AFA welcomes the recent decision by NICE to recommend approval of dronedarone as a second line treatment option for Atrial Fibrillation, reversing its previous draft guidance published in December 2009.

As many of you will recall, on Christmas Eve 2009 NICE published its first Appraisal Consultation Document (ACD) which had recommended NOT approving the innovative new medication. At this point the AFA team cut short their festive break to seek advice from the Trustees and opinion from members.

When it soon became clear that up to 40,000 AF sufferers in England and Wales would be affected by this negative ruling, and that Committee D, representing NICE, had not had the benefit of a full panel of patient and arrhythmia experts present when considering dronedarone – the first new anti-arrhythmic medication in twenty five years to come to market, AFA responded.

With only four weeks available, and Christmas and New Year within this, the AFA team had to work fast in order to seek a second review by NICE and ensure that this time all ‘expert’ members would be available to attend. Knowing that a reversal of an ACD was rare but possible, AFA called upon members, and your response was overwhelming!

The first three weeks in January were packed with activity! An information letter was sent to all members calling upon their support by writing to NICE, their MP and the Minister for Health. This was followed by a request to medical members to sign an open letter to NICE – within two weeks almost two hundred signatures had been added! Meetings with representatives from the House of Lords and House of Commons were held and a cross party EDM was tabled with questions being raised in both the House of Commons and Lords. By late January John Maples MP and Paul Keetch MP jointly hosted a Parliamentary Stakeholder Investigation meeting to enable patients, carers, clinical leaders and nurse specialists to vocalise their concerns about negative

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“Letter signed by 191 Healthcare Professionals”

Dronedarone to be Approved!
guidance, discuss the clinical and cost effectiveness of dronedarone and consider arguments about innovations in healthcare.

Along the busy route obstacles were met but overcome, including members who had been told by NICE that responses could only be accepted via the NICE website. AFA approached NICE explaining the restrictions this placed on many AF patients and carers. As a result, arrangements were made and both Sir Andrew Dillon, Chair of NICE and Andrew Burnham, Secretary of State for Health, assured us that letters would be accepted.

“The campaign had brought together all members of the ‘AF community’ and raised awareness of Atrial Fibrillation, its symptoms, limited management options and prevalence to the public, the government and decision makers.”

The second review meeting was scheduled for February 22nd, and AFA held its breath to see if an ‘expert panel’ would be invited to attend. The answer was YES, with representatives from primary care, a heart rhythm specialist, cardiothoracic surgery and two patient representatives being invited to attend.

Held on 24th February, evidence from the dronedarone trials was again reviewed but this time benefiting from the presence of a fully represented ‘expert’ panel. Professor Peter Clark, Chair of Committee D, commented on the responses received and highlighted that in total more than 1300 individual comments had been sent to NICE following the first ACD!

On 30th March, NICE published the 2nd ACD — and was now recommending the approval of dronedarone for certain groups of AF patients! Together we had persuaded NICE to review and amend!

NICE’s Appraisal Committee recognised that dronedarone can and should occupy a currently vacant place in the care pathway, and that for a large and growing number of patients it could represent the only treatment option open to them.

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When interviewed, CEO, Trudie Lobban MBE, said: “I would like to thank all the patients, carers and clinicians who took time to respond to the first Appraisal Consultation Document by NICE. Your replies ensured that a second review was
An overview of NICE’s role in the UK

Many people are used to reading about NICE in the media, usually in the context of the availability of new medications. By understanding how NICE works patients and relatives can see what role they can play within its processes to support NICE in making appropriate decisions which ensure suitable options are available.

About NICE

NICE stands for The National Institute for Health and Clinical Excellence and is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. It is an independent organisation. It was set up in 1999 to evaluate medications, treatments and procedures and decide whether they should be available on the NHS in England and Wales. It is important to remember that Scotland and Northern Ireland have separate organisations to make these decisions.

The aim of NICE is to determine which medications, treatments and procedures are clinically effective and cost effective and to ensure people have equal access to them, regardless of where they live. This process was intended to do away with the ‘postcode lottery’, which denied drugs or treatments to patients on the basis of where they lived.

What NICE does

NICE has two main functions:

1. To provide guidance on the NHS’s use of specific new treatments following clinical and cost-effective assessments called Single Technology Appraisals (STAs).
2. To provide guidelines on how particular conditions (eg Atrial Fibrillation) should be managed in the NHS (including all aspects of care from prevention and diagnosis to treatment and follow-up care).

In making a decision, NICE considers whether a treatment benefits patients, will help the NHS meet its targets (for example, by improving heart disease rates) or provides value for money (is cost effective). Once NICE issues guidance, NHS trusts and primary care organisations are required to make the drugs or treatments available.

In making a decision NICE asks for expert opinion and scientific evidence from medical and other health professionals (such as senior consultants in their field), patients and patient organisations (such as the AFA, which is why your views and experiences are so important to us!) and industry.

