

Witness Name: PERRY EVANS

Statement No: WITN1212001

Exhibits: WITN1212002

Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PERRY EVANS

I, Perry Evans will say as follows:-

Section 1. Introduction

1. My name is Perry Evans. My date of birth is GRO-C 1961 and I live at GRO-C
GRO-C I live with my wife Heather and our two children, Isaac and GRO-C I am by occupation an IT Project Manager for an investment bank.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

3. I have haemophilia A, classified as mild. I was born in GRO-C South Wales and I was diagnosed with haemophilia at 15 months old. I was the first known haemophiliac to be diagnosed in the family, although 4 great uncles (on my mother's side of the family) died from bleeding episodes. My mother

was a teacher and my father a policeman. They were shocked at the diagnosis but a little relieved as health professionals had been concerned about my numerous bruises.

4. I was under the care of Hammersmith Hospital, Du Cane Road, Hammersmith, London from the early 1960s to 1984 for my haemophilia. From 1985 onwards, I have been treated at the Royal Free Hospital, Pond Street, Hampstead, London NW3 2QG by Professor Christine Lee and her team
5. I am co-infected with HIV and Hepatitis C, Genotype 1a.
6. I was infected with contaminated blood. I refer to pages 1-3 of the Exhibit WITN1212002 which is the Patient Annual Treatment Record provided by UKHCDO listing the blood products I received from 1969 to 2016.

HIV

7. I was told that I had contracted HIV on the date of 5th August 1985, more than 1 year after I was infected. I do not recall whether it was a routine hospital appointment or whether I was called in but I was told at the Royal Free by Dr Goldstein, a haematologist with Riva Miller (social worker) present. Dr Goldstein said there was a risk to haemophiliacs of HIV and that 'unfortunately' I was HIV positive. I was told I had 2-3 years to live. I was numb. I was told the bad news but didn't feel different and didn't really understand. I felt well. 'I would be dead within 3 years? Dead by 27 if I was lucky?' I could not grasp it. I was fairly intelligent person but it did not seem real or right.
8. They did not give me any advice on how to manage the HIV. There was also nothing about treatment either. I knew the facts about it being sexually transmitted and it may have been covered in the conversation. I was left to my own devices to go home and absorb the information; that I would die young. I'd suffer and die a horrific painful death. The outlook was bleak and terminal.

HEPATITIS C

9. I first became aware of the Hepatitis C diagnosis upon receiving a letter dated 19th November 1990 from Dr Lee at the Royal Free Hospital. The letter states I had tested positive on 10th September 1990. The letter offers to see me at next review or sooner (if I would like to make an appointment). I refer to it at page 4 of the Exhibit WITN1212002.
10. I do not remember who was there at my next appointment. Riva I think was present and I believe I would have asked what treatment there was and the answer was that there wasn't any. Over the course of the following years I would always ask about treatments. Sometimes I would be told 'we are working on it' or 'there has been an exciting breakthrough' but the exciting breakthrough was always 5 or 10 years away in getting anywhere. The only up side to Hepatitis C was we were told the incubation period was between 20 to 40 years. I was told that they believed that I had been exposed in the early 1980s. I was determined to stay positive mentally. I thought I was going to die of AIDs first anyway.

Advice Given regarding the Risk of Infected Blood Products

11. No advice was ever given to me and/or my parents about the risk of infected blood products.
12. I refer to page 5 of the Exhibit WITN1212002 being a letter 13th July 1983 amongst my GP records from Hammersmith Hospital intimating that I had been invited in that week for a discussion about the AIDs risk to haemophiliacs. I was never copied in to that letter and no discussions at the hospital in relation to the risk of HIV/AIDs ever took place. No discussion took place prior to the date of 5th August 1985 when I was told of the diagnosis. I am sure that the date of 5th August 1985 is correct as Heather and I had a small celebration on the fifth anniversary of the date of being told given that I had survived 5 years.

