Witness Name: Jennifer Hardiman

Statement No.: WITN5539001 Exhibits: WITN5539002-4

Dated:

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WRITTEN STATEMENT OF JENNIFER ANN HARDIMAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 February 2022.

I, Jennifer Hardiman, will say as follows: -

Section 1. Introduction

- 1. My name is Jennifer Ann Hardiman. My date of birth is GRO-C 1968 and my address is known to the Inquiry. I am the daughter of Reginald Hardiman (known as Reg), whose birthday was GRO-C 1933. He died on 1 July 1995. He was a Haemophiliac.
- 2. My mother Christine Josephine Hardiman, who was my dad's wife will assist me with dates within this statement. I will speak about my dad's HCV infection.
- 3. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and my life.

Section 2. How Affected

- 4. My dad was named Reg, and mum is called Jo. My eldest brother was born in 1963, and is not affected at all by haemophilia. My sister and I are haemophilia carriers and also have low levels of factor IX or mild haemophilia. My sister was born in 1964, but died in 2008. Her death was due to non haemophilia or blood related issues. I was born in 1968.
- 5. My dad had Haemophilia B, originally known as Christmas disease. My dad had severe Christmas disease, with less than 1% of factor IX.
- 6. Due to his haemophilia, my dad was over protected by his mother. He couldn't go to school a lot of the time due to his illness, during part of the World War years he was tutored 1:1. He was 6 years old when World War II started. My nan was paranoid of him being knocked or hurting himself.
- 7. He had callipers as a teenager, a special metal framing for his legs. He lived a sheltered life, and couldn't do much. It affected his relationships with siblings, as he was seen as the special one.
- 8. He had tutoring and schooling locally. He then went to a college in Devon which was a special college, it was a residential college for disabled persons but I don't know the name of it. He trained to be an antique watch and clock repairer.
- 9. Late 2021, my mum was going through paperwork stored in the attic and found some old papers that had belonged to my dad's mum. There was a letter which my mum remembers being told by my dad, it was given to my Nan by a doctor when he was a baby. It was written in a very unsympathetic way and made for a very grim reading. They didn't know much at the time as it was the 1930's, but it was still very grim, in advising he would die young and should never marry.

- 10. There was no treatment when my dad was younger, he would have to just lie in a hospital bed in pain if he had a joint bleed, which is how my mum and dad met at King George hospital, Ilford Essex, when she was training to be a nurse. Dad was a patient and he was ill there. He met mum in 1960.
- 11. He married my mum in 1962. Then my brother, Paul came 10 months after, then Eileen came 20 months after that. Dad went to a Devon college, to learn to do watch and clock repairs. I remember growing up, there were clocks everywhere in the house. He later worked for the Ministry of Defence, as a Quality Controller to deal with submarine missiles.
- 12. Before my mum married my dad she was warned by others "you will be looking after him for the rest of your life" and even received an anonymous letter warning her. But he did everything, and even had 3 children. The haemophilia nurses from the Royal Free would make home visits regularly. They would be horrified as he would be up a ladder. He did all the renovations at home, and was a very 'hands on' dad. He had a very full life once he married. Despite the health professional's advice, he lived his life and did what he wanted to do.
- 13. In the 1960's, his right knee was completely shot from repeated bleeds, but then he got his right knee fused. He had a straight leg and was disabled. During this time, he had a buggy type "disabled" car called an invalid carriage. He was treated at the Royal Free Hospital. When they started, they began the Haemophilia Centre in just a caravan. This was a small group of staff in the early years consisting of Dr Catherine Dormandy, Dr Peter Kernoff and Dr Ted Tudenham who helped my dad.
- 14. In the 1960's and early 1970's before the new hospital opened he had to travel to the haemophilia centre in the little caravan off site to receive his medication and then later around the late 1970's he was given cryoprecipitate. He did his intravenous treatment at home. My mum was trained as a nurse, but he always did his own treatments. He kept her out of

the loop. He sheltered her from everything and always attended hospital appointments alone or sometimes with me.

15. I spent most of my childhood in the Royal Free Hospital. I sometimes spent my birthdays there as Dad spent a lot of time in hospital. At 14 years old I was trained by them to give IV drugs, so that I could give his factor IX treatment. He used to use the word precipitate when he talked about his treatment. He would regularly go to hospital if he had a bad bleed.

