

# Arrhythmia Alliance The Heart Rhythm Charity

### The Role of Arrhythmia Alliance

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





- 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.

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# 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

### THE A-A PARTNERSHIP

Government, Dept. of Health, Cardiologists, EPs, Nurses, Physiologists, GPs, Practice Nurses, Paediatricians, Geriatricians, PCTs, Cardiac Networks, SHAs, Ambulance Services, Resuscitation Council, Patient Groups, Post Graduate Centres, Industry, Individual patients and carers

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





## 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

A Patient choice

# Arrhythmia Alliance bridges the information-care gap

**PROBLEM** 

Tens of thousands churning in the healthcare system not properly diagnosed

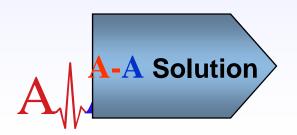
Thousands treated but no support mechanism

- 100,000 sudden cardiac deaths
- 1 million arrhythmia suff
- 120,000 loss of consc usness p
- 30% adults & 39% ch 'dren are incorrectly diagnosed epilepsy, many have an underlying, potential fatal, cardiac arrhythmia
- 1.5 million hospital days.









Build awareness in General Population & Primary Care

Support network

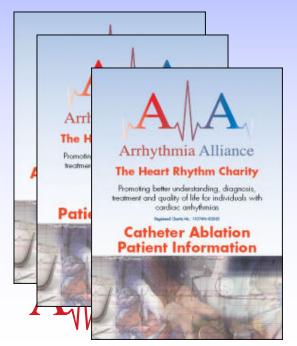
# This is achieved through a number of information channels





 Information booklets: general/patients/carers

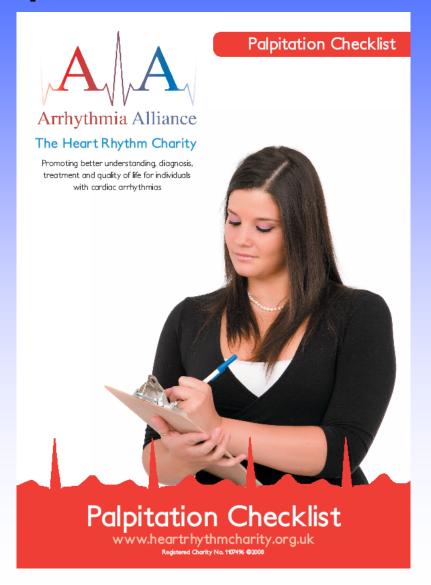




- Website
- Congresses
- Articles, Newsletters
- Telephone helpline
- AAAW



## Palpitations Checklist





## Arrhythmia Checklist





# 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

Tel: 01789 451830 campaigns@stars.org.uk







### **Affiliation**

To support existing groups, charities and voluntary organisations & help establish new groups

www.heartrhythmcharity.org.uk

### **Affiliated Groups** Arrhythmia Alliance The Heart Rhythm Charity Cardiovascular British Cardiovascular Society (BCS) IDAS Aberdeen and North East Heart Support Group - Heartlink Derby Heart Support Group gh ICD Support Group - Nottingham Cardiac Heart Support Group SADS Canada - SAFEBEAT - Derbyshire Arrhythmia Heart Support Group Essex ICD Support Group - Middlesex ICD Support Group - The 'Coventry Healthy Hearts' Support Group - Poole Hospital ICD Support Group - Southend Hospital 'Pacers & fads' ICD Support Group HeartBeat East Suffolk ICD Support Group - UPBEAT ICD Support Group STARS STARS US (O6G) Atrid Fibrillation Association (AFA) Restort Swansea ICD Support Group - Oxford Heartbeat Club ICD Support Group Medway Pacemaker Support Group - Good Hope Sutton ICD Support Group Milton Keynes ICD Support Group - The Trent Cardiac Network Arrhythmia Collaborative Heart Support Group Darlington Cardiomyopathy Self Support Group Bolton ICD Support Group - SPARKS Hardfield Hospital ICD Support Group High Wycombe and District ICD Support Group - North Gloucestershire ICD Support Group Rhythm for Life Kent ICD Support Group - West Dorset ICD Support Group - Nottingham ICD Support Group

