



atrialfibrillationassociation

August 2009 Issue 4

Providing information, support and access to established, new or innovative treatments for Atrial Fibrillation

# 'Know Your Pulse' Campaign Continues



Professor A John Camm reminded the audience at Westminster that, "This is not just a week-long campaign – but an ongoing national and international campaign ensuring that members of the public are aware of their pulse and possible irregular heart rhythm disturbance and that pulse checks become a routine test when visiting your GP."

**This year's Arrhythmia Awareness Week saw more than 1,100 events across the UK, from the Shetland Islands, to North Wales, across to Kent and into London and the far South West.**

From early spring, AFA received a large number of enquiries requesting posters, display packs, leaflets to pass to local medical centres and... the **Pulse Check Cards**, as AFA members, medical staff and supporters began the 2009 awareness campaign.

AFA is working closely with the NHS Improvement Programme and this year's campaign reflects our joint vision and marked the public launch of the long term campaign to be **'Pulse Aware'**.

With awareness displays planned for libraries, shops, leisure centres, schools, medical practices and hospitals, the message spread, that a simple pulse check can save lives.

Teams of medical professionals joined with us and organised 'Pulse Check' stands in local shopping centres, work environments and hospitals.



Father Michael highlighted AAW in the Sunday service.

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Dr Matt Fay, ran a Cardiac Café in his own surgery; a northern church displayed information and offered free pulse check cards after the Sunday service. Arrhythmia nurses took their work literally into the community – to shopping malls and supermarkets, and the work began! In fact, more than 100,000 Pulse Check Cards were distributed!

At the Westminster launch, AFA Chief Executive Officer, Trudie Lobban, MBE, underlined the



importance of the campaign and announced that the 'Know Your Pulse' campaign was not just an event for a week or a month; it was a campaign which would only pause when pulse checks



Pulse check clinics were held across the UK, from shopping centres, libraries and offices to GP surgeries!

became a routine check for EVERY patient visiting their GP.



SO – if you delayed, missed the launch... or were enthused and would like to do more, then don't despair... there is much more to be done!



Pulse check cards, posters and information booklets are still available from Atrial Fibrillation Association.



Following impressive results, as recorded in Dr Fay's article, on page 3, AFA would like to encourage all Flu Check Clinics to offer pulse checks too. So, help make a difference, help save lives, **Think Flu Jab, Think Pulse Check!**

Order your pulse check cards now to pass on to your local GP centre. Be 'Pulse Aware' and help make this year's flu vaccinations an even greater health care event.



Patients and surgery staff teamed up to run pulse check clinics.



## Kirsten's News



Many of you will have read about Kirsten's struggle for diagnosis and treatment of Atrial Fibrillation, as recorded in a national newspaper in April of this year. As a result of the article,

AFA received almost 3000 enquiries, from around the world! The first 2000 arrived in just two days! Thanks to Kirsten, many more people received information about AF and are now reassured they are not alone with this condition. I am sure you will all

be interested to read a short update on Kirsten's road to restoring a quality of life.

Following her catheter ablation at Papworth Hospital in April, Kirsten has made a steady recovery and is due to have a follow up appointment when the treatment and medication are reviewed, later this summer. When I spoke with her, Kirsten said:

*"Currently I am still taking medication and having some ectopic beats, but generally feeling much better. As before, I struggle to remain in a steady*

*therapeutic range for my INR levels, however, later in August I will be back at Papworth when all the drugs will be reviewed, and who knows! I have tired weeks and good weeks, but am far less physically sick and exhausted than before – which is great. The AFA Forum has been brilliant, all of the lovely people who post have kept me smiling – thank you to them all."*

A new AFA Fact Sheet on 'Ectopics' will be available this autumn – look on the AFA website or contact Jo to order a copy.

# Pulse Checks and Flu Vaccinations

A health check event lead by Dr Shane Gordon,  
a GP in NE Essex, which really did make a difference

Prior to diagnosis, patients who suffer from symptomatic Atrial Fibrillation (AF) are most likely to seek medical help. In these cases it is easier to detect AF and thus proceed to assess and manage their stroke risk appropriately.

However for the many patients who are not symptomatic and so unaware that they have developed AF, detection may only occur if opportunity arises to feel their pulse.

**“It is a clinically proven fact that taking the pulse is a very simple way to detect AF”**

The practices of North East Essex should be proud of their detection rates for AF. The national prevalence figures for Atrial Fibrillation are published at 1.2%, however the practices of North East Essex are already recorded at 1.6% with some individual practices having a prevalence of almost 5%. As would be expected with so much AF being detected in this above national average age population, the practices also were above the national average for stroke. However, the practices felt that there was more AF in their local population that was yet to be identified and decided to do something about this.

It is a clinically proven fact that taking the pulse is a very simple way to detect Atrial Fibrillation. The group of GPs decided that all the patients who would attend for their flu vaccination in the autumn of 2008 would have a simple pulse check. This campaign targeted the population most at risk of having Atrial Fibrillation and most at risk of stroke due to AF – the over 65s; it also targeted people who would not normally be attending their practice, who enjoyed generally good health

or attended for issues which would not normally warrant a pulse check.

During the flu campaign almost 34,201 people were screened in 37 GP practices over a six week period, with a simple manual pulse check. Of these people 3,154 (0.99%) patients were found to have an erratic pulse rhythm and needed a more detailed examination.

