Toolkit to Establish an Arrhythmia Alliance National Partner

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Arrhythmia Alliance
The Heart Rhythm Charity
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Introduction

In the autumn of 2003, a handful of arrhythmia patient groups in the UK began a grassroots campaign to persuade the UK Parliament to establish guidelines for the treatment of arrhythmias. In the UK at that time, although 1 million people had cardiac arrhythmias, and 100,000 people per year died of sudden cardiac arrest, there were no government arrhythmia guidelines. A shortage of healthcare professionals trained to diagnose and treat arrhythmias meant that many people with arrhythmias did not know where to turn to learn about treatments, or for hope and encouragement that they could achieve a good quality of life. Healthcare professionals quickly learned of the campaign, and suggested they could help to try and convince the Department of Health of the need to act.

The campaign succeeded beyond anyone’s dreams. It led to a vital change in government policy, resulting in the inclusion of an additional chapter in the National Service Framework for heart disease, specifically covering arrhythmias and sudden cardiac death. It led to a new, government endorsed, national plan to improve the timely and effective diagnosis and treatment of arrhythmias, drawn up through collective dialogue with patients, family members, healthcare professionals, and the government. Arrhythmia Alliance (A-A) was born.

Now, just a few years later, the case is stronger than ever that great things can be achieved through the power of a coalition of patients, carers, and healthcare professionals working together to improve the lives of people with arrhythmias.

Arrhythmia Alliance runs an annual awareness event, World Heart Rhythm Week, and an annual Heart Rhythm Congress for patient, medical, allied professional and industry communities to raise the understanding of scientific issues. In the UK A-A has developed educational resources for patients and healthcare professionals that are endorsed by the Department of Health. A-A has created a platform for discussion of innovative approaches, such as Rapid Access Clinics representing a number of relevant specialists working together to seek patient diagnosis. A-A initiates and supports the work of a variety of affiliated groups such as the Atrial Fibrillation Association, and ICD and syncope patient information groups.

Fundamental to the work of Arrhythmia Alliance: the patient’s voice remains at the centre of activities.

Today, countries around the world share many of the same challenges and priorities. This toolkit is a practical guide to help others establish an Arrhythmia Alliance National Partner. It draws on the experience of Arrhythmia Alliance in the UK - its successes and lessons learned. This toolkit will continue to evolve, drawing from best practices of A-A National Partners as they develop. We look forward to you joining this effort.

Trudie Lobban MBE
Founder and Trustee, Arrhythmia Alliance

Professor A. John Camm
President, Arrhythmia Alliance

A-A National Partners and Affiliates

A-A is an organisation that brings together the strengths of the medical community (e.g. heart rhythm societies) and patient representatives (e.g. patient information groups).

A-A International

A platform for unifying best practices in arrhythmia services, and advocating for equal patient access to high quality services in countries around the world

A-A National Partner

A national nonprofit organisation with the structure, mission, and aims of A-A, with an agreed partnership with A-A International

Examples:
A-A Portugal, PACE South Africa

A-A Affiliate

A national or regional organisation that promotes A-A's mission and activities.

Example:
A-A UK has 50+ UK affiliates such as pacemaker and ICD information groups, and British Cardiovascular Society.

The 8 Steps to Start an A-A National Partner

8 Steps Toward Establishing an A-A group

1. Enlist your leadership
2. Establish your mission
3. Register as a charity
4. Begin fundraising
5. Begin outreach: hold two patient education meetings
6. Develop a website
7. Raise awareness on arrhythmias during World Heart Rhythm Week
8. Develop a 2 - 3 year strategic plan

Step 1:
Enlist Your Leadership

- Step 1: Enlist Your Leadership
- Step 2: Establish Your Mission
- Step 3: Register as a Charity
- Step 4: Begin Fundraising
- Step 5: Begin Outreach
- Step 6: Develop a Website
- Step 7: Raise Awareness
- Step 8: Develop Strategic Plan

Step 1: Enlist Your Leadership

A. Start by identifying five or more people to help with start-up. They should include at least one doctor, one nurse, and one patient representative* with an interest in arrhythmias.

B. If your initial group has only healthcare professionals, hold a patient education meeting as a way to identify patient representatives who could help.

C. Form three committees:

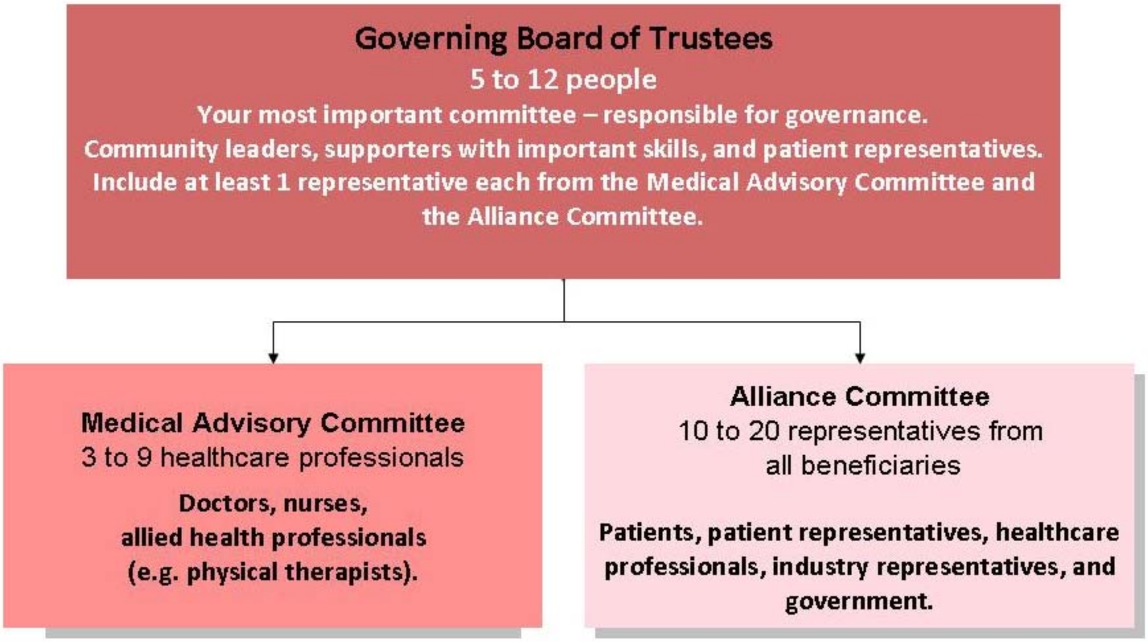
   Governing Board of Trustees

   Medical Advisory Committee

   Alliance Committee -- of all beneficiaries

D. Identify national or regional organisations in your country that could promote A-A's mission and activities, i.e. a heart rhythm society and patient groups. Invite them to become A-A Affiliates.**

