Witness Name: Professor Charles Richard Morris Hay
Statement No: WITN3983192
Exhibits: Nil
Dated: 31/7/2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PROFESSOR CHARLES RICHARD MORRIS HAY

I provide this statement in response to a request under Rule 13 of the Inquiry Rules 2006 dated 26 January 2023 in relation to the statement of W3983.

I, Professor Charles Richard Morris Hay, will say as follows: -

Section 1: Introduction and Background

1. Professor Charles Richard Morris Hay MBChB MD FRCP FRCPath

   Consultant Haematologist Manchester Royal Infirmary since December 1994.
   Director Manchester Adults Haemophilia Comprehensive Care Centre since December 1994
   Professor of Haemostasis and Thrombosis.
   Senior Lecturer in Haematology Liverpool University and Director Liverpool Haemophilia Centre, Royal Liverpool Hospital 1987-1994.
   Director UK National Haemophilia Database since 2002.
   Member UK Haemophilia Centre Doctors Organisation (UKHCDO) Regional Committee from 1987 and then Advisory Committee since 2007 (when the committee's name changed).
   Vice Chairman UKHCDO 1997 to 2005.
   Chairman UKHCDO 2005-11.
   A copy of my curriculum vitae and publications have already been submitted as exhibit WITN3298007.

2. The Manchester Haemophilia Comprehensive Care Centre (Adults) is based in Manchester Royal Infirmary. At the time of Witness W0165's treatment, this was the third largest Haemophilia Centre in the United Kingdom. In 2020, it is now the second largest with >2500 patients with bleeding disorders registered.

3. When I took up post in late 1994, I was the only consultant specialising in adult Thrombosis and Haemostasis in the North-West Region, assisted by a part-time clinical assistant, Dr Monica Bolton. We now have four consultants with this specialism. In 1994, we had three Haemophilia Specialist Nurses, one of whom also did counselling and went into the community. There were no clinical research staff. There were no joint clinics and no formal liaison with any other supporting specialism or profession allied to medicine, such as physiotherapy. All the follow-up clinics were conducted in the Haemophilia Centre without the assistance of any junior staff. There was no internal training rotation for junior staff, so they spent all their time treating leukaemia. I was on call 1:1, i.e. 365 days a year except when away or on holiday.

4. This group of patients is complex and many need multidisciplinary care and so this situation was unsatisfactory. In the first year in that post, I introduced an internal training rotation for junior staff so that we had a registrar attached to Thrombosis and Haemostasis most of the time. I introduced weekly multidisciplinary meetings and arranged for Physiotherapy input for our patients. I rapidly established joint clinics for Orthopaedics and subsequently joint HIV clinics and joint Obstetric clinics and later joint Adolescent clinics with the paediatric service. Liaison with Hepatology was very close throughout this period but not formalised around a clinic. As we acquired more consultants specialising in Thrombosis and Haemostasis, first in 1999, then in 2003 and in 2018, the patients were reallocated among the consultants.

5. I was consultant Haematologist for Witness W0165 from December 1994 until 2003, when we were Joined by Dr Paula Bolton-Maggs and Witness W0165 was transferred to her care when we shared the patients between us. I was his brother's Consultant Haematologist between December 1994 and his death in February 2001. Both brothers were managed prior to 1992 by Dr Richard Wensley, and between 1992 and 1994 by Dr Guy Lucas. Witness W0165 was managed from 2004 by Dr Bolton-Maggs until her retirement and by Dr Jecko Thachil until his death.

6. We would see the patients regularly for review in outpatients and they were trained to treat themselves at home for more minor bleeding or prophylaxis, dropping into the Haemophilia Centre for more serious problems. Patients with HIV were reviewed at least every three months as outpatients, and when they were inpatients, they would be reviewed by myself three times a week and more frequently, if necessary, with the registrar ward rounds on the days between the consultant ward rounds. They would be reviewed by other teams as necessary - see below.

7. The two brothers bled frequently into their joints, particularly knees, ankles, and elbows. This required treatment with blood products to stem the bleeding. In the 1960s this treatment would have been with plasma or cryoprecipitate, but through the 1970s this was increasingly replaced by pooled Factor VIII concentrates used as home-therapy.

