Witness Name: **Susan Anne STAFFORD**
Statement No. **WITN0373001**
Exhibit Nos. **WITN0373002–WITN0373005**
Dated: 09 / 11 / **2021**

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT
OF
SUSAN ANNE STAFFORD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 21st January, 2019.

I, Susan Anne Stafford, will say as follows:-

Section 1 - Introduction

1. My full name is Susan Anne Stafford and I was born on GRO-C 1960. I live at an address in the West Country which is known to the Infected Blood Inquiry. I am a retired nanny and school lunchtime supervisor. I am a wife, a mother and a grandmother.

2. I intend to speak of my having been infected with Hepatitis C, something which happened as a result of a blood transfusion I had to have in 1988. In particular, I would like to tell you of the nature of my illness, how this has affected me, the treatment I have received, and the impact Hepatitis C infection has had for me, for my family and friends, and for our lives together.

Section 2 - How Infected

3. In 1988 I fell pregnant, but it was an ectopic pregnancy. Having suffered with severe stomach aches and bleeding, I attended my general practitioner (G.P.) for assistance and was sent on to the Accident and Emergency Department (A&E) of what was then my local general hospital, The Royal Free Hospital in Hampstead, London.

4. In spite of my condition, I had to wait in A&E for some six hours before being seen by a doctor who decided that I needed to be scanned. The scan revealed the ectopic pregnancy, something I had had no idea of beforehand – I hadn't even known or even suspected that I was pregnant.

5. The doctor told me that I needed to have an operation to deal with it, and so I signed a consent form. I had no idea how far into the pregnancy I may have been at the time, or perhaps more importantly in the long-term, that I would need a blood transfusion.

6. The doctor explained to me what had happened in so far as the ectopic pregnancy was concerned, what it was, why surgery was necessary, and what would happen in the operating theatre. I was told of the outcome, that my child would not survive, but that it was because I was only a short time into the pregnancy and the child would not have developed sufficiently to be capable of surviving at that stage.

7. I have recently had the opportunity of reading my medical notes from the time, and could see that I am noted as having suffered internal haemorrhaging – I did not know this at the time but I had bled a lot, and was in so much pain that I knew something had to be done.

8. By the time I had gone to see my G.P., I had already waited a couple of months, but over that period the pain I was experiencing had progressively worsened with the bleeding having become ever more pronounced. I can remember that the female doctor treating me commented that I must have had a very high pain threshold to have been able to put up with it for so long.

9. Following the operation, the same lady doctor told me that *"everything was fine,"* but didn't once mention the fact that whilst in the operating theatre I had been given a blood transfusion. I had been unconscious at the time, anaesthetised, so I had no person knowledge of this having happened myself.

10. I remained in hospital for four days, and although placed on an intravenous drip, do not recall having been given any additional blood or any blood products during that time. It was only when I accessed my medical records, much later on, and read what had happened, that I learned that I had been given a blood transfusion at all.

11. This had been in 1988, and from around the time of the birth of my second child, in 1989, I began to experience health problems. It seemed as though every couple of weeks, I'd come down with yet another illness. Following the 1988 surgery, and my then falling pregnant again, I had been a regular visitor to my G.P. and my blood had been tested, but each time I had been told that *"there was nothing wrong,"* but I do not know what, if anything in particular, they may have been looking for and there were no full, intensive tests, undertaken.

12. In 2016, many years after the blood transfusion, I went to see my G.P. and had another blood test. This revealed that my platelet count was a little low and so I was referred to a Dr. Alex MORGAN (Consultant Haematologist at the North Devon District Hospital) as a consequence.

13. Here my liver was scanned and further blood tests undertaken. The scan revealed that my liver had developed a 'spongy texture' which meant that I had cirrhosis. More blood was taken for testing, far more intensive investigation than had taken place previously, and which had to be undertaken at a laboratory in Exeter as it couldn't be done on site.

14. It was about a month before the results of these tests became available and I was given the resultant diagnosis – I had Hepatitis C (which is also known or referred to as Hep' C and / or HcV). I was not told if I had been tested for anything else, but was in such a state of shock when told of the HcV that I didn't then think to ask.

15. Hearing this news left me dumbfounded, I simply couldn't believe it. I had exposed myself to none of the 'risk factors' associated with this disease, and in particular had only ever had one sexual partner throughout my entire life. Hearing the test result hit me hard, I was disgusted, absolutely gutted at the news. I 'phoned my husband, and then my daughter immediately.

16. About a month later, I returned to the hospital for a follow-up appointment where, following the more exhaustive tests, a doctor asked me if I knew how I may have contracted the disease? I thought, rightly or wrongly, that it was something only 'druggies' suffered from and couldn't but think, *"how the hell have I caught this?"*

17. I was extremely upset, on the brink of tears all of the time, and could not believe what had happened, what was happening, to me. I thought back, and the only time when I thought anything untoward could have happened was during my time in The Royal Free Hospital, so I asked my G.P. to access my medical records at the hospital.

