Welcome to the Atrial Fibrillation Association

Launched in October 2007 and affiliated to the Arrhythmia Alliance (A-A), the Atrial Fibrillation Association is the first UK and European charity to offer medically approved and Department of Health endorsed information and support to AF patients.

The AFA website: www.atrialfibrillation.org.uk, went live in January 2008, offering patients downloadable information, updated AF news from around the world, ‘Frequently Asked Questions’, a moderated AF Forum, ‘Ask The Expert’ and links to related sites. There are also pages designed for medical professionals, hosting study evaluations, AF papers submitted by AF specialists, sample PCT Care Pathways and Primary Care guidelines, weekly AF medical news from around the world and links to podcasts.

By early summer a database of Specialist Clinicians in arrhythmias will be available on the website. Listing Consultant Cardiologists, Electrophysiologists, Arrhythmia Nurses and GPs with a Special Interest, it is hoped that the database will support doctors and patients seeking local AF specialists.

Clinicians wishing to be included on the database can do so via the website, or by emailing Jo at Info@atrial-fibrillation.org.uk.

Jo Jerrome
Support and Information Officer

Trudie Lobban
Chief Executive Officer

Short of ideas?

‘Adopt a surgery’: Deliver AFA information to your local GP surgery, ambulance service or hospital.

Hold an awareness event: man a stand in your local hospital or in a public place – we will provide the materials!

Fundraise for AFA: Whether you hold a coffee morning or a golfing event, help us to raise the funds we need to continue to support those with AF.

For further information contact Jo.

www.atrialfibrillation.org.uk  info@atrial-fibrillation.org.uk
The Faces of AFA

We are pleased to introduce our three Trustees, all specialists in cardiac rhythm problems.

Professor A John Camm

Professor Camm is a Specialist in Cardiac Arrhythmias but he is also much involved in clinical cardiac electrophysiology, cardiac pacemakers, risk stratification in post myocardial infarction, heart failure and cardiomyopathy patients. He has a major interest in cardiovascular safety of cardiac and non-cardiac drugs. Professor Camm has given over 1000 lectures to international audiences, written more than 822 papers and appears on over 1193 abstracts.

Dr Richard Schilling

Consultant Cardiologist, and honorary reader, Dr Richard Schilling, from St Bartholomew’s Hospital, London. Dr Schilling is one of the UK’s leading electrophysiologists and has presented to UK and European audiences.

Mrs Jayne Mudd

Jayne has worked as a Specialist Arrhythmia Nurse for the past nine years at the James Cook University Hospital (JCUH), Middlesbrough. During this time Jayne has taken the lead role in the Arrhythmia Nurse Specialist Team and has been responsible for developing specialist nursing roles within the multi disciplinary Cardiac Rhythm Management Team covering the catheter laboratory, out patient setting and ward areas. More recently she has taken on the role of Senior Arrhythmia Care Coordinator setting up rapid access outreach clinics within the community for patients experiencing or at risk of experiencing arrhythmia.

AFA is delighted to welcome Baroness Smith as Patron.

Baroness Smith

The Baroness was created a life peer of Gilmorehill, a district of Glasgow, in 1995 following the death of her husband, Rt Hon John Smith M.P. who was the Leader of the Labour Party at the time of his early death at the age of 55.
A relatively high proportion of patients with atrial fibrillation develops serious consequences. The heart may disturbance does have some potentially incapacitating. The rhythm disturbance although it may be highly symptomatic, very intrusive and serious consequences. The heart may enlarge and beat sluggishly if “heart failure” develops.

A relatively high proportion of patients with atrial fibrillation will suffer strokes or mini strokes known as transient ischemic attacks (TIAs). Fortunately this arrhythmia (and similar rhythm disturbances such as atrial flutter) can be treated very effectively and most of the complications can be avoided. About 1% of health care costs relate to this rhythm disturbance.

Unfortunately many patients with this rhythm disturbance are not receiving optimal treatment, often because the arrhythmia is “silent” and produces no symptoms until too late, for example when a stroke occurs. Doctors are now encouraged to look actively for this rhythm disturbance, for example by taking the pulse (which is usually very irregular in a patient with atrial fibrillation) or by recording an electrocardiogram (which produces a definite diagnosis if the arrhythmia is present at the time). Once the arrhythmia is discovered it is crucial to assess the patient’s risk for stroke.

At the first level this can be very easily done by asking a few questions and adding up a risk score. If the patient is at risk an anticoagulant (blood thinning tablet) is usually recommended provided that there are not reasons why the patient could not tolerate the medicine. Intermediate risk patients are usually advised to take aspirin whilst low risk patients need no treatment to prevent stroke. When the urgent business of protecting the patient against stroke has been considered it is then necessary to look for any underlying cause of atrial fibrillation.

Many of these can be corrected and the rhythm disturbance may then respond completely to treatment. In most cases, however, the underlying cause cannot be discovered or cannot be fully corrected. It is then necessary to decide whether to try and restore the normal rhythm and/or prevent relapses back to atrial fibrillation, or to allow the arrhythmia to continue whilst ensuring that the heart rate (pulse) is well controlled and the symptoms are minimised. This is described as the choice between rhythm and rate control. In many patients there is only one option but sometimes there is a choice.

