

ANONYMOUS

Witness Name:

GRO-B

Statement

WITN7401001

Exhibit No.

Dated:

18/11/22

INFECTED BLOOD INQUIRY

WRITTEN WITNESS STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of The Inquiry Rules 2006, dated 10 November 2022.

I, **GRO-B** will say as follows:-

Section 1 Introduction

1. My full name is **GRO-B** and I was born in the USA on **GRO-B** 1950 and I am now 71. For the past 33 years I have lived permanently with my husband at an address that is known to the Inquiry. I have a son called **GRO-B** who was born on **GRO-B** 1977 and I have a daughter, **GRO-B** who was born in 1983.
2. I intend to speak about how I became infected with hepatitis C (HCV). In particular how I came to be infected, the nature of this illness in so much as how it affected me, the treatment I received and its impact upon my life, my family and my career.
3. I first moved to the UK in 1972 on a temporary basis. I decided to move to the UK on a permanent basis in March 1977 as my cousin studied at **GRO-B** **GRO-B** and was happy for me and my husband to live with him, then when I fell pregnant we lived in **GRO-B** London.

Section 2 How Infected

4. Whilst giving birth at St Mary's hospital in Paddington on GRO-B 1977 I sustained a severe bleed which required stitches and I needed to have a blood transfusion with more than 2 units of blood my husband says he recalls it was 4 bags of blood but I don't recall exactly how many it was. I was concerned with the origin of the blood to be given to me as I was from the USA where my father had regularly volunteered giving blood donations and he told us he saw others there who were homeless, down and outs and drug addicts also donating blood as at that time they were paid if they donated blood, therefore I did not want to risk being given unsafe blood. I mentioned my reservation but the doctor at St. Mary's reassured me that the blood had been checked and was safe therefore I agreed to the blood transfusion.
5. I stayed in hospital for I think it was 1 to 2 weeks and could not sit up for around 2 weeks due to my stitches. I was extremely tired and exhausted whilst in hospital and I raised this with the doctors on a follow up visit who put it down to me being a new mother.
6. I felt extremely tired over the years and in 2018 after a visit to my GP at GRO-B
GRO-B I had another blood test which showed I had anaemia, low platelets, and a low white blood cell count. My GP referred me to Dr Abboudi, a haematologist at Queen Mary's hospital and Kingston Hospital.
7. When I saw Dr Abboudi at Queen Mary's Hospital Roehampton my sister was visiting me. She also recalls when he told me my blood tests showed that I had had "Hepatitis C (HCV) and I'd had it for a long time". I found this very upsetting and confusing. This may have been the brain fog which I believe I was also experiencing and am still experiencing. When I questioned this fact that I had HCV with my GP, I seem to recall he told me that he or someone at the practice had previously advised me of this? However, I do not recall being told this, and as I'm an educated person with a Master's degree, I know I would have immediately enquired about and expected to have been referred for HCV treatment if I would have previously been informed that I had HCV, but I was not. Therefore I am dubious of this and I would have expected my GP to follow

up a HCV diagnosis with me as they must have a duty of care to their patients. In retrospect, I find this very concerning, as if the HCV was diagnosed previously, why was this not treated earlier or immediately? Also I don't know why but even earlier this week when I checked my records for the first time on the 'MY GP' app I didn't see anything regarding a HCV diagnosis in 2018 and although it could possibly be an admin mistake I do wonder why this wasn't recorded and isn't visible where I could see it on my medical records and I can see most of my other health issues?

8. Additionally when the NHS realised the bloods used in the period of concern were contaminated, I'd like to know why did they not try to contact the patients, like myself, who received the bloods? I was never contacted by anyone about this and admittedly I did move from GRO-B (in 1977 or 1978) but an NHS number should travel with the patient, I thought? I apologise if I'm stating the obvious, as this may have already been asked by others previously, but I feel this shows a definite lack of an adequate duty of care and negligence.
9. I am an educated woman with a BSc and MA. However I am not trained in medicine and therefore I can't definitively say all my medical problems are attributed to HCV, but I think it's fair to conclude that some of them definitely are; I personally think it could have very possibly prevented many of the further serious health issues I've got had this been discovered and treated earlier. I don't normally discuss my personal health issues with anyone but a doctor, but I'm referring to: Hepatitis C, damage to my liver function, chronic cirrhosis, enlarged spleen, neuropathy, numbed toes, exhaustion, anaemia, gallstones, myelodysplasia, Acquired renal artery stenosis, hypertension, Type 1 insulin dependent diabetes, iron deficiency anaemia, gastritis/abdomen pain, fatty liver, pulmonary embolism, heart failure, UTIs, chronic Stage 3 kidney disease, oesophageal varices, retinopathy, etc. If: - A) the HCV had been discovered and diagnosed much earlier and B) treated much earlier.
10. I never took intravenous drugs, I never had any tattoos or had any medical procedure abroad. I did not live a promiscuous sexual life and I had 1 blood transfusion in 1977 at St Mary's Hospital, Praed St. Paddington and this was

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whilst giving birth to my son which was decades before my HCV diagnosis. I therefore attribute my blood transfusion in 1977 as the cause of my HCV.

