Witness Name: Stephen Martin Finney
Statement No: WITN1047001
Exhibits: WITN1047002
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN MARTIN FINNEY

I, Stephen Martin Finney, will say as follows:-

Section 1. Introduction

1. My name is Stephen Martin Finney. I was born on GRO-C 1971 and I live at GRO-C, Dorset, GRO-C.

2. I have an older brother and sister.

3. 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

4. I was diagnosed with severe Haemophilia A at birth. I was treated at Churchill Hospital Oxford and I was under the care of Dr Charles Rizza.

5. On 28 January 1974, I was given one of my first doses of Factor VIII (FVIII) concentrate, from which I believe I contracted Hepatitis B (Hep B). This was confirmed in GRO-C 1974 by a "routine" screening which was requested by Dr Craske. I was just over 2½ years old at that time. It appears that viral

transmission risks (of Hep B or other known blood transmissible viruses) in FVIII concentrates manufactured from large pooled donations of human sourced plasma was, in the very least, suspected at this stage, if not already known about by the physicians. Otherwise, what reason would they have to be routinely testing a non-symptomatic 2.5 year old child for Hep B.

6. When I was about 4 years old, I was having a succession of nose bleeds down to my Haemophilia. My mother was my main carer at the time as my father was usually at work and my elder brother and sister would have been at school. Around the same time, my mother was quite ill for a significant period. I subsequently discovered at a much later stage in my life that I had infected my mother with Hep B through blood to blood contact and simultaneously had been a significant infection risk to anybody that may have had to deal with any of my external bleeding episodes.

7. On 24 December 1982, I started administering FVIII myself after being taught to do so by one of the Haematology doctors, Dr Bell, in the Haemophilia treatment room at the Royal Victoria Hospital (RVH) in Bournemouth. I was able to keep a stock of FVIII at home in the fridge and be able to administer it to myself rather than going to the hospital and waiting a lengthy period of time before being treated.

8. In 1985, I was 14 years old during the backdrop of the press hysteria when the media released the now infamously scary adverts about AIDS. At this time, I was notified by my haemophilia consultant, Dr Oscier at the RVH that I had contracted HTLV-III (HIV) as it was known then.

9. In December 1990, I was told that I had tested positive for Hepatitis C (Hep C).

10. I do not believe that my parents were given adequate information beforehand about the risk of being exposed to infections from blood products to be able to make a sufficiently informed decision about whether or not to accept using FVIII balanced against the risk of not treating at all.

11. My parents, who were members of the Haemophilia Society group, had group discussions about the HIV crisis when that became an issue and I know for a fact that when this occurred, it was a very difficult time for all involved on what possible guidance or advice they should be giving to what were now their increasingly fearful members.

12. The only information we received from official medical sources was about how to best manage my Haemophilia condition and that now this new FVIII treatment was becoming available, I should be able to lead a relatively normal life. It was never about the clear or present dangers of potentially deadly viral pathogens associated with FVIII.

13. In fact the only indication you would ever find would be by the way of a very small print disclaimer on the product itself stating that it 'could not be guaranteed to be free of (insert pathogen here)' but it was always stated by the doctors at least that the risk of any infectious pathogens was negligible in contrast to the huge benefits of the treatment.

14. I do not believe we were given adequate information to help understand and manage the infections at the time.

15. I remember being given advice by Dr Oscier about having to adhere to safe sex practices by using condoms but also as a consequence of this that I would unlikely father any biological children of my own or indeed even be alive by the time that the opportunity to be able to do so occurred.

16. Given the fact that the doctors knew I had HIV, I do not believe that much advice was given to my parents about the risk of me infecting them, because even as a child, I do not remember my mother being issued with something as cheap as rubber gloves for her own protection. I would have noticed this change in the difference.

