Witness Name: Mrs Susan Wathen
Statement No.: WITN1995001
Exhibits: 0
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WITNESS STATEMENT OF MRS SUSAN WATHEN
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Susan Wathen. My date of birth and address are known to the Inquiry.

2. I live at home with my second husband. I have two children both of whom are adults. I used to work as a school teacher. Following a period of seven months off work through sickness, I made the decision to hand in my resignation. I returned to work for two months and gave up teaching in July 2016. I no longer do any paid work.

Section 2: How Infected

3. In 1976 I was diagnosed with ulcerative colitis, a form of inflammatory bowel disease. The treatment at that time was with a drug called Salazopyrin which had the side effect of causing anaemia. As I did not respond to oral iron medications it was necessary for me to have blood transfusions on numerous occasions. It

has been difficult to determine the precise occasion(s) on which I received blood transfusions; including the contaminated blood, as I have not been able to retrieve my records, but in the absence of any other potential causative factor I believe that I became contaminated in this way. There is a letter in my medical records from my Inflammatory Bowel Disease (IBD) consultant to my GP stating "this lady has received numerous blood transfusions". This, along with her physical examination of me, led my Consultant Hepatologist, Dr Anne Day at Bedford Hospital to inform me that contaminated blood was almost certainly the route of transmission.

4. Uniquely, I recall that on one occasion whilst having treatment at Kettering General Hospital that I had an adverse reaction to a blood transfusion. Whilst being infused with the second unit of blood I developed severe swelling around my eyes and a rash over most of my body. Whilst this was quite distressing the nurses assured me that it was nothing to worry about and I was given high dose antihistamines. I do not recall how long this lasted and have no way of knowing whether this has any significance in relation to the contaminated blood. I was treated at Kettering Hospital until 1978 when I and my treatment moved to Bedford Hospital. I have since returned to live in East Northamptonshire and have been treated at Kettering Hospital, but not for the Hepatitis C.

5. My treatment for anaemia continued at Bedford Hospital and I was given blood transfusions throughout the years spanning both my successful pregnancies, the miscarriages in between and those following my successful pregnancies. I gave birth to my son at 34 weeks; GRO-C GRO-C, he had jaundice GRO-C GRO-C The frequency of blood transfusions varied but I would estimate that I had approximately two every year. I cannot be sure but I believe that I stopped having blood transfusions as a form of treatment in around 1989 when the treatment switched to monthly injections of iron.

6. Following this pregnancy, and over the next five years, I suffered four miscarriages. The reasons for these were not determined so any possible link to

Hepatitis could not be established. Since my diagnosis with Hepatitis C I have asked the question about whether there was a possible link between the miscarriages and the infection and I was given answers such as "it is possible" and "I suppose that could be the case" but I was also told that investigations would have needed to be carried out at the time to establish a causal link. Following one of the miscarriages; I think it was in around 1983, and while I was still in hospital, I was told that there was an "anomaly" in my blood and that I could not go home until I was given some treatment for this. When I was about to be discharged I asked what medication I needed for whatever they had detected in my blood and they simply said "you don't need anything". At the time, I wondered what they had detected and looking back now I wonder if they knew that what I had was Hepatitis C. Was there a test for it at that time, if not for Hepatitis C, then hepatitis? These are all questions I sincerely wish I had asked at the time. Had I been told that there was a risk of infection from blood transfusions I may well have done just that. The thought that it may have been hepatitis never crossed my mind. I simply wish, with hindsight, that I had pushed for answers

7. I was not infected as a result of a relationship with another person.

8. At no point was I ever told that there was any risk to my health from having blood transfusions! In fact, it would be fair to say that the reverse is true. I was told that this was the quickest and most beneficial way of dealing with the anaemia. On no occasion was there any mention of a risk of infection from transfused blood.

9. I was infected as a result of being given a blood transfusion or transfusions with Hepatitis C.

10. In April 2014, I went to see the GP because of some post menopausal bleeding. The GP sent me to a clinic for further tests. It was at this clinic that I was asked if I had a blood transfusion pre-1991. Having answered yes, I was tested for Hepatitis A, Hepatitis B and Hepatitis C, HIV and CJD. I was not given any information about the possible results, other than when I could expect to hear

back. I was, at that time blissfully unaware of the contaminated blood situation so I can honestly say that I did not ask any questions because I felt absolutely sure that I would be ok. It was approximately two weeks later that I received a phone call telling me I had tested positive for Hepatitis C and would require another test to confirm the diagnosis. The same afternoon of the phone call, I had a scheduled appointment with my IBD consultant so I asked him to carry out a test for Hepatitis C. This test was done that afternoon and I received a letter confirming that I was a carrier of Hepatitis C. This letter was dated 5 June 2014.

