Patients Day 2018

Sunday 7th October 2018, Birmingham ICC

AF Association Patients Day 2018 is already looking to be an exciting and informative day. You spoke, and we listened. The feedback that you have given us has helped us to create this year’s agenda.

This year’s subjects will include Healthy living with AF, Driving and DVLA guidelines, Medication interactions plus many other topics including an interactive session. Full agendas with updates will appear in our monthly e-bulletins in the coming months. Remember to register your interest as early as possible to avoid disappointment!

Email info@afa.org.uk or call 01789 867 502 to secure your place at AF Association Patients Day 2018.
AF Association Patients Day 2017

Patients Day 2017 was extremely successful with an almost full house chaired by Dr Matthew Fay in the morning, and Professor Nicholas Linker in the afternoon. Patients found all of the presentations interesting. The afternoon sessions focused predominantly on healthy lifestyle and AF, which raised interesting points and has inspired not only many of the topics of this newsletter, but also the agenda for Patients Day 2018.

Patient comments include:

“This was our first visit and my husband found it very reassuring having been diagnosed with combined SVT and AF last year. Extremely informative.”

“Even though we’ve come for a number of years I always learn something new so thank you.”

“The information was very helpful.”

We hope to see you again next year for what is shaping up to be another interesting day!
AF Causes a Stir in the House of Lords

We were proud to see Lord Black of Brentwood putting forward a question in the House of Lords, demonstrating understanding and importance of AF and anticoagulation:

“To ask Her Majesty’s Government how many people with a diagnosis of atrial fibrillation who were admitted to hospital with a stroke in 2016-17 were not on an appropriate anti-coagulation therapy prior to admission.”

Key points:
- Lord Brentwood: “more than 7,000 people in England who were admitted to hospital with a stroke last year were known to have AF but were not receiving proper therapy. Is my noble friend aware that the National Clinical Directors for cardiovascular disease prevention and stroke recently stated: “Failure to prescribe an important treatment”, such as this, “needs to be seen as an error that is equally as serious as prescribing the wrong treatment”?
- Lord O’Shaughnessy: “atrial fibrillation is easily diagnosable and treatable.” … “the variation in the prescription of anti-coagulants demonstrates that there is not uniform understanding of the options.”
- Lord Cormack: “I urge my noble friend to try to ensure that greater publicity is given to it.”
- Baroness Jolly: “regular checks of the pulse rate can help indicate whether someone has atrial fibrillation. These should be carried out at the five-yearly general health check that GPs offer to those aged between 40 and 74.”
- Lord Colwyn: “it is quite clear that many people do not receive the anti-coagulants that they need”… “Since 2012, four novel oral anti-coagulants—NOACs—have been recommended by NICE as both clinically and cost effective for the prevention of stroke in patients with AF.”

Action points:
Lord O’Shaughnessy to write to NHS England to find out could the Government undertake to ascertain from NHS England why the commissioning of day-case ablation for the treatment of atrial fibrillation is way below the European average, and report to Baroness Finlay of Llandaff.

Lord O’Shaughnessy to find out how many GP practices routinely call patients for this health check, whether they are paid to do so and how many patients take up the opportunity and report to Baroness Jolly.
How Do You Control Your AF?

We asked members of our online community at Health Unlocked what methods they use to get back into NSR (normal sinus rhythm) during an episode of AF. We found that there are many different ways that people use, but because no two people are the same, and react differently to methods, none of these are fail safe quick fixes. Whatever method you find works, you should discuss them with your doctor.

In general, it is hard to “get it under control” since it seems to go when it goes. But I have been successful with the following:

1. Sit up – Lying in the wrong position, including lying flat, can make it worse or maintain the AF
2. Adopt “child position” – on knees folded over with head near ground
3. Controlled breathing
4. Take more rhythm and/or rate control medication
5. Mindfulness

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<thead>
<tr>
<th>Method</th>
<th>Description</th>
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<tbody>
<tr>
<td>Sit up</td>
<td>Lying flat or in the wrong position can make it worse or maintain the AF.</td>
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<tr>
<td>Adopt “child position”</td>
<td>Sitting on knees with head near ground can help.</td>
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<tr>
<td>Controlled breathing</td>
<td>Helps regulate heart rate and rhythm.</td>
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<tr>
<td>Take more rhythm and/or rate control medication</td>
<td>Increases the effectiveness of medication control.</td>
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<td>Mindfulness</td>
<td>Practices such as meditation and breathing exercises can manage symptoms.</td>
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<td>I drink a slush puppy as they are so cold that they seem to shock the heart back into rhythm</td>
<td>A cold beverage can cause a reflexive response to normalize heart rhythm.</td>
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<tr>
<td>I try to relax, perhaps watch something on TV (not a drama!)</td>
<td>Techniques like relaxation techniques can help manage symptoms.</td>
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<tr>
<td>I get on my bike and cycle and normally go back into NSR after a hill.</td>
<td>Exercising can help regulate heart rate and rhythm.</td>
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<td>Sometimes Valsalva’s manoeuvres work, sometimes, I try tapping, breathing and relaxation, other times I listen to a normal heartbeat</td>
<td>Valsalva’s manoeuvre involves holding breath while exerting pressure.</td>
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<td>Lying down on my right side normally controls and eventually stops it.</td>
<td>Resting in a specific position can help stabilize heart rhythm.</td>
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<td>I find that Tai-Chi helps</td>
<td>Tai-Chi practices can promote relaxation and regulate heart rate.</td>
</tr>
<tr>
<td>I find coughing vigorously works if I catch an episode just coming on.</td>
<td>Deep coughing can cause a reflexive response to normalize heart rhythm.</td>
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<td>I find that altering my position and gently walking around can sometimes help</td>
<td>Adjusting body position can help in some cases.</td>
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<td>Helpline: 01789 867502</td>
<td>Contact for further assistance and support.</td>
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Don’t Stop Eating Your Greens!