11. For the record, I was also given blood only one other time in my life and this was in October 2018 at St George's hospital and this was five months after the Haematologist told me I had had HCV as an emergency & A&E Dr. suspected I had blood loss/bleeding, as I had abdomen pains and dark stools, low platelets, anaemia, etc. following an endoscopy the Hepatologist required me to have at St George's Hospital, before I could commence the HCV treatment. I had to have this endoscopy procedure a couple times before I was actually allowed to start the HCV treatment course and I always find this procedure extremely stressful as I gag throughout it. This also caused me to miss the birth of my grandson as I was admitted to hospital after the endoscopy complications which happened at the time he was born. As I had the HCV and due to these complications, I was unable to be there to support my daughter when she needed me most also as I was worried about passing the HCV on to anyone, especially a new born baby. We didn't tell her I was in hospital then as she'd have been worried about me at a time when she should be tranquil bringing her baby into the world. I was also unable to help care for her new born son afterwards as I hadn't been treated for the HCV yet and was worried I'd pass it on. I was very conscious of this illness and very embarrassed about having HCV so I had to distance myself from my family and friends and was very isolated for this period until I was told the virus was cleared and gone.

Section 3 Other Infections

12. So far as I am aware I have no other infections apart from HCV as a result of the transfusion I was given at this stage; however, I do have many other associated illnesses I believe are as a result of the infected blood transfusion and HCV.

Section 4 Consent

13. I consented to have a blood transfusion at St Mary's hospital because I lost a lot of blood during my son's birth and I was told I needed it. I was informed by the doctor that the blood was safe after specifically raising concerns about the safety of the blood. I was aware of the risk of unsafe blood as I grew up in the USA where, my father regularly donated blood and he warned us of this as he saw first-hand down and outs and drug addicts giving blood to make some money as they used to be paid to donate their blood in the USA. I have lived in the UK permanently and been a legal, registered UK resident since 1977 and I don't know if this still happens nowadays? Therefore there was a risk that blood could be contaminated with a disease from them. But as the doctor in 1977 reassured me the blood for my transfusion was safe and there was no risk associated with it, I had no other choice apart from accepting the blood transfusion as I believed what the doctor told me and I needed to have a blood transfusion. I do now feel very upset and let down by this.

Section 5 Impact

14. I had diabetes in 1983 after I gave birth to my daughter and attributed being exhausted from 1983 up until 2018 to my diabetes and low blood and anaemia. I also worked full time and brought up our two children during the 1980s and 1990s. My tiredness at that time gradually got worse and I therefore also attributed my tiredness and exhaustion to working full time and bringing up my children as well. I have never applied for or received any unemployment benefits or any state benefits, except my state pension which I've received when I was the eligible age after I retired.

15. I began experiencing pain in the 1990s when I suffered from severe abdominal pain and also gastritis and a gastric ulcer. This has continued on and off since the 1990s which is uncomfortable for me. I also suffered from nausea on and off with the feeling I wanted to throw up.

16. I was also diagnosed with oesophageal varices, Gastritis and Duodenitis in October 2022 and diabetic neuropathy in Aug. 2022, and I had an unprovoked pulmonary embolism and heart failure in April 2022 and anaemia again in May 2022, although this diagnosed much earlier too, and heart failure in June 2022. About 5 or 6 years ago I also started experiencing problems with my feet and was diagnosed with neuropathy and started suffering from severe pain and burning sensations in my feet and numbness and stiffness of the toes and ankles and drop foot and swelling of the feet and my ankles which have all had an adverse effect on my mobility which has deteriorated more each year. In 2021 I was diagnosed with glaucoma and in 2020 with gallstones and I was diagnosed at Queen Mary hospital with peripheral neuropathy in 2018? In 2017 I was diagnosed at Queen Mary hospital with myelodysplasia. In 2013 I was diagnosed with chronic kidney disease stage 3 and retinopathy. In 2006 I was diagnosed with renal artery stenosis and in 1991 I was diagnosed with hypertension. In 1984 I became insulin dependent diabetic, Type 1 and I've continually suffered for years from muscle aches and pains (in my calves and hands and wrists mostly) and I've bruised very easily for decades. Furthermore, again, I do not know if it's associated, but in case it could be, please may I mention, that my son (who was breastfed by me in 1977/8) was diagnosed with a Ewing's sarcoma in his tibia when he was a teenager, and he initially had an internal prosthesis put in and he had to have high dose chemotherapy and radiotherapy which thank God got rid of the cancer but it also caused permanent damage to his liver and kidneys and he also acquired a chronic infection in his leg for which he was on high dose antibiotics for years then he had to have his leg amputated in 2020. Apologies for anything I've mentioned not relevant to this inquiry.

