Witness Name: Kimberley Mobey
Statement No.: WITN1941001
Exhibits: WITN1941002-
WITN1941051
Dated: 16 October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KIMBERLEY MOBEY

Section 1. Introduction

1. I, Kimberley Mobey, will say as follows:

2. My date of birth GRO-C 1992. My address is known to the Inquiry.

3. I write this statement as an affected person as my father was infected with Hepatitis C (HCV). My father had three children from his first marriage. He married his second wife, my mother, and had three more children, of which I am the eldest child.

4. I am a support worker and live in Wiltshire with my six year old daughter.

Section 2. How Affected

5. My father, Christopher Mobey, was born on GRO-C 1963 and died on GRO-C GRO-C 2001, aged 38 years. My father was a funny, kind, loving and caring man who I loved to bits.

6. I was born in 1992 and was a child throughout my father's illness. I was eight years old when he died, so my recollection of what happened is sometimes limited. I have provided as much detail as I am able to in this statement and have referred to his medical records, where they are available, to assist with the history.

7. My father had severe Haemophilia A and was also diabetic. I remember he received treatment for his haemophilia throughout his life from an early age, first at hospital and later by self-injection at home with Factor VIII. He also taught me how to inject him. He was covered in bruises from injecting himself and had bruises on the back of his hands from cannulas. His haemophilia treatment centre was at the Oxford Haemophilia Centre, Oxfordshire. I also remember him receiving treatment in a Birmingham Hospital also but do not know which one.

8. The medical records from John Radcliffe Hospital include a record of his early treatment from 1963, the year he was born, onwards **(WITN1941002)**. **WITN1941003** is his record of surgery and dental extractions. **WITN1941004** is his home treatment record from 1974 to 2000. **WITN194105** illustrates some of the treatment he received at Treloars, where he was a student. **WITN1941006** confirms he commenced home treatment at 16 years old, in around 1978. **WITN1941007** is a record of therapeutic materials used and the patient response. He had many, many hospital admissions over the years.

9. Medical records also show treatment with Factor VIII, described as Cutter FVIII Koate, in 1985 with all batch numbers, a total of 27 treatments in one year (**WITN1941008**). Such treatment continued at a similar level in the years that followed, with Alpha FVIII (Profilate) being introduced in 1987, BPL FVIII 8Y in 1988, Monoclate in 1989, BPL Replenate in 1996, and Alphanate in 1998.

10. I believe my father was infected through use of Factor VIII, something which is confirmed in his medical records, for example, a discharge summary from 1998 records, 'Hepatitis C contracted through Factor VIII' in his list of diagnoses (**WITN1941009**).

11. Very early records for my father contain a letter dated 30 October 1968, when he would have been five years old, from Dr Rizza, his consultant physician at the Oxford Haemophilia Centre, describing his condition, saying as follows: 'Christopher suffers from classical haemophilia and so is liable to bleed following injury. In addition to the bleeding from cuts and grazes, these boys also bleed internally into muscles and into their joints. It is important to treat this latter type of bleeding early, since the damage to the muscles and to the joints can cause crippling. We feel that if these bleeds into the muscles and joints are treated early, that is within an hour or two of the on-set, they can be halted and the boy can be back at school within the next day or two. If treatment is not given in time the joint becomes very swollen and very painful and he may be off school for two to three weeks. In addition, to this of course, he may have damaged his joint considerably.' (**WITN1941010**).

12. A note from 1972 describes my father as follows, 'he is a very bright little boy, doing very well at school and with any luck should do well in his education' (**WITN1941011**).

13. A discharge summary from the haemophilia centre from 9 May 1972, when he was aged nine years old, notes he was admitted to hospital with a mild haemarthrosis of the left knee. The summary ends, 'In view of the fact that this patient has received AHG concentrate which had been prepared from a large pool of blood donations, we would be interested to be told at the earliest date of the subsequent occurrence of jaundice'. (**WITN1941012**).