**“Doctors in NE Essex show pulse checks save health care problems and NHS funds”**

Of the people who were offered further assessment, 189 (0.55%) were found to have Atrial Fibrillation that was not previously known about; 342 (0.99%) of patients were found to have other heart rhythm issues that were now diagnosed and discussed with the patient. A further two patients were unaware they had ‘complete heart block,’ which is a serious condition requiring a pacemaker!

Of these 189 patients with undetected AF, 10 (5%), could be expected to have a stroke in the following 12 months. With current data suggesting that two thirds of those who suffer a stroke in Atrial Fibrillation die within the year following the stroke, appropriate treatment with warfarin can reduce this risk by 70%. People can only opt for treatment if they know they have a problem.

The doctors of North East Essex discussed the potential of checking pulses with their Primary Care Trust (PCT), the PCT agreed to a payment of £70,000 across all 37 practices for this check. With the number of new cases of AF identified this would suggest a cost

per diagnosis of £362, that is not much in medical economic terms. If we work through the annual cost of Stroke to the UK economy, which is £8.9bn, (putting to one side the immense personal costs to the individual, family and carers), it comes to approximately £44,000 per year. So, even if the GPs of North East Essex could only prevent half of the possible strokes in the patients they now found to have AF, they have potentially saved £220,000 per year. For the financial director of the Primary Care Trust this is a return on his investment of 322%.

**“They have potentially saved £220,000”**

The health of the population cannot be reduced to pounds, shillings and pence however financial considerations are important. The doctors of North East Essex have shown through application of their clinical skills, a simple, cheap test can make a tremendous difference to peoples’ health risks and suffering as well as save the NHS funds.

The flu campaign nationally saves lives by reducing the risks of the viral illness by vaccination. In North East Essex the flu campaign reached further, reducing illness, disability and death through appropriate detection, education and treatment of patients who, unknowingly, were at significant risk of stroke due to AF.

**Dr Matthew Fay, GP**  
AFA MAC, National  
Clinical Lead NHS  
Improvement  
June 2009



# Question Time

With Dr Andrew Grace, PhD FRCP Consultant Cardiologist  
at Papworth Hospital, Cambridge

**My brother and mother have AF, am I more likely to develop it?**

For many years it's been recognised that there are families in which AF occurs more commonly than in other families. More recently, the possibility of a genetic link has had a more formal scientific appraisal and it is now clear that there are some families with a strong genetic basis for their AF. A number of studies have been completed worldwide. One from the Massachusetts General Hospital has indicated that in those with a personal history of lone AF, the chance of a close relative being affected can be high. With pre-specified ascertainment, they found that nearly 40% of individuals with lone AF had at least one relative with the arrhythmia, and a substantial number reported having multiple relatives with AF.

In terms of the specific question, that is in an individual with a family history, should they be particularly concerned that they are going to get AF - that is, of course, more difficult. They are undoubtedly at higher risk statistically but whether they as an individual are, in fact, going to go on to get AF would be unknown. There are no specific and particular proactive actions that would be taken other than general advice, that is, to keep healthy, to keep weight under control, have regular check ups of blood pressure, minimise alcohol consumption and similar in terms of maintaining a general overall healthy life style.

**Is the risk of stroke greater when I am in AF than in normal sinus rhythm?**

The overall stroke risk in an individual with AF relates to a whole range of factors. Many of these will be the general status of the patient that include factors, such as age and sex but an individual who is diabetic or hypertensive will also be an increased risk.

There was some discussion as to whether the risk was greater if the pattern of AF was persistent or paroxysmal, the general consensus amongst cardiologists is now that the risk under both conditions is approximately the same and the more general factors should be the ones that determine whether Warfarin is recommended.

The question as to whether an individual with paroxysmal AF would have a stroke during the fibrillation itself or at a different time during normal rhythm is, from the cardiologist's point of view, a rather technical question in that the main decision is whether to start Warfarin or not. There is certainly evidence that in those with AF the time when the clots likely form in the heart is in the period after the AF has terminated. In individuals who have had prolonged attacks there is a period after restoration of normal rhythm when the atria are said to be stunned. This is the time when the atria are not properly contracting and clot can form under these conditions and this can provide the conditions under which a stroke could occur.

The main bottom line question is: 'are you as an individual at increased risk of a stroke?'. The anticipated level of risk should be discussed with your cardiologist and Warfarin should be initiated or not.

**I have been told I am overweight and that this can trigger AF, if I was to lose weight would it reduce my episodes of AF?**

There is absolutely no question when reviewing studies in large populations of patients that obesity is a risk factor for AF. In general, it occurs in combination with a number of other factors in that individual, such as, high blood pressure and possibly a diabetic tendency that often comes

along with the obese state. The advice of all doctors to their patients should be to try and fight against being overweight as that will make them feel better and will allow treatments for other diseases to work more effectively.

In the situation with AF where there are likely to be a variety of factors contributing to the appearance of atrial fibrillation, losing weight in itself is unlikely to resolve AF. There is absolutely no doubt, however, that the reduction of weight will make treatment of the condition much easier.

