Witness Name: Frederick Bates

Statement No: WITN0393001

Exhibits: WITN0393002 – WITN0393015

Dated: 11 May 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF FRED BATES

Section 1: Introduction

1. I Frederick Bates of GRO-C Manchester, GRO-C, will say as follows:

2. I was born on GRO-C 1949 and diagnosed with Haemophilia at age 2.5years. I suffer from Haemophilia A, which causes occasional bleeds in various joints including my knees, ankles, elbows and wrists. I have a twin brother, who unlike me, is not a haemophilia sufferer.

3. I married my wife Eleanor in 1977 and we have one son together, (Allan born in 1977). I have a stepdaughter as Eleanor had a daughter from a previous relationship. When Eleanor was pregnant with Allan, we were advised that if we have a girl, the child would be a haemophilia carrier, but that if it was a boy, the child would be fine. Dr Delamore offered my wife an abortion which was refused.

4. I have lost an uncle who died from HIV in the 1980s/90s and a cousin who also died from HCV. Another uncle passed away from the effects of haemophilia. Both uncles were treated at Newcastle Hospital. I myself had considered going to this hospital for a knee replacement operation, but very fortunately had

decided against it on the basis that it was too far to travel. I am now aware that I would not have survived had I have been treated at Newcastle.

Section 2: How infected

5. Up until the age of 7, I was treated at Booth Hall Hospital and thereafter my treatment was at the Manchester Royal Infirmary.

6. All of the treatment that I received was freeze dried Cryoprecipitate. I can recall how it would leave me shaking from how cold it was.

7. I believe I received contaminated Factor VIII concentrates for my condition in the 1970's / 80's from which I was infected with Hepatitis A, B and C and exposed to the risks of CJD. (see extracts from records attached WITN0393002)

8. I am of the view that the Hepatitis C infection occurred in 1984 when I was treated regularly with Factor VIII, over a period of 6 weeks, when I was very unwell (summary attached WITN0393003). At no time was I advised of the risks associated with the Factor VIII.

9. This is supported by my records which state *'It is most likely that Mr Bates has had chronic hepatitis C for over 30 years and is likely to be cirrhotic'* and *'He has had multiple blood products before 1984*. There is also a letter from Dr G Lipscomb to the Consultant Haematologist stating I was "*diagnosed as having Hepatitis C in 1993 and that in 1980 I had a scan which showed an enlarged liver and spleen"*. Dr Warnes letter of 14.10.97 states I **'***developed Hepatitis C in 1983 as evidenced by an ALT of 381 and AST of 164 but that his LFT's are normal'***.** I have tabbed the aforementioned documents at WITN0393004.

10. Due to the various spontaneous bleeds (knee joints, ankles, elbows) I regularly required Factor VIII concentrates which was administered solely at the hospital until 1984. It was not until 1991 that I began home treatment and all records in

relation to home administration have been kept and can be made available to the Inquiry, if required.

11. I have had several surgeries and treatments for my ankles and have undergone knee replacement surgery in 1991 which then had to be replaced in 2002 following an infection. Previously I had a lump on my wrist which was cancerous, I remember being passed around as no-one wanted to treat me.

12. I was never diagnosed with the infections. The way this information came about was when I found out about the Hepatitis in mid-90's, after querying this with the hospital following concerns triggered by an appointment with my then solicitor.

13. The diagnosis was only confirmed to me after I questioned the hospital after reading a leaflet passed on to me by a fellow Haemophiliac which raised serious concerns around late 1993.

14. When I queried this again with the hospital, it was then that I was told I was positive. Dr Guy Lucas confirmed a positive diagnosis to me and told me there was nothing to worry about. Having visited the hospital for years for treatment I was shocked that no one had ever told me about my infections.

15. As per my medical notes which I have tabbed as WITN0393005, I received the following batches and amounts of Factor VIII containing a donation from a donor who subsequently developed vCJD:

FHB4189 Date of first dose 18.05.94 total dose 6,090 units
FHC0289 Date of first dose 31.07.90 total dose 765 units

16. My medical records also evidence a Hepatitis B positive test result dated 12.11.84. I was not informed that I was Hepatitis B positive until 1995. I refer you to WITN0393006.