14. My father's medical records note that he attended the Lord Mayor Treloar College, leaving on 15 June 1979 when he would have been 16 years old. A letter from Dr Wassef at the Treloar haemophilia Centre dated 26 June 1979 notes, 'this term he has had more than average number of bleeds mainly into his right knee and both elbows. At some stage because of his alarming frequency of bleeds we thought of putting him on prophylaxis to save material. As he has successfully completed our course in self therapy and is competent to transfuse himself, I feel that supplying him with the material and advising him to treat himself at the easiest sign of a bleed, will very much help in reducing his material requirements.' (**WITN1941013**). This letter goes on to list the limitation of joint movements and records abnormal liver function tests with SGOT (AST) as 'variable. Normal or slightly raised up to 62 IU/L (normal range 3-40 IU/L)'. The 'material used' is recorded as 'NHS and Commercial concentrate'. His medical records contain many pages of treatment records during his time at Treloar's.

15. This record is not the first to note raised AST levels, with an earlier record on 10 August 1978 recording a raised AST level of 67 (**WITN1941014**).

16. I believe my father discovered he had HCV in 1993. The virus had lain dormant until this point when it was also discovered he had cirrhosis of the liver and required a first and then a second liver transplant. I remember he was quite yellow and used to joke he looked like one of the Simpsons. The first transplant initially went well but the liver became seriously infected and he underwent a second transplant which became even more severely infected.

17. Records from John Radcliffe Hospital include a 'Hepatitis C Checklist' dated 6 December 1994 which records in a list the following, all of which have been circled, apart from number 6:

'I have discussed the following topics with the patient:

1. Anti-HCV result.
2. Current liver function test results.
3. Follow-up arrangements.
4. Synergistic effect of alcohol consumption.
5. Risk of transmission to sexual partners.
6. Treatment options.

The patient was already aware of his result' (**WITN1941015**).

I recall my father drinking a bit but I would not have classed him as a heavy drinker. I also do not know whether he ever received treatment for his HCV.

18. The medical records from John Radcliffe Hospital show a first positive test for HCV antibodies and HCV RNA on 8 November 1991 (**WITN1941016**). However, an earlier record of 3 October 1989 shows a positive result for 'CMV', which has been crossed out and replaced with handwriting noting, 'Hep C' (**WITN1941017**). An even earlier lab report with a collection date of 22 September 1989 shows 'Anti Hep C Detected'. The clinical details on the report are 'haemophilia, liver disease' (**WITN1941018**). If my father was only informed of his HCV diagnosis in 1993 then there appears to have been a delay in telling him about the infection.

19. A letter dated 7 March 1996 notes, 'He was first noted to be hepatitis C antibody positive in 1991. His AST however was first noted to be markedly elevated in May 1987.' (**WITN1941019**). As set out above, other medical records note his AST levels were raised from as early as 1978, when he was 16 years old. His ALT levels were reported to be raised from February 1980, when he was 18 years old (**WITN1941020**).

20. A letter from the haemophilia centre to whom it may concern for a proposed holiday to Spain, dated 18 September 1987, explained his

condition as follows: 'This young man is a severely affected haemophilia with 0% factor VIII. As a result of past bleeding episodes he has restricted movement in his right elbow which moves from 45°-88° (0° = straight) and his right knee 30°-137°. His left elbow and right ankle are also slightly restricted in movement. He treats small and early bleeds himself at home and requires on average 1 or 2 doses of 500 units factor VIII a week. He has never been jaundiced but his liver function tests which had been slightly abnormal for quite a long time, became more abnormal in May 1987 probably related to a high intake of alcohol. He was advised not to take alcohol and since then his tests have begun to improve.' (**WITN1941021**).

21. A letter from Dr Trowell to his GP of 9 June 1987 documents their first meeting in May 1987 after he had been found to have an AST which was consistently elevated to more than 320. The letter notes, 'I pointed out to him that the amount he was drinking was quite adequate to cause serious physical damage and that in addition to this as a haemophiliac he undoubtedly needed factor VIII from time to time, which in itself carries some risk of recurrent and even chronic liver damage.' The letter goes on to explain Dr Trowell advised abstention from alcohol in order to assess the result and 2 weeks later he had done so and had only felt unwell once, his itching had gone and he had no further episodes of severe pain. 'When I examined him he was not icteric, was tender on deep palpation of the right side of his abdomen and his liver function tests did show some improvement with an AST that had fallen to 200. I stressed to him that it was necessary to abstain and we will arrange to monitor his liver function tests regularly over the immediate future.' (**WITN1941022**).

