AF Aware Week 2016

The focus of AF Aware Week 2016 was Detect, Protect, Correct.

Detect AF by a simple pulse check
Protect against AF-related stroke using anticoagulation (not aspirin)
Correct the irregular rhythm with access to appropriate treatment

During the week, which ran from 21-27 November, we asked patients and Healthcare Professionals to raise awareness of atrial fibrillation (AF) and hold Know Your Pulse events. You did not disappoint!

Know Your Pulse events took place all over the UK and internationally. AF Association held and attended various events:

- A Know Your Pulse event took place in Kingsgate Shopping Centre, Huddersfield. Barry Sheerman, MP was in attendance to help raise awareness.
- AF Association also attended a Know Your Pulse event at Southwark Council, London.
- MPs were invited to sign our AF Screening Pledge at the AF Association All-Party Parliamentary Group on AF meeting held at Westminster.

AF Screening Pledge

The current UK National Screening Committee (NCS) recommendation on atrial fibrillation and screening in adults does not recommend systematic population screening. Arrhythmia Alliance, AF Association and the All-Party Parliamentary Group on Atrial Fibrillation are asking that the National Screening Committee reconsider this decision.

We ask you to visit the AF Association website to pledge your support and to write to you MP using our template letter. You really can make a difference!

Please visit our website to learn more about AF Aware Week and to pledge your support to our AF screening campaign:
www.afa.org.uk

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  Coping strategies that other patients find beneficial

- Ablation for AF
  The different types of ablation

- 3D mapping and robotic navigation
  An insight into newer technologies

- Understanding your ejection fraction (EF)
  Including tips on how to improve your EF score
Strategies for managing your AF

Coping strategies that other AF patients have found beneficial include:

Diet:
- Eat smaller suppers, no later than 7pm if symptoms regularly come on at night.
- Avoid alcohol and caffeine or replace these with decaffeinated or alcohol free options.
- Be aware that cheese, cured and pickled foods (which may contain a natural chemical which stimulates the heart called Tyramine sometimes trigger AF in some people but not everyone).
- Avoid chocolate which contains caffeine and the naturally occurring stimulant phenethylamine.
- Follow a low sodium diet, especially if blood pressure is a factor.
- Follow a low-fat diet (and watch cholesterol intake).
- Cut out nicotine (a cardiac stimulant which is also known to cause coronary heart disease).

Medical strategies:
- Ask your specialists about options such as ablation and pacemaker implantation if your symptoms are uncontrolled.
- Be aware that the ingredients of some herbal remedies, may contribute to AF.
- Ask your doctor or pharmacist before using over the counter cold remedies and nasal sprays.

Physical and psychological strategies:
- Exercise to a safe and reasonable level (having sought medical advice and approval).
- Physical activity like walking helps to create a positive, upbeat mood, and it regulates daily biological rhythms, thus helping you to get a good night’s sleep, and is also an important component of weight control.
- Deep breathing (take advice on this).
- Address any stress issues and take specific steps to deal with them.
- Be mindful of emotional health, anxiety, and depression.
- Your GP can refer you for a course of cognitive behavioural therapy (CBT) if you have negative thought patterns associated with your AF.
- Plan a holiday.
- Reintroduce pleasant, fun or rewarding activities which may have fallen out of your routine due to time restraints or lifestyle.

Always speak to your GP or healthcare professional before embarking on exercises or changing your diet and lifestyle.

Getting social

Many people find that talking to other patients with a similar condition can be very helpful. You can access an online support system 24/7 by visiting www.healthunlocked.com/afassociation.

This is an online community forum with members worldwide. The members on this forum are not medically trained, and an enquiry on the forum should never replace a visit to your GP or consultant. However, they are a knowledgeable and supportive network and we signpost our Friends here regularly. The forums are monitored by AF Association, and where necessary, we will reply to posts with information.

Go online: www.afa.org.uk • info@afa.org.uk
Ablation for AF

Successfully managing atrial fibrillation can be difficult. At some point, doctors will likely discuss the options for trying to treat the condition with you. The term ablation will be used frequently and in this context, means the destruction of abnormal conducting tissue.

Using the various different types of ablation, the abnormal electrical signals within the heart can be blocked. The success of each approach varies and the type of AF you have can play a role in the options that are available.

Ablation is not suitable for everybody and is currently indicated for those who have failed to respond to two different drug strategies and whose symptoms impact severely on their lives.

The most frequently used form of ablation is catheter ablation. Trials and research have shown this style of ablation procedure to have relatively low complication rates and good success rates for the appropriately selected symptomatic AF patients.

