Witness Name: GRO-B
Statement No: WITN4006001
Exhibits: WITN4006002-7
Dated: February 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF
GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I was born on GRO-B. I live at GRO-B. I am currently single and have no children. I work in the public sector as a GRO-B for GRO-B, GRO-B. This enables me to deal with my own health problems whilst also earning a living.

2. I was infected with Hepatitis C as a result of being treated with contaminated Factor VIII concentrates.

3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

4. I suffer from Mild Haemophilia A although I was initially diagnosed with Von Willebrand's Disease in GRO-B. **Exhibit WITN4006002** records this diagnosis as not being made until GRO-B. However, my mother's recollection was that I had been diagnosed with Haemophilia A by the time I was aged around GRO-B. In my view this exhibit is incorrect as it records GRO-B GRO-B *Congenital factor VIII deficiency"*, which would put the diagnosis some GRO-B years later than my mother's recollection.

5. I believe that I received Factor VIII concentrates on numerous occasions throughout my childhood (during the 1970s and 1980s) at GRO-B Hospital GRO-B in GRO-B and QAH. My mother, who passed away in GRO-B, told me that on one particular occasion I developed very dark rings under my eyes following an infusion of Factor VIII concentrate. This concerned her so she took me back to GRO-B to be checked.

6. **Exhibit WITN4006003** is a copy of a letter dated GRO-B from Dr GRO-B GRO-B Consultant Gastroenterologist at GRO-B, GRO-B to GRO-B, GP, which states "*I note that he has a past history of mild Haemophilia A for which he received plasma products in the 70s and 80s and believes he caught Hepatitis C secondary to that. He has no other risk factors for Hepatitis C, has never used IV drugs, blood transfusions or gay sex"*.

7. **Exhibit WITN4006004** is a copy of my UKHCDO records which are incorrect because they do not list any of the treatments I had in the 1970s and 1980s.

8. I was treated at GRO-B Royal South Hants Hospital (RSHH), Southampton, QAH, GRO-B and Hammersmith Hospital (HH), London.

9. My mother took my health very seriously and placed her absolute trust in the clinicians in relation to Factor VIII concentrates. I do not believe that my mother was given any information or advice regarding the risk of infection from Factor VIII concentrates.

10. In or around GRO-B I was living in GRO-B, London, and I had a discussion with my GP about my Haemophilia. He referred me to the Haemophilia Centre at HH, however, this was only due to my intrigue to find out more about my condition and it was not because he felt that I needed to be referred due to health reasons. I duly went along to the Haemophilia Centre at HH where I was seen by Dr Mike Laffan. I asked him a number of questions about Haemophilia in order that I could understand more about the condition. We discussed my family history and he also drew diagrams illustrating percentages regarding Haemophilia facts, which I didn't really understand.

11. Following our conversation, I then had a blood test which I was led to believe was a routine test to ascertain my Factor VIII levels. However, unbeknown to me, it was a test for Hepatitis C. This test was carried out without my knowledge and therefore without my consent.

12. Shortly afterwards, I was told by Dr Addada at HH that I had been infected with Hepatitis C. He said this in a very matter of fact manner and I don't think he even said the word "*sorry*". This came as a terrible shock to me and I don't think I have ever recovered from it. It really was a "*bolt out of the blue".*

13. **Exhibit WITN4006002** records GRO-B *Hepatitis C antibody test positive".* **Exhibit WITN4006003** records *"He tells me that he was diagnosed to have Hepatitis C in* GRO-B *when he was living in London"*.

14. It was such a devastating blow, made even more difficult by the fact that I was in a happy and supportive relationship with my girlfriend at the time. Furthermore, I had always put my Haemophilia to the back of my mind, although it remained a frustration of mine.

15. I have a family history of Haemophilia, yet I had never had any communications from a Haemophilia Centre prior to GRO-B. In my recollection this was the first time in my life that I had ever been to a Haemophilia Centre and I was aged GRO-B. As a child, I experienced numerous nose bleeds, however,

I have never had the contact or support from medical professionals and centres which has been afforded to other Haemophiliacs.

16. Dr Addada did not give me sufficient information to allow me to understand or manage my Hepatitis C and I was given no information about the risks of transmission.