13. I refer to page 6 of the Exhibit WITN1212002 which is my Patient HIV data record provided by UKHCDO attributing the date of the 10th July 1984 as first testing HIV positive. My last negative result is recorded to be 10th January 1984. I have no memory of this being communicated to me. There is nothing within the medical notes and records I have recently obtained as to the precise date of infection albeit I have also seen it attributed to June 1984. The medical notes and records around that time period are either missing and/or non-specific. My HIV positive status only appears on my Royal Free hospital notes from 1st February 1985 onwards (after I had transferred from Hammersmith). By way of example and as referred to by me at page 7 of the Exhibit WITN1212002, Dr Lee at the Royal Free wrote to my GP in 1988 stating that I had been HIV positive since 'at least February 1985'.
14. Before I left Hammersmith my notes stated that I was tested for HTLV (HIV virus) but the results were not available then. To my recollection I was not made aware of the test nor its purpose. I had also been tested (negative) for Hepatitis B between 1983 and 1984. I was not aware of this.
15. I refer to pages 8 and 9 of the Exhibit WITN1212002, Dr Lee at the Royal Free writes to my GP on 26th September 1986 that my 'abnormal' liver tests were almost certainly due to being non-A non-B hepatitis 'commonly seen in people receiving factor concentrates'. I was not informed of this and the consequences.
16. No advice was given to me about managing my condition(s) or treatment when diagnosed.
17. When I had girlfriends I declared my HIV status to them. I did not think it fair that someone else should be lied to or invest their emotions into someone who would die soon. I am a Christian. I never had sex which also hindered my relationships.
18. In 1987 I became engaged to Heather. She understood that I'd die soon, that things could be nasty and that we'd never have children. My belief was that I

would die within a few years and then Heather would be a free agent. She was gorgeous, funny, intelligent and highly desirable.

19. When Heather first came to one of my appointments in June 1988, Doctor Goldstein and Riva Miller grilled her about the prospects of marrying someone with HIV. At the time it was rather a stark and brutal appointment due to the content of the discussion and I was unaware that they had intended to address her. I think they wanted to put the fear of God into Heather and give her the chance to call the wedding off.

Section 3. Other Infections

20. I refer to the documents at pages 10 to 14 of the Exhibit WITN1212002 containing confirmation that I was assessed at risk of vCJD on 24th September 2004 to include my patient exposure record. There were news reports at the time but I do not remember receiving very much information from the hospital. I do not recall attending a specific consultant's appointment and/or being told that I had been exposed to the implicated batches. I was at the time in remission from Non-Hodgkinson's Lymphoma. I thought that things could not get any worse for me and I would just carry on until it became an issue in terms of any physical effect/symptoms.

Section 4. Consent

21. I believe I was treated with Factor VIII and subsequently tested for a variety of infections without my knowledge and consent and without adequate or full information. I was clearly tested for HIV without my knowledge and consent from the early 1980s and not informed of the diagnosis in mid 1984 until August 1985. Similarly I was not aware of the testing for HBV in 1983 and 1984 and the testing for HCV from (at least) 1986. I was not informed that I was at risk or being tested. Prior to diagnosis I felt as fit as a fiddle and hardly ever needed treatment. In my youth I loved sports and played as many as I could. I was reprimanded when I informed the hospital I'd made a couple of

parachute jumps and had my ear pierced. I assumed that if I was at risk I would of course be told.

Section 5. Impact

Physical effects of HIV and Hepatitis C

22. I have suffered from chest infections, pneumonias and night sweats since becoming infected. I began HIV treatment with AZT in August 1990 and an (unsuccessful) Interferon trial from June 1992 for HCV. By around 1993 I found any form of exertion like playing football or even climbing the stairs to be exhausting. My heart would pound and I would gasp for air. Moreover I was susceptible to many infections and had eye infections and skin rashes.