Linda from Isle of Wight was diagnosed with AF in May 2012 (age 59) and has been taking Warfarin since September 2013. Here she shares how she enjoys a diet including fresh green vegetables and still has control of her INR levels.

The first dose of Warfarin at 5 mg a day did not keep me in range, I am sure because of my love of green vegetables. I was aghast when my INR had dropped to 1.8, so it was increased to 5mg a day plus 1 mg extra one day a week.

However, since that time, I have only been ‘out of range’ about four times and from my observations it seems there has always been a reason for this - either due to a virus or being under the weather, taking antibiotics or a change in eating habits, like holidays. I will cite an example of this!

Christmas! Yes, we all eat a little or a lot differently at that time, don’t we? As hard as we try not to! So, when I was tested on 29th December, the nurse got more than a little concerned because my INR’s were 3.6 (highest they have ever been). She immediately wanted the computer to change the dose, but I knew if I dropped the dose by a whole 1mg, by the next test I would probably be out of range the other way! After all, what does a computer know about me?

Out of 10 tests last year (2016), only 2 were very slightly out of range (over 3), so I know by very little tweaking and reverting to my usual ‘diet’, I can get myself back on track. So on the one day the computer suggested I drop to 4mg, I took 4 and ½ mg. I am not suggesting that everyone tries this, but if you are a diligent monitor, you can usually work out what has caused the glitch!

“Balance and consistency are the key words!!”

My next test (7 days later) read 2.5, then 2 weeks later was 2.3 and 1 month later 2.7. Please note, I try and have my INR’s checked approx. once a month. I think this should be
the same for everyone (who is not self-testing) because as we know, they can alter so drastically in only 7 days - in this instance from 3.6 to 2.5!!

Here is roughly how I still eat my greens and keep my INR's stable:

For lunch most days I eat a sandwich or a tin of fish, or soup and bread (I have to watch my cholesterol too!!) and with it, I always have a handful of green leaves and a couple of cherry tomatoes.

With my main meal in the evening, I include 2 or 3 scoops (meaning one of those large slotted serving spoons) consisting of a mixture of green beans/broccoli/peas/ cabbage /cauliflower, also carrots or other coloured veg. Go easy on the sprouts – when I eat sprouts, which I LOVE, I never eat more than four at one sitting.

Of course, no one eats green veg every single day, so if I have a day without either veg or salad leaves, I allow myself a little more the following day. Or I sometimes just dip into a bag of leaves while I am cooking the dinner! It works for me!

The Benefits of Healthy Living

Diet
What you consume can have a significant impact on your AF and the symptoms that you experience, and not just for those taking Warfarin. There are thought to be several common food triggers for people with AF, which may be worth avoiding.

It is fairly well known that larger meals can trigger symptoms of AF. Try eating smaller portions more regularly and grazing throughout the day. If you are particularly symptomatic at night, it may be advisable to avoid eating after 7pm.

Any stimulants can cause havoc for AF. Drink less alcohol as it can affect the way that the body functions. Try replacing tea and coffee with decaffeinated options. Chocolate also contains stimulants which can trigger AF in some people.

Other helpful tips for healthy eating with AF are to cut down on sugars and starches, avoid carb heavy meals, follow a low-fat diet and cut down on salt, particularly if you have high blood pressure.

If you do take warfarin, be mindful of the vitamin K levels in food as this has a knock-on effect on INR levels, which in turn affects your dose of warfarin. There are many foods that are thought to affect warfarin control. If you require a copy of our ‘warfarin and diet’ factsheet, please do let us know.

If you are unsure of what seems to trigger your AF, we suggest that you try to keep a food diary to track it. This is often enough to find the trigger.

Helpline: 01789 867502
Exercise

Exercising with AF can be a daunting and confusing prospect. You know that exercise is good for you, but at the same time you are worried about going into AF as a result.

The answer here is to listen to your own body. While some people are comfortable with running marathons, others may feel better going for a slow walk. As we know with AF, nothing is black and white and the same rules do not apply to everybody.

Exercise is an important part of a healthy lifestyle, but exercising at a level with which you are individually comfortable is very important from a cardiovascular perspective. Prolonged periods of inactivity can even be as harmful as overly strenuous exercise.

If you are not sure where to start, try beginning slowly with a simple, slow walk.

If you are not sure where to start, try beginning slowly with a simple, slow walk. A good tip is to count the lamp posts or trees that you pass as you walk. You may notice that with each passing day, it becomes easier for you to walk further and count more trees or lamp posts as you go. As you start to feel more comfortable and confident, you can try exploring other exercise options such as yoga, tai-chi, Zumba, or looking at your local keep-fit classes. If you attend a gym, leisure centre or any other classes, just make sure that the instructors are aware of your condition for your own wellbeing and safety.

Why not try to incorporate some exercise into your lifestyle this new year? Just remember, nobody knows your body like you.

You can order our Make Your Heart Feel Good triple DVD for just a £3 donation towards P&P from the shop at www.afa.org.uk
Beta-blockers (β-blockers) are a group of medicines which are crucial in the management of cardiovascular conditions such as atrial fibrillation, heart failure, sudden cardiac death and preventing recurring heart attacks.

β-blockers prevent adrenaline from binding to beta receptors in your body. When β1 receptors are activated by adrenaline your heart beats faster and works harder. Blocking these β1 receptors slows down your heart rate and reduces the demand on your heart, which is essential in managing all the conditions mentioned above.

“There is very strong, high quality evidence which demonstrates that β-blockers significantly reduce the long-term risk of death and sudden cardiac death following a heart attack.”

