



Arrhythmia Alliance
The Heart Rhythm Charity

www.heartrhythmcharity.org.uk

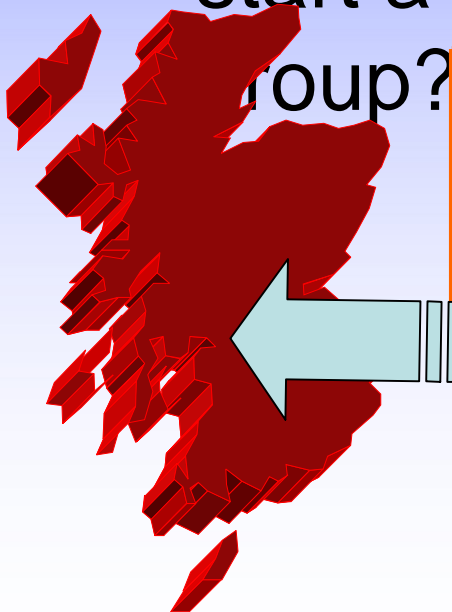
*Promoting better understanding, diagnosis, treatment and quality of life for
individuals with cardiac arrhythmia*



***Working together with individuals,
families and medical
professionals to offer support
and information on syncopes
and reflex anoxic seizures***

It started with Francesca...

- Glasgow, Scotland
- “Trudie, would you start a little support group?”



Prof J.B.P.
Stephenson

Facts & Figures

- Syncope poorly investigated
- 50% population are affected at some stage in life by syncope
- 100,000 experience loss of consciousness
- 30%(A)& 39%(C) Epilepsy misdiagnosed
- 3% of cases presenting in casualty
- 1% all hospital admissions
- 50% leave hospital without a diagnosis

Falls and Syncope common in older patients

Reasons for A & E attendance >75 yr (Italian study)

21% general decline

15% SOB

15% Falls

13% Abdo Pain

9% Chest Pain

7% Syncope

5% Stroke

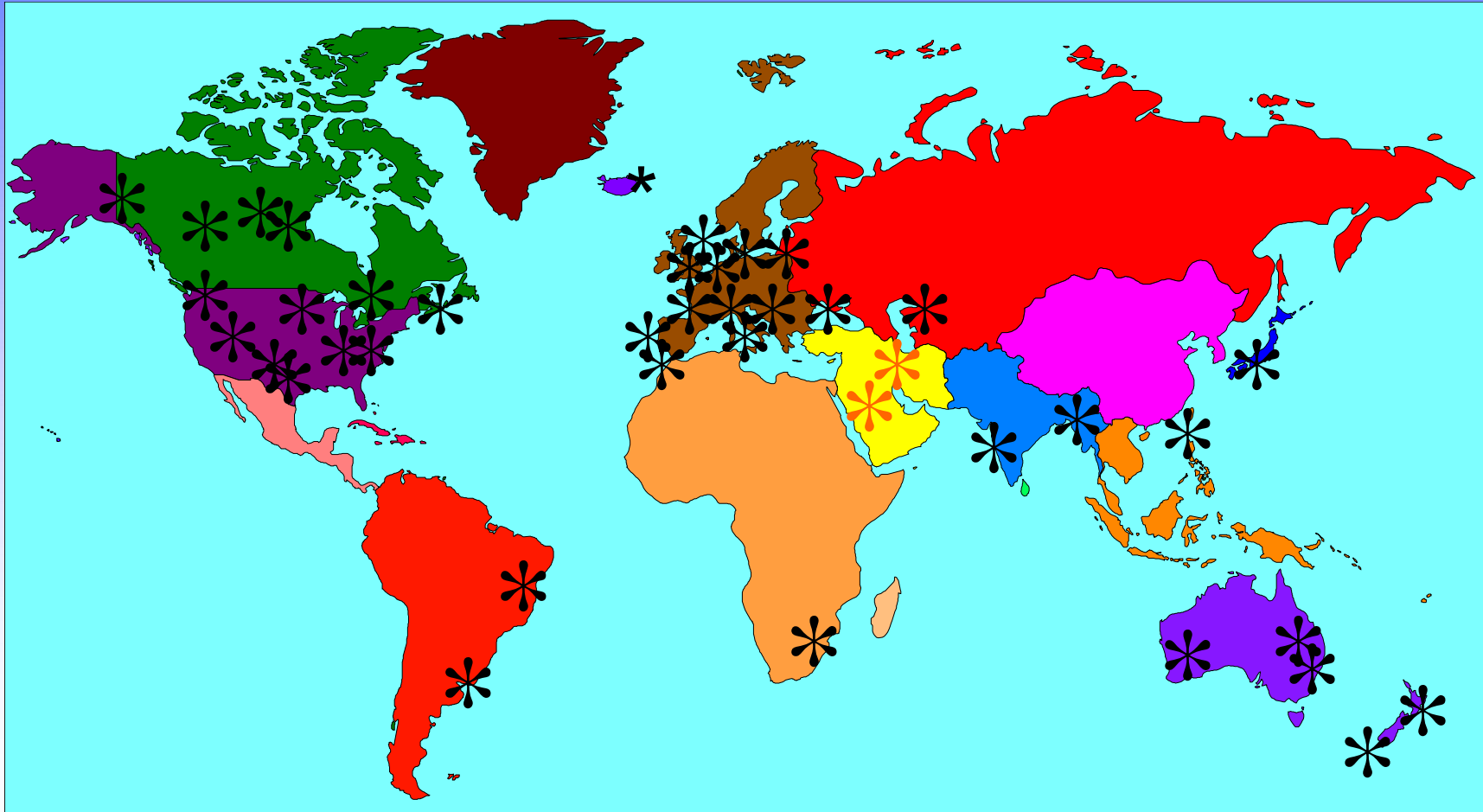
More common than Stroke/Chest Pain - and taken together - the commonest presentation