Organisational Structure



Governing Board of Trustees
5 to 12 people
Your most important committee – responsible for governance.
Community leaders, supporters with important skills, and patient representatives.
Include at least 1 representative each from the Medical Advisory Committee and the Alliance Committee.

Medical Advisory Committee
3 to 9 healthcare professionals
Doctors, nurses,
allied health professionals
(e.g. physical therapists).

Alliance Committee
10 to 20 representatives from
all beneficiaries
Patients, patient representatives, healthcare professionals, industry representatives, and government.

**A patient representative is a patient, family member, caregiver or friend who can represent the patient's voice in the alliance.*
*** More information on Affiliates is in Appendices*.

Step 1: Enlist Your Leadership –
Roles Within The Alliance

Shared Roles

- Raise awareness and educate patients, caregivers/family members and the public about best practice in the diagnosis, treatment, and long term management of arrhythmias
- Identify gaps in patient education
- Promote good communication between healthcare professionals and patients
- Identify gaps in arrhythmia care services
- Advocate changes in health policies and improve access to services at local and national level. Patients will have the strongest voice in advocacy

Unique Role of Patients and Patient Representatives

- Develop and review patient education information, working with healthcare professionals
- Engage with media to raise awareness by "telling the patient's story"

Unique Role of Healthcare Professionals

- Develop and review medical and patient publications
- Serve on a variety of forums to develop guidelines and best practice models
- Assist patient groups with resources and expertise

Role of Government

- An A-A National Partner should establish a relationship with its national health authority to seek endorsement of publications, and to work collaboratively to improve arrhythmia services and support

Role of Industry

- Representatives of corporations and industry, such as pharmaceutical and medical device companies, can offer guidance and training on aspects of A-A activity (i.e. how to work with the media), and provide funds or in-kind donations
- We recommend you develop a Partnership Agreement that describes how you work with industry, and put this on your website so your company partnerships are transparent. *(See example Partnership Agreement in appendices)*

Step 1: Enlist Your Leadership –
Duties of the Governing Board of Trustees

Set policy, exercise oversight and provide strategic direction in these areas* :

- **Mission:** The Trustees safeguard the charity's mission by making sure there is a clear direction shared throughout the organisation, a good mission statement, and appropriately planned and evaluated programmes and services

- **Values:** The Trustees define organisational values and set the standard for professional conduct through their own behaviour as well as in the policies established for others to follow

- **Resources**: The Trustees ensure the charity has adequate resources—human, material, and financial—by hiring staff, monitoring the financial health of the organisation, ensuring the acquisition of sufficient resources, and assisting in resource mobilisation

- **Outreach:** The Trustees promote the charity in the community and serve as a link between members, donors, beneficiaries and other supporters

**Source: The Handbook of NGO Governance, by Marilyn Wyatt*

Step 1: Enlist Your Leadership – Duties of the Alliance Committee

- Come together to discuss the needs of patients from a variety of viewpoints, develop priorities, and generate ideas for initiatives to improve the lives of patients with arrhythmias.

- Make recommendations to the Governing Board of Trustees.

Who Serves on the Committee

The Committee members represent a range of beneficiaries concerned with arrhythmias. They are enlisted by the Governing Board of Trustees.

- Patients
- Family members and caregivers
- Healthcare professionals – cardiologist, GP, nurse, allied professionals e.g. physical therapists
- Community leaders
- Patient organisations (e.g. ICD and pacemaker groups, heart rhythm societies)
- Government – National Health Authority, Members of Parliament
- Industry – pharmaceutical companies, medical device companies

Step 1: Enlist Your Leadership – Duties of the Medical Advisory Committee

- Review and approve all A-A medical publications prior to submission for endorsement by health authorities
- Review other communications for medical accuracy, i.e. website content, newsletters, press releases
- Serve as medical experts and spokespersons for media interviews
- Represent the charity on health panels and other public forums
- Answer questions and give advice on medical/patient inquiries, i.e. in ‘Ask the Experts’ section of website
- Provide expertise on guidelines for government health initiatives
- Support A-A medical/patient conferences by helping organise and present at educational sessions

Who Serves on the Committee

- Cardiologists
- Electrophysiologists
- Nurses with a special interest in arrhythmias
- Psychologists
- Allied professionals such as physical therapists

Step 1: Enlist Your Leadership – How to Find Volunteers to Serve on Committees

Healthcare Professionals

- Ask your national heart rhythm society to identify individuals who can help from among their electrophysiologists, cardiologists, and nurses with an interest in arrhythmias
- Ask one or more of the major hospitals in your country with heart rhythm specialists if they can recommend professionals who might help
- Make a brief presentation about your A-A plans to both of these groups
- Ask a health professional already involved to ask colleagues if they will help
- If your country has heart rhythm Centres of Excellence, ask if they could suggest volunteers from among their health professionals
- Try to seek geographic balance so your committees have national representation, by enlisting volunteers from at least 3 different cities or regions
- Ask healthcare professional groups (e.g. heart rhythm society) if they wish to become an A-A Affiliate

