Witness Name: GRO-B
GRO-B
Statement No.: WITN1902001
Exhibits: WITN1902002
Dated: 26 September 2019

WITNESS STATEMENT OF GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B My address details are known to the Inquiry.

2. I have always lived with my parents; they both take care of me. I have pets that are my life. I call them "*my kids*" because I love them.

3. I am single and I do not work. I cannot drive and am wholly reliant on other people to help me to get out into the outdoors. I hate this, it causes me a lot of upset.

Section 2: How Infected

4. I was diagnosed late with T-cell acute lymphoblastic leukaemia in 1987. I was only three years old at the time. My parents tell me that I was transferred to GRO-B Children's Hospital on 14 October 1987 for specialised treatment. From the medical records I have seen, investigations revealed that I was in respiratory distress, had superior vena cava obstruction and incipient airway obstruction, secondary to a huge anterior mediastinal mass. Despite some treatment I experienced profound toxicity and multi-system dysfunction. In summary, I was very unwell.

5. I required various treatments including a laparotomy on 4 November 1987, a gastroscopy on the 13 November 1987, and a sigmoidoscopy on 19 November 1987. I understand that I was suffering from severe gastrointestinal bleeding which did slowly settle over time and eventually resolved. As a result of all of this I was given a number of blood transfusions and other treatments. I have a record which indicates that from a haematological perspective my platelet count remained below 100 x 10 / 1 for nine weeks and I required platelet support on 32 days during that period of time. My peripheral blood counts regenerated to normal and I became platelet independent by 12 December 1987.

6. My consultant paediatric oncologist explained in a letter (which I do not have the first page for and so I am unable to date reference) that I survived devastating complications and achieved a secure remission.

7. I was described as significantly immunocompromised and my prognosis for long-term disease control and cure was considered to be less than average, in the region of 50 percent. I was seen in weekly clinic for several years and received blood and blood products even after I was discharged. Looking today at the documentation that I have which was sent to my GP by the LookBack programme that I actually received fresh frozen plasma in the form of

leucocytes on 5 November 1987, at the GRO-B Children's Hospital, the documentation indicates that the infected batch number was "*460260*" and donation number was "*715596H4*". It also indicates that the component type was "*Leucocytes Single Dose*".

8. I had always believed up until today that I was infected as a result of receiving a blood transfusion. I understand that fresh frozen plasma is technically a blood product but that it is made from the liquid portion of whole blood, so it is a component of whole blood and not a manufactured blood product. I have no idea how the Blood Transfusion Service can tell it was this that infected me and not something else. I would also like to point out to the Inquiry that there is a record that I have which indicates the blood treatments that I received on the 5 November 1987. There is a line which I find to be quite interesting which states I received Buffy Coat, 25mls, with the note attached "*have queried before*". I wonder if this person was double checking whether the blood was alright. I have provided this documentation to the Inquiry **[WITN1902002]**, in 9 pages.

9. I was not infected as a result of receiving blood from another person.

10. As I was only three years old at the time, I have no idea as to what occurred prior to my treatment but my parents who were there, have told me that they were not told that there was a risk of me being exposed to infection from the receipt of blood. They have said that the consultant did not know how to treat me at the time and essentially he told them that he would have to make up my treatment as he went along.

11. I was infected with hepatitis C as a result of receiving blood/blood products.

12. I cannot remember the detail but my mum has told me that we received a call to the house one day from my GP in around July 1995. The GP spoke to my mum.

13. We were asked to attend the surgery as I needed to be seen by the GP. Mum and I went to see the GP within the next week. He explained that he had received a letter from a programme which advised that one of the donors that I had received blood from was infected with hepatitis C, so I needed to be tested to see if I too had contracted the virus.

14. I provided a blood sample to the GP surgery within approximately one week. It was sent off for testing. It took approximately eight weeks to find out the results. Mum had to call the GP surgery repeatedly to see whether the results had come in. The GP came to my home on 19 September 1995 to give me the results; I was only 11 years old at the time. He told me that I had contracted the hepatitis C virus. He told me this in the company of my mum and dad.

15. On that particular day the GP did not tell me or my parents about the hepatitis C virus. He asked us to return to the surgery once we had processed the diagnosis to discuss it further. When we did, he explained that he did not know what it meant and that he had needed to do some research to find out. I cannot remember anything about this myself so I am reliant upon my parents to remind me, but my mum and dad think that the GP indicated that the virus was serious.