Impact of syncope in adults

- Anxiety and depression 73%
- Daily activity affected 71%
- Restricted driving 60%
- Changed employment 37%

Linzer et al study (1994)

*..we've gone world wide with
www.stars.org.uk....*



*... we've brought together medical
specialists from every field...*

NEUROLOGY

CARDIOLOGY

PAEDIATRICS - GERIATRICS

PSYCHOLOGY

to form:

**Medical Advisory Committee
(STARS MAC)**



**The
Blackouts
Trust**

*"working together with individuals, families and medical professionals
to offer support and information on syncope and reflex anoxic seizures"*

THE BLACKOUTS CHECKLIST

**HELPING YOU AND YOUR DOCTOR REACH
THE CORRECT DIAGNOSIS**

**DO YOU OR YOUR CHILDREN
SUFFER FROM UNEXPLAINED
LOSS OF CONSCIOUSNESS
(BLACKOUTS)?**

www.stars.org.uk

PO Box 175 Stratford-upon-Avon Warwickshire CV37 8YD
Tel: +44 (0) 1789 450 564 Fax: +44 (0) 1789 450 682
Email: trudie@stars.org.uk

Registered Charity No. 1084898

STARS aims ...

- ★ to offer support and information

- ★ to raise awareness

- ★ to promote research

 - ★ every day

 - ★ for every age group

 - ★ in every country in the world

 - ★ with doctors from every relevant field

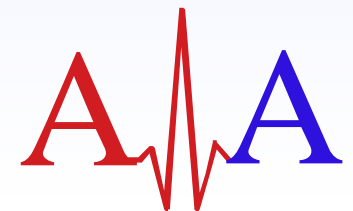
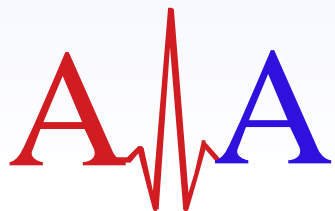
Joining Forces September 2003

→ Active Members

- CMA
- SADS
- STARS

→ Supporters

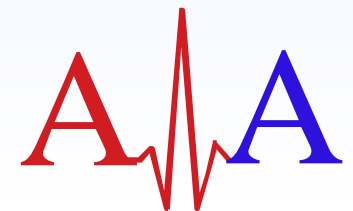
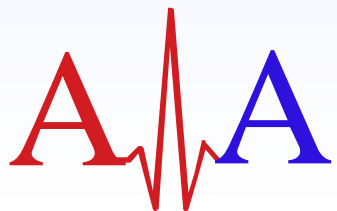
- BCPA
- BHF
- CHF



A large graphic of an ECG waveform in orange and red, overlaid on a white grid background. The waveform is stylized and serves as a decorative element for the main title.

Arrhythmia Awareness Week

To improve Awareness, Diagnosis and Treatments leading to a better Quality of Life for those with Cardiac Arrhythmias



AAAW 2004 Objectives

- **Raise awareness of cardiac arrhythmias**
- **Prompt government to set targets for their diagnosis and treatment**

***Sir Roger Moore's
letter to Tony Blair***

Dear Prime Minister

I learnt recently of your worrying medical experience, which the media have reported as a rapid heart rate....

I know from personal experience how frightening and worrying this can be for yourself and your family, and in your case also for the government and the country!