Patients and Patient Reps

- Ask three or more of your healthcare professionals already involved to each identify patients and patient representatives (caregivers, family members, friends who represent the patients' voice) who might wish to volunteer
- Hold an informal meeting to discuss how they might support A-A's development in your country
- If hospitals in your country have patient support groups (ICD group, pacemaker group, groups of patients with Long QT, Brugada Syndrome etc.), ask if you can make a presentation to them about A-A and your need for volunteers. You can also search online for these groups
- Ask the patient groups if they wish to become an A-A Affiliate.
- Hold a patient education meeting, giving information on the latest research and therapies, and ways to provide emotional support to patients. Advertise the meeting at clinics and hospitals in the target city. At the end of the meeting, describe your plans for A-A and ask for volunteers

Step 1: Enlist Your Leadership –

Enlist Additional Volunteers

In addition to working with your three committees, we suggest you enlist 5 to 20 volunteers, organised by geographic region, who can help with raising awareness, advocacy, and fundraising.   Your long term goal is to have volunteer support groups in a number of cities and regions around the country.

Volunteers can also offer advice and emotional support to patients, i.e. by responding to non-medical enquiries received by phone or via the website. You can set up a telephone helpline for patients, patient representatives and medical professionals with questions. Trained volunteers can come to an office to answer these calls, or the calls can be routed to their home on a rotating basis with other volunteers.

You can find volunteers by networking among your patients, patient representatives, and community members, and also through your A-A Affiliates such as patient information groups.

Step 1: Enlist Your Leadership –
Consider Employing Professional Staff/Consultants*

If you have the funds, we recommend you hire professional staff, consultants, and/or administrative help, either for a project or long term. Select them to complement the skills you have in your volunteer committees. They can add to the professionalism of your work, help identify resources, and shorten the timeline for you to be become an effective organisation. They can help you with:

Strategic and operational management – Develop a strategic plan and a business plan, identify leadership, suggest qualitative and quantitative methods for measuring success.

Resource management and fundraising – Develop a 3-5 year income and expense budget, develop a fundraising plan, identify potential fundraising sources, develop your case for support, and organise fundraising events.

Communications– Develop a communications plan, work with the media, write publications and presentations, develop the website, train volunteer spokespersons.

Step 2: Establish Your Mission

Step 2 Establish Your Mission

The Governing Board of Trustees should discuss and adopt A-A's structure, mission, and aims

Structure

Arrhythmia Alliance (A-A) is a coalition of charities, patient groups, patients, carers, medical groups and allied professionals. These groups remain independent, however, they work together under the A-A umbrella to promote timely and effective diagnosis and treatment of arrhythmias.

A-A can become a country's leading authority and comprehensive source of information for patients and healthcare professionals.

Mission

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

Aims

- Develop the knowledge and skills of health professionals concerned with arrhythmias
- Assess and address the unmet need among patients
- Promote centres of excellence for arrhythmia diagnosis and treatment
- Provide support to patients and carers and medical professionals
- Improve quality of life for those affected by cardiac arrhythmias
- Share and exchange ideas, resources and best practices
- Build networks to ensure that the patient is at the centre of healthcare reform

Step 3:
Register as a Charity

Step 1: Enlist Your Leadership
Step 2: Establish Your Mission
Step 3: Register as a Charity
Step 4: Begin Fundraising
Step 5: Begin Outreach
Step 6: Develop a Website
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Step 8: Develop Strategic Plan

Step 3: Register as a Charity

1. You should apply to your national government to be a registered charity as soon as you have enlisted your Governing Board of Trustees and developed the documents below. It can take several months to get approval. Once you receive charitable status, you may get a higher level of confidence and clarity about your mission from your beneficiaries, and you will be in a better position to request gifts to support your work.

2. Countries have varying rules on what is needed to apply. Usually you must submit:

   - A copy of your organisation's governing documents, often called your "Governing Documents", "statutes" or "constitution" *

   - A list of your Governing Board of Trustees

   - A list of the elected officers of the Governing Board (chair, vice chair, treasurer, secretary)

** Example of Governing Documents is in the Appendices.*

Step 4: Begin Fundraising

Step 4: Begin Fundraising

1. **Develop your case for support** – why an institution or individual should make a gift to help your work. Write it as a 3-4 page word document, and as a PowerPoint. Key elements are:
   - The Need – Why are arrhythmias important? Statistics on the number of people affected in your country, and the cost to society if they don't get the treatment needed. What's the evidence to show that arrhythmia services need to be improved in your country, and in what ways? What area have you chosen to focus on now and why?
   - Background – When did you start your national A-A? What is its relationship to the larger movement (A-A International)? What are your mission and aims? What are your priorities and programmes this year? What experience and skills does your leadership have to run these programmes (governing board of trustees; committee members; staff; consultants). Show your trustee-approved A-A income and expense operating budget, even if quite modest in Year 1.
   - Request – What is the purpose of the programme for which you are requesting support? How much are you requesting? Show an income and expense budget for the project. What will success look like? How will you measure success?
   - Sustainability – Will there be long term benefits to your work? How will they be sustained?
2. **Develop a list of organisations and individuals** you will ask to support your National A-A.
   - Ask those closest to the organisation to give first – your governing board, committee members, volunteers, and then ask them for suggestions of others who might give. Ask if they will help you make the contact with the company or individual they have suggested.
   - Ask patients, family members, and friends for support. They understand best the importance of your work.
   - Ask pharmaceutical and medical device companies for support, and other companies interested in healthy communities.
   - Hold one or more events to raise money.
   - Have a section of your website on your fundraising goals – projects and amounts needed.
3. **Send out your requests**.
   - Follow up with a personal call or meeting with the contact for the request. If they give, THANK THEM, and offer them visibility for the gift if they wish (i.e. name in donor listing; logo on website)

Step 5: Begin Outreach

- Step 1: Enlist Your Leadership
- Step 2: Establish Your Mission
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Step 5: Begin Outreach – Hold Two Patient Education Meetings

Goals

- Increase the number of patient representatives and healthcare professionals working to establish your A-A.
- Build geographic diversity of leadership, so you are on the path to achieving a national voice on the needs of arrhythmias patients across the country, and to providing awareness and education on a national level.
- Promote regional outreach to raise awareness at a grassroots level.