17. A copy of my National Haemophilia Database is exhibited at **'WITN1047002'**.

Section 3. Other Infections

18. I do not believe that I have any other infections as a result of FVIII concentrates. However, I was once tested for Cytomegalovirus (CMV). There was no follow up in relation to this and I assume it was because I tested negative.

19. I received a letter in the early 2000s from the HPA stating I had been exposed to vCJD. My consultant hit the roof as she thought it was completely out of order to cause further panic and grief to her haemophilia patients (whether they were infected or not) and at the very least have an opportunity to forewarn us that this letter would be heading our way and how to interpret and disseminate the information that it contained in the correct manner.

20. She offered to find out for me whether I had actually been given the infected batch with vCJD. However, I chose not to be told whether I had used the same infected batch with vCJD as I felt as though since there was no treatment for it, there was no point in going through added mental distress. If I was told that I had vCJD on top of all the other infections I already had, it would have made me psychologically worse.

Section 4. Consent

21. As previously stated, I do not understand why I was routinely checked for Hep B at 2½ years old. I believe the doctors knew I already had Hep B, but did not tell my parents. I was therefore treated and tested without my parents' knowledge and consent and without being given adequate or full information.

22. I believe I was probably tested on for the purposes of research, although not maliciously. At that point however, I did not have any such suspicions.

Section 5. Impact of the Infection

23. I suffered mental effects as a result of the HIV and Hep C. Having to mentally process a future was an extremely difficult situation for an adolescent boy of 14 years old to have to deal with the contradiction of both a life sentence (no

treatments, no cure) that is at the same time a death sentence (you are pretty likely to die before treatment becomes available anyway). Simultaneously, not having the realisation that the very people that I had been entrusting my health to had put my life in serious danger, but the fact that as a result of medically sanctioned treatment I had myself potentially become a serious danger to anyone around me. I suffered from long term depression, for which I had to take anti-depressants. I also have long term untreated post-traumatic stress disorder as a result. I have only had 2 visits to a psychiatrist who said I was fine. Suicidal thoughts have crossed my mind but I never considered going through with it.

24. I believe if I had, then those who I believe are/were responsible for what happened to me and others would have got away with what they have done and that of policy strategy of lethal indifference would have been allowed to continue unchallenged with deadly treatments blighting the system. It is very rare, even to this day, that a day has gone by when I have not thought about it but the thought of just basically becoming another digit on the ever-increasing mortality statistics of this tragedy keeps me from giving in to it. After all it would seem illogical and a huge insult to the memory of those who have had their lives ended by it. In any case I think for cognitive behavioural therapy (CBT) to work effectively in this case would mean that the treating psychiatrist would have to accept that I was repeatedly exposed to viruses through treatment. However, as the government and medical profession at the time were flatly refusing to take any responsibility for it, it would only have made me out to come across as some sort of mad conspiracy theorist.

25. I have also suffered physical effects as a result of the Haemophilia. I have severe haemo-arthritic pain in both my ankles which now require surgical fusion that I have been putting off for 25-30 years and they have now been worn out. My ankles are so weak that they need proper support or the joints could collapse. I take strong opiate based painkillers for my severe arthritis but these pain killers cause more depression and have to be taken in moderation due to the risk of long term addiction.

26. In May 2002, having laid dormant in my system for nearly 25 years, the Hep B came back, causing me the most physically traumatising health episode I have had to endure by far. I came down to breakfast one morning and my dad looked at me and said I looked yellow. I looked in the mirror and then called my haematology consultant at the time and told her I was showing jaundice symptoms associated with hepatitis. I was then tested and had physical examinations, after which I had a liver biopsy at Southampton General Hospital (SGH). I was still very jaundiced at this point. As I took a few steps outside the back door of my house in order to drive to see the consultant for a follow up appointment, I completely passed out and went crashing down on the path.