The advantages and disadvantages of the two strategies should be explained to the patient and together with his/her doctor the best course of action for each particular individual patient should be chosen.

Medical drugs are available which encourage the heart rhythm to remain normal (anti-arrhythmic drugs) and other agents can be used to slow the heart rate to normal levels whilst leaving the rhythm disturbance in the atrium unchecked. Of course the drugs are not always effective and most have one or more side effects. However, it is usual for medication to be used as first line therapy. In recent years more invasive treatments have become available – for example it is possible to use a technique known as “catheter ablation” to permanently interrupt a rhythm disturbance and restore the normal rhythm (usually referred to as “sinus rhythm”).

These procedures involve inserting wires through veins in the groin or neck into the heart, using the x-ray to place them in the correct position. Once in place the energy such as heat or cold can be delivered to the heart in order to ablate (destroy) the electrical conducting ability of the tissue. In this way triggers for the rhythm disturbance can be isolated from the rest of the heart and the atrial fibrillation will not be provoked, or electrical pathways in the heart can be interrupted so that the rhythm disturbance cannot be sustained. In the right patient these techniques are highly effective but they also carry some risks and should not be attempted in patients who are unsuitable.

I have only provided the briefest description of these heart rhythm abnormalities, but it should be realised that it is important to diagnose and treat these arrhythmias in the best way possible. Much suffering can be prevented and many medical catastrophes can be avoided.

The Atrial Fibrillation Association has been established to ensure that patients and their relatives are well informed about atrial fibrillation and atrial flutter.

Over the next weeks and months more and more material will become available from the AFA and will also appear on its website (www.atrialfibrillation.org.uk). We are designing responses to frequently asked questions and regular articles about the rhythm disturbance and its treatment.

John Camm
Trustee Atrial Fibrillation Association
President, Arrhythmia Alliance
Professor of Cardiology
St. George’s Hospital,
London

www.atrialfibrillation.org.uk info@atrial-fibrillation.org.uk
AFTER months of setbacks and frustrations a vital heart operation looks set to go ahead for 61 year old Dorothy Simpson thanks to the Atrial Fibrillation Association (AFA). Dorothy contacted AFA after being refused treatment for her AF as recommended by her consultant. AFA supported and advised Dorothy while also liaising with the local PCT and her local MP. Following a press release highlighting the story and the need for funding to enable the operation to go ahead, the North Yorkshire and York Primary Care Trust agreed to overturn an earlier decision, and made funds available for Dorothy to access the treatment which might cure her AF. “I’m delighted with the result and really grateful for the help given to me by the AFA. I just hope that my story gives hope to other sufferers because when you’ve been told you’re too old for the operation at 61 it comes as a real body blow and you feel really down,” says Dorothy. We were delighted to help Mrs Simpson!

If you have a story to share or feel that you do not have access to treatment as recommended please contact AFA and we will do our best to help.

DOROTHY’S OPERATION IS JUST A HEARTBEAT AWAY

Pulmonary Vein Isolation (PVI)

By Joe Burnie

I was diagnosed with Paroxysmal Atrial Fibrillation PAF in April 2005 at the age of 47. I tried various medicines to no avail and my cardiologist referred me to an EP in March 2006.

I underwent a PVI in June 2006. It didn’t work at all. Later that year I underwent a tricuspid isthmus isolation, once again this was not successful.

In February 2007 the PVI was re-performed, and my EP did a lot more, most of which he described to me the day following the procedure when I was not feeling 100% so cannot recall all the detail! This was done in the most impressive new cath labs.

I was then rather unfortunate to suffer from Dressler’s Syndrome and was admitted to Cardiac High Care to have a pericardiocentesis to drain half a litre of fluid. Cardiac High Care is one hell of a place and made me realise how lucky I was to have an almost healthy heart.

Following about six months of lots of extra beats at night and funny heart rates when exercising, everything began to settle down in November 2007. I now enjoy NSR for 99% of the time and can exercise without any heart rate problems. I am delighted with the treatment I received and would recommend the procedure to anyone who suffers from PAF where the drug solutions do not work.

Sudden Cardiac Arrest kills 100,000 people every year in the UK…

It can strike anyone, anywhere, at anytime, without warning…

So where’s the AED?

For more information on how you can place an AED in your community and help prevent deaths from sudden cardiac arrest visit www.wherestheaed.org.uk or contact Laura Nelson on 01789 451823 / campaigns@heartrhythmcharity.org.uk
How do I find the right doctor to treat my AF?

Atrial fibrillation is treated by different types of doctor and it is important that you are aware what treatments are offered before you decide who to see.

Initially you will usually consult your general practitioner who may arrange some investigations before referring you to a cardiologist (heart specialist) – this cardiologist may or may not have a specialist interest in heart rhythm disorders.

After appropriate diagnosis, some patients will respond to medication and in this case it may be that no further treatment will be required.

Cardiologists who specialise in heart rhythm disorders, may usually also be called an electrophysiologist – this type of doctor will offer ablation treatments, and some will perform large numbers of ablation procedures for atrial fibrillation.

If you are seen by a general cardiologist you may be referred to see an electrophysiologist, but if this is not offered you can request specialist referral from either your general practitioner or cardiologist.