Patient Education Meetings

- Plan to hold a 2 hour patient education meeting in at least 2 cities, in the evening or on the weekend.

- Publicise the meeting through flyers at heart rhythm clinics and hospitals in the targeted city, in their newsletters, and in the local media. To generate media attention, ask a local heart rhythm patient, paired with his/her heart specialist, “to tell their story” to the press, an effective way to illustrate the need for more education and support for heart rhythm disorders. Give national statistics on the incidence of arrhythmias and sudden cardiac arrest – your heart rhythm society will probably have this information.

- For the meeting, identify 1 or 2 heart rhythm specialists to give a 45 minute presentation* on the latest heart rhythm research and therapies, and ways to provide emotional support to patients. Content can vary, depending on the interest of your audience.

- Near the end, have a dialogue with meeting participants about their views on the needs and priorities for arrhythmia services. Then describe your plans to develop an A-A and ask for volunteers to help.

- Establish an e-forum, blog, or Facebook page to keep in touch with patients/caregivers in these cities.

- Invite participants to become members of your A-A once it receives charitable status.

**Contact A-A for an example of a Patient Education Presentation which you can translate and adapt for your country.*

Step 6: Develop a Website

Step 6: Develop a Website

1. A-A International can establish a website for you, with a domain in your country, that can be easily edited. This is done as an extension of the A-A International website. This should allow you to get started relatively quickly and easily, and provides a framework for you to populate the site with basic information needed. Over time, you may wish to establish your own independent site, as the information you wish to post becomes larger and more complex.

2. A-A International has developed extensive patient and professional educational material on its website that you can access to translate and adapt for use on your own website. This material can be sent to you once you have submitted a signed A-A Memorandum of Understanding and Translation and Use of A-A Materials Contract. Contact A-A for more details.

3. Ask your Medical Advisory Committee members if they can help with translation of the patient and professional educational material, to keep costs minimal, and then you will have confidence in the quality of the translation and in the adaptations of the text if they are needed in your country.

4. Ask your national health authority for their endorsement of these educational materials. This will add greatly to the acceptance of the information, and confidence in your new organisation.

5. A suggested list of content for an A-A National Partner website is on the next page.

Step 6: Develop a Website

Suggested Frameworks

A suggested format for the website is as follows:

- Home (Showcase special projects, newsletter, news releases, upcoming events)
- About Us (Mission, Aims, Governing Board of Trustees, Governing Documents, Medical Advisory Committee, Alliance Committee, History)
- Donate (Information on how and why to donate)
- Supporters (You can list corporate sponsors and a statement of transparency)
- About Arrhythmias (Resources, prevalence)
- Patient Information
- Information for Medical Professionals (password protected)
- Projects and Campaigns
- News and Events
- Affiliates (List patient groups and organisations that have become affiliated)
- A-A International
- Share Your Story (Patient stories of diagnosis and treatment)
- Database of Specialists
- Contact Us
- Forum - for discussion/Blog/Facebook/Twitter, etc.
- Links

Step 7:
Raise Awareness

Step 7: Raise Awareness

Make Plans for World Heart Rhythm Week

1. World Heart Rhythm Week (WHRW) is organised by A-A International in partnership with the International Cardiac Pacing and Electrophysiology Society to promote awareness of heart rhythm disorders across the globe.

2. A-A International prepares a toolkit for WHRW with ways you can get involved, a template press release, and poster.

3. Identify and train several patients who are willing to “tell their story” during WHRW. Patient stories are an excellent way to attract media attention. A ‘Share Your Story’ invitation letter posted online, that requests case studies, is a good way to spark interest from patients and their families.*

4. Contact the local media in communities where you have patients or health professionals, offering interviews with them during WHRW.

5. Activities you could organise:
    - A speaker to present on heart rhythm disorders at a public meeting or in a hospital
    - Medical professionals could conduct ‘pulse check sessions’ in their clinics/hospitals/community centres
    - Individuals and groups could distribute pulse check cards to doctor offices, clinics, community centres
    - Have a group meeting where attendees all take their pulse together, i.e. spectators take their pulse at half time during a sporting event, led by a celebrity sports player
    - Find a celebrity or community leader willing to be a spokesperson for A-A

6. Encourage your affiliates to provide information about their events during WHRW.

**A sample ‘Share Your Story’ request letter can be found in the Appendices.*

Step 8:

Develop a Strategic Plan

Step 8: Develop a Strategic Plan

1. Once you have your leadership selected, you should develop a 2-3 year strategic plan

2. If possible, hire a consultant to facilitate the planning meetings and help you draft the plan

3. Your governing board of trustees should be very involved in developing the plan, and must approve it once completed

4. Identify other key volunteers on your committees who are thoughtful and experienced to help with planning

5. Some organisations use a SWOT analysis to frame the discussion, identifying strengths, weaknesses, opportunities, and threats

6. Whatever framework you use, we suggest you bring your beneficiaries together to identify the barriers in your country to all patients having access to high quality care for arrhythmias*

7. Prioritise and decide which are the few key barriers you want to address

8. Brainstorm possible solutions to those barriers**

9. Consult A-A in the UK for examples of best practice. The experiences of other countries can sometimes carry more weight in your advocacy efforts with authorities in your own country

10. We hope over time to collect information on these various barriers and solutions, and share a European-wide overview

** See next page for examples of barriers.*

***Following pages outline campaigns developed by A-A to overcome barriers to access, with more info in the Appendices.*

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

A Planning Tool - Identify Barriers and Possible Solutions

Planning Tool

Work with your Governing Board of Trustees and members of your Medical Advisory Committee and Alliance Committee.

