Witness Name: GRO-B
Statement No.: WITN1819001
Exhibits: WITN1819002-
WITN1819010
Dated: 17 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. I, GRO-B, will say as follows:-

2. My date of birth is GRO-B My address is known to the Inquiry.

3. I am married with two children. I live with my husband and youngest son in GRO-B, my elder son having now grown up and left home. I am a GRO-B

4. I write this statement as an affected person on behalf of my mother, GRO-B: M, who was born on GRO-B and died on GRO-B aged 62. My mother had two children, my brother and I, and was married to my step-father. She worked as a receptionist in a law firm and later as a GRO-B. My mother lived in GRO-B GRO-B My brother worked abroad for most of the later years of her life, and my mother's sister lived in GRO-B After my step-father

passed away I was therefore the only relative who lived close to my mother.

Section 2. How Affected

5. My mother became infected with Hepatitis C (HCV) when she received a blood transfusion at the John Radcliffe Hospital, Oxford, following the birth of my younger brother in GRO-B 1985. She did not know she had been infected for 32 years and was only diagnosed in May 2017. Further testing discovered extensive liver cirrhosis, kidney and spleen damage and a tumour in her liver. She received a TACE procedure (transarterial chemoembolisation) to attempt to limit the rate of tumour growth, but it was already too large and too late for successful treatment. The growth rate of the tumour was rapid, she experienced organ failure and died eight months after initial diagnosis, in GRO-B 2018.

6. My mother received a blood transfusion at the John Radcliffe Hospital following the caesarean birth of my younger brother on GRO-B My mother did not know why they gave her a transfusion, but at the time she believed it was standard procedure and did not question it. **WITN1819002** is the discharge summary following the delivery which confirms my mother received two units of blood. There is no record of the reason for the transfusion.

7. My mother was not given any information, advice or warning beforehand about the risk of being exposed to infection. If she had been made aware of risks at the time she would have questioned the need for the transfusion. If she had been made aware of the risks at any later date she would have requested that she be tested.

8. As a result of being given infected blood my mother was infected with HCV.

9. My mother found out about the infection as follows. She had a number of persistent health issues for decades following the blood transfusion. Between 2014 and 2017 her health problems seemed to be getting much worse, but even after various organ scans, blood tests, colonoscopy and endoscopy, nothing significant was diagnosed. Nothing seemed to explain why she was having continual health problems. She was suffering with extreme fatigue, digestive issues and stomach pains that prevented her from being able to leave her house for weeks at a time. By this time she was feeling very depressed.

10. Eventually, one of these investigative scans in April 2017 accidentally captured a section of her liver which appeared abnormal (see two letters from her Consultant Respiratory Physician, Dr GRO-B dated 2 May 2017, **WITN1819003**). As a result she was scheduled for a scan of her liver to have a better look. During this time her GP ordered a test for HCV. My mother thought nothing of it, and that it was just another test after years of testing, and so was very surprised when her GP called to inform her that she had a diagnosis of HCV, which was most likely contracted as a result of her blood transfusion in 1985.

11. A letter from 19 May 2017 from her hepatologist to the GP confirmed the diagnosis of HCV and noted my mother's risk factors for HCV as blood transfusions from 1986 at the John Radcliffe, noting she also had tattoos but had never used intravenous drugs or had a history of heavy alcohol intake (**WITN1819004**).

12. My mother was not given adequate information to understand and manage the infection. She was only told that the next step would be to have her liver scanned to check for damage, as this seemed to be the priority. Following this, no treatment or management for HCV was discussed with her, as her consequential diagnoses of extensive cirrhosis and liver tumour became the only focus for treatment. Her GP records contain a letter from Public Health England on 18 May 2017 noting she

had been exposed to HCV and suggesting tests to be performed and referrals to be made (**WITN1819005**). The letter mentions an information sheet about HCV being enclosed: I do not know whether this information sheet was given to her, but she certainly felt she did not have enough information about this new diagnosis.

13. My mother believed that information should have been given to her the moment she was diagnosed by the GP. It was never suggested that other members of the family get tested, but I researched the condition myself and decided to get myself tested, and the result was thankfully negative.

