Arrhythmia Alliance Charity Overview

Mrs Trudie Lobban MBE FRCP (Edin)
Founder & Trustee

CPVT Patients Day
7 October 2018
Welcome to the first dedicated CPVT patients day

• In September 2017 we held our first CPVT focus group.
• In December 2017 we added CPVT to the patient day agenda following our focus group
• In January 2018 we produced our first factsheet for CPVT
Why CPVT?

- To provide information and support
- To understand CPVT and the difficulties patients face
- To include CPVT on our cardiac update agenda
About Arrhythmia Alliance

“working together to improve the diagnosis, treatment and quality of life for all those affected by arrhythmias”

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

• A-A was launched in 2003 at the start of the first Arrhythmia Awareness Week in Parliament in the UK to raise awareness and highlight the deficiencies in the treatment and care of arrhythmia sufferers.

• A-A continues to strive for access to early diagnosis, appropriate treatment, ongoing patient support and improved quality of life for those affected by cardiac arrhythmias.
Who are we?

Arrhythmia Alliance, AF Association & STARS are patient representatives. We support patients through:

• Helpline
• Websites
• Resources
• Campaigns and events such as **Know Your Pulse** and **Defibs Save Lives**
• Patient Days
• Patient Surveys
CPVT

• Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT) is an inherited arrhythmia (heart rhythm disorder).

• CPVT is sometimes known as a channelopathy. This is because CPVT is caused by an abnormality of ion channels which allows calcium to accumulate in the heart muscle cell.

• This can lead to abnormal heart beats – usually during exercise or when adrenaline is released in stressful situations.
CPVT

• If there are runs of fast beats from the atria or ventricular tachycardia these are known as atrial or ventricular tachycardia.

• In CPVT the heart usually has a normal structure.

• It is thought that about 1 in 10,000 people have CPVT, although the exact numbers are unknown.
Our Campaigns

• Our core campaign ‘Know Your Pulse’ teaches individuals to be aware of their own pulse – the **quickest and easiest** way to detect a potential arrhythmia.

• Our Defibs Save Lives campaign supports fundraisers in placing public access defibrillators in the community for the public to use in an emergency.

• We run awareness events throughout the year, culminating in an annual World Heart Rhythm Week which encourages old and new supporters to promote awareness of cardiac arrhythmias.
Know Your Pulse

The simplest way to detect an arrhythmia (irregular heart rhythm disorder) such as AF is through a simple pulse check.

www.knowyourpulse.org
Know Your Pulse

Our resources include:

- Know Your Pulse
- Atrial fibrillation (AF) patient information
- Which ECG is Right for You?
- Identifying the undiagnosed person
- Arrhythmia Alliance
- STARS
- Arrhythmia Alliance
- AF Association
- Syncope Trust And Reflex anoxic Seizures

Know Your Pulse in four steps:
1. Place one finger on your wrist, above your thumb.
2. Take off your watch and hold your left hand with your palm 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 be below the bone on the edge of your wrist and the artery under your thumb should be the one you feel. Follow the pulse for 15 seconds.
4. Count the number of beats you feel in 15 seconds and multiply by four to find the rate in beats per minute.

Every 15 Seconds someone suffers an AF-related stroke

- Detect: AF by a simple pulse check
- Protect: from AF-related stroke using anticoagulation (not aspirin)
- Correct: the irregular rhythm with access to appropriate treatment
- Perfect: the patient care pathway

www.knowyourpulse.org
www.heartrhythmalliance.org
www.afa.org.uk
www.afa-intermural.org
www.syncope-trust.org
www.syncope-trust.org.uk
www.syncope-trust.org.uk
On November 1st, we held a Know Your Pulse Event in New York City, which focused on the importance of knowing how to take your pulse and being aware of your heart rhythm.

The event was open to the public where approximately 96,596 people passed the set-up.

Of those, 36,439 were reached.

During the event, Arrhythmia Alliance staff and iRhythm volunteers conducted 1-1 demonstrations of manual pulse checks and 1 lead EKG/ECGs using Alivecor Kardia mobile app devices.
Together, we can work to secure early diagnosis and improve outcomes for the many millions of people across the globe affected by arrhythmias.

Our annual Heart Rhythm Week aims to raise awareness of heart rhythm disorders around the world through information & awareness events, media outreach and Parliamentary events.
This year:

• World Heart Rhythm Week was even bigger and better than ever before, with a special focus to ‘Take Fainting to Heart’.

• The week consisted of hospitals, doctor’s surgeries, support groups and patient groups around the world holding know your pulse events in support of Arrhythmia Alliance WHRW, with the mission of raising the awareness, treatment and diagnosis of arrhythmias.