Examples of Barriers	Examples of Possible Solutions
Low patient awareness and education	Run a public awareness campaign during World Heart Rhythm Week Develop a toolkit to improve the dialogue between patient and doctor
Misdiagnosis	Support the establishment of Rapid Access Clinics for appropriate diagnosis and treatment
Insufficient number of arrhythmia specialists	Advocate for increased numbers of trained specialists Offer educational resources for use at training courses
Poorly developed care pathways	Promote Centres of Excellence for arrhythmia diagnosis and treatment Support healthcare professionals with diagnosis, referral and treatment
Low public awareness of Sudden Cardiac Arrest	Partner with local services and centres to increase public awareness of Sudden Cardiac Arrest; run a national campaign to place automated external defibrillators in communities
Patients lack info on how to live with their disease/condition	Offer a helpline service and patient information

A-A UK Events and Campaigns

World Heart Rhythm Week (WHRW) 7th – 13th June 2010

This annual global event encourages all participants to promote awareness of heart rhythm disorders: www.whrweek.org

Heart Rhythm Congress

An annual international event which offers an educational opportunity for members of the medical, allied professional and industry communities to increase their own and others' knowledge of heart rhythm disorders. The congress offers a full programme of scientific sessions, a Patients' Day, industry sessions and trade exhibition. The event hosts the annual 'International Roundtable' to collaborate on unifying health policies and sharing best practice methods across the globe: www.heartrhythmcongress.com

Regional Meetings

These meetings are aimed at all those involved in providing a service and care of patients with cardiac arrhythmias including healthcare professionals, patient groups, carers and industry:
www.heartrhythmcharity.org.uk/html/nsf_regional_meetings.html

Know Your Pulse

A campaign to raise public and medical awareness of the pulse as a means of identifying potential cardiac arrhythmias. In the UK, A-A is promoting routine pulse checks in primary care: www.knowyourpulse.org

Restart The Heart

To raise awareness of Sudden Cardiac Arrest (SCA) and the importance of early defibrillation by placing Automated External Defibrillators (AEDs) in local communities:
www.heartrhythmcharity.org.uk/html/where_s_the_aed_.html
(See Appendix: Restart The Heart)

Affiliation

A patient focused initiative to provide support, guidance and networking to patient organisations ensuring a national standard is reached:
www.heartrhythmcharity.org.uk/html/affiliated_groups.html
(See Appendix: Affiliates)

Rapid Access Clinics

To develop Rapid Access Clinics for T-LoC (transient loss of consciousness) patients to prevent misdiagnosis:
www.stars.org.uk/campaigns-projects/t-loc
(See Appendix: Rapid Access Clinics)

Syncope Awareness

To promote awareness and education on syncope and provide a forum for patient support:
www.stars.org.uk/campaigns-projects/safe
(See Appendix: Syncope Awareness)

Atrial Fibrillation Awareness

To provide information, support and access to established, new or innovative treatments for Atrial Fibrillation (AF):
www.atrialfibrillation.org.uk
(See Appendix: Atrial Fibrillation Awareness)

Appendices

- Appendix I: Partnership Agreement
- Appendix II: Affiliates
- Appendix III: Sample Governing Documents
- Appendix IV: Know Your Pulse Campaign
- Appendix V: Restart The Heart Campaign
- Appendix VI: Rapid Access Clinics
- Appendix VII: Syncope Awareness Campaign
- Appendix VIII: Atrial Fibrillation Awareness
- Appendix IX: Regional Meetings

Appendix I:
Partnership Agreement

A-A relies on funding and donations from numerous sources; Trusts, Foundations, industry, public donations and individuals, for the continuation of its operations. In order to ensure its independence, A-A does not accept donations that are dependent on policies set by others. The Trustees exercise care that funding does not condition its priority setting, the mission, messages, or any other activities of the organisation, thereby ensuring the independence of A-A to carry out its mission and objectives.

Our funders including industry, organisations, Trusts and Foundations are of high standing and reputation, all of whom reinforce A-A's overall mission and work, and help support the integrity of the organisation. Our working relationship is established on the basis of shared interest, transparency, trust, and mutual benefit. Funders and sponsors do not represent A-A as an endorser of any specific product or service, nor does any partnership imply A-A's endorsement of a corporation, its products or its services.

Appendix II:
Affiliates

An A-A National Partner may offer affiliation to patient information groups, medical societies and organisations with the same shared interest in promoting awareness and education of heart rhythm disorders in their country.

Affiliation provides an opportunity to develop and disseminate information, best practice methods, and develop a unified voice to advocate for the aims and activities of an A-A National Partner.

