

Witness Name: Barbara Scott

Dated: 8 December 2022

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN SUBMISSION OF BARBARA SCOTT**

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1. My name is Barbara Scott and I am an unrepresented core participant. My husband Ronald Scott had severe haemophilia and he died in March 1993 as a result of being given Factor 8 infected with HIV and Hepatitis C. He endured a decade of poor health, anxiety and uncertainty before he died. Ronald was kind, generous, loving, brave, stoic and clever. We had a good marriage and we were mostly a happy family.
2. I have been a widow for longer than I lived with my late husband as we only managed to have 22 years together.
3. We had three children, our daughter was born in 1974, our first son in 1976 and our youngest son in 1981.
4. In 1977, the first signs of his illness began to appear. He was hospitalised, and whilst he did recover, we received the diagnosis that he had Hepatitis Non-A Non-B.
5. The impact of infected blood has been very difficult and a source of sadness for our children and I. The secrecy around Ronald's diagnosis caused some tension within our immediate family, particularly in the early years after his death. Secrets in families are toxic, even if the intention for concealment is from the best of motives.

6. I prepared a written statement for the Inquiry which can be found under witness statement number WITN1020001, which provides a detailed account of our history.

### **Impact of this Inquiry**

7. It is self-evident that this Inquiry should, when it ends, give participants a sense that they have had justice and compensation for losses and difficulties they have endured since the 1980s.
8. For myself, I hope that when the report is published it will give me a clearer overview of the way this treatment disaster played out, with analysis of the role of key players and decision makers and organisations.
9. I know through lived experience, the impact on my family and I, and I have heard some of the truly harrowing descriptions of the impact of the viruses, their treatment and the truly dreadful financial impact for some individuals and families. What I don't have is an aerial view of the way the disaster played out and what did or didn't contribute to the disaster. I certainly don't believe it was bad luck.
10. I hope the report addresses the intransigent stubbornness of politicians of all stripes who have simply refused to consider that they might have taken a more sympathetic view of the people caught up in this disaster. My impression, from my rather limited engagement in and viewing of the Inquiry, is that there was little real regret. Their overriding concern was for cost, if there was any admission of fault or liability. They feared an endless stream of supplicants seeking redress. This stopped a sympathetic response in its tracks and once this view established there was no going back. I hope the Inquiry has quite a lot to say about this.

11. The hubris of some political contributors exposed their patronising view of people affected as being “other” and viewed as being unfortunate, but of lesser importance. There have been some notable exceptions.
12. There is a wider point, which should be made in the report which applies to the suggestion that others, as well as the infected blood community, are denied justice for decades, because it’s simply too inconvenient or expensive to take their views or experiences seriously.
13. New arrangements for families bereaved through public tragedy are long overdue. The title of Bishop James Jones’s Hillsborough report “The Patronising Disposition of Unaccountable Power” encapsulates the experience of many of the infected blood community, as well as those involved in Hillsborough, Grenfell and probably many others.
14. What is the purpose of the Government if one of its functions is not to protect and support citizens in times of crisis and difficulty? I think there are good arguments for a no-fault compensation scheme for the times when things go wrong in healthcare. Why do we have to have such adversarial systems where health bodies do their best to avoid saying mistakes have been made?
15. Bishop James Jones has already suggested a different approach for those who find themselves bereaved by events over which they have little control, stunned by tragedy, and then have to battle for an apology and some sort of award to allow them to continue to care or recover. I’m sure cost is at the heart of this, but in the long term it surely costs more and the loss of trust is never assessed. Organisations can hardly expect clinicians or others to practise in a reflective way if this culture does not exist in public life.
16. I am still firmly of the belief that a publicly funded health care system is the fairest and most economical way of delivering healthcare. However it is almost treated as a belief system where questioning is treated as heresy. This in itself, leads to an erosion of confidence. People are scared to challenge and often do not have the language or confidence to raise questions. Better scrutiny,

challenge and greater user involvement surely could make a difference. Class is one of the health services unaddressed difficulties. The necessity of scrutiny and challenge is especially important where people have to manage a condition on a lifelong basis.

17. The sheer length of time we have waited for this inquiry and its recommendations is embarrassing and mean spirited compared to other jurisdictions who have acted much more quickly to deal with the fallout from infected blood.

18. The beginning of reparations has been made for some people such as myself, but is not yet clear what the final arrangements will be. I very much hope that compensation arrangements will be sufficiently generous and will not leave people feeling aggrieved or pit one group against another.

19. Given the length of time it has taken to get to this point I hope it will be as unbureaucratic as possible, time is pretty critical as it has already run out for some.