The outcomes from atrial fibrillation ablation, as with many other procedures, are generally better in more experienced hands. Before proceeding with ablation you should ask the electrophysiologist about his / her personal level of experience and results.

A team approach to atrial fibrillation ablation is important and you should also ask about the number of cases performed in the hospital where you will have the procedure. An electrophysiologist who has a specialist interest in atrial fibrillation ablation will usually perform over 50 procedures of this type per year.

To summarise, these are the services typically offered by each type of doctor:

(1) General Practitioner - overall responsibility for patient care and prescription of medication. May offer simple investigations and monitoring of anticoagulation therapy.

(2) General Physician / Cardiologist – investigation of heart disease, initiation and monitoring of drug treatment, cardioversion.

(3) Electrophysiologist – all aspects of heart rhythm diagnosis and treatment, including ablation procedures. Some electrophysiologists perform a high volume of ablation procedures for atrial fibrillation.

By Dr Neil Davidson, MB BS (Hons), MD, FRCP
Consultant Cardiologist / Electrophysiologist
University Hospital of South Manchester NHS Trust

PHILIPS EP COCKPIT

Electrophysiology is one of the fastest growing areas in cardiology. However, many electrophysiology departments are having difficulty in dealing with the increasing demand for these procedures and the need to perform more complex patient treatments.

EP procedures, although highly specialised requiring dedicated equipment and facilities, are often performed in catheterisation labs that are not specifically designed for this purpose. EP labs are frequently cluttered, temporary and inefficient. Working with many different systems in different places, ERP professionals are struggling to find an efficient process.

Philips EP cockpit can support clinicians and staff in the treatment of cardiac rhythm disorders, including complex ablation therapies. This new concept in electrophysiology labs combines Philips’ interventional Allura X-Ray lab solution with a number of innovative instruments to help make EP labs more convenient and efficient by creating a more intuitive working environment and integrating data management across the EP care cycle.
Frequently Asked Questions

Q - What are the symptoms of Atrial Fibrillation?
A - Common symptoms are breathlessness, tiredness, palpitation (awareness of the heartbeat), rare symptoms are light headedness.

Q - What causes AF?
A - There are many possible associated factors, such as high blood pressure, heart disease, thyroid problems. It is associated with getting older, but is also seen in people in their 20s and 30s. In a few patients certain activities or food and drink may bring on AF. It is helpful to try to keep a diary of episodes so that a possible trigger could be identified.

Q - Is it automatic that a person with AF or another arrhythmia will eventually develop heart failure?
A - It does not necessarily mean that because a person is diagnosed with AF that they will go on to develop heart failure. However you may wish to discuss this with your specialist.

Q - I am usually quite active, but have been diagnosed with AF, what is the prognosis for the future?
A - It is worrying when you are diagnosed with a condition after leading an active life, however with AF, if managed and treated appropriately, life can return to almost normal!

Q - What are the main drugs I can be offered?
A - There are a number of different drugs, which will be discussed with you in clinic. You will be offered the correct drug for you by your specialist. AFA have a Drug Information booklet available on the web site or this can be sent to you by contacting AFA.

Q - What is the difference between taking aspirin or warfarin?
A - They work differently. There are clinical guidelines which outline the risks and benefits of each drug. You may be prescribed either drug based on a number of factors including your age and other medical problems.

Q - Can a special diet, or supplements, help my AF?
A - No, there is no medical evidence to suggest a special diet would help AF, however, keeping to a balanced, healthy diet is always sensible.

Q - Why do some patients with AF have a pacemaker fitted? Can it help AF?
A - Some people also have a slowing of the heartbeat (called conduction disease), which means that they need a pacemaker for that problem. If they also have AF, certain pacemakers have some features which may help to prevent episodes of AF. You will need to discuss this with your Consultant.

Q - On the advice of my acupuncture practitioner for an unrelated condition, she detected that I had an irregular pulse rate and suggested I ask my GP to check it out. Although he couldn’t detect an irregular pulse rate he arranged for me to have an ECG. This did show up an irregular heart beat which he said was an ‘ectopic beat’ I wondered if an ectopic heart beat is one and the same condition, or what is the difference, if both relate to an irregular heart beat?
A - Generally, an ectopic heart beat is a small variation in an otherwise normal heart beat; Atrial Fibrillation (AF) is an irregular and often very fast heart beat caused by chaotic electrical activity in the upper chambers of the heart. Both can be detected by an ECG, although in patients suffering from AF there may also be other symptoms such as breathlessness, feeling lightheaded, palpitations, tiredness and chest pains. Please be reassured that an ectopic heart beat is not the same as AF and does not automatically lead to AF. However, if in the future, you experience any other symptoms, or feel unwell, then it is always best to make an appointment to see your GP.

Q - I am due to have a Pulmonary Vein Isolation, generally I am fit, what sort of recovery time should I expect?
A - Usually a few weeks is all that is needed, however, take advice from your Consultant and listen to your own body – don’t be eager to do things too soon.