B2 receptors are found on the airways in your lungs. When these receptors are blocked they cause your airways to narrow making it more difficult to breathe which can trigger an asthma attack. As a consequence of this, traditionally Beta blockers have been avoided in people with asthma. Likewise, many clinicians have historically avoided the use of β-blockers in COPD (Chronic Obstructive Pulmonary Disease) as a study showed they caused a reduction in lung function and some resistance to reliever therapy i.e. salbutamol.

Despite this, there is a wealth of evidence supporting the use of cardioselective β-blockers in all patients when there’s a clinical need. Cardioselective β-blockers such as bisoprolol, atenolol and metoprolol work predominantly on the heart. It must be noted that they are relatively selective and do exert some β2 receptor blockade but to a lesser extent than non-selective β-blockers such as

Beta Blockers and Your Lungs
By Sotiris Antoniou - Consultant Pharmacist at St Bartholomew’s Hospital, London

Helpline: 01789 867502
propranolol. There is very strong, high quality evidence which demonstrates that β-blockers significantly reduce the long-term risk of death and sudden cardiac death following a heart attack. In atrial fibrillation they are the drug of choice for treating the symptoms associated with having a rapid heart rate.

They drastically reduce the risk of death, hospital admissions and disease progression in patients with heart failure. This is extremely important seeing as heart failure is one of the leading causes of death in people with COPD.

In fact, more recent evidence suggests when added to regular inhaled therapy, β-blockers (predominantly cardioselective) may reduce COPD exacerbations and increase survival rates regardless of the severity of airway disease even without cardiovascular disease.

Most importantly, these benefits were observed with no worsening of lung function which is currently the main reason why β-blockers are withheld in COPD.

Unlike COPD asthma is a reversible condition, therefore people with asthma are more sensitive to the blockade of β2 receptors. Nonetheless, only a small percentage of people with asthma will respond negatively to β-blockers thus the benefits associated with their use may still outweigh the risk.

In view of this, only under specialist supervision should a person with asthma be trialled on a β-blocker to monitor their respiratory symptoms and ensure the therapy is safe. If the β-blocker is not tolerated it will be stopped as the risk will outweigh the benefits. If a β-blocker is deemed to be unsuitable for whatever reason, there are alternatives that can be explored such as calcium channel blockers.
Extended Continuous Ambulatory Monitoring  
(A Longer-term Wearable Heart Monitor)

Currently, continuous ECG monitoring with a Holter monitor can record cardiac electrical activity for between 24 and 48 hours.

However, if a patient is experiencing only one or two episodes a week, it is a lottery whether one of these monitors would be suitable.

There is also the implant Cardiac Monitor (ICM) which is a small thin device that is fitted under the skin (as a day patient) to monitor heart rhythms if episodes are less frequent than every 30 days. These loop recorders can remain for up to three years.

What is the new extended continuous ambulatory monitoring?

Often arrhythmias (irregular heart rhythms) may occur occasionally, therefore, they may not be detected during a routine 12-lead ECG. A longer, continuous ECG may be required to capture the arrhythmia to enable your doctor to diagnose or confirm there is no irregularity.

This much-needed long-term wearable heart monitor allows a doctor to track and analyse your heart rhythm during normal activity. The monitor comes in the form of a small adhesive patch that you can wear on the upper left side of your body for up to two weeks, during which time the device will record and store data from your heartbeat and rhythm.

You can also highlight the points at which you experience symptoms by pressing a button on the patch to enable your doctor to see any correlations with your heart rhythm.

At the end of the prescribed period you can remove the patch, post it back in the box provided and a detailed report will be generated and sent to your doctor to identify whether you have an arrhythmia and to determine a diagnosis and appropriate treatment if needed.

Who is it designed for?

It would be beneficial for an individual whose symptoms are infrequent so the 24/48 hour monitor would not be appropriate. However, a monitor that spans up to two weeks is more likely to detect an episode. The device is unobtrusive and will provide all the necessary information with minimal disruption.

How is it fitted?

The patch is a one-time use monitor that can be applied by your GP/nurse. The skin is cleansed so the patch will stick effectively and remain in place for the prescribed period. Any symptom can be recorded by pressing a button on the patch and noting it in a booklet.

Will it affect my day to day activities?

This new form of monitor is designed for extended wear and to cause as little upset to an individual as possible. With no wires, you will be able to continue normal activities, including showering and exercise. You will only need to press a button to mark symptoms and mailing the patch upon completion.

Helpline: 01789 867502
Hybrid Ablation

There are many treatment options available for atrial fibrillation, but it can remain stubbornly persistent for some patients. Whilst ablation often helps patients with paroxysmal AF, it does not work so well against persistent AF. This is where treatment with hybrid ablation comes in.

Hybrid ablation is a promising new treatment for patients with persistent AF. This approach combines the best of two well established procedures, catheter and surgical ablation, where a cardiac surgeon ablates on the outside of the heart first, then 2-3 months later, an electrophysiologist ablates from the inside using catheter.

It is thought to have an 80% success rate in patients with persistent AF, which is already higher than the average success rate of only 50-60% for catheter ablation alone.

During trials in between 2013 and 2015, of 38 patients who underwent the hybrid ablation procedure 80% were arrhythmia free and off antiarrhythmic drugs just 1 year afterwards.

Hybrid ablation is still under investigation and is slowly being rolled out across some specialist hospitals in the UK. Some of them began with the surgical ablation in December 2017 and are due to be followed up with catheter ablation any time now. We are waiting with bated breath to hear the outcomes!

To find out more about ablation techniques, contact our patient services team on 01789 867502 or email info@afa.org.uk

New Publications

We have recently published two new information booklets; ‘Identifying the undiagnosed person’ and ‘Which ECG is right for you?’. If you would like to order a copy of either booklet, please do let us know by emailing info@ heartrhythmalliance.org or call us on 01789 867 502.
Heart Devices: Saving Lives and Preventing Infection

Over two million people are alive today because of cardiac implantable electronic devices (CIEDs), also referred to as heart devices. These include pacemakers, implantable cardioverter defibrillators (ICD) and cardiac resynchronisation therapy (CRT). These devices are specifically designed to help keep your heart functioning normally.