How NICE works

The Department of Health (for England) and the National Assembly for Wales decide what medications, treatments and procedures should be submitted to NICE. However, anyone can suggest a topic for NICE to review by simply logging on to the NICE website (www.nice.org.uk). The website also lists the topics (such as new guidance on treating a particular condition) that NICE is currently considering, as well as the different ways patients, carers and members of the public can get involved in the process, either by serving on a committee or submitting their opinion on a particular topic.

NICE divides its guidance into three main areas:

Health technology (specific medicines, treatments and procedures), clinical practice (how doctors and nurses should treat particular conditions) and public health (preventing illness and health promotion).

NICE has launched a guidance webpage for patients and the general public.
To read more please visit the NICE website page: http://www.nice.org.uk/patientsandpublic/index.jsp

STOP PRESS..... Sandra Harman is entering the Jane Tomlinson York 10km on 1st August. When husband Martin was diagnosed with AF at the age of 33, it changed our lives. AFA provided us with much needed help, information and support. Please help me to support AFA by donating either online at: www.justgiving.com/sandraharman or by cheque to AFA.
Coming to terms with AF long after successful treatment
Maggie’s Journey

I was first diagnosed with AF in 2003 post operatively. I’ll never know if the surgery/anaesthetic triggered the AF though I could say with hindsight I had felt fatigued a lot of the time, breathless on stairs.

Initially I was prescribed Flecainide, though I found this hard to tolerate developing an itchy rash on my limbs. Eventually I was switched to Propafenone, needless to say the rash disappeared but new side effects presented themselves. Finally I settled on Sotolol.

It was a whole new experience adjusting to a suitable medication over what seemed an endless period of time. No doubt we all have a similar story to tell. Fatigue and breathlessness were part and parcel of every day life, although it was only now I was really aware of any flutters and palpitations.

“**I was terribly frightened**”

In early 2007 I had my first catheter ablation procedure. I was terribly frightened and there was simply nowhere to turn to for support or reassurance. I wish AFA had been operational then with their helpline! I really wish I had been able to turn to someone informed and willing to listen in order to work through my fears during those early days. I do urge everyone to use the support lines which are now in place. Reassurance is like getting a great big hug and saying everything is alright.

As the year wore on it became clear the ablation had failed and a second one was scheduled for early 2008. My recovery time was slow and I eventually returned to work four weeks later though at a slow, steady pace. It is easier to look back and understand more than I could at the time. I can now see that so many of my fears were simply a fear of the unknown. I should have asked more questions, but that is easy to say now especially when AFA is here and able to offer information in a friendly manner. My own experience back then was far different. I strongly feel that I did not receive the reassurance I so desperately needed from my GP or practice. Perhaps he too did not know, but when he simply advised me to bring forward my specialist appointment after the procedure I felt myself falling into a spiral of despair and worry. So much so that even when my Consultant reassured me that my heart was at long last in sinus rhythm and that the pulmonary veins had been successfully ablated, I felt no relief or joy.

I firmly believe that I would have benefitted from being managed throughout by a specialist arrhythmia team and if this had been possible I would have felt less desperate and alone. All concerns I have now I direct to my specialist and I shall forever remain indebted to him for his patience and reassurance.

There is no quick cure, but I would urge anyone to not waste their consultation times as I felt I did in those early days. I know I should have asked questions, discussed what I might look to expect in order to understand how to manage what I might face. I have found the whole experience has overwhelmed my life in a way I had not known before. It was and still is difficult to deal with at times.

_Maggie, London_

You can read more AF Case stories on the AFA website, or have opportunity to meet and talk with fellow AFA members at the AFA Patient Day on Sunday 3rd October at the Hilton Birmingham Metropole

www.atrialfibrillation.org.uk  info@atrial-fibrillation.org.uk
New Research Highlights Further Significant Risk Factors Linking AF and Stroke

People who suffer from Atrial Fibrillation are often at an increased risk of stroke. Thinning the blood can reduce this risk, but each individual must rely on being appropriately assessed and advised on the most effective medication for their own needs.

By looking at large groups of people with AF, data has been collated which can help to indicate those most at risk of strokes. In the past this information has been used to inform clinical guidelines which help doctors and specialist nurses to make individual assessments. NICE (National Institute for Health and Clinical Excellence) published the Stroke Risk Stratification algorithm in its guidelines on AF management:

- **Critera**
  - C Congestive heart failure: 1
  - H Hypertension – treated high blood pressure: 1
  - A Age 75 years+: 1
  - D Diabetes: 1
  - S Stroke or previous TIA: 2

Some patients, such as those with artificial heart valves and previous rheumatic fever, will need anticoagulation. Others can be evaluated using the CHADS2 system. If a person’s total score is two or more the patient should take Warfarin unless there is a good reason for not doing so (e.g., allergy or a history of previous bleeding problems).

This system is simple to use, but research has shown that it fails to consider many other factors which may lead to a recommendation to anticoagulate, most usually with Warfarin. A person’s annual risk of stroke rises from under 2% in a year with no risk factors to over 10% per year with a CHADS2 score of five or six.

Research undertaken by Professor G Y H Lip at the Birmingham Centre for Cardiovascular Sciences, City Hospital, Birmingham, and by colleagues in the Department of Cardiology, Maastricht University Medical Centre, in The Netherlands, has shown that in order to further reduce the risk of stroke – in particular in the group who would have only scored a ‘zero’ or ‘one’ in the CHADS2 table, and yet who went on to suffer a stroke, identified crucial factors which had otherwise not been widely considered in current assessment systems.