18. As requested, the G.P, assisted me in accessing the records, and I could then see for the first time that in 1988 I had been given a blood transfusion but not told of it – this was the only possible cause of the Hep' C I had been found to have.

19. Although I had been diagnosed with having Hepatitis C, there was no information made available to me about the disease, no written pamphlets or advice. Not was I given any information concerning the cirrhosis. I knew nothing or either and found that I had to look on the internet for information and learn for myself as no one amongst those treating me had placed anything before me to help me understand.

20. GRO-C GRO-C I found this a terrible thing to have had to do, it made me feel dirty, pretty rubbish really, even though none of this had been my fault. GRO-C but nevertheless I still felt depressed and couldn't stop thinking, *"why me?"*

Section 3 - Other Infections

21. I have not been infected with anything other than Hepatitis C.

Section 4 - Consent

22. At no time prior to the operation conducted in 1988 was I told that I would or might require a blood transfusion. I wasn't told that I had been given a blood transfusion after the surgery either. However, had I have been told that I may need a blood transfusion pre-op', then I would have consented to it all the same – I would never have considered any risk of the blood having been contaminated, you don't assume that sort of thing when you are in a position such as I found myself in at the time.

23. In 1988 I wasn't aware of anything untoward having taken place as regards the blood being used in transfusions – I knew nothing of 'contaminated blood,' and assumed that all blood being used would have first been checked by the hospital to ensure that it was safe to use.

24. Looking back, this is all a bit of a nightmare, as it doesn't appear that anyone knew what was going on in 1988 and if they did, then their knowledge wasn't widely known – I knew or had heard, nothing.

Section 5 - Impact

25. I had never had a transfusion before 1988 and haven't had one since. I've never taken drugs, do not drink, do not smoke and had always been healthy and 'clean living.' Throughout, all I could think was, *"How has this happened?"*

26. As a result of my infection, I developed minor dysplasia, have had to have two bone marrow biopsies performed upon me, and have had to be given an iron infusion. To date, I haven't had to have a liver biopsy, but my liver has only ever been scanned the once, which resulted in cirrhosis having been diagnosed.

27. I have never experienced any difficulties obtaining medical treatment, and was put onto a programme to deal with the Hep' C without question, although I knew how lucky I had been to be accepted onto the course of treatment – in this regard I was put on six month course of Zepatier which appears to have rid me of the virus as subsequent blood testing showed that I was clear and no further tests would be required.

28. Thankfully, I did not suffer any ill effects / side effects from the course of treatment I had to undergo which cleared me of HcV.

29. I did have to tell my dentist that I had Hepatitis C, but fortunately he was fine with that – I was the one who felt bad about it, it was embarrassing. Dentists don't know your full medical history, but I had to take a list of my background with me to tell him and to explain it all. I have never had any problems being treated and all I have ever been asked to do is to inform them of any changes with my health.

30. From the time of my diagnosis, I have been acutely aware of the impact my infection stood to have on my family. I tried to keep my distance, for safety's sake, not wanting to risk cross-infection, and it was hard knowing that I couldn't go up to them as I may have liked to do, to kiss or cuddle the children.

31. Risk of infection was ever-present. If I had a cut or a graze, anything like that, it was a worry. I felt awful about it – our grandchildren were told that I *"wasn't well,"* but I didn't really know how to cope and questioned how I could deal with it. I'd been given a horrible disease, something that should never have happened.

32. Hepatitis C has left me extremely lethargic and lacking energy. Doing things with the grandchildren is what I'd love to be able to do, but requires levels of energy that I simply do not have and I find that very upsetting.

33. My children have also had undue worry to contend with – my youngest daughter has a young child of her own and has been very worried about the child becoming infected by its grandmother. This has kept the child from me to a certain extent, something which is very hard for both of us to deal with. None of my children could believe what had happened to me.

34. My husband has been very understanding. He knows that I have been living through a nightmare and our relationship remained strong, he has always been there for me and gone through everything that's happened and fortunately, the necessary 'restraint' placed upon the physical side of our relationship hasn't been a problem.

35. I have tried to keep my problems known within just a few 'need to know' people, my close friends and family only. I don't, and haven't told others, I found and find it embarrassing and I felt dirty and a risk to others, so I kept myself to myself and even today still feel pretty horrible about it all.

36. In 1996 I returned to work as a school lunchtime supervisor and naturally had to tell the school of the infection. They were very supportive, telling me that it *"wasn't a problem,"* for them, but I was always very much aware of it and conducted myself accordingly, with great caution.

37. I loved children but didn't enjoy being around them as a result of my knowledge of the risk posed to them. I had worked at the school for about twenty years before my diagnosis, but left the job shortly thereafter as I couldn't cope, couldn't manage the risk I believed I posed to the children against my love of the job.

38. Hepatitis C wasn't the only factor in my retiring from work as at the time my mother also needed my help as she was poorly, but it was the major factor in my decision to stop.

39. My husband and I found that our money was very tight. I had kept having to take time off from work because of recurrent illnesses and at one time, in an effort to make ends meet, I held no fewer than five jobs, albeit each part-time. As time progressed and my condition worsened, I found it harder and harder to keep my jobs – each time I fell ill it took longer to recover and accordingly I needed to take longer and longer off.

