

Dear Affiliate Members,

Welcome to Arrhythmia Alliance's first Affiliates Newsletter!

To support the Affiliation Scheme and encourage groups to network across the UK, we will develop and distribute biannual patient-focused newsletters to all of our affiliate members. This way, we are able to keep you all in the loop with our current projects, campaigns and achievements.

As this is our first edition, we thought we'd give you a brief update of our work in 2009, but we'd like to highlight that this newsletter is for you so please feel free to submit articles or get in touch to request particular topics and we will do our best to ensure that they are covered.

So here goes... The Affiliation Scheme saw a dramatic rise in numbers during 2009 and we are proud to have 45 affiliated patient information groups and organisations across the UK.

These groups range from general heart patient information groups to pacemaker and ICD specific information groups, charitable organisations such as Syncope Trust and Reflex anoxic Seizures (STARS), Atrial Fibrillation Association (AFA) and the British Cardiovascular Society (BCS).

We would like to thank you all for your involvement and support during 2009 – without your help, we could not continue the work we do.

The Affiliation Scheme in Action

With more cardiac devices being implanted throughout the UK, there are an increasing number of patient groups being established. These are currently a mixture of patient, physiologist and/or nurse-led groups, all meeting at regular intervals throughout the year.

One issue that has become apparent is the need for networking and standardisation of the information that is provided to arrhythmia patients/carers and also the need to run the group with professional input. Affiliation to Arrhythmia Alliance ensures a national standard is reached with regards to all patient information.

Affiliation of a patient group or organisation to Arrhythmia Alliance has a number of benefits. Most importantly, the link to Arrhythmia Alliance enhances a group's credibility. It also means that a group has access to advice, support and information that is accredited and endorsed by the Department of Health and independent medical professionals who sit on the Arrhythmia Alliance Executive Committee.



Arrhythmia Alliance Founder Awarded MBE

On Tuesday 24th November 2009, Trudie Lobban, founder of Arrhythmia Alliance and STARS (Syncope Trust And Reflex anoxic Seizures), received her MBE at Buckingham Palace.

Trudie, who started the STARS charity from her kitchen table in 1993, was given the award in the Queen's Birthday Honours list earlier this year for services to healthcare.

STARS was founded after her younger daughter was diagnosed with a little-known heart rhythm disorder, Reflex Anoxic Seizures, aged three and she could find nowhere to turn for help.

Since then, the charity has expanded internationally, with a division in the United States.

In 2004, Trudie launched a campaign that succeeded in changing a government health policy. The campaign brought about the inclusion of heart rhythm disorders, or arrhythmias, into national standards for coronary care with the aim of improving diagnosis and treatment for



all people with abnormal heart rhythms.

Trudie went on to establish Arrhythmia Alliance as an umbrella organisation that brought together patients, medical professionals and

industry to further the gains she had already made. A third charity, based in Bristol, focusing on patients with Atrial Fibrillation has also been formed and in addition, Trudie now sits on many medical boards.

Trudie is actively helped in her charity work by her daughters, Charlotte and Francesca who are both now adults. Charlotte has almost completed training to become a doctor herself. The charity now employs 12 staff and is based near Stratford-upon-Avon.

Trudie says "I am so delighted to be receiving this award today. It's been a long road and hard work but we have achieved so much in our efforts to help people with cardiac arrhythmias. I want to share it with the people who have worked with me to make a difference."

Trudie's husband, Charles, who worked tirelessly alongside her, sadly passed away in 2008 from Sudden Cardiac Death, before her MBE was awarded.

The Rhythm of My Heart - by Dave Bailes

POW!...somehow does not quite adequately describe the sensation of having 800 volts delivered to your heart. If one is asleep when this happens, or half asleep as I was, one is very much awake afterwards!

Years after my heart attack I was thought to be at risk of suffering VF (Ventricular Fibrillation) where the heart beats very fast and chaotically.

Going into VF at home, far from health professionals and their defibrillator, is



often fatal. Beating fast and erratically the heart can't pump blood properly, so the first thing to suffer is the brain as it gets starved of oxygen. If the patient is awake, he or she is aware of a fainting feeling; if it goes on long enough collapse will occur. After a few minutes brain damage may occur, and brain death follows not that long after.

My personal POW! was not given by a health professional but was delivered automatically, at 3am one morning, whilst I was alone in bed.

Back in May 2008 I was fitted with one of the cleverest pieces of technology in the world, an "Implantable Cardioverter Defibrillator" (ICD).