Q - Is there any advice on how to help yourself during an episode of AF?
A - Some patients find simple things like watching an engrossing DVD, looking at the internet or trying to read a good book, etc. can help to distract the mind. While others find resting or even continuing gently with the activity you were planning best. It is very individual and dependent on how unwell you are feeling. Many patients say they set themselves a time limit after which if the heart rhythm hasn’t returned to sinus in that time, they would seek medical advice. Having that safety can be reassuring.

Q - I have AF which severely limits my mobility; would I be eligible for disability help?
A - Disability allowance is assessed on an individual basis, and so there are no set criteria for an AF patient. It may be advisable to apply for and complete an application form allowing the DLA to assess your needs. When completing the form, explain how your medical condition affects you on a daily basis and what you are not able to do (or only with assistance). There are guidelines sent with the application form and a help line if you need to talk to any one about completing the form.

Either telephone the DLA/AA line on: 08457 12 34 56, or write to: Attendance Allowance/Disability Living Allowance Unit, Warbreck House, Warbreck Hill, Blackpool FY2 0YE.
AFA is often approached by AF sufferers seeking guidance on finding holiday travel insurance. This is not an exhaustive list and AFA cannot accept responsibility for the reliability of the information included in this list.

The Association of British Insurers (ABI) has provided the following list of travel insurance providers who are able to provide insurance for people with medical conditions. Inclusion in the list does not constitute approval from the ABI or the Atrial Fibrillation Association and any insurance provided is the responsibility of the individual concerned.

Most insurance offers are subject to medical screening and restrictions may apply.

**Tesco Travel Insurance**
Case individually assessed based on medical information 0845 3008800

**En Route Assess**
Individually on destination and medical information. 01832 732225

**Free Spirit Travel Insurance**
02392 419080

**J & M Insurance Services**
0500 525550

**Leisurecare**
No cover for over 65s 01793 750150

**MARRS**
0208 366 2222

**Medicover Insurance Services**
Cases individually assessed 0870 735 3600

**MIA Master Travel**
Protection Plan 01268 782745 e: master@miaonline.co.uk

**City Bond**
Cases individually assessed 0870 4446431

**Perry & Gamble**
Single cover to 79, annual up to 75yrs 0208 542 1122

**Age Concern Insurance Services**
Assessed individually via medical screening line. 0845 6012234

**All Clear Insurance Services**
0870 7779339

**Post Office Counters**
Condition must be declared. Case individually assessed depending on medical information and destination. 0800 387858

**Saga Insurance**
0800 0565464

**Travelcare Ltd**
VentureSure 0800 181532

**AA Travel Insurance**
0800 0320891

**Brunsdon & Co Online**
www.brunsdon.com 0117 942 6877

**Freedom Travel Insurance**
www.freedominsure.co.uk 0870 774 3760

**NSP Travel Co.**
01253 596659

**Fish Insurance Brokers**
01772 760055

**Tyser (UK) Ltd**
01268 284361

The Directgov Blue Badge parking map has been significantly improved from February 2008.

The Blue Badge parking map provides information on blue badge parking bays. There will be a large increase in the number of locations featured as well as additional information on accessible toilets, train stations, Shopmobility sites and much more. For further information visit http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG_10038295
12:30 pm on the 12th of September 2007 is not a date I will forget. Having had a thumping chest and butterfly feelings for 13 hours I decided to ring my GP for advice. After catching it all on an ECG and physical examination I was dispatched to hospital where I went back into regular sinus rhythm before being seen. Various tests later and I was diagnosed with Paroxysmal Atrial Fibrillation and sent home.

Six weeks later I again went into A Fib and as it had been happening all night my GP admitted me onto the hospital’s Medical Assessment Unit and luckily the hospital saw me. I was given flecainide intravenously as I had been in A Fib so long and within minutes I was in normal sinus rhythm. Since then I have been on the tablet form of flecainide and low dosage aspirin and thankfully have not been in A fib (to my knowledge) again. I do get odd ectopic beats a few times a day and some other “weird” feelings from time to time. It could be that I am still having some kind of mild AF disturbances and my medication might need a little adjusting but until I see the cardiologist for a follow-up next month I won’t know. The hospital said my follow up would be about 2 weeks after an echocardiogram, but it will be 3 months by the time I go. It is only my enquiring to the hospital as to when my appointment was that I got it then. I do feel neglected, but I hasten to add this is not my GP’s fault. They have been great. My echo was clear and no reason can be found as to why I have PAF I was only 54 when it started, AF didn’t worry me at first and I thought tablets would do the trick.

It was only when I started reading about it and saw the fears, worries and problems other people had (on forums) that I got scared. I also realised for the first time it could be a life-long thing. My GP had already told me that irregular heartbeats/AF were a common heart condition and my only risk was an increased risk of a stroke but I was in the low risk half of that.

“I was so pleased to chance upon Arrhythmia Alliance and then the Atrial Fibrillation Association. I have nothing but praise for them.”

It calmed me, I was not alone and the help, care and information I received was second to none. Now that I realise AF itself is not life threatening if controlled and my only risk is a stroke if left untreated, I am not scared or worried about my condition. I would be lying if I didn’t say that the thought of a stroke, even at low risk doesn’t exactly fill me with joy but it isn’t worth thinking about. I was so pleased to hear about the launch of AFA and want to give it my fullest support. It is only with organisations like this that we can find common ground and work together to find the best ways forward for patients, the medical profession and everyone concerned.