16. We did not know how bad it was. It is my parents' recollection that there was nothing that could be done about it at that time but we did go to a local hospital for blood tests every six months to check on the virus activity. Some time later; my parents have a vague recollection of it being around two years later, we went to GRO-B Children's Hospital to discuss the virus and treatment options with the liver specialist.

17. My parents have informed me that the liver specialist provided adequate information to enable them to understand and manage the infection. I was still a child at the time. The specialist answered the questions that my parents had at the time. They have said that it seems that the medical profession did not really have that much information to give. My parents found out that it could a

be very serious infection, that it affects the liver, and that I might need a transplant but that I would not be eligible for one. My parents were told that there was no treatment available at that time, but there was something being worked on. They did not know whether I would qualify for any treatment but that would be kept under review. The plan was for me to be reviewed once every six months.

18. I think that information should have been provided to me sooner at least at the point of confirming my diagnosis in 1995. This would have helped me and my parents to manage the risk of potential infection to others.

19. My parents say that I was told in a very kind way, but no information about the infection was given. They appreciated the doctor coming to our home to tell us. This showed he cared.

20. The risks of other becoming infected were discussed with the liver specialist. My parents vaguely recall discussing how it could be passed on, but only in relation to what to be careful of; so for example we should avoid sharing toothbrushes, razors and towels. No other information was provided. I sought information myself from the hepatitis C nurse around ten years ago.

Section 3: Other infections

21. I understand that I have received the hepatitis C virus only.

Section 4: Consent

22. As I was a child at the time of receiving the blood and the blood products, I cannot answer this, I have asked my parents this, they believe that I was not treated or tested without their consent or without their knowledge but they do think that I was treated without adequate and full information being given because they were never informed that I might need a blood transfusion or

blood products or about the risks involved in receiving either.

23. My parents do not believe that I was treated for the purposes of research although my mum and dad and I query why on the record dated 5 November 1987 there is a hand written note against the 25mls of Buffy Coat which I received, which states "*have queried before*". This is the day that the Blood Transfusion Service say I received the contaminated leucocyte.

Section 5: Impact

24. I was only three when I received the contaminated blood or blood products. I do not know what my life would have been like had I not received that blood because for as long as I remember, it has been a part of my life. I know I struggled to fit in at school we think that this is partly because the leukaemia treatment affected how I function but we cannot be sure because the infection arrived while I was still being treated for the leukaemia.

25. I was diagnosed with depression in my early teens and I am prescribed medication for that. I have had the medication for so long that I think it was stopped working. I have been feeling suicidal ever since I was diagnosed; this is something that I have to manage every single day. I have tried many times to commit suicide. I cannot stand it any more. I cannot stand how this hepatitis C has changed my life. I only get to go out twice per week, this plays on my mind a lot. I am constantly very tired. I need to sleep all the time, but I don't actually want to sleep.

26. I used to do lots of other things like crafts and jewellery and toy making but I cannot do any of this any more. I can sometimes do card making but I find it hard. I also find it hard to clean out the kids' cages. I miss doing this and they miss me doing it. It was our play time, our bonding time together. They used to join in and make me laugh. They would play with me during it. If I had known

all this, how my health would change, I wouldn't have had them. This is because it is not fair on them that I cannot do this with them anymore and the difference they see in what I used to do with them before and how little I can do with them now. It is not fair. I must rely on someone else to clean their cages for me. If it was not for this help, I would have had to let them go and this would break my heart. I think I would not be around anymore too if that happened. I wouldn't want to be here is I had to let them go.

27. I notice that I don't remember things anymore, my friend who lives down the road might tell me the name of something or someone and by the time I get home two minutes away, I have forgotten. I have noticed how it has got worse over the years. I also get confused. By this I mean I have an idea of what I want to say but I cannot explain it. Then I find my mind is completely blank.

28. I have never really had a good appetite, for me this means that I don't ever want to eat. I don't really want anything to eat. I need to be encouraged to eat all of time. This has been a huge problem in the family and has been going on for years. I get bad indigestion and chest pains. I have been prescribed something for the indigestion. I have noticed that my hands aren't as flexible as they were before. They get so painful that I have to stop what I am doing to rest. My hands, legs and feet also shake a lot. I also get very angry and frustrated and suffer mood swings.

29. Apart from what I have explained above I am not sure whether there are further complications or conditions that are related to the hepatitis C. I was diagnosed with epilepsy two years following my leukaemia treatment. At this stage I had received the hepatitis C virus so it is difficult for me to say with any certainty whether this is related to it.

30. I have been treated twice for the hepatitis C. The first lot of treatment I

received in around 1997. I received ribavirin and interferon for period of eight months. The dosage was reduced two months into the treatment as I could not tolerate the full amount. I was supposed to be on the treatment for eleven months, but it was stopped early because they said I was not responding any further to it. My levels dropped significantly to start with and then just levelled off.