27. The next 9 days of my life were completely missing because I was kept in a chemically induced coma in the ICU at Royal Bournemouth Hospital (RBH) because my condition was deteriorating rapidly and the doctors were not sure why exactly I had suddenly become so ill. At RBH, I was mainly under the care of Dr Alison Worsley. My condition worsened in the 9 day period and my entire renal system was starting to shut down. I was transferred to the regional renal hospital at Dorset County Hospital (DCH). I received the test results taken at RBH and found out that as well as being ill with the Hep B, I had likely contracted E-Coli 0157 from the liver biopsy and this was what was effectively causing my system to go into septic shock. At DCH, I asked the renal consultant what my CD4 count was and he said 10 and that the chances of me not seeing Christmas that year was fairly high, unless I started to take Highly Active Antiretroviral Therapy (HAART). The consultant was very honest and said if I wanted to live, I really had no other choice.

28. My condition was not improving sufficiently and it was decided that I needed to be transferred to King's College Hospital (KCH) as the likelihood of having to undergo a liver transplant surgery was becoming a distinct reality. I was then treated and I spent a couple of months recovering at RBH. I spent a total of 28 weeks in 4 different hospitals. I weighed 12½ stones when I was first admitted and when I was discharged, I weighed just over 7½ stones. It took 2 more years to recover fully and put the weight back on again.

29. In 2010, I had my first fibroscan and the result was below 8 which is only slightly abnormal and it was in the 'the nothing to really worry about category'. It was at the same time that my father was diagnosed with Alzheimer's disease and I became his primary carer. Whilst looking after my father, my own health started to slowly deteriorate. I went for a further fibroscan and the result was 18, which was a dangerous level. My father died on GRO-C 2015 having spent most of the final years of his life with me.

30. I was offered AZT treatment for the HIV, but it was decided that I would only start the treatment or whatever the best treatment was at the time when I was showing HIV symptoms or if my CD4 count dropped below 200 on more than 3 repeat tests. I never had the AZT treatment and it was not until 18 years after being diagnosed that I started the HAART to deal with the HIV. By this time, the treatment meant that if I took it regularly, the viral load would decrease to below detectable levels.

31. For Hep C, there was only one type of treatment available that was offered to me a few months after the diagnosis. It was a 48 week lengthy course of Pegylated Alfa-Interferon injections and oral Ribavirin tablets. I decided not to take this treatment as I was not showing any symptoms and there was not any guarantee that the treatment would work either. I was regularly tested (every 3 or 4 months) and monitored and did not have significant increases in viral load. In October 2015 however, I started the Hep C treatment consisting of Sofosfubir/Ribavirin. After having my first dose of treatment, I stopped vomiting multiple times daily and my appetite returned. After just 10 days of treatment, I had gone from having a Hep C viral load of 2.7 million to 0. However, the Ribavirin caused anaemia and so the dosage treatment had to be reduced and the course of treatment extended from 12 to 16 weeks. The treatment was successful and I am now clear of Hep C.

32. I have however been left with several more health issues as a direct consequence of the viral infections on the ability of my liver to function properly. These include osteoperosis, hepatic flouridosis, hepatic encephalopathy, low platelet levels (increasing the risk of thrombocytopenia), oseophaegeal varices and long term joint stiffness and pain (non haemo-

arthritis related) due to the side effects of the HAART treatment for the HIV combined with long term prophylaxis use of factor VIII use.

33. My infected status has impacted on my treatment, medical and dental care. Certainly in the early days of my diagnoses, I was kept as the last patient of the day. Whenever I went to the dentist, it was more like I was walking into a laboratory as everything was covered up, because of me. I always told the dentist about the infections as I did not want to and would never put a medical professional at risk. It was also a policy back then that when you take blood tests, yellow stickers are put on your blood form to say that you are an 'infection risk'. People further down the line could see and knew that I was infected. Nowadays it is rare that medical professionals wear gloves when dealing with me but back then they wore gloves as they assumed the infections can be passed on easily just by touching. For the past 20 years, I have been receiving dental care at a Specialist NHS dentist for people with difficulties. In the beginning, my previous dentist used to cover everything up before treating me. However, my current dentist is excellent and does not do things like that. I have had teeth fillings without being given numbing injections as my previous dentists were afraid I would bleed (as anaesthetics cause more significant bleeding). However, there was a particular technique to inject anaesthetics without causing any bleeding but they would not do it.