**I have always been very active, but since developing AF find exercise can trigger an episode, should I try to continue? Is it safe?**

The question of exercise and heart disease has been one that cardiologists have discussed over many years. There are areas now in which we have obtained consensus. For example, in those with heart failure (that's when the pump of the heart doesn't properly function) then it is now widely felt that exercise is useful for patients and can improve their quality of life and also help with prognosis. Similarly, in some patients with angina (chest pain due to coronary disease) and claudication (pain in the legs due to an impaired blood flow) then, again, exercise can lead to some improvement in the situation, although exercise should only be embarked upon after proper medical assessment.

In regard to the issue of cardiac arrhythmias and exercise, it is generally felt that if an individual has exercise-induced arrhythmias, then the arrhythmia should be dealt with in the first instant. In addition there is no major beneficial effect of exercise in terms of reducing the likelihood of events. Accordingly, pushing to the point of inducing arrhythmias would not generally be

recommended. This would not necessarily be because it is going to cause any direct and immediate harm, rather it is not going to be good and in general terms, for example, with AF, in which the more attacks one has the more one's going to get, then one could argue it's going to perpetuate and exacerbate the medium to long-term situation.

Accordingly, exercise should continue but ideally not to the point of triggering events. No immediate harm is likely to arise but as time goes forward it's likely more events will occur. Referral for expert care is needed.

### What are ectopic beats?

There is no systematic terminology that refers to ectopic, extra, or missed beats. The derivation of the term ectopic refers to coming from a different place, and that is indeed what usually occurs, that is, the beats emerge from the atria, the junction between the atria and the ventricles or from the ventricles (not the sino-atrial node). The main impact is not related to where they come from but their timing. Individuals, after an extra (ectopic) beat, will often describe a missed beat because there is a slight pause before the next normal beat arises. Even experienced cardiologists taking the history from the patient cannot tell where the beats are coming from and will need an ECG or even a 24 hour ECG recording to determine the general origin of these extra or ectopic beats. They represent a general excitability of a particular part of the heart that generally doesn't concern cardiologists in terms of any implied risk.

### Can I have an anaesthetic if I have been diagnosed with AF?

Cardiologists are often asked, usually by anaesthetists, as to whether a patient will be fit for a general anaesthetic because their pulse has been found to be irregular. In general, AF of itself is not a contraindication for a general anaesthetic and for operative treatment. If an individual is found

to be in atrial fibrillation a general assessment of their cardiovascular health should however be undertaken. In addition, if the anaesthetist has found the AF, then the operation may well proceed but after the operation then the AF will require it's own assessment and management. In essence, the operation will have in passing provided an excellent opportunity for screening and the identification of the problem.

### Is there an alternative to beta-blockers, I have found side effects so difficult to manage but do understand they slow my heart rate?

One of the major current difficulties with the management of AF is the few drugs that we have to manage the condition. In the very near future it is anticipated that the range of drugs will increase (e.g. Dronedarone). Even then with more drugs, there will be times when an individual will be intolerant of the range of drugs available.

One problem with the current situation is that many of the drugs we use have beta blocking activity (this includes Propafenone and Amiodarone) and some drugs, such as, Flecainide, cannot be taken by all patients.

If an individual is intolerant of drug therapy and each appropriate drug has been tried then this is an absolute indication for a referral to an AF specialist who can then discuss other options, such as ablation, that are available for the management of the condition.

### Will the new anti-arrhythmic drug mentioned in the press be available to all AF patients? How can I be considered for it?

In a condition as frustrating to live with as AF sufferers will appropriately seek out new therapies. The approach of the careful doctor is to try and introduce new medicines cautiously because there may, later on, be unforeseen issues that include side effects that cannot be fully anticipated. Accordingly, when new drugs do

become available, then not all patients will be suitable and even some patients who may be suitable might be better kept on conventional and well-established treatments until more experience is gained. It is certain that new drugs will become available in the near future and their cautious introduction will be the appropriate way forward.

### Is there an alternative to Warfarin?

Warfarin is still perceived as a difficult drug, although in practice the majority of patients find it an easy drug once they are established on therapy and, in fact, it is a relatively low risk drug even though there is much adverse misinformation.

The fact is that Warfarin is enormously beneficial in the nearly all the patients to whom it's given. Aspirin does not provide significant protection against the risk of stroke in AF whereas Warfarin does and therefore the search for alternatives to Warfarin that have similar action has been a major objective of scientists and the drug industry.

Their efforts are now bearing fruit and it is anticipated that in the relatively near future a range of drugs with the benefits of Warfarin without some of the inconveniences will become available. Once these drugs are available to the doctors then the relative use of such new drugs compared to Warfarin will have to be addressed. The general approach to the introduction of a new drug is to not immediately to move en masse from one to another as that may have unforeseen and potential adverse consequences. Accordingly, when these new drugs become available, if your doctor does not immediately recommend them, this may be entirely appropriate.

**A 'Frequently Asked Questions' booklet will be published by AFA later this year.**

## PATIENTS DAY REGISTRATION FORM

Thursday 24th September 2009 London Hilton Metropole Hotel

The Organisers and Faculty of Europe AF 2009 would like to invite patients to join them in a Patient session on Thursday 24th September at the London Hilton Metropole Hotel. Attendance to patients and an accompanying person is complimentary.

For further details please contact:

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BS40 8WB

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## On warfarin?