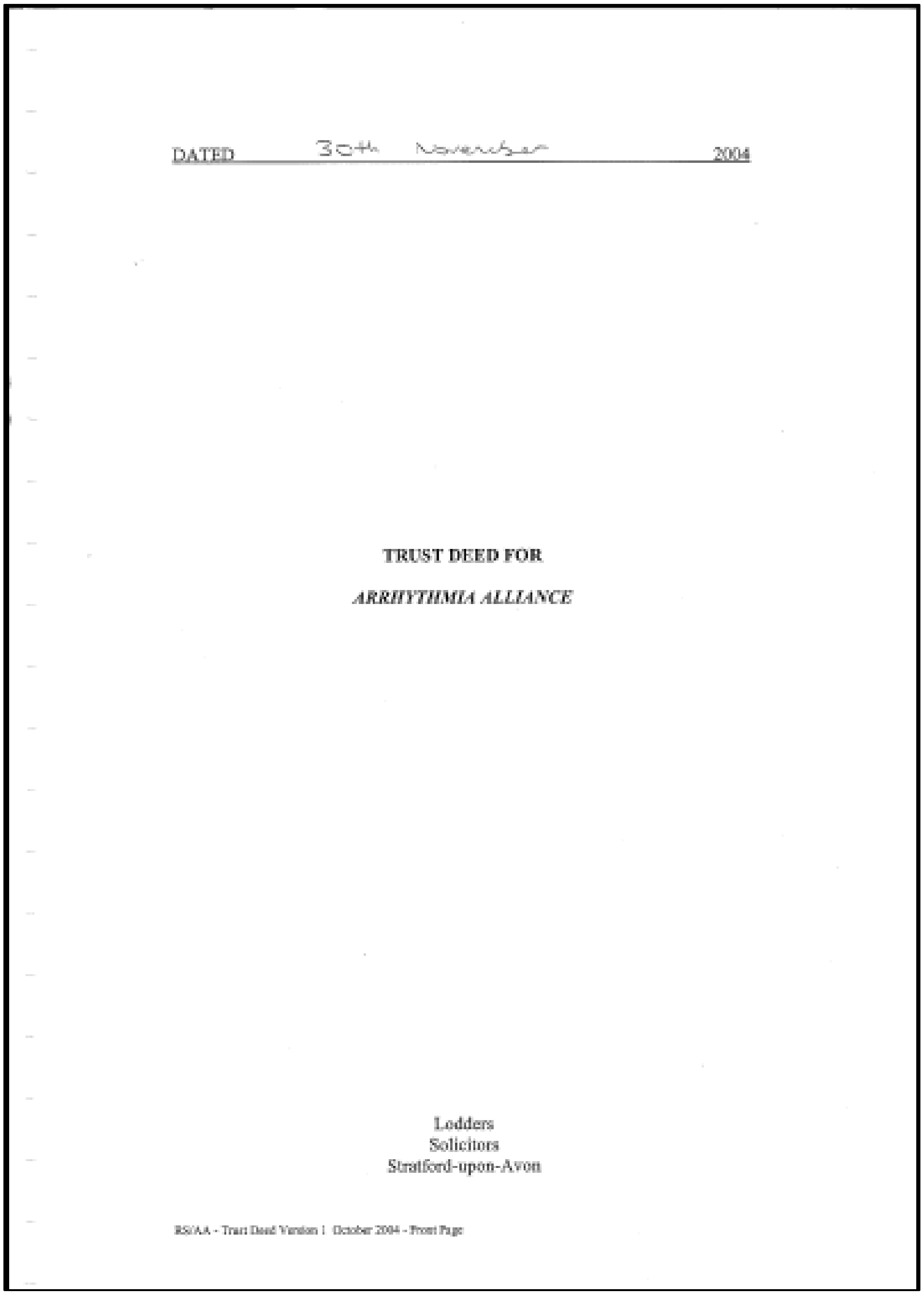
Arrhythmia Alliance offers support to its affiliated patient information groups, including:

1. Opportunity to join forces on projects and campaigns
2. Support and advocacy
3. Feature and link on the A-A website
4. Opportunity to advertise events, conferences and meetings on the A-A website and e-bulletins
5. A-A materials available for translation and distribution

For further information, please visit:www.heartrhythmcharity.org.uk/html/affiliation.html

Appendix III:
Sample Governing Documents

A-A UK’s Governing Documents, called the Trust Deed, is available upon request from Arrhythmia Alliance