... I would like to extend a personal invitation to meet you at the launch of the Arrhythmia Awareness Week campaign at Westminster...

I do hope you will lend your support...



10 DOWNING STREET
LONDON SW1A 2AA

27 December 2003

THE PRIME MINISTER

Dear Roger,

Thank you for your letter of 5 December enclosing information about STARS (Syncope Trust and Reflex Anoxic Seizures) of which you are Patron. I was interested to read of the important work that the Charity has done in recent years to raise awareness of various types of syncope.

I well understand how you felt about your recent experience. I do hope that the first UK Arrhythmia Awareness Week in May will be a success. Unfortunately due to my other diary commitments I will be unable to attend the launch but I wish you and the other campaigners every best wish for 2004.

I am amazed at how many people seem to suffer from this, so I'm in good company! I am sorry I can't make the launch but I would be happy to see a message of support.

Have a great Christmas,

Yours sincerely,

Tony Blair

Sir Roger Moore KBE

Tony Blair's letter to Sir Roger Moore

Tony Blair's letter to AAAW partners



10 DOWNING STREET
LONDON SW1A 2AA

THE PRIME MINISTER

I congratulate the partnership on coming together for the first UK Arrhythmia Awareness Week and wish you every success. The partnership between STARS, the Sudden Adult Death Trust (SAD), the Cardiomyopathy Association (CMA) and the British Cardiac Patients Association (BCPA) during this week will increase the profile and improve knowledge of cardiac arrhythmias within the community.

The Government is committed to reducing mortality rates from heart disease by at least 40 per cent in people under 75 by 2010. The National Service Framework for Coronary Heart Disease, published in March 2000, set the agenda for the modernisation of CHD services over a ten year period and set standards for improved prevention, diagnosis, treatment and rehabilitation and goals to secure fair access to high quality services. This investment will lead to quicker access to diagnosis and treatment for people suffering from rhythm disturbances.

A handwritten signature in blue ink that reads "Tony Blair". The signature is written in a cursive style and is underlined with a single horizontal line.

12 May 2004

STARS volunteer takes her campaign to London

Mum raises awareness at Westminster launch

Mother highlights abnormal heartbeats

Heart disorder targets to be revealed

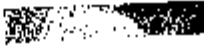
Mike Waites
Health Correspondent

Heart specialists warn of Welsh risk

WALLES risks falling behind the rest of the UK in heart patients and measures are taken to reduce the risk of abnormal heartbeats that can reduce the risk of a heart attack - will be made available over the summer.

Cash needed for pacemakers

HEALTH Secretary John Reid could save up to



Arrhythmia Alliance has health awareness groups.

By Cathrine Reid
STARS volunteer
STARS is a charity for people with arrhythmia

Mum to lobby MPs on seizures trauma

By Nigel Gould
HEALTH Correspondent

WHEN he was just five months old, four-year-old Joel Reid "fainted" in his mother's arms. It was to be the first of a series of transient seizures, where the little Banbridge boy's heart stopped beating for up to 10 seconds. Now, mum, Cathrine is in Westminster to lobby MPs and raise awareness of the redoubtable rare Reflex Anoxic Seizures (RAS), which her son suffers from.

She will be joining a number of other mums in the UK to launch a campaign to highlight Arrhythmia Awareness Week. The illness is triggered by unexpected stimuli such as pain or shock. It causes the heart to stop breathing to eyes to roll up into

'I hope Colin did not die in vain' - mum

due to a problem to become the only white/grey, often the only one the month and as the boy is still in hospital and

an hour. "Joel was five months when he had his first seizure," she said. "It occurred in a relatively normal situation. I lifted him out of the bath and placed him on the floor and he lay flat for a few minutes. He stopped breathing and his body went

vain' - mum

Cathrine tells MPs and medical experts about her son's condition

THE following is the speech which Cathrine Reid delivered to delegates attending the launch of Arrhythmia Awareness Week.

newspaper coverage, presentations, and television appearances. I have also been actively involved in fundraising for

Arrhythmia has changed our lives. Joel is now able to play rough and tumble with other children, without me constantly hating and tick-

Results

- Lobbying and letter writing

14 October 2003

“There are no plans to extend the National Service Framework (NSF) for Coronary Heart Disease”

Melanie Johnson, Public Health Minister

Results

- Lobbying and letter writing

1 January 2004

“The issue of arrhythmia and its management and how this might relate to the NSF is currently under consideration.”