In this system patients are determined to be at ‘low’, ‘moderate’ or ‘high’ risk of stroke. More recently, this has been further developed in the ‘CHADS2’ score which is now increasingly referred to, as a simple and easy way to assess stroke risk.
The researchers analysed data for patients diagnosed with AF in the Euro Heart Survey who had been discharged from hospital without anticoagulation and for whom, one year later, stroke outcomes were known. In this analysis, the patients’ average age was 66 years, and almost 60% of them were male, with 40% being female. The team used evidenced-based UK NICE guidelines on AF management and tested them against other tools including a CHADS2 and the Framingham Study risk assessment. Evidence gathered in this way showed that up to 60% of patients were classified with an ‘intermediate risk’, which in real terms meant that most would not have been suitably anticoagulated as doctors would be uncertain which is best given that guidelines say ‘Warfarin or aspirin’ for this category. However, increasing evidence shows that Warfarin is actually better than aspirin in such patients.

The researchers noted that high blood pressure was the most prevalent stroke risk factor (67.3%), followed by coronary artery disease (38.4%). Review of the data lead to the researchers finding significant additional stroke risk factors and developed two new ways of evaluating risk. These are slightly more complex than CHADS2 but still very easy: the CHA2DS2-VASc Scoring System as shown in the tables below:

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>Congestive heart failure/Left ventricular dysfunction</td>
</tr>
<tr>
<td>H</td>
<td>Hypertension —treated high blood pressure</td>
</tr>
<tr>
<td>A2</td>
<td>Age 75+</td>
</tr>
<tr>
<td>D</td>
<td>Diabetes</td>
</tr>
<tr>
<td>S2</td>
<td>Stroke/TIA/TE (thromboembolism)</td>
</tr>
<tr>
<td>V</td>
<td>Vascular disease — corona artery disease (CAD), myocardial infarction (heart attack), peripheral artery disease (PAD), or aortic plaque</td>
</tr>
<tr>
<td>A</td>
<td>Age 65-74</td>
</tr>
<tr>
<td>Sc</td>
<td>Sex - Female gender</td>
</tr>
</tbody>
</table>

In the CHA2DS2-VASc Scoring System above, high risk equals a score of two or greater.

The flow chart below is an additional way of identifying who should be on anticoagulants.

Having one combination risk factor would make someone at intermediate risk and so probably benefit from Warfarin. This is further supported by research in the Birmingham Atrial Fibrillation Treatment of the Aged Study (BAFTA), which showed that ‘Warfarin is superior to aspirin in people aged 75 and older, and that there was no evidence to suggest any difference in major bleeds with an INR of 2.0–3.0 and 75 mg of aspirin in an elderly AF population in primary care’.

If you’re not on an anticoagulant, but this new schema suggests that you should be, it’s worth considering a re-assessment from your doctor and highlighting CHA2DS2-VASc Scoring System to him or her.

Please contact AFA to order your AFA Fact Sheets on Warfarin Therapy, Warfarin and Medication and Warfarin and Diet.

Since I married my husband nearly ten years ago he’d always said ‘when I’m 60 we’re going to sell the business and party’. Two years ago he had a stroke, just three weeks before his 60th birthday and the nearest I got to partying was when I took cream cakes in for the nurses on the stroke ward where my husband was on MY birthday! That is about the only very small joke I can make about the last two years. Oh yes, that and a dear friend’s hubby buying me a stethoscope so I could listen to everyone’s heart properly! I couldn’t even find the heartbeat of her dog and horse with it but by ear I can hear anybody’s. In fact I’m very nearly a doctor…

The stroke was caused by an undiagnosed heart arrhythmia. I say undiagnosed but that’s not strictly true. Just a few weeks before it happened we were lying in bed watching TV and I had my head on his chest. I said to him ‘God, your heart’s all over the place’. I never gave it another thought until three weeks later when the doctor in A&E asked if he had any known heart problems. I try not to go down the road of what ifs.

1st March 2008 at 1:45 – we had just got back from shopping and I called upstairs to James. He didn’t answer which was nothing unusual. The second time I called I heard a grunt and felt scared, the third time I felt panic and just knew. I ran upstairs and he was leaning over the banister, face lopsided, incoherent. I didn’t need the F.A.S.T campaign to know he’d had a stroke. Ten minutes later we were in an ambulance with the blue light and sirens on. I didn’t know anyone who had suffered a stroke and knew nothing about causes, recovery etc.

I now know more than I ever wanted to know and that goes for AF too. We were booked into an hotel in London the following weekend for our birthdays, theatre, dinner. I remember wondering whether he would be well enough for us still to go, how ignorant was I? He was in hospital for 12 days. He didn’t really speak to me or anyone else much for three months but by comparison I spoke non stop to stroke and heart consultants, their secretaries to get reports, the GP, physios, neuro physios, speech therapists, INR nurses and our PCT. I filled forms for Disability Allowance, SSP and insurances. We were perpetually in one hospital or another.

