Witness Name: Paul Mouncey
Statement No.: WITN0904001
Exhibits: **WITN0904002**
Dated: 31st July, 2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL MOUNCEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 April 2019.

I, Paul Mouncey, will say as follows: -

Section 1. Introduction

1. My name is Paul Mouncey. My date of birth is GRO-C 1945 and my address, which I have lived in for four years, is known to the Inquiry. I studied Microbiology at University and had several jobs over my career before I was asked to retire by the health board at fifty-four, due to stress and subsequent related ill-health.

2. I was married to my wife, Jane Mouncey for twenty-four years before she passed away in 1993. We had two children together.

3. I intend to speak about Jane's infection with the Hepatitis C Virus ("HCV"), which she contracted as a result of being given an infected blood transfusion.

4. In particular, I intend to discuss the nature of Jane's illness, how the illness affected her, the treatment she received and the impact it had on her life and the life of my family.

5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

6. I can also confirm that I have had explained to me the use of my statement form. I am happy to sign the consent form on the basis that it will be submitted when my statement is signed.

Section 2. How Affected

7. Jane was born on GRO-C 1948. She was infected with HCV in early 1989, at Stirling Royal Infirmary, where she received a blood transfusion, which was required as she was receiving chemotherapy at the time.

8. Jane was trained as a nurse and had been working down in England as a district nurse. She moved to Scotland with me in 1988 and continued to work in the health services.

9. Whilst on holiday in Newtonmore during the summer of 1988, Jane started to feel extremely unwell. Upon our return, we sought advice from the dentist, as she appeared to be bleeding from her gums. The dentist referred her to the dental hospital in Glasgow. Later, I received a call from the hospital to say that something serious had shown up in Jane's blood analysis and that she should go to Stirling Royal Infirmary.

10. Initially, a young consultant haematologist at Stirling Royal Infirmary misdiagnosed Jane with Myeloma. I knew the Specialist on the ward and I said to her that it had only been about three or four days after her blood analysis. I said that the diagnosis is a bit soon, as from past experience I know that you cannot do the confirmatory test for Myeloma in that short a

time. I knew that it took around ten days or so to conduct such a test and therefore, told the Specialist that I did not think the diagnosis was right. She said I had better speak to a consultant haematologist. I believe that the consultant I spoke to was Dr. Reith.

11. Jane was then transferred to the Western Infirmary in Glasgow. It was confirmed that Jane was misdiagnosed with Myeloma and she was re-diagnosed with Waldenstrom Macro Globular Anaemia ("WMGA") by Dr. Lucy. The treatment for this was a completely different type of chemotherapy. It was a good thing that I knew about microbiology, as having the wrong chemotherapy may have had disastrous effects on Jane.

12. As the disease manifested, Jane had her first blood transfusion in late 1988. The transfusions were necessary, as the chemotherapy had destroyed all of her bone marrow.

13. Jane was required to have regular blood transfusions, around every five to six months, in large quantities. She needed around eight pints to replace the red blood cells and the platelets. In September 1988, Jane was left in an isolation unit to repair the bone marrow.

14. In early spring 1989 Jane had her second transfusion at Stirling Royal Infirmary. Within a few days of the transfusion she displayed symptoms that would resemble those of hepatitis. She became jaundiced and could not eat. She experienced joint problems and suffered severe weight loss, all whilst at home.

15. The incubation time did not seem long at all; it was around ten days from Jane's second transfusion to her symptoms of hepatitis. I rang the hospital and they said that she had to come in. After running several tests, Jane was diagnosed with HCV.

16. We questioned the hospital about why Jane had been infected with HCV. They later informed us that they had traced back the infected blood to a male donor. No more information was given to Jane, or myself, despite us asking appropriate questions about how this could happen. Nothing was made clear about the screening of blood products. We were never given any indication that there was a risk from the transfusion. We were simply told Jane's infection with HCV had come from the blood transfusion and that was that.

