted or blocked.
- Electrical impulses originate from another part of the heart.

SYMPTOMS:

Some symptoms are barely perceptible; while others are so dramatic that they can cause cardiovascular collapse and death -

- Premature beats, palpitations or skipped beats;
- Dizziness;
- Fatigue;
- Light-headedness;
- Fainting or near fainting.

DIAGNOSIS AND MISDIAGNOSIS:

So why might misdiagnosis be so prevalent? Syncope (or fainting) in many patients is indicative of a potentially fatal heart rhythm irregularity. A lack of awareness of syncope in the medical community means that syncope often goes unrecognised or, worse, misdiagnosed as epilepsy.

Correct diagnosis is obtained in a number of ways. An Electrocardiogram (ECG or EKG) diagnoses arrhythmias by recording the timing of atrial and ventricular contractions. A Holter Monitor is a device that can record 24 hours of ECG signals and an event monitor can last up to about 30 days. For arrhythmias that occur less frequently, an Implantable Loop Recorder can be implanted under the skin of the chest to record heart activity for more than a year. A simple exercise test on a treadmill may be used in order to provoke an arrhythmia, whereas a tilt-table test might be used to induce fainting. An Electrophysiological study (EP study) can also be done to manually stimulate the heart to induce fast heart rhythms, which may be an indication that the patient is prone to dangerous arrhythmias.

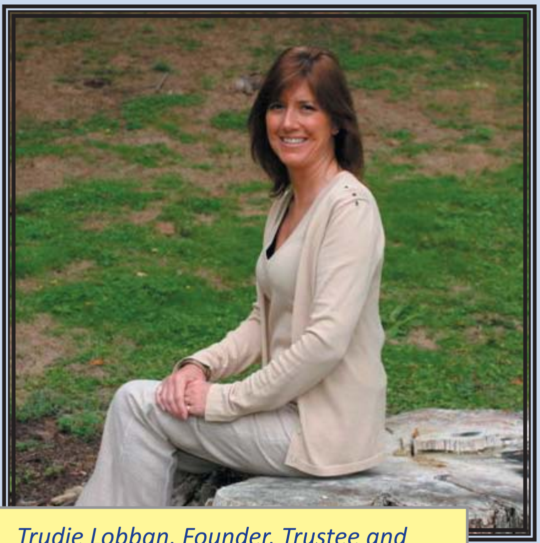
TREATMENT:

Bradycardic conditions can be treated with medications that help improve the transmission of impulses through the conduction system. A more common treatment for bradycardia is with a cardiac pacemaker; a tiny implantable device that is placed just beneath the skin in the upper chest. Small wires (leads) connect the device to the inside of the heart where it provides support if the heart beats too slowly on its own.

For the more dangerous tachycardias – such as ventricular tachycardia (150-250bpm) or the potentially lethal ventricular fibrillation (250+bpm) – anti-arrhythmic drugs and other medications are used, but recent clinical trials have shown that a small device called an Implantable Cardioverter Defibrillator (ICD) is the most effective treatment for these arrhythmias. These are slightly larger than a pacemaker, but implanted in much the same way. An ICD monitors the heart and provides electrical pulses or shocks to slow down a heart that begins to race out of control.

A message from Trudie Lobban Founder and Trustee

Another year of excellence underlines the commitment and dedication of Arrhythmia Alliance (A-A), since the charity was founded in 2003. This reinforces the shared goal of putting arrhythmia patients first when it comes to early diagnosis, correct treatment and quality of life.



Trudie Lobban, Founder, Trustee and Chief Executive of Arrhythmia Alliance.

In 1993, when I set up the patient support group STARS (Syncope Trust And Reflex anoxic Seizures www.stars.org.uk) as a direct result of my own experiences in the care and diagnosis of my daughter Francesca's heart rhythm disorder, I could never have envisaged where we are today. Both in terms of the scope of the further organisations that have born out of our initial set up and the incredible work these organisations have undertaken. It has been an amazing journey yet there is so much more work to be done.

Thank you to all those who have supported the growth of Arrhythmia Alliance since the charity's inception. The next 12 months will prove equally challenging for A-A and that reflects the high standard of achievement The Heart Rhythm Charity sets itself. Although some goals, like Awareness Week are a recognised calendar date, the growth in awareness across the world will probably impact A-A's story as a whole – it might just lead to a truly international Arrhythmia Alliance one day.

The table below shows the rising number of hits to our website as well as the increasing number of calls and emails that we have received in the past year. A-A responds to enquiries and requests for information from all over the world, thus highlighting the growing need for the services that we provide and the significance of a strong international coalition.

Source	2007 Hits	2008 Hits
Website	**4.85 M**	**9.0 M**
Telephone	**23,500**	**24,322**
E-Mails	**205,064**	**415,340**

Arrhythmia Alliance (A-A), The Heart Rhythm Charity is a coalition of patients, carers, patient groups, independent medical and healthcare professionals, medical groups, charitable organisations and allied professionals. The work of A-A is endorsed by the Department of Health.

Whilst maintaining their independence, members work together under the A-A umbrella to promote:

- Timely and effective diagnosis.
- Access to appropriate treatment for cardiac arrhythmias.
- Ongoing patient support.
- Improved quality of life for those affected.

Heart Rhythm Congress (HRC)

In October 2008, Arrhythmia Alliance and HRUK held the third annual Heart Rhythm Congress at The Hilton Birmingham Metropole Hotel – the largest event of its kind in the UK.

Over 2,600 delegates attended HRC, an event which brought together all those with an interest in arrhythmias including medical and allied professionals, cardiac networks, patient groups and industry.

The Patients' Day provided an unprecedented opportunity for patients and carers to meet and liaise directly with medical professionals, to pose relevant questions and gain a greater insight into developing technologies and techniques regarding their condition; information which is not otherwise readily available or accessible.

2008

Arrhythmia Alliance Regional Meetings

In 2008 Arrhythmia Alliance hosted eight successful regional meetings across the UK and received excellent feedback. The meetings were held to assist GPs, arrhythmia nurses, cardiologists, commissioners and other cardiac community staff in optimising local patient care for cardiac arrhythmia. All the attending delegates were positive about the contents of the meetings they had attended. The responses indicated that the meetings had allowed them the chance to network with a range of professionals, support groups, carers and patients. Delegates enjoyed the diversity of topics and the opportunity to hear experts in the field.

Arrhythmia Awareness Week (AAAW) 2008

The fifth AAAW in 2008 drew global support with over 750 events held across the UK and hundreds more throughout the world.

The general aims of AAAW are to raise awareness of cardiac arrhythmias and sudden cardiac death, but also to monitor the progress of policy implementation. The general theme for 2008 was: '*Access to Arrhythmia Services – has anything changed?*' This allowed for reflection on the three years since the publication of Chapter 8 (Arrhythmias and Sudden Cardiac Death) in the National Service Framework for Coronary Heart Disease.

A range of key activities took place during the week, including a Parliamentary Reception at the House of Commons, London and clinical meeting at the Scottish Parliament.

Patients, carers, affiliates, and medical professionals across the UK gathered in support of Arrhythmia Awareness Week at Portcullis House, the 'hub' of parliamentary activity in London. The event not only marked the start of the awareness week, but also the fifth anniversary of Arrhythmia Alliance – so was a cause for celebration of the achievements of the coalition since 2003.

If your heart is racing but you're not.

Call us.

For a free* ECG check up in the heart of the city call London Bridge Hospital 08444 121912

Up to 1 million people could be affected by arrhythmia and while troublesome most are not life threatening and many can be easily treated. London Bridge Hospital and 31 Old Broad Street Outpatients have joined together in support of Arrhythmia Awareness Week and World Heart Rhythm Day to offer you this free test.

CITY HEART WEEK

Supported by LONDON BRIDGE HOSPITAL

June 9th - 13th 2008

Above: (City Heart Week poster) – In 2008, City Heart Week saw over 200 city workers at their pulse check clinics.

A welcome address from host, John Maples MP and speeches from Roger Boyle, head of the heart team at the Department of Health, Professor A. John Camm, President of the Arrhythmia Alliance Executive Committee and Trudie Lobban, Founder and Trustee of Arrhythmia Alliance, reflected these achievements and provided updates from the field. However, it was arrhythmia patient, Thomas Hall's words that drove the message home – we must not be complacent, there is an awful lot more work to be done to improve the patient experience.

In Scotland, Nanette Milne MSP hosted a reception in the very modern Parliament building to mark Arrhythmia Awareness Week. Nicola Sturgeon, Cabinet Secretary for Health and Wellbeing addressed an audience of patients, carers, industry members and medical professionals, highlighting the commitment of the Scottish Government to working towards greater awareness, timely diagnosis, improved services and patient support.

Below: Ilmington School hosted a balloon launch to raise funds for AAAW.

The reception was followed by a clinical meeting, where participants learnt about various arrhythmic conditions and discussed services in the country. It is hoped that this meeting will be the first of many organised by Arrhythmia Alliance and that future meetings will present an opportunity for discussion of best practice and become a forum for not only education but innovation.