A pacemaker is a small device that is placed in the chest to help control abnormal heart rhythms (arrhythmias). It uses a battery and electronic circuits connected to the heart by one or more wires (leads) to prompt the heart to beat at a normal rate. These leads are passed along a blood vessel to your heart and the pacemaker box is usually implanted under the skin in your upper chest. The pacemaker can monitor your heart and produce electrical impulses to treat abnormal heart rhythms.

An ICD is a device that monitors the heart rhythm continuously. If the heart starts to beat dangerously fast the ICD is able to detect this and treat it, potentially saving the person’s life. There are two types of ICDs being implanted today; transvenous ICD systems (through the veins and into the heart) and the subcutaneous S-ICD, which does not touch the heart but sits just under the skin.

There is between a 1% and 7% chance that the device will become infected at the time of surgery.

Cardiac Resynchronisation Therapy (CRT) devices are used to help treat heart failure, and can be either a permanent pacemaker, or an ICD. They work by making the lower heart chambers (ventricles) pump at the same time (synchronously) and improve the overall function of the heart so that you potentially feel less breathless and have more energy.

There is between a 1% and 7% chance that the device will become infected at the time of surgery. Preventative measures are taken to safeguard against infection, but extra precaution is advised for heart device surgery as this procedure carries a higher infection risk.

What are the consequences of a surgical site infection?
Surgical site infections can be difficult to control. Readmittance to hospital to treat the infection with possible additional surgery to replace the device may be necessary. In severe cases, surgical site infection can be life-threatening.
An antibacterial envelope has recently been introduced to hospitals that can help prevent these potentially serious surgical site infections.

How is a heart device surgical site infection treated?
A heart device surgical site infection is usually treated by removing and replacing the device. A new device cannot be implanted until the infection is treated and eliminated. This means after the device is removed, the patient will be given antibiotics for up to six weeks.

New innovative technology – The antibacterial envelope
An antibacterial envelope has recently been introduced to hospitals that can help prevent these potentially serious surgical site infections.

There are specific types of bacteria responsible for over 70% of heart device infections, many of which are becoming resistant to commonly used antibiotics.

Clinical studies have shown that patients at high risk of heart device infection who have been implanted with an antibacterial envelope develop 70%-100% fewer infections than similar patients who are not given this protection.

The envelope is an antibacterial mesh sleeve that holds the device when implanted in the chest. It effectively stabilizes the device and reduces the chance for movement or skin erosion. It is the only antibacterial device for heart device implants that is fully absorbable. This is important to surgeons if or when a heart device may need to be replaced.

What are the benefits of the envelope over current antibiotic protection?
There are specific types of bacteria responsible for over 70% of heart device infections, many of which are becoming resistant to commonly used antibiotics.

Clinical studies have demonstrated that patients who are given the additional protection of an antibacterial envelope have significantly fewer heart device infections.

To find out more about devices and this new technology, please contact us:
info@afa.org.uk or 01789 867502
### Be a Member of Your Own Healthcare Team

The Watch BP is a device recommended by NICE to be used to routinely monitor your blood pressure at home. This way you can know for certain when you are in AF and how it is affecting your blood pressure and vice versa. Find potential triggers for your high or low blood pressure (BP), and share the results with your doctor to ensure your condition is being managed effectively.

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<tr>
<th>Watch BP Home S</th>
<th>Save on RRP – Now only £45</th>
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<tr>
<td>• Screening for Atrial fibrillation (AFIB) at home is recommended by leading medical societies</td>
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<tr>
<td>• The WatchBP Home S can detect risk factors such as high blood pressure and the presence of AFIB with high accuracy and reminds patients to contact their physician with an animated alert.</td>
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<td>• Going-to-doctor symbol: reminds the user to visit the doctor.</td>
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<td>• Easy-to-read: large screen displays and easy-to-read numbers.</td>
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<td>• Lightweight and compact for convenient storage.</td>
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<th>Watch BP Home A</th>
<th>Save on RRP – Now only £75</th>
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<td>• Screening for AFIB with high accuracy (at 97%–100% sensitivity and 89% specificity) while measuring blood pressure. Easy and convenient to use</td>
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<td>• Embedded ESH/AHA measurement guidelines lead to accurate home measurement data physicians can trust</td>
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<td>• Automated data tabulation displays averages for morning, evening and overall measurement</td>
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<td>• Detects Atrial Fibrillation (AF) and it is also validated for use in pregnancy pre-eclampsia</td>
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<td>• Supplied with a Medium (22 - 32cm) size cuff but other cuffs available to purchase separately in Small (17 - 22cm) and Large (32 - 42cm) size from the manufacturer.</td>
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Order from our online shop at www.afa.org.uk or by calling us on 01789 867502

Turn to page 32 for your chance to win a Watch BP Home S
AF Association Celebrates 10 Years

On Thursday 23rd November 2017, AF Association celebrated 10 years since the charity became established. To increase information, support and access to established, new or innovative treatments for atrial fibrillation (AF), an event was hosted in Westminster.

The event was invite only to Members of Parliament, Peers, Healthcare Professionals, Members of the charity’s Medical Advisory Committees and a few selected patients of which 104 attended, two of whom were Lords.

During the event, sponsors demonstrated their products to attendees explaining how they contribute to helping AF related disorders. Throughout the event all attendees were treated to a range of hot and cold beverages and a range of canapés. This was followed by four speeches, summarising how AF Association has grown over the past 10 years, and the huge steps we have taken to support AF patients globally. Glyn Davies (MP and host) gave an introduction into the background of AF Association and his personal experience of AF.

