An introduction to Arrhythmia Alliance - Australia
Trudie Lobban, MBE
What is a heart rhythm disorder?

A heart rhythm disorder (cardiac arrhythmia) is the medical term for an irregular heartbeat or abnormal heart rhythm.

Arrhythmias may occur at any age. Some are barely perceptible, whereas others can be more dramatic and can even lead to sudden cardiac death.

Hundreds of thousands of individuals are affected by arrhythmias in Australia.
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!
Supporting advancement in arrhythmia care

AF Association
www.afa-international.org

STARS
Syncope Trust And Reflex anoxic Seizures
www.stars-international.org

ABN 32 162 163 902
AF Association

AF Association represents patients and provide information, support and access to established, new or innovative treatments for AF.

Aims:
1. Provide support and information on AF
2. Advance the education of the medical profession and general public on AF
3. Promote research into the management of AF

www.atrialfibrillation-au.org
STARS (Syncope Trust And Reflex anoxic Seizures) is the leading patient advocacy organisation providing information, support and education on syncope.

STARS aims to ensure that anyone with unexplained loss of consciousness receives timely and accurate diagnosis, effective treatment, support and signposting to appropriate medical specialists.
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
Our newest affiliate – The AF Association Australia
Online support

www.aa-au.org

ABN 32 162 163 902
Benefits of patient advocacy groups

Patient advocacy groups:

- Represent live accounts of patients and carers
- Reflect the views of members, bringing beneficial perspectives to the fore to ensure that change is led by the people and for the people
- Represent and promote partnerships between professionals, patients, government, organizations, and industry
- Facilitate rapid and complete communication between all interested parties
The patient journey

Fear and confusion
Pre diagnosis can be a long and anxious search for explanation of symptoms

Despondency
Uninformed and unsupported, dismissal of symptoms, no grasp of what future might hold

Turmoil
Emotional distress, fear, loss of hope, unpredictable and invasive symptoms

Relief and hope
Diagnosis, validation, control and hope
The burden of arrhythmias

“Just two years before his 60th birthday, we were watching TV and I had my head on his chest. I said ‘God, your heart is all over the place’, and laughed. … Three weeks later my husband suffered a stroke caused by an undiagnosed arrhythmia.”

Jenny H

Families are forced to adjust to massive changes:

• Communication
• Mobility
• Personal care

A financial, emotional and physical burden
What is needed?

• **Education** - reliable, quality information and guidance to improve patient outcomes

• **Awareness** - to achieve timely and accurate diagnosis and treatment e.g. through media campaigns

• **Reassurance and support** - A network of services e.g. patient organisations and groups, helpline etc

• **Advocacy** - to ensure the patient voice is heard so that healthcare policy makers and professionals can provide a better patient experience
Education to improve patient outcomes

- Currently, lack of understanding and poor or non-adherence to treatment
- Early detection is essential
- Patients face multiple challenges yet can play a crucial role when empowered through information
- Urgent need to provide the public with better information about arrhythmias and to improve education for healthcare professionals
Campaigns to raise awareness

Heart Rhythm Week

Arrhythmia Alliance (A-A) holds an annual international event, Heart Rhythm Week (HRW) to raise awareness of heart rhythm disorders and sudden cardiac death.

Supporters, organisations and individuals around the globe focus attention on heart rhythm disorders.

6,000+ events took place this year for HRW.

Do you know the life-saving difference you can make?

Performing CPR and using an AED can increase sudden cardiac arrest survival from 5% to more than 50%.

www.heartsandgoals.org

Know the difference. Make a difference.

Fabrice Muamba

ABN 32 162 163 902
Heart Rhythm Week in Australia

Pulse checks, Wesley Hospital, Brisbane
Know Your Pulse

The easiest way to detect an arrhythmia is to feel your pulse.

The Know Your Pulse campaign was the cornerstone of Heart Rhythm Week in 2010 and 2011.

The campaign continues today, promoting the need for us all to be aware of our pulse, and for the need to include routine manual pulse checks within the healthcare system.
International campaign

The Know Your Pulse campaign has been adopted across the world

- India
- USA
- South Africa
- Uruguay
- Argentina
- Colombia
- Mexico
- Denmark
- Saudi Arabia
- Sweden
- New Zealand
- China
- Australia & many more

Papá, conoce tu Pulso
PODRÍA SALVAR TU VIDA

ABN 32 162 163 902
Hearts & Goals

Tackling the UK’s biggest killer

[Website link]

www.heartsandgoals.org
Public awareness campaigns

UK facing a ‘stroke epidemic’

Better heart treatment could avert thousands of strokes, says charity

UK Heart Patients Among the Most Under-Treated in Europe, Reveals Major New Report

Doctors to check pulse of every patient to prevent 12,000 strokes a year

Pulse check on every patient ‘will save 12,000’

Government and Health Providers Must Act Now to Prevent a UK Stroke Crisis, Major Report Warns

Hundreds undergo health MOTs

Muamba in heart health campaign
Patient information & support

- Helpline
- Website
- Signposting to arrhythmia specialists
- Patient booklets and information resources
- Patient meetings and support groups
- Articles, newsletters

www.aa-au.org
Advocacy to increase access to care

- Email your MP about pulse checks
- Parliamentary events and meetings
- Recommend minimum standards of care for arrhythmia patients
- Surveys and reports:
  - Documenting economic burden of arrhythmias upon patients and society
  - Key actions to dramatically improve care
  - Understanding the patient experience
- Press releases publicising issues that affect care
Appropriate management has a positive impact for everyone

- Nobody chooses to become a patient
- Information empowers the patient to access appropriate help
- To feel in control of making informed choices
- Protects those who care for them
- Management of arrhythmias restores the patient to a person, giving back to society
What can we achieve together?

- Improved quality of life
- Patient education
- Awareness
- Advocacy
- Understanding amongst the medical profession of patients needs