HCV infection

- 16. He used cryoprecipitate blood products and then Factor IX concentrate for his Haemophilia B. I don't know the dates he stopped one and started the other one.
- 17. Everything changed in the early 1980s. I was in school in 1981 1982, I remember him sitting me down, warning me not to talk about haemophilia to others, and I was told to say that he had arthritis in his leg if anyone asked about his fused knee. I didn't understand the news re AIDS and that people might reject us if they knew he had haemophilia or that there was a stigma attached to this.
- 18. I remember coming home from school, and my Dad was being tested for HCV and it was a big deal in the house. I didn't understand. That was around the same time I was told about AIDS. My mum told me her physical relationship stopped with my Dad then. She didn't understand why. But she just assumed he had it as he never actually told her if he had HCV or not, it was simply never talked about as he always sheltered things from her.
- 19. But he would tell me everything, well most things. I went to college in 1984 and I was donating plasma to the Royal Free in the late 1980's. In 1987, I was nursing AIDS and HIV patients in Guys hospital, I would always talk about all this stuff with my dad. We also talked about Interferon, it was a

treatment for HCV. I don't remember him ever saying he needed this treatment or had been offered it but I do remember him asking me what I knew about it. We talked about treatments etc so I thought my mum was aware of it, but she says she wasn't.

- 20. He was diagnosed with HCV in June 1993 but my mum and I were not aware of this at the time and my father was never treated for HCV. I don't know what information they gave to him. I only knew he definitely had HCV when I had access to the Skipton Fund paperwork.
- 21. I still didn't know positively if he was infected because everything happened around the same time. He was diagnosed in May 1995 with cancer in the pancreas, Stage 4. My mum and I as nurses knew that he only had weeks to live, he had some care at the Royal Free, then moved to St Francis Hospice, Romford.
- When he died, we were all in the house. I took a call from the undertakers, who had taken the body from the hospice. I remember talking to the undertaker he told me: "I have your father here. We have a body bag. It's an infected body bag, is he infected or is he not, does he have Hepatitis or AIDS? He has been sent out in a coloured bag". I said "I think he has HCV, but contact the hospice or hospital they will tell you". The undertakers were called 'Gilderson & Sons Funeral Directors'. Surely the hospice should have told them he had HCV?
- 23. On the death certificate, carcinomatosis, and cancer of the pancreas was there, but nothing about his HCV. We had a wake, and an open coffin at the funeral. He wasn't embalmed properly because of the HCV, he was decomposing. I think undertakers did a limited embalming as he was an infected person, as he was in a really bad way. It wasn't for good viewing, there was an odour. As a nurse I know what is normal and that was not normal.

24. There was still a grey area. Did he have HCV or not? The hospice and undertakers should have clearly known.

Haemophilia

- 25. My dad spent my whole life apologising to me and Eileen, he didn't fully understand the carrier status before we were born and that we would be affected. When he realised, he immediately had a vasectomy. My mum recollected that it was because he said "we completed the family", but I was told by him it was because it was haemophilia related and he didn't want to pass it on further.
- 26. The Royal Free became our second home. He had all his treatments at the Royal Free and he only went to King George's in Ilford when he was young before blood factor treatments were available. He by-passed doing any tests at a GP. He was only treated at the Royal Free hospital from the 1960's onwards.
- 27. I have given the investigators some papers, which they photographed, see below for a table of these exhibits:
 - WITN5539002 I think he was the first haemophiliac in the world to have a double surgery for a shoulder and elbow replacement. His case went to the USA to be presented at the time. He met the Duchess of Kent at the Royal Free because of his case.
 - WITN5539003 notes that the Royal Free Haemophilia Centre had 160 patients registered and 40% were HIV positive.
- 28. In 1993, he may have had a blood transfusion at the Royal Free Hospital for his surgery. My dad had every blood test, scan, at the Royal Free Hospital.

Section 3. Other Infections

29. We thought he was never infected with anything other than HCV, but in his medical notes it says he had Hepatitis B (HBV) (**SKIP0000035_038**; **p24** refers) These could be treated. From the inquiry, they have shown up in the Skipton Fund medical notes but I didn't know this before. I want to know why he had treatable infections but was never treated.