Indoors, I spent all day, every day on the internet researching stroke and AF and what could be done. This led me to the AFA and thank God it did. There were times when if I’d met myself in the street I wouldn’t have recognised myself. Frustrating wasn’t the word. I shopped till I dropped for the few minutes buzz it gave me. Every phone call from well meaning friends – and they were well meaning and I shall be forever grateful for their support, revolved around strokes and heart beats. I was given one outstanding piece of advice from an ex nurse friend and that was ‘don’t look any further than tomorrow and break the future into bite size pieces’. I was frustrated, short tempered, always on the verge of tears. I filled the diesel car with petrol. The only bit of peace I had was for those first few seconds when you wake up in the morning before your brain kicks into gear and you remember quite what a pile of rubbish your life has become.

I always thought and still do think that the stroke, although not life threatening in our case was the worst of the two things that happened.

Someone said right at the beginning that it takes a year, maybe 18 months to get over a stroke. I decided then and there that I would write off the next year and it did take a year for my husband to return to work. We are now one cardioversion, three ablation procedures and two years down the line. Life is not the same and it never can be. I always thought and still do think that the stroke, although not life threatening in our case was the worst of the two things that happened.

The AF could be dealt with and hopefully this time it has been, but a stroke affects the brain and that tiny piece of brain will never recover. A period of mourning is required because in essence you have ‘lost’ the person you once had. This is a fairly mild account of an extremely trying time that need not have happened. The Know Your Pulse Campaign is vital to avoid the likelihood of a stroke. We could have saved ourselves so much and we are one of the lucky ones.

Jenny, UK
At the end of 2009, national newspapers highlighted the advent of a new heart procedure in which AF patients, who were previously assessed as at high risk of suffering a stroke, undergoing a surgical procedure to implant a device which would reduce their stroke risk to a similar degree as warfarin drug therapy. For some patients this is very attractive because warfarin has caused problems for them, or because it is difficult to control or as a result of excessive bleeding.

The commonest cause of stroke with AF is clots forming in blood that stagnates in a blind ending pocket in the left atrium called the appendage. The new procedure involves implanting a permanent umbrella like device into the patient’s heart to block the entrance to the appendage and thus stop harmful blood clots entering the blood stream. Currently in the UK only a few specialist centres are able to offer this, but for individuals who are unable to tolerate current blood thinning medication, referral for assessment is possible via your own GP or specialist.

AFA has received many enquiries regarding this new procedure. Professor Richard Schilling, Consultant Cardiologist at St Bartholomew’s hospital and Trustee of AFA, who has performed the surgery, explains; “According to a US/European study* of 700 patients over five years, the Watchman device has been shown to be as protective against strokes as warfarin. In AF, the irregular heart rhythm can cause blood to stagnate and form clots, in particular in an area of the heart called the left atrial appendage (LAA). This area is approximately the size of a thumb and looks like a small pouch on the top of the heart. If a clot forms, it can increase a person’s chances of having a stroke or other related problems.

The new procedure is minimally invasive, involving the device being inserted into the patient’s heart using a flexible tube (catheter) which is placed inside a vein in the upper leg. It is then implanted permanently in the left atrial appendage - effectively closing it. Recovery is usually quick with a patient only needing to stay in hospital overnight. There are risks with the procedure although these are rare and include cardiac perforation and bleeding, needing repair and displacement of the device requiring surgery to retrieve it.

The new device is particularly suited to AF patients who have been unable to safely commence or continue anti-coagulation therapy. However the study proving the devices effectiveness did require patients to be on warfarin for 45 days after the implant before it was proven that it was working properly.”

*The US/EU study of patients who have received the WATCHMAN device is entitled Protect AF and was published in The Lancet in August 2009 (Volume 374, pages 534 to 542)

Professor Richard Schilling Consultant Cardiologist, St Bartholomew’s Hospital

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**Fundraising can seem so difficult, time consuming and hard work.**

This has to be the ultimate arm chair fundraising opportunity!

Simply gather friends and challenge them to the ultimate ‘Let me reveal your age’ with a donation for each correct answer you reveal!

1. Pick the number of times a week that you would like to have chocolate (more than once but less than 10)
2. Multiply this number by 2
3. Add 5
4. Multiply it by 50
5. If you have already had your birthday this year add 1760, If you haven’t, add 1759
6. Now subtract the four digit year that you were born

You should have a three digit number...

The first digit of this was your original number (i.e., how many times you want to have chocolate each week)

The next two numbers are YOUR AGE!

Sit back and pass the hat round for AFA! Who knows, promise to keep all answers confidential and more may be donated!
Fundraising in 2010

Working hard 365 days of the year AFA ensures every penny counts, however we do need your continued help.

Perhaps hold a coffee morning, raffle or enter a sponsored event? Small or large, your help is valued and does make a difference.

