Witness Name: GRO-B
GRO-B
Statement No.: WITN6433001
Exhibits: **Nil**
Dated:

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 25 June 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1996 and my address is GRO-B I have worked as a clinical support worker since I was 19. I care for children with autism and cerebral palsy. I live my long-term girlfriend.

2. I am the youngest daughter of GRO-B: M GRO-B who was infected with hepatitis C ("HCV") as a result of receiving an infected blood transfusion. During childbirth my mother transmitted HCV to my elder sister, GRO-B: S I intend to speak about my mother's and my sister's infections with HCV, as well as my sister's cancer and untimely death. In particular, the nature of their illnesses, how the illnesses affected

them, the treatment received and the impact it had on my mother, sister, our family and our lives together.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

4. My statement should be read in conjunction with my mother's statements provided to the Inquiry: GRO-B

Section 2. How Affected

5. I first began to realise that my Mum was ill when I was nearing the end of primary school. As I began secondary school I was aware that my Mum was going to hospital for regular treatment but I was not certain what exactly was wrong with her.

6. My Mum told me that she was undergoing treatment for HCV around 2007. I cannot remember when exactly I learnt about her HCV infection, though she used to keep toothbrushes and razors away from me which probably led her to explain why. I remember her and my sister S going to hospital regularly throughout this time.

7. When I learnt about my Mum and S infections with HCV, I did not really appreciate the severity of the illness. Nonetheless I was shocked to learn that they were both ill. I can recall learning about HCV at school and being told that it was associated with drug use. I believed that it was completely misunderstood and that there was a lot of ignorance about the virus.

8. Upon learning of my mother and sister's illnesses, I decided not to tell other people. I possibly told my best friend at the time, but in general I kept it private. I was aware that HCV was associated with drug use and hence decided not to tell people.

9. My sister S started treatment after my Mum, in 2008. I later learnt that my Mum wanted to have the treatment first as she wanted to know how badly it would affect S Throughout their respective courses of treatment I was cognisant of the fact that they were both evidently depressed and unwell.

10. I witnessed both of them self-injecting the medication into their stomachs, which I did not enjoy watching. It was the first time I had seen anything like that. I remember there being yellow bins for medical waste around the house. This was eye-opening and difficult to witness.

11. I was only around 11 or 12 throughout this period. It was confusing for me to see stockpiles of medicine at home. I thought that it was chemotherapy but I knew they did not have cancer. On reflection, if they did have cancer I would have received a lot more help from school. As it happened, HCV was not discussed. It was kept as a secret and I just had to get on with it.

12. On one occasion around this time, I remember going to Lancaster Hospital with my Mum for an appointment with Dr Keating. She came out of the appointment in tears. All of this weighed heavily on me and this began to affect my behaviour and school work.

13. Lancaster Hospital offered me very little care and support. They showed a complete lack of understanding as to how this was affecting me at such a young age. This was also the case with regard to S treatment. Her concerns, it appeared to me, were ignored. She would often be upset and crying after appointments, which was incredibly distressing for me to see.

14. My mother and sister both suffered enormously during their treatments for HCV. None of the clinicians ever explained to me what the effects of the treatment would be. Everything I learnt was secondary. In retrospect I needed a better understanding of what was going on. To hear this from

a health professional would have made it more understandable and comforting.

15. Both my mother and sister's treatments in 2007 and 2008 were ineffective in clearing the HCV. This felt like a big kick in the teeth. I had seen them endure the horrendous side-effects of these treatments, so to then hear it hadn't worked was devastating. It felt like there was no light at the end of the tunnel.

16. After the treatments failed I felt deflated and angry. We were back at square one.

17. S pregnancy with GRO-B seemed ok, if a bit uncomfortable at times. I am unable to say whether this was exacerbated by her HCV infection. I was shocked by S birth, in particular how there was blood everywhere and how unwell she looked afterwards.

18. Soon after giving birth, my sister S was diagnosed with cancer. During her pregnancy the doctors had found a fibroid. The medical professionals told her that it would 'shrink to a walnut' and consequently S was not overly concerned. Then, a short time after her pregnancy, they found that it was a tumour.

19. She completed a course of radiotherapy but this did not work. She was then told that she needed trial medication but she could not receive this because she was infected with HCV. I felt so angry and felt like we were at a dead end.