In some circumstances, surgical ablation is a very effective treatment, however this is carried out by a Cardiothoracic Surgeon, and is usually considered for AF patients either already undertaking an open-heart procedure, or for whom catheter ablation may not be the most appropriate option.

What are the most common methods of catheter ablation?

**Radiofrequency ablation** energy is applied from the tip of the catheter creating short bursts of high temperature heat to burn small areas of tissue. In order to isolate the electrical impulses causing the AF, a series of small dots are made around the pulmonary veins to create a ring which then completely isolates the area.

**Cryoablation** is often used for treating paroxysmal AF and can isolate the pulmonary veins. The catheter has a small balloon at the tip that is filled with liquid nitrous dioxide which is extremely cold. This causes freeze damage around the affected tissue at the entrance to the pulmonary veins. These are then isolated from the rest of the heart, blocking erroneous impulses responsible for AF.

**Laser balloon ablation** can only be performed on individuals who are able to tolerate a general anaesthetic because the procedure requires the patient to be absolutely still. The catheter has a balloon positioned at the tip as well as a camera (endoscope) inside it which allows the doctor to see inside the left atrium. This then allows the Electrophysiologist (EP) to use the laser energy under direct vision and create a circle of ablation around the entrance to each pulmonary vein predominantly for patients with paroxysmal AF.

Will the procedure work for me?

The success of this procedure depends on several factors:

- The type of AF you have (paroxysmal, or persistent)
- Whether or not you have any other heart disease
- The experience and the equipment available to the hospital where you have the procedure performed.

You should discuss these factors with your heart rhythm specialist. To achieve the levels of success for paroxysmal and persistent AF, it may be necessary to undergo two or more procedures.

You can read more information on ablation in our booklet Ablation for AF available to download from our website: www.afa.org.uk, or in print by phoning our office on +44 (0)1789 867502.
3D Mapping and Robotic Navigation

Professor Richard Schilling and Dr Ross Hunter, St. Bartholomew’s, London

3D Mapping

Catheter ablation procedures have become increasingly involved over the last 20 years. The cardiac chambers that are navigated are 3D structures that are anatomically complex and variable between patients.

The use of x-rays alone to help the operator navigate catheters within the heart for such involved procedures can involve moderate doses of radiation. The orientation provided by x-ray alone is also somewhat crude and gives little anatomical detail.

3D mapping systems provide computer generated images of catheters within the body. There are different mapping systems in use which locate catheters using either magnetic fields generated by a magnet under the bed, electrical measurements between the catheters and stickers placed on the body surface, or a combination of both.

By moving catheters around the chambers of the heart the mapping system can remember everywhere the catheter has been, and so, can generate a 3D model of that chamber and show the catheter moving within it. Once a 3D model has been generated it is then possible to annotate, marking timings of electrical signals to ‘map’ arrhythmia or mark sites of ablation for example when creating lines of ablation surrounding the pulmonary veins for atrial fibrillation.

It is also possible to import x-ray images into the mapping system, for example from CT scans to show greater anatomical detail – although the 3D models constructed just by moving catheters around inside the heart are so good with modern mapping systems this facility is rarely used now in most centres.

With the use of 3D mapping systems many centres have managed to reduce their use of x-rays substantially, with a few high-volume centres using almost no x-rays at all now. The ability to navigate within the heart to within a millimetre or 2 has also made many procedures possible that would not have been otherwise, such as mapping atrial tachycardias following AF ablation and VT ablation. In fact, there is increasing use of 3D mapping systems for relatively simple catheter ablation procedures now, aiming to reduce x-ray usage and increase the precision and quality of the procedures.

Figure 1. The left atrium with ablation lesions around the pulmonary veins shown on the Carto mapping system. The yellow shell shows the left atrium reconstructed from a CT scan. The catheter is then visualized moving within this. The red dots are markers where ablation has been performed. These are surrounding the pulmonary veins where ablation is performed for atrial fibrillation.

Robotic Navigation

Laparoscopic surgery has been likened to painting your hallway through the letter box. If this is the case, performing catheter ablation within the heart from the leg is perhaps like rewiring the attic fuse box through the letter box. Operators have become skilled at moving catheters around the heart, but ultimately, we can only move a catheter in or out, or rotate it. There are elaborate techniques involving inverting catheters into a loop, or building up torque to hold catheters in contact with the heart surface. There are limitations...
to such techniques though, and robotic navigation has attempted to circumvent these. The primary aim is to increase safety and efficacy by increasing the precision of movement and the stability of catheter placement.