Melanie Johnson, Public Health Minister

Results

- Lobbying and letter writing

16 February 2004

*“...NSF for Coronary Heart Disease...
does not mean it is incapable of extension.”*

Melanie Johnson, Public Health Minister

Results

- Lobbying and letter writing

1 April 2004

*“... could lead to the drafting of a new
chapter...”*

Melanie Johnson, Public Health Minister

Results

- Lobbying and letter writing

26 April 2004

“...reassure you that we are aware of this area of concern, and are giving the management of arrhythmia active attention.”

Melanie Johnson, Public Health Minister

AAAW Supporters

May 2004

- Prime Minister
- Sir Roger Moore
- Health Minister
 - Heart Tsar
- DoH Heart Team
 - 200+MPs
- Patient Support Groups

- BPEG (HRUK)
- Independent Medical Prof.
- 100 Hospitals
 - Industry
 - Patients & Carers

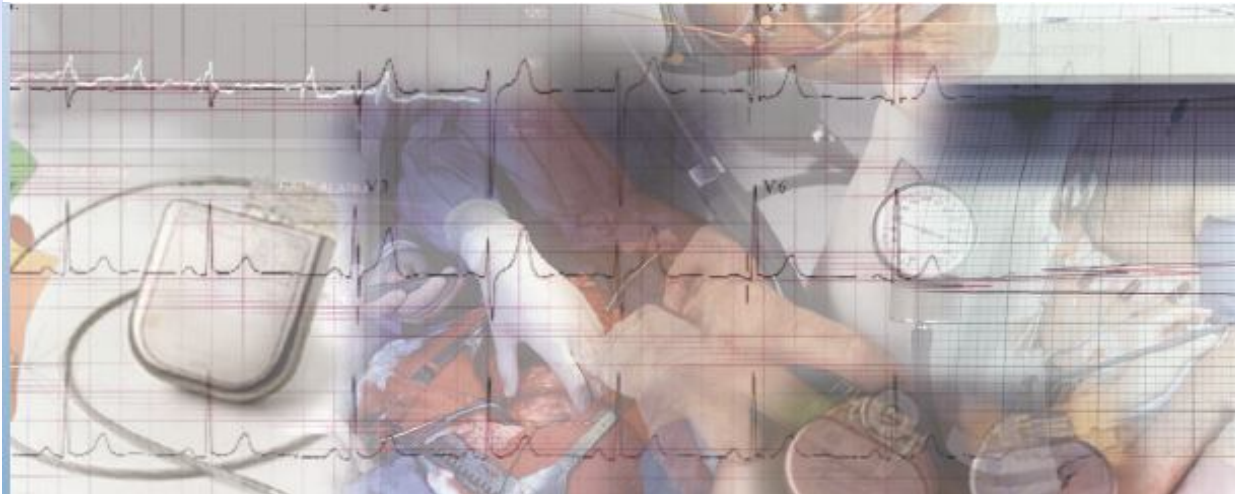
Results

- House of Commons event
 - Attendance by Public Health Minister and Heart Czar, 98 MPs, 75 clinicians and healthcare executives, and 150 charity volunteers
 - Additional media coverage of arrhythmias (and the importance of their diagnosis and treatment)
 - Promise by Government officials to amend the NSF with a new chapter on arrhythmias

Arrhythmia Alliance

The Heart Rhythm Charity

Trudie Lobban
Founder & Trustee





- Is a coalition of charities, patient groups, patients, carers, medical groups and allied professionals. These groups work together under the A-A umbrella to promote timely and effective diagnosis & treatment of arrhythmias.
- The A-A supports and promotes the aims & objectives of the individual groups.

A-A DATABASE

Cardiologists, EP's, Nurses, Physiologists, GP's, Practice Nurses, Paediatricians, Geriatricians, PCT's, Cardiac Networks, SHA's, Ambulance Services, Resuscitation Council, Patient Groups, Post Graduate Centres, Industry, Individual patients and carers

TOTAL: 17,500 (+RCN 400,000!)



Coronary Heart Disease

National
Service
Framework

Chapter Eight

Arrhythmias and Sudden
Cardiac Death

8



www.dh.gov.uk

Executive Committee

President - Prof A John Camm

Dr Phillip Batin

Mr Pierre Chauvineau

Dr Campbell Cowan

Dr Neil Davidson

Dr Wyn Davies

Mr Steve Gray

Mr Robert Hall

Dr Guy Haywood

Mrs Sarah Jacob

Mrs Anne Jolly

Ms Sue Jones

Dr Gerry Kaye

Dr John Morgan

Mrs Jayne Mudd

Dr Francis Murgatroyd

Dr Richard Schilling

Dr Graham Stuart

Mrs Jenny Tagney

Mr Paul Turner

Trustees - Dr Derek Connelly Dr Adam Fitzpatrick Mrs Trudie Lobban



Arrhythmia Alliance
The Heart Rhythm Charity

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

**NATIONAL REQUIREMENTS -
LOCAL IMPLEMENTATION**
Summary of National Service Framework for
Arrhythmia's & Sudden Cardiac Death



