Patient advocacy in Australasia

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About Arrhythmia Alliance

Arrhythmia Alliance (A-A) is a coalition of charities, patient groups, patients, carers, medical groups and allied professionals.

A-A UK was launched in 2004 and was fundamental in pushing through one of the most essential policy issues to affect cardiology and cardiac patients.

Since 2004, A-A has grown into an international organisation, reaching across the globe to promote awareness of heart rhythm disorders and ensure the patient is at the centre of healthcare developments.

A-A is established in Sweden, Portugal, Czech Republic, Japan, Italy, China, Argentina, South Africa, Brazil, Uruguay, Mexico and now Australia!
Patient advocacy

Grassroots advocacy:
- Case studies in the media
- Campaigns
- Patient empowerment
- Healthcare provider education
- Awareness activities in the community

Policy level advocacy:
- Lobbying government with member outreach
- Engaging with MPs & MEPs
- All party parliamentary group
Local level advocacy
Placing case studies in the media to raise awareness

Charity’s goal to ensure everyone gets help to survive like Muamba

I SHOULD BE DEAD...I SHOULD NOT BE ALIVE
Ex army officer tells of moment his heart stopped

Faint hell gran’s life is a misery
BY STUART PATTERSON
Published: 16th January 2013

Richard’s toughest trek highlights health threat
Fundraising: Everest adventure to aid blackout victims

Watch out for danger signs as erratic heartbeat led to two years of anguish
Nottingham Post

Teacher ‘died’ for five minutes after rugby match

Your Heart Health

How’s THE WEEK?
What’s THE NEWS?
Mummy feet

In your sleep

AFAssociation
www.afa-international.org

AA
Arhythmia Alliance
The Heart Rhythm Charity
www.aa-international.org

STARS
Syncope Trust And Reflex Anoxic Seizures
www.stars-international.org
The easiest way to detect an arrhythmia is through manual pulse check. In 2009, Arrhythmia Alliance launched the ‘Know Your Pulse’ campaign, teaching members of the public how to check the pulse and why it is important.

Know Your Pulse

IT COULD SAVE YOUR LIFE

www.knowyourpulse.org

What is your pulse?

- Your pulse rate
- Your heart rate
- Your heart rhythm

One of the easiest places to feel your pulse is on your wrist, just below your thumb. You can check your pulse in either arm of your body, including the crease of your elbow or behind your knee.

Why and when should you check your pulse?

Being aware of your pulse is important because it may indicate an abnormal heart rate or rhythm. It’s a good idea to try taking your pulse at various points throughout the day (while you eat, while you walk) and at rest. As you age, your pulse may change during the day depending on what activity you are doing. This is normal. If you get your baseline pulse and normal rhythm, try taking your resting pulse when you wake in the morning and before going to bed.

What is a normal pulse?

Between 60 and 100 beats per minute. However, there are normal reasons why your pulse may be slower or faster. This may be due to your age, medications, fever, level of fitness, other therapies, blood conditions, stress and anxiety.

When should you seek further advice?

- If your pulse rate is not returning to normal after at least 6 months and you are feeling well.
- If your pulse rate is too fast or slow, even if you do not feel well.
- If your pulse feels irregular ("jittery") even if you do not feel well.
- If your pulse feels hard or difficult to feel.
- If you notice a difference in pulse rate or difficulty breathing.
- If you have any other symptoms.

Count for 30 seconds and multiply by 2 to get your heart rate in beats per minute.

- If your heart rate is in the normal range, it is safe and does not need to be checked again.
- If your heart rate is in the abnormal range, it is safe and does not need to be checked again.

Record your pulse here

- Record your pulse in the table below.
- Record the pulse rate for each activity.
- Your pulse rate should be checked at least once a year.
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Arrhythmia Alliance
The Heart Rhythm Charity
www.afa-international.org

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www.stars-international.org

AFA
AFAssociation

STARS
Syncope Trust And Reflex anoxic Sequences
Campaigns - Hearts & Goals

Hearts & Goals was launched by Arrhythmia Alliance (A-A) to tackle the UK’s biggest killer; sudden cardiac arrest (SCA).

The central aim Hearts & Goals is to help communities place public-access automated external defibrillators (AEDs).

Since the start of the campaign we have helped communities place 150 defibrillators up and down the country, with many more communities ready to launch their devices in coming months and new fundraising campaigns being launched on a daily basis; all receiving media coverage.
Campaigns – Take Fainting to Heart

• Take Fainting to Heart is a public awareness campaign aims to educate Americans about the important link between fainting and heart health.

