ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN5364001
Exhibits: WITN5356003-
WITN5356005
Dated: 03/10/21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 May 2021 2021.

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

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1974. I live in GRO-B and my full address is known to the Inquiry. I am a doctor, currently practising as a General Practitioner ("GP") and I live with my wife and children. We have four kids, aged between 13 and two. My father also lives with us, as did my mother before she sadly passed away.

2. I intend to speak about my mother's infection with hepatitis C ("HCV"), transmitted via a blood transfusion which ultimately led to her death. In particular, I will discuss how she came to be infected, the nature of her illness, the treatment she subsequently received and the impact it had on her and my family.

Section 2. How Infected

3. My mother, GRO-B was born in Pakistan in 1953 and came to the UK around twenty years later in 1973. She married my father soon after and they had two children together; my older brother and myself. In GRO-B 1974 my brother was born, just ten months before me. I was not aware of this previously, but it appears from the records submitted to the Skipton Fund, that my mother was given a blood transfusion because she suffered with a post-partum haemorrhage after my brother was born. I exhibit here (**WITN5356002**) her discharge note, dated GRO-B 1974.

4. In 1979, my mother received another blood transfusion, which I learnt many years after. My parents told me that she suffered a miscarriage whilst at home; there was blood all over the landing and she lost such significant amounts of blood, that she wasn't able to speak and could barely move. My father took her to the hospital where she was given further blood transfusions. The doctor told him that it was touch and go at one point. I exhibit here (**WITN5356003**) her discharge note, dated 28 December 1979, which does not mention a blood transfusion. However, I also exhibit here (**WITN5356004**) a memo from the same care period showing that two bottles of blood were cross-matched for transfusion.

5. Other than these instances, my mother was always fit and well and very rarely needed to be treated in hospital or visit a doctor. Even when I finished my medical qualifications, she rarely asked me any questions as she was in such good health. She was one of those people that never complained; she was very tough. In 2009, she underwent a minor surgical procedure as an outpatient to remove a polyp. It was after this surgery that it became clear something wasn't quite right with my mother's health.

6. As I mentioned before, my mother never asked me any medical questions or sought advice with regard to her health. But, shortly after her polyp surgery, she did so for the first time. She told me that she

noticed some very dark blood in her stools. I am aware that such symptoms often indicate that the source of the blood is higher up in the body, as it gets darker as it moves through the digestive system. I assumed the surgeon must have cut her skin accidentally during the procedure, so I advised her to keep an eye on it and let me know if it started to deteriorate. At the time, I didn't suspect anything more sinister.

7. The same day, my wife had an appointment with her doctor, so I took her to the hospital, along with our daughter. I vividly remember returning home and as we pulled onto the drive, I had a strong feeling that something was not right; an instinctive feeling that my mother was in trouble. I went straight up to my mother's bedroom and knocked on the door, but there was no answer. The door was locked, but I then heard a very loud vomiting noise coming from her ensuite bathroom. We couldn't get the door open and I started to think about breaking the door down, but we eventually got it open. As soon as I opened the door, I saw she was sitting in the shower cubicle and there were pools of bloody vomit overflowing in the shower.

8. I was in complete shock – even as a doctor, I had seen nothing like it before. She was barely responsive and couldn't answer my questions. We called an ambulance straight away and tried our best to comfort her whilst we waited. The ambulance took us to St James's University Hospital in Leeds. The doctors there were unable to find any of my mother's veins as her haemoglobin levels were so low. A normal haemoglobin level is around 13 and my mother's levels sat around 3.

9. Initially, there was a lot of back and forth between the various specialists as they couldn't work out what the issue was or where the blood was coming from. The gynaecologist and the gastro-intestinal (GI) specialist disagreed over the source of the blood, despite me informing them that I witnessed it come from her mouth. My mother was given a very deep vomit bowl, but it didn't take her too long to fill the whole thing up with even more bloody vomit. I remember the nurse turning to the GI

specialist and saying, ‘are you happy now?’, as she was right about the source of the blood.