23. By 1995 I had to stop work as commuting and working was too much for me. All I could do at the end of a working day was to eat and sleep until the morning. I was able to return to work in 1996/97 having endured a course of antiretrovirals that had made me violently sick and I did not believe I would be able to endure the drugs despite the benefits. This HAART treatment was horrible. I had to take 12 huge tablets daily. My outlook felt bleak but I got through it.

24. In 1998 we explored the possibility of sperm washing and artificial insemination to eliminate the risk of passing on the HIV virus to any off spring. A physical and highly emotional journey ensued, but we were blessed. Our son Isaac was born on GRO-C 2001.

25. I was diagnosed with cancer, Non-Hodgkins Lymphoma cancer in August 2002 GRO-C after the birth of our son GRO-C. A scan revealed that cancer nodes had appeared across my body after I discovered a lump in my left groin. The cancer was classified as 3a Large B-Cell High Grade Lymphoma. I was treated with 6 months of chemotherapy the majority of which I was hospitalised. This was devastating for me and Heather. I had survived

HIV 17 years from being told I had it and we had found joy in the birth of our son Isaac. Heather had endured 2 years of physically and emotionally onerous (pioneering) sperm washing treatment and Isaac's embryo had miraculously gone to full term. Around this time I appeared on a 2 part TV documentary 'Stephen Fry: HIV and Me'. The producers of the programme did not believe I would survive. I had been told I had just a 30% chance of coming through the treatment and that without it I would be dead in 2 to 3 years.

26. Heather and I were told that the likely effect of the chemotherapy would be to destroy my sperm count, so we quickly froze some sperm to have an option in the future. We were told after the last cycle of M-BACOD that the treatment had been successful and Heather and I made the decision to try for another baby GRO-C

27. On GRO-C 2005, our daughter GRO-C was born.

28. As a side effect of chemotherapy and compromised immune system I had many chest infections and pneumonia (involving hospital admissions of several days). I was diagnosed with bronchiectasis with right iliac fossa mass, and lower left in April 2005.

29. In April 2006 I was treated with a new antiretroviral drug, Truvada. From around February 2007 onwards, I also suffered intermittent stomach pain, with pain levels of what I would describe as 8 or 9 and only touched by morphine. I often woke in the night bent double in pain. I had to be starved for 3 or 4 days at a time to release the pressure off the bowel. I have had various scans and swallowing cameras to ascertain cause of blockage but nothing conclusive.

30. Around this time I was treated with interferon and ribovirin over a course of 48 weeks. The clearing treatment was horrendous and worse than chemotherapy, with fatigue, sickness and depression that left me in despair. The treatment failed. It was stopped because of liver failure symptoms.

31. In March 2008 with the HCV virus still present, I suffered hypertension and varicies. A shunt was placed around the liver so that blood flow pressure was relieved. I was diagnosed with cirrhosis of the liver.

32. In August 2008, having endured the severe abdominal pain over 18 months, I was admitted to hospital with a blocked intestine and had to have an emergency laparotomy, internal wash out, heart stops, CPR, acute mass perforation, contracted sepsis and was placed in intensive care in an induced coma. Surgeon reported that internal organs were matted together in one lump. Impossible to conclude as to the cause of this damage. I did not wake up out of the coma for 10 days and there was a real fear (over a 24 hour period) on the part of my family that I would not make it to the extent that the my funeral arrangements were planned with our vicar. A biliary stent and draining fistula were fitted. I spent another 6 weeks in hospital and lost 20KG of body weight. I was very weak and very scared. At one point 7 tubes were fitted around body. It took months of recovery with PEG feeding and complications to include continued fistula discharge and a contemplated stoma bag.

33. I was able to return to work in 2010 and I successfully cleared Hep C in 2015. I have however had a lot of chest infections and in 2016 admitted twice to A&E with excessive bleeding from the lungs as a consequence of bronchiectasis. I have osteoporosis (a side effect of the drugs) and broke my left hip in 2016 after falling (from a modest height) off a stepladder. Some of the side effects from the various drugs I have needed include dry skin, vomiting, osteoporosis, , anaemia, memory gaps, tiredness, fatigue and dizziness.