This may also reduce x-ray exposure to operator and patient and has the added benefit of reducing operator fatigue (and therefore potentially improving performance) for long procedures.

Perhaps the cheapest and simplest robotic system is the Amigo system (by Catheter Robotics). There is an arm at the bedside which holds the catheter handle, and using a joystick the operator can operate the controls on the catheter handle. The catheter is therefore operated in much the same way as usual but is controlled remotely. Perhaps the main advantage of this system is that the operator can be seated at a distance from x-rays.

The Sensei robot (by Hansen Medical) has an arm at the bedside which controls a robotic sheath which extends inside the body to the catheter tip. A sophisticated joystick then controls the device. Rather than controlling the catheter handle it therefore physically moves the catheter tip to the desired location and holds it there.

The Sensei system has been shown to produce very precise catheter movement and hold the catheter tip in a very stable position during mapping and ablation. This seems to be superior for creating an ablation lesion and there is early evidence coming through now that this may be improving outcomes for complex procedures such as catheter ablation of AF. There is emerging data on its use in VT ablation also which is a particularly technically challenging procedure where robotics may develop a niche.

Another system which might be considered robotic is the Niobe system (by Stereotaxis). Here the catheter is moved inside the body by powerful magnets placed around the patient in a custom-built catheter laboratory. Again, a joystick controls the catheter movement (although catheter movement is controlled remotely, some might argue it is not strictly a robot as there is no device moving the catheter just magnets).

Nevertheless, it offers excellent catheter manipulation and may add value in patients where there is particular anatomical complexity, such as in those with congenital heart disease where one might have to navigate around several bends. A challenge for the system has been to generate sufficient contact force between the catheter and the cardiac tissues. A reasonable force is required to make high quality lesions, and this has limited the use of this system for complex procedures such as AF and VT to date.

Later iterations of this technology have reportedly made some progress in this area, but it remains to be seen whether it will reach routine clinical practice for procedures such as AF and VT ablation.

The enclosed “Make Your Heart Feel Good” Dance DVD is a gift for you!

We are also sending some information sheets and we would appreciate it if you wouldn’t mind sharing these with your doctors’ surgery, gym, library etc to raise awareness of AF and the importance of knowing your pulse!

AF Association has moved to Oxfordshire!

We have moved offices to Chipping Norton but nothing has changed. We are still here providing information, support and reassurance through our dedicated helpline. Our address is: Unit 6B, Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR. Our telephone number is unchanged at 01789 867 502.
John’s story

At the time of writing I am at a crossroads with treatment for persistent atrial fibrillation (AF) and I thought it might be useful to share my experience of symptoms and treatments since the onset of my AF in September 2014.

Otherwise perfectly fit, I was diagnosed AF during a routine visit to my GP through a simple pulse check. This was then confirmed by ECG at the surgery. I was immediately prescribed a low dose beta blocker and referred to the warfarin clinic. The main concern the doctor explained was the risk of stroke, but at the time no explanation was offered of possible cause, prognosis, or treatment options. There was also no mention of other medication options or the alternative choice of anticoagulants, non-vitamin K antagonist oral anticoagulants (NOACs). So, began the frequent visits to the warfarin clinic to achieve INR stability.

“Otherwise perfectly fit, I was diagnosed with atrial fibrillation during a routine visit to my GP through a simple pulse check.”

A month later I was seen by a Consultant Cardiologist and given a further ECG and transthoracic echocardiogram. With no history of any other heart related issues the Consultant confirmed the AF diagnosis and arranged a cardioversion. My hopes and expectations were immediately raised when I was advised that the procedure had an excellent success rate (80% - 90%) of returning my heart to sinus rhythm. No mention was made at the time of the significantly lower success rate over the longer term (which I discovered later through my own research). Additionally, at this point the options and implications of rate versus rhythm control were not explained or presented as options.

The cardioversion was pronounced ‘successful’ and I remained in sinus rhythm for 48 hours. In the early hours of the morning I began to feel uncomfortable, very quickly my pulse began racing and I was back in AF. As this possibility, had not been explained I became extremely concerned and was admitted to A&E with a heart rate of 160bpm. Treatment was given, by way of an increased beta blocker dose and, with my heart rate reduced to 120bpm, I was released four hours later. Back in AF and very disappointed.

At this point I began my own more intense research into AF, and treatment options, and it was only then that I became aware that my AF was probably ‘persistent’.

