After nearly 60 years since the release of warfarin, the National Institute for Health and Clinical Excellence (NICE) has approved not one, but two, new oral anticoagulants within weeks of each other; dabigatran etexilate and rivaroxaban were both given the go-ahead in March.

On Thursday 15th March 2012, dabigatran etexilate - commonly known as ‘dabigatran’ - was initially approved by the health authority and, in quick succession, rivaroxaban was approved on Friday 30th March 2012.

The clot-busting drugs will be used as an alternative to warfarin for the prevention of stroke and systemic embolism in adult patients with nonvalvular atrial fibrillation (AF). Patients will be eligible if they possess one or more risk factors such as: congestive heart failure, hypertension, age 75 years or older, diabetes mellitus, prior stroke or transient ischaemic attack.

The use of rivaroxaban once daily and dabigatran, administered twice-a-day, will greatly reduce the need for routine dose adjustments and regular coagulation monitoring, which is necessary when using warfarin.

“After nearly 60 years...”

However, NICE has advised that patients currently prescribed warfarin who are considering switching to one of the two new anticoagulants, should discuss the potential risks and benefits with their GP.

Founder and CEO of the AFA, Trudie Lobban MBE, comments on the news of the approvals:

“These are exciting times, with 45% of all embolic strokes caused by AF; the approval of dabigatran and rivaroxaban is a fantastic leap forward in anticoagulation therapy. The decision by NICE at last provides doctors and AF patients with new options to prevent a potentially fatal or debilitating AF related stroke. AFA would like to thank the NICE committee for issuing guidance on both anticoagulants.”

“The approval of dabigatran and rivaroxaban is a fantastic leap forward.”
Atrial fibrillation (AF) is a heart condition that causes an irregular and sometimes abnormally fast heart rate. AF occurs when abnormal electrical impulses override the heart’s natural pacemaker, and make the heart’s upper chambers - known as the atria - beat in an abnormal rhythm. It is the most common heart rhythm disorder in the UK.

What causes AF?

Atrial fibrillation can affect adults of any age, but becomes more common the older you get. It affects about 10% of people over 75. It is pretty rare up to the age of 55 - a prevalence of just 0.2% in men and 0.1% in women, but increases quickly as you get older. It is thought that around 15% of cases are hereditary - if a parent has AF it may increase your risk by as much as doubling it.

Many people develop AF for no explainable reason, and this is called ‘lone AF’. But AF in general is more likely to affect people with conditions, including high blood pressure, coronary heart disease, heart failure, thyroid gland disorders and lung conditions.

Can I cut my risk of getting AF?

Carbon monoxide poisoning is linked to AF, so ensuring you have a monitor or alarm in your home is one good idea; alcohol or drug abuse or misuse may also be a cause for some people, as can smoking.

Obesity directly causes electrical abnormality in the heart, increasing the risk of AF, so weight management is important. Diabetes can be linked to a significantly greater risk, especially if blood sugar is not well controlled, so ensuring you stick to your diabetes treatment could help reduce the risk.

How would I get a diagnosis?

If you have any of the symptoms, visit your doctor, especially if you have additional risk factors such as, a family history of high blood pressure. If you have risk factors but no obvious symptoms, check your pulse! Watch the video at www.knowyourpulse.org

If your pulse exceeds 100 beats per minute for more than three days in a row, go and see your GP. An irregular pulse also requires you to see your doctor, as there are other conditions, which can give rise to an irregular heart beat. Your doctor may ask you to have an electrocardiogram (ECG - a test that records the rhythm and electrical activity of your heart) and refer you to a heart specialist, known as a cardiologist. Other tests may include an echocardiogram (an ultrasound scan of the heart), a chest x-ray, or blood tests to rule out causes such as an overactive thyroid.

If I do have it, what are the treatment options?

• Medication is the most common option, as there are ‘anti-arrhythmics’ to restore a normal heart rhythm, plus drugs that can slow down a fast heart rate, such as beta blockers. If you have AF and your stroke risk is assessed as high enough, you will also be prescribed medication, known as an anticoagulant, to reduce the blood ‘stickiness’, cutting the risk of blood clots that can cause stroke;

• If medication does not have the required effect on the irregular heart rhythm, you may be referred for cardioversion, where the heart is given a controlled electric shock to try to restore a normal rhythm;

• Catheter ablation is another option if nothing else works – heat is used to destroy affected heart cells;

• Some people with AF may have a pacemaker fitted under local anaesthetic to ensure a steady heart rhythm. Pacemakers do not cure atrial fibrillation they can only ensure that the heart is beating fast enough.
Can I reduce the number of AF episodes?