17. We were now attending clinics in Glasgow under Dr. Lucy. We had been told that Jane's survival time with WMGA would likely be ten years with the chemotherapy and on-going blood transfusions. We were, however, left completely void of any information on the effects that HCV would have on her prognosis, despite asking questions of Dr. Lucy, who said absolutely nothing. Jane already had a compromised immune system and now to have to fight off another infection, we knew it would be hard.

18. It was difficult to know what effects the Hepatitis had and was having on Jane, as she was already ill. We were hoping that the ten years of expected life could provide time to find a cure for Jane's WMGA.

19. I do not remember what treatment Jane was given for HCV; we had to be careful as she was already being treated for WMGA. I do remember she was taking tablets, I do not think that she had to take any injections.

20. Jane or I were never told how to manage the infection or how to deal with it. We were not told how to stop the disease spreading or any information in regards to this.

21. As mentioned, we were provided with no information that a blood transfusion could pose a risk factor for any blood carrying diseases. In addition, we were not told about the risk to the family of cross-infection. Communications, despite our questions were totally inadequate and neither the haematology department nor the hospital gave us any

information about the future management of any chronic effects of the disease. The general practice, which Jane was registered with, gave no help or information.

22. From the time we were told Jane had ten years to live, she only survived five of them. She passed away on 24 September 1993 at the age of forty-five, at the Southern General Hospital. This was unexpected and left us to wonder how much the HCV had shortened her survival time. No information was given to me in regards to this.

23. Her death in 1993 was unusual for the diagnosis of IWMGA. Her death certificate stated that she had passed away from a Cerebral Venous Infarction ("CVI"), [See Exhibit **WITN0904002]**. I am aware that HCV can cause a CVI. On her death certificate there is no mention of HCV. Normally, CVI is not a condition that can be a cause of death by itself. I did question this but I was not in any fit state, emotionally, to follow any queries through. I have, not in the intervening years had any further explanation relating to Jane's HCV. Either, as to how it was contracted or it's effect on the treatment she was already receiving. I have been left wondering why none of my questions have ever been answered. I am sure that it had some role in exacerbating her decline to eventual death.

24. My family and I were not allowed to see Jane after she had passed away. I was told that she was not in a good state. It is hard to know exactly why. But this is so unusual and I wonder if they were worried about the risk of infection.

Section 3. Other Infections

25. Apart from HCV, to the best of my knowledge, I do not believe that Jane has contracted any other infection associated with her contaminated blood transfusion.

Section 4. Consent

26. I have been asked if I believe Jane has ever been treated or tested without her knowledge or consent and the answer is no, as far as I am aware, she always consented to her treatments. As far as I am aware she was always provided with the best treatment that was available, although in respect of the HCV I cannot remember the name of the medicine used.

Section 5. Impact

27. I know that many people develop chronic hepatitis and therefore, experience significant symptoms of fatigue. This may have explained, in part, Jane's severe lack of energy once she was diagnosed with HCV. As previously mentioned, other physical effects included jaundice and loss of appetite. She also suffered from aching joints and endured rapid weight loss.

28. After Jane's illness and infection we could not go anywhere on holiday, even in Scotland. Her health at any stage could deteriorate very quickly, within two or three days. Therefore, we always needed to be near Glasgow where she could get the treatment she required.

29. My son was seventeen when Jane was diagnosed with HCV. My daughter was thirteen at the time of infection. They were twenty-two and eighteen when Jane had passed away. This was extremely hard for them, the effects on my daughter were devastating. She cannot talk about it even now; she has never come to terms with it. She gets angry and emotional if I raised the subject of her mother. It is not a nice thing for your children to witness the gradual deterioration of their mother in front of them and they know there is nothing they can do. My daughter was going to go to university but she did not end up going, as she could not cope. She wanted to be near her mum. My son coped slightly better but he has been quiet about it. I remember the time when Jane attended his graduation.

She was so proud. But it took so much effort on her part and she looked so unwell.

30. It was extremely hard for me to cope. I would have to come home and cook and clean; this meant that my family life was completely disrupted. I could not devote as much time to my children as I would have wished. There is so much frustration and feelings of hopelessness when you see your wife endure so much suffering and pain and you know that possibly it did not have to be this way. She passed away earlier than expected and to an extent I feel that time lost with her was stolen from me by the NHS.

