(1) LINDA SUSAN SMITH
(2) WITN0122001
(3) Exhibits: WITN0122002 - WITN0122014
(4) 02/01/2019

INFECTED BLOOD INQUIRY

FIRST WITNESS STATEMENT OF LINDA SUSAN SMITH

I, Linda Susan Smith (DOB GRO-C 1955) of GRO-C GRO-C say as follows:

Section 1: Introduction

1. I am the above named Witness in this matter. Save for where otherwise stated the facts set out in this witness statement are within my own knowledge. I exhibit a bundle of documents marked "WITN0122" which are numbered ["001 to 013"] and contains the documents to which I will refer in this statement.

2. I married Raymond "Ray" Edward Smith GRO-A 1942) on 20/07/1974 and we have two children, Faith and Luke. I am a retired school teacher.

Section 2: How Infected

3. In January 1982 I was admitted to Doncaster Royal Infirmary due to complications with my pregnancy. After spending 10 weeks in hospital under

observation I gave birth to my first child, a daughter who we named Faith, on GRO-A 1982. After giving birth I began to haemorrhage and as I had lost a significant amount of blood I was taken to theatre so that they could try to control the bleeding. As I was dipping in and out of consciousness at the time and was unable to give consent the doctors asked my husband, Ray, to sign a consent form for the procedure. It is my understanding that he was advised that this was the only option to keep me alive. I am not aware if at this this point Ray was explained any of the risks. Whilst in theatre I received a blood transfusion to counteract the blood I had lost whilst haemorrhaging. I believe that I received approximately 6 units of blood. When I woke following surgery I was not advised of any risks of having received blood through transfusion nor was I provided any further information or advice. After recovering for 9 days in hospital I was then discharged and sent home with my new baby.

4. In GRO-C 1986 I gave birth to my son, Luke. Although a difficult pregnancy, Luke was born safely on GRO-C 1986.

5. Over the years I attempted to give blood on several occasions, as I had done previously before receiving a transfusion. I was told a number of times I could not give blood due to various factors including low iron levels. I was given iron tablets but this did not appear to increase my iron count.

6. On 7th May 2003 I gave blood at a "pop-up" donation at the Education Department building, Danum Road, Doncaster. On 02/06/2003 I arrived home after work to find that I had received an unsealed letter from National Blood Service [exhibit WITN0122002]. It stated that I had tested positive for Hepatitis

C [HCV] and that I should call to discuss matters. Unfortunately by this time the telephone lines had closed and there was no other information given to me on the letter about the infection. It was extremely distressing to find out through a letter and also incredibly worrying that I had to wait until the following morning to speak to someone. At this point I was unaware if it would affect my son, Luke, or my husband, Ray. I rang my deputy head teacher and explained what had happened. She told me to stay home, ring the hospital at 9am, then come into school. I did not feel it was right to call in sick as I was not ill. Consequently, that night we did not sleep. I phoned the hospital first thing the next morning and spoke with someone, we sorted out a few things and left for school. Ray phoned to say I was on my way and the head was waiting for me in his office to sort out what was going to happened next. I had sole use of his office for hospital phone calls for me. I was so grateful for this support.

7. I arranged an appointment to attend the Blood Transfusion Centre on 10/06/2003 [exhibit WITN0122003]. During my appointment I asked several questions including how I had become infected and they said that they did not know. They informed me that it would be best to only tell people when necessary about the infection, namely my GP and Dentist. During the meeting they made no mention of the risks to Ray or Luke. When I asked if they could re-test Ray (he had also given blood but had not received a letter and so we believed he had not tested positive) the Blood Transfusion Centre refused. The doctor even suggested we used other sexual precautions, even though they would not retest Ray. Needless to say I was quite horrified by this, asking if they could ever prove he hadn't been infected during this time. He offered no

reply or answer. I asked if they would test Luke as I had given birth to him after the blood transfusion which I considered may have been the cause, they again refused and suggested if I wanted him to be tested I should take him to a Sexually Transmitted Disease clinic. I did point out he was under age as he was only 17 at the time. I thought this may also have an impact on my job or his future if anyone recognised us, and informed them that I believed this was unacceptable. It felt as though they were blaming me for contracting the infection. The Doctor took details of my history including drugs, tattoos and partners. This was extremely distressing to have go through, and I was made to feel as though I was at fault. I was provided with limited information on the infection and how to manage it. I had to ask a lot of questions in order for me to develop a better understanding of what the infection was, how it needed to be manged and the risks of others being infected. I was then referred straight to Hallamshire Hospital in Sheffield. This appointment came through after Faiths wedding (July 2003) in August 2003. As a Christian I found this quite traumatic, very worrying and upsetting, leading to lots of tears for my family to cope with.

