Witness Name: GRO-B
Statement No.: WITN5961001
Exhibits: **0**
Dated: 20th February 2022

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 18 January 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1963. I live in GRO-B and my full address is known to the Inquiry. I am a quantity surveyor, employed through the company that I set up and own. I am married with two grown up children, aged 29 and 27 years old.

2. I intend to speak about my infection with hepatitis C (HCV) through infected blood products. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and the lives of my loved ones.

3. I am not legally represented and I am happy for the Inquiry Team to help me in providing this written statement.

Section 2. How Infected

4. I was diagnosed with Christmas disease which is also known as Factor IX deficiency or Haemophilia B when I was around 8 or 9 years old, following a football injury that made me turn black and blue. Prior to this, my family had no idea that I had a clotting disorder. I think this was because I was less severely affected than people who have Factor VIII deficiency.

5. My haemophilia diagnosis happened at the Haemophilia Centre at the Royal Victoria Infirmary (RVI) Newcastle-Upon-Tyne and I have been treated there since then. At the time, Dr Peter Jones was in charge of the centre and he was a leading name in haemophilia care in those early days. Sister Maureen Fearns was also heavily involved in the centre's work.

6. Dr Jones was an amazing guy and was very supportive of me. He encouraged me to live life as normally as possible, telling me I could continue playing football if I wanted to. Both Dr Jones and Sister Maureen did a great deal for the Centre and I wouldn't say anything against them.

7. Following my diagnosis with haemophilia, the RVI decided to look at my family tree, to see where this gene had come from. My mum was found to be a carrier of the gene, although I think she might be an affected carrier as she bleeds and bruises very easily.

8. My grandfather was found to have haemophilia B, the same as me. He had a serious accident where he fell off a conveyor belt at British steel in the 1960s, and you can imagine the suffering he went through as they did not know about his haemophilia at the time and he received no treatment for it. He only started receiving treatment for haemophilia after I was diagnosed.

9. When I moved to secondary school, the school was aware that I had haemophilia and did not allow me to play for their football team. In those days, you moved up the ranks to play for county teams from your school team, so

this was very disappointing for me as I was very good at football at the time and felt I could have progressed well in the sport. I would play for men's teams at the weekend, so it did not make sense that I couldn't play in the school team.

10. I went to Amsterdam with the school football team when I was about 14 years old, as I think my dad nagged them to take me and Dr Jones wrote a letter to the school telling them it was safe for me to go. We played the AJAX junior football team but I was only allowed to play for 10 minutes.

11. Whilst the school team was playing in the game, at the side of the main pitch, I was playing a friendly game on the side with some of their players and I recall one of them being impressed with my skills and he asked me why I wasn't playing on the main team. I am sure that haemophiliac children nowadays don't miss out on these types of opportunities, but there was a lack of understanding back then.

12. Dr Jones asked me whether I wanted to start treating myself at home with Factor IX, but I said that I did not want to. I didn't want to have to stick a needle in myself and have to make a decision about whether I needed treatment or not. Sometimes an ice pack could manage it, but if you have the ability to inject yourself you may just do it without really even needing it.

13. I do have a pretty good idea of when I actually need to have an injection of Factor IX. For example, If I have a knock on my knee or leg, I can feel it pulsating if I have suffered a bleed. On one occasion in around 2007, I had suffered quite a bad ulcer related bleed and I went to our local hospital, The James Cook Hospital in Middlesbrough, as I needed an injection of Factor IX as soon as possible, and did not want to go all the way to the RVI in the middle of the night.

14. Normally, the doctor would give me one injection of Factor IX and then wait for 4 hours and give me another injection. However, on this occasion, the doctor did not want to give me a second injection and said he would observe

me again in the morning. I just knew I needed a second injection and in the end I told my wife to call the RVI so I could be moved there. I was taken to the RVI in an ambulance as by that point I was bleeding heavily. Some doctors in a general ward just don't understand how it works, but Julie, my nurse specialist at the RVI, always said that I would know if I was bleeding or not. I would not just have treatment for the sake of it.