“It is so important to remember that there is life after A Fib and a good one at that.”

Would you or someone you know like to be the proud owner of this 2007 framed Red Arrows photograph signed by the 2007 team?

AFA is holding a ‘secret’ bid, e-mail your bid to info@atrial-fibrillation.org.uk or post to AFA, PO Box 1219, Chew Magna, Bristol BS40 8WB

Minimum bids to start at £15.00. Closing date 31st May 2008. All funds received will go directly to Atrial Fibrillation Association
Gardening for Hearts and Minds
Gardening activities to support rehabilitation and recovery for people affected by heart disease and stroke

Thrive, the national charity that promotes the advantages of gardening for everyone with a disability, is encouraging more people to try gardening as part of their rehabilitation.

Gardening can offer people a form of rehabilitation that:-

• may already be familiar
• can be achieved at home – even in a high-rise flat
• is accessible and affordable
• can be small-scale (a window box) or more ambitious (an allotment)
• offers daily exercise with a purpose and a bonus!

Thrive’s pocketbook ‘Just 30! Gardening for hearts and minds’ is a step-by-step guide of gardening activities for people who have heart problems or have had a stroke. Funded through the Department of Health, the guide will be distributed across rehabilitation units in England. Fully illustrated, it guides you through a series of progressive practical garden activities which can be done at home, such as seed-sowing, potting or weeding, and are suited to improving specific common problems such as strength and mobility. The guide also includes, contacts for further information, tool information plus lots more.

For more details please contact:
Cath Rickhuss
Just 30 Project Manager
Thrive
The Geoffrey Udall Centre
Beech Hill
Reading RG7 2AT
E: info@thrive.org.uk   W: www.thrive.org.uk
Would You Like To Help Raise Funds In Aid Of AFA?

Help AFA to fund raise and have fun by joining in our spring competitions!

Be quick off the draw and win a pair of leather garden gloves signed by Alan Titchmarsh!

Enter our fun time quiz... only £1.00 per entry, to win

All funds raised will go directly to the Atrial Fibrillation Association
Cheques and postal orders made payable to AFA. Competition closing date: 31st May 2008, when winning entry will be randomly selected from all correct entries received.

Puzzles devised by Kevin Stone. Copyright 2008 Kevin Stone

Please send your entry to AFA remembering to include your name and a contact address to which the prize can be sent.
A bumper pack of 2 postcards, 2 photographs and 2 information booklets on the 2006 Red Arrows Team could be yours!

Only £1.00 per entry

All funds raised will go directly to the Atrial Fibrillation Association
Cheques and postal orders made payable to AFA. Competition closing date: 31st May 2008,

Do remember to include your name and a contact address to which the prize can be sent!
MEMBERSHIP APPLICATION FORM

Membership is free, however donations are gratefully received. Cheques should be made payable to AFA. If you are interested in receiving further information, becoming a volunteer or fundraiser, please do not hesitate to contact us.

### PLEASE PRINT -

**Patient**
- **Title:** Mr / Mrs / Miss / Ms / Dr
- **Full Name:** _______________________
- **Address:**
  - ...............................................................  
  - ...............................................................  
  - ...............................................................  
- **Postcode:** _________________________
- **Daytime Telephone no:**
  - ...............................................................  
- **Evening Telephone no:**
  - ...............................................................  
- **E-mail:**
  - ...............................................................  
- **Date of Birth:** _________________________

**Carer**
- **Name:** _________________________
- **Tel:** _________________________
- **Email:** _________________________
- **Address:**
  - ...............................................................  
  - ...............................................................  
  - ...............................................................  

**Patient Diagnosed:** Yes [ ] No [ ]

**Diagnosis:** _________________________

If Diagnosed by whom:
- GP [ ]
- Cardiologist [ ]
- Geriatrician [ ]
- Paediatrician [ ]

- **Name:** _________________________
- **Hospital/Medical Centre:** _______

Tick box if happy to receive newsletters and updates from AFA [ ]

GIFT AID DECLARATION

**Name of taxpayer:** ____________________________________________

**Address:** ____________________________________________

**Postcode:** ____________________________________________

Please tick to allow AFA to claim an extra 28p for every £1 you donate, at no cost to you. [ ]

I want AFA to treat all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. [ ]

I currently pay an amount of income tax and/or capital gains tax at least equal to the tax that AFA reclains on my donations in the tax year (currently 28p for each £). I may cancel this declaration at any time by notifying AFA. [ ]

I will notify AFA if I change my name or address. Please note full details of Gift Aid tax relief are available from your local tax office in leaflet IR 65. If you pay tax at the higher rate you can claim further tax relief in your Self-Assessment tax return. [ ]

Please return to: AFA, PO Box 1219, Chew Magna, Bristol, BS40 8WB  
Telephone: 01789 451 837  
Email: info@atrial-fibrillation.org.uk  
Registered Charity No: 1122442 © 2008

Registered Charity No: 1122442

AFA, PO Box 1219, Chew Magna, Bristol, BS40 8WB  
Tel: +44 (0) 1789 451837
Would you like to meet other AF patients?

Hear case studies presented by AF patients?

