

Witness Name: HEATHER JOY EVANS

Statement No: WITN2718001

Exhibits: 0

Dated: JULY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HEATHER JOY EVANS

I, Heather Joy Evans, will say as follows:-

Section 1. Introduction

1. My name is Heather Joy Evans. I was born on GRO-C 1964 and I live at GRO-C Hants GRO-C. I live with my husband Perry and our two children, Isaac and GRO-C
2. My husband, Perry Evans (born on GRO-C 1961), is co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) Genotype 1A from contaminated blood products. Perry has given his own Witness Statement to the Inquiry (WITN1212001).
3. This witness statement has been prepared without the benefit of access to Perry's full medical records. If and in so far as we 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 Affected

4. Perry has Haemophilia A, classified as mild.
5. Perry was under the care of Hammersmith Hospital, Du Cane Road, Hammersmith, London from the early 1960s to 1984. From 1985 onwards, he was treated at the Royal Free Hospital, Pond Street, Hampstead, London NW3 2QG by Professor Christine Lee and her team.

HIV

6. The details in relation to how Perry was told that he had HIV are set out in his Statement. In short, when Perry was told that he had contracted HIV in August 1985, he was told that he had just 2-3 years to live. He was thought to have become infected the previous year. He was not given any treatment options or told how to manage the infection.

HCV

7. Perry first became aware of the HCV diagnosis when he received a letter dated 19th November 1990 from Dr Lee at the Royal Free Hospital. The letter said that Perry had tested positive on 10th September 1990. Perry was told that there was no treatment available but that the incubation period was between 20 to 40 years. We thought it had a long gestation period so Perry believed he would not be alive long enough for it to affect him anyway.
8. No advice was given to Perry and/or Perry's mother about the risk of infected blood products.
9. No advice was given to Perry about managing his condition(s) or treatment when diagnosed.

Section 3. Other Infections

10. Perry received notification that he had been exposed to vCJD in September 2004.

Section 4. Consent

11. Perry was tested for a variety of infections without his knowledge and prior consent and without adequate or full information. Perry was tested for HIV without his knowledge and consent from the early 1980s and not informed of the positive result in mid 1984 until August 1985. Perry was not aware that he had been tested for Hepatitis B in 1983 and 1984 and non-A non-B Hepatitis (later known as HCV) in 1986 when the hospital informed our GP of Perry's 'almost certain' positive status.

Section 5. Impact

12. Perry and I met each other through our Church. I was an actress in a charity theatre company doing youth work. We began to get to know each other, had a couple of dates and Perry implied that he had some health issues. Perry then informed me that he was a haemophiliac and had HIV but that he would be OK. I did not realise the enormity of it. I mentioned it to my landlady (now a very close friend) and she and her husband spoke about it and told me that there was 'a little more to it' than I thought. They gave me the Don't Die of Ignorance Leaflet and I took the leaflet with me to Perry's home and asked him why he had said it wasn't serious. He accepted that it was serious and that his life expectancy was a short one.

13. Perry and I became engaged in 1987. That June, I went with Perry to one of his haemophilia appointments. He wanted me to find out more about the condition and how it affected him on a daily basis. I did not expect to be addressed by Dr Goldman and Riva Miller let alone rounded on them together

trying to dissuade me from marrying Perry. They said "he won't live long" and "you won't be able to have children". I was shocked by the grilling but not dissuaded. You don't just turn your back on someone you love because they are ill. Riva Miller asked us to provide verbal consent to her video recording all the meetings we attended with her. There was a camera in the corner of the room. Over the years Riva was around less and the recordings stopped happening. I remember non-A, non-B being mentioned as a risk at later appointments.

14. We told no-one about Perry's HIV status except for family and very close friends. This caused tension over who to tell. One of my bridesmaids found out through a chance incident where she shared a lift with Perry's cousin. She was angry and confronted me about it, believing that *she* should have been told. As a consequence there were issues on our wedding day (1988) that were never repaired and spoiled the day. We married believing we would be very lucky if we had 5 years together and wouldn't have children.
15. Perry had HIV treatment with AZT in August 1990 and an Interferon trial from June 1992 for HCV. That treatment over 8 or 12 weeks was horrible and it didn't work.
16. Perry started to get very ill in 1996. His GRO-C had deteriorated over time and had been at zero for two years. I was in my second year studying for my degree and we did not think Perry would be around to see me graduate. I confided in my tutors. It was the first time that I had told anyone outside of our inner circle about Perry having HIV. Perry managed to keep working through his HCV clearing trial but he had to stop working when his GRO-C crashed but he was able to start on GRO-C. When I graduated the following year, we went to America together. We thought it would be our last holiday. Perry was taking 6 large tablets twice a day. They were difficult to tolerate. If Perry didn't take them with a certain type of food or at the wrong time, he would be sick straight away. He was often sick after meals and was losing weight. His medication needed to be kept chilled so we had to find hotels with fridges limiting where we could stay.