15. When I was around 20 years old, I suffered a severe bleed after tearing a muscle. My car had a flat tyre and I jacked it up to change it, but the jack collapsed and I ended up holding the car up. Although someone saw me and helped me, I really injured myself in the process. At first I was in agony, but as my Dad drove me to the RVI I felt the pain going down. It turned out that the bleed was so severe that it had destroyed my nerves, which is why I wasn't feeling pain.

16. I ended up staying at the RVI for over a week or so following that incident, as I couldn't move my right leg for a while and needed lots of Factor IX treatment. I had to do various exercises to help get my muscles working again but the RVI helped me sort it. It shows how quickly severe bleeds can develop.

17. I believe I was in my 20s when hepatitis was first mentioned to me. I think they were doing blood tests on me regularly, as they were seeing patterns of these infections within the haemophilia community, and this is when they identified that I had it. At that time it was never associated that the hepatitis was linked to the Factor IX blood products I had been given over the years.

18. At the time, I don't remember being very worried about HCV but obviously now people are more knowledgeable about what HCV means and the associated risk factors. I was just told that I had a viral infection and told about some precautions to take. They said they would continue to monitor the situation but they really did not know much about it at the time, other than the fact that it might impact the liver.

19. It was only in around 2002/2003 that I had further conversations with Dr Schmid about HCV and I realised it was a more significant problem than I thought. I had spoken to my doctors about HCV every year or so, but this was the time when I learned about the significant impact HCV could have on my liver and my overall health.

Section 3. Other Infections

20. I believe I was probably tested for HIV many times over the years, as many haemophiliacs had been infected with it. Thankfully, I have never been HIV positive.

21. In a way, I was fortunate to have a Factor IX deficiency as opposed to Factor VIII deficiency, as less people required this treatment and as a result heat treatment began to be implemented faster for Factor IX than it did for Factor VIII products, as they had to produce less Factor IX products overall. If I had a Factor VIII deficiency, I feel there would have been a higher chance of me testing positive for HIV in addition to HCV.

22. In around 2002, there was concern about vCJD being discussed for the first time. I required an endoscopy procedure and I recall nurse Julie saying to me that they had kept aside a separate endoscope camera in my name due to the risk of vCJD. Despite this, I haven't heard anything about vCJD in recent years.

Section 4. Consent

23. As far as I am aware, I have never been tested without my consent. I would always consent to any tests that the doctor suggested.

24. I also always consented to the HCV treatment I received. When I declined any types of treatment because I did not think the chances of it working was high enough, my wishes were always respected.

Section 5. Impact

25. When hepatitis was first discussed with me when I was in my 20s, I really didn't know what it meant or the impact it would have on my life, and I don't think the doctors treating me really knew this either.

26. As I mentioned above, my grandfather was diagnosed with haemophilia after I was found to have it. It was only at that point that he started to receive Factor IX treatment, so he was not actually treated for his haemophilia for very long. About 15 years after he was diagnosed, he suddenly became poorly and his liver had been impacted and his condition deteriorated very suddenly.

27. My grandfather died aged 82 years old. Following his death, he was found to have had HCV, which had caused his liver to fail. I do think in a way it was a blessing that he was diagnosed with haemophilia as late as he was; if he had received Factor IX or other blood products in his younger years, he may have been infected with HCV much earlier, or even HIV.

28. In 2002/2003, Dr Schmid at the RVI explained that HCV was more serious than we thought and that it could be having a really negative impact on my liver. He seemed quite concerned about it, and this was the first time that I realised HCV was quite serious. The risk factors relating to HCV had been discussed with me over the years, but this was the first time following a number of fibroscans I realised just how severe HCV could be.

29. I have never been a heavy drinker but I think it was around 2002 that I decided not to drink going forward. Now there are lots of non-alcoholic versions of drinks available and I don't mind not drinking; the most I will ever drink is a glass of wine at our evening meal when I am on holiday with my wife. My friends do not know why I don't drink but I will always offer to drive everyone home after a night out.

30. At this time, Dr Schmid mentioned an HCV treatment that was available but when I asked him what the probability was of this curing me, he said there

was only a 20-30% chance of it clearing my HCV. I decided that the odds were not good enough, and I decided to wait until a better treatment became available.