Fundraising Events:

Michelle, an AFA member, is raising funds for AFA through Just Walk. If you would like to sponsor Michelle please contact info@atrialfibrillation.org.uk

Could you raise money for AFA? Just Walk could help. Just Walk is a fantastic sponsored UK charity walk for anyone wanting to raise money for the charity of their choice. Take on the challenge of 10, 20, 40 or the BIG 60km Walk and have a great day out in the spectacular South Downs. This fundraising event is open to all charities and anyone who is keen to get active and walk for charity!

This charity walk offers enthusiastic walkers the chance to experience a breathtaking walk over the picturesque South Downs in West Sussex.

Website: www.acrossthedivide.com/just-walk

Donations:

THANK YOU to all members who have so generously donated or raised money for Atrial Fibrillation Association. From £2.00 to £1000.00, every penny really does make a difference.

~ Ian P ran a musical evening with fellow piano students and sent a cheque for £147.70 to AFA!
~ Generously members have donated towards the postage and materials for information received.
~ Bob and June were involved in making a training film for employees of a company developing treatments for AF, and both agreed for their honoraria to be given to AFA.
~ John Laing (his employer) applied to John Laing (his employer) for the company’s annual charitable grant to be donated to AFA. Brilliantly, his application was successful and AFA received a cheque for £1000.00!

Thank you Adam for thinking of AFA and thank you John Laing for your generosity!
As a 6'4" heavily built former rugby player I had always thought of myself as being pretty indestructible. I had never spent a single night in hospital with my visits largely being to the A & E for an assortment of sports related injuries rather than any illness of note or concern. I am very happily married to Louise and we have two gorgeous daughters, Emily and Megan. In my professional life I have enjoyed success in a demanding job that frequently exposes me to potentially stressful situations, but I enjoy the work thoroughly. Until 2009, life was good. Very good in fact – or so I thought.

In the spring of 2009, at a time when, perversely, I had finally started to take more exercise and had started to lose the weight that had bothered me for some time. Buoyed with initial success of losing 2½ stone, I attended a fairly routine appointment with my GP. He was pleased with what I was doing and suggested that I undergo an ECG which was performed later that day. I was delighted when the practice nurse returned from showing the Doctor the ECG printout to tell me that everything was fine.

However, by the end of April I was suffering from shortness of breath when out walking any distance let alone the five or six miles that I had regularly been enjoying. I was not sleeping at night and generally felt unwell. On 6th May I returned to my surgery and was sent to the hospital for a chest X-ray. By Friday 8th May however I had to book another appointment with my GP when I was eventually told that he thought I was suffering from Atrial Fibrillation which was then explained to me. I felt vulnerable, scared and worried for myself and my family. There was no history of heart problems in my family and I have never smoked although my alcohol indulgence at weekends was admittedly on the high side. Above all however I was shocked that in just seven weeks I had gone from having an excellent ECG result to a position whereby my heart was failing. It was then that the bomb was dropped.

My GP explained, rather sheepishly and reluctantly, that the earlier ECG, in fact, was not OK. It clearly showed that I had been in AF as early as 20th March and during the intervening seven weeks when I had received no treatment I had been at an extremely high risk of a stroke or heart attack. My GP explained that I would be referred to a cardiologist. I was prescribed beta blockers and aspirin and basically sent home to wait for the Consultant's call. I am, however, luckier than most in that I have two sisters-in-law who are, for want of a better expression, "in the trade"; one a Consultant Anaesthetist who specialises in heart surgery and has written textbooks on the subject. She offered immediate sound advice but was too far away. Closer was Liz, a senior arrhythmia heart specialist nurse just twenty miles away. How lucky is that? Liz came to our home the next day armed with a portable ECG. She confirmed immediately that I was in AF and offered to show the read out to her consultants at work on Monday.

She calmed my tortured nerves

Liz gave me sound advice that day. She explained more about AF. She calmed my tortured nerves. She confirmed that the beta blockers and aspirin would assist for now but advised that I should be on Warfarin and so I waited anxiously for Monday to arrive. The 11th May 2009 is a day that I will never forget.

I managed to get to work, but frightened everyone at our pleasant office with my grey complexion and general lethargy. I could hardly climb the stairs to my office and my colleagues spent more time coming into my room, checking that I was OK, I was really struggling. I had never felt so ill. I had never been so frightened. By 3:30 I packed up and went home. Little did I know that it would be more than three weeks until I saw my desk once more. I presented with my symptoms at the local hospital. I left two extremely worried children; the elder of whom was starting her GCSEs the very next day. The hospital was fantastic. I was admitted and conveyed to the high dependency ward of the cardiac unit. If I had any delusions about the seriousness of my predicament they were quickly dispelled. I had strict orders to remain in bed, wired to a HR monitor. As I looked around the ward I could see the other five patients monitor readings. 58, 72, 68, 84 and 81, Mine was peaking at 158 and all I was doing was lying there!

Over the next week I was subject to a myriad of tests and assessments. The condition was fully explained together with the treatment. And I was introduced to Warfarin. I already knew that a form of this drug was used as rat poison. Little did I think that I would come to rely upon it and to become acutely aware of another reading that had previously been anathema to me – INR!
“At 49 I have no desire to remain in AF”

By the time I was discharged I had accumulated a mountain of information and an acute understanding of what lay ahead. In September I presented for a cardioversion. It didn’t work and I was introduced to Amiodarone. I read all I could about this drug and its side effects. If I had any reservations about submitting to this prescription they were dispelled when Liz informed me that she would have no hesitation in taking it if she ever found herself to be in AF. If it’s good enough for Liz, it’s good enough for me. I trust her advice implicitly.