A-A also worked with City Heart Week in London to hold 'Feel Your Pulse' clinics. Staff at London Bridge Hospital offered free pulse checks and ECGs to members of the public, specifically targeting London city workers.

At local level, community events such as barbeques and balloon launches and a 'Patient Day' allowed patients and healthcare professionals to come together to discuss their condition and current treatment. One young man even found himself on the shores of France having rowed across the English Channel to raise thousands of pounds because his girlfriend is an arrhythmia sufferer.

Events held across the UK...

- STARS balloon launches in 11 locations, including;
  - Poole
  - Northern Ireland
  - Warwickshire
  - Scotland
  - Kent
  - Bristol
- SADS UK balloon launch and candle lighting.
- Royal Brompton Hospital Arrhythmia Awareness Patient Event.
- Lincolnshire Heart Failure Arrhythmia Meeting.
- Trent Cardiac Network/ Derbyshire County PCT GP Study Day.
- Europe AF Conference and AFA Patients' Day.
- South London Cardiac & Stroke Network Clinical Meeting.
- AF audit, Queensway Day Hospital , Yeovil.
- Blood Pressure and Pulse Checks – Motherwell and Oatridge College, Scotland.
- Sponsored 10KM run in Scotland.
- Sponsored 10KM walk in Scotland.
- Sponsored English Channel Single Skull Row.
- Charity Dinner and Dance in aid of STARS.
- Awareness stand at the Brackley Carnival.

Left: Arrhythmia Nurses held a display during Arrhythmia Awareness Week
Below: Bristol supporters held an awareness display.

St Helier Hospital held a stand during Arrhythmia Awareness Week.

Below: Arrhythmia Awareness Week has achieved continued political recognition through the support of the Early Day Motion in 2008.

EDM 1677 ARRHYTHMIA AWARENESS WEEK 2008

Keetch, Paul 20 signatures

Breed, Colin	*Campbell, Gregory*	*Corbyn, Jeremy*
Cryer, Ann	*Drew, David*	*Durkan, Mark*
George, Andrew	*Holmes, Paul*	*Hopkins, Kelvin*
Hoyle, Lindsay	*Jones, Lynne*	*Key, Robert*
Moss, Malcolm	*Murphy, Denis*	*Russell, Bob*
Scott, Lee	*Spink, Bob*	*Stunell, Andrew*
Wareing, Robert N	*Winterton, Ann*	

That this House welcomes Arrhythmia Awareness Week 2008 from 9th to 15th June; notes that cardiac arrhythmia claims the lives of 100,000 people each year, making it the UK's single biggest killer, and that it is also an independent risk factor for strokes; congratulates organisations, such as Arrhythmia Alliance, which are working to raise awareness of this cardiac condition which affects one million people in the UK; supports the placement of medical devices such as automated external defibrillators in the community to save lives; and calls upon the Government to continue to support the implementation of Chapter 8 (Arrhythmias and Sudden Cardiac Death) of the National Service Framework for Coronary Heart Disease.

Arrhythmia Awareness Week

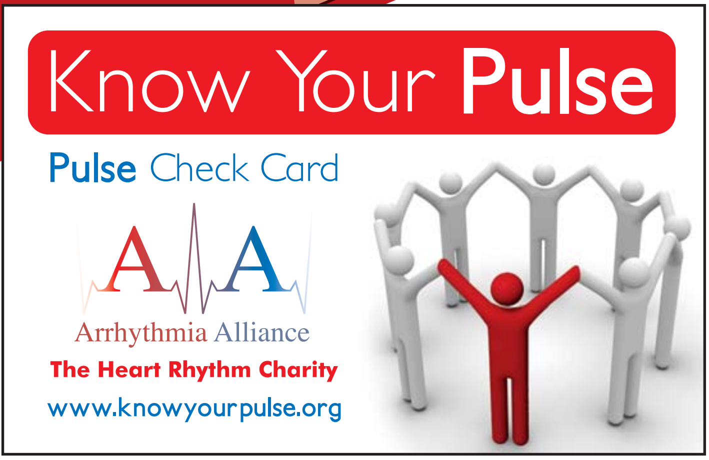
8th – 14th June 2009: 'Know Your **Pulse**'

www.knowyourpulse.org

A global alliance of patients, carers, patient groups, community groups, medical and healthcare professionals, government and allied professionals will come together to raise awareness of cardiac arrhythmias from 8th - 14th June 2009, as part of the sixth annual Arrhythmia Awareness Week (AAAW), held in conjunction with World Heart Rhythm Week.

AAAW promotes effective diagnosis, treatment and quality of life for those affected by cardiac arrhythmias by raising awareness of the condition. Arrhythmias, where the heart beats too quickly, too slowly or irregularly, affect the heart's ability to pump blood around the body, which may cause individuals to experience palpitations, light-headedness, and even loss of consciousness. This can be very unpleasant and scary for those affected.

2009


Know Your **Pulse**

Pulse Check Card

Arrhythmia Alliance

The Heart Rhythm Charity

www.knowyourpulse.org

In the UK, there are currently more than 2 million people with an arrhythmia, including 1.2 million people with Atrial Fibrillation (diagnosed and undiagnosed). Sadly, cardiac arrhythmias are one of the world's biggest killers, more so than lung cancer, breast cancer and AIDS combined.

To continue the success of the arrhythmia awareness week, planning for AAAW 2009 is well underway. A Parliamentary Reception in the House of Commons on the 8th June will launch the week, followed by various activities co-ordinated by Arrhythmia Alliance, STARS, AFA, City Heart Week, further charities, world organisations, members and affiliates, communities and individual supporters.

'Know Your Pulse' will be the overriding theme of the week. The pulse is one of the most effective means to identify potential cardiac arrhythmias. AAAW will encourage routine pulse checks with the aim that they become as common as blood pressure and weight checks. Working with AFA and City Heart Week, Arrhythmia Alliance will be running 'Pulse Check' sessions, led by medical professionals, in public places across the UK, such as shopping centres, libraries, leisure centres, GP surgeries and schools. Supporting awareness events and activities held by local, national and international groups and organisations will complement these Pulse Check sessions by promoting understanding of this simple health check procedure at all levels.

City Heart Week is again due to coincide with AAAW. Doctors, nurses and cardiac physiologists will be talking to city workers and showing them how to monitor their pulse and spot the signs of an irregular heartbeat or arrhythmia – a silent disease which for many is easily curable but for others, if left untreated, can mean sudden death or debilitating brain injury from a stroke. Dr Richard Schilling, of London Bridge and St Bartholomew's Hospitals, who is one of the country's leading experts in arrhythmia, said city workers were working at a time of unprecedented stress. "We have to make people more aware of the dangers of arrhythmia. City Heart Week is about training people to identify whether they are at risk by monitoring their own pulse. It's simple and it could be a life saver," he said.

Arrhythmia Alliance will encourage members of the public to get involved in educational and fundraising activities, such as holding awareness displays, cake sales and coffee mornings, events, and distributing information to promote awareness of cardiac arrhythmias. AAAW 2009 also aims to raise awareness of sudden cardiac arrest (SCA). In the UK, 250 people a day die from SCA – the equivalent of a jumbo jet crashing daily.

Sudden cardiac arrest can strike anyone, anytime, anywhere and Cardiopulmonary Resuscitation (CPR) with an Automated External Defibrillator (AED) is the only way to re-establish the heart's normal rhythm. School events such as 'Adopt a School' and non-uniform days, will promote fundraising and awareness at grassroots level.

Further individual and community led activity is expected to add to the success of AAAW in 2009.

KNOW YOUR PULSE

Arrhythmia Alliance
The Heart Rhythm Charity
www.heartrhythmcharity.org.uk

Did You Know . . .
- ♥ Your pulse is a sign of your heartbeat
- ♥ A fast heart rhythm could indicate a risk of Sudden Cardiac Arrest (SCA)
- ♥ Sudden Cardiac Arrest (SCA) can strike at any age and without warning
- ♥ SCA kills 250 people each day

ARRHYTHMIA AWARENESS WEEK 8th - 14th JUNE 2009
www.aaaw.org.uk
joannag@stars.org.uk / 01789 451 823

Did You Know . . .
- ♥ When someone is in Sudden Cardiac Arrest they have no pulse
- ♥ Automatic External Defibrillators (AEDs) together with cardiopulmonary resuscitation (CPR) is the only way to re-establish the hearts normal rhythm

. . . Using an AED is as simple as. . . .

RESTART THE HEART

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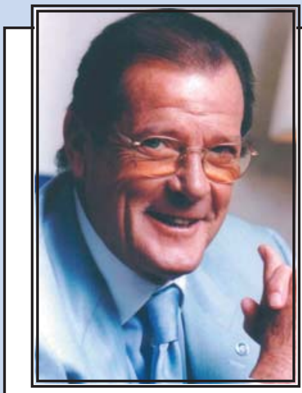
Registered Charity No. 1107496 ©2009

endorsed by DH Department of Health



I am pleased to send my support for Arrhythmia Awareness Week 2009. The contribution this event makes towards raising awareness of cardiac arrhythmias extends nationally and internationally. I congratulate Arrhythmia Alliance on their success over the past years and look forward to all they will achieve in the future.

