

Witness Name: Jamie Alexander Blackmore

Statement No: WITN2592001

Exhibits: WITN2592002 - WITN2592011

Dated: July 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN WITNESS STATEMENT OF JAMIE ALEXANDER BLACKMORE

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I, Jamie Alexander Blackmore will say as follows:-

#### Section 1. Introduction

1. My name is Jamie Alexander Blackmore. My date of birth is the GRO-C 1967 and I live at GRO-C with my partner. I do not have children. I have worked for the British Transport Police for the last 2 years in a control room, whereby I dispatch officers and take phone calls in shift work.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006.
3. This witness statement has been prepared without the benefit of access to my full medical records. If an in so far as I have been provided with limited records the relevant entries are set put in the medical chronology at the end of this statement.

#### Section 2. How affected

4. I was born with a mild haemophilia B and have a clotting level of 9 iu/dl. I was diagnosed when I was around 3 months old when I was tested, as Haemophilia B runs in my family. My Uncle<sup>™</sup> Len, who has recently died of liver disease also suffered from Haemophilia B.

5. I was initially treated at the Great Ormond Street Hospital (GOSH) from when I was a child and then I transferred to the Royal Free Hospital (RFH) when I was 16 years old. I do not remember the names of all of my consultants. The ones that I do remember are Dr Chairman and Dr Christine Lee at RFH.
6. I had treatment on demand; whenever I had any major bleeds, dental work or any major procedures. Since I am a mild haemophiliac, I did not require treatment for minor bleeds, nor prophylaxis. Factor IX was the only treatment I received. I started receiving it as a child; before I can remember.
7. Being a mild haemophiliac I did not have to have my treatments very often; I had it probably a couple of times a year. I exhibit my UKHCDO records at WITN2592002, however the records from GOSH are redacted. From my medical records it appears that I was given Fresh Frozen Plasma (FFP) in 1972 when I was 5 years old, then Factor IX twice in 1973, 1978 and once in 1979 (Batch No 9D1204). Factor IX was also given to my parents to take on holiday in 1980. In 1981 I was given epsilon-aminocaproic acid (EACA) and in 1984 I was given Tranexamic Acid (TEA) to prevent my nosebleeds. I was then given Factor IX in 1987 after I was hit in the face by a glass bottle and required surgery. I was also given Factor IX in 1990.
8. When I was a child I was taken to GOSH by my parents, however, I do not know whether they were advised of any risks. As my parents are now in their 80s I have not discussed this with them, as I do not want to cause them stress.
9. I have a very vague recollection of what happened in terms of my infection. I found out that I contracted Hepatitis C in my early 20s. I received a letter inviting me to attend a meeting at RFH as I might have been exposed to Hepatitis C. I do not recall whether the letter specifically stated that I had Hepatitis C or whether it stated that I might have it but I had never heard about Hepatitis C before then. I spoke with my parents about that letter, and they told me that it was something to do with the liver. I found it very worrying. I attach a copy of this letter which I have found in my medical notes dated 9 July 1990 at exhibit WITN2592003.

10. I attended a meeting at RFH which I believe was with Dr Lee, but cannot find a record of it in my clinical notes, as I have not been provided with any documents between 9 May 1990 and 3 October 1990, which I believe would cover the period I had the meeting with Dr Lee. It was confirmed that I had contracted Hepatitis C and if I wished to, I could proceed with a trial treatment. I was not provided with any more information about the virus or what it meant for my purposes, or for the purposes of anybody around me.
11. However I discussed Hepatitis C in my 1991 and 1992 reviews and I attach copies of my clinical notes dated 4 January 1991 and an undated note, which was from a meeting 20 November 1992 at WITN2592004.
12. I was tested positive for Hepatitis C in possibly 1990, 1991, 1992 and 1996. However, further tests in 1999 and 2003 were consistent with a hepatitis C infection. I exhibit these tests test results along with a letter and clinical notes dated 14 May 1996 and a letter dated 12 June 2007 which confirms my HCV RNA is negative and Hepatitis C antibodies positive at WITN2592005.
13. I was not aware of being tested for Hepatitis C. I was also not given adequate information to help me to understand the infection, or to manage it. I was also not informed about whether it was contagious at all.
14. If the doctors were aware of my infection earlier, then I believe that they should have informed me about it earlier. It is clear that they had suspicions that I had been exposed to the virus, as this is the reason why they tested me in the first place.
15. I believe that the only appropriate way to inform someone about having such serious illness is by inviting them to a meeting and giving them the opportunity to bring someone with them for support. I have since been treated for prostate cancer, and the whole experience was totally different and certainly more appropriate than how I found out about Hepatitis C.
16. After being told I had Hepatitis C I was asked if I wanted to go on a trial and immediately agreed and started treatment. This consisted of an injection,