31. Around this time in 2002, I decided to start my own business so I could work for myself. I had always worked since I was 17 years old, and before starting my business, I was working as a commercial director of a family owned construction company that was worth over £40 million. I had never told my employers about my haemophilia let alone HCV, and if I ever needed treatment I would just take the day off rather than explain what was going on.

32. Over the years, I had become more comfortable with my colleagues and did consider telling them about my health problems. However, one day at a work function, haemophilia and HIV came up as a topic of conversation and one of the fellow Director's wives said something like, "I don't know why they allow haemophiliacs to have children". My wife and I exchanged glances. After that comment, I never again considered telling anyone about my haemophilia. It was shocking that a comment like that could come from a woman who was considered intelligent.

33. Although I had loved my job, I started my own business for the flexibility it allowed, as I wanted to spend more time with my young children and do things like coach my daughter's football team. I no longer had to travel back and forth to the office and I could decide how I spent my day. The only travel I have to do is for site visits, and the lack of commuting also saved me a huge amount of time.

34. In 2002, I saw a gap in the market for a business doing my kind of role and thankfully my wife, who was working as a childminder at the time, was very supportive of my decision to start my own business. This was despite the fact that we had a new mortgage and a young family to support, but thankfully it worked out well.

35. Working for myself has also allowed me flexibility in relation to accessing treatment, as I can go to the doctors whenever I feel the need to without having to make excuses or explain my situation to an employer. Even though this was not the reason I left my old job, it has been useful. For example, even now when I feel like I need to see the physiotherapist about something haemophilia related, I can go as soon as he can fit me in rather than adjusting appointments around my work schedule.

36. In around 2002/2003, I started to have fibroscans which were done by a specialist nurse at the Newcastle Freeman Hospital. I never had a biopsy before this, due to the associated risk of bleeding with my haemophilia.

37. Over time, my fibroscan results were going up and gradually went from being around 16 on the scale to 34, when a healthy person's reading would be about 4 or 5. There is always a danger of going on the internet and reading up about things, but I did look up my results and realised they were high. However, there were people on there with much higher readings which showed me that my readings would probably get worse and worse if I did not get treatment at some point.

38. I continued to have fibroscans and ultrasound scans of my liver every 6 months from that point onwards, and still do to this day. These scans are done at the Freeman Hospital, GRO-B My latest scans show that my liver is scarred and that I have cirrhosis of the liver, but it is not getting any worse.

39. In January 2010, I had a serious discussion with Dr Schmid about my HCV and about a new type of HCV treatment that was now available. This time, he said the chances of this working were around 50% and I decided that it was worth trying the treatment on this occasion. Dr Schmid had said something like, "If you don't do anything about the HCV you could be seriously ill in 12 years", which was upsetting for my wife to hear and I felt I should give this treatment a chance.

40. It was going to be a 48 week treatment with pegylated Interferon injections and Ribavirin tablets. I had to visit the RVI each 2 weeks while on this treatment, which was over GRO-B from my house. Thankfully, as I was now self-employed, this was not a problem. I would see my specialist nurse Julie, and she is just fantastic.

41. When on the treatment, I was extremely tired and lacked energy. I continued to do my football coaching but usually I would play with the team at the end, and I just could not do this. No one outside of the family knew what I was going through as I did not want to share this with anyone.

42. I also recall that there was a lot of snow on the ground at one point over the winter, but I just could not get out to clear the path which is something everyone in the neighbourhood would do. I had to ask my son to do it instead as I was so fatigued even after just 5 minutes of exertion.

43. My wife also told me that I had become very direct while I was on the treatment. I have always been a fairly black and white person as a result of my job, but during this time it would not have been good for example, if I got a bad meal at a restaurant! Normally I avoid being too confrontational, but my personality was different during this time.

44. I have always been a glass half full rather than half empty kind of person. I am always positive and a bit of a clown, as I feel that life is too short to take things too seriously. I did have some anxiety while on the medication, but it wasn't too severe or impactful. I can understand the impact the treatment could have on someone who was naturally more inclined to anxiety and depression.