*Accuracy and precision in  
INR monitoring are vital*

### Would you like to:

- Test your own INR at home?
- Spend less time in anticoagulation clinics?
- Improve your quality of life?
- Spend more time doing the things you want to do?

If your answer is yes to any of these, self testing may be an option for you.

To find out more call our Careline free on **0808 100 7666**,<sup>†</sup> and ask for our free information pack, or visit [www.coagucheck.co.uk](http://www.coagucheck.co.uk)

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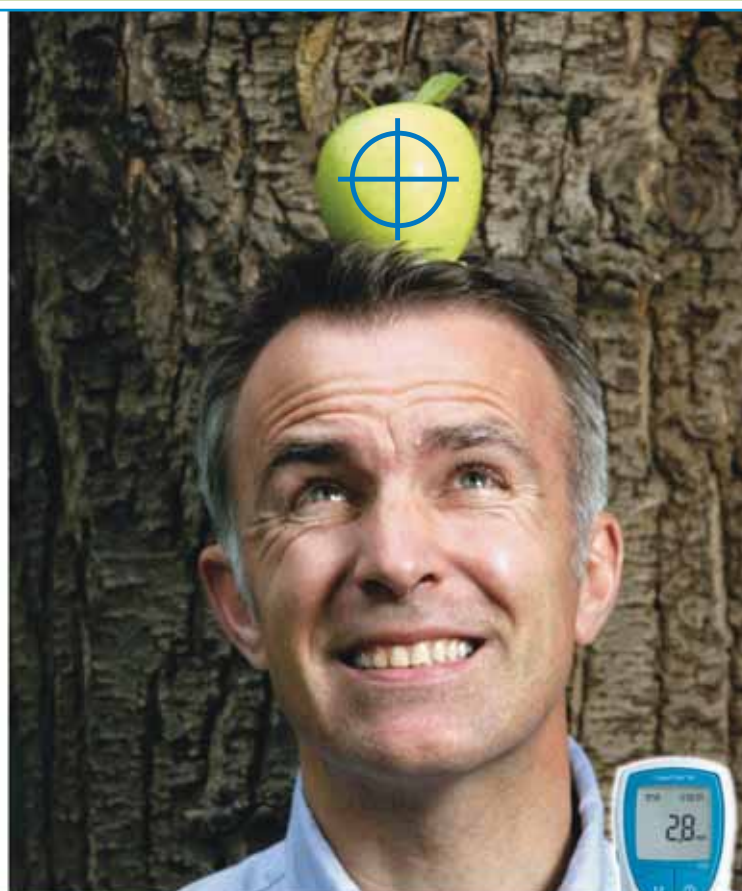
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#### Reference:

1. Kullina W *et al.* Seminars in Thrombosis and Haemostasis 1999.

<sup>†</sup> Lines are open Mon-Fri: 9.00am-5.30pm.

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 Diagnostics

# Paroxysmal Atrial Fibrillation

## Accessing *effective* treatment to reclaim my life



With my son in July 2008

I finally felt 'cured' of Paroxysmal Atrial Fibrillation in November 2008 aged 33, thanks to an ablation by an excellent doctor I will always be indebted to, Dr Vias Markides.

### But how had it all begun?

In December 2004, I gave birth to my son, my recovery from giving birth was slow and I suffered regular dizzy spells. I put this down to exhaustion, breast feeding, a large baby - over ten pounds at birth. So, I pushed on and just thought it would improve. However by August 2005 the dizzy spells seemed to be getting worse and more frequent and I was continually exhausted. I was getting comments from my husband and family so I decided to go and get checked out by my family doctor.

The first thing the family doctor did was a blood test (which came back clear), so there was no follow up. Time went on, and I was still struggling, but the next time I

experienced dizzy spells I made an emergency appointment with my family doctor who told me to go immediately to Accident and Emergency (A&E). When I arrived (by foot!), I was immediately put on a heart monitor and they made an ECG. Atrial Fibrillation was detected and I was kept in over night until they could get my heart out of AF by a combination of drugs and probably just time.

Over the next two months I was admitted to hospital approximately five times. Struggling and feeling desperate, I tracked down a doctor with a specialism in Atrial Fibrillation. He immediately put me on a waiting list (nine months in The Netherlands) for an ablation as I had been on various drugs, none of which worked and all of which had awful side effects which tended to make me feel worse than I did without the drugs. I couldn't face such a long wait, my life was just a daily struggle, so I asked for alternatives and I was referred to Belgium. Subsequently I had two operations but unfortunately neither worked.

With the support of my husband and family, I persevered and kept looking for alternative centres where results looked hopeful but waiting times were shorter. Finally, with support, I was referred to a specialist in the UK.

Privately I got an appointment in a week, and an operation two weeks later. For me and my family, hope was restored.

Thankfully, the ablation this time was successful, and two years on I am still free of AF.

I guess what I learnt was that you shouldn't just accept what your doctor says first time, just keep asking. If you are not happy with the answer, go for a second opinion. I also treated my AF like it was a project (I have two files full of all my hospital records at home!). I did go private but only because a nine month wait for an operation was like a life sentence to me. With a lively two year old to look after and a constant feeling of exhaustion, the time I had so looked forward to with my young child was passing by and I think I would



May 2008 back to full strength

have despaired delaying any longer than absolutely necessary.