11. I was given no explanation initially as to what the Hepatitis C or the viral load meant. It was not until later; in around July 2014, when I saw the hepatitis consultant and I asked about the viral load that she put it into perspective by telling me that 800,000 was considered high.Myviral load vat bthe time of diagnosis was 2,600,000.

12. Even at the point at which I saw my hepatitis consultant I was given little information to help me to understand and manage the infection, for example I was not told about how it would progress and what treatments were available. This information came later; in around October 2014, at an appointment with the hepatitis nurse. The hepatitis nurse was very good at answering my questions, when I knew what to ask. I had to research the condition myself first to understand what I needed to ask and then ask any questions I had before I was given the information. Most of my knowledge came from my own research on the Internet and eventually from the Hepatitis C Trust which I signed up to soon after diagnosis.

13. I think that information should have been given to me sooner; at the point at which they knew patients were being put at risk. I think that I should have been told there was a risk attached to receiving a blood transfusion, and then I would have been on alert as to possible symptoms. I think that information should have been available at the GP surgery asking people if they had a blood transfusion pre-1991. The Hepatitis C Trust had really good posters that were inside the

Hepatitis C Trust building. I thought every surgery in my locality should have one. I asked my specialist nurse at the hospital if I could have some posters to distribute in my area but I have never received them.

14. I consider that the way in which I was told I was carrying the virus was appalling; receiving a letter informing me that I had Hepatitis C and my viral load was 2,600,000 was a dreadful way to inform someone that they have such a serious virus.

15. I was advised by my Hepatologist to contact my GRO-C GRO-C. I was told that the infection could be passed on by blood-to-blood transmission.

Section 3: Other infections

16. I have been infected with Hepatitis C.

17. The transfusions that I had over the years also infected me with syphilis. In 1980, following a blood test during one of my pregnancies that ended in miscarriage, I was told that the blood test had shown a positive for syphilis. I was dumbfounded! I could not believe what I was hearing, how could this be right?! I was told that my GRO-C GRO-C. Can you imagine the humiliation of having to speak to my mother about this sexually transmitted disease? My husband, of course, could not understand how I had become infected without having had sexual contact with someone other than him. I firmly believe that this, along with my persistent bouts of illness put an intolerable strain on our marriage. My GRO-C I was treated with antibiotics. Yet again I was not given any explanation as to how this could possibly have happened to me. I have no idea if there is any record of this in my medical notes from Bedford Hospital as I know that not all appointments/ tests for the Sexual Health Clinic are recorded in medical records and I do not recall whether I was asked about whether this information should be passed onto

my GP. My children have not been aware of this until now.

Section 4: Consent

18. Yes, I believe I was treated without my full knowledge, full consent and without being given adequate or full information. I was never given any information about the possibility of a risk involved in receiving blood transfusions. The only consent I ever remember giving was for the procedure I had to undergo.

Section 5: Impact

19. Over the years I have suffered many physical effects that I believe are attributed to the hepatitis c. I have suffered bouts of persistent ill health which bore no relation to my ulcerative colitis and puzzled many doctors. I can only assume that I was deemed "sickly" and prone to ill health. I continued to suffer from extreme tiredness and fell prey to any infections and viruses that were "doing the rounds".

20. In addition to that I was admitted to Bedford hospital in the latter part 1988 with septicaemia the cause of which was never determined. I do recall one specialist asking me if we had animals, to which I replied "a cat". His comment was "not domestic pets, I mean livestock!" I have no idea of the significance of this but he was obviously at a loss as to where I had contracted the infection.

21. In 1995 I injured my heel on a gate. It was a deep wound and I was treated at the hospital on the same evening. It became infected, failed to heal properly and although I continued to work it was necessary to wear backless sandal type shoes whatever the weather. This went on for months. The nurses who dressed the wound put my inability to heal down to poor circulation, but further tests were not carried out.