Section 3. Other Infections

14. I do not believe that my mother received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

15. I do not know whether my mother was treated or tested without her knowledge or consent, or for the purposes of research. From what my mother told me when she was alive, she did not know why she had been given a blood transfusion. She did not think it was entirely necessary and she would have certainly recovered from the birth if she had not had it. Looking back, she felt at the time that it must have been standard procedure following a caesarean section. She did not know, and was not informed, of the risks of contracting a disease from the blood used. She said she entirely trusted that the blood used by a hospital would surely be disease free. She said that if she had been aware of the risks, she would have later requested tests when these became available to explore the possibility of infections, especially considering her poor health following the transfusion. In the 32 years that followed, she never considered the

possibility she might have received contaminated blood or that she could have contracted an illness from her transfusion.

Section 5. Impact

16. The mental and physical effects of being infected with HCV on my mother included tiredness, fatigue, pain and joint issues. She didn't initially return to work after my brother was born due to poor health, only later managing to work as a GRO-B Gradually, she stopped going out on day trips due to ill health. As time progressed she suffered with stomach pains and digestive issues, kidney issues, blood in her urine, extreme fatigue, lethargy and exhaustion, depression and tearfulness, social withdrawal, loss of appetite, jaundice, extremely itchy skin (with multiple scars on arms and face from picking at her skin) flu like symptoms including aches and shivers, and finally, death.

17. In terms of further medical complications and conditions which resulted from the HCV infection, she suffered with liver cirrhosis, a liver tumour, portal hypertension, intra-abdominal varices, spleen and kidney damage, gastric problems, sepsis, organ failure and death, all caused by HCV. She also suffered with the following conditions which may or may not have been linked to her HCV: cellulitis, diabetes, obesity, gallstones and renal stones. **WITN1819006** is my mother's death certificate, listing cause of death as 'I (a) Hepatocellular Cancer (b) Cirrhosis of Liver (c) Hepatitis C Virus'.

18. In terms of the treatment my mother received for HCV, unfortunately, by the time the tumour was diagnosed the options for treatment were very narrow. She was desperate to do whatever she could to survive and made a deal with Dr Cobbold, her consultant at the John Radcliffe Hospital, that she would be put on the liver transplant list if she reduced her BMI to the number they agreed. She began working on this

immediately and very quickly reached the target BMI and Dr Cobbold agreed to begin the process of getting her on the list for liver transplant (see various letters regarding treatment dated June and July 2017, **WITN1819007**). In the meantime she was referred to Dr GRO-B for a TACE procedure at the Oncology Department at the GRO-B in GRO-B He agreed that although the tumour was slightly larger than it should be for the procedure, it was their only option and therefore worth going ahead with. Unfortunately, during the wait for this procedure she contracted an infection, and because of her weakened condition, it led to sepsis and she was hospitalised.

19. At this time she was extremely ill and we prepared for the worst and did not expect her to pull through, especially considering her compromised health. But she was determined to survive and Dr Cobbold was very surprised by her improvements when he visited her bedside a few days after admission and decided that although her organ health had declined considerably due to this set back and her tumour had grown, she should still receive the TACE procedure. He explained that the chances of success were much lower now that her illness had progressed so far, but without other options this seemed worth a try.

20. Only days after leaving hospital she had the TACE procedure. Immediately afterwards she was in a great deal of pain, but in the weeks that followed she became confident that she was feeling much better and thought that it had worked. She was talking about how this would give her the time she needed to get on the transplant list. Sadly, upon further scanning, it was discovered that the TACE had failed, the tumour had started to develop further masses and there would be no further procedures. I feel it is important to note that she discovered this alarming news indirectly by only receiving a copy of the consultant's letter to the oncologist, so she experienced this piece of bad news alone at home with no way of asking questions or obtaining support. She then had to wait weeks before seeing any consultant again to discuss this failure.

During this time, she became very worried and understandably fearful for her life. She wanted to know if that was the end of treatment entirely and whether it meant she would definitely die now. **WITN1819008** is a copy of this letter, dated 5 December 2017.