34. My infected status impacted on my social life massively. I knew I was a possible risk to others and so avoided getting into relationships at all. Fortunately for me, most of my friends who I was close to as a teenager are still friends with me now but I have had some people, particularly in the 80's who I was friends with who I had to end the friendship with usually as a result of them publicly disclosing my status that I had disclosed to them in confidence at a time in my life that I was choosing a non disclosure policy for personal safety reasons.

35. There was a stigma attached to HIV at the time. At that point in time, relatively little was known about this virus other than it was predominant in the homosexual community and intravenous heroin users. Now, I make no secret of the infections as we have kept silent for far too long. In the early

days, only my close friends knew that I was infected and I told them to keep it private as they were aware that there was a stigma attached to it. Back then, people's houses were being painted with horrible words and they were bullied.

36. My infected status has also been detrimental to my education. The fact that I had been diagnosed with HIV and not knowing how long I had left to live played on my mind constantly during school. As a result, I did not get a chance to go into further education and left school. Prior to the diagnosis, I was quite a bright child at school. It is more of a regret now that I did not get a chance to go into further education. I wish I could go back and get A-levels as well as a degree. I believe that if I had an education, I would have had a better career and could have had a job which would have paid a lot more.

37. I also suffered work-related effects as a result of the infections. After I left school, I found it hard to get a job. Even though I did not tell my employers that I had HIV, I did tell them that I was a haemophiliac. At that time, Haemophiliacs were being closely associated with HIV and so I believe for this reason I was rejected for employment. I then went onto working as an electronics engineer with my brother.

38. My family was impacted on as a result of my infected status and particularly my mother. My mother felt guilty as I was born a haemophiliac and my elder brother was not. She felt responsible for bringing me into the world knowing that haemophilia ran in her family, and she was a haemophilia carrier herself. She tried to conceal her guilt in order not to make me feel upset but I always knew what she felt. As a result, my mother and I had a very close bond. My brother was 12 years older than me and my sister was 10 years older than me and when I was diagnosed, they were shocked as HIV was a big deal back then.

Section 6. Treatment/care/support

39. The treatment, care and support that I received from the doctors was pretty good so I do not and have never considered them as personally responsible.

I believe they were mostly just the means of delivery of what were the approved treatments mandated by the civil servants. The doctors and nurses who knew or suspected what was going on at the time could not have spoken out loud without risking their career or possible prosecution by the state.

40. However, I am also aware that the haemophilia treatment framework (blood sourcing and how the treatments were manufactured), the civil servants and government ministers that were responsible for setting down these protocols there were certain senior pathologists and medical professionals that were included as part of the consultations and decision making processes in regards to the supply and manufacturing costs, efficacy and safety.

41. I also think that the extraordinary lack of acknowledgement by both the policy decision makers through to the commercial blood product manufacturers involved in the blood collection and blood product supply chain and the possibility that their practices could in any way be harmful let alone kill anyone. After all blood is considered to be the gift of life not a gift of death.

42. To them the possibility of anything even remotely like this was completely unthinkable. Once they finally realised that this was exactly what had happened and the thought of the possibility of being seen to have blood on their hands it was to them even more unthinkable that they were going to be held to account for it and from that point on adopted a code of silence. I think because the 'higher up's' employed this policy and were able to implement it from the top down and has had a very detrimental type of trickle down effect on any financial or psychological support programs of any kind that may have in any way have been associated with it.

43. If you do not accept that a problem exists in the first place then why should there be a need for any kind of support system to be implemented for a non-existent problem. It was also this type indifference that contributed to delays in the screening for blood donations. It seems as if a particular level of fatalities rather than infections had been met in order to finally justify the costs of blood product heat treatment or of any blood donation screening program to prevent it.