which I had every couple of weeks or months. I had around 2 or 3 injections, and thankfully I managed to clear the Hepatitis. I do not remember whether the treatment was Interferon or something else. Thankfully, I did not suffer from any side-effects of the treatment. I cannot find details of the treatment I received in my medical notes, however, exhibit a letter dated 20 February 2019 which confirms I was treated Hepatitis C at WITN2592006.

17. However, I do not remember ever being told that I had cleared Hepatitis C, nor any further implications or damage that the virus had caused; it felt like they wanted to tell me that I did not have it anymore, and that I should just move on. I cleared it in a relatively short period of time. From reviewing my medical records I have located a letter from Professor Lee to me dated 26 May 1999 advising '*this means that you have probably cleared hepatitis C infection*' which I exhibit at WITN2592007. It has also been suggested in recent medical records that I self-cleared the Hepatitis C.

18. I was also tested for HIV and thankfully the result came out negative. I attach the UKHCDO records showing that a blood sample dated 29 September 1986 was tested on 2 November 1987 at WITN2592008. There is a note in my medical records that I was concerned about HIV and my consultants discussed it with me in 1985 and 1988.

### **Section 3. Other Infections**

19. As mentioned above I received letters about being exposed to vCJD on 3 December 1997, 20 September 2004 and 18 February 2009. I enclose my Patient vCJD exposure form signed 22 September 2004 and UKHCDO record for vCJD at exhibit WITN2592009.

### **Section 4. Consent**

20. I am not aware of being treated without my knowledge or tested without my consent, for any other purpose than what I have already mentioned above; however, I would also not say that it is out of the question, considering that I have been tested for the above infections without my knowledge.

21. I had regular blood tests done whenever I went to the hospital for my check-ups; however, I never questioned their purpose. I do not believe that I received updates about all my test results. From my notes I can see that I was tested regularly for Hepatitis B from 28 July 1981 until I was vaccinated. From my medical records I was tested for HIV from 1986 until 1999.

22. Considering that my treatment was a part of the trial and I did agree to take the treatment, so did I give consent to the trial. In 1990 I took part in a study into '*genetic mutations in patients with Factor IX deficiency*', in 1999 I completed a questionnaire studying '*the occurrence of fatigue in individuals with inherited bleeding disorders*', in 2004 a '*European Study of Clinical, Health, Economic and Quality of Life Outcomes in Haemophilia Treatment*'; in 2007 a study into '*Determinants of thrombin generation in haemophilia: Does this associate with phenotype?*'; and in 2010 an international into '*Cardiovascular disease in adult haemophilia patients*'.

## **Section 5. Impact**

23. My infection affected me on the mental level more than on the physical level. I suffered from severe depression. I was given antidepressants by my GP and had private cognitive behavioural therapy (CBT), soon after I was given my diagnosis. I am not sure whether the depression stemmed directly from the knowledge about my illness or whether the knowledge contributed to it.

24. My depression caused me to drink excessively and I was not able to work. I had a good job with great career progression prospects in the back office of Barclays in the City of London. However, due to my depression I stopped going to work and I started drinking a lot. I was off work for about 6 months. Eventually, I could not face going back to work so I was made redundant. I received statutory redundancy.

25. I did not experience any difficulties, when it comes to accessing my treatment for Hepatitis C. In fact, the medical staff seemed to be rather keen on putting me onto the trial treatment and made it easily available to me. I am not aware,

as to whether there was any other treatment out there that ought to be made available to me, but was not.