My referral back to the hospital resulted in the recommendation that I undertake a further cardioversion with the inclusion of amiodarone medication. Although the clinician who recommended the procedure played down the side effects of amiodarone, my own research had given me real cause for concern over long, and short term side effects of the drug. As my concerns were echoed by my own GP I elected not to take this treatment option and then I decided to take further advice from other sources. I researched all of the NICE information and from the internet discovered the AF Association.

I finally had the detailed documented information which had not been readily forthcoming from the NHS or my GP. I discussed catheter ablation with the AF Association and they very quickly signposted me to an Electrophysiologist at my local hospital. As the waiting list for appointments was significant I elected to see him privately and was seen within one week.

Only then, six months since the first diagnosis, was I given a detailed analysis, by a specialist medical practitioner, of my specific condition, causes and the treatments available including catheter ablation. At this point I remained very confident that my condition could be ‘cured’ and agreed to undertake a catheter ablation. I was reassured that the chance of success following the ablation was somewhere between 70% and 80%, although it was explained that a total of two procedures may be required. I was also given assurance that the procedure would not make my symptoms any worse.

“My symptoms on original diagnosis were fairly mild; I was aware of the pulse irregularity and felt a little more tired, but otherwise I was not debilitated.”

My symptoms on original diagnosis were fairly mild; I was aware of the pulse irregularity and felt a little
more tired, but otherwise I was not debilitated. As time went on I became aware of feeling more tired and occasionally short of breath following exercise.

The ablation took place in August 2015 and was pronounced successful. I was back in sinus rhythm and discharged from hospital later the same day. However, my hopes were short lived when within 24 hours I was back in AF. Here began my first real doubts about the likelihood of a cure for my condition.

The next medical protocol required that I wait six months before further tests and a second cardioversion. This all had to be undertaken before consideration could be given to a second ablation.

“In the post ablation period, I became noticeably more tired and short of breath and as a result I began to actively manage my symptoms.”

In the post ablation period, I became noticeably more tired and short of breath and as a result I began to actively manage my symptoms.

A second cardioversion was carried out in February 2016 and when I remained in sinus rhythm for only one day before reverting to AF I was ‘listed’ for a second ablation, with an NHS waiting list of between 12 and 14 months.

My second ablation is now due to take place shortly, but in the intervening period my own research including the AF Association, NICE and attending Patients Day at the Heart Rhythm Congress, together with the treatment failures to date, have raised significant doubts about the realistic chance of success. I have a pre-procedure appointment with my Electrophysiologist next week and feel that I will need to be convinced about the chance of success before undertaking a further invasive procedure. The alternative option is to now decline the procedure, accept the symptoms associated with persistent AF, and learn how control and live with them.

“By the time you read this, my decision will have been made, and hopefully it will turn out to be the right one.”

I began by explaining that after two years I was at a crossroads with the way ahead for AF treatment. By the time, you read this, my decision will have been made, and hopefully it will turn out to be the right one. However, for those of you reading this, I hope that my experience has been of some value and I offer the following recommendations to anyone finding themselves in a similar position.

Once diagnosed, research all of the material available in order to better understand the diagnosis, treatment, and both short and long term prognosis of your AF. Do not be reluctant to use all of the sources available to you to research and question. Start with your GP, your specialist, NICE guidance and the wealth of experience and information available through organisations such as AF Association. Ensure that you fully understand the type of AF applicable to you and the implications it has for you.

“Do not be reluctant to use all of the sources available to you to research and question.”

Discuss at the outset with your GP the medication options as they pertain to you and in particular the warfarin versus NOACs choice.

Feel positive about the treatment but set realistic expectations. In this regard ensure that cardioversion/ablation outcomes in both the short and the long term are fully understood and also discuss with your specialist/GP all of the medication options available to help with your condition.

Read up on rate versus rhythm control and discuss which is more appropriate for your condition.

Ensure that your GP/specialist sets out a long-term treatment plan which you buy into. It is essential that you participate in the decision-making process armed with all of the relevant information and have regular dialogue with the specialists involved in your treatment. Do not be reluctant to ask questions however trivial they may appear to you.

Finally, try to remain upbeat throughout, be patient, and learn to manage your symptoms to minimise their impact on your lifestyle both during and after treatment.

