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

Dronedarone Denied: Shock first Ruling by NICE

AFA calls upon members to ACT NOW to seek a review

The Atrial Fibrillation Association is calling on all members to appeal to NICE, the body which approves medication in England and Wales, to reconsider its recent decision to refuse approval for the use of Dronedarone (Multaq) for AF patients.

Despite both AFA submitting written evidence to the committee and giving evidence at the meeting on 25th November 2009, NICE regrettably announced that it is proposing to deny Dronedarone, the first new anti-arrhythmic drug (AAD) in more than twenty years, to patients with AF.

Extensive trials have shown that Dronedarone is not only effective in treating AF in large numbers of Paroxysmal AF patients, it is also the only anti-arrhythmic medication that improves long term cardiac health in AF patients.

To the relief of all AF sufferers, trials also revealed that the new medication was well tolerated and caused far fewer side effects than commonly experienced by patients using currently available drugs. It is thought the drug could be suitable for at least 55% of patients with Paroxysmal AF (episodes which come and go).

The drug is already approved for use in Europe and the USA, leaving UK patients lagging behind through a decision which puts money before quality of life.

The shock decision by NICE will deny many AF sufferers who are currently struggling to manage this potentially debilitating condition, the chance to restore their long term health.

Make YOUR Voice Heard

AFA is urgently calling for YOUR help. We need your support in making representations to NICE and the Department of Health.

It is imperative that NICE, the Department of Health, Ministers and MPs understand the scale of opposition to this draft guidance. We need as many patients, carers, supporters and health professionals to write expressing a response to the consultation.

We need you to WRITE to NICE by January 24th and ask that they re-think this preliminary decision and rule to allow this medication to AF patients in England and Wales.

Please send your letter to the Chairman of the NICE Appraisal Committee, Professor Peter Clark (address to the right). Include your personal experiences of living with AF, how beneficial the new treatment could be, and the need for clinicians to have a choice of treatment options to help improve the quality of life for patients.

I hope you will be able to write a personal letter, as this is a powerful way to demonstrate the strength of feeling about this draft decision.

However, if you are unable to write a personal letter, please use the enclosed sample/outline letter, to help make your voice heard.

We would urge you to also write to: *Prof. Mike Rawlings, Chair of Nice; Andy Burnham MP, Health Secretary* as well as *your local MP*, explaining the situation and seeking their support (addresses below).

Please, **ACT NOW!**

There is a great strength of feeling across the health and AF communities that the draft NICE guidance on Dronedarone will deny patients an innovative new treatment option.

Life with AF and the potential benefits of Dronedarone for patients must be understood if NICE is to re-evaluate its decision. Make your voice heard.

Details on the appraisal can be viewed at: <http://tinyurl.com/ycndso5>

More information and a copy of the sample letter can be viewed online at www.atrialfibrillation.org.uk

Send your letters to:

NICE, Mid City Place, 71 High Holborn, London, WC1V 6NA;

Rt Hon Andy Burnham MP, Secretary of State for Health, Department of Health, Richmond House, 79 Whitehall, London, SW1A 2NL

Please send a copy and responses you receive to AFA (or email).

AFA Patient Day

Sunday 18th October 2009 at the Heart Rhythm Congress

It was amazing to see so many AFA members at the Birmingham Metropole who had travelled from all corners of the UK to meet, learn more about Atrial Fibrillation and have an opportunity to ask questions about AF to leading arrhythmia medical specialists.



Martin recalled his struggle to find information

Two patients, Bob and Martin, generously shared their moving and inspiring accounts of living with AF. I think the whole audience were grateful to them and benefited from hearing how they had eventually restored quality and health back into their own lives.

"I came away understanding so much more, and feeling empowered to begin at long last to ask questions about my own care."

This was followed by the lively and thought provoking debate, "Where is AF care best managed?" between Dr. Matthew Fay, GP and Professor Richard Schilling, EP.

Professor Patrick Doherty gave an informative presentation about 'AF and Exercise' which almost had us all heading for the gym!

Talks considering triggers for AF and whether Catheter Ablation is a cure, answered and equally raised questions; however, a far greater

understanding of the complexity of treating AF was achieved.

"I am a GP with AF – attending the recent AFA Patient Day has helped me both as a patient and carer... I would recommend it to all GPs and patients!"

Ground breaking results from recent trials on a new system to assess the risk of stroke in an individual were summarised by Professor Gregory H Y Lip. The work had further refined the CHADS2 risk assessment system in order to focus on those at 'moderate' risk of stroke who were often faced with an unclear choice between anti-platelet (e.g Aspirin) or anti-coagulant (e.g Warfarin) treatment.

With further talks considering, 'Cognitive behaviour therapy for AF' and 'The role of the general cardiologist' it was clear that finding prompt and informed medical support was critical in the journey to re-gaining a good quality of life.

Feedback from those who attended has been extremely positive, and AFA look forward to meeting more members as well as seeing returning friends in 2010.

Comments and opinions volunteered by members help to inform AFA on what further information is needed and how this can best be delivered.

Raising awareness of the patients' experience with AF will help change and improve services. Therefore recording YOUR experiences and sharing YOUR opinion is very important!

Please consider sharing your experiences with us, either by letter or email to info@atrialfibrillation.org.uk so that together:

WE CAN MAKE A DIFFERENCE

Book Now for AFA Patient Day at HRC 2010 and Receive Early-Bird Discounts!