I was also not happy being on medication in the time between the operations, it made me feel so ill, and I was worried about the long term effects (as it was I was down to 59 kilos (my normal weight is around 63/4 kilos). I also figured that was what savings were for.

Having AF did and still has a definite impact on my life; it has made me aware how important it is to listen to your body and ensure that you get the right treatment for you and on your timescale, not

on the doctor's. To get effective treatment keep your own file and when in front of a new doctor put a summary upfront about the key events. This helped me to keep track and ensured that whoever I saw (I had numerous cardiologists) had a short, clear and concise overview of my medical history. You have to make life easy for the cardiologists. They are, in the end busy helping put our hearts back into rhythm!

Hiking in the Alps in September 2008



**Kate,  
The  
Netherlands**

The AFA Checklist has been designed by a medical panel to help you summarise your medical history, just as Kate found helpful.

A copy of the Checklist can be downloaded from the AFA website.



**Dr Richard Schilling**

## ...UPDATE on new trials

There has been a lot of interest in the newest technique for paroxysmal AF ablation developed at Barts and the London Bridge Hospital and the AFA have asked me to clarify some points about it.

At the moment this new burn and freeze treatment has shown early promise but this is not the same as the hard evidence supplied by randomised trials.

Understandably for a treatment to be accepted by the NHS it has to have robust evidence supporting it particularly when the costs are greater than conventional treatment. In the private sector cost issues are still important but not as acute as they are with the NHS and this has allowed us to develop the initial data suggesting that this technique may be better. In the NHS we are currently in the process of establishing a clinical

trial. At the present time the trial has been approved by our ethics committee and we are starting the trial. The trial will give NHS patients the chance to take part in research involving this treatment. However even then patients will be randomly allocated to one of three treatment strategies:

- a) conventional radiofrequency ablation,
- b) cryo (freezing) ablation or
- c) radiofrequency and cryo.

There will therefore be a 1 in 3 chance of a patient being allocated to a particular treatment. It may appear unfair or silly to not use what we think is the best treatment, but there are many examples in the history of medical science of a treatment that at first appeared much better, which then proved no better than conventional treatments when

tested scientifically, so these trials are very important. If you do wish to be considered for this type of treatment then asking your GP to refer you as an NHS patient is the best way of doing this. However if you do not want to take part in research (which is entirely voluntary) it may be better to wait for the trial to be completed and the results known, which can take over 18 months, before you have treatment. An important thing to remember is that the conventional treatments (radiofrequency or cryo alone) have excellent results but have the disadvantage that they often need repeating more than once to get the best results.

Therefore if you have paroxysmal AF you still have a very effective treatment in conventional ablation. The real question to be answered by the research of this new technique is can it be better?

# Explaining Clinical Trials

**Atrial Fibrillation (AF)** can cause troubling symptoms and predisposes to serious complications such as stroke. Because it is so common and causes so much disease, AF is an area of intensive research.

Some of the most well known research currently being undertaken includes, Dronaderone, which has been the subject of clinical trials aiming to restore the normal rhythm in patients with AF. It appears to be safe and effective, although there are still concerns about its use in the context of heart failure. It is not available in the UK at the time of writing.

Catheter ablation for AF is being used increasingly for symptomatic patients unable to tolerate medications. Several aspects are currently being examined and/or studied. Which include, (i) Methods used in catheter ablation; (ii) Ways of guiding catheter ablation; and (iii) Effect of ablation on outcomes.

Some AF patients are at an increased risk of stroke, which may be high enough to justify anticoagulation or

'thinning the blood'. Currently only warfarin is licensed for this purpose, but warfarin can be troublesome as it requires monitoring with blood tests (to make sure the blood is not under or over 'thinned'). There are other anticoagulants in testing that are more predictable and do not need monitoring, perhaps making them more convenient and safer.

In each situation, clinical trials are used in medical research to investigate the safety and effectiveness of a new drug, device or procedure. Trials may also test the effectiveness of an existing intervention or drug in a new setting, or with a different dose. In a clinical trial subjects are normally assigned at random to two or more different treatment groups. This can be to compare two different treatments, or sometimes a treatment versus no treatment or 'placebo'.

A placebo is something that is not an active treatment and has no effect. This eliminates any bias introduced by telling someone they are receiving treatment. This can have a positive effect in itself known as the 'placebo effect'. If the medical team is

also blinded to the treatment that the patient is receiving the trial is said to be 'double blind', which eliminates any potential bias on their part.

All participants involved in any trial will need to complete a 'consent form'. Where there are important implications and potential risks, consent is taken formally (signed, written agreement). Both the patient and the person taking consent sign a 'consent form' to say they have agreed on a proposed action. This is a contract giving permission to the health care professional to proceed with treatment. However, even after signing the consent form the patient still has the right to change their mind at any stage. The consent process formalises an agreement and protects both doctor and patient.

Dr R Schilling and Dr R Hunter

New AF fact sheets will shortly be available from AFA, four titles focus on clinical trials:

- Ongoing Trials in Atrial Fibrillation.
- What is a Clinical Trial?
- What Does Randomisation Mean?
- What is a Consent Form?