21. Eventually she received an appointment where she was formally informed of the failure of the TACE and it was suggested that she take a drug (Sorafenib) in an attempt to only prolong her life. She was referred back to the Oncology Department and again waited weeks for an appointment. By the time she actually had the appointment to discuss this treatment she was very unwell but she had to wait for an hour and a half in the waiting room. The consultant, who had never met her before, told her in a very matter of fact way that her condition had worsened and she was no longer a viable candidate for this drug (this letter dated 13 December 2017 is at **WITN1819009**). It was clear to us at this appointment that the end of her life was drawing near. Following the appointment, my mother's strong will to survive completely left her and she lost all hope. Her decline was rapid and she died six weeks later.

22. A Do Not Resuscitate Order dated 19 January 2018, a few days before she died (**WITN1819010**). The reason for the DNAR decision is recorded as 'CPR is unlikely to be successful due to Advanced Hepatocellular Carcinoma. HCV with cirrhosis.'

23. In terms of whether my mother faced any difficulties or obstacles in accessing treatment, as I have described above, all diagnoses and treatments took too long. If she had been diagnosed years earlier, her illness could have been treated and her symptoms better managed. She and others around her could have understood her limitations and her relationships and psychological health could have been improved. The decline in her organ health could have been slowed or even stopped. She died at 61, she could have had years more life. Even when she was

diagnosed, it was four months before she was able to have the TACE procedure. Appointments kept being cancelled at the last moment and she would have to wait weeks for another one. Sometimes she attended appointments that had been cancelled without her knowledge. Treatment and consultations needed to be chased up all the time, sometimes even her GP had to get involved to find out what was taking so long. Therefore, the whole treatment process was too long for the rate of tumour growth and caused my mother a great deal of frustration, fear and anxiety. She felt that if she had received the TACE procedure quickly after diagnosis when her tumour was smaller, it could have been successful and she might have had a chance of survival. I therefore believe that the treatment options proposed ought to have been made available to her much more quickly. As I have described, the mental and physical effects of the wait for treatment caused her great emotional distress and her physical decline was rapid. I do not know whether her infected status was in any way a reason for the delays she experienced.

24. HCV greatly impacted on my mother's marriage to my step-father. He became extremely frustrated by her tiredness, scratching, depression, apparent apathy, lack of ambition and drive over the many years when she was undiagnosed. She was unable to look for a job that paid better because she was too tired to work all year round, so they had little money. She had no idea why she felt so tired all the time and assumed that it must be because she was inherently a "rubbish and weak" person. This contributed to her low self-esteem and self-confidence that lead to depression. The strain in their marriage only got worse over the decades. My step-father GRO-B never knowing that she had this illness and had understandable reasons for her behaviours.

25. My mother's illness impacted on our family life. My brother and I were affected during our childhood by my mother not being able to participate in family activities such as day trips together. My step-father would take me and my brother out places and she would have to stay at home and

rest. This meant that we didn't get to spend this quality time with our mother. She did her best but was always too tired or had some kind of health issue that prevented her from partaking in family activities. My step-father got extremely frustrated by her apparent lack of willpower and an inability to motivate herself and often referred to her as "lazy". She used to get so tired working at the GRO-B all day that she would have no energy left for anyone else by the time she got home. This led to a gradual increase in resentment from my step-father that resulted in many serious arguments. If he had known that she had an illness, I believe he would have seen things differently and been more understanding. When she was eventually diagnosed years after his death, she wished she could have told him why she had been so tired all the time, but it was too late by then.

26. My brother and I also regarded our mother as weak. We decided that her health issues were related to a poor attitude that affected her lifestyle and therefore in our opinion was entirely her own fault. We would often suggest the things we felt she should be doing to improve her life and health. We lectured her endlessly on diet, exercise, hobbies, habits, cleaning, employment and social relationships in an attempt to motivate her. We criticised her when her attempts to make improvements failed time after time. This made us feel so frustrated with her that sometimes we couldn't even face visiting her. I went for months without seeing her because I would get so angry with her sitting apathetically, complaining about her symptoms, when in my mind she wasn't doing anything to improve her situation. I can't imagine how much worse this must have made her feel.

