Witness Name: Judith Howells
Statement No.: WITN0344001
Exhibits: **NIL**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JUDITH HOWELLS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 February 2019.

I, Judith Howells, will say as follows: -

Section 1. Introduction

1. My name is Judith Howells. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I work part-time with my husband, Roger, for a business that we have shares in. I have a son and daughter from a previous marriage, and two grandchildren who I regularly visit.

2. I intend to speak about how my son, Sam McMahon, was infected with Hepatitis C (HCV). In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.

3. The dates that I provide are approximate guesses as most of the events that I detail in this statement happened over 20 years ago. I am aware that my son is engaging with the Inquiry. He will be able to provide more exact details regarding dates.

4. NOT RELEVANT

Section 2. How Affected

5. My son was born on GRO-C 1976. My grandfather had haemophilia, which I made the hospital aware of so that 6 weeks after my son was born he was tested. The test confirmed that he was a mild haemophiliac. Sam was later infected with HCV through blood products that he received as treatment for haemophilia. Specifically, Sam received the blood product Factor 8. I still do not know the exact date on which Sam was infected as he received Factor 8 throughout his childhood.

6. When Sam was born I was living in Birmingham so he was treated for his haemophilia at Birmingham Children's Hospital (BCH) until he was 16 years old. We moved to GRO-C after Sam turned 5 years old, this was also after the tests the BCH started doing on him for jaundice. Sam had his first injection of Factor 8 when he was about 8 or 9 months old. He had cut himself by grabbing onto something sharp on the side of the fridge and the bleed would not stop so I took him to BCH. As he grew up he had more Factor 8 injections intermittently. Sometimes he could go months without one but then at other times he would have two in one month.

7. When Sam was 5 years old, BCH asked me to take him in for blood tests every three months. I was told this was to test for jaundice but I now know that was a lie. There was another child who also went for these regular check-ups at BCH. He had severe haemophilia and was

more regularly in the hospital than at home. Within the first year of tests, that child's mother informed me that they were testing for HIV, not jaundice. That child died from AIDS at the age of 9. I knew then that the blood from BCH was infected.

8. A few months after the other child's mother told me about the testing for HIV, I asked the head haemophilia nurse at BCH, Sister Marion, what the tests were actually for. She told me the truth, that Sam was being tested for HIV. I am glad for her honesty. Prior to this no one had ever told myself, nor Sam, that there was a risk of infection from injecting Factor 8. After the first year of testing, the tests were done every 6 months and then it became yearly.

9. Sometime after the testing began at BCH, Bayer, a pharmaceutical company, gave the parents of the children with haemophilia a pager. We all knew it was a 'sweetener'. Sam was about 11 years old at the time and it was becoming common knowledge that the blood products were sometimes infected. Bayer told us that the pager was provided to support us so that if our children had an emergency, we would know sooner and therefore be able to take them to hospital quicker. We used it perhaps a few times, but it was mostly unnecessary.

10. Throughout this period of our lives more information, opinion and judgment was spread about HIV and AIDS in the media. Fear of it, as the disease that would kill everyone, started to set in. I thought the worst. It was on the news constantly. There was one particularly harrowing advert about AIDS, which had tombstones all over it that I still remember. It was the most awful advert. I feared Sam had HIV and, in my head, I had buried my child already.

11. The hospital did not give us the all clear until Sam was 16 years old. For 11 years I had worried constantly that he may have HIV. In retrospect, I know we are lucky because he is still alive. It is heart breaking for others who were not so fortunate. This is especially so because I believe it could have been stopped.

12. During the period of regular testing, between the ages of 5 and 16, Sam continued to receive Factor 8 treatment. I made sure everyone knew he had haemophilia so that he would not get hurt as much. I know he was quite protected growing up. For example he played football with his friends in the local area but I didn't let him play for the football team at school.

13. After his 16th birthday, Sam moved to Birmingham's Queen Elizabeth Hospital (QEH) for haemophilia treatment under Dr Wilde. The doctor confirmed that Sam did not have HIV, and confirmed that provided Sam was always given heat-treated products, he would be fine and would never contract HIV. Sam remained at that hospital for about two years before my husband and I moved to Bristol, and Sam moved to London for university. He was 19 at the time.

14. Sam registered at a London hospital near his university. I cannot remember the name of that hospital. He also registered with the hospital in Bristol because he came to visit me regularly.