22. A letter from Dr Trowell to his GP of 8 October 1987 notes him to be 'symptomatically better with no vomiting but he is still drinking about 4 pints of alcohol about one night per week and his symptom when he saw me last month was of pain over his liver, especially at night. On

examination his was minimally tender in this area and his AST is still over 300.' (**WITN1941023**).

23. A letter from the health visitor to my father on 3 November 1987 says, 'just to let you know that your last liver test has gone up higher again from 200 i.u. in September to 400 i.u's this time'. (**WITN1941024**).

24. His medical records contain regular notes of bloods being tested for LFTs (for example, from August 1978 where ALTs are 56 (**WITN1941025**) and many tests after this date) and yet there appears to be no investigation of why this might be happening. I am unsure why his abnormal liver function tests were not investigated at this time and were instead put down to alcohol intake.

25. A letter dated 5 July 1988 from Dr Joan Trowell to my father's GP notes his drinking pattern and says, 'On examination, he still has a palpable liver and spleen, and his liver function tests remain persistently abnormal with an AST of over 200. I again stressed to Christopher that to some extent his alcohol was undoubtedly influencing his liver, although there may be a background of resistant non-A/non-B hepatitis related to factor VIII. However, we have found the prognosis to be much worse in those haemophiliacs who continue to drink heavily, as there may be a possible synergistic effect.' (**WITN1941026**).

26. A letter dated 23 October 1989 from Dr Joan Trowell to my father's GP notes his drinking levels and says, 'he has a palpable liver and spleen but no ascites or peripheral oedema. His liver function is still abnormal and I am sure that he has chronic underlying liver disease possibly related to a non-A non B hepatitis but his alcohol consumption must be exasperating the situation. Unless there is a crisis in the meantime I have asked to review his progress in a year's time.' (**WITN1941027**).

27. A further letter dated 6 July 1990 from Dr Joan Trowell to my father's GP again notes his drinking levels. The letter goes on to note, 'he is not jaundiced and has a palpable liver but no localised tenderness. His liver function is abnormal. His total bilirubin is 27 with an AST of 175 and GGT of 145. These are slightly worse than on the assay six months before. His serum albumin is however well maintained at 40. I am sure that this young man's symptoms are related to his drinking and I stressed this to him. I have made arrangements to preview his progress in six months' time.' (**WITN1941028**). I do not know why there is no mention of possible HCV despite other medical records for my father recording 'Anti Hep C Detected' as early as September 1989 (see above).

28. A letter dated 1 August 1991 from Dr Rizza to the orthopaedic consultant notes, 'in addition to this problem [limitation of movement] he also suffers from chronic hepatitis. His HIV serology is negative.' (**WITN1941029**). I do not know whether my father was informed that he had tested negative for HIV, however a further record dated 2 October 1989 shows a circle around option 3, 'no I do not wish to take part in the study', and then a signature from my father under the wording, 'I agree to the results of my anti-HIV tests being given to Dr Catalan for the purpose of this study'. (**WITN1941030**). There is a negative sign in brackets in handwriting on the paper, '(-)'.

29. I do not know when my father was informed of his HCV status. Clinic notes covering the period 8 November 1991 record on this date, 'blood taken for HCV study' (**WITN1941031**). The next entry in the clinical records on the same page is for an orthopaedic clinic and does not mention any test result for HCV. As set out above, a newspaper article records my father being informed of his HCV status in 1993, which suggests there was a delay in him being informed of the infection.

30. I do not know whether my father was ever given information or advice beforehand about the risk of being exposed to infection through blood or blood products. Medical records note under the question 'safe sex?' that 'does not use a condom' is recorded, so it would appear from this that little information about containing the infection was provided (**WITN1941032**).

31. As a result of receiving infected blood my father was infected with HCV.

32. I do not know how my father found out he was infected with HCV or any of the circumstances surrounding him being informed of the infection.

33. A note in his medical records from John Radcliffe Hospital from 24 July 2000 states, 'spoke to Julia Drown (Labour MP for South Swindon) about Hepatitis C as Mrs Mobey had contacted her. I explained that virtually all haemophiliacs treated with factor concentrates before 1985 were exposed to Hepatitis C, which at the time had not been identified, (it was discovered in 1989). The government has refused no fault compensation. I don't think he will be able to demonstrate any negligence by his doctors.' (**WITN1941033**). A letter to Ms Drown (undated) following this conversation is at **WITN1941034**.