The wait for another cardioversion was excruciating and I prayed that it would be successful. However, despite several attempts and the Amiodarone, it was unsuccessful. At the time of writing I am awaiting an appointment with a new consultant. I do hope that his proposed treatment will make significant headway. It is nearly a year since original diagnosis and actually more than a year since the symptoms were first present. My current medication, Amiodarone, Perindopril, Bisoprolol, Warfarin and a soluble Aspirin daily keeps me feeling OK. But this is far from ideal.

I am told that the consultant is a leading expert in these kind of disorders and I have faith in him. The appointment however can not come too soon. At 49 I have no desire to remain in AF, dependent upon beta blockers and Warfarin for the rest of my life. I am determined that I will return to sinus rhythm.

Personally I feel well although my exercise has fallen off and I need to tackle that. I did want to celebrate my 50th birthday this summer by cycling around the coast of Wales. I would prefer to do that without AF and am currently not fit enough, however it does remain an ambition that I am determined to fulfill. I look forward to receiving the AFA newsletters and feel that I have become a member of an exclusive little club. A club that no one wants to be a member of but one that I feel secure in because of its support. Recently I read of the experiences of a famous English rugby player, Bill Beaumont. Bill was diagnosed with AF at the same age as me. We are of similar build. I am told that it took eight years before Bill was out of AF following an ablation. His story was warming, comforting. That said I do not want to wait eight years before I am out of AF.

“IT never crossed my mind I would end up as a heart patient. I had thought I was indestructible”

It never crossed my mind that I would end up as a heart patient. As I said earlier, I had always thought that I was indestructible. This whole experience has taught me that you can never take anything for granted and the support of my family has been unwavering and fantastic.

“I want to celebrate my birthday cycling around the coast of Wales”

And I am grateful for all the medical support that I have received so far with the exception of my initial misdiagnosis by my GP. That said, the GP surgery have been great since and I remain their patient. They have held up their hands and been fully honest with me in confirming that there was a misdiagnosis. I have accepted their apologies and moved on. They made a mistake but fortunately all that resulted in was a delay in my treatment. It was not their fault that I ended up in AF after all.

I hope that my story can be of some use to others. I have experienced the full range of emotions through all this. I was pleased to originally be told my ECG was perfect. Worried when I started to become ill. Terrified to be informed that I had a heart condition. Relieved to be admitted to the care and consideration of the hospital. Angry that my GP had missed the diagnosis. Happy to be undergoing treatment. Frustrated at how long it is taking. Comforted by the stories of others. Grateful for the continued expertise of the medics. Grateful for the support and love of my family. Things could be worse. They will soon be better.

David E, AF Patient

Glossary: What’s that then?

Bombardeed by terms or acronyms? Let AFA (Atrial Fibrillation Association!) assist:

AF - Atrial Fibrillation, irregular heart rhythm.
Atrial Flutter – a rhythm disorder characterised by a rapid but regular atrial rate but not as high as AF.
Anti-arrhythmic drugs – drug used to restore the normal heart rhythm.
Anti-coagulants – drugs which help to thin the blood.
Arrhythmia Nurse Specialist – a nurse who is trained in heart rhythm disorders.
Cardioversion – a therapy to treat AF or Atrial Flutter which uses electrical shock to revert the heart back into normal rhythm.
Catheter ablation – a treatment which destroys a very small area inside the heart causing the AF.

Dyspnea – a medical term for shortness of breath.
Echocardiogram – an image of the heart using echocardiography sound-wave technology, is also called an ‘echo’.
Electrocardiogram – a representation of the heart’s electrical activity or ECG (sometimes EKG) in the form of wavy lines.
Electrophysiologist – a cardiologist who has specialised in heart rhythm disorders.
Heart failure – the inability (failure) of the heart to pump sufficient oxygenated blood around the body.
Sinus rhythm – normal rhythm of the heart.
The meetings are open to all Healthcare Professionals and will include:
a study day pack and resources, free support materials, opportunity to learn more about IT tools, local and national support, access to exhibition, lunch and beverages.

Register on line (www.atrialfibrillation.org.uk)
or by contacting AFA: info@atrialfibrillation.org.uk

Full agendas for each meeting are available on the AFA website

Venues include:
Belfast I Birmingham I Bristol I Cambridge I Cardiff I Edinburgh I Glasgow I Leeds I Leicester
Liverpool I London (N) I London (S) I Manchester I Newcastle I Norwich I Oxford
Plymouth I Reading I Stoke I Southampton I Wrexham

‘Know Your Pulse’

Arrhythmia Awareness Week (AAAW)
7th – 13th June 2010

The days are counting down to Arrhythmia Awareness Week. To ensure your pulse check materials arrive in time, place your order now!