My ICD, the size of a very streamlined stainless-steel mobile phone, sits just under the skin of my chest below my left shoulder with two leads going into my heart through a vein. Most of the time I forget it is there, there is just a small sensitive area where the leads come

close to the surface. The ICD monitors the heart and helps keep the lower half, the ventricles, beating at a steady rate, with an allowance for a slightly faster rate for exercise. If the beat rate of the ventricles goes over a set upper limit number the ICD then delivers a shock straight into the heart to try to get it beating regularly again.

My 3 a.m event brought me fully awake. I could not get back to sleep and, feeling very lonely and vulnerable I called NHS Direct. In the end I was taken into A&E and given a range of tests, all of which gave the correct results.

I like my little electronic friend a lot, as the consultant said, "But for that device you would not be sitting here now."

The only real down side is that one has to surrender one's driving licence for six months after implantation and after every subsequent event. Suffering a fainting spell followed by an electric shock does not make for safe driving!

Arrhythmia Alliance Patients' Day

Last year's Arrhythmia Alliance Patients' Day was held on Sunday 18th October at the Birmingham Hilton Metropole Hotel.

Patient members came together to listen to a wide range of presentations and browse the first dedicated Patient Exhibition. Both the Atrial Fibrillation Association (AFA – www.atrialfibrillation.org.uk) and Syncope Trust And Reflex anoxic Seizures (STARS – www.stars.org.uk) held Patient Day meetings at the same event.

"The day was excellent and I look forward to next years Patients' Day"

Once registered, delegates could select from more than 20 presentations, many of which are on our website: www.heartrhythmcharity.org.uk.

The day was a huge success, highlighted by patient stories and the ever popular 'Ask the Experts' opportunity.

"Great to meet so many people who KNOW what it's like".

Following the success of last year's event, we shall be holding our next Patients' Day on Sunday 3rd October 2010, at the Birmingham Hilton Metropole Hotel. We will share the agenda with you as soon as possible so keep an eye out on our monthly e-bulletins.

To register your attendance, please email Heather at heather@heartrhythmcharity.org.uk.

Regional Meetings 2010



Following the success of the Arrhythmia Alliance Regional Meetings in 2009, we will be hosting 11 patient meetings in 2010, providing information for patients and carers on how to get the best out of their local services.

We will be inviting a local arrhythmia nurse to demonstrate pulse checks, raising further awareness of the 'Know Your Pulse' campaign. A local GP will explain what patients should expect at a Primary Care level and the developments in arrhythmia care, including new drugs and new services.

We will be hosting meetings in the following regions;

Bristol - 30th June (TBC)

Cambridge - 7th July (TBC)

Glasgow - 25th June

Leeds - 4th June

London (Croydon) - 23rd June

Manchester - 23rd June

Oxford - 25th May

For more information, [click here](#)

Arrhythmia Awareness Week 7th-13th June 2010

Following the success of Arrhythmia Awareness Week 2009, we will continue our Know Your Pulse campaign for AAAW 2010 between 7th- 13th June.



In the UK, the 'Know Your Pulse' campaign aims to raise awareness of the pulse as a way to identify potential cardiac arrhythmias.

The long term goal is for pulse checks to become routine procedure during GP visits.

By raising awareness of this simple health check, more people can be diagnosed and treated for potentially lethal cardiac arrhythmias.

During AAAW 2010, events will take place to highlight the need for people to be 'pulse aware'. Your local initiatives are so valuable to raise awareness of the campaign amongst those with no prior knowledge of how important it is to 'Know Your Pulse'.

What you can do...

Pulse Check Cards – For individuals, friends and family. The Pulse Check Card is a self-educational tool that teaches the reader how to take their pulse, what it means and when they should seek further advice for an irregular heartbeat.

Posters and Leaflets Pack – Ideal for distributing information and promotional items, individuals can take this pack to their GP surgery, hospital, medical centre, care home, local school, work place, and community centre.

Pulse Check Pack – With a selection of information and promotional items, this pack is for those holding a Pulse Check Clinic teaching people how to take their pulse.

It can also be used for those holding a display stand at your local hospital, shopping centre, GP surgery or community centre. It includes Pulse Check Cards, checklists, and promotional materials.

We are determined that with your help, AAAW 2010 will be even more successful than in previous years. We want to have greater impact on the key issue of pulse checks in GP surgeries to ensure that more people receive the correct diagnosis and treatment.

For more information about how to get involved or order your Awareness Week materials visit our website www.aaaw.org.uk, or call 01789 451823 or email joanna@heartrhythmcharity.org.uk.

Please note, if you are attending any Regional Meetings, we can ensure that your Awareness Week materials are available to collect on the day.