• A national survey released in 2011 by the patient advocacy group STARS shows that one in two Americans are unaware that fainting could be a warning sign for a serious, potentially life-threatening heart condition.
Patient empowerment

Providing information and support to patients to work with their doctor to ensure they get on the right pathway to diagnosis.
The Heart of AF is a central resource primarily for healthcare professionals to access the latest research, source information, share pathways/protocols and to be kept updated on established, new or and innovative treatments and guidelines for atrial fibrillation (AF).
World Heart Rhythm Week

Provides the opportunity for individuals, groups and organisations to raise awareness and promote better understanding of heart rhythm disorders. This year’s Heart Rhythm Week was the biggest and best yet with over 6,000 events taking place in the UK and across the world.

Mass pulse checks
Jersey's General Hospital was inundated with people getting their heart checked using a new piece of kit. Instead of rigging patients up an ECG machine, Jersey Hospital trialled a new iPhone heart monitor.

Media awareness
In South Africa, Dr Franciska Rossouw, A-A South Africa, organised ‘Know Your Pulse’ television advert starring two Springbok rugby players that was aired during World Heart Rhythm Week.
World Heart Rhythm Week

AED donations
A-A UK donated five defibrillators to local communities during World Heart Rhythm Week. New data released by A-A UK during Heart Rhythm Week showed that more than half of people in the UK underestimate their potential to save somebody's life if they suffer a sudden cardiac arrest.

Walkathons
Madras Medical Mission in India organised an awareness march on Marina Beach by students of Arrhythmia and Heart Failure academy.

CPR and AED training
Al Quassimi Hospital arranged CPR training for bystanders. Members of the public were given hands on experience performing CPR and information on what to do in the event of an SCA.
International campaigns

A-A and AF Association has partnered with patient organisations from 20 countries to produce the [Global Atrial Fibrillation Charter](#).

Aim is to get 1.7 million signatures on the Charter, which represents every person killed or disabled by AF-related stroke.

A-A and AF Association is supporting 1 Mission 1 Million, calling for further awareness, resources and research into the prevention of AF-related stroke.

AF Association launched the [Take Action Now – Action Plan](#).

The plan was developed in partnership with the Arrhythmia Alliance (A-A), AntiCoagulation Europe (ACE) and the Stroke Alliance for Europe (SAFE) to provide practical guidance on how to campaign effectively for the improved management of AF so that stroke risk is properly managed in all those patients for whom anticoagulation therapy is required.
Policy level advocacy
Lobbying with member outreach – National Service Framework

- **2000** – NSF published on cardiology with virtually no mention of arrhythmias
- Patient groups began sustained call for change
- **2003** - Lobbying and letter writing began
- **2004** - Creation of the A-A during inaugural Arrhythmia Awareness Week
- Response from lobbying came 1 January 2004
  - “Issue of arrhythmia and its management” under consideration
- **2004** - Health minister announces need for arrhythmia content and invites A-A to assist drafting
Advocacy to increase access to care

• ACT on AF Friday
• Email your MP about pulse checks
• Campaign against a draft policy statement to restrict LAAO procedure
• Workshop in Parliament:
  - Recommend minimum standards of care for AF patients
• Surveys and reports:
  - Documenting economic burden that AF places on patients and the NHS
  - Suggest seven key actions that would dramatically improve AF care
  - Understanding the AF patient experience
## Affecting AF care

### The challenge

Anti-arrhythmic drug fails to win UK cost agency backing. Too pricey for NHS, says NICE, drug costs 45 times more than generic comparator.

### The response

NICE 'should allow a £2-a-day heart drug on the NHS that could help thousands'. A total of 176 cardiologists, backed by 25 MPs and peers, wrote to NICE calling on the organisation to reverse its decision.

AF-A called on MPs and patients to protest against a decision to refuse funding for a new drug that could improve the lives of thousands of people with atrial fibrillation.

### The result

Conservative MP, John Maples, tabled an Early Day Motion raising concern at decision and calling on NICE to ensure patients, carers, and health professionals are allowed to give evidence at second appraisal.