10. They put a camera down her throat and subsequently diagnosed oesophageal varices, which are essentially enlarged veins within the oesophagus. From my understanding, there can be several causes of oesophageal varices, but the primary cause relates to liver damage.

11. She was on no medication that could have caused any liver issues and as a Muslim, she did not drink at all. After running some tests, it was confirmed that she had end stage liver cirrhosis and it wasn’t long before doctors also informed us that she had liver cancer. Finally, after numerous further tests and assessments, my mother was informed that she tested positive for hepatitis C and had a primary hepatocellular carcinoma.

12. I recall discussing the possible risk factors which could have led my mother to be infected with HCV with her doctors, but struggled to come to a conclusive explanation, or at least one that made any sense. She moved to the UK aged 20 from Pakistan, where she had not undergone any surgery or medical procedure. She married my father shortly after her arrival in this country and they both were wholly faithful. She never used drugs and had no tattoos or piercings.

13. We were told about various different diagnoses, one after the other, each one worse than the last; it was very upsetting and we didn’t give a lot of thought to how she came to be infected at the time. Since then, and having thought about it in more detail, the only realistic route of infection was via the blood transfusions she received on the two occasions during the 1970s.

Section 3. Other Infections

14. To my knowledge, my mother was not exposed to any other infection, only the HCV as a result of her treatment with blood transfusions.

Section 4. Consent

15. I cannot comment on whether my mother was asked for consent when she was given the blood transfusions that led to her infection. However, from what I know about the circumstances of those treatments, the transfusions appear to have been necessary and proportionate. I do not believe that she would have withheld her consent if it was sought.

16. Similarly, with testing, I cannot recall any of us being asked to specifically consent to an HCV test. But we would not have withheld this consent if we were asked, as we would have trusted that such a test was necessary and wanted the doctors to get to the bottom of my mother's illness.

17. Following her diagnosis, I can also only assume that my mother consented to all the treatment she received. It does not seem that consent is an issue in my mother's case.

Section 5. Treatment/Care/Support

18. When my mother was diagnosed, the risks of transmission were explained to the whole family and we were all advised to get tested ourselves. We had to organise our own testing, as it was not offered to us. Thankfully, no one else was infected. At the time of diagnosis or subsequently, no counselling or psychological support was offered to my mother, myself or other members of the family.

19. We were told that the best possible course of treatment for my mother was a liver transplant. However, the doctors were not able to guarantee that she would be put on the list as they needed to assess her suitability. In order to improve the chances of the doctors finding a viable donor, they considered members of the family. I was the only candidate out of my mother's relatives that was a potential match, so I had a complete

check-up including an examination and consultation with a transplant surgeon, blood tests and an MRI.

20. The tests confirmed I was a potential match. It was a partial transplant, so I would only be required to donate a part of my liver and essentially, we would share a single liver between the two of us. While discussing the potential implications of me being a live donor, my wife and I weighed up all the risks, understandably, my wife was very scared about the procedure. We gave the Liver unit the go ahead and were waiting for the final results of all my tests when we found out that the hospital identified a donor. As with most transplant waiting lists, we were contacted as soon as a liver became available. My mother received a liver transplant at St James's Hospital in 2009.

21. Whilst my mother was waiting for a suitable match, an incident with a nurse on the GI team occurred. Being a doctor myself, I know how frustrating it can be when relatives interfere in a patient's care and I was always conscious of not doing so myself. On one occasion, I visited my mother in the hospital and she was adamant that she had not taken her medication. Oddly, her drug chart indicated that she had in fact received her medication, so I simply raised it with the nurse.

22. She took me into another room and asked me why I was interfering. I explained that I hadn't intended to draw attention to any errors made, but it just happened that I noticed the disparity. They made a big fuss out of it, asking if I was going to escalate the situation to a formal complaint. The nurse who signed the chart then returned and informed me that she had signed it without giving my mother her medication, because she was really busy with a very sick patient! In response to that I said, '*well how sick must they be if my mother wasn't important enough*?' - It was terrible. In retrospect I should have complained, but I didn't want to make a fuss as ultimately, my mother was at that time waiting to see if she would be eligible to get on the transplant list.