**Arrhythmia Alliance** 





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

## The Blackouts Checklist





## Rapid Access Blackout **Clinics**

### **GUIDELINES ON HOW** TO ESTABLISH RAPID ACCESS CLINICS The Heart Rhythm Charity

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



www.heartrhythmcharity.org.uk



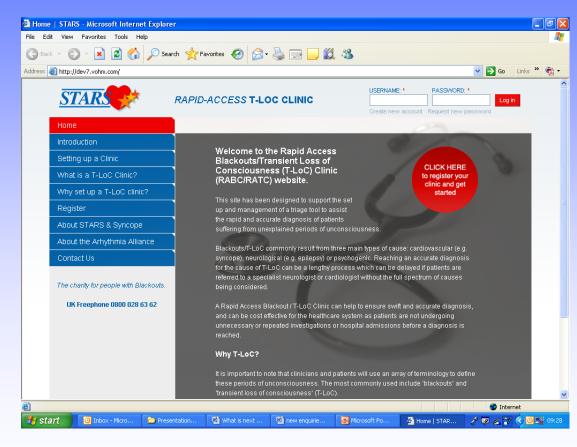
- Promoting rapid access to correct & accurate diagnosis
- Efficient & cost –effective diagnosis





# Rapid Access Transient Loss of Consciousness Clinic Website

- Website provides
   basic information you
   need to research and
   establish an RATC for
   your own centre
- •RABC website to be launched soon







### Support and Information

# **Education Project**

Freephone: 08





#### SHINE A LIGHT ON EDUCATION

STARS is pleased to introduce its new educational web-site.



Online information. downloadable lesson plans, sample care plans and support materials designed for educators and families managing the care and education of young people with syncope.

This new site introduces

Sammy Star, hosts a blog, a moderated message board and offers information and advice for those who have been diagnosed with syncope or RAS.

So whether you are a teacher supporting a child with syncope or RAS, a pupil wondering how to tell your friends or you simply want to talk to others, why not visit

www.education.stars.org.uk





Don't just blame.....

- Bad eye sight
- An uneven pavement
- A knee giving way

## Have you considered.... SYNCOPE as a cause of your fall(s)?

Each year 35% of adults aged 65 and over experience syncope (blackout, faint or transient loss of consciousness) and this can be the reason for a fall. Treatments are available...

> For information on blackouts, transient loss of consciousness, and syncope contact STARS

> > www.stars.org.uk Tel: 01789 450564



Working together with individuals, families and medical profession as to offer support and information on Syncopes and Reflex Anoxic Seizures







www.atrialfibrillation.org.uk



# Raising Awareness



Checklist

ww.atrialfibrillation.org.uk Tel: +44 (0)1789 451 837









# Signposting to Specialist









NEW

Advances In Cardiac Care At Musgrove Park Hospital...

Search

#### Home

**Atrial Fibrillation Association** 

Patient Information

**Case Studies** 

Medical Professionals

**AF Specialists** 

**News & Events** 

Forum

**Podcast** 

Links

**Publications** 

Join AFA

Donate

**UK Atrial Fibrillation Specialists** 

Clinicians have kindly given permission for their details to be added to the AFA database. This is not an exhaustive list, and AFA cannot verify any of the names included on the list. All referrals to a specialist must be through your own GP.