Mental effects of HIV and Hepatitis C

34. I never believed I would have a girlfriend because of my HIV status. The thought of sharing that news and the consequence of rejection was quite difficult to cope with so I did not entertain the thought. When I finally did have a relationship I viewed it as short term due to my life expectancy. Marriage

and parenthood were not an expectation. But I did marry despite the scrutiny of medical staff and concern of friends and family. Marriage whilst brilliant also came with rules - **GRO-C** care when using toothbrush, higher level of cleanliness and nose bleeds or cuts dealt with disinfectant. The prospect of no children became more depressing as our peers started their families. There was a sense of missing out and being punished.

35. Initially we only told a few close friends and family. Whilst it was important to us to have the support, we felt that infection would become the centre of our lives and the number one topic and maybe the only topic others would talk to us about. I had to do a lot of soul searching as I have been conflicted about who to tell and my motives for telling them. There is a painful impact when people hear bad news so when they know someone is going to die they start to mourn but equally by not sharing something so big in your life you are being a false friend. My mum has a deep sense of guilt that she was in some way responsible for the infections because **GRO-C** Something I don't believe and challenge vermontly. A constant need for knowledge is a drain and can be a point of conflict. What should be happy families is spoilt by a desire to chew the fat of the latest results and speculation on the months ahead.

36. There is also the risk of being stigmatised. One of Heather's bridesmaids found out about my HIV status from my cousin just before the Wedding and confronted Heather in anger that she had not been told. It was very awkward and upsetting.

37. My sisters and close friends have walked this journey of pain and suffering with us. We all believe that justice is overdue. We'd like the truth. We'd like those in authority to stop hiding, shifting blame and stand up and say this should not have happened and will never happen again on their watch. The government and NHS have a public duty to serve the public. That is what they signed up for. They cannot shift responsibility nor kick us into the long grass and hope that we will continue to rot. This inquiry is not a witch hunt, it's

never been a witch hunt. It's to seek and understand the truth, To shine a light on the facts. To understand the broken processes and misdeemeanors of those in authority. Why have they been so defensive, devious, for so long?

38. Dental care has been an issue throughout my whole life. In the early years I felt like it as going into a quarantine room. The dentist and nurse would be dressed in barrier clothing and the chair etc. would be covered in plastic. When I moved to Winchester in 2005 the first dental practice I found would not treat me because of the vCJD risk. But it is not like that now.

39. I lived a normal life prior to my diagnosis. I was treated with cryoprecipate in my younger years, perfectly adequate for mild haemophilia sufferers. In my teenage years I was very active, I represented my school at cricket, I got into fights. My deepest disappointment was not being able to play rugby. I missed some education but scraped into university and obtained a degree in mechanical engineering. In 1986, I bought a 50% stake in a house with a work colleague GRO-C I declared my medical history to the building society and requested an endowment policy, so required a discussion with doctor. Fortunately, and still somewhat bizarrely doctor said that the application could be approved. I was unable to obtain life insurance.

40. I have had to stop working for significant periods of time as my health deteriorated and I became very ill and/or needed to be hospitalised. I have had 4 lengthy periods off work. Missing work has had a huge impact on my life and it has each time felt that this was the beginning of the end. I loved the intellectual challenge, the pressure, the team camaraderie, the fun, the sense of achievement, the buzz, the people, a sense of being a worthwhile human doing their bit. My illnesses have taken that away. I have been with the bank for 25 years, since 1983. I am not currently working. I dream and desire to return to work. I've done it before but right now it would be churlish to try.

41. My career opportunities at work have been limited as I was ineligible for overseas posts. I had many hours off work for checkups, including dental work which always took place in hospital. I also had sick days for chest

infections or hospitalisation because of pneumonia. This has impacted on my eligibility for bonuses and my income when on extended sick leave. My wife has given up her career as a teacher to care for me when I was sick. I've not dared to look to further my experience or pay or prospects by looking for other jobs because of the fear of redundancy. I have therefore made the best of where I am, and my employer has been understanding and supportive.