15. The first time he went to the hospital in Bristol my husband took him, although my husband was not in the room when Sam met the doctor. Following his appointment, Sam told my husband that he had contracted HCV from infected blood products. Sam then called me to tell me the same. According to Sam the doctor was very blasé and told him without sympathy. The doctor did not give him any information on HCV. At the time we did not realise how serious HCV was. All the information that we gathered about it afterwards was from our own research, through the Haemophilia Society and later on through Google.

16. We were very shocked. We thought Sam was in the all clear after receiving confirmation that he did not have HIV. Then came along the realisation that no one from QEH had told him he had HCV. We do not know to this day when the test for HCV was done. As Sam was told on

his first visit to the hospital in Bristol, there was no opportunity for that hospital to have done the test before informing Sam. The test must have been done at QEH yet nobody had informed us.

Section 3. Other Infections

17. Sam never developed any other infections from blood products that I am aware of. GRO-C

GRO-C

18. It may not be connected but it does make me fear that something else could pop up. I still live with that constant concern.

Section 4. Consent

19. I gave consent for each of the Factor 8 injections Sam was given as a child, however I was never told there was a risk of infection, not even when awareness of HIV increased.

20. I have been asked whether I believe Sam was ever treated or tested for the purposes of research. I do not believe Sam was given Factor 8 or ever treated and tested for the purposes of research.

21. Sam was never told that he was going to be tested for HCV, and therefore he could not have given consent for the test. As I have already explained, Sam was only told about the test results by the hospital in Bristol when they did not do the test themselves.

22. Sam did provide consent for the HCV treatment he received, however I do not believe that Sam was given adequate information in regards to

the side effects of the treatment. Dr Wilde from QEH told Sam that taking it was like a really bad flu. The side effects that Sam experienced had a much more significant impact on his life than Dr Wilde had indicated. I have detailed the side effects and the impact that the treatment had on Sam further below.

Section 5. Impact

23. When Sam was told he had HCV, the doctor also said that there was basically no cure and Interferon was the best they could offer. The doctor told Sam to go to university and live his life for the next three years. He also stated that Sam had probably had the virus in his system since he was a child, so his body would be slightly immune to it. Therefore the doctor's advice was that Sam should finish university and after that period, there would hopefully be a treatment better than Interferon available.

24. Sam ended up in university for a total of four years as he changed his degree from History to Philosophy. Throughout his university experience, Sam thought he was going to die. The doctor who told Sam that he had HCV had also informed him that HCV symptoms do not usually show until around 20 years after infection. Sam had nearly hit the 20-year mark since he had first started taking Factor 8 injections so he worried about it. Sam was not a normal student because of this. He did not drink alcohol because it could lead to cirrhosis. Whenever I bought him products from the pharmacy to help his liver, he took them all in hope that they could perhaps postpone a decline in his health.

25. During university, Sam had a girlfriend who was very supportive and helped him through his challenges. This was especially so when Sam started the treatment for HCV.

26. When Sam finished university, he came home to Bristol to start treatment. However, he was told first by the Bristol hospital, and then by the hospital in London at which he was registered, that they did not

have the treatment for HCV. When asked why the Bristol hospital did not have the treatment, the hospital could not offer an explanation. They also offered no alternative for him so Sam got in touch with QEH in Birmingham, hoping that because he had previously been a patient there, he could register there again. Although QEH had the treatment, Dr Wilde told Sam he had to be referred to QEH given that he was no longer registered with that hospital. Fortunately, my mother still lived in Birmingham so Sam moved to live with her. My mother explained the situation to her GP, who then referred Sam to QEH. I think if it was not for my mother, Sam would never have had the treatment.

27. Sam started his treatment for HCV from QEH in September 2000 and lived at my mother's house throughout the 12 months of treatment. He received Interferon, taken weekly as an injection, and daily Ribavirin pills.

28. I drove to Birmingham every week and picked him up to take him to hospital for the Interferon injections. Eventually he was able to take it at home by injecting it himself in to his stomach. When we went to the hospital for the injections, I remember looking around the room and being able to tell straight away which were the patients on the treatment and who was there for support. All the patients were skeletal and looked as if they dying.