22. Migraine type headaches affected me over many years. I can remember them occurring when my younger son was a toddler right up to when my elder son

drove me to a pharmacy to pick up medication after a visit from the out of hours doctor. I recall having to "take to my bed" and lay in a darkened room until the pain and associated sickness passed. These would strike randomly and possibly every couple of months, it is difficult to remember the regularity when looking back. I was given various tablet treatments and one which was an "epic pen style" medication that I had to jab into the upper part of my leg. These headaches were followed by at least one day of symptoms not dissimilar to a hangover; nausea and a dull headache which was also unpleasant and debilitating.

23. Over the years, I experienced debilitating tiredness and weight loss and my general health continued to fluctuate. There were many occasions where it took all my strength to simply get out of bed and although I continued working part-time I struggled daily with the pervading tiredness.

24. Apart from the persistent tiredness, frequent mouth ulcers and inability to fight off every germ that passed through school I found that my skin had become very itchy. I assumed that this was due to allergies but I now have my doubts. The problems with my skin continued and I developed clusters of blisters on various parts of my body. Those on my legs and face were clear blisters but the ones on my hands were large blood blisters. My doctor diagnosed pemphigoid. I believe this is an auto-immune disease which affects the skin. I was given steroid cream but the clusters of blisters continued for several months. I wore large plasters over the backs of my hands as they were extremely unpleasant to look at and a colleague of mine jokingly remarked that I looked as though I had the Black Death!

25. In 2004; the same year that I celebrated the blessing of my marriage to my second husband and my 50th birthday, I became ill with cluster headaches. I believe that these headaches are sometimes referred to as "suicide headaches" and I can understand why! The pain on one side of my head was SO great that I really imagined I could die. I went to the doctor who diagnosed a return of migraine but I knew that this was so much more. I recall sitting on the floor of my

dining room, clutching my head, rocking and wailing. It was at this point that my husband decided to take me to Accident and Emergency. Various tests were carried out at the hospital and by a process of elimination they determined that they were cluster headaches. These went on for many weeks and I can honestly say that I have never been in such pain. It was at this point that on a planned trip to Stratford upon Avon I dragged myself around between headaches feeling truly dreadful and wondering if I would get actually through this.

26. Having survived the cluster headaches I proceeded to have problems with my chest. Having never been a smoker I was shocked to suddenly be hit by one chest infection after another. These went on for months and although I continued to teach for most of the time there were at least two occasions where I was coughing so much that it made me vomit, mostly mucus and extremely unpleasant. After the first occasion I carried a plastic container in the car and deemed it wise to keep a change of clothing in my car also. My colleagues started to comment on my hacking cough saying that "I sounded as though I smoked 50 a day". I seemed to be constantly taking antibiotics but to no avail.

27. It was during this period that I recall sitting in my classroom during lunchtime, marking books. I felt so desperately unwell that I was crying. A teaching assistant entered the room and declared that I should be at home and that she was getting the Head teacher who came and told me that I must go home. I went to see my GP who had sent off previous sputum samples but decided that he would send another which tested positive for pseudomonas which is, as the name suggests, akin to pneumonia. I went into Kettering General Hospital (the nearest hospital to my home address) the next day. There, I was treated with intravenous antibiotics and after several days the infection had declined enough for me to return home under the care of an outreach team who visited three times a day for a further two weeks to administer the intravenous medication.

28. When recovered I returned to work but continued to suffer from chest problems. It was at this point that my GP suggested I should be put on long term antibiotics. I believe I was given Azithromycin which I took three times a week for the next

two years and the constant chest infections eventually abated.

29. The mental effects of the Hepatitis C were no less debilitating:

30. My initial diagnosis came as an enormous shock but it was not until my first appointment with the hepatitis consultant that I started to understand the potential severity of the infection. I vividly remember that the following day it started to overwhelm me. I sat and cried !! Just writing this now I feel very emotional remembering what I perceived as the enormity of the road ahead. The possibility that I may have unknowingly passed the virus on to those I love, or even a stranger, was a deeply traumatic thought.

31. I had blithely thought, prior to this hepatitis consultant appointment that since I had the virus for thirty years it would just be a case of monitoring my health; but, the reality was that I was now faced with the reality that I needed to have treatment which had the potential of life changing side effects that could impact on every aspect of my life.

32. As I started to research the virus and the new treatments I knew that I wanted to be treated with Harvoni. I had mistakenly thought that all victims; such as myself, would have access to the new treatments. It was another massive blow to find that I was very wrong. I began a two year fight for the Harvoni treatment which was both mentally and physically exhausting. Each "knock back" delivered another blow.