John, Lancashire

If you have any questions or concerns regarding atrial fibrillation, ablation or cardioversion, please do not hesitate to call our Patient Services Team on +44 (0)1789 867 502 or by email: info@afa.org.uk

Helpline: 01789 867502
Understanding your Ejection Fraction (EF)

Ejection Fraction (EF) is the percentage of blood that is pumped out from a filled ventricle during each beat. If you are offered an echocardiogram, which uses sound waves to produce an image of your heart, your EF will usually be taken to indicate how well your heart is pumping, if you have heart failure or other kinds of heart disease.

50-75%
Heart’s pumping ability is NORMAL

36-49%
Heart’s pumping ability is BELOW NORMAL

35% & Below
Heart’s pumping ability is LOW

A low EF is an early sign of heart failure. Heart failure is a condition where the heart does not pump enough blood to the rest of the body. However, many people live a relatively normal life with heart failure, once they are receiving treatment. Symptoms of heart failure include: shortness of breath, fatigue and swelling of the feet.

Your doctor may provide medications depending on your EF score. However, there are different steps you can take to improve how well your heart pumps.

Exercise regularly
Just 30 minutes of aerobic activity can help strengthen your heart and improve its pumping ability. Please consult a healthcare professional to check which exercise program is right for you.

Manage fluid intake
When you have a low EF, fluid can build up in the lungs, making it difficult to breathe. Your healthcare professional will be able to advise how much fluid you need daily based on your EF.

Cut back on salt
Adults should eat no more than 6g (2.4g sodium) of salt a day. With a low EF, your kidneys get less blood than they need so it makes it more difficult for them to get rid of excess water and salt. Eating too much salt can lead to fluid build-up which in turn increases your blood pressure, making an already weakened heart work harder.
Clifford’s story

On holiday in Gibraltar I was under the ‘Rock’ when I suffered my first AF attack and thought I was going to spend the rest of my days down there.

I returned to the UK and saw my GP who admitted me to hospital where I was treated with IV propranolol, potassium, and warfarin.

“I looked on the internet and found that volunteers were needed for a clinical trial…”

I was discharged on these medicines in tablet form and reviewed at out-patients where I was told to cease work and retire. I refused to accept this, and looked on the internet where I found that volunteers were needed for a clinical trial of a ‘robot’ that would introduce a catheter through the groin up into the heart and would ‘ablate’ the areas that were sending out the false signals to contract to the chambers of the heart. This trial was in St. Bartholomew’s Hospital in London and I lived in Louth in Lincolnshire. It would mean a lot of travelling and staying overnight.

I suffered post-op inhalation pneumonia after the first ablation. This was due to the oesophageal ECG pre-op. I stayed a couple of nights and then returned home only to revert to atrial fibrillation after a matter of days.

“I stayed in a couple of nights and then returned home only to revert to atrial fibrillation in a matter of days.”

Another visit to St. Barts was arranged and a date set for another ablation. The same procedures were carried out although this time I did not develop aspiration pneumonia and I remained in sinus rhythm for considerably longer. However, I did collapse in town due to the warfarin causing my old gastric ulcer to bleed which meant an emergency admission to hospital.

On discharge I was still in slow atrial fibrillation and a third admission was arranged at St. Barts for ablation and another trip made. After reading my consultant’s post ablation report, I was and still am certain that his ‘mapping’ had found the correct point from which the signals for premature atrial contraction were emanating from.

It is now several years since my third and final ablation and I have recently celebrated my 85th birthday. I still have runs of atrial tachycardia but I am knowledgeable about the Valsalvas Manoeuvre and am therefore able to abort such attacks quite quickly.

“I was and still am certain that his ‘mapping’ had found the correct point from which the signals for premature atrial contraction were emanating from”

I have had a pacemaker inserted and a Watchman device (left atrial appendage occlusion device) and so I hope that I have many years ahead of me yet.

Clifford, Lincolnshire

Clinical trials

If like Clifford, you would like to learn more about participating in clinical trials, please download the What is a clinical trial? factsheet from the AF Association website: www.afa.org.uk.

In-depth information to help you a clear understanding of what is involved, if you participate in a clinical trial, can also be found via the UK Clinical Trials Gateway website: www.ukctg.ac.uk.
Fundraising

Simon Clough ran the Virgin Money London Marathon on behalf of AF Association raising £5,889 including Gift Aid. Simon wanted to share his experience:

“I was built for short distances, and distinctly remember from my childhood that I thought the four hundred metres race was ‘long distance’.

You can now imagine how bizarre it was for me to decide to run the London Marathon!

In fairness people were very polite when I told them about my entry, but a raised eyebrow was a clear sign of what they really thought!