Arrhythmia Alliance

P O Box 3697 Stratford Upon Avon Warwickshire CV37 8YL



Working In Partnership:

- Government
 - Engaging with Health Secretary
 - Hosting reception at Westminster
 - Reception at No 10 Downing Street
- Dept of Health
 - Expert group to produce guidelines
 - Implementation Board
 - SCD Board
 - NHRMD Taskforce
 - Patient Education, Information & Support
- British Heart Foundation
 - Steering Group – arrhythmia nurses
 - Steering Group – education & training
 - Steering Group – Teen web site

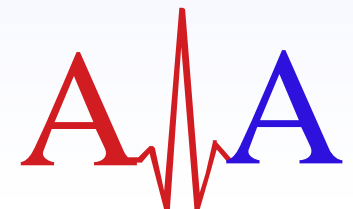
Arrhythmia Alliance plus

- Patient Groups
 - STARS / SADS UK / CMA = AAWW
 - Identify ICD Groups, develop guidelines and become 'accredited' producing national standards – National Voice
 - Recruit & train volunteers
- Government & Dept of Health
 - Change government policy and influence future policy maker
 - Bridge the gap between patient/clinician/government
- Medical Groups
 - Influence government & provide accredited information
 - Ensure patients receive the treatment to which they are entitled
- Industry
 - Resources & Expertise
 - Procurement

AAAW Supporters 2006

www.aaaw.org.uk

HR UK; HR UK Nurses; Heart Rhythm Society; Physiologists; RCN; Government; Dept of Health; Industry; LMCA; Age Concern; ICD Support Groups; BHF; CHF; Patients Association; British Army Corps; USA Patient Groups; Eurordis; NORD; IAPO; Spanish Heart Patient Groups; French ICD Support Groups (APODEC); SADS UK; SADS USA; SADS Canada; SADS Australia; CMA; STARS; etc



What can we achieve together?

- Awareness
- Patient education
- Advocacy with Dept of Health
- Greater understanding amongst the medical profession of patients needs
- Stronger fund raising – for research, education projects

Why do we need an alliance?

Force in numbers

Dept of Health approach the Alliance before
the medical professionals!

Medical Profession approach the Alliance before the
Dept of Health!

Government officials LISTEN to the voter!

Trust – there is no ulterior motive

No perceived conflict of interest

Patient choice

Arrhythmia Alliance Vision

- “Every person affected by an arrhythmia will receive *information, support* and *rapid access* to appropriate treatment”
- Will achieve this through advancing

Awareness

Diagnosis & Treatment

Improved
Quality of Life of those affected

Arrhythmia Alliance bridges the information-care gap

PROBLEM

Tens of thousands churning in the healthcare system not properly diagnosed

Thousands treated but no support mechanism

- 100,000 sudden cardiac deaths pa
- 1 million arrhythmia sufferers
- 120,000 loss of consciousness pa
- 30% adults & 39% children incorrectly diagnosed with epilepsy, many have an underlying, potential fatal, cardiac arrhythmia
- 1.5 million hospital days

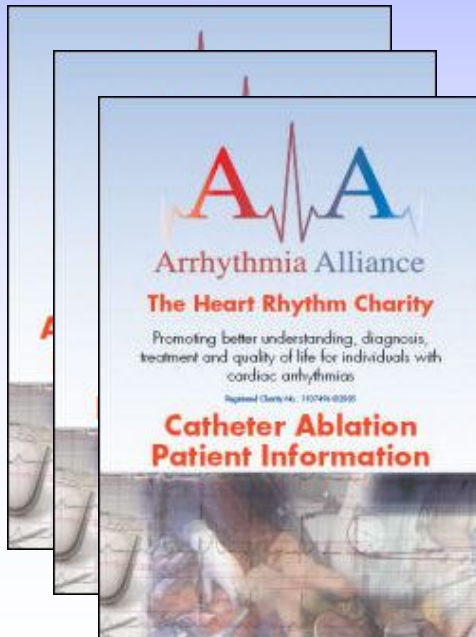
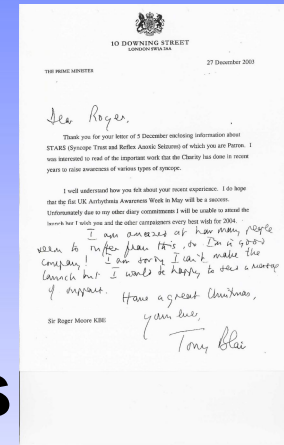
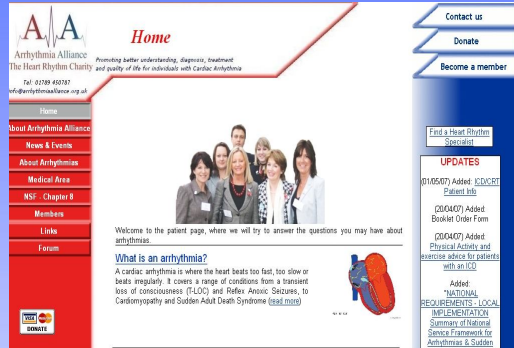