Listen to a range of AF medical specialists inform you on treatments and care pathways in the UK?

Then sign up now!

Join AFA Patient Days 2008

June 15th 2008 will see the first AFA Patient Day at the Europe AF Conference in the London Hilton Metropole Hotel.

In October AFA will be hosting their second Patient Day during the Heart Rhythm Congress being held in Birmingham, further details to follow.

Further details are enclosed or contact:
Jo Jerrome: info@atrial-fibrillation.org.uk
Tel: 01789 451837
Hello, my name is Clive; I am 51 years old, a non-smoker and a very occasional drinker and was diagnosed with Paroxysmal Atrial Fibrillation.

One day, I came home after a hard day’s work and as usual, ran up the stairs, got a cold beer out of the fridge as it was summer and knocked it back. Within a few minutes “I was aware of my heart going like a train, beating very rapidly.” If you’ve never experienced anything like this before it can be quite frightening, and I was frightened.

Several hours passed with no abatement and my wife and I became increasingly worried. We were trying to think of why this was happening and why it wouldn’t seem to stop. I had been working with solvents that day and wondered whether that coupled with rushing up the stairs and drinking alcohol could have fuelled this attack. It settled down after around 12 hours and I seemed to be fine again.

“I woke one night and my heart felt as though it was jumping out of my chest.”

They gave me an ECG, put me on a treadmill, I had an ultrasound and a chest X-ray, all tests were normal, we all presumed that this was going to be an isolated incident so I just put it to the back of my mind because you want to. However, a few weeks later, just as I was waking, I was experiencing the sensation of what I can only describe as my heart acting like a piece of blancmange, quivering on a plate. Immediately after I woke up properly and my brain clicked into control, the quivering stopped suddenly and I was back to normal. This continued for several mornings and if my wife put her hand on my chest she could feel this happening.

“I was aware of my heart going like a train, beating very rapidly.”

Looking back, I had been working behind a desk for the last 2 years on a contract where I had little time for exercise. Previous to these 2 years I had kept myself quite fit. I had started exercising again and at the time of my first attack, I believe now I had gone too excessively into exercise again by not building up my fitness gradually. Since researching on the internet etc, I have read that excessive exercise can be a trigger for AF as it can potentially stretch the pulmonary veins which allow the conduction of rogue electrical pulses. I understand these veins are much more flexible when you are younger. I went to see my GP and was sent up to hospital.

When the Senior Registrar came I was given 150mg of flecainide acetate. I was moved into the cardiac ward where my condition remained unchanged for the next few hours. I felt as though I had to sit up for awhile, and in front of the staff, as I just sat up normally, the heart monitor just went instantly back to normal sinus rate, it literally dropped like a stone.

“Sir, you have Paroxysmal Atrial Fibrillation (PAF).”

A half hour later a Consultant Cardiologist came around, looked at the ECG print out and told me “Sir, you have Paroxysmal Atrial Fibrillation (PAF).” He told me to book an appointment to see a cardiologist and they would enlighten me...

“Finding the A-A’s website opened my eyes! At last I had found a source of information and the names of people who could help me fully understand my condition and what to do about it.”

It must have been fate as very shortly after this, a gentleman being interviewed on TV was describing his condition, and it seemed to be what I had. He talked about a procedure he needed but he couldn’t get because of the post code lottery, and essentially his health authority said he was too old at age 61! Behind him there was a little poster propped up that said something like “Support the Arrhythmia Alliance”, something I had not heard of before.
My summary of that first meeting with my electrophysiologist (EP) was that he was a man I had total confidence in and I came out feeling calm and assured. We started off with some drug therapy, a beta-blocker, bisoprolol 5mg each evening with food and a clopidigrel 75mg going to bed to give me protection against a stroke because of my heart acting like blancmange. Flecainide Acetate 150mg I kept in my back pocket always for the onset of an attack of my racing heart, all over the place. Nearly every time this worked within 20mins to bring my heart rate back to normal, but on a couple of occasions it went through the 20min barrier and then couldn’t take any more of the drug for 12 hours.

The usual pattern of AF is that it happens more often and for longer periods as time goes on and I did not want to transgress from PAF into full blown AF unnecessarily if at all possible. Also the muscle of your heart actually remodels itself over time with everything that is going on. The big one is obviously an increased mortality going on. The big one is over time with everything that is

The next thing I knew, I was coming round in my bed with my wife standing next to the bed. This was a very emotional moment and I can remember saying to my wife “did they get all the gremlins?” and she said the Consultant could see why I had been so uncomfortable and he was very confident. He said they had left a mapping probe in my heart, after they had ablated for quite some time to check for further occurrences before removing the catheter.

“I have worked hard in my life and I want to make sure I’m around for as long as possible.”

I felt a little nauseous coming round, but can only describe the immediate feeling as a difference between night & day. A total and instant relief. That night I slept like a baby, my sinus rhythm was 84bpm. I had a little difficulty in breathing in because of the work they had done, but it had already been explained beforehand what I may feel and why this was normal. The following morning a nurse then came along and showed me how to administer a drug called clexane, which turns off the body’s normal mechanism to allow blood clotting. I was also given Warfarin.