8. I believe it would have been less traumatic to find out through any other means than a letter. I had so many questions I needed answering but no one to ask at that moment in time. If someone had come to visit me or even telephoned to relay the test results then I would have been able to have my questions answered immediately and I would have been provided important and necessary information immediately. Instead, I received inadequate information 8 days later.

Section 3: Other Infections

9. I do not believe I have received any infections other than HCV as a result of receiving infected blood.

Section 4: Consent

10. I do not believe I have been treated or tested without my knowledge or consent. However, I did sign a consent form at Hallamshire Hospital during one of my early visits which I believe was for the purpose of research.

Section 5: Impact

11. I suffered from physical effects of the infection for years prior to my diagnosis. Following Faith's birth I was aware that I felt different, even after a matter of weeks. In the years after Faith was born, I had shingles three times which I was told was unusual and I was never able to develop a tan. Before my diagnosis I often went through spells of feeling unwell and on a number of occasions I consulted my GP. For example in June 2002 I became so ill that I was admitted to Doncaster Royal Infirmary where they ran several blood tests, although I stayed in hospital for 5 days they were still unable to reach a diagnosis and they discharged me.

12. I believe the mental effects of being infected with HCV have been significant. The trauma of having to tell both my children and my parents was

unimaginable, my parents were devastated and heartbroken. As Luke had the potential to also be infected it was unbearable to have to tell him. The mental impacts of living with disease made what should have been times for making happy memories instead a blur. My daughter, Faith, was married in July 2003 and although I was present, I remember very little of that time as I was so distraught, worrying about future appointments and what would happen next. At Luke's wedding I had just completed treatment, and had just finished sick leave, and don't really think I was there. I also had to tell my brother and sister-in-law that night why I looked so ill. They, along with my father, were horrified that I was going back to work when I looked so ill. Luke and Faith, along with Ray, both informed them that I was 10 weeks better. Family times have been worrying too. During my daughter's pregnancy with twins I was distraught through a fear of blood transfusions and questioned if she would make it through her pregnancy and the birth unharmed. This happened again with my daughter-in-law when she was pregnant with GRO-C in GRO-C 2013, and again through both my daughter and daughter-in-law's subsequent pregnancies. These should have been happy and exciting times and I was so worried about them.

13. To my knowledge I have not had any further medical complications or conditions as a direct result of the infection.

Section 6: Treatment/Care/Support

14. I did not face any difficulties or obstacles in accessing treatments for HCV however I did chose to wait before receiving treatment for the infection. At the

time there were treatments available but the doctors did not believe they would be relevant to me as I was generally well [exhibit WITN0122004]. I attended doctors' appointments every 6 months and had liver biopsies every 3 years. Appointments were very traumatic, wondering what would be said and what would happen next. I had very little sleep before appointments.

15. I began treatment in September 2009 which was due to go on for 26 weeks. The form of treatment undertaken was Interferon. This included weekly injections, and daily tablets, followed by weekly appointments, for the first month. Then monthly appointments, eye clinic appointments [exhibit WITN0122005] and other more frequent appointments as necessary. The treatment was severe and had multiple side effects. I looked grey, suffered from hair loss and was plagued with fatigue. I could not eat as I was nauseous and suffered with insomnia. I sometimes struggled to even make it up the stairs.

16. In January 2010, in week 22 of treatment, I became so unwell I collapsed in my bathroom. I was taken to Doncaster Royal Infirmary by ambulance and was admitted. While I was in Doncaster Royal Infirmary, a phone call was made to Hallamshire hospital in Sheffield and the doctor there made the decision that I was too unwell due to the adverse side effects of treatment to continue to 26 weeks. In August 2010, after 6 months of waiting, I was informed I was all clear of the HCV infection.

17. The stigma of the HCV infection was extremely limiting and made the diagnosis of the disease even more traumatic. The stigma surrounding the HCV infection also extended to medical professionals. In particular my dentist who would

always offer me the last appointment of the day before they would then do their deep clean of the surgery. Although I was never refused treatment I was made to feel uncomfortable. Telling people, I was infected by HCV was difficult. I have found that whilst some people accepted the news and were worried about me and often didn't sleep the night after being told, others didn't touch me or even backed off from me, I assume through fear of the unknown.