17. From 1994 I was employed by GRO-B University first as the
 GRO-B Then from 2008 I was an
 GRO-B for GRO-B
 University, where I GRO-B
 GRO-B I loved my job however working became
 more and more of a chore throughout the years and in 2015 although I didn't
 want to, I was forced to retire early as I no longer felt up to the job, due to my

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exhaustion and associated medical conditions I'd developed. I wish I could have continued working as I loved my job however as I was continually exhausted and started experiencing brain fog it forced me to retire earlier than I'd wanted to.

18. I was on an income of circa £45,000 a year whilst working at the University which was a good income, then after I retired I had no income, except my pension, which meant I had to radically change my lifestyle and be careful with what I spent.

19. I now have concerns with the impact HCV has had on my liver which resulted in chronic cirrhosis and it has caused my liver and kidney function to deteriorate. Had I been diagnosed and treated earlier then I would have probably avoided having chronic cirrhosis of the liver and varices of the oesophagus, etc. which must be routinely checked for bleeding and worsening. My quality of life would have been better and I want to live as long as possible to be there for my husband, children and watch my grandchildren grow up, God willing.

20. In 2018 when I was diagnosed with HCV I was fearful I could have given it to my husband, children or grandchildren and this made me depressed. I felt very guilty when I learnt I had passed it to my husband. However, fortunately this guilt was only short lived because my husband managed to get rid of his HCV without the need for treatment and I pray it will never come back. I am relieved by this and only wish my body had got rid of HCV naturally too, or better yet had I'd never got HCV.

21. In 2018 I became introverted and unsociable after I was diagnosed and whilst taking Zepatier tablets to cure my HCV. For many decades I have sung in our church choir and I withdrew from that too as I was embarrassed and didn't want to risk passing it on to anyone or for anyone at church to know. I was upset that I had not been diagnosed previously despite all my symptoms that my GP and Queen Mary hospital were aware of. I also did not enjoy taking the medication as the tablets were painful to swallow due to their size and all this

got me down. Whilst I was not formally diagnosed as being depressed I now believe I was depressed.

22. The attitude to HCV has improved somewhat recently largely due to past media coverage and public perception (similar to HIV); however, in the past and even for me in 2018 and still to date, public perception of HCV is still very negative, despite knowledge by some of the Infected Blood scandal. I try to be informed but even I didn't know about the infected blood story until recently and I wonder why no doctors ever mentioned it to me? HCV carries a similar stigma to HIV which has fortunately benefited and improved vastly through the many adverts and education programmes in place, in the general public's mind. I feel HCV could also benefit from this though I never saw any adverts or leaflets on infected blood with regard to HCV.

23. Apart from my sisters, children and husband, I did not want anyone to find out I had HCV. I will not tell my grandchildren I have HCV until they are adults. I find it too humiliating and feel it would harm my image. Even today apart from the few people in my immediate family I initially told, I do not tell anyone else about my HCV because of the stigma associated with it. I find the fact that I had it very embarrassing and feel there's still a stigma attached to one having HCV. I know I did nothing wrong to bring this on myself, but others don't know one's past health issues and they may have misjudged me and thought less of me had they known I had HCV, so I had to keep it to myself. I've always been a respected person/colleague and a member of my parish and church choir and I didn't want this fact I'd had HCV to damage my reputation.

Section 6 Treatment / Care / Support

24. In 1983 after giving birth to my daughter I developed type 1 diabetes and was treated at The Beta Cell in Queen Mary Hospital as my blood sugar levels were too high and out of control. I took tablets for 6 months to 1 year which did not work thereon I was prescribed insulin.