I am now half way through a minimum 3 month course of Warfarin and have my INR blood level checked regularly. This is to make sure my blood remains thin enough during this healing time. I feel like a new man. It is just like turning the clock back to an earlier time in your life when you were young and fit. You do not realise what a slow, debilitating slope AF puts you on until you feel the difference afterwards. Touch wood, I have had no ectopic beats at all, my sleep is undisturbed, I’m off all other drugs bar the course of Warfarin, my feet are warm because my heart is beating regularly and I feel 110% better and totally optimistic for the future. If I do have a recurrence I will certainly go and have another ablation if I need to.

“The theatre was like the Starship Enterprise, it was fantastic, nothing like the usual operating theatre.”

The EP and his team have given my wife and me our life back. I cannot thank him enough for his unrivalled attention and total professionalism.

For anyone reading this I would urge you to consider that you have the right to be referred by your GP to a hospital of your choice and I’m sure the vast majority would wish to help you in your cause. However, if their answer is no, don’t just sit there and accept it, you have to be prepared to go the extra mile and insist, if necessary, drawing attention to your plight. I didn’t suffer this situation but in reality we have all heard of the postcode lottery.

You must check how experienced the consultant is, ask how many ablations have they done as this is still an extremely specialised area of electrophysiology. This is your right, you are entrusting your life to them and you do not want to be a guinea pig. If they refuse to tell you how many times they have done this operation just walk away.

Finally, if only someone in the government would recognise a national standard process for treating AF they would drastically reduce the number of stroke victims in the UK and in turn seriously cut spending on post stroke treatment. This of course means they can claim they have achieved something!
Join AFA, membership is free and provides you with news updates and regular information. Complete the enclosed membership form on page 12.

Atrial Fibrillation Notice Board
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“Af is a very lonely condition so I think coping can be done by communicating with others, it can be very reassuring to hear other people feel exactly the same.” AF Notice Board

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What is atrial fibrillation?

Atrial fibrillation (AF) is the most common sustained heart rhythm abnormality in the UK. Patients affected by AF have disorganised electrical signals in the upper chambers of their heart, which lead to an irregular and rapid heart beat. Common symptoms of AF include shortness of breath, dizziness, fatigue, and palpitations. The severity of these symptoms can range from relatively mild to very severe, with some individuals being completely debilitated. In addition to these symptoms, patients with AF face a 3-to 7-fold increased risk of stroke, which can be fatal. AF is a significant challenge for the healthcare system in this country, accounting for 96,000 hospital admissions and consuming 1% of the total NHS annual budget. AF falls into one of three categories that describe the progression of the disease, ranging from occasional episodes to the complete absence of a normal heart rhythm:

1. Paroxysmal AF – multiple episodes that cease within 7 days without treatment;
2. Persistent AF – episodes lasting longer than 7 days, or less than 7 days when treated;
3. Longstanding persistent AF – continuous AF with more than one-year duration.

How is atrial fibrillation treated?

Drugs are currently the most usual treatment for AF, and have the aim of alleviating symptoms and reducing the likelihood of stroke. Commonly prescribed medicines include warfarin, sotalol, flecainide, amiodarone, and beta blockers. For many patients, these drugs do not reduce symptoms or provide side effects that may actually prove to be worse than the symptoms arising directly from the disease. Physicians may also elect to perform an electrical cardioversion, a procedure in which high-voltage current is delivered through metal paddles positioned on the chest wall. Cardioversion will often “shock” the heart back into its regular rhythm. For patients undergoing surgery for other types of heart disease, including coronary surgery or mitral valve repair, an additional procedure called surgical ablation may be performed to treat AF. The surgical procedure involves making multiple, strategically placed incisions, or lesions, in the upper chambers of the heart. These lesions are intended to isolate and stop the abnormal electrical impulses that cause AF, thereby restoring the heart to normal sinus rhythm (NSR). For many patients not needing surgery, a less-invasive procedure called catheter ablation is now thought by many specialists to be the most appropriate treatment. In 2006, the National Institute for Health and Clinical Excellence (NICE) issued a guidance document that supports catheter ablation for patients with AF who are not adequately treated with drugs. According to the NICE guidelines, catheter ablation can successfully cure AF in up to 80% of patients and reduce mortality by more than 50%.

Who is eligible for an ablation procedure?

In May of 2007, a number of internationally-recognized organisations got together and jointly issued an expert document on the optimal treatment for AF. The consensus statement found that catheter ablation is appropriate when patients continue to have AF symptoms or intolerable side-effects despite undergoing drug treatment. They also concluded that catheter ablation may be considered as the “first line” option in some patients. In the UK, the local Primary Healthcare Trust manages treatment decisions for AF patients. A person with questions about their symptoms and treatment options should consider asking their General Practitioner for a referral to a heart rhythm specialist (Cardiac Electrophysiologists).

What happens during a catheter ablation?

Techniques for AF ablation have rapidly evolved since first reported as a curative approach in 1994. Nearly all ablation approaches use radiofrequency (RF) energy to generate heat, which cauterises the cardiac muscle and blocks local electrical activity by creating a “lesion”. A hallmark of all AF ablation techniques is the electrical isolation of one chamber of the heart, the left atrium, from the pulmonary veins that supply it with...
What makes the new system different?

