Witness Name: SUSAN CHADWICK
Statement No: WITN1148001
Exhibits: WITN1148002
Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN CHADWICK

I, SUSAN CHADWICK will say as follows:-

Section 1. Introduction

1. My name is Susan Chadwick. I was born on GRO-C 1952 and I live at GRO-C with my husband Colin.

2. 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

3. I have Von Willebrand's Disease. I was treated at the Leeds Haemophilia Centre at St James University Hospital, Leeds under the care of Dr Swinburne, Dr McVerry and Dr Barnard. I am now under the care of Dr Horn.

4. I am co-infected with the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) as a result of being given contaminated Factor FVIII (FVIII) blood products.

5. I was treated with FVIII on a number of occasions as and when needed to treat cuts and bleeds and also ahead of surgical procedures to include dental treatment. I received a lot of FVIII until the 1990s when my treatment was switched to man made products.

6. I was not provided with any information or advice beforehand about the risk of being exposed to infection from blood products. My parents were not warned of the potential risk either. I was simply told if I did not have treatment, I would bleed to death. I thought I had no choice in the matter. I believe that I should have been told of the potential risk and at the very least my doctors should have told me what FVIII consisted of and where it had come from. I only found out that FVIII was imported from other countries and from donors within a high risk group when I was diagnosed with hepatitis.

7. I was informed that I had been infected with hepatitis after a bowel biopsy in May 1980. I have never felt well since the bowel biopsy. It had not been scheduled to take place and I told the doctors that I needed preventative treatment cover. The doctors carried on regardless without giving me cover and I ended up having a large quantity of FVIII because of a very bad bleed.

8. After discharge, I was so poorly that I collapsed at work. My GP thought I was suffering with exhaustion. Within the same week as my GP appointment, I went for my biopsy check up at the hospital. Dr Miloszewski took one look at me and said “How long have you been this yellow?” I was not aware that I was yellow. Dr Miloszewski wanted to admit me there and then. He said that he felt confident from my symptoms that I had hepatitis but he did not know in what form. Colin and I met and married at a young age and I had two babies at home to care for. I did not want to stay in hospital and went home promising to rest.

9. I returned for the blood test results a week or so later and Dr Miloszewski confirmed I had HBV. He told me that I had had FVIII from the same batch as someone similarly infected with HBV. I felt really ill but refused to given in and stay in hospital. I had to rest at home for something like six weeks.

10. I refer to **Exhibit WITN1148002** being letters sent by (or on behalf of) Dr Miloszewski to my GP dated 13th and 27th June and 23rd July 1980. The letters detail how unwell I was after the biopsy and confirm that I had hepatitis described as 'likely to be Australia antigen positive hepatitis'. In addition to being told that I had HBV, I now believe it to be possible that I was also infected with HCV at that time.

11. Dr Swinburne was also very concerned about my health and initially saw me on a monthly basis for monitoring and blood tests. After a while I was seen and tested on a six monthly basis. Because of the passage of time, my memory has faded. I do not recall when but I believe that I was informed of the HCV diagnosis by Dr McVerry some time in the mid 1980s. I remember him telling me that I still had HBV but that it did not look 'as bad'. He asked me how I was feeling and I told him that I still felt unwell and pretty much exhausted all of the time. He told me that I "now" had HCV "as well". He may have referred to it as 'non-A, non-B Hepatitis' but I do not remember.

12. I recall Interferon was suggested by Dr Swinburne on a different occasion as a possible treatment option. Dr Swinburne seemed to prefer a wait and see approach and I never had treatment. I was advised to be very careful when having sex; to either take precautions or abstain altogether. I was told not to go near to anyone if I cut myself and was bleeding. The doctors told me that if anyone had even so much as a superficial cut or graze then they could become infected from my blood. I was traumatized. My children were very little and the early years of my diagnoses were worrying and stressful for me and Colin.

13. Around that time, I also remember attending a Conference at the hospital in relation to the HIV/AIDs risk. We were collectively given reassurances about the risk of being infected with HIV. I was also tested for HIV. It was terrifying to have to wait for test results, wondering whether you have that virus and wondering whether that might be the reason for feeling so very unwell. Colin was also tested for HIV and hepatitis.

14. I have been given confusing and conflicting information about my hepatitis diagnosis over the years. Around three years ago , I was told that the viruses have cleared (naturally) and that I am anti-body positive only. I no longer know what to believe.