This, and people’s incredible support through their sponsorship gave me the motivation to see me through the cold, wet runs over the winter months - the dark days of training, the merciless mileage programme, and the painful exploration of the ‘chafe zone’ and all its connotations were made much more bearable by people’s kind messages and thoughts.

Needless to say I did not trouble Eliud Kipchoge on the day, but I live in hope that he only broke the course record because he thought I was chasing him down. I was quite pleased that he only finished three and a half hours faster than me. Quite close really!

My enduring memories of the day include being overtaken by a rhino at mile 24. His jaunty-but annoying little waggling tail still makes me laugh when I think about it.”

“The crowd were unbelievable - incessant shouts of support and encouragement, offers of jelly babies, and even ‘punch here to get superpowers’ placards. I’m not sure I punched them in the right place.

Anyway, it was a midlife crisis goal achieved. I am now surprising myself with serious thoughts about doing it again.

Sincere thanks to everyone who supported me - it meant a great deal.”

“AF Association does not just help the people affected in this way. They also work closely with medical professionals and the NHS, and others in the medical community to help in detecting, diagnosing and managing atrial fibrillation.”

“Atrial fibrillation does affect my fitness, but it doesn’t stop me - this will be my second Tough Mudder, and I want to help AF Association to raise awareness and help others that are in the same place I was when diagnosed.”

After the run, he added: “I did it! I completed the course in full, despite cracking my ribs just before the halfway point. The rest of the course became a lot tougher, but with the help of my teammate and plenty of other mudders, I completed the obstacles and remaining six miles of Yorkshire hills!”

Well done Stuart, and thank you for pushing through the pain!

Stuart Hoff took part in the Tough Mudder challenge in August managing to raise £350 for AF Association. Stuart says “When I was diagnosed several years ago, it was a shock. I found AF Association, and through their community and stories of others affected I was able to manage my concerns.”

Go online: www.afa.org.uk • info@afa.org.uk
Malcolm Brand ran the Great South Run in October and raised over £150 for AF Association.

Thank you to the Black Horse Inn in Shipston on Stour for holding a quiz night. The proceeds of £27.50 were donated to AF Association. Although the turnout was small, a great evening was had by all!

15-year-old Lily ran the British 10k in London in July for AF Association. She raised a fantastic £125. Thank you, Lily, and well done!

Andrew Grey took part in the Big Heart Bike Ride in February to raise money for AF Association. Andrew said: “I have suffered from atrial fibrillation all my life. I never knew I had it until a year ago, I knew I had a problem with my heart but not sure what it was. Having an attack is very terrifying but luckily mine only last an hour. Some people can have attacks for weeks on end. The AF Association offers a lot of support and information for sufferers and an online community. Doing this bike ride will not only be an amazing experience but will also help go towards a charity I personally want to support.” It’s not too late to sponsor Andrew, and you can do so by visiting: www.justgiving.com/fundraising/Andrew-Grey1

Scott Lovering ran the Surrey Half Marathon on 12 March 2017 in support of his girlfriend Connie and in memory of her dad Dave (right) who sadly passed away recently as a result of AF. Scott decided to run the half marathon to raise money for the AF Association as he believes it is a great cause. The half marathon took place the day after Dave’s birthday making it a timely event to raise some money in memory of a generous man. Scott raised a wonderful £3,650 for AF Association – Thank you Scott!

It’s not too late to donate though! If you would like to show Scott your support, please visit his Just Giving page at: www.justgiving.com/fundraising/Scott-Lovering

Order your AF Association running vests and t-shirts

If you are taking part in an event to raise money for AF Association, we will send you a t-shirt as a thank you and to wear on the day. However, if you would prefer a running vest, or would like to purchase any additional items for you and your supporters, please visit the AF Association online shop via the website: www.afa.org.uk

If you would like to raise funds for AF Association, please let us know! It does not have to be running a marathon, perhaps you could hold a pub quiz night, bingo night, or a cake sale... ANYTHING! We would love to hear about all fundraising efforts. You never know, your picture could appear in our next newsletter.

Please call: 01789 867 502 or email: info@afa.org.uk.
The Anticoagulation Achievement Awards

We are delighted to announce the launch of the Anticoagulation Achievement Awards, together with Arrhythmia Alliance, Anticoagulation Europe, Thrombosis UK, Anticoagulation in Practice, and Thrombus.

It is important that those who are passionate about providing excellent anticoagulation services should be recognised and rewarded.