17. Perry recovered sufficiently to be able to return to work and I did my teacher training. We bought a house in [GRO-C] and had some relative calm in our lives. Perry has consistently suffered with chest infections, pneumonias and night sweats since becoming infected. I was teaching for 4 years and then stopped to have our son Isaac. The IUI sperm washing treatment we had to eliminate the risk of passing on HIV was traumatic: firstly, you had to undergo "counselling" to be admitted to the programme. This was not counselling it was more like an interview or test you had to pass. I remember we had to go to a [GRO-C] I found this interview an awful experience as we sat in a waiting room with a collection of all sorts of patients that you might find [GRO-C] The process then involved monitoring your cycle, injections, the secrecy involved. It was clinical. It was painful. It was a very new procedure and the hospital staff were nervous and cautious with procedures. [GRO-C] we had Isaac in [GRO-C] 2001. Most of our friends had already had children and we just caught the tail end in joining them in becoming parents ourselves.

18. Perry was diagnosed with cancer (Non-Hodgkins Lymphoma) in August 2002 (less than one year after Isaac's birth). [GRO-C] [GRO-C] without chemotherapy Perry had no more than 6 months to live. It was terrible news. It was really cruel. We booked family photos to be taken that weekend and Perry started chemo on the Monday. He was in isolation in London. Visitors had to wear barrier materials, aprons and gloves to enter his hospital room. We had gone public about Perry having HIV when Isaac was just 3 months old. People had not known long before suddenly Perry was very ill. We had also moved house in the January and we had building work going on. I remember how wonderful our friends were in supporting us. They put together a rota with people visiting him, doing our ironing and cooking and cutting our grass. I can't remember how long he was in hospital for but it went on for a long time. When he did come home he was very weak.

19. In [GRO-C] 2005 our daughter [GRO-C] was born. We were forewarned that chemotherapy would cause impotence, so prior to starting his treatment Perry

had to make deposits to store to give us a chance of future children. It made trying for [GRO-C] a much more expensive process.

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

21. Perry then started to develop symptoms, conditions and complications more associated with HCV. He had ascites with a bloated stomach. He had excruciating stomach pain over a period of approximately 2 years. He had to be starved for 3 or 4 days at a time to release the pressure off the bowel. He had various scans and endoscopies to ascertain the cause of any blockage but nothing was conclusive.

22. In 2007 Perry was treated with Interferon and Ribavirin over a course of 48 weeks. The clearing treatment was horrendous, with fatigue, sickness and depression that left Perry in despair. The treatment failed. It was stopped because of liver failure symptoms.

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

24. In August 2008 I took a phone call from the hospital that Perry had had a bad turn and I needed to get there. They were going to do an emergency operation in the middle of the night. They could not guarantee that he would make it. Perry had a blocked intestine and contracted sepsis, he had to have an emergency laparotomy, and internal wash out, his heart stopped, CPR was administered, he had acute mass perforation, he was placed in intensive care in an induced coma. The surgeon reported that Perry's internal organs were matted together in one lump and it was impossible for them to identify the cause of this damage. He said there was nothing more they could do and the next 24 hours was crucial. It was frightening. We prayed. The intensive care

unit was a very traumatic experience. It was very strict visiting and procedures. We lined up to take turns in washing and donning aprons to take a turn at his bedside. Our vicar came and we discussed Perry's funeral. There were people dying in the beds next to him.

25. When Perry woke up he was **GRO-C**. He was what I would describe as **GRO-C**, **GRO-C**. I was very frightened. I thought the **GRO-C** was permanent and worried how we would manage. He was **GRO-C** so they put him in an induced coma for another 10 days. When he did wake up he was still **GRO-C**. Then one day a nurse rang and said 'he has a list for you, he wants a t-shirt and some biscuits'. I knew then Perry was back.

26. Perry was moved from intensive care. He was a **GRO-C**. He had to be **GRO-C** because he was too weak. He was on **GRO-C**. It goes straight to **GRO-C**. The Doctors said he could not be on it for long though as it is not good for the body. He was wasting away and it was horrible. They then changed him to PEG feed with a nasal gastro tube. He eventually left hospital but was still many months with the NG tube. Very visible! When he became strong enough he would collect the children from the school playground at the end of the day with the NG tube still attached to his face.