Section 3. Other Infections

34. A letter in my father's medical records from 11 August 1975 from the Treloar Haemophilia Centre records that he had received blood products infected with Hepatitis B (HBV) as follows, 'he was transfused with kryobulin batch nr. 09M6575 which as you know has been found to be HBsAg positive by Dr Danes laboratory. He appears to have antibody by the I.e.o.p test and hopefully this will protect him' (**WITN1941035**).

35. I understand that my father may have also been infected with cVJD. A note in my father's medical records from 2 December 1997 records,

'spoke to pt about recent recall of BPL products and that he had received product to which a donor who subsequently developed vCJD contributed' (**WITN1941036**). A further record notes, 'I have discussed new variant CJD derived factor VIII concentrate with Christopher Mobey on the telephone. He has received our letter to patients about this issue. He would prefer to change treatment from Replenate to Alphanate, dated 17 December 1997 (**WITN1941037**).

36. **WITN1941038** is a letter to my father dated 3 December 1997 explaining the above risk of CJD.

37. My father's medical records also contain information about product recall including a letter from his haematologist on 4 November 1998 about the recall of Alphanate, noting 'there appears to be no real risk to patients' and explaining the necessity to revert to using the 'only alternative', BPL products, which were phased out some months previously due to concerns around vCJD (**WITN1941039**).

38. A letter dated 19 January 1999 from his haematologist informs him that the British manufacturer BPL has recently started to import American plasma from the US as a result of concerns surrounding BSE and vCJD, however, the letter goes on to state that stocks derived from British plasma needed to be used up first before the new product is used (**WITN1941040**).

39. **WITN1941041** is a further letter to my father dated 22 January 2001 explaining as follows:

'A blood donor in the UK who donated plasma back in 1996 has recently been diagnosed as having new variant CJD (nvCJD). Plasma from this donor was used by Bio Products Laboratory (BPL) to manufacture a number of blood products, including plasma-derived factor VIII and factor

IX concentrates. The batches made from this material were issued in 1997 and 1998.

Our records show that you/your son received some of the implicated batches. Whilst we recognise that this news may generate anxiety, we feel that our patients are entitled to be informed of all the facts about their treatment. However, we also sincerely hope that you will be reassured by the fact that there is no evidence of transmissibility of new variant CJD through plasma products.

We would have preferred to have written to you or spoken to you on an individual basis, but this has simply not been practical given the large number of our patients involved. [...]

It is regrettable that the Department of Health did not follow the unanimous advice of the UK Haemophilia Centre Directors' Organisation and adopt the use of recombinant factor VIII some years ago as this problem could have been avoided. It remains a matter of concern to us that recombinant factor VIII and IX are still denied to most patients with haemophilia in England, although these products are now available to all people with haemophilia in Wales, Scotland and Northern Ireland.'

40. My father's medical records make clear that he was frequently tested for HIV infection, which results were thankfully negative. An undated letter, possibly around 1986, from the haematology team to his GP notes enclosed a letter to my father which explains he has been tested 3 times for the AIDS-related virus and all have been negative. The letter goes on to explain the precautions all haemophiliacs, regardless of test results, should take when giving home treatment. The letter also states that the test will be repeated from time to time and hopes he will be willing to continue to collaborate in this work (**WITN1941042**). As set out above, I do not know whether my father knew he was being regularly tested for

HIV, the earliest test I can find in his medical records is 14 May 1987 (**WITN1941043**).

Section 4. Consent

41. I do not know whether my father was treated or tested without his knowledge or consent or for the purposes of research, but from what I have found in his medical records I suspect there were tests, for example for HCV, which were done without his consent and the results of which he was not informed of for several years.

Section 5. Impact

42. My father was too unwell to work and I remember him having to walk up the stairs backwards because he couldn't bend his knees due to the frequent bleeds he suffered. A letter in his medical records written in support for his application for council rehousing in July 1992 notes, 'Mr Mobey is a severely affected haemophiliac with a factor VIII level of <1% of normal. As a consequence of past bleeding episodes involving the joints in the knees, ankles, and elbows, he has some limitation of movement of these joints, in particular his right knee [...] As is the case with most severely affected haemophiliacs who have joint damage his joint changes are progressing gradually and as time passes he will become more limited in mobility. Ideally he should live in a house without stairs and which would be suitable for a wheelchair which he may need when he has acute bleeding [in] a knee or ankle joint or when the chronic arthritis becomes more troublesome.' (**WITN1941044**).