Professor Huon Gray (National Clinical Director for Heart Disease for NHS England) highlighted the importance of identifying the undiagnosed person with AF. Professor John Camm (President of the Arrhythmia Alliance and Trustee of AF Association) spoke about the last ten years in relation to the management of AF and emphasized that with an aging population the figure of 1 in 4 people who are diagnosed with AF, will increase to 1 in 2.

Finally, Trudie Lobban (Founder and CEO of AF Association), concluded the speeches by explaining how AF Association makes a difference. The remainder of the event gave attendees a chance to meet with others and explore the range of sponsors exhibitions. The celebration highlighted the achievements of AF Association, but most importantly drove the message that there is still so much that can be done.

“With an aging population the figure of 1 in 4 people who are diagnosed with AF, will increase to 1 in 2.”
A Week in the Life of...
Trudie Lobban, MBE, Founder and CEO

AF Association Global AF Aware Week certainly kept me on my toes!

Monday brings a 7am start, catching the train into London, not without checking in with the UK-staff in the office, to recap from the weekend and touch base ahead of the coming week.

Upon arriving into London, I quickly scramble for the tube and make my way across London as I embark upon today’s activities, primarily involving Global AF Aware Week and a media day tour. The first interview commences at 11.05am and they run back to back throughout the day. I never say ‘no’ and rarely, if ever, stop. Phone calls quite regularly are carried out long past 5.30pm and into the evening. And when on the go – whether that be travelling by road, rail or air, my time is always utilised with emails and telephone calls.

Tuesday - day two of Global AF Aware Week and the media tour. 7.10am and 8.10am, two interviews with BBC Radio Oxford. From then on, back to back meetings in various locations around London up until 5pm, when it’s over to Westminster for the APPG-AF (All-Party Parliamentary Group on AF) meeting on AF awareness. Finishing at 6.30pm, a quick turnaround, and off to the next meeting at 7.30pm, still in London. Come 10pm it’s not quite bed time yet, not until I have spoken to the US-team to catch up on their activities and whereabouts.
Wednesday, and it’s another day in London, this time at St Barts Hospital, then in the afternoon, it’s over to Pancras Square to the Google Headquarters for a meeting with their team. At 4pm, some of my staff and I meet to set up for the Patient Focus Group meeting on Thursday. Following this, another dinner meeting, and then a repeat of last night’s routine, catching up with the US team to find out how their Know Your Pulse event went at their local gymnasium in South Carolina.

Thursday begins at 8am with the Patient Focus meeting taking place, then come 12.30pm, it is time for me to attend a Parliamentary reception in Westminster; ‘Identifying the Undiagnosed Person with AF’ building on our Detect, Protect, Correct & Perfect campaign; as part of AF Association’s 10th Anniversary Celebration. This runs until 3pm, then quickly on to the next meeting with MP Mike Gapes, which was due to take place at 3.10pm.

“I never say ‘no’ and rarely, if ever, stop. Phone calls are regularly carried out long past 5.30pm and into the evening. And when on the go whether that be travelling by road, rail or air, my time is always utilised with emails and telephone calls.”

Finally, it’s Friday, it’s back to London for more meetings and to support Global AF Aware Week. Friday evening, and the weekend is upon us. Another Know Your Pulse event on Saturday from 11am-2pm to attend. What a week!

Hello! My name is Charlene and I joined Rachel and Jenni in the wonderful Patient Services team at the end of August.

I’m sure that I have spoken to lots of you already, but let me introduce myself if I haven’t yet. I joined this amazing charity through a love of what it stands for, and for the opportunity to be able to truly help people who need my help.

I’m the proud owner of Jasper the German Shepherd and Otis the cat, and enjoy spending my free time with friends, family and my lovely husband. Please do get in contact with us if we can help at all.
AF Association Global AF Aware Week 20-26 November 2017

AF Association Global AF Aware Week 2017 was a huge success with over 2000 Know Your Pulse events taking place globally.

Atrial Fibrillation, or AF, is the most common arrhythmia (heart rhythm disorder). Over one million people have been diagnosed with AF in the UK alone, although experts estimate that at least a third more remain undiagnosed. With an ageing population, this number is expected to double by 2050.

For this reason, this year we focused on ‘Identifying the Undiagnosed Person with AF’ with our Detect, Protect, Correct & Perfect campaign. We asked all our supporters to spread the word, by simply sharing and displaying information, holding an AF Awareness activity, or fundraising and donating to AF Association.

Patients and health care professionals alike held events all around the world, from Times Square, New York to Westminster and the John Radcliffe Hospital, Oxford, which consisted of taking manual pulse checks, some using AF detector devices such as the Alivecor Kardia. If AF was detected, the participant was advised to visit their GP for further investigation with the option in some cases to go immediately for a full ECG rather than waiting for an appointment.

Save The Date! 19-25 November 2018
If you would like to fundraise to help us continue holding these events, please get in touch fundraising@afa.org.uk or 01789 867502

AF Association staff with arrhythmia nurses at John Radcliffe Hospital, Oxford
Healthcare Pioneer Awards were of an exceptionally high standard this year with a very high pass rate meaning that they have been accepted into the next booklet. Topics included: “Don’t wait to anticoagulate”, “Smartphone technology” and “Patient centred care in atrial fibrillation”. Many of these innovative ideas were developed by enthusiastic teams who were eager to give their patients the best possible service.

Charles Lobban Volunteer of the Year award was awarded posthumously to Louise Power 1953-2017, one of the first ICD patients to receive this device. Louise was instrumental in setting up St George’s ICD patient support group. Despite her serious health problems, she wanted to give something back, so she became a BACAP accredited counsellor and was able to support other patients through her sensible and compassionate approach. Tragically, before we could present this award, Louise died through heart failure that was resistant to treatment. Sue Jones from St George’s Hospital who supported Louise as well as being a friend received the award.