23. The surgery was quite traumatic, but the transplanted liver appeared to be taking well and my mother came home shortly after the procedure. It was not long until she began to deteriorate and became very unwell; she became jaundiced very quickly and her whole body was bright yellow; she was not able to do anything for herself; and was completely bed bound. To my mind this was rather unusual, compared to the 'normal' recovery periods post-transplant, but I hoped that on this occasion, it was just a long period of recovery. I remember speaking to my mother about realistic estimates of how long she could expect to live with her new liver. She was content with knowing that the prognosis was quite good with a successful liver transplant.

24. Sometime after the transplant, when they realised she was not doing well with her transplant my mother was offered Interferon treatment by the hepatologist. Of course, the newly transplanted liver was not infected with hepatitis C, but her viral load was still high. She was given an initial dose of Interferon and it surprisingly brought her viral load down to a log of ten. They were considering a variety of different treatments, but because the risk of making things worse outweighed the benefits, it just wasn't seen as a viable option. We discussed the options in depth, but nevertheless we trusted the experts and followed their judgment.

25. Within a few months of the procedure, there were some complications. Once again, she was admitted to hospital where they discovered that the transplant had not been as successful as first thought. I called the transplant centre at St James's, as my mother was getting very confused and they told me not to bring her there, but to take her to A&E instead. As soon as I got to A&E, the nurses told me she should have gone to the transplant centre – my mother was completely confused, almost delirious, and I was entirely fed up. She had no idea what was going on and it was obvious that something was glaringly wrong.

26. Eventually she was taken to the ward and it turned out that there was a problem with the blood supply to her liver; if I remember correctly, there was a blockage in a nearby artery. We were informed by her medical

team that they planned to insert some stents to widen the artery and as such, she was taken down to radiology. It was quite traumatic as she was utterly terrified of going in on her own. In the end, the stents weren't used as the artery was too small.

27. My mother stayed in the hospital for around a month. There are a number of incidents that occurred during this period that I would also like to raise. There was one time I went into the hospital to see her and she had bruises all up her side, covering the whole left side of her body, from shoulder to thigh. I asked the nurse how it happened and it turned out she had rolled out of bed. My mother must have been lying on the floor for a long time for that level of bruising to occur. It's quite sad that my mother hadn't even realised what had happened to her; at this stage she had become somewhat delirious. I knew the doctors were trying their best, but it was quite upsetting to know she had been left on the floor like that.

28. The consultants that cared for my mother were all very nice, but there was one that was very rude and he even made comments which I believe to be borderline racist. His name was Dr Mervyn Davies. On one occasion, I asked a registrar how my mum was and this particular consultant tore into me in front of the whole ward. He said, '*The staff didn't have time to tell everyone in the family every little thing*'. I wasn't even asking him, but he really went out of his way to shout me down. I would never have expected a clinician to speak to patients or their relatives like this.

29. On other occasions, the same consultant said things like, *'you people take donated organs, but you never give them'*. It was terribly rude and showed a complete lack of sensitivity to the cultural and religious differences within the community he served. It was definitely to do with race and undoubtedly inappropriate. But he was caring for my mum, so I wasn't going to make a fuss. I thought it could affect her care.

30. When my mother's doctors realised that the blood supply problem was not going to be solved with the insertion of stents, they called us all in and said there was not much more they could do. The only possible option was to get a second opinion from Kings College in London and see if she could get another transplant. But the impact of the first had been so monumental that I think we all knew it wasn't a possibility.

31. I remember around this time her being in extreme pain and getting a load of strong painkillers. I think she had suffered another bleed as she was crying out in pain. Suddenly after that, and after being told there was no more treatment, she changed. Her mental capacity was diminished. I remember having to explain to her what a palliative doctor was. She eventually said, '*take me home, I don't want to be here anymore*.' She was very confused and I remember her saying that she was going to be ok after all. We took her home on Friday GRO-B 2010.

Section 6. Impact

32. On Friday we took my mother home. I spoke to some relatives who said they will come see her the following Monday. What's sad is that I knew she wouldn't hold out for that long and I advised them that they should come sooner. I also had some extended family at the house in her final days and we were all doing shifts to sit with her. It was such a sad and depressing time. Her mental capacity was going down very rapidly and she was often in the states of delirium.