33. My MP Tom Pursglove was enormously supportive and helpful but I recall the replacement hepatitis nurse saying to me "Oh you are the lady who has got the MP involved; that's not helpful". My reply was along the lines of "maybe not to you, but he is helping me". This only fuelled my feelings that I was fighting the system that should be helping me.

34. The feelings I had over the two years of fighting for treatments were those of being utterly let down by the system. The fact that contaminated blood was

known about for so many years was shattering. I could not understand or accept how so many successive governments and associated civil servants has managed to keep it so well hidden? I consider myself to be a reasonably well informed person yet I did not know about it previously and I meet people every day that still do not know.

35. I think the knowledge that someone, or a succession of people, chose not to stop contaminated blood when they had every opportunity to do so, lives with me every day. The enormousness of the situation both personally and for everyone else who has been affected will never leave me.

36. Looking back I can say that the impact of this on my private, family and social life has been huge.

37. In June 1989; GRO-C weeks after my father died GRO-C, my first husband left. A contributing factor to that happening was my unpredictable and every present ill heath which influenced and affected every aspect of our lives. My first husband was not able to understand how very ill I felt at times; he thought I was imagining my many and varied ailments. In 2004 I married my current husband. He was, and is, very supportive of my health issues. He accepted that I was not always well enough to do the things I really wanted to do. Sometimes I had to leave important functions that I wanted to be there for, but was unable to be because I was so sick.

38. I feel enormously sad when I realise the impact this obviously had on my ability to be a good mother. Seeing your mother frequently and unpredictably ill must have been very difficult for my children. It certainly influenced the things I could and could not do with them. I tried as far as possible to do lots of things with them but without the support of my mother, who was by this time, a widow I would have found it almost impossible to cope. It saddens me enormously that my children did not have the childhood I would have liked them to have.

39. In 1988 I decided to switch from full time to part time teaching in an attempt to

alleviate my bouts of ill-health. Looking back this is an obvious work-related example of how the Hepatitis C affected me. Under different circumstances I would still be teaching, it was a job I loved. It is not a job that can be done from behind a desk. It requires enthusiasm, dedication and stamina, involves long hours, even when working part time, and I knew that my health issues would not allow me to be the teacher I would want be.

40. Thinking back I realise what an enormous impact my poor health must have had on my partner, children, parents, and other family members.

41. In relation to my parents and children; as a parent myself, to now adult children, I cannot imagine what they all must have gone through. My aunt has told me that my mother was very concerned at various times that I may die. I certainly had no idea what an impact my ill health was having on those closest to me.

42. The impact of my diagnosis, along with my fight for treatment, was very difficult for all members of my family. Upon diagnosis I was advised to tell my first husband and my children that there was a possibility that I could have passed the virus on to them. This was obviously a concern to them but also to me. Being infected myself was bad enough, but the thought that I could have passed the virus on to my children was unthinkable.

43. My second husband was very supportive but very worried about me over the years and particularly during my fight for treatment. Friends have subsequently confided in me that he was extremely worried about me throughout all my bouts of ill health and even more so when I was first diagnosed with Hepatitis C.

Section 6: Treatment/Care/Support

44. Yes, I do believe that I faced difficulties and obstacles obtaining the correct treatment, care and support in consequence of being infected with Hepatitis C.

45. Soon after my diagnosis in July 2014, I had an appointment with my hepatitis

nurse who recommended I have a liver scan. At that time, the shortest wait time was 10 weeks at Norfolk and Norwich Hospital, some 94 miles from my home. The technician who carried out the scan informed me of the current treatments and new drugs that were "in the pipeline" called Direct Acting Antivirals (DAAs) which were supposed to have a much higher cure rate and very few side effects.

46. The results were sent to Bedford Hospital where they offered me a combination interferon based treatment but when I researched it I realised that it had a long list of debilitating side effects I was reluctant to proceed because I was already very unwell. I attended the 2015 Hepatitis C Trust Patient Conference with treatments in mind and I spoke to a professor from Nottingham University Hospital who was presenting at the conference and who was knowledgeable on current and emerging treatments. I informed him that I have ulcerative colitis; he told me that he considered I would not respond well to the combination treatment and that I should be treated with one of the new drugs.