20. S HCV infection meant she was out of options to treat her cancer. This affected me hugely and only went to reinforce the anger I felt about her HCV. I knew someone at work who had breast cancer and had undergone a successful course of trial medication. It was especially difficult for me to see my sister not being offered the same opportunity. The HCV was a further obstacle to her cancer treatment.

21. In September 2015 a consultant told S that she had until April 2016 to live. My Mum told me this on the phone straight after hearing the news. I went to see S at Lancaster Hospital and the whole thing felt surreal. I used to think 'why is this happening to us?'. It was a very hard time.

22. I went to stay with S in GRO-B after hearing the news. I remember having to isolate with Mum after she got gastroenteritis from the ward she was staying on.

23. My Mum and I went to GRO-B and stayed at a house for families affiliated to Lancaster Hospital. Thankfully my employers were very accommodating and understanding of the situation. My boss is a good family friend; if I had worked anywhere else, I believe this would have been more difficult.

24. The Macmillan nurses were very supportive during S last few months. In comparison to the support offered when she underwent treatment for HCV, they were extraordinary.

25. After S death, I moved away from my hometown. I was trying to escape from all the trauma I had witnessed. Being around GRO-B just reminded me of all the negativity and troubled times. It is a small town and everyone knew me as the one whose sister died. I wanted to get away to somewhere different with nightlife and shopping.

26. Two months after S died, the girl with cerebral palsy who I cared for died during my shift. My grandfather had also died the year before, and my half-sister's boyfriend also died six weeks after S I had lost my sister, my half-sister's partner, my granddad and a child who I cared for all within a short period. It was constant barrage of bad news and I struggled to deal with it.

27. I was living away from home when my Mum underwent her second and third courses of treatment for HCV around 2017-18. I was aware that she was struggling throughout this. She was clearly depressed. I used to

dread coming home to visit my Mum as it reminded me of all the upsetting events that had happened.

28. Thankfully my Mum cleared HCV at the third attempt. I am worried at the fact that my Mum has permanent liver damage. I am anxious when my Mum goes for her liver check-up every 6 months. It terrifies me to think I will be the only one left if my Mum dies.

Section 3. Other Infections

29. I do not believe that my mother or sister received any infections other than HCV.

Section 4. Consent

30. As far as I am aware both my mother and sister consented to testing and treatment for their HCV.

31. I was tested for HCV when I was a baby, which my mother consented to. I was also tested for HCV when I was around 12 years old. I knew I was being tested for this as I knew about my mother and sister's infections with HCV.

Section 5. Impact

32. Before I learnt about my Mum's diagnosis with HCV I was aware that my Mum was tired and in bed a lot. I did not understand this as a child. I used to question why we did not go out and do the normal things that families did. I began to accept this and I knew my Mum was more fatigued than the average parent.

33. After learning of my Mum and S diagnoses, I took on a lot of responsibility as regards housework. I used to go and get the shopping and collect my Mum's child benefit payments. I had to put money into

her bank account to pay for direct debits and I would often collect her and S prescriptions.

34. It seemed that all the household jobs fell on my shoulders. At the time I did not enjoy this responsibility but in hindsight at least it made me grow up and become independent.

35. My struggles with the emotional pressures at home were reflected in my behaviour at school. I was not offered any help or counselling from school and as a result I was badly behaved. I was put in classes with other 'naughty' pupils which made things worse.

36. I remember being sent to the 'red shed' one day. This was literally a red shed where the pastoral support team were based. I was reluctant to visit them and to explain what was going on. I internalised everything as opposed to sharing it with people.

37. After school I avoided going home. I would go to sleepovers with my friends rather than go home. Whenever I did go home, my Mum was always asleep. As a result of my bad behaviour I was eventually expelled from school before starting year 11.

38. Overall my education was significantly affected by what happened to my Mum and S I was annoyed by the situation at home and used to let it out on my teachers. I barely studied and ended up in a crowd of other badly-behaved pupils who did not study either.

39. After leaving school early, I enrolled at college instead of starting year 11. I never told the college about my Mum or sister's illnesses. I was only at college for a year but it was a lot better than school. Afterwards I started a GRO-B apprenticeship at a hotel before I started my current role as a support worker.

40. Around this time I began to spend less and less time with my Mum and S Perhaps they were trying to shield their ill health from me. I

remember S especially appearing fatigued and she lost a lot of weight.

41. My Mum suffered greatly as a result of her HCV infection and treatment. In particular she suffered with depression and debilitating fatigue. I was forced to take on a lot of household responsibilities and it was upsetting to see my Mum tired or in bed all the time.