33. To deal with the whole ordeal, my dad went out to get some herbal medicine as he thought it would help and even cure his wife. I didn't argue with him, they had been married for 40 odd years and we all needed a way to cope with it all and that was his.

34. Upon returning home, my mother deteriorated very quickly and she passed away in the early hours of Monday GRO-B. I exhibit my mother's death certificate here (**WITN5356005**).

35. I have a vivid memory of carrying my mother down the stairs once she had passed. You try to block these things out, but I can remember how different she looked. It was very traumatic. Luckily, we had no problems with the undertakers – I know other families have been stigmatised when their undertakers know about their loved one's HCV infection.

36. Of course, the most obvious impact of my mother's infection and illness was her death. She was only 57 years old. Not only had we lost my mother, but we all had gone through a hugely upsetting and traumatic year following her diagnosis with HCV. It went from one awful piece of news, to another and then another. From blood-filled vomit, to varices, to cirrhosis, to liver cancer, to the fear of our possible infections, to the failed transplant, and then her passing – it went on and on and on.

37. I don't really think there are a lot of side effects usually associated with HCV that I can now say my mother had. For example, In the early 2000s we went on a holiday to the US and she was completely fine. In her later years, she was a little overweight, but she was active and her weight wasn't outside of the normal range. She loved hosting big dinner parties and was a very social person. Above all, and throughout most of her life prior to her diagnosis, she was completely well.

38. When I was younger, she was prone to episodes of anaemia, but it didn't cause her any serious medical problems. I suppose it made it that much worse to find out she had this awful illness, when we believed her to be in good health the entire time.

39. Then, when she fell very ill, it all happened so quickly and that made it very hard for me to understand the extent of the impact it had on me and our family at the time. It was really difficult to track how it all impacted us, let alone her, especially as my mother and the rest of my family leant entirely on me. In the last few weeks of her life, we all knew what lay ahead, but we had lots of hope and I tried to have a positive outlook. My dad was quite optimistic and hopeful something would change, my

brother cried a lot as he was very emotional, and I took on the role of supporting them both.

40. I believe my strong personality and knowledge from being a doctor meant that I naturally took on this role. My wife could tell that I was holding a lot on my shoulders; I was carrying the whole family. Nobody wants that role, but people look to you for answers and support.

41. During the time my mother was hospitalised, I was working full time. I used to finish my hospital shift in GRO-B then run into the house and get something to eat, and then go to the hospital for the evening. It was a crucial time in my career, so I couldn't take a lot of time off. As I was preoccupied with all of this, I feel I neglected my daughter who was around 2 or 3 at the time.

42. Everything was such a haze and as I mentioned previously, it all moved so quickly. By far, this had the greatest impact on my mental state. We never had a good run; if there were a few days of positive progress, it almost inevitably followed with something bad just around the corner. Post her diagnosis, there was not one occasion where she was in a good state for more than a few weeks.

43. Prior to my mother falling so poorly, I had been offered a job in Australia and as a family, we had planned to move there whilst the kids were still quite young and when it wouldn't disrupt their education. But it had to be turned down, along with a number of other opportunities that I had to reject. My mother's situation completely changed our lives; we had to re-think our future. I would say that we missed a good window of opportunity not taking my job offer in Australia, but that's the way life is.

44. My father was depressed for a long time after his wife's death. He used to sleep on the floor as he didn't want to sleep in their bed without her. He wouldn't throw out any of her clothes. He laid out pictures of my mother on her side of the bed and to this day he still doesn't sleep on her side. He sometimes sprays her perfume around the room. He'll go

and spend a long time sitting with her and including her in his day. It affects everyone in a different way and my father likes to hold onto her in every way he can. Even my own children say to my father, *'do you have a wife…where's grandma?'.* The impact of her death has filtered through generations and it saddens me that my own children have also been affected by this.