8. Both would have developed chronic hepatitis C in the sixties or seventies and their liver function tests were monitored regularly from the late nineteen seventies. Witness W0165 had a liver biopsy in the early eighties, which required written informed consent and a 3-day hospital stay. Presumably he was made aware at that time that this was a test to assess the severity of chronic hepatitis, (known as non-A, non-B hepatitis at the time). Both would have been diagnosed with non-A non-B hepatitis. Both were tested for hepatitis C in 1992/3 by my predecessor, Dr Guy Lucas.

9. Witness W0165's brother unfortunately also contracted HIV. The late 1980s and early 1990s were a particularly terrible time for people with HIV. Before the advent of triple therapy two thirds of HIV- infected patients died. In 1995 15% of the patients died in a single year, often accumulating 4 or 5 AIDS-defining illnesses or liver failure before they died. It was awful, for the patients and for their families.

10. We tried to manage the patients in a holistic and empathic way. Most had been attending for many years and had a closer relationship with the Centre than with their General Practitioners and would consult us about a whole range of things. Because of the hereditary nature of the condition, we would often be involved with other family members, or even generations of the same family. It was common and encouraged for patients to bring their relatives or spouses and partners with them to Clinic.

11. The affected patients and their families required a great deal of support at that time. Uncertainty was very difficult for anyone (patient or doctor) to cope with. I would say

most bore this with an admirable degree of fortitude. A minority of patients became understandably angry, bitter, and distrustful, and were antagonistic towards the Centre staff. Whilst this was entirely understandable, given the circumstances, it did make it much more difficult to provide emotional support for those patients.

12. Some patients were very distrustful of doctors in general, dealt with their condition by denial, and were reluctant to accept what they were told. For that reason, and because patients wished to avoid treatment side-effects, it was not uncommon for patients to defer or refused treatment for HIV, sometimes for years, when it was offered to them. I think some felt that it was "the beginning of the end" to accept treatment. Certainly, it was a big step.

13. Interferon base treatments for hepatitis C became available during the 1990s and improved until the mid-2020s. These regimens were quite toxic and commonly caused depression and bad temper and fatigue as a specific drug side effects. Before embarking on such treatment, I would explain this to the patient, preferably with their spouse present because relationship problems commonly arose as a direct consequence of these treatment side effects. After the mid-noughties there were no significant advances until the introduction of sofosbuvir in 2013/4.

14. Witness W0165 unfortunately failed to respond to an interferon-based regimen in 1998 after several discussions over several months though he suffered significant side effects including severe depression. His hepatitis C was eventually eradicated by these new treatments in 2016.

15. Sadly, although eradication of hepatitis C reduces the risk of hepatocellular carcinoma it does not eliminate it, especially in patients with cirrhosis of the liver. Unfortunately, in 2018/19, Witness W0165 developed hepatocellular carcinoma, and despite chemotherapy sadly died later in 2019.

16. Haematology and hepatology did their best for Witness W0165 and his brother while they were under my care and the care of the hepatologists. Neither brother was particularly trusting of the medical profession adopting an overtly sceptical manner in outpatient consultations, which led to significant delays in starting advised treatment in both brothers, which was particularly damaging in Witness W0165 brother's case.

17. I would like to take this opportunity to offer my condolences to Witness W3983 and her family.

Specific Criticisms:

18. In her statement dated 16 June 2020, disclosed to me with the Rule 13 notice dated 26 January 2023, Witness W3983 repeats various criticisms of my management of both Witness W0165 and his brother, which I have already addressed fully in my statements WITN3289001, dated 21 February 2020 and WITN3298027, dated 11 June 2020. I refer back to those statements and suggest that they are read in conjunction with this statement.

19. In paragraph 69 of her statement, Witness W3983 suggests that I tried to persuade her daughter to have an abortion. This is incorrect.

20. The consultation in question would have involved a discussion of the heredity and current management of haemophilia and the reproductive choices available to a carrier of severe haemophilia. This would include fetal sexing by DNA analysis at 8 weeks gestation, chorionic villus sampling at 10.5 weeks gestation, but *only if the patient wished to terminate an affected pregnancy*, late amniocentesis at 34 weeks gestation to establish if the baby was affected to facilitate delivery planning, delivery planning, and finally the possibility of pre-implantation selection of embryos. The technicalities and risks of the various procedures would be described. This is presented as neutrally as possible to avoid pushing the patient one way or the other, because some of these decisions are decisions of conscience. The objective of this consultation is to equip the patient to make an informed decision. Given the complexities, our preference is to conduct this consultation with an obstetrician and with the patient's partner present, and preferably before pregnancy so the patient has time to think about it, and to invite them to come back to cover the same ground again. They would also be offered the opportunity to meet with parents bringing up a haemophilic child. In my experience, very, very few carriers wish to terminate an affected pregnancy, although I understand that this is still common in the south-east of England.