31. I do feel as though if Jane had not passed away I could have progressed further throughout my career. Even years later, I was still reeling from the impact of what had happened. In the end, I had to leave my work. I was forced to take early retirement from working in the National Health Service, owing to stress and subsequent ill health in 1998.

32. In terms of stigma, we always kept the information surrounding Jane in the family. We were very confined so we did not experience much stigma, as people did not know.

33. I ended up having to sell my house in 1995, as I could not afford to keep maintenance on the house and wanted a fresh start, there was too much to do on the house. I moved into lodgings as my daughter had moved out; my son had already moved to Dundee.

34. Financially, I have been fortunate as I have always sold houses and have invested money. If it had not been for this, I would have really struggled. I was struggling before I sold the house in 1995.

35. I am now very critical of some of the things that go on in the health service. Having worked with GP's and dealing with them after my wife's infection, I was horrified by what I saw. I am aware that the Government are held to ransom by GP's and I believe that they do not take general

practice in the right direction. They seem to work hardly any hours and it appears that they put themselves before patient's well-being. It has made me reticent to see a GP.

Section 6. Treatment/Care/Support

36. I do not believe that Jane was ever denied or refused treatment in relation to her infection. Jane did have to go to the dental hospital as she could not go to the normal dentist but this may have also been because she was suffering with WMGA.

37. I can confirm that my wife and my family were. never offered any psychological support to help us manage the infection and the results of the consequential treatment.

38. I can also confirm that during my interview with the Inquiry, I have been informed about the access to the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

39. My wife and I were never told about the ways in which financial support was made available. We were never told about Skipton or the England Infected Blood Support Scheme. We, therefore, did not apply for any financial support. At the time I was not necessarily concerned about it.

Section 8. Other Issues

40. Jane worked for Anthony Nolan bone marrow trust for years and was well known. She was sponsoring a boy in a far away country and was exceptionally intelligent.

41. When it came to her funeral, my family could not cope. We decided to have a little family gathering but there was an outcry as she was so

popular in the local community. There was a memorial service for Jane, for which money was donated, around £1,200. This money was given to Dr. Lucy's laboratory in Glasgow. There was a promise that the hospital would keep in touch with their research programme on bone marrow and blood related cancers. To this day we have heard nothing about the said research from Dr. Lucy other than an initial thank you for the money.

42. I would like the Inquiry to know that I have also asked for Jane's medical records. I contacted all the hospitals and eventually sought legal advice. I was informed that the hospital had destroyed all the records, as they only needed to keep them for five years. I was shocked, as records like this should never be destroyed because of the extenuating circumstances surrounding Jane's death.

43. I have some criticisms of the hospitals involved in dealing with Jane:

(i) Stirling Royal Infirmary – Initially gave Jane a wrong diagnosis that could have been the end of her straight away. I was relieved to get Jane moved. I cannot recall the name of the Consultant involved.

(ii) Southern General Hospital – there were doctors there who appeared to be totally incompetent. I asked one doctor why another doctor was operating with critically ill patients when he seemed so incompetent. The answer was that he was new and was getting to grips with what needed to be done. I said I had seen him make some basic errors and that there was concerns from various people on the ward. In relation to Jane, he got her medication mixed up. There was no response.

44. I would also like the Inquiry to know that I find it absolutely appalling that the NHS have certainly appeared to attempt to hide information or destroy it. The infected blood scandal has been the biggest scandal in the health service history. I want to know why it has taken so long to bring an inquiry to the people; it really shocks me. For me, the Government must be responsible for not pushing it forward. It has changed peoples lives completely, the people infected and those affected.

45. The feelings that one gets when you have somebody close to you that has been infected. You ask the question why? When you hear the reasons why they are, it is appalling. Getting blood that has not been tested at all is inconceivable. We, as a modern nation with all our background in medical innovation should not have allowed this to happen.

Statement of Truth

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

Signed GRO-C

Dated 31st, July 2019.