If you are a clinician with an interest in AF and would like to have your name included on the database, please contact <a href="mailto:info@atrial-fibrillation.org.uk">info@atrial-fibrillation.org.uk</a>

A B C D E E G H I J K L M N Q P Q R S T U Y W X Y Z

Location	First Name	Surname	Title	Area of interest	Medical Centre
Aberdeen	Paul	Broadhurst	Dr	Arrhythmia clinics and AF ablation	Aberdeen Royal Infirmary
Basildon	Stuart	Harris	Dr	Consultant Cardiologist, Management of AF including catheter ablation with latest techniques	The Essex Cardiothoracic Centre
Birmingham	David	Fitzmaurice	Professor		The University of Birmingham
Birmingham	Christopher	Boos	Dr	Specialist Registrar in Cardiology, AF	Queen Elizabeth Hospital



# Atrial Fibrillation Patient and Primary Care Checklist







www.atrialfibrillation.org.ux

### Feel the pulse to beat the stroke!



FACT

Atrial Fibrillation (AF) is the most common heart rhythm disorder



FACT

AF is often a silent condition going undetected



FACT

Atrial Fibrillation causes an irregular pulse



FACT

An irregular pulse can cause small blood clots to form making stroke more likely



FACT

1 in 4 stroke victims have Atrial Fibrillation



### Feel Your Pulse

the easlest way to detect AF



Atrial Fibrillation Association: Providing Information, support and access to established,

new or innovative treatments for Atrial Fibrillation



Affiliated to Amhythmia Alliance www.heartrhythindharity.org.uk

Fagistared Charity Number: 1122442 www.artalfbrillation.org.uk Telephone: +44 (0) 1769 451837 E-mail Jo: Info@atrial-fbrillation.org.sk POBox 1219 Chev Magna: Bristol BS40 8V&





### Heart Rhythm Congress

- Hilton Birmingham Metropole
- International Speakers
- Live Cases
- Patient Day
- Devices and Intervention Courses

HRC 2009 – 18th-21st October www.heartrhythm.org.uk



### The British Society for Heart Failure













日本医療政策機構

Health Policy Institute, Japan













The Blackouts Trust





www.stars.org.uk







Cardiac Inherited Disease Group **New Zealand** 

www.cidg.org























HR-UK Heart Rhythm UK















# Heart Knytnm Societies Joining AAAW 2008

**Australian Heart Foundation Austrian Heart Foundation Belgium Heart Rhythm Association British Cardiovascular Society Canadian Cardiac Society** Cardiac Association – South Africa Chinese Society of Cardiology **Emirates Cardiac Society European Heart Rhythm Association** European Cardiac Arrhythmia Society Heart Rhythm Society – USA International Cardiac Pacing & Electrophysiology Society Japanese Heart Rhythm Society **Russian Cardiac Society** Sweden, Ireland, Portugal, Spain, Italy, S America etc!!!



## ARRHYTHMIA AWARENESS WEEK 8-14 JUNE 2009

### **Aims:**

- •To raise awareness of heart rhythm disorders amongst the general public and provide support network for patients and carers
- •To promote the theme 'Know Your Pulse' and an understanding amongst the public of this health-check procedure
  - •To promote awareness and support activities relating to the work of A-A, including projects such as 'Restart the Heart'





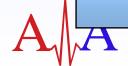
# Our Goal In 5 years

Everyone will understand arrhythmias as they do chest pains

All those affected will be diagnosed accurately, have access to appropriate services & receive support and information

Widespread placement of AEDs in public places

Sister organisations internationally



# A-A — Europe?

















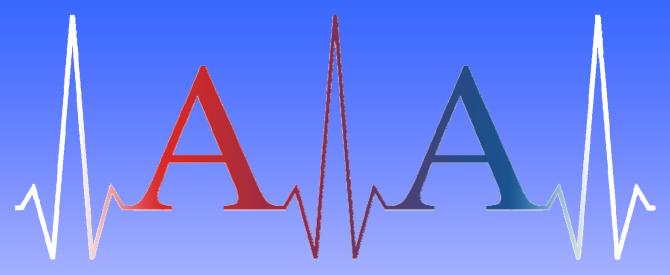












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