21. In paragraph 130 of her statement, Witness W3983 states that Witness W0165 regularly had to change treatments for his haemophilia, to save money. Whilst I cannot comment on treatment policy prior to me taking up post in December 1994, I know that our only concern was to obtain the safest products that we were able to obtain for our patients and was not to save money. I certainly never discussed the cost of treatment

with patients or justified treatment changes on that basis. In fact, treatment changes generally increased rather than decreased treatment cost.

22. Witness W3983 suggests (at paragraphs 189-190 of her statement) that I was responsible for the inquest touching upon Witness W0165's death being delayed and suggests that I should have cancelled a holiday to avoid the delay. I am not sure why she has gained the impression that my availability influenced the date of the inquest. I was not on holiday or otherwise unavailable in December 2019. A delay of 7 months for an inquest is not unusual, I agree with her that this is regrettable. Families are re-traumatised by the inquest.

23. Witness W3983 (at paragraphs 191 and 192 of her statement) complains in relation to my interaction with an observer from the Infected Blood Inquiry, apparently by the name of 'Jack'. I recognised this person from inquests concerning other patients, when he came in and greeted the family, whom he clearly already knew. He was obviously not a family member and when we all sat down, he came and sat immediately behind me, so Witness W3983 was not a witness to our conversation. I asked him perfectly politely if he came to all the inquests, and who he was. He said that he came to some but not all the inquests but did not identify himself. The Hempsons lawyer representing me at the inquest, (who was under the impression that this individual was a lawyer from Collins LLP and was representing the family, then advised me not to talk to him.

24. Witness W3983 complains that I did not speak to the family or offer my condolences. This is true. It is my usual practice to talk to the family directly before or after an inquest because it is the decent thing to do and because it is a useful opportunity to offer condolences and put things into context. Families usually find it useful. However, in this particular case, because of the background, including the family's previous longstanding hostility I was advised not to attempt to engage with them. I found this regrettable at the time, but I hoped they would understand.

25. Witness W3983 has criticised the way I gave my evidence, which she describes as 'cold'. This was a formal courtroom setting. I gave my evidence in the same way that I gave my evidence at all inquests and to the Infected Blood Inquiry.

26. Witness W3983 has stated that she would have preferred it if someone else had attended the inquest rather than me. I attended because the Coroner requested me to do so, although I was surprised to be asked, given that I was not Witness W0165's consultant for the last 16 years of his life. It would have been more usual for the

Coroner to request the attendance of the consultant responsible for the patient at the time of death. It was therefore not clear why I, rather than Dr Thachil, had been summoned to attend. It transpired that I had been summoned because Witness W3983 had submitted a statement to the Coroner in which I was named. I was nevertheless pleased to be able to assist the inquest, in reaching a verdict with which the family agreed.

27. I can understand that Witness W3983 and relatives of Witness W0165 and his brother are angry. Both patients died from viruses contracted from their treatment and suffered greatly before they died. Witness W0165's final illness was particularly awful and difficult to manage, despite a multidisciplinary team including hepatologists and gastroenterologists as well as haematology. This will have been an immense and enduring trauma for the whole family that nothing can assuage.

28. Witness W3983 complains in relation to my interaction with her sister-in-law, Witness W0145. Witness W0145 was extremely and understandably distressed by the catastrophic and rapid deterioration in her husband's health, and our collective inability to arrest that deterioration. Unfortunately, neither she nor Witness W0165's brother could accept or come to terms with advice from Haematology, Hepatology or the nursing staff in relation to Witness W0165's brother's health, management, and very poor prognosis, and consequently she made many unfounded allegations both before and after his death and was aggressive and confrontational towards all members of the team throughout his hospital stay. Healthcare workers, including myself, do not respond in kind in such situations and necessarily fall back on a degree of formality and firmness when confronted with anger or abuse.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C

Signed

Dated 31/7/2023