Being held on Sunday 3rd October at the Birmingham Metropole hotel. The day will offer presentations from leading arrhythmia specialists, accounts from AFA Patient members, opportunity to ask questions and time to meet fellow AFA members.

Early-bird registration (until 01.06.2010) is at the reduced price of £20.00 per person; after this date it will be £30.00.

All patient registrations through HRC are £50.00. To register for discounts please book DIRECTLY through AFA. Send the form below to:

Jo Jerrome AFA PO Box 1219, Chew Magna, Bristol, BS40 8WB

Title: _____

Name: _____

Email: _____

Telephone: _____

Address: _____

Post Code: _____

I enclose £20 cheque (payable to AFA) to attend HRC AFA Patient Day.
Tick as appropriate

I am a patient

I am a carer

Other (please specify)

Arrhythmia Awareness Week - The Campaign Continues

Last year more than a thousand events took place across the UK to highlight our 'Know Your Pulse' campaign and AFA supported a parliamentary launch at the House of Commons, with over 100 attendees being present. The event was also educational with nurses on-hand to teach guests how to take their own pulse.

Following the success in 2009 of the campaign, AFA is again joining together in partnership with Arrhythmia Alliance to continue this very important initiative. Arrhythmia Awareness Week 2010 (AAAW) will be held during 7th–13th June, although there is an early start for AFA on Friday 4th June, with the first AFA Ball held at the Queens Hotel, Leeds.

Promising an evening of good food, entertainment and ensuring the 'fun' is in 'fund raising', please contact AFA so you can reserve places and avoid disappointment.

A few days later, on Monday 7th June, Arrhythmia Alliance will launch AAW 2010 at the House of Commons, again campaigning to 'Know Your Pulse'.

The primary aim of the 'Know Your Pulse' campaign is to raise public and medical awareness of the pulse as a means of identifying potential cardiac arrhythmias like AF. The long term goal is to ensure pulse checks become routine when someone visits their GP.

How YOU can help

You too can play an active role in this campaign. We are asking all members to write to their GP and the Chief Executive of their Cardiovascular Network to ask the following questions:

- Have you or are you planning to include routine pulse checks in the annual flu inoculation programme?

- Are manual pulse checks planned to be included in your own 40 – 74 year old Health Checks?
- Do you offer pulse checks as part of your routine GP service?
- If you have begun any of these programmes, do you have any information of the number of arrhythmia patients newly identified?

Simply drop your letter in at your local GP surgery, and at the same time, ask for the address of the local Chief Executive of the Cardiovascular Network.

Alternatively, call AFA (01789 451837) for assistance in finding the appropriate address.

Your letters will help raise awareness of this initiative, the need for it, and so support our campaign to make the simple, manual pulse check a routine part of a trip to the GP.

Regional Meetings 2010 - Patient Meetings

Atrial Fibrillation Association is pleased to partner Arrhythmia Alliance in 11 Patient Meetings between March and July 2010 and we would love you to come.

These meetings will provide information on how to get best out of your local services. There will be opportunity to ask questions and find out more about Arrhythmias, and Atrial Fibrillation. As well as time to meet and talk with fellow members.

Registration fee is £13.50 person. This includes refreshments and lunch.

Regional Meetings Locations: Midlands – Birmingham • Midlands – Oxford • East Midlands – Cambridge • South – Reading • North Leeds • North West – Manchester • North Wales – Wrexham • South Wales – Cardiff • South West – Bristol • Scotland – Glasgow • Northern Ireland – Belfast.

To register to attend a Regional Meeting, please complete and return this form:

Full Name: _____

Email: _____

Telephone: _____

Address: _____

Post Code: _____

Regions interested in: _____

I am a **patient** / I am a **carer** - please delete as appropriate

We will email / phone when dates and venues have been confirmed. Please send to: Jo Jerrome, PO Box 1219, Chew Magna, Bristol, BS40 8WB or email: Jo@atrialfibrillation.org.uk

Is Your Finger On The Pulse?

Be Part of AAWW 2010: June 7th -13th

Hold a Pulse Check Clinic - Pulse Check Your Friends and Family – using the A-A Pulse Check sheets, help those close to you to become more 'pulse aware' and monitor their pulse during AAWW. Email or send your results with us, sharing any previously undetected arrhythmias discovered that week.

Write to your MP asking them to promote the importance of procedural pulse checks and encourage local constituents to download the Pulse Check Card.

Share your story - Patient stories are an important way of getting the message out there. And this is where we really need your help. If you were diagnosed with an arrhythmia by having your pulse checked, your story could help to reinforce the importance of this simple health check procedure.

Fundraise with a coffee morning, raffle, sponsored event, cake sale, quiz, ball or dinner.



Send a letter to your health authorities to find out what they are doing about pulse checks in their area.

Hold a display with a Display Pack at a hospital, clinic, GP surgery or community centre with a selection of information and promotional items.

Find Out More at:

www.knowyourpulse.org

or contact

jo@atrialfibrillation.org.uk

Post Posters and leave leaflets with a GP Pack - Distribute booklets and promotional items to local medical centres, schools, libraries, GP surgeries, leisure and community centres.

Did You Know?



The Atrial Fibrillation Association (AFA) and Arrhythmia Alliance (A-A) provide Department of Health endorsed resources including Pulse Check Cards. You can access these either via the web site through contacting Jo Jerrome: +44 (0) 1789 451837 for free paper copies or download them from our web site: www.knowyourpulse.org

The AFA web site at www.atrialfibrillation.org.uk, also offers medically approved booklets, toolkits and fact sheets.

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www.atrialfibrillation.org.uk

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