Section 4. Consent

30. I have no awareness or knowledge of this matter.

Section 5. Impact

- 31. My dad told me not to tell anyone he was haemophiliac. I think it was preparatory. I know it affected him but I don't know if there were external instances that occurred. He went into himself, he associated himself and haemophilia with this worldwide scandal.
- 32. The 'tombstone' which was seen on TV and posters everywhere, it could be you next, it all really affected him. The programs and adverts during that time, he felt he was part of it. People complaining about drugs addicts, and gay people, he thought he was part of the unsavoury world. It wasn't until much later that I understood the blood products were related to the scandal and the risk to what he was injecting into himself each week.
- 33. Haemophiliacs of my age and younger, the young ones, have no clue what life was like being a haemophiliac in the early days before treatment. It was a big deal having haemophilia, it affected every aspect of our life and even where you went to on holidays, and we never travelled abroad past Ireland. Even the car you drove, we had a special disabled car, which was obvious to everyone.

- The infection thing, HCV just made things a lot worse on top of a hard life having haemophilia. The stigma was a lot worse, the activities you can't do are a lot worse. He spent his whole life, apologising for us being carriers, through no fault of his own. My sister never spoke about it, never acknowledged she had low Factor IX. I know how bad he felt and how hard it was for his 2 children.
- 35. Eileen's tonsil bled after surgery as a child and she had to go back to theatre. When she had a baby she bled and had to go to theatre as well, to stop the bleeding after the birth. He spent his whole life apologising for us being carriers. Then on top of that there were the extra challenges. Being born with haemophilia in his era was very hard, life was hard, and then they got infected through no fault of their own and then they had it harder. It's so unfair.
- 36. My dad worked and carried on with a normal life. But he was very protective, and we didn't tell people. My mum knew about plasma, Factor IV etc from her nursing knowledge. But he protected her as a wife, and a mother. He always wanted to protect her. He always went on his own to the hospital appointments, then I was invited later on.
- 37. I trained as a nurse and a midwife. My mum and I worked in cancer care. For the last week of his life, we stayed 24/7 in the hospice and cared for him as much as we could. They were very good at the hospice. We knew about cancer and how to care for him and they let us. We knew the prognosis was bad when we got the results. I was a nurse at the time but now I am a healthcare manager.
- 38. I sent documents as exhibited below to the Inquiry. In a document relating to haemophilia, it notes that 'Females in a known "Bleeder" family should not marry' (WITN5539004).
- 39. I went to Genetic testing at the Royal Free when I was pregnant. I remember how flippant the young doctors were about haemophilia. They didn't see it as

a big deal for having haemophilia, and couldn't see why I was so traumatised about the prospect of potentially having a haemophiliac son. But our generation, my dad's generation, were affected by it. He was registered disabled and disadvantaged because of it in so many ways. For example he couldn't get a mortgage, he physically couldn't play and run with us when we were children and we had the stigma of him driving (known as "an invalid carriage"). He was also unable to travel due to having to keep treatment in a fridge in the earlier days and he spent a lot of our childhood in hospital in the Royal Free over an hour away from home.

There was so much stigma. They hadn't trained during a time where it was a huge debilitating disease. My mum was concerned that I would have a boy. We had a huge falling out as I possibly would have a haemophiliac boy and she said I should just could not let that happen and if it did I should have a termination.

41.	My mum has been talking abo	out the past recently since	l have been		
	speaking with the Inquiry. She to	d me in the early 1980s, wh	en she was in		
t	her 40s,	GRO-C			
	GRO-C	. She just assumed it	was to do with		
	the HIV and hepatitis scandal at that time and that he might be infected. My				
	dad's HCV affected him, but	GRO-C	, but		
	he was also affected psychologica	lly.			

- He was paranoid about sharps, obsessed about sharps bins and had a lot of anxiety. But we were still not definitely told whether he was properly infected with HCV and he never said. It's a big grey area and then it begs the question, why was the undertaker asking those questions? Why was it so grey, surely it should have been more black and white and documented in his hospice notes? It seems now he definitely had HCV, when hearing about these Skipton notes that the Inquiry has shown me and seeing he tested positive in 1993.
- 43. He did everything in Royal Free, even his dental work.

44. He didn't have any tattoos and was not aware of any blood transfusions.

Section 6. Treatment/Care/Support

45.	I think he got tested in the early 1	980s before the 1993 test when infected
	blood products were known about.	It would explain his behaviour, his asking
	about treatments for HCV and	GRO-C
	GRO-C	

- He had no treatment for HCV unfortunately. But he was diagnosed in June 1993, so why didn't he get any treatment immediately? He was only 60 years old then? This infection was treatable, he was well, so why didn't they treat him? There was no reason. He didn't get cancer until 1995
- 47. I don't know if he received any counselling.

