Witness Name: Professor Charles Richard Morris Hay
Statement No.: WITN3289175
Exhibits: Nil
Dated: 25/08/2022

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 2 June 2020 in relation to the statement of witness W1743.

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

Section 1: Introduction

1. Professor Charles Richard Morris Hay MBChB MD FRCP FRCPath
   Consultant Haematologist Manchester Royal Infirmary since December 1993.
   Director Manchester Adults Haemophilia Comprehensive Care Centre since December 1993
   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 and then Advisory Committee since 2007.
   Vice Chairman UKHCDO 1997 to 2005.
   Chairman UKHCDO 2005-11.
   I have already provided a copy of my Curriculum Vitae to the Inquiry

2. In May of 1987, I took up post as Senior Lecturer in Haematology and Honorary Consultant Haematologists and Director of the Liverpool (Adults) Haemophilia Centre Based at what was then known as the Royal Liverpool Hospital. Although nominally only 6/11 of my sessions were clinical, I was the only specialist in Thrombosis and Haemostasis (both for adults and paediatrics) in the Mersey region and serving North

Wales. I also had responsibility for management and follow up of a third of all the Malignant and General Haematology coming into the Royal Liverpool Hospital including bone marrow transplantation. This situation continued until 1992, when I was finally able to give up malignant haematology. I was on-call one day in three for most of the time from 1987 until 1994. I left this post in December 2004 to take up post at Manchester Royal Infirmary. In the 25 years that have elapsed since then there has been no change in the number of support staff for Haemophilia but the consultant numbers have increased to four.

3. When I took up post in Liverpool in 1987, I found that there was no haemophilia centre as such. The patients would come to the Haematology laboratory if they had a bleed. There were no haemophilia nurse specialists, no physio input, no social worker and no joint clinics of any sort. Comprehensive haemophilia care had not been established in Liverpool in any meaningful sense. Furthermore, the block contract for haemophilia care made expansion of the service difficult and this had to be replaced by individual patient contracts and fees to provide the funding necessary to improve the service.

4. Additionally, the proportion of patients infected with HIV was above the national average and those patients were receptive and appreciative of attempts to improve their care on the one hand but on the other hand harboured a good deal of anger, having been informed of their HIV status by my predecessor by post rather than face to face and having been offered little or no psychological support prior to my arrival.

5. By degrees and as rapidly as possible over a period of about three years, I built up a Comprehensive Care Service, first establishing a weekly multidisciplinary Comprehensive Care Clinic with a Physio and then also a Haemophilia Nurse Specialist and then adding a social worker and a second Specialist Nurse and a multidisciplinary meeting which would include lab staff as well. We also established a Joint Orthopaedic Service and a close working relationship with Professor Ian Gilmour, Consultant Hepatologist, who did his clinic in the room next to my Multidisciplinary Haemophilia Clinic and was therefore very freely available for advice and to see patients as required.

6. This was the most difficult period following the advent of HIV. We were all, doctors and patients alike, learning about the natural history of this previously unknown condition and treatment was evolving. The patients were struggling with uncertainty

and increasing ill health. Treatment for HCV was in its infancy and not very effective for most patients. To start with, there was no treatment for either condition and then anti-retroviral drugs were slowly introduced and administered in maximum tolerated doses. This was only transiently and partially effective in arresting the progress of HIV and was poorly tolerated. It was during this period that most of the patients with HIV died, either from AIDS or from liver failure. In 1995, triple therapy was introduced and HIV-related deaths reduced to a very small number and liver deaths also fell dramatically.

7. The entire team were very actively involved in offering this group as much support as we could. It is noteworthy, that when I left to take up the post in Manchester, almost 40 of my patients followed me and our Senior Haemophilia Nurse and Social Worker both resigned and took up posts in other areas because they were "burned out". This is a common phenomenon amongst carers of highly stressed patient groups requiring a lot of psychological support and especially where the staff get to know the patients and their families well.

8. Patients with HIV or serious liver disease would be reviewed once a quarter in clinic, every six months if they did not have these complications or had mild liver disease and more frequently as necessary. All patients were offered a drop-in service for acute problems or if they wanted to come in and discuss things more informally. When they came to clinic they would usually see me but would sometimes see the Senior Registrar. If a patient specifically requested to see the consultant and assuming I was present, then they would see me. If the registrar was not sure what to do they would ask me.

9. Patients with liver disease had their liver function tests (liver biochemistry including transaminases) conducted every six months from the late nineteen seventies and were investigated further for exposure to hepatitis B, A and C when the tests first became available. Hepatic ultrasound was conducted approximately every two years and sooner if something changed.

10. I was witness W1743 late son (Graeme's) haematologist from May 1987 until 1993. I do not have access to his medical records because I have not worked in the Royal Liverpool Hospital for over a quarter of a century.

11. I remember him and his family very well. His family were very active in the Haemophilia Society when I first knew them, withdrawing to some extent latterly because they found the whole situation with HIV too distressing. My impression was of a very nice family struggling to deal with a desperate situation. I do not recognise witness W1743's statement that the doctors at RLH treated Graeme's parents as the enemy and thought that I had a good relationship with his parents right up to the end, at which point we disagreed about his management.