27. Perry successfully cleared Hep C in 2015. However he had a lot of chest infections and in 2016 was admitted twice to A&E with excessive bleeding from the lungs as a consequence of bronchiectasis. Perry has osteoporosis (a side effect of the drugs) and broke his left hip after falling (from a modest height) off a stepladder. Some of the side effects from the various drugs include dry skin, vomiting, osteoporosis, anaemia, memory gaps, tiredness, fatigue and dizziness.

28. Currently Perry is **GRO-C**
GRO-C
GRO-C Perry understandably
hates hospitals but it is a source of tension between us **GRO-C**
GRO-C

29. Perry loved his job working as an IT Project Manager for an investment bank. It depresses him that he is unable to work because of his health. He hates it because he likes to be useful. My ability to work in my chosen career as a teacher has also been significantly detrimentally impacted. A permanent position was out of the question. I took work as a supply teacher because I knew I needed to be flexible but I still had to let work down when Perry would suddenly become unwell. I then trained as a cycle instructor but Perry became ill whilst I was doing my probation. I ended up telling the course leader, a lady I barely knew everything about Perry's health in order to explain why I wasn't able to continue the work. It is always difficult for us to gauge what and how much we should tell other people about Perry. I often feel vulnerable having laid ourselves bare for all to see. I now own and manage my own cycle hub. It has cost us money to run but it is fun and I can work flexibly. We are still developing the business.

30. I worry for Isaac and **GRO-C**. I worry about them being singled out at school. In year 8 Isaac was in a biology class and they were learning about HIV. Isaac said 'my dad's got that'. The teacher was thrown and there followed a flurry of emails and letters from the school. We did not want to make a big deal of it. Isaac had been oblivious to it all until then. Isaac is currently sitting his A levels and has recently had the **GRO-C** of exams compounded by sitting beside his father as he gave evidence to the inquiry, listening to him giving oral evidence on the first day of the Inquiry.

31. **GRO-C** also came to me recently and said 'in Science I think we are doing about HIV next week'. She was concerned because "... boys say stupid things about people having AIDS".

32. Holidays have been problematic for us. Three or four have been cancelled, some cut short, I have gone alone and/or we have gone without. There have also been [GRO-C] Perry has had some help. There have been things he has wanted to do [GRO-C] [GRO-C].

33. Perry was [GRO-C] I was with him when they called everyone to a hotel and said [GRO-C] [GRO-C] It was Hobson's choice. It felt like blackmail. There were all sorts of people in the room. Everybody felt the same [GRO-C].

34. At the time of the [GRO-C], I was made to feel insignificant and excluded from the process. The lawyers were very clear on who [GRO-C] according to marital status, dependents and whether the infected person was married at the time they were infected. I felt excluded. I was low down in the chain of importance compared to others because we had married knowing Perry was HIV+, and we had no children. Over the years and whenever there was any form of consultation, I felt I was not to be a part of it. It was only at the opening of the Inquiry, when Sir Brian said he wanted to hear from infected and affected that I felt I could be listened to.

Section 6. Treatment/Care/Support

35. The sperm washing treatment and the IUI was funded privately by Perry and I. I think 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.

36. There was very little psychological support for us. I felt that Riva Miller was in awe of Perry. She would say he was 'an example to us all' but there were times when we needed support rather than compliments. We have had support from friends and family but not professionals. We were not offered

any one to one counselling. I paid for counselling for myself after I had **GRO-C**. I was really struggling and the counselling was helpful so I know that professional counselling can help. Looking back I probably should have claimed the counselling from a trust, but, it did not enter my head as a possibility. Anyway, I can imagine the process of applying and getting approval would have been arduous. We just got on with it ourselves with our own support networks.

Section 7. Financial Assistance

45. Perry received two lump sum payments from the MacFarlane Trust for £20,000 and £32,000 respectively and the monthly payment. Perry has also applied for various grants for items like bedding and a tumble drier. Perry has had to jump through hoops to obtain the grants, justifying the need, obtaining quotes and keeping receipts. He has at times been refused the funding we needed.
46. Perry also received regular monthly payments (stage 1 and 2) through the Skipton Fund again he had to jump through hoops to get it.
47. Perry now receives monthly payments through EIBSS. I know Perry is frustrated by the fact that the funds are means tested and this is unfair when Perry is trying to save for his family.
48. It worries me that if Perry dies or becomes incapacitated I would have to deal with EIBSS. I think I would find that really hard. I don't know how we would manage. The widow's payment is very confusing. If you're not good at admin I don't know how you would manage with all the forms.

49. I have seen Perry's frustration with the trusts. The decisions seem arbitrary without transparency no reasoning is given for the outcome. He is adept at examining and meeting a given criteria and filling in forms. It is his thing, but he has jumped through all the hoops and still been turned down.

Section 8. Other Issues

50. There are no other issues.

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

22/7/19

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.