47. Following the conference I asked my consultant at Bedford Hospital if I could be treated with Harvoni as opposed to the combination Interferon therapy that I had been offered. Harvoni was one of the new drugs that I had learned about from the liver scan technician and the Professor. Bedford Hospital said that they would apply to Addenbrookes Clinical Commissioning Group (CCG) for permission to treat me with the new drug. The consultant at Bedford and her team applied on two separate occasions but my application was denied as I was "not ill enough".

48. I went to see my MP Tom Pursglove to ask for his help in obtaining this new drug. In view of the fact that I had been infected by the NHS he, like I, considered that they should be giving me the best available treatment.

49. Addenbrookes CCG agreed in May 2016 to my treatment with Harvoni; two years after my diagnosis.

50. The only support I was offered was by the specialist nurse and was in the form of

a peer support group for people with Hepatitis C.

Section 7: Financial Assistance

51. It was during my initial appointment with Consultant Hepatologist, Dr Anne Day at Bedford Hospital in around July 2014 that I learned there was a probability that I had been infected with contaminated blood. She said that she needed to examine me for signs of intravenous drug use and tattoos to eliminate those as a possible cause of transmission. After the examination she told me that I may be eligible for a payment from the Skipton Fund. She explained that in order to apply for the lump sum ex-gratia payment of £20,000 it would be necessary to complete a lengthy application form and provide evidence. She kindly offered to look for the evidence in my records in order to support my application.

52. I sent off the application and included a copy of the single cross matching blood form that was available to her in my records. The Skipton Fund decided that there was insufficient evidence and turned down my application.

53. Once again Dr Day came to my assistance and offered to review my records another time. She eventually discovered a letter from my Inflammatory Bowel Disease Consultant to my GP which stated "this lady has had numerous blood transfusions". Fortunately, this was accepted by the Skipton Fund.

54. I received the £20,000 ex-gratia lump sum payment in around February 2015 in and am in receipt of the Stage 1 payments from England Infected Blood Support Scheme. This amounts to £4,000 per annum; £500 of this is a Winter Fuel Allowance. I do not understand the discrepancies in payments between Scotland and England. Recipients in Scotland receive a £50,000 ex gratia payment and whilst they are now governed separately we were all treated and contaminated by the NHS. Also the victims from other EU countries such as Eire receive substantially more. We have all suffered in the same way. I think that the English victims are being unfairly treated.

Section 8: Other Issues

55. In relation to my medical records:

56. I have made several requests to Kettering General Hospital for any medical notes that date from 1975 to 1978 and have received written confirmation that those records no longer exist.

57. The fact that Dr Day the Consultant Hepatologist at Bedford Hospital was only able to trace one solitary blood match form record from the entirety of my records is in itself evidence that my medical records from Bedford are incomplete. I think it was lucky that Dr Day found the record saying I had numerous transfusions. I have had numerous blood transfusions over the years stemming back from my treatment for the anaemia resulting from my ulcerative colitis. I cannot understand why there is not more information of this in my records. Not only are the records incomplete but it would appear that, for whatever reason, there are no remaining notes pertaining to blood transfusions, no charts that show the administration of the blood and only one cross matching form remains in my file. Whether this is by accident or design it would appear to be the case that the only remaining hard evidence of my numerous blood transfusions is that solitary blood match form and two letters from my Inflammatory Bowel Disease Consultant (dated 10/12/84 and Feb 1992) to my GP stating I had anaemia and had undergone numerous transfusions.

58. It is my hope and expectation, that the inquiry will uncover:

    a. What was known about the prevalence of contaminated blood in blood stocks within the UK?;
    b. What was known about the likelihood of contaminated blood being imported from outside the UK?;

c. What was known about the prevalence of hepatitis within the prison population of the UK at a time when prisoners were giving blood to boost UK blood stocks?;

d. Who knew all of the above?;

e. When did they know, and what, if anything did they choose to do about it?;

f. Why was nothing done to find those who had been affected, to avoid a situation where people such as myself should go undiagnosed for over 30 years?;

g. What were the guidelines/ recommendations during the "LookBack" exercise?;

h. What was done to make sure that those recommendations were adhered to?;

i. Why did the NHS continue to import potentially contaminated blood after that risk was known and who made the decision to do so?;

j. Why are people who have been infected with contaminated blood not given priority access to the latest/ best available treatments?

Statement of Truth

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

Signed: GRO-C

Full Name: SUSAN MARY WATHEN

Date: 30th January 2019