RESTART THE HEART

As you may be aware, Sudden Cardiac Arrest (SCA) is the abrupt and unexplained loss of consciousness caused by a malfunction in the heart's electrical system.

SCA can happen to anyone, anytime, anywhere and without warning. The only treatment for a patient of SCA is the administration of a defibrillation shock to the heart.

The 'Restart The Heart' campaign aims to facilitate the placement of Automated External Defibrillators (AEDs) in communities. This is achieved by raising awareness of SCA and supporting individuals and groups across the country who wish to place AEDs in their locality. By placing an AED in your community, for public access, you could save the life of a relative, a friend, a neighbour or a colleague.



The Restart The Heart campaign has five principle aims:-

- To increase public awareness of and understanding about SCA
- To increase awareness of the importance of AEDs as emergency life-saving equipment
- To increase public confidence in the use of AEDs
- To increase the placement of AEDs in local communities
- Provision of, and improvements to, AED locator mapping

CPR Alone = 5% Chance of Survival
CPR & AED = 50% Chance of Survival

We insist that all AED placements run in collaboration with the local Ambulance Service and, if present, the Community First Responder (CFR) team. The intention of the campaign is to promote all initiatives in relation to public access

defibrillation and to enhance and compliment the current emergency service frameworks.

As part of the campaign, we are able to offer a range of resources to help promote an AED placement project, such as information booklets, awareness posters, press releases and presentation slides.

We also have a Community AED Placement Toolkit which has been designed as a practical guide to help you through the entire process of an AED placement and to answer any questions you may have.

Mini-Anne CPR & AED Training Kit

We are also pleased to announce that a 'Mini-Anne Self Directed CPR & AED Skills Learning Programme' is now available to purchase. With a fully interactive DVD, the self directed Mini-Anne kit allows individuals to learn core skills of Cardiopulmonary Resuscitation (CPR) and the use of an Automated External Defibrillator (AED).



The kit is suitable for people of all ages and levels of prior knowledge, providing an invaluable source of AED training and demonstration.

It includes the complete set of apparatus needed to simulate the process of performing CPR and using an AED; from identifying a patient in need of medical assistance to the arrival of the emergency services.

The interactive DVD is a revolutionary method of teaching these life-saving skills. It employs a unique "watch and do" technique where the user can practice CPR (30 compressions: 2 breaths) on a personal manikin (Mini-Anne) and learn how to use an AED.

For more information, please [click here](#) or contact a member of the Arrhythmia Alliance team on 01789 451830 or by email at rth@heartrhythmcharity.org.uk

Fancy a chat with someone who understands?

The Heart Rhythm Charity message board is a moderated forum enabling arrhythmia patients and carers to talk with fellow Arrhythmia Alliance members.

The board is confidential with no mandatory full names or contact details disclosed and it is free to join via the A-A website: [Click here to view it](#)

The aim of this moderated message board is to provide the opportunity for patients, carers and family members to express any worries they may have, discuss stories and experiences and reassure each other at difficult and unfamiliar times.

Join the Heart Rhythm Charity Message Board...

Useful Links and References



As part of our ongoing support to affiliate members, this section of the Affiliates Newsletter shares some useful links and references which provide information on relevant topics affecting arrhythmia patients and carers.

The purpose of the 'Useful Links and References' is to provide guidance on topics that have been identified through our communications with affiliate members and medical professionals.

This will be a growing section of the newsletter and if you have any topics that you would like further information on, please let us know and we will aim to include an article or link in forthcoming publications.

1. Planning to go away but worried about your implanted device?

Here at Arrhythmia Alliance, we often receive enquiries from members who are concerned about travelling abroad with their ICD or similar cardiac management device.



We have done our research and found the following website which gives details of implant centres and therapy providers in 120 countries across the globe:

<http://www.medtronic.com/traveling>

I hope you find this link reassuring for travelling safely.

2. Want to hear the latest from the DVLA about driving with a heart rhythm disorder?

The DVLA rules and regulations are revised periodically. Their most up to date advice is listed on their website: <http://www.dft.gov.uk/dvla/medical/ataglance.aspx>



The '[At a Glance](#)' booklet available to download from this site provides the current medical standards of fitness to drive. As a heart rhythm patient, you should refer to chapter 2 of the document.

Download your '[At a Glance](#)' booklet today to find out more.

3. Looking for Travel Insurance?



It can sometimes be difficult to find cost-effective travel insurance if you have a medical condition.

The Association of British Insurers (ABI) has compiled a list of travel insurance providers who are able to provide insurance for people with medical conditions. You can download this list from the Arrhythmia Alliance website. For more information and to view [visit the website here](#).