Roger Moore

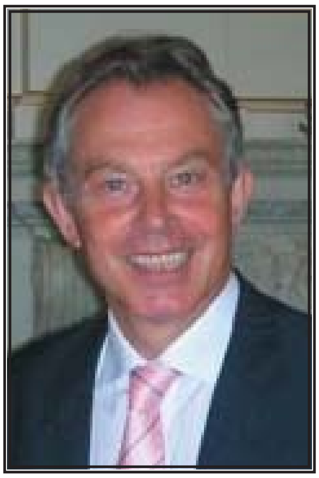
Sir Roger Moore KBE, Patron of STARS

The cut and thrust of politics can certainly make the heart beat faster. But in my case it wasn't a tough political decision, I had a potentially dangerous heart rhythm problem which fortunately was picked up early and treated effectively.

The 'Know your Pulse' campaign provides a tremendous way for everyone to keep track of their own body and identify the early warning signs of a racing or irregular heart rate. I urge everyone to download the how-to guide from www.knowyourpulse.org

Tony Blair

Rt. Hon Tony Blair, Patron of Arrhythmia Alliance



Tributes to Arrhythmia Alliance

The Department of Health enjoys a very special relationship with Arrhythmia Alliance. Not only was A-A instrumental in the conception and development of a new chapter of the CHD NSF, to cover arrhythmias and sudden cardiac death, no other organisation has done as much to drive the development of these services.

Arrhythmia Alliance works on a number of fronts: it raises awareness of arrhythmias and 'educates' patients on what they should expect from the service, what questions they should ask their GPs and other clinicians and, importantly, what role they themselves should play in managing their condition; it provides urgent advice and support to those that need it; it brings together clinicians, academics, industry and government to discuss key issues.

If ever there were a model for how a patient organisation should operate, the model that Trudie Lobban and her colleagues have developed is it – and A-A has been recognised on a number of occasions for the enormous contribution it makes, and the leadership and professionalism with which it conducts its business.

We wish Arrhythmia Alliance all the very best for the future.

Mike Yates
Team Leader for Heart Services
Department of Health

DH Department of Health

It gives me great pleasure in Arrhythmia Awareness Week 2009 to renew my support for the Arrhythmia Alliance. Thousands of people with heart rhythm problems have benefited from their work and support over the last year.

The work of the Alliance has helped also to develop national clinical policy as well as the implementation of Chapter Eight of the National Service Framework.

Professor Roger Boyle CBE
National Director for
Heart Disease and Stroke

DH Department of Health

World Heart Rhythm Week 8th - 14th June 2009

The Belgian Heart Rhythm Association (BeHRA) encourages international organisations, supporters, and health professionals to pledge their support for World Heart Rhythm Week (8 - 14 June 2009). A global coalition of organisations supporting activities and events for World Heart Rhythm Week will ensure the effective diagnosis, treatment, and quality of life for individuals affected by cardiac disorders.

Marnix Goethals MD PhD
President, Belgian Society
of Cardiology

BeHRA
Belgian Heart Rhythm Association

It is a great pleasure for Heart Rhythm UK to add support to Arrhythmia Alliance, particularly for Arrhythmia Awareness Week and World Heart Rhythm Week, 2009.

The 'Know Your Pulse' theme for Awareness Week will go a long way to highlighting the significance of detection and appropriate treatment for heart rhythm abnormalities. Important heart rhythm problems still go undetected, and enormous benefits will flow from earlier diagnosis and more effective treatment. Initiatives such as these will be important in improving the management of rhythm problems such as atrial fibrillation, the commonest of the sustained rhythm abnormalities and the consequences of which can be so devastating.

Our partnership with Arrhythmia Alliance is of crucial importance – we share the same determination to improve patient care and access to appropriate treatment.

HR-UK
Heart Rhythm UK

Edward Rowland
President, HRUK

Arrhythmia Awareness Week 2009

I write on behalf of the British Cardiovascular Society to express our support for Arrhythmia Awareness Week and the work you are doing to enhance awareness and aiding diagnosis with the "Know your Pulse" campaign. Increasing the understanding of potentially life threatening heart rhythm disturbances and the modern treatments available will greatly benefit patients and encourage early diagnosis and referral.

Iain Simpson
Vice-President Education and Research
British Cardiovascular Society

British Cardiovascular Society

World Heart Rhythm Week
8th - 14th June 2009

World Heart Rhythm Week (WHRW) is set to coincide with ArrhythmiA Awareness Week (AAAW) from the 8th - 14th June 2009. Arrhythmia Alliance has responded to increasing international demand and growing awareness of cardiac arrhythmias, by establishing WHRW.

Arrhythmia Alliance
The Heart Rhythm Charity

ICPES

Arrhythmia Alliance works to promote awareness of heart rhythm disorders internationally. In 2008, Founder, Trustee and CEO, Trudie Lobban, visited and attended events all over the world, some of which have been identified on this map.

Whilst AAAW is UK focused, WHRW aims to bring individuals and organisations together from across the globe to highlight arrhythmias on an international scale.

Working under the A-A umbrella, international members will work together to strengthen the patient voice in health care, through an effective union of medical professionals, patients, and patient groups. WHRW brings recognition to the worldwide issue of cardiac rhythm management and those organisations working to improve cardiac arrhythmia services.

WHRW 2008 welcomed the second year of international participation in AAAW. The International Cardiac Pacing and Electrophysiology Society (ICPES) partnered with Arrhythmia Alliance to co-ordinate what developed from World Heart Rhythm Day (13th June) in 2007, to World Heart Rhythm Week. ICPES was helpful in inviting international cardiac societies to add their support.

International Alliance of Patients' Organizations
A global voice for patients

“Supported by the International Alliance of Patients' Organizations”

The work of Arrhythmia Alliance is in keeping with IAPO's vision of patient centered healthcare worldwide. During WHRW, the organisation will lend its support to the continued awareness raising campaign.

Sixty international organisations, including charities and national health associations pledged their names in support of the Week. Awareness raising activities and clinical meetings were also held in a number of countries, notably China, Hong Kong and Germany, which attracted media attention.

Arrhythmia Alliance is pleased to announce its continued partnership with ICPES for WHRW 2009. This year promises to bring even greater awareness and increased numbers of international supporters. A global coalition for WHRW 2009 will positively ensure that patients, clinicians and governments internationally continue working towards improved health care services for cardiac conditions.

Individuals and organisations across the globe are encouraged to host events relevant to their mission and objectives under the umbrella of WHRW to focus on improving the effective diagnosis, treatment, and quality of life for individuals affected by cardiac disorders. The coverage and support of such initiatives will positively strengthen the coalition and ensure that patients, clinicians and governments internationally continue working towards improved arrhythmia services.

European Heart Rhythm Association
European Society of Cardiology

EHRA, European Heart Rhythm Association, has endorsed Arrhythmia Alliance for WHRW. Panos Vardas, incoming president of EHRA is calling for support from European patients, carers, patient groups, health care professionals, and organisations to get involved in promoting awareness of cardiac arrhythmias.

Arrhythmia Alliance International

Integral to the work of Arrhythmia Alliance is the international alliance of patient-focused individuals and organisations seeking improvement in arrhythmia services and patient care across the globe. Patients, medical health professionals, allied professionals and governments are brought together to work towards change. As a result, Arrhythmia Alliance will celebrate the official launch of the international organisation during the Arrhythmia Awareness Week Parliamentary Reception at the House of Commons on 8th June 2009.

Dr Thomas Fahraeus with Prof A. John Camm .

Europe

Arrhythmia Alliance is pleased to announce the official establishment of A-A Sweden. Instrumental to this accomplishment is Dr Thomas Fahraeus, recognising the need for patient-centred services in Sweden as exist for A-A in the UK. Special recognition for A-A Sweden and Dr Fahraeus' efforts will be made at the Parliamentary Reception in June.

In the last year, Arrhythmia Alliance has supported international initiatives to establish Arrhythmia Alliance models across Europe. Arrhythmia Alliance Portugal was established in February 2008 at Academia Lusa in Porto Santo. Arrhythmia Alliance is soon to be established in Italy, with ongoing discussions to move forward for this initiative in Germany, France, and Eastern European countries.

> On behalf of Arrhythmia Alliance Sweden, I urge other European countries to join together for Arrhythmia Awareness Week and World Heart Rhythm Week to ensure the effective diagnosis, treatment, and quality of life for individuals affected by cardiac disorders. Through a strong coalition we can inspire others around the world and achieve results.
>
> Thomas Fåhraeus
> A-A Sweden

South Africa

South Africa is moving ahead to improve arrhythmia outreach and patient support services. The patient support group, PACE (Prevent Arrhythmic Cardiac Events), an affiliate of Arrhythmia Alliance, has made national awareness, education, and support to patient groups their main focus.

Future plans for A-A International include moving forward to collaborate with eastern European countries. Inquiries of interest arrive from Czech Republic, Hungary, Macedonia, Finland, and Netherlands. In addition, interest has been sparked in India and Egypt.