27. Ultimately, she died of this illness and I lost my mother, as did my brother. I can't speak for my brother, but I know I am wracked with guilt over the decades of harsh judgment I directed towards her. During her

final months I had the chance to apologise and did what I could to provide the physical and emotional support she needed until her death.

28. In terms of the educational effects of the illness for my mother, she was unable to finish the BTEC course she was following in 1991. Her dream and goal was to follow an art career. As she could not continue her course, or find energy to do art work, her dream was never realised. Her friends on the course, however, did become successful and this made her feel like a failure.

29. As for work, she was only able to work as a GRO-B GRO-B because this meant that she did not have far to commute (a five minute walk) and allowed her to have long breaks during the holidays. Close to the end of the school term she would become so extremely tired that she would often get home and fall asleep without making a dinner and not wake until the next day. She would spend most of the school holidays resting and recovering, despite having made plans for productive activity. This job paid very little, but she would not have the energy to do a job which required longer hours.

30. Financially, as a result of her inability to work longer hours due to her lack of energy, our family finances were low. She continued to work for as long as she could, but eventually she became too sick. This was very upsetting for her as the GRO-B she worked at was an integral part of her life and was very important to her. She missed being there, the people and the children, some of whom she knew she would never see again. The financial difficulties also meant that my mother never got to go on holiday, and even when she received the payments from the Skipton Fund it was by then too late and she was far too unwell to go away, even though she made plans to do so right up until the final weeks of her life.

31. My mother's HCV also affected my education, work and financial situation. As I have set out above, my mother's marriage to my step-

father became very strained over the years as she suffered with the symptoms of undiagnosed HCV and their arguments intensified. As a result of the arguments, I left home at 16 and was put into foster care. I dropped out of school and did not complete my A-levels. I was unemployed for several years and became pregnant at 19. I was homeless during most of my pregnancy and lived in a hostel in GRO-B I had distanced myself from my friends and my only social contact was with my mother. I travelled to see her once a week in GRO-B and would help her with her weekly shop and carry it home for her, even when heavily pregnant. I would then return to GRO-B by bus. Although she always talked about coming to see me she was always too tired for the journey. Years later, through therapy, I realised how angry and resentful I was that she had never been able to come to see me, even though I was struggling too.

32. At the age of 21 I managed to turn my life around, moving back to GRO-B and completing an access course for a year. I then studied for a degree in psychology which I greatly enjoyed and did very well at. After I finished my degree I worked as a mentor for young people. I think if I had not left home at 16 I would have completed my A-levels and degree before starting a family. I think it would have then been easier for me to pursue a career in psychology after my undergraduate degree, perhaps even with a masters, which is what I had wanted for myself: I had the passion for it, and was highly motivated and ambitious. However, this was not something I was able to do because of my childcare responsibilities which meant I could not travel very far from home and had very limited financial resources.

33. The impact of my mother's illness on my life has been overwhelming. Her HCV impacted on our relationship and my mental health. As a child I felt she leant too heavily on me from a very young age, and this caused me anxiety. I remember on my ninth birthday looking at all the presents she had bought me and feeling so guilty because I knew they struggled

financially. The next day I pretended to be ill so I wouldn't have to go to school and could spend the whole day cleaning the house to try to do something in return to help my mother. I remember feeling really sorry that it was my birthday. As a teenager I continued to worry about her and would try to think of solutions to her health problems, as well as providing practical support, like helping her cross the road. I also used to give her my pocket money to try to help out financially. I supported her all the time and grew to resent it. She gradually became my responsibility and somewhere along the way it felt as if I had become her mother.

34. I continued to feel anxious through my teenage years and at the age of 18 suffered a breakdown. I managed to come through it but continued to feel scarred by my relationship with my mother: I was overly sensitive to every complaint, every little cough and scratch. I felt worn down by years of coping with her to the point where just hearing her voice on the phone made me anxious and irritated. As I began to work through my own issues, including being diagnosed with a personality disorder based on severe anxiety, I became more resentful of her, as all my health problems appeared to stem from my relationship with her.

35. Later, when my mother's symptoms had become much worse but she was still undiagnosed, my step-father had passed away, so I became her main support, both practically and emotionally, as there was no one else who lived close enough. I met my husband and had a second child, but we remained living close to my mother because I was her only support. When my husband was offered the chance to emigrate to GRO-B through his work we had to decline because of my responsibilities caring for my mother.