43. As described above, I believe my father was informed of his HCV infection in around 1993. The mental and physical effects of the infection caused my father to be in bed a lot of the time. He also spent a lot of time in hospital during my childhood but would frequently discharge

himself so he could come home and spend time with us. His medical records describe physical symptoms including anaemia, jaundice, palmar erythema (reddening of the palms), spider naevi, purpuric rash, hepatic foetur (unpleasant odour), haematemesis (vomiting blood), ascites and gastrointestinal bleeds.

44. In terms of medical complications and conditions which resulted from the infection, my father suffered with cirrhosis, portal hypertension, gastric varices, liver cancer, liver failure and hepatic encephalopathy and required a liver transplant. He also suffered from diabetes but I do not know whether this was related to his HCV.

45. A discharge summary dated August 1999 records a background history of previous heavy alcohol intake and notes, 'the previous alcohol history probably accounts for why at 36 he has developed progressive liver disease as a consequence of his hepatitis C infection'. As I have already set out above, I am unsure why his abnormal liver functions tests from aged 16 onwards were not investigated and why his liver disease was attributed to alcohol.

46. The course of my father's illness was a slow decline in his health resulting in two liver transplants and, ultimately, his death. I remember the second liver transplant, but not the first: he showed me his scar and it led from his neck right down across his tummy, with staples not stitches. He was ill throughout my life until I was eight years old, when he died. Extracts from his medical records set out in the following paragraphs provide further details of the progression of his HCV infection.

47. A letter from his consultant at the John Radcliffe Hospital to the Queen Elizabeth Hospital on 12 August 1999 noted as follows, 'thank you for seeing this 33 year old haemophiliac with portal hypertension secondary to hepatitis C (no biopsy). He had two gastro-intestinal bleeds in 1998 for which no cause was found and was subsequently lost to follow up in

Oxford. He re-presented on 8 August with haematemesis and was transferred from Swindon Hospital where had had an 8 unit blood transfusion and the source was not identified. An endoscopy in Oxford showed active bleeding in the stomach and gastric varices. An angiogram confirmed large gastric varices and a patent portal vein. He has continued to ooze despite glypressin and unfortunately we were unable to insert a TIPPS this afternoon. He has had 12 units of blood since Sunday with appropriate factor cover, but if he continues to ooze I think he would be better transferred to you in Birmingham.' (**WITN1941045**).

48. A letter dated 19 November 1999 from the consultant hepatologist at University Hospital Birmingham describes his state of health prior to his first liver transplant, 'from the clinical point of view Mr Mobey remains severely incapacitated following his TIPPS. He is troubled both by ascites and encephalopathy. His liver function remains still rather poor and I think the way forward may be to go for a liver transplant. He knows this is not without risk and the Hepatitis C will infect his graft. Nonetheless in view of his recurrent encephalopathy and the ascites I do no think there is another realistic way forward and I will bring him in shortly for mutual assessment.' (**WITN1941046**).

49. A letter dated 16 July 2001 from the Queen Elizabeth Hospital to the Princess Margaret Hospital after his second liver transplant notes,

'I reviewed Christopher in clinic on 16th July. He has graft failure due to the effect of the hepatitis C. He has portal hypertension and has bled from gastric varices on more than 1 occasion. The options are not terribly good.

We have proposed TIPSS as treatment of his portal hypertension. He is however reluctant to pursue that. He had a TIPSS before his first transplant and this precipitated encephalopathy and behavioural

changes. In particular he was concerned by his change of behaviour in the presence of his 3 young children.

Regrafting may be an option, but of course that could only be undertake[n] if we had some significant improvement in our plan to protect his next graft. Chris would be willing to undertake antiviral therapy from the time of transplantation and this may be an option. I will discuss these options with colleagues. If regrafting were agreed to be an option then he would be an extremely high risk candidate for both early and late mortality. Overall it may be our conclusion that we cannot justify the use of another liver under such high risk circumstances. Clearly we need to consider the fate of the transplanted liver and there are other recipients who have a much better chance of benefit. We will keep you informed of his progress.' (**WITN1941047**).