40. It seemed to me that if ever there was a 'bug going around,' I would catch it. In one year, despite having had my annual winter flu vaccination, I went down with influenza four times alone. On top of these type of illnesses, I felt tired all of the time, progressively more so as time went on and generally felt awful, unwell all of the time. As the time passed and my jobs by consequence of my illnesses fell away one by one, I received no benefits or other financial assistance.

41. Even now I still do not feel good in myself and constantly fall foul of viruses. Not a week seems to pass where I haven't got something or other wrong with me. My immune system is so low that the effects of my having had HcV is constant. In addition, I had the situation with my liver to contend with. I hadn't seen a specialist for some years following the initial cirrhosis diagnosis, and worry over what may have been going on left me feeling quite low a lot of the time, not helped by my constantly feeling tired. I have however now seen a liver consultant and as no treatment or further monitoring appears necessary, I can only assume that all is now well, but that is an assumption on my part.

Section 6 - Treatment / Care / Support

42. I had been informed that I may have been eligible for Hepatitis C treatment and that the hospital would *"look into it"* for me, but I also knew that you had too be extremely lucky to be chosen for treatment, but my hospital had apparently just had a new form of treatment made available to them and felt that I may have been a suitable patient to be given it. I felt that at least I had a chance.

43. Over a period of about eight weeks, I received a course of Zepatier which was administered by and monitored through the North Devon District Hospital. I had to take one tablet per day and my progress was monitored by a specialist nurse who called me on a weekly basis to assess how I was getting on. I was also provided with a 24 hour emergency helpline number, just in case I needed treatment, so whomsoever was treating at the time me could speak to someone who knew about the drug and my condition.

44. Although the medication was only taken for two months, I had blood taken for tests each month for six months, to assess how I was progressing. I am pleased to say that the drug worked and I am now clear of HcV, but its legacy and in particular liver cirrhosis, remain.

45. I have never been offered or referred for any form of counselling or to any self-help groups that may exist in my area or further afield. I happen to think that it would be nice to have been able to meet with people in a similar situation and / or to have things explained to me in more detail – in general terms, I was left to get on with it myself and all that I learned, I gathered myself, from the internet.

46. I had been given information leaflets about dysplasia, but never anything for Hepatitis C. I had absolutely no idea of the damage Hep' C could do to my body, or what it has in fact done. I know that it has damaged my liver but do not know of any impact it may have had upon any other organs which gives me further concerns, but thankfully at least the damage to my liver doesn't appear sufficient to necessitate a transplant or any other form of treatment.

Section 7 - Financial Assistance

47. One of my children saw something online about various funds that had been set aside to help people like me and mentioned it to me. I was in two minds as to whether or not to apply, as I didn't want to be taking any money out of the National Health Service (NHS), so I decided to contact my local Member of Parliament (MP), Peter Heaton-Jones, for advice.

48. On his advice, and with the support of my G.P., I applied to The Skipton Fund (subsequently replaced by the England Infected Blood Support Scheme or EIBSS). The application process appeared to work okay and I certainly didn't encounter any problems with it although I did note that they wanted an awful lot of information which only my G.P. would then have had access to.

49. The application was accepted and I received a first stage payment, but when cirrhosis was diagnosed, one of my children suggested I apply for a second time, which I did and received a second 'lump sum' payment. I now receive monthly payments through the EIBSS.

50. These payments have really helped and kept me afloat. Without them I simply do not know where I would be financially, as I now haven't been able to work for a long time. I live off of this money and as such it has been vital.

Section 8 - Other Issues

51. If H.M. Government knew of the NHS use of infected blood, then as soon as they became aware they should have told people instead of trying to cover things up. So many people have lost their lives as a result of this, something which should have been avoidable.

52. In order to assist the Infected Blood Inquiry, I now produce a number of documents in support of the information provided, now exhibited as follows:-

WITN0373002 - A copy of an extract from my hospital medical record as a Gynaecological Outpatient, dated 2/12/1988 showing surgery on 11/10/1988 (first line from top) followed by a post-operative transfusion (second line from top).

WITN0373003 - A letter dated 12/01/2017 from the Consultant Gastroenterologist of the North Devon District Hospital to my General Practitioner stating that I had Hepatitis C, Genotype 1A, but that I should be eligible for 'newer treatments.'

WITN0373004 - A letter dated 04/09/2017 from the Gastroenterology Department of the North Devon District Hospital to my General Practitioner providing detail of what was then on-going treatment for Chronic Hepatitis C with Zepatier. This letter also details other medical issues being faced, including Cirrhosis, Vestibular Neuronitis, Myelodysplasia, Functional Dyspepsia and Epilepsy.

WITN0373005 - A letter dated 18/06/2018 the Haematology Department of the North Devon District Hospital to my General Practitioner providing an updated overall diagnosis that I remained HcV+ and had other continuing health problems. The Hepatitis C treatment received had been unsuccessful.

Statement Of Truth

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

Signed: GRO-C

Dated: 09-11-21