17. A further entry is noted as me being Hepatitis B & Hepatitis C PCR clear in 09.01.96.

18. Other entries state that I was Hepatitis A positive by July 1993. Again, I was not made aware of the diagnosis until I questioned it with the hospital myself. The records state I was cleared by 16.11.95, please see notes tabbed WITN0393007.

19. Unbeknownst to me, I was tested for HIV in 1987 as a result of the exposure to blood products but luckily, I was negative. I refer to letter at WITN0393008. The first time that HIV was put on my radar was after watching the News at 10.

20. I find it very hard to get my head around why the diagnosis was withheld. I am sure that I would not have found out if it was not for my inquisitions. The Trust had this information for years but never informed me, despite all of my attendances at the hospital over a long period of time. The details and information held in my case are highly relevant to the issues surrounding available knowledge at the time and wrongful withholding of information.

21. My situation further reflects and evidences denying patients, choice of treatment options, and the delay in the communication of results. Upon reflection, I am adamant I would have stayed in bed and rested rather than take on such a risk, given that I did not suffer from any life-threatening bleeds.

22. When I was informed of the Hepatitis C, I was advised it was nothing to worry about and to go home and forget about it. What precautions could have been possible if this was the advice being given?

23. One of the most upsetting aspects has been the fact that, up until 1994 I was classed as a mild haemophilic with a clotting factor of 5%, which then changed to 1%, rendering me a severe haemophilic. I believe this was a result of the HCV.

24. From January 1998 – January 1999, I was put on Interferon Alpha treatment for a period of 12-months. This was a very difficult treatment to tolerate; I suffered from depression, forgetfulness and a host of other symptoms. Unfortunately, this treatment failed. My Hepatitis C PCR came back positive after stopping the alpha treatment WITN0393009.

25. I note the misinformation in my notes which state that, partly due to my membership of various 'support' groups, I was not happy about being advised by Dr Hay that I am not a suitable candidate for Interferon, and that I demonstrate enthusiasm for trying alpha- interferon treatment. There is also an entry saying "of a patient pressure group". These notes can be found at WITN0393010.

26. My initial treatment consisted of Pegylated Interferon over 12 week period. This failed and I was then treated with Sovaldi over a 6-month period. I really did not want to take Ribavirin as I had heard of the side effects of this and yet my medical notes say that I was eager to go on it. This raises concerns regarding the documenting of records correctly which falls within the terms of reference of the Inquiry and is a highly important issue to be examined.

27. No advice was given to me about the effects of these treatments and I recall waking up, shaking like a leaf on the first night of taking Interferon.

28. In or around January 1998, I was switched from Replenate to Alphanate Factor VIII due to a variant CJD scare. Please see letter tabbed WITN0393011.

29. Around August 2002, I received a letter from Dr Hay saying I am eligible for the current BPL clinical trial of continuous infusion of factor VIII, which he had invited me to discuss. I agreed to par-take in the trial and it is noted that I was getting on well with the clinical trial of 3rd generation recombinant factor VIII PFM. Please see letter tabbed WITN0393012.

30. I also consented to an open study to investigate the safely and efficacy of Optivate in Haemophilia A patients undergoing surgery. The purpose of the

study was to evaluate the new dual inactivated high purity factor VIII concentrate. It was confirmed to me, that apart from changing to the new product Optivate, the treatment regime will not change in any way. I refer to letter dated August 2002 from Jason Keegan relating to this study, which can be found at WITN0393013.

31. The damage to my liver became apparent after undergoing a number of scans. I can recall refusing a biopsy due to the possibility of a bleed. The hospital was unable to do a Radioisotope scan. I underwent a Fibro scan, and the level found was 9-14 indicating that there was quite severe liver scarring.

32. I recall Dr Tabnor at Withington hospital wanted me to have regular blood checks but at that time, I did not know the significance of this.

33. Very recently, I have been offered a treatment which I have been told brings X and Y cells together but that it comes with a high risk of thrombosis. I am likely to refuse this treatment; however, it is important to note that when I questioned about the treatment, I was advised by the hospital that they have to keep their drug companies happy. This is concerning and I consider it is important for this Inquiry to investigate and highlight current medical practices with a view to ensuring patients are not put under any risks and are made aware of any potential risks to new treatments, so that history does not repeat itself. It should be re-iterated, that patients have a right to make informed decisions about their lives and any treatment options, and Haemophiliacs should be treated any differently in this regard.