## Trudie Lobban honoured with MBE!

"It was a wonderful surprise to learn that Trudie Lobban had been awarded the MBE – there is no-one more deserving of this honour. Trudie has worked long and hard for children with the dramatic symptoms of sudden loss of consciousness. Her work has made a huge difference to both these children and their parents. I am very impressed by the energy and dedication that Trudie gives to this and her other charities in the field of heart rhythm disturbances. Her work has improved the quality of life for so many."

**Professor A John Camm**  
**AFA Trustee**  
**Professor of Clinical Cardiology**  
**St George's University Hospital, London**





*"We have recently received your patient guide, 'Gardening for Hearts & Minds' and were very impressed with the booklet... this booklet, for those who enjoy gardening, will be very useful."*

Suzanne, Manager of a Cardiac Rehabilitation Trust, is just one of an increasing number of health professionals who are using gardening activities to support the rehabilitation and recovery of people affected by heart disease and stroke. Hospitals that are using gardening activities with their patients have shown a variety of positive rehabilitation outcomes

## Gardening is growing in rehabilitation...

an update from **Thrive**, the national charity that promotes the advantages of gardening as part of cardiac and stroke rehabilitation.

including increased motivation in rehabilitation, improvements in standing balance and postural control, better weight transference and increased fine motor control.

The Just 30! Project aims to improve personal engagement and self management in the rehabilitation process by including the everyday leisure activity of gardening in the recovery process. In May 2008 Thrive launched the Just 30! gardening for hearts & minds guide, a step-by-step guide of practical gardening activities that can be done at home and are suited to improving specific common problems such as strength and mobility.

Funded by the Department of Health, the guides are being distributed across rehabilitation units in England and are being used to encourage people to achieve their 30 minutes of physical activity each day through regular gardening.

The gardening for hearts & minds guide is supported by interactive

training workshops delivered by Thrive to patients and professionals in hospital rehabilitation units and outpatient support groups. Participants in the workshops learn how gardening activities can help with rehabilitation, practices a gardening activity and review useful tools that can make gardening more accessible. The workshops often spark an interest in people to do more in the future.

*"It's great that you're able to come back as the previous group was very positive about the session Thrive did with them. One group member even brought her plant back at the end of the course to show that it was still alive!"*

**Senior Occupational Therapist, Southampton**

For more information about the Just 30! Project or to request copies of the guide, contact Harriet Evans, [harriet.evans@thrive.org.uk](mailto:harriet.evans@thrive.org.uk) **0118 988 5688**, [www.thrive.org.uk](http://www.thrive.org.uk)

## Did you know that you can store your INR level with MedicAlert?

The MedicAlert Foundation is the only non-profit making, registered charity that provides a vital life-saving service for children and adults with hidden medical conditions and allergies.

Medical Identification ensures that in an emergency situation those around you would know that you have a hidden medical condition. Wearing an Emblem also ensures that all information on medical conditions, medications, and next of kin is available.

*"In an emergency situation it is essential that ambulance professionals receive as much information about a patient's condition as quickly as possible. MedicAlert holds a detailed*

*record for each individual, this can include medication, blood group type, target INR range, organ donation wishes and other important information."*

**Dr George Sikharulidze,  
Head of Services The MedicAlert  
Foundation**

MedicAlert members wear either a bracelet, necklet, wristband or watch, known as an Emble. This bears the international symbol for medicine and is engraved with important medical details such as main medical conditions, a personal ID number and a 24 hour emergency telephone number providing access to the Member's medical records and personal details from anywhere in the world in over 100 languages.



### How to become a Member

Membership starts from £25 plus the cost of their choice of Emblem. As a special incentive to readers, if you call freephone 0800 581 420 and quote AFA you will receive a discount of £5 from the initial joining fee.

To view the entire range of award-winning stylish jewellery suitable for men, women and children visit [www.medicalert.org.uk](http://www.medicalert.org.uk)

# AFA Patients' Day 2009

Sunday 18<sup>th</sup> October 2009, Hilton Birmingham Metropole, UK.

Including presentations from medical specialists and AF patients, refreshments and lunch... book now to avoid disappointment!

## Registration Form

This year, AFA is offering subsidised rates to all AFA patient and carer members registering for the AFA Patient Day directly through AFA – a discount of 50% bringing delegate tickets to £25.00 per person.

### The day will include:

- A Patient's Journey To Diagnosis
- AF and Community Care
- Seeking an Understanding of My AF
- Cause and Triggers of Atrial Fibrillation
- Current and New Developments in Drug Management
- Cognitive Behaviour Therapy for AF
- Anticoagulation, what does this mean for the patient?
- Exercise and AF
- Catheter Ablation for AF. Is it a cure?
- Question Time

A full agenda and travel details will be sent as a receipt of your registration.

Please tick in the box whether you are a:

Patient

Carer / friend

Please record the name of each person attending with you:

Dietary Requirements Please let us know if you have any specific requirements or allergies.

### PERSONAL DETAILS

Full Name:

Address:

Town:

County:

Postcode:

Country:

Contact Details

Telephone:

Mobile:

Email:

Please enter your email address clearly – Patient Day details will be sent to this address.

If you are unable to provide an email address we will post information to you.

Please return your completed registration form to AFA at the address shown below.