31. The second lot of treatment started in 2017 and for a period of eight weeks. This time I had harvoni and it cleared the virus.

32. The first treatment was a trial and we did not have any difficulties in accessing that. The problems surfaced in trying to access the harvoni treatment. Almost 20 years passed between the finishing of the ribavirin and interferon treatment and the start of the harvoni treatment. We were told that there was nothing else available to me. A balancing act was struck between my condition deteriorating and the impact of the treatment on me.

33. I was first told about the harvoni treatment in around 2015 when my hepatitis C nurse told me that she would make a case to the board of the Trust for me to receive the treatment. I was told that they were only allowing certain people to receive it. Apparently it was only going to be made available to the most seriously ill people. This strikes me as unfair in a way because I was infected by the NHS in the first place. It turned out that the application to the board was successful.

34. I was due to start the treatment as soon as I was adequately withdrawn the epilepsy medication as it was not supposed to be used with harvoni. I had to see a specialist in order to find out which other epilepsy medication I could have. This led to considerable delays. In the end, when I had gone through a very long process with my GP and the specialist to withdraw myself from the epilepsy medication I presented to the liver specialists for the harvoni, they said that I could no longer have it as they were now using a cheaper drug. My

parents and I were extremely upset about this and my mum fought the decision and wrote to the Trust explaining that it was wrong to deny me the treatment. Mum said that we would not accept their decision, it was just too unfair. They reversed their decision soon after.

35. I think that I should not have had to wait as a long as I did for the harvoni, I think that it should have been offered to me as soon as it was available.

36. I cannot remember very much about the interferon and ribiviran treatment my parents have said that the side effects were very severe. I was in bed sleeping 70% of the time. When I was awake I didn't do anything at all apart from have really significant mood swings. I was extremely volatile. I was constantly in pain. I suffered hair loss. I became anaemic. My family and I just focussed on getting through the treatment. I stopped the medication early as it was decided it was not going to clear the virus. With the harvoni treatment the side effects were much less severe, I might have had a few days when I was feeling unwell but over all it was much better. Coming off the epilepsy medication in order to receive the harvoni caused the main problems for me.

37. The impact of the hepatitis C on other treatment is that I have to tell people about my infected status and this causes me a lot of anxiety. The treatment I have received as a result has been good.

38. I don't like telling people that I am infected. I haven't had a relationship with another person because I would not want them to know. I feel frightened that they might think less of me and that they might tell others I just avoid the possibility of telling someone else to avoid the stress that might come with it. I only have two very close friends who know and understand the situation. They have known for years because my mum had to tell them in order that they could be prepared for a situation where I might pose a risk to them in some way, for example through an accident at play.

39. I think that this virus has affected my family life quite significantly.

40. When I think about how this has impacted on my parents, I am not sure what to say. It has always been part of the life I have known and it has always been something that they have had to deal with, with me. If I did not have the virus I think I would have my own flat and I would drive, and I would go out at the weekends and on holidays with friends and so I wouldn't be in my parents' life so much and needing their help and support as much as I do. The biggest problem for me is that I am devastated that I do not have the independence that I crave in my life. When I am dealing with hygiene issues I have to be extra vigilant which I find very difficult to deal with and this upsets me a lot.

41. I don't think that I have been impacted by the stigma attached to this but I am not sure. I have chosen to tell as few people as possible so that the risk of being treated differently is minimised.

42. I have always had problems at school. At primary, I was never accepted and faced bullying. I never felt like I fitted in. I attended a special school when I reached the aged of 11, I did not face bullying there but I struggled academically and to feel like I fitted in. I think that my depression had an impact on my schooling, I felt like I was different, I felt like I was dirty. For the most part, I kept to myself.

43. I did do some school work but not a lot. I missed a lot of school because I was so ill. I rarely went to school at all during the treatment. I was late going to school because of the leukaemia, and afterwards I missed school because I was unwell. At times of stress my epilepsy worsens. I have not gained any academic qualifications.

44. I have never been able to go to work. I did some volunteering but I had to give it up because I lost my energy and became more tired and I could not do it.

45. I have never been able to earn an income so I think that the financial effects have been significant.

46. I have had support workers for a number of years now. Support workers change, and I did not want to have to keep telling each new person that I had contracted hepatitis C. In the end, I developed a plan with my parents to overcome how I felt, so I wore an SOS bracelet which contained information about my hepatitis C and I advised the carers not to touch me if I had an accident and to contact emergency services immediately and to look at my bracelet. I think it has been very difficult on my parents having a child with a lot of problems and one without. My parents do almost everything for me.