A-A Solution

Build awareness in General Population & Primary Care

Support network

This is achieved with a number of information channels

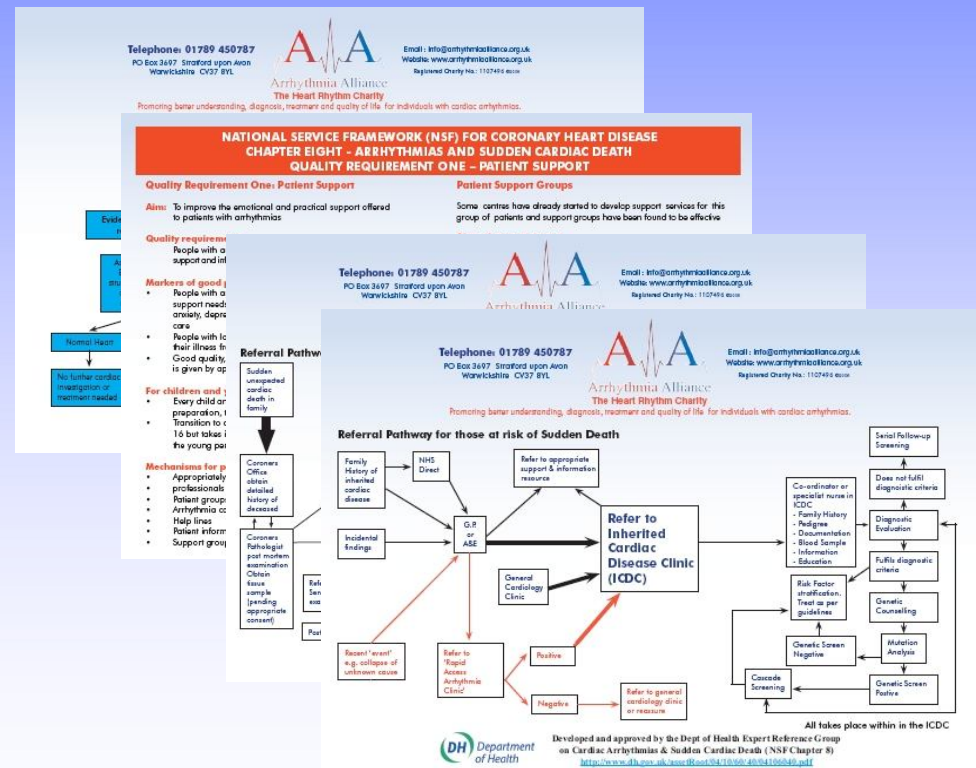


- Information booklets: general/patients/carer's
- Website
- Congresses
- Articles, Newsletters
- Telephone helpline
- AAWW



Achieving our goal will save thousands of lives and millions of pounds

- Awareness
- Accredited information
- Support
- Job Descriptions
- Business Case Template
- Care Pathways
 - Management after resuscitation from Cardiac Arrest
 - National Framework Patient



NEW Patient Information Leaflets:

Bradycardia

Tachycardia

Exercising with your ICD

ICD/CRT

Pacemaker/CRT

Sudden Cardiac Arrest

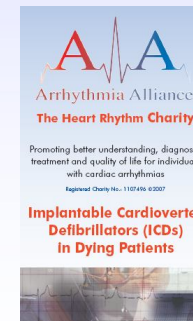
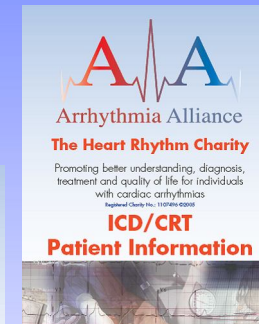
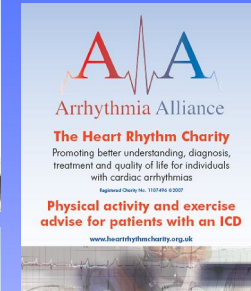
How to Establish Rapid Access Clinics