42. I was aware that my Mum felt there was a stigma associated with HCV. I believe her cognisance of this made me more worried about people knowing about her infection. I decided to keep it within a very small circle. Even now I believe there is a stigma associated with HCV and a general ignorance surrounding it.

43. My Mum's infection with HCV caused her to lose all trust and confidence in the NHS and the medical profession. Although I think the NHS is a great thing, the whole blood scandal angers me and has knocked my confidence in the NHS. If I was to go for an operation now I would want to know a lot of details, especially if I had a need to receive blood. I definitely question things medically a lot more as a result of this.

44. After completing her treatment, my Mum decided to get us a dog. This helped to motivate us to get out and do things together. It gave us all a bit of a routine and helped my Mum in particular.

45. My Mum goes for a liver scan every 6 months to monitor her liver damage. I am fearful of the day when something goes wrong. I know that this will last for the majority of my life. I am scared that I will be the only member of my family left if my Mum dies.

46. After S diagnosis with cancer I was annoyed at her being denied trial treatment. This was all a result of her HCV infection, which she should never have contracted. It all felt so unfair and all I wanted was for her to have the best treatment available.

47. Macmillan were a tremendous support to S, my Mum and I. When they were undoing treatment for HCV there was nothing available to them. There was no support helpline or leaflets. Compared to cancer, there is nothing for HCV support. I feel that it is a hidden issue that is swept under the rug.

48. When S was in hospital I helped to look after GRO-B It was a lot to manage and I found it quite stressful. S and I tried to make the most of it with GRO-B when we could. I remember being extra cautious around S by protecting her from infections. Her weak immune system meant she was very susceptible to infections.

49. S missed all the opportunities to do things with her son that every mother should have. She could not take GRO-B swimming, away on holiday or on days out. I find this sad and upsetting when I reflect on it. She missed out on so much with her son.

50. In spite of this, S tried to stay positive. She had a wonderfully positive mentality. I used to organise fundraising events for Macmillan, including a charity walk up Ben Nevis and a Bingo charity night. All in all we raised close to £25,000. I could not have done this without S infectious positivity.

51. After S died I was told that I was allowed 1 day's paid leave. I was angry at their lack of understanding. I went back to work just a week after the funeral. Part of me wanted to keep busy as this is my coping mechanism. I continued working and keeping busy so as to push all the negative thoughts to the back of my mind.

52. GRO-B has been left to grow up without a Mum and this will affect him hugely for a long time. He has a lot of support and a good Dad, but I just hope that he does not struggle at school like I did. I have a close bond with him when I see him and I feel like he is looking for a mother figure a lot of the time. He enjoys seeing me and my girlfriend. He is very like his Mum; affectionate and loving.

53. Within a short period of time I lost my sister, my half-sister's partner, my grandfather and a child who I cared for. I did not deal with this for a while. I went out partying and just brushed all the trauma under the carpet. I did not want to stop and think about it.

54. I used to wonder why I did not contract HCV but S did. I could not comprehend this and I felt guilty that it was her and not me. I used to question why I had been the lucky one. All this caused me a great deal of grief.

55. I've explained everything that happened to my girlfriend. We have been together for 3 and a half years now, so she knows how much it has affected me. She has been a great support and she gives me a different perspective. It is good to be able to talk to someone who is not family and was not directly involved in what happened.

56. There is a big hole in my life after S death. This will never be replaced. She was like another mother figure when my Mum was unwell. I miss her terribly. I know she would've wanted us to be a big part of GRO-B life and to help bring him up.

Section 6. Treatment/Care/Support

57. My sister S was ineligible for trial cancer treatment as a result of her HCV infection. Consequently, I feel that she was denied the opportunity to try different treatments that would otherwise have been available to her.

58. I was never offered counselling or psychological support, both from the NHS nor my school. I was grateful to my family and work colleagues for listening to and supporting me.

Section 7. Financial Assistance

59. I am not aware of any financial assistance that my mother or sister may have received in respect of their infections with HCV.

Section 8. Other Issues

60. I am providing this witness statement on behalf of my sister S She certainly would have had plenty to say and it is only right that I provide evidence to the Inquiry in her honour. She would have been proud that Mum and I have both provided a statement and that her story will be recognised. She was a very kind and caring person who did not deserve anything that happened to her as a result of the contaminated blood scandal.

Statement of Truth

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

Signed: GRO-B

Dated 02/10/21