I enclose a cheque for £

/ I enclose a postal order for £

AFA, PO Box 1219, Chew Magna, Bristol, BS40 8WB Tel: +44 (0) 1789 451 837

# Publication List

AFA publications are accredited by the **Medical Advisory Committee** and endorsed by the **Department of Health**



PATIENT INFORMATION BOOKLETS	PLEASE TICK
Atrial Fibrillation (AF) Patient Information	
Atrial Fibrillation Drug Information	
Blood Thinning in Atrial Fibrillation	
Cardioversion of Atrial Fibrillation	
The Heart, The Pulse and The Electrocardiograph	
Catheter Ablation for Atrial Fibrillation	
Atrial Fibrillation Checklist	
Patient and Primary Care Checklist	
A4 AFA FACT SHEETS:	
Atrial Fibrillation	
Amiodarone	
Aspirin	
Beta-Blockers	
Cardioversion	
Digoxin	
Flecainide	
Medical Cardioversion	
Pacemaker and AV Node Ablation	
Pill-in-the-pocket Cardioversion	
Rate Limiting Calcium Channel Blockers	
Rate versus Rhythm Management	
Warfarin	
AFA Newsletter	
INFORMATION AND GUIDANCE FOR MEDICAL PROFESSIONALS:	
AFA Tool Kit (CD)	
Focus on AF	
Seeking Patients with Atrial Fibrillation	
Anticoagulation and Bleeding Risks	
Stroke Prevention in AF	
Primary Care Pathways for Atrial Fibrillation	
Care Pathways for Atrial Fibrillation and Atrial Flutter	
Rate versus Rhythm Management	
Ablation of the AV Node and Pacemaker Implantation	
Complications of AF Ablation	
Top Ten Tips Leaflet	

*All publications are sent free of charge to AFA Patient members and the AFA Tool Kit is available free of charge to Medical Professionals. For larger orders please contact AFA. A contribution of £2.00 towards the cost of postage is very much appreciated.*

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# Winning Back!



Not only was this an immense physical achievement for Martin, but also a gold medal award in fund raising for AFA! On 8th June, Martin presented staff at AFA with a cheque for £1172.00!

Amazing Martin... we are in awe of both achievements and extremely grateful to you!



After several years of determination to restore his life to something resembling the way it had been prior to AF, Martin Harman has every right to feel elated! "I did it!" were the shouts as he completed a recent triathlon with a race time of 1 hour 7 minutes 25 seconds, beating his target time of 1 hour 15 minutes.

## AFA would like to thank

all members who have so kindly donated to AFA, funds are desperately needed to support the running of the 24/7 Help Line - a vital service which provides informative, friendly support to all callers. AFA totally relies on fund raising and donations to operate, could **YOU** raise money for AFA? Please help us to continue offering 24/7 support, make 2009 the year you

**Acquired a Fiver** for AFA – every penny can make a difference.

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CLOSING DATE 31<sup>st</sup> OCTOBER 2009

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# Is it Right for Me? – AF Treatment Options

I was inspired to outline my experiences with AF after reading literature recently sent to me by the AFA. I am certainly now more knowledgeable about AF, but wonder if I was right to have always accepted the prognosis. Should I have sought second opinions?

Just over two and a half years ago I was first diagnosed with AF. In hindsight I had probably been suffering with the condition long before then but I had put the symptoms down to pressure of work. Palpitations, chest discomfort, tiredness, disturbed sleep, waking

Prior to this I had generally enjoyed very good health; I am 59 years of age, have been a Head Teacher for ten years and before this, a PE teacher. I have run many marathons and was used to visiting the gym regularly. I could have counted on one hand the number of days I been away from work. Now I was given the first of what became many, many sick notes. Despite wanting to return to work as soon as possible I accepted my GP's advice. I was prescribed Warfarin to reduce the risk of a stroke and Tildiem to help control my heart rate.

able to see him privately within eight weeks. I was desperate to return to work, after talking things through with my wife we decided to have the private consultation.

The outcome of this, was that an ablation was not suitable. My medication was changed and I was advised that a second electro cardio-version could be performed after a minimum of four weeks taking the new medication. However, the NHS waiting list for the procedure was now ten weeks. Living in the West Midlands has some advantages, one is having a number of hospitals in the area. I took it upon myself to telephone around other hospitals to try and get an earlier date. I was successful! However, as it happened, in the three weeks leading up to my cardio-version my INR levels became very erratic and my appointment had to be postponed again.

I was still desperate to return to work, I had been away for almost the entire academic year. My GP advised that as long as my INR level and blood pressure could be maintained and that I listened to my body, it would be O.K. However, before this happened

## “Are NHS decisions based on financial constraints?”

up more tired than when I went to bed, panic, lack of confidence, dizziness, tearful, lack of concentration and sometimes words coming out slurred. I know now that these are all symptoms of AF as well stress.

Early in October 2006 I took to my settee one Saturday afternoon to watch sport. Drifting in and out of sleep and feeling as though a strong elastic band was tightening around my chest I awoke with my left arm numb and tingly - I put this down to having slept on that arm! These feelings continued throughout the weekend but not until midday the following Monday as I climbed the stairs to my office, did I realise something was really amiss. I was completely out of breath, dizzy and the bands around my chest were tight. Luckily I was able to get an appointment at my local surgery that same evening.

After relating my symptoms and having my pulse taken I was given an ECG and subsequently taken to hospital by ambulance. I had never been in an ambulance or stayed overnight in a hospital before, but here I was diagnosed with chronic sustained AF and high blood pressure.