Endorsed by the Department of Health and available free of charge for AAAW, packs can include:
♥ Posters
♥ Pulse Check Sheets/Cards
♥ Arrhythmia Checklists
♥ Press Packs
♥ Promotional materials

Visit www.aaaw.org.uk to place your order or contact joanna@heartrhythmcharity.org.uk +44(0) 1789 451 787 for further information.

www.atrialfibrillation.org.uk info@atrial-fibrillation.org.uk
I took early retirement from Customs & Excise in 1995; following an accident which involved crashing a car on black ice and falling out of a tree, a distance of twenty feet and resulted in me breaking my pelvis, I found myself needing medical help. In 1998, while receiving treatment for chronic back pain, the nurse could not find my pulse and an irregular heartbeat was suspected. The hospital consultant used an echocardiogram to examine my heart and confirmed an irregular heartbeat.

He was also able to tell that there were no further heart problems and diagnosed Lone Atrial Fibrillation. I had a cardioversion procedure to try to cure this, but it failed and after a period of time I now have permanent Atrial Fibrillation and take Warfarin, possibly for life. I realise that if the irregular heartbeat had not been diagnosed, I would have been at risk of a stroke, but now the Warfarin tablets act as an anti-coagulant and help prevent a clot forming, which could lead to a stroke. If only GPs took pulses as a matter of course every time we visited them, I firmly believe that more AF would be diagnosed and lives would be saved. So I fully support the AFA and Arrhythmia Alliance (A-A) ‘Know Your Pulse’ campaign for this.

Locally, after diagnosis, I joined Poole Heart Support Group but foolishly criticised the spelling mistakes in their magazine... which resulted in my being asked to be Magazine Editor! We publish articles by NHS staff, including Poole Hospital, who work closely with PHSG, as well as PHSG members. I have a special interest in heart arrhythmias, both for myself and the Heart Support Group. I joined Arrhythmia Alliance as a patient member and this was soon followed by affiliation to A-A for Poole Heart Support Group. It means that all members benefit from e-newsletters, printed information informative articles for the newsletter. In the past, Heart Support Groups traditionally affiliate to The British Heart Foundation (BHF) and benefited from grants and support, however I have found that affiliation to A-A compliments the benefits offered by BHF and all members are able to access a reliable source of further information and contact. If you would like to receive further information on affiliation to Arrhythmia Alliance, please email: info@heartrhythmcharity.org.uk

When treatment is worse than the AF

Although I was told I had AF during a health check in 1977, I had been reassured that ‘ignoring it’ unless it raised any health problems, was acceptable.

So for three years I enjoyed an active life with little thought to the irregular rhythm. In 1999 I found myself in A&E on many occasions, and in the past year, despite infusions of Amiodarone, was passing out and feeling increasingly worried. Then, on a cold November day, I called AFA.

After so long, I discovered so much and was even signposted to an AF specialist. It was the start of a new journey freeing me from the assortment of medication I had previously been given but struggled so hard to tolerate. Within a month I saw an ‘EP’ and two months later had a ‘pace and ablate’. Hope has returned and I now relish a safe trip to the hairdressers without blacking out; a journey free from the necessity of an escort.

Thank you,
Dr Rowlend and AFA.

Ahlan, Norfolk
Introduction

Internal Cardioversion is a growing treatment for Atrial Fibrillation which is now being offered at more than forty hospitals in the United Kingdom. Internal Cardioversion is particularly useful for patients where other treatments have failed, or where there is a poor probability of success such as in the overweight or obese patient, and for those in Atrial Fibrillation for greater than six months.

What is the treatment for Atrial Fibrillation?

If you have been diagnosed with Atrial Fibrillation, and your doctor has decided that your condition requires treatment to change your irregular heartbeat back to its normal rhythm, then there are numerous ways to do this. Your doctor may give you a medication that may convert your heart rhythm back to normal. However, if this doesn’t work then your doctor may propose a procedure called Cardioversion.

There are two common forms of Cardioversion; External and Internal. External Cardioversion involves providing an electrical shock of around 200J through two patches placed on your chest after first being given a general anaesthesia. Although External Cardioversion is generally very effective, not all patients with this type of irregular heartbeat can be restored to a normal rhythm with this treatment.

Another method of treating Atrial Fibrillation is the delivery of a low energy shock through a special catheter placed inside your heart to convert your heart back to a normal rhythm. This is known as Internal Cardioversion.

What is the Internal Cardioversion system?

The Internal Cardioversion system consists of a catheter (long flexible tube containing wires for electrical conduction), which will be inserted into your heart, and an Energy Delivery Device which is a piece of equipment placed by the bedside and connected to the catheter to deliver the shock energy to stop your irregular heartbeat.

The catheter is temporarily inserted into your heart through a vein, in your arm, neck or groin. X-rays will be taken to guide the proper placement of the catheter in your heart.

After the catheter is properly positioned, the catheter is connected to the Energy Delivery Device, and one or more low energy shocks of less than 30J will be given to stimulate your heart into a normal rhythm.

The whole procedure takes place within about thirty minutes and doesn’t usually require a general anaesthetic although heavy sedation is required.

What can I expect?