This system was designed to make AF ablation procedures safe, efficacious, and cost-effective – while also reducing procedure time and complexity. In addition, the system was developed to be able to treat all types of AF, including paroxysmal, persistent, and long-standing persistent (also known as chronic). We have found that the safety profile of the system is likely to reduce the overall risk of AF ablation and in addition a larger population of AF patients should now be eligible for the procedure. Also, since the Ablation Frontiers system has a relatively short learning curve and is not dependent on expensive, complex tools – such as 3D mapping or remote steering systems – several centers across the UK have quickly adopted the technology and this has helped significantly to increase their volume of AF ablation procedures. With broader adoption, we believe this technology along with other developments offers the potential to increase the capability of the NHS to offer ablation to more AF patients within the UK.

Are all UK patients eligible for catheter ablation of AF?

Since the procedure of catheter ablation is still considered a “complex” procedure and is performed only by highly-skilled specialists in larger medical centers, not all AF patients are currently offered the option of ablation. In the UK, the local PCT determines if or when a patient can be approved for the procedure. Although AF is the most common heart rhythm disorder, there are fewer than 50 electrophysiologists in the UK routinely performing catheter ablation for AF. In addition, patients with AF are frequently misdiagnosed because many General Practitioners lack the expertise to correctly diagnose the disease. All NHS patients are entitled to request a referral to a heart specialist, such as an electrophysiologist.

Despite this option for referral, some patients may find that the ablation procedure is not offered in their local clinic or that their PCT does not consider them eligible for this treatment. Some patients that have been denied the option for ablation have successfully applied for a funding transfer to another PCT that will perform the procedure. If approved for an AF ablation, patients should receive their treatment within 4-5 months, per the recent NHS “18 weeks delivery” initiative (www.18weeks.nhs.uk).

Are there any new developments in catheter ablation of AF?

Towards the end of 2006, a promising catheter ablation system was introduced to the marketplace by the company Ablation Frontiers. Papworth Hospital was one of the first three European centres to collaborate with Ablation Frontiers on the development of this new and exciting technology. Clinical investigations, along with technology and design optimisation, commenced at Papworth Hospital in June 2005. Since then, several studies have demonstrated that the technique has excellent medium term efficacy and a very strong safety profile – nearly 1,000 patients have been treated with this system worldwide without any significant reported complications.

At Papworth, we have been impressed with both the improved technique and the promise that this new technology could allow for treating more patients with AF.
How does the new system work?

The system consists of a novel RF generator and three anatomically-designed catheters that facilitate ablation in certain areas in the heart: PVAC for the pulmonary veins (Figure 2a), MASC for the left side of the septum (Figure 2b), and the MAAC for the left atrial body (Figure 2c).

The catheters have multiple electrodes which can both map and ablate the target areas of the heart. A unique feature of the system is that the electrophysiologist can select any or all of the electrodes to ablate simultaneously over a large area, thereby tailoring their approach to the needs of each patient. It seems likely that the relatively large catheter surface area, or “footprint”, reduces the risk of complications such as perforation or tamponade. The Ablation Frontiers GENius generator also offers the ability to tailor lesion depth by using different ratios of unipolar and bipolar energy. With a larger proportion of unipolar RF, the cardiologist can achieve greater depth for thick areas of the heart like the septum.

For thinner areas like the pulmonary veins, cardiologists can choose a larger proportion of bipolar energy. Another unique feature of the system is the highly efficient RF application required to create lesions, typically performed with just 3-7W and limited to maximum of 10W. The ability to tailor lesion depth, and the highly efficient delivery, contributes to the safety profile by reducing the likelihood of ‘collateral damage’ to other anatomical structures.

Has the new system been proven superior to current approaches?

Since the system is still fairly new, long-term results are still being evaluated. At the 2008 American College of Cardiology Meeting held in Chicago we presented the first published data for patients treated with the Ablation Frontiers system. In a multi-center study of 53 patients with long-standing persistent AF (also known as chronic AF), 80% of patients were in normal sinus rhythm after 6 months, having received 1 or 2 ablation procedures.

A single-center registry published at the Boston Atrial Fibrillation Symposium reported that 80% of patients with paroxysmal AF were free of symptoms after 6 months following a single ablation, with the average procedure lasting only 1.5 hours. These results, combined with our experience at Papworth, have led us to believe that the new system offers numerous advantages over current techniques for several of our patients. For more information about the Ablation Frontiers system, you can visit the company’s website: www.ablationfrontiers.com.

References

The full document with complete references can be obtained from AFA or downloaded from the AFA website.

www.atrialfibrillation.org.uk  info@atrial-fibrillation.org.uk
Register now for the
International Atrial Fibrillation Registry

The European Association for Cardiothoracic Surgery (EACTS), in conjunction with Dendrite Clinical Systems, has recently launched the International Atrial Fibrillation Registry (IAFR).

The key objective of the IAFR is to capture data and report patient outcomes following surgical treatment of atrial fibrillation, and publish the findings in a comprehensive report. This will be achieved through the collection of data at the individual patient level, which can then be used to track individuals and cohorts of patients. The report will be made freely available to all contributors.

If you or your colleagues are interested in registering please complete the on-line registration form at:


Alternatively, email:

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or phone:

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