Many people with AF notice they have ‘triggers’ which can make an episode more likely. These can include drinking alcohol (particularly binge drinking), putting on weight, drinking lots of caffeine, such as tea, coffee or energy drinks (try herbal teas, rooibos tea, and decaffeinated coffee instead), taking illegal drugs, particularly amphetamines or cocaine, and smoking.

A heavy bout of exercise if you are not used to it may also be a trigger, but exercising is good for AF, so don’t give up on it, talk to your doctor about how to exercise safely. One small study of 49 people in 2011 showed three yoga classes a week, plus practice at home could reduce the number of episodes in people with AF by as much as 50%.

Scientists are also investigating whether some non-steroidal anti-inflammatory painkillers, such as ibuprofen may also make episodes more likely with long term use, so talk to your pharmacist or GP about other sources of pain relief, if possible (for example heat packs, ice packs, TENS machines).
In January of this year, rower Tom James was forced to miss an Olympic training camp in South Africa, after doctors diagnosed him with atrial fibrillation.

The 27-year-old is among a growing number of young adults, especially athletes, diagnosed with the heart rhythm disorder.

With the common misconception that AF only affects the older generation, the gold medallist was surprised to find out he had AF. Speaking to the BBC and Wales Online he said: “It was a bit of a shock to hear you’ve got a heart issue when you’re 27 and leading a healthy lifestyle.”

The sportsman, from Wrexham in Wales, had become ill over the Christmas period and thought he had caught a bug, which presented as a high heart rate – reaching 220 beats per minute at its peak. As a consequence, his doctors sent him for tests which revealed he had a heart rhythm disorder.

“It was a bit of a shock to hear you’ve got a heart issue when you’re 27 and leading a healthy lifestyle.”

Dr Andreas Wolff, GP, comments on AF in athletes: “According to published evidence and resulting hypothesis, competitive athletes are more prone to atrial fibrillation as a result of their extensive training regimes. Their hearts’ change to adapt to the intense exercise practices, coined ‘athletes heart’, it is characterised by enhanced vagal tone, an enlarged left atrium and fibrous tissue formation, which might contribute to the development of atrial fibrillation.”

Undeterred by the diagnosis but with medical guidance, Tom is back to training with the GB Rowing squad, after receiving medication to control his AF, and finished fourth in the Olympic Trials in the men’s pairs in March 2012.

“I feel fit and came back pretty quickly,” said Tom, who trains daily with only one day off a week.

He continues: “When you are ill or injured you have to try and get through things the best you can. When you are working in a stressful environment with a high heart rate with plenty of adrenaline, it is not ideal. [But] I have been trying to reduce any natural stresses, [and] I am on top of it at the moment, so we will see what happens.”

Tom hopes to defend his 2008 gold medal at London 2012. Good luck, Tom!
The new ‘Surgical Ablation’ booklet - all you need to know and more...

The resource discusses the procedure and the different types of ablation surgeries, such as open-heart and minimally invasive surgical ablations.

The booklet also covers what to expect after the procedure and who would benefit from undergoing the ground breaking surgery.

Mr Jonathan Hyde, cardiac surgeon, comments on the new technique: “VATS ablation is a major breakthrough and hundreds of these procedures have now been performed worldwide with excellent results. Some units are reporting AF cure rates in excess of 90% for paroxysmal AF patients.”

Someone who knows the benefits of surgical ablation, Tim Cross, an AF patient who underwent the innovative VATS procedure, said:

“I suffered symptomatic paroxysmal AF for around nine years prior to my successful VATS ablation procedure three years ago. Before the procedure, my episodes always occurred around two or three in the morning and typically lasted around nine hours. This left me feeling exhausted, worried and unable to work properly, and as a self employed designer this impacted on my business.

“After the surgery, which took three hours, I was monitored on the HDU ward and was allowed home the next day. I was back in the office about a week or two later and fully fit soon after.”

Reports published by AFA now available from www.afa.org.uk
AF sufferer Louise tells her harrowing story, from her initial AF episode to her second ablation procedure, and her slow but steady road to recovery.

“I started getting lone paroxysmal atrial fibrillation at the end of January 2009. I was sitting at home and my heart started beating very fast, it just wouldn’t slow down so I called the doctor. He said that if it didn’t slow down within an hour then I should go to the hospital. After an hour, I made my way to the nearest hospital, upon arrival I kept on having to use the toilet, which I later discovered is one of the symptoms of AF. Straight away I was put onto an ECG machine, and I think sometime after I went into resus, which was very frightening. Little did I know that I would be going into resus practically every time I went into hospital, and was therefore given amioderone to slow my heartbeat down. I stayed in hospital for four days and they confirmed I had AF and was put on sotalol as a consequence. I stayed on sotalol until the end of the year and tolerated it quite well to begin with. As I went into 2010, my AF episodes became more frequent.