Section 3. Other Infections

17. I do not believe I have been infected with anything other than Hepatitis C.

18. I had an HIV test many years ago which came back negative.

19. **Exhibit WITN4006005** is a copy of a letter dated GRO-B from H. M Hirri, Consultant Haematologist to GRO-B, GP which states "*I am writing to inform you that your patient,* GRO-B *may fall into this group of patients who are being asked to take special precautions to reduce any possible risk of further transmission of vCJD".*

20. Finding out about the potential vCJD risk was another compounding factor. I now had yet another thing to contend with on top of the Haemophilia and Hepatitis C. I would describe it as "*like getting an atom bomb dropped on me".*

Section 4. Consent

21. I refer to the contents of Paragraph 11 of this witness statement.

22. I believe that I have been tested without my knowledge and therefore without my consent. I also believe that I was used for the purposes of research without being advised of the same.

Section 5. Impact of the Infection

23. Since finding out about my infection in GRO-B I believe that I have been living in a state of shock which has continued to the present day. This manifests itself in different states. I would describe being infected as an "*out of body*" experience.

24. I have lived with Hepatitis C for years and have, at times, felt lethargic and depressed but never really knew what to put this down to. However, once I got the diagnosis I started attributing how I felt to the Hepatitis C. You then ask yourself the question, in terms of symptomatology "*What is due to the virus and what is not due to the virus?*"

25. My medical records confirm that I felt depressed and stressed which of course makes sense. I feel depressed knowing that I have had Hepatitis C but I am also aware that Hepatitis C causes depression so we are dealing with a complex situation.

26. Ironically, for someone who has had no or little follow up from clinicians, my health is in a pretty good state and I sometimes feel a fraud for that.

27. When I was told about my infection by Dr Addada I don't think he even directed me towards an advice leaflet. I was literally left alone to deal with some shocking and life changing news. There was no one to speak to and no aftercare or support arranged by the Haemophilia Centre. I felt abandoned. I was desperate to speak to someone and I was scared that my girlfriend would not want to be with me anymore. I was unable to speak to my mother as she was working nights so I telephoned my GRO-B, who was a teenager at the time, but I know this was wrong as I was putting my problems onto GRO-B at such a young age and I did not want to be a burden. However, I felt that I had no choice.

28. I have always been conscious that growing up with Haemophilia meant that I was different and I never wanted to divulge this to anyone. I GRO-C

when I was a kid and hung out in a gang so I had to be streetwise. I was pretty tough and I liked this way of life as I think it distracted me from my Haemophilia, which felt like a "*weakness*" at the time. I kept my Haemophilia as a secret, holding that secret is also a burden.

29. Sadly, I also don't have a lot of family support. My family make out that they are going to the ends of the earth for me and often call me selfish. However, the reality is that they need to do a lot more, but I still understand they have their own worries. Only one of them contacted me before my meeting with Collins Solicitors to say that they were thinking of me as I prepared my witness statement. I felt very apprehensive about coming to the meeting but my fears were allayed and I felt included and accepted following the meeting.

30. Conversely, during some of my interactions with the Inquiry I have been made to feel uneducated. I was the first one in my family to go to university, despite not growing up with much money.

31. Life post infection is stressful. You have doubt and only very occasionally hope. Seeing an envelope addressed from the hospital makes me nervous. I have no faith in the NHS and their clinicians. The cover up has been disgraceful. I only have frustration with the medical profession. These people have families and children yet they go through their whole career *"saving their backsides"*.

32. Things have not really changed much in the NHS. I was not followed up for a long time and when I was mistakes were made. One of my blood test results was incorrectly labelled as **GRO-B** by clinicians at QAH. I only found this out when I was looking through my medical records on 17 February 2020. Furthermore, when I saw the Haemophilia Nurse, most of the time I didn't know why she was taking blood from me and rarely was I was told of the "*result*". I haven't seen the Haemophilia Nurse at QAH for a few years since she discussed mine and extended family history in that appointment and I believed my medical history would likely have been shared with other family members and others too.

33. Reading through my medical records is a frightening experience. I don't like the tone in which I am written about. I feel violated by the tone of these records. The clinicians write with such arrogance, particularly about my Hepatitis C. They also appear to have a habit of "*copying in*" a number of other clinicians which I believe is so they can ensure that everyone is telling the same story.

34. In GRO-B I received a memo contained within requested copies of medical records from Camberwell Green Surgery (CGS) advising that my records for 1972-1973 were temporarily missing. One of the copied letters sent to me by CGS referring to me having had a blood transfusion was partially covered by a photocopy which was beyond a joke.

35. It has been very difficult living with the stigma. I struggle to express how I feel and when you talk to people you are always trying to speak about anything else, almost as a distraction to try and escape the harsh reality of your diagnosis. It has impacted upon me so massively, especially as I found out when I was relatively young. I feel emotionally battered.

