

Working together to improve the diagnosis, treatment and quality of life for all those affected by arrhythmias

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PATIENT DIES AFTER BEING DENIED ACCESS TO LIFE-SAVING TREATMENT DUE TO LACK OF NHS FUNDING

**High risk patients living with ‘ticking time bomb’ as Cardiac Centres prevented from
providing urgent treatment due to indefinite NHS England ‘evaluation process’**

- **Family of tragic patient and patient on waiting list both available for interview**
- **Arrhythmia Alliance campaigner available for interview**

Wednesday 13 September: London, UK: Arrhythmia Alliance is calling on NHS England to reconsider its ‘Commissioning through Evaluation’ (CtE) process, following the death of a high risk atrial fibrillation (AF) patient from a bleed to the brain after being refused a potentially life-saving treatment. The evaluation process of left atrial appendage occlusion (LAAO), a treatment approved by the FDA and used across Europe, has meant hundreds of patients being denied access to this treatment with no guarantee when the evaluation will be completed to allow access.

LAAO is the only treatment available to prevent an AF-related stroke in hundreds of patients in whom oral anticoagulant drugs are contra-indicated. Many of these high-risk patients who are suitable for LAAO have suffered from previous strokes or transient ischaemic attacks, and many have also suffered from intracranial haemorrhage or major bleeds at other sites.

GF, 74, from Hertfordshire, tragically suffered a bleed to the brain on 24 July 2017, and passed away three days later when his children agreed to turn off his life support. In August 2016, GF was told that the best option to treat his AF would be to have LAAO. After having this procedure delayed at the last minute when a clot was found on his heart, he was devastated to be told in January 2017 that the treatment was no longer being funded by the NHS. He was placed on anticoagulation therapy but sadly suffered a major bleed on 24 July. Full details of his story, photographs and interviews with his family can be obtained through Arrhythmia Alliance.

The cost of an LAAO as used by NHS England for CtE was £7,470 – however, the first-year cost per patient that suffers an AF-related stroke is calculated at well over £13,000.

“We have warned NHS England repeatedly for over a year that this tragic situation would occur while patients are waiting indefinitely for this potentially life-saving treatment. Our heart goes out to the family who wanted us to let others know what happened to their father, and grandfather, in the hope that others would not suffer the same fate. We know of many patients living with this ticking time-bomb, across the UK, who are at seriously high risk of suffering

President: Prof A. John Camm, QHP, MD, FRCP, FACC. **Trustees:** Mr Mark Bullock, Professor Richard Schilling, MB, BS, FRCP, MD, Mr Nigel Farrell, LLB (Hons), Dr Adam P Fitzpatrick, MD, FRCP, FACC, Mrs Trudie Lobban MBE FRCP Edin
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an AF-related stroke and the only treatment option open to them is LAAO,” stated Trudie Lobban MBE, CEO and Founder, Arrhythmia Alliance.

Angela S from Wokingham, Berkshire, is one such patient, “I was diagnosed with AF ten years ago, and when I reached 65 last year, my doctor suggested I start taking warfarin to prevent an AF-related stroke. However, I pointed out that due to a pre-existing condition I could not take any form of anticoagulation therapy due to the severe risk of a bleed to the brain. I was then referred to a cardiac specialist at University College London to identify other options to prevent an AF-related stroke. The best option was LAAO but due to funding restrictions I am now on a waiting list with no knowledge of when, or if, I will get this treatment.”

She added, “I live in fear every day of suffering an AF-related stroke, it is like living with a ticking time bomb.” Angela’s details plus photo, and interview, can be arranged through Arrhythmia Alliance.

A Freedom of Information request made by Arrhythmia Alliance to specialist cardiac centres across England uncovered that many patients suitable for LAAO are unable to receive treatment on the NHS due to funding constraints, while the CtE evaluation process is completed. Some of the most high-risk patients are now being offered the treatment privately as the only means to receive this potentially life-saving treatment.

“Although we believe in the concept of CtE, we cannot accept such high-risk patients with AF being unable to receive this often life-saving treatment. The Arrhythmia Alliance together with many UK Cardiac Specialists is urging NHS England to allow those centres already in the CtE process to continue to provide LAAO while the wider funding decisions are taken.” Said Trudie Lobban MBE, CEO & Founder, Arrhythmia Alliance.

Ms Lobban concluded, “We believe it makes sense both clinically and economically for NHS England to allow this specific sub-population of patients to receive this potentially life-saving, and life-improving technology, whilst the data evaluation is completed.”

To arrange an interview with Trudie Lobban, the family of GF or Angela S please contact:

nigel@hearhythmalliance.org or on 07785 277343

-ENDS-

Notes to editors

ARRHYTHMIA ALLIANCE

Arrhythmia Alliance, are global advocates, working in partnership to reduce deaths and impact on individuals caused by cardiac arrhythmias and their associated morbidities. By raising awareness and campaigning for the improved detection and care of heart rhythm disorders, Arrhythmia Alliance aims to extend and improve the lives of the millions around the world that these conditions affect. Visit website www.hearhythmalliance.org

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ATRIAL FIBRILLATION (AF)

More than 1.4 million people in England have AF, 2.4% of the total population. Nearly 500,000 people in England have undiagnosed AF. The majority of people with AF are suitable for, and can tolerate, anticoagulation to prevent an AF-related stroke. Unfortunately, there are a small percentage of people who are unable to tolerate anticoagulation, or who are at high-risk of a bleed due to anticoagulation, and therefore need an alternative option to prevent an AF-related stroke.

COMMISSIONING THROUGH EVALUATION (CtE)

In 2014, NHS England decided to put LAAO into the CtE programme to carry out further assessment on its effectiveness, limiting funding to a total of 450 patients across ten specialist cardiac centres in the country. The CtE programme is now in its 'assessment phase', which means no more funding is available for any patient until the evaluation has been reported and, if approved, the level of funding agreed. This means no access to LAAO on the NHS for these very high-risk AF patients until the financial year commencing in April 2018 – at the earliest.

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