AF Association – Working for You

Mrs Trudie Lobban MBE FRCP (Edin)
Founder & CEO

Patients Day, HRC
7 October 2018
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- Founder of STARS (Syncope Trust And Reflex anoxic Seizures), in 1993. In 2003, umbrella charity Arrhythmia Alliance, and AF Association in 2007
- My daughter had RAS
- My husband died from cardiac arrest
- Both of my parents have AF
How we began

After finding that 51% of calls to Arrhythmia Alliance were from patients with AF, we realised that we needed a dedicated charity helpline just for you.

AF Association was launched internationally in 2007 and has gone from strength to strength ever since.
Our mission

➢ To raise awareness of the most common arrhythmia – Atrial Fibrillation

➢ To provide information and support to you, the patient

➢ To continue working with specialists to ensure new treatments are available to all
Our website is full of information and advice for AF Patients. We also send out monthly e-bulletins, keeping you updated on news, events, support groups as well as new patient stories and new resources.
Our first Newsletter was published in Spring 2008. We continue to produce these newsletters and send out over 500 copies plus we make it available to view on our website.
What have we already achieved?

➢ AF Association was represented in NICE Guideline updates in 2014 and we sit on the board for the next update.
➢ We sit on numerous committees for NOACs
➢ Partnered with iPACT
➢ More recently, we influenced CtE for the LAAO procedure
Funding for Left Atrial Appendage Occlusion was withdrawn for Commissioning through Evaluation.

It is now expected that around 400 patients will be treated in year one, building to more than 1,000 patients treated each year by year five.

This is thanks to AF Association’s tireless campaigning efforts.
Pressure put on Government to make GPs screen for atrial fibrillation

Cardiovascular experts, along with UK MPs, are mounting a new push to overturn the UK National Screening Committee’s decision to rule out a GP screening programme for atrial fibrillation (AF).

Last year Pulse revealed that GP practices could be offered incentives through GOFF to screen elderly people for atrial fibrillation, under new regulations.

Self-monitoring to reduce risk of AF-related stroke

AF patients say ‘yes’ to the freedom that self-monitoring gives them
How we reach the world

➢ A media tour of radio stations in November 2017 reached 14 million people across America

➢ World Stroke Day 2018 say Trudie appear on TV reaching a further 23 million viewers!
Our Patient Services Team

From a humble kitchen table, to a global team of 10, our patient services is here for you. We provide information and support when you need it.

01789 867502
info@afa.org.uk
Our resources include...
Our booklet, ‘Atrial Fibrillation and You’ has received a BMA Patient Information Award

AF Association has been awarded a commendation at the British Medical Association (BMA) Patient Information Awards 2018, for its booklet, *Atrial Fibrillation and You*.

The award-winning resource contains a glossary of words which help patients understand the language surrounding their condition, as well as an explanation of diagnosis, treatment options and medication, and the other impacts AF may have on several aspects of patients lives.
Did you know?

➢ We have a board of medical advisors ready to help

➢ They ensure that our resources are correct and up to date

➢ They are also available to help us answer your enquiries
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!**
What do AF patients face?
Challenge to Diagnosis

AF Screening Survey

- A staggering 30% of those diagnosed with AF were UNDER 60 years of age.
- 43% received screening following symptoms.
- 13% experienced a TIA or stroke.
- (transient ischemic attack)

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

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

AF Screening Survey, © AF Association, 2017
Further surveys showed that 30% of AF patients feel that their healthcare team is not aware of all of the problems they face with their AF.

2018 AF Association survey of approximately 700 patients.
AF: The condition
Concerns

Concerns about the condition

- possibility of having an AF related stroke: 65.56%
- being at risk of dementia: 26.03%
- risk of developing heart failure: 20.55%
- bleeding: 39.80%
- other: 23.73%

Our surveys are important in helping us understand the needs of you, the patient. They provide vital information which help us better advise more AF patients, and adapt our aims as a charity.

2018 AF Association survey of approximately 700 patients.
All-Party Parliamentary Group on Atrial Fibrillation

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

The APPG-AF looks at a number of ways in which we can improve the treatment and diagnosis of AF and help prevent AF-related stroke. We also work with a broad range of parliamentarians from across the political spectrum to highlight the issue of AF from within parliament.
A finger on the pulse of the world

We have reached over 45 million people worldwide,
And taken over 1.5 million pulses!
Heart Rhythm Week
03-09 June 2019

➢ Every year sees pulses being checked around the world

➢ You can get involved next year. Keep an eye on our social media and website
AF Association Global AF Aware Week raises awareness of the fact that Atrial Fibrillation, or AF, is the most common arrhythmia (heart rhythm disorder).

For Global AF Aware week, we are promoting our Detect, Protect, Correct & Perfect campaign, and asking all of our supporters to help us spread the word.

It is vital that you Know Your Pulse to Know Your Heart Rhythm.
How you can get involved...

➢ Share & Display information about AF and the importance of Detect, Protect, Correct & Perfect

➢ Hold an AF Awareness activity to seek out and 'Identify the Undiagnosed Person with AF’ – order your pack at the tables in the foyer

➢ Fundraise & donate to enable us to continue to raise awareness and offer support
What difference does it make if you share with us?

➢ Too often, a diagnosis of AF can result in a person feeling alone and frightened.

➢ By sharing your experience on “Stories From the Heart” on our website, you can help people to understand that they are not alone.

➢ Reading other people’s experiences, and finding out what treatments have worked, can be invaluable. If you have a story to share, please email info@afa.org.uk.
Donations do make a difference...

➢ As a registered charity, AF Association relies on regular donations to continue to offer our valuable information and advice service.
➢ Ask us for a donation form, or set up a monthly payment online.

£5 will help inform a family about a new diagnosis of AF

£10 will help provide personalised support via our helpline

£25 will enable us to continue to develop our library of resources
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<thead>
<tr>
<th>What else can you do?</th>
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<tbody>
<tr>
<td><strong>Volunteering:</strong></td>
<td><strong>Fundraising:</strong></td>
</tr>
<tr>
<td>✓ AF Association relies on volunteers to keep our resources up to date.</td>
<td>✓ We are so grateful to everyone who fundraises for us.</td>
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<tr>
<td>✓ We NEED more support groups – contact us to find out how you can set one up</td>
<td>✓ From cake sales, to marathons – every penny helps (We have a place in 2019 London Marathon – get in touch to apply to take part!)</td>
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<tr>
<td>✓ Share our resources with your GP</td>
<td>✓ Contact us to find out how you can fundraise</td>
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<td>✓ Write to your MP</td>
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Our promise to you

We will continue to help you to receive the most appropriate treatment
Finally...

Be in Control of AF
Don’t Let AF Control YOU!

Worrying doesn't take away tomorrow's troubles
it takes away today's peace.

Lessons Learned In Life
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