Outstanding Individual who has contributed to Arrhythmia Services award was presented to Dr John Bourke, consultant cardiologist at Freeman Hospital, for his rich and varied contributions to cardiology and electrophysiology both nationally and internationally. As head of the EP department for ten years, he has overseen the expansion and use of new technologies in this very successful area.

Team of the Year award was awarded to the Whipps Cross day case AF ablation team for development of a model that provides a much-needed service to meet increasing demands of catheter ablation for atrial fibrillation.

If you would like to nominate a Volunteer, or a particularly helpful Health Care Professional for our awards, please get in touch!
World Heart Rhythm Week 4\textsuperscript{th}-10\textsuperscript{th} June 2018: Take Fainting to Heart

For World Heart Rhythm Week 2018, our focus is to ‘Take Fainting to Heart’, and we will be again joining with sister charities (STARS and Arrhythmia Alliance) to increase detection of arrhythmias around the world. It is a significant year for ‘big sister’ STARS (Syncope Trust And Reflex anoxic Seizures) as it celebrates its 25th Anniversary.

There is no such thing as a simple faint, and with 50\% of individuals experiencing a faint in their lifetime, we want to make sure that those caused by an arrhythmia are correctly diagnosed and treated.

In 2017, our aim was to ‘identify the undiagnosed person’, and for Arrhythmia Alliance World Heart Rhythm Week we exceeded our goals to:

- Make 1 million people pulse rhythm aware
- Take 10,000 pulse rhythm checks
- Identify 1,000 people with an irregular heart rhythm
- Hold 100 'Know Your Pulse' events

To order your World Heart Rhythm Week pack and hold a Know Your pulse event, or even if you would just like to share a poster and some resources with your surgery, please email info@afa.org.uk

Helpline: 01789 867502
Leaflets, posters and promotional materials also available.
To order please contact info@afa.org.uk, 01789 867502 or download from www.afa.org.uk

**Booklets**

- Ablation for AF
- Accessing Appropriate Treatment Options
- AF and You
- Atrial Flutter
- FAQ
- Oral Anticoagulant Therapy
- Preventing AF-Related Stroke
- The Heart The Pulse and The ECG
- Atrial Fibrillation Patients Information
- Cardioversion of AF
- Drugs Information

**Factsheets**

- AF and heart failure
- AF-related stroke
- Amiodarone
- Anticoagulant Alert Card
- Anticoagulation and AF
- Anticoagulation and self-monitoring
- Apixaban
- AF and Aspirin: Frequently asked questions
- Atrial Fibrillation (AF)
- Atrial Flutter
- Being a NICE patient expert
- Beta blockers

**Checklists**

- Cardioversion
- Cognitive behavioral therapy (CBT)
- Dabigatran
- Digoxin
- Dronedarone
- Ectopic Heartbeats
- Edoxaban
- Flecaïnide
- Heparin
- Miniature insertable cardiac monitor (ICM)
- Pacemaker and AV-Node Ablation
- Pill-In-The-Pocket cardioversion
- Rate Limiting Calcium Channel Blockers
- Rate versus Rhythm Management
- Rivaroxaban
- Transcatheter Closure of the Left Atrial Appendage
- Warfarin therapy
- Warfarin and diet
- Warfarin and other medication
- What is a Clinical Trial?
- What is a Consent Form?
- What does Randomisation mean?
With Summer Around the Corner Use

Make an appointment with your doctor. They know your medical history, so they are always the best person to advise you.

- Tell them how long you are going for
- Ask if you need to take any precautions
- Ask if any immunisations are necessary
- Ask if any significant local time changes will make a difference to how you take your medication – your pharmacist may also be able to advise on this topic
- Discuss any other particular concerns which you may have
- Take advice from your INR clinic if applicable on change of diet while travelling

Find out about local medical facilities and make a list of hospital telephone numbers and addresses, and if applicable, pacemaker and device specialist centres. If you have a device fitted, it may be uncommon at some exotic locations.

Get some flight socks (also known as compression stockings) to help blood flow. Studies show that wearing them during flights of four hours or more can significantly reduce swollen ankles and risk of DVT. They come in a variety of sizes and there are also different levels of compression. Flight socks are available from pharmacies, airports and many retail outlets. It’s vital that compression stockings are measured and worn correctly.

Ill-fitting stockings could further increase the risk of DVT. Take advice on size and proper fitting from a pharmacist or other health professional.

Remember to pack more medication than you will need in your baggage.

Travel insurance for people with pre-existing medical conditions works in exactly the same way as insurance for typical travellers and is designed to cover you for the unforeseen such as cancellation or lost luggage. The only exception is that it also covers the cost of care for any medical condition you currently suffer from or may have had in the past.

This is not included in typical travel insurance as standard meaning that specialist cover is vital for holidaymakers with a history of illness. You’ll usually pay more, as insurers

Helpline: 01789 867502
consider you to be more of a risk than those with a clean bill of health. Some conditions are more difficult to cover than others, so consider your needs carefully. If you have, or have had, mild asthma or high-blood pressure you may still be able to get cover via your normal insurers. Remember that you must tell your insurer about your condition – even if you don’t deem it particularly serious.

A number of comparison sites will help you find quotes. MedicalTravelCompared.co.uk is a travel insurance price comparison site with a difference. It is specifically designed to help travellers who are over 65 or who need travel insurance cover for pre-existing medical conditions, and what’s more they will give 10% to AF Association if you purchase a policy through them. There are a number of travel insurance companies and brokers who will provide insurance to people with pre-existing conditions. You can find a comprehensive list at www.afa.org.uk

**Top tip:** Don’t forget to take your European Health Insurance Card (EHIC) when travelling in Europe. An EHIC will enable you to access state-provided healthcare in European Economic Area (EEA) countries, at a reduced cost, or sometimes for free. It will cover your treatment until you return to the UK. It also covers treatment of pre-existing medical conditions however the card is not an alternative to travel insurance. Anyone over the age of 16 can apply for an EHIC card online or call the automated service on 0300 3301350.
My name is John, a 71 year old “gym bunny”. I never had a love for any form of exercise as a youngster, avoiding sport as much as possible, even taking short cuts in my cross country races at school. However, I did enjoy cycling, and this developed as I reached middle age.