45. My brother lived abroad for a few years before this all happened and so it affected him very differently to me. He wasn't there, seeing it first hand, living with her, and living through all the pain and suffering. I can't say if that was better or worse. I remember it all so vividly and it took me a lot of time to get over that. He didn't see her in that awful state so it was just a very different experience. My wife and I cared and looked after her and have graphic images in our head of cleaning up her bloody vomit with blood clots the size of lemons. I'm not sure if I will ever forget these images, but as they say, time is a healer.

46. I would like to think that, in the end, you do come to terms with these traumatic things. That said, some things can't be healed completely. I try not to remember the date of her death. Even when I go to her grave, I try not to look at it. Or whenever I see the oncology wing of the hospital she was in; I don't like looking at it. The whole thing has had such a big impact on our lives. In fact, it has changed the course of our lives entirely; If none of it had happened, our lives would be very different.

47. My mother did experience some stigma after her diagnosis, but this came from her own relatives. Some of them would wear masks and gloves when they came to see her. No one really wanted to say anything about it or make a fuss. I didn't speak to her about it specifically, but I knew she felt uncomfortable about it, as did my wife and I. She felt much more comfortable when my wife or I changed her nappies or bedding, and would often ask for us, as we treated her no differently. It wasn't a huge thing, but I imagine it upset her a bit.

Section 7. Financial Assistance

48. I didn't have much to do with the application process. My father dealt with the application to the Skipton Fund whilst my mother was still alive. I remember my brother mentioning that our old family GP, Dr GRO-B had helped them to complete the forms and obtain relevant records. I am also informed that the initial application was made in 2009, where she was awarded both Stage 1 and Stage 2 payments and that, for a brief period before her death, she received a monthly payment as well.

49. When my mother passed, we decided to donate a lot of the Skipton money to various charities. Charity is a major part of our religion and we wanted to make a difference by donating money in my mother's name. Around the time of her death, there was a big earthquake in northern Pakistan and we donated a lot of the money towards the building of a mosque in a remote area of Pakistan that had been hit hard by the earthquake. We made the donation in her name, as well as donations to various charities in India and Bangladesh. We donated money that helped to build lots of wells and water pumps that now bear my mother's name. We thought it was a fitting way to remember her.

50. I think it is hard to say whether the amounts given were sufficient. At the time, I thought it was quite generous. But then I remembered that she passed away and I asked myself, had she not died, would it have been enough for her to live on for the rest of her life? She was 57 which isn't old at all, considering I am now in my 40s. When I remember how much she has missed out on, the trauma that we all went through, the love that her grandchildren will miss out on – it is not a lot at all.

Section 8. Other Issues

51. One specific issue I would like to raise is the cause of death as noted on my mother's death certificate; oddly, it is recorded as *'Hepatitis C (Naturally occurring).'* I can't think why this would be, as HCV isn't naturally occurring at all. I have no idea how it came to be there and, in my opinion, there is no medical justification for such a term. The doctor

that signed that off, Dr Bargh, was my mother's GP, who had very little to do with her care after her diagnosis.

52. Though there were undoubtedly shortcomings in the standard of care my mother received, I do not like to criticise the doctors and nurses that cared for her. In retrospect, I should have pursued complaints against the nurse that failed to give my mother her medication and the consultant that made racist remarks, At the time, I did give serious consideration to doing so, but when my mother was alive, I had far too much on my plate and once she had passed, it felt a little futile. As a proud employee of the NHS myself, I do not like to criticise medical professionals unnecessarily and I do not blame them for my mother's infection, her illness or her early death.

53. I do, however, find myself questioning how this could have happened. Before my mother's diagnosis I knew very little about the risks that were taken when treating people with blood and blood products in the 1970s and 1980s. I find it hard to get my head around, now knowing that blood was taken from drug users and prisoners (very obvious high risk donors) without being screened before being given to patients. We always assume that we move forward as a society; medicine progresses, technology advances, and ultimately, the risks are reduced. But that's not always the case. I cannot comprehend why people weren't questioning those methods back then. It is inexcusable. We will all miss out on the love and warmth our mother gave us. But she is the one who has lost the most – life itself. There has been so much suffering caused by this error.

Statement of Truth

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

Signed GRO-B

Dated 03/10/21