Plans are underway for the first Pan-European roundtable at the Heart Rhythm Congress hosted by Arrhythmia Alliance in October 2009. This international roundtable will bring countries together to collaborate on best practices for their respective countries and brainstorm on ways to improve patient support services across the globe.

The success of Arrhythmia Alliance illustrates how effective collaboration can improve arrhythmia services and ultimately, life for the individual patient. Coverage and support with international initiatives will positively strengthen the coalition and ensure that patients, clinicians and governments continue working towards improved arrhythmia services.

Ryoji Noritake
Project Manager for A-A Japan.

Japan

Japan has seen greater outreach efforts for patients suffering from arrhythmias due to the proactive efforts of Ryoji Noritake on behalf of Arrhythmia Alliance Japan. Since its inception in 2008, A-A Japan has established an executive board, patient support groups, and is currently finalising the A-A Japan website. Ryoji was recently welcomed to the A-A office in Stratford upon Avon for a visit to meet new staff, learn of new developments in the UK, and share A-A Japan's upcoming objectives and plans. Arrhythmia Alliance thanks Ryoji for his outstanding commitment to promoting awareness of heart rhythm disorders in Asia.

Everything started on March 22, 2007. Trudie Lobban's presentation on her experiences within the UK and the rapid expansion of Arrhythmia Alliance at the International Patient Organization Symposium, United Nations University, Tokyo, impacted greatly upon Japanese patients.

Unlike cancer, cardiovascular patients have been largely excluded from Japan's political arena and patient leaders were desperately seeking a solution. The answer was there. It does not need to be in London or in Tokyo; it can start from a small town. Patients do not need to fight against someone; they can work together with anyone.

The answer is here. Health Policy Institute, Japan, (independent think-tank and patient advocacy support organization), supports Arrhythmia Alliance Japan as the advocacy platform for Japanese cardiovascular patients. The website will be launched in June during Arrhythmia Awareness Week, 2009.

We admire the worldwide initiative led by Arrhythmia Alliance in the UK, and it is our honour to join this spirit. We are very much looking forward to collaborating with our team mates all over the world.

Ryoji Noritake
Project Manager for A-A-J

I am delighted to join in celebrating AAAW 2009 and the following events. They are of immense importance for patients and medical professionals around the world. My respect and admiration for the work of Arrhythmia Alliance are shared by the health community in Japan. We are honored to help establish A-A Japan as an advocacy platform for Japanese patients. I hope that our collaboration will help enhance awareness on both sides of the ocean.

I would like to express my deepest appreciation to all the organizations of AAAW 09, and would like to extend a warm welcome to the participants.

M. James Kondo
Co-Founder, Vice Chair of the Board and President
Health Policy Institute, Japan

World Heart Rhythm Supporters

Arrhythmia Alliance
The Heart Rhythm Charity
www.heartrhythmcharity.org.uk

Organisations across the globe unite to raise awareness of heart rhythm conditions

ICPES

EUROPEAN Heart Rhythm ASSOCIATION

EUROPEAN SOCIETY OF CARDIOLOGY®

BeHRA
Belgian Heart Rhythm Association
BELGIUM

ARYTMI ALLIANSEN
A-A SWEDEN

SADS FOUNDATION
Sudden Arrhythmia Death Syndromes Foundation
USA

The British Society for Heart Failure

The Anthony Bates Foundation
USA

Australian Sudden Arrhythmia Death Syndromes SADS Foundation
Sensitive Hearts Support Group
AUSTRALIA

SAVING YOUNG HEARTS
from Sudden Cardiac Arrest
USA

HONG KONG

International Alliance of Patients' Organizations
A global voice for patients

Ashley Jolly sad
Sudden Adult Death Trust
SADS UK
Sudden Arrhythmic Death Syndrome

JAPAN

Arrhythmia Alliance Nederland
NETHERLANDS

nhsalliance
UK

IranBehdasht
Healthy Lifestyle, Healthy Heart

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USA

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AFNET
GERMANY

Sudden Cardiac Death in the young Support Group
IRELAND

AFA
atrialfibrillationassociation
www.atrialfibrillation.org.uk

STARS
Syncope Trust And Reflex anoxic Seizures
www.stars.org.uk

British Cardiovascular Society

SADS
The Canadian SADS Foundation

Cardiac Inherited Disease Group New Zealand

ECAS

جمعية القلب الإماراتية
EMIRATES CARDIAC SOCIETY
UAE

IRISH HEART FOUNDATION
IRELAND

STARS US
Syncope Trust And Reflex anoxic Seizures

Heartbeat International
Pacemakers as peacemakers.

PACE AFRICA
PREVENT ARRHYTHMIC CARDIAC EVENTS
AFRICA

INSTITUTO PORTUGUES DO RITMO CARDIACO

APPPC
PORTUGAL

ÖSTERREICHISCHER HERZFONDS
AUSTRIA

PARENT HEART WATCH
USA

APAPE Associação Portuguesa de Arritmologia, Pacing e Electrofisiologia
Sociedade Portuguesa de CARDIOLOGIA

HR-UK
Heart Rhythm UK

HEALTH POLICY INSTITUTE, JAPAN

HCMA
HYPERTROPHIC CARDIOMYOPATHY ASSOCIATION
USA

JAPANESE HEART RHYTHM SOCIETY
JAPAN

PACES
the Pediatric & Congenital Electrophysiology Society
USA

SOCIEDAD BOLIVIANA CARDIOLOGIA
BOLIVIA

TAIWAN SOCIETY OF CARDIOLOGY
TAIWAN

Sudden Cardiac Arrest Association
Power and passion, saving lives
USA

Heart Rhythm Society
USA

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Keep it Beating - Midatlantic Cardiovascular Foundation - Norwegian Heart & Lung Association- Simon's Fund
Slovenian Society of Cardiology - Society of Cardiology of the Russian Federation - STIN - Swiss Heart Foundation
The Myotonic Dystrophy Support group - The Travis R. Roy Sudden Cardiac Arrest Fund - World Heart Federation

Arrhythmia Alliance, PO Box 3697, Stratford upon Avon, Warwickshire, CV37 8YL, UK. T: +44 (0) 1789 450787

Chapter 8 of the Coronary Heart Disease National Service Framework ('Chapter 8'):

Arrhythmias and Sudden Cardiac Death – A progress report

Chapter 8, which sets out markers of good practice and quality requirements for the NHS for the development of arrhythmia and related services, was launched in 2005. Much has happened over the last four years, but there is still an enormous amount to do.

The Department of Health and NHS Improvement, which supports the 28 cardiac networks across England, have been focusing on some specific projects at a national level and this is a brief report of that work.

Sudden Cardiac Death and Inherited Cardiac Conditions

This is a very complex clinical area, but a hugely important one. Inheritable heart conditions that show no symptoms can strike suddenly and cause a sudden cardiac death. Most sudden deaths of young people occur as a result of one of these conditions, and one of the main 'triggers' is thought to be sustained exercise. These considerations exacerbate the devastating effects that sudden cardiac deaths have – striking fit, young people and not allowing family and friends to say goodbye.

There have, in the past been calls for screening either the whole population or perceived 'at-risk' groups, such as young athletes. Unfortunately, because of the number and complexity of the conditions in question, there are currently no tests that can determine accurately enough whether someone is at high risk, and then predict whether the condition will ever affect them. This makes things tricky, because if a young athletic person is told that they may be at risk, they will face the dilemma of whether or not to give up a sporting profession or start a family in the future.

Insurance premiums can also be adversely affected if someone has to declare that they may have a familial heart condition. Alternatively, tests may not pick up the presence of a condition and a sudden death may result anyway. All of this has led to the National Screening Committee (NSC) to conclude that a screening programme would not be effective at this time. The NSC, with the health departments of all the UK countries, are keeping an eye on research taking place in this area and will consider what future research might lead to an effective test for these conditions.

Chapter 8 states that where a sudden cardiac death has occurred, the NHS should do all it can to assess the risks to other family members and treat them according to that risk. The pathway is complex, involving coroners and pathologists at the start of the process to clinical geneticists and other specialist health service staff. Some key developments have taken place to ensure that those at risk are detected and referred to a high-quality specialist service. We have concentrated our efforts in three areas:

Coroners and Pathology Services

When a sudden death occurs, it is important to determine as quickly as possible whether that death was as a result of an inherited heart disease, and whether other family members might be at risk. This obviously depends on the knowledge and expertise coroners and coroners' officers have, but also the availability of expert pathology help and advice for them. Although there is still much to do in terms of educating coroners and their officers, many of them are now picking up cases of this kind. A network of cardiac pathologists has also been established so that coroners around the UK have access to specialist cardiac pathology expertise when needed. A database was recently established for the cardiac pathology community and, in time, this should give us a lot of information on incidence, but also where good links are developing with coroners.