The prestigious Anticoagulation Achievement Awards are seeking applications from outstanding clinical teams and individuals who provide exemplary care for any patient who has been diagnosed with atrial fibrillation or a blood clot such as a DVT (deep vein thrombosis) or a PE (pulmonary embolism).

If you are a clinician or you know a clinician, or clinical team, who makes all the difference to patient care for any of these conditions, please share this information with them. Not only could they receive national recognition for their services and care, but will also win a £1,000 bursary.

Applications must be received by the 10th May 2017. The Awards ceremony will be on the 11th October 2017 in The Houses of Parliament. Further information and application forms are available on: www.anticoagulationawards.org

Anticoagulants are prescribed to prevent harmful blood clots that can lead to stroke. They are designed to prevent or treat clots, but can increase the risk of bleeding. Patients and carers need advice and information about how these medicines work, and their potential side effects.

The new video, Starting Anticoagulation with Jack, has been developed to meet this need for patients, their family and carers after anticoagulants have been prescribed.

It explains about clotting and why abnormal clots can form as people age. The different types of medicines are shown, and Jack and his son discuss common concerns, side effects and sources of support.

We know that many people taking anticoagulants do not fully understand what side effects to look out for, or when to seek help. Starting Anticoagulation with Jack has been created to prevent people becoming unwell while on anticoagulant medicines, and avoid unnecessary admissions to hospital.

Please do watch Jack and share the film with your family and friends. There is also an information leaflet by linking to http://www.wessexahsn.org.uk/jack

Once you have watched the film, we would be grateful for your feedback via our brief online survey at https://www.surveymonkey.co.uk/r/VS66ZFB

Go online: www.afa.org.uk • info@afa.org.uk
Heart Rhythm Charity Award winners 2016

Amongst the winners of these prestigious awards was Gaynor Richards who won the Charles Lobban Volunteer of the Year Award. Gaynor, an arrhythmia nurse specialist in Dorset, supports ICD patients and also oversees her own ICD support group. This vital group is not just educational for patients but also tackles the social exclusion that is often felt by a patient with this device.

The Charles Lobban award is very special for AF Association’s sister charity, STARS as Charles, Trudie’s late husband, was an integral part of ‘Team Lobban’ in establishing STARS in 1993.

Congratulations must also go to the Cardiac Rhythm Management Team at Oxford University Hospital who won Team of the Year Award. This team is unique because the Advanced Nurse Practitioners are the only nurses in the UK who undertake advanced cardiac physiologist roles, including solo insertion of implantable loop recorders. This has allowed this common procedure to be removed from the EP and Device Labs, creating extra capacity and reducing waiting times, which is what we all want!

The award to the Outstanding individual for contributions to arrhythmia service went to Professor Ben Freedman from the University of Sydney for his work in screening for atrial fibrillation.

Please donate to AF Association

AF Association relies on donations to enable us to maintain our helpline, resources and support services to patients and carers. Please support us, so that we can continue to support you.

Please consider adding Gift Aid to your donations. Gift Aid adds a massive 25% to your donation at no cost to you. Every penny really does make a difference. Gift Aid can be arranged verbally, or alternatively, please contact us for a Gift Aid form.

You can donate by calling: +44 (0)1789 867 502 or via our website: www.afa.org.uk.
AF: Understand the risk

- If you have AF, your heart beats irregularly and may not pump all of the blood through properly.
- If blood does not move quickly and smoothly, dangerous blood clots may form.
- Blood clots that travel from the heart to the brain can cause a stroke.

Know the facts of AF in the UK

- The lifetime risk of getting AF is 1 in 4.
- This number is increasing.
- Men are more often affected by AF than women.
- The risk doubles with every decade after the age of 1.

- Hypertension
- Angina Pectoris
- Diabetes

AF increases your risk of having an AF-related stroke 5x.

In the UK, every 18 mins someone suffers from an AF-related stroke. This equals 30,000 Strokes per year.

Prevalence in % by gender and age:

- Male
- Female

Top 3 AF-related conditions

1. Hypertension
2. Angina Pectoris
3. Diabetes

Check your pulse to see if your heart rhythm is regular:

1. Hold out one of your hands, with your palm facing upwards and your elbow slightly bent.
2. Place your index and middle finger of your hand on the inside of your wrist.
3. Press lightly. If you can’t feel your pulse, press a little harder and move your fingers.

Most common symptoms:

- Shortness of Breath
- Tiredness
- Dizziness

Normal heart rhythm:

- a) regular and
- b) between 60-100 beats a minute when resting

AF heart rhythm:

- a) irregular and
- b) sometimes abnormally fast

In case of irregular or very fast heart beat:

See your doctor!