29. Sam graduated from the London Metropolitan University in December 2000 with a 2:1 (upper second class) philosophy degree. In the 3 months he had been receiving treatment by that stage, he had changed dramatically. GRO-C

GRO-C

30. Around the treatment period, Sam started acting different and weird. GRO-C GRO-C Mentally, he also did not act himself. GRO-C GRO-C GRO-C When I picked him up for the weekly injections he would hardly speak to me. I could see he had completely changed from the treatment. I called him every night, and sometimes he would not come to the phone, the treatment seemed to alter his personality. He hardly saw his girlfriend at that point too. They were regularly speaking to each other I believe, and she did visit a few times, but he was so tired and would need to sleep a lot.

31. GRO-C GRO-C Sam then told his girlfriend that he was going to kill himself. She told me and I spoke to the hospital about it. Dr Wilde told Sam to not take any more tablets or injections. This was in September 2001 when Sam was on his final week of the year-long treatment.

32. I took Sam in to speak to Dr Wilde about his mental health. Although for confidentiality reasons Dr Wilde could not let me know what was said, he implied that Sam would not speak to him. I asked Sam whether he wanted to kill himself and he would not answer me either. According to the doctors, it was impressive that Sam was able to remain on the treatment for 12 months. Usually people only lasted 3 months.

33. Sam was successfully cleared of HCV as a result of the treatment. The hospital carried on testing for a good year after the treatment to make

sure, but they finally confirmed that the HCV was categorically cleared and would not come back. However, Sam continues to go back every year for tests.

34. Sam's health gradually improved after the treatment ended, but his personality had changed. In October 2001, my husband and I paid for a cruise around the Mediterranean for Sam and his girlfriend, which seemed to do him some good.

35. One day around the end of 2001, I received a call from Sam's tutor from university who was asking after Sam. The tutor was not aware that Sam was a haemophiliac, never mind that he had HCV so he was surprised to hear that Sam had been unwell. The stigma of both haemophilia and HCV has had an ongoing and detrimental effect on Sam. He did not feel that he was able to tell even those that supported him about what major events he had going on in his life. The tutor said that Sam was the best student he had ever had. Sam apparently understood everything and the tutor had thought Sam would himself go into tutoring. I said I hoped he would too when he was better.

36. After the treatment ended, Sam wanted to go back to London. He got a job at the Health Protection Agency in 2002. It paid poorly so my husband and I subsidised him. The job was rubbish but it was what he wanted and it meant he was near his girlfriend. I hoped this would bring him back to normality GRO-C GRO-C GRO-C. Throughout the treatment and following the treatment, Sam's mood swings and depressions continued GRO-C GRO-C

37. When Sam came back to Bristol, he had lost contact with all of his friends. It was an intentional decision on his behalf to not tell his friends he had HCV because of the stigma associated with it. This meant he

could not explain to his friends why he had lost contact with them over the year he had been on the treatment. GRO-C

GRO-C

38. I tried to help Sam out of his loneliness. I went to find an old friend of his from college in GRO-C. I knocked on doors in the area until I found the family of Sam's old friend. The dad answered the door. I thought he might not remember Sam but he did and told me that his son had moved to Bristol after finishing university in Cardiff. I could not believe that of all the places Sam's friend could have moved to, it would be so close to Sam. I asked the dad for his son's number and when I got back home told Sam to call him. Sam did call him and they became close friends again. I think it helped Sam through his depressive episodes. They still see each other now.

39. GRO-C

40. My husband and I took Sam to Florida in 2004, before he started his next job, which seemed to help him too. I also bought a cat for Sam to look after, which I think comforted him. As I worked full-time back then, he had to care for the cat, and so Sam had to look after himself so that he could look after his cat. As a result, I think that helped him.

41. When Sam came to Bristol in 2003, he got a job at GRO-C GRO-C where he was in charge of finances. It is a company my husband and I have shares in. Since starting, Sam has made a large impact on the company, and it runs smoothly because of his dedication. At one point he was recruited by a charity but he turned the offer down. Six years ago, he trained as an accountant part-time while still working at GRO-C. He is a dedicated and intelligent man.

42. Being infected with HCV, and the subsequent treatment, had a massive impact on Sam. It makes me question what he could have done if he hadn't been infected. As he excelled at university, he might have stayed in London and his earning capacity would have been higher. Sam is comfortable at GRO-C and he does not think he could handle working elsewhere, but I believe he is wasted there. His confidence has been severely affected by what has happened to him and he is always seeking reassurance, even in relation to small every-day decisions. I know he would be further along in his career and living in London if it were not for his infection with HCV.