12. Graeme was a pleasant, intelligent and brave young man, who latterly worked as a teacher, until illness forced him to give up. I think he was probably moderately depressed for at least the last two years of his life, during which time he lurched from one AIDS defining illness to another. He was profoundly immunosuppressed. The HIV treatment caused side effects and was only partially effective. This was the era before the advent of triple therapy. He suffered repeated infection including ocular toxoplasmosis, which threatened his sight. Ultimately, he developed intracerebral lymphoma, which is an incurable complication of HIV. This required radiotherapy which had the unfortunate side effect of causing somnolence, which is temporary, and loss of short term memory. At this point in 1993, it was very clear that he was soon going to die. Graeme knew this. We arranged respite at Bethany. He was 27.

13. Graeme usually attended clinic on his own or with his brother. In the early days, his father would accompany him but not latterly and his mother never came. I suspect his parents found his medical situation increasingly distressing, which is understandable. Since Graeme was an adult, it would be him and not his parents with whom I would communicate unless he requested otherwise. For that reason, I do not know how well they understood the details of his condition, its treatment and his outlook. I suspect, but do not know, that Graeme may have been shielding them to some extent. At the time I thought that he kept them fully informed. With hindsight, I wonder whether that was the case.

14. Late in 1993, Graeme's father came to see me. I saw him with Sister Cathy Marsden, one of our Haemophilia Nurse Specialists. He indicated that he and his wife had lost faith in our treatment and wished to move his management to Fazackerly Hospital. I had no indication of this from the patient and was anxious to establish if it was also the patient's wish, especially since I gained the impression from Graeme and his father that this was instigated by Graham's mother and not Graham. Whilst appreciating and understanding that Graeme's parents were deeply upset by his

plight, my team and I felt quite strongly that such a move, when the patient was near to becoming terminally ill, was not in the patient's best interests. A second opinion can be helpful in a difficult and unclear situation, but that was not what was being proposed here. The proposal was to move him in the last stages in his life to a hospital where he knew nobody and where they were unfamiliar with his complex past medical history. It was also a hospital lacking a haemophilia centre. We were, also upset by his apparent criticism of our management, which we felt to be unjustified. The patient's father invited me to agree that Graeme's treatment had been substandard. The Haemophilia team, including a counsellor, nurse specialists and a social worker had invested a great deal in Graeme's care and we were all quite upset by this unexpected turn of events. I tried to explain to Graeme's father why we did not think this move was in his best interests, but he was not very receptive. It was a very difficult conversation and ended with me saying I would speak with Dr Nick Beeching at Fazackerly and, at the very least, talk over his management.

15. I spoke to Dr Beeching the following day. I knew Dr Beeching already and we had discussed a few cases together over the years. He confirmed that he had been contacted by the family and that he would take the patient if required. We discussed the past history and current situation in detail, and the past treatment history. He confirmed that he did not feel he had anything special to offer, not least because Graeme was sadly at a very advanced stage of AIDS. Dr Beeching had no criticism of Graeme's previous treatment. My recollection is that he had been contacted by the parents and not the patient, and neither of us was convinced that we knew exactly what Graham wanted. I said I would speak to the patient and family again.

Section 2: Responses to criticism from Witness 1743

16. At paragraph 47 of witness W1743's statement the witness states that: *"Dr Hay had told Graeme that he could go blind as a result of HIV. This was a heartless, cruel and untimely comment that, although possibly true, was nevertheless only a possibility and delivered to Graeme when he was unaccompanied and at a very low ebb."*

17. I cannot remember the context of this particular conversation. I would agree that it is not ideal to impart such bad news when the patient is unaccompanied and depressed. However, when a patient with ocular toxoplasmosis attends outpatients alone and asks the question *"What is the worst that could happen?"* one cannot lie and one cannot defer or send them away until they are less depressed or are

accompanied. One has to be honest and answer the question. Such news is bound to be a shock, whenever and however it is delivered.

18. At paragraph 75 of witness W1743's statement, the witness states that:

    "Graeme felt so unhappy about his treatment at RLUH that he wished to transfer to Fazakerley Hospital. We therefore took Graeme to FH and the Doctor there agreed to accept Graeme and said he would talk to Dr Hay about it. However Dr Hay refused the transfer and registered his annoyance by an angry telephone call to me which is when I voiced my opinion of the way Graeme was being treated under his care"

19. My recollection is that I never got a clear answer from Graeme about what he wanted. He indicated that the motivator for all of this was not him but his mother. Whether he was trying to spare my feelings or not, I will never know. One way or the other, having quietly and calmly discussed with him the contents of my conversation with Dr Beeching, he agreed that to move his care was probably pointless. Had he expressed the desire to be transferred, I would have arranged the transfer.

20. My recollection is that Graeme's mother telephoned me and not the other way around. She was distressed, very emotional and combative. It was one of the most difficult telephone calls of my career and, regrettably, voices may have been raised by both parties.

Statement of Truth

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

GRO-C

Signed

Dated ______25/8/2022________ _________