36. Growing up on a council estate, I felt I never had any support (either financial or emotional), partly because my family had no money. I moved to London when I was aged 17, initially working in GRO-B for two and a half years. My cousin was the only role model I had.

37. I would like to share a little about who I am and where my passions lie. I studied GRO-B as part of my GRO-B Degree at University which is where my interest in GRO-B was sparked. I am very interested in why people experience GRO-B and GRO- which led me to GRO-B GRO-B I was a student GRO-B at the GRO-B GRO-B in GRO-B I observed someone getting arrested and was told to go away by the police, so I started to walk away, GRO-D GRO-D. When I told them that I had Haemophilia GRO-D which continued once they GRO-D

GRO-D

GRO-D I really enjoyed GRO-B as I felt that it would help in the fight for justice and be a witness to history. I also liked the adrenaline rush of going to GRO-B

38. I have already touched upon the fact that having Haemophilia frustrated me and this was before the Hepatitis C diagnosis came along. It makes you want to do more and to do things that you should refrain from doing. So called normal people don't have such limitations imposed on them. I find it frustrating and it makes me push myself to do more than I should. Sometimes I am made to feel that I am second rate, unhealthy and have a disability. Such feelings have been particularly heightened when I have been abroad.

39. Initially my girlfriend was very supportive when I found out that I had Hepatitis C. I am upset for her and gutted that she had to experience this news with me and ultimately that she now has to live with the guilt of splitting up with me, because of my infection, at a time when I needed her most. The relationship came to an end at the beginning of GRO-B after I had been living with her for two years and we had been together for three. She was GRO-B. I GRO-B GRO-B. It was heart breaking that she left me and I have had to live with, and try to assimilate, that heartbreak.

40. I am not a bad looking guy and growing up I never had a problem with girlfriends. However, once I received my diagnosis all of that changed. Naturally things got harder and I lost confidence. I started to struggle to maintain relationships and to form new ones.

41. It was not until GRO-B that I formed another meaningful relationship and she was a lovely GRO-B girl. However, her mother split us up in GRO-B because she

was only in her [redacted] As a result of my Hepatitis C I felt, and still feel like I lost out on so many years of my life. I actually feel a lot younger than I am. It is both stressful and sad that I haven't been able to maintain relationships and have children. Some people think that I am a loser, without knowing about my haemophilia and living with the impact of having Hepatitis C. I know I'm not a loser. Society is hypocritical of what is important to you when you have Hepatitis C. It is like they expect you not to want or expect things that ordinary people want or expect.

42. I have travelled the world and I have been to [redacted] countries. I like to travel on a shoestring and it is my way of dealing with the "*cards I was dealt".* I went to [redacted] just before the [redacted] [redacted] I could not bear to be with my family as I have never really felt welcome and it would remind me of my mother which I really struggle with as Christmas was a special time. My Mother made it feel special. However, I have taken the active decision not to travel for a while in order to be sensible and to try and see the Inquiry through. I feel like I have been running away from things all of my life but now I feel that I am facing things "*head on*". The Inquiry process, despite its limitations, has given me some form of comfort, although it is also a harrowing experience.

43. A part of me actually thinks that the Government are only having an Inquiry now so that they can monitor and watch the infected population. In that way I feel like a guinea pig. I think they are looking through all of our documents to build up a picture of what we are doing and where we are based around the country.

44. I am now aged [redacted] and I cannot get a mortgage. I have been surviving and struggling throughout my life with this virus. I have lived in many different houses. This virus has meant that I have never been able to settle anywhere in life. I have also had to deal with difficult matters alone and have not had the support which others have probably taken for granted.

45. I just plod on and keep going, a bit like my mother had to. I don't know any different. What choice do I have? I have been unemployed in the past and nobody helps you. I have lived a double life which consists of the fake me and the real me. People think that there is something wrong with me because at age GRO-B I am not married and I don't have kids. I therefore try to be "*someone else*" but the whole façade is exhausting. I am completely worn out trying to deal with everything and I have no one to take care of me.

46. My mother passed away in GRO-B due to GRO-B which she didn't know she had, despite having multiple tests and GRO-B I therefore have two fights on my hands at the current time; the first being the fact that there were errors in the report on my mother by the coroner and the second being the Infected Blood Inquiry.

Section 6. Treatment/care/support

47. Initially, I did not qualify for any treatment for Hepatitis C. **Exhibit WITN4006006** is a copy of a letter dated GRO-B from Dr S Taylor-Robinson, Consultant Gastroenterologist, to Dr Mike Laffan, Consultant Haematologist, which states "*Unfortunately his girlfriend left him because of the Hepatitis C and he feels physically, mentally and emotionally tired because of it. He would like to clear the virus but under current NICE guidelines, he has only mild hepatitis and does not fit into treatment criteria*".