ICD Deactivations

Testing Using Drug Injections

Drug Treatment for Arrhythmias

Blackout Checklist



STATS 2006

	Hits	Distinct Hosts
Website	2.14 M	83,110
Telephone	22,626	
E-Mails	131,889	

STATS 2007 to date

Website		Hits	Hosts
Jan		208,888	1967
Feb		295,018	3167
Mch		399,997	3506
Apl		1,006,443	3546
E-mails			
Jan		20,526	
Feb		21,706	
Mch		20,489	
Apl		16,867	
Telephone		2,638	

MEETINGS 2007 to date

- **Volunteer Day 10th March including discussions towards helping with ICD Support Groups.**
- **ICD Group Meetings – Oxford, Bournemouth, Liverpool, Wolverhampton, N Glos**
- **Meetings with Industry around Europe highlighting the work of A-A**
- **Regional Meetings – North, North West, South, South West, Midlands and London – Implementation of NSF Chapter 8**
- **USA / NORDIC / NETHERLANDS / FRANCE / SWITZERLAND / SPAIN**
- **RCN School Nurses Conference – London**
- **The 7th York Cardiac Care Conference – Rehabilitation**
- **DoH – SCD / NHRMD Taskforce**
- **AED – First responders & AED coys**
- **BHF – ACC / CVD TASKFORCE**

UK Heart Rhythm Congress 2006

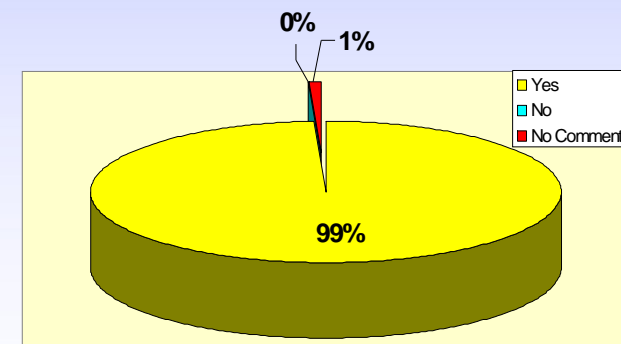


- Held at The National Motorcycle Museum, Birmingham.

• Only 150 delegates were expected to attend, 800 delegates registered for the meeting.

• Evaluation results show that nearly 100% of delegates would attend HRC07

UK HEART RHYTHM CONGRESS 2006
I would attend the meeting again next year



Endorsed by



Heart Rhythm Society



EUROPEAN
Heart Rhythm
ASSOCIATION
A Registered Branch of the ESC

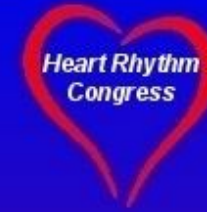
British Society for Heart Failure



British
Cardiovascular
Society

Heart Rhythm Congress

2007



Hilton Birmingham Metropole

- International Speakers
- Live Cases
- Patient Day
- Devices and Intervention Courses



www.heartrhythm.org.uk

Tel 01789 451831

E-mail: aa@stars.org.uk

Endorsed by



Heart Rhythm Society



EUROPEAN
Heart Rhythm
ASSOCIATION
A Registered Branch of the ESC

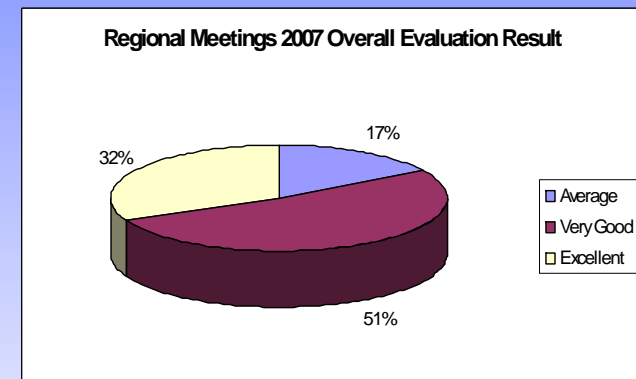
British Society for Heart Failure



British
Cardiovascular
Society

REGIONAL MEETINGS 2007

- Meetings within the regions of North, North West, South, South West, Midlands and London.
- Implementation of the NSF Chapter 8
- Wales Regional Meeting will be on Tuesday 18th September and Scotland Regional Meeting is yet to be confirmed.
- Possibility of an Irish Regional Meeting
- Up to 100 delegates at each meeting
- Evaluation results show that all meetings were, again a success