50. A letter dated 8 August 2001 from the Queen Elizabeth Hospital to the Princess Margaret Hospital notes,

'I saw Mr Mobey in clinic on 6th August 2001. Unfortunately his condition has deteriorated. He now has quite massive ascites which is causing significant discomfort. Also it sounds as if his gastric varix has started to bleed once again. Therefore I have arranged for his admission to undergo paracentesis. Clearly we need to deal with the gastric varix since this is the precipitant of most of his recent hospital admissions.
Concerning the possibility of regrafting, I have sought advice from numerous colleagues around the world. It is a consensus that regrafting would be futile. Therefore I think we should exclude that possibility. Further management will be focused on the alleviation of symptoms.' (**WITN1941048**).

51. On the day of my father's death I remember he collapsed at the top of the stairs. He had always been a joker and my mum thought he was joking. He was saying 'my eyesight has gone, my eyesight has gone'. Mum still

thought he was joking and laughed, but he said, 'no, I can't see anything'. Mum called an ambulance and he died in hospital later that day. His medical records from John Radcliffe Hospital record on 30 August 2001, 'Chris died at PMH [Princess Margaret Hospital] Swindon on GRO-C 01. Liver failure/bleeding following re-infection of 2nd liver with Hep C' (**WITN1941033**).

52. Subsequently, on 29 October 2001, his medical records contain a letter from a consultant haematologist to the coroner giving background information on my father, confirming he died some months after receiving a liver transplant in Birmingham and noting as follows, 'I confirm that he was previously under the care of the Oxford Haemophilia Centre for many years, and he had severe haemophilia. This is a bleeding disorder, associated with congenital deficiency of clotting factor VIII in the blood. The routine treatment involves the administration of blood products and Mr Mobey, like many others with haemophilia in the UK, was exposed to hepatitis C at some stage. It is accepted by us that he acquired the infection through his blood products. It is not possible to say exactly when he became infected, but it will have been some time prior to 1985 when heat-treated concentrates were introduced. It is actually likely to be much earlier, when he first received coagulation factor concentrate. He was under the care of Dr Joan Trowell, Consultant Physician with a specialist interest in liver diseases, here in Oxford for some years. The progressive nature of hepatitis C infection ultimately resulted in cirrhosis, and after this stage we have no further contact with him as liver transplantation also cured the underlying haemophilia (as factor VIII is made in the liver).

53. I was however, of course aware that he had died but have no further information to add about his post-operative treatment and management.' (**WITN1941049**).

54. There was an article in the local paper, the Gazette & Herald, on 30 May 2002 (**WITN1941050**), 'Widow vows to fight on for justice', after the inquest which noted that the Coroner recorded a verdict that my father's death was misadventure. The article notes the Coroner said, 'the verdict is misadventure, because Mr Mobey's death came about from a human act, which was the formulation and giving of the contaminated product [...] The effect was unknown at the time but it was a deliberate act which lead to the infection of his liver which lead to his death'.

55. I do not know whether my father received treatment for his HCV and, if he did, what side effects he suffered. I also do not know whether he faced difficulties or obstacles in accessing such treatment. He first tested positive for HCV infection in 1989 but appears not to have been told until 1993. I can find no record in his notes to suggest that any treatment options with drugs such as Interferon and Ribavirin were suggested, and I do not know why this would not have been offered to him.

56. My father went on to receive a first and second liver transplant, and had a TIPPS procedure following several gastrointestinal bleeds, though again I do not know whether he faced any difficulties or obstacles in accessing such treatments. As is recorded above in the correspondence quoted from 16 July 2001 (**WITN1941047**), his treating doctors clearly considered the justification for using another liver in my father, including 'the fate of the transplanted liver and [that] there are other recipients who have a much better chance of benefit'.

57. My father appears to have faced some difficulties in accessing home treatment for his haemophilia, being reminded of the cost of such treatment as demonstrated by the following record: a letter from his haematologist on 8 October 1998 asked him to ensure he kept treatment records of all the factor VIII he uses. The letter points out that my father had not filled out his treatment records for some years and that this is important not only for his treating doctor's records, but also for the health

authorities who are 'now putting units like myself under increasing pressure to provide hard facts on usage of these expensive products'. The letter notes that, 'in the last month alone, we have supplied you with 70,000 units of factor VIII, which costs the tax payer £19,000'. The letter concludes that my father would have to attend for hospital administration of factor if he failed to complete treatment records in future (**WITN1941051**). I find it upsetting that my father would be reminded of the cost of his haemophilia in this way, particularly when it was the administration of blood products which caused his HCV infection, which led to his death.