For more information visit:

- anticoagulationeurope.org
- stroke.org.uk
- afa.org.uk
- heartrhythmalliance.org
- thrombosisuk.org
- nhs.uk
- www.mytherapyapp.com/atrial-fibrillation-app

Sources: NHS, Anticoagulation Europe, British Heart Foundation, Stroke Association, Atrial Fibrillation Association, British Medical Journal

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Go online: www.afa.org.uk • info@afa.org.uk
The Internet has not only become a go-to destination for informing ourselves, websites and apps are progressively turning into tools that help manage AF. The “Battling Atrial Fibrillation Online” initiative aims to increase patient safety by educating patients and caregivers on AF and the new tools available. Originally initiated by AntiCoagulation Europe and the MyTherapy app, we joined in to spread the word and we think you should, too.

Safety by education

Adherence to anticoagulation therapy is key when it comes to safeguarding patients against AF-induced stroke. Often, we find that it is those patients struggling with adherence, that have not had the chance to understand how their medication works. E.g. patients stop taking their anticoagulant as they feel that it does not mitigate their irregular heartbeat. Similarly, patients miss more doses than necessary being unaware of supportive tools like specialised reminder apps. And while there is always room for improvement, doctors and nurses cannot close this educational gap alone.

Educating where the patients are

More than 75% of UK internet users are regularly looking for health information online. Millions of them are affected with Atrial Fibrillation directly or indirectly. With high-quality and easily digestible content, the “Battling AF Online” initiative aims to be where these patients are: On health websites and blogs, on social media sites like Facebook or Twitter, or on health-related apps. To achieve this, and to be more visible than much of the existing content of often questionable quality, we encourage everyone to join in: Supporting our cause is as simple as sharing our infographic and future materials on social media or putting it on a blog.

Staying protected with apps

Educating others about managing AF is good, but staying protected yourself is more important. While apps neither can nor should replace a consultation with your healthcare professional, they can lower the burden of taking an active part in your own health. Apps like ‘MyTherapy’ support you in never missing a dose of your medications. The free app works with all medications. Whenever a dose becomes due, the app triggers an alert on your phone. No matter if you skip or confirm the intake, the app tracks your action with its built-in health journal. This not only proves handy in case you are unsure if you already took your dose for the day. You can also digitally share it with your caregivers, e.g. in the case of a missed dose, family can then immediately engage. Right from the app you can generate a PDF report of your medications and everything else you’ve tracked. You can use this for your records and, more importantly, take it to your doctor. Because also with digital helpers, when it comes to interpreting your data, your doctor is the person to trust.

MyTherapy

The app for anticoagulant therapy.

Protect yourself from stroke or pulmonary embolism: MyTherapy reminds you of your anticoagulant and other medications and keeps track of your weight, blood pressure and symptoms.

Free Download – Try it out!
AF Association Patients Day 2017
Sunday 1 October at The ICC, Birmingham

A full programme of some of Europe’s leading heart rhythm specialists is planned for Patients Day 2017. As the biggest information and support event for AF Association members and their carers in the country, it is anticipated that once again this will be a sell-out.

Sessions with leading medical experts will include amongst others:
- Treatment options for atrial fibrillation
- Anticoagulant options
- Accessing the best available care for you
- How AF affects my emotional wellbeing
- Rhythm management

For more information email becky@heartrhythmalliance.org or call +44(0)1789 867 523

The cost to attend for a full day meeting with refreshments and lunch is:

- Registration for non-members or on the day £50.00 (if places available)
- Friend of AF Association £25.00
- Carer if registering with a Friend £35.00
- Early bird registration (until 31 July 2017) Friend £20.00/Carer £30.00

Registration Form

1st attendee details

Full name:
I am: Patient ☐ Carer ☐ Other ☐
If other please state: ........................................................
Special requirements (please give details)
Dietary ☐ Access ☐
Address:
Telephone:

2nd attendee details (if applicable)

Full name:
I am: Patient ☐ Carer ☐ Other ☐
If other please state: ........................................................
Special requirements (please give details)
Dietary ☐ Access ☐
Address:
Telephone:

Payment details - Please select your payment method below:

- Credit/debit card: Please call +44 (0) 1789 867 523 to pay over the phone ☐
- Cheque: Please make cheques payable to ‘AF Association’ ☐

Please send your cheques to: AF Association, Unit 6B, Essex House, Cromwell Business Park, Chipping Norton, Oxfordshire, OX7 5SR