HandPICKED
HOTELS

Sponsored by



WEBSITE / SECURE MEDICAL AREA

73 Members and counting



- Accredited information for medical professionals
- Care Pathways
- Job Descriptions
- Information on establishing Rapid Access Blackout Clinics
- Drug Protocols
- Cardiac Rehabilitation
- Business Case Templates
- Collection of presentations
- Medical Papers
- Medical Forum

Our Goal In 5 years

Everyone will understand arrhythmias (incl syncope and scd) as they do chest pains

All those affected will be diagnosed accurately and have access to services as specified in the NSF

All those affected by arrhythmias & sudden cardiac death will receive appropriate support & information

Widespread placement of AEDs in public places

Key milestones for next year

First rapid access blackout clinic

Patient information in all hospitals

Education & Support

STARS Shine a Light on Education Project!

- **Aim:** To educate teachers, staff and carers of syncope & arrhythmia sufferers
- **Need:** Children excluded, staff panic and over-react, inadequate support provided, basic lack of awareness
- **Resources:** Website, Information pack, Staff Training DVD, In-school Presentations

Identifying & establishing ICD Groups

- **Aim:** To identify existing ICD Groups & establish new groups = National

Affiliation to A-A

Accredited information endorsed
by Dept of Health

What can A-A offer ICD Groups?

- Design of website
- Information/funding advice
- Volunteer Training
- Helpline support and advice
- Promotion of events & meetings via A-A website & e bull
- Free membership for patient & carer

ICD SUPPORT GROUPS

A-A is offering affiliation to ICD support groups to ensure best practice & national standardisation of the information and support provided to patients.

Affiliate groups will receive:

- Accredited & DoH endorsed information
- Helpline support & advice
- Free website hosting & design
- Group management guidance
- Free A-A membership

'Where's the AED?' Campaign

AIMS:

- To raise awareness of cardiac arrest and AEDs & promote their placement in public places

NEED:

- Approx. 100,000 people suffer cardiac arrest per annum in UK

RESOURCES:

- Website, awareness materials, media campaign, public launches

AAAW 2006 - 2007

AAAW 2006 was very successful with 165 events taking place throughout the UK. Those involved included Cardiologists, Doctors, Nurses, PCT's as well as patients and individuals. Events took place in Hospitals, GP Surgeries, Schools, Libraries, Shops and other venues within the Community. All events reported good attendance and feedback demonstrates the need for greater awareness.

AAAW07 will focus on further awareness and fundraising to ensure that more Automated External Defibrillators (AED) are available to the general public to be trained in their use in order to save more lives.

We are looking for even more volunteers to help during AAW07 and would like to at least double the number of events (www.aaaw.org.uk).

“It is important that healthcare services meet the needs of patients affected by arrhythmia and they receive the same expert care that I received. I was lucky to have expert advice and treatment. My heart goes out to families who have suffered bereavement through sudden cardiac death”.

Bill Beaumont OBE - Patron of Arrhythmia Alliance

Arrhythmia Awareness Week 07

11th-17th June 2007

Objectives:

- Raise awareness to ensure the ongoing implementation of the NSF
- Highlight greater awareness within primary care
- Target GPs in person with A-A/STARS promotional material
- World Awareness Day – 17th June 2007

With volunteers hosting events to achieve these objectives



www.rrhythmiaalliance.org.uk



www.stars.org.uk



www.sadsuk.org



www.parentheartwatch.org

USA



www.scdyoung.ie

Ireland



www.paceafrika.org.za

South Africa



www.sads.org

USA



www.cidg.org

New Zealand



www.suddencardiacarrest.org

USA



www.stin.nl

Netherlands



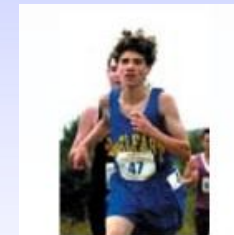
www.TakeItToHeart.org

USA



www.savingyounghearts.org

USA



www.safeathletes.org

USA



www.hruk.org.uk

UK



www.pediatricpsociety.org

USA



www.livewiresni.org

USA



www.anthonybates.org

USA



www.bsh.org.uk

UK

What more is needed?

- Volunteer-based organization growing to 250 volunteers and 20 staff
- Work to support & promote the aims & objectives of the individual patient group members of A-A
- Booklets in every hospital and widely in primary care
- Educational presentations distributed to public
- Professional Telephone support 24/7
- Congresses, patient meetings, awareness events
- Leverage links with international sister

**The
Power
of an
Alliance**