58. I also do not know whether his infected status impacted on his medical treatment or dental care for other conditions.

59. I do not know how the infection impacted on his life. I thought his illnesses and death was caused by haemophilia and it wasn't until after his death that I found out he had been infected with HCV.

60. My father's infection with HCV and subsequent death impacted on my life in so many ways.

61. My father died when I was eight years old. My little brother was six years old and my sister was still a baby. I did not attend his funeral and was not given the choice to do so. I have never attended a funeral since as I do not feel able to. I wanted to keep something from my father's possessions to remember him by but everything was sent off to charity or given to other family members and I was given nothing.

62. As dad had died during the summer holidays when term started we didn't go back straight away but had a few weeks at home. When we did return one of the teachers gave me a special book where I could write my memories of my father, and anything I wanted to say to him. I do not recall the last two years of primary school. At secondary school I didn't want to fit in and wanted to be on my own much of the time.

63. My mum struggled to cope during the last stages of his illness and death and life at home became very difficult. I wanted to talk about dad but had no one to talk to. My little brother and I had been close but he started to push me away, he never spoke about dad and seemed to blank it out. I struggled with living at home and frequently ran away, staying with a maternal aunt for a year and spending a lot of time with my grandparents. I was diagnosed with obsessive compulsive disorder and borderline personality disorder three years ago and now understand that this is learnt behaviour from my childhood. I continue to take medication for this.

64. Because life at home had become so unbearable, my behaviour at school changed from a young age. I began to rebel massively, particularly leading up to my GCSEs, and hardly passed any exams. I am now having to retake them. My peers at school would talk about what they wanted to be when they were older, but I never dreamt of anything other than to be happy, and that meant having my dad back, which was the impossible. I began to resent people who spoke about their parents with a smile on their face.

65. My financial situation is affected because I am still in education at the age of almost 27. I'm redoing tests now that I couldn't bear to think about sitting in my teenage years.

66. In regards to my working life, I am currently working as a support worker and have started my NVQ in health and social care. My aim is to work as a child bereavement counsellor as I am passionate about helping children overcome the cruel reality of what happened to me.

67. From the age of about eight years old I was no longer hugged by either parent or shown any affection, my father being too unwell and mum not coping with his illness. I chose to be a closed book and felt sick if I saw emotion expressed by others. I could not show affection myself or tell

people close to me that I loved them. I have continued to feel like this, with the exception of my daughter who is six years old. I don't want her to not feel wanted and tell her every day how much I love her.

68. I have not suffered any stigma associated with my father's diagnosis of HCV.

69. The impact of my father's infection and death on our family has ripped us apart. We have become distanced from each other and there have been family arguments leading to rifts over the years.

Section 6. Treatment/Care/Support

70. I do not know whether my father was offered counselling or psychological support in consequence of being infected with HCV.

71. I remember going to counselling sessions not long after my father died. The counsellor drew a timeline of me as a baby and me now, aged 10, and asked me to connect the dots, with a straight line being alright, an up line being good, and a down line being sad. I drew a straight line to begin with, and then up, and then straight down. She asked if I could reconnect the dots and I said no, the line doesn't go back up. Apart from those few sessions I was offered no further counselling and no one ever asked me how I was.

Section 7. Financial Assistance

72. I do not think my father received any financial assistance from any of the Trusts or Funds set up to administer payments, although I understand that he may have received a one off payment of £250 when he was first informed of his infection by the Princess Margaret Hospital. After he died mum received widow's benefit. I have not received any financial assistance.

Section 8. Other Issues

73. I hope the Inquiry will consider how those with deceased parents are affected. When I lost my father I also lost a loving family home. I had no help or support and was unable to speak about my father to anyone, save during the few counselling sessions I had. My daughter lost her grandfather decades before she was born.

74. I hope the Inquiry will uncover what happened and how it was allowed to happen.

Statement of Truth

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

Signed GRO-C

Dated 16/10/2019.