48. I telephoned the Haemophilia Society (HS) helpline to speak to them about my frustrations and anxiety caused by being turned down for treatment. They told me to demand treatment so I went back and did just that.

49. **Exhibit WITN4006007** is a copy of a letter dated GRO-B from Dr S Taylor-Robinson to GRO-B GP, which states "*With regard to* GRO-B *himself, he feels tired and somewhat depressed. The Government guidelines have changed somewhat since we last saw him and patients with genotype* GRO-B *hepatitis C are now eligible for treatment with Interferon and Ribavirin without the need for further biopsy*".

50. I commenced my Hepatitis C treatment in GRO-B I endured the full GRO-B of treatment. It was not horrific but I felt groggy, lethargic and depressed. I was working during this time in GRO-B at a GRO-B company in GRO-B

51. When I was finally told that I had cleared the virus I cried due to the extreme emotion I felt. It was a relief but it did not change how I had suffered and the way I felt about what had happened to me.

52. In GRO-B I got into a fight and I fractured my nose. I went to the QAH where I had packs put in and this young female Doctor was treating me said "*'You haven't got HIV have you?*" I was mortified that she had asked me that and I wondered why on earth she would have asked me that. I demanded an apology and after demanding received an apology from the same Doctor.

53. I am not impressed with the service I have received from QAH. I feel like I was used as a guinea pig and for someone else's benefit. The clinicians appeared intrigued when they discussed my family tree and drew elaborate diagrams. I just wanted to be happy but it made my emotions more extreme when I had to deal with such behaviour and was asked difficult questions about my family tree.

54. I also went to my GP relatively recently about lumps on my testicle. The GP told me that it was just a twisted tube but it turned out to be tumours, albeit non-cancerous ones. I feel like I am not treated with respect by the clinicians and I wish that there was somewhere I could go to get my whole body checked and this place would have to staffed by people I could trust. I always say get a second opinion and trust my own intuition, due to the lack of belief that I have in the medical profession.

55. I have seen a counsellor on three occasions. However, I have never been offered counselling in consequence of my Hepatitis C diagnosis.

Section 7. Financial Assistance

56. In reality I have struggled for money for over forty years.

57. I received was the Stage 1 Payment of £20,000 from the Skipton Fund (SF). I found about the SF via the HS helpline. I found the process of applying relatively straightforward and my consultant haematologist satisfactorily completed his section of the requisite application form.

58. A few months ago I accidentally stumbled across the EIBSS on social media in an article I was reading on the BBC website. I then searched online for EIBSS and found a contact telephone number. I found the staff at EIBSS friendly and helpful throughout and the application process was straightforward.

59. Following my application to EIBSS, I received a confirmation letter by email on GRO-B. My payments were back dated to 2016 which reflected my eligibility since then.

60. I currently receive monthly payments of GRO-B of every month. I received a one off payment of GRO-B I also received a one off winter fuel payment of £531 on GRO-B

61. I feel guilty about receiving these payments because there are others who are much sicker than me who don't qualify for support from EIBSS and I feel like I am betraying those people. In comparison to some people, I don't feel that my life is that bad because I have managed to lead a relatively interesting one.

Section 8. Other Issues

62. I have no faith in the justice system in this country and I have no faith in obtaining justice from the Inquiry. It is extremely shoddy for the Inquiry not to grant CP status to infected persons including myself. This, in itself, is already a miscarriage of justice. In my view, the Inquiry is already trying to suppress and isolate voices who could assist in the search for the truth.

63. I would like sufficient compensation from the Inquiry. When my mother passed away I did not have enough money to contribute to her funeral which was upsetting. I have also started to think about my own mortality and funding my funeral. Some of the support money I have received has been put towards my family and paying a small amount of their debts. I have also helped my father. I want to ensure they are always looked after.

64. Compensation would also help me to purchase a property where I can finally rest. My parents got evicted from their property in GRO-B just after completing my treatment and follow up for Hepatitis C. Therefore, it is incredibly important to me to find a long term home.

65. In my view, the general public is not able to grasp the severity or scale of the infected blood scandal. A very carefully thought out, focused, sophisticated and emotive media campaign needs to be employed. The difficulty is that the public love the NHS and this divides people. I believe that I would be well placed to be able to bring people together and to find the right balance in terms of a media campaign.

Anonymity

66. I want to apply for anonymity and I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.. GRO-B ....

Dated............... 18.04.20 ....