26. I left school in June 1986 after taking my A levels and worked at Leeman Brothers and Barclays in the back office as I planned to have a career in stockbroking. I worked as a settlement clerk in the stock exchange.
27. Losing my job at Barclays affected my finances greatly. When I was able to work again I did some manual labour for about 6 months, which I should not have done because of my haemophilia. There was also a period of time when I did not have any job.
28. Eventually, I got a job as a civilian at the Metropolitan Police in 2003. I believe that if I had kept my original job at Barclays Bank, I would be on a much higher salary now than I am on now. I still keep in touch with someone who I worked with at Barclays, who started at the same position at me and he recently retired; however, whilst he was still working he earned millions.
29. As a result of losing my job at Barclays I had to downsize and move from a house I owned to a small flat. I bought a very nice property when I was 19 years old, which was close to a station, but I was no longer able to afford it, so had to move to a smaller property in a different area.
30. I do not believe that being Hepatitis C positive affected my medical treatment at the time while I still had it and was aware of it. However, I recently had a couple of operations and I realised that my medical records still refer to Hepatitis C, as seen in a note dated 15 June 2019 which I exhibit at WITN2592010. It seems like my notes have not been updated to say that I had cleared Hepatitis; in fact, I had to tell the medical staff that I am clear.
31. As to the impact of my infection on my private and family life, I decided not to tell anybody about it. The only people, who knew about it, other than the medical staff, were my parents. I have also since told a couple of my friends about my Hepatitis C infection, however, overall I feel like it is nothing to be shared with people.

32. Overall, I do not recall any instances when I was stigmatised, as a direct result of my infection.

33. I did have a couple of issues with Professor Lee as I did not find her a very pleasant person. In around 2004 I wanted to try scuba diving, as a part of my holiday plan. I needed her to sign a letter to certify that I could do it. Originally, she said that she would sign it for me; however, once I went to see her she refused to do it and I exhibit copies of letters concerning this at WITN2592011. In the end, I went to see another doctor in London, who thankfully signed the certificate for me. I am not sure whether this was as a direct result of my Hepatitis C, or whether there was any other reason for it.

#### **Section 6. Treatment/Care/Support**

34. As mentioned above, I have not experienced any difficulties or obstacles, when it comes to my treatment for Hepatitis C.

35. One aspect of my treatment, which was missing, which I think would have been of great help is counselling. I was never offered any counselling from the NHS. The only help which I had received for my depression from my GP were antidepressants. However, after speaking to a good friend of mine, I was advised to speak to a counsellor, who he recommended to me. I had around 10 or 12 sessions with the counsellor at the Priory and I had to pay for them by myself, while I was out of work. I do not recall how much each session cost, but I recall that they were rather expensive. Thankfully, they worked.

#### **Section 7. Financial Assistance**

36. I did not get any financial help or assistance in relation to my Hepatitis C infection. I have never heard about the Skipton Fund before.

#### **Section 8. Other Issues**

37. I feel very lucky because my treatment worked so quickly and my nursing staff proved to be fantastic. I feel very sorry for the people who were not so lucky.



38. Nevertheless, this inquiry has brought about a lot of memories, which I have been trying to hide, which I do find difficult.

**Anonymity, disclosure and redaction**

39. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the inquiry.

40. I wish to be called to give oral evidence.

**Statement of Truth**

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

Signed.....

GRO-C

Dated.....

4/7/19



## Medical Chronology

(This summary is not intended to be exhaustive but sets out key point in the records relevant to the statement)