Section 6: Treatment/Care/Support

47. I have stated above the problems encountered with accessing the harvoni but I think that the main difficulties I have had have been in relation to my depression and my suicidal thoughts. I have struggled to access the care and support that I desperately need. I have been given help from time to time over the years but this care and support has been inadequate because it as either not been available for long enough or not of the correct type to really help me. I need someone who will understand me and work with me to help support my life and this has not really been available. My parents have constantly struggled to get me the help I need and the only reason that I can have this is because I receive direct payments, but the local authority is trying to cut my hours.

48. Even though I have cleared the virus I am left with many health conditions that were caused by the HCV virus and then the treatment. For example, at the moment I have problems with my teeth. I had to have them out because they were going bad. I think they went bad because of the HCV treatment. I decided to have them taken out now because I was told that I would have to

have them out at some point and I couldn't bear having any more treatment on my teeth or needles stuck into my mouth so I decided to get them taken out. I had to wait a long time to get them taken out. I wanted to go to the hospital to get them all taken out at once as I could not put up with the pain I experienced at the dentist as the dentist was taking them out individually. I just wanted them all done at once. The dentist referred me to the hospital, but not as an urgent referral.

49. While I was waiting, I was in constant pain and taking so many pain killers – I was taking too many. It took much too long for me to get the appointment. During that time, I couldn't eat solid food – it all had to be liquidised. I was told the dentist had to refer me urgently, but she didn't and so we had to ask her to make an urgent referral. We had to follow that up at the hospital as it was passed between departments. It took ages to get the appointment at the hospital, I think about 2 to 3 months. During that time, I was in constant and excruciating pain and I could not eat.

50. Over the years I have had times of experiencing terrible chest pains, but I was told it was indigestion. The doctors don't seem to know what is wrong and I wonder if it is connected to the HCV or the HCV treatment.

51. Counselling and psychological support has never been made available to me in consequence of me being infected with hepatitis C. In fact no-one has connected my depression with the hepatitis C. They have never connected any of my symptoms with the hepatitis C.

Section 7: Financial Assistance

52. I have received financial assistance from Skipton and the England Infected Blood Scheme (EIBSS). I think that I found out about the Skipton Fund through my hepatitis C nurse. I cannot remember when she told me but my first

payment arrived in March 2005 so it would have been a short time before then; this was obviously eight years following my diagnosis.

53. I received my first payment of £20,000 from Skipton in March 2005; I think the regular payments from Skipton started three years ago when I began to receive £252.50 on a monthly basis. The payments transferred to EIBSS in around October 2017 and increased to around £300 at around the same time.

54. I cannot recall anything about the process of applying for financial assistance, my mum did this for me and I have asked her but she cannot recall. I don't think that there were any obstacles or difficulties encountered as there is nothing sticking in our minds. I think that we had to sign that I would not pursue a legal case or take things further upon receipt of the £20,000.

55. I have no further observations to make other than to say that I have no idea whether I am receiving my full entitlement.

Section 8: Other Issues

56. I am very happy with the Terms of Reference and hope very much that the Inquiry will leave no stone unturned to answering the questions that come from those terms.

57. I want the NHS to know what they did to me, and to ask why they gave me the contaminated blood and why the contaminated blood was given to Children's Hospital especially when the children were so sick and close to death anyway. To be given this in a Children's Hospital is unbelievable. I want the Inquiry to find out the truth, I want the Inquiry to find the people responsible for what has been done. I would like people to face serious consequences for the decisions that they made that have affected so many people.

58. I have no concerns about the accuracy and completeness of my records now; however, I have no certainty about this.

59. My parents have had difficulties accessing my records initially when they were supplied they were only part supplied and in a format that was difficult to access. They were also sent to a local post office who could not send them on as the postal fee had not been paid. They were sent in inappropriate packaging which had split during delivery and which concerned my family and I greatly because of the nature of the information.

60. I have no real concerns about the way I have been treated by hospital staff, but I have concerns about the approach of my GP to my condition. My GPs have not connected my various side effects to my hepatitis C. There seems to be lack of understanding, awareness, a lack of training. I cannot understand this. I believe that my tiredness and depression are related to the hepatitis C but they have never stated that it is. I am not really sure what of my health issues connect to hepatitis C. I would like there to be more information about what else might be caused by hepatitis C.

Statement of Truth

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

Signed GRO-B

Dated ...26 September 2019..........