Unless you are already hospitalised you will be admitted to the hospital for the Internal Cardioversion procedure. Several routine lab. tests including blood work and an ECG (electrocardiogram recording of your heart rhythm) may be performed sometime prior to the procedure.

On the day of the procedure you may be asked not to eat to drink anything before the test but you may take sips of water with your medications. The doctor will review your medical history and examine you. He will explain the procedure, its purpose, potential benefits and possible risks. This is a good time to ask questions, and, most importantly share any feelings or concerns that you may have about the procedure. As in many procedures done in the hospital, you will be asked to sign a consent form that gives the doctor permission to perform the procedure. You may be asked to change into a hospital gown and taken to a special room or laboratory where the procedure will be performed. There is a chance that this procedure may need to be repeated in the future.

Who should not have Internal Cardioversion?

Internal Cardioversion should not be used on patients who can not have temporary pacing leads inside the heart, and/or have internal low energy shocks. Your doctor will also make the decision if they feel you are not suitable for this procedure. You should let your doctor know if you have an implanted device (such as a pacemaker), a mechanical heart valve or have a known allergy to latex. Cardioversion should always be undertaken with at least six weeks prior treatment with Warfarin which is usually continued for a further month following successful cardioversion.

What are the benefits of Internal Cardioversion?

Your heart’s rhythm may be returned to normal, and you may feel relief from the symptoms associated with these irregular heartbeats. It is possible that Internal Cardioversion may be able to stop irregular heartbeats in patients who cannot be successfully treated with external high energy shocks. Patients treated with Internal Cardioversion do not generally require general anaesthetic and do not experience skin burns which are a potential side effect of External Cardioversion.

Dr C Morley MA MBCh FRCP DM, Consultant Cardiologist, Bradford Royal Infirmary
Join AFA in 2010 at UK regional wide meetings and the extremely popular

AFA Patient Day 2010

AFA is pleased to announce details of the 2010 AFA Patient Day which will be held during the Heart Rhythm Congress at the Birmingham Metropole Hotel, Birmingham on Sunday 3rd October 2010.

Agenda topics will include:

- The athlete’s heart and AF
- Cardioversion
- What’s new in AF therapy
- Under 60 with AF
- AF ablation
- Living with AF
- Options on managing stroke risks in AF
- Managing AF - hypnotherapy
- Question Time

Early bird rate of £20.00 is now available until 30th June 2010. Book directly with AFA to receive discounts; a delegate rate of £30.00 payable after this date. (Please note bookings directly with HRC are not subject to AFA discounts).

To register to attend please complete and return this form with full payment:

Full Name: ........................................................................
Tel: ....................................................................................
Email: ...............................................................................
Address: ...........................................................................
.................................................................................. Postcode: ...........
I am a patient / carer – please indicate .........................

This year’s Regional Meetings begin soon

Agenda topics include:

- ‘Knowing your local services’
- ‘How to access the specialists in your area’
- Learning more about ‘Know Your Pulse’

The day will enable you to meet other members, have opportunity to talk, ask questions and learn more about new innovations from industry. Open to all AFA patient and carer members, the delegate rate of £13.50 includes lunch and tea / coffee.

Please complete the form below to reserve your place and send a cheque, made payable to AFA to: PO Box 1219 Chew Magna Bristol BS40 8SU Or register on line: www.atrialfibrillation.org.uk

Local agenda available on request from AFA or online on the AFA website.

Oxford 25th May The John Radcliffe Hospital
Leeds 4th June The Queens Hotel, Leeds
London 23rd June Selsdon Park, Croydon
Manchester 23rd June Radisson SAS Manchester Airport
Glasgow 25th June Holiday Inn Theatreland
Bristol TBC TBC
Cambridge 7th July TBC
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### FACT SHEETS: PATIENT

- Atrial Fibrillation
- Amiodarone
- Aspirin
- Atrial Flutter
- Atrial Tachycardia
- Beta-Blockers
- Blood Thinning
- Cardioversion
- Digoxin
- Dronedarone
- Eclectic Beats
- Flecaainide
- Medical Cardioversion
- Pacemaker and AV Node Ablation for AF
- Pill-in-the-pocket Cardioversion
- Rate Limiting Calcium Channel Blockers
- Rate versus Rhythm Management
- Stroke
- Warfarin Therapy
- Warfarin and Diet
- Warfarin and other Medication
- What is a Consent form?
- What does randomisation mean?
- Ongoing clinical trials for AF
- What is a clinical trial?

### CHECKLISTS:

- Patient and Primary Care Checklist
- Atrial Fibrillation Checklist

### FACT SHEETS: FOR HEALTHCARE PROFESSIONALS

- Focus on AF
- Innovations in Anti-coagulation Therapy
- Seeking Patients in AF
- Stroke Prevention in AF
- Primary Care Pathways for AF
- Atrial Flutter
- Rate versus Rhythm Management
- Ablation of the AV Node and Pacemaker Implantation
- Dronedarone

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

Name
Address
Postcode
Tel
Patient / Carer / Medical Professional
Email

www.atrialfibrillation.org.uk

Return to: Atrial Fibrillation Association, PO Box 1219, Chew Magna, BS40 8WB UK

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