**August 2010** – Revised guidance published in favour of controlled use of the anti-arrhythmic.
The All-Party Parliamentary Group on AF

- Raises awareness of AF to Parliamentarians and key decision makers
- Brings together clinicians, commissioners and patients to discuss high quality AF care
- Acts a thought leader, publishing research like the Healthcare pioneers report
- Each meeting focuses on a key policy lever
- APGs represent an effective, tried and reliable route to engagement and influence with healthcare policy makers
- An effective APG enables focus, generates credibility and provides cohesion and consistency for all efforts to pull policy levers
APGAF's influence

• APGAF discussed the development of the Cardiovascular Outcomes Strategy
• The group heard from the Strategy lead who listened to the views of clinicians and MPs
• He pledged to include AF in the Strategy and to examine the group’s recommendations
• AF was later referenced several times within the Strategy
GRASP-AF

Guidance on Risk Assessment and Stroke Prevention for Atrial Fibrillation (GRASP-AF)

GRASP the Initiative Report was launched by the AF Association at the House of Commons in October 2012.

• The report found that 8,000 AF-related strokes could be prevented every year with the use of GRASP-AF in primary care.

• GRASP –AF could save countless lives and prevent long-term disability from this type of stroke, which is particularly debilitating.

• Moreover, the use of GRASP-AF could save the NHS £96million.
Left Atrial Appendage Occlusion

- **2012** - A draft policy statement was issued by the Specialised National Commissioning Board (SNBC) to restrict the commissioning of a very important therapy for people unable to take oral anticoagulation - Left Atrial Appendage Occlusion (LAAO).

- **February 2013** - AF Association asked for patients, carers and healthcare providers to support the campaign against this.

- **April 2013** - Following the high number of responses from patients, carers and healthcare professionals to their MP's and service providers, AF Association was reassured by the SNBC that all responses received were included in the review of this statement.
Whole Hearted

Whole Hearted calls upon government and policy makers to tackle the issue of sudden cardiac arrest so that NHS patients are no longer denied life-saving treatment:

• A commitment by the Government to direct efforts to raise the UK level of ICD implant rates to at least 100 per million people in the UK, and pacemaker provision to that of European average.
• A greater understanding of why local variation in implant rates is occurring.
• Full implementation and a regular audit of NHS England’s specialised services ICD service specification.
• Comprehensive implementation of NICE guidelines on ICD implantation.
• Access to one-to-one specialist nursing care for all heart rhythm patients who require support.
• A public awareness drive to increase knowledge of sudden cardiac death and how it differs from a coronary heart attack.
• More external defibrillators to be placed in public areas, to provide life saving assistance to those who suffer a cardiac arrest.
Evidence and data

Whole Hearted evidence and data.

1. Graph showing the UK’s position in Western European ranking of ICD implantation rates (adapted from Cardiac Rhythm Management UK National Clinical Audit). ICD Implant Rate 2011 – per million population.
Engaging European members of parliament

- Presented in European Parliamentary meetings
- Arranged meetings with MEPs on access to treatment and to discuss prioritising AF to avoid a stroke epidemic
- A-A and AF Association are part of the working group on Action for Stroke Prevention
Conclusion

• Patient organisations can effectively work with policy makers to effect change
• Lobbying to bring issues affecting patient care to the forefront and building on previous successes
• Healthcare policy makers need to hear the patient’s voice on issues that are important to their care to facilitate improved care
• Patient groups are critical partners in this effort
• A-A provides expertise and promotes the patient perspective
Launch of A-A Australia

Purpose: To promote better understanding, diagnosis, treatment and quality of life for those affected by heart rhythm disorders (cardiac arrhythmias).

The aims of the charity are to promote:

• Awareness of causes, symptoms, diagnosis and treatments
• Better understanding, awareness and quality of life
• Improved diagnosis and treatment
• Education of medical and allied professionals
• Multi-centre and multi-disciplinary research and centres
• Awareness and availability of treatment options
• Prevention of misdiagnosis
• Research and assessment
A-A Australia website

Publications
Click on the links below to view accurate, medically-approved information for patients about the diagnosis, treatment and management of heart rhythm disorders.

Share your story
Help others who may be awaiting or undergoing treatment for an arrhythmia. Your words can support and reassure patients on the road through treatment as well as those newly diagnosed or caring for someone with an arrhythmia. Many of the people we speak to are unsure about what to expect and the treatment options available to them; your words present a real-life account that can be shared to promote awareness and improve understanding of cardiac arrhythmias.

Help us to help others, with your consent we will use your words and your voice to promote awareness and lobby for improvements in diagnosis and management of cardiac arrhythmias.

Email your account to info@aa-australia.org: you never know how your words might help.

Patient stories available to view and download, courtesy of AF Association Australia:

www.aa-au.org
Our newest affiliate

www.afa-au.org
Arrhythmia Alliance – Australia
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Founder and Trustee: Arrhythmia Alliance UK