44. As previously stated, I saw a psychiatrist in order to talk about my depression. However the psychiatrist said I was fine and I did not go more than 2 times. No counselling or psychological support was ever offered to me by the hospitals when I was first diagnosed with HIV and Hep C.

Section 7. Financial Assistance

45. I was involved in the 1991 HIV litigation. We were given a choice that those who had not been infected or were newborn haemophiliacs could be supplied with the newly available type of recombinant treatment or we as the infected group of haemophiliacs could receive no fault compensation but not both. It felt like we were being blackmailed and being forced into a binary choice of whether to selfishly take the money for ourselves (at this time most of us thought we wouldn't be alive for much longer anyway) or to ensure that from that moment on that the haemophiliacs that were not infected never would be.

46. We collectively decided that this had to stop now and almost unanimously decided on the latter. This was a pre-condition that was imposed. I believe they should have put us all on the recombinant treatment and given the infected compensation as well. Recombinant treatment was a lot safer than FVIII as it was man-made product and not sourced from human blood. As someone infected I was not put on to recombinant treatment until about 10 years after it was became available. Whilst recombinant treatment wouldn't have given me the same peace of mind that someone who was uninfected would have got from it I would at least have felt that they were at least taking some positive action on the issue but I guess going that far could also have been seen as an admission of guilt and therefore liability. I apologise for sounding so cynical but this is due to the repeated patterns of the inactions of those that could and should have acted and the huge length of time that we have been fighting for the answers.

47. In 1991, I received two payments of about £20,000 and £23,000 from the Macfarlane Trust.

48. I also receive monthly payments in the sum of £1,500 from the Macfarlane Trust when it first became available.

49. In 2007, I received a grant from the Macfarlane Trust for patio doors.

50. In October 2015, I started receiving monthly payments from EIBSS in the sum of £3,000 a month (2 payments of £1,500, paid at different times).

51. In October 2015, which was when I started the treatment for Hep C, I received the Stage 1 payment in the sum of £20,000 from the Skipton Fund and subsequently the Stage 2 payment in the sum of £50,000 in the same year.

52. I found out about the Skipton Fund from a nurse who was treating me for Hep C. I found out about the other trusts and funds from the Haemophilia society.

53. The process for applying for any financial assistance was complicated and you had to jump hoops to get any financial assistance.

54. I faced many delays when I was applying for the financial assistance. The delays are a lot shorter now. The staff working for the trusts and funds are getting paid to assist people and I believe they should do their job properly.

55. I believe the Skipton Fund was better run than the Macfarlane Trust. I did not have any problems with Skipton Fund, it was pretty straightforward. However, I had many difficulties with the Macfarlane Trust.

Section 8. Other Issues

56. I knew a lot of people that are no longer alive as a result of the scandal. So many people have been affected by the scandal and I believe that what could possibly be the worst peacetime disaster of the twentieth century. I feel I would be being hugely disrespectful to the memories of those who have died as a result of this scandal if I myself were to maintain my anonymity because to me many of the people who have lost their lives were not and are not nameless victims.

57. I did not think that I would be alive to see the Inquiry. The Penrose Inquiry's terms of reference were far too narrow and did not have the geographical jurisdictional clout as it was aimed at Scotland only, but I believe this Inquiry has far more scope in the terms of reference and is UK wide and I am cautiously optimistic that a more satisfactory outcome may avail itself.

58. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the investigation matters and I am unable to do so in this statement. I have spent well over 30 years looking into this scandal and have built up a detailed knowledge base of not only the UK blood scandal but also the other inquiries that have taken place worldwide.

Anonymity, disclosure and redaction

59. 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.

60. I wish to provide oral evidence at the Inquiry.

Statement of Truth

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

Signed...... **GRO-C**

Dated 28TH APRIL 2019.