Section 3. Other Infections

15. I am not aware of being infected with anything other than HBV and HCV.

Section 4. Consent

16. I do not specifically recall being told that I was going to be tested for HCV. It was an unhappy surprise to be informed that I was "now" found to be infected with that virus. I was not given adequate or full information about the testing process. The trust that I formerly had in my doctors has now broken down.

17. I have asked for copies of my medical notes and records and have been informed by Dr Horn that there is little point in me having them. She told me that she has looked and that the information relevant to the issue of my blood contamination is missing. Dr Horn can be evasive and dismissive of me.

Section 5. Impact of the Infection

18. When I was first told that I had hepatitis, I was so poorly. My skin was yellow, I was exhausted and I felt sick and unable to eat all the time. I had stomach

and bowel problems (which I continue to have). I was told that my liver was enlarged.

19. I have a number of chronic/very serious physical health conditions. My GP informed me some 10 years ago that he believes all my illnesses to be connected with hepatitis and it's impact on my immune system. I have not felt well since diagnosis.

20. I suffer with myositis ossificans in which soft tissue and muscle calcifies and turns into bone. As a result I am disabled and I can barely walk. I am currently waiting for a CAT scan or MRI scan to see whether the muscles surrounding my organs are also affected. My Consultant (based in Watford) has taken an interest in my hepatitis diagnosis as he believes it may have triggered the myositis ossifcans condition.

21. I have lupus which is a long-term condition causing inflammation of the joints, skin and other organs. The lupus also triggers fibromyalgia. I have sjogrens syndrome, adversely affecting my body's production of liquids, creating problems with my eyes and mouth. I have diverticulitis. I suffer with hemiplegic migraines. I no longer sleep properly, my body aches and I am exhausted.

22. I am a former silver service waitress. When I was younger and in better health, I was very hard working and had two jobs. During the week, I worked at Leeds University and at a hotel in Leeds at weekends. I loved both jobs. I have not been able to work at all for over 20 years.

23. I feel that I am missing out on life because I can no longer go out with Colin and/or do things with our grandchildren. We do not take holidays or cruises as we used to because of my health. There is always a high risk of having to cancel a holiday booked and paid for at the last minute. I no longer go out with friends.

24. From the late 1990s/early 2000s, I received Disability Living Allowance and was on the highest payment category for mobility. Since the change to Personal Independence Payment I have been reduced to medium category. We now struggle financially. My husband is still working at the age of 66 as a part time delivery driver at the age of 66 in order to supplement our income as a result.

25. I have felt stigmatised and continue to feel singled out and stigmatised. My dentist always wore gloves (before it became standard practice) and used different instruments to those used on others when treating me. I am treated differently to other patients at hospital. I have big red stickers with the words "BEWARE INFECTIOUS" on my x-ray cards and I was made to cry as recently as last year when I queried the necessity for it. I asked a nurse donning a pair of gloves what it meant. She responded by challenging me in saying "well, don't *you* know? You have Hepatitis B and C". I said that I have been told that I am clear of the viruses. I am nevertheless still labelled as infectious.

26. Within the last 6 or 7 weeks, I was again upset (this time) by a stranger waiting to have her nails done. My nail technician, Claire, nicked my finger whilst filing my nails and I gently suggested she put a plaster on it (as a precaution) because 'I used to have hepatitis'. Unbeknown to me the lady waiting was a nurse and she started shouting at Claire not to touch me as I 'infectious' and that she (Claire) could sue me for not telling her beforehand. She argued with me when I said that I was now alright saying 'you are never alright. You've always got it'. I went straight to the nurse at my GP surgery in tears for reassurances that she gave me. I would never knowingly put anyone at risk. It was a horrible experience.

Section 6. Treatment/care/support

27. I was not given any treatment for the HCV or HBV. The doctors mentioned Interferon but the viruses cleared.

28. I was never offered any counselling.

Section 7. Financial Assistance

29. I have had nothing from the Caxton Fund or the Skipton Fund. About two years ago, I was informed that I am not entitled to anything because I am clear of HCV. This is, in my view, very wrong as I am in such poor health.

Section 8. Other Issues

30. There are no other issues.

Anonymity, disclosure and redaction

31. I do not wish to remain anonymous and I understand this Statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

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

Dated 30|1|19