Specialist Inherited Cardiac Conditions Services

At the other end of the patient pathway are the specialist assessment services to which family members thought to be at risk are referred. There are about 20 centres in the UK providing this highly specialised service. We have to ensure that these services offer the highest quality assessment, treatment and care to those that are referred. A couple of years ago, the Department of Health in collaboration with others, issued a service 'blueprint' of what we expect these services to include. But this was really only the start of the process. We will be working with a number of local and national organisations over the next couple of years to draw up more accurate service and quality standards, audit how well the centres providing this service meet those standards and then consider designation of centres for the provision of these services. We will be working with specialist commissioning colleagues to ensure that only services fit for purpose provide assessment services in this highly complex clinical area.

Information and Support for families, and referrals to the right health services

Advice and support for patients and families is a crucial part of the pathway. Because the conditions and treatments in this area are complex, it is essential that the right sort of information is communicated effectively. Patient organisations, most notably Cardiac Risk in the Young, the Cardiomyopathy Association, SADS UK, Arrhythmia Alliance and STARS are already doing a tremendous amount to raise awareness of the conditions and the risks, and offering bereavement support for those who have lost a loved one. But the sharing of clinical information between coroners, clinicians, GPs and family members has been a little 'hit and miss' in the past, and this has probably meant that many people who should have been referred to a specialist inherited cardiac conditions service have not been referred. The Department of Health has been working with the British Heart Foundation (BHF) on the establishment of a genetic information helpline. In cases of sudden death where an inherited heart condition is the suspected cause, coroners will ask first-degree relatives of the deceased to contact the helpline. The helpline will then provide information for the relatives to take to their GPs, including the names and addresses of services they should be referred to. The BHF helpline goes live in April and should ensure that more people are referred by their GPs to specialist assessment services.

Many people have been involved in the development of inherited cardiac conditions services over the last few years and together they are ensuring that those at risk are getting the support and care they need.

Atrial Fibrillation

The recent establishment of the Atrial Fibrillation Association (AFA) was both inspired and timely, and all those involved should be congratulated.

Atrial Fibrillation (AF) affects over 1% of the whole population; 4% of the over-65 population. The overall incidence of stroke is about 5% per year in people with the condition. This is a serious condition with serious consequences if not detected and treated properly. The work of AFA and other organisations is crucial in raising awareness of AF and working with other stakeholders to improve prevention and treatment.

At a national level, NHS Improvement has been conducting a major piece of work with clinicians, academics, patient organisations and others to understand how AF services are provided now and how they ought to be provided in the future. A consensus meeting was held at the end of 2008 and the results of the discussions at that meeting will soon be communicated. The Department of Health has also conducted a full cost-benefit analysis of providing AF services and this will form part of the communication.

But one of the key changes we have been progressing is how we improve primary care services to not only pick up those with AF but also prescribe medication to manage the condition and reduce the risk of stroke. It is thought that only around half of those with AF who should be prescribed anticoagulants to prevent stroke are receiving them. We have been looking at how we might change the AF inclusions in the GP contract and are making some headway with this.

Heart Rhythm Management Devices

Pacemakers, implantable defibrillators (ICDs) and new, more sophisticated heart rhythm devices are helping restore the quality of life of patients with arrhythmias. But traditionally, this country has had some of the lowest implantation rates in Europe and the rest of the world. In addition to this, implant rates vary across the country.

A taskforce was set up a couple of years ago with the aim of raising the rate of implants to a level that compares with the Western European average by 2016. Several pieces of work have been initiated to support this aim.

For a number of years now, the Department of Health (with Medtronic at the start of the process) has been funding the Network Devices Survey Group, to collect and disseminate information on implant rates to all cardiac networks, showing the network rates and those of constituent PCTs. Provision of this information alone is already having a positive effect on implant rates. We are now looking at how better use can be made of this information.

But what we must do in the future is discover why rates in this country remain low. Dr Janet McComb and her colleagues in Newcastle have been doing some work to understand practices in this area better. We will build on this work in the future to see where the barriers to provision are and then see how we can support the commissioning process to ensure that everyone who needs one of these important devices gets one.

The Future?

So what will we be focusing on in the future? Although there is still a lot of unfinished business in terms of sudden cardiac death and arrhythmia services, we can no longer consider these services in isolation. There is crossover and commonality with other heart diseases and treatments like heart failure and cardiac rehabilitation - two areas the service needs to focus more on in the future. But heart disease generally must be recognised as just one of several vascular conditions that need to be prevented. Heart disease, stroke, diabetes, kidney disease and other related conditions have now been brought together at a national level as a vascular disease programme. The future emphasis will clearly be on prevention as the underlying causes of all these diseases carry similarities. A programme of vascular checks for all people between the ages of 40 and 74 is being established as we speak.

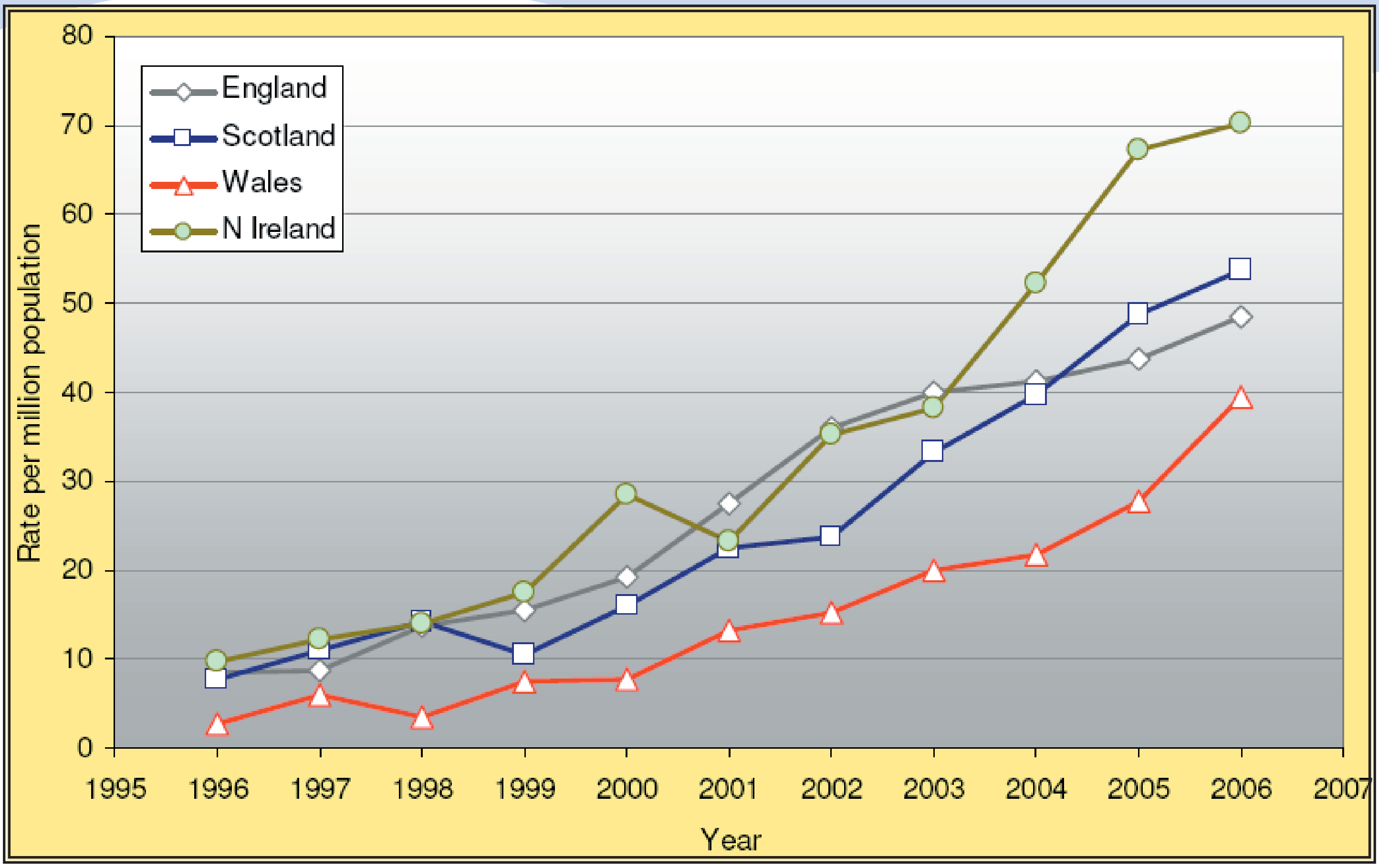
But this also gives us the opportunity to look at how we improve services for those with chronic and long-term disease to the standards that those with acute illness are now experiencing. It will also allow us to focus more on inequalities and ensuring that everyone gets the same quality of service.

Mike Yates
Head of Heart Service
Department of Health

Dr Campbell Cowan,
National Clinical Lead for Arrhythmias in NHS Improvement said:

Two issues relating to device implant rates give cause for concern. The first is that device implant rates in the UK are much lower than in the rest of Europe. The second is that, even within the UK, marked variation in implant rates is seen. This inequity is not confined to the newer "high tech" devices (defibrillators and re-synchronising pacemakers etc); it applies equally to simple pacing. Data is available from the Network Survey Group which clearly documents both national under provision and inequality. Addressing these problems is proving more difficult and will only be achieved through a collective and collaborative effort involving Cardiac Networks, Commissioners, Provider Trusts, HRUK and the voluntary sector, represented by Arrhythmia Alliance. NHS Improvement hopes to work with all concerned to address inequity and to achieve the Department of Health's aim of parity with Europe for device implants by 2016.