DATED 30th November 2004

TRUST DEED FOR

ARRHYTHMIA ALLIANCE

Lodders
Solicitors
Stratford-upon-Avon

RS/AA - Trust Deed Version 1 October 2004 - Front Page

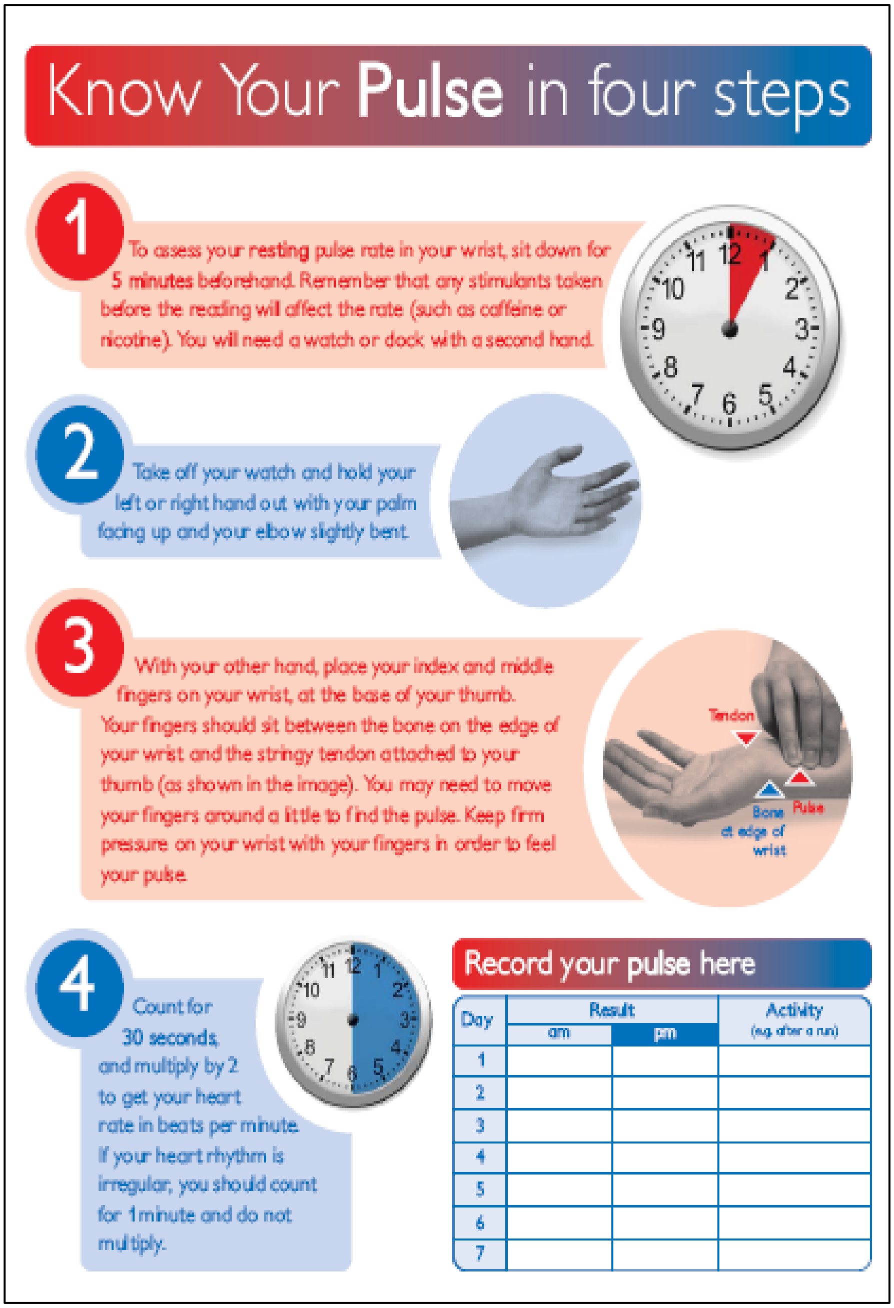
Appendix IV:
Know Your Pulse Campaign

The pulse is one of the most effective means to identify potential cardiac arrhythmias.

The Know Your Pulse campaign encourages routine pulse checks with the aim that they will soon become as common as blood pressure and weight checks.

The Pulse Check Card:

This educational guide provides information on what the pulse is, what it means, when people should take their pulse and a table where individuals can record the results over a seven day period, and seek further advice from a medical professional, if required. The Pulse Check Card is suitable for all individuals with an interest in their personal health and is available to download at: www.knowyourpulse.org.



Know Your **Pulse** in four steps

1 To assess your **resting** pulse rate in your wrist, sit down for **5 minutes** beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.

2 Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.

3 With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.

4 Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

Record your pulse here

Day	Result		Activity (e.g. after a run)
	am	pm	
1			
2			
3			
4			
5			
6			
7			

Appendix V:
Restart The Heart Campaign

The Restart The Heart campaign aims to place Automated External Defibrillators (AEDs) in communities and to raise public awareness of sudden cardiac arrest and the importance of early defibrillation.

A **Restart The Heart toolkit** has been developed to guide groups through the entire process of placing a community AED (from project proposals to fundraising, and launching the unit).

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

MiniAnne CPR & AED

Life Saving Skills for the Community

You can make a difference
Restart The Heart

Learning Technology by Laerdal

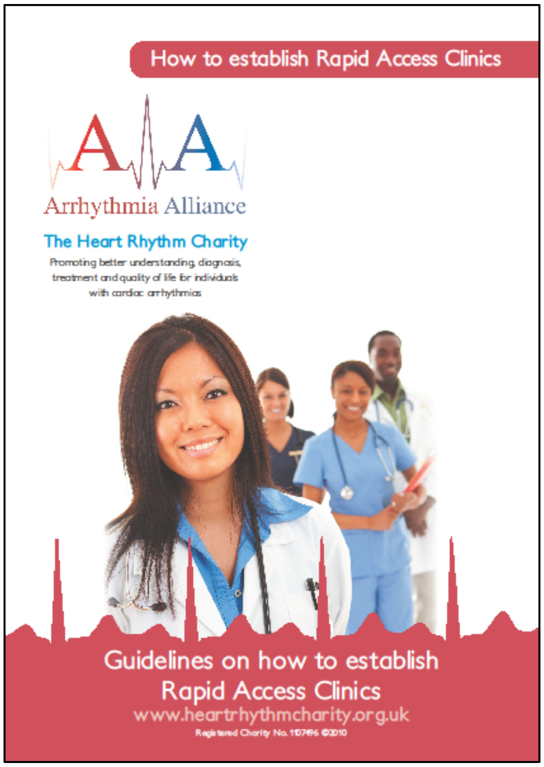
Arrhythmia Alliance
The Heart Rhythm Charity
www.heartrhythmcharity.org.uk

In addition to the toolkit, the **Mini-Anne CPR & AED kit** allows individuals to learn the core skills of Cardiopulmonary Resuscitation (CPR) and the use of an AED in less than an hour. It simulates 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.

For further information, please visit:
www.heartrhythmcharity.org.uk/html/where_s_the_aed_.html

Appendix VI:
Rapid Access Clinics

A-A has been instrumental in the development of Rapid Access Clinics designed to ensure patients are always diagnosed and treated by the appropriate expert. Rapid Access Clinics achieve this by taking referrals from all parts of the health system when patients present with a blackout or a fall. The clinic combines several disciplines to develop ‘blackout experts’ who will direct the patient to the most appropriate specialist.



How to establish Rapid Access Clinics

Arrhythmia Alliance

The Heart Rhythm Charity

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

Guidelines on how to establish
Rapid Access Clinics
www.heartrhythmcharity.org.uk
Registered Charity No. 1107496 ©2010

A Rapid Access Transient Loss of Consciousness (RATC) website: www.stars.org.uk/campaigns-projects/t-loc -hosted by STARS (Syncope Trust And Reflex anoxic Seizures), affiliate of Arrhythmia Alliance, has been designed to support the set up and management of a triage tool to assist the rapid and accurate diagnosis of patients suffering from unexplained periods of unconsciousness. A new RATC website will be available soon to provide information and guidelines on how to establish a Rapid Access Clinic.

Appendix VII:
Syncope Awareness Campaign

STARS

Syncope Trust And Reflex anoxic Seizures

www.stars.org.uk

Have you ever fainted?

Do you know why?