My cardiologist said that ablation would help me, but of course I didn’t know what it was at the time. My symptoms included very fast heart beats (up to 200 bpm), severe dizziness (on the verge of passing out) and breathlessness. I was washed out every time and felt very upset.

I eventually met with an electrophysiologist and he put me on the waiting list for an ablation in November 2010. He did warn me that AF can get worse and become persistent, so it was best to do the ablation whilst my symptoms were intermittent. I underwent my first ablation in September 2010 and was well enough to go home the very next day. After three weeks, I was back in hospital again with another AF episode and felt very disappointed. I was put on a low dosage of bisoprolol, which was increased gradually during 2011. From April to August 2011, I was AF free and thought the ablation had worked. However, in late August I had another episode but I was due to see my electrophysiologist for a review the next day. He said “let’s get rid of this for you” and I had my second ablation on 22nd December 2011. I watched while they performed the procedure and didn’t feel scared. I’m getting a few ectopic beats, which I have been told is normal and I’m still in my recovery period. This should last until the end of March 2012, which is when I go back to see my electrophysiologist.

I haven’t been able to work for four years now as I’ve had around 30+ attacks, most of which, have resulted in a hospital stay.”
Craig from Newcastle will be participating in two marathons and running a total of 52 miles in a bid to raise money for AFA.

Craig, who suffers with atrial fibrillation and was diagnosed in 2011, will take part in the Boston Marathon on 16th April 2012 followed by the Berlin Marathon on 30th September 2012.

Craig’s diagnosis of AF came as a surprise as he had always been very active, he explains: “It was a big shock when I was diagnosed with AF, as I’m only 44. I’ve always been very fit and have participated in five marathons and numerous half-marathons.”

After his diagnosis, Craig wanted to continue as normal with a healthy lifestyle, he said: “Three months after I was treated for my AF I went on to run the New York Marathon, and this year I’m running the Boston and Berlin marathons.”

The work of the AFA was of great support to Craig and, as a result, he intends on raising an admirable £500 for the AFA.

To help Craig achieve his fundraising target visit http://www.justgiving.com/CraigBostonBerlin

AF sufferer, 44, to run not one but two marathons

AFA member wanted for University of Leeds project

A research team from the University of Leeds, led by Duncan Petty, is applying for a research grant to find out more about why patients with AF who could benefit from warfarin do not receive it.

If funded, the proposed study will start in 2013. We are keen to ensure active patient involvement in planning and doing this study. We would like to invite at least one AFA member to become a member of our research team.

This would involve attending up to three project advisory group meetings during the study, and feeding back to other members of the AFA about the study through your regular forums. Members will be reimbursed for their time and any related travel expenses.

If you would like to be involved in helping with this important research, or have any further questions about the study, please contact: Carolyn Montana (Research Fellow) in the first instance; c.montana@leeds.ac.uk or call 0113 343 1964.
Budding Yorkshire celebrity Martin Harman hosted and competed in the Atrial Fibrillation Sportive bike ride in March, to raise £2,400 for the AFA and towards his travel to the European Triathlon Championships 2012.

A whopping 96 riders turned up to take part in a challenging 60-mile bike ride through the scenic Howardian Hills, Castle Howard Estate and the North Yorkshire Moors National Park.

Martin, 39, who was diagnosed with AF in 2006, was surprised at the overwhelming success of the fundraiser and said: “WOW! What a weekend! The day was a huge success with an extra 10 riders signing up on the day. I have also had some fantastic feedback from lots of riders on how much they enjoyed the day and how well organised it was. So much so, that the cycling club ‘Malton Wheelers’ and the bike shop ‘Big Bear Bikes’, have asked me to do it again next year with their help and support.”

After Martin was diagnosed with AF he became somewhat of a serial triathlonist, and subsequently qualified to compete in this year’s European Triathlon Championships in Eilat, Israel in April. Funds raised from the charity bike ride have also gone towards his sporting challenge.

He says: “I enjoy participating in triathlons for the challenge of the sport, and it’s also my way of proving to myself that atrial fibrillation may well live with me, but it will not live for me.”