Dr Campbell Cowan
Leeds Teaching Hospitals NHS Trust

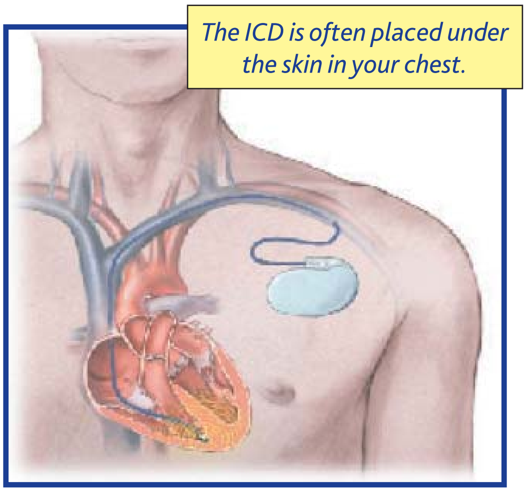


Source: David Cunningham, 'National targets and trends: What is optimal UK device provision?' Presentation, 11 December 2008, Chapter 8; Arrhythmias and Sudden Cardiac Death - Cardiac Networks & Heart Rhythm Devices: Confronting under-provision and inequity.

“THINGS HAPPEN AND PEOPLE MOVE ON”

Jagdeep Leil’s Story

My name is Jagdeep and at the age of sixteen I suffered a cardiac arrest whilst playing rounders at my school. Having been a perfectly healthy student, with no previous heart complaints or family history, I reached out to catch the ball and BOOM…I fell to the ground. My heart just stopped!



The ICD is often placed under the skin in your chest.

My P.E. teacher had no idea what to do, but acted fast. Together with the school nurse, I was given Cardiopulmonary Resuscitation (CPR) until the paramedics arrived.

I was rushed to A&E at the Leicester Royal Infirmary and doctors were shocking my heart like they were recharging a car battery with jump leads, shock after shock, jump after jump but it was no good, I was dead! But they didn’t give up. Then…a miracle, all their hard work paid off and I was brought back to life.

I was fitted with an Implantable Cardioverter Defibrillator (ICD) and kept under close observation in ICU for seven days. During this time I had visitors every day but I didn’t have the slightest idea who they were. They were all complete strangers to me. The cardiac arrest had caused severe memory loss and I also lost my feelings, emotions and other senses within my body. I was like a dead body living.

Things happen and people move on. I just had to accept the fact that I would be a heart patient for the rest of my life. But this didn’t stop me! I enrolled on a photography A-Level course and was keen to pursue this as a career. But when I kept fainting in the darkroom, I knew this wouldn’t be possible. My consultant advised me that the infra-red lighting was surrounded by a magnetic field that was affecting my ICD and that I should consider changing my course. I felt upset and angry.

One of my options was to change my course to English Literature. English was one of my weaker subjects and as part of the treatment for my memory loss, I was advised to read as much as possible. Not only would this help to educate me but it would also help me to remember things.

As an individual I have realised that I have grown up to make decisions for myself. I have learnt to be independent and not rely on anybody else to do things for me. I look at life from a positive view and try to live the way I want to. My life changed in a matter of seconds and has made every day more challenging. But I am no longer a sixteen year old school girl - I am now in my final year at Stoke University, studying English Literature.

> **“My life changed in a matter of seconds and has made every day more challenging”**

I love to stroll through parks and nature reserves at times when I feel low; I find that a walk in the park can lift my spirits. I have also taken up dance classes which I enjoy very much, particularly bhangra, street dance and RnB, so if I feel down I just dance away!

Looking back at it all, my school life, my heart stopping and being in hospital has been an emotional rollercoaster for me, my family and my friends but the main thing is, how am I going to live my life from now?

“Life is not always HA HA HEE HEE” as Meera Syal writes in one of her novels, simply because we are all individual with individual needs.

A ZEST FOR LIFE

Gritt Liebing's Story

My name is Gritt Liebing. I am 43 years old and I live together with my partner Harald and my three dogs in Darmstadt, Germany, close to Frankfurt.

I have a fatal heart disease called Brugada Syndrome. This is a genetic defect, which can cause Ventricular Fibrillation (VF). One of the only therapies is an Implantable Cardioverter Defibrillator (ICD). This device gives electrical impulses to my heart whenever it is needed.

I have been brought back to life over 150 times in the past ten years thanks to my defibrillator. I got my first device implanted in 1999, the second in 2003 and my third in 2008. I give names to my defibrillators, since they are so close to my heart and I trust them 100%. So the first one was TED – at that time I was reading a story and one character was Ted the bug: clever and always around. The second one was BOB – everybody who has children has heard of 'Bob the Builder' and he always says, 'Yes, we can make it!' The one I have now is OCH, which means angel of the sun. I trust my ICD completely and am very aware of the fact that without them I would not be here today. The ICD is a brilliant technical device, saving the lives of people all around the world each day. The progress of medical technology is fascinating.

Previous to my first implant in 1999, I had been a very active, professional career woman with a great job, travelling around the world. Suddenly, I had total blackouts almost every other day. I just thought of it as stress and didn't really care about it very much, until I fell and broke my nose. My doctor sent me to the hospital immediately, and after some weeks of testing, VF was recorded. That was the first time I had ever heard of an implantable defibrillator, and just one week later, my first device was implanted.

> **“I have been brought back to life over 150 times in the past ten years thanks to my defibrillator”**

Since that time I have learned to enjoy life in a very special way. It would be a lie to say that my life hasn't changed. One thing that has not changed is my attitude towards human beings and animals. Filling my days with useful work, I help as a volunteer in an animal shelter and I established an ICD patient support group.

The other thing in my life which I refused to give up is sports. My Dad took me to my first running competition when I was just 3 years old. So my slogan is: Don't stop running! Well, sometimes I don't run, but I go forward: step by step. Whenever I have many life-saving shocks from my ICD and I feel I can't go on, I remember there is always a reason to get up in the morning. That reason is very simple: it's life and I love it! I love to take my 3 dogs for long walks in the rain, snow and sunshine. And I love to just sit out in the countryside, hear the birds sing, look up at the sky and be grateful that I am alive.

Since I am aware of the fact that my life depends on this small metal device and I know that I can rely on it, I have kept my biggest dream alive. I have always wanted to be an Ironman finisher. The Ironman triathlon is a 3.8 km swim, 180 km cycle and a marathon run, totaling 42,195 km. When I told my doctors in 2006 that I was planning to do an Ironman in 2007 they weren't really happy, but they knew that competing in sports means a quality of life for me. It was hard work and discipline for my trainer and me, in addition to a lot of understanding and support from family, friends and doctors. The result was that I made my biggest dream come true. On July 8th, 2007 I was one of 2200 finishers of the Ironman Austria. I was not fast and left only about 200 people behind me, but I crossed the finish line and that's what counts.

What I want to say is: follow your dreams, never give up and always be aware of how good it is to be alive! Thanks to my little friends TED, BOB and OCH!

Nicola Meldrum: The Role of the Arrhythmia Nurse Specialist

When my ICD nurse specialist role was set up in January 2004, the aim was to work collaboratively within a team of highly specialised clinicians and physiologists to optimise the quality of care given to patients with an Implantable Cardioverter Defibrillator (ICD) and their families.

The Oxford model of an arrhythmia/ICD nurse specialist role differs from other models in the UK, in that the technical aspect of arrhythmia care is also provided by the specialist nurses. Other centres follow a different model whereby cardiac physiologists undertake the technical aspects, such as ICD follow-up and implantation, assisting with electrophysiology (EP) procedures, and the nurses ensure patients receive education, support and information, whilst setting up and running various clinics (from blackout and palpitation clinics to atrial fibrillation clinics). This highlights the varying needs of arrhythmia patients and their service providers.

However, there are fundamental aspects of the role which are provided by all arrhythmia nurses. The common aim is to provide seamless and co-ordinated care, to facilitate timely and appropriate patient management and also to address national targets and standards. Education of patients, staff and other healthcare professionals is a large part of the nurses' role which helps to reduce conflicting patient advice and management, thereby increasing patient confidence in healthcare professionals. This has been greatly developed by Arrhythmia Alliance, which produces a huge range of patient information, all of which has been accredited by specialists in heart rhythm management throughout the UK, is endorsed by the Department of Health and is reviewed and updated annually.

From a clinical point of view, the nurse specialist usually sees arrhythmia patients from the outset, either as a new referral or once they have been assessed by a cardiologist or electrophysiologist (a cardiologist who specialises in heart rhythm management). Following their assessment in clinic, patients are normally given the specialist nurses' contact details. This nurse will become the first point of contact for patients for the duration of their treatment and follow-up care. If patients proceed to further intervention, eg ICD/pacemaker implantation or catheter ablation, the nurse may be involved in the actual procedure and/or subsequent follow up. This has been shown to reduce anxiety levels by providing continuity of care and helps build a relationship of trust and support for patients and their families.