Section 3: Other Infections

34. N/A

Section 4: Consent

35. No precautionary advice was given nor information about the infection itself or the treatment side effects. I remember waking up the first night on the treatment shaking like a leaf which was very scary.

36. Why was I left ill prepared for this treatment and its consequences? This knowledge would at the very least have enabled myself and others who were infected and their families to come to terms with what was to come and prepared them for the difficult time ahead.

Section 5: Impact

37. I recall that at the age of 11-12, my mother was taken into a room by one of the doctors where she was advised that I would probably be dead soon. I heard this comment through the glass doors but never let my mother know that I had heard this. Naturally, such news at such a young age had a very traumatic impact on me and resulted in me growing up in fear of death. I was aware that at that time, the oldest living haemophiliac was aged 48. This inevitably made me feel like I may not have long to live so I was unable to plan my life.

38. I attended a special school for those with disabilities and would describe it as a not so pleasant experience. I was often in and out of hospital. In the event of a bleed, a nurse would wrap me up and send me to the hospital in an ambulance which was of course the worst thing to do. I was glad to leave the school when I turned 15.

39. The first job I was offered via my local jobcentre was medical glass work which was not ideal for haemophiliacs and so I declined.

40. I then started working for a bakery. I had an early start each day at 4am but I still enjoyed this job. Unfortunately, after some time I left.

41. I then went into printing work, but those with disabilities were not treated well by the manager there which resulted in me leaving this job.

42. I went to work for Johnson's which suited me very well. I was promoted to managerial level and was earning extremely good wages, (£148 p/w plus bonus).

43. Life became quite challenging and despite being the breadwinner in the house, I was forced to give up work. My treating Physician advised me to give up work and survive a little longer or keep working to the detriment of my own life.

44. I found it more and more difficult to do things around the house, suffering from forgetfulness, lack of concentration, sweating, lethargy and sometimes jaundice.

45. Sadly, due to my medical complications and on doctor's advice, I retired in 1979/80, aged only 32/33. I was still on Cryoprecipitate at this point. When I returned to see the doctor at some point in the future, he asked me if I was still working and when I confirmed that I had retired upon his advice, he was surprised and asked: 'Did I say that'?

46. This meant a reduced income in the household from £145 per week to £45 per week which brought about its own challenges. The payment from Skipton was insufficient for our needs with two young children to support. This case reflects on the impact on life where the breadwinner is forced to retire so young on the grounds of ill health with a young family and the appropriateness of any payments from the Trust funds in support.

47. I have had to live my life in secrecy given the great stigma attached to my condition. I was too scared to tell anyone about it and if questioned, I would say that I had arthritis. I even kept my diagnosis a secret from my children. I recall once having to seek help from my son to put my socks on; Allan had an inkling that something was wrong. Soon he started asking his mother if I was ok and would always want to know where I was as soon as he got in from school.

48. I regret that I was unable act normal with my grandchildren over the years. There have been occasions where I have had to avoid them or yell at them for their safely, like if there was a needle or something in the vicinity. It has made me feel awful that I had to be this way.

49. I was unaware about the possibility of contracting AIDS until I watched a TV programme aired about it. Luckily I was not infected with HIV but I have lost lots of friends based on the possibility that I could be infected. Eleanor and I have also lost many 'infected' friends which has been difficult for us.

50. Treatment from dentists had been rejected in the past and it took a significant effort to find a dentist who would be prepared to treat me. I had to use my money from the Skipton Fund to pay for any treatment when I did eventually find someone who was prepared to treat me.

51. I have fought against the attitude that the stigma attached to HCV is less significant than AIDS and I consider the Secretary of State for Health (Mr Frank Dobson) in the late 90's, was unfair in saying at the fringe meeting at the labour party conference in Blackpool, that haemophiliacs with hepatitis C will not get any compensation as the stigma is not there as is the case with HIV, and that there are already benefits in place.