Following twenty four hour echocardiography and blood pressure tapes, I received my appointment for a consultation with a cardiologist. It was now January 2007, three months after having been diagnosed with AF. and decided the most appropriate was electro cardio-version. It was a further 6 weeks before I received an appointment for the procedure to take place. The February procedure was cancelled as my blood pressure went through the roof while waiting to be anaesthetised. I was prescribed

## “I had chronic sustained AF and high blood pressure.”

Amlodipine and Losartan to reduce my blood pressure and had to wait for the medication to take effect before a re-scheduled cardio-version could take place. I eventually underwent my first procedure in March 2007 but AF returned within three hours.

Weeks passed before my next appointment to see the cardiologist again. He referred me to a specialist in ablation procedures to ascertain whether this might be suitable for me. There was a thirteen week NHS waiting list to see this specialist but I would be

I was informed of a cancellation and so my procedure came on July 10th. The procedure was successful and I returned to work the following week, just three days before the end of the summer term.

All was now well and I travelled to France at the end of July. I would need to have my INR levels checked whilst there. Initially what I thought to be a daunting prospect turned out to be no problem at all - seeing a Doctor and visiting a private clinic and paying just 10€ for each test.

For approx twelve months following my second procedure my heart remained in normal rhythm. Amlodipine and Amiodarone were reduced. I was back at work and things were going well.

Then AF returned, Paroxysmal AF with periods of Persistent AF. In light of everything that had happened in the past, I decided to retire earlier than my proposed retirement planned for later that year. I was hoping that, without the stresses of work, my heart would not get worse and might even return to normal rhythm by itself. My hopes, however, did not come to fruition and in December my heart reverted back into AF all of the time.

### **“I expressed my concerns about poor quality of life”**

I saw a cardiologist in April 2009. The outcome was to have a third cardio-version, but now with a warning that should this prove to be unsuccessful again, I should resign myself to having the condition for the rest of my life. However, this time I went to this consultation armed with information gleaned from an article written in the Daily Mail from the AFA website. My specialist did not agree with all of the information, and I was again advised to consider cardio-version.

I expressed my concerns about poor quality of life, about my breathlessness, and that previously I had always been very active and now I was not able to sustain exercise for long. I was prescribed Verapamil for my breathlessness and a procedure was scheduled to take place on the second of June. The Verapamil has yet to have any positive effect.

Throughout all this my GP has been very sympathetic and supportive, however, I am concerned that I have never seen the same cardiologist more than once and the lengths of time that I have had to wait

between each appointment/procedure have been too long. More recently I have growing concerns about differing/contrary information and the opinions of heart specialists. I have no complaints about the care/treatment received through the NHS which, when eventually received, has been very good.

AF continues to impact adversely on my quality of life and since retiring over a year ago symptoms have persisted - albeit not all of the time, not all at once and not all experienced to the same intensity.

As well as taking Warfarin I am now taking Amiodarone, Losartan, Amlodipine and Verapamil on a

daily basis. The AFA booklet ‘Catheter Ablation for Atrial Fibrillation’ states that “presently AF ablation is reserved for those with intrusive symptoms that

### **“I should expect to have the condition for the rest of my life”**

impact significantly on quality of life, are refractory to treatment with medication or where medical therapy is contraindicated because of other conditions or intolerance”. But this should be taken in the context of the individual. If my cardiologist believes that an ablation is not for me should I accept this or seek a second opinion, and what about a pace-maker?

My future, who knows? I do find it difficult to come to terms with my condition and want to return to how I was before all this began.

My third cardio-version took place on 2<sup>nd</sup> June 2009 as planned. Lying in the recovery ward my first question was had it been successful? It had taken two attempts, but yes, my heart was now in a normal

rhythm. I was informed that I would be seen again by my cardiologist.

Just two and a half days later AF returned (yet again)! My disappointment was immeasurable. I contacted my cardiologist the same day who reiterated (well his secretary did) that my next appointment would be in two months (even though my heart had returned to AF full-time) and that if I had any problems I should to see my GP.

My GP was, as always, very supportive but could not understand why I had been told to consult him. We discussed my history and the newspaper article/information that I had obtained from the AFA website. My GP is not a heart specialist, what could he do for me? What could he do but write to my cardiologist - which is what he did.

At times I feel very desperate, very frustrated, and extremely powerless. I am now waiting again for my next appointment with my cardiologist

(in two months time). Again I feel impotent. There is nothing I can do to speed up the process. I still have no idea what the future holds for me. Perhaps I had been too optimistic in hoping for ‘third time lucky’, I was really hoping things would get back to some sort of normality. I still get out of breath and experience dizziness. I often feel tired, have disturbed sleep and wake up more tired than when I went to bed. I take so many tablets a day I rattle when I walk. My despair and frustration is growing.

Is there anyone who can help me see the light at the end of the tunnel?

**Rick,  
West Midlands**



# ECGs for Primary Care

The recording of ECGs is increasingly common place in Primary Care. ECGcourses.com therefore offers an intensive, one-day clinical course - 'ECGs for Primary Care', for GPs and GP trainees to develop the essential remit of skills required in this area and to advise on strategies for dealing with abnormal ECGs.

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