From left to right: Nicola Meldrum, Dr David Tomlinson and Angela Griffiths.

The role of the arrhythmia nurse is received well by both patients and healthcare professionals. Waiting times are reduced, access to arrhythmia services is improved and queries and concerns are addressed in a timely and competent manner. Since 2004 when there were only 12 such posts in the UK, the number has increased to well over 100 nurses who provide specialist arrhythmia care and this number is set to rise. We welcome feedback from patients and carers on how they would like services to develop and aim to continue working closely with Arrhythmia Alliance to ensure patients are given the best possible service.

RESTART THE HEART

RESTART THE HEART

The cabinet for an Automated External Defibrillator (AED).

Arrhythmia Alliance is running a national campaign to place AEDs (Automated external Defibrillators) in local communities. A-A promotes Heart Safe communities by facilitating the placement of AEDs in public places so that emergency life saving equipment is available whenever it is needed.

SAVING LIVES

Approximately 100,000 people die from sudden cardiac arrest (SCA) every year in the UK. It can strike anyone, anytime, anywhere. In fact it is estimated that 12% of incidents occur in public places. An AED used with Cardiopulmonary Resuscitation (CPR) is the only way to re-establish the heart's natural rhythm.

RESTART THE HEART

Sudden Cardiac Arrest can strike anyone, anytime, anywhere...

CPR alone = 5% Survival
CPR + AED = 50% Survival

An Automatic External Defibrillator (AED) together with CPR is the ONLY way to re-establish the heart's natural rhythm!

CAN YOUR COMMUNITY RISK NOT HAVING ONE...?

Arrhythmia Alliance is helping to place AEDs in local communities

Help us to help you

PO Box 3697 Stratford-upon-Avon Warwickshire CV37 8YL

Tel: +44 (0)1789 451830 Email: rth@stars.org.uk
www.heartrhythmcharity.org.uk

An AED is an emergency life-saving device for use in the event of a sudden cardiac arrest. SCA results from an abrupt and complete loss of heart function. This is most commonly caused when the heart enters an extremely rapid or chaotic rhythm called ventricular fibrillation. SCA is often confused with a heart attack, but although heart attacks can lead to cardiac arrest, the root causes are entirely different.

Rapid defibrillation and Cardiopulmonary Resuscitation (CPR) is vital within the first few minutes of collapse, as studies show that survival rates fall 10% for every minute that passes without this emergency treatment.

CPR alone = 5% survival
CPR + AED = 50% survival

HEART SAFE COMMUNITIES

The first Heart Safe community was piloted in the Chew Valley area, with 16 AEDs located outdoors around the locality. Arrhythmia Alliance launched the project in November 2007, in association with Great Western Ambulance Service and local Estate Agent, Clive Setter. The project has now been running successfully in the area for nearly 18 months; the AED has been called into action on numerous occasions and each time it has reached the scene of an incident before paramedics and Community First Responders (CFRs).

In November 2008 the project was expanded to include an AED placement in the town of Keynsham. Keynsham's location and distance from the nearest hospital means an AED will increase a person's chances of survival. Donated by Rotary, the AED was fitted outside the fire station on the high street. It is intended that this will be the first of several AED placements in the local area.

Arrhythmia Alliance project team at the Keynsham launch. From left to right: Trudie Lobban, Joanna Goldberg, Joanne Burke, Mary Rustic and Ben Fry.

CPR and AED training in Stratford, West Midlands.

In Stratford-upon-Avon, the Mayor Joyce Taylor, performed the opening ceremony and unveiling of the AED that has been fitted outside Prontaprint, for use by members of the public in the event of an emergency. This was officially launched for the community in January.

Arrhythmia Alliance is now working in partnership with numerous local groups and ambulance services across the country to place AEDs in public places in communities.

Can your community risk not having an AED? Help us to help you! Email rth@stars.org.uk for further information about the campaign.

Arrhythmia Alliance Affiliation

The aims of the affiliation scheme are to provide support, guidance and networking to patient groups and organisations. Arrhythmia Alliance (A-A) recognises that local groups and organisations provide an invaluable service to arrhythmia patients, carers, families and medical professionals. Affiliation to A-A ensures a national standard is reached with the information and support available.

What are the benefits of affiliation to Arrhythmia Alliance?

The degree of involvement with A-A is entirely optional for each group and organisation. Affiliation to A-A includes the following opportunities:

- Free membership and medically endorsed literature.
- Involvement in the annual Arrhythmia Awareness Week (AAAW) and Heart Rhythm Congress (HRC).
- Advocacy for the work of the independent organisation.
- Free hosting and/or design of the group webpage on the A-A website.
- The opportunity to advertise events, conferences and meetings in the A-A monthly e-bulletin.
- Signposting to relevant organisations and A-A members.
- Links and contacts with other organisations.
- Involvement in current projects and campaigns.
- A-A attendance at events/meetings.
- Funding advice and activity ideas.
- Independence will be fully retained.

Can any group or organisation become affiliated?

The affiliation scheme is available to patient groups, organisations and those with an interest in cardiac arrhythmias. Groups may be specific to atrial fibrillation patients, ICD/pacemaker recipients or may cater for 'heart' patients in general.

A-A offers affiliation to groups and organisations which share similar aims and objectives to those below.

- To raise awareness of cardiac arrhythmias.
- To improve diagnosis of cardiac arrhythmias.
- To improve treatment of cardiac arrhythmias.
- To improve quality of life for people affected by cardiac arrhythmias.

Can A-A help establish new patient groups?

Yes! A-A offers free advice on how to establish and lead a successful group together with answers to frequently asked questions. A-A appreciates how meetings provide a much needed forum for members to gain information, seek emotional support, discuss common concerns and experiences and learn more about their condition.

Milton Keynes ICD Support Group.

How does a group or organisation become affiliated to Arrhythmia Alliance?

Upon registering an interest in affiliation, you will receive a 'Guidelines and Information' document, outlining all aspects of the affiliation scheme. Simply sign and return the application form together with a copy of your group or organisation's aims and objectives (constitution) which will then be processed by the Affiliation Committee. Once approved, you will receive affiliation confirmation together with the Arrhythmia Alliance logo for your use.

If your group/organisation is interested in becoming affiliated please contact *development@stars.org.uk*

Alternatively, with the help of A-A, why not establish your own group?

To become affiliated to Arrhythmia Alliance or to register an interest in establishing your own support group, please contact Ben Fry at development@stars.org.uk or on +44 (0)1789 451 830

Affiliated Groups

- 🔵 ICD Patient Groups
- 🔴 Heart Patient Groups
- ⚪ Pacemaker Patient Groups

1 Backup

St Georges Hospital, London
Contact: Sue Jones
sue.jones@stgeorges.nhs.uk
020 8725 3597

2 Bournemouth Area Defibrillator (BAD)

Bournemouth
Contact: Gaynor Richards
arrhythmia.nurses@rbch.nhs.uk
01202 726154

3 High Wycombe and District ICD Support Group

High Wycombe
Contact: Bryan Longson
bryan.longson@btinternet.com
01494 812280

4 Jumpstart

Nottingham University Hospitals, Nottingham
Contact: Ellen Berry & Helen Padgett
jumpstart@nuh.nhs.uk
01159 691169 ext 54482

5 Kick Start

Good Hope Hospital, Sutton
Contact: William Pontin
bill@thecastle39.freeserve.co.uk
07785 703498

6 Livewires

Northern Ireland
Contact: Errol Hutchinson
errol@hiddenloop.com
028 2565 3874

7 Milton Keynes ICD Support Group

Milton Keynes, Buckinghamshire
Contact: Sam Shunmoogum
sam.shunmoogum@gmail.com
01908 368294