36. I would check on my mother constantly and became a listening ear for all her health problems. I helped her with the tasks that were too taxing for her, arranged her appointments, and chased up the urgent appointments

that had become lost in the system. I tried to motivate and encourage her not to give up fighting her illness but I worried all the time. The level of care she needed was a huge drain on our relationship. In 2015 I suffered a second breakdown when my anxiety and frustration accumulated to such an extreme that I became very ill myself. I was unable to sleep, eat, or leave my house. I felt nervous, shaky, sick and weak all the time. Eventually, I became so sick I had to have an emergency psychiatric assessment which turned into two years of continuous psychiatric support with the Adult Mental Health Team. Eventually, my severe anxiety stabilised after a year of high doses of anti-psychotics, diazepam and sleep medication. I now continue to take only the diazepam and sleep medication on an 'as needed' basis in order to manage my ongoing anxiety issues. During my recovery I became fully aware of how much the combination of frustration I felt towards (what I thought at the time was) my mother's "apathy" and my concern about her health, affected my mental health. If I had known that she had an illness making it difficult for her to manage her life, I believe I would have been much more understanding and less frustrated with her.

37. Even after mum was finally diagnosed with HCV it was very hard to turn the resentment off. I was outwardly positive and at every appointment with the consultant I would try to keep her positive too, but inside I still felt frustrated because when I took her to an appointment she would list all her problems. It sounds terrible of me and I loved her dearly but it felt as if it was just me dragging her through it. She needed me to keep her emotionally stable and use to say to me, 'GRO-B keep me strong'.

38. The worst memory that is left with me is her very last day, when she was still at home but almost unable to speak. The nurse came from the hospice, because a place had become available, and I had to ask mum where she wanted to die. I felt that was the first and only time that I admitted to mum that it was over. When I asked her where she wanted to die she wouldn't answer me. The look in her eyes showed

disappointment and defeat, her last bit of hope gone. Rationally we knew it was over, but it was the first time I had admitted it and it was the first time I cried in front of her. She died that night in the hospice. The look she gave me that day has stayed with me and I feel like I let her down.

Section 6. Treatment/Care/Support

39. No counselling or psychological support was ever made available to my mother when she was diagnosed with HCV or the resulting liver tumour. She was not given any leaflets, booklets or advice on how she could manage her terminal illness until a nurse handed her a pile of leaflets about HCV, liver cancer, coping with a terminal illness, details of support groups and a diet plan at an oncology appointment six months later. By this time she only had weeks left to live and so, despite following the high protein diet plan, she could not access the drop-in support group that was mentioned because by then she was too unwell to attend. It seemed desperately unfair that she was only given this information when she was weeks from death and had not known about the support available for months and months.

Section 7. Financial Assistance

40. My mother was not made aware of any financial assistance from the Trusts or Funds available to her following her diagnosis or treatment. None of the doctors, consultants or nurses she saw in regards to her condition mentioned their existence. However, my husband and I researched the matter ourselves and discovered the Skipton Fund.

41. I applied for the forms and helped my mother complete them. She gave the forms to the relevant doctors and consultants who signed them and sent them off in June 2017. She received the Stage 1 payment from the Skipton Fund in around July 2017. It took a while before she was paid,

and I had to call them a few times, firstly because we had not heard anything for a while, and then again because we'd received confirmation but after a number of weeks still no payment. This delay was difficult for her as she was aware of how little time she had left and she was then unable to go back to work. I then ordered the application forms for Stage 2 as she had cancer as a result of the HCV and, once she had Stage 1, she was then allowed to apply for Stage 2. She received the lump sum and then the ongoing Stage 2 payments for around six months until her death in January 2018. These processes seemed to move far too slowly.

42. I have not received any financial assistance myself.

Section 8. Other Issues

43. I hope the Inquiry will ensure the whole truth comes out, with nothing left covered up. I would like those responsible to be named and for them to accept responsibility for what has happened.

Statement of Truth

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

Signed GRO-B....

Dated ..17 December 2019....