- 9/10/1968 RFH Letter to GP. 'As you know this little boy's maternal uncle has Christmas disease, and his parents were anxious to know if he, too, is affected. The investigations we did here on 4/10/1968 suggest that he is, but only mildly so; his assay shows him to have 17% of Factor IX.' Repeat test in 6 months.
- 9/12/1968 suspected Christmas disease. Yesterday fell onto face. Bleeding from .. upper lip, very little but continuous bleeding several hours. Stopped overnight. Started again 11.00am and has bled a little on and off today
- 5/4/1969 Banged head on cot. Became immediately swollen – bruising now seems to be becoming more diffuse over R frontal region. Re investigations – seen here at 1 yr. – told Xmas disease likely but not certain & tests should be repeated when older. Mother did not bring him back. Strong FH (family history) of Xmas disease ...
- 18/4/1969 Haematology test. Factor IX Assay (one stage) 7% (Normal range 50 – 200%)
- 11/4/1972 Casualty. Bumped L occipital region ... **FFP 2 units**
- 10/7/1973 Haematology. Blood taken to check Hb and Factor IX level. Factor IX assay = 9.0%
- 8/9/1973 surgical. Still c/p stomach ache & headaches as well now. Poss not so bad. Pelvic colon still loaded 4/12. Bruise L leg 4 days ? Spontaneous ... **IX 860u**

- 18/7/1978 Pulled R thumb back last week. Now swollen & tender/ O/E movements reduced not hot but bruised. For X-ray – no fracture then **FIX x 2 580u**
- 26/9/1978 history of recurrent epistaxis. No bleeding now. For **FIX 610u IV**  
GOSH Hepatitis B tests - negative
- 6/3/1979 GOSH Hepatitis B tests - negative
- 18/11/1979 Nosebleeds following trauma with ball 3/52. Rx **FIX 680u (x2 total)**  
Batch No 9D1204
- 20/2/1980 GOSH Hepatitis B tests – negative
- 3/3/1980 letter GOSH to Prof Horn, Caernarvon & Anglesey General Hospital  
'This boy has mild Christmas disease (%). He rarely requires treatment, usually once a year, and **usually bleeds only after trauma when he is treated with Factor IX concentrate**. He is going on a school holiday in Snowdonia ...'
- 10/3/1980 letter GOSH to Spanish hospital. 'This boy will be staying at the address below for 2 weeks... He has mild Christmas Disease (Factor IX level 9%) and rarely has spontaneous bleeds. **His parents will be provided with a supply of NHS Factor IX concentrate** and I would be very grateful if you could give him any treatment required. His Hepatitis B surface Antigen is negative'.
- 18/2/1981 GOSH Hepatitis B tests – negative
- 3/3/1981 letter Ian Franklin GOSH to Dr Stern RFH. 'He has occasional bleeds which are stopped by EACA, and the Blackmore's wondered if you could prescribe it in future. The dose is 4 grammes t.d.s. for 5 days.'  
Letter Ian Franklin GOSH to Dr P B A Kernoff RFH. 'At present his blood count and liver function tests are normal'.

- 28/7/1981 transferred to RFH. Tested age 3/12 because Mothers brother (Leonard McAfee) has mild Xmas disease. Diagnosis originally made at Barts. Main problem has been epistaxis but never needed BT (blood transfusion) or hospitalisation.. **Has had several injections of IX conc for epistaxis & bumps, last one several months ago. Also had plasma some years ago...**  
We have a policy of carrying out routine blood checks (blood count and liver function tests) at 6 monthly intervals in all our patients who have received blood component therapy, so we should be seeing Jamie again for this purpose in January 1982.
- 30/7/1981 blood result showing ALK Phosphatase (30-110) 343\* in name of Janice Blackmore (mother) with handwritten note 'Probably Jamie in view of high ALP. PK'. This document shows Jamie's DOB
- 11/8/1981 letter Dr Kernoff to Dr Stern. Jamie has received several injections of factor IX concentrate at Great Ormond Street for epistaxis and bruises, and some years ago was treated with plasma.
- 7/1/1982 blood result ALK Phosphatase (30-110) 283\*
- 28/7/1982 blood result ALK Phosphatase (30-110) 209\*
- 26/7/1983 annual review. Troubled my more frequent epistaxis
- 29/7/1983 blood result ALK Phosphatase (30-110) 131\*
- 22/3/1984 1<sup>st</sup> HBV vaccination
- 23/3/1984 blood result ALK Phosphatase (30-110) 123
- 19/4/1984 2<sup>nd</sup> Hep B vax given
- 30/8/1984 3<sup>rd</sup> HB Vax