45. After 12 weeks on the treatment, Dr Schmid told me that my body's initial response had been positive and he wanted me to continue on with the treatment. Week by week my HCV levels were reducing, but not clearing. I believe I was meant to finish the treatment just before Christmas, but then Dr Schmid said that he would like me to do another 4 weeks on the treatment, as

my HCV levels were reduced but not clear. I remember saying to him jokingly that he was moving the goalposts.

46. Unfortunately, after 52 weeks on the treatment, Dr Schmid told me that it had been unsuccessful in fully clearing the HCV. He said he was very sorry about it and he was visibly upset, but I had known there was a 50-50 chance of it working in the first place. As I had genotype 1A hepatitis C, I was told that this was apparently quite a severe version of HCV and harder to clear. This was of course disappointing, as I had undergone a year of intensive treatment without any success.

47. Within a week of coming off the treatment, I had my stamina back and my wife even said, "It's nice to have you back again". I was told by Dr Schmid that I would be notified when a more effective treatment became available. I continued to get on with my life as normal although my liver and HCV levels were monitored regularly.

48. On 28 November 2015 I started a new HCV treatment which consisted of Harvoni and Ribavirin tablets for 12 weeks. This treatment did not cause me any mental or physical side effects and I was not a miserable sod this time! This treatment was successful and thankfully, I was cleared of HCV.

49. Since clearing the HCV, I see a liver specialist, Dr McPherson at the Freeman Hospital once a year and I continue to have fibroscans every 6 months, as I mentioned above. I also have at the RVI Heamophilia Centre a yearly appointment I have a full MOT and they check me for everything. Since I have stopped playing football, I don't have a lot of treatments now and only really require them if I need dental work for example. Dr Kate Talks is now in charge of the haemophilia centre and she is great.

50. My children have always been aware that I had haemophilia and HCV, but it has never really impacted their lives. My daughter is a carrier of haemophilia as my mother was. My son is clear of haemophilia.

51. As people are often uneducated about haemophilia and HCV, I have not really shared details of this aspect of my life with friends and colleagues. When I ran the football team, I did not tell people about it as it is impossible to judge their reactions. My cousins and close family members know about my health problems, but it is not something I openly discuss outside my immediate family due to the associated stigma.

52. Whenever I have medical treatment, I always joke around with the doctors and nurses and they say I am the most positive person they deal with. I could get knocked down by a bus tomorrow so I feel like I have to be positive and enjoy life as much as I can. I know my situation is not as bad as most people have it and I am grateful for that. My wife has worked with people with special needs, and I have realised there are people far worse off than me.

53. I feel that whatever has happened has happened, and the people I deal with at the RVI were not party to that. They have done everything they can to provide me with a remedy to cure my HCV, and finally this became available in 2015.

54. Although it will not completely cure the problems I have with my liver, I do my best to look after myself to give myself as best an outcome as possible. Things have come on so much in 20 years that they are now even talking about gene therapy to get rid of haemophilia.

55. Through hard work, my wife and I are doing alright now financially. The most important thing for me is having a pension pot in place for my wife, so I know that if my health deteriorates and I am no longer here she will be okay and looked after. However, I continue to look after myself. I am now trying to wind down my business and hope to retire next year.

Section 6. Treatment/Care/Support

56. I have always said that I am lucky to have always been treated by the top people when I have had problems with my health, and even now I see the top doctors. I have no negative comments about the treatment I received from the RVI over the years and I have only had one bad experience in relation to haemophilia treatment at James Cook Hospital. However, I think this was down to a lack of experience with haemophilia on the part of the ward doctor treating me.

57. Generally, everyone who has been involved in my care has been excellent and I am glad they can leave with a smile on their face after treating me, as you can't beat a bit of positive humour. It must be a very stressful job for them and not easy to deal with what they see day to day.

58. Following my diagnosis with HCV, I have always been offered HCV treatment as it has become available and have been given the choice as to whether I want to proceed with it or not. I decided to wait to have treatment until there was at least a 50-50 chance of it working, as early treatments were known to be less effective. When the first treatment of Interferon and Ribavirin did not work in 2010, I was offered a new treatment in 2015 which was successful.