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25. I had regular blood tests to check my HB A1c, liver and kidney function, etc. After being diagnosed with Type 1 diabetes in 1983; to my knowledge, I never had a specific blood test to check for HCV. I therefore received no treatment for HCV until I was diagnosed in 2018/19 and I am upset as the Drs and Queen Mary hospital either failed to diagnose or did not advise me earlier if they did diagnose HCV. I also feel it's negligent that the NHS didn't try to contact me and others like me that had potentially been given infected blood in 1977 even before and after and up until they found out about the infected blood. Had the NHS made contact with those affected earlier, many innocent lives could have been saved and/or people, including myself, could have had HCV treatment earlier and been cured sooner and hopefully avoided getting the other HCV associated health problems that I have. I've lived permanently in the UK in London for the past 45 years and at no time was I ever contacted by the NHS about this, nor was I ever informed by any of my doctors or anyone about the infected blood or the England infected blood support scheme which I find puzzling.
26. I also started getting regular abdominal pains and gastritis off and on in the 1990s and attended the GP for treatment however no mention of HCV was given to me.
27. I apologise again for mentioning all my medical issues, as I don't normally reveal my personal health issues to anyone but a doctor, but I feel obliged to do so in this statement as I feel I've been ignored or not been listened to on some issues in the past. About 5 or 6 years ago I attended Queen Mary Hospital where I was diagnosed with peripheral neuropathy and in 2017 I was diagnosed with myelodysplasia. Perhaps this may have coincided with the Infected Blood scandal if it was on the news back then, though I didn't know about it then and only heard about it recently. I also had anaemia and low platelets and if I was asked I would have definitely informed the hospital that I had a blood transfusion in 1977; however, there was no mention ever of HCV despite them probably knowing about the Infected Blood scandal. In retrospect, it sadly does seem like there was possibly a cover up by the doctors and

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hospital, in failing to mention the possibility that I could have received HCV from an infected blood transfusion which is extremely concerning and unethical.

28. In 2018 I was treated by Dr Gess at St George's hospital for HCV. I was given a tablet called Zepatier which I took for 3 months until I was cleared of HCV. I still have chronic cirrhosis of the liver and I am still under the care of Dr Gess. I am due to see him at my next appointment in December. I received no counselling or psychological support after being diagnosed with HCV nor was the EIBSS mentioned to me at any time.
29. I have an appointment on roughly a 6 monthly basis with Dr Gess, Hepatology, at St George's hospital and I had an ultrasound scan and a CT scan last month to check my liver. The gastroscopy I had last year and recently confirmed I have varices in the oesophagus and this will need to be continually monitored for life and I pray they don't start bleeding and causing other problems.
30. After being diagnosed by Dr Abboudi as HCV positive, I was initially sent to Kingston hospital to be seen by the gastro-enterologist team. Then for no explained reason I were transferred to St. George's and I was seen by Dr Gess and my husband was also tested for HCV. He was also diagnosed as HCV positive. My husband did not need treatment because, as mentioned previously, he cleared the HCV naturally after approximately 6 months. I also need to thank my husband for having been so supportive over the years whilst I've been suffering from so many health issues.
31. I received no information from Queen Mary hospital or St George's hospital or the GP or anyone about any financial support I may be entitled to following diagnosis with HCV.
32. I received no advice from Queen Mary or St George's hospital about precautions to be taken with blood to blood contact after being diagnosed with HCV. Nevertheless, I always worried I could pass on my HCV to my 4 grandchildren who I helped to care for when I felt up to it after retiring.

Section 7 Financial Assistance

33. Having received no financial support, nor ever been informed of any financial support available after being diagnosed with HCV in 2018 I thought nothing of this. I had never heard of the McFarlane Trust, Skipton Fund, England Infected Blood Support Scheme or the £100,000 interim compensation payment which I am told was announced by the UK government on 17 August 2022. I was made aware by the Infected Blood Inquiry that the McFarlane Trust and Skipton Fund no longer exist therefore I will be applying for payments from the England Infected Blood Support Scheme and the interim compensation payment. The first time I was made aware of the financial support available was when I contacted by the Infected Blood Inquiry in 2022 and I thought that financial support was only available to people on benefits and presumed the process was means tested.

34. As I only found out about payments I am entitled to in 2022 it means I have lost out on payments since 2018 when Queen Mary and St George's hospital should have made me aware I was entitled to them. As there was a failure to diagnose me with HCV until 2018 I have also lost out on previous payments from the McFarlane Trust and Skipton Fund as I can no longer make a claim from them as they no longer exist. I also believe I am not entitled to retrospective payments from the date that the English Infected Blood Support Scheme first started making payments therefore I have lost out on this too.

Section 8 Other Issues

35. I would have thought that once the government was aware the NHS had infected patients with HCV, they would have wanted treatment to be given to these patients as soon as possible. There should have been a thorough look back exercise to find all the infected patients in order to trace and then treat them. If this had happened then I would have been contacted a long time ago

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as the NHS had my NHS number. I could have been treated for HCV a lot earlier which would have meant I would have avoided suffering from cirrhosis of the liver and varices of the oesophagus, etc. I would like to know why a thorough look back exercise did not take place and why patients who had been infected were not contacted.

Statement Of Truth

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

Signed:

GRO-B

Dated:

19/11/22