



Mr Neville Sinclair,
West London Coroner's Office,
25 Bagley's Lane,
Fulham
SW6 2QA

11th May 2026

Dear Neville,

PREVENTION OF FUTURE DEATHS ORDER – 14TH APRIL 2026 – ADAM ANKERS B19/10/2006

I refer to the above and have the following to report.

The Trustees of Sudden Cardiac Arrest UK (Charity 1200875, England and Wales) note the instruction from Coroner, Valerie Charbit in terms of paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroner's (Investigations) Regulations 2013.

Coroner's Concerns , Section 5 – Point E states :- **That cascade communication of genetic or hereditary diseases is imperfect and does not reach more than half of those in families that need to know about it.**

Section 6 , Action should be taken , states:- *In my opinion action should be taken to prevent future deaths and I believe you AND/OR your organisation have the power to take such action.*

Sudden Cardiac Arrest UK is a peer to peer support group, providing survivors and co- survivors of sudden cardiac arrest with the tools to optimise their recovery. Our Trustees are in main, volunteers who have either survived or co survived a sudden cardiac arrest and have no medical qualifications. We have one Trustee who is a medical professional who advises Trustees on medical matters.

Our group aim focusses on the consequence and recovery from a sudden cardiac arrest and not the cause. Whilst discussions do take place surrounding cause, this is minimal and not the focus or remit off our group.

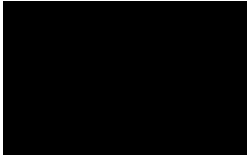
We fully understand that our survivor members may have concerns surrounding potential genetic or hereditary disease, however, feel that the cascade of this information should be led by medical professionals at source on a case to case basis.



If required, we could consider any initiative to support POINT E, however do not feel that we are either qualified to comment on such matters, or that it is within our remit as a peer to peer support charity.

Submitted for the attention of Valerie Charbit, Assistant Coroner, West London Coroner's Court.

Yours sincerely



Secretary
Sudden Cardiac Arrest UK