During the 70s, “meditation on the move” and “the runner’s high” were in along with a healthy lifestyle, so with my long hair, my Zappata moustache and an enduring love of West Coast music, I began jogging. I used to set the alarm on my heart rate monitor to the 220 minus your age formula and then switch off the alarm when it beeped during a run.

I soon discovered Orienteering, and running in woods whilst map-reading was a blissful combination. I became the obsessive runner who gets twitchy without the daily fix of a run.

By the time I was sixty my resting heart rate was 47 – 52 and I found Spin classes. One day I ventured into a Spin class run by “Killer Kath” who played great music tracks. She worked hard and expected you to do the same: amazing classes. My maximum heart rate of 195 bpm was found by a number of sprints on a bike ending in a flat-out hill climb.

Kath’s sprints in a Spin class would regularly take me close to that. I was being monitored for arrhythmia around then. I had a tilt table test that I sailed through without a twitch.

Eventually, I was attending a Spin class run by an ex-Olympian, followed by a 1 hour core/abs class, then a 1 hour Pilates class! I was also cycling to work and attending a 2nd gym in my lunch hour, and leaving meetings early to do yoga – not that I was obsessed!

“I wasn’t prescribed an anticoagulant as I’m a bleed risk.”

In 2014 my GP decided that I needed treatment for AF. I was prescribed Dronedarone and, shortly after, Amiodarone whilst in hospital.

On a third admission to hospital, it was confirmed that I had pulmonary toxicity / cryptogenic organising pneumonia secondary to Dronedarone and Amiodarone. I believe the chances of that are 0.06%.

That night they wanted to place me in the ICU, sedate me and place me on a respirator.
I refused as I had read I would have a 50% chance of survival. The respiratory team did a great job and I was breathing 70% oxygen for two days, but I was told that I would probably have scarred lungs.

I made a very speedy recovery but it took until late 2015 and several relapses to be weened off the Prednisolone that I was prescribed for pulmonary toxicity. The Prednisolone gave me high blood pressure and the ability to eat everything in sight and I put on 13kgs, but I wasn’t prescribed an anticoagulant as I’m a bleed risk.

I’m now secretary of a volunteer group who clear scrub in a local nature reserve; I am at my happiest using a bow saw and bill hook.

I’m also a mystery patient for first and second year medical students in sessions led by my GP.

They have to determine my medical condition by questions and examination. To date I’ve had three sessions and hopefully this helps students to appreciate that stereotypes don’t apply to people with AF and/or a full stroke.

I’ve also completed an advanced driving assessment for 16 year olds (!) on non-public roads, and I’m waiting to hear if the DVLA Medical Group will grant me an assessment that could reinstate my licence.

If you would like to help us to continue supporting people like John, please consider fundraising for AF Association. See overleaf for what others have done.

"I’m a mystery patient for medical students. They have to determine my medical condition by questions and examination."

In April 2015, I was back at the gym, determined to shed the weight I had gained. On 6th July 2016 I had a full stroke at home and was initially prescribed Apixaban but I became unwell, and was prescribed Pradaxa, which I have taken without a problem.

I had permanently lost my sight on the right hand side (hemianopia) due to the stroke, and for days could not find the bathroom in our small bungalow. It took some weeks before I could use a computer again.

My driving licence - clean for 50 years - was rescinded due to the hemianopia. However, I was welcomed back to a Pilates class and I slowly and gently worked towards rejoining the gym.

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Fundraising Champions!

Stow on the Wold Tescos in The Cotswolds raised a wonderful £3200 with their Bags of Help campaign. Here we see Rachel from Patient Services collecting the cheque.

A huge thank you to Gill and the residents of Luddington village who raised a fantastic £1500 throughout the year. Here is Dr Matt Fay, Trustee of AF Association accepting the giant cheque! Apart from rattling collection boxes, the money was raised by members of the Mayor’s Committee who accepted The Mayor’s Challenge 2017 which was to complete the Yorkshire 3 Peaks in under 12 hours. We are delighted to report that all 8 participants crossed the finishing line in time.

AF Patient Stuart and his daughter Marsha swam the entire 10 mile length of Lake Windermere on 2nd September – In fact, Marsha swam it twice! Together they raised over £600 for AF Association. We would like to say a huge thank you to you both, especially knowing how hard it must have been for Stuart!

Christine and her groups of Slimming World members in Shipston on Stour and Moreton in Marsh have raised £140 by simply holding a collection box in group. Thank you so much Christine!
Mark from Bedfordshire will be running the Virgin Money London Marathon on Sunday 22nd April. Mark says "I personally have suffered with AF for the last two years, and will be running to raise money for AF Association and to show and hopefully inspire other sufferers that AF is a condition that can be overcome, and that anything is still possible.

Mark is hoping to raise £2,500. We wish Mark lots of luck. If you would like to support him, please visit http://www.hearthrhythmalliance.org/afa/uk/virgin-money-london-marathon-2018

**Fundraiser Packs**

We want to support all our fundraisers as much as possible, so for everyone who takes part in an event to raise money for AF Association, we will send you a fundraising pack.

**Each pack will contain:**

![Fundraiser Pack](image)

**Fundraising Ideas**

Regardless of your age or ability, there are so many ways to fundraise for AF Association. We appreciate everyone's efforts, from simple afternoon tea events and bake sales to marathon runners and skydivers.