52. This is far from the truth, the reality is that Hepatitis C suffers, like myself and others were left on benefits, we were unable to afford life insurance due to the hefty premiums, we could not get a mortgage, we lost a number of good friends who were frightened their children might catch HCV, not only did we suffer the physical challenges brought about by my HCV condition but we lived quite isolated lives having to boil and wash bedding, towels etc separately.

53. This together with the inability to provide for families in the event of their death, is in no way any less significant than the challenges brought about by HIV.

54. It is issues such as the disparity in compensation for haemophiliacs that have led my wife and to fight for justice

55. The reality for me is that I have to live every day in the knowledge of the risk of liver cancer and possibility of reverting to PCR positive. Although I am now in the clear, I am still fearful of incidents happening, and I find that my immediate reaction is to behave as if I am still infected.

Campaigning efforts:

56. My wife and I have campaigned extensively on various issues relating to the issues relevant to the Inquiry. This can be evidenced by the enclosed correspondence. I have been part of the Manor House Group and have had meetings and/or interaction by correspondence with prominent figures in relevant offices in order to raise awareness and to fight for justice. This includes Member of Parliament (MP) for Wythenshawe and Sale East, Andy Burnham, Andrew Lansley, Virginia Bottomley, Mike Kane, Allan Millburn, the late Paul Goggins, Lord Morris of Manchester and other significant members in office, in relation to a whole host of issues relevant to the work of the Inquiry. I attach correspondence in relation to this which I still hold - WITN0393014.

57. My wife and I were also part of the Manor House Group for whom we did a lot of research. We have actively campaigned at the House of Commons over the years, including protesting outside party conferences.

58. The Inquiry is referred to the enclosed newspaper articles, a snippet of documents from Westminster Hall in which our efforts have been referenced by Amber Rudd and sample letters showing other campaigning efforts in their pursuit for justice WITN0393015.

Section 6: Treatment/Care/Support

59. I was offered counselling at Manchester Royal Infirmary, but I would not attend, as I had witnessed a staff member speaking openly about a different patient's issues and laughing at one of the client's problems, post visit.

Section 7: Financial Assistance

60. In terms of the Skipton Fund, a stage 2 payment of £32k was received which was then increased to £50k. I now get £18k a year to be increased to 22k soon with the increase. Eleanor and I use this fund for essential needs.

61. As we were not financially stable we were unable to purchase a house, which we would have loved to. Due to my infections, my health deteriorated which meant my work and earning potential decreased significantly. Money became very tight and earnings dropped from £148 p/w to £45 p/w. With 2 children to support and me being the breadwinner in the house, life became difficult.

62. We never went out for a meal as we could not afford it and could not have attended any meetings held by the Haemophilia Society, as could not have afforded to travel. We were unable to afford a holiday until Allan turned 15.

63. We were brought up with the mindset of avoiding debt, so just managed the best we could without incurring debt.

Section 8: Other Issues

64. I believe this case highlights the further issue that if the infected were not being provided results of such life changing conditions then what impact this would have had on the management, monitoring and care of the condition. This poses the very important question of why the infected were knowingly being exposed to the risk of further unnecessary problems.

65. In 2019, my wife and I made an application seeking permission to issue Judicial Review proceedings on foot of two decisions of the Chairman of the Infected

Blood Inquiry, where he granted my wife and myself core participant status, but refused to designate Malcomson Law UK as our recognised legal representatives. We sought to challenge the decision refusing to designate MLaw as our legal representative.

66. Unfortunately our application was unsuccessful on our first attempt and also upon appeal. I felt that MLaw as a firm with extensive experience had very much to offer and the refusal to designate them as our recognised legal representative hinders my ability to contribute to the Inquiry, therefore undermining the effect of recognising me as a core participant.

67. I remain very disappointed that I have been unable to instruct and have MLaw to represent my interest during the course of the Inquiry. I have therefore been left as an unrepresented core participant and I admit that I have been totally let down by the Inquiry as a whole.

68. Finally, after all of this time, we would like the following addressed:
    - the full truth about what happened
    - accountability
    - adequate financial assistance to give me the life we would have had if I did not have to give up my career
    - an apology
    - changes within society and specifically for haemophiliacs to be treated with respect.

Statement of Truth

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

Signed GRO-C

Fred Bates

Dated 11·5-2021