To find out more about fainting, blackouts, and unexplained loss of consciousness contact **STARS** now…

info@stars.org.uk **www.stars.org.uk**

Tel: 01789 450564

Affiliated to Arrhythmia Alliance
www.heartrhythmcharity.org.uk

endorsed by DH Department of Health

Working together with individuals, families and medical professionals to offer support and information on Syncope and Reflex Anoxic Seizures

Registered Charity No. 1084898 © 2009

The Syncope Awareness campaign aims to:

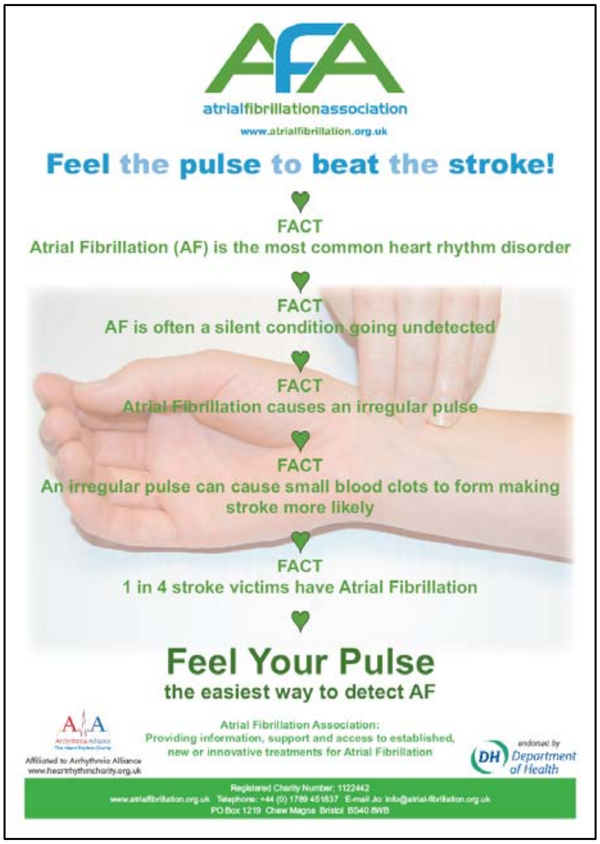
- Alleviate the effects of and provide support and information on syncope and Reflex Anoxic Seizures, to those in distress as a result of these seizures, whether suffered by themselves or as a member of the family group.

- Advance the education of the medical profession and the general public on the subject of syncope and Reflex Anoxic Seizures and its implications for the individual and family.

- Promote research into the management of syncope and Reflex Anoxic Seizures and publish the results. STARS has brought together experts from every field (healthcare professionals, allied professionals, geriatricians) to ensure the proper diagnosis and access to effective treatment and support. The STARS Medical Advisory Committee (MAC) is pivotal to the charity's work. The committee is comprised of a panel of international medical experts who act as an advisory, support and management committee for STARS, as well as advisory on all literature.

For further information, please visit:
www.stars.org.uk/campaigns-projects/safe

Appendix VIII:
Atrial Fibrillation Awareness



AFA
atrialfibrillationassociation
www.atrialfibrillation.org.uk

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 easiest way to detect AF

Affiliated to Arrhythmia Alliance
www.heartrhythmcharity.org.uk

Atrial Fibrillation Association:
Providing information, support and access to established, new or innovative treatments for Atrial Fibrillation

endorsed by Department of Health

Registered Charity Number: 1122442
www.atrialfibrillation.org.uk Telephone: +44 (0) 1789 451837 E-mail Jo: info@atrial-fibrillation.org.uk
PO Box 1219 Chew Magna Bristol BS40 8WB

Atrial Fibrillation (AF) is the most common arrhythmia – heart rhythm disturbance. It occurs when chaotic electrical activity develops in the upper chambers of the heart (the atria). As a result, the atria no longer beat in an organised, regular rhythm, so the patient's pulse is irregular. So the pumping of the heart is less efficient. Across the UK approximately 1.2 million people suffer with Atrial Fibrillation.

The Atrial Fibrillation Awareness campaign aims to:

- Provide information, support and access to established, new or innovative treatments for Atrial Fibrillation.

- Raise awareness of Atrial Fibrillation by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing Atrial Fibrillation.

For further information, please visit: www.atrialfibrillation.org.uk

Appendix IX:
Regional Meetings

A-A National Partners may choose to follow the success of the Regional Meetings hosted by Arrhythmia Alliance in the U.K. These meetings are aimed at all those involved in providing a service and care of patients with cardiac arrhythmias including: GPs, Primary Care Trusts, Electrophysiologists, Department of Health, Cardiologists, Clinicians, Cardiac Network Leads, Arrhythmia Nurses, Paediatricians, Geriatricians, Ambulance Services, Charitable Organisations, Patient Groups, Patients and Carers and Industry. Each regional meeting is divided into two sub-meetings for the day: a clinical meeting and a patient meeting.

Clinical Meeting

A-A aims to continue efforts to increase awareness of arrhythmias and their effects upon healthcare professionals across the UK. To facilitate this, each meeting contains a session dedicated to ‘Taking Arrhythmia Services to Primary Care' and includes topics such as ‘Drugs or Devices?', ‘Arrhythmias from a Primary Care Perspective' and ‘Referral – When, Where and Who?' Each meeting focuses on bringing national services to a local level, the latest ESC Guidelines for Syncope, Anticoagulation issues and addressing whether there is a need for an Arrhythmia Care Coordinator.

Patient Meeting

Held alongside the Clinical Meeting, the aim is to provide information for patients and carers on how to get the best out of their local services. A local arrhythmia nurse demonstrates pulse checks, raising further awareness of the Arrhythmia Alliance Know Your Pulse campaign. A local GP explains what patients should expect at a Primary Care level and developments in arrhythmia care including new drugs and new services.

Regional Meetings help to improve service provision amongst the medical professionals and government, so that patients, who are at the centre of healthcare, receive timely and accurate diagnosis and access to arrhythmia services.

Contact us:

Please contact Arrhythmia Alliance (A-A) to answer any questions concerning National Partner start-up activities:

Trudie Lobban, MBE
A-A Founder and Trustee

+44 (0) 1789 450787

trudie@heartrhythmcharity.org.uk

Arrhythmia Alliance in the UK has developed a range of templates and models of best practice that are available to download from the secure Partners area of the website.