59. I have been offered counselling many times following my diagnosis and I say that if the counsellor is feeling down, I can go and cheer them up! Even just a few months ago Dr Kate Talks asked me whether I want to speak to their new counsellor, but I said no, not really. Kate always asks me how I am feeling and stresses that I can talk to someone if I feel like I need it.

60. I am glad that these counselling services are available for people that genuinely need it, but I am lucky that my natural ability to be positive has helped me through difficult times in my life. Everyone is different and handles things differently. I know if I was just sat at home and not busy with work, lots of hobbies and social activities, it could be awful for my mental health. As I don't think I need the support, I leave it for those that do.

61. I have my dental treatment at the dental hospital in Newcastle, and I see the best guy there who is actually in charge of the school. I have never been refused dental treatment as a result of my HCV.

62. I was not asked to shield by the Government but I do not think that I needed to anyway. My wife and I have managed to avoid Covid as she retired before the pandemic and I work from home, only doing site visits once a week or so. We have not gone out much and have been careful. I did receive a letter recently before the booster jab saying I am regarded as vulnerable and asking me to get vaccinated, so they must be aware of my health conditions.

Section 7. Financial Assistance

63. Around 2015, Dr Schmid mentioned the Skipton Fund to me and said I should apply to them for financial assistance. I had not heard about this Skipton Fund prior to this and no one from the Skipton Fund had ever reached out to me to say that I should apply for their support. I would not have learned about this without Dr Schmid.

64. In hindsight, I think I should have been told about the Skipton fund earlier as it was not well publicised at all, but I don't hold a grudge about this. I'm sure the hospitals have a register of haemophiliacs and they should have told them to get tested for HIV and HCV, and also let them know that financial assistance is available to them. Things probably should have been better organised as notification about the Fund's existence seemed to be done on a very ad-hoc basis.

65. Dr Schmid filled out the relevant medical documentation for my application to the Fund. He also helped do the same in relation to my grandfather's situation, and my mother received some financial support from the Skipton Fund as a result of this.

66. I received £25,000 as an initial payment from the Fund, and then I received £50,000 as a second stage payment, as my liver had been damaged by cirrhosis as a result of the HCV I had been infected with.

67. More recently, I received a letter saying that in order to bring the financial assistance offered in England in line with other nations, the first stage payment will become £50,000. However, it did not say that the second stage payment will be reduced to £25,000, which means that if you had already had the second stage payment, you would not be receiving any additional financial assistance.

68. This letter was drafted appallingly and was very misleading. It was only when I queried it that I was told that I would not be receiving any additional lump sum payments, as the second stage payment had gone down to £25,000. This misinformation would have been upsetting to some people who are struggling financially and thought they might be receiving a further £25,000 in financial support. I think the letter should have been reissued with a further explanation.

69. I now receive monthly payments from the English Infected Blood Support Scheme (EIBSS). I believe I receive £2,390 a month, the amount gradually went up over time. Despite these increased payments, I think there is confusion for those infected about what the future holds financially. If the Inquiry concludes promptly and properly, hopefully there will be more clarity about financial assistance or compensation going forward.

70. I was not invited to provide any input in relation to the Robert Francis review into a compensation framework. To be honest, I do not think I can put a value on how much people should be given and I would prefer to just be told what it is going to be, so we are able to plan our futures more effectively. I think this applies even more so to people in dire financial situations, who desperately need this support.

Section 8. Other Issues

71. Before I was contacted by the Inquiry and asked whether I wished to provide a statement, I did occasionally listen to Inquiry hearings that related to my areas of interest. However, when you listen to stuff like that your perspectives can often change and I was thinking in a 'glass half empty' kind of way, which is unlike me. I also used to read information sent from the haemophilia society, but it is quite doom and gloomy and can make you feel quite down, and I often think 'why did I bother', so I try to avoid this.

72. From my personal perspective, I think we got the best from the RVI and since the HCV situation blew up I cannot fault the care I received. It is the place to go to if you need treatment. However, I do know that some people in a similar situation to myself are angry and I have met people in the waiting room while at the RVI who have a very different perspective on the situation. I am now just waiting for the outcome of the Inquiry so that I can have some closure.

Statement of Truth

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

Signed GRO-B

Dated 20th February 2022