8 North Gloucestershire ICD Support Group

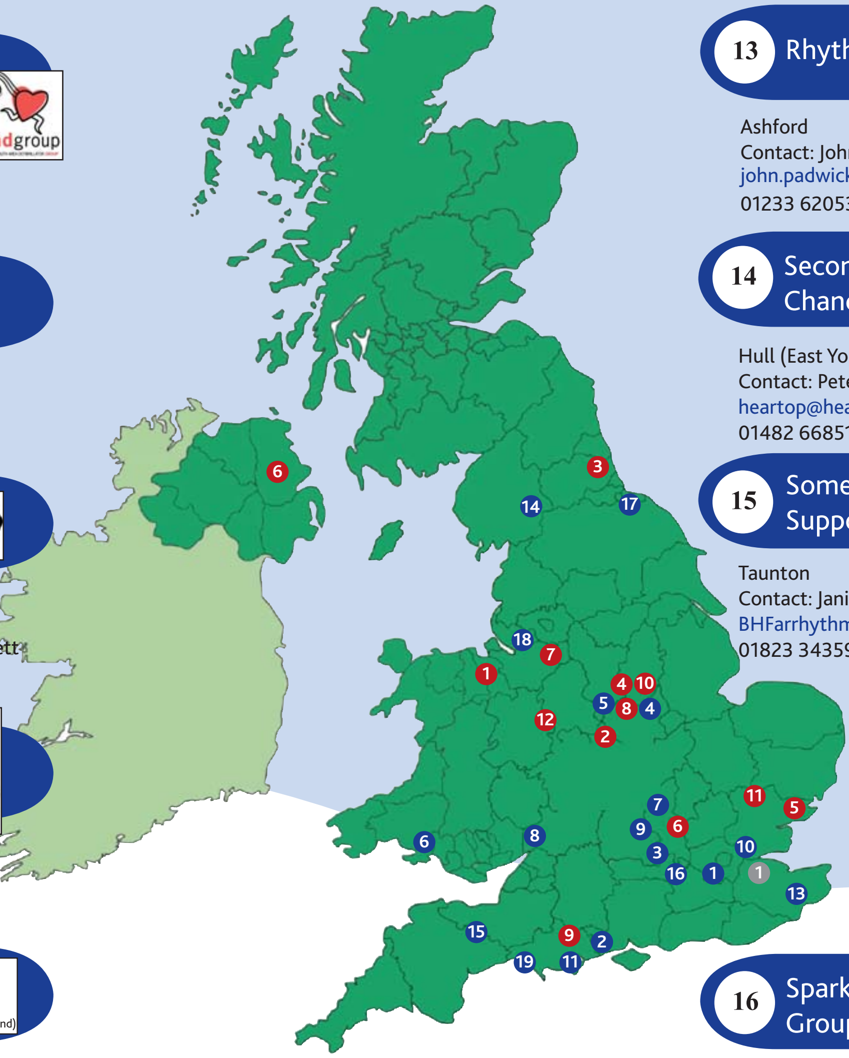
North Gloucestershire
Contact: Colin Prottey & Robin Harvey
info@icd-gloucestershire.org.uk
01242 527588

9 Oxford ICD Support Group

Oxford
Contact: Geoff Shaw
geoff@icf.org.uk
01280 812547

1 Medway Pacemaker and ICD Support Group

Gillingham
Contact: Margaret Wickens
mardel1@blueyonder.co.uk



10 Pacers and Fads

Westcliff-on-Sea
Contact: Diane Daly
diane.daly@southend.nhs.uk
01702 385033

11 Poole ICD Support Group

Poole, Dorset
Contact: Fiona Keene
fiona.keene@poole.nhs.uk
01202 442876

12 Restart

Swansea
Contact: Phill Abbot
restart.group@btinternet.com
07740 739314
Contact: Elizabeth Williams
BHF Arrhythmia Nurse Specialist
01792 618 843

13 Rhythm for Life

Ashford
Contact: John Padwick
john.padwick@virgin.net
01233 620532

14 Second Chance

Hull (East Yorkshire & North Lincolnshire)
Contact: Peter Nicholas
heartop@heartop.karoo.co.uk
01482 668511

15 Somerset ICD Support Group

Taunton
Contact: Janice Bailey & Jacqui Kemp
BHFarrhythmianurses@tst.nhs.uk
01823 343595

16 Sparks ICD Support Group

Harefield
Contact: Nicky Margerison
n.margerison@rbht.nhs.uk
01895 823737

17 The Beat Goes On

Middlesbrough
Contact: Sue Hackett
sue.hackett@stees.nhs.uk
01642 282806

18 The Bolton ICD Support Group

Bolton
Contact: Diane Walsh
dmobrien99@yahoo.co.uk
07967 760387

19 West Dorset ICD Support Group

Dorchester
Contact: Kay Elliot
kay.elliott@dchft.nhs.uk
01305 254920

Arrhythmia Alliance, PO Box 3697, Stratford upon Avon, Warwickshire, CV37 8YL, UK. T: +44 (0) 1789 450787

1 Chester Heart Support Group

Chester
Contact: Mike Norfolk
mail@norf19.fsnet.co.uk
01244 659133

2 Coventry Healthy Hearts

Coventry
Contact: Lee Johnson
lee.johnson@talktalk.net
02476 422038

3 Darlington Cardiomyopathy Self Support Group

County Durham
Contact: John R Waterson
j.waterson@hotmail.co.uk
01325 264806

4 Derbyshire Arrhythmia Group

Derby
Contact: Margaret Adamowicz
margaret.adamowicz@derbyhospitals.nhs.uk
01332 254933

5 HEARTBEATS (East Suffolk)

Ipswich
Contact: Len Tate
len.tate@hotmail.com
01206 393292

6 HERTBEATS

Hertfordshire
Contact: John Coad
johnrcoad@aol.com
01582 764826

7 HEARTLINK

Tameside
Contact: Danny Jenkins
danny81jenks@yahoo.co.uk
01457 862741

8 Nottingham Cardiac Support Group

Nottingham
Contact: Michael Wagstaff
michael.e.wagstaff@btinternet.com
01773 717648

9 Poole Heart Support Group

Poole, Dorset
Contact: Alan Bristow
a.bristow60@ntlworld.com
01202 694886

10 Trent Cardiac Network Arrhythmia Collaborative

Nottingham
Contact: Jamie Waterall & Ellen Berry
jamie.waterall@nuh.nhs.uk
01159 249924

11 UPBEAT Heart Support Group

West Suffolk
Contact: David Camp
dc@davidcamp.demon.co.uk
01787 376723

12 Wolverhampton Coronary Aftercare Support Group

Wolverhampton
Contact: Ken Timmis
kenneth.timmis@blueyonder.co.uk
01902 755695 Mob: 07889 063647

Affiliated Organisations

Atrial Fibrillation Association
Providing information, support and access to established, new or innovative treatments for Atrial Fibrillation
Location: UK **Web**: www.atrialfibrillation.org.uk

Anthony Bates Foundation
A non profit organisation, dedicated to saving young lives through early detection of Hypertrophic Cardiomyopathy
Location: USA **Web**: www.anthonybates.org

APPPC (Associacao Portuguesa de Portadores de Pacemakers e CDI's
(Portuguese Association of Pacemakers and ICDs)
Our mission consists of informing about the usage of pacemakers and ICDs, promoting social contact and social well-being among pacemaker and ICD bearers, as well as promoting workshops and clarification sessions.
Location: Portugal **Web**: www.apppc.com.pt

British Cardiovascular Society
BCS, together with our affiliated groups, is the voice for those working in cardiovascular health, science and disease management in the UK; we aim to promote and support both the healthcare professionals who work in cardiology and the patients for whom we want to encourage the best possible treatment.
Location: UK **Web**: www.bcs.com

The Cardiac Arrhythmia Syndromes Foundation
Dedicated to the prevention of Sudden Cardiac Arrest via education, advocacy and heart screening with electrocardiograms. We strive to make heart screening available and affordable for all students and athletes to save lives via early detection of Cardiac Arrhythmia Syndromes.
Location: USA **Web**: www.SafeBeat.org

Cardiac Inherited Diseases Group
We aim to reduce sudden cardiac death due to cardiac inherited diseases.
Location: New Zealand **Web**: www.cidg.org

Heart Care Partnership – UK (HCP-UK)
HCP (UK) was set up in 2003 in response to a request from the British Cardiovascular Society, to draw together users that could represent patients and carers within the process for cardiac service improvement.
Location: UK **Web**: www.bcs.com (affiliated)

HeartScreen America
HeartScreen America is leading the way to make heart screenings available and affordable to all. Our mission is singular and clear: To Screen Hearts and Save Lives
Location: USA **Web**: www.heartscreenamerica.com

PACE
Through support, awareness, research and fundraising, PACE aims to prevent arrhythmia cardiac events which can lead to sudden death.
Location: South Africa **Web**: www.paceafrica.org.za

SADS Canada
The Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation is a registered Canadian charity committed to saving lives and supporting the families of children and young adults who are generally predisposed to sudden death due to heart rhythm abnormalities.
Location: Canada **Web**: www.sads.ca

STARS-UK
Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures.
Location: UK **Web**: www.stars.org.uk

STARS-US
Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures.
Location: USA **Web**: www.stars-us.org

Arrhythmia Alliance Regional Meetings 2009

Arrhythmia Alliance's 2009 Regional Meetings, in partnership with the Heart Improvement Programme (HIP) and the Department of Health (DoH) are intended for general practitioners, clinicians, cardiac networks, arrhythmia nurses, physiologists, industry members, charitable organisations and patient groups. We also welcome patients and carers. Topical issues such as heart failure, atrial fibrillation, anti-coagulation, syncope and sudden death are covered in presentations given by experts from across the UK.

To find out more, view the agendas and download a registration form, visit our website www.heartrhythmcharity.org.uk and click on the Regional Meetings link.

Heart Rhythm Congress 2009

Heart Rhythm Congress

18 – 21 October 2009
Birmingham
UK

www.heartrhythmcongress.com

Tel: +44 (0) 1789 451822 Email: congress@heartrhythmcharity.org.uk

Promoting better understanding, diagnosis, treatment and quality of life for individuals with cardiac arrhythmias

Arrhythmia Alliance PO Box 3697 Stratford upon Avon Warwickshire CV37 8YL UK
Telephone: +44 (0) 1789 450 787

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endorsed by DH Department of Health

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