- 16/7/1984 has been having epistaxies' ++ over week from R nostril. None since last year. Tranexamic Acid – 1g loading iv. 1 g gas x 5/7
- 3/9/1984 blood result ALK Phosphatase (30-110) 102
- 30/9/1984 Review. Has had epistaxis since 16/7/1984 and been on TEA continually since (finds when stops TEA gets another nosebleed in 24 hrs). support stop of TEA. If epistaxis a problem will phone & we can make apt for ENT opinion for possible cauterization of a lesion in R nostril under cover of TEA
- 6/3/1985 worried re AIDS risk. Told a) IX concentrates not associated with AIDS  
b) may not need blood products in any case. See again after ENT review
- 22/10/1985 blood result ALK Phosphatase (30-110) 98
- 30/11/1985 had further talk about AIDS; modes of transmission and precautions to take. Not worried about it at all
- 29/9/1986 review. Doing very well. No bleeds anywhere. Nose bleeds stopped by themselves a year ago without any medical intervention. **Hasn't had any factor treatment before. Only cryoprecipitate when he was five.**
- 30/9/1986 blood result ALK Phosphatase (30-110) for 29/9/1986 ? 84 or 94
- 2/10/1987 oral surgery sutures removed
- 9/10/1987 oral surgery
- 3/11/1987 blood result ALK Phosphatase (30-110) – 6 readings between 21/9/1987 – 30/10/1987 ranging from 88 – 113

- 3/5/1988 blood result ALK Phosphatase (30-110) – 5 readings between 4/11/1988 – 28/4/1988 ranging from 102 - 115
- 2/9/1988 review age 21. Settlements clerk stock exchange. No treatment since facial injury Sept 1987. Attending cut today because nasal septum deviated ? need for further operation. Only 2 treatments in life prior to his. Has had HB vax March 84. Anti-HBs > 30iu April 88. Knows about heating of conc. No concerns re HIV or hepatitis
- 12/9/1986 blood result ALK Phosphatase (30-110) 120
- 27/9/1987 suturing of facial laceration. Factor IX given (when assaulted with glass bottle)
- 6/9/1988 letter Dr Lee to Dr Stern. Annual review. He is HIV antibody positive and he works as a settlement adviser on the Stock Exchange. During his life he has had two treatments with fresh frozen plasma and then first and only treatment with Factor IX concentrate to cover a facial injury 18 months ago, he had a broken glass pushed in his face.... He has no problems regarding his haemophilia and he understands that Factor IX is now sterilized... AST 23 iu/l
- 19/9/1989 review. Po x2 @ FFP in the past. 1 exposure to FIX
- 16/3/1990 admission – right scaphoid fracture (right forearm) playing indoor football
- 19/3/1990 bone graft from L iliac crest to R scaphoid (hip bone put into arm)
- 20/3/1990 treated with FIX 5,050 units



21/3/1990 am – infused with Factor VIII by Haemophilia team. For Factor IX at 23:00 hrs. Factor VIII will be given by haematology meeting @ 3pm Factor IX 1,515 units given 15:45

22/3/1990 treated with 1,500 units of Factor IX

2/4/1990 had stitches removed under FIX cover 30/3/90. Had FIX 31/3/90 & 1/4/90

29/4/1990 stubbed right big toe while running to catch train. Factor IX

9/7/1990 letter Dr Lee to client advising positive for anti-HCV in March 1990.

4/1/1991 Works in small building contracts (office). General discussion of HCV: emphasized no current evidence of liver problems but possibility of 'dormant' virus which might be looked for with new tests. Liver not palpable, SRR not felt. No clinical signs of liver disease. Note: LFTs normal, although last report Sept 88. High level anti HBs – vaccinated 1984 & 1986

7/1/1991 blood biochemistry for 4/1/1991. ALP (35–130) 102. AST (5-40) 31

13/11/1992 Annual review with Dr Wood. Clinical notes. Discussion of HCV positivity – LFTs have always in N – explanation of our understanding of issues. May be off to Tanzania on holiday in about 2/92 then offer HAV vax if appropriate  
blood biochemistry ALP (35–130) 84. AST (5-40) 25

20/11/1992 letter Dr Marion Wood to Dr Stern. He is HIV negative but Hepatitis C positive. We spent some time discussing our understanding of Hepatitis C infection; Jamie has always had normal liver function tests and they were again normal on re-testing at this review.