If you would like to do something for AF Association, but are stuck for ideas, please get in touch fundraising@afa.org.uk
AF Association relies on donations to enable us to maintain our helpline, resources and support services to patients and carers.

**Ways to donate**

### £5
- will help to 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

**Post:**
You can send a cheque payable to AF Association to Unit 6B Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR

**Phone:**
To make a one-off donation over the phone, please call us on 01789 867502

**Payroll:**
Give as you earn, tax-free, straight from your Payroll. Email to find out more info@afa.org.uk

**Online:**
To donate online, please visit our JustGiving page: www.justgiving.com/atrialfib

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**The Importance of Gift Aid**
If you are a UK tax payer, declaring Gift Aid allows us to reclaim 25% of your donation from HMRC at no extra cost to you. We can claim Gift Aid on all donations, but sadly we cannot claim it on any purchases you make through us.

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**Gift Aid Form**

Name:..........................................................................................................................................

Address:.......................................................................................................................................

............................................................................................................. Postcode:.......................

☐ *I want to Gift Aid my donation of £___________ and any donation I make in future or have made in the past 4 years to AF Association

*I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify us if you want to cancel this declaration, change your name or home address or no longer pay sufficient tax on your income and/or capital gains. Your address is needed to identify you as a current taxpayer.

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**What can I do?**
You need to make a Gift Aid declaration for us to claim. You can do this by completing the form below. You can include all donations from the last four years as long as you were a tax payer. Visit www.gov.uk/donating-to-charity/gift-aid for more information.

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Helpline: 01789 867502
Since its formation in 2007, AF Association has been instrumental in improving the care pathway for patients with AF. From diagnosis through to treatment, AF Association has continued to guide NHS guidelines and practice, to ensure that patients receive the best possible care.

Today, with your help, we continue to offer expert knowledge and support to individuals affected by or involved in the care of atrial fibrillation.

A gift to AF Association in your Will doesn’t have to be large to make a difference. Your legacy can be a big part of our future.

Although we understand that your family and friends are your priority when writing your Will, we cannot express in words just how important your donations are to us.

We know this can be a big decision, and you may find it helps to talk it through with your loved ones. Including AF Association in your Will could give other families affected by atrial fibrillation the chance to spend more precious moments together.

I already have a Will, how do I include a gift to AF Association?

If you already have a Will and want to add a gift to AF Association, you can make an amendment (codicil); please speak to your solicitor about how to do this.

What information do I need to include AF Association in my Will?

Once you have decided what you would like to leave as a legacy to AF Association, you will need our full name and charity number to share with your solicitor:

Charity Name: AF Association
Registered Charity Number: 1122442
Address: Unit 6B, Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR

How would my gift be used?

Regardless of the size, a gift left in your Will would make a vital difference to our work; your legacy will mean that the support given to those affected by AF continues and develops. Ultimately, your gift will improve and even save the lives of AF sufferers in the future.
Win a Watch BP Home S

All but one of these answers can be found in the grid – complete the form and tell us which one is not there. Entries cost £5

1. AF is short for ... (6, 12)
2. An ... reduces your risk of an AF-related stroke (13)
3. AF is the most common ... in the world (10)
4. An ... is a type of treatment for AF, which destroys the heart tissue by freezing or burning (8)
5. A ... is a quick and effective electrical shock treatment to convert the heart rhythm (13)
6. ... , mindfulness and relaxation can help you cope with stress related symptoms (10)
7. Which online community forum does AF Association signpost people to? (14)
8. Symptoms of AF can sometimes be controlled through diet and ... (8)
9. The hearts normal rhythm is also known as ... rhythm (5)
10. A lot of people with AF benefit from attending a patient ... group (7)
11. It is advised to follow a healthy, low fat ... (4)

Prize Draw Terms and Conditions:
- Entry for AF Association 2018 wordsearch is £5 per entry.
- The closing date for the AF Association 2018 wordsearch prize draw is Monday 14th May 2018
- Please return entry form together with £5 payment to AF Association, Unit 6B Essex House, Cromwell Business Park, Chipping Norton, OX7 5SR
- AF Association accepts no liability for any incorrectly addressed, undelivered or late entries.
  Any monies received after the closing date will be treated as a donation.
- The prize draw will take place on Friday 18th May 2018 at the AF Association office, Chipping Norton.
- The winner will be randomly selected from all correct entries received by the closing date.
  Winner may be asked to provide a photograph for future promotions.
- Winner will be contacted on the draw date by phone, and will subsequently be announced on our website and social media.

Gambling Support - GamCare provides support, information and advice to anyone suffering through a gambling problem. If you are worried about your gambling, or that of someone you know, please contact GamCare on 0800 8020 133 or visit www.gamcare.org.uk.

Helpline: 01789 867502
Win a Watch BP Home S

Name: ........................................................................................................................................
Address: ....................................................................................................................................
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................................................................................................ Postcode: ...................................

☐ I enclose £5 cash/cheque entry fee

Telephone No: ..................................................

Answer:

info@afa.org.uk • Go online: www.afa.org.uk
Stay In Touch

We like to keep in touch about the vital work we do for those affected by atrial fibrillation.

Data Protection regulations are changing and from 25 May 2018, we cannot contact you unless you give us consent.

We NEVER share or sell your details with anyone else – we treat all communication as confidential.

We want to continue to provide information, education, resources and support so please contact us by calling 01789 867502 or email info@afa.org.uk to let us know you still want to hear from us - you are important to us.

Social Media

You can also connect with us and other patients through various forms of social media. For instant updates and extra information, follow us on Facebook (facebook.com/atrialfibrillation), Health Unlocked (healthunlocked.com/afassociation) and Twitter! @atrialfibuk

Support Groups

For more information about arrhythmia support groups in your local area, please look on our website www.afa.org.uk or call us on 01789 867502.