18. Being infected with HCV impacted every aspect of my private, family and social life. This was made even worse by the fact I could not tell my extended family or friends why I was ill due to the stigma attached to the disease. I was unable to talk about it at church, in prayer meetings or with my friends. This is where I would usually seek advice and support but instead, I had to keep the burden of the secret without being able to share my worries. The fact I was unable to share it at my church was one of the hardest things, this is where I should have able to share and have lots of support. The stigma of the disease has made this extremely difficult.

19. Being infected with HCV has had a significant impact on my career. As a school teacher I was unable to attend appointments midweek without requesting leave from work. I had to take several days off sick whilst undergoing treatment [exhibit WITN0122006], as well as taking time off to attend hospital appointments. Due to the stigma around HCV I felt unable to discuss it with my colleagues. Only a select number of work colleagues were aware of my illness and were only told where necessary. In 2003 when I first found out, there didn't seem any point in going for promotion, or additional training, as I didn't know what the future held or even if I would be alive.

20. In or around January 2010 I was subject to Human Resources investigations into my high levels of sickness and ambiguous nature of my sick notes. I had been advised by the Hallamshire hospital to get my teaching union involved, previous to undergoing treatment, as there was a strong possibility I would be unable to work at multiple points during my diagnosis and treatment. Although I had the support of my school's Head Teacher who was aware of my illness this was an extremely anxious and stressful time. After two attempts by human resources eventually no further action was taken, although I have no written record of this. My head informed me she was not prepared for HR to use the school rooms or even personally attend, telling them the union were already involved.

21. Overall I believe being infected with HCV has had a detrimental impact on furthering in my profession. After my treatment and being so ill, life with my family was more important and I took early retirement at Christmas in 2010 at the age of 55, in consultation with the union, with a percentage loss of my teacher's pension

22. In addition to the impact on my career, I also suffered financial detriment due to the infection. Although as a public sector employee I received sick pay, I had to incur travel costs when attending hospital appointments, this included train fares, car parking and petrol expenses. I was also required to pay for my prescriptions for illnesses I believe were as a result of a weakened immune system caused by the infection [exhibit WITN0122007]. At 59, The Skipton Fund paid me, by way of cheque, for my yearly prescription charge. In addition

I am now required to pay for my flu jabs until I turn 65, despite all the years of having a weakened immune system and liver problems.

23. I believed I have faced obstacles whilst trying to receive counselling. I was suggested counselling by the staff at Hallamshire Hospital, my GP wrote 3 times in an attempt to secure me an appointment but did not receive a response [exhibit WITN0122008]. Consequently, the hospital service offered some counselling during my regular appointments. I also received some counselling by a dedicated counsellor at Hallamshire Hospital when I would attend for my regular appointments at the hospital [exhibit WITN0122009]. I finally received a response to my requests but was only offered a counselling session 2 weeks after I had finished treatment [exhibit WITN0122010]. I feel that this was totally inadequate support to receive during such a traumatic time in my life. The counsellor didn't seem very sympathetic to my needs in fact kept stopping to talk to other patients, and staff, telling me she had no training to deal with someone like myself. She suggested I didn't receive any further counselling, as I was not really open in talking to her and I was pleased with the decision.

Section 7: Financial Assistance

24. I have received financial assistance from the Skipton Fund. I was asked by the Hallamshire Hospital to complete a form whilst attending an appointment. After completing this form, it was sent to the Skipton Fund and then on to my GP to be completed by them. I am unsure of the reason that I received monies from the Skipton Fund save that it may be a dedicated fund for the HCV infection. Before being asked to complete this form, at the hospital I was not made aware

of any funds being available to me. I have never to my knowledge received monies from any other trusts or funds. The process was simple, quick and I do not believe I faced any difficulties in obtaining financial assistance.

25. I received £20,000 from the Skipton fund in or around 2004/2005. This was received in one lump sum although before receiving the monies I was required to sign a waiver stating that I agreed never to seek any further monies or compensation. However, at a later stage I was contacted by the fund and told I was entitled to free prescriptions. As I was unaware of this and had already been paying for my prescriptions I received a further £100 approximately direct from the fund as a reimbursement. At this time I was nearly 60, and would then receive free prescriptions. I am also in receipt of other financial benefits including a monthly sum of £250 from EIBSS [exhibit WITN0122011], Winter Fuel Allowance [exhibit WITN0122012], Special Category Mechanism [exhibit WITN0122013] and a payment towards my funeral plan [exhibit WITN0122014].

Section 8: Other Issues

26. As a whole this has been an extremely traumatic experience to live through and has caused a great deal of upset to not only myself but for the other members of my family, friends, and colleagues.

Statement of Truth

I believe the facts stated in this statement are true.

Signed. **GRO-C**

Dated this 2/1/19