1/6/1994 last hepatitis A vaccination

- 22/2/1995 letter Dr Pasi to Dr Kindness, City Medical Centre (regarding application to join BZW as a clerk). Jamie is hepatitis C antibody sero-positive following exposure to unsterilized blood products prior to 1985. He is however hepatitis C RNA PCR negative and has had resolutely normal liver function tests on testing.. He is immune to hepatitis B surface antibody following vaccination and is anti-HIV antibody sero-negative (all patients in receipt of large pool blood products prior to heating have been tested for anti-HIV antibody as part of routine follow-up and care)
- 21/2/1996 removal of wisdom teeth. Mild FIX deficiency. No spontaneous bleeds. Give 5,000 u Factor IX. Clinical notes – PMH Hep C infection
- 13/5/1996 Hepatitis A T AB Positive. Hepatitis C IgG AB \*Positive\*  
blood result ALT 27.  
Clinical notes – concerned about HCV RNA NEG indeterminate abs. LFTs normal. Repeat all virology. See 6/12. May have cleared infection. If poss – refer after repeats in 6/12 – J Pasi
- 14/5/1996 Letter Dr John Pasi (RFH) to Dr Stern. 'His main concern today was about hepatitis C infection. He has in the past had indeterminate antibody results to hepatitis C infection but has had normal LFT and on one occasion was HCV RNA negative. He may well have had previous exposure but at the moment not be viraemic'
- 15/5/1996 blood biochemistry for 13/5/1996 ALP (35–130) 106. AST (5–40) 27
- 4/9/1996 seen with epigastric discomfort beginning August. Still discomfort.
- 12/9/1996 endoscopy
- 25/5/1999 review. HCV probably 'cleared'

HCV May '96 per? Neg. Indeterminate RIBA. Consistently normal transaminases. Has had FIX conc (unsterilized) ? at GOS pre 1981, see Dr Kernoff's note. Conc – check HCV pcv – write patient

- 26/5/1999 blood biochemistry for 25/5/1996 ALP (35–130) 131\*. AST (5-40) 55\*  
Letter Professor Lee to GP. He is HIV negative and he has probably cleared hepatitis C... He probably became infected with hepatitis C when he received unsterilized factor IX concentrate at Great Ormond Street in the early 1980's. However, he has been persistently PCR negative and also has had normal transaminases. We will repeat these today with a rather more sensitive test, but I have reassured him that it is likely he has cleared his hepatitis C  
Letter Professor Lee to client. I am happy to report that the test for virus in your blood was negative and that the transaminases showed levels of AST 35 (NR 5-40) ALT 55 (NR 5-40). This means that you have probably cleared hepatitis C infection
- 13/3/2001 blood biochemistry for ALP (35–130) 124. AST (5-40) 50\*  
review. HCV PCR –ve May '99.  
HAV +ve May '99 (+ve 13/3/2001).  
HBV 6914/L May '96 (332 13/3/2001)  
HCV Ab +ve in May '96 (HCV PCR not detected 13/3/2001).  
Conc - Check HCV Ab status again
- 3/9/2003 letter Dr Mark Hamilton, Consultant Physician and Gastroenterologist to Dr A Samtini. I note his most recent blood tests from the Royal Free in May 2003 show slightly abnormal liver function tests with an elevated ALT at 52 U/L
- 28/1/2004 letter from Professor Lee et al to client Re: Recombinant Roll Out with enclosed 5 page document including history and perceived safety issues relating to plasma derived concentrates
- 22/9/2004 Patient vCJD exposure assessment form with batch numbers

31/3/2011 operation disc prolapse. L5/S1 root decompression

9/9/2016 L5 nerve root block injection

8/10/2016 Sacroiliac joint injection

7/6/2017 right side testicular swelling and discomfort. Ultrasound – right sided intratesticular cyst