• Tens of thousands of pulse checks were taken in countries all over the world, making millions of people pulse rhythm aware.
World Heart Rhythm Week

How can you get involved?

• **Share & Display** information about arrhythmias, and the importance of Knowing Your Pulse

• **Fundraise & donate** for example by baking some goodies to sell, holding a coffee morning, quiz night or create your own event.
Arrhythmia Alliance

World Heart Rhythm Week

03 – 09 June 2019
All-Party Parliamentary Group on Arrhythmias

The All Party Parliamentary Group on AF (APPG-A) champions awareness of Arrhythmias from within the heart of Westminster.

You can get involved by signing up to our call to action, and writing personally to your local MP.
Pressure put on Government to make GPs screen for atrial fibrillation

Cardiovascular experts, along with UK MPs, are mounting a campaign to overturn the UK National Screening Committee’s decision to drop screening programmes for atrial fibrillation (AF).

Last year Pulse revealed that GP practices could be offered through GOSH to screen elderly people for atrial fibrillation, which is a potentially life-threatening condition. The decision was made after the committee recommended that AF screening was “not cost-effective”.

MSP Brian Whittle supports campaign to combat Atrial fibrillation (AF) disease

The Hippocratic Post

Self-monitoring to reduce risk of AF-related stroke

AF patients say ‘yes’ to the freedom that self-monitoring gives them

SURVEY

AF patients say ‘yes’ to the freedom that self-monitoring gives them

Related article

Prevalence of atrial fibrillation in elderly people with coronary artery disease

Stroke

“We should be a nation that knows about its heart rhythm”

Trudie Lobban of the Arrhythmia Alliance explores AF-related strokes

STARS

Syncope Trust And Reflex anoxic Seizures

AAA

Arrhythmia Alliance

AFA

AF Association

www.heartrythmmalliance.org
Surveys are an important way for us to find out patient opinions on treatment, medication options and other aspects of patient life.

The results of these surveys show how YOU are really making a difference...THANK YOU!
Gather patient’s opinions through surveys

Mobile ECG Devices

AF Screening Survey

- 43% received screening following symptoms
- 13% experienced a TIA or stroke

Symptoms included:
- Palpitations - 65%
- Fatigue - 59%
- Breathlessness - 50%
- Light-headedness - 46%
- Anxiety - 40%
- Frequent urination - 30%
- Chest pain - 18%
- Excessive sweating - 18%
- Syncope - 8%

However...
- 7% had NO SYMPTOMS at all

Implanted Devices - Infection

INR Self-Monitoring vs Clinic Visits

79% When asked if patients would prefer to self-monitor over clinic visits, 79% agreed that indeed they would.

78% Our results showed a conclusive response of 78% in agreement with "convenience" being an important factor in self-monitoring.
From a 2017 survey of around 150 patients
How we have helped you

It is important for us to know the ways in which we have helped our patients, in order to know what we can do to improve as a charity. We found that you were most helped by:

• Information and support on our health unlocked forum
• Information from our resources
• Our website
• Providing comfort to newly diagnosed patients
• Patient stories to help understand your condition

From a 2017 survey of around 150 patients
Donate your heart rate data using the Heart for Heart app.

Participating in medical research can be done in a variety of ways. One example is through Apple's ResearchKit. Only in the Netherlands is there an app called Heart for Heart. This app helps in research on heart health.

Survey shows nearly 90% of patients on warfarin would like to self-monitor.

Research shows that patients on warfarin would like to monitor their own heart health.

Interview with Trudie Lobban MBE, Founder & Trustee of Arrhythmia Alliance.

Trudie Lobban MBE is the Founder & Trustee of Arrhythmia Alliance. Here's what she has to say about the organization and its mission.

What is Heart Rhythm Week?

Heart Rhythm Week is an annual event to raise awareness about heart rhythm disorders.

Wearable Technology: Safeguards will help boost sales.

Wearable technology is on the rise, and its potential in healthcare is significant.

Atrial fibrillation affects tens of millions.

Atrial fibrillation is a condition that affects millions of people worldwide.

Syncope Trust And Reflex anoxic Seizures

The Syncope Trust is dedicated to the prevention and treatment of syncope.

Arrhythmia Alliance

The Arrhythmia Alliance is dedicated to improving the lives of people with arrhythmias.

AF Association

The AF Association is committed to raising awareness and providing support for those affected by atrial fibrillation.
Resources relevant to you

We aim to provide resources relevant to your conditions, in order to give you all the information you need.

www.heartrhythmalliance.org
Multiple languages available
Heart Rhythm Congress

6-9 October 2019
The ICC, Birmingham UK

Providing education and training to promote diversity and improved technology for all involved in the treatment of arrhythmia patients.

www.heartrhythmcongress.org

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