When the AFA newsletter went to print, Martin was well on his way to reaching his fundraising goal of £10,000, having already received over £4,000 in donations. However, if you would like to make a donation to this worthy cause, please visit http://www.justgiving.com/mharman

Casino Royale couple win big and donate to AFA

James and Jenny, from Nottingham, gave James Bond a run for his money and donned their best fancy dress outfits to participate in a casino night on New Years Eve. Ten couples took part in the casino event and with £10 a stake from each couple, the prize total stood at £100. Despite claiming not to be very good, the couple won the £100 and kindly donated their winnings to AFA. Thank you James and Jenny, AFA really appreciates your support and generosity.
AF patient and mother-of-four writes book for children affected by atrial fibrillation

Kirsten Millinson, a mother-of-four and an accomplished writer, has recently published her fourth book ‘My Mum has Heart Hiccups’.

The children’s book describes atrial fibrillation to young readers in a simple, non-scary and illustrative manner - so young people can understand what AF is and why it happens.

The children’s book, published earlier this year, is narrated from a young boy’s perspective and mirrors Kirsten’s family life. In fact, the publication features the family’s nickname for AF ‘heart hiccups’, and is aimed at families - similar to Kirsten’s - who are affected by atrial fibrillation. She explains: “The book is written to help families like mine, who have been touched by heart hiccups, the name my family calls atrial fibrillation.”

“When I first went into hospital, my children were rushed to our friends so my husband could come to the hospital. They were left not knowing what was going on - a horrible feeling for them and for me. I see one of my roles as mum is to keep them safe and free from fear if possible, and if not possible, to explain what is going on and why.”

When looking for AF literature for children, Kirsten found that there was little to no information and the material found was too gruesome. She says, “I was aware when looking for information to help our family there wasn’t much at all. However, I did find a video on catheter ablation, but it took me several weeks to pluck up the courage to watch it myself and the children didn’t want to see the video.”

Having already penned three books previously, Kirsten saw this as an opportunity to do something about the lack of materials available. She explains: “I had written other books in the past, one of which explained births of siblings born at home to children, and this book seemed like the next step. So rather than moan, I did something about it.”

“We didn’t know anything about atrial fibrillation and what effect it would have on me.”

Since it’s publication in March, ‘My Mum has Heart Hiccups’ has received positive comments from friends and family, and Kirsten has already sold a number of copies. To purchase your own copy of the children’s book for the small price of £8, visit www.lulu.com
Sue’s story

Sue describes her journey of AF discovery and finally receiving an ablation: from misdiagnosis to cardioversion and beyond.

“In 2005, I first experienced symptoms that I thought were neurologically based, or psychological due to anxiety.

I wanted to be referred to my local neurology department, in order to rule out a brain disorder. I was quite aware of how the mind can play tricks on one, but felt that if a neurological cause could be ruled out, I would be reassured that stress had caused the problems and they would eventually go away. I was a psychologist and had recently taken early retirement from my main job, a decision due in part to stress, and was working part-time in a less well qualified position, as a stop smoking adviser.

I saw a neurologist at my general hospital and was told there was no indication of a neurological disorder. But while having my pulse checked, the reading on the machine was very low and, as a result, the nurse took my pulse manually which confirmed something was wrong. She asked me if I'd like a referral to the cardiac department and I agreed.

A few months later, I saw a registrar in the cardiology outpatients department of my local hospital. I had an x-ray, an ultrasound, ECG and an echocardiogram - I think? They diagnosed me with an ectopic ventricular heartbeat. Every fourth beat came from the ventricle and not the atrium. This beat was weaker than the others so might not be detected by machines. I was told that the structure of the heart was sound and that this condition does not reduce life expectancy or quality of life substantially. However, if I wanted I could be treated with medication.

A few months later, my anxiety was better and I was happier but I was still feeling tired and woozy. I was aware that I took a long time to get things done and I found work tiring. After nearly a year, I asked my GP for another referral to cardiology. I talked to the nurses in the cardiology outpatients department, and they recommended a consultant electrophysiologist.

I saw the consultant electrophysiologist and he said that after my last GP visit, a letter had been sent to my GP to put me on bisoprolol, a beta blocker, for my condition. This was the first I’d heard about that and I guessed that either my GP had not received the letter or it had been filed away or lost. The consultant explained that the condition I had did not require any more treatment other than a beta blocker, that it was the kind of arrhythmia that caused no concern. Thereafter, I received a letter from my GP to say he had a prescription for bisoprolol as advised by the heart specialist, and I should visit the surgery to pick it up, which I did.