Section 7. Financial Assistance

- 48. I was happy with the services from the Royal Free, except for the lack of information inputted on the Skipton Fund paperwork. I feel it was completed by them inadequately. He was known to have HCV but they never completed part 2A of the form probably because they never treated him despite having treatable infection.
- 49. My mum got £20,000, for Stage 1 as it was shown that he was infected, but he was turned down for Stage 2 funding. I can't remember if I helped mum with the form at the time, but I was aware of it, I knew about the Skipton fund as she told me. I don't recall and seemed fine.
- 50. When Dad was diagnosed with pancreatic cancer in 1995, he told me his liver was in a bad way, he had a scan and biopsy of the liver, he told me he had a completely diseased liver, and dark spots on it. I spoke to Deborah

Pollard, who was a consultant nurse, she may be retired now at the time of the Skipton fund when mum was turned down for the stage 2 funding. I asked her about his diseased liver and the fact we believed he had cirrhosis and a badly diseased liver at the time they did the scan and biopsy with his cancer diagnosis. She kept saying "he didn't have it". We didn't know if she meant HCV or cirrhosis. This really confused me and we still didn't know what he had, hence the subsequent confusion over the years and at death as to whether he was infected or not. Deborah kept saying "he simply doesn't have it". This was in 2011 at the time of the Skipton fund.

- 51. **SKIP0000035_038** demonstrates that there was evidence of liver cancer following his HCV diagnosis. My dad's notes show all these various issues, including masses, and spots. However cirrhosis is not mentioned, hence they refused the Skipton application initially and this just doesn't make sense. The medical notes didn't mention cirrhosis. But he had a bad diseased liver, so it doesn't make sense. Professor Christine Lee signed off that he had died through carcinoma of the pancreas (**SKIP0000035_038**; **pg 54**).
- At the Haemophilia Centre at the Royal Free, I was so disappointed with the junior doctor who was looking at my dad's case notes as part of the Skipton Fund application. They didn't do much at all. The first application was accepted, the second application (stage 2) was declined due to no triggers. The fund was looking for the exact word 'cirrhosis'. I feel the form was inadequately completed and part 2A of the form should have been completed as my dad was known to have tested positive for HCV and had a badly diseased liver. I feel because the scan was related to a cancer diagnosis the report focused on that, and omitted the word cirrhosis despite the liver being diseased.
- We didn't appeal. We went to Deborah and she said "he simply didn't have it". These medical staff were like family members, we had known them for years, we never questioned them, and we accepted then that we weren't eligible, so we just didn't appeal the decision. We had them on such a high

pedestal. But in hindsight, I regret not questioning more. Having viewed the Skipton fund paperwork it seems like it lacks vital information. Only two answers circled yes, no other information, like they saw it as a tick box exercise, and signed the letter.

Section 8. Other Issues

- 54. I don't want to be anonymous; I am sick of being quiet. I want to end this uncertainty and confusion.
- My dad was treated as a second-class citizen, it's not about the money, it's just the justice of it, he never had a normal life, HCV was the 'tin hat' on it. He didn't live a lot longer. He had it tough, and then had it tougher. I just want someone to hold their hands up and say "I'm sorry".

Section 9: Documents

Table of exhibits

Exhibit Number and Page	Date	Description
WITN5539002 1 page	1993/ 1994	Slide 1 - used in the US for lecture when clinical staff from the Haemophilia centre at the Royal Free
WITN5539003 1 page	1993/ 1994	Slide 2 - used in the US for lecture when clinical staff from the Haemophilia centre at the Royal Free
WITN5539004 7 pages	1930's	Letter dating back to the 1930's from JH's Grandmother's possessions. (poor quality scan) This does not relate to the JH's family.
WITN5539004 A 7 pages	1930's	As above Exhibit WITN5539004 with the pages rotated for ease of reading: Page 1 to 4 General description of haemophilia carriers within a family referring to haemophiliacs as 'Bleeders'. N.B. Bottom of page 3 and top of page 4 states. 'Females in a known "Bleeder" family should not marry'. Pages 5 to 7 3 x generational tree of a non-specific family of 'Bleeders'. The last line of page 7 states - 'Copied from medical encyclopaedia.

Statement of Truth

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