43. Ten years ago, Sam got married GRO-C GRO-C GRO-C They have never had children, nor will they, because of Sam's infection with HCV and the treatment he went through. Sam decided he did not want to have children because of the experiences he went through.

44. Sam still has treatment for his haemophilia. GRO-C GRO-C

GRO-C

45. Even if this recent incident is not related to infected blood products or HCV, the fear of it remains. The HCV still has a psychological impact on Sam and I now, despite Sam having cleared the infection 15 years ago.

46. HCV was not just awful because of the physical illness, it impacted and continues to have an impact on Sam's personal life. Shortly after the incident in February 2019, Sam was going to Thailand with my husband and I for a family holiday. However after the incident, Sam had to inform his travel insurers and they said that they would not protect him if something were to happen in Thailand. It nearly ruined the holiday for him, but my husband and I said we would pay for him no matter the cost. We found a new insurance company that said that they would cover Sam and it ended up being an extortionate £500, but we wanted Sam to go and live his life fully.

47. GRO-C Sam often takes himself for walks, which does seem to help. He also speaks to his wife and his close childhood friend who now lives in Bristol. They have supported him through these challenges. Recently, since the Inquiry started, Sam has spoken to me about his experiences more.

48. Overall, I believe the HCV and the treatment affected Sam's education and earning potential. He received a 2:1 from university, yet Sam's tutor was surprised because he was so intelligent and hard working. He expected him to have done better in his exams. Sam has told me before that when he was at university, he would spend time wondering why he was even at university if he was going to die soon. It was a worry that was constantly on his mind and must have affected his ability to focus at university. The year that Sam was on the HCV

treatment, where he was constantly tired, was a loss of a year's worth of wages as well. I believe Sam would be living in London with a higher salary than he is currently earning if it had not been for the infection.

49. I worry about him even now, I have not stopped worrying since he was 5 years old and they started doing tests on him. First it was the fear of HIV, then we got told he has HCV and had to undergo incredibly difficult treatment GRO-C GRO-C. I convince myself, every time something new comes up, that he is going to die and it is something I blame myself for. I have never been offered support or advice.

Section 6. Treatment/Care/Support

50. As I have already detailed, Sam faced a lot of difficulties in receiving treatment for HCV. Not only were two hospitals unable to provide treatment, they also did not explain how he could go about getting treatment from alternative sources. This is despite the fact that the doctor who originally told Sam he had HCV said that Sam would be able to go on treatment when he returned from university.

51. If it had not been for my mother living near Birmingham, I am not sure how Sam would have received the treatment. He may very well have still had HCV and by this point it would have affected his liver.

52. GRO-C

53. Throughout this whole experience, the medical support was only ever given when we demanded it. This included information on HCV, as well as the extent of the side effects of the treatment for HCV.

Section 7. Financial Assistance

54. As I am a member of the Haemophilia Society, I found out about the Skipton Fund and told Sam about it. I know the government would never have been in touch with Sam directly to tell him.

55. While I am aware that Sam received payments from the Skipton Fund, I do not have many details regarding this matter and I have had no involvement with them myself. I know Sam received a lump sum payment of £20,000 in about 2004.

56. I think that was another 'sweetener'. Sam had to sign his life away to receive that money so that if anything else popped up as a result of infected blood products, he could not go back and claim more money. Although the funds helped him put down a deposit for a mortgage at the time, it was not enough for a disease which has affected his whole life.

57. The funds he received are not the government saying 'sorry we have poisoned you', they are saying 'we feel sorry for you' I believe. This is not acceptable and they need to take responsibility.

58. **GRO-C**

59. I have never been offered financial assistance as a result of Sam's infection with HCV through infected blood products. I am not interested in financial assistance for myself, but I do believe Sam should receive more.

Section 8. Other Issues

60. I believe we all know there has been a cover up since day one. The government were told blood may be infected and they did not do anything about it. They have never apologised or taken responsibility,

and they should be ashamed of themselves. I remember watching a Panorama, a BBC documentary programme, that showed that the blood that the UK used came from prisons. I believe America warned us that HIV and other hepatitis viruses were in the imported blood, yet the UK brought it into our country. I am of the view that the government have got blood on their hands.

61. The government needs to stand up and admit liability. I am of the view that everyone who has been infected should get proper compensation. The infected and the affected deserve an apology.

Statement of Truth

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

Signed GRO-C

Dated 5/4/19.