Soon after, I changed my GP and switched to a larger surgery, one with a GP whose area of special interest was skin, as I had terrible acne! I visited this GP asking for tablets to clear up the acne. She looked at my notes, told me she would have to check my heart before risking prescribing antibiotics for my acne. The GP took my pulse and told me she was concerned and I needed to have an ECG, which she arranged immediately. She confirmed I had atrial fibrillation - I can’t tell you how grateful I am to this doctor!”

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AFA holds Parliamentary event to promote Quality Standards for patients

Glyn Davies MP, chair of the All-Party Parliamentary Group on AF (Conservative, Montgomeryshire), recently hosted an event in the House of Commons to highlight the importance of promoting high quality standards of care for patients. Speaking alongside him was CEO and Founder of the AFA, Trudie Lobban, and two patient speakers, Martin and Chris.

The meeting focused on the challenges faced by those diagnosed with AF and the importance of securing a Quality Standard in AF, to set out NHS guidelines on what best practice in treatment, care and support means. MPs, Lords and medical professionals gathered to hear the first hand experiences of two patients both diagnosed with AF, and to debate what they would like to see included in any quality standard that is developed over the coming years.

A Quality Standard (to be developed for use in the NHS in England) is a set of 10-15 statements, setting out high quality care which commissioners and clinicians should work towards. The Standard can also be used by patients so they can see what type of care they should be receiving.

Just over a year later, I started to experience symptoms again and the AF had come back. Since my last visit to my consultant, I learnt about catheter ablation from the AFA and found out that my consultant was a specialist in the procedure. So I asked him if I could have a catheter ablation.

He explained that the chances of success with an ablation, in my case, were 60% increasing to about 80%; if you count partial success.

He explained ablation was best done when the AF was still intermittent, however, he agreed to perform the procedure. I had to have another cardioversion and the ablation was done in August 2011.

Since my ablation I feel well and I am still taking warfarin, which I will continue to do until I next see my consultant in April.”

Attendees heard how those with AF are often not effectively diagnosed, and a lack of information provided by the NHS leaves them without the answers that they need. Similarly, problems with late diagnosis can lead to stress as well as negative implications for work and family life.

In order to improve patient care, the Parliamentary Group discussed how the NHS can best eliminate these problems. Attendees agreed that by introducing a Quality Standard to highlight best practice, the NHS can better deliver high quality care. They also discussed what in particular should be in a Quality Standard - such as access to arrhythmia nurses or access to information.

Following the meeting, it was agreed that the AFA and All-Party Parliamentary Group would work with patients and AFA supporters to continue to lobby for an effective Quality Standard on AF, which will ultimately help commissioners, clinicians and patients see what good quality care should look like.

“Just over a year later, I started to experience symptoms again and the AF had come back. Since my last visit to my consultant, I learnt about catheter ablation from the AFA and found out that my consultant was a specialist in the procedure. So I asked him if I could have a catheter ablation.”

“I was prescribed warfarin and was referred back to the consultant electrophysiologist who agreed I had persistent AF. A few months later I had a cardioversion.

I felt a dramatic improvement, being able to go on rambles, go upstairs easily, even while carrying the vacuum cleaner which I could not manage before. I could take part in activities for much longer each day.

Eventually, I came off warfarin. This was a welcome relief because my INR levels had been quite tricky to get right at times.

BREAKING NEWS... Quality Standard for AF by NICE to be included in 2012 work programme
ATRIAL FIBRILLATION ASSOCIATION
PATIENTS DAY

Sunday 23rd September 2012
10:00-16:30

At our new venue: The ICC, Birmingham, UK

10:00  Why do I have atrial fibrillation and what are the risks?
10:30  Young with AF, what are my outcomes?
11:00  Who should manage my AF?
11:30  Anti-arrhythmic drugs: are they safe, who are they for?
       Any questions
12:45  Lunch
13:30  How safe is catheter ablation?
14:00  How can I find local support?
14:30  I feel so ill, when should I get help and who from?
15:10  Workshops and discussions:
       - Improving AF care
       - AF and my life
       - AF and my family
16:00  Question Time

Register before 30th June to receive early bird discount! Full day meeting, refreshments and lunch £20.00 per person.

To register please complete the form and send to the AFA address below.

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Credit/Debit Card: Please call +44 (0)1789 451 837 to pay over the phone

Cheque: Make payable to ‘Atrial Fibrillation Association’.

Please write delegate name(s) on back of cheque and post PO Box 1219, Chew Magna, Bristol, BS40 8WB

Be part of 2012 Heart Rhythm Week, and display your poster enclosed with this newsletter.
To order further copies or awareness materials, please contact AFA.