42. Travel has been problematic since becoming infected. The process to obtain a visa to travel to USA for work was arduous with no guarantee of actually gaining entry. Every time I travelled to the USA I was held back and interrogated by immigration despite a valid visa.

43. On a family trip to Disney in or around 2014, I was detained for questioning at entry and separated from Heather and the children whilst I explained to them that HIV was no longer classed by them as an infectious disease. I had a valid entry ESTA and ultimately had to urge them to google their own entry restrictions. It was a relief to be allowed to rejoin my family and leave the airport. The cost of travel insurance is still prohibitive due to my medical conditions.

Section 6. Treatment/Care/Support

44. In terms of treatment, I always had doctors that would push for me and I would push too. I would always volunteer for treatment trials. A lot of people were unable to access the latest Hep C drugs but I was. The sperm washing treatment and the IVF was funded privately by me and Heather. I think perhaps that should have been funded by the NHS given the circumstances. However, the gift of children is priceless and they have been a gift from God to us.

Section 7. Financial Assistance

45 I received two lump sum payments from the MacFarlane Trust for 20,000 and 32,000 respectively and the monthly payment. I have also applied for grants for bedding and a tumble drier because of the night sweats and a sofa bed

because I couldn't get upstairs. In doing so you are required to justify your need and then keep receipts. I had no difficulty with this but it is time consuming and I can see why others might struggle.

46 I also received regular monthly payments (stage 1 and 2) through the Skipton Fund albeit you had to jump through hoops to get it.

47 Within the last year I applied for a grant for a new boiler through EIBSS and was turned down. You used to be able to deal with one or two people at the MacFarlane Trust. The decisions seem to be somewhat arbitrary with a lack of transparency in relation to the reasoning behind the outcome. There is no personal relationship anymore as you speak to a different person each time. The EIBSS funding is now means tested. It has been important to me to save and prepare for when I am not around so my wife and children are taken care of. It feels wrong that I am now penalised for saving for a time when I can't support my family. I believe the award should be about making amends and not about current means.

Section 8. Other Issues

48. I am thankful to be alive. I do everything I can to be alive for one more day at a time. I take nothing for granted. The most precious things I hold dear are Heather, Isaac and GRO-C I want to be there for them, to see them grow, mature and flourish

49. I have had it tough. It's been nasty, horrible, and excruciatingly painful but for some reason I survived. I'm not special, I like to think of myself as normal. I don't give in too easily and these viruses have defined a part of me that makes me look at the world with a different perspective. People and relationships are far more important than other things.

50. Yes I believe I have been wronged but anger, bitterness, hate are feelings I've not entertained. I suspect that they would have killed my spirit a long time ago

had I done so. My faith has kept me strong as has the support I've had from family and friends. The past cannot be undone, but the future can be made safer and those in need through this tragedy can have those needs addressed. That is what I hope for.

Anonymity, disclosure and redaction

51. 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. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

GRO-C

Dated

29.11.2018

MEDICAL SUMMARY

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

Significant entries from medical records

- 13.07.1983 RF to GP. Patient attended clinic the same week upon invitation to discuss risk to haemophiliacs of AIDs. **No recollection of receiving invitation and/or any appointment or discussion surrounding risk of HIV/AIDS.**
- 10.01.1984 UKHCDO record. Negative HIV test result.
- 15.06.1984 Earliest date attributed to possible HIV positive diagnosis.
- 10.07.1984 UKHCDO record. Positive HIV test result.
- 01.02.1985 Date HIV positive status first appears on notes at Royal Free.
- 05.08.1985 Informed of HIV status
- 26.09.1986 RF to GP advising of 'almost certain' non-A non-B Hepatitis status.
- 19.11.1990 RF to patient to advise of Hep C diagnosis from 10.09